



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

As we get ready to put 2018 in the rear view mirror, I want to wish my entire CHARGE family Happy Holidays and Happy New Year. For me, December is always a time for family, friends and a bit of reflection. I took a little time to look through some newsletters and financial statements from years ago. I am proud of our history and the progress we continue to make and I am optimistic about our future. I am also realistic about the challenges we will continue to face and hopeful that we will exceed all expectations.

During this year we expanded our State Liaison program, increased the number of EWRAP recipients, produced high quality webinars, started a CHARGE grief support group, funded an endowment to protect the future of the Foundation, allocated more money for regional gatherings and continued to fund high quality research. This is ALL due to the hard work of our volunteers and the financial support of our donors and fundraisers.

While we did a lot this year, we have much more to do. Our 2019 Conference planning is in full swing and the weekend will be spectacular! While getting ready for conference, we want to continue to expand our other programs. To make it all happen in 2019 we need more volunteers and more financial support. If you are willing to volunteer please reach out to us at info@chargesyndrome.org. There are so many ways to lend financial support: become a member, donate, and/or fundraise. Don't forget, for every \$3,000 you raise through Charge It for CHARGE, you earn a free conference registration!

Hope to see ya'll in Dallas this summer. Happy Holidays,

David

David Wolfe, President

A CHARGE CONFERENCE IS A LIFE-CHANGING EXPERIENCE!

*Families come from all over the world to share with each other and learn from dedicated professionals who are experts in all things CHARGE.
Make your plans to join us in Dallas, August 2-5, 2019*

HOTEL RESERVATIONS

\$169 per night. Make your hotel reservations using [this link](#). Email neal@chargesyndrome.org if you need a suite or an accessible room.

CONFERENCE REGISTRATION

OPENS MARCH 2019

\$325 adult or child attending camp,

\$225 child not attending camp, \$175 Professional Day

SCHOLARSHIPS & FUNDING GUIDE

Scholarships are available to Foundation members. ***Join today!***

Applications and funding guide will be available in January 2019.

VOLUNTEERS

We rely on volunteers to make our conference a success. We especially need skilled signers to help in camp. [Click here for the volunteer application](#). Email joanne@chargesyndrome.org with questions.

Texas families: Please share with your child's teachers and therapists

SILENT AUCTION & BASKET RAFFLE

Do you know anyone with a condo or timeshare?

Do you have access to sporting events or amusement park tickets?

Do you know someone who owns a business and would like to help a child with CHARGE?

Are you willing to ask a business to donate an item that could raise money to improve the lives of people with CHARGE syndrome?

If you can say yes to any of these, we need your help! The CHARGE Syndrome Foundation is looking for awesome Silent Auction and Basket Raffle prizes! The more donations we collect, the more money we can raise for the CHARGE Syndrome Foundation! ***We are looking to start collecting prizes now!!***

The donation form and letter can be found [here](#). If you have any questions, please contact Deanna Steinhauser at deanna@chargesyndrome.org



**EARN A FREE
CONFERENCE
REGISTRATION!**
SEE PAGE 12

CALL FOR PRESENTATIONS IS NOW OPEN

We invite those who would like to share their CHARGE expertise with conference attendees to submit a proposal. [CLICK HERE](#).

Presenters are invited to apply to present at both Professional Day (shorter, more technical presentations, geared to other professionals) and the International Conference (longer presentations, geared to families), as well as to create posters summarizing their work.

