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VOLUME 20, ISSUE 1

SPRING, 2010

President's Message

Celebrating 20 Years of CHARGE Accounts!

If you haven't noticed yet, this is Volume 20, Issue 1 of the newsletter, which means this is the 20th year of publication for CHARGE Accounts, which was started in 1989 by Marion Norbury and Meg Hefner, predating the Foundation by several years. Look for a history of the Newsletter in an edition later this year. I would like to thank the Education Committee for helping to solicit articles for this edition of the newsletter, and especially thank Lisa Weir for bringing it all together. The new, online newsletter is a Herculean effort and without Lisa's expertise with technology we would never be where we are today. If you are interested in writing an article for any future issues of CHARGE Accounts, please contact Lisa at lisa@chargesyndrome.org

It's hard to believe that we only have 15 months left until we meet in Orlando for our 10th International Conference. Putting on these conferences requires thousands of hours of work and we are in need of volunteers to help on the conference committee. If you live in the Orlando area, or if you live 3000 miles away you can still be a big help. Please contact Janet Murray at janet@chargesyndrome.org and she can let you know exactly where you can be of assistance. If helping with conference is not your thing, you can participate in the Foundation by joining one of our other committees. Please visit our website at www.chargesyndrome.org to see what is best for you.

Perkins Presents...

CHARGE Syndrome: The Impact on Communication & Learning

From Perkins:

"This insightful webcast explains the physical, sensory and neurological issues shared by many children with CHARGE and how these issues can affect their success in school. Martha Majors, who has worked with many children with CHARGE in the Deafblind Program at Perkins, offers guidance for educators in developing an effective educational program that will improve the emotional well-being and success in learning for students with this syndrome."

To view the webcast online, visit <http://support.perkins.org/chargecommunication>



Addressing Social Challenges of Students with CHARGE Syndrome in Middle School: a Practical Approach

Nancy Salem-Hartshorne, PhD., Central Michigan University

Mitchell T. Ridley, Student, Mount Pleasant West Intermediate School



*“When students
are educated
together, they
spend time
together, work
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create
friendships.”*

Many children with CHARGE have social challenges. As they grow into early adolescence, these become more prominent. Even as many adolescents with CHARGE seem to be on-track academically, they may remain behind their peers socially, appearing immature. During the middle school years, when social status becomes all important to young teens, this can be particularly problematic. This article provides some practical suggestions for parents and school personnel to assist adolescents with CHARGE syndrome to make better social connections during those sensitive years.

1. Inclusive Education: The number one way to encourage social acceptance in school is to be sure all students are educated together. Connections and friendships are made most easily when students have regular access to one another. Think about where you met your spouse or best friend. More than likely, it was because you both were a part of a larger group that got together regularly. If you had never met or spent time together, you would not be together today. This is also true in school. Children who are segregated from nondisabled classmates for all or part of the day are just not going to make connections with those classmates unless given specific opportunities to do so. When students are educated together, they spend time together, work together, and create friendships.

2. Parallel/Cooperative Learning Curriculum: Okay, so let's say you have an individual with CHARGE syndrome included in your classroom, but they still are not making connections. Are they doing the same work as the other students? Do they have the ability to do so? If not, they may be experiencing segregation *within* your classroom. How can that be changed? There are at least two valid and relatively easy ways to address this problem. First, a parallel curriculum for the student can be developed with the collaborative help of the special education team. By parallel curriculum, I mean that whichever topic is being taught to the nondisabled students in your classroom can usually easily be altered to address the curricular (IEP) needs of the student with CHARGE syndrome. Second, the concept of cooperative learning can be applied. Cooperative learning is a teaching method that encourages groups of students to work together to achieve a common goal. Students rate one another's' progress, contributions, and overall achievement in the group. Students with cognitive or learning disabilities contribute in ways that allow them to learn at their own level and to make valuable contributions to the group as a whole. Let's have an example:



A seventh grade science class is studying plant cells and making models out of various materials. They must identify chloroplasts, mitochondria, nucleus, cytoplasm, cytoskeleton, cell wall, and cell membrane. Four “typical students” and one student with CHARGE syndrome who has some learning “limits” are in a group together. The group must innovatively brainstorm ways for everyone to contribute and cooperate to learn and achieve the objectives of the lesson. It is quite amazing how students apply themselves to this problem.

The student with CHARGE has an IEP objective focused on handwriting skills, and another focused on social skills. The students decide that they will each construct two parts of the cell. The student with CHARGE is assigned the cell wall and cell membrane, and the labeling of the parts. She uses a paper plate with a layer of wax paper over it to represent the cell wall and membrane, and the rest

of the students use this as a background on which to place their more complex cell components. The students as a group make small flags to label parts of the cell. The student with CHARGE uses her best handwriting to fill in the labels. All students have participated, all students have learned, and students appreciated one another's contributions to the project.

3. Extra-Curricular School-Based Activities: Encouraging students with CHARGE syndrome to take part in extra-curricular activities can sometimes be a challenge. If they are not independent, school districts must pick up the slack and provide support where needed. At other times, "natural supports" are all that are needed. Track and Cross Country programs at middle schools are often easily accessed. Large groups of students spend time most afternoons working out. An individual with CHARGE, no matter what their physical abilities may be, can be included in this activity and have lots of contact with non-disabled students, even if they are segregated during the rest of the school day.



Many middle schools have afterschool programs to assist students with homework and give them opportunities to access enrichment-type programs. These are generally open to all, are often free, and usually quite accessible. Enrolling students with CHARGE in these programs will also give them more frequent access to friends.

4. Social Skills Groups: Often, school counselors, school psychologists, or school social workers will offer social skills training groups. The purpose of these is to assist students with fewer or less appropriate social skills to practice age-appropriate skills with supportive, non-disabled peers. A student with CHARGE and another student having social difficulties may meet with a school psychologist and several non-disabled, but socially adept and possibly popular, peers. They are given social scenarios to practice, such as, 1) What to do when greeted with a "high five", 2) How to respond to bullying behavior (so common in a middle school setting), 3) How to approach students to sit with them in the lunch room or to hang out with them during free time, and 4) How to react to jokes. In addition to the valuable practice, the non-disabled peers often become "natural supports" and "safe to approach" in these outside settings, giving the student with CHARGE a great starting point.

