Welcome to the 15th International CHARGE Syndrome Conference, the largest worldwide gathering of individuals with CHARGE, their families, professionals and experts on CHARGE syndrome.
## AGENDA

*Updated July 13, 2023. See the Conference App for any changes.*

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tr>
<td>12:00–6:00 PM</td>
<td>Conference Registration &amp; Sales Center Open</td>
<td>Satellite Registration</td>
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<tr>
<td>12:00–6:00 PM</td>
<td>Professional Day Registration</td>
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<td>12:00–6:00 PM</td>
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<td>1:00–4:00 PM</td>
<td>Pool Party</td>
<td>Cabana Pool and Gatlin Terrace</td>
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<td>6:00–9:00 PM</td>
<td>Reception</td>
<td>Sebastian J/K</td>
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<td>7:00-8:00 AM</td>
<td>Poster Session Set Up</td>
<td>Panzacola H2</td>
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<td>7:30-8:45 AM</td>
<td>Breakfast</td>
<td>Panzacola H3/H4</td>
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<tr>
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<td>General Session</td>
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<tr>
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<td>1:05-3:20 PM</td>
<td>Clinical &amp; Scientific Breakout Session</td>
<td>Sebastian I1/I2</td>
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<td>Education, Behavior &amp; Communication</td>
<td>Sebastian I3/I4</td>
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<td>Breakout Session</td>
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<td>Professional Day Closing Session</td>
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<td>Reception</td>
<td>Sebastian J/K</td>
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GENERAL SESSION 9:00–11:15 AM Sebastian I1/I2

Recent Advances in Biomedical Technologies at their Relevance to CHARGE Syndrome
Donna Martin MD, PhD, Amanda Moccia PhD, Yehoash Raphael PhD

Growth Charts for CHARGE Syndrome
Dieuwerke Djik PhD

Airway Issues in CHARGE Syndrome
Catherine Hart MD

Successful Physical Education for All
Lauren Lieberman PhD

The Development of an Educational Checklist for Students with CHARGE
Lily Slavin PhD

Bulldog CHARGE Syndrome Research Lab Updates
Kasee Stratton-Gadke PhD
### PROFESSIONAL DAY PROGRAM

Separate fee and registration required

#### BREAKOUT SESSIONS  1:05–3:20 PM

**Clinical & Scientific Research**  
Sebastian I1/I2

- A Zebrafish CHARGE Model: From Brain Development, Behaviour to Drug Discovery  Kessen Patten
- CHARGE Patient iPSC-Derived Organoid Model Reveals Defective Neural Crest Migration  Yiwen Zhai PhD
- The CHD7/ Kismet Family Links Blood–Brain Barrier Glia and Serotonin to Developmental Sleep Defects  Mireia Coll–Tané PhD
- Altered Developmental Senescence as the Basis of CHARGE Syndrome Vestibular Defects  Marta Magariños
- Swallowing Dysfunction and Aspiration: Diagnosis and Management  Catherine Hart MD

**Education, Behavior & Communication**  
Sebastian I3/I4

- Great IEPs Begin With a Strong Psycho–Educational Assessment  Darlene Norman
- Interveners and Research to Inform Intervener Training  Beth Kennedy PhD
- Applying the ICF Model to CHARGE Syndrome  Catherine Murphy DPT, Lauren Kling DPT
- Social Play in Children with CHARGE Syndrome  Megan Schmittel
- Teaching Communication and Social Strategies  Rebecca Darden–Perry PhD
- Anxiety of Individuals with CHARGE Syndrome: Behavior, Diagnoses, and Interventions  Shanti Madhaven–Brown PhD
- HKNC Overview and Programs for DeafBlind Young Adults  Eleanor Coley–Brody & John Filek
- 4 to 24 Transition App  Karla Antonelli & Anne Steverson
Genomic Etiologies of CHARGE Syndrome, Related Conditions and Structural Anomalies
Alba Guxholli & Amanda Moccia PhD

Mouse models as tools to explore mechanisms in CHARGE Syndrome
Jennifer Skidmore PhD

Role of Chd7 in retinal cell development and potential implications in CHARGE syndrome
Kessen Patten & Laura Krueger PhD

Abdominal Migraine in CHARGE Syndrome
Angela Arra & Kim Blake, MD

Digital Organizational Tips and Tricks: Simplifying Your Advocacy to Avoid Burnout and Promote Wellness
Darlene Norman

Sandra Davenport CHARGE Syndrome Fellows Program
Sara Espanet

Bulldog CHARGE Syndrome Research Lab Updates
Kasee Stratton-Gadke PhD & Bulldog CHARGE Syndrome Research Lab

