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CHARGE Accounts

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FALL, 2010



President's Message

By: Neal Stanger

As you peruse this current issue of *CHARGE Accounts*, you will read about individuals and families as they share stories about their past, how they've grown, and how they've survived. You will also learn about exciting things happening in the present as well as about making plans for the future.

This newsletter has forced me to reflect on how far we've come as a Foundation. When I first joined the Board more than 14 years ago, I never imagined how far we could take the Foundation; and when I first became president, I only dreamed of some of our current advances. Now I am left wondering what we will achieve and where we will be in another five years.

This year, the Foundation has made more steps forward than in any other year in our history. We are in the process of hiring a Director of Outreach; we have updated *CHARGE Accounts* into an electronic format, saving the Foundation thousands of dollars in printing and postage; we have committed more money to research than we ever have in the past; and we have made many enhancements to our website as well. The first book on CHARGE syndrome was also recently published. (http://www.pluralpublishing.com/publication_cs2.htm)

Our 2011 conference will be July 28-31 in Orlando, Florida. We have tried very hard to keep costs as close as possible to past years. This year, we will not be charging a registration fee for individuals with CHARGE syndrome, and although our registration fees have gone up slightly, they will now include dinner on Friday night. All of this is a direct result of our fundraising efforts, including our major campaign, Charge It for CHARGE. Our third annual campaign will begin in October. If you have not worked with us before on this campaign, I urge you to give it a try—because without your help, none of our accomplishments would have been possible.

Website Update:

Upcoming Events

As some of you may have noticed, we have a new button on the CHARGE Syndrome Foundation website. This will take you to the newly created "[Upcoming Events](#)" page.

The purpose of this portion of the website is to make people aware of certain events that may be of interest to our members, such as fundraising events for the Foundation, conferences, workshops, research opportunities or other events that may be of interest. If you have, or know of, an event coming up that should be listed on this page, please contact lisa@chargesyndrome.org.



**“I believe people
with CHARGE
have a good
fighting spirit...”**

Surviving CHARGE Syndrome as a Person Who Has CHARGE

By: Ellen Howe

I thought I would talk about how I survived CHARGE syndrome and give some tips as a person who has CHARGE. Those on the listserv will have seen some of this before, but here is my story.

I am now 25 years old. I have coloboma of the eyes, cleft lip and palate, and major gut issues. I am tube-fed and have major hormonal issues. I have spent many years in and out of the hospital, undergoing numerous tests and operations. I got through each day by making friends in the hospital. I still have many friends from the hospital on Facebook, and I have always had great people around me.

When I was in the hospital, I would read a lot and try to get out as much as possible. I also went to hospital school, which helped me stay on top of my schoolwork and kept me from falling behind. Also, we had a great number of people who would come around to say hello to the kids. My favorites were Fairy Sparkle (a REAL fairy) and Captain Starlight. I would go into the starlight room and the fairy garden whenever I could.

Surviving Tests and Operations. This part was hard—I hated the waiting. Who doesn’t? If I was off my pump for too long, sometimes I would get dehydrated, but I was lucky as a lot of the anesthetists knew me well. One particular lady would see me on her list and make sure I was in with the first lot, and if I couldn’t be, she would make sure I was on IV fluids. Sometimes when I was going in because of a central line not working, this was hard, so she or others would just care for me in their time, not the doctors’ times.

I had a great team of doctors and nurses who always worked with each other to help me. They always answered any questions we had. We would always be able to ask more if we still felt uncomfortable. Some of these doctors went above and beyond. My pediatrician even rang the bedside one time to tell Mum she had to go off urgently on a trip to see her dying relative but she would leave me in the care of the immunologists, who were checking the infection in my line anyway. These doctors took care of me while she was gone and did as good a job as she would have. If she was unsure of something, she would research and would ask other doctors for their opinions. She got lots of opinions on what to do with me—some worked, some didn’t.

When it came to blood tests, I had a great team of pathologists who knew me very well; they would sit as long as it took to get a vein. In the X-ray department, many knew me too. I remember one funny lady in the barium section who would make jokes to everyone to lighten their nerves. This was great; she was one of my favorite people. I still see her in the shops sometimes, and I give her a big hug.

Surviving the Loss of Friends. Aaah! This was another hard one, but I got through it. Whenever a friend died in the hospital, it was very hard for everyone, whether it was CHARGE-related or not. I wasn’t in the hospital with many other people who had CHARGE. I was mainly in with people who had cystic fibrosis and eating disorders. I became very close to some of these great people and their families. They would take me under their wings as one of their own.

One time when my mum and I were both in the hospital, one mum rang the doctors because another doctor had come in and said I needed a new tube. She rang their family doctor, who put the tube in. She knew me well and was able to give a good opinion on what I needed. She didn’t even let Mum know about the new tube until she got the doctor’s word that it was OK. It was people like this who kept me going. Mum would go out to dinner with these other mothers, and they would attend hospital committee meetings together.

Whenever someone we knew in the hospital died, we would have good memories and share them. We would go to the funeral if we could, and we always continue to remember them. Now it is hard, though, when I read on the list that other people with CHARGE have passed away. I always feel happy that they are at peace but sad at the same time. It’s an odd feeling. I always wish they could have lived longer, but I know they weren’t meant to. I believe people with CHARGE have a good fighting spirit and none of us go without the good fight .

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**Ellen Howe, from
Australia**

Continued from page 2

Reactions. I get many different reactions when I go out and about because I'm in a wheelchair. Some people are more than willing to help me, and I thank them for that. But others just stare, and some just walk away. To these people I just say, "I wish you could be like this for a day. Then you will know what it is like." Sometimes I think people just can't be bothered to think about others' feelings, so they do nothing. They don't know how it is to be in a wheelchair and not able to do something. I may not hear, walk, talk, or anything as good as you do, but I think I have a better brain—that is what I think to some people. I believe if you have a positive outlook on everything in life, you will get by just fine.

Always be prepared to ask questions. Don't be afraid about asking the wrong question about CHARGE—no question is stupid. And remember, every person with CHARGE is different. If you aren't satisfied with an answer, get a second opinion—there always will be help out there. I got lots of help, and I'm lucky to be where I am today.

I am very thankful for my doctors, especially my former pediatrician, my former and current tummy doctors, my tube man, my endocrinologist, my ENT, and all the nurses and doctors I have had in my life. I am also thankful for caretakers at CPP, family, friends, teachers and aides at school, and the CHARGE syndrome listserv. Without these people in my life, I don't think I would have made it this far.

