CHARGE Accounts

Summer 2008 A Quarterly Newsletter for Families and Friends Vol. 18 No. 2

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

CHARGE SYNDROME
FOUNDATION, INC.
BOARD OF DIRECTORS
President: Neal Stanger
Vice-President: James Thelin
Secretary: Lisa Weir
Treasurer: John Wynne
Directors:- Lacey Friedman
Donna Lacey - Matt Murray
Marilyn Ogan - Pamela Ryan
Brownie Shott - Lori Swanson

SPECIAL ADVISORS
TO THE BOARD
Meg Hefner
Kathy McNulty

EXECUTIVE DIRECTOR
Marion A. Norbury

ADMINISTRATIVE ASSISTANT
Lori Bookstaver

EDITORIAL STAFF
Marion A. Norbury
Meg Hefner, M.S.

CORRESPONDENCE & MAILING
Marion A. Norbury
2004 Parkade Blvd
Columbia, MO 65202
1-573-499-4694 (voice/fax)
1-800-442-7604
marion@chargesyndrome.org

ANNUAL MEMBERSHIP
Family $15
Professionals $20
Organizations, Institutions, & Libraries $30

WEBSITE
www.chargesyndrome.org

© All rights reserved
CHARGE Syndrome Foundation Inc.
2008

SPECIAL ISSUE CELEBRATING

★ ★ ★
★ ★
★ ★ ★

CHARGE Syndrome Foundation's

15th Anniversary

1993 - 2008

★ ★ ★
★ ★
★ ★ ★

18th Year
of
CHARGE Accounts

Marion Norbury's
75th
Birthday

In this Issue . . .

! ! ! Deadline for the Fall Issue - September 8 ! ! !

Marion is 75, CHARGE Syndrome Foundation is 15

Meg Hefner

This issue of CHARGE Accounts is a celebration of major milestones for the Foundation and one of it's founders. We have notes from Neal Stanger, Foundation President, Jim Thelin, who was in on all of this from the beginning and Marion herself. I mostly just pulled this stuff together and found some photos to go with it.

Since the beginning of CHARGE Accounts, I have been an editor. For the early issues, I gathered the professional information and helped Marion pull together and edit the family Personal Accounts. It was truly a joint effort. As I got busier with "day job" and family, Marion took over more and more. These days, I still edit, but it's more proofreading than pulling it all together. This issue I am again pulling much of it together.

One thing I noticed in reading the accounts from Neal, Jim and Marion, is that each has their own memory of who came up with ideas and how they were carried out. And my version would be different yet again. I was quite amused by this, and decided to leave many of the discrepancies in. When we do an official History of the Foundation, we will go back to the records and argue with one another about which version is closer to the actual events. I noticed Jim left out the part about my making him proofread the booklet as he lay in a hospital bed, recovering from broken ribs! It was a sledding accident and a wonderful thing, as it got him to quit smoking. He wasn't doing anything else – why not some light reading?

It is really hard to get across the significance of Marion's involvement. At first, she offered her house as the mailing address for inquiries about the booklet and helped coordinate the printing and mailing (we mailed one to every genetic counselor in the country back then). Back in those days, she knew a lot about hearing loss, but not about CHARGE. Fortunately for us, she really did not know what she was getting herself, her house and her husband in to. If we had told her it would take over an entire room of her home, many hours on the phone every week, a full mailbox, and on and on, I doubt she would have agreed. And she just happened to have a husband who was knowledgeable about non-profits from his work with Kiwanis, Habitat for Humanity and having worked for the IRS. The Foundation would not have happened without Lee's help, too.

But the CHARGE families are just so wonderful – the stories, the phone calls, the letters – they are so wonderful that we all just got sucked right in and went along for the ride! Somehow we don't mind this adventure taking up so much of our time and energy. You all make it worthwhile. Marion, Jim and I all thank you for making this a wonderful journey.

Marion, Jim and Sandy
1995 Portland Conference

Meg, Marion, and Sandy
1995 Portland Conference

The CHARGE SYNDROME FOUNDATION'S STORY

A FEW OF THE MAJOR MILESTONES

1987 - CHARGE Syndrome: A booklet for Families is published

1988 – CHARGE Questionnaire was developed to determine needs of families

1989 - First issue of CHARGE Accounts is published

1993 - The CHARGE Syndrome Foundation, Inc. is established in Columbia, Missouri

First International CHARGE Syndrome Conference in St. Louis, Missouri (220 people)

1994 - A toll-free telephone number is available

1995 - Second International CHARGE Syndrome Conference in Portland, Oregon (300 people)

This conference included a clinic, from which the revised diagnostic criteria originated

1997 - Third International CHARGE Syndrome Conference in Boston, Massachusetts (350 people)

Expansion of the Board to 12 members

1999 - Fourth International CHARGE Syndrome Conference in Houston, Texas (400 people)

