



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.

OFFICERS

President: David Wolfe

Vice-President: Lisa Weir

Treasurer: Brownie Shott

Secretary: Neal Stanger

DIRECTORS

Julie Brandrup

Karin Dagley

Minnie Lambert

Joanne Lent

Christian Lobaugh

Amrit Mehta

Pamela Ryan

SPECIAL ADVISORS

Tim Hartshorne

Meg Hefner

Donna Martin

DIRECTOR OF OUTREACH

Sheri Stanger

DIRECTOR OF ADMINISTRATION

Jody Wolfe

DEVELOPMENT & DATABASE MANAGER

Jackie Alshawabkeh

The CHARGE Syndrome Foundation, Inc.

318 Half Day Road
Buffalo Grove, IL 60089

800-442-7604

www.chargesyndrome.org
info@chargesyndrome.org

President's Message

At this time of year, many of us are focused on our upcoming conference. Will we be able to travel this year? Can we afford registration, travel and hotel? The Foundation is here to help!

- Our Charge It for CHARGE fundraiser provides every participant an opportunity to earn free registrations [[click here](#)].
- We developed a very useful funding guide [[click here](#)].
- Members are eligible for scholarships [[click here](#)].

We want to see as many of you as possible in Orlando!

Conference is not the only exciting activity going on at the Foundation. Applications for our 3rd Annual Ethan Wolfe Recreational Assistance Program are available [here](#). We want all individuals with CHARGE to have a chance to play!

We are expanding our research program and have added a Clinical Advisory Board to spark more clinical research. At the same time, we are continuing to fund the research grants administered by our Scientific Advisory Board. Applications for all research grants will be available in the next month.

In addition to the wonderful programs that are going on at the Foundation, our newsletter highlights some of the fantastic stories about our friends in the CHARGE community. Whether family events, publications, or individual achievements, our CHARGE family has much to be proud of! Enjoy the newsletter.

I hope to see you in Orlando!

David

David Wolfe, President



CONFERENCE REGISTRATION OPENS FEBRUARY 28!

Join us in Orlando, July 27-30, 2017

Register for Conference

We encourage you to register as early as possible. Note that we will not be the only group at the hotel, so **everyone must be registered and wear name tags at all times** in order to participate in meals and events. Registration opens February 28. Deadline: June 1. [Click here](#).

Register Children for Camp

A separate registration is required for all children who will be participating in the camp program. [Click here](#).

Reserve Your Hotel Room

We're returning to the beautiful Rosen Shingle Creek hotel. [Click here](#) for hotel information.

USE [THIS LINK](#) TO RESERVE YOUR ROOM

Apply for a Scholarship

**[BECOME A MEMBER](#) BY APRIL 1, 2017
TO BECOME ELIGIBLE FOR A SCHOLARSHIP**

First-time conference attendees can apply for the **Norbury Scholarship**.

The **CHARGE for Connor Scholarship** supports families who need help with hotel costs.

Any Foundation member can apply for the **CIFC Scholarship**, which is supported by the annual **CHARGE It For CHARGE** fundraising campaign.

[Click here](#) for the scholarship application. Application deadline April 1.

Visit the Conference Page

[Click here](#) for the latest news on programming and activities.

CONFERENCE AT A GLANCE

PROFESSIONAL DAY

Thursday, July 27

Sessions 8:00 – 5:30

Separate registration fee required

CONFERENCE

Thursday – Sunday

July 27–30

Thursday Afternoon

Family time at the pool!

Thursday Evening

Welcome reception 7:00 – 9:00
for families & professionals

Friday

Sessions 9:00 – 5:00

Camp Program (full day)

Exhibitor Fair

Poster Presentations at Info Central

Friday Evening

Signing Time with Rachel Coleman

Saturday

Sessions 9:00 – 5:00

Camp Program (full day)

Saturday Evening

CHARGE-A-Palooza

Silent Auction & Basket Raffle

Sunday

Presentations 9:00 – 12:00

Camp Program (half day)

Breakfast and lunch included with
Professional Day registration.

Snacks and light dinner included on

Thursday. Breakfast, lunch, dinner, and

snacks included on Friday and Saturday.

Breakfast included on Sunday.

Donate a Basket

Adults and kids alike enjoy the Saturday night Silent Auction and Basket Raffle. With your help, we'll have something for everyone! Some ideas: Sensory toys, spa day, game night, chocolate lovers, or a basket of items from your hometown or state, worth at least \$50. We are also looking for high end prizes, such as sports tickets and memorabilia, timeshares, fine jewelry, and electronics. Visit the [Conference Events page](#) for the donation form. Contact [Neal Stanger](#) for additional information.



Recruit a Volunteer

The success of the conference camp program depends on volunteers - **especially volunteers who sign** so the kids in camp can communicate.

FLORIDA RESIDENTS: Please reach out to your child's teachers and therapists, as well as friends and family. [Download and submit the volunteer application](#) and contact joanne@chargesyndrome.org with any questions.

Become a Foundation Member

We depend on the support and commitment of our members to help create a better, more understanding and accepting world for all individuals with CHARGE. Lifetime members get a 10% discount off registration. [To join or renew, click here.](#)

Annual - \$30 Lifetime Silver - \$250 Lifetime Gold - \$1,000
Lifetime Platinum - \$5,000 Lifetime Diamond - \$10,000

Reminder...



