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VOLUME 22, ISSUE 2

SUMMER 2012

President's Message

By David Wolfe

July is here! I hope everyone is enjoying their summer and staying cool despite the intense heat facing many parts of the United States. Summer is always a great time to get together with your extended CHARGE family. Don't wait until the next conference. Whether you grab a quick cup of coffee, go to the park, do lunch, or take a trip together, it's a great time to reach out to families in your area. The relationships we build with other families enrich our lives. If you are looking for families in your area, please contact our Director of Outreach, Sheri Stanger, and she will put you in touch with other families.

July is one of my favorite months of the year: it is always almost conference time. It is hard to believe that our 2013 conference is just one short year away. It is never too early to start planning for Scottsdale. Line up your funding, request the time off from work, and start looking for good deals on airfare. Lisa Weir and her team are hard at work making sure our 2013 conference will be second to none. We hope to see everyone in Scottsdale.

July is the perfect time to wish all of you a healthy, safe, and happy summer. Enjoy the time with your families!



Me, Myself, and I

By Sheri Stanger, Director of Outreach

Summer months are approaching, and with children finishing school, many parents turn their thoughts to vacations, leisurely summer afternoons, and slowing down. Having a child with CHARGE syndrome typically means that we go, go, go. We take care of medical appointments and surgeries in the summer months so our children don't miss school. We continue with therapies and extended school year to ward off regression. We plan for our children to start the school year on a positive note. We're fantastic! We make things happen and our children thrive. So where do WE fit into the picture? Yeah, you! I'm talking to you! I know you long for some summer fun and downtime. Doesn't that sound nice? Didn't we use to relax?



Why should thoughts of taking care of ourselves fill us with guilt? We love our children and do everything we can for them. Don't we deserve a little free time to unwind? The answer is "yes, we do." It may sound selfish with all the complex needs of our children, but if we don't take care of ourselves, we won't be able to take care of our kids.

I recently spoke with a few families who have children with CHARGE syndrome, and the sheer exhaustion in their voices gave me pause. They do so much for others that I asked how they get some much needed respite for themselves and how they utilize that free time. Some moms said their husbands will stay with the kids, and some families have grandparents and siblings who can assist in the care of their child. This can be a huge help. This free time allows these parents to attend religious events, shop for food and clothing, go out to lunch, and perhaps even see a movie. This is typically the norm for most families, but it can be a challenge for us. If we don't have family nearby, the challenge is finding a respite worker or sitter who we can learn to trust over time. That was a key point from the families I spoke with—building trust and letting go of some control for a short period of time. While nerve wracking in the beginning, the families found it got easier over time.

Finding respite care can be quite a challenge and can be different from country to country, state to state, and even county to county. Families from more rural areas often have the greatest challenge with respite care. Some ideas I have for parents are:

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"Having a child with CHARGE syndrome typically means that we go, go, go."

"...if we don't take care of ourselves, we won't be able to take care of our kids."

Me, Myself, and I (cont.)

- Contact your state deaf-blind project for suggestions. Go to <http://www.nationaldb.org> and click on State DB Technical Assistance Network for your state's contact information.
- Contact your county's Developmental Disability Service Office (DDSO) as well as a Parent Training and Information Center (PTI). You can find a listing of state PTI's at <http://www.parentcenternetwork.org/>.
- Contact nonprofit sectarian and faith-based community agencies that offer respite care and trained personnel. Your PTI should have that information.
- Don't hesitate to call other families in your area who have a child with CHARGE syndrome to compare notes. Sometimes word of mouth from other parents is your best option. If you need a parent-to-parent contact list for your state, province, or country, please contact me at sheri@chargesyndrome.org.

We need to find resourceful ways to carve out some quiet moments, such as locking ourselves in a room and reading a book or leaving the house for an enjoyable activity. I heard a very creative suggestion from a parent who contacts the directors of special education programs, deaf education programs, and OT and PT programs at local universities to inquire about students who might be interested in spending one day a week with her daughter in the summer. The intent is to get her daughter out into the community to participate in various activities. This mom writes up a brief summary of her daughter's interests and special needs, such as basic sign language, and then she and her husband hold face-to-face interviews with the interested students to find the best match. This requires some legwork, but provides a great payback—free time for mom and dad and community experience for their daughter.



Let's face it—a happier parent means a happier family! So the next time you see my number pop up on your caller ID, be prepared. My first question may not relate to your child. I may ask about YOU! I hope you will all find some time to relax this summer—and remember, it's for your own good. And if that doesn't motivate you, then tell yourself it benefits your child. So go out and walk your dog, read a book, see a movie—and don't forget to laugh. Have a fabulous summer!

“Sometimes word of mouth from other parents is your best option.”

“Let's face it—a happier parent means a happier family!”

iPads and the Itinerant

By Lisa Weir

Outside of my life as a parent and CHARGE Syndrome Foundation board member, I am an itinerant teacher for students who are deaf or hard of hearing. Instead of having a classroom, I travel around to a number of school districts and work with the schools and also on a 1:1 basis with students who have hearing loss. I also spent part of this year in a teaching position for students who are blind or visually impaired. I wrote this article for my fellow itinerant teachers, but I thought some of the folks who read the *CHARGE Accounts* newsletter might also find it interesting. In this article, I talk about a recent webinar on iPads that was produced by Perkins and my own experience using the iPad with my students who have both vision and hearing loss.

Recently, I watched the Perkins webinar, “Appolutely Engaging and Educational,” featuring Eric Jerman. Eric is an Orientation & Mobility Specialist and the father of a young boy with a metabolic disorder and cortical vision impairment (CVI). I wanted to watch this because I received an iPad in December and had begun using it in January with some of my students who are blind/visually impaired (BVI) and since March with my students who are deaf/hard of hearing (DHH). It’s been really interesting to see students’ reactions to a variety of apps.

