



12th International
CHARGE Syndrome
Conference
Chicago 2015

Schaumburg, Illinois
Renaissance Schaumburg Hotel
and Convention Center
July 30 - August 2, 2015



“Joel graduated today!
We couldn’t be more proud.”

Perkins School for the Blind is more

than just an education. It's an opportunity. For Joel's parents, it was an opportunity to proudly watch their son graduate.

Is Perkins right for your child?

Visit our booth to learn about our programs for children with CHARGE syndrome.

Perkins.org

Perkins
SCHOOL FOR THE BLIND



Perkins
SCHOOL FOR THE BLIND

Visit our booth to learn about our programs
for children with CHARGE syndrome.

Perkins.org

SCHOOL FOR THE BLIND Perkins.org



SCHOOL FOR THE BLIND



 SCHOOL FOR THE BLIND

for children with CHARGE syndrome.

Perkins.org



12th International CHARGE Syndrome Conference



*This project is supported in part by Perkins School for the Blind.
Watertown, Massachusetts.*

CHARGE Syndrome Foundation, Inc.

2013 - 2015

Officers, Directors and Advisors

President

David Wolfe

Vice President

Lisa Weir

Secretary

Neal Stanger

Treasurer

Brownie Shott

Board of Directors

Eric Bluestone

Joanne Lent

Amrit Mehta

Pamela Ryan

Lori Swanson

Incoming Board Members

Karin Dagley

Minnie Lambert

Christian Lobaugh

Board Advisors

Meg Hefner

Donna Martin

Welcome!

The Sky's the Limit

What a perfect title for our 12th International CHARGE Syndrome Conference. As over 1,200 people, including at least 230 with CHARGE, from 38 states and 11 countries join together to learn, share ideas, renew friendships and make new ones, the opportunities are truly limitless. Every day and night is packed with a perfect balance of presentations, fun, and time to mingle with other families.

Our presenters come from all over the world to help us better understand the complexities of CHARGE syndrome. They all volunteer their time and pay their own way! We simply could not host this conference without their generous support. Throughout the weekend, I hope you will join me in thanking them for everything they continue to do for our extended CHARGE family.

It took over 2 years and 1000's of hours of time to put this conference together. I can't possibly list all of the generous donors, fundraisers, members, volunteers, interpreters, Advisors, and Board members who made this event possible. In addition, our sponsors helped reduce the more than \$250,000 budget shortfall for this conference. Thank you ALL for your time and support.

There are 4 people that I have to single out for a special thank you: our Vice President Lisa Weir; Treasurer Brownie Shott; Secretary Neal Stanger and Director of Administration Jody Wolfe. Each of these individuals has volunteered more than 2000 hours since our last conference. The conference would not have happened without their selfless dedication to our Foundation.

Finally, THANK YOU to everyone who traveled from near and far to be part of an extraordinary event. As we join together to continue to make the world a better place for all individuals with CHARGE syndrome, let's all remember that **The Sky's the Limit**.

David Wolfe

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



Foundation Contact Information

CHARGE Syndrome Foundation, Inc.

318 Half Day Road, #305

Buffalo Grove, IL 60089

(516) 684-4720

(800) 442-7604

(888) 317-4735 fax

info@chargesyndrome.org

www.chargesyndrome.org

Director of Administration - Jody Wolfe

Jody@chargesyndrome.org

Director of Outreach - Sheri Stanger

Sheri@chargesyndrome.org

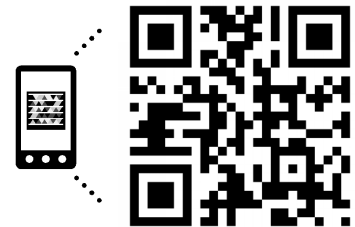
1-855-5CHARGE (524-2743)

Connect with us!



Now you can connect with us
using your smartphone.

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

Special Thanks

Sponsors

Diamond Sponsor

J. Edward Mahoney Foundation

Platinum Sponsors

CHARGE for Connor
Perkins School the Blind
Sorenson Communications

Gold Sponsors

Ace Hardware
Cochlear Americas
Fresh Wave
Texas Chargers

Silver Sponsor

Capital One Commercial Banking

Bronze Sponsor

GeneDx

Official Conference Photographer

Buller Photography

Special Thanks

In-Kind Donors



Aaron's

Provided televisions for camp and lounge



Camp Abilities

Provided Camp Abilities experience within our camp for all campers. www.campabilities.org



Purell

Provided Purell for conference attendees and camp



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!

12th International CHARGE Syndrome Conference

Wednesday, July 29th, 2015

9am-5pm Registration & Sales Center Open

Thursday, July 30th, 2015

<i>Time</i>	<i>Event</i>	<i>Location</i>
7:00-5:00	Conference Registration & Sales Open	Schaumburg Foyer North
9:00-5:30	Professional Day (Separate Registration Required)	Utopia Ballroom
12:00-6:00	Camp Discovery & Camp Explorer Registration	Schaumburg Foyer North
2:00-5:00	A Time To Meet for Families	Schaumburg A-D and West
6:00-9:00	Reception - Appetizers included (6:00-7:30). Cash bar available.	Schaumburg Ballroom

[illegible]

4th International CHARGE Syndrome Professional Day - Thursday, July 30th, 2015

Time	Event	Location
7:00-9:00	Registration	Schaumburg Foyer North
7:00-8:30	Poster setup	Utopia Threshold
8:00-9:00	Breakfast	Nirvana Ballroom
9:00-10:45	General Session - Utopia Ballroom Welcome Remarks, Plenary Speakers: Hale & Martin: Revised Diagnostic Criteria; Marena & Liebl: Synaptic Abnormalities in a Drosophila Model; Steele & Panel: Intervener Modules; Junghans & Benstz: We have CHARGE, So What?	
10:45-12:00	Poster Session	Utopia Threshold
12:00-1:00	Lunch	Nirvana Ballroom
1:00-2:30	Breakout Sessions #1	See Details Below
2:30-2:45	Break	
2:45-4:15	Breakout Sessions # 2	See Details Below
4:15-4:30	Break	
4:30-5:30	Recap and Closing Remarks	Utopia Ballroom

Breakout Session #1 — 1:00 - 2:30

Euphoria Ballroom: Medical/Clinical Approaches	Utopia A-B : Genetics/Research	Utopia C-D: Education
<ul style="list-style-type: none"> - Corsten et al: Arch Vessel Anomalies - de Geus et al: Clivus Abnormalities as diagnostic criterion - van Ravenswaaij et al: CHD7 & Cerebellum Development (additional diagnostic criterion, mouse model) - Trider et al. Development of Comprehensive Checklist 	<ul style="list-style-type: none"> - Skidmore et al: CHD7-iCRE transgenic mice for lineage tracing and gene deletion - Scacheri & Martin: CHD7 & CRISPR/ Cas-based DNA Editing Strategies - Raphael & Martin: Novel Treatments for Hearing & Balance Disorders (hair cells, gene therapy) - Sperry et al.: CHD7 & inner ear development & function 	<ul style="list-style-type: none"> - Spratling: Concept Development in children with sensory loss - Seljestad & Andersen: Self-Identity & Self-Esteem - Harkins & Panel: Family Leadership & Empowerment - Lauger: Educational Model to Decrease Passivity & Increase Self-Determination

Breakout Session #2 — 2:45 - 4:15

<ul style="list-style-type: none"> - Stratton: Pain & Behavior - Wong: Immunological & Adrenal Function - Stratton & Kirk: Sexuality & Hormones - Hartshorne et al. CHARGE Lab at CMICH 	<ul style="list-style-type: none"> - Steele et al: Zebrafish & Gastrointestinal Morphology and Motility Changes - Gervais: CHD7 & COMPASS (drosophila intestine) - Basson: CHD7 controls cerebellar growth via Reelin - Genetics: General Discussion 	<ul style="list-style-type: none"> - Bashinski & Bruce: Positive Behavior Supports for Young Adults - Wanka: Development of a Staff Training Program - Kennedy & Alsop: Intervener Services for Children and Young Adults - Education: General Discussion
---	--	---

Professional Day Poster Sessions

Expressive Communication Skills of Children with CHARGE Syndrome Alexandria Cook and Charity Rowland, Ph.D.

Genetic Testing in Patients Suspected of Having CHARGE Syndrome Cheryl Scacheri, MS, LGC, Chris Lauricella, MS, CGC; Toni Lewis, MS; Rebecca Fowler, MS, CGC; Jennifer Siegel, MS, LCGC; Jane Juusola, PhD, FACMG; Sherri Bale, PhD, FACMG

CSCDP: CHARGE Syndrome Clinical Database Project - Fun Facts Meg Hefner, MS, Kevin Ballard MCS MHI, Joanne D'souza BS

Advice from siblings of persons with CHARGE Hayley Hoesch and Timothy S. Hartshorne, Ph.D.

Role of CHD7 in nerve formation Fumiaki Imamura, Ph.D.

Camp Abilities Brockport: A Counselor's Experience Gretchen Imel, Tim Hartshorne, Ph.D.

CHARGE Syndrome & Parental Relationships Dominik Keller, Mady Sully, & Kasee Stratton, Ph.D.

Assessing attachment in mother-child relationships in rare syndrome contexts Nicole Vian

Review of Two Research-Based Methods for Improving Sleep of Children with Developmental Disabilities Benjamin Kennert and Tim Hartshorne, Ph.D.

Common Psychotropic medications used in CHARGE syndrome and what we know about them Claire Latus-Kennedy and Timothy S. Hartshorne, Ph.D.

"Wow, that Sounds Familiar": Parent-Child Playgroups for Families of Children with Deaf-blindness Julie Maier

Parental Decision Making in the Removal of Gastrostomy Tubes Rachel Malta, and Timothy S. Hartshorne, Ph.D.

The Brain in CHARGE Mandy Odren and Timothy S. Hartshorne, Ph.D.

Development of Play in CHARGE Syndrome Megan Schmittel, M.S. and Timothy S. Hartshorne, Ph.D.

