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Notes from the President

By Neal Stanger

This is the 6th year that I am writing to wish you all a happy and healthy New Year, and this year I truly believe the Foundation has grown the most. Here are a few highlights from 2010.

- Earlier this year, the Foundation committed \$30,000 to help fund research projects.
- In October, we hired our new Director of Outreach. Sheri Stanger will be working part-time in this position and can be reached at sheri@chargesyndrome.org or at 1-855-5CHARGE. Please feel free to contact Sheri for any information that you need.
- The Foundation has committed more money than ever before to help underwrite the cost of our conference next summer. For the first time, we are not charging any registration fees to individuals with CHARGE who attend our conference in July 2011. Additionally, our standard registration fee will only cover about 50% of what it costs us to put the conference together.

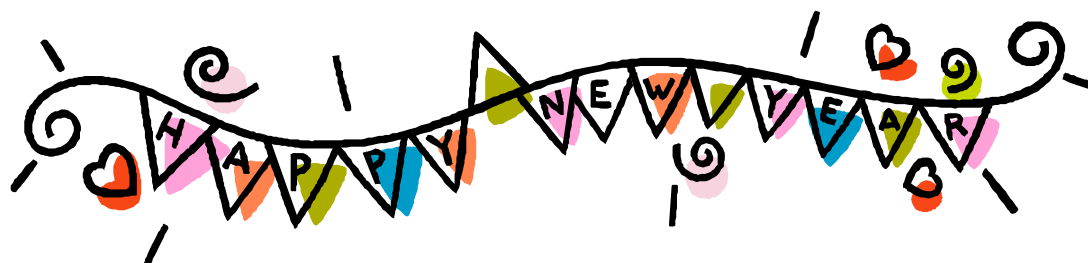
The difficulty is that we cannot do all of this without support from our members and friends. We encourage all of you to support the Foundation in every way you can. To begin, please make sure you renew your membership or become a member of the Foundation. An easy way to avoid having to renew each year is to become a lifetime member. We offer multiple lifetime membership options starting at \$250. Lifetime members receive two lifetime member pins that they can proudly wear next year in Orlando and in their community to promote CHARGE syndrome awareness.

I also encourage all of you to help us raise the much-needed funds for our Foundation. If you haven't done so already, I urge you to participate in our 3rd Annual Charge It for CHARGE fundraising campaign. You can easily start your personal web page on our thon site:

<http://thirdannualcific.kintera.org/faf/home/default.asp?ievent=434831>

If all of our members sent emails or letters to their families and friends asking them to support the Foundation, we could easily raise enough money to cover all of the projects listed above and be able to start additional projects on our wish list as well.

Finally, we always need volunteers for the Foundation. Please contact me to see how you can help us to help you. From all of us at the CHARGE Syndrome Foundation, we wish you and yours Happy Holidays!



CHARGE Foundation Quotes 2010

By David Brown

That the most complex and challenging syndrome I have ever known should have resulted in the creation of the most impressive, inclusive, exciting, and creative nonprofit organization I have ever known is probably a coincidence. Perhaps more remarkable is the fact that an organization started by a tiny group of dedicated professionals has so rapidly become an outstanding example of parent initiative and control, and has also developed the concept of parent-professional collaboration to such powerful effect.

It is impossible to imagine what the whole international field of CHARGE syndrome would be like today if the Foundation had never existed. For many of us from all over the globe, the Foundation has provided a strong, central focus. It has been our prime catalyst, inspiration, and reassurance as we work to understand and deal with the paradoxes and complexities of CHARGE syndrome. From my very first contact with the Foundation, it has played a key role in my professional growth by the way it welcomed and included me, shared information with me, linked me with others, and encouraged me to share my own experiences and opinions. I know many other people who say the same thing about what the Foundation has meant, and continues to mean, in their lives.

Although the Foundation does many important things, the wonderful biennial conferences provide the most obvious and visible evidence of this central, supportive, and embracing role. A seminar, a talking-shop, a party, a vacation, a networking paradise, a battery recharger (pun unavoidable), a morale booster, a school reunion—each conference fulfills all of these functions, but most importantly facilitates learning by providing a surprisingly intimate sense of safety, sharing, and support. How does the Foundation manage to make a hall with 750 people in it feel like my family?

Look around a room where any conference session is taking place: the audience listening and learning will be made up of parents, grandparents, other family members, people with CHARGE, family friends, and many different professionals (teachers, lawyers, therapists, psychologists, nurses, doctors, college professors, statisticians, and so on, and so on), all mixed in together, and the “expert” up on the platform making the presentation could be any of those people too. The conference model established by the Foundation is unique and is being replicated in a growing number of other countries by people who have traveled to a Foundation conference and been excited and inspired. In most cases, these travelers have themselves been the parents of children with CHARGE, so the concept of a meeting controlled and organized by parents but with full professional collaboration has been central to developments in those other countries.

Any attempt to explain and describe the Foundation should begin and end with people with CHARGE syndrome themselves. For almost 30 years I have been asserting my view that people with CHARGE syndrome provide admirable role models for all of us. In 1997, for example, I wrote that:

“I know of no identified sub-group within the population of people with multi-sensory impairment who have so many medical problems, of such complexity and severity, and with so many hidden or delayed difficulties, and yet no sub-group has shown such a consistent ability to rise triumphantly above these problems...People familiar with CHARGE syndrome often speak about iron willpower, great spirit, and a marked sense of humour being distinctive features of most people with this syndrome.”

