



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

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

Insight Into Adulthood	2
EW RAP	6
Davenport Fellows	7
Parent Liaisons	11
Insight Into Adulthood	12
Announcements	17
Research Grants	19
Charge It For CHARGE	20

President's Message

Happy New Year! As we enter 2016, I am reminded how different non-conference years are from conference years. While your Board, staff and volunteers are all busy putting together our next fantastic conference, I know we are still around 18 months away from seeing each other again. There may be no conference to look forward to this year, but there are plenty of exciting things going on at the Foundation.

At our recent Board meeting, we approved our largest research budget. This will not only fund biomedical research, but also support more research into the clinical and medical diagnosis and treatment of CHARGE syndrome. The grant applications are available online, and money will be available by July. We look forward to new and exciting research.

In addition, we are rolling out our second round of awards for the Ethan Wolfe Recreational Assistance Program. This program is obviously very near and dear to my heart. Watching an individual with CHARGE get to participate in a recreational program that he or she might not be able to afford on their own is incredibly rewarding. After all, everyone deserves a chance to play!

Please enjoy the wonderful newsletter that Joanne Lent has assembled for you. There are some fantastic insights into adults with CHARGE, information about our programs such as Research Grants, Parent Liaisons, EW RAP, Davenport Fellows and more. Plus, the newsletter outlines many ways everyone can help our large CHARGE family: become a parent liaison, write an article for the newsletter, join Charge it For CHARGE, become a member of the Foundation, to name a few.

As always, please feel free to contact me with any questions, comments or concerns. Most importantly, I wish each and everyone one of you a very healthy, happy 2016.

David

David Wolfe
President

The CHARGE Syndrome Foundation, Inc.

318 Half Day Road, #305 • Buffalo Grove, Illinois 60089

info@chargesyndrome.org • 800.442.7604 • www.chargesyndrome.org



Insight into Adulthood



One size does not fit all for adults with CHARGE syndrome and the challenges can be greater and more varied than during the school years.

In many cases, living at home is the best option; some individuals can live independently; others require support 24:7. Several families have shared a peek into their lives.

Sarah

by Doris and Joe Behan

Sarah lives at home with her family and needs increasing support. Until recently, New York State did not allow her parents to be her paid caregivers. What did we do? We embarked on a 5 year journey to change the law! Why did we do this? Sarah needs assistance to stay in her home and be safe, healthy, and happy. It is critical that support people are caring, trustworthy, reliable, and competent. When and if you can find help it may not be for the times you need. Depending on this is not an option if you have to work!

We have a caregiving crisis locally, statewide, and nationally. The work force is just not there. Parents are forced to cut hours, leave the workforce or take early retirement. Financial and personal hardships are the result. As parents we are willing to sacrifice much to keep our disabled adult children at home and out of residential placement. Our responsibility is to protect our children. Some need more care than others and for longer periods of time.

New York has programs in place that focus on keeping our disabled adult children in the community and at home, yet Sarah was not allowed to choose her parents to be paid to provide these services. Yes, we are parents but we are also advocates for those who cannot advocate for themselves. We as parents wanted to be part of the solution as allies in creating a cost efficient and effective system that provides the needed services for our disabled adult children. All we wanted was to be able to keep our daughter at home.



New York Governor Andrew Cuomo recently signed a bill that will include parents among those who qualify to provide personal care services for adults with disabilities. There is no one who understands the complex needs and challenges of a child with a disability better than a parent. This legislation will take effect in April.

We went out to dinner as a family to celebrate what I am now calling Sarah's bill! As we sat having dinner we talked about how hard this year has been for Sarah, and how much this is going to help us as a family. Sarah then looks me straight in the eye and says now you can stay home and take care of me. Yep—burst out in tears right there in Nick's restaurant. I asked her if she is excited about the bill and she says "it is so awesome, I mean a lot awesome." For those who don't know Sarah, her motto is "Life is good" and "Awesome."

I promised Sarah the day she was born that I would always take care of her and make her life as happy as I could. I started this mission for Sarah, but it is so much bigger then I thought. Sarah's bill will help so many families that struggle, and for that I am grateful. My next mission is to meet Senator Chuck Schumer. Maybe we can get this mission to go national!

Read more at [A parents mission to keep their disabled adult child at home](#)



Brandon

Join me as I tell you a story about a man who has felt different for his entire life.

My parents went through a bitter divorce when I was very young. My mom and I moved from California to Arizona when I was about 20. Arizona. Land of dryness, hot summers and very cold winters. Even after 13 years here I've yet to get used to the weather.

It took me a few months to get a job when I first moved to Arizona. I worked in a supermarket or two, then retail for a few years. I didn't have a car or driver's license. That was a very hard battle with my mother. When the time came for my driving tests, who was the one who took me? My grandmother. She was the one person who believed in me, aside from my sister. I passed the tests with flying colors. My grandpa gave me my first car, a white Saturn wagon. It was my baby until an accident took it from me. On my grandfather's death he left me a beautiful dark blue truck. My mother didn't want me to have it but I'm happy to report that after seven years, no accidents at all. And only one speeding ticket. That's a pretty good record if I say so!

While I was still in California, I attended a dance class with my girlfriend. Being a typical guy, I laughed and said to her that there's no way I'm going to stand around in a room full of people and look like a dork attempting to dance. Wouldn't you know it, I fell in LOVE with it after the first couple of weeks. I had a natural rhythm, go figure. That class ended around the same time I packed up and moved to Arizona. I stopped dancing for a while after moving. In mid-2008 I heard about a new dance studio less than 10 minutes from my house so I figured I'd give it a try. I was welcomed warmly by the owner. He convinced me to stay and try it out and I fell in love with more than one type of dance – 13 in all! My brain was in overload.

I soon started working at the studio. My boss, who is a wonderful man, turned out to be the father figure I needed, or more like a brother. Around 2012 I started taking a class to teach people how to teach dance.

Dancing has enriched my life in many ways. It's helped me become a bit more outgoing, more confident. I competed in several dance competitions for fun and met many new friends who accept me for who I am. I'm honored to call Fatcat Ballroom my home, filled with laughter, fun, dancing, and a real sense of feeling like I belong somewhere now.

A few years ago something amazing happened. I found a group of people – thousands in fact – other families who have kids, even adults with CHARGE. I kinda always figured I was not alone, but to actually attend a conference in my home state was simply amazing. I found out about CHARGE Idol so of course I was going to perform. I found my people!



Chicago 2015. I knew right from the start it was going to be an intense uphill battle with my mother. She tried everything to get me to not go. I refused to listen to her as this was my one chance to prove I could be an adult, do the research and make the trip on my own. At first I wasn't very successful as she tried to make me feel guilty at every turn – right up until the last couple of days before my trip. But I did it! Bright and early that July morning I awoke, made my breakfast and headed to the airport. A few hours later I landed in the Windy City, was scooped up by two lovely ladies who have CHARGE, then off to the hotel we

went. My mother, being the extreme worrywart, called me just about every day, sometimes 4 or 5 times a day. I ignored most of her calls because I was there on vacation, and what a fun vacation it was. It was like attending a very big family reunion with over 1,200 people. We all agreed on one thing: Orlando 2017 we would meet again.

