

# CHARGE Accounts



Winter 2008

A Quarterly Newsletter for Families and Friends

Vol. 18 No. 4

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

*May 2009 Bring  
You and Yours  
Good Health,  
Happiness,*



*and*



*Joy*



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**!!! Deadline for the Spring Issue - February 28 !!!**

**\*\*\* Time to Renew Your Membership \*\*\***

# CHARGE Syndrome Foundation and People First Language

by Lisa Weir

When Kennedy was first born, I had the great fortune to find Casey Fisher's web site about her son, Aaron, while Kennedy was still in the hospital. We connected via the Internet and I made my first online friend who had a child with CHARGE syndrome. It was wonderful. Not only did I make a new friend in Casey, I also joined the listserv that she started, which put me into contact with a number of families who had children with CHARGE. It became a part of my daily life to interact with this new online family of which I had become a member.

One of the things a number of the families did on the listserv to help us know more about each other's children was to sign the email postings we sent in with our child's name and then the letters of the word 'charge' capitalized to indicate which symptoms of CHARGE our child had. Some children's names were followed by ChArGE, or CHArGe, or with whatever configuration of symptoms from the acronym their child had been diagnosed. Another thing a lot of people did was to refer to their children as 'CHARGERs'. Again, being a newbie to the world of disability in general, I thought this was pretty cute and began to refer to Kennedy as my little 'CHARGER'. I even helped organize a slide show of pictures of our little 'CHARGERs' at the second conference I attended.

I attended a session at the first conference about People First Language when Kennedy was 12 months old. I think, though, I was still so overwhelmed with everything I was learning about this whole new world of CHARGE syndrome, that I never really 'got' the full message that was being shared at that time. I also can remember wondering early on why I didn't see the cute 'CHARGER' term being used in any of the CHARGE Syndrome Foundation publications. I also wondered why the people from the Foundation didn't seem to be so excited about my "Our Miracles, Our CHARGERs" slide show I had prepared for the second conference. It was nothing explicit in anything they said or did, just a feeling I got.

As time went on, I began university, reading lots of journal articles and doing lots of research. Having access to all the journals, I read and studied things I was interested in that were not necessarily a part of my course load. One of those things was obviously the world of disability. In studying journal articles on disability, I began reading more about People First Language and the powerful impact that our language has on other people's beliefs, attitudes, and actions, and so on. It was then that I started to realize the reason I hadn't been seeing the CHARGER term in any of the Foundation documents and I began to think that calling Kennedy my 'CHARGER' might not be the best idea. I discontinued the practice, even though before I really began to learn about language and its power, I thought it was an endearing way to refer to her. Someone once pointed out to me another example that really drove the point home when he said, "Do people who have children with Down syndrome call their kids, 'Downers'?" Another parent shared with me that he used to call his son his little 'charger' until he was about seven or eight years old. One day, his son looked at him and said, "Daddy, I am not your charger, I am Justin." That ended that father's usage of the term.

Last summer, I took a course where I had the option to write a paper about my philosophy of education and I want to share a short excerpt with you from that paper about language and thought. This may help illustrate a bit of what I learned:

### *Language and Thought*

The language we use also affects our thinking. As Kodish (2003) states, "A large part of human evaluative processes relates to language behavior or use" (p. 386). In the world of disability, for example, it is no longer acceptable to speak about people with disabilities using their diagnosis as a means of labeling them.

The movement for People-First Language recognizes the prejudicial nature of using a diagnosis to characterize someone and are working to ensure everyone recognizes this and makes the change in their language used to describe individuals with disabilities. As Snow (2008) states, "Words are powerful. Old, inaccurate descriptors and the inappropriate use of medical diagnoses perpetuate negative stereotypes and reinforce a significant and an incredibly powerful attitudinal barrier" (p. 1).

The language one uses when discussing education then, also affects his or her thinking about the subject. Therefore, careful consideration of the language used and the recognition that language can and does affect the way in which one thinks, must be undertaken. In the words of George Orwell, "If thought corrupts language, language can also corrupt thought" (QuoteWorld, 2008).