Eric began the “Appolutely Engaging and Educational” webinar by mentioning some of the categories of apps he would be discussing: Cause & Effect, Read to Me Stories, Music & Sound, Communication, and Accessibility. He talked about and demonstrated the different ways in which one can interact with the iPad: tapping, touch & hold, tap & swipe, talking to it (and having it echo back), etc. One thing Eric mentioned early on was the fact that, when thinking about apps, one should consider that, “Less is more, especially with people who have low vision.”



Under each of the categories, with the exception of accessibility, Eric demonstrated several apps he has found useful. His handout included a list of many apps, along with information about each one. Seeing the apps being demonstrated was useful. Eric also talked about “Bonus Apps”—those preloaded on the iPad, such as the photos app, which can be useful in terms of loading pictures that are important for the student using the iPad to meaningfully customize communication apps. Eric is also a big fan of using YouTube videos.

All in all, the webinar was useful in terms of learning about some new apps I wasn’t already using and having some time to think about the apps he was demonstrating and the different ways in which I could use them. I would recommend watching something like this to anyone who is considering getting an iPad to use with their students (or with their child). Even if you don’t have an hour to watch the webinar, the handout is worth a download. You can get the info here: <http://www.perkins.org/resources/webinars/>.

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“...when thinking about apps, one should consider that, ‘Less is more, especially with people who have low vision.’”

iPads and the Itinerant (cont.)

Some of my own thoughts on the iPad so far...

I've used the iPad with both my students who are BVI and/or DHH, and I'm finding it to be a very useful teaching tool. There are a lot of apps out there for language, speech, communication, literacy, etc., and many apps designed for individuals with visual impairments as well. I am still relatively new to this, but some tips I would give include:

- **Find some sites you trust.** Read what they're saying about apps, which ones they like, why, what features they have, etc. For DHH, sites like Super Duper have their own apps, and a number of SLP websites that review apps are quite good. For BVI, Perkins and TSBVI are good starting points to look for info on apps for students with visual impairments.
- **Try the Lite versions.** I download a bunch of free lite versions and give them a whirl—usually the students dictate whether they're going to be useful. You usually get a watered-down version or a version with fewer features, but you get a good idea of what the app is going to be like.
- **Think outside the box.** Maybe it's because I'm seeing lots of students with many differing needs, but I find myself looking at the app "Tap-n-See Zoo," which was designed for students with cortical visual impairments, and thinking, "Wow, that'd be great to reinforce the basic concepts of big and small with my young DHH students or DHH students with multineeds." I also use a silly app called "Crazy Face" for speech work; it's good for getting kids involved and trying to work on their speech sounds to make the crazy face move. I guess my point is, although the app may be designed for one purpose, you might think of other ways it could benefit your students.
- **Invest in a great iPad case.** If you're making this type of investment and letting your students (or child) use it, you want to have a great case for safety purposes. I use the Otterbox Defender, but there are a number of other good options out there.
- **Check your settings.** You may need to do some tweaking depending on the student with whom you're using the iPad; for example, I have turned off "Multitasking Gestures" in my settings so that using multiple fingers does not slide/change the screen. Many students with fine-motor issues can't limit their interaction with the iPad screen to only one finger.
- **Research the app.** Be aware that if you don't have your own data plan, accessing school wireless networks can be an issue, and some apps may require Internet access. Be sure to really check out an app well before purchasing it to make sure you can use it in the schools.

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"There are a lot of apps out there for language, speech, communication, literacy, etc...."

"...although the app may be designed for one purpose, you might think of other ways it could benefit your students."

“If you come across apps you love, share with others.”

iPads and the Itinerant (cont.)

- **Share the love.** If you come across apps you love, share with others. I’m still scratching the surface, but here are a few of my favorites:

DHH	BVI
Articulation Station (speech)	Art Of Glow
Picture the Sentence (listening for critical elements, understanding pronouns, etc.)	I ♥ Fireworks
Following Directions (listening for critical elements)	Baby Vision
Crazy Face (speech)	Baby First Look – Moving Patterns
Kids Find & Learn (vocabulary, categorization)	Flashlight (have used this as a mini “light box” several times—much more portable!)
Phonics Rhyming Bee	Baby’s Musical Hands
QuestionIt (helps with <i>wh</i> - questions)	Flannel Animals
Speech Pairs	Tap-n-See Zoo (CVI)
Reading A-Z leveled books (same ones that are on ReadingA-Z.com)	Baby Finger
Interactive Touch Books (interactive stories)	Baby Shapes

Other Useful Apps for Kids with Special Needs

By Leslie Kauffman



There are many websites that list recommended apps for children with special needs, but one of the most comprehensive I’ve found was compiled by Eric Sillers and can be found at <http://www.scribd.com/doc/24470331/iPhone-iPad-and-iPod-touch-Apps-for-Special-Education>.

The apps are grouped by categories such as Speech and Language, Sign Language, Organization and Scheduling, Fine-Motor Development, and many more. Each app is briefly described and is hyperlinked directly to the iTunes store for more information and purchasing. The list is updated frequently.

LET'S HEAR FROM YOU!

Submissions for the Fall 2012 edition of *CHARGE Accounts* are due by **September 15th**. We would love to include more personal stories from families as well as those with CHARGE syndrome. Pictures would be great, too. To submit an article or story for the newsletter, please send it to leslie@chargesyndrome.org. Submission guidelines can be found at <http://chargesyndrome.org/documents/CSFNewsletterGuidelines.pdf>.



Ohio Workshop Recap

By Leslie Kauffman

On May 5, 2012, the Ohio Center for Deafblind Education held a parent workshop on “Educational Considerations for Children with CHARGE Syndrome.” The guest speaker was Dr. Susan Wiley from the Department of Developmental and Behavioral Pediatrics at Cincinnati Children’s Hospital Medical Center. The workshop was designed to help families relate the priorities in their children’s educational and functional needs, taking into consideration medical, developmental, and social–emotional needs. Parents also shared strategies they have used to advocate for their child within the educational setting to meet their child’s potential. Dr. Wiley provided a helpful planning worksheet that parents can fill out and give to their child’s educational team. If you would like a copy of the worksheet, please contact me at leslie@chargesyndrome.org.