For all you CHARGE families out there who are going through tough times right now with your children, it does get better. I pray every day for your children to reach every milestone, to grow into the well-rounded adults we met in Chicago who don't let a six letter word define who they are. CHARGE is just a word. Don't let it hold you back. Be anything you want to be.



Meri

Hello, my name is Meredith Dwyer but everyone calls me Meri. I am a 22 year old adult with CHARGE syndrome. I live in Mount Sinai, New York with my family. I'm the middle child of three. My sister, who moved out and is getting married, is the oldest and my brother, who still lives at home, is the youngest. I am currently attending Suffolk County Community College part-time. I am also on a job search with the Helen Keller National Center. I recently had an interview for a possible file clerk position. Mondays and Fridays I participate in a vocational program known as J-STEP. Fridays I have lessons where I work with horses. Most of the week I have staff from a program known as Self Direction. With my staff, I hang out with friends, run errands, go shopping, get Dunkin' Donuts and Starbucks and go to the library. I enjoy writing stories and reading fantasy, mystery and science fiction novels. I also enjoy sweets such as chocolate and lattes. Sometimes CHARGE gets in my way, but I don't let it stop me from doing what I love. I am currently working on a novel about a group of people with disabilities, mostly CHARGE, who have to fight a group of evil aliens from outer space. It's titled *Anything's Possible*. It's a work in progress and when I get a chance to work on it, I have so much fun! When I read out loud, I do fun voices. It drives people crazy! I also have Tourette's syndrome, which drives me up the wall, but I can still do what I love. I am hoping one day to be an author. Maybe not as famous as J.K. Rowling Veronica Roth or Susanne Collins, but famous enough that people walking down the street will look at me and say, "Hey! That's Meri! She has disabilities, but I really like her stories!"



Meri

Mom's perspective

by Audrey Dwyer

Meredith was diagnosed at 3 days old and we were lucky enough to get services in place right away. She is deafblind with hearing and vision on the right side. Her hearing has fluctuated slightly in the past, but has remained at the mild loss level for all of her life. In her right eye she is legally blind, she has a 15% field of peripheral vision and a best corrected of 20/600. Her biggest challenges are her vision changes and Tourette's syndrome (which is characterized by uncontrollable movements and vocalizations).

Meredith graduated from our local high school at 18 years old, with an advanced regents diploma. She worked very hard all through high school to make passing grades. With the assistance of resource room teachers and a 1-1 in her mainstreamed classes, she graduated with a B+ average. It was one of her proudest moments. Although school was very hard, it was great to have all the services in place. These services included a vision teacher that would ensure she had all the supplies she needed (enlargements, magnifiers, cctv's etc.), physical therapy, adaptive physical education, and a great support staff. That combined with Meri's tenacity made the school years very successful.

When Meri graduated the challenge began—who would have thought that it could be even more challenging? Once you are out of the school system,

your eyes are truly opened as to the lack of services available to the adult population. We were fortunate that Meredith was approved for services while still in high school. Meri is VERY routine oriented (as I am sure many of you can relate!) and it was necessary to get her in to some type of daily routine immediately. She always wanted to attend college but we knew she could not handle a full day of a college load. Because of the Tourette's, she can't sit still for that many hours, her tics are too severe. So she took one class on campus, and one class online. That was only two days out of the week, so we put her in a sneeds adult program that was every day. She stuck it out a year, at which time we knew it was not going to work. She was then accepted into Helen Keller Independent Living Skills Program. She spent a year and a half in their residential setting learning independent living skills that had not been taught at school, and that were tailored to the deafblind population. She worked, did her own laundry, lived in an apartment setting where she made breakfast, lunch, and dinner and cared for her home. She did wonderfully. She came home a year ago in June.

After that program ended we were back to the lack of structure that we feared when high school ended. It was then that we started to use her Consumer Support Services. We enrolled her in classes again at the local college, hired staff to take her out in the community, and she started a local vocational program two days a week. She has a job coach

(Continued on page 5)



Cassy

Hi, my name is Cassy Brown and I was born with CHARGE syndrome. I am 25 years old. I had a lot of surgeries when I was younger. I graduated from East Lansing high school in 2009. I just recently moved to South Carolina. I don't work and don't go to school, but I do keep myself busy by working out and eating healthy. I like to cook and I like to make recipes for a meal. I also I like to help my aunt clean around her house. I I like to read and watch shows. I also like to use the computer for socializing and for Facebook. I play on Facebook also.

I can't drive because of the limited resources. I did have a job but they told me I was not fast enough. I did go to college but I did not understand the material. I do take care of everyday needs and I try be positive about things.

Ellen

I am 30 years old with CHARGE syndrome. My life was hard when I was younger but has gotten easier as I got older – with my health anyway. I now attend a day programme where I work on life type skills and I work two days a week doing packaging in a sheltered workshop. I go to respite once a month. Respite can be hard because they put me in with people with mixed disabilities and some don't talk and are quite violent.

I love being with friends and family. I live with mum and dad and my brother and his wife at home. I enjoy Facebook, playing Farmtown, chatting to friends and when I am not on Facebook I enjoy going to the shops, going bowling, going anywhere with my friends or family. I love to swim and have long baths – I find this relaxes me.



Meri

(Continued from page 4)

from our New York State Commission for the Blind and Visually Handicapped department who has been working hard to find a suitable part time job for Meri. Currently she lives at home with us. In the future she plans to live independently. I would like her to have a roommate for socialization. She will require support staff to make sure she is on task, to take her shopping and to help her to make good food choices, someone to help her stay organized and help her clean her apartment. (All the things that, in thinking about, I need too!) Meredith is very social but at times has trouble socializing. She is academically typical but her social skills vary between high school and middle school; because of that it has been difficult to find friends who share her interests. Fortunately she is willing to keep trying. The hardest thing for Meredith is not her CHARGE syndrome even though the vision issues are frightening to deal with, but

her Tourette's syndrome. The tics are so severe that it makes concentrating difficult and with the vision and hearing loss that is already a difficult task.

Transitioning to adulthood has proven to be very challenging. I always considered myself very "on top" of everything when Meri was in school and I knew everything she needed, had awesome supports in place to help us, and felt that I really had parenting a differently-abled child down! I am now constantly reminded how unprepared I was for this stage of her life, so I work on making myself a better parent to a differently-abled adult. The rewards far exceed the challenges!

Meredith is an amazing woman with a strength and tenacity like I have never, ever seen. She is always a glass half full person and I am in awe of her. She loves reading, the library, the mall, eating, going for coffee and lattes, her computer, and colorful hair. Most of all she loves to write and plans to be a great author one day.



