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Without You

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Notes from the President

By Neal Stanger

Wow, it's less than four months until conference!! If you haven't registered yet, please do so as soon as possible on our conference headquarters website:

<http://www.chargesyndrome.org/conferencehq-2011.asp>. You should also book

your hotel on the same page. The hotel has agreed to hold our rate of \$149 per night from July 19th–August 6th, so if you want to vacation in the Orlando area before or after conference, you can stay in one place.



This year we are expecting nearly 1,000 people to attend our conference from over 15 different countries. Susan Wolfe has been overseeing our online registration this year, and thanks to her hard work in setting up all these programs, our registration process has been smoother than ever. I would also like to thank the Executive Committee members for their unending work in planning all the details for this conference. I couldn't ask for a stronger, more dedicated team to not only help run this conference but also to bring the Foundation to the next level of professionalism in the future.

You will see an article later in the newsletter about nominations and elections for our Board of Directors. If you are interested in running for the Board or have questions of what is really involved in being on the Board, please feel free to email me at neal@chargesyndrome.org, or you can call me on my cell phone at 914-629-0564.

As many of you know, I am ending my third term and sixth year as President of this fine organization. I will not be seeking reelection as President, although I will be staying on the Board of Directors for another two years. It has been my privilege and honor to lead this organization, and I know I will be leaving the Foundation in very capable hands. Thank you, and I look forward to seeing you all in Orlando at the end of

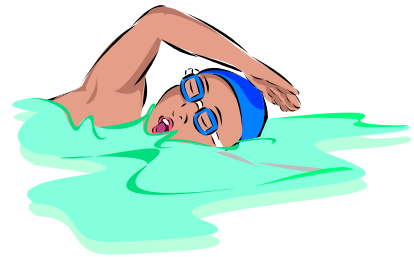


CHARGE in the News

Super Swimmer!

Click the link below to read about an 8-year-old with CHARGE syndrome named Sarah Willes who hails from Chingford, London. Sarah was recently awarded a Kellogg's ASA Swimtastic Award!

<http://www.swimming.org/asa/news/swimming/the-kelloggs-asa-swimtastic-awards-2010-focus-friday/7016/>



Celebrating Jodie

The life and spirit of Jodie Hietpas, a 33-year-old woman who had CHARGE, is remembered in this article. Jodie was a huge sports supporter in her local community. After learning of her passing, one of the local sports teams adopted a 'Jodie' acronym in her memory and has printed them on stickers that they wear on their helmets. Click here to read more about this beloved sports fan:

<http://www.thenewtribune.com/2010/11/19/1430787/theres-a-lot-of-jodie-in-bellarmino.html>



Cover Boy

By Candi Meadows

I just wanted to share that my 3-year-old son, Luke, is on the cover of a recent issue of *ADVANCE for Speech-Language Pathologists and Audiologists*. The feature article is about a feeding group that he is in at our local Children's Hospital. We love the group and Luke's therapists. Here is a link to the magazine online if you would like to take a look. There are more photos inside, but they don't talk specifically about any of the kids or their particular feeding issues.

<http://speech-language-pathology-audiology.advanceweb.com/ebook/magazine.aspx?EBK=SP112910>



Cheerleaders for CHARGE

The first annual Rising Stars Cheerleading competition was held on March 20, 2011, at École Millidgeville North School in Saint John, New Brunswick Canada. In honor of their teammate, Kennedy Weir, the team decided to donate half of its take from the 50/50 draw to the CHARGE Syndrome Foundation.

Pictured to the left are the North Stars Cheerleading team performing their routine, and to the right is Kennedy, accepting a check for the Foundation from school principal Pat Laskey and team coach Denise Vautour.



Thank you North Stars!

Connections

By Sheri Stanger

Time and time again, I am reminded that the parent-to-parent connection is crucial to the well-being of a family. Who else understands our daily struggles and successes in raising a child with CHARGE syndrome? Parents want and need to stay connected to others who share their life's journey. We have a lifelong connection to CHARGE syndrome. From birth to adulthood and through all the transitions in between, we need the support that can only come from other families living with CHARGE syndrome. We need to teach each other and share our resources. What better way to achieve this support and knowledge than by staying connected to each other through the CHARGE Syndrome Foundation!

I am now in my fifth month of working part-time as the Director of Outreach for the Foundation and have talked with many members and new parents. I have had wonderful conversations with professionals who work with our children and support our mission, and have had the opportunity to meet with all the state deaf-blind projects at the Fall Deaf-Blind Leadership Meeting in Washington D.C. in November 2010. I've gathered with parents at state family meetings in both New York and New Jersey, and presented on a webinar entitled "Network Supports and Resources for Families" through the National Consortium on Deaf-Blindness (NCDB), which is archived on their website at www.nationaldb.org.

This small world of ours is well-connected and has much to offer families. As the Foundation that serves people with CHARGE syndrome, their families, and professionals, we want to ensure that families and professionals receive the information they need. Each family has knowledge to offer. I learn something new each time I talk with one of you. I wish I had unlimited time, but since I don't, I am asking all of you to please contribute your support to this wonderful Foundation. You can contribute an article to our newsletter; do a fundraiser; inform us of upcoming events in your area; join a committee; or get information out to doctors, hospitals, and all the places that work with our children. More knowledge leads to better outcomes for our children. Be a part of this connection!

I look forward to speaking with you and meeting many of you at our upcoming conference in Orlando this summer. Please contact me with any questions or ideas you may have for our Foundation. Don't hesitate to call to say "hello" and introduce yourself. It is truly our Foundation. Together we can make a difference!

"This small world of ours is well-connected and has much to offer families."

10th International CHARGE Syndrome Conference

Volunteer Opportunities:

Please visit <http://chargesyndrome.org/documents/VolunteerInformationPacket.pdf> for more information on sharing your talents with us as a volunteer at the conference.

Exhibitor Opportunities:

Information can be found at <http://chargesyndrome.org/documents/ExhibitorMaterial.pdf> if you wish to become an exhibitor, sponsor, or advertiser at the conference.





THE MAGIC
HAPPENS HERE

July 28 – 31, 2011
Orlando, Florida



Conference
Registration &
Payment
Deadline:

JUNE 15, 2011

**All Payments
Made After the
Deadline are
Subject to a Late
Fee of \$75**

10TH INTERNATIONAL CHARGE SYNDROME CONFERENCE

The 2011 Conference is just over 100 days away. Have you completed your to-do list? Conference Headquarters 2011 provides all the information you need, and the step-by-step to-do list will ensure you haven't left out any steps in the registration process.

