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President's Message



WOW, what a conference we just had. Throughout this first online version of *CHARGE Accounts*, you will be reading many articles about the wonderful events, sessions and great time had by all at the conference. That being said, none of this could have happened without the team put in place by conference chair, Brownie Shott. Brownie gave up her life for the first seven months of this year to ensure every detail was looked after so that all of us would be well cared for and have a great time at the conference. I have thanked Brownie many times both publicly and privately, but would like to take this opportunity to thank both her and her team once again.

As some of you already know, I have a brand new Executive Board working with me for the next twenty-four months: Lisa Weir is now Vice President, David Wolfe is Treasurer and Brownie Shott is Secretary. I am looking forward to many great things coming from this group. I would also like to announce that Cynthia Antaya & Diane Haynes have joined our Board of Directors this year. Diane works as State Coordinator of the Kentucky Deaf-Blind Project and Cynthia is a school psychologist, who not only has a son with CHARGE syndrome, but also has CHARGE syndrome herself. I am certain Cynthia and Diane will be huge assets to the board.

Unfortunately, I am sad to have to report that I have accepted the resignation of Dr. James Thelin. Jim has been a Board member for six years, Vice President for the last four years, and Program Chair for the last two conferences. I am proud to call Jim a friend and I will miss his insight and his wisdom on the Board.

Record-Breaking Attendance



See how the conference has grown, from the first in 1993 in St. Louis with 200 people to:

Portland (1995) - 250

Boston (1997) - 400

Houston (1999) - 450

Indianapolis (2001) - 500

Cleveland (2003) - 492

Miami (2005) - 540

Costa Mesa (2007) - 625

Bloomington
(2009): **756!!!**

There were ten countries represented, including: 130 individuals with CHARGE syndrome (20 adults and 110 children), 291 parents, 53 grandparents, 126 professionals, 21 caregivers, 108 siblings under the age of 16 and 16 siblings over the age of 16.

CHARGE Conference Idol Extravaganza

The 2009 CHARGE Conference Idol winner was pianist Sean Timberland, pictured here after being presented with the 1st place trophy.



Pam Ryan asked me to judge Conference Idol, so I couldn't say no. But I wasn't comfortable with the idea of a competition, with winners and losers, and me sitting in judgment. Well, as soon as I saw about 40 trophies lined up on the judges' table I knew I probably didn't have to worry.

Yes, there had to be a big winner, a Conference Idol, but there were no losers – and the only competition was be-

tween the four judges as we all tried to be the nicest, friendliest, most encouraging one at the table.

Sean Campbell's opening violin solo set the standard high, and it remained right up there as 22 others followed him in dazzling variety - instrumentalists, singers, dancers, storytellers, stand-up comics, even a stuffed toy balancing act!

In my notes I see I scribbled the word 'winner' next to the names of the first nine per-

formers, then I gave up trying to decide, because this was not really a talent contest but a talent show full of nerve, energy, poise, humor, drama, and – talent! Clearly this has to be a feature at future conferences, and next time I look forward to enjoying it from the audience not the judges' table.

Submitted by: David Brown

Two Judges Give A “Surprise” Performance

Judges Joe McNulty and David Brown performing “I Got You Babe”.



The CHARGE Conference Idol audience got an extra special treat when judges Joe McNulty and David Brown were “invited” up onto the stage by emcee Sheri Stanger to take care of some “housekeeping items.”

Little did Joe or David know, after they were each handed a microphone, a karaoke version of Sonny & Cher's “I Got You Babe” was set to begin.

Both gentlemen were extremely good sports. Although nobody is quite sure who was Sonny and who was Cher, and Joe adlibbed some of the words to say, “I Got You Dave,” all in all these two judges were a runaway success!

Who knows what these two may have planned for Orlando in 2011?

Pictured below are the idol judges, from left to right: Joe McNulty, Michele Sinopoli, Sally Thelin and David Brown.



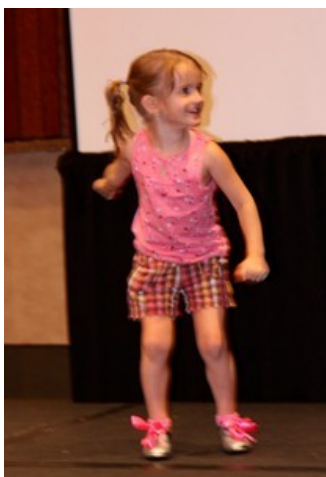
Honestly...we all came to the conference for inspiration, support and new knowledge. To see the spectacular Charge Idol definitely proved everything that the "official presentations" were saying. We must expect great things from our kids! So to me, the Charge Idol should take one whole day at the next conference because it's the important stuff – celebrating our kids!

*-Catherine Rose,
Alexis' Mom*

Meet the “Stars” of Conference Idol 2009...



Sean Campbell



Emily von Dohre



Sean Timberland



Amy Garner



Kennedy Weir



Megan Stanger



Aubrie Westmaas



Brian Cavella



Dane Robertson



Destiny Chinnici



Linda and Karlee Ludwig

*See more STARS
on the next page!*

More Conference Idol 2009 Stars...



Seasyn Williamson



Sophia Reyes



Shannon Boelter

"Wow, you did a very great job with the CHARGE Conference. I loved being there. Such wonderful families. As a matter of fact, I had a hard time pulling away – I stayed for the talent show – so wonderful. Thank you for the education on CHARGE, your well organized event, the opportunity on a business level and a great day with many kind and dedicated people. I wish it was in the Chicago area all the time so I could participate."

-Sherre
Vendor, Discovery Toys



MacKenzie Cutcliffe



Josh Nunner



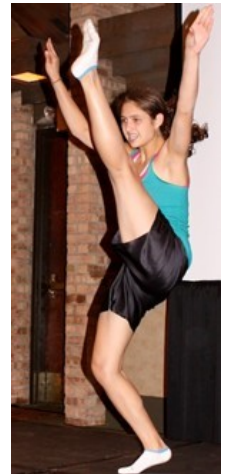
Gretchen Wood

Max McKinley
(with mom, Amy)

Melissa Costello



Clare O'Toole



Sara Kotnik

Conference Idol Photos
by: Meg Majors



First CHARGE Syndrome Conference for Professionals



This year, the CHARGE Syndrome Foundation hosted the First CHARGE Syndrome Conference for Professionals on Thursday, July 23, 2009.

Historically, professionals had met informally on Thursday afternoons before the CHARGE Conference. It had long been thought that more time was needed for the professionals to network, share ideas, update each other on current research projects and so on. This was the impetus for creating a more formalized conference for professionals.

Families were also invited to attend the conference, with the under-

standing that this was a time for the professionals to discuss their work as opposed to individual cases.

There were one hundred twenty-six attendees at the professional conference. Twelve platform and sixteen poster presentations were presented on a variety of topics relating to CHARGE syndrome.

Dr. James Thelin, who spearheaded the Professional Conference, will be providing CHARGE Accounts with a more in-depth article on the professional conference in the next issue.

"The meeting in Chicago was one of the best organized and best run I have attended in a long time. The program was uniquely sensitive to the families and their needs, which made it 'super special' and wonderful.

The professional meetings on Thursday were so helpful. Thank you for letting us be a part of the conference."

