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President's Message



First of all, I would like to say what an honor it is to serve as the next President of the Foundation. I would also like to extend a special thanks to Neal Stanger for the excellent job he has done as President over the past six years. We are fortunate to have a dedicated group of advisors and board members. With Lisa Weir as Vice President, Brownie Shott as Treasurer, and Neal Stanger as Secretary, we could not ask for a better executive committee.

We have come a long way in the last 19 years and have reached many milestones. However, when I hear the phrase "I have never heard of CHARGE" or speak with a doctor with more questions than answers, I realize we have only scratched the surface in the areas of research and awareness. Together we can, and will, do so much more. However, the Foundation cannot achieve its lofty goals without your help. We need all of you to be active in the Foundation. If you believe it is important to increase awareness, support education initiatives, fund more research, and/or grow the Foundation, please get involved and become a member now! Encourage your friends and family members to join you. Participate in our 4th annual "Charge It for CHARGE" campaign. Host a fundraising event or participate in an event to promote awareness. If you know of a good physician, therapist, or other service provider in your area, fill out our Provider Recommendation form. Sign up for research studies when they become available. Check out our website at <http://www.chargesyndrome.org> for all these opportunities and more. Or feel free to contact me at david@chargesyndrome.org with any questions, ideas, comments, or concerns.

Once again, thank you for the opportunity to help guide this Foundation. I look forward to working with everyone to make the magic from our 2011 Conference carry into 2012. As you enjoy our newsletter and relive or read about some of the special moments from the Conference, I hope you will plan to join us in Scottsdale, Arizona, in 2013.

As we set out to improve the lives of all individuals with CHARGE syndrome one small step at a time, please remember: **IT CAN BE DONE!**

2nd Annual CHARGE Conference Idol Extravaganza

By: Lisa Weir

The first-ever CHARGE Conference Idol in 2009 was a huge hit. As I began planning the 2011 CHARGE Conference Idol, I have to admit that I wondered if we could replicate that same magic. My fears were soon put to rest, however, as 20 superbly talented performers managed once again to capture the hearts of all in attendance with their fantastic performances and displays of talent.

The big winner from the "Stage" category was Rachel Allen, who wowed the audience with her signed rendition of "Firework" by Katy Perry. She certainly had the audience "fired up" as I think everyone was clapping and tapping along during her performance! Other fabulous runners-up from the Stage category included:

- Kristin Ogan, who very elegantly modeled two lovely outfits (move over Kate Moss!) to the timeless classic, "Moon River"
- Katie Garewski, who delivered an inspiring performance of "Over the Rainbow"
- Josh Nunner, who cracked us all up once again with his clever jokes
- Megan Stanger, who would've done Walt Disney proud with her rendition of "There's a Great Big Beautiful Tomorrow"
- Clare O'Toole, who brilliantly sang the theme song from Nickelodeon's *iCarly*, "Leave It All to Me"
- Mary-Kate Partridge, who danced and sang her heart out to Miley Cyrus's "Party in the U.S.A."
- Sam Partridge, who regaled us with his hilarious knock-knock jokes
- Meredith Dwyer, who brought some Broadway to our show by delivering a beautiful performance of "Seasons of Love"
- Rachel Partridge, who would've done the Fab Four proud with her piano version of "Let It Be"
- MacKenzie Cutcliffe, who graced us once again with her amazing voice singing Sarah McLachlan's "Angel"
- Brothers Daniel and Ethan Wolfe, who displayed some great sibling teamwork with their exuberant performance of "Head, Shoulders, Knees, and Toes"
- Philip Wismer, who had everyone's sides splitting with his hilarious story about three good friends
- Last year's Idol winner, Sean Timberland, who tickled the ivories with two great performances: "Minuet in G" and "Checkers"
- Charlotte Cosenza, who displayed some very unique and amazing backward spelling skills
- And finally, Kennedy Weir, who would've done her beloved Justin Bieber proud with an energetic dance she choreographed and performed to his song "Baby"

The 2011 CHARGE Conference Idol winner in the "Stage" category was Rachel Allen, pictured here after being presented with the 1st place trophy.



2nd Annual CHARGE Conference Idol Extravaganza (cont.)

Thanks to the suggestions from previous attendees, we also added a “non-stage” talent component to the show for individuals who wanted to share works of art or other self-created items. The first winner of this category was Jason Jones, who constructed an extremely complex, absolutely amazing Ferris wheel from K’NEX. Close runners-up in the “Non-Stage” category were:

- Abby Martin, who shared her lovely and intricate circular puzzle art
- Win Edwards, who shared a wonderful display of some of his many incredible drawings

Congratulations to all of the performers for the 2011 CHARGE Conference Idol Extravaganza!

I would like to close by extending a few well-deserved thank-you notes:

- To Sheri Stanger: You did a bang-up job of emceeing our show for the second time. I can’t imagine doing it without you!
- To the judges—Rob Last (all the way from Australia!), Marianne Riggio, and Celie Harris: This is not an easy task, and you all did a superb job of addressing each of the performers and making sure everyone felt like a star!
- To Pamela Ryan and Betsy Bixler: Thank you so much for helping organize our stars and for getting everyone going in the right direction and at the right time. You certainly helped to keep everything running smoothly!
- To MacKenzie Colp: Thank you so much for agreeing to carry all of the signs across the stage so everyone could read the names of the performers. You certainly got your exercise and did a fantastic job!
- To Matt Stanger and Josh Murray: Thank you for helping out with all of the backstage duties. You were both such a big help!

I’m looking forward to seeing what amazing talent the 2013 CHARGE Conference Idol in Arizona has in store for us!

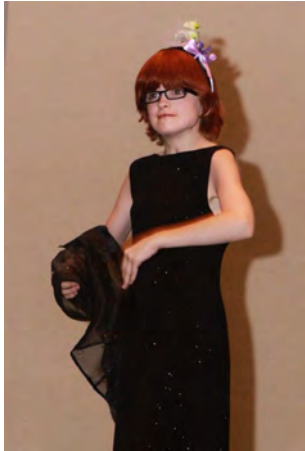


The 2011 CHARGE Conference Idol winner in the “Non-Stage” category was Jason Jones, pictured here with his 1st place trophy.

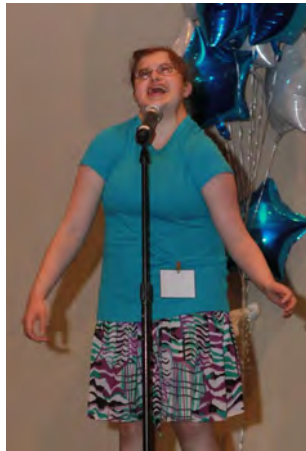


Pictured are the Idol judges, from left to right: Celie Harris, Rob Last, and Marianne Riggio.

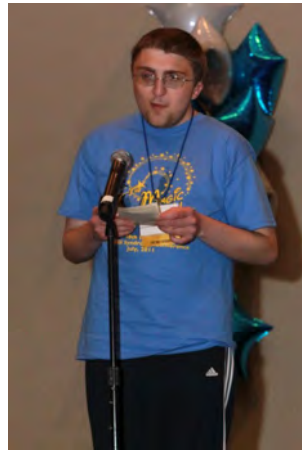
Meet the “Stars” of the 2011 CHARGE Conference Idol Extravaganza...



