

CHARGE Accounts



Fall 2005

A Quarterly Newsletter for Families and Friends

Vol. 15 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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CHARGE Syndrome
Foundation, Inc. 2005

7th International CHARGE Syndrome Conference July 22 - 24

!!! Largest Conference Ever !!!

Total Attendance - 540

Adult Family Members and Friends - 289

Professionals - 38

Speakers/Presenters - 34

Adults/Young Adults with CHARGE Syndrome -10

16 years of age and under - 169

77 of whom have CHARGE Syndrome

Countries represented -

**Australia, Austria, Belgium, Brazil, Canada, France
New Zealand, Norway, Spain, The Netherlands, United Kingdom
United States, Uruguay, and Western Australia**

28 Breakout Sessions

Research Updates

Camp Fiesta

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YOUR HELP IS NEEDED!

Please share your stories, parent tips, questions, book reviews and suggestions for other features you would like to see included.
Remember this is your newsletter!

Deadline for the Winter Issue - November 15

September 27, 1981 - Medical report, Portland, OR - *“His features include microphthalmia, microtia, ptosis on left, bilateral neurosensory deafness, retinal colobomas, blindness on the left and decreased vision on the right, partial facial paralysis on the right, upper body hypotonia, short toes, choanal hypoplasia, abnormal Barium swallow, and cardiac defects involving an atrioventricular canal-type defect and Wolff-Parkinson-White Syndrome. He also had problems with lacrimal stenosis and has required PE tubes. There are feeding problems and growth hormone insufficiency.”*

FAST FORWARD

August 27, 2005 – Acceptance Speech, Minneapolis, MN - *“Thank you very much. I am honored to receive the Jay and Rose Phillips Award*. Growing up in the Twin Cities I have been helped by many Courage Center** programs including:*

- 1. Courage Riders*
- 2. Camp Courage North*
- 3. Swimming at the Courage Center pool*

Courage Center has been a very positive part of my youth, so I want to thank Courage Center for all these things as well as this wonderful award.

I also want to thank the U.S. Army Corps of Engineers for giving me a chance to work. I have learned a lot at the Corps of Engineers. Many people there are wonderful and they supported me and taught me new skills and responsibilities.

I began working part time after high school and now work full time while taking college classes. I hope I have a long career with the Corps. But no matter what the future holds for me, I will always take pride in my work and career, and I will never let vision or hearing slow me down. I also want to thank my parents for advocating for me and teaching me to never give up.

I'm proud of my job, and I can't imagine not working. I don't think I'm special, but I am very honored and thankful for this special recognition.

Thanks again!” Andrew Prouty

Andrew's short speech was the culmination of the celebration at the Medtronic Celebration of Courage Gala. He invited his sister Liz, Mom, Dad and friend, Jamie, to join in his celebration. The evening began with a champagne social honoring the five Phillips Awardees and the National Courage Awardee, Tricia Meili, known for years as the Central Park Jogger. (Past honorees include Christopher Reeves, Senator Bob Dole, Itzhak Perlman, Stephen Hawking and I. King Jordan) Andrew was provided access to the evening with his own interpreters as well as a Courage Center Escort whose duty it was to introduce him to local celebrities.

Eventually, over 400 people trickled in to the Gala where the theme was summer camp. The white-clothed tables were decorated in a camping theme including tree boughs, tackle boxes, rubber bugs, snakes and even marshmallows topping a long roasting stick. Dinner too, followed the camping theme with B-B-Qed chicken and S'more desserts. After dinner, the program began which was MC'ed by a local television news anchor. The honorees received their awards through the night and were given time to speak.

Andrew received his award with a sparkle in his eyes and was fortunate to benefit from the talents of an excellent ASL interpreter who conveyed Andy's signed message brilliantly. He was not an ounce nervous to stand up in front of 400+ people to receive his award.

Andrew, born with CHARGE syndrome, has never let his vision or hearing loss get in the way of work or career aspirations. He has worked continuously since high school; as a YMCA camp counselor, as a dishwasher in a local bakery, as an intern



Andrew Giving His Speech

with the Regional Service Center for the Deaf, and for the past 3 years as an office clerk with the U.S. Army Corps of Engineers in St. Paul. He also continues to take college courses from Metropolitan State University and hopes to some day pursue a career in computer design and animation.

*Established in 1964, the Jay and Rose Phillips Awards are administered by the Courage Center(www.courage.org), with funding made possible by the Jay and Rose Phillips Family Foundation. The \$1,500 cash award honors individuals with disabilities who have achieved financial and vocational independence. Winners are selected for their professional success, leadership skills and their contributions to their community.

**The Courage Center is a nationally-known, non-profit rehabilitation and resource center for people with physical disabilities, brain injuries, speech, vision and hearing impairments. Established in 1928, Courage offers comprehensive services to people of all ages, serving more than 16,000 people with disabilities each year.



Andrew and Jamie at the Gala

Stars in CHARGE

Stars in CHARGE is the Foundation's highest award. It is given for significant contributions over a period of time. The award is a crystal star with the Foundation logo and the name of the recipient(s) etched in the award. The award is usually presented at the International Conference. This year three stars were awarded to: David Brown, Tim Hartshorne, Neal Stanger.

David Brown is one of the most knowledgeable people in the world when it comes to education of children with CHARGE. His powers of observation and skill in translating those observations into practical suggestions in both educational and home settings have improved the lives of countless individuals with CHARGE and their families.

Tim Hartshorne has been instrumental in encouraging and coordinating the efforts of countless professionals looking at behavior issues in CHARGE, resulting in the Behavior Symposium at the Cleveland Conference and the special issue of the American Journal of Medical Genetics.

Neal Stanger has served on the Foundation Board of Directors for 8 years and has just started another 4 year term. He has spent countless hours working for the Foundation. A few of the things he has done: served as program planner for the 2003 Conference, as 2005 Conference Chair, held the first silent auction, developed the website, served as Secretary-Treasurer and Vice President.

Hello everyone,

I would like to introduce myself. My name is Neal Stanger and I have recently taken over the office of President for the CHARGE Syndrome Foundation, Inc. Although I am new to the presidency I am not new to the foundation board. I am starting my 9th year as a board member and held many positions in the past including Secretary, Treasurer, Vice President and Conference Chair. I am very accessible if anybody needs me for anything. Please feel free to email me at neal@chargesyndrome.org or you can reach me by telephone at any of the following numbers: 914-793-8330 (work); 914-478-7248 (home); or 914-629-0564 (cell).

This year has already been a very busy one for the Foundation: We learned more about the new CHD7 gene that was discovered and a special issue of the American Journal of Medical Genetics that was devoted entirely to CHARGE syndrome was published. We held our 7th International Conference in Miami Beach, Florida where we hosted over 540 people from 14 countries. Recently we sent a team to California and finalized our location for the 2007 conference, which will be held in Orange County, CA, and our board just finished a strategic planning meeting at Perkins School for the Blind in Watertown, MA the beginning of this month.

Our board has undergone many changes as well; we have had four board members retire this past July. I would like to thank each of them for their hard work and dedication to our children. Steve Hiscutt and Rick Ogan each retired after serving one term, Donna Lacey retired from the Board after serving eight years (two as President), and Bruce Appell also retired after eight years of service, six of which as President. We have added two new board members. Marilyn Ogan is back on our board after a short

respite. She was a board member from 1997 – 2001, hosted the 2001 conference in Indianapolis and will be the chair of the 2007 conference. Our other new board member is Bonnie Haggerty. Bonnie brings new ideas to our board and we are excited that she has joined us. We look forward to a very productive future and, as always, welcome your input.

EXECUTIVE DIRECTOR'S NOTE

Marion Norbury

2007 Conference

Our 7th International CHARGE Syndrome Conference was held in Miami Beach, Florida on July 22-24, 2005. There were 540 individuals in attendance. It was our largest conference yet. This number includes speakers, board members, professionals, and families (parents, grandparents, other family members and children). The 169 children ranged in age from 2 months to 16 years. 76 of these children have CHARGE syndrome. We also had 10 young adults who have CHARGE. Several of them were on the program and their speeches have been reprinted in this newsletter.

Our attendees came from 14 countries: Australia, Austria, Belgium, Brazil, Canada, France, New Zealand, Norway, Spain, The Netherlands, United Kingdom, United States, Uruguay, and Western Australia. 20 families received the Lee E. Norbury Memorial Scholarship. This scholarship is awarded to families attending their first conference and pays their registration fees and hotel room.