Support means everything in the end. I'd like to thank Lisa and Casey for our list. They are the ones who created it, and this is why we have the network we have today. If people have questions, they can ask the listserv and we will try to help!

Update on Kendall

By: Karen R. Collins

We have recently reconnected with *CHARGE Accounts*, and I would like to share a short story about our daughter, Kendall, who has CHARGE syndrome.

When Kendall was born on July 25, 1990, we had no idea she would have any medical problems. Several hours after birth, however, she was rushed to Texas Children's Hospital in Houston because of her serious heart complications. When my husband and I arrived, we were told that our daughter had CHARGE syndrome...and our journey began.

By the time she was 6 years old, Kendall's heart problems, choanal atresia, and hearing and vision problems had been addressed surgically and medically. Then began the process of Kendall becoming a young adult. She has very limited vision in the left eye, but 20/30 corrected vision in the right; she is virtually deaf in the left ear, but has fairly good hearing in the right ear. She finished physical therapy when she was in fifth grade, and has continued to have fine motor delays through the present. She uses a laptop to complete schoolwork. Kendall worked through some OCD, depression, and emotional problems when she was in high school, but with the help of a talented psychiatrist (who prescribed successful medications) and a counselor who helped her talk through her emotional issues, Kendall was able to successfully complete high school at a private school in our small southern town.

Kendall's hard work and perseverance paid off, and she was accepted into a small private university in Texas—even earning scholarships for achievement and community service. In May, she completed her first year in college, living in a dorm three hours away from home. Although she didn't achieve all As, she made good enough grades on her own to be able to register for classes for next year without provisions. She has made wonderful friends and is actively pursuing her driving license this summer. We fully intend to send her back to college for her second year with a car and a heart full of confidence!

When Kendall was born we were given a dire prognosis, but with love, support, and lots of qualified professionals, Kendall is working her way toward becoming an independent, intelligent, caring, and fully functional adult who will change the world for the better. Medically and mentally challenged? NO! Medically and mentally successful? YES!!! I have recently gone through some medical challenges of my own, and Kendall's courage, perseverance, and positive attitude have been my example. Kendall has touched so many lives, and the world is a better place because she is shining her light in it!



Kendall, age 19.

Using Augmented Input Intervention Strategies

By: Michael D. Harris Ph.D., CCC-SLP

University of Wisconsin–River Falls

The American Speech-Language-Hearing Association (ASHA) defines augmentative/alternative communication (AAC) as “a set of procedures and processes by which an individual’s communication skills (i.e., production as well as comprehension) can be maximized for functional and effective communication” (ASHA, 2002, p. 2). Until the late 1980s, AAC interventions focused exclusively on expressive communication. More recently, interventionists have used augmented input strategies to promote language comprehension.

Wood, Lasker, Siegel-Causey, Beukelman, & Ball (1998) introduced an AAC Input Framework (AACIF) that continues to be a valuable tool. The AACIF integrates several augmented input techniques into four components: (1) *augmenting the message*, (2) *augmenting message retention*, (3) *developing a pool of response options using objects and symbols*, and (4) *mapping language and symbols*.

(1) *Augmenting the Message*. Augmenting the message simply refers to techniques that enhance the meaning and saliency of a message. Two commonly used techniques include the use of a *picture recipe* and the use of a *picture schedule*. A picture recipe can be used to enhance written and verbal directions. Picture recipes can also be used to enhance the meaning of directions in academic, leisure, and vocational activities.

Picture schedules provide input regarding upcoming events. Schedules provide predictability to an individual’s day and can be particularly useful for the person who exhibits challenging behavior during transitions. Individuals who require three-dimensional symbols can use a variation of a picture schedule known as a calendar box. A calendar box consists of a series of boxes (or “cubbies”) that contain objects representing the sequential events of the day.



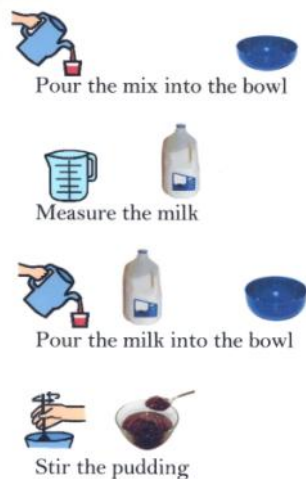
Picture Schedule

(2) *Augmenting Message Retention*. Augmenting message retention refers to the use of objects, photographs, or line drawings to facilitate an individual’s recall of a message. These techniques assist individuals in retaining information more efficiently. Examples of augmented message retention techniques include *graphic symbol shopping lists*, *graphic “to-do” lists*, and *remnant books*. Graphic shopping lists remind individuals of items that needed to be purchased.

Graphic “to-do” lists remind individuals of chores or other activities that need to be done (Doss & Reichle, 1991). In the example below, note that a preferred activity is the last item on the list.



Graphic “to-do” List, with preferred activity of watching T.V. as the last item on the list.



Picture Recipe

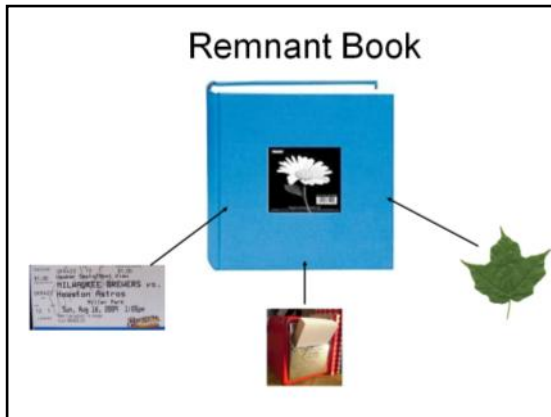
Shopping List



Graphic Symbol Shopping List

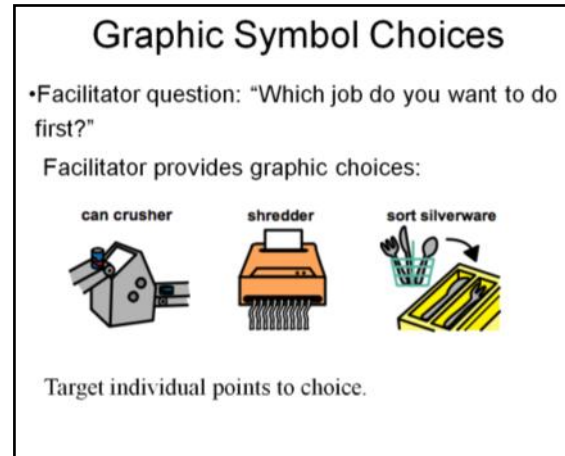
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Remnant books contain materials saved from activities in which an individual engages. These books allow beginning symbol users with limited verbal skills to tell others about events that happened during the day or over the weekend (Beukelman & Mirenda, 2005).