Kristin Ogan



Katie Garewski



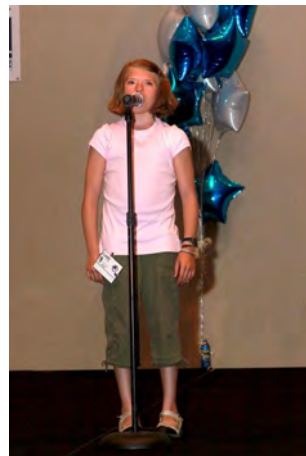
Josh Nunner



MacKenzie Colp



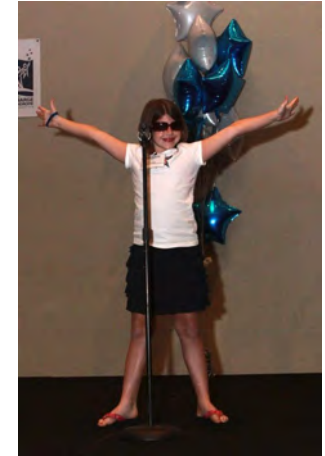
Megan Stanger



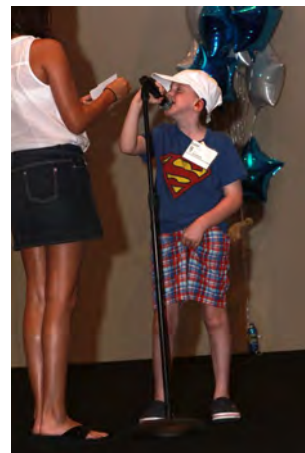
Clare O'Toole



Rachel Allen



Mary-Kate Partridge



Sam Partridge

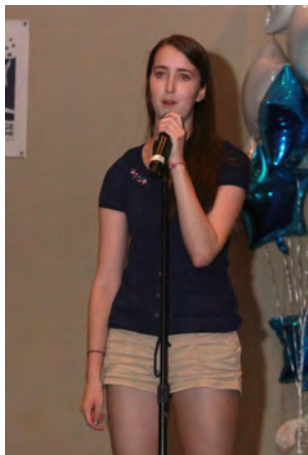


Meredith Dwyer



Rachel Partridge

More 2011 CHARGE Conference Idol Extravaganza Stars...



MacKenzie Cutcliffe



Daniel and Ethan Wolfe



Philip Wismer



Charlotte Cosenza



Sean Timberland



Kennedy Weir



Abby Martin's puzzle art



Jason Jones



Win Edwards

CONFERENCE IDOL PHOTOS BY: MEG MAJORS



Record-Breaking Attendance



See how the conference has grown, from the first in 1993 in St. Louis with 200 people to:

Portland (1995) – 250
 Boston (1997) – 400
 Houston (1999) – 450
 Indianapolis (2001) – 500
 Cleveland (2003) – 492
 Miami (2005) – 540
 Costa Mesa (2007) – 625
 Bloomington (2009) – 756

Orlando (2011) – **850!!!**

There were 40 states and 13 different countries represented, including:

- 160 adults and children with CHARGE syndrome
- 310 parents
- 75 grandparents
- 145 professionals
- 110 siblings

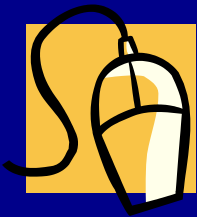
Conference Photos



Meg Majors, our official photographer, took many wonderful photos at this year's conference, which can be viewed at <http://www.majorsphotography.com/charge2011>. Photo orders can be placed directly at the website. If you would like more information, please contact Meg at meg@majorsphotography.com. Thanks again to Meg for donating her time and for the excellent pictures of our magical event!

Breakout Session Highlights

The following pages feature the moderator reports submitted for the majority of the breakout sessions held at the conference. They are meant to be an outline of the presentation, which will give you an idea of what went on in each session. If you are interested in more information, you can download the 2011 conference handouts from the Foundation's website (<http://www.chargesyndrome.org>). Go to Resources, CHARGE Conference Information, and click on "Information about past conferences is available here."



Breakout Sessions

BREAKOUT SESSION: I

“CHARGE 101”

Presenters: Meg Hefner and Kim Blake

Attendance: 85

Moderator: Dorinda Rife

Moderator Report:

Aimed at newcomers to the conference, this session provided an overview of CHARGE syndrome. Topics discussed included the medical and diagnostic criteria and critical areas of management, including BOTOX injections, anesthesia, and sleep apnea.

Dr. Kim Blake is doing a study on sleep apnea and encouraged attendees to enroll in the study.

BREAKOUT SESSION: I

“So Many Ways to Have a Conversation”

Presenter: Martha Majors

Attendance: 138

Moderator: John Reiman

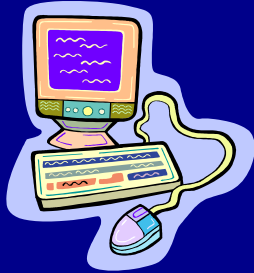
Moderator Report:

The development of communication for children with CHARGE syndrome can be challenging for both the child and his or her team of family members and educators. Martha stressed that the best solutions come from a team approach where several disciplines join together to consider the “whole child” —not only communication but use of vision, hearing, and physical presentation—and total communication.

This was a highly informative session featuring case study information, including a video, that engaged participants at a very practical level. Many people wanted to, and did, ask a seemingly infinite number of child-specific and situation-specific questions. Attendees were invited to talk to the presenter individually after the session.

“...the best solutions come from a team approach where several disciplines join together to consider the ‘whole child’...”





“I felt like I was a small cat walking among the big dogs.”

Breakout Sessions (cont.)

BREAKOUT SESSION: 1

“Technology for Learning and Fun: Using Assistive Technology in the Home and Classroom”

Presenter: Holly Cooper (TX Deafblind Outreach)

Attendance: 79

Moderator: Peggy Malloy

Moderator Report:

This presentation included an overview of assistive technology and computer applications that are both useful and fun in the home or classroom for children with low-vision needs and other challenges. Tablet computers, e-readers, magnifiers, and communication devices were also discussed.

The session included information about adapting toys and appliances for switch activation, as well as easy-access computer games, for individuals with fine-motor difficulties.

Members of the audience had lots of questions and shared their own knowledge and experiences with a variety of devices.

BREAKOUT SESSION: 2

“CHARGE: Personal Case Study of Post-Secondary Transition”

Presenters: Christopher Sence and Kathleen Sheriff

Attendance: 50

Moderator: Beth Jordan

Moderator Report:

Chris Sence, a college senior with CHARGE syndrome, shared his secondary and post-secondary successes and the learning opportunities, strategies, and interventions he experienced in high school leading him toward his post-secondary goal of achieving a college education. Chris, 29, is set to graduate from San Houston State University in December 2011 with a degree in Technical Theater.

Chris, who graduated from high school at age 20, described how he had one true friend in school. In Chris’s words, “I felt like I was a small cat walking among the big dogs.”

Some of Chris’s secondary and post-secondary successes mentioned were working part time, volunteering in his community, being the team manager for the wrestling team, being the statistician for the school’s baseball team, and being a leader in the Deaf-Blind Young Adults in Action (DBYAA).

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Breakout Sessions (cont.)

BREAKOUT SESSION: 2

“CHARGE: Personal Case Study of Post-Secondary Transition” (cont.)

Chris’s mother, Kathleen Sheriff, shared her decisions regarding his transitions and the past and current support he receives from his family. She discussed how Chris uses his OCD tendencies as strategies to keep his life organized, and that the key was to allow Chris to mature and learn in his own time (it has been ten years between Chris’s high school graduation and his college graduation). Her fitting description of Chris was that he is a “take-charge” person with CHARGE.

Chris has been dating a young lady for nine months and plans to relocate to Austin after graduation to be near her and to find a job.

BREAKOUT SESSION: 2

“CHARGE 102”

Presenters: Sandra Davenport and Rob Last

Attendance: 88

Moderator: Dorinda Rife

Moderator Report:

Dr. Sandra Davenport showed parents a simulation activity on how colobomas affect visual functioning. She also explained how early eye and ear development are different for in-utero babies with CHARGE. She touched on how sensory impairment might affect a child in the education setting.

Rob Last spoke about speech and communication and what might be important at birth with crib placement and interactions. He gave general information about acquiring sign language and also discussed communication and behavior and various communication challenges.



“Under conditions of stress and sensory overload, individuals with CHARGE are likely to find it difficult to self-regulate and easy to lose behavioral control.”



Breakout Sessions (cont.)

BREAKOUT SESSION: 2

“Problems with Self-Regulation and Behavior”

Presenter: Tim Hartshorne

Attendance: 117

Moderator: Rick Ogan

Moderator Report:

Handling stress is much different for individuals with CHARGE. Their mechanisms for coping vary, and their thresholds often change. Under conditions of stress and sensory overload, individuals with CHARGE are likely to find it difficult to self-regulate and easy to lose behavioral control. This presentation explored difficulties with self-regulation of thinking, behavior, emotions, and sensory systems. For each area, it examined how parents, teachers, and other adults can plan and organize activities to support the development of self-regulation.

