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WINTER, 2009

President's Message

2009 was an amazing year for the Foundation. I would like to take a little time to go over some of the milestones and also talk about our future.

In February, we made a decision that by the end of the year we would be going green; we now only print about a dozen newsletters while the rest are sent electronically. In March, we accepted the resignation of Marion Norbury, the Founder of the Foundation. While this was a difficult transition for the organization, it also showed the resiliency and strength of our new office. April, May and June were mainly filled with conference planning. Thanks to Brownie Shott and the entire Wolfe family, this year's conference was our biggest and best ever. We started the weekend with our first Professional day that was attended by over 125 people. On Friday, we had over 750 people come to our opening session and stay throughout the entire weekend, including our Saturday night carnival, where the kids loved listening to Rachel Coleman and the parents got to spend some money at our silent auction. I am proud to say that the Foundation was able to offset well over \$100,000 from the cost of the conference to keep it affordable to all families. We also welcomed our two newest board members in July and Cynthia Antaya and Diane Haynes have already proven to be huge assets to our group. Our new Executive Board was also formed in July with Lisa Weir (VP), Brownie Shott (Secretary) and David Wolfe (Treasurer). We have been talking and meeting on a regular basis to ensure that 2010 and beyond are even stronger years for the Foundation.

In the next year we will have more money available for research, we will no longer charge registration fees to our conferences for anyone with CHARGE syndrome and we will now offer a first year membership at no charge for any immediate family of a newly diagnosed individual with CHARGE syndrome. We are also busy planning our 2011 conference in Orlando and looking into sites for our 2013 conference. Finally, if you need me for anything please feel free to call me at 914-629-0564 or email me at

neal@chargesyndrome.org.

I hope you all have a happy and healthy 2010.



It Can Be Done

2009 has been a very special year for the Foundation. One of the most important things the Foundation does is the biennial conferences. They are very expensive and cost the Foundation over \$100,000 more than we take in from registration fees. This year, thanks to all of the fundraising efforts, we were able to offset and absorb over \$100,000 in conference related expenses and not drain the Foundation dry!



We have enough that the Board of Directors was able to earmark \$30,000 for research. Our Research Committee is actively searching for the best ways to allocate these funds. We also decided to cover registration and childcare fees for anyone with CHARGE syndrome attending our 2011 conference!

(continued on page 2)



Jody, Ethan and Daniel Wolfe, participating in the Joshua Kurby Memorial run for the CHARGE Syndrome Foundation.

“...fundraising is rewarding on many different levels.”

It Can Be Done

(continued from page 1)

None of our recent accomplishments would be possible without the hard work and dedication of the people mentioned in this issue of *CHARGE Accounts* and others like them.

Despite the many achievements of the Foundation, there is so much more work to be done. Budgets for programs that assist individuals with CHARGE syndrome are being slashed. Many charities are reducing services, while others are closing their doors. So many medical professionals, educators and even families, still have no idea how to effectively work with an individual with CHARGE. We need to renew our dedication to our mission statement by providing **more** support to individuals with CHARGE and their families, **more** information about CHARGE and **more** research about its identification, cause and management. All of this can be done if we work together to raise money for the Foundation.

In this season of giving, I hope all of you will join us and support your Foundation. As you can see by reading the stories in this newsletter, fundraising is rewarding on many different levels. Never underestimate the personal satisfaction you will get, knowing you made a difference in the lives of all those dealing with CHARGE. Fundraising brings increased awareness. Your friends, family and colleagues may gain greater appreciation for the remarkable accomplishments of individuals with CHARGE. If you have not started already, please begin your online fundraising campaign. Every donation counts.

As you set your New Year's resolutions, make it a goal to give generously with your time. Plan a run, walk, golf outing or other benefit. Encourage your friends and family to join the Foundation. Together, we can make a difference. Remember, IT CAN BE DONE!

Happy Holidays.

David Wolfe
Treasurer, and Fundraising Chair
CHARGE Syndrome Foundation, Inc.
david@chargesyndrome.org

Editor's Note

On page 13 of the Summer/Fall 2009 issue, the last line of the article at the top of the page was missing. Here is a reprint of the last paragraph of that conference report about smell and puberty, with the missing line included. We apologize for any inconvenience this may have caused our readers.

The importance of puberty beginning at the typical age includes fewer socio-emotional problems and a reduced risk of osteoporosis. A smell test may be helpful in predicting whether spontaneous puberty will occur in individuals with CHARGE as smell and puberty problems were 100% correlated in this study. Decisions about treatment for delayed puberty can occur ahead of time instead of just waiting and waiting to see if it happens spontaneously.

Celebrating Fundraising



An enthusiastic participant at an Illinois bowling fundraiser for the Foundation.

In the next series of articles, we will be focusing on stories about fundraisers that have been held in the past. I would like to take a moment to thank everyone who submitted stories and photos. We hope they will inspire others to get involved in whatever way they feel they can.

If you, or someone you know, has undertaken a fundraiser or is planning on doing one in the future to support the Foundation, we want to hear about it! We will be celebrating the wonderful fundraising achievements of everyone throughout the newsletters to come.

It doesn't matter if your event is big or small, every penny counts and we want to share your efforts with all of our readers!

Please send your fundraising stories and photos to Lisa (lisa@chargesyndrome.org).

Enjoy the newsletter!

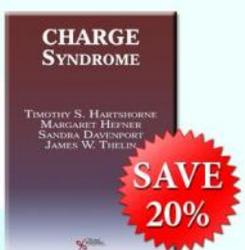
"I decided to do the fundraiser to help raise money for research for CHARGE as there are still so many questions unanswered..."

Bola Walk in Support of CHARGE Syndrome

I first learned about CHARGE syndrome when my son Jacob was born. He was diagnosed based on his choanal atresia, blindness, deafness, cerebral palsy, a heart condition and his overall growth and development was significantly delayed. Before his birth, I had never even heard of CHARGE syndrome. Jacob did not survive as a result of his physical complications. I decided to do the fundraiser to help raise money for research for CHARGE as there are still so many questions unanswered regarding his conditions.