*-Herb Byrd,
Director,
Comprehensive Educational
Resource Center
Tennessee School for the Deaf*

Message from Brownie Shott, 2009 Conference Chair

Greetings from the very hot state of Texas! I'd love to have some more of that lovely weather we experienced at the conference. I've been home just over 3 weeks and am beginning to return to my version of normal. I think I'm experiencing a kind of withdrawal from the wonderfully high emotions of the conference experience. Running on adrenaline for so many weeks leading up to the conference re-

sulted in some major sleep time post conference.

The conference was worth every moment of planning and hard work that went into it. It was truly a collaborative effort of people who are passionate about making this biennial conference a fabulous event for families, individuals with CHARGE syndrome and professionals. The reward was seeing everyone come together to share

experiences and create new memories.

I am very thankful for the wonderful team who worked with me from the very early planning stages to the final packing of boxes. It's now time to look forward to Orlando in 2011. So, I pass the conference torch to Janet Murray who I'm sure will achieve even bigger and better things. See you in two years!

Breakout Session Highlights

The following pages will feature the moderator reports submitted for each of the breakout sessions held at the conference. These are meant to be an outline of the presentation, which will give you an idea of what went on in each session. If you are interested in more information, you have a couple of options: audio cds of each session or a cd containing the handouts and

other information given out to conference attendees.

AUDIO CDS

All of the conference sessions were recorded. Specific session recordings can be ordered or they can all be ordered as a complete set.

To order, visit DCP.Providers online or call (630) 963-8311.

CONFERENCE CDS

Additionally, the Foundation has put all of the conference proceedings such as schedule, speaker handouts, and contact information together on a CD, which is available for \$20, including shipping. To order one of these, please contact info@chargesyndrome.org or call Lori at the office: 800-442-7604 or 516-684-4720.



Breakout Sessions



David Brown with a friend at the Thursday evening reception.

What worked when you talked to your child about having CHARGE?

“Keep a sense of humour and be realistic.”

BREAKOUT SESSION: I

“Minding the Gap”

Presenters: David Brown and Gail Deuce

Moderator: Lisa Weir

Attendance: ~200

Moderator Report:

This session presented the findings of interviews conducted by David and Gail with parents of people with CHARGE. They asked a number of questions relating to talking to their child about having CHARGE syndrome.

The questions were as follows:

1. Had they talked about it with their child?
2. Why did they feel it was important to talk or not talk about it?
3. When or why did they decide to share?
4. What information did they share or not share?
5. How was the information shared? What worked/didn't work?
6. What advice or support were you given to help with this process?
7. What other information/support/advice would've been helpful in going through this process?

Some of the answers for questions 1-4 included:

- they talked about things as they came up
- it was an ongoing process
- they were open and honest
- the details of what was shared depended on the communicative abilities of the child, etc.
- fertility was an issue for some families and some felt they didn't have enough information to adequately explain it.

For #5, all parents waited for a 'trigger' to get more in depth discussions going. All also reported that they tried not to get too heavy about things. Another common thread was trying to focus on the fact that their child was a *person*, and that CHARGE did not define them. Keeping a sense of humor and being realistic were reported to be helpful in the process. Others stated that meeting other people with CHARGE syndrome, giving the two individuals an opportunity to interact, ask each other about things, then discussing it later with their child was also helpful. One or two families involved outside professionals, such as a counselor from a mainstream educational setting, to come in to talk to the person about having CHARGE syndrome. One parent recommended that it is important not to *teach* about it, but to *talk* about it with your child.

Regarding #6, most reported they had little support with the process of talking to their child about having CHARGE. Some were supported by [Sense UK](#) but most had to do their own research to get the information required to do it properly. Some had help gathering information from CHARGE organizations and groups in [Australia](#) and the [US](#) as well as [State Deafblind Projects](#).

Question #7:

Families reported the most important thing that would've helped them was access to more professionals who understood CHARGE syndrome. A common occurrence was families having to explain it to the professionals, instead of receiving the information and support from the professionals. Support groups for people with CHARGE to meet and talk with each other and a booklet or some set of guidelines were also mentioned as possibilities for resources that would make the process easier for families.

Other important points from the families included:

- before talking to the person with CHARGE, talk about it yourselves and within your families
- there is no one right way to do this, each family will know their child best
- most felt it was important to talk about CHARGE to help with the individual's sense of self-identity
- professionals need to increase their knowledge about CHARGE, otherwise how can they support the families?
- it is helpful for parents to have clear information such as the professional packet, research articles, etc, about CHARGE.
- families need to know about support groups and take advantage when possible.

David Brown made another important point, "Remember, they have more of *your* genes than CHARGE genes, so not everything is CHARGE syndrome's fault!"

"The most important thing that would've helped them was more professionals who consistently understood CHARGE syndrome."

BREAKOUT SESSION: I**Grandparent Meeting**

Facilitator: Len Stanger

Attendance: 45

Moderator: Len Stanger

Moderator Report:

We had a fantastic number of grandparents and our meeting went extremely well. It was light, fun and easy-going. Rather than talking about their grandchildren and the progress they are all making since birth, we talked about our feelings when we heard our new grandchild had CHARGE. We also discussed how their lives changed and the effect on them, their relatives, and friends. The general consensus was everyone involved became better people and advocates for all people with disabilities. Thanks for giving me the opportunity to chair this wonderful meeting.

Conference Photos



Meg Majors, our official conference photographer, took a lot of amazing photos at the conference.

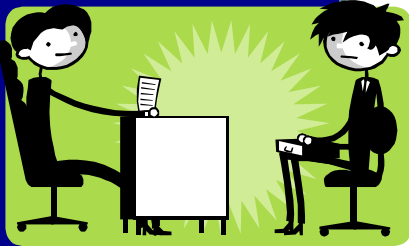
These photos can be viewed and individuals can order as many photos as they want at the following web site: <http://mmmajors.smugmug.com/>

gallery: CHARGE Conference 2009 | FAMILIES

password: chicago

You can also order a slideshow DVD of selected conference photos.

Slideshow DVD's are \$15. Please [email Meg](#) to order your copy!



"We had a fantastic number of grandparents and our meeting went extremely well."

-Len Stanger

*Moderator,
Grandparents' Forum*

Breakout Sessions (continued)

BREAKOUT SESSION: I

"CHARGE into Vocational Training"

Presenters: Christa Gicklhorn, Wendy Bridgeo

Attendance: 10 adults with CHARGE

Moderators: Pamela Ryan/Kathy McNulty

Moderator Report:

Presenters used a game format to engage the young people (age 18 to 44) in conversation about their current or past work experiences and to prompt discussion about future goals for work.

The game, "Fun Feud" involved two teams, whose members answered questions using a buzzer. The Dolphins swept Las Vegas, answering questions such as:

What do you bring to a job interview?

How do you find a job?

Who can help you find a job?

Why do we work?

Questions were designed to help the team members talk to one another, think about the importance of being on time, attending to hygiene (dressing appropriately, cleanliness), asking and answering questions from interviewers, and understanding the importance of work and how it affects one's overall pride, skill development, community integration, and ability to earn money and be self-sufficient.

