



CHARGE *Accounts*

The mission of the CHARGE Syndrome Foundation is to lead and partner to improve the lives of people with CHARGE syndrome locally, nationally and internationally through outreach, education, and research.

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In This Issue

Communication Challenges

Parent Connections

Data Dispatch

Focus on Fundraising

Taking CHARGE!

Announcements

President's Message

Spring showers bring...conference planning. Your Board of Directors is meeting the first weekend in June to discuss the details of our 2017 conference: **"Taking CHARGE in Orlando."** Be sure to mark your calendar for July 27-30, 2017 for our 13th International conference. Stay tuned for information about our room block, program, and other exciting conference information over the next six months. If you are willing to volunteer to assist with the many tasks that take place prior to or at conference, please contact us at info@chargesyndrome.org.

This is also an exciting time of year. Over the next two months, we will announce the recipients of the 2nd annual Ethan Wolfe Recreational Assistance Program and our 2016 research grants. We are pleased to be able to support CHARGE research and assist individuals with CHARGE in participating in recreational activities. Thank you to everyone who has donated and/or raised money for the Foundation over the past year to help make these programs possible.

As we complete the funding for our 2016 programs, we turn our attention to the future. The need for our programs, and therefore additional funding, has never been greater. There are several upcoming runs, golf outings and parties planned to benefit the Foundation. We also have several active Charge it For CHARGE fundraisers. We simply need greater participation to be able to continue to help individuals and families. We do this by maintaining the above mentioned programs, keeping conference free for individuals with CHARGE and covering a large percentage of the conference costs, providing scholarships for conference, hosting webinars, developing resources, promoting advocacy, connecting families to each other, and so much more.

I hope you will take advantage of the nice weather and the coming summer months to fundraise for the Foundation. For information or questions about fundraising, please contact me at david@chargesyndrome.org.

I hope everyone has a great end of the school year and a fantastic summer. Enjoy this very informative newsletter.

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



Communication Challenges



Early Communicators - What Can We Do At Home?

by Lisa Weir

A lot of parents get frustrated when their sons or daughters aren't speaking or signing and think they aren't communicating, when in fact they are—through presymbolic means.

Outside of my life in the world of CHARGE syndrome—raising a daughter with CHARGE and my volunteer work as an executive of the Foundation—I have been working as a specialist teacher for students who are deaf or hard of hearing since 2009. In 2013, I took a new position within my organization as the consultant for students who are deaf or hard of hearing with additional challenges, working with the specialist teachers and school teams or families on communication development.

When I think about communication, I would have to say that most of the emphasis and discussions I can recall between families who have sons/daughters with CHARGE over the past 18 years are in terms of individuals who are signing and/or use oral speech. A lot of individuals, however, have not yet developed this type of communication. This article will talk about some of these early communicators. I feel passionate about supporting teams who are working with early communicators: helping them to understand, first and foremost, that even though the communication might not be what they typically think of when they think of communication, their students are in fact communicating and there is a lot we can do to encourage further development!

One of the tools I use frequently with early communicators is the Communication Matrix. The Matrix breaks down communication into seven levels; the first

four of which are pre-symbolic, meaning that there are no symbols (i.e. objects, pictures, speech, Braille, sign) used. There are few tools out there that look at these earliest types of communication so this is a valuable assessment tool in my opinion. We featured the Matrix during our May 2014 Assessment Theme Month and Dr. Charity Rowland, one of the Matrix authors, presented at our 12th International CHARGE conference last summer. She demonstrated the online version of the Matrix and discussed the new community of practice that was developed to provide support to professionals and families supporting individuals with complex communication needs.

I wanted to share a few of the recommendations that come from Matrix assessment results that I commonly work on with team/families to support their son's or daughter's early communication development:

Be a great observer. Watch your child closely and look at how they respond in a variety of situations, when they are enjoying or not enjoying something. What motor movements do they use that are under their control? Examples might include: eye-widening, limb movement, facial expressions, etc. Don't worry about what they aren't doing; focus in on what they are doing and keep track of this information. Why? There are a couple of reasons: these responses can be used as targets for developing more symbolic communication and it's important to share it with others who are interacting with your child so everyone is responding in a consistent way. This consistency will assist your son or daughter in developing an understanding that his or her behaviors have an effect on others, a stepping stone toward developing the intent to communicate with others.

