

#### OFFICERS

President: David Wolfe  
Vice-President: Lisa Weir  
Treasurer: Brownie Shott  
Secretary: Neal Stanger

#### DIRECTORS

Leslie Kauffman  
Amrit Mehta  
Marilyn Ogan  
Pamela Ryan  
Melva Strang-Foster  
Lori Swanson

#### SPECIAL ADVISORS

Meg Hefner  
Kathy McNulty  
Susan Wolfe

#### DIRECTOR OF

OUTREACH  
Sheri Stanger

#### CONFERENCE LIAISON

Matthew Murray

#### ADMINISTRATIVE ASSISTANT

Lori Bookstaver

#### EDITORIAL STAFF

Leslie Kauffman  
Lisa Weir  
Meg Hefner, M.S.

#### INSIDE THIS

##### ISSUE:

Potty Training from a  
Parent's  
Perspective

Reflections and  
Projections

Provider  
Recommendation  
Project

Holiday Wish List

Update on the Hearing Aid  
Tax Credit

CHARGE Clinics and  
Seminars

Focus on Fundraising

CHARGE in the News

Resources

Upcoming Events

Texas Chargers – 6th  
Annual Retreat: Parent and  
Professional Perspectives

# CHARGE Accounts



VOLUME 21, ISSUE 3

WINTER 2011

## President's Message

By David Wolfe

The months since the 2011 Conference have been action packed. On November 11–13, our Board, Advisors, and Director of Outreach met in Chicago for over 16 hours of meetings. We also had a wonderful meet-and-greet with 25 Illinois family members, where we shared some great Chicago pizza and an enjoyable evening of stories and plans. The evening was capped off when Corki Roth presented the Foundation with a check for more than \$5,000 from the Walk for Alivia. We hope to visit other states where our families are doing great things. Please let us know what is going on in your state, and perhaps we will see you at our next meeting.



At our recent board meeting, we approved a Scientific Advisory Board ("SAB") to help guide our scientific research agenda. The board authorized \$100,000 in pilot research grants. These grants will be made available in the next few weeks, and our SAB will help us select deserving recipients. This is our largest single allocation to research, and we hope it is just the beginning.

We also have great news on the education front. Lori Swanson and Kathy McNulty have put together an exciting new webinar program. Tim Hartshorne and Kasee Stratton will kick off the program in February, and David Brown will follow in May. More exciting, informational webinar programs will follow. All our webinars will be recorded; however, the live webinars are limited to 100 participants. Foundation members will be given the first opportunity to sign up. If you are not a current member, please make sure you join!

As 2011 comes to a close, I hope you will remember the Foundation in your year-end giving and encourage your family and friends to do the same. We hope to make 2012 a phenomenal year for the Foundation by starting new programs, expanding existing programs, and funding additional research. We need your help to make it happen.

From all of us at the CHARGE Syndrome Foundation, Happy Holidays and best wishes for a happy, healthy New Year!

# Board of Directors Meeting

The CHARGE Syndrome Foundation's board of directors recently met in Chicago:



Front Row, L–R: Neal Stanger (Secretary), Lisa Weir (Vice-President), David Wolfe (President), Brownie Shott (Treasurer)

Back Row, L–R: Kathy McNulty (Special Advisor), Leslie Kauffman (Director), Marilyn Ogan (Director), Sheri Stanger (Director of Outreach), Amrit Mehta (Director), Meg Hefner (Special Advisor), Susan Wolfe (Special Advisor), Lori Swanson (Director), Melva Strang-Foster (Director)

Missing from photo: Pamela Ryan

## CHARGE Foundation Store

Many of you have asked to be able to purchase CHARGE-related items every month of every year rather than the limited opportunity at biennial conferences. Just in time for the holidays, we are pleased to announce that we have partnered with Creative Promotional Products, Ltd. to create our first-ever CHARGE Syndrome Foundation store.



You can reach the store either through the CHARGE Syndrome Foundation website or directly through this link: <http://chgsyndpromo.creativepp.com/>. Logo merchandise helps create awareness (and the Foundation receives 25% of the purchase price). Wear and use your CHARGE merchandise with pride.

# Potty Training from a Parent's Perspective

By Jody Wolfe

We all have hopes and dreams for our children. One of my hopes for my son Ethan was for him to be potty trained. Finally, at 9 years old, I can officially say that has happened! I will share with you our experience of what worked for us. However, as we all know, every child with CHARGE is different, so what worked for us may not be the answer for all.

I am a firm believer that you can't start potty training your child until the child shows an interest in it. Therefore, we waited until Ethan was able to communicate that he had to go potty and showed some curiosity. We also made sure that Ethan was medically able to be potty trained. Laurie Denno from the Perkins School for the Blind reiterated that fact during her presentation at the International CHARGE Syndrome Conference in Orlando. (Laurie's handouts from the conference can be found on the CHARGE Syndrome Foundation's website, under Resources/CHARGE Conference Information/2011 International CHARGE Conference.)

After we completed these prerequisite skills, we started recording data on when Ethan would go to the toilet. Keep in mind that at this point, WE were taking him to the potty the majority of the time and he was still wearing a pull-up. Sometimes he would urinate on the toilet, and sometimes he would urinate in his pull-up. We were using reinforcers such as a lighted toy, but there seemed to be no consistency. For us, this lasted about 6 months to a year.

We knew at this point we weren't progressing with the potty training. The next step was to switch him to underwear and try the "intensive" training method by staying at home for days until he was initiating going to the potty by himself. We chose a time when there was no school, and we cancelled all of his therapies. We also enlisted the help of Ethan's behavioral therapists, Alice Belgrade and Erica Schwab from The Potty People.

The first thing we did was to get Ethan used to the underwear. We had to cut the underwear from larger to progressively smaller holes to get him to understand that it was different than a pull-up. Then, we "flooded" Ethan with water. Since Ethan was new to drinking and, at that point, was not taking much liquid orally, we put extra water in his g-tube. This would make his bladder full and, hopefully, he would initiate going to the toilet. We would play and wait. Every 10–15 minutes, we would ask Ethan if he was dry. Note that we wouldn't ask him if he needed to go to the bathroom, though. By doing that, we took the initiation away from him.

*"...as we all know, every child with CHARGE is different...."*



(continued on next page)



***“The key to Ethan’s success was that he was motivated.”***

## Potty Training from a Parent’s Perspective (cont.)

At the beginning when he had an accident, we would use a negative reinforcer by making him clean up after himself. But for Ethan, that didn’t work. After a few accidents, we quickly realized that when we provided negative reinforcement from an accident, this just caused Ethan to obsess about the wetness and enjoy the attention he got from being wet. Therefore, we changed our thought process and “ignored” him when he had an accident and started a positive reinforcement system. After every time he initiated going to the potty, he earned a star. After he earned three stars, he would get time with a favorite toy (in Ethan’s case, his iPad). Even today, we still regularly ask Ethan if he is dry. When we are out in public, we show him where the toilet is and remind him to tell us if he has to go to the potty.

