

# CHARGE Accounts



Fall 2007

A Quarterly Newsletter for Families and Friends

Vol. 17 No. 3

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

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2007

## *The 8<sup>th</sup> International CHARGE Syndrome Conference Was the Greatest Ever!*

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In this issue, we have included a conference summary, a report from the conference chair, descriptions of the breakout sessions, the awards that were presented, the introduction of the ASL sign for CHARGE Syndrome, a first time attendee writing about what the conference meant to her and her family and more . . .

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**!!! Deadline for the Winter Issue - December 1 !!!**

# CONFERENCE RECAP

by Marilyn Ogan, 2007 Conference Chair

## CONFERENCE ACCOUNT

Well, a large part of my time is now available once again! It took a lot of time to organize and plan the 2007 CHARGE Conference; but it is so exciting to know that we had the largest group of participants we've ever had at a conference. It is even more satisfying to know that the networking, breakout sessions, information exchanges, and just plain fun was enjoyed by so many. There were few glitches, and any that occurred were handled quickly and, I hope, to the satisfaction of those involved. But that can't happen without the vast support that I received in planning, organizing, and implementing the conference details.

I want to thank all who had a part in making this conference such a success, and made my job that much easier. The CHARGE Syndrome Foundation gratefully acknowledges the contributions (monetary or in-kind), assistance, and in some cases sheer determination to make this conference the best yet!

**The Hilton/Perkins Program of  
Perkins School for the Blind  
The Helen Keller National Center  
The Bill & Bonnie LeVine Charitable Foundation  
– In Memory of Bonnie LeVine  
Madison Moore: Chores-4-Charity  
Jennie Tannenbaum: Kids Walking for Kids  
The Variety Club  
California DeafBlind Services [CADB]  
– Maurice Belote, Director  
Blind Children's Learning Center  
Costa de Oro Chapter of Foresters  
Ruth & Jerry Schwartz  
Michael & Laurie Schwartz  
Sue Meckley  
Sandy Pilon  
Boeing Corporation  
Boeing Volunteer Corps  
Scott Pilon, EMT**

**John Bruning, EMT  
Michelle Melancon, Nurse  
Fullerton State College Volunteers  
Kiwanis Key Club Volunteers  
Hilton Costa Mesa Staff  
Kiddie Corp  
Michael's Crafts  
T.M.G. Copiers  
Discovery Store, Costa Mesa  
Costa Mesa Fire Department  
Central Michigan University  
University of Tennessee  
Wal-Mart Foundation  
FunServices (Carnival)  
Wendy Keedy  
Jackie Kenley  
Julie Brandrup  
VolunteerMatch.org  
James Thelin, Program Chair**

I know I have not adequately thanked everyone, nor have I possibly included all who assisted; but I must acknowledge the advice, support, and commitment from the Board of Directors and the staff of the CHARGE Syndrome Foundation, Inc. The time sacrifices of their families allowed much of this conference to happen...and kept me sane! This type of conference – and size of it – cannot be accomplished successfully without a lot of help.

And finally, I was amazed at how accepting and accommodating the hotel staff at the Hilton Cost Mesa was. The CADB staff had done sensitivity training and orientation with the hotel staff; but I could not have asked for a more helpful, eager-to-please attitude from all the hotel staff. They really made our conference enjoyable from an organizer's viewpoint. (And they were fabulous with my daughter, Kristin, who was all over the hotel while I was busy handling details in the week before the conference.) We enjoyed being there and I was told repeatedly that they were truly happy to have our organization and participants... and would we please come again when we next head west!

The Board discussed the evaluations during our meeting in September. We hope to take the comments/suggestions and discuss ways to integrate them in future conferences. Brownie Shott will be the 2009 Conference Chair. I wish Brownie much luck and support in making the next conference even better. I'll be there...I hope you all will be too!



**Online Shopping is coming soon to our website - [www.chargesyndrome.org](http://www.chargesyndrome.org). Check it out!**



# ***8th INTERNATIONAL CHARGE SYNDROME CONFERENCE***

**by Betsy McGinnity**

**National Coalition on Deafblindness**

In July 2007, the 8th International CHARGE Syndrome Conference was held in Costa Mesa CA. More than 600 participants from 35 states, Puerto Rico and eight other countries were welcomed. As always, this was a very busy event. The three-day conference agenda offered several keynote sessions and concurrent presentations in six categories: education or development, family support, general interest, medical or genetic, new family information, and transition to adulthood. In addition to the breaks and mealtimes, a carnival, dance and silent auction gave participants ample opportunities to network and socialize. Outside of the sessions, a photographer took portraits, medical researchers enlisted families to participate in genetic studies, and children with cochlear implants participated in screenings for a research project. Children also took part in screening for a study that is attempting to establish the characteristics of the feet of children with CHARGE syndrome.

Tina Prochaska of the Tennessee School for the Deaf presented a keynote session addressing the important role that siblings play and the unique needs they present. She noted that, in many ways, the issues faced by children who have a sibling with CHARGE are similar to children who have siblings with any disability. However, in her work with children who have a sibling with CHARGE, she has seen differences, perhaps because youngsters with CHARGE experience so many medical issues in their early years. Siblings had several opportunities to participate in Sibshops during the rest of the conference. There were also special sessions for Dads and Grandparents.