Figure out LOTS of things your son or daughter likes. Most of us feel we have a good understanding of



The Communication Matrix is a free online assessment tool created to help family members and professionals support people with severe communication disorders in their journey toward greater self-expression.

what our children like or dislike but knowing about a lot of different preferences will provide for lots of opportunities to practice communicative behaviors. Think about trying many different activities and experimenting with many different materials to see what your child likes best and how they respond. Do the activity or present the materials to your son/daughter for a short period of time and watch for behaviors that indicate they are enjoying it or not enjoying it and keep track of what they are doing to let you know whether they like or dislike it. Note: It's important to try and present to only one sense at a time because you want to be sure to determine which activity or object they are responding to. For example, if you are doing a rocking activity to see if they enjoy that movement, you don't want to be singing at the same time.

Develop and use routines. Early communicators benefit from a highly consistent and reliable environment. Routines can help minimize stress, develop anticipation, encourage active participation and allow for communication opportunities as your child starts to learn and predict the next steps. These routines can be developed around a daily care activity such as dressing to start. Think about your son's or daughter's day and activities where predictable routines could be developed. It may be helpful to write the routines down so everyone who interacts with your son or daughter is engaging with them in the same way. Some of my families have

developed and posted cue cards near where these activities commonly take place so everyone is consistent. Here's a short example:

Shirt Off and On

- Show article of clothing and allow them to touch it while labeling the activity: "Shirt on"
- Touch cue: shoulder to wrist touch (left) while saying "arm out" or "arm in" (pause)
- Help get arm out
- Touch cue: shoulder to wrist touch (right) while saying "arm out" or "arm in" (pause)
- Help get arm out

Use consistent language, Consistent touch and consistent sequence patterns (such as left arm first, then right, every time). Use the pause time to give your son or daughter time to process the information they've just received and look for signs that they know what is going to happen next. You can also use information about your child's preferences to develop routines using those activities or materials.

If your son or daughter has service from a teacher for students who are deaf/hard of hearing and/or blind/visually impaired, they should be a great resource if you want to see if the Communication Matrix assessment or any of these strategies might be useful for your early communicator.

Co-drawing as a Form of Communication by Kimberly Lauger

Often when we think of hand-under-hand, we think of using it to teach someone how to do a task, use scissors, zip their coat, or write their name. It is an alternative to hand-over-hand, where the helper's hand is on top, making the student's hand perform tasks, they aren't yet doing on their own. Hand-under-hand in contrast involves an invitation for the student to rest their hands on yours, so they can "see" through your hands; "see" what you are doing, "see" the object of discussion, "see" aspects of the environment, or to even "see" how to do something. It is an approach that allows the child to maintain control of their body, and to be an equal partner in exploration and interaction. When, I started signing with Dylan in this way, he did not resist, because we already had a history of sharing relationship through touch. Information about hand-under-hand and resources for helping students get familiar with this type of touch are readily available through a simple search of the Internet. But now I want to share a less familiar practice called co-drawing.

Dylan was only four when I first heard Dr. Stephanie McFarland share an overview of Dr. van Dijk's Curricular Approach, including "Drawing Instructional Strategies." If you're like me, you might have thought, "But I can't draw," and then left that strategy for someone else. At the time of her talk, I was focused on modeling American Sign Language and exploring what type of symbol, such as object, photograph, or line drawing made sense



to Dylan. It never crossed my mind that co-drawing was something I could use at home, as a “language.” Using hand-under-hand to co-write has been a part of our home life, but co-drawing? Not me.

Co-drawing was something that was done at school, with Dylan’s fabulous communication specialist, Megan Mogan, and his incredible Intervener, Doe. I loved hearing the stories of how some fabulous breakthrough happened during their co-drawing exchanges and I loved looking at the co-drawn experience stories that came home every day. Dylan and I shared a brief glimpse of his day through these stories.

Even better were the videos; videos that showed the connection and engagement that occurred as Dylan and Megan or Dylan and Doe wrote together. You can see this process in action in the video below, as Megan was helping Dylan grasp the concept of up in connection with the sign for up through co-drawing. As great as that was, it still didn’t occur to me, that I could draw with him like they did.



Then Dylan’s school placement was changed to home, and I became Dylan’s day-to-day teacher. “Umm, now what?” I thought, “I can’t draw.” I clearly recalled my struggles in 7th grade art class. Nope. Drawing wasn’t for me. But as with everything we do in our School-Home, I learned from Dylan.

Fortunately Dylan “got it” with my rough stick figures and real objects traced on to the pages of his stories as I ventured into co-drawing with him. His engagement as we drew, led me to try basic drawings, such as a house or a tree, to provide more information. I began to let go of my need to be “good” at drawing in favor of the connection with Dylan and his learning.

