

CHARGE Accounts



Spring 2009

A Quarterly Newsletter for Families and Friends

Vol. 19 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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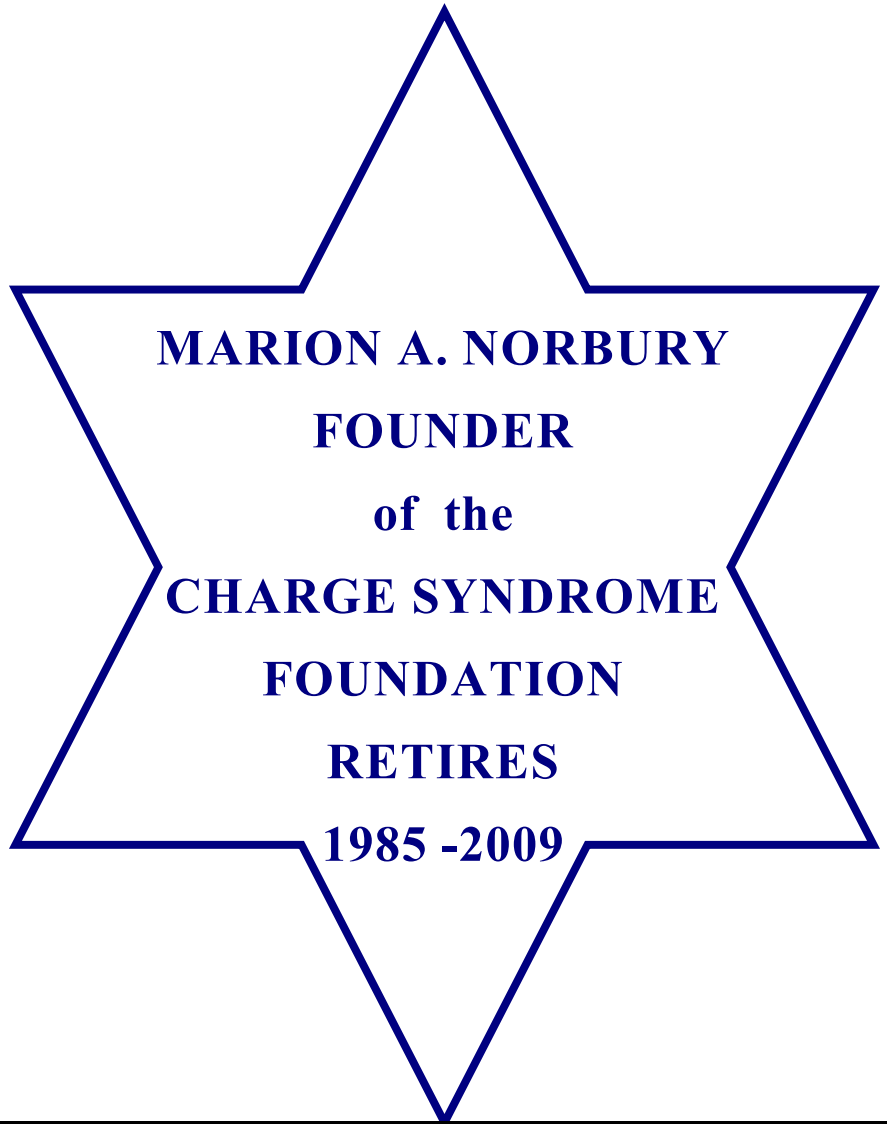
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!!! Deadline for the Summer Issue - June 1 !!!

I am a proud grandmother of two little girls ages 6 and 3 years old. The younger one, Halyn, was born with CHARGE syndrome in Montgomery, Alabama. In August 2005, doctors in the neonatal nursery were uninformed about CHARGE syndrome. They observed her low-set, misshapen outer ears and the paralysis on the right side of her face. The doctors conducted tests to verify that she had no malformations of the brain and ordered a genetic test for Down syndrome. Nurses scolded my daughter because Halyn was consuming so little formula at each feeding, but Mom and baby were released from the hospital with only a curt verbal report from one of the doctors that Halyn had “failed both of her hearing tests.”

Eight months after her birth and after referrals to Ear Nose and Throat specialists, Pediatric Ophthalmologists and the genetics clinic at Children's Hospital and the University of Alabama Hospital in Birmingham, Halyn's parents finally had a definitive diagnosis. Halyn was born with CHARGE syndrome. She has colobomas in both eyes, severe hearing loss and wears a hearing aid. She has absent semicircular canals in both ears, and has significant developmental delay. She also demonstrates the characteristic hand flapping behavior and preference for lying on the floor with one foot crossed over the knee. She has had several surgeries to open her nasal passages that were completely blocked at birth, but not discovered until six weeks after birth.

In June 2008, Halyn was finally able to transfer to an Easter Seals Child Care facility that accepts children with physical and mental challenges, as well as those who do not have any significant challenges. From birth up to this point Halyn had attended a very good day care facility that provided outstanding care to her older sister but was completely unprepared to deal with Halyn's special needs. At the time of her transfer, Halyn was not drinking any liquids and mealtime was a nightmare. She could not feed herself and screamed constantly throughout the meal as we tried frantically to “shovel” food into her mouth as quickly as possible. At nearly three years of age, she was still using the “commando crawl” as her preferred means of mobility.

In the spring of 2008, the CHARGE Syndrome Foundation Education Committee finalized the compilation of articles for the *Information Packet for Professionals*. It was posted to the Foundation website in May. This collection

of documents provides a comprehensive picture of the physical and behavioral manifestations of CHARGE syndrome in a way that addresses the professional interests of behavioral therapists, speech and hearing therapists; occupational therapists, special education teachers, etc. Board member Pam Ryan and Special Advisor Meg Hefner were instrumental in gathering the information together and editing it into its current format.