(3) *Developing a Pool of Response Options.* Beukelman and Mirenda (2005) indicated that choice making occurs when an individual selects preferred items or activities from an array of two or more options. Choice making can be accomplished either independently or when someone else offers the options. On the right is an example of a choice-making scenario.



(4) *Mapping Language and Symbols.* Mapping language and symbols refers to augmented input techniques that assist an individual in associating symbols with their referents. In mapping, the communication partner uses objects, photographs, real objects, line drawings, manual signs, written words, and/or spoken words (i.e., the learner's symbol set) in association with their referents in the environment. Two commonly used intervention techniques are *Aided Language Stimulation* (Beck, Stoner & Dennis, 2009; Harris & Reichle, 2004) and the *System for Augmenting Language* (Sevcik, 2006; Ronski & Sevcik, 1996). Both techniques use modeling as the primary intervention strategy. In the scripted routine that follows, the words written in uppercase represent examples of when the interventionist models (points to [or signs]) the corresponding symbol during a snack time interaction.

"Corey, it's time for SNACK. Let's WASH our HANDS. Okay, you can SIT over here. Oh, I need HELP. Please HELP me OPEN the MILK CARTON. THANK YOU! Now you need to POUR the MILK into the CUP. Oops, you SPILL(ED) some MILK! I'll HELP you CLEAN up the MESS. Let's GET a SMALL NAPKIN...etc."

It is important to keep the interaction as natural as possible. If using a speech-generating device (SGD), it is likely that a combination of words and phrases will be activated when pointing to the associated cells on the device.

In summary, while AAC interventions often exclusively address expressive communication needs, families and interventionists should also use strategies that promote language comprehension. The AACIF can serve as a valuable tool in this endeavor.

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Survival Strategies: Six Tips

By: Catherine Rose

1. First, I have all of Alexis's medical stuff in one Word document. I update it when I feel like I'm getting overwhelmed or am likely to forget something. The document includes information from Alexis's last doctor visit, when her next appointment is, which doctor last saw her, information on all of her specialists, etc. It's a much better summary of Alexis than any of the doctors have been able to write, which isn't surprising considering I have four years of in-depth practice with Alexis.

2. I keep a detailed spreadsheet/calendar in Excel of all activities and have them color-coded for who does what and when. It's my way of keeping up with who is where at what time. My husband, Matt, can't make sense of the spreadsheet—he says it is too complicated—but to me it makes perfect sense!

3. I make a daily chore list. I am a procrastinator, and I hate cleaning the house. I make a list and schedule of the chores that should be done. The list includes only about five main items each day, such as laundry on Tuesdays and Fridays, dishes on Mondays and Thursdays, a reminder to measure out Alexis's medicines each day—that sort of thing. This list is also in Excel. It's printed and kept in a sheet protector on the refrigerator so that I can "get credit" for marking something off the list each day. (Remember, I hate chores and housework!)



4. I married a man who cooks. I don't cook, except for foods that require the oven to be set to only one temperature (fish sticks, chicken fingers, French fries). I also cook in the microwave. If anything needs to be attended to, adjusted, or whatever, it's a disaster—I just don't do it. I've ruined enough meals to convince Matt that he's the cook in our family. I guarantee that this "disability" allows me to have at least 10 free hours per week. I do provide "prep-chef" help and will prepare cook-ahead items. I also do 95 percent of the grocery shopping to keep the chef's cupboards full. (This tip is related to the fact that I'm not particularly food-motivated, so eating chicken fingers and French fries each night would not be a problem for me!)



5. I live with my computer. I do a ton of work at night to make up for the hours in the day that I'm not attending to work but otherwise handling Alexis's and Jessica's appointments and schedules.

6. We have the kids on a sleeping schedule. I don't know whether it's because Matt and I are both good sleepers and "sleep" is perhaps a gene that is passed down from parents, but both of our kids are in bed by 7 P.M. and awake at 6:30 A.M.—each and every day; good, bad, or indifferent. They are very predictable. It gives Matt and me recuperation time at night, and gives us some housework time and "us" time each day.



There are probably more tricks I use to survive, but those are most of them!

Have a survival tip you'd like to share?
Send it to lisa@chargesyndrome.org

A Tricycle to Love

By: Marilyn Ogan (with contributions by Michele Westmaas)

I know transportation, independence, and leisure activity have been big issues for many individuals with CHARGE syndrome in the past. Let's think of that: "In the past"? Indeed! A commercial trike is available that has given new independence to at least two young ladies! There are individuals

who may never be permitted to drive a motor vehicle due to vision issues or physical limitations. I thought people might be interested in information about (and seeing) a recumbent tricycle. Kristin received hers on August 17th and is absolutely thrilled beyond imagination! She rode around the apartment complex for three hours the first day!!!! This has become her favorite leisure time activity.

We had a trail-along bike (attached to mine but now too small); not good when you are signing! Looked at a tandem; again, not good for communication. Tried training wheels on a bike from a general merchandiser; the training wheels kept coming loose. With this trike I know she is secure, balanced, stable, and has total control. And for signing, it is great! In Indiana (US), we are legally permitted to ride two abreast on roadways. (We haven't done that yet since she just got the bike recently. We are practicing "rules of the road" in a safe environment before I venture out with her.) That means I can be beside her for quick things, such as indicating directions, warnings, etc. For more in-depth things, I'll just tell her to "hold" until we can stop in a safe place.

It is a Sun X-3sx SpeedLite Adult Recumbent Tricycle. For anyone with balance issues, this bike is: *Terrific! Fantastic! Fabulous! Absolutely Won-der-ful! The greatest thing since Kristin learned to swallow!*

The three wheels give balance; the backrest gives stability (less effort needed to remain upright and balanced on the seat) and the ability to apply more pressure to the pedals; and the lower style (20" vs. 24" for a "typical" adult trike) means easier and safer on/off. I was told that the adult trikes you see many older people riding have a tendency to tip when turning because they sit higher. The recumbent trike is actually a 21-speed; but the man at the store stated that it can be locked into a single low gear if needed.