BREAKOUT SESSION: 2

“A Disturbance in the Force: Sensory Processing Differences”

Presenter: Kate Beals

Attendance: 137

Moderator: Donna Consacro

Moderator Report:

To an attentive crowd, Kate Beals shared her professional and parental experience about the impact of sensory information gone awry. Kate gave a rundown of the seven sensory systems; how individuals with CHARGE syndrome often have differences in the way they receive, process, and integrate information from the seven sensory systems; and what might happen in a child with CHARGE when those systems either overcompensate or underperform. She explained how children with CHARGE syndrome may not experience the world in the same way as their parents, family members, and friends do, but understanding the sensory differences may lead families to better comprehension of some of the behaviors that occur when a child has CHARGE syndrome.

Kate’s humor and her personal affection for children with CHARGE came through in this most-informative session. Families and professionals gained valuable information in helping them understand why sensory issues cause problems, how those problems might manifest, and how to accept the compensatory tactics that children use to address their sensory issues.

Breakout Sessions (cont.)

BREAKOUT SESSION: 2

“Understanding My Team: The Roles and Responsibilities of the Team Members”

Presenter: Gloria Rodriguez-Gil

Attendance: 18

Moderator: Emily Taylor-Snell

Moderator Report:

Understanding the roles and responsibilities of team members is critical for good collaboration because parents can know what to expect and ask from each team member. It is also critical for parents to understand their own roles and responsibilities within the team so they can become active participants in their child's education.

Some of the roles and responsibilities of various team members were discussed in the session:

Parent

- Is the driving force and the most consistent team member
- Is a unique source of information on the child and on CHARGE syndrome
- Is an advocate for the child



Program Specialist

- Manages individual cases
- Attends educational decision-making meetings
- Helps to develop the IEP with both academic and social goals

Classroom Teacher

- Collaborates with the IEP team
- Ensures accessibility to materials and environment

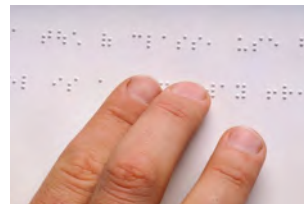
One-to-One Assistant/Intervener

- Facilitates environmental access, communication, and social-emotional support
- Is the bridge/connection between the individual with deaf-blindness and the world



Teacher of the Visually Impaired

- Performs functional vision assessment
- Determines which visual materials are appropriate for student
- Evaluates and modifies visual environment



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Breakout Sessions (cont.)

BREAKOUT SESSION: 2

“Understanding My Team: The Roles and Responsibilities of the Team Members” (cont.)

Orientation & Mobility Specialist

- Teaches how to move safely in the environment
- Teaches how to use other senses to maintain orientation
- Develops adaptations that allow interaction with the public (e.g., communication cards for public transportation)

Deaf-Blind Specialist

- Provides statewide and regional trainings to IEP teams
- Connects team with resources
- Observes the child in his/her natural environment and takes notes, then has a debriefing with the team

Speech-Language Therapist

- Helps with speech disabilities and other communication modalities
- Coordinates with the deaf and hard of hearing teacher
- May help with feeding issues

Deaf and Hard of Hearing Teacher

- Checks functioning of hearing aids, cochlear implants, and FM systems
- Helps with sign language and accommodations
- Helps with language development (spoken and written)

Occupational Therapist

- Assesses/Designs a plan to provide various experiences using motor and sensory activities
- Works on feeding and hand use
- Works on sensory integration and develops a “sensory diet” to help create an arousal level to assist with learning

Physical Therapist

- Works with large muscles to help with posture, strengthening, mobility, and endurance
- Works on gross-motor abilities

Psychological Services

- Provides evaluations/assessments and interprets results
- Provides counseling
- Assists in the development of positive behavior plans

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Breakout Sessions (cont.)

BREAKOUT SESSION: 2

“Understanding My Team: The Roles and Responsibilities of the Team Members” (cont.)

The educational team should:

- Collaborate as a team and support each other.
- Share good teaching strategies.
- Develop goals/objectives together.
- Ensure the IEP is implemented.
- Meet the unique needs of the student.

BREAKOUT SESSION: 3

“Transition to Independent Living”

Presenters: Tim and Nancy Hartshorne

Attendance: 67

Moderator: Rick Ogan

Moderator Report:

Tim and Nancy’s son, Jacob, has CHARGE syndrome. They wanted him to be a more independent person, so they bought him his own house right next door to theirs. Jacob is able to stay in his own house with caregivers through the Hartshorne’s use of the Michigan Choice waiver program through Community Mental Health for Central Michigan and the state. The program gives the family a portion of the funds that would normally be used to care for Jacob in a state-run facility and instead allow him in-home care.

Tim and Nancy gave some background information about their decision to buy the house for Jacob and all the hard work that went into making it happen, including choosing the interveners and implementing a process and schedule. The presentation gave hope for a great transition upon graduation from school.

BREAKOUT SESSION: 3

“CHARGE 103”

Presenters: Meg Hefner, Kim Blake, Sandra Davenport, and Rob Last

Attendance: 75

Moderator: Dorinda Rife

Moderator Report:

This public question-and-answer session was very productive.



Tim Hartshorne speaks at the 2011 CHARGE Conference.

Breakout Sessions (cont.)

BREAKOUT SESSION: 3

“What Worked for You?”

Presenter: Marlyn Minkin

Attendance: 180

Moderator: Deborah Fields-Harris

Moderator Report:

This session allowed parents to share their experiences, ask questions, and discover what strategies other parents may have used in similar situations. Topics of discussion included:

- Communication roller coaster
- Trusting yourself to make decisions
- Behavioral medications and psychotropic drugs
- Sign versus speech debate with cochlear implants
- Obsessive–compulsive behaviors
- Impact of deafness on communication
- Conformers for the eye
- Techniques for wearing hearing aids and glasses in kids with malformed ears, plus surgical options for malformations
- Profound deafness and missing nerves
- Weight issues and suggestion for weight maintenance
- Growth hormone testing and therapy

BREAKOUT SESSION: 5

“Taking Back the IEP and Making It Work for Our Kids”

Presenter: Ellen Steinbrick

Attendance: 41

Moderator: Gloria Rodriguez-Gil

Moderator Report:

This session started with Alex, Ellen Steinbrick’s 13-year-old son who has CHARGE syndrome, discussing his college dreams and life activities.

Ellen Steinbrick stressed in her presentation to use clear and specific language in the IEP, and she talked about four pages in the IEP that are critical:

Page 1. Prior written notice

- Defines the services that have been suggested and, if there are some that have been refused, clearly specifies why they refuse to provide them (i.e., what information they based the refusal on)

“...use clear and specific language in the IEP...”

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Breakout Sessions (cont.)

BREAKOUT SESSION: 5

“Taking Back the IEP and Making It Work for Our Kids” (cont.)

Page 2. Present level of achievements and concerns

- Lists the child’s strengths, concerns, and how the disability impacts the child’s ability to access the general education curriculum

Page 3. Program accommodations and modifications

- Lists modifications and accommodations to help the student make progress and be involved in general education
- Addresses what, when, how, and who will implement them

Page 4. Special education, related services, and regular education

- What are the goals?
- Who will implement them?
- How often?
- Where will the services take place?

BREAKOUT SESSION: 5

“Bringing You Protected Tomorrows: Your Journey Through an Eight-Step Special Needs Planning Program”

Presenter: Mary Anne Ehlert

Attendance: 76

Moderator: Rick Ogan

Moderator Report:

Mary Anne is the head of Protected Tomorrows, Inc., an advocacy firm that enhances the lives of people with special needs through a comprehensive life-planning process. She is a mother and has a sister with special needs. She was a wonderful presenter, and her presentation discussed the whole picture of a “whole life.” The presentation was very helpful to those who draw Social Security/Disability Income.

Topics included:

- How to create a map of the future
- How to prepare legally and financially
- How to incorporate and maximize government benefits
- How to prepare for transition



Breakout Sessions (cont.)

