



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: Amrit Mehta

Treasurer: Brownie Shott

Secretary: Joanne Lent

DIRECTORS

Julie Brandrup

Karin Dagley

Minnie Lambert

Christian Lobaugh

Pamela Ryan

Neal Stanger

Deanna Steinhauer

SPECIAL ADVISORS

Megan Cote

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 #305

Buffalo Grove, IL 60089

800-442-7604

www.chargesyndrome.org

info@chargesyndrome.org

President's Message

I am honored to start my 4th term as the President of this amazing organization. I continue to be impressed by the accomplishments of our CHARGE families and individuals with CHARGE. This issue of CHARGE Accounts highlights the CAN DO spirit of a couple of young individuals with CHARGE: Gannon and Sullivan. We also recognize our family members, Pamela Ryan, Cathy Lyle and Robert Last, who all recently won awards for their tireless dedication to the deafblind community.

While I lurk on Facebook and celebrate the many accomplishments of our families, I recognize that there is still much work to be done. Too often I am greeted with news of illness, hard times, and even death. This has been a very tough start to the year for some of our families. As a Foundation, we will continue to dedicate resources to increased scientific and clinical research. New grant recipients will be announced this fall. We are also formally monitoring social media to determine what information our families need. We will strive to provide more answers for our families in these CHARGE Accounts and on our website. Our Director of Outreach is available for advice or to assist you in connecting with other organizations. There is much to do, but we are up for the challenge.

Before you read the newsletter, I need to take a moment to thank a few dear friends. After 10 very productive years on the Board, Lisa Weir decided not to run for another term. She continues to be very involved with the Foundation and will always be a large part of our CHARGE family. Neal Stanger, who has held almost every position on the Board has stepped off the Executive Committee, but will remain an active member of our Board. I remain surrounded and supported by a dedicated team of volunteers. Brownie Shott enters her 11th term on the Executive Committee. Brownie and I are privileged to welcome Amrit Mehta and Joanne Lent to the Executive Committee. Please check out the article about Amrit and Joanne and all the other great articles.

David

David Wolfe, President

Facebook Top Topics

by Julie Brandrup

Let's face it, sometimes the place to find information about CHARGE syndrome isn't the doctor's office or a medical webpage, it's Facebook. Finding exactly what you need to know is often as simple as posting a message to your favorite CHARGE group and soon multiple offerings of advice and support will pop-up.*

Facebook, with its large, diverse, and rapidly evolving knowledge base, has greatly benefitted our families. It's personal and immediate and the information is coming from people who have lived with CHARGE syndrome. The CHARGE Syndrome Foundation is looking for ways to take advantage of this resource and the information it holds. Popular topics on the various CHARGE Facebook pages help the Foundation develop future webinars and other materials and prioritize the areas of our website that need additional information.

Resources and Materials Committee member Chantelle McLaren compiled a list of questions frequently asked on several of the group pages (at right). Communications Committee member Jennifer Call researched a few of the more common topics to help you get started with on your search for answers to your specific questions (next page). Additional CHARGE Facebook pages will be researched and other topics will be addressed in the future.

It is exciting to see our CHARGE community connect and support each other on social media. It is also easy to see that we have so much in common no matter our age or location. We need to continue to look for ways to take advantage of technology and our wide knowledge base. Using common themes from Facebook, website searches, conference feedback and surveys, the CHARGE Syndrome Foundation hopes to be able to keep our materials and resources up to date and relevant to everyone's needs.

If you would like to turn your Facebook time into volunteer hours for the Foundation, please [contact me](#) to join the Resources and Materials Committee for this important work. **We especially need input from parents of younger children with CHARGE.**

**Keep in mind that another family's response to a question posted on social media is no substitute for professional advice.*

CHARGE Syndrome Group

(6,471 members)

- Behavior, helping the school system understand the child's sensory needs.
- RSV/Immune system
- Sleep issues.
- Autism vs DB sensory diagnosis.
- Recurring fevers
- Anxiety - general/medical/school. When did your child notice they were different?
- Teaching organization skills to children with multi-sensory issues
- Dental care/teeth coming in weird/odd angles
- Weight gain

CHARGE UK (875 members)

- Constipation/gas/gastrointestinal issues
- Transitioning child to adult hospital
- Weight/height issues
- Swallowing
- Networking with local families based on a common symptom.
- Behavior (hair pulling)
- Teeth grinding/dental
- Toys for sensory needs (links needed for non US residence)
- Schools and immune systems, dealing with schools being hygienic
- Bruising easily
- Vestibular system ... why CHARGE kids (and adults) will seem to defy logic (i.e., can bike in a straight line, but can't seem to walk without bumping into things)

Adult CHARGE group (112 members)

- Navigating work vs not working related to disability and medical coverage.
- Insecurity

CHARGE Australia/NZ (472 members)

- Teeth grinding
- Sensory toy suggestions/suppliers
- Behavior and dealing with strangers' reaction to the child's behavior.
- Improving communication between parents and the school system
- Disciplining kids with multi sensory issues.
- Transitions from sheltered childhood to adulthood

CHARGE Syndrome - Members Only (1971 members)

- Immune issues
- Help connecting to families
- Gut issues

Frequently Asked Questions ... and Some Answers

1 Behavior Challenges - Communication

Behavior is communication. This means that we use behavior to relay a message to other people. If we understand the purpose of the behavior, then any behavior can make sense. Tim Hartshorne, a CHARGE syndrome behavior expert, addresses this topic in the Management Manual for Parents: [CLICK HERE](#)

