

New England Consortium for Deafblind Technical Assistance and Trainings presents...

The "CHARGE Lunch Bunch" Monthly Phone Connections

Topics for the 2014 Season

THE PURPOSE: The CHARGE Lunch Bunch phone network will provide a support network for families of children and youth who have CHARGE syndrome. Through discussion of key issues, families from Connecticut, Maine, Massachusetts and New Hampshire will share ideas and strategies in parenting a child with dual sensory loss (deafblindness).

Lead Facilitator: Pam Ryan School Psychologist, Perkins School for the Blind, Deafblind program

March 21, 2014 The Intersection of CHARGE Syndrome, Behavior Challenges, and Mental Health Issues

Facilitator: Laurie Denno, Behavior Analyst at Perkins School for the Blind, Behavior and Learning Consultation

Many students with CHARGE syndrome display typical behavior challenges. They have a tantrum when they don't get their own way or throw their math papers if the work is too hard. These behavior's usually respond well to behavior analytic interventions. However, many students display more unusual behavior challenges such as anxiety behaviors, frequent questions asking, extreme rigidity, sleep disorders, repetitive behaviors that serve no clear function (OCD-like) and aggression and self-injurious behaviors when prompted away from these OCD-like behaviors. These behaviors may respond to behavior analytic interventions but other interventions such as psychiatry and medicine should be considered.

April 16, 2014 What Your Team Should Understand About CHARGE and Your Child

Facilitator: Pam Ryan School Psychologist, Perkins School for the Blind, Deafblind program

Parent Panel: Ellen Steinbrick, Laurie Suter, Karin Dagley

Round Table Discussion - "Members vs. Warriors Team" These three parents will discuss where their children go to school, how they built their child's team and the three different programs they are in.

May 16, 2014 Siblings: Too Important To Ignore

Facilitator: Tina Prochaska, Tennessee School for the Deaf, Communication Specialist/Sibshop Coordinator

The sibling relationship is often the longest-lasting one in the family. Historically, parent support programs have been offered by schools and agencies, with minimal programming provided for other family members. Sibshops, developed by Don Meyer, is an international program that offers peer support and guidance for children who have siblings with special needs. An overview of the Sibshop model will be discussed.

This presentation will cover the advantages and challenges of growing up with a sibling with special needs as well as the role and importance of the sibling relationship. Emphasis will be placed on the importance of planning for the future, making sure that typically developing siblings stay involved in the process. The presenter is an adult sibling of a deaf man and will incorporate personal experiences, as well as current research findings, into the presentation. Special challenges faced by children with siblings who have CHARGE Syndrome will be discussed.

June 6, 2014 CHARGE Syndrome: Quality of Life in Adolescence and Adulthood

Facilitator: Kim Blake, Professor of General Pediatrics, IWK Health Center, Dalhousie University

Testing, Medical Issues, Adolescent Medicine. Very little is known about the quality of life of individuals with CHARGE syndrome during their adolescent and early adult years. Data was gathered both during the previous CHARGE syndrome conference in Illinois, and over the phone and via mail. There were more than fifty respondents, most from the United States. Participants consisted of individuals aged 13 and up. Participants and their parents or guardians gave details, through interview and checklist, about their CHARGE features, developmental histories, medical and behavioral concerns, and independent abilities. They also completed measure of general quality of life and health-related quality of life. Results will be presented and implications about findings will be discussed so that parents and professionals may have awareness of this information when working with individuals with CHARGE syndrome.

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Coming in

September 2014

Advocating for the IEP

Facilitator: Martha Majors, Assistant Education Director, Deafblind Program, Perkins School for the Blind
Common Core Curriculum, Expanded Core Curriculum, and What Parents Need to Know.



To log into the call dial:
1-866-884-0530
7936952279 - To Enter

*Abstract content will be recorded (less the ending parent closed discussion of each call) and posted to the NEC web/wiki site for future viewing.

- Call-in times are: 12:00-1:00 pm. Most calls are on Fridays.
- There is no charge for these calls. Minute use fees may apply from your cell phone if you go over your limit.

OUTCOMES: To increase knowledge of educational and medical considerations for children with CHARGE syndrome, and their families.

BIOGRAPHIES:

Pamela Ryan, Pamela Ryan is a School Psychologist in the Deafblind Program at the Perkins School for the Blind. I have worked with individuals with deafblindness for 42 years--32 of those years as a School Psychologist. Before doing my graduate studies work at Gallaudet University, I worked for several years at Perkins in the cottages (our dormitories) as a Child Care Worker and then as an Assistant Teacher in the classrooms. My work focus as a School Psychologist is primarily educational/cognitive assessment for the students in our program and for individuals who come to our school for an evaluation from various parts of the country. I also have a great interest in syndromes and their impact on education and "life". This has led me to the acquisition of a CAGS in Clinical Genetics through Brandeis University and Simmons College. The students I serve at Perkins and through consulting are deafblind/deaf-multihandicapped with additional handicapping conditions such as ADHD, seizure disorder, chronic health issues, cognitive impairments, behavior/emotional disorders (ie: anxiety, OCD, etc). The students I work with have a wide variety of syndromes all leading to special learning issues and educational needs and in particular, CHARGE Syndrome. I have been a Board Member of the CHARGE Foundation for several years and have enjoyed the privilege of meeting families with children with CHARGE syndrome from around the world.