5. Circles of Friends: If the above methods have been tried and the student is still having difficulty fitting in socially, school personnel may consider creating a "Circle of Friends" to support the student. The Circle meets frequently with the student and a school advisor to discuss the students' most prevalent social issues and find ways to address them in positive ways. Example: The student is having difficulty fitting in at lunchtime, and is not sure what to do or where to sit. Circle members may decide to each specifically invite the student to sit with them for a while until the student feels more comfortable and/or is seen as more acceptable to others in the student population.

These are just a few of the research-based and well-proven ideas for helping students achieve better social skills and higher social status within middle schools. This will logically lead to the most important outcome: friendships!



Second Annual CHARGE'd Up for Golf on Memorial Day

Second Annual CHARGE'd Up for Golf on Memorial Day Monday May 31, 2010 in Galena, Illinois
Catherine Kouzmanoff Email: cat@inter7.com

Miss Kitty is proud to announce the second annual CHARGE'd-Up for Golf on Memorial Day Outing. Miss Kitty invites all residents, tourists, and businesses to join them for an enjoyable day of golf at Eagle Ridge Resort & Spa's 9-Hole East Course in Galena, Illinois in support of the CHARGE Syndrome Foundation.

This challenging 9-hole golf course is a Par 34. The course has numerous elevated tees, tight landing areas and large, undulating greens. This course is for everyone! All proceeds from this golf outing will support The CHARGE Syndrome Foundation, Inc.. Your donations and fees are tax deductible.



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Registration is \$100/person or \$175/couple

Registration Deadline is Friday, May 7, 2010

For information or to participate in the Golf Outing please contact Catherine Kouzmanoff at:

Miss Kitty's Grape Escape

233 S. Main St., Galena, IL

(815) 238-8651 cell

cat@inter7.com

Schedule of Events on Monday May 31, 2010

1:00 pm Registration & Shot gun tee-off

Couples Best Ball (must use ladies drive 3 times in 9 holes)

4:00pm – 7:00 pm Awards ceremony and dinner (including vegetarian dishes); Cash Bar.

Participant Perks

-- Churchill and Burns are sponsoring hole 1 with complimentary cigars!

-- Each participant will receive a complimentary gift bag, a fabulous dinner and an opportunity to win prizes from local businesses.

-- Prizes will be awarded for longest putt, closest to pin (Par 3) and closest to EAR, HEART, EYE.

-- Each participant will automatically be entered into a raffle.

-- Pictures will be taken of "couples/foursomes" and presented at the awards ceremony & dinner.

-- PRIZE FOR BEST DRESSED COUPLE

-- Win a chance to golf with a famous burlesque performer: Kitten DeVille, Francean Fanny, Sabina Kelly, and Michelle L'amore.



*"Do you know of
any particularly
helpful
professionals that
might be
interested in
presenting?"*



Upcoming Call for Papers

Marilyn Ogan marilyn@chargesyndrome.org

Soon a Call for Papers for the 10th International CHARGE Syndrome Conference, (including the 2nd Professional Day) will be sent to professional, medical and educational networks. The conference will be at the Rosen Shingle Creek Hotel in Orlando, FL.

Points to ponder:

What issues do you or your loved one(s) face daily?

What topics do you want to see addressed in conference breakout sessions?

What professionals would you like to see presenting at the conference?

What do you believe to be a topic that all participants would enjoy or from which they can benefit?

Do you have a particularly helpful professional that might be interested in presenting?

Are there professional outlets you know, to which we need to submit the Call for Papers?

Please send comments or suggestions regarding programs to Marilyn Ogan, Conference Program Chair at marilyn@chargesyndrome.org. Other conference comments may be submitted to Janet Murray, Conference Chair at janet@chargesyndrome.org.

2011 in Orlando: Calling All Volunteers



Photo by Rosen Shingle Creek

Janet Murray janet@chargesyndrome.org

Hello!

Do you live, work, and/or play in Florida? Do you have contacts (personal or business) in Florida? Would you be willing to help me connect with them to ask for their assistance?

Although it is only March of 2010, work has already begun for the CHARGE Syndrome Foundation's 10th biennial conference July 29-31, 2011, in sunny Orlando, Florida.

As conference chair, I need to make contacts in the Orlando area as well as in the entire state of Florida. Connecting with

individuals and families who have an interest in CHARGE syndrome is the first step to establishing a **volunteer base** for the conference. From that base, we will expand to bring in even more volunteers to assist with every aspect of running the conference: the Thursday night social, the Friday night CHARGE Idol, the Saturday Carnival and Silent Auction, and Childcare. Volunteers can come from many sources: family, relatives, friends, co-workers, community groups, boy and girl scouts, and other service organizations.

Along with gathering volunteers, we are seeking sponsors and donors. To do this, we will need to contact businesses, civic organizations, state agencies, charitable organizations, and any other source we can think of to approach. We are looking for both cash donations and in kind donations such as snacks, toys, office supplies and other supplies.

We need help in many areas, so even if you are not in Florida, we can still use your talents and skills to make this conference one to remember. Please send me an email if you can help or have suggestions for me. I will be making phone calls and sending e-mails to gather a base group to keep moving toward our destination.

Looking forward to working with you!

Janet

**"We need help
in many
areas...to
make this
conference
one to
remember."**

How Karate Class Changed My Life

Chip Dixon

I'm 30 yr old young guy, with mild CHARGE syndrome and growth hormone deficiency, I'm Chip Dixon. I'm hard of hearing and nearsighted, and got some other physical limitations and I have been taking karate class for around four yrs now.

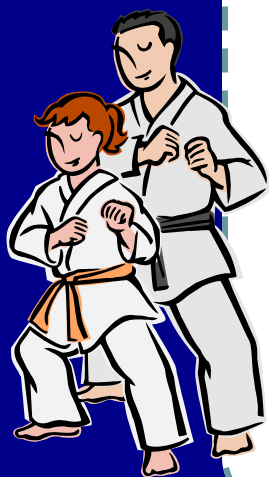
I first heard about karate from one of my deaf friend's mom, she got my friend Eric and me into karate. Eric stayed at karate for a while, then after one of the sensei [teachers] quit (she was the only one who knows sign language, and could sign for me and Eric), Eric started to quit too! I know his reasons, but for me I decided to stay there longer.

