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President's Message

By David Wolfe

My kids have returned to school! The challenge of keeping our children busy, adjusting to life without a set schedule, and cramming in numerous doctors' appointments has been replaced by hectic mornings, afternoon activities, and nightly homework rituals. This time of year serves to remind me that life, with or without a child with CHARGE, is always busy. We have so many demands on our time. It is often difficult to fathom taking on one more project or task.



We are fortunate to have many people take the time to add the Foundation to their "to-do list." Whether you wrote an article for the newsletter, volunteered at conference, participated in a previous Charge It for CHARGE campaign, served on a committee, hosted a fundraising event, or helped out in many other ways, we greatly appreciate EVERYONE who gets involved. Our members and volunteers are the lifeblood of the organization.

The Foundation has only two part-time employees. Someday we hope to be able to expand. We are managed and run by dedicated individuals who receive no compensation for their efforts. For those of us who choose this path, it is a true labor of love. All we want is to see the Foundation continue to grow and better serve all individuals with CHARGE. We cannot do it alone.

These last three months in 2012 will set the stage for what we can accomplish in 2013. Please carve out a little time to make sure the Foundation will thrive in 2013. What can you do? Write an article for the newsletter. Help create awareness materials. Participate in our 5th Annual Charge It for CHARGE campaign(<http://FifthAnnualCIFC.kintera.org/>), or host an event to benefit the Foundation. Become a member and donate as generously as you can. Volunteer to serve on a committee or help with conference. Be as creative as you can. The possibilities are endless.

Let's ensure that 2013 is a spectacular year. With your help we can sponsor more research, host more webinars, hold our best conference yet, and so much more.

With your help, IT CAN BE DONE!

How I Spent My Summer Vacation

By Sheri Stanger, Director of Outreach

I hope that everyone had a restful summer and time to unwind with your families. We all need that opportunity to recharge (no pun intended) our batteries so we can continue to be effective advocates for our loved ones with CHARGE syndrome. While I was able to grab a bit of family vacation time with my crew, I had the opportunity to spend time at various deaf-blind related conferences during the month of July. It was a lot of traveling, but it inspired me to do more as an advocate. I also learned more about supports for our children.



“...it was clear that
Interveners is the hot
topic.”

My conference hopping began with a 6-day trip to Austin, TX, for the NFADB Symposium on Individualized Supports for People with Deaf-Blindness. With the Texas School for the Blind being our fabulous host and more than 100 family leaders, people who are deaf-blind, and professionals in the room, it was an intimate setting in which to learn, discuss, and action plan for individualized supports for our children across the age span. While the topics were focused on Interveners, Interpreters, and Support Service Providers (SSPs), it was clear that Interveners is the hot topic. We learned of the new parent booklet, *A Family's Guide to Interveners for Children with Combined Vision and Hearing Loss*. To learn more about Interveners and how to obtain this free publication, please visit <http://intervener.org>. It was amazing to meet and reunite with such a wonderful group of family leaders, consumers, and professionals. If we all share information and ideas together, we can improve the lives for all people with CHARGE syndrome and deaf-blindness.

I continued my travels to Washington, D.C., for the Deaf-Blind Project Director's Meeting on Sunday, July 22. While this meeting is intended for federally funded projects such as the National Consortium on Deaf-Blindness and the State Deaf-Blind Projects, a few parents were invited to represent family organizations and the family voice. Once again it was wonderful to reunite with the professionals in the field of deaf-blindness with whom I often work and speak. I had the opportunity to do a panel presentation entitled *Deaf-Blind Network Collaborations in Action: Family Engagement and Leadership*. I discussed the collaborative efforts of the CHARGE Syndrome Foundation with this roomful of people to greater advance the mission of the Foundation. In addition, I was able to schmooze with the wonderful new cohort of HKNC Fellows—the future educators in the field of deaf-blindness.

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How I Spent My Summer Vacation (cont.)

Although driving and flying were becoming tiresome, I still had one more trip. I was asked to represent the CHARGE Foundation at the NAPVI (National Association for Parents of Children with Visual Impairments) conference, *Families Connecting with Families*, in Newton, MA, from July 27–29. With the help of board member Pam Ryan, we set up a CHARGE booth in the exhibitors' hall where I was able to connect with new parents, meet some old friends, and educate others about the Foundation and the complexities of CHARGE syndrome. I ran a breakout group for families who have a child with CHARGE syndrome and presented on a transition panel for people who are visually impaired with multiple challenges. My daughter, Megan, sat on the panel with me and two other moms with their young adult sons. We were asked questions about our transition plans and our hopes for the future.

While a major part of my role as Director of Outreach for the CHARGE Syndrome Foundation is working to support, inform, and connect families, another aspect of my job is to work collaboratively with professionals. This summer afforded me the opportunity to do both in face-to-face settings. This was a real treat to be able to personally connect with new families, family leaders, and professionals in one summer. Now we must utilize these connections to work effectively and collectively so we can improve the lives of our children with CHARGE syndrome. I hope your summer travels—whether they were near, far, or virtual—afforded you the chance to connect with interesting people who will help enhance the lives of your children. As always, I look forward to connecting with you, learning about your families, and hearing your ideas to improve the lives of people with CHARGE syndrome.

Social Skills: Social Stories and Video Modeling

By Lori A. Swanson

“This (social) problem is too big for me! I just can’t figure it out!” a child said to me. Some social situations that children face are daunting and cause the child distress. Although children with CHARGE syndrome are very social, they tend to struggle with the nuances of everyday interactions. Parents, teachers, and speech–language pathologists need tools to facilitate children’s understanding of social situations and their conversational skills. Two intervention techniques include **social stories** and **videotape modeling**. These intervention procedures are easy to implement and readily available. Both techniques are routinely used with children who have autism spectrum disorder (ASD).

“Now we must utilize these connections to work effectively and collectively so we can improve the lives of our children with CHARGE syndrome.”

“Although children with CHARGE syndrome are very social, they tend to struggle with the nuances of everyday interactions.”

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"It is imperative that we provide our children with the language for all social situations, particularly those which are rarely discussed."



Social Skills: Social Stories and Video Modeling (cont.)

Social stories provide children with ways to handle everyday social situations. Each story includes a series of pictures (e.g., photographs or black-and-white drawings) as well as written text. The Gray Center (<http://www.thegraycenter.org>) provides a short video of Carol Gray describing the components of a social story as well as several examples. Carol believes that one-half of social stories used with a child should involve situations they handle well, whereas the other half can address situations in which they struggle. The basic format of a social story is 1) description of problem, 2) solution, and 3) positive outcome if solution is followed. It is important to write the social story at the child's comprehension level to promote understanding of the situation.

