



5th Professional Day - Thursday, July 27, 2017

7:00-12:00	Registration in Satellite Registration Desk	
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>



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	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}.

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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

Professional Day Breakout Sessions

Session #1 - 1:00pm – 2:30pm	
Location – Sebastian I 1/2	Location – Sebastian I 3/4
Educational/Behavioral/Communication	Clinical/Scientific Research
<p>“Taking – too much – CHARGE?” A discussion on the aspects of responsibility Wenche Andersen and Eva Seljestad</p>	<p>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</p>
<p>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</p>	<p>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</p>
<p>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</p>	<p>External Quality Assessment Clinical Genetics: CHARGE syndrome as an educational case Conny van Ravenswaaij-Arts, MD, PhD, University of Groningen, University Medical Center Groningen</p>
<p>Managing the Sensory Environment Sarah Bis, MS, OTR/L, C/NDT and Sarah Maust, MOT, OTR/L, Perkins School For The Blind</p>	<p>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</p>
Session #2 – 2:35 – 4:05pm	
Location – Sebastian I 1/2	Location – Sebastian I 3/4
<p>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</p>	<p>Putting Genetics in CHARGE Amanda Moccia, MS, Department of Human Genetics, University of Michigan</p>
<p>Who Needs an Intervener? Beth Kennedy, M.Ed.DB Central: Michigan’s Training & Resource Project and Central Michigan University</p>	<p>Rapid drug discovery in genetic models of CHARGE syndrome Kessen Patten, Phd, INRS-Institut Armand-Frappier</p>

Professional Day Breakout Sessions

Session #2 – 2:35 – 4:05pm	
Location – Sebastian I 1/2	Location – Sebastian I 3/4
<p>The Behavior Triangle for CHARGE Syndrome Timothy S. Hartshorne, Ph.D., Central Michigan University</p>	<p>Genetic epistasis contributes to inner ear and neuronal development via regulation of chromatin remodeling and retinoic acid synthesis Hui Yao, PhD., Pediatrics Department, University of Michigan Medical School Jennifer M Skidmore¹, Ethan D Sperry^{2,4}, Donald L Swiderski³, Shigeki Iwase², Peter Scacheri⁵ and Donna M Martin^{1,3,4}; Departments of Pediatrics¹, Human Genetics², and Otolaryngology³, and the Medical Scientist Training Program⁴, The University of Michigan, Ann Arbor, MI and Department of Genetics⁵, Case Western Reserve University, Cleveland, OH</p>
<p>The CHARGE Syndrome Research Lab at Central Michigan University Timothy 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, Aaron Hartshorne, Central Michigan University</p>	

Professional Day Posters

* Posters marked with an asterisk will also be presented on Friday at the full conference

Location: Panzacola H/Sebastain I Prefunction Area	
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 Sensory Base of Unusual Behaviors in Children with CHARGE*	Aaron Hartshorne, Timothy S. Hartshorne, Ph.D., Central Michigan University
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

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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 Schmittel, Bree Kaufman, Shanti Madhavan-Brown, Anna Weatherly, Shelby Muhn, Rachel Wilson, Gretchen Imel, Deborah Ferriera, Blair Tieso, Aaron Hartshorne, Central Michigan University
What do I have today? Calendar Systems and sensory impairments	Shanti Brown, 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

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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 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
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*	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

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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

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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
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
What do I have today? Calendar systems and sensory impairments	Shanti Brown, Timothy S. Hartshorne, Ph.D., Central Michigan University