

CHARGE Accounts



Spring 2006

A Quarterly Newsletter for Families and Friends

Vol. 16 No. 1

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

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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 Summer Issue - May 15 !!!

PERSONAL ACCOUNT

Editor's note: The Bar Mitzvah (or Bat Mitzvah for girls) is a traditional Jewish rite of passage at age 13 that signals the passage from childhood to adulthood. It is a ritual for an individual, and also a tradition to be shared as a community

with the congregation. Both Joel and Aaron have CHARGE syndrome.

Link to newspaper article: "Teen overcomes odds to prepare for bar mitzvah" The full article will be available on the Web for a limited time: <http://www.miami.com/mld/miamiherald/news/front/13520454.htm>.

Dear CHARGE Accounts,

On January 1, 2006, our son, Joel Saruski, celebrated his Bar Mitzvah in Miami Beach, Florida. As my husband Michael read from the Torah, Joel signed the verses his father was singing. This celebration was the first Bar-Mitzvah to be carried out in sign language in our Jewish Community in Miami Beach. The story was covered in the Miami Herald, where it appeared in the front page of the December 31st edition. It was also subsequently covered in the Miami Herald's Spanish Counterpart, El Nuevo Herald.

Although this event took lots of preparation, we feel incredibly blessed that Joel was able to participate in this important rite of passage in the Jewish religion. We made this day possible by having Joel's school teacher translate the English Torah portion into sign language simple enough for Joel to be able to understand what he was signing. For months, Joel and his teacher practiced the Torah portion, until Joel knew it perfectly. At the time, we did not want to overwhelm Joel with too much information, so we did not tell him about the ceremony. The week prior to the Bar Mitzvah, we practiced everyday at the synagogue, and it was at that point that Joel realized the importance of all his months of learning.



At the ceremony, Joel signed his Torah portion flawlessly while his Dad sang it, and was afterwards bombarded with candies thrown at him from the audience, signifying their wishes for him for a sweet, joyful life.

Joel's Bar-Mitzvah ceremony was followed by a big party for his family and friends. The theme of the party was Mardi Gras. Joel particularly enjoyed being lifted on a chair, as is customary in Jewish celebrations, while well wishers gathered around him dancing the hora, the Jewish dance of celebration. He danced all afternoon and was very sad to see the party end.

We feel blessed that Joel was able to achieve this important milestone in his life, and that we were able to raise awareness of CHARGE Syndrome with the media coverage the Bar-Mitzvah received. We became pioneers of the special needs Bar Mitzvah, and we feel that every Jewish child should be given the opportunity to have a Bar Mitzvah, regardless of their abilities.

Ana and Michael Saruski
Miami Beach, Florida
Proud parents of Joel, 13 years old

Dear CHARGE Accounts,

Aaron Sorkin, CHARGER aged 13, had no problem communicating his happiness and pride at his *Bar Mitzvah* in November, 2005. Aaron does not talk and has multiple physical and developmental disabilities, but he stood strong and proud at the altar along side his two rabbis for two hours, wearing the *yarmulke* (skull cap) and *tallit*, the traditional Jewish prayer shawl made by his mother. He held the *Torah* (the scroll containing the Jewish Old Testament), signed some of the prayers, and even played a drum to a Jewish hymn.

As his parents, we had become used to the questions about Aaron's upcoming Bar Mitzvah. "How can it be a real Bar Mitzvah?" and "How can Aaron really participate?" were commonly asked. We saw the skepticism on people's faces.

True, it was not exactly a typical Bar Mitzvah ceremony. But it was as meaningful a ceremony as any person could ever hope to attend. The Bar Mitzvah (or Bat Mitzvah for girls) is a Jewish rite of passage at age 13 that signifies the young person has

accepted the religious obligations and commandments of being an adult in Judaism. We also view it as not just a ritual for an individual, but as a tradition to be shared as a community with our congregation.