Thinking back now, it was probably difficult for the people on the Board of Directors of the CHARGE Syndrome Foundation to figure out a diplomatic way to tell me why they were not thrilled with the title of the slide show I'd created. Knowing

someone had worked really hard on something like that for the conference and that many families submitted pictures, I am sure that they did not want to make me or anyone else feel badly for referring to our children as ‘CHARGERs.’

Now that I have the privilege of serving as a member of the Board of Directors of the CHARGE Syndrome Foundation, I know for sure that making anyone feel badly is not, nor was it ever, the intention of the Foundation. It is also not about anyone telling anyone else what they can or cannot say about their own child; that will obviously always be the decision of the family. We certainly realize that families are not calling their child ‘CHARGER’ to invoke negative attitudes in others toward our children; it just is something that seems like a cute thing to do.

As a Board, however, we have made the choice to recognize the power of language and its effects on the beliefs, attitudes and actions of others. The Foundation has adopted an official policy that it will use People-First language at all times, when referring to individuals with CHARGE syndrome or any other type of disability. So that is the reason why you will not see ‘CHARGER’ in any of the publications produced by the Foundation.

As for myself, I have never apologized for my previous usage of the term, nor will I ever look down upon anyone who chooses to do so. I am a huge believer in the right of each family to choose what they think is best in every facet of their child’s life. For me, discovering about language and its implications is yet another thing I have learned on this tremendous journey that has been my life since Kennedy was born. As a parent, I totally understand the Foundation’s decision to use People First Language. Just as I respect the families and their decisions, so do I respect the Foundation and the decision it has made in this regard.

If you want to read more about People First Language, there is a wonderful web site called, “Disability is Natural.” This web site contains a document written by Kathie Snow about People First Language and is located at: <http://www.disabilityisnatural.com>. The PDF document about People First Language is available here: <http://ftp.disabilityisnatural.com/documents/PFL8.pdf>.

In closing, I will share the end of the document written by Kathie Snow, where she explains the “why” question about People First Language. Hopefully, it will help to further explicate the decision of the Foundation to engage in People First Language when referring to individuals with CHARGE syndrome:

The Civil Rights and Women’s Movements prompted changes in language and attitudes. The Disability Rights Movement is following in those important footsteps. People First Language was created by individuals who said, “We are *not* our disabilities.” It’s not “political correctness,” but good manners and respect.

We can create a new paradigm of disability. In the process, we’ll change ourselves and our world—as well as the lives of millions of children and adults. It’s time to care about the feelings of the *people we’re talking about* and the *perceptions* of people with disabilities which we create with our words.

Isn’t it time to make this change? If not now, when? If not you, who? Using People First Language is the right thing to do, so let’s do it!

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Kodish, B. I. (2003). What we do with language – what it does with us. *ETC: A Review of General Semantics*, 60(4), 383-395.

QuoteWorld. (2008). *George Orwell Quote*. Retrieved June 12, 2008, from <http://www.quoteworld.org/quotes/12637>

Snow, K. (2008). *To Ensure Inclusion, Freedom, and Respect for all, it’s time to embrace People First Language*. Retrieved July 16, 2008, from <http://ftp.disabilityisnatural.com/documents/PFL8.pdf>



## SPECIAL ACCOUNT

### *People First – from a professional perspective*

**Meg Hefner, Genetic Counselor and  
Special Advisor to the CHARGE Syndrome Foundation**

In addition to my work with CHARGE syndrome, I am a genetic counselor in clinical practice. This means I work with children, parents, and prospective parents in a medical genetic setting on a daily basis. If a family sees me, it is either because there *is* a problem (with a child or a pregnancy) or there is a *significant chance* of a problem (with a pregnancy).

I first came across the specific idea of People First language through parent members of the CHARGE Syndrome Foundation Board of Directors (Brownie Shott, if memory serves correctly). My initial thought was “Oh, yeah, more of the politically correct stuff.” In my work, I had found that the terms families want us to use change every few years. I’ve been around long enough to see the evolution from the terms “mental retardation” and “retarded development” to “developmental delay” and “developmental disability,” over the years. It seems each new generation of parents takes offense at the terms used by the previous generation and comes up with something new. I think this is completely understandable when you think about each generation’s struggle to gain more acceptance and greater autonomy for themselves and their children. It is important, but I think it is somewhat different from the People First language movement.

