

CHARGE Accounts



Fall 2008

A Quarterly Newsletter for Families and Friends

Vol. 18 No. 3

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

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2008

UPCOMING FUNDRAISING CAMPAIGN

by David Wolfe, Chair

FUNDRAISING ACCOUNT

The Foundation is about to embark on a new, exciting, email fundraising campaign and we need your help. With the investment in new technology we now have the ability to manage and run targeted email campaigns to reach our friends, family and business colleagues. In addition, we have a state of the art donor management system to better handle the Foundation database. We are going to run customized fundraising campaigns, get better responses and save valuable time and resources.

In the future, the Foundation is going to rely more on email communication. It is faster, cheaper and good for the environment. Whether you see yourself as a future fundraiser or not, please take a brief moment to help us update our email records. Send us a quick email at lorib@chargesyndrome.org with your name and email address.

All of you will be receiving information about the upcoming Fundraising campaign in the next few months. With a computer and less than an hour of your time, you can all make a huge difference in the continued financial success of the Foundation.



In this Issue . . .

Calendar	5	Fundraising Account	
Conference Account		Fundraising Campaign	1
General Information	Insert	International Account	
Scholarship Application	Insert	A Letter from Germany	5
Foundation Account		Order Form/Resources	Insert
CHARGE Syndrome Foundation		Special Account	
Awards	6	Things Learned at Tennessee	2
Editor's Note	7	A Foundation Summarized in 15	
Education Survey	7	Minutes	3
President's Note	7	Thank You's	8
		Websites to Help with Holiday Shopping	4

!!! Deadline for the Winter Issue - November 22 !!!

David Brown's presentation(s) over the 3 days of the TENNESSEE CHARGE Syndrome/Deafblind weekend were absolutely fabulous! The opportunity to hear, converse, and pick his brain in a small, intimate setting was truly a memorable time for me. And his humor and insight is always wonderful! I think one of the best quotes he stated at the beginning of the conference was by Ed Morrow: "Anyone who isn't confused doesn't really understand the situation". The people who work with our children that think there is a cut and dry solution (the "Oh this works with *all* our other children" mentality) really don't understand our children at all.

**Fun Time !**

David stated that CHARGE Syndrome is the most complex syndrome he has seen in the 32 years he has been an educational consultant and teacher. That he has come to have the level of insight into this syndrome that so few professionals reach is truly amazing. I am thankful to have been able to be a part of the weekend that gave me the opportunity to catch a glimpse of what he has come to learn, experience and know about CHARGE.

He also reinforced what I have been telling our daughter's school for years: Kristin's multi-sensory impairment can make her unavailable for instruction due to sensory issues and feeling "unsafe". (School has improved some since they now understand that Kristin is deafblind, even though she is not "legally blind". She has good acuity, but has various visual impairment issues.) Genetics (CHD7 microdeletion) does not affect cognition; multi-sensory impairment can and does impact cognition. In general, this unsafe feeling can lead to lower cognition levels: If a person is trying to keep in control of, or needs more/different input to the senses, that person is less likely to be able to focus beyond those sensory needs, resulting in what many may view as negative behaviors (licking things, hand flapping, etc.). In order for a person to be available to learn, he/she may need a safe rest place – often the person can place him/herself in "time out" when needed - in order to meet the sensory needs. Another aspect of an individual's behaviors and the sensory problems is our own perception of them. We should not attempt to remove compensatory behaviors until their function is established. Hand flapping was a great example David used. If you flap your hands really hard and quickly, then suddenly stop, your hands may feel tingly or heavy. This may be done in order to let the individual know where the hands are in space. It is a compensatory behavior that is viewed in a negative manner, but provides valuable input to the individual. Likewise, stomping or heavy footfalls may tell an individual where the

feet are. (Or in our case, it explains Kristin's preference/need for very heavy shoes.)

During a question and answer session, I asked how one goes about "documenting" senses, especially the vestibular and proprioception senses. How can a quantitative vs. qualitative value be placed on a sense? Schools (and I imagine to an extent, adult services) require quantitative values to be expressed in order to obtain services or sometimes even a diagnosis. Documentation of senses (touch, smell, pain, vestibular function, balance, proprioception) can be obtained through OT observation of what the individual seeks as a "sensory diet".

The sensory diet is comprised of the input sought by an individual to stimulate - or calm - a particular sense (rocking, walking on toes, hard vs. soft touch, etc.). David noted that there is a book and evaluation tool by Jane Korsten called Every Move Counts. Winnie Dunn, an OT in Michigan, also has a Sensory Profile. Utilizing a Vestibular Clinic can give numeric values that will verify OT observations. The best way to evaluate sensory function is to simply step back and observe!