CHARGE Syndrome & Characteristics of Autism Spectrum Disorder: Examining Similarities and Differences Hallie Smith, M.S., Doctoral Candidate, School Psychology, MacKenzie Sidwell, M.S., Specialist Student, School Psychology, and Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist

How do we raise awareness for CHARGE? A study of Facebook and Twitter Outcomes Daniel L. Gadke, Ph.D., NCSP, BCBA, Assistant Professor, Hailey Ripple, B.S., Doctoral Candidate, School Psychology, Somya Mohanty, Ph.D., Assistant Research Professor, Arthur Cosby, Ph.D., William L. Giles Distinguished Professor

The Bulldog CHARGE Syndrome Research Lab at Mississippi State University Hailey Ripple, MacKenzie Sidwell, Hallie Smith, Mady Sully, Reeva Morton & Dominik Keller, Students

Take Time For Yoga Rebekka Valian Teacher of the Deafblind

The role of CHD7 in differentiation of neural progenitor cells Hui Yao, Ph.D. and Donna M. Martin, M.D., Ph.D.

For university, hospital or other affiliations, please see the poster presentation list for Information Central in Friday's session information.

Friday, July 31st, 2015

Time	Event	Location
7:00-5:00	Conference Registration	Schaumburg Foyer North
7:00-5:00	Sales Center Open	Schaumburg Foyer North
7:00-9:00	Breakfast	Adventure Hall
7:00-9:00	Camp Discovery & Camp Explorer Registration	Utopia & Nirvana Foyer
8:00-5:30	Exhibits Open	Schaumburg Foyer East
8:30-11:30	Sibshops Session A	Innovation
8:30-11:45	Camp Discovery & Camp Explorer Morning Session	Utopia & Nirvana Ballrooms
9:00-9:35	Welcome and opening remarks	Schaumburg Ballroom
9:35-10:20	Keynote - Marla Runyan	Schaumburg Ballroom
10:20-10:45	Break	
10:45-11:45	Breakout Session #1 - See Next Page for Session Titles	
11:45-1:00	Lunch	Adventure Hall
12:30-4:45	Camp Discovery & Camp Explorer Afternoon Session	Utopia & Nirvana Ballrooms
1:00-4:00	Sibshops Session B	Innovation
1:00-2:00	Breakout Session #2 - See Next Page for Session Titles	
2:15-3:15	Breakout Session #3 - See Next Page for Session Titles	
3:15-3:30	Break	
3:30-4:30	Breakout Session #4 - See Next Page for Session Titles	
5:00-6:15	Dinner	Adventure Hall
6:30-9:30	CHARGE Syndrome "CONFERENCE IDOL" Talent Extravaganza	Schaumburg Ballroom

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
Schaumburg A - B	#1 Planning for the Future-Part 1 Rubin	#8 Planning for the Future-Part 2 Rubin	#14 Positive Behavior Supports for Young Adults Bashinski & Bruce	#20 Psychiatric Issues Q&A Julian
Schaumburg C - D	#2 Gut Motility Blake, Steele & MacDonald	#9 Mothers and Fathers and Siblings, Oh My! Hartshorne, T.	#15 Feeding Issues Pimentel	#21 Homemade Tube Feedings Ek
Schaumburg West	#3 Fathers Forum	#10 Talking to your son/daughter about having CHARGE Stratton	#16 ENT Choo	#22 Cochlear Implants in CHARGE Tournis & Young
Schaumburg East	#4 Assessment Brown & Maier	Information Central Set-Up	Information Central	
Schaumburg E - F	#5 Posture & Respiratory Issues Massery	#11 CHARGE 101 Hefner et al.	#17 CHARGE 102 Hefner et al.	#23 Communica- tion, Behavior, Play & Passions Last
Schaumburg G	#6 Grandparents Forum	#12 Communica- tion Matrix Cook, Rowland & Parker	#18 Importance of Movement Foster	#24 Immunologi- cal & Adrenal Function Wong
Schaumburg H	#7 Young Adult Share (Young Adults 16+) Stratton & Gadke	#13 Healthy Relationships (Young Adults 16+) Beck & Simon	#19 Vision, Planning & Com- munity Westmaas & Westmaas	#25 Education Is- sues (Spanish) Berg & Medina

Notes _____

Saturday, August 1st, 2015

Time	Event	Location
7:00-5:00	Conference Registration & Sales Center	Schaumburg Foyer North
7:00-9:00	Breakfast	Adventure Hall
8:00-4:00	Exhibits Open	Schaumburg Foyer East
8:30-11:45	Camp Discovery & Camp Explorer Morning Session	Utopia & Nirvana Ballrooms
8:30-11:30	Sib Shop C	Innovation
9:00-9:15	Welcome and Housekeeping	Schaumburg Ballroom
9:15-10:25	Foundation General Board Meeting: Reports, Updates and Awards	Schaumburg Ballroom
10:25-10:45	Break	
10:45-11:45	Breakout Session #5 - See Next Page for Session Titles	
11:45-1:00	Lunch	Adventure Hall
12:30-4:45	Camp Discovery & Camp Explorer Afternoon Session	Utopia & Nirvana Ballrooms
1:00-4:00	Sib Shop D	Innovation
1:00-2:00	Breakout Session #6 - See Next Page for Session Titles	
2:15-3:15	Breakout Session #7 - See Next Page for Session Titles	
3:15-3:30	Break	
3:30-4:30	Breakout Session #8 - See Next Page for Session Titles	
6:00	CHARGE-A-Palooza: Dinner, Carnival and Silent Auction	Schaumburg Ballroom

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
Schaumburg A - B	#26 Concept Development Spratling	#31 Independent Living Skills at Home Bis & Stelzer	#36 Behavior & Sensory Processing Beals	
Schaumburg C - D	#27 Intervener Services for Children/Young Adults Kennedy, Alsop & Panel	#32 Sibling Experience Braga & Braga	#37 Language Acquisition through Motor Planning Halloran	
Schaumburg West	#28 Sex Hormones & Safe Sexuality Kirk & Stratton	#33 Basics of Behavior Stratton & Gadke	#38 Family Leadership & Empowerment Harkins & Panel	
Schaumburg East	#29 Neurology Constantinou	#34 Compulsive Behaviors and OCD Salem-Hartshorne	#39 Anticipation & Behavior Hartshorne	#41 Power of Jacob Hartshorne
Schaumburg E - F- G	#30 Interactive Genetics Seminar I Corsten & van Ravenswaaij	#35 Interactive Genetics Seminar II Corsten & van Ravenswaaij	#40 Feeding & Heart Corsten & van Ravenswaaij	#42 Balance, Coordination & the brain in CHARGE Geus et al.
Schaumburg H	RESEARCH PROJECTS* Wong, van Ravenswaaij - Growth, Bashinski - prelinguistic communication, Stratton - Autism & CHARGE, Martin & Bielas - Genetics, Hudson, Blake - Eating/Overstuffing, Schmittel & Hartshorne: Play Sign up for all research projects is at research table near registration or via emails included on research page (found at end of session descriptions).			
*Other research projects include: de Geus & Ravenswaaij: cerebellum in CHARGE syndrome: anatomy, ataxia and balance & sloping shoulders (in hospitality suite)				

Sunday, August 2nd, 2015

7:00-9:00	Breakfast in Adventure Hall
8:30-12:15	Camp Discovery & Camp Explorer Session in Utopia & Nirvana Ballrooms
9:00-9:45	Welcome and Presentations in Schaumburg Ballroom
9:45-10:45	Adult Panel: Shannon Boelter, Dylan Lauger, Meredith Dwyer and Belinda Arnell in Schaumburg Ballroom
10:45-11:00	Break
11:00-11:45	“Passions” - Lisa Weir with Rob Last, Conny van Ravenswaaij, Pam Ryan, Kasee Stratton, Aubrey Williams, Brownie Shott and more!
11:45-12:00	2015 Conference Farewell - David Wolfe

Notes

[illegible]

Friday, July 31 - 10:45-11:45 - Breakout Session #1

1. Planning for the Future Part I - Brian and Benjamin Rubin - Schaumburg A-B

As attorneys and as the parent and sibling of Mitchell, who has Autism, Brian and Benjamin Rubin hold a unique perspective. Since 1982, Brian's law practice has been dedicated to serving the legal and future planning needs of his fellow families of children and adults with intellectual disabilities, developmental disabilities, and/or mental illness. Brian and Benji will speak on a variety of future and estate planning topics including, but not limited to: government benefits, special needs trusts, gifting by grandparents and extended family members, and guardianships and alternatives.

2. Can't Stomach This: A Discussion on Gut Motility in CHARGE Syndrome Including Data from Recent Research - Kim Blake MD, Shelby Steele and Meghan MacDonald - Schaumburg C-D

A common and long term issue for CHARGE syndrome individuals is eating and gastrointestinal motility problems. This presentation will outline the common gastrointestinal (GI) problems; identify professionals and treatments that are available; and present the clinical and basic science research that is hot off the press.

3. Fathers Forum - Tim Hartshorne - Schaumburg West

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.

4. Looking at the world through rose-colored glasses: Approaches to positive assessment - David Brown and Julie Maier, Educational Specialist with California Deaf-Blind Services - Schaumburg East

This presentation will examine and discuss the perspectives and assumptions educators, medical professionals, and other related service providers often employ when viewing students with CHARGE syndrome. These perspectives and assumptions then influence the direction taken during assessment and planning development of educational goals and programs for individuals with CHARGE syndrome. During this presentation, David and Julie will share a more effective, child-centered approach.

5. Breathing and Posture: More Linked than you Think! - Mary Massery, PT, DPT, DSc - Schaumburg E-F

Each child with CHARGE presents with unique physical deficits that can progress to significant postural deficits by adulthood. This session is designed to educate families about the link between breathing mechanics, postural alignment, movement strategies, and balance deficits, and to demonstrate how these interactions may adversely affect the child's postural maturation. The focus is on educating the families about the big picture, the long haul, to empower them about the value of periodic physical therapy and other supportive services throughout childhood and into adulthood, rather than just during Early Intervention.

