



Conference Sessions Agenda

16th International CHARGE Syndrome Conference

July 24-27, 2025

**JW Marriott Phoenix
Desert Ridge Resort
& Spa, Phoenix, AZ**

The 16th International CHARGE Syndrome Conference, the largest worldwide gathering of individuals with CHARGE syndrome, their families, professionals and experts on CHARGE syndrome.



THE GRAND ADVENTURE
RISING FROM CHALLENGES TOGETHER
16th International CHARGE Syndrome Conference
Phoenix, AZ - July 24-27, 2025

Preliminary Agenda - Subject to Change



Thursday, July 24, 2025

MEG HEFNER PROFESSIONAL DAY PROGRAM

Separate fee and registration required

Preliminary Agenda – Subject to Change

GENERAL SESSION

9:00 AM – 12:00 PM

- **Behavior in CHARGE: What I have learned** Timothy Hartshorne, PhD
- **Research Updates from the Bulldog CHARGE Syndrome Research Lab**
Kasee Stratton-Gadke, PhD
- **Rady Children's Care Model for CHARGE syndrome** Daniela Carvalho, MD
- **Gene Therapy for Hereditary Balance and Hearing Deficits**
Donna Martin, MD, PhD, Yehoash Raphael, PhD
- **Developing a Health Informatics Algorithm to Identify Patients with CHARGE Syndrome** Tyler James, PhD, Kim Blake, MD
- **Walking Gait Parameters of Individuals with CHARGE Syndrome without Support** Beth Foster, PhD

BREAKOUT SESSIONS

1:30–3:00 PM

Communication/Education

- **Touch as the Key to Unlocking Communication in Children with Hearing & Vision Loss** Susanne Morrow
- **Importance of Finding Your Social Network: CHARGE Adult Socials**
Kasee Stratton-Gadke, PhD, Susanne Morrow, Cecelia Powell
- **Behavior, Communication and Connection** Nehuen Rodriguez Picatto
- **HKNC Overview and Programs for DeafBlind Young Adults** Marilyn Trader, MSW

Medical

- **Prevalence of Postural Orthostatic Tachycardia Syndrome (POTS) Symptoms in CHARGE Syndrome** Kim Blake, MD, Laura Burge
- **Constipation, Gastrointestinal and Feeding Issues in CHARGE Syndrome**
Kim Blake, MD, Annie Kakamousias
- **iPSCs are a Powerful Tool for Studying CHARGE Syndrome** Lindsey Wilson
- **Airway, Aspiration and Swallowing Dysfunction** Catherine Hart, MD



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AGENDA

Preliminary Agenda - Subject to Change

Wednesday, July 23, 2025

12:00 PM

Registration Opens

Thursday, July 24, 2025

1:00–4:00 PM

CHARGE Family Physical Activity Workshop
Preregistration required

6:30 PM

Dinner & Welcome Reception

Friday, July 25, 2025

7:00–8:45 AM

Breakfast

8:30–11:45 AM

Camp Discovery & Camp Explorer Morning Session

9:00–10:20 AM

General Session: Keynote Speaker David Brown

9:30–11:30 AM

Sibshops Session #1

10:45–11:45 AM

Breakout Session #1 *see below*

11:45AM–1:00 PM

Lunch

12:30–5:00 PM

Camp Discovery & Camp Explorer Afternoon Session

1:00–4:45PM

Breakout Sessions #2–5 *see below*

1:15–4:15 PM

Sibshops Session #2

6:30 PM

Dinner & CHARGE Syndrome Art Show



BREAKOUT SESSSIONS

Preliminary Agenda - Subject to Change

Friday, July 25, 2025

BREAKOUT SESSION #1

10:45–11:45 AM

Touch as the Key to Unlocking Communication in Children with Hearing and Vision Loss

Susanne Morrow

Panel on Behavior in CHARGE

Timothy Hartshorne, PhD, Kasee Stratton-Gadke, PhD,
David Brown, Lillian Slavin, PhD, Rachel Collins

Transformando Vidas: De nuestra Experiencia con CHARGE a una Red de Inclusión en América Latina

