

14th International CHARGE Syndrome Conference

Dallas, Texas
Hilton Anatole
August 2-5, 2019

WELCOME TO TEXAS

FROM



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Welcome!

DEEP IN THE HEART OF CHARGE

President's Welcome

As I complete my 8th year as President of the Foundation, I remain amazed how much our extended CHARGE family accomplishes every year. Over 1,200 people will unite Deep in the Heart of CHARGE. The slogan for this year's conference is a catchy play on words; combining a popular song with a part of our anatomy that is often impacted by CHARGE syndrome, but perhaps it is a little more symbolic than just a clever change of words.

HEART is what makes this conference possible. Without Heart, we could not count on our fantastic presenters to volunteer their time, and pay their own travel and registration expenses to help us better understand CHARGE. Without Heart, we would not have an unpaid Board of Directors, Officers and Advisors. They all spend 100's, and in some cases almost 1,000, volunteer hours to make this weekend special. Our generous sponsors, donors, fundraisers, members, volunteers, and interpreters all give from the Heart so we can learn, laugh and even cry together.

Each year the Foundation continues to do more. The Ethan Wolfe Recreational Assistance Program and the Sandra Davenport CHARGE Syndrome Fellows Program continue to thrive and grow. We increased our conference scholarships, improved our website, published more newsletters, expanded our Parent Liaison Program, funded more research, and so much more. We are better today because of all the support we received from everyone that donated, fundraised and volunteered.

While it clearly takes many volunteers to make the Foundation run, a few amazing people still handle most of the work and deserve an extra special THANK YOU. None of these people get paid and all of them help run the Foundation because they have extraordinary hearts. So when you see our Vice President Amrit Mehta, Treasurer Brownie Shott, Secretary Joanne Lent, Conference Chair Neal Stanger, and Director of Administration Jody Wolfe, please give them a huge CHARGE thank you.

This conference has something for everyone: general sessions, breakout sessions, exhibitors, poster presentations, social events, camp and time together as one large CHARGE family. If you take advantage of all our conference has to offer, I am certain you will feel something truly special deep in your heart. Perhaps that is what it really means to be Deep in the HEART of CHARGE.

David Wolfe

David Wolfe
President and Fundraising Chair
CHARGE Syndrome Foundation, Inc.



Foundation Contact Information

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Connect with us!
Check on Upcoming Events,
CHARGE Research or Donate!



www.chargesyndrome.org



People First Language DisabilityIsNatural.com

A handicap has been defined as an obstacle which society imposes on a person with a disability, i.e. inaccessible transportation or buildings, no signage, etc.

Handicapped is not a term to describe human beings. A disability has been defined as a body function that operates differently. It's that simple! It's just a body function that works differently.

People First Language seeks to put the person first and the disability second!

People with disabilities are people first and foremost.

Example: "person who uses a wheelchair" vs
"confined to a wheelchair" or "wheelchair bound"

CHARGE Syndrome Foundation, Inc.

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Buller Photography

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Camp Abilities

Provided Camp Abilities experience within our camp for all campers. www.campabilities.org



GoodTimes Action Games

Provided Bingo activity and supplies for Saturday night Bingo and Baskets



It would be impossible to thank all the wonderful people who have helped us produce this conference, but every effort, big or small, is appreciated. Thanks to all of you for making this a wonderful event!

Notes

It's No Secret!



**Silent Auction
and Basket Donors
Are The BEST!**
Thank You!



14th International CHARGE Syndrome Conference
Dallas, Texas • August 2-5, 2019

THURSDAY, AUGUST 1, 2019

Time	Event	Location
10:00-5:00	Conference Registration Professional Day Registration Sales Table	Trinity Pre-Function
10:00-5:00	Camp Discovery & Camp Explorer Registration	Trinity Pre-Function

FRIDAY, AUGUST 2, 2019

Time	Event	Location
7:00-5:00	Conference Registration & Sales Table	Trinity Pre-Function
7:00-12:00	Professional Day Registration	Trinity Pre-Function
7:00-5:30	Professional Day Conference <i>see following pages</i>	Coronado Ballroom
9:00-5:00	Camp Discovery & Camp Explorer Registration	Trinity Pre-Function
1:00-4:00	Pool Party!	Jade Oval & Leisure Cove
6:30	Reception Light dinner included. Cash bar available.	Chantilly Ballroom

Notes:

14th International CHARGE Syndrome Conference

6th PROFESSIONAL DAY Friday, August 1, 2019



Professional Day at conference is a venue for professionals to exchange information about the procedures and methods for understanding and treating CHARGE. The day begins with a general session for all attendees followed by a poster session. The remainder of the day features platform presentations divided into two categories: Educational/Behavioral/Communication and Clinical/Scientific Research and ends with a general session for all attendees.

7:00-12:00	Professional Day Registration in Trinity Pre-Function
7:00-8:30	Poster setup in Wedgwood Ballroom
7:45-8:45	Breakfast in Coronado Ballroom
8:45-11:15	General Session in Coronado Ballroom: <i>Plenary Speakers:</i> <ul style="list-style-type: none">• CSF-Sponsored Research: Past and Future Dr. Donna Martin• NIH Research Initiatives Dr. Tiina Urv• Novel Genetic Etiologies in CHARGE Syndrome Identified With Whole Genome Sequencing Stephanie Bielas• Gastrointestinal (GI) and Feeding Difficulties in CHARGE Syndrome; The Guts of It Dr. Kim Blake• Linking Assessment to Intervention: Functional Analyses and CHARGE Hailey Ripple
11:20-12:30	Poster session in Wedgwood Ballroom
12:30-1:30	Lunch in Coronado Ballroom
1:35-2:55	Breakout Session 1 <i>see following pages</i> Educational/Behavioral/Communication in Senators Lecture Hall Clinical/Scientific Research in Governors Lecture Hall
2:55-3:10	Coffee Break
3:10-4:30	Breakout Session 2 <i>see following pages</i> Educational/Behavioral/Communication in Senators Lecture Hall Clinical/Scientific Research in Governors Lecture Hall
4:35-5:30	Recap and Closing Remarks in Coronado Ballroom

CSF-Sponsored Research: Past and Future – Donna Martin, MD, University of Michigan; Yehoash Raphael, MD, University of Michigan

The CHARGE Syndrome Foundation is dedicated to promoting new knowledge and discoveries that positively impact individuals with CHARGE. Toward this end, the foundation provides funding to support a wide variety of basic science and clinical research, including Davenport fellowships, biennial symposia, human genetics, gene discovery, animal models (mice, fish, flies), and stem cells. In 2004, CHD7 was identified as the major gene involved in CHARGE, thus opening new opportunities to understand CHARGE mechanisms and develop therapies. In 2012, the Foundation established an annual pilot research award program to support individual researchers working on CHARGE-related studies. In 2014, the foundation established biennial symposia held in Ann Arbor at The University of Michigan to promote basic science discoveries in CHARGE. In this presentation, we will provide an overview of the past seven years of foundation supported pilot awards, and the three symposia. We will discuss the impact of these activities on our understanding of CHD7 and on the lives of individuals with CHARGE. We will also present an overview of new innovative technologies and progress toward development of therapies.

NIH Research Initiatives – Tiina Urv, PhD, Program Director, Office of Rare Diseases Research, National Center for Advancing Translational Sciences, National Institutes of Health

Novel Genetic Etiologies in CHARGE Syndrome Identified With Whole Genome Sequencing – Stephanie Bielas, Amanda Moccia, Julia Eisenberg, Donna Martin, MD, University of Michigan School of Medicine; Marsha Wheeler, University of Washington

Solving the genetic basis of developmental disorders is a powerful approach to gain a better understanding of the underlying pathogenesis, as evident from the discovery of the role of CHD7 variants in CHARGE syndrome. However, pathogenic CHD7 variants are not detected in all individuals with clinical features of CHARGE. These findings suggest additional genetic etiologies for CHARGE lie within the non-coding regions of CHD7 and of the genome. Our initial studies demonstrate that pathogenic variants in genes associated with other Mendelian disorders account for a portion of this missing genetic etiology, but not its entirety. Non-coding regions of the genome show promise for this missing heritability. Here, we evaluate proximal and distal cis-regulatory elements of CHD7 and other developmentally related genes to identify novel genetic etiologies of CHARGE. Screening these regions has led to identification of candidate variants. Functional validation using CRISPR/Cas9 to introduce variants or deletions in human pluripotent stem cells will be critical to model the pathogenicity of these variants. This approach will lead to a better understanding of the molecular and developmental mechanisms of CHARGE syndrome.

Gastrointestinal (GI) and Feeding Difficulties in CHARGE Syndrome; the Guts of It – Dr. Kim Blake, Dalhousie University

Over 95% of individuals with CHARGE syndrome experience feeding and gastrointestinal (GI) dysfunction. The structural abnormalities, motility impairment and sensory impairment all contribute to the GI issues and are potential treatment targets. I will describe how cranial nerve abnormalities underlines the pervasive GI dysfunction and the need for further research on gut motility and the microbiome. Much of the work has come from Dr. Blake's laboratory/team at Dalhousie University in Canada. She will describe the clinical and basic science research that has been completed over the last 10 years. A recent publication titled "Etiology and functional validation of gastrointestinal motility dysfunction in a zebrafish model of CHARGE syndrome" will be discussed. Dr. Blake will also touch on the microbiome and preliminary data from her students.

Linking Assessment to Intervention: Functional Analyses and CHARGE – Hailey Ripple, Kasee Stratton, PhD, Mississippi State University

Among the multitude of medical concerns that present in CHARGE Syndrome is engagement in problem behaviors that vary across topography and etiology (e.g., pain, anxiety, sensory concern). Studies examining the use of assessment procedures of problem behavior in the CHARGE population are limited, but are a necessary first step in order to inform efficient and effective treatment. This presentation will review a study that examined the utility of brief functional analyses (BFA), a well-documented procedure used to identify the function(s) of problem behaviors, for the first time in individuals with CHARGE Syndrome. Participants included individuals between the ages of 8 to 22 years old diagnosed with CHARGE Syndrome who presented with varying problem behaviors. Results indicated that BFA procedures were successful in identifying the function of problem behavior with four out of five participants. Participants will leave with greater understanding of the role of behavioral assessment, the need for determining the function (reason) of challenging behavior and how this maps onto intervention design and outcomes.

BREAKOUT SESSION 1: CLINICAL/SCIENTIFIC RESEARCH

GOVERNORS LECTURE HALL 1:35–2:55 pm

Feeding Difficulties and Aspiration in CHARGE Syndrome – Catherine Hart, MD, Cincinnati Children's Hospital Medical Center

Dysphagia and aspiration are common in children with CHARGE syndrome, affecting 90% and 60% of children, respectively. There are anatomic, developmental, and behavioral factors that contribute to dysphagia and aspiration. These will be discussed along with diagnostic considerations and management options.

Application of Behavioral Strategies to Address Feeding Difficulties Among Children with CHARGE Syndrome – Dr. Hallie Smith, Kennedy Krieger Institute

This presentation will provide professionals with an overview of various evidence-based behavioral strategies to address food refusal and food selectivity in a pediatric population while also presenting data from 3 case examples to demonstrate the application of these strategies to children with CHARGE Syndrome. Data from 3 individuals will be presented to support the use of various behavioral strategies at decreasing tube dependence, increasing acceptance of solid food and liquid by mouth, increasing variety of food consumed, increasing self-feeding, and decreasing problem behavior during meal times. This presentation will also include a discussion of the differences between sensory-based and behavioral-based approaches to treatment as well as outcome data regarding the two approaches and recommendations regarding an individual's appropriateness for the use of behavioral-based strategies. Overall, this presentation will provide attendees with an increased understanding of how feeding difficulties in children with CHARGE syndrome can be addressed from a behavioral perspective as well as an understanding, based on data, that behavioral strategies do lead to positive feeding-related outcomes among individuals with CHARGE syndrome.

