



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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Jackie Alshawabkeh

The CHARGE Syndrome Foundation, Inc.
318 Half Day Road
Buffalo Grove, IL 60089
800-442-7604
www.chargesyndrome.org
info@chargesyndrome.org

President's Message

The Holidays are behind us and the New Year is here. As the temperatures in the Chicagoland area dipped below ZERO, I had plenty of indoor time to think about our large CHARGE family. Over the past year, we celebrated many individual achievements, offered encouragement for those struggling with the "challenges" of CHARGE and shared the triumphs and tribulations of our families. It is truly a privilege to serve as your president.

I am pleased to let all of you know that the Foundation enters 2018 stronger than ever! Thanks to some increased fundraising efforts, we are starting an endowment while also allocating more money to all of our programs. The article about Kate Stone, Tamera Cary and the Charlebois family is a perfect example of how friends, family and an entire community can join together to make the world a better place for individuals with CHARGE. Thank you to all of you who have, or who are going to, become part of the solution and raise money for the Foundation.

As you will read in this newsletter, there are many ways to get involved. Sheri Stanger outlines ways to get involved with outreach. Each of our committees need more members. If you need a little inspiration, this newsletter is filled with great examples of how our conferences and Foundation make a positive impact on people.

The Ethan Wolfe Recreational Assistance Program will begin taking applications around February 15. Make sure you are a member so you can take advantage of this program, and many others. Check your emails and our website on a regular basis for news about EVRAP, Conference, webinars, and exciting research developments.

Enjoy the newsletter and let's have a great 2018!

David

David Wolfe, President

Director of Outreach Update

by Sheri Stanger

We just ended a very busy year for our Foundation as we increased our outreach efforts amongst families, professionals, and partners in the world of deafblindness. When we all work together, we can have a great impact in the lives of our constituents, as witnessed at our 13th International CHARGE Syndrome Conference this past summer. I'd like to share this brief synopsis of my work as your Director of Outreach and encourage each of you to get involved with the Foundation in any way you can.

In addition to my regular outreach to families that have a new diagnosis, I continue to call or email all of our New Members and Lifetime Members in order to provide information and resources, encourage parent connections, and thank people for their support. In case you weren't aware, I have a direct toll free number to speak with people new to our Foundation, those seeking guidance and information, and those who just need to hear the voice of someone who understands and knows about CHARGE syndrome. That toll free number is 855-5CHARGE (855-524-2743). To encourage parent connections, parents who are on the Foundation's mailing list can request a Parent Contact List by state, province or country by emailing or phoning me.

One of the resources I offer to families is a **Provider Database**. This was a direct result of people requesting the names of physicians and therapists in their state, province or country that specialize in or understand CHARGE syndrome. You can request this list from me via email. The Foundation does not endorse or recommend these Providers but we are happy to share the information we receive. Since the Provider Database is only as good as the recommendations we receive, I encourage you to submit the names of the physicians and therapists that have been helpful to your family to help other families in need. To submit a referral, [click here](#)

Then there is my **State Liaison Project**. I currently have 15 liaisons who meet with me on a quarterly basis, stay abreast of information and share it with the families in their respective states and with their state deaf-blind project. I plan to increase our state liaison representation to eventually include one person from each state. ***If you have an interest in this position, please contact me.*** To review the primary functions of a state liaison and for a current list, please [click here](#).

SUPPORT YOUR FOUNDATION BECOME A MEMBER

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



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

[CLICK HERE TO JOIN TODAY](#)

I also participate in board activities and sit on the **Family Engagement Committee** as well as the **Communications Committee** planning webinars. You asked for it and we listened: The webinar committee has planned a 3-part series on Interveners. The first webinar of the series was on Jan 21st and is archived [here](#). Please watch for the registration announcement for the next two webinars in the series, scheduled for February 25th and March 25th. The Family Engagement Committee is working hard to improve our interactions with families, grow our state liaison project and spotlight family stories. Please read more about these committees on page 5.

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Director of Outreach

Finally, my outreach efforts include working with professionals in the field of deafblindness and advocacy. I currently belong to various committees that work to increase collaboration and better inform families. Through the National Center on Deaf-Blindness (NCDB) I belong to the **Partnering with Families Work Group** and **The Family Engagement Technical Work Group**. I am also a member of the Helen Keller National Center (HKNC) **National Community of Practice**. I am invited to attend the annual **Deaf-Blind Summit** and plan to present at the **Deaf-Blind International (DBI)-Network of the Americas** in April 2018 with colleagues from NCDB and the **National Family Association for Deaf-Blind (NFADB)** on "Working Together to Support Families." When time allows, I go to Washington D.C. each February for the Annual **Capitol Hill Advocacy Day** to advocate for the issues affecting individuals with deafblindness. In addition, I was recently interviewed by the **National Institutes of Health (NIH)** Office of Rare Diseases as part of an innovation grant from HHS (Department of Health and Human Services) for Improving Services to rare disease groups. I attempt to keep CHARGE syndrome at the forefront of discussion whenever possible.

I look forward to hearing from you and I encourage your much needed participation in our wonderful Foundation. Let's continue to work together to support our families! I wish everyone a happy and a healthy New Year!