Deadline: January 31, 2019

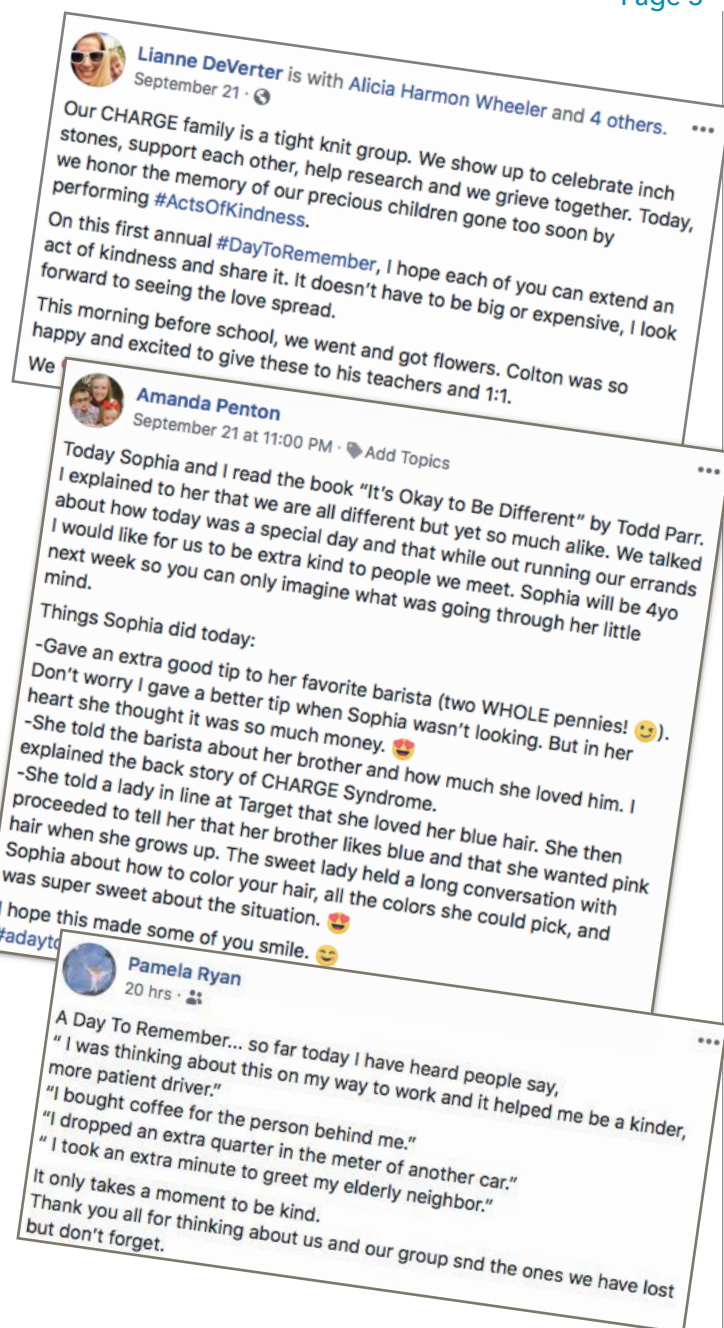
A Day to Remember

On September 21, which was also the International Day of Peace, we honored the memory of those individuals with CHARGE who passed away with A Day to Remember. We asked everyone to perform an act of kindness and share it with us on social media using the hashtag **#adaytoremember**. We loved seeing your photos of joy and kindness.

The goal was to spread as much kindness as possible on that day. It could have been something as simple as sending an encouraging e-mail, making a donation, or spending time with loved ones.

These kind acts showed our solidarity as a CHARGE community and signified to the families who have lost their loved ones that we will ALWAYS REMEMBER.

[Click here for more photos and stories](#)



CHARGE Foundation State Family Liaison Project

In 2014, The CHARGE Syndrome Foundation launched the “State Parent Liaison Project” to provide families access to information and resources to better advocate for their child. Recently, the Foundation renamed the program “State **Family Liaison Project**” and decided to expand the criteria for serving in this critical volunteer position to include family members of individuals with CHARGE syndrome. Why? Because we know that sometimes grandparents and adult siblings can be just as invested and passionate about supporting and connecting families as parents are AND they may actually have more time to serve in this role. Our ultimate goal is to have a family member from every state serving as a liaison between the Foundation and the State Deaf-Blind Project. All work is done via email, social media and phone, with quarterly virtual meetings with the Family Engagement Committee.

Since its inception, the program has grown to 18 liaisons in the following states: AR, AZ, CA, DE, FL, KS, KY, MI, MN, MO, NH, NJ, NY, PA, SC, TN, TX, UT. If you are a family member of an individual with CHARGE syndrome, the Foundation encourages you to reach out to your state liaison (if you have not already), to introduce yourself and your family, and to see how you can connect to the work they are doing in your state.

The current list of liaisons can be found [here](http://chargefoundation.org). If your state is not one of the states listed above, and you or someone you know is interested in applying for this volunteer position, we strongly encourage you to reach out to Minnie Lambert, Family Engagement Committee Chair (minnie@chargesyndrome.org). She would be more than happy to answer any questions you have.