6. Grandparents Forum - Pam Ryan - Schaumburg G

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

7. Young Adults with CHARGE Syndrome Only: Share experiences, concerns, and ask questions! - Kasee Stratton, Ph.D., NCSP & Dan Gadke, Ph.D., NCSP, BCBA - Schaumburg H
This forum is devoted to young adults only—ages 16 and up. Kasee and Dan will provide a safe and confidential space for young adults with CHARGE to ask questions, discuss concerns, and share with each other. Previous groups have discussed sexuality, getting and keeping jobs, having relationships and friendships, planning for independent living, and so much more. No question is off limits.

Friday, July 31 - 1:00 - 2:00 - Breakout Session #2

8. Planning for the Future Part II - Brian and Benjamin Rubin - Schaumburg A-B
As attorneys and as the parent and sibling of Mitchell, who has Autism, Brian and Benjamin Rubin hold a unique perspective. Since 1982, Brian's law practice has been dedicated to serving the legal and future planning needs of his fellow families of children and adults with intellectual disabilities, developmental disabilities, and/or mental illness. Brian and Benji will speak on a variety of future and estate planning topics including, but not limited to: government benefits, special needs trusts, gifting by grandparents and extended family members, and guardianships and alternatives.

9. Mothers and Fathers and Siblings, Oh My! - Timothy S. Hartshorne, Ph.D. - Schaumburg C-D
A child with CHARGE syndrome clearly impacts all the family members, but little is known about exactly how. This presentation reports on research conducted by the Central Michigan University CHARGE lab on the experience of mothers, fathers, and siblings of children with CHARGE, and then discusses the findings in the context of family systems. It concludes with some thoughts on family well-being.

10. How to talk to your child about having CHARGE - Kasee Stratton, Ph.D., NCSP - Schaumburg West
When and how do I tell my child they have CHARGE Syndrome? While each family will decide when the time is right for them, it is never too early or too late to learn how to begin this discussion. Dr. Stratton will cover the benefits of letting your child know about CHARGE and will address specific talking points. Child- and family-friendly strategies for introducing the diagnosis to your child will be presented.

11. CHARGE 101 - Meg Hefner, MS, Genetic Counselor and Nancy Salem-Hartshorne, Ph.D. - Schaumburg E-F
CHARGE 101 is a standard at the CHARGE Syndrome Conference. This series of presentations is intended for families with new babies and/or new to Conference. It is a combination of an overview of CHARGE and an orientation to the rest of conference. The session will provide information on diagnostic criteria and medical features of CHARGE, how sensory deficits (especially hearing, vision and balance issues) affect early development, key medical issues in infancy, especially regarding breathing, sleep, and anesthesia and communication options. Participants will have the opportunity to ask questions and interact with each other throughout. Families can also receive guidance in terms of which sessions will cover topics they are most interested in, experts who can answer their questions, including experienced parents, who will be available and in attendance for part of the session. This session will examine diagnostic criteria, medical features and sensory influences on early development with Meg Hefner.

12. Demonstrating the Communication Matrix Online Assessment & Community of Practice: Applications for Children with CHARGE Syndrome, Their Families, and Educators - Amy Parker, Ph.D. National Center on Deaf-Blindness, Charity Rowland, Ph.D., Professor and Project Director, Oregon Health Sciences University and Alexandria Cook, Project Assistant, Oregon Health Sciences University - Schaumburg G

The Communication Matrix is an assessment tool used world-wide for individuals with complex communication needs. It demonstrates how individuals at the earliest stages of communication express themselves. Data entered into the website (www.communicationmatrix.org) are mined to provide detailed information about behaviors used to communicate and messages expressed. This presentation will feature a demonstration of the Communication Matrix and the new virtual community of practice, and will include data on individuals with CHARGE syndrome from the Matrix database.

13. Let's Learn About Healthy Relationships! - Krescene H. Beck, QIDP, LNHA and Penina Simon - Schaumburg H

Self-advocates age 16 and over only are invited to come together for a time of active learning and teaching about healthy relationships; healthy sexuality; rights, boundaries, and consent; and safety and support. People with disabilities experience sexual violence at a disproportionate rate. They are also less likely than others to identify abuse and seek services when violence does occur. One of the factors that contribute to the increased risk is the lack of information and education people with disabilities receive on issues related to healthy relationships, sexuality, sexual violence prevention and body safety. This type of education, long denied or overlooked, is central to empowering people with knowledge of healthy relationships as well as information on how to report sexual violence when it occurs.

Friday, July 31 - 2:15 - 3:15 - Breakout Session #3

Information Central - Presentation of Posters and Opportunity to Visit With Presenters and Exhibitors - Multiple presenters - Schaumburg East

14. Identifying Effective Positive Behavioral Supports for Young Adults with CHARGE Syndrome - Susan M. Bashinski, Ed.D. and Susan M. Bruce, Ph.D. - Schaumburg A-B

Drs. Bashinski and Bruce will share findings from an action research study that examined three elements of positive behavioral interventions & supports (PBIS): adult use of language, environmental arrangement, and sensory system sensitivities and needs. They will utilize videos to demonstrate the application of proactive and reactive behavioral intervention strategies with five young adults who have CHARGE syndrome. Excerpts from profiles of these young adults will also be shared.

15. Addressing Feeding Issues in CHARGE Syndrome: Implications for Future Oral Motor and Speech Development - Whitney Pimentel, MA, CCC-SLP - Schaumburg C-D

In this presentation, Whitney will address feeding skills in the population of individuals with CHARGE Syndrome. Early feeding skills are critical in development of later oral motor skills, mature feeding skills, and speech clarity. Participants will learn what to look for in "good" feeding skills rather than simply "safe and adequate" feeding. Addressing these skills early is critical and will reduce later "bad habits" that evolve around spoon feeding, cup drinking, straw drinking, chewing and swallowing. However, these skills can also be taught in older children who have not had feeding and/or Oral Placement Therapy. Participants will learn techniques to facilitate lip closure, tongue retraction, tongue lateralization, and jaw grading for chewing. Families will also become aware of medical, environmental and sensory experiences and how they can alter feeding outcomes. Videos of both positive and negative experiences will be shown as part of the learning process.

16. ENT Issues in CHARGE Syndrome - Daniel I. Choo, MD and Susan E. Wiley, MD - Schaumburg West

The proper evaluation and management of Otolaryngologic (ENT) issues in the setting of children with CHARGE syndrome (CS) can pose a significant challenge. A multitude of clinical issues can range from choanal atresia to cleft lip and palate, to ear malformations and hearing problems, to subglottic stenosis. This discussion will focus on 3 of the main challenges (in the ENT domain) among children with CS.

17. CHARGE 102 - Meg Hefner, MS, Genetic Counselor and Nancy Salem-Hartshorne, Ph.D. - Schaumburg E-F

In the second part of the CHARGE 101 series, Nancy will give an introduction to communication in children who are deafblind, which will be followed by an overview of behavior features. A discussion on what is known about developmental outcomes will round out the session.

18. The Importance of Movement in the Life of an Individual with CHARGE Syndrome - Elizabeth (Beth) Foster, ABD, CAPE - Schaumburg G

The purpose of this session is to provide information about the importance and benefits of movement throughout the life of an individual with CHARGE syndrome. Beth will provide strategies to develop meaningful and accessible movement activities. A systematic approach based on best practices will be used to develop appropriate adaptations and explore with movement. Participants will understand the definition of physical education, student rights, and options for instruction to develop a positive, meaningful experience.

19. Expect ExtraOrdinary: Using Vision, Planning, and Community to Expand Possibilities - Aubrie and Michele Westmaas - Schaumburg H

Individuals with CHARGE syndrome face a myriad of physical and sensory challenges. However, society's limiting view of people with disabilities can be the greatest barrier to achieving their ultimate potential. Aubrie and Michele share their experience and perspective to empower participants to envision a future full of possibilities, share their dream with others, plan for positive outcomes, and purposefully make their place in the community.

Friday, July 31 - 3:30 - 4:30 - Breakout Session #4
Information Central - Presentation of Posters and Opportunity to Visit With
Presenters and Exhibitors - Multiple presenters - Schaumburg East

20. Psychiatric Issues in CHARGE - John Julian, M.D. - Schaumburg A-B

Parents and professionals often have concerns about OCD, anxiety, aggression, self-injurious behavior, and medications. During this one-hour question and answer session, attendees will have the opportunity to discuss these issues or other psychiatric topics with Dr. Julian, who has consulted to the Perkins School for the Blind for 12 years and worked with many children who have CHARGE.

21. Homemade Tube Feedings - Carrie Ek, RD, LDN, MBA - Schaumburg C-D

This session will examine homemade or blenderized tube feedings as an alternative to prepared formulas. This will be a discussion of benefits of using "whole foods" and the potential problem areas. Nutrition needs for specific ages and for kids with Charge syndrome will be discussed in detail. Carrie will also touch on mixed (not put in a blender) options.

22. Cochlear Implants in children with CHARGE Syndrome

Elizabeth Tournis, Au.D. and Nancy Young, M.D. - Schaumburg West

Cochlear Implantation provides children who are deaf with the opportunity to have useful hearing that will assist them in achieving their communication and educational goals. The Lurie Children's Cochlear Implant Program, has been in the forefront of providing implants to diverse candidates including those with CHARGE syndrome. In their experience, many of these children derive tremendous benefit from an implant. Dr. Tournis and Dr. Young will include case presentations with outcomes data demonstrating the impact of cochlear implants on this population.

23. Quality Not Quantity - Thoughts on Communication, Behaviour, Play and Passions - Rob Last - Schaumburg E-F

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

24. Defense mechanisms: Immunological and adrenal function in CHARGE syndrome - Monica T.Y. Wong, MD, PhD student - Schaumburg G

Children with CHARGE syndrome have problems in many organ systems and can be more vulnerable to illness. The immunological and adrenal system can prevent children from becoming ill. Dr. Wong will discuss how otitis and airway infections, including pneumonia, often occur in children with CHARGE syndrome and how their immune system shows decreased numbers of certain immune cells and reduced responses to vaccination. However, adrenal function is almost always normal in children with CHARGE syndrome. This presentation will also highlight information on the aspects of immunology and endocrinology to be further studied in CHARGE syndrome.