Anyway, it helped me a lot taking karate classes, been going to tournaments, been improving myself, pushing my limitations, learned about the 'I Can I Will' poster thing. It improved some of my flexibility, improved my balancing issue, and I think it has made me mature, calm, relaxed, and more responsible too! I started working for Kyoshi [one of the teachers], and it also helped me too! I have been improving my diets better, trying to cut back on junk and sweet foods, be more responsible and hard working on the job.



Chip, showing off the trophy he won at the 2009 Te-Kenjutsu-Kan 7th Annual Cup Food Drive Karate Championship.

Continued on next page



**"I don't give
up that easy,
I Can...and I
Will!"
-Chip Dixon**



(continued from page 5)

Whenever I'm at any kind of classes, or other places I'm at, I'm always in the front of everyone because of my vision and hearing problem, so I can see and hear better. I guess it's an old habit I been doing for a long time now. One of my sensei (or shihan) knows a bit of sign language, sometimes he'll say water break in sign language! Kyoshi doesn't really know sign language, but that's okay with me. I can hear him just fine, only low voices and far away/distance voices are hard for me to hear. I can also lip read- too. Anyway, taking karate class has changed my life, and working there too! I have become more responsible and more mature, focused and calm too! I also have to break some habits, control some obsessions, and I'm doing better every day now.

Future of karate...well I'm working on getting my next belt right now. And also, I'm thinking of becoming a kohai or shihan [master teacher] someday, to teach kids with special needs and adults someday. Maybe I will teach some people who are deaf/hard of hearing some karate too! One of my hearing friends is taking karate, and she is training to be a kohai! So yeah, karate is here to stay, I found my true calling, found something I'm good at for a change. It changed me to a better person, changed my life, and I'm not a quitter! I don't quit, I don't give up that easy I Can...and I Will!

Supporting Young Adults with CHARGE Syndrome toward Successful Transition to Adult Life - *10 Tips for Parents*

Dr. Jerry Petroff

The transition from school to adult life for youth with CHARGE syndrome very often evokes the memories and experiences that parents went through in the beginning of their child's education. These are feelings of fear, uncertainty and sense of not being in control, again. Therefore, it is extremely important that appropriate steps are taken to manage this transition as smoothly as possible. These young people with the most complex and specialized education needs require specific efforts in both transition planning and its associated programming. Although this group of youth spans the entire spectrum in degree and variety of disability, there seems to be a set of similar practices that need to be considered for all. The following represent the basics for promoting successful transition to adult life for individuals with CHARGE:

Start Early - Although the federal regulations mandate planning for the transition to adult life to begin at age 16, for young people with CHARGE syndrome it must start much earlier. This planning process is best initiated in late elementary and early middle school years. During these early years, children are provided experiences that will show their talents and build their skills and abilities.

Expanding preferences and interests - Many children with CHARGE syndrome demonstrate a narrow set of interests and many times they focus on very specific topics. This is the time to begin to provide them with well planned opportunities to experience a wider variety of age-appropriate activities reflecting varied interests and preferences. Since variety is often met with resistance, it is better to be systematic and deliberate in your transition planning.

Assure that your IEP is transition friendly - Very often IEPs are written to assure that each component is represented and therefore, schools tend to check off that they have identified a post-school outcome and that planning toward it has occurred. However, the reality sometimes shows that the goals and objectives of the IEP are not congruent and may even be disassociated from the desired outcomes. It is best to ask yourselves, how does this goal relate to my son or daughter's adult goals and outcomes?

(continued from page 6)

Conduct a person-centered plan - Person Centered Planning (PCP) is a process designed to assist you and your child to plan a future that is congruent with your values, desires, and personal goals. It is a flexible planning process that supports areas of growth such as self determination, independence and overall attributes of quality of life. At the beginning of the formal transition planning period (which should be by 14 or at least 16 years old), parents should participate in a person-centered planning process that includes their son/daughter.

Make sure your child is building a resume - A well planned secondary education for young people with CHARGE syndrome should present opportunities for learning that can be documented in a portfolio of accomplishments. Many youth with CHARGE do not clearly present their talents, skills and experiences. Therefore, building a resume or portfolio is a critical component of their transition planning process. In addition, the portfolio will show where there are gaps that need attention or demonstrate future needs for further education and training.

There are no prerequisites for Community Based Instruction - The benefits of gaining and practicing skills in "real life" situations or within the community is well documented for all students with disabilities. Due to the perceived difficulties that some youth with CHARGE present, they may be determined as "Not Ready" for community-based instruction. It should be noted that there are no prerequisites for developing and implementing a community-based instructional program barring medical conditions or under circumstances in which parents and school personnel feel it is unwarranted. Youth should be experiencing instruction within their communities in the form of job samplings, career awareness, and recreational activities.

Insist on Career Development - All students in secondary education should build from their primary education knowledge of careers and have deliberate instruction focusing on a possible career path that they may enter.

Make "real" linkages - It is critical for the all youth with disabilities to be linked to adult services and supports as well as to community partners that may benefit their transition to adult life. For youth with CHARGE this is a huge factor in assuring successful adult outcomes. Many students have interveners or personal assistants as well as a variety of supports ranging from assistive technology devices to specialized medical needs. Therefore, it is important to link to adult service agencies to assure that these supports are maintained into adulthood.

Continuing education should be a post school goal for everyone - It is recognized that furthering your education is key to building a successful adult life; therefore, youth with CHARGE should plan for some type of post school education including the consideration of college. There are a growing number of college programs that are designed for youth with developmental and intellectual disabilities and therefore, a range of opportunities are available. These include everything from full 4-year college programs to adult school opportunities. However, it is important to identify and make contact with these programs while the youth is in transition.

In summation, this list of tips or things to consider are presented as a "good beginning" to your consideration of the transition planning and associated educational program for youth with CHARGE syndrome. There are many available resources for parents and teachers that address the overall process of transition for students with disabilities such as the National Secondary Transition Technical Assistance Center (<http://www.nsttac.org/>). Remember, it does not matter where you begin planning for the future - JUST BEGIN.

Dr. Petroff is an Associate Professor at the College of New Jersey in Ewing, NJ. He is also the director of the NJ Deaf-Blind Project. Dr. Petroff's research interests include transition to post-secondary life for students with severe disabilities, early communication and family life. He has been on faculty since 2001. He has recently authored the textbook *Assistive Technology in the Classroom: Enhancing the School Experiences of Students with Disabilities* published by Prentice Hall.