BREAKOUT SESSION: I

"Bone Anchored Implants: BAHA"

Presenter: Dr. Lisa Christenson

Attendance: 45

Moderator: Martha Majors

Moderator Report:

Lisa presented an overall summary of the BAHA process from "beginning to end" with specific emphasis on the process appropriate for young children. She provided current information related to the BAHA options and the available accessories; she clearly described each of the processors that are currently available. She provided "helpful hints" related to pre-surgery and follow up to parents so that parents would be better informed. Lisa addressed challenges through case study examples of young children with CHARGE syndrome. Sharing and questions were at the end of the session.

BREAKOUT SESSION: 1**“CHARGE 101 for New Families”**

Presenters: Meg Hefner and Kim Blake

Attendance: 65

Moderator: Lori Swanson

Moderator Report:

Hefner, genetic counselor, reviewed the four Cs of CHARGE: coloboma, cranial nerves, choanal atresia, and characteristics of CHARGE ears. She stated that choanal atresia often requires 4-5 procedures to keep the passageways open. Balance problems (part of the characteristic ears) often result in a 5-point crawl in which the children lie on their backs and use their heads to crawl. Children with CHARGE start walking at 3-4 years of age. They often exhibit autistic-like behaviors and may have obsessive-compulsive disorder (OCD). Parents were cautioned that if their toddlers appear developmentally delayed, there can be catch up! Lack of input due to sensory deprivation can cause developmental delays.

Blake, pediatrician, talked about the risks of anesthesia. Unfortunately, post-operative airway events are common in children with CHARGE. Blake stated that when 215 surgeries were reviewed, 35% had problems. 60% of these were major complications. She urged parents to inform physicians of these staggering statistics. Parents need to encourage surgeons to perform multiple procedures at one time under one anesthesia, as going in and out of anesthesia is the problem, not the length of the surgery.

“...post-operative airway events are common in children with CHARGE.”

BREAKOUT SESSION: 2**"Genetic Diagnosis of CHARGE syndrome"**

Conny M.A. Ravenswaaij-Arts, M.D., PhD.

Attendance: ~120

Moderator: Pamela Ryan

Moderator Report:

Dr. Conny shared details of the "hows" and "whys" of genetic testing for CHARGE syndrome. She started her presentation by talking of the clinical diagnosis of CHARGE syndrome (based on known features—phenotype) and providing information about "normal" chromosome analysis and then the need for further analysis at the DNA level (genotype). Dr. Conny went on to describe the process of sequencing the CHD7 gene followed by comparative studies of percentages of people with positive *genetic* (DNA) diagnosis versus those with negative genetic diagnosis.

Dr. Conny's use of graphs and charts was aimed at explaining gene mutation and how researchers look for and find the mutations.

**BREAKOUT SESSION: 2****“CHARGE 102: Sensory Loss: How Does that Change Early Development?”**

Presenter: Dr. Sandra Davenport

Attendance: ~90 to 100

Moderator: Kathy McNulty

Moderator Report:

Dr Davenport is a presenter who can take complex medical information and present it in a very clear and understandable manner. This session reviewed the anatomy of the eye and ear and explained what happens to a child's vision and hearing as a result of having CHARGE syndrome.

Parents particularly enjoyed the activities that simulated vision and hearing loss. Using simple low-tech materials, such as multiple layers of clear plastic baggies and foam earplugs, Dr. Davenport creatively and effectively demonstrated what the world looks like for individuals with vision and hearing loss.

Breakout Sessions (continued)

BREAKOUT SESSION: 2

“Cochlear Implants for children with CHARGE syndrome”

Presenter: Beth Tournis, Au.D.

Attendance: 40

Moderator: David Wolfe

Moderator Report:

Dr. Tournis spoke generally about assessing the candidacy for a patient to receive a cochlear implant. She pointed out some of the difficulties in measuring the benefit that an individual with CHARGE syndrome may receive from a cochlear implant. She presented two case studies of individuals with CHARGE syndrome who were both implanted and evaluated by her team. The case studies showed the very wide range of outcomes individuals with CHARGE syndrome may have. One individual had very little, if any access to sound. The parents reported some change in behaviors and that the child continued to wear the implant; however, the child did not really react to sound. The second individual could understand and respond to speech. Dr. Tournis showed video of him performing tasks as instructed by his therapist and mother. Dr. Tournis believes that with proper screening and appropriate expectations, all individuals with CHARGE deserve an opportunity to hear.

BREAKOUT SESSION: 3

“CHARGE 103: Setting the Scene: Babies and Toddlers”

Presenter: Rob Last

Attendance: ~50

Moderator: Lori Swanson

Moderator Report:

Rob Last's presentation focused on providing early intervention for the development of communication skills. He emphasized that “communication” includes body language, facial expressions, gestures, manual signs, and speech. The complications of CHARGE often necessitate the use of multiple communication modes. Therefore, families are encouraged to use both manual signs and speech during the early stages of language development. Parents should embrace the use of signs at birth to give the child a means of communication. To learn sign language, parents should seek the help of teachers of the Deaf, members of Deaf community, children of Deaf adults (CODAs), and attend sign classes. Last also recommended the use of “voice off time” at home as a means of promoting manual communication. Use of signs should involve more than just “key words.” It should provide children with the rich input children receive from speech. The development of early communication skills will prevent the behavior problems caused by the inability to communicate one's wants and needs. Best practice for children with CHARGE equals early amplification and the use of multiple modes of communication from infancy.

“...families are encouraged to use manual signs and speech during the early stages of language development.”

Sign Language Websites

- American Sign Language Browser: <http://aslbrowser.commtechlab.msu.edu/browser.htm>
- ASL Pro: <http://aslpro.com/>
- ASL Dictionary: <http://www.masterstech-home.com/ASLDict.html>
- Signing Time Kids: <http://www.signingtimekids.org/>



BREAKOUT SESSION: 3**“Resources for Physical Education, Sport & Fitness for Children with CHARGE Syndrome”**

Presenter: Lauren J. Lieberman, Ph.D.

Attendance: 103

Moderator: Marilyn Ogan

Moderator Report:

Physical education concepts are important for children with CHARGE. Participation is not the end all, be all. They need to do the same things as their peers. If a straight-legged cartwheel is a requirement, it should also be the goal for a child with CHARGE, although modifications may be necessary. Adaptive PE is the service that makes the adaptations to the environment or modifications within inclusive settings. The importance of having qualified professionals for making the modifications for students with CHARGE was also emphasised.

One strategy is to incorporate an extra day of PE, so you can pre-teach the student with CHARGE, enabling the student to be able to achieve with peers – this can include pre-teaching concepts, terms, and positions. Also, if using sign language, it is important to make sure when teaching the soccer concept in ASL, for example, to make sure student understands that it is S-O-C-C-E-R spelled out, so they are able to pass a written test on the concept.

The Brockport Fitness Test and resources for students with visual or hearing issues were also presented. These included: Walk-Run for Fitness Kit (it was noted that the Quota Club will often provide funds for the kit if applied for through the PE teacher), ropeless jump rope, beeping balls, tactile food pyramids, tactile sports mats, and information on websites and Camp Abilities.

“Physical education concepts are important for children with CHARGE.”

