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President's Message

By David Wolfe

Happy New Year! As we wrap up another year and look ahead to a great 2013, I am extremely grateful for all the wonderful people who have helped the Foundation. Thanks to the hard work of many, we funded more research than in any prior year, created our own webinars, expanded our outreach, and so much more. There isn't enough space in this newsletter to list every accomplishment or to thank everyone individually for their excellent contributions. So if you are a member, donated or raised money for the Foundation, contributed to the newsletter, helped at conference, served on a committee, or made the world a better place for individuals with CHARGE syndrome in some other way: **THANK YOU!**



While we accomplished a lot in 2012, we can and will do more in 2013. Our conference is going to be a phenomenal event filled with the proper balance of education, support, sharing, and fun. I hope you can come "Experience the Wonder." In 2013 we are also committed to more outreach, webinars, and research. At the same time, we are implementing a strategic plan to solidify the financial stability of the Foundation to ensure our assistance for the next generation.

Whereas so many contributed to our recent success, a few deserve special mention. Without the tireless efforts of our Executive Committee—Lisa Weir, Brownie Shott, and Neal Stanger—we could not have come so far nor have planned so much for 2013. Working with them is a privilege and a pleasure. Our Director of Outreach, Sheri Stanger, continues to reach out to all new families and assist our members in many different ways. Susan Wolfe works full-time, without compensation, for the Foundation, managing our blasts, database, Charge It for CHARGE, and more. I am honored to serve with such a special group!

Enjoy the newsletter. As always, please feel free to contact me with any questions, comments, or concerns. Most importantly, I wish you and your families a very Happy and Healthy New Year.

Information as Inspiration

By Sheri Stanger, Director of Outreach

As Director of Outreach, my intent is to create awareness and inform professionals and parents about CHARGE syndrome and the Foundation. In my last newsletter article, I wrote about my summer travels to perform outreach with families and professionals in the field of deaf-blindness. As I talk with families, I find they crave information. I share a lot of resources, but I always wonder if it is too much information. Will I overwhelm the families? While I know that information is important, what is the right amount? I tell families that the information will always be there and they can choose to use it as they see fit; however, I want to make sure what they receive will be helpful. Recently, I got involved in a conversation on one of our CHARGE Facebook groups, and it reminded me that the problem doesn't always lie in the amount of information, but rather in the quality of that information and the message it conveys.

"...the problem doesn't always lie in the amount of information, but rather in the quality of that information and the message it conveys."

Parents tell me they receive worst-case scenarios from doctors, read articles about the complexities of CHARGE, and learn about all the different problems that can occur and the challenges that lie ahead. Where is the information that gives us hope? Where is the information on positive outcomes and inspirational stories of success that keep us going from day to day? This really made me think about what types of information I'm disseminating. No matter how good the resource, perhaps I should offer more balance with my suggestions. The [New Parent Packet](#) and [Parent Management Manual](#) are examples of fabulous resources developed by the Foundation, but maybe we need to balance those resources with inspirational stories and achievements.

I speak with parents who have newborns, as well as parents who have adult children with CHARGE. I hear stories of these adult children going to college and getting jobs; I hear about first steps that weren't yet expected, solid food swallowed when that parent had difficulty believing that milestone may never be achieved. These are stories we should be sharing with each other as well as with professionals in deaf-blindness and the medical community. It is not all doom and gloom—our kids can grow up to lead wonderfully fulfilling lives. I remember the days when I never thought my daughter would chew and swallow a sandwich, and now she can eat an entire steak! I remember the days when she fell every few feet and the fear of stitches loomed over our heads. Now she runs for her school track team, skis down a mountain on a black diamond trail, and participates in activities of her choice. If I hadn't talked with other parents and attended conferences and trainings to keep up my hope, would I have pushed her to achieve these milestones? I know it was important for my family to see other people with CHARGE syndrome pushing the limits despite what they were told they would never achieve. Information that inspires is just as important as information that educates. Let's stick together and share our success stories with one another. Hope helps.



The Role of Opportunity in Successful Adult Outcomes for Students in Transition

By David Wiley, Transition Specialist, Texas Deafblind Project

When thinking about transition planning from school to adult life for students with CHARGE syndrome, or deafblindness in general, I think we in schools sometimes get tied up in our processes and curricula. We sometimes have the feeling that if we have the right meetings, follow certain procedures, and complete them according to plan, transition planning can be deemed a success. However, the bottom line for the success of transition planning shouldn't be whether students learned the right lessons or made the appropriate connections, but whether they have moved on to successful adult lives.

What do I mean by success? As a system, we define success in specific, measurable outcomes, such as whether the student is employed or enrolled in college within a year of graduation. Those outcomes are important, but I think somewhat narrow in scope. If I ask most typical adults to look back and judge whether they have had a happy life, a good life, or a successful life, most probably wouldn't answer, "Yes, I was employed and/or enrolled in higher education within one year of graduation." Instead, their answers would probably focus on the special people they have known; the places they have gone; the things they get to do for fun; the things they have been able to do for and with others; memorable, happy moments; and joyous occasions.

Of course, "success" in those terms is harder to measure, because how that kind of success looks is different for every person, based on his or her personal preferences and abilities. I like to describe it as finding purpose, satisfaction, and joy in life. This kind of success is harder to program for, and is sometimes more the result of the opportunities you find than the skills that you have.

So in addition to academic skills, work skills, and living skills, I believe it is equally important that students and the families who support them have an additional skill—the ability to recognize, create, and take advantage of opportunities. One important aspect of this skill is identifying what is personally important to students, and what kinds of life activities will lead toward purpose satisfaction and joy. In that way, students and their advocates will know what they are looking for and be more ready to recognize opportunities as they arise.

This is why it is beneficial to participate in more personal planning for individual students. One great outcome of transition planning is identifying or discovering what every student feels is most important in life. This is essential in making the most of opportunities throughout a lifetime.

"...the bottom line for the success of transition planning shouldn't be whether students learned the right lessons or made the appropriate connections, but whether they have moved on to successful adult lives."

"...it is equally important that students and the families who support them have an additional skill—the ability to recognize, create, and take advantage of opportunities."



It's hard to believe, but there are less than 210 days until we meet in Arizona for the 11th International Conference. The planning committee is hard at work fine-tuning the program, camp, registration, and event details. We hope you and your family will be there to enjoy all of the learning and fun that happens when families and professionals come together at a CHARGE conference.

If you haven't already begun to explore funding options, our [Fall 2012 newsletter](#) features a comprehensive guide on locating funding to attend. The article includes a sample grant request letter, a spreadsheet to calculate costs, as well as a list of granting agencies. Don't let funding issues keep you from missing out on this fabulous event.

Conference registration will be open in early March, and once again we will be offering early-bird registration prizes. The Grand Prize is three free hotel nights during conference. There will also be four runners-up prizes of \$50 gift certificates for our conference sales table. Keep your eye on the conference information page, <http://www.chargesyndrome.org/conference-2013.asp>, for more details on conference registration in early 2013.

Hotel registration is now available – you may book online at: <https://resweb.passkey.com/go/chargesyndrome>. We have a great rate of \$109 per night, so book your rooms early!