BREAKOUT SESSION: 5

“Creating Calm from CHARGE Chaos”

Presenter: Catherine Rose

Attendance: 60

Moderator: Donna Consacro

Moderator Report:

As a mother of a child with CHARGE, Catherine discussed strategies to simplify managing medical care, build an outstanding team to address children's needs, and create calm out of CHARGE chaos. She shared tips on organizing information; sharing information with team members; and managing multiple problems, events, activities, etc. Her main message was to encourage families to organize and share up-to-date information with team members as a time-saving and chaos-reducing strategy.

“...organize and share up-to-date information... as a time-saving and chaos-reducing strategy.”

BREAKOUT SESSION: 5

“Molecular Studies to Uncover the Cellular Functions of CHD7”

Presenter: Peter C. Scacheri

Attendance: 46

Moderator: Susan Green

Moderator Report:

Dr. Scacheri spoke about his lab's work using advanced genomic technologies to explore the functions of the CHD7 protein. He showed that CHD7 binds to many places on DNA in the cell and regulates the expression of several thousand genes, many of which orchestrate development of tissues that are affected in CHARGE syndrome.

Gabe Zentner, a graduate student, presented work showing that CHD7 is contained within a specialized compartment in the cell nucleus, called the nucleolus, where it regulates the production of ribosomal RNA, a critical part of the cell's protein-making machinery essential for cell growth, especially during development.



Graduate student Stephanie Balou presented her use of zebrafish to model CHARGE syndrome.

Research assistant Cindy Bartels gave information about a new sequencing technology that can be used to rapidly and cheaply detect CHD7 mutations.

Breakout Sessions (cont.)

BREAKOUT SESSION: 6

“Toilet Training and CHARGE Syndrome”

Presenter: Laurie S. Denno

Attendance: 82

Moderator: Gloria Rodriguez-Gil

Moderator Report:

This session described how to toilet train a child who has CHARGE syndrome.

Laurie pointed out that 30 percent of children with CHARGE syndrome have structural or functional limitations that inhibit their ability to be toilet trained, so it is important to evaluate the child for these problems before attempting toilet training.

Laurie gave two main approaches for toilet training: (1) wait until the child is ready and (2) rapid toilet training. Laurie stated that she prefers the second approach.

She pointed out some facts that parents should be aware of before attempting toilet training, such as most children regulate bowel movements before urination and daytime continence happens before overnight continence. Some prerequisites that the child should display before they are toilet trained are that they should be able to sit for 5 minutes, should be able to follow one-step directions, and should have periods of dryness for 1–2 hours.

Laurie said that parents should plan accordingly by purchasing the equipment and materials (e.g., potty seat, potty chair, seatbelt, etc.) they’ll need in advance. (Equipment and materials for potty training can be found at <http://www.pottysolutions.com>.) All the equipment and materials should be left in the bathroom so that access will be immediate when needed.

To motivate the child to toilet train, Laurie offered the following suggestions:

- Read or sign social stories related to toilet training.
- Have a schedule for the child.
- Use dolls to model.
- Tell the child: “You’re a big boy(girl)!”
- Talk to the child about the new, exciting toilet training program.

She stated that toilet training takes a lot of time, so parents should be sure to choose a time when they are not stressed out. Parents need to be relaxed and give their undivided attention to the child. Also, toilet training should occur at a time when the child is healthy.



“...toilet training takes a lot of time, so parents should be sure to choose a time when they are not stressed out.”

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**“Practice
makes a
difference!”**

**“The vision should
describe what will bring
the person satisfaction,
purpose, and joy.”**

Breakout Sessions (cont.)

BREAKOUT SESSION: 6

“Toilet Training and CHARGE Syndrome” (cont.)

When starting the plan, parents should introduce the toilet schedule to the child. For example, if the child is dry every 30 minutes, the parent should take the child to the toilet every 25 minutes. Have the child sit for 5 minutes, and if they will stay longer, have them sit for 10 minutes. However, the parent should not insist if the child does not want to stay longer, as the parent should try to make the experience pleasant and fun and avoid any power struggles. Each time the child goes to the bathroom, the parent should go through the entire process of drying and wiping, even if the child does not do anything. With the child’s first success, the parent should give immediate praise and reinforcements (the key being “immediate”). Over time, however, the parent should remove the reinforcements. After the child becomes acclimated to using the toilet, the parent should teach him/her to wipe.

Laurie mentioned that accidents are bound to happen. If the child does have an accident, she offered the following suggestions on how a parent should best handle it:

- Stay calm and do not reprimand.
- Sit the child on the toilet for 1 minute and go through the whole process, even though you know he/she already went.
- Change the child on another chair in the bathroom rather than on the toilet.

Laurie pointed out that special considerations should be taken in regards to children with CHARGE syndrome. For example, boys should sit during toilet training. Once the child is trained, then the parent can teach him to stand up and use the toilet. Also, if the child has balance or low muscle tone issues, the parent should consider using a seatbelt and/or a potty chair with arms and a foot stool or foot rest.

*The conclusion from the presentation was: **Practice makes a difference!***

BREAKOUT SESSION: 6

“Using Person-Centered Planning to Enhance Transition from School to Adult Life”

Presenter: David Wiley

Attendance: 30

Moderator: Betsy McGinnity

Moderator Report:

This session discussed how transition planning and establishing transition goals are mandated by IDEA. Real, meaningful goals should be based on a vision of the future and should be in the IEP by age 16. The vision should describe what will bring the person satisfaction, purpose, and joy.

(continued on next page)

Breakout Sessions (cont.)

BREAKOUT SESSION: 6

“Using Person-Centered Planning to Enhance Transition from School to Adult Life” (cont.)

Unlike systems planning, person-centered planning is focused on the individual. Rather than gathering information through formalized assessments, person-centered planning gathers information through personal stories. Person-centered planning teams include all kinds of people—neighbors, friends, family members, and professionals—who care about the student.

The session’s overall message was that person-centered planning is a tool that families can use to plan for their child’s future.

BREAKOUT SESSION: 6

“Balance Group: Why Does It Work?”

Presenter: Maryann M. Girardi

Attendance: 92

Moderator: Susan Green

Moderator Report:

Maryann, a physical therapist at Perkins School for the Blind, reviewed the mechanisms of balance and gross-motor skills. She presented accommodations, activities, and equipment to use for promoting improvement in balance and gross-motor skills.

This was a great, interactive session! There were many therapists and parents with young children present who asked many questions and provided suggestions themselves.

BREAKOUT SESSION: 7

“Children with CHARGE: A Longitudinal Study 1993–2010, A Film”

Presenter: Rob Last

Attendance: 130

Moderator: Peggy Malloy

Moderator Report:

Rob showed videos of four children taken from a DVD that he created (the DVD includes ten children). The children were filmed at three points in time: 1993, 2000, and 2007. The video shows their development and ongoing perspectives about their lives over this time span.

Rob Last presents his “Children with CHARGE” study at the 2011 CHARGE Conference.



Breakout Sessions (cont.)

BREAKOUT SESSION: 7

“No More Confusion About the Transition to Adult Services”

Presenter: Beth Jordan

Attendance: 47

Moderator: Mary Zatta

Moderator Report:

Beth talked about the key differences between high school and adult services entitlement versus eligibility, funding, and individual responsibility.

Beth also discussed the importance of practicing self-advocacy. She emphasized the importance of first identifying the goals and then looking for supports (not the reverse).

Beth shared information about person-centered planning as a means of collaborating with a team of people to create a “dream for the future.”

She also shared a list of services and supports for employment, specifically services provided by Vocational Rehabilitation and the range of employment options.

BREAKOUT SESSION: 7

“My Intervener Is Deaf!”

Presenters: Dottie Snyder and Djenne-amal Morris

Attendance: 8

Moderator: John Reiman

Moderator Report:

This session provided a small and intimate group opportunity to learn about the role/function of interveners and ask practical and situation-specific questions of the presenters and each other.

