



CHARGE Accounts

The mission of the CHARGE Syndrome Foundation is to lead and partner to improve the lives of people with CHARGE syndrome locally, nationally and internationally through outreach, education, and research.

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President's Message

This edition of CHARGE Accounts nicely summarizes how many in our CHARGE community may be feeling these days. Together we celebrate our 25th Anniversary. At the same time, we mourn the loss of far too many individuals with CHARGE.

We gathered together at events and conferences around the globe. We also eagerly look forward to our 14th International CHARGE Conference in Dallas next year. We take pride in the many achievements of individuals with CHARGE. Whether it is graduation from college, a new job, or a recently learned skill, we all cheer each and every bit of good news.

For me, I am grateful for the opportunity to celebrate life, while acknowledging the grief in our family. We received so many kind words and saw even more smiling faces as our 4th Annual Ethan Wolfe Recreational Assistance Program award recipients received their bikes, lessons and assistance with other recreational activities.

If you like the work the Foundation is doing, please make sure you are a current member. Please consider hosting a fundraiser or making a donation. Our 2018 research grants will be announced very soon. The more money we raise, the more research, outreach, and conference scholarships we can fund!

Enjoy the newsletter

David Wolfe, President

THE VERY FIRST CHARGE CONFERENCE HAPPENED BECAUSE A FAMILY WHO LOST THEIR CHILD WANTED TO CONNECT WITH OTHER FAMILIES.

— MEG HEFNER



Death has hit the CHARGE community pretty hard. Death sucks. Particularly the death of a child. Any child. But the death of one with CHARGE reminds us that our own child is always at risk. So we feel terrible for the family who lost a child, but we also feel terrible for ourselves and what we are facing.

There is never a death without guilt. All parents who lose a child experience this. “If only...” and “why didn’t ...” and “We should have...” The reality is the parents did their best, and sometimes there is just nothing anyone could do. The rest of us feel guilty too because we should have been better supports and we should do something, even though we feel helpless.

Things we can do: If you can find an address, send the family a card. While I believe a card is best, messages and email are helpful too. Finally, posts on Facebook are fine, although not all families will look at them. “I’m sorry for your loss” is a bit of a cliché. If you knew the child at all, recall any

memories you have. If you did not, just tell the family why you feel so sad. It is also okay to tell them what you imagine they are experiencing, like “I can only imagine how this loss is affecting all of you, given how it is affecting me.” I try to avoid anything that sugarcoats the situation, such as “your child is in a better place now.” That may comfort you, but may not help the family, although they will still be pleased that you reached out.

Memorials are terrific, although no one should feel like they have to contribute to one. A donation to the CHARGE Syndrome Foundation in the child’s name could be a nice way to honor their memory.

Finally, hug your children. Appreciate every day you have with them. Join with the CHARGE community in expressing our shared sorrow. We need each other as we go through this CHARGE journey, with all of its joys and sorrows.

— Tim Hartshorne



THE DEATH OF A CHILD CAN BE EXTREMELY CHALLENGING. FINDING RESOURCES THAT FIT YOUR NEEDS CAN HELP IN YOUR HEALING.

Click [HERE](#) to access resources, support groups, and ways everyone in our CHARGE family can help

We can’t do what we do without you!

*Your membership supports all the free information and outreach we provide families.
It also funds research and conference scholarships.*



Annual: \$30 per year
Lifetime Silver: \$250
Lifetime Gold: \$1,000
Lifetime Platinum: \$5,000
Lifetime Diamond: \$10,000

**CLICK
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SUPPORT**

In This Issue ...

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A Major CHARGE Anniversary

Twenty five years ago was the very first International CHARGE Syndrome Conference in St. Louis, Missouri. We really did not know what to expect. When we were planning it—we thought maybe 100 people would come from nearby states. As it turned out, it was attended by 250 people, including 46 individuals with CHARGE (ages 3 months to 19 years) and 40 siblings from many states and countries! We had child care (not yet “Camp”) and even took the kids (CHARGE and sibs!) to the zoo. The day before the conference, we had our first “Professional Meeting” which included both medical and education professionals. We knew we could all learn from each other and come to understand CHARGE better. Some of the professionals still come to the conferences and/or have published extensively on CHARGE. By bringing together both families and professionals, we hoped the conference would be especially meaningful for everyone. From a personal point of view, my highlight (after a year of planning) was at the opening mixer Thursday evening, when one of my “local moms” came up to me with tears in her eyes and said, “Meg, it is already worth it.” Here is a story from that conference 25 years ago.

The Picnic None of Us Will Forget - OR - The Saturday Night Surprise

One of the highlights we scheduled for the conference was a Family Picnic at a local park — where we could all get outside, let the kids run around, relax, and get to know one another better. It turned out to be quite the adventure. We thought we already had our adventure, as the conference was in St. Louis at the very height of the “Great Flood of ’93.” All of the rivers of the Midwest had been at flood stage for two months and were still rising. Friday night of the conference a major levee broke, flooding the interstate highway just west of the hotel. Conference planning during all of that was quite a challenge. Most volunteer efforts in the area had gone toward sandbagging and otherwise providing for those flooded out of their homes.

Saturday, August 2 was a typical hot, muggy St. Louis summer day — around 90 degrees and near 100% humidity with no breeze. The sky was not cloudy,



but a bright white haze — afternoon thunderstorm weather.

By mid-afternoon, I had to make a decision about the picnic: whether to go ahead at the park or move it to the indoor site (which had been chosen when we were still planning for only 150 people). The park was close to my house, where all of the food was being stored. At 2 pm (the picnic was scheduled for 4:30), the weather forecast was “50% chance of scattered, severe storms.” We decided to go ahead outdoors, but warned everyone about possible storms so anyone who did not want to risk it could stay at the hotel.

A Major CHARGE Anniversary

At 4, it rained for a few minutes at the hotel (5 miles from the picnic site), then brightened up. We loaded up a school bus and several hotel courtesy vans and headed off. Those of us with cars stopped at my house to pick up pizza, hot dogs, ice and other food. By the time I got to the park, the rain had passed, the sky was bright and kids were all over the playground. I was so pleased – we had pulled off the conference “come hell or high water.” I was only thinking of the high water and how hard it had been to plan for the conference during the flood of the century. Little did I know that “the hell” was yet to come!

Just as we were about to break open all the food in the pavilion, a black cloud appeared to the north. The rest of the sky turned green, the wind began to BLOW and it started raining horizontally. Everyone rushed to the shelter. We were beginning to discuss whether to wait out the storm or go back to the hotel when the tornado sirens went off! Someone yelled, “Everybody grab something and RUN!” Everyone grabbed something – a child, a case of coke, boxes of pizza – and ran to the parking lot. We still had the bus, but the hotel vans had long since gone back to the hotel. Nevertheless, in less than five minutes, everything and everybody was in the bus or a car. Fortunately the magician, interpreters and nurse had all joined us and had their cars. The last door slammed and the heavens opened. It was raining so hard windshield wipers did no good. It was the hardest rain I have ever experienced. The caravan left to drive slowly back through the storm to the hotel as warnings came

over the radio “Take cover immediately, tornadoes have been sighted.”

I ran the two blocks to my house, where my husband and small children were in the basement. I had to call the hotel and warn them of the imminent return of the conference-goers. (Remember this was 25 years ago – no cell phones.) I knew they could not put us in the ballroom where we had our meetings that day – a wedding was happening there. I could just imagine all the wet, excited, scared people descending in to the lobby during the wedding! I managed to reach the hotel and asked if she could find a place for us and all of our food. Then I waited for the tornado siren all-clear before heading over myself.