25. Conociendo los derechos básicos de Educación Especial

(Getting to know the basic rights about Special Education) - Clara Berg (New York Deaf-Blind Collaborative) & Myrna Medina (California Deaf-Blind Services) - Schaumburg H

Note: This session will be presented in Spanish only

Para familias de habla hispana y que tienen niños con el Síndrome de CHARGE, así como también para el equipo educacional y otros especialistas que son parte del equipo (OT, PT, TVI, enfermera, etc.) es de extrema importancia que estén bien informados de los derechos que tienen los niños para recibir una educación libre y apropiada. A veces por falta de comunicación o traducción apropiada, los padres no están al tanto de los derechos educacionales que están garantizados bajo las leyes estatales y federales. Esta va a ser una sesión interactiva para aclarar dudas o temores que tengan las familias acerca de derechos educacionales básicos para sus hijos.

(For Spanish speaking families who have children with CHARGE syndrome, as well as the educational teams and other specialists who typically serve them (OT, PT, TVI, nursing staff, etc.), it's extremely important to be informed about the rights the children have to receive a free and appropriate education. Sometimes because of lack of communication or appropriate translation, parents are not aware of the educational rights their children are guaranteed by state and federal laws. This is going to be an interactive session to clear the doubts or fears that families might have about basic educational rights for their children.)

Information Central Session

Title	Presenters
Expressive Communication Skills of Children with CHARGE Syndrome	Alexandria Cook and Charity Rowland, Ph.D. Oregon Health and Science University
The CHARGE Syndrome Research Lab at Central Michigan University	Timothy S. Hartshorne, Ph.D., Benjamin Kennert, Megan Schmittel, Rachel Malta, Hayley Hoesch, Gretchen Imel, Amanda Odren, Claire Latus-Kennedy
Mouth over-stuffing during meals in individuals with CHARGE syndrome	Alexandra Hudson, MD Candidate 2018, Dr. Kim Blake, Department of Pediatrics, Dalhousie University, Halifax NS, Meghan Macdonald, MD Candidate 2017, Faculty of Medicine, Dalhousie University
Review of Two Research-Based Methods for Improving Sleep of Children with Developmental Disabilities	Benjamin Kennert and Timothy S. Hartshorne, Ph.D., Central Michigan University- CHARGE Syndrome Research Lab
The Development of Play in CHARGE Syndrome	Megan Schmittel, M.S. and Timothy S. Hartshorne, Ph.D., Central Michigan University CHARGE Syndrome Research Lab
Assessing attachment in mother-child relationships in rare syndrome contexts	Nicole Vian, Milano-Bicocca University, Department of Human Sciences for Education and Health Sciences Department, School of Medicine
Camp Abilities Brockport: A Counselor's Experience	Gretchen Imel, Tim Hartshorne, PhD., Central Michigan University CHARGE Syndrome Research Lab and Lauren J. Lieberman Ph.D
"Wow, that Sounds Familiar": Parent-Child Playgroups for Families of Children with Deaf-blindness	Julie Maier, California Deaf-Blind Services
Communication Matrix-Growing a Virtual Community of Practice to Support Students with Complex Communication Needs	Amy T. Parker, Ed.D. & COMS, Charity Rowland, Ph.D., and Alexandria Cook
Atypical features associate with CHD7 mutations and CHARGE syndrome: a proposal for revised clinical diagnostic criteria	Caitlin L. Hale, B.S., Jane Schuette, M.S. C.G.C., Stephanie Bielas, Ph.D., and Donna M. Martin, M.D., Ph.D.
CSCDP: CHARGE Syndrome Clinical Database Project - Fun Facts	Meg Hefner, MS, Kevin Ballard MCS MHI, Joanne D'souza BS, Saint Louis University
Role of CHD7 in nerve formation	Fumiaki Imamura, PhD., Pennsylvania State University

Common Psychotropic medications used in CHARGE syndrome and what we know about them	Claire Latus-Kennedy and Timothy S. Hartshorne, Ph.D. Central Michigan University CHARGE Syndrome Research Lab
Modeling CHARGE syndrome in zebrafish: A look at the innervation and function of the gastrointestinal system	Kellie Cloney, Department of Medicine, Shelby L. Steele, Department of Pediatrics, Matthew Stoyek, Department of Physiology and Biophysics, Roger P. Croll, Department of Physiology and Biophysics, Frank M. Smith, Department of Medical Neuroscience, Kim Blake, Department of Pediatrics, Jason N. Berman, Departments of Pediatrics, Microbiology and Immunology, and Pathology, Dalhousie University, Halifax NS, Canada
Experiences with feeding and gastrointestinal motility in children with CHARGE syndrome	Meghan Macdonald, Faculty of Medicine, Dalhousie University, Halifax NS, Alexandra Hudson, Faculty of Medicine, Dalhousie University, Halifax NS, Angela Bladon, Feeding and Swallowing Team, McMaster Children's Hospital, Hamilton Ontario, Canada, Elyanne M. Ratcliffe, Division of Gastroenterology and Nutrition, Department of Pediatrics, McMaster University, Hamilton Ontario, Canada, Kim Blake, Department of Pediatrics, Dalhousie University, IWK Health Centre, Halifax NS
Parental Decision Making in the Removal of Gastrostomy Tubes	Rachel Malta, and Timothy S. Hartshorne, Ph.D., Central Michigan University CHARGE Syndrome Research Lab
The Brain in CHARGE	Mandy Odren and Timothy S. Hartshorne, Ph.D., Central Michigan University CHARGE Syndrome Research Lab
CHARGE Families in the Know Read and Listen to ...	Lori Swanson, Sheri Stanger, and Megan Cote
"What About Me?" Guiding Your Standard Developing Child Through Their Experience of Being A Sibling To An Individual With CHARGE Syndrome	Michael Braga BS, M.Ed., Ruth Braga MSN, RN and Mindy Braga
Generation and characterization of Chd7-iCre transgenic mice as a tool for lineage tracing and gene deletion	Jennifer M. Skidmore, B.S, Donald L. Swiderski Ph.D., and Donna M. Martin, M.D., Ph.D., Departments of Human Genetics and Pediatrics and Otolaryngology, The University of Michigan, Ann Arbor
Roles for Chd7 in inner ear development and function	Ethan D. Sperry, B.S., B.A., Diana F. Syam, M.Sc., and Donna M. Martin, M.D., Ph.D., Departments of Human Genetics and Pediatrics, The University of Michigan, Ann Arbor
The Development of a Comprehensive Checklist Guiding Health Screening and Management Considerations of Individuals with CHARGE Syndrome: a Delphi Technique	Carrie-Lee Trider, MD (Pediatric Resident, PGY 2), Queen's University, Angela Arra-Robar, RN MSN, Clinical Nurse Specialist, IWK Health Center, Kim Blake, MD, MSc, FRCPC, Professor of Pediatrics, Dalhousie University, IWK Health Center
Advice from siblings of persons with CHARGE	Hayley Hoesch and Timothy S. Hartshorne, Ph.D. Central Michigan University CHARGE Syndrome Research Lab

CHARGE Syndrome & Characteristics of Autism Spectrum Disorder: Examining Similarities and Differences	Hallie Smith, M.S., Doctoral Candidate, School Psychology, MacKenzie Sidwell, M.S., Specialist Student, School Psychology, and Kasee Stratton, Ph.D., NCSP, Assistant Professor, Licensed Psychologist, School Psychology, Mississippi State University
How do we raise awareness for CHARGE? A study of Facebook and Twitter Outcomes	Daniel L. Gadke, Ph.D., NCSP, BCBA, Assistant Professor, Hailey Ripple, B.S., Doctoral Candidate, School Psychology, Somya Mohanty, Ph.D., Assistant Research Professor, Arthur Cosby, Ph.D., William L. Giles Distinguished Professor, Mississippi State University
The Bulldog CHARGE Syndrome Research Lab at Mississippi State University	Hailey Ripple, MacKenzie Sidwell, Hallie Smith, Mady Sully, Reeva Morton & Dominik Keller, Students, Mississippi State University
CHD7 controls cerebellar growth via Reelin	M. Albert Basson, PhD, King's College London
Genetic Testing in Patients Suspected of Having CHARGE Syndrome	Cheryl Scacheri, MS, LGC, GeneDx, Inc., Chris Lauricella, MS, CGC; Toni Lewis, MS; Rebecca Fowler, MS, CGC; Jennifer Siegel, MS, LCGC; Jane Juusola, PhD, FACMG; Sherri Bale, PhD, FACMG
Keeping it Simple: Strategies for Managing Behavior	Kasee Stratton, Ph.D., NCSP & Dan Gadke, Ph.D., NCSP, BCBA, Mississippi State University
An educational model to reduce passivity and increase self-determination in deafblind learners resulting in improved connection, communication, and learning	Kimberly Lauger, Redtail Neurodevelopmental Center, Consultant for the Arizona Deafblind Project
Open-Hands, Open Access, Deaf-Blind Intervener Learning Modules: Using A National Resource to Meet State Specific Training Needs	Nancy Steele, National Center On Deaf-Blindness, Michelle Clyne, M.Ed., Project Reach, Illinois Deaf-Blind Project. Jody Wolfe, Parent Leader, Chicago, IL Amy T. Parker, Ed.D. & COMS

Let the Games Begin: Choosing appropriate games for your child with CHARGE Syndrome	Sarah Bis, MS, OTR/L, C/NDT and Sharon Stelzer, M.Ed, Perkins School For The Blind
Breathing and Posture: More Linked Than You Think!	Mary Massery, PT, DPT, DSc
How to talk to your child about having CHARGE	Kasee Stratton, Ph.D., NCSP, Mississippi State University
Take Time For Yoga	Rebekka Valian Teacher of the Deafblind, W. Ross Macdonald School for the Blind, Deafblind Unit
Looking at the world through rose-colored glasses: Approaches to positive assessment	David Brown and Julie Maier, Educational Specialist with California Deaf-Blind Services
We Have CHARGE, So What?	Claudia Junghans, 1st President of CHARGE Syndrom e.V. (Germany), Dr. Julia Benstz, Vice president of CHARGE Syndrom e.V. (Germany)
Pain and Coping: Identifying and Easing Pain	Kasee Stratton, Ph.D., NCSP, Mississippi State University, Assistant Professor/Licensed Psychologist
CHARGE Syndrome & Parental Relationships	Dominik Keller, Mady Sully, & Kasee Stratton, Ph.D., NCSP, Mississippi State University
Research Projects	
Genetics of CHARGE syndrome	Donna M. Martin, MD, PhD, Donita B. Sullivan, MD Research Professor of Pediatrics, Associate Professor of Pediatrics and Human Genetics, University of Michigan Medical School Stephanie Bielas, PhD, Assistant Professor of Human Genetics, University of Michigan Medical School
3D Imaging	Richard A. Spritz, M.D. and Ms. Sheri Riccardi Professor and Director, Human Medical Genetics and Genomics Program, University of Colorado School of Medicine
Growth Charts for Children with CHARGE Syndrome	Conny van Ravenswaaij-Arts, MD, PhD and Monica Wong, MD, PhD student Genetics, University Medical Centre Groningen

Notes _____

Saturday, August 1 - 10:45 - 11:45 - Breakout Session #5

Research Projects* will be taking place in Schaumburg H and in Hotel Hospitality Suite (TBD) throughout the day

26. Promoting Early Concept Development through Adapted Books - Christine Spratling - Schaumburg A-B

Concepts are the ideas that give meaning to our world. We constantly develop concepts based on how we experience the world around us. Children who have sensory loss(es) and additional health issues often have limited experiences and therefore develop concepts that appear counterintuitive to us. Christine will share how adapted books can be used as a powerful and fun tool to help children develop accurate concepts about their specific environment.

