

CHARGE Accounts



Summer 2007

A Quarterly Newsletter for Families and Friends

Vol. 17 No. 2

CHARGE Syndrome:
CHARGE has four
major features -
Coloboma, Choanal atresia,
Cranial nerve abnormalities, and
Characteristic ears
More information on website

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JULY 27-29, 2007

8th INTERNATIONAL CHARGE SYNDROME CONFERENCE

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!!! Deadline for the Fall Issue - September 1 !!!

CONFERENCE ACCOUNT

Conference Update - "CHARGING WEST"
Marilyn Ogan, 2007 Chair

California, here we come!! Things are about set for the 8th International CHARGE Syndrome Conference, July 27-29, 2007 in Costa Mesa, California!

Neal Stanger (Foundation President) and I will be meeting to finalize details with hotel staff and meet with area volunteers as this issue of CHARGE Accounts goes to print!

Michael Schwartz and Ruth Schwartz have been working tirelessly to garner the volunteer commitments from local organizations and Lacey Friedman has made a great connection for even more volunteers. The confirmation letters have been sent; the program Jim Thelin has coordinated is varied and impressive; the Saturday evening Carnival looks to be set for a great time; the childcare (Beach Club) is ready to swing into action; and your Foundation Board members are excited and ready to make this a great experience for all.

We have some wonderful crafts planned for the kids who are participating in the Beach Club. Please be sure your children are registered online with KiddieCorp (information is in your confirmation letter) as well as with the Foundation (you should have mailed that in to us). This allows us to plan for the number of craft supplies to purchase and KiddieCorp to provide the appropriate number and type of staff.

This year's Saturday Auction will be handled by Luis Vasquez and the Orange County Foresters organization. If you have items to donate, please send in your auction donation forms (even if you are bringing the item with you). The items need to be entered in the database for tracking and final log in. This will help immensely with getting the auction ready to go on Saturday evening. Send your donations to Sue Meckley, 737 Stanford Rd, Burbank CA 91054, 818-842-0041.

I am still lining up interpreters (ASL/SEE/Spanish) and hope to have that wrapped up within the next week. We will have a large group of individuals using sign language, so those of you who are "rusty"...practice up! I'm sure you'll have plenty of opportunity to try your conversational signing skills. We have participants coming from Chile, Puerto Rico, and the Dominican Republic! And presenters will be arriving from all over the world!

I look forward to meeting all who are coming to the conference and will miss those who will not be able to attend. Since I won't be writing here again before the conference arrives, I hope everyone's travels will be peaceful and uneventful!

More Conference News
by Jim Thelin, Program Chair

Research at the 2007 Conference

There will be two research projects conducted at the Conference in Costa Mesa. Look for posters and fliers at the Conference that will tell you when and how you can participate.

(1) The Feet in CHARGE: This project will be conducted by Maryann Girardi and Liz Breadon of Perkins School for the Blind. It turns out that feet of individuals with CHARGE are unique. There will be a booth where Maryann and Liz will be photographing feet and asking for information related to feet.

(2) Vestibular Function in CHARGE: The Vestibular Research Group from the University of Tennessee will be conducting a brief vestibular test and collecting information related to balance and mobility. Though ~90% of individuals with CHARGE have vestibular anomalies, very few individuals receive a vestibular evaluation because of technical difficulties in making measurements and because of the ability of the examinee to cooperate. This research is part of an attempt to develop evaluation procedures that can be used on children and adults with CHARGE.

"For those attendees who are members of the CHARGE ListServ, we will have a special sticker to put on your name tag so you can more easily connect with other members of the List. Be sure to ask at the Registration Table for your sticker."

TRAVEL BY AIR THIS SUMMER

by Sheryl Doolittle

The conference is almost here and many of you will be traveling by air. My daughter Jessica started attending Perkins School for the Blind last September. In traveling from Iowa to Massachusetts by air, we have run into some difficulties getting supplies through the security check points under the current guidelines. With the conference fast approaching, I would like to share with you some ideas that might make your trip less stressful as you fly based on our recent trips to Boston.

