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VOLUME 22, ISSUE 1

SPRING 2012

President's Message

By David Wolfe

Spring is a time of renewal, growth, and excitement. That is exactly the way I feel about the many initiatives, activities, and developments happening at your Foundation.

Special thanks to Tim Hartshorne and Kasee Straton for their fantastic webinar on "Pain Issues in CHARGE Syndrome." This is just the first in our webinar series. Stay tuned for our next webinar featuring David Brown! Remember, members get the first opportunity to fill the spots. If you have not joined or renewed your membership, please do so as soon as possible.

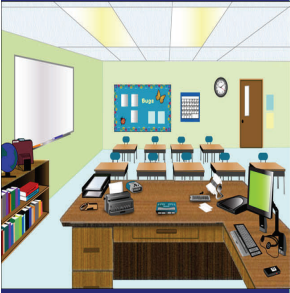
Our Scientific Advisory Board is reviewing the research grant applications we received. We look forward to sparking more research about CHARGE through our pilot grant programs. It is wonderful to see the increased interest in CHARGE from the scientific community.

Please check our website for upcoming events in your area. We try to post information about regional get-togethers, fundraising events, meetings, and other opportunities that might interest our CHARGE families.

Finally, please remember that nothing we do would be possible without the generous support of our donors and fundraisers. Thank you to everyone who has donated and raised money for the Foundation. There is so much more that we want to do to make the world a better place for all individuals with CHARGE. We need everyone with a connection to CHARGE to get involved. Whether large or small, every effort makes a difference.

IT CAN BE DONE!





"Most young ones will fully embrace your child as a peer once they understand the reasons for the 'differences' they observe."

Introducing CHARGE to the Classroom

Recently on the CHARGE listserv, a parent whose child was starting school asked for advice on how to share information about his daughter with the other children in her classroom. We would like to share some responses here, as they may be helpful to other parents as well.

From Melva Strang-Foster (grandmother to 6-year-old Halyn):

My granddaughter, Halyn, was in daycare and preschools up until the time she entered public-school kindergarten last year. She was in a facility for children with disabilities for only about a year, and even then she was integrated with "typical" kids. Because I frequently picked her up from daycare and kindergarten, I had the opportunity to interact with her classmates. They often asked me questions about Halyn and her various "appliances," such as her hearing aid, her walker, and the splints she wore to strengthen her ankles. Their questions were of natural curiosity and were sweet and simple. I tried to answer them in the same spirit. I told them that the "pink thing" she wears on her ear helps her to hear because her ears don't work as well as theirs. Furthermore, I told them that, to make sure Halyn hears what they say to her, they need to speak to that ear because the other one doesn't "work" at all. I told them she uses the walker because her muscles are weaker than their muscles and she has a hard time balancing herself when she stands up. (I asked them if they ever had trouble walking after spinning around so they could relate.) I gave them a similar explanation for the ankle braces.

I recommend going into the classroom and either sitting in a low chair or on the floor. Identify yourself as _____'s mom/dad. Then tell them that your child has CHARGE syndrome, and because of that he/she has trouble hearing, talking, walking, eating (whatever applies to your child). Then tell them about the appliances and/or therapies your child needs to use during the school day. Give the kids a chance to ask you questions, and then answer them in a simple language. Most young ones will fully embrace your child as a peer once they understand the reasons for the "differences" they observe.

Over the six years with Halyn, we have observed that most of her classmates adore her and vie for opportunities to help her. Almost all of the children are very protective and loving in their interactions with Halyn. They try to make sure that she has an opportunity to participate in the "fun" activities in which the class is involved.

From Linda Baker (mother to 27-year-old Jeff):

Melva's comments were wonderful! The only thing I might add is, after talking about the ways your child is different, show some pictures of your child doing fun things, such as going to a park, swimming, snuggling with Mom/Dad, etc., while talking about all the ways your child is the same as the other children. Their feelings are the same as the other children's...they want to have friends, be accepted for who they are, be loved by their family, etc. But as Melva said, keep it simple so the children can relate to it.

(continued on next page)

Introducing CHARGE to the Classroom (cont.)

From Leslie Kauffman (mother to 10-year-old Katie):

I have a one-page, color handout that I update at the beginning of every school year. It includes information about the things that make Katie unique, but the info is integrated in such a way that it emphasizes, above all else, that she's a regular kid, just like her classmates. I include pictures of Katie doing some of her favorite activities, such as riding a horse at hippotherapy and playing in the pool at aquatic therapy. I explain that she is deaf and uses sign language, and that the kids will see her interpreter and an aide with her to help her communicate and participate in the classroom. I write it at a lower level that the kids will understand. Sometimes I go into the classroom on the first day of school and read it to the class; other times the teacher reads it. The teacher then puts a copy in each child's backpack to take home, so parents can talk more to their children about Katie and answer any questions they might have. I include the CHARGE Syndrome Foundation's web address at the bottom of the page if parents want more information on CHARGE.

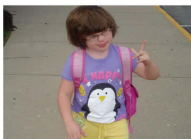
I also developed a PowerPoint presentation a few years ago, geared toward Katie's educational team. It explains the various characteristics of CHARGE and how they specifically affect Katie. I update it every year and present it to Katie's teachers and therapists right before school starts. It has been very helpful in raising their awareness of CHARGE syndrome as well as introducing them to some of Katie's challenges that they may experience in the classroom.

C = Coloboma of the Eye

- Eye does not form properly in utero ("cleft" of the eye)
- Causes vision loss
 - Severity depends on position
- Frequency is 80%–90%
- May also be accompanied by:
 - Microphthalmia (small eye)
 - Anophthalmia (missing eye)

Effects on Katie

- Left eye:
 - Coloboma in optic nerve
 - Blind, but thought to detect light and motion
 - Smaller than right eye
- Right eye:
 - Coloboma on side; doesn't affect vision
 - Moderately nearsighted
- Functional vision:
 - Very good; uses vision extremely well
 - Likely has depth perception issues
 - Can see pretty well close up and within 3–4 feet
 - Wears eyeglasses; receives vision services at school



If anyone would like a copy of the handout and/or PowerPoint presentation to adapt for your child, email me at lakcharge@yahoo.com and I will be glad to share the files.



Hi, I'm Katie Kauffman!

I turned 9 on January 17.

I am excited to be in third grade in Mrs. Wallace's room. I attended preschool, kindergarten, and first grade at MECC, and second grade here at Western Row. Before that, I attended the Perlman Center at Cincinnati Children's Hospital for 1½ years. I love school!

My favorite activities are looking at books, watching videos, and taking trips in the car. I like Mickey Mouse, Clifford, and Winnie the Pooh and Tigger. I also like

horseback riding and swimming. I've been riding at Cincinnati Therapeutic Riding and Horsemanship since I was 2½. It helps me with my balance.

I was born deaf. I use mostly gestures, pictures, and sign language to communicate. I know all my letters, my

numbers from 1 to 100, and about 300 words in American Sign Language. I am also learning to read. I am learning lots of new signs and hope you will learn some too so you can talk to me!

Ms. Wanda is my educational interpreter. She helps me communicate and do my school work and get around safely. Mrs. Moorman will be my support educator, and you will also see lots of other people coming to work with me on things like physical, occupational, and speech therapies. I sometimes have trouble transitioning

to new things, especially when they aren't part of my normal routine, so Ms. Wanda and my paraprofessional, Ms. Bev, will help me follow my calendar schedule and make good transitions.

I'm looking forward to making lots of new friends this year!

For more information on CHARGE Syndrome, visit www.chargesyndrome.org.

August 2011

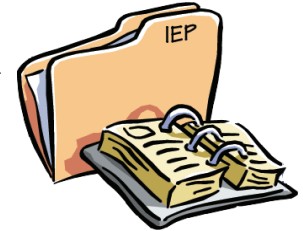
A Lesson in Education

By Sheri Stanger, Director of Outreach

“One of the biggest concerns I hear from parents, all over the country and from around the globe, is a great frustration with the educational system.”

“What feels like an isolated journey doesn’t need to be.”

As your Director of Outreach, I spend much of my time talking and corresponding with families. We chat, talk about their child, and discuss resources and connections to other families and professionals. Often, our conversation begins on the surface but quickly gets to the heart of our concerns. One of the biggest concerns I hear from parents, all over the country and from around the globe, is a great frustration with the educational system. Why can’t my child receive a free and appropriate public education? Why do I have to fight for every little thing I want for my child in their IEP (Individualized Education Plan)? No one is working on transition goals, and I don’t know what to do. My child is isolated throughout the school day and being taught by an aide rather than a certified teacher.