If you are looking for the human beings who are the greatest achievers, the most creative adapters, the most persistent and determined survivors, you need look no further than this population. It cannot be a coincidence that the families themselves display similar qualities of resilience and determination, and have created and maintained this extraordinary organization.

I was still living in England in 1989 when I first heard rumors about a U.S. CHARGE organization. It took many phone calls and letters, over a period of more than a year, before I was given Marion Norbury's name and address. The speed, warmth, and professionalism of Marion's response set the tone for all of my future dealings with the Foundation. This contact with the Foundation lifted our work with children with CHARGE onto a whole new level throughout my country and the several others in which I was working.

Continued on next page...



Author David Brown with some friends at the 2007 conference.

“It is impossible to imagine what the whole international field of CHARGE syndrome would be like today if the Foundation had never existed.”

Continued from page 2

Now, 20 years later and thanks to the Internet, it is much easier to locate the Foundation and tap into the wealth of information, energy, and support that it offers. Yet many of us are still meeting families who were left in the dark about their child's diagnosis and did not even hear mention of the word "CHARGE" until their child was several years old. So the need to keep researching, informing, and widening access to knowledge about CHARGE syndrome is as great as ever, and surely the Foundation is our best hope for doing this. We all owe the Foundation so much.

Brady's Christmas Wish



By Cynthia Antaya

As Brady's parents, Keith and I have always attacked Brady's language head-on to make sure he always has access to communication. I have a wonderful story to tell that clearly demonstrates the progress Brady has made with social language and social conversation. I'm sure by the end of the story, you will all be cheering Brady on!

I brought Brady to his relatively new daycare recently. He had only been attending for about a month when this happened. I drop him off at 7 A.M. every morning, and there is consistently one other boy there who is about 4 years old. Every morning, Brady HAS to bring a train with him. To me, I thought it was a comfort thing, something familiar. Little did I know...

We walk into the infant room where all the "early birds" gather before they have breakfast. Brady's friend is already there, and he approaches me and says, "How come Brady doesn't have Diesel #10?" Now to clarify, Diesel #10 is a train in the Thomas series that came out with the new movie, "Misty Island Rescue." I was about to respond, when Brady ran up next to me and said to his friend, with perfect eye contact, "Santa will bring it." His teacher turned and looked at me and said, "It seems all the boys are creating early Christmas lists this year."

I nearly fell over and started crying because I've never seen Brady process such a conversation AND interrupt to provide his own input. First, I didn't realize he totally comprehended WHO Santa was, never mind that Santa was going to bring him something special. To complicate things further for me, while I'm standing there, Brady and his friend walk off and are discussing Brady's Percy train he brought with him. I didn't realize there was a "Thomas Club" going on, and I didn't realize Brady was having conversations about the trains with other boys.

I am happy that when we send Brady off for the day, he is communicating his likes and needs to others appropriately. Hopefully Santa reads *CHARGE Accounts* and has heard Brady's wish!



The Magic of Christmas

By Crystal Masionis



"The holidays make me feel the love around me and the magic of miracles."

Christmas with our family is always magical. We do our best to make sure our children are happy and enjoying the holiday. I want my kids to remember their childhood as magical and happy. All three of my kids LOVE putting up the Christmas tree, which we normally do the weekend after Thanksgiving. Eva LOVES the lights on the tree and will lie under the tree for hours just watching the little lights twinkle. She is amazed with all the decorations and all the new things in the stores that sing and play Christmas songs. I love watching her eyes light up and enjoy it, and as she has gotten older she shows more and more excitement.

For the past few years, someone has helped us in some way during the holiday season. Right before Eva's first Christmas, a policeman came to our door, and it scared me—I thought we were about to lose our house. But instead, he had a letter telling us that we were nominated for the "Shop with a Cop" program and that each of our kids would receive \$100 to spend at Walmart and free tickets to a movie. To this day, I still do not know who did that for us.

For Eva's second Christmas, our names were given to a church to help us again, and the kids got new clothes and a few toys. The next year, my friend's and my mom's workplaces bought gifts for us and the kids. AMAZING!! We were also given free food for a wonderful holiday dinner. Last year, we were nominated for the "Shop with a Cop" program again. We still do not know who did many of these things, but I know we have angels around us. In return, we have done our best to pay it forward when we can. For example, last year the kids wrote letters to help the Make-a-Wish Foundation.

We also visit Santa every year. Eva really checks this man out, from his beard to his gloves. What I love the most is how my boys, Alex and Bailey, who are 15 and 7, do everything they can to make sure their sister does and sees it all. Since Eva started school, she sees Santa about three times before Christmas: at the mall, at her school holiday party, and at our family party, where a special Papa comes dressed like Santa.

The holidays make me feel the love around me and the magic of miracles. I cry every time I hear "Silent Night" and see my sweet children watching holiday cartoons that I used to watch as a child. Our tradition every year since Dan and I met is to get a family ornament. It's so much fun looking for a new one that means something to us.

I also think the biggest reason Christmas is special for me is that in 2004, just before Christmas, I had a level 2 ultrasound when I was expecting Eva. They told us our child had too many health issues to be born alive and breathing. That Christmas, I did my best to be happy and keep my head up for my family and my baby. Now about to turn 6, Eva has proved them all wrong and is doing GREAT!!!

I know miracles do happen, and Christmas is the time of the year I feel the miracles and magic the most.

We hope everyone has a magical Christmas!

Crystal, Dan, Alex, Bailey and Eva (5-year-old with CHARGE) Masionis



The Masionis children enjoy a visit with Santa Claus.

Hockey Dreams



Goalie Jake Martin was recently featured in USA Hockey magazine.