**ALL CONFERENCE
ATTENDEES**

**MUST WEAR
NAME TAGS AT
ALL TIMES**

**FOR ADMISSION
TO MEALS AND
PROGRAMS.**

Questions?

[WATCH THE CONFERENCE 101 WEBINAR](#)

[READ THE CONFERENCE NEWSLETTER](#)

FOR ADDITIONAL INFORMATION

Stay Up To Date

[Click Here To Sign Up For E-News](#)

The Importance of Movement for Individuals with CHARGE Syndrome

By Dr. Beth Foster

This is the first in a series of articles focused on the importance of movement for individuals with CHARGE syndrome. The articles will provide information and strategies to enhance and increase movement through different opportunities. Let's start this series out with a question:

Why is movement important for individuals with CHARGE Syndrome?

CHARGE syndrome often results in developmental delays, including motor delays. In addition, many children with CHARGE syndrome spend much of their infancy and childhood in and out of the hospital for various surgeries, which can impact their motor development due to the restricted environment. The loss of both distant senses of vision and hearing also potentially impacts overall motor development. For instance, balance and mobility rely on vision and vestibular function, which are affected by vision and hearing loss, and for movement to occur, children must have a minimal level of balance. However, motor development and movement are possible and should be a focus in your child's development.

There are many benefits to moving, such as increased:

- Social Skills
- Self-esteem and self-determination
- Ownership
- Perception
- Sense of belonging
- Common bond with non-disabled peers
- Independence
- Orientation and Mobility Skills
- Physical endurance and fitness
- Spatial awareness
- Gross motor skills

Previous research has indicated a strong relationship between independent walking in children with CHARGE syndrome, the attainment of symbolic communication/language and an increase in the ability to adapt to their environment. Therefore, with an increase of movement and the ability to walk independently, an additional benefit for your child may be increased communication and language skills and his or her ability to adapt to environmental changes.

Children with deafblindness have fewer opportunities to participate in physical activities and are overall less active than their peers. Specifically, for children with deafblindness, movement provides a means to explore the world around them. Movement allows the child to explore new objects, people, and environments. This exploratory movement has been shown to be associated with perceptual and cognitive development.

(continued on next page)



A child's mobility is affected by his or her ability to process the environment, to know when and how to move, and how to interact with the surrounding environment. A child with deafblindness has limited motivation needed to stimulate purposeful movement within the environment due to their sensory loss. Motivation is thought to trigger movement; therefore, environments that encourage safe and successful movement are beneficial to overall development and growth. Exploration and movement throughout the environment broaden a child's perspective of his or her world and increases knowledge. Movement is crucial for the overall development of children with deafblindness. Acquiring independent movement is a stepping-stone to gaining independence, knowledge, and experience about the world around them.

Dr. Beth Foster, CAPE is an Assistant Professor in Adapted Physical Education, Department of Kinesiology and Health Promotion at California State Polytechnic University, Pomona.

[Click here to read this article with academic references.](#)

Fall CHARGE Meet & Greet

By Aubrey Williams

Last fall, I hosted a meet and greet for CHARGE families in Missouri and Kansas at a local pumpkin patch here in Missouri. It is always nice to get together with people you can relate to. Several families, including my own, were able to attend and even though the weather wasn't as nice as we hoped, the day was still filled with a few hours of fun. We saw a pig race, went on a hayride and got some pumpkins along the way, had pumpkin donuts, and much more!

I enjoyed getting to meet and talk to people I had before only known from Facebook. We talked about our shared experiences and even managed to get a family photo before it was time to go home. Big thanks to those who helped me plan this and make it a success!

I am glad we were able to have this event and look forward to our big family reunion in Orlando in July!



From left to right: The Lebron family, the Williams family, the Jacobs family, the Hall family, and the Collette family.



Diego's Superhero Adventure

Through imagination and the healing power of giving, the [Colten Cowell Foundation](#) helps transform kids into Super Heroes. Recently, Diego got to visit the Colten Cowell Foundation's Crime Fighting Cave in Phoenix, Arizona.

The night was an incredible success, with more than 25 people experiencing the fun and excitement, including rides in the Batmobile and trips on the Crime Fighting Cycle. Diego's mom, Lucia, chose the CHARGE Syndrome Foundation to be recognized with a \$2,000 donation (along with Feeding Matters, a nonprofit organization working to make a better world for children with pediatric feeding disorders, which sponsored Diego's adventure) because of the extensive support her family has received over the years from both nonprofits. Lucia summed up the trip:

"It was a day where he got to be a Hero. We were honored to have dear friends and families join us in such a special day for Diego. I would've never imagined he'd liked to go down the pole like Batman and Robin. He wanted to do it again and again. He loves cars and getting to ride on the real Batmobile and Batman's motorcycle was so cool! He kept signing 'more' over and over. A fun evening and a day he got to be himself ... my happy super hero."



Oh, Booger!



Artist Sam Fawns has been hard at work at Martha Layne Collins High School in Shelbyville, Kentucky creating his own unique pottery known as his "Booger Bowls." In October, Sam and his art teacher set up a booth outside the St. James Art Fair to display his work to help raise money for further research into CHARGE syndrome. They raised over \$2,000!