Michele recently purchased the same bike for her daughter. Her comments comparing this recumbent to a standard adult trike were:

It is awesome!...We just got Aubrie the exact same bike—only blue! What a coincidence! It has changed her life. I never thought she'd manage a bike. We've tried several options... We did the trail-behind bike too. Aubrie rocks, so I couldn't keep the bike stable... Training wheels weren't stable enough for her... We started on this bike quest a few weeks ago. Someone in our community has a four-person Rhoades car for sale—like you see on the Boardwalk or at other vacation sites. We tried it out, but it was pretty big to maneuver and quite expensive for a used vehicle. That led to dreaming about independent biking or some other kind of dual-biking opportunity. We went into the bike shop expecting a traditional adult trike. Luckily, this store had the traditional trike and the recumbent side-by-side on the showroom floor with room for Aubrie to try each outside. We tried the recumbent first. Then I wanted to try the other because it was significantly cheaper. Well—with the higher center of gravity, it was very tippy. And Aubrie could not make it go from a stop. She can still tip the recumbent if she swerves quickly (something she did often at the start), but we are working on that. She can start it from a stop and even on a hill.



12-year-old Aubrie, enjoying a ride on her new trike.

for her balance and safety, and would last throughout her adulthood.



18-year-old Kristin, getting ready to go out for a ride.

I will say that I don't find our recumbent trike tips easily—I tried!—and Kristin has turned sharply without encountering problems so far. I think the difference in Aubrie's tipping is that we did not inflate the tires to their maximum pressure. Kristin's are inflated to about midway of the suggested pressure range, possibly giving a better "grip" on the surface.

Like Michele, we had tried different things—and looked at others. I saw a "stabilizer wheel" in a magazine and online. This looks like an oversized training wheel (about the size of the front tire of the recumbent trike) with a heavy-duty bracket. One (yes, that is one!) cost around \$115. By the time I bought two of them—plus a new bicycle, which is what started this whole thing off because hers became too small, and paid shipping, handling, taxes, etc.—I figured I might as well buy something that I knew could be adjusted to fit her better, was better

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The handlebars are in front instead of at the hip (under-seat mounted), which can be difficult for individuals with special needs to control. One other thing about this trike is that it pedals so easily that it is better on Kristin's knees and ankles with her arthritis. She would ride very little on her other bike, even when the training wheels stayed on for any time. She'd come in complaining of her back and knees hurting from pushing so hard—and I think balancing also.

The school psychologist noted that, "It is a gorgeous tricycle. Very socially appropriate bike! Very cool, does not even look 'out of place.' The pictures make Kristin look happy and independent." The social appropriateness is so right on. I hadn't thought of that angle before, but that makes it that much more cool for Kristin. This is one more thing to facilitate social interaction of a positive nature. What I like most is that it doesn't have that "special needs" look about it! (Yet, it provides everything she needs—even getting her closer to the ground for visual needs.) It is a very cool-looking bike that just happens to have two wheels in the back instead of one.

This trike will last throughout her adult years if she takes care of it appropriately. (And she will!) Kristin worked over the summer and used all of her earnings, as well as all of her birthday money and some other contributions, for her bike. Can you say, "motivated and independent"?

Kristin thinks she is really cool!! I said I will have to call her my little "Biker Chick"—HA! I think I am as thrilled as she is! I feel much as Michele does regarding Aubrie's new trike:

She took off on this and has done beautifully! We rode together to her school registration the other night. I was near tears realizing what a huge deal it was that I was on a bike ride with my daughter.

Yes, it is a huge deal, Michele: Happy biking with your daughter!

You can tell by the smiles that each girl loves her new bike!

Go, Biker Chicks, Go!



Picture Credit:
www.sunbicycles.com

For more information on the X3 SX trike, visit

Sun Bicycles at:

[http://www.sunbicycles.com/product_detail.php?
short_code=X3+SX+Trike&cl1=RECUMBENT](http://www.sunbicycles.com/product_detail.php?short_code=X3+SX+Trike&cl1=RECUMBENT)

Do you have a favorite piece of equipment or other therapy tool? Write and let us know all about that one thing you or your child can't live without!



10th International CHARGE Syndrome Conference

July 28-31, 2011 Orlando, Florida

Schedule of Events:

Thursday Evening

Families/Professionals

7:00 - 9:00pm

- Reception

Friday

- Sessions 9:00 - 5:00
- Vendor Fair
- Poster Presentations
- Interact Central
- Idol Extravaganza

Saturday

- Sessions 9:00 - 5:00
- Silent Auction
- CHARGE-A-Palooza

Sunday

- 9:00 - 12:00
- Presentations
- Closing

The conference planning team hopes you have marked your calendar for the upcoming 10th International CHARGE Syndrome Conference in Orlando, which will undoubtedly be our biggest conference to date.

You do not want to miss out on learning more about CHARGE with our top-notch informative program, including: keynote and breakout sessions, opportunities to interact

with professionals at 'Information Central' and poster sessions. We mix learning with big doses of **FUN!** We invite you to attend the sequel to the wildly popular CHARGE Idol Extravaganza on Friday evening and our CHARGE-A-Palooza fun fair and dinner party on Saturday night. As always, sharing experiences is the heart and soul of our conference. Please join us in Orlando for a wonderful opportunity to spend time with old friends, meet new families, and share ideas and stories.

Please stay tuned to both our website and your email for conference updates as well as tips on how to find funding for you and your family to attend. Online registration will be available March 1, 2011.

JULY 2011						
SUN	MON	TUES	WED	THURS	FRI	SAT
31					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

Conference Website:

<http://chargesyndrome.org/conference-2011.asp>

MAGIC HAPPENS

Fundraising Account: Skate for CHARGE

By: Josh Sirota

On April 11, 2010, months of hard work and planning paid off. My sister and I executed our long-awaited fundraiser, Skate for CHARGE, at the Mennen Sports Arena in Morristown, NJ. The fundraiser was a great success, and the experience was nothing less than astonishing in many ways.