BREAKOUT SESSION: 3**“Special Needs Future Planning: Trusts, Government Benefits, Guardianship, etc.”**

Presenter: Brian Rubin

Attendance: 110

Moderator: David Wolfe

Moderator Report:

Brian Rubin spoke about planning for the future of a child with special needs. He gave an overview of what parents and others can do to impact future government benefits. He outlined some of the important steps that families can take to insure that their hard earned savings do not prevent an individual from qualifying for certain government benefits such as SSI, SSDI, Medicaid and Medicare. In many cases, the best way to protect an individual with special needs is the Special Needs Trust. Mr. Rubin stressed the importance of seeking legal advice from an attorney specializing in special needs planning.

He outlined many of the pitfalls that exist for families and some of the ways to avoid the most common mistakes. The law in this area is very complicated and state specific. Brian offered to refer anyone to an attorney in their area to assist them with coming up with an estate plan that would meet their needs.

**Editor's Note:* For more information or a state by state listing of Special Needs Alliance Member Attorneys, visit <http://www.specialneedsalliance.org> or call 1-877-572-8472. During the presentation, Mr. Rubin also agreed to provide information to the Canadian families in attendance about someone who could help them. Two names were provided: Graeme Treeby with the Special Needs Planning Group, phone number (905) 640-8285 and Kenneth Charles Pope in Ottawa at 1-866-KEN-POPE or 613-567-9724.



*“Most parents
thought their child
could smell even
when they had no
sense of smell.”*



Breakout Sessions (continued)

BREAKOUT SESSION: 3

“Impact of Cochlear Implants for Children with CHARGE Syndrome: Preliminary Findings”

Presenters: Susan Bashinski and Kat Stremel Thomas

Attendance: 31

Moderator: Jennifer Vick (TN Deafblind Project)

Moderator Report:

Preliminary findings were shared from a research study investigating outcomes for children with CHARGE syndrome who have received cochlear implants. The initial grant looked at progress children with implants have made and the amount of time it has taken to see progress for some. A second grant will look at developing intervention strategies and materials, especially for those who may not have access to Auditory Verbal Therapy (AVT). Investigators are not advocating for or discouraging cochlear implants; they are interested in collecting more data on individuals with CHARGE and/or deafblindness who have been implanted.

BREAKOUT SESSION: 5

“Smell and Puberty in CHARGE Syndrome”

Presenters: Jorieke Bergman, M.D. and Conny van Ravenswaaij-Arts, M.D., Ph.D.

Attendance: 75

Moderator: Marilyn Ogan

Moderator Report:

How we smell and anosmia (inability to smell) were both explained. Normal puberty and development in boys and girls was outlined and the variations that can occur with CHARGE. Twenty-six individuals with CHARGE were tested at a clinic in the Netherlands. They received endocrinology evaluations and the UPSIT (University of Pennsylvania Smell Identification Test). Problems encountered with the UPSIT were communication issues, developmental issues, some children who were tube fed could not identify food items and one child was excluded because of bilateral choanal atresia. Evaluation can also be made by examining the olfactory bulbs on MRI brain scans. We cannot yet make the correlation to smell based on scan of brain structure, though.

Findings showed that some individuals with CHARGE *can* smell. The study showed that those with smell had started puberty spontaneously, and those without smell all had delayed puberty. There was no correlation found between the type of CHD7 mutation and smell or puberty problems. There was variability within families. For example, a father had smell and normal puberty, but the daughter was unable to smell and had no puberty despite having the same CHD7 mutation. The study showed that most parents thought their child could smell even when they had no sense of smell.

Reasons that smell is significant were presented:

- alarm system (spoiled food, smoke)
- amplifies sense of taste
- social (body odors)
- linked to memory and learning
- bonding

It was reported that anosmia cannot be cured, but preventative measures can be put in place such as: smoke alarms, gas detectors, expiration dates on food, deodorant, and help of friends.

The importance of puberty beginning at the typical age includes fewer socio-emotional problems and a reduced risk of osteoporosis. A smell test may be helpful in predicting whether spontaneous puberty will occur in individuals with CHARGE as smell and puberty problems were 100% correlated in this study. Decisions about treatment for delayed

***“A smell test
may be helpful
in predicting
whether
spontaneous
puberty will
occur in
individuals with
CHARGE...”***

BREAKOUT SESSION: 5

“Going to College: What do I Need to Know?”

Presenters: Beth Jordan and Belinda Montgomery

Attendance: 12 individuals with CHARGE

Moderator: Kathy McNulty

Moderator Report:

Wonderful strategies on how to choose/select a college were identified and discussed.

Participants generated a list of accommodations and supports that would be of benefit to a college student with a vision and hearing impairment. There was a lively discussion with lots of questions; it was a very interactive session.

Scholarship Opportunity

The Bella Cavallo Foundation is offering two scholarships to students with CHARGE syndrome who are seeking to pursue higher education. The deadline for applications is December 31, 2009. More information and the application form can be found at

<http://www.thebellacavallofoundation.org/scholarship.pdf>

BREAKOUT SESSION: 5

“Developing Meaningful Conversations”

Presenter: Diane Haynes

Attendance: 80

Moderator: Emily King Miller

Moderator Report:

When we converse, or interact, there are two partners: one sending and one receiving.

In seeking more/better output from our children, we have to consider our own input. One must make sure to have the person's attention first, and then watch how much information we are sending at one time. A computer analogy was presented that talked about computer command information being entered completely, accurately, purposefully. If the input is not correct, the computer response or “output” will be inaccurate.



(continued on next page)

Breakout Sessions (continued)

(continued from page 13)

There are several receptive functions, or reasons why you are communicating with your child. These include such things as: greetings, getting someone's attention, telling one about an upcoming event, etc. You have to make sure you are communicating exactly what you intend and consider what receptive form is most appropriate for the child. These forms include: speech, tactile/touch cues, object cues, picture cues, gestures, tactile signing, platform signing, and natural or contextual cues.

Questions we need to ask relating to communication include:

What does the child/student understand?

Is my function/purpose of communication clear to the child/student?

Am I addressing all critical functions of receptive communication?

Do I need to modify the form(s) I am using to send information to the child/student?

*"In seeking more/
better output from
our children, we
have to consider
our own input."*



**Father and son
sharing a moment
at the conference.**

BREAKOUT SESSION: 5

"Parenting Children with CHARGE Syndrome: Perils and Promise"

Presenter: Tim Hartshorne, Ph.D.

Attendance: 265

Moderator: Jennifer Vick (TN Deafblind Project)

Moderator report:

Presentation topics included:

- Typical characteristics of children with CHARGE
- Parent experiences: guilt, defend and protect, expectations, coping
- Courage! (it is not denial!)
- Executive functions
- Importance of family meetings
- Encouragement
- Behavior and misbehavior
- Self-regulation
- Punishment and rewards

Other points from the presentation included:

Respecting communication and provision of choices

Reducing stress through providing routines, consistency, choices and sensory breaks

Providing powerful encouragement

Working on optimal eating, sleeping, health

Medication should not usually be the first thing to try

BREAKOUT SESSION: 6**“Balance: What is It? How Does It Work?”**

Presenter: Dr. Mary Ann Girardi

Attendance: ~125+

Moderator: Kathy McNulty

Moderator Report:

Dr. Girardi gave excellent, concrete examples that helped the parents understand the function of the vestibular system and the connection it has to balance and motor skills.