Webinar: “The Forgotten Senses”

By Lisa Weir

On May 20, 2012, the CHARGE Syndrome Foundation held its second live webinar, with David Brown speaking on “The Forgotten Senses”—proprioception and the vestibular sense. During the webinar, David discussed these two senses, what happens when they are not functioning properly, and tips for working with individuals who have dysfunctional proprioceptive and vestibular senses. The webinar is available via the Foundation website. To listen to the webinar, visit <http://chargesyndrome.org/resources.asp#webinars>.





Conversations and Creativity

My Brother, the Superhero

By Jessika Van Spronsen

I heard the sweetest thing the other day in my youngest son's classroom that I wanted to share. Jonah is my oldest son and has CHARGE syndrome; Samsun is my youngest son. The boy who stood up for both of them is Sam's best friend. It was amazing!

Here is the conversation that I had the privilege of overhearing:

Boy 1: What's wrong with your brother, Sam?

Sam: Nothing is wrong with him!

Boy 1: Well, then, why does he look different and have that thing in his neck?

Boy 2 (my son Sam's best friend): Because he is a limited edition action hero!

Boy 1: WHAT???

Boy 2: You know, like how G.I. Joe comes with extra special parts to play with. Well, Jonah has very extra special parts that make him have superpowers!

Sam: Yeah, my brother is a superhero!

Boy 2: Yeah, he is, and he's my hero!

Boy 1: That is so cool! I wish my brother had superpowers!



Samsun and Jonah

Interview with Cameron Andrew Anderson, Age 10

Conducted by Rebecca Anderson

Why did you write *The Water Book*?

I'm actually in the process of writing four books, including *The Water Book*. The others are *The Air Book*, *The Stone Book*, and *The Fire Book*. They are fairly short, as short as five pages and as long as seven pages. I'm not just writing these books for fun. People are supposed to learn from them by following the advice.

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Conversations and Creativity (cont.)

What is it like having CHARGE syndrome? What do you want people to know about it?

Sometimes I forget I have CHARGE syndrome. CHARGE doesn't affect me very much—except for my balance and hearing loss. Sometimes I like to thank God because my hearing loss enables me to connect to both worlds—the deaf world and the hearing world. I'm grateful to the person who created hearing aids. Being able to sign (ASL), I can communicate with deaf people. My ability to speak English and use hearing aids means I can communicate with hearing people. I'm very grateful that I'm not the only one with CHARGE. I would be lonely if I was. Sometimes I like to sign and sometimes I want to talk. I'm glad I can do both!

I like to swim, run, read, and build with LEGOs and K'NEX. I'm not that athletic, so I don't think I'm going to be in the Olympics. When I was born, I had a cleft lip and palate. My balance was bad and my hearing was also bad, but my mom was so happy when I could hear a plane without any hearing aids! Ask someone who has hearing aids how loud a plane sounds with hearing aids.

My advice to people is: don't go beyond what God enables your body to do.

The Water Book

By Cameron Anderson, Age 10

A cat of war like Catman and PuffBall is helpful but at times a peaceful cat such as A-cat is also helpful. The mind is water, let the mind flow like water. Water can be like PuffBall and rage or like A-cat and be calm. Learn from water.

Water supports all life and a war will not help. Try a war. It was a man war. Man was made not to war but to help and be like A-cat, calm and peaceful.

Have you been mad? Then you have been raging water. Have you been calm? Then you have calm waters. Rage not o waters, as calm is good.

Water was a war of the mind. Minds of rage and minds of peace are antonyms. And a mind of both is a mind well made.

Remember the waterfall. Don't lose your canoe. Is calm a curse? No. Waterfalls are a change. Accept them.

Waterfalls are a change. And as a rage will lose you your canoe, a calm will not.

“Sometimes I like to sign and sometimes I want to talk. I'm glad I can do both!”



Conversations and Creativity (cont.)

Poem

Submitted by Helen Simpson

As an assignment in my daughter Danielle's 7th grade English class, she had to write an "I am..." poem. She entitled her poem "I Am Proud of Being Myself" and wrote the poem about her older brother, Nicholas Simpson, who has CHARGE syndrome. Her teacher indicated that Danielle's poem was the best in the class. I am very proud of my daughter for writing this poem. I would like to share the poem with everyone:

I am a sixteen year old boy who has charge syndrome
 I wonder what my future is and if I will reach my dreams one day
 I hear people laughing, lockers slamming and kid's footsteps rushing to class
 I see big smiles and helpful people all around me
 I want the world to see I am just another person but with some quirks, but everyone does too
 I am a sixteen year old boy who has charge syndrome

I pretend I am the star hitter on the San Francisco Giants
 I feel everyone should let go and enjoy life and don't listen to what others say
 I touch my heart and feel the beating because of the excitement in life
 I worry that people won't accept me for me and they will just judge me by what they see
 I am a sixteen year old boy who has charge syndrome

I understand I am different. But that's okay because everyone is. No one is perfect.
 I say be proud of who you are and I would never want to be "normal" or anybody else because that's boring and nobody is normal. We are all different in some way. I am proud of being different and most of all being ME!
 I dream that one day I will work for the San Francisco Giants and do what I love every day
 I try to do my personal best and accomplish my personal goals in life
 I hope for my chance and my own place in the world and help younger kids that have disabilities, just like me
 I am a sixteen year old boy who has charge syndrome

Written by Danielle Simpson

7th Grader

Lincoln Middle School

Alameda, CA



Save the date and start making plans to attend conference!

Planning is well under way for next year's conference, which will be held on July 25–28, 2013, in Scottsdale, Arizona, at the **Fairmont Scottsdale Princess** (<http://www.fairmont.com/scottsdale>). There's something for everyone at a CHARGE Syndrome Conference, whether it's your first or your eleventh. It's a chance to learn; connect or reconnect with other families; meet amazing, dedicated professionals involved with CHARGE; and, of course, have some fun at our evening events. Come with us to beautiful Scottsdale, Arizona, and experience the wonder of a CHARGE Syndrome Conference.