Our temple, Central Reform Congregation in St. Louis, is known for fostering a sense of community among its rapidly growing membership, and strives for diversity and inclusiveness. Aaron's Bar Mitzvah provided an excellent opportunity to strengthen the bonds of the congregation. Helping Aaron throughout the service were his 30 religious school classmates, who had agreed to make participation in Aaron's Bar Mitzvah part of their class curriculum. In addition to working on their own Bar or Bat Mitzvah, the students attended several practices for Aaron's throughout the year. During the service, Aaron's classmates read prayers, helped to carry the Torah around the sanctuary, and led the several hundred people in attendance in signing the closing song. Aaron's sister Hannah, age nine, also played a major role, reading several passages and reading a major portion in Hebrew.

Planning for the Bar Mitzvah had begun a year or more earlier, when Jeane met with Rabbis Susan Talve and Randy Fleisher. Aaron has always loved being in a sanctuary and clearly feels it to be a special place. Everyone was determined to provide Aaron with the opportunity to participate fully in all of the ritual and joy that make up the Bar Mitzvah service. Jeane had already begun to teach Aaron to sign the important Jewish prayer known as the *Shema*, and with some helpful cues, he led the congregation in the prayer.

Aaron has moderate hearing loss in one ear that is aided, and profound loss in the other ear. He is legally blind and does not read. He struggles with expressive communication and finding a combination of communication systems that work for him has been difficult. He understands a fairly large number of signed words, but hesitates in using sign language himself. But on that morning, Aaron clearly understood that he was participating in, and helping to lead, something very important to him, his family, and the whole congregation.



At the end of the Bar Mitzvah, Rabbi Talve said, "Aaron, you have found a way to lead us in prayer and teach us Torah. You have given all of us a much bigger gift than you'll ever know."

As proud family and tearful congregants enjoyed the community lunch, Aaron stayed at the altar, refusing to leave that holy place and not ready to stop leading the congregation.

Steve Sorkin & Jeane Vogel
St. Louis, Missouri
Proud Parents of Aaron Sorkin, 13 years old

Andrew-His 36 Hours - A Grandfather's Reminiscence

by Bill Peckham

Monday November 20, 1985

"Hi, Dad. I need help."

It is my son, Jim, on the phone. The anguish in his voice is evident.

What's happened? I wonder.

Christine, his wife, is pregnant and due in a month. Beads of sweat form on my upper lip and my mouth is dry

PERSONAL ACCOUNT

as dust. My daughter, Donna, miscarried in July; will we lose this one too?

"Hi, Jim. What's up?" I hope the apprehension is not noticeable in my voice.

"I'm with Christine at St. Catharine's General Hospital."

Oh, Lord, what is it? A knot tightens on my stomach.

"The doctor at the hospital wants her to go to

McMaster University Hospital, in Hamilton (Ontario, Canada,) as soon as she can be transported there; complications have set in," Jim tells me.

"How soon?"

"The ambulance is on its way here, now. Can I borrow your car? Mine won't make it that far," Jim says frantically.

"Sure, Son. Come to the office; I'll drive you to the hospital."

"Thanks, Dad... on my way."

It is only five minutes from St. Catharine's General Hospital to my office. I call my wife, Betty, at her school and tell her about Christine.

"I'm taking Jim to McMaster Hospital. The doctor wants Christine there... complications have set in." Hot, stinging tears, fill my eyes. I grit my teeth and swallow, vowing not to get emotional.

"I'll come to the hospital as soon as I can get away from school... see you there." She hangs up.

"Dear Lord, please help Christine. Please save the baby," I pray.

That knot has put a strangle hold on my stomach... I am going to be sick.

The pungent smell of exhaust fumes permeates the air as Jim's old clunker comes to a grinding halt outside my office. As he enters, his tight jaw line tells me he is trying to hold on. Neither of us wants to fall apart.

"Had the ambulance arrived before you left the hospital?" I ask him.

"No, but it will be there soon."

"Then let's go."