By Tracy Martin

When our son Jake was born, the only obvious medical issue was his cleft lip, which really at the time did not give an indication of CHARGE syndrome. When he was a few months old, however, his vision impairments became evident. The first doctor we saw said to a very young Mike and me, “Your son is blind.” A few days later, we saw a wonderful specialist in San Francisco who first introduced CHARGE syndrome to us, but Jake didn’t quite fit the bill. Dr. Hoyt reassured us that Jake could, in fact, see, but that he had retinal colobomas, with

the left eye being much more severe and the coloboma being almost directly over the optic nerve.

Years went by and, little by little, Jake’s impairments and anomalies added up: deaf in his right ear, submucous cleft palate, developmental delays, hockey stick palmar crease (being a hockey lover, Jake loves this!), rounded ears, etc. It wasn’t until 3½ years later, when I was expecting Jake’s younger sister Cameron, that we found out Jake also had a heart defect. Fortunately, it was minor (PDA) and was fixed with a simple, same-day procedure. The “exciting” part for the doctor was that she was finally able to come to a conclusive diagnosis of CHARGE. The diagnosis changed nothing about Jake and his anomalies, but the doctor will probably never come across another case of CHARGE. We’re so glad we could fulfill that part of her career! (Can you hear the sarcasm?)

We lived in Maryland when Jake first started playing hockey—one of the rinks being the same rink that the Washington Capitals used for practice. He got to meet nearly every player on the team at the time. When Jake first developed an interest in hockey, Mike and I were supportive, but we never imagined he would be playing as goalie at a competitive travel level. It hasn’t been easy—he has had to work really hard, attending extra clinics and even working with a private goalie coach to stay competitive.

In order to play youth hockey at the travel level, you have to be a member of USA Hockey. *USA Hockey* magazine goes out each month to all members. My husband, Mike, reached out to *USA Hockey*, suggesting that Jake could be the subject of a good story. They thought so, too. After a few months of back-and-forth scheduling, an interview was finally set up. Mick, a freelance journalist, came to one of Jake’s practices, just to get an idea of who Jake was and his history/ties to hockey. Mick then came to our house to spend the afternoon with Mike and Jake in order to get to know Jake better. Then came the photo shoot. I think this was the most exciting part for me—it finally seemed real. When other parents asked me what it was all about, I was very proud to tell them about the upcoming article. *USA Hockey* also arranged for Mike and Jake to go to a preseason game to watch the Boston Bruins vs. the Washington Capitals.

Then came the wait. It seemed to take FOREVER for the October 2010 issue of *USA Hockey* to come out. Jake practically stalked the mailman each day. To add to the anticipation, his friends started posting facebook comments that they had received the magazine and saw the article before our issue arrived!

Jake has enjoyed his 15 minutes of fame with friends, family, and teachers, but today, when we were discussing the *CHARGE Accounts* newsletter, he said to me, “I don’t consider myself to be disabled.” That was heartwarming to me, and I am glad he thinks of himself in that light. I had to remind him, though, that because of his eyes and ears, he has to work a lot harder than others. Mike and I have never let Jake use his disabilities as an excuse not to do something, yet at the same time we realize that there are limitations to what he can do.

Jake and Cameron have the typical brother/sister relationship—she annoys him, he bothers her—but deep down they both support each other. Even though Cameron is four years younger than Jake, she has at times stuck up for her brother, of course without his knowing. (We all know that people can be cruel.) Jake may not admit it (yet), but hanging out at the farm or at a horseshow to watch Cameron compete does have its perks. There are always lots of girls there!

Jake is a little more than quirky (as we’re finding most goalies are) and actually loves that musty, nasty, icky, sweaty, and god knows what else, stench of his gear. When he hasn’t been on the ice for a few days, he gets antsy. When he isn’t on the ice, he is playing hockey on his Xbox or in the driveway, or browsing the NHL team websites, YouTube videos, etc. He lives for hockey! He may never play in the NHL (of course, I will hear all about this statement if and when the Caps call him up!), but he will ALWAYS play hockey.

To view the *USA Hockey* article, visit: <http://www.usahockeymagazine.com/article/2010-10/taking-charge>

“...we never imagined he would be playing as goalie at a competitive travel level.”



The Martin Family from Rhode Island

Learning about CHARGE from flies

By Dan Marenda

In the study of human disease, animal models often act as surrogates for people when (as is often the case) testing on humans is unethical or not feasible. The common thread of evolution among species allows for discoveries that are made in nonhuman species to be applied across the diversity of life forms, from single-celled bacteria and yeast to large, complex, many-celled human beings. These nonhuman surrogates are collectively known as “model organisms.” They bring with them an enormous battery of sophisticated experimental tools that allow for the study of human diseases and offer clues about the underlying factors that contribute to these diseases.

One of these model organisms, the fruit fly *Drosophila melanogaster*, has been a powerhouse in the understanding of many human diseases. As a model organism, the fruit fly has been used for over 100 years. Through study of the fruit fly, a staggering number of fundamental biological truths have been discovered that are applicable across species, including our own. In fact, the fundamental basis of the science that allows for detection of disease-causing mutations in humans (called genetic linkage analysis) was first discovered in *Drosophila* in the lab of Dr. Thomas Hunt Morgan in 1913. Dr. Morgan first observed that genes (the basic units of heredity) are arrayed in a linear fashion along chromosomes (the larger units of heredity). In this same laboratory in 1910, Dr. Morgan discovered that male flies had different sex chromosomes (XY) than female flies (XX). This configuration was later found to be exactly the same in humans. Sex-linked inheritance was discovered, and the differences in the frequency of certain diseases between males and females (color blindness, hemophilia, and muscular dystrophy, for example) was finally explained.

