

CHARGE Accounts



Fall 2006

A Quarterly Newsletter for Families and Friends

Vol. 16 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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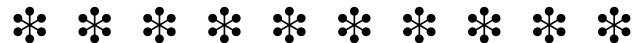
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CHARGE Syndrome Foundation Mission Statement

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.



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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 Winter Issue - November 15 !!!

PRESIDENT'S NOTE

Neal Stanger

FOUNDATION ACCOUNT

COMMITTEES

For a description of what each committee is responsible for, please go to

www.chargesyndrome.org or contact the chairperson or the Foundation Office.

Hello everyone,

Wow, it's only 9 months till our 2007 conference in Costa Mesa, California!! You are now able to make hotel reservations on-line for the conference. The hotel has also agreed to hold our rate of \$119 (plus tax) per night for a few days before and after conference. Remember, our meeting starts at 9:00 on Friday morning.

As we get closer to conference, the Board has to make many tough decisions. The hardest of those decisions was to significantly raise the registration fees. Each adult at the conference costs the Foundation over \$350 and with our new policy of using professional childcare, each child will cost the Foundation over \$500. We realize that many families could never afford to pay this much to attend; therefore we will only be charging the following registration fees in 2007:

- Adult Foundation members (including those 15 yrs of age and up) . . . \$160.00
- Children attending the childcare program \$160.00
- Children (under 15) not attending the childcare program \$ 80.00
- Adult non-members of the Foundation \$200.00

These fees include breakfast and lunch on Friday, breakfast, lunch, and dinner on Saturday, and breakfast on Sunday. As I said earlier, these are significant increases and we would not do this if we didn't have to. Even at these rates, the Foundation needs to raise close to \$100,000 in additional funds to pay conference expenses.

Many of you have asked what you can do to help raise funds and awareness for the Foundation. We now have that answer for you. This month we are kicking off the "Friends and Family Campaign", a grass roots effort that allows each of us to gather support from the people who already care about our children and our cause. The cornerstone of this campaign is a "fundraiser in a box". This kit has everything you need to host a fun and successful fundraiser in your home or another favorite spot. The kit includes invitations, brochures, pledge cards, thank you cards, etc. Most importantly, the kit includes a DVD copy of a spectacular new video about CHARGE Syndrome and the Foundation. This classy 14 minute presentation will educate our guests and encourage them to support the cause. The Friends and Family campaign will be kicked off in a special mailing to all members and friends of the Foundation. But the kits are ready to go now. For more information or to request your kit, contact Dennis O'Toole, our fundraising chairperson, at dennis@chargesyndrome.org

Please keep checking our web site for more updates on the Foundation. We should have even more exciting news to announce to you later this year and into next year. Lastly, if there is anything that you would like to see the Foundation do for you, please do not hesitate to let me know.

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: Susy 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.

FUNDRAISER IN A BOX

A Special Letter will be in your mailbox in a few days to give you more details on the "Fundraiser in a Box" that President Stanger mentioned in his note above.

→ → → Be sure to watch for it. ← ← ←

EXECUTIVE DIRECTOR'S NOTE

Marion Norbury

The brochure that most of you have received was written in 2001. It has been revised and is now available.

As this newsletter is being prepared, a group in Texas is getting ready for their Retreat on October 7. Cathy Springer, who has a child with charge, has been planning this for many months and we wish her a very successful meeting. It has been on my wish list for several years to add small regional meetings in the off-conference years. With what we learn from this meeting and with Cathy's help, I hope we will be able to plan similar meetings in the near future. The Family Services Committee would welcome your suggestions.

Another of our parents, Molly Roberts, who is also in Texas, has just completed her second annual fundraiser for the Foundation. So far in 2007, she has raised \$2,000.00. Thank you, Molly, your family and your supporters!

There is much information in this issue about the 2007 Conference to help you in your planning. Recognizing that right now obtaining the funds for the trip may be your most important concern, I am listing some possible sources of help. Start early contacting the ones in your area, be prepared to explain what charge syndrome is and why this conference is important for you and your child. If this will be your first conference, be sure to fill out the scholarship application and return it before the February 1 deadline.