Day after day, I hear stories from families that make me wonder how children with CHARGE can ever receive a solid education to make progress and become productive citizens to the best of their abilities. I wish I had the answer for each parent who calls me, but unfortunately I don’t. My suggestions to parents are directed at increasing their knowledge of the IEP process, fostering connections with the school staff and administration, keeping excellent records, and knowing educational law. I don’t mean you need to become a special education lawyer, but it is good to understand where our kids with hearing and vision loss and possible developmental delays fit into the system. I often refer families to their state education website to learn about the specific state laws and also to Wrightslaw (<http://www.wrightslaw.com>) and the Individuals with Disabilities Education Act (IDEA) to better understand the national implications of special education law as it pertains to their child. We also need to be aware of how behavioral issues and the classroom environment impact our child’s learning, and what safeguards are in place to protect our child.

What feels like an isolated journey doesn’t need to be. I hear of parents traveling this road alone with no support from other families that have gone before them. I encourage families to connect to other parents in their state to learn how they made progress within their school district. I also encourage families to connect with their State Deaf-Blind Project. The State Deaf-Blind Projects are federally funded projects through the U.S. Department of Education’s Office of Special Education Programs (OSEP) and provide technical assistance to families and school systems. They can be a great resource for state-specific information and ways to access services for someone who is deaf-blind. The state projects can connect families just as the CHARGE Syndrome Foundation can help connect families within a state (or province or country) through our parent-to-parent contact lists. These lists can be requested by e-mailing me at sheri@chargesyndrome.org or calling me toll-free at 1-855-5CHARGE (1-855-524-2743).

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A Lesson in Education (cont.)

Don't get me wrong. We are making progress. More and more people are learning about CHARGE syndrome through the outreach efforts of the Foundation and its members. As we learn what works for our individual child, we need to share our stories with each other. I hear success stories from families, and our membership needs to hear more of these. I encourage you to share your educational success stories with me so I can relay them to our membership in future newsletter issues.

Read up on the IDEA and find support from other parents through the CHARGE Syndrome Foundation, State Deaf-Blind Projects, and State Deaf-Blind family groups. Educating yourself is the first step to ensuring an excellent education for your child.

To read more about educational issues in CHARGE syndrome, please go to the website for the National Consortium on Deaf-Blindness at <http://www.nationaldb.org>. They house DB-LINK, the National Information Clearinghouse on Deaf-Blindness, where you can search the entire deaf-blind database for articles and information.

Many Ways to Have a Conversation

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

Background

This topic was presented at the 10th International CHARGE Syndrome Conference in Orlando, Florida, in July 2011. This is a modified article as the original presentation included several video clips.

This article demonstrates that students with CHARGE can have meaningful conversations in unique ways. Four case studies are presented, each illustrating that every child learns to communicate in his or her own distinctive manner. There are common strategies and modes that each child can access.

The message throughout is that regardless of age, cognitive level, and degree of hearing and/or vision loss, the use of Total Communication (multiple modes) is critical to the development of language and communication. It is the responsibility of the team (professional staff and families) to assess and to make a determination about the primary modes of communication to be used by all members, keeping in mind the primary needs of the child.

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"More and more people are learning about CHARGE syndrome through the outreach efforts of the Foundation and its members."

"...every child learns to communicate in his or her own distinctive manner."

Many Ways to Have a Conversation (cont.)

Total Communication

The children in the Deafblind Program at Perkins School for the Blind have access to Total Communication as part of the overall philosophy of the Program. Total Communication, as implemented by the Program, is defined as:

The use of any means of communication—sign language, speech, fingerspelling, lipreading, writing, gesture, pictures, and/or objects—to assist people in the learning of language and to encourage their communication.

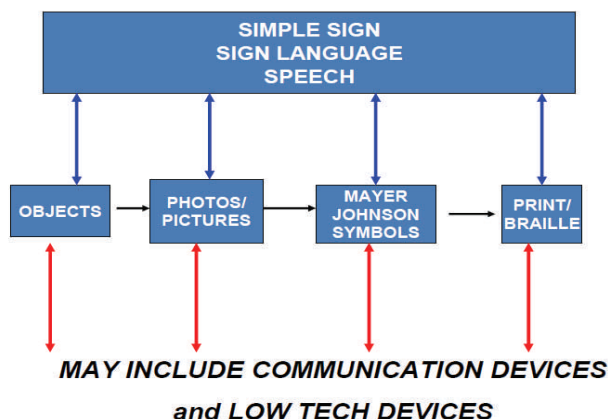
Given the nature of the children in our Program, we have expanded the definition to include a larger continuum of communication modes that our students can access, including technology.

Through observation of many children with CHARGE syndrome in the Deafblind Program, we have seen that these students can develop ways to communicate. In some cases, students have developed their own unique communication style; others need more support and structure to foster spontaneous and more formal communication. We have also observed that all students with CHARGE learn to communicate using components of the Total Communication definition. Some students' communication is delayed, and therefore they do not communicate at the expected developmental level. We know that if we are persistent and consistent, then students can learn over time and become more formal communicators.

Regardless of each student's communication level, they do learn and they do communicate. It seems that the use of a visual system supports the learning of sign language and its subsequent use over time. In addition, some students maintain the use of a visual system simultaneous to using sign language.

"We know that if we are persistent and consistent, then students can learn over time and become more formal communicators."

Communication Flow Chart Learner's Expressive Language



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Many Ways to Have a Conversation (cont.)

The flowchart on the previous page represents the expressive modes of communication that are typically used with children with hearing impairments and children with CHARGE syndrome. It appears through observational data that many children with CHARGE also benefit from additional supports. As you can see from the chart, this can include objects, photos/pictures, Mayer-Johnson symbols, line drawings, print or Braille, and more recently, an array of technology options.

Technology is an added component and can include a variety of communication devices such as voice output, an iPad using a variety of applications, etc. More recently, the iPad has been introduced for specific use as a communication tool.



*Martha's full article, including specific case studies, can be found on the "Resources" page on the CHARGE Syndrome Foundation's website (<http://www.chargesyndrome.org/resources.asp>).

Webinars

By Lisa Weir

On February 12, 2012, the CHARGE Syndrome Foundation held its first live webinar: "Pain Issues in CHARGE Syndrome" with Dr. Timothy Hartshorne and Dr. Kasee Stratton. If you were unable to make it, the recording is available at <http://hknc.adobeconnect.com/p6p2t2fxsiq/>. Parent Amy Russo shares her thoughts about the webinar:

"Webinars are perfect for us! Because of our son's intense medical needs, we aren't able to physically attend a lot of events in person (e.g., conferences, local get-togethers, etc). And if we do attend in person, it is usually just one of us that can go so the other can stay home and care for our son. But we are both very interested in learning more and finding ways to help him with his struggles. The 'Pain Issues in CHARGE Syndrome' webinar happened to touch on a subject that is very appropriate for our son, so it was just WONDERFUL for both of us to be able to listen and learn. The information was very helpful, and connecting with a group of people that understands the issues was comforting. Plus, having the webinars posted online afterwards is perfect because I am able to refer people who work with our son to the site to watch."

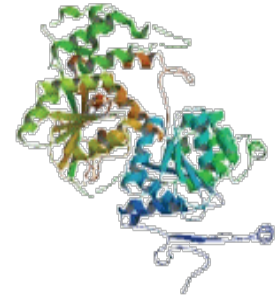
The next webinar, "The Forgotten Senses," is scheduled for May 20th with David Brown, who will present on the often-forgotten vestibular (balance) and proprioceptive (pressure) senses. His presentation will provide simple explanations of these two senses, how they work, the purposes they serve, and how important they are to child development. Current members of the Foundation will receive notification about registering for the webinar in the coming weeks. To ensure you receive the notification, please make sure your membership is up to date by e-mailing info@chargesyndrome.org.

"The information was very helpful, and connecting with a group of people that understands the issues was comforting."

New Screening Method for CHD7

By Meg Hefner, MS, Genetic Counselor

Why is testing CHD7, the major CHARGE gene, so involved and so expensive? CHD7 is a very large gene. It is made up of 188,000 base pairs of DNA, organized into 38 exons (coding regions of DNA). The protein created from this gene contains nearly 3,000 amino acids. To put this in perspective, 188 kilobase pairs (kbp), if strung out like words, would make up a 100-page manuscript. The vast majority of mutations in CHD7 are point mutations—typos in the manuscript. Therefore, sequencing the entire coding region of the DNA to look for a single point mutation is like trying to find a single typo in a 100-page book. No wonder it is expensive and takes so long.