At the insistence of a few parents, I began using People First language. First, it was simply out of respect for the parents – if it was important to them, I would go along. But I soon found that Lisa and George Orwell are right – changing language changes thinking. Saying the *person* first really does make it a “*child* with CHARGE syndrome.” I found my language changing in my everyday world of genetic counseling. When speaking to a pregnant woman, I would talk about the “baby with Down syndrome” and not the “Down syndrome fetus.” I tried to subtly model (and later explicitly demand) People First language for my colleagues. Most people don’t even realize what they are doing, but once I point out the difference, no one has disagreed with its importance. Genetic Counseling training programs now use People First language in training of new genetic counselors and insist on it in all of the writing done by genetic counselors. Simply using People First language has helped me gain a new understanding and respect for people with all sorts of “differences.” I encourage each and every one of you to use People First language. And point it out to the professionals who work with your children. Most will appreciate it and some will even start using it!



## FUNDRAISING ACCOUNT

### **CHARGE It for CHARGE**

Our first Charge It for CHARGE fundraising campaign is up and running! The early results are very encouraging. After only two weeks we have raised more than \$16,000 -- and that was with only 12 people participating! Imagine what we can accomplish if everyone joins the fun.

If you have not yet registered to be a fundraiser, please start now. All you need is a computer, e-mail and some friends and family. The registration process is very simple and should take less than 30 minutes. Register, send some e-mails and watch the money roll in. In the process you create awareness about CHARGE and might be surprised by all the positive feedback. Remember, every small donation matters. Whether you send 10 e-mails or 1,000 your contribution is needed.

If you did not receive our e-mail about the fundraiser, please e-mail us at [fundraising@chargesyndrome.org](mailto:fundraising@chargesyndrome.org). We will send you a quick link and you will be ready to help.

**WE NEED YOUR E-MAIL ADDRESS.** Drop us a quick note at [lorib@chargesyndrome.org](mailto:lorib@chargesyndrome.org).

The Foundation is going to send out newsletters and important information by e-mail. Don’t be left out.

**David Wolfe, Fundraising Chair**

Another year has come and gone and I am happy to report that the Foundation has made a lot of progress and introduced many new programs in 2008. Instead of going through a list of all of our accomplishments for the year I would like to let you know about a few recent developments and programs that the Foundation has been involved with.

At our last Board meeting in November, we voted unanimously to adopt "Person First Language" in all of our future publications, presentations, etc. What this means is that we will respect the person and always use language that refers to the person before the syndrome. For example we will refer to our children as "children with CHARGE," not "CHARGE kids" or "CHARGE'rs." See the article by board member Lisa Weir for a more complete explanation.

Our new email fundraising campaign is under way but we desperately need your help. As of this writing, the Foundation had sent emails to over 500 members and past members asking you to join our efforts by starting your own Fundraising Page and emailing it to all of your family and friends. As of early December, only 13 people had joined the campaign, but we had already raised over \$20,000. Just imagine what we can do when 100 or more of you take only 20-30 minutes to set up your own page and help us. If you need any help setting up your page, please send an email to [fundraising@chargesyndrome.org](mailto:fundraising@chargesyndrome.org).

Lastly, the Foundation has made a conscious effort to go green with our newsletter. Starting in 2009, we will be emailing as many newsletters as possible instead of printing them and mailing them. Besides going green this will save the Foundation a few precious thousand dollars every year. Please take a few minutes to email your contact information or fill out and fax/mail the Going Green flyer to Lori Bookstaver at the NY office.

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

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.

 **Reminders** 

***Renew membership now***  
***Respond to Going Green Flyer***  
***Contribute to the Education Survey***  
***Contribute to the CHARGE Emergency Booklet***

## Time to Renew Your Membership

It is time again to renew your membership in the Foundation. All membership terms are on a calendar year - due in January. Check your mailing label. If it says 2008, your 2009 membership fee is now due. You may use the order form 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 2008. So whether you joined in January 2008 or July 2008, you need to renew now for 2009. **Membership renewals are due by March 1 to receive the Spring Issue of CHARGE Accounts.**

## 2009 International Conference

Registration information will be available by late February/early March. General information is on our website [www.chargesyndrome.org](http://www.chargesyndrome.org).