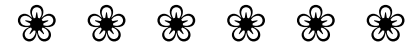
Your State Deafblind Project
Lions Club Kiwanis Club
Rotary Club Optimist Club
Sertoma/Other Sororities
Check with Chamber of Commerce
for other service clubs
Shriners Churches
Children's Hospitals
Early Intervention Agencies
School f/t Blind School f/t Deaf
Special Education Co-ps
Disability Advocacy Groups
Independent Living Council
Council on Aging and Disability

Governor's Planning Council
Regional Centers
Other State Agencies

SURVEY PARTICIPATION

Brownie Shott

Many of you participated in our recent web based survey, and we want to say thank you. Your input is so valuable to us, and we are already beginning to take the information you shared with us and use it in making plans for the foundation. We had more than 30% of our membership participate in the survey which is an incredible percentage in the world of surveys. Of course, we know that our members are not your average Joe. You are people who care deeply about individuals with CHARGE Syndrome and their families. If you did not get an opportunity to take the survey and would like to do so, please contact me directly at brownie@charge_syndrome.org. Thank you so much for your participation.



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

Conference

Le Vine Enterprises CA
Jerome & Ruth Schwartz CA

General

Havre de Grace Lions Club MD
Stephen Perreault MA
Vendetta Service Inc. Doug Perri NY
Peter & Cheryl Scacheri OH
Brownie Shott TX
Len & Joan Stanger NY
John & Beverly Terzani NY
United Way of Central New Mexico
United Way of Kitsap County
Employees Community Fund WA
United Way of Tucson & Southern
Arizona AZ

2006 Roberts Fundraiser

Margaret H. Bailey TX
Ryan Senior High School TX
Susan M. Bruce TX
H. R. Curtis TX
Sarah Davee TX
Leslie B. Erickson TX
Rebecca Hartford TX
Cynthia R. Hawkins OK
Karen Hillard TX

Brenda Latham TX
Laura Malins TX
Erin L. Malloy TX
Sherri M. McGee TX
Jennifer E. Miller TX
Mrs. E. R. Rice Jr. TX
Molly Roberts TX
Theressa Robinson TX
Kathy Salisbury TX
Ellie J Schulz HI
Stacie J. Test, DDS TX
Treva A. Thompson TX
H. L. Vaughn TX
Gene Wilson TX

Cincinnati Fundraiser

Dr. Kenneth & Dorothy Sandker OH

In honor of Clare O'Toole

Lauren R. Mooney OH

In honor of Erika Feather

Mr. & Mrs. William Muir PA

Tyler Matthew Memorial

Tera L Martin OH
Joe, Bryony & Hailey SySantos DE

In honor of Evan Storrs' 1st Birthday

Jeremy & Sarah Storrs WA

In honor of MaKenzie Dougherty

Betty McKnight OH

In honor of Max Carroll

Keith A. Carroll SC

In honor of Sabrina Bluestone

Todd & Kellie Ackerman CT

In honor of Sylvia Dressler's 90th Birthday

Joan & Leonard Stanger NY

In memory of Pearl Rosen

Staci Triandafellos NJ
Nili & Andrew Yolin NY
Petra Pet, Inc - Steven Mendal and
Jacob Tepper NJ

In memory of Ryoto Yabuki

Munehisa, Akiko & Souma Yabuki WA

In support of Neal Stanger and the Foundation

William Wu & Carol Scheiner NY

I am really getting excited about the things happening in preparation for the 2007 CHARGE Syndrome Conference in Costa Mesa, CA! We have a team of dedicated volunteers that I am so impressed to be working with!

Mike Schwartz has been recruiting volunteers, finding a group to handle our silent auction, putting in proposals for donations and grants, and so much more. Ruth and Jerry Schwartz (yep, Mike's folks) have been writing tirelessly to obtain grants from corporations and other organizations, as well as trying to obtain items for the silent auction and "freebies" or character visits from Disney. This family has been invaluable in terms of the local contacts in California, and they continue to beat the bushes for things we need.

Pat and Kevin Moore have energetically taken on the Saturday night family event. At the volunteer meeting back in March (2006), Pat ran up to me and begged to take this major event on! How could I possibly refuse? I am truly excited by their concept, and I'm sure everyone will come away from the evening having had a wonderful time. Their 10-year old daughter, Madison, has even become active in helping to raise funding for the conference. Check out her website at www.chores-4-charity.com!

I am particularly anticipating working with the California Deafblind Project's staff. We've gotten commitment that their staff will be available to plan and conduct an in-service with the hotel personnel regarding our attendees' needs. The Project Director also stated they could help in locating interpreter services, and numerous other aspects. I am so excited that, since 2007 is a year the CADB Project would normally have a conference, they have "replaced" theirs with ours! CADB will also be an invaluable resource for the childcare rooms. This will help reduce the cost of the professional childcare organization that we will be utilizing; it is quite a large amount of savings.

Wendy Keedy is busily working with a graphic designer to formalize our conference logo. Their ideas are just fabulous and I can't wait to see the finished product! I'm also looking forward to what Uncle Kenny's Corner (Kenny and Cheryl Moretz) might dream up for the children to create this time for lasting mementos of their California conference experience.

