



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: Lisa Weir

Treasurer: Brownie Shott

Secretary: Neal Stanger

DIRECTORS

Julie Brandrup

Karin Dagley

Minnie Lambert

Joanne Lent

Christian Lobaugh

Amrit Mehta

Pamela Ryan

SPECIAL ADVISORS

Meg Hefner

Donna Martin

DIRECTOR OF OUTREACH

Sheri Stanger

DIRECTOR OF ADMINISTRATION

Jody Wolfe

DEVELOPMENT & DATABASE MANAGER

Jackie Alshawabkeh

In This Issue

In Memory of Marion	2
Personal Passports	4
EW RAP	6
Davenport Fellows	7
Deaf-Blind Summit report	11
Family Leadership	12
Announcements	13
Applying for Disability	17
Charge it for CHARGE	18

President's Message

It has been a busy spring and summer at the Foundation, filled with many accomplishments, but also our share of sad news. I hope everyone takes a few moments to take a look at our new website. It is so much easier to use and will allow us to better communicate with the world.

We just awarded four additional research grants; bringing the total spent on research over the past 5 years to well over \$650,000. The amount of genetic and clinical research on CHARGE continues to grow. People we have worked with and/or funded have now received major funding from other sources. Many of them will gather at the University of Michigan this October for a meeting that is co-sponsored by the Foundation. We look forward to exciting advances in the diagnosis and treatment of CHARGE.

At the same time we continue to grow and advance, we mourn the loss of one of original founders, Marion Norbury. For my family, she was the original voice of the Foundation. Her dedication and compassion will live on through the work of the Foundation and The Norbury Scholarship, which supports families attending Conference for the first time. We also continue to see too many of our families coping with the loss of individuals with CHARGE. Our CHARGE community continues to see struggles with medical, behavioral and educational issues. We can only join together to support each other as the Foundation strives to provide more answers and support.

On October 1, 2016 we will start our 9th Annual Charge It for CHARGE campaign. This campaign will allow participants to earn free conference merchandise and registrations. Stay tuned for the details in late September. I hope every one of you will join to help the Foundation do more to provide information and direct support to our CHARGE family.

Enjoy the newsletter.

David

David Wolfe, President



In Memory of Marion Norbury

Co-Founder, CHARGE Syndrome Foundation

written in 2008, edited by Meg Hefner, 2016

Marion grew up in St. Louis, but lived in Columbia, Missouri since 1959. Before CHARGE, she was a second grade teacher and later the Director of Children's Services at the Library. Marion always had a pet golden retriever, all named after coins. The latest one was Nikki. Her hobby was quilting.

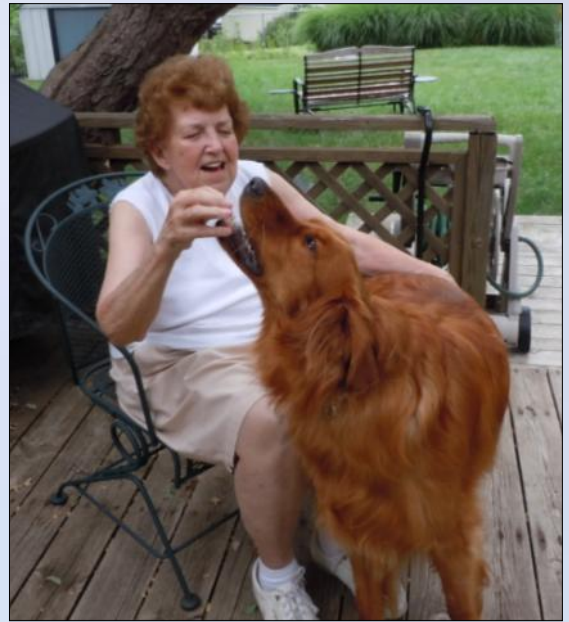
Marion's CHARGE syndrome story began in 1986 through Quota International, a service organization whose main emphasis is helping the speech and hearing impaired. Through Quota, Marion became friends with Dr. James Thelin, then the Chief Audiologist at the University of Missouri. In 1986, Jim arranged for Quota to fund publication of the first information for families on CHARGE – a 50 page booklet. Marion agreed to mail it out from her home. Thus Marion's involvement in CHARGE began. Little did she know what a large part of her life it would become. For many years, the CHARGE phone was Marion's phone, the address was her home. She was often the first contact for families – on the phone or by mail. In response to requests from parents, Meg and Marion started the newsletter in 1989, with Marion as the editor, printer and postmistress. Her husband, Lee, often answered the CHARGE phone line in their house, as it was their home phone. Lee also provided his expertise to the Foundation as a former employee of the IRS.

In the spring of 1993, as Meg, Sandy, and Marion were preparing for the first CHARGE Conference, Marion was the one who insisted we incorporate as the CHARGE Syndrome Foundation, Inc., again based in Marion's home. Although still working part-time, Marion spent several days a week filling orders, returning calls, writing letters, maintaining membership records, preparing the newsletter and working on other CHARGE projects. In those days, there were many letters, Christmas cards and calls from families desperate for information.

Marion served as a volunteer Secretary-Treasurer on the Foundation Board until 1999, when her position was changed to Executive Director. In 2008, she became the Director of Family Services, the office was finally moved out of Marion's home and her phone line became her own again. Marion retired from the Foundation in 2009, but remained in touch with many of the families. At the 2015 conference, Marion was honored as one of the founders of the CHARGE Syndrome Foundation. Read past Foundation president Steve Sorkin's introduction of Marion and the other founders [here](#).

Marion passed away on August 3, 2016 from complications of dementia. She was 83. Her beloved dog, Nikki (pictured above with Marion), has found a loving home on a farm.

(Continued on page 3)



The Norbury Scholarship

We honor the life of Marion, as her legacy lives on through the work of the Foundation.

In celebration of her life, we would like to announce a name change to one of our conference scholarships: The Lee E. Norbury Memorial Scholarship will now be The Norbury Scholarship in recognition of the many contributions of **both** Marion and her husband, Lee. The Foundation will continue to offer funding for first time conference attendees in their memory.