When I arrived at the hotel, I found that the staff had opened up all of the second floor conference rooms for our “picnic.” Everyone was eating and chatting and the magician was making balloon animals for the kids. No one had been hurt or lost in the melee. We opened the windows to the rain-cooled air. Successful picnic in the hotel!

But we were not quite done yet. By about 8 pm, things were winding down and everyone was heading to their rooms. But we had food left over – what do you do with 100 cooked hot dogs? We thought about the floods and all of the volunteers and relief shelters who might use it. Even though it was Saturday night, there were still volunteers at Operation Food Search who were happy to take our food, with promises to get it to a shelter in the morning. That was an evening I will never forget.



**Your donation of \$25 in celebration of our 25th Anniversary
will enable us continue to support families affected by CHARGE for many years to come**

[CLICK HERE](#)

Learning and Connecting Around the Globe ...

NORTHEAST

The first-ever Northeastern Regional CHARGE Syndrome Conference was held on May 4-6, 2018. This event was made possible through the collaboration of several federally funded state deaf-blind grants, including the New York Deaf-Blind Collaborative (NYDBC), the New Jersey Consortium on DeafBlindness (NJCDB), the Pennsylvania Deaf-Blind Project and the Virginia Project for Children and Young Adults with Deaf-Blindness, with the approval of the U.S. Department of Education, Office of Special Education Programs. Additional collaborators were the New York Parent Association for DeafBlind and the CHARGE Syndrome Foundation with participation from Helen Keller National Center and iCanConnect. The multi-state conference was held in a central location in Plainsboro, New Jersey to accommodate travelers from the northeastern and Mid-Atlantic states. The Crowne Plaza hotel proved to be extremely accommodating and supportive of our event, meeting our every need!

The conference drew a very large crowd with over 30 families, more than 70 children, over 40 professionals, an amazing team of American Sign Language and Spanish interpreters, and project staff from each respective state. Participants came as far north as Maine and as far south as North Carolina!

The demand for such a conference derives from the very significant and complex needs of children with CHARGE syndrome. Also, in recent years, there has been a dramatic increase in the identification children with CHARGE syndrome. Perhaps due to increased awareness and an identifying genetic marker, more and more young children and their families are being connected with the state projects and are in need of critical content related to the syndrome.



The conference had three main targeted outcomes:

- Sharing of critical information from content experts,
- Connecting parents with other parents for the sharing of experiences, and
- Informing and linking parents with critical resources to support them and their child.

To address the above needs various presenters were invited based on their knowledge and level of expertise, including the following: “CHARGE Syndrome & Current Medical Findings” and “Puberty & Development in Adolescents with CHARGE Syndrome” with Dr. Kasee Stratton, “How We All Learn” with Mark Campano, “Understanding Access and Literacy for Young Learners with CHARGE Syndrome” with Kim Lauger, “Feeding & Swallowing in Children with CHARGE Syndrome” with Christina Raschella, “Educational Assessments for Learners with CHARGE Syndrome” with Dr. Tomina Schwenke, and “Touch Access for Young Learners with CHARGE Syndrome” with Adriana Reali, a member of the adult DeafBlind community. The child program was a skilled team of volunteers under the leadership of Abigail Miller, a graduate student of the adapted physical education program led by Dr. Lauren Lieberman at SUNY Brockport. Professionals and families remarked on the high quality of content shared and found great application to their individual situations.

The conference had an area dedicated to exhibitors who serve families with children and young adults who are deafblind, including the New York Parent Association for DeafBlind (NYPADB), the National Family Association for DeafBlind (NFADB), the CHARGE Syndrome Foundation, the Helen Keller National Center, iCanConnect (iCC), the Marie Katzenbach/NJ School for the Deaf, and the NJ Statewide Parent Advocacy Network and the state deafblind projects.

But all work and no play does not make for a fun family conference! Families were able to meet face-to-face, connect, learn, and have fun at the Saturday night dance party, sponsored by NYPADB and NJCDB and facilitated by NJ Family Specialist Jennifer Henkle, and NY Outreach Specialist Suzanne Chen, also Interim President of NYPADB. There was a DJ from the visually impaired community who rocked the party, a



face painter who knew sign language, giveaways, snacks, and raffles! “Priceless” is the word to describe the joy and excitement witnessing such a wonderful event. The success and impact that the conference left on families and professionals is a direct result of months of planning between the state deaf-blind projects, our

determined state parent support groups, and the families and professionals who attended!

For further information or details regarding the event, please contact Susanne Morrow, NYDBC Director, at susanne.morrow@qc.cuny.edu



GERMANY

Professionals and families from all over Europe gathered in Oberwesel, Germany last month for the 12th German CHARGE Conference and 3rd Professional day. Approximately 85 people attended professional day and 290 attended the conference, including 60 individuals with CHARGE syndrome (photo above). Participants traveled from multiple countries including Australia, Austria, Denmark, France, Germany, Great Britain, Luxembourg, the Netherlands, Switzerland, and the USA. These events were organized by the German CHARGE Syndrome group (e.v.) led by their president, Claudia Junghans.

The German conference is held annually but every two years the organizers invite international professionals to come and give lectures. This year's presenters included teachers, professors, consultants, and researchers from Australia, Great Britain, the Netherlands, and the US. David Brown, Dr. Timothy Hartshorne, and Shanti Madhavan-Brown gave a joint presentation on behavior diagnoses commonly given in addition to CHARGE and useful interventions. Dr. Nancy Salem-Hartshorne discussed Obsessive-Compulsive Disorder (OCD) and

OCD-like behavior while Dr. Gail Deuce talked about management of behavior in the classroom. Rob Last gave a new presentation on belonging and friendships and hints for new and seasoned parents were reviewed by Dr. Hartshorne. A joint presentation on the basics of CHARGE for new parents was given by Dr. Conny van Ravenswaaij-Arts, David Brown, and Rob Last.

An interview with two parents of children with CHARGE (Valeria Risi and Tanja Rack) was presented to the attendees of the professional day. On the final day of the conference, a panel of four adults with CHARGE syndrome described their life, wishes, and aims to conference attendees. Additionally, four graduate students (Shanti Madhavan-Brown, Shelby Muhn, Lily Slavin, and Anna Weatherly) from Dr. Hartshorne's CHARGE Syndrome Research lab presented posters on a range of topics including Fun Chi, restorative environments, fatigue, anxiety, post-traumatic growth, and an education checklist.

Throughout the day professionals and family members listened to lectures and consulted with the presenters.

The child program offered many fun activities including craft stations, gold panning, mini soccer competitions, swimming, a photo booth, and caricature drawings. During breaks in the conference, attendees explored the town of Oberwesel and the nearby grounds of the Schönbürg Castle and museum. In the evenings, there was time for socializing and networking along with several planned events such as the viewing of the Germany vs. Sweden World Cup game, which

Germany won 2-1! A group of young adults with CHARGE helped close the conference by giving a dramatic improvisation performance which delighted the crowd. There were many smiles and some tears as people left the conference this year but they are all looking forward to when they can meet in Oberwesel again.