I wanted to try and turn something so negative (the loss of our son) into something positive (helping others). I wanted to raise money to help for possible prenatal testing. My first year goal of raising money and bringing people together for a good cause was successful. I was able to raise \$3,600. There were approximately 100 participants and 15 sponsors. Two months prior to the event, I sent several businesses a letter, telling them a little about Jacob's story and about CHARGE. I posted flyers at several local businesses and informed people through word of mouth. This event was obviously very personal for me, so I tried to do as much of it as possible myself. To anyone looking to start a fundraiser, I would recommend getting as many people involved as possible. It helps in spreading the word and informing people about CHARGE. I wish I had started sending the letters a little sooner too. Overall, it was a great day and I am definitely looking forward to doing it again in June of 2010.

Submitted by MacKenzie Bola



New CHARGE Syndrome Book

A new book on CHARGE syndrome, written by Timothy Hartshorne, Margaret Hefner, Sandra Davenport and James Thelin, is due out in summer 2010. The book is available for preorder now. All copies ordered in advance receive 20% off the cost. To preorder your copy, visit Plural Publishing at:

http://www.pluralpublishing.com/img/flyers/CHARGE/web_flyer_charge.html

Inaugural Joshua Kurby Charge for CHARGE 5K



Joshua's twin brother Joey, finishing the race.

"Some of our greatest compliments were from people we didn't know..."

More race participants heading to the finish line...



CHARGE Accounts interview with Sandy Kurby, who organized an event in memory of her son, Joshua.

CA: What is your connection to CHARGE syndrome?

Sandy: I first became aware of CHARGE syndrome after my twin boys were born on July 3, 2008. A few days after their birth, Joshua was diagnosed with CHARGE syndrome, although he never tested positive for the gene. Within moments of hearing his diagnosis we were in the NICU on a laptop looking up CHARGE and came to the CHARGE Syndrome Foundation website. We had the nurses print out the manual, and the entire site, Foundation, and members have been the best support ever since.

CA: Why did you decide to do a fundraiser?

Sandy: On March 14, 2009 my son Joshua passed away at 8-1/2 months of age. While he did not die because of CHARGE syndrome, it was considered a secondary cause because of his compromised system. I had been an avid runner for years before Joshua and Joseph were born and wanted to do something in honor of Joshua while raising awareness about CHARGE. It wasn't until the very end of March that I decided to commit to hosting the 5K event.

CA: Tell me about the event, how did it go?

Sandy: The Inaugural Joshua Kurby Charge for CHARGE 5K was a run/walk event held in our local park. We had many volunteers helping out with water stations, start/finish, registration, etc. We came up with the course, got permits for the race and for sound amplification since we had a DJ there as well, got sponsors to donate bagels, got other food, water, and Gatorade, designed and printed t-shirts, bib numbers, and made signs to direct participants on the course, thank our sponsors, and also a sign to inform others about what CHARGE syndrome is. The event went really well. There were many CHARGE families, Josh's NICU nurses, friends, neighbors, and people we didn't know that attended. Some of our greatest compliments were from people we didn't know:

-I wanted to take a moment and thank you for the Charge 5K event. I enjoyed the course immensely, rarely do you have an opportunity to run a path that doesn't end up as an out and back or a twice-around. I didn't become bored or impatient and was able to relax into a great run. The bagels were a nice touch. Please tell Panera thank you from me. I appreciate that they would support their community in such a generous fashion. The bagels were the wonderful. I have always been a Panera patron and now I like them even better.

Kind regards,

-- Rebecca

Just wanted to take a moment and Thank You for the wonderful event you hosted this weekend. My girlfriend and I were in town on business and chose your event because we liked the cause and the location. You and your volunteers did a great job with

(continued from page 4)

sponsorship, registration, course layout, timing, and all the small things that make for a pleasant event. Most important, your group created a welcome atmosphere with lots of friendly, smiling faces eager to help in any way they could. Congratulations on a successful inaugural event. Hope you were able to further the CHARGE cause and thanks for educating us and letting us help support this worthy endeavor. I hope you will sustain it for years to come. And, I hope I will be able to attend again.

Thanks again, and well done.

Rob

P.S. As a result of their sponsorship of your event, Panera Bread has gained a fan as well as a customer. I will make it a point to stop at one of their shops whenever I can.

I had a great time. I would have liked to have stayed and talked more, but I had to get my son to Taekwondo lessons. I am glad the rain held off for most of the event to make it easier on everyone. I hope your sister felt it was a success. I certainly did. I hope she is able to have it again next year.

Since I am not very familiar with CHARGE, I don't know the details of how it affects kids and families, but given the mortality rate associated with it, I am surprised it hasn't received more media attention. Hopefully, with awareness events like this, it will get more attention, funding, and research.

Please let your family know it was a great inaugural race.

Ryan

Thanks, Sandy,

*It was a nice race and I'll be looking forward to doing it again next year.
Rock (a gentleman that placed in the race)*

CA: What advice would you give to others trying to plan a fundraising event?

Sandy: The advice I'd give others trying to plan a fundraising event is to think about your personal interests and experiences and go from there. I had been a runner for several years, ran 8 marathons before my twins were born, and felt like I knew what necessities are a part of holding a run/walk event. I learned that there was more that goes into hosting a race than I thought. The other piece of advice is to pick your event and commit to it. The hardest step for me was setting the date: calling the village and park district to make sure the date was ok, and contacting our race timing company to ensure the date would work for them as well. Once I made that first commitment, and wrote that first check it was scary. You wonder if you'll make the money back that you are putting in (next year I would like to get sponsors to make the event cost free to us, but given our short time to really plan I couldn't seek sponsorships like I would have liked), you wonder if anyone will show up, and you wonder if you are crazy for doing it. It is well worth it. Everyone had a great time- participants, volunteers, those that just came to cheer others on. It is a great way to raise awareness and raise money for the foundation. I think the first year is the hardest, but there are people willing to help, willing to sponsor, and willing to make your event the best it can be. All you have to do is start the process.

CA: Would you do this event again?

Sandy: Definitely! I am going to make this an annual event. I decided before the race that I would take a month off before thinking about or planning for next year, but I can't help but let the wheels spin in my head while I come up with ways to improve or things to change for next year. It was such a worthwhile event and most of the volunteers I had already told me to count them in for next year.