2 Behavior Challenges - Changing Behaviors

Eliminating "misbehavior" is not achievable and by itself is most likely not desirable. Behavior is not random. All behavior has a purpose. The primary objective of behavior management is to understand the purpose and communication underlying misbehavior, and to use that to help the child find more appropriate communication methods to achieve their goals. See page 159 (Section IV - 2C) of the Management Manual for Parents: [CLICK HERE](#)

3 Understanding the Child's Sensory Needs

A child's brain is a sensory processing machine, nourished by having fun through play and movement. The child who learns to organize his play is more likely to organize the activities that required for daily living. Read about sensory integration on page 201 (Section IV - 6B) of the Management Manual for Parents: [CLICK HERE](#)

4 Communication Between Parents and School

The Education Professional Packet was developed to provide a brief introduction to the complex world of CHARGE and some strategies to consider in education and therapeutic settings. The packet is available for download: [CLICK HERE](#)

5 Sleep Issues

Research has found evidence of significant sleep disorders in well over half of children with CHARGE. **Sleep cycles** are frequently disturbed, even in those without significant visual impairments. The cause is unknown: [CLICK HERE \(see page 15\)](#) for information presented at the 2015 conference and [CLICK HERE](#) for a thesis abstract on the subject. [CLICK HERE](#) for a published research paper.

6 Autism Diagnosis

Do children with CHARGE also have autism? Some may be labeled "autistic" because they do not appear to make eye contact and they have poor communication skills due to deafblindness. [CLICK HERE](#) for an overview of how sensory loss influences development.

Tim Hartshorne states in [this Perkins Learning webcast](#): "As soon as you call it autism, you lump a bunch of stuff together and people think you know what you're talking about and they stop focusing on what's unique

about the way children with CHARGE behave because, 'Oh, well, it's just autism.'"

This topic will be addressed in depth in the future.

7 Weight, Height, and Growth Concerns

Although some children with CHARGE have growth hormone deficiency, much of the slow growth in CHARGE is likely due to nutritional status and general medical problems. Growth issues associated with a delay in puberty occurs in a large number of children with CHARGE. There is evidence that adolescents continue to grow into their 20s. [CLICK HERE](#)

8 Vestibular System

The Vestibular system is unique in providing a continuous flow of information between the person and the environment; it tells a person how they are interacting in the environment and it monitors and directs muscular activity and body position to maintain secure and functional postures. David Brown discusses the interplay between the vestibular system, vision, touch and proprioception in this article [CLICK HERE](#) and in this CHARGE Syndrome Foundation webinar [CLICK HERE](#).

9 Another Child With CHARGE

The likelihood of having another child with CHARGE is the topic of a [special issue of CHARGE Accounts](#)

To the Naysayers

by Tracey Busby

My son Sullivan passed grade 12 math this year and I celebrated! I mean, I really celebrated. While Sullivan still has a few electives to complete before he finishes grade 12, he has now completed all the required credits (as we call them here in Manitoba) to graduate with a Department of Education, High School Diploma.

This was no easy feat. Sullivan has always been behind his peers in his learning. He's a typical individual with a diagnosis of CHARGE syndrome, so his physical challenges (low vision, significant hearing loss, frontal lobe issues affecting executive function) have meant that he was always trailing behind. However, his learning curve was always upward, he eventually "got it" so I persevered with him on an academic path in his formal learning.

We hit our first big roadblock when he was entering grade 7. I was told by the Special Education Consultant for our school division that Sul would be in academic programming; however, the head of the department envisioned Sul going on adventures with other "special ed kids," riding a bike in the hallways of the school and just about everything except spending time in class learning. We were told as parents that we were too involved and had unrealistic expectations, advised that they were the professionals, and were generally ignored. Anyone who knows me knows that I don't give up without a battle or 2 or 10.

We made it to grade 9 and knew Sul's biggest roadblock would be math, especially (in this province) grade 9 math. We went with the resource teacher's advice to do a year getting caught up using a homeschool math program out of the U.S. Nearing the end of grade 9, the teacher stated that Sul still wasn't caught up but he wanted to continue with this program. Something in my gut told me this was not the best plan for my child and, in consultation with outside professionals, my concerns were validated. We were also having a huge battle with the administration and special education department trying in a back-handed way to modify Sul's

curriculum in such a way that he would not be expected to meet any academic goals, and thus not graduate with an academic diploma. Honestly, I almost had a nervous breakdown, this situation being so bad. Thankfully, that administrator retired, a new one came in and we approached her with caution and optimism.

In Manitoba, a student requires 30 credits to graduate from high school (grade 9 to 12). There are the required credits and electives. The legislation states that during a student's tenure in high school the requirement for up to two credits can be replaced with an elective course. We suggested to the principal that our son have the requirement for grade 9 math removed (it truly is the dark spot of our education system). Although our school division had never used this piece of legislation, she was open to giving it a go. In fact, she stated she would also remove the requirement for grade 12 math. Sul would just have to pass grade 10 and 11 math to keep moving forward.

