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INSIDE THIS ISSUE:

President's Message
Social Media: Is It Really
Helpful? It's How You
Use It
The 11th International
CHARGE Syndrome
Conference
Open Hands, Open
Access: Deaf-Blind
Intervener Learning
Modules
What a Webinar Series!
Trailblazer Award
A Pilot Grant Recipient
Is Published
The Diagnosis Is Not the
Person
Parent Ingenuity: The
Backward Bathtub
CHARGE Around the
World
Resources
Upcoming Events
Focus on Fundraising
CHARGE in the News

CHARGE Accounts

VOLUME 23, ISSUE 1

SPRING 2013



President's Message

By David Wolfe

Spring in the odd-numbered years is always exciting. It means we are less than four months away from our next conference! Go to <http://chargesyndrome.org/conferencehq-2013.asp> if you have not yet registered and sign up now. We provide links to everything you need. Come join our extended CHARGE family and "Experience the Wonder" that is a CHARGE conference.

Conference is not the only exciting thing happening with the Foundation. Our Scientific Advisory Board will begin reviewing the next round of research grant applications. It is extremely rewarding to see our hard work paying off as the scientific community becomes more interested in CHARGE-related research.

Our Education Committee is hard at work planning additional webinars. Check out the past webinars on our website, and stay tuned for more in 2013.

We are also closing in on a record number of members. If you share our vision of a better world for people with CHARGE syndrome, go to <http://chargesyndrome.org/membership.asp> and join or renew your membership today. Your membership is a vote in support of our vision!

As we approach our 11th Conference, I can look back at how far we have come as an organization—and look forward to a promising future. If you have ideas to increase funding, awareness, outreach, education, or research, please contact me at any time. While we have come a long way, we still have so much more to do. I always welcome your feedback.

Hope to see you all in Arizona!



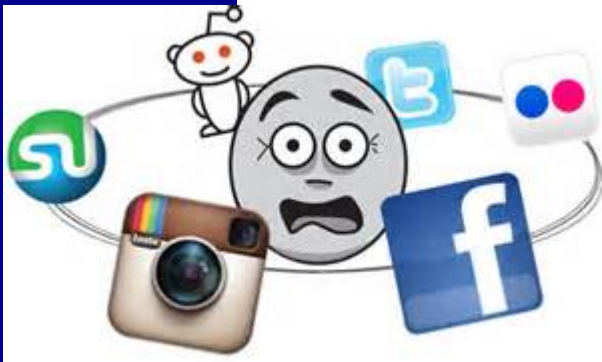
Social Media: Is it really helpful?

It's how you use it!

By Sheri Stanger, Director of Outreach

Read. Cut and paste. Share, share, share. Post, post, post. Aside from my phone calls, this is the rhythm of my day. Social media has infiltrated our lives at every level. We use it to stay connected, to gather information, to help us with work and school, and to have fun. As I read through the e-mails I plan to share with our membership, I think about the time spent on social media. We all know it can suck you in and drain you of time and affect face-to-face social interactions. It preys on our curiosity and our need to stay connected to other human beings. This can be good or bad, depending on how you use the medium and for what end.

"Social media has infiltrated our lives at every level."



The way we access information has changed so drastically since my daughter was born 19 years ago. What if I had access to user friendly websites, list serves, Facebook groups, and Twitter? Would that have changed anything for us? Would I have done things differently because of it? The information would get to me faster, but is that better?

CHARGE syndrome awareness has grown over the years. Social media has played a role in awareness, and our access to information has allowed us to become better-informed advocates

for those who have CHARGE syndrome. I am a big advocate of parents staying connected for many reasons. First and foremost, it helps us to know that we are not alone in our struggles and achievements in this world of CHARGE syndrome. There is nothing like a face-to-face meeting with another parent or group of parents who truly understands your situation. This is the beauty of our International CHARGE Syndrome Conferences.

Yet, in this world of budget cuts, it is not possible for professional and family organizations to connect in person to the extent that occurred 19 years ago. Long distances between families and those who aren't able to travel preclude many from meeting and obtaining that personal support. So what have we done in the world of disabilities that we are often forced to do out of necessity? We think outside the box, and we use technology to assist in our connections. We are now able to have seminars in people's homes through webinars, connect multiple people on conference calls, watch informational videos (webcasts), and text and chat with each other from great distances—all with a click of a button. We are so used to technology that we don't stop and realize its importance! The ability for me in New York to connect to another parent across the country or on the other side of the world is amazing! To be able to ask a question on Facebook and get many answers almost immediately is incredible.

"We are so used to technology that we don't stop and realize its importance!"

But no matter how incredible and amazing this ease of connection now is, we need to be mindful that not all information is correct and that we can become easily overwhelmed by too much information. We also need to be mindful that the information we put out there on Facebook and social media sites no longer belongs to us. It becomes public information, and we need to be careful about confidentiality issues.

I think how great it might have been to connect immediately to families after my daughter's diagnosis. Parents can connect so easily now, I'm almost jealous. I had to call the Foundation once I heard of its existence through NORD, wait for a list of families to arrive in the mail, write letters, and wait for responses. It happened at a slower pace, and while I have to admit that I checked my mailbox daily for replies, it also gave me time to process information. That need to obtain, process, research, and use information is critical for our role as a parent of someone with CHARGE syndrome. I think we all need to be cognizant of the information we receive on a daily basis and try not to get overwhelmed.

So, to go back to my previous questions—do I think having access to social media makes our lives better? I certainly think it can make our lives easier if we use it wisely and don't rely on it for all of our answers and needs. I think of a parent in the NICU who gets the CHARGE diagnosis, and while they are sitting they can search "CHARGE syndrome," find our website, read information, and connect to other parents through social media for support. I think that is priceless. The flip side is getting too much information at once with the risk of being overwhelmed and feeling helpless. That's where I hope my role as Director of Outreach can help guide a family through that mountain of information and help them develop more personal connections with both families and professionals. I like social media. I like to connect with people from different countries and share our experiences. It is also a great tool for advocacy. While I wish I had those options when my daughter was born, the reality is that I didn't, but I made my connections the best way I could at the time. Who knows what will be available to us in the future? Let's use what we have and use it effectively to be the best advocates for our families! See you on Facebook! 😊



"That need to obtain, process, research, and use information is critical for our role as a parent of someone with CHARGE syndrome."

Sheri Stanger, Director of Outreach, battles information overload while keeping our members informed and connected.

**CONFERENCE SCHEDULE
PROFESSIONAL DAY**
Thursday, July 25
Sessions 8:00 – 5:30

CONFERENCE
Thursday – Sunday
July 25–28

Thursday Evening
Reception 7:00 – 9:00 for
families & professionals

Friday
Sessions 9:00 – 5:00
Camp Program (full day)
Exhibitor Fair
Poster Presentations
Interact at Info Central
Idol Extravaganza

Saturday
Sessions 9:00 – 5:00
Camp Program (full day)
Silent Auction: New Format
CHARGE-A-Palooza

Sunday
Presentations 9:00 – 12:00
Camp Program (half day)
Closing

Breakfast and lunch included
on Professional Day.

Breakfast, lunch, dinner, and
snacks included on Friday
and Saturday. Breakfast
included on Sunday.