Joe McNulty, Director of the Helen Keller National Center, emphasized the importance of parents, family members, professionals, and young people with CHARGE learning from one another. He noted how much the knowledge about CHARGE has increased over the 14 years since the first International CHARGE Syndrome Conference. During those years, families, medical professionals and educators have all been able to learn from each other and improve services. Now, as more and more individuals with CHARGE syndrome transition into the world of rehabilitation and adult services, the information sharing and learning process needs to include those who work with adults as well as to more fully include the young people with CHARGE syndrome themselves.

The final keynote session was a special presentation by a panel of adults with CHARGE. The panelists included a woman in her 40s whose diagnosis of CHARGE came after her school years. One was still in high school and several other were more recent high school graduates, including a young man who will become a full-time college student in the fall, and another who is a part-time college student and full-time worker. Two moms were also on the panel, each representing young adult daughters who did not have the ability to represent themselves. After the panel did their formal presentations, the session was opened up to questions from the audience. It was obvious that the families in the audience appreciated the opportunity to learn from the very diverse panel and that having many role models helped them think about future options for their children.

Seventy-five new families attended their first CHARGE Conference this year. As the group prepared to leave Costa Mesa, many of these newcomers as well as regular attendees were making plans to come to the 9th International CHARGE Syndrome Conference scheduled for July 2009 in Bloomingdale near Chicago, Illinois.



## **BREAKOUT SESSIONS**



### **Grandparents Session**

**Moderator: Nancy Hartshorne**

25 grandparents of children with CHARGE shared experiences; joys, worries and stories with one another. Newer grandparents reminded more experienced parents of early experiences and more experienced grandparents shared lessons learned. All were in agreement that children with CHARGE are wonderful and are accepted for who they are.

### **Cracker Barrel on Cochlear Implants**

**Kathleen (Kat) Stremel, Nancy Hartshorne, Gloria Rodriguez-Gil**

Kat presented preliminary information from the NCDB [National Consortium on Deaf-Blindness] research objectives on success in CI [cochlear implant]. Nancy related her experiences as a parent whose son with CHARGE has a cochlear implant. Gloria reviewed potential complications of CI. There was a lot of discussion by many parents about CI issues – implantation on the side with facial weakness, toleration of loud sounds with the CI, and explanation. This was a full session of discussion that could have gone on for a very long time. Many parents joined the NCDB listserv.

## **DB-LINK & Sex**

### **Betsy McGinnity, Maurice Belote**

Betsy presented an overview of the NCDB [National Consortium on Deaf-Blindness] website [www.nationaldb.org] and highlighted resources on transition which can be found on the website. The group looked at the selected topic, listing over 70 items. The overall theme of the presentation was the need for sex education. But how to do that? The presentations had wonderful humor, how it was in the past, etc. It is important to keep personal values/beliefs separate. No real sex education took place. John became a sex educator because of a chronic problem with a student. Parents want this taught! The research that has been done on the abstinence only approach shows that it is not very effective. Good, appropriate sex education can lead to reduction of sex abuse. They talked about defining what is appropriate to discuss. Keep it factual (very important). Keep the weirdness level down!! Begin teaching before middle school. Start with things like: How to use a public rest room; Identifying body parts; Appropriate and inappropriate touch.

## **CHARGE 101**

### **Meg Hefner, Kim Blake**

When asked how many were attending their first CHARGE conference, virtually everyone raised their hand. Due to problems with technology, only Meg was able to present during the first session. While her presentation was what I would describe as “CHARGE 101”, the level of questions was very high (sophisticated) for first time attendees. The audience was well versed and knowledgeable. A number of the questions were more medical in nature and were answered by Kim.

## **CHARGE 102**

### **Kim Blake/Sandra Davenport**

Kim presented on issues related to anesthesia and then took audience questions. Sandra presented on the sensory organs (visual, hearing, vestibular system). There were major issues with the technology, including computer failed and there were some difficulties with timing. But, in the end, it all worked out and all the participants seemed happy.

## **CHARGE 103 Babies Can't Wait to Communicate**

### **David Brown**

It's never too early to begin educational interventions. Even with newborns, interactions such as interactive turn-taking games, touch cues, and similar activities can have a profound impact on how a young infant or child learns about the world and all of the people she or he interacts with. Words and signs are not all of communication – they are building blocks built on a previously established foundation of trust and reciprocal interactions. Remember these communication steps for a child with sensory deficits: 1) alert child to your presence; 2) alert child to the coming activity; 3) introduce the activity; 4) do and discuss the activity; 5) on completion, review what you have done (e.g. what is different now); 6) let the child know that you are leaving. “Personal Passports” are a great way to document who the child is, so that others [people new to the child – new nurses, teachers, therapists, and classmates] can quickly learn a child's communication systems, preferences, etc.

## **Strategic Conflict Management Skills in Special Education**

### **John Reiman**

John has been involved with people with deaf-blindness for 25 years. He is the Associate Director, National Consortium on Deaf-Blindness. He is also the Mediation Specialist at the Center on Dispute Resolution in Special Education. He used the audience to emphasize some problems in listening skills! Look at positions and interests in communicating needs. For example, a parent will state a position, what they want, but the listener doesn't always receive the information in the way it was intended. A parent needs to supply as much information to justify the request to lessen the opportunity for conflict.

## **Transition to Adulthood: A Glimmers of Promise**

### **Joe McNulty/Kathy McNulty**

This was an overview of services for DeafBlind/multi-handicapped adults. The audience consisted of parents of individuals with CHARGE over age 18 (about half), parents of teens (a quarter), and parents of younger individuals (a quarter). First a historical perspective was presented – where adult services began and how we have arrived at current services. Access to services has never been easy and currently they are getting harder to access. Parents need to get involved early – learn jargon and the intent of new laws: Start early, stay informed, encourage team planning, talk to/with other families; find a vital person to help connect with adult services.