Two additional resources for social stories include <http://www.positivelyautism.com/free/09social.html> and stories by Tania Kraus related to manners (<http://tp053.k12.sd.us/Manners.htm>), friendship (<http://tp053.k12.sd.us/Friendly.htm>), and being at school (<http://tp053.k12.sd.us/Following%20Rules%20at%20School.htm>). Some of these stories are of situations we feel comfortable discussing, while others are of more unnerving topics. It is imperative that we provide our children with the language for all social situations, particularly those which are rarely discussed. They need to practice responding to "peer pressure" and "rejection" as well as accepting a compliment graciously. Although premade stories can save time, parents and educators can compose social stories that are unique to situations faced by their child.

Videotape modeling involves having the student watch video clips of the target behavior (e.g., saying "no" to peer pressure). Two primary advantages of video modeling are that the clips can be shown several times and the clips are relatively short. The footage can be of the student or another child in a social situation. iPads and iPods allow educators/parents to capture students in everyday social situations with little effort. Commercially available video clips (e.g., <http://www.socialskillbuilder.com>, <http://www.watchmelearn.com>) can save "filming" time, but then the educator may need to search for clips that best match his/her student's needs.

After the student watches the clip, the child then critiques him-/herself or another child in that situation. It is important for the student to feel safe during the evaluation process. The parent/educator should help the child notice the positives! Difficulties with the target behaviors can then be discussed. Allowing the student to "self evaluate" allows for generalization of the target behavior to all social situations. Ideally, the child should watch several different videos of the same target behavior to avoid rote learning of the target behavior in one context.

Reference for social story websites: Kuster, J. M. (2012, January 17). "Internet: ASD Social Skills Websites." *The ASHA Leader*.

National Family Association for Deaf-Blind 2012 Symposium

By Patti McGowan, Secretary

The National Family Association for Deaf-Blind (NFADB), originally started by and for families of individuals who are deaf-blind, now extended to all persons and organizations that wish to support individuals and families who are deaf-blind, held its first National Symposium July 13–15, 2012, at the Texas School for the Blind and Visually Impaired in Austin, TX.

Fifty-one family leaders and four self-advocates from 24 states; Washington, D.C.; and Puerto Rico attended the 2012 NFADB Symposium, *“Preparing Leaders for Today and Tomorrow: Family Leadership in the 21st Century.”* The overarching goal of the Symposium was to give family leaders the understanding and knowledge needed to be effective in advocating for individualized communication supports. These supports are necessary to allow individuals with deaf-blindness equal access to auditory, visual, and environmental information that is often not accessible to them.

The leaders were given information on three crucial individualized supports for those with deaf-blindness: Interveners, Interpreters, and SSPs (Support Service Providers), and how when properly trained, these supports can dramatically enhance life for someone with deaf-blindness. At the end of the Symposium, the family leaders were asked to identify their vision for individual supports for a person with deaf-blindness. They addressed not only their personal vision, but also what they would like to see happen at the local, state, and national levels. The theme of collaboration and leading other parents in advocating for individualized supports became universal at the NFADB 2012 Symposium.

The National Family Association for Deaf-Blind is a nonprofit 501(c)3 organization which exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs. If you would like more information regarding NFADB, or are interested in membership, please contact NFADB at 1-800-255-041 or NFADB@aol.com.



“The theme of collaboration and leading other parents in advocating for individualized supports became universal at the NFADB 2012 Symposium.”

Bipartisan Action Offers Rare Disease Patients Hope

Excerpted from NORD Press Release

By Mary Dunkle, Vice President, Communications, NORD

Millions of Americans who have serious rare diseases and no treatment may face a brighter future as a result of an act signed into law on July 9, 2012.

“We salute the Senate for decisive and bipartisan action in approving the FDA Safety and Innovation Act (S. 3187),” said Peter L. Saltonstall, president and CEO of NORD (National Organization for Rare Disorders). “And we applaud the House of Representatives for approving in a similarly bipartisan manner the House version of this bill.”

Saltonstall said the legislation provides broad-ranging and innovative measures to speed the development of safe and effective treatments for people who desperately need them. “Only about 250 of the nearly 7,000 diseases considered rare in the U.S. have therapies,” he said. “But treatments are desperately needed because most rare diseases are serious, many are life-threatening, and about two-thirds of the patients are children.” He added that “NORD and its members have worked long and hard to raise awareness of the challenges of living with rare diseases. We are grateful for the hard work and thoughtful deliberation that both the House and Senate have brought to this process.”

Among others, some features of the bill that Saltonstall said were especially important to NORD and the rare disease patient community include:

- enhancing accelerated patient access to new medical treatments
- encouraging the development of Humanitarian Use Devices, or medical devices for small patient populations
- providing for accelerated development of “breakthrough therapies”—or ones that show early promise
- enhanced consultation with rare disease medical experts
- a rare pediatric disease priority review voucher incentive program

The new law is the result of a process that has been underway for nearly two years and for which NORD has provided significant input, the reauthorization of the Prescription Drug User Fee Act (PDUFA). This legislation, which authorizes the Food and Drug Administration (FDA) to collect user fees from companies seeking to have products reviewed, must be reauthorized every five years.



“...treatments are desperately needed because most rare diseases are serious, many are life-threatening, and about two-thirds of the patients are children.”

Research, Research, and More Research

By David Wolfe

In 2011, the CHARGE Syndrome Foundation established its first Scientific Advisory Board to serve as a scientific resource, assisting in the identification, funding, and development of scientific research projects. Thanks to a year of strong fundraising efforts, the Foundation was able to offer pilot grants. Proposals for the grants were submitted in late 2011 and early 2012. All proposals were carefully reviewed by our Scientific Advisory Board. The purpose of these grants is to promote new biomedical research into the etiology, genetic, and molecular mechanisms and treatment of CHARGE syndrome. Proposals could be in any area of basic, clinical, translational, or epidemiological research. Preference was given to investigators who are new to CHARGE research and to projects with clear potential to lead to future funding from other agencies.

The Foundation was pleased to award four 2012 pilot grants. The grant period runs from May 1, 2012, to April 30, 2013. The following is a list of the grant recipients and their projects.

Ching-Pin Chang, M.D., Ph.D., Stanford University School of Medicine

Project title: Heart development and CHARGE syndrome.

Kelvin Y. Kwan, Ph.D., Rutgers University

Project title: Identification of molecular markers to determine cochlear implant candidacy in CHARGE syndrome.

Robert Hevner, M.D., Ph.D., University of Washington

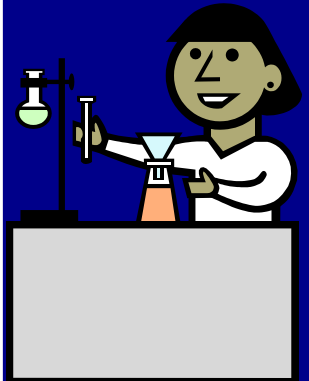
Project title: Cerebral cortex development in a mouse model of CHARGE syndrome.