Drosophila have since continued to aid in our understanding of many different diseases, from cancer to developmental disorders. Yet for CHARGE syndrome, there was no *Drosophila* model. My lab decided to bring the power of the fly model to bear on CHARGE. The human gene known to cause CHARGE is CHD7. The equivalent gene in animals is referred to as Chd7. The *Drosophila* equivalent of Chd7 is called “kismet.” We were able to create a *Drosophila* model of CHARGE by inactivating the kismet gene. Once we had this model, we could test the behaviors and investigate the central nervous system function of these flies. We discovered that kismet is required in the muscle cells of the fly for both posture and coordinated movement. We found that it is also required in the fly brain for memory. We then analyzed the cells within the brain that control these behaviors, and found that kismet is required for the maintenance and growth of axons (structures in brain cells that function similarly to telephone wires, bringing information from one part of the brain to another). By better understanding some of the basic functions of kismet, our hope is that we can shed light on similar functions of CHD7 in humans. Eventually, we hope that our findings can help give the researchers working on CHARGE syndrome information that will help in developing therapeutic interventions for individuals with CHARGE.

“We were able to create a *Drosophila* model of CHARGE by inactivating the kismet gene”



The work of Dr. Marenda and his colleagues was recently featured in the Journal of Human Molecular Genetics. To see the cover with the flies used in the research, visit:

<http://hmg.oxfordjournals.org/content/19/21/NP.2.full.pdf+html>

CHARGE in the News

Winning Design

Six-year-old Tori Yoho, who has CHARGE syndrome, has designed this year's cover photo design for the annual Easter Seals Children's Art Calendar. To read more about Tori's winning Butterfly design, please visit the Easter Seals site listed below:

http://www.easterseals.com/site/PageNavigator/ntl_2011_Childrens_Calendar_Vote?printer_friendly=1

Way to go, Tori!



Photo source: Kentucky Kernel

A True Princess is Crowned

Six-year-old Abby Martin, who has CHARGE syndrome, was crowned the "Little Princess" of the Kentucky Children's Hospital by Miss Kentucky herself. To read more about Princess Abby and see a photo of her official crowning, please visit:

<http://kykernel.com/2010/11/01/miss-ky-2010-crowns-hospital%E2%80%99s-%E2%80%9998true-princess%E2%80%999/>

Camp for Children with Disabilities

Camp RAE, a summer program for children with disabilities, offered an opportunity this past summer for intensive, one-on-one therapy that most of the kids would have never gotten otherwise.

South Carolina parent Allison King, who has a daughter, Evelyn, with CHARGE syndrome, in conjunction with another parent of a child with cerebral palsy, has set up a summer camp program for children with disabilities. The camp offers intensive, one-on-one therapy. To read more about Camp RAE, please visit:

<http://media.www.patriotnewsonline.com/media/storage/paper1198/news/2010/10/06/Campus/Camp-Rae-3939979.shtml>

Resources

(1) Coalition of Organizations for Access to Technology: <http://www.coataccess.org/>

(2) American Foundation for the Blind (AFB) Job Seekers Toolkit
<http://www.afb.org/Section.asp?SectionID=7&TopicID=209&DocumentID=5319>

(3) Hawaii DB Project produced a video on Kai Hsin

Victory and Fragrance: Kai Hsin's Story [DVD]

The Pacific and Hawai'i Deaf-Blind Projects, 2010, 17 minutes.

This DVD tells the story of Kai Hsin, a girl who has CHARGE syndrome. The video is narrated by Kai Hsin's mother, who describes her daughter's history of medical problems and surgeries, the educational and other special services that helped her learn and develop, and how she and her husband have cared and advocated for Kai Hsin throughout her life. At the end of the video, Kai Hsin (now 11 years old), who communicates via sign language, tells her own story of her family, her school, her interests, and what she would like to be when she grows up. Cost: \$10.00. To order, go to <http://www.cds.hawaii.edu/main/store> or call 808-956-5861.



Families' Perceptions of Disability-Related Supports and Services: Report of a National Survey of Families Who Have Children with Deafblindness

By Kathleen Kyzar, Ph.D., Jean Ann Summers, Ph.D., and Megan Cote, M.Ed.

This research study focused on (a) learning families' perspectives of disability-related services and (b) evaluating if services have an impact on families' lives. Please find a summary of the study below. For more information about this study, contact Kathleen Kyzar at kkyzar@ku.edu or 785-864-7601.

Why study families' perceptions of disability-related services?

Most research in the disability field focuses on the child. However, a child's family has an effect on his or her ability to grow and learn. Therefore, it is important that services meet family needs as well as the needs of the child. Because children with deafblindness can have complex needs, families often access services and supports in multiple service systems (for example, health services, education services, service coordination) and can experience satisfaction with services at varying levels. The purpose of this study was to learn how helpful families of children with deafblindness feel these services are and whether these services are making a difference in their family quality of life.

How did we conduct the study, and who participated?

A research team at the Beach Center on Disability at the University of Kansas partnered with 16 state Deafblind Technical Assistance Projects across the United States in distributing surveys to families of children between the ages of birth and 22 who were active on the deafblind census in their respective state. A total of 227 families returned surveys. The majority of the participants were female, White, and described themselves as the parent (biological, step, foster, or adoptive). Participants were asked to report any disabilities the individual with deafblindness in the family had in addition to his or her dual sensory impairment. Most noted that their child had a speech or language impairment, a developmental delay, and a physical disability. Only five participants noted that their child had no additional disabilities.