The beauty of co-drawing, as with any hand-under-hand technique, is Dylan has a “voice” in it. The feedback between our hands constantly guides the story or lesson that emerges before us. Dylan is able to direct me to a part of the page as a request to elaborate. After just a couple of exposures, his hand can guide the direction of mine, expressing his knowledge of how to draw a rough outline of the United States for example. He also lets me know when I am starting to draw something he doesn’t want to talk about or doesn’t understand by either guiding my hand in a different direction, or taking the page, crumpling it up and throwing it in the trash.

Starting in school as a way to illustrate a concept or create an experience book for the day, co-drawing has evolved to a dynamic communication form wherever we are. I no longer have to worry about having the right picture communication symbol with me, when we leave the house. As long as we have paper and markers, Dylan and I can communicate about anything. It allows for spontaneity of topic, easy adaptations to our schedule, and best of all the opportunity for us to just “talk.”

If you saw Dylan on the Young Adult Panel at the 2015 International CHARGE Syndrome conference, you saw us co-drawing together as we waited his turn. You might have wondered what we were drawing together. Quite simply, I was interpreting for him, in the form of co-drawing, letting him know who was talking, key points of her talk, when his turn was, and what he was going to do. What you couldn’t see as he and I co-signed his presentation, was his “speech” lying there on the table, written out in co-drawn form for him to “read” from as we went along.

For a recent presentation, I looked up information on co-drawing, and found Dr. McFarland’s article, which was written about the time I first heard her talk about Dr. van Dijk’s Curricular Approach. As I read anew the key benefits of “drawing instructional strategies,” I thought about Dylan. Yes, co-drawing does promote the use of his residual



vision, as placing his hands on mine draws his eyes to the page. Yes, co-drawing does allow Dylan and I to have communication that is clear to him and to me. Yes co-drawing does encourage Dylan to be an active participant in learning, and life. Yes co-drawing does provide a static communicative referent; that is it provides communication in a form that he can hold onto and refer to again and again. What the article doesn't list is the benefit of competence and self-determination for Dylan and contentment for me, as we "talk" together through this shared media. I encourage you to give it a try.

Kim's article originally appeared on the Communication Matrix website, with additional images and links

Read more of Kim's posts about Dylan's communication on the Communication Matrix website

Keys to Communication

by Wendy Keedy

Nearly 30 years ago, when our daughter with CHARGE Syndrome was born, little was known about this condition. In fact, it had only been a short time since the features had been studied and connections had been made, leading researchers to call CHARGE an Association. Had the internet been available to me, surely I would have googled some physical symptoms Kendra had at birth. Tiny ears, difficulty swallowing and breathing plus a small cleft palate were apparent soon after she was born. Later, a rare H-type tracheal-esophageal fistula, a double aortic arch (vascular ring), a patent ductus arteriosus, facial nerve weakness, small chorioretinal colobomas, middle and inner ear differences and deafness were discovered. Like others with CHARGE Syndrome, Kendra has experienced more than 25 surgeries and procedures under anesthesia. A tracheostomy and gastrostomy were necessary for many years.

Though physical attributes of CHARGE Syndrome present minor as well as very major and sometimes life-threatening difficulties, one non-physical aspect of CHARGE can present long term challenges. Communication. Communication is perhaps less studied and less understood than some other components of CHARGE. Deafness or blindness or deafblindness are among elements that may influence the ease with which one learns to communicate.

The following quote by George Herbert, a Welsh poet, orator and Anglican priest, sums up how I view paths that may be taken when considering avenues to support communication. Try as we may, it can be difficult to know at the outset how to proceed in teaching language. George Herbert said:

"Do not wait; the time will never be 'just right.' Start where you stand, and work with whatever tools you may have at your command, and better tools will be found as you go along"

When Kendra was identified as deaf at age two, we entered a new realm. Health issues had been addressed. Life was 'settling down'. We didn't anticipate the journeys we would embark upon when seeking ways to support language acquisition.

First stop was a local school for deaf children that used listening and speaking. Kendra had new hearing aids. The trach tube had been removed. It was an ideal time to practice speaking. Over time, though, it became apparent that speaking was not happening easily. Cued Speech was added to our repertoire. At about this time Kendra's behavior began to change and she regressed. She lost eye contact, began to have difficulties sleeping, started having serious tantrums and began spinning in circles. With these developments, we re-focused and changed to a 'Total Communication' type of program thinking that more options might help language develop with more ease.