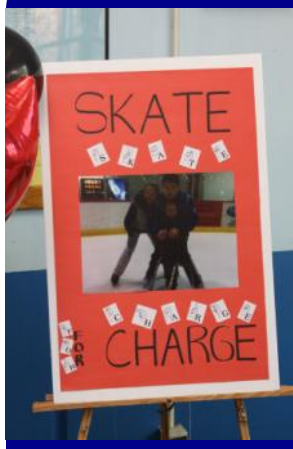
Since we wanted to raise awareness of CHARGE syndrome, we knew we had to tell as many people as possible about our event in hope of a BIG turnout. My sister and I decided to divide and conquer. I asked the manager of my hockey team to circulate our event flyers to all the Mennen hockey teams. My sister and I told our teachers about our brother and the Skate for CHARGE fundraiser. We did a presentation at a Friendship Circle weekly meeting, telling approximately 50 kids about our BIG event. ("The Friendship Circle extends a helping hand to families who have children with special needs and involves them in a full range of Jewish and social experiences. The Circle...introduces teenage volunteers to the children and through shared experiences both are enriched.") I posted our event information on my Facebook page (so did my mom). Our friends and family helped us get the word out. We were on a roll; we even told the town newspaper, and they ran an ad campaign. All this legwork helped achieve our goal!!

In addition to raising awareness, we wanted our fundraiser to be a BIG financial success. My sister and I decided to have a bake sale and a raffle and to sell CHARGE stuff. My sister was in charge of the CHARGE stuff. She designed a CHARGE T-shirt, pajama pants, and car magnets. She then went to a local printer who transformed her idea into reality. Her clothing line really took off. We had orders from all across the country—we even shipped shirts to Canada. In fact, the CHARGE line became like a fundraiser in itself. Many people helped us sell our merchandise. The Deafblind Program staff at the Perkins School for the Blind helped us keep track of all the orders (we delivered boxes to the school). A BIG thank you to everyone!!!

Now, back to the rink...when we first arrived, we soon realized that our work had just begun. Our posters needed to be arranged throughout the arena, our merchandise needed to be placed on tables, numerous food items for the bake sale needed to be arranged carefully, we needed to speak to the photographer (yes, Meg Majors was our wonderful photographer), we needed to put on our skates, and lastly, I needed to understand how to control the sound system. We finished with only minutes to spare as people started flocking in. Shockingly, the variety of people who came was immense.

Our supporters included many familiar faces and many faces that we have not seen before. The participants included CHARGE families from NJ and NY, our school teachers, friends (school and sports), family members, professionals in the field of special education familiar with CHARGE (or wanting to learn about CHARGE), and even a skating teacher who was nice enough to offer her expertise to kids who needed assistance skating on the ice. In all, the turnout was unbelievable, and the people who came made the event spectacular. We were lucky to have Martha Majors join us to provide information and support to families. Thank you, Martha, for your support.

In conclusion, Skate for CHARGE most certainly exceeded my expectations. It is something I would consider doing again in the future. We raised awareness of CHARGE syndrome in our community; we met other kids with CHARGE and their siblings; parents got to socialize with other parents and professionals; we got to ice skate, which is always fun; and, last but not least, we raised money that we donated to the CHARGE Syndrome Foundation. To be able to help kids with CHARGE in such a fun and enjoyable way was awesome and something I recommend many others to try as well.



David gets geared up for the skate.



Author and event organizer Josh Sirota, skating with his brother, David



Working hard at the bake sale.



CHARGE In the News



Klinghofer Bean Bag Toss

The Klinghofer family from Illinois held a bean bag toss fundraiser in support of the CHARGE Syndrome Foundation on August 7th, 2010. David Wolfe, treasurer and fundraising chair for the Foundation, was able to attend the event and relates, "The Klinghofers were able to turn a traditional tailgate activity into a fun afternoon at the park. While many of us demonstrated that professional bean bag tossing is not in our future, a great time was had by everyone who attended this fantastic event." The bean bag toss was featured in the Daily Herald and can be found at:

<http://www.dailyherald.com/story/?id=396968>

New Webcast on CHARGE Syndrome

Perkins Educational and Training Resources Program announced a third webcast on CHARGE syndrome: Teaching Strategies for Children. The webcast is available at:

http://support.perkins.org/site/PageServer?pagename=Webcasts_CHARGE_Syndrome_Teaching_Strategies_For_Children

Five-year-old Gets Wish

Julianna Correia, from East Providence, RI, is featured in this article, which explains how she got her wish from Children's Wishes, a nonprofit organization created in 2009 to provide wishes to children with life-threatening illnesses. The story is available at:

<http://www.eastbayri.com/detail/137822.html>



Five-year-old Julianna Correia

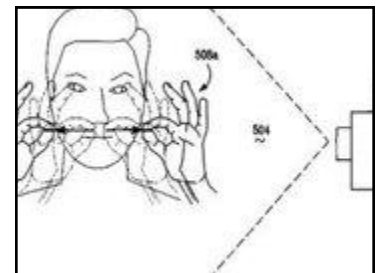
Photo Credit: www.eastbayri.com

In Other News...

New Kinect Technology Recognizes ASL

Microsoft is releasing a new technology that will recognize ASL, enabling users to sign communications within a game on Xbox and have them transmitted to other users for auditory display. For more information about this new technology, visit:

<http://www.gamespot.com/news/6272656.html>



**From the gamespot.com website:
Kinect Technology will recognize ASL.**

iPhone Communication App for Users with Disabilities



When Martin Brooks tried to find an app that would help his daughter to communicate, he came up short. He then decided to design his own app that would help his daughter, who has cerebral palsy, to communicate. The result was an iPhone app that allows the user to make a choice between various items by using their eyes.

For more information about this amazing new app, visit:

<http://www.dailymail.co.uk/sciencetech/article-1276195/Father-creates-iPhone-app-gives-voice-severely-disabled-daughter.html>

For more information about the iComm app, visit: <http://www.miasapps.com/icommm.html>

Martin Brooks with his daughter, Mia.

Photo Credit: <http://www.dailymail.co.uk>

The MAPs Planning Process for our Daughter Alexis

By: Deb D'Luna

I first heard about the idea of futures planning while attending the CHARGE Syndrome conference in Costa Mesa, California in 2007. A couple of moms from California presented the technique of MAPs (i.e., Making Action Plans) and were very positive about the process.

As we approached Alexis's 22nd birthday, I became anxious about the end of my daughter's public education and the dramatic changes that would bring. My husband and I visited adult day programs of many different sorts: work, recreation, vocational, arts. We found it exciting and worrying. I developed charts to make sense of our options. The world of adult services is a big paradigm shift. I was prepared to try to think differently about my daughter – to focus on her abilities, achievements and potential for success.



At the same time, I realized that much of the recreational and social opportunities that Alexis enjoyed were evaporating along with her high school attendance. The natural proximity and energy of other young people with and without disabilities is something that Alexis takes for granted and thrives upon. I began fretting about how we could meet those needs.