Elizabeth A. Hurd, Ph.D., and Adam B. Stein, M.D., University of Michigan

Project title: Investigating the role of CHD7 in neural crest lineage cells.

We are also happy to announce that Drexel University is hosting a CHARGE syndrome mini-symposium on November 2, 2012. All members of our Scientific Advisory Board, some of the 2012 pilot grant recipients, and other researchers and scientists will attend this meeting. These collaborative efforts will only help to strengthen CHARGE-related research.

Your Foundation is committed to continued support for research. As additional money is available, we will request proposals for a new round of pilot grants. We look forward to receiving updates on CHARGE-related research at our 2013 conference. If you have any questions about CHARGE research and our selection criteria, or would like to help fund additional grants, please contact me at david@chargesyndrome.org.



"Your Foundation is committed to additional support for research."

Conference Funding

By Melva Strang-Foster

Can you believe that it's October already? It is now less than a year until our next CHARGE Conference in Scottsdale, AZ!

Our Yahoo! listserv and Facebook pages are being peppered with excited chatter about this conference. We are also seeing some concerns about being able to afford the full cost of attending the conference. In response to these concerns, the Board has taken to the Internet to seek sources that you might be able to tap into for help in funding your trip. We have identified a number of organizations that offer grants to individuals and families of children with developmental disabilities.



Our primary source of information was the *Wonder Baby Newsletter* published by Perkins Institute (<http://www.wonderbaby.org/articles/ipad-funding-special-needs> and <http://www.wonderbaby.org/articles/conference-fundraising#proposal>). The first link provides some wonderful information on resources for money to purchase specific items such as iPads—insurance companies, schools, local charities, fundraisers, and grant applications to specified organizations.

The second link gives more great hints on how to go about getting a sponsor/advocate and writing a successful proposal letter to request financial aid for attending a conference. Using this article as a guide, we developed a [sample letter](#) specifically focusing on obtaining funding to attend the 2013 CHARGE conference. We hope that you will find it a good starting place for writing your own letters. We also created an [Excel spreadsheet](#) that you can download from the CHARGE Syndrome Foundation's website to calculate your family's travel and conference costs. This spreadsheet will allow you to create a document to attach to your letter that shows your detailed, categorized, conference-related expenses.

Using the lists of organizations found in these two *Wonder Baby* articles, we exercised our online search engines to learn more about them. In all, we researched over 40 organizations that have offered grants to individuals and families. Some have significant geographic limitations or require membership in specific ethnic groups, while others have national and international service coverage. We attempted to [summarize information about these agencies](#), including how to contact them, specific information about their grant processes, and their application deadline dates (where available), in a list. The first section of this list shows organizations that serve the entire United States. The second section is sorted by state abbreviation to help you find organizations that serve your state, and in some cases specific counties within a state. The last page lists agencies that serve internationally.

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"In all, we researched over 40 organizations that have offered grants to individuals and families."

Conference Funding (cont.)

Now it is **your** turn. This is how I would get organized to apply for one or more grants to attend the conference:

1. Start **NOW!**
2. Carefully read both *Wonder Baby Newsletter* articles referenced on the previous page.
3. Print a copy of the second article, ***Beyond Bake Sales: How to Raise Money So You Can Attend a Family Conference***, to use as a quick reference.
4. Find a sponsor/advocate for your family, as recommended.
5. Do your financial homework. Go to **Hotwire**, **Priceline**, and similar sources to get a sound estimate of your airfare costs. Will an airport shuttle meet your needs, or will you need to rent a vehicle? If you plan to rent a vehicle, use these same websites to get estimates for the cost of the rental and factor this into your transportation costs. Are you a lifetime member of the Foundation? If so, this will reduce your conference registration fees by 10%. Download the [Excel worksheet](#) from the Foundation's website to calculate your family's cost to attend the conference. You will need to provide this documentation with your grant requests.
6. Download the [list of granting agencies](#) from the Foundation's website and read it carefully.
 - a. Identify the agencies that you want to contact.
 - b. Go to their websites and read them carefully. Make note of their application requirements. (Do you need to submit proof of financial need? Do they require letters of reference from professionals to substantiate your need for conference attendance? Etc.)
 - c. Assemble the required supporting documentation and have it ready when each agency opens its application period. Create a separate file folder for each agency and keep your documentation in that folder. Do NOT wait until the application period starts to begin this project.
 - d. Mark your calendar with the dates on which you can apply, and carefully follow the instructions when you assemble your package for submission. **Hint: Don't get your request rejected on a technical or clerical oversight, such as missing a deadline or not including requested information!**
7. Download the [sample grant proposal letter](#) from the Foundation's website. Use it as a starting point to create the one you will use for your family's needs.
8. Send this letter to as many agencies as are available in your city, state, and region. This might result in partial funding from multiple agencies that can add up to 100% funding of your costs.

Continue with plans for fundraising and feeding piggy banks to save money for the conference, but don't overlook the possibility of securing one or more grants to help cover those expenses, too. Even if a letter you send doesn't result in financial aid for the conference, it has served another purpose: educating people about CHARGE syndrome and how it affects the individual and their families.

Good luck with your grant applications! See you in Arizona in July!



"Do NOT wait until the application period starts to begin this project."

Conference Funding (cont.)

SAMPLE GRANT REQUEST LETTER

Organization's Name
Organization's Address
Date

Dear _____:

I am writing to ask for your financial assistance in providing necessary travel and conference funding so that I (or my family and I) may attend the **11th International CHARGE Syndrome Conference, to be held July 25–28, 2013, in Scottsdale, AZ.**

I (or my son/daughter) was born with CHARGE syndrome. CHARGE syndrome is a recognizable (genetic) pattern of birth defects that occurs in about one in every 9–10,000 births worldwide. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. In our case, CHARGE has affected me (my child) in the following ways: [Insert a description of the physical, behavioral, and educational challenges encountered and what you/your child have done to overcome them]. *(Hint: Try to focus on the positive aspects, not the negative. You aren't asking for sympathy; you are asking for funding to help you do something positive related to CHARGE.)*

Because the syndrome is so rare, the CHARGE families are often widely dispersed in each state and most only have the opportunity to meet at these conferences. This is where we interact and meet with other families and a wide range of professionals from all over the world who are knowledgeable of CHARGE syndrome and its medical, educational, social, and developmental challenges. For most of the people diagnosed with CHARGE, the conference represents their only chance to interact with same-age peers who also cope with similar challenges.

Furthermore, this conference is designed to support our entire family. Not only does the conference provide “camp” experiences for children born with CHARGE and their siblings, but it also offers “Sibshops” for their brothers and sisters 8 years and older while their parents attend conference sessions. Sibshops often give siblings their only opportunity to share with peers and trained counselors about their life experiences and the emotions that stem from having a family member who has multiple physical and developmental disabilities specific to CHARGE.