Even though we were successful in getting Ethan to initiate when he had to urinate, having a bowel movement was another story. Because he became very constipated, we started him on a regular dose of MiraLAX. We tried putting him on the toilet with his favorite DVD and having him sit for up to 10 minutes. In addition, we created a social story to help with this part of the toileting. Then, one day, it just happened! He was very excited and proud of himself! We made a big deal of it and, eventually (after almost two months!), he was doing it on his own.

The key to Ethan’s success was that he was motivated. If you can find something that motivates your child and make sure your child is self-initiating, then I believe most of our children can be potty trained.

Ethan has a T-shirt with a turtle on the front that says, “No need to rush, I’m setting my own pace.” To me, that says it all. It may not happen in the “typical” timeframe, but there is hope that it WILL happen!



**Ethan with his stars and his iPad.**

# Reflections and Projections

By Sheri Stanger – Director of Outreach

It's hard to believe that it's been one year since I started working as the Director of Outreach for the CHARGE Syndrome Foundation. It's been a very busy year of connecting with families, professionals, and organizations. I've also had the opportunity to attend a few board meetings and participate in the preparations for one of our fabulous international conferences. I had ideas for my new position, and many are coming to fruition along with opportunities to affect families in ways I hadn't anticipated. Many ideas come directly from speaking with our members. You have shared with me your needs, your frustrations, and your successes. I feel privileged to be a part of your lives, and I hope that my work with the Foundation continues to help improve the lives of the families and professionals we serve.

Let me tell you a bit about myself. I am a Certified School Counselor by profession and the mother of a teenage daughter with CHARGE syndrome and a teenage son. I've been a board member and the president of the National Family Association for Deaf-Blind, and I am married to the former president of the CHARGE Syndrome Foundation. I have lived this life for many years, but now I participate in the Foundation at a different level. Even with my past experience, I never presume to know what parents, people with CHARGE, family members, and professionals will want from this organization. Everyone's needs are unique, and I approach my conversations that way. However, we are all connected by one similarity: CHARGE syndrome—this rare and complex syndrome that unites us and connects us to the greater deafblind community. And that is the basis from which I work each day. I strive to build our network; strengthen our connections to each other; and support and energize our new families, as well as the ones that have been doing this for a long time.

So what have I been doing this past year? I've been getting to know all of you! I've been calling and sending e-mails to our members, speaking with our new contacts, and responding to international requests for assistance. I've been answering calls and e-mails from professionals searching for resources to educate our children, lending support to parents and grandparents when there is a new diagnosis, and sharing resources and information with parents and people with CHARGE. I keep up with many of you through the CHARGE LISTSERV as well as the Foundation's Facebook page. I am finding ways for our members to volunteer and feel a sense of ownership in their Foundation. I am learning about all the fabulous and creative ways families fundraise for our organization and share those ideas with other families. I connect parents to each other so they feel supported and less alone.

(continued on next page)

*"I feel privileged to be a part of your lives, and I hope that my work with the Foundation continues to help improve the lives of the families and professionals we serve."*



*“Let’s work together to share our knowledge, build the capacity of our Foundation, and let the world know what we know—that our children are truly incredible human beings!”*

## Reflections and Projections (cont.)

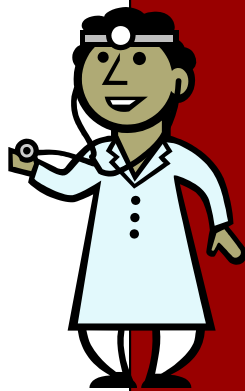
So where do we go from here to increase our outreach efforts? We will continue to move forward by listening to our families, collaborating with professional organizations, and starting projects that will benefit us all. We started a Provider Recommendation project that will benefit families around the globe as we build our database. Through a partnership with the Jewish Guild for the Blind, we are starting a weekly teleconference call for parents in the U.S. and Canada. We plan to improve on our connections to the greater deafblind community and keep you informed of new resources and changes that affect our families. So check your voicemail and e-mail because it may be from me. I know you are all working hard to improve the lives of our children, but you don’t need to be an island. Let’s work together to share our knowledge, build the capacity of our Foundation, and let the world know what we know—that our children are truly incredible human beings!

Feel free to contact me anytime by e-mail ([sheri@chargesyndrome.org](mailto:sheri@chargesyndrome.org)) or through the Foundation’s toll-free number (1-855-5CHARGE or 1-855-524-2743). I look forward to continuing my conversations with you!

## Provider Recommendation Project

Our Provider Recommendation project has gone live! If you want to know about great doctors and therapists in your area (state, province, or country), please e-mail Sheri Stanger, Director of Outreach, at [sheri@chargesyndrome.org](mailto:sheri@chargesyndrome.org). Sheri will search the Provider Database for you, and if she finds what you are looking for, she will e-mail the list to you.

### WE NEED YOUR INPUT!



We are still in need of many more submissions for our Provider Recommendation database. The more submissions we receive, the more families we can help!

Visit <http://www.chargesyndrome.org> to submit your recommended professionals.



# CHARGE Clinics and Seminars

## **CHARGE Clinic**

By Pamela Ryan, Psychologist at Perkins School for the Blind

In October 2010, Dr. Angela Lin, MD, contacted me about the idea of a clinic for people with CHARGE syndrome and how Perkins (and me, specifically) could be involved. She had an idea that she could open up her specialty genetics clinic on a Friday to focus on CHARGE syndrome. Dr. Lin's idea was to be able to offer this specialty clinic two times a year and to be able to include various specialists (ENT, orthopedic, developmental, genetics, neurology, etc.) as time goes on in the clinic. Her idea was that 5–6 families could be a good fit time-wise.

With all that in mind, and in conjunction with Massachusetts General Hospital, Perkins School for the Blind, and the New England Consortium of Deafblind Projects (NEC), the first-in-our-area CHARGE Clinic took place on October 7, 2011. Forty-six letters were sent to families who were listed with the NEC, and we received positive replies from 38 families (8 families did not respond). Six families were chosen to attend the clinic, with others being placed on the list for the next clinic.

Much work was done in preparation for the visits (records review, family histories and pedigrees, assignment of hospital registration numbers, questions to be asked/answered, etc.) so that the one-hour visit could be spent interacting directly and not reading. Each appointment included a physical exam, a discussion of CHARGE clinical features present, and time for parents to ask questions. It is noteworthy that one family, whose son had no unifying diagnosis of his various conditions, was ruled as "not CHARGE," and Dr. Lin was able to discuss a different diagnosis with the family.

It should also be noted that Dr. Lin's medical resident, a genetic researcher interested in CHD7 and Kallman syndrome, and a genetic counselor were involved in the preparation for this first clinic. Prior to clinic day, Dr. Lin provided several recent articles about CHARGE, and she also had the new CHARGE syndrome book available to them for review before the clinic.

## **CHARGE Day**

By Pamela Ryan, Psychologist at Perkins School for the Blind

During the 2010/2011 school year, I worked with Betsy Bixler at the Perkins Training Center to offer a series of seminars related to the "Genetics of Vision Impairment." We offered six seminars with leading specialists from the Boston area that came to our school to discuss topics such as genetic testing, Bardet-Biedl syndrome and associated vision issues, and albinism, just to name a few. The sessions were open to parents and professionals (and we had some young people attend who had some of these identified vision conditions/syndromes). All of the seminars were well attended, and reviews were positive.