As this newsletter is published, we are less than 110 days away from conference! Both hotel and conference registrations are now open, and we encourage everyone to register as early as possible. The deadline for registration is June 15, 2013. Don't forget to register siblings for sibshops, or if you have any performers in your home, for Conference Idol! All of the information regarding the program, camp, sibshops, Conference Idol, and more are available at the conference registration headquarters:

<http://www.chargesyndrome.org/conferencehq-2013.asp>

SILENT AUCTION: Items are still needed for the silent auction. We have prepared a donation letter and form to help you with gathering and submitting items. For more info, contact neal@chargesyndrome.org.

[Silent Auction Donation Letter](#)

[Silent Auction Donor Form](#)



For more information about anything conference-related, please contact lisa@chargesyndrome.org

See you in Arizona!

<http://www.chargesyndrome.org/conferencehq-2013.asp>

Conference Auction

By Neal Stanger

We are once again looking forward to a fun-filled auction on Saturday night, July 27, at our CHARGE Conference in beautiful Scottsdale, Arizona. Thanks to the suggestions from our members, we are tweaking the format to combine a "basket" auction with a traditional silent auction. We hope this change will provide for a fun, exciting process for everyone and eliminate the long checkout at the end of the evening.

We are in need of auction items and donations of themed baskets with a value ranging from at least \$50 (dinner and a movie, family blockbuster night, day of beauty, sports collectibles, scrapbooking, jewelry, coffee lovers, chocolate fanatics, wine aficionados, etc.). Please help us by soliciting local businesses, friends, family, and colleagues. We are also looking for a couple dozen higher-ticket items to include in the silent auction. If you know anyone willing to donate a timeshare, fine jewelry, airline tickets, electronics, sports memorabilia, or any other high-end items, please let us know.

Please feel free to contact me directly with any ideas or questions via e-mail at neal@chargesyndrome.org or by phone at 914-629-0564.

Who Wants to Play Golf in Scottsdale?

Our conference host city is home to some great golf. For those interested in playing one of the best desert courses in the country, TPC Scottsdale's Champions Course is adjacent to our hotel. We are planning an unofficial group outing on Wednesday, July 24, as early in the day as possible to beat the heat. The payoff for summer golf in Arizona is that greens fees are less than half of what they are in the peak season.

All conference attendees are invited to join for a fun, casual round of golf. If you are interested, please email Bob Dagley at bobdagley@mac.com. When we have a better count of how many want to play, we'll provide more detailed information.



Open Hands, Open Access: Deaf-Blind Intervener Learning Modules

By Amy Parker, Associate Director
National Consortium on Deaf-Blindness

Wisdom is like fire. People take it from others.
~ Hema (Democratic Republic of Congo) proverb

In 2011, NCDB was asked by the Department of Education's Office of Special Education Programs to develop recommendations for improving intervener services in the United States. The recommendations were published in the summer of 2012 and are available online at <http://interveners.nationaldb.org/index.php>. A key theme that emerged during the process of gathering information to guide the development of the recommendations was a need for readily available materials (including videos and online learning activities) that could be used to support current and future intervener training programs—for example, programs that might be offered by community colleges or state deaf-blind projects.



Beth Kennedy, Director of the Michigan Deaf-Blind Project, leads a planning session with Luis Miranda (TX intervener), Jennifer Lester (TX teacher), Debbie Sanders (UT teacher and HK Fellow), Patti McGowan (PA parent leader), and Diane Foster (GA parent leader).

In order to address the challenge of creating high-quality, open-access intervener training materials, NCDB has been deeply engaged over the past six months with parents of children who are deaf-blind and professionals with expertise in deaf-blindness to create an initial series of eight learning modules called “Open Hands, Open Access.” The modules are being developed using a participatory process that involves 24 parent leaders, teachers, interveners, state deaf-blind project staff, and a university faculty member. Participatory methods like this for creating relevant learning materials for communities are not only respected by educational leaders around the world, they are a means of incorporating the wisdom, experiences, and passions of those who have been “walking the path” (Taylor, 2005).

After seeking guidance from 19 expert advisors, the 24 module developers split into four teams to work intensively on the modules. So far, the teams have completed drafts of modules 1–4 and are working on modules 5–8. The first four modules are in the process of being reviewed and tested using a well-known, accessible, open-source learning management system called Moodle. Feedback from the reviewers and field testers will be used to further revise and shape the modules. The target date for the first four modules to be completed is June 2013. We hope that the joint efforts of the individuals who have participated in this process will be useful to the national community of those involved in the lives of children who are deaf-blind and will help to support the availability of intervener services around the nation.

[Taylor, Peter](#). (2005). How can participatory processes of curriculum development impact on the quality of teaching and learning in developing countries? *Background paper for the Education for all global monitoring report 2005: the quality imperative*; Publ: 2004; [12 p*](#); 2005/ED/EFA/MRT/PII/47.

What a Webinar Series!

By Lori Swanson and Kathy McNulty
Co-chairs of the Education Committee

Our CHARGE syndrome webinars have received fantastic reviews! The Education Committee has held four outstanding webinars over the past 18 months. The next webinar (May 19, 2013) will feature Laurie Denno speaking on the topic of "Top Ten Strategies for Promoting Positive Behavior in Children with CHARGE." These webinars have been available to the CHARGE syndrome community at no cost. Members of the Foundation receive priority registration for all webinars. Early member registration for the Behavior webinar begins the third week in April. To guarantee your participation and ability to ask questions of our presenter, please join us. If you have missed any of the previous webinars, they are available on [our website](#). You may listen to the recordings or read the transcripts of the webinars.

The first four webinars included the following nationally and internationally recognized experts on CHARGE syndrome:

1. Tim Hartshorne and Kasee Stratton – ***Pain Issues in CHARGE***

Pain is ever-present in CHARGE syndrome, but not every person with CHARGE experiences pain in the same way or is able to describe it. Hartshorne and Stratton discuss sources of pain in persons with CHARGE, how pain may influence behavior, and the assessment of pain in those who are unable to label or talk about their pain.

2. David Brown – ***The Forgotten Senses***

David Brown discusses two senses that are important for all aspects of child development and for effective functioning in all skill areas, but most people know nothing about them, not even their names. These senses are called the vestibular (or balance) sense and the proprioceptive (or pressure) sense. Children with CHARGE syndrome are at increased risk of having problems with these two senses. This presentation explains these two forgotten senses: how they work, what purposes they serve, and why they might present difficulties for children with CHARGE syndrome. David Brown explores adaptations as well as play/teaching materials that can often result in greatly improved functioning.

3. Kim Blake – ***CHARGing Into the Teens***

This presentation covers a broad range of adolescent and adult issues for individuals with CHARGE and their parents: bone health, puberty delay, and some of the forgotten medical issues. Dr. Blake also presents some of the research results from her study with Nancy Hartshorne.

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"Members of the Foundation receive priority registration for all webinars."



“What better way to help us sponsor webinars than by becoming a member!”

What a Webinar Series! (cont.)

4. Sara Rosenfeld-Johnson – *Techniques to Improve Feeding Skills & Speech Clarity*

Sara Rosenfeld-Johnson describes and teaches the techniques she has developed in her work with infants and children with the diagnosis of CHARGE syndrome to improve feeding safety and speech clarity. Oral Placement Therapy utilizes tactile teaching interventions to supplement what is used in traditional feeding and speech therapy. The information and techniques taught in this presentation can be used by therapists and parents to improve muscle control.

Each webinar is 90 minutes long, with 20–30 minutes devoted to questions. The presenters have provided engaging discussions, as well as resources to utilize following the webinars. Once again, Foundation members receive priority registration for all webinars. What better way to help us sponsor webinars than by becoming a member! The Education Committee is thankful to these professionals for providing time and expertise to the CHARGE Syndrome Foundation.

