

CHARGE Accounts



Winter 2005

A Quarterly Newsletter for Families and Friends

Vol. 15 No. 4

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: Dennis O'Toole
Treasurer: John Wynne
Directors: Bonnie Haggerty
Susy Morales - Matt Murray
Marilyn Ogan - Brownie Shott

SPECIAL ADVISORS
TO THE BOARD
Bruce Appell
Meg Hefner

EXECUTIVE DIRECTOR
Marion A. Norbury

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

CORRESPONDENCE &
MAILING
Marion A. Norbury
409 Vandiver Dr Ste 5-104
Columbia, MO 65202
1-573-499-4694
(professionals & fax)
1-800-442-7604 (families)
marion@chargesyndrome.org

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

WEBSITE
www.chargesyndrome.org

© All rights reserved
CHARGE Syndrome
Foundation, Inc. 2005

Holiday Greetings

to all our

families and friends

from

the

CHARGE Syndrome

Foundation



In this Issue . . .

Calendar	6	Manual Revision	4
Corporate Account		President's Note	3
Botox Use in CHARGE Syndrome	4	Order Form/Resources	Insert
Choosing Toys	5	Personal Account	
Foundation Account		CHARGE Syndrome Fundraiser	2
Committees	3	Thank You's	5
Executive Director's Note	3		

YOUR HELP IS NEEDED!

Please share your stories, parent tips, questions, book reviews and suggestions for other features you would like to see included.

Remember this is your newsletter!

!!! Deadline for the Spring Issue - February 15 !!!

CHARGE SYNDROME FUNDRAISER - TEXAS STYLE

by Molly Roberts

PERSONAL ACCOUNT

Three and one half years ago our little boy, Christian, was born and diagnosed with CHARGE Syndrome. He was born in Dallas Fort Worth, a large metroplex, yet most people had not heard of CHARGE Syndrome and many doctors had only read about it. When I discovered that CHARGE Awareness Week was in July, I wanted to do whatever I could to bring attention to these remarkable individuals and possibly raise funding for the CHARGE Syndrome Foundation.

First I mailed support letters to all our friends, family, doctors and anyone who may have heard of Christian. I asked for support in all areas, including contacts, advice, prayers and donations. We decided to do a vendor extravaganza complete with snow cones, cotton candy, kettle corn and bounce house. I worked very hard at pulling together over 30 vendors who all paid a small fee to take part in the event and they all agreed to donate a percentage of their profit. I contacted several local newspapers and five of them published articles with pieces about CHARGE Syndrome, Christian's life and the Fundraising event.

It was amazing to see our community rally with support. A printing agency donated 4000 colored copies, another company donated an enormous banner, a local church donated the venue, a local store donated balloons, several businesses and individuals donated to the silent auction, over 20 stores welcomed donation canisters and flyers, local high school students held posters and many people volunteered their time.

Two weeks before the event several friends and family helped waitress at a local drive in restaurant. We all wore CHARGE t-shirts and handed out flyers for the event. We raised over \$1000 in tips, which helped fund the event. Therefore ALL money raised on the day of the event went to the CHARGE Syndrome Foundation.

The Vendor Extravaganza was a HUGE success!! We raised over \$6000. But, most importantly, we were able to hand out brochures about CHARGE Syndrome and share Christian's personal story with several individuals who had never heard of CHARGE. We are very excited about our next fundraiser. We have learned a lot and look forward to the 2006 Vendor Extravaganza being BIGGER and BETTER.

I hope you will have the opportunity to raise awareness in your own community. It truly is a rewarding experience!

Molly Roberts
Lewisville, Texas



Editor's Note:

Other ideas for fundraisers:

Ask family and friends to contribute to the Foundation in honor of someone's birthday, anniversary or other special occasion.

Sponsor an activity at school or in your community. For example, recently a Mom wrote us about her son's school who had a "Tag Day". The children were allowed to dress out of uniform in return for a donation to the Foundation. Others have sponsored a walk, a golf tournament, or a letter campaign.