— Shanti Madhavan-Brown

AUSTRALIA

The Live Strong CHARGE On conference was held in Melbourne Australia on May 25-27. With a full line up of events it was once again a huge success! Organized by Madeline Rich, Belinda Arnell, Liz Lavensque, Rob Last, and Louise Adams, Friday kicked off with a professional day held at Monash Children's Hospital; 45 medical professionals attended. The day saw presentations from David Brown, Tim and Nancy Hartshorne, Kim Blake, George Williams, Kasee Stratton, the Bulldog CHARGE Syndrome Research Lab and the CMU CHARGE Syndrome Research Lab. Sean Rich, Madeline's son, talked about his life. It was well received and one nurse said it changed how she

saw CHARGE. Friday night was a meet and greet at our conference hotel, the Bayview Eden. Saturday was the start of the official conference with over a hundred people and a superb line up with our U.S., Canadian and Australian presenters. Topics were multidisciplinary care, teenage and adult issues, vestibular system, behavior and more. There were poster presentations from Bulldog and CMU labs and from Monash. Our event would not have been complete without a talent show. Hosted by Rob Last and Mandy Nolan, it was enjoyed by all, as was a disco after with dancing and fun. On Sunday, the last day of the conference, Kasee and Dan Gadke hosted a young adult

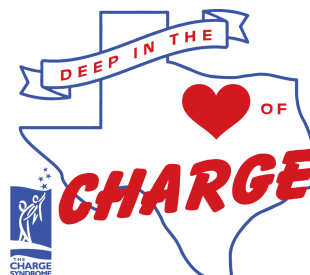


session, two families shared stories and my mum, Marea, presented on legal issues. We had a woman talk about the national disability insurance program and a fabulous young adults panel chaired by Belinda Arnell. David Brown tried to do "deep thoughts" but he only had fifteen minutes. Our former president, Lisa Russell, stood aside but is still a director. Madeline Rich has taken on the role and we look forward to working with her. As always, it was a great conference. I feel like I am home, in a place where everyone gets it, and I know many share my feelings.

—Ellen Howe

**THE 14TH INTERNATIONAL
CHARGE SYNDROME CONFERENCE
IS JUST ONE YEAR AWAY!**

**WATCH THE CONFERENCE INFORMATION PAGE
FOR UPDATES**



14th International CHARGE Syndrome Conference
Dallas, Texas | August 1-4, 2019

CINCINNATI CHILDREN'S

As a mom of a child with CHARGE syndrome, there is really nothing comparable to walking into a room full of other CHARGE parents and providers dedicated to improving the lives of our kiddos. Immediately greeted by old friends, familiar faces, doctors who have vastly improved your child's life, and families you've met on online but have been waiting to hug in person. I knew I was going to enjoy myself as soon as I walked in!

The Cincinnati Children's CHARGE Syndrome Conference was held over two days on July 26 and 27, 2018. The first day kicked off with an update on genetic research being performed by Dr. Donna Martin and her team. I loved hearing about their efforts to study the inner ear changes caused by CHD7 mutations by injecting white paint into the ears of mice! Following Dr.

It may be that our efforts to get children to function normally are precisely what lead them to develop more extreme dysfunctional behavior. —Tim Hartshorne

Martin, we met two young women living with CHARGE who shared their experiences growing up and living with the syndrome. The biggest take aways for me were the importance of creating a loving and supporting village, and providing multiple options for communication early on and throughout life. One of the young women told us that even though she communicates verbally and can hear well with her aides, when the environment is loud or overwhelming it's more convenient, faster and easier to her to sign. It's so important to give our kids communication options and let them choose! Later we heard from Dr. Sian Cotton who shared information on the effect of chronic stress on caregivers. She took us through a few exercises that are aimed at helping the body regulate stress and cortisol levels: a guided imagery exercise and a brief meditation and breathing exercise. This was the first time I've been at a CHARGE event where I can remember thinking about myself and my own health and wellness and I really appreciated the opportunity! What a novel idea.

The afternoon was a deep dive on hot medical topics. We heard about sleep issues from Dr.

I found several take-aways in all the topics covered since there are so many areas of life touched by CHARGE—our kiddos and our lives as well. I enjoyed meeting so many parents and professionals and found a whole new area of my life stimulated! I am now working on registering on the Ohio DeafBlind website and finding Mackenzie's genetic testing to forward to Dr. Donna Martin. I have emailed David Brown for his slides and will be taking an updated look at the Foundation's webpage. I'm hoping that laundry doesn't stand in the way of my cape flowing behind me. The teen panel inspired me to see how determined and successful kids with CHARGE can be. We should never underestimate them, always work our hardest, and LISTEN to what our kids are telling us!

—Holly Ward

Dr. Cotton taught us how to use our minds to get away from the chaos of life for just a few minutes. I was lost in the exercise and completely forgot where I was. Great therapy! One Mom commented that she finds it hard to get into herself because she's too busy being into HERself, meaning her daughter. So true! A conference highlight was listening to the speakers on the CHARGE teen panel. It was absolutely inspiring to hear their stories and I really appreciated their candor! They were even open enough to tell us parents not to be afraid to let them do the tough stuff!

—Jennifer Kile

Our family has attended every international conference since the birth of our daughter in 2002. One of the charms of a smaller, regional conference is being able to interact with everyone. Combining international presenters David Brown and Tim Hartshorne with the Cincinnati Children's team created a very high quality program. Even as a "veteran" parent, I have added to my list of ideas that may help Anna. This was my first time participating in a moms panel, and while I am currently suffering a bout of amnesia regarding whatever I said, I know my Mom Squad grew in heart and hope this weekend. We were able to schedule medical appointments and tests around attending the conference—a real two-fer!

—Ingrid Lobaugh

I was honored to give a short speech about the Cincinnati CHARGE center coordinator, Lucy Marcheschi. She truly is amazing and we are very thankful for her. Lucy is an extraordinary nurse. Lucy has sat with families in the OR waiting room and visited families when they are inpatient. Lucy goes the extra five miles with all of her CHARGE families. She is the glue that keeps everything running. The parents who call Cincinnati Children's CHARGE center their "home" gave Lucy an award and small gift basket as a thank you for her dedication, hard work and love she has shown all of us.

—Sally Strange



Susan Wiley and Dr. Christine Heibu, including the impact vision impairment can have on circadian rhythm and melatonin release, and how to diagnosis and treat obstructive sleep apnea. Dr. Eniolami Dosunmu gave us a lesson on the structure of the eye and some of the common eye problems in CHARGE. Dr. Meilan Rutter, an endocrinologist, gave a great lesson on the role and function of the endocrine system and common issues seen in CHARGE. We ended the day with a presentation from the infamous David Brown, focused on understanding multi-sensory impairment and appropriate educational approaches when working with a multi-sensory impaired child. All of that in one day...no wonder I was exhausted!

Day 2 kicked off with some information sharing from the Ohio deafblind project. Their project manager shared how important it is that we register our children on the deafblind census. He also shared the challenges states have with making sure there are enough teachers trained in sensory impairment and how they are working with college deans to train teachers. Friday's keynote brought the wit and insight of Tim Hartshorne, challenging us to put ourselves in our kids' shoes to understand their behavior. He also posed the idea, "It may be that our efforts to get children to function normally are precisely what lead

them to develop more extreme dysfunctional behavior." Food for deep thought. He was followed by a group of warriors—by that I mean four CHARGE moms who shared their insight, expertise, and successes. They moved us all to laugh and cry during their panel discussion. After lunch we heard from Dr. Catherine Hart on aspiration and feeding challenges and how to medically address these issues. She noted that as the CHARGE clinic at Cincinnati grows, they are learning how important it is to address aspiration issues as early as possible to prevent permanent lung damage. Finally, we split into breakout groups focused on managing hearing loss in children with CHARGE and immune issues in CHARGE syndrome. Personally, my son's immune deficiency was diagnosed much later than it should have been, so I will always advocate for a consult with immunology for any CHARGE family dealing with recurrent illness and I was so glad to find it is on the radar of Dr. Kim Risma and the Cincinnati CHARGE team.