Trailblazer Award

Adapted from 2013 Texas Symposium on Deafblindness: Hands Matter! *Event Guide*

CSF Executive Board Member Brownie Shott was recently presented with the Trailblazer Award at the [2013 Texas Symposium on Deafblindness](#), which took place February 21–23, 2013, at the Omni Austin Hotel in South Park.

The Trailblazer Award is given to a family member or members who have, through their advocacy or efforts on behalf of their family member with deafblindness, blazed a trail that has made it easier for other families who follow. This year’s recipient is much loved and well-deserving of this award.

Brownie Shott was a family leader long before that title became a status symbol. Brownie not only works hard to make sure her son, Taylor, has the services and supports he needs, but also supports Texas families in learning from her experiences. Brownie doesn’t limit her support and encouragement to families, but provides them to educators and medical providers too. She served as lead in hosting the CHARGE Conference when it was in Houston in 1999 and is a long-time board member and executive committee member of the CHARGE Syndrome Foundation. Despite having a job, a family, and a son with CHARGE who has required numerous and ongoing surgeries, Brownie always makes time to be involved in advocating for the needs of children and young adults with deafblindness. Brownie has worked tirelessly for the CHARGE Syndrome Foundation for many years. As part of the Foundation, Brownie also serves as a liaison with Texas Chargers. We are all lucky to have Brownie with her incredible trailblazing spirit in Texas!



A Pilot Grant Recipient Is Published

We are pleased to advise that Dr. Ching-Pin Chang, one of our first pilot grant recipients, was recently published in the *Proceedings of the National Academy of Sciences*. We are fortunate to have the opportunity to support this research and look forward to continuing to assist other research projects.

About two-thirds of individuals with CHARGE syndrome have an identifiable mutation in a gene which codes for CHD7, a protein that is important during development. CHD7 is active very early, as the embryo is forming its critical organs like the heart, eyes, ears, and nervous system. CHD7 functions in the cell nucleus to guide expression of many other important genes, although the details of how this happens are still not clear. A recent study by Li et al. from Dr. Chang's lab at Stanford University¹ provides one explanation for how CHD7 might be acting during heart development.

By studying mice which lack another nuclear protein, Brg1, Li et al. discovered that CHD7 binds Brg1 in the nucleus of cells in a part of the developing heart called the "cardiac neural crest." This region of the heart is highly sensitive to CHD7 and Brg1 function. Together, CHD7 and Brg1 activate another gene called PlexinA2, which helps guide the proper migration of cardiac neural crest cells. This observation suggests that CHD7 is also necessary for normal migration of cardiac neural crest cells to areas of the heart that give rise to critical blood vessels and structures.

These studies help provide an explanation for how heart defects might arise in individuals with CHARGE and CHD7 mutations. Additional studies could now be directed at correcting these abnormalities in mice and other model organisms, with the hope that one day such therapies might be useful for humans.

We congratulate Dr. Chang on his publication in this very prestigious journal and look forward to his presentation at the 2013 CHARGE Syndrome Foundation Conference.

1. Li, W. et al., Brg1 governs distinct pathways to direct multiple aspects of mammalian neural crest cell development. *Proceedings of the National Academy of Sciences*, (early edition) 2013.

2013 Pilot Grants

The Foundation is now receiving applications for 2013–2014 pilot grants. The purpose of these grants is to promote new biomedical research into the etiology, genetic, and molecular mechanisms and treatment of CHARGE syndrome. Proposals may be in any area of basic, clinical, translational, or epidemiological research. The deadline for application is **April 30, 2013**. For more information on the grant application process, go to:

<http://chargesyndrome.org/documents/pilotgrants2013.pdf>



**2013 Pilot Grants
Deadline for Application:
April 30, 2013**

The Diagnosis Is Not the Person

Posted on [December 11, 2012](#) by [allthathathlife.wordpress.com](#)

Ty and I have been talking lately about how incredibly *bad* Evie looks on paper. There's a reason every single person who has read Evie's list of diagnoses is shocked to no end when they actually meet her. She's NEVER what they expect.

Her long list of past and ongoing issues cannot capture her spunk. There's never a spot in her medical records for "Smiles with whole body and makes hearts melt," or "Loves to pick fights with big sister because she wants to wrestle," or "Is one of the top snugglers in the world and can make her mama's heart swell with so much love and joy."

No. You won't see *those* things in her medical records.

In a culture where it only takes a doctor sharing a *possible* diagnosis with expectant parents for that child to be deemed worthless, this is incredibly sad. An ultrasound. A blood test. Neither can tell the parents WHO their child is, only list some of his or her possible struggles.

And then I wondered, who DOES look good on paper? If someone were to list all *your* struggles, all *your* "imperfections," all *your* past and ongoing issues, all *your* possible future challenges, with no mention of your accomplishments, your personality, or your impact on those around you, how would YOU look? Is it something you'd want to pass out to everyone you meet? Would you want it to dictate your value to the world? I know I wouldn't!

"There's never a spot in her medical records for 'Smiles with whole body and makes heart melt'..."

Dysphagia
Tube Fed
Patent Ductus Arteriosus
Bilateral Bony Choanal Atresia
Mild to Severe Mixed Hearing Loss
Failure to Thrive
Cranial Nerve Abnormalities
Vestibular Dysfunction
Abnormal Electrocardiogram
Gastroesophageal Reflux
Multiple Hemangiomas
Tracheostomy
Developmental Delays
Immunocompromised
Small Semi-Circular Canals
Ankle Foot Orthotics
Esophagogastric Fundus
Hypotonia
Tracheal Granulation Tissue

"And this isn't even all of them!!"

So why do we do that to children? Why do we base their value on just the "con" side of the list?

One reason, I think, is that the general population does not understand that a medical diagnosis has degrees. One label can have a huge spectrum of severity. Take Evie. She is labeled DeafBlind. DeafBlind does NOT necessarily mean that someone is 100% deaf and 100% blind. It simply means that both senses are impaired to some degree (or in a child's case, are possibly impaired. Evie's vision seems to be great despite the coloboma in her left eye, but she'll keep this label until she can tell us her

vision is okay since kids can compensate so well.) People see a label staring out at them and don't realize that label can mean a whole slew of things. They let the fear of the extreme case in a textbook dictate their actions.

Another reason is that (most) doctors are incredibly pessimistic. I'm sorry. It's true. We learned pretty quickly in the NICU that a doctor will give the worst-case scenario and the nurse will give you the truth. I imagine there's some legal stuff going on, doctors feeling that they need

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The Diagnosis Is Not the Person (cont.)

to be all doom and gloom so you don't come back and sue them, but there's also their focus on the "facts" instead of the child. When we left the NICU, we were told Evie was going to be deaf and blind and never really do much. We only heard discouraging "facts" about "Evie, the CHARGE baby" ("facts" that didn't truly represent the huge spectrum present in CHARGE). But what about *who* Evie was—the spunky baby with so much determination to do what *she* wanted to do (like yank out her feeding or breathing lines)? What about the Evie who loved to look at her mobile? Or the Evie who moved and wiggled once she got her trach and could finally breathe? Or the Evie who became agitated when the suction machine was on or a particular neonatologist was talking? (Somewhat random funny/sad story: Evie would get upset and cry, dropping her oxygen levels and shooting her heart rate up, whenever the neonatologist who had admitted her the day she was born would come in her room and talk. That doctor was only with Evie for a few hours when she first arrived, but weeks later when that same doctor showed up, she freaked out! We finally got to a point of making the doctor stand outside whenever she wanted to talk to us! Babies DO remember. Don't let anyone tell you otherwise. Fortunately, they're also very resilient.) They painted an extremely grim picture for us, one that was incredibly discouraging to us, and she was ALREADY here in our arms! I hurt for the mothers who are given such a grim prognosis for their unborn babies. And yes, all of those things COULD HAVE BEEN TRUE. But do we base a child's value on what *could* happen? On what their limitations *might* be? **Or do we start teaching ourselves to see a *child* instead of a diagnosis? A child that, regardless of limitations, is valuable.**

I wish a diagnosis could be given by another parent walking that road. Instead of a doctor delivering the "facts," I wish another mother could come in, hold her hand, and interpret the "facts" for her—explaining what the long list of diagnoses *actually* look like in the real world instead of a textbook. And then offer her the "pro" side of the list to compare with the "cons."

