

CHARGE Accounts



Spring 2008

A Quarterly Newsletter for Families and Friends

Vol. 18 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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2008



*We Are Celebrating
the
15th Anniversary
of the
CHARGE Syndrome Foundation
1993-2008*

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!!! Deadline for the Summer Issue - May 15 !!!

Our Little CHARGEr Improved His Swallow Function, Avoided Surgery & Improved His Quality of Life Through VitalStim Therapy

by Shawn Herrick

My husband and I sat nervously in the all too familiar, small conference room at Cincinnati Children's Hospital. We were waiting for Cole's team of doctors to come tell us the next step in his treatment after scoping his airway and lungs. The door opened and in walked Dr. Wood, his pulmonologist, and Dr. Cotton, his otolaryngologist, as well as several resident physicians and nurses. Dr. Wood told us that Cole's repeated pneumonias were most likely a result of aspirating his secretions. This was also causing his lungs to get progressively worse. Ultimately, Cole would need a drool procedure. My husband and I questioned almost in unison, "a drool procedure?" Dr. Cotton responded by saying, "I will remove three of his four salivary glands and we will schedule the surgery in about four to six months." The conversation continued but I no longer heard the words or meaning. I only knew that our 1-1/2 year old son would need yet another surgery. He already had endured multiple surgeries and procedures including an esophageal atresia and tracheoesophageal fistula repair approximately six hours after he was born, a heart surgery (patent ductus arteriosus repair), placement of a tracheostomy tube and a Nissen fundoplication with the placement of a gastrostomy tube. He has also had numerous other smaller procedures.

Despite Cole's many obstacles and challenges, he is full of life and energy. He enjoys being the center of attention, giving directions to all those around him, looking at books, playing with family and friends, and throwing a ball to our dog. When I heard this, I hated the thought of yet another surgery, another hospital stay, as well as being concerned about the potential long term effects of producing less saliva (e.g. dental problems). I started fervently searching for other options.

When we got home, I couldn't get to the CHARGE Syndrome Management Manual quickly enough. I also joined the CHARGE listserv to try to find out what others have done. Through the CHARGE Syndrome Foundation, I e-mailed Meg Hefner, Sandra Davenport and Joan Arvedson, a speech pathologist who is well known in her field with vast experience in swallowing and with CHARGE. All had wonderful suggestions and thought that Cole's swallow would likely improve with age. But I didn't know if time was on our side. We talked to a handful of families of children who had the drool procedure. A couple of the families felt that the results of the drool procedure were wonderful, while others did not see much change. After numerous long discussions with my husband, taking into account the input from professionals, parents and current research, we decided that if Cole needed surgery to keep him and his lungs healthy, then that is what we would do. We scheduled his surgery for six months out.

During the next four months, we tried most of the options that we found through our research. We tried Botox injections to his four salivary glands, Bi-Pap, numerous allergy medications and considered other medications that ultimately were found unsafe for him. Cole's condition did not improve. He continued to get heart-wrenchingly sick every two weeks where he cried, coughed endlessly, gagged, threw up. He required breathing treatments every four hours, almost constant suctioning and chest x-rays. He would get three to four days of antibiotic shots followed by 10 days of oral



Easter 2008

antibiotics only to start the cycle all over again once the antibiotics were out of his system. I, then, reluctantly decided to consider our last option suggested by some parents on the CHARGE listserv: VitalStim therapy (neuromuscular electrical stimulation). This uses electrodes to stimulate a swallow by placing the electrodes over the neck area.