## CHARGE SYNDROME EDUCATION SURVEY

The Education Committee for the CHARGE Syndrome Foundation would like your input on educational issues.

Please visit: [http://www.surveymonkey.com/s.aspx?sm=DZXYAnKhJLKPfym5zMGthg\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=DZXYAnKhJLKPfym5zMGthg_3d_3d) to access the survey.

Thanks in advance for your participation!

**Lisa Weir, Education Chair**

*Holiday*

*Greetings*

## CALENDAR

2009

February 1	Deadline for Conference Scholarship Application
February 28	Submit items for next issue of CHARGE Accounts
March 1	Membership Renewal by this date
March	Spring Issue of CHARGE Accounts
March	Conference Registration Packet in the mail
May 31	Submit items for next issue of CHARGE Accounts
June	Summer Issue of CHARGE Accounts
August 31	Submit items for next issue of CHARGE Accounts
September	Fall Issue of CHARGE Accounts
November 30	Submit items for next issue of CHARGE Accounts
December	Winter Issue of CHARGE Accounts

I am embarking on a new project and would very much like your input. To give credit where credit is due, I got the idea from the Prader-Willi Syndrome Association (another parent support group). They have published a sturdy little booklet (about 4"x 6" bound, with a dozen plasticized pages) called **PWS: Medical Alerts**. In it are lots of little bits of useful information. What a cool idea! Here is what I plan to do for CHARGE:

I want to produce a small booklet which will easily fit in a purse or glove compartment. Let's say you are in Chicago at the CHARGE conference and your child gets sick. You go to the nearest emergency room. What is it that the ER personnel need to know about CHARGE in general or your child in particular to make it easier for them to take care of your child? How is your child different from the next child that comes into the ER? To do this right, I need lots of input from you. Please think about this and send me your thoughts on the following:

What issues are most likely to require a trip to the ER? Some examples might be g-tube issues, trachs, other respiratory problems, seizures, etc. I need to know the **most common reasons**. Please be specific: what sort of trach problems send you to the ER? I know they can vary by the age of the child, so tell me what the reasons are/were at different ages.

What are the (very few) most important things that the ER personnel need to know about your child? These things fall into two categories.

The first (and most critical) are what they **NEED** to know to not hurt your child. Some examples of those might be a Latex allergy, has a g-tube, has a CI (or some other reason to NOT do an MRI!!),

The second are what you **WANT** them to know to better understand your child and be able to treat him/her more effectively. Some examples might be high pain threshold, doesn't like to be touched in a certain way, communicates by sign so don't tie his hands down...

If you have specific descriptions of things that might be useful, send me those, too. The PWS booklet had URL references (e.g. [www.chargesyndrome.org/xxxxx](http://www.chargesyndrome.org/xxxxx)) so doctors could access more detailed information online. If there are procedures or other things that you have had to educate ER people about, send those to me and I'll see if I can incorporate some of those things.

You will come up with other ideas that I haven't thought of – send them along!

I will be sure there is a place in the back for a **medications list**. If there are other bits of information you always need to give ER folks, tell me about them. Other comments, suggestions are welcome (but may or may not be incorporated!). This will NOT be a miniature of the manual – I will try to keep things as brief and to the point as possible. You can mail, fax, or email your input to me. Please do this right away, while you are thinking of it, so I can get all the information at once. Thanks in advance for your input.

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**THANK YOU FOR YOUR SUPPORT . . .**

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**Katherine Rose Thelin**  
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Lisa Peterson FL

**CHARGE....And All That Jazz!**  
**Biennial Conference in Chicago in 2009**  
**by Brownie Shott, Conference Chair**

**CONFERENCE ACCOUNT**

Plans are in full swing for the 2009 Biennial Conference in Bloomingdale, Illinois on July 24-26, 2009. The program is being assembled, and there will be new events preceding the conference. For the first time, an official, full Professional Conference Day will be held on Thursday, July 23<sup>rd</sup>. It is designed as a forum for professionals from many disciplines to meet, present research, compare notes and learn from one another. The conference will be available to parents, etc. (for an additional fee) but the content will be geared towards professionals.