Everyone Deserves a Chance to Play

*The Wolfe family, along with the CHARGE Syndrome Foundation,
is pleased to accept applications for the*

3rd Annual Ethan Wolfe Recreational Assistance Program (EWRAP)

We look forward to helping more families and individuals with CHARGE.

APPLICATIONS ARE DUE BY APRIL 1, 2017.

Award recipients will be notified no later than May 1, 2017.

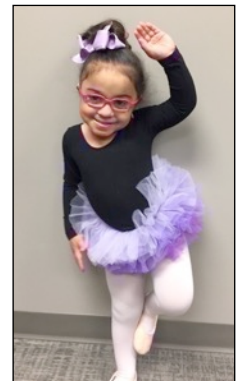
Click here for the Application

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.

Below are comments from the parents of previous recipients:

Jayne Weinert - mom to Layla

We are beyond grateful for the opportunity that the EWRAP scholarship has given our 3 year old daughter Layla this year. She is absolutely loving her tap/ballet dance class! It is so exciting to watch Layla enjoy the same activities as her typically developing peers. Not only is this a fun opportunity for Layla to release some of her energy each week, I am amazed by all of the hidden therapies it is providing her. Each week it tests her physical stamina and balance, her listening skills and how to appropriately follow instructions, as well as the benefit of peer modeling and what appropriate social interaction looks like at her age. The chance to provide some normalcy in her world full of appointments and therapies is something that we certainly do not take for granted.



Yara Cluver - mom to Isabel

Ysabel loved riding her horse, Watsun, a palomino quarter horse at People Animal Learning Services in Bloomington, Indiana thanks to the generous support of the grant we received through the Ethan Wolfe Recreational Assistance Program. Her lessons helped her improve her balance and greatly increased her self confidence. She connected not only with the horse, but also with her teacher and helpers, improving her social interaction skills. She can't wait to get back to lessons in the spring as soon as the weather warms!.

Sandra Davenport Fellowship Program

The Sandra Davenport CHARGE Syndrome Fellowship program was established in 2015 to facilitate mentoring of the next generation of CHARGE professionals by bringing them to conference (Professional Day and International Conference) and encouraging them to become involved with the greater CHARGE community. The first class of fellows was comprised of nine individuals from a variety of backgrounds – graduate students in psychology, genetic counseling and medicine and one teacher of the deafblind early in her career. They were all nominated by their mentors, who are professionals who have been active in the CHARGE community for a long time, in some cases decades. Previous issues of [CHARGE Accounts](#) have included stories from six of the Fellows. Here are stories from the final three of the class of 2015. For more information on the Fellowship program, including the application for the 2017 conference, [click here](#).

Sara Espanet, Teacher, Perkins School for the Blind, Deafblind program

The 2015 CHARGE conference was my first and will not be my last. I feel so fortunate to have been a part of the first class of Sandra Davenport Fellows. To be able to experience the conference with such a unique group of young professionals was extremely valuable to me as a teacher. If I had come to the conference on my own, I would not have had the opportunity to interact with professions in the genetics field or professionals working in CHARGE labs. My experiences will change the way that I teach my students with CHARGE. This fellowship is one of the best things the Foundation can do to help young professional attend the conference. In order to capture every detail, I kept a journal of my experiences.

Wednesday July 29th

Today is the day! I have been waiting for months now, and I am so excited that I am finally on my way. Some of the other Fellows have already worked with many CHARGE experts. Despite my excitement, I am intimidated, and nervous that what I bring to the table is not comparable to those who will sit next to me.

When I arrived at the hotel and saw the signs for the conference, I felt so honored to be here, and a wave of emotions rushed over me. This is something that I have been tirelessly begging my aunt and uncle to attend. My cousin is 20 years old and has CHARGE syndrome. They have never attended a conference, and feel like they are alone in their struggles. In my time as a teacher at Perkins School for the Blind, I have met so many people who have said that the CHARGE conference is the best place for families. Being here, I feel like it is my job to learn as much as I can, and to bring that information home to share with my family. Then there is the teacher in me; I am finally at the conference that everyone at school has been talking about since the day I started. I am so excited to learn more about my students and to learn different strategies to make me a better teacher.

We (Perkins crowd) arrived early, so we had some time to eat lunch and relax at the hotel bar. One of my students, Ashley, came into the restaurant with her mom and grandmother. Ashley is a quiet girl who keeps to herself at school. I went over to talk to Ashley and her family. We talked for a bit before Ashley got a message on her phone and left the table. Her mother said that she was meeting a friend here, and they had been texting daily since the last conference. Five minutes later, Ashley came running around the corner with her friend Kristen. I have never seen Ashley so happy! She introduced us and then the two of them were off for the evening. I hadn't even been at the conference a full day and I was already so touched and amazed by what it can do for the individuals with CHARGE.

Ed. note: Kristen flew from Indiana to Massachusetts for Ashley's graduation from Perkins in June 2016.

[Click here to read the story on our website.](#)



Ashley and Sara at the opening reception.

(continued on next page)

Thursday July 30th - Professional Day

To say I was nervous is an understatement. The day was filled with experts in the field, sharing their work. I was very excited but intimidated by those around me. I don't come from a research background so some of the presentations were difficult to follow. My knowledge is in the area of teaching strategies, behavior management, and working with families. Leaving the morning sessions, I felt a little overwhelmed and nervous that I had taken on more than I was ready for.