TO DO LIST:

1. Explore funding sources. ([Fall 2012 newsletter](#)) ✓
2. Register at hotel. (available NOW) ✓
3. Register for conference. (available early 2013) ✓
4. Make travel arrangements. ✓
5. Get ready to “Experience the Wonder” in Arizona! ✓

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.

Click here for a copy of our [donation letter](#) and a copy of our [donor form](#). 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.



Nominations for Board of Directors

The CHARGE Syndrome Foundation is looking for hard-working Foundation members who are interested in donating their time and expertise as a Board member. Guiding the Foundation is an incredibly rewarding experience. If you or someone you know has the dedication, time, and skills to help our Foundation flourish, please nominate them to serve.

Nominations are now officially open for the Board of Directors for the CHARGE Syndrome Foundation. You can find a nomination form online at www.chargesyndrome.org/documents/nominations.pdf.

Below is a timeframe for the nomination and election process:

April 1, 2013 – All nomination forms will be due to the Foundation office either by postal mail or e-mail.

May 15, 2013 – The initial interview process will be completed by the nominations committee, and a slate of potential Board members will be confirmed. If more than six people are running for the positions, an e-mail blast will be sent to all current Foundation members with a ballot to vote. If six or less people are running for the positions, there will be no reason to send out a ballot and all nominees will be elected by acclamation.

June 1, 2013 – All ballots will be due back to the Foundation.

June 15, 2013 – All applicants will be notified by the nominations committee to let them know if they have been elected to the Board.

July 2013 – The new Board officially takes office at the general membership meeting during our conference. The new Board will meet a few days before conference and elect new officers of the Executive Committee.



All applicants should familiarize themselves with our Policies and Procedures. Please e-mail David Wolfe at david@chargesyndrome.org to obtain a copy of the policies or to discuss serving on the Board. Please remember that this is a working board; if you are running, please make sure you are willing to put in an average of five hours or more per week before nominating yourself.

Together, we can make a difference!

Leading the Charge: Band Beyond the Scores

Submitted by Susan Hiscutt

This article appears on the Youth Education in the Arts website (www.yea.org).

By Allison Watkins

In the competitive marching arts, it is nearly impossible to remain completely unaffected by the thrill and frustration of the contest. Pride in your school and band program, in your friends and all your collective hard work, tells you that you deserve to beat other bands. At the end of the night, the drum majors line up on the field facing a row of faceless judges in the press box, and it feels like picking teams in gym class, but in reverse order. You cringe, hoping not to hear your name called too early. This isn't *Who's Line*; the points *do* matter.

But sometimes, amidst rivalry and scores, one student reminds us why we're all really here, that it's not just about carrying a two-story, gold-tinted trophy back to the buses. It's not even about learning that hard work always pays off, because the truth is, it doesn't always pay off in the ways we hope. But for all competing bands this year, the true meaning of the 2012 marching season can be summed up in the experience of a boy named Aaron Hiscutt.

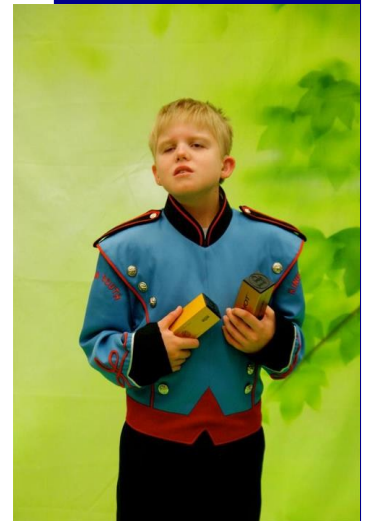
By the book, CHARGE syndrome is a genetic disorder that affects about one in every 9,000 to 10,000 children worldwide. While symptoms vary from child to child, children with CHARGE often experience complex heart defects, difficulty breathing and swallowing, loss of hearing and vision, and balance problems, which hinder their development and communication.

"It's a pretty daunting diagnosis when you get it," said Aaron's mom, Susan Hiscutt. "Aaron does have hearing and vision impairment. He does have balance issues. He does have growth and development delays, but we're 15 years into it now, and to know what the textbooks say is wrong and to really see your child living with it... it's very different."

In spite of severe impairments, children with CHARGE tend to be determined and resilient. Many accomplish more than is originally expected of them, and Aaron is leading the charge on that front. "I think it was fourth grade when the kids started on recorders," Susan said. Because of Aaron's respiratory issues, he couldn't breathe, blow, and play, so his teacher said, "Well, shoot, let's just let him play the chimes!" While the other fourth graders tooted and squawked on every parent's least favorite instrument, Aaron played the same notes on the chimes.

"He mastered all of his songs," Susan bragged. "And then the teacher had him play a solo for his fifth grade graduation." The parents of the "typical" kids sat in awe, as a little blond boy, nearly blind and deaf, played "Amazing Grace" on the chimes in front of the crowd with no sign of nervousness. "He couldn't have cared less about all those people. He wasn't focused on that," Susan said.

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Leading the Charge (cont.)

After fifth grade graduation, Aaron's parents found themselves in a middle school band room, speaking with the band director about the possibility of Aaron playing percussion. "It's hard for kids to experience the world without putting them in it," Susan said. The director happened to be a drummer, so he was open to letting Aaron participate in the band program. "Some kids have soccer or basketball; Aaron has his music. He ended up playing the drums through sixth, seventh, and eighth grades," Susan said.

Aaron's parents never really considered high school band, but a friend's mom suggested it and took the initiative to start speaking with Kenneth Carrico, the band director at Sullivan South High School in Kingsport, TN. "He actually seemed very open to it, so we went and did it!" Susan said. Aaron just completed his freshman season as a member of the front ensemble of the Sullivan South High School Marching Band. "We try not to limit him and tell him what he can and can't do," Susan said. "And with marching band, we tried to say that he could, but we didn't know. I definitely think he exceeded our expectations."

Jon Swengler, one of USBands' Band Relations representatives, heard about Aaron when Kenneth Carrico called to ask if he would be allowed to compete in the USBands Tennessee State and Southern States Championships. "Of course!" Jon exclaimed over the phone. "It's not even a question." Jon was the event manager for Tennessee State, and he stopped running around long enough to stand on the sideline and watch Aaron perform with Sullivan South. When he reported back to the entire staff the following Monday morning, he recounted the story with tears in his eyes. "Watching Aaron perform was one of the most inspirational moments to witness and be a part of. Observing him reminded me, and I think a lot of other people, why we do what we do here at USBands," he said.

Susan's family was blown away by the acceptance that the Rebel Band's students, parents, and instructors showed Aaron. "Aaron is nonverbal," she said. "We're not sure if that's the result of his hearing impairment or more complex symptoms, but from what we can tell from his sign language, he really enjoys marching band."

And while this season has been a great experience for Aaron and his parents, he teaches a much greater lesson to his peers and teachers every day: At the end of the season, this isn't about which group of hardworking kids should have beaten another group of hardworking kids. It's about the exhilaration of performance and the thrill of creating music as a team.

Aaron has been nominated for an award for the Council of Exceptional Children. You can see a video of Aaron Hiscutt performing with the Sullivan South High School Rebel Band [here](#).