But maybe there are ways to speed up the process of finding those typos without sacrificing accuracy. A novel way to detect and identify mutations in CHD7 has been developed by a group of geneticists in France and discussed in their article “Complete Screening of 50 Patients with CHARGE Syndrome for Anomalies in the CHD7 Gene Using a Denaturing High-Performance Liquid Chromatology-Based Protocol,” which appears in the January 2012 issue of the *Journal of Molecular Diagnostics*. To continue the manuscript analogy, rather than read every sentence, their method involves breaking the gene down into smaller pieces (aliquots) and looking at each one at a time. They are taking advantage of the fact that most mutations are private. (Each person with CHARGE has a unique change in the DNA.) That way, patients can be used as controls for one another. It is as if they are taking two copies of the same manuscript and holding equivalent pages (from two patients) up to a light. If they are the same, the type on both pages will line up. If there is a typo, there will be a spot on the page that does not line up. Once they identify a spot (i.e., squiggles on a chromatograph) that does not line up, that section is sequenced. They scrutinize the one page for a typo (mutation).

If you are really interested in molecular laboratory techniques, then I suggest that you read this paper, which can be found at <http://download.journals.elsevierhealth.com/pdfs/journals/1525-1578/PIIS1525157811002595.pdf>. It is a very interesting read and has lots of tables, graphs, and figures to supplement the article. From a practical standpoint, the geneticists propose a protocol for lab tests on someone who may have CHARGE, starting with chromosomes and FISH for 22q deletion, moving through their technique, and then (if no mutation is found) on to other places to look. This is the sort of technique that we hope will move into the clinical arena in the next few years, potentially drastically reducing the cost of CHD7 DNA analysis.

CHARGE Syndrome Clinic — Update

By Meg Hefner, MS, Genetic Counselor

The third official CHARGE Syndrome Clinic in the United States was held on February 21, 2012, at SSM Cardinal Glennon Children's Medical Center. Our team—Dr. Stephen Braddock, director of the Division of Medical Genetics at Saint Louis University; CHARGE syndrome expert Dr. Sandra Davenport; speech-language pathologist Dr. Barbara Braddock; genetic counselor and child development expert Katherine Christensen; and myself—saw five patients, ranging from 5 to 25 years of age. Four of the patients were children who were known to have CHARGE syndrome, while the fifth patient was an adult who did not have CHARGE syndrome, but rather something similar to it.

What we are finding, for the most part, is that medical care for children with CHARGE syndrome is excellent. Unlike the early days (Dr. Davenport and I have been doing CHARGE work since the mid-1980s), no one knew what CHARGE syndrome was or how to take care of babies and children inflicted with CHARGE. Now, many doctors have heard of CHARGE syndrome, and if they haven't, there is a wealth of information out there. However, we are still finding significant issues with coordination of care and especially with management of developmental and educational issues. That is what we are trying to provide for the families who come to the clinic. First, we take a comprehensive look at where the medical issues stand and make any appropriate recommendations to the doctors caring for the kids. Then, we look at the developmental and educational picture—what is going on, what needs to be going on, and what recommendations we can make for people to take home with them. I have been very pleased that we have been able to have a significant impact, even for families who are already getting superb medical care.

We plan to have the clinics three or four times a year. The next two clinics will be on June 19, 2012, and sometime in August or September (specific date still to be determined). We are partnering with the CHARGE Syndrome Foundation to provide scholarships toward hotel and food costs for families coming from a long distance to attend the clinics. If you are interested in attending the upcoming clinics, please feel free to contact me: meg@chargesyndrome.org.

CHARGE Database — Update

As mentioned in the Winter 2011 Newsletter, as an adjunct to the Charge Syndrome Clinic and as part of the Center of Excellence plan, Meg Hefner and Kevin Ballard are in the process of creating a database and registry for CHARGE syndrome at Saint Louis University. Once complete, it will be possible for parents of children with CHARGE or adults with CHARGE to enter their medical information into a database via the Internet. Please note that the database continues to evolve and will be available shortly.

"What we are finding, for the most part, is that medical care for children with CHARGE syndrome is excellent."

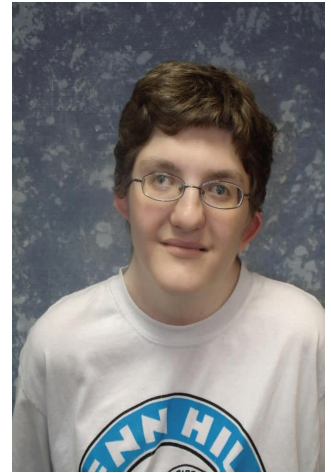
"...we are still finding significant issues with coordination of care and especially with management of developmental and educational issues."



Update on Nate

By Nate Mathewson

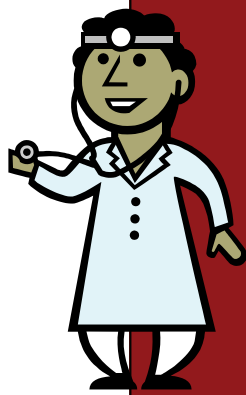
Hello there, I'm Nathan Mathewson, and I am an 18-year-old with CHARGE syndrome. I am legally deaf-blind, and in the past few years I've gotten more independent. I was recently accepted to the Community College of Allegheny County in Pittsburgh. I am attending a summer program run by the Office of Vocational Rehabilitation and the Blind & Visual Rehabilitation Services of Pittsburgh for young adults who are preparing for college. I am getting ready to graduate from high school and these two organizations have helped me transition somewhat better than I would have on my own, even though this past year I have done a lot of the advancing towards college myself. Currently, I am focusing on my senior project, which is on whether the school day and year should be longer or shorter.



Provider Recommendation Project

Our Provider Recommendation project has gone live! If you want to know about great doctors and therapists in your area (state, province, or country), please e-mail Sheri Stanger, Director of Outreach, at sheri@chargesyndrome.org. Sheri will search the Provider Database for you, and if she finds what you are looking for, she will e-mail the list to you.

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.

Upcoming Events

University of Michigan CHD7 Stem Cell Study

Dear CHARGE Syndrome Foundation members,

We in the University of Michigan Departments of Neurology and Pediatrics would like to make you and your family members aware of a new study beginning at our institution. This study is designed to develop a new research model of inherited neurological disorders like CHARGE syndrome. To this end, we are recruiting subjects with CHD7 mutations and their relatives (whether they are carriers of the disease or not) to enroll in this study.

What is the purpose of the study?

This study is based on the recent discovery that pluripotent stem cells can be created from patient skin cells. These stem cells can then be used to study the cell biology of nerves derived from subjects with inherited neurological disorders such as CHARGE syndrome and compared with subjects without CHARGE. These cells will be studied for their ability to survive, to change into different cell types, and for features that distinguish them from healthy cells in a laboratory setting. These stem cells will help us better understand what it is that makes the CHD7 mutation so harmful. Furthermore, they will help with research into the development and testing of new drugs to treat these conditions.

Who can participate in the study?

We are recruiting subjects with a known diagnosis of CHARGE syndrome to participate in this study. In addition, we are recruiting related and unrelated individuals to act as control subjects in the study. To be eligible to participate, they must also have a clinic visit during the study period. You must be able to understand and communicate in verbal and written English.

What does the study involve?

The study will involve a single visit with a pediatrician at the University of Michigan. As a part of the study, all participants will undergo a small skin biopsy on the back of the wrist. In some patients, this biopsy may be taken from a different site. This procedure is done with numbing medication and takes approximately 30 minutes. It leaves a small scar that gradually fades over time so that it may become almost invisible.

This skin biopsy will be used to make human stem cells through a reprogramming process in a laboratory. These stem cells will be genetically matched to you and may be used in research that involves genetic or chemical manipulation of the cells. These stem cells will be used to study the cell biology of nerves derived from patients with CHARGE syndrome and compared with controls. Samples will be kept in a secure facility in a locked room and freezer.

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Upcoming Events (cont.)

Who will pay for the costs of the study?

The study will pay for research-related items or services that are provided only because you are in the study. Neither you nor your insurance company will be billed for any costs of the study.

Will I be paid or given anything for taking part in this study?

There is no monetary compensation for this study.

Who can I contact about this study?

For more information on this study, please contact:

Donna M. Martin, MD, PhD

Associate Professor, Pediatrics & Human Genetics

University of Michigan

Mailing Address: 3520A MSRB I, 1150 West Medical Center Drive, Ann Arbor, MI 48109-5652

Telephone: (734) 647-4859

Peter K. Todd, MD, PhD

Assistant Professor in Neurology

University of Michigan

Mailing Address: Department of Neurology, 1500 East Medical Center Drive, Ann Arbor, MI 48109

Telephone: (734) 763-7274

**This Study has been evaluated and approved by the University of Michigan Institutional Review Board for Human Subjects Research (IRBMED).*

Survey for Parents of Children with CHARGE Regarding Behavior Problems

By Kathy Sheriff

My colleagues and I are looking for parents of children with CHARGE syndrome to participate in a research survey study on parent and teacher perceptions of challenging behavior in their children with CHARGE syndrome. Parent participants will be asked to give the e-mail addresses of teachers and educational professionals to participate in this study, which will be sent to them.