*(continued on next page)*

*"...the first-in-our-area  
CHARGE Clinic took  
place on October 7,  
2011."*



## CHARGE Clinics and Seminars (cont.)

*“Those who had never had the chance to hear Meg or David speak before (especially up close and personal) were truly inspired by their knowledge, thrilled by their interest in children with CHARGE syndrome, and moved by their overall compassion.”*

*“One of my long-term goals...has always been to have a designated CHARGE Syndrome Clinic.”*

In that light, and in conjunction with the Perkins Training Center and Klarman Family Foundation, the 2011/2012 "Genetics of Vision Impairment" series was implemented and began with a seminar on CHARGE syndrome on December 3. The previous sessions were two-hour presentations in the evening, but for this first session of this year, we had a full day devoted to CHARGE. This full-day workshop was conducted by Meg Hefner and David Brown, leading authorities in the area of CHARGE syndrome. Topics discussed were clinical and genetic diagnoses of CHARGE syndrome, medical and behavioral implications for children with CHARGE syndrome, and implications and strategies for effective educational programs. The seminar was very well received! Approximately 60 people—parents (with children of all ages) and professionals (physical therapists, speech therapists, nurses, occupational therapists, etc.)—attended the workshop. Those who had never had the chance to hear Meg or David speak before (especially up close and personal) were truly inspired by their knowledge, thrilled by their interest in children with CHARGE syndrome, and moved by their overall compassion.

### **CHARGE Syndrome Clinic**

By Meg Hefner, MS, Genetic Counselor

One of my long-term goals as a genetic counselor in the Department of Pediatrics at Saint Louis University has always been to have a designated CHARGE Syndrome Clinic. That goal was also part of the vision of Dr. Stephen Braddock, who came on as the director of the Division of Medical Genetics in July 2010. We are very pleased to announce that we are making progress on that goal.

The first official CHARGE Syndrome Clinic in the United States was held on July 12, 2011, at SSM Cardinal Glennon Children's Hospital. A second clinic was held on August 23, 2011. (A planned third clinic for November 2011 had to be postponed due to other conflicts.) Along with Dr. Braddock and myself, the clinic is staffed by CHARGE syndrome expert Dr. Sandra Davenport (who is based in Minnesota but comes to St. Louis), speech-language pathologist Dr. Barbara Braddock, and genetic counselor and child development expert Katherine Christensen. We bring in other specialists (audiology, ophthalmology, neurology, etc.) to consult as needed. Much of what we are doing for families is reviewing previous medical and educational evaluations, and helping plan and coordinate care for the future. We cannot provide ongoing treatment for children who live far away, but we can make recommendations to local providers.

We plan to have the clinics four times a year. The next two clinics will be on February 21, 2012, and June 6, 2012. We are partnering with the CHARGE Syndrome Foundation to provide scholarships toward hotel and food costs for families coming from a long distance to attend the clinics. If you are interested in attending the February, June, or future clinics, please feel free to contact me: [meg@chargesyndrome.org](mailto:meg@chargesyndrome.org).

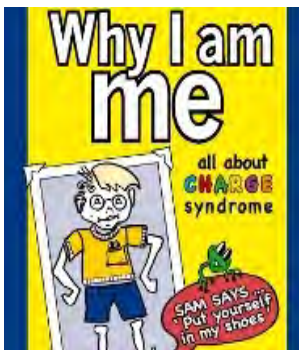
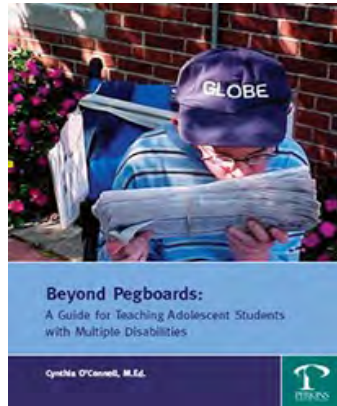


# Resources

## Book – *Beyond Pegboards: A Guide for Teaching Adolescent Students with Multiple Disabilities*

Written by Cynthia O'Connell, this is a practical guide that uses a theme-based approach to help teachers create meaningful learning opportunities for students with multiple disabilities. It's filled with easy-to-replicate activities that can become a springboard for more activities and ideas. For some free sample pages from the book, visit:

[http://support.perkins.org/site/MessageViewer?em\\_id=11763.0&printer\\_friendly=1](http://support.perkins.org/site/MessageViewer?em_id=11763.0&printer_friendly=1)



## Book – *Why I Am Me*

*Why I Am Me* is a story published by the CHARGE Syndrome Association of Australasia about a boy named Sam, who has CHARGE syndrome, and his friend Jess. As the story progresses, Jess learns about CHARGE syndrome and the challenges Sam faces on a day-to-day basis. Visit the link below for more details on the book, as well as information on how to order it:

<http://chargesyndrome.org.au/whyiammeallaboutchargesyndrome.html>

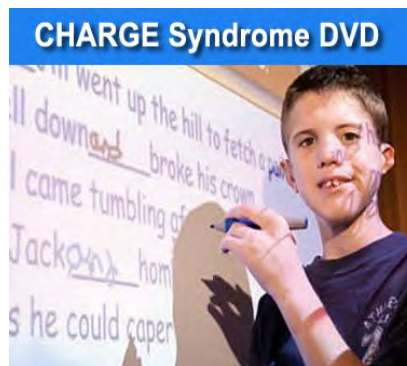
## DVD – *CHARGE Syndrome*

This DVD contains three CHARGE syndrome webcasts produced by Perkins School for the Blind:

- CHARGE Syndrome: An Overview
- CHARGE Syndrome: Teaching Strategies for Children
- CHARGE Syndrome: The Impact on Communication and Learning

The cost of the DVD is \$15. For more information on the webcasts found on the DVD and to order the DVD, visit:

[https://secure2.convio.net/psb/site/Ecommerce?VIEW\\_PRODUCT=true&product\\_id=7961&store\\_id=1101](https://secure2.convio.net/psb/site/Ecommerce?VIEW_PRODUCT=true&product_id=7961&store_id=1101)



**2011 Annual Memberships will expire at the end of this month. Please click to visit the online membership section of our website or contact the Foundation to renew your membership today!**



# CHARGE SYNDROME FOUNDATION

## HOLIDAY WISH LIST

There are many ways to include the CHARGE Syndrome Foundation in your holiday or year-end giving plans. This wish list will provide you with some ideas about areas in which we could use your assistance. Any size donation will help and is greatly appreciated!

