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13th International **CHARGE Syndrome** Conference



CHARGE Syndrome Foundation, Inc.

2015 - 2018

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Welcome!

TAKING CHARGE IN ORLANDO AND BEYOND

Whether this is your first conference, or your thirteenth, we are all here to Take CHARGE. Approximately 1,200 people will gather together over these 4 days. We come from all walks of life and from all over the world. It is our chance to reunite with old friends and make new ones. Most importantly, we are here to learn from the experts, share our experiences with each other and have a lot of fun in the process.

So many people work together to make this conference possible. Our presenters volunteer their time and pay their own travel and registration just to help us better navigate and understand the complexities of CHARGE syndrome. This amazing weekend could not happen without the dedication and generosity of our presenters.

I can't calculate how many total hours have gone into planning this conference. What I do know is that this conference is planned and run almost entirely by volunteers. We could not pull this off without our generous donors, fundraisers, members, volunteers, interpreters, Advisors, and Board members. Thank you all for helping us Take CHARGE. A special thank you to our sponsors who help fund our conference scholarships and kept the cost of registration far less than the actual cost of conference.

Over the past 6 years I have been president, I watched our conferences and programs grow. We continue to expand our research grants, added the Sandra Davenport CHARGE Syndrome Fellows Program and Ethan Wolfe Recreational Assistance Program, increased conference scholarships, produced webinars and newsletters, and so much more. Many of you played a role in our fantastic growth and expansion.

THANK YOU to everyone who helped us TAKE CHARGE.

A few amazing people continue to shoulder the vast majority of the work and deserve a special thank you. When you see our Vice President Lisa Weir; Treasurer Brownie Shott; Secretary Neal Stanger and Director of Administration Jody Wolfe, please let them know how much you appreciate all the time they volunteered for the Foundation. It is not an understatement to say that the Foundation and this conference would not be what it is today without all their time and effort.

Over the next 4 days, please take advantage of everything our conference has to offer. From general sessions, breakout sessions, exhibitors, info central, social events and time with each other, there is something for everyone. I hope that you will also join me in looking forward to the future, as we **Take CHARGE beyond Orlando.**

David Wolfe

David Wolfe
President and Fundraising Chair
CHARGE Syndrome Foundation, Inc.



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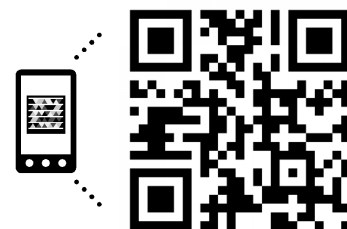


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Check on Upcoming Events,

CHARGE Research or even Donate!



www.chargesyndrome.org

People First Language

A handicap has been defined as an obstacle which society imposes on a person with a disability, i.e. inaccessible transportation or buildings, no signage, etc. Handicapped is not a term to describe human beings. A disability has been defined as a body function that operates differently. It's that simple! It's just a body function that works differently. People First Language seeks to put the person first and the disability second! People with disabilities are people first and foremost.

www.DisabilityIsNatural.com

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It would be impossible to thank all the wonderful people who have helped us produce this conference, but every effort, big or small, is appreciated. Thanks to all of you for making this a wonderful event!

13th International CHARGE Syndrome Conference

Wednesday, July 26th, 2017

**9am-5pm Conference & Professional Day Registration
& Sales Center at Registration Desk in Transportation Lobby**

Thursday, July 27th, 2017

<i>Time</i>	<i>Event</i>	<i>Location</i>
<i>7:00-5:00</i>	<i>Conference Registration & Sales Open</i>	<i>Transportation Lobby</i>
<i>7:00-12:00</i>	<i>Professional Day Registration</i>	<i>Transportation Lobby</i>
<i>7:00-5:30</i>	<i>Professional Day Conference</i>	<i>Sebastian I / Panzacola H</i>
<i>9:00-5:00</i>	<i>Camp Discovery & Camp Explorer Registration</i>	<i>Transportation Lobby</i>
<i>1:00-4:00</i>	<i>Pool Party (If pool is closed due to weather we will be indoors in Panzacola F1/F2/G1)</i>	<i>Gatlin Terrace and adjoining pool</i>
<i>6:30-9:00</i>	<i>Reception - Light dinner included. Cash bar available.</i>	<i>Sebastian I/J</i>

[illegible]

5th Professional Day - Thursday, July 27th, 2017

7:00-12:00	Registration in Satellite Registration Desk in Transportation Lobby	
7:00-8:30	Poster setup in Sebastian I3/I4	
7:45-8:45	Breakfast in Sebastian I1/I2	
9:00-10:45	General Session in Panzacola H – Welcome Remarks, Plenary Speakers: Vestibular issues in CHARGE syndrome: anatomy, physiology, testing, behavioral outcomes David Brown and Dr. Daniel Choo/ The Neuromuscular Phenotype of Shoulder Deformities in CHARGE Syndrome prof. C.M.A. van Ravenswaaij, MD, PhD on behalf of Christa (C.M.) de Geus, MD / Dissecting the functions of CHD7 in brain development using mouse models M. Albert Basson, PhD	
10:45-12:00	Poster session in Sebastian I3/I4	
12:00-1:00	Lunch in Sebastian I1/I2	
1:00-2:30	Breakout Sessions #1 – Panzacola H1/H2 (Educational/Behavioral/Communication), Panzacola H3/H4 (Clinical/Scientific Research) - See Below	
2:30-2:45	Coffee Break	
2:45-4:15	Breakout Sessions #2 – Panzacola H1/H2 (Educational/Behavioral/Communication), Panzacola H3/H4 (Clinical/Scientific Research) - See Below	
4:30-5:30	Recap and Closing remarks in Panzacola H	
	Panzacola H1/H2: Educational/Behavioral/Communication	Panzacola H3/H4 : Clinical/Scientific Research
Breakout Session #1 1:00 -2:30	<p>“Taking – too much – CHARGE?” A discussion on the aspects of responsibility - Wenche Andersen and Eva Seljestad</p> <p>The CHARGE IEP: What have we learned?- Hailey Ripple & Kasee Stratton</p> <p>Communicative Forms & Functions Used by Individuals with CHARGE Syndrome - Susan M. Bashinski</p> <p>Managing the Sensory Environment - Sarah Bis and Sarah Maust</p>	<p>A new feeding scale for use in CHARGE syndrome - Alexandra Hudson, Dr. Kasee Stratton, Dr. Kim Blake</p> <p>Cochlear implants for CHARGE patients: sound present and better future - Brandi Griffin, Yehoash Raphael</p> <p>External Quality Assessment Clinical Genetics: CHARGE syndrome as an educational case - Conny van Ravenswaaij-Arts</p> <p>Dissecting the causes of frontal cortex abnormalities in a mouse model for CHARGE syndrome - Alex P A Donovan</p>
	Panzacola H1/H2: Educational/Behavioral/Communication	Panzacola H3/H4 : Clinical/Scientific Research
Breakout Session #2 2:45 – 4:15	<p>Assessment and treatment of problematic behavior in students with CHARGE Syndrome - Caleb Davis, and Zachary Bird</p> <p>Who Needs an Intervener? - Beth Kennedy</p> <p>The Behavior Triangle for CHARGE Syndrome - Timothy S. Hartshorne</p> <p>The CHARGE Syndrome Research Lab at Central Michigan University - Timothy S. Hartshorne, Megan Schmittel, Bree Kaufman, Shanti Madhavan-Brown, Anna Weatherly, Shelby Muhn, Rachel Wilson, Gretchen Imel, Deborah Ferriera, Blair Tieso, Aaron Hartshorne</p>	<p>Putting Genetics in CHARGE - Amanda Moccia</p> <p>Rapid drug discovery in genetic models of CHARGE syndrome - Kessen Patten</p> <p>Genetic epistasis contributes to inner ear and neuronal development via regulation of chromatin remodeling and retinoic acid synthesis Hui Yao, Jennifer M Skidmore, Ethan D Sperry, Donald L Swiderski, Shigeki Iwase, Peter Scacheri and Donna M Martin</p>



13th International CHARGE Syndrome Conference **Professional Day: Thursday July 27, 2017**

Professional Day at conference provides a venue for professionals to exchange information about the procedures and methods for understanding and treating CHARGE. The day begins with a general session for all attendees featuring three plenary sessions, followed by a poster session. The remainder of the day features platform presentations divided into two categories: Educational/Behavioral/Communication and Clinical/Scientific Research and a general session for all attendees at the end of the day.

Plenary Sessions:

Vestibular issues in CHARGE syndrome: anatomy, physiology, testing, behavioral outcomes David Brown¹ and Dr. Daniel Choo²

¹ self-employed Deafblind Educational Consultant, San Francisco, CA

² Cincinnati Children's Hospital, Division of Pediatric Otolaryngology

The Neuromuscular Phenotype of Shoulder Deformities in CHARGE Syndrome

prof. C.M.A. van Ravenswaaij, MD, PhD on behalf of Christa (C.M.) de Geus, MD

Department of Clinical Genetics, University of Groningen, University Medical Center Groningen

Dissecting the functions of CHD7 in brain development using mouse models

M. Albert Basson, PhD, King's College London, Department of Craniofacial Development and Stem Cell Biology and MRC Centre for Neurodevelopmental Disorders

Co-presenters: Danielle E. Whittaker^{1,2}, Kimberley L. Riegman¹, Alex Donovan¹, Christa de Geus³, Jacob Ellegood⁴, Jason Lerch⁴, Conor Mohan¹, Cathy Fernandes^{5,6}, Conny van Ravenswaaij-Arts³ & M. Albert Basson^{1,6}.