“Everyone had a great time- participants, volunteers, those that just came to cheer others on.”



Phil and Sandy Kurby, Joshua's parents and organizers of the run.

Joshua Kurby Memorial Run: A Participant's Thoughts



Crystal Masionis is pictured here with (L-R) race organizers Sandy & Phil Kurby and her husband, Dan.

"It will keep Joshua's memory alive forever."

This morning was the walk/run Sandy and Phil Kurby put together in memory of their son Joshua. Let me tell you a little bit about this wonderful couple: sadly I met them in one of the most horrible moments a parent can go through, the loss of their child.

I was on the CHARGE listserv one day and I noticed another child with CHARGE had passed away, then I noticed they had a blog. I went to it and saw they live here in Illinois. I knew I had to go and pay my respects to the family.

When I met them, they were so loving and so caring, they also seemed VERY happy to see another little one with CHARGE. Eva gave them all light and they just loved having her there. I told them at the funeral I want to do my bowling fundraiser not only in honor of Eva but in memory of Josh (I am also doing it in memory of Ava). Sandy and Phil LOVED the idea, I think it also sparked something in Sandy because she wanted to do something as well.

Sandy likes to run, so she put together this wonderful 5 K run/walk for CHARGE syndrome in four months. I think it's amazing how someone who is going through one of the hardest times of their life can do something like this and turn a bad thing into something good. Sandy and Phil are such strong, loving and caring people and the fact that they came to the conference and plan on going to more, even though Joshua is gone shows they have fallen in love with our CHARGE family. We are honored and blessed to have them here for us. I do believe this is a way to heal; doing something in honor of a loved one like this not only keeps you busy but energized to keep going and doing more for others. It was an amazing morning, even if I did wake up a little late and missed the start, but I feel honored to have been there none the less.

Thank you Sandy and Phil for all your hard work!!

Submitted by Crystal Masionis

Running to Promote Awareness

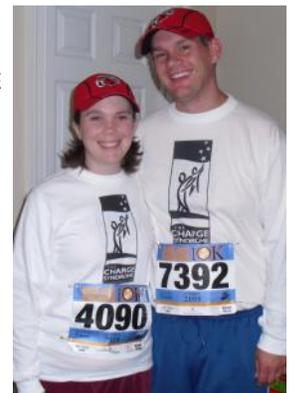


Cynthia running in the 2009 Marine Corps Marathon 10K race.

On October 25, 2009, my husband Keith and I participated in the 2009 Marine Corps Marathon 10K race. We ran with shirts that proudly displayed the CHARGE Syndrome Foundation logo. We got MANY inquiries about CHARGE and the Foundation. Super exciting! Anyway, we had a great race and it was an honor to represent the Foundation in this event. Keith finished at 1:26 and I finished at 1:34.

Submitted by Cynthia Antaya

Are you a runner? Is there an upcoming run in your area? If you're going to be participating, why not considering using the race as an opportunity to raise awareness of, or funds for, the CHARGE Syndrome Foundation? Please contact fundraising chair, David Wolfe (david@chargesyndrome.org) for ideas on how we can help support you in your endeavor!



Board member Cynthia Antaya and husband Keith, gearing up for the big race.

Christmas Music Fundraiser



Michael Clark has a niece with CHARGE syndrome. He runs a network of Internet radio stations that play Christmas music year-round and is launching a fundraiser. This year, part of the proceeds he raises will be donated to the CHARGE Syndrome Foundation.

What made Michael decide to do this fundraiser?

Clark says, "My niece has CHARGE, she's now four years old. Her parents have been

to two CHARGE conferences so far, and they have nothing but positive things to say about the Foundation."

To check out Michael's fundraiser and listen to some great holiday tunes, please visit: <http://www.christmasmusic247.com/>



"We also want to be ambassadors and educators so that the number of people who say "What is CHARGE?" dwindles to nothing."

Karaoke Fundraiser in Memory of Trey

My son, John Thomas Chatham III "Trey" was born 6 weeks early on March 23, 2009. He passed away due to brain trauma and complications from CHARGE syndrome. He is our inspiration to help the many families with loved ones who bravely live with CHARGE. We also want to be ambassadors and educators so that the number of people who say "What is CHARGE?" dwindles to nothing.

We wanted to honor the day he was conceived with a benefit because that marked the day our CHARGE journey began. This is the first of many ideas we had to raise money. My favorite karaoke bar, Faces Lounge, in Marietta, Georgia was happy to host the event. We held an auction and sang the night away. We also sold the Trey soundtracks I made while I was pregnant with him. Lots of family, friends, and new friends showed up and we raised \$3707! We had the help and support of a dear friend of mine, Karen Dedier, who has organized auctions for her daughter's marching band.

I would suggest that whatever type of event you choose to do, recruit someone who has experience with that type of event so their expertise will increase the success of the event. I would DEFINITELY do this event again. I have lots of other ideas as well, but that night was so much fun and for a worthy cause!



Some of the goodies up for grabs at the silent auction table.



Trey's parents and fundraising organizers Sharon and John Chatham at the big event.

Bowling for CHARGE



Some of the bowlers at the first Bowling for CHARGE event in Illinois.

On Sept 19th, 2009, I held my very first fundraiser ever. I have done the online money raising thing and I have been to plenty of fundraisers, but this was different. This was mine and for a cause I hold dear to my heart, CHARGE syndrome.

I started planning this back in January. I talked to a manager of a bowling alley near Chicago and booked a day for the fundraiser. From that point on, I could invite people and collect donations. I got donations from many local companies along with American Girl Doll, Chicago Cubs, Chicago Bears and many more. We asked for a donation for bowling: \$25 for adults and \$15 for kids. They were able to bowl and have pizza and soda.

We also gave each paid bowler a raffle ticket. We had a room with all of our donated raffle prizes, with about 35 prizes for people to choose from. People could not believe all the prizes we had. Everyone had lots of fun. We had about 60 people there and I have to say that is pretty good for all word of mouth and for my first fundraiser. I also made a wonderful slide show with pictures of Eva and info about CHARGE syndrome, which played during the whole fundraiser. I also had a slideshow in memory of Joshua Kurby. Our fundraiser was also in memory of Ava Barbarino. Joshua and Ava had both passed away recently.