What services and supports did families rate?

- **Health Services** (for example, nursing services, nutrition services, well-child checks)
- **Education Services** (for example, special education, vision and hearing services)
- **Related Services** (for example, physical therapy, intervener, orientation and mobility)
- **Information Services** (for example, state deafblind technical assistance projects, parent training and information centers, state department of education)
- **Child Care Services** (for example, respite care, center- or home-based child care)
- **Friend and Family Support** (for example, extended family, friends, parent-to-parent support)
- **Service Coordination** (for example, medical home, service coordination or care coordination)

In addition, we asked families to rate their satisfaction with their family quality of life and with the partnerships they have with professionals (e.g., their child's teacher, their service coordinator, their health care provider).

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Continued from page 8

What did we find?

In this study, there were three main findings:

Families rated Health Services as highest in meeting their needs and Service Coordination as lowest. Refer to Figure 1 for more information about the overall ratings of services. The scale ranges from 1 (the service did not meet family or child needs at all) to 5 (the service completely met family and child needs).

Taken on the whole, services and supports did make a difference in family quality of life. In particular, Related Services and Friend and Family Support were the most important in having an impact on families' lives. Figures 2 and 3 highlight families' ratings of particular Related Service and Friend and Family Support items. Again, the scale ranges from 1 (the service did not meet family or child needs at all) to 5 (the service completely met family and child needs).

Partnerships influenced the impact that services had on family quality of life. That is, the level of family quality of life a family experiences depends on how satisfied they are with their family–professional partnerships *and* how satisfied they are with the services they receive.

What is the take-away message from this study?

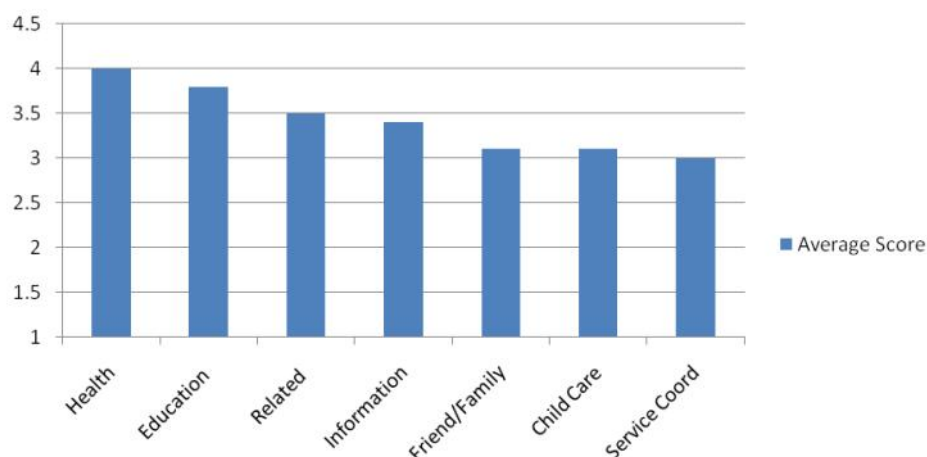
This national study is one of the few that has sought to understand the perspectives families of children with deaf-blindness have about disability-related services and supports. The findings showed that, in general, families are satisfied with the services they receive; however, they have the best experiences with Health and Education Services and experience challenges with Child Care and Service Coordination. More research is needed to understand what factors lead to families' satisfaction with health services. This information could then be used to improve other services.

One of the main findings of this study was that services and supports can make a difference in families' lives. Related Services and Friend and Family Support have the biggest impact. Attention is needed to ensure that families receive quality Related Services and the appropriate amount of these services. Related Services providers should receive professional development so that they are able to effectively partner with families; this will maximize the outcomes both families and their child experience as a result of service provision. All service providers should consider the sources of supports families have, e.g., friends or extended family, and capitalize on those resources as they plan services for the child and family.

Finally, the impact of services and supports was dependent on how well families felt service providers partnered with them in meeting the needs of their child. This finding is encouraging. In areas where services are less adequate, service providers

“...service providers can potentially make up for negative effects services have on the family.”