Dr. Girardi provided wonderful examples of activities and equipment that promote balance.

The parents asked many questions such as how do you teach a child to jump or what type of shoes and orthotics are the best to wear. The presenter demonstrated great experience and expertise in answering all questions.

BREAKOUT SESSION: 6**“Person Centered Planning as an Adjunct to Psychoeducational Evaluation for Individuals with CHARGE”**

Presenter: Nancy Salem-Hartshorne

Attendance: 66

Moderator: Susan Hiscutt

Moderator Report:

Nancy Salem-Hartshorne presented information regarding Person Centered Planning, a technique she has used to assist families and professionals to come together to meet the needs of students with CHARGE.

Nancy discussed traditional assessments, why they are used and how information is typically gathered using traditional assessments. Nancy then explained how Person Centered Planning is used to assess students by “determining their strengths, needs, communication skills/ preferences, and their preferences for people, activities and settings all with an eye to the future.” Nancy explained that “individuals with CHARGE have unique and complex needs that are not easily met through traditional assessment techniques.”

Nancy also showed how she has used one type of Person Centered Planning, called MAPS (Making Action Plans) to help two individuals with CHARGE and their families to determine goals and achieve desired outcomes.

The “take home message” from this presentation was, “If an evaluation doesn’t 1) answer evaluation questions and 2) result in recommendations that help ‘in reality’ to improve the persons’ life in some way – Why waste your time?”

BREAKOUT SESSION: 6**“CHARGE Syndrome: The ‘R’ and ‘G’”**

Presenter: Jeremy Kirk

Attendance: 135

Moderators: Rick and Marilyn Ogan

Moderator Report:

Dr. Kirk adapted his presentation to reflect questions that were generated by the parents – especially those asking for more clarification between growth hormone and sex hormones. Jeremy presented some basics about growth then took direct questions from the audience. He commented that idiopathic (unknown cause) short stature is now approved for growth hormone therapy in the US.



“Natural supports and accommodations are important and expectations of employment are key.”

BREAKOUT SESSION: 7

“Taking Charge of Your Life, Developing a Positive Vision Toward Employment”

Presenters: Michael Fagbemi and Joe McNulty

Attendance: 17 young adults with CHARGE

Moderator: Nancy Hartshorne

Moderator Report:

This session described employment and national agenda items related to young adults with deafblindness and CHARGE. Suggestions were made for putting together vocational training portfolios for students while in school regarding vocational experiences. Often, there is a disconnect between education and transition services, leaving families and individuals with few options.

Eighty (80) percent of young adults who are deafblind are unemployed and continue to be somewhat isolated in their communities. Customized employment stands on the shoulders of supportive employment. This method identifies existing skills to help translate those into potential job skills. Customized employment utilizes good employment practices to assist in developing a negotiated job that both helps the employer and uses the interest and skills of the individual employee. Salaries are negotiated at the prevailing wage. The job seeker is represented by an advocate in this process. The focus is on contribution as opposed to competition - what can this person do that will move the company forward? Natural supports and accommodations are important and expectations of employment are key.

BREAKOUT SESSION: 7

“Successful Teaching Strategies and Key Components for Use in Educational and Community Settings”

Presenters: Martha Majors and Sharon Stelzer

Attendance: ~125

Moderator: Lisa Weir

Moderator Report:

Martha and Sharon presented key factors and teaching strategies for individuals with CHARGE syndrome. Major topic areas included communication, curriculum, and environments.

Communication:

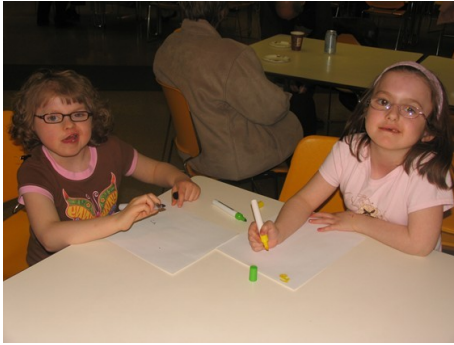
The importance of understanding the combined sensory losses and their effects was stressed. Martha reminded that we need to know “where” to communicate to a person with CHARGE, which can be individualized depending on their specific losses. How we communicate via the materials we use must also be considered. These materials may need to be individualized depending on the student and may include such items as: slant board, large print, varying distance from materials, etc. A variety and combination of accommodations may be required and should be part of the student’s IEP.



A total communication approach benefits many students. It may include: sign, speech, gestures, symbols (Mayer-Johnson, e.g.). The communication mode for each child will be based on the child him/herself and will involve the families as the ones who will make the decision as to what works best.

Using the child’s interests to motivate and help them learn as well as using sensory-themed age-based activities were recommended. An example was shown of using a “Mr. Potato Head” to learn money concepts in math.

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Curriculum:

The content should be fun and age appropriate with a range of options. Learning can occur both in the class and in natural learning environments. Activities should be motivating, functional, involve variety and include social skills. Skills should be taught across a variety of settings.

A list of what every child with CHARGE must learn was shared, and includes learning how to effectively communicate, make choices, help out, be social, be part of a group, negotiate, be organized, anticipate activities, take turns, and cope with behaviors.

“...the class environment and schedule must be flexible in order to accommodate the student’s needs.”

A number of teaching strategies were presented, with emphasis on keeping things motivating, following the students’ lead and negotiation. Concrete examples were given regarding the characteristics of students and strategies of how to address them. For example, if a student is displaying over-attention to detail (or getting “stuck” on a topic), use negotiation, set time limits and have a flexible teaching attitude. If a student needs to calm his or her anxiety, use partial vs. full participation, set clear expectations, use SMI (sensory motor integration techniques) and signals to help calm the student.

Structure and routine were also emphasised as being important for students with CHARGE syndrome. It is important to not get into power struggles with students who have CHARGE. Take the “person factor” out of it when a struggle seems imminent. For example, instead of telling the student, “We have to go now, it’s time for gym,” take yourself out of it, show the student the calendar and remind them, “The calendar says we have gym now, so we have to go.”

Other strategies include: choice-making, use of prompt levels, giving pause time for student response, using task analysis, modeling, fostering an awareness of hands/touch, allowing student to share, and emphasising beginning-middle-end.

Environments:

It is important to recognize when sensory breaks are needed. Students must be observed for signs of fatigue and adequate room should be available for them to relax, calm and quiet themselves. Learning to anticipate the need for sensory breaks and allowing the student to have a quick break can be critical to his or her success in the classroom setting; therefore, the class environment and schedule must be flexible in order to accommodate the student’s needs.

BREAKOUT SESSION: 7

“What’s There to Stress About?”

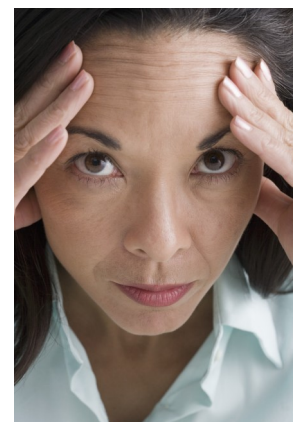
Presenter: Kasee K. Stratton

Attendance: ~150

Moderator: Michele Westmaas

Moderator Report:

In this session, Kasee Stratton, doctoral student in school psychology under Tim Hartshorne at Central Michigan University, shared findings from interviews conducted with young adults with CHARGE. The focus was on stress and early pain experiences and how young people with CHARGE experience and communicate pain. One hypothesis is that individuals with CHARGE don’t have a high pain threshold; rather they express their pain experiences differently through behavior and other such cues.