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

Silent Auction 2011: Shooting for the Stars

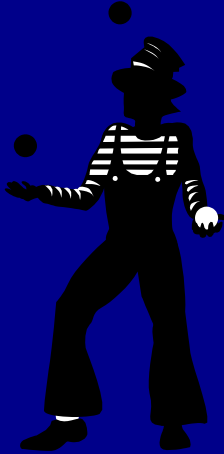
For more than a decade, the CHARGE Syndrome Foundation conference has celebrated Saturday evening with a silent auction. The tradition continues this year with our magical event at a magical conference. Fun for the entire family, it doesn't get any better than outbidding your good friends or getting a good deal on an item while supporting the Foundation.

But we're getting ahead of ourselves. Before the fun can begin, we need donated items. Together we can exceed our goal of \$20,000+. Please chip in and help us gather donations suitable for auction. Handmade items such as jewelry, pottery, and quilts have been popular auction items. Restaurant gift certificates, electronics and themed baskets such as movie night, board games, and gardening all make enticing donations. Please join in the fun and help us reach our goal. Let the stars in our conference logo be the limit!

For instructions and tips, donation request letter and, donation form, visit:

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

Thank you for supporting this great event!



“The CHARGE Syndrome Foundation is looking for hard-working Foundation members who are interested in donating their time and expertise as a Board member.”



★ 2nd CHARGE Conference Idol Extravaganza ★

There are still a few slots open for the 2nd CHARGE Conference Idol at this year's conference. The deadline to sign up for CHARGE Conference Idol is **June 15, 2011**. There will be a limit of 25 on-stage performers, so if you're eager to showcase your talents, be sure to register early and indicate on the registration form that you would like to participate.

Remember that Foundation members receive priority if numbers exceed twenty-five. You can become a member by visiting <http://www.chargesyndrome.org/membership.asp>.

Performers and those submitting artwork will be contacted by June 20, 2011. Once contacted, performers must send in any music they wish to use in the show no later than July 1, 2011.

Whether you sing, dance, tell jokes, paint, draw, play the spoons or, something else, be sure to indicate on your registration form that you would like to be a part of making the magic happen at the 2011 CHARGE Conference Idol Extravaganza!

See you in Orlando!

Nominations for Board of Directors

The CHARGE Syndrome Foundation is looking for hard-working Foundation members who are interested in donating their time and expertise as a Board member. Nominations are now officially open for the Board of Directors for the CHARGE Syndrome Foundation. You can find a nomination form online at www.chargesyndrome.org/documents/nominations.pdf.

Below is a timeframe for you to follow:

April 30, 2011 – All nomination forms will be due to the Foundation office either by postal mail or e-mail.

May 15, 2011 – Initial interview process will be completed by the nominations committee and a slate of potential Board members will be confirmed. If more than six people are running for the positions, an e-mail blast will be sent to all current Foundation members with a ballot to vote. If six or less members are running for the positions, there will be no reason to send out a ballot and all members will be elected by acclamation.

June 10, 2011 – All ballots will be due back to the Foundation.

June 15, 2011 – All applicants will be notified by the nomination committee to let them know if they have been elected to the Board.

July – The new Board officially takes office at the general membership meeting during our conference. The new Board will meet the previous week and elect new officers of the Executive Committee.

We have a few new policies that have recently gone into effect in regards to running for the Board; if you would like a copy of these policies, please e-mail Neal Stanger at neal@chargesyndrome.org. Please remember that this is a working Board; if you are running, please make sure you are willing to put in five hours or more per week before nominating yourself.

Taking CHARGE of Communication

By Julie Brandrup

Choices

I don't know why I didn't read *Choices in Deafness* from cover to cover. Looking back on it, I probably should have read it more than once. But when we began our journey with a profoundly deaf daughter, the initial decisions were fairly straightforward. Would we begin sign language, or would we pursue hearing and speech through a cochlear implant? There were bumps in the road, but relative to all our other decisions, it was not a hard choice to shoot for the moon with a cochlear implant. My husband and I are optimistic people, and I don't like to apologize for that, but in the case of our daughter, Adele, things don't always go as planned.

Adele made quite an entrance to the world in May 2004. With no warnings or complications during pregnancy, everyone was surprised when she needed resuscitating at birth. She was whisked to the NICU, and there were not many encouraging words for us first-time parents. There was literally no time for a single "congratulations" before the silence of worry and concern set in. Within a few days, Adele was diagnosed with CHARGE syndrome, a complex genetic disorder that affects multiple areas of development. Over the next three months in the hospital, almost every specialist had something to add to her list of diagnoses, which included inability to swallow, heart abnormalities, and possible blindness; so the fact that Adele had failed several hearing tests just fell into the pile of bad news. It would be almost a year before she was medically stable enough to really consider our options for hearing.

Because Adele spent 86 of her first 118 days in the hospital, the inpatient audiologists had plenty of opportunities to visit with us. We also were able to learn more about CHARGE syndrome and found out that 90% of patients have hearing loss and many are also vision impaired. CHARGE syndrome is in fact the leading genetic contributor to the deaf-blind population. Thankfully, by the time Adele was 6 months old, she was showing signs of good vision and we knew she would not be blind. We were elated that she could see and continued to think positively and prayerfully about her hearing.

Auditory-Verbal Therapy

Adele was wearing a hearing aid at 9 months of age, and multiple tests had confirmed that she was profoundly deaf. As her medical condition became more stable, we began making visits to the Speech and Hearing Center to discuss our options. As with all potential implant candidates, it was a team effort. Our speech therapist was focused and realistic, our surgeon was experienced and thorough, and we as parents listened and processed everything as best we could. It was decided that she was a good candidate for a cochlear implant, but due to inner-ear abnormalities and facial paralysis, there were a few extra steps necessary to determine which ear to implant. The implant surgeon referred us to the University of Michigan for a second opinion, including a procedure to test the nerve viability on both sides (promontory stimulation). The results of that visit were positive to go forward on her right side (opposite facial paralysis), and we allowed ourselves to get excited.

