

CONFERENCE AGENDA

15th International CHARGE SYNDROME
CONFERENCE

JULY 20-23, 2023

ROSEN SHINGLE CREEK, ORLANDO, FL



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



**Connect
in the
Conference
App!**



Wednesday, July 19, 2023
Thursday, July 20, 2023

AGENDA

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

WEDNESDAY

12:00–6:00 PM	Conference Registration & Sales Center Open	Satellite Registration
12:00–6:00 PM	Professional Day Registration	Satellite Registration
12:00–6:00 PM	Camp Discovery & Camp Explorer Registration Open	Satellite Registration

THURSDAY

7:00 AM–5:00 PM	Conference Registration & Sales Center Open	Sebastian Registration
12:00–5:00 PM	Camp Discovery & Camp Explorer Registration Open	Sebastian Pre Function
7:30 AM–4:30 PM	Professional Day Conference	Separate Registration Required
1:00–4:00 PM	Pool Party <i>Weather Permitting</i>	Cabana Pool and Gatlin Terrace
6:00–9:00 PM	Reception Dinner and meet-up with other families	Sebastian J/K

Thursday, July 20, 2023



PROFESSIONAL DAY

Separate fee and registration required

BREAKOUT SESSIONS
Details on page 7

7:00 AM	Registration	Sebastian Registration
7:00–8:00 AM	Poster Session Set Up	Panzacola H2
7:30–8:45 AM	Breakfast	Panzacola H3/H4
9:00–11:15 AM	General Session <i>Details on page 4</i>	Sebastian I1/I2
11:15 AM–12:00 PM	Poster Session <i>Details on pages 6 & 7</i>	Panzacola H2
12:00–1:00 PM	Lunch	Panzacola H3/H4
1:05–3:20 PM	Clinical & Scientific Breakout Session	Sebastian I1/I2
1:05–3:20 PM	Education, Behavior & Communication Breakout Session	Sebastian I3/I4
3:20–3:40 PM	Coffee Break	
3:45–4:30 PM	Professional Day Closing Session	Sebastian I1/I2
6:00–9:00 PM	Reception	Sebastian J/K

Thursday, July 20, 2023



PROFESSIONAL DAY PROGRAM

Separate fee and registration required

GENERAL SESSION

9:00–11:15 AM

Sebastian Il/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 Dijk 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 11/12

- 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**
- Vagal Nerve Stimulator as a Novel Treatment Approach in CHARGE Syndrome, Controlling POTS Symptoms and Seizures: A Case Report
Kim Blake MD, Lekaa Elhajjmousa & Roya Vakili MD
- Swallowing Dysfunction and Aspiration: Diagnosis and Management
Catherine Hart MD

Education, Behavior & Communication

Sebastian 13/14

- Great IEPs Begin With a Strong Psycho-Educational Assessment
Darlene Norman
- Intervenors 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**
- The Development & Implementation of Language & Communication Profiles & Planning for Multimodal Multilingual Users **Jodi Falk PhD & Chrissy Morris**
- Anxiety of Individuals with CHARGE Syndrome: Behavior, Diagnoses, and Interventions **Shanti Madhavan-Brown PhD**
- HKNC Overview and Programs for DeafBlind Young Adults
Eleanor Coley-Brody & John Filek
- 4 to 24 Transition App **Karla Antonelli & Anne Steverson**



Thursday, 11:15 AM–12:00 PM
Saturday, 8:00 AM–5:00 PM

Panzacola H3/H4
Sebastian L3

POSTER SESSIONS

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



Thursday, 11:15 AM–12:00 PM
Saturday, 8:00 AM–5:00 PM
Meet the Presenters 12:45–2:00

Panzacola H2
Sebastian L3

POSTER SESSION

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



AGENDA

Friday, July 21, 2023

7:00 AM–5:00 PM	Conference Registration Open	Sebastian Registration
7:00 AM–5:00 PM	Sales Center Open	Sebastian Pre Function
7:00–7:30 AM	Exhibitor Setup	Sebastian Pre Function
7:00–8:45 AM	Breakfast	Sebastian J/K
7:00–9:00 AM	Camp Discovery & Camp Explorer Registration	Wekiwa Registration
8:30–11:30AM	Sibshops Morning Session <i>preregistration required</i>	Suwannee 12
8:00AM–5:00 PM	Exhibits Open	Sebastian Pre Function
8:30–11:45 AM	Camp Discovery & Camp Explorer Morning Session	Wekiwa & Suwannee
9:00–10:20 AM	General Session Celebrate 30 years of the CHARGE Syndrome Foundation!	Sebastian J/K
10:45–11:45 AM	Breakout Session #1	See page 9
11:45 AM–12:45 PM	Lunch	Sebastian J/K
12:30–4:45 PM	Camp Discovery & Camp Explorer Afternoon Session	Wekiwa & Suwannee
1:00–4:00 PM	Sibshops Afternoon Session <i>preregistration required</i>	Suwannee 12
1:00–2:00 PM	Breakout Session #2	See page 9
2:15–3:15 PM	Breakout Session #3	See page 10
3:15–3:30 PM	Coffee Break	
3:30–4:30 PM	Breakout Session #4	See page 10
6:00–9:00 PM	Dinner & Evening Activity: Brainteasers& Basket Raffle	Sebastian J/K