Here are some things to think about as you begin to make your plans:

- Start exploring funding opportunities in your local area and apply early and to multiple agencies to ensure funding is in place for you and your family to attend.
- Stay tuned to the **conference information page** (<http://www.chargesyndrome.org/conference-2013.asp>) for links to register for conference and camp, make your hotel reservation, and read about the program and all of the other exciting events we have planned.
- Not a Foundation member? Changed your email lately? Make sure the Foundation office has your latest up-to-date contact information so you're receiving e-mail notifications about registration, deadlines, and other conference-related information. Visit our **membership page** (<http://www.chargesyndrome.org/membership.asp>) to join or renew your membership or contact Lori at info@chargesyndrome.org with any updated email addresses/other contact information.
- You can also follow our **conference page on Facebook**, where all of our updates will be posted: (<http://www.facebook.com/11thInternationalChargeSyndromeConference>)
- If you have any questions, please contact Lisa at lisa@chargesyndrome.org.

See you next summer!



Upcoming Events

VISIONS/Services for the Blind and Visually Impaired: Early Intervention Residential Program

Date: Summer 2012

Location: Spring Valley, NY

VISIONS/Services for the Blind and Visually Impaired (<http://www.visionsvcb.org>)

provides training to legally blind adults and

children in the home to ensure safe and effective performance of activities of daily living (ADLs)

and Orientation and Mobility. This summer, VISIONS is providing an early intervention

residential program in Spring Valley, NY. The program is of no cost to the family. (Cost of travel

is the responsibility of the family.) The program is designed to provide instruction to families on

how to foster independence, to the extent possible, when working with a child who is legally

blind. If interested, please contact:

Bill Hixson, OTR/L, CVRT, COMS

Director of Rehab

VISIONS/Services for the Blind and Visually Impaired

500 Greenwich Street, 3rd floor

New York, NY 10013

(212) 625-1616 ext. 145



Two Steppin' for CHARGE Syndrome

Date: Every Friday and Saturday night

Location: KP's Music Rodeo, 1276 State Route 183, Troy, TN 38260

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

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.



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Upcoming Events (cont.)

Tyler Trot Run/Walk 5K for CHARGE Syndrome

Date: August 4, 2012

Location: Antietam National Battlefield, Sharpsburg, MD
Bike-friendly, pet-friendly, stroller-friendly, kid-friendly, runner-friendly, walker-friendly event! Last year, we exceeded our expectations and raised over \$14,000! This year, our goal is \$20,000!!



For more information, please visit <http://www.tylertrot.org>.

4th Annual Joshua Kurby Charge for CHARGE 5K

Date: August 18, 2012

Location: Due to some construction at Armstrong Park, the event will be held at St. James Farm in Warrenville, IL, right off of Butterfield Road.

The registration form, as well as online registration, will be available soon. Stay tuned!

2012 Australasia CHARGEability Conference

Date: September 29–30, 2012

Location: Penrith, New South Wales

For more information on the conference, visit

<http://www.chargesyndrome.org.au/home/conferences/2012sydney>.



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.



7th Texas CHARGERS Annual Retreat

Date: November 2–4, 2012

Location: Camp Allen, Navasota, TX

Presenter: David Brown

Registration begins in August. Please contact Leigh Fultz at leighfultz@gmail.com for registration information.

For more information on the event, visit <http://www.texaschargers.org/events.html>.

Upcoming Events (cont.)

Health & Wellbeing in Children, Youth and Adults with Developmental Disabilities: Challenging Behavior – The Tip of the Iceberg

Date: November 15–17, 2012

Location: Vancouver, BC

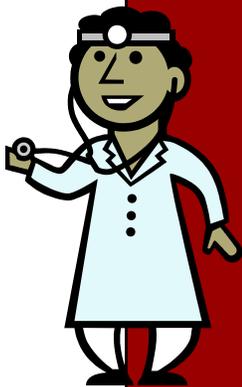
This conference will provide educational and informative updates on psychiatric, behavioral, and complex health components specific to individuals with developmental disabilities, and showcase best practices in the field. Specifically, the conference will focus on approaches to complex challenging behaviors, contributing medical issues, and new developments in medication and behavioral treatment. In addition, the conference will address important health and mental health issues and will review common genetic syndromes such as Down syndrome and Fragile X. This conference will engage health care providers and educators from a wide range of professional disciplines in knowledge transfer and interprofessional collaboration in order to maximize health and wellbeing so as to minimize disability and improve quality of life. The format will include plenaries, breakout sessions, and poster sessions.

For further information, please visit <http://www.interprofessional.ubc.ca/HealthAndWellbeing/default.asp> or contact Ian Chipperfield at ian.icpe@ubc.ca or (604) 827-3112.

Provider Recommendation Project

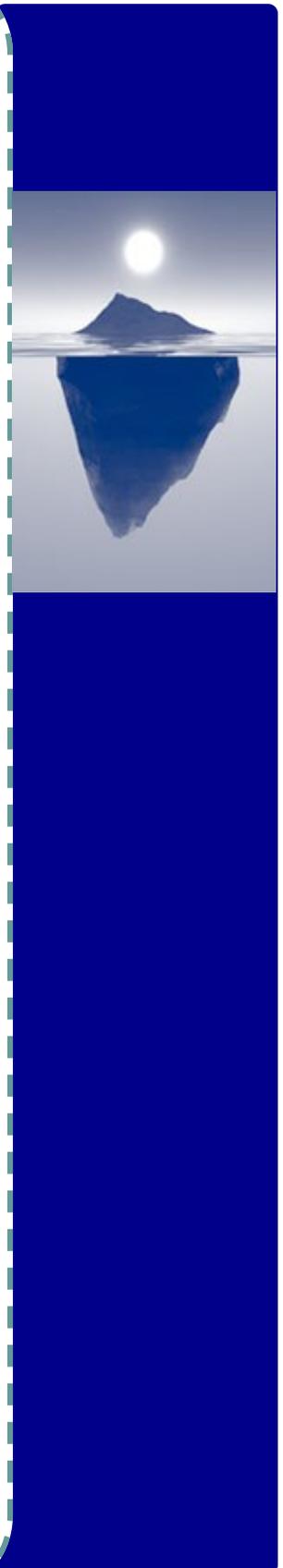
Our Provider Recommendation project has gone live! If you want to know about great doctors and therapists in your area (state, province, or country), please e-mail Sheri Stanger, Director of Outreach, at sheri@chargesyndrome.org. Sheri will search the Provider Database for you, and if she finds what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