BREAKOUT SESSION: 8

“Ways & Means: Educating Children with CHARGE Syndrome in Local Schools”

Presenter: David Brown

Attendance: 115

Moderator: Susan Hiscutt

Moderator Report:

There is a widespread and growing myth that children with CHARGE syndrome cannot be educated successfully in the local school system. While it is true that these students might need some very specific adaptations and approaches, there are no obstacles that cannot be overcome if the district is flexible, creative, open to innovative ways of evaluation and teaching, and prepared to collaborate fully with everyone involved with the student.

(continued on next page)

“...there are no obstacles that cannot be overcome if the district is flexible, creative, open to innovative ways of evaluation and teaching...”

Breakout Sessions (cont.)

BREAKOUT SESSION: 8

“Ways & Means: Educating Children with CHARGE Syndrome in Local Schools”

David shared a case study about an 8-year-old girl who he worked with and helped to set up a better school environment for the child. David also shared information about the wealth of resources and literature that has greatly increased in availability for families of children with CHARGE.

There were also discussions about how CHARGE affects ALL of the senses and about how kids with CHARGE self-stimulate and have poor self-regulation and executive function disorders.



David Brown conducts a session on “Educating Children with CHARGE Syndrome in Local Schools.”

BREAKOUT SESSION: 8

“Transition: Parent Panel”

Presenters: Jillana Holt-Reuter, Sandra Mack, Mary Hancock, and Kathy McNulty facilitated the panel.

Attendance: ~50

Moderator: Pamela Ryan

Moderator Report:

Three parents from different parts of the country (Texas, Rhode Island, and Florida) described their experiences with the “transition process” as it related to the particular needs of their young adult (age 18+) children with CHARGE as well as the family’s needs.

Each of the panelists introduced her child and then described where they are in the process: (1) just entering and identifying local, state, and private agencies to plan for the future; (2) recent and ongoing use of local and state agencies to solidify and assure the young adult’s participation in appropriate community and vocational experiences; or (3) a view of “been there” from the mother of a 26-year-old man who is living in a home situation with supports that the family designed with local and state agency assistance.



Parent Panel: Three parents from Texas, Rhode Island, and Florida describe their experiences with the “transition process” and their young adult children.

Breakout Sessions (cont.)

BREAKOUT SESSION: 8

“The Heart and CHARGE Syndrome”

Presenter: Nicole Janssen

Attendance: 18

Moderator: Emily Taylor-Snell

Moderator Report:

This session began with a review of basic heart development in utero. At 3–8 weeks, the heart starts to develop, even before a woman knows she is pregnant. Eight of every 1,000 children born have some type of heart defect. The types of defects range in severity and include structural problems, rhythm problems, and muscle disease. Ten percent of children with heart defects also have other anomalies.

The results of the first large study on the relation between CHD7 mutations and heart defects, based on data of more than 300 patients, were presented. The study focused on data collected since the 2004 discovery of the CHD7 gene.

Questions Used in Study:

1. What is the frequency of heart defects among individuals with CHARGE?
2. What types of defects are present?
3. Do they occur with other CHARGE features?

Results:

1. Of the 345 individuals with CHARGE with CHD7 mutation:
 - 74% have heart defects
 - 26% have no heart defects
2. Of the individuals with CHARGE with heart defects:
 - 27% have septal defects
 - More than 35% have conotruncal defects
 - An exact percentage for atrial ventricular syndrome deficit is unknown, but it is much higher than either septal heart defects or conotruncal heart defects.
3. Heart defects are greater in number in individuals with CHARGE who have tracheo-oesophageal fistula, choanal atresia, and mutation with complete CHD7 gene.



Further study of 50 patients with conotruncal heart defects or AVSD with one additional CHARGE feature is being conducted to find out:

1. If the CHD7 gene is the cause of congenital heart defects in individuals with CHARGE
2. Which additional CHARGE features are most prevalent

Breakout Sessions (cont.)

BREAKOUT SESSION: 8

“National Cochlear Implantation Studies with Children Who Experience Deaf-Blindness: Results for Participants with CHARGE Syndrome”

Presenter: Susan Bashinski

Attendance: 24

Moderator: John Reiman

Moderator Report:

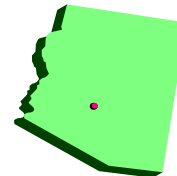
This session presented results from a national study on children with CHARGE who experience deaf-blindness and have received cochlear implants. The results provided data regarding their skill gains and included information specific to factors that appear to be related to communication development, specifically age at implant and “time in sound.”

Attendees were able to ask questions related to implantation and their own children. They also discovered common themes, new information, and novel resources through dialogue with other parents.



2013 Conference

At the Saturday morning general session, the location for the next conference was announced by President David Wolfe. We will be heading to sunny Scottsdale, Arizona, for the 11th International CHARGE Syndrome Conference on July 25–28, 2013.



The venue for the conference is the Fairmont Scottsdale Princess Hotel. Circle the dates and start planning now, as you do not want to miss it!

The conference chair for 2013 is Lisa Weir. Please contact either Lisa (lisa@chargesyndrome.org) or the Foundation office with any questions or ideas for 2013.



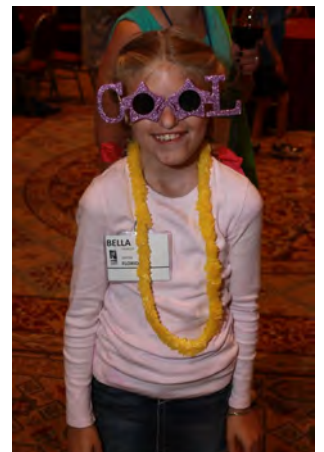
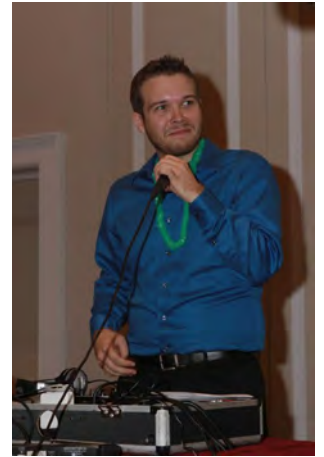
More conference details, as well as online registration, will be available on the website as the date draws nearer.

<http://www.chargesyndrome.org>

2013 Conference City: SCOTTSDALE, ARIZONA!

CHARGE-A-Palooza

On the last night of the conference, everyone enjoyed a fun, festive night of dinner, music, carnival games, and a silent auction. It was the perfect way to cap off a perfect conference!



More CHARGE-A-Palooza Pics...



Personal Account

By: Ellen Howe

After months of planning, I was able to travel from Australia to the U.S. for the first time and attend the 10th annual CHARGE Syndrome Conference in Orlando, Florida, in July. I would like to share my experiences of the trip and the Conference with you.

My friend Sev, her family, my cousin, and I left Sydney on Friday, July 22nd. After a long flight, we landed in Los Angeles. Even though some of my family members said that we'd most likely have problems at Customs due to my feeding pump, going through was a breeze. However, getting to our hotel was another story! We waited and waited for a taxi and finally ended up taking a shuttle bus to our hotel, the Ramada Inn.

While we were in L.A., we went to Disneyland. I enjoyed riding some of the rides and watching the parade. We also took a stroll in Hollywood. It was very interesting! We went to LEGOLAND as well. Everyone we met was very nice and helpful.

From L.A., we took a shuttle bus to Las Vegas. While in Vegas, we stopped at M&M's World, Cirque du Soleil, and a few other places.

Next stop was Orlando. When we arrived, we had some issues with the shuttle buses not wanting to take us due to my wheelchair. After finally getting one to take us, we were all exhausted by the time we got checked into the hotel at 3AM. After catching up on some sleep, we wandered down to the registration area, where I chatted with lots of people and registered. I went swimming and then to the "meet and greet." It was great fun finally getting to meet my friends I had made on facebook and the CHARGE listserv as well as making some new ones.



Friday was the official start of the Conference. I wandered into a Technology session and then went to the "CHARGE 103" session, both of which were very interesting. I went to a few other sessions and then to the CHARGE Idol talent show. It was amazing! Idol highlights for me were Kennedy Weir, Rachel Allen, and Meri Dwyer, but I thought everyone did a great job. I believe it's wonderful to bring out the talent in kids with CHARGE and not focus on their medical problems for awhile. I am hoping we can have a CHARGE Idol at our next Australasian Conference, so if anyone is interested in helping me try to get one together, please feel free to contact me.