Everyone Deserves a Chance to Play

The Wolfe family, along with the CHARGE Syndrome Foundation, is pleased to announce the

2nd Annual Ethan Wolfe Recreational Assistance Program (EWRAP)

We look forward to helping more families and individuals with CHARGE.

Applications are due by April 1, 2016.

Award recipients will be notified no later than May 1, 2016.

<http://www.chargesyndrome.org/documents/EthanWolfeRecreationalAssistanceProgram2016.pdf>

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 in order to participate in recreational programs or purchase recreational equipment. The first round of awards was a tremendous success. Below are excerpts from interviews conducted with parents of previous recipients:

Holly Johnson – mom to Cody
Recipient of an adaptive bike

Why did you apply for the EWRAP program?
I thought it was a great program that would give my son an opportunity to get a bike that would otherwise be out of our reach financially.

What has being a recipient of the EWRAP program meant to your family?
Our family is incredibly grateful. We now can go together on family bike rides. Also, typically Cody doesn't enjoy going outside so having the bike has encouraged all of us to be more active and get outside more often.



Melissa Shikora - mom to Hannah
Recipient of gymnastic classes

Describe how your daughter has benefited from being awarded the recreational activity.
Hannah is getting stronger physically from participating in gymnastics. Also, the classes have helped her gain some social independence as she has to interact with other peers.

Other than the EWRAP program, what is the most important thing that the Foundation does to help families?

The Foundation helps families from day one of diagnosis with information and support. The website is a great resource of free information which is available to parents, doctors, teachers and therapists.



Sandra Davenport Fellowship Program



The spring 2015 edition of **CHARGE Accounts** included a description of the newly created **Sandra Davenport CHARGE Syndrome Fellowship** program. This program was established to bring young professionals to the **CHARGE Syndrome Conference** and encourage them to become 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 all nominated by their mentors, who are professionals who have been active in the **CHARGE** community for a long time, in some cases decades.

This is the first installment of excerpts from reflections of their experiences at the 2015 conference and how it affected them. More to come in future issues of **CHARGE Accounts**!

Lauren Siems

Genetic counseling student, Northwestern University

Expectations

The conferences left me with a whirlwind of memories, information, experiences, and emotions. Participating as a Davenport Fellow exceeded my expectations of a conference and enlightened me about CHARGE syndrome. Participation by genetic counselors in family conferences is encouraged in order to relate to patients beyond the clinical setting. I hoped to gain this kind of experience at so I could be a better resource for CHARGE families in the future. As an undergraduate, I had worked with a research project on a gene in the same family as CHD7. I am fascinated by how the dysfunction of a single gene could have such a multi-system effect on an individual.

Having been to research conferences before, I was expecting poster sessions, PowerPoint presentations, academic discussions and information overload. I was excited and wanted to learn about CHARGE. These expectations were completely met at Professional Day. Then my expectations were completely exceeded by the rest of the conference. I

(Continued on page 8)

Hailey Ripple, PhD student in Educational psychology, Mississippi State University

Before attending the CHARGE Conference, I knew that interacting with families was going to be a unique and rewarding experience. I was very excited to meet and gain better insight into the lives of individuals with CHARGE and their families. I was also looking forward to interacting with professionals from other fields, including medicine and genetics.

My experiences at the conference surpassed my expectations. While attending Professional Day, I had the opportunity to attend talks given by professionals outside of

(Continued on page 10)

Ethan Sperry

MD/PhD candidate, University of Michigan

The 2015 CHARGE Syndrome Foundation Conference was my second, so I arrived in Chicago with some idea of what to expect at Professional Day and the Family Conference. Perhaps most importantly, I was prepared to expect the unexpected. For me, this happened at Friday breakfast.

Cerebro-costo-mandibular syndrome and my research

First, some background is required. My interest in CHARGE syndrome is most directly linked to my studies in the laboratory of Dr. Donna Martin at the University of Michigan. I am an MD/PhD student with research interests in the genetics of developmental disorders, particularly disorders involving the craniofacial structures. These interests are a direct result of my own diagnosis of cerebro-costo-mandibular syndrome. While I have spent a good portion of my efforts focused on understanding the science behind my genetic disorder, only more recently have I spent time carefully considering the psychosocial aspects of looking and sounding different than those around me. In thinking about what it means to have an externally apparent genetic disorder, I have spent time observing the social dynamics at family conferences such as the CHARGE Conference. Among the first things I noticed was how the conference provides a “safe space” for discussion of many topics that people with genetic disorders typically avoid in daily conversation. These topics include 1) dealing with issues affecting the activities of daily living (e.g. feeding issues in people with abnormal oropharyngeal structure), 2) discussion of how much of one’s life is consumed by “going to the doctor,” 3) chronic pain and how it affects daily

(Continued on page 9)



Lauren Siems

(Continued from page 7)

was not expecting how family and individual-focused the talks would be. This added to the deeper story and experience that comes with the CHARGE community. I learned about the family experience, the worries and the happy moments of individuals with CHARGE—and much more that would not be the focus of a more research-oriented conference.

I was not expecting the high degree of variability in the clinical features and medical needs of all the children and adults with CHARGE. From a medical perspective, genetic counselors focus mostly on body issues and health concerns of a genetic disorder. I was not expecting to listen to four adults with CHARGE give speeches about their lives from birth to present, complete with big hopes and plans for the future. This makes me extremely hopeful and excited to be able to share this knowledge with families in the future. Listening to the talks, speaking with families, and interacting with the children confirmed to me that CHARGE is not just a set of features—it represents a group of individuals who learn and experience the world in the most resourceful of ways.

Personalities

I was surprised with how friendly the children and adults with CHARGE were. When I would sit down with a family, the child with CHARGE syndrome would be the first to ask my name and introduce herself. I was impressed with their enthusiasm and ability to make me feel more comfortable as a medical professional at a family conference. I was not expecting families to be as open and honest in describing their kids, from their diagnostic history to the many surgeries to where their child is on the wide spectrum of CHARGE. I see that this conference is probably the safest place to discuss their family's journey, and I feel honored that several families let me be a part of their weekend.

Other Davenport Fellows

It was valuable to be able to reflect and share with the other Davenport Fellows throughout the conference. Each day, we got to hear the experiences of the other fellows, which helped to inform my own experience at the conference. I was excited to learn that other fellows had met the same families that I had and were able to share stories of the hilarious personalities of some of these kids. From a more academic perspective, I was also curious to hear what research interests and careers had brought the other fellows to the conference. I particularly liked hearing Sara's perspective, as she teaches several of the conference participants at her school [Sara's story will appear in the next issue of CHARGE Accounts]. She was

so involved and connected with the families that I felt like I knew some of the children before I even met them.

Volunteering for camp was one of my favorite parts of the conference – I would have volunteered more if I had realized how much fun I would have with the kids. I owe a great deal of gratitude to the children I met during camp because prior to the conference I had a clinical rotation that caused me to shy away from pursuing a future in pediatric genetic counseling. It was hard for me to connect with my patients in the pediatric setting. After attending the conference, I feel more open to a possible pediatric genetic counseling specialty.