What is this research study?

This study is called Parent and Teacher Perceptions of Challenging Behavior in Their Children and Students with CHARGE Syndrome. This is a survey research study and it will help us to understand parents' and teachers' perceptions regarding challenging behavior in children with CHARGE syndrome.

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Upcoming Events (cont.)

What would you do if you participate?

You will be asked to complete a survey that should take no longer than one hour of your time. In the survey, you will be asked to nominate your child's teachers for survey participation.

How do I participate in the survey?

Just go to <http://www.surveymonkey.com/s/YJP2LNG> and follow the on-screen instructions.



Can you quit if you become uncomfortable?

Yes, absolutely! The Texas Tech University Protection Board, Dr. Roseanna Davidson, Dr. DeAnn Lechtenberger, and I have reviewed the questions and think you can answer them comfortably. However, if for some reason you start to feel uncomfortable while answering the questions, you can discontinue the survey at any time you wish. Participating is your choice.

How are we protecting your privacy?

Research participation is completely confidential. The survey will not request your name or your child's name or any personal information in order to protect your privacy.

If you have questions about this study, who can you ask?

This study is being run by Dr. Roseanna Davidson, Dr. DeAnn Lechtenberger, and Kathleen Sheriff, M.Ed., from the Department of Special Education at Texas Tech University. If you have questions, you can contact:

Dr. Roseanna Davidson: (806) 742-1997 Ext. #246 or Roseanna.davidson@ttu.edu

Dr. DeAnn Lechtenberger: (806) 742-1997 Ext. #324 or deann.lechtenberger@ttu.edu

Kathleen Sheriff, M.Ed.: (936) 661-1661 or Kathleen.sheriff@ttu.edu

Texas Tech University also has a board that protects the rights of people who participate in research. If you have any questions, you can contact them at (806) 742-2064. You can also reach them by mail at:

Institutional Review Board for the Protection of Human Subjects
Office of the Vice President for Research
Texas Tech University
Lubbock, Texas 79409.

THANK YOU for participating!



Upcoming Events (cont.)

DeafBlind Transition Camp – 2012

In order for deafblind teenagers to become self-advocates and succeed in college and competitive employment, they need a positive and solid foundation on which to build. To help establish this foundation, DeafBlind Central and Self Help for Independency in Michigan Equalizing the DeafBlind (SHI-M=EB) will be holding their fourth DeafBlind Transition Camp (DBTC) from July 8–11, 2012, at Michigan State University. DBTC is free and available to individuals between the ages of 16 and 19 who have combined vision and hearing loss and the desire to enter college or competitive employment.

“The DBTC agenda emphasizes the skills and knowledge that college students require for success and independence...”

The DBTC agenda emphasizes the skills and knowledge that college students require for success and independence, including social, time-management, problem-solving, self-advocacy, and self-determination skills, as well as the use of assistive technology. Through information sessions, students learn about a variety of resources, including support services and consumer groups for students with disabilities. Other DBTC topics include: Tips on Using a Dog Guide, Use of Assistive Listening Devices and Other Technology, The Rights of a College Student with Disabilities, Self-Defense, Substance Abuse, as well as presentations by successful adults who are deafblind. The camp also provides many opportunities for teens to socialize and develop friendships with deafblind peers. For many, it will be the first time they have ever encountered another deafblind person their age.

Teens who participate in the camp will benefit from an experience that mirrors college life. The teens will be assigned a same-sex roommate and eat dorm food, so they can gain some insight into what campus living is like. In addition, social activities and games are coordinated to help the teens get to know one another and experience success to boost their self-esteem. The camp is 100% accessible, 100% of the time. Braille, large print, interpreters, captioning, assistive listening devices, etc., are provided upon request, and all games are adapted to be accessible for all campers. We are certain that this experience will make a difference for the teens that attend, and we have received overwhelmingly positive feedback from past participants!

Registration materials can be found at <http://www.dbcentral.org>. For more information, please contact Beth Kennedy at (989) 774-2725 or (989) 774-2726 or Jill Gaus at (517) 764-6178 or (517) 917-0016. Please help us to spread the word!

DeafBlind Transition Camp
DBTC

Upcoming Events (cont.)

American Foundation for the Blind (AFB) Scholarship Program 2012

AFB administers seven post-secondary education scholarships for up to 11 deserving students who are legally blind. The following is a list of scholarships offered:

DELTA GAMMA MEMORIAL SCHOLARSHIP – One (1) scholarship of \$1,000

- Undergraduate or graduate study in the field of rehabilitation and/or education of persons who are blind or visually impaired.

FERDINAND TORRES SCHOLARSHIP – One (1) scholarship of \$3,500

- Undergraduate or graduate study in any full-time program in any field.
- Applicant need not be a U.S. citizen, but must reside in the United States. Preference given to New York City metropolitan area residents and new immigrants to the United States.

GLADYS C. ANDERSON MEMORIAL SCHOLARSHIP – One (1) scholarship of \$1,000

- Undergraduate or graduate study in classical or religious music.
- Applicant must be female.

KAREN D. CARSEL MEMORIAL SCHOLARSHIP – One (1) scholarship of \$500

- Graduate study in any full-time program in any field.

PAUL W. RUCKES SCHOLARSHIP – One (1) scholarship of \$1,000

- Undergraduate or graduate study in engineering or in computer, physical, or life sciences.

R. L. GILLETTE SCHOLARSHIP – Two (2) scholarships of \$1,000 each

- Undergraduate study in a four-year degree program studying literature or music.
- Applicant must be female.

RUDOLPH DILLMAN MEMORIAL SCHOLARSHIP – Four (4) scholarships of \$2,500 each

- Undergraduate or graduate study in the field of rehabilitation and/or education of persons who are blind or visually impaired.

Visit <http://www.afb.org/scholarships.asp> for further information and to fill out the application form. Deadline is April 30, 2012. For any other questions or additional information, please contact:

American Foundation for the Blind Information Center

Toll-Free Telephone: (800) 232-5463

E-mail: afbinfo@afb.net





Upcoming Events (cont.)

Two Steppin' for CHARGE Syndrome

Date: Every Friday and Saturday night

Location: KP's Music Rodeo, 1276 State Route 183, Troy, Tennessee 38260

Raising money as well as bringing awareness to people who have never heard of CHARGE syndrome. 100% of the proceeds go to the CHARGE Syndrome Foundation.

For more information or to make a donation, please contact Kirk Morris or Kelly Berry at (731) 536-5678, visit <http://www.facebook.com/kpsmusicrodeo>, or e-mail kpsmusicrodeo@att.net.

Addressing Educational Barriers for Children with CHARGE Syndrome

Date: May 5, 2012, 10:00AM–2PM

Location: The Ohio Center for Deafblind Education, 936 Eastwind Drive, Suite 100, Westerville, OH 43081

Speaker: Dr. Susan Wiley, Developmental Pediatrician, Cincinnati Children's Hospital Medical Center

A light lunch or snacks and reimbursement for mileage driven will be provided. No child care will be provided. For more information, please contact Leanne Parnell at lparnell@ohiodeafblind.org or (800) 229-0844.

Child and Youth Mental Health Matters: Three Conferences in One

First National Parental Mental Health Conference

First International Young Carers Congress

Third International World Congress on Children of Parents with Mental Illness

Date: May 6–8, 2012

Location: Vancouver, BC

This three-day conference brings together an interdisciplinary group of professionals working in the field of mental health with young people and parents and other stakeholders to share knowledge and experiences related to child and youth mental health. This first-ever gathering of this nature will provide a forum for focusing on the needs of young people and families as they struggle with issues related to mental health concerns across the generations. The overall goal of the concurrent conferences is to help us develop a common language and understanding of the needs of young people and families. By bringing together people from diverse backgrounds, we hope to enrich our collective knowledge of mental health strategies, best practices, and the latest research in order to improve outcomes for young people and families.



(continued on next page)

Upcoming Events (cont.)

There are three themes woven through the conferences: Parental Mental Health, Young Carers, and Children of Parents with Mental Illness. The conference will begin with an afternoon of network meetings concerning each of the three theme areas. For the remainder of the conference, presentations and panels will be held both on specific themes and cross-theme areas. We will be providing opportunities throughout the conference for people to formally and informally gather to discuss issues of common concern. In addition, we will have keynote presentations on each of the theme areas.

For more details on the conferences, including a complete conference brochure and registration information, visit <http://www.interprofessional.ubc.ca/CYMHM>.

Parent Webinar: David Brown – “The Forgotten Senses”

Date: May 20, 2012, 7PM (EST)

Host: CHARGE Syndrome Foundation

David Brown will present on the often-forgotten vestibular (balance) and proprioceptive (pressure) senses. His presentation will provide simple explanations of these two senses, how they work, the purposes they serve, and how important they are to child development. There will be opportunities for questions from the audience in the webinar.