¹King's College London, Department of Craniofacial Development and Stem Cell Biology, Floor 27, Guy's Hospital Tower Wing, London, SE1 9RT, UK

²Royal Veterinary College, 4 Royal College Street, London NW1 0TU

³University of Groningen, University Medical Center Groningen, Department of Genetics, PO Box 30.001, 9700RB Groningen, Netherlands

⁴Department of Medical Biophysics, University of Toronto, Mouse Imaging Centre, Hospital for Sick Children, 25 Orde Street, Toronto, Ontario M5T 3H7, Canada

⁵MRC Social, Genetic & Developmental Psychiatry Centre, PO82, Institute of Psychiatry, Psychology & Neuroscience, King's College London, De Crespigny Park, London SE5 8AF, UK

⁶King's College London, MRC Centre for Neurodevelopmental Disorders, 4th floor, New Hunt's House, London, SE1 1UL, UK

Session #1 - 1:00pm – 2:30pm	
Location – Panzacola H1/H2	Location – Panzacola H3/H4
Educational/Behavioral/Communication	Clinical/Scientific Research
“Taking – too much – CHARGE?” A discussion on the aspects of responsibility Wenche Andersen and Eva Seljestad	A new feeding scale for use in CHARGE syndrome Alexandra Hudson, MD Candidate 2018, Dalhousie Medical School, Halifax, Nova Scotia, Canada Dr. Kasee Stratton, Director of Bulldog CHARGE Syndrome Research Lab, Mississippi State, MS, USA Dr. Kim Blake, Professor, Department of Pediatrics, Dalhousie University, Halifax NS Canada
The CHARGE IEP: What have we learned? Hailey Ripple, M.S., Doctoral Student, School Psychology, Mississippi State University Kasee Stratton, Ph.D., NCSP, Assistant Professor, School Psychology, Mississippi State University	Cochlear implants for CHARGE patients: sound present and better future Brandi Griffin, clinical audiologist, Department of Otolaryngology Terry Zwolan, Professor of Otolaryngology Yehoash Raphael, Professor of Otolaryngology, University of Michigan, Ann Arbor
Communicative Forms & Functions Used by Individuals with CHARGE Syndrome Susan M. Bashinski, Ed.D., Director of Graduate Programs in Education Associate Professor, Special Education Missouri Western State University	External Quality Assessment Clinical Genetics: CHARGE syndrome as an educational case Conny van Ravenswaaij-Arts, MD, PhD, University of Groningen, University Medical Center Groningen
Managing the Sensory Environment Sarah Bis, MS, OTR/L, C/NDT and Sarah Maust, MOT, OTR/L, Perkins School For The Blind	Dissecting the causes of frontal cortex abnormalities in a mouse model for CHARGE syndrome Alex P A Donovan, Craniofacial Development and Stem Cell Biology, King’s College London
Session #2 – 2:35 – 4:05pm	
Location – Panzacola H1/H2	Location – Panzacola H3/H4
Assessment and treatment of problematic behavior in students with CHARGE Syndrome Caleb Davis, M.S., BCBA and Zachary Bird, M.S., BCBA, Perkins School for the Blind	Putting Genetics in CHARGE Amanda Moccia, MS, Department of Human Genetics, University of Michigan
Who Needs an Intervener? Beth Kennedy, M.Ed.DB Central: Michigan’s Training & Resource Project and Central Michigan University	Rapid drug discovery in genetic models of CHARGE syndrome Kessen Patten, Phd, INRS-Institut Armand-Frappier

Professional Day Posters	
Location: Sebastian I3/I4	
<i>* Posters marked with an asterisk will also be presented on Friday at the full conference.</i>	
Poster Title	Presenter(s)
CHARGE Syndrome Checklist: Health Supervision Across the Lifespan*	Angela Arra-Robar, RN MSN Clinical Nurse Specialist, Complex and Medically Fragile Children, IWK Health Centre
Anxiety in CHARGE Syndrome*	Shanti Brown, Timothy S. Hartshorne, Ph.D., Central Michigan University
The Neuromuscular Phenotype of Shoulder Deformities in CHARGE-Syndrome	Prof. C.M.A. van Ravenswaaij, MD, PhD on behalf of Christa (C.M.) de Geus, MD, Department of clinical genetics, University of Groningen, University Medical Center Groningen
Growth in CHARGE syndrome*	Dieuwerke Dijk, MD, University of Groningen, University Medical Center Groningen Bas Penders ¹ , Willem-Jan Gerver ¹ , Monica Wong ² , Conny van Ravenswaaij-Arts ² , Gianni Bocca ² ¹ Maastricht University Medical Centre (MUMC+), ² University Medical Centre Groningen
Dissecting the causes of frontal cortex abnormalities in a mouse model for CHARGE syndrome	Alex P A Donovan, Craniofacial Development and Stem Cell Biology, King's College London
CHARGE Syndrome in Brazil*	Debora Ferreira, Timothy S. Hartshorne, Ph.D., Central Michigan University
You Asked, We Listened: What's missing on the IEP for students with CHARGE?*	Matthew Ferrigno, Doctoral Student, School Psychology, Mississippi State University Hailey Ripple, M.S., Doctoral Student, School Psychology; Megan Anderson, Doctoral Student, School Psychology; Tierra Kilbert, Eds. Student, School Psychology, Savannah Trice, Eds. Student, School Psychology, Haley Grant, Undergraduate, Kasee Stratton, Ph.D., NCSP, Assistant Professor, School Psychology, Mississippi State University
Radiological Imaging Findings in CHARGE Syndrome*	Lauren Fogarty, MD Candidate 2020, Faculty of Medicine, Dalhousie University Dr. Kim Blake, Department of Pediatrics, IWK Health Centre, Professor Pediatrics, Dalhousie University; Dr. Pierre Schmit, Department of Diagnostic Imaging, IWK Health Centre, Professor Diagnostic Radiology, Dalhousie University; Alexandra Hudson, MD Candidate 2018, Faculty of Medicine, Dalhousie University

Location: Sebastian 13/14

Poster Title	Presenter(s)
The Behavior Triangle for CHARGE Syndrome*	Tim S. Hartshorne, Ph.D., Central Michigan University
The CHARGE Syndrome Research Lab at Central Michigan University*	Tim S. Hartshorne, Ph.D., Central Michigan University Megan Schmittell, Bree Kaufman, Shanti Madhavan-Brown, Anna Weatherly, Shelby Muhn, Rachel Wilson, Gretchen Imel, Deborah Ferriera, Blair Tieso, Aaron Hartshorne, Central Michigan University
The Sensory Base of Unusual Behaviors in Children with CHARGE*	Aaron Hartshorne, Tim S. Hartshorne, Ph.D., Central Michigan University
CHARGE syndrome: the importance of inner ear MRI and CHD7 testing for diagnosis as the dysmorphology is not always obvious*	Meg Hefner, MS, Saint Louis University
Milestones in CHARGE Syndrome*	Meg Hefner, MS, Saint Louis University, Emily Fassi, MS, Washington University in St. Louis, Kevin Ballard
A new feeding scale for use in CHARGE syndrome*	Alexandra Hudson, MD Candidate 2018, Dalhousie Medical School, Halifax, Nova Scotia, Canada; Dr. Kasee Stratton, Director of Bulldog CHARGE Syndrome Research Lab, Mississippi State, MS, USA; Dr. Kim Blake, Professor, Department of Pediatrics, Dalhousie University, Halifax NS Canada
Overview of Sexuality Education*	Chathuri Illapperuma, Doctoral Student, School Psychology, Mississippi State University Jordan Parker, EdS. Student, School Psychology; Emily Mathis, Doctoral Student, School Psychology; Mallory Eddy, Doctoral Student, School Psychology; Alexander Clarke, EdS. Student, School Psychology; Kasee Stratton, Ph.D., NCSP, Assistant Professor, School Psychology, Mississippi State University
Trends in and Barriers to Recreation Participation in CHARGE Syndrome*	Gretchen Imel, Tim S. Hartshorne, Ph.D., Central Michigan University
Profiles of Ability in CHARGE Syndrome*	Bree Kaufman, M.A. , Tim S. Hartshorne, Ph.D., Central Michigan University

Location: Sebastian 13/14

Poster Title	Presenter(s)
Modelling hypoventilation and anesthetic recovery in a zebrafish (Danio rerio) model of CHARGE syndrome*	<p>Jessica MacLean, Department of Pediatrics, Dalhousie University/IWK Health Centre, Halifax NS CANADA</p> <p>Jaime Wertman, Department of Microbiology and Immunology, Dalhousie University, Halifax NS; Emily Chedrawe, Department of Pediatrics, Dalhousie University/IWK Health Centre, Halifax NS; Shelby Steele, Department of Pediatrics, Dalhousie University, Halifax NS; Sergey Prykhozhij, Department of Pediatrics, Dalhousie University, Halifax NS; Kim Blake, Department of Pediatrics, Dalhousie University/IWK Health Centre, Halifax NS; Jason N Berman, Departments of Pediatrics, Microbiology and Immunology, and Pathology, Dalhousie University/IWK Health Centre, Halifax NS</p>
Moving forward with the transition to preschool through collaborative planning*	Julie Maier, Educational Specialist, Myrna Medina, Family Engagement Specialist , California Deafblind Services
Decision-making in the removal of gastrostomy tubes or buttons in CHARGE syndrome*	Rachel Malta, Tim S. Hartshorne, Ph.D., Central Michigan University
Let's Talk About Sex: Implications for Future Research in Sexuality Education*	<p>Emily Mathis, Doctoral Student, School Psychology, Mississippi State University</p> <p>Alex B. Clarke, Specialist Student, School Psychology, Mallory Eddy, Doctoral Student, School Psychology, Chathuri Illapperuma, Doctoral Student, School Psychology, Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist,</p>
Post-Traumatic Growth in parents of children with CHARGE*	Shelby Muhn, Tim S. Hartshorne, Ph.D., Central Michigan University
Examining the Measurability and Attainability of IEP Goals for Individuals with CHARGE Syndrome*	<p>Hailey E. Ripple, M.S., Doctoral Student, School Psychology, Mississippi State University</p> <p>Johnna Dowdy, Doctoral Student, School Psychology, Olivia Kesler, Undergraduate, Katherine Johnson, Undergraduate, Kasee Stratton, Ph.D., NCSP, Assistant Professor, Mississippi State University</p>