A great sensory tool to use with our kids is a therapy ball chair. Someone noted that Staples will sell families a ball chair for \$7.00 (seven dollars!) instead of the usual \$85 with an OT report or recommendation. I'm sure many of our children have used these during therapy sessions. I've looked for one that would be inexpensive enough that we could have at home, and now I know where to go!

One quote early in the weekend (David was great with the quotes!) was that "...nature is always honest – you have to look at what your question is." Sometimes when we aren't getting the answer we want, we have to phrase the question differently. Always think outside the box! I need to really encourage and challenge Kristin's school to start thinking outside the box more. And that has to start with me rephrasing the questions. David's presentation(s) have given the information I need to be able to accomplish that.

**Jim Thelin and David Brown**

A Foundation Summarized in 15 Minutes!

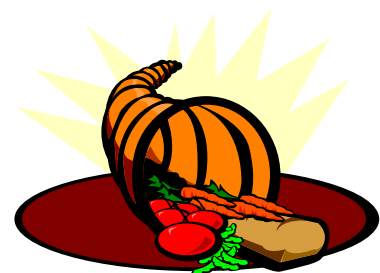
Reported by Marilyn Ogan

SPECIAL ACCOUNT

John Wynne and I had the opportunity to represent the CHARGE Syndrome Foundation at the Tennessee CHARGE Syndrome/Deafblind Weekend, July 11-13, 2008 in Kingsport, TN. We were asked by Jennifer Vick of Project TREDIS to present information about the Foundation to the participants.

In our brief presentation time, John reviewed the mission statement of the Foundation and I quickly noted the milestones the Foundation has accomplished over the last 15 years (Did I have to talk fast!):

- * Opening the new office at HKNC
- * The hiring of Lori Bookstaver to free up Marion for more direct family interaction and CHARGE Accounts preparation
- * Two face-to-face meetings of the Board each year, alternating between HKNC and Perkins
- * Collaborative work with:
 - National Coalition on Deafblindness
 - Perkins School for the Blind
 - State Deafblind Projects
 - Helen Keller National Center
 - National Family Association for Deaf- Blind
 - CHARGE Syndrome support groups in other countries
 - Jim Thelin invited to serve on boards for both NCDB and the "Study on Cochlear Implants for Children Who are Deafblind"
- * Support of research and studies for furthering the understanding of CHARGE (funding and/or mailings to the Foundation's membership):
 - Adolescence
 - Feeding Study
 - Osteoporosis
 - Behavior
 - Growth in CHARGE
 - Survey of Balance & Vestibular Issues
 - Survey of Adults
 - International CHARGE database
- * Development of:
 - Management Manual (including developmental update)
 - Spanish version of Manual
 - New Parent Folder
 - Revised Brochure
 - Professional Packet
 - Fundraiser-In-A-Box
 - Information video added to website
 - Ability to donate to Foundation on-line via PayPal
 - American Sign Language Manual Sign for CHARGE Syndrome (developed and introduced by young adults w/CHARGE)
 - Award and Certificate program to recognize service and/or exceptional dedication to the Foundation or CHARGE Syndrome
 - Increased accessibility of all materials on website (incl. full manual)



* Eight (8) successful biennial conferences

1993	St. Louis, MO	2001	Indianapolis, IN
1995	Portland, OR	2003	Cleveland, OH
1997	Boston, MA	2005	Miami, FL
1999	Houston, TX		
and			
2007	Costa Mesa, CA		
Total Attendees:	625	Professional Attendees:	72
(15% increase from 2005)		(Nearly double from 2005)	
Young Adults/Adults w/CHARGE: . .	27	Speakers/Presenters:	45
15 years of age & under:	177	(in 31 breakout sessions)	
(including 84 individuals w/CHARGE)		(32% increase from 2005)	
(4% increase overall; nearly a 10% increase		Foundation Staff:	2
in number of individuals w/CHARGE)		35 States, Puerto Rico, and nine (9) other countries	
Adult Family/Friends:	302	represented	
(Over 5% increase from 2005)			

[As one can see from these numbers, the Foundation's conferences are reaching more and more individuals, families and professionals. Our Board has taken very seriously the tasks encompassed within the Mission Statement of the Foundation.]