On Wednesday, July 22<sup>nd</sup>, the first CHARGE Syndrome Foundation Golf Tournament will be held at the Indian Lakes Resort (which is now a Hilton property) golf course. There is also a miniature golf course which will be available to us at the conference. I think some tournaments for our children may be in our future! The golf tournament on Wednesday will be a great opportunity to raise funds for the Foundation and raise awareness among some local residents. We hope that many of our families will make plans to come in early and participate. More information will be available after the first of the year.

We are moving to a different childcare company this year for the Kids Camp. They have proposed many new and different ideas. One option that will be available is one-on-one support for your child (for an additional fee). As those plans finalize, we'll keep you posted. Our Saturday night activity is being sponsored by the Texas Chargers, Inc. Rumor has it that they have some very special plans for the evening. We'll also be having our Silent Auction on Saturday night so be on the lookout for information about that. This is just a taste of all the excitement that will be a part of the 2009 CHARGE Syndrome Foundation Conference. Start making your plans now to join in on the fun!



***I know there's money out there, but how do I get it?***

**by Marilyn Ogan**

In these trying economic times, many of you may be asking, "How can I find the money to attend a conference?" It can be confusing to figure out where – and *how* - to obtain funds to assist you in attending the conference. To that end, I have been asked to share my thoughts about how to garner the best result (approval) from the agency or organization(s) involved in providing financial assistance for individuals and families to attend conferences related to disabilities. In the previous issue of CHARGE Accounts (Fall 2008), one page of the Lee. E. Norbury Scholarship form listed possible sources for obtaining funding for attending the conference. Here are my tips and pointers, as well as what agency expectations are when applying for personal funding.

**#1: Be Aware of deadlines and funding limitations or restrictions!**

Often, State agencies are committing funding early in the year. Contact them directly for an application and be sure to note any deadlines. An agency may only cover registration fees. They may also limit the number of family members (typically two). Most agencies will not cover airfare. (*Do* include airfare in your proposed budget. It may be considered by the agency as part of the funds you need to "match", if required.) A very few agencies have no restrictions on how funds are used as long as they are used directly for conference attendance. Most agencies will only reimburse expenses after the conference is completed and all paperwork has been submitted. If you need assistance in paying for fees prior to the conference, ask the agency about their advance payments policy. If an agency offers to advance the airfare cost, book flights far in advance to obtain the best pricing. Usually, the earlier you book a flight the cheaper it is!

**#2: Apply to more than one agency/organization.**

Use their requirements to your best advantage: If an agency only pays registration fees, apply to another agency for hotel costs. *Do* indicate/note any other agencies/organizations to which you have already applied (or intend to apply) for funds. Most agencies like the fact that you are actively looking everywhere you can. In addition, specify what funds are being requested (airfare, hotel, registration) from each particular agency.

**#3: Follow all directions carefully on the specific agency supplied form(s).**

Some funding forms generated through State agencies can appear daunting and downright confusing. Contact the agency representative listed and ask about any questions you may have. They want to help you!

**#4: You may need to complete a separate funding request form for each individual.**

Some agencies will allow multiple requests on one application. Others require a separate application for each individual (self, spouse, child, grandparent, caregiver, etc.) Minor children are typically included with a parent/guardian, but funding is not usually available for children. If you can make a case for the sibling(s) of an individual with a disability becoming an advocate (in school, at your religious organization, Boy Scouts, Girl Scouts, 4-H, etc.), you may receive funding. Do include children in your budget to show total anticipated costs.

**#5: Include all contact information with your request.**

A representative may need to contact you to modify or clarify your application. Some also request contact information for any other attendees for whom funds are requested, even if submitted on one form. Give them any means to contact you that are available: Home phone, cell phone, fax, e-mail, and/or pager.