## **Father's Forum**

### **Moderator: Tim Hartshorne**

Each participant shared something positive about their experience of having a child with CHARGE. General discussion focused on how their experience is different from their wives.

## **Psychotropic Drugs**

**Lee Wachtel, Tim Hartshorne, Veronika Bernstein**

Lee spoke about the fact that a child with CHARGE can have ANY type of psychiatric disorder in addition to developmental disorders and that the two must be differentiated. This is often a very difficult, time consuming process. Veronika spoke about the need for a “team” to coordinate appropriate prescribing of multiple medications. It is not unusual for several additional medications to be added with the onset of puberty. Tim reminded the audience that all behavior is communication. Behaviors should not be automatically attributed to CHARGE. Drugs, he pointed out, do not cure challenging behavior. To really stop the behavior, the communication [source or outcome of the behavior] must be understood and behavioral interventions must be applied. He recommended that drugs never be used independent of a behavior change plan.

## **Home Schooling**

**Shirley Minster**

In this session, Shirley Minster, founder of Home Education & Family Services, a full time organization offering a wide variety of resources and help for home-schooling families, and Royal Academy, a home-based educational K-12 school, which uses the home-school mentoring model, spoke about the many aspects of home schooling. Topics included were helpful hints, real life examples and a question and answer period.

## **Fund Raising**

**Neal Stanger, Steve Perrault, Lacey Friedman**

“Fundraiser in a Box” was reviewed. Brownie Shott spoke about the pizza party fundraiser she did, as well as how easy it was to do. Eric Bluestone also talked about his cocktail party fundraiser as well as how he planned it. Lacey Friedman, as new fundraising chair, discussed some easy fundraising ideas. Group held an open discussion.

## **Behavioral Phenotype**

**Tim Hartshorne**

Tim stressed that all behavior is communication. It is important to assist children to communicate in ways other than behaviors. Make sure the child knows you understand what they want/need. Results from Tim’s survey: kids with CHARGE have extreme preferences; there is often preoccupation with things or items; most have difficulty in making same age friendships. He discussed underlying causes of behavior, including attachment problems; sensory difficult (CHARGE kids align more closely with behavior from deaf-blindness than autism), parenting styles, stress, pain, illness, hospitalization, sleep (initiating and maintaining), communication and language, self-regulation, cognitive ability. He presented a first draft of a CHARGE behavioral phenotype.

## **Educational Issues**

**Martha Majors & Sharon Stelzer**

This presentation was an overview of techniques and strategies to encourage, empower, and enable learning in students with CHARGE. Each team member interacts around the child to accomplish goals and objectives using communication, routines, choice-making and motivating ideas and activities to facilitate success.

## **Person Centered Planning**

**Nancy Steele, Donna Consacro, Susan Hiscutt**

The “three musketeers” from Tennessee gave an informative and heart warming presentation on person-centered planning. It was a truly collaborative offering of best practices, with examples that brought the topic to life.

## **Pain Issues**

**Veronika Bernstein**

Veronika is conducting research on pain. She presented a listing of facts on pain: e.g. pediatric chronic pain affect 15-20% of children. She spoke on pain and developmental disabilities, pain as a concept, pain mechanisms. She explained physiological pain response in people with developmental delay and in particular CHARGE. She explained the difference between acute pain and chronic pain. She discussed the research on pain in infants and the long-term effects of early pain. She shared strategies on how to cope with pain and some of the results of her research/survey.

## **Emotional Competence**

**David Brown**

David’s mother inspired this talk – she always asks, “Yes, but are they happy, loved, comfortable, satisfied, confident, healthy, not lonely — these are the important things to consider. When these are okay, everything else will fall into place.”

There is often too much focus on vision and hearing (distance senses), while other fundamentally important systems are often ignored. Self-regulation is often missed and needs to be on the educational agenda for these kids. David stressed the importance of not separating education and therapy. These things are especially likely to get lost with individuals who have CHARGE because so much else is going on. Programs for students with CHARGE are typically very goal-oriented (measurable goals for future), with little or no emphasis on mental health/happiness. Strategies for developing emotional intelligence were explored. Social and emotional competencies were discussed, as well as self regulation and its complexity for all people, not just those with CHARGE. “Feeling safe, secure and understood makes successful learning possible.”

## **Genetics/Smell**

### **Conny Van Ravenswaaij/Jorieke Bergman**

Conny explained that her group decided to look at familial CHARGE syndrome to try to begin to describe the mild end of the spectrum. Surprisingly, they found that 3% of people with CHARGE have a sib or parent with the CHD7 mutation – they wanted to know why. Conny reviewed CHD7 gene information. She explored and discussed familial cases of CHARGE syndrome. When multiple generations had CHD7 mutations, they usually had very mild findings. Discussion ensued about how mosaicisms occur. If parent is affected, the recurrence risk (for another affected child) is about 50%. If there is mosaicism in the parent, the recurrence risk is very difficult to predict. Prenatal diagnosis is available for CHD7 (when a mutation has been identified) – but severity cannot be predicted. Several prenatal diagnostic options were reviewed.