In the end, we had a day of fun and raised nearly a thousand dollars! I know it can be a lot of work, but in the long run everyone that came had a lot of fun and learned more about CHARGE. Some people took home some great prizes. It was a day I will never forget. I cannot wait to do it again next year!!

Submitted by: Crystal Masionis



Raffle table at the Bowling event.



Eva Masionis takes in some of the action from her super-cool wagon!



Happy faces all around at the Bowling for CHARGE event!

Other "Fun"draising Ideas

Facebook:

Are you on Facebook? Have a birthday coming up? If you are a member of the CHARGE Syndrome "Cause," you can set up a Birthday Wish. Causes will advertise your upcoming birthday and your "wish" for your friends to make a donation that will benefit the Foundation. The CHARGE Syndrome Cause on Facebook can be found at: <http://apps.facebook.com/causes/100537?m=3f1cca43>. They have step by step instructions for setting up your birthday wish.

The Foundation also has its own Facebook page now – you can find us at:

<http://www.facebook.com/group.php?gid=2239201315>



CHASE Community Giving Campaign



Another fundraiser currently available to all of you Facebook users is the CHASE Community Giving Campaign. CHASE bank is giving away five million dollars to various charities and they want YOUR help in choosing which charities get the money. The CHARGE Syndrome Foundation, Inc. is listed as one of the eligible charities.

To vote for the Foundation, log into your Facebook account and go to: <http://apps.facebook.com/chasecommunitygiving/>.

You will see a box that says, "Search for a Local Charity and Vote Now". Type "CHARGE Syndrome Foundation" in the box and it will pop up. After you become a fan of CHASE bank, you can vote for the Foundation.



"He uses the technology so well, and he realizes the benefits that the technology gives him."

CHARGE In the News

Day in the Life

Lori Myers and family from Texas, were featured in the Summer, 2009 online magazine, "Thrive" with a "Day in the Life" article. The article can be found on page 18 at:

<http://www.pageturnpro.com/Dallas-Child-Magazine/6458-DallasThrive-Summer-09/index.html>

Ethan's achievement

Congratulations to 7-year-old Buffalo Grove resident Ethan Wolfe, who has won the "Outstanding Technology Achievement Award" from Infinetec, the technology branch of United Cerebral Palsy.

"Ethan was born with CHARGE syndrome (www.chargesyndrome.org) and spent the first few months of his life in the NICU," mom Jody Wolfe said. "The first few years he was sick with pneumonias, underwent many surgeries and spent much time in the hospital. Although he's faced many medical challenges and is considered deaf-blind, he continues to thrive both medically and developmentally.

"He can walk independently, is learning to read, can communicate his wants and needs with his communication device or by sign language and is starting to eat by mouth. He has had a cochlear implant for 4 years and can hear and understand speech. He is a happy little boy who loves to play and laugh."

At school, Ethan has a Dynavox, which is a small computer with certain phrases programmed to say what he wants. When he presses the keyboard, it talks for him. He also uses a CCTV, a closed circuit TV with a magnifier to see close up or at a distance. Additionally, Ethan uses a "Big Keys" keyboard for people with low vision.

"His assistive technology team from school nominated him, and he was the youngest winner from all across the north and northwest suburbs," Jody Wolfe said. "He uses the technology so well, and he realizes the benefits that the technology gives him. He can expressively communicate his wants and needs with all the different methods of communication."

(This article appeared in the Buffalo Grove-Countryside paper on July 9, 2009.)

Have you seen a CHARGE-related article in the news? Pass it along to CHARGE Accounts at lisa@chargesyndrome.org



7-year-old Ethan Wolfe, receiving the Outstanding Technology Achievement Award.

Charge It for CHARGE: A Parent's Perspective

I just wanted to share my two cents about the Charge it for CHARGE online fundraising campaign.

For us, at this point, the idea of hosting an event (even a pizza party, which is a great idea) was too much to take on. We've got two little ones, and last year we were both working. Gracie's medical issues are still pretty significant and we were approaching our cross-state move. Once we moved, we had no nursing help and didn't have any family or friends to help us out locally. Clearly, event planning was still out of our grasp of reality. But, when Charge it for CHARGE rolled out, I thought, "That's something I can do."

Little did I know what the response would be! Our family and friends have always wanted to help in some way possible and most of them couldn't in a tangible way (which is what they wanted to do in addition to the emotional support they give us). "Charge it for CHARGE" was something tangible they could do to support Gracie, honor her, support us, and of course, support the Foundation that they know has been instrumental in providing us with critical resources and information, especially in those first, very scary couple of years.

I sent out an email from my own database (I did not use the site's email feature for ease of time for me) and the response was unbelievable. Our page generated donations from friends and family, of course, but also from some people that we don't even know personally! I was amazed. I was completely touched by everyone's generosity, people gave what they could and in this economic climate, a dollar is hard to part with.

The important thing I'd want to stress to anyone else about this is: *it took me all of 30 minutes*. Except for very personal thank you's to donors, all I had to do was send out one email about CHARGE and the campaign. I always intended to follow-up, but never had the chance. This is something so simple that can have such a profound impact, especially on a Foundation as small as ours. Events are fabulous. They create publicity and community knowledge, etc., but for those who just can't get something together (and even for those who can) I think it's so important for people to realize that this campaign is a very simple way to help make a difference. It takes so little time and so many people in all of our lives truly want to help and can't in any other tangible way. I actually received emails from several people thanking me for giving them the opportunity to finally do something! *Thanking me* for the opportunity to make the donation... can you believe that?!

The campaign is a brilliant idea - - and I can't wait to see how much more can be raised this year!

- Kristi Swann

The following quote came along with a donation made in Gracie's honor to the Charge it for CHARGE

"This is for all the lovely children born with CHARGE. Through Gracie, I have witnessed courage, perseverance and strength I would have considered impossible in children so young and faced with such daunting challenges. Since her birth, my heart and soul have been filled by her; at times with sorrow for her pain and condition, at others with admiration for her strong personality and desire to overcome any obstacle, but always by my love for her and the love she returns, total and unconditional. I'm in complete awe of these children and the dedicated and loving parents, family members, doctors, care-givers, teachers, friends and researchers who give so much to make their lives happy, healthy and complete. I love you all."