**#6: Include a copy of your completed registration.**

This will show the registration fee(s), included meals, conference agenda/schedule, and a description of activities. You may want to include a copy of the payment method used to pay registration fees.

**#7: Include an Expected Outcomes (Purpose) Statement for all applicants.**

An outcomes statement, even for children for whom you are not requesting funding, and whether the agency asks for one or not, can increase your chances of getting those funds! Agencies want to know you are going to take some type of action when you return from the conference.

***What is an Expected Outcomes Statement?***

An *Expected Outcomes Statement* simply tells what you hope to learn by attending the conference. How will you or your family member with a disability benefit by attending? How will attending the conference increase independence, productivity, and/or integration? What do you intend to learn or gain by attending? How and with whom will you share your knowledge?

Some agencies may have a prescribed form with this item included; other organizations may not. A single paragraph of explanation can be sufficient. Some agencies may request a report after conference (see below). Again, this is usually short, but it can be very helpful to the agencies. It can also be a good way to educate more people about CHARGE and the CHARGE conference.

**#8: Create an anticipated budget.**

This is, seemingly, the most difficult aspect of submitting funding requests. Include airfare/travel costs (mileage if driving, parking fees at airports), registration fee(s), hotel cost, meals outside of those included in your conference registration. (Many will have a per diem noted on the forms.) Airfare, depending on your request and the time frame submitted, may need to be an estimate, based on general information gained through early contacts with the airlines. If your travel arrival/departure dates are outside the conference dates by more than one day, you will need to justify the reason for these dates. (Examples: Airline schedules do not allow arrival before conference starts; Medical issues require extra day of travel.) Extending dates for family/personal vacation will not be acceptable to an agency, regardless of how long it has been since you had one! You know the registration fees and your hotel costs based on the information already published in CHARGE Accounts.

Some agencies may require you to show a matching amount. This means they will expect you to pay a certain percentage of the expenses/costs reflected in your proposed budget. Often, it is 30%, and usually less than 50%. Include all attendees in your budget, even children for whom you are not requesting funds, to show what your total expenses are anticipated to be. Some families or individuals receiving SSI, SSDI, or other State/Federal assistance may not be required to meet the matching requirement. Follow the directions on your request forms.

**(After the conference)**

**#9: Submit paperwork on time!!!!**

Be aware of deadlines!! Requirements for funding will typically include a deadline for submission of additional forms and *original receipts*. Often, you will need to submit items within two weeks following the conference.

Additional forms requested by the agency may include: Actual Expenses Reimbursement form(s), Outcomes Statement, Action Plan, etc.

Non-reimbursable items usually include activities or fees not associated with the conference:

- a. outside trips not affiliated with the conference or noted on the agenda
- b. tips/gratuities, events that don't provide training (outside of inclusion with registration)

- c. sight seeing trips, ground transportation not associated with travel to/from airport, car rental (if airfare paid), phone calls
- d. Continuing Education Units (CEUs), to name a few.

### #10: Outcomes Statement

Be sure that everyone receiving funding submits an outcomes statement, even children.

This states what you *actually* learned or gained by attending. It does not have to be different from your expected outcomes statement; but it can be. Maybe you learned more. Maybe you learned something you had not anticipated when you submitted your Expected Outcomes Statement with your funding request.

The funding agency may want to know how you will use your knowledge for the benefit of the community. How will you share that? You might state you will share information with family and friends, school staff, civic organizations, disability advocacy groups, support groups, parent-to-parent contacts, etc. Be willing to write an article for their newsletter or other publications.

Some State agencies may want a commitment about what advocacy you will be involved with or perform. Such areas of advocacy might include: Attend the Partners In Policymaking Academy (a State sponsored organization that teaches advocacy for and by individuals with disabilities), organize a disability awareness activity, participate in voter registration of individuals with disabilities, survey polling places for accessibility, provide testimony at public hearings regarding disability issues, perform a media watch, etc. Many of these items do not require a large amount of time, just the commitment to accomplish them.

With a little searching, research, good writing and attention to detail, obtaining funding to assist your family with conference expenses can be easier than you think. Agencies and organizations that promote a better life for individuals with disabilities are willing to assist if you just know how to approach them and do the paperwork.

