

The Third Class of Sandra Davenport CHARGE Syndrome Fellows

PART 2

by Megan Schmitt and Sara Espanet

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 interested in CHARGE syndrome, as well as honor Dr. Sandra Davenport for all of her work in CHARGE. The Program provides scholarships for young professionals to have the opportunity to attend the biennial conferences. The hope is that Fellows will become an integral part of the next generation of CHARGE professionals, and that they will go home and use their knowledge and experiences to teach other professionals and influence outcomes for individuals with CHARGE syndrome. Each fellow is asked to write up their reflections after attending the CHARGE conference. Visit the [CHARGE Syndrome Foundation website](#) for an overview of the Fellows program and reflections from Rebecca Darden-Perry (PhD candidate in special education) and Elaine Ritter (Postdoctoral Research Fellow in cellular and molecular neuroscience). Here we present the reflections of Rilla Hammett (teacher) and Hallie Smith (Licensed Psychologist and BCBA). Watch for reflections from the remaining Fellows in upcoming issues of CHARGE Accounts.

Rilla Hammett

Rilla Hammett is a teacher in the Deafblind Program at Perkins School for the Blind, located in Boston. Rilla hoped to gain valuable information as a fellow at the 2019 CHARGE Conference to help her better serve her students.

For the past three and a half years I have had the pleasure of being a teaching assistant in the Deafblind program at Perkins School for the Blind. Over the years I have learned a lot about CHARGE. I thought that Perkins would teach me just as much as I needed to know about CHARGE. However, my ignorance became so clear when I had the chance to attend the 2019 CHARGE conference in Dallas, Texas. It had been my dream to attend the conference since I started at Perkins and my excitement was through the roof when I found out that I would be able to attend as a Davenport fellow. While I knew that I would learn a lot as part of such an amazing opportunity, I had no idea how much the conference was going to humble me, help me grow, and make connections that I never knew were even possible.

Wednesday, July 31 and Thursday, August 1

After a hectic morning leaving Boston, I finally landed in Dallas on Wednesday afternoon. When I got to the hotel I had to laugh to myself as I looked around at the people who were attending the conference that the hotel was still hosting. Professionals dressed to the nines, formal attire only, tables of solid food and hot coffee. I giggled to myself as I imagined the complete 180 that the hotel would do over the next few days as they got ready for the CHARGE population and their families to take over. However, over these first few days it was clear to see when some of our families started to trickle in. Standing by the elevator I saw a

family get out. Clearly they were headed to the pool. I didn't think much until I saw a little boy jump in his mother's direction, tap her on the shoulder, and sign "I love you." There it was! It was finally happening! I felt a combination of excitement and peace as I realized that this is exactly where this family has been waiting to be. They looked at ease and full of joy. Over the course of these first two days, every time I saw a family start to trickle in, I felt more and more of a sense of excitement as I saw families connecting with each other and settling in!

Friday, August 2

Going into professional day, I knew that there would be a lot of new information. We started off with a presentation from Donna Martin. She began her presentation by showing pictures of her son as he has grown up over the years and I immediately felt emotional as I tried to put myself in the shoes of a parent who has raised a son with CHARGE. Looking at some of his successes was inspiring and thought provoking. She discussed the idea of gene editing and how animals have helped us learn a lot about CHARGE. The day proceeded with presentations and a lot of new information. During one of the afternoon breakout sessions it was a pleasure to be able to listen to Tim Hartshorne speak about behavior. One point that he made that stuck out to me is that behavior has meaning. While I have had the chance to learn this through some of my students, he framed it in a way that broadened my thinking and further pushed the importance of looking at behavior as communication. If we just simply try to make a behavior stop happening,

continued on page 3

Hallie Smith

Hallie Smith, PhD is a Licensed Psychologist in the Pediatric Feeding Disorder Program at the Kennedy Krieger Institute in Baltimore, MD. Hallie received her Ph.D. from Mississippi State University (MSU), where she was an active member in the Bulldog CHARGE Syndrome Lab. At the 2019 CHARGE Conference, Hallie hoped to connect with families who have children that may have difficulties with feeding.