If you have fundraising suggestions, please send them to the foundation office. Thanks.



Christian Roberts - 3 years old

Mark Your Calendar !
Eighth International CHARGE Syndrome Conference
July 27 - 29, 2007
Costa Mesa, California

Hello everyone,

I hope everyone is having a wonderful holiday season and I would like to wish all of you a happy and a healthy new year. We are ending 2005 with some big events. We have just redone our website at www.chargesyndrome.org. I would like to thank Jay Brandrup and his staff at Kinetic Communications for their tireless work on rebuilding this site for us. We have also recently announced the dates for our next conference. The 8th International CHARGE Syndrome Conference will be held July 27 – July 29, 2007 in Costa Mesa, California. We are pleased to be going back to the West Coast for the first time in over a decade.

This coming year should be a very exciting year for the Foundation as well. We have just created a new position called “Special Advisor” These Advisors will be appointed by the President with the advice and approval from the entire Board.

Our first Advisor to the Foundation is Meg Hefner. Meg has officially stepped down from the Board of Directors to become a Special Advisor. We know that all members of the Foundation will benefit greatly from her advice and guidance in the years to come. For those of you who do not know Meg, She is a Genetic Counselor at Saint Louis University. She was one of the founding members of the CHARGE Syndrome Foundation in the early 90's and was the primary organizer of the first several conferences, starting with the St. Louis conference in 1993. Meg has been on the Board of Directors for 12 years and has held positions such as Vice President, Conference Chair, Professional Advisory Board Chair and Research Committee Chair (a position she will continue to hold). Bruce Appell has accepted a Special Advisor position as well. Bruce was on the Board of Directors from 1997 to 2005 and served as Board President from 1999 to 2005.

Please remember that the CHARGE Syndrome Foundation is here for you. If there is anything you would like to see the Foundation do or be involved in, please let us know and we will do our best to meet or exceed your expectations.

I hope to see you all in California in 2007,
Neal Stanger

**EXECUTIVE
DIRECTOR'S NOTE**

Marion Norbury

Time to Renew Membership

It is time again to renew your membership in the Foundation. All membership terms are on a calendar year - due in January and running out the following December. Check your mailing label or your membership card. If it says 2005, your 2006 membership fee is now due. You may use the membership form that is included with this newsletter. A self-addressed envelope is enclosed for your use. Please renew early. Remember to make note of any changes in your address, phone numbers, or email. If this was your first year as a member, you were credited for the year 2005. So whether you joined in January 2005 or July 2005, you need to renew now for 2006. Membership renewals are due by March 1 to receive the Spring Issue of CHARGE Accounts.

Did you notice that this is the 60th Issue of CHARGE Accounts? That's 15 years that we have been publishing this newsletter! It has changed a lot over the years and we hope that you have found it informative and a source of hope.

Remember, this is your newsletter. Please let us know what you would like to have included. We also welcome your stories, parent tips and questions.

At our Board Meeting in October, the committee structure was revised. For a description of what each committee is responsible for, please go to the web site www.chargesyndrome.org, contact the chairperson or the Foundation Office.

Conference Committee

Chairperson: Marilyn Ogan

Fundraising Committee

Chairperson: Dennis O'Toole

Medical/Research Committee

Chairperson: Meg Hefner

Family Services Committee

Chairperson: Marion Norbury

Adult Services Committee

Chairperson: Bonnie Haggerty

Education Committee

Chairperson: Suzy Morales

Collaboration Committee

Chairperson: Neal Stanger

Public Awareness Committee

Chairperson: 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.

Manual Revision-We Need Your Help!