(continued on next page)

Personal Account (cont.)

On Saturday, I attended the general session, where they gave out awards and also provided details about the 2013 Conference in Scottsdale, Arizona. Then I went to a Transition session, which was good but was mostly aimed at younger kids. Next, I went to an ENT session. I also went to hear Jeremy Kirk speak about the “P” in CHARGE (puberty) and how it relates to smell. I found this interesting because I have smelling issues due to hormonal problems. Finally, I went to the “Children with CHARGE” video session presented by Rob Last. His video includes me and several of my friends with CHARGE.

I had a great time at the Saturday night carnival. It was a lot of fun looking at everything, dancing, and visiting with all the families.

Sunday was the young adult panel. Everyone loved me and the others. David Brown gave the best closing speech ever. I think I might try to get someone to make him do our next Australasian Conference! LOL

After the conference, I went to the Harry Potter theme park. Being a huge Harry Potter fan, I’ve always wanted to visit there. I loved it!

The next day we flew back to L.A., where we had a layover, and then back home. I slept the entire flight home from L.A.!

It was a great trip! I hope to see everyone in Arizona in 2013!



Me with three of my favorite ladies—board members Leslie Kauffman, Pam Ryan, and Lisa Weir.

2011 Award Recipients



Every two years at conference, the Foundation recognizes those who have made significant contributions (individuals or couples, groups, or organizations) in any of the following areas:

- To the Foundation and its work with service or financial support,
- To persons with CHARGE or their families, or
- To the understanding, management, and treatment of CHARGE syndrome.

The awards include:

1. **Stars-in-CHARGE Award:** This is the Foundation's highest award, which is given for significant contributions over a period of time. The award is a crystal star with the Foundation logo and the name of the recipient(s) etched in the star.

These were awarded to: David Wolfe, Jeremy Kirk, and Susan Wolfe.

2. **CHARGE Recognition Award:** This is the award given by the Foundation for a very significant contribution in any of the three areas listed above. The award is a plaque with the Foundation logo and the name of the recipient(s) engraved on the plaque.

These were awarded to: Eric & Sabrina Bluestone and Nancy Hartshorne.

Waterproof Hearing Aids

After receiving some inquiries about the waterproof hearing aid that her daughter Clare was wearing in the pool at the 2011 Conference, Colleen O'Toole has graciously passed along some information regarding the relatively new waterproof hearing aid that is sold by E.A.R. Inc. out of Boulder, Colorado. Colleen states:

"We purchased the SHS Waterproof Hunter for Clare about three years ago for \$300 from E.A.R. Inc.'s website. Our local audiologist said he could not find us a waterproof aid that came close to this price and that it was worth a try. We have been very pleased with it so far. It has just started to show touches of rust in the battery compartment, but considering Clare swims on a weekly basis, it has had a lot of use. We use double-stick toupee tape (which can be found at beauty supply stores or online retailers such as Amazon.com) to keep it held to Clare's ear since she does not have enough rigid cartilage to keep it in place snugly while she swims. Although it is not as clear in sound as her regular aid, it does have some volume options. We feel she is safer, and she feels she can participate more in conversation."

The SHS Waterproof Hunter retails at \$380 for one or \$730 for a set. Visit E.A.R. Inc.'s website at http://www.earinc.com/shop/product_info.php?products_id=47 for more information on, as well as an order form for, the SHS Waterproof Hunter.

David
Wolfe



Jeremy Kirk



Susan
Wolfe



Eric &
Sabrina
Bluestone



Nancy
Hartshorne



Upcoming Events

Take CHARGE for Alivia 5K Walk-a-Thon

Date: October 22, 2011 from 12 – 4PM

Location: Emricson Park, 898 W. South St., Woodstock, Illinois 60098

We will be raising money for my daughter, Alivia, who has CHARGE, as well as donating 30 percent of the proceeds to the CHARGE Syndrome Foundation.

For more information or to make a donation, please contact Corki Roth at 815-814-7722 or email corkih1208@comcast.net.

Walk-a-thon



6th Texas Chargers Annual Retreat

Date: November 4–6, 2011 (must register by October 7, 2011)

Location: Camp Allen, Navasota, Texas

For more information or to register, please visit: <http://www.texaschargers.org/events.htm>.

CHARGE'd-Up for Golf on Memorial Day

Save the Date: May 28, 2012



Two Steppin' for CHARGE Syndrome

Date: Every Friday and Saturday night

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

We are raising money as well as bringing awareness to people about CHARGE syndrome. One hundred percent of the proceeds go to the CHARGE Syndrome Foundation.

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

Do you have an event you would like to have placed on our Upcoming Events page on the website and/or here in the newsletter? Send it to lisa@chargesyndrome.org.

Do We Have Your Correct Email Address?



Have you changed your email address lately? If so, please make sure we have your current email address so that you are receiving all the news from the Foundation. Send your up-to-date email address to info@chargesyndrome.org.



CHARGE in the News

Get Ready to Wiggle!

Click the link below to read about how Billy Russell, a 2-year-old born with CHARGE syndrome and many other medical issues, received a genuine act of kindness from popular children's group The Wiggles.

<http://www.sunshinecoastdaily.com.au/story/2011/06/08/wiggles-brighten-brave-billys-day/>



CHARGE
Foundation
president David
Wolfe crosses the
finish line at the
Joshua Kurby
Charge for
CHARGE 5K.

Honoring Joshua

For Sandy Kurby, carrying her son Joshua through a troubled, shortened pregnancy was only the beginning of the difficulties in store for her baby boy. Joshua was born with CHARGE syndrome and many other birth defects that led to his death at just 8 months old. In August, a 5K was held to honor Josh's memory and to raise money for the CHARGE Syndrome Foundation. Click the link below for more information on Joshua and the 5K, and read a passage from two of the 5K participants, David and Jody Wolfe, about their son Ethan, who is overcoming the challenges of CHARGE, and what the 5K means to them.

<http://www.dailyherald.com/article/2011/08/15/news/708159881/>

Honorary Pitcher

Click here to read an article about 9-year-old Steffan Zimmer, who was born with CHARGE syndrome. Steffan got to throw the ceremonial first pitch at a recent Toronto Blue Jays baseball game!

<http://www.simcoe.com/news/local/article/1017883>



CHARGE Database

Click the link below to read about how Meg Hefner, a St. Louis University genetic counselor and CHARGE expert, has teamed up with an IT professional and master's degree student to create a global database that will help researchers, physicians, and parents to better understand the condition.

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

Thank You

Donations

America's Charities
 ATDC (Angela's House)
 Belinda Arnell
 Calais Regional Hospital
 Cathie Josephson
 Charles Heald
 Colleen O'Toole
 Constance Marshall
 Crystal Masionis
 Deby Davis – United Way of Kentucky
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 Dominic & Andrea Mediate
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 Pamela Ryan – DeafBlind Program, Hilton Building – Perkins School for the Blind
 Real Mex Restaurants
 Research Library, Perkins School for the Blind
 SAP Matching Gift Program
 Thomas King
 Tiffani Lanting

United Way California Capital Region
 West Community Health Charities
 William Pierce

In Honor of all the brave children in the world with this syndrome
 Natalie Levy

In Memory of Leo Ray Banks, the "Music Man" & Val. Love, Lindsay Fitzgerald
 Tom Fitzgerald

On the Special Occasion of Eli Bluestone's Birthday
 Sid & Barbara Hausen

On the Special Occasion of Eli Bluestone's 80th Birthday
 Larry Herman

In Memory of Norman Bluestone
 Bobbie & Sid Hausen

In Honor of Bryce
 Jenny Mastenbrook

In Honor of Dodge Rockabee Byrne
 Deborah Williams

In Memory of Eleanor C. Devine
 Christopher Droney
 Dominick Castelli
 Dr. & Mrs. Michael Betten
 Eileen & Arney Kaplan
 Faulkner & Boyce LLC
 Helen Raab
 The Injaychock Family
 James Murphy Jr.

In Memory of Eleanor C. Devine (cont.)