Focus on Fundraising



Garage Sale Tips

By Tracy Roth

We began planning for our garage sale several months in advance because I knew that the more “stuff” we had, the better. I sent an e-mail to all of my friends and family and asked them, as they were cleaning out their homes to make room for new stuff around the holidays or doing their “spring cleaning,” that rather than donate their items to Goodwill, to donate them to us for the garage sale. This worked really well because everyone usually clears out their stuff once or twice a year, so I ended up with an entire garage full of stuff!

Our original plan was to hold the garage sale in the spring, but I had collected so many things that the idea of pricing everything was a little overwhelming and I kept thinking I didn’t have time to devote to it. I was able to overcome the whole idea of needing to price everything by grouping similar items together—children’s clothing, books, etc.—and pricing by the type of item and just hanging large signs so shoppers knew how much each group of items was. We held the garage sale in July (2011), and I called the village beforehand to make sure we didn’t need a permit.

We didn’t advertise in the newspaper because I didn’t think we needed to and ultimately it would take away from the profits. Instead, we made huge signs and placed some of them at the nearest busy intersections to my home, with others on the inner streets and in our front yard. Where we live, there are LOTS of people who love garage sales and scour the neighborhoods for them in the summer. We had multiple customers come by the day before the sale even opened because we were in the garage sorting and pricing with the door open and they wanted to buy stuff early. And we let them—what the heck!



We made sure that the signage was large and that it showed that all of the proceeds were being donated to the CHARGE Syndrome Foundation. That was really important because it made people less likely to haggle over price and it raised awareness. We also had a stack of the Foundation brochures handy so that, when people were paying, we could hand them one or put one in their bags and explain to them why we were having the sale. This was great because several folks really wanted to stay and talk about CHARGE.

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Focus on Fundraising (cont.)

In the end, we made \$1,100! I was super-happy with this because frankly I thought I would be satisfied with \$500. Then, because both my employer and my husband's employer match charitable contributions—mine up to \$1,000 and my husband's the full amount—we requested matching donations from each, so in the end we ended up with a \$3,200 donation to the Foundation!

Illinois Families Garage Sale

By Jody Wolfe

A few Illinois families recently gathered for a community-wide garage sale. Our almost \$200 raised was given to the CHARGE Syndrome Foundation.



Daniel Wolfe and his friend



Jody Wolfe and Deanna Steinhauser

MY CAN CAN



That red fundraising can sat around my house for months. I saw cans and boxes from so many other charities at local stores. Life kept getting in the way of putting mine out. I finally asked a friend who worked at a local cleaners if he would mind putting it by the cash register. A couple months later, he returned that can stuffed full of dollars and coins! It is now back in his store for a second tour of duty. It's a win-win situation—hundreds of people get a brief introduction to CHARGE and we raise money in the process.

Send us an email about how your can is doing. If you haven't started, remember that **your can can, too!**

Focus on Fundraising (cont.)

The Adventures of Flat Charlie Continue

By Leslie Kauffman

Flat Charlie continues on his journey to the 11th International CHARGE Syndrome Conference in Scottsdale, Arizona, in July 2013. Recently, Charlie visited the Czech Republic and Canada. So far, Team Flat Charlie has raised almost \$1,400 for the CHARGE Syndrome Foundation.



To read more about Flat Charlie's whereabouts, see pictures, and get updates, visit <http://www.facebook.com/groups/300145663351626/>.

Big or Small, We Love 'Em All

By David Wolfe

We have all been touched by someone special who has CHARGE. We celebrate their milestones and amazing achievements, and feel their pain when they are ill. We do everything in our power to love and support our children, families, and friends who deal with CHARGE on a daily basis. We are bound together by our desire to see everyone with CHARGE reach their full potential.

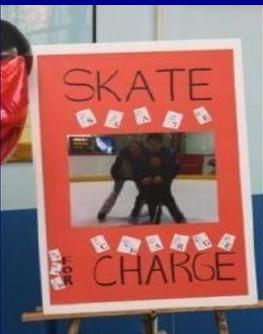
The Foundation exists to support our hopes and dreams for all individuals with CHARGE syndrome. We need more research, outreach, webinars, education, publications, and conferences. All of these goals are supported by the events hosted by individuals to benefit the Foundation. **Without these events, the Foundation simply could not thrive.**

Whether you host a party, run, golf outing, Charge It for CHARGE, bake sale, or garage sale, **every effort matters.** Go to <http://www.chargesyndrome.org/fundraising.asp> to see a nice summary of some of the recent events hosted by our friends and families.

We know we are missing summaries of so many events. We want to have a complete archive of the events that our friends and families have held over the years. Please send us a brief summary and a picture of your event so we can add you to our list.

Don't wait, make 2012 the year you host an event. Remember, whether you raise \$250, \$2,500 or \$25,000, we need you. Big or small, we love 'em all! Good luck and keep me posted on your success. Feel free to contact me if you need help with fundraising ideas.

David Wolfe
President and Fundraising Chair
david@chargesyndrome.org



CHARGE in the News

All About Ashley

Ashley Riva is a 17-year-old student at Perkins School for the Blind, who, along with three of her classmates, participated in the White House Easter Egg Roll in April. Click the link below to read a profile of Ashley.