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Discussion related to many stress-related themes: school, friendship, family, anxiety, etc. Suggestions for helping individuals with CHARGE include recognizing that a child's early pain experiences can play a role in behavior, developing appropriate communication of pain and stress responses, understanding the many facets of CHARGE, enlisting the support of specialists (OT, PT, O&M, etc.), developing friendships, reducing stress (reducing workload, allowing breaks, etc.) and using one-on-one support when needed.

Future work will investigate multi-dimensional pain assessments appropriate for individuals with CHARGE and provide parents/caregivers/educators with the behavior and communication signs that may signify pain.

“...the best functional vision skills may not come from the individual with the best vision!”
-David Brown



BREAKOUT SESSION: 8

“Vision Issues for People with CHARGE Syndrome”

Presenter: David Brown

Attendance: ~95

Moderator: Rob Last

Moderator Report:

David focused on the complex visual issues faced by individuals who have CHARGE syndrome. Emphasis was placed on early childhood when visual motivation and behaviors are established. Types of vision loss were discussed as well as the “Equilibrium Triad,” which involves touch/proprioception, vestibular sense and vision.

Brown presented a list of things to consider regarding vision and individuals with CHARGE:

- the eyes, and ocular defects
- the nerve pathways that connect the eyes to the brain
- the brain itself
- muscle tone, and the obstacles that abnormal muscle tone present to effective use of vision
- broader issues of postural control, and energy levels and fatigue
- distractibility and the place of vision in the individual's hierarchy of the senses (i.e. is vision an important resource for this person, or does it seem very low priority for them?)
 - Expectation, previous experience, and motivation of the individual (and of the people around them)
 - Environmental factors such as visual clutter, physical placement of things in relation to the individual, lighting levels, other distractions that might compete for the individual's attention

Brown reminds that we don't see with our eyes, but with our brain; the eyes collect the information that the brain “sees” and that the best functional vision skills may not come from the individual with the best vision!

BREAKOUT SESSION: 8**“Nanny 411”**

Presenters: Laurie Denno and Deanna Rothbauer

Attendance: 196

Moderator: Sally Prouty

Moderator Report:

Children with CHARGE syndrome have learning challenges due to their sensory and health/medical issues. Laurie Denno (behavior analyst with 30 years experience) and Deanna Rothbauer (parent of 13-year-old Danny) provided excellent guidance and shared practical experiences with promoting positive behavior to a packed conference room. Laurie provided practical suggestions and Deanna followed up with her trying experiences with Danny. Time ran too quickly as the audience absorbed these wonderful pearls of wisdom from these experienced presenters.

BREAKOUT SESSION: 8**“Look At Me Now”**

Presenters: Costello Family, Donna Consacro and Jennifer Miller

Attendance: ~60

Moderator: Michele Westmaas

Moderator Report:

This panel presentation showcased Melissa, a vivacious young woman with CHARGE syndrome who has been successfully included in home, school, and community throughout her life. The panel included Melissa's parents, siblings, and staff from the TN Deafblind Project.

Many session attendees recognized Melissa from her Idol performance the night before. Melissa is a lovely young woman with a supportive family. The experiences and insights they shared were inspirational to the sometimes teary-eyed audience who left the session feeling that anything is possible.

By sharing Melissa's life and successes with us, the panel gave us the hope and belief that similar successes are possible for our loved ones with CHARGE.

*“By sharing
Melissa's life
and successes
with us, the
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belief that
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loved ones with
CHARGE.”*

BREAKOUT SESSION: 8**“Anesthesia Complications in CHARGE Syndrome”**

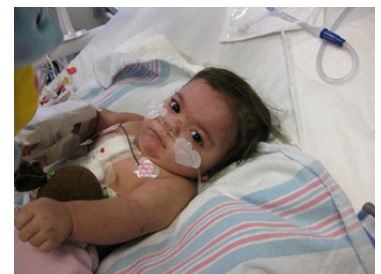
Presenters: Kim Blake, M.D. and Jill MacCuspie

Attendance: 19

Moderator: Rick Ogan

Moderator Report:

Dr. Kim talked about surgical anesthesia complications in people with CHARGE. They reviewed nine children, who had a total of 215 surgeries (147 anesthetics). In 51/147 (35%), there were anesthesia complications. The top three surgeries that had complications were: Nissen funduplications/gastrostomy/jejunostomy tubes (g or j-tubes), scopes, and heart surgeries. **The take home message was to combine as many procedures as possible under one anesthesia; the risk does not increase with multiple procedures. The anesthesiologist must be aware that even with the simplest procedures, individuals with CHARGE syndrome have a high risk of complications.**



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Botox injections were also discussed. They were shown to have stopped secretions in one two-month old child with CHARGE. The Botox worked for five months before needing to be repeated. The Botox helped reduce his secretions and aspirations. He was given one shot in each of the four salivary glands and still gets prophylactic injections of Botox about every 7-8 months to prevent increases in oral secretions/aspirations.



Rachel Coleman signing an autograph for Claire Springer

"It was an awesome experience to be able to meet Rachel in person and share her with all our children!"

Some of the Texas CHARGErs group with Rachel Coleman.



Event Highlights



Texas CHARGErs Present Rachel Coleman from "Signing Time"

The Texas CHARGErs is a family support group in Texas which was started in 2006 to assist families affected by CHARGE syndrome at the local level. The Texas CHARGErs are over 80 families strong and want to help and support our National Conference. In 2007 at the National Conference, it was announced that Brownie Shott, a Texas CHARGE parent and Foundation Board Member, would be the chairman for the 9th International CHARGE Syndrome Conference. Immediately, our Texas CHARGE board decided that we wanted to help her with her party. As we love to throw parties in Texas we decided the best way to help our National group was to help with the entertainment. That's when we knew we had to have the one and only Rachel Coleman from Signing Time at our Saturday night Social!

We worked with her for 2 years to make sure she was available to attend the national conference. The time was well worth the wait! Rachel was awesome! She fit in perfectly with our families and during her introduction became a little choked up. She said, "There is no crying now, maybe later, but now we will play." Rachel told the story of how she accidentally started her career which was to really teach her daughter to sign. Then the fun began. Rachel started singing, "Signing Time," the first song on all her DVDs.

The excitement and joy in the children's faces was incredible. Rachel sang twelve of her most favorite Signing Time songs, including "Silly Pizza". She took special requests and made our children feel special by getting up and signing with her. Rachel stayed and visited with every family that wanted a picture. She signed autographs, laughed, and played with our children. It was really a most heart felt time. Rachel has been such a huge part of the lives of our families in our living rooms by teaching us sign language on TV. It was an awesome experience to be able to meet Rachel in person and share her with all our children!

Submitted by Cathy Springer & Josh Fultz

A Tribute: Marion A. Norbury, Founder, CHARGE Syndrome Foundation, Inc.



Marion, giving a wave at her tribute ceremony.