Investigating the Response to Anesthesia in a Zebrafish Model of CHARGE Syndrome – Jessica MacLean, Emily Chedrawe, Kim Blake, MD, Dalhousie University/IWK Health Centre

Individuals with CHARGE syndrome experience adverse events during and following anesthesia. We examined the response to anesthesia in a zebrafish model of CHARGE (loss of *chd7* expression) to investigate causative factors. We used zebrafish retaining *chd7* expression as control. We were able to demonstrate differences in response to anesthesia between CHARGE compared with control zebrafish.

CHARGE zebrafish took longer to become anesthetized, which is consistent with what is seen clinically. During recovery, the CHARGE zebrafish had higher respiratory rates. Future work will investigate survival outcomes of CHARGE versus control zebrafish.

Puberty and CHARGE Syndrome – Jeremy Kirk, MD, FRCPC, FRCP, Birmingham Women's and Children's Hospital UK

Pubertal issues are common in CHARGE syndrome, and especially in males. Characteristically sex hormone replacement (when required) is the standard treatment, although this is non-physiological, often started late, and may not produce optimal results. Recently, therapies which more closely mimic normal hormone production are being developed and utilized. Data will be shown on variation in current treatment between different units and countries. Although there is little data on outcomes in CHARGE syndrome, overlap with other similar conditions such Kallmann syndrome gives insight in to how these therapies might work.

BREAKOUT SESSION 1: EDUCATION/BEHAVIOR/COMMUNICATION

SENATORS LECTURE HALL 1:35–2:55 pm

That's Weird. Why Would My Child Act This Way? Trying To Make Sense Out of Behavior. – Tim Hartshorne, PhD, Central Michigan University

Before we try to change a behavior, it is a good idea to have some sense as to why the child is engaging in it. Once the purpose of a behavior is recognized, the behavior starts to make sense. Diagnosis has limited explanatory value. Looking for changes in the child's environment, possible sources of pain, anxiety, and the sensory environment may improve our understanding. These issues will be illustrated.

The IFHE: Functional Hearing and the IEP – Adam Graves, Amy Baxter, Texas School for the Blind and Visually Impaired

Auditory test results for students who are DeafBlind and have multiple disabilities can often be difficult for IEP teams to interpret. These students may demonstrate the ability to use their hearing certain environments that can seem inconsistent with audiometric results. To help teams provide data on how these students use their hearing in a variety of settings, the Texas School for the Blind and Visually Impaired (TSBVI) has developed the Informal Functional Hearing Evaluation (IFHE). The results of this collaborative evaluation can help provide IEP teams with ideas for the development of strategies and accommodations that utilize and build on the functional hearing skills of students who are DeafBlind.

Meeting the Needs of Students with CHARGE Syndrome with Proficient Communication Skills in General Education – Robbie Blaha, M.Ed., Texas School for the Blind and Visually Impaired

The field of deafblindness has appropriately focused on learners with emerging language and multiple disabilities. This is a result, in part, of the Rubella epidemic that was foundational in the development of the field we have today. In the past, academic students with deafblindness were typically those with Usher Syndrome.. Currently, as an effect of significant changes in etiology and quality of medical interventions, there is a growing population of congenital students with CHARGE who have formal language. These students are undergoing and presenting considerable challenges to local districts that serve them. Though many of the essential strategies and best practices in our field do not address their needs, the underpinnings of the deafblind learning style: significant and ongoing lack of incidental information, concept development and social issues are very much at play with these students. These academic children and youth with deafblindness need our attention and support to assure that there are new and unique strategies that address the needs of this growing academic population.

Take CHARGE in the Classroom – Rachel Collins, Deafblind Specialist, Round Rock ISD

This session will present an educational approach for children with CHARGE that takes into account the child's access to their current learning environment, and will provide ideas on how to enable children to be more active participants in their environments. Overviews of assessment tools (mostly free) that apply to proficient communicators and emergent communicators will be reviewed. Both the Expanded Core Curriculum for Students who are Deaf or Hard of Hearing and for those who are Visually Impaired will be woven into the session. Additionally, strategies for supporting all levels of communicators will be covered.

BREAKOUT SESSION 2: CLINICAL/SCIENTIFIC RESEARCH

GOVERNORS LECTURE HALL 3:10–4:30 pm

Sleep in Children with CHARGE Syndrome – Christine Heubi, MD, Susan Wiley, MD, Cincinnati Children's Hospital Medical Center

Sleep problems in CHARGE syndrome are estimated to occur in 59% of patients, and can be related to anxiety and behavioral concerns. Limited research has been performed, with parental survey as the primary source of reported issues. Caregiver well-being has been found to be affected by sleep problems in children with CHARGE, and recommendations need to be made once the underlying issue is determined: medical issues (night time feedings or treatments, obstructive sleep apnea, pain), visual impairment, hearing loss, or environmental factors. Both behavioral and environmental interventions can be successful, however, further evaluation and treatment may be necessary. Light therapy and supplementation with melatonin, or other medication, can lead to clinical improvement in certain patients. In other patients, attention is focused on evaluation and management of upper airway obstruction. Sleep endoscopy and cineMRI are employed for diagnosis of the site of obstruction; treatment includes surgery, positive airway pressure (PAP) therapy, and/or medication. Case presentations will be used as examples for the work-up and management of children with CHARGE who have sleep problems.

Investigation of Two Methods for Treating Sleep Problems Among Children with CHARGE Syndrome – Benjamin Kennert, Central Michigan University CHARGE Lab

Sleep problems are common among children, especially those with developmental disabilities, visual impairments, and behavioral problems. Among children with CHARGE syndrome, recent research indicates a particularly high prevalence of clinically-relevant sleep problems for this group. This presentation will review a recent study using an explorative survey with parents of children with CHARGE syndrome in order to identify the types of sleep problems and the interventions most commonly used among this population. A follow-up study of two small sample groups of children will then be discussed, during which the treatment utility of two intervention strategies (i.e., melatonin treatment and a behavioral treatment package) were investigated, both separately and combined. Implications for results will be discussed.

The CHARGE Syndrome Research Lab at Central Michigan University – Timothy Hartshorne, Central Michigan University

The CHARGE Lab at Central Michigan University began about 1999 when Tim Hartshorne started to study behavior in children with CHARGE. At first, it was quite small, but over time, more students, both graduate and undergraduate, have become interested in CHARGE and the work of the lab. Some of the graduates continue to work with children who have CHARGE. This presentation provides a bit of history, and then describes the research of the current lab members.

BREAKOUT SESSION 2: EDUCATION/BEHAVIOR/COMMUNICATION

SENATORS LECTURE HALL 3:10–4:30 pm

ABA, Cognitive-Behavior Therapy, or Word of Mouth: What Treatment is Right? – Laura Quintero, Lyndsay Fairchild, Kasee Stratton-Gadke, Bulldog CHARGE Syndrome Research Lab, Mississippi State University

Navigating through the vast options of available treatments can be extremely challenging for practitioners working with the deaf-blind population. While various treatments exist, it is imperative that professionals utilize treatments that are empirically supported and data driven. This presentation will focus on three types of evidence-based treatments (Applied Behavior Analysis, Cognitive Behavior Therapy and Acceptance and Commitment Therapy) that can provide professionals direction as it pertains to their clients/students. An overview of each of the treatments will be discussed as well as the current state of research using these evidence based practices with the deaf-blind population, and directions for future research.

An Educational Checklist for CHARGE Syndrome – Lily Slavin, Central Michigan University

The Educational Checklist for Individuals with CHARGE Syndrome was developed in collaboration with an international panel of experts, the CHARGE Syndrome Research Lab at Central Michigan University, and a sampling group of parents, professionals, and state deafblind project employees. This presentation will discuss the development of the Educational Checklist and implications for professional practice. The presentation will include an overview of the educational needs commonly experienced by individuals with CHARGE Syndrome and examples of strategies professionals can use to address those needs in the schools.

Promoting Social Skill Development in Children with CHARGE – Megan Schmittell, Central Michigan University and Perkins School for the Blind

Social skills include a variety of behaviors that allow individuals to engage in positive interactions with others. Children with CHARGE are often described as socially interested but socially immature. Children with CHARGE syndrome may experience delays in social skill development because of their multi-sensory impairment. Because of the limited information they receive through their senses, children with CHARGE often do not know how to act in social situations. Additionally, children with CHARGE often spend a lot of time in the hospital and may not have exposure to early social interactions that teach children how to appropriately play with other children. Finally, children with CHARGE syndrome are often medically fragile, so they may be inhibited from having social experiences. Without these experiences, children with CHARGE are unable to adequately develop social skills. To help promote social skill development, caregivers and teachers can provide explicit instruction on social skills and opportunities to socialize with others to practice skills taught.

Orientation and Mobility Strategies to Address Balance and Stability – Suzanne Dinwiddie, M.Ed., Tennessee Deaf-Blind Project; Lee Ellen Whitefield, M.Ed., Metro Nashville Public Schools; Kristi Jones, Tennessee Deaf-Blind Project

Orientation and Mobility Instructors (O&M) working with individuals with CHARGE Syndrome must address the significant impact of balance and low muscle tone. Low muscle tone slows an individual's response and they need extra time achieve balance while moving. Balance is achieved and maintained by the coordinated sensory input from vision, proprioception, and the vestibular systems. A properly functioning balance system allows individuals to resist gravity, determine direction and speed of movement, and make postural adjustments to maintain posture and stability when traveling on a variety of surfaces. O&M techniques and strategies can increase balance and endurance by structuring the environment, incorporating exercises into daily routines, and instructing adults on how to modify travel techniques to address safety. Some strategies discussed will include adapted mobility devices, "stability" landmarks within daily routes, using task analyses to "break down" transitional movements, and incorporating adaptive exercises and PE strategies.

POSTER PRESENTATIONS IN WEDGWOOD BALLROOM

PROFESSIONAL DAY: 11:15 am–12:25 pm

INTERNATIONAL CONFERENCE: 10:45 am–5:00 pm

presenters available to meet with attendees Saturday & Sunday 12:30-1:15 pm

4 to 24: Development of a Transition Resource App for Parents

Karla Antonelli, Anne Steverson, NRTC on Blindness & Low Vision

A Visual Understanding of the Ophthalmic Pathway in CHARGE

Eniolami Dosunmu, MD, Cincinnati Children's Hospital Medical Center

ABA, Cognitive-Behavior Therapy, or Word of Mouth: What Treatment is Right?

Laura Quintero, Lyndsay Fairchild, Kasee Stratton-Gadke, Bulldog CHARGE Syndrome Research Lab, Mississippi State University;

"All About Me" Journals: Sharing Essential Information With New Educational Teams

Julie Maier, California Deafblind Services

An Educational Checklist for CHARGE Syndrome

Lily Slavin, Central Michigan University

An Interactive Seminar in Genetics: All You Want To Know About the Genetics of CHARGE Syndrome

Christa de Geus, MD, University Medical Center Groningen

Anxiety in CHARGE Syndrome

Shanti Brown, Central Michigan University; Timothy Hartshorne, PhD, Central Michigan University

Application of Behavioral Strategies To Address Feeding Difficulties Among Children with CHARGE Syndrome

Dr. Hallie Smith, Kennedy Krieger Institute

Are Parents Satisfied? The Ins and Outs of IEP Goals

Lyndsay Fairchild, Jasmine Sorrel, Kasee Stratton-Gadke, Mississippi State University
Bulldog CHARGE Syndrome Research Laboratory

Assessing the Quality of Behavior Services for Students With CHARGE Syndrome

Emily Mathis, Kasee Stratton-Gadke, Mississippi State University, Bulldog CHARGE Syndrome Research Laboratory

Breakdowns in Parent and Professional Communication

Sydney Randle, Tim Hartshorne, PhD, CHARGE Syndrome Research Lab at Central Michigan University

Can We Play? Building the Bridge Between Children With CHARGE and Their Peers

Emma Mayes, Deafblind Services Minnesota

Charting the LifeCourse: a Framework and Tools To Support Families and People With Disabilities To Build a Brighter Future

Crystal Bell, Missouri Family to Family

Conserved Roles for CHD7 in Transcriptional Elongation of Genes Involved in Neural, Neural Crest, and Inner Ear Development

Elaine Ritter, University of Michigan

Counseling Parents of Children with CHARGE

Timothy Hartshorne, Central Michigan University;

Developing and Nurturing Leadership and Advocacy in DeafBlind Students

Amita Srinivasan

Developing Zebrafish Models To Study the Link Between SoxC Transcription Factors and CHARGE Syndrome

Laura Kreuger, Ann Morris, University of Kentucky

Effects of a Modified Version of Tai Chi 'Fun Chi' on Academic Engagement

Shelby Muhn, Tim Hartshorne, PhD, CHARGE Syndrome Research Lab at Central Michigan University

Examining Attitudes Towards Sexuality in CHARGE Syndrome

Emily Mathis, Kasee Stratton-Gadke, Mississippi State University, Bulldog CHARGE Syndrome Research Laboratory; Daniel Gadke, Mississippi State University

Fatigue: A Proposed Study on the Experiences of Adolescents and Young Adults with CHARGE Syndrome

Kathryn Parker, Tim Hartshorne, PhD, CHARGE Syndrome Research Lab at Central Michigan University

From Interaction to Emerging Language: the Deafblind Communicator

Chris Montgomery, Texas School for the Blind and Visually Impaired, DeafBlind Outreach Department

Garland CHARGE Through Public Education, Garland Goodwin

Gut Microbiome Survey in Individuals with CHARGE Compared to Sibling Controls

Emily Chedrawe, Dalhousie University; /IWK Health Centre

How a Feed Study Changed my Life. No More Overnight Pump!