John & Pat Droney
 Julia & Thomas Parker
 Julia Marsili
 Letizia Magats
 Linda Bush
 Michael Shaute
 Patrick Clifford
 Paul & Ann Vasington
 Peggy Schepp
 Polito & Quinn, LLC
 Sally & James Germain

In Memory of Eleanor Devine from Mark & Teresa Cordelli and Ann Pascucci and Family
 Mark & Teresa Cordelli

In Honor of Jessica Doolittle. In Memory of Barb Beech.
 Donna Conway

In Honor of Jessica Doolittle and in memory of Freda Vance – great grandmother of Jessica

Arleen & Merrill McCuddin
 Barbara Kimzey
 Bob & Joyce Reynolds
 Diana Burkholder
 Dianne Reuschling
 Esther Johnson
 Gene Smith
 Jeanette & Robert Hagan
 Jerry & Karen Cooley
 Joan Bonham
 Joe & Sonnie Brommel
 Kay & Gary Doolittle
 Kenny & Judy Stills
 LaVon & Clyta Howell
 Mary Jo Belieu
 Marvel Loomis
 Mel & Sue Stills
 Merrell & Marie Mitchell

In Honor of Jessica Doolittle and in memory of Freda Vance – great grandmother of Jessica (cont.)

New Virginia Garden Club
 Nick & Erin Doolittle
 Paul & Joan Stuart
 Riach & Mary Jean Hatcher
 Richard & Anne Kelly
 Sally Hougland

In Memory of Elsie Guentzel, In Honor of Jessica Doolittle
 Donna Conway

In Honor of Jessica Doolittle and in memory of Freda Vance
 Sharon & Jerry Dunkin

In Memory of Freda Vance (1910–2011)
 Pamela Atkins

In Honor of Makenzie Dougherty
 Betty McKnight

In Honor of Braden Dustman
 Lois Hendricks

In Honor of Erika Feather
 Marc Sigismondo

On the Special Occasion of 50th anniversary of the ordination of Rabbi Daniel Fogel
 Eli Bluestone

In Honor of Ruxson Frost
 Your friends at the City of Clayton

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
 CHARGE SYNDROME FOUNDATION

Thank You

Donations (cont.)

In Memory of Ruxson Wade Frost

Maggie Trimbach

In Memory of Alex Gilman

Allison Jones

In Honor of Tyler Hardwick and Family of California

Vacaville Police Officers Association

In Honor of Tyler Himself, and his great family...Jason Matthew's and Family

Jeremy Alford

In Memory of Claire Harris

Lisa Weir

On the Special Occasion of Tyler Hicks' 90th Birthday. Sorry we couldn't be with you for your celebration. Best Regards from Emma & Eli

Eli Bluestone

In Honor of Halyn Jones

Melva Strang-Foster

On the Special Occasion of Becky Klinghofer

Nirupama Soni Abbott

In Memory of Joshua Roy Kurby

Stephanie Klinger

In Memory of Joshua Roy Kurby. We love you always, Happy Birthday!

Rosalie and Chris Kurby

In Memory of Tyler James Matthew

Dawn Szarek

In Memory of Tyler James Matthew...With Love, Alex, Jake & Brody

Shelly Anderson

In Memory of Tyler Matthew and the Tyler Trot runners

Cathy Wynkoop

In Memory of Jo Ann Morgan

Elizabeth Hutton

Van Williams

In Memory of Jo Ann Crabtree Morgan (Judy Robertson's mother)

Chris Kirk – CBRE

Scott Dyche – Trammell Crow Company

In Memory of Jo Ann Crabtree Morgan

Robert and Susan Sulentic

In Honor of Christian

Roberts

Bekkie Cobb

In Honor of Drayson Dane Robertson

Kiffin Collins

In Memory of Muriel Roth, mother of Bell Smith-Downey

Eli Bluestone

In Memory of Emily Roundtree

Bruce Gittinger

Erin Roundtree

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In Honor of Emily Rose

Roundtree

Jan Gaskins

In Honor of Ben & Erin Roundtree & daughter Emily

Mary Carter

In Honor of Ben Russo

Lynn & Trent Martin

In Memory of Miles Bryce Sherman

Rebecca Friedman

In Memory of Mavis Simpson

Jamie & Steve Stratton

In Honor of Nate Stahl

William Hemminger

In Memory of Carlynn E.

Tracey

Annette Shaw

Helen Meade

Mary Jo Kennedy

Pat Moore

Ron & Marjorie Daniels

In Memory of Carlynn

Tracey, grandmother of

Alfredo E. Cordova who has CHARGE

Mary T. Brown

In Memory of Carlynn E.

Tracey, grandmother of

Alfredo E. Cordova who has CHARGE

Helen Roddy

In Honor of Tyler Trot

Kathleen Holtzclaw

In Honor of the Wolfe Family

Arlene Midkiff

In Honor of Jake Wynne

Susan Szanyi

In Memory of Addison Grace Yarborough

Kay Manning

Mary Yarbrough

Sondra Ham

In Memory of Addison Grace

Yarborough – Claxton, GA

Perry & Marie Bacon

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

CHARGE ACCOUNTS

Thank You

Charge It for CHARGE Tributes

In Honor of all parents who are raising children with challenges

Eileen DeSanctis

On the Special Occasion of 2011 Bags Tournament and Raffle

Dafna Aaronson

On the Special Occasion of The Bean Bag Toss Fundraiser

Jody Wolfe

Bauman Family, Israel

Efraim Bauman

On the Special Occasion of Eric and Sabrina Bluestone

Kathleen Parisi

In Honor of the Bluestone Family from GF55 Partners

Shay Alster

In Honor of Zachary Bluestone

Ann Soja – First Sterling

Blondel Pinnock

Chika Yamada – GF55 Partners

Claudia Wagner –

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Daniel Lansen – Compufit, Inc.

David Higgins – MDU

Integrators, Inc.

Don Rathe

Ed Kern

Elio Vecchiarelli

In Honor of Zachary Bluestone (cont.)

Elysa Goldman – Triangle Equities

Frank Anelante

Ira Lichtiger

Janet & Edward Bortz – The

Kislak Company

Jay Seiden

Jody Kass

John Martin – All New York Title

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Richard Singer

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Thomas DeCaro – Benchmark

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In Honor of Zachary

Marni & Eric Majorelle – Alive Structures

In Honor of Zach

Steven Bluestone

For Zachary Bluestone

Donald Capoccia

In Memory of Kenny

Crossman

Lisa Weir

In Honor of Elusia

Janina Staszal

In Honor of Elusia

Beata Boldyrew

Danuta Kulask

In Honor of parents and grandmothers of a wonderful girl

Danuta and Stanislaw Kozieliec

In Honor of Emily

Diane Balsamo

In Honor of Taylor Ferlazzo!!!

Ashley Pruitt

In Honor of Elizabeth Forsch

Marlene and Harold Forsch

In Memory of Alex Gilman

Deanna Steinhauer

In Memory of Hilda Gutierrez

Amory Gutierrez

In Honor of Brian Haberkamp

Holly Lynch

Tim & Mary Hilgenberg

Mary Hilgenberg

In Honor of Aaron Hiscutt

Carol & Matt McGee

Dr. & Mrs. Edmond Alley

Gerald Green, Jr.

John Thompson

Kimberly Ladd

Laura & French Moore

Linda Jones

Margaret Bays

Michael & Jeannette Derum

Robert Keith

Sharon Esposito

In Honor of Aaron Hiscutt – Kingsport, Virginia

Betty Vandiver

In Honor of Aaron Hiscutt's Charge It for CHARGE

Hugh Peterson, Jr.

Sally Poole

In Honor of Aaron, Susan and Steve Hiscutt. God Bless, Kathy & Ray Feagins

Ray Feagins

In Honor of Aaron

Rebecca Feagins

Julie Lunn

In Honor of the Hiscutt Family

Jeffrey Fenyves

In Honor of Aaron, Susan and Steve Hiscutt

Chris and Laura Woods

In Honor of The Hiscutts –

Aaron, Steve & Susan

Phyllis Zeoli

In Honor of special little girl Elizabeth Kijowski

Veronica Galica

In Honor of Elizabeth

Joanna Miskiewicz

Kathy Parys

Leah Toppel

In Honor of Eli Klinghofer

Allison Recker

Amy Mullen

Anne & Jeffrey Penteris

Anola Edwards

Becky and Ilan Klinghofer

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

Thank You

Charge It for CHARGE Tributes (cont.)