As a member of the Education Committee, I volunteered to “test drive” this packet as Halyn approached her 3rd birthday and her transition into the care of the public school. In preparation for this transition to the Special Education Department of the Montgomery school system, the program coordinator contacted Halyn's parents to schedule a preliminary conference prior to the actual meeting in which her Individual Education Plan (IEP) would be finalized. Halyn's parents invited me to attend this meeting with them. Before the meeting I printed copies of the *Informational Packet for Professionals* and gave them to the Coordinator, saying that the document contains information on CHARGE

syndrome and how it affects the student with CHARGE physically, their classroom behavior, and also offers hints from teachers who are experienced in working with students who have CHARGE. At the same time we also provided a copy of the *Information Packet for Professionals* to the staff of her new child care facility to help them better understand the special needs of a child born with CHARGE syndrome.



Halyn Jones

A few weeks later we met to finalize Halyn's IEP for the 2008-2009 school year. We were amazed to see that each of the professionals representing the Special Education Program had her own copy of the *Information Packet*. Each copy was “dog eared”, highlighted and contained notes in the margins. While I can't tell you that the school system is providing 100% of the therapeutic support that we requested, I can say that her special education teacher and all her therapists have a good understanding of Halyn's special behavioral and physical needs that are unique to a child with CHARGE syndrome.

Today (February 26, 2009) Halyn can “speed walk” with her walker and crawls up on the couch to watch TV or take a nap. She is delighted to independently feed herself (fingers, spoon, and fork) and she drinks water, milk, and fruit juice from sippy cups from which the valves have been removed.

She attends class with other 3-year-olds where she sits in a chair with her classmates during “circle time” and voluntarily crawls on her cot at naptime. She attends a music class that is offered to all students attending the daycare and now spontaneously “sings” along with theme songs of her favorite television programs in the evenings. I am convinced that much of this astounding progress is directly attributable to her teacher, therapists, and caregivers having direct access to the *Information Packet for Professionals*.

Lisa Weir, chair of the CHARGE Syndrome Foundation’s Education Committee has facilitated distribution (by email) of the *Information Packet for Professionals* to each State Department of Special Education, the Technical Alliance for

Parents and all Part C programs in the United States. A similar distribution is planned for Canada. The Education Committee is currently exploring other agencies whose clients will benefit from receiving the packet.

Although the Education Committee is making these mass distributions of the *Information Packet for Professionals*, copies of this document may not “trickle down” to the local level as soon as we would hope. Therefore, I urge parents of children with CHARGE to proactively download this informational package from the CHARGE Syndrome Foundation website (<http://www.chargesyndrome.org/>) and make sure that it plays a prominent role in your IEP conferences. It has been beneficial to Halyn’s development and it has the potential to do the same for your child.

Meet Chris Woodcock **by Christopher Woodcock and Trish Gober**

My name is Christopher Michael Woodcock. I am 33 years old, soon to be 34 on April 17th. I live in Montgomery Alabama, the same city where I was born. I was born with a 55 per cent hearing loss and total blockage in the back of my nose. I also have had big problems with heavy fluid in my ears and nose. I also am short in height. I had learning disabilities and difficulty with school. I had tubes in my ears six times before I was three years old before they discovered I had a real hearing loss. At six years old they replaced the bones in my left ear. When I was eight years old they opened the back of my nose by cutting the bone and skin. The bones were replaced in my other ear when I was 10. The skin grew back over my nose three times and they had to r e p e a t t h e surgery. The last time they did laser surgery and I was under for a long time. My tongue became so swollen I stayed in intensive care 3 days on oxygen to breath. I had the last surgery on my ear this past year when I was 33.



Chris Woodcock

I was told I had CHARGE when I was 19 when I went to a geneticist. In school I played soccer, baseball, tennis, bowling, and golf. I had difficulty with sports because breathing could be difficult and my nose ran all the time. I like to fish also. I like music, woodworking, working in the

yard, cards, puzzles, animals and church.

I have had a few jobs, but only for short periods of time. I worked delivering food, stocking shelves and in maintenance at the zoo. I attended trade school for auto mechanics for six months. I also went to E. H. Gentry a school for the deaf and did assembly line work for about a year. When I work I have difficulties with stress and interacting with people. I will be working with a local veterinarian’s office part time. I do better with part time work.

I have lived in a college dorm at E. H. Gentry and tried living in a group home for a while. The group home was not very supportive and it could be dangerous as some people acted out. I now live in my own home, but spend a lot of time with my parents. I have friends at church and some at the activities I attend.

My advice to anyone with CHARGE is to know they can only do their best and not be upset by what others say or do.

Mom’s Support

Chris lives fairly independently. I help him mainly with finances, transportation, medical decisions and providing emotional support. He can buy groceries, take his medication, keep his home clean and take care of the yard. He takes care of his own hygiene and lets me know when he needs any type of support. I have found that it is important to find the right doctors and to work hard to have them share information. Most doctors want to treat only one issue and with CHARGE they must understand the issues as a whole. One impacts the other. It was also important for me to be an advocate for education as Chris proved he was much more capable than many educators gave him credit for. Sometimes they judge children by others’ abilities instead of focusing on the individual and their capabilities. Chris is very impulsive and sometimes makes poor decisions, especially when others influence his thinking. It is important to work with them on helping with a social life, especially as an adult.

Trish Gober

3rd Annual CHARGE Retreat in Denton, Texas by Josh Fultz

The hot Texas wind made a strong cooling shift to the north welcoming participants to the 3rd Annual CHARGE Retreat held at the Merritt Bois D' Arch Buffalo Ranch in Denton, Texas on November 16th, 2008. Anticipation was high, as the event was postponed to November due to Hurricane Ike. The wait was well worth it.

More than 30 families made the journey, with approximately 150 total attendees. The Texas CHARGE board, as well as many others behind the scenes had worked diligently to make the rescheduled event happen and to make it the retreat everyone had looked forward to.

The activities began Saturday morning as family members registered and received their CHARGE designated shirts. Thus began the reunion of friends old and new. Volunteers designated by white shirts waited anxiously inside the door to meet their little CHARGErs. The day had been well-planned with lots of emphasis on events for the kids, including arts, crafts, games, scavenger hunt, hayride and more fun events.