Slamming my Toyota sports car into reverse, we back up onto the street. I kick it into first and jam my foot down on the accelerator; the wheels spin and lay some rubber. We're on the highway right behind the ambulance.

"Go as fast as you want. I can keep up," I mutter to the ambulance as I accelerate to 120.

"Dad, you're making good time but we can slow down a bit," Jim tells me.

"Okay! But I want to get to the hospital with Christine. They might need you," is my sharp response.

"Dad, she'll be alright... I know it."

We drive the forty-five minutes to McMaster Hospital, each of us deep in thought... in his own world of fear. Words just do not seem to come. Placing my hand on his I try to comfort him. He looks at me and tries to smile with confidence, but... the feeling of despair is all too evident in his tearful eyes. I can feel my son's pain; I have never felt so helpless in my life. It is a time when any words are... inadequate.

"There's the ambulance and they're just unloading

Christine," I hear myself say.

I don't remember the trip on the highway... just remember driving like a man possessed.

The quiet of this small waiting room is comforting... just like home, I reflect.

Waiting visitors are comfortable and relaxed, but the ever-present scent of a hospital assails my nostrils. No matter what is done, there is always an olfactory reminder... this is a hospital.

"Jim, what's happened?" I ask.

The fear of what his answer might be fills me with dread.

We settle into our chairs and Jim begins to fill me in on the details of Christine's condition, as he knows it now.

"I don't know exactly what is happening. I took Christine to the doctor's for her weekly visit. He examined her and told her he wanted her to go to St. Catharine's General Hospital where he would meet us."

"What happened at St. Catharine's General?"

"Her doctor had called ahead, so they were able to rush her into an examining room, where a specialist was waiting. After a thorough examination the specialist told us he wanted her to come here to McMaster Hospital. It was serious, and she needed attention, right away." Holding back tears, he adds, "Dad, I'm so scared. We could lose the baby... our first. What can I do?"

"Jim, will you come with me for a few minutes?" A doctor asks from the waiting room door. "Your father can wait here."

Jim returns twenty minutes later; he is white and shaky. His liquid eyes reveal the worst. Putting my arms around him, I hold him and wait until he can talk.

My son is a big man... six-foot... 200 lbs, but at that moment he is my baby, and I fear for his baby, and his wife. Tears of sorrow and grief well up in our eyes... I pray for strength. The Lord gives me the strength I need now... and it carries me over the next thirty-six hours.

"Tell me, son, what's happening?"

Brushing the back of his hand across his eyes, he takes a deep breath. Panic rattles in his throat.

"Christine and the baby are in danger; the doctor wants to induce labor. There are serious complications – both lives are in jeopardy."

I weep with my son, as anger, fear, sadness and a sense of emptiness flood up inside me.

Christine's mother and father, Mary and Len, arrive a few minutes later. Mary, who is a registered nurse, can help Jim understand the complications.

Betty arrives at the hospital while Jim is in conference with the medical team. We four grandparents sit... and wait.

After a lengthy meeting Jim returns with the doctor.

"We'll wait overnight and see. If there's no change

then labor will be induced tomorrow morning,” the doctor tells us.

“Dad, I don’t want to leave Christine yet. Can you leave your car here and ride home with mom?” Jim asks.

Visions of Jim driving home alone that night fill me with apprehension. This has been a traumatic experience for him, and I fear for his safety.

“I’ll leave for home now,” Betty tells us. “I have lesson plans to prepare for tomorrow’s classes. When the baby is born I want to be able to leave the classroom, right away. I have talked to my principal and he will fill in for me for the rest of the day.”

Christine’s mom and dad leave then, as well; she is on duty at St. Catharine’s General Hospital at 11pm.

I stay.

“Jim, spend the evening with Christine. I’m here if you need me.”

“Thanks, Dad. I love you.”

Christine, although not completely out of danger is comfortable and sleeping. At 11pm Jim and I leave. We drive back home in silence, lost again in our own thoughts and grief... it has been a long stressful day and we are both tired.