The link to the Hilton Costa Mesa Hotel from the CHARGE Syndrome Foundation website is up and running, so you can start making your reservations now! Or you may call for reservations at 714-540-7000. When calling, be sure to mention the conference to get the special rate and to be counted in our block of rooms.

There are several airport options for flying to the conference. Los Angeles International (LAX); John Wayne-Orange County (SNA) and only one exit from the hotel exit off the interstate; and a little more limited in airline choices, but also available, is Long Beach (LGB).

Surf's up and we're riding the wave to a great 2007 conference! Hope to see you all there!

* * * * *

Program Plans for the 2007 Conference
James Thelin, Program Chair

We began planning the 2007 Conference Program by evaluating the many comments that we received from the participants at the 2005 Conference. We are also relying on a Program Advisory Committee and the Board for recommendations for presenters and activities. We have several objectives: (a) to provide basic information that needs to be presented at every conference; (b) to present updates in areas in which new information has become available; and (c) to emphasize a specialty area in which a significant body of information has accumulated (like the behavior strand at the Cleveland conference and new CHARGE gene information in Miami).

You should be aware that the CHARGE Syndrome Foundation distinguishes itself from other support organizations in its support, since its inception, of research and development of a knowledge base for CHARGE. We have the problem that CHARGE has many facets and the knowledge base is expanding so rapidly that we are forced to limit what we can present in a 2-1/2 day conference. In 2007, we will have presentations that will focus on three age-related groups:

- Young and first-time participants – including the introductory course CHARGE 101 (a 3-hour sequence of presentations).
- School-age group (developmental, educational, and communication issues)
- Adolescents and young adults.

We are in the process of planning special sessions for fathers, for grandparents, and for siblings. There will be medical specialty programs and a special emphasis on ENT-related problems. There will be a poster and exhibit session that will include research, special presentations, and information about organizations with whom we are affiliated.

A number of people have made suggestions to me and other members of the Board for topics that they would like to be covered. You need to be aware that ALL of those requests are being taken into consideration. If you have suggestions or requests, please contact me at jim@chargesyndrome.org. In the next issue of *CHARGE Accounts*, we will have a listing of many of the presentations and program activities planned for the 2007 Conference.

RESEARCH ACCOUNT

New Survey for Adults with CHARGE Syndrome **Laurie Denno & Pam Ryan**

As some of you may remember, Laurie Denno and Pamela Ryan presented a pilot survey entitled "Adults with CHARGE, Who We Are" at the poster session at the 2005 CHARGE syndrome conference in Miami. After further refinement with some excellent feedback from Meg Hefner, the survey has been updated. The project has been approved by the CHARGE Syndrome Foundation research committee and Board of Directors. It is ready to send out to those who wish to participate.

The adult with CHARGE and/or a family member or support staff can fill out the survey. Topics include where the adult with CHARGE is living and working and what they do in their free time. The survey is open to all adults with CHARGE who are over 18 years of age and graduated from high school or 21-22 years of age and graduated from special education. The survey information will be strictly confidential in that no names will ever be shared. The results will be compiled and hopefully shared at the next CHARGE Syndrome conference.

If you would like to participate in this survey, please contact Laurie Denno at laurie.denno@perkins.org or Pam Ryan at pamela.ryan@perkins.org. If you have any questions, you can call Laurie at 617-972-7891 or Pam at 617-972-7505.

Report from the Education Committee **Susy Morales**

The goal of the Educational Committee is to produce instruments that will help educators, clinicians and parents of children who have CHARGE syndrome. This will be a long road ahead and we are beginning with a short questionnaire that will allow us to compile enough data to produce a short instrument to aid in EIP meetings as well as in the everyday educational environment.

Your name: _____ Email: _____

Parent ___ Educator ___ Clinician ___ Caregiver ___

Child with CHARGE has: Hearing impairment ___ Vision impairment ___ Both hearing and vision impairments ___

1. Please list the top five strategies you employ with your students with CHARGE.
2. What teaching strategies do you use the most?
3. Please list the characteristics that typify students with CHARGE.
4. Do you use a Schedule? If so, please describe it. How effective is it?
5. Is there a certain type of language that you use with your students with CHARGE?
6. Are there any other strategies, teaching methods, or ideas you would like to share?
7. What resources have you found most helpful in dealing with the education of students with CHARGE?
8. What additional resources would you find most helpful?