While the kids were being entertained, the parents, grandparents, and siblings were offered educational information from agencies from the State of Texas in the form of a speaker's panel. Agencies attending included TSBVI (Texas School for the Blind and Visually Impaired), DARS (Texas Department of Assistive and Rehabilitative Services), HKNC (Helen Keller National Center), and an Education Service Center Specialist from Region 13. They discussed the challenges of deaf/blindness. It was a poignant reminder to everyone that there is help out there.

The lead speaker, Amy Parker a PhD. candidate from Texas Tech working with the National Coalition on Deaf-blindness, explained her goal to help gain assistance from the federal government for children with sensory impairments. She indicated that the funding for children with deaf-blindness has stayed generally the same amount, \$12.8 for the last 20 years. She assured the audience she was working to get that amount increased and asked for assistance from participants in the form of support for the increase.

Always emotional and thought provoking, the Parents Panel gave unique perspectives of parents dealing with CHARGE. The panel was comprised of five parents of children with CHARGE syndrome who range in age from 6 to 26. The parents described their struggles and their achievements parenting children with CHARGE. One parent noted that raising a child with CHARGE is similar to swimming up a waterfall. One should stop and take a look back because the view from a waterfall is beautiful. The profoundness of the statement struck a deep chord with all.

Also included in the day's activities were various forums. Participants could attend the forum that was most fitting for them. There were forums for fathers, mothers, and grandparents. The fathers sat in a large circle downstairs and

shared their experiences. Also discussed were the differences in dealing with CHARGE as fathers compared to mothers. Each father praised their wife/girlfriend for all the support and responsibilities that the role of mother entails.

The mothers met upstairs in the loft meeting room and discussed how important it is to take time for themselves, as well as how to be the best moms possible for their kids with CHARGE. They shared ideas and stories of how their child with CHARGE has made them smile/laugh. It was a great bonding time for all the mothers. Also discussed were the frustrations and emotional challenges of being the primary caregiver to a child with special needs. The grandparents networked and discussed the many facets of being



grandparents to a child with CHARGE, including concerns about their own children (the parents of the children with CHARGE). Each forum provided an excellent and unique opportunity for openness and honesty and to share ideas and mindsets.

After serious discussions it was time for a little fun. Everyone lined up to immortalize this third retreat in a group picture. Then it was time for some good eats. Not only was the meal great, so was the 2008 Star CHARGE, Kayla Orregon. Kayla shared her life challenges with CHARGE. Everyone was delighted when she declared, "I have CHARGE syndrome but I like to think of it as I am in charge and can do a lot about it." Kayla's goals include helping other people in life. She thanked her family for all their support. She stated she considered herself just like any other young woman.

Following dinner, a genuine Texas CHARGE Hoedown was celebrated with a bonfire and smore's, music, popcorn and cotton candy. Everyone danced and played as they came to the end of another educational, emotional, and life-changing retreat for families and children with CHARGE.

Josh Fultz, Navaasota, Texas, Leigh Anne's Dad

Editor's Note: This letter was written in response to an article in the Winter2008 CHARGE Accounts that stated the Foundation's policy on use of People First Language. You may view this issue of Accounts on our website www.chargesyndrome.org.

Dear CHARGE Syndrome Foundation Board:

Let me preface my response to your official policy of exclusively using “People First Language” with the following: I adore all of you for all the great work you do for our children. I appreciate your respect for the decisions of others. I clearly understand the goal and good intention of your policy. I respect and agree with that policy for all official correspondence, and I surely do not intend to create divisions. I do, however, desire to make you aware of latent divisions you might be unaware of creating when criticizing parents' benign reference to their children.

The goal of People First Language is to make language conform to attitudes which we deem are more appropriate. That is a laudable goal; I agree that formal usage of People First Language is proper and good. Language, however, comes in many forms and contexts. I would hate to see our informal reference to our children condemned as uncaring. Context and individual expression should be respected. When making multiple and informal expressions regarding children with CHARGE, the accumulation of prepositional phrases sounds awkward and contrived. Many parents feel the locution, “CHARGE_r”, is a particularly endearing and empowering one. The image conveyed by the term “CHARGE_r” uniquely portrays the indomitable spirit of our children.

It is interesting that reference is made to George Orwell in justifying universal restriction of language to that prescribed and proscribed by others. The very quotation used, “If thought corrupts language, language can also corrupt thought” was an injunction against the power of one to tell another how to speak. Orwellian political correctness is the very concern I have in conflating formal language with the idiomatic expressions of our families and children.

In fact, George Orwell provided for six “rules for writers”. Among them are:

- Never use a long word where a short one will do
- If it is possible to cut a word out, always cut it out
- Never use the passive voice when you can use the active

In other words, shorten, simplify, and strengthen words in order to communicate most effectively. The “short” and “active” term, CHARGE_r “cuts out” excessive verbiage and powerfully communicates the image of a group of children that we all know and love. Between ourselves, when speaking directly and informally, we should be comfortable and non-judgmental. For sure, there is enough stress in our lives that we need not impose rules of rhetorical behavior on each other.

I would rather use the poetic words of one of the world's most gifted writers, Alexander Pope, who wrote of the language of the common man:

*Unlearn 'd, he knew no schoolman's subtle art,
No language, but the language of the heart.*

We parents of children with CHARGE, speak from the heart. When we refer to those children as CHARGE_rs, that heart is no less caring, loving, or respectful.

Please read the enclosed poem that I wrote soon after my infant daughter was diagnosed with CHARGE. It is entitled “Charge On”. I wrote it in the absence of a full understanding of the syndrome that would reshape all of our lives. The power of the acronym, “CHARGE” fortified my optimism about her ability to overcome her obstacles.

The analogy of not “calling children with Down syndrome ... ‘Downers’” is a *non sequitur*, because the acronyms CHARGE/CHARGE_r are truly befitting the persevering nature of our children. If my daughter's syndrome had the acronym, “WIN”, I would proudly call her my “WIN_ner”. Although I respect the desire of the Board to restrict my formal description of her to that which may include passivity and prepositional phrases, I remain happy to *informally, occasionally, and unapologetically* call her my sweet CHARGE_r (or, more specifically, my CHARGE_r).