I hope I can hold it together. Jim is going to need all the strength I can give him. I fall apart at the least little thing these days... getting old, I guess.

Tuesday, November 21, 1985

At 9am, only an hour after our arrival at the hospital, a healthy-looking baby boy is born. Jim & Christine name him Andrew Guerin, after his paternal great-grandfather. Christine is still in danger, and Andrew is on life support.

Mary and Len arrive at 10am. We grandparents are then allowed to see Andrew. He is so small and full of tubes, but seems to be surviving. The tears flow as we look at our grandson.

What is to become of this tiny bundle? I wonder.

“I’ll call your mom at school. She’ll want to come to the hospital right away,” I tell Jim.

“Thanks, Dad.”

It all seems like a nightmare... one that goes on and on. My eyes are sore and red from crying and I feel completely drained. I can’t imagine how Jim must feel.

Betty arrives at 4:30pm. She has taught a full day and will stay with us until late this evening. Betty, who is stronger than I, helps all of us cope with this unforeseen event.

Christine sleeps most of the day. Jim sits with her while we grandparents spend time reading, talking and praying. Mary is on duty again that night, so she and Len leave at 6pm. Betty stays until 10pm.

“Dad, there is no change in Andrew or Christine and they are fast asleep. It’s midnight – I think we need some sleep too... let’s go home.”

The stress shows in his face, he is exhausted and looks old beyond his twenty-five years.

Wednesday, November 22, 1985

Jim and I arrive back at the hospital at 8am. We talk about Andrew and our hopes for his strength, but privately I wonder just what the outcome will be this day.

At 9:30am the doctor comes to the waiting room.

“Jim, we’d like you to be present at a medical-team meeting concerning Andrew. Will you come with me now?”

He leads Jim down the hall and into a conference room.

Christine’s mom and dad arrive at 10:30am. The three of us, sitting quietly waiting for Jim, share our thoughts and feelings but, mostly, we just sit and stare.

Jim is visibly shaken when he returns from the team meeting. His pale face, shaking hands and tearful eyes, tell the story.

“If we take Andrew off life support he’ll die. If he’s left on life support, he’ll be in hospital the rest of his life, with no quality of life at all, and surgery almost every day. I have to decide whether to leave him on life support and watch him suffer, and eventually die, or to withdraw life support and let him die peacefully now. Christine is in no condition to help me with this... I must decide on my own. I know none of you can make this decision for me, but I know you’ll support me whatever my decision.”

“Of course we will.”

Our love for this young man in pain is palpable as we hug him. The silence in the room speaks volumes.

“What exactly is wrong with Andrew?” I suddenly ask, fearing the answer.

“The doctor says he was born with very acute ‘CHARGE Association or Syndrome.’ I’m not quite sure what all that means. I couldn’t take it all in, but they’ll go over it with me again later. If we keep him alive, his life will never be life as we know it to be,” Jim’s explains quietly.

“I’ve called your mom. She is on her way now.”

“Thanks, Dad. I hope she gets here in time.”

The nurse gently removes Andrew’s life support systems... wraps him in a warm flannel blanket. One at a time each of us grandparents holds this tiny, fragile bundle, and prays our own prayer for him.

I shed tears for my grandson... I know this will not be the last time I will do so.

Finally at 9pm, cradled lovingly in his father’s arms Andrew dies peacefully.

This has been Andrew’s 36 hours.

Author's note:

Jim approved an autopsy on Andrew... his hope was that it would provide more insight into this devastating problem. The autopsy showed the frontal lobes of Andrew's brain were fused, his esophagus emptied into his lungs, and there were more holes in his heart than they were able to count. Andrew would have been in the hospital all of his life, and most of that time he would have spent on life support.

CHARGE Association was first described by Dr. Hall in 1979, just five years prior to Andrews's birth. At that time, not much was known about CHARGE Syndrome.