I saw a picture recently of a young man with Down syndrome, and it said "Your words, attitudes & actions impact my life more than my disability"—and it is so very true. I dread the day when Evie will be able to see how people respond to her, sometimes with disgust and fear. It breaks my mama heart that even now people only see Evie's equipment and can't see HER. I mean, come on! She is *ridiculously* adorable! Seriously. How can people look at this sweet face:

And be afraid or disgusted?

How? Because they only see her diagnosis. They only see the trach, the hearing aids, the G-tube, the AFOs.

Please see **her**.

The diagnosis is NOT the person. Please see our children for *who* they are, not what's listed in their medical records.



"But what about who Evie was—the spunky baby with so much determination to do what she wanted to do...?"

"She's not what you'd expect after reading that long list, is she?"

Parent Ingenuity: The Backward Bathtub

By Amanda Penton



I would like to share our experience with the Fisher-Price Penguin Pal Tub. This tub works great because you can use it from birth and up. My son is 10 months old, and we use it backwards to bathe him every day. It uses a lot less water than a regular bathtub or bath chair. The tub comes with a yellow divider that stops the child from slipping forward, keeping him seated upright. It works great for children who cannot sit independently, and it allows you to have your hands free while bathing them. I pin a foam baby bath pad to the back of the tub so Kalob has some added comfort. I place the tub on my bathroom countertop so he can splash around and it can be easily wiped up. Placing the tub on the countertop also saves my back! I just fill the tub with warm water, place him in it, wash him up, and drain it. The tub comes with a neat, little water pail with a shower-like top. My son loves the water pail!

The tub can be found at Target for \$27.99:

http://www.target.com/p/fisher-price-penguin-pal-tub/-/A-14352245?ref=tgt_adv_XSG10001&AFID=Google_PLA_df&LNM=14352245&CPNG=Baby&kpid=14352245&LID=PA&ci_src=17588969&ci_sku=14352245



CHARGE Around the World

Weekend for Siblings of Children with CHARGE Syndrome

Submitted by Claudia Junghans

Chairperson, CHARGE Syndrom e.V. (CHARGE Syndrome Association of Germany)

The motto was "I am important!" An exciting knight's weekend in the youth hostel of Altleiningen, an old medieval castle, took place in October 2012.

It was the first weekend only for siblings of children with CHARGE syndrome, organized by the German CHARGE Foundation. On October 12–14, nine children accompanied by at least one parent each proceeded into the Middle Ages. Knights, kings, a damsel, and the wonderful castle of Altleiningen all provided a wonderful backdrop for this weekend!

When the kids arrived on Friday evening, the sign-posting of the knights' chambers with a suitable coat of arms began. Every family formed their own coat of arms and decorated their room door with it. Later in the evening, when it was dark, the group followed a great narrator into the castle woods for a walk. In the middle of the dark woods, a creepy story was told. Everyone was fascinated.

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CHARGE Around the World (cont.)

After the tired kids were brought to bed, the not-yet completely exhausted parents had time to converse and exchange experiences.

After the following morning's breakfast, the program continued. Attendees were shown how to create wall pictures with felt and fairy tale wool. This activity proved equally demanding for both children and adults. The results were worth the effort and no doubt will find a suitable place in the participants' homes.

After lunch, an informal conversation session for the children only was held with Falko, a family therapist and father of a child with CHARGE. Following this part of the program, everybody was invited to create his or her own suitable Middle Ages outfit. Creative limits were few.

After this creative session, the big knights' tournament took place. Everyone could prove their skills with ring throwing and balancing of a thick bag (and hustling their rival of the beam). At the end of this magnificent day, a festive banquet in the hallway of the knights was held. In the tradition of the Middle Ages, everyone had to eat with their fingers.

After Sunday breakfast, the families had to leave their knights' chambers. Before their departure, everyone built and decorated professional arrows. Since the weather was quite good, everyone demonstrated their talent with using a bow and arrow—to all with a lot of success.

Based on the positive feedback, we plan to hold a similar weekend for siblings in 2013.



CHARGE Around the World (cont.)

CHARGE in the Amazon

By Denise Teperine Dias

Educator specializing in visual, deafblind, and multiple sensory deficiencies

Adapted from *Dbl Review*, the magazine of Deafblind International, Number 47, July 2011

Working for the benefit of the people who are deaf-blind in Brazil, a country of continental dimensions, imposes different challenges than those we normally face on a daily basis as educators.

In 2006, the Brazilian group that supports residents who are deaf-blind and multiple sensorial deficient started a two-year project, taking us to all regions of Brazil. We learned the reality of daily life for the residents who are deaf-blind and their families. On one of the trips, we went to Manaus, in the Amazon, where I met a family who was grappling with the unknowns of CHARGE syndrome and its development implications.



When I met 4-year-old Nuno, something touched me. I stayed there, watching him hit his head on the ground and observing all the people around him who didn't know what to do. The suffering of the family was real. They had searched for all the best doctors in the country; however, their son lived in a state of self-infliction. We came back to São Paulo and continued to have contact with the family. But simple orientations weren't enough; each day, Nuno was having more difficulty interacting.

Three years earlier, I had the opportunity to meet a group of interveners from Canada. I couldn't stop thinking about my desire to do something similar here in Brazil. (I say "similar" because our reality here has no comparisons to Canadian culture—even less so with the Amazonian experience that would impose different professional and personal challenges.) After just three months of working on the project, I decided to return to the Amazon, work with Nuno, and fight for the establishment of a school for Amazonian children with severe disabilities.

I knew I was alone in taking the risk to pioneer this step. I was leaving behind my solid career as a public school teacher to live in a different reality. I was going to live in a different climate with high temperatures, holding the possibility of contracting tropical diseases, but also with the risk that my future student would not survive because of chronic respiratory issues. But my desire of sharing the knowledge I had acquired through the years was greater than my fears, and I didn't hesitate. I sold everything I had and moved to Manaus by myself.

I arrived in Manaus on January 12, 2008, and met Nuno, who was now even further removed from his surroundings. He was still on the ground, engrossed in self-stimulation. He didn't know

(continued on next page)



CHARGE Around the World (cont.)

how to communicate, nor did the people around him know how to communicate with Nuno. He didn't understand what was happening in his environment. His fragile body was incapable of handling itself, so he was always being held on someone's lap, fed with bottles and given no solid food. I realized then that the situation would be more difficult than I had imagined.