CHARGE'd-Up for Golf on Memorial Day

Date: May 28, 2012



The Southeast Regional Weekend for Families and Professionals: Supporting Kids with Combined Hearing and Vision Loss

Date: July 13–14, 2012

Location: Franklin Marriott Cool Springs, Franklin, TN

Registration details can be found at <http://www.treds-deafblindproject.com>. The registration deadline is May 31. Please contact Jacque Davis (je.davis@vanderbilt.edu) with any questions.

Tyler Trot Run/Walk 5K for CHARGE Syndrome

Date: August 4, 2012

Location: Antietam National Battlefield, Sharpsburg, MD

Bike-friendly, pet-friendly, stroller-friendly, kid-friendly, runner-friendly, walker-friendly event! Last year we were able to raise a little over \$14,000! We are hoping to do the same, if not more, this year!

For more information, please e-mail Kristen at matthew_12067@msn.com.



Upcoming Events (cont.)

4th Annual Joshua Kurby Charge for CHARGE 5K

Date: August 18, 2012

Location: Due to some construction at Armstrong Park, the event will be held at St. James Farm in Warrenville, IL, right off of Butterfield Road.

The registration form, as well as online registration, will be available in the next couple of months. Stay tuned!

Health & Wellbeing in Children, Youth and Adults with Developmental Disabilities: Challenging Behavior – The Tip of the Iceberg

Date: November 15–17, 2012

Location: Vancouver, BC

This conference will provide educational and informative updates on psychiatric, behavioral, and complex health components specific to individuals with developmental disabilities, and showcase best practices in the field. Specifically, the conference will focus on approaches to complex challenging behaviors, contributing medical issues and new developments in medication and behavioral treatment. In addition, the conference will address important health and mental health issues and will review common genetic syndromes such as Down syndrome and Fragile X. This conference will engage health care providers and educators from a wide range of professional disciplines in knowledge transfer and interprofessional collaboration in order to maximize health and wellbeing so as to minimize disability and improve quality of life. The format will include plenaries, breakout sessions, and poster sessions.

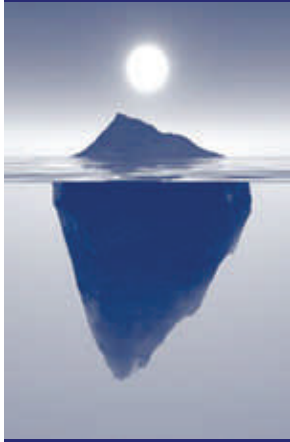
For further information, please visit <http://www.interprofessional.ubc.ca/HealthAndWellbeing/default.asp> or contact Ian Chipperfield at ian.icpe@ubc.ca or (604) 827-3112.

11th International CHARGE Syndrome Conference

Next year's conference will be held on July 25–28, 2013, at the Fairmont Scottsdale Princess Hotel in beautiful Scottsdale, Arizona. Mark your calendar and start making plans to experience the wonder of the 11th International CHARGE Syndrome Conference!

The conference chair for 2013 is Lisa Weir. Please contact either Lisa (lisa@chargesyndrome.org) or the Foundation office if you have any questions, ideas, or would like to volunteer with planning or at the conference.

More conference details, as well as online registration, will be available on the website (<http://www.chargesyndrome.org>) as the date draws nearer.



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

Fundraiser in Honor of Garrett Lee

By Ray and Lynn Lee

On New Year's Eve, we hosted a 50th birthday party for Lynn and a fundraiser in honor of Garrett, who has CHARGE syndrome, at the Elks Lodge in Farmington, Maine. Instead of gifts, guests were asked to make a donation to the CHARGE Syndrome Foundation. The theme of the party was "Hula Day." Many guests attended wearing their Hawaiian attire and were greeted at the door with a lei. The evening started out with a pot luck supper, and music was provided by a local DJ service. A 50/50 raffle and a Chinese auction were held to raise money for the Foundation as well. It was a fun evening, and those who attended had a wonderful time. We especially had a fun time planning this event for the cause and look forward to our next fundraising event for CHARGE.



Steinhauser Fundraisers Update

As mentioned in the Winter 2011 Newsletter, Bill and Deanna Steinhauser set up a "Christmas Trees for CHARGE" fundraiser at their family's Ace Hardware stores, in which they sold Christmas trees at each cash register (the cashiers all had a stack of trees) throughout the month of December. People could make a donation in any amount, and then their name went on a tree that got displayed at the store. Bill and Deanna are happy to report that they raised over \$2,000! They also held a Super Bowl pool earlier this year and raised another \$2,000 doing that! They plan on approaching other Ace Hardware stores to do a "May Flowers" fundraiser for CHARGE in May. Congratulations to Bill and Deanna on a job well done!



Focus on Fundraising (cont.)

Chuck-A-Puck for CHARGE

By Daniel Wolfe

Over Thanksgiving weekend, my hockey team and I sponsored an event for the CHARGE Syndrome Foundation at The Glacier Ice Arena in Vernon Hills, Illinois. I combined my love for hockey and for my brother by organizing a fundraising event called Chuck-A-Puck. During and before the game, my teammates and I sold hockey pucks with specific numbers to the people in the stands. We took their name, puck number, and \$2 for each puck. During intermission of the game, the fans tossed their pucks from the stands onto the ice. The closest one to the center dot won half of the profit made. Lucky for me, all of the winners that day donated their winnings back to the CHARGE Syndrome Foundation. We ended up raising over \$700! In addition to raising money for the Foundation, we also spread awareness about CHARGE by setting up a table explaining more about CHARGE syndrome. Many people stopped over and picked up some information. My teammates and I had a great time. In the end, I learned that fundraising can be fun and easy for kids to get involved in, too!



My brother Ethan and I at the fundraising table



My teammates, my brother Ethan, and I at the Chuck-A-Puck fundraiser



Rasha with her siblings

Employee Jeans Day

The Renaissance Companies (TRC) has implemented a fundraising program called "Employee Jeans Day" by encouraging their employees to donate a small (or large!) amount out of their paychecks every two weeks. In return, participants get to wear their favorite work-appropriate jeans on payroll Fridays. TRC's team members' generous donations being collected for the first six months are being sent to the CHARGE Syndrome Foundation. This one hits close to home, since a member of the TRC family is also part of a CHARGE Syndrome family, as TRC Property Manager Janay Hayes-Mohamed's daughter, Rasha, has CHARGE. We would like to thank The Renaissance Companies for their support!

Focus on Fundraising (cont.)

The Adventures of Flat Charlie

By Lisa Weir

To raise funds for the CHARGE Syndrome Foundation, the Flat Charlie Project was conceived by parent Minnie Lambert, who was inspired after her son's class read a book titled *Flat Stanley* and participated in a class project where Stanley got mailed about and people wrote in a journal about what went on while he visited with them. The Flat Charlie Project works in a similar fashion. Flat Charlie is on a journey to the 11th International CHARGE Syndrome Conference in Scottsdale, Arizona, and is visiting lots of families affected by CHARGE along the way. Host families take turns posting pictures and stories about things they've seen or done during Charlie's time with the family. They "pay" for their leg of Flat Charlie's journey by raising at least \$100 while Charlie visits.

Charlie's journey began in South Carolina this January with Minnie's son, Andrew. He then made his first trip to Michigan with Brayden Case and his family, then on to the Bowers family, and then on to Dr. Donna Martin, chair of the Scientific Advisory Board for the Foundation. He has had quite a stay in Michigan before he heads out to his next location. He has been to speech therapy, early intervention, physiotherapy, the circus, and even met up with Dr. Tim Hartshorne on the slopes of Challenge Mountain, just to name a few things. His next stops include England, Canada, Australia, and many other areas of the U.S. before he reaches his final destination at the 11th International CHARGE Syndrome Conference in Scottsdale, Arizona, in July 2013, where he will be presented to the Foundation from all of the families involved, along with a grand total of how much money he has collected along his journey.

To read more about Flat Charlie's whereabouts, see pictures, and get updates, visit

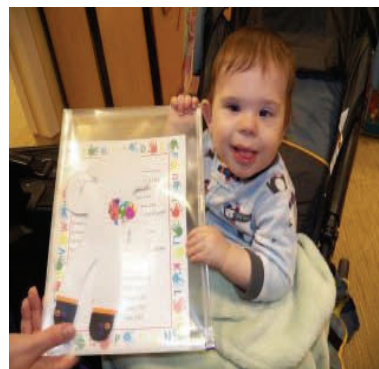
<http://www.facebook.com/groups/300145663351626/>.



Andrew Lambert with
Flat Charlie



Brayden Case with Flat Charlie



Sammy Bowers with Flat Charlie



"...and even more impactful to us was learning what would not get done if the Foundation were left without more support."