PERSONAL ACCOUNT

Dear CHARGE Accounts,

Life is full of new things and surprises. Some of them are wonderful and pleasant and some are just plain scary. I think from the beginning of Laura's life we have faced some of the toughest surprises that parents can face. As Kierkegaard says, we only understand these scary things backwards but I am writing this in hopes of sharing with families and also hopefully preparing others.

Our daughter, Laura, who turned 21 in February of 2006, has had many things to overcome and learn to live with or around but had never had a seizure that we knew of. Laura has CHARGE syndrome and is profoundly deaf and has only limited vision mainly in one eye. She has faced two open heart surgeries for repair of tetralogy of Fallot and for mitral valve suture. She also had surgeries for ear tubes and for muscle repair in one eye. Her petite body has sustained so much. She is a true fighter and teacher of life for us.

In August of 2005, Laura had just finished a long luxurious morning bath. As she was getting out of the bathtub, she began to quiver. This was not unusual in itself but the quivering went into shaking and her whole body became stiff. She was unable to hold herself up as her eyes rolled back and she turned blue around her mouth. I realized that she was not breathing and yelled for my husband to come and help.

From that point on, we did almost everything wrong! We did not realize what was happening and had no idea what to do or expect. It felt like Laura was slipping away from us. We called 911 and Laura's dad turned her upside down in case something was caught in her throat and keeping her from breathing. At one point we hung up on 911!! Somehow the dear people at 911 called us back and from that point walked us through the process of obtaining help. We then put Laura on the floor on a bathmat and very soon we had

Today, there are many web sites with information on this subject.

This story was written from my recollections, after twenty-one years, of the birth of my grandson, Andrew Guerin.

Jim and Christine subsequently had another child... Mary Elizabeth. Mary was born at McMaster University Medical Centre in June 1987. In September 2005 she entered McMaster University to pursue an education in medicine.

**Life can only be understood backwards;
but it must be lived forwards.**

**Soren Kierkegaard
Danish philosopher (1813 - 1855)**

paramedics with us and realized that Laura had begun to breathe on her own and was regaining her color.

The rest of that day was spent in the ER having blood tests and CAT scans and speaking with doctors and nurses. The word seizure was used over and over and we began realizing that is what had occurred. I was so relieved when Laura began trying to take the IVs out and signing "eat" and "drink" very energetically. At the end of a long day, we left the ER with some knowledge of seizures and Laura being able to walk and eat and drink. She had not eaten the whole day as that was next on her agenda the morning of the seizure. Laura was sent away with appointments for EEG and MRI.

Six weeks later, I was called by her teacher at school to hear that another seizure had occurred. Laura had seemed a bit ill at school before this seizure. She had eaten and been a little active but not herself. The afternoon after this second seizure she was quite nauseated and vomited several times. I was told that having a seizure is like "running a marathon" for the body and to allow her to rest. The next morning she was better and we were thankful.

Laura's EEG was unsuccessful - she doesn't like things on her head! The MRI showed tiny spots of mineralization within the right occipital lobe and decreased size of the right pons (portion of the brain stem) and right cerebral peduncle (stem connecting parts of the brain to each other). The mineralization could reflect prior infection or a congenital malformation. They are suggestive of cortical abnormalities which sometimes increase the risk for seizures. The decreased size of the right pons (in the brainstem) likely represents loss of the axons (parts of nerve cells that allow them to communicate with each other) from earlier cortical atrophy.

[Ed. Note: it is often helpful if a child has had a previous CT or MRI as a baseline. Then when testing is done for a seizure

or other problem, it is easier to determine if the finding (e.g. mineralization) is new or has always been there.]

Trying to have the hospital understand Laura's needs during medical testing was challenging but we finally got the message across. Communication is a major issue in testing and I needed to be the conduit for the medical staff. Since that time, Laura has been taking valproic acid and we have not seen a tonic-clonic seizure for several months.

I am trying to work with the CHARGE Syndrome Foundation and other families to try and collect some documentation on seizure activity in people who have CHARGE syndrome. I also wanted to write this article with some important information on seizures that may be helpful to some families as they "live life forward."