Cullen Drew, Sensity Deafblind and Sensory Support Network of Canada

Improving Adaptive Behavior in a Child with CHARGE Syndrome; a Case Study

Megan Anderson, Alexander Clarke, Mississippi State University, Bulldog CHARGE Syndrome Research Laboratory

Improving Your Student's IEP

Kaycee Bennett, Northwest ISD

Investigating the Response to Anesthesia in a Zebrafish Model of CHARGE Syndrome

Jessica MacLean, Emily Chedrawe, Kim Blake, MD Dalhousie University; /IWK Health Centre

Investigation of Two Methods for Treating Sleep Problems Among Children with CHARGE Syndrome

Benjamin Kennert, Central Michigan University; CHARGE Lab

Novel Genetic Etiologies of CHARGE Syndrome Identified With Whole Genome Sequencing

Stephanie Bielas, Amanda Moccia, Julia Eisenberg, Donna Martin, MD, University of Michigan School of Medicine

Oh, the Places They Could Go: Why Your Child Needs a Transition Plan

Megan Anderson, Tierra Kilbert, Mississippi State University, Bulldog CHARGE Syndrome Research Laboratory

Parent Decision-Making in the Use of Psychotropic Medications With Their Child with CHARGE

Emily Hanlon, Natalie Noble, Tim Hartshorne, PhD, CHARGE Syndrome Research Lab at Central Michigan University;

Partnering to Give Parents a Voice

Megan Cote, National Center on Deaf-Blindness; Sheri Stanger, CHARGE Syndrome Foundation; Melanie Knapp, NFADB

Physical Education Accommodations: Is Your Child Receiving Assistance?

Jasmine Sorrel, Kasee Stratton-Gadke, Mississippi State University, Bulldog CHARGE Syndrome Research Laboratory

Planning Together

Mike Fagbemi, National Center on Deaf-Blindness

Post-Traumatic Growth in Parents of Children with CHARGE Syndrome

Shelby Muhn, Tim Hartshorne, PhD, CHARGE Syndrome Research Lab at Central Michigan University;

Postural Orthostatic Tachycardia Syndrome (POTS) in Adolescents and Young Adults with CHARGE Syndrome

Julia Morrison, Dalhousie University/IWK Hospital

Preparing the Body and the Environment. Orientation and Mobility for Individuals with CHARGE Syndrome

Suzanne Dinwiddie, M.Ed., Tennessee Deaf-Blind Project, Lee Ellen Whitefield, M.Ed., Metro Nashville Public Schools; Kristi Jones, Tennessee Deaf-Blind Project

Presence of Sensory Integration Therapies in the CHARGE Syndrome Community

Kathryn Parker, Tim Hartshorne, PhD, CHARGE Syndrome Research Lab at Central Michigan University

Prevalence of Balance Issues and Common Accommodations in Individuals with CHARGE Syndrome

Taylor Jarnigin, Tim Hartshorne, PhD, CHARGE Syndrome Research Lab at Central Michigan University

Promoting Social Skill Development in Children with CHARGE

Megan Schmittel, Central Michigan University and Perkins School for the Blind

Sandra Davenport Fellowship Program

Sara Espanet, Perkins School for the Blind

Sharing Information with Caregivers

Sarah Cawthon, MD

TDB Models: Making the Role of Teachers for Students with DeafBlindness Work for Your District

Kaycee Bennett, Northwest ISD; Rachel Collins, Round Rock ISD

That's Weird. Why Would my Child Act This Way? Trying To Make Sense out of Behavior.

Tim Hartshorne, PhD, Central Michigan University

The Bulldog CHARGE Syndrome Research Lab at Mississippi State University

Jasmine Sorrel, Mississippi State University; Kasee Stratton-Gadke, Mississippi State University, Bulldog CHARGE Syndrome Research Laboratory

The CHARGE Syndrome Research Lab at Central Michigan University

Timothy Hartshorne, Central Michigan University

The Impact of Having a Child With Complex Needs on the Family: the Importance of Self-Care

Jana Villemez, CAYSI - Arkansas Department of Education Deafblind Program

Unique Pattern of Social Skills in Individuals with CHARGE Syndrome

Dr. Lori Swanson, University of Wisconsin-River Falls; Meg Hefner, Saint Louis University; Jennifer Wilking, University of Wisconsin-River Falls

Using Photos to Tell Your Child's Story to their Educational Team

Donna Carpenter, KY DeafBlind Project



Saturday August 3, 2019

Time	Event	Location
7:00-5:00	Conference Registration	Trinity Pre-Function
7:00-8:00	Vendor & Exhibitor setup	Trinity Art Corridor
7:00-5:15	Sales Center	Trinity Pre-Function
7:00-8:45	Breakfast	Trinity Ballroom
7:00-8:45	Camp Discovery & Camp Explorer Registration	Peacock Foyer
8:00-5:00	Exhibitors & Vendors	Trinity Art Corridor
8:30-11:45	Camp Discovery & Camp Explorer morning session	West Wing
8:45-11:45	Sibshop session #1	Room 101 - 28th floor
9:00-10:30	General Session: Welcome & Keynote <i>Kathy Buckley: Inspiring Laughter. Breaking Barriers. Empowering Change.</i>	Trinity Ballroom
10:30-10:45	Coffee Break	
10:45-5:00	Poster Presentations	Wedgwood Ballroom
10:45-11:45	Breakout Session A <i>see following pages</i>	
11:45-12:45	Lunch	Trinity Ballroom
12:30-1:15	Poster Presenters meet with attendees	Wedgwood Ballroom
12:30-5:00	Camp Discovery & Camp Explorer afternoon session	West Wing
1:30-4:30	Sibshop session #2	Room 101 - 28th floor
1:30-2:30	Breakout Session B <i>see following pages</i>	
2:45-3:45	Breakout Session C <i>see following pages</i>	
3:45-4:00	Coffee Break	
4:00-5:00	Breakout Session D <i>see following pages</i>	
6:30	Dinner, Bingo & Basket Raffle	Trinity Ballroom

Saturday Breakout Sessions

	Session A 10:45-11:45	Session B 1:30-2:30	Session C 2:45-3:45	Session D 4:00-5:00
Wedgwood Ballroom	Poster presentations 10:45-5:00 • Meet the presenters 12:30-1:15			
Grand Ballroom A/B	#1 Panel – Parents of Adults Stanger & Morris	#7 Teaching Safe Sexuality Kirk & Stratton	#13 Counseling Parents Hartshorne, T	#19 Sibling Panel Beavers & Lent
Grand Ballroom C	#2 GI Issues: Does Your Gut Talk to You? Blake	#8 Sleep Heubi	#14 Emerging Language Montgomery	#20 Creating Communication Opportunities Bashinski
Grand Ballroom D/E	#3 Motor Skills, Balance & Physical Activity Beach & Lieberman	#9 Intervener or Interpreter Morrow	#15 Ear and Hearing Management Choo	#21 Why Your Child Needs a Transition Plan Anderson
Chantilly Ballroom East	#4 IEP – Like a Pro Johnson & Stratton	#10 Why are Children with CHARGE So Lazy Brown	#16 Autism or CHARGE Maier & Belote	#22 Airway & Anesthesia Blake & Hart
Chantilly Ballroom West	#5 CHARGE 101: Diagnosis, Features Hefner	#11 CHARGE 102: Sensory Deficits Beals & Denno	#17 CHARGE 103: Communication and Play Last & Mayes	#23 Parent and Nurse as Co-Advocates Marcheschi
Governors Lecture Hall	#6 Grandparents	#12 Grandparents	#18 Adults with CHARGE age 16+ only Stratton	#24 Adults with CHARGE age 16+ only Stratton

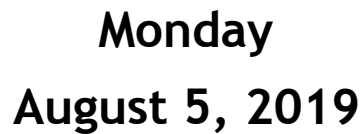


Sunday August 4, 2019

Time	Event	Location
7:00-5:15	Sales Center	Trinity Pre-Function
7:00-8:45	Breakfast	Trinity Ballroom
8:00-5:00	Exhibitors & Vendors	Trinity Art Corridor
8:30-11:45	Camp Discovery & Camp Explorer morning session	West Wing
8:45-11:45	Sibshop session #3	Room 101 - 28th floor
9:00-10:30	General Session	Trinity Ballroom
10:30-10:45	Coffee Break	
10:45-5:00	Poster Presentations	Wedgwood Ballroom
10:45-11:45	Breakout Session E <i>see following pages</i>	
11:45-12:45	Lunch	Trinity Ballroom
12:30-1:15	Poster Presenters meet with attendees	Peacock Foyer
12:30-5:00	Camp Discovery & Camp Explorer afternoon session	West Wing
1:30-4:30	Sibshop session #4	Room 101 - 28th floor
1:30-2:30	Breakout Session F <i>see following pages</i>	
2:45-3:45	Breakout Session G <i>see following pages</i>	
3:45-4:00	Coffee Break	
4:00-5:00	Breakout Session H <i>see following pages</i>	
6:30	CHARGE Hoedown Dinner, Carnival, Line Dancing & Silent Auction	Trinity Ballroom

Sunday Breakout Sessions

	Session A 10:45-11:45	Session B 1:30-2:30	Session C 2:45-3:45	Session D 4:00-5:00
Wedgwood Ballroom	Poster presentations 10:45-5:00 • Meet the presenters 12:30-1:15			
Grand Ballroom A/B	#25 Proprioceptive Training Foster	#31 Gross Motor, Fitness & Sports Hilgenbrinck & Cavanaugh	#37 Orientation & Mobility Dinwiddie	#43 Interveners: Key Members of the Education Team Kennedy
Grand Ballroom C	#26 Proficient Communicators in Gen Ed Blaha	#32 The Endocrine System Rutter	#38 Teaching Social Skills Schmittel	#44 Person Centered Planning Hartshorne, N
Grand Ballroom D/E	#27 Understanding the ophthalmic pathway Dosumnu	#33 Friendship, Belonging & Connection Last	#39 Using Photos to Tell Your Child's Story Carpenter	#45 Growth Dijk
Chantilly Ballroom East	#28 How to Tell Your Child They Have CHARGE Grant	#34 I Wish They Could Tell Me What They Need Stratton	#40 Genetics deGeus	#46 Sensory Strategies in the Classroom Stelzer & Espanet
Chantilly Ballroom West	#29 Feeding & Aspiration Hart	#35 Behavior Strategies: Feeding Smith	#41 Trying to Make Sense of Behavior Hartshorne, T	#47 Functional Behavior Analysis & Intervention Ripple
Governors Lecture Hall	#30 HKNC Programs Supporting Transition Sinanan	#36 Understanding the Impact of Grief on Families Cote & Wolfe	#42 Life Activities During Transition Wiley	



Notes:

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14th International CHARGE Syndrome Conference Program Breakout Sessions

BREAKOUT SESSION A Saturday, August 3, 2019 – 10:45–11:45 am

A1 • Days of our Lives - a Snapshot of Adulthood – Sheri Stanger, Director of Outreach, CHARGE Syndrome Foundation; Djenne-amal Morris; Mary Hancock; Tina Steed

Are you the family member/caregiver of an adult child or a child in transition to adulthood? Ever wonder what happens after your child leaves the education system? Come hear a panel of parents of adult children with CHARGE syndrome share their unique and diverse experiences on the evolution of creating a fulfilling adult life for their child. Each panelist will share their successes and challenges on their journey to navigating the adult world.