Kendra's kindergarten teacher introduced picture communication with her signing. This approach allowed Kendra to pick a picture, give it to a communication partner and thereby express a need or want. She picked this skill up readily. The first day of use the teacher excitedly told me Kendra knew how to use 18 different pictures! While elated, I wasn't totally surprised. I knew inherently that Kendra had a lot to share but couldn't use the communication modalities of speaking or signing yet. Words were added to the pictures. Kendra demonstrated she could read. At this time, she picked up

the manual ASL alphabet and began to spell requests. Instead of signing “ice cream” for example, Kendra spelled each letter of the name of the local ice cream shop. When I demonstrated how to sign ice cream, Kendra invariably re-spelled the shop’s name. I began to suspect that there were differences in the way Kendra processed information. While pleased she could spell and type, we didn’t seem to be making headway in interpersonal communication. Although seeing sign language daily, Kendra neither responded to sign nor used sign spontaneously.

Many techniques that encouraged language learning then surfaced in the literature. We taught Kendra vocabulary through a Verbal Behavior model of Applied Behavioral Analysis. Kendra continued to gain signs and read vocabulary words. Still, conversation was elusive. It seemed that a more complete immersion in American Sign Language might help, so our family moved to be near a school for Deaf children with an extensive special needs department. This seemed a perfect fit. To our surprise, Kendra did not appear to understand or use language spontaneously in this environment. In fact, while she answered questions at home and spelled some requests, the teachers said they never saw her sign. One day an occupational therapist observed Kendra at school. To the teachers’ amazement, the OT saw Kendra signing with her hands generally under the table where they were not seen by others. This supported what we had learned from an ASL researcher. He had confirmed our suspicion that Kendra had limb apraxia affecting her signing. It was easier to produce a stationary letter than to move her hands to produce signs. While she signed some words, signs were produced slower or faster or lower or higher than could be easily read by another person. We learned from specialists that there were problems with vision use, too. Brain research began pointing to nutrition and digestion as elements affecting learning. We studied this and made changes. Over time, in the fully signing high school environment with a signing I:1 assistant, and with the recommended changes, spontaneous signing began to emerge. Medication helped dramatically resolve or reduce OCD, sleeping problems, spinning, and tantrumming.



Kendra smiling at a recent meeting with her typing club/RPM friends

Fast forward to today. We recently found another tool that has opened doors for individuals with seemingly limited communication. Due to Kendra’s interest in spelling, typing, reading and signing, the Rapid Prompting Method (RPM) offers support. While new to this approach, Kendra is already expressing herself more readily on a variety of topics and enjoys interacting with others using skills that are being built through RPM.

With limited communication, making friends can be difficult. A positive aspect of RPM is that Kendra regularly meets with a group of friends who communicate through typing and spelling. Kendra is using her language with peers and developing friendships – something we have been hoping to find all these years!

This journey has confirmed that one makes choices given the information one has at any moment. Nobody knows the future. Seemingly unrelated areas such as visual processing, the food one eats and digests, apraxia that might affect speech or sign may all relate to difficulties some individuals with CHARGE experience in gaining language. Had I known from the outset about these factors, different choices may have been made. continuing to find resources offers hope that communication skills can further expand. Stay tuned.

FROM OUR ARCHIVES:

For more communication strategies, read [Many Ways to Have A Conversation](#)

By Martha Majors, Assistant Education Director, Deafblind Program, Perkins School for the Blind



The Importance of Parent Connections

by Sheri Stanger, Director of Outreach

Addressing the communication needs of people with CHARGE syndrome and multiple sensory needs is essential. Without communication how does one express their wants and needs to the world? How do we take what's building up inside ourselves and have it make sense to those around us? We often talk about communication and connections to the world when it comes to our children because it is extremely important, but today I'm taking a different focus. It's also important for the parent or guardian to connect with other parents to address their own needs. A parent who is well connected, informed and able to share their experiences with other parents becomes a better advocate.

Outreach to parents is a major part of our mission. If you are connected to the Foundation you know that we provide e-news to our constituents, webinar trainings, free resources on our web site and this wonderful newsletter. But we also facilitate parent connections. If you are on our mailing list, you can request a parent list by contacting me at sheri@chargesyndrome.org or toll free at 855-5CHARGE (855-524-2743). Our lists are generated by state, province or country and provide the names of parents that are known to us and agree to share their information with other families. To protect confidentiality, there is no information listed on the child, but you can email and/or phone the parent to make the initial connection. In addition, our state parent liaison project will continue to grow and you will be able to contact your state liaison to inquire about parent gatherings, state family groups and additional parent connections. And of course, we host our biennial

international conference to ensure that families have an opportunity to gather at a venue where they can learn and share experiences in a welcoming environment.