Families' Ratings of Services and Supports



**Figure 1.
Families' Ratings of
Services and
Supports**

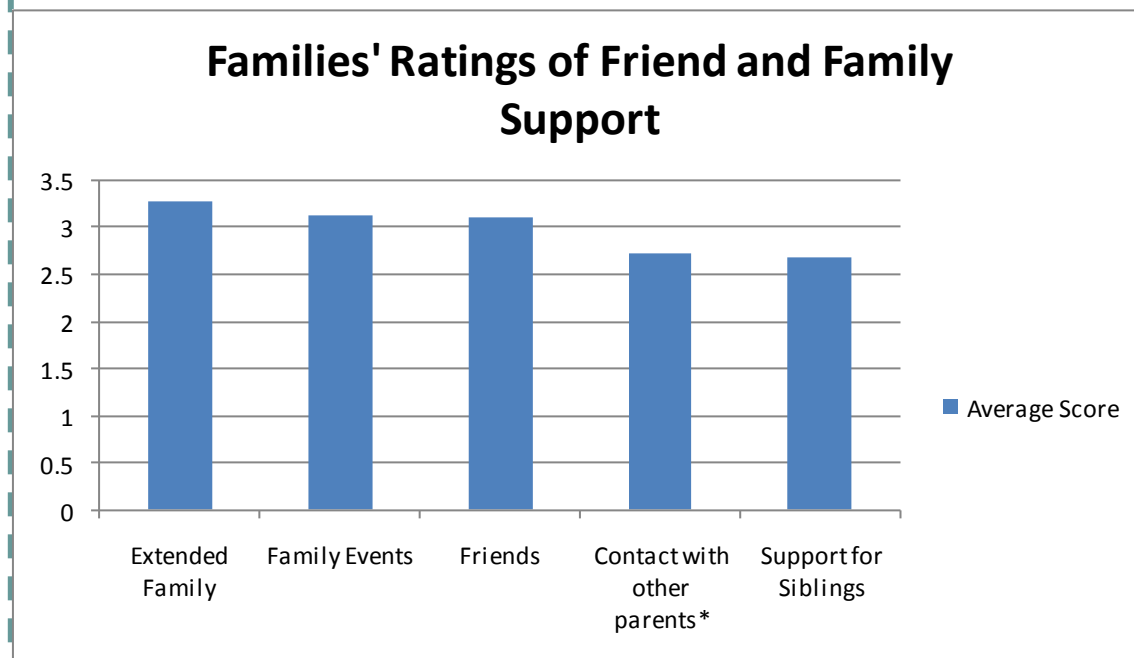
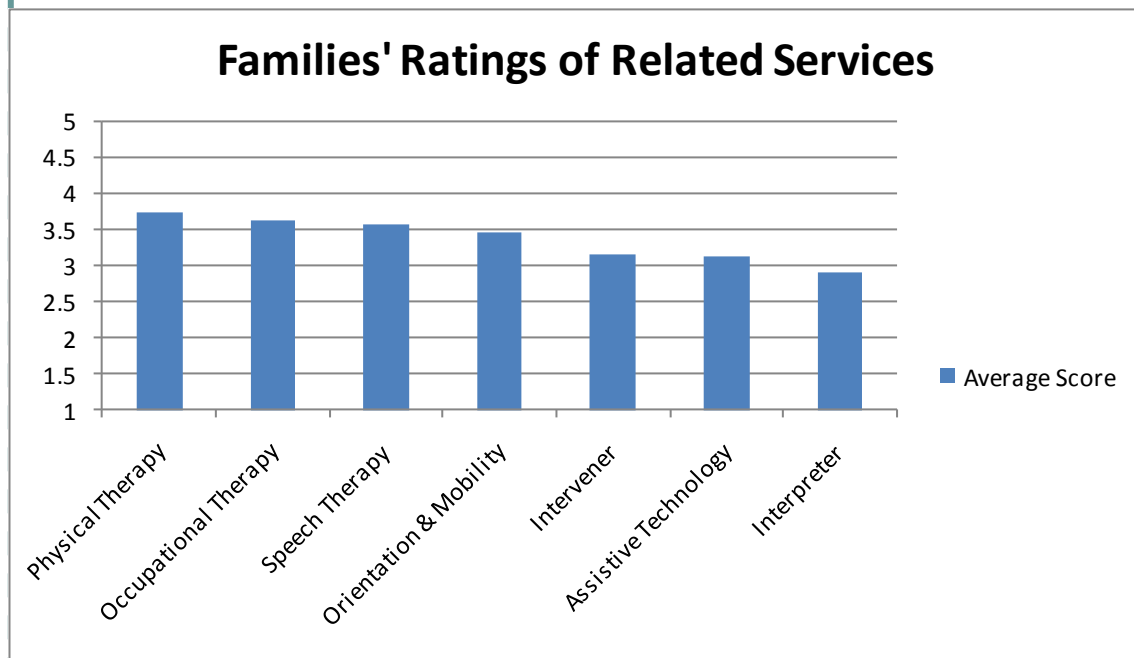
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Figure 2
Families' Ratings of
Related Services

*"These findings...
add to the
knowledge about
how to effectively
support families of
children with
deafblindness."*

Figure 3
Families' Ratings of
Friend and Family
Support

Continued from page 9



*Contact with other parents of children with deafblindness or similar etiology

CHARGE Syndrome: A Book Review

By Melva Strang-Foster

I ordered a prepublication copy of the book *CHARGE Syndrome*, but had only read the introduction when I gave that copy to my daughter to help her prepare for an upcoming appointment with a new endocrinologist. I immediately ordered three more copies—one for me and the other two for Halyn's pediatrician and one of her therapists.

It is about 6:30 A.M. on Sunday morning. I began reading *CHARGE Syndrome* around midnight, thinking that I would probably nod off to sleep after the first couple of chapters. WRONG! I couldn't put it down. Thanks to the editors for all the hard work that went into getting this book to press.

I am completely blown away by the comprehensive coverage of so many critical topics related to CHARGE syndrome. There were times that I wanted to throw up my fist with a triumphant "YES!" when I read passages that validated our family's observations/conclusions regarding Halyn's capabilities and potential for future milestone achievements. I laughed aloud when I read the section describing these children's mischievous giggles and sense of humor! Other times I was moved to tears as I recognized the universality of so many of the frustrations and challenges these kids and their families face throughout their lives.

The timing of the release of this publication was a godsend to our family. Halyn is 5 and has just entered public school kindergarten. We are educating her special education team about CHARGE and its impact upon her physical stamina, behavior, communication, etc. (She is the only child in Montgomery, Alabama, diagnosed with CHARGE.) Because of this book, we are recognizing that we need to back up and reassess the family's expectations for Halyn's use of spoken language at age 5 and determine the best path to follow to help her develop more symbolic communications skills at this point.