Hearing from siblings

One of the most memorable moments at the conference was the talk given by siblings. I knew it would be interesting to hear the perspective of a sibling, but I was not prepared for how emotionally touching the discussion would be. The younger sister of a young man with CHARGE syndrome delivered a mature and enlightening account of what her life is like growing up with her brother. She talked about the stresses and worries that arise when a sibling has a condition like CHARGE, as well as the many reasons why she loves her brother. The room was full of parents with questions for this 14-year-old. The discussion was very emotional as parents reflected on their own stresses and worries that inevitably affect their other children, both positively and negatively. I felt as if I was part of an intimate and vulnerable setting for these families, which emotionally affected me, too. This emotional experience was unexpected, but welcomed as I gained a deeper understanding of the parent and sibling experience of living with a child with CHARGE.

What I will take away

I feel confident in the knowledge and grateful for the memories, both of which I am now able to bring into the remainder of my genetic counseling education and future career. I have met some talented young people and accomplished adults, all unique individuals who happen to share the same genetic syndrome but certainly not the same ways of living life. I can now speak about CHARGE to classmates and colleagues with a much deeper understanding of the families that live with the condition. I can now add a perspective to the clinical setting that involves the unfathomable potential of a child with CHARGE instead of focusing on the limitations created by

(Continued on page 10)

Ethan Sperry

(Continued from page 7)

life, and 4) adjusting communication strategies in the absence of normal speech patterns. I have been able to talk to my parents about these and many other issues quite freely; however, to see these discussions happening between families whose only connection is having CHARGE syndrome is quite fascinating to witness.

I know how it feels

Most individuals with an externally apparent genetic disorder have, at some time, been stared at, asked uncomfortable questions, and even openly mocked. My response to these interactions often has been to provide informative answers as to why I look the way I look and speak the way I speak, and so forth. I know that this measured response is shared by many individuals with CHARGE through listening to their stories. While these interactions with people unfamiliar with a genetic disorder are often frustrating and can be unexpectedly blunt, I have generally chosen to believe that the questions come from a desire to understand differences in the environment. I welcome these questions, although not necessarily in the blunt manner in which they are asked, and I do my best to answer them in a way that does not make the questioner uncomfortable.



Friday breakfast encounter

At Friday breakfast, a young girl with CHARGE was finishing her meal and saw me walking past. She stopped me and asked me: "What is wrong with your face?" I was briefly taken aback, as this is not considered a typical salutation; however, I did realize I was speaking with an eight-year-old child and bluntness is their specialty. I explained my condition and, in an attempt to help her understanding, I briefly compared my condition to CHARGE syndrome. She was so happy to talk to someone about our collective abnormalities that she completely ignored her mother's pleas to be socially appropriate. A smart, young child, she was asking several questions in an attempt to see if I had experienced the same medical and social interactions she had over the course of her short life. She asked if I had surgical operations, if I saw several different physicians, and if I had

trouble talking with other people as a result of speech impairment. She was clearly enthralled with being able to relate to someone about her experiences with CHARGE syndrome, remarkably realizing that despite my not having CHARGE, my own experiences must be similar to her own. Following the end of our brief conversation, her mother expressed how sorry she is that her daughter was so blunt and intrusive. I did my best to reassure her that I was completely fine, not offended, and actually delighted to have spoken with her child. Indeed, this interaction reassured me that *all* people are curious about their environment and that we should do our best to educate those around us rather than criticize individuals for being inquisitive. Specifically, I realized that these types of interactions are encouraged at family conferences such as the CHARGE Syndrome Foundation Conference and that they provide individuals and families with CHARGE the ability to learn about others' experiences in a safe and inclusive environment.

My conversation with this young child certainly was not unique to me at the conference. Indeed, I saw many individuals with, and families affected by, CHARGE learning from each other. To me, these interactions represent the perfect example of why the CSF Conference is so important. The conference provides a place for individuals to ask difficult, oftentimes socially inappropriate questions about CHARGE syndrome, and even other genetic disorders, as a way to learn about the medical mysteries of our existence. By providing this environment, collectively we are encouraging open discussion of genetic disorder-relevant issues in our lives. Further, we are developing ideas to help improve the quality of life for all individuals in our world, including those with medical issues that significantly alter the course of one's life.

What it meant to me

Through my experiences at the CSF Conferences, I have been deeply inspired to find meaningful ways to contribute to this fascinating, rapidly growing community. After all, this community provided me with a safe outlet to just *think* about all of the issues I deal with on a daily basis as a result of having cerebro-costo-mandibular syndrome. With the many invaluable sessions set up by the parents,

(Continued on page 10)

Hailey Ripple

(Continued from page 7)

psychology and to speak personally with some of these professionals. Presenting during the poster session gave me the opportunity to explain my research to individuals outside of my field. Throughout the conference I enjoyed being able to meet and get to know some of the families. The events at night made that very easy and comfortable to do. The reception, talent show, and carnival were wonderful and it was fun to be able to see the kids interact with one another!

While I was already planning to continue to be involved in CHARGE research throughout my graduate career, my experiences at this conference made me feel more connected to the research I have been working on over the past year. It was very meaningful to have to opportunity to meet the people that your work is impacting. Going to sessions and talking with families about the things they have to worry about for their children every day – things I take for granted – makes me want to help improve the lives of those with CHARGE in any way I can.



After leaving the conference, I felt motivated and passionate about continuing my research through Dr. Stratton's Bulldog CHARGE Research Lab and attending CHARGE conferences in the future. Through our lab, we plan to stay in contact with some of the families. We have discussed having a family that lives near us come to a research team meeting so that those who were not able to attend the conference could have an opportunity to meet an individual with CHARGE syndrome. I would also like to stay in touch with the other Fellows, Meg Hefner, and Dr. Davenport. I am interested in getting updates about everyone's research and plans for the future.

January 2016 Update: Since the conference this summer I have been working on a study to evaluate the content of Individualized Education Programs for individuals with CHARGE. We hope that this study will help us gain a better understanding of the experiences parents have during the IEP process. Getting to know CHARGE families at the conference helped me develop my questions for the survey targeting parent perceptions of the IEP process! This study will be presented as a poster at the National Association of School Psychologists conference in New Orleans in February. As of now, I am planning on attending CSF 2017 and I look forward to seeing everyone again!

Ethan Sperry

(Continued from page 9)

caregivers, and professionals involved with the Foundation, I was able to witness how this open, caring environment helped individuals with CHARGE not only think about what it means to have CHARGE but also to speak openly about it in a safe and enjoyable environment.

January 2016 update: Since CSF 2015, I have been continuing my doctoral research on the inner ear, specifically the vestibular system, and CHARGE. I am working hard towards linking CHD7 with other downstream effector genes as relevant for semicircular canal development. In addition, I've been working in a multidisciplinary group of researchers looking into the broader genomic roles for CHD7 in the developing mouse. Also, I currently have a clinical report under review describing a potentially interesting chromosomal abnormality in a child with CHARGE syndrome. I will likely move from the lab back to my medical training prior to CSF 2017; however, if I can make it, I will be sure to attend!