Kate Smith, the Family Liaison for Missouri, sent in her successes to share with the group. Kate has been the liaison since March 10, 2017. She has made immense progress, starting with meeting with the Missouri Deaf-Blind Project staff to talk with them about her position

and what motivates her in this role. The Deaf-Blind Project is putting plans in place to do a “Deafblind 101” training for teachers in the St. Louis area and will be working with Kate to assemble a parent panel to make sure CHARGE is represented at the training. She is also working with a local nonprofit, Delta Gamma Center for Children with Visual Impairments, to organize a get-together for CHARGE families. If that’s not cool enough, the Missouri Deaf-Blind Project also helped to cover her cost to attend the conference sponsored by the CHARGE Center at the Cincinnati Children’s Hospital held on July 26-27, 2018. She plans to share all of the information she collected at the conference with the families in Missouri. Kudos to Kate for getting in there to make good things happen for families in her state!

If you live in Arkansas and have a family member with CHARGE syndrome, you’ve hit the jackpot with Casey Adams as the Family Liaison in your state. Casey is married to Nic and they are raising two adorable sons, Kash (6) and Kolt (5). In recent months, Casey has been working closely with the Arkansas Deaf-Blind Project (known as Children and Youth with Sensory Impairments–CAYSI) to ensure that the families of children with CHARGE syndrome are aware of her role and know how to connect to her and to the Deaf-Blind Project. They have also been formalizing plans for how they will partner to ensure that families are better connected to one another and needed services. Talk about great teamwork! Thanks Casey for all of your hard work on behalf of the foundation! And a big thanks to CAYSI for their willingness to collaborate to enhance services for families.

We also thank all of the other amazing parent liaisons for all of the personal time they commit to making the Foundation stronger and connecting families. We value all of you! To learn more about all the liaisons and their families, click [here](http://chargefoundation.org).





North Carolina Family Hosts Summer Lake Party

On July 21st, Jacob Jones and the Jones family hosted their second lake party on Lake Norman, NC for individuals with disabilities including CHARGE syndrome, Deaf-Blindness, and Cerebral Palsy. This event was started 3 years ago when Jacob asked to have a party where past and new friends could gather for fun and socialization. Lake activities included swimming, boat rides, jet ski rides, inner tubing, kayaking, golf cart rides, balloon toss, arts/crafts and a lot of great food. Families were able to come together for fun and networking. Jacob (CHARGE syndrome, 23) starts planning months in advance with party planning and preparations being incorporated into his daily activities. Families as far as VA (formerly from NC) made the trip to reunite with friendships of 20 years. Thanks to family members from VT, TX, and FL who assisted in the event.

Jacob lives in NC with his family. Public awareness of CHARGE syndrome and a push for systemic improvements for services relating to individuals with disabilities remains a key family goal.

Please visit – www.jacobincharge.com or #jacobincharge

Jonas' Cookery School

Jonas has a plan: To get rid of the tracheotomy at 16, to have a beard at 17, to drive a car at 18, and to live alone at 20.

For Jonas to remain motivated, everything he learns must have a purpose. In his case, his big goal of living alone at the age of 20 gives him all the motivation he needs to learn how to cook. Read his mom's diary of Jonas' first cooking lessons on our [website](#).



A Hidden Bowel Defect

by Megan Gross

In the summer of 2014, we finally felt like we had hit a good point with our daughter Evie. She'd just turned three, she'd stopped having monthly hospital stays for colds, and she seemed to be getting stronger. Mid-July, another virus hit, and within a few days we were in the hospital with her vomiting blood. A tip from a CHARGE mom (Thanks, Amanda!) led me to ask the doctors to do an abdominal ultrasound to look for an intussusception (the intestine telescopes inside itself and then gets stuck). She didn't have any of the classic symptoms (stomach distention, dark red jelly-like stools, increased heart rate) and the doctors didn't think that was the problem, but it was non-invasive and we had a good relationship with them.

And there on the ultrasound was an intussusception, a literal bullseye on the screen. Unfortunately, not every doctor was convinced, particularly the surgeon. Despite the clear evidence of an intussusception, he dismissed all FOUR ultrasounds because he didn't feel Evie was in enough pain. "I'm a simple man who likes simple answers. This is just a stomach bug."

Tip: if one of your doctors insists on simplicity, they are not the right fit for CHARGE.

Following a rather large and scary overdose of a sedative, the intussusception resolved. From there, Evie would have periods of being fine and then times when she would writhe around, her stomach would get distended, and her heart would slow. Then she'd have a mucous stool and be fine.

This began a long journey of recurrent and worsening symptoms. Most of the time, Evie would be fine, but

then she'd have another bout of pain and vomiting followed by a mucousy stool.