#### **Funding Request Sample Letter**

*[This was my first attempt – in 1997 - at submitting a Governor’s Planning Council funding request letter to attend a conference. It easily covered all the requirements. You can see it is not a complicated letter. Then I just included the required forms and budget information. My anticipated budget was \$1,162. I matched 30% (\$383.46) and requested \$778.54, which I received once all paperwork was completed within the deadline after the conference.]*

Mr. Shankland [*Director*],

I am requesting Consumer Involvement Fund support from the Governor’s Planning Council for Persons with Disabilities in order for my husband and me to attend the 3rd International CHARGE Syndrome Conference, July 25 through 27, 1997. The conference is to be held in Boston, Massachusetts at the Boston-Newton Marriott Hotel. Enclosed is a copy of the schedule and registration information, as well as a brochure describing CHARGE syndrome. Also enclosed is a budget of anticipated expenses for participation.

The CHARGE Syndrome Conference, held every two years, will provide an opportunity to network with other families whose children are also diagnosed with CHARGE, which is a rare congenital disorder. The opportunity to associate with, converse, and glean information from parents and professionals who deal with CHARGE routinely is a unique opportunity.

We will use the information from the conference in conjunction with referrals received from the Indiana Parent Information Network (IPIN), the Human Growth Foundation, and parents we are in contact with through the Indiana School for the Deaf, where there are currently four children diagnosed with CHARGE. We are also working to establish communication with the Indiana School for the Blind (where there is one child with a diagnosis of CHARGE) to receive family referrals from that agency. We will be sharing educational service information with the special education parent group (approximately 15 families) within our local school district. Additional avenues we will be investigating are contacting Noble Center, Crossroads Rehabilitation Services, and Riley Children’s Hospital to become parent resources for those agencies. We will also share information with staff at all noted locations and with our school district’s Director of Special Education.

Our 8-year old son wants to be available to other families who have siblings to children with special needs/disabilities. We feel he can be a valuable resource to families who need to know what siblings need within the family dynamics, but are often overlooked. This can be established through the same agencies noted as contacts for my husband and myself.

Sincerely,  
Marilyn Ogan  
Parent of Kristin

## **The Parent Road Map; Your Guide to Raising a Child with Combined Hearing and Vision Losses** by Sally Prouty, Minnesota DeafBlind Project

My son Andy was born 27 years ago with CHARGE Syndrome. This was before the days of the Internet and I did not have the support of the CHARGE listserv and CHARGE Syndrome Foundation website. I always dreamed of some type of guidebook for our family on what seemed like a very lonely journey. Several years ago a parent at the Minnesota DeafBlind Project Family Weekend casually said, "We should write a book, we have so much wisdom to share" and the Road Map is the result. It's written entirely by parents and was designed by a professional freelance designer with thirty-three Minnesota families contributing photos and/or pearls of wisdom. One third of the contributing parents have children with CHARGE Syndrome.

The Parent Road Map; Your Guide to Raising a Child with Combined Hearing and Vision Losses can be downloaded at [www.dbproject.mn.org](http://www.dbproject.mn.org). The 32 pages are full of photos and parent quotes and the seven section titles include:

- We're on this road together – Welcome to Holland 3pp
- Coming to Terms 4pp
- Taking Care 4pp
- Getting Help 4pp
- Teaching Basics 8pp
- Reaching Out 4pp
- Caring for Family 8pp



The Road Map was developed through the Minnesota DeafBlind Project, and is posted on their website: [www.dbproject.mn.org](http://www.dbproject.mn.org). Because the file is quite large, it can be downloaded in 7 PDFs or the entire document in a .ZIP file at the bottom of the page. Feel free to read online or print and share as you would like. Please allow time for a full download as almost every page has photographs, which can be time consuming. We hope you enjoy it!