CHARGE Syndrome: A Management Manual for Parents - Part 1 is published

Marion Norbury becomes the Foundation's Executive Director

The Lee E. Norbury Memorial Scholarship Fund is established

The first Stars in CHARGE Awards are presented

The CHARGE Syndrome website is established

2001 - Fifth International CHARGE Syndrome Conference in Indianapolis, Indiana (500 people)

Part 2 (Developmental sections) of the Manual is published

Spanish Version of Manual - Part 1 is published

First CHARGE Syndrome Awareness Week

2002 - Spanish Version of Manual - Part 2 is published

New Parent Folder

2003 - 10th Anniversary of the Foundation 1993-2003

Sixth International CHARGE Syndrome Conference in Cleveland, Ohio (500 people)

Second CHARGE Syndrome Awareness Week

Translation of the Manual into Japanese

2004 -CHD7, the CHARGE gene, is identified by researchers in the Netherlands. They contacted the Foundation with the news before it was published.

2005 - Seventh International CHARGE Syndrome Conference in Miami Beach, Florida (540 people)

Website is upgraded and updated

2007 - Eighth International CHARGE Syndrome Conference in Costa Mesa, California (625 people)

2008 - 15th Anniversary of the Foundation 1993-2008

Professional Packet of Information

President's Note

Neal Stanger

It seems as if I just left California last month off the high of what I feel was our best conference yet. I still can't believe it was a full year ago already. Now I look one year ahead to our next conference in Bloomingdale, Illinois. How do we top that last one? I'll tell you how! We have Brownie Shott chairing the conference. We have Jim Thelin doing the program. We are strongly considering adding another day to the conference for professionals on Thursday, July 23rd. We are most probably going to have our 1st golf outing on Wednesday, July 22nd. We have the Texas CHARGE Family support group running our Saturday evening entertainment (and you WILL be entertained. I just can't tell you how yet). We will have a wonderful, professional day care system set up for the kids, along with a miniature golf tournament on the grounds. There will be many more things going on as well; check the website often for more info on the conference and I promise you that you will not be disappointed.

Now that I teased you with a little bit about 2009, you should know that I am busy with a site selection committee to choose our location for 2011. We are looking at many east coast locations for this conference, and we are already starting to look at west coast locations again for 2013.

As you know in this issue we are celebrating Marion Norbury, but I feel we also need to celebrate the power behind Marion, her dog Patty. Over the past 12 years Patty has been working in the office with Marion as a volunteer for the Foundation; she has always been ready to give a hug when Marion needed one and she also gave her opinions to Marion whether they were asked for or not. Marion started collecting information about CHARGE syndrome in 1983 under a small grant from the Quota Club. When that funding ran out, she kept doing the work out of her house anyway. In the late 80's and early 90's Marion had a vision of putting together a small outing in St Louis for family members to get together. As you are all aware now, this turned into the First International CHARGE Syndrome Conference in 1993 with more than 200 people present. It was such a success that the foundation has been doing it every 2 years since. On a personal note, I am glad Marion is there pushing me as a Board member to do more and more every year. I have known Marion for about 13 years and my respect for her continues to grow annually.

Now let me tell you about some exciting things that the Board has done since you saw us last. We had a Board meeting in Bloomingdale, IL in April, where we had a strategic planner come in to work with our full Board, employees and special advisors. We had a full weekend (30+ hours of meetings over two days) where we all worked with you in mind to become a greater Foundation and a smoother running corporation and I would like to thank Kathy McNulty of NCDB for arranging this for us.

Pumpkin Patty Today

Pumpkin Patty 5 years ago (see p. 11)

A Tribute to MARION NORBURY: The Beginnings of the Foundation
By James W. Thelin

On July 20, 2008, Marion Norbury will celebrate her 75th birthday. The CHARGE Syndrome Foundation will celebrate its 15th birthday. I wish to celebrate Marion's birthday by describing to the members of the Foundation how I have known this extraordinary woman.

About 35 years ago, I was introduced to Marion by my boss – the Chief of Otolaryngology, Donald J. Joseph - at the University of Missouri-Columbia School of Medicine. Marion was active in the Quota Club of Columbia, Missouri – an organization for professional women that was created at a time when civic organizations accepted only men. For several years, through Marion's efforts, the Quota Club helped support Hearing Research at the Medical School. Among other things, the club provided equipment used with the hospital's first electrophysiological newborn hearing screening program.

It was Dr. Joseph who made it possible for Marion, Sandra Davenport, Meg Hefner and myself to come together and for a working group that has never stopped – even though all but Marion had left Columbia by 1990! In the early 1980's our working group began to see patients that the genetic group believed to have a new syndrome. In fact, it *was* a new syndrome that had recently been described by Hall and named "CHARGE" by Pagon and her co-workers. As we were seeing these patients, Meg was repeatedly asked by the parents for something they could read and take home about CHARGE – something for their families and for the local doctors working with their children. We decided we really needed to communicate our growing knowledge to parents and to other professionals who were beginning to see children with this previously unrecognized syndrome.