On Sunday, July 26, at the 9th International CHARGE Syndrome Conference, a tribute to Marion Norbury, who has just retired from the CHARGE Syndrome Foundation, was held. Jim Thelin invited ten individuals to speak about Marion's contributions to the CHARGE Syndrome Foundation, and reflect the feelings of a multitude of people. Jim introduced the speakers: Donna Lacey (read by Meg Hefner), Meg Hefner, David Brown, Steve Sorkin, Bruce Appell (read by Marilyn Ogan), Wendy Keedy, Marilyn Ogan, Bonnie Morrison, Nancy Hartshorne, and Rob Last.

Bruce's opening tribute perhaps best sums up many of the areas touched upon by those who felt honored to have spoken:

"First, I want to share my top 5 reasons why Marion decided to get involved with CHARGE [Syndrome]:

#5. Being a librarian, she knew she would be organized and keep all the files

in the correct order.

#4. She wanted to be able to have a party every other year since 1993, in a different city, and have the guest list keep getting larger at each party.

#3. Marion loves to talk on the phone.

#2. Marion had an extra room in her house and did not know how to fill it or decorate it, so she thought a foundation office would be a nice touch.

AND the #1 reason:

Marion has a heart filled with love for each and every family touched by CHARGE. No one will ever be able to take your place."

All those reasons - humorous as they seem on the surface - touched a cord with everyone there. Marion has kept so much of the Foundation in her home...and our families in her heart. Who has not spoken to Marion on the phone? And who did not look forward to seeing and talking with Marion at each conference - since 1993?

Some tributes noted the first involvement Marion had with CHARGE Syndrome. Personally, I believe that CHARGE Syndrome: A Booklet for Families (1986), was an inspired project. Contacted by Meg Hefner, Jim Thelin, and Sandra Davenport, Marion took on this project while involved with the Quota Club of Missouri. That booklet was my family's first real information after five months of confusion and medical nightmares. It also gave that wonderful phone number that connected us to Marion. Nancy Hartshorne also noted that booklet as the first real helpful information she received. Without Marion, that booklet - and the Foundation, website, manual, professional packet, new parent packet, and on and on - might never have come to fruition. We are profoundly grateful that Marion became involved - OK, was conned into it by the infamous trio (Jim, Sandy and Meg). We're so fortunate that they were so convincing!

Neal Stanger presented Marion with a crystal vase from the Foundation to commemorate the occasion of her retirement. We hope Marion will have a wonderful retirement, and that she will continue to attend future conferences and talk to us on the phone. She made a point of telling us that her phone number is the same as the Foundation 800 number, with a different area code: 573-442-7604. After all, she has to come in order to see how our families and children have grown!

Marion's Wish List—Off-Conference Year Gathering

Marion shared her "wish list" of things she wanted for the Foundation with the crowd at her tribute. One of those was that there should be smaller, off-conference year gatherings in various areas. Illinois parent Crystal Masionis has decided to try and put together an off-conference year gathering next summer:

Attention WI, IL, MN, MO families and all others in that area!

I am working on an off-conference year CHARGE Family get together in Wisconsin Dells. We love it there and there is so much to do for families. I am in the process of getting hotel info and discount rates for groups along with discounts for other attractions. The dates will be July 23rd-26th, 2010. I need to know how many families would be interested in attending so the hotel can figure out the discount.

If you are interested please contact me, Crystal Masionis crystalml1476@hotmail.com or call 847-739-6696.

"Marion has a heart filled with love for each and every family touched by CHARGE. "
-Bruce Appell

Personal Account



Makenna Susil, who had a great time meeting new friends at the CHARGE conference.

We are home from another great conference. I wanted to let you know I posted a few pictures from the conference on my blog if you are interested:

<http://kennancami.blogspot.com/>

Makenna had a great time meeting other kids like her! It was an important experience for her. It made her feel better about herself and let her know it was okay to be

just the way she is, which is hard for me to get across to her when she goes to school with kids that don't have hearing aids, g-tubes, trachs, etc.

Of course, it was nice to meet new families and see old friends. It makes me feel better to see that other kids are experiencing the same issues as Makenna. The incessant questioning that has been driving me mad is

common - it was nice to not only know that in my head, but also to witness it and to look at a mom or dad and know they "got it" without saying a word.

Now it is time to make some medical appointments and get things squared away with some issues we have been having. I feel refreshed, renewed and ready to do battle again.

Special Presentation



Cynthia, with her son, Brady and husband, Keith

On Sunday morning, new Board member Cynthia Antaya shared the story about her life. From growing up with a variety of medical issues and discovering, after her son Brady was born and diagnosed with CHARGE syndrome, that she too had CHARGE syndrome. It was

such an inspiration to listen to Cynthia's story: her early life, her family's determination that she could do anything, her school and college life, her marriage and birth of her children. We invite you to read this amazing journey that Cynthia describes as the "puzzle" that until Brady

arrived, could not be solved.

Cynthia's entire speech is available on the Foundation website at:

www.chargesyndrome.org/cynthiaspeech2009.asp.

2009 Award Recipients

Every two years at conference, the Foundation recognizes those who have made significant contributions (individuals or couples, groups, or organizations) in any of the following areas:

- To the Foundation and its work with service or financial support,
- To persons with CHARGE or their families, or
- To the understanding, management, and treatment of CHARGE syndrome.

There are several types of awards:

- I. Stars-in-CHARGE Award: this is the Foundation's highest award, which is given for significant contributions over a period of time. The award is a crystal star with the Foundation logo and the name of the recipient(s) etched in the star. These were awarded to Brownie Shott and Lisa Weir.

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2. CHARGE Recognition Award: this is an award given by the Foundation for a very significant contribution in any of the three areas listed above. The award is a plaque with the Foundation logo and the names of the recipient(s) engraved on the plaque. These were awarded to: Bryan Hall, Kathy McNulty, Susan & Joel Wolfe and David & Jody Wolfe.

3. CHARGE Syndrome Foundation Certificates of Appreciation - these were presented to: Bonnie Morrison, Eric & Sabrina Bluestone, Jay Brandrup, Herb Byrd, Carol Robbins, Tina Prochaska, and all of the interpreters for the 2009 conference.

4. Partner Awards: these were given in recognition for the partnerships these organizations have made with the Foundation: Helen Keller National Center (accepted by Kathy McNulty), Perkins School for the Blind (accepted by Martha Majors, pictured at right), and to the National Consortium on Deafblindness (accepted by Kat Stremel).



2011 Conference: Orlando, Florida

2011

Conference

City:

ORLANDO,

FLORIDA!



At the Friday morning general session, the location for the next conference was announced by President Neal Stanger. We will be heading down to sunny Orlando, Florida for the 10th International CHARGE Syndrome Conference in July 28-31, 2011.

The venue for the conference is the Rosen Shingle Creek Hotel. Circle the dates and start planning now, as

you do not want to miss it!

The conference chair for 2011 is Janet Murray. Please contact either Janet or the office with any questions or ideas for 2011.

More conference details, as well as online registration, will be available on the web site as the date draws nearer.

<http://www.chargesyndrome.org>

Next Issue: Focus on Fundraising

The next issue of CHARGE Accounts will focus on fundraising. We will be featuring stories about individuals, groups, families, and companies who have raised funds for the CHARGE Syndrome Foundation in a variety of ways. More information about our 2009 Charge It for CHARGE will be shared as well as tips and advice for organizing your own event.

