

SATURDAY SESSIONS

A1 • Days of our lives - A snapshot of adulthood – Sheri Stanger, Director of Outreach, CHARGE Syndrome Foundation; Djenne-amal Morris; Mary Hancock; Tina Steed

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

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

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

A5 • CHARGE 101: Introduction for new families (diagnosis and features) – Meg Hefner, MS, Saint Louis University; Kate Beals, OTR/L, Southland Pediatric Therapy

A6 • Grandparents Gathering

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

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

B9 • Interpreter or Intervener? Identifying the best role for communication support in the classroom – Susanne Morgan Morrow, MA, CI, CT

B10 • “Why are Children with CHARGE Syndrome So Lazy?” – David Brown, deafblind educational specialist

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

B12 • Grandparents Gathering

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

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

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

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

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

C18 • CHARGE Adult Workshop *This session is designed for individuals with CHARGE ages 16 and up.*

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

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

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

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

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

D24 • CHARGE Adult Workshop *This session is specifically for individuals with CHARGE ages 16 and up.*

SUNDAY SESSIONS

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

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

E27 • A visual understanding of the ophthalmic pathway in CHARGE – Eniolami Dosunmu, MD, Cincinnati Children's Hospital Medical Center

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

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

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

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

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

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

F34 • "I wish they could tell me what they need": Increasing communication through behavior – Dr. Kasee Stratton, Mississippi State University

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

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

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

G38 • Promoting social skill development in children with CHARGE – Megan Schmittel, Central Michigan University and Perkins School for the Blind

G39 • Using photos to tell your child's story to their educational team – Donna Carpenter, Kentucky DeafBlind Project

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

G41 • That's Weird. Why would my child act this way? Trying to make sense out of behavior – Tim Hartshorne, PhD, Central Michigan University

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

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

H44 • Unlocking the door to an enviable life: Person-Centered Planning benefits, strategies, and case examples – Nancy Salem-Hartshorne, PhD, Delta College

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

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

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

PROFESSIONAL DAY

CSF-sponsored research: Past and future – Donna Martin, MD, University of Michigan; Yehoash Raphael, MD, University of Michigan

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

Gastrointestinal (GI) and feeding difficulties in CHARGE syndrome; the guts of it – Dr. Kim Blake, Dalhousie University

Linking assessment to intervention: Functional analyses and CHARGE – Hailey Ripple, Kasee Stratton, PhD, Mississippi State University

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

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

Investigating the response to anesthesia in a zebrafish model of CHARGE Syndrome – Jessica MacLean, Emily Chedrawe, Kim Blake, MD, Dalhousie University/IWK Health Centre

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

That's Weird. Why would My child act this way? Trying to make sense Out of behavior. – Tim Hartshorne, PhD, Central Michigan University

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

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

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

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

Investigation of two methods for treating sleep problems among children with CHARGE Syndrome – Benjamin Kennert, Central Michigan University CHARGE Lab

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

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

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

Promoting social skill development in children with CHARGE – Megan Schmittel, Central Michigan University and Perkins School for the Blind

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