Why is it so important to communicate our experiences with other parents? Why divulge our concerns and daily challenges with others we may barely know? As your Director of Outreach and a parent to a young woman with CHARGE syndrome, I find there is great joy and relief in making connections to those that understand our daily struggles and achievements. Who else understands the very complex and specific challenges we face as caregivers to our children? It is one of the reasons I host a weekly CHARGE tele-support group. It's an opportunity for parents to share their stories, give and receive advice. And sometimes it is nice to have people listen and say they "get it." It's great to be heard after the frustrations of battling insurance companies or special education teams or the excitement when your child has taken his/her first step or signs or speaks "mommy" or "daddy" independently for the first time.

Communication is critical for our kids but it is important for us too. Our emotional state affects our kids' well being. Get connected, get informed and receive support from other parents. Don't delay in getting connected to the Foundation. Become a member. Request that parent contact list. Join our Facebook Group. Attend a conference. Call or email your Director of Outreach to get you started. Communication amongst parents begins with a single step and leads to a lifetime and a lifeline of support.

Join or Renew Your Membership Today!

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

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

Email: info@chargesyndrome.org

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





Coming Soon: CSCDP Version 2.0

by Meg Hefner

What is CSCDP?

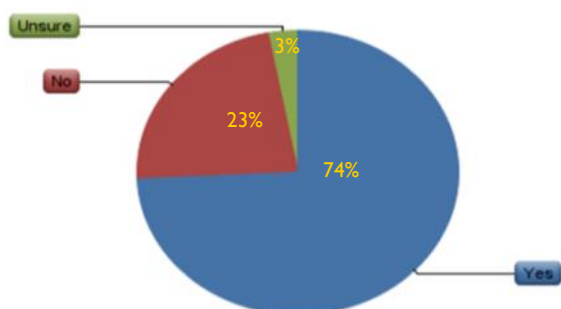
The CHARGE Syndrome Clinical Database Project (CSCDP) is a web-based, parent-entered database and registry for CHARGE syndrome.

Why have a database and registry?

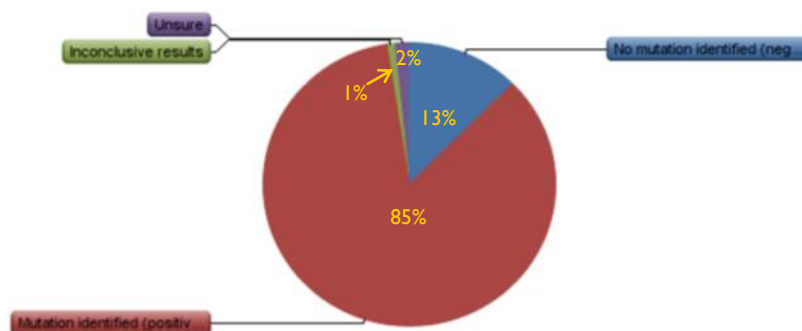
1. To have a registry of people with CHARGE
2. To answer your questions. Some of you will have noticed my answers to questions on Facebook. For instance, a parent may ask, how old were your children when they were able to sit alone? Sure, several other parents will answer the question. But when I chime in with information from the database, I can tell you, of the 121 people who answered that question, the average age was 14 months, with the oldest at 32 months.
3. For research. The CSCDP team and others can determine lots of interesting things from the information entered. But just as importantly, data entered in CSCDP can help others do CS research. Think about it – before research can be done, anyone who wants to do research on CHARGE needs to:
 - a. Find people with CHARGE
 - b. Make sure they really have CHARGE (based on accepted medical criteria)
 - c. Know which particular features of CHARGE each person has
 Once that information is in place, the researcher can ask specific questions.

What interesting information is in there already? Here is an example from the Genetic Testing section.

Has CHD7 testing been done?



What were the results of CHD7 testing?



Sounds great! Can I participate?

Not at the moment, but soon. If you want your child's information included in CHARGE research, CSCDP is an easy way to do that, because we will share data with all other approved CHARGE researchers. We can find people with CHARGE and provide baseline information on those people as a starting point for research. CSCDP is currently closed for renovation. Data entry will begin again with version 2.0.

Why Version 2.0?

We launched version 1.0 of CSCDP in May, 2013. Since that time, we have collected information on about 150 people with CS. We have learned a lot already, but we also found things that needed to be improved. We need to add a bunch of questions, based on entries in "other" categories and comments. We need to make the sharing process easier so the data can be used by others around the world. And in the process, we need to be sure the information is handled in responsible, secure ways. For all of those reasons, we made the decision to change the database platform from Qualtrics to REDCap (Research Electronic Data Capture). Huh? You say.... The details are not important, except that REDCap was designed specifically to handle medical research, multicenter studies and secure sharing of data. Moving forward with the times.