My drive back to St Louis gave me a chance to reflect on everything I'd learned. First, I can't wait for Monday when I'm planning to call Lucy Marcheschi, the nurse coordinator for the CHARGE syndrome clinic at Cincinnati, and thank her for organizing the conference, and then add several doctors to our schedule when we go back for my sons annual follow up this fall. Second, I was reminded how complicated and wide reaching CHARGE syndrome is. There is no doubt this is a challenging path for any family. I also thought about the young adults with CHARGE who inspired me and felt immense peace getting a glimpse into my son's potential future. Finally, I thought about the sense of community I had embraced for the last two days. No one could have predicted the bond I'd share with so many amazing parents from across the country, and how they would continue to be my greatest support system. It was truly a gift to be able to escape the day to day and spend time with my extended family. I can't wait for Dallas 2019!

—Kate Smith



The organizing team relaxing after a successful conference.

The presentations from the conference will be available soon on the CHARGE Center at Cincinnati Children's website

CHARGE Awareness Store

**T-Shirts for mom, dad and siblings
Order by August 15.**

[CLICK HERE TO SHOP](#)



Mom T-shirt



Sibling T-shirt



Dad T-shirt

IRELAND

The Anne Sullivan Centre For Deafblind hosted an evening for parents of children with CHARGE syndrome across Ireland. The evening, at the Clybaun Hotel in Galway (who set up and donated a lovely tea and sweets), was facilitated by Deirdre Leech, who is the Deafblind Outreach Consultant at the Centre, and Grace Kelly, who is the CEO of the Centre. Eight parents of children with CHARGE of different ages came together and welcomed CHARGE



Syndrome Foundation board member Pam Ryan (seated, second from left) to join them. Two of the young people with CHARGE offered some of their perceptions of life with CHARGE.

We had an interesting discussion of the issues that these families face in Ireland as compared to the issues that families in the US face. The biggest discussions were around assessment; recognition of deafblindness and how that is different than autism; behavior; communication; health; and acquisition of developmental milestones. There were also questions about current research and Pam shared the most recent information from the American Journal of Medical Genetics.

Pam also encouraged everyone to join the CHARGE Syndrome Foundation (as separate from the CHARGE Facebook pages) and to take advantage of some of the “perks” of membership. We talked of the next CHARGE conference in Dallas, Texas in 2019 and Pam added that there is a scholarship program for members. Deirdre also added information about the Germany, Australia, and UK conferences.

Pam added that the CHARGE website has a great deal of information and the “Resources” section could be very helpful in terms of answering questions and finding further information about CHARGE-related issues. This was a fun evening and Pam had a great time meeting everyone!

CALIFORNIA

California Deafblind Services (CDBS) found a way to keep their former colleague, David Brown, closer to home by hosting free weekend training events on CHARGE syndrome for families and educators in Southern and Northern California. In January CDBS partnered with the San Gabriel/Pomona Regional Center in Southern California to host a Friday evening meet and greet social for families and local educators followed by an all-day workshop, “CHARGE Syndrome-Development, behavior, and education,” presented by David Brown. Seventy people attended the event, including families, teachers, early interventionists, paraeducators, and university students. It was wonderful watching families from across Southern California connect with each other and with the educators who joined us on Friday evening for conversation, games, and face painting. It was also a treat for our state deafblind project to meet, as well as reconnect with, so many families with children with CHARGE.



Saturday morning started off with a welcome from Rosa Chavez of the San Gabriel/Pomona Regional Center and our CDBS Family Engagement Specialist, Myrna Medina. Sheri Stanger, the Director of Outreach for the CHARGE Syndrome Foundation, then joined us via video call to share a lot of useful information about the Foundation, its mission and activities, and ways to use their resources and get involved. The rest of the day was spent learning from David Brown about the countless things he’s learned about the developmental

and educational aspects of CHARGE Syndrome over the past 35 years. Anyone who has heard David present knows it was enlightening, entertaining, and went by too quickly.

The CHARGE Workshop Weekend in Southern California was so successful that CDBS has decided to replicate it in Northern California. This time we are partnering with the San Andreas Regional Center in San Jose to host a Family and Educator Social on Friday, September 7 and an all-day workshop on Saturday, September 8, again led by David Brown. For more details about this FREE Northern California event check out [CDBS events link](#).

— Julie Maier, CDBS, Educational Specialist



NEW HAMPSHIRE

I am the CHARGE State Family Liaison from New Hampshire. My daughter Lacey has CHARGE and is 19 years old. I wanted to have a CHARGE Family get together for our families in New Hampshire. We are a small state, with only about six or seven families. The Lin Family generously opened up their home for a Pizza Party. We had three families attend: the Herod Family, the Lin Family, and Lacey and I. We had a wonderful, fun time. It was so nice to get together and just talk and support one another. We hope to get together again sometime in the summer and hope more families will come. Getting together is so important! We need each other!

—Laurie Suter



MICHIGAN



The Michigan CHARGE Family Picnic was held in Mount Pleasant, MI on a warm Saturday in July. The families gathered for a potluck and fun activities in the park. The event was sponsored by DBCentral, the CHARGE Syndrome Foundation, the Michigan Association of Deafblindness, and the CMU CHARGE Syndrome Research Lab.



The CHARGE Syndrome Foundation is pleased to offer financial support for regional CHARGE events.

[Click here for the application.](#)

Everyone Deserves a Chance to Play

4th Annual Ethan Wolfe Recreational Assistance Program (EWRAP)

EWRAP was created and funded in 2014 through generous gifts from the Wolfe family and friends in memory of Ethan Wolfe. The program provides families with funding for recreational programs or to purchase recreational equipment

Congratulations to this year's recipients!

AJ, Himnish, Ryder, Emily, Noah & Summer - Adaptive Bikes
Cesar - Summer Camp • Jeremy - Bike Trailer • Logan - Tae Kwan Do Club
Bryce - Hippotherapy • Aaron - All-terrain mobility chair



Logan absolutely loves his Tae Kwon Do. Not only has been so good for his self esteem and confidence, but we have seen so much improvement in his flexibility and balance too. We feel so blessed by this generous scholarship. Thank you so much!!!



At the CHARGE conference in Orlando, we talked with a company called Freedom Concepts. They manufacture bicycles for individuals who cannot ride a conventional bicycle. The bikes are fully customizable and sounded wonderful but were way out of our price range. In the Spring we applied for the grant and a couple of months ago we were notified that **Noah's** application was approved and he would be receiving one of these awesome adaptive bikes! He even got to pick the color.



There are no words to say how thankful we are for this scholarship. **Bryce** loves to ride every Friday. If he didn't have riding to do as an activity, he would be a homebody and this gives him the opportunity to open up and be himself and not feel like an outsider and lonely as he usually does. Thank you!!!



We received **AJ's** new tandem bike a few weeks ago and have now enjoyed a handful of rides. While he loves pedaling and zooming along the trails and sidewalks, I also love this new time we get to spend with him just chatting, the iPad momentarily forgotten! One of AJ's favorite phrases now seems to be, "First we'll bike, then we'll..." Of course, it's also joyful to hear, "I want to ride the bike with daddy" (or mommy).