Lauren Siems

(Continued from page 8)

the syndrome. I look forward to my continuing participation in future conferences and the CHARGE community as I move forward in my career as a genetic counselor.

January 2016 update: I have been working hard to finish my Master's degree in Genetic Counseling. I am currently

in my final pediatric rotation, during which I plan on presenting a talk about CHARGE syndrome and my experience with the Foundation. I am applying for jobs after graduation. I am focusing more on prenatal, cancer, and industry jobs, but after the CHARGE conference, I am not excluding potential pediatric positions. As for attending future conferences, I plan to incorporate funding for conferences into my salary negotiations. Fingers crossed! Finally, I have encouraged many of my program's first year students to apply for the next fellowships.



State Parent Liaison Project

Volunteers Making a Difference

by Sheri Stanger

It's hard to believe that a small idea well over a year ago has turned into a program that has the potential to reach and affect many of our families. As your part time Director of Outreach it is my job to stay connected to families as well as the professional organizations that assist them. In a discussion about outreach and collaborative efforts with one of our past advisors, Kathy McNulty, an idea to enlist volunteer parent leaders to enhance our outreach efforts emerged.

After much discussion, the idea of the State Parent Liaison was born. It began as a pilot initiative by the CHARGE Syndrome Foundation to recruit 10 to 15 parent/family volunteers to act as liaisons between their State Deaf-Blind Project and the Foundation. A letter was sent to the State Deaf-Blind Projects in late April 2014 to inform them of this pilot project. During Deaf-Blind Day at the Project Director's Meeting in Washington, D.C. that summer, I made a formal announcement about the project. It was underway!

The State Parent Liaison Project is a new model of collaboration to improve the Foundation's outreach to both families and professionals at the national level. The position will be used to build relationships, network, collaborate and disseminate information.

The primary function of a State Parent Liaison is to:

- **Share the latest CHARGE resources with the State Deaf-Blind Projects and the families**
- **Assist in helping both the Foundation and the State Projects in identifying families**
- **Update the Foundation on available state resources**
- **Promote connections among the CHARGE families in the state**

Since its inception, I have been meeting quarterly with 9 state parent liaisons. Each of these parents was chosen because of their history of leadership or for their potential to be parent leaders in their state and their ability to work collaboratively with other parents and professionals. In our first year it was important to have these liaisons make contact with their state project, set up a contact person at the project and begin to reach out to families in their state and share resources and information. Each liaison became educated in the Foundation's resources, social media sites and website as well as the resources and family supports within their own state. I am working to formalize our process and increase the number of liaisons in the next year by 10. With the support of the National Center on Deaf-Blindness, we set up a private workspace for the liaisons to communicate, share documents and resources and stay better connected to each other.

Our current State Parent Liaisons are:

Allie Strang Jones from AL, Maureen Schultze from IL
Karin Dagley from MA, Michelle Case from MI
Laurie Suter from NH, Mary McDonald from NY
Minnie Lee Lambert from SC, Kathi Barksdale from TX
and Amy McKinley from WA.

All worked hard this year to establish this program and now as we move forward we are looking to grow and improve on our work. Together we are making a difference for families!

Do you have an interest in becoming a State Parent Liaison for The CHARGE Syndrome Foundation?

Please contact
Sheri Stanger, Director of Outreach
1-855-5CHARGE
or sheristanger@chargesyndrome.org

SHOP AT AMAZON.COM

amazon smile

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



A Home for Jacob

by Tim Hartshorne

We had a Person Centered Planning Meeting for Jacob when he was entering kindergarten. Part of the process is to list dreams you have for the child. Nancy said “Someday he will live in his own home.” If I did not roll my eyes it was out of politeness. How was this kid who was deafblind, in a wheelchair, with limited communication skills ever going to live in his own home? My point is that if you do not dream it, it will never happen.

We live on a corner lot in Mount Pleasant, Michigan. The homes on this street were all built about the same time and in the same style, small, one floor, two bedrooms. The original owner of our home added two stories next to the house to create a tri-level. But the house next door to us was not changed, and in fact its floor plan is identical to our main floor plan. The house next door was inhabited by an elderly lady who kept mostly to herself. However, Nancy spoke to her granddaughter one day and told her that when the time came to sell the house we would be interested in buying it for Jacob. The woman lived to age 95 and then we bought the house. Jacob was not quite 21.



We invited people who cared about Jacob to come to the house for a planning meeting. We had butcher paper on the walls in each room and people wrote down their suggestions for the house. Then we started the process of remodeling. It is important to note that the house was well taken care of, and did not absolutely require remodeling, but we wanted to make it as perfect as we could.

My biggest worry was funding. We had been hiring caretakers for Jacob out of pocket for a number of years to work in our own home, but that was not a sustainable model. We met with Community Mental Health, which in Michigan is responsible for adults with developmental and intellectual disabilities, and I was stunned when we were funded. Nancy and I own the house (although Jacob will inherit), pay the utilities, and the upkeep. The state pays for the staff.

The way the house runs has evolved over the five-plus years Jacob has lived there. We have about 12 staff at a given time, mostly college students (but also two alumni who don't want to leave Jacob). There is considerable turnover as the students graduate. There is one lead worker, who takes care of scheduling, running the monthly staff meetings, and getting the payroll in (which we only have to sign). Most of the changes have to do with communication and routines. It is frankly to the point that Nancy and I really could not just step in and do the job anymore—we no longer know his routines! This is ideal. Jacob is so much more independent that he used to be. He has learned more signs and more routines. Since he no longer goes to school, he goes out to job sites. He does some cleaning in a restaurant and bags dog biscuits at a pet store. He also has his own business, called “Jacob Can,” where he returns bottles and cans for the 10 cent deposit. He will donate the money to the CHARGE Syndrome Foundation.

We have hit a snag this last year. Community Mental Health informed us that the way Medicaid rules are now being interpreted in the state means that they can only pay for face-to-face time, which does not cover when he is sleeping. Their first suggestion was to move him to a group home. Their second suggestion was to use a call service, where a phone line is kept open and he can call for assistance. They said we would only have to teach him to recognize the voices on the other end. That is tough since Jacob is completely deaf. We have hired an attorney who is filing a federal lawsuit, and we have asked the Federal Office of Civil Rights to investigate, which has begun. If we are serious as a society in believing that everyone deserves to live in the least restrictive environment, which is the federal law, then we have to make sure that it is possible. Jacob would lose all of his gains in a group home. Because he is undemanding and does not have severe behavior, and because he is quite happy just lying on his bed in his room with the door shut, he would be not be challenged as the staff dealt with the other residents. For five years we have seen how he has blossomed with a terrific staff that promotes his independence and sense of self. Stay tuned.