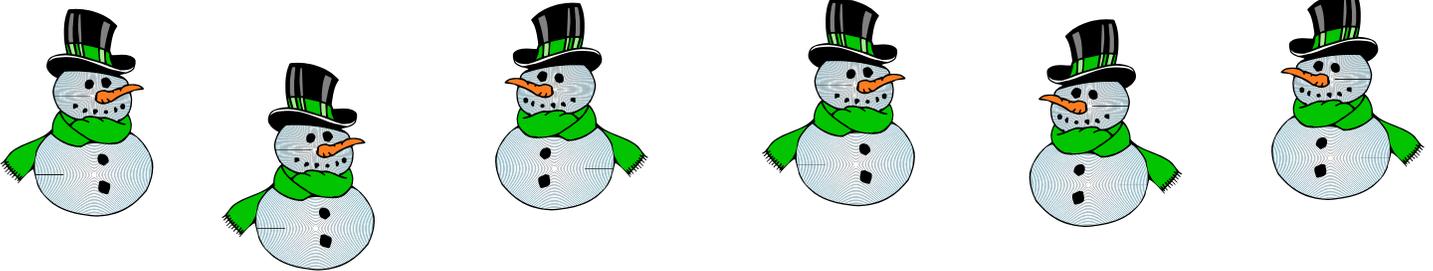
FOUNDATION ACCOUNT

The Charge Syndrome Foundation office is beginning the process of revising our manual- CHARGE

Syndrome: A Management Manual for Parents. The current version is from 2002, so some changes are in order. We would appreciate any feedback you can offer us on the current version of the manual. What information is missing? What areas need more information? What do you love? What do you hate? Are there new sections that would be helpful? Are there resources missing? Do you have experiences that might help others? Do you know of therapies or medications which may help?

We would love to hear from parents of children of all ages, as we know your needs change over time. Please email Kyna at: kyna@chargesyndrome.org with your thoughts. If you do not have email, you can mail us a note, or give us a call. Our hours are Mon., Wed., and Fri. from 9-1 pm central time. We want the manual to be the best resource possible, and for that we need input from those who use it. Thank you for your help!

And finally, we will let you know through the web site and the newsletter when the updated version is available. This process will probably take several months so be patient. We will keep you informed on our progress.



Botox Use in CHARGE Syndrome Prevents Tracheotomy

CORPORATE ACCOUNT

Health Day News, an online news publication at www.healthday.com, reported in September that Botox was used to prevent a baby with CHARGE Syndrome from undergoing tracheotomy to drain excess saliva from his lungs. They report a Montreal otolaryngologist injected Botox into the salivary gland of the one-month-old, whose saliva was accumulating in his lungs and constricting his breathing. Within 10 days of the injection, the baby was taken off the ventilator he had needed to breathe, and went home. Dr. Sam Daniel, director of the Saliva Management Clinic at Montreal Children's Hospital, performed the procedure. As many parents of children with CHARGE syndrome know, the normal procedure to treat the excess saliva is a tracheotomy, a surgery where a tube is placed permanently in the throat so that saliva can be regularly suctioned from the lungs by a machine attached to the tube.

According to the article, Dr. Daniel successfully paralyzed a major salivary gland, but left the smaller glands intact so the baby's mouth was left moist. Botox's effectiveness lasts for about six months, so the infant underwent a second injection after 6 months and is reported to continue to do well. According to a quote from Dr. Daniel, the major benefit to this procedure is that there is another option to offer kids who have excess saliva secretion necessitating intubation. He believes this is worth a try before offering something more invasive. They report this is a procedure that has been very commonly done over the last five years, and there are good studies on it, but what is unique in this case is the age of the patient. The difficulty is in knowing exactly the dose to use as Botox can be toxic. It is encouraging to see that this procedure may be able to be used in younger patients, particularly those with CHARGE Syndrome. Families may wish to explore this option with their physician. For the complete article, see www.healthday.com.