I then asked John to speak about the Lee E. Norbury Memorial Scholarship Fund. He explained what the fund was, and how it originated to honor the support and contributions Lee made to the Foundation (in supporting Marion's work). John then went on to explain – quite emotionally, and most effectively! – what the scholarship had meant for his family and how they attended their first conference only because of being able to access those funds. John expressed that their first conference gave them so much information and additional resources they hadn't known were available. You can see Michelle (John's wife) in the fundraiser/information video, and know that their family felt much of what each of us felt upon getting the CHARGE diagnosis: Shock; fear; a need to know what comes next. The conference gave them tools and knowledge to bring to the professionals in their son's life. John's testimony to the importance of those scholarship funds cannot be measured except by seeing how it has impacted his commitment (and his family's) to his son's betterment and to what the CHARGE Syndrome Foundation can do for its members.

We then put in a plug, naturally, for the 9th International

CHARGE Syndrome Conference to be held July 24-26, 2009 at Indian Lakes Resort in Bloomingdale, IL. Afterwards, I had numerous individuals who enthusiastically stated that they were going to plan on attending the conference. For many, it will be their first experience.

We had a table set up with samples of materials available from the Foundation, including the new Professional Folder. I should have asked Lori Bookstaver to send about two dozen to the hotel! I had to tell several professionals they could download from the website, or contact Lori at the office for additional folders.

One Grandmother, after looking over the Management Manual, stated she was interested in helping the Foundation. She said she could spend many hours getting the manuals into hospitals in her state. Both John and I are involved in the Public Awareness committee, and you can be sure we will be taking advantage of this offer!

I think it was important – both to us as a Board, and to the individuals attending – that the Foundation was present at the TNDB conference. There were some families who had no knowledge of the Foundation. Still others were aware, but didn't know what the Foundation could do, or what resources were available through the Foundation. I hope we can be a much bigger presence at other regional or local meetings in the future.

Websites to Help With Holiday Shopping for Individuals with CHARGE Syndrome

General Guidance:

Buying Toys For Children With Disabilities. <http://www.securityworld.com/ia-118-buying-toys-for-children-with-disabilities.aspx>. The National Lekotek Center, which provides education and information on play for children with disabilities, has established a list of the Top Ten Things to Consider When Buying Toys for Children with Disabilities. This page provides a good overview of things to consider when buying toys for your child -- or a reference you can give to relatives and friends who want to know how to shop for Holiday and Birthday gifts, etc.

Sources for Toys and Therapeutic Items:

Flaghouse, Inc. <http://www.flaghouse.com/shop.asp> *Mission Statement:* To enhance the quality of life for all people, with resources for physical activity, recreation, therapy, and the development and support of life skills. Offers product categories: P.E. and Recreation; Special Populations; Activities for Life; and Sensory Solutions. This site offers a broad range of products at widely ranging prices. Some items are quite expensive and probably intended for use in therapeutic facilities. Others are less expensive and designed to meet several of the challenges people with CHARGE face from infancy to adulthood. Flaghouse, Inc is a multi-national retail business.

TFH. <http://specialneedstoys.com> - *Mission Statement:* We are providers of carefully selected fun products designed to help you or those in your care enjoy life, and achieve more. Use this site and our catalog to stimulate your imagination, begin programs, or reinforce encouraged behaviors, there is a lot that we can achieve...while having Fun. Categories of product offerings parallel those of Flaghouse. However, the highest priced items on the TFH website appear to top out at a significantly lower range than Flaghouse. For the budget-minded Holiday Shopper, TFH even offers options to seek all items costing \$25 to \$50 or less. TFH is based in the UK but offers multinational websites.

Clothing:

Rackety's. <http://www.tanniandanni.com/racketys/adaptivclothing.htm> *Mission Statement:* Rackety's design and sell clothing for adults, teens and children with disabilities. Rackety's is based in the UK and all prices are shown in "pounds".

Iowa State University Extension Publication (Feb. 2003). <http://www.extension.iastate.edu/Publications/PM1911.pdf>. Provides general information on things to consider when buying clothing for people with special needs. It also includes a bibliography of other internet sources for clothing to meet the needs of children and adults.

Dear Marion,

I just want to share a little information about our last CHARGE Conference here in Germany. As you might recall, in 2005 we managed to establish a CHARGE Syndrome, non-profit organization. Ever since we have been working very hard, but, of course, compared with what you're doing in the States, we are working on a much smaller scale. Our goals and objectives are the same, though: giving parents and individuals with CHARGE a platform to meet, exchange, and help each other. It is also a chance to get to know each other and make new friends. We are trying to involve more and more professionals to give them an opportunity to meet more children with CHARGE, bundle their experience, and help our children achieve outcomes at their full potential. Especially in the tracheotomy section this is now functioning very well.