Chip

Right now I'm still living at home with my mom in my hometown, Duarte, California. My brother moved out a long time ago, he's married with his own family. I've been wanting to move out and I hope my fiancé and I can live together, get married and start our life together! My fiancé's name America. She lives in Alabama. Right now I'm going to start job searching at this new deaf employment place called Deaf Ability Resources.



I just finished my cooking culinary arts major at Mt San Antonio College (Mt Sac). I take karate class once or twice a week with the specially challenged students and I also volunteer to clean the karate studio. Saturday mornings, I'm always going to Special Olympics bowling.

My typical day, well, I like to travel around by bus or my mom will drive me around. I can even take trains too. When I was at college, I used to get up and get ready for school, and then take three buses to Mt Sac.

I like to play video games, and I like to collect stuff like owls, seals, Pokémon, ninja turtles, Disney Pluto and Stitch too! But right now I decided to change my hobby to coins and stamps, and model car kits instead. I like to go to malls and shop around, talk to my fiancé on the video phone for DHH, chatting online and texting too! I also enjoy drawing animations/cartoon pictures, and sometimes typing stories too! I like walking my dog Sophie, going to flea markets, antique malls and stores, movies, and malls too! I like to watch YouTube videos, sometimes I'll record videos of me signing songs I like in ASL.

Sometimes CHARGE syndrome gets in my way. When I am using stairs I have to hold onto the rails. Even at karate classes, I can't balance well on certain stances, but I'm always improving my balance. And since I can't smell, I worried about how it's going to affect my cooking skills. I just worked my way around it. I found a way to check the foods using my sight and hearing (with my glasses and

(Continued on page 14)

Destiny

Hello, my name is Destiny Chinnici and I'm 23. I live with my mom and my brother in Smithville New Jersey, we have two cats named Maxine and Mittens and we have a dog whose name is Sophie. I currently work part time in the cafeteria at our local hospital as a food service aide. The people I work with like me and I have some friends. When I work, I wrap up the bagels, doughnuts, and the danish, help with labeling the desserts, and wipe down the tables before lunch starts. After my lunch break I help keep the salad bar nice and neat while keeping it stocked.

When I'm not working or doing anything, I sleep in since I tend to stay up late. When I get up, I get ready for the day then go let our dog out. Once I give my dog water and give her breakfast after letting her back in the house, I get my breakfast and go up to my room and be on my computer most of the day. I never leave my dishes in my room, so I take them back to the kitchen and put them into the sink. What makes me happy is my family and my dog since they are special. Video games, being on the computer, drawing, listening to music I like, and talking to friends also makes me happy. What also makes me happy is to see my collections, I used to collect a lot of stuffed dogs when I was growing up, but I really slowed down on collecting now since they can be costly and can take up space in my room. CHARGE syndrome doesn't get in my way because it's the way I am.

Some people may find me to be a little bit annoying, but I don't let it bother me. Since I'm deaf on my left ear and hard of hearing on my right, people sometimes forget that I can't really hear them well on the left, so when they want to say something into my left ear, I remind them to go to my right. When I'm someplace that's noisy, I can't hear someone talking very well since my hearing aids are picking up all of the loud noises.



Back in May of 2015, I got my computer moved from our living room to my bedroom, it was a challenge to me at first since I was used to having my computer in the

(Continued on page 14)



Tara is a young woman with Kabuki syndrome but her issues are largely the same as many individuals with CHARGE. The family lives in Regina, Saskatchewan, Canada. As in the US, services vary by province.

by Margot & Dean Schmiedge

Our 26-year-old daughter moved into her own fully supported home in June of 2012. To read about our journey, please read [Transition to Adulthood](#). Now that we have a few more years under our belt, we would like to reassess her transition – how we feel about her home situation, what is good, and what we still need to strive towards.

Tara shares her home with one other young lady, who is in her last year of high school (in our province individuals with special needs can attend until age 22). They live in a regular neighborhood home that was built in the 90s and remodeled prior to their moving in. Generally, during waking hours there are two supports present, with one support sleeping over at night. The supports are carefully screened and trained by Creative Options Regina in the [Gentle Teachings philosophy](#). During the day Tara's roommate attends high school while Tara and her support carry out her personalized day activities.

To properly assess Tara's current situation, we need to compare it against our original dreams.

I) That Tara live in her own home that she would share with one or two other young ladies with special needs and support staff. That this home be filled with loving individuals who truly care for her well-being.

Initially, Tara's home was purchased with the intention of her sharing it with three other young ladies. This proved to be a mistake due to the high psychological/sensory needs of the girls. A year later another home was purchased and two of Tara's roommates moved into that one. This change has been very successful for Tara.

Tara's home (obviously also her remaining roommate's home, but for ease we will refer to it as Tara's home) has been re-designated as a three-person home. Although

(Continued on page 15)

Destiny

(Continued from page 13)

living room with my mom as she watched TV. But I got over it after a few days since in my room, I can be on the computer without ear buds (except late at night when everyone's sleeping) and I can play with my 3DS with the sound all the way up and not bother anyone. I wish that in the future, I become more independent and become a dog groomer some day.

When we lived in Staten Island New York (an island across the bay from Manhattan) until we moved to New Jersey when I was 9 years old, my elementary school participated in an Adaptive Phys Ed carnival with other schools in the N.Y.C. school district and I won a silver medal 2 years in the row! During my elementary school years in New Jersey, I played soccer. My parents divorced in 2004. I have a medal from playing soccer. The trophies from playing soccer are in the box in the attic since they were taking up some needed space. I take transportation for those with disabilities to where I need to go and travel by myself. I can also draw very well.

Chip

(Continued from page 13)

hearing aides in if course), touch and taste. Funny that I can't smell, but I could taste foods instead.

Back in the early 2000s, I thought I could be a vet and work with animals, but I couldn't do it due to physical limitations. I tried pet grooming, but the pet shampoo gave me a skin allergy and I couldn't lift and handle big dogs. I also used to work at Burlington Coat Factory in Fall 2011 for temporary seasonal position, REI (outdoor sport store) for 6 years (2007 to 2013), then Old Navy in

Winter of 2014 for temporary seasonal position too. Now I'm going to try a different approach. New job coach at a different deaf employment program, this time I'm going to search for prep and Mexican restaurant positions, since I know how to make empanadas, meatloaf, and other dishes too!

My wish is to move out of the house, so I can live on my own with my fiancé, getting her to move back to California from Alabama. My wish is to find a good job that will match my skills, that will keep me and never let me go, like my past jobs did. Hopefully this new year will start out right and I get a good job so I can support me and my fiancé.

Tara

(Continued from page 14)

social services has not yet approached the topic of adding another individual, we are very concerned about the possibility. As part of having Kabuki, Tara has high levels of anxiety and sensory disability. Each additional roommate adds not only the individual herself, but also additional staffing, visiting therapists, family, friends, etc. As such, we will be taking a very proactive approach to this issue. Ultimately, we hope to change Tara's home designation to a two-person home.