Jackie Kenley
San Francisco, California
Mother of Laura Kenley, 21 years old

This information is from the Epilepsy Action website: <http://www.epilepsy.org.uk/info/firstaid.html>
Also see this website: <http://www.epilepsyfoundation.org>

First Aid for Generalized Tonic-Clonic (Grand Mal) Seizures:

DO

- Protect the person from injury-(remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing them in the recovery position once the seizure has finished
- Stay with the person until recovery is complete

DON'T

- Restrain the person
- Put anything in the person's mouth
- Try to move the person unless they are in danger
- Give the person anything to eat or drink until they are fully recovered
- Attempt to bring them around

Call for an ambulance if...

- You know it is the person's first seizure
- The seizure continues for more than five minutes
- One tonic-clonic seizure follows another without the person regaining consciousness between seizures
- The person is injured during the seizure
- You believe the person needs urgent medical attention.

Calling All Chargers in Texas Mark Your Calendars

A group in Texas is currently being formed for infants, children, and teenagers with CHARGE Syndrome along with their siblings, parents and professionals. We're called the Texas Chargers and we are dedicated to helping give the Texas Chargers a better quality of life. The goal of the Texas Chargers is to meet bi-annually to discuss the physical and emotional needs of these children with charge through the sharing of information and the building of a support network. So, mark your calendars for the 1st Texas Chargers Retreat on October 7th 2006 at Peaceable Kingdom Retreat (peaceablekingdomretreat.org) in Killeen, Texas.

This retreat will provide a stress free day for the families to come out and connect with others. The Day will include sharing information on raising a child with special needs in Texas and activities such as a carnival with balloons, arts and crafts, face painting, cotton candy, snow cones and a train ride. We will also be having lunch and enjoying the activities at Peaceable Kingdom which include an Indian campground, miniature golf, dinosaur tracks, a theatre & game room, swimming pool and nature trails.

If you would like to receive a registration package or be on the membership list, please contact Cathy Springer at dacspringer@austin.rr.com or 512-255-3176. You won't want to miss all the fun so make sure you mark you calendars! Keep reading future newsletters for more information about the Texas Chargers and we look forward to seeing all of you on October 7th at Peaceable Kingdom.

PRESIDENT'S NOTE

Neal Stanger

Hello everyone,

It's hard to believe that we are starting to plan for the 2007 CHARGE conference already. With just over 15 months left until the conference in Costa Mesa, the Conference Committee is getting very busy with preliminary plans. Marilyn Ogan is leading a team of volunteers and Jim Thelin will be in charge of plans for the program and agenda. If you would like to be involved in helping Marilyn or Jim, please email them (marilyn@chargesyndrome.org, jim@chargesyndrome.org). They will let you know how you can be of assistance.

If helping on the conference is not your thing, but you'd like to be involved in the Foundation, you are invited to join one of our other committees: Public Awareness, Adult Services, Collaboration, Education, Family Services, Medical/Research and Fundraising. For information on these committees, please visit our website at www.chargesyndrome.org/committees.asp

One of my personal projects over the next year is to try and get all of the different CHARGE syndrome related organizations throughout the world together to see how we can work to better the lives of all individuals with CHARGE syndrome. If you would like to get involved in this project, or if you represent an organization, email me at neal@chargesyndrome.org

Please keep checking our web site at www.chargesyndrome.org for more updates on the Foundation. We will be having lots of exciting news to announce to you throughout the year. Lastly, if there is anything that you would like to see the Foundation do for you, please do not hesitate to let us know.

Neal Stanger



FOUNDATION ACCOUNT

EXECUTIVE DIRECTOR'S NOTE

Marion Norbury

I want to thank everyone for their contribution to our 2005 Annual Drive. It was very successful! We received \$10,000 in contributions to the Drive. I also want to thank those who designate the Foundation as their charity of choice when they have lost a family member or friend and those who select the Foundation to honor someone. We appreciate your choosing us. I often get asked how we handle acknowledgments to the family or individual. We send a thank you to the contributor and a card or letter to the family or individual. We keep a record of these special donations and send updates as needed.