(Continued on page 13)

Many Ways to Help

by Deanna Steinhauser

I hear it all the time: Fundraising is so hard, I don't know how you do it. I'm here to say it is not hard and most people want to help, they just don't know how. Give people a way to help and they usually will! In the 8 years Dominic has been alive we have raised over \$50,000 for the Foundation. It can be done!!!

Before you start any fundraising you **MUST** set up a Charge It for CHARGE page!!! You can find this page at <http://CSFeighthAnnualCIFC.kintera.org/>. Make your goal \$2,017 for conference in 2017! Can you imagine if every one of the people in our foundation raised this kind of money? We could do some incredible research and offer even more help for our kids! On this page, and anywhere else that you fundraise, the key is to make it personal. Be willing to share about yourself or your child. Our fundraising efforts are always titled "Do it for Dominic and his friends with CHARGE." Explain to people how hard life can be and how many children we lose to CHARGE syndrome.

The Foundation has an all volunteer board and we need funds—not to pay them, but to pay for research, conference and other programs! People need to understand where the money is going to help our kids!

Here's some examples of the simple fundraisers we have done over the last few months.

- We had **t-shirts** made and sold them to support Dominic! If you do pre-orders then the cost to you is zero and you make a profit!
- We had a **garage sale** and donated the proceeds. If you have junk in your house that you've been trying to get rid of it and didn't have the motivation, use the CHARGE Syndrome foundation as your motivation. It

takes time and energy but there is no cost to you.

- I have a friend who teaches **Zumba**. She made one of her classes open to the public. People could come and paid a flat fee and part of the fee went to the CHARGE Syndrome Foundation! It took some Facebook posts and emails, but barely any planning and it raised money!!
- This is my favorite one and I think others have done this too. I just turned 40 and decided to have a "**Party with a Purpose**" I found a bar that would serve food and drinks for a set price. I then made a ticket price higher and asked everyone to come celebrate my birthday while raising money for CHARGE syndrome! This took minimal planning. I sent evites so invitations were free and all my friends were excited to celebrate with me and donate to a great cause!!



If any of this seems too much then start slow, create that Charge It for CHARGE page, post it on Facebook, send some emails and see what happens. There are many good people in the world and they want to help! They especially want to help kids that are sick and struggle the way many of our kids do! You just can't be afraid to ask!

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



Focus on Fundraising



Change for CHARGE

by Karen McGinn, National Junior Honor Society Adviser

During the month of February, the National Junior Honor Society of the Alfred E. Zampella School in Jersey City, New Jersey held their annual coin drive. We decided to raise money and spread awareness for all of those with CHARGE syndrome. Our inspiration was Kyle Dabydeen, the son of our beloved Librarian, Cynthia Dabydeen. Kyle is an incredibly smart and handsome boy diagnosed with CHARGE Syndrome. He is profoundly deaf, has vestibular issues, and also has a hole in his heart. However, he has taught us that with the proper support, children with CHARGE can overcome insurmountable obstacles.

Kyle and his loving family captivated our hearts and helped us kick off our Change for CHARGE Fundraiser. Our goal was to collect \$5,000 in four weeks to donate to the CHARGE Syndrome Foundation. A local paper, the Jersey Journal, printed our story on NJ.com. and halfway through our coin drive, after our story was shared on CBS news, we received donations from people near and far!



We heard many stories of students donating large sums of their own money and collecting donations from their family and friends, and teachers matching their class totals. **We are thrilled to announce that our school collected \$8,266 for the CHARGE Syndrome Foundation in just 4 weeks!** That's more than \$3,000 over our goal!

Something for Everyone

by Kari Slusser

Raising Awareness for CHARGE syndrome is mostly simple: you just talk to people about the syndrome, post photos, wear the royal blue, and so on. But we all know it's a constant battle to keep it fresh in people's minds.

Raising money—as the Foundation and all of us know—is an entirely different challenge. I have failed many times but I've also had some successes. It can be truly frustrating when people are not reaching into their pockets to

support your cause, a cause you feel so emotionally tied to. I've learned to not get myself down if I didn't raise much money with a campaign. You simply can't expect everyone to support your cause overnight. In my recent campaigns I decided to fundraise with T-shirts. We see a lot of T-shirts and that's fine. Don't think that just because you see a lot, you can't create your own to fundraise.