Sheri Stanger, MA, EdM
Director of Outreach
sheristanger@chargesyndrome.org
855-5CHARGE (855-524-2743)

Intervener Webinar Series

What are Interveners?

Why are they critical for individuals with deafblindness?

What training is required for an Intervener and how can a parent advocate for one?

If you've asked any of these questions, join us for a three part webinar series on Interveners.

Part 1

Available on our website

Interveners: Who are they?
Why are they critical for individuals with deafblindness?

**INTERVENER
WEBINAR
RECORDING
AVAILABLE NOW!**

WATCH YOUR EMAIL - REGISTRATION OPEN SOON:

Part 2 - February 25th

What training is required and how can the need for Intervener services be determined?

Part 3 - March 25th

How can parents advocate for Intervener services for their children?

***DID YOU MISS ONE OF OUR PRIOR WEBINARS?
CLICK HERE TO FIND THEM ON OUR WEBSITE***

- Ask The Expert: Q&A With David Brown
- Strategies that Work in the Home and in the Community
- Why Does My Child Do That? Compulsive Behaviors and OCD in CHARGE Syndrome
- CHD7 and CHARGE Syndrome Research: Unveiling the Mysteries
- Pain Issues in CHARGE
- The Forgotten Senses
- CHARGing Into the Teens
- Techniques to Improve Feeding Skills and Speech Clarity
- Top Ten Strategies for Promoting Positive Behavior
- Physical Education for Children who are Deafblind
- A Conversation about Intellectual Assessment: What Parents Need to Know

Remembering Dr. Jan van Dijk

We remember Dr. Jan van Dijk, an expert in assessment and communication in children with deafblindness. Dr. van Dijk presented at several CHARGE Syndrome Foundation conferences and contributed to the 2005 American Journal of Medical Genetics special issue on behavior in CHARGE. Dr. van Dijk traveled the world over his 50 year career and helped make the world a better place for people with CHARGE syndrome.

Dr. Jan van Dijk has had a profound influence on the development of the field of deafblindness. His approach to assessment and interaction with students opens up a world of possibilities for communication, concept development, relationships, movement, and play. Dr. van Dijk has left an indelible imprint on thousands of professionals, family members, and children because he taught us how to listen, observe, respond, and relate in new ways. Dr. van Dijk was recently diagnosed with pancreatic cancer and died peacefully at home in the Netherlands on January 23, 2018. His compassion and leadership will continue to influence the lives of individuals with deafblindness and multiple disabilities for generations to come.

— Amy T. Parker
Professor of Special Education
Portland State University



Photo: Perkins School for the Blind

[CLICK HERE to read about Dr. van Dijk's approach to education on the NCDB website](#)

[CLICK HERE for Dr. van Dijk's article on behavior in CHARGE syndrome](#)

KeepOns for Glasses

Keeping glasses on our sons and daughters with CHARGE can be challenging given the malformations and floppiness so commonly seen with their ears. One of the teachers with whom I work submitted this tip and I wanted to pass it along to the CHARGE community, as it may be useful for some of your children depending on the challenges they have keeping eyeglasses in place.

"One of my students plays several sports and has had trouble with his glasses not staying in place. He started wearing these silicone "KeepOns" on the arms of his glasses a few months ago, and they're great! They're inexpensive, they can be used with most glasses since they stretch a bit, and they really work to keep his glasses from sliding down his nose. He bought his at [a local] Optical, but they sell similar designs on Amazon, and you can probably find them at other places, too."

— Sherrie G.



Wanted: Committee Members

In our continuing effort to provide the information and support our families need, we have established the following committees and are looking for volunteers. Joining a committee is a great way to learn more about the Foundation and to help us help other families like yours.

The **Communications Committee** looks after the website, social media accounts, webinars and newsletter. The goal of the committee is to reach as many people as possible, keep the Foundation relevant and on the radar of both families and professionals interested in learning more about CHARGE syndrome. We are always on the lookout for volunteers to help with content ideas, solicitation and development, monitors for the website and social media and input on how to improve communication with our constituents. To join the Communications Committee, email joanne@chargesyndrome.org

Fundraising Committee: Fundraising is the backbone of our Foundation. Through our fundraising efforts we create awareness and provide financial support to all of our programs. We are looking for more people who are excited about raising money and awareness. We want to set up "how-to-guides," develop new fundraising activities, and increase the revenue of the Foundation. You don't need experience fundraising. Just bring your passion for the Foundation and your willingness to help! To volunteer, contact deanna@chargesyndrome.org

The **Resource and Materials Committee** is focused on improving what we offer families and professionals as they search for answers about this rare and complex syndrome. If you are interested in helping improve access to our materials, it will involve studying our website, the Parent Manual and the CHARGE syndrome book.

We are also looking into using video clips to provide information from professionals and we welcome volunteers with video script and production experience.

Lastly, we are assessing how to use the information found within the multiple Facebook groups related to CHARGE. There is a wealth of information within these groups but most of the

content is not easily searchable. If you are a regular contributor to any of the CHARGE Facebook groups, we would appreciate your involvement with this committee.

By reviewing all of our Resources and Materials, this committee hopes to identify common themes and questions and make it easier to find the most current information. Committee members Julie Brandrup, Joanne Lent, Amrit Mehta, Chantelle McLaren, and Hollie St. Arnauld look forward to working with our devoted professionals and members on this important project. Email julie@chargesyndrome.org if you would like to be involved.