Being in high school naturally makes you a part of a community. You are a high schooler and wear school spirit wear. There are cheerleaders, sports teams, a marching band, choral groups and clubs all identifying with, and proud to be, members of your high school. I wondered how we could replace or create a substitute for all that “community belonging” in Alexis's life.

I asked Gloria Rodriguez-Gil to facilitate a MAPs meeting. We determined that we would focus attention on the areas of social and community life. Gloria's suggestion that I preview the MAPs materials with Alexis was very helpful. I had intended to take it slow and perhaps go over a single category of the MAPs with Alexis each day (e.g., the likes and dislikes section). Gloria had provided me with a colorful, graphical representation of the process and Alexis related strongly to these materials. Each page had a person icon in the center and I wrote Alexis's name across the front of each icon. I told Alexis we were planning a meeting about her. Here is the link to the pages we used: <http://www.nationaldb.org/documents/products/MAPSEnglish.pdf>

Alexis became so engaged that she wanted to keep on working through the different aspects of her life: likes, dislikes, strengths, dreams, and fears. We were very specific and Alexis really enjoyed the process. I think the process was a positive way to review her life and it helped her to think analytically about herself. Here are some examples of the information we generated with Alexis:

Things she likes: her family, parties, holiday decorations, chewing gum, movies & popcorn, having nails & hair done, travel – especially cruises, feeling proud, going out, being with people, a cup of tea

Things she dislikes: getting stuck or things getting stuck, being sick, being frustrated, people arguing, loud voices, other people coughing or sneezing because of sudden loud noise, losing her balance, being alone outside in the dark

Strengths: working hard, concentrating, being funny, patient waiting, good swimmer, being a happy person, asking for help, delicate in movements, good manners, loving, keeps trying, good self-help skills.

Dreams: having friends to go out with, to go to college, work, be happy and healthy, live in apartment with friends.

My husband was somewhat doubtful about what the MAPs would accomplish. He felt that we were already well aware of Alexis's needs and singularly prepared to make decisions about her future. We were also both concerned that the process would put pressure on the attendees to do something for Alexis. We have always felt that planning and providing for Alexis is our responsibility and that others should not feel burdened or stressed by our situation.

Continued on next page...

Continued from page 12...

Nonetheless, we set aside a Sunday afternoon and invited extended family, specific friends and care providers. I cast a wide net, but I was thoughtful about who I invited. My criteria for who to include was that the invitees should have demonstrated an interest in Alexis and be likely to be involved in her life in the future. There are many wonderful folks who could have contributed what they knew of Alexis and who care about her, but whose future involvement in her life is unlikely, so these individuals were not invited. Examples of attendees: her interveners, her final teacher, her yoga and piano teachers, and close friends who have a history of interacting with her and who are supportive of us as Alexis's parents.

I sent out invitations stating the date, time (including how long the meeting would last), location and that lunch would be served. Also, I included the following so that those invited would have some idea about the purpose of the occasion:

Gloria Rodriguez-Gil of California Deaf-Blind Services will facilitate a futures planning meeting on behalf of Alexis. California Deaf-Blind Services is a federally funded project to support deaf-blind individuals in California from birth to age 22. Gloria Rodriguez-Gil is an educational specialist with extensive experience in the field of deaf-blindness.

You are among a small group of people who know, are interested in and care about Alexis. A happy, healthy and productive future is something that may not evolve naturally for Alexis and needs to be planned for. The purpose of this meeting is to develop a shared vision of Alexis's future. This vision will help us make choices that will bring about a truly favorable result.

We hope you can come because you have a unique perspective. Your participation will help us think about and plan for Alexis's future. You will not be asked to do anything except share what you know about Alexis, as well as your dreams for her future.

Gloria was accompanied by two interns from the CDBS-San Francisco State University teacher training program in deaf-blindness. One intern wrote everyone's comments as bullet points on large pieces of poster paper which were taped around the room to be visible during the process. The other intern took notes on a laptop computer. This was tremendously helpful as Gloria was able to focus all of her attention on facilitating the meeting.

At the beginning of the meeting, Gloria provided guidelines to keep the meeting focused. Participants were asked to be concise and to direct their thoughts to the entire group. She also designated a timekeeper and kept us moving through each section so that we made swift and efficient progress. We did not break for lunch, so everyone was invited to get up and serve themselves the sandwiches and finger food we had provided.

We are blessed with a supportive family who love and dote on Alexis. She is accepted and loved just as she is and everyone caters to her; telling humorous and amazing stories about her is a common family activity. Fortunately, everyone also always supports our decisions without question. The MAPs meeting was a real eye opener for our extended family because unlike us (with 22 years of IEPs behind us), they were unused to thinking analytically about Alexis. Seeing ways they could help her make forward progress was extremely empowering and everyone found a way they could contribute. Each of our family members has since taken the opportunity to express their appreciation for being included in the meeting, to say how interesting and helpful they felt it was.



For example, one of my nephews emailed us: "Thanks for sharing the MAPs.

It's been wonderful to be a small part of helping Alexis map out her near term future, and I look forward to helping her progress in the months ahead. I think, just like for all of us, if she takes on things in bite-sized chunks, that she'll really flourish in the time ahead. I envision a wonderful future for her, where she continues to grow, and enrich the lives of all around her."

My sister in law emailed: "Thanks so much for allowing us to have an active part in helping Alexis have such a productive life. You two have created this wonderful circle of friends, neighbors and family available to her by creating this immensely strong foundation for her to live her life as normal as she can. We feel she is so much a part of our own family and for that we have you all to thank for as we continue this journey with all of you. We will continue to do all that we have been doing and above as this new chapter in her life begins in 2010. We are available to you all anytime so please call. Thanks for including us in these life decisions as we love her so very much and very deeply and our love extends to all of you as well."

Alexis' teacher (a special educator of 35 years) wrote me a note of thanks that said the MAPs was the most productive and meaningful meeting she had ever attended for one of her students. "It was amazing!"

Continued on page 14...

*“When I think
back on the day
we held the MAPs
for Alexis, I feel
pride about what
we accomplished.”*

Continued from page 13

One of my friends was so impressed with the event that she told her daughters and husband about it in detail during the holidays when both girls were at home from college. Her youngest daughter, who is a junior at UCLA, approached her mom after hearing about the MAPs with a plea that the family do a MAPs on her in order to help her get through a stressful period when she couldn't see the direction of her own future. As a consequence, my friend used Alexis' results as the blueprint to do her own MAPs! The daughter even spent a couple of hours developing her own vision of herself (as Alexis had done). The young woman found this way of looking at her future potentials to be tremendously helpful; my friend said that she could see the anxiety lifting from her daughter as they progressed through the MAPs. She said it was a wonderful opportunity to positively point out not only her daughter's tremendous gifts and potentials, but also areas of need. In that circumstance, the young woman was very open to hearing things that otherwise might have been seen as hurtful criticisms.