### Outreach



\$25 pays for 1 hour of outreach

\$100 pays for ½ day of outreach

\$1,000 pays for 1 week of outreach

[Click here to support Outreach](#)

### Supporting Families

*"Finding the website and getting in touch with the Foundation literally saved our child's life. I don't know what we would've done without you."*

### Conference



\$25 pays for crafts at camp

\$100 helps pay for carnival games

\$500 sends an individual with CHARGE to Conference and Camp

\$2,500 Gold Sponsorship of Conference

[Click here to support the Conference](#)

### Quotes from 2011 Conference Attendees:

*"I'd go anywhere for this conference."*

*"There is nothing like it!"*

*"Thanks for your hard work to make us informed, energized and encouraged!"*

### Research



\$25 funds 1 hour

\$200 funds 1 day

\$500 funds ½ week

\$1,000 funds 1 week

\$5,000 funds 1 month

Are you interested in having a research grant named after a loved one? If so, contact us about funding and grant-naming possibilities:

[david@chargesyndrome.org](mailto:david@chargesyndrome.org)

[Click here to support Research](#)

### Understanding CHARGE

In the fall of 2011, a Scientific Advisory Board was formed to help the Foundation administer pilot grants. A sum of \$100,000 has already been allocated to this program, but more funds are needed.



Our wish is to increase understanding about CHARGE syndrome through multiple research projects, support even more families through the development and dissemination of materials and outreach programs, and continue providing a top-notch conference where families can share and learn from professionals and each other. We can't do it without you!

Thank you for considering the CHARGE Syndrome Foundation in your holiday giving.

Visit <http://www.chargesyndrome.org> for more information on donating to our Holiday Wish List.

Contact Us:

**Mailing Address:** CHARGE Syndrome Foundation, 141 Middle Neck Road, Sands Point, NY 11050

**Phone:** 1-800-442-7604

**Email:** [info@chargesyndrome.org](mailto:info@chargesyndrome.org)

## Update on the Hearing Aid Tax Credit



The Hearing Aid Tax Credit (HATC; H.R. 1479 & S. 905) currently has 57 House and 9 Senate co-sponsors. Both bills offer a \$500 tax credit per hearing aid to people with hearing loss. The Senate bill covers people of all ages, while the House bill covers only children (dependents) and people age 55 and older. Reps. Tom Latham (R-IA) and Carolyn McCarthy (D-NY) and Sens. Tom Harkin (D-IA) and Olympia Snowe (R-ME) are the lead Congressional sponsors for the bill, which has always received bipartisan support. "The bill is not

likely to be considered on its own, but will be part of major tax or health care-related legislation in the future," said Andy Bopp, director of government relations for the Hearing Industries Association (HIA), a lead backer for the legislation. HIA, the national trade association of manufacturers of hearing aids, leads a coalition that is working towards passage of the Hearing Aid Tax Credit (HATC) by organizing meetings with congressional representatives and staff on Capitol Hill and by sponsoring local events to thank representatives for their support. The HATC coalition members include AG Bell, the Hearing Loss Association of America, American Academy of Audiology, American Speech-Language-Hearing Association, International Hearing Society, and AARP, which supports the Senate version of the bill.

Public support and House/Senate co-sponsorship is crucial for the tax credit's passage. The Better Hearing Institute has set up a page at <http://www.hearingaidtaxcredit.org> where you can send a letter to Congress asking your representative or senator for support, or thanking them if they are already a co-sponsor.

## Focus on Fundraising

### **Christmas Trees for CHARGE**

This holiday season, Bill and Deanna Steinhauser are setting a perfect example of the old adage, "Giving is better than receiving." Bill and Deanna's family owns a couple of Ace Hardware stores, where they are selling "Christmas trees for CHARGE" at each cash register (the cashiers all have a stack of trees) throughout the month of December. People can make a donation in any amount, and then their name goes on a tree that gets displayed at the store. Since Bill and Deanna started the fundraiser on November 28<sup>th</sup>, they have already sold almost 700 trees and raised over \$1,000. Thanks to Bill and Deanna's efforts, that's almost 700 people who now have heard of CHARGE syndrome, as well as \$1,000 raised in just two weeks! For those of you who know Bill and Deanna, please congratulate them on a job well done!

(continued on next page)



*"Thanks to Bill and Deanna's efforts,...almost 700 people...now have heard of CHARGE syndrome...."*



## Focus on Fundraising (cont.)

### Yard Sale for CHARGE

By Allie Jones

I guess the journey to our first attempt at a fundraising event began about five years ago when my Dad moved in with us because he could no longer live alone. In order to ease his transition, we tried to incorporate as many of his things as possible into our household—things like kitchenware, bookcases, coffee tables, etc.

Since then our needs have changed. This summer, before the conference, Damon (my husband) and I found ourselves overwhelmed by too much “stuff” in the house and agreed that we needed to have a yard sale to clear some of these things out and that we would donate the proceeds to the CHARGE Syndrome Foundation. We scheduled our sale for Saturday, October 29<sup>th</sup>. For the things on which we stuck price tags, we kept the prices low and decided not to price the clothing, asking people to pay what they thought an item was worth.

We divided up the tasks. Damon was the salesman and helped folks pack their purchases in their cars and trucks. I handled the money, and my mom, Melva, passed out the pamphlets about CHARGE syndrome published by the Foundation. We also placed “Change for CHARGE” cans on the sales tables. Upon learning that all proceeds would go to the Foundation, many people made a donation in one of the cans or gave me additional money before they left.

At the end of the sale, the financial “take” was about \$350. EVERYONE who came by said they had never heard of CHARGE syndrome before. We know that at least 100 people in Montgomery, Alabama, have now heard about CHARGE and were given a pamphlet. (To our knowledge, our daughter, Halyn, is the only child with CHARGE syndrome in Montgomery.)

I believe that the increased awareness is an important intangible benefit to the CHARGE family. I’m happy that we raised enough money to more than cover the Foundation’s costs for paying the way for one person with CHARGE syndrome to attend the 2013 conference in Arizona. On a personal note, I also am very happy to have a de-cluttered house and to have a place in the kitchen for our cookware!

I encourage other families to try this approach to fundraising for the Foundation. It is relatively easy to do, and it helps “recycle” things that are still in good condition but are no longer needed. If you have any questions about our sale, feel free to contact me on the CHARGE Syndrome Facebook page (<http://www.facebook.com/groups/chargesyndrome/>). I’ll be happy to share!





# Focus on Fundraising (cont.)

## Tyler Trot 5K Walk and Run “CHARGE Ahead!”

On Saturday, August 6, 2011, nearly 200 men, women, and children participated in the first annual Tyler Trot at the Antietam National Battlefield in Sharpsburg, Maryland. The event was organized by Kristen Matthew in remembrance of her son, Tyler, who passed away from complications from CHARGE syndrome. Below are some pictures from the event:



Over **\$14,000**  
raised for the  
CHARGE Syndrome  
Foundation!

Nearly 200 men, women  
& children participated  
in the 1st Annual “Tyler  
Trot”!