We were so excited as Sul progressed through his academics in grade 10 and 11 and we saw a real shift in his maturity. He was much more engaged in learning, stayed focused, asked questions and his marks began to matter. He passed both grade 10 and 11 math levels and we were ready to plan for grade 12. We met with the principal again and she suggested we just give grade 12 math a try. If he didn't pass, we wouldn't view it as a failure and would move on to another elective to meet the

continued on page 5



Sullivan with his first lager

This Kid Goes to College!

by Sara Moseley

Gannon's blind and low vision teacher, Kelly Lloyd, works at several different schools and also teaches a college course regarding adaptive activities for children with special needs. She invited Gannon to come talk to her University of Indianapolis students about everything he CAN do. This class was so welcoming to Gannon. I was so proud of how he shared some things about himself and about CHARGE syndrome. He even kicked the butts of some real-life college wrestlers! He is so lucky to have such a sweet teacher.



To the Naysayers

requirement to graduate. We began to get nervous when Sul's wonderful resource teacher of the last few years retired. She was replaced with a teacher who had no resource experience, none in special education and really had no clue about the challenges that Sullivan faced so we began the new school year with some trepidation but remained hopeful. After all, only a satisfactory score of 50% was needed to pass the course. I remained quite involved as decisions were made about how to best teach him and my recommendations were respected. Sul worked really hard with his teaching assistant, who was amazing, and he persevered through some difficult chapters in the course and earned some really good marks. His end of term mark was in the high 60's, I was ecstatic, he only had to complete the provincial grade 12 math exam. We calculated that he needed about 35% on the exam to pass the course, which for a student with high exam anxiety could be a challenge. I was on pins and

continued from page 4

needles, we all were. His mark was back within days and he got 38% on the exam and his final mark in grade 12 math was in the mid 50's.

He passed! I wanted to pop the cork on the champagne and celebrate. I was so happy for Sul passing his grade 12 academic requirements. It truly meant that he had proven all those professionals wrong; all those people who judged Sul on his appearance, not what they could teach him. They considered putting him into a silo of learning that would not just limit his school choices but ultimately limit his life choices. One day I would love to go to those educators who didn't want to teach him and say "I told you so," but I'm happy and content to simply say **"neener neener neener."**

Update: I feel another "neener neener neener" moment coming on. Midterm marks: 80 in sewing, 88 in geography and 95 in American history! I am beyond elated for Sullivan.

New Faces on the Executive Committee by Julie Brandrup

It's an exciting time for the CHARGE Syndrome Foundation Board of Directors. We welcomed two new officers at our annual meeting. Congratulations to **Amrit Mehta**, our new Vice President and **Joanne Lent**, our new Secretary, as they begin 2-year terms as some of the hardest working volunteers to be found. Like the Foundation members they serve, Amrit and Joanne have a passion for CHARGE syndrome and are inspired to use their experience to help others.

Amrit brings a global perspective to Board, having lived and worked in India, UAE, UK, and Canada. He now resides in Michigan with his family, including a 16-year old son with CHARGE

syndrome. Amrit has served on the Board since 2011 and, among other responsibilities, has managed the camp program at conference and worked on the Foundation website. In his new role, Amrit is eager to be involved in the business decisions of the Executive Committee, with an emphasis on improving workflow systems and collaboration.

Joanne and her husband have two children, including an 18-year-old son with CHARGE syndrome who attends Perkins School for the Blind. Upon joining the board in 2013, Joanne put her publishing background to work by producing the newsletter. In addition, Joanne has been the conference volunteer coordinator. With the added responsibilities of being on the Executive Committee, she is especially eager to use her professional and personal experience to ensure CHARGE information is current and accessible.

Amrit and Joanne have big shoes to fill as former Vice President Lisa Weir retired from the Board after 10 years of service. We are also grateful that 20+-year Executive Committee veteran **Neal Stanger** will continue as conference committee chair for our 2019 conference.

David Wolfe will continue his leadership as President for a fourth term and **Brownie Shott**, the longest-serving officer, returns as Treasurer.



Joanne, Brownie, David, and Amrit relax following a day of conference planning.

Committee Volunteers Needed!

- The **Communications Committee** works on the website, social media accounts, webinars and the newsletter. We want to reach as many people as possible, keep the Foundation relevant and on the radar of both families and professionals. Contact: joanne@chargesyndrome.org
- The **Family Engagement Committee**'s goals include increasing family involvement and expanding our connections with other deafblind family organizations. To help, please contact minnie@chargesyndrome.org
- Through our **Fundraising** efforts we create awareness and provide financial support to all of our programs. Contact: deanna@chargesyndrome.org
- The **Resources and Materials Committee** is working to identify common themes and make it easier to find the most current information. Contact: julie@chargesyndrome.org
- Conference Planning** will soon be underway and it takes a great team to put on a great event! Contact: karin@chargesyndrome.org.