There were 28 breakout sessions and two general sessions. We have reports on several of the breakouts in this newsletter. Saturday night we had a carnival atmosphere with games for the children, a silent auction, and a dance floor with a great mc who kept

everyone hopping. Child care in Camp Fiesta was provided by the Florida Outreach Project, Kiddie Corp, and the wonderful volunteers recruited by Susy Morales. Also, many family members attending the conference lent a hand and Uncle Kenny and Cheryl Moretz helped the children create their own souvenirs to take home.

We hope you enjoy this wrap-up of another very successful conference. If you haven't attended one yet, we hope to see you at the next one in 2007.

On p. 20 there is a list of conference items now available from the Foundation office. Some have the Foundation logo; others have a design made especially for the conference.

Three of our members had very successful fundraisers this summer - Ana Saruski, Susy Morales, Molly Roberts. Together they raised over \$33,000 for the Foundation. Ana and Susy designated their contributions toward the Conference Fund; Molly marked hers for the General Fund. We send our congratulations and grateful thanks to all of them.



Committee Chairs

Conference – Marilyn Ogan

Research – Meg Hefner

Fundraising – Dennis O'Toole

Education/Outreach – Jim Thelin

All board members have a special email address:

[\(firstname@chargesyndrome.org\)](mailto:(firstname@chargesyndrome.org))

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 child's physician.

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On Friday Belinda Arnell, a young adult from Australia who has CHARGE syndrome, gave a keynote speech at the Opening General Session. Then on Saturday, four young adults who have CHARGE syndrome served on a panel.

Each gave a speech about their life and how CHARGE had affected them. They then took questions from the audience. We are honored to share their speeches with you in this newsletter: Belinda Arnell from Australia, Chip Dixon from California, Chantelle McLaren from Ontario, Christine Nieder from British Columbia, and Philip Wismer from Pennsylvania.

Belinda Arnell

Good morning, everyone. My name is Belinda and I am 22 years of age. I have been asked to talk to you about some of my experiences of living with CHARGE syndrome.

I live with my Mum and Dad, two sisters, one brother and three mad dogs in Melton, Victoria, Australia.

My particular CHARGE eye conditions are bilateral coloboma and high myopia, which result in severe vision loss even with my glasses which I have had since 13 months old, and contact lenses that I have worn since I was nine. I have bilateral Choanal Atresia for which I have had many repairs. Because I used to have tubes sticking out my nose, people would come up to my Mum in the supermarket and say things like "Excuse me, is your baby alright, there are straws or something stuck up its nose?" I have had delayed puberty for which I have been on hormone therapy since I was thirteen, though I only recently went on to a full dose. I was kept on a low dose so I could achieve my maximum growth.

I have central nervous system defects including facial palsy, ptosis, poorly coordinated swallowing and no sense of smell! You can imagine this can be quite handy at times but difficult at others... I remember a lot of brownie and school camps where I would be asked to clean the toilets because I couldn't smell them. I don't have a particular heart defect, but my Dad had a Patent Ductus that was repaired at a young age. He apparently doesn't have CHARGE Syndrome but after hearing at a conference that many CHARGE children have a preference for strongly spiced foods, probably due to their lack of sense of smell and reduced taste, and knowing how much tomato sauce my dad smothers on his pizza, I'm beginning to think otherwise! My other major defects are ear defects and moderate, severe deafness, for which I wear two hearing aids. I also used to wear a Radio Frequency unit that allowed me to be able to hear the teacher more efficiently. I remember in primary school I used to wear it and the teachers who wore it would often forget to turn it off and I could sometimes hear what was going on inside the staff room. Once I heard that my teacher was leaving and we were getting a new one mid year and told everyone and I've also heard a few toilets flushing as well at recess.

When I was younger, I was often extremely sick and required many medical appointments, medicines and operations. I needed constant suctioning and help with feeding. Food and milk were forever coming out my nose, the colour depending on what I had just eaten or drank. I had to visit 7 or 8 medical doctors and another 5 or 6 therapists. Mum said I used to cooperate to some extent doing speech and physio stuff each day, but Mum used to have to think of more interesting ways to get me to do things. She used to con me with treats, games, and telling me it was my aunt's favorite exercise or food if she wanted to make me do or eat something. I don't think I minded going to doctors that much, probably because I got lots of attention and sometimes chocolates from them. I remember for about eight years when I was younger, I couldn't chew or swallow meat or other foods very well and I used to hide them down the side of the chairs and Mum or Dad would find them a month or so later. My mum is convinced I have obsessive-compulsive disorder due to my obsession with the phone and computer.

I got glasses when I was 13 months and hearing aids when I was 17 months which helped me to learn a lot more. The first optometrist I saw didn't bother giving me glasses at six weeks old when he diagnosed my coloboma and myopia. Obviously, he didn't think it was any use improving someone's vision who had so much else wrong with them. Luckily my parents and now many other CHARGE families in Victoria discovered Dr. Hector Mclean who assisted everyone he saw to reach their maximum vision. Oh yeah and he had delicious chocolates.

I lived in a very busy family, who were always reading with me and bugging me to try and help me learn. Apparently I've paid them back over the years with my chatter and questioning and my real payback, loud singing practice and my loud arguing voice. I used to have trouble sleeping when I was younger and would wake up in the middle of the night in my sister's room and start playing. I couldn't understand why she didn't want to play with me at 3 or 4 a.m. I used to be the first person up at 5am and do lots of puzzles. I went to both regular and special playgroup to widen my experiences. I was always breaking my glasses when I fell over or knocked into things due to very bad balance and vision, and also losing or hiding my hearing aids. In early primary school, my teachers used to find my hearing aids buried in the sandpit or hidden behind a building. Once I told my Mum I wasn't wearing my glasses anymore because my friends said I had to be the mum when we were playing mummies and daddies because I had glasses.

I spent a lot of time playing on the trampoline even before I could walk very well. My mum put balls or lots of soft toys on

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it and I would try to bounce them off. I played a variety of games on the trampoline too with my brother and sisters which helped my balance despite quite a few dives into the ground. I liked to explore and climb up on

everything and one time I climbed up on the car roof and fell off and got a tennis ball size lump on my head. This didn't stop me from getting up to mischief.

At primary school, I had an integration aid for about eight hours per week and the Royal Victorian Institute for the Blind sent out a visiting teacher once a week to help me maximize my learning. I also had a teacher for the hearing impaired come out weekly. I started doing lots of extra activities outside school including swimming, drama, calisthenics and reading piles of books. I really needed to wear my glasses when I was swimming at the beach with my boogie board. I lost a few lenses when huge waves would come along. I used to spend ages looking for them and would often mistake a jellyfish for them. I never did find any of those lenses. I can just imagine there is some fish swimming around with super vision! Another time, a lens came out of my glasses at a calisthenics competition. I just kicked it off the stage and kept going.

I'd like to tell you about how I've stopped a few rides in my life. I was on a huge toboggan ride and was in an individual car that flew off the track because I didn't see the sign to Slow Down and my hearing aid flew out and I fell off. They had to stop the whole ride while they got my car back on and found my hearing aid. Once they had to stop a water slide on an extremely hot over 30 degrees Celsius day for about an hour while they looked for my glasses lens. I got contact lenses when I was 9 and have lost many and found few. I lost one down a coal mine, I found another one a few days after losing it at the bottom of the Weetbix box, and another one after many hours of searching everywhere, in my eye. (up under my eyelid)

High school was a challenge. I had extra help with an integration aid for about eight hours per week and I continued to have visiting teachers. I also did lots of drama and singing as extra activities. I've always been interested in acting and performing and I have been involved in many plays and musical productions both at school and in the wider community. In one drama production, I fell off the stage because I wasn't aware of where the edge of the stage was. I just got back up and kept acting.

Whilst still at High School, I received my Radio Announcers license as our local radio station is on the school grounds. I also gained a Certificate Qualification in Information Technology from Victoria University, which I completed instead of one of my V.C.E. subjects. (final year of high school) In 2001 after I had finished High school, I was granted a Scholarship from the Royal Victorian Institute for the Blind that included a laptop computer and other equipment to assist me with my studies.

I am currently at University studying Bachelor of Arts Criminal Justice Studies. Prior to this I have completed an Advanced Diploma of Justice, a Certificate in Legal Administration and first year of a Psychology Degree. In my first year of university I had a scribe to take down notes for me, however, I now use a monocular to obtain the class notes from the board myself, or the teachers give me copies of overheads and notes, and now I also am able to download lecture notes from the Internet.

My current hobbies include reading, chatting, spending time with friends, Calisthenics and of course shopping. Because of bone structure abnormalities in my shoulders, I am not able to achieve as high a level at Calisthenics as I would be able to. I am not able to compete but I have a very understanding coach who values my efforts and allows me to participate socially. This is important to me because I feel like everyone is accepting of me and still makes me feel like I am part of the team.