What Do We Need to Know? Survey Outcomes for Supporting Adults With CHARGE
Kasee Stratton-Gadke PhD & Bulldog CHARGE Syndrome Research Lab

Schedule Systems for Individuals with CHARGE Syndrome
Emily Teevens & Abbey Maynard

Social Play in Children with CHARGE Syndrome
Megan Schmittel PhD
Educational Supports of Students with CHARGE: Identified Gaps and Future Directions
Lily Slavin PhD

The Development of an Educational Checklist for Students with CHARGE
Lily Slavin PhD

Constipation in CHARGE Syndrome
Kim Blake MD & Annie Kakamousias

4to24: An App Supporting Parents of Students with Hearing and Vision Impairments
Karla Antonelli & Anne Steverson

Anxiety and Obsessive Compulsive Disorder (OCD) in Individuals with CHARGE Syndrome
Shanti Madhavan-Brown PhD & Megan McColloch

Transitioning Out of High School: Where Do We Go from Here?
Bulldog CHARGE Syndrome Research Lab

The CHD7/ Kismet Family Links Blood–Brain Barrier Glia and Serotonin to Developmental Sleep Defects
Mireia Coll-Tané PhD

The CHARGE Syndrome Foundation Family Liaison Program

Walking Gait Parameters of Individuals with CHARGE Syndrome With and Without Support
Beth Foster PhD
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<th>Time</th>
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<td>7:00 AM-5:00 PM</td>
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<td>Breakfast</td>
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<td>Camp Discovery &amp; Camp Explorer Registration</td>
<td>Wekiwa Registration</td>
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<td>8:30-11:30 AM</td>
<td>Sibshops Morning Session</td>
<td>Suwannee 12</td>
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<td>Sebastian Pre Function</td>
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<td>8:30-11:45 AM</td>
<td>Camp Discovery &amp; Camp Explorer Morning Session</td>
<td>Wekiwa &amp; Suwannee</td>
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<td>9:00-10:20 AM</td>
<td>General Session</td>
<td>Sebastian J/K</td>
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<td>10:45-11:45 AM</td>
<td>Breakout Session #1</td>
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<td>12:30-4:45 PM</td>
<td>Camp Discovery &amp; Camp Explorer Afternoon Session</td>
<td>Wekiwa &amp; Suwannee</td>
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<td>1:00-4:00 PM</td>
<td>Sibshops Afternoon Session</td>
<td>Suwannee 12</td>
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<td>1:00-2:00 PM</td>
<td>Breakout Session #2</td>
<td>See page 9</td>
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<tr>
<td>2:15-3:15 PM</td>
<td>Breakout Session #3</td>
<td>See page 10</td>
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<td>3:15-3:30 PM</td>
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<td>3:30-4:30 PM</td>
<td>Breakout Session #4</td>
<td>See page 10</td>
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<td>6:00-9:00 PM</td>
<td>Dinner &amp; Evening Activity: Brainteasers &amp; Basket Raffle</td>
<td>Sebastian J/K</td>
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<td><strong>BREAKOUT SESSION #1</strong></td>
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<tr>
<td><strong>CHARGE 101: Overview of CHARGE Syndrome for New Families</strong></td>
<td>Panzacola H1/H2</td>
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<td>Introduction to Development</td>
<td>Meg Hefner MS</td>
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<td><strong>The Power of Story: Empowering Families</strong></td>
<td>Panzacola H3/H4</td>
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<td>Jana Villamez &amp; Donna Carpenter</td>
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<td><strong>Let’s Clear Up Some Confusion – Interveners and Intervener Training</strong></td>
<td>Sebastian I1/I2</td>
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<td>Beth Kennedy</td>
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<td><strong>Parent Stress and Coping</strong></td>
<td>Sebastian I3/I4</td>
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<td>Tim Hartshorne PhD &amp; Courtney Scholl</td>
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<tr>
<td><strong>Private Session for Adults With CHARGE</strong></td>
<td>Sebastian L1/L2</td>
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<tr>
<td>Kasee Stratton-Gadke PhD &amp; Bulldog Charge Syndrome Research Lab</td>
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<tr>
<td><strong>CHARGE 102</strong></td>
<td>Panzacola H1/H2</td>
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<tr>
<td>How Sensory Deficits Common in CHARGE Syndrome Impact Motor Development and Balance</td>
<td>Catherine Murphy DPT &amp; Lauren Kling DPT</td>
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<td><strong>Swallowing Dysfunction and Aspiration: Why it Matters and How To Treat It</strong></td>
<td>Panzacola H3/H4</td>
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<td>Catherine Hart MD</td>
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<td><strong>Families in CHARGE: Empowering Parents to Provide Support to Their Children With CHARGE Syndrome</strong></td>
<td>Sebastian I1/I2</td>
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<td>Jerry Petroff PhD</td>
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<td><strong>Socioemotional Impact of the Pandemic on Children With DeafBlindness and Their Families</strong></td>
<td>Sebastian I3/I4</td>
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<td>Carlie Rhoads PhD</td>
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<td><strong>I Want A Job! What Do I Need to Do?</strong></td>
<td>Sebastian L1/L2</td>
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<td>David Volper &amp; Robert McLendon</td>
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Eniolami Dosunmu MD & Karen Harpster PhD OTR/L