Please send your responses to:

Susy Morales, 15186 SW 172nd Terrace, Miami, Florida 33187 or SusyV@aol.com by November 15, 2006

My Charge-daughter was born in July 1999 and the diagnosis of CHARGE was made three days after birth. In the following weeks, we found out the CHARGE foundation by Internet and wanted to know more about CHARGE and CHARGE conferences. But Lavinia was too sick at that time. In 2001 we came to Indianapolis. By then, I personally saw two other children in Germany and talked to three other German families on the phone. It was an overwhelming experience coming to Indianapolis and again to Miami changing my live completely. Ever since I hoped for something alike in the German-speaking countries of Europe. In May 2005, after so much has changed in CHARGE-Land, two big german deaf-blind Institutes (Würzburg and Hannover) organized a weekend workshop for their professionals on CHARGE. They invited David Brown, Dr. Conny van Ravenswaaij and Dr. Marjolin Jongmans. It was a great meeting and 13 families had the opportunity to meet for the first time. A few Charge-mummy's met in a big German forum regarding special-needs children (www.rehakids.de).

One of them, Claudia Ludwig, with good internet knowledge started the first German-speaking forum. In less than one year we reached 80 members and in Spring 2006 we felt that a regular meeting should start. Claudia and I managed to get nine families together. We met in a most comfortable place in the country-side of Hessisch-Rhön, Fladungen (Germany). We were lucky. We got sunny weather, a big garden, a big buffet of homemade cakes and a wonderful barbecue at night, beside a full stuffed kitchen to prepare all specialities for our kids, too.

A few people came only for the day, but four families stayed over night. We decided to found a CHARGE Syndrome group for German speaking countries of Europe. Now, we are preparing the legal issues and the group will be registered in the next few days. In the meantime, we hope you all will be curious to visit us in Internet (www.charge-syndrom.de) (syndrom - without "e"). We hope to meet you again at the next conference in California 2007 with a big "thank you" to the great American Charge family making walking in Charge-Land much easier for all of us.

Best greetings from Claudia Ludwig, mum to Charger Jonas 2 yrs and Julia Benstz, mum to Charger Lavinia 7 yrs.

p.s. In another message Julia wrote that they expect to be legally registered as an association "Charge Syndrome e.V" by the end of September. She also wrote that "they personally had a new milestone these days: Lavinia entered school. She is now a first grader. And I'm so proud because she's going as an integrated child!"

Editor's note: The German speaking countries include Germany, Austria, Switzerland, Liechtenstein and Luxembourg.

CALENDAR 2006

November 15 **Deadline for Articles in the WINTER Issue of CHARGE Accounts**

December 15 **WINTER Issue of CHARGE Accounts in the mail**

2007

January **Time to renew your membership for 2007**

February 1 **Deadline for Scholarship Applications for 2007 Costa Mesa Conference**

February 15 **Deadline for Articles in the SPRING Issue of CHARGE Accounts**

February/March **Conference Registration Forms in the mail**

March 15 **SPRING Issue of CHARGE Accounts in the mail**

July 27 - 29 **8th International CHARGE Syndrome Conference, Hilton Orange County/Costa Mesa in 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/**



800-822-7884 Voice/TTY
415-405-7562 FAX
www.sfsu.edu/~cadbs

Fact Sheet

Strategies for Successful Medical/Dental Appointments for Individuals who are Deaf-Blind

by Maurice Belote, CDBS Project Coordinator

Many individuals who are deaf-blind have medical needs that may require frequent medical appointments. These individuals also require regular dental care that may also be complicated by physical/health issues. Medical/dental visits can be very frightening for the person receiving treatment if the procedures are not expected or understood. As the individual who is deaf-blind becomes frightened, he/she may express fear through behaviors (e.g., tantrums, aggressive behavior, rigid body postures, etc.) that will make the examination and/or procedure difficult. The visits can also be very frustrating for the families and care providers assisting these individuals during the examinations as they try to explain and manage the behavior expressed.

The following points are some general guidelines to promote a successful and positive experience during medical/dental appointments. It is suggested that family members and care providers review these guidelines with health care professionals when the appointment is made or upon arrival at the office. A copy of this fact sheet can be left with the medical/dental staff to inform them of the needs of their patients who are deaf-blind. [Please note that these ideas represent what might be considered the ideal medical/dental visit and that each strategy may not be possible in every situation.]