<http://www.metrowestdailynews.com/news/x1082436864/Deaf-nearly-blind-Marlborough-teen-visits-White-House>



The Deaf-Blind in Uganda



The article in the link below includes details on Uganda's deaf-blind population; the Uganda School for the Deaf; and comments from students, their parents, and instructors at the school.

<http://www.newvision.co.ug/news/629883-In-a-world-with-no-sound--color.html>

A Dream Come True

Click the link below for a brief news clip and article about how President Obama made one of 16-year-old Myriah Soukup's dreams come true.

<http://minnesota.cbslocal.com/2012/06/01/new-ulum-girl-thrilled-to-meet-president/>

The Girl with the Bionic Ear

Alicja Nowicki, deaf from birth as a result of CHARGE syndrome, became the first Irish-born child fitted with a bionic ear earlier this year. Read more about Alicja at:

<http://www.thesun.co.uk/sol/homepage/irishsun/irishsunnews/4284844/Hip-hip-hearing-aid-for-my-Alicja.html>



Savannah's Story



Visit the link below for an article that profiles Savannah, a 5-year-old with CHARGE syndrome, and includes comments from Savannah's parents, who discuss the ups and downs of parenting a child with CHARGE syndrome.

<http://www.piedmontparent.com/articlemain.php?CHARGE-Syndrome-The-Ups-and-Downs-1498>

Resources

National Tele-Support Group

By Sheri Stanger, Director of Outreach

In January, I started a national CHARGE tele-support group for parents/guardians of children with CHARGE syndrome. This support group is offered to families through The Jewish Guild for the Blind's National Tele-Support Network for Parents of Children with Visual Impairments in collaboration with the CHARGE Syndrome Foundation. I facilitate this weekly support group at no cost to the participants on Tuesdays at 1PM (EST). The group can last from 1–2 hours with a predetermined topic discussed each week. Guest speakers are invited to join us from time to time. Calls are conducted in English and are open to families in the United States and Canada.



This new venture has been an exciting experience and a wonderful way for parents/guardians to discuss shared experiences, challenges, and achievements. And while I have a steady group of participants, I have room to accept a few more dedicated individuals. If you are a professional, please distribute this information to your families that have a child with CHARGE syndrome. If you are a parent and would like to join or simply want more information, please contact me at 1-855-5CHARGE (1-855-524-2743) or at sheri@chargesyndrome.org.

I am excited to add a few more parents/guardians to this national call. I look forward to hearing from you!

Article on National Tele-Support Group

By Sheri Stanger, Director of Outreach

An article about the tele-support group that I submitted to the New York Parent Network (NYPN)—the deaf-blind family group for New York—was included in their Fall/Winter 2011 newsletter. Visit <http://tinyurl.com/NYPNarticle> to read the article. (The article appears on pp. 3–4.)

Perkins Webcasts

Perkins School for the Blind offers a series of on-demand webcasts presented by experts in the field of visual impairment and deaf-blindness. There are six CHARGE syndrome webcasts available for viewing at <http://www.perkins.org/resources/webcasts/charge-syndrome.html>. Topics include: An Overview of CHARGE Syndrome, Providing Physical Therapy, Teaching Strategies for Children, The Impact of Communication & Learning, Behavioral Issues in CHARGE Syndrome, and Preparing for the World of Work.

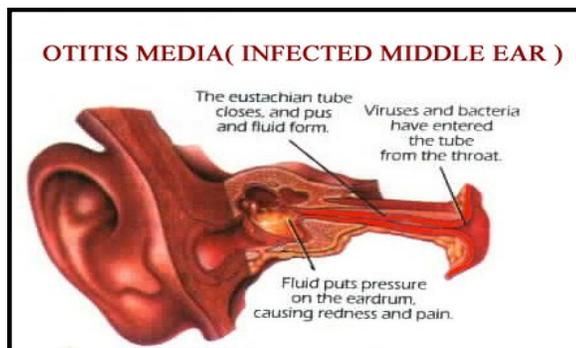
Resources (cont.)

Otitis Media in a New Mouse Model

Otitis media is a middle ear disease common in children under 3 years old. Otitis media can occur in normal individuals with no other symptoms or syndromes, but it is often seen in individuals clinically diagnosed with genetic diseases such as CHARGE syndrome. Although otitis media is common in human CHARGE syndrome patients, it has not been reported in mouse models of CHARGE syndrome. In a recent study, scientists found a mouse model with a spontaneous deletion mutation in the CHD7 gene and with chronic otitis media of early onset age accompanied by hearing loss. These mice also exhibited morphological alteration in the Eustachian tubes, dysregulation of epithelial proliferation, and decreased density of middle ear cilia. This is the first mouse model of CHARGE syndrome reported to show otitis media with effusion, and it will be valuable for studying the etiology of otitis media and other symptoms in CHARGE syndrome.

To read the report, go to:

<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0034944>



CHARGE Foundation Store

In partnership with Creative Promotional Products, Ltd., the CHARGE Syndrome Foundation store is now open. The store offers everything from clothing apparel to drinkware to home and office supplies.

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.

Promotional
Merchandise
& Gifts

Thank You

Donations

America's Charities
 Amy Cronk
 Bernadette Van DenTillaart
 Candi Meadows
 Crystal Tenney
 Cynthia Norton
 Deby Davis – United Way of
 Kentucky
 Emmadell Vernon
 Erin Rossi
 Harry Meester
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 Karen Arroyo
 Katherine Ang
 Marly Stoneberg
 Melva Strang-Foster
 Real Mex Restaurants
 Rick Smith – Rick's Barbeque,
 Inc.
 Sharon Hill
 TIAA-CREF Employee Giving
 Campaign
 Wells Fargo Community
 Support Campaign

**In Honor of Aaron's
 Education Team**
 Susan Hiscutt

**In Honor of Alexandra
 Barksdale**
 Emmadell Vernon

**In Honor of Anthony
 Campos**
 Gina Grayum

**In Honor of Christian
 Roberts**
 Bekkie Cobb

In Honor of Claire O'Toole
 Bart & Nancy Stovicek

**In Honor of Colleen
 O'Toole's birthday**
 Kathleen Brennan
 Kelley & Donna Brennan
 Harold Farling
 Kathryn & Thomas Karg
 Camille & James Mordaunt
 Miguel Quinones