Sasha Franco, Piero Franco

Session in Spanish

CHARGE 101: Medical and Developmental Issues

Susan Wiley, MD

CHARGE-ing to Independence: A Panel for Adults with CHARGE Syndrome*

BREAKOUT SESSION #2

1:00–2:00 PM

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

Marrit Hitzert, MD, PhD

Taking CHARGE at Home: Strategies and Teaching Tools to Use at Home

Rilla Hammett, Sara Espanet, Brandie Martinez

Balance and Walking Strategies You Can Do Now

Beth Foster, PhD

CHARGE 102: Communication

Communication and CHARGE: Systems and Strategies Neha Sharma, SLP

Emerging Communication and Touch Cues
Angela Mancini TVI

Supporting Your Journey: A Q&A Panel for Adults with CHARGE Syndrome*

**Private Sessions for Adults with CHARGE*



BREAKOUT SESSSIONS

Preliminary Agenda - Subject to Change

Friday, July 25, 2025

BREAKOUT SESSION #3

2:15–3:15 PM

Behavior, Communication and Connection

Nehuen Rodriguez Picatto

From Storytime to Lifelines

Sharon Stelzer, Krista Oleson, Minnie Lambert

Growth in CHARGE Syndrome

Jeremy Kirk, MD

CHARGE 103: Early Intervention, IEPs, and Navigating the System

Nancy Hartshorne, PhD, Lillian Slavin, PhD

Supporting Your Journey: A Q&A Panel for Adults with CHARGE Syndrome (continued)*

BREAKOUT SESSION #4

3:30–4:00 PM

Exploring the Benefits of Interveners

Beth Kennedy, PhD

Integrating Technology and Curriculum to Support DeafBlind Learners and Their Families

Marissa Chappell, M.S., CCC-SLP, Anna Martin

Nursing Care – A Parent Perspective

David Bowdoin

Live Beyond School

Claudia Junghans

Your Employment Journey *

Jonathan Pringle, Leanne Cook

**Private Sessions for Adults with CHARGE*



BREAKOUT SESSSIONS

Preliminary Agenda - Subject to Change

Friday, July 25, 2025

BREAKOUT SESSION #5

4:15-4:45 PM

Language and Literacy for DeafBlind: Supported by Interveners

Kaylyn Abbott

Aerodigestive Care in Children with CHARGE Syndrome

Matthew Brigger, MD, Kimberly Morris, CCC-SLP,
Kumar Soma Kumar, MD. PhD, Annette Kiviat, PA-C,
Aparna Rao, MD

Advances in Stem Cells to Develop Treatments for CHARGE Syndrome

Donna Martin, MD PhD

Mini-Puberty and Puberty in CHARGE

Jeremy Kirk, MD

Together Rising Towards Success: Collaborative Approach Toward Achieving Successful Employment*

Marilyn Trader, MSW, Tammie Christian

**Private Sessions for Adults with CHARGE*



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Saturday, July 26, 2025

7:00-8:45 AM	Breakfast
8:30-11:45 AM	Camp Discovery & Camp Explorer Morning Session
9:00-10:30 AM	General Session: Featured Speaker Kim Blake, MD
9:30-11:30 AM	Sibshops Session #3
10:45-11:45 AM	Breakout Session #6 <i>see below</i>
11:45AM-1:00 PM	Lunch
12:30-5:00 PM	Camp Discovery & Camp Explorer Afternoon Session
1:00-4:45PM	Breakout Session #7 - #10 <i>see below</i>
1:15-4:15 PM	Sibshops Session #4
6:30 PM	Dinner & CHARGE-A-PALOOZA - Glow Night! Basket Raffle/Auction



BREAKOUT SESSSIONS

Preliminary Agenda - Subject to Change

Saturday, July 26, 2025

BREAKOUT SESSION #6

10:45–11:45 AM

Hearing Loss in Children with CHARGE Syndrome

Erin Pinsky, AuD, CCC-A

Personal and Environmental Influences on Physical Activity and Motor Development

Lauren Lieberman, PhD, Melanie Perreault, PhD, Pamela Beach, PhD

The ABC's of IEP's.... Or What I Wish I Knew Before I Sat Down In There!

Trish Northrup

Airway, Aspiration, and Feeding Difficulties

Catherine Hart, MD

Guiding the Path: Transitions and Post-School Options for Individuals with CHARGE Syndrome

Kasee Stratton-Gadke, PhD, Cecelia Powell, Jamie Moss, Aubrey Williams

BREAKOUT SESSION #7

1:00–2:00 PM

Parent Stress and Coping

Timothy Hartshorne, PhD, Courtney Scholl

Supporting Balance Goals of Children with CHARGE Syndrome

Emily Weber, DPT, Lauren Kling, DPT, Alysha Croke, Catherine Murphy, DPT

Focus on Vision

Lauren Hennein, MD

Creating Communication-Rich Environments and Building Connections

Julie Maier

Transition Planning for Young Adults with CHARGE

Susanne Morrow

BREAKOUT SESSION #8

2:15–3:15 PM

Using Person-Centered Planning to Prepare for Future Grand Adventures

Julie Maier, Aubrey Williams

Considerations for Auditory Brainstem Implantation in CHARGE & Updates on Surgical Technologies for Hearing Management in CHARGE

Daniel Choo, MD, Jacqueline Weinstein, Soraya Abdul-Hadi Martinez

Cranial Nerve Anomalies in CHARGE Syndrome

Roya Vakili

Understanding Financial Tools for Individuals with Disabilities

Katie Helde

Panel on Mental Health

Shanti Madhavan-Brown, PhD, Megan Schmitt, PhD, Sarah Schneider, PhD

BREAKOUT SESSION #9

3:30–4:00 PM

The Blended Diet

Kaleigh Fruits, Sara Moseley

The Law & Role of Educational Interpreters

Susanne Morrow

School is Over, What Now?