Meg Hefner headed the effort to produce the first CHARGE Booklet for Families in 1985-86. I went to Marion and asked if the Quota Club of Columbia would be willing to finance the publishing and distribution of the booklet. They published it as a memorial to one of their long-time club members. At first, a few hundred copies were printed. Ultimately, I believe that 10,000 were produced. And, though I may not have the facts straight, I believe they were primarily distributed by Marion from her home at 2004 Parkade Boulevard in Columbia, which was the home of the Central Office of the CHARGE Syndrome Foundation for nearly 20 years. She did all of this with the kind approval and support of her husband, Lee.

At one point, I went to Marion and suggested that maybe we needed to have an organization with a newsletter and meetings. (As an audiologist and a professional, I am obligated to suggest work for others but not actually perform the work myself.) Marion, however, seized the opportunity to work for "our" families and has not stopped for more than 25 years.

From this point forward, the rest of the story is the creation and development of what was to become the "CHARGE Syndrome Foundation, Inc." For a number of years, Marion received all of the calls from parents and professionals -- on her personal phone at home and later via an 800 number but still in her home. Everyone knew Marion. The members of the working group had all moved away and all calls, correspondence, and information were routed through Marion at the "central office."

In 1993, there were two significant events. The First International CHARGE Syndrome Conference in St. Louis was organized by Meg Hefner. This took our organization to a new level. I stood in the lobby of the conference hotel and watched the parade of families who all wanted to meet Marion Norbury in person! The conference was a huge success –even if all of our kids were nearly blown away by a tornado or carried off by a flood.

At that Conference, the second major event was that the Foundation was incorporated. The Board of the Foundation was structured such that Marion and the professionals who had given birth to the organization would play a subordinate role to the parents of children with CHARGE. For Marion and those of us who were involved from the beginning, we knew that the true owners of the Foundation were the parents who had no choice but to "live" CHARGE. However, on the special occasion of Marion's 75th Birthday, I would like the members of the Foundation to take this opportunity to contact Marion and thank her for her role in bringing to life this Foundation that has given so much to so many.

PRESIDENTS OF THE CHARGE SYNDROME FOUNDATION

Steve Sorkin 1993 - 1997
Donna Lacey 1997 - 1999
Bruce Appell 1999 - 2005
Neal Stanger 2005 -

My CHARGE Story

Marion A. Norbury

My personal story is this. I am a native of St. Louis, Missouri and have lived in Columbia, Missouri since 1959. Before CHARGE came into my life, I was a second grade teacher and later the Director of Children's Services at the Daniel Boone Regional Library in Columbia. I was on the Newberry Award Committee the year From the Mixed Up Files of Mrs. Basil E. Frankweiler was chosen for the award. I was married to a very supportive husband, Lee, who passed away in January 1999. The Board of Directors honored Lee by establishing the Lee E. Norbury Memorial Scholarship Fund. (In the early days when calls came in on our home phone, it was often Lee who took your calls); I have four children by marriage, eight grandchildren and two great-grandchildren; and my home is governed by one very spoiled golden retriever - Pumpkin Patty (the most recent in a long line of goldens and other dogs). Her job is to bring in three newspapers a day, to remind me to take time to play with her and relax from my work on the computer, and to sleep the rest of the time. My hobby (avocation) is quilting - although I don't have much time to do it these days. In 2000 I joined the Columbia Golden K Kiwanis Club of which Lee was a charter member and where I now serve as secretary.

My CHARGE Syndrome story began in 1986 when I was a member of the Quota Club of Columbia, Missouri. Quota International is a service organization whose main emphasis is helping the speech and hearing impaired. For several years we had worked with Dr. James Thelin, then the Chief Audiologist at the University of Missouri-Columbia Hospital and Clinics. When we approached him about our desire to find a special project to be done in memory of a Quota member, he suggested that we finance the publishing of a booklet on CHARGE syndrome. Dr. Sandra L.H. Davenport, Meg Hefner, M.S., Dr. Joyce Mitchell, and Dr. Thelin had already been working together for three years studying this syndrome and they recognized that there was a need for a publication written for families. So our CHARGE project was born and I met Meg (Sandy had already moved to Minnesota – I met her later). We printed 1,000 copies of "CHARGE Syndrome: A Booklet for Families" in 1987 and thought they would last for many years. After only 18 months we had to do a reprinting because families would end up asking for multiple copies to give to everyone involved with their child. In late 1989 we published the first issue of CHARGE Accounts as a response to families who asked for more information about CHARGE and a connection with other families (the Internet didn't exist back then).