Sandra Davenport CHARGE Syndrome Fellows: Reflections from the 2017 Conference

by Meg Hefner

The Sandra Davenport CHARGE Syndrome Fellowship program was established in 2015 as a way for the CHARGE Syndrome Foundation to educate and encourage young professionals who are involved in the world of CHARGE. The Fellowship provides a scholarship for the professionals to attend both Professional Day and the biennial International CHARGE Syndrome Conference. The Fellows meet daily with the other Fellows and the Fellowship mentors Pamela Ryan, Meg Hefner and Sandra Davenport. They are also each matched with a “host family” to help them get to know at least one family well and better understand daily life in CHARGE-land. Our hope is that their Fellowship experiences will help them become professionals more expert in CHARGE and encourage them to continue to be involved with CHARGE research and with the Foundation. Each Fellow is asked to write up their reflections shortly after the conference. Previous issues of *CHARGE Accounts* ([Fall 2017](#), [Winter 2018](#) and [Spring 2018](#)) included reflections from Emily Fassi (Genetic Counselor), Chathuri Illapperuma (Educational Psychology grad student), Kareem Tawfik (Otolaryngology physician), Lauren Fogarty (medical student), Bree Kaufman (Educational Psychology grad student) and Alex Donovan (PhD student). This issue includes reflections from Zachary Bird (behavior analyst at Perkins School for the Blind) and Dieuwerke Dijk (physician with Conny van Ravenswaaij-Arts in the Netherlands). Watch for reflections from the remaining Fellows in the next issue of *CHARGE Accounts*.

Zachary Bird's reflections

The buzz around the 2017 CHARGE conference started in 2016 at Perkins School for the Blind, when I first saw a flyer about it. I remember being surprised to hear about a conference that researchers, professionals, parents, and individuals with CHARGE syndrome (CS) would all attend. The professional behavioral analytic conferences I'd attended in the past weren't quite that open and it was hard for me to imagine how that would work out. Sounded like a fun time though; plus, who wants to be left behind as half the school goes to Orlando?

As time went on, I posted a conference flyer near my desk and as I glanced up at it every so often, I would get motivated to ask others how I could get involved. I heard there would be research presented and Caleb (the other behavior analyst in the Deafblind program) and I thought we might benefit from joining in and submitting a presentation ourselves. With the help of all of the veteran CHARGE conference goers, we decided on a topic and a plan for how we might contribute to this interesting gathering.

The Davenport Fellowship came onto my radar and I was immediately interested. A previous Fellow [Sara Espanet – see her reflections from 2015 [HERE](#)] was telling me all about it and how it changed the way she thinks about CS and the families involved with the CHARGE Syndrome Foundation. It was important to me that I would not just attend the conference but get the most out of it I could. I wanted to understand more about the culture and I thought the Davenport

Fellowship would be a unique opportunity if I were to be selected.

It wasn't long before I had approval to go, I was selected as a Davenport Fellow and the conference was just months away. Each Fellow is paired with a “host family” and I was lucky enough to be paired with Mighty Max McKinley and his family. It was great to hear about him and read the blog his mother, Amy, had written about their experiences and the day-to-day life successes and struggles they had as a family.

I was happy to see that Mighty Max and Amy had experience with Applied Behavior Analysis (ABA). It was something we had in common because, after all, I'm a behavior analyst and I consider it my life's work. It was really exciting knowing we would all be in Orlando to meet each other in person.

When we arrived in Orlando, I felt nervous. I had never been to this type of conference before and I really didn't know what to expect. Was it going to be a chaotic, carnival like atmosphere where everyone socialized and got along or an uptight group unwilling to let this “new guy” into the fold? The hotel was huge and this didn't reduce my anxiety at all. I felt like I was swimming upstream trying to find my way to my hotel room after registering for the conference. Once I made it to the room and settled in, everything was slowing down but I still couldn't relax because I was nervous about our presentation the next day. That

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Sandra Davenport CHARGE Syndrome Fellows

Dieuwerke Dijk's reflections

Writing this essay about my experiences as a Sandra Davenport Fellow really feels like a challenge. Not because there is so little to write about, but because there is so much. However, I will try to explain why attending the 13th international CHARGE conference as a Davenport Fellow was such a great experience.

As a physician I am very interested in how the body works and how things can go wrong. During medical school I realized that one of the things I like the most is making contact with people for whom it is harder to express themselves, which led me to pediatrics. Now I am a resident in training to become a physician for people with intellectual disabilities. This medical specialty only exists in the Netherlands and was officially recognized by the Dutch government in 2000. Because healthcare for this group of patients is often very complex, I often work with specialists in other fields, including physical therapists, behavioral scientists, and speech and language therapists.



Dieuwerke Dijk (right) with Conny van Ravenswaaij-Arts

My research is about growth and puberty in CHARGE syndrome (CS), where I work with Gianni Bocca (pediatric endocrinologist), Conny van Ravenswaaij-Arts (professor in clinical genetics), Bas Penders (researcher and medical student) and Willem Jan Gerver (pediatric endocrinologist).

We had big plans for the conference. We wanted to present our project and also conduct research. For me, it was also a great opportunity to learn more about CS. One of the things I liked most about the conference was the fact that families and professionals meet and learn from each other.

In the weeks before conference, I prepared my poster presentation and for the research (taking photographs of children to learn more about body proportions). I created a

personal schedule for the conference, which Meg ended up sending to the other Fellows so they could also plan their conference time. My schedule was full from minute to minute, but that was absolutely worth it!

About CHARGE

Before I went to the conference I thought of CHARGE mostly as a complex syndrome with the co-occurrence of many different features. The first sessions at professional day offered another perspective that was really interesting to me: You can also think of CS as a syndrome with many problems of the senses (visual, hearing, smell, vestibular/balance). This way of looking at it gives some understanding to what kind of challenges an individual with CS has to deal with on a daily basis.

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Zachary Bird's reflections

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evening the Davenport Fellows met for the first time. I was impressed by the pedigree of the Fellows. Everyone was pleasant, friendly, and brilliant. We got to know each other and spent some time discussing what would be happening during the conference.

Thursday was Professional Day. There was a wide range of presenters and an excellent poster session. We gave our talk on functional behavior assessment and it went pretty well. We were part of a larger symposium so we could tell that not everyone was there to see us. I was happy to see others from Perkins arriving throughout the day. In the evening, the Fellows met again. This time we did a deafblind

simulation (photo at right), which involved some glasses that included vision imperfections and blind spots. We also had some ear plugs that blocked some but not all of the sound around us. This was the first time I had done this type of simulation. I found it to be beneficial, but it was not comfortable. We could still have conversations but most of us found ourselves standing much closer to each other when speaking. When we looked at magazines, it just wasn't very enjoyable. From a behavior analytic perspective, it increased effort and devalued conversation and visual experiences as reinforcers.

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Zachary Bird's reflections

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At the Thursday night reception we met our assigned host families. Meeting Amy and Max in the large auditorium was fun. It was a bit tricky to find each other but once we were together we had a great time. The experience of meeting with them while at the CS conference was probably much different than if we had met in some other place. The first thing I noticed was that the families were given permission from each other to let go of the typical social norms of keeping their children "well behaved." It's not that the children became poorly behaved when given the chance, instead it was that they were able to go exploring without any social disapproval. Everyone seemed to have an understanding that this is what happens; this is the place we let our guards down. It was bizarre but also a relief. I was able to get down on the floor and do my best to relate to Max. We had one moment where he and I connected. He was playing with some popsicle sticks on the ground. He was collecting them so I joined in. I gave him another one. I saw a few more on the ground so I grabbed those ones too. He received several more from me until he had a handful of them that we were both proud of. As I searched for others to give my newest friend, I looked over just in time to see what he had in mind for them. Come to find out, he really wanted to use them to poke people in the eyes. This gave me some regrets about providing him with so much ammunition but at the same time I did feel grateful for the short activity we shared. Amy and I talked about Max and his experiences with ABA. It was nice to hear about the improvements he's made over the years and all of the communication he was able to show while we were all hanging out.