Mid-October, another respiratory illness hit and Evie stopped tolerating her feeds completely, forcing us to move from bolus to continuous g-tube feeds.

When we arrived at Cincinnati Children's for scheduled scopes in November, Evie was lethargic, having all mucousy stools, and her heart was only beating at half her normal speed. An ultrasound showed transient intussusceptions. Essentially, the bowel was telescoping in and out in the same place over and over, getting stuck at times. We were told that shouldn't cause any problems. It's only when the intestine gets stuck for long periods of time that it is problematic. Bull.

A month long hospital stay was frustration after frustration. Evie's labs looked terrible, her heart rate was low, and at one point she became septic with lactobacillus (a very weak and strange bacteria to cause a blood infection when the patient does not have a central line OR a severely compromised immune system). I knew there was a bowel defect in there we were missing and I knew it was only a matter of time before we had a full blown bowel perforation. But all imaging came back normal. No bowel defect. No signs of perforation. No inflammation. "Unremarkable."

Christmas and New Year's were spent dealing with c.diff caught during her month long stay, but she didn't improve with the antibiotics and we started to notice black in her stools. She was bleeding. Low heart rates were the only other sign along with hair pulling which we'd learned was her signal for pain. Otherwise, she seemed fine, but we knew something was very wrong.



Evie "before"

After a week of trying to convince her doctors that this was not just a small amount of blood, her pediatrician agreed to order labs.

That night, she called and told us we needed to bring Evie into the local children's hospital right away. Her hemoglobin had dropped several points and she likely needed a blood transfusion.

We did various testing to try to find the source of the bleeding, but it had always stopped by the time we were looking for

continued on page 11

CHARGE Doesn't Stop Us From Traveling

by Laurie Suter

We are the Suter Family from New Hampshire and we love to travel! I am a single mom to four children and three have significant special needs. My oldest daughter Amanda, 29, has brain malformation, autism and seizures; son Jordan is 28; Lacey, age 19, who has CHARGE and is medically complex, uses a wheelchair, has a surgical J-tube for feeding and a G-tube for meds. She also has a seizure disorder. She can eat a little by mouth - purees only. My youngest son Noah, age 6, also uses a wheelchair and has CP due to brain injury from Shaken Baby Syndrome. He also uses a G-tube for feeding. Lacey has been traveling since she was a baby despite her numerous medical challenges. She loves going on airplanes, always sits in the window seat and loves playing with the shade. I make sure I bring new toys and sensory items for the plane ride and her iPad of course! She does awesome on the plane! We have traveled to so many places and CHARGE hasn't stopped us! Lacey has been to England and Italy. We cruised around the Mediterranean to Italy, Greece and Turkey. She even went up to the Acropolis in Athens. It was bumpy and fun pushing her wheelchair. She loves the bumps! We love going on cruises and last year went to beautiful Alaska (we loved it!) and enjoyed a cruise to Bermuda from Boston. Lacey especially loves the warm water so she loved Bermuda! We love going to Disney World and Lacey loves all the fast rides, of course, including Expedition Everest and Tower of Terror.



Packing is fun!! It can get overwhelming but I pack at least a week before a trip. I write out a list and check everything off. There is so much to pack! Formula for both Lacey and Noah, g and j tube supplies, briefs (diapers) and pull-ups and numerous medicines. Even though it is tiring, it is worth it to see my children having fun and experiencing the world! We are flexible too. When we go to Disney World we get there for rope drop, have a good touring plan and stay in the park until lunch and then go back to the hotel to go in the pool. Lacey loves the water and enjoys the pool! It is a nice break for her and everyone too. We go back to the park in the evening.

Nothing holds us back from enjoying life!



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 young professional to attend both Professional Day and the biennial International CHARGE Syndrome Conference. The 2017 Fellows met together daily along with Fellowship mentors Pamela Ryan, Meg Hefner and Sandra Davenport. Each Fellow was also 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* 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), Alex Donovan (research grad student), Zachary Bird (ABA specialist) and Dieuwerke Dijk (Pediatrics & Developmental Disabilities physician). Charlotte Reimer (SLP grad student) and Hui Yao (research post-doc) reflect on their experiences in this issue. Watch for the final installment in the Winter 2019 issue.

If you or anyone you know might benefit from being a Davenport Fellow at the 2019 conference, watch for announcements and application in January 2019

If you would like to have your family matched with a Fellow at the 2019 conference, watch for announcements in the spring.