A2 • Does Your Gut Talk to You? Review of Gastrointestinal (GI) Motility and the Connection to the Vagus Nerve and Microbiome in CHARGE Syndrome – Dr. Kim Blake, IWK Health Centre

Review of Gastrointestinal (GI) motility and the connection to the vagus nerve and microbiome in CHARGE syndrome. Gastrointestinal (GI) dysfunction including feeding, and digestion difficulties are highly prevalent and represent a serious challenge for many individuals with CHARGE syndrome. We are much further along the journey in understanding the GI tract which is the largest organ of the body and deserves more attention. In this presentation we will summarize in an easy digestible format the knowledge to date; this will help you understand and advocate for the gut in CHARGE. We are excited in sharing with you the research undertaken by the Atlantic Canadian CHARGE syndrome research group. We have been studying the type of bacteria found in the gut called the “Gut microbiome”. We are continuing to recruit for this research at the conference, pop by and see us to learn more.

A3 • Motor Skills, Balance, and Physical Activity in Children with CHARGE Syndrome – Pamela Beach, PhD, SUNY Brockport; Lauren Lieberman, PhD, SUNY Brockport; Melanie Perreault, SUNY Brockport; Elizabeth Foster, PhD, Cal Poly Pomona University

The findings from the CHARGE conference in 2017 were that the children with CHARGE Syndrome had deficits in motor skills, particularly running and throwing. They also had difficulty with many of the balance tasks both static and dynamic. Increasing these motor deficits will likely increase motor competence for physical activity participation. These fundamental motor skills if not addressed at a young age will likely result in decreased quality of life in adulthood. With some careful and planned interventions these deficits can be remediated, improving the ability desire to be physically active and increasing their movement independence. Attendees will walk away with a better understanding of the importance of physical activity and the acquisition of motor skills as well as practical activities to promote motor competence in individuals with CHARGE Syndrome. They will also learn about new resources and programs that promotes physical activity for individuals with visual impairment or deafblindness.

A4 • Looking and Feeling like a Pro: Preparations for Walking into the IEP Meeting – Savannah Trice, Katherine Johnson, Kasee Stratton-Gadke, PhD, Mississippi State University

Do you have an upcoming IEP (Individualized Education Plan/Program) meeting? Whether you have felt the common intimidation entering the IEP meeting or this is your first—this presentation is for you. We will provide an overview of the importance of the IEP meeting, why this is a legally binding document, and what to expect during the meeting. Our goal is to provide strategies and information to decrease the intimidation factor and to increase parent participation and advocacy during the IEP meeting.

A5 • CHARGE 101: Introduction for New Families (Diagnosis and Features) – Meg Hefner, MS, Saint Louis University; Kate Beals, OTR/L, Southland Pediatric Therapy

The 101, 102, 103 series is designed for families with young children or new to conference and for professionals looking for a comprehensive overview of the medical and developmental features of CHARGE. In the 101 presentation, Meg will cover the diagnostic criteria and other medical features of CHARGE, including how various features affect early infant development. Why various labels are used (CHARGE, CHARGE-like, CHD7-related). How every child is unique and outcomes vary. Kate will elaborate on the differences in the sensory systems (especially hearing, vision, balance, proprioception) and sensory processing in CHARGE affect the way children experience themselves and the world around them. By understanding how the seven sensory systems operate differently in children with CHARGE, families, caregivers, therapists, and teachers can learn to recognize behaviors that suggest specific sensory processing issues and needs. Tips for dealing with these issues and needs will be presented. Kate's presentation will continue in the CHARGE 102 presentation.

A6 • Grandparents Gathering

BREAKOUT SESSION B Saturday, August 3, 2019 – 1:30–2:30 pm

B7 • Sex Hormones, Puberty and Teaching Safe Sexuality – Dr. Kasee Stratton, Mississippi State University; Jeremy Kirk, MD, FRCPC, FRCP, Birmingham Women's and Children's Hospital UK

All you ever wanted to know about sex hormones, preparing for puberty, and sexuality in CHARGE! Prof. Kirk will cover the current and potential future therapies to optimize puberty and also prevent long-term issues, such as osteoporosis. Dr. Stratton will present on the development of sexuality from identifying body parts to preparing for masturbation. Specific resources will be provided to guide educators, parents, and other professionals navigating sexuality from a young age through puberty.

B8 • Sleep in Children with CHARGE Syndrome – Christine Heubi, MD, Cincinnati Children's Hospital Medical Center; Susan Wiley, MD, Cincinnati Children's Hospital Medical Center

Sleep problems in CHARGE syndrome are estimated to occur in 59% of patients, and can be related to anxiety and behavioral concerns. Caregiver well-being has been found to suffer in children with CHARGE syndrome and sleep problems. Recommendations need to be made once identification of the underlying issues is determined. Sleep issues in children with CHARGE will be discussed including: (1) medical issues (night time feedings or treatments, obstructive sleep apnea, circadian rhythm disorder, pain), (2) visual impairment, (3) hearing loss, (4) environmental factors. Successful behavioral and environmental interventions will be described, as well as when further medical evaluation and treatment is needed. The use of light therapy and supplementation with melatonin will be reviewed as it applies to clinical improvement in certain patients. Attention will also be given to the evaluation and management of sleep

disordered breathing and upper airway obstruction. Case presentations will be used as examples for the work-up and management of children with CHARGE who have sleep problems.

B9 • Interpreter or Intervener? Identifying the Best Role for Communication Support in the Classroom –
Susanne Morgan Morrow, MA, CI, CT

An educational interpreter and intervener have overlapping roles in the classroom, which may cause confusion to parents of children with CHARGE Syndrome, thus leading to challenges when advocating for the best means of communication support in the classroom. This presentation will explore the differences and the similarities in the roles and assist families in identifying what role would best suite their child. Detailed examples will be provided to understand the variables that impact various types of communication needs. A case study approach will be used to assist in understanding

B10 • “Why are Children with CHARGE Syndrome So Lazy?” – David Brown, Deafblind Educational Specialist

This session will aim to provide an overview of the many issues which present challenges for the development and behaviour of people with CHARGE syndrome. The connection between these issues and the behavioral outcomes they provoke is often missed or misunderstood, and the session will clarify those connections and also suggest strategies which can help to improve developmental and behavioral outcomes.

B11 • CHARGE 102 – Kate Beals, OTR/L, Southland Pediatric Therapy; Laurie Denno, PhD, Behavior and Learning Consultant

Most children with CHARGE are not just deafblind (hearing and vision deficits) but have multiple sensory deficits: there are also issues with balance, smell, and even touch. This creates differences in the way they receive and process sensory information, which in turn affect how they experience themselves and the world around them. All of this has a significant impact on early motor development, later motor development and behavior. In this presentation, Kate will continue her 101 presentation: review the relationship between the sensory and motor systems of the body and explore how sensory processing differences are reflected in motor function (sitting, walking, moving, etc). Then Laurie will outline common behavioral challenges seen in children with CHARGE and point out the interaction of behavior and the environment. She will then present possible ways to mold behaviors and teach socially acceptable behavior through behavior analytic interventions and outline additional avenues for behavior improvement.

B12 • Grandparents Gathering

BREAKOUT SESSION C Saturday, August 3, 2019 – 2:45–3:45 pm

C13 • Counseling Parents of Children with CHARGE – Timothy Hartshorne, Central Michigan University

Early research suggested that families of children with severe disability were likely to be hopelessly damaged by the experience, with depression, anxiety, low self-esteem, loss, guilt, feeling overwhelmed, and marital troubles predominating. However, many researchers have begun to recognize that many families do quite well, and many report positive experiences and perceptions and even personal transformations. Some parents may turn to counseling for assistance. The question is, how counselors can work with families, and parents in particular, to help them cope with the negatives, and come to appreciate the unique, positive aspects of raising a child with severe disabilities. To accomplish this, counselors need to understand that personal transformation is possible, and that what on the surface appears to be an overwhelmingly

negative experience, can develop into something very positive. For the general conference, this presentation will emphasize the potential benefits of going to counseling for support in coping with the guilt and stress of raising a child with CHARGE. Issues addressed include guilt, stress, siblings, marriage, the future, and behavior. Pitfalls for counselors include misunderstanding the nature of this kind of grief, not understanding the parent experience, mistaking courage for denial, and seeing “specialness” in the parents (you are so strong). Objectives of counseling include focusing on strengths and good enough parenting, helping parents make connections and network, developing marathon skills, and personal growth.

C14 • From Interaction to Emerging Language: The DeafBlind Communicator – Chris Montgomery, Texas School for the Blind and Visually Impaired, DeafBlind Outreach Department

Have you ever considered how a person with DeafBlindness establishes the concepts that you and I (as sighted hearing people) learn incidentally, through our distance senses ... from observation? In this discussion, we will investigate how to initiate conversation and develop meaningful shared experiences. Exploring the importance of human connectedness through the lens of co-presence, mindfulness, and moments of joy; strategies for incorporating these ideas into our daily life will be examined.

C15 • Ear and Hearing Management in CHARGE – Daniel Choo, MD, Cincinnati Children's Hospital Medical Center

The ever-evolving state-of-the-art in interventions for hearing loss, and the ever-increasing understanding of the importance of communication abilities in the setting of CHARGE syndrome, creates a unique opportunity where the healthcare community is well-positioned to support the hearing and communication needs of individuals with CHARGE syndrome. However, the complexities intrinsic to CHARGE make accurate diagnosis and optimal treatment selection extremely challenging. Considerations need to be given to clinical and anatomic factors, developmental and behavioral factors as well as the individual and family's communication preferences. However, continual improvements in all of these facets create a compelling imperative to offer these options to patients and families. By enhancing communication, it is possible to achieve tremendous outcomes in terms of health outcomes, educational performance, family and social performance, as well as attaining the full level of an individual's potential.

C16 • Autism or CHARGE? Why Autism and CHARGE Syndrome Can Look So Much Alike and Identifying Effective Educational and Behavioral Interventions for These Learners – Julie Maier, California Deafblind Services; Maurice Belote, California Deafblind Services

There have been a lot of questions and discussion in the past several years about individuals with CHARGE also receiving a diagnosis of autism. During this presentation we will take a look at profiles of learners with autism spectrum disorders (ASD) and learners with CHARGE syndrome, point out similar characteristics in both profiles, and share a brief explanation of how vision and hearing loss and other sensory impairments can explain these “autistic-like” features. This presentation is NOT a discussion about the problems or merits of a dual diagnosis, but instead we will consider which educational and behavioral interventions can be most effective and helpful for learners with this profile. The majority of our presentation will focus on information about evidence-based practices in the field of autism and highly recognized field-based best practices related to deafblind education. We will offer families and educators suggestions for how to match and tailor several evidence-based ASD practices with deafblind practices when planning instruction and supports that provide the most beneficial outcomes for a learner with CHARGE.