The **Family Engagement Committee** is a pivotal part of the Foundation. Our goals are to help families form a better connection to the Foundation, help increase family involvement within the Foundation and expand our connections with other deafblind family organizations. We hope to provide assistance to the state parent liaisons as we expand provide support to families in all 50 states in the years to come.

Our team is currently made up of the Foundation's Director of Outreach, Sheri Stanger; Board Members Minnie Lambert and Pamela Ryan; and Board Advisor Megan Cote. We are looking for enthusiastic volunteers. Please contact minnie@chargesyndrome.org today to volunteer for the Family Engagement Committee!

The **Conference Planning Committee** is seeking volunteers for all aspects of the 2019 conference in Dallas, Texas, including prep work, planning, special events, etc. It takes a team to put on a great event! We would love to hear from you about how you would like to get involved. Please email karin@chargesyndrome.org. The committee will begin meeting in late spring/early summer 2018.

Focus on Fundraising

Hello! My name is Kate Stone, and I am the proud mother of two beautiful girls: Natalie, 6, who has CHARGE, and Savannah, 4, who does not. On November 1st, 2017, I received a Facebook message from Tamera Cary, the 27 year-old daughter of one of my father's long-time employees. The message read:

"I am holding a huge fundraising event to raise money for the CHARGE Syndrome Foundation... Your dad is letting a bunch of people set up in the show rooms [of his company building] for a few hours and we will be donating proceeds to the foundation... I currently have about 25 retailers that will be setting up and I am gathering things for a silent auction... I also have a few companies that have told us that they would match the proceeds we raise! I started selling LuLaRoe and I really wanted to do a fundraiser before the end of the year. You guys all mean so much to me, that I really wanted to show my support and love for you. I have reached out to some vendors and it has taken off. So many people were interested in what the syndrome was and they researched it and then they decided they couldn't resist, and they even told friends..."

Six and a half weeks later, my husband, Aaron, and I arrived to the event with Natalie, Savannah, and many members of our extended family. We had travelled from Framingham, Massachusetts to

Milton, Vermont (our former home state) where the event was being held. As we arrived, we were delighted to see pictures of Natalie decorating the walls of the entryway and the *many* vendors corralled by Tamera



over the course of the six weeks who were selling various goods, including clothing, tupperware, food, jewelry, makeup, you name it ... and all of whom had agreed to donate a portion of their proceeds to CHARGE. We were then amazed to see the silent auction section, where we learned of the *dozens* of local small businesses who generously donated items for this event.

Tamera greeted us at the door with a big smile and a: "Hope we get some good exposure and money for CHARGE today!" Boy, did she ever. The total raised for the foundation after all was said and done: \$33,096. \$23,000 of this was from four incredibly generous donors: Ron and Mary Charlebois of R.R. Charlebois, Inc. in Milton, Vermont; Randy and Paola Charlebois of Premier Coach Company in Milton, Vermont; Roger and Patty Charlebois of Charlebois Rigging in Burlington, Vermont; and J. Peter and Margie Noonan of North Falmouth, Massachusetts. The remaining \$10,000 came from a combination of donations from individuals and local companies, silent auction proceeds, and LuLaRoe's matched donation. And exposure? The local news station came by the event that day and ran a story on their evening news. Amazing.

There's just one problem: I think I'm going to spend all of 2018 trying to figure out how to even BEGIN to thank Tamera!

Click [here](#) to see the local news coverage of the event.

We were touched by this sweet note from Aubrey Williams. All donations, big or small, help the Foundation serve our families.

For my (Aubrey Williams's) 10th annual CHARGE it For CHARGE Page. I am happy to donate online since I don't have a credit card yet, so I wanted to mail a cash donation since it's giving Tuesday. Thankful for all the work the foundation does for families like mine! This donation is in honor of ~~my~~ wonderful CHARGE friends who have become family ♥
-Aubrey Williams

Announcements

Everyone Deserves a Chance to Play



The Ethan Wolfe Recreational Assistance Program (EWRAP) will be accepting applications soon!

Watch your email for the announcement!

EWRAP was created and funded in 2014 through generous gifts from the Wolfe family and friends in memory of Ethan Wolfe. The program provides families with funding for recreational programs or to purchase recreational equipment.

SAVE THE DATE!



Individuals with CHARGE Deserve the Very Best You Can Help!



Click here to register for the 10th Annual Charge It for CHARGE campaign.

Every dollar raised helps us meet the growing needs of our families.

- Use email and social networking to ask everyone you know to help.
- Friends, family and business associates want to help, you just need to ask.
 - Sign up as an individual or create a team.
- Load a picture, tell your personal story, and start sending emails now.
- Make our shared dream of a better world for people with CHARGE come true.

New Program Offering at HKNC



Effective January 2018, HKNC is expanding services to individuals with additional disabilities who are seeking opportunities to discover vocational interests, strengths and abilities and benefit from community work based learning to gain skills for future employment. The invitation is being extended with the intention of services being available in January 2018. Individuals who would benefit from this program are those who can manage the demands of a residential training program with minimal behavioral supports. The assessment and training experiences are tailored to the needs of the individual with an emphasis on a person-centered, functional approach leading to the development of a preferred lifestyle in the domains of work, home and community.