Can and Should ABA Be Used To Effectively Treat Feeding Problems For Individuals With CHARGE Syndrome?
Hallie Smith & Hailey Ripple PhD

Parent and Professional Partnerships: The Skills and Thrills to Empower Parents
Suzanne Chen & Emily McClain MD

Meaningful Movement: Stay CHARGED
Beth Foster PhD

Exploring the Outdoors With CHARGE Syndrome
Yessica Elliott

The Path to Self-Determination: Practices That Support This Path and Perspectives on the Journey
Julie Maier & Aubrey Williams

Airway Issues in CHARGE Syndrome
Catherine Hart MD

6 Things Most People Don’t Know About CHARGE Syndrome
David Brown

Worried? Anxiety and OCD in Individuals With CHARGE
Shanti Madhava Brown PhD & Megan McColloch

Andrew’s Journey to Supportive Decision Making
Krista Olsen & Minnie Lambert

CHARGE 103: Communication Development
Susan Bashinski PhD
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<tr>
<td>7:00 AM-8:00 AM</td>
<td>Poster Set-Up</td>
<td>Sebastian L3</td>
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<td>Sebastian Registration &amp; Pre-Function</td>
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<td>7:00-8:45 AM</td>
<td>Breakfast</td>
<td>Sebastian J/K</td>
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<tr>
<td>8:30-11:45 AM</td>
<td>Camp Discovery &amp; Camp Explorer Morning Session</td>
<td>Wekiwa &amp; Suwannee</td>
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<td>8:00 AM-5:00 PM</td>
<td>View Poster Sessions &amp; Meet the Researchers 3:15-4:45PM</td>
<td>Sebastian L3</td>
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<td>8:30-11:30 AM</td>
<td>Sibshops Morning Session</td>
<td>Suwannee 12</td>
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<td>8:00AM-5:00 PM</td>
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<td>Sebastian Pre Function</td>
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<td>General Session</td>
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<td>Camp Discovery &amp; Camp Explorer Afternoon Session</td>
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<td>1:00-2:00 PM</td>
<td>Breakout Session #6</td>
<td>See page 12</td>
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<tr>
<td>2:15-3:15 PM</td>
<td>Breakout Session #7</td>
<td>See page 13</td>
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<td>Coffee Break</td>
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<td>3:30-4:30 PM</td>
<td>Breakout Session #8</td>
<td>See page 13</td>
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<td>6:00-9:00 PM</td>
<td>Dinner &amp; Evening Activity: Party Like It's 1993!</td>
<td>Sebastian J/K/L</td>
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### Breakout Session #5  10:45–11:45 AM

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<tr>
<td><strong>Parent Storytelling Panel: Age 6–13</strong></td>
<td>Panzacola H1/H2</td>
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<tr>
<td><strong>An Interactive Seminar in Genetics – All You Want to Know About Genetics in CHARGE Syndrome</strong></td>
<td>Panzacola H3/H4</td>
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<tr>
<td>Marrit Hitzert MD, PhD &amp; Conny van Ravenswaaij-Arts MD, PhD</td>
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<tr>
<td><strong>Contemporary Management of Hearing Loss in CHARGE</strong></td>
<td>Sebastian I1/I2</td>
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<td>Daniel Choo MD</td>
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<td><strong>Postural Orthostatic Tachycardia in CHARGE and a Novel Treatment Using Vagal Nerve Stimulation Therapy</strong></td>
<td>Sebastian I3/I4</td>
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<tr>
<td>Kim Blake MD &amp; Roya Vakili MD</td>
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<tr>
<td><strong>Picking Your Priorities: Walking, Talking, What Should You Pick First?</strong></td>
<td>Sebastian L1/L2</td>
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<tr>
<td>Kasee Stratton-Gadke PhD, Cecelia Powell &amp; Jamie Moss</td>
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### Breakout Session #6  1:00–2:00 PM