Location: Sebastian 13/14	
Poster Title	Presenter(s)
IEP Transition Plans for Individuals with CHARGE Syndrome*	Hailey E. Ripple, M.S., Doctoral Student, School Psychology, Mississippi State University Elizabeth Struna, Doctoral Student, School Psychology, Matthew Ferrigno, Doctoral Student, School Psychology, Katherine Johnson, Undergraduate Student, Kasee K. Stratton, Ph.D., NCSP, Assistant Professor, School Psychology, Mississippi State University
Social Play in Children with CHARGE Syndrome*	Megan C. Schmittel, Tim S. Hartshorne, Ph.D., Central Michigan University
Research on Headaches in CHARGE Syndrome*	Lily Slavin, Tim S. Hartshorne, Ph.D., Central Michigan University
The Bulldog CHARGE Syndrome Research Lab at Mississippi State University*	Kasee Stratton, Ph.D., NCSP, Assistant Professor, School Psychology; Megan Anderson, Doctoral Student, School Psychology, Mississippi State University
The CHARGE IEP: What Accommodations and Rulings are Common?*	Elizabeth Struna, Doctoral Student, School Psychology, Mississippi State University Hailey Ripple, M.S., Doctoral Student, School Psychology; Amanda Cosgriff, M.S., Doctoral Student, School Psychology; Whitney Driskell, EdS. Student, School Psychology; Savannah Trice, EdS. Student, School Psychology; Tierra Kilbert, EdS. Student, School Psychology; Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist, School Psychology, Mississippi State University
What makes up a family in CHARGE: Family Dynamics and Demographics*	Madison Sully, Specialist Student, School Psychology, Mississippi State University Megan Anderson, Doctoral Student, School Psychology; Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist, School Psychology, Mississippi State University
Adverse Effects and Behavioral Analysis of Psychotropic Drug Use with Children with CHARGE Syndrome*	Blair Tiseo, Tim S. Hartshorne, Ph.D., Central Michigan University

Friday, July 28th, 2017

Time	Event	Location
7:00-4:30	Conference Registration	Panzacola Registration
7:00-4:30	Sales Center	Panzacola Foyer
7:00-8:45	Breakfast	Sebastian I/J
7:00-8:45	Camp Discovery & Camp Explorer registration	Wekiwa Registration
7:00-8:45	Poster setup	Panzacola F1/F2
8:00-5:00	Exhibits	Panzacola East Foyer
8:30-11:45	Camp Discovery & Camp Explorer morning session	Wekiwa & Suwannee
9:00-10:30	Welcome/ Keynote "Taking CHARGE: No Limits" with deaf-blind adventurer, advocate & storyteller Bill Barkeley/General Session	Sebastian I/J
10:45-5:00	Info Central	Panzacola F1/F2
10:45-11:45	Breakout Session #1—See next pages	
11:45-12:45	Lunch	Sebastian I/J
12:30-5:15	Camp Discovery & Camp Explorer afternoon session	Wekiwa & Suwannee
1:00-2:00	Breakout Session #2—See next pages	
2:15-3:15	Breakout Session #3—See next pages	
3:15-3:30	Coffee Break	
3:30-4:30	Breakout Session #4—See next pages	
5:15-6:15	Rachel Coleman Signing Times Concert	Gatlin D
6:30-7:45	Dinner	Sebastian I/J
7:30	Rachel Coleman Signing Times Meet & Greet	Panzacola Foyer

Friday Breakout Sessions

	Breakout Session #1 10:45 - 11:45	Breakout Session #2 1:00 - 2:00	Breakout Session #3 2:15-3:15	Breakout Session #4 3:30-4:30
Panzacola F1/F2	<p align="center">Info Central (10:45 – 5:00) Manned from 3:30 – 5:00</p> <p align="center">posters, demonstrations, meet professionals and more</p>			
Panzacola F3 /F4	#1 Cochlear Implants in CHARGE syndrome Griffin & Raphael	#6 Promoting Recrea- tion in Transition Lieberman, Haibach- Beach & Foster	#11 Managing the Sensory Environment Bis & Maunst	#16 Vestibular Issues Brown & Choo
Panzacola G1	#2 Assessment & Treatment Behavior Bird & Davis	#7 Capacity Building Assessment Maier	#12 Got the AAC De- vice...Now What? Weir	#17 Neurological Issues de Geus (Ravenswaaij)
Panzacola G2	#3 CHARGE 101 Hefner & Beals	#8 CHARGE 102 Beals & Salem- Hartshorne	#13 CHARGE 103 Last	#18 Connect the Dots: Sensory and Motor Issues Q&A Beals & Bushey
Panzacol H1/H2	#4 Father's Forum Hartshorne	#9 Special Needs Planning Ehlert	#14 Cardiology Morales	#19 Dreaming into the Future Allen & Allen
Panzaca H3/H4	#5 Grandparent's Forum Ryan	#10 Behavior in School Setting Stratton & Gadke	#15 Working Together to Support Families Stanger & Cote	#20 Oh the Places You'll Go...after High School (transition) Jordan & Goel


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Saturday, July 29th, 2017

Time	Event	Location
7:00–4:30	Conference Registration & Sales Center	Panzacola Foyer
7:00-8:45	Breakfast	Sebastian I/J
8:30-11:45	Camp Discovery & Camp Explorer morning session	Wekiwa & Suwannee
8:00-4:00	Exhibits	Panzacola East Foyer
9:00–10:30	General Session	Sebastian I/J
10:45-11:45	Breakout Session #5—See next pages	
11:45-12:45	Lunch	Sebastian I/J
12:30-4:45	Camp Discovery & Camp Explorer afternoon session	Wekiwa & Suwannee
1:00-2:00	Breakout Session #6—See next pages	
2:15-3:15	Breakout Session #7—See next pages	
3:15-3:30	Coffee Break	
3:30-4:30	Breakout Session #8—See next pages	
6:30	CHARGE-A-Palooza: Dinner, Carnival and Silent auction	Gatlin C/D

Notes _____

Saturday Breakout Sessions

	Breakout Session #5 10:45 – 11:45	Breakout Session #6 1:00 – 2:00	Breakout Session #7 2:15-3:15	Breakout Session #8 3:30-4:30
Panzacola F1/F2	#21 Siblings Salem-Hartshorne, Braga, Beavers	#27 Transition Supports (In Baseball parody format) Sheriff & Sence	#33 Incorporating literacy routines at home & school Veto	#37 Multidisciplinary ap- proach to feeding Pimentel et al.
Panzacola F3 /F4	#22 Adult Track 1 (Individuals 16+ with CHARGE syndrome ONLY) Stratton & Gadke	#28 Adult Track 2 (Individuals 16+ with CHARGE syndrome ONLY) Stratton & Gadke	#34 Adult Track 3 (Individuals 16+ with CHARGE syndrome ONLY) Stratton & Gadke	#41 IEP and Family De- mographics Re- search: Preliminary Results Stratton & Bulldog CHARGE Lab
Panzacola G1	#23 Behavior Diagnosis & Intervention Part I Hartshorne & Brown	#29 Behavior Diagnosis & Intervention Part II Hartshorne & Brown	#35 5 Hints for New and Seasoned Parents Hartshorne	#38 Purposeful Play: how wrestling & playing can benefit... Braga
Panzacola G2	#24 Nonconventional Signal Dictionaries for Presymbolic Communicators Bashinski, Darrah & Spratling	#30 Quality Adapted PE Foster	#36 Variables that affect walking Foster	#39 Parents' Perspec- tives: Types & Pur- poses of Communi- cation Bashinski
Panzacola H1/H2	#25 Intervenors – who needs one? and A Day in the Life! - Case studies Kennedy, Cameron & Drew	#31 Interpersonal Inter- actions  Wanka		#40 Raising a child who is deafblind Snyder
Panzacola H3/H4	#26 Teaching Strategies Between Home & School Stelzer	#32 Taking Charge of GI Issues Blake et al.		

Sunday, July 30th, 2017

7:00-8:45	Breakfast in Panzacola F/G
7:00-12:00	Sales Center in Panzacola Foyer
8:30-12:30	Camp Discovery & Camp Explorer morning session Wekiwa & Suwannee
9:00–10:15	General Session in Panzacola F/G
10:15-11:00	Adult Panel in Panzacola F/G Nate Mathewson, Caitlin Caulfield, Symone Griffin, Michael Archuleta
11:00-11:45	Deep Thoughts by David Brown in Panzacola F/G
11:45-12:00	2017 Conference Farewell in Panzacola F/G

Notes

This image shows a single sheet of white paper with horizontal black lines, resembling notebook paper. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



13th International CHARGE Syndrome Conference

Program Breakout Sessions

Friday, July 28 – 10:45 – 11:45 – Breakout Session #1

Cochlear implants for CHARGE patients: sound present and better future - Brandi Griffin, Au.D., Teresa Zwolan, Ph.D. and Yehoash Raphael, Ph.D.