This year's meeting was June 20th - 22nd. This conference was very special because David Brown accepted our invitation to speak. This was our 2nd official CHARGE conference as a registered, non-profit organization. And it was almost an international conference. In attendance was one Australian dad now living in Austria; an Irish dad who lives in Switzerland; and Rosemarie from Chile who attended the 2007 International CHARGE Syndrome Conference in California. It was a very informal meeting located in a Youth Hostel! (Except for David who got some rest in a nearby castle.)

We had a total of 120 participants, 36 of whom were individuals with CHARGE. Our oldest individual with CHARGE is 27 years old. We also had several teenagers. Hormone therapy was a very important theme.

The main presentation Saturday morning was about communication. As parallel programs were individual meetings / clinics with professionals: genetics (medical), feeding problems, Vision impairment (medical), hearing aids and supportive systems (Phonak), nutrition (nurse), tracheotomy (medical). All Saturday afternoon David Brown spoke with simultaneous translation. As I knew before, from my personal experience from 2001 in Indianapolis, David is an eye-opener in showing you a way to understand your child with CHARGE so much better. As I know from a lot of parents, such a conference is an emotional and physical challenge for them. By understanding more about the complexity of CHARGE, they understand also that their journey with this child will never end, even when they are grown up.

What made our meeting so enjoyable was that so many friends were involved. There is our great photographer, Robert Buehler, who always takes hundreds of photos for us. And there's my dear friend, Christiane, who created a special work station. Not to forget Thomas and Joachim who recorded David's lecture. Our primary expense was the big budget we spent in childcare. To be honest, Marion, as you can clearly see, we took the shortcut. We just adapted the fundamental basics of the processes you established over 15 years experience – but on a much smaller scale (German-speaking countries only have a combined population of about 95 million people.)

My initial inspiration and interest in CHARGE was sparked by my adorable child with CHARGE – Lavinia, who appears twice on your promotion video. However, my CHARGE passion started with a scholarship in 2001 – and, I remain impressed by my experiences at that conference.

Many, many greetings,
Julia Benstz

CALENDAR

2008

November 20 **Deadline for Articles in the Winter Issue**

December 15 **Winter Issue in the mail**

2009

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



CHARGE Syndrome Foundation Awards

The CHARGE Syndrome Foundation, Inc. wishes to recognize those who have made significant contributions (individuals, couples, families, groups, or organizations) in any of the following areas:

- (1) To the Foundation and its work with service or financial support,
- (2) To persons with CHARGE syndrome or their families, or
- (3) To the understanding, management, and treatment of CHARGE syndrome.

Recipients need not be members of the Foundation.

AWARDS

Stars-in-CHARGE Award

This is the Foundation's highest award. It is given for significant contributions over a period of time. The award is a crystal star with the Foundation logo and the name of the recipient(s) etched in the award

CHARGE Recognition Award

This is the award given by the Foundation for a very significant contribution in any of the three areas listed above. The award is a plaque with the Foundation logo and the names of the recipient(s) engraved on the plaque.

NOMINATIONS FOR AWARDS

Any person or group may nominate an individual, a couple, a family, a group, or an organization. The nominator is encouraged to submit a well-documented nomination that includes the following information:

- (1) Name and contact information of the nominator(s): address, telephone number, and email address,
- (2) Name(s) of the nominee(s) and contact information: address, telephone number, and email address if possible,
- (3) Description of the nominee(s) and the nominee's service or activities that are to be considered for recognition. A carefully-prepared, thorough nomination will give the Foundation the best opportunity to evaluate the nomination fairly.
- (4) Specify whether the nomination is for the Stars-in-CHARGE award, the CHARGE Recognition Award, or for either award (at the discretion of the Foundation).

However, if an individual wishes to submit a nomination with no supporting information, the nomination will be accepted, but the request may then be made for the individual to assist the Foundation in developing the supporting information.

Nominations are welcome at any time. Traditionally these awards are presented at the International CHARGE Syndrome Conference. Please submit nominations to **Marion Norbury, 2004 Parkade Blvd, Columbia, MO 65202-3121** or to marion@chargesyndrome.org.

by Neal Stanger

Unfortunately I am going to start this article by letting you know that I have accepted the resignation of two (2) of our board members this past month. Donna Lacey and Lacey Friedman have both resigned from the board for personal reasons. Donna was the co-chair of the Adult services committee which Pam Ryan will now be chairing by herself. Lacey Friedman was the chair of the fundraising committee and that will be chaired by David Wolfe. David has not only taken over the committee, but the board appointed him to fill Lacey's term on the board through 2011. David brings fresh thoughts and points of view to the board and I personally look forward to working with him for many years to come.