Carrying Formula

Since liquids have been limited, it can be difficult getting the formulas through security. I insist on traveling with a two day supply of formula in my carry on bag. The TSA says they have the right to limit you to the quantity necessary for you to reach your destination. That doesn't take into account those delays that always seem to happen when you are not prepared. To avoid being limited, I carry a written prescription written on prescription pad paper (some agents won't accept just a letter) from the doctor to show that it is a prescription only formula that I can't just purchase at the local store. I also have a letter from the pharmacy stating that it is a special order formula to reinforce that you can't just find it anywhere. I also suggest contacting the TSA call center at 866-289-9673 to request the name of your local TSA Screener Manager to discuss any specific requirements that they might want you to abide by. To reduce my hassles, I now contact the airports that I am traveling through to let them know of our flight times, and the amount of excess liquids that I will be traveling with. They then notify the appropriate screener supervisors that we have been given the ok to have our quantity of formula so that we have less hassle at the check points. I still get questioned but now all I have to do is have the screener check with their supervisor because we called ahead and we then get to move on through the line.

Remember, you have to declare all liquids and gels at the security check points. You will want them all in one place so when packing your liquids and medications; I suggest that you place all liquids in one bag before heading to the airport. Once you are through security, then you can place what you need in your diaper bag to have accessible during the flight.

Feeding pumps

For those of you with feeding pumps, I suggest that if you could have it empty and disconnected as you go through security, you will have less hassle. I assume they will need or want to scan it to make sure it is ok. It's more work to get it ready and to hook up your child after you pass through security, but you might appreciate getting through security faster in doing it this way.

Coats, blankets

I don't know for sure how they check babies, but Jessica was sleeping very hard when we tried to go through security one day and she needed to be in a wheelchair. She had to be

given a quick pat down. I had to make sure her coat was off (I assume blankets would need to be removed from a baby) and once the agent said she was ready to check Jessica, I was instructed that I could be near her to observe and assist if needed but if I were to touch her, then I would become subject to a pat down and private search as well. To make sure that Jessica does not get left unattended, I always send whoever is traveling with me through security first. Once they have been cleared, then I send Jessica, then myself. That way I know there is someone to be with Jessica while I am dealing with the liquids and equipment.

Medical equipment and carry-on allowance/valet check

Speaking of equipment, medical equipment is not supposed to count against you for your carry on bag allowance. If you are traveling on any smaller planes, they will usually make you valet check your bag plane side. However, when I explained to them that the bag had almost 20K in medical equipment and assistive devices, they did allow me to keep it with me. So that I don't have to valet check the bag, I always make sure I pack it so that I know I can get it stowed in the overhead or under my seat properly.

Northwest, American and Delta do not count an infant diaper bag against your carry on and 1 personal item per "ticketed" passenger allowance. However, if your child is not a "ticketed" passenger, they do not have an allowance and their carry on baggage will count against your allowance.

Wheelchair/luggage assistance

I always ask for wheelchair assistance. Jess is mobile but when you have so much to transport from one place to another, it makes getting from one gate to another. If you have several bags and are changing planes, don't hesitate to ask for assistance. It is best to notify the airline of your needs before your trip and then confirm the request at the ticket counter. When you are leaving the airport, I have also asked for and gotten luggage assistance. That really helps if you have a lot of bags and are short of hands.

Planes are flying full these days. But, it does not hurt to ask when you get to the gate if there are any seats where you could give your child more room. Sometimes they can adjust the seating to give you that extra seat so your child can feel less confined.

Ship ahead!

If you will need lots of supplies while at the conference, you might think about having your supply company ship what you need directly to the hotel. That will minimize the amount of luggage you need and make things a little easier. If you are packing liquid formula in a checked bag, remember to pad it well. Bags are tossed and thrown. One leaker and your clothes are a mess.

Last but not least, remember to allow yourself plenty of time to get through security. That way you won't feel rushed and if you do have any trouble, you will know that you are prepared for anything they throw your way.

I hope that everyone has safe and smooth travels. If anyone has any other questions, I can be contacted at sdoolittle@hughes.net.

Sheryl Doolittle, Mom to Jessica, age 20
Indianola, Iowa

PRESIDENT'S NOTE

by Neal Stanger

Can you believe we have another conference coming up right around the corner? My first conference was in 1995 and this year will be my family's 7th conference; each one attended by our entire family (including my parents and in-laws). When we attended our first conference Megan was just under two years old, and like many of you it was our first time being around so many other kids that were just like her. I remember her sitting on a boy's lap who must have been around 14 years old, he was an inspiration to us and we were amazed at how self determined and independent he was. Well, now Megan is a teenager, we just celebrated her Bat Mitzvah in April and now she is the inspiration for us.