This presentation will answer many questions you may have about cochlear implants, including who is a candidate, and what tests are used to determine if someone is a candidate for a cochlear implant. We will review how a cochlear implant works, and discuss the kinds of outcomes that can be expected when a patient with CHARGE receives a cochlear implant. We will review recent developments in cochlear implants that will include a description of hearing preservation, electrode arrays, and new developments in speech processors. The presentation will include a discussion of factors that impact performance, and things that can be done to enhance performance. You will learn about novel biological approaches for making the ear a better recipient of the implant.

Assessment and treatment of problematic behavior in students with CHARGE Syndrome - Caleb Davis, M.S., BCBA and Zachary Bird, M.S., BCBA

CHARGE syndrome engaged in problematic behavior that interfered with learning throughout their school day. Presenters will focus on describing the assessment process for each student and how results informed treatment development. In addition, the presentation will describe the three P's of behavior management (i.e., Prevent, Promote, and Provide).

CHARGE 101: Diagnostic criteria and other features of CHARGE and their effects on early development - Meg Hefner, MS, Kate Beals, OTR/L, Danielle Bushey, PT, DPT, NCS

CHARGE 101, 102 & 103 (# 3, 8, and 13) are for anyone who would like a comprehensive overview of CHARGE: from diagnosis to development to outcomes. 101 will start with Meg reviewing how the clinical diagnosis is made and other features seen in children with CHARGE. Kate and Danielle will describe how the sensory deficits (hearing, vision, balance) affect early childhood development. See the descriptions for CHARGE 102 (#8) and CHARGE 103 (#13).

Father's Forum – Tim Hartshorne

CHARGE affects every member of the family. This meeting is only for fathers who have a child with CHARGE syndrome. It is their opportunity to have an open discussion and share experiences with other fathers.

Grandparent's Forum – Pamela Ryan

CHARGE affects every member of the family. This meeting is only for grandparents who have a grandchild with CHARGE syndrome. It is their opportunity to have an open discussion and share experiences with other grandparents.

Friday, July 28 – 1:00 – 2:00 – Breakout Session #2

Promoting Recreation and Physical Activity in the Transition Process - Lauren J. Lieberman Ph.D., Pamela Haibach-Beach Ph.D., Beth Foster Ph.D.

This presentation will share strategies for parents, teachers and specialists to ensure that every child has the basic fundamental skills provided in physical education, IEP meetings, transition meetings and beyond. The laws related to these educational requirements will be reviewed to provide tools and strategies to ensure every child is prepared to have a quality of life. Lastly, many resources will be provided to help support the teachers and families to ensure their children have a strong foundation to live their lives to their full potential.

What should we be looking for? Child-centered and capacity-building assessment approaches - Julie Maier, Educational Specialist

Individuals with CHARGE syndrome who cannot effectively use formal language to communicate are difficult to accurately assess using norm-referenced assessment approaches and tools. This presentation will examine how one can use more authentic, effective and child-centered approaches to identify and learn about the abilities, intelligence, interests, and support needs of these individuals and use results from more authentic assessment approaches to develop and plan more effective adaptations, services and supports. Related authentic assessment resources will be shared.

CHARGE 102 Effects of CHARGE features on development, behavior and outcomes - Kate Beals, OTR/L, Nancy Salem-Hartshorne, PhD, Danielle Bushey, PT, DPT, NCS

Kate Beals and Danielle Bushey will continue their presentation from 101 (#3) by presenting ideas on how to set up play and learning activities so the child derives optimum physical benefits from the experiences. Nancy Salem-Hartshorne will then present an overview of what we know about behaviors and developmental outcomes in CHARGE based on 20 years of research and observations. Nancy will also introduce communication options appropriate for children with CHARGE – which will be continued in CHARGE 103 (#13).

Your Journey Through a Special Needs Planning Program - Mary Anne Ehlert CFP

The presentation will be uplifting and educational, as well as provide a good basic understanding of some important facts. Participants will develop the foundation for their family's own personal Future Care Plan. Some topics of discussion include: how to create a map of the future; how to prepare legally and financially; how to incorporate and maximize government benefits; how to prepare for transition; and how to communicate your Future Care Plan to your family.

Behavior Management in the School Setting - Kasee Stratton, Ph.D., NCSP and Daniel Gadke, Ph.D., NCSP, BCBA

Knowing what behavioral supports are needed in the educational setting can be confusing and challenging for parents, particularly when various interventions are being used across settings. This presentation will discuss how to navigate behavior issues in the school setting and how to advocate for behavioral supports. Functional behavioral assessments and behavior intervention plans will be discussed in everyday language to guide parents and professionals.

Friday, July 28 – 2:15 – 3:15 – Breakout Session #3

Managing the Sensory Environment - Sarah Bis, MS, OTR/L, C/NDT and Sarah Maust, MOT, OTR/L
Multi-sensory deficits impact the ability of individuals with CHARGE Syndrome to gather, interpret, and use sensory information across settings. By adapting the sensory environment in which individuals with CHARGE Syndrome live, play, and learn, we can help them better access sensory information and participate in their world. Accommodations and adaptations will be discussed related to the needs of children with CHARGE Syndrome in the educational environment. Participants will leave the session with a list of ideas for sensory-based accommodations that may be implemented at home and in the school setting immediately.

Got the AAC Device...Now What? - Lisa Weir, MEd. (DHH), CTD.

Sometimes parents or even school teams secure a wonderful device to assist with the acquisition of expressive communication for their student/child. The device arrives and unfortunately sometimes, gets left on the shelf or repurposed to more of a game/movie device because, "They aren't really using it." We will look at some fundamental skills and starting points for families so they can better support communication development in their sons or daughters who have an Augmentative and Alternative Communication (AAC) device.

CHARGE 103 Communication, Play and Passions - Rob Last

Rob will focus on early communication and address the importance of establishing meaningful communication systems for children with CHARGE and the strategies that may be available for this. Play strategies will be illustrated through discussion and video. Passions/obsessions will be explored as educational opportunities and illustrated through video and photos.

Latest Advancements in Congenital Heart Surgery: Their Potential to Help Children with CHARGE syndrome and Congenital Heart Disease - David L.S. Morales, MD

Congenital Heart Defects (CHDs) are common in children with CHARGE syndrome (75-85%) and include typical ventricular/atrial septal defects, patent ductus arteriosus, but many have complex CHDs. New advances in mechanical circulatory support (i.e. artificial hearts) can be beneficial in the management of these problems when surgical options are no longer possible. 3D printing/animations as well as augmented reality are now starting to be used to better plan complex cardiac repairs more accurately and improve patient and family education about heart defects and the palliative/corrective operations. The development of tissue engineered patches and valves have started to be used clinically and may change how we approach some of these children's defects since placing a valve in infancy may now last a lifetime.

Working Together to Support Families - Sheri Stanger, MA, Ed.M and Megan Cote, MS Ed

We will explain the distinct roles of the National Center on Deaf-Blindness, the CHARGE Syndrome Foundation, and the National Family Association for Deaf-Blind and describe how work conducted by the three organizations supports families to access the knowledge and services they need to promote better outcomes for their children who are deaf-blind. Attendees will learn what each organization offers and how to take part in the training and connections they provide.

Friday, July 28 – 3:30 – 4:30 – Breakout Session #4

Vestibular issues in CHARGE syndrome: anatomy, physiology, testing, behavioral outcomes - David Brown and Dr. Daniel Choo

One of the most common (but poorly understood) features in children with CHARGE syndrome is absence or malformation of the inner ear vestibular structures (e.g. semicircular canals). These anomalies can impact a child's balance, body control, walking and other complex activities (such as riding a bicycle, sports, use of vision, etc). However, some of the very typical CHARGE behaviors, postures and positions may indeed be related to the abnormal vestibular organs and functions in these children. This presentation offers a primer on inner ear vestibular anatomy and physiology, as well as the current state of the art vestibular testing performed in the clinical setting.

Neurological issues in CHARGE syndrome: our experiences so far - Prof. C.M.A. van Ravenswaaij, MD, PhD on behalf of Christa (C.M.) de Geus, MD

Most people with CHARGE syndrome experience some neurological symptoms. However, comprehensive research on the neurological problems in CHARGE is lacking.

In 2014 we started a project in our CHARGE expert center aimed at creating a comprehensive dataset on neurological issues in CHARGE. We have focused on collecting broad data; on the relationship between cerebellum abnormalities and balance/coordination; and on the occurrence and cause of sloping shoulders. In this presentation we will give an overview of our results so far.

Connect the Dots: An open forum question-and-answer session focused on sensory and motor issues in CHARGE Syndrome - Kate Beals, OTR/L and Danielle Bushey, PT, DPT, NCS

Huh? What's all this stuff about sensory processing? What does that even mean? And why do they keep talking about balance problems? What can I do to help? Got questions about how it all fits together? Bring your questions – even if you're not quite sure how to ask them – to this informal session with a PT and an OT, who will help you "connect the dots" about **sensory** and **motor** issues in CHARGE syndrome.

Dreaming Your Way into your Future - Catherine Allen and Rachel Allen

How do I plan for the future when I can barely get through each day? There is a place and there will come a day when 'official life & career planning' will be urgently scribbled on your TO-DO list. But, it's never too early to adopt a philosophy of Life Design based on the unique desires, needs, and dreams of an individual and his/her family. Quality of life improves and career paths become clearer when all choices are filtered through that design rather than through disabilities and obstacles.

Oh the Places You'll Go...after High School - Beth Jordan, Med and Divya Goel, AAS

High school graduation. Does that idea cause you anxiety or excitement? If it's anxiety, consider learning more about the summer programs available to young adults at HKNC. With the passage of recent legislation, it's never been a better time to be a young adult who is interested in college and work after high school. Let's generate some excitement!