Please note that the **American Journal of Medical Genetics' March 15, 2005 Issue** is on our Order Form this time. We still have some copies if you didn't get one last year when the Journal was published. This issue is devoted entirely to CHARGE syndrome. The cost is \$20. You can read about it on our website (www.chargesyndrome.org) under Resources.

This is another big issue of CHARGE Accounts. We hope you enjoy reading it and find it informative and interesting. Remember - if you have an article, a helpful tip, a favorite book or a great photo, please send it to the Foundation Office. We do want to hear from you.

Although this is not a conference year for us, we are busy making plans. On March 30, there will be a meeting with families in the southern California area who are interested in volunteering to help with the 2007 conference in Costa Mesa. The Foundation's Board of Directors will be meeting on March 31-April 1 at the Hilton Costa Mesa where the conference will be held. If you are in the area and can attend the

meeting on Thursday evening, please contact Marilyn Ogan, marilyn@chargesyndrome.org or Marion Norbury marion@chargesyndrome.org or call 1-800-442-7604.



COMMITTEES

For a description of what each committee is responsible for, please go to www.chargesyndrome.org or contact the chairperson or the Foundation Office.

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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 physician.

The CHARGE Syndrome Foundation was invited to present at the NTAC Project Directors meeting in Virginia last October (2005). Kathleen Stremel, Director of the National Technical Assistance Consortium (NTAC) had extended the invitation. NTAC is responsible for Deaf-Blind programs in all 50 states and some territories. Kat (as she is called) has also been a presenter at CHARGE Syndrome conferences. The CHARGE Foundation Board has been communicating with NTAC because evidence has been accumulating that children with CHARGE often are served best in deaf-blind programs. We are seeking to collaborate with these organizations to learn how those with CHARGE may be helped educationally and vocationally. We also have learned that on the NTAC census, CHARGE is now the leading cause of congenital deaf-blindness in the United States.

Since this was the first time that we had presented at this type of conference, we thought that we would have only a small place on the program. As it turned out, we were among the featured speakers and our presentations were highly anticipated. Our presentation was entitled "CHARGE Syndrome Foundation: Evolving Knowledge and Evolving Mission". Neal Stanger provided background information on the Foundation and I presented scientific information about CHARGE syndrome. Both parts of the presentation generated a great deal of interest. It is significant to note that the scientific body of knowledge that the CHARGE Syndrome Foundation has accumulated over the past 20+ years makes our organization unique and well-respected among professionals who deal with deaf-blindness. This has been accomplished primarily through the efforts of individuals like Meg Hefner, Sandra Davenport, Kim Blake, Tim Hartshorne, and David Brown.

At the NTAC conference, we made many new contacts and interacted with old friends. Sheri Stanger gave a presentation as president of the National Family Association for Deaf-Blind (NFADB), and CHARGE Syndrome Foundation Board member Susy Morales attended as a board member of NFADB. Kathy McNulty (NTAC) who has served as an advisor to the CHARGE Syndrome Foundation and Joe McNulty (Helen Keller National Center) who has presented at our conferences were active participants in this conference. As a result of conversations at this meeting, Nancy Steele (a Southern Region Director for NTAC – Area 3B) moved her office from Atlanta to Jim Thelin's Department of Audiology and Speech Pathology at the University of Tennessee. We are expecting that this will result in the development of valuable collaboration in research on communication and education for individuals with CHARGE. We anticipate other positive outcomes as a result of the growing cooperation between the CHARGE Syndrome Foundation, NTAC and other organizations which focus on deaf-blindness.