Jorieke spoke about smell disorder & puberty delay – why is it occurring in CHARGE (because of CHD7 & its effects on olfactory & hypothalamus) and why it is important to screen for it. Decreased smell: almost 100% of people with CHARGE have decreased or absent sense of smell. She discussed normal puberty onset in girls and boys. Jorieke explained the link between smell and puberty – embryologically, the olfactory bulbs and the hypothalamus develop together, if one doesn't develop normally, there is a good chance the other will not either. She mentioned that anosmia and delayed puberty are also seen in Kallman syndrome. She reviewed the reasons why it was important to screen for delayed puberty. With screening and detection, preventative measures can be put in place (hormone replacement) to prevent osteoporosis. Some of the reasons sense of smell is important include its alarm function, amplification of our sense of taste, social interactions (body odor, passing gas, perfumes), and links between smell and memory.

## **Transition to Adult Services**

### **Sue Ruzenski, Philip Wismer, Cathy Kirscher**

Program options at HKNC [Helen Keller National Center] were reviewed. Strategies for connecting with a learning community at HKNC were presented. Philip [19 year old with CHARGE] talked about his experiences at HKNC and what he learned there: teenager programs, teamwork, being a leader, summer evaluation and training program; his experience as a mentor in the teen program; PFP (personal future planning), and IEP, and then he shared his futures planning preferences. He also talked about his prior work experiences, and how HKNC has helped prepare him for college. Philip's goals include becoming a Deaf Ed teacher in elementary school or a meteorologist or work with computers. HKNC has helped him greatly in preparing for his future. Sue talked about the PATH program for individuals who are DeafBlind with developmental disability. She also discussed obstacles to transitional success. She talked about the importance of starting out with an expansive view, not a limited or small one. She talked about intangible goals – the perspectives a person has about themselves. Cathy talked about the importance of connecting back to the home community, how individuals can be supported in their own community following in-site training programs like those at HKNC. The importance of having a vital contact when dealing with adult services and knowing who your HKNC regional representative is for your state was stressed [see [www.hknc.org](http://www.hknc.org)]. Another important suggestion was to check in with the vocational rehabilitation in your state *two years* before you will be finished with your school program. Other sources of information and support are developmental disability services, state DB projects, American Association of the Deaf-Blind, and NFADB (National Family Association of the DeafBlind).

## **Educational Processes**

### **John Reiman**

John explained the processes of resolution, mediation and IEP facilitation in educational settings. He spoke about the benefits and potential pitfalls of each process and about the importance of the student's own participation in the processes. He talked about the importance of a strong process to help avoid conflicts. He highlighted the key components of written agreements. John presented how conveners of IEP meetings are being trained to best facilitate the meetings, as well as how parents can best prepare for the IEP meeting. People may email him at [reimanj@wou.edu](mailto:reimanj@wou.edu) to get a copy of this training document. His information was very relevant and helpful to anyone attending a similar type of meeting or involved with a similar process, even those outside the US.

## A FIRST TIME ATTENDEE'S CONFERENCE EXPERIENCE - - -

*Rebecca Anderson sent this letter to the CHARGE Listserv after the conference and has graciously permitted us to share it with our readers.*

[CHARGE] First conference thanks...a bit long

We are finally home from the conference - it was part of a 2,800 mile, two week road trip. The boys were really great and we didn't even have any hand held games or a portable DVD player to keep them entertained - although I had a few moments wishing for one. But bribing them with money - a dollar for each hour they didn't bicker/fight - worked very well. And having things to color and read and build (I'll probably be finding crayons and Legos in the van for the next few weeks) also helped.

This was our first conference. I wasn't sure what to expect but in my heart I knew it would be a good experience. I really enjoyed meeting so many familiar names - and meeting new ones as well. It was great that those on the listserv had stickers on their name tags so we could make connections faster. But I'm sure I didn't meet everyone.

Spending time in the pool was delightful and just seeing so many other kids with CHARGE throughout the hotel warmed my heart. One of the times in the pool our oldest son Nathan commented how great it was that all the kids in the water had CHARGE. He was also impressed that his brother's "super hero powers" got us on the rides quicker at Disneyland and Legoland. (smile)

All the presentations I attended yielded information which will help me be a better parent and advocate for Cameron. In Tim Hartshorne's presentation about behavior I had a "light bulb" moment when I realized that for the last two years Cameron had the wrong teacher. But to his defense I probably didn't emphasize enough just how challenging Cameron's lack of vestibular function could be (because I didn't realize it myself) and that might have been part of the reason that Cameron typically had several "meltdowns" every day at school.

Cameron is very high functioning and his language skills are pretty good, so for the most part he seems fairly typical - until he has meltdowns that seem to come out of nowhere. I'm beginning to realize how important it is to be even more clear with him and really make sure he understands an activity or an event before beginning it.

I also enjoyed David Brown's presentation and especially appreciated his comments during the professional Q&A session on Sunday. I have most of it on digital video and plan to watch it after I've had a particularly frustrating moment as the parent of a child with CHARGE. The presentation by the Perkins staff really drove home how much Cameron has to compensate for what he lacks physically, but that he also has the possibility of improving as he gets older. The professional poster session was great - a chance to get more personal time

with presenters. Everyone was so supportive. As someone else mentioned, we are part of a family. A few of us who have kids without out vision-impairing colobomas - or none at all - realized that the lack of a functioning vestibular system in fact has quite a negative impact on vision. One of my action items from the conference (and I have quite a few) is to look into having Cameron classified as deaf/blind.