The CHARGE Syndrome Conference always provides information on cutting-edge medical, educational, and behavioral research and provides an opportunity to speak directly with the researchers regarding ways to apply their research specifically to my/my child's needs. It strengthens our family's bond with the worldwide CHARGE community of individuals and families who strive daily to deal with the challenges that CHARGE syndrome brings. Cross talk with others with CHARGE (or other parents of children and young adults with CHARGE) is invaluable.

The cost for me/our entire family to attend the conference will place a significant financial burden on me/our family. The detailed costs of attending the CHARGE Syndrome Conference are detailed in Attachment 1. I/We have also applied to [list other agencies you have contacted] and have held/plan to hold fundraisers to help defer these costs, but we [describe the remaining gap between the costs and your resources].

After the conference, I will be happy to share information I gain from attending with your organization. I would be happy to speak to your group following the conference with a description of the program and to share information about multi-sensory impaired children/adults in general. I also hope to gather other parents in the community after the conference so that I can share the many things I learned.

You can contact _____ at _____ to obtain additional information about me/my family and how beneficial attending this conference will be. [Note: If you include this sentence, you should have already contacted a teacher, therapist, physician, etc. who has agreed to serve as your sponsor/advocate.] You can also view more detailed information about CHARGE syndrome and the conference at the CHARGE Syndrome Foundation website (<http://www.chargesyndrome.org/conference-2013.asp>). My contact information is as follows: [add your contact information].

Sincerely,

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Conference Funding (cont.)

Attachment I						
Detailed Costs to Attend the CHARGE Syndrome Conference						
(Sample—use the Excel worksheet to create your own)						
Plane tickets via [Airline] will cost:	\$400.00	×	4	=	\$1,600.00	\$1,600.00
			(number of people flying)			
Shuttle/Taxi fare from the Phoenix airport (round trip):			\$80.00		\$80.00	\$80.00
Total Transportation Costs						\$1,680.00
Conference Registration* is:	\$250.00	×	3	=	\$750.00	\$750.00
	Per person attending conference/camp					
	\$175.00	×	0	=	\$0.00	\$0.00
	Per person 15 and younger not attending camp					
	\$0.00	×	1	=	\$0.00	\$0.00
	Per person with CHARGE					
Subtotal Conference Costs						\$750.00
Less 10% for Lifetime CHARGE Syndrome Foundation Members						(\$75.00)
Total Conference Costs						\$675.00
Hotel costs at the Scottsdale Fairmont Princess conference center will be:	\$109.00 per night	×	3	=	\$327.00	\$327.00
			(number of nights)			
Total Hotel Costs						\$327.00
Grand Total for Attending the CHARGE Syndrome Conference						\$2,682.00

*Registration fees include “camp” activities for preteen children and conference sessions for adults and teens over age 15, plus breakfast, lunch, dinner, and snacks on Friday and Saturday and breakfast on Sunday.

Call for Presentations

The CHARGE Syndrome Foundation is seeking proposals from presenters and speakers for the 11th International CHARGE Syndrome Conference, which will take place July 25–28, 2013, in Scottsdale, AZ. The conference serves as a venue to provide information to individuals with CHARGE syndrome, their families, and professionals. The event begins with Professional Day, followed by 2½ days for the full conference. While there are various opportunities to make presentations, presenters are urged to present at both Professional Day and the full conference.

For more information, go to <http://www.chargesyndrome.org/documents/2013cfp.pdf>. The deadline for submission is November 1, 2012.



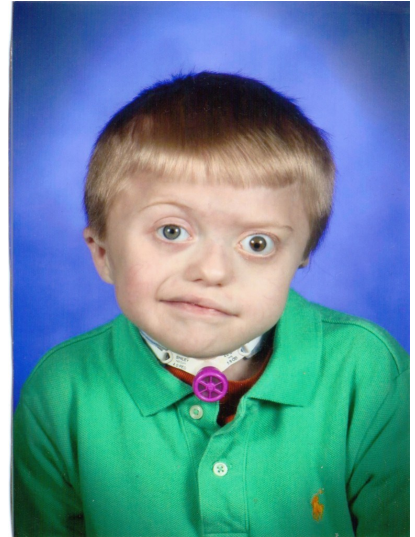
Profiles and Updates

Noah Goodman

By Sondra Stewart Nimety

Noah Michael Cameron Goodman was born on January 15, 2004, in Johnson City, TN. He received a clinical diagnosis of CHARGE syndrome in April of that year. Since that time, Noah has gone through many surgeries and illnesses. But despite his difficulties, he has grown into a charming 8-year-old with loads of personality flavored with endless humor. Determination is definitely his most outstanding attribute.

Noah attends second grade in an inclusive/regular education classroom. He loves pretend play, watching TV, and playing games on his iPad. He has two brothers, Seth (22) and Austin (17), and two sisters, Lara (24) and Alyssa (11). Noah has one nephew, Cole, who is his “partner in crime.” Noah doesn’t have a pet of his own but dreams of someday owning a bird. He resides with his family in Southwestern Virginia.



Amélie Chan

By Lesley Chan

Our daughter Amélie was born seven years ago with CHARGE syndrome. According to professionals, she probably would not survive the early years or achieve much in life. One referred to her as “seriously neurologically impaired and in a vegetative state.”



This is Amélie zip-wiring alone from the ADULT zipwire, not once but twice after she signed “again” once she first landed. If I am honest, I was anxious on the ground, watching to make sure the harness had not whipped out her tracheostomy, but Amélie didn’t appear fazed at all. My husband was not too thrilled that he had to walk up the million stairs to the top of the tower with her a second time to jump. He said he was knackered, but when our girl wants another go of anything, there is no such word as “no.”

Life is for living and letting our children achieve everything their siblings and/or friends do. It’s sometimes just a case of “in their own time.” We buzz off our girl’s enthusiasm and zest for life.

Profiles and Updates (cont.)

Brady Antaya, Five Years Later

By Cynthia Antaya

Five years ago, on July 13, 2007, our son Brady made his long-awaited arrival into the world. As with most children with CHARGE syndrome, the event did not come smoothly. He was born at 34 weeks' gestation via an emergency c-section. Many of our CHARGE family members know Brady's history, and know that after his birth I was also diagnosed with CHARGE syndrome at age 27.

We were told on July 14, 2007, to expect the worst with Brady. He might never talk, walk, eat with independence, or moreover, recognize us as his parents. Keith and I just looked at each other quite frequently after receiving this news and tried to put two and two together. How could a geneticist tell us that I had CHARGE syndrome and that Brady, having the same diagnosis, would never do the things I could? I have a specialist degree in School Psychology, am a National Certified School Psychologist, and hold a full-time position in the field. Keith, with his background in special education, said from the get-go, "We're never going to give up." "Never give up" seemed to take off as our motto from then on.