In the Spring of 1993, I prepared the necessary papers to create the CHARGE Syndrome Foundation, Inc. The families were clamoring to meet each other, so Meg, Sandy and I took the plunge and planned the 1st International CHARGE Syndrome Conference to be held in St. Louis, Missouri, where Meg had moved a few years earlier. We had no idea how many would come (it was at the height of the great Midwestern flood of 1993) so it was a great feeling to have 220 in attendance. Two weeks after the conference, I received word that we had been granted exempt status by the IRS as a 501(c)(3) non-profit organization. That fall, the Columbia Quota Club disbanded and the CHARGE Syndrome Foundation was now on its own. In those days, I worked for another organization three days a week so I spent my two "spare" days filling orders, returning calls, writing letters, maintaining membership records, doing the bookkeeping, preparing the newsletter and working on other projects. It did take a lot of time but it was and is worth it! The letters, the Christmas cards, the calls are so rewarding. While it is difficult for me to grasp all that you are going through caring for your special family member (since I do not have a family member with CHARGE), I do know that you are very, very busy. I am so glad that I can do this and I plan to be involved with the Foundation as long as I am able - helping it to continue to grow. Everything we have done has just seemed to evolve as we added another aspect to the program - the booklet, the newsletter, the conferences, and the manual. It has been a learning process all the way - sometimes it works and sometimes we have to make changes - even drastic ones.

Until 1999, I served as Secretary-Treasurer on the Foundation Board and "CHARGE" ruled my life and still does. At the Board meeting in Houston in 1999 we established the position of Executive Director, the position I held until recently. My new title is Director of Family Services. With the addition of the office in Sands Point, New York to handle the day-to-day tasks, I am freed up to work more with our families and those who are providing them services. Although my title has changed, I am still taking orders, returning calls, writing letters, preparing the newsletter, working on conference details and other projects. One project I want to work on is a detailed history of the Foundation (to be a highlight of a later newsletter); others are the development of regional meetings on the off-conference years and the organization of support groups either by state or region.

In 1989, Jim Thelin sent me a memo (which I still have) suggesting ways the Quota Club could continue to support their CHARGE project. His suggestions were: 1. newsletter, 2. National CHARGE Day (we topped this one with a 3 day International Conference), and 3. CHARGE Hotline 800#. We have done these and more.

Today the Foundation offers:

Information: publications, web site
Four ways to contact the office: mail, 800 #, fax and email
Person-to-person: conferences, parent-to-parent contacts

"Big trees from little acorns grow" is a familiar saying to most of us. No one thought our little Quota Club memorial fund project would grow like it did from the first printing of 1,000 booklets to eight International Conferences, a quarterly newsletter (now in its 18th year), and an ever expanding recognition around the world.

Thank you all for helping us to achieve so much and we look forward to serving you for many years to come.

Marion

p.s. One thing I miss are the Personal Accounts that we included in the earlier newsletters. With the advent of the Internet, emails, and now blogs, we don't get those letters to print in the newsletter. These were the letters and photos families sent us about their child with CHARGE -- describing the problems they had faced, the accomplishments that they had made and ending with words like these:

"In spite of Michael's limitations, he is very lovable, funny, happy, and a joy to have in the family. We believe one day things will greatly change for the better for him, and we look forward to that day."

and . . .

"We waited a longtime for our daughter and thank God for giving her to us. She has taught us a lot about bravery and determination. She has made a wonderful difference in our lives."

and . . .

"I would like to thank everyone involved in producing this newsletter. It was such a God send to receive and was so inspiring to my husband and I. My definition means my son is:

C UTE
H UGGABLE
A DORABLE
R ESILIENT
sometimes **G** RUMPY
but still **E** XTRAORDINARY"

Please send us your personal accounts.

They give other families so much comfort and hope.

Marion and Lee Norbury

Birthday Greetings

Many thanks to you, dear Marion, from one of the older CHARGE Families-the Kenleys-Laura, Jackie & Mac Your smiling face and your dear voice on the phone have been a life saver to all of us! Your devotion and care helped guide us when there wasn't much help out there. Thank you for being such a big part of what has become the Foundation and thank you most of all for caring!

Happy Birthday and Many Happy Returns of the Day!
Sending love,
Laura, Jackie and Mac Kenley

****

It was about the time Kennedy was about a month old that we first found out about the Foundation and made that first phone call. We were so relieved to reach that kind voice of Marion's on the other end of the phone. During what was a very dark time, Marion was like a light to us, as she seemed to be the first one we spoke to who actually *knew* about CHARGE and was going to send us some information. I distinctly remember talking to Marion as one of the points in time where I thought things just might not be as bad as we'd initially thought. I had the pleasure of meeting Marion in 1999 at the Houston conference for the first time (and at every conference since!). On behalf of the entire Weir family, I would like to wish Marion a very happy 75th birthday and thank her so much for all of her time and commitment to the CHARGE community.