When preparing for this conference, I honestly did not know what to expect. I had been to one conference previously and had a great time, and loved meeting individuals with CHARGE syndrome for the first time. At the conference in Chicago, I was still in graduate school, still training to be the professional I am today and had no idea what the next four years would bring. For me personally, me coming to the conference this year, as a professional, sharing the research I have been doing with other professionals and families, was an incredible experience. It was something I had hoped I could do when I was at the conference in Chicago, and now it was actually happening! I felt so fortunate that I was able to share the experiences and the work I've been doing with families and professionals. I had told myself that if the things I was sharing at this conference helped one family, in some way, that would be all the reinforcement I needed! And, I definitely did get that experience. I had the opportunity to consult with a sweet family and provide recommendations, resources, and support to them. It was incredible to get to work with this family and get to know them on a personal level as well, in such a short time span. Aside from the work I was sharing at this conference, I learned so much from the other sessions at the conference. The highlight for me was really the sibling panel session that I attended. Listening to the siblings of individuals with CHARGE syndrome was an eye-opening

experience. I was so impressed with their maturity, their wisdom, and their vulnerability as they shared really personal moments with their siblings and their families. It was inspiring.

Being a fellow this year was such a privilege and I feel so fortunate to have had this experience. Being able to talk so comfortably with other professionals from totally different disciplines yet with the primary interest of supporting children and families with CHARGE syndrome was something I have never really been able to do. I don't have that opportunity in my current role, and I definitely learned so many things about CHARGE syndrome, and about how to work with these families better because of the other fellows! I so enjoyed meeting these incredible women and learning more about them and their experiences with individuals with CHARGE. I really enjoyed participating in the small break out groups that we had each day, my group was really open with one another and we really did become closer across those few days.

The family contact that was built in to the fellowship program was such a great opportunity to get plugged in to the CHARGE community on a really personal level. Getting to see how these families experience daily life with a child with CHARGE was eye opening and astonishing. Seeing these parents and caregivers who already give so much to their child, spend days learning more about CHARGE syndrome, learn more about effective interventions that may be appropriate for their child, and learn how to better advocate for their child was humbling.

As tired as I was at the end of the conference, I felt reenergized and refreshed returning back home and

back to work. This conference gave me hope and gave me a renewed passion for what I do as a behavioral psychologist every day. It reminded me that families are doing the best they can for their child, and that when I get to be even a little part of it, it's special, and it is a privilege. Because of my experiences at the conference this year, I will continue to be an advocate for this community and continue to conduct research to continue to enhance the lives of individuals with CHARGE syndrome and their families!



Hallie, left, participating in a deafblind simulation with Fellow Ira Padhye.

Rilla Hammett

continued from page 1

what we are doing is taking away an opportunity to communicate, which is never okay. This idea stuck with me and will help me as a teacher when I am in situations with students who are expressing challenging behaviors. On Friday I also had the chance to present during the poster presentations (photo, right). I felt honored to be able to stand with Sara Espanet as we presented about the Sandra Davenport fellowship and what it meant to be a Fellow. One mother came up to the poster and immediately started crying. She expressed that nothing was wrong, and that actually, for the first time since her son was born four years ago, everything was right.

After meeting the rest of the fellows, it was clear to see that this group of individuals were hitting the ground running with our passion for CHARGE in our respective fields and it was reassuring that although there are board members and CHARGE advocates that are simply irreplaceable, there are people who have interest and passion for helping the future of the CHARGE world flourish. We all went down to the opening reception and I was in complete awe. Families hugging, siblings running around, adults with CHARGE chatting, people dancing, g-tube pumps beeping. It was something that could be seen as the most chaotic and overstimulating setting ever, but it felt just right, and it was just right. Everything was just so normal! I went to bed that night feeling exhausted, but I couldn't turn my brain off. The wheels were turning, ideas were flowing, and although I was tired, I was hungry for more information.

Saturday, August 3

Going into Saturday morning, Kathy Buckley took us on an emotional roller coaster throughout her journey through life as a deaf individual. She discussed the importance of communication for EVERY individual no matter what that communication looks like. She reminded us all that nobody is more human than the next person and to treat everyone with love and equality. However, the biggest takeaway for me was the idea of resilience. As she spoke, I thought about my students with CHARGE and how for every ten steps they take forward, they get hit with setbacks based on so many factors. But they are so resilient!! Resilience is something that is unteachable but these individuals with CHARGE seem to have it wired in somewhere because the amount of resilience is remarkable. It reminded me of the importance of facilitating resilience and independence as a teacher, which was humbling and inspiring.



Throughout the rest of the day I got a chance to learn about motor, about helping students understand where their bodies are in space, how to use communication effectively, and how to pause and allow students to do things on their own. Susan Bashinski discussed the importance of giving a direction and then closing our mouths and sitting on our hands and allowing individuals with CHARGE the chance to do the action on their own, which is so important and one of my biggest challenges as a teacher. I then had a chance to have lunch with Jacob and his family (my family match). During lunch, Jacob's mother expressed how school has been really challenging for them over the past five years. It broke my heart to hear this but it was inspiring to hear how optimistic his family was about the changes that will happen this upcoming year for him. During our fellows meeting we did a deafblind simulation. It was extremely powerful to be put in the shoes of someone who is deafblind so that I can be the best teacher I can be. After our fellows meeting we got to do our scavenger hunt and play BINGO. My favorite part of BINGO was watching some of the young adults with CHARGE. They were front and center as they socialized with each other without their parents. One mother came to give her son his medications and she received a very age appropriate eye roll as she signed, "I'm sorry but we have to," to him. Having mainly worked with younger students, it made me think about what the future might look for some of them and it was very thought provoking to imagine them sitting up there one day playing BINGO with their friends.