"We try not to limit him and tell him what he can and can't do."



SAFFE Day in Kilgore, Texas

Submitted by Shanda Branch

My daughter, Maggie Branch, has CHARGE syndrome. Our town recently held an event in honor of individuals with special needs. I asked our Fire Chief, Johnny Bellows, to write a recap of the event that we could share with everyone. His recap is below. I have also included some pictures of Maggie at the event.

About three years ago, I attended the National Fire Academy for a TRADE seminar with many large fire departments represented from across the nation. One of the speakers, Mike Day, spoke of a program sponsored by the Overland Park, Kansas, Fire Department involving a day for children with special needs. I was touched by his presentation and thought, "I need to bring this idea back to the Garland, Texas, Fire Department."

Shortly thereafter, the city of Kilgore, Texas, hired me to be its Fire Chief. As I learned about Kilgore and its benevolence—a community that cares about people and always extends a helping hand—I thought, "This is the place this event needs to be held." I saw the vision of SAFFE (Special Abilities Family En Event) Day as being a part of the caring community of Kilgore.

Several months ago, I made a presentation to our firefighters about a day for individuals with special needs, children to adults. The Kilgore firefighters were receptive to the plan and began building props and developing ideas for making this a special day. As a department, we wanted this to be an opportunity for individuals of all ages with special needs to come out with their families and enjoy a rewarding day of fun, education, activities, shows, games, entertainment, and food.

The firefighters didn't just put their minds and bodies into this event—they charged forward with their hearts. We visited with area businesses, churches, and community groups who were inspired by the idea of SAFFE Day. We distributed letters to the Northeast Texas-area schools as well as many support groups. Donations began to come in, volunteers began to come forward, and activities began to be planned and organized. Our firefighters wanted this event to be rewarding first and foremost to anyone with special needs, but also to citizens, volunteers, businesses, churches, and civic groups, and to the firefighters as well.

Kilgore, as a community, came together to make this special day happen. Approximately 200 volunteers took part in the event; firefighters, sheriffs, and police personnel from area departments assisted; organizations and churches came out; people of all ages lent their support. The celebration was a huge success with more than 700 people in attendance. This became not just a fire department function, but a community event—one where we saw all groups working toward a common goal of making a special day for some special people with special needs and their families.



"The firefighters didn't just put their minds and bodies into this event—they charged forward with their hearts."

SAFFE Day in Kilgore, Texas (cont.)



The Kilgore firefighters worked long hours for months to make this event successful. After being up late the day before, getting up early the morning of the event, and then staying late after everyone had left—cleaning the streets of props, litter, and debris, and assisting others to return our town back to normal—the firefighters were more impressive than ever. They didn't complain to me that they were exhausted; instead, they

walked up to me and said, "This was great, let's do it again next year." Their dedication brought tears to my eyes, and at that point I knew this was to be an annual event in the city of Kilgore.

Plans are underway for the Second Annual SAFFE Day event to be held September 21, 2013, in the beautiful city of Kilgore, Texas.

Johnny Bellows
Chief, Kilgore Fire Department

Bedwetting Solution

By Amy Russo

We have been trying to find a solution to bedwetting for years because our son eats 800 mLs of formula over a pump while he sleeps. We finally found the answer, so I wanted to share!

We don't change our son through the night because it wakes him and he doesn't go back to sleep. We had tried putting him in one of those big, overnight diapers with a Tena Overnight incontinence pad inside it. The position of the pad is critical. Since he is a boy and sleeps on his right side, we put the widest end at the top, lined up where the absorbent part of the diaper starts, and ran it down the side, almost off the diaper side. This technique was successful for a while, but then stopped working.

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Bedwetting Solution (cont.)

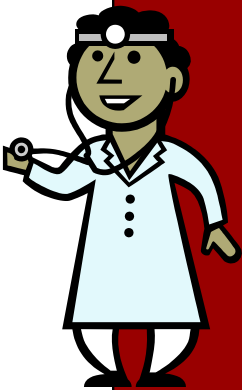
We then tried the diaper and incontinence pad in combination with a store-bought, washable bed pad just over his bottom area. This method soaked everything up but made him feel wet, which in turn woke him up super-early. It was still better than changing him during the night, because he now awoke at 4:00 a.m. instead of 2:00 a.m. However, the washable pads started to smell over time.

After trying every diaper and pad combination possible (Poise, booster pads, etc.), we still found the Tena Overnight pad to be the best with a nighttime diaper. So we tried a plastic diaper cover over the diaper, but that didn't work because our son's legs are so thin that it still leaked. After talking to many companies, my mom then stumbled upon something called a wool diaper cover. All the "natural" companies were recommending it to wear over cloth diapers for typical kids and told us nothing worked better. We bought the biggest size they sold, followed the steps to lanolize it, and put it over the nighttime diaper/pad combo. It worked like a charm! We didn't have a single wet bed or pajamas for a week.

The wool did start to stretch a little, so we had to order a size down, even though our son wasn't in the recommended weight group, because of his thin legs. We couldn't believe how well it worked, and he slept in so much longer. We now use this combination along with a plastic mattress cover, just in case of any accidents. Wool is supposed to absorb moisture but keep it wicked away from the skin. It keeps you warm in the winter and cool in the summer. It is naturally antibacterial, too. It doesn't smell, needs washed only monthly, and hangs to dry. For children too big for the diaper covers, wool mattress pads are also available. I highly recommend the wool diaper covers. They are worth every penny to avoid all the laundry from bedwetting and have your child sleep better. The company we ordered them from is Organic Caboose (<http://www.organiccaboose.com>).



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.

Profiles from Germany

Submitted by Claudia Junghans, Chairperson, CHARGE Syndrom e.V.

The following profiles were published in the CHARGE Syndrom e.V. (CHARGE Syndrome Association of Germany) newsletter.

Andreas Kamps

By Andreas Kamps, September 2012, translated from German

What is your name?

My name is Andreas Kamps.

How old are you?

I am 17 years old.

Do you have any brothers or sisters?

I have two siblings. My brothers are Daniel and Niklas. Daniel is 13 years old, and Niklas is 11 years old.

What are your CHARGE-related symptoms?

Undescended testes, heart anomaly (hole in the heart), ADHD/ADD and tics, impaired vision, autistic-like behaviours, hormone and growth development issues, reduced balance, occasional problematic behaviours, teeth grinding.

Can you talk? Or do you use sign language?

I sign.

Where do you go to school?

In Putbus, on the island of Rügen in Mecklenburg-Western Pomerania, Germany.

What do you enjoy doing in school?

I like school, especially natural history, computers, and swimming.

What are you especially good at?

Signing, being helpful, swimming.

Is there anything you don't like?

Squabbles, death, snakes.

What irritates you?

My brothers, sometimes, when they pester and annoy me.

What annoys you?

My brothers, the other inhabitants in the residential home.



"I like school, especially natural history, computers, and swimming."

Profiles from Germany (cont.)

Anna Heising

By Anna Heising, August 2012, translated from German

I am Anna Heising. I am 11 years old, and I go to the Realschule Rheinbach (normal Middle School/Secondary School). After the holidays, I will be starting 6th grade. My favourite subjects are German, Biology, and Politics. There are 29 children in my class. During breaktime, I walk around with my girlfriends and chat.