See the Winter 2018 issue of CHARGE Accounts for more information

Sandra Davenport CHARGE Syndrome Fellows: Reflections from the 2017 Conference

by Meg Hefner

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

Davenport Fellow Alex Donovan: *Alex is a PhD student in the Department of Craniofacial Development and Stem Cell Biology at King's College, London. He was nominated as a Fellow by Dr. Albert Basson, whose lab studies chromatin remodeling aspects of the CHARGE gene, CHD7 in mice and other animal models. Dr. Basson has been a recipient of a research grant from the CHARGE Syndrome Foundation. Alex's project is focused on the possible role of Chd7 and executive functioning in mice. He presented his research as a poster and as a platform presentation at the 2017 Professional Day conference.*

Day 1 – Professional Day. Never having been to an international conference before, I was both excited and anxious about speaking. Waking up nervous, my apprehension about presenting to so many CHARGE experts was quickly put at ease upon meeting several of them at breakfast. The friendly reception and immediate interest in my studies made me feel welcome and at ease. This was furthered by seeing fantastic speakers from a wide range of disciplines giving confident and compelling talks throughout the morning. At the poster session I and several other

Fellows presented summaries of our work. I not only had conversations with others who do lab research, but also had the chance to explain my research to people from other fields. This put me in the unique situation of breaking down what I do for people not from

research backgrounds, something you do not become accustomed to when working exclusively in a research environment. Having to explain things in a simple and logical way not only helped me learn how to convey my research to others, but reminded me of the fundamental questions of my own studies that often become clouded by complexity. I regret that I didn't get much of a chance to walk around to see other posters, but meeting and speaking with the other Fellows gave me a valuable insight into the breadth of CHARGE syndrome research going on across the world.

That afternoon I gave my talk and, though extremely nervous in the run-up, I settled in quickly to what ended up being a valuable experience. I received feedback on my work and now have ideas for possible new collaborations in the future. Exhausted from the day's events, we then had our second daily meeting of the Fellows. Hearing what each person had gained from the day highlighted how different people had valuable, distinct experiences throughout the day. This was the first time I had the opportunity to hear about



continued on page 10

Davenport Fellow Bree Kaufman is a PhD graduate student in educational psychology at Central Michigan University (CMU). She was nominated for the Fellowship by Dr. Tim Hartshorne, who was been instrumental in developing the description of the behavioral phenotype of CHARGE and who has mentored several generations of graduate students who are researching behavioral and educational aspects of CHARGE syndrome. In addition to her duties as a Davenport Fellow, Bree presented a poster on her ongoing research at the 2017 conference.

My initial involvement with CHARGE syndrome was essentially a serendipitous accident that I now can only explain as fate. Although I have been aware of CHARGE syndrome since I first met Dr. Tim Hartshorne in 2013, it was not until 2015 that I discovered that CHARGE syndrome would change the course of my life.

When I first began my graduate school journey, I heard about CHARGE syndrome primarily through my peers



who were involved in the CMU lab, but at this point it was merely curiosity. Fortunately, Dr. Hartshorne became aware of my interest just when an undergraduate student in his lab informed him that she would not be able to attend the 2015 International CHARGE Syndrome Conference near Chicago. Dr. Hartshorne extended an invitation to me to go in her place.

The Chicago conference solidified my interest in CHARGE. Shortly after we returned to Michigan, I asked Tim how I could contribute and stay connected to the CHARGE community. I was thrilled that he was able to open a spot for me in his lab. I have been involved in CHARGE research ever since, including attending the 2016 Biennial Australasian CHARGE Syndrome Conference in Queensland and working on my own research regarding degrees of functioning in individuals with CHARGE.

I was honored to receive a Davenport Fellowship to attend the CHARGE Syndrome conference in Orlando in 2017. As a Fellow, I was able to have an even more

meaningful conference experience. What I found most valuable was the opportunity the Fellowship created for networking with other new professionals interested in CHARGE and to learn more about other professions and their connection to CHARGE. From the other Fellows' posters and platform presentations, we were able to learn about each other's research and goals. I developed friendships with the other Fellows and would feel comfortable contacting them to collaborate on projects in the future. Building this bridge across professions and across the world is invaluable for advancing research in CHARGE.

As were all the Fellows, I was paired with a specific family. Eddie is 17 years old and a student at Perkins School for the Blind. I spent time with Eddie and his family at meals and in camp. Eddie does not use speech, and is working on using some signs. His interests are mainly sensory. I found that he likes water, swinging, music, chewing, vibrations, and textures. This Fellow-family pairing helped me learn more about Eddie, CHARGE syndrome, and challenges for individuals with CHARGE and their families.

I also enjoyed discussing my research with parents and professionals at the poster sessions. Through detailed discussions, I received valuable feedback on my project as well as ideas for future research and collaborations.

I met many individuals with CHARGE while at the conference. I searched the name tags to find people who lived close to me in Michigan. I introduced myself to a young woman from Grand Rapids, Michigan who has CHARGE syndrome. I spent a lot of time with her and developed what I hope will be a lasting friendship. We have similar taste in movies and other things and we made plans to visit back in Michigan. I also was able to reunite with people I met at previous CHARGE conferences. I have plans to see Belinda [from Australia] when she comes to Michigan for (yet another!) Tori Amos tour. The nature of CHARGE conferences allows people to make meaningful and lasting connections. I have made true friends at these conferences and I keep in contact with these people regularly. I look forward to attending the next CHARGE conference in 2019 in Dallas, Texas and I hope to see my fellow Fellows there as well!

AWARDS & HONORS

AUSTRALIA DAY 2018 HONOURS

THE ORDER OF AUSTRALIA, MERITORIOUS AND MILITARY AWARDS

We congratulate Rob Last, a frequent presenter at CHARGE syndrome conferences over the past 30 years, who was recently honored with an Australia Day Award for "significant service to children who are deaf, deafblind, or have low vision, and their families, particularly to those with CHARGE syndrome."