Visit www.hellenkeller.org/hknc to contact your regional representative for additional 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. The fall issue of CHARGE Accounts included reflections from Emily Fassi (genetic counselor) and Chathuri Illapperuma (Educational Psychology grad student). Here we present the reflections of Kareem Tawfik (Otolaryngology physician) and Lauren Fogarty (medical student). Watch for reflections from the remaining Fellows in upcoming issues of CHARGE Accounts

Davenport Fellow Kareem Tawfik is physician who completed his Fellowship in Otolaryngology and Head and Neck Surgery at the University of Cincinnati. He was nominated for the Davenport Fellowship by Dr. Daniel Choo, the co-director of the CHARGE Center at Cincinnati Children’s Medical Center. Dr. Tawfik and Dr. Choo (right) were two of the co-authors of an article on Inner Ear Manifestations in CHARGE in the recent issue of the *American Journal of Medical Genetics* devoted entirely to CHARGE syndrome. Dr. Tawfik’s reflection notes the importance of connection to families in the education and practice of physicians.



For any aspiring physician, the path to becoming “legitimate” can be extremely consuming, emotionally and physically exhausting, and implausibly long. From the time an undergraduate commits to pursuing medical education, the necessity of making sacrifices begins. When we have reflected together, my physician friends and I have shared the opinion that the undergraduate basic science coursework prerequisite to matriculation into medical school was sometimes enjoyable and intellectually stimulating, but often it was difficult, anxiety-provoking, and apparently extraneous. How would our lessons in advanced physics, calculus, and organic chemistry prepare us for our future vocations? What was their purpose other than to ‘weed out’ the weakest among us? In a lecture hall filled with 500 other undergraduates, I wondered how many of my classmates aspired to careers in medicine. To my mind, these people – fiercely competitive and highly accomplished – posed an inscrutable threat to my own success. As their undergraduate careers progressed, some of my peers decided against pursuing medicine. A few had discovered other passions and vocational interests, but others had become disillusioned, disheartened, and even jaded upon experiencing the unpleasantly surprising culture of hypercompetitiveness among the “pre-med” student body. If that culture betrayed the character of the aspiring physician, then certainly medicine did not suit them. I, too, shared in that disillusion, but it was less pronounced for me than for some, perhaps because my coursework in the humanities – I ultimately earned degrees in French language and Human Biology – served as a healthy distraction.

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Davenport Fellow Lauren Fogarty is a medical student at Dalhousie University in Halifax, Nova Scotia Canada. She was nominated for the Fellowship by Dr. Kim Blake, who has been involved with the CHARGE community since before she moved to Canada from the UK in the early 1990s. Kim has followed many individuals with CHARGE, has done research on many clinical aspects of CHARGE and has mentored numerous medical students and residents in CHARGE research projects. In addition to her duties as a Davenport Fellow, Lauren presented a poster and continued meeting with families to gather data for her research on X-rays and other imaging in children with CHARGE syndrome.

Before coming to conference, my experience with CHARGE syndrome was limited in many ways. I had not met many individuals with CHARGE syndrome. What I did know was the literature around my area of research – looking at diagnostic imaging in CHARGE syndrome. I had been told that the CHARGE conference provided a unique experience to learn not only from a variety of professionals but also from the many families that attend. I came to conference expecting to learn from professionals, share my research and hoping to meet some families. What I found was what I had expected and much more. The families were welcoming and open, sharing their knowledge. I was able to get the perspective of parents and caregivers of children with CHARGE syndrome about their experiences reaching far beyond the medical.

The first day of the conference (Professional Day) was when I was able to spend the most time attending talks before I started data collection for my research project. From the first talk in the morning, I knew I was going to learn a lot! I was excited about the range of topics covered. My aim was to try and cross over between the room that focused on behavioral and educational work and the room with more clinical and science presentations. I got caught up in the clinical sessions and time seemed to fly by. Luckily I was able to hear a recap of the behavioral sessions and see some of the information during the poster session.

I presented my poster during Professional Day as well as during the main conference. The poster session was more engaging and enjoyable than any I have ever attended. I had some very interesting and insightful conversations with professionals, and particularly with parents, who were able to suggest additional barriers to diagnostic imaging for individuals with CHARGE syndrome.

The CHARGE conference was also one of the busiest conferences that I have attended. The presentations and activities ran most of the day, especially with our additional Fellows meetings. The diversity of the content also kept it very engaging and I didn't want to miss out on any of it. At meals I met a number of families and was able to hear about their experiences with their health care teams. They have had some very positive and supportive clinicians as well as some that have been poorly prepared for the care of their child. One thing they emphasized to me as a future physician, was to make sure I am always aware of the competencies of all members of the health care team. Especially when working with such complex kids, it is essential to have plan B, and even plan C and D lined up.

Walking into the opening reception Thursday evening, I was completely taken by the energy and seeing all the families there! Kids were running around and there was lots of chatting, reunions, and new meetings happening. One of the highlights of attending the conference as a Fellow was being matched with a family. I was fortunate to meet Denise and John Sherwin, whose daughter Gabby has CHARGE syndrome. It was comforting before going to conference to



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Creativity Corner

The Final (Exam) Challenge, Part 1

by Meri Dwyer

I'm standing before the castle door, my pink hair blowing in the breeze.