We've faced numerous medical challenges with Brady over the last five years, including nine surgeries (he will have surgery number ten in October of this year), most of which involved repairing his choanal atresia again and again because of scar tissue. He's had so many cases of pneumonia that we've lost count. For nearly three years, Brady aspirated all thin liquids and required SimplyThick. Brady contracted the 2009 H1N1 flu, despite being vaccinated, and was hospitalized for five days in the intensive care unit. He's been in and out of the hospital all five years of his life.

However, all of the things that we were told he would never do, Brady has far surpassed. He orally spoke his first word at 13 months. He started walking at 19 months. His eating is nonstop, and in June of 2011 he was cleared to consume thin liquids again. Brady is so proud of his independence.

Brady just recently started kindergarten at a local charter school where he is fully included in a general education kindergarten setting. He receives services from a teacher for the deaf, occupational therapist, and speech-language pathologist. He uses an FM system with his hearing aids each day. Brady loves school and is so eager to learn how to read. We love that he comes home each day and tells us all about his experiences. He is so animated in his conversation, and the excitement he experiences when he tells us all that is going on in his life just lights up his eyes.

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Profiles and Updates (cont.)

We simply could not ask for a better outcome given that dire talk the geneticist had with us five years ago. It goes to prove that doctors should not label a child based on a condition. The child has to be allowed room to grow and prove differently. We provided Brady with all of the services he needed from the start, and now we just continue to live with our “never give up” perspective, waiting to see what Brady will do next.

CHARGE and Me

By Ellen Howe

My name is Ellen Howe. Many of you already know me, but I thought I would introduce myself to any newcomers to our CHARGE family. I am 27 years old and live in Australia with my mum, dad, brother, his wife, and their cat Minni. I was born with a cleft lip and palate; colobomas (I have 6/60 vision); and hearing loss, for which I wear a Baha soft band. Thankfully, I wasn't born with any heart problems, though. When I was 18 years old, I had my gall bladder removed, and have also had a few other surgeries.



Being a person with CHARGE syndrome can be difficult, but I am generally very positive and happy. I have many friends and family I am close to. Last year, I was able to make some new friends at the CHARGE Conference in Orlando, FL. I am looking forward to attending next year's conference in Scottsdale, AZ, and hope to see everyone there!

I attend a day program at Northcutt Disability Services three days a week. My favorite activities there are art, swimming, and gardening (I'm quite dangerous with a garden hose! LOL). I also attend a sheltered workshop two days a week where I package various items.

Currently, I am working on a PATH, which is basically the same as an IEP but with more focused goals. One of my goals is to become a “person-centered champion,” which means I will be helping people at Northcutt Disability Services and in the community be more person-centered and focused on themselves. As a person with CHARGE syndrome, I think this is a good thing since, as we know, a lot of people with CHARGE syndrome need to feel in control of what they are doing. Through being a person-centered champion, I also plan to be an advocate for CHARGE syndrome.

Profiles and Updates (cont.)

Gannon Mosely

By Sara Mosely

Meet Gannon, our 3-year-old guy with CHARGE syndrome. He has many challenges, but he perseveres through it all. Like many others with CHARGE, he has a long list of medical conditions, but I'd rather not focus on that. I'd rather share with you his strengths and triumphs. He has so many!

Gannon attends a preschool for deaf and hard-of-hearing children. He is excelling and is really a model student! He looks forward to school every day and has made lots of friends. He works hard using sign language to sing songs and communicate in other ways. He does everything that is asked of him. Most recently he was calendar helper, and it brought me much joy to see him help out the teachers in this special way.

Gannon is such a great learner in so many respects. He picks up sign language very quickly and has a vocabulary of around 300 words! Recognizing all the letters in the alphabet is a breeze for him. He is so patient with all his medical procedures—allowing the nurses and doctors to listen to his heart and lungs, getting suctioned, receiving his nebulizer treatments, checking his oxygen saturations with his pulse oximeter probe, wearing his oxygen nasal canula, and taking his g-tube feedings.

Gannon has made huge progress in the way of his health as well. He remained out of the hospital for over a year. He still gets ill at home frequently, but he is able to overcome it and receive home treatment. His mobility has improved tremendously, as he's able to navigate our home without his walker. Outside our home, he is able to get around quite well with his walker, starting and stopping and going up a single step.

I'd like to end this with some of Gannon's favorite things in life. They include going everywhere he possibly can with the family, which includes a lot of his brothers' football/baseball/basketball games. He enjoys his home life a lot, too. His time at home is spent keeping up with his brothers, Dylan and Ian. He likes to wrestle with them, play hide-and-go-seek, watch TV (SpongeBob and Mickey Mouse), and just play with toys. Life, in general, seems to be a favorite of Gannon's! He wakes up each day ready to enjoy it, overcome the hurdles, and bring joy to everyone around him. I hope that one day some of you can meet him!



In Memory

By Ellen Howe

On June 22, 2012, the CHARGE syndrome community lost a very special member. Crystal Masionis passed away at age 35 from metastatic melanoma. Many know her as “Eva’s mummy” from Illinois. Crystal was a supportive member of the CHARGE community, always taking the time to share in others’ joys and challenges. Crystal often contributed her time to educating others about CHARGE syndrome and raising money for the Foundation, organizing “Bowling for CHARGE” and other benefits as well as making and selling bracelets. Crystal leaves behind her husband, Dan; two sons, Alex and Bailey; and a daughter, Eva.

Rest in peace, Crystal. You are missed within the CHARGE family.



CHARGE Foundation Store

In partnership with Creative Promotional Products, Ltd., the CHARGE Syndrome Foundation store is now open. The store offers everything from clothing apparel to drinkware to home and office supplies.

You can reach the store either through the CHARGE Syndrome Foundation website or directly through this link:

<http://chgsyndpromo.creativepp.com/>. Logo merchandise helps create awareness (and the Foundation receives 25% of the purchase price). Wear and use your CHARGE merchandise with pride.



LET'S HEAR FROM YOU!

Submissions for the Winter 2012 edition of *CHARGE Accounts* are due by **December 1st**. We would love to include more personal stories from families as well as those with CHARGE syndrome. Pictures would be great, too. To submit an article or story for the newsletter, please send it to leslie@chargesyndrome.org. Submission guidelines can be found at <http://www.chargesyndrome.org/documents/CSFNewsletterGuidelines.pdf>.