*This event was dedicated to  
the loving memory of Tyler  
James Matthew (2004-2006)  
Beloved son, grandchild,  
nephew...  
Our “**Silent Soldier**”*

# Focus on Fundraising (cont.)

## The Flat Charlie Project

By Minnie Lambert

A recent book that my son, Andrew, and his class read has inspired me to kick off a very unique fundraising project to benefit the CHARGE Syndrome Foundation. Andrew's class read a book titled *Flat Stanley*. There is a project that goes along with the book that takes Flat Stanley on a journey. Students begin by reading the book and becoming acquainted with the story. Then they make paper "Flat Stanleys" and keep a journal for a few days, documenting the places and activities in which Flat Stanley is involved. The Flat Stanley and the journal are then mailed to other people who are asked to treat the figure as a visiting guest and add to his journal, then return them both after a period of time.



Now on to OUR project. With the help of many of you, I am hoping to launch The Flat Charlie Project. You may ask, "Who is Flat Charlie?" Flat Charlie is a little guy who is trying to get to the 11<sup>th</sup> International CHARGE Syndrome Conference in Scottsdale, Arizona, in July 2013 and is wanting to visit lots of families affected by CHARGE along the way! However, he needs your help. He is in search of host families that will take care of him and add a missing piece to him. Each family will also have to raise money to help send Flat Charlie on to his next destination as he CHARGEs around the world on his way to the 11<sup>th</sup> International CHARGE Syndrome Conference in Arizona.

The project will work as follows: Flat Charlie will be nothing more than a blank little paper boy that will leave our home first. Andrew and I will add a very special piece to him to help him on his journey. When he arrives at your home, it will be your family's responsibility to add a missing piece to him. It is important to get the children involved as much as possible. This is a way for Flat Charlie to belong to all the children. Be as creative as you want, but keep in mind each family will have to pay postage for his travels, so we need to keep him as light as possible.

The amount of time that you keep Flat Charlie will depend on how many families we can get involved. He will arrive with a list of his host families and a map of his journey. You will cross your family's name off of the list, mark your spot on the map, and send Flat Charlie and the map to his next destination. I hope to give each family as much time with him as possible. I will try to group certain places together to cut down on travel time. The last leg of Flat Charlie's journey will send him back to my family, and we will be responsible for getting him to Arizona in 2013.

*(continued on next page)*

*"It is important to get the children involved as much as possible."*



## Focus on Fundraising (cont.)

It will also be each family's responsibility to raise funds to "pay" for their leg of Flat Charlie's journey. We ask that each family try to raise at least \$100. How you raise that money is up to you. You can take up donations from others who want to sponsor your family as a host family, have a bake sale...the possibilities are endless. You can also begin raising money at anytime—not just while you have Flat Charlie.

A fundraising team has been set up with the CHARGE Syndrome Foundation called Team Flat Charlie. To become a member of Team Flat Charlie:

1. Go the CHARGE Syndrome Foundation's website (<http://www.chargesyndrome.org>).
2. Click on the "Click Here for CHARGE IT FOR CHARGE" link on the right-hand side of the homepage.
3. Click on the ">>more" link in the "Team Rank" box on the right-hand side of the page.
4. Click on the "Team Flat Charlie" link.
5. Then click on "Join Our Team."
6. Fill out the form.

The Foundation limits 50 members per team, but we will create as many teams as we need. We will all be individual members of the same team. All host families will have to join the team to be able to send their donations in to count towards the team's goal.

I have also made a group page on Facebook called "The Flat Charlie Project" (<http://www.facebook.com/groups/300145663351626/>). You can go to this page and upload pictures of your family with Flat Charlie, make posts of what your family is doing with him, and let the next family know that he is on the way. Let's keep everyone informed as to what Flat Charlie is doing!

The goal of this project is to get the kids and their families involved in a fun exercise to help support the CHARGE Syndrome Foundation. The project is expected to launch in February, and the final destination will bring him back to our family in May 2013. He will be presented to the Foundation from all of the families involved at the 11<sup>th</sup> International CHARGE Syndrome Conference in Scottsdale in July, along with a grand total of how much money he has collected along his journey. If you have any questions or concerns about the Project, you can reach me on my Facebook page (<http://www.facebook.com/minnieleel>).

I am excited to launch this project, and I hope that you will want to join my family in helping Flat Charlie reach the 11<sup>th</sup> International CHARGE Syndrome Conference in Arizona in 2013! Sign up and let's see just how we can all work together as one to help Flat Charlie CHARGE his way to Arizona!!!



*"The goal of this project is to get the kids and their families involved in a fun exercise to help support the CHARGE Syndrome Foundation."*

# CHARGE in the News

## **A Home for Laura**

Jackie Kenley's 26-year-old daughter, Laura, was born with CHARGE syndrome. She is on the severe end of the spectrum and communicates with limited sign language and object communication. Laura has been in supported living through the Arc of San Francisco for three years now. In spite of her limited vision and profound deafness, Laura has learned her way around her first private home for supported living, as well as her new Section 8 apartment, amazingly well. For an interview with Jackie in which she shares her thoughts on Laura's transition, please visit the link below.

<http://www.cadbs.org/newsletter/resources-fall-2011/>

Also, a recent video made by the Arc of San Francisco spotlights Laura and shows how the Arc supports her in her home. Says Jackie, "The smile on her face tells how well this fits her!" To view the video, please go to:

<http://vimeo.com/31232349>

## **Malik's Story**

Fifteen-year-old Malik, a student at Wilson's Eastern North Carolina School for the Deaf (ENCSD), is deafblind and has CHARGE syndrome. The following article discusses what life is like for Malik and talks with Krystal, his deafblind intervenor at ENCSD:

<http://www.wilsons-times.com/News/Feature/Story/6927556---Most-have-5-senses--he-has-3>



**Meg Hefner and Kevin Ballard have collaborated to create a global database of patients with CHARGE syndrome.**

## **CHARGE Database**

As an adjunct to the Charge Syndrome Clinic (discussed on page 14) and as part of the Center of Excellence plan, Meg Hefner and Kevin Ballard are in the process of creating a database and registry for CHARGE syndrome at Saint Louis University. Once complete, it will be possible for parents of children with CHARGE or adults with CHARGE to enter their medical information into a database via the Internet. For more on the database, please visit:

<http://www.slu.edu/x53845.xml>

## **ClearCaptions**

A new service called ClearCaptions may be of benefit to individuals with CHARGE who use captioning. ClearCaptions adds captions to your phone calls so you can read what the caller is saying to you. For more information on ClearCaptions and a video to see how it works, please visit:

<http://www.clearcaptions.com>

# Upcoming Events



## Two Steppin' for CHARGE Syndrome

**Date:** Every Friday and Saturday night

Raising money as well as bringing awareness to people who have never heard of CHARGE syndrome. 100% of the proceeds go to CHARGE Syndrome Foundation, Inc.

**Location:** KP's Music Rodeo, 1276 State Route 183. Troy, Tennessee 38260

For more information or to make a donation, please contact Kirk Morris or Kelly Berry at 731-536-5678, visit <http://www.facebook.com/kpsmusicrodeo>, or e-mail [kpsmusicrodeo@att.net](mailto:kpsmusicrodeo@att.net).

## CHARGE Seminar

In the fall of 2010, Betsy Bixler and Pamela Ryan of the Perkins Training Center organized a two-day symposium on CHARGE that was well attended. Betsy has been working with folks in New York (outside of the city), and the group she is currently working with would like a similar seminar. Betsy and Pam are in preliminary planning at this time to determine dates (probably spring) and a specific topic focus. Stay tuned!