The Weir Family ~ Lisa, Graeme, Ryan, Kyle & Kennedy
New Brunswick, Canada

****

While Marion was not my first contact with the CHARGE Foundation, she has become my "go to girl". Marion always has many of the answers I might need and this has been true since my first conference (the FIRST conference). Her seemingly steel-trap mind holds facts and faces that she has been able to call up as reference for an important contact that I would just need to know. "Pamela, have you met_________? " and if the answer is, "No" then my hand is instantly in hers and I am meeting a new family or child.

Marion is also the "Muse of Registration" as families come in and NEED to meet her: the person who led them into the CHARGE family.

I also had the pleasure of meeting Lee and seeing Marion and Lee together was always a warm part of coming to conference--She busily arranging things and he doing what the rest of us did: what she asked us to do! :) in order to make sure things kept moving and got done.

Happy Birthday, Happy Anniversary....and love
Pam Ryan

****

Love & Hugs
Lesley Chan, Supermum to Gabrielle 14, Olivia 12, Fleur 4, Amélie 3
and wife to my very lucky hubby Darren xxxxxx

****

Happy birthday Marion !!!

If it weren't for Marion and the wonderful scholarship set up in honor of her husband we would not have been able to attend our first CHARGE conference in Indianapolis. It was wonderful to see we were not alone and to meet all those wonderful people from the list serve, and even more that weren't on the list! It was an extremely helpful conference; we learned so much. We took away a host of knowledge and more new family members than we could count! Each conference we attend makes that bond stronger and it all started because of a lovely lady named Marion!

Love the Hallorans: Pat, Maria, Timmy, Keegan, and Liam

PERSONAL NOTE

by Marion Norbury

First, I need to apologize for the lateness of this issue of CHARGE Accounts. When the idea of celebrating our Foundation's Anniversary, the 18th year of our Newsletter and my xx Birthday was proposed, it meant a shift in our plans for this issue. We do hope you enjoy it and we plan on being back on schedule with the Fall issue (October 1) which will have information on the 9th International CHARGE Syndrome Conference next July so you can begin making your plans to attend.

Second, I want to thank Meg, Jim and Neal for their stories about the Foundation and my part in its creation. Back in 1986, we had no idea that we would be where we are today and there is so much more that we want to accomplish. With your support we will do it.

Third, I want to share **Pumpkin Patty's Story**. So if you are not a dog lover, please move on to the next section.

Neal, Meg, Jim and I all mentioned a certain golden retriever named Pumpkin Patty. Patty was born on October 28, 1006. She came home with us on a cold, rainy night in December and quickly took over our lives. She was two when my husband died on January 1, 1999 and since then she and I have been a family. She is my fourth golden and by far, the one that understands words the most. She also understands my moods and when I am sad or upset, she will come from the other room to sit by me or lean against my leg.

FOUNDATION ACCOUNT

In 2003 when we were at the conference in Cleveland, Ohio, I received a message that Patty's rear end was completely paralyzed and I left the conference early Sunday morning to return home. We were fortunate that we lived in Columbia where we have a great College of Veterinary Medicine and where Patty received the best of care. Although she had never been boarded outside the home before and I was concerned that she would be traumatized by what was happening, Patty thrived on all the attention (especially in the ICU). She never gave up and kept trying to stand up. I was able to visit her almost every day and the staff told me they knew when I had arrived by the way Patty acted.

At the end of the first week, there was a little movement in her back leg and her tail. 7-1/2 weeks later after receiving physical therapy, water therapy and lots of TLC, she came home with a doggy cart (see p. 4). Five years later, the cart is hanging in the garage and the tires are flat. We were the lucky ones. Many dogs do not make the recovery that Pat did. Today, she still carries the mail and papers and reminds me to stop and take a break although it is more difficult for her now to get up without help. Thank goodness she has a big, strong tail so I can give her the boost that she needs. Patty is almost twelve years old now and hopefully she will be with me for a few more years. Meanwhile we are a team and will continue to do all we can for the CHARGE Syndrome Foundation.

The *NO CHARGE* 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

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

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

Foundation Committee Chairs

Adult Services - Donna Lacey & Pam Ryan

Collaboration - Jim Thelin

Conference - Brownie Shott

Education - Lisa Weir

Family Services - Marion Norbury

Fundraising- Lacey Friedman

Professional Board - Jim Thelin

Public Awareness - John Wynne

All board members have a special email address:(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.