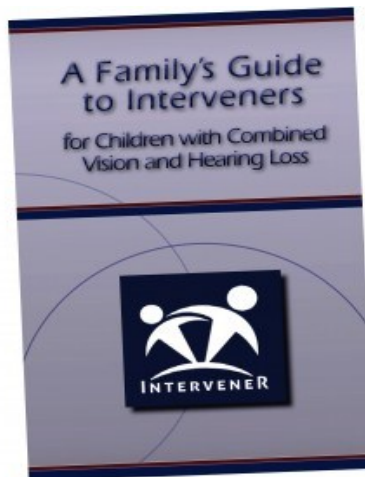


Resources

New Intervener Parent Booklet

Interveners.org is excited to announce a new publication created especially for parents of children who are deafblind—*A Family's Guide to Interveners for Children with Combined Vision and Hearing Loss*. This booklet briefly describes deafblindness and the role of interveners, and then guides parents through the components of the IEP process that are most critical to determining the need for intervener services in educational settings.

Each print copy of this 62-page booklet includes the DVD, *Deafblindness and the Intervener*, and a laminated card with important questions to ask during the IEP development. This publication is now being disseminated through the SPARKLE program to families, as well as Parent Training and Information Centers in each state. State Deafblind Projects and others can order a copy of this booklet by contacting Fran Payne at fran.payne@usu.edu or (435) 797-5591. In addition, an electronic copy of the booklet is available online at <http://intervener.org> and <http://www.sparkle.usu.edu>. Families can call 1-855-357-5571 if they have questions or concerns.



To download the Parent Booklet, click on the following link, [A Family's Guide to Interveners](#).

Resources (cont.)

Bookshare: Online Library – FREE Digital Books and Reading Technologies



Many CHARGE Syndrome Foundation members, as well as parents and educators of children with CHARGE, may not know about Bookshare, 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. It is funded through federal awards from the U.S. Department of Education, Office of Special Education Programs.

Bookshare memberships enable students and their parents and teachers, on their behalf, to download digital books from the collection. Today, the library holds over 150,000 titles in K–12 and postsecondary textbooks, children’s literature, reference information, bestsellers, and periodicals and newspapers. There are books in Spanish, Arabic, and other languages in addition to English. Members can also download two free reading technologies that offer text-to-speech for hearing content read aloud and/or seeing large print on a computer screen. The digital books and reading technologies can make all the difference for children to have long-term independence.

FREE Membership Options

Schools and organizations, as well as parents, can sign up students who qualify. Proof of disability is required for two types of memberships:

1. *Organizational membership* – Any U.S. public school that serves children with qualified print disabilities may obtain a free organizational membership to Bookshare. Having your child on a school membership is necessary so that teachers can download K–12 ([NIMAC](#)) textbooks for your child. Schools may sign up as many teachers or sponsors as required to download books on behalf of students. With this type of membership, a qualified professional in the school or district certifies that a student is eligible.
2. *Individual membership* – Sign your child up for an individual membership in addition to his/her school membership. This establishes a habit for lifelong learning and reading. Students can download as many books as they want on any subject. This extends their learning and the ability to read books for pleasure. Proof of disability can be submitted by a qualified professional, such as a special education teacher, assistive technology specialist, physical therapist, speech and language teacher, occupational therapist, medical doctor, and more.

(continued on next page)

“The digital books and reading technologies can make all the difference for children to have long-term independence.”

Resources (cont.)

Reading Technologies

Members can download titles in digital text, audio, and digital braille formats. Braille readers can also download books directly to some braille displays to read with refreshable braille or transfer books to a braille display from a computer. Depending on the device used, two audio formats—MP3 and DAISY audio—can be used to read books aloud. Bookshare also introduced two “on-the-go” reading apps for visually impaired readers:



1. [Read2Go](#) for iOS devices has a wide range of font sizes and colors for reading in large print. It offers two built-in voices for reading books and works with or without Apple’s accessibility software called VoiceOver. It can connect to braille displays via Bluetooth. Read2Go is available in the Apple iTunes Store for \$19.99.
2. [Go Read](#), a free Android app, also offers text-to-speech using whatever voices are available on the device. It is optimized for readers with visual impairments.

Learn more about Bookshare’s free reading tools at <http://www.bookshare.org/readingTools>. Remember, when selecting assistive technology software or a device for reading, please discuss the options with teachers and specialists to select the right device for the child.

Breaking Down Barriers to Reading and Literacy

Bookshare’s goal is to break down barriers to reading and to bring reading to life for students who cannot read standard print. Children with CHARGE syndrome may qualify for free memberships. Use the resource links below for further information.

- Article in Spring 2011 Issue: [Perspectives for Deaf/Blind](#)
- For Membership Options: <https://www.bookshare.org/membershipOptions>
- For Qualifications: http://www.bookshare.org/_/membership/qualifications
- How to find books on Bookshare tutorial: [YouTube video](#)
- What are the free reading tools? <http://www.bookshare.org/readingTools>
- What other assistive technology (AT) devices read Bookshare books?
http://www.bookshare.org/_/gettingStarted/readingTools/devicesAT

* Individuals who are not U.S. students can join Bookshare for a nominal membership fee.

Resources (cont.)

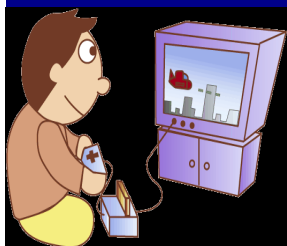


National Tele-Support Group

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 sheri@chargesyndrome.org.

National Deaf-Blind Equipment Distribution Program

The goal of the National Deaf-Blind Equipment Distribution Program (NDBEDP) is to ensure that every person with combined hearing and vision loss has access to modern telecommunication tools and the training necessary to use them, granting every individual the opportunity to interact with the world as an involved, contributing member of society. The program —promoted by iCanConnect—provides outreach, assessments, telecommunications technology, and training free of charge to those who meet federal eligibility guidelines. For more information, visit <http://www.iCanConnect.org>.



AbleGamers Foundation

The AbleGamers Foundation is dedicated to bringing greater accessibility in the digital entertainment space so that people with disabilities can gain a greater quality of life and develop a rich social life that gaming can bring. The AbleGamers Foundation is proud to offer a one-time grant for gaming equipment. The child must be 15 years or younger. Visit <http://www.ablegamers.com/ablegamers-2012-grant.html> to fill out an application.

Hearing Aids for My American Girl® Dolls

American Girl now offers a new hearing aid option for its American Girl dolls. The hearing aid option is available for all My American Girl® dolls at the time of purchase. Hearing aids for any of American Girl's other existing or newly purchased dolls are available at its Doll Hair Salons and the Doll Hospital.

The dolls can have hearing aids fitted in one ear (left or right) or both ears. The price is \$14 for hearing aid service and covers one or both ears. The hearing aid is fitted onto the doll by drilling a hole behind the ear; a peg is then inserted through the hearing aid and into the hole. The white wire curves around the doll's ear and nestles the amplifier into the ear canal. Dolls fitted with hearing aids may also wear eyeglasses and earrings.