## CHARGE'd-Up for Golf on Memorial Day

**Save the Date: May 28, 2012**



## New Webinar Series for Parents

We are pleased to announce that the CHARGE Syndrome Foundation will be sponsoring two webinars for parents who are current members of the Foundation in 2012. The webinars will be broadcast on Sunday evenings beginning at 7:00 p.m. (Eastern Time). The first webinar, to be held on February 12<sup>th</sup>, will feature Dr. Timothy Hartshorne and Dr. Kasee Stratton discussing sources of **pain** in persons with CHARGE syndrome. Their presentation will explain how pain may influence behavior and how to assess pain in those who are unable to label or talk about their pain. The second webinar will be held on May 20<sup>th</sup> with David Brown, who will present on the often-forgotten **vestibular (balance)** and **proprioceptive (pressure)** senses. His presentation will provide simple explanations of these two senses, how they work, the purposes they serve, and how important they are to child development. There will be opportunities for questions from the audience in both webinars.

Information on webinar registration will be sent out to parents who are current members of the Foundation in early January.

## 11th International CHARGE Syndrome Conference

**Host:** CHARGE Syndrome Foundation

**Date:** July 25–28, 2013

**Location:** Fairmont Scottsdale Princess, Scottsdale, Arizona

For more information on this event, please stay tuned to <http://www.chargesyndrome.org>.



**DO YOU HAVE  
AN EVENT YOU  
WOULD LIKE TO  
HAVE PLACED  
ON OUR  
UPCOMING  
EVENTS PAGE ON  
THE WEBSITE  
AND/OR HERE IN  
THE  
NEWSLETTER?**

**SEND IT TO** [lisa@chargesyndrome.org](mailto:lisa@chargesyndrome.org).

## Texas Chargers — 6th Annual Retreat

By Debika Ingham, Treasurer of Texas Chargers, Inc. and parent of 4-year-old with CHARGE

Texas Chargers, Inc. is a group of Texas families, friends, and professionals dedicated to helping children and young adults living with CHARGE syndrome. Our two key goals are to provide an annual retreat to help families access the information and resources specific to the state of Texas and to support the CHARGE Syndrome Foundation in every way possible. This article gives a recap of our most recent Retreat and Conference and shares our 2011 progress and some of our 2012 plans.

### **6<sup>th</sup> Annual Retreat and Conference Recap**

Texas Chargers held its 6<sup>th</sup> Annual Retreat and Conference in Navasota, Texas, on November 4–6. We chose Camp Allen in Navasota for its relatively central location (Texas is a mighty big state, so central is a big area in itself!), its wonderful amenities, and our familiarity with holding a retreat of this size at this facility. Approximately 30 families and 22 individuals with CHARGE gathered to share their trials and tribulations, pose questions, provide a shoulder to lean on, and, most importantly, celebrate each and every one of their roles in supporting families and individuals with CHARGE. With more than 150 people in attendance and 60 volunteers to help with child care, activities, and other logistics, the 6<sup>th</sup> Annual Retreat and Conference was packed with great moments and lots of new approaches to our traditional events.

The traditional parent panel kickoff for the weekend changed into a CHARGE focus panel, which not only included parents of children with CHARGE but also teen and adult individuals with CHARGE. The viewpoints offered by our younger panelists helped shape a broader and richer discussion about what parents and children go through over the years. With the benefit of hindsight, they also gave advice to parents on how to respect them as individuals first and to view CHARGE as one of many attributes that make them unique.

We concluded the evening with a discussion about legislative updates. Texas has gone through a brutal legislative session where budget cuts threaten to impact the services and support our families receive. We received updates on what changes have been made, what changes are looming, and ways to continue to influence the decision with our lawmakers in Austin.

Our keynote speaker, Sally Prouty, shared the story of her 30-year quest to ensure that her son, who has CHARGE syndrome, had access to quality medical, educational, and social services. Sally, who has been instrumental in defining, developing, and coordinating services for the deafblind, including intervenor services, offered a presentation on “How to Get What Your Child Needs by Being Respectfully Demanding.” She stressed the importance of understanding and building relationships with the other stakeholders in your family’s success. The key is how to go about demanding what you and your child need without alienating those people that hold the resources in their hands.

*(continued on next page)*

**Keynote speaker Sally Prouty gives a presentation on “How to Get What Your Child Needs by Being Respectfully Demanding.”**



*“One of the great things about Texas Chargers is how vested the agencies themselves are in our mutual success.”*

## Texas Chargers — 6th Annual Retreat (cont.)

A few other highlights of the Retreat and Conference focused mostly on the individuals with CHARGE and their needs, perspective, and talents. We added a sensory room to allow those with CHARGE who were overwhelmed by the bustle of the conference a chance to have a peaceful place for respite. We also added a visual simulation station so people could “see” for themselves what vision loss and impairment is like. We had a Cochlear representative onsite to answer questions about hearing loss, devices, and eligibility, and to demonstrate various conductive devices. One teen liked an upgrade to her Baha® Cochlear device so much that she signed, “I’m happy now,” and ran off with the demonstration device down the hallway!

We celebrated the art of living in a world with CHARGE by asking those with CHARGE to enter an art contest. The mom’s support group turned its focus from the moms themselves and instead worked with a fabulous array of donated scrapbooking materials to put together a portfolio for their children with CHARGE to share with educators, family, medical professionals, and other communities.

The culmination of our focus on the individuals themselves comes in a special presentation every retreat that we call “Star Charger.” This year’s Star Charger, Rachel Gibson, gave a wonderful multimedia presentation, which her mother voiced and she signed along. Rachel shared details about her family, her school, and her likes and dislikes, and gave a snapshot of the world according to her. That evening, we all celebrated living with CHARGE at a wonderful family social filled with dancing to a DJ, balloons, face painting, and a chance to smile. Last year’s Star Charger, Rachel Allen, gave an encore performance that won her the best of the “Stage” category at the International CHARGE Syndrome Conference in Orlando, Florida, this past year.



**Lexi at work**  
creating her first-place  
work for the art show.

For those families that could not attend the 10<sup>th</sup> Annual International CHARGE Syndrome Conference in Florida this year, Brownie Shott, a Foundation Board member, gave an overview of this year’s conference, logistics for 2013’s conference, and a highlight of the CHARGE Syndrome Foundation’s key goals and plans for the upcoming year.

After things wrapped up on Sunday, the Texas Chargers Board met to review business feedback from the members. While much of the feedback was positive, we took to heart the constructive criticism and have earmarked time to discuss how to further improve the conference. One of the most exciting decisions reached at the meeting was ways to further our mission to support the CHARGE Syndrome Foundation. We’ve decided to provide all families who attended our conference with family memberships to the CHARGE Syndrome Foundation. We are certain this will supply our families with valuable information made available by the Foundation; help foster increased dialogue with our group on how best to serve the Foundation’s goals; and provide better “numbers” at a national level, which helps draw attention to the need for research and additional financial support.