Adele's surgery day did not go as expected. Midway through the procedure, the surgeon let us know that she would probably not be able to get an implant. Though undetectable on all the previous imaging, Adele had a large blood vessel blocking the path to the cochlea, putting her at increased risk for complications. It was a big disappointment, but a few weeks later we had a new option. Our surgeon contacted the University of Michigan surgeon and felt that if they worked together, they could safely work around the vein. So, in an inspiring medical collaboration, the two surgeons came together in one operating room and implanted Adele's right ear in December 2005; it was a very good day.

A few weeks later, Adele's "turn on" day was not as dramatic as some, but we were delighted to begin Auditory-Verbal therapy. Adele made some progress, but after nine months of therapy she had not mastered the first-level benchmarks. Our concern was strong enough that along with our Auditory-Verbal therapist's recommendation, we began looking at sign language options. Up to this point, our decisions about Adele's hearing had not been that difficult; all of our hopes had been in the implantation and with hearing and speech. Choosing which type of sign language—Signing Exact English or ASL—was much more difficult.



Young Adele having a listen!

"It would be almost a year before she was medically stable enough to really consider our options for hearing."

...continued from page 6

American Sign Language (ASL) and Signing Exact English (SEE)

We knew virtually nothing about either type of sign language and were very anxious. We immersed ourselves in reading materials and the Internet and tried to find unbiased opinions. Even now, I don't know how anyone can make a decision between SEE and ASL when you have so little personal experience. Nonetheless, we officially chose SEE because of the emphasis on English word order and our long-term goals of strong reading and writing skills. However, ASL was also part of our world because of our strong ties with other special needs children at local therapy centers. Our entire family also regularly watched the "Signing Time" video series.

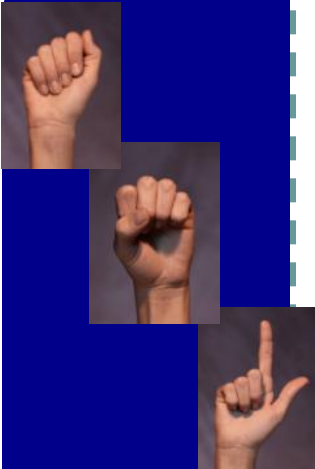
This was a period of quick acquisition of sign language and a first introduction to Deaf culture. What a new world for us! Watching Gallaudet's documentary *Through Deaf Eyes* made us excited for how accomplished people with hearing loss can be. But it also made us very sad because we were starting to realize that often people with multiple disabilities, such as CHARGE syndrome, are not a part of Deaf culture. Through other readings and discussions, we learned that sometimes this is by choice but oftentimes it is by exclusion, which made us extremely concerned for Adele's future within the Deaf community.

Balancing that sadness, however, was the delight that Adele was learning signs as quickly as we were. Adele was proving to be very bright and as many people like to say "as quick as a whip." It was reason to celebrate and one of several factors (including very good dexterity) that led our therapist to remind us about another option for communication: Cued Speech. From *Choices in Deafness* and other sources, we learned that Cued Speech is a method for visually communicating English using the phonemes of the language, not symbols for the words like sign language. In simple terms, it is a combination of lipreading and about 40 hand signals that match the consonants and vowel sounds of English. In addition to Adele's cognitive and fine-motor strengths, several events led to our consideration of Cued Speech.

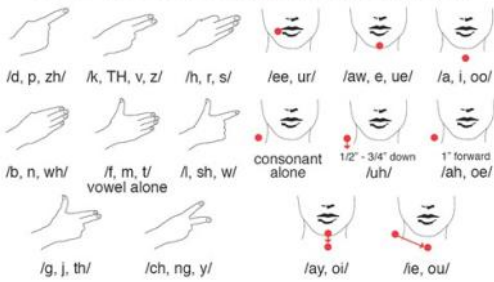
We realized that even though we were very devoted to learning sign language and were gaining vocabulary rapidly, there was a strong possibility that Adele's communication needs could outpace us. There were no local classes being offered to learn sign language, and we were trying to teach ourselves through worksheets and websites. We did the math, and the number of words we needed to learn per day was somewhat overwhelming. If it was overwhelming to us as parents, what could we expect from everyone else in our lives? Without a strong circle of signing friends, including our own adult friends and family, it would be difficult for us to learn sign language beyond a third-grade level (3,000–5,000 words) and it would never be our natural language (as it is for Deaf parents of Deaf children). It seemed more common than not, that at some point, parents were not able to say everything they wanted to say to their children because of vocabulary limitations. That was very concerning to us, especially since there was a chance that the signing Deaf community would not embrace Adele's special needs.

Of more immediate concern was that I was finding myself unprepared to talk to Adele about what she was interested in on a daily basis. On a trip to the zoo, I prepared thoroughly and thought I knew the sign for every animal she could possibly want to see: monkeys, lions, tigers, elephants, zebras, rhinos, parrots, giraffes, turtles, bears, seals, etc. But when she stopped to intently watch the flamingos and the ostriches, I did not know those signs—and even worse, could not find them in the sign language book we had in our bag. At 2½ years old, Adele was not interested in fingerspelling. We had lost that teachable moment forever, and there would be more to come.

“...I was finding myself unprepared to talk to Adele about what she was interested in on a daily basis.”



CUED SPEECH FOR AMERICAN ENGLISH



Cued Speech

From our initial feelings on sign language, we still had a strong appreciation for the literacy-building opportunities in SEE (Signing Exact English). Cued Speech offered even more advantages for learning to read and eventually write. The phonemic awareness from Cued Speech allows children to learn to read in the same way hearing children can learn. Through the hand cues, they have a visual reference for the sounds in a word and can "sound it out," allowing them the same opportunities as hearing children. If Adele is like most kids, we foresee a lot of e-mailing and texting in her future and would like her writing to reflect strong language skills and not be limited just because she cannot hear.

As we learned about Cued Speech from the book and other writings and research, we were intrigued but not without concerns. We read as much as we could and found one invaluable resource in another parent of a child with CHARGE syndrome who had started Cued Speech in preschool. Their story was not without challenges and hurdles, but the positives seemed to fit our interests very well. Their child had done very well in school and was living a relatively independent life with strong communication skills. We were impressed enough to give Cued Speech a try.

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Our biggest concern was how well Adele would be able to expressively communicate using Cued Speech. Because the mouth shape/lipreading is a key component of Cued Speech, Adele's facial palsy and oral motor weakness posed a greater challenge. It was an unknown risk that we talked about, but we felt that even if her expressive language fell into the worst-case scenario, there would be ways to overcome it. The pros seemed to outweigh the cons, and we moved forward.