Hui Yao, postdoctoral fellow in the lab of Dr. Donna Martin

I am Hui Yao, a postdoc at University of Michigan in the lab of Dr. Donna Martin. I attended the 2017 International CHARGE Syndrome Conference in Orlando as a Davenport Fellow. I was paired with Aaron and his family. Aaron is 30 years old and has CHARGE. He speaks not very clearly - only his sister Jillian can really understand him. I believe it is really love that made the sister adopt her brother and give so much so careful care to him. To take care of a person with CHARGE, you need much more patience, love and time, to learn many special skills to take care of them and train them for independent life.

Meg [Hefner] told all the Fellows to not only focus on our own research field, but also to keep an open mind to all of the fields concerned with CHARGE. The first conference I attended in Chicago I paid much attention to the children with CHARGE. This time I told myself I should learn more about CHARGE family life. I stood in the lobby of the hotel, and looked at all the people around me. I saw a father trying to catch one boy who cannot stop rolling on the ground, I saw a mom who was telling a 10-year-old boy to be careful and keep away from a table. I went ahead to talk with a mom, and she told me they like conference because there they found friends and family who understand. Another mom told me what they suffered because of the disease, the whole family lost privacy because of medical care needed in the home and emergency situations keep appearing from the birth of the child with CHARGE. Also because it is a rare disease, not too many people around a CHARGE family can really understand what they are suffering and not much emotional support can be gotten from relatives and friends.

Pam [Ryan] gave us some special glasses and ear plugs so the Fellows could experience some of the real life challenges of children with CHARGE [deafblind simulation]. Wearing these glasses and ear plugs (right), I experienced difficulty in



continued on page 11

Charlotte Reimer, SLP graduate student

I have always believed in the power of stories. Indeed, I decided to become a speech-language pathologist (SLP) because I believe every person has a right to communicate and share his or her experiences. When I was selected as one of the Davenport Fellows, my personal goal, beyond professional development, was to hear stories from the perspectives of people with CHARGE and their families. After four days immersed in the world of CHARGE, so vividly embodied in the faces and words of those I met, I was so much more aware of the struggles, hopes, disappointments, and joys within this community. Here I will share and reflect back on some of the special, inspiring stories I heard.

David Brown concluded the 2017 Conference with “Deep Thoughts,” a much more contemplative speech than the one-liner jokes on Saturday Night Live of the same title. When I first arrived in Orlando, I barely recognized his name (so well known within the CHARGE community) because my experiences and knowledge of CHARGE were limited. Before attending this conference, I had independently stumbled into the world of CHARGE through my first client as a graduate student of speech-language pathology at California State University East Bay. Her family told me about the Conference and her speech therapist introduced me to California Deaf Blind Services. It was only over the four-day conference that I truly realized the full extent of David Brown’s expertise, his groundbreaking research, and his extraordinary outreach work with people with Deafblindness. In his concluding remarks, David described the devotion of families to their loved ones with CHARGE as so profound that even strangers to the family, including professionals, might view it as “irrational.” *The kind of speech-language pathologist I want to be, I thought, is someone who will always attempt to acknowledge the devotion and love from a child or adult’s family and to work with them as rational people.* Of all the remarkable things I learned as a result of my experience as a Fellow, what inspired me the most was the support, generosity, knowledge, and kindness of those involved in CHARGE. The unshakable devotion of family members to their loved ones with CHARGE awed me daily. Each part of the CHARGE community, from the individuals with CHARGE and their families and friends to clinical and/or scientific professionals and other graduate students, instilled in me knowledge that



Charlotte and Grace

will follow and influence me beyond my graduation date in December (2018).

My host family

One story stands out among the crowd: my experience with my host family, the Dagleys, and their daughter Grace. I spoke only once with Karin Dagley before meeting her family in Orlando, and yet this strong, tenacious family gave me the greatest gift you can receive as a new clinician: honesty, trust, and a comfortable, open dialogue about their struggles and their achievements. Eleven-year-old

Grace is a non-verbal, mostly pre-symbolic communicator with a playful vivacity for life. During the CHARGE-A-Palooza carnival on Saturday evening, I watched Grace smile and spin, dancing for what seemed like hours with an energy only matched by her younger brother Jack as he zipped around the room. During Camp, Grace and I played together in the sensory room, laughing at the sounds from a light-up toy. She communicated through gestures or movement and an occasional sign, but I still struggled to understand her wants.