*(continued on the next page)*



## Texas Chargers — 6th Annual Retreat and Conference (cont.)

The 7<sup>th</sup> Annual Retreat and Conference will be held on November 2–4, 2012.

For more information on this incredible organization, visit our website (<http://www.texaschargers.org>) or join our “Texas Chargers” group on Facebook (<http://www.facebook.com/groups/22139420985/>) to receive updates and participate in our ongoing discussions. Our contact information can also be found under “Resources” on the CHARGE Syndrome Foundation’s website. Feel free to contact me (Debika Ingham, [debikaingham@yahoo.com](mailto:debikaingham@yahoo.com)) or any of the other board members listed on our website with comments, questions, or family referrals.

## Texas CHARGE Retreat: Professional Perspective

By Holly Cooper, Ph.D., Deafblind Educational Consultant, Texas Deafblind Project, Texas School for the Blind and Visually Impaired

Texas Chargers, Inc. is a group of Texas families, friends, and professionals dedicated to helping children and young adults living with CHARGE syndrome. They hold an annual retreat and conference every year at which families and individuals with CHARGE gather to share trials and tribulations, pose questions, and provide support for one another.

The first time I went to the Texas Chargers’ Annual Retreat and Conference was four or five years ago when the conference was in its early years. I wanted to learn more about these fascinating students with CHARGE syndrome that I was seeing in classrooms in my work as a statewide deafblind educational consultant. I learned so much and had such a great time during my initial visit that I’ve been back each year since then.

It is interesting as an educator to watch children with CHARGE in non-school environments at these retreats. What I have noticed every year I’ve attended is that these children and young people with CHARGE are active, curious, and social. Some of them know one another from previous retreats and find each other again and hang out. Many of them have favorite toys or topics that they want to talk about and get others to talk about. *Star Wars*, school buses, trains, and other vehicles are favorite subjects of drawings, writing, and discussion.

The more relaxed atmosphere of the retreat allows them freedom to choose some of their own activities in a setting where no one is trying to make them fit into a regular routine and stay focused. They don’t have to sit at desks working on the same task for long periods of time; instead, they can rest or run—whichever they need to do. Special meals are not provided, but it is common to see families tube-feeding their son or daughter at the table, or giving them pudding, mashed potatoes, or Ensure. During the evening social time, the kids dance to loud music, watch strobe and light effects, have their faces painted, and draw pictures with me.

(continued on next page)



*“I learned so much and had such a great time during my initial visit that I’ve been back each year since then.”*



## Texas CHARGE Retreat: Professional Perspective (cont.)

If you are a teacher, therapist, orientation and mobility specialist, or other educational professional working with a student with CHARGE, or a parent of a child with CHARGE, I encourage you to attend conferences and retreats such as the ones held by the Texas Chargers and the CHARGE Syndrome Foundation. I believe I have learned more that has helped me support students with CHARGE by going to family conferences than I would by going to workshops for professionals. I have also had a great time at these events. It's really energizing and instructive to see the young people with CHARGE and their families who have been through so much, but have learned to find joy in each other.

Holly creates a quilt as a raffle prize each year and gets some of the individuals at the retreat draw pictures on paper that is pre-cut to the size of a quilt block so she can iron them on! Here are a couple of the drawings she received this year:



Dipsy by Rachel



Anime art by Sarah, who cleverly writes her name backwards so when it is transferred to a quilt made by Holly as a fundraiser, it comes out the right way!

*"It's really energizing and instructive to see the young people with CHARGE and their families who have been through so much, but have learned to find joy in each other."*

# Thank You

## Donations

Accent Screen Printing Inc.  
America's Charities  
Anna Thompson  
Betty Dwyer  
Calais Regional Hospital  
Corporate Kids Events, Inc.  
GoodSearch  
IBM Employee Services Center  
Jannine Hinterstein  
Jeffrey West  
Joe Barbour  
Karen Miller – HNI Corporation  
Marly Stoneberg  
Media Executive Resources LLC  
Melva Strang-Foster  
Microsoft Matching Gifts Program  
Network for Good  
Paula Mullane – Daiwa Capital Markets  
Tevis Bartow Jacobs  
United Way California Capital Region  
University of Wisconsin-River Falls – National Student Speech Language Hearing Association  
Wells Fargo Community Support Campaign  
West Community Health Charities

**In Memory of Addison Yarbrough**  
Cynthia & Jackie Cox

**In Memory of Addison G. Yarbrough**  
Southeastern Technical College

**In Memory of Addison Grace Yarbrough**  
Arthur & Kathryn Downs  
Kathy & Martin Moses

**In Memory of Miss Addison Grace Yarbrough**  
Byron & Matha Haire

**In Honor of Alison Kofahl – marathon**  
Amy Thornton

**In Honor of Alivia Roth**  
Bill Hobson

**On the Special Occasion of Brandon Thomas' Birthday!! Love, Uncle Tris, Aunt Theresa & Robert**  
Theresa Bescher

**In Honor of Charlotte Cosenza**  
Andrea Bartelloni  
John Passarelli – Long Island Eye Surgical Care P.C.

**In Honor of Cheyenne Brittell**  
Irene Lucas

**In Honor of Conor R. Lloyd**  
Bill Green – Jean Massieu Foundation

**In Memory of Donald R. Lloyd**  
Bill Green – Jean Massieu Foundation

**In Honor of Eli Klinghofer**  
Mary Strandberg

**In Honor of Emilee Kay Hullings**  
Peggy Darczuk

**In Honor of Ethan**  
Susan Wolfe

**In Honor of Finley Roth**  
Margaret Botchie

**In Honor of Gabrielle Jones**  
KP's Music Rodeo

**In Honor of Halyn Jones**  
Damon Jones

**In Memory of Jerry Schwartz**  
M. Athey  
Joann Stichman  
Marilyn & Jerry Finkelstein

**In Memory of Jerry Schwartz, Beloved Husband**  
Marilyn Friedman and Family

**In Memory of Husband Jerry Schwartz**  
Edward/Rochelle Elowitz

**In Honor of Jim Wendoll's presidency**  
Sheila & Stan Kay

**In Honor of Jody Wolfe**  
Nancy Young

**In Honor of Makenzie Dougherty's dedicated and loving parents, love Bumpa and Grandma**  
John Dougherty

**In Honor of Molly Grace Foster**  
Cynthia Norton

**In Memory of Ruxson Frost**  
James & Sarah Welkert  
Susanne & Helfried Schaffranek

**In Memory of Ruxson Wade Frost**  
Amy Nelson  
Catherine & Leonard Hutton  
Cathy & Mike Klingler  
Dick & Helen Shell  
Donna Thole  
Eve Georgiou  
Jerry Phillips  
Joni Reel  
Mike Romano  
Rick & Teresa Edwards  
Ruth Anne Risser  
Thomas Koehlke – Koehlke Components, Inc.