On Friday we were all able to enjoy many of the great talks at the conference. As a new person at the conference, I had heard of some of the speakers but hadn't actually had the chance to see them in person. Caleb and I also gave our talk on Friday. It was a great turnout and we were so happy to see so many people interested in our topic. Everyone was so kind and we spent several minutes after the presentation speaking with parents and educators who had questions or thoughts about what we said.

Another valuable thing from the conference was the opportunity to see people that have moved to other areas but still were involved in the Foundation. I saw students and people who used to work at Perkins. I suspect coming to conference becomes even more valuable the longer one is in the field. You could tell that many of the families knew each other and it felt a little like a large family reunion. Teachers knew other



Fellows Chathuri Illapperuma, Hui Yao and Zachary Bird

teachers, families knew other families, service providers knew other service providers; and then people from each group knew people from every other group. Being my first time, I felt like I had been married into this large family. I didn't really know who people were but I was hopeful that I could find a way to fit in. I was able to observe it as an event from the outside but also take part being on the inside.

I thought camp was an incredible service offered to families at the conference. I can imagine that it would be really helpful for families to have the opportunity to enjoy the presentations, talk to other parents, and have a little time for themselves while the children were in a fun and safe environment. Being a Fellow, we had the chance to volunteer and spend some more time with the kids in Camp. This was great for those of us who don't have an opportunity to spend much time with folks with CS. One of the more thought-provoking things said by one of the other Fellows was that he does his work in the lab researching CS but really hasn't met anyone with CHARGE before. Being from Perkins, I have the chance to see individuals with CS and their families nearly every day. It's fascinating to think about someone dedicating their life to understanding a syndrome and, if it not for the CHARGE Syndrome Foundation, never getting to see what they're working for.

Taking the time to reflect on my experience as a Davenport Fellow, I am very pleased and thankful to have been able to take part. I get the sense that the conference was carefully designed, conscientiously planned, and thoughtfully organized. This was what made the situation work. This is what made the family reunion atmosphere mesh with the professional and research oriented presentations. I look forward to going to the conference in 2019 and staying in touch with my new-found family.

Dieuwerke Dijk's reflections

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Learning about how vestibular issues influence behavior was an eye-opener to me and definitely something I wanted to pass on to other residents in my class.

Meeting “CHARGErs” and their families, the other Fellows and other professionals

One of the best things at conference for me was just to sit down in the big hall during at mealtime and look around: watching children run around or lie down on the floor, seeing friends meet again, and people signing everywhere. I wished I knew how to sign too. Makenna, a 16 year old girl with CS, was my match for the conference. She and her family have been to previous conferences and it was very nice to see how she and her sister met their friends again and had a good time. One thing I learned from the family is how many different professionals you meet when you have a child with CS and how each can all tell you different things about your child. For a professional, it is important to realize that you are just a small part in a big chain and parents actually are the experts about their child. I also learned how important it is to have someone who can help coordinate care.

Meeting the other Fellows was a good way to reflect on the things we learned and saw. One of the things I liked the most was the fact that everyone had a different background and had different perspectives on

their experiences. There is one experience that we all shared: how the presence of the families inspired us to keep learning about CS. Meg, Pam and Sandra (Fellow Mentors) did a great job of making us feel welcome and getting us to learn not only from each other but also from their many years of experience. One of the great things they did was to let us experience how it is to be deafblind by giving us dark glasses and earplugs. I felt very tired just after a few minutes.

Part of our research project on growth and body proportions included taking photographs of children with CS. This turned out to be a great opportunity to meet many “CHARGErs” and their families and to hear some of their stories. We are very happy that we were able to take photographs of 32 children!

After the conference

After the conference I stayed a bit longer to see a bit more of Florida. I returned home refueled and very much inspired to continue with my research. My experiences at the CHARGE conference have not only been an inspiration for my research project, but also for my clinical work. I have presented much of what I learned to other residents in training in my class. We have started to analyze the photographs and hopefully we can present the results in at the next conference. I hope to return and see you all in Dallas in 2019!

Educating Educators About CHARGE



Every year a select group of educators from across the globe is invited to Perkins School for the Blind to take part in the Educational Leadership Program (ELP). The ELP program offers advanced training to teachers of the visually impaired and other professionals from developing nations. Participants are immersed in expert instruction and hands-on learning experiences inside and outside of the classroom. They attend lectures, conferences and workshops and visit agencies and schools related to their training. The ELPs live, work and study at Perkins from September to May and then return to their home countries to share knowledge and enact major improvements to services for children and young adults who are visually impaired, deafblind, or blind with multiple disabilities.

This year's class included Emi Kamei who is from Japan. Emi has been a familiar face at the past two CHARGE conferences where she immersed herself with families and professionals in order to learn more about CHARGE research, family issues, and educational concerns. While at Perkins, Emi spent a great deal of time of time with the staff in the Deafblind Program. Emi graduated from the ELP program and has gone back to Japan prepared to teach and train others specifically in the area of CHARGE syndrome.

—Pamela Ryan

College and Beyond: My Story

by Andrew Prouty

Why College?

I have been going to school since I was 6 months old, so I guess you could call me a life-long learner. After graduating from high school and the VECTOR Transition program, where I had a part time job with the U.S. Army Corps of Engineers, I began working full time with the Corps and after several years I transferred to the U.S. Fish and Wildlife Service. During this time, I took evening classes at St Paul College then at Metro State University. Most of the time, I took just one class each semester because I was working 40 hours a week. I went to college because I wanted to develop skills and give me more career opportunities. College helped broaden my worldview and gave me exposure to different ways of thinking, cultures, and better understanding of the variety of ideas and views in the world.

Full-time or Part-time?

One good thing about being a part-time student was that I didn't feel too stressed in completing my assignments on time and preparing for exams. As a part-time student, I was able to work full time, pursue a career, and enjoy living independently. One bad thing being a part-time student is it took me much longer to complete my degree. But I kept at it, and 18 years later, I graduated from college. Sometimes I got tired of taking classes but with encouragement and support from my parents, I kept on going.

Online Classes

The majority of my classes were taken online for several reasons.

First, I was concerned that Metro Mobility (MM) would arrive late, causing me to be late for my classes. MM is a transportation service for those who would have a hardship using public transportation. I took a few classes on-campus because they were not available online. So when I did have to take MM to campus, I set my ride to arrive there an hour or two early.

Second, online classes provided me tons of flexibility. They allowed me to study at any time on any day. (Of

course they do have deadlines to complete assignments and study for exams.)

Third, there was no need for interpreters or note takers.

Fourth, online classes were more cost effective for me considering the commuting costs.

However, online classes require self-discipline in order to succeed.

Picking a Major

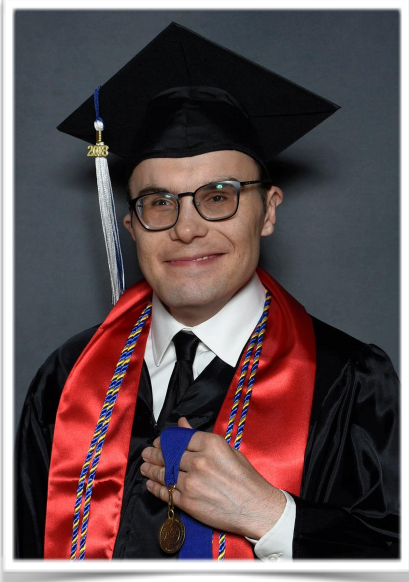
Many students change their majors due to personal discoveries, I'm no different. When I first started my college studies, I was interested in computer design (St. Paul College) and then Java programming (Metro State University). However, teachers and advisors told me these majors were not a good match for me because they are very competitive and fast paced. Because of my low vision, I tend to take more time compared to most people in this field. But I didn't give up; I eventually decided to study 3D animation, which I will discuss later. When I took a new job at the U.S. Fish and Wildlife Service, I put my studies on hiatus for a few years because I was happy with my job. However, my dad told me that with a Bachelors degree I will have a higher chance of getting a better job.