Saturday, July 29 – 10:45 – 11:45 – Breakout Session #5

Sibling Panel - Nancy Salem-Hartshorne, PhD., Aaron Hartshorne, Mallory Beavers

Siblings of individuals with disabilities have unique experiences. Siblings of individuals with CHARGE have even more unique experiences. Within these, there are still more variable experiences, depending on birth order, severity of disability, and parenting styles, among other things. This panel of young adults will describe their experiences, both rewarding and challenging, of being raised with a sibling with CHARGE syndrome. Moderators will then ask specific questions, after which audience questions will be welcomed.

Adult Track 1 - Kasee Stratton, Ph.D., NCSP and Daniel Gadke, Ph.D., NCSP, BCBA

This three-session track will provide a series of presentations, discussions, and question and answer formats *for adults with CHARGE syndrome ages 16+ only*. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods. (See also #28 and #34)

CHARGE Syndrome and Behavior: Diagnoses and Intervention (Part I) - Tim Hartshorne, David Brown, Megan Schmittell, Shanti Madhavan-Brown, and Shelby Muhn

Part one: Diagnosis of behavior. Individuals with CHARGE are often diagnosed with a variety of psychiatric disorders such as autism, OCD, and ADHD. This session addresses the problem of psychiatric diagnoses in children with CHARGE: what are these diagnoses, why are they given to children with CHARGE, and what problems do they create, and are they appropriate?

Creating and Using Nonconventional Signal Dictionaries and Communication Portfolios to Support Individuals who Communicate Primarily without the Use of Symbols - Susan M. Bashinski, Ed.D., Carol Darrah, M.S., Christine Spratling, Ed.S.

For individuals at the earliest, non-symbolic, stages of communication development, the implementation of consistent communication strategies enhances their participation in interactions and promotes their ongoing communication development. Learn how to build receptive and expressive Nonconventional Signal Dictionaries (written scripts and video clips) and to create Communication Portfolios (pictures and written descriptions) to support children as they enter new learning settings, participate in community activities, meet new service providers, and interact with family members and friends.

Who Needs an Intervener? and A Day in the Life! A Case Study of 2 Adults with CHARGE and their Intervenor Services - Beth Kennedy, M.Ed., Cullen Drew, and Leah Cameron

Beth will discuss students who have a combined vision and hearing loss and their unique educational support needs. Some students require the specialized services of a trained intervener. This session will provide a brief overview of the wide range of students who qualify as deafblind, compare the role of an intervener to that of a paraprofessional and an interpreter, and provide strategies for determining which level of support is appropriate. This will be followed by Leah and Cullen's presentation, which will feature a case study of 2 adults with CHARGE whom are currently supported by CDBA Ontario through Adult Intervenor Services. CDBA Ontario's vision is that all people who are deafblind will live rich meaningful lives.

Teaching Strategies: building bridges between home and school - Sharon Stelzer, M.Ed.

For this presentation the presenter will share teaching strategies that work for children with CHARGE Syndrome. She will present how these strategies are used in school. With input from families of children with CHARGE Syndrome Sharon will link strategies that work at home to strategies that educators use in the classroom. She will discuss the importance of using similar vocabulary in the IEP process and methods to share strategies with the school team.

Saturday, July 29 – 1:00 – 2:00 – Breakout Session #6

Personal Reflections on Transition Supporters in Baseball Parody Format: Take Me Out to The Ballgame - Christopher Sence, BFA and L. Kathleen Sheriff, Ed.D.

Chris Sence, a 35-year-old man born with CHARGE syndrome, reflects on his personal transition support system in parody format emphasizing teaming together as a baseball team program to ultimately win at the game of life. He and his mother, Dr. Kathleen Sheriff, share his story of transition supporters matched with baseball program positions from little league to adulthood regarding the choices of majoring on the majors in life. Chris hopes this personal reflection adds to the lives of younger children with CHARGE syndrome and their supporting parents and transition teams.

Adult Track 2 - Kasee Stratton, Ph.D., NCSP and Daniel Gadke, Ph.D., NCSP, BCBA

This three-session track will provide a series of presentations, discussions, and question and answer formats *for adults with CHARGE syndrome ages 16+ only*. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods. (See also #22 and #34)

CHARGE Syndrome and Behavior: Diagnoses and Intervention (Part II) - Tim Hartshorne, David Brown, Megan Schmittle, Shanti Madhavan-Brown, and Shelby Muhn

Part two: Interventions for challenging behavior. This session describes interventions that can help to reduce the behaviors that often lead to psychiatric diagnoses. These interventions follow the principle that the behaviors are functional for the child given their various impairments. The interventions address issues of pain, sensory processing, and anxiety.

Quality Adapted Physical Education and Recreation for Individuals with CHARGE Syndrome - Dr. Elizabeth (Beth) Foster, CAPE

Many individuals with CHARGE Syndrome do not have the same movement opportunities in their schools and in their communities. Come to this session to learn about the federal laws and advocacy skills to obtain a quality physical education or an adapted physical education program for your child at their school. Learn about the motor assessment process and proper Individual Education Programs (IEPs) related to movement and motor skills. Participants will also leave with valuable information to assist in the inclusion of their child in recreation activities within their community.

Analyzing interpersonal interactions in CHARGE syndrome - Andrea Wanka, PhD.

CANCELLED

Interpersonal interactions are the basis for connection and communication. This presentation analyzes the interactions between a father and his young son with

CHARGE. In the first video, the boy is sitting on his father's lap engaged in movement and rhythmic vocalizations. In the second video they look at a picture book. The analysis, utilizing the cue model (Nafstad, Rodbroe 2015), looks at social interaction and play, physical closeness and attachment, exploration and categorization, and conversations.

Taking CHARGE of Your Gastrointestinal Issues - Dr. Kim Blake, MacKenzie Colp, Alexandra Hudson
Gastrointestinal (GI) symptoms and feeding difficulties are highly prevalent but are often a neglected area of diagnosis, treatment and research. In this presentation a young adult will report on her ongoing story with gastrointestinal problems, we will review what is known in the literature and treatment options; some of which have been gathered from you as parents, and from individuals with CHARGE syndrome.

Saturday, July 29 – 2:15 – 3:15 – Breakout Session #7

Incorporating Literacy into Daily Routines at School and at Home - Martha Veto and Christine Spratling, Ed.S

Children with combined vision and hearing loss have a hard time developing concepts about the world around them. Learning routines are an effective tool to help. In this session we will use materials from the Open Hands, Open Access (OHOA) learning modules to show the power of using routines to develop concepts, language and literacy skills. Participants will have an opportunity to use an OHOA tool for planning routines for individual students.

Adult Track 3 - Kasee Stratton, Ph.D., NCSP and Daniel Gadke, Ph.D., NCSP, BCBA

This three-session track will provide a series of presentations, discussions, and question and answer formats for adults with CHARGE syndrome ages 16+ only. Sessions will include topics such as sex, sexual dysfunction, sustaining friendships, guidance on drinking, social media skills, advocating on the job and in the community, and question and answer time periods. (See also #22 and #28)

Five hints for new and seasoned parents: Raising your child with CHARGE syndrome - Tim Hartshorne
Parenting is always challenging, but particularly with a child who has challenges, such as one who has CHARGE. This presentation reviews five considerations for parenting a child with CHARGE.

Variables that Impact Walking in Individuals with CHARGE Syndrome - Dr. Elizabeth (Beth) Foster, CAPE

Children with CHARGE syndrome are often delayed in the attainment of independently walking. The purpose of this session is to provide information about variables that impact walking and the benefits of walking in individuals with CHARGE syndrome. The session provides strategies to develop meaningful and accessible movement activities to enhance walking and provide children with movement confidence. Activities based on best practices and parent input will be presented. Participants leave with strategies that can be implemented when they get home.

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Saturday, July 29 – 3:30 – 4:30 – Breakout Session #8

Breakthroughs in Sensory Motor Processing & Feeding using Alternative Multi-Disciplinary

Treatment Approaches - Whitney B. Pimentel MA, CCC-SLP, Isabel Lara PT, SIPT, Carmen Romero

In this presentation Whitney B. Pimentel, Isabel Lara, and Carmen Romero will discuss common deficits such as sensory, physical challenges, oral challenges, feeding, and speech difficulties associated with CHARGE syndrome. They will teach a unique multi-disciplinarian approach of continually assessing the sensory system to determine a baseline at the beginning of each therapy session. Demonstrations of a variety of techniques will be taught to assist parents, therapists, and other educators in creating a therapeutic intervention program to address the needs of these individuals outside of traditional methods. An in-depth discussion will explain how and when to incorporate sensory motor developmental activities, core stability exercises, and cranial sacral therapy into a therapy program.

Purposeful play, how wrestling and playing can benefit children with CHARGE - Michael M. Braga M.Ed

During the day, we all receive input by walking, talking and even eating. Some with CHARGE may not receive all of this input that their brains still need. Using structured play, we can help them obtain this input. Come learn strategies that will help your children while you have fun with them and see how beneficial playing around can be.

Parents' Perspectives: Types and Purposes of Communication Used by Their Children Who Have CHARGE Syndrome - Susan M. Bashinski, Ed.D., Barbara Braddock, Christopher Neal, & Jennifer Heithaus

The extant literature base in special education supports the position that development of their child's communication skills is one of the most, if not THE most, critical area of need reported by families of children with CHARGE. This session will present results from a research study conducted during the 2015 International CHARGE Conference held in Chicago. At that conference, 27 families completed individual interviews for this study. Findings will be summarized and possible implications discussed.