I thought the interpreters were highly skilled and I enjoyed watching them and learning new signs. Cameron uses his voice and ASL (mostly in English word order). But he went on vacation with only one hearing aid and then the other one stopped working towards the end of the trip so we were (again) grateful to have another language to use for communication. It didn't seem to slow him down much.

Cameron was not diagnosed with CHARGE until he was about 18 months old. At the conference I was sharing this fact with another mom (I think it was Sally Prouty) and also recalling how my mother didn't understand why I was so determined to find a diagnosis for our son when he was a baby. Being in the category of "undiagnosed special needs" is like being in an ocean. It is huge, vast and varied. You don't feel like you quite fit in with anyone you meet but you certainly don't fit in with parents of typical kids. Being diagnosed with CHARGE Syndrome is like finding a harbor safely tucked away in a protected bay. It's still connected to the special needs ocean, but there are boundaries and you have more in common than not with other families. For me, being at the conference was like being in a safe harbor. It was a time to feel like everybody else and just blend in. You didn't have to explain yourself or your child to an uneducated stranger. We all spoke the same language. (smile)

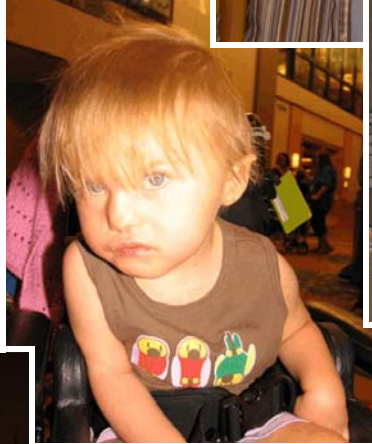
I really enjoyed meeting everyone and I'm so glad we went. Thanks to everyone for being so kind and supportive.

Rebecca Anderson

Mom to Cameron, 5, CHARGE and Nathan, 7 (a brother with "super powers" of his own) Wife to Linden - a big man with a heart that matches his size.

**Mark your calendar now and start planning to attend the 2009 International CHARGE Syndrome Conference \* July 24-26 \* in Bloomingdale, Illinois**







# 2007 CHARGE Syndrome Foundation Awards

\* \* \* \* \*

It is a tradition of the CHARGE Syndrome Foundation to recognize some special individuals at our biennial conferences. This year we presented Certificates of Appreciation, Special Recognition Awards and two Stars in CHARGE Awards. Our congratulations to all our honorees.

## Certificates of Appreciation presented

### 1) For volunteer services that helped make this conference possible:

Jackie Kenley	Luis Vasquez	Laurie & Michael
Maurice Belote	Sandy Pilon	Schwartz
Wendy Keedy	Sue Meckley	Jay Brandrup

### 2) For financial support of the Foundation through fundraising:

Sabrina & Eric Bluestone	Susy & Sergio Morales
Ana & Joel Saruski	Thomas Morrison

## Recipients of the “Special Recognition Award”

### - **Jeremy Kirk**

Jeremy Kirk is an endocrinologist from the United Kingdom who feels like family to our Foundation. He has shown incredible dedication to our families by making himself available to them throughout the conference and by email at other times -- to present information, to help clarify an endocrine question, and/or to advise families on how to communicate with their local endocrinologists. In addition to his interest and research on the endocrine aspects of CHARGE, he has led the UK gene study, in collaboration with Kim Blake in Canada. Jeremy has attended several CHARGE conferences, often at his own expense and usually bringing his entire family. It is for these reasons that Jeremy was presented with the “Special Recognition Award.”

### - **Kenny and Cheryl Moretz (Uncle Kenny’s Corner)**

During the 2007 conference, many noted the absence of Uncle Kenny’s corner and the two beloved individuals who brought much joy to our children, both those with CHARGE and their siblings. This couple began doing crafts during the Mid Atlantic Conference in 1998. They continued at the Mid Atlantic conferences in 2000 and 2002. They volunteered to bring their ideas and talents to the International CHARGE Syndrome Conference in Indianapolis in 2001. This continued at the Cleveland (2003) and Miami (2005) International Conferences. Unfortunately, the Moretzes were unable to travel to the 2007 conference, but the Foundation wishes to recognize their contribution to our children and the success of our conferences with the “Special Recognition Award.”

### - **Dennis O’Toole**

Dennis O’Toole just retired from the Foundation Board of Directors. He has been Secretary to the Foundation and Chair of the Fundraising Committee. As the fundraising chair, Dennis was instrumental in the development of the “Fundraiser in a Box” and the spectacular DVD which is used with the “Box” as well as a tool to educate people about CHARGE and the CHARGE Syndrome Foundation. Dennis was not able to be at the conference this year because his daughter, Clare, recently had surgery, but the Foundation wishes to present Dennis with the “Special Recognition Award” for all of his efforts for the Foundation.

### - **Conny van Ravenswaaij**

Conny van Ravenswaaij is a medical geneticist from the Netherlands. It was in Conny's laboratory that the CHD7 gene was discovered in 2004. Although the discovery was made under Conny's direction in her laboratory, she gave the credit (first authorship on the paper) to the student who made the finding (Lisenka Vissers). One of the first things she did after making the discovery was to contact the CHARGE Syndrome Foundation and alert us to the publication date. Since the gene discovery, Conny has collaborated with other researchers around the world in efforts to fine tune the gene sequencing, begin to look at families with more than one individual with CHARGE, and to begin to determine how changes in the CHD7 gene result in the features of CHARGE syndrome. Conny has traveled the globe with other colleagues and students to describe the discovery and to give it meaning to individuals and families affected by CHARGE everywhere. Many of her findings have been presented at our conferences before they were published in the medical literature. We are honored to present her with the "Special Recognition Award."