As you may be aware, the Board of Directors of the CHARGE Syndrome Foundation changes every 2 years at conference. Two current members are leaving our Board in July. I would like to personally thank both Dennis O'Toole and Susy Morales for their work for the Foundation. Susy has been the chair of the Education Committee and was also the chair of the 2005 Conference in Miami, Florida. Dennis was on the Executive Committee for the past two years. While serving as secretary, he also chaired the Fundraising Committee. Dennis was the creative force behind our current campaign (Fundraiser in a Box) as well as the driving force of the wonderful DVD that goes with it. He and his wife Colleen chaired the 2003 Conference in Cleveland, Ohio.

As these two members depart, we are welcoming three new Board members. I am pleased to announce that Lacey Friedman, Lori Swanson and Pam Ryan will be joining us. Lacey lives in California with her son Lucas (who has CHARGE), Lori is a Speech-Language Pathologist at the University of Tennessee in Knoxville, and Pam is the School Psychologist in the Deafblind Program at Perkins School for the Blind in Watertown, MA. The final change to our Board is that Lisa Weir, from New Brunswick, Canada has filled a vacant Board position this past spring. Our Executive Committee will be changing as well. I will be starting my second term as President next month, Jim Thelin and John Wynne are staying on as Vice President and Treasurer respectively and Lisa Weir will be joining us as Secretary. Lisa is our first International Board member and we know she will be bringing loads of enthusiasm and great ideas to our Board.

Our Executive Board and entire Board are here to serve you, our families, in any way possible. Please do not hesitate to call or email if there is anything that we can do for you.

FOUNDATION ACCOUNT

EXECUTIVE DIRECTOR'S NOTE

by Marion Norbury

We are continuing our discussion on PAIN with the Non-Communicating Children's Pain Checklist and an article by Dr. Jude Nicholas from Norway.

In the Spring Issue we asked you to think about your child and his or her experiences with pain or discomfort. How did you know your child was uncomfortable? How did you figure out what was wrong? What strategies have helped your child experience less pain or more effectively communicate pain? There is still time to send your stories, thoughts and comments to Tim Hartshorne at harts1ts@cmich.edu so we can share them in the Fall Issue of **CHARGE Accounts**.

ANNOUNCING A NEW PUBLICATION

The National Consortium on Deaf-Blindness is pleased to announce our newest publication, Harmonious Interactions. It describes the importance of teaching families and educators the techniques to create and maintain high-quality interactions with children who are deaf-blind, and is based on research and training activities conducted by Marleen Janssen, Marianne Riksen-Walraven, Jan van Dijk, and Bernadette van den Tillaart.

This is the first of a series of NCDB publications, entitled Practice Perspectives, designed to expand and broaden the use of current information resources.

The document is currently available on the Web: <http://www.dblink.org/pdf/harmonious-interaction.pdf>. A print version will be available soon.

For more information contact:
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The Teaching Research Institute
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345 N. Monmouth Ave. Monmouth, OR 97361
Voice: 800-438-9376 TTY: 800-854-7013
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Email: info@nationaldb.org

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“BIRTHDAY” FUNDRAISER IN A BOX

by Lisa Weir

In the last issue of *CHARGE Accounts*, Brownie Shott related her experience with the “Fundraiser in a Box”, wherein she organized a simple pizza party, and with the help of the kit, was able to raise over \$1500. I was amazed at how simple Brownie made it out to be, but still was wary that I’d be able to find the time, as a busy full-time university student and mom to three, to pull something like that off. I temporarily shelved the idea of doing a similar fundraiser, especially with exams coming up.



Kennedy Weir

The first week of June, I had the privilege of joining the Board of Directors of the CHARGE Syndrome Foundation and attending my first-ever board meeting with the group. Over the course of the weekend, I learned more about the Fundraiser in a Box idea from Dennis O’Toole and had the opportunity to view the DVD. You cannot really put into words how powerful that DVD is and what a great job Dennis and his group did with putting that together. Seeing that DVD made me realize that I had to come up with some way to do it!