I've worked casually at a music store and worked casually at Kmart for couple of years. I've done work experience at child care, special school and in the computer industry. I've done volunteer work at a childcare centre, community legal centre and the Melbourne Law Court. I had to complete volunteer work at the Law Court as part of my Justice Course which I really liked and I would love to work within the courts in the future.

I've had a few operations in the past ten years including an eye squint, an eyelid lift and a double jaw break and adjustment for Orthodontics. Due to small airways in my nose, the anaesthetist had to put the airway tube through my neck. I also had two palate repairs of a small hole that was left from an earlier Choanal Atresia operation. I still have quite a few medical specialists I need to see, particularly the endocrinologist, the ophthalmologist and hearing checks. A few recent incidents I've had to contend with were losing my dental plate in the surf, losing my contact lens in a mosh pit, and being ejected from a night club because my eye defect was mistaken for a stoned/drugged appearance.

I've always tried to be independent to the fullest extent I could be. I think this began at about three years of age when my mum accidentally left the gate open and I decided to take my trike on a 'holiday' down a few blocks and ended up at the police station where I was able to give them all my details. Although I've tried to be extremely independent, I've realized to succeed, I still do need to listen and take advice selectively from others. I travel independently to university on public transport. I have a travel pass for blind/vision impaired citizens which gives me free transport and which I use extensively.

Despite the attitude I have been proud to hold, presently, there are some factors that can cause me ongoing concern. I feel I have an increased and more experienced awareness now of how others perceive or act towards me. This ranges from seemingly

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accepting and loyal friends, to those that seem to continue to treat me differently and can lead to me not feeling very good about myself. Despite some brief stints at minimal hours, part time work and some quite successful work experience and college course placements, I find that after 3 to 4 years of regularly seeing a Government Disability Employment Officer who is specially trained to help me find and sustain employment, I am at this stage fully dependant on my Blind/Disability pension.

I have over 3 to 4 years put out my resume to over 100 nearby and local businesses, been to several interviews, sometimes with my Disability Employment Officer. This is quite disheartening as I believe I have an extremely positive attitude, excellent computer and people skills, and I have 3 tertiary qualifications and completed nearly half of a university degree.

Nevertheless, I know that just because you have a disability it's not the end of the world. God put us all on this Earth for a reason and you can still aim to do your best and achieve to the fullest extent, whatever that may be.

We've all heard so many times about what the letters in CHARGE stand for and I've tried to think of some alternative words just for fun and for a change. You might like to try this also to match your child.

C: Challenging, Chocoholic Calisthenics

H. Hope and too much Homework

A: Ambition and Achievement and Adventure

R: Rebellious and Rest (I love sleeping in)

G: Go For It

E: Eager, Enthusiastic and lots of Effort

Chip Dixon

My name is Chip Dixon. I was born with a mild form of CHARGE Syndrome, little bit of Kallman Syndrome, and also have Growth Hormone Deficiency too! [Ed Note: at the conference, Dr. Kirk told Chip that Kallman syndrome and growth hormone deficiency are both part of CHARGE in Chip]. Let me start by telling you where I was born. I was born at San Diego Community Hospital on June 16, 1979. I had so many health problems, that they had to put me in intensive care unit. I had a hole in my heart, but it closed up on it own. But, I did have some swallowing problems, and my mom fed me through the NG-Tube down my throat (not on my stomach, like most other CHARGErs do). Then, as I became a toddler, I started going to school, and also learned how to walk and swallow too! My first deaf and hard of hearing class was back at 1987-1988, at Mrs. Snell Class. From that time to now, I have been around to a lot of deaf and hard of hearing people, learned how to use sign language, and also learned a lot about the Deaf Culture!

I went to Granada Elementary School, Alhambra High School, then I went to Mt Sac for 4 ½ years, and graduated with a Pet Science Certificate. Then, I went to La Puente Adult Education-Dog Grooming Training School for the next 1-1/2 years. I graduated earlier this year on January 15, with an Animal Attendant/Brusher and Bather Certificates! Right now, I got a job as a brusher and bather, and I seem to enjoy it well.

Anyway, I first discovered I got Charge Syndrome myself when I was in high school, when I was looking through my mom's medical files for me. Because, I noticed that most of my friends were getting older, and their body changes a lot, and my body was still the same, and I still got the same look on my face too! Even my voice stays the same, right? Then, from one of her medical papers, I saw the word Charge Syndrome and Growth Hormone Deficiency! For the first time in my life, I found out what I was really born with! I finally figured out why my mouth looks funny, why I'm short and skinny, got swallowing problems, and so on! I was shocked, scared, and also a bit sad and lonely because, I felt like I'm the only one with this rare condition.

I also have been taking medications during my life time. When I was a teenager in high school, I started taking Growth Hormone Shots. I was the smallest, lightest kid in the whole school! Well, not the whole school, but you know what I mean. For around 5 years, more or less, I grew up to 5 ft and 5 inches tall. I also gained so much pounds, and now I'm 80 lbs, woo-hoo! Oh, my weight gain problem, I started gaining weight a little bit from Androderm Patch. But, I only took it for like a year because there were some bad side effects. It didn't really work out too well, it just got me more moody and grouchy for no reason, sigh! Now, I'm searching new ways to gain weight. Like drinking a lot of milkshakes, eating a lot of pastas, even weight lifting helped a lot to build up some muscles too! My doctor might give me a new medication, or a special kind of milkshake, to help me gain some more weight.

Around the fall of 1998, when the Internet was first invented, I started looking up some websites and groups, where I can make new friends with CHARGE. And I did! Yahoo got a special kind of group on the List Serve called, 'Charge Syndrome List Serve', cool man!

I remembered my very 1st few Charge friends, and I still talk to them now. I met the owner/moderator of the group, Lisa Weir, and she told me all about the group. And, she also talked about her children, and one of her children got Charge. And, her name is Kennedy. They're from Canada. Kennedy was around a toddler when I first met Lisa online. Now, Kennedy is a

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young girl taking dancing class, cool huh? I even met Chantelle from Canada, Melissa from Minnesota, Belinda from Australia, and also Jacob from England. For around 7 years now, I felt so comfortable and relive that

I made a new family on the group, new friends, we all got something in common and we're not afraid to talk about our problems.

I was also curious if there were other CHARGErs here in California? Then in the summer of 2001, at my birthday party, I got to meet Wendy and her CHARGE daughter, Kendra! I was so happy to meet someone like me. Wendy and Kendra both lives in Riverside County, and Kendra goes to the school for the deaf called, 'CSDR.' (California School for the Deaf of Riverside).

But, I noticed that Kendra got a moderate form of CHARGE. I was wondering if there is a mild CHARGEer, like me here in California. That is when my old friend, Jacob online, was telling me about a young teenager name Keith Persico! So, I found out that his mom, Yuka is on the CHARGE list. So, I sent her an email, and she got Keith to email me, and we started chatting and became best friends! I met Keith and his family in person, around the spring of '02. They're all from Simi Valley, in Ventura County.

Then, Wendy started mentioned me about another CHARGEer in Kendra's school, who is actually a friend of Wendy and Kendra. She told me about a young lady name Heidi! Heidi got a mild-moderate form of CHARGE, kind of like me. She told me that Heidi is just like me, both of us like to talk a lot, we're both funny, and we would get a long well and be best friends, right? So, I got to meet Heidi at Kendra's school in the spring of '04. She was a bit shy at first, and then around 5-10 minutes later, she started chatting with me. At that time, she didn't ask for my phone number, because she just met me and didn't know me too well. Then in November last year, at Kendra's belated birthday party, I got to meet Heidi again, yay! This time, we got to know each other and we exchanged phone numbers. A month later after we met, we started dating.

I also made other new friends with CHARGE around the states too! Paul from Washington DC, Patty from Massachusetts, and Andrew from Minnesota. Now, I felt so much better that I made a lot of wonderful friends just like me, and now I'm no longer shy, sad, disappointed, and lonely anymore. I also found my true love who is just like me, and some of my best friends (even Heidi is considered both my best friend and my girlfriend) got CHARGE like me too! Now, I got some wonderful company of CHARGE friends, and we all share our stories, our medical history, show each other our scars (well, I got one, and I didn't want to show it to them, too private you know), and I'm happy that I found the Yahoo Group that started it all. Best Friends 4ever!

