The Third Class of Sandra Davenport CHARGE Syndrome Fellows

by Megan Schmittel and Sara Espanet

Another group of Sandra Davenport Fellows has become part of our CHARGE Family! 14 Fellows who were chosen from a wide group of international applicants attended the 14th International CHARGE Syndrome Conference in Dallas in August. This year's group of Fellows was larger than previous years because of additional financial support from some of the institutions where the selected Fellows work. The 14 included young professionals and graduate students in education, behavior, medicine, genetics, audiology, and neuroscience. Their interest and experience in CHARGE varied widely and they all benefited from the diverse professional perspectives. The Fellows shared why they wanted to be a Fellow, previous knowledge, and what they gained from their experiences at the conference. Each Fellow is matched with a family with an individual with CHARGE at conference. They get to know the family, share a meal with them, and spend half a day volunteering in Camp with their family's child.

What are Sandra Davenport CHARGE Fellows (SDCF)?

Dr. Sandra Davenport is a (now retired) pediatrician, geneticist and deaf-blind specialist who was a founding member of the CHARGE Syndrome Foundation. In recognition of her lifelong work with the CHARGE Syndrome Foundation, the Fellowship program started in 2015 was named in Sandra's honor. The program provides scholarships to bring young professionals to the biennial conferences. Fellows are selected based on their demonstrated knowledge and interest in CHARGE. The hope is that they will become an integral part of the next generation of CHARGE professionals. They will go home and use their knowledge, experiences, and connections in their chosen fields to assist families, teach other professionals, and influence educational outcomes for individuals with CHARGE syndrome. The program was initially run by Meg Hefner, Sandra Davenport and Pamela Ryan serving as mentors. In the spirit of passing the torch, this year it was largely taken over by Fellows Sara Espanet and Megan Schmittel. We anticipate the SDCF program will continue to be self-sustaining, with each new batch of Fellows mentored by previous Fellows.

Back Row (left to right): Rilla Hammett, Dieuwerke Dijk, Ira Padhye, Julia Morrison, Elaine Ritter, Lily Slavin. Front Row (left to right): Hallie Smith, Laura Krueger, Megan Schmittel, Sara Espanet, Megan Anderson, Meg Hefner, Brianna Ralston, Sandra Davenport, Sarah Schoffstall

What do Fellows do?

All Fellows attend both Professional Day and the International CHARGE Conferences. Many of them had platform presentations or posters of their CHARGE work. Each day, all of the Fellows meet with the mentors to discuss their experiences of the day (presentations attended, families met, time spent in camp, etc.). New elements in Orlando (2017) included participating in a deafblind simulation and the Family Match. Each Fellow is matched with a family with an individual with CHARGE at conference. They get to know the family, share a meal with them, and spend half a day volunteering in Camp with their family's child.

At the 2019 CHARGE conference several more components were added to enhance the Fellow experience. Fellows expanded their knowledge about life with CHARGE syndrome by hearing first hand from a young woman with CHARGE and from an adult sibling. Fellows participated more fully in Professional Day by moderating sessions and presenting summaries of sessions at the end of the day. At the International Conference, Fellows helped out with the kids during BINGO and passed out bandanas at the hoedown. To help the Fellows connect as a group, they started Professional Day by having breakfast together as a group and later participated in a team scavenger hunt. We continue to strive to innovate to make the Fellowship experience well-rounded, educational and fun at each conference.

How did the Davenport Fellows find their CHARGE family match?

Meg and Pam "put out a call" to our CHARGE families asking if they would like to "host" a Fellow. Families were matched with a pair of Fellows based on the families interests and the Fellows' areas of expertise. Families and Fellows were introduced via email and exchanged information prior to conference. They first met up at the Opening Reception. Families shared their insights into life with CHARGE syndrome and Fellows shared their experiences and knowledge of CHARGE. If you might be interested in being matched with your own Fellow in Phoenix, watch for information in Conference materials in early 2021. So how did it all go? In each of the next several issues of the newsletter, we will present reflections from the Fellows. (You can see reflections from past Fellows in each of the 2015-2018 issues of CHARGE Accounts). We start with articles by Rebecca Darden-Perry and Elaine Ritter.