Lunch was a different story, and it helped me to feel confident in what I know. We sat with parents of a young adult with CHARGE and talked about how this was my first conference. When I told them I worked at Perkins they asked me some questions about transitioning from school to adult placements. This is something that I know, and could talk about for hours. I have been working with young adults with CHARGE for the past 6 years, and have been on many transition teams. It was amazing to be able to share my knowledge with these parents, and to help them with their decisions regarding adult placement for their son.

The afternoon included specific Education sessions. It was great to be able to relate to the information that was being presented. My favorite session was on Concept Development. This is something that I can take back and use in my classroom. I think it was beneficial to have these sessions for teachers.

Later, as I met with the other Fellows, we could see the families making their way to the opening reception. Walking into the ballroom for the reception was like nothing I have ever experienced. It was incredible to see the families and individuals with CHARGE. There were friends catching up and excited to see each other; there were young kids lying on the floor while other kids navigated their way through. That room made you feel like CHARGE was normal. One mother told me "It's so nice to be here, our son can be himself without people staring. He is just like any other kid here." The first official day of the conference was promising. I was excited for what was yet to come.

Friday July 31st

This morning was the official start of the Conference. The first presentation I heard was

(continued on next page)

Rachel Malta

Educational Psychology Graduate Student
Central Michigan University

Prior to the CHARGE Syndrome conference in 2015, I attended the 2014 Australasian CHARGE Syndrome conference in New Zealand. It is a smaller conference, which allowed everyone to get to know each other in a more personal way. I had been told to expect the American conference to be vastly different, as the attendance was much higher and we may not have the opportunity to meet everyone, and the professionals would be difficult to talk to. I had also expected that the Professional Day, while important, might be less than exciting, especially because I had already had the opportunity to hear many of the presenters the previous year. However, as a graduate student, researcher, and future school professional, I knew that it was important to glean as much knowledge and information as possible to use in future work with children, especially those with sensory impairments or medical conditions. I was most looking forward to the half-day of volunteering in Camp with the kids; after all, being able to work with children is the reason I chose my profession and the reason I love being involved in the CHARGE Syndrome Research Lab with Dr. Hartshorne at Central Michigan University.

While the conference in Chicago had a different atmosphere and "feel" to it, the entire experience, from the Fellowship to the more general mingling with the families, was invaluable. The many presentations at Professional Day allowed me to hone in on the areas I was particularly interested in: education and common issues families face within the schools, especially when advocating for their children. The presentations included stories from parents who had been through the school system – both the situations which hindered their child's development and those teachers and support staff who helped unlock their child's potential. They highlighted what put them at ease and what was helpful to them from those who were in a role that I now have in the special education system.

I was also pleasantly surprised with the speakers on complex science terminology such as genetics. These are topics that usually go over my head and

(continued on page 17)

David Brown's incredible discussion on the way we assess our students. He said that oftentimes we force our students to sit at a table to do work so that we can assess them when we should really be watching them play and allowing them to do activities in a way that is most comfortable for them. Listening to him talk about this made me think about the way that I teach my students. I can use this philosophy when I am teaching math and ELA.

My afternoon was spent in Camp with the kids. I was excited to be with the younger kids with CHARGE because most of my experience has been with students who are 15-22 years old. I was matched with Jacob,



Sandra Davenport and Jacob at Camp.

a preschool student from Perkins, whose mom had asked me to watch over him because it was his first time at Camp. I was also with two other boys, Noah and Christian, and the group of us hung out for the afternoon. I usually see Jacob at school in passing and have always wanted to work with him. Noah and Jacob were both 3 years old and ready to play! The energy was incredible. They were like any other 3 year old boys, wanting to play with the trucks and balls; but when playing they needed to lean on staff or a ball because they had poor balance. They would need to sit down and take a break every so often because they were quick to tire; but when you asked them if they wanted to take a break they would say or sign "no" and get right up and play

again. The highlight of Camp for me was when Sandra Davenport came into our room, played ball with Jacob and came to the petting zoo with us. Jacob loved her and wanted to make sure she was following us when we went to the zoo. Camp is so important to the families, and we could see their relief when parents would check in and see their kids playing happily with other kids just like them.

After dinner was the CHARGE Idol show. I had heard so many stories and I couldn't wait to see it for myself. Everyone was amazing, and the judges were great. My favorite performances were the sibling acts. It was so touching to see the brothers and sisters get up and do a dance routine or magic routine with their sibling with CHARGE. One thing that I noticed was that none of these kids had any stage fright! They got up on stage and performed without skipping a beat! It was impressive. CHARGE Idol lived up to all the hype!

Saturday August 1st

I was excited to be able to go to sessions all day. I was looking forward to the Concept Development session with Christine Spratling. She was so interesting on Professional Day, but only had twenty minutes to present that day, so I wanted to hear her full presentation. She gave me new ideas on how to create materials for my students. She showed us how she made books for her students by using simple materials that I already have in my classroom. The thing she spoke about that connected with me the most is the manner in which we teach our students: We need to immerse our students in a concept, not just show them. If we are teaching our students about the concept of "in," we must place our students IN something so that they can fully understand and have a full body experience. I really enjoyed what she had to say about this, and would like to try and carry over these concepts to my own teaching.