It bothered me that I still couldn’t figure how I could possibly find the time to do it when an idea struck – a birthday party! No matter how busy we all are, how crazy life is at any particular time, we *always* find time to celebrate our children’s birthdays. I think as parents of children who have CHARGE syndrome, we have an even more astute recognition of just how amazing it is that our children have made yet another trip around the sun.

So, the birthday party idea is the way I plan on doing this fundraiser – next year when Kennedy celebrates her tenth birthday, I will incorporate the Fundraiser in a Box into the party and hopefully be successful in raising some awareness to those who don’t know a lot about CHARGE, as well as some funding for the Foundation. To be honest, I’ve tried to think of some type of alternative to gifts for a few years now; if your child is anything like Kennedy, they probably already have all the toys, clothes, and other goodies they can possibly fit into their rooms! What better alternative gift than a donation to the CHARGE Syndrome Foundation!

2007 CALENDAR

July 27 - 29	8th International CHARGE Syndrome Conference, Costa Mesa, California
September 1	Deadline for Articles in the Fall Issue of CHARGE Accounts
September 25-30	Deafblind International Fourteenth World Conference, Burswood International Resort Convention Centre, Perth, Western Australia. More details: www.dbiconference2007.asn.au/
September 30	Fall Issue of CHARGE Accounts in the mail
November 20	Deadline for Articles in the Winter Issue of CHARGE Accounts
December 20	Winter Issue of CHARGE Accounts in the mail

Donald J. Joseph, M.D., 1922-2007

On April 23, 2007, Donald Joseph passed away in Lebanon, IL. Dr. Joseph was the former Chief of Otolaryngology at the University of Missouri, School of Medicine. Though he was never a part of the CHARGE Syndrome Foundation, he provided the work environment and encouraged the collaboration of Sandra Davenport, Meg Hefner, and Jim Thelin in the early 1980’s. He treated patients with CHARGE in the 1970’s before the syndrome had been described. And finally, he introduced the CHARGE research team to Marion Norbury of Quota Club of Columbia, MO. The Quota Club supported the publication of the first CHARGE Syndrome Booklet for Families. When the Club disbanded, Marion continued her work with CHARGE. She became the driving force behind the establishment of the Foundation, was on the founding Board of Directors and has served as Executive Director of the CHARGE Syndrome Foundation. It is my wish that Dr. Joseph be remembered by the Foundation as being the catalyst for many good things that have happened to help individuals with CHARGE and their families.

Jim Thelin

***Thank You to Everyone for Your Generous Support of the
CHARGE Syndrome Foundation***

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In honor of Logan Bizantz

Greenwood H.S. Extra-Curricular Account IN

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Alison & Bradley Walter RI

In honor of Megan Stanger's Bat Mitzvah

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Irene Lucas CA

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Nicola Anderson WA

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from the guests at Andrea Rother & Joseph Coleman's wedding OH

In memory of Dale Lewis Miller

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City of Chardon Street Dept OH

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Christine Perry OH

Nathan Speelman OH

In memory of Don Taylor (Cameron Holweger's grandfather)

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Jack & Petreta Watson TX

In memory of Donald J. Joseph, M.D.

James Thelin TN

In memory of Russell Malool

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In honor of Jacob Hartshorne's High School Graduation

Jacob Hartshorne MI

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Chronic Pain in CHARGE: A Constant Companion?

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SPECIAL ACCOUNT

Pain has many valuable functions. It often signals injury or disease and produces a wide range of actions to stop it and treat its causes. Memories of earlier pain, for example, warn us to avoid potentially dangerous situations. Another effect of pain, especially after serious injury or surgery, is to make us rest - thereby promoting the body's healing process. Yet despite these valuable features of pain, there are negative aspects that challenge our attempts to understand the puzzle of pain. Chronic pain, however, clearly is not a warning to *prevent* physical injury or disease. Some individuals with CHARGE syndrome truly have chronic pain, from ear infections, sinus infections or abdominal migraines, for example. In these situations, the main obstacles are communication of the pain and medical management of the sources of pain. In other situations, chronic pain is the result of *neural mechanisms gone awry*. The latter is the focus of this article. In either case, the chronic pain in individuals with CHARGE is often substantial and long lasting, with serious implications for functioning.