**Mom's Weekend Get-Away**  
*(for Mom's whose children have a combined vision and hearing loss)*  
Sally Prouty  
[mndb@skypoint.com](mailto:mndb@skypoint.com)



Eighteen women spent a relaxing 48 hours away from their every day responsibilities to unwind and learn with experts – themselves and professionals -- in deafblindness. These Moms, from every corner of the state, have children ranging in age from 17 months to 27 years. For many, this was their first time meeting others, but they quickly became a cohesive group. It was a refreshing weekend that included much learning, laughter and a few tears.

This 5th Weekend Get-Away was held just outside Minneapolis. We began Friday evening with dinner followed by introductions facilitated by me and Marlyn Minkin. Marlyn is a Marriage and Family Therapist from Seattle who has a long history of working with parents and individuals who have combined vision and hearing losses. When Marlyn wasn't leading the group, she chatted individually with each woman, supporting and recharging them through her vast experience.

Jerry Petroff, Project Director for the New Jersey Consortium on DeafBlindness was uplifting with his humor. He helped energize the women by understanding the usefulness of Person Centered Planning and a Values & Belief statement for their child.

There was plenty of free time built into the schedule. Over the years various Moms have done short presentations on topics where they have knowledge and expertise, including medical organization, skin care, crafts and yoga. Everyone had an opportunity for a massage. We enjoyed hilarious presentations in the evenings. Rather than sleep at night, some roommates talked into the wee hours.

These 18 women returned home Sunday afternoon energized, revitalized and more knowledgeable about deafblindness.\*

\*The rejuvenating Mom's Get-Away is sponsored by the MN DeafBlind Project and DeafBlind Services Minnesota. We've also hosted Dad's Weekends and Dad's Nights Out.

## Photos from the Mom's Weekend Get-Away

Who knew that tasting a cracker could be so frightening.



Many of the Mom's said the vision/hearing loss simulation activities were "life changing".

Safety was discussed, but we did not educate them on proper guide techniques prior to the activity.

They had a "real life" experience.

We had vision and hearing loss simulations – these Mom's are waiting to be guided inside and outside the building



**Thank You for Your Generous Support of the  
CHARGE It for CHARGE Campaign . . .**

**In Honor Of:**

***Burke Elias Nelson***

Julie & Gerry Wood CA  
Karen Bertero CA  
Laurence Bowman MN  
Karl & Connie Kramer WA

***Charlotte Cosenza and her family***

Lindy EyeCare Staff NY

***Ethan Wolfe and his family***

Naomi Amsterdam MD  
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Michael & Sherri Wolfe IL

***Jacob Hartshorne's Circle of Friends***

Denise Anthony MI

***CHARGE Syndrome***

Kim Blake Canada

***Nate and Chris Nelson***

Gary Nelson WA

***Jacob Hartshorne and his family***

Connie Spillers IN  
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Linda Salem CA

***Jacob Wynne and his family***

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***Justin Murray***

Bob Benn MA  
Pamela Dowd MA  
Chung-Li Ling CA  
Matt Murray MA

***Kennedy Weir and her family***

Rick & Shelly Campbell Canada  
Felipe Garcia Canada  
Fawn Ginn Canada  
Tanya Henderson Canada  
Julie Holmes Canada  
Della Pitre Canada  
Michele Sinopoli CO  
Stephane Baril Canada  
Doug Randolph WI

***Kimi Swanson's Adoption Day***

Lynn Swensen MN

***Kristin Ogan and her family***

Monica Desiderio CA  
Diann & Obi Andy TX  
Ruth Metz CA

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LuAnn Gatewood OH  
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Bob & Barb Miller OH  
Doug & Angie Rapol OH  
Sue Reed OH  
Jenny Sampson OH  
Carenina Waite OH  
Charlie & Marcy White OH  
Peggy Armentrout WV

***Mariana Machado and her family***

Percival Junior Caropreso Brazil  
Andrea Araujo Switzerland  
Roger Busby Ireland  
Barbara Fonseca US  
Anna Maria Machado Brazil  
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Margaret Bahe MO  
Jaye Shyken MO  
Susan Wiedenbeck PA

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***Irwin & Marilyn Brafman's 60th Anniversary***

Leonard & Joan Stanger FL

**In Memory of:**

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Ellen Branfman MA

***June E. Teefey***

Patrick Grady IL

***Justin Greenberg***

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