The rest of my day was spent with the Hartshornes. I was able to sit in on both Nancy Salem-Hartshorne's and Tim Hartshorne's discussions on OCD, behavior and CHARGE. For me the most moving and relatable presentation from the Hartshornes was "The Power of Jacob." I was inspired by Jacob's caregivers and what life is like for an adult with CHARGE in his own home. It would be beneficial to have a similar presentation on what it is like for a family to have their child in adult placement as it would show parents that it is ok. Not everyone is going to be able to buy a home for their adult child and staff it the way the Hartshornes have for Jacob.

(continued on page 12)

Neeraja Reddy, Genetic Counseling Graduate Student, Brandeis University

I remember walking through the gates of Perkins School for the Blind the first time and realizing I was being given a great opportunity to explore the world of deafblind individuals. I was a first year Masters student in the Genetic Counseling Program at Brandeis University and had never heard of CHARGE syndrome. Neither did I realize that my journey would continue beyond my experience at Perkins. After my first day in the Deafblind Program, I noticed the complexity and variation within CHARGE syndrome. It intrigued me not only as a genetic counseling student, but also due to my interest in children with special needs. I spent most of my time at Perkins observing children of different ages with CHARGE. I would often go back the office of Pamela Ryan (my mentor at Perkins) at the end of the day to discuss my thoughts.

When Pamela contacted me about an opportunity to attend the International CHARGE syndrome conference, I was very excited to be a part of it. The Davenport Fellowship gave me the opportunity to meet the families of the children I worked with at Perkins, to better understand the lives of these wonderful, inspiring people, to observe the bonds between parent, child, and siblings. It gave me the chance to increase my understanding of genetics and medical complications of the syndrome.

I expected the Professional Day to be a lot of didactic lecture-based sessions on various aspects of CHARGE. However, the talks ranged from behavior, psychological and sexual development to developing checklists for management. In addition, parents' experiences with their children and anecdotes from their lives made the professional day all the more engaging. At the opening reception, I had the chance to talk to many families - some from Perkins, and others from the New England region. One father explained how his feelings evolved after his child was diagnosed with CHARGE. This was very special to me, as it is not common to hear fathers talk about their feelings. He explained that he



remained shocked the first few months, but then slowly accepted his child's diagnosis and now enjoys seeing him meet his goals.

As a Fellow, I also spent time in Camp with the children. My most vivid memory from camp is of two four-year-old girls with CHARGE. They communicated their needs, emotions and personality well. One wanted to be best friends while the other preferred more personal space. One demanded constant attention, the other wanted to spend some time alone with her toys.

I have previously worked with organizations in India to improve access to education and medical interventions for children with special needs. During my genetic counseling training, my desire to contribute to my home country has only gotten stronger. The fundraiser presentation inspired me to identify ways in which we could sponsor a child with special needs to receive medical services. I came to the CHARGE conference with the idea of understanding more about CHARGE syndrome and the lives of families, but I gained more than that.

One of my long-standing career goals is to be a part of a parent support group. I would like to continue working with families by reaching out to them and being a resource. Based on my current experience in Telegenetics, I would be happy to contribute to the development of strategies to reach out to families, nationally or internationally. I would like to continue working with the CHARGE Syndrome Foundation and help develop new strategies for outreach, or talk to families who may need help. As a young woman on the panel stated - Do not tell me sky is the limit when men have set foot on the moon.

For more information on the Fellowship program, including the application for the 2017 conference, [CLICK HERE](#).

Sara Espanet (continued from page 10)

After the sessions, the Fellows again met to talk about how this conference has affected us. I became a little emotional. It had been hard to be at the conference knowing that this is something my aunt and uncle should have attended years ago. It was bittersweet to finally be here, but not be able to share it with my family. Nonetheless, I was excited and was moved by all that I had seen. The part that got me was the adult transitions. I spoke about a student who just graduated and the uncertainty of his adult placement. While he would be going to a group home, no one can ever be certain that it will be a good fit. The idea of sending our students off into the world after graduation has always been hard for me. We work with our students so closely, and we become attached. Although some might say we are simply their “teacher,” we become our student’s teachers, caregivers and protectors while they are at Perkins. After five years of working with my student, I became emotional talking about it. Having that group of Fellows and sharing our experiences was so important.

That night was CHARGE-A-Palooza! It was a fun night filled with dancing, raffles, face painting and being together as one big CHARGE family. The Perkins group had our faces painted and took some rather silly pictures with David Brown. The night was an amazing way for everyone to enjoy themselves.

Sunday August 2nd

It’s hard to believe that the conference was coming to a close and that I would have to wait another two years to come back. The morning was filled with emotional talks on why we all do what we do every day. The Passions talk was incredible; it allowed us to hear from parents, professionals, and individuals with CHARGE. Each person told us about what they were passionate about. The first to come up was the mother of a young boy with CHARGE who had passed away. Her strength to stay part of the community was truly inspiring. CHARGE for Connor [her family’s charity] continues to raise money and send families to the conference each year, showing us that no matter how hard things may be for them, they are still going to CHARGE ON. I also enjoyed hearing from the professionals who are so passionate about their work and looked forward to coming to the conference as much as the families did. I can relate to them. I spend 6 hours a day with my students with CHARGE, and have developed strong relationships with them. We have bonded over their achievements and struggled together to get there. Working with my students and seeing them grow is my passion.