From a DVD tutorial and later from a speech therapist, my husband and I learned the hand shapes and placements for Cued Speech in about a month. (It can be learned much faster if you are in a camp or workshop setting.) Soon, we could put it all together to say anything we wanted to Adele without having to look it up. Our speaking was very slow at first, but it was very liberating to be able to say anything without first consulting a book. It also didn't take long to notice that because Cued Speech forces your focus to the mouth area, Adele was paying more attention to our voices and using the hearing that she does have from her cochlear implant. We know that she can hear some common routine words without cues, and her lipreading skills are also quite good. Given her challenges, these skills can only add to her long-term competence in the hearing world.

Thankfully, Adele's preschool embraced our decisions, and the school system has continued to support her with a Cued Speech transliterator. In the four years we have been cueing, Adele's receptive language has flourished, and she is still proving how quickly she can learn. In kindergarten, she is doing well academically and is reading at grade level, which has been one of the most joyous rewards of our journey. Literacy continues to be a driving force, and reading has been one of the best ways to advance her vocabulary and increase the speed of our cueing. To her delight, both Adele's grandmothers have learned to cue, as have her aunt and several therapists and babysitters. Her younger sister is also learning to cue just from the home environment. We have taken Adele to two summer camps for Cued Speech and met families from all over the country who cue. We have also met a few more families with children with CHARGE syndrome who are cueing.

Even with our emphasis on Cued Speech, Adele continues to use the initial signs she learned as a base of expressive language, as well as cues and gestures. It is worth noting that most Cued Speech advocates recommend that a child learn ASL at some point, and we agree. The social aspects can be very rewarding, and we hope that will be the case for Adele. Even though we, her parents, will probably never be as fluent as we would like in ASL, we will find other settings in which she can learn when she is a little older. There is no doubt that with Adele, the opportunities to learn something new will always be there!

Augmentative Communication

With Cued Speech, Adele's receptive language has sustained amazing growth, but her expressive language was not progressing as rapidly. This is not unusual in any child's development, but we saw that the gap was widening instead of narrowing. This gap was especially concerning because of behavior issues that are often a part of CHARGE syndrome. It wasn't hard to foresee a difficult future when you pair behavior problems and communication problems, so we continued with the good offense strategy and started looking for another piece to our ever-growing communication puzzle.

It was challenging to find professionals who felt they had adequate experience to make a recommendation for Adele's situation. We were able to get feedback from universities in New York, North Carolina, Maryland, and Michigan, and of course from our home team in

Birmingham. The evaluations were not formal, but the recommendations were unanimous for incorporating an additional approach: Augmentative Communication. One of the therapists at Cued Speech camp recommended a book with an unusual title, *Schuyler's Monster*. It is a father's story about his voiceless (but hearing) daughter's journey to communication. While I do not agree with a lot of the author's feelings, their story related to ours in many ways. They were using an Augmentative Communication device, and it seemed more than not, this could be a good option for us as well.

It took almost a year before we were convinced to try Augmentative Communication; we did not want to overwhelm Adele, ourselves, our family, our therapists, our school system, and others. But during the summer of 2009, when Adele was 4, we went through the evaluation process (and insurance process for coverage). We decided on one of the most language-rich devices, the Prentke Romich Company's [Vantage Lite](#). At our house and school, it is known as the "Talker," and sometimes Adele just signs "pink" because of its bright pink case. If you are not familiar with Augmentative Communication, it is a small, computer-like device that uses symbol icons to offer many choices of language (up to 5,000 words) and it speaks them for the user. Another benefit of the device is that it spells the words and sentences on the screen, furthering opportunities to build literacy.

Because Adele cannot necessarily discriminate the device's voice output, we are cueing everything to her as she learns what words the icons represent. It can be quite a juggling act, but we have found the Talker to be relatively easy to learn to use. As Adele's vocabulary has grown, there are many words she visually recognizes on the Talker and no longer needs them cued. Additionally, with the symbol icons given for each word, the device has proven helpful to give Adele a more meaningful way of learning new words.

As complicated as it sounds, Adele has found her own way to manage how she communicates. If she is with a familiar person who knows Cued Speech and her set of signs and gestures, she generally will not need the Talker. But in times she cannot get her point across, or more often when we cannot decode what she has cued, she will seek out the Talker. In these situations, the Talker can truly save the day. If Adele is with children and/or adults who do not know Cued Speech, we encourage her to use the Talker and she generally does. Her sentences are getting longer, and her grammar and sentence structure improve daily. She also has started to ask other people to communicate to her by using the Talker, and we have found that children really enjoy exploring it with her.



Adele's Talker:
Prentke
Romich
Company's
[Vantage Lite](#).

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Conclusion

Perhaps in reading this, you might wonder if we could have chosen a simpler path. It is a reasonable question but also one that is impossible to answer with any confidence. Like any parents, no matter how much we intervene, we cannot predict exactly what will happen with our children and their future. What I do know is that we made each decision with thoughtful consideration based on the information we had at the time.

Even though our journey with a profoundly deaf daughter has not taken an ordinary path, it has not been haphazard in the sense of being aimless or careless. It just turned out that many of our choices have not gone as smoothly as we hoped—but none of our redirections or additions has been without benefits and rewards. We will continue to be open-minded to what is available to help Adele and will change our course if needed. For now, we are very content with our decisions and especially that Adele is at our neighborhood school making friends, learning to read, and more.

In the well-known poem, the road less traveled is glorified as the nobler path, but in the reality of deafness, it is not as simple as two paths meeting in a wood. There are many, many choices based on a variety of challenges of the child with hearing loss, and in our case the additional special needs of CHARGE syndrome. But since we have unintentionally found ourselves on that “road less traveled,” we are hoping that it will conclude the same and will make “all the difference” for Adele and our family.

For More Information on Cued Speech, visit: <http://trivisualcommunications.com/cued-speech/>

For More Information on AAC Devices, visit: <http://www.asha.org/public/speech/disorders/AAC.htm>

“I recommend hiring someone while you’re still at home for a while so they can be trained and you can watch their interactions with your son.”