"It's time for the final battle!" Luce says. "Get ready, everyone!"

I bet you're wondering what a fourteen year old girl is doing in a castle. Well, I'll give you a hint: Pink everything. If you guessed Magical Girl Heroine, then hooray for you! I'm assuming you'd like to know *how* I became a Magical Girl before diving into the final battle, huh?

My name's Sakura Hikari. I'm a Magical Girl, known as a Magilyte. I'm fourteen with brown hair and eyes. Just a Plain Jane, y'know? Here's how it happened. Here's how a Plain Jane like myself became a superhero:

It all began in my eighth grade English class. Ms. Edgeworth was giving us a speech about the upcoming ELA, which did I mention we have to take *as well* as our English final? I love books and everything, but *this* is totally ridiculous!

Despite her peppy cheerleader-like *you-can-do-its*, I and pretty much the rest of the school didn't really think we *could*. Something seemed off about her that day in particular. Her frosty blonde hair that usually fell in neat waves down her back was mussed and her brown eyes that normally smiled seemed different.

She was handing out packets to help us review for our big test. When she got to my desk, I asked, "You all right?" "Yes, I'm fine, dear." Her smile seemed forced. But I didn't press the matter. After all, she could've just been tired, right? I mean, it *was* very hot outside and in the school it was no cooler. Heck, *I* was very tired. I just nodded and told her to drink some water. I come from a family of athletes, after all.

Before Ms. Edgeworth could approach her desk, she'd collapsed. A collective gasp was emitted from the entire class. Nobody moved. I was panicking. *What did Dad say to do if someone passed out? Think! Think! THINK SAKURA!* I was drawing a blank. *Water!* I finally realized. I had to get her water. My water bottle was running low, so that wouldn't help. I bolted from the room and hurried to the nearest vending machine.

I was about to pull out my wallet when something pink and fluffy caught my eye. *Huh?* I reached out to the pink ball of fluff.

"Sakura?" I jumped at the voice. Did someone just call my name? I looked around, but no one was around. No one but me and the ball of fluff. "Hello?" I called. The ball of fluff moved. I gasped. Was I hallucinating? *I better write a letter to this school to get better AC! If I pass out...*

"There you are!" The voice was cute and high pitched. The ball of fluff leapt into the air and landed on four tiny feet. I staggered back. "Hello, Sakura Hikari." I took another step back. "D-did you ... did you just ... *talk?*" maybe it was just a prank. Well, that's what I *thought* it was.

"The name's Luce! You're a Magilyte, and it's your destiny to save the world from Elana! She's an evil queen!"

I rolled my eyes. "Ha-ha. Very funny, Frank. I know it's you, so cut it out!"

Luce, the bunny, tilted her head in confusion. "Who? It's not a prank, Sakura." Her tone was serious. "Okay,

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Creativity Corner

then..." I decided to catch the prankster in the act. "Prove it."

"If I'm some sort of magical girl—which I'm clearly *not*—where's my transforming device, hmm?" I tried for a smirk, but it was a shaky one. I could never smirk. Not like my siblings.

"Sakura! Sakura, come quickly!" I turned to see my best friend, Miku Higurashi running towards me. "Something's wrong with Ms. Edgeworth!" "Yeah, I know. I'm getting her water and—"

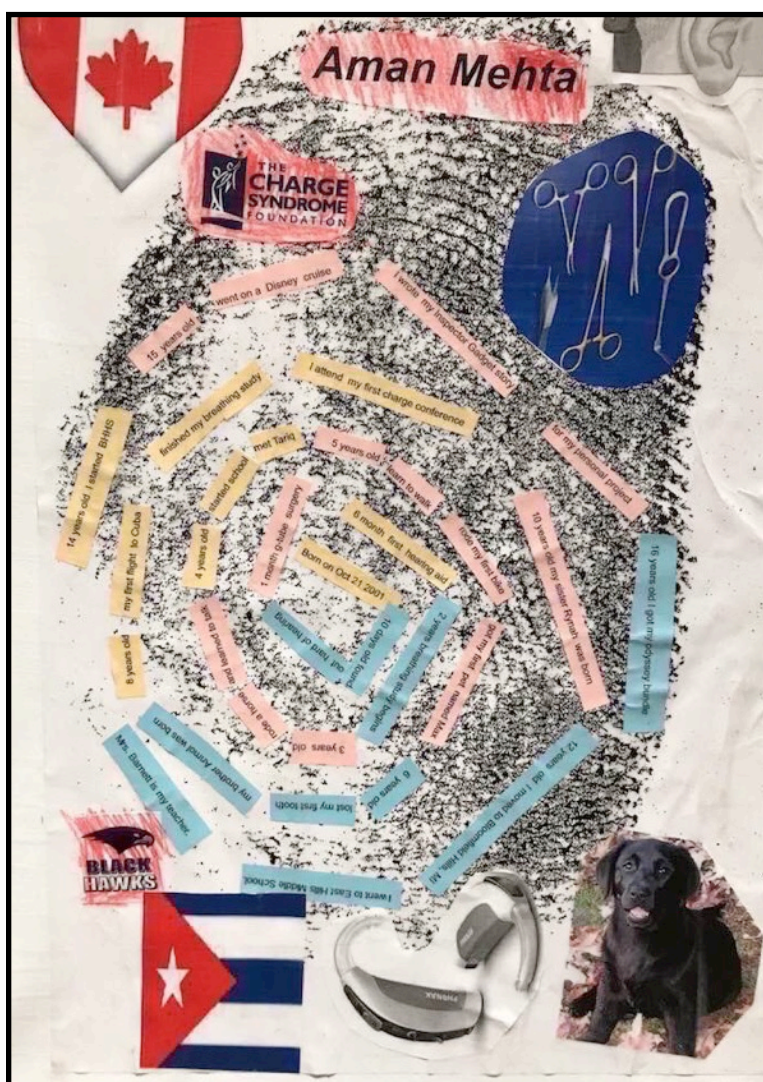
"She's possessed by Elana!"