The young adult panel was a great way to end the conference. It reminded us that life with CHARGE goes far beyond school years. The panel was a group of adults with varying abilities and different experiences. It was important for parents to see that some adults will still live at home and require assistance, some will move to adult placements, and others will live independently. The panel did a great job representing this, and showing that no matter their placement, they were all happy and successful in their own ways.

When the conference came to a close, I again found Ashley. She couldn’t wait to go back to school so we could share our experience with everyone. Ashley was also sad it was over. She told me that this was the hard part, saying good-bye to friends that lived far away, not knowing when she would see them again. This seemed to be the feeling for so many families and friends as people hugged good-bye. For a few days, families and individuals with CHARGE came together to create a community where they were the normal. Everyone understood them, and no one stopped to stare. These past few days have shown me so much about the students I work with and my cousin Tim. I am forever thankful for the opportunity that the Foundation gave me, and am honored to be a part of the first class of Davenport Fellows.

We will introduce the second class of Davenport CHARGE Fellows at the 2017 Conference. To add to the experience, this year we will match each Fellow with a family.

This is your chance to get to know a young professional with a growing passion for CHARGE and introduce her or him to your family.

We will be looking for families who are coming to conference and will have a child in Camp. Hosting will include being in touch by email before conference, meeting at the opening reception, having a meal together and helping the Fellow understand life with a child with CHARGE.

If you are interested in being a Fellow Host Family, watch for more information in the next newsletter and in Conference email blasts.

Meg Hefner and Pamela Ryan, Davenport Fellowship Advisors.

Why It's OK to Ask Me About My Child

By Nicole Feeney

Our culture is one of show and tell. Kylie Jenner did what? To what part of her body? We look. I look. A paleo blogger tweets about the breakfast she made. She shares. I look. As a society we “share,” “tweet” and “update” people about our lives. We share. People look.

Whether we like it or not, people also look at our differently-abled kids. They may draw attention for their assistive devices, the way they look, or how they behave.

I am not surprised when we're in public and people look at Shelby. People love to comment on two things about Shelby: her glasses, “Oh she has taken off her glasses! You should fix them,” or it is her left eye which doesn't face forward and all you see is the white, “Someone is sleepy!” These comments irritate me and I'm starting to think they shouldn't because before I had Shelby I never understood “special needs things.” How can I expect others who don't have a special needs child in their life to not stare or be curious? (I *can* expect them not to be rude.) I'm rethinking my role and my response to onlookers.



We all benefit from empathy ripples

I'm starting to wish people would just come up to me and ask, in a polite and kind way, “Your daughter is beautiful! I noticed she has an eye condition. Would you tell me about it?”

Why would I wish this upon myself? How else will people learn about CHARGE syndrome if I don't tell

them? And how else will these onlookers learn empathy for my daughter and her friends if I don't enlighten them? When strangers hear our family's story I want them to be more empathetic to other special needs kids they come across after our encounter. When I share about Shelby and her “Shelbyness” I'm breaking down walls and misconceptions; I'm dropping a pebble in a pond and creating ripples, empathy ripples. I hope that other parents of special needs kids begin to openly share when people stare or comment so that I'll be the recipient of their empathy ripples as well.

I know nothing about autism. A friend at a parent seminar told the group how her autistic son had a meltdown during a shopping trip. I now have a new appreciation for what she goes through and in the future I'll be more tender hearted if I see any kid, autistic or not, having a meltdown. Empathy ripple.

I'm more than an Advocate...

I'm an Ambassador

How am I rethinking my role? For starters I'm expanding my job description, I'm already Shelby's Advocate; but I'm adding the title of Ambassador. It is my role to, in a dignified way, educate others about being deafblind and how this shapes but doesn't define my Shelby Peach. I may be called to represent her and her needs to strangers, educators or even family, but I don't mind especially if it creates an empathy ripple.

Another way I can be Shelby's Ambassador is by not using my Facebook status as a place to post a sassy, passive aggressive response to the insensitive person at the supermarket... “She's not sleepy, she's blind!” I'm using Facebook to create empathy ripples.

I'm excited to view myself as an Ambassador. It is so empowering! And if I don't feel like I'm making enough empathy ripples maybe I'll just buy some custom-made buttons on Etsy that say, “It's ok to ask me about my child.”

[Read more by Nicole on WonderBaby](#)

A Perkins School for the Blind online resource for parents

Embracing the Different

By Suzanne Chen

I never noticed adults or children staring when Parker was younger. I was just so happy to take him out for a walk, or go to a store with him and do “typical things” that moms do with their infants. I didn’t get to experience that for the 13 months that he was in the NICU, PICU and rehab. His being premature and having CHARGE Syndrome took that away from me. My husband Ed said he noticed it (people and children staring) but never told me. I never saw Parker the way some adults or children saw him.

When he looked in the mirror and I saw him, he looked perfect. I didn’t see the asymmetrical face, the crooked smile, because I knew how long it took for him in speech therapy to get that half smirk. Months and months of therapy, oral motor exercises, electrical stimulation, repetition, trusting strangers to show me and him what the body he was born with didn’t allow him to do.