Focus on Fundraising (cont.)

"It All Adds Up" CHARGE Fundraiser

By Julie Brandrup

Writing an article about fundraising is only slightly less intimidating than my initial thoughts on actually having a fundraiser for the CHARGE Syndrome Foundation. But now that it is over, I realize how much fun we had raising \$10,000 (and counting) for the Foundation, and it is so exciting to think how the funds can benefit people with CHARGE. I hope sharing what we did will encourage other parents to give it a try.

First of all, fundraising has always felt a little uncomfortable to me. I don't like to ask people for money, especially when it feels a little self-serving (since my daughter, Adele, has CHARGE syndrome). But at the Chicago CHARGE Conference, Jay and I started to feel the pressure to raise money. And by pressure, I don't mean peer pressure; I mean the internal feeling that if we weren't willing to do something, who else could be expected to? One of the conference presentations that year gave us a better understanding of how the Foundation uses the money, and even more impactful to us was learning what would not get done if the Foundation were left without more support. Research grants were of particular interest to us, especially with the attention sparked by the discovery of the CDH7 gene. I remember hearing that some researchers merely ask the Foundation to help with their postage costs and wouldn't it be nice not to have to turn them down ever again?

That's when our idea was planted, but we waited for a specific milestone in our own life to make it happen. Some of you may know that Jay and I are exactly the same age, literally born on the same day and year—so we are always looking for creative ways to celebrate the unique occasion. We decided to make our 40th birthday a fundraiser for CHARGE syndrome. It seems fairly common to throw a party for your spouse on the big 4-0, so we decided to do it for each other and ask for donations to CHARGE in lieu of gifts. To help people understand they were being invited to more than a birthday party, we gave it the theme: "It All Adds Up." We hoped this was a clever way to explain that the party was for both of our birthdays and was also a fundraiser.

Our first step in planning was to contact some fundraising superstars, the Bluestones in New York and the Wolfe family in Chicago, to help us with how to word the invitations and handle the donations. They were all so helpful and inspiring. We used the Foundation's website to start our own "Charge It for CHARGE" webpage for online donations. To tell our story, we made a custom webpage that explained more about the event and why the Foundation is so important to us. See the webpage at <http://www.brandrup.com/40>. (Something similar could possibly be done on Evite.com or a blog site.) From there, we linked the "Charge It for CHARGE" donation page.

(continued on next page)

Focus on Fundraising (cont.)

We received more than half of the donations before the actual party, and with each new e-mail telling us of a new donation, our excitement and enthusiasm for fundraising was growing. The night of the party, our daughters Adele and Margo put on new outfits, and we all went to celebrate not only birthdays but also the love and support being shown to us by our friends and family. Having Adele there allowed everyone to see for themselves how much progress she has made and hopefully was inspiring to them. Additionally, the party venue had a view of our Children's Hospital so we were able to reference Adele's time there. We took a few minutes to toast our family and friends and say a few words about how "It All Adds Up." Afterwards, everyone sang "Happy Birthday" to us, and we blew out our "80" candles atop a four-layer cake decorated for each decade of our lives. I wish we had a photo of Adele's face when she saw her name next to the ASL sign for "I Love You"—it was a priceless moment.

Going into it, Jay and I had a good idea that celebrating our birthday with friends and family would be fantastic fun, but I think we both were a little surprised by how enjoyable the fundraising portion was. What's more, because the webpage and "Charge It for CHARGE" page could stand alone as a virtual fundraiser, we have received donations in honor of our birthdays from friends and family from all over the country who weren't at the party. Some of those donations, whether large or small, made us realize that even people who are not in our everyday lives are still very in touch with our story and want to contribute. People really do want to give, and sharing a little of our personal story made for an extremely meaningful event. It felt like a huge success, and it certainly helped take the edge off turning 40.

Excerpts from party speech:

"In planning this night, we wanted to make it bigger than ourselves. And have long wanted (and needed) to raise more money for the CHARGE Syndrome Foundation.

*To be honest, it has always felt a little awkward to ask for donations to something that affects what sometimes feels like **only us**. But over the last 7½ years, we have learned CHARGE syndrome affects people in all parts of the world, and most of them are in desperate need of information about this complex and sometimes overwhelming syndrome. Starting with Adele's diagnosis at 5 days old, the CHARGE Syndrome Foundation has been our primary source of support and, to this day, no single organization has done more for us. But in a kind of twisted vice versa, it is the families affected by CHARGE who end up financially supporting the Foundation, and that only goes so far.*

There's a running joke among CHARGE families that we need a celebrity to have a baby with CHARGE to get some serious financial backing and attention. If it's 1 in 10,000, it might as well be a celebrity. We mean no harm, but can you imagine the publicity if (insert current celebrity) had a child with CHARGE syndrome? In the meantime, we've realized that it's just the immediate CHARGE families and the people who care about them...to raise the needed funds.

(continued on next page)



"...in a kind of twisted vice versa, it is families affected by CHARGE who end up financially supporting the Foundation, and that only goes so far."

Focus on Fundraising (cont.)

There is a lot the Foundation wants to do, including being able to provide research grants to the medical communities, which is one of the things we are most excited about.

“Adele is doing better than almost anyone imagined. We get a lot of credit for her progress, but we can say most everything we do has started from the CHARGE Syndrome Foundation....”

Adele is doing better than almost anyone imagined. We get a lot of credit for her progress, but we can say most everything we do has started from the CHARGE Syndrome Foundation—someone’s story in the newsletter, a piece of research, a posting on the website, a conference presentation, so many little things that we would not have known about without the CHARGE Syndrome Foundation. They provide an incredible amount of information that allows us—and families like us—to give our child every possible advantage.

We are grateful to be in the position to have caring, generous, and supportive friends—and what can sometimes seem like an “only us” situation, doesn’t feel like it at all tonight. What you have given—and will give—will make a significant difference. It is an overwhelming night of gratitude and joy.

Stars for CHARGE!

The 2nd École Millidgeville North School Shining Stars Cheerleading Competition was held on March 18, 2012. The host team, École Millidgeville North Stars, once again donated 25% of their 50/50 draw to the CHARGE Syndrome Foundation. Here are the girls with their 2nd place banner. Great job at the competition, and thank you for the donation! Keep up the great work, girls!



MY CAN CAN



That red fundraising can sat around my house for months. I saw cans and boxes from so many other charities at local stores. Life kept getting in the way of putting mine out. I finally asked a friend who worked at a local cleaners if he would mind putting it by the cash register. A couple months later, he returned that can stuffed full of dollars and coins! It is now back in his store for a second tour of duty. It’s a win-win situation—hundreds of people get a brief introduction to CHARGE and we raise money in the process.

Send us an email about how your can is doing. If you haven't started, remember that your can can, too!

CHARGE in the News

A Learning Experience

Marie Patterson, whose daughter has CHARGE syndrome, has been assisting in the writing of a book on CHARGE Syndrome. Visit the following link to read more about how Marie has found working on the book to be a learning experience:

<http://macarthur-chronicle-campbelltown.whereilive.com.au/news/story/charge-syndrome-daughter-inspires-new-path-for-marie/>



Support for Charley



Charley is a 3-year-old who was born with CHARGE syndrome. To read about how Charley's family is receiving support from both local and national businesses to help pay for their expenses, visit the two links below.

<http://www.euroweeklynnews.com/news/mallorca/90431-thumbs-up-for-charley> <http://www.euroweeklynnews.com/news/mallorca/91664-local-businesses-support-charley>

Respite Workers Love What They Do

Clearbrook's "Take a Break" program provides respite, or breaks, for parents of young children with special needs. The article in the link below highlights this rewarding work by including comments from some of Clearbrook's volunteers. It also includes comments from the parents of a young girl with CHARGE syndrome who receive respite care.

<http://www.dailyherald.com/article/20111218/news/712189870/>



Leading the CHARGE

Click the link below to read about 4-year-old Matthew, who was diagnosed with CHARGE syndrome when he was 10 months old. The article also discusses how Matthew's parents have taken action to raise awareness for this rare genetic disorder by launching a grassroots nonprofit organization called the CHARGE Ahead Foundation.

<http://www.mysuburbanlife.com/villapark/topstories/x3496726/Leading-the-charge>

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CHARGE in the News (cont.)

A Profile of Jesse

The following article provides an in-depth profile of 8-year-old Jesse, who has CHARGE syndrome, and discusses what life is like for Jesse and his family:

<http://kc.vanderbilt.edu/kindredstories/Story.aspx?id=3164>

Kayla Overcomes Challenges

Kayla is a 4-year-old with CHARGE syndrome. The article below provides a profile of Kayla and her achievements thus far, and also discusses the many struggles her family has had with raising a child with CHARGE syndrome.