Thinking about CHARGE syndrome and its complexities, it became clear that learning through direct exposition and diverse stimuli, such as visual, aural, and tactile, wouldn't contribute to Nuno's relational formation and cognitive abilities. A deaf-blind person who is exposed to diverse stimuli without the proper intervention of a mediator instructor becomes stressed because of the saturation of information displayed in a nonfunctional manner.

The results of observation, from the initial period to therapeutic visits, revealed that Nuno would need an environment that provided not only therapies but physical contact stimulation, which for him was still frightening. My first thoughts were that Nuno needed to be taught about his environment and how to be aware of and accept the people around him. How could he be stimulated, through physical contact, toys, and games, to develop the desire to know his environment? In addition, he had to acquire a means of expressive communication.

In the first months, I focused on the aspects related to Nuno's non-interaction with others. I also sought to ensure that everyone involved with Nuno would change the way in which they saw him. I wanted to encourage them to have a more positive attitude and to invest more of their time towards developing individual relationships. So I started to search everything in the literature about CHARGE syndrome. What could be done to stimulate Nuno and strengthen his self-esteem? How could we think about his future?

When I learned that these challenges were common to a child with CHARGE, I felt it necessary to broaden my knowledge about specific aspects of development. To get Nuno to the point of using his hands as receptors and an expressive channel, it was necessary to go through an intense program where the routine—the anticipation of events, people, and activities—was structured in such a way to give Nuno awareness of the world around him through his tactile sense.

Individuals with multiple sensory impairments obviously struggle more with social interaction and exploration of their environment. These abilities can be taught as part of a routine program focused on communication. As an intervener/mediator, I invest much time and effort doing these daily activities that seem so simple and mundane, yet are so critical in creating communication.

In closing, the opportunity to work full-time (10 hours a day, 6 days a week) with a child has made me believe even more strongly that when a child has extreme challenges, his functional communication and emotional development can be positively improved if there is someone to take on the role of an intervener. When a person devotes time, effort, and dedication to helping a child in a high-risk group, it is most rewarding because one sees the child developing, getting stronger physically and emotionally, and preparing to overcome any boundaries.



"When I started my work with Nuno, he could not even stand up. Now he kicks a ball and does so many other things with his body."

Resources

New Perkins Webcasts

Vision Issues for People with CHARGE Syndrome

In this webcast, David Brown provides an overview of the impact that CHARGE syndrome has on vision and, in turn, on the behavior of the student with CHARGE syndrome. David, an Educational Specialist with California Deaf-Blind Services in San Francisco, has spent many years researching various aspects of CHARGE syndrome. In this webcast, David provides an overview of the ocular defects, muscle tone, and vestibular issues present in individuals with CHARGE syndrome and the subsequent impact on the individual's behavior. David cautions the viewer to take these factors into account when working with individuals with CHARGE syndrome and encourages the recognition of compensatory behaviors that are often exhibited as a result.

<http://www.perkins.org/resources/webcasts/charge-syndrome.html>

CHARGE Syndrome: Sensory Processing

In this webcast, David Brown provides an overview of the impact that CHARGE syndrome has on sensory processing. He describes the impact of sensory processing on proprioception, the vestibular sense, and behavior. In addition, David talks about the educational implications resulting from sensory processing issues.

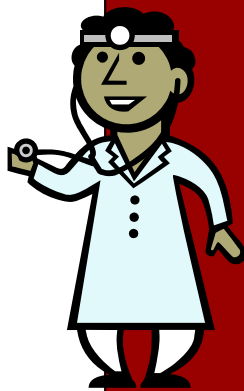
<http://www.perkins.org/resources/webcasts/charge-syndrome.html>

Visual Fields with Luisa Mayer

In this webcast, Luisa Mayer, Ph.D., demonstrates the role of the visual field in daily life and the challenges faced when there is a field loss. Dr. Mayer describes the strategies for assessing field loss in individuals who are visually impaired with additional disabilities and the developmental implications of a visual field loss. She also talks about how to interpret assessment results.

Dr. Mayer is an internationally known specialist in visual field/functional vision testing.

<http://www.perkins.org/resources/webcasts/vision-impairment-and.html>



WE NEED YOUR INPUT!

We are still in need of many more submissions for our Provider Recommendation database. The more submissions we receive, the more families we can help!

Visit <http://www.chargesyndrome.org> to submit your recommended professionals.

Resources (cont.)

National Deaf-Blind Equipment Distribution Program

NDBEDP has been established to provide support for the local distribution of a wide array of accessible communications technology to the thousands of Americans who have combined hearing and vision loss. The goal of the NDBEDP is to ensure that everyone with combined vision and hearing loss has access to telecommunication tools and training. The program provides outreach, assessment, technology, and training free of charge to those who meet federal eligibility guidelines. For more information and to find the certified program for distribution in your state, visit <http://www.icanconnect.org/>.



Bookshare

Bookshare is a nonprofit online library offering a vast collection of accessible “digital” books for children and adolescents with print disabilities. The library is free to U.S. students of all ages who are blind, deaf-blind, or have low vision, a severe reading/learning disability, or a physical disability. For more information, visit <https://www.bookshare.org/>.



National Conference Calls in Spanish for Parents

The New York Deaf-Blind Collaborative (NYDBC), in collaboration with NCDB, hosts national conference calls in Spanish for parents who have children with Usher syndrome or CHARGE syndrome. For dates and registration information, contact Clara Berg via phone (718-997-4855) or e-mail (clara.berg@qc.cuny.edu) or check the [NCDB website](#).

National Tele-Support Group

The CHARGE Syndrome Foundation now offers a national CHARGE tele-support group for parents/guardians of children with CHARGE syndrome. Facilitated by Sheri Stanger, Director of Outreach, this weekly support group is offered at no cost to the participants. Contact Sheri at 1-855-5CHARGE (1-855-524-2743) or at sheri@chargesyndrome.org.

LET'S HEAR FROM YOU!

Submissions for the Summer/Fall 2013 edition of *CHARGE Accounts* are due by **September 1st**. We would love to include more personal stories from families as well as those with CHARGE syndrome. Pictures would be great, too. To submit an article or story for the newsletter, please send it to leslie@chargesyndrome.org. Submission guidelines can be found at <http://www.chargesyndrome.org/documents/CSFNewsletterGuidelines.pdf>.

Upcoming Events

CHARGE Syndrome Clinic

Date: April 23, 2013

Location: Cardinal Glennon Children's Medical Center, Saint Louis University

Why a CHARGE clinic? After all, we cannot provide ongoing care to children who live far away.

Why come to the Cardinal Glennon CHARGE Clinic at Saint Louis University?

- If the diagnosis of CHARGE is uncertain, we are experts in CHARGE (30 years' experience) and in the conditions that overlap with CHARGE. In many cases, we can confirm or rule out the diagnosis.
- If the diagnosis is certain, we can help you better understand everything.

At our CHARGE Syndrome Clinic, we pay attention to the whole child, not just each individual medical issue.

- We can review the medical, developmental, and educational status of your child.
- We will do our best to answer any questions you may have:
 - Is this the best diagnosis?
 - Are there other specialists to see or other tests to run?
 - What is likely to happen in the future?
 - What local specialists can you recommend?
- We recognize the importance and interconnectedness of the physical/medical issues and developmental and educational issues of CHARGE.
- We will discuss sensory issues (vision, hearing, balance, etc.) and explain how those affect your child's health and development. Again, our unique expertise lies in being able to connect all aspects of CHARGE and make sense of them.

How does all this work?