I didn’t see the misshaped ears, the coloboma eye. I didn’t think, why is he so small for his age. I marveled that we made it through each day, way week, each month. I didn’t see the tracheostomy in his neck, I just knew it kept him alive, breathing and safe. I didn’t see the oxygen tank and beeping pulseox machine under my stroller basket, because it monitored him and alarmed me when he was moving or needed suctioning.

My friends and family never shunned him, they embraced him. They were curious and sometimes concerned and they asked questions, but it



Parker, left, with siblings Pierson and Piper

was because they loved me, Ed and our new family. They included him in parties and celebrations, we went for playdates and I brought him to an infant program to learn to communicate with him.

But the world we live in is not always like that. After Ed opened my eyes, I did notice some children or adults staring, or parents grabbing their kid’s hands if they wanted to come and talk to Parker, or siblings nudging each other to look as we walked down the street. I always approached the situation as a teachable moment and compared it to something the kids could relate to, a superhero with special powers or a Mr. Potato Head with missing pieces, a Bionic man or woman. They always thought it was cool or interesting.

But Parker also made me that way, embracing the different, learning to be patient, understanding, and kind. He taught me (and is still teaching me) that he is proud of who he is, and how far he’s come, celebrating each small or big accomplishment, and that when things get rough or rocky or you feel like giving up, all you need is that big, genuine, unconditional hug.

The world can and will be cruel sometimes to that face, but I know how amazing and special that face is. He is beautiful.



Rare disease research is crucial to providing families with the answers and solutions they need, including treatment, a cure, or improved care.

The CHARGE Syndrome Foundation is pleased to sponsor research into CHARGE syndrome through pilot grants, research at conference, and symposia such as that at the University of Michigan in November.

We want you! Get ready for Research at Conference

By Meg Hefner meg@chargesyndrome.org

In 2015, we had almost a dozen research projects taking place at conference and we hope to have many opportunities for you to participate in research in Orlando. Watch for more information as conference draws near. But what if you aren't going to conference? Or what can you do now? Every project needs baseline information on the individual with CHARGE. The CHARGE Syndrome Clinical Database Project (CSCDP) was created for research and to provide baseline information directly to other researchers. You can enter information on your child and upload photos and medical documents.

Information on CSCDP, including how to get started, is here: [CSCDP](#).

If you would like to conduct research at conference, click for more information: [Conference Research](#)

Chromatin in Development and Disease

By Donna M. Martin, MD, PhD donna@chargesyndrome.org

The 2nd “Chromatin in Development and Disease Symposium” was held on Monday, November 7, 2016 at The University of Michigan in Ann Arbor. The symposium was sponsored by the CHARGE Syndrome Foundation and the Departments of Pediatrics, Human Genetics, Biochemistry, and Neurology at The University of Michigan. There were 10 invited speakers, 5 local speakers, and over 100 registered guests who gathered for a full-day of presentations, discussions, and posters to share exciting new research in the area of chromatin and its involvement in development and disease. Chromatin is the term describing proteins and DNA that are responsible for orchestrating and instructing cells about which genes to turn on or off. Many developmental conditions, including CHARGE Syndrome, are caused by changes in chromatin and gene expression.

The goal of this symposium was to explore new research topics related to stem cells, gene editing, enhancer biology, and basic mechanisms of human development and disease. Many new collaborations were forged as a result of this symposium, and we look forward to learning more about discoveries that result from this exciting research.



Provider Recommendation Database – We Need Your Help!

When I began my job as Director of Outreach in 2010, I received numerous requests for doctor recommendations and I knew the Foundation needed to provide this service to families. In July 2011 the Provider Recommendation Database was born.

There's just one problem – we don't have enough submissions! We need more! If you know of a provider who understands the complexities of CHARGE syndrome, who is knowledgeable about CHARGE syndrome, who has been helpful to your family, or who has been willing to go that extra mile and learn about CHARGE, please consider submitting their name and contact information to the Foundation. The submission form is confidential and takes a couple of minutes to complete.

We are always looking for new recommendations, so please [click here](#). If you are a service provider and wish to be listed, please submit a self-referral at the same link (the person submitting the referral will not be listed).

If you are looking for a physician or therapist in your area, please email Sheri Stanger, the Director of Outreach: sheri@chargesyndrome.org. Be sure to indicate your name, your state/province/country, and the type of provider you seek. While the Foundation does not endorse or recommend any specific providers, we are happy to share the information we received from our families and members.

The Foundation provides this service only to our registered constituents. If you are not registered with the Foundation, please do so before requesting the provider list. To register please [click here](#).

Once you receive the list of providers, we hope it will be helpful as you research the best medical professionals for your child or yourself. Please keep me from telling families that I don't have any doctors listed in their area. Our CHARGE community is incredible with the support they provide each other. I know I can count on for these recommendations. Thank you for taking the time to help another family.

Sheri Stanger, Director of Outreach
sheri@chargesyndrome.org
1-855-5CHARGE (855-524-2743)



The CHARGE Center at Cincinnati Children's—the only center of its kind—recognizes that caring for children born with CHARGE syndrome is complicated. The Center was created to provide the help needed to negotiate both the medical and developmental challenges associated with CHARGE.

Videos of the presentations from the CHARGE Center at Cincinnati's CHARGE conference, held in October, are available [here](#).