Rebecca Darden-Perry

Rebecca Darden-Perry is a PhD candidate (special education) and currently a teacher of the deafblind in North Carolina. She anticipated that attending the conference as a Fellow would accelerate her knowledge and understanding of many areas of CHARGE, which would be useful both for her doctoral work (which is on CHARGE) and in the classroom.

Attending the CHARGE conference as a Davenport Fellow forever changed my life. When I first arrived at the Conference hotel and met the other Fellows, I was nervous and excited at the same time. Being the first Fellow that is deaf/hard of hearing was exciting and challenging. After introducing myself and meeting the other Fellows, I learned quickly we all had a desire to learn as much as possible about individuals with CHARGE. Some of us were new to CHARGE and others were not, but we all wanted to delve deeper. I feel like we formed a bond during the conference that will never be forgotten. Everyone genuinely cared about one another and all the Fellows tried their best to communicate clearly with me, which meant the world. I feel honored to have been Fellow and look forward to attending future conferences as a Fellow, and perhaps one day be on the CHARGE Syndrome Foundation board.

Thursday August 1, 2019

I arrived at the conference hotel and was greeted with open arms and smiles by two guys with CHARGE. One of them immediately began signing and helped me locate the front desk and conference registration. I was amazed to see so many individuals with CHARGE. I was truly excited. Instinctively, I wanted to sit down and just watch everyone, since my research is on social development, but I knew that I had to get settled in and prepare for the first Fellows meeting. I met Meg and Sandra Davenport at registration and they also greeted me with big smiles lots of questions. The thing that I remember most about that conversation with them is that they both encouraged me to continue my research and document everything. They said one thing

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Elaine Ritter

Elaine Ritter, PhD (cellular and molecular neuroscience) is a Postdoctoral Research Fellow in the lab of Dr. Donna Martin at the University of Michigan. Her research is focused on defining roles of the CHD7 gene in the development of neural crest lineages that contribute to the development of the inner ear. These roles may underlie hearing and balance deficits seen in individuals with CHARGE. She presented a poster of her research at conference.

The International CHARGE Syndrome Conference was unlike any other professional meeting I have ever attended. As a PhD researcher working in a lab, conferences that I normally attend are geared entirely toward research, and the focus is typically on a broad field. Those meetings tend to be rather large (many thousands of attendees), and it's easy to fall into a void in the typical research science meeting. With so many people and so many topics, you can feel somewhat isolated, and it can be a struggle to find and connect with others with similar interests and goals. The CHARGE Conference was a very welcome "break from the mold" – smaller, more focused, with an over-arching goal of improving the lives of individuals with CHARGE syndrome. I had the privilege of presenting my work to people who are personally and emotionally invested in CHARGE research. Having attended dozens of conferences over my career, I can truly say it was a unique and wonderful experience.

The feeling of belonging and community I experienced at the CHARGE conference was due in large part to the Davenport Fellowship program. I felt like I was part of a core group of other young professionals who have goals and interests similar to mine, which prevented me from feeling isolated as I sometimes do at other meetings. I especially enjoyed the fun and silly aspects of our Fellows group, like running around doing the scavenger hunt together (see photo, top right). The social bonds made during these activities are important for fostering relationships that are more likely to be maintained in the future. In other words, we are less likely to fall off each other's professional radar, because we made each other laugh.

One of the most valuable aspects of the Davenport Fellowship program for me was the Family Match. Prior to the CHARGE conference I had only met one other individual with CHARGE, a high-functioning adult. Matching with the Johnson family and their 3-year-old son, Holden, gave me a new perspective on what daily life is like for a family with CHARGE. Holden and I had so much fun together in Camp with the other children, and I was able to see first-hand the diversity of features in kids with CHARGE. It's one thing to read about it in the academic literature, but seeing it for myself made it click in my mind. The Johnsons and I also bonded over our shared faith, adding an even greater depth to our time together. Since the end of the conference, I learned that Holden has already improved in his ability to walk independently and is enjoying his new school – this news filled my heart with so much joy! I'm looking forward to staying in touch with them and seeing this beautiful family again at future CHARGE conferences.