- Before the clinic visit:
 - You will be mailed a form to collect some information.
 - We will arrange a time during the week before the clinic to talk by phone to fill in history, including family history information.
 - The phone conversation is a good time to list what questions you have and what you hope to get out of your visit.
- At the clinic visit:
 - We will complete the family, birth, and developmental histories as needed.
 - Your child will be evaluated from a medical genetics and developmental standpoint.
 - Some children will see a speech pathologist as well.
 - If we know ahead of time it is needed, we may be able to coordinate evaluations with other specialists (e.g., ophthalmology, audiology, ENT, endocrinology) on the same day.

(continued on next page)

"At our CHARGE Syndrome Clinic, we pay attention to the whole child, not just each individual medical issue."



Upcoming Events (cont.)

- Most importantly, you will have the opportunity to consult with and ask questions of experts in CHARGE syndrome.
- You and your doctor will receive a summary of the evaluations and recommendations.
- The clinic evaluations will be billed as are all evaluations. Please check with your insurance company to see if the evaluations will be covered or if you need prior approval for anything.

The point of the clinic is not to substitute for the specialists your child already has. Our evaluations will result in recommendations back to your local team.

Travel stipend: If you live more than 150 miles away, you will be given a stipend of \$150 towards a hotel room and meals so you can arrive in St. Louis the day before the clinic. We want to see your child fresh, not exhausted from a trip. This stipend is funded by the CHARGE Syndrome Foundation in support of our clinic.

Questions? Contact Meg Hefner at meg@chargesyndrome.org.

If you would like to schedule an appointment for your child, please contact the Medical Genetics Clinic at 314-577-5639 or contact Loletta Zasaretti at zasarela@slu.edu.

Parent/Professional Series – Genetics & Visual Disorders: CHARGE Syndrome

Date: April 29, 2013 6:00pm – 8:30pm

Location: Grousbeck Center for Students and Technology at Perkins School for the Blind, 175 N. Beacon Street, Watertown, MA

This evening session with Dr. Angela Lin will present an overview of CHARGE and its genetic implications. For more information and to register (space is limited), please visit <http://www.perkins.org/resources/training-conferences/training-center/schedule.html#parentprofessional>.

5th Annual Joshua Kurby Charge for CHARGE 5K

Date: June 29, 2013, 9:00am

Location: [St. James Farm](#) (Illinois)

To register online, visit

<https://www.signmeup.com/site/online-event-registration/89528/SMUCalendar>.

For more information, please contact [Sandy Kurby](#).

3rd Annual Tyler Trot

Date: August 3, 2013

For more information, please contact [Kristen](#).



**DO YOU HAVE
AN EVENT YOU
WOULD LIKE TO
HAVE PLACED
ON OUR
UPCOMING
EVENTS PAGE ON
THE WEBSITE
AND/OR HERE IN
THE
NEWSLETTER?
SEND IT TO
lisa@chargesyndrome.org**



Upcoming Events (cont.)

Dbl CHARGE Network Preconference CHARGE Day

Date: August 27, 2013 8:30am – 5:00pm (in advance of the 8th Dbl European Conference)

Location: Hotel Lille Centre Gares, Lille, France

Main topics being presented are social-emotional skills and communication.

If you are interested in attending or have further questions, contact

Andrea-Wanka@dbicharge.org, gail.deuce@sense.org.uk, or Martha.Majors@perkins.org.

AER International Orientation & Mobility Conference 2013

Date: December 11–14, 2013

Location: New Orleans, LA

For more information, please visit <http://aerbvi.org/O&M2013/>.

AER International Conference 2014

Date: July 30–August 3, 2014

Location: San Antonio, TX

For more information, please visit

<http://www.aerbvi.org/modules.php?name=Content&pa=showpage&pid=28>.

Feeding Challenges Registry

The “Feeding Flock” research team at the University of North Carolina at Chapel Hill is developing a registry of families with children who have eating difficulties.

For more information, please visit <http://feedingflock.web.unc.edu/>.

Focus on Fundraising

2nd Annual Tyler Trot

The 2nd Annual Tyler Trot 5K Walk/Run and Kids Fun Run was held August 4, 2012, raising more than \$18,000 for the CHARGE Syndrome Foundation. This annual event is held in loving memory of Tyler James Matthew (2004–2006).

Thank you, Matthew Family, for your continued generosity and outstanding fundraising efforts!



Focus on Fundraising (cont.)

CHARGE It for Landon

By Michelle D'Agostino

Our son, Landon, is 2 years old. At 6 months, he was diagnosed with CHARGE syndrome. After his two-month stay in the NICU at Tufts Floating Hospital for Children in Boston, we knew he would have some challenges in his life ahead.

Landon was born with tracheoesophageal fistula, which was surgically repaired on day 3 of his life. With that also came reflux and feeding issues, leading to him being primarily G-tube fed. Landon also failed his newborn hearing test, and we quickly learned he has bilateral hearing loss. He began wearing a BAHA Softband on his right side when he was 6 months old, and he continues to wear it today. Landon was born with partial facial paralysis on the right side. He cannot blink his right eye, so we continually give him eye drops to keep his eye protected. Landon also has a VSD and a leaky mitral valve, which we follow with Cardiology closely but have no plan to surgically repair at this time, unless he becomes symptomatic.

During the week, we have numerous visits from early intervention therapists, including speech/feeding therapy, physical therapy, and a nurse service coordinator. Landon also attends a group twice a week for kids under 3 who are hard of hearing. Throw in some appointments for follow-ups with all of his specialists, and we are one busy family!

Our biggest daily challenges are Landon's feeding issues. He seems interested in oral feeding and is on a blenderized diet for his nutrition. But at times, it is noticeably difficult for him to get past his gag reflex and actually swallow liquids/soft foods.

Despite his medical challenges, Landon is your typical 2-year-old. He just starting walking before his second birthday—and is into everything! He is starting to really babble and speak words clearly. We started a family sign language program so we could learn more ASL. Landon picks up signs quickly, and when he shows that he understands the meaning, he is quick to verbalize the word. So for us, ASL is helping him become more verbal.

When we became members of the CHARGE Syndrome Foundation, we were exposed to so much information that was helpful in so many ways. Being a part of some of the parent groups on Facebook helps me as a mother get through the tough days, when I think no one understands what I'm going through. The support that the Foundation and other members and families have given us in the last two years has been amazing. It has really been our saving grace. For that reason, we wanted to organize a fundraiser—to not only give back to the Foundation, but also to help our family get to this year's conference in Arizona.

(continued on next page)



"The support that the Foundation and other members and families have given us in the last two years has been amazing."

Focus on Fundraising (cont.)



This beautiful balloon sculpture was made for CHARGE It for Landon by 17-year-old Brian Bouchard, a self-taught balloon artist. To see more of Brian's creations, visit his website: balloons-bybrian.weebly.com.

CHARGE it for Landon was held on March 16 in Lynn, MA. The fundraiser was a "night out" event. It was held at a local hall, where we had an abundance of raffles including silent auction items, live auction items, gift baskets, and gift certificates that were all donated for our guests to try to win. We also had a DJ to provide entertainment and had plenty of food for all of our guests. We charged a fee for admission, and guests bought raffle tickets for our organized raffles. The turnout was great! We were surprised and thankful for the people who showed up, as well as for those who donated but did not attend. The volunteers who ran the event that night were amazing, allowing our family to enjoy the night and greet our guests. The event was a lot of work to plan and organize, but with the help of so many caring people, the night was a success!