Prior to Cole's birth, I had worked as an occupational therapist in pediatrics and knew that "electrical stimulation" had been used successfully in other parts of the body and that the principals of VitalStim were similar to that stimulation. While in theory this sounds simple and was the only intervention that targeted "fixing" the problem by actually improving his swallow, I was reluctant to try this on my own son. Did I really want electricity on his neck? As we were now only two months away from his scheduled surgery, I thought that it was at least worth trying. After several VitalStim sessions, we saw many positive changes in Cole. He stopped getting respiratory infections and pneumonia, his vocalizations increased, his ability to safely wear his Passy-Muir valve improved, and he required fewer breathing treatments. He was

swallowing more. Would this be enough to prevent surgery? Cole was scheduled for a chest x-ray and visit with Dr. Wood one week prior to his surgery date. After the x-ray, we waited for Dr. Wood to read the results and examine Cole. Dr. Wood was astonished with Cole's chest x-ray as well as our positive reports about Cole's progress. With this, Dr. Wood and Dr. Cotton decided that the drool procedure was no longer necessary and the surgery was cancelled! My husband and I are thankful that VitalStim seemed to be one of Cole's many "miracles"!

Since this time, I have become certified to provide VitalStim therapy so that I could work on eating by mouth with Cole. He started to make progress with oral feeding and began to safely drink liquids as well as eat pureed foods in very small quantities. The next step was to work on taking some of his nutrition by mouth rather than solely through his gastrostomy tube.



"The Trach Is Out!"

However, after Cole had his tonsils and adenoids removed (to open his airway for the possibility of decannulation); he was no longer safe to eat by mouth. We are ecstatic at the possibility that he might have his trach removed this spring and wonder if VitalStim may have also played a part in strengthening his airway. Prior to VitalStim therapy, all of Cole's routine scopes by Dr. Cotton and Dr. Wood showed laryngomalacia due to large arytenoids (part of the larynx) and severe tracheobronchomalacia due to a "floppy" airway. His malacia is still present but improved enough to begin to consider possible decannulation.

While we are incredibly thankful for Cole and his numerous accomplishments, it has been hard to see him regress with oral feeding and I am hopeful that someday he will eat by mouth. I also hope that VitalStim will continue to be one of the "miracles" that will help Cole and others who have CHARGE syndrome with swallowing and feeding difficulties.

When I attended my first CHARGE Syndrome conference this past year, I was inspired and grateful for all of the families and professionals that I met. At one of the sessions related to feeding, I became overwhelmed by the need for formal research on whether or not VitalStim is a good option for others who have CHARGE Syndrome. Since that time I have been working to find resources to help me conduct research. I'm excited that Spalding University, in Louisville, KY where I received my degree in occupational therapy, is interested in helping me pursue this. We are planning to make this a research project for master's degree students in the 2008 to 2009 academic school year. When I have more information on how to

be a possible participant in this research, I will provide this information through the CHARGE Accounts Newsletter as well as put a post on the CHARGE listserv. I would greatly appreciate participation in this research when the time comes as I hope to help others in their difficult decisions.

Shawn Herrick, mom to Cole - age 3
Louisville, Kentucky

ps: Since this has been written, we are incredibly excited to report that Cole is going on 2 weeks without his trach and doing well.



Online Shopping is coming soon to our website - www.chargesyndrome.org. Check it out!



by Angela Vacca

One evening in March, I went to Wal-Mart with my three kids to try to get a head start on Easter shopping. It turned out to be quite an experience. I was with my three kids: Alissa (CHARGE), who is two, was in her stroller; Steven, who is four quickly scooped out the toy section wondering what toy he can bring home with him; and Matthew, who is seven, totally took my breath away. Here's my story:

Usually, it's "Mom, can we buy a toy?" but on this day it was, "Mom, I'll push Alissa's stroller so you can push the shopping cart." As we walked through the various sections, Matthew periodically checked in on his little sister in her stroller as she slept quietly -- to make sure she's ok. In the past, he was usually playing hide-and-go-seek in the changing rooms having fun.