"There are many available resources for parents and teachers that address the overall process of transition for students with disabilities..."

Transition Training Opportunities



Free webinars from
PEATC 2010

*“...it does not
matter where
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planning for the
future - JUST
BEGIN.”*

-Dr. Jerry Petroff

The Genetic Alliance (www.geneticalliance.org) provided the following information on upcoming transition training opportunities:

1.) PEATC 2010 Transition Webinar Series

The PEATC 2010 Transition Webinar Series began Monday, March 1. All webinars are free and will be archived within 3 business days of initial broadcast for future reference/access. CEU and CRC credits are offered for this transition webinar series. Even if you cannot join on the scheduled days, please register to access the archives of this nationally recognized transition resource.

<http://www.nextsteps.peatc.org/peatc.cgi?template=webinars>

Information on the 2008 and 2009 archived webinar series may also be found at the above link.

2.) The Pathway from High School to a Career: Promising Strategies, Supports, and Partnerships in Secondary Transition 2010 Research to Practice Series

The 2010 Research to Practice Series from the UNH Institute on Disability focuses on several unique strategies for developing effective, outcome-based educational experiences that promote the successful transition of students with disabilities and students at risk to their chosen post-secondary experiences. The sessions feature distinct content and objectives, including student-directed models support the development of career goals, sector-based strategies that link high school programs to employers and post-secondary education, ways to use assistive technology to improve educational and employment outcomes, and a school-wide framework that allows educators, parents, and students to utilize the emphasized high school reform. Please see the individual workshops below for more information.

Assistive Technology and Transition <<http://iod.unh.edu/events.html#rtp3>>

Date: Thursday, April 15, 2010 | Time: 9am to 3pm

Registration Fee: \$75

Instructor: Therese Willkomm

High School is Transition: A Framework for Reform that Allows Schools to Educate All Students <<http://iod.unh.edu/events.html#rtp4>>

Date: Thursday, May 13, 2010 | Time: 9am to 3pm

Registration Fee: \$75

Instructor: JoAnne Malloy

Location: Holiday Inn, 172 North Main Street, Concord, NH

Full workshop descriptions, presenter information, and online registration: Visit <http://www.iod.unh.edu/events.html> or call 603.228.2084.

*Registration fees include continental breakfast, lunch, and materials, except the March 1 session, which does not include lunch.

*Workshops qualify for Staff Development Credits/Contact Hours.

CHARGE in the News from UK and Australia



St John Ambulance award winning cadet Christopher Ayers, 15. picture by Jennifer Burton.

Royal Reception for Christopher

This article appeared in the Isle of Wight County Press Online on November 28, 2009. The article can be found online here: <http://www.iwcp.co.uk/news/news/royal-reception-for-christopher-30003.aspx>

By Jon Moreno

A teenager left disabled by a rare life-threatening condition, received a personal congratulation from Princess Anne at Buckingham Palace this week when honoured for his achievements with St John Ambulance.

Christopher Ayers was one of 45 young people from around the country to attend the reception, which recognised the commitment of St John Ambulance badgers, cadets and young carers made throughout the year.

During Wednesday's Young Achievers' reception, the 15-year-old cadet chatted to the Princess Royal about his experiences, what he enjoyed most about volunteering with St John Ambulance and his aspirations of becoming a paramedic.

Christopher, of Colwell Lane, Freshwater, who joined St John Ambulance two years ago and who received the charity's IW Cadet of the Year award, was born with Charge Syndrome, a rare, life-threatening condition which affects different parts of the body.

The St George's School student has managed to complete first-aid training and other modules while coping with a heart condition, breathing through a permanent tracheotomy, profound deafness and impaired sight and hearing.

He said meeting Princess Anne was very exciting and he is delighted he will soon receive a Young Achievers' Award.

"I enjoy the training and have made a lot of friends. It has given me a lot of confidence," he said.

Christine Stratton, commissioner of the IW branch of St John Ambulance, said the decision to nominate Christopher for this year's award was a unanimous one.

"When you consider the number of medical conditions he has, Christopher has been brilliant. He's always enthusiastic about everything he does and likes to participate in all he possibly can," she said.

"I enjoy the training and have made a lot of friends. It has given me a lot of confidence."

A tough year ends on a high for Ringwood North boy

This article appeared in the Manningham Leader on December 19, 2009. The full article can be found here:

<http://manningham-leader.whereilive.com.au/news/story/a-tough-year-ends-on-a-high/>

A BRAVE little boy was given the chance to fly high after battling through a tough year.

David Sedgwick, 11, saw what life was like at the top when his mates at the Wyena Pony Club treated the Ringwood North youngster to a helicopter ride.

Suffering from a rare condition called CHARGE syndrome, David has spent most of the year in and out of hospital. But his friends at the South Warrandytepony club organised the special day so he could finish the year on a high note.

In 2007, the Make a Wish Foundation granted David's wish of owning a horse and he now spends most of his time with his four-legged friend Josie at the pony club.

David's condition means he has hearing and vision problems, a silent heart murmur and difficulty keeping solid food down. This year, David was also struck with pneumonia and hair loss condition alopecia.

His mum, Debby Sedgwick, said doctors often attributed David's rapid recovery during hospital stays to his desire to get back on his horse.

"The pony club have been absolutely wonderful to us and the helicopter ride was a really magical time for David. He loved it," Mrs Sedgwick said.

"It has been a tough year, but David has always kept a smile on his face, but it was even brighter that day after the generosity of the pony club."



David Sedgwick's friends at the Wyena Pony Club treated him to a helicopter ride.

Strategies for Supporting Multi-Modal Communication:

Practical Pointers for Families

Dr. Susan M. Bashinski

Families of children and adolescents with CHARGE syndrome frequently report that development of an effective communication system for their child is one of their top priorities, if not their single most critical concern. This article is written for families whose children struggle the most with communication—those children and adolescents who neither speak nor sign, or who demonstrate only a very limited number of spoken words and / or expressive manual signs.

Building an effective communication system for any child begins with a belief—a belief that the child *is* already communicating! Whether it's a family or an educational team, the most significant first step is commitment to the idea that the child's communication partners are responsible to "meet the child where she is"—and figure out what the child is currently communicating through her behavior. A communication partner's pledge to "listen with more than just ears" (that is, to *listen* with eyes, hands, and heart) and to assign meanings to the behaviors a child demonstrates most frequently is the place to begin.