-Kristi's stepfather, Jim Carey

"...this campaign is a very simple way to help make a difference."



Kristi and Gracie Swann.

Charge It for CHARGE: A Step by Step Guide

This year's campaign has a great new feature for new users to Charge It for CHARGE – a step by step instruction guide. It is available on the campaign website and reprinted here for your convenience.

The first thing you need to do is visit the campaign web site at:
<http://cfcsecondannual.kintera.org/faf/home/default.asp?ievent=324400>

At the website, just follow these step by step instructions and you'll be on your way to becoming one of the "top fundraisers" in the 2nd Annual Charge It for CHARGE campaign:

- Select "register now" to become a fundraiser.
- Fill in the required name/address and e-mail information.
- Create a username and password. Keep it simple. Remember your username and password.
- At this point, you can enter your own donation to get the campaign up and running.
- Set a fundraising goal and click "continue." (Each fundraiser's thermometer reflects the progress against that goal.) You can always change your goal.
- Click on "start here", and then click on your personal page.
- Fill out line 1 and line 2.
- Select an image from the library or upload your own small photo or just use the default photo.
- We suggest that you leave the "choose a background theme" as "standard."
- Edit the caption and edit the text under the photo if you want to.
- Click "preview" to proof your personal page. If complete, click "submit" to finish the web page. Then, click on "e-mail."
- Use the standard template with minor revisions or create your own personal message for friends, family and colleagues. Be sure to substitute your own name at the bottom of the standard text. Don't forget to save your personal template.
- Enter a subject and message that will appear in the center of the e-mail (or just use the defaults.)
- Preview the e-mail.
- Enter e-mail address (up to 30 at a time), and then enter the appropriate greeting for each email (e.g. Dear Aunt Margaret, Dear Penelope, or Dear President Obama. Do NOT add a comma or colon - that's system generated.)
- Click "Send Email" and watch the funds roll in.
- The system automatically sends a receipt/thank you to anyone who donates.

"...follow these step by step instructions and you'll be on your way to becoming one of the top fundraisers."

Discover Conference at Perkins

Perkins School for the Blind, the National Association for Parents of Children with Visual Impairments (NAPVI), and the New England Consortium Deafblind Project (NEC) recently hosted the Discover Conference.

This conference was held at Perkins, in Watertown, MA with sessions focused on advocacy, technology and sharing of wisdom and experiences amongst families. Of the 60 attendees, 12 were family members who had a child with CHARGE, seen here in a group photo taken at the conference.



The CHARGE contingent at the Discover Conference, pictured with Board member Pam Ryan and Martha Majors, Assistant Education Director, Deafblind Program

For more information about the Discover Conference, please visit:
<http://www.perkins.org/whatsnew/discover-the-possibilities.html>

Websites for Parents of Children with CHARGE Syndrome

Jula Charoenying, a student from the University of Wisconsin-River Falls who is studying under Foundation Board member Lori Swanson, has compiled a list of web sites for parents of children with CHARGE syndrome. If you know of a website that would be helpful for folks to know about, please email it to us at lisa@chargesyndrome.org and we'll be happy to include it in the newsletter!

CHARGE Websites:

CHARGE Syndrome Foundation <http://www.CHARGEsyndrome.org/>

This website offers a packet of information for new parents of children with CHARGE, the Foundation newsletter (*CHARGE Accounts*), a video about CHARGE, information about the Biennial International CHARGE conferences, and links to journal articles and other resources. There is a section devoted to clinical diagnostic information. The Foundation has Board members who are parents of children with CHARGE and professionals dedicated to this population.

Parent Road Map by Sally Prouty (May, 2008) <http://www.dbproject.mn.org/>

This manual is for new parents of children with CHARGE. The author is a family specialist and the coordinator of the Minnesota Deaf-Blind Technical Assistance Project. The manual focuses on issues parents face at the beginning of their child's life with CHARGE as well as subsequent challenges.

CHARGE Lab at Central Michigan University http://www.chsbs.cmich.edu/timothy_hartshorne/

This website has an excellent list of research publications related to CHARGE.

CHARGE Syndrome Listserv <http://health.groups.yahoo.com/group/CHARGE/>

This is a support group for families, caregivers and professionals with an interest in CHARGE..

CHARGESyndrome.info: Sharing our experience with CHARGE <http://www.CHARGESyndrome.info/>

This site has stories about one child with CHARGE, Kennedy, to which you can relate to while raising your child with CHARGE. This website also has links to many other family sites related to CHARGE.

International CHARGE Syndrome Websites:

- Hilton Perkins <http://www.perkins.org/international/about/hilton.html>
- CHARGE Syndrome Canada <http://www.CHARGEsyndrome.ca/>
- CHARGE en Francais <http://lenob.club.fr/index.htm>
- CHARGE Syndrome German <http://www.CHARGE-syndrom.de/>
- Dutch CHARGE Syndrome Network <http://www.CHARGEsyndroom.nl/>
- CHARGE Syndrome Association of Australasia Ltd. <http://www.CHARGEsyndrome.org.nz/>
- The CHARGE Family Support Group UK <http://www.chargesyndrome.org.uk/>



DeafBlind Websites:

Helen Keller National Center <http://www.hknc.org/>

The Helen Keller National Center enables deafblind students to choose where they live and work. This website contains information on rare syndromes, vocational and rehabilitation services, and grant services among many other resources. This website offers practical advice for educational opportunities and community involvement for people who are deafblind.

Perkins School for the Blind <http://www.perkins.org/>

The Perkins School for the Blind is located in Massachusetts. The Deafblind Program offers admission to children who are deafblind from birth through twenty two. The School has an early learning center, a lower school, a Secondary school, Deafblind services, Health services, an Assistive Device center, and the Pappas Horticulture Center.

National Consortium on Deaf-Blindness <http://www.nationaldb.org/>

This website contains the DB library, conferences and training programs, job opportunities, and new publications. NCDB provides technical assistance to youth who are deafblind as well as information on educational programs for children and their families. The website has information for assessment, communication, curricula, early intervention, and family resources including parent information, IEP preparation, instructional strategies and modifications.