Miku's green eyes widened. "W-was that...?"

The pink bunny stepped out from behind my legs and leapt into the air and there was a blue light. "Wha-what? Don't tell me...Miku, too?" A bracelet with a blue stone appeared on Miku's wrist. "WOW! IT'S SO PRETTY! Sakura, where'd you get this magic bunny that gives out free jewelry?"

"I'm one of a kind! My name's Luce. It's nice to meet you, Miku!" "H-hello. Um, can I, uh, pet you? My hands are clean!" I was surprised Miku wasn't totally freaked out! She seemed to enjoy seeing this...this *thing* in the middle of our school hallway! I mean...Luce is cute! But, this is all just too strange for my liking! I love Magical Girl anime, but I don't want to *live* one!

16-year-old Aman Mehta's class project



I snorted at the name. "Seriously? I'm sure you could come up with a better name than *that*!" But Luce's cherry blossom colored eyes showed true fear. "I'm serious, Sakura." "So am I."

"Sakura..." "No! I'm no hero! Now, if you'll excuse me, I'd like to wake up from this crazy dream!" I stormed off down the hall. I was about to make it back to my English classroom when I saw my science and math teachers unconscious on the ground. *Oh no! Are they...no, no, no! This can't be happening!* Before I could react, both teachers were on their feet, eyes glowing red.

"You must defeat the Fearful Four!"

I gasped. *N-no way...I guess this is real. I have to transform and fast!* Of course I didn't know *how* to do it. Mr. Jonas and Miss Fletcher lunged at me. "HELP ME!" Before I knew it, I was engulfed in pink light...

To be continued...

The Importance of Movement for Individuals with CHARGE Syndrome

Strategies and Equipment to Assist Movement

By Dr. Beth Foster

Independent walking is the most important and most impressive developmental motor milestone as it allows the hands to be free to explore the environment. This is particularly important for children who are deafblind, as their hands many times act as their eyes and ears as they explore their environment tactilely. For children with CHARGE syndrome, it is important to develop muscular strength, endurance, and balance to assist in movement development. So how can we do just that?

Strategies to Assist Movement:

- Collaboration is key! Make sure that service providers are working together and sharing beneficial knowledge. Ask about ways you can implement strategies and increase opportunities to practice at home.
- Teach or interact from behind the individual. For individuals with dual sensory loss it is important to allow their hands to do the exploring and manipulation. At times, when someone is interacting in front of them, they may be distracted by the person present and not attend to the task or object in front of them.
- Pre-teaching is a teaching strategy that is used before the start of a new physical education unit or movement experience. The child or student can learn and review the environment, layout, equipment utilized, rules, strategies, and teaching cues. Then, when the unit or experience occurs, the child or student will already have an understanding of the topic and be able to make choices and increase their independence level and performance.
- Peer tutors or peer modeling can be used to provide motivation to a child or student to move and increase their activity level and attentiveness. Peer modeling can also provide multiple sensory feedback by demonstrating the appropriate movement of a specific task or skill to the child or student.
- Provide time for curiosity and exploration of the environment and any additional objects within the setting. If movement occurs or is increased, observe the interaction of the child or student with the particular object or space in the environment to gain information of his or her preferences and comfort levels.



- Providing tactile modeling or physical guidance can increase understanding of the movement pattern and how to complete the skill. With physical guidance, a peer, parent, or teacher moves the student through the motion while maintaining a hand under hand position. The strategy of tactile modeling allows the child or student to feel the peer, parent, or teacher moving through the skill. This enables the child or student to be in control and feel the body parts if they do not understand the movement components related to the skill.
- Coactive movement allows the child or student and another person to perform the activity together and be engaged with each other

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Strategies and Equipment to Assist Movement

while moving. An example can be dribbling or kicking a ball, taking turns or performing the skill together – both the child or student and other participant are engaged and having fun in a positive environment while increasing movement experiences and providing feedback.

- Increase your processing and response time. WAIT.... then wait some more. Once you see movement or any action, then you can respond.
- Add rhythm to any movement task to focus on the beat and then change the speed of the beat to adjust movements.
- Make sure the child or student is anticipating movement prior to movement experience. Anticipation is very important when interacting and providing opportunities for movement.