Before I take Halyn for another hearing assessment, I plan to reread and make notes on the pertinent chapters so I can share them with the audiologist. Halyn's parents, Allie and Damon, will do the same thing as they prepare for their appointments with Halyn's doctors.

Please pass along my praise and appreciation to the editors who collaborated to produce this wonderful reference book for the families and professionals who work with children, adolescents, and adults born with CHARGE syndrome.

"I am completely blown away by the comprehensive coverage of so many critical topics related to CHARGE syndrome."

CHARGE Syndrome Ordering Details

If you have not already purchased a copy of the CHARGE Syndrome book, you may order one online at

http://www.pluralpublishing.com/publication_cs2.htm

As well as being a wonderful resource about CHARGE syndrome, all of the author (editor) royalties are being donated to the CHARGE Syndrome Foundation.

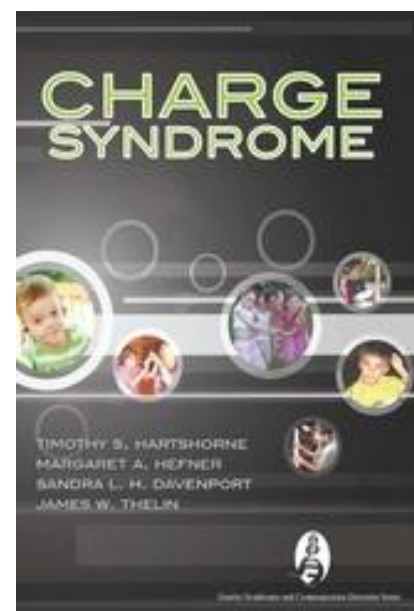


Photo source: Plural Publishing

“B” in CHARGE

By Annette Stocker

The 9th biennial conference of the CHARGE Syndrome Association of Australasia Limited was held at the Esplanade Hotel in beautiful Fremantle, Perth, Western Australia, October 8–10, 2010. “B IN CHARGE” was the theme of the conference, and this theme was carried through by certain committee members who literally became a Bee! Pictured at left is Conference Committee chairperson Sharon Barrey Grassick embracing Sophie the Bee on Friday night. The Bee, which Sophie made, was introduced to the children and delegates at the Friday night “Meet and Greet.”

The Esplanade Hotel was a superb venue for the conference, which was able to provide on-site childcare with excellent facilities. A wonderful array of food was on offer each day for lunch, and no one went hungry!

Thirty children, including 17 with CHARGE, attended the conference. In addition, the conference was attended by 86 delegates, including three speakers— Tim Hartshorne, David Brown, and Kasee Stratton from the USA; Jeremy Kirk from the UK; with our very own Rob Last from Melbourne and George Williams from Sydney. Kim Blake provided an interesting presentation on Endocrinology and recent updates in the world of CHARGE by DVD from Canada. The DVD was well received and included answers to questions previously sent to Kim from parents. Hopefully one year we will be able to have Kim attend a conference in person. Thanks must go to each of our presenters who freely give up their time to attend our conferences and provide the most recent research and guidance to parents and other professionals working with children with CHARGE.

This year, the childcare was overseen by Sophie (the Bee) Makse. Sophie is an early childhood trained teacher and has worked in deafblind education for three years. Sophie organized some great activities for the children, including visiting Cicerellos Seafood Restaurant so the children could touch and feel the marine life in the special pool that is set up for people to have this unique experience. Forty-eight volunteers, most with signing skills, assisted Sophie in the childcare. The volunteers were from TAFE Auslan class, teachers of the deaf and special needs, education assistants, and educational interpreters. This was a fantastic turnout of skilled people looking after our very special children.

The Friday afternoon clinics with the specialists were well attended, with a waiting list having to be drawn up. This is proving to be a sought-after event and one that shows how much the parents enjoy the one-to-one time with professionals to gain advice and guidance on any issues they may be having.

Congratulations to the conference committee of Sharon Barrey Grassick, Lisa Watson, Marie Ingley, Jon Ingley, Paul Drok, Shirley Ciccotosto, Sophie Makse, Robin Hamilton, and Karen Wickham, who provided a well-run conference with the presenters covering a broad range of topics. One of the most inspiring presentations for me was Sharon’s “Sign Chi.” As a qualified Tai Chi Instructor and Deafblind Educator, she has adapted basic Tai Chi moves to incorporate key signs. This was something I have never done, and I was so impressed by the calming influence as well as learning some new signs that I will be able to bring back to New Zealand. I am hoping my daughter’s school will take up this activity and include the whole school.

A big thank-you must go to Belinda, Ellen, Kimberley, and Yasmin who presented on the young adults’ panel about their lives and progress on their careers since the conference in 2008. These four ladies are truly inspirational with their current achievements and goals for the future.

The Association’s Annual General Meeting was held on Friday night, with all the current directors being reappointed to their positions. Two new members were appointed as Directors. We are pleased to welcome Lisa Kerr from Auckland, New Zealand, and Nada Lee from Queensland.

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Sharon & Sophie the Bee

“...the parents enjoy the one-to-one time with professionals to gain advice and guidance on any issues they may be having.”

Another bee in attendance at the conference





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At the Saturday night dinner, there was host of entertainment with a magician (I still cannot work out how he did some of those card tricks!) and three belly dancers! I was disappointed that the conference committee was not up there strutting their stuff! The evening was topped off with Rob Last being presented with a book, "This Is Your Life, Rob Last," by Marie Paterson. As most of you are aware, our Rob has been involved with CHARGE and deaf/blind services for a considerable number of years now. The book contained photos from Rob's career and stories from both professionals and families who have been privileged to work with Rob over the years.