Ellen Howe, an adult with CHARGE from Australia who has known Rob since she was a child, is one of many individuals Rob has helped: "Rob means the world to me. He is one of the most supportive people there is. He has always been willing to be there for any doctor's appointment or anything I need him for."

The Perkins Anne Sullivan Award

Pamela Ryan, longtime CHARGE Syndrome Foundation board member and recently-retired Perkins School for the Blind deafblind program psychologist was honored for her years of service to individuals with deafblindness with the Anne Sullivan Award at the recent DBI of the Americas Conference.

Lifetime member and friend of the Foundation Cathy Lyle from the Minnesota DeafBlind Project was also honored.

On behalf of everyone positively impacted by your work... **Congratulations and THANK YOU!**



Alex Donovan

continued from page 7

the experiences of Meg [Hefner], Pam [Ryan] and Sandra [Davenport], not only from the conference, but throughout their careers. The colorful stories they told us gave insights into the unusual trajectory that research can often take, rarely following the expected linear paths we plan for.

That evening was the official opening of the main conference. As over a thousand people flooded into the ballroom for dinner, I and many of the other Fellows stood semi-stunned at the edge of the room. The sheer scale of the event left us awestruck for a time, but after getting our food we quickly relaxed. Something that came as a surprise to me was the incredible amount that could be learnt through simple observation of people interacting and playing. Sitting at

there were 9 different research projects enrolling subjects at conference]. After breakfast, I went with Anne and Adam to his first appointment: a study of motor skills. It was interesting to talk to the researchers and entertaining to watch Adam launch an animated attack on the tasks set before him. As we looked on, Anne told me about the things they enjoy doing together in their home state of Utah, from mountaineering to trips to the lakes. This was also the first time I got to experience one of Adam's favorite activities – having extensive conversations with Siri, the disembodied AI within an iPhone. He would ask Siri questions ranging from how she was feeling to if she enjoyed the conference, usually ending in an impromptu marriage proposal, which she quickly rejected. On the walks between appointments I really got to chat with Adam and get to know him better. He was very happy to

Sitting at the edge of the room with my dinner plate I probably gained more of an insight into the behaviors of individuals with CHARGE than if I had read a thousand published papers.

the edge of the room with my dinner plate I probably gained more of an insight into the behaviors of individuals with CHARGE than if I had read a thousand published papers.

Later that evening, the eleven Fellows were called to the front of the ballroom, given placards with ages and told to beckon over families with children of the ages displayed. After dozens and dozens of children flocked to the placard I was holding, I recognized Adam [the child I was matched with] and his family. I sheepishly approached them and introduced myself, something which was met with as warm a greeting as possible and introductions to the many family members who had accompanied him to the event. Anne, his mother, introduced me to his father Ron, his brother Alex and his grandparents, Joe and Maureen. As it was late, we quickly had to go our separate ways for the evening, but they had already made me feel welcome and I had nothing but eagerness to get to know them over the days to come.

Day 2 – First day of the main conference. From the very start of the day I was welcomed into the life of my host family. As I sat and ate breakfast with them, we spoke about my research and their own experiences with CHARGE. I asked them what their plans for the day were and decided to tag along with Adam to his research appointments [Ed Note:

hear about my familiarity with “In the night garden,” a British television show that many of my own nieces and nephews love. The topics of Siri and “In the night garden” remained the predominant topics of discussion for the remainder of the trip.

At lunch, I spoke with the rest of the family about their experiences with CHARGE and how difficult it can often be in a country as large as the U.S. It was heartening to hear about the opportunities Adam has had to go to things such as camps to give him individualized experiences that he may not get during school life. That evening in the Fellows meeting, we each talked about our conversations and experiences

continued on page 11



Alex Donovan

continued from page 10

with our host families. The stories told ranged from funny to some with more somber themes. This really made the peaks and valleys so many families with CHARGE traverse throughout their lives evident, and gave unrivaled new perspectives to what I previously knew. We also had the chance to experience a deaf-blind simulation, which gave us some insight into the difficulties having multiple sensory impairment can present in an interactive and memorable way.

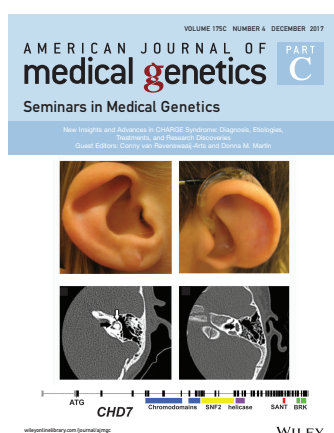
Day 3 – Camp and Carnival. The morning was spent shadowing the family as I had done before. I started by attending Adam's research appointments, this time studies of growth and behavior. The rest of the day was spent at Camp, which proved to be one of the most enjoyable and rewarding experiences of the trip. Being able to spend a significant amount of time getting to know Adam was both entertaining and informative. Simply seeing the kinds of toys he preferred gave an insight into his own experience with CHARGE syndrome. The moment we arrived at Camp, he torpedoed towards the toy box, and excavated all of the toys with flashing lights or noises. Simple interactions like this give me so much insight into the kinds of sensory stimulation many children with CHARGE value. It was also particularly impressive to watch Adam painstakingly dissect the layers of a Kleenex tissue to make it softer to the touch, something his parents had previously told me he enjoyed on a regular basis. The camp staff were also introduced to Adam's turbulent yet loving relationship with Siri, which entertained them for much of the remainder of our stay.