<http://bangordailynews.com/2011/12/23/news/aroostook/one-year-later-4-year-old-presque-isle-girl-overcoming-big-challenges/>



Cameron's Trip

For one night only, the New Plymouth Repertory Theatre's production of *Understanding Women* will become a fundraising event for 19-year-old Cameron and his mother's trip to the 2012 CHARGE Syndrome Conference in Sydney.

<http://www.stuff.co.nz/taranaki-daily-news/news/midweek/6571186/Show-to-help-rare-teen>

CHARGE Foundation Store

In partnership with Creative Promotional Products, Ltd., our first-ever 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.

Resources

New Literacy Website

Are you looking for literacy strategies for children with sensory losses? Children who do not use a formal language system? Children who have multiple disabilities and complex learning challenges? If the answer is “yes,” then you are encouraged to visit the new “All Children Can Read” website (<http://literacy.nationaldb.org>).

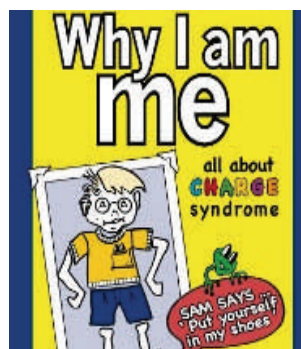


Development of the “All Children Can Read” website began in 2006 as part of the work of the National Consortium on Deaf-Blindness’s Literacy Practice Partnership. This group envisioned the creation of a central location to provide information and resources to individual state deaf-blind projects, teachers, family members, and related service providers interested in beginning or enhancing literacy instruction for children who have combined vision and hearing loss and children with other complex learning challenges. Following literature reviews of literacy learning for all children, children who are blind or visually impaired, children who are deaf or hearing impaired, children with multiple disabilities, and children with deaf-blindness, a set of literacy indicators and corresponding strategies was developed to help guide instructional planning. The “All Children Can Read” website is built on a framework that incorporates stages of literacy development and key components of reading into instructional strategies for children with dual sensory challenges. Content is organized around evidence-based strategies identified as being effective in building emergent literacy skills and moving children along a continuum toward independent reading. The website has been designed to present these strategies in a user-friendly, interactive manner that utilizes existing resources and provides practical examples.

Book – *Why I Am Me*

Why I Am Me is a story published by the CHARGE Syndrome Association of Australasia about a boy named Sam, who has CHARGE syndrome, and his friend Jess. As the story progresses, Jess learns about CHARGE syndrome and the challenges Sam faces on a day-to-day basis. Visit the link below for more details on the book, as well as information on how to order it:

<http://chargesyndrome.org.au/whyiammeallaboutchargesyndrome.html>



Thank You

Donations

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America's Charities
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Bill Criswell
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Yara Cluver
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In Honor of Adam Hamill
Rob/Roseann Byrne

In Honor of Adele Brandrup
Jay Brandrup

In Honor of Aiden Lanting
Renae Barrett

**In Honor of Aileen Sayce
from Jim and Jimmie Lou
Bowden**
James Bowden, Jr.

In Honor of Alice Pedersen
Dr. A. Capobianco
St. James Cathedral School

**In Honor of Jim Pedersen's
Granddaughter Alice**
Thomas Reinarts

**In Honor of Jim Pedersen's
granddaughter Alice
Pedersen**
Alan Litke
Karen Pedersen

**In Honor of Alice Pedersen
and in memory of James O.
Pedersen**
Dorothy & Frederick Pedersen

**In Honor of Alice Pedersen
and in memory of her
grandfather, Jim Pedersen**
Jean Seiffert – Pilot Club of
Titusville, Inc.

**In Memory of James O.
Pedersen**
Amy Carter
Joe and Peg Pedersen

**In Memory of James O.
Pedersen (Granddaughter
Alice)**
Keith & Jan McMillen

In Memory of Jim Pedersen
Theresa Dioguardi – CH2M HILL
Lockerbys and Brejchas
Linda Lopardo
From his nieces and nephews,
Mike, Debbie, Scott and Kathy
Metzger
Marco Ross
Jim & Marilyn Vydra
Bill and Jennifer Zosel

**In Memory of Jim Pedersen
and in honor of Alice Pedersen**
Linda & Stephen Bain
Suzann Bain
Ann Edwards
Carolyn Rudman
Susan Willis

**In Memory of Jim Pedersen
and in honor of Jim's
granddaughter Alice Pedersen**
David and Ruth Flowers

**In Memory of James Pedersen
and in honor of granddaughter
Alice**
L.F. Herff

**In Memory of James Pedersen,
devoted grandfather of Alice**
Harry McNamara

In Memory of Brianna
Amon Seagull

**On the Special Occasion of
Catherine's BIRTHDAY**
James Kouzmanoff

**In Honor of the inspiration
Charlotte Cosenza**
Staff at Lindy Eye Care

**In Memory of Charlotte
Grieder**
Kelsi Logsdon

**In Honor of Christian
Roberts**
Bekkie Cobb

**In Honor of Christine
Hoffman from the Patel &
Lilly Families**
Seena Patel – Small Steps Therapy

**On the Special Occasion of
Christmas**
Friends at OptumInsight in South
Portland, ME

**On the Special Occasion of
Christmas gift to Grandma,
Poppy and Aunt Lanette**
Megan Dwyer

In Memory of Douglas Roth
Donna Rudder

**On the Special Occasion of
the birth of Granddaughter
Ellery Stella**
Emma & Eli Bluestone

**In Honor of Emma and Diane
Katapodis**
Hilda Bodenstein

In Honor of Erika Feather
Mark Mills

Thank You

Donations (cont.)

In Memory of Ethan Marsh

Barbara Bingham

In Honor of Ethan Wolfe

Jason Altman

Staci, Mike, Ilexa and Ian

Axelrod

On the Special Occasion of the wedding of Franca and Bruce

Chet & Laura Bogdan

In Honor of Garrett Lee and family

Megan Adams

In Honor of Gracie Swann

Alice Dunbar

On the Special Occasion of Grayson Rago and his mom, who together are fighting the odds.

Gail Baitx

In Honor of Hannah Green

Susan Green – National Family Association for Deaf-Blind

Joyce & Barry Miller

In Honor of Jadyn Fultz

Laura Powers

In Honor of Jasmine Goldthorpe

Catherine Lavery

Linda Therien

In Memory of Jerome Schwartz

Bernard & Edna Carlin

In Honor of Katie Kauffman

Archie Kauffman

In Memory of Lou Narducci

Joyce Harney

In Honor of Makenzie Dougherty

Betty McKnight

In Memory of Marilyn Hopbell, wonderful grandma of Tori Hopbell Yoho & wonderful daughter of Marcie. RIP lovely lady. Love to a very special family during this Christmas season.

Ellen Howe

In Honor of Mary Catherine Patrick, great-grandmother of Peyton & Cy Young

Tim Young

In Memory of Matthew Conn

Jacqueline Nerem

In Honor of Matthew Froning

B. Elizabeth Brannock

In Honor of Maya Kelly

Emmanuel Presbyterian Church

In Honor of Meredith Dwyer

William F. Dwyer

In Honor of the Miele Family

Mrs. Sauer's 4th Grade Class at Cornwall Elementary School

On the Special Occasion of Natalie Charlebois's 1st Birthday!!!! Happy Birthday, Natalie.

Melissa Mills

In Honor of Natalie Stone

Roger Charlebois

Kate Stone

In Honor of Natalie Laurie Stone

Jennifer & Scott Hempey

On the Special Occasion of Natalie Stone

Randall and Paola Charlebois

Jonathan & Julie Rock

On the Special Occasion of Natalie Stone's First Birthday!!

Michele Prendergast

On the Special Occasion of Natalie Laurie Stone's first birthday!!!! Happy Birthday, Natty

Maureen Prendergast

In Honor of Pam Ryan

Lucinda Garthwaite

In Honor of Board of Directors member Pamela Ryan for her open ended commitment to the children, parents and families.

Marcia Furst

In Honor of Patty Haggerty

Jill & Bob Hale

Nan & Robert Hawes

In Honor of our dear friend Pam Ryan who celebrated a BIG birthday recently!