Experiences of families raising a child who is deafblind and teacher response to their shared experiences - Donna Snyder, Ed.D, Kim Zeigler

This presentation will explore the experiences of families raising a child who is deafblind and teacher response to those shared experiences using the photovoice method with short digital videos. Family photovoice interviews uncovered five overarching themes. Project staff will share their experiences that initiated this study and the impact of findings as well as the change in service delivery of how the project introduces a child on the census to their educational team.

CHARGE Research: Preliminary Results on the CHARGE IEP and Family Demographics Studies – Kasee Stratton, PhD. and members of the Bulldog CHARGE Lab

Kasee, along with researchers from the Bulldog CHARGE Lab, will present preliminary findings from two recent research studies on accommodations and rulings on the CHARGE IEP and also family demographics seen in CHARGE syndrome.

Notes

Info Central

Location: Panzacola F1/F2 Friday 10:45am – 5:00pm (manned from 3:30 – 5pm)

Poster Title	Presenter(s)
The CHARGE Syndrome Research Lab at Central Michigan University	Tim S. Hartshorne, Ph.D., Central Michigan University Megan Schmittel, Bree Kaufman, Shanti Madhavan-Brown, Anna Weatherly, Shelby Muhn, Rachel Wilson, Gretchen Imel, Deborah Ferriera, Blair Tieso, Hannah Charville, Central Michigan University
The Behavior Triangle for CHARGE Syndrome	Tim S. Hartshorne, Ph.D., Central Michigan University
CHARGE syndrome: the importance of inner ear MRI and CHD7 testing for diagnosis as the dysmorphology is not always obvious	Meg Hefner, MS, Saint Louis University
Milestones in CHARGE Syndrome	Meg Hefner, MS, Saint Louis University, Emily Fassi, MS, Washington University in St. Louis, Kevin Ballard
A new feeding scale for use in CHARGE syndrome	Alexandra Hudson, MD Candidate 2018, Dalhousie Medical School, Halifax, Nova Scotia, Canada Dr. Kasee Stratton, Director of Bulldog CHARGE Syndrome Research Lab, Mississippi State, MS, USA; Dr. Kim Blake, Professor, Department of Pediatrics, Dalhousie University, Halifax NS Canada
Overview of Sexuality Education	Chathuri Illapperuma, Doctoral Student, School Psychology, Mississippi State University Jordan Parker, EdS. Student, School Psychology; Emily Mathis, Doctoral Student, School Psychology; Mallory Eddy, Doctoral Student, School Psychology; Alexander Clarke, EdS. Student, School Psychology; Kasee Stratton, Ph.D., NCSP, Assistant Professor, School Psychology, Mississippi State University
Trends in and Barriers to Recreation Participation in CHARGE Syndrome	Gretchen Imel, Tim S. Hartshorne, Ph.D., Central Michigan University
Profiles of Ability in CHARGE Syndrome	Bree Kaufman, M.A. , Tim S. Hartshorne, Ph.D., Central Michigan University

Location: Panzacola F1/F2 Friday 10:45am – 5:00pm (manned from 3:30 – 5pm)	
Poster Title	Presenter(s)
Modelling hypoventilation and anesthetic recovery in a zebrafish (Danio rerio) model of CHARGE syndrome	Jessica MacLean, Department of Pediatrics, Dalhousie University/IWK Health Centre, Halifax NS CANADA Jaime Wertman, Department of Microbiology and Immunology, Dalhousie University, Halifax NS; Emily Chedrawe, Department of Pediatrics, Dalhousie University/IWK Health Centre, Halifax NS; Shelby Steele, Department of Pediatrics, Dalhousie University, Halifax NS; Sergey Prykhozhiy, Department of Pediatrics, Dalhousie University, Halifax NS; Kim Blake, Department of Pediatrics, Dalhousie University/IWK Health Centre, Halifax NS; Jason N Berman, Departments of Pediatrics, Microbiology and Immunology, and Pathology, Dalhousie University/IWK Health Centre, Halifax NS
What do I have today? Calendar systems and sensory impairments	Shanti Brown, Timothy S. Hartshorne, Ph.D., Central Michigan University
Decision-making in the removal of gastrostomy tubes or buttons in CHARGE syndrome	Rachel Malta, Tim S. Hartshorne, Ph.D., Central Michigan University
Let's Talk About Sex: Implications for Future Research in Sexuality Education	Emily Mathis, Doctoral Student, School Psychology, Mississippi State University Alex B. Clarke, Specialist Student, School Psychology, Mallory Eddy, Doctoral Student, School Psychology, Chathuri Illapperuma, Doctoral Student, School Psychology, Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist, School Psychology, Mississippi State University
Post-Traumatic Growth in parents of children with CHARGE	Shelby Muhn, Tim S. Hartshorne, Ph.D., Central Michigan University
Examining the Measurability and Attainability of IEP Goals for Individuals with CHARGE Syndrome	Hailey E. Ripple, M.S., Doctoral Student, School Psychology, Mississippi State University Johnna Dowdy, Doctoral Student, School Psychology, Olivia Kesler, Undergraduate, Katherine Johnson, Undergraduate, Kasee Stratton, Ph.D., NCSP, Assistant Professor, Mississippi State University
Reach & Match®: Children With Sensory Impairments Play With Peers	Tristan Pierce, MIA, American Printing House for the Blind
Parents' Perspectives: Types and Purposes of Communication Used by Their Children Who Have CHARGE	Susan M. Bashinski, Ed.D., Barbara Braddock, Christopher Neal, & Jennifer Heithaus

Location: Panzacola F1/F2 Friday 10:45am – 5:00pm (manned from 3:30 – 5pm)

Poster Title	Presenter(s)
IEP Transition Plans for Individuals with CHARGE Syndrome	Hailey E. Ripple, M.S., Doctoral Student, School Psychology, Mississippi State University Elizabeth Struna, Doctoral Student, School Psychology, Matthew Ferrigno, Doctoral Student, School Psychology, Katherine Johnson, Undergraduate Student, Kasee K. Stratton, Ph.D., NCSP, Assistant Professor, School Psychology, Mississippi State University
Social Play in Children with CHARGE Syndrome	Megan C. Schmittel, Tim S. Hartshorne, Ph.D., Central Michigan University
Research on Headaches in CHARGE Syndrome	Lily Slavin, Tim S. Hartshorne, Ph.D., Central Michigan University
The Bulldog CHARGE Syndrome Research Lab at Mississippi State University	Kasee Stratton, Ph.D., NCSP, Assistant Professor, School Psychology; Megan Anderson, Doctoral Student, School Psychology, Mississippi State University
The CHARGE IEP: What Accommodations and Rulings are Common?	Elizabeth Struna, Doctoral Student, School Psychology, Mississippi State University Hailey Ripple, M.S., Doctoral Student, School Psychology; Amanda Cosgriff, M.S., Doctoral Student, School Psychology; Whitney Driskell, EdS. Student, School Psychology; Savannah Trice, EdS. Student, School Psychology; Tierra Kilbert, EdS. Student, School Psychology; Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist, School Psychology, Mississippi State University
What makes up a family in CHARGE: Family Dynamics and Demographics	Madison Sully, Specialist Student, School Psychology, Mississippi State University Megan Anderson, Doctoral Student, School Psychology; Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist, School Psychology, Mississippi State University
Adverse Effects and Behavioral Analysis of Psychotropic Drug Use with Children with CHARGE Syndrome	Blair Tiseo, Tim S. Hartshorne, Ph.D., Central Michigan University

Location: Panzacola F1/F2 Friday 10:45am – 5:00pm (manned from 3:30 – 5pm)	
Poster Title	Presenter(s)
Restorative Environments	Anna Weatherly, Tim S. Hartshorne, Ph.D., Central Michigan University
Issues in Psychotropic Medication Use for Children with CHARGE Syndrome	Rachel Wilson, Tim S. Hartshorne, Ph.D., Central Michigan University
Impact of Variables on the Attainment of Walking in Children with CHARGE Syndrome	Dr. Elizabeth (Beth) Foster, CAPE, California State Polytechnic University, Pomona
Neurological issues in CHARGE syndrome: our experiences so far	Prof. C.M.A. van Ravenswaaij, MD, PhD on behalf of Christa (C.M.) de Geus, MD, Department of clinical genetics, University of Groningen, University Medical Center Groningen
Dissecting the causes of frontal cortex abnormalities in a mouse model for CHARGE syndrome	Alex P A Donovan, Craniofacial Development and Stem Cell Biology, King's College London
CHARGE Syndrome and the IEP: What do parents think?	Whitney Driskell, Educational Specialist Student, School Psychology, Mississippi State University Liddie McPhail, Undergraduate Student, Educational Psychology; Hailey Ripple, M.S. Doctoral Student, School Psychology; Tierra Kilbert, Educational Specialist Student, School Psychology; Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist, School Psychology, Mississippi State University
The Able Act: EnABLE Savings for Life	Mary Anne Ehlert CFP, President & Founder Protected Tomorrows Inc., Protected Tomorrows Inc.
10 years of support and activities for people with CHARGE Syndrome in Germany and German speaking areas	Claudia Junghans, CHARGE Syndrom e. V., Germany
Effective Positioning Interventions to Facilitate Fine Motor Skills in School-Aged Children with CHARGE Syndrome and/or deafblindness	Samantha Kublin, OTD, OT/s, Sarah Bis, MS, OTR/L, C/NDT, Diane Smith, Ph.D., OTR/L, FAOTA, Perkins School for the Blind and MGH Institute of Health Professions

Location: Panzacola F1/F2 Friday 10:45am – 5:00pm (manned from 3:30 – 5pm)