A little while later, on his third spot check on his little sister sleeping, Matthew said in a panic, "Mom, Mom, look at Alissa -- her hair is soaking wet, and her cheeks are all red, and there is a little bit of sweat on her nose." I looked down and he was absolutely right! He had noticed every little detail! We realized Alissa's jacket had made her so warm that she was sweating and she was soaked. I quickly took her jacket off -- with Matthew's help, and then took her sweater off -- again with Matthew's help. As I pulled her sweater off over her head, her sweaty hair became a mess. Matthew gently brushed it down and blew on her forehead to cool her off. I never said a word. I never asked him to help; he just took it upon himself. He saw his sister in need and wanted to help her. I could see in his face that he felt so badly for her. We continued to walk through the store and every now and then I would turn around and see Matthew stopping to blow fresh air on his sister's little head to cool her down.

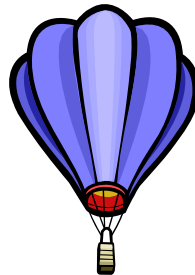


Steven, Alissa, and Matthew Vacca

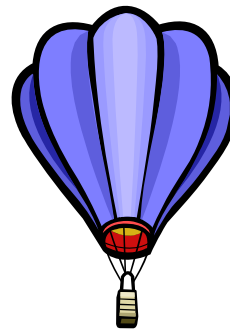
It took everything in me to hold back the tears. Here was a little boy who is usually running through the aisles, hiding in the changing rooms, crying for the 20th Ninja Turtle to add to his collection, begging to buy a candy bar. Here was my seven year old little boy saying to me before he fell asleep that night, "Mom, I like kids with disabilities." I said "Really, why?" "I like to take care of them."

This is why I am truly blessed!

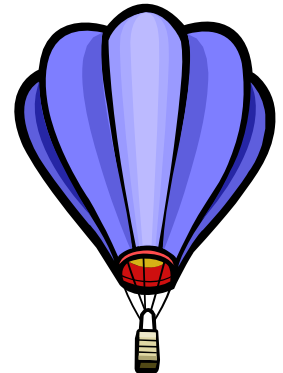
Kindest Regards,
Angela Vacca and Family
Richmond Hill, Ontario, CANADA



Alissa



Steven



Matthew

What's new at the website?

CHARGE Syndrome Professional Packet

Practically every week, we at the Foundation get a request from one professional or another, asking for information on CHARGE. Most often it is a therapist or educator who has or soon will have a child with CHARGE in their classroom or as a client. They want to know many things, including, What is this thing CHARGE? What do I need to know about it? How can I best serve this child? In response to these requests, we have put together a packet of information for professionals. The sections were written by a variety of professionals with many years of experience with children with CHARGE syndrome.

CHARGE Syndrome Professional Packet Table of Contents

Introduction to the Packet	Meg Hefner
1. ASHA Leader Review Article on CHARGE Syndrome	James Thelin (Ed.)
2. Behavior in CHARGE	David Brown
3. Welcoming the Child in the Classroom	Laurie Denno
4. Checklist for Behaviors	Martha Majors and Pam Ryan
5. Physical Characteristics	Maryann M. Girardi
6. Occupational Therapy	Anna Shinkfield
7. Speech and Language Therapy	Lisa Anne Guerra
8. Technical Assistance	Betsy McGinnity
9. Vision	Donna Bent
10. Oral Motor and Feeding	Anna Shinkfield and Lisa Anne Guerra
11. Educational Needs	Martha Majors and Sharon Stelzer
12. Resources for Teachers	Betsy McGinnity

This project was a collaborative effort. I especially want to thank Pam Ryan, who not only helped figure out what needed to be in the packet, but also found professionals to write the sections in a timely manner.

Although we feel this is already a fabulous resource, we know it can be expanded and improved. We need feedback: what works, what is missing (and who do *YOU* know who can write the parts that are missing), what can be improved..... Please keep in mind that this is in no way meant to replace the Management Manual for Parents. It is a supplement for educators and therapists. Send all of your comments and other feedback to me at meg@chargesyndrome.org.

How do you get this packet? It is available for download at the Foundation website www.chargeysdrome.org, at the *Resources* tab, the *Professional Packet*. You can download the whole thing or individual sections. If you need to order a printed version, contact the Foundation. There will be a charge to cover printing and postage on printed versions. Pass this information on to the professionals who work with your children, even those who already have lots of experience!