For more information, call American Girl Customer Service at 1-800-845-0005 or (608) 831-5210 (available Monday – Sunday 7am – 10pm CST).

Upcoming Events

Epigenetics and Disease: A Mini-Symposium on the Epigenetic Transcription Factor CHD7 and CHARGE Syndrome

Location: Drexel University, Papadakis Integrated Sciences Building, Room 103

Date: November 2, 2012, 9am – 5pm EST

Presenters:

Donna Martin, MD, PhD (University of Michigan): “Clinical and research advances of CHARGE”

Peter Scacheri, PhD (Case Western): “Molecular functions of CHD7”

Brian Brooks, MD, PhD (NEI/NIH): “The genetics of uveal coloboma”

Faith Liebl, PhD (Southern Illinois University): “Regulation of synaptic function”

Robert Hevner, MD, PhD (University of Washington): “Neuropathology in CHARGE syndrome”

Kelvin Kwan, PhD (Rutgers University): “CHD7 in cochlear progenitor cell differentiation”

Daniel Marenda, PhD (Drexel University): “Neural circuit formation and behavior”

Special Guest Speaker:

Tiina Urv, PhD (Program Officer with the NICHD/NIH) speaking on funding mechanisms for rare diseases including CHARGE syndrome.

7th Texas CHARGERS Annual Retreat

Date: November 2–4, 2012

Location: Camp Allen, Navasota, TX

Presenter: David Brown

For more information on the event, visit <http://www.texaschargers.org/events.html>.

Webinar: CHARGing into the Teens

Date: November 11, 2012, 7pm EST

Presenter: Kim Blake

The Foundation is excited to announce the third webinar in our series. [Registration](#) is now open on a first-come-first-served basis, available only to members of the Foundation at this time.

Dr. Kim Blake began her involvement with CHARGE syndrome 30 years ago at Great Ormond Street Hospital in the United Kingdom. She published some of the earliest papers on CHARGE and helped organize the UK family support group. At Dalhousie University in Halifax, she has continued her research on CHARGE, with focus on anesthesia, feeding, sleep, and issues of the adolescent and adult with CHARGE.

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



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

Upcoming Events (cont.)

The 3rd Health & Wellbeing in Children, Youth and Adults with Developmental Disabilities

Date: November 15–17, 2012

Location: The Coast Plaza Hotel & Suites, Vancouver, BC

Conference Brochure:

<http://www.interprofessional.ubc.ca/HealthAndWellbeing/documents/Brochure.pdf>

Registration:

<http://www.interprofessional.ubc.ca/HealthAndWellbeing/registration.asp>

For further information and updates, visit <http://www.interprofessional.ubc.ca>.

The 5th Annual Joshua Kurby Charge for CHARGE 5K

Date: Saturday, June 29, 2013 at 9:00 a.m.

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

Save the date—more details to follow. For more information, please contact [Sandy Kurby](#).

Focus on Fundraising

2nd Annual Tyler Trot 5K & Fun Run

The 2nd Annual Tyler Trot 5K & Fun Run was held August 4, 2012, at the historic and scenic Antietam National Battlefield in Sharpsburg, MD. This event is dedicated to the loving memory of Tyler James Matthew (2004–2006).

Thank you to everyone who helped make the 2nd annual Tyler Trot so successful. With your support, this event has become the leading national fundraiser for the CHARGE Syndrome Foundation. This year exceeded all expectations, with 250 race participants! To date, donations total \$18,500. Visit <http://www.tylertrot.org> for more information and pictures of the event.

The 4th Annual Joshua Kurby Charge for CHARGE 5K

The 4th Annual Joshua Kurby Charge for CHARGE 5K was our biggest race ever in terms of registrants and money raised. We had a new location with a scenic course for walkers and runners (however, we are going to change our walking course next year once some construction is finished) and a shaded pavilion with ample room for our participants. Walkers and runners came from Illinois, Indiana, Michigan, and Ohio, with many CHARGE families represented. We raised more than \$3,000 in registration alone, and others provided additional donations. We also worked with an Avon consultant, who donated a percentage of orders (\$350) to the CHARGE Syndrome Foundation. We are hoping for another successful year in 2013 as we move our date up to June 29 so everyone can train, race, and recover before the conference!



Focus on Fundraising (cont.)

Flat Charlie Update

By Minnie Lambert

This summer, Flat Charlie made one stop in Ceske, but he spent most of his time in Canada, making five stops while there. Charlie is now in Australia visiting Ellen Howe and accompanying her to the CHARGE Syndrome Association of Australasia's conference, where she will hand him off to our dear friend David Brown, who will bring him back to the States. Then Charlie will start his journey back across the USA!

To date, the Flat Charlie Project has raised \$2,121 for the CHARGE Syndrome Foundation, with hopefully MUCH MORE to come. We hope to add new families anywhere we have an opening in the schedule. If you are interested in joining our team, please contact Minnie Lambert at mllambert123@yahoo.com.



CHARGE in the News

Walmart Is All Heart

Nine-year-old Andrew Delaney and four other children had their wishes come true on August 9th thanks to Walmart Heart and the generosity of eight Walmart truck drivers. Walmart Heart is a volunteer program in which Walmart truck drivers make youngsters with medical conditions and/or disabilities honorary drivers for the day and give them rides in their 18-wheeler trucks. Read more about this special event at:

http://www.clarendoncitizen.com/article/walmart-heart-brings-joy-children?fb_action_ids=355036034574439&fb_action_types=og.recommends&fb_source=aggregation&fb_aggregation_id=246965925417366



Hearing Loss No Longer an Issue for Mitchell

Click the link below for a brief article on how Australian Hearing has helped 11-year-old Mitchell to hear.

<http://whitehorse-leader.whereilive.com.au/news/story/hearing-a-better-world-for-berwick-boy/>

One of the Chosen Few

High school senior Bry Russell, who was born with CHARGE syndrome, was recently one of six individuals, nationwide, chosen to attend the Helen Keller National Center for Deaf-Blind Youths and Adults this past summer. Read more about Bry and what she learned in this link.

<http://www.emporiagazette.com/news/2012/aug/25/kansan-one-six-chosen-helen-keller-program/>



CHARGE in the News (cont.)

A Random Act of Kindness



Read about English soccer player Craig Gardner's amazing act of kindness and generous gift to the family of Danyl Brough, a 2-year-old with CHARGE syndrome, in the links below.