The ability of psychological factors to influence the development of chronic pain by shaping behavior and amplifying peripheral sensations is well supported by research. However, there is increasing evidence to show that specific neurobiological mechanisms within brain stress systems may participate in the pain process, sometimes derailing recovery and mediating the progression to chronic pain. In other words, stress can interfere with recovery and lead to a cycle of chronic pain. In attempts to understand the nature of pain disorders, researchers have moved from a purely biomechanical model (looking at biological and muscular systems) towards one with a biopsychosocial emphasis (concerned with the biological, psychological, and social aspects). This understanding has led to the increasing use of self-regulation interventions in the management of pain.

Chronic stress is a source of pain

We are so accustomed to considering pain as simply something sensory – something we feel -- that we have ignored the obvious fact that injury does not merely produce pain: it also produces stress. By recognizing the role of the stress system in the pain process, we realize that the scope of the puzzle of pain is vastly expanded. These new pieces of the puzzle provide valuable clues in our quest to understand chronic pain.

Stress systems may contribute to the development of persistent pain in many ways. The way the nervous system is involved in chronic pain is basically a feedback loop:

psychobiological sensitization within neural loops is maintained by sustained activation. "Sensitization" describes increased efficiency in a neural circuit due to a change in neuronal synapses from repeated use. This feed-forward mechanism increases the response to a stimulus. Sensitization is a typical feature of pain pathways: pain produces pain. This neural sensitization concept of pain may give us a better understanding of some of the chronic pain seen in CHARGE syndrome.

Self-regulation and the perception of pain

Self-regulation is often viewed as a biologically-based attribute that is governed by the prefrontal structure of the brain. It is defined as the capacity to manage one's thoughts, feelings and actions in adaptive and flexible ways across a range of contexts. Self-regulation can be thought of as including three dimensions: cognitive (or intellectual), emotional and behavioral self-regulation. When understanding chronic pain, each of the three aspects of self-regulation should be considered separately.

Cognitively, one must understand the source of the pain and how to avoid or manage it. Emotionally, one must know the appropriate response to a particular level or type of pain. Behaviorally, one must know when to shout, cry, or scream at pain, when to ask for help, when and how to self-soothe, and so on.

David Brown highlights the role of self-regulation in a child's attempts to manage pain. If you have watched a toddler trip and fall, the child will usually look up at the parent. If the parent seems upset, the child will burst into tears. If the parent smiles and says "oops," the child may smile. In a developmental context, such emotion is initially regulated by others, but is increasingly self-regulated over the course of early development, mostly as a result of *repeated social interaction*. In other words, "what the child can only do with the help of the adult today he will do on his own tomorrow."

The child's capacity to regulate their emotions is intimately associated with that child's perception of pain. Impairments in emotional self-regulation in the form of poorly regulated negative affect play a crucial role in the interpretation of pain. Typical children learn about the emotional regulation of pain through observational learning, modeling by peers and adults, and social reentering. Social referencing is using the emotional expressions of others to learn about an ambiguous or novel object or situation. Social referencing includes learning to recognize, understand, respond to, and alter behavior in response to emotional

expressions. The limited “communication bubble” in individuals with CHARGE severely restricts opportunities learning about emotional regulation through typical social channels. Finding alternative ways to educate children with CHARGE to understand pain (physical and emotional) is an important component of pain management for this population.

A major challenge we face with children who have CHARGE is trying to understand and interpret their expressions of pain. Another is how to provide opportunities for the observational learning, modeling and social interactions necessary to learn emotional self-regulation. How

can we help a child with limited vision and hearing and limited communication abilities build up a mental image of pain? There are no easy answers. The degree of success depends largely on the ways in which the environment is supportive and involved in sharing emotions and communicating pain. That means one has to build up shared events and shared meanings around specific pain experiences. If you have experiences you can share which helped your child with pain and/or emotional regulation, please send them to us so we can compile examples to share with other families.



On April 13, 2007, Eric and Sabrina Bluestone hosted a fundraiser in New York City for the CHARGE Syndrome Foundation. We thank everyone for their generous contributions.

- | | | |
|---|--|---|
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