### - **Seema Lalani**

Seema is a pediatrician and medical geneticist who has been working on CHARGE in the Cardiogene study at Baylor School of Medicine in Houston since 2000. She is a truly compassionate person who is more than just a scientist studying CHARGE syndrome. Research is her job, but it goes beyond that. In fact, it was her passion and dedication that helped secure the \$600,000 Doris Duke Foundation grant that has allowed for so much more research than might otherwise have been done. Although Seema did not discover the CDH7 gene, she looked for changes in CHD7 in all of her samples as soon as the discovery was announced. Seema spent nearly the entire 2005 conference meeting privately with each family to explain their CHD7 results. She sees many families clinically in Houston, spends time visiting with families at conference, and has participated in fundraising in the Houston area. The Foundation wishes to acknowledge Seema's many contributions with the "Special Recognition Award."

### - **Pamela Ryan**

Pam Ryan is an educational psychologist in the DeafBlind Program at The Perkins School for the Blind in Watertown, Massachusetts. She has evaluated and worked with many, many children with CHARGE. Pam has a large network of families with whom she has maintained contact over the years. As one of the most active members of the CHARGE listerv at yahoo groups, she is always available to provide suggestions, support and encouragement. In 2007, Pam became a member of the Board of Directors of the CHARGE Syndrome Foundation. At the Costa Mesa conference, she was involved with the presentation of the ASL sign for CHARGE syndrome and with Meg Hefner in planning and executing two activities with young adults with CHARGE syndrome. As part of additional graduate work in genetics, Pam has produced a DVD about CHARGE for adults and young adults with CHARGE. Pam prefers to work behind the scenes, but now she must step forward and accept the Foundation's "Special Recognition Award."

## **Recipients of the "Stars-in-CHARGE Award"**

### **Robert Last**

Rob Last, who is a teacher of the deaf in Australia, has been a quiet but strong supporter of the CHARGE Syndrome Foundation and its families from the very beginning. In the process of planning the very first conference in 1993, Meg Hefner received a fax from this unknown (to Meg) guy in Australia essentially saying, "If you invite me to speak at your conference, my institution will pay my way." Who can resist an offer like that? And then he turned out to be one of the most popular speakers we have at conferences! Since then Rob has presented at every CHARGE Syndrome Foundation International Conference in the US and many others around the world. With Dr. George Williams, he created the Australasian CHARGE Association. Rob is truly Australia's 'Man in CHARGE' and but we feel he is equally one of us. For this reason, we wish to present him with our highest honor, the "Stars-in-CHARGE Award."

In an incident of true irony, Rob was in the hospital in Australia during the Costa Mesa conference. He is now doing quite well, but that caused him to miss his first CHARGE Conference in the U.S. We asked his friend, David Brown, to come forward and accept the award for Rob. The Star was presented to Rob in August at the International DeafBlind meeting in Australia.

## The Ogan Family

### **Marilyn, Rick, Kenny, and Kristen and Grandparents Richard & Clara Young**

This is a family that has given its all in support of the Foundation. Marilyn and Rick have both served on the Board of Directors and Marilyn has been Conference Chair twice (Indianapolis 2001 and Costa Mesa 2007). Rick helped secure used laptops for the Board of Directors as well as AV equipment for conferences from his employers. Together Marilyn and Rick made two trips to Columbia to set up computers in the new office space. They have both participated on the CHARGE listserv, sharing their experience and knowledge of CHARGE. In 2001, the entire family worked to make the Indianapolis Conference a great success. Rick kept the audio-visual equipment going; Marilyn directed the overall conference (especially the childcare); Kenny spent hours at the airport greeting families and helping them find transportation to the hotel; Kristin was busy showing her energy and teaching others about CHARGE by just being Kristin; and the Youngs manned the Registration Table for hours: checking people in, answering questions and giving directions. In addition, Clara coordinated airport pickups and made numerous trips to the airport herself. In 2003, the Youngs again helped with registration.

When the Foundation considered this nomination, it was clear that, for many reasons, it was necessary to present the “Stars in CHARGE Award” to the entire extended Ogan Family.



### **CONFERENCE STATISTICS**

**Total Attendance - 625**  
**Adult Family Members and Friends - 302**  
**Professionals - 72**  
**Speakers/Presenters - 45**  
**Adults/Young Adults with CHARGE Syndrome - 27**  
**15 years of age and under - 177**  
**84 of whom have CHARGE Syndrome**  
**Breakout Sessions - 31**  
**Research Updates**  
**Beach Club**  
**Countries represented - Australia, Belgium, Canada,**  
**Chile, Dominican Republic, The Netherlands,**  
**Philippines, United Kingdom, United States**  
**(including 35 States & Puerto Rico)**

## PRESIDENT'S NOTE

by Neal Stanger

I have to admit it took me almost a month to come down off the high of hosting our largest and best conference yet. This past July, at the 8th International CHARGE Syndrome Conference in Costa Mesa, California, we had more than 625 attendees coming from 8 different countries, 35+ states and Puerto Rico. This conference saw about 100 new attendees, over 30 adults with CHARGE syndrome and more than 100 professionals attending, many who were not speakers or even involved with our organization in the past. We would not have been able to pull this off without the tireless work of Marilyn Ogan, our conference chair and Jim Thelin, who arranged for the speakers. I know I have publically thanked them many times, but they deserve even more.