We are happy to announce that we are donating \$7,000 to the CHARGE Syndrome Foundation. Thanks to all of you who became a part of our support system. We really feel a part of the CHARGE family and are looking forward to Conference in July, when we can meet other families who relate to us in so many ways.

Keep CHARGEing on!

The D'Agostino's (Lynn, MA)

Flat Charlie Update

By Minnie Lambert

Flat Charlie continues his journey around the world. He recently made stops in Texas and Alabama and is now in Boston. He has been a busy little man! He even attended a CHARGE Syndrome Foundation board meeting while he was with Brownie Shott. He also paid a visit to his first host family, who hosted him in honor of their daughter with CHARGE who had passed away many years ago. Charlie is currently with Pam Ryan, Foundation board member and School Psychologist at Perkins School for the Blind.



Charlie has signed in as an official Perkins visitor, where they have some exciting activities planned for him, including organizing a bake sale and traveling to the MA State House for Deafblind Awareness Day.



Flat Charlie has helped to raise donations for the CHARGE Syndrome Foundation, and we continue to ask everyone for their support. A donation can be made to any team in honor or memory of your beloved person with CHARGE. Charlie will continue his journey and is looking forward to seeing everyone in Arizona in July for Conference! To support Charlie and the Foundation, visit the Fifth Annual Charge It for CHARGE webpage:

<http://fifthannualcific.kintera.org/faf/home/default.asp?ievent=1035740>.

CHARGE in the News

Nathan Proves Doctors Wrong

Six-year-old Nathan, who was born with CHARGE syndrome, walks, talks, and loves football, despite the grim diagnosis his doctors gave his parents when he was born. Read more about his triumphs at: <http://www.the-gazette.co.uk/news/roundup/articles/2013/03/08/449543-baffled-doctors-told-us-our-precious-little-nathan-could-die/>

Teen Maps Out a Way to Win

Ben Wehrle, an eighth-grader at Turkey Foot Middle School in Edgewood, KY, won the school's National Geographic Bee and has taken a test to qualify for the state tournament. Read more of his inspiring story at:

<http://nky.cincinnati.com/apps/pbcs.dll/article?AID=/AB/20130301/NEWS0103/303010037/>

When You Wish Upon a Star

On Saturday, Kaitlin Knezacky, 13, who has CHARGE syndrome, was formally presented with a trip to the Happiest Place on Earth by the Sunshine Foundation. Read more about her dream to go to Disneyland becoming a reality at: <http://globalnews.ca/news/401943/dream-to-go-to-disneyland-comes-true-for-kelowna-teen-with-life-threatening-illness/>

Little "Tank" Battles On

Two-year-old Lawson, affectionately nicknamed the "tank" by his grandfather, exudes strength and perseverance that not only allows him to thrive, it also inspires his parents. Read more of Lawson's story at: http://lexch.com/news/local/little-tank-thrives-despite-health-issues/article_5a72e9ae-9657-11e2-9c7a-001a4bcf887a.html



CHARGE Syndrome Foundation, Inc.

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USA

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Toll Free: 1-800-442-7604
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Annual Membership

Family – \$25
Professionals – \$40

Lifetime Membership

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

Director of Outreach

Sheri Stanger

Toll Free: 1-855-5CHARGE
(1-855-524-2743)

Phone: 914-479-0079

Fax: 914-478-1204

Email:

sheri@chargesyndrome.org

NEW: Members receive priority registration for our webinar series.

NEW: Lifetime members receive a 10% discount off of conference registration.

Email: info@chargesyndrome.org

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



Thank You

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 Wells Fargo Community Support Campaign
 West – Community Health Charities
 Yvonne Lee

In Honor of Aaron Sorkin's 20th Birthday
 Steve Sorkin

In Honor of Abby Barr
 Jeff Barr

In Honor of Abby Martin
 Farrah Martin

In Honor of Aileen Sayce
 James Bowden, Jr.

In Honor of All the wonderful children and their families I have met over the last 18 years. You inspire me!
 Donna Consacro

In Honor of Alex Bartkowiak
 Brian Bartkowiak

In Honor of Brian Bartkowiak
 David & Barbara Cash

In Honor of Alice Pederson, granddaughter of the late Jim Pederson
 J.P. Pederson

In Honor of Angela and Doug Beebe
 Steven Cook

On the Special Occasion of Angela & Doug Beebe
 Corie & Mike Chaplin
 Robin & Tom Ledyard

On the Special Occasion of the Wedding of Angela Thompson and Doug Beebe
 Ed & Anne Haskins

On the Special Occasion of the Marriage of Angela & Douglas Beebe
 Teresa Heil
 Christina & David Mason

On the Special Occasion of Angela Thompson & Doug Beebe on Their Wedding
 James Leich

In Honor of Austin Clifton
 Karen Zimmerman

In Honor of Barbara Henschel's 75th Birthday
 Joan Stanger

In Honor of Benjamin Russo
 Deborah DeRoss

In Honor of Brett Ford
 Lindsay Tomek

Thank You

In Honor of Bethany Davies. A little girl who triumphs despite her challenges. She is a pleasure to watch growing up.

Tracy Still

In Honor of Burke Elias Nelson – a hero in our eyes

Gary Nelson

In Honor of Charlotte Cosenza

Lindy Eyecare

On the Special Occasion of CHARGE Syndrome Foundation

Silvia Stikkelorum

In Honor of Christian Roberts

Bekkie Cobb

In Honor of Cole Herrick

Sharon Evans

In Honor of David and Jody Wolfe

Douglas Rallo – Law Offices of Douglas Rallo P.C.

In Honor of Douglas Roth

Donna Rudder

In Honor of Eddie Lent

Joanne Lent

In Honor of Emma and Diane Katapodis

Hilda Bodenstein

In Honor of Grayson and his family who are the strongest people I know. I love you all so very much. XXXXOOOO

Gail Baitx

In Honor of Frankie

Christina Carr

In Honor of Hannah Shikora

Melissa Shikora

In Honor of Hayes-Mohamed Family

Paul Russo – The Renaissance Companies

In Honor of Janay Hayes-Mohamed

Renaissance Realty Group, Inc.

In Honor of Jasmine Goldthorpe

Catherine M. Lavery

Linda Therien

In Honor of Jaxson Cole Alexander

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In Honor of Jennifer Siewicki

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Kelly Rae

In Honor of Joseph Lavelle

Margery Bodenhamer

In Honor of Katherine Broich

Bonnie Morrison

In Honor of Lori Swanson

Dawn Schuett

In Honor of Makenzie Dougherty

Betty McKnight

In Honor and Love to our Granddaughter Makenzie Dougherty from Bumpa & Grandma

John & Bobbie Dougherty

In Honor of Meredith Dwyer

Robert & Margie Dwyer – Living Trust

Michael Pandolfini

In Memory of Eugene Dwyer and In Honor of Meredith Dwyer

Tom Dwyer – Dwyer Appliance

In Honor of Michael Kruger

Cheryl Kruger

In Honor of Nicholas Buono

Dominick Bellitteri

In Honor of Pam Ryan

Sherri Mahne

In Memory of Phillip Edward Brooks

Jack & Elaine Pugsley

In Memory of Richard Carroll

Jody & David Wolfe

In Memory of my son Rick (45 years)

Jan Van Dijk

In Honor of Mr. & Mrs. Robert Hale, Mr. & Mrs. Roger Templeton, Carolyn Hale Hill Gfunblee