Participation with augmentative devices

Though it is critical to operate from a belief that every child with CHARGE syndrome communicates, it is also very important for families and educational teams to differentiate "communication" from "participation." It is not uncommon for a special education teacher or speech pathologist to make some sort of voice output device available to a child who does not yet speak or sign, and then provide necessary supports to assist her to use the device to make a comment or provide information. This type of class participation is very important—it not only provides practice for the child in "taking a turn" (so critical to both social and communication development), but even more importantly, it potentially changes the way in which a learner with CHARGE is viewed by her classmates (i.e., it helps her to be perceived as a "communicator"). Such opportunities for participation should be promoted! Even so, it is critical that teachers and families *not* be misled to believe the child's true level of communication development matches the level of the words she "speaks" through augmentation. A misunderstanding of this difference, especially for those children who struggle the most with communication, can have long-term, negative effects—by preventing the child from receiving communication programming directed to her actual needs and instructional level.

Schedules

One effective strategy for helping to build a bridge from participation to true communication is the use of a schedule. Most adults rely on some sort of calendar or planner to organize their days; similarly, a child with CHARGE who does not yet speak or sign can derive numerous benefits from a concrete schedule (American Foundation for the Blind, 2010). A concrete schedule provides structure to a child's day, makes the day's activities more predictable, and results in the world feeling like a safer place to be. A beginning schedule for a child who experiences multiple disabilities will be an adequate support for early communication development if it includes information regarding what the child: has done, is doing presently, and will be doing next. In addition to organizing a child's day, use of a schedule can help to ease the anxiety associated with a transition, particularly from engagement in a highly preferred activity to a lesser preferred activity.

Visual supports

A second key strategy for building communication skills involves



Chat PC – sample of an augmentative communication device

Photo credit: www.saltillo.com

"Building an effective communication system for any child begins with a belief—a belief that the child is already communicating!"

Visual support used to teach order of events.



Photo source:

<http://www.dinf.ne.jp/doc/english/resource/brenda.html>

Continued on next page

the use of visual supports. Though related to schedules, visual supports are more broadly based. Use of visual supports involves the addition of a variety of visual cues throughout a child's activities and environments, to make the abstract language system more concrete. For example, a sequence of photographs could be displayed next to the bathroom sink, to lead the child through washing her hands; a display of object cues mounted on a cabinet door could assist the child to set the table; or photographs of classmates could be used as attendance is taken, to help the child learn classmates' names. The addition of visual elements to the contexts a child

encounters throughout the day can help her to learn there are many different ways to communicate. Visual supports are appropriate for most children with CHARGE because these help to provide a enriched environment for literacy learning; visual supports are even helpful for children who speak or use manual sign who sometimes lose speech intelligibility when they become anxious.

Gestures

A final element critical to the establishment of an initial communication system with a child who has CHARGE syndrome is the incorporation of conventional gestures. It is not uncommon for speech pathologists or special education teachers to "jump" too quickly to try to teach abstract language to a child who does not yet speak or sign. In typical communication development, young children learn and rely on a variety of gestures for communication—long before they begin to speak. Examples include: handing an object to another person for help to activate it; extending an open palm to request an item; and pointing to an interesting object. Families and educational teams are strongly encouraged to not overlook the importance of gestures as a means of expression and, for those children with CHARGE syndrome who do not currently use gestures, to implement a program to systematically teach at least some gestural communication. One strategy with demonstrated effectiveness in this area is adapted prelinguistic milieu teaching (A-PMT). Several video clips that demonstrate A-PMT techniques are available on the internet at: <http://www.nationaldb.org/ISSelectTopics.php> (Malloy & Bashinski, 2009).



"In typical communication development, young children learn and rely on a variety of gestures for communication"

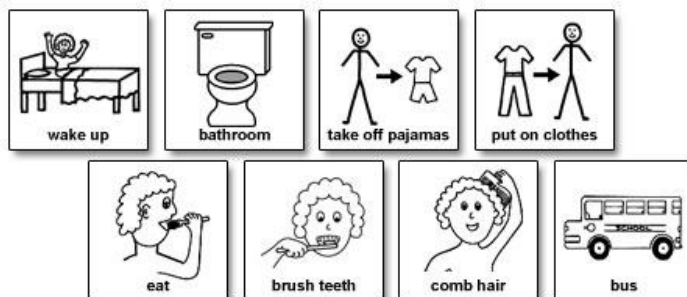
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Dr. Susan M. Bashinski is an Associate Professor at East Carolina University, Greenville, North Carolina with more than thirty years experience in the field of Special Education. She has been the recipient of numerous teaching awards. Dr. Bashinski has extensive experience in providing professional development and technical assistance across the United States, particularly in the areas of augmentative communication and nonsymbolic communication for learners who have low-incidence disabilities, including deaf-blindness. She is currently conducting research on how cochlear implants impact the development of young children with deaf-blindness, and the



Sample of a visual schedule depicting a morning routine.

Assistive Technology from a Parent's Perspective

Jody Wolfe



Ethan, using technology to magnify learning materials

"I am thankful everyday that Ethan was born in time where assistive technology is readily available."

What would we do every day without our e-mail and cell phones? We live in a technology-based world and count on it to stay connected with the world. Technology can give us instant information, but can also take over our lives. Having a child with CHARGE syndrome, I appreciate the many opportunities technology provides for our children.

Recently, I had the wonderful experience of watching my son Ethan win an assistive technology award given by Infinetec, the technology branch of United Cerebral Palsy of Greater Chicago. There were eight other children from the Chicagoland area who shared the honor of winning this award. Each has different disabilities, but their similarity is that they use their assistive technology to help them to learn and communicate. Assistive technology (AT) is any device or service that can provide assistance to anyone with physical or developmental disabilities. AT devices can help with communication, mobility, writing, hearing, vision and activities of daily living, to name a few. AT devices can either be high-tech or low-tech. With all of the attention given to high-tech devices, it is important to remember that low-tech devices can also provide benefit and certainly are more cost effective. Low-tech devices can be as easy as using raised line notepaper, a slant board, or a pencil grip.