[CLICK HERE TO DONATE TO THE NORBURY SCHOLARSHIP FUND](#)

(Continued from page 2)

MILESTONES (excluding conferences)

- 1987 • CHARGE Syndrome: A Booklet for Families is published
- 1989 • First issue of *CHARGE Accounts* is published
- 1993 • The CHARGE Syndrome Foundation, Inc. is established in Columbia, Missouri
 - First International CHARGE Syndrome Conference in St. Louis, Missouri
- 1994 • A toll-free telephone number is available
- 1997 • LISTSERV started with Casey Fisher
- 1999 At the Fourth International CHARGE Syndrome Conference in Houston, Texas ...
 - *CHARGE Syndrome: A Management Manual for Parents - Part I* is published
 - Marion Norbury becomes the Foundation's Executive Director
 - The Lee E. Norbury Memorial Scholarship Fund is established
 - The first Star in CHARGE Awards are presented
- 2001 At the Fifth International CHARGE Syndrome Conference in Indianapolis, Indiana ...
 - Part 2 of the Manual is published
 - Spanish Version of Manual - Part I is published
 - First CHARGE Syndrome Awareness Week
- 2002 • Spanish Version of Manual - Part 2 is published
 - First New Parent Packet is published
- 2003 • 10th Anniversary of the Foundation 1993-2003
 - Second CHARGE Syndrome Awareness Week
 - Translation of the Manual into Japanese
- 2008 • Professional Packet is published



Marion with Rob Last in 1993, top; with Foundation co-founders Jim Thelin and Sandra Davenport in 1995, center; and with the Foundation Board in 2008, left.

Repetitive Strain Injury

by David Brown

Parents of children with CHARGE syndrome often report their weariness and frustration at having to introduce and explain their child, and the syndrome, over and over again to each new professional they meet. In the early years this happens primarily in the medical arena, and various strategies have been devised to help parents condense the key issues affecting the child to show to these professionals. Even the most condensed record, however, has to be fairly long and detailed to provide all the most important and relevant information. Of course, no strategy is foolproof, and parents have to get used to the look of disbelief on professionals' faces, their inability to grasp that any condition could be this multifaceted and complicated.

When it comes to trying to describe the child's development, learning styles, and behavior, the situation is even more complicated. There are challenges with finding the right words to describe the child and their actions with any precision. Then there are challenges with interpreting these behaviors to attribute meaning to them as correctly as possible. And the variables depending on time-of-day, location, people present, state of health, and other things can be mind-boggling. The idea of personal passports as a way through these difficulties developed in several places in the early 1990s. Basically, a personal passport is a little book that introduces the child, describes their likes and dislikes and the behaviors that demonstrate liking and not liking, or wanting and not wanting. If the book is written in the first person, as if it is

the child themselves addressing the reader, then it is likely to have a more powerful and positive impact than if the book simply conveys somebody else's ideas about the child. In 1996 I wrote an article about personal passports, "[Knowing the child](#)," which can also be found at the [California Deafblind Services website](#).

This idea is still very valid, and in the course of my work as an advisory teacher many families of children with CHARGE syndrome have produced powerful personal passports that vary greatly in their length and style. The great complexity of the syndrome results in patterns of development and behavior that are easy to misunderstand and misinterpret, so it is especially important to find ways to let people know what the children might be thinking and feeling, and how this can be ascertained from their behavior. The original idea was to produce passports only for children at the very earliest stages of communicative awareness, but as more and more parents have heard of the idea, a much wider range of children (varied by chronological age, by developmental level, and by receptive and expressive language level) have been given passports. These days it is not unusual to see a passport created with the active involvement of the child, who may have provided some of the words, chosen the topics included, selected the photographs, or provided artistic input to the 'look' of the passport. Children sometimes insist that the passport contains information about their early sensory and medical issues (heart and other surgeries, balance problems, feeding tubes, visual field loss, and so on) complete with photographs of surgical scars in order to demonstrate their challenges and clarify their achievements. A well-made passport can be a very helpful component of ability awareness training before the child enters a new school or a new classroom, and generally they are a potent aid in all kinds of transitions involving new places and new people.

The format of the passports has always varied even on paper, but with the advent of computer and video technology we have seen this variety increase dramatically. I have seen personal passports on sheets of paper stapled together, on laminated plastic sheets in loose-leaf binders, in Power Point slide format, and embedded on iPads or

(Continued on page 5)

**Do you have a story
you'd like to share?**

**An upcoming event to
promote?**

Please tell us about it.

**Submissions for the next edition of
CHARGE Accounts are due by October 5th.**

Submit articles to

joanne@chargesyndrome.org

[CHARGE Accounts Submission Guidelines](#)





(Continued from page 4)

smartphones. I have seen them written totally in a light humorous manner (but containing really important information) but also in a more formal way, even with references to useful articles included at the end. For me the most interesting development in the past few years was when a family recently showed me a personal passport in the form of a simple trifold (see next page) – an idea I talked about in a [CHARGE Syndrome Foundation webinar](#) in May.

The guidelines for creating a passport are actually quite simple:

- *Keep it totally personal and individual*
- *Keep it as brief and as simple as possible while still being comprehensive*
- *Choose the words carefully to avoid ambiguity*
- *Include plenty of photographs to introduce your child and to demonstrate the things you are writing about (eg. facial expressions, postures, head movements, and so on)*
- *Discuss ideas with other people where possible (and remember that these discussions and the process of creating the passport may be even more useful than the finished document itself)*
- *Use humor in your writing to create a rounded picture of your child (and also to keep the reader interested and intrigued)*
- *Be prepared to alter or update the passport when necessary*

Contact me at welshgold@gmail.com if you want to see some additional examples of real personal passports, if you feel stuck, or if you want to discuss ideas!