American Association of the Deaf-Blind <http://www.aadb.org/>

This website contains a host of resources and the front page has headlines about what is new within the Deaf-Blind Community. One topic of interest for website visitors is the Support Service Provider Summit which examines SSP services across the country. The Deaf-Blind Count is a project that helps to determine statistics of people with combined vision and hearing loss around the country.

National Family Association for Deaf-Blind (NFADB) <http://www.nfadb.org/aboutus.htm>

The mission of the NFADB is to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs. This website is a good resource that offers links to many articles and websites within the DB community, including lots of information on CHARGE syndrome.

SKI HI Institute <http://www.skihi.org/>

The SKI HI institute is an organization that is dedicated to enhancing the lives of children with disabilities. There is a link section to the Hadley School for the Blind, a preservice training program in deafblindness, fundraisers like the Alaskan Bike Run, and links to the newsletter, resources and materials.

Kentucky Association for Deaf-Blind http://www.aadb.org/resources/db_organizations/kentucky.html

This is an extension of the American Association of the Deaf-Blind. The mission of the association is to insure that people who are deafblind achieve their potential as independent, productive and included members of communities.

Sense for deafblind people <http://www.sense.org.uk/>

This website has an area which answers "What is deafblindness?" It describes various conditions which lead to deafblindness, including CHARGE. The CHARGE section has a link to a CHARGE family support group.



Continued on next page...

(Continued from page 13)

Other Helpful Websites:

The Lighthouse, Inc. <http://www.lighthouse.org/>

The Lighthouse provides Vision Rehabilitation through low vision service, Mental Health and Social Services, Orientation and Mobility Training, Occupational therapy, and Assistive Technology Training. The education center offers the Filomen M. D'Agostino Greenberg Music School, the Child Development Center, the Lighthouse center for Education, and the Assistive Technology Center.

Texas School for Blind and Visually Impaired <http://www.tsbvi.edu/>

The Texas School for the Blind and Visually Impaired offers educational services for children who have any visual impairment. They also have a wonderful assortment of articles and information you can download.

The Low Vision Gateway <http://www.lowvision.org/>

The Gateway offers resources on low vision aids, rehabilitation services, vision loss, impairment and blindness.

Seeing, Hearing and Smelling the World <http://www.hhmi.org/senses/>

The Howard Hughes Medical Institute offers insight into all of the human senses in articles that explain how the human body works.

Coloboma Group <http://groups.yahoo.com/group/coloboma/>

This is a listserv for people and families with coloboma. They have really good diagrams and information about effects of coloboma.

Congenital Heart Defects <http://www.congenitalheartdefects.com>

The Congenital Heart Defects Community is connected and supported on this informative website.

Family Connect <http://www.familyconnect.org/parentsitetime.asp>

Family Connect offers interactive support for families with children who have visual impairments to lead a life that they will enjoy.



*Do you know of
any great
websites we
should share
with other
families?
Please send
them in!*

*Send us
your stories
about
making the
decision
about
whether to
have
another
child.*



Upcoming Newsletter Topic

We need your input!

Many parents have questions about conceiving again after they have had a child with CHARGE syndrome. We are looking for your stories about having or not having another child after your child with CHARGE.

What influenced your decision? Did you have another child or decide not to? We would love to hear from as many parents as possible.

Please send any stories and pictures to lisa@chargesyndrome.org.

Research Participation Opportunity

This research opportunity is for adolescents and adults with CHARGE syndrome regarding quality of life and the ongoing medical issues

If you are 13-years or older, and have CHARGE syndrome, we would like to invite you and/or your parent or guardian to participate in our current research study.

There is still little known generally about the problems older people have when they're growing up with CHARGE syndrome. We would like to ask you questions about your life with CHARGE syndrome. The questionnaire will take approximately 30-45 minutes to fill out. Some of the questions will be about things that are good in your life, some about what is not so good. This is described as "the quality of life."

This research study is being conducted by a medical doctor, Dr. Kim Blake, and a psychologist, Dr. Nancy Salem-Hartshorne. Kim has worked with people with CHARGE for more than 20 years. Nancy has a son with CHARGE syndrome.

If you volunteer to participate, a packet will be sent to you that will include consent forms and the questionnaire to be sent back to us.

Please contact us via email or telephone if you would like to be a part of this important research!

Nancy Hartshorne:
harts1ns@cmich.edu
(989) 774-6469

Dr. Kim Blake
kblake@dal.ca
(902) 470-6499

"There is still little known generally about the problems older people have when they're growing up with CHARGE syndrome."

Medical Supplies Available

The following medical supplies are available from Sandy Kurby, who can be reached at joshypooshyk@yahoo.com

Tube feeding stuff:

- back pack that held a kangaroo pump and bag
- 30- Kangaroo pump set/TF bags 1000ml

Trach Stuff:

- 4.0 ped Shiley
- 4- 3.5 Ped Shiley
- 1- 3.0 Ped Shiley
- 1 - 4.0 Neo Shiley
- 1- 3.5 Neo Shiley
- 7- 3.0 Neo Shiley
- 1- 3.5 Neo Shiley
- 1- 3.5 Neo Smiths
- 40- suction catheters 8 Fr.
- 30- Neotech Little Suckers2-BBG nasal aspirator



- 40- Humid-vent mini's
- 1- canister top and tubing for suction machine
- Trach tube holders- Dale 240 Blue "Fits Most"
- 2 Airlife for neonates and infants
- 1 Airlife one size fits most
- 2 Nonconductive connective tubing 5mmx1.8m (for suction machine)
- Nonconductive connective tubing 20"1 3/16 diameter (for suction machine)
- 22mm tubing (Hudson)- 100 feet can be cut for humidifier/trach collar

Miscellaneous:

- 18 small packets Surgilube
- 3- 60 ml (2 oz) Syringe
- 1-Infant face mask size
- infant nasal cannula infant (for O2)
- 21- adult/neonatal
- 1 L bottle sterile water
- SpO2 disposable sensor
- 2-1L bag sterile water
- 30- small saline droppers
- 1-Ambu bag

History and Helpful Info about the Texas Chargers Family Retreat



“We love attending the retreat each year, just to be around other families that have walked down our similar journeys with these special children!”
 - Father of a child with CHARGE

The Texas Chargers organize an annual two and a half day family retreat. This retreat provides a stress free environment for families to connect with others affected by CHARGE syndrome, so they can share their joys and challenges and give the children with CHARGE opportunities to meet friends so they know they are not alone.