Ethan is seven years old and uses among other things a Dynavox, a CCTV (closed circuit television), an enlarged keyboard and magnification software for his computer, a monocular, and a cane. Dynavox is a speech-generating augmentative communication device which allows him to communicate when signing or writing is not an option. For example, Ethan's writing is not very legible because of fine motor delays. So instead of having him write the answers to his math homework, he will answer them on his Dynavox. CCTV allows for magnification of materials. Because Ethan's vision impairment prevents him from seeing at a distance, his magnifier (called an Onyx) has a camera and monitor which allows him to see the teacher and the blackboard even when he is far away from them. With these devices at school, he is better able to participate in educational activities and discussions. It also provides him a way to communicate with more confidence and less frustration. Another very useful resource is Ethan's assistive technology team. They make sure he has all of the necessary equipment available to him.

If your child is not using assistive technology at school, do your research on what technology may be the best for your child. There is so much information on the internet about assistive technology. There may be local seminars that you can attend through your special education school district or in the community. I had the opportunity recently to attend an assistive technology vendor fair sponsored by the Assistive Technology Industry Association (ATIA). At this fair, there were over 100 vendors present displaying their assistive technology products. After spending three hours at the fair, my head was spinning, but I had so much more information about different technology options that are available for Ethan. In Illinois, there is an agency called Illinois Assistive Technology Program (www.iltech.org) which provides alternative financing, device reutilization, and even has a device loan program that you can use to try out a device before purchasing. Check to see if your state offers a similar program.

I am thankful everyday that Ethan was born in time where assistive technology is readily available. Ethan has continued to overcome the many obstacles in his life and I believe the use of assistive technology has played a large role in his accomplishments and progress. He would not be where he is today without technology.



Ethan with his mom, Jody, receiving his Assistive Technology Award

Bittersweet World of CHARGE



Sara Buono

October 18, 2007: My husband and I were in the O.R. awaiting the birth of our first child. I had to have a C-section because the baby was in a breech position. If only that were the only issue we had to face. Nicholas James was born at 2:01 a.m. While waiting for our newborn's first cry, we realized something was terribly wrong. We never got to hear that cry the day he was born. Nicholas James had to be intubated. The Ob/Gyn assured us the baby must have swallowed some amniotic fluid, which is common and everything would be OK.

Nicholas James Buono, whose mother describes him as, "happy, charming and resilient"

Eight hours after Nicholas' birth was when we first heard the words "CHARGE syndrome." CHARGE was suspected because the doctors were unable to pass a naso-gastric tube through Nicholas' nares. We were told that Nicholas had bilateral choanal atresia. Our expectations of a healthy newborn were shattered. This began as what we refer to as "our darkest days."

At two days of age, Nicholas had to be transferred to a children's hospital 40 miles away from our home. This is where Nicholas would undergo his first surgery: choanal atresia repair.

Overwhelmed, heart-broken and scared by everything CHARGE encompasses, we learned that choanal atresia often requires multiple surgeries, the possibility of visible stents and sometimes even a tracheostomy.

Nicholas underwent choanal atresia repair at six days old. Nicholas' ENT, Dr. Parikh, of the Children's Hospital at Montefiore (Bronx, NY) performed the surgery successfully. We were told that we would have to wait six weeks to know whether or not there was a need for further atresia repair. Dr. Parikh ordered the off-label use of Ciprodex twice daily via nares. Ciprodex has antibiotic and steroidal components. This combination helps to reduce the risk of the nares scarring down (which is why so many need multiple surgeries). After a few weeks of Ciprodex, Nicholas was switched to Nasonex due to high BUN and creatinine levels. Those resolved immediately once Ciprodex was discontinued.

With weekly scopes of Nicholas' nares, we heard a resounding "nares are wide open." By week six, we were in the clear. No need for stents or even another surgery. We owe this success story to Dr. Parikh and his use of Ciprodex. We have heard of many horror stories where patients needed up to 12 surgeries for choanal atresia alone. After all the surgeries our kids have to endure, this surgery should be done one time only whenever possible. Our children are at a higher risk for adverse reactions to anesthesia and we should try anything to reduce their exposure.

Although, Nicholas required a trach anyway (due to a depressed respiratory drive), it wasn't due to choanal atresia. This enabled Nicholas to become decannulated at five months of age, bypassing many of the repercussions of having a tracheostomy.

Nicholas has been decannulated since March of 2008. He is a very happy, charming and resilient little boy. He makes a lasting impression on everyone he encounters and leaves them with a smile. This is just one of our many experiences with the bittersweet world of CHARGE.

"Our children are at a higher risk for adverse reactions to anesthesia and we should try anything to reduce their exposure."



It's All About Perspective



Jeanie Colp

It's funny how our definition of success has changed since becoming part of the CHARGE world. MacKenzie recently surprised me with an "I hate you." I was shocked and my mom was mortified; but my shock was with the fact that she said "hate." H's have always been hard for her. I was kind of proud.

Siblings Making a Difference

Skate for CHARGE



Josh, Gabby and
David Sirota

*"We were filled
with so much
pride and joy
that our little
brother shares
the same passion
on the ice."*



Front and back view of a
t-shirt designed by Gabby
Sirota to promote
awareness of CHARGE
syndrome



Letter written by Josh Sirota, on behalf of himself and his sister, Gabby

Dear All,

The word "charge" is defined as "to make an onset or rush as an attack." To our family it means something a world apart. To us it means a syndrome. CHARGE syndrome is a recognizable genetic pattern of birth defects and occurs in around 1 in every 10,000 births world-wide. It is a very complicated, almost cryptic syndrome to understand and, unfortunately, my little 6 year old brother was born with it. CHARGE syndrome affects sensory, physical, medical, and developmental aspects of the body. When David was born, he could not eat and breathe at the same time, he could not hear well or see well and had more surgeries before he turned 3 than all my other family members combined.

This means that David lives a life far different from many other individuals, but so does our whole family. David is considered to be DeafBlind because he has problems with both his hearing and his vision. David wears a cochlear implant in his ear to enable him to hear and he needs glasses to see. Because our brother does not yet talk, we use sign-language to communicate with him and day by day we are striving to learn more signs. David now attends the Deafblind program at the Perkins School for the Blind located near Boston, MA where he is taught both education and essential life skills that will enable him to have a place in our society. You probably have a job and with the help of Perkins, David will eventually be able to have one as well.