Poster Title	Presenter(s)
Teaching Gross Motor Skills and Balance to Children with CHARGE Syndrome	Lauren J. Lieberman Ph.D., Pamela Haibach-Beach Ph.D., The College at Brockport Beth Foster, Ph.D., California State Polytechnic University, Pomona
What should we be looking for? Child-centered and capacity-building assessment approaches	Julie Maier, Educational Specialist, California Deafblind Services
Moving forward with the transition to preschool through collaborative planning	Julie Maier, Educational Specialist, Myrna Medina, Family Engagement Specialist , California Deafblind Services
Recently recognized late emerging medical issues in an eighteen-year-old with CHARGE syndrome: a case report	Angus Morgan, BSc , Dalhousie University faculty of Medicine
Working Together to Support Families	Sheri Stanger, MA, Ed.M. – Director of Outreach for the CHARGE Syndrome Foundation Megan Cote, MS Ed - Initiative Lead for Early Identification and Referral and Family Engagement for the National Center on Deaf-Blindness
The Third Wheel in Marriage	Joan Borton & Jerry Borton, MS
Social Skills of Individuals with CHARGE Syndrome	Lori A. Swanson, Ph.D., University of Wisconsin-River Falls; Meg Hefner, M.S., St. Louis University Medical School; Bridget Leukuma, B.S., University of Wisconsin-River Falls
Issues surrounding fertility and sexual function for families or individuals affected by CHARGE syndrome	R. Matthew Coward, MD FACS, Assistant Professor of Urology, UNC School of Medicine, Director of Male Reproductive Medicine and Surgery, UNC Fertility

CHARGE RESEARCH - WE NEED YOU

The CHARGE Syndrome Conference is the largest gathering of individuals with CHARGE and their families and provides a unique opportunity for CHARGE research. Yes, Research on CHARGE is happening here and projects are listed below. Some are “walk up” while others require appointments. More info is available at the **Research Table**, at **Information Central on Friday afternoon** and outside the ballrooms on Saturday. Here are the projects and the people you can contact for more information. Many will be wearing buttons, too.

APPOINTMENTS NEEDED

GROWTH proportions in CHARGE: make an **appointment** (check Research Table for possible sign up) to have a photo taken of your child standing (in underwear), to be used to measure body proportions (15-20 minutes). Dieuwerke Dijk d.r.dijk@umcg.nl

Motor Skills & balance (appointment): fill out a questionnaire, then have your child (who can walk, with or without aids) recorded doing a series of tasks in Camp Abilities area. Contact Pamela Haibach-Beach, phaibach@brockport.edu or Lauren Lieberman, llieberman@brockport.edu

Social Skills (appointment): parents, teachers and individuals with CHARGE (8-18 yo) will complete questionnaires that ask about social skills. 15-20 minutes. Contact Lori Swanson lori.swanson@uwrf.edu 715-441-4897

WALK UP

3D IMAGING: answer a few questions and have a 3D photo taken to create a database of what CHARGE looks like (walk up, 10-15 minutes). Find our table or call/text Annie Pham (470)236-2911

DNA samples (from saliva) will be collected from people with CHARGE, their parents and siblings to look for new genetic causes & genes that influence features (walk up, 20-30 minutes). Donna Martin [734-645-3564](tel:734-645-3564) or Stephanie Bielas [858-525-1757](tel:858-525-1757)

GI/feeding issues: fill out a questionnaire about what treatments have been tried (meds, surgery, behavior) for GI and feeding difficulties (walk up or online, 10 minutes) **Alexandra Hudson** dalmed.charge@gmail.com

Imaging: answer questions about what X-ray/CT/MRI studies have been done (walk up, 20 minutes): Lauren Fogarty lauren.fogarty@dal.ca 902-229-6267

Family demographics: answer questions about the demographics and composition of your family (walk up, 15-20 minutes). Madison Sully Mas1190@msstate.edu 704-516-2640

CHARGE Syndrome Clinical Database Project Enter your baseline data & upload photos in the online project database and registry - we will share it with other projects. **Meg Hefner** meg@chargesyndrome.org <https://redcap.slu.edu/redcap/surveys/?s=ob9YsEXASu>



The Ethan Wolfe Recreational Assistance Program ("EWRAP")

EWRAP provides individuals with CHARGE syndrome the opportunity to participate in recreational activities. Thanks to a generous gift from the Wolfe family and friends, in 2015 the Foundation launched a new need-based program designed to give members of the Foundation the opportunity to purchase recreational equipment or participate in recreational programs. During Ethan Wolfe's 12 years of life, he rode an adaptive bike, attended special recreational camps, participated in swimming lessons, music class and much more. We are pleased to honor Ethan's memory by helping others pursue similar, fun activities.

Over the last two years, our EWRAP award recipients received bikes, swimming and horseback riding lessons, gymnastic classes and summer camp experiences. Our 2018 applications will be announced this winter. Check our newsletters and website for more information.

Everyone deserves a chance to play!

Vision: A Better World for People with CHARGE Syndrome

Mission: We lead and partner to improve the lives of people with CHARGE syndrome locally, nationally and internationally through outreach, education, and research.

- Provide a broad network of support to individuals, families and professionals
- Engage in knowledge acquisition, development and dissemination
- Promote innovative scientific and clinical advancements
- Champion the lifelong potential of people with CHARGE syndrome

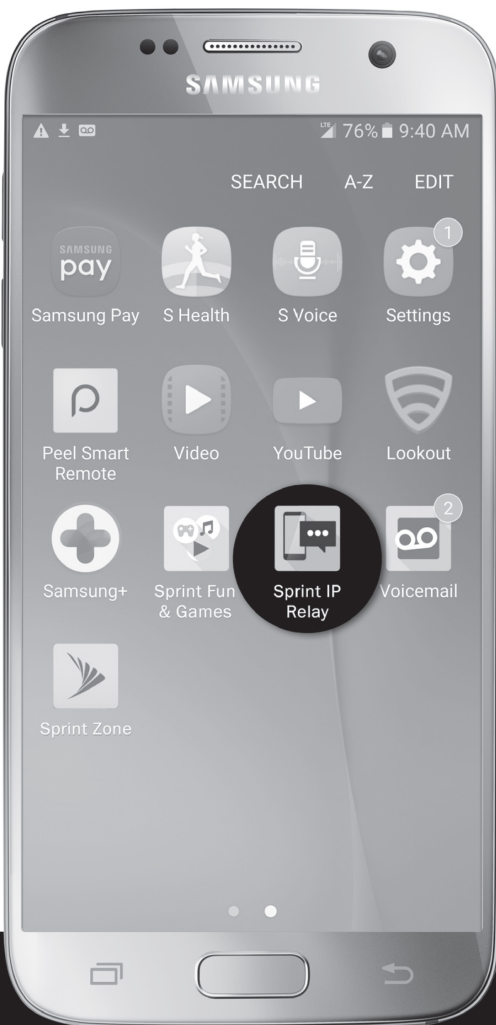
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and its members who are improving the lives of people with CHARGE syndrome locally, nationally, and internationally through outreach, education and research.



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CHARGE for Connor

Nikki Logsdon

513-349-5359

chargeforconnor@gmail.com

www.chargeforconnor.org

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CHARGE for Connor is a nonprofit organization formed in 2014 as a way to remember Connor Logsdon and carry on his legacy. Our mission is to help promote awareness of CHARGE syndrome while supporting the CHARGE community through aiding individuals with CHARGE syndrome, being involved with The CHARGE Syndrome Foundation and helping to guide the formation of a CHARGE clinic at Cincinnati Children's Hospital.

Cincinnati Children's Hospital Medical Center

CHARGE Team

3333 Burnet Avenue

Cincinnati, Ohio. USA. 45229

Phone: 513-636-2518

CHARGE@cchmc.org



Medical Directors:

Susan Wiley, MD, Director, Division of Developmental and Behavioral Pediatrics

Daniel Choo, MD, Director, Pediatric Otolaryngology Head and Neck Surgery

The CHARGE Team at Cincinnati Children's is comprised of a multidisciplinary group of clinicians, therapists, counselors and family advisors whose goal is to provide a comprehensive and coordinated model of healthcare to children and families with CHARGE syndrome in order to help these children reach their full potential. Our objective is to deliver the best interventions at the optimal time and in a well-coordinated approach in order to change the outcome for these children.

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Sarah K Keifer, CEO
PO Box 10560
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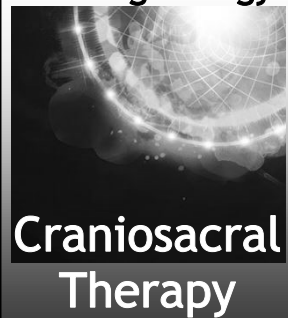
Growing Independent Eaters provides families with expert and effective guidance for weaning their children from feeding tubes and to joyful family mealtimes. We empower parents to trust themselves and their children around food, provide detailed plans for creating positive mealtimes and introducing appetite, and offer a team of support professionals for the journey. Our successful consultations provide an affordable, personalized, and caring path to *your* family table.

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NDBEDP/ICC supports local programs that distribute equipment to low-income individuals who are deaf-blind (have combined hearing and vision loss) to enable access to telephone, distance communications, and information services.

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NATIONAL CENTER
ON DEAF-BLINDNESS

The National Center on Deaf-Blindness, funded by the U.S. Department of Education, partners with families and state deaf-blind projects to promote learning and improve quality of life for children who are deaf-blind. Visit our website to find extensive information on deaf-blindness and learn about our current initiatives: Family Engagement, Early Identification and Referral, Literacy, Transition, and Interveners and Qualified Personnel.