Love to all the Board and thanks again for all you do,
Paul Cosenza (Charlotte's dad)
South Carolina

9th International CHARGE Syndrome Conference

July 24-26, 2009

Bloomington, Illinois

The National Library Services for the Blind and Physically Handicapped (NLS) is committed to providing library service for special needs populations. All over the United States, students and adults are enjoying the magic of reading through a network of regional libraries.

This **free** program is available for eligible children and adults who cannot read standard print due to a visual, physical, or reading disability. NLS provides books on cassette tape and in braille although some regional libraries also offer large print books and descriptive videos. The NLS program loans each participant a four-track cassette player needed to play the specially recorded books on tape.

While NLS does not have textbooks as part of the collection, the library offers thousands of books that students can use in their schoolwork. In addition to providing fiction and non-fiction books, NLS offers a selection of magazines for use in school or recreation.

To register, you need to fill out an application form and have it certified. A list of professionals who may certify your application form is on the back of the application. Once registered, your state's regional library will contact you to begin service. Reader Advisers will be happy to assist you with book selections and other aspects of the service.

To register for services, visit the NLS web site located at <http://www.loc.gov/nls/> and go to the link "How to sign up." You will find a downloadable online application along with more information about NLS services.

If you have questions, would like an application mailed to you, or need additional information on what qualifies as a reading or learning disability, please contact NLS at 1-888-NLS-READ or email nls@loc.gov.

Sent to us by Emma K. Schroth
Services for the Blind and Physically Handicapped
State Library of Louisiana

We are Going Green

Starting this year we will be emailing our newsletter. To be sure you get the next newsletter, please send us (by email, fax or postal mail) your membership name, complete address (so we know which member you are), phone number and email address as soon as possible. Send it to:

Email: lorib@chargesyndrome.org

Postal mail: CHARGE Syndrome Foundation, Inc
141 Middle Neck Road
Sands Point NY 11050

Or fax to: Lori Bookstaver – CHARGE Syndrome Foundation
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CHARGE ON

Look deeply into my bright eyes ...
Watch as they reflect back on yours ...
And on all the wonders of the world you gave me.
See them laugh and speak to you,
And dissect everything in their reach,
As I charge on.

Touch the gateway to my heart ...
Feel the steady flow within ...
And how it beats with your laughter and love.
Feel it embrace your soft touch,
And resonate with my happy family,
As I charge along.

Feel the warm breath of my life...
Bask in its strong, gentle breeze ...
And in fascination that floats on its wings.
Hear that young voice call out to you,
To sing of my innocent joy,
As I charge ahead.

See how my little body expands ...
When it reaches out to your features ...
And to the security of your sweet smile.
Watch me blossom as I grow,
To explore my secret garden,
As I charge forward.

Tickle my toes and call me your girl ...
Play games that only mommy can ...
And always remember me as I am right now.
Walk me through the fertile crescent,
To help mold me into a woman,
As I charge beyond.

Share with me the sounds of laughter...
Hear whispers of autumn's rustling leaves ...
And know how I long to live them with you.
Listen to your own heart as it leads us both,
Over rocky roads -- into bold new worlds,
As I take charge of my life.

Happy Mother's Day
Love, Charlotte
5/2/04

A Few Topics from the CHARGE Listserv**Respectfully submitted, Paul Cosenza, father of Charlotte (5)**

Editor's note: Paul has been doing summaries of discussion threads on the CHARGE Listserv. This is a small sample of what has been discussed in recent weeks. You can find out more about them or search the list by keyword at www.yahogroups.com. If you are not a member of the Listserv, there is a link under Resources on our website www.chargesyndrome.org.

Expressive language: Concerns about children who have ability to sign, but don't. Encourage total communication to reinforce whatever communication styles work.

Knuckle cracking: Possibly for stress relief, proprioceptive sense, or sensory issues in general.

Autism: (vs. autistic-like behaviors): Do we want the label to help access services or do we want to avoid the added label? Bottom line: it is good to know about autism because of the significant overlap of behaviors with CHARGE. More info at the HANDLE Institute: www.handle.org

OCD meds: Depakote, Wellbutrin (and other SSRIs). Some of these have negative side effects, so be careful in employing them. Possible OCD improvement with supplementation of zinc.

Mood swings and pain: (including self-abuse): may be improved with Tylenol or other pain relievers. Migraines, ear pain, GI disturbance as possible causes were discussed.

"Against Medical Advice": Book about a boy with Tourette-like tics, who knew his behavior was wrong, but couldn't stop.

Inspirational story: Wendy told about a child who asked if Kendra could "talk with her hands" ... and then went on to fingerspell her own name.

Balance: HANDLE techniques, hippotherapy, lycra suits, bicycling w/training wheels, walking on flat, then progressively hilly surfaces, swimming, tilting the child and forcing him/her to correct, exercise balls. Bottom line: child uses whatever skills he/she can best use (vision, proprioception, vestibular, etc).

Airway issue: complication of tracheomalacia compression by arterial ring (aorta?). Vascular ring surgery *may* be needed, or possibly trach placement, oxygen nasal cannula, Bi-Pap, etc.

Frequent high fevers: possible reasons include recurrent infections (esp. with kidney reflux), or due to hypothalamus irregularities.

Sleep: waking up in middle of night: apnea, allergies, digestive problems/gas, reflux, either esophageal (acid) or intestinal (bile)?
Medications used for sleep: Melatonin (to get the child to sleep), but not effective for all and may reduce his/her natural production of melatonin. SSRIs, can be helpful. **Sleep apnea:** Sleep posture may affect apnea; apnea may affect general health, including hypertension, weight gain, and diabetes. Special pillows/wedges/mattresses may help. Apnea in CHARGE can occur either from airway obstruction or CNS issues.

Teeth grinding: common in CHARGE, even when asleep. May be partly to reinforce proprioception or to help reduce inner ear discomfort. Advice: attach "chewy" to shirt to use instead of grinding; use mouth guard (see dentist) when asleep; massage the jaw bone by hand or with a knobby "Gertie ball". It may decrease over time and as frustrations are resolved.