<p>Medical Stuff</p> <ul style="list-style-type: none"> • I need to be suctioned and wear oxygen so that I can breathe easier. • There's a feeding tube in my belly so I can eat and drink. I can't have anything in my mouth. It's important that my feeding tube be covered at all times so it doesn't get pulled out. • Over 20 surgeries/procedures have helped me and even saved my life. Includes heart surgery (PDA), g-tube, jaw distraction, nissen fundoplication, salivary gland removal and ligation, orchiopexy, multiple ear tubes, laryngeal cleft repair, multiple airway and esophageal scopes, biopsies, multiple MRIs and CT scans. • Germs are very bad for me and can make me much sicker than average kids. I use hand sanitizer, sometimes need reminded to keep my hands out of my mouth, and may need to stay home when certain illnesses are going around in class. • I have a busy schedule to keep. I have a long day medically which typically starts at 6:30am and ends at midnight. I'm also up throughout the night to be suctioned. I spend many hours outside of school at appointments and therapies. Please be kind to me as I go through a lot. • My face may look a little different than yours because I have some paralysis. My smile is a little crooked. I like to smile with my tongue out. I have some scars on my face due to surgeries to help me breathe better. The band-aids on my face just hold my tubing in place. • I am still a medically fragile guy but I have come so far. I just want to have all the same opportunities as my peers. 	<p>2016 #gettoknowgannon</p>	<p>Gannon Moseley</p>  <p>A Little About Me...</p> 
---	-------------------------------------	---

<p>Important Things to Know About Me</p> <ul style="list-style-type: none"> • I am a quick learner and I have a great sense of humor. • I am visually impaired and I see best with my left eye. It is helpful if I am at eye level when viewing the Smart board and I use large print materials. • I wear hearing aids and hear better out of my left ear. • I communicate in many ways: I love to talk and once you get to know me, you'll understand me better. I also use sign language and I have a really cool iPad that talks for me. My nurse/intervener, Codi, helps bridge any gaps in my communication. • I love school, I like to be involved with my classmates, and contribute to all class activities. I dislike missing school, but unfortunately I do get sick easily and have many medical appointments. • I can't put any food or drink in my mouth.  <p>This is me, Mom, Dad, Dylan, Ian, and my best friend Addy!</p>	<p>What Works for Me</p> <ul style="list-style-type: none"> • Codi is not only my nurse, but my eyes and ears. She can adjust my environment throughout the day to ensure I am understanding what is being taught. • I need a front row seat on the right side and the flexibility to move as necessary. • It is important that new concepts and vocabulary are broken down for me. • My experience book helps me practice and remember new concepts. It is a great tool to keep my team on the same page. • Lunch buddies is a fun time for me. It's a good time for me in a quiet environment to get to know my friends. • My FM system is also a good tool for communicating with my teacher/peers. • Some days I might have poor balance, so I need someone close by to help me with my equipment. • I love when my teachers and therapists learn about CHARGE Syndrome and deaf/blindness. 	<p>Vision for Gannon</p> <ul style="list-style-type: none"> • Fully included and accepted in his community • Going to college • Meaningful, real wage, full-time work with benefits • To create, full, rich, independent life for Gannon in his community with the support which he needs to be successful    <p>I love to play Minecraft, Baseball, and cook with my brothers!</p>
--	--	--

We presented this brochure at Gannon's IEP meeting. He is transitioning to a new school and his awesome blind and low vision teacher had the idea. She worked together with our family to put this together. I think it's neat for not only school staff but home therapists, maybe even some doctors and family members. Thought I would share in case others might benefit from it.

by Sara Moseley



Everyone Deserves a Chance to Play

Congratulations to the recipients of the 2nd Annual Ethan Wolfe Recreational Assistance Program (EWRAP)

EWRAP was created and funded through generous gifts from The Wolfe family and friends in memory of **Ethan Wolfe**. The program provides families funding in order to participate in recreational programs or purchase recreational equipment. This year's recipients are:

- ♦ **Ryan & Daryl: Summer Camp/Intervenor at Camp**
- ♦ **Trevor: Swimming Lessons** ♦ **Laci: Adaptive Tricycle**
- ♦ **Carter, Ysabel & Ryder: Hippotherapy** ♦ **Layla: Dance**
- ♦ **MacKenzie: Fitness Center Membership** ♦ **Ava: Bike Trailer**



*Look for applications for the 3rd Annual
EWRAP at the beginning of 2017.*





Sandra Davenport Fellowship Program

The 2015 conference was the inaugural year for the Sandra Davenport CHARGE Syndrome Fellowship Program. This program was established to bring young professionals to the CHARGE Syndrome Conference and encourage them to become more involved with the greater CHARGE community. The first class of Fellows was comprised of nine individuals from a variety of backgrounds – graduate students in psychology, genetic counseling and medicine and one teacher of the deafblind early in her career. They were nominated by their mentors, professionals who have been active in the CHARGE community for a long time, in some cases decades.

Each Fellow participated in Professional Day and the full International Conference. They volunteered a half day in Camp and met each day with the program mentors. In 2017, we will again bring in young professionals as Davenport Fellows. Watch for more stories and information about how you can be involved in the next newsletter. Your [membership](#) and [donations](#) to the Foundation help make this program possible.

Caitlin Hale

Genetic counseling student, University of Michigan

Before coming to the 2015 CHARGE conference, my only experience with CHARGE syndrome was in the context of a genetics clinic visit or participating in a genetics research study. I was very excited to learn about aspects of CHARGE syndrome that come up across the lifespan. I was looking forward to interacting with individuals with CHARGE syndrome and their families outside of a doctor's office. I think the first thing that struck me, which is somewhat obvious but I guess was more visually obvious at the conference, is that CHARGE syndrome affects families from every walk of life. I met young parents whose first child was born with CHARGE syndrome, families whose last child was born with CHARGE syndrome, families from large cities and families from rural areas, parents who were physicians and parents who had no medical experience until their child was born. It was interesting to observe how these families take their own unique backgrounds and use it to adapt to their child's diagnosis, and to become their child's best advocates.

Coming from the medical world, I was surprised by the amount of research that is done on the developmental

(Continued on page 15)

Alexandra Hudson

Medical student, Dalhousie University
Halifax, Nova Scotia Canada

I first heard about CHARGE syndrome from Dr. Kim Blake on a medical research information day. I had never heard of CHARGE, but I was intrigued. After learning the multitude of medical problems these individuals faced and the complexity of their needs, I knew that I wanted to learn even more and decided to start a research project in this area. Through the rest of my first year of medical school, I never once heard this term used in any of our lectures or small-group tutorials. Many of my classmates would give me a puzzled look when I described my research project on CHARGE syndrome. One of my favorite ways to explain this genetic disorder was the way my research supervisor often described it as, "Now stand on one leg, cover one ear, cover one eye, and hop around. Isn't life pretty difficult now?"