National Family Association for Deaf-Blind (NFADB)

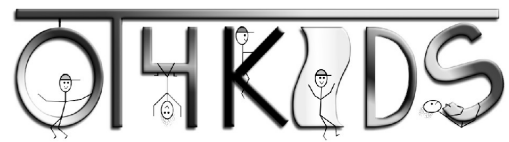
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The National Family Association for Deaf-Blind (NFADB) is an organization founded on the belief that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community. NFADB runs a large national network of families who focus on issues surrounding deaf-blindness. NFADB advocates for all persons who are deaf-blind of any chronological age and cognitive ability; supports national policy to benefit people who are deaf-blind; encourages the founding and strengthening of family organizations in each state dedicated to assisting families of persons who are deaf-blind; shares information, provides resources, referrals and collaborations with professionals who work with persons who are deaf-blind.

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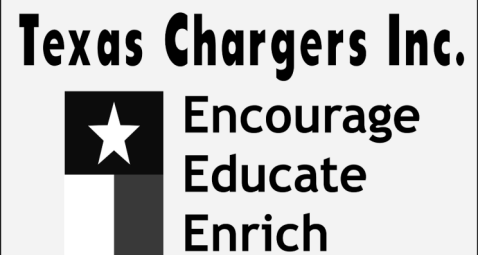
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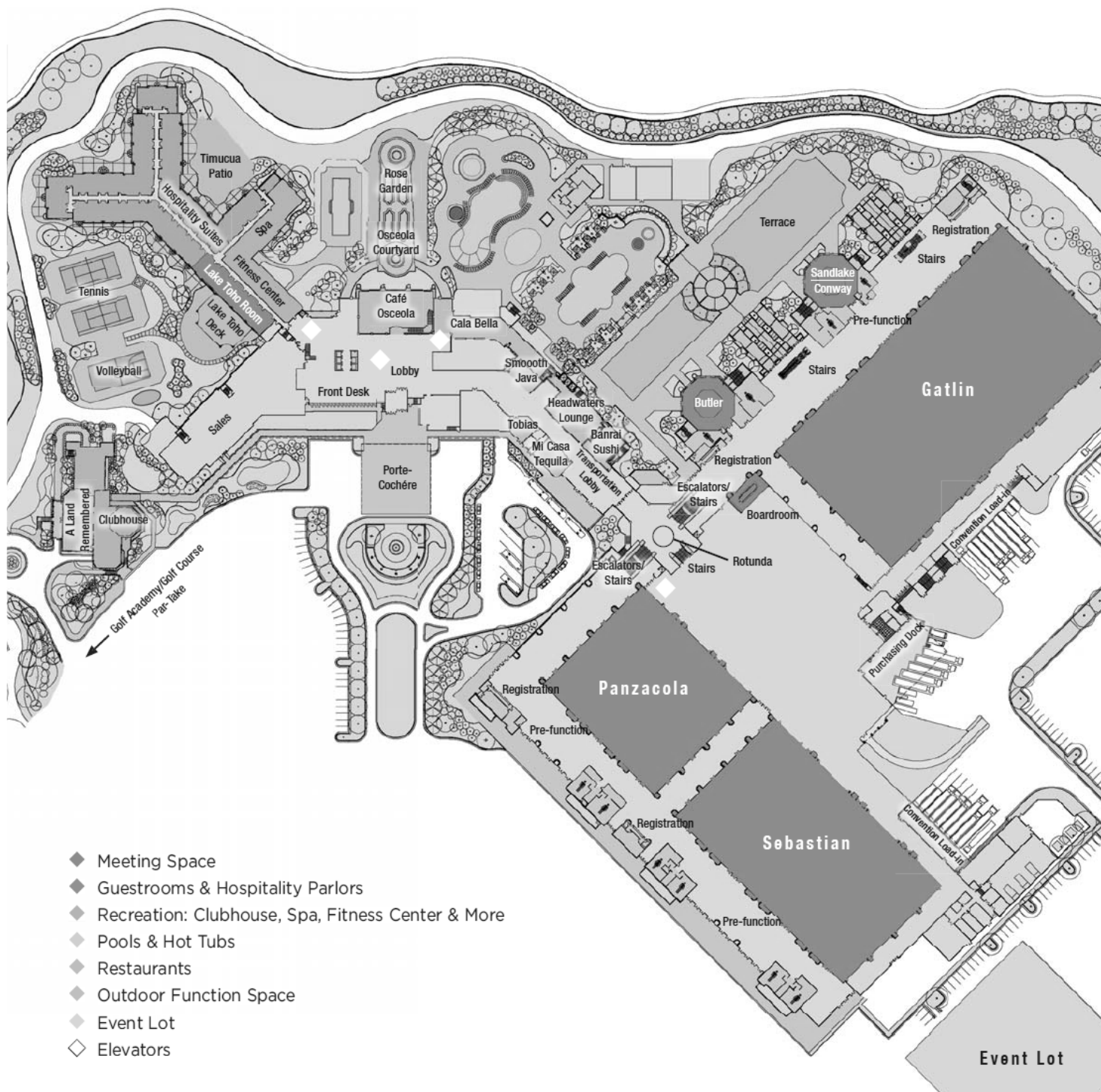
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kathi@centex.net
325-456-6591
www.texaschargers.org

Texas Chargers, Inc. encourages, educates, and enriches individuals and families living with CHARGE syndrome. One of the ways we accomplish our mission is by organizing an annual two and a half day family retreat. Starting in 2005 with a handful of families, the retreat has grown to 40+ families. The retreat provides a stress free environment for families to connect with others touched by CHARGE syndrome, so they can share the joys and address the challenges of raising, supporting, or being a person living with CHARGE syndrome.



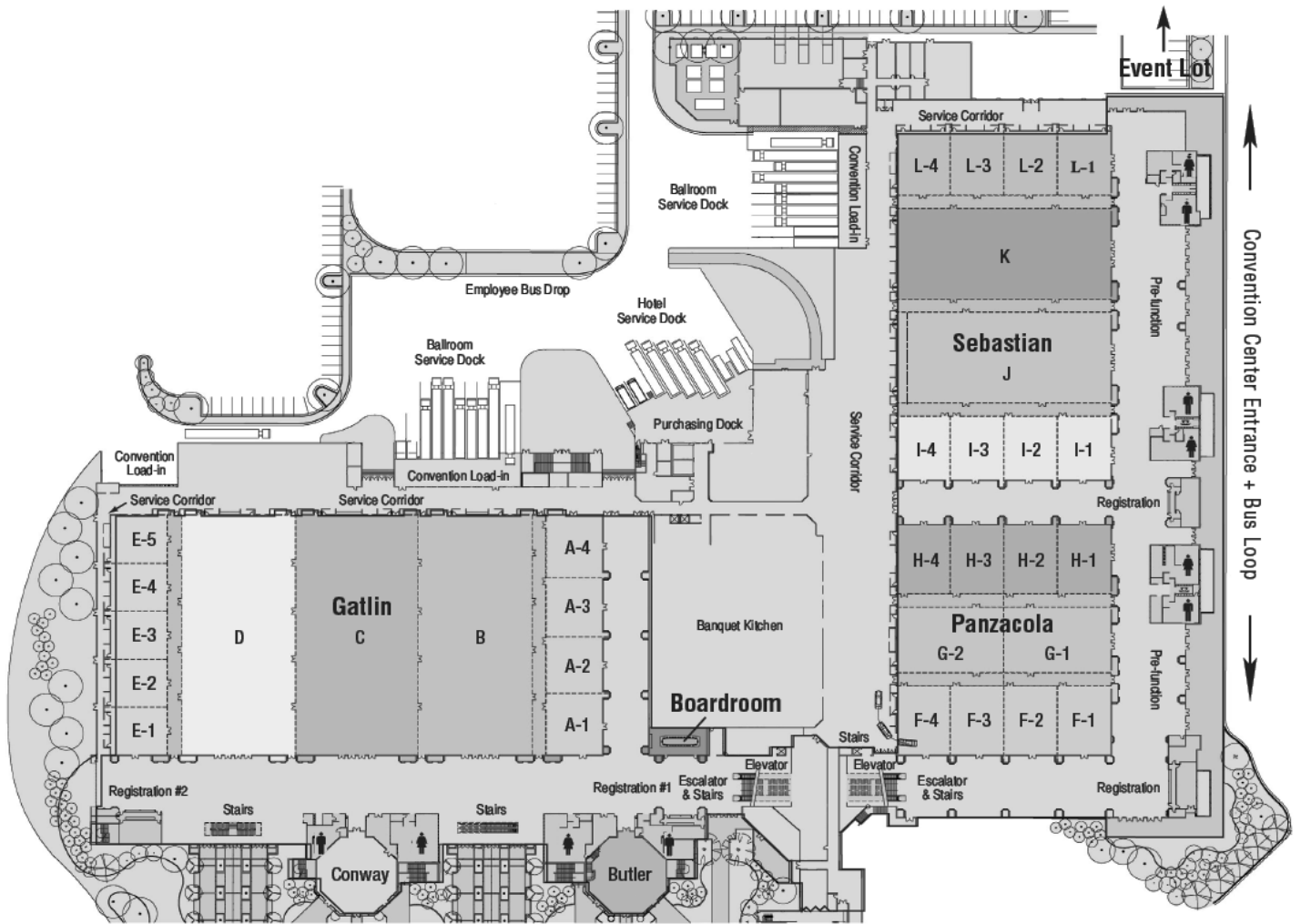
Notes

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Notes

Ballroom Capacities



And Remember, if you receive an email from Hormel it might be Spam.



CHARGE for Connor



Connor Michael Logsdon

September 29, 2012 – January 10, 2014

As a way to celebrate Connor's life and continue his legacy we have formed the **CHARGE for Connor** nonprofit organization. The purpose of this public charity is to raise awareness for CHARGE syndrome and assist the CHARGE community.

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