Having spent hours rushing around the various play rooms, seeking out particular toys and games, both Adam and I decided it was time for a rest, so we lay on

the floor and talked about topics ranging from our favorite characters from various television shows to why Siri was unable to accept his marriage proposals. He also expressed his love of the conference and told me that he had attended several previously. It was a good that we all got a fair amount of rest in our day, as that evening we had CHARGE-A-Palooza to look forward to, which was filled with hours of games, dancing and activities.

Day 4 – Final Conference Day. It felt like an eternity since my arrival at the conference. Having been totally immersed in the incredible CHARGE community was a fantastic experience and it was hard to believe it was coming to an end. Be that as it may, I made the most of the time I had left with my host family, spending the morning with them. They had really made me feel like a member of the family – including me in every aspect of their trip. The insight I got through simply speaking to them about their experiences gave me a perspective on CHARGE that you can't get through reading academic texts. One central flaw of much lab-based study is the detachment it sometimes creates. But the motivation gained through meeting people that care about your work is unrivaled and will stay with me throughout my studies.

Day 4 – Epcot. Though the conference had come to an end, my time with Adam's family did not. After the conference had officially ended, they generously invited me to go with them on a family day at Disney's Epcot. It was a fantastic day out. We went on all the rides offered, including the Frozen-themed ride (Adam's favorite) multiple times. We spent the entire day there and as we left, Alex and I exchanged Disney badges with the flags of our respective countries. Mine now sits on my desk reminding me of all the amazing people I met.



The December 2017 issue of The American Journal of Medical Genetics is devoted entirely to CHARGE syndrome

12 PAPERS TOTAL

[Read summaries of the papers](#)

[Read the complete issue on the publisher's website](#)

Creativity Corner

The Final (Exam) Challenge, Part 2

by Meri Dwyer

When the light faded, I was in a different outfit. Instead of my usual shirt and jeans, I was in a cherry blossom pink shirt and skirt. I also had on a darker pink cape, fingerless gloves that reached my elbows with matching boots that reached my knees. My hair was also a pretty shade of pink.

“HEART SCEPTER!” I found myself shouting with my left hand high in the air. That’s when I pretty scepter with a heart at the top appeared in my outstretched hand. “PURIFICATION BEAM!” I shouted. My two teachers were engulfed in pink light.

“NOOO!” They screeched and black ooze slid out of their mouths. I shuddered. *Totally gross!* Before they could cause any more damage, the blobs vanished.

“Sakura!” I heard running footsteps and turned. “Heh! Guess you didn’t need us, after all!”

“Who...?” I didn’t recognize the four figures. One was in a blue ballerina-like dress with matching slippers and gloves. “M-Miku?” I asked when I spotted the girl in blue’s bracelet. Her hair was a midnight blue. It was such an un-Miku-like color! So dark compared to her bright blonde hair that normally had a streak of pink in it.

The girl with light purple hair, dark skin and purple jumpsuit smirked. “It’s me, silly! Chika!”

“Oh,” My eyes landed on the last two girls. One had yellow hair and donned a yellow dress and bracelets with matching high heeled shoes. The other was in a green sporty-looking outfit. “Rosa? Kari?”

“Yes,” said Rosa.

“Why does my hair have to be green?” Kari complained and I giggled.

“So, what happened to the other two?” I asked.

“We took care of them! Y’see, Sakura, me, Rosa and Kari had our powers before you!”

“B-but...” I was completely confused! Why didn’t they tell me?

“We were gonna tell you today at lunch.” Chika said as if reading my mind. “We found Mr. and Mrs. Carlson and were able to free them before you met Luce.”

“Well, that was easy. I guess all I have to do is swing my scepter and Elana will just turn to dust!”

“Don’t get cocky,” said Luce when she approached us. “Those were only her minions. She won’t be so easily defeated!” I rolled my eyes and righted myself. “So, where is she? We’ll take her down, no problem!” *Then I can get back to my life!*

“Oh! She’s...”

“Well, well, well! I have all five little Magilytes in one place! How perfect!” Ms. Edgeworth loomed over us. Her hair was black and wild and her eyes seemed to glow red. “Now, who shall I eliminate first?”

“No one! PRETTY TWISTER!” Swirling blue lights were emitted from Miku’s hands.

“FOOL!” She caught the beam and hurled it right back at us! We fell into a row of lockers.

“My turn! BLAZING BLITZ!” Chika seemed to glow red when she blasted fire at Ms. Edgeworth.

She dodged, but her skirt was caught in the blaze. She rolled on the ground, which put out the flames. “Nice try! Now it’s my turn!”

continued on page 13

The Final (Exam) Challenge

continued from page 12

Ms. Edgeworth slapped a palm to the ground in a very *Naruto*-esque way and the floor cracked. Dead roots encircled Miku and Chika's waists, arms and legs. "No!" cried Rosa.

"Cheater!" Kari charged at our enemy, only to get entwined in a root of her own!

Rosa opened her mouth as if to scream, only to get captured herself. I form a silent "O" with my mouth. She was just too darn fast! I had to do something! I lifted my scepter high in the air. "HEART PURIFICATION!" I shouted at the top of my lungs and the tree roots vanished and my friends were free.

I glanced at Ms. Edgeworth. Her hand was clutched to her chest and she was breathing heavily. Did I do it? "M-Ms. Edgeworth?"