Coloboma: website <http://www.nei.nih.gov/health/coloboma/factsaboutcoloboma.pdf>

Toilet training: decreased sensation may lead to difficulty sensing when a trip to the toilet is needed. Advice: spend 1-2 hours playing with a "bottomless" child on a linoleum surface, get him/her to the toilet as soon as needed to help the association. Of course, the child has to have some readiness and willingness to cooperate.

Ankle braces: How to properly size shoes? Some standard, wide-design shoes/sneakers may work. Website which may help: www.keepingpace.com

Trach tip: instead of using a catheter when suctioning, use a 1-cc syringe (with "wings" removed) or a Neotech "Little Sucker" on the end of the suctioning tube. This is more effective and less traumatic than the catheter!

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.

President's Note
by Neal Stanger

As I sit and write this I can't believe that we are only four months away from our 9th International Conference. I have just seen the most current version of the program and I can't wait to get out to Chicago and hear all of the latest information that will be presented. I would like to give a big thanks to Jim Thelin for tirelessly putting this program together once again. In addition to the Conference program, Jim is also in charge of the program for the first official Professional Day, scheduled for Thursday, July 23rd. If you haven't already done so, please check out the Foundation web site at www.chargesyndrome.org for information about the conference, hotel, silent auction and some new scholarships that we have available to help bring as many people as possible

to conference. We are able to offer more scholarships thanks to the fundraising campaign that we started in the winter. To date, we have raised over \$50,000 with our "Charge it for CHARGE" campaign and hopefully more money will keep filing in. If you would like to participate in fundraising so we can offer even more financial assistance to families, please email David Wolfe, our fundraising chair, at david@chargesyndrome.org.

As part of the upcoming conference, we will be inducting new Board members for the Foundation. If you are interested in running for the Board, please download the application at www.chargesyndrome.org/nomination and mail it to the Foundation office. Applications will be open until May 31st, and a ballot will

go out to our membership sometime in June. We will be voting on six Board positions. If you have any questions about running for the board, please email me (neal@chargesyndrome.org).

By now, I am sure most of you are aware that Marion Norbury has retired from her position with the Foundation. Marion has been a huge influence on my work with the Foundation over the last 12 years and I would like to personally thank her for all that she has done. This newsletter is her last official act as an employee and I would like to once again thank her from the bottom of my heart. Marion will be attending the conference this summer as a guest of the Foundation and we will be celebrating her career in an appropriate manner.

Editor's Note
by Marion A Norbury

As this is the last issue of *CHARGE* Accounts for which I will serve as Editor, I want to thank everyone who has contributed to its success. Editing the newsletter for the past twenty years has been one of the things I have enjoyed the most. It has been a challenge and an opportunity for me to be creative. I have truly appreciated the notes and comments you have shared with me over the years about what *CHARGE* Accounts has meant to you and your families.

I have always had a wish list of things I would like to see the Foundation accomplish and unfortunately, I am leaving before we see some of them come true. There are two that I still hope will happen: regional meetings in off-conference years and local support groups and/or a network of families by state or area. Since travel will be shorter, hopefully more can attend a regional meeting and if they are only for one day or a day and a night, the cost will be less. A network of families in each state could help new families find the services available in their area and plan a get-together so they can all meet - maybe a picnic at a state park. Please remember, this is your Foundation and as members, it is your responsibility to let the Board of Directors know what you want from the Foundation.

As I retire from the CHARGE Syndrome Foundation, I want to Thank You for your Friendship and Support. We have accomplished so many things in the 25 years that I have been involved in this effort to provide information and support to individuals with CHARGE syndrome, their families and those who serve them. We had no idea 25 years ago when we started this journey that we would be where we are today.

I send each and everyone of you Best Wishes for Good Health, Happy Times, and Success in all things. I can be reached at 2004 Parkade Blvd, Columbia, MO 65202-3121; phone 573-442-7604 or mnorbury@centurytel.net.

Marion

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CHARGE Syndrome Foundation . . .

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Brandon Kouzmanoff

James Kouzmanoff IL
Catherine Kouzmanoff IL

Brian & Matthew Murray

Randi Goldberg NJ
Sari Laurence NJ
Donna Nardiello NJ
Beth Pike NJ
Janine and Alan Rubin NJ
Amy Smith NY

Carolina Vilalva

Anna Stolk PT

Carolina Vilalva & Mariana Machado

Allen Schick MD

Charlotte Cosenza

Tom and Alba Cosenza FL
Maureen Fraas NY

Christian McCants

Leo Lenaghan IL

Christian Roberts

Nick Perone TX
Derrell Roberts TX

Daniel B

Rebecca Moody FL

Edward Lent

Ronnie DiGiacomo NY
Anthony Varriano NY

Ethan Wolfe

Paul Anderson IL
Howard Ankin IL
Margo and Paul Berkowitz AZ
Mark & Kim Broderick WI
Stacey Chazin NJ
Allyson Hodgkins TX
Karen Jacobs MN
Julie Machtinger IL
Wendi Muise IL
Lisa Roseman IL
Peter Wachowski IL
Margaret Weides IL

Ethan Wolfe & Family

Shani and Gary Fox OR
Sandra Newberg TX

Gracie Lu Freebush

Shantell Rawlings CA

Gracie Swann

David & Kristen Bellig CA
Alison Burt CA
Jim "Papa" Carey CA
Christy Clements CA
Steve and Helen Colburn CA
Brian Corey CA
Julie Divird CA
Alice Dunbar CA
William Grabner CA
Karen Kilbert CA
Cordelia & Bob Mendoza CA
Denise Pappas CA
Judy Rainbow CA
Natalie Smalley CA
John O. Swann CA
Tracy Williams CA

Gracie Swann & Family

Rebecca Morazzini CA

Halyn Jones

Bill Campbell AL
Melva Strang AL

Jacob Hartshorne

Karrie Baldwin MI
Laurie Smith KS
Shirley & John Stark KS

Jake Wynne

Jim & Marilyn Erker OH

Tammy Whetsel OH
Terry/Dennis Wollschleger
OH
Dale & Lina Wollschleger OH

Jasmine Goldthorpe

Loree Christianson Canada
Linda Goldthorpe Canada
Lesley Hutton Canada
Catherine Lavery Canada