My hobbies are ballet, reading, and meeting my friends. I love listening to music, especially Rihanna, Lady Gaga, Katy Perry, and Top Ten. Every week I spend my pocket money on *Bravo* and other magazines. Otherwise, I read a lot—all the *Vampire Sisters* books, *Warrior Cats*, *H2O* (about mermaids), and others. During the 5th grade, we studied *Mit und ohne Hotte*, by Sigrid Seevaert, which I quite liked. I often write imaginary tales or stories based on real life and then read them out loud to my mum.

I enjoy playing with my dog, Paul, who is 3 years old. My friend Lulu and I really love listening to loud music and dancing through the house. (When my mum is out or walking the dog, we turn the volume up!) Lulu often sleeps over, and we stay up late or even the whole night through. Actually, I like staying up late anyway, always during the holidays or on the weekends. Sometimes I like to share Mum's bed too.

I have lots of girlfriends with whom I meet. My friend Sakura always makes me laugh a lot. My friend Lisa is a bit quieter, and we play board games or do craftwork and chat about this and that. Otherwise I surf the Internet, looking up the stars, and when I turn 14 I will be allowed to use Facebook. I like spending time on my PC and playing SIMS.

I sometimes watch films in the evenings. My favourite films are "Mamma Mia" and "Vincent will



Meer" (a German film about the adventures of a boy with Tourette's syndrome). I also think a few TV series are quite good; for example, "H2O" (my aunt painted a whole wall in my room using the motto of this mermaid) series, "Dance Academy," "Alien Surfgirls," and the detective series "Da kommt Kalle." I sometimes use my iPod to shoot short films about my dog or about having fun with my girlfriends.

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"I often write imaginary tales or stories based on real life and then read them out loud to my mum."

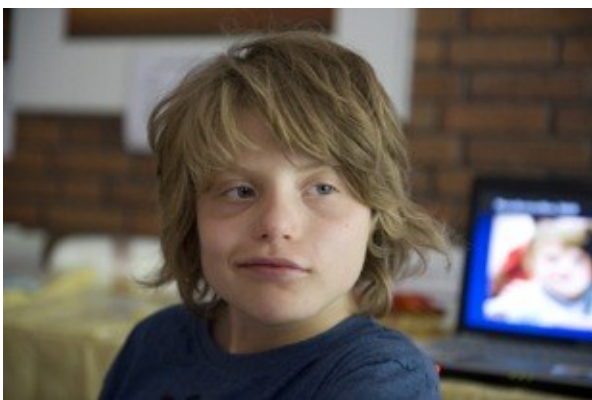
Profiles from Germany (cont.)

"I am not really sure what I want to be as there is so much that I find interesting."

Every year, my school hosts a "Girls Day" when we are allowed to do a work experience. In the 9th grade, the work experience runs for three weeks. This year I spent the day with my primary school teacher. Next year I think I shall shadow my respiratory therapist, whom I like very much. I am not really sure what I want to be as there is so much that I find interesting. I used to want to be an emergency/casualty doctor or a veterinarian. At the moment, I would like to work at the Youth Welfare Office or become a psychologist or perhaps a singer or an actress. I think the job of radio presenter would also be good. Mama thinks I will become an author. I am looking forward to my birthday. We are going to a recording studio, and my friends and I are going to record a real CD. I just don't know yet which song we will sing.

Jannis Oppermann

By Jannis Oppermann, October 2012, translated from German



Hello, I'm Jannis Oppermann. I am 16 years old (born 21st April 1996, in Bremen) and am deaf. I have CHARGE syndrome, although the doctors only discovered that much later on. The reason being, I didn't have to have as many operations as other children with CHARGE—only on my heart (because my ductus didn't close), my intestines (because they were twisted), and my ears. I've had five operations total. I was

born two months early. I also started to walk late. I may need hormones, but for now I am being treated homeopathically. Since those difficult, early days after my birth, I have gotten better and better, but no one knew then that I have CHARGE.

At first I went to a playgroup for children who are deaf and to a kindergarten for children who can hear. I didn't have any problems there because the children and teachers learned to sign from my mother and me.

In 2002 I went to school in the Marcusallee in Bremen, but I only stayed a year because we moved in 2003 to Nordwalde in North Rhine Westfalia. I went to the Bernhard-Stahm School as it was called then. (It was since renamed Münsterland School.) In 2008 I started at the Realschule (normal Secondary/Middle School) in Dortmund. I am now in the 9th grade. I only found out about CHARGE syndrome last year, thanks to Claudia Junghans, because a doctor believed that I have CHARGE.

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Profiles from Germany (cont.)

At the CHARGE Conference in Lauterbach in 2011, I discovered that some of my friends have CHARGE too, like Andreas Kamps and Can-Marlo Baseren. I know Can from a camp and Andreas through a friend. Many of my friends don't know that I have CHARGE. I don't look as if I have CHARGE. But I do: hearing impaired, sensory disorder, hair shaking, asymmetrical face, physically small, and in November 2011 I was operated on for undescended testes.

I can take the train by myself, go on excursions, ride a bike (I learned when I was 12!), swim (also learned late, but so did my brother and he doesn't have CHARGE), and lots more. Naturally I have had difficulties when starting some things, but I have to say, I impress myself! But, I do have limitations, so there are some things I'm not so good at.

I have a younger brother, Jonas (12). My parents separated in 2009, so Jonas, Mama, and I, together with our dog Balu and the cats, moved to Dülmen and Papa moved to Bremen. I have found it quite difficult to come to terms with my mum and dad's separation, but now it's OK.

I love being around animals. At the moment we just have Balu and a small tomcat that Jonas found a couple of weeks ago. Later I would like to have guinea pigs. When we lived in Nordwalde, we used to have loads of guinea pigs and rabbits! Here in Dülmen I look after two ponies on a shared basis. One of my favourite hobbies is football. I play on a team, the GSV Recklinghausen, a team for players who are deaf. I am an ardent Bayern München fan, but I think Schalke 04 is also good. My other hobbies include riding, swimming, reading, watching "whodunnits" on TV, meeting friends, taking the dog out, and lots more.

Most of my friends have normal hearing, but I also have many friends who are deaf. I have found lots of new friends through Claudia Junghans' CHARGE Group. Honestly, I don't care if someone else has a disability. For me, all are the same and each one is individual.

My mother Christina has taught me healing and grounding techniques, and I use them to control my hair shaking and all sorts of other things. They make me calmer. I think it could help parents and their children with CHARGE to become calmer and to control symptoms (twitches, shaking, etc.) if they use healing/grounding techniques. Grounding is when you connect to the cosmos and Earth and release everything that you don't want, or draw strength from the Earth. It really helps. Obviously it doesn't change everything permanently, so you have to do it again and again, but it really is very easy. You have to concentrate. The best way is to start by breathing in and out. This connects you with your heart and soul. Then you connect with the divinities and with the Earth. No distractions! You really have to be deeply focused on your body.

My mother and father and my whole family believe in me and trust that I will make my own way. It has given me lots of strength and courage.