The conference closing was topped off by the children, siblings, and caregivers all joining in to sing and sign the wonderful and emotional song of the Beatles, "Let It Bee." I'm sure there was not a dry eye in the room.

The next conference, scheduled in 2012, will be the 10th Conference held by the Association and will be back where it all started in Sydney! I look forward to seeing you all there.

Australasian Conference Recap

By Ellen Howe



I attended the 9th Australasian CHARGE Conference in October. What a great time! Fremantle was lovely, the people were wonderful, and we can't leave out the professionals, either.

Friday's "meet and greet" provided good fun, catching up with old friends, finding some from facebook, and making new ones. Dinner Friday night with Rob (Last), Kasee (Stratton), George (Williams), David (Brown), and Tim (Hartshorne) was great. I also spent break with them on Friday, Saturday, and Sunday.

Saturday sessions were excellent. I have to say that listening to Dr. George, being first up after the slideshow, a wonderfully moving opening message from one of the CHARGE mums, must have been hard for some of the newer parents, but as usual he had some interesting things to say. He said that America and Canada have more children with CHARGE than we here in Australia and New Zealand do. How interesting is that! He also said that abdominal migraines and such are a part of CHARGE related to the cranial nerve (I think he said #7) that runs from the middle of your face

down into your stomach. This nerve often has abnormalities, which can result in not only facial paralysis and related issues but other problems as well.

David Brown noticed he was speaking between George and Tim, so he decided to go light. (LOL) He made some jokes, but on the serious side, he spoke about the importance of professional-parent relationships. It is important to be all at one with your team, he stressed. He also said that it's good to write a brief book about your child that you can hand to doctors and other team members.

Tim spoke about behavior. He said that some behaviors may be the only way a child has to communicate something. A particular behavior can sometimes be stopped by teaching a better behavior in its place.

Kim Blake presented via DVD. She spoke about the issues with cranial nerves and swallowing, similar to what George had said. She's seen success in a couple of patients who've had BOTOX injections in the salivary glands. You just have to keep repeating the sessions and only in the two side glands. She also said it's a good idea to group a few procedures under one anesthesia, if you can.

Then there was the adult panel. Everyone loved me, Belinda, and the others. Saturday night dinner was good and provided an opportunity to see everyone. Rob received a special book. He's been with the CHARGE group for nearly 20 years.

Sunday morning, Kasee (Tim's graduate student) spoke about studies being done on pain in CHARGE. She said these studies show that most people with CHARGE experience chronic pain. However, some of the behaviors that we think are pain related might be just typical CHARGE behaviors. For instance, she said spinning and similar types of behaviors are probably just typical CHARGE behaviors, but something that one doesn't do often could be a pain-related behavior. She thinks we need a pain scale based on CHARGE.

The other speaker was Jeremy Kirk, another great presenter. It was a wonderful conference and a wonderful time!



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10TH INTERNATIONAL CHARGE SYNDROME CONFERENCE

We hope you are making plans to join us next summer for the 10th International CHARGE Syndrome Conference. Hotel registration is available now, and online registration will be available in early 2011. Be SURE to stay tuned to the conference website for information regarding an early bird contest. Those who register and pay early will be in the running for some amazing prizes!

In addition to sessions on a wide variety of topics, next year's conference will feature a transition strand. The sessions in this strand will address transition issues that occur at various ages/stages in the lives of individuals with CHARGE.

Hotel Registration

https://reservations.ihotelier.com/crs/g_reservation.cfm?groupID=488116&hotelID=6840

TO DO LIST:

1. Explore funding sources.
<http://chargesyndrome.org/documents/FundingResources.pdf>
2. Register at hotel. (available NOW)
3. Register for conference. (available early 2011)
4. Make travel arrangements.
5. Get ready for a GREAT time!



Conference Website <http://chargesyndrome.org/conference-2011.asp>

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**In Honor of our beautiful
and wonderful son Nathan,
who has taught us more
about enjoying life and
facing adversity than
anyone else ever could. We
love him with all our hearts.**
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CHARGE ACCOUNTS



It is that time of year again when we gather with our friends and families and celebrate the holidays and New Year. We also reflect on the many things for which we are grateful and look forward to an exciting 2011. The Foundation is thankful for all your efforts to support our mission. **THANK YOU** to everyone who has raised money for the Foundation, donated, become members, or volunteered. Without your continued support and contributions, we would not be able to fund research, raise awareness, provide educational material, run our 2011 conference, or assist individuals with CHARGE syndrome and their families.

December is the number one month for charitable giving. We hope you will consider joining our online Charge It for CHARGE fundraising campaign. Simply visit our website to become an online fundraiser. If online fundraising isn't your preference, please consider planning a fundraising event. Whether you like to walk, swim, run, bike, bowl, golf, or eat, you can turn your passion or hobby into an appropriate event for you. Remember, no online fundraising campaign or event is too large or too small. The whole is much greater than the sum of its parts. Lots of campaigns of any size add up to one giant success for the Foundation. Please join us.

Every donation and membership allows the Foundation to continue to fulfill its mission. If you have not joined the Foundation or need to renew your membership, simply visit <http://www.chargesyndrome.org/membership.asp>. If you wish to make a donation, visit <http://www.kintera.org/autogen/home/default.asp?ievent=341543>

Please keep the Foundation in mind this holiday season! THANKS AGAIN for all of your efforts, donations, and memberships! We would not be where we are today without all of you. Happy Holidays.

David Wolfe
Treasurer and Fundraising chair
david@chargesyndrome.org

Please Join Us!

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