I am a hockey player and I always dreamed for David to skate on his own. Because David struggles to keep his balance, I did not think it was possible. But, over the holidays we went ice-skating with my family and decided to let David try to ice skate. We put little skates on his feet and took him on the ice. A miracle happened!!! He was skating with our help. He wanted to keep on going and did not stop for a whole hour. While on the ice, David's face lit up with happiness. His expression just stayed frozen in our minds. We were filled with so much pride and joy that our little brother shares our passion on the ice. This gave my sister and me the idea of having a Skate for CHARGE fundraiser. We are very proud of our brother and believe that with the appropriate education David can do anything. Our little brother David is not alone. He is one of hundreds of kids in New Jersey and thousands across the nation who have CHARGE syndrome. We want others to know about CHARGE syndrome and to know that with the appropriate education, kids like my brother can learn and grow up to be productive members of society.

You may be wondering why we are writing this letter to you. Believe me, it is not to make you cry and feel sympathy towards us. The purpose for this letter is to ask for your support in helping to make our fundraiser "SKATE for CHARGE" a huge success. The money we raise will go towards the education of children with CHARGE syndrome. The CHARGE Syndrome Foundation is a 501(c)(3) organization and your donations are tax deductible. For more information about CHARGE syndrome and the CHARGE Syndrome Foundation please visit www.chargesyndrome.org. Please join us on April 11th at the Mennen Sports Arena located in Morris Township, NJ from 12:15 pm – 1:45 pm. If you are not able to

make it, you can still donate through Charge it for CHARGE online at <http://www.kintera.org/faf/home/default.asp?ievent=324400>.

Thanks so much for your support. Your donation will make an impact on the future of these amazing children who do everything despite all odds!!!

Josh and Gabby Sirota

Wisconsin Dells CHARGE Family Gathering

Crystal really needs to hear back from any families planning to attend as soon as possible to make the arrangements and reservations for the events. The deadline for registration is May 15th, 2010. Below you will find all of the information about what promises to be a great, fun-filled family event.

Our CHARGE family weekend is planned for July 23-26th 2010.

We will be staying at:

Wintergreen Resort

www.wintergreen-resort.com

60 Gasser Rd, Wisconsin Dells, WI 53965

1-800-648-4765

Tell them you are with the CHARGE Family Weekend group.

Rooms are \$109 per night if you stay Friday- Monday, or \$119 a night if you only stay Friday –Sunday.

This price is for a double queen room.

These rooms will be held until 3 weeks before our CHARGE family weekend.

You also get a free pass for each night you stay to the Mt. Olympus water and theme park.

www.mtolympuspark.com



**Please find a
printable
registration
form on the
next page of
the
newsletter.
REGISTER
TODAY!**

Activities for the weekend:

Friday July 23rd at 1:30pm

Knuckleheads Bowling and Indoor Amusement Park 150 Gasser Rd Lake Delton, WI 53940.

www.dellsknuckleheads.com

We will be bowling and having food and drinks. Price is \$8.50 per person. That includes one game of bowling, pizza and soda. I thought this would be a great place to start our weekend were we will all be together and having fun. There is an indoor amusement park in the bowling alley as well -- if you want to do that, it costs extra.

Saturday July 24th

Noah's Ark Water Park 1410 Wisconsin Dells Pkwy, Wisconsin Dells, WI 53965

Open from 9am-8pm

www.noahsarkwaterpark.com



Price is \$29.50 for kids 13 and under, \$31.50 for everyone 13 and older, 2 and under are free. This price includes entry to the water park and our catered lunch. We will also have our own Picnic Pavilion so we can do our g-tube feedings and whatever else needs to be done in private. This is an awesome price and we are still getting a great discount, normal cost to get into the park is \$34 per person.

Sunday July 25th

Wisconsin Dells Ducks Tours 1890 Wisconsin Dells Pkwy, Wisconsin Dells, WI 53965

www.wisconsinducktours.com

Time: TBA

As soon as I know how many people want to go I can book our time and we can all be on the same tour.



Price is \$17.25 for everyone 12 and over, \$7.50 for ages 6-11, 5 and under are free.

This is a wonderful and fun ride on a Wisconsin Dells Duck, ducks can go on land and water. The ride is fun and has beautiful sites to see. I thought these were great things to do as a group and it also give us time to do other things with our own family. If you want to see what else you can do or see in the Dells check out their website at

www.wisdells.com

Printable sign up sheet is on the next page of the newsletter. Hotel cancellation policy is 72 hours notice. Once tickets are ordered for individual events, there are no refunds.

Wisconsin Dells CHARGE Family Weekend Registration Form

Come and join us for a wonderful weekend of fun, food, family and friends!!

Contact person for family: _____

Address _____

City _____ State _____ Zip _____

Phone number (_____) _____ Best time to call if I need to contact you _____

Family members attending:

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Name of family member with CHARGE _____

Email address _____

May I share your info with other attending the weekend?

Yes _____ No _____

Events you will be attending:

Knuckleheads Bowling party (\$8.50 per person)

Number of adults _____

Number of kids _____

Total Cost _____

Noah's Ark Water Park (\$31.50 for >12, \$29.50 for 2-12)

Number 13 and older _____

Number of under 13 _____

Total Cost _____

Wisconsin Dells Ducks Tour (\$17.25 for >11, \$7.50 for 6-11)

Number 12 and older _____

Number 6-11 _____

Number under 5 (free) _____

Total Cost _____

Total cost for all events for your group _____

"I will take care of all the fees and make sure all you need to worry about is coming and having a great time.

Please make sure you make your reservation to get our discounted price before May 15th 2010."

-Crystal Masionis, Event Organizer

Please send your money and forms in to Crystal Masionis by **May 15th, 2010**

2311 N. Lancaster Ln

Round Lake Beach, IL 60073

OR email them to me at crystalm1476@hotmail.com

CHARGE Syndrome Foundation Lifetime Members

THE BOARD OF DIRECTORS FOR THE CHARGE SYNDROME FOUNDATION WOULD LIKE TO ACKNOWLEDGE THE SUPPORT AND COMMITMENT OF ITS LIFETIME MEMBERS.

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“Lifetime members demonstrate their lifelong commitment to CHARGE.”

Continued on next page

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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.