I am on Facebook and have e-mail if you would like to get in touch, but Facebook is best.

"Naturally I have had difficulties when starting some things, but I have to say, I impress myself!"

"Honestly, I don't care if someone else has a disability. For me, all are the same and each one is individual."



“To their credit, staff at the FCC conferred with individuals who are deaf-blind and other interested parties for months to develop the rules...”

I Can Connect!

The New National Deaf-Blind Equipment Distribution Program

By Betsy McGinnity, Perkins School for the Blind

Sending an e-mail or text, checking the weather forecast online, or searching for the best price for that new gadget are things that most of us do each day without much thought or effort. It's just part of life in the 21st century. For individuals with combined hearing and vision loss, however, these tasks may not be so easy. In order to successfully access the same distance communication technology and services as hearing-sighted people, those who are deaf-blind often require specialized equipment and training. The equipment is often expensive, and the training can be hard to find in many areas. Fortunately, there is a new program to address these challenges—the National Deaf-Blind Equipment Distribution Program (NDBEDP), sponsored by the Federal Communications Commission (FCC) to help people who are deaf-blind achieve their distance communication goals.

The NDBEDP was established as part of the landmark 21st Century Communications and Video Accessibility Act (21st CVAA), a wide-ranging law passed by Congress in 2010 that is designed to ensure access by people with disabilities to all aspects of modern communication. Recognizing that deaf-blindness leads to significant barriers in communication and video access, the framers of the 21st CVAA included a section mandating the FCC to establish the NDBEDP and authorized spending up to \$10 million annually for equipment and training for individuals who are deaf-blind. The funding is allocated to states based on population.

It took several years and leadership from Congressman Ed Markey and other lawmakers to pass the 21st CVAA. Advocates, including individuals who are deaf-blind, were intensely involved in persuading Congress to pass the law and also provided input to the FCC as it developed the rules that will govern the NDBEDP. To their credit, staff at the FCC conferred with individuals who are deaf-blind and other interested parties for months to develop the rules and carefully considered the feedback they received from consumers, families, and service providers. Because there was no precedent for such a program and there were a number of issues upon which no real consensus could be reached, the FCC decided to initiate the NDBEDP as a 2-to-3-year pilot program. Final rules will be established after the pilot phase has been completed.

As part of the pilot program, the FCC invited organizations and agencies in each state to apply for certification as the state entity that distributes equipment for the NDBEDP. Although only one entity in each state could be certified, applicants were encouraged to form partnerships to carry out the program. Applications were submitted in November 2011, and the equipment distribution entities were selected on July 2, 2012.

(continued on next page)

I Can Connect! (cont.)

The FCC also invited applications for participation in a national outreach program to raise awareness of the benefits of this new initiative throughout the United States. Perkins School for the Blind (Perkins) in partnership with the Helen Keller National Center for Deaf-Blind Youth and Adults (HKNC) was awarded this grant, which began July 1, 2012. NDBEDP is being marketed as iCanConnect (www.iCanConnect.org). Perkins, in partnership with HKNC, took a leadership role in helping a large number of states develop their applications and deciding how best to establish the deaf-blind equipment distribution in their states. Perkins and HKNC are also designated as the certified equipment distribution entity in 10 states, Puerto Rico, and the U.S. Virgin Islands, and they serve in a supportive role in 18 additional states.

Through iCanConnect, eligible individuals can get equipment that enables them to use telephone communication, access the Internet, and use what the FCC refers to as “advanced communications” (e.g., Internet-based voice communication, e-mail, instant messaging, and video conferencing services) (FCC, n.d.). Equipment covered includes hardware and software applications that may be either specialized equipment or “off-the-shelf” items, such as smart phones and iPads. The FCC did not establish a list of approved types of equipment, but any equipment provided must support distance, not face-to-face, communication. It is anticipated that most solutions will be customized for each eligible individual. The type of equipment needed by a specific individual will be determined through an assessment of his or her communication goals. As technology changes, more effective and creative solutions will be incorporated.

In order to be considered eligible to receive equipment and training, an individual must meet the following definition of deaf-blindness as established in the Helen Keller Act: “In general, the individual must have a certain vision loss and a hearing loss that, combined, cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation (working)” (FCC, n.d.). Individuals must also have an income that does not exceed 400% of the federal poverty guidelines. There are no age restrictions or work requirements. It is important to remember that the equipment is to be used only by individuals who are deaf-blind, not by their family members or service providers. For a detailed description of the program, see <http://www.fcc.gov/guides/national-deaf-blind-equipment-distribution-program>.

In some instances, if an individual has significant vision loss, the ability to read Braille may be necessary. That said, it is important to note that a person who uses pictures or gestures to communicate and who is able to use a service like Skype to chat with a distant family member may be eligible. In establishing the rules for the program, the FCC sought to include as many eligible consumers as possible. It is expected that one of the largest groups that will benefit is that of individuals who have lost hearing and vision as a result of aging. They may be experienced in using advanced telecommunications technology but have been cut off from using it because of sensory loss.

(continued on next page)



“In establishing the rules for the program, the FCC sought to include as many eligible consumers as possible.”

I Can Connect! (cont.)

Distribution entities in several states have already started to process applications for equipment from individuals with deaf-blindness and verify their eligibility. Once an individual is deemed eligible, he or she will meet with an assessor to discuss his or her communication goals. The assessor will help individuals identify equipment to support those goals and test sample equipment. When the assessment is complete, the equipment will be ordered. When the equipment is delivered, a trainer will be sent to install it and train the consumer to use it. Recognizing the great diversity in the population of individuals with deaf-blindness, the FCC did not set any limit on the number of training hours.

In recent decades, technology has vastly expanded the way most people communicate through voice, data, and video services, but the high financial cost of this technology and associated training for individuals with combined vision and hearing loss have prevented equal access to it for people who are deaf-blind. The goal of the National Deaf-Blind Equipment Distribution Program is to address this imbalance by ensuring that every person with combined hearing and vision loss has access to modern telecommunication tools and the training necessary to use them, thus granting each the opportunity to interact with the world as an involved, contributing member of society. To learn more about this program, visit iCanConnect.org or call 1-800-825-4595.

Reference

Federal Communications Commission. (n.d.). *National Deaf-Blind Equipment Distribution Program: Guide*. Retrieved from <http://www.fcc.gov/guides/national-deaf-blind-equipment-distribution-program>.

Resources

National Deaf-Blind Child Count Report

The 2011 National Deaf-Blind Child Count Report is now complete and posted on the National Consortium on Deaf-Blindness (NCDB) website at <http://www.nationaldb.org/TACHildCount.php>. This count is the only deaf-blind specific child count maintained nationally, and is the first and longest running registry and demographic knowledge base of children who are deaf-blind in the world. Representing a 30+ year collaborative effort among many individuals and organizations across the country, the deaf-blind child count is critically important in understanding the needs of infants, children, and youth who are deaf-blind. Additionally, these data are used to help identify national and state technical assistance needs of children, families, schools, and organizations.

“...the deaf-blind child count is critically important in understanding the needs of infants, children, and youth who are deaf-blind.”

Resources (cont.)