I was very fortunate to be able to attend the 2015 International CHARGE Syndrome conference in Chicago, Illinois as a Davenport Fellow. The conference attendees consisted included not only professionals, but families, their children with CHARGE syndrome, and their unaffected siblings. When I presented my research poster,

(Continued on page 9)

Benjamin Kennert

PhD student, School Psychology
Central Michigan University

I began working with Tim Hartshorne on CHARGE syndrome research in 2012 as a randomly-assigned graduate assistant, and I had no idea what I was getting myself into. I have wanted to help people for as long as I remember and that is ultimately what brought me to the school psychology program at Central Michigan University. However, I didn't know what CHARGE syndrome was,

had never met someone with CHARGE, and therefore didn't expect to become interested in CHARGE.

That all changed when I attended my first CHARGE Syndrome conference in Scottsdale, Arizona in 2013. After spending long months reading about CHARGE and all the difficulties and impairments involved, I was expecting to meet a group of children with limited skills, worn-out families, and a long list of needs. I will never forget what I experienced that weekend. I saw a group full

(Continued on page 8)

Benjamin Kennert

(Continued from page 7)

of positive energy, a sense of community, empowerment, laughter, joy, and determination. Although the difficulties and struggles were present and very real, there was an overwhelming sense of energy that I didn't expect, and I immediately wanted to be a part of it.

In Chicago in 2015, I wanted to gain a greater depth of understanding from all that the conference had to offer. I knew much more, had met many children and families in the CHARGE community, and had completed a few research projects. My goal was to not only experience the conference, but to understand it. I wanted to learn more about CHARGE, from the professionals, the families, and the children.

After Professional Day, I spent most of my time trying to meet children and families, attending presentations, and meeting some of the expert professionals in the CHARGE community. I asked several parents three questions that I was interested in: (1) How many conferences have you been to, (2) What has been your biggest take-away so far, and (3) What is the most important connection you have made here?

Some parents were very interested in gathering as much information as possible from the presentations. Some parents were hoping for help with addressing specific difficulties. Other parents were there simply to make new friends or see old friends. Others still were hoping for professional guidance.

I loved hearing the many stories and I enjoyed when families would ask me questions about my research and how it could help them. For example, one family struggled

with getting their child to go to bed on time. Since my current area of research is in sleep intervention, I was able to offer suggestions that they hadn't thought of before. At the same time, they were able to share information with me that I didn't know, which helped me to gain a better understanding of their child.

I particularly enjoyed observing the behaviors of the children with CHARGE, and trying to figure out why they were doing what they were doing, and what they might be trying to communicate. For example, I spent a half-day in camp with a 7-year-old child who only communicated through sign. As I don't know sign language, I had to determine what he wanted through an interpreter or though watching his behavior. Eventually, I was better able to determine when the child wanted to walk, when he needed help, and when he was frustrated. Communication seems to be the major theme with children with CHARGE, and learning more about how to communicate, as well as recognize a child's needs, was invaluable for me as a professional.

I enjoyed the Fellowship greatly. We kept very busy, which was sometimes overwhelming, but in order to gain the best experience I don't see a way around that. It was nice to meet other professionals early in their career who

are interested in CHARGE and I hope those relationships will continue to grow at future conferences.

Editors note: Ben is continuing his studies with Dr. Tim Hartshorne. Ben was an author of an article with Alexandra Hudson: Quality of life in adolescents and adults with CHARGE syndrome. Hartshorne N, Hudson A, MacCuspie J, Kennert B, Nacarato T, Hartshorne T, Blake K. *Am J Med Genet A*. 2016 Aug;170(8):2012-21. doi: 10.1002/ajmg.a.37769. Epub 2016 Jun 8.



Alexandra Hudson

(Continued from page 9)

One of the most powerful messages I took from meeting so many families and individuals with CHARGE syndrome was that the power of one should not be taken for granted. Although there are not as many children affected by CHARGE as compared to many other conditions, there is still a need for attention to be drawn to the issues they face. I knew that I had really connected with one young girl I had met previously in Halifax when she came

up to me at the conference and pointed at my research poster while indicating approval with a 'thumbs up' sign. I had included a photo of her with me from our initial meeting in the corner of the poster board. Although we weren't able to verbally communicate, at that moment I knew that we had a mutual understanding and appreciation. I hope that as I move forward in my medical career, I am able to continue my research into this genetic disorder and continue to meet such amazing families and individuals with CHARGE syndrome.

(Continued on page 16)

Alexandra Hudson

(Continued from page 7)

many families approached me and were interested in research and connecting with professionals and students. The most amazing part of this conference was its ability to connect children and adults with CHARGE syndrome. Old friends and acquaintances from all over the world were able to see each other and reunite. With so many individuals with CHARGE attending, it was almost impossible for a child to feel “different.” One of my favorite quotes (heard by my research colleague at this conference) came from a young girl with CHARGE syndrome who exclaimed when the elevator opened, “Another kid with CHARGE syndrome! The DNA is everywhere!”

One of my most memorable moments was talking to a 36-year-old with CHARGE syndrome who experienced mouth over-stuffing and food pocketing during eating, a feeding difficulty that had not been addressed in his previous feeding therapy. He was so grateful that researchers were working on ways to increase public awareness regarding CHARGE-specific medical issues. Through my research project on feeding difficulties in this genetic population, it is my hope that occupational therapists and speech language pathologists will alter and target their therapy specifically for individuals with CHARGE. Many feeding therapists and professionals have not encountered an individual with CHARGE syndrome in their practice, so increased awareness of the issues they face is continuously needed. The most powerful tool is a knowledgeable parent, armed with appropriate and accurate resources, which they are able to take to the health care provider and advocate for their child. To be able to print off a paper specifically discussing feeding

issues in CHARGE syndrome and bring it to the feeding therapy team could help address feeding behaviors that are dangerous to the child and choking hazards that typically developing children may not experience.