When I think back on the day we held the MAPs for Alexis, I feel pride about what we accomplished. My husband and I feel supported by the friends and family collected and focused on supporting us and can see the beginnings of a path of through the thicket of likely future difficulties and opportunities. The plan we developed that day has already been tremendously helpful in filling in the social and community gaps that quickly developed post-graduation.

This article was reprinted with permission from the California Deaf-Blind Services Winter 2010 newsletter.

Welcome New Lifetime Members

The Foundation would like to welcome and recognize its latest lifetime members. Thank you for your support of the work that we do!

GOLD

Karen Collins

Kristin Knutson

SILVER

**Daniel Marena
Drexel University**

**Megue Nakazawa
National Institute of
Special Needs Education,
Japan**

**Deborah Nunner
George Saul**

Shelly Snyder

**Lori Swanson
University of WI-River
Falls**

Mike Young



*For more information on becoming a
member of the Foundation, please see
page 15.*

Thank You

THANK YOU FOUNDATION SUPPORTERS!

Click on the
membership
button below if
you are reading
online to go
directly to our
membership
form.

Wells Fargo Community
Support Campaign
Microsoft Matching Gifts
Program
Magda Hernandez
Marcelyn Yoho
Samantha Eskenazi
Marcelyn Yoho
Gloria Crouch
Kristin Knutson
Fried Green Tomatoes, Co
I Click ROI
INTER7.COM
A+ Reservations
Galena Gazette
Joseph B Tassone Ins.
Agency Inc.
Kouzmanoff Financial & Ins.
Services, Inc.
America's Charities
Abbott Laboratories
Employee's Community Fund
of the Boeing Company
Tyler Dean
Lacey Friedman
Robin Gittrich
Virginia Haigh
Jane Holland
Janelle Keefer
Richard Kelly
William Kelly
James Kouzmanoff
Jeffrey Kouzmanoff
Catherine Kouzmanoff
Melissa McGuire
Dan Melick
D & K Limited Inc

Terri Richardson
Jeffrey Schroy
Jeffrey West

**In Memory of Martha
Brixhoff**
Viola Baucom

**In Memory of Chuck
Factor**
Wally & Roberta Korhonen

**In Memory of Mark
Sommer**
Roberta & Wally Korhonen

**In Memory of Joshua
Kurby**
Rosalie Kurby

**In Memory of Dr. John E.
Lent**
Michael Conway
Joan Gruenfelder
Joan Vecchio

**In Memory of Mrs.
Martha Francis Mayo
Brixhoff**
Richard Burns
Burns Robinson, PC

**In Honor of Ms. Finley
Roth**
Laurie Fulton

**In Honor of Christian
Roberts**
Bekkie Cobb

**In Memory of Claire
Elizabeth Anne Nagel**
Vickie Bender
OSU Coll Med Education
Patricia Capella
Kathleen Cohen (Kathy
Imbrock)
Jamie Colley
Judy and Bruce Colley
Jamie Davis
Worthington Education
Association

Mike and Margie Glaros
Jenell Hebert
Karen Hittepole
John Hughes
Randi Marty Lewis
Beverly Swihart

**In Honor of Eli
Klinghofer**
Irene Drizin

**In Honor of The Wolfe
Family**
Arlene Midkiff

**In Honor of Zeta
Brabham**
Sue Clark
Heather Connelly
Baynard Connelly
Patricia McBride

Forrest Thompson
Drew Thompson

**In Honor of Kate
Leininger**
Joanne Tranchina
The Solana Beach
Community Pre-School

**On the Special Occasion
of Karen Miller's Bat
Mitzvah**
Richard Chatel
David Kessler
Susan Hess

**On the Special Occasion
of Marie Copeland's
Birthday**
Emily Dziuban

**On the Special Occasion
of Finley Roth's 1st
Birthday!! Happy
Birthday Sweet Girl!**
Andrea Aardsma

**Quad City Metropolitan
Enforcement Group and
the Stahl family**

HOW TO BECOME A MEMBER OF THE CHARGE SYNDROME FOUNDATION

Becoming a lifetime member or a yearly member has never been so easy. This year, we have introduced an online membership system that saves the hassle of printing and mailing forms to you and having you mail them back to us. We'll save some time and some trees in the process.

If you visit our membership page on the website at <http://www.chargesyndrome.org/membership.asp>, you will find all of the information and options about becoming a member. You will also see a button in the top right corner that looks identical to the one pictured at left. If you click on that, it will take you directly to the online membership form, where you can enter your information and either join the Foundation or renew your membership. It's very simple and quick! Also, if you are reading this online, you can click right on the button here in the newsletter to take you to the online membership form.

If you prefer to mail in your membership and payment, that option is also still available. There is a printable form on the membership page that you can print off, fill in and mail back with your payment.

We appreciate your support and look forward to having you as members!

MEMBERSHIP

Please Click on the Button Above
to Join or Renew

Thank You

On the Special Occasion of Finley Roth's 1st Birthday

Margaret Botchie

Sylvia Walker

Carol Mollenkamp

Steven Muzzillo

Happy Birthday Finley from the
Moore family. -Kristine Moore

On the Special Occasion of Edwina & Kent Lockridge's birthdays and In Honor of Caitlin McMullen!!!

Chris & Steve Pilarski

On the Special Occasion of Kate Dols' birthday, and in honor of her daughter Erica.

Teresa Polk

Second Annual CHARGE It for CHARGE Donors

In Honor of Eli Klinghofer

Dafna Aaronson

Douglas Adolph

Tzila Elrad

Haya & David Holzmenn

Ashley Horn

Adam & Carolyn Kaplan

Kimberly Klinghofer

Adi Klinghofer, Prestige
Distribution

Susan Komers

David Nehmadi

Anne & Rich Salter

Becky Shiffman

Heather & Jason Spiewak

Tim & Mary Hilgenberg

Relly Klarman

Supporting the handsome guy, Eli!