27. Making it Happen: Intervener Services for Children and Young Adults Who Have Vision and Hearing Losses - Linda Alsop, M.Ed., Beth Kennedy, M.Ed. and Panel - Schaumburg C-D

You know that an intervener is what your child/student needs- but how do you make it happen? In this presentation, general information on interveners, their practice, training and credentialing will be examined along with important information for families and other members of the team for making the case for intervener services. A parent panel will share personal stories of how interveners were added to their children's Individualized Education Plan (IEP), and what a difference having an intervener has made for their child.

28. All you ever wanted to know about sex hormones, preparing for puberty, and sexuality in CHARGE! - Kasee Stratton, PhD, NCSP and Jeremy Kirk, M.D, FRCPCH, FRCP - Schaumburg West

Dr. Kirk will cover investigation of pubertal problems and optimal hormone replacement, achieving the best results whilst avoiding unacceptable side effects. Dr. Stratton will present on the development of sexuality from identifying body parts to preparing for masturbation. Specific teaching tools will be presented to help your son or daughter better understand the changes to their body.

29. Neurological Issues - Dr. Jules Constantinou, MD FRACP - Schaumburg East

30. An interactive seminar in genetics: All you want to know about the genetics of CHARGE syndrome - Conny van Ravenswaaij-Arts, MD, PhD and Nicole Corsten-Janssen, MD - Schaumburg E-G

After a short introduction, all questions of the participants regarding genetics, the CHD7 gene, mutations, recurrence risk, et cetera, will be answered using instructive illustrations. Based on the experience of previous years, Conny and Nicole will offer parents the opportunity to discuss the specific genetic test results of their child.

Note: this session will be offered again during the 1:00-2:00 time slot.

Saturday, August 1 - 1:00 - 2:00 - Breakout Session #6

31. Helping out at Home: Building Independent Living Skills in the Context of Family Routines - Sarah Bis, MS, OTR/L, C/NDT and Sharon Stelzer, M.Ed. - Schaumburg A-B
Independent Living skills are a critical part of the Expanded Core Curriculum. Unlike typically developing children who may learn through observation, children with CHARGE syndrome will need to be directly and explicitly taught these skills. In this presentation, parents and caregivers will learn how to break down independent living tasks and embed teaching and practice into everyday routines. Participants will leave the session with a list of ideas that may be implemented at home immediately.

32 “What about me?” Guiding your standard-developing child with their experience of being a sibling to a child with CHARGE - Michael Braga BS and Ruth Braga BA, MSN, RN - Schaumburg C - D

As parents, our homes are often consumed with the care of our sons and daughters who have CHARGE syndrome. Between doctor visits, therapy, education and other issues, there comes a point when our children who are typically developing are left asking, “What about me?” With help from their 14-year-old daughter, Michael and Ruth will address the challenges that siblings face and how to implement survival strategies. Learn, share and hear from others and return home with new ideas to help each of your children flourish!

33. Keeping it Simple: Strategies for Managing Behavior - Kasee Stratton, Ph.D., NCSP & Dan Gadke, Ph.D., NCSP, BCBA - Schaumburg West

In this session, the goal is to provide some clarity of what to do when your child engages in challenging behavior. Kasee and Dan will teach strategies to understand the basics of behavior in CHARGE and to also better understand behavior of all children (that’s right...siblings, too!). They will cover why challenging behavior occurs, how to identify the function of the behavior, and what to do next to intervene.

34. Why Does My Child Do That? Explanation of and Strategies for Dealing with Compulsive Behaviors and OCD in CHARGE Syndrome - Nancy Salem-Hartshorne, Ph.D. - Schaumburg East

All of us have repetitive or compulsive behaviors. All of us have hobbies. But when we see these obsessions and compulsions in our children with CHARGE, they can look odd or disturbing, or may prevent them from accomplishing all that they can, and we worry. Anxiety is the key! Dr. Hartshorne will talk about strategies to address anxiety and OCD-like behaviors in children with CHARGE syndrome.

35. An interactive seminar in genetics: All you want to know about the genetics of CHARGE syndrome

See notes under session 30

Notes

Saturday, August 1 - 2:15 - 3:15 - Breakout Session #7

36. Which Way is Up? - How behavior reveals sensory processing differences in children with CHARGE Syndrome - Kate Beals, OTR/L - Schaumburg A-B

Children who have CHARGE Syndrome are known to have problems with sensory processing across multiple systems, which affects the way they experience themselves and the world around them. Kate will explain how the seven sensory systems operate differently in children with CHARGE Syndrome, and how families, caregivers, therapists, and teachers can learn to recognize behaviors that suggest specific sensory processing issues and needs.

37. Language Acquisition through Motor Planning (LAMP): AAC for Individuals with CHARGE Syndrome - John Halloran, M.S., Speech Language Pathologist - Schaumburg C-D

Language Acquisition through Motor Planning (LAMP) is a therapeutic approach using motor learning principles and a voice output communication aid to give non-verbal individuals with CHARGE syndrome and other developmental disabilities a method to develop independent and spontaneous communication. Strategies and tools to teach language/communication skills within this framework will be discussed.

38. Family Leadership and Empowerment: The Lived Experience of Parents of Children with Charge Syndrome in Advocating and Navigating Systems - Seth Harkins, EdD, Janay Mohamed, Maria & Dan Roeters, Scott Boroff, Allison & Scott Stahl, Karen Windy (Deaf-blind specialist) - Schaumburg West

Dr. Harkins, along with a panel of parents of children who have CHARGE syndrome and a deafblind specialist, will discuss the challenges in advocating for their youth as they navigate the complex maze of special education and human service systems. This presentation will examine the narratives of parents and their experiences in developing and sustaining partnerships with professionals, as they and their children traverse early intervention services through public education, and transition to adult services. Effective leadership, advocacy, and collaboration strategies are examined.

39. Anticipation and Behavior - Timothy S. Hartshorne, Ph.D. - Schaumburg East

Anxiety about what is occurring or going to happen is one source of challenging behavior for children with CHARGE. This presentation reviews calendar systems and activity routines as ways to increase the predictability of life for those who have CHARGE, and to reduce the experience of anxiety and the incidence of challenging behavior.

40. Feeding problems and how they can be related to the heart

Nicole Corsten-Janssen, MD and Conny van Ravenswaaij-Arts, MD, PhD

Most individuals with CHARGE syndrome have feeding problems. Feeding problems can have multiple causes. This presentation will focus on the relation between feeding problems and heart defects, especially on the less well known arch vessel anomalies. Arch vessel anomalies occur in CHARGE syndrome and may cause problems with feeding due to compression of the esophagus. It can be difficult to recognize this often treatable cause of feeding problems, so awareness is important.

Saturday, August 1 - 3:30 - 4:30 - Breakout Session #8

41. Power of Jacob - Timothy S. Hartshorne, Ph.D. and panel of Jacob's caregivers: Toni Hayward, Trevor Karr, Mandy Odren, Amber Schwennesen - Schaumburg East

Disability is often associated with a great deal of discouragement. How can a person with severe limitations possibly contribute to society? Jacob is a 26 year old young man who functions on the severe end of the CHARGE continuum. In this presentation, some of Jacob's caregivers will talk about his impact on their lives.

42. Ataxia in CHARGE: a novel feature? - Christa (C.M.) de Geus, MD - Schaumburg E-G

One of the problems that children with CHARGE syndrome face is a lack of balance due to absence of the semicircular canals. Recent research has shown that cerebellar anomalies occur in 55% of CHARGE patients. The cerebellum plays an important role in balance and coordination. We wondered whether cerebellar dysfunction may contribute to balance and coordination issues (ataxia) in CHARGE syndrome and have started a study investigating this.

Notes.

Research at the 12th International CHARGE Syndrome Conference

This Conference is the largest ever gathering of individuals with CHARGE and their families! It provides a unique opportunity for CHARGE research. There are nine research projects taking place here at conference.