1. Try to locate a medical/dental professional who has experience with individuals who are deaf-blind. If you are in need of a referral, call California Deaf-Blind Services (CDBS) at 1-800-822-7884; a CDBS Family Specialist may be able to link you with someone in your area who has information regarding local providers.
2. Call the medical/dental office staff in advance of your visit to let them know what to expect (e.g., difficulty waiting, unusual and/or loud vocalizations, challenging behaviors, etc.).
3. If the family and medical/dental staff can manage this, give the individual who is deaf-blind an opportunity to visit the medical/dental office in advance of the appointment so that he/she can become familiar with the provider, office staff, equipment, smells and sounds, etc. Identify name cues or signs for some of the key people who will be providing the medical/dental services. This pre-appointment visit provides an opportunity to collect sample instruments to use in role-play activities (see next recommendation).
4. Provide opportunities for role-play activities prior to the medical/dental visit. When appropriate, give the individual who is deaf-blind the chance to be the provider and use the sample equipment on others (i.e., family members, teachers, classmates, etc.). Allow opportunities for the individual's peers to do the same with the individual who is deaf-blind. Make the experience fun and relaxed, and use this role-play activity to reinforce language that will be used during the medical/dental visit.
5. Bring something for the person to do during periods of waiting at the office.
6. If the individual has a favorite object and can hold or touch it during the procedure, bring it to the appointment. It may provide the patient with a level of comfort/security that will help him/her through the procedure.

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals with dual sensory impairments. The information applies to students 0–22 years of age. The purpose of the fact sheet is to give general information on a specific topic. More specific information for an individual student can be provided through individualized technical assistance available from CDBS. The fact sheet is a starting point for further information.

7. Bring the person's medical records to decrease the repetition of developmental history, waiting for records to be sent, and duplication of unnecessary exams. Include addresses and phone numbers of all service providers.
8. Bring information about the person's specific medical issues if the medical/dental professionals are new or unfamiliar with the particular syndrome or condition (e.g., Congenital Rubella Syndrome, CHARGE Syndrome, etc.).
9. Whenever possible, introduce each of the medical/dental professionals to the person who is deaf-blind before the professional touches the person. This can be done with a name sign, a name cue, a concrete object of reference, or a distinctive scent.
10. Let the person know how the exam is proceeding. Tell the person what will happen next and what the reasons are for the particular examinations.
11. Model and reward cooperative behavior, appropriate waiting, confidence, acceptance and relaxed body posture.
12. If medical/dental professionals request it, give them feedback and/or acknowledgement regarding their interactions with the patient and the patient's family member/care provider (e.g., terminology used, bedside manner, emotional tone, willingness to work with you, etc.). This information might be helpful to the professionals when they plan for future appointments.
13. Reward yourself and the patient following medical/dental procedures. Stop on the way home and have a treat, buy some new music or a movie, take a swim at the community pool—whatever you do to reward yourself. As a rule, we don't reward ourselves enough for getting through challenging situations.
14. Collect items to use as a record of the visit so that the experience can be discussed in the future, such as when preparing for additional appointments. The experience can be recorded in an "experience book" that may include photos, objects, words in print and/or Braille or other items that will help the individual remember the event. Be sure to include a record of the post-visit reward so that it might serve as a motivator for future visits.

Tips for Professionals

1. Warm hands or instruments before touching the person who is deaf-blind.
2. Tell the person what each procedure will entail prior to beginning the procedure. This can be accomplished by allowing the person to examine the equipment by touch. You can then touch the patient's body part that will be examined by that piece of equipment. Pause for a few seconds to allow the person to prepare for the exam before it begins. You can also have the medical/dental professional demonstrate the procedure on the family member/care provider to model appropriate responses.
3. Allow sufficient time for the patient to process information. Many individuals who are deaf-blind require extra time to process information, and processing time may be increased if the individual experiences stress or anxiety.

For more information, check out:

Dental Care Every Day: A Caregiver's Guide. Published by the National Institute of Dental and Craniofacial Research, U.S. Department of Health and Human Services, 2004. [NIH Publication No. 04-5191]

First Impressions Module 2: Grooming. Videotapes and teachers' guides published by James Stanfield Publishing Co., Santa Barbara, California. [www.stanfield.com]

Perspectives of Dentists, Families, and Case Managers on Dental Care for Individuals with Developmental Disabilities in Kansas, by Amanda Reichard, H. Rutherford Turnbull, and Ann P. Turnbull. From the August 2001 issue of *Mental Retardation*, the journal of the American Association on Mental Retardation (Vol. 39, Number 4, pages 268–285).

Practical Oral Care for People with Developmental Disabilities. Published by the National Institute of Dental and Craniofacial Research, U.S. Department of Health and Human Services, 2004. [NIH Publication No. 04-5196]

Revised (2006) from *Strategies for Successful Medical Appointments for Individuals with Deaf-Blindness* (1996) by Susan Sternberg-White, former CDBS Project Coordinator.