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<td><strong>Parent Storytelling Panel: Birth–5</strong></td>
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<tr>
<td><strong>An Afternoon Discussing School and Family Partnerships – Breakout Sessions #6, #7, #8</strong></td>
<td>Panzacola H3/H4</td>
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<tr>
<td><strong>Transition Journey – Families Navigating Through the System</strong></td>
<td>Sebastian I1/I2</td>
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<tr>
<td>Eleanor Coley-Brody, Marilyn Trader MSW &amp; John Filek</td>
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<tr>
<td><strong>Using Touch to Take CHARGE of Navigation</strong></td>
<td>Sebastian I3/I4</td>
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<td>Suzanne Dinwiddie</td>
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<tr>
<td><strong>Top 10 Strategies For Promoting Positive Behavior in Children With CHARGE Syndrome</strong></td>
<td>Sebastian L1/L2</td>
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<td>Laurie Denno PhD</td>
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### BREAKOUT SESSION #7 2:15–3:15 PM

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<th>Panel Storytelling Panel: Age 14+</th>
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<td>An Afternoon Discussing School and Family Partnerships – Breakout Sessions #6, #7, #8</td>
<td>Panzacola H3/H4</td>
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<tr>
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<tr>
<td>Growth Charts for CHARGE Syndrome</td>
<td>Sebastian I1/I2</td>
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<td>Dieuwerke Dijk MD</td>
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<td>Intervener vs. Interpreter? Assessing the Best Communication Support For Your Child</td>
<td>Sebastian I3/I4</td>
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<td>Susanne Morrow</td>
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<td>Behavior Challenges: What is the Behavior Communicating and How Do You Respond?</td>
<td>Sebastian L1/L2</td>
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<td>Kasee Stratton-Gadke PhD, Cecelia Powell &amp; Jamie Moss</td>
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### BREAKOUT SESSION #8 3:30–4:30 PM

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<th>Adulting! It Can Be done!</th>
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<tr>
<td>Nancy Hartshorne PhD</td>
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<tr>
<td>An Afternoon Discussing School and Family Partnerships – Breakout Sessions #6, #7, #8</td>
<td>Panzacola H3/H4</td>
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<tr>
<td><strong>See full description on page 14</strong></td>
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<tr>
<td>The Guts of CHARGE: Gastrointestinal (GI) Issues in CHARGE Syndrome Including Constipation and Abdominal Migraine</td>
<td>Sebastian I1/I2</td>
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<tr>
<td>Kim Blake MD &amp; Angela Arra</td>
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<tr>
<td>Parental Role in the Promotion of Motor Development</td>
<td>Sebastian I3/I4</td>
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<tr>
<td>Melanie Perreault PhD, Lauren Lieberman PhD &amp; Pamela Beach PhD</td>
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<tr>
<td>The How and When: Telling Your Child They Have CHARGE Syndrome</td>
<td>Sebastian L1/L2</td>
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<td>Kasee Stratton-Gadke PhD</td>
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An Afternoon Discussing School and Family Partnerships
Breakout Sessions #6, #7, #8

- **IEP Pro: The Ins and Outs of an IEP**
  Cecelia Powell & Jamie Moss

- **Understanding Psychoeducational Assessment Scores: What Do Those Numbers Really Mean?**
  Darlene Norman

- **Balance, IEPs, Equipment, Oh My! How Physical Therapists Can Support Your Child In the Classroom and Beyond**
  Catherine Murphy DPT & Lauren Kling DPT

- **Social Play in Children With CHARGE Syndrome**
  Megan Schmittel PhD

- **Taking CHARGE At Home: A Teacher’s Guide on Bridging the Gap Between School and Home**
  Sara Espanet & Rilla Hammett

- **Educational Checklist for Students With CHARGE**
  Lily Slavin PhD

- **The Family’s Voice in the IEP Process: Facilitating a Meaningful Partnership**
  Susan Bashinski PhD & Samantha Teed
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<th>Time</th>
<th>Activity</th>
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<tr>
<td>8:00 AM–12:00 PM</td>
<td><strong>Sales Center Open</strong></td>
<td>Sebastian</td>
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<td>Registration &amp; Pre-Function</td>
<td>J/K</td>
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<tr>
<td>7:30–8:45 AM</td>
<td><strong>Breakfast</strong></td>
<td>Sebastian J/K</td>
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<tr>
<td>8:30 AM–12:30 PM</td>
<td><strong>Camp Discovery &amp; Camp Explorer Morning Session</strong></td>
<td>Wekiwa &amp; Suwannee</td>
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<tr>
<td>9:00–12:00 PM</td>
<td><strong>General Session</strong></td>
<td>Sebastian J/K</td>
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<td>As we bring Conference to a close, hear from adults with CHARGE and learn about the sibling experience.</td>
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