Have you, or someone you know, organized or participated in an event benefiting the Foundation? If so, we would love to hear about it. We don't want to miss any great stories.

Please contact Lisa at lisa@chargesyndrome.org with your stories and photos.

Thank You

In Honor of Aaron

Hiscutt:

Raymond Nelson Jr.
Kathleen Stremel

In Honor of Tomer

Gerstein:

Jim Gerstein

In Honor of Christine Huff & Red Hat Society:

Stephen Huff

In Honor of Dr. James Thelin:

Donna Smiley

In Honor of Elizabeth Forsch:

Teri Anderson

In Honor of Makenna Susil:

Fritzi Gibson

In Honor of Ethan Wolfe & Family:

Miss Lenz's 4th Grade Class
Martin Glink
Alana, Ricky, Scotty & Brett
Max
Cetina Michael
Arlene Midkiff
Debbie & Gregg Stern

In Honor of Charlotte Cosenza:

Paul Cosenza
Anthony Mitzman

In Honor of Joan and Ray Holland:

Buddy & Susan Glines

In Honor of Dominic

Steinhauser & Family:

Kristen Anast
Caryl Barnes
Lynn Bartos
Amy Forrest
Juliann Geijer
Bill & Karlene Henshaw
Lisa Sneddon
Marsha Sullivan
Lisa Weir
Dawn Wojtowicz

In Honor of Halyn Jones:

Melva Strang-Foster

In Honor of Gracie Swann:

Erin, Sean, Steph, Johnny &
Lincoln Holbrook
Bob & Elaine Johnson
Diane Krishna
Christine Lichti
Austin Milligan
Amy Toth

In Honor of Christian

Roberts:

Bekkie Cobb

In Honor of Marion

Norbury:

Marlowe Schlegel

In Honor of Elizabeth

Kijowski & Family:

Agnieszka Baran
Sophia Kowalczyk
Izabela, Andrzej Piaskowski
K. Secor-Losos
Bozena Stoch

In Honor of Erika Feather:

Carol Pfeiger
Marc Sigismondo

In Honor of Nate Stahl:

William Hemminger

In Honor of Justin Murray & Family:

Pamela Dowd
Charles Good
Nicole Hanchay
Erica Hanlon

In Honor of Karlee Ludwig:

Rachel Delph

In Honor of Katie Ann

Staunton:

Thomas Staunton
Catherine Staunton

In Honor of Michael Kruger:

Ruth Downey

In Honor of Kate

Leininger:

Ralph Searles
Joanne Tranchina

In Honor of Sara Brown:

Jennifer Brown
Lindsay Mullinax

In Honor of Taliah Skye Wendoll:

Donna Wendoll

In Memory of Bonnie L. Gahagan:

Daniel Gahagan

In Honor of Megan

Stanger:

Elisabeth Brenhouse
Valerie Mace
Catrin Perih

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

CHARGE ACCOUNTS

Thank You

In Honor of Zachary Bluestone & Family

James Angley
Seth Bornstein
Thomas DeCaro
Jane DeCoursey
William Drysdale
Samuel Gaccione
Matthew George
Mark Ginsberg
Stephen Hayes
Susan Hyman
Lynn Iurato
Olga Jobe
Peter Kaplow
Aaron Koffman
Rita Lascaro
Matthew & Susan Metz
Seamus O'Callaghan
Cathy Poritzky
Mark Rubin
Steven Schleider
Lisa Skelton
Stephen M. Starensier
Michael Stoop
Julie Testwuide
Chrysanthe Toumanios
Elio Vecchiarelli
Steven Weiss

In Memory of Mert Mason:

Leonard Stanger

In Memory of Joshua Kurby:

Joanne Beda
James & Pamela Hall
Sandra Kurby
Peter Paulsen
Lynn Poepp
E. Pope
Sue Schroeder
Gary Schulze
C. Tapling
Anne Watson
Lawrence Weiser
Donna Yormark

In Memory of Tyler James Matthew:

Michelle & Edwin Carter
Trey & Kelli Cobb
Pam, Bryan & Jackson Day
Lori DeCarlo
Maureen DeGrange
Tera DePaoli
Wendy Ebersole
Megan Fraser
Christa Gahagan
Bryan Glines
Buddy & Susan Glines
Jeff & Melissa Gredlein
Michael Holland
Stacie Johnson
Nancy Kirkpatrick
Joseph Lindemon
Dean & Terri Martin
Nancy Miller
Megan Mosley
Dawn Murphy

In Memory of Tyler James Matthew (continued):

Bryony & Joe SySantos
Shelbie Villa
Jim & Connie Wagner

In Memory of Mildred Katapodis:

Hilda Bodenstein

In Memory of Stephanie Aschermann, grandmother of Peyton & Tate Young:

Arlene Aschermann
Todd Birkner
Jill Bruenderman
Amy Buchheit
Linda Collmeyer
Carol Glazebrook
Pamela Haines
Cheryl Hood
John Osman
Christine Wilferth

In Memory of Taliah Skye Wendoll's great grandfather, Ray Barnett:

Barbara Heiman
Donna Wendoll

In Memory of Taliah's Great Grandma Irene:

Barbara Heiman

In Memory of Meghan Graham:

Don Graham

In Memory of Trey Chatham:

Carol Bowser
Barbara Chatham
Jennifer Corbin
Robin Darsie
Karen Denker
Julia Haver
R. Hayes
Cortney Hinton
Sharon Kellner
Delia Amida Lance
Karen Lee
Jane Myers
Gerrienne Riddle
David Rousculp
Allen Simon
Susan Volentine
Diane Wickham
Suzanne Willhite
Melissa Wilson

In Memory of Charleen Ward:

Marie Solis

In Memory of Irene Yerigan:

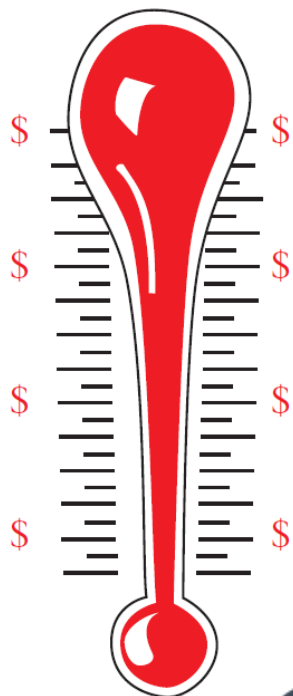
Donna Wendoll

In Memory of Jacob Bola:

Deana Chase



HOW HIGH CAN WE GO?



Our first annual Charge It for CHARGE campaign is coming to a close. We have raised approximately \$90,000! Our second annual Charge It for CHARGE campaign will begin in just a few short weeks. Stay tuned for the details in an upcoming e-mail announcement.

In addition to the on-line 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 www.chargesyndrome.org or by mailing a check directly to the Foundation. No amount is too large or too small.

Come Join Us!

CHARGE Syndrome Foundation, Inc

141 Middle Neck Road
Sands Point, NY 11050
USA

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

Annual Membership

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Professionals \$20
Organizations, Institutions \$30

Lifetime Membership

Silver \$150
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