C17 • CHARGE 103 – Robert Last, CHARGE Syndrome Association of Australia and New Zealand; Emma Mayes, Deafblind Services Minnesota

Communication is key to both learning and social interaction. Play is the work of young children. Rob will focus on early communication and behavior and the importance of establishing a meaningful

communication system as early as possible. Communication strategies from touch cues, pointing and pictures to sign and oral communication will be presented.. Play strategies will be demonstrated through video, photos and discussion. Emma will talk about optimizing educational settings for inclusive play. A challenge in the education of children with multiple sensory impairments is to help them acquire social skills which other children typically develop incidentally. These skills are needed for successful interactions with others in school and at home. Physical environments must be prepared for ease of movement, use of objects and toys. Staff must be educated so they understand and can help normalize the child's experiences within inclusive social settings (classroom, lunch, recess). Strategies will be presented, including the use of social stories, facilitating communication, teaching social language and norms, guiding appropriate interactions, and using play-based strategies to build strengths and facilitate the most accessible and inclusive socialization setting for the student. If time permits, Rob will present the use of passions in these strategies.

C18 • CHARGE Adult Workshop

This session is designed for individuals with CHARGE ages 16 and up.

Only interpreters and interveners are able to attend with the adult with CHARGE. The goal is to provide a safe and welcoming space to discuss topics specifically related to individuals with CHARGE and young adulthood. We will provide a series of presentations, discussions, and question and answer format presentations. Sessions will include topics such as sex, making and keeping friendships, using social media and dangers online, and advocating for yourself and discussing CHARGE with others, for example on the job and in the community. Time will also be allowed for open questions and answer.

BREAKOUT SESSION D Saturday, August 3, 2019 – 4:00–5:00 pm

D19 • Sibling Panel – Sarah Lent, Mallorie Beavers, Aaron Hartshorne, Macon Jones, Matthew Stanger, Kylie Steinhauer, Julia Williams, Daniel Wolfe

Siblings of individuals with CHARGE have unique experiences. This panel of siblings will share their experiences, both rewarding and challenging, of being raised with a sibling with CHARGE syndrome. Moderators will ask specific questions, after which the panelists will share their experiences and be available to answer questions about life in a CHARGE family.

D20 • Creating Communication Opportunities and Diversifying Choice-Making – Dr. Susan M. Bashinski, Missouri Western State University

The presenter will provide potential communication partners with *specific strategies* they might implement to: (a) increase the number of communication opportunities with which a learner is provided, and (b) facilitate a learner's growth in making authentic, meaningful choices. Participants in the session will learn how to structure a diversity of choice-making by embedding opportunities in the family's / learner's daily routines (e.g., with whom to complete an activity, how the task is to be completed, what the learner is to do after her choice is made). The presenter will, also, provide participants with structures for tracking a learner's preferences and choice she may/ may not make independently. The primary take-away from this session should be that communication partners should *not* make choices *for* the learner which she can learn to make for herself!

This session extends the content Dr. Bashinski presented in her two-webinar series for the CHARGE Syndrome Foundation during Spring 2019: *Laying the Foundation for Communication Exchange: Critical Points of Understanding and Practical Strategies*. It is important to note, however, that information included in this session will stand alone, for potential attendees who did not participate in either of the two webinars.

D21 • Oh, the Places They Could Go: Why Your Child Needs a Transition Plan – Megan Anderson, Mississippi State University

Transition plans are an important part of each students' Individualized Education Plan as they help students reach their potential to becoming as independent as possible as adults. When examining individualized education plans, it is often found that transition services are lacking or nonexistent. This presentation will not only explain the importance of transition plans for students with CHARGE, but also highlight important information parents need to know to appropriately advocate for their children when setting transition goals. Identifying goals that are appropriate, making sure those goals are measurable and making sure the goals help achieve a practical, positive outcome for students will be discussed.

D22 • Airway and Anesthesia Risks for Individuals with CHARGE Syndrome. How Can You Advocate for Best Practice? – Dr. Kim Blake, Dalhousie University; Dr. Catherine Hart, Cincinnati Children's Medical Center; with Jessica MacLean and Emily Chedrawe

Dr. Blake and Dr. Hart will give this platform presentation, which will help families recognize risks associated with airway problems and anesthesia. Individuals with CHARGE syndrome can have a variety of airway problems that can lead to airway obstruction, obstructive sleep apnea and difficulty managing the airway in an emergency. They also experience both minor and severe adverse events during and following sedation and general anesthesia. We will review the anatomic considerations and characteristic airway findings in children with CHARGE syndrome and discuss both clinical knowledge and basic science research in this area. This knowledge will empower families and individuals to advocate for best practice and care when interacting with anesthesiologists and surgeons. Key messages will be to combine surgeries and procedures under a single anesthesia whenever possible to minimize the number of anesthesia episodes.

D23 • Win:Win. When Parent and Nurse become Co-advocates – Lucy Marcheschi, Cincinnati Children's Medical Center; Ingrid Lobaugh

This presentation provides a framework of how to best organize, manage and communicate the needs of your medically complex child with your care providers, enabling the creation of a healthcare TEAM (Together Everyone Achieves More).

D24 • CHARGE Adult Workshop

This session is specifically for individuals with CHARGE ages 16 and up.

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BREAKOUT SESSION E Sunday, August 4, 2019 – 10:45–11:45 am

E25 • Proprioceptive Training – Elizabeth Foster, PhD, Cal Poly Pomona University

In addition to auditory and visual information, the proprioception sense also plays an important role in postural stability and feedback to the body on where the body is in space and how to respond to the environment and movement. These senses although typically examined separately are interdependent and intertwined in regards to the information that is provided to the brain. In children with CHARGE syndrome, typically there is an impairment to each of these three sense systems which may cause motor development

delay and different motor skills to be exhibited. However, any increase in function and development or recognition of the proprioception sense could potentially contribute to an increase in motor development and postural control. Gain a better understanding of the proprioception system and the impact it may have on motor skills, balance, and motor control while gaining insight into proprioception training activities that you can implement.

E26 • Meeting the Needs of Students with CHARGE Syndrome with Proficient Communication Skills in General Education – Robbie Blaha, M.Ed., Texas School for the Blind and Visually Impaired

The field of deafblindness has appropriately focused on learners with emerging language and multiple disabilities. This is a result, in part, of the Rubella epidemic that was foundational in the development of the field we have today. In the past, academic students with deafblindness were typically those with Usher Syndrome. Currently, as an effect of significant changes in etiology and quality of medical interventions, there is a growing population of congenitally deafblind students with CHARGE who have formal language. These students are undergoing and presenting considerable challenges to local districts that serve them. Though many of the essential strategies and best practices in our field do not address their needs, the underpinnings of the deafblind learning style: significant and ongoing lack of incidental information, concept development and social issues are very much at play with these students. These academic children and youth with deafblindness need our attention and support to assure that there are new and unique strategies that address the needs of this growing academic population.

E27 • A Visual Understanding of the Ophthalmic Pathway in CHARGE – Eniolami Dosunmu, MD, Cincinnati Children's Hospital Medical Center

The eye, the visual pathway and visual function are very important in CHARGE syndrome. This session will aim to show you the eye, the way the ophthalmologist sees it, and to show you how the CHARGE child, or adult sees the world. Using visuals, one will “look” into the eye of a CHARGE patient, and then “look” out at the world like a CHARGE patient. Following which, we will discuss ways to optimize visual acuity and visual function for the CHARGE patient. The session will also address Cortical Visual Impairment in CHARGE syndrome.

E28 • “CHARGE Syndrome Is Only a Part of You!”: How and When To Tell Your Child They Have CHARGE Syndrome – Haley Grant, Mississippi State University; Mary Aultman Hurley, Mississippi State University; Kasee Stratton-Gadke, PhD, Mississippi State University

When and how do I tell my child they have CHARGE syndrome? While each family will decide when the time is right for them, it is never too early or too late to learn how to begin this discussion. This presentation will cover the benefits of letting your child know about CHARGE and will address specific talking points. Child- and family- friendly strategies for introducing the diagnosis to your child and continuing the conversation will be presented. Dr. Stratton has worked with many families introducing this topic and will share examples and things to avoid when discussing this topic.

E29 • Feeding Difficulties and Aspiration in CHARGE Syndrome – Catherine Hart, MD, Cincinnati Children's Hospital Medical Center

Feeding difficulty affects up to 90% of children with CHARGE syndrome and aspiration is seen in 60-70% of children. Both dysphagia and aspiration can have significant impact on a child's health and quality of life. We will discuss anatomic, developmental and behavioral factors that contribute to feeding and swallowing difficulties. We will also review how aspiration is diagnosed and discuss management options.

E30 • HKNC Programs Supporting Transition – Molly Sinanan, Helen Keller National Center
Michael Richards, Helen Keller National Center

The Helen Keller National Center is the only Federally funded training facility in the U.S. for adults and youth who are deaf-blind. HKNC believes in person-centered training that supports individuals to live and work in the community of their choice. This presentation will be an overview of training programs at HKNC for transition aged youth, with a special emphasis on HKNC's new Deaf-Blind Immersion Experience program. The presentation will include descriptions of programs and consumer testimonials, as well as, a brief overview of communication strategies that can be utilized in the community and at work.

BREAKOUT SESSION F Sunday, August 4, 2019 –1:30–2:30 pm

F31 • APE Specialists and Parents Collaborate: A Dynamic Discussion of Physical Gross Motor Needs, Fitness, and Sport for Children with CHARGE – Dr. Linda Hilgenbrinck, Denton Independent School District; Dr. Lauren Cavanaugh, Buena Vista University; Dr. Lauren Lieberman, The College at Brockport; Molly Roberts; Callie Sutcliffe

Given the available research on health and medical concerns for children with CHARGE, there is agreement that movement skills are often delayed and/or poorly developed and that children with CHARGE display significant physical gross motor difficulties in reaching motor milestones. Such difficulties continue throughout the school year, impacting overall fitness and opportunities to develop sport interest and involvement. Individualization of physical education programs can only occur after a comprehensive physical motor assessment (TGMD2/3) has been conducted by a highly qualified educator. However, in addition to formal assessment, parents play a critical role in conveying their personal experience in support of their child's physical education, adaptations, fitness, and sport involvement. This session will feature how gross motor skill assessment data can be appropriately shared with parents in partnership for optimal outcomes. Recommendations will be shared on the need to effectively advocate and collaborate with others so children with CHARGE may develop the functional physical gross motor skills necessary to enhance fitness and sports skills that lead to life-long involvement in physical activities.

F32 • The Endocrine System in CHARGE Syndrome – Meilan Rutter, MD, Cincinnati Children's Hospital Medical Center

The endocrine system is important for many functions of the body, including growth, weight gain, puberty and bone health, and for sustaining life. Endocrine issues are common in people affected by CHARGE syndrome. The most frequent of these are slow growth, and the lack of hormones needed for development of the genitals before birth and changes in the body at puberty (the lack of these hormones is called "hypogonadotropic hypogonadism"). However, many families and people affected by CHARGE syndrome may not receive proactive or optimal endocrine care, or care that is integrated with their other complex health needs. This presentation will: (1) provide a general overview of the endocrine system, (2) review the endocrine issues in children and adolescents with CHARGE syndrome, and (3) discuss the evaluation and options for treatment of these issues. Finally, proactively addressing endocrine needs is an important part of interdisciplinary care, and may improve health and psychosocial adjustment for people with CHARGE syndrome.

F33 • Friendships, Belonging and Connection – Rob Last, CHARGE Syndrome Association of Australia and New Zealand

Over the years in discussions with parents the topic of 'friendships' has arisen and the challenges children and young adults sometimes experience in developing and sustaining friendships. Often, apart from the

family, it is the medical, therapy, early intervention and education teams who become the friendship circle rather than kids from the neighbourhood. In this presentation I will explore friendships, belonging and connection. This will include discussion on diversity and difference, self-esteem and confidence, peer acceptance, bullying, building capability and strategies for nurturing friendships at home and at school.

F34 • “I Wish They Could Tell Me What They Need”: Increasing Communication Through Behavior – Dr. Kasee Stratton, Mississippi State University

How do I teach my child to communicate? Why does my child gain a few signs/words and then lose them? What do I do when my child tantrums because I don't understand what they want? We hear you! This presentation will discuss an approach to building communication beyond speech therapy—functional communication training (FCT). FCT is a well-researched, evidenced-based approach to understanding behavior and increasing day-to-day communication, including your child's daily wants and needs. We will include all forms of communication including vocal speech, sign language, augmentative technologies (i.e., communication device), and picture exchange, as well as videos of individuals with CHARGE participating in communication training.