Intervener Services Initiative

In July 2012, the NCDB published *Recommendations for Improving Intervener Services*. The full publication is available as a web-based report: <http://interveners.nationaldb.org>. There is also a link to a printable version on the recommendations home page. The next steps for the Intervener Services Initiative include work on some of the higher-priority implementation strategies outlined in the report. These include initiation of work groups that engage stakeholders from the deaf-blind network in recommendation activities, adoption of a consistently applied definition of intervener services, development of guidelines that IFSP/IEP teams can use to make informed decisions about the need for intervener services, and development of national open-access intervener-training modules. NCDB is partnering with members of the deaf-blind network, as well as experts who are outside the field of deaf-blindness who have expertise in module development, to produce and evaluate a foundational set of eight training modules by the end of June 2013. To stay up to date with news about the Intervener Services Initiative, sign up for the Intervener Services Network Connections Group at <http://network.nationaldb.org>.

Training Modules Include Deaf-Blindness

East Carolina University and the Office of Special Education Programs have produced a series of topical modules to be used in courses to prepare special education teachers or for professional development activities. The MAST modules cover a number of topics and include a [5-modules series on Students with Deafblindness](#).

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. (See the Fall 2012 issue of *CHARGE Accounts* for more information on Bookshare.)



New Link to Deaf-Blind Book Collection: <https://www.bookshare.org/browse/collection/44/Deaf%20and%20Deaf-Blind%20Special%20Collection>

New Bookshare Blog Post: <http://wp.me/pSDO6-Ei>

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 and children with 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](#).



Resources (cont.)

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 sher@chargesyndrome.org.

New iPad App

We all know the importance of families telling their stories as part of their advocacy efforts. Now there's an iPad app to help. "Telling Your Story" is a tool that persons with disabilities, family members, and other advocates can use to compose and practice the personal story they'll present to elected public officials or other policymakers at all levels of government when seeking policy changes or increasing awareness about disability issues. The app guides users through the steps, from introducing yourself to identifying the specific issue to the best methods for presenting a compelling personal story. After entering the text of their story, an audio recording feature allows the user to rehearse their story. Users can also select and preview a photo they may wish to include.

You can view the app in the iTunes Store at <http://itunes.apple.com/us/app/telling-your-story/id541403749>. (To use all the features of this app, an iPad 2 or newer is required.)

Upcoming Events

Northeast Regional Seminar:

Medical and Behavioral Aspects of CHARGE Syndrome

Date: February 1, 2013, 1pm – 4:30pm EST; February 2, 2013, 8:30am – 4:30pm EST

Location: Helen Keller Regional Center, 141 Middle Neck Road, Sands Point, NY 11050

Presenters: Meg Hefner, Genetic Counselor; Kim Blake, General Pediatrician; Laurie Denno, Certified Behavior Analyst

Registration: http://www.perkins.org/assets/downloads/perkins-training-center/20120913charge_announcement.pdf

The speakers are leading authorities in the area of CHARGE syndrome. The information they present will enhance the seminar participant's basic understanding of the genetics of CHARGE syndrome; provide valuable medical information that impacts those with CHARGE syndrome, and identify behavioral issues that also impact the daily lives of those with CHARGE syndrome.

Upcoming Events (cont.)

2013 Texas Deafblind Symposium

Date: February 21–23, 2013

Location: Omni Austin Hotel in South Park, 4140 Governor's Row, Austin, TX 78744

For more information or to [register](#), visit <https://www.signup4.net/public/ap.aspx?EID=20123930E&OID=50>.

Virginia AER 2013 Vision Conference

Date: February 27 – March 1, 2013

Location: Wyndham Virginia Crossings Hotel and Conference Center, Richmond, VA

For more information, visit [2013 Virginia AER Workshop](#).

Literacy for Learners with Deaf-Blindness and Multiple Disabilities

Date: Spring 2013

Location: TBA

For more information, visit www.vcu.edu/partnership/vadbproject.

2013 Virginia Transition Forum

Date: March 11–14, 2013

Location: Holiday Inn Koger Conference Center, Richmond, VA

For more information, visit [VA Transition Forum](#).

The 5th Annual Joshua Kurby Charge for CHARGE 5K

Date: June 29, 2013, 9am CST

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

Save the date—more details to follow.

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

Dbl CHARGE Network Preconference CHARGE Day

Date: August 27, 2013 8:30am – 5pm (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.

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/>.



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.

Focus on Fundraising

CHARGE Across America 2013

In 2003, Chuck Chandler and Mike Brennan dipped their wheels in the Atlantic Ocean and set out on a 3,000-mile bike ride to benefit the CHARGE Syndrome Foundation. CHARGE syndrome is a cause that's near and dear to their hearts. Mike's family was helping to host the International CHARGE Syndrome Conference in 2003 in Cleveland. Their goal was to cover around 100 miles per day, bike all summer, and get back to Cleveland in time to volunteer at the conference.



After 43 long days of biking in the summer heat, over mountain passes and through deserts, they arrived at the Pacific Coast. They met amazing people who helped them along their journey, and were able to raise over \$10,000 for the Foundation. The journey changed their lives forever.

Ten years later, and...they're doing it again! Chuck and Mike hope that you will join them on their journey to again CHARGE Across America, to raise money and awareness so that the families affected by CHARGE syndrome have the information and resources they need. This journey will begin on July 4th in Bar Harbor, Maine, and conclude on Labor Day in San Diego. The goal is to present the CHARGE Syndrome Foundation with a check at their upcoming conference on July 25th in Scottsdale, Arizona.

Visit www.chargeacrossamerica.org for more information.

Car Magnets Available Soon

Beginning in January, we will have car magnets available for sale on the Foundation website. The magnets will sell for \$5 each and are a great way to raise awareness of CHARGE syndrome.



Focus on Fundraising (cont.)

The Further Adventures of Flat Charlie

By Kate Beals, OTR/L, Technical Assistance Specialist

(This article appeared in the Autumn 2012 edition of the *Trellis*, the newsletter of the South Carolina School for the Deaf and the Blind.)

In January 2012, a little paper boy was born, right here in South Carolina. He is not the kind of paper boy who rides his bike around the neighborhood to deliver the morning newspaper, but an actual piece of paper, cut out in the shape of a boy. The brain-child of Mrs. Minnie Lambert, the little paper boy was given the name "Flat Charlie," and from the very first moment, he has been a boy with a mission.

Flat Charlie—known to his closest friends by the affectionate nickname "Flat"—was immediately adopted by the CHARGE Syndrome Foundation, and given the job of goodwill ambassador and fundraiser extraordinaire. Flat Charlie has been busy all year, traveling the globe and raising money to help families attend the 11th International CHARGE Syndrome Conference in Scottsdale, Arizona, July 25–28, 2013. At each stopping place, Flat Charlie's host family gives him something he needs for the trip to his ultimate destination, Scottsdale, and tries to raise at least \$100 for the scholarship fund. As of this writing, the Flat Charlie Project has raised \$2,595, and his journey is far from over.