I would like to go over a few of the key aspects of the conference with you and I urge you to start making plans to join us at Indian Lakes Resort in Bloomingdale, Illinois on July 24-26, 2009. We will have hotel and conference information on our website in the coming months.

We have a committee of young adults with CHARGE syndrome who report to one of our board members. This past year they were given the task of creating a sign for CHARGE syndrome. This group worked via email and all 6 members came up with 3 options. All 18 of these were then randomly sent out to the group and they narrowed it down to their top 6. After that they all voted again and came up with the sign. I think the hardest part for them after that was keeping it a secret from their family, their friends and the list serve until it was announced at conference. At this point we had the members of the committee who were in attendance show the sign to the full membership. After the announcement, the foundation sold mouse pads with the sign on it. (There are still some available and the information is available on the website at [www.chargesyndrome.org/sign-story.asp](http://www.chargesyndrome.org/sign-story.asp))

Another key aspect happened weeks after the conference. During the conference we showed a copy of the fundraising DVD during our general session. Many people asked me about having the DVD available for training and other purposes, not just for fundraising. I asked Jay Brandrup, who created our web site, to contact the producer of the DVD and see if they can arrange permission for us to have it available on our web site. That meeting went phenomenally well and you can now watch the DVD from our home page at [www.chargesyndrome.org](http://www.chargesyndrome.org)

At our board meeting in September we had 2 changes to our board that I would like to announce. First, I regret to say that I accepted the resignation of Bonnie Haggerty from the Board of Directors. Bonnie served on the board for 2 years and was the chair of the adult services committee. Replacing Bonnie on the board will be Donna Lacey. Donna served on the board from 1997 – 2005 and was president of the foundation from 1997 – 1999. Donna felt that it was time to start giving back to the foundation again and the entire board

## FOUNDATION ACCOUNT

is excited to have her back.

Lastly, even though it is 4 years away we are starting to look into places for the 2011 conference. If you would be interested in volunteering for the conference, or having your city host the conference, please let me know immediately. You can contact me at [neal@chargesyndrome.org](mailto:neal@chargesyndrome.org) with any thoughts or suggestions you may have.

Thank you and I look forward to seeing you all in Chicago in only 21 months.

## EXECUTIVE DIRECTOR'S NOTE

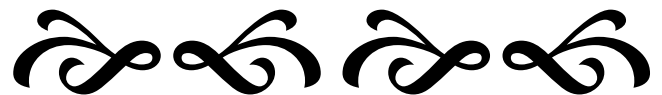
by Marion Norbury

In June we welcomed a new employee to our staff - Lori Bookstaver. Lori is in our New York office. Her address is 141 Middle Neck Road, Sands Point, NY 11050. You may contact her at phone: 516-684-4720; fax: 516-883-9060; email: [lorib@chargesyndrome.org](mailto:lorib@chargesyndrome.org). Lori is handling requests, mailings, and other tasks as she learns more about our organization.

I will continue to work in the Columbia Office (which is back in my home) taking phone calls, editing the newsletter, developing new publications, and doing the many other tasks needed to keep us going. Hopefully there will be time to start on a history of the Foundation which will celebrate 15 years in 2008.

The Foundation Website has had many new features added to it. Be sure and check it frequently as we continue to update it with new information. Bookmark the address [www.chargesyndrome.org](http://www.chargesyndrome.org). Online shopping is coming to the website soon - just in time for holiday shopping.

In the Winter Issue we will have reports on a Walk-A-Thon held in Charlotte, North Carolina by a high school student and her friends and the Texas Parents' 2nd Weekend Get-Together.



The CHARGE Accounts newsletter is intended for general information only. Medical or treatment information and/or opinions are not necessarily endorsed nor recommended by CHARGE Syndrome Foundation, Inc. or its officers. Readers are reminded that the best source of medical advice is always their physician.



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

**SPECIAL THANKS to:**

CHARGE Walk-A-Thon  
Ardrey Kell High School - HOSA  
Club (Liz Segall) NC  
Phillies Charities Inc PA

**In honor of**

**Adele Brandrup**

Jay Brandrup AL

**Charlotte Cosenza**

Donna Ingersoll PA  
Stan & KarenConner GA

**Master Braedon Croghan**

Scott & Laura Moser & Family MD

**Erica Feather**

Marc J. Sigismondo PA

**Aidan Gaucher**

Mary Kramer MO  
Matthew & Megan Senkowski PA

**Katapodis Family**

Theresa Hertman NY  
Beatrice Thompson NY  
Martha Rhodes NY

**Katie Kauffman**

Leslie Kauffman OH

**Maxwell McKinley**

Jill Mayhew AL

**Clare O'Toole**

Ronald & Laverne Krause OH  
Nancy O'Toole OH

**Christian Roberts**

Bekkie D. Cobb TX

**Dr Larry & Ruth Rosen**

Irving & Natalie Weinstein CA

**Megan Stanger**

Neal Stanger NY

**Makenna Susil**

Fritzi Gibson OH

**Gracelyn Swann**

Linda Rafferty & Jennifer Ryan CA

**Jack Waggoner**

Kathryn & Michael Collins NY  
Christian & Diana Miller NY  
Kerry & Matthew DeLisa NY