F35 • Application of Behavioral Strategies to Address Feeding Difficulties Among Children with CHARGE Syndrome – Dr. Hallie Smith, Kennedy Krieger Institute

This presentation will include an overview of various evidence-based behavioral strategies to address food refusal (e.g., tube dependence, liquid dependence, crying/screaming when food is presented, turning head away from or hitting the spoon of food) and food selectivity (e.g., eating only a few select foods, refusing to eat foods from all food groups, eating only certain brands/types of foods) in children with CHARGE. The presentation will also discuss three specific case examples. Data from three individuals will be presented to support the use of various behavioral strategies at decreasing tube dependence, increasing acceptance of solid food and liquid by mouth, increasing variety of food consumed, increasing self-feeding, and decreasing problem behavior during meal times. Overall, this presentation will provide attendees with an increased understanding of how feeding difficulties in children with CHARGE syndrome can be developed and addressed from a behavioral perspective as well as an understanding (based on data) that behavioral strategies do lead to positive long-term feeding-related outcomes among individuals with CHARGE syndrome. This presentation will also provide resources for locating professionals in this field.

F36 • Sensing Connections: Peer-to-Peer Grief Support for Families – Megan Cote, National Center on Deaf-Blindness; Jody Wolfe, CHARGE Syndrome Foundation

Over the course of the past 8 years, an average of 91 children birth to 21 years of age have died annually on the national deaf-blind child count. Due to this, the National Center on Deaf-Blindness brought together a group of parents from across the deaf-blind network (with kids of varying age and etiology) to talk about what would have helped them in terms of support that could have been provided by the deaf-blind community when their child died. As a result, individuals were trained in grief support, a 10 week curriculum was created, and the “Sensing Connections Peer-to-Peer Grief Support ” began to provide much needed connection and healing for these families.

G37 • Preparing the Body and the Environment. Orientation and Mobility for Individuals With CHARGE Syndrome – Suzanne Dinwiddie, M.Ed., Tennessee Deaf-Blind Project; Lee Ellen Whitefield, M.Ed., Metro Nashville Public Schools; Kristi Jones, Tennessee Deaf-Blind Project

Orientation and Mobility (O&M) develops the skills necessary for purposeful travel. For individuals with CHARGE Syndrome moving through different environments can be difficult because CHARGE is a multisensory impairment that affects all aspects of an individual's life; especially movement. Individuals must develop a sense of "where they are" before they can move beyond their personal space. This awareness is exceptionally difficult with individuals who have vestibular and proprioceptive dysfunction. To expand their world, a person first needs to understand and explore the setting "within reach" in a meaningful way. Practical strategies such as "anchoring" the body to a stable site, embedding a movement into daily routines, and using consistent communication methods are essential. Once oriented, strategies can be implemented to promote meaningful movement and travel. O&M techniques demonstrate how to optimize visual and auditory abilities, engineer landmarks to provide best visual, tactual, and auditory input, and provide literacy opportunities through travel journals and route books. Strategies implemented should be in alignment with every person's unique sensory impairments and needs in mind and used across all settings.

G38 • Promoting Social Skill Development in Children with CHARGE – Megan Schmittell, Central Michigan University and Perkins School for the Blind

Social skills include a variety of behaviors that allow individuals to engage in positive interactions with others. Children with CHARGE are often described as socially interested but socially immature. Children with CHARGE syndrome may experience delays in social skill development because of the multi-sensory impairment they often experience. Because of the limited information they receive through their senses, children with CHARGE often do not know how to act in social situations. Additionally, children with CHARGE often spend a lot of time in the hospital and may not have exposure to early social interactions that teach children how to appropriately play with other children. Finally, children with CHARGE syndrome are often medically fragile, so they may be inhibited from having social experiences. Without these experiences, children with CHARGE are unable to adequately develop social skills. To help promote social skill development, caregivers and teachers can provide explicit instruction on social skills. Additionally, they can provide them with opportunities to socialize with others practice skills taught. The presentation will take an in-depth review of strategies to promote social skill development.

G39 • Using Photos To Tell Your Child's Story to Their Educational Team – Donna Carpenter, Kentucky DeafBlind Project

Using Photos to Tell Your Child's Story to their Educational Team Answering all your educational team's questions using a short digital video that includes 20 photos and your narrative. Share your valuable perspective of your child as part of your family. Your short digital video will provide the educational team information about strengths, preferences, who your child's favorite person is, what pets are at home and family vacations. Change your child's educational team's perspective about your child from a "can't do" to a "can do" mindset.

G40 • An Interactive Seminar in Genetics: All You Want To Know About the Genetics of CHARGE Syndrome – Christa de Geus, MD, University Medical Center Groningen

After a short introduction, all questions of the participants regarding genetics, the CHD7 gene, mutations, recurrence risk, et cetera, will be answered using instructive illustrations. A handout that explains the main

issues for a lay audience will be provided. We will also present the results of our recent update of the CHD7.org website. CHD7.org aims to be a comprehensive source of clinical and molecular genetic information on known CHD7 mutations. Based on the experience of previous years, we will offer parents the opportunity to discuss the specific genetic test results of their child with us in short sessions after the seminar.

G41 • That's Weird. Why Would my Child Act This Way? Trying To Make Sense out of Behavior – Tim Hartshorne, PhD, Central Michigan University

The first thought that seems to accompany concern about the behavior of an individual with CHARGE is how to stop it. However, it is very hard to change a behavior you do not understand. Behavior does not occur in a vacuum; behavior is chosen because in some way it works for the individual. Our first thought should be how it works. Why does the child with CHARGE hang upside down? Because it compensates for some of their sensory deficits. Knowing what to do, if anything, to change a behavior benefits enormously from understanding why the child does it. Instead we are tempted to provide a diagnosis, particularly autism, to explain the behavior. But such “explanations” do not explain anything. Typical questions we should be asking ourselves include, “is this behavior a way to cope with pain,” “is this behavior a means for dealing with anxiety,” “does this behavior help compensate for sensory issues,” “does this behavior make the person feel more secure in their environment?” These are the questions that lead us to interventions that can work.

G42 • Organizing Contexts for Adult Life Activities During Transition Planning – David Wiley, Texas School for the Blind and Visually Impaired and Texas DeafBlind Project

Transition Planning in schools often centers around a one-dimensional focus on preparation for college and career. Though this is important, for some students this traditional focus does not seem like a good fit. These students, especially those who expect to need long-term support or care in adult life, need a different focus and way to plan. For all students, adult life is much more wide-ranging than any narrow focus. In addition to career and learning opportunities, people typically find purpose, satisfaction, and joy in forming social relationships; joining organizations; doing community service; developing hobbies; engaging in group and individual recreation and leisure activities; and actively participating in family and home life. All these contexts are important. Student may experience sensory barriers to easy information gathering or limited opportunities to explore new activities. In such cases, students may have conceptual gaps in understanding community roles and finding contexts to pursue personal interests. For transition to be most meaningful, students must have support to explore and discover personal interests, and support in organizing those interests into achievable contexts.

BREAKOUT SESSION H Sunday, August 4, 2019 – 4:00–5:00 pm

H43 • Interveners - Key members of the Educational Team – Beth Kennedy, DeafBlind Central: Michigan's Training & Resource Project

Interveners provide support for students who are DeafBlind. CHARGE Syndrome is a leading cause of deafblindness, and people who have CHARGE can benefit from the increased access to environmental and educational information that interveners provide. The intervener can serve as a key member of the educational team, helping students who are deafblind to achieve more and reach their potential. Interveners accomplish this by working with other team members to increase the implementation of the IEP goals.

H44 • Unlocking the Door to an Envable Life: Person-Centered Planning Benefits, Strategies, and Case Examples – Nancy Salem-Hartshorne, PhD, Delta College

Person-centered planning is a powerful and holistic tool that helps people with and without disabilities make and realize life goals, especially during times of transition. It works for children, adolescents, and those moving to adult services, employment, and living arrangements. Individuals and those who love them have the main say in the services and supports they receive, are able to build confidence and strength, and have opportunities to take a major part in planning for and controlling their lives. Person-centered planning can help people to be seen by their strengths rather than being defined by their weaknesses or disabilities. The support team focuses on the individuals with disabilities and their needs by putting them in charge of the direction for their lives, and does not rely on the systems that are set up to serve them. This puts the emphasis on "thinking out of the box." This presentation will highlight the powerful reasons for using person-centered planning, Person-Centered planning tools and how they are used, and some case studies that show how Person-Centered Planning processes have recently changed the lives of individuals who are deafblind, and most especially those with CHARGE syndrome.

H45 • Growth in CHARGE Syndrome – Dieuwerke Dijk, MD, University Medical Center Groningen

Growth retardation affects 60-72% of children with CHARGE syndrome and is therefore one of the most prominent problems. We systematically searched for studies that presented growth data and reviewed them. In this presentation, we will discuss why it is important to monitor growth and what is currently known about growth in CHARGE syndrome. This will include factors that may influence growth in CHARGE syndrome and possible interventions to prevent or minimize short stature. There will be time to share personal experiences, for questions and discussion

H46 • Taking CHARGE of the Classroom: a Teacher's Perspective on Sensory Strategies in the Classroom – Sharon Stelzer, M.Ed., Perkins School for the Blind; Sara Espanet, M.Ed., Perkins School for the Blind

In this session, the presenters will discuss the importance of sensory breaks and sensory strategies for students with CHARGE Syndrome. They will give concrete examples of ways to incorporate sensory strategies throughout the school day. There will be interactive discussion as well as question and answers. Participants will come away with an understanding of how various sensory techniques can be used within the classroom or at home.

H47 • Linking Assessment to Intervention: Functional Analyses and CHARGE – Hailey Ripple, Mississippi State University; Kasee Stratton, PhD, Mississippi State University

Among the multitude of medical concerns that present in CHARGE Syndrome, another common concern is engagement in problem behaviors that vary across topography and etiology (e.g., pain, anxiety, sensory concerns; Hartshorne et al., 2017). Studies examining the use of assessment procedures of problem behavior in the CHARGE population are limited, but are a necessary first step in order to inform efficient and effective treatment. This presentation will review a study that examined the utility of brief functional analyses (BFA; Northup et al., 1991), a well-documented procedure used to identify the function(s) of problem behaviors, for the first time in individuals with CHARGE Syndrome. Participants included individuals between the ages of 8 to 22 years old diagnosed with CHARGE Syndrome who presented with varying problem behaviors. Results indicated that BFA procedures were successful in identifying the function of problem behavior with four out of five participants. Participants will leave with greater understanding of the role of behavioral assessment, the need for determining the function (reason) of challenging behavior and how this maps onto intervention design and outcomes.