Saysha Blazier

In Honor of a wonderful and very cute boy, Eli

Candace Gildin

In Honor of Baby Eli

The McHugh Family

For Eli Klinghofer

Alfred Perlin

In Honor of Eli Klinghofer & family

Timothy Schmidt

For the family of Becky & Ilan Klinghofer

Yan Shi

In Honor of Eli, with love and support

Diana Strandberg

In Honor of the Klinghofer Family and especially Eli

Brenda Weitzberg

On the Special Occasion of Beanbag Toss Tournament

Jin Lee, MFLUENT, LLC

In Honor of Glenn Annis "Grampy Annis" & his 60th birthday celebration! Love, Brady

Brady Antaya

This is for my son-in-law's brother Brian Haberkamp who will be 33 years old on 08/09/2010 and also has CHARGE. Good luck to everyone.

Hollis Lynch

In Memory of Joshua Kurby

Linda Baranowski

Brian Berg

Steven Daluge

Kathleen Gumbach

Wayne Leland

Nancy McLeod

John McGill

Jennifer Tavernier

Alex Teckenbrock

In Memory of Joshua Roy Kurby. Happy Birthday!

Mark & Miya Wayman

On the Special Occasion of Joshua's 2nd Birthday.

Happy Birthday boy! We love and miss you!

Mommy & Daddy, Joey and
Jillian

On the Special Occasion of 2nd Annual Joshua Kurby Charge for CHARGE 5K!

Sandra Kurby

In Honor of Sandy & Phil and in loving memory of Joshua

Amy Kaczmarek

On the Special Occasion of Finley Roth's 1st Birthday

Adam Bries

Erin Ford

Dean Stoeber

Joe, Amy and Drew Kain

Paula Maloney

Love, The Michalaks

Liza Parke

In Honor of Smiling Finley!

Jodi Cyr

On the Special Occasion of Miss Finley Roth

Mike, Susie and Quinn Rowan

Happy Birthday Finley!

Love, Jen, Jay and Leah Stiles

In Honor of Finley Roth & the celebration of her 1st Birthday!!

Adam & Joyce Krezel

Joshua Murray

Michael Deamicis

In Honor of Justin Murray Mow!!

Pamela and Paul Dowd

On the Special Occasion of John & Kristi's 11th anniversary

Jacqueline Dominick

In Honor of Gracie Swann

Jacqueline Dominick

In Honor of Amazing Grace

Robert Dwyer, OTC The
Dwyer Consulting Group

In Memory of William E Taylor, Sr

Kathie Gerritzen

Sharon Stolarski

Kathryn Miesner

God bless Clare and all her friends in CHARGE

Colleen O'Toole

In Memory of Trey Chatham

Timothy Hargis, K.A.S.P.A.R.
Productions

Christine Hong

Monica Jacobs

Jason Lee

In Honor of Ethan Wolfe, on IMPACT Day

Michael Wolfe

In Honor of Ethan

Shelley & Gary Morris

In Honor of Halyn Jones, our sweet CHARGE

Melva Strang-Foster

Max is a rock star!

David Nold



Upcoming Newsletter Topics

Holidays: CHARGE Style

It's hard to believe, but our next issue is set for December, when many folks are celebrating a variety of holidays. Do you have a favourite holiday story about your child? Has your child written a letter to Santa you'd like to share? Is there a special recipe you & your child enjoy making each year? What are some of your favorite family traditions? Share your best holiday stories with *CHARGE Accounts* readers.

Topics of Interest to our Readers

We would love ideas from our readers about what issues or topics they would like explored in future newsletters.

CHARGE In the News



Have you seen a great article about someone with CHARGE or about CHARGE syndrome itself in the news (either online or in a newspaper/magazine)? Send it along!

Celebrating Accomplishments

Do you have a story about yourself or your child that you would like to share? A story they wrote or a picture they drew? Send it to me with a picture if possible so we can share in your or your child's accomplishments.



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

10th International CHARGE Syndrome Conference

Call for Platform Presentations, Poster Presentations, Exhibits, Demonstrations and On-site Research Projects

<http://chargesyndrome.org/documents/CallforPresentations2011.pdf>

Deadline for Submission: November 1, 2010

Presentation Proposal Form:

<http://chargesyndrome.org/documents/2011PresentationProposalForm-1.pdf>

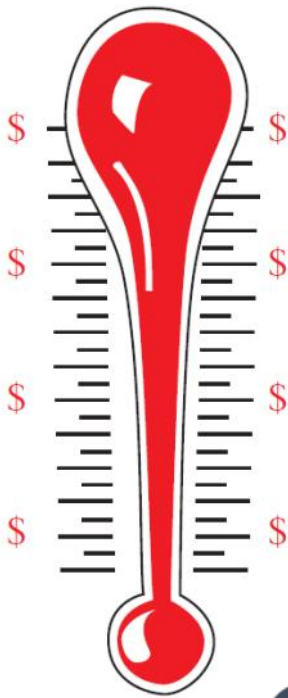
Exhibitors, Sponsors and Advertisers

We are actively looking to add more exhibitors, sponsors and advertisers to our event. The Conference provides a unique opportunity for companies to reach hundreds of families affected by CHARGE syndrome and the professionals who work with them. We expect over 900 people to attend!

If you, or someone you know, should exhibit, sponsor or advertise at the 2011 conference please contact David Wolfe at David@chargesyndrome.org or Brownie Shott at Brownie@chargesyndrome.org. We look forward to your feedback.



HOW HIGH CAN WE GO?



The giving season is upon us once again. Our second annual Charge It for CHARGE is coming to a close with almost \$90,000 raised. (What is Charge It for CHARGE? Our annual email fundraiser. You set up your own personal page, send emails to friends, family, colleagues and businesses where you spend your money. They donate and you watch the mercury rise on your fundraising thermometer!)

In October, we roll out our third annual Charge It for CHARGE. The importance of our online fundraising campaign has grown as we expand our conference, hire a Director of Outreach, sponsor additional research and constantly strive to enhance the services that we offer. Help the Foundation continue to improve and grow. Please visit our website when we begin our campaign on October 1st and register to become an online fundraiser.

If online fundraising isn't your preference, please consider planning a fundraising event. Whether you like to walk, swim, run, bike, bowl, golf or eat, you can turn your passion or hobby into an appropriate event for you.

We are available to help with the details. Please contact David Wolfe at david@chargesyndrome.org to share ideas or for assistance. Remember to get your friends and family involved with the Foundation.

Come Join Us!

CHARGE Syndrome Foundation, Inc.

141 Middle Neck Road
Sands Point, NY 11050
USA

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

Annual Membership

Family \$25
Professionals \$40

Lifetime Membership

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



Email: info@chargesyndrome.org

Visit us on the web: www.chargesyndrome.org