Chantelle McLaren

Hi everyone,

It's a pleasure to be here today to talk to you all. I am 26 years old and have CHARGE syndrome. I have "all the letters" that make up the old Dx. Basically that means I have most if not all the major criterion for the Dx of CHARGE. As well as the major criterion, I also have many of the minor criterion.

I had a lot of surgeries over the years for my jaw, atresia and my ears so they are looking less like "CHARGE" features then they did when I was much smaller. I think though some of the charge characteristics softened over the years because when I look at pictures from my early years I do see a lot more charge features then I do now.

My characteristics are as followed. Vision- Coloboma of the eye. Even though my vision isn't the greatest, I can still see fairly adequately up to 5 feet. I mean I can see small objects, but it takes me longer to find a small object on the floor. I do use a mobility cane mostly at night but also during the day when I'm walking in bright areas, busy areas, uneven places that are new to me, and in the winter when there is ice and snow everywhere.

With hearing- I have profound to severe loss of high frequencies in my left ear and moderate hearing loss of low frequencies in my right. I find it hard to locate sound though. Especially if the person is far away. I have some mild development delays in puberty. I am supposed to be taking hormone therapy which once I get some medical coverage it will be covered. I also have possible seizure activity. I was tested with the EEG and MRI and they did detect some seizure activity. I have not had any recent follow up but I probably should soon. My heart condition was mostly fixed when I was a child but I still have an enlarged left ventricle and some leakage backwards, but apparently it's so minor that it's more risky to operate on it then to leave it alone.

I have mild bilateral facial palsy and a very mild sense of smell and bilateral choanal atresia which I have to have one last operation to complete the repair that was done when I was a younger child. I used to be extremely short but I took growth hormone to get me to my current height. I currently have scoliosis in my back as well as sloping shoulders. I also have really bad heartburn, I am always tired and lack energy to get tasks completed.

I also have the behavioral issues associated with CHARGE. I think my behavioural issues I've had for most of my life making it hard for me to make and keep friends. I know I still have a lot to work on with my behaviours. I think though some of my behaviours are due to somewhat questionable family life incidences as well as some bad peer and teacher interactions.

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When I was 6, I stopped using sign language because none of my teachers knew sign. I really wish I continued to use sign because I have such bad hearing and I frequently miss instructions. I did go to a deaf classroom for grade 6 and 7, and used a lot of sign language and I felt those years my behaviour issues were the least of an issue because I was able to communicate well with my peers and teachers. In the deaf class we were encouraged to speak aloud, but sign was used with speech for the maximum effectiveness.

When I was in high school I did a lot of physical and occupational therapy through AND Canada and The Institute for Human Potential in the States. I did horse back riding and swimming lessons too. I felt all of these therapies were very good in helping me cognitively and also with my balance and breathing. AND Canada and my riding lessons I had the best experiences and I would recommend it for other CHARGE kids. I think though it would have been best if I started them at a much younger age, but it still helped me alot in high school for understanding math and reading comprehension. The therapy also helped improve my breathing and my speech greatly.

Once I turned 18, Sick Kids, my pediatrician and my mother seemed to think that I should be able to take care of my medical issues on my own. I think this was a bad judgment call. I know now I can take care of most of it fairly well but I still need support from others whether it be guidance on where to get help or to get appointments coordinated. I think parents should make sure that before their child reaches 18 (or year of majority for your country), that you have doctors and specialists who will follow your child after they have reached adulthood. Even if your CHARGER is independent, its important to help them maintain their independence by helping them move from the childhood doctors to the new doctors. Please don't rely on hospitals to do that for you; not all doctors or hospitals take that much care, besides they have so many patients, it does help if the parents help too.

Also make sure you inform the hospital of which hospital you want your child's documents transferred to. For me what happened was I was living in a town 40 minutes west of Toronto and my health records were transferred to a hospital on the far east end of Toronto. Might not seem like a big deal but when your deaf/blind, trying to get to a doctor's appointment on your own, it would help if the hospital was not complicated to get to.

The good news now in my life is I finally feel like I'm going in the right direction. I am hoping to get the support I need to live independently and have a meaningful life. I know I still have a long way to go. I am hoping to get a CCTV so that I am able to read newspapers, books and any educational material. Finally in September I am going to go back to school to gain training and education in daycare because that interests me. Some of the technology I would need is a FM system, which I could use at all times to better hear people talking to me and for classes so I can hear the teacher. I would need the computer note taker machine which would allow me to type notes as I find it very hard to write notes by hand. Usually my handwriting is so messy I can't read it and it takes too long to print. I also want to get zoom text so I can get a computer and read the print on a computer. I feel so much closer to getting all these support, certainly better then I did a few years ago.

Christine Nieder

Growing up, I never realized that I was really all that different then anyone else. I thought I saw the world the same way everyone else did and that it was normal to bump into things, not recognize faces, and trip over things. And no one really told me any differently. I thought I was just plain clumsy. My Dad used to tell me I just wasn't paying attention. And I also thought I was just stupid, that I couldn't do anything right. I remember running into garbage cans in the hallways of the Elementary school, getting hit by balls in PE, and constantly hitting stuff with my bike. But for the most part I really had a pretty normal childhood. My parents didn't coddle me. I went skiing, snow mobiling, hunting, dirt biking, camping and so much more. You name it, I did it! This really installed a sense of adventure that has passed on to my adult life. But as I got older, it became apparent to me that I was different from my peers. Thus started a life long journey of self discovery and eventual acceptance.

It was going into secondary school, which is grade 8-10 that made me realize I was different. Kids would walk down the hallway, screwing their faces to look like me, they would imitate my voice, throw gum, and other food products at me, trip me every chance they got and just plain and simply made my life a living hell. The friends I had in Elementary school suddenly disappeared because it was no longer cool to hang out with the disabled girl. Teachers and special educators tried to help me by making accommodations and even attempted to teach me to use a white cane but I was too angry. I did not want anything that I felt segregated me more from my peers. When I finally started asking for help in high school, no one was there to give it. They figured I had gotten this far on my own so why bother making an effort now.

I'm sure people are wondering where were my parents in all of this. My mother passed away was I was 10. She was so supportive and helped me out so much. It was devastating to lose her as well as the single most important support system in my life. My father died four years after my mom from cancer. So from the age of 14-18 I lived with my sister who is only a few years older then me. My sister and I get along for the most part, but like all siblings we have had our moments! In '97 I was supposed to graduate high school, however a couple months before grad I dropped out. Although many people told me this

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would be my biggest regret in life, 8 years after the fact I still feel I did the right thing. I was just miserable in school and was not learning anything. I skipped so many classes to avoid having to be there with my classmates.

Ironically I spent a lot of time at the downtown library studying the subjects I was interested in.

In the summer of that same year I moved to Halifax, Nova Scotia. That is a long story, and one that's not worth telling. During my two years there I got into teaching Jujitsu, a very old form of martial arts. I stuck to teaching the people with disabilities and the kids classes. This started my interest in teaching. I moved back to British Columbia and started thinking about going back to school. I knew it wasn't going to be easy but I was really not prepared for the fight I was about to undertake. My first thought was Early Childhood Education as I have always loved working with kids and had a great deal of experience in that field. I met with the gov. organization that assists people with disabilities with their post secondary education and told her of my goals. Her response was heart breaking. She told me I would never be allowed to work with kids because of my disability. She said parents would view me as a liability. She suggested I go into office administration or social work. I left the meeting feeling completely discouraged and with no hope of ever going back to school, and feeling like I was being told to just study what I call the typical blind fields, which is what they feel is the only thing we can do!

I was pretty discouraged for quite some time; however at a friends insistence I took a couple computer courses online. I passed them with flying colours. I reconsidered my options and decided to speak with a woman who taught adaptive technology to the blind and visually impaired. She told me about a program she took called the Provincial Instructor Diploma. I decided to re-approach the gov. organization to see if they would fund this program. I was not optimistic. However as luck would have it I was reassigned to a new case worker who was married to a totally blind woman. He was completely enthusiastic about whatever I wanted to do and agreed to fund the program with no hesitation. I applied to the program, again not feeling very optimistic, but luck was on my side and I was accepted. It proved to be the stepping stone in my academic career. I finished the program in one year and went on to do the advanced program in Adult Education and a certificate in Online/Elearning, which is designing distance ed courses online. Which coincidentally I finished the day before I came out here. I am now doing a Bachelors of Adult Education going into my third year this September. I plan on going into a Masters Program in either Special Education or Adaptive Technology later on.