The trick to being successful is to find something everyone would buy. I found a design a lot of people liked and ran with it. I listened to my fellow families and added many options to the design. Lastly, I ran the campaign more than once. The first time around the Foundation received over \$328.00 in profit; the second time around \$0 and the third time around I raised another \$175.00 for the CHARGE Syndrome Foundation. I plan on doing more fundraisers in the future.

CHARGE may be rare, and we may feel alone, but we are not alone, we are a family. And there is nothing I enjoy more than giving back to my family!



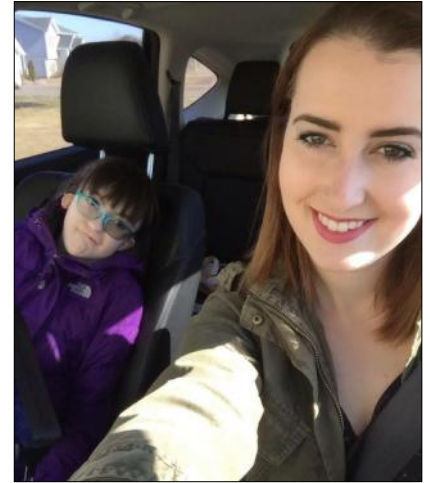
Taking CHARGE!



How to Escape a Speeding Ticket

by Mackenzie and Charley Cutcliffe

I learned that Charley is the best wingman when you get pulled over. I got out of a ticket last month because the officer came to the window and Charley started yelling, "We're late for horseback riding for PEOPLE WITH DISABILITIES!!!" She then explained CHARGE syndrome to him and when that didn't work she proceeded to make up a story about how the graveyard beside us was being grave robbed, which was far more important than my speeding. The poor officer really had no choice but to let us go. Thanks Charley!



CHARGE-ing in the Show-Me-State

by Aubrey Williams

Last month, I had the opportunity to speak in front of special education teachers and students attending the Council for Exceptional Children conference in St. Louis. I did not know in advance that I would be speaking so I did not have anything prepared, but when asked if I would like to, I thought "Why not?"

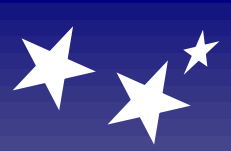
I told them about what CHARGE was, and about the wonderful work the Foundation does to help individuals with CHARGE syndrome and their families. I also talked about the importance of raising awareness and fundraising for research, resources and our conferences every two years. I was asked what advice I would give to teachers and interveners about people with CHARGE syndrome, and made sure to stress that no two people with CHARGE are exactly the same. We differ in our abilities and in the struggles we face, and I believe that getting to know each person as an individual is very important. Get to know their needs and their personality because what the textbook tells you will work is not going to work for everyone. Often, an individual with CHARGE will teach you just as much as you teach them.



It was great to hear the questions and comments from people excited to learn more. There were a few people who had heard of CHARGE, some who knew people on the Foundation board, a couple who knew some of my friends with CHARGE syndrome and a mom of a little girl with CHARGE.

People from all over the country came to this conference. We heard first from a couple of people who spoke about the Cogswell-Macy Act: an education reform bill for those with visual/hearing impairments like deafblindness. They emphasized the importance of advocating for this, and asking our congress members to sponsor it. The afternoon wrapped up with a 9-year-old girl from Florida, who is visually impaired and recently won an award for advocating for people with special needs. She told us about the things she is doing and plans to do in the future to advocate for a better world for people who have visual/hearing impairments. Then everyone walked around and picked up brochures from the tables. We visited, took pictures, and exchanged contact information. All in all, it was a great learning experience for everyone who was there. We made some new friends, and had fun spreading awareness along the way!

Taking CHARGE!



Advocating for Opportunities

by Cathie Josephson

I recently spoke at the New York State Assembly Minority Task Force on protecting the rights of people with Developmental Disabilities. Parents were asked to speak on the Olmstead decision (segregation of persons with disabilities constitutes discrimination and is in violation of the Americans with Disabilities Act) and how it impacts their families; the effectiveness on current transition plans, sheltered workshops and programs and identifying opportunities and integration in our communities.

My daughter is a beautiful, multiply disabled young woman with CHARGE Syndrome. Erika is legally deafblind. When she was born, they suggested we “let her go” or “give her up.” These were not options for us. She has had over 50 surgeries and but always perseveres. For years we have battled the school system for her to be included. She was “kicked out” of our school district because they no longer had a program for her that was accessible. She was “kicked out” of a State School for the Deaf because she was too medically involved.

