



Information Central

CHARGE Syndrome Checklist: Health Supervision Across the Lifespan

Angela Arra-Robar, RN MSN

Presenter Information

Angela Arra-Robar is a Clinical Nurse Specialist with children with medical complexities at the IWK Health Centre in Halifax, Nova Scotia. Angela is a graduate of the University of Western Sydney (Australia) and Canyon College (USA) where she completed her Masters of Science in Nursing in 2006. Over the past twenty-one years, Angela has held a variety of nursing positions in both Canada and the United States. Most of her clinical experience has been in the specialty of medical-surgical nursing in both adult and pediatric settings. She has worked as a staff nurse, clinical instructor and nurse educator prior to her current role as a CNS.

Angela has worked with children with CHARGE syndrome in Atlantic Canada for the past 13 years. Together with Dr. Kim Blake, they run a monthly clinic specifically for children and youth with CHARGE in order to provide continuity in care and support youth and their families to be able to self-manage their healthcare. Angela's passion for teaching is evident through her collaboration with staff, patients and their families to share knowledge, build capacity and promote a truly family-centred care environment.

Presentation Abstract

A comprehensive approach to health screening and management for individuals with CHARGE syndrome is essential. We developed a checklist organized by body system and age to guide the healthcare provider in their approach to care. The checklist was evaluated using a modified Delphi method to develop a final consensus. We anticipate that these recommendations will promote improvements in care by preventing missed diagnoses, allowing for anticipatory counseling, and facilitating early referral for interventions and treatments.

CHARGE SYNDROME CHECKLIST: HEALTH SUPERVISION ACROSS THE LIFESPAN (FROM HEAD TO TOE)

**Shaded boxes indicate key assessment points*

		INFANCY (0-2 years)	CHILDHOOD (3-11 years)	ADOLESCENCE (12-17 years)	ADULTHOOD (18+ years)
GENETICS	Clinical diagnosis (Blake et al. or Verloes or Hale et al. criteria)				
	Genetic testing – Genetics consult (CHD7 analysis, array CGH)				
	Genetic counselling				
NEUROLOGY	CNS malformations/hypoplasia olfactory bulb/temporal bone (semi-circular canal) malformations – requires MRI/CT				
	Seizures – more common at older ages – consider EEG				
	Cranial nerve problems – monitor for absent sense of smell, facial nerve palsy, sensorineural hearing loss, vertigo, swallowing problems				
EYES, EARS, NOSE AND THROAT	Coloboma, risk of retinal detachment - Ophthalmology consult (dilated eye exam in infancy, vision assessments)				
	Corneal exposure – lubricating eye drops				
	Photophobia – tinted glasses, sunhat				
	Choanal atresia/cleft palate/tracheoesophageal fistula - ENT/Plastics consult				
	Audiometry and tympanometry, monitor for recurrent ear infections				
	Adaptive services for individuals with deafness/blindness				
	Cochlear implant assessment if applicable				
	Obstructive sleep apnea – monitor for tonsil/adenoid hypertrophy				
	Excessive secretions – consider Botox, medication				
	Dental issues – consider cleaning under anaesthetic				
CARDIOLOGY RESPIROLOGY	Cardiac malformations common – major/minor defects, vascular ring or arrhythmias possible (echocardiogram, chest x-ray, ECG) - Cardiology consult				
	Sinusitis, pneumonia, asthma - monitor				
	Anesthesia risk (difficult intubations/post-op airway obstruction/aspiration) – extensive pre-operative assessment, combine surgical procedures				
GASTROENTEROLOGY GENITOURINARY	Gastroesophageal reflux – Gastroenterology consult – consider motility agents with proton pump inhibitor				
	Poor suck/chew/swallow - feeding team assessment/intervention				
	Aspiration risk, tracheoesophageal fistula – swallowing studies				
	May need supplemental feeds – frequently requires gastrostomy tube or gastrojejunostomy tube				
	Constipation – consider Senna glycoside with polyethylene glycol				
	Renal anomalies – abdominal u/s +/- VCUG, blood pressure monitoring				
ENDOCRINOLOGY	Hypogonadotropic hypogonadism – LH, FSH by 3 months				
	Genital hypoplasia (if undescended testes - consider orchidopexy)				
	Delayed puberty – Endocrinology consult - gonadotropin levels, HRT				
	Osteoporosis – DEXA scan				
	Poor growth – Endocrinology consult – GH stimulation test, GH therapy				
	Obesity - monitor				
	Fertility and contraception - discuss				
IMMUNE SYSTEM	Note presence of thymus at open heart surgery				
	Routine immunizations/antibody titres to immunizations in adolescence				
	Recurrent infections – Immunology consult				
MSK	Scoliosis/kyphosis- monitor				
	Mobility (affected by ataxia, hypotonia) - evaluate				
PSYCHOLOGY DEVELOPMENTAL	Assess gross and fine motor skills – Occupational Therapy, Physiotherapy				
	Communication, language, writing abilities – Speech Language Therapy				
	Consider deaf-blind consultant				
	Prepare for transitions to school, situations, places, systems				
	Psychoeducational assessment, Individualized Education Plan				
	Sleep disturbances – consider melatonin				
	Behavior management – self-regulation, impulse control, anxiety, obsessions, compulsions, anger				
	Toileting skills - support				
	Life skills/adaptive behaviour/social skills/social play				
	Address sexuality				
	Family stress – offer supports and resources				
	Medical self-management – work on managing medications, understanding conditions, seeing healthcare provider independently				