BREAKOUT SESSIONS

Friday, July 21, 2023

BREAKOUT SESSION #1

10:45–11:45 AM

CHARGE 101: Overview of CHARGE Syndrome for New Families

Panzacola H1/H2

Introduction to Development **Meg Hefner MS**

The Power of Story: Empowering Families

Panzacola H3/H4

Jana Villamez & Donna Carpenter

Let's Clear Up Some Confusion – Interveners and Intervener Training

Sebastian I1/I2

Beth Kennedy

Parent Stress and Coping

Sebastian I3/I4

Tim Hartshorne PhD & Courtney Scholl

Private Session for Adults With CHARGE

Sebastian L1/L2

Kasee Stratton-Gadke PhD & Bulldog Charge Syndrome Research Lab

BREAKOUT SESSION #2

1:00–2:00 PM

CHARGE 102

Panzacola H1/H2

How Sensory Deficits Common in CHARGE Syndrome
Impact Motor Development and Balance

Catherine Murphy DPT & Lauren Kling DPT

Swallowing Dysfunction and Aspiration: Why it Matters and How To Treat It

Panzacola H3/H4

Catherine Hart MD

Families in CHARGE: Empowering Parents to Provide Support to Their Children With CHARGE Syndrome

Sebastian I1/I2

Jerry Petroff PhD

Socioemotional Impact of the Pandemic on Children With DeafBlindness and Their Families

Sebastian I3/I4

Carlie Rhoads PhD

I Want A Job! What Do I Need to Do?

Sebastian L1/L2

David Volper & Robert McLendon



BREAKOUT SESSIONS

Friday, July 21, 2023

BREAKOUT SESSION #3

2:00–3:15 PM

Vision in CHARGE: Visual Acuity, Visual Fields, Functional Vision, and Cortical Visual Impairment

Panzacola H1/H2

Eniolami Dosunmu MD & Karen Harpster PhD OTR/L

Can and Should ABA Be Used To Effectively Treat Feeding Problems For Individuals With CHARGE Syndrome?

Panzacola H3/H4

Hallie Smith & Hailey Ripple PhD

Parent and Professional Partnerships: The Skills and Thrills to Empower Parents

Sebastian I1/I2

Suzanne Chen & Emily McClain MD

Meaningful Movement: Stay CHARGED

Sebastian I3/I4

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

Sebastian L1/L2

Julie Maier & Aubrey Williams

BREAKOUT SESSION #4

3:30–4:30 PM

Airway Issues in CHARGE Syndrome

Panzacola H3/H4

Catherine Hart MD

6 Things Most People Don't Know About CHARGE Syndrome

Sebastian I1/I2

David Brown

Worried? Anxiety and OCD in Individuals With CHARGE

Sebastian I3/I4

Shanti Madhavan Brown PhD & Megan McColloch

Andrew's Journey to Supportive Decision Making

Sebastian L1/L2

Krista Olsen & Minnie Lambert

CHARGE 103: Communication Development

Panzacola H1/H2

Susan Bashinski PhD



AGENDA

Saturday, July 22, 2023

7:00 AM-8:00 AM	Poster Set-Up	Sebastian L3
7:00 AM-5:00 PM	Conference Registration & Sales Center Open	Sebastian Registration & Pre-Function
7:00-8:45 AM	Breakfast	Sebastian J/K
8:30-11:45 AM	Camp Discovery & Camp Explorer Morning Session	Wekiwa & Suwannee
8:00 AM-5:00 PM	View Poster Sessions & Meet the Researchers 3:15-4:45PM	Sebastian L3
8:30-11:30 AM	Sibshops Morning Session <i>Preregistration Required</i>	Suwannee 12
8:00AM-5:00 PM	Exhibits Open	Sebastian Pre Function
9:00-10:30 AM	General Session Including: <i>The Science of CHARGE Syndrome</i> Foundation updates and awards	Sebastian J/K
10:45-11:45 AM	Breakout Session #5	See page 12
11:45 AM-12:45 PM	Lunch	Sebastian J/K
1:00-4:00 PM	Sibshops Afternoon Session <i>Preregistration Required</i>	Suwannee 12
12:30-4:45 PM	Camp Discovery & Camp Explorer Afternoon Session	Wekiwa & Suwannee
1:00-2:00 PM	Breakout Session #6	See page 12
2:15-3:15 PM	Breakout Session #7	See page 13
3:15-3:30 PM	Coffee Break	
3:30-4:30 PM	Breakout Session #8	See page 13
6:00-9:00 PM	Dinner & Evening Activity: Party Like It's 1993!	Sebastian J/K/L