***Research Projects - Schaumburg H**

Growth in CHARGE syndrome - Conny van Ravenswaaij-Arts, MD, PhD and Ms. Monica T.Y. Wong, MD, PhD student, University of Groningen, University Medical Center Groningen - Estimated time 10-15 minutes. **Monica T.Y. Wong** charge@umcg.nl

Nonsymbolic Communication - Dr. Susan M. Bashinski, Associate Professor, Special Education Missouri Western State University and Dr. Barbara A. Braddock, Assistant Professor, Department of Pediatrics, St. Louis University, Knights of Columbus Child Development Center Groningen - Estimated time: 45 - 90 minutes. **BY APPOINTMENT Dr. Susan Bashinski** sbashinski@missouriwestern.edu

CHARGE Syndrome & Characteristics of Autism Spectrum Disorder: Examining the Similarities & Differences - Kasee K. Stratton, Ph.D. Kasee K. Stratton, Ph.D., (PI) Assistant Professor, Licensed Psychologist, Mississippi State University and Daniel L. Gadke, Ph.D., (Co-PI) Licensed Psychologist, Mississippi State University - Total estimated time: 1.5-3 hours. **BY APPOINTMENT Dr. Kasee Stratton** kstratton@colled.msstate.edu or call/text **989-621-2303**

Genetics of CHARGE Syndrome - Donna M. Martin, MD, PhD, Donita B. Sullivan, MD Research Professor of Pediatrics, Associate Professor of Pediatrics and Human Genetics, Stephanie Bielas, PhD, Assistant Professor of Human Genetics, University of Michigan Medical School - Estimated time 20 minutes. **Dr. Donna Martin** donnamm@med.umich.edu

Feeding/Swallowing Issues and Mouth Over-Stuffing - Alexandra Hudson, MD Candidate 2018, Department of Medicine, Dalhousie University, Halifax NS - Estimated time: 45 minutes. **Alexandra Hudson** dalmed.charge@gmail.com

3D Imaging - Richard A. Spritz, M.D., Professor and Director, Human Medical Genetics and Genomics Program and Ms. Sheri Riccardi, University of Colorado School of Medicine - Estimated time: 10-15 minutes. **Sheri Riccardi** sheri.riccardi@ucdenver.edu

CHARGE Syndrome Clinical Database Project - Kevin Ballard, MCS MHI, Saint Louis University - Estimated time: sign up takes 5 minutes. **Meg Hefner** hefnerma@slu.edu

Checklist for management of individuals with CHARGE - Carrie-Lee Trider, MD (Pediatric Resident, PGY 2), Queen's University - Estimated time: 15 minutes. **Carrie-Lee Trider** 13CLT2@queensu.ca

Research Projects - Hotel Hospitality Suite (TBD)

Sloping shoulders in CHARGE syndrome - Christa (C.M.) de Geus, MD, Department of Genetics Renate Verbeek, MD, PhD, Department of Neurology, University of Groningen, University Medical Center Groningen - Estimated time: 30-45 minutes. **BY APPOINTMENT Dr. Christa de Geus** CHARGE@umcg.nl

The cerebellum in CHARGE syndrome: anatomy, ataxia and balance - Christa (C.M.) de Geus, MD, Department of Genetics, Renate Verbeek, MD, PhD, Department of Neurology, Linda Meiners, MD, PhD, Department of Neuroradiology, University of Groningen, University Medical Center Groningen - Estimated time: 30 minutes. **BY APPOINTMENT Dr. Christa de Geus** CHARGE@umcg.nl



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.

In June of 2015, our First Annual EWRAP award recipients began to receive their bikes, swimming lessons, Hippotherapy, gymnastic classes and summer camp experiences. Our 2016 applications will be announced this winter. Check our newsletters and website for more information.

Everyone deserves the 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

Values:

- Excellence • Community
- Inclusion • Collaboration



The APH Intervention Continuum

Three Sequential Kits

APH recommends that learners use the following three products sequentially:



Sensory Learning Kit (SLK)

Extensive set of sensory items and written materials that help significantly challenged learners increase their curiosity and develop specific skills.

SAM: Symbols and Meaning

Kit for students with visual & multiple impairments and pre-school children with visual impairments who are just beginning to use symbols.



Tactile Connections: Symbols for Communication

Helps teachers create a tactile card system for visually impaired and blind learners who have additional disabilities and/or lack a formal means of communication.

<http://shop.aph.org>



American Printing House for the Blind, Inc.
800.223.1839 • info@aph.org • www.aph.org

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 mission of this public charity is to raise awareness for CHARGE syndrome and assist individuals in the CHARGE community.

www.chargeforconnor.org
chargeforconnor@gmail.com
facebook.com/chargeforconnor

Photos that touch your heart!



Buller Photography has been serving the special needs community since 2004. We specialize in photography and films of all the important moments of your life—imagery that touches your heart and moves your spirit. We offer everything from portraits and weddings to special event and family legacy videos. Our award-winning, family-oriented images reflect all of God's beauty. Available worldwide.



*Come say hello to us at the CHARGE conference!
We'll be the ones with the cameras!*

Janet & Sandy Buller | 281-375-5377 | BullerPhotography.com

GeneDx offers genetic testing for **CHARGE Syndrome**

Prenatal and Postnatal Tests include:

- CHD7 Gene Sequencing
- CHD7 Deletion/Duplication Analysis

For more information, please call **301-519-2100** or visit www.genedx.com



207 Perry Parkway Gaithersburg, MD 20877

T 1 888 729 1206 (Toll Free), 1 301 519 2100 • F 1 201 421 2010 • E genedx@genedx.com • www.genedx.com

© 2015 GeneDx. All rights reserved.

Texas Chargers Inc.



Encourage
Educate
Enrich

**10 Years
of Service**

Supporting
Texas Families



**Products for Deaf,
Deaf-Blind and
Hard of Hearing!**



**HARRIS
COMMUNICATIONS**

www.harriscomm.com

(800) 825-6758



*Request a
FREE Catalog!*

It's No Secret!



**Silent Auction
Donors
Are The BEST!**
Thank You!

Sponsor, Exhibitor & Advertiser Information

Ace Hardware

16725 South Oak Park Avenue
Tinley Park, IL 60477



Ace Hardware's mission is to provide consistent and superior customer satisfaction for the communities we serve, revolutionize the independent segment of our industry and be the market leader in the convenience hardware/home improvement market.

American Printing House for the Blind

1839 Frankfort Avenue
Louisville, KY 40206
800-223-1839
camback@aph.org
www.aph.org



American Printing House
for the Blind, Inc.

APH is the world's largest company devoted to making products for people who are visually impaired and blind, and is the official supplier of educational materials for blind students in the U.S. working at less than college level. Visit our website at www.aph.org or call 800-223-1839 for more information.

An Exceptional Fellow by Svein Olav Kolset

PB 4416 Nydalen
Oslo, Norway 0403
+47-95154131
s.o.kolset@medisin.uio.no



An Exceptional Fellow is the unsentimental and powerful story of a child with multiple disabilities and his family. The boy is Torgeir, now 35 years of age. The father, Svein Olav, relates the shock he and his wife experienced one day in May, 1975 when Torgeir came into the world. We hear the story of a young student couple's struggles in everyday life and about the significance of friends and family in the social circle surrounding Torgeir. Torgeir is a tough guy. He is another kind of Viking. Against all odds, he has fought for and achieved a life of dignity. He experiences mastery and meaning on his own terms. How is that possible with serious sensory debilitation and other physical impairments? His father tells us how, and about the journey to an accurate diagnosis - CHARGE.

Notes

Sponsor, Exhibitor & Advertiser Information

Canadian Deafblind Project - Ontario Chapter
Susan Hall, Director of Services
Canadian Deafblind Association Ontario Chapter
50 Main St.
Paris, ON
N3L 2E2
519-442-0463
shall@cdbaontario.com



Canadian Deafblind Association Ontario Chapter has been providing services to individuals who are deafblind and their families for 25 years. CDBA Ontario is recognized within Canada and around the world as a leader in the field of Deafblindness. Each one of our services is designed to fulfill our vision that “all people who are deafblind will live rich meaningful lives”.

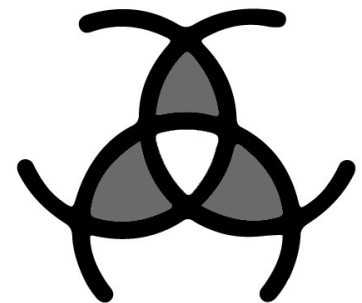
Center for AAC & Autism
The Center for AAC and Autism
PO Box 1317
Wooster, OH 44691
Phone: (866) 998-1726
E-mail: courtney@aacandautism.com
Web: www.aacandautism.com

The Center for
AAC&Autism

Learn. Hope. Share. Succeed.

The Center for AAC & Autism believes that every child has the desire and the ability to communicate despite physical and neurological challenges. By providing specialized clinical training to health care professionals, teachers, and parents... empowering clients and families with education, resources, and information... and supporting clinical research, our aim is to give all children the ability to speak their mind and heart and become engaged in their world.

Chakiris for CHARGE Syndrome
Yara Cluver
2311 N. Headley Rd.
Bloomington, IN 47408
812-272-0738
chakirisforcharge@gmail.com



George Chakiris, Oscar winner for his role as Bernardo in the 1961 classic film *West Side Story*, befriended Ysabel Clüver, a 16 year old individual with CHARGE a couple of years ago. Together they have created an organization called Chakiris for CHARGE Syndrome (www.chakirisforcharge.org) and have designed a line of products with the slogan: I've Got the Chakiris Chill. Proceeds of sales will go to the CHARGE Syndrome Foundation. Learn more about our efforts at our exhibit booth!

Notes

Sponsor, Exhibitor & Advertiser Information

CHARGE for Connor

Nikki Logsdon
513-349-5359
chargeforconnor@gmail.com
www.chargeforconnor.org
facebook.com/chargeforconnor



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.

CHARGE Syndrome Clinical Database Project (CSCDP)

Meg Hefner, MS
Saint Louis University
St. Louis, MO
hefnerma@slu.edu
<http://chargesyndrome.org/CSCDP.asp>



Saint Louis University is the location and a sponsor of the CHARGE Syndrome Clinical Database Project. CSCDP is a database and registry of medical and developmental information on individuals with CHARGE. The web-based surveys collect information that can be used as baseline information for other CHARGE researchers - so you don't have to answer the same questions over and over for each study.

SAINT LOUIS
UNIVERSITY

The Chicago Lighthouse for People who are Blind or Visually Impaired

Veramarie H. Baldoza, MA, NIC
Deaf-Blind Technology Instructor
National Deaf-Blind Equipment Distribution Program
iCanConnect Illinois
Voice Phone: 312.666.1331 Ext. 3722
Video Phone: 312.957.4865
Veramarie.Baldoza@chicagolighthouse.org
www.chicagolighthouse.org



The Chicago Lighthouse Deaf-Blind Program assists people throughout Illinois who have varying degrees of visual and hearing losses, providing access to other Lighthouse programs, community services, and appropriate referrals to agencies. For more information about Deaf-Blind Services or the iCanConnect Program, please call or visit our website. The Lighthouse is one of the nation's most comprehensive social service organizations.