"NO! THIS CAN'T BE! H-How...?" Her eyes and hair turned back to normal. "No...NO! I REFUSE TO LOSE TO A CHILD!" The voice I was certain was Elana let out a shriek. "I'LL GET YOU! IF YOU WISH TO SAVE THE WORLD, LITTLE MAGILYTE, I DARE YOU TO FIGHT ME AT MY CASTLE!"

Ms. Edgeworth fell to the ground. We did it! We won! "S-Sakura..." I knelt by my teacher's side. "I-it's...it's not...it's not over..."

My friends were instantly at my side. "Ms. Edgeworth, what do you mean?" asked Miku.

"Th-the...final battle...Sakura...I...I'm not...I wasn't Elana's true vessel. I-it's really...my cousin..."

Rosa gasped. "M-Miss Ella?" Miss Ella was always so nice! How could she have been a vessel this entire time? "We'll save her." I found myself saying. "We'll go the Elana's castle and save Miss Ella!"

"P-Please...hurry...Th-The Final Bell...time is running out..."

"Where's the castle?" Chika asked Ms. Edgeworth.

Before our teacher could speak, Luce—who I totally forgot about, by the way—spoke up. "You girls can teleport there! I know where it is, as I was captured there once!"

The five of us nodded at each other and joined hands with Luce in the center of the circle.

"So...um...how do we...?"

"POWER OF LIGHT! PLEASE SEND US TO THE EVIL QUEEN ELANA'S CASTLE!" Luce shouted.

There was a blinding light. And here we are—Miku, Chika, Rosa, Kari, Luce and myself—at the base of the evil queen's castle.

"How do we get in?" I ask Luce. "Knock? Doorbell? Trojan Horse? Pizza delivery?"

Luce makes an irritated sound at the back of her throat. "Use your sword."

"Sword?" I'm confused. I thought my weapon was a scepter!

"Try it, Sakura!" Miku encourages.

I shrug. "Okay." I raise my left hand high and shout, "SWORD OF LIGHT, COME TO ME! Um, please? Pretty please with sugar on top?" I'm nervous. What if this doesn't work?

That's when a sword appears in my hand. "Sweet! HIYA!" I wave my sword and the door collapses with a mighty *thwump*!

"Yay! It worked!" Rosa cheers. It was way too easy....

To be continued...

Click here to read Part I of the Final Exam Challenge, which appeared in the Winter 2018 issue of CHARGE Accounts

Planning Ahead

by Mary Anne Ehler

Where do we start, when do we start, and who do we trust? These are just some of the questions I hear when meeting parents who have a child with special needs. We want to help these families get the information and resources they need, when they need them. I've met thousands of families at my presentations and workshop over the past years – including at the 13th International CHARGE Syndrome Conference in Orlando. Their “children” range in age from birth into their 50's. Each family is unique and each family has different needs, but the one thing they need, when thinking of the well being of their child, is answers.

When it comes to planning for the future, many parents don't know when to start. The answer is NOW! The sooner parents begin a plan of action the better. It will ensure key decisions are made at the appropriate times so their child reaches their fullest potential throughout their life. Parents should first think about two areas that go hand in hand: legal options and financial planning, specifically a special needs trust and government benefits.

Special Needs Trust

As a parent, you need to start with a solid estate plan that includes a special needs trust. This special type of trust is a way for parents to put money aside without jeopardizing government benefits. It is a vehicle that holds assets that can be used for supplemental care for your child. It answers the question of who is in charge and if there are limits to how the money for your child is used. Seek an experienced attorney who specializes in this type of trust, but before meeting with an attorney, make some decisions with a qualified special needs future care professional who can provide objectivity, guidance, knowledge and, most importantly, empathy to your family.

Decide when to create it. You can create a special needs trust so it's activated either at death or while you're still living. A “testamentary trust” takes effect upon your death, but its disadvantage is if certain laws change, the trust could be negatively affected. Having a stand-alone trust now has a couple of advantages: it offers flexibility to change the trust through a “trust amendment,” or

“grandfathered” rights if the law changes. Setting up a trust as a standalone trust also allows friends and family to refer to the trust for such things as gifts or inheritances.

Decide what type of trust. The third party special needs trust that will likely provide the most flexibility throughout your child's life is the “revocable trust,” with an “irrevocability trigger provision” when certain changes occur, such as death. More common, since the third party trust may be funded during your lifetime, you might consider having an irrevocable trust created, but make sure that it can be amended to stay compliant with the law. You should also familiarize yourself with the “payback trust,” which often is reserved for those cases when money is incorrectly left in the name of the child with special needs. This payback trust is often used in the case of divorce to accept child support. Also referred to as the OBRA 93 trust, its purpose is to place assets owned by the person with the disability into the trust to be spent on supplemental care during the life of the child with special needs; however, when the child passes away, the money remaining in the trust is first used to reimburse the state for benefits paid during the child's lifetime before it is distributed to the remaining designated heirs.

Decide who will be the trustee(s) and future caregivers. These are difficult decisions for many parents, and ones that should not be taken lightly. You need to consider who you will want to handle the day-to-day living responsibilities (caregivers) and money matters (trustee) for your child. Who is willing to learn what is involved in making daily decisions for your child? Ask potential caregivers to take the child for the weekend and see how they manage. Also, consider if the future guardian and trustee should be the same person.