**On the Special Occasion of
 Colleen O'Toole's Birthday**
 Kathleen Stephens

**On the Special Occasion of
 Colleen O'Toole's birthday.
 Please designate this
 donation to the Scholarship
 Fund.**
 Julie & Chuck Heald

**On the Special Occasion of
 Colleen O'Toole's 50th
 Birthday**
 Colleen Brennan

**On the Special Occasion of
 Colleen O'Toole birthday
 request**
 Edward Cavazos

**On the Special Occasion of
 the 80th birthday of our dear
 friend Dan Fogel. "A
 generous donation from Em-
 ma & Eli Bluestone"**
 Emma & Eli Bluestone

**In Honor of the Dowdy
 Family**
 Allen & Linda Tennbaum

**In Honor of my ETSU Spring
 Semester 2012 Medical
 Aspects Class...dedicated to
 working with children with
 special needs**
 Lorie Coleman

**In Honor of Jack & Claire
 Waggoner**
 Sarah Holt

In Memory of James Pedersen
 Mary Ann Ross

**In Memory of James Pedersen
 and In Honor of Alice
 Pedersen**
 Jack & Mary Bashlor

**On the Special Occasion of
 Kylie's second birthday**
 Bonita Herod

In Honor of Lexie Barksdale
 Emmadell Vernon

**In Honor of Lincoln
 Weinstock**
 Norman Weinstock

**On the Special Occasion of
 Lincoln Weinstock Bar
 Mitzvah Project – running for
 Charge Syndrome**
 Melissa Irvin

In Memory of Marsha Lawn
 Gary Coleman
 Virginia Grant

**In Memory of Mrs. Marsha
 Ann Lawn**
 Mary Ann & Carl Kraft

**In Memory of Mrs. Marsha
 Ann Lawn, 64, of Monrovia,
 died Saturday, April 21, 2012,
 at her home after a
 courageous battle with
 cancer**
 Linda Rebrovick – Consensus
 Point Team

**In Honor of Nolan Wilson &
 In Memory of Marsha A.
 Lawn (grandmother)**
 From Anita Taylor, Doris Field,
 and Marjorie Lentzen

**In Honor of Nolan Wilson,
 grandson of Marsha Lawn,
 and in memory of Marsha
 Lawn**
 Shirley Campbell-Grizzle

In Memory of Martha Buck
 Larry & Adrienne Nelson

**In Memory of Martha Bray
 Buck**
 Don & Lillie Alexander

In Honor of Maya Kelly
 Fran Royston

In Honor of Natalie Stone
 Mayra Figueroa & Declan Kearns

In Memory of Trey Chatham
 Donna Downey

**In Memory of John Thomas
 Chatham III, known as
 "Trey," for his 3rd birthday**
 Yolaine Dupont

Thank You

Charge It for CHARGE Tributes

In Honor of Adele Brandrup

Amy Bickell
Eric & Dawn Brown
Dona Cash
Michelle Clark
Joe & Kathy Daniel
Joy Daugherty – Interiorscapes, Inc.
Amanda Howes
Ed & Amy Monroe
Michael & Amy Murphree
Glenn & Betty Schilberg
Charmoin and Crawford Tatum
Rhonda Wakefield
Brad & Kris Walden
Jamie & Julie Warren
Danielle Bart Yancey

In Honor of Adele (Doll). Love, Drew
Dawn Brian

In Honor of Adele Brandrup (Jay & Julie Brandrup)
Brian & Kryss Barrett

In Honor of Adele Brandrup and her family
Mitch, Paige & Ellie Willcutt

In Honor of the amazing and darling Adele Brandrup! She is an inspiration!
Mindy Beebe

In Honor of Adele & Julie Brandrup – two of the strongest women I know.
Duncan Blair

In Honor of Adele Brandrup for Julie and Jay Brandrup's birthdays
Chris O'Connell

In Honor of Adele Brandrup and Julie & Jay's 80th birthday celebration!
Mindi Belmont
Michael Steffeck

In Honor of Adele for Jay and Julie's 80th!
Lori & Brian White

In Honor of the Brandrup Family. Adele, from your classmates Ben and Grayton, and for our friends on their "80th" bday, Julie and Jay
Cary & Daniel Murray

In Honor of Julie and Jay Brandrup's 40th Birthdays and in honor of Adele
Bill & Patricia Webb

On the Special Occasion of the Brandrup's 80th...and their love and kind heart to all. Especially to and for Adele, keeping our hearts on fire!
David Davis – DavisDenny Advertising & Related Services, Inc.

In Honor of Jay & Julie's 80 Bday!!! Happy Birthday you two! We are so thankful for you both, Jay and Julie, and your precious girls!
Melanie & Jerry Grant

On the Special Occasion of Julie & Jay Brandrup's Birthday
Mary Scott Pearson

On the Special Occasion of the 80th birthday party of some great friends!
Brad White

In Honor of Jay & Julie's Birthdays!!!
Elizabeth Burgess

In Honor of Jay & Julie's "80th"
Lisa & Kennedy Weir
Jim Windsor

On the Special Occasion of Julie/Jay 80th birthday
MiMi & Papa

On the Special Occasion of Julie and Jay Brandrup's Combo 80th Birthday!
Jamie Roberts

On the Special Occasion of 2 special birthdays – I great idea! Happy 80th, my friends.
Carol Wadley

On the Special Occasion of Julie & Jay Brandrup's 40+40 "It all adds up" birthday party/ fundraiser 3.3.12
Liz & Curt Rozzelle

In Honor of Jay, Julie and Adele Brandrup
Leesa Moore Dean

In Honor of Adele, Julie, Jay and Margo Brandrup
Shannon & Dan Price

In Honor of Julie, Jay, Adele & Margo Brandrup
Dana & Scooter McCain

In Honor of Jay & Julie Brandrup and their two little angels
Linda Smith

In Honor of Julie and Jay Brandrup
Mark & Carla Huegel

In Honor of the Brandrup's
Lacey Bacchud

In Honor of the Brandrup Family
John & Barb Christensen
Jamey & Suzanne Roberson

In Honor of the Brandrup Family!
Ceil & Bill Heath
Brian O'Neill

On the Special Occasion of Andrew Delaney's 9th Birthday. Happy Birthday Andrew!
Jenny Richardson

In Honor of Andi Bean Miller
Emily Kattawar

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

Thank You

Charge It for CHARGE Tributes (cont.)