CHARGE RESEARCH - THANK YOU

Many of you have participated in research at previous conferences. Information gathered from those projects is critical to furthering knowledge about CHARGE. Results and other information resulting from YOUR PARTICIPATION in research is being presented here in Dallas. Check out some of the presentations and posters, including:

PD = Professional Day Conference **ICC** = International CHARGE Conference (session #) **Pos** = Poster

ABA, Cognitive-Behavior Therapy, or Word of Mouth. Lindsay Fairchild. **PD & Pos**
Are Parents Satisfied? The Ins and Outs of IEP Goals. Lindsay Fairchild. **PD & Pos**
Assessing the Quality of Behavior Services for Students with CHARGE Syndrome. Emily Mathis. **Pos**

Behavior Strategies: Feeding. Hallie Smith. **ICC #35 & Pos**

Conserved Roles for CHD7 in Transcriptional Elongation of Genes Involved in Neural, Neural Crest, and Inner Ear Development. Elaine Ritter. **Pos**

Creating Communication Opportunities. Susan Bashinski. **ICC #20 & Pos**

Development of an Educational checklist. Lily Slavin: **PD & Pos**

Fatigue: A proposed study on the experiences of adolescents and young adults with CHARGE Syndrome. Anna Weatherly. **Pos**

Functional Behavior Analysis & Intervention. Hailey Ripple. **ICC #47 & Pos**

Growth in CHARGE syndrome. Dieuwerke Dijk & Monica Wong. **ICC #45 & Pos**

IEP like a pro. Kasee Stratton & Johnson. **ICC #4**

Investigation of Two Methods for Treating Sleep Problems Among Children with CHARGE Syndrome. Ben Kennert. **PD & Pos**

Motor Skills, balance, and physical activity in children with CHARGE Syndrome. Pamela Beach & Lauren Liberman. **ICC #3 & Pos**

Novel genetic etiologies of CHARGE syndrome identified with whole genome sequencing. Stephanie Bielas. **PD & Pos**

Postural Orthostatic Tachycardia Syndrome (POTS) in Adolescents and Young Adults with CHARGE Syndrome. Julia Morrison. **Pos**

Promoting Social Skill Development in Children with CHARGE. Megan Schmitt. **ICC #42 & Pos**

Sandra Davenport Fellowship Program. Sara Espanet. **Pos**

Teaching Safe Sexuality. Kasee Stratton and Emily Mathis. **ICC #7 & Pos**

Unique Pattern of Social Skills in Individuals with CHARGE Syndrome. Lori Swanson & Meg Hefner. **Pos**

Why Your Child Needs a Transition Plan. Megan Anderson. **ICC #21 & Pos**

CHARGE RESEARCH - WE NEED YOU

The best information about CHARGE comes from people with CHARGE and their families. There are 10 projects enrolling here in Dallas. Please look these over and participate in whatever you can. For more information, go to the Research Table by Registration, go to Research Area on 28th floor or contact the researcher by email or text message

- 1) Fathers' Experience with CHARGE. Any Father (bio, step, guardian, father figure). Confidential interviews (30-60 minutes) to identify key themes and issues around fathers' involvement in their child's health care, overall development and education settings. Jerry Petroff petroff@tcnj.edu 856-577-2400
- 2) Early Childhood Home Environment and Motor Skills. How might home environment affect motor development? Parents of children age 18 months to 42 months. Parent questionnaire, 15-30 minutes. Melanie Perrault mperrault@brockport.edu 585-755-5101 NEAR CAMP ABILITIES AREA
- 3) Impact of Home Intervention on Gross Motor Skills. Can a home program help improve gross motor skills and balance? For children 4-12 years of age, 30-45 minutes. Parent questionnaire, assess child's motor skills & balance, practice at home. \$50 compensation at the end. Melanie Perrault mperrault@brockport.edu 585-755-5101 NEAR CAMP ABILITIES AREA
- 4) Stool Microbiome in CHARGE. Test to see if the gut microbiome is different in individuals with CHARGE compared to those who do not have CHARGE (especially their brothers and sisters). Child with CHARGE age 2-18 years, plus sibling control, 15-30 minutes. Parent questionnaire and stool collection kits for child and sibling (mail back). Emily Chedrawe emily.chedrawe@dal.ca 902-489-1887
- 5) CHARGE Syndrome Genetics Research. DNA samples (from saliva) will be collected from people with CHARGE features, their parents and siblings to look for new genetic causes & genes that influence features. All ages, 15-30 minutes. michiganCHARGEresearch@med.umich.edu
- 6) Social Play in Elementary Age. Interview parents about social play in children with CHARGE. Parents of children with CHARGE in grades 1-6 (~6-13 years of age). Short video training; questionnaire, 30-60 minutes. Megan Schmittel schmi2m@cmich.edu 636-359-3291
- 7) Fatigue in CHARGE. Understand more about physical and mental exhaustion in CHARGE. Individuals with CHARGE 15 and up. Online questionnaire; interview. *If you need ASL interpreter, we need to know ahead of time. 60 minutes. Anna Weatherly weath1a@cmich.edu 601-606-2461
- 8) Attitudes About Sexuality in CHARGE. Confidential interview and questionnaire just to ask about your opinions. Adults with CHARGE (18 and over) and parents of individuals with CHARGE (all ages). 15-30 minutes. Emily Mathis eas216@msstate.edu 601-606-2461
- 9) POTS -- Do you get dizzy? Really tired? Heart beat fast? Hot weather bother you? POTS (postural orthostatic tachycardia syndrome) may be more common in CHARGE than in the general population. Individual with CHARGE 12 years and older, with parent. Questionnaire. 30 minutes. Julia Morrison julia.morrison@dal.ca 902-981-8371
- 10) Self-Injury Behavior in CHARGE. We want to learn more about these behaviors - frequency, severity and body site of self-injury. Parents of children over 1 year of age. Questionnaire. 15-30 minutes. Lyndsay Fairchild lmq8@msstate.edu 601-519-9460



The Ethan Wolfe Recreational Assistance Program ("EWRAP")

EWRAP provides individuals with CHARGE syndrome the opportunity to participate in recreational activities. Thanks to a generous gift from the Wolfe family and friends, in 2015 the Foundation launched a new need-based program designed to give members of the Foundation the opportunity to purchase recreational equipment or participate in recreational programs. During Ethan Wolfe's 12 years of life, he rode an adaptive bike, attended special recreational camps, participated in swimming lessons, music class and much more. We are pleased to honor Ethan's memory by helping others pursue similar, fun activities.

We've helped dozens of individuals with CHARGE participate in biking, swimming, horseback riding, music & computer classes and summer camp. Applications for the next round of awards will be available in early 2020. Check our newsletters and website for more information.

Everyone deserves a chance to play!

Vision: A Better World for People with CHARGE Syndrome

Mission: We lead and partner to improve the lives of people with CHARGE syndrome locally, nationally and internationally through outreach, education, and research.

- Provide a broad network of support to individuals, families and professionals
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CHARGE for Connor

Nikki Logsdon

513-349-5359

chargeforconnor@gmail.com

www.chargeforconnor.org

facebook.com/chargeforconnor

CHARGE for Connor is a nonprofit organization formed in 2014 as a way to remember Connor Logsdon and carry on his legacy. Our mission is to help promote awareness of CHARGE syndrome while supporting the CHARGE community through aiding individuals with CHARGE syndrome, being involved with The CHARGE Syndrome Foundation and helping support the CHARGE Center at Cincinnati Children's Hospital.



Notes

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Cincinnati Children's Hospital Medical Center

CHARGE Team
3333 Burnet Avenue
Cincinnati, Ohio. USA. 45229
Phone: 513-636-2518
CHARGE@cchmc.org



Medical Directors:

Susan Wiley, MD, Director, Division of Developmental and Behavioral Pediatrics
Daniel Choo, MD, Director, Pediatric Otolaryngology Head and Neck Surgery

The CHARGE Team at Cincinnati Children's is comprised of a multidisciplinary group of clinicians, therapists, counselors and family advisors whose goal is to provide a comprehensive and coordinated model of healthcare to children and families with CHARGE syndrome in order to help these children reach their full potential. Our objective is to deliver the best interventions at the optimal time and in a well-coordinated approach in order to change the outcome for these children.

DEAFBLIND CITIZENS IN ACTION

9939 Hibert Street
San Diego, CA 92131

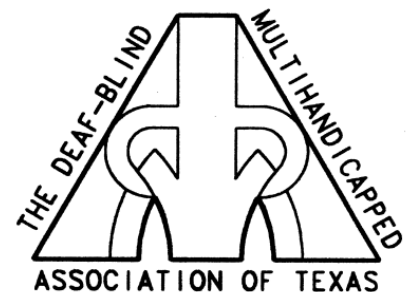
DeafBlind Citizens in Action (DBCA) is a disability rights organization that strives for a better world for all. It was founded by young deafblind adults. Their mission is to empower people who are deafblind through education, technology, and legislation and to ensure that deafblind persons have a strong political voice so that they may lead productive lives with equal opportunities.



DBMAT

The Deafblind Multihandicapped Association of Texas
Vivecca Hartman, President
Cell: 713-231-7508
President@dbmat-tx.org
www.dbmat-tx.org

DBMAT is a family and professional support group in Texas. We adopted formal By-Laws in 1975 and were chartered by the state of Texas as a non-profit organization in July 1976. The MISSION of DBMAT is to promote and improve the quality of life for all Texans who are deaf-blind multihandicapped. We support the establishment of educational, rehabilitative, vocational and independent living opportunities of these individuals for all ages.



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Texas School for the Deaf

Educational Resource Center on Deafness
1102 S. Congress Avenue
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The Educational Resource Center on Deafness serves the outreach mission for the Texas School for the Deaf to provide statewide support, services and programs to deaf/hard of hearing students, their families and the professionals who serve them. Services and programs we provide include Family Signs, Texas Deaf/Hard-of-Hearing Mentor Program, Family Weekend Retreat, Texas Guide By Your Side and Communication Skills Workshop.

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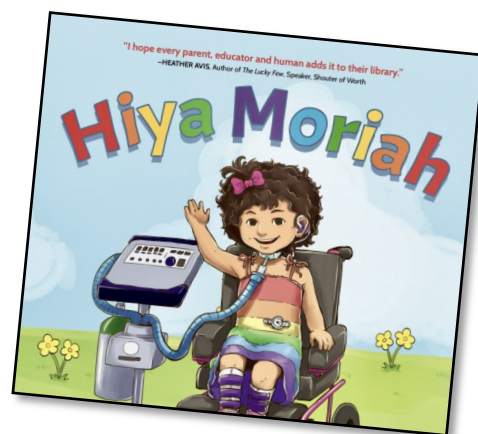
Hiya Moriah

Victoria Nelson

www.victorianelsonbooks.com

408-500-7317

Victoria lives in the greater Los Angeles area, and is Mama to 4 children. Victoria wrote Hiya Moriah in honor of her late daughter, Moriah. Hiya Moriah is about a young girl's journey with CHARGE Syndrome, with a timeless message of love and acceptance, and just waving and saying "hiya" when making a new friend with different abilities.



Helen Keller National Center

141 Middle Neck Road

Sands Point, NY 11050

516-944-8900

www.helenkeller.org/hknc

South Central Regional Office

516-393-7997 (voice)

512-605-0714 (videophone)

molly.sinanan@hknc.org



Helen Keller
NATIONAL CENTER
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The mission of the Helen Keller National Center is to enable each person who is deaf-blind to live and work in his or her community of choice. HKNC is the only federally funded training facility in the nation for youth and adults who are deaf-blind. HKNC offers consultation and specialized services to consumers, families, and professionals, nationwide, to develop a greater understanding of the abilities and preferences of individuals who are deaf-blind or who are experiencing combined loss of vision and hearing. Our eleven (11) regional representatives and senior adult specialists are the first point of contact in providing information and referral, resources, and training opportunities.

iCanConnect

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www.icanconnect.org

iCanConnect provides free equipment and training for people with both significant hearing and vision loss who meet disability and income guidelines, to help them connect with family, friends, community and the world. iCanConnect, also known as the National Deaf-Blind Equipment Distribution Program, is a program of the Federal Communications Commission (FCC), with local contacts in each state. Find your local contact at iCanConnect.org or call 800.825.4595.

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Kathy Buckley

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Kathy Buckley is a five-time American Comedy Award Nominee as Best Stand-Up Female Comedienne and the winner of countless other awards for her work. Her inspirational Goalcast video has been viewed over 30 million times. An active volunteer for causes close to her heart, Kathy helps numerous children's charities such as No Limits for Deaf Children. A sought after speaker, we welcome Kathy back for her message of love, acceptance, and overcoming struggles.

National Center on Deaf-Blindness (NCDB)

The Research Institute at Western
Oregon University
345 N. Monmouth Ave.
Monmouth, OR 97361
info@nationaldb.org
www.nationaldb.org



NATIONAL CENTER ON DEAF-BLINDNESS

The National Center on Deaf-Blindness (NCDB) is a technical assistance center funded by the Federal Department of Education to improve the quality of life for children who are deaf-blind and their families through our 6 national initiatives: 1) Early Identification and Intervention; 2) Family Engagement; 3) Assessment, Planning and Instruction; 4) Interveners and Qualified Personnel; 5) Transition; and 6) the National Child Count.