Whether you choose to become a lifetime or yearly member of the Foundation, we appreciate your support and look forward to having you!

Thank You

In Memory of Miles Bryce Sherman

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In Honor of a refuah for our Shira

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On the Special Occasion of Kimi Swanson's birthday

Lynn Swensen

In Honor of all the children with CHARGE syndrome who made me a better behavior analyst

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In Honor of Baby Coco

Dean & Liza Parke

In Honor of "Princess" Finley Roth

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Cari Miller

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Daron Romanek
Neil & Naomi Arnold
Ray Roman

In Honor of Eve Layla Ali

Tracey & Luis Calderon
Danielle Jefferys
Geoff Spilar
Natalie Kemp
Danielle Parker

In Honor of Halyn Jones

Melva Strang-Foster

In Honor of Ami's beautiful little girlfriend

Rebecca, Gil, Nava and Ami Feldman

In Honor of Jim Dever

Rick Bunn

In Honor of Joel Saruski & Family

Michael & Stephanie Gilfarb
Loly Acuna
Jennie & Jeff Bernstein
Jennifer Enslein
Joyce Herman
Karen Saruski
Russ & Jessica Wige
Vivian Mechaber
Carol & Jaime Suchlicki
Tia Helen & Tio Bernie Broide

In Honor of Joshua Kurby

Kelly Faulkner
Rosalie Kurby

In Honor of Justin Murray

Bob Benn
Pam Dowd
Bob & Sally Ells
Nicole Hanchay

In Honor of Kennedy Weir

Lenna McNeill
Joey Ann Baird

In Honor of Kristin Ogan

Wayne & Ruth Metz
Gary Young
Darla Northrup-Tippitt

In Honor of Makenna Susil

Fritzi Gibson

In Honor of Gracie Swann

Alison Burt & Lindsey

In Honor of one of my favourite little patients

Jaime Viau

In Honor of Shira Schwartz & Family

Marina Makovoz
Marina Oganyan
Azriel Novograder PT
Lisa Pollack

In Memory of Glenn Horne

Jane Horne

In Honor of Super Girl Alexis

Catherine Rose

In Honor of Taylor Shott & Family

Sam Schultze
Carol Bonaccorso & friends at Tradition Bank
David Ball
Shirley Bracksieck
Rebecca Underwood
Amanda Canon
Jonni Webb
Gail Stolzenburg
Richard Smith
Marilyn Small
John & Bonnie Shott
Thomas Shacklett
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Kimberly Griffin
Regina Danley
Ray Crosby
Paul & Kara Conrad
Holly Chervnsik
Bonnie Cerny
Joe Belgara
Michelle Bailey
Sarah Spruill
Tim Guhlin

In Honor of the spirit & strength of children with CHARGE everywhere

Lisa Jacobs

In Honor of Trey Chatham

Sandy Chatham

In Honor of Vivian's teachers at JWPOSD: Janet, Alicia and Sayard

Hannah Maniago

In Memory of George E. Robshaw

Marylou Kivler

In Memory of "Mucca" (Sharon Chatham's grandmother)

Dawn McElhaney

In Memory of Miles Bryce Sherman

Karl von Brockdorff
William Croll
Carolyn & David Gordon
Richard Gottscho
Isabelle Guis
Carol Hollander
Brian Mansfield
Adrienne McCallister
Gerald Smith
Rachel Tyler
Roselyn White

In Memory of Richard W. Baumgratz

Mary Ann Baumgratz

In Memory of Ronald Wynne

The Executive Board of the CHARGE Syndrome Foundation

On the Special Occasion of Alexis' 4th birthday

Bridget Butler

On the Special Occasion of Hanukkah

Debbie & Greg Lehmen

On the Special Occasion of Kenneth Sayce's 90th Birthday

Ken & Aileen Sayce

In appreciation of Paul Koppel

Karen Kaunitz

In Honor of Jacob Hartshorne

Alexander Scotford

John & Ruth Wynne

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

CHARGE ACCOUNTS

Thank You

Second Annual CHARGE It for CHARGE Donors

**In Honor of Maxwell McKinley
(Mighty Max)**
Suzanne Holman
Amy McKinley

In Honor of Miles Bryce Sherman
Alissa Reindel

In Honor of Michael Kruger
Cheryl Kruger

In Honor of Matt's Bar Mitzvah
Leonard Stanger
Matthew Stanger

In Honor of Megan Stanger & Family
Barbara Bernard
Robert Cohn
Donald Conklin
Barbara King
Ellen Matz
Shoshana Chazen

Michele Lantow
Gregory Kadair
Paul Koppel
Tasha & Charley

**In Honor of Pam's work with
children and their families**
Linde D'Andrea

Upcoming Newsletter Topics

Having More Children

We are still looking for your stories about conceiving again after having a child with CHARGE syndrome. We are looking for your stories about having or not having another child after your child with CHARGE.

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



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

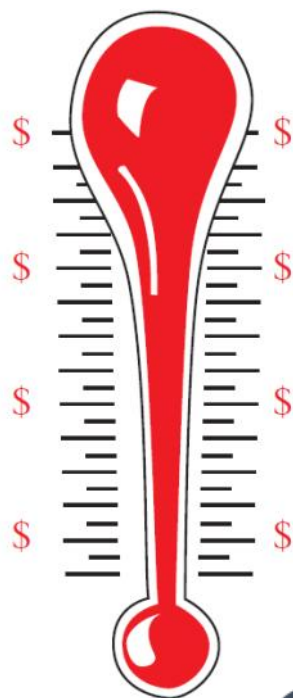
Do you have a story about yourself or your child that you would like to share? A story they wrote or a picture they drew? Send it to me with a picture if possible so we can share in you or your child's accomplishments.



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



HOW HIGH CAN WE GO?



SPRING INTO ACTION!!! There are many ways to help the Foundation reach its goal of raising more than \$100,000 and earmarking another \$50,000 for research and education. Our Second Annual Charge It for CHARGE campaign has raised over \$55,000. If each of our members joins the campaign we can exceed our goal and put even more resources toward research and education.

In addition to the on-line fundraising, spring is a wonderful time to plan an event. Whether you like to run, walk, swim, golf, bike or just get together with friends, you can host an event that interests you! Please contact our fundraising chair, David Wolfe at david@chargesyndrome.org with any ideas or questions.

Let's make a difference for our kids and our families.

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