<http://www.thisisstaffordshire.co.uk/Football-star-s-pound-500-gift/brave-Danyl/story-16446440-detail/story.html>

<http://www.whoateallthepies.tv/sunderland/130098/craig-gardner-withdraws-500-from-cash-machine-pays-for-disabled-childs-equipment.html>

Making Wishes Come True

One more child's wish will be granted after a check for \$12,512.78 was presented to the Children's Wish Foundation. Connor Creemer, a 14-year-old with CHARGE syndrome, had a wish granted by the Foundation years ago and accepted the check on behalf of the Foundation. Read more about Connor, the check presentation, and the Children's Wish Foundation in the link below.

<http://www.kingscountynews.ca/News/2012-08-05/article-3043593/Making-wishes-come-true/>



CHARGE Syndrome Foundation, Inc.

141 Middle Neck Road
Sands Point, NY 11050
USA

Phone: 516-684-4720
Toll Free: 1-800-442-7604
Fax: 516-883-9060

Annual Membership

Family – \$25
Professionals – \$40

Lifetime Membership

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

Director of Outreach

Sheri Stanger

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

Phone: 914-479-0079

Fax: 914-478-1204

Email:

sheri@chargesyndrome.org

NEW: Members receive priority registration for our webinar series.

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

Email: info@chargesyndrome.org

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



Thank You

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 Microsoft Matching Gifts
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 Campaign

In Honor of Alexandra Barksdale
 Emmadell Vernon

**In Memory of beloved daughter
 Ariana Marie**
 Emma & Eli Bluestone

**In Honor of Christian
 Roberts**
 Bekkie Cobb

**On the Special Occasion of Daniel
 Wolfe's bar mitzvah and in honor of
 Ethan Wolfe**
 Tim & Victoria Lovely

**In Honor of Ethan Wolfe's 10th
 Birthday**
 Nori & Rob Spiro – Dry Cleaning
 Factory

**In Honor of The Herz Family's birth
 of their daughter Ellery Stella**
 Emma & Eli Bluestone

**In Honor of my daughter with
 CHARGE syndrome, Emilee Hullings**
 Wells Fargo Community Support
 Campaign

In Memory of Joshua Hwang
 Andrew LeBlanc

**In Memory of Joshua Hwang, with
 deepest sympathy from Paul
 Mongillo and everyone on the
 Patriot Team**
 Paula Millard – Raytheon Company

In Honor of Katie Kauffman
 Terry & Theresa Carpenter

In Honor of Lestat Ormsby
 Wells Fargo Community Support
 Campaign

**In Memory of Marsha Bird Lawn
 from SPA Class 1965**
 Linda Sullivan

In Memory of Martha Buck
 Majorie Smith

In Honor of Max's Birthday
 Amy McKinley

In Honor of Mighty Max
 Elizabeth Boyle

**On the Special Occasion of Mighty
 Max's Birthday!!!!**
 Sandy Harless

In Honor of Natalie Stone
 Kim Corley

**In Honor of Natalie Stone's 1st
 Birthday**
 Jessica Rabidoux

In Honor of Grandson Nicholas Miele
 Sandra Miele

**In Memory of Richard Eugene "Dick"
 Young from the Executive Committee
 of the CHARGE Syndrome
 Foundation**
 Lisa Weir

In Memory of Ron Kaufmann
 Vared Klinghofer

**In Memory of your daughter-in-law
 Stephanie Ginsberg**
 Emma & Eli Bluestone

In Memory of William P. Banning
 Jean & Earl Johnston
 Linda & Rick Yersak

**In Memory of my friend William P.
 Banning and his family, the Rossers of
 Bel Air, MD**
 Ephe Olliver

Thank You

Charge It for CHARGE Tributes

In Honor of Alice Pedersen and her awesome parents!

Christina Hagen

In Honor of Ariane Lefrance

Carine & Pascal

In Honor of Carolina Lopez

Hazael & Laura Becerra
Jose y Carmen

In Honor of Carolina Monique Lopez, my daughter, who has CHARGE. Precious.

Manny Lopez

In Honor of Carolina Monique "Mi Preciosa"

Manny Lopez

On the Special Occasion of CHARGING for Carolina

Jaime Villarreal

In Honor of Chantelle participating in the Flat Charlie Project and the awesome job that she did with him!

Minnie Lambert

In Honor of the Cress Family participating in the Flat Charlie Project

Minnie Lambert

In Memory of Dakota Benay Adams

Desiree Adams
Erin Kane
Dawn Perkins
Brian Phillips
Diego Rodriguez

In Memory of Dakota Benay and In Honor of her lovely mother Dara

Mini n Gid

In Memory of Dakota Adams, my little niece. We love you and never forget you!

Aunt Hollie and family

In Honor of Daniel's bar mitzvah and Ethan

Victoria & Tim Lovely

In Honor of David & Jody Wolfe

Richard Hannigan

In Honor of Finley Roth

Rebecca, Gil, Nava & Ami
Feldman
Anne Pease

In Honor of Princess Finley!

Kristin Galan

On the Special Occasion of Finley's Birthday

Barbara Nicolas

On the Special Occasion of Finley's 3rd Birthday!

Jennifer Stiles

In Honor of Jay, Julie and Adele Brandrup

Collins & Trey Clegg

In Honor of Julie and Jay's Birthday

Julie Calligan
Daphne Dickinson

In Memory of Joshua Kurby

Stephanie Klinger
Carol & Wayne Miklautsch
Jill Moy
Genevieve & Scott Neubert
Joan Rickard
Dan & Sharon Sawicki
Marie Wakeman
The Wayman Family

In Memory of Joshua Kurby. Love, Bridget Rada

Bridget Rada

On the Special Occasion of Joshua's Birthday! From Mom, Dad, Joey and Jill. In memory of Joshua – Happy Birthday!

Sandy Kurby

In Memory of Joshua Roy Kurby. We love you and miss you on your birthday and always, Nonna and Grampa

Rosalie Kurby

In Memory of Joshua Kurby – Donation made for James

Gervasio 80th birthday
Denise D'Andrea

On the Special Occasion of 4th Annual Joshua Kurby Charge for CHARGE 5K!

Sandy Kurby

On the Special Occasion of Josh's Race Day. From the Wayman Family – in support of Josh's Race. We'll do even better next year!

Miya Wayman

In Honor of Justin "Mow" Murray

Paul & Pam Dowd

In Memory of Liz & Dick Young (Kristin Ogan's grandparents)...they would have loved Charlie. Miss you Mom & Dad!

Marilyn Ogan

In Honor of Minnie Lee Lambert, mom of Andrew and Flat Charlie

Marcelyn Yoho

On the Special Occasion of Noah Ashton

Ed Ashton

In Honor of my brother Noah

Elijah Ashton

In Honor of the Ashton Family participating in the Flat Charlie Project

Minnie Lambert

In Honor of Miss Rylee participating in the Flat Charlie Project

Minnie Lambert

In Honor of Taylor Shott

Cora B. Taylor

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 email 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!