In Support of Anna Miller and Andi Bean – just a miniscule way in which we will always be there for the most beautiful little girl in the world, Andi Bean. Love, Uncle Jason and Aunt Carrie
Carrie Trant

In Memory of Colin Smith
Robin Ellyson
Leigh Gagnon

In Honor of Dominic
Jillian & Algis Baliunas
Nicole & Lee Borys
Sem & Leonard Borys
Timothy Bulfer
Elizabeth & Recardo Castrejon
Donna Dakes
Laura Estock
Lynette Falbo
Janet & John Fitzgerald
Amy & Jason Forrest
Corrie & Gerald Gleason
Paul Gnap
Shana & Matthew Goetz
Mark Goodman
Jewel & Arthur Howard
Hillary & Kevin Jebbitt
Tina & Michael Kaczynski
Holly & Michael La Dere Jr.
Christopher Lafferty
Heather & Joseph Lamonto
Christine & Scott Maccormack
Wendy Macri
Frank & Joann Mannerino

Patricia Mazurek – Vernon & Maz, Inc
Alison & Jeremy Melnick
Heather & Mark Meskimen
Remco Paap
Katherine & Michael Pandolfo
Candi & Ronald Reiche
Rosisela & Seferino Rojas
Corki Roth
Maureen & Justin Schultze
Denise Sherwin
Tracey & John Signore
Brad Skowronski
Robert Spindler
Nicole & John Sullivan
Jennifer & Ryan Swedko
Beth & Paul Tieri
David Twombly Jr.
Brian Wozniak

In Honor of Ethan
Joseph Sorce – Goldberg
Weisman Cairo
David & Jody Wolfe – Wolf & Wolfe, Ltd

In Honor of Eva, Lukas and Honzik participating in the Flat Charlie Project
Minnie Lambert

In Honor of Finley Roth
George & Jeanene Galan

In Memory of H. George H. Wood
Lisa Weir

In Honor of Jesse Goswell – Light for Team Flat Charlie!
Rachel Goswell

In Honor of Jesse Goswell participating in the Flat Charlie Project
Minnie Lambert

In Memory of Joshua Roy Kurby
Nonna & Grampa Kurby

In Honor of Justin Murray
Pamela Dowd

In Honor of Kishore, Pushpa and Amrit
Sheila Nasta

In Honor of Kristin Ogan and In Memory of Clara Young
Richard E. Young

In Honor of Laynie
Calyn Petersen – gLockets

In Honor of Lincoln Weinstock
Jodi & Richard Briden – Your Wellness Partner, LLC
Lori Seese
Weinstocks in CT

In Honor of Lincoln Weinstock's Bar Mitzvah
The Baturin Family
Leslie & Dan Ocko
Linda Pressman
David, Carol, Jake & Abby Weinstock
Madelaine & Jason Weinstock

In Honor of Lincoln Weinstock's Bar Mitzvah Project
Ira Weinstock

In Honor of the Bar Mitzvah of Lincoln S. Weinstock
Kersti & Floyd Baturin

In Honor of Lincoln Weinstock's Bar Mitzvah. Mazel tov!
Lizabeth Abramson

In Support of the Martin Family and the Flat Charlie Project
Minnie Lambert

In Honor of Megan Stanger
The Bernards
Donald Conklin – Dixie Home Carpets
Hayadee & Arthur Cornfeld

In Honor of the Murray Family
Erica Hanlon

On the Special Occasion of Noam Raphael's 18th Birthday
Donna Martin

In Honor of Pam Dowd's nephew. If he is anything like Pam, then the world is blessed to have him.
Melissa Hasenfus

In Honor of Sammy
Grandpa Bruce Pratt

In Honor of Samuel Wayne Bowers
Rod & Ellen Bowers

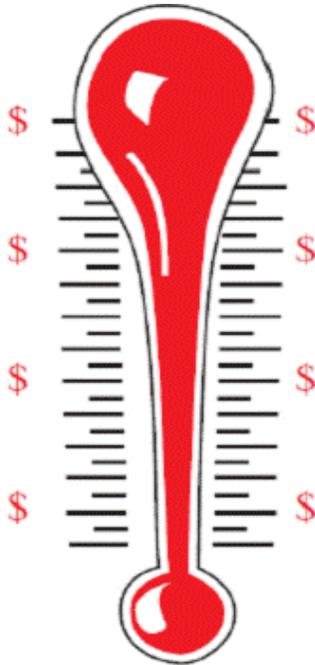
In Support of Miss Tori Yoho in the Flat Charlie Project
Minnie Lambert

In Memory of Trey Chatham
Jason Diamond



fourth annual Charge It for CHARGE

HOW HIGH CAN WE GO?



Our fourth annual Charge It for CHARGE campaign is now underway. So far in 2012 we have raised more than \$68,000! 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 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

Annual Membership

Family – \$25

Professionals – \$40

Phone: 516-684-4720

Toll Free: 1-800-442-7604

Fax: 516-883-9060

Lifetime Membership

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Gold – \$1,000

Platinum – \$5,000

Diamond – \$10,000

Director of Outreach

Sheri Stanger

Toll Free: 1-855-5CHARGE

(1-855-524-2743)

Phone: 914-479-0079

Fax: 914-478-1204

Email: sheri@chargesyndrome.org

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