Picking the Right College/University

Metro State University (MSU) means a lot to me because it offered flexibility and support. I had a difficult time finding a major at MSU, so my college advisor suggested an individualized study degree,

which allowed me to fashion my own major. I began taking classes focusing on different minority cultures in the US, ethnicities, disabilities, and history. I also took classes focusing on women and STEM (Science, Technology, Engineering, and Math) and the influences of technology and media on children, as well as a class that taught me different ways to solve problems. I designed a self study class that allowed me to advocate for the Cogswell-Macy Act in the US Congress. These classes helped me

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Making Connections in New Jersey

I work at the Marie H. Katzenbach School for the Deaf in NJ. For two years that I worked with Molly, a little girl with CHARGE syndrome, in the Preschool program, I went to workshops, had deafblind training through NJCDB and learned everything I could about CHARGE. It was also a busy time for my husband and I: we were in the process of adopting a little girl from China who was a year older than the child I was working with. All we knew about her at the time was she was Deaf. When we finally brought our little girl home we found out she has CHARGE syndrome too. So not only did I learn everything I could to help the child I was working with, without knowing it, I was preparing myself for my daughter, Ramona. It really was meant to be!



Molly, Jason and Ramona

—Catrina Nowrey

My name is Jason Cruz, I am 21 years old and have CHARGE syndrome. Growing up I didn't know anyone with CHARGE. When I started work as a paraprofessional at the School for the Deaf, I met two little girls with CHARGE and it changed my life. I feel connected to them like they are my little sisters. I went to the Northeast CHARGE Conference and felt a sense of belonging. It was nice to be part of the event and tell my story. I'm hoping to be part of more conferences and to continue my life as part of the CHARGE community and with my CHARGE little sisters, Molly and Ramona.

College and Beyond

figure what major I should pursue. Because I want to help improve the world for women, minorities, and people with disabilities, I decided to pursue a major in ethnic and disability related communication.

I faced many challenges in getting a B.A. degree, but I managed to overcome them, thanks to support from my family. For example, my dad is a very good editor. We agreed that he would lend his English skills and I would help him improve his ASL. Also a few of my classes required community participation, so either my parents or my sister provided me transportation in order for me to complete my college assignments. The reason for this is because I cannot drive due to my low vision. Also, I developed problem-solving skills. For example, I was able to use creativity to overcome challenges. When I need more time working on an essay, I would save my essay on Google drive so I could work on it via my iPad while riding for hours each day on Metro Mobility to work or home.

Thanks to all the support I received from family and MSU, I am finally a college graduate! My relatives flew all the way from California to Minnesota to watch me accept my diploma and celebrate with me! I had a great graduation party. I invited many people who supported me through my educational years. My preschool teacher even flew from Oregon to

congratulate me. I was so honored!

Here I am now, beginning a new chapter of my life with a B.A. degree. I am currently looking for a better job with the government which will give me new challenges and opportunities.

Finally, as I mentioned earlier, I've gotten interested in animation because I want to teach people sign language through animation! (I have posted several sign language animation videos on the CHARGE Facebook page.) I was able to take two self-directed animation courses at Metro State, but since they do not offer a major, I will take coursework at a community college to fulfill my dream: maybe I can sell my 3D animations to schools with ASL classes.

Summary

As you can see, my educational journey was long with many turns. I faced challenges finding the right college and right major for myself. Many times I thought about giving up but I persevered. Support from family and college really helped me. My message for everyone is do not let anything get in the way of your goal. If you put your mind to it, you will succeed!

Andrew Prouty lives in St. Paul, Minnesota. He graduated with honors from Metro State University in April, 2018.

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A Leap of Faith

by Rowena Barker

In late March, we were fortunate enough to travel to New York and attend the Deaf Blind Immersion Seminar at Helen Keller National Center for Deaf-Blind Youth and Adults. We were blessed to have a talented and invested team join us for this experience. David Pacetti, our son Jack's Low Vision Instructor from Webb Street School, joined us, along with Andrea Blackwood from East Carolina University Teacher Support as well as Kerri Massey, Chief Program Officer from Holy Angels. We were grateful to receive some financial support from the North Carolina Deaf Blind Project which enabled our family to participate. It was a challenging week, yet it revealed some beautiful things to us about Jack and the deafblind community. The staff at HKNC was a committed and passionate group of professionals. Their dedication was inspiring. Jack was pushed beyond his comfort zones, and frankly beyond our comfort zones for him. However, we learned that his capabilities and capacities are far more than we ever knew.



There were many highlights for us during our week. Jack really prospered from his sessions with the orientation and mobility specialist who worked with Jack with a tandem cane ... something he had never done before. Those sessions were fruitful as were the vocational sessions. Jack stocked magazines on shelves at a bookstore, loaded the dishwasher in the cafeteria, stocked vending machines, cleaned and wiped down tables in the cafeteria, and folded towels in a hospital laundry. Jack was also able to make an "order card" using photos, print, and braille and placed his own order at Smashburger for exactly what he wanted to eat. The joy and empowerment he felt from that opportunity was beautifully evident.

The team who attended with us had a productive meeting at the end of our week at HKNC, and our collaboration has yielded beneficial progress for Jack upon our return home. We are implementing new goals and adjusting existing ones, and have a much clearer plan moving forward. We are now placing a stronger emphasis on numbers and braille, and just recently Jack made great strides in this area. Also, HKNC helped us film a video about "sighted guide" with Jack, and we now use it with all professionals who work with Jack to help provide guidance and consistency. Although Jack was the student at HKNC, we feel that our entire team learned as much as he did and that we returned home with far greater integration, communication, and synchronicity in Jack's plan for the future.



Creativity Corner

The Final (Exam) Challenge, Part 3

by Meri Dwyer

"Huh. That was...rather easy." I mumble.

That's when the castle begins the shake! "SPOKE TOO SOON!"

"SAKURA, LOOK OUT!" Chika shoves me out of the path of a falling stone, taking my place.

"OMG! CHIKA!" cries Miku.

That's when we hear inhuman wails. "It's her demon army!" cries Luce. "Sakura, go! We'll handle this."

"B-but...M-Miku..." Tears sting my eyes.

"Just go, you idiot!"

"K-Kari..."

"They're right. You're our only hope to save the world!"

"R-Rosa...you guys..."

"S-Sakura..." Chika fights to get to her feet, she's injured but still alive. "You're the hero of this story... not us...don't give us the wimpy anime heroine tears, alright?" She smirks her trademark Chika smirk.

"Chika..." She's right. They're all right!

"Guess I have no choice." I try to be light, but it comes out funny.

"You go girl!"

"Okay Elana, I'm coming to save the world!" I run down a hall and up a winding staircase, leaving the sounds of battle behind me. I hope my friends will be

okay. Please let them be okay... I think as I run. I do not know why the heck all villains have to be at the waaaaaaay top

floor. That doesn't matter now. I only have an hour to save the world before Final Bell. (In case you're wondering how I know, Luce told me on my way up!) Scared yet? I am and I'm the *heroine* of this story!