BREAKOUT SESSIONS

Saturday, July 22, 2023

BREAKOUT SESSION #5

10:45–11:45 AM

Parent Storytelling Panel: Age 6–13

Panzacola H1/H2

An Interactive Seminar in Genetics – All You Want to Know About Genetics in CHARGE Syndrome

Panzacola H3/H4

Marrit Hitzert MD, PhD & Conny van Ravenswaaij-Arts MD, PhD

Contemporary Management of Hearing Loss in CHARGE

Sebastian I1/I2

Daniel Choo MD

Postural Orthostatic Tachycardia in CHARGE and a Novel Treatment Using Vagal Nerve Stimulation Therapy

Sebastian I3/I4

Kim Blake MD & Roya Vakili MD

Picking Your Priorities: Walking, Talking, What Should You Pick First?

Sebastian L1/L2

Kasee Stratton-Gadke PhD, Cecelia Powell & Jamie Moss

BREAKOUT SESSION #6

1:00–2:00 PM

Parent Storytelling Panel: Birth–5

Panzacola H1/H2

An Afternoon Discussing School and Family Partnerships – Breakout Sessions #6, #7, #8

Panzacola H3/H4

See full description on page 14

Transition Journey – Families Navigating Through the System

Sebastian I1/I2

Eleanor Coley-Brody, Marilyn Trader MSW & John Filek

Using Touch to Take CHARGE of Navigation

Sebastian I3/I4

Suzanne Dinwiddie

Top 10 Strategies For Promoting Positive Behavior in Children With CHARGE Syndrome

Sebastian L1/L2

Laurie Denno PhD



BREAKOUT SESSIONS

Saturday, July 22, 2023

BREAKOUT SESSION #7

2:15–3:15 PM

Panel Storytelling Panel: Age 14+

Panzacola H1/H2

An Afternoon Discussing School and Family Partnerships – Breakout Sessions #6, #7, #8

Panzacola H3/H4

See full description on page 14

Growth Charts for CHARGE Syndrome

Sebastian I1/I2

Dieuwerke Dijk MD

Intervener vs. Interpreter? Assessing the Best Communication Support For Your Child

Sebastian I3/I4

Susanne Morrow

Behavior Challenges: What is the Behavior Communicating and How Do You Respond?

Sebastian L1/L2

Kasee Stratton-Gadke PhD, Cecelia Powell & Jamie Moss

BREAKOUT SESSION #8

3:30–4:30 PM

Adulting! It Can Be done!

Panzacola H1/H2

Nancy Hartshorne PhD

An Afternoon Discussing School and Family Partnerships – Breakout Sessions #6, #7, #8

Panzacola H3/H4

See full description on page 14

The Guts of CHARGE: Gastrointestinal (GI) Issues in CHARGE Syndrome Including Constipation and Abdominal Migraine

Sebastian I1/I2

Kim Blake MD & Angela Arra

Parental Role in the Promotion of Motor Development

Sebastian I3/I4

Melanie Perreault PhD, Lauren Lieberman PhD & Pamela Beach PhD

The How and When: Telling Your Child They Have CHARGE Syndrome

Sebastian L1/L2

Kasee Stratton-Gadke PhD



BREAKOUT SESSIONS

Saturday, July 22, 2023

An Afternoon Discussing School and Family Partnerships

Panzacola H3/H4

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



AGENDA

Sunday, July 23, 2023

8:00 AM-12:00 PM

Sales Center Open

Sebastian
Registration &
Pre-Function

7:30-8:45 AM

Breakfast

Sebastian J/K

8:30 AM-12:30 PM

**Camp Discovery &
Camp Explorer
Morning Session**

Wekiwa & Suwannee

9:00-12:00 PM

General Session

*As we bring Conference to
a close, hear from adults
with CHARGE and learn
about the sibling
experience.*

Sebastian J/K