**In Memory of Tom Morris**  
KP's Music Rodeo

**In Memory of Trey Chatham**  
Kelly Nelson  
Mary Hall  
Michael & Mandy Woodruff  
Robert & Rachelle Moran

**In Memory of Trey Chatman, brave CHARGER**  
Sharon and John Chatham

**In Honor of Tyler Matthew**  
Jason Matthew  
Patricia Haupt

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE  
CHARGE SYNDROME FOUNDATION

# Thank You

## Charge It for CHARGE Tributes

### Keep up the great work!

Peter Morse – Morse, Bolduc & Dinos

### In Honor of Alivia Roth

Joan Vehlowl  
The Roth Family  
Valorie Hobson

### In Honor of Aman Mehta

Gerd DeBeer

### For Aman and other kids like him—the fighters! :-)

Radhika Chopra

### In Honor of Cole Herrick

Sharon Evans

### In Honor of Cora Taylor

Sarah Spruill

### For Doug, Angie, Olivia & Jack Rapol

Douglas Rapol

### For David Wolfe: Congratulations on becoming president of “CHARGE.” Keep up the good work.

Steve Salk

### On the special occasion of David’s presidency

Susan & Joel Wolfe

### For Ethan

Bernice Frisch

### In Honor of Ethan

Brian Borkan  
James Kogut  
Joseph Utic  
Shelley and Gary Morris

### In Honor of Ethan from The Law Offices of Wolf & Wolfe, Ltd.

David and Jody Wolfe – The Law Offices of Wolf & Wolfe, Ltd.

### In Honor of Ethan’s Birthday

Julie and Marc Machtinger

### In Honor of Ethan Wolfe

Debbie Stern  
Genevieve Bentley  
Gregory Szul  
Kathy Wilcox  
Mary DaVanti  
Michael and Susan Zelik  
Nick Avgerinos – Capron & Avgerinos, P.C.  
Peter C. Wachowski – Bellas & Wachowski, P.C.  
Rhonda Jensen – Jensen Reporting  
Sheldon Brenner  
Stephen Whited – Northwestern Mutual

### In Honor of Ethan Wolfe and Family

Daniel Fuchs

### In Honor of Joel & Susan Wolfe

Ed & Dee Flax  
Jon Rysdon

### In Honor of the Wolfe Family

Lee Laudicina

### In Honor of the Wolfe Family and their dedication to research and assisting others

Howard Ankin – Ankin Law Offices, LLC

### In Honor of the awesome Wolfe Family!

Peter Moroh

### In Honor of Halyn

Bob Frye

### For my niece Jade who works with autistic children in PEI and has a very special friend Charly (female) with CHARGE syndrome to whom she taught dancing and social skills.

Ashley P. Robinson

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE  
CHARGE SYNDROME FOUNDATION

# Thank You

## Charge It for CHARGE Tributes (cont.)

### In Honor of Joshua Kurby

Henry Anderson

### In Memory of Joshua Kurby

Brian Berg  
Christine & Christopher Wade  
Dan & Sharon Sawicki  
Patrice & Ronald Simon  
Stephen Flora  
Susan & Joel Wolfe  
Thomas & Josephine Halleran

### On the Special Occasion of Josh's 3rd Race

Miya Wayman

### On the Special Occasion of the 3rd Annual Joshua Kurby Charge for CHARGE 5K-race day!

Sandy Kurby

### In Honor of the Kurby Family

Dawn Medina

### In Honor of Kennedy

Lisa Weir

### In Memory of Lucille Solomon Taylor, my mother who saw the best in everyone

Emily Taylor-Snell – Florida Outreach Project DB

### In Honor of Makenna Susil

Charlie & Marcy White  
Chris, Juna, Ty and Maddie Garber  
Karen Miller

### In Honor of Mariana Machado

Carolina Vilalva

### In Honor of Dr. Mark Volk at Children's Hospital Boston

Cynthia & Keith Antaya

### In Honor of Megan

Shirley & Harold Horowitz  
Susan Visoky

### In Honor of the amazing Megan!

Euphemia Johnson

### On the Special Occasion of Megan starting work at the Target company

Veronika Bernstein – Perkins School for the Blind

### In Honor of Megan Stanger

Jodi & David Chen  
Leigh Ann Winick  
Sheri & Neal Stanger

### In Honor of Megan Stanger. Go Megan!! Love, The Gencarellis

Alison Gencarelli

### In Honor of Mia Merrifield

Patricia Willick

### In Honor of Taylor Shott

Mark Magee – Edward Jones

### In Honor of Taylor. We love you Taylor! From your Tradition Bank Family

Carol Bonaccorso – Tradition Bank

### On the Special Occasion of Winnie Annis' 60th birthday. For the mother AND grandmother in CHARGE, we hope you have a fabulous birthday! Love, Cynthia, Keith & Brady

Cynthia & Keith Antaya

### In Memory of my mother

Mehta Kishore – Genesis

### From a member of the extended family! What amazing work.

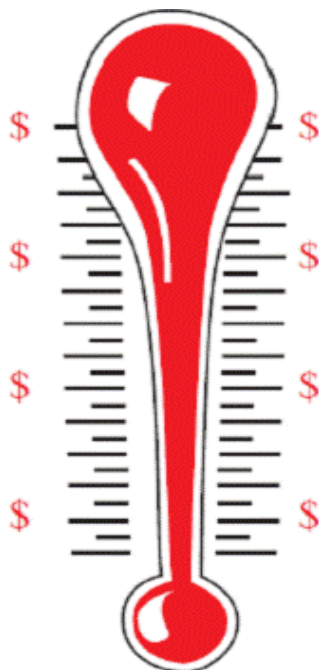
Imogen Gorman

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE  
CHARGE SYNDROME FOUNDATION



## fourth annual Charge It for CHARGE

# HOW HIGH CAN WE GO?



Our fourth annual Charge It for CHARGE campaign is now underway. Charge It for CHARGE is the primary fundraising campaign of the CHARGE Syndrome Foundation. With 30 minutes of your time and the e-mail addresses of friends, family, colleagues, and businesses where you spend your money, you can help individuals with CHARGE and their families. To get started, go to <http://FourthAnnualCIFC.kintera.org/>.

In addition to the online 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](mailto: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 <http://www.chargesyndrome.org> or by mailing a check directly to the Foundation. No amount is too large or too small.

## Please Join Us!

### **CHARGE Syndrome Foundation, Inc.**

141 Middle Neck Road  
Sands Point, NY 11050  
USA

Phone: 516-684-4720  
Toll Free: 1-800-442-7604  
Fax: 516-883-9060

### **Director of Outreach**

**Sheri Stanger**

**Toll Free:** 1-855-5CHARGE  
(1-855-524-2743)

**Phone:** 914-479-0079

**Fax:** 914-478-1204

**Email:** [sheristanger@chargesyndrome.org](mailto:sheristanger@chargesyndrome.org)

### Annual Membership

Family – \$25

Professionals – \$40

### Lifetime Membership

Silver – \$250

Gold – \$1,000

Platinum – \$5,000

Diamond – \$10,000

Email: [info@chargesyndrome.org](mailto:info@chargesyndrome.org)

Visit us on the web: <http://www.chargesyndrome.org>