History and Birth: Cathy Springer, an energetic mother of four, the youngest of whom was born with CHARGE Syndrome, was approached by Texas School for the Blind and Visually Impaired to be on a Deafblind Leadership program in 2005. Through this program she was required to have a project. It was Cathy’s dream to have her little girl meet other children with CHARGE, so she decided to throw a party for all the families affected by CHARGE Syndrome in the state of Texas. The Texas Chargers held their 1st Retreat in October of 2006 in Killeen, Texas with 21 people who have CHARGE attending and 100 family members. The numbers were so large that the grandparents of Lexi Barksdale, Wallace and Emmadell Vernon, offered to start a non-profit with a few other families that would support families affect by CHARGE Syndrome. In October of 2007, we gained our non-profit status and in November of 2009, our support group has grown to over 80 families, including grandparents.

Mission of the Non Profit:

The Texas Chargers, Inc. is a group of Texas families, friends, and professionals who are dedicated to helping children and young adults who live with CHARGE Syndrome.

The primary function of our organization is to support the emotional and educational needs of people with CHARGE Syndrome and the families and professionals working to provide them with a better quality of life.

What Makes the retreat a success:

- Special speakers on Charge syndrome topics
- Trained Volunteers to care for children with Charge during seminars
- Gift basket of Charge related resources
- State Agency Representatives present their services
- Panel and small group discussions from Charge parents
- Fun activities for the families and their children
- Location held at a camp or conference center
- T-shirts to identify children, parents, and grandparents

Each family pays a minimal fee as their commitment to the weekend.

Transportation mileage costs are usually reimbursed by a state agency

Retreat promotes the National Charge Conference

Families interact and build lasting friendships

Children with Charge develop new friends who have Charge

How is the retreat funded:

Each family approaches their state agencies for financial support for training...

The Texas Chargers raise funds through grants, relationships, etc.



Continued...

Our major sponsors for The Texas Charger’s are TSBVI Outreach, DARS –Blind Children Program, ESC – Region 13, Personal Donations, Lions Club, Specialty Children Organization, And Family Voices.

Suggested Resources for Additional Funding:

Your State Deafblind Project

Local Service Clubs

Service Clubs -Lions Club, Kiwanis Club, Rotary Club, Shriners, Optimist Club, Sertoma/Other Sororities.

Check with Chamber of Commerce for other service clubs:

Easter Seals

Churches

Children’s Hospitals

Early Intervention Agencies

School for the Blind, School for the Deaf, Special Education Co-ops

Disability Advocacy Groups, Independent Living Council, Council on Aging and Disability , Governor’s Planning Council, Regional Centers

Other State Agencies and Supportive Stores.



If you would like to know more about The Texas Chargers, Inc. and the family retreat please visit:

<http://www.texaschargers.org>

or e-mail Cathy Springer, the President, at dacspringer@austin.rr.com.

More “Fun”draising Ideas

Twitter:

The Foundation is now on Twitter! Follow us at <http://www.twitter.com/chargesyndrome> for information on the top ‘Charge It for CHARGE’ fundraisers, as well as other notifications from the Foundation.



Restaurant Fundraisers

Illinois parent Crystal Masionis set up a fundraiser with a local restaurant in her area, Uno Chicago Grill. These restaurants give out coupons, which you hand out to friends, family, and others. They bring their coupon and eat at the restaurant during the time period of your “fundraiser” and the restaurant donates a percentage of sales to the Foundation. Here is the information from Uno about their fundraising program: <http://www.unos.com/fund.html>

New Membership Rates

After eighteen years with the same membership rates, it was decided at the recently held board meeting to revamp the membership levels and rates. Please note below the new membership rates and options, which will become effective in January 2010.

Family / Individual (1 year) - \$25

Professional (1 year) - \$40

Lifetime Silver Membership - \$250

Lifetime Gold Membership - \$1000

Lifetime Platinum Membership - \$5000

Lifetime Diamond Membership - \$10000

Thank You

In Honor of Alexis Schnaderback:

Donna LoBasso
Catherine Rose
Bonnie Louthan
April & Shawn Wilmar

In Honor of Ben Russo:

David Berardi
Thomas DeRoss
Gretchen Dorsey

In Honor of Brady Antaya:

Gail Desrochers
Stacey Messier
Donna Morere
Meredith Vickery
Mark Griffin

In Honor of Makenna Susil:

Deb Lapp
Katie & Jay Susil
Tiffanee Brownrigg
Kristy Corbin
LuAnn Gatewood
Julie Huffmann
Charlie & Cindy McCloud

In Honor of Makenna Susil (continued):

Pete & Vicki Rapol
Doug & Angie Rapol
Charlie & Marcy White
Christina Doelling
Annette Newcome
Sue Reed
Eva Sieber
Kay Timm
Carenina Waite
Karen Miller

In Honor of Ethan Wolfe & Family:

Joey & Maddie Harris
David Wolfe
Susan & Joel Wolfe
Corinne N. Darvish
Terry Bachenheimer
Matt Belcher
Meg Bentley
Greg Bolduc
Andrew Bresler
Jessica Burtnett
Andrea & Brent Cantor
Ed & Dee Flax
Al Gaither
Cathy Hoefs
Peter & Amanda Jacobson

In Honor of Ethan Wolfe & Family (continued):

Paul Johnson
Helene & George Kolosov
Frances Mohrmann
Jen Novak
Steven Salk
Char & Stan Sliva
Neal Strom
Luke Tober
Joe Utic
Stephen Whited
Daniel Fuchs
Naomi Amsterdam
Rhonda Jensen
Charleen Svoboda
Victoria & Tim Lovely

In Honor of Cheyenne Brittell:

Lori Brittell
Irene & Jim Lucas

In Honor of Christian Roberts:

Bekkie Cobb

In Honor of Ellen Howe

Graeme, Lisa & Kennedy Weir

In Honor of Taylor Shott:

Harry Capers

In Honor of Jacob Hartshorne:

James Engleman

In Honor of Halyn Jones

Melva Strang-Foster

In Honor of Kennedy Weir & family:

Maura & Oren Cook
Felipe Garcia
Phil & Margaret Small
Nic Steenekamp
Lisa Weir
Jeanie Colp
Debbie Demora
Leslie Spiller

In Honor of Finley Roth, Mike and Tracy Roth:

Margaret Botchie

In Honor of Kristen Ogan:

Gary & Susan Hoffmeyer

In Honor of Mark Grant & Wendy Knight:

Mark Grant

In Honor of Talia Abadjian:

Liana Harmandjian

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

Thank You

In Honor of Megan Stanger & Family:

Dan D'Andrea
Susan Visoky
Nicole Horne
Jodi & David Chen
Sy & Linda Cohen
Geoff Cohen
Richard Frank
Carisa & Tim Hays
Judith Knispel
Marvin & Ivy Mansky
Peg Burch
Michael Galuskin
Bob Marion
Kim Carl
Scott Blum
Shirley & Harold Horowitz
Andrew Spring
Leigh Ann Winick
Julie Warwick

In Honor of Savannah Tyler:

Audrey Griffin
Emma Reeves
Shannon Smith
Jenn Duke

In Honor of the Bar Mitzvah of Andrew Walter, grandson of Harriet & Joe Walter:

Allen Tennbaum

In Honor of the Rossi-Steinhauser Family:

Beth Maro-Hennessy

In Honor of the birth of Miles Sherman:

Barbara Kagen

Thank you very much for taking care of one of the most needy subpopulation of the society. In my home country, Kurdistan Region of Iraq, we also have a lot of families who have a child with CHARGE syndrome. God Bless You and God Bless America.

-Rizkar Mohammed-Ameen

In Honor of Matthew Stanger's Bar Mitzvah:

Howard Greenberg

In Honor of Amy, Mike & Ben Russo:

David Spurio
Maureen Russo

In Honor of Mary Smith, with Williams syndrome:

Donny Smith

In Honor of Pam Ryan and her many contributions:

Steve Rothstein

In Honor of Nicholas Buono:

Esther Zumbo

In Honor of Justin Murray & Family:

Grace Dorn
Pamela Dowd
Mark & Sandra Antonucci
Judy Gustafson
Erica Hanlon
Shirley Minster
Matthew Murray
Mary & Gerald Sullivan
Carlton Zeigler

In Honor of Ryan Warter:

Sheryl Kaufman

In Memory of Colin Luke Smith:

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Maureen Portmann
Antonetta Prati
Thomas Mills
Jamie Lynn Thompson
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Robyn Palmero

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Ellen Branfman

In Memory of Trey Chatham:

Lisa Williams
Sharon Chatham
Kelly McCluskey
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Glenda Kemp
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In Memory of Pauline LaMorge and in Honor of Christopher LaMorge:

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Martha Simmons
Raymond Vanasse
Cheryl Fillmore
JoAnn Yablonka
Nancy Tyborowski

In Memory of Evelyn Houssaye:

Lynne Blennerhasset

In Memory of Mrs. Frances Rossi:

Bonnie Poortenga

Thank You

In Memory of Rylee Brennan Meyers:

Preeya Govan
Jennifer Lalonde
Crystal Minaker
Sarah Sharpe
Shannon Baker
Michelle Hughes

In Memory of Raymond L. Bujak

Bryan Barnett
Michael Barnett

In Memory of Alba Cosenza:

The Staff at Lindy Eyecare

In Memory of Corinne Ursula Bernat:

John Bernat

In Honor of Dave & Lisa Marcelletti:

Lisa Marcelletti

In Memory of Will Spanfelner, son of Michael & Amy Spanfelner:

Karen & Peter Miller

Other Donations Received from:

Elizabeth Alpert
Cheryl Antonucci
Phliss Buono
Annie Dowdy
Carla Greene
Clare Huff
Hans Kerekes
Crystal Masionis
Bryan McAlhany
Mary Frances Mercier
Bill Muir
West Community Health Charities
Margaret Wilson
Wells Fargo Community Support Campaign
Network for Good
Abbott Laboratories
Employee's Community Fund of the Boeing Company



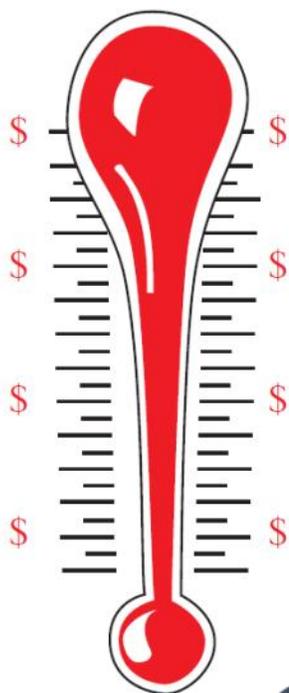
THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION



second annual
Charge It for
CHARGE



HOW HIGH CAN WE GO?



Our second annual Charge It for CHARGE campaign is up and running. We have raised over \$32,000, but still have a long way to go to beat last year! Please go to our website and register to become an online fundraiser. Imagine what we can accomplish if we all join in the fun.

In addition to the on-line fundraising campaign, many members have planned fundraising events. If you would like to host an event, we are always available to help you with the details. Please contact our fundraising chair David Wolfe at david@chargesyndrome.org to share ideas or for any assistance. Whether you prefer to run, walk, golf, bike or just have a party, there is an event that can fit your style!

You can also help the Foundation by making a donation at www.chargesyndrome.org or by mailing a check directly to the Foundation. No amount is too large or too small. Please remember the Foundation in your year end giving.

Come Join Us!

CHARGE Syndrome Foundation, Inc.

141 Middle Neck Road
Sands Point, NY 11050
USA

Phone: 516-684-4720
Toll Free: 800-442-7604
Fax: 516-883-9060

Annual Membership

Family \$25
Professionals \$40

Lifetime Membership

Silver \$250
Gold \$1,000
Platinum \$5,000
Diamond \$10,000



Email: info@chargesyndrome.org

Visit us on the web: www.chargesyndrome.org