Joseph Lavelle

Margery Bodenhamer OH

Justin Murray

Pamela Dowd MA
Carlton Zeigler MA

Katherine Broich

Bonnie Morrison MD

Katie Ann Staunton

Thomas Staunton IL

Keith Persico

Suzanne Mortimer-Crawford
CA

Kennedy Weir

Nancy Buckley Canada
Theresa Faulkner Canada
Heidi Stoddart Canada

Kentucky DeafBlind Project

Scott McCormick KY

M&B

Marc Zimmet NJ

Machado Family

Vinicius Eid BR

Makenzie Dougherty

Betty McKnight OH

Matthew & Brian Murray

Fran Batson PA
Nina Krouk NJ
Maria & Gino Mallamaci NJ

Matthew & Brian Murray & Family

Mary & Scott Reinecke MD
Joy Ryan NJ

Matthew Schultze

Char Laursen IL
Kristin Noonan IL
Rachael Schuler NC
Kathy Zak MO

Megan Stanger
Haydee & Arthur Cornfeld NM
Bob & Carol Dressler CA
Harvey Dvoskin NJ
Gladys & Ed Friedlander FL
Marshall Goldstein NY
Michael Gordon NY
Paul Koppel NY
Robert Marion NY
Chris Mayer NY
Spencer Miller MD
Marc Rosenberg NY
Mark Singer NY
Andrew Spring NY
Ivan Tennbaum NY
Allen Tennbaum NY
Susan Visoky NY
Brian Zane NY

Megan Stanger & Family
Shoshana Chazen NY
Peg Burch NY
Howard Hirsch NY
Leonard Isaacs NY

Michael Kruger
Ruth Downey MN
Murray Family
Aunt Leba & Uncle Neal NJ
Neal & Sheri Stanger
Steven Rothstein MA
Pamela Ryan
Deborah Chase MA
Paul, Brenda & Shane
Shawn Hurley MA

Philip Wismer
Alan Wismer PA
**Sarah Myers and in memory
of our CHARGE angels**
Trent Myers TX

Saralene and Melissa Mark
Jenee Libby VA
Jennifer Mosley FL

Saralene Mark
Christopher Guandolo PA

Sweet Sara
Amy Maclean MD

Sweet Sara's Chargers
Kimberly Wagner NY

Taliah Skye Wendoll
Faith Gobuty CA
Barbara Heiman CA
Rachel Klausner WA
Mary Jane Zukin CA

Taylor Ferlazzo
Theresa Ritter PA

The Diamond Family
Kimberly Diamond CA

William A. Muir
Kathy Miekley NY

Wynne Family
Becky & Jim Lee OH

In Memory of:
**Michael David Hartshorne &
Katherine Swift Hartshorne,**
Jacob Hartshorne's Brother &
Sister
Phoebe Zimmermann CA

Megan Paige Desai
Spencer Desai MO

Nancy Jordan
Heidi Rae Harris MD

Peggy Bowden McWilliams
Nancy Black TN

Ryoto Yabuki
Munehisa Yabuki WA

Tyler James Matthew
Kelly Cash MD
Heather Gross MD

Bulletin Board

Reminders:

Going Green - Please notify the Foundation Office of your email address so you can receive future newsletters by email.

Board Nominations - Interested in joining the Board of Directors? Deadline for applying is May 31st.

Membership in the Foundation is for the Calendar Year. If you haven't renewed yet for 2009, fill in the order form enclosed with this newsletter.

Silent Auction - Have something for the Auction held during the Conference? A donation letter and a form for your item(s) are included with this newsletter.

Conference Packet - Information on the 9th International CHARGE Syndrome Conference, July 24-26, 2009, in Bloomingdale, Illinois is included with this newsletter. You can also find all the information and the registration form online at www.chargesyndrome.org

CHARGE Syndrome Foundation Board Nominations

If you would like to nominate yourself or someone else for the Board of Directors, now is the time. Nomination forms can be found at www.chargesyndrome.org/nomination

Ours is a working board comprised of 12 Foundation members. Terms are for four years, with six members elected every two years. We ask that all prospective Board members be able to work at least 5-10 hours per week on Board and Foundation business. Much of the business is done by email. Face-to-face Board meetings occur twice a year over a long weekend. New Board members will begin their term at the end of the Conference, July 26, 2009. If you have any questions about running for the Board, what we do or anything else, please feel free to email me at neal@chargesyndrome.org. Nominations will be accepted until **May 31st, 2009**.



9th International CHARGE Syndrome Conference
July 24-26, 2009
Hilton / Chicago Indian Lakes Resort
Bloomington, Illinois

General Information

Interact at Info Central

Online Registration

CHARGE Syndrome Conference for Professionals July 23, 2009

Conference Childcare Information

Counselor in Leadership Training Program at Conference

Silent Auction

Something New for Young Adults with CHARGE at Conference!

Talent Competition – Be the First CHARGE Conference Idol !!!

Conference time!! Conference for Families: July 24-26, 2009

It will soon be conference time and what an incredible conference we have planned for this summer at the Hilton Chicago/Indian Lakes Resort on July 24-26, 2009. There is going to be something for everyone. Lots of new things are happening including **online registration**, a new childcare company, special events, a Professional Day, *Conference Idol*, and special entertainment on Saturday night.

The program for the 9th International CHARGE Syndrome Conference will include a few new highlights. All three days will begin with a breakfast and a general session. At the general sessions, you will hear information about the Foundation and Board, listen to keynote speakers and see the presentation of awards.

Following the general sessions, there will be simultaneous breakout sessions with platform presentations. In addition to CHARGE 101 for first-timers, topics will include:

- | | |
|---------------------------------------|-----------------------------|
| -Education, development, and behavior | -Medical and genetic issues |
| -Family support | -New family information |
| -Hearing and vision | -Therapeutic approaches |
| -Transition-to-adulthood | -General information |

The presenters have been selected not only for their expertise, but also for their ability to deliver information in a family-friendly manner and their willingness to answer questions parents have about their own children. The complete program has not been finalized but a list of some of the presenters and their topics is at the end of this article.