I walked away from the CHARGE syndrome conference with more than I could have ever predicted. I learned several words in sign language as I watched families interact and children greet one another. I witnessed the roles of the parents as caregivers, health experts, and advocates. I was able to see the sibling interactions between that of a typically developing child with their sister or brother with CHARGE syndrome. Most importantly, I was able to meet face-to-face a wide range of individuals with CHARGE syndrome—children, adolescents, and adults.

As part of the Fellowship program, I spent some time in camp, mostly with the youngest group of children. Simply observing the children play and interact allowed me to appreciate the differences in children with and without CHARGE. Children with CHARGE syndrome often needed thick glasses and hearing aids, and walkers to be able to balance and walk around. I spent most of my time with one young girl who loved to play with the fuzzy blankets and carpets, as it seemed to provide sensory feedback. What struck me most was that despite all of the sensory, balance, and cognitive issues, children with CHARGE syndrome were really just like any other children. They wanted to explore the room and play with toys, and they never let any of their altered physical abilities get in the way. What we might see from the outside as deficits and inabilities, to them it was just their normal, daily way of functioning.

Meg Hefner, one of the mentors of the Fellows Program, related that during the early conferences, many medical professionals did not know about CHARGE. She mentioned that she recently attended a pediatric conference where the speaker started off the talk with, “now you all already know what CHARGE syndrome is...” This story stuck with me as it showed the importance of general awareness of the syndrome. I am committed to research in this field and have begun a second project developing a comprehensive feeding questionnaire specifically for those with CHARGE syndrome. It is up to us as professionals and students to continue to develop tools that can benefit all individuals with CHARGE.



(Continued on page 8)

The CHARGE Syndrome Foundation is proud to announce the recent launch of our new website!

Come visit us at www.chargesyndrome.org



Our new and improved website offers:

Improved Navigation - Find what you want quickly with easy-to-navigate menus, sidebar menus and more.

Support for Families - Whether newly diagnosed or a family who has been involved for years, you will find what you need.

Professionals Section - Doctors, educators, psychologists, and therapists will benefit from information specific to their area of expertise in our new professionals section.

Ways to Get Involved - A new section devoted to helping you learn about all the ways you can support the Foundation and help improve the lives of people with CHARGE.

Upcoming Events & Conference Information - Redesigned to easily provide all the information you need for conference and other CHARGE-related events.

Built-in Accessibility - Our new site features **Sitecues** technology that allows user to magnify the page, turn speech on, set focus and reading enhancements, as well as set personal preferences for color themes and mouse.

It is our hope that everyone who visits our website will find the information and resources they need easily; there is something for everyone! We hope you will take some time to explore the new site and [let us know what you think](#).



Our new website was made possible by the commitment and guidance of Jay Brandrup, father of Adele, and his team from Kinetic. Jay and his team are featured on our [Volunteer Spotlight](#) page.

Thank you, Jay,
For your support of the Foundation.
We couldn't have done it without you!

Report from the Deaf-Blind Summit

by Sheri Stanger, Director of Outreach

I love spending time in our nation's Capitol. There is so much to see and do. You can feel the city's vibrancy as you walk through the Capitol building, past the White House and visit the wonderful museums and monuments. Policy and law are part of this city and the federally funded deafblind children's initiatives are approved or denied here.

It is critical for us, as parents, to know about the process and to support the national initiatives that come out of the National Center on Deaf-Blindness (NCDB) and the State Deaf-Blind Projects because they serve many of our families. These organizations write for a 5 year federal grant to continue their work to impact the lives of children and students who are deafblind, their families, and those that serve them. As of October 2016 they will be entering year 4 of their current grant cycle. Those initiatives will impact our lives and we should be prepared to provide input about the needs of families that have a child with CHARGE syndrome for the next grant cycle.

I had the opportunity to attend the Deaf-Blind Summit in Washington D.C. on July 31, 2016. The Summit brought together the State Deaf-Blind projects, NCDB and representatives from national family organizations. The purpose of this year's summit was to renew the understanding of what it means to provide deafblind technical assistance as a network. It was all about sharing resources and building partnerships. We came together to reflect, share information and strategize about ways to increase our effectiveness in achieving desired outcomes for children, families, and educational teams. It was an honor to be invited to the Summit to participate and to share the concerns of our CHARGE community.

The current national initiatives are Interveners and Qualified Personnel, Early Identification, Family Engagement, National Child Count, Literacy, and Transition. These topics are all of great importance to our families as we advocate for qualified personnel, try to find and engage more families, address great concerns about evidence based educational strategies and transitioning our young adults to life after school. We need to be part of the discussion and we need to understand how we can have an impact as families. If you haven't visited the NCDB web site (nationaldb.org), I encourage you to do so. It has wonderful information for both families and educators, as well as information on the national initiatives.

The DB Summit allowed for large group presentations but then had us all break down into smaller discussion groups around these national initiatives. It gave us an opportunity to hear an overview on these initiatives from NCDB and the Deaf-Blind Projects and then discuss successes, challenges and strategies in a smaller setting. The day was all about giving the projects an opportunity to receive information about and participate in collaborative work around each initiative. It was helpful for me to hear about each initiative and participate in the discussions from the parent perspective. I am part of the Family Engagement Technical Work Group, which has been meeting over the past year to discuss ways to collaborate with the Parent Centers around the country. There is a lot of good work going on to increase collaboration and share information.

My goals at the DB Summit were to listen, learn and share the concerns of our Foundation and to let NCDB and the State Deaf-Blind Projects know that we want to be part of the dialogue and we want to collaborate to provide exemplary services to families. While a large part of my job is to work directly with families, I also work with the professionals in the field of deafblindness. Family involvement is critical if we want the professionals to understand and respond to our needs.

We have their ear, let's be vocal!

iCanConnect

**The National Deaf-Blind
Equipment Distribution Program
was just made permanent.**

Through iCanConnect, consumers who are deafblind and who meet income guidelines can receive free equipment designed to make telecommunications, Internet access, and advanced communications services accessible. Installation, training, and other technical support are also available.