The Cincinnati Children's Hospital CHARGE conference gets underway with Meg Hefner and a great deaf blind simulation.

Photos by David Brown

Tell your health care providers!

There is a new article in the *American Journal of Medical Genetics* on how to care for someone with CHARGE.

Written by professionals long involved with CHARGE, based on their own expertise and information gathered at CHARGE conferences:

*Developing a **CHARGE syndrome** checklist: Health supervision across the lifespan (from head to toe).*

Trider CL, Arra-Robar A, van Ravenswaaij-Arts C, Blake K.

Am J Med Genet A. 2017 Feb 4. doi: 10.1002/ajmg.a.38085.
[Epub ahead of print] PMID: 28160409

Rachel Malta *(continued from page 9)*

leave me daydreaming, but most speakers were able to break down the scientific jargon into bite-sized “average people” pieces, interspersed with humorous analogies. This kept my attention and left me excited about new discoveries and future directions for researchers. At the International Conference, I enjoyed the variety of panels and presentations offered. I especially appreciated presentations on topics that are seldom discussed in schools or at other professional conferences, such as sex, hormones, and related behaviors. These apply to my work in the schools, regardless of whether or not a student has CHARGE syndrome, since these areas should be covered for all kids who often are not able to learn about appropriate sexual behavior indirectly. I presented a poster regarding my graduate thesis project on CHARGE. The community of parents and family members were incredibly excited about research that may seem small to those outside of “CHARGE Land.” They asked questions and related anecdotes, which served to renew my drive to finish my project and get the data and information out to families. It is remarkable to know what you are doing is making a difference.



My expectations for volunteering at Camp were exceeded. I was matched with a nine-year-old boy, E, who I later learned had a cochlear implant that he was not wearing, and an easy-going staff member. While it was not the experience I was expecting, I spent the entire afternoon laughing. Tim Hartshorne constantly tells his students and families that children with CHARGE have a unique sense of humor, despite their sensory impairments and challenges. I found that to be true with E. From the beginning, it was clear he had gotten into a routine with his staff member and was not looking for anyone additional. The three of us spent hours walking up the hallway, down the hallway, riding down the escalator, up the escalator, and repeat. Despite being completely deaf without his cochlear and being paired with two adults who did not know any sign language, he managed to communicate. E loved holding the hand of the staff member hand while we walked, though mine was unwelcome. For the first few hours, the E would start walking down the hallway and veer off toward the elevators. We adults thought he was changing his route, so we followed him. However, each time, he would look back, see me following him, and immediately go back to his regular route, pushing me back toward the elevator and waving goodbye to me. While this may have been off-putting or disheartening to some, I was mostly amused by how often he tried to “fake me out.” Later, during the Home Depot building project, E allowed me to help him hammer nails in. The most touching moment I had working with him was during that project. I was holding the nail straight in the wood project and helping by guiding the hammer over the nail while E applied appropriate force. One time, he saw my fingers were in the way and could be potentially smashed when we were hammering. He made sure to grab my hand and move it to a safe place before we resumed our pounding of the nail. To me, E embodied what I know of children with CHARGE: they are funny, sometimes mischievous, but with a heart of gold and usually empathy for those they interact with. It was one of my favorite periods over the weekend.

By far, though, the best part of the conference was the camaraderie I witnessed between the families -- whether they had known each other for years or had just met for the first time. There were events every night where people celebrated their child or children who happened to have CHARGE and enjoyed their time together. No one was embarrassed by any behaviors and were able to let their child be themselves without fear of consequences or “looks.” I often heard snippets of conversations that involved, “My kid does...” and, “Oh wow, mine does that too!” These collective moments are most special to me, especially as a professional working in schools. Oftentimes, we might be the door to resources and people

(continued on next page)



Charge It for CHARGE The Online Fundraising Campaign of the CHARGE Syndrome Foundation.

Your support helps fund research, outreach, scholarships and biennial international conferences. You can make a difference!

BECOME A FUNDRAISER SUPPORT A FUNDRAISER

SIGN UP HERE

***We want all of our families to be able to join us
As we Take CHARGE in Orlando in July.***

Participate for Prizes and Free Conference Registration!



Raise \$2,500* - Earn One (1) Free Conference Registration, Conference T-Shirt & Sweatshirt

Earn an Additional Registration (up to 4) for Each Additional \$2,500 Raised

Raise \$1,000* - Receive a Free Conference T-Shirt & Sweatshirt

Raise \$500* - Receive a Free conference T-Shirt



***By June 1, 2017. Limit One (1) T-Shirt and One (1) Sweatshirt Per Fundraiser**

Rachel Malta (continued from page 17)

so that parents do not feel alone amidst difficult decisions and friends whose children may be achieving milestones on a “typical” timeline.

The Sandra Davenport Fellowship was crucial in helping me attend this conference. I learned a great deal from the cross-collaboration of fellows in different fields and professions, which I would not have been able to do outside of this program. I also enjoyed the debriefings with Sandra Davenport and Meg (Hefner), as they have been in the field for many years and had wisdom and insight into experiences we discussed. I hope to be able to continue attending CHARGE conferences in the future in order to maintain connections, refine my skills, and grow as a professional and person. Regardless of the busy schedules and chaos of everyday life, there is always this time set aside to keep in touch with the community and my intention is to take advantage of those opportunities when they come my way.