Meg Hefner, Genetic Counselor and Special Advisor to the Board

EXECUTIVE DIRECTOR'S NOTE

by Marion Norbury

With this issue of CHARGE Accounts, we start our 18th year. So much has changed in the information we provide and the way we prepare, print, and distribute it (Recent copies are now on our website.) The first two years were devoted to the issues represented by the letters in CHARGE; then we began to get wonderful letters from families (Personal Accounts); and we expanded to news from the Foundation (Foundation Account) and articles about CHARGE Syndrome (Corporate Account). Occasionally we have a Special Account feature. I really miss the Personal Accounts. With emails and the internet today, the letters we get are very rare. Maybe you have a story you would like to share, especially with those who do not have a computer or the time to spend at the library searching the internet?

On behalf of the Board of Directors, I want to thank everyone who participated in our Annual Fund Drive. Your support helps us in our efforts to provide information and other resources to our families and those who work with them.

!!! THANK YOU !!!

CALENDAR

2008

May 15 **Deadline for Articles in the Summer Issue**

June 25 **Summer Issue in the mail**

July 11-13 **Charge Syndrome/Deafblindness Weekend
Kingsport, Tennessee (see p. 7)**

October 3-5 **Australasian CHARGE Syndrome
Conference * Christchurch, New Zealand
<http://www.austcharge.com.au>**

2009

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



**Have you visited our website lately
for new information
and helpful links to other sites?**

FOUNDATION ACCOUNT

Education Committee

Lisa Weir, Education Committee Chair

The Education Committee is in the process of deciding on future goals and direction. We would very much appreciate input from the members of the CHARGE Syndrome Foundation with regard to what types of goals they feel would be beneficial for the committee to be pursuing.

Please do not hesitate to bring up an idea; if you are thinking about it, there are likely a number of other families thinking about the same thing. You can contact me at lisa@chargesyndrome.org or by phone at (506) 633-8445 (Atlantic Standard Time).

Thanks in advance!

Foundation Committee Chairs

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Conference - Brownie Shott

Education - Lisa Weir

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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.

Supply Swap Corner

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

It's as simple as: you list it, you provide contact information and then you wait for someone to contact you. The CHARGE Syndrome Foundation may use its discretion in which items may not be appropriate for listing and takes no responsibility for donated items.

Please send a short description of the item you want to donate and contact information to marion@chargesyndrome.org.

Supply Swap

Small green therapy ball and a couple of eye patches that fit over glasses - contact Nancy at csieber001@tampabay.rr.com

Free supportive chair on wheels by James Leckey Design, 6 1/2 years old (you pay shipping). Comes with tray. Chair adjusts as child grows. Cushion covers remove for washing. Contact Jocelyn at jdmjmd@verizon.net

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

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

CHARGE Syndrome/Deafblind Weekend For Families & Professionals July 11th, 12th, 13th 2008

Come One, Come All, for a 2-1/2 day Conference with Internationally Recognized Expert on CHARGE Syndrome and deafblindness- David Brown. David will focus on Sensory Systems, Obsessive Compulsive Behavior, Self Stimulation, Intervention Strategies, and be available throughout the weekend to answer questions from parents and professionals. Free Child Care will be available onsite for children. SibShops will also be provided free for siblings.

Brought to You By: Tennessee/South Carolina Deafblind Projects & NCDB

Where: MeadowView Conference Resort & Convention Center, Kingsport, Tennessee

Contact for information: Jennifer.L.Miller@vanderbilt.edu (615) 322-7194

Are you planning a meeting, get-together, picnic for families this year? Send us the information and we will post it in the next newsletter. We can also help you to reach families in your area. Call 800-442-7604 or email marion@chargesyndrome.org.

Do you have any favorite websites, books, articles, tips that you found helpful and would recommend to others? Let us know about them too.

Remember this is your newsletter. We welcome and appreciate your contributions.

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

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