by Kyna Byerly



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

General Fund

Charge Across America

Charles T. Chandler CO

John and Deborah Chandler OH

In honor of Megan Stanger

Lauren Elliott NY

In honor of Katherine Broich

Ida Lou Dawson WV

In honor of Neal Stanger's 40th Birthday

Alison and Bradley Walter RI

Friends of Molly & Derrell

Roberts

Jennifer McLaughlin TX

Jose Ceja TX

In memory of Rosa Saruski

Jorge and Pilar Martinez AL

Sara and Rafael Kapustin FL

In memory of Will Spanfelner

David and Kathleen Spanfelner

CA

Bill & Sandy Muir PA

HR Curtis TX

Allstate Giving Campaign VA

United Way Kitsap County

Employees Community Fund of
the Boeing Co WA

Conference Fund

Family and Friends of Susy &

Sergio Morales

Lisette Alverez FL

Luis Prieto FL

Orlando Collazo FL

Ann J. Martinez-Torres FL

Carolyn Guerra FL

Maite Garcia FL

Juana Sanchez FL

Denise Pena FL

Carlos Mier FL

Cristina Martinez FL

Harry Raskin, Inc FL

Admiral International FL

Maria Mosienko FL

SPF Investments Inc FL

Allied Property Group Inc FL

Juana Barbosa FL

Brian Enriquez FL

Horizon International FL

Maribelle Day Spa, Inc FL

Family and Friends of Ana & Michael Saruski

Hialeah Dental Health FL

Oscar and Ana Sklar FL

Erica and Suzanne Kahn FL

Judy Loft FL

Rafael and Rebeca Kravec FL

Kevin Moore CA

Cathy Lyle MN

Thank you all

CHOOSING TOYS

Recently on the CHARGE List Serve, a Mom asked for suggestions on selecting toys. She was seeking ones that would work with her child's therapies. Although it may be too late to use these tips for this holiday season, I'm sure there will be other opportunities during the year when you may find them helpful.

Here are three web sites with ideas.

The AblePlay Rating System can be found at www.ableplay.org. The system provides a snapshot of the toy's appropriateness for children with special needs. At the heart of the AblePlayT Rating System are the comprehensive AblePlayT Toy Reviews. These reviews detail the "hows and whys" of each product, specifically for children with disabilities

Toys "R" Us puts out a catalogue at Christmas time geared towards children with disabilities. The pictures are of children with special needs and the descriptions tell you if it is good for hearing, vision, ambulatory, balance etc. The catalogue is called "Guide for Differently Abled Kids!" Search the internet for Toys "R" Us or click on www.amazon.com.

The National Lekotek Center, a nonprofit dedicated to using toys and play as a way to fully include children into family and community life, has a list of questions that their experts use in choosing toys. They ask about such things as multisensory appeal, safety and durability, self-expression, and potential for interaction. Their web site is www.lekotek.org/.

Another good resource for trying out toys is your state deaf-blind project. They may have a lending library for you to use.

And be sure to consult with your therapists on what they think your child needs to explore, ask to see the catalogues that they receive, and then use their guidelines when you shop.

CORPORATE ACCOUNT

CALENDAR

2006

February 15	Submit items for next issue of CHARGE Accounts
March 1 March	Membership Renewal by this date Spring Issue of CHARGE Accounts
May 15	Submit items for next issue of CHARGE Accounts
June	Summer Issue of CHARGE Accounts
August 15	Submit items for next issue of CHARGE Accounts
September	Fall Issue of CHARGE Accounts
Sept.29 - Oct. 17th	Australasian CHARGE Syndrome Association Limited Conference, Novotel Twin Waters Resort, Sunshine Coast, Queensland. More details: www.austcharge.com.au
November 15	Submit items for next issue of CHARGE Accounts
December	Winter Issue of CHARGE Accounts

2007

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

❄ ❄ ❄ **IT'S TIME TO RENEW** ❄ ❄ ❄

❄ ❄ **YOUR MEMBERSHIP** ❄ ❄

❄ **FOR 2006!** ❄