Decide how to fund the trust. Any asset—including proceeds from life insurance policies that you have for the benefit of your child—should be titled under the trust or have the trust as the beneficiary. There are two primary ways that a third party trust can be funded: inheritance and savings on the child's behalf, or have the trust

continued on page 15

Planing Ahead

continued from page 14

as the beneficiary. It is very important that you remember to change the beneficiary of your retirement, annuity, IRA and life insurance accounts to the child's special needs trust. If not, you'll likely be forced to set up a less than desirable payback trust. Turn to a financial professional before you take action so you are aware of certain tax consequences. Also, decide the percentage of money to go to the trust versus your other able-bodied children. Remember, the special needs trust is a tool in the planning process that provides for care above and beyond the basic living needs and allows you to maximize the benefits that your child receives.

Government Benefits

As your child's needs evolve throughout their life, you have to consider such things as medical expenses, early intervention and various programs. Your child's biggest resource for funding may be government assistance programs, which can be confusing to access. An advisor who specializes in special needs planning can provide information about the proof you will need to show that your child has disabilities, the questions government officials will ask and the actual visit to the social security office. Here are a few things you need to know government benefits and other programs to access for your child.

Entitlements. Social Security Disability (SSDI)/ Social Security Administration (SSA) and Medicare are benefits most Americans get because they paid into it throughout their working years. Your special needs child benefits from your contributions. It is important that you always save your social security statements for review. They tell you a lot about not only your own benefits, but also what your family receives when you retire and/or die. SSDI/SSA provides cash to meet daily living expenses and to supplement any other benefits, while Medicare assists with medical needs. Medicare does not pay for prescriptions unless one has Medicare Part D.

Needs-based benefits. Supplemental Security Income (SSI) and Medicaid go hand in hand and will only help your child after a review of your income level and assets (or your child's income

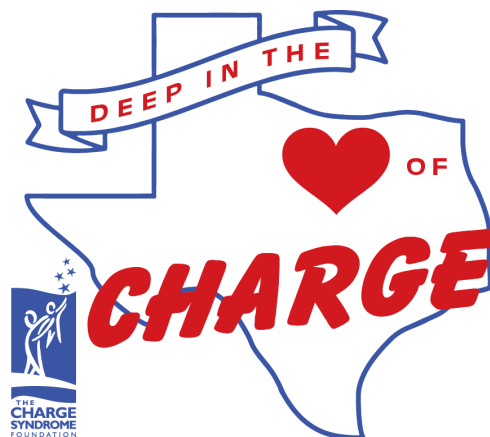
and assets once they reach the age of 18). Eligibility requirements need to be met to qualify. SSI provides cash to meet daily living expenses. With Medicaid, you can also have health insurance; Medicaid then pays for deductibles and co-pays that your health insurance does not cover, but the most beneficial reason for your child to qualify for Medicaid is to gain access to funding that may provide for your child's programs, workshops and residential housing.

Local benefits. It's also important to know if your advisor is involved with special needs organizations and informed about the issues that you, as a parent, and your child face. In addition to serving as your advocate, so you can give your child more personal attention, these special needs planners can connect you to non-financial programs, support groups, recreational opportunities and many other resources in your state your family might benefit from. A planner also keeps up with law changes and new programs to help you navigate the system. A knowledgeable special needs planner and an experienced estate attorney are invaluable assets to your family as you plan the future for your child with special needs. By working with your team of specialized professionals **today**, the dreams for your child with special needs will be closer to a reality **tomorrow**.

Mary Anne Ehlert, CFP®, President and Founder of Protected Tomorrows, Inc., is a financial professional and sister to an individual with disabilities.

SAVE THE DATE!

AUGUST 1-4, 2019



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

10th Annual

★ Charge It for CHARGE
★ Join Today!

Become A Fundraiser!
Support A Fundraiser!

NO FUNDRAISING CAMPAIGN OR EVENT IS TOO LARGE OR TOO SMALL.

Send emails, post on social media, design awareness items.

Host an event or party, have a garage sale.

Participate in a run, walk, or bike trip to benefit the Foundation.

**Contact David Wolfe, our president and fundraising chair,
with any questions about fundraising.**

YOU CAN MAKE A DIFFERENCE!

Have you heard of iCanConnect ?

iCanConnect is a national deaf-blind equipment distribution program that provides individuals who have both significant vision loss and hearing loss with free equipment and training to help them stay connected with friends, family, and the world.

Get an overview of the program, learn how it works and find out how to connect with your local iCanConnect agency during a **Wednesday, May 23rd webinar at 12:00 PST**.
[Details can be found here.](#)

Presented by:  NATIONAL CENTER
ON DEAF-BLINDNESS

 DEAF-BLIND NETWORK
TECHNICAL ASSISTANCE ACROSS THE NATION

We Need Your Contributions For the Next Newsletter!

We're working on the following topics:

What works for you?

We want to know all your great tips and tricks.
How do you and your family manage life with CHARGE?

Did you host an event?

We love to hear about CHARGE families
getting together to laugh and learn!

Send to joanne@chargesyndrome.org

Deadline: July 15 for the summer issue

SUPPORT YOUR FOUNDATION BECOME A MEMBER

Membership supports all the free programming, outreach and information we provide families! It also funds research, conference scholarships and the Ethan Wolfe Recreational Assistance Program.



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

CLICK HERE TO JOIN TODAY