CONFERENCE ACCOUNT

Programs at the 2009 CHARGE Syndrome Conference for Individuals with CHARGE, Parents, and Professionals

July 24-26, 2009

James W. Thelin, Conference Program Chair

With each succeeding CHARGE Conference, the programs have expanded in response to the rapidly expanding knowledge base and the demand for information to meet the needs of individuals and families. At the 2007 Conference, we focused on the needs of the adolescents who are transitioning into adulthood. This is an area in which we have just begun to scratch the surface and it will be emphasized again in 2009. There will be special programs for adolescents and adults with CHARGE as well as presentations directed at parents of individuals in these age groups.

Professional Conference

A major change for 2009 will be the addition of a full-day Professional Conference on Thursday before the main part of the conference begins. In the main conference on Friday, Saturday and Sunday, speakers and topics are selected because of their appropriateness for families and individuals with CHARGE. The Professional Conference will be a forum for professionals to present to other professionals using scientific, medical, and educational terminology and methods. One of the unique aspects of the Foundation has been that it has been actively involved in the development and dissemination of knowledge about CHARGE not only to individuals and families, but also to professionals. At this time, there is no meeting devoted to CHARGE in which the professionals have the chance to exchange information among themselves. Individuals with CHARGE and their parents are invited to attend (space permitting?) – with the realization that the purpose of the meeting is to deal with general issues and not the needs of specific individuals. For all who attend the Professional Conference, there will be a separate registration fee; CEU's may be available for some professions; and child care will not be available.

In addition to the programs discussed above, we will do our best to continue to provide information to address the medical, sensory, behavioral, educational, social, vocational, and recreational needs in every age group.

Would you like to present in 2009? Informal call for papers

If you are an individual with CHARGE, a parent, or a professional who is interested in presenting at the 2009 Conference, I would like you to contact me and provide me with an informal description of your topic and tell me how I can best contact you. There will be platform presentations and posters that can be presented as a part of the main conference or the professional conference. There will also be opportunities for booths promoting organizations or products. There may be opportunities to conduct research on individuals with CHARGE at the conference.

Contact me at jthelin@utk.edu.

Over the past several months, I have received several inquiries about the 2009 program to which I have not responded. To those who did not receive responses, I will be responding to you over the next month or so. Please accept my apologies.

Within the next month or so, a more formal call for papers, posters, and presentations will be sent to every individual who is known to the Foundation who has presented in the past. The proposals will be reviewed by a committee of professionals and parents and notification will be made to prospective presenters. We have a wonderful hotel with a lot of space for this conference, giving us a great opportunity for the transmission of information to all those who attend. We look forward to your participation.

CALENDAR

2008

September 8	**Deadline for Articles in the Fall Issue**
October 1	**Fall Issue in the mail**
October 3-5	**Australasian CHARGE Syndrome Conference * Christchurch, New Zealand** http://www.chargesyndrome.org.au/

2009

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

FUNDRAISING IN A BOX

Alli Stahl

Nate and Scott Stahl

I would first like to introduce my family. Nate was born April 2004. As soon as he was born, we knew many things were wrong. He had many surgeries and procedures, but was not officially diagnosed with CHARGE until June of 2006! Nate is four years old and he is doing so well. He is a fun, active, easy going little guy. He is busy learning sign language and loves to ride his tricycle. Scott and I are so proud of Nate. We also have a 17 month old son named Jake. Jake loves to challenge Nate and Nate is learning to love his little brother.

Last year I read an article about the fundraiser in a box. We decided we wanted to raise some money and awareness for the CHARGE Syndrome Foundation. Our fundraiser was a huge success! We raised over $2,200! It was so easy. Everything you need comes in a box with instructions.

We had another added bonus at our fundraiser. We were able to meet the Lee Family. Brenda, Bailey's mom, and I have been talking and supporting each other over the phone for a few years now. We were so excited to finally meet each other in person. It was also great for our family and friends to meet another child with CHARGE.

I would highly recommend this fundraiser for all families. Not only are you able to raise money and awareness, but the support and love you will feel will overwhelm you! Scott and I are so blessed and we were so glad we could help raise money and educate our friends and family. Feel free to give me a call if you have questions or need help planning your fundraiser. We need to do all we can to help this Foundation grow and this is an easy way to do that. Hope to meet all of you in Chicago next summer at the conference!

Alli Stahl
Colona, Illinois
309-441-5618
army1993@mchsi.com

Raise Funds for the CHARGE Syndrome Foundation!

Have a Pizza Party and Have Fun!

The Stahl and Lee Families

FUNDRAISING ACCOUNT

THE HEARTS PROJECT

Introduction

Marion A.Norbury

This past school year, the third grade class at the Sunshine Elementary school in Springfield, Missouri created a poster for their Hearts Project. The purpose of the project was for the children to do something for others. They chose to do this for the CHARGE Syndrome Foundation because one of their classmates had a brother who has CHARGE. A flyer was prepared and 75 copies of their poster were printed. For a contribution of $5.00, one received a poster.

