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SUBJECT TO CHANGE
ALL TIMES EASTERN

PRELIMINARY AGENDA

FRIDAY, JULY 16

7:00-9:00 PM Welcome Reception & Breakouts

SATURDAY, JULY 17

9:15 - 9:45 AM Morning Yoga
10:00-10:40 AM General Session

10:45-11:45 AM

- **CHARGE 101**
 - **Time to become uncomfortable: Ableism** Presented by Chey McLaren
 - **Teaching Emotion Regulation Skills to Children with CHARGE syndrome** Presented by Megan Schmittell, Perkins School for the Blind
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12:00-1:00 PM

- **CHARGE 102**
 - **Preparing for Independence** Presented by Megan Anderson, Mississippi State University and Maricar Marques, HKNC
 - **Motor Development & Motor Competence** Presented by Melanie Perreault, Pamela Haibach-Beach and Lauren Lieberman, PhD, SUNY Brockport
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1:30-2:30 PM

- **CHARGE 103**
 - **Anxiety of Individuals with CHARGE Syndrome: Behavior, Diagnoses, and Interventions** Presented by Shanti Brown, Central Michigan University
 - **Do Job Coaches Change Diapers? Tackling Employment for the medically fragile adult with CHARGE** Presented by Ruth Braga, MSN, RN
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2:45-3:45 PM

- **Facilitating the Development of Communication Skills Across All Modalities and All Levels of Symbolization** Panel presentation with Susan Bashinski, PhD, Missouri Western University
- **Building Positive and Supportive Peer Relationships Throughout the School Years** Presented by Julie Maier, California Deafblind Services and Aubrey Williams
- **Using Behavior Analytic Strategies to Address Feeding Difficulties Among Children with CHARGE Syndrome** Presented by Hallie Smith and Hailey E. Ripple, Mississippi State University

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SATURDAY, JULY 17

4:15-5:15 PM

- **Ugh! Toilet Training: Teach me the basics!** Presented by Jasmine Sorrel, Chelsea Thorpe and Kasee Stratton, Mississippi State University, Bulldog CHARGE Lab
 - **Preventing Exclusion** Presented by Jerry Petroff, PhD, NJ Center for Deafblindness and Kelley Cagle
 - **Supporting Availability for Learning for Students with CHARGE Syndrome** Presented by Christopher Russell, Christopher Russell, New York Deaf-Blind Collaborative
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6:00-8:00 PM Family Entertainment

SUNDAY, JULY 18

10:15-10:45 AM Morning Yoga

11:00 AM-12:20 PM General Session, including Adults with CHARGE panel: David Carlile, Sophia Chandy Lisa Chen, and Vicky Huff

12:30-1:30 PM

- **All you want to know about CHARGE syndrome and genetics** Presented by Christa deGeus, University Medical Centre Groningen
 - **Taking CHARGE of transition from pediatric to adult healthcare: What families need to know.** Panel presentation by the CHARGE Clinic at CCHMC & Children's Hospital at Dartmouth-Hitchcock
 - **How and when to talk to your child about having CHARGE Syndrome** Presented by Kasee Stratton, PhD and Aubrey Williams, Mississippi State University, Bulldog CHARGE Lab
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1:45-2:45 PM

- **Eye Rubbing and Cortical Visual Impairment** Presented by Eniolami Dosunmu, MD, CCHMC
 - **Can We Play?** Presented by Emma Mayes & Michael Braga
 - **Intervener Services: What is Happening at Local, State, and National Levels?** Panel Presentation with Linda Alsop and the National Intervener & Advocate Association
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3:15-5:30 PM Private Session for Adults with CHARGE

3:15-4:15 PM

- **Evaluation and Management of Airway and Aspiration in CHARGE syndrome** Presented by Catherine Hart, MD, CCHMC
 - **What About Dads?** Presented by Jerry Petroff, NJ Center for Deafblindness
 - **Using the Educational Checklist: Starting School on the Right Foot** Presented by Lily Slavin & Penni Echols
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PRELIMINARY AGENDA

4:30-5:30 PM

- **Dysautonomia and CHARGE Syndrome** Presented by Julia Morrison, Dr. Kim Blake and Dr. George Williams
 - **Behaviors - Why would my child choose to do that?** Tim Hartshorne, PhD
 - **Taking the STEPS to Encourage Movement** Presented by Beth Foster, PhD
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5:30 PM Wrap-up & Farewell

Plus

ON DEMAND SESSIONS

- **How We Started...How It's Going: Reviewing CHARGE Syndrome Research Advancements**
Presented by Kasee Stratton, Chelsea Thorpe and Aubrey Williams, Mississippi State University Bulldog CHARGE Lab
- **What's In Your Toolbox? Practical Tools to Help You Navigate Life with CHARGE** Presented by Dr. Kim Blake; Kasee Stratton-Gadke, PhD; Angela Arra and Lily Slavin
- **What is an Intervener and How Does a Person Learn to Be an Intervener?** Presented by Beth Kennedy, Michigan deafblind project and Central Michigan University
- **The Law & Role of Educational Interpreters** Presented by Susanne Morrow - New York Deaf-Blind Collaborative
- **Physically Active Family Time: How to plan physical activity as a family** Maebh Barry and Matt LaCortiglia, Perkins School for the Blind
- **Retiring for 3 and Journey Through an 8 Step Planning Program** Presented by Mary Anne Ehlert, President and Founder of Protected Tomorrows Inc.
- **Panel: "The Impact of ABA: An overview and panel of parents with a child receiving ABA"**
Presented by Kasee Stratton, Mississippi State University, Bulldog CHARGE Lab
- **Experience Stories & Social Stories: Learning through Doing!** Presented by Sharon Stelzer, Perkins School for the Blind and Minnie Lambert
- **CHARGE Syndrome Diagnosis and Management: Beyond the Classic Signs** Presented by Brittany Simpson and Rob Hopkin, CCHMC
- **CHARGE-ing to Total Communication** Presented by Neha Sharma, Emily Macklin, and Amber Skerry, Perkins School for the Blind

AND POSTER PRESENTATIONS ... *Details to come*

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Visit the CHARGE Syndrome Foundation website for additional information