James Thelin is Professor of Audiology, University of Tennessee, Knoxville, TN

Intervention in Kentucky

Tim Hartshorne, PhD

If professionals had a better understanding of CHARGE, then perhaps they could develop more appropriate services and reduce the extent to which behavior difficulties arise. This was the logic that made me decide to offer a day of training while visiting Lexington, Kentucky, to consult with a school and family about the behavior of their 12-year-old son with CHARGE. I gathered a team of five. Sandy Morgan is a psychologist at Central Michigan University, Lee Wachtel is a psychiatrist at Kennedy Krieger Institute in Baltimore, and Amanda Leshk and Kasee Stratton are students at CMU.

The intervention was structured so that on the first day Sandy and Amanda worked at the school assessing the boy and possible interventions. Lee, Kasee, and I did an all day workshop on CHARGE. The second day all five of us worked with the family and the boy to develop and test possible interventions. The workshop had four components to it. For the first part I presented an overview of CHARGE – what it is, how it is diagnosed, and complications. For the second part I reviewed challenging behavior in CHARGE, including sensory issues, stress (with Kasee's help), and possible interventions. The third part focused on severe challenging behavior. Lee reviewed the in-patient program she has and presented two cases of severe challenging behavior in CHARGE and the intervention program that addressed these. The fourth part was question and answer.

Although the announcement of the workshop was sent out only about two weeks prior to the event, over 100 people registered and attended. The Kentucky Deafblind Services organized the entire project and were wonderful. Two families who attended the workshop with educational professionals from their schools have reported that the information presented energized the team. Understanding what CHARGE is and how it can affect children helped them to put the child they work with into a context that made more sense.

So the workshop was a success, and the intervention that was developed for the boy in school, with the assistance of one of the Kentucky Deafblind Services team members, and the intervention developed for use in the home, both seem to be working very well. There is no substitution for being able to see the behavior in the child's own environment and having the luxury of trying out interventions to see what might work. However, in order to sustain the intervention, some systems change is necessary, and we hope that the workshop information has helped to initiate some of that change. Finally, also critical to success, is the involvement of local resources like the Kentucky Deafblind Services team.

Tim Hartshorne is Professor of Psychology, Central Michigan University, Mount Pleasant, MI

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CALENDAR

2006

- March 30 - April 1 CHARGE Syndrome Foundation Board Meeting, Hilton Costa Mesa, California
- May 15-17 CHARGE Ahead - 2006 Topical Workshop: CHARGE Syndrome
Missouri Deafblind Technical Assistance Project (See below for details)
- Sept. 29 - Oct. 1 Australasian CHARGE Syndrome Association Limited Conference, Novotel Twin Waters
Resort, Sunshine Coast, Queensland. More details: www.austcharge.com.au
- October 7 First TEXAS CHARGERS Retreat at Peaceable Kingdom Retreat in Killeen, Texas (See p. 7
for details)

2007

- July 27 - 29 Eighth International CHARGE Syndrome Conference, Costa Mesa, California
More details will be available in future issues of CHARGE Accounts
- September 25-30 Deafblind International Fourteenth World Conference, Burswood International Resort
Convention Centre, Perth, Western Australia. More details: www.dbiconference2007.asn.au/
-

Save the Dates!

Missouri Deafblind Technical Assistance Project's 2006 Topical Workshop: CHARGE Syndrome

When: Monday – Wednesday, May 15 – 17, 2006

Where: St Louis, Missouri

Who: Education and service teams of individuals with CHARGE Syndrome, ages 3 through
22 years in the State of Missouri and surrounding states. Priority will be given to those
residing in Missouri. *

Presenters: Michele Westmaas, Meg Hefner, David Brown

How: For more information and to receive workshop registration materials, please contact:
Larry Rhodes, Coordinator, Missouri Deafblind Technical Assistance Project
3915 Magnolia, St Louis, MO 63110
(314) 776-4320 x 255 lrhodes@msb.k12.mo.us

You may go to the Missouri School for the Blind website: www.msb.k12.mo.us to download the
registration materials. Deadline to register is April 14.

* NOTE: This workshop is designed to train professionals and staff to better support children and youth
with CHARGE Syndrome in school, day programs, and/or group homes/supported living environments.
Parents are invited to participate as *part of their children's educational and/or service teams*.