Alex and Trish Chatfield

In Honor of Rasha Mohamed

Kathryn Kleisch

In Honor of Rasha

Wayne Worley

In Memory of Savannah Grace Barber

The Witthar/Gerald Family

In Memory of Tyler Matthew

Heather Gross

Wade and Aliza Edwards Fund

Mariam Noland – Community Foundation for Southeast Michigan

In Honor of Whitney B. Wells

Bethany Pattie

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

Thank You

Charge It for CHARGE

Tributes

In Honor of Adele Brandrup

Jennifer Andress
Tariqa Bhuta – McCool & Bhuta, ENT Specialists
Nicole Brandrup
Jennifer Kramer
Angie Saunders
Dan Sinnreich
Rachel Stone
Tony Truitt
Jill Wiggins
Bayless Ydel

In Honor of Adele

Julie & Jay Brandrup
Michele and Paul Hill
Josephine Lowery
James Lyman

In Honor of Julie, Jay and Adele Brandrup

Kate Darden

In Honor of Jay, Julie, Adele and Margo

Elizabeth & Reece Alford

In Honor of Jay & Julie Brandrup

Cass Klimcak – Cass Klimcak, D.M.D.
Mike & Tracey Nowack

In Honor of Jay and Julie Brandrup, 40th Birthday celebration

Jennifer Johnson

On the Special Occasion of The Brandrup's 80th!

Jen & Matthew Dent

On the Special Occasion of 40 + 40 = 80. A great story.

Kevin & Katie O'Meara

On the Special Occasion of Jay and Julie Brandrup's 40/40 Party and Adele Brandrup

Patrick Scarborough

On the Special Occasion of Jay and Julie Brandrup's 40th Birthday. In honor of Adele and Margo too!

Catherine and Andy Meehan

In Honor of the Brandrup Family

Donna Brandrup
Nancy and Max Hale

In Honor of Alivia Roth

Christine Alexander

On the Special Occasion of Alivia Roth

Dawn LaBuy-Brockett

In Honor of Alivia Roth & her father on his birthday

Dawn LaBuy-Brockett

In Honor of Aman Mehta

Richa Khan – Wunderman

In Honor of Aman Mehta, my big brother and my hero

Veera Chandani

In Honor of Aman Mehta. Dear Aman, Aim for the stars and you will touch the sky. Stay strong.

Rajiv, Nilam and Niraj Mehta

Amrit and Jan Nasta – Best Wishes for Christmas

Amrit Nasta

In Honor of Andrew Delaney

Jennifer Lambert

On the Special Occasion of supporting Andrew Delaney in the Flat Charlie Project

Minnie Lambert

On the Special Occasion of Mr. Andrew's Birthday!

Jen Coleman

In Support of Andrew and family, from your cousin Candace

Candace Lambert

In Honor of Brayden

Joe
Vic

On the Special Occasion of Brayden Case and Flat Charlie!

Yuka Persico

In Honor of Brayden, Michelle and Flat Charlie. You all inspire. Love, Cousin Nic and his family (Johanna, Catherine, Audra, cats and dog...)

Nicolas Piechotte

In Honor of Brayden Coon

Mr. Hartle

In Honor of Cheyenne Brittell

Aunt Gwen

In Honor of the Brittell Family

Delores & Bob Anderson

In Support of Chris & Corki Roth

Marti Roth

On the Special Occasion of David's Presidency

Susan & Joel Wolfe

In Honor of Ethan

Al Gaither – Darling International
Thomas Reed – Reed Detective Agency, Inc.
Daron Romanek – Romanek & Romanek
George Xamplas – Law Office of George C. Xamplas

In Honor of Ethan Wolfe

Paul Anderson
Andrea & Brent Cantor
Misha Guth – Guth Mediations, Inc.
Chris Ory – Law Offices of Christine M. Ory, P.C.
Ed Placencio
Kristi and Stan Sliva

In Honor of Ethan Wolfe & his family

Wendy O'Kane

In Honor of Finley Roth

Kayla Block
Jodi Cyr
Lynne Gapsis
Laura Inverarity
Lisa Michalak
Lisa Michalak and Thirty-One Gifts

On the Special Occasion of Flat Charlie

The Beaver Family – In support of Flat Charlie for CHARGE syndrome

Thank You

Charge It for CHARGE Tributes (cont.)

Thanks guys for hosting Flat Charlie on his journey!
Minnie Lambert

In Honor of Garrett Lee
Wendy & Michael Atwood
Gena & Ernie Cloutier
Carol & Henry Cochran
Charlotte Cushman
Susan & Michael Fogg
Sharon & Robert Harper
Cynthia & Ronald Hazelton
Joy & Gregory Lake
Linda Lee
Lynn Lee
Nancy & David Morgan
Stephen Morrison
Laureen & Michael Pratt
Joanne Stinneford
Rebecca Wetzell

In Honor of Halyn Elizabeth Jones
Memorie Elliott

In Honor of Halyn Jones & her family
Melva Strang-Foster

On the Special Occasion of Jasmine Goldthorpe's Bat Mitzvah
Ken Neuman

In Honor of Joseph Lavelle
Margery Bodenhamer

In Memory of Joshua Kurby
Steph & Don Klinger

In Memory of Joshua Roy Kurby. Merry Christmas – Nonna & Grampa love you always.
Rosalie Kurby

In Honor of Justin Murray
Robert Ells
Lynne Russo

In Honor of Justin "Mow" Murray. Lots of Love.
The Dowds

In Honor of Katherine Broich
Bonnie Morrison

In Honor of Kristin
Marilyn Ogan

In Memory of Kristin's grandmother Clara Young
Executive Board

In Honor of Makenna Susil
Carenina Waite

In Memory of Matthew Padilla Froning's grandfather, Alfred P. Froning
Monica Padilla Froning

In Honor of Megan!
Nicole Horne
Ken Kissel – Live Wire Security

In Honor of Megan Stanger
George Barna
Mark Chazen
Gwen Jagde
Norman Massry – Massry Charitable Foundation Inc
Susan Rutman
George Stephan

In Honor of our amazing cousin Megan! We love you!
Alison, Brad, Ivy and Bentzi Walter

In Honor of the Stanger Family
Alan & Danielle Engler
The Macedo Family

In Support of Natalie Stone
Madison Carpentier

In Honor of Nicholas Buono
Louis Buono Jr – Buono's Flooring Co.

In Honor of Oliver L. Paulus
Andrew Paulus

In Honor of Patricia Ulloa
Isabel Sandoval
Kim Bo Ly Smith =D

In Honor of Ryan Warter
Sheryl Kaufman

In Honor of the adorable Sam Bowers
Joyce Francisco

In Honor of Sir Sam
Alicia Rittenhouse

In Honor of Sammy, my great grandson
Great Grandma Adonis Coombs

In Support of Sammy in the Flat Charlie Project
Minnie Lambert

In Honor of Taylor
Amber & William David

In Honor of Taylor Shott
Heidi Glover
Susan Marquez – Southern Living at Home
William Yeoman

In Support of our nephew, Taylor Shott
Morgan & Everett Gibson

In Honor of Team Taylor Shott
Renata Lauden

In Honor of Taylor Shott and his family
Mayson Salley

In Honor of Tobias Yost
Deanna Yost

In Memory of our loving brother Vikram
Mander & Simraan Kulkarni

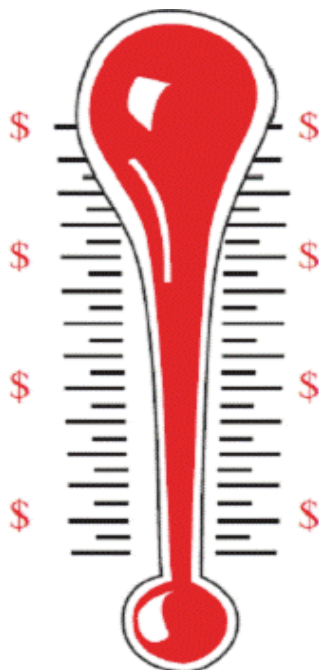
In Honor of My Beloved Brother Vikram Gehani
Preeti Gehanni – Sunshine Homes Real Estate

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION



fourth annual Charge It for CHARGE

HOW HIGH CAN WE GO?



Our fourth annual Charge It for CHARGE campaign is now underway. So far in 2012 we have raised more than \$63,000! Charge It for CHARGE is the primary fundraising campaign of the CHARGE Syndrome Foundation. With 30 minutes of your time and the e-mail addresses of friends, family, colleagues, and businesses where you spend your money, you can help individuals with CHARGE and their families. To get started, go to <http://FourthAnnualCIFC.kintera.org/>.

In addition to the online fundraising campaign, many members have planned fundraising events. If you would like to host an event, we are always available to help you with the details. Please contact our fundraising chair David Wolfe at david@chargesyndrome.org to share ideas or for any assistance. Whether you prefer to run, walk, golf, bike, or just have a party, there is an event that can fit your style!

You can also help the Foundation by making a donation at <http://www.chargesyndrome.org> or by mailing a check directly to the Foundation. No amount is too large or too small.

Please Join Us!

CHARGE Syndrome Foundation, Inc.

141 Middle Neck Road
Sands Point, NY 11050
USA

Annual Membership
Family – \$25
Professionals – \$40

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Toll Free: 1-800-442-7604
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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 upcoming webinar series.

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

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