In Honor of Eli Klinghofer (cont.)

Beth & Sean Evans
Brenda & Moshe Weitzberg
Carlos Nakazato
David & Carol Thomlinson
David Nehmadi
Debra & Michael Rubashkin
Dori & Dennis Klocek
Drora Kopernik
Dyanne Wallner
Edith & Benjamin Belkind
Edward Goldman
Erica Portnoy
Heather Spiewak
Irina Krop
Jessica & Scott Erickson
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Joanna Williams
Julie & Erik Levene
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Molly & Jason Keppler
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Sandra Applebaum Friedman
Sara & David Efron
Sarah Brady
Stacey & Robert Wolfe
Susanne McHugh
Vered Klinghofer
William O'Mara

In Honor of Eli!!

Angie Schlender
Brandon and Carissa Miller
Christy Compobasso
Igor Elkin
Laura Elder
Vered Klinghofer

In Honor of Mr. Eli Klinghofer!!

Adi Klinghofer
Adi Klinghofer – Prestige
Distribution, Inc.

In Honor of Eli, with lots of love!

Diana Strandberg

In Honor of Eli Klinghofer...

We love you
Laurie Wassman

In Honor of Eli and the Strandberg & Klinghofer Families

Douglas Adolph

In Honor of Eli Klinghofer Bean Bag Tournament

Sandy Kurby

On the Special Occasion of Eli Klinghofer's Bean Bag Tournament

Amy Lund – Springfield Public
School District 186

In Honor of the Klinghofer Family

David Podell

In Honor of the Klinghofer's

Hedy Smith

In Honor of Shelley Ritter- Kozuch's son Taylor

Aejaz Issa – Ai Orthodontics

In Honor of Taylor

Jennifer Gonzalez

In Memory of Josh Kurby. Happy Birthday! Love, The Wayman Family

Miya Wayman

In Memory of Joshua

Charlotte Sopko

In Memory of Joshua Kurby

Sue Bilotti
Trisha Trinco

In Memory of Joshua Kurby – With me always in my heart, Love Grandma

Denise D'Andrea

In Memory of Joshua Kurby. I wish I could be at the race this weekend!

Theresa Sheldon

In Memory of Joshua Kurby. Nonna and Grampa love you

and think of you always
Rosalie Kurby

In Honor of my sweet butterfly Eva Nichole Masionis

Crystal Masionis

In Memory of Carrie McKay

Lisa Weir

In Memory of Philip McNeill

Lisa Weir

In Honor of Kirsten McWilliam

Robin McWilliam

In Memory of Douglas Charles Roth

Marilyn August

In Honor of Princess Finley

Jodi Cyr

In Honor of Beautiful Finley and her new super cute glasses!

Rebecca Feldman

In Honor of Beautiful Finley!!!!

Kristin Galan

In Honor of Finley Roth

Lynne Gapsis
Tracy Roth

In Honor of the AWESOME Ms. Finley Roth!!!

Valorie Hobson

In Honor of Finley

Kristine Moore
Liza Parke

In Honor of Finley Roth who continues to make tremendous progress. Way to go little Princess!

Sylvia Walker

Donated in the name of Finley Roth

Paula Norkus

In Honor of Sami

Claudia Pruitt
Jill Budnick

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION

CHARGE ACCOUNTS

Thank You

Charge It for CHARGE Tributes (cont.)

In Honor of Sami (cont.)

Katee Franson
Landra & Ron Hallock
Mary & Don Knoy
Sandra Decker

In Honor of Sami – From Meredith, Madailein and Margaret

Margaret Walker

In Honor of Alexis Schnaderbeck

Nora Donovan

In Honor of the brave Alexis

Nilton Junior

In Honor of Colin Luke Smith!

Sharon and John Chatham

In Memory of My Godson...Colin Luke Smith

Kathy Altman

In Memory of Colin Smith

James & Elizabeth Mulvey
Laura Kerekes
Victoria O'Malley

In Memory of Colin Luke Smith

Elizabeth Ruszczyk
Lisa Lee
Mary Mills

In Memory of your sweet angel son.

Jennifer Miller

In Memory of our loving son Colin Luke. We miss you son!

Jeanne, Gary & Liam Smith

In Honor of Megan Stanger

Gregory Kadair

In Honor of Megan Stanger and her fabulous family

Suzanne Page

In Honor of Neal Stanger

Jay Olshonsky – NAI Friedland

In Honor of the Stanger Family

Howard Greenberg

In Honor of Sheri, Neal, Matt & Megan Stanger

Ray Imperato – Better Carting Service

In Honor of Dominic Steinhauser

Lorrian Ippoliti
Tia Schoen

Dominic Steinhauser

Billie Hunt

In Honor of Gracie Swann

Brandon Davids
Toby Tullis

In Honor of Gracie Swann. You continue to inspire us with your endless determination! We love you!

Natalie Smalley

In Honor of Gracie baby. May you have ten times more this beautiful occasion of 8 years. We love you.

Rachel Schumacher

In Honor of Gracie Swann – 8 is Great!

Sorry we are late.

Jacqueline Dominick

On the Special Occasion of Gracie Swann

Amy Beth Warde
Kevin Smith

On the Special Occasion to honor and celebrate Gracie on her 8th birthday!

Helen Colburn

In Honor of Sugar Girl! Wow, Gracie. I cannot believe another year has gone and you are 8!! Loved the pics of you at the bubble show. From your Mom's beautiful letter to you, it seems your love just continues to grow. You have an unending supply and you dole it out generously to those around you. I am a little late this year, but you were not forgotten. I was sorry to hear you were sick on your special day. I truly hope you are much, much better. Happy, happy birthday, Gracie. Love you, Judy
Judy Rainbow

On the Special Occasion of Kristi Swann's Birthday

Jacqueline Dominick

In Honor of Preston Swann's 4th birthday.

Jacqueline Dominick

In Honor of Kennedy Weir

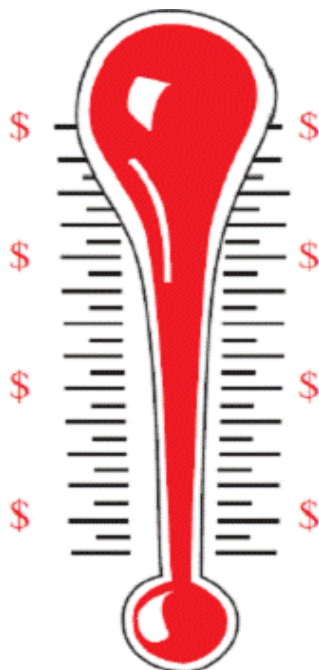
Lisa Weir

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE
CHARGE SYNDROME FOUNDATION



fourth annual Charge It for CHARGE

HOW HIGH CAN WE GO?



Our third annual Charge It for CHARGE campaign is coming to a close. We have raised more than \$90,000! Our fourth annual Charge It for CHARGE campaign will begin soon. Stay tuned for the details in an upcoming email announcement. For those of you eager to get started, go to <http://FourthAnnualCIFC.kintera.org/>.

In addition to the online fundraising campaign, many members have planned fundraising events. If you would like to host an event, we are always available to help you with the details. Please contact our fundraising chair David Wolfe at david@chargesyndrome.org to share ideas or for any assistance. Whether you prefer to run, walk, golf, bike, or just have a party, there is an event that can fit your style!

You can also help the Foundation by making a donation at <http://www.chargesyndrome.org> or by mailing a check directly to the Foundation. No amount is too large or too small.

Please Join Us!

CHARGE Syndrome Foundation, Inc.

141 Middle Neck Road

Phone: 516-684-4720

Director of Outreach

Sheri Stanger

Sands Point, NY 11050
USA

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Phone: 914-479-0079

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Annual Membership

Lifetime Membership

Email: sheri@chargesyndrome.org

Family \$25

Professionals \$40

Silver \$250

Gold \$1,000

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