On May 30, on the last day of school at the school awards/recognition assembly, Andy Lewis, representing the Foundation, was presented with the class' donation of $200.00. Andy and Martha Lewis live in Springfield, Missouri and are the parents of Katie, a young woman who has CHARGE. Katie is 24 years old. We want to thank Eduardo Flores, the PTA President who came up with the idea of "The Hearts Project" and the class for selection our Foundation. (I now have a copy of the poster hanging by my desk.)

The Flyer

Mrs. Downing's 3rd grade class is happy to announce the first ever "The Hearts Project". This was an effort to introduce a service project to the students by incorporating art, writing and generosity. Mrs. Downing asked her students to think of charities they would like to support.

The students performed online research and wrote persuasive papers. The papers were read to classmates and the students voted for their top choice. Mrs. Downing incorporated the persuasive paper writing exercise in her class preparations for MAP testing. (Note: MAP = Missouri state assessment program)

The children voted to support the CHARGE Syndrome Foundation. CHARGE syndrome is a recognizable (genetic) pattern of birth defects which occurs in about one in every 9-10,000 births worldwide. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. The vast majority of the time, there is no history of CHARGE syndrome or any other similar conditions in the family. Babies with CHARGE syndrome are often born with life-threatening birth defects, including complex heart defects and breathing problems.

To create the beautiful poster displayed above, the students, at the direction of Sunshine's art instructor, Mrs. Nimmo, cut out hearts and placed them on watercolor backgrounds. The result is a colorful, original piece of art, suitable for framing. To complete the project, a representative from CHARGE, will be joining Mrs. Downing's class, to accept the proceeds from the sale of the poster.

You can own one of these bright, colorful posters and help Sunshine Elementary students support the CHARGE Syndrome Foundation. Posters are only $5 and all proceeds go to the Foundation. To obtain a poster, please send your donation in an envelope marked "The Hearts Project" to your child's teacher with the enclosed order form. Thank You!! for your support of this project.

……

Teacher's Name: ____

Child's Name: ____

Quantity of Posters: ______________

Checks made Payable to: CHARGE Syndrome Foundation

SOME OF LACEY'S FAVORITE BOOKS

Lacey Friedman has sent us a list of her favorite books. If they are not available at your library, ask them to locate a copy through inter-library loan. You can find out more about a title on the web sites of these bookstores: i.e. Amazon, Barnes & Noble, Borders.

Adam, God's Beloved by Henri J. M. Nouwen 1997

Changed by a Child by Barbara Gill 1998

Chicken Soup for the Soul: Children with Special Needs: Stories of Love and Understanding for Those Who Care for Children with Disabilities by Jack Canfield, Mark Victor Hansen, Heather McNamara, Karen Simmons 2007

The Child With Special Needs: Encouraging Intellectual and Emotional Growth by Stanley I. Greenspan, Serena Wieder, Robin Simons 1998

Deaf Daughter, Hearing Father by Richard Medugno 2005

The Elephant in the Playroom: Ordinary Parents Write Intimately and Honestly About the Extraordinary Highs and Heartbreaking Lows of Raising Kids with Special Needs by Denise Brodey 2007

From the Heart: On Being the Mother of a Child With Special Needs by Jayne D. B. Marsh 1994

From Emotions to Advocacy: The Special Education Survival Guide by Peter W. D. Wright and Pamela Darr Wright (Wrightslaw) 2006

Grief Recovery Handbook by John W. James and Russell Friedman 1998

Journey Through Heartsongs by Mattie J. T. Stepanek and Jimmy Carter 2001

Playing the Hand That's Dealt to You by Janet Morel and Francois Poisson 2000

Reflections from a Different Journey: What Adults with Disabilities Wish all Parents Knew by Stanley Klein and John Kemp 2004

Resilient Family, Living with Your Child's Illness or Disability by Paul W. Power and Arthur E. Dell Orto 2003

Shut Up About...Your Perfect Kid! (Shut Up About. . .) by Gina Gallagher Patricia Konjoian 2007

Special Kind of Love, For Those Who Love Children with Special Needs by Susan Titus Osborn and Janet Lynn Mitchell (Paperback - Jan 2004)

Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child With a Disability by Robert A. Naseef (Paperback - Jul 2001

Special Kids Need Special Parents: A Resource for Parents of Children with Special Needs by Judith Loseff Lavin 2001

You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children With Disabilities by Stanley Klein and Kim Schive 2001

Editor's note: Do you have a favorite book(s)? Let us know so we can include it next time. Email marion@chargesyndrome.org.

We send congratulations to our member in Australia - - -

MARIE PATTERSON

On June 9, 2008, many members of the British Commonwealth were honored by the Queen of England on her birthday. In Australia, the Order of Australia Medal was presented to **Marie Patterson** for her service to the community through the Australasian Charge Syndrome Association.