During all the positive changes in my education, another change was going on in my life. I lost some of my vision due to some complications with cornea scarring. I adjusted very quickly to this but I did find it slowed down my mobility. I was much more cautious. I tried switching to a white cane, but found it just wasn't for me. So I applied for a Guide Dog in the summer of 2002. I was accepted to Guide Dogs for the Blind in Oregon and began to eagerly await my training date. For some reason they kept pushing my date back and I was quite worried they were having trouble finding a dog for me. Little did I know, they had the perfect dog for me, they just needed to finish her training so she could go out into the field. On September 21st I met Velda. I kept telling the trainers how badly I wanted a black lab and would accept nothing but. But then when Velda came bounding into the room to greet me I said they could keep their black labs, this was my dog for sure! (Ed. Note: Velda is a yellow lab.) We trained for 28 days required by law in Canada and the US. It was truly one of the most difficult experiences in my life. Contrary to what most people think, a person just doesn't pick up the harness and go. It takes a lot of hard work, learning commands, hand and feet positions, trouble shooting techniques and most importantly it takes a long time to learn to fully trust each other. They say it takes about a year on average to develop that trust. It's also a great responsibility. Not only does she watch after me, but I watch after her. But once that trust is there, the relationship between Guide dog and handler is more intimate then anyone can possibly imagine. I don't like to say that Velda makes me independent, I like to say that she enhances my independence. I get around faster and with more confidence. You have all seen her as a well behaved, quiet dog but I assure you that is merely her work persona! She is quite the lively and energetic dog and gets into so much mischief! She has taken a chocolate bar from a store display, loves to dig up my flowers on my balcony, gotten loose on a beach and I had to chase her for 10 minutes while she ran up and down the beach chasing the waves and she has even eaten a lightbulb! She keeps me on my toes but I love it! I also have to add how proud I am of her this week for handling the long flight, although she has flown many times before and loves it, handling the crowded and noisy airport at Las Vegas and now being here at the conference and even resisting the urge to guide me right into the pool! I can tell she really wants to jump in there though! She truly is a remarkable dog and I think we make a pretty good team!

Coinciding with all these changes in my life I also finally found out I had CHARGE. I have only known for the past two years even though I was diagnosed at a very early age. My parents just died when I was so young that they never got a chance to really tell me anything. The symptoms I have are the coloboma, small eye, hearing impaired, typical CHARGE ear, cleft palate, narrow nasal passages, and small throat. Although I have heard that being short is part of the symptoms, for me it just runs in the family so its unlikely it's a symptom in my case. All my cognitive testing has proved higher then the average person my age, no heart defects or stunted growth. I was never on any medication as a kid nor had any major medical problems other then the normal things every kid gets. I did however have quite a few surgeries to do with nose, palate and lifting of the eyelid.

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But I was so young I really don't remember any of it. I really don't think of myself as someone who has CHARGE, or someone who is blind or hearing impaired. I'm just me. I may have to do things a little bit differently, but that's

what makes us all unique.

So now I am 26 years old, and I live a pretty normal life. I live on my own with my dog and two cats. I have good friends who I hang out with in coffee shops and go for long walks. I enjoy a variety of activities, from cooking, gardening, reading, writing, volunteering with Velda at her other job as a therapy dog at a seniors' home, traveling and of course, the most popular Canadian pastime, cheering for my favorite hockey team, the Vancouver Canucks. I just wouldn't be a Canadian if I didn't do that eh?

I'd like to end my talk by giving some advice to the families, kids and professionals. Encourage your kids to try new things, expose them to as much as possible. And last but not least, a lesson my mother taught me: The only limits you have are the ones you put on yourself. Thank you very much.

Philip Wismer

Hello, my name is Philip Wismer. I live way north, in a small quiet town, Doylestown, which is 30 miles north of Philadelphia, Pennsylvania. I live there with my mom and dad and two sisters. I came to speak about myself and how I experienced living with CHARGE syndrome. I was born on April 8, 1988 in a local hospital, but transferred to a children's hospital in Philadelphia. My parents found out that I was Deaf and I had CHARGE, and the doctors thought I would not be smart, but it turned out they were wrong and I was very smart.

I have had 18 surgeries. Three of them were open-heart surgeries. I had open-heart surgeries because I had problems with mitral valve regurgitation; one of the valves in the heart was not functioning properly, because some of the blood came in the wrong way. Therefore, I had my heart fixed, but the procedure did not work, so I had a second procedure, but it did not work. The third time it worked. I had surgery on my kidney and several other surgeries were in my nose. I had some trouble with breathing through my nose. I had choanal atresia. The doctor did many laser surgeries to try to open my nose. Finally, the surgeons opened my palate and made the openings in my nose larger. I have colobomas of the retina in both eyes. I am legally blind in my left eye. I do not have a tear duct in my right eye. The doctor put a tube in to drain my tears into my nasal cavity. I am profoundly deaf in both ears.

I can remember myself falling down so many times when I was little, because my legs were weak, they had almost no balance. So, I had the walker, it helped my legs get better. One time I fell down the stairs and my forehead bled and we had to go to the emergency room and get it stitched. Many times I had to get my forehead stitched. One time when I was with my Uncle and my Aunt, hiking on the Appalachian Trail, I fell down the rock area and needed medical attention.

Now you might be thinking that my childhood was full of unfortunate occurrences, but do not pity me. Something wonderful did happen to me when I was 7. I received a "dream" from the Dream Come True Organization. They gave our whole family a trip to Disney World. On the day that we were to go to Florida, I gasped when I was a limousine come in our driveway, and we went in the limousine, and I felt like a movie star. We went to the airport and flew to Orlando, Fl. We then went to the villa and we had a room with a Jacuzzi bath. I even got to bathe in it. It was so relaxing. We had daily eating at the free restaurant nearby; it looked like a gingerbread house. Then we went to Disney World. One of my favorite rides was the Splash Mountain. Two years ago while I was mainstreamed, I had an opportunity to take Latin. I had an interpreter with me and I learned Latin. I got a B in that class.

I am now 17. I attend the Western Pennsylvania School for the Deaf in Pittsburgh. I have been there just one year. I transferred from my hearing school to WPSD because I needed more socializing with Deaf people. I am a residential student and come home every weekend. I will be a junior this fall. I have many wonderful friends at WPSD. One of those friends is my best friend, Shane Wright. He will graduate this year. We have lots of fun together.

Last fall I participated in the Mr. & Miss WPSD pageant. There were 9 girls and 6 boys. We had a pre-pageant interview, on-stage interview, formal wear, and talent competitions. My talent was that I told jokes. I was very surprised to learn that I won and was crowned Mr. WPSD.

My hobbies are reading, computers, NASCAR, Instant Messaging with my friends, and traveling (I recently went to Africa with my mom and Grandpop to visit my aunt and uncle and my cousin & her family). I am planning on going to college. Right now I am considering Gallaudet University or National School for the Deaf in Rochester, New York. I would like to be a Meteorologist or work with computers. I have even recently thought of becoming a teacher.

As you see, my life is full of positives and negatives. I am still a smart deaf boy who has a very good life. God made me special.

Challenging Behaviors in Charge Syndrome: Psychiatric and**Behavioral Approaches to Assessment and Treatment****Lee Elizabeth Wachtel, MD & Sung Woo Kahng, PhD****Bonnie Haggerty, Reporter**

Lee Wachtel first presented and described the various forms of the behavioral disturbances that are often seen with children who have CHARGE Syndrome, including “self-injury, aggression and disruptive behaviors.” She spoke of the degrees of these behaviors and how they impacted everyone’s lives, especially the child’s learning and development.

Sung Woo Kahng then discussed these behaviors, the many reasons children who have CHARGE syndrome exhibit these behaviors, and possible management strategies. Some of the causes of these behaviors include the child’s sensory impairments, environmental causes, and the changes occurring within the brain during puberty. Dr. Kahng stated it was important to first identify the causes of the behavior. Assessments are extremely important and to then develop an individualized treatment plan for the child. He discussed task analysis, providing schedules and requiring predictable routines. It is also important to train the parents on the specific treatment plans. Along with behavioral intervention techniques being used, he also discussed pharmacological treatments and possible side effects of them. As there was little time for questions during the presentation both presenters stayed after and individually spoke with parents asking questions for well over an hour.

Observing, Defining, and Treating Repetitive Behaviors in Charge Syndrome**Laurie Denno, PhD****Bonnie Haggerty, Reporter**

Laurie Denno is another of the CHARGE specialists at the Perkins School for the Blind. Her presentation consisted of looking at specific CHARGE related behaviors and how these challenging behaviors can be treated. Laurie spoke of the abundance of students who have CHARGE Syndrome attending the Perkins School for the Blind in MA and the remarkable experiences she (and other professionals on campus) are able to observe and learn from these children. She broke down the repetitive behaviors into four main categories: self-stimulatory behaviors, maladaptive routines, obsessive compulsive disorder and tics. This identifying of behaviors must be done by observation, defining the behaviors and then the use of Functional Analysis of the behaviors. As she stated, the treatment options for each category are different and not all treatments work for all students.