Sponsor, Exhibitor & Advertiser Information

Cincinnati Children's Hospital Medical Center
CHARGE Team
3333 Burnet Avenue
Cincinnati, Ohio. USA. 45229
Phone: 513-636-4611
ashley.wright1@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.

Cochlear Americas
13059 E. Peakview Avenue
Centennial, CO 80111
Bobbi Scheinin, Au.D. - Group Product Manager
(303) 264-2404
(720) 940-9705 Cell
(303) 524-6861 Fax
<http://www.cochlearamericas.com>



Hear now. And always

Cochlear is the leader in implantable hearing solutions. The Baha® System is the most innovative treatment of conductive/mixed hearing loss and single-sided deafness. The Cochlear™ Nucleus® System is the most advanced cochlear implant for treating severe-to-profound sensorineural hearing loss. Visit us at www.cochlear.com/us.

Discovery Toys
Sherre Burtzkus
(847)905-1293
sherre@core.com
www.discoverytoyslink.com/sherre

The premier educational toy company that provides learning toys, books and games for children of all ages. We nurture the development of skills, knowledge and the child's belief in their own abilities through play.



Sponsor, Exhibitor & Advertiser Information

Freedom Concepts Inc.
2087 Plessis Road, Unit A
Winnipeg, Manitoba
R3W1S4 Canada
(800) 661-9915
mobility@freedomconcepts.com
www.freedomconcepts.com



Freedom Concepts Inc. has been imagining, designing, and building a full line of adaptive bicycles, alternative seating, and mobility devices for over twenty years. Freedom Concepts products allow individuals from 18-months-old, all the way through to adulthood to discover mobility and enjoy life.

Fresh Wave - OMI Industries, Inc.
1 Corporate Drive, Suite 100
Long Grove, IL 60047
O. 847.304.9111
www.freshwaveworks.com



Fresh Wave products remove odor by absorbing odor molecules and breaking them down naturally. There are no masking fragrances or harsh chemicals - just essential plant oils blended in a way to remove odors anywhere in your home. Fresh Wave products are sold in Ace Hardware, Bed Bath & Beyond, The Container Store, True Value, and Whole Foods Market.

GeneDx
207 Perry Parkway
Gaithersburg, MD 20877
Phone: 301-519-2100
genedx@genedx.com
www.genedx.com



GeneDx is highly respected laboratory, specializing in genetic testing for inherited disorders. GeneDx offers next-generation sequencing and deletion/duplication testing for inherited cardiac disorders, mitochondrial disorders, neurological disorders, inherited cancer disorders, prenatal disorders and other rare genetic disorders. GeneDx also offers whole exome sequencing and microarray-based testing.

Notes _____

Sponsor, Exhibitor & Advertiser Information

The Hadley School for the Blind

Student Services
700 Elm Street
Winnetka, IL 60093
800-526-9909
student_services@hadley.edu
www.hadley.edu



The Hadley School for the Blind

The Hadley School for the Blind offers distance education courses (in your home, office or on the go!) at no charge to eligible students who are blind or visually impaired 14+ years of age and their families. Additional services include online Seminars@Hadley and instructional videos related to iOS accessibility features. Stop by the exhibit booth to learn more!

Harris Communications

(800) 825-6758
info@harriscomm.com



Harris Communications has an unbeatable selection of products for Deaf, Deaf-Blind and hard of hearing. Products include: amplified phones, TV amplifiers, loud/vibrating alarm clocks, signaling systems and emergency notification. 100% satisfaction guaranteed: free shipping and returns. Request a free catalog!

Illinois Advocates for the Deaf-Blind

818 DuPage Blvd.
Glen Ellyn, IL 60137
630-790-2474
mariamccar@comcast.net
www.philiprockcenter.org



IADB is an organization of parents, families, friends and consumers dedicated to protecting the rights and advocating for the needs of all individuals with deaf-blindness.

We accomplish our Mission by: Collecting/sharing information.

Advocating for improved services for the entire lifetime of individuals who are deaf-blind.

Providing family to family support. Promoting awareness of the unique needs that accompany deaf-blindness.

Notes

Sponsor, Exhibitor & Advertiser Information

Innovative Vision Products

Sloan Morris
1424 Saranell Ave.
Naperville, IL 60540
Toll Free: 888-504-5300
ivisionpi@aol.com
www.enhancedvision.com



Innovative Vision Products, Inc.

Enhanced Vision and Innovative Vision Products, Inc. offer the most extensive variety of video magnifiers. Our devices assist low vision individuals with reading, writing and distance viewing. We also offer devices with text-to-speech capabilities. Desktop and portable units are available. Please inquire about a no obligation, in-home demonstration.

Invitae

Mike Zuba
458 Brannan St
San Francisco, CA 94107
415-374-7782
mike.zuba@invitae.com
www.invitae.com



INVITAE

Invitae, a genetic information company, is aggregating the world's genetic tests into a single service with better quality, faster turnaround time, and lower price than most single-gene tests today. Our mission is to bring genetic information into mainstream medical practice to improve the quality of healthcare for billions of people.

Know Your Rights

Paul Khouri - Paulus.khouri@gmail.com
Kathryn Carroll Esquire
Jessica Hunt, Attorney Advisor
jessicalynhunt@gmail.com
Rachel Boll - rachelboll@gmail.com

Know Your Rights
Resources for CHARGE Syndrome

Disability rights advocates Paul Khouri, Kathryn Carroll, Jessica Hunt and Rachel Boll are all young professionals with disabilities who are available to share what they know about the rights of people with disabilities, including those with CHARGE Syndrome. Visit this table to learn about numerous resources, policies, and organizations that are available for people with disabilities, especially those who are D/deaf or blind.

You can also get more information about the laws and rights that protect us against discrimination. Mr. Khouri is a professional disability rights advocate, Ms. Boll is a deaf/blind vocational assistant, Jessica Hunt is an Attorney Advisor at the DC Office of Disability Rights and Kathryn Carroll is an attorney and disability expert and consultant.

Sponsor, Exhibitor & Advertiser Information

National Family Association for Deaf-Blind (NFADB)

141 Middle Neck Road
Sands Point, NY 11050
800-255-0411
nfadb@aol.com
www.nfadb.org
Find us on Facebook



The National Family Association for Deaf-Blind (NFADB) is a non-profit 501(c)3 organization that has served families of individuals who are deaf-blind since 1994. NFADB exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs.

Oticon Medical, LLC

580 Howard Avenue
Somerset, NJ 08873
1-888-277-8014
www.oticonmedicalusa.com



Oticon Medical is the manufacturer of a bone conduction hearing implant system, the Ponto. Ponto is indicated for conductive losses, mixed hearing losses and single-sided deafness. To learn more about the Ponto system, stop by the Oticon Medical exhibit during the meeting or visit us on the web at www.oticonmedical.com

Perkins School for the Blind

175 Beacon Street
Watertown, MA 02172
617-924-3434
www.perkins.org

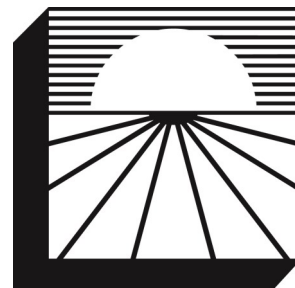


Perkins School for the Blind, the first of its kind in the U.S., was the first school in the world to formally educate children with deafblindness - including Helen Keller. Our programs today feature a Deafblind Program that serves the world's largest population of students with CHARGE syndrome, a low-incidence genetic condition that often results in combined vision and hearing loss. In addition to developing communication and academic skills, we support every student in their transition to successful, engaged adults.

Notes_____

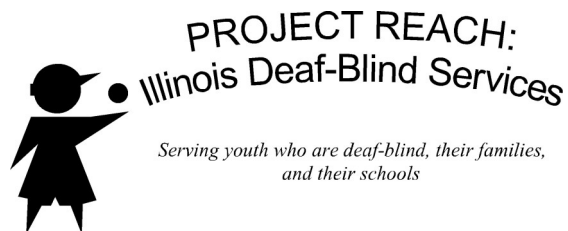
Sponsor, Exhibitor & Advertiser Information

Philip J. Rock Center and School
818 DuPage Blvd.
Glen Ellyn, IL 60137
630-790-2474
sharkins@philiprockcenter.org
www.philiprockcenter.org



PRC offers a residential, extended day/year program for children with deafblindness who have additional disabilities and require an intensive program that cannot be provided in a day school. Programming emphasizes expanded core curriculum (communication, living skills, orientation and mobility, etc.) as well as highly individualized functional academics. The service center provides a library, information referral, and Family Specialists to support families.

Project Reach: Illinois Deaf-Blind Services
818 DuPage Blvd.
Glen Ellyn, IL 60137
630-790-2474
mclyne@philiprockcenter.org
www.philiprockcenter.org



Project Reach supports children/youth with deafblindness by coaching their families and schools. Topics include supporting sensory needs, positive behavior supports, communication, accessing academics, and others. Services are individualized and include trainings, library loans, and on-site visits that build adult skills. Regional Deaf-Blind Specialists develop coaching relationships with families and teams. New evidence-based practices are shared throughout the state.

Sorenson Communications
4192 South Riverboat Road
Salt Lake City, UT 84123
801-287-9401
www.sorenson.com



Sorenson Communications® (www.sorenson.com) is a provider of industry-leading communications products and services for the deaf. The company's offerings include Sorenson Video Relay Service® (SVRS®), the highest-quality video interpreting service; the Sorenson ntouch® VP videophone, designed especially for use by deaf individuals; ntouch® PC, software that connects users to SVRS by using a PC and webcam; ntouch® for Mac®, software that connects users to SVRS by using an Apple® computer; ntouch® Tablet, which turns the Apple iPad® with a front-facing camera into a larger-screen mobile VP; and ntouch® Mobile, an application empowering SVRS communication via mobile devices. Using state-of-the-art equipment, coupled with the highest-quality professional interpreters, deaf and hearing callers are empowered to communicate in real-time, each in their preferred language.