Another great tool to use when assisting in movement task or increasing movement opportunities is motivation. Why should the child or student perform? Make sure to use preferred items, such as colors or textures. Also, reward them with a preferred item (e.g., iPad) when they perform the skill or task that you are asking of them. Then remove the preferred item, by the use of a timer or letting them know that you need it back, ask again for motor performance of that skill or task, then present the reward or preferred item or interaction again. It is important that communication is utilized through movement experiences to assist in understanding the movement. Incorporating signs or matching a movement with a particular object or symbol promotes choice and control for the child or student. It also allows the child or student to communicate their wants and needs by using the sign, object, or symbol for that movement skill or task. Also, make sure to provide confirmation and feedback to the student or child based on their performance in order to validate their movement attempts.



Assist motor development by utilizing:

- Various positions and postures
- Reach, grab, and release
- Push and pull: Proprioceptive input
- Kick and strike objects with hands and feet
- Body awareness: identify body parts, then identify location of body parts to objects
- Different tactile surfaces
- Cross midline of body with arms and legs
- Varying play objects (i.e., grab toys, iPad, balls, flashlights, personal fans)
- Varying supportive objects (i.e., furniture, walker, stander, box)

Equipment Resources

- American Printing House for the Blind www.aph.org (search physical education)
- School Specialty <https://store.schoolspecialty.com> (search special needs or physical education)
- Gopher Equipment <https://www.gophersport.com>
- Flaghouse Equipment <https://www.flaghouse.com/Special-Needs/> (search special needs or sensory)
- MaxiAids <https://www.maxiaids.com>

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

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already know a little bit about them [through email correspondence] and having the anticipation of meeting them in person. When we found each other in the crowd during the reception and I was met with a hug and warm smiles. I felt I was really being welcomed into a new large CHARGE family. Denise and John were very open with me and took the time to chat and answer my questions. Gabby is 6 and generally a ball of energy (although she was exhausted when I first met her at the reception). Their older son, Nathan, is a sweet, friendly kid. It was fun to watch the other kids come up to them and see all the reunions that were happening between friends who hadn't seen each other since the last conference. The value of shared friendships and supports among the families was immediately apparent.

My experience at conference overall was one of warmth, energy and learning.

From talking with so many different people at the conference, I was able to develop a much better understanding of the big picture implications of CHARGE. I learned a lot more about some of the educational challenges and barriers that can impact individuals with CHARGE. I had never heard of an intervener before attending conference, and learned about all the amazing ways that they can help a child who is deafblind. From the Sherwins, I learned about the big strides that can be made in a short time when the right people are in place to assist with a child's education. I heard stories of successes and gains over a summer after a year of frustration and setbacks, thanks in large part to an educator who was willing to listen and work with the family to meet Gabby's needs.

During the first day of the international conference I was focused on setting up my research table and starting to collect data on how many X-rays, CT scans and other imaging children with CHARGE have had. I can't say enough about the families who took time out of their busy, jam packed conference schedules to stop by and fill out my questionnaire, as well as participate in the other research going on. No

one wants to miss a minute of the sessions going on, but still parents took the time to sit down with me and share details of their child's medical experiences and life experiences- thank you! I learned so much about the individual family stories and how different each experience can be.

One recurring theme that came across from parents at the conference was the need to always be an advocate for their child. As I prepare for my medical career, I am humbled to witness the knowledge and experience of every parent and caregiver that I encountered. I was told many stories of professionals in both educational and medical settings that have been dismissive of parent concerns and input, a mistake I hope never to make in my future practice. Each family is truly the specialist when it comes to their own child; this is particularly important in a syndrome with such a huge range of experiences.

The nightly Fellows meetings that I attended were a perfect addition to my conference experience and I feel very fortunate to have participated in them. They provided a platform for reflection and discussion every evening, as well as an opportunity to hear from other professionals and trainees about their experiences with different aspects of CHARGE. I enjoyed hearing what brought each Fellow and their mentors to the world of CHARGE syndrome. It always seems to go back to individual patients or students who made a big impact them and caused them to want to learn more. Meeting all the fantastic individuals at conference certainly was a great motivator for me to continue my research in CHARGE syndrome and to continue to be involved in this special community.

After listening to the other Fellows chatting about their experiences at camp all week, I have to say I was excited for Sunday morning when at last my time at camp had come! On this final day, Gabby was exhausted and after a fun trip admiring all the flashing lights on a fire truck she decided to have a nap. I met Michael, another camp attendee, early in the day. He had become a buddy to Gabby throughout the week at camp. I was told he always wanted to help her out with anything she needed. Michael uses sign language

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The Impact of the 2017 CHARGE Conference

by Lily Slavin

I joined Tim Hartshorne's CHARGE Lab at Central Michigan University in June 2016 to gain research experience before applying to school psychology graduate programs. My experience began as a resume builder but ended up changing my life by sparking my passion for researching CHARGE syndrome. I was extremely excited when I was accepted into the school psychology doctoral program at CMU with Tim as my advisor. I am currently a first year student.