Sunday August 4, 2019

Waking up on Sunday morning, it was time to go to the vision in CHARGE breakout session. It was incredibly informative to have someone explain how

Rilla Hammett

CHARGE impacts vision in terms that I could truly understand. It was amazing to see how the presentation was targeted towards families and not just medical professionals. I work with several students who are at high risk for retinal detachment and it really helped me understand what that means and how I can be preventative as a teacher. Once the presentation was over, it was time for camp.

Jacob had already demonstrated that he is the type of individual who is right up my alley. He wanted nothing to do with ANY of the activities I presented him with. His eyes were glaring at me for nearly the whole first hour as I presented him with a variety of activities and things to do. I knew that this was not going to work all day. Luckily, Sara had made communication boards for all of the fellows! I got mine from my bag and showed it to Jacob, who had very limited expressive communication. As expected, he swatted it away onto the floor. I picked it up and signed to him that he could use it to tell me what he wanted. He looked at it again, and I modeled how he could use it. He stared at the board, looked at me, and grabbed onto my clothes. Then, he looked at the board again, started at the Mayer Johnson symbol for “mom” and began to circle it with his finger. I signed to him, “that says mom, you will see mom later.” He immediately let go of my clothing and we proceeded through the day. It was clear to me that he finally felt like he was understood! He participated in a variety of activities to the best of his ability and I worked with him to advocate for breaks if he wanted them. It was so powerful to see how even just allowing him to communicate changed the whole dynamic of the day. Throughout the rest of the day Jacob and I laughed, we sang songs, and although we still had our fair share of behaviorally challenging moments, it was a truly incredible day. But the day was not over.

We had our fellows meeting where Ashley Riva, a young adult with CHARGE, came to speak to us. We shared our big takeaways with each other, Meg Hefner, and Sandra Davenport and emotions were high as we reflected on a jam packed few days. From there, we went as a group to the hoe-down. I looked around me as families entered and saw fellows hugging the families they got to know, high five-ing siblings, and handing out bandanas to joyful and energized families. The connections that we made in just a few days were

undeniable and extremely powerful. We laughed and danced (boy did we dance), the evening away and interacted with families that we knew, and didn’t know.

It was a room full of beautifully organized chaos. Some kids were on the floor getting sensory input from the vibrations, other kids were melting down, some were dancing independently, some were using their equipment, and some were on their parents’ shoulders. I looked around and noticed that every single quirk, behavior, medical device, adapted communication, and difference, was something that was completely celebrated in that moment. I took a moment, and I couldn’t help but think about the overwhelming bliss that was unfolding around me. I will remember that moment forever and take what I learned at the conference to kickstart my teaching career with that moment of bliss in my mind. There will be moments that will be far from blissful, there will be heartache, frustration, sadness, and the feeling of defeat. That is the reality of the situation. But after seeing this all unfold and learning what I learned, I now know that those blissful and celebratory moments are possible no matter what. I can only hope to be half as resilient as these individuals with CHARGE and their families and I feel so supported by this amazing network of fellows.



Rilla with Perkins student Grace.

Monday August 5, 2019

I knew that eventually Monday was going to happen even though I didn’t want it to. I woke up and finished up my final packing before heading downstairs for the adult panel. This group of adults blew my mind. To see four individuals with such a large range of communication, skills, life experiences, and more, was incredible. Although they all had their clear differences, they all touched on three main points that I will carry with me forever. Firstly, the importance of advocacy. They were able to learn how to advocate for themselves and from there, the world was theirs.

Secondly, defying the odds. Each of these individuals defied the odds medically, socially, academically, and emotionally and are thriving despite what they were told they would not be able to do. Lastly, they all discussed that for their whole lives, people have been giving them a set of limitations. People have told them again and again what they CAN'T do and have never focused as much on what they CAN do. However, their resilience played in time and time again and they

have been able to live fulfilling lives that have high quality, importance, and so much love. As the panel wrapped up, families began to leave. Hugs were exchanged, tears were flowing, and the room was full of chatter about Phoenix 2021. I can truly say that my heart is full, my brain is full, and there has been a fire lit in me that I will use to ignite the potential in my students with CHARGE throughout my teaching career.



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