"Elana, I've come to stop you!" I say as I dash into the throne room, Crystal Sword held high.

"So much for stealth..." Luce mutters and I roll my eyes. I swing my sword at the evil queen. But wait! Something's wrong! Oh! Right! She has Miss Ella! I freeze.

Elana laughs evilly. "To get to me, you must defeat her!"

I can't hit my teacher's cousin! Then I remember something. Wait! I'm a *Magical Girl*! DUH! I can *purify* her!

My sword morphs into a scepter with a heart with wings at the top. "CRYSTAL LIGHT BEAM!" I shout. Yeah, I know! I keep forgetting my attack's name! My bad! Ella falls to the ground. My scepter turns back into a sword. "Okay. Now it's your turn!"

Elana turns into a big black dragon. "Fool! You are too late! I am Chaos, ruler of worlds!"

"Oh, crud!" I gasp. I dodge a burst of fire, back flip and land on the throne.

"GET OFF MY THRONE, GIRL!" Chaos hisses.

"Wah, wah, wah! You're the *queen* and you're whining over a *throne*! Laaaaame!" I'm so busy laughing that I don't see her next attack.

I'm thrown back, my head crashing into the wall. Dots swim before my vision. There's an eerie wailing sound.

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Meet the Author

Hi-hi! My name's Meredith Dwyer, but you might know me as Meri! I'm twenty-five years old and I enjoy writing stories! First it started off as a series of stories based on my family and our wacky adventure to save the world from an evil sorcerer, then fan fiction and now I'm writing actual novels and even a few therapy stories! When I'm not working on these, I'm either at a coffee place reading, reading at the library or Barnes and Noble, reading at home or watching anime and playing video games! I truly hope you all enjoyed my story! XOXO [Click here to read Part 1 & Part 2](#)

Creativity Corner

“Hah! Time’s up, Magilyte!”

“Wha-what? N-no!” I stagger to my feet. “I won’t let you destroy the world!”

“Sakura, you must use the Crystal!” “What Crystal?”

“The Heart Crystal!” My bunny explains. “It is the only way to save the world now! Quickly! Before the clock strikes twelve!”

I look at an hourglass on the castle wall. The sand is almost completely gone from the top!

I close my eyes and summon the power from my friends. “I call upon the power of light! Lend me your power to vanquish this evil!”

There’s a bright pink light.

“DIE!” I’m hit by dark energy and my light vanishes.

I’m in pain. So much pain.

“Sakura!” I hear the voices of my friends, Miku, Chika, Kari and Rosa.

“You can do it!” Rosa—Kind and quiet Rosa—says. “I give you my power!”

“We’re with you!” Chika says. I can see the grin on her face. “Forever! I lend you my power!”

“I shall give you my power! You can win!” Cool-girl Kari says. “Now win, or I’m never speaking to you again!”

“Come on, Sakura! I know it’s tough, but...but we’ve been through tougher times than this! I *know* you can defeat this monster!” Miku. My best friend. Her words motivate me the most. “I lend you my power!”

I listen to my friends. *I can do this! With the power of the Crystal and my friends, I shall save everyone!* “SUPER CRYSTAL HEART BEAM!” I push all the energy out of my body and into this final attack.

“No!” I feel a dark beam of energy pushing against my own. “You will die! Ten seconds to twelve! Ten... nine...”

“No, right back at you!” I smirk.

“Three...two...” “RELEASE!”

“One!” The hourglass shatters. Pink light floods the room. “What?! This cannot be!”

“Power of love and friendship, baby!” I say. I flip in the air and with one final blow from my glowing pink sword, it’s over.

And everything goes black.

I don’t know what time it is when I open my eyes. What I do know is that everyone—my friends, family, teachers, everyone—is alright.

“You did it!” Miku gives me a big hug.

I hug her back. “Yeah,”

“Just in time, too,” says Rosa.

“I’m gonna kick your butt later, you know!” Kari says.

“Huh? Why? I saved the world!” I’m baffled.

She gives me her trademark smirk. “You know why!”

“Why?” I ask.

Chika, Miku and Rosa stand and get ready to defend me.

Then I see it. Kari’s eyes are brimming with tears! She runs over and hugs me. “Don’t you ever scare me like that again!” She sobs.

“Kari...”

“I have to admit, it *did* start to get a bit scary by the end!” Chika nearly giggles.

“Yeah,”

“Sakura! Sakura, wake up!”

I’m in the gray fog between waking and sleeping. “C’mon, sweetie! You have a test today!”

I bolt up in bed, feeling dizzy from getting up too fast. “Wha-what? I’M GONNA BE LAAAATTTTEEE!” I cry as I get ready for school. I laugh when I realize I really *do* sound like an anime heroine!

So, that’s that! It was all a totally crazy dream!

Of course, I’d take fighting monsters over taking difficult tests any day...

What’s next in the Creativity Corner?

Send your submissions to joanne@chargesyndrome.org

Focus on Fundraising

The 10th Annual Charge it for CHARGE has come to an end, with a total of \$111,000 raised.



Thank you to everyone who participated!

Jeff Alexander	Minnie Lambert	Alivia Roth
Cynthia Antaya	Sabrina Landau	Deanna Rothbauer
Eric Bluestone	Joanne Lent	Kate Smith
David Brown	Christian & Ingrid Lobaugh	Hollie & Chad St. Arnould
Alexa Burtley	Amy McKinley	Sheri & Neal Stanger
Suzanne Chen	Amrit Mehta	Deanna & Bill Steinhauser
Melissa Coward	Rajiv Mehta	Laurie Suter
Dixie Cunkelman	Mike Miele	Melanie Waterman
Karin Dagley	Anna Miller	Lisa Weir
Cole Herrick	Anne Moore	Tamara Wendoll
Christa Houghton	Imogen/Tim Nasta	Alicia Wheeler
Kathy Jones	Cherie Obiri	Aubrey Williams
Allie Jones	Rhonda Ramseur	Philip Wismer
Jennifer Kile	Megan Reeves	David & Jody Wolfe
Ashley Kulas	Sara Owens	
Sandy Kurby	Tracy Roth	



***Watch for our next campaign in the fall.
Until then, the fundraising continues on Facebook!***

Thank you to all who have used Facebook to raise over \$6,400!

Cindy & Michael Archuleta	Donia Shirley Douglas	Sarah Lent	Barbara Sadler
Makayla Baugh	Kris Ferguson, Sr.	Brandon Marshall	Julie Savage
Sarah Bermudez	Estelle Francis	Christian McCants	Samantha Schahilly
David Brown	Pamela Floor	Ellen McLean	Heather Schloenleber
Jessica Carpenter	Jody Gartin	Krissy Nelson	Josh Sirota
Kathy Connors	Erich Glave	Darla Nemsky	Kellie Skeoch
Christina Hullings Darczuk	Beth Halsey	Cherie Obiri	Lisa Stewart
Kimberly Dillard	Hanna Jones	Laurne Ormsby	Phil Wismer
Chip Dixon	Sara Jannae	Lauren Rossi	

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Paul Marsolan, the father of an individual with CHARGE syndrome and a lifetime member of the Foundation, created a fantastic app with his CHARGE family in mind. **CHANGE BOWL** is a mobile platform that enables **YOU** to give easily by rounding up your regular purchases. The platform takes your transactions and rounds up to the next dollar. Donating on **CHANGE BOWL** is easy. This platform enables you to make a single donation, multiple donations or recurring roundup donations to the Foundation easily and at any time. It takes less than 5 minutes to sign up, connect a debit or credit card, and select the CHARGE Syndrome Foundation.