From my six months in the lab prior to beginning graduate school, I had a vague idea of the topic I wanted to research: educational issues in CHARGE syndrome. I am very thankful that I had the opportunity to attend the 13th International CHARGE Syndrome Conference in Orlando just a few weeks before graduate school. The conference was unlike any other conference I had ever attended. I can't quite capture how inspiring it was to be able to speak to and collaborate with some of the leading researchers in CHARGE in the world. As a student who was just starting my research in CHARGE syndrome, I really appreciated the mentorship that I received from established researchers at the conference. I had been admiring those researchers for the past year and speaking with them and hearing their words of encouragement made me feel like I could really make a difference in CHARGE syndrome, which meant the world to me.

My experiences at the conference helped me develop my research idea more than months of prior independent research had. I was able to see what other researchers were working on, which helped me narrow my research topic; speak with parents about the issues they face, which added important insight to my topic; and interact with individuals with CHARGE Syndrome, which gave me personal connections to remind me of the impact my research could have. The conference was also super fun in addition to helping me develop professionally. I walked away from the conference with a very specific project in mind and a list of other researchers I could consult with. After working on my project for several months, I look forward to attending more CHARGE conferences so I can share my research with other professionals and families!

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and after only a crash course in the basics of ASL before coming to conference, I was nervous that it would be difficult to for me communicate with him. It didn't take long to realize this was not the case. Michael's sense of humor shone through before long and in no time we were playing games and having many laughs as he kept beating me and bumping me off the board in Sorry!

My experience at conference overall was one of warmth, energy and learning. Although this conference is fairly large there is a level of intimacy and personal connection that is really extraordinary. My understanding of CHARGE syndrome was broadened and I was inspired and challenged by the individuals I met. It is easy for us all to get caught up in our own specific niche. For me that involves the diagnostic imaging in CHARGE syndrome and the medical implications for individuals with CHARGE. Stepping back to learn from other professionals and the experiences of families helps to make us better in our own work and hopefully ultimately leads to better support for individuals with CHARGE syndrome. As a trainee, I am thankful to have these experiences help shape my future clinical practice as well as my research.



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When I began my medical school education, I expected that my coursework – and the time I invested in study – would surely *matter* more. Gone were the days of arbitrary learning endured for the sake of checking off a box and advancing one's career. Of course, I would spend my first two years intensely focused on the basic sciences, but this was *medical* school and, in turn, I hoped that the content of my curriculum would have more obvious applicability to the practice of medicine. In my first semester, I was challenged by my coursework in anatomy and biochemistry, and even though at times I marveled at the stark excess of knowledge my instructors expected their pupils to master, I now possessed an amplified sense of purpose. I worked diligently to learn without passing judgment on the course material, despite whatever deficit of utility it might have. (And anyway, how could I know what utility it would have at all?) I was also motivated by my peers, whom I admired for their commitment.

My third and fourth years of medical school consisted entirely of clinical rotations on inpatient wards and outpatient clinics. These formative years, and subsequently my residency training, finally brought the rewards I had excitedly awaited. It was and still is exhilarating to experience the gratifications, challenges, desperations, triumphs, and complexities of practicing medicine. Having recently completed my residency training in Otolaryngology, I have been reflecting heavily on my education, career goals and clinical interests. It was my interest in the otologic manifestations of CHARGE syndrome that first impelled me to learn more. As a resident, I had cared for several children with CHARGE, usually in the context of medically critical situations. My mentor, Dr. Choo, suggested I apply for the Davenport Fellowship and he promised that attending the CHARGE Syndrome Conference would certainly be an eye-opening experience. He was right. I was surprised, however, to find the greatest value of the conference was not the Professional Day or our daily meetings with the other Fellows, but the time I spent learning from mothers and fathers and their children with CHARGE syndrome. This being *human* with these extraordinary people – was immensely enriching. The

parents of these children inspired awe. For them, 'parenting' has a different meaning than it does for most of us. It is more intensive, more exhausting, more complicated, more fraught with uncertainty, and it is unrelenting. I had a memorable conversation with the mother of seven children. Her daughter Hope had recently passed away as a result of complicated pulmonary hypertension, an unfortunate manifestation of CHARGE syndrome in her case. Hope, despite living in a wildly busy household, was central to the life of the family. Hope was tracheostomy- and G-tube-dependent, had frequent ear infections, and between hospitalizations, she lived a happy, albeit complicated life at home. Her mother showed me numerous photographs of Hope with the rest of the family, and I thought of my wife and two children. I expected Hope's mother to cry, but instead she continued sharing stories about her daughter, like the time she saw their ENT at University of North Carolina, and he diagnosed her with an extremely rare ear infection caused a bacterium similar to the one that causes tuberculosis. She went on to tell me that she had known for some time that Hope's life would be short. Her death, when it came, was peaceful, and she passed in the company of family. Her mother came to the conference because she felt compelled to do *something* to pay tribute to Hope.

The greatest value of the conference was not the Professional Day ... but the time I spent learning from mothers and fathers and their children with CHARGE.

Sometimes I wonder at the investments I have made in my medical education. I do not regret any of it. I love my profession. I love caring for patients, and the gratification of seeing someone through illness to cure is profound. Nonetheless, a conversation with Hope's mother; a few hours with Gracie, a 15-year-old girl who has CHARGE syndrome; standing in a hotel ballroom with a hundred children with CHARGE syndrome and watching their excitement swell in acknowledgment of their sameness and their differences – for a physician, experiences like these are a richer education than any formal schooling can offer.