Much of Friday afternoon will be devoted to one *LARGE* Multi-Purpose Session with poster presentations, exhibits, vendors, demonstrations, and opportunities to meet and talk with the professionals who will be presenting at the conference. In addition, there will be a special program for Young Adults with CHARGE that will include presentations, activities and a lounge for relaxation and socializing.

By popular demand, we will again have three *SIBSHOPS* sessions at the conference. These are workshops for the siblings (age 8-13 years) of individuals with CHARGE. In the *SIBSHOP*, children talk with each other about what it means to have a brother or sister with CHARGE. *SIBSHOPS* will be conducted by a group from the Tennessee School for the Deaf. In the past, children who participated in these workshops gave them the highest possible ratings. **If you want your child to participate, register your child early; attendance is limited to 12-15 per workshop.** Youth and young adults who are 14 years or older can participate as *Junior Leaders*. They need to register as well; there are positions for three *Junior Leaders* for each of the three workshops.

Some Program highlights:

David Brown – Vision issues in people with CHARGE syndrome

Meg Hefner, Sandra Davenport, Kim Blake & Rob Last – CHARGE 101

Kim Blake – Anesthetic management of individuals with CHARGE syndrome

Susan Bashinski, Kathleen Stremel – Impact of cochlear implants

Brian Rubin – Special Needs Trusts and Estate Planning

And Many, Many More...

Interact at Info Central

A new activity at this year's conference will be a 2 hour session called **Interact at Info Central** that will have poster presentations, exhibits, demonstrations and opportunities to meet and talk with the professionals who will be presenting at the conference. Although we have had poster presentations at past conferences, this large session will be much broader in scope with more than just posters. Additionally, there will not be other sessions going on at the same time so everyone will be able to participate.

Online Registration for the 2009 9th International CHARGE Syndrome Conference

For the first time ever, registration for conference will be online! By putting registration online at our website, we can streamline the process and save money by reducing our printing and mailing costs. Childcare registration is also online, along with lots of information about many aspects of the conference. The online conference headquarters and registration is available now. Just check out our website at www.chargesyndrome.org. If you need a hard (paper) copy of the registration form or any other conference material, please call the Foundation office at 800-442-7604.

CHARGE Syndrome Conference for Professionals July 23, 2009

The 1st CHARGE Syndrome Conference for Professionals will be held on Thursday, July 23, 2009 at the Hilton Chicago/Indian Lakes Resort. *This is the day before the 9th International CHARGE Syndrome Conference for Families and Professionals.* To our knowledge, this is the first conference in which professionals will address other professionals about their research and work related to CHARGE syndrome. At the Conference for Families, presenters are selected because they have the interest and ability to share information with families and to answer questions about specific individuals with CHARGE. At the Conference for Professionals, there will be discussion of scientific and clinical issues not related to any specific individual. The conference will be a means for professionals to transmit information to other professionals about the procedures and methods for understanding and treating CHARGE. There will be presentations in the areas of education, communication, medicine, genetics and sensory disorders.

Though this conference is for professionals, parents and individuals with CHARGE may register and participate, with the understanding that personal issues will not be addressed in the discussion at the conference. Parents are asked to take into consideration that the primary purpose of the Conference is for professionals to communicate with their fellow professionals.

The format of the conference will include participants introducing themselves and their research, platform presentations, poster presentations and discussion groups.

The registration fee of \$90 will cover the cost of a conference manual, a luncheon and snacks and refreshments. Registration amount is for the Professional Conference only. The regular conference registration fees apply for the remainder of the Family Conference, July 24-26, 2009.

Conference Childcare Information

We are happy to be able to once again provide childcare during the program sessions on Friday, Saturday and Sunday. Childcare will be provided by Corporate Kids Events (CKE). Only children who have registered in advance will be allowed to participate in childcare. Although the cost of childcare is through Conference registration, additional registration information (through CKE) is also required. This is available online (linked through the CHARGE Syndrome Foundation website). If you prefer a hard (paper) copy of the CKE registration form, please call the Foundation office at 800-442-7604.

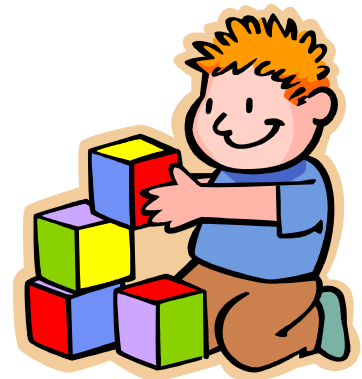
You will also need to register your child in person with CKE at the hotel before your child can enter the childcare area. That on-site registration will be Thursday from 1:00 pm until 6:00 pm and on Friday from 6:30am-9:00am and 4:00-6:00pm. We encourage you to register your child on Thursday if at all possible to speed up the process on Friday morning.

There will be more structure in the childcare areas than at past conferences. Each family will be given a complete schedule of the childcare events. Below is a sample of a schedule from another conference. Ours may have different activities, but will have the same level of structure.

Kids	Counselor	7:30-8:00	8:00-8:30	8:30-9:30	9:30-10:30	10:30-11:00	11:00-12:00
Anaya, Vanessa	Melissa	Sign In	Music Therapy	Sensory Room	Fire Truck Tour	Play it up	Magic Show
Phillips, Marlee	Melissa	Sign In	Music Therapy	Sensory Room	Fire Truck Tour	Play it up	Magic Show
Moore, Jamal	Jeremy	Sign In	Music Therapy	Play it up	Fire Truck Tour	Arts & Crafts	Magic Show
Carroll, Nathan	Jeremy	Sign In	Music Therapy	Play it up	Fire Truck Tour	Arts & Crafts	Magic Show
Fulks, Sebastian	Jeremy	Sign In	Music Therapy	Play it up	Fire Truck Tour	Arts & Crafts	Magic Show
Bolger, Rachel	Dawn & Samantha	Sign In	Music Therapy	Arts & Crafts	Fire Truck Tour	Outdoor Activities	Magic Show

Two Options for Childcare Area This Year

We are pleased to announce that in response to requests and feedback from earlier conferences, we have two options in the childcare area: Camp Discovery and Camp Explorer. Parents may choose either camp for any child – the cost is the same. Camp Explorer will have more structure and a lower staff-to-child ratio for those parents who think their children would benefit from such an environment. At times, participants from both camps will be together for certain activities. There will also be a Sensory Room available. If you want one-on-one care for your child, there is one additional \$138 charge (per child, covering all 3 days). More detailed information is available online with other conference information. You will select a camp when you register your child (online, ahead of the conference) with CKE.