With just over 9 months left until our next conference I need to stress to you once again how much money we need to run a conference. The conferences cost us over \$250,000 to run and our revenues from registration fees are usually under \$100,000. The Foundation will be introducing a new and easy fundraising campaign shortly and we need all of you to take some time and help us raise some funds. Please see David's article on page 1 to see how you can help.

Thank you once again for supporting the Foundation, and I look forward to seeing all of you in July 2009.

* * * * *

EDITOR'S NOTE

by Marion Norbury

* * * * *

The 9th International CHARGE Syndrome Conference will be at the Hilton Chicago/Indian Lakes Resort, Bloomingdale, Illinois, July 24-26, 2009? Are you interested in attending the conference? Be sure to save the Conference Information insert included with this issue of Accounts. It will help you in your planning. The registration form will be available after the first of the year.

Did you know that the CHARGE Syndrome Foundation provides scholarships for families attending their first International CHARGE Syndrome Conference? The scholarship covers a family's registration fees and/or hotel accommodations. An application is included with this newsletter. The deadline for applying is February 1, 2009.

Beginning next year we will be offering our members a choice of receiving their newsletter by email or through the mail. You will be given an opportunity when you renew your membership to indicate your preference. More on this in the next CHARGE Accounts!

In this issue we have reports on the conference in Germany and the one in Tennessee. I want to invite you to share with us your reports on conferences, meetings, and get-togethers you have participated in. We would like to know about them. The deadline for the Winter Issue is November 20.

* * * * *

Upcoming Education Survey

by Lisa Weir, Education Chair

The Education Committee is planning a couple of new projects and we are looking for some information from families and/or others with an interest in educational issues and CHARGE. We will be conducting an online survey, which should be available by mid to late October. Please check the web site often if you wish to participate. I will send a note out to the CHARGE listserv members but I wanted to ensure we reached as many folks as possible, including people who are not on the listserv. There will be a notification about the survey up at the Foundation web site as soon as the survey is ready to go. The address is: <http://www.chargesyndrome.org>.

Thanks in advance, Lisa

Foundation Committee Chairs

- Adult Services - Pam Ryan
- Collaboration - Jim Thelin
- Conference - Brownie Shott
- Education - Lisa Weir
- Family Services - Marion Norbury
- Fundraising- David Wolfe
- Professional Board - Jim Thelin
- Public Awareness - John Wynne

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.

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

Our Shining Star goes to: Clare's Lemonade Stand - Clare O'Toole, daughter of Dennis & Colleen O'Toole OH

GENERAL ACCOUNT

G. Richard & Constance Goetchius NY
Massry Charitable Foundation Inc. NY
Southside Automotive c/o Timothy &
Darlene Lusher IN
Monica Padilla Froning CA
Robbin & Nick Popowycz WI
Luiz Machado & Carolina Vilalv
BRAZIL
Ann & Clarke Hamilton PA
Colleen & Chris Turpin MA
Employee's Community Fund of the
Boeing Co. IL
Hewlett-Packard Co. Employees DC

RESEARCH ACCOUNT

Dr Jan van Dyk NETHERLANDS

SPECIAL DONATIONS

In honor of a beautiful boy Willie

Reluzco

Katharine Smith NY

In honor of Jordan Saruski's Bar

Mitzvah

Ana Saruski FL

In honor of Marion Norbury & In

memory of Lee Norbury

Kyna A. Byerly MO

In honor of Tyler Matthew's

Birthday

Joseph & Bryony Sysantos DE

In memory of Edward Gray

Lori Corso PA

In memory of Phil Doran, Hunter

Doran's grandfather

Louise Heymen FL

In support of Stanger Family

Better Carting Service c/o Ray

Imperato NY

The *NO CHARGE* Corner

Do you have any supplies that you are no longer using and would like to offer to other 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

Pony Gait Trainer, Size 2, purple. Only pay shipping. It was \$1700.00. You can see one at www.adaptivemall.com. I shipped a Size 1 to California from New York for around \$75 - contact Cathie Josephson at nptqueenie@aol.com.

Small green therapy ball and a couple of eye patches that fit over glasses - contact Nancy at csieber001@tampabay.rr.com or 1-727-724-6166.

Free full-sized suction machine (you cover shipping) - contact Lacey at lacedoxie@yahoo.com

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

*The mission of the Charge Syndrome Foundation is
to provide support to individuals with Charge syndrome
and their families; to gather, develop, maintain and
distribute information about Charge syndrome; and to
promote awareness and research regarding its
identification, cause and management.*