Nan & Robert Hawes

In Honor of Samuel Beachy

Brian & Dana Habig

In Memory of Samuel Beachy

Valentina Flores-Mitchem

Lois Sanford

In Memory of Samuel Beachy, beloved son, grandson, brother, nephew, and cousin

Doris Lancaster – D's Taxes & Bookkeeping/D-Script-ions

In Honor of Samuel Beachy

Brian & Dana Habig

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

Thank You

In Memory of Samuel Patton Beachy

Ivan E. Beachy
Scott & Diane Beidler
Kerry & Kathy Griffin
Joan E. Koperniak
Deborah Marcus

In Honor of Sarah Myers

Lori Myers

In Memory of Mrs. Sofia Klinghofer

David Nehmadi

In Memory of Sofia Klinghofer

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Tamar Uziel
Brenda Weitzberg

In Memory of Sofia Klinghofer & In Honor of Eli Klinghofer

Mary Strandberg

In Honor of Tyler Hardwick

Nancy & Larry Murray
Vacaville Police Officers Association

In Honor of Tyler J. Hardwick

Dayna Hardwick

In Memory of Tyler Matthew

Heather Gross

In Honor of Tyler J. Matthew

Jason Matthew

In Honor of Vance Kauffold

Mary Zeigler

In Memory of William and Veronica Yon

Bonita Herod

Charge It for CHARGE Tributes

In Honor of Aiden Lanting

Mary Armstrong
Jeanne Meyers

In Honor of Aman Mehta

Rohini Arya
Simraan Kulkarni

In Honor of Andi

Tami & Jason Taliaferro

In Honor of Beautiful Lil' Andi!

Deborah Trant – Huron Consulting Group

In Honor of Andi Miller

Molly Devine

In Honor of Andi & Anna Miller

Adrienne Healy

In Honor of Anna, Cory and Andi Miller! You are the best!

Shannon Smith Hartwell

In Honor of Cory, Anna and Andi Miller

Carrie Trant

In Honor of Andrew Delaney

Ronald & Martha Ackerman

On the Special Occasion of Arnav's first birthday

Hari Lunayach
Nylah & Inara, Sadia Syeda

On the Special Occasion of Arnav's 1st Birthday. Congratulations Andy & Rohini on your sweet baby boy's first birthday. He's not just one...he's 12 months old. Always keep that beautiful smile, Arnav. Love you.

The Virk Family

In Honor of Arnav's first birthday

Neeti & Ajay Tandon/Gupta

On the Special Occasion of Arnav and family

Divya Amarayil

On the Special Occasion of Arnav, Happy Birthday

Narasimhan Thiruvengadam & Family

In Honor of Arnav Singh

Vivaan Aggarwal
M & M Bruns
Kevin Fantacci
Avni & Family

On the Special Occasion of Arnav Singh

Vivek Talwar

In Honor of Dominic Steinhauser

Tracy Roth

In Honor of Elizabeth Forsch

AZ Finnegans

In Honor of Ethan

David & Jody Wolfe – Wolf & Wolfe, Ltd

In Honor of Ethan Wolfe

Mike Block – Block, Klukas & Manzella
Anthony Cuda
Kelly & Mark Dinos
Al Gaither
Greg & Misha Guth – Guth Mediations, Inc.
Richard Hannigan – Hannigan & Botha
Julie & Marc Machtinger

In Honor of The Wolfe Family

Daron Romanek – Romanek & Romanek
Wendy O'Kane

On the Special Occasion of Joel Wolfe's 70th Birthday

Stacey, Marty, Josh & Adam Chazin

Thank You

In Honor of Eve Ali

Pamela Morin
Kartik Sharma

In Honor of Finley

Tracy Roth

In Honor of Finley Roth

George & Jeanene Galan

**In Honor of Gary Antaya, Brady
Antaya's "Pepere," and his
retirement from the United States
Department of Defense after
35 years of service**

Keith & Cynthia Antaya

**On the Special Occasion, Happy
Holidays to CHARGE Families**

Michele Lantow – MCL Worldwide Site
Services/Helms Briscoe

**In Memory of Josh, Merry Christmas
Baby!**

Mommy & Daddy

**In Memory of Josh, Merry Xmas Big
Guy!**

Uncle Don

**In Memory of Joshua Roy!! Nonna &
Grampa love you and miss you at
Christmas and always.**

Nonna & Grampa

In Memory of Joshua Kurby

Stephanie Klinger

**In Memory of Joshua Kurby. Merry
Christmas, Josh!**

The Wayman Family

In Honor of Kennedy Weir

Elizabeth Linfield
McKay's Blueberries in Pennfield, NB
Customers

In Honor of Kristin Ogan

Gary Young

In Honor of Lacey Suter

Nancy Suter

In Honor of Megan

Donald Conklin – Dixie Home Carpets
Marie Graham – The Refreshed Home
Leona Jerris
Marc Rosenberg

**On the Special Occasion of Megan
on her great work at school and her
19th birthday**

Howard Greenberg

In Honor of Megan Stanger

Barbara & Dick Bernard
Haydee Cornfedl
Michael Gordon
Victoria Graham
Ken Kissel – Live Wire Security
Susan & Daniel Rutman
Andrew Spring & Robin Kalish
Marilyn & David Stanger
Lauri & Paul Stein

**In Honor of my amazing cousin
Megan**

Spencer

In Honor of Stanger Family

Barbara & Mark Chazen

In Honor of The Stanger Family

Shirley & Harold Horowitz

In Honor of Mia Menconi

Scott Adelson

**On the Special Occasion of The
Miller's participating in the Flat
Charlie Project!**

Minnie Lambert

In Memory of Mom – Grandma – GG

Joe & Marti

**In Honor of The Ogan's participating
in the Flat Charlie Project!**

Minnie Lambert

In Honor of Patrick

The Cox Family

**On the Special Occasion of The
Peterson Family participating in the
Flat Charlie Project!**

Minnie Lambert

**On the Special Occasion of our
nephew Taylor**

Morgan & Everett Gibson

In Honor of Taylor Shott

Sharon Dore
Robbi Lauden
Doris Mims – Kalmia Garden Supply
Jonni Webb

**In Honor of Taylor Shott with love
from Bobby & Barbara R. Bryant**

Barbara & Bobby Bryant

**In Honor of The Teed's participating
in the Flat Charlie Project!**

Minnie Lambert

**In Honor of Theo Koumjian, my
adorable nephew**

Heather Simone

In Memory of Walter Whittaker

The Weir Family

**In Support of Wendy Keedy's Flat
Charlie fundraiser**

Camille Malmquist

For You

Paul Ke

**THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION**



fifth annual Charge It for **CHARGE**



Help us **SOAR** to new heights!

- **More Support**
- **More Outreach**
- **More Awareness**
- **More Research**

Our fifth annual Charge It for CHARGE is underway! This year we hope to raise more than \$150,000 for support, outreach, awareness, and research. With less than one hour of your time and the e-mail addresses of friends, family, and colleagues, you can help us reach our goal. To get started, go to <http://FifthAnnualCIFC.kintera.org/> to begin your campaign or to make a donation to another participant.

You can also combine the Charge It for CHARGE campaign with other fundraising events. If you are hosting an event or participating in a run, walk, or bike trip, create your own page to make it easier for people to support your efforts! For any questions about fundraising, contact our president and fundraising chair, David Wolfe, at david@chargesyndrome.org.

IT CAN BE DONE!