National Family Association for Deaf-Blind (NFADB)

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Sands Point, NY 11050
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NFADB is a nonprofit national organization that has served families with individuals who are deaf-blind since 1994. Originally started by and for families, it has expanded to include any interested professionals and other individuals or organizations who wish to empower the voices of individuals who are deaf-blind.

Notes

Sponsor, Exhibitor & Advertiser Information

National Research & Training Center on Blindness & Low Vision

PO Box 6189
Room 150 Industrial Education Building
108 Herbert South
Mississippi State, MS 39762
662-325-2001
800-675-7782
blind.msstate.edu



The NRTC on Blindness & Low Vision at Mississippi State University uses research and knowledge translation to support our mission: To enhance employment and independent living outcomes for individuals who are blind or visually impaired through research, training, education, and dissemination. In addition to research, the center offers on-line courses, training activities, workshops, education outreach, conferences, and webinars. Our staff is also available to help employers, consumers, and professionals with technical assistance in a variety of areas.

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partnersresource@sbcglobal.net
www.prntexas.org



Partners Resource Network is a non-profit agency that operates the Texas statewide network of Training and Information Centers (PTIs) funded by the U.S. Department of Education—Office of Special Education Programs (OSEP). The three PTI Projects: PATH, PEN, and TEAM serve parents of children and youth with disabilities from the ages of 0 to 26 as well as youth self-advocates ages 14-26.

We help parent and self-advocates: Understand disabilities, find program and service options, participate as team members with professionals during IEP preparation, understand state and federal laws, communicate more effectively with professionals, gain needed advocacy skills and build a support network. All of our services are provided at NO COST for parents of children and youth with disabilities ages 0-26.

Perkins School for the Blind

175 Beacon Street
Watertown, MA 02172
617-972-7573
Amy Fox Ferreira
Director of Admissions & Enrollment
amy.ferreira@perkins.org
www.perkins.org



Perkins School for the Blind serves students with visual impairments, CVI, deafblindness and CHARGE from birth through age 22. We teach the Expanded Core Curriculum to help students access core academics and acquire the social and independent living skills their sighted peers learn incidentally. Learn more at Perkins.org.

Sponsor, Exhibitor & Advertiser Information

Sensity Deafblind and Sensory Support Network of Canada

50 Main St.
Paris, ON
Canada
N3L 2E2
1-877-760-7439
info@sensity.ca
www.sensity.ca



Sensity – Deafblind and Sensory Support Network of Canada believes that the principle of equal rights and self-determination is the cornerstone to living a meaningful and fulfilled existence. It is the path to happiness, growth and independence. At Sensity we deliver meaningful experiences for people who are deafblind, so they are empowered to make their own choices and to experience life to its fullest.

We understand that people who are deafblind connect, communicate and experience the world differently. At Sensity, we deliver programming, support services, training, education and awareness to help people who are deafblind and their families have meaningful experiences and a level playing field.

Sorenson Communications

4192 south Riverboat Road
Salt Lake City, UT 84123
801-287-9401
svrs.com



Sorenson Communications, LLC (svrs.com) is the leading provider of Video Relay Service (VRS), which connects Deaf people who use sign language with the hearing world. Sorenson's innovative products and services offer Deaf callers the option to conduct real-time calls (including 911 emergency calls) through a qualified American Sign Language (ASL) interpreter.

Sprint IP Relay

801 2nd Ave., Suite 842
Seattle, WA 98104
206-330-0861
www.sprintrelay.com

Sprint Accessibility for All: Bridging the telecommunications gap for people with disabilities: products and services that eliminate barriers, enhancing people's lives, including individuals who have hearing or speech loss. Sprint offers IP Relay, Captioned Telephone, Sprint Teleconference Captioning, Federal Relay Service, wireless Relay and Sprint Vision Stores; Accessibility Care, and Video Customer Service in American Sign Language. sprint.com/accessibility



Notes

Sponsor, Exhibitor & Advertiser Information

Talking Book Program

Texas State Library and Archives Commission
P.O. Box 12927
Austin, TX 78711-2927
www.TexasTalkingBooks.org
1-800-252-9605
Tbp.services@tsl.texas.gov

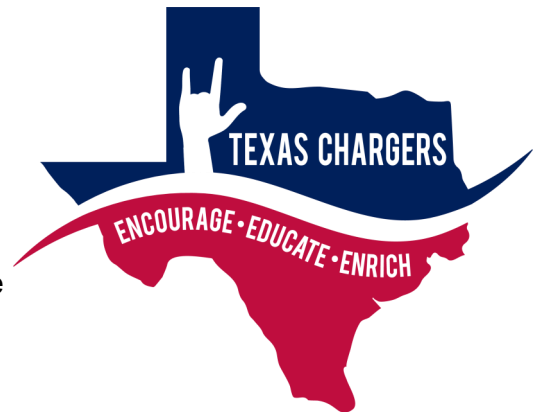
The Talking Book Program (TBP) provides digital audio, large print and Braille books and magazines to Texans who cannot read standard print due to a qualifying visual, physical or reading disability. The Talking Book Program is part of the National Library Service for the Blind and Print Disabled, Library of Congress.



Texas Chargers, Inc.

213 Boulder Drive
Navasota, TX. 77868
kathi@centex.net
325-456-6591
www.texaschargers.org

Texas Chargers, Inc. encourages, educates, and enriches individuals and families living with CHARGE syndrome. One of the ways we accomplish our mission is by organizing an annual two and a half day family retreat. Starting in 2005 with a handful of families, the retreat has grown to 40+ families. The retreat provides a stress free environment for families to connect with others touched by CHARGE syndrome, so they can share the joys and address the challenges of raising, supporting, or being a person living with CHARGE syndrome.



Texas Tonix

325-456-6550
www.texastonix.com

Texas Tonix is Texas owned and Colorado grown, providing certified third party tested CBD products to support your family's health. We carry a variety of full spectrum and 0.0% THC oils, sports rubs and more to fit your needs. At Texas Tonix, we believe in Family Principles, Trust, Quality and Transparency in our CBD supplements. Plus, a 100% satisfaction guarantee!



Notes

Sponsor, Exhibitor & Advertiser Information

Texas School for the Blind and Visually Impaired

1100 West 45th Street
Austin, TX 78756
512-206-9183
Debra Sewell, Curriculum Director
sewelld@tsbvi.edu
www.tsbvi.edu



The Curriculum Department at the Texas School for the Blind and Visually Impaired, TSBVI, develops content and methodology that is modified to meet the needs of different student populations including students who are blind, have low vision, and those with DeafBlindness. Our curricula are used on our campus, throughout the state of Texas, across the nation, and around the world.

Office of Deaf and Hard of Hearing Services

Rehabilitative & Independence Services
Health, Developmental & Independence Services
dhhs.mailbox@hhsc.state.tx.us
Voice: 512-438-4880
Videophone: 512-410-1387



TEXAS
Health and Human
Services

The Office of Deaf and Hard of Hearing Services works in partnership with people who are deaf or hard of hearing to eliminate societal and communication barriers to improve equal access for people who are deaf or hard of hearing. DHHS advocates for people of all ages who are deaf or hard of hearing to enable them to express their freedoms, participate in society to their individual potential, and reduce their isolation regardless of location, socioeconomic status, or degree of disability.

Deaf and Hard of Hearing Services

Vispero (Freedom Scientific, Enhanced Vision, & Optelec brands)

17757 US Highway 19 N., Suite 560
Clearwater, FL 33764
1-800-444-4443
www.vispero.com

Vispero™

Company description:

Vispero is the world's leading assistive technology provider for the visually impaired. We have a long history of developing and providing innovative solutions for blind and low vision individuals that help them reach their full potential.

Vispero combines two Latin words: visio and spero. Visio means "the vision"; and spero means "hope". At Vispero, we inspire hope, determination, and independence through our family of brands: Freedom Scientific, Enhanced Vision, Optelec, and The Paciello Group.

Notes



CHARGE for Connor



Connor Michael Logsdon

September 29, 2012 – January 10, 2014

As a way to celebrate Connor's life and continue his legacy we have formed the **CHARGE for Connor** nonprofit organization. The purpose of this public charity is to raise awareness for CHARGE syndrome and assist the CHARGE community.

www.chargeforconnor.org
chargeforconnor@gmail.com
facebook.com/chargeforconnor



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- Access to Sprint Accessibility Care
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- Improved accessibility for people who are Deaf, Hard of Hearing, DeafBlind, or have Speech Disability

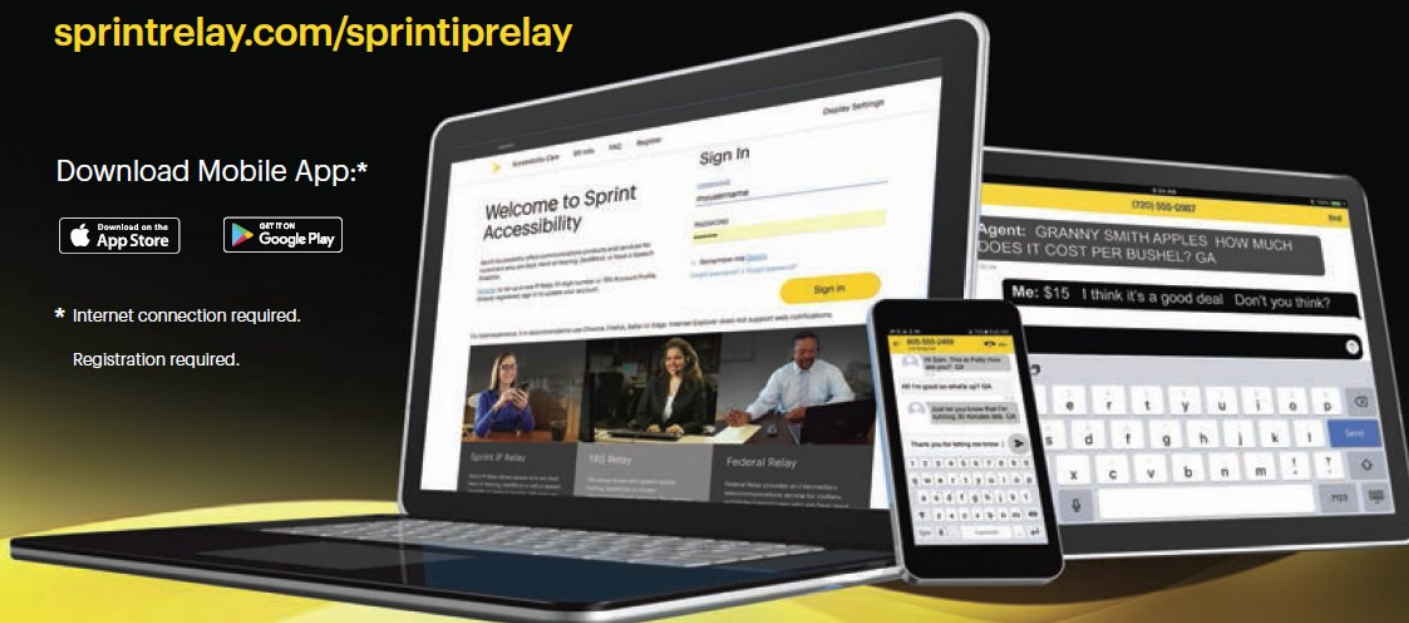
sprintrelay.com/sprintiprelay

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Registration required.



Although Sprint IP, Fed IP, and Sprint Mobile IP app can be used for emergency calling, such emergency calling may not function the same as traditional 911/E911 services. By using Sprint IP, Fed IP, and Sprint Mobile IP app for emergency calling, you agree that Sprint is not responsible for any damages resulting from errors, defects, malfunctions, interruptions or failures in accessing or attempting to access emergency services through Sprint IP, Fed IP, and Sprint Mobile IP app; whether caused by the negligence of Sprint or otherwise. Other restrictions apply. For details, see www.sprintrelay.com © 2019 Sprint. Sprint and logos are trademarks of Sprint. Other trademarks are the property of their respective owners.

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