Going Back to Work: Sharing Our Experiences

Recently, a question was posed on the CHARGE listserv that asked about whether to hire a daycare or a nanny to care for a child with CHARGE whose mother was returning to work. This issue has been discussed many times over the years, and it is a difficult decision for any parent. The thread provided a wide variety of answers and advice to the mother who posed the question, some of which are shared here. *CHARGE Accounts* would love to hear from you with your stories about going back to work after you have had a child with CHARGE. What worked for your family? To share your story, please email lisa@chargesyndrome.org.

Sheri’s experience:

As far as my personal experience, I went back to work when my daughter (now 17 years old) was 3 months old. I cut down from full-time to three days a week and did some paperwork from home. We hired a sitter to be with my daughter on the days I was working at home so she could stay at home instead of going to daycare. Our sitter came recommended from a neighbor who no longer needed her because her girls were getting older. My husband works close to home, so that kept anxiety down too since I worked in New York City and we live in the suburbs. If possible, I recommend hiring someone while you’re still at home for a while so they can be trained and you can watch their interactions with your son. Good luck! It’s not easy heading back to work. And I hope that you will check out the Foundation’s website for information and will consider becoming a member of this great organization.

Sheri Stanger

Tracy’s experience:

We ended up finding someone through the website Care.com and went this route because we were unable to get approved for nursing care for my daughter. We ended up with a gal who is a retired NICU nurse and has experience dealing with g-tubes and blood sugar testing, etc. And as a bonus, she lives only about three miles from our house. She’s been with us for over a year now and is like part of our family. Best of luck! I know it seems like a daunting process to try to find someone, but don’t lose hope—you will!

Tracy Roth



...Continued from page 9

Sara's experience:

I tried to return to work at eight weeks and just couldn't do it. At the time, Gannon was still in the NICU, and he remained there until he was 4 months old. He had a few surgeries and a lot of desats to zero, and I just couldn't really function at work while worrying about him and getting calls about things going less than smoothly when I was 45 minutes away. I decided after two weeks at work (during which time I was not reliable at all) that it just wasn't in the cards for me to be at work at that time. I was able to stay with Gannon in the hospital and, once he came home, I provided nearly all of his care along with my husband when he wasn't at work. Plus, we got approved for only four nursing hours per day for the first several months Gannon was home. Additionally, Gannon would be hospitalized nearly 30 times before his second birthday for respiratory issues. With the complexity of Gannon's care (suctioning, other respiratory issues, tube feedings, etc.), I was not comfortable with him being inpatient without me or my husband being there 24 hours a day.

I know this is a very long answer, but I wanted to give some backup to my reasoning. I should also add that we eventually got approved for eight hours of nursing care a day (while my husband was at work). But I needed that care during the daytime so I could take Gannon to his doctor visits, take care of my two other small children, keep up the household, and ultimately stay with Gannon much of the time while he was in for all of his inpatient hospital stays. My nights were spent being up with Gannon—suctioning, addressing oxygen, and much of the time just staying at the hospital. Work was just not an option for us. Even now, we do not have reliable nursing care. Granted, we are very particular about who we allow to provide nursing for Gannon. We do not receive all the nursing hours we request, which makes it difficult to get some relief and to spend quality time with our other children.

I commend you for taking the step of going back to work, and I hope it works out for you. As I'm sure you are learning, every child with CHARGE syndrome is unique, so only you know in your heart what the right decision is. Time will tell as well.
Sara Moseley

Brandi's experience:

I wasn't working at the time the twins were born. I'm grateful for that because Meagan was so medically complex, I can't see how I could have juggled work and her care. We, too, had PT, OT, ST, feeding, and Phoenix DaySchool for the Deaf coming weekly to teach us sign language for the first three years of Meg's life. Meg also had 11 medical

specialists who wanted to see her monthly or bimonthly for the first two years. It wasn't until she was 3 years old that her health stabilized and she went into the school system, where she received services. Two years ago I started working minimally part-time at the church I attend, and God has lined things up as such that I am now a director for the church bookstore, putting in 40 hours a week. But Meg is 6 now and, most importantly, is doing amazingly well!

So it's hard to answer your question. Is your work demanding? Does your beautiful son have lots of medical follow-ups and needs? It really depends on you as well. Emotionally, I was not strong enough, but there are some amazing moms on this listserv who continue to blow me away with their strength for taking care of their kiddos who are medically complex.

Another idea is, can you find something from home? My neighbor, who shattered her foot in a car accident and has had troubles now for years, works for U-Haul out of her home. She books out trucks for people all over the world. She gets decent pay and benefits! I hear the big flower companies do the same thing. And please don't think I am recruiting, please! But, about a year ago, I joined Scentsy (warmers that melt scented wax using a light bulb, not a flame) and sell it on the side to anyone in Canada and the states. It's so easy and fun, and I get paid for it. I'm hoping to grow my business so that I can eventually quit my job and go back home to the kiddos—and it's totally doable, mostly from home! Meg is in kindergarten now, and I had a parent-teacher conference last night which has me realizing that if I put more hours into following up with her teaching at home, she could be doing so much better. So my goal is to work from the home soon using my Scentsy business to do it.

“...only you know in your heart what the right decision is.”

There are a lot of options out there to keep an income coming in while working from home. I hope this helps!
Brandi Melton

For some general tips on returning to work after having a baby, visit:

http://www.pampers.com/en_US/parenting-articles/returning-to-work-after-pregnancy/1682

3rd Annual Joshua Kurby Charge for CHARGE 5K Run

By Sandra Kurby

We will be having the 5K this year on Saturday, August 20, at 8:00 a.m. The place remains the same: 391 Illini Drive in Armstrong Park, Carol Stream, IL. We are going to be included in the race calendar February issue of *Competitor's Magazine*, so we'll see if that helps our field grow even more!

Please take the time to mark this date on your calendar so you can run, walk, or volunteer. If you would like to volunteer, please let me know! More details, registration forms, etc. are to follow, and I will update more info on our blog as well as our Charge It for CHARGE page, so please check in from time to time. Hope to see you on August 20 (if not sooner)!

Kurby Family Blog: kurbyfamily.blogspot.com



McKinley Honors March Developmental Disabilities Awareness Month



Rep. McKinley with his grandson, "Mighty Max"

Washington, DC – Rep. David B. McKinley, P.E. (R-WV) spoke on the House floor recently in honor of March Developmental Disabilities Awareness Month. Awareness for developmental disabilities is a personal cause close to McKinley's heart.