Treatment options that have been successful for self-stimulatory behaviors in many of the students who have CHARGE are sensory motor integration, teaching new substitute behaviors, allowing appropriate self- stimulatory time and to use positive reinforcement for behaviors. In general, medications were not very helpful with self-stimulatory behaviors.

For maladaptive routines, Laurie advised the use of task analysis in teaching new routines. Treatment included teaching a new routine or task. This must be taught step by step. Positive reinforcement is of great benefit for the child. She cautioned that at Perkins, they have found many children with CHARGE syndrome have difficulty in redirection. She suggested changing environments to disrupt maladaptive routines. Another treatment is to reinforce flexibility as early as possible. Medications can be considered though may not help with maladaptive routines.

Tics were the third topic. Laurie shared that it was important to tell the child what it is, to give it a name. She also said it was beneficial to the child to have time to be allowed to “tic” by use of a schedule or an appropriate place to tic. Laurie stressed that it is important to teach the child that others in society might view tics as irritating and to teach the child coping strategies to get through this. Psychiatric consultation for medication might be beneficial.

The last was Obsessive Compulsive Disorder. Treatments include keeping the person busy and active. It has been discovered through the children at Perkins that those who have CHARGE syndrome have difficulty with redirection as a treatment for OCD. Laurie tries to allow the behavior at first, and to then redirect. This relieves the “driven” feelings of the OCD. Another treatment is to teach rules for the behaviors such as appropriate times or places the behavior can be performed. A treatment used only by properly trained therapists is placing the student in situations where the obsession occurs and then having them resist the compulsion. Medication is extremely helpful.

Laurie’s presentation was enlightening to all including parents and professionals in attendance. It was standing room only!



Timothy Hartshorne, PhD.

Bonnie Haggerty, Reporter

Tim Hartshorne is a professional psychologist and the parent of a child who has CHARGE syndrome. He spoke of his wife and their personal experiences as parents of a child who has CHARGE syndrome. He shared that “while the birth of a child with CHARGE syndrome is a challenge for parents, the literature suggests that many families of children with severe disabilities are able to adjust. Coping with stress is related to perceptions or meanings, resources, and, perhaps most importantly, to courage. Courage is understood as focusing on what one has instead of what one lacks. The courage parents demonstrate is often confused by professionals who do not understand that parents must both accept their child as they are and push for their child’s future. Actions by parents are often interpreted as denial when they are not.”

Throughout his presentation Tim shared research and perceptions on families in a humorous and enlightening way. He spoke of the effect of having a child who has disabilities has on work, friendship and love. He shared “the problem is how to love your child with no need for your child to be any different, without giving up hope that your child may progress with time and resources.” He then shared about family challenges, social support and its effects, coping outcomes and the need for people’s sense of community. He had the audience laughing and crying all at the same time. Tim ended with things that will be needed for a life time, which a few are to know your self and family, love your child unconditionally, to take charge and to establish a balance. After participating in his presentation, the audience could see why he received the Stars in CHARGE award this year along with David Brown.

CHARGE 101 the Basics for New Families

Meg Hefner, MS, Sandra L. H. Davenport, MD, Kim Blake, MD, Rob Last, Communication specialist

Bonnie Haggerty, Reporter

Meg Hefner, genetic counselor, presented on how CHARGE syndrome is diagnosed clinically. Her presentation consisted of the features in CHARGE, the anomalies and their potential consequences. During her presentation she provided useful pictures of the anomalies for the parents to understand. Meg then spoke of what it means to not be able to smell, to have colobomas, to have swallowing difficulties, etc.

Dr. Kim Blake shared descriptions of the risks that are common with medical and surgical procedures typical of CHARGE. For example, many physicians and surgeons many not be aware of the specific risks with CHARGE and anesthesia. Dr. Blake recommends finding a doctor who will serve as your advocate for the child’s care. Since children with CHARGE have so many surgeries issues related to anesthesia are particularly critical for all to understand.

Dr. Sandra Davenport talked about how the features of CHARGE develop before birth. She explained vision, hearing loss and balance difficulties, and how those features affect infant and early childhood development. She then combined that with vision, hearing, smell, taste and touch and how all are related in CHARGE syndrome. Sandra spoke of the critical influences of all of the sensory losses and their effect in development.

Rob Last began with how to begin early communication with children who have CHARGE syndrome. He shared how important it is to take time to communicate to the child about what is going to happen before it happens. He also shared the different types of communication approaches. In addition to that he advised, no matter what the approach, to always talk, to always gesture and to also have a literacy rich environment. He recommended the use of some sort of “total communication” approach.

All presenters used PowerPoint presentations, and overhead pictures and videos to enable the audience to see children who have CHARGE syndrome, including a video of an adult who has CHARGE. They all also stopped and were open to questions and comments by the audience throughout their presentations.

What Parents Need to Know About Transition

Joe McNulty, Kathy McNulty, Betsy McGinnity, Amy Parker, Mary Hancock and Janette Peracchio

Marilyn Ogan, Reporter

This workshop encompassed so much more than can be contained in this brain in the two-hour session. Joe McNulty, Executive Director of the Helen Keller National Center, gave an overview of the legalities involved in IDEA 2004 and the relationship of Individual Education Plans to transition services.

Kathy McNulty, National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC), discussed aspects of what parents need to know about transition while their child is still in school. She

highlighted the need to begin early, gather knowledge, keep records, and use person-centered planning maps, in order to smooth the way later. Ms. McNulty discussed building a personal profile that includes a Relationship Map of family, friends, and service providers. It also should include a Vision Map of school life, community life, home life, work and relationships. The worksheet about translating preferences into meaningful activities is a wonderful aid. It focuses on what an individual's preferences are (being outdoors), activities they might engage in (gardening/landscaping, boat rides, horseback riding), possible work sites (nursery, marina, stable, town parks), and possible recreational activities/leisure sites (boating/fishing, amusement park). This grid is an easy tool to use, and very helpful.

Betsy McGinnity, with DB Link, discussed different avenues for assistance such as Medicaid and Supplemental Security Income. The website address <http://cms.hhs.gov/medicaid/consumer.asp> was given as a resource to gain general information about the program. Ms. McGinnity also discussed state Vocational Rehabilitation (VR) agencies. Each state has one or more VR agency, and some have specific VR for the Deaf or Blind. VR agencies have people with expertise in employment, technology, assessment, training and a variety of other services.

Amy Parker is a Regional Representative for the Helen Keller National Center. She discussed creative ways for people to find community supports. The first aspect that had to be discovered was getting to know the person (needs, goals) and help them identify those goals. Second, you must get to know the environment/community (resources, power bases, economic bases) and what other people share the same needs (transportation, interpreters, access). Third is to build teams around the needs (work collaboratively to expand and increase resources, and seek out untapped resources). Ideas of places to start seeking social service systems are: Employment services, housing services, independent living centers, legal/medical/advocacy groups, transportation services, and post-secondary education services. One of the biggest ideas I brought from this session was that each person I encounter is a potential person for sharing ideas and resources – don't overlook anyone!

Mary Hancock and Janette Peracchio are parents of young adults who have been through transition into the community. Both shared their family's story of transition into adult services and the community.

Kids with CHARGE Syndrome who like to be in CHARGE: What do I do? Teaching Strategies that can HELP **Martha Majors and Sharon Stelzer** **Marilyn Ogan, Reporter**

Martha Majors and Sharon Stelzer are both "employed with" (I put that in quotes because I feel they are actually "devoted to") the Deafblind Program at Perkins School for the Blind. They are currently serving 14 students with CHARGE Syndrome. I have heard more than one parent say that "Perkins gets it." After seeing their presentation at the conference, I can indeed understand why parents make that statement.

Ms. Majors and Ms. Stelzer made a wonderful case for curriculum flexibility. I loved the first slide of the presentation: Education is all about FUN! They first evaluate what the family tells them is important: Friends, social opportunities, communication skills, good and age appropriate content, and how to be "a step ahead." The curriculum has to be practical and functional as well as fun and age appropriate (building on the child's interests), and highly motivating. They utilize total communication (sign language, gestures, simple signs, objects, pictures, printed words, Braille) and implement calendar systems to give visual information of verbal/signed information.