**For more information and to find the contact for your state, visit the iCanConnect website:
<http://www.icanconnect.org>**

Mobilizing a National Family Leadership Network

by Minnie Lambert

I recently attended the 2016 NFADB Family Symposium in Austin, TX on behalf of the CHARGE Syndrome Foundation's new Parent Liaison Project. The theme of the weekend was "Mobilizing a National Family Leadership Network." The Friday before the Symposium began I had the honor of attending an NCDB Pre-Symposium Training: "Taking a Strategic Approach to Connecting and Engaging Families."

During the training I learned more about what the Family Specialists at the State Deaf-Blind Projects do to connect to our families. I was proud to hear the Family Specialists talk about the great family connections that our families have to one another and they raved about our biennial conferences. I explained the Parent Liaison Project to them and how we hope to help them reach our families and open the doors for better communication between us all. We all learned about being members of teams that make decisions for families: We analyzed the strengths and weaknesses of our families on both a state and national level. It really helped to put things in perspective for me when I looked at things from the Foundation's national level then also the challenges that we have in my home state of South Carolina.

Saturday morning brought the beginning of the NFADB Symposium and the wonderful opportunity to learn more about what was happening in the world of deafblindness. Keynote speaker George Stern from Deaf Blind Citizens in action opened up the Symposium. He spoke of the word "NORMAL" and how this word prevents some parents from seeing their deafblind child as capable. "Be ABNORMAL!"; "Empower deafblind kids to live fully and productively"; "Destroy normal and get it out of your vocabulary. Normal has no meaning... that is worthwhile anyway." Our children are held back if we keep trying to "make" them normal. Accept them as they are and fight to give them what they need to be successful and whole. With these thoughts, George let me know that I was about to be part of a great, motivating weekend!

During the Saturday night social I made it a personal mission to connect with as many CHARGE families as I could—almost 15 of them, including some that were not connected with the Foundation. We gathered for a CHARGE "family" picture (see next page), then the next morning laughed about just how many people were missing from the photo!

We were so happy to be together, but Mr. Carter from Missouri STOLE the show! After all, CHARGE babes are the cutest babies in existence!

On Sunday morning Mark Richert, Director of Public Policy for the American Foundation for the Blind, and Robbie Blaha, spoke about Cogswell-Macy Act, HR 3535, and the "peculiar needs" of those who are deafblind. They called for ALL of our families to help push this to become a law because our children need this! They electrified us all to the point that we wanted to step outside and call our state representatives to plead with them to join in on this great cause.

During the parent panel we learned how having qualified personnel makes a difference and listened to CHARGE

(Continued on page 13)



Today's schools are not prepared to help children who are deafblind, deaf or hard of hearing, blind, or visually impaired develop to their full potential. To ensure that these students receive the education they deserve, the Alice Cogswell and Anne Sullivan Macy Act (H.R. 3535) was introduced in Congress in September 2015.

The Cogswell-Macy Act is the most comprehensive special education legislation for students with sensory disabilities to date. This act seeks to expand the resources available to these students, and their parents and educators, through the Individuals with Disabilities Education Act (IDEA).

<http://www.afb.org/info/get-connected/take-action/12>

<http://www.petition2congress.com/21317/pass-cogswell-macy-act-so-that-americas-children-can-succeed-thri/>

(Continued from page 12)

mom Suzanne Chen share her son Parker's successes. The Parent Panel on Adults was very touching. We heard from parents who are supporting their adult children to realize and live THEIR dreams.

On Monday the Symposium came to an end after a presentation that shined the light on NFADB, NCDB, and the CHARGE Syndrome Foundation, and what each organization does for our families. Our very own Director of Outreach, Sheri Stanger, spoke about the CHARGE Syndrome Foundation and how we hope to continue to bridge the gap between our families and the deafblind community. We need the help of one another so our children can grow up to become all that they can be.

We said goodbye to our friends, new and old, and headed our separate ways back to our home states to focus on our action plans and how we hope to change the world for our families. I told Mr. Carter goodbye and that I would see him next summer with his mom and dad in Orlando. Looking at his precious little face I knew that the



purpose of all of this learning was much deeper than myself and my son Andrew. It was for all of Andrews and Carters to come. We never know what we can do as individuals to change this world, but I am certain that by working together we can get the job done faster!

I came home to the great state of South Carolina with a renewed desire to connect our families to one another and to the knowledge and resources that are available. I know just how important the State Family Liaison Project is and how the individuals who are volunteering for this position will play a vital role in connecting our families to one another and to the state and national resources that we all need to THRIVE!

ANNOUNCEMENTS



Research on Headaches in CHARGE

You are invited to participate in a study about the prevalence of headaches in individuals with CHARGE syndrome being conducted by the CHARGE Syndrome Research Lab at Central Michigan University.

If you are the parent/guardian of a child with CHARGE syndrome under the age of 18, the guardian of a child 18 or older, or if you are an individual with CHARGE 18 or older, you are eligible to participate. Participation in this project involves answering questions on an anonymous, web-based questionnaire.

You can find more details and participate by going to this website:

<https://www.surveymonkey.com/r/Z26GCJR>

ONLINE COURSE

The Role of Interveners in Educational Settings

October 3 - November 7, 2016 Sponsored by NFADB and NCDB

Learn about:

- The role of interveners.
- The principles of intervention.
- How interveners function as members of students' educational teams.

Format:

Primarily self-study, but hosts are available to provide assistance. We will also have several optional online video sessions.

Time commitment: 2 hours per week for 5 weeks
(you work on your own at times that are convenient for you).

Hosts: Patti McGowan (NFADB) and Peggy Malloy (NCDB) will provide online support and feedback.

Content: The training will use Module 3 ("The Role of Interveners in Educational Settings") from the Open Hands Open Access (OHOA) Deaf-Blind Intervener Learning Modules.

What you will need: A computer and a good Internet connection.

Cost: It's free!

[Contact Patti McGowan for more information](#)

It's less than one year until the 13th International CHARGE Syndrome Conference!