[\(NOTE: The following are prepared remarks: for video of McKinley's speech as delivered, click here.\)](#)

Mr. Speaker/Madam Speaker, I ask unanimous consent to address the House for one minute.

In 1987, President Ronald Reagan officially declared March Developmental Disabilities Awareness month. He called for people to provide understanding, encouragement, and opportunities to help persons with developmental disabilities to lead productive and fulfilling lives.

There are currently over 7 million Americans who experience developmental disabilities. Disabilities have no boundaries. It cuts across the lines of racial, ethnic, educational, social, and economic backgrounds, and it can occur in any family.

As an individual with significant hearing impairment and a grandfather to a child with special needs, I am very familiar with the hardships of overcoming the obstacles of disabilities. My grandson, Maxwell, has CHARGE syndrome and deals with intensive developmental and medical challenges every day. He is a true inspiration to our family and community.

During Developmental Disabilities Awareness Month, I encourage us all to learn more about the people in our community who have developmental disabilities and to recognize that all of us have talents and abilities that we can offer to make this a better place to live.

Thank you, and I yield back.

"I encourage us all ... to recognize that all of us have talents and abilities that we can offer to make this a better place to live."

New Book on CHARGE Syndrome (German)

A new book on CHARGE syndrome has been published in Germany (also available in English).

Compendium on CHARGE Syndrome: Multi-disciplinary and international perspectives

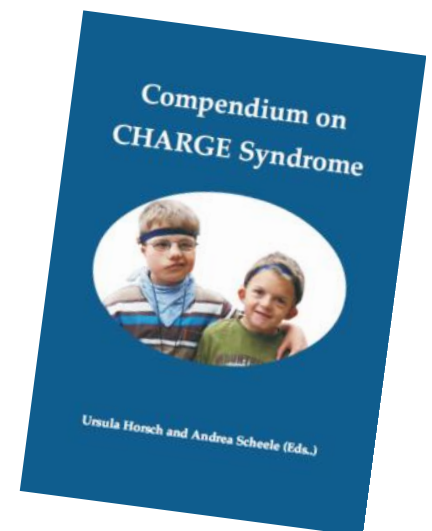
NEW 1st edition 2011 · 300 pages · paperback

\$79.00 total price (\$63.00 + delivery by airmail: \$16.00) ISBN 978-3-941146-15-0

This compendium on CHARGE syndrome covers multidisciplinary and international perspectives. Special highlights are genetics, cardiology, urology, visual and hearing-related perception, phoniatrics, cochlear implantation and research on dialogue training in early educational processes, as well as multisensory impairment and deafblindness. The volume also focuses on cognitive semiotics, challenging behavior, parental perspectives, and supervision. Articles on endocrine specifics, balance, physical education, and sports complete the editors' selection.

Authors: Prof. Dr. Boulos Asfour, Prof. Dr. Frans van Erckelens, Prof. Dr. Margit Fisch, Dr. Silke Riechardt, Prof. Dr. Jürgen Kohlhase, Dr. Silke Pauli, Prof. Dr. Barbara Käsmann-Kellner, Prof. Dr. Roland Laszig, Prof. Dr. Rainer Schönweiler, Prof. Dr. Joachim Thüroff, Dr. Christian Thomas, Prof. Dr. Antje Aschendorff, Dr. Susan Arndt, Prof. Dr. Timothy Hartshorne, Prof. Dr. Jeremy Kirk, Dr. David Brown, Prof. Dr. Lauren Lieberman, Prof. Dr. Pamela Haibach, Dr. Anna Wolff, Martha Majors, Adele Farhart, Flemming Ask Larsen, Hanne Pittroff, Prof. Dr. Ursula Horsch, Andrea Scheele.

Please order by e-mail at: vertrieb@median-verlag.de and provide us with the address for billing and delivery.



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Suzanne Koudelka

Emily Murray

Sharon Hill

Scott O'Neal

Valerie Johnson

Cheryl Kruger

Eli Bluestone

Debbi Bruner

David Cash

Elizabeth Corthouts

Enza Dolce

Arlene Griffone

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Hamaoui

In Honor of Grace Gagliardi
Network for Good

In Honor of Charlotte
Cosenza

Staff at Lindy Eye Care

In Honor of Pat Simmons &
Alex Bartkowiak

Brian Bartkowiak

In Honor of Aileen Hiscutt
Sayce

James Bowden

In Honor of Emma & Diane
Katapodis

Hilda Bodenstein

In Honor of Alayna Josephine
Greaves

Debbi Bruner

In Honor of Christian
Roberts

Bekkie Cobb

In Honor of Nick Schwartz,
on his Bar Mitzvah,
January 8, 2011

Bernard Carlin

Ed Elowitz

Estelle Reich

Joann Stichman

Janet Koch

In Honor of Eva's Bowling
for CHARGE

Margaret Couillard

In Honor of our
granddaughter Makenzie
Dougherty

John Dougherty

In Honor of Bob & Jill Hale
whose niece Patti has
CHARGE

Robert Hawes

In Honor of Luke Joseph
Snyder

Jim, Renee Hegarty

In Honor of Maya Kelly

Julie Lopez

In Honor of Gino Gaucher

Sandra Merrill – Scarlet Team
Teachers

In Honor of David Sirota

Aleksandr Tarasula

In Honor of Katie Kauffman

Sara Wilson

In Memory of John Kirk

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In Memory of Milly Barbalata

Emma Bluestone

In Memory of Elizabeth J.

"Betty" Fitzgerald

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In Memory of Eldon Stahl,
father of Greg Stahl

James Breitbarth

In Memory of Tyler
Matthew. Donation made on
behalf of Sue & Buddy Glines
Tyler's grandparents.

Heather Gross

In Memory of Joshua Roy

Kurby

Stephanie & Donald Klingner

Rosalie Kurby

In Memory of Don Stein

Vered Klinghofer

In Memory of Miles Bryce

Sherman with love from

Liza, Brian, Amy and Tylor

Massouda

In Memory of John E Lent

Pamela Matthews, on behalf of
the co-workers of John Lent at
the Office of the State

Comptroller

In Memory of Douglas Roth

Donna Rudder

In Memory of Brianna

Seagull Goldberg

Fanya Seagull

In Memory of Our beautiful
boy Colin Luke Smith who
lost his battle to CHARGE at
only one week old!