As mentioned, the staff are carefully screened and trained in the Gentle Teaching philosophy. At present, the supports are mostly young girls in their 20s who are attending university. The advantages of this age group are two-fold: 1) they're wonderful age-appropriate peers 2) they have not yet developed 'bad habits' and are therefore very receptive to the Gentle Teachings philosophy. The disadvantages are: 1) they've had minimal experience in running a household, cleanliness and organizational skills 2) many of the supports will move onto other careers once graduated from university.

At present the advantages outweigh the disadvantages. Tara has developed close bonds with many of her supports. They are respectful, kind and show great love for Tara and her roommate. The feeling of Tara's home is warm and loving. It's evident when we go there, and also in Tara's willingness to be there. With time we hope to work with Creative Options to ensure greater house cleanliness and accountability of various weekly chores.

2) That Tara have a personalized day program that includes both volunteer and recreational activities, and that those activities give her joy.

Our first challenge was convincing social services that Tara would not fit into the existing center-based day program—that she needed personalized activities. The second challenge was acquiring enough funding for the one-on-one support necessary to carry out her personalized day. Once those hurdles were overcome, the developing of the jobs themselves was not so difficult.

Tara delivers Meals on Wheels and assists with the weekly groceries. In addition, she collects recyclables from numerous businesses, and checks a local company's portable signs in the city to make sure they have not been vandalized, reporting back to the company every week. Tara uses her profits from these paying jobs to help pay for her entertainment. The recyclables, in particular, have helped her gain understanding that a job equals cash. As Tara has become familiar with the jobs and the supports have gained confidence, she is now much more willing to

actively participate. Summer months add other jobs – for instance we have built three large raised garden boxes in her backyard and will add this activity to her agenda this coming summer. We continue to meet with Creative Options every three or four months to assess progress and brainstorm for new ideas.

We cannot stress enough the success of Tara's personalized day activities/jobs. Large population center-based programs do not work well for individuals with high anxiety/sensory disabilities. These programs tend to produce one crisis after another for the individual. It's unfair to the individual and much more costly to manage. When an individual's day is in sync with their abilities, the rest falls into place.

3) That Tara continue frequent contact with her family.

The first year that Tara moved into her home, she was often in crisis. As such we were there almost daily. Our intention was to take Tara on outings several times/week on a sporadic basis, but we quickly realized this idea didn't fit with Tara's need for predictability. We began with five outings/week but have gradually settled into three times a week on specific days. In addition, we take Tara on two short holidays each year, one of those being a visit to her sister, brother-in-law and niece, who live in California. She also often sees her other sisters and niece who live here in Regina. The regular scheduled outings have worked very well for Tara and ourselves. We do errands, stop for a drink, go for supper, visit her sisters, go to the library, pool, etc.

4) That Tara develop friendships with people other than paid staff.

Tara has maintained a unique, close relationship with her retired high school teacher. They continue to go on regular outings. She is also part of Best Buddies which organizes events every month. Although the supports are paid staff, they too have become close friends. The Gentle Teaching philosophy challenges caregivers to change themselves and base their interventions and relationships on unconditional love. That culture fosters friendships vs. caretakers.

Most heartwarming is Tara's growing relationship with her roommate. For that relationship, Tara needs to be the instigator. It's a clear indicator that she is feeling very comfortable in her home and her anxiety is at a manageable level.

(Continued on page 17)

Rachel

by Catherine Allen

I've been preoccupied with Rachel's and then my own bronchitis/pneumonia since early December. I started noticing that Rachel was really, really "down." At first, I thought she just didn't have her stamina back. When she got home from school one Friday, she put herself to bed at 4:30 and didn't get up until mid-morning the next day, took a nap in the early afternoon and then was in bed by 8:30. She was awake a lot but didn't want to get up and didn't even want to get on her phone. She has been



retreating more and more back into her pretend world as a substitute for the friendships and social life she has lost since graduation.

I noticed, but was still not feeling well and was busy trying to catch up on so many things that fall by the wayside when you're caring for someone 24/7 for four weeks and then get sick yourself and still have to take care of someone else. Early the next week, I knew Rachel was discouraged, possibly depressed.

It's really hard to be a social butterfly who is deafblind, intellectually disabled, medically fragile who speaks sign language and is dependent on someone else to orchestrate all your meaningful interactions and friendships, especially when the person who does that for you is sick. It really affects Rachel when I'm not feeling

well. She is such a sensitive soul and I think she understands and accepts my limits, probably more than I do. She also knows that without my help, her life – at least life as she has come to know it – doesn't exist.

By Wednesday, I was feeling somewhat better and I began sending texts and emails hoping to get some people on Rachel's schedule for some fun time for her. By Thursday morning I knew I had to call in the big guns for a non-stop Sign Language Chat and Laugh Intervention. All my love and gratitude to Rachel's friend Lindsay for making the time to hang out! This precious friendship is just pure love and joy.

We are so very thankful for all the many professionals that are in our lives, many of whom we consider some of our closest friends because of the amount of time we spend with them and just because they are awesome. But there is a lot to be said about building a Village of non-paid people who are strictly friends around a special needs individual. All of our paid nurses, caregivers, teachers, therapists, interveners – the people we spend all our time with because of the nature of the relationship – eventually fade out of our lives. Rachel is particularly vulnerable to this because all of her peers also eventually grow up and move into an adult life she will never be able to have.

Things are changing. We are adapting to this. While Rachel will always be dependent on paid caregivers and interveners, we are also creating a more structured Village that will allow Rachel to be supported in the kind of life she has come to know and desperately desire – one full of meaningful work and play, where she can shine brightly as the person she is, while surrounded by those who have chosen to be a part of her life and allow her into theirs.

This Village will be extensive and will require the different talents and skills of a lot of people – some hands on with her and some more involved in managing different areas of her life.

*Thank you to all the adults and families who shared their stories.
We can all learn so much from your experiences.*

**Read the story of another adult with deafblindness
on the National Center on Deaf-Blindness website:**

<https://nationaldb.org/pages/show/davids-journey>

Tara

(Continued from page 15)

5) That Tara have breaks from every day hum-drum life (holidays, entertainment opportunities, etc.).

In Tara's childhood, we spent entire months camping with family and friends. She managed these trips well while she was young, but as she got older, her level of anxiety increased and changes were difficult for her. With our kids having grown and moved onto their own activities, we were traveling less as a family. As such, we needed to establish a new routine for Tara.