Every report from every provider describes her as an extremely social person – this is her strongest asset – but she never really had many typical friends, due to being in a self-contained environment and her medical issues. Over the last few years, she is finally socializing and meeting more young adults. We have learned that there are others like her in our community. She is having fun and making friends. She has a new friend, her support worker “Mari” (below, with Erika), who is close to her age. Mari takes Erika out into the community. They go to clubs, movies, classes, shopping and spend time in our community as well as do volunteer activities. My daughter has a purpose and is happy.



Erika graduates in June and we are excited for her next phase of life. I have looked at day-habilitation programs and have been even more disappointed than when we were looking for schools. When I showed up for one scheduled tour they had the wrong date and were not prepared. We toured anyway. A young adult was lying in a corner on the administrator's office floor. When we

looked at the “activity room” the students were sitting at a table, not doing much, as the staff chatted on the other side of the room. Then I heard a “bang” as a young adult fell out of his chair onto the floor! The staff took their time to help him up. Other young adults were just sitting in beanbag chairs. We looked at the lunchroom; a student in a wheelchair was all alone 50 feet from everyone else, just sitting in the middle of the room. I left there in tears, and knew for sure that my daughter could not be in a day-habilitation program all day and that she would benefit from self-direction. Erika needs structure and routine so we are considering a blended program, where she could have a program base for routine but she will also have community based activities.

We plan for her to live with us as long as we can care for her, but we need support. I could never have her live in a group home not knowing how she is cared for or who is caring for her and wondering if she is sitting in a corner all alone or being mistreated. Erika cannot talk, she communicates with us with gestures and basic sign language, most of which only people that really know her understand.

I was told by someone who is advocating for group homes that I was doing my daughter a disservice and that a group home could better care for her. My husband and I are with her every step of the way, we adore her, she is the light of our life. We take her on vacations to the Caribbean, she has been parasailing, swimming with dolphins, been to Disneyland for roller coasters, and she has her own adaptive seat on our boat, where we spend summer days tubing! Just because she has special needs does not mean she has to be isolated.

She is not able to walk without a lot of assistance, she has a feeding tube, and she has respiratory issues, but this doesn't hold us back from enjoying a wonderful life with her. She is a very happy young lady who brings so much joy to everyone around her. We worry about what her life will be after we are gone. We want to make sure she continues to be happy and can interact with others being social and have a productive life as an adult with friends and support.



Taking CHARGE!



Granting Wishes

Congratulations to 9-year old Reuben Dodd, who recently had the honor of serving as the Wish Kid Ambassador for the Make-A-Wish Greater Los Angeles Walk for Wishes in Exposition Park.



Photo by Catherine Lacey Dodd

Advocacy in Action

The deafblind community joined forces on April 14, 2016 – what would have been Anne Sullivan Macy's 150th Birthday – to support the Cogswell-Macy Act.

The Cogswell-Macy Act is intended to improve the delivery of appropriate special education and related services to all students with sensory disabilities, including students with additional disabilities. **Each state would be required to specifically address deafblind issues in the development of its state plan.** The legislation will also ensure that properly designed and individually tailored services are provided consistently nationwide and that the specialized educators who offer such services are prepared and supported to do their jobs well.

The official Call-In-Day may have passed, but you can still contact your senators and representatives and ask them to support children with sensory disabilities! For more information and sample messages, go to [American Foundation for the Blind](http://AmericanFoundationfortheBlind.org) or intervener.org

Click here to view the Perkins School for the Blind/CHARGE Syndrome Foundation webinar on the *Cogswell-Macy Act*

Send news of your or your child's activities, events, awards and successes for publication in the next issue of CHARGE Accounts to joanne@chargesyndrome.org

Data Dispatch



(Continued from page 8)

What is the timeline?

We closed Version 1.0 in Qualtrics to new data entry on April 1. So if you had signed up but not gotten around to entering data, you'll have to sign up again with the new version. We are deep in the process of re-creating the database in REDCap and preparing the data extracted from Qualtrics to be uploaded into the new database. Once that has been accomplished, we will be ready for new participants. We hope to have Version 2.0 ready for data entry by early June. Watch the newsletter, Facebook and email blasts for more information.

Can the data so far answer more questions?

Sure, let me know what questions you have and I'll provide some answers in future editions of Data Dispatches. You can reach me by email at meg@chargesyndrome.org



Registered attendees will get an opportunity to submit questions in advance of the webinar and live questions will also be taken during the event. David is often asked about and will entertain questions on a wide variety of topics, including: unusual postures, retinal detachments, dental issues, and assessment approaches.