We miss you baby! 9/30/09-
10/7/09

Jeanne Smith

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

Thank You

In Memory of Ronald Sly

Lisa Weir

In Memory of Gail Walsh

Lisa Weir

On the Special Occasion of Nick Schwartz's Bar Mitzvah – from Nick Schwartz

Michael Schwartz

On the Special Occasion of Catherine Kouzmanoff's 40th birthday & Brandon too!

Louise Bauer

On the Special Occasion of Alayna Josephine Greaves Happy 2nd Birthday!

Debbi Bruner

On the Special Occasion of Emilee Hullings first Christmas!

Peggy Darczuk

On the Special Occasion of Birthday #40 - Catherine Kouzmanoff

James Kouzmanoff

On the Special Occasion of Eva's Bowling for CHARGE

Crystal Masionis

Charge It for

CHARGE Tributes

In Honor of Brady Antaya

Annis Winifred

In Honor of Brady & Cynthia

Elaine Gover

In Honor of The Bluestone Family

John DeCoursey
Karen Donaldson
Matthew George
David & Elise Graham

In Honor of Zach Bluestone

Todd Ackerman
RCLOB Ackerman

Shari Besteman

Eli Bluestone

Greg Bolduc

Dave Bonner

Meta Brophy

Michael Byron

Cynthia Coutsouros

Tricy Cushner

Josephine Dippolito

Josephine Dippolito

Rick & Cindy Horgan

Suzan & Ira Katz

Rita Lascano

Nancy Leader

The Lichtmans

Elizabeth Makar

Ann Pisetznier-Soundview

Construction Advisors

Rebecca Seger

Gail Strassman

Tom & Elyse Stringer

Lili Van Zanten

Woda Family

Genevieve Bentley

Margaret Bentley

In Honor of Zachary & Our Friends, the Bluestone Family

Rosemarie & Joe Pelatti

The world should have more people like the Bluestone Family. I hope the Oktoberfest Fundraiser was a huge success!

Lisa Cook-Lisa A. Cook

Consulting

In Honor of all those parents meeting the difficult challenge of CHARGE head on. You have our support and great admiration!

Michael Stoop-Metropolitan Risk Advisory

In Support of Zachary

Gail Chen

On the Special Occasion of A Bluestone Family Oktoberfest The D'Orio Family

Janine D'Orio

In Honor of Gracie Swann and the love she brings to our hearts.

Jaqueline Dominick

On the Special Occasion Merry Christmas Gracie!

Lance Schumacher

In Honor of Maxwell McKinley

Elizabeth Boyle

Suzanne Holman

In Honor of Mighty Max McKinley

Lisa Sprouse

In Honor of The most amazing, beautiful, loving, silly boy in the world... MIGHTY MAX!

Amy McKinley

In Honor of Brian & Matthew Murray

Marsha Bloomberg

Patrice DaCunto

Maria Mallamaci

Beth Pike

Sharyn Fisher

Sari Laurence

In Honor of the Murray Family

Mary Reinecke

Jennifer Walker

From your best "special" friend Jake and his mom Joy

Joy Ryan

In Honor of Brian, Matthew, Emily and Jay!!

Nilin & Andrew Yolin

In Honor of M&B

Marc Zimmel

In Honor of Brian & Matthew Murray we love you! The Goldberg Gang

Randi Goldberg

In Honor of Justin Murray

Matthew & Janet Murray

In Honor of Justin Mow Murray Love the Dowds

Pamela Dowd

In Honor of Love you, Justin Murray :)

Paul & Pamela Dowd

In Honor of Ethan Wolfe

Richard Alekxy

Sheldon Brenner

Sharon Bresler

Debbie Brown

Jessica Burtnett

Richard Busick

Karen & Michael Cutler

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Michael Wojtas-Law Office of

Michael Wojtas

David & Jody Wolfe-Wolf &

Wolfe, Ltd

Jason Wright

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
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Thank You

In Honor of You Rock Ethan!

Peter Moroh

In Honor of Ethan & his very special family

Naomi Amsterdam

In Honor of the Wolfe Family

Howard Ankin-Ankin Law Office LLC

Victoria Lovely

Peter Morse-Morse, Bolduc & Dinos

John Stuart-Better Business Planning, Inc.

Nick Avgerinos-Capron & Avgerionos, P.C.

John P. Connolly

Daniel Fuchs

In Honor of the Wolfe Family & Especially the Big E!!

Bill Furie

In support of Ethan Wolfe. The Kakavas Family

Jolana Kakavas

On the Special Occasion of David & Jody Wolfe's Annual Campaign on behalf of Ethan Wolfe

Wendy O'Kane

E-man we love you!!!

Barry Wallis

With Love to Ethan

Paul Berkowitz-North
Scottsdale Behavioral Health,
P.C.

In Honor of Joseph Lavelle

Margery Bodenhamer

In Honor of Alivia Roth

Michelle Coddington

In Honor of Kristin Ogan

Judy Espinosa

Ashley Hermanson

Carolyn Jewell

In Honor of Cousin Kristin Ogan

Darla Northrup-Tippitt

In Honor of Kristin being an amazing daughter, and Ken being a great son and sibling!

Marilyn Ogan

On the Special Occasion of Grandma Joan's & Cody's birthdays!

Kristin Ogan

In Honor of Kennedy Weir

Ann MacIntosh

In Honor of Christine & Kennedy

Phil Small

In Honor of Alayna

Kathleen Orris

In Honor of Dominick Salva

Eileen Senzel

Michael Veltri

In Honor of Dominick Salva & Family

Lynda Hickey

In Support of Dominick Salva

Michael Hickey

In Honor of Megan Stanger

Scott Blum

Jodi & David Chen

Donald Conklin-Dixie Home Carpets

Judy Feder

Bill & Cindy Nibur

Susan Rutman

In Honor of the Stanger Family

Barbara Bernard

Harold Horowitz

Judith Knispel

Susan Levine

Ellen Shindelman Kowitz

Ruth Ann Smith

In Honor of Megan & Family

Tasha & Charley Macedo

In Honor of Megan and her great successes everyday!

Martha Majors

In Honor of Sheri

Allen & Linda Tennbaum

In Honor of the work of Neal and Sheri Stanger in helping families with CHARGE Syndrome.

Monica Corton

In Honor of Team and Families at CHARGE

Syndrome Foundation

Michele Lantow-Helms Briscoe

In Honor of Taylor Shott

Michelle Bailey

Harry Capers

Holly Chervnsik-

SuburbanBuzz.com

Robbi Laudon

Nancy Naghavi

Virginia & Brian Paschal

Tom Shacklett

Judy Stienecker

In Honor of Taylor, Brownie and Tom Shott from your Tradition Bank Family!