Teen/Sibling Alert: Counselor in Leadership Training Program at Conference

Corporate Kids Events (CKE), our new conference childcare company, has a unique program that is available for up to five teenagers (ages 15-17) who would like to gain valuable experience and training in working with and supervising children: Counselor in Leadership Training (CILT). You will work with professionals from CKE in a variety of areas in the camps. You will get the most out of this if you commit to participating in the CILT program for the entire childcare program (2-1/2 days). We require a minimum commitment of at least one full day. Participants will receive a certificate of completion of the program, along with the number of hours they participated.

All teens in the CILT Program receive the following:

- Valuable training during the pre-event staff orientation.
- Hands-on experience with the kids. Each CILT will be assigned to work with a CKE staff member working with a particular age group of children.
- A staff manual for reference while working with children in the future.
- Team building instruction. A CKE Certified Team Building Instructor will lead the teens in fun, team building exercises. These help promote problem solving and communication skills, cooperation, self esteem, and group unity.
- A Certificate of Completion for the CKE Counselor in Leadership Training Program. This certificate can and has been used by many teens to obtain employment in the childcare industry or towards community service hours.

To be considered for the CILT Program, the interested teenager must submit contact information (Name, date of birth, address, phone numbers, email address), a list of school and extra curricular activities, and a one page (maximum) explanation of why she or he would like to participate in the program. Applications are due no later than **May 15, 2009**. Applicants will be notified of the status of their application by June 15, 2009. Applications may be emailed or faxed to: brownie@chargesyndrome.org Fax 1-866-543-2920 (Questions? Call Brownie voice: 713-545-9191).

Silent Auction

On Saturday night during the conference, we will be having our 6th Silent Auction fundraising event. In addition to being a fun event, the silent auction raises much needed funds that are used to help offset costs of the conference. We hope that you will be a valuable part of the planning for this event by gathering items to be included in the auction. A Letter of Donation and a Donated Item Form is available for download on the website. The Letter of Donation can be used to help you as you solicit items for the auction. If you're mailing the Letter of Donation, you might want to attach a cover letter with a little bit about your family member with CHARGE Syndrome. You might even want to include their picture on the cover letter. Each donated item must have a completed Donated Item Form. Please submit the forms to the contact person on the form as soon as you get a donated item. You can indicate on the form whether you are shipping the item before the conference or if you are bringing it with you, but we need the form as quickly as possible for planning purposes. There are many great possibilities for silent auction items including handmade items (quilts, jewelry, pottery, etc.), national chain restaurant gift certificates, items of interest to many (coolers, electronics, etc.) and much more. Just put your thinking cap on and let the sky be the limit. Together we can make this a great event!

Something New for Young Adults with CHARGE at Conference!

By popular demand and for the first time, the International CHARGE Syndrome Conference is offering program sessions designed solely for the young adult attendee. This conference strand will strive to conduct highly interactive group discussions on topics that are of interest to young adults with CHARGE.

The 2009 sessions will focus on:

Going to College - What Do I Need to Know?

Applying to a college or training program after high school can be an overwhelming task. This session is designed to help the young adult consider what supports he or she might need during the college application process and/or when in a classroom on a campus. Participants will receive **A Guide for Students Who Are Deaf-Blind Considering College**. This tool provides a simple and easy way to determine the level and types of accommodations that a college offers a student with a vision and hearing impairment (e.g. interpreter services, note takers, readers etc.).

Seeking Competitive Employment

Making a good impression on a perspective employer is a critical factor in getting a job. This session will show strategies that job seekers can use. This will include writing a resume that matches your strengths to the job, preparing for an interview so questions are handled comfortably during the meeting, social etiquette before, during and after the interview and tips on how to dress to impress.

These sessions are for individuals currently considering applying to college or looking for employment or over the age of 18. Session handouts will also be available to people who do not attend the sessions.



- ~ Because we will be in Chicago...
- ~ Because our theme is "CHARGE...and All That Jazz".....
- ~ Because we have many talented youngsters, teenagers, young adults and families.....

WE ARE PLEASED TO ANNOUNCE THE VERY FIRST
Super CHARGED Talent Celebration!

There will be a talent show that is open to everyone including individuals, groups, families, etc. on Friday evening. Each performance will be limited to 3 minutes. Judges will determine winners in each category, and they will perform Saturday evening at the Carnival. Then, the CHARGE Conference Idol will be announced.

Talent categories include:

Singing

Dancing

Playing an instrument

Miscellaneous (magic, jokes, comedy, etc.)



If you would like to participate, bring your act and any instruments, costumes or other equipment with you to the conference. You will need to bring your own musical accompaniment. We will have a cd player available for your use.

Be prepared to **WOW** the Judges.

Have a chance to be the first ever...

CHARGE Conference Idol

We would appreciate it if you would notify us at Pam@chargesyndrome.org by June 30th if you plan to participate. Please send the name(s) of the participant(s) along with the anticipated category. This will help us with our event planning. You may also register at the conference if you don't pre-register or you can change your mind about participating or about your category. We'd just like to have an idea of the number of participants in each category.

So, if performing in a talent show isn't your idea of a good time, we hope that watching others is! Friday night is a free night at the conference so this will be a great activity full of laughs and beauty and a wonderful time with family and friends!

Come Join In the Fun!