Flat Charlie took his first steps in Kingstree, South Carolina, where Andrew Delaney and his classmates at Kenneth Gardener Elementary School gave him a nice pair of comfortable shoes. He crossed the Ravenel Bridge to visit the beach in Charleston, South Carolina. Next he was off to Michigan, where he stayed with several great families and got to meet CHARGE syndrome expert, Tim Hartshorne. He toured Europe, then moved on to Australia. David Brown, another expert on CHARGE syndrome, intercepted Flat Charlie in Australia and escorted him back to the USA, where he has been visiting families on the West Coast since October.

Flat Charlie has collected quite a few souvenirs during his travels. He has new eyes and glasses, a BAHA (bone anchored hearing aid), many colorful stickers, plus a rhinestone-studded heart and sparkly g-tube port! He has flown in an airplane, attended a sleep-study in the hospital, gone to a yoga class, and visited the San Diego Zoo. He even went trick-or-treating on Halloween and displayed impeccable manners at Thanksgiving dinner in California!

Flat Charlie will be back in South Carolina in May 2013, before heading for his final destination in July.

If you are interested in joining the Flat Charlie team, please contact Minnie Lambert at mllambert123@yahoo.com.



LET'S HEAR FROM YOU!

Submissions for the Spring 2013 edition of *CHARGE Accounts* are due by **March 15th**. 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/>

CHARGE in the News

May We Help

May We Help is an organization based out of Cincinnati, Ohio, that engineers and builds devices for people with disabilities to enhance their lives at no cost to them. Read more about this generous organization at:

<http://cincinnati.com/blogs/considerthisclermont/2011/07/01/may-we-help-volunteers-engineer-solutions-for-disabilities/>

You can also visit their website at <http://www.maywehelp.org>.



CHARGE in the News (cont.)

Donating for CHARGE

Bill Steinhauser's annual Toys for Tots drive and semi-annual push for the CHARGE Syndrome Foundation have come to be recognized as two ways of doing business at his family's local hardware store. Read more about Bill's efforts at:

<http://oakforest.patch.com/articles/touched-by-an-angel-save-energy-save-a-kid-too>

Also, the following YouTube clip on DuPont's involvement in the construction of Ronald McDonald Houses features Bill's wife, Deanna, and their son Dominic, who has CHARGE syndrome. Deanna talks about the role that the Ronald McDonald House has played in her family's life.

<http://www.youtube.com/watch?v=RueGecVUyDc>



A Poem for Jesse

View this touching YouTube clip in which a girl reads a poem she wrote about her friend, Jesse, who has CHARGE syndrome.

<http://www.youtube.com/watch?v=WGwjNKjkHol&>

Photos of Sydney CHARGE Conference 2012

The CHARGE Syndrome Association of Australasia held its 2012 conference on September 29th and 30th. You can view photos of the conference at:

<https://picasaweb.google.com/104420516585450424226/SydneyCHARGEConference2012>

For full-size versions of the photos, please contact paul.bartlett@chargesyndrome.org.au.

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USA

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Toll Free: 1-800-442-7604
Fax: 516-883-9060

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Director of Outreach

Sheri Stanger

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Fax: 914-478-1204

Email:

sheristanger@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

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Thank You

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In Honor of Andrew Boehi
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In Honor of Barbara Heymach
 Leah Enright

In Memory of Ceila Posner
 Emma & Eli Bluestone

In Honor of Christian Roberts
 Bekkie Cobb

In Honor of Christopher Clayton
 Gilbert & Gini Floyd

In Honor of Colleen O'Toole's 50th
 Nora Hennessy

In Honor of Colton Conner
DeVerter
 Margie Cunningham

On the Special Occasion of the 5th
Annual Mustache Party...in honor of
Eli Klinghofer!!!
 Stacey Wolfe

In Honor of Emilee Hullings
 Peggy Darczuk

In Honor of Erika Feather
 Marc Sigismondo

In Memory of Grayson Shephard
 Donna Peak
 Susan Wiley

In Memory of Jaycee Biscamp
 Shane, Katy, Rebecca, Jason, Cameron &
 Annabelle Carter
 Ellen McLean

In Memory of Joe Taylor (Joseph
Taylor)
 Ginger Avery & Jack Buckner – Alabama
 Civil Justice Foundation
 Pat & Jim Edelen
 Rob, Stacey & Noah Ellis
 Nancy & James Fawns (grandson Samuel
 Fawns)
 Linda Lipsen – Kentucky Justice
 Association
 Barbara Martin – Shelby County Schools
 Tammy & Christopher Rannells

In Memory of Joseph "Joe" D. Taylor
of Campbellsburg, Kentucky
 Timothy Lange – Benson, Risch & Lange

In Memory of Joseph D. Taylor (Joe
Taylor)
 Linda & Fred Cowan
 Gay Dwyer
 Mary & Phillip Fawns
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 Robert Sanders – The Sanders Law Firm
 Schachter, Hendy & Johnson, P.S.C.
 Linda & Stephen Stoltz
 Angela & Tom Underwood
 Kathleen Wilson – National Association of
 Trial Lawyer Executives
 Kathleen Wooldridge
 Jeffrey Yussman

In Memory of John Thomas Chatham
III (Trey)
 Tom & Linda Hargis

On the Special Occasion of Kim
Packard & Joe Amato's wedding!
 Kara Herlihy

On the Special Occasion of Kimberly
Packard and Joseph Amato
 Margaret McConnell

Thank You

**On the Special Occasion of
Auntie Kimmie and Uncle
Joe's wedding**
Theresa Passmore

**In Honor of Kim & Joe's
wedding**
Annette Packard

**In Honor of Madeline
Wellard**
Scott Wellard

**In Honor of Mallory Ellen
Pigage**
Ellen Elliott

In Honor of Sammy!
Kimberly Packard

**In Honor of Steve Visoky's
50th birthday! Love, Aunt
Linda and Uncle Allen**
Linda & Allen Tennbaum

In Honor of Tyler Criswell
Greater Kansas City
Community Foundation
Sugar Lakes Foundation

**In Memory of Tyler
Matthew**
Elizabeth & Kurt Bodine

**In Honor of the Wolfe
Family**
Arlene Midkiff

**On the Special Occasion of:
Glad to see the website
works! Thanks for the
wonderful visit. Happy New
Year!**
Bernice Frisch

Charge It for CHARGE Tributes

**In Support of All Children
who overcome the
impossible!**

The Downs Family (Erika, Mike,
Justin & Lailah)

In Honor of Abigail
Juan Carlos & Christine
Fontaneda

In Honor of Aidan Lanting
Karen Sheehy

**In Honor of my AMAZING
granddaughter – Alivia Elaine
Roth!!!**

Valorie Hobson

**In Honor of my
granddaughter, Alivia Roth.
And in Memory of my cousin,
Anne Guettler**
Sally Roth

**In Honor of Chris, Corki,
Alaina and Alivia Roth**
The Benedetti Family

In Honor of Aman Mehta
Gerd DeBeer – DeBeer, Stokes &
Partners Inc.