Carol Bonaccorso-Tradition

Bank

In Honor of Taylor!!!!

Harry Capers

Morgan & Everett Gibson

In Honor of Taylor Shott's amazing spirit!

Carol LaBroski

In Honor of the Shott Family

Dr. Brett & Fatima Donaldson

In Honor of Taylor, Brownie & Tom Shott

Bev & Dave Long-The Window

Shop

In thanksgiving for Cora Taylor.

Sarah Spruill

For Taylor Shott

Eileen Pavlovich-Katy Scholars

For Brownie, Tom and Taylor! Love Coffee News Australia

Sue Mazur-Coffee News

Australia

Brownie and Tom Shott – great work for a great cause.

Jeannie Bollinger-Houston West

Chamber

On the Special Occasion of Thanksgiving 2010. I wish Taylor and the family the greatest of Holiday wishes. We have so much to be thankful for. Praise be to God!

Tim Guhlin

On the Special Occasion of Taylor Shott & Family... Have a Wonderful Christ Filled 2010 Christmas!

Shirley Bracksieck

In Honor of Alexis

Schnaderbeck

Nancy Westmaas

In Honor of Douglas Roth

Samantha Anne

In Honor of Frankie

Carparelli

Cris Carr

In Honor of Abigail Northway

Juan Carlos & Christine

Fontaneda

In Honor of Maya Kelly

Clare & Ross Swanes

In Honor of Melissa Brown (Sara)

Allison Tyler

In Honor of Alivia Roth

Joe Benedetti-Wells Fargo

Advisors, LLC.

Valorie Hobson

Jim & Barb Roth

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
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Thank You

In Honor of Kate Marvin and the Marvin family
Amy Campbell

In Honor of Katie, Leslie & Arlin Kauffman
Jane Coil
Jean Findley
Carol Sturzenberger

In Honor of Katie Kauffman
Karen Hamm
Twila Kauffman
Archie Kauffman
Susan Klein
Mark Sears
Peggy Shelton
Ed & Mary Varnell

In Honor of Katie Kauffman and her loving and dedicated parents.
Suzanne Schuetter

In Honor of our niece, Katie Kaufman
Marlo & Deanna Kauffman

In Honor of Makenna Susil
Maddie & Ty Garber
LuAnn Gatewood
Deb Lapp
Nana & Baba Miller
Sharon Newman
Peter & Vicki Rapol
Sue Reed

In Honor of Joshua Roy Kurby We love you always, Nonna & Grampa
Rosallie Kurby

Merry Christmas Joshua. We love you and will never forget our Christmas together. Love, Mom, Dad, Joey & Jillian
Sandy Kurby

In Honor of Aaron's Education Team
Susan Hiscutt

On the Special Occasion of John Swann's birthday.
Kristi Swann

In Honor of Precious Finley!!!!
Kristin Galan

For Our Precious Granddaughter
Jeanene Galan

In Honor of Catherine Kouzmanoff Birthday #40
James Kouzmanoff

In Honor of a special princess, Finley.
Sylvia Walker

In Memory of Ronald D. Wynne
Ruth M. & John P. Wynne Jr

In Memory of Donna Selger. One of my first audiologists who diagnosed my hearing loss.
Cynthia Antaya

In Memory of Corinne Ursula Bernat
Cora Bernat

In Memory of Douglas Roth
Kelli Bernstein
Frances Brady
Barbara Brown-Meaden*Moore
Joanne Buttolph
Bruce Combs-M&M BS
Marilyn Corrigan
Karen Czerniawski
Mary Holter
Debra Hucik
Leslie Kasten
Margaret Lavelle
Mary Grace Maul
Francis McCafferty
Pete McGreal
Margaret Morris
John Norton
Mary Ellen Oshea
Susan Randolph
Mary Ann Reichhardt
Robert Roth
Julius Salerni
Linda Sobey
Karin Spoerke

In Memory of my son: Kristafor Scot Buchanan
June 16, 1978-November 1, 2009
Lynn Buchanan-Techniprint Inc.

In Memory of Raquel Morel
Andrew Henschel

In Memory of Dorothe Thompson
Crystal Holmberg-Coffee News Fort Bend County

In Memory of Frank Felice
Becky & Jim Lee

In Memory of David Salk
Steven Salk

In Memory of Jim Burch
Peg Scott

In Memory of Pam Ryan's mother
Lori Swanson-Univ of WI-River Falls

Here's hoping Maya gets to enjoy Disneyworld next summer!
Pamela Wenz

In Memory of Joshua Kurby
Denise D'Andrea

In Memory of Sylvia Dressler, mother of Robert
Robert Dresslert

On the Special Occasion of Kimi Swanson's birthday (1/17/11)
Lynn Swensen

On the Special Occasion of a great organization
Jan van Dijk

On the Special Occasion of The Big Pumpkin 5k for Sweet Sara's Chargers. Go team! Lots of love to Sara!!
Susan Weiler

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION



Many of us are putting the finishing touches on our plans for this summer. Hopefully they include a family trip to Orlando to attend our 2011 Conference. For those of you who have attended a conference, you know what a life-changing experience it can be. This year's theme is "The Magic Happens Here." While I know that the Orlando conference will be a truly special weekend for those in attendance, the real magic often occurs long before the Conference ever takes place.

It is the tremendous effort and generosity of our fundraisers and donors that enables the Foundation to offer scholarships to those who cannot afford to attend, allows all those with CHARGE syndrome to attend for free, and permits the Foundation to underwrite an expected Conference deficit of approximately \$200,000. We could not continue to put on such high-quality, entertaining conferences without the support we have received from our members and their friends, families, and business associates. THANK YOU for helping to make the magic happen in 2011.

Despite our many accomplishments, there are still too many people who cannot afford to attend the Conference. There is too much research that needs to be done. Please get involved! It is never too late to join our online Charge It for CHARGE fundraising campaign. You can also contact me about planning any type of fundraising event. If you have any ideas about how to raise money for the Foundation, please email me at david@chargesyndrome.org.

Hope to see all of you in July.

David Wolfe

Treasurer and Fundraising Chair

Please 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

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Email: info@chargesyndrome.org

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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