One visual cue I thought was of great value was the use of a red "X" on a picture if something is cancelled. This is much more concrete and visual than the abstract sign for "cancelled". Ms. Majors and Stelzer emphasized that the curriculum has to be meaningful to the child and contain exciting ideas. The curriculum has to be set up for flexibility and use what works with that child.

Siblings, Too Important to Ignore **Herb Byrd, Audiologist; Tina Prochaska, Communication Specialist; Carol Robbins, Coordinator -** **Tennessee School for the Deaf** **Marilyn Ogan, Reporter**

This workshop focused on the reasons to conduct SibShops, a workshop for siblings for children with special needs. The presentation was enlightening for me, even though our son, Ken, has been to several workshops based on the SibShops model. As a parent, I knew that a SibShop was a "safe" place for siblings to air concerns, worries, or just plain embarrassments about

having a sibling with special needs, and to do this in a relaxed atmosphere. What I did not know was the number of unusual concerns and circumstances the SibShops address.

Unusual concerns for siblings can include over identification (“Can I catch it?” or “Did I cause it?”), embarrassment (“He’s drooling all over the game!”), guilt (over their own abilities or health), isolation/loneliness/loss (from parent’s attention/information/peers), resentment (unequal treatment, failure to plan for the future), increased responsibilities (caregiving), and pressure to achieve (make up for parents’ loss in relation to sibling).

However, unusual opportunities are also present for siblings of special needs children. Siblings are typically more mature than their peers because their experiences are different. One aspect that was brought up during the session was a “loss of innocence.” Because these siblings see at an early age that “life is not fair” and that bad things happen to good people, their early innocence is lost. But with that loss of innocence comes insight (appreciation for family, siblings’ abilities, and their own health/capabilities), social competence, tolerance, pride, vocational opportunities, advocacy, and loyalty.

You can find more information at www.thearc.org/siblingsupport. I encourage anyone who has more than one child to consider sending the sibling(s) of your special needs child to a SibShop. I learned a great deal more than I thought at this session on siblings; and I think your children can only walk away from a SibShop feeling empowered and recognized for who they are.

Growth in CHARGE syndrome

Combined workshop with Dr. Jeremy Kirk and Dr. Kim Blake Meg Hefner, Reporter

Dr. Kim Blake began by presenting results from her osteoporosis study. This was a relatively small study, with some information on 30 individuals (16 females and 14 males) age 13 and up. Dr. Blake got reports on DEXA scans on as many individuals as possible. DEXA scans are special X-rays which provide information on bone density. Every single DEXA scan on both teens and adults with CHARGE syndrome were abnormal, with bone densities all below the normal range. In teens, this would be called osteopenia; in adults, it is osteoporosis. Although some of the decreased bone density could be due to CHARGE itself, it is very likely that much of it is related to diet (not enough calcium and vitamin D) and lack of exercise. Part of the study included a survey asking about exercise and other activity. It was much decreased in individuals with CHARGE syndrome, especially in older individuals – if they were not in specific physical therapy programs, they often had very low levels of activity. Individuals who were treated for low bone density showed significant improvements. The take-home messages were 1) to pay attention to diet and exercise and 2) to begin having evaluations of bone density beginning in the early teen years.

Dr. Kirk, pediatric endocrinologist, addressed issues related to growth hormone and hormone replacement therapy (HRT – puberty and/or sex hormone treatment). He explained that in the first two or three years, growth is really tied to nutrition and general health. Many children with CHARGE are small in the first couple of years because of feeding difficulties, lots of illness, and lots of surgeries. By age three or so, growth hormone begins to have an effect on growth. At puberty, sex hormones also affect growth.

Some children with CHARGE syndrome have clear growth hormone deficiency. Others probably have mild or moderate growth hormone deficiency, which can be very difficult and expensive to diagnose. Diagnostic testing often involves several blood draws over a number of hours, and repeat testing is sometimes needed to get a complete picture. Growth hormone treatment definitely speeds up the growth in kids with CHARGE, but we do not yet have enough data to prove that growth hormone therapy will significantly affect ultimate height.

The vast majority of individuals with CHARGE syndrome do not have normal puberty. Typically, they either do not enter puberty at all on their own, or they begin puberty, but it does not progress beyond the early stages. Most individuals with CHARGE syndrome will require HRT to achieve full puberty. Many will benefit from long-term HRT, even after puberty is complete.

Take home messages from this were: 1) children with CHARGE syndrome should all be seen by a pediatric endocrinologist by age three. Starting at this point will help you to develop a relationship with the endocrinologist and allow the endocrinologist to accumulate growth data over a period of time. Most want their own points on a growth curve for 6-12 months before they consider treatment. 2) Do not wait until age 14 or 15 to decide puberty isn’t beginning. If the individual with CHARGE does not show signs of beginning to enter puberty by age 10 or 11, consider beginning HRT at that time.



CHARGE Gene Information

Dr. Conny van Ravenswaaij, Dr. Marjolin Jongmans,

Dr. Seema Lalani, Brandi Blaisdell

Meg Hefner, Reporter

CONFERENCE ACCOUNT

Dr. van Ravenswaaij and Dr. Jongmans are from the group in the Netherlands who discovered the first, and probably most important, CHARGE gene, CHD7, in 2004. Dr. Lalani is the geneticist at Baylor in Houston who has been doing research looking for a CHARGE gene for several years and who just completed CHD7 mutation screening on those of you who had blood drawn at previous conferences. Brandi Blaisdell is a genetic counselor with GeneDx, the private company which is offering CHD7 testing.

Previous editions of CHARGE Accounts have covered the discovery of CHD7, a gene on chromosome 8, and mutations in it which can cause CHARGE syndrome. That detail will not be repeated here.

CHD7 is a very large gene – 87 kb (87,000 base pairs of DNA) long. Changes (mutations) as small as a single base pair change or as large as an entire missing section of the gene can result in CHARGE syndrome. Genes are comprised of promoters (regions of DNA which are in part responsible for turning genes on and off), exons (coding regions of DNA, which eventually result in proteins) and introns (non-coding regions of DNA, which are spliced out before proteins are created). The CHD7 gene is too big to look at every single base pair in the entire gene, even in a research setting. Instead, the researchers are trying to look very closely at all of the exons (coding regions). The techniques used by the different labs vary somewhat, although they are all cooperating and sharing information about what techniques appear to yield the most complete information.

The Dutch group has found mutations in the CHD7 gene in the vast majority of individuals with definite CHARGE syndrome – 10/17 (about 60%) in the original report from 2004, and a higher percentage in the individuals with CHARGE syndrome studied over the last year. In people with definite CHARGE syndrome including abnormalities of the temporal bones of the inner ear, the chance of finding a mutation in CHD7 may be as high as 90%. They have a couple of familial cases (siblings in one family, identical twins in another). In the same family, the two affected individuals carry exactly the same mutation. However, the clinical features (medical problems) are not the same, even in the identical twins. So other things besides the presence of the CHD7 gene have an effect on the medical findings of any one person with CHARGE syndrome. The type of mutation did not help predict the clinical severity. That is, mutations that prevent the protein from being made were not necessarily worse than those that result in an altered protein being made.

For the most part, Dr. van Ravenswaaij and Dr. Jongmans' group found different mutations (unique changes in the huge CHD7 gene) in each person with CHARGE. That means there is no easy way to do the DNA testing – each individual with CHARGE needs DNA sequencing, which is very time consuming and expensive. Once a mutation is identified in an individual with CHARGE, it is relatively easy to look for that same mutation in other family members or to offer prenatal diagnosis looking for that CHD7 mutation in later pregnancies.

Dr. Lalani presented information on the CHD7 findings on the 110 individuals with CHARGE screened through the Baylor program. Five of the 110 were familial cases (either two children with CHARGE or parent and child with CHARGE). Dr. Lalani found mutations in the CHD7 gene in 64/110 (about 60%). She used the same criteria for “definite CHARGE syndrome” as the Dutch group, but did not often have any information on possible temporal bone abnormalities. Again, the type of mutation did not predict medical severity and when there was more than one person with CHARGE in the family, they did not have the same features. When she compared individuals who were “mutation +” (mutation detected) with those who were “mutation -” (have CHARGE by clinical criteria, but could not find a mutation), there were some interesting findings. Those with a mutation were more likely to have facial palsy, heart defects, and coloboma.

Recurrence risks and mosaicism were two issues discussed during the question/answer period. The researchers explained most people with CHARGE have a new mutation which is not inherited from either parent. Because they have the mutation they have a 50% chance of passing it on to their children. A small number of parents carry the mutation in a small percentage of their cells, but do not have any clinical features of CHARGE. This is called mosaicism, and accounts for many of the cases of two siblings with CHARGE. Mosaicism cannot always be identified through testing; therefore recurrence risks for a parent to have another child with CHARGE are 1-2%. This is a combination of those families with mosaicism, who have a very high risk, and those with no mosaicism with a very low risk, because the two groups cannot be separated.