Carlie Rhoads, PhD, Michael Fagbemi

Following Her Lead

Emily Teevens, Maggie Camelio

Adult Medical Issues in CHARGE Syndrome

Kim Blake, MD, Claudia Junghans



BREAKOUT SESSSIONS

Preliminary Agenda - Subject to Change

Saturday, July 26, 2025

BREAKOUT SESSION #10

4:15–4:45 PM

Your Child's Story: Writing a Meaningful IEP Parent Statement for Your Child with CHARGE Syndrome

Darlene Norman

Importance of Finding your Social Network: CHARGE Adult Socials*

Kasee Stratton-Gadke, PhD, Susanne Morrow, Cecelia Powell

Empowering Transition through Collaborative Services

Leanne Cook

Taking Charge of My CHARGE

Lanna Slaby, Lacey Long

Adult Medical Issues in CHARGE Syndrome

(continued)

Kim Blake, MD, Claudia Junghans



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Sunday, July 27, 2025

7:00–8:45 AM

Breakfast

8:30 AM–12:30 PM

Camp Discovery & Camp Explorer Morning Session

9:00 AM–12:00 PM

General Session

*Adults with CHARGE Panel
CHARGE Sibling Panel
2027 Conference Announcement*



AGENDA

Preliminary Agenda – Subject to Change

Poster Sessions

POSTER SESSIONS

Thursday, 12:15 PM–1:30 PM
(Meg Hefner Professional Day registrants only)

Friday, 10:45 AM–5:00 PM
Saturday, 10:45 AM–5:00 PM

Are You Connected? Your State Deafblind Project and the Child Count

Carlie Rhoads, PhD

Accommodations and Modifications for School Aged Individuals with CHARGE Syndrome

Sara Espanet, M.Ed., Sharon Stelzer, M.Ed.

ART is for EVERYONE!

Sara Espanet, M.Ed.

Caregiving for Children with CHARGE Syndrome

Lauren Lieberman, PhD, Melanie

Perreault, PhD, Pamela Beach, PhD, Afeez Hazzan, PhD

Cleft Palate and Lip in CHARGE Syndrome

Jeremy Kirk, MD

Communication and CHARGE: Systems and Strategies

Neha Sharma, SLP

Constipation, Gastrointestinal and feeding issues in CHARGE syndrome

Kim Blake, MD, Annie Kakamousias

Cranial Nerve Anomalies in CHARGE Syndrome

Roya Vakili, MD

Examination of Walking Gait in Individuals with CHARGE Syndrome without Support

Beth Foster, PhD

Expanding the Reliability and Validity of the CNVPA: Psychometric Validation Across Age Groups

Kasee Stratton-Gadke, PhD, Jamie Moss



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Thursday, 12:15 PM–1:30 PM
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Friday, 10:45 AM–5:00 PM
Saturday, 10:45 AM–5:00 PM

Funding Analysis of the U.S. National Institutes of Health Investment in CHARGE Syndrome Research Lillian Slavin, PhD, Tyler James, PhD, Muhammad Othman

HKNC Overview and Programs for DeafBlind Young Adults Marilyn Trader

Integrating Deafblindness into the IEP: Strategies for Success
Julie Maier, Darlene Norman

Notes to Your Younger Self Project Jerry G. Petroff, PhD

Sandra Davenport CHARGE Syndrome Foundation Fellows Program
Sara Espanet, M.Ed.

The Beethoven Project Adaptive Melodies

The Development of an Educational Checklist for Students with CHARGE Syndrome Lillian Slavin, PhD

Understanding the Mental Health Needs of Adolescents and Adults with CHARGE Syndrome Cecelia Powell, Kasee Stratton-Gadke, PhD

Unlocking Your Rights: Understanding Procedural Safeguards, Independent Educational Evaluations & Due Process Darlene Norman

Volvulus and Recurrent Bowel Obstruction in CHARGE Syndrome – A Case Series
Kelcie Burke, Kim Blake, MD

What's going on at the Bulldog CHARGE Syndrome Research Lab?
Kasee Stratton-Gadke, PhD, Cecelia Powell, Anna Ritchie, Marlie Jones