We hope you will join us for the largest gathering of individuals with CHARGE, their families, researchers, and experts in the field.

More than 1,200 attendees learned, laughed, and celebrated together at the 2015 Conference and the excitement is building for 2017, and we hope you can join us at Rosen Shingle Creek. Whether this will be your thirteenth conference or your very first, a CHARGE conference is an experience you won't want to miss.

Keep an eye on our website and your inbox in the months to come for more conference details.



*Together, let's commit to **Taking CHARGE** in Orlando in 2017!*

SAVE THE DATE • JULY 27-30, 2017

ATTENTION FLORIDA FAMILIES

Signing Volunteers Needed!

Many of our children with CHARGE use sign language to communicate, but we typically have fewer signing volunteers in camp than we need.

Can we count on you to recruit your child's teachers and therapists, and your friends and family, to make camp accessible and fun for all?

Email joanne@chargesyndrome.org to volunteer or for more information

You'd like to help but don't sign? No problem.

We need local volunteers before and during conference to help with silent auction, registration, conference bags, and more.

Caitlin Hale

(Continued from page 7)

and educational aspects of CHARGE syndrome. It became obvious after speaking with families and hearing the questions that were asked at presentations, that development and education are some of the most pressing concerns for families. I attended a presentation about positive assessments, and the idea of a developmental assessment that focuses on what a child can do, rather than on what they cannot do, had never occurred to me. This revelation fit in nicely with the keynote speaker Marla Runyan's message about gold medal moments, and was a theme I saw several times over the course of the conference.

One of the connections I made at the conference that I am most excited about was the chance to meet Julie Maier, one of the education specialists at the California Deaf Blind Project. Even though coming into the conference I would have considered myself to be fairly knowledgeable about CHARGE syndrome, I was not familiar with state Deaf Blind Projects and the services they provide. Julie works as part of the California Deaf Blind Project. She told me how to refer families to her service and how the Deaf Blind Project can help families. After spending a half-day in camp, I could really appreciate how intervention from the Deaf Blind Project could help a family develop strategies for communication. Volunteering in camp as part of the Fellowship program posed somewhat of a challenge for me, as I did not intuitively know the best way to try and communicate with the children. After learning more about communication for those who are deafblind, I have a much better appreciation for how these individuals are able to effectively communicate using various modes of expression.

The experience of attending the CHARGE syndrome conference did change my career goals in a bit of an unexpected way. I was so impressed by the scale of the conference and the quality of the presentations that were provided to families. It struck me that there are many other conditions out there with support groups that are not as well developed, and that do not have such strong



involvement and backing from members of the medical and scientific community. I decided that I would love the opportunity to be involved in building a support group of a less well-described syndrome in the hopes of someday providing resources and support on the same scale as the CHARGE Syndrome Foundation.

I think my favorite moment of the conference was watching the documentary made by the CHARGE syndrome group in Germany. I shared the [link to the video](#) with my former genetic counseling classmates because I thought it was such a unique opportunity to hear individuals talk about how they view their diagnosis. To hear the individuals who starred in the documentary described what having CHARGE syndrome means to them in such an insightful way was really inspiring. To me, the video drove home the point that a diagnosis is not a prognosis, and most importantly that a diagnosis does not define a person.

2016 follow up

Caitlin is now working as a genetic counselor in California. Her graduate thesis on broadening the clinical diagnostic criteria for CHARGE syndrome was recently published: Atypical phenotypes associated with pathogenic CHD7 variants and a proposal for broadening CHARGE syndrome clinical diagnostic criteria., Hale CL, Niederriter AN, Green GE, Martin DM., Am J Med Genet A. 2016 Feb;170A(2):344-54. doi: 10.1002/ajmg.a.37435. Epub 2015 Nov 21

SHOP AT AMAZON.COM

amazon smile
The Shop Amazon gives

DONATE TO THE
CHARGE SYNDROME
FOUNDATION

SHOP FOR CHARGE ALL YEAR LONG!

Amazon Smile enables shoppers to easily donate to charity.
Search for the CHARGE Syndrome Foundation and you will find us.
0.5% of your eligible Amazon Smile purchases will be donated.
Start shopping at smile.amazon.com

TECHNOLOGY IS SO MUCH FUN!

Ask any student in Erika Cutter's class. Erika's nine students are the first at Crotched Mountain School in Vermont to use an interactive SMART Board that simultaneously connects to each student's personal assistive device. This is notable because each device—iPad, laptop or other communication device—is custom-programmed to address a student's unique needs in the areas of vision, hearing, speech and movement, creating a true universal learning experience. "Most of my students have limited mobility and motor control, and many are non-verbal or have a hearing or vision impairment," Erika explains. "This technology allows them to access communication pathways that they wouldn't otherwise be exposed to."

One of the students is Lacey, 18, who has both visual and hearing impairments as a result of CHARGE syndrome. Lacey uses the SMART Board as an enhanced touch screen and a canvas for writing and drawing, which increases her range of motion. "For students like Lacey," Erika points out, "this is a great tool for creating projects and visualizing concepts."

From the Crotched Mountain Foundation publication "Horizons," Spring 2016 issue



Alexandra Hudson

(Continued from page 8)

The Davenport Fellowship gave me the opportunity to attend this conference, present my research findings, and connect with affected families and individuals without worrying about the financial burden of traveling from Halifax to Chicago. I couldn't be more appreciative. As a medical student, I am already facing a huge amount of debt and without this financial help I'm not sure if I would have been able to come. The Fellowship also helped me to meet and connect to other like-minded students from around the USA and Canada. I will never forget this experience.

Since the CHARGE conference I have published my paper on pocketing of food. I am working on developing a feeding scale specific for CHARGE syndrome. This tool will aim to better assess feeding difficulties specific to CHARGE which may not be adequately tracked using standardized tools developed for the typically developing pediatric population. Speaking with so many families at the conference really helped me gain a deeper understanding of the feeding difficulties they face and how they can vary so much. We are aiming for it to be a user-friendly scale that parents and feeding therapists can use to keep track of the oral feeding progress.