It was really exciting to hear the presentations of the Dutch group and the Baylor group. This is cutting edge genetics – information that has not yet been published in the medical literature. Our conference was seen as important enough to be the place to first announce these findings!



CONFERENCE ACCOUNT

Finally, Brandi Blaisdell, a genetic counselor, from GeneDx talked about clinically available DNA testing of CHD7. The Dutch group and Baylor have done DNA testing using research money. Now that the gene has been found, there will be very little research money available to offer free or reduced cost DNA testing. We are delighted that a commercial company has stepped forward to offer CHD7 testing. The down side is that, because CHD7 is a big gene and has to be sequenced (shortcuts don't work), it is very expensive – nearly \$4000 to sequence the gene. If a gene is identified (by GeneDx or by one of the research teams), it is much cheaper (around \$300-400) to confirm the DNA test or to test anyone else in the family for the same mutation. GeneDx personnel will work with insurance companies to get as much reimbursement as possible. As of the conference time, they had received samples on 36 individuals and had completed analysis on 20 of them.

It is important to remember that CHARGE is still a clinical diagnosis – based on the features seen in any one individual. Somewhere between 10% and 40% of people with CHARGE will not have a detectable mutation in CHD7. That does NOT mean they do not have CHARGE. They may have mutations in the promoter regions, or there may be other genes which can also cause CHARGE – that is typical of many genetic conditions. Consultation with a geneticist and genetic counselor can clarify the diagnosis of CHARGE, help determine if DNA testing should be pursued, and determine what recurrence risks are for each family. The research teams in the Netherlands, Baylor and the commercial lab GeneDx have given families lots of new information and options regarding the genetics of CHARGE Syndrome.

Sensory Deficits and How They Can Impact Feeding and Speech

Sara Rosenfeld-Johnson, M.S., CCC-SLP

Randy Goodwin, Reporter

This particular session was very informative, covering many aspects of feeding and speech. I personally found Sara's session to be helpful in the way our family will address feeding and speech in the future. Sara Rosenfeld-Johnson has over 30 years of experience in speech and language pathology. Her unique brand of muscle based speech therapy has had an extremely high level of success in children with CHARGE, Down syndrome and Moebius syndrome. Her techniques have been a success when all others have failed.

The first topic was the need to identify oral tactile sensitivity. There are two types, hypersensitivity and hyposensitivity. Hyper meaning over sensitivity, and hypo meaning decreased sensitivity.

Sara suggested that if your child can sign, they should be able to speak: speech is a motor skill just as signing is a motor skill. If your child cannot speak, you may want to pursue intensive speech therapy. She says that all speech begins in the back of the mouth, but speech therapy should never start in the mouth. First, gain the trust of the child by starting at the fingers and working up the arms to the neck area, possibly the back area and then on to the face and mouth. If the child resists in any area stop and try again later. The thought here is that if it is not comfortable for the child it will not be productive in the therapy. Once you have gotten to the point where the child trusts you to massage their jaw area, then move onto working inside their mouth.

Sara gave this presentation Friday afternoon and offered to evaluate kids afterwards. She was still doing evaluations well into Saturday evening. She was the talk of the conference in the fact that she was going above and beyond to help our kids. She is a valuable asset to our CHARGE community and I would like to say "Thank You" on the behalf of the families she helped.

Facilitating Gross Motor Development in Children with CHARGE Syndrome

Maryann M. Girardi, PT, ATP & Elizabeth Breadon, PT

Randy Goodwin, Reporter

These two women have over 40 years of combined experience as physical therapists working with multi-handicapped children and adults. This includes 17 years working with individuals with deaf-blindness, including children with CHARGE syndrome. They involve families and school staff in their unique method to develop gross motor development in children with CHARGE syndrome.

This was an outstanding presentation that discussed all aspects of gross motor skill delays. The presentation gave very good time /age expectations of kids with CHARGE, thus giving a realistic time frame of when children with CHARGE are likely to crawl and walk (2-6 years of age, if memory serves me right).

Also discussed were preventive measures we parents should use such as discouraging the "W" sitting stance. This particular stance pushes the legs up and into the hip area, locking the muscle in place. This stance does provide some stability, but at a cost to the muscle and hip joints. The "criss-cross" sitting stance is preferred, for it works on both control and balance of the upper body (weak muscle tone).

Children with CHARGE thrive in familiar settings because of predictability and schedules. Time constraints are of great

importance to our kids for they know when to predict change. Clear and concise expectations are very important so they can have a goal to move toward. One goal in gross motor development is to keep their hands out of their mouths, for they cannot sign with them in their mouth.

Reading Behavior as Communication

Tim Hartshorne, PhD, Sharon Barrey Grassick, B Sc, M Sc

Randy Goodwin, Reporter

CONFERENCE ACCOUNT

Tim has a 16 year old son with CHARGE. He has done extensive research in the CHARGE syndrome arena. He is presently the director for the School of Psychology at Central Michigan University. Sharon has been involved in the field of sensory disabilities for over 30 years. She is the author of several training videos and is the secretary for the Australian Deaf-Blind Council. She most recently has been nominated to chair the Scientific Committee for the upcoming World Conference of Deafblind International to be held in Australia in 2007.

Communication is a complex process involving words, gestures and other behaviors to suggest an idea, goal need, or state of being. For example, babies cry to communicate hunger, sleep or a diaper change. Due to their sensory problems and medical issues, the attempts by children with CHARGE to communicate may not be easy to understand. Whether or not a behavior is considered “challenging” depends on what side of the behavior you are on! When a child makes an effort to communicate and his or her behavior is acknowledged, or worse, stopped and disciplined, the child must surely see the communication partner as the one with the problem. Through a series of video clips we were shown that every movement our kids make is some form of communication. It may be very subtle or to the point, but it is communication.

I wrote this synopsis straight out of the handout for what ever I write about these two presenters would not be enough. You would have had to be in the crowd to understand what I am trying to say. They were obviously passionate about their research and about our kids. Having people like them on our team is a definite plus to the families and the foundation.

Emotional Health as the Key to Successful Educational and Development

David Brown Deaf-Blind Education Specialist

Lisa Weir, Reporter

I'd like to preface my report on David's presentation with some personal comments on how profoundly David Brown has impacted my understanding of CHARGE and of my own daughter. I've attended his session every time I've been at a conference; each time, I leave with a better understanding of the possibilities of why Kennedy does the things she does and how her little body works. David's gentle manner, along with his uncanny knowledge about these individuals, always forces me to think about things in a different way, to broaden my mind and think about other factors that may be contributing to certain behaviours or delays in development. I've often wished as a mother, that I could be “inside” Kennedy's body for a day to feel what it's like, to help me to understand her; in my opinion, it's almost like David has done that, he has such an astonishing understanding of these children. Listening to him is the closest I've felt that I've ever come to achieving that wish. David's words about the consistent triumph of these children adorn the cover of Kennedy's School Information Binder; I want everyone who is working with my daughter to think about her in the same way he does. This Miami conference was my husband's first, and as he and I poured over the available breakout sessions, making decisions about what we'd attend, I told him that I didn't care what he attended throughout, but that it was a must to attend David's session.

Once again, David's presentation in Miami highlighted those issues that individuals living with CHARGE deal with constantly, which may be overlooked and/or underestimated in their importance towards the overall success of the individual. He spoke about the proprioceptive and vestibular senses as the “forgotten senses,” their effects on the child's feeling of overall safety and comfort, and the impact that each can have on a child trying to develop and learn. Strategies were presented to facilitate the successful accommodation of these oft-missed pieces of the puzzle.

Obstacles with regards to various communication styles were discussed, as well as sensory dysfunction and the objectives of Sensory Integration Therapy. David again left us with a quote that will hopefully compel us to think about all of the senses together, the emotional health of the individual, and all of their effects on successful development and education:

In my work with children with CHARGE I am always thinking about their “sensory comfort” and their “sensory confidence”.

As always, David's talk just made such complete sense to me; concepts that seemed so complex were made very understandable. I realize that as a parent, with many of the medical issues, life-threatening surgeries, and ongoing general day-to-day appointments and care of these individuals, it is extremely imaginable that it would be easy to miss some of these crucial points. I'm just so thankful and happy that he is out there; one of the amazing professionals involved with CHARGE syndrome, with his extraordinary interest and compassion, thinking about all of these other things and so generously sharing his insight with us.

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