Laurie S. Denno, Ph.D., is a board certified behavior analyst and a licensed mental health counselor. Laurie has over 30 years of experience working with individuals who have developmental disabilities and developmental disabilities with mental illness. Laurie has worked in public schools, private schools, vocational programs and day habilitation programs. Laurie has testified in educational hearings and conducted behavioral assessments for schools, parents and vocational programs. Laurie works part time at the Perkins School for the Blind as a behavior analyst. Laurie is on the faculty of Simmons College as a supervisor in behavioral education. Laurie also is an instructor in the behavior analysis certificate program at Antioch University New England. Laurie's primary interests are CHARGE syndrome, deafblind education and behavior analytic applications for mental illness. Laurie is a frequent presenter at the biannual CHARGE Syndrome Foundation International Conference and also presents nationally on behavior analytic topics for children with deafblindness.

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Martha M. Majors, Assistant Education Director, Deafblind Program, Perkins School for the Blind. She has worked in the Deafblind Program for more than 40 years. She initially worked as a teacher and has been an administrator for more than 30 years. She oversees learners needs related to IEP, Curriculum, and Curriculum Alignment as well as Expanded Core Curriculum (for state wide curriculum as well as National curriculum) for learners ages 3-22, both day and residential. Martha has trained staff both nationally and internationally to relate all of these areas to the IEP. Martha offers guidance for educators in developing an effective educational program that will improve the emotional wellbeing and success in learning for a variety of learners who are Deafblind as a result of many different syndromes.

Dr. Kim Blake, Dr. Blake has been involved with CHARGE Syndrome for 30 years and presented her first Grand Rounds in 1985 at Great Ormand Street Hospital for Sick Kids in the United Kingdom. She has completed numerous research projects one of which was the Canadian Pediatric Surveillance of CHARGE Syndrome. Her recent research interests are Sleep Apnea, Post-Operative Anesthesia Risk, Botox Use (salivary glands) and Cranial Nerve Involvement in CHARGE Syndrome. One of her greatest pleasures is to attend and present to the families and professionals at the bi-annual International CHARGE Conference. Dr. Blake was awarded the annual prestigious award "Star in CHARGE" in 2006 from these families. Dr. Blake's other academic interests are research in Medical Education, particularly formative feedback and standardized adolescent patients. Dr. Blake is internationally known and is regularly consulted on complex issues CHARGE Syndrome related.

Ellen Steinbrick: Single mom and parent to 16 year old teenager (and I mean teenager) Alex who attends our local public High School he is the manager of the girl's basketball team, getting good grades, he is an active board member for Hear Here Hartford and their teen activity coordinator....who happens to have CHARGE syndrome...It has been my job for the last 16 years to advocate for Alex's needs and educate the staff in public school system here in CT...Alex has now taken the role of self advocate (so very proud of him).... and when I can I try to help my fellow moms navigate the special education system.

I have a degree in fashion design and display....which during this journey I was able to use my design/sewing skills to create clothing when Alex was in a body cast and needed to still go to so many doctors appointments. For fun I try to do things that keep my hands busy like baking cupcakes or birthday cakes, creating homemade cards or crocheting scarves. I also have been in the past been involved in CTDBFUN (a deaf blind family group)...I did have a workshop at the Orlando CHARGE conference and I am a member of the CHARGE foundation.

Laurie Suter: Is a single mom and the youngest of 7 daughters. Her love of working with children with disabilities started when she babysat for a child with Cerebral Palsy (CP) as a teen. She migrated to working in a group home for adults with developmental disabilities and there her love grew for this work. At 31 she decided to adopt. As a single mom she adopted 3 children at ages 10 weeks, 26 weeks and 2 years old -several years apart, from Illinois, New Hampshire and California, and has followed them through the school system. Her oldest still lives at home, her son works at the airport and graduated high school with a diploma, and her youngest is still in high school. Laurie has nurtured her children through many health issues including 25 bouts of pneumonia, several trips to the hospital, doctor's visits and several surgeries. She has worked with the hospital, doctors and the school system to get the programs her children need. Laurie continues to advocate for her children even though at times she cried and felt she wasn't heard. Laurie's children are now (ages 25, 24 &16 years) medically involved, have developmental disabilities and have Educational Plans. She is now waiting on the adoption of her fourth child from Massachusetts!

Karin Dagley: Is a parent and graduated from Siena College in Albany, NY with a degree in International Business. She was working as a photo shoot production coordinator with the Orvis company in Manchester, VT when she met her husband of 10 years. Bob and her moved to Hilton Head Island, SC where she found her dream job as a special Events Coordinator. In 2005 she had an amazing daughter Grace, who was diagnosed with CHARGE Syndrome at 3 months. Through all her challenges, she is a beam of joy. Her contagious laughter and unconditional love fill my heart. She is so thankful be her mom. In 2008 they were blessed with Grace's little brother, Jack. He is bright, funny and has more energy than we could ever hope to keep up with. And he loves his sister. He always looks out for her. In 2010 after learning about the Perkins School for the Blind, and how they so wonderfully understand our kids with CHARGE, we knew it was time to leave Hilton Head. Without a plan or a place to live, we headed home. Bob is originally from Weymouth, MA just south of Boston and has a large family who all reside there. After a year of complexity and determination we were able to get Grace into the Perkins School. It wasn't easy, but it was absolutely worth the battle. Grace, now 8 is in her third year at Perkins. She loves school and has made friends with many of her peers. Who could want more?