At several points during our time together, Grace did get upset. As it turns out, she was most likely suffering from stomach or constipation pain and had no way to express it to me beyond frustrated verbalizations. In those moments, I felt strongly how much Grace wanted to convey her message clearly. I had seen how her mother, father, and brother could often understand her in a way I could not—they could recognize which sound or movement meant what emotion or want. Observing their interactions solidified my determination to always incorporate families in speech therapy, especially within special education communities. Karin told me about many positive and sometimes negative experiences the family has had with therapists and other professionals, all of which offered insight into how I should interact with families once I begin working in a school, hospital, or private practice. Families can help the world comprehend a loved one’s voice, amplifying that voice through their intimate knowledge. I cannot thank this Fellowship enough for the chance to meet the Dagleys and Grace, and I cannot thank them enough for sharing their story with me.

Other Fellows

Graduate students, including the other ten selected Fellows, also inspired me and shaped my overall

Charlotte Reimer, continued

experience at *Taking CHARGE in Orlando*. Right away, I knew my Fellow roommate Chathuri, a doctoral student of school psychology, and I would get along. Her passion for school psychology and her area of research, sexuality education, vibrated through her every word as we headed downstairs to breakfast on our first day, Professional Day. Chathuri introduced me to her graduate student colleagues from Mississippi State University and during the poster sessions I tried to visit each and every one of them, learning from their research on IEPs of students with CHARGE. As I moved on to other posters, I was impressed with the extent and variety of research. There was Emily Fassi (also a Fellow) displaying her work on documenting milestones in children with CHARGE syndrome. As examining typical and delayed milestones plays a significant role in diagnosis in speech-language pathology, we had a lot to share with each other. *If it were not for this Fellowship*, I thought, *I would not have known how much research on CHARGE syndrome existed!* With every student I met and smile we exchanged, I felt as if I was building my own professional network with a group of excited, passionate students and soon-to-be professionals.

Professional Day and Conference

While my fellow graduate students and Fellows introduced me to emerging research on CHARGE syndrome, the talks by seasoned professionals expanded my knowledge base extensively. Expertise in communication and communication disorders relies heavily on many different fields, from neuroscience to audiology to otolaryngology and more, and listening to many specialists at one conference discuss various aspects of one syndrome was an ideal learning opportunity for me. I savored the chance to listen to so many speakers from outside my field, especially as other professional conferences I have attended have been mostly limited to SLPs and audiologists. As a Fellow I was also able to meet many of these leading professionals, either through our Mentors or through my cohort of Fellows. Besides their warmth and desire to hear about my experiences, every professional I met imparted to me a strong desire to build my own clinical or research group centering on CHARGE. The Fellowship mentors—Pam Ryan, Meg Hefner, and Sandra Davenport—were especially encouraging and fostered an equal environment

within the Fellows, where everyone felt comfortable sharing their experiences and capabilities. I had not realized before what a privilege I had earned as a Fellow—to be granted the unique opportunity to converse and learn from the women who literally wrote the textbook on CHARGE syndrome and who started the Foundation. I felt again the strong connection and sense of community amongst our mentors and the other scientists, clinicians, specialists, and educators.

An array of experiences

I have only begun to scratch the surface of all the interactions the 13th International CHARGE Syndrome Conference gave me: A young girl with CHARGE sat in my lap at Camp and gave me her bracelet as we watched a reptile show. An audiologist knew one of my professors in California and chatted with me about her work. I shared breakfast and conversation with Fellow Dieuwerke Dijk, her mentor, Dr. Conny van Ravenswaaij, and a family. I listened to talks by SLPs and genetic researchers, each one augmenting knowledge from my graduate school classes while also teaching me about gene mutations and *CHD7*. I sat enraptured as Sandra Davenport told stories from her work as a medical geneticist. Every moment added up, finally tipping over into an overwhelming feeling of gratitude. My experiences as Fellow surpassed my expectations, granting me a true sense of determination to raise awareness about CHARGE and Deafblindness and the desire to push myself even harder to become a better SLP. I made professional connections, yes, but also friends and the chance to be part of a community. I am now currently enrolled in an ASL course and in discussion with my supervisors and mentors at California State University East Bay about how I can do more to spread the word about CHARGE. With the stories and voices of those I met at the conference echoing through me, I make this pledge: I will advocate for communication access and for the stories of individuals with CHARGE to be shared again and again and again.