Overall, the Davenport Fellowship program and the CHARGE conference were priceless experiences both professionally and personally. Sometimes when experiments in the lab don't work and frustration sets in, it can be easy to lose sight of the big picture of why my research is important. Connecting with individuals with CHARGE and their families and seeing the broader landscape of clinical, scientific, and social research focused on CHARGE put my own research in a whole new light. I'm more motivated than ever to keep working hard "at the bench." I'm excited for the next conference and wish I didn't have to wait two years!

Elaine (center) enjoying conference with friends.

Rebecca Darden-Perry

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that is lacking in the literature is documentation of educational best practices. I promised them that I would do this, and I am!

At our first Fellows meeting, we all introduced ourselves and each spoke briefly about our field of expertise. We had been given bios of each other prior to meeting one another, but it was awesome to meet in person. I met my roommate Sarah Schoffstall and learned that she is fluent in sign language. Sarah was very energetic and like me always looking at the bright side of things. The Fellows were given our agenda and encouraged to get to know one another and our assigned family.

Friday August 2, 2019

The next morning Sarah graciously woke me up, since I am deaf without my cochlear implants and I was all smiles! We headed down to breakfast with all of the Fellows before heading to Professional Day (PD). The other Fellows were all just as excited as I was! We chatted about our interests what we hoped to gain from the conference. PD had general sessions in the morning and then posters and breakouts. I liked how the breakouts were divided into medical/scientific topics and educational topics. As an educator I want to know about the scientific side of CHARGE but not so much in depth - I wanted to attend the educational presentations and perhaps learn some new strategies to use. The sessions I got the most out of on found most interesting on PD were on Sleep and Taking Charge in the Classroom. I have had previous experience with individuals with CHARGE that have severe sleep issues and the parents are always asking me what they can do to help their child sleep. I hoped the session on sleep problems might help me provide some guidance for families. I learned that there are many reasons individuals with CHARGE do not sleep well, including sleep apnea, pain, and environmental factors. Behavioral strategies that might help improve sleep include: avoid night feedings, encourage the child to return to the bed, and keep a chart on how the child is sleeping. Some environmental strategies include change the lighting in the room, change the temperature, and avoid iPad or other electronics. Medication was also mentioned as sometimes helpful.

Rebecca with her roommate, Sarah

“Taking CHARGE in the Classroom” had lots of useful information for me. Assessment was emphasized - so that the educator can better know the needs of the student. They provided a few sample curricula that can be used with individuals with CHARGE and are available on the Internet. There is no one curriculum that is best for all students but often a curriculum for deaf and hard of hearing students and a curriculum for visually impaired students can be intertwined to better meet more needs. I was able to come back to my deafblind classroom with the hearing and vision curricula and a better understanding of how to combine the two. I realized that teaching individuals with CHARGE requires a multi strategy approach which emphasizes communication and social development.

Saturday August 3, 2019

I woke up Saturday with enthusiasm and excitement once again, this time for the International Conference. I attended a session on motor skills, balance, and physical activity. I noticed that many individuals with CHARGE experience balance issues. Again, I was provided with a curriculum for physical activity free of charge on the Internet, another great resource to take back with me to North Carolina.

I now know that as educators of individuals with CHARGE, we must encourage physical activity to help them have a better quality of life. Individuals with CHARGE often have both static and dynamic balance issues. One way to address these issues is to encourage physical activity such as throwing a ball, jumping, balancing on one foot, using a balance board, and playing games with these components present. I chose to attend “Communication options and the importance of play and passions in the young child” because my research is on communication and social development in CHARGE. I saw various modes of communication and play that can be used with children with CHARGE. Play is important both to help with communication and so children can feel included.

I met with my “matched family” and talked with the parents about what they experience. The mom and dad expressed that it takes a lot of energy. They had recently put their child in a new school and talked

Rebecca Darden-Perry

about how the transition was difficult for mom but easier for her child. In talking with this family, I learned how strong and courageous CHARGE parents are. I could do nothing but praise the family for their strength and courage as I was in awe.