Sponsor, Exhibitor & Advertiser Information

Sweet Spirit Productions

Buller Photography

Janet & Sandy Buller

Pattison, TX 77466

281-375-5377

www.sspwse.com



Sweet Spirit Productions has been serving the special needs community since 2004. We specialize in films and photography of all the important moments of your life - imagery that touches your heart and moves your spirit. We offer everything from family biographies to portraits to wedding and special event videos. Our award-winning, family oriented images reflect all of God's beauty. Available worldwide. Visit BullerProductions.com for editorial, commercial and

TalkTools

2209 Mechanic Street

Charleston, SC 29405

888-529-2879

info@talktools.com

www.talktools.com



TalkTools' mission is to help families overcome the obstacles of speech disabilities and improve their quality of life. Our programs and tools have made us a primary worldwide source for oral placement, sensory and feeding therapy supplies. TalkTools' training programs have successfully taught thousands of therapists how to use our techniques to help people all over the world.

Texas Chargers, Inc.

213 Boulder Drive

Navasota, TX. 77868

kathi@centex.net

325-456-6591

www.texaschargers.org

Texas Chargers Inc.



**Encourage
Educate
Enrich**

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 _____

Sponsor, Exhibitor & Advertiser Information

Tobii Dynavox
2100 Wharton St
Pittsburgh, PA 15203
800-344-1778
support@tobiidynavox.com
www.tobiidynavox.com

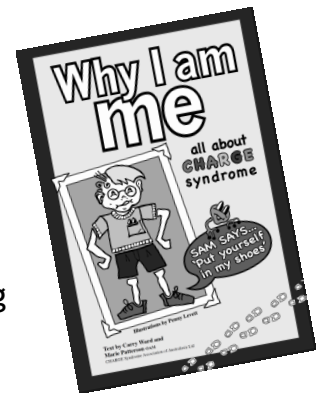
tobii dynavox
Power to be You

Tobii Dynavox, the leading provider of touch and eye tracking based assistive technology hardware and software, is dedicating to supporting those with communication and mobility impairments. Our mission is to help those individuals speak up, be heard, and take control of their lives through easily available communication solutions. Visit www.tobiidynavox.com.

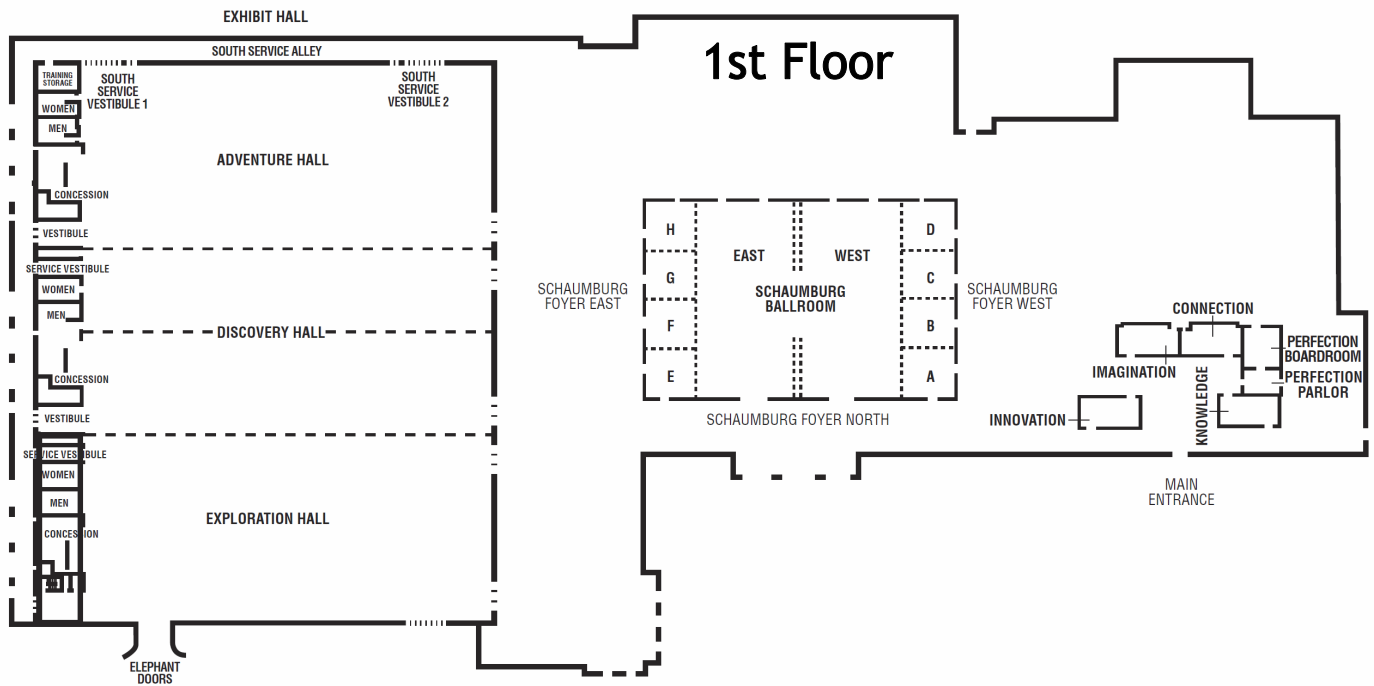
Why I Am Me all about CHARGE syndrome

Carry Ward & Marie Patterson, Authors
www.chargesyndrome.org.au

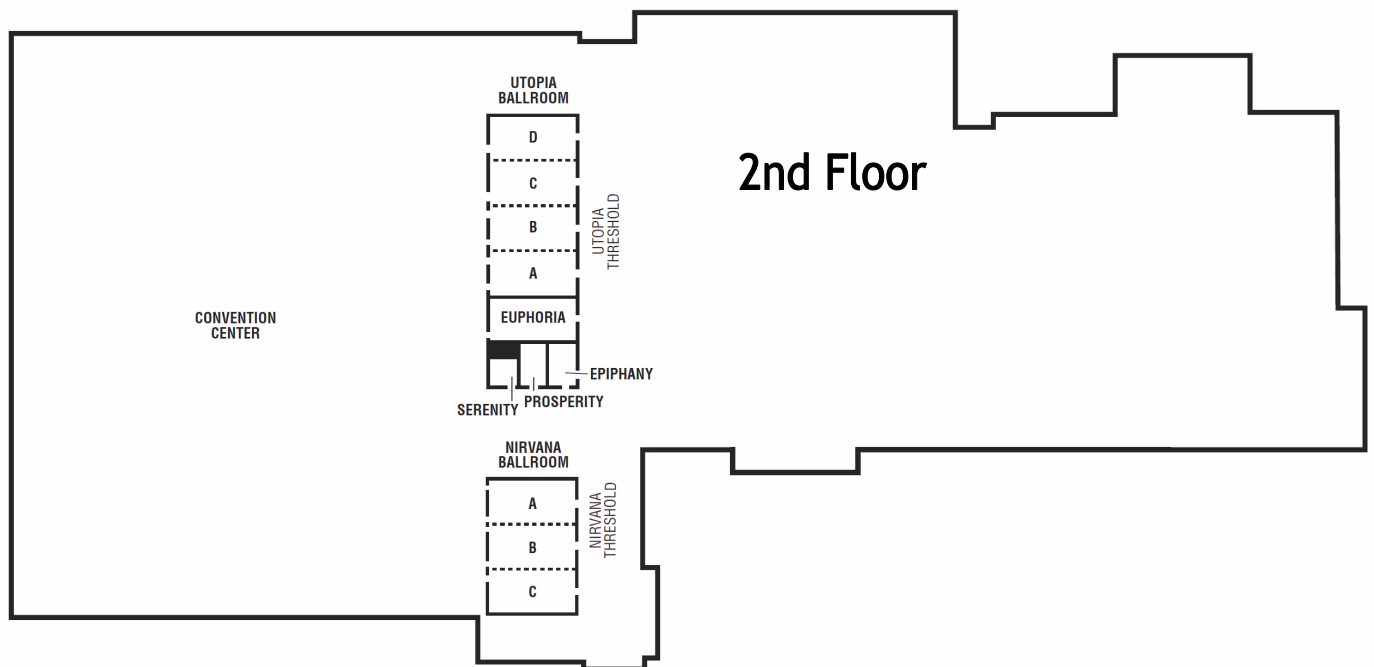
Why I Am Me is a story about a boy called Sam who has CHARGE syndrome and his friend Jess. As the story progresses Jess learns about CHARGE syndrome and the challenges Sam faces on a day-to-day basis. Written by Carry Ward and Marie Patterson with illustrations by Penny Levett, the idea for this book was sparked by questions asked by a young person with CHARGE. As a result this book is written from a unique perspective. The story is supported by medical information, diagrams and photographs of children and young persons with CHARGE. It includes simulation activities to provide greater insight into what it might be like to have CHARGE. Books are available for purchase at this conference or purchase online from www.chargesyndrome.org.au

[illegible]

FIRST FLOOR



SECOND FLOOR



Notes



Do Something You Love

You can make a difference in the lives of those you interpret for. Sorenson Video Relay Service® (SVRS®) is a world-class video relay service provider for the deaf and hard-of-hearing community. We are always looking for highly-qualified professional interpreters

to join our team. Come share your talents with us and we'll provide you with an array of benefits including healthcare, flexible schedules, retirement, vacation, on-going professional development and more. Join the Sorenson team today and do something you love.



For more information visit
www.svrs.com/jobs

THEY SAID NOTHING COULD BE DONE ABOUT HEARING LOSS. GOOD THING HE DIDN'T LISTEN.

What drove Dr. Graeme Clark to invent the first multi-channel cochlear implant over 30 years ago? What kept him going when others called him crazy and sometimes worse? His father was profoundly deaf and growing up, all he wanted was to find some way to help. His invention came too late for his dad, but for the hundreds of thousands of people whose lives he helped change, it's been nothing short of a miracle. Let there be sound.

Today they can hear because one man chose not to listen. Read their stories at Cochlear.com/US/Hear. Or to connect with a Cochlear Concierge call 800-483-3123 or email Concierge@Cochlear.com.



Cochlear®

Hear now. And always