I and two medical students from Nova Scotia, Canada, who also attended the conference, wrote a reflection

piece on our conference experience—a conference unlike any other that we have been to before. This article was published in the Dalhousie Medical Journal. We all thoroughly enjoyed our experiences. I am definitely planning on attending the CHARGE Syndrome Foundation conference in 2017 and can't wait to see everyone again.

2016 follow up:

Alex and her mentor, Dr. Kim Blake, have continued their research into feeding and other issues associated with CHARGE and have published several articles in medical journals:

Quality of life in adolescents and adults with CHARGE syndrome. Hartshorne N, Hudson A, MacCuspie J, Kennert B, Nacarato T, Hartshorne T, Blake K. *Am J Med Genet A*. 2016 Aug;170(8):2012-21. doi: 10.1002/ajmg.a.37769. Epub 2016 Jun 8.

Packing and Problematic Feeding Behaviors in CHARGE Syndrome: A Qualitative Analysis. Hudson A, Macdonald M, Blake K. *Int J Pediatr Otorhinolaryngol*. 2016 Mar;82:107-15. doi: 10.1016/j.ijporl.2016.01.009. Epub 2016 Jan 21.

Newly Emerging Feeding Difficulties in a 33-Year-Old Adult With CHARGE Syndrome.

Hudson A, Blake K. *J Clin Med Res*. 2016 Jan;8(1):56-8. doi: 10.14740/jocmr2288w. Epub 2015 Dec 3.

Pocketing of food in cheeks during eating in an adolescent with CHARGE syndrome.

Hudson A, Colp M, Blake K. *J Paediatr Child Health*. 2015 Nov;51(11):1143-4. doi: 10.1111/jpc.13012.

**This is the second of three articles from the Sandra Davenport Fellows.
Part I appeared in the [Winter 2016 issue of CHARGE Accounts](#)**

Applying for Disability for a Child with CHARGE Syndrome

By Bryan Mac Murray, Outreach Specialist, Social Security Disability Help

Many children with CHARGE syndrome face lifelong struggles and require ongoing medical and supportive care. Others may require multiple surgeries during infancy and early childhood but with only minor medical involvement after these hurdles are overcome. Either way, ensuring a child's needs are met can be a challenge for parents or guardians. Social Security disability benefits can help ease financial concerns.

Child Benefits

Children most often qualify for benefits through the Social Security Administration's Supplemental Security Income (SSI) program, though some can additionally receive Social Security Disability Insurance (SSDI) under the Social Security account of a parent or guardian. SSI is need-based, with financial eligibility rules, while SSDI is available to disabled workers, or in some cases their dependents.

A child cannot have more than the allowable monthly income or financial resources available to him or her and be found eligible for SSI. For 2016, the monthly limit is \$733. The SSA must look closely at your family's finances to determine your child's eligibility, but only a portion of your family's income and assets are "deemed" or assigned to your child.

Because SSI is based on financial need and only certain income and assets are assigned to children, many kids are able to receive monthly support through this program. The SSA's financial eligibility determination rules are quite complex and can be difficult to decipher on your own. Knowing if your son or daughter can qualify for SSI requires meeting with a Social Security representative. An SSA representative can help you understand if SSDI benefits may be available to your child as well.

Medical Eligibility Requirements

Some of the effects of CHARGE syndrome are relatively consistent. Other signs and symptoms vary greatly from one child to the next. The most severe cases of CHARGE usually qualify for benefits under the Blue Book listing in [Section 110.08 A or B](#).

There are a number of other disability listings under which your son or daughter may qualify for benefits, including:

[102.00](#) for visual impairments

[104.00](#) for heart defects or cardiovascular complications

[111.00](#) for cranial nerve malformations and related impairments

[112.00](#) for intellectual and/or developmental disabilities

Work closely with your child's doctor to understand the medical eligibility requirements and the disability listing under which your son or daughter is most likely to qualify for benefits.

Application Processes

When you apply for benefits on behalf of a child, whether SSI or SSDI, a personal interview is necessary. These application meetings are usually held at the local SSA office, though some parents and guardians do apply over the phone instead. If you need to schedule an appointment or wish to apply via phone, call 1-800-772-1213. Otherwise, you can simply stop in at your [local SSA branch](#). Before applying, you'll want to review the SSA's [Child Disability Starter Kit](#). This online resource gives guidance on the types of documentation you'll need for your application. It additionally contains forms for you to complete prior to your application interview.

For additional information about social security disability programs:

<http://www.socialsecuritydisabilityhelp.org/faq.html>

<http://www.socialsecuritydisabilityhelp.org/aboutUs.html>



Join or Renew Your Membership Today!

We depend heavily on the commitment of our members to help create a better world for all individuals with CHARGE syndrome.

Annual – \$30 Lifetime Silver – \$250 Lifetime Gold – \$1,000
Lifetime Platinum – \$5,000 Lifetime Diamond – \$10,000

Thank you for your support



**Eighth Annual
Charge It for
CHARGE**



GOAL: \$150,000

Thank You!

**to everyone who participated in our
8th Annual Charge It for CHARGE campaign.**

Together we have raised over \$92,000!

This campaign will end on September 30, 2016.

We still have a little time to work together to exceed \$100,000.

Go to <http://CSFeighthAnnualCIFC.kintera.org/> to support any of our fundraisers

We want to extend a special thanks to our top 15 fundraisers:

David & Jody Wolfe
Sheri & Neal Stanger
Deanna & Bill Steinhauer
Hollie & Chad St. Arnauld
Sandra Kurby

Abby Barr
Gavin & Alexa Burtley
Kathy Jones
Tracy Roth
Amy Bumford

Amrit Mehta
Anne Moore
Tom & Brownie Shott
Jodie Beavers
Aubrey Williams

***Every one of these awesome participants raised
more than \$1,000 for the Foundation!***

**We invite everyone to join us for the
9th Annual Charge It for CHARGE**

to begin on October 1, 2016 and run through our 2017 Conference

Help the Foundation fund our largest ever conference, research, and EWRAP budgets while earning **free conference merchandise** and **free conference registrations** for you and your family!

Details will be announced soon.

WE CAN'T DO IT WITHOUT YOU!