We began with one-night stays at local provincial parks. This has been very successful. We then began suggesting a visit to her sister in California, but she flat out refused. In part, this was because she had memories of driving there a few years earlier—a very long road trip. For Tara, the anxiety about an upcoming event is always far greater than the event itself. Much of her anxiety revolves around her sensory issues with food (an explanation of this would take another article!). To make this more manageable, we booked a flight and told Tara that we were going on a one night holiday and because our van was in the shop, we would be taking a plane (white lies are a must!). It wasn't until we were in California that we told her that we

would be staying for more than one night. This may seem like a recipe for disaster, but we simply would not have gotten her onto the plane otherwise. We stayed for three weeks. Although Tara managed reasonably well, we realized that three weeks was too long. The entire following year she told us she wasn't going to California again. However, we booked another flight for September. A few hours before boarding, we told her we were going to California again, but this time only for 'seven sleeps'. After her initial upset (rightfully so!) she had a wonderful time! Now, when she discusses next September, she tells us she's coming. Such is the way with Tara for many facets of her life. If we allow her anxiety to rule, she would have very few experiences. We try to find a balance. Tara needs to trust that we will do only good for her. At the same time, we try to broaden her horizons.

We are very confident that Tara is well on her way to a meaningful, rich adult life. She lives in her own home, is surrounded by people who care for her, and her days are filled with activities within her ability. We would be interested in hearing from other families to hear what has worked for their children and situations. It helps to share our creative juices! You can contact us at margot@kabukisynndrome.com.

ANNOUNCEMENTS



Our 13th International CHARGE Syndrome Conference has no theme!

We invite all of you to come up with a theme that fits the spirit and location of our 2017 conference.

Clare O'Toole, an amazing young woman who just happens to have CHARGE syndrome, created our 2015 "The Sky's the Limit" theme.

What should we do for Orlando in 2017?

Please send any suggestions to info@chargesynndrome.org.

SAVE THE DATE! JULY 27-30, 2017

ANNOUNCEMENTS

We are pleased to announce the first Foundation webinar of 2016 :

The Education of our Children: Helping Everyone to Thrive with 3535

with Mark Richert on February 21st, 2016 at 7 p.m. EST (Closed Captioned).

Registration is limited and, as always, on a first-come-first-served basis. If you wish to participate in this live webinar and ask questions of our presenter, please [register now](#) to reserve your spot.

Mark will be speaking about the act that he authored: H.R. 3535, the [Alice Cogswell and Anne Sullivan Macy Act](#). He will explain how this act will strengthen the Individuals with Disabilities Education Act (IDEA) and improve results for the more than 500,000 children and youth who are blind, visually impaired, deaf, hard of hearing, or deafblind (sensory disabilities), including those who also have additional disabilities. Mark will also provide information on how you can support the act to improve education for our students with multiple sensory loss and additional disabilities To learn more about Mark Richert, [click here](#).

**Join us to learn more about this historic act and what you can do to help.
You can make a difference!**

The 3rd Member of the Flat Family, CHARGE Syndrome Ambassadors, Is About to Begin His Journey!

Chuck heard about all the fun that both Flat Charlie and Flat Charlotte had and now he wants HIS turn. Chuck is a little younger than his brother and sister so he thinks that he needs his friend Pup with him. Chuck loves his pup dearly but has never given him a name, so ...

***The family or professional that raises the most money on their team page
will have the honor of NAMING PUP!***

Flat Chuck began his journey with the Lambert/Delaney Family in South Carolina. He showed up just in time to help Andrew cheer on his Clemson Tigers during the Orange Bowl when they played Oklahoma! At each stop along the way, Chuck and his pup will get a souvenir and their personalities will begin to emerge. Chuck and his pup will travel around the world and end their journey at the 13th International CHARGE Syndrome Conference in Orlando in July of 2017!

Be part of an awesome adventure! It's easy and FUN!

*Join our CHARGE it for CHARGE team

<http://csfeighthannualcific.kintera.org/faf/search/searchTeamPart.aspx?event=1143831&lis=0&kntae1143831=7FAB38B666A643AC80A5B91D4E625F61&team=6572823>

*Sign up to receive Flat Chuck and his pup for a visit with your family.

*Post pictures of your adventures with them on their Facebook page so that all team members and supporters can follow his adventures

<https://www.facebook.com/groups/300145663351626/>

*Commit to raising at least \$150 for your family's page.

***Any questions about this project or to sign up as a host family
please contact Minnie Lambert mllambert123@yahoo.com***



ANNOUNCEMENTS

The CHARGE Syndrome Foundation, Inc. announces the availability of research grants of up to \$50,000.

The purpose of these grants is to promote:

- a) new biomedical research into the etiology, genetic and molecular mechanisms and treatment of CHARGE syndrome or
- b) new research into clinical and medical diagnosis and treatment of CHARGE syndrome.

The deadline for application is **April 30, 2016**.
For more information on the grant application process, go to:



There is so much more to learn about CHARGE and with more research comes the possibilities for better treatment, management and outcomes that can be developed for people who have CHARGE syndrome.

www.chargesyndrome.org

<http://chargesyndrome.org/documents/ResearchGrants2016.pdf>



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.

Individual/Family – \$30
Lifetime Silver – \$250
Lifetime Gold– \$1,000
Lifetime Platinum– \$5,000
Lifetime Diamond– \$10,000

MEMBERS RECEIVE 10% OFF CONFERENCE MERCHANDISE
LIFETIME MEMBERS RECEIVE 10% OFF CONFERENCE REGISTRATION

Join today!

Email: info@chargesyndrome.org

Visit us on the web: <http://www.chargesyndrome.org>

Thanks to your membership support and fundraising efforts ...

- ♦ Individuals with CHARGE attend conference **FREE** and do not pay for camp
- ♦ Scholarships are available for conference attendees
- ♦ Information about CHARGE syndrome is **FREE** on our website
- ♦ Webinars are developed and offered **AT NO COST** to families and others interested in CHARGE
- ♦ Research is being conducted on CHARGE syndrome with the financial support of the Foundation

***"I didn't become a member for a 10% discount.
I'm claiming a stake in this Foundation for my child and my family."***

—Minnie Lambert, mom to Andrew



Eighth Annual
Charge It for
CHARGE



GOAL: \$150,000

Congratulations & Thanks To Our Top 10 Fundraisers

**David & Jody Wolfe • Sheri & Neal Stanger • Abby Barr • Kathy Jones
Amy Bumford • Amrit Mehta • Anne Moore • Deanna & Bill Steinhauser
Tom & Brownie Shott • Tricia Seckerson**

Thanks to their efforts and the efforts of all our participants,
we are more than 40% of the way to our goal of \$150,000
with only a small percentage of our constituents participating.

If everyone strives to sign up and send email to friends and family, we can easily have
our best CIFC campaign ever. That means more outreach and more research.

Go to <http://CSFeighthAnnualCIFC.kintera.org/> to begin your campaign.

Your family and friends want to help. All you need to do is ask!

If you are hosting an event or party, or participating in a run, walk, or bike trip to benefit
the Foundation, we can help you create your own web page to collect donations and track
your progress. For any questions about fundraising, contact our president and fundraising
chair, David Wolfe, at david@chargesyndrome.org

WE CAN'T DO IT WITHOUT YOU!

Do you have a story idea? We Want to Hear from You!

We would love ideas from our readers about what issues or topics you would like explored in
future newsletters. Please send ideas, stories and pictures to joanne@chargesyndrome.org

[CHARGE Accounts Submission Guidelines](#)