**Daniel Wolfe**

Oksana & Edward Bass IL  
Larry & Janet Chapman IL  
Lorri & Lorenzo Davis IL  
Ellen & Virgil DeLay IL  
Edward & Colleen Hein IL  
Kathleen & Michael Hohner IL  
David Horwitz & Associates, Ltd IL  
Fred & Mindy Lucas IL  
Marc & Julie Machtinger IL  
Dino & Jill Maraldo IL  
Larry & Patricia Mix IL  
Gary & Shelley Morris IL  
Lisa Roseman IL  
Donald & Penny Silich IL  
Randi & Robert Sobel IL  
Ryu & Noriko Tate IL  
Branko & Slavica Vukotic IL  
David & Sara Wechsler IL  
Wolf & Wolfe, Ltd IL

**In memory of**

**Donald Bodenstein**

Richard & LindaWebber NY  
Lois Altvater NY  
Carolyn & Roland Dornhoffer NY  
Diana Kraye NY  
Theresa Hertman NY  
Beatrice Thompson NY  
Martha Rhodes NY

**Jacob Logan Davis**

Michelle Enterline TX

**Glenn Horne**

Massry Charitable Horne Foundation NY

**Olivia Marie Lesko**

Bradley & Patricia Nelson CA  
Cynthia Crutcher CA  
Charlotte A. Weinberg CA  
David Platus & Sheryl Colby CA  
Donald H. West CA  
Robin Johnson CA  
Mark Taylor CA

**Tyler Matthew**

Brian & Tera DePaoli OH  
Sara & Kirk Chesla MD  
Kyla O'Connell MD

**Princess Jayda**

Jody Dominguez MA  
Wilma A. Lora MA  
Jose Dominguez MA

**General**

Rebecca & Jason Altman IL  
Joseph G Ciampa NY  
Laura & Saverio Fasciano NJ  
Melva Foster AL  
Lacey Friedman CA  
Catherine Kouzmanoff IL  
Donald R. Olinger NY  
Clare O'Toole OH  
Dr Jan van Dijk The Netherlands  
Katrina Walter-Williams MI  
Heather Wegley AZ  
Allstate Giving Campaign VA  
Employees Community Fund of the  
Boeing Co WA  
Freeport-McMoRan Foundation LA  
JP Morgan Chase Foundation NY  
TAP Connected to the Community  
Giving Campaign NJ

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**CALENDAR**

2007

December 1                      Deadline for Articles in the Winter Issue of CHARGE Accounts  
December 28                     Winter Issue of CHARGE Accounts in the mail

2008

January 1                         Membership Fees for the 2008 Year are now due  
October 3-5                       Australasian CHARGE Syndrome Conference

Christchurch, New Zealand \* Visit <http://www.austcharge.com.au>

2009

July 24-26                        9th International CHARGE Syndrome Conference \* Bloomingdale, Illinois

## COMPUTERS FOR CHARGE FAMILIES WHO DO NOT HAVE ACCESS TO THE INTERNET???

**REQUEST #1.** The Hewlett-Packard (**hp**) Corporation has designated the CHARGE Syndrome Foundation as a charity to which **hp** employees may contribute and receive matching funds or substantial discounts for the purchase of **hp** equipment. At the suggestion of a featured speaker at the Costa Mesa conference, an employee of **hp** has already made a commitment to the Foundation and **is attempting to locate other hp employees who would like to join him.** There is money available for a **very short** period of time if we can locate **hp** employees who would like to contribute.

If you know anyone who is an **hp** employee or if you know someone who knows someone who is an **hp** employee, we are requesting that you contact those people and ask if the **hp** employee might be interested in contributing through the Corporation to support efforts of the CHARGE Syndrome Foundation. ***This is an urgent request if we are to receive any support this year.***

When you speak to the **hp** employees you can tell them that our project for this year is to attempt to gain computers for families that have a member(s) with CHARGE Syndrome and DO NOT HAVE a computer that will allow them to have access to the internet and all of the information that is available on CHARGE syndrome.

**REQUEST #2.** We need to locate the families that need a computer for this purpose. Your help in identifying the **number** of CHARGE families in your state who need a computer would be most helpful. No personal contact information on the families is needed at this time. The Foundation only needs to submit the number of families in need and the number of states in which they reside.

Please send your information to Jim Thelin at [jthelin@utk.edu](mailto:jthelin@utk.edu) or contact him at home at 865-539-2179. Please email or call if you have any questions.

Your help with this is greatly appreciated.  
Jim Thelin, Vice President, CHARGE Syndrome Foundation, Inc.



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### Supply Swap Corner

This is a new section in our newsletter and we hope it will be helpful to all. It will be used to list any supplies that you are no longer using that you would like to offer to other children and families.

It's as simple as: you list it, you provide contact information and then you wait for someone to contact you. The CHARGE Syndrome Foundation may use its discretion in which items may not be appropriate for listing and takes no responsibility for donated items. Some examples include therapy items such as weighted vests, enteral supplies such as IV poles, DME such as gait trainers, and miscellaneous items such as unused/unopened eye patches, 2 x 2's, etc.

So if you are so happy that your child has outgrown their walker or no longer needs a suction machine, or if you are just plain tired of looking at that therapy ball - offer it to another family and save them some money, time and hassle. Please send a short description of the item you want to donate and contact information to [marion@chargesyndrome.org](mailto:marion@chargesyndrome.org).

### Supply Swap

Free full-sized suction machine (you cover shipping) - contact Lacey at [lacey@chargesyndrome.org](mailto:lacey@chargesyndrome.org)

2 ReSound Digital programmable hearing aids (8 yrs old) - contact Marilyn Ogan [marilyn@chargesyndrome.org](mailto:marilyn@chargesyndrome.org)