UPDATE: since this was written last fall, Charlotte has completed her SLP degree, presented a poster on “Communication issues in CHARGE syndrome” at an SLP conference and met up with her Fellow roommate, Chat (left), in San Francisco.



A Hidden Bowel Defect

it. By her third bleed and third transfusion, Cincinnati sent their plane to take her back there. At that point, we were desperate for them to do some kind of exploratory surgery, but the GI team still refused. "She looks really good," they'd say and I'd try to hold back my screams. She ALWAYS looks okay. Even when she lost 40% of her blood, she still looked okay!

Finally, Evie's amazing Aerodigestive team stepped in and took over, having one of their surgeons take a look at her intestines. When we heard they found something, I nearly fell out of my chair with relief. Evie had a mangled section of bowel that we now are fairly sure was a birth defect, since its removal resolved many issues she'd had since she was born.

Recovery wasn't easy. Evie's bowels took much longer than normal to wake up, and with an anaphylactic allergy to IV lipids, we had about three full weeks with virtually zero calories. We watched her waste away in front of us and with every ounce fought for prior to that, I saw little hope of her recovering that weight anytime soon. Instead, she grew. FAST. Before even increasing her calories from her previous level, she gained nearly fifteen pounds in a matter of months. And height! She suddenly was shooting upwards! Her feeding rate more than doubled! Her volume then increased dramatically!

Evie had never even been CLOSE to getting onto the growth charts and suddenly she was up at the 30th percentile for height and weight. She's continued to climb the charts. Today, Evie is healthy and strong. The low heart rates she'd struggled with since birth and that had worsened during the bowel issues have resolved. It is rare for her to go so low anymore.

Hui Yao, continued

talking with others because I couldn't hear clearly and I wasn't able to pick up visual cues from the speakers; I felt like I'd rather keep alone. I also found reading was so hard with the blurry glasses. Especially after wearing the glasses, I understood why children with CHARGE come up and check my ID card so closely. With more and more learning about CHARGE syndrome, I know clearly that I want continue the research about CHARGE after I finish my postdoctoral job. In Professional Day, after I finished my presentation, one mom and her daughter came to tell me that they hope for me to continue the good work. Maybe for them, research on CHARGE means future hope. At that moment I felt duty and trust.

Thanks to the CHARGE Syndrome Foundation and Davenport Fellowship program for giving me so much different experience.

continued from page 6



Evie "after"

I started reading all I could about the vagus nerve after that. I think part of why we struggled so long to find the problem was that her vagus was keeping her body calm when it should have been panicking. Normally, when you have damage and trauma, your body reacts, helping you pinpoint problems, but in Evie, that vagus being stimulated seemed to keep inflammation and her heart rate low. Is this why we seem to see kids go from stable to crashing overnight? I don't know, but I hope we'll see more research into both bowel defects and the vagus nerve in the future.

continued from page 8



We remember Sharon Barrey-Grassick, a friend of the Foundation, who passed away earlier this year.

"The children who are deafblind I have worked with and their families have inspired me in more ways than they can ever imagine."

PHOTO CREDIT: VICTORIAN DEAF EDUCATION INSTITUTE

A Little Extra Incentive

We understand that the cost of attending conference is significant so we've created a way to make it easier to get to conference and enable the Foundation to help others at the same time. **From now until 6/1/19, you can earn a free conference registration for every \$3,000 raised** through Charge It for CHARGE (CIFIC). The more you raise, the more free conference registrations you earn! We hope this "Little Extra Incentive" will encourage YOU to give CIFIC a try and help get you and your family to conference.



Charge It for CHARGE (CIFIC) is our primary online fundraising campaign. Donations through CIFIC help us send individuals with CHARGE to conference, purchase adaptive bikes through the Ethan Wolfe Recreational Assistance Program, and fund research grants. In the few remaining weeks of this year, we hope to far exceed our \$150,000 goal so that everyone who wants to attend can join us at our 14th International Conference in Dallas, Texas on August 2-5, 2019.

CLICK HERE TO START A CIFIC FUNDRAISER OR TO MAKE A DONATION



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A new CHARGE sign, aluminum power bank, pendants, nurse's t-shirt and tech items all make great gifts.

Use your CHARGE logo items with pride to help create CHARGE awareness and support the mission of the Foundation.

Spend \$50 and receive a free CHARGE magnet. We can now ship worldwide; calculated shipping rates apply.



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