In Memory of Ashley Martin
Lisa, Graeme & Kennedy Weir

In Memory of Ashley Rain
Kerri Anderson
Sarah Woodall

**In Memory of my beautiful
niece, Ashley Rain**
Melissa Crook

**In Memory of Ashley Rain
Memorial**
LeAnn Meeks

**In Memory of Ashley's 14th
birthday**
Jackie Haynes
Gail Vick

**In Memory of Ashley Rain, on
what would have been her
14th Birthday**
Minnie Lambert

**On the Special Occasion of
Ashley Rain. Happy 14th
Birthday!**
Melva Strang-Foster

**In Honor of Charlotte
Cosenza**
Paul Cosenza

In Honor of Cheyenne Brittell
Andy & Jodi Taggart

In Honor of Cheyenne
Lin Anderson
Melissa Trombley

**In Honor of Cleo, amazing
daughter**
Sandra Munoz

**In Memory of Colin Luke
Smith – my beautiful
grandson**
Mary Mills

**In Memory of Colin Luke
Smith**
Loretta Cypert – Lords & Ladies
CDC, Inc.
Mark & Rebecca Drummond
The Esteves Family
Doreen Gallagher
Melissa Garaio
Thomas Mills
Joanna & Matt Mulvey

**On the Special Occasion of
Colin Luke Smith – Happy
Birthday sweet boy! We all
miss you so much!**
The Chathams

**In Honor of Daniel's Bar
Mitzvah**
Corinne N. Darvish, Attorney at
Law
Barbara & Thomas Harris

**In Honor of Dominic
Steinhauser**
Deanna Steinhauser – Park Ace
Hardware

In Honor of Ethan Wolfe
Genevieve Bentley
Andrea & Brent Cantor
Joe & Mary DaVanti
Sharon Kleszynski
Rhonda Nussbaum
George Xamplas – Law Office of
George C Xamplas
Barry, Amy, Justin & Megan
Wallis

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

Thank You

In Honor of Ethan and his accomplishments

David and Jody Wolfe – The Law Offices of Wolf & Wolfe, Ltd

In Honor of Ethan from Change for CHARGE

David & Jody Wolfe – The Law Offices of Wolf & Wolfe, Ltd

In Honor of Ethan Wolfe. Best wishes and good luck!

Michael Sarcia – Kemper

In Honor of Ethan Wolfe. You rock!

Peter Moroh

In Honor of Ethan Wolfe and Family

The Fuchs Family

In Honor of The Wolfe Family

Jeffrey Alter
Rhonda Jensen
Lee Laudicina
Neal Strom – Strom & Associates
John Stuart – Better Business Planning Inc.
Michael & Susan Zelik

In Honor of The Wolfe family for all their wonderful efforts on behalf of so many

Steven Seidman

In Honor of The Wolfe family. Keep up the good work!

Peter Morse – Morse, Bolduc & Dinos

In Honor of The Wolfe Pack

Steven Salk

In Honor of beautiful & amazing Finley Roth

Valorie Hobson

On the Special Occasion of Finley's 3rd Birthday (better late than never!)

The Krezel Family

On the Special Occasion of Finley's 3rd Birthday!! A bit belated; Happy Birthday, Beautiful!

Liza Parke

In Honor of Andrew & Minnie Lee Lambert, the starters of the Flat Charlie Project

Ellen Howe

In Honor of the Flat Charlie Project and Minnie Lambert!

Wendy Keedy

In Honor of The Campbell Family participating in the Flat Charlie Project

Minnie Lambert

In Honor of Miss Ellen participating in the Flat Charlie Project

Minnie Lambert

On the Special Occasion of Flat Charlie's visit to San Francisco

David Brown – CDBS

On the Special Occasion of David Brown hosting Chaz

Minnie Lambert

On the Special Occasion of the Keedy family participating in the Flat Charlie Project

Minnie Lambert

On the Special Occasion of the Weir Family participating in the Flat Charlie Project

Minnie Lambert

In Honor of the Wendoll's participating in the Flat Charlie Project

Minnie Lambert

On the Special Occasion of Flat Charlie's travels around the globe... from the patrons of McKay's Wild Blueberry Farm Stand in Pennfield, NB

Lisa, Graeme & Kennedy Weir

In Honor of Jacob Hartshorne

Connie Spillers

In Memory of Joe Taylor – Family of Maresa & Randy Fawns, Samuel & Joseph

Suzanne Keith

On the Special Occasion of Joshua Kurby Charge for CHARGE 5K Avon Fundraising donations – from Avon Fundraising

Sandy Kurby

In Memory of Joshua Kurby. From Grandma, with love

Denise D'Andrea

In Honor of Kennedy Weir

Sheri Moore

Christina Taylor

In Honor of Kristin Ogan

Judy Espinosa

Thank You

In Honor of Lacey Suter

Nancy Fleming
Joseph Ward

In Support of Lacey Suter

Gwendoline Grant

In Support of Lacey

Robert & Yvonne Brooks

In Honor of Max McKinley

Shelley Capito
Ernie Dellatorre – McKinley &
Associates
Suzanne Holman

In Honor of Megan Stanger

Richard Frank
Bill & Cindy Nibur
George Stephan

In Honor of Megan

Carol Balik
Suzanne Page
Sheri & Neal Stanger

In Honor of Megan Stanger.

We love you, Megan!
Alison Gencarelli

In Honor of our dear granddaughter Megan!!

Linda & Allen Tennbaum

In Honor of Megan Stanger. Wishing you the best!

Mark & Elaine Plansky

In Honor of Megan Stanger!

We love you and are so proud of you and your parents for all that you do for the CHARGE community!

The Walter Family

In Honor of Meredith Dwyer

William Dwyer

In Honor of The Amazing

Mia Menconi
Kara & Adam Graper

In Honor of Mia Menconi

Nishant Bubna – Houlihan Lokey
Patti Komara – Patti's
All-American
David Lewis
Jackie Staton

In Honor of Mia Menconi, the child who is so loved by her parents, Tina & Rik
Patrick & Nancy Hurst

In Honor of Mia

Scott Jackson

In Honor of Mia, our miracle baby!!!

Debbie & Larry Senffner

In Honor of My Little Monkey...Mia Menconi!

Rhonda Zaluckyj

In Honor of Mia, Tina and Rik Menconi

JoAnn & Ed Fouts

In Honor of Rik, Tina & Mia Menconi

Kapil Jatindarya

In Honor of The Menconi Family

Gary Brewster

In Honor of Rik, Tina and Mia, always in my thoughts

Lori Cazel

In Honor of Mr. Lopez, Pace High School

E. Ruth Villarreal

In Honor of Noah Ashton

Mary Ashton

In Honor of Savannah Tyler

Audrey Griffin

In Honor of sweet little Savannah Tyler!!

Hana Lynch

In Honor of Sweet Savannah, who always warms my heart

Sara St. Clair

In Honor of my princess Savannah Elizabeth Tyler

Emma Reeves

In Honor of Sweet Savannah, with the beautiful smile.

From the Hailes' and the Duke's! We love you!!

Hailes' & Duke's

In Honor of Sean Campbell

The Campbell Family
Ruth Campbell

In Honor of The Campbell Family

Stacey Adams

In Honor of Taliah Wendoll

Michael Heiman
Donna & James Wendoll

In Honor of Taliah Wendoll & Flat Charlie

Barbara Heiman

In Honor of Taylor – We love you Taylor! From all your friends at Tradition Bank

Carol Bonaccorso – Tradition Bank

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!