At the Saturday evening Fellows meeting, we participated in a deafblind simulation. We put on glasses that imitated different types of vision loss and those who could hear put in earplugs (I just took my implants off). With our vision loss and hearing loss we walked around the room and completed an activity. I tried to put a puzzle together, which was challenging. We all then discussed how we felt and how challenging and exhausting it was to do this.

Sunday August 4, 2019

I woke up knowing today was the day I was going to volunteer at Camp in the afternoon. In the morning, I attended "A visual understanding of the ophthalmic Pathway in CHARGE," where I learned about the anatomy of the eye, how some individuals with CHARGE see the world, as well as some brief activities involving cortical vision impairment. Experiencing the deafblind simulation the night before and learning how and why the individual with CHARGE sees the world gave me more knowledge and understanding than I could have imagined.

In camp, I was with 9-12 year olds, where I met a little girl named Arial. She was so smart. When her parents dropped her off, she was a little upset but then calmed down when they offered her chocolate. I knew it must be hard on Ariel to be in a strange place with people she did not know. We were very busy during Camp, and I found Arial to be a joy and learned that she was very social. She helped those around her who could not walk well, she offered her toys to others, and she wanted to participate in activities. This was the first individual with CHARGE I had worked with that had high social skills and good communication skills. It was good to see the wide array of functioning of all the children.

After this day's Fellows meeting, we were divided into two teams for a scavenger hunt. My favorite scavenger item was doing something silly with our team and taking a picture. My team came up with the idea of creating the letters of CHARGE with our bodies. We were all laughing and having so much fun, it was a good set up for the hoedown that evening. The dance floor opened and everyone danced! It was great seeing the individuals with CHARGE dancing and having the time of their life. I felt like we were all one big family with one big heart fighting for the best research and education for individuals with CHARGE.

Monday August 5, 2019

I woke up this morning knowing this was the last day we would all be together. We all ate breakfast and said our farewell to our families, to the professionals, and to one another. I found myself with tears in my eyes, for I knew our time had come to an end. I rode with Sarah (my roommate) to the airport, and we talked about how we were going to stay in touch. I walked into the airport alone with tears pouring down my cheeks. Music was playing and when I looked up, I saw a four-year with CHARGE dancing to the song spinning in circles. I stopped to give the family a hug and to say goodbye - we all held on for a while, then parted with tears. This conference has forever changed my life. It has made me want to continue my research for individuals with CHARGE and further investigate the impact of multimodal communication and social skills development. I know that I will be forever a lifetime member of CHARGE Syndrome Foundation. I look forward to the next conference with more research!

Sample Headline

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Rare Disease Day

I As we all know the last day of February is Rare Disease Day. In 2019, Carson was healthy enough to be in school and wanted to do something for CHARGE. Carson is 7 1/2 years old and was born with CHARGE syndrome. He is the only child in our county that we are aware of. We have been very open to raising awareness so that people are not "afraid" and more open to choosing kindness. Last year we read "We are all wonders" to the kindergarten classes and wanted to support disease day but unfortunately from the 1st week of January until the end of the school year Carson was too sick to be in school.

This year with a new principal at the school he was very eager to support Rare Disease day and CHARGE syndrome. The students along with the staff all wore jeans and the staff and a few students including Carson wore the same t-shirt that one of the volunteers made! We did "pennies for CHARGE" and all of the students were so excited to bring in their pennies! With that said the school raised around 870 dollars! WOW! For the first year. The school is very excited to do this bigger next year! The school is all very accepting of Carson and love him! They make going to school so much smoother for Carson as he enjoys going every day to see his friends! The staff all love him and when he's out sick (like currently due to the flu) they all miss him and are concerned!

Carson is always willing to explain CHARGE whenever someone asks "what's wrong with him" he is very proud to be him!

email to get picture ...
jessie beals
j5c0818@hotmail.com

Save the Date

#GIVINGTUESDAY
DECEMBER 3, 2019