Marie Patterson is the mother of Julia Patterson who has CHARGE Syndrome. Julia, was one of the first children in Australia to be diagnosed with the syndrome. The Pattersons live in Glenwood, NSW where Marie and her husband Ken have worked for the past 18 years helping other families in Australia, serving as officers in the CHARGE Syndrome Association of Australasia and organizing their biennial conferences (in the even years). The entire Patterson family attended the 1993 Conference in St. Louis, MO, Julia's picture was on the title page of our first brochure and Ken joined us at our 2007 Conference.

Marie, this honor was much deserved and again we congratulate you.

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

Our Shining Stars go to:

In honor of the Founders of the CHARGE Syndrome Foundation, Inc. - A Thank you from Shawn, Raymond & Cole Herrick who held a Golf Tournament called "Cole's Classic" last September
Mount St. Michael Academy Students Fundraiser
Ardrey Kell High School-HOSA Club held a Walk-A-Thon
In honor of my little princess Layke Wachholz - Lance Wachholz
Alli & Scott Stahl hosted a "Fundraiser in a Box" Party

GENERAL ACCOUNT

Heart of West Michigan United Way MI
Hewlett-Packard Co. Employees DC
VIP-Solutions IL
Great Aunt Ruth & Rita IL
Eric Bluestone NY
Michee Cadhit Makati
Lyn Carmichael IL
LL Trucking IL
Greg & Susan Chenoweth IL
Chuck & Marie Donaldson IL
Millicent Edusei NY
Jackie Epperly IL
Lacey Friedman CA
GE Foundation Matching Gifts CT
Judy & Ray Grimes TX
Meg Hefner MO
Mary L. Kramer MO
Craig & Tricia Henkhaus IL
Roger & Elaine Hodel IL
Jennifer Johnson IL
Gary W Joyner IL
Steve & Sarah Kautz IL
Jerry Knobloch IL
Sandra Koutouvidis IL
Nicholas Kozey NY
Gary Krampf NY
Richard & Ann Kube IL
Chris Kuster IL
Marilyn Martin IL
Robert & Dawn McNabb IL
Lindsey & Tony Munson IL
Claire Newman IL
Monica Padilla Froning CA
Dan & Gina Pearson IL
Marilie & Gerry Pfeiffer IL
Nancy Platania IL
AJ & Rebekah Reynolds IL
Glen & Christy Sancken IL
Larry & Judy Schulte IL
Brett Smith CA
Dustin Smith IA
Lyle & Gail Smith IL
Terry & Catherine Sommers IL
Greg Stahl IL
Lisa Stahl IL
Eldon & Irene Stahl IL
Melva Strang AL
Kristi Swann CA
Robin Testerman VA
Mike & Marcy Volkstorf IA
Ken & Pam White IL
Kevin Winslow IL
Martin Wyler NY
David & Mary Wynne-Peaspanen OH
Kim Zeigler KY

CONFERENCE ACCOUNT

Sabrina & Eric Bluestone NY
Maryann Girardi MA
Joanne Lent NJ
Yuka Persico CA
In honor of Clare O'Toole
Nancy M. O'Toole OH

RESEARCH ACCOUNT

Maria D. Rodriguez CA
In memory of Meghan Graham
Julie & Don Graham MD

SCHOLARSHIP ACCOUNT

Cathie Josephson NY
Sharon Stelzer MA

IN HONOR OF

Alexander Mousouris
Barbra Mousouris CA
Caitlyn McMullen
Jeanne & Michael McMullen PA
Cheyenne Brittell
Irene & Jim Lucas CA
Debby Kern
Ken Budd NC
Christian Lee Roberts' 6th Birthday
Janet & Nick Perone TX
Donny & Bekkie Cobb TX
Emma and Eli Bluestone
Sherie Coyner NY
Erika Feather
William Muir PA
Lucas Vasquez
Julia Ritter CA
Makenzie Dougherty
Elizabeth McKnight OH
Michael Rivers
Barbara Rivers MN
Mr & Mrs Ken Sayce
Dr. & Mrs. James H Bowden Jr VA
Clare O'Toole
Rocky River Junior Women's Club OH
Thomas DiCristofaro
Arline Kennelly PA

IN MEMORY OF

Daisy Donivan
Jennifer Elfalan VA
Jack & Betty Brown CA
Bernard Wozniak CA
Mr. & Mrs. Gene Hauser CA
Albert & Marilyn DiNicola CA
Donald Bodenstein
The Bodenstein Family, friends of the Katapodis Family NY
Dorothy "Dot" Benson
Bill & Sherry Hartman TX
Katherine Rose Thelin (Granddaughter of Dr. & Mrs. James W Thelin)
Kay & Drew Gross TN
Dept of Audiology & Speech Pathology University of Tennessee TN
Matthew R. Tilton
Marilyn & Art Herbert FL
Lisa McPherson SC
Alice King NC