CHARGE SYNDROME CHECKLIST: HEALTH SUPERVISION ACROSS THE LIFESPAN (FROM HEAD TO TOE)

Abbreviations Used in Checklist

CGH - comparative genomic hybridization
CNS - central nervous system
CT - computed tomography
DEXA scan - dual energy X-ray absorptiometry
EEG - electroencephalogram
ENT - ear, nose and throat

FSH - follicle stimulating hormone
GH - growth hormone
HRT - hormone replacement therapy
LH - luteinizing hormone
MRI - magnetic resonance imaging
MSK - musculoskeletal
U/S - ultrasound
VCUG - voiding cystourethrogram

Resources

- ☐ The CHARGE Syndrome Foundation (<http://chargesyndrome.org/about-charge.asp>)
- ☐ The CHARGE Informational Pack for Practitioners (SENSE UK) (<https://www.sense.org.uk/content/charge-information-pack-practitioners>)
- ☐ Book - CHARGE Syndrome (Genetics and Communication Disorders), 1st ed. Hartshorne TS, Hefner M, Davenport S, Thelin J. 2011
- ☐ OMIM Entry #214800 CHARGE Syndrome (<http://www.omim.org/entry/214800>)
- ☐ CHARGE Syndrome International Conference
- ☐ CHARGE Syndrome Listserv
- ☐ CHARGE Syndrome Facebook Group
- ☐ Perkins School for the Blind e-learning (<http://www.perkinselearning.org/videos>)
- ☐ Deafblind International (<http://www.deafblindinternational.org/index.htm>)
- ☐ Open hands, open access: deaf-blind intervener learning modules (<http://moodle.nationaldb.org>)

Key General References

1. Blake K, Prasad C. 2006. CHARGE syndrome. Orphanet J Rare Dis 1: 34
2. Brown D. 2005. CHARGE syndrome “behaviors”: challenges or adaptations? Am J Med Genet Part A 133A: 268-272
3. Hsu P, Ma A, Wilson M, Williams G, Curotta J, Munns CF, Mehr S. 2014. CHARGE syndrome: a review. J Pediatr Child Health 50: 504-511



Information Central

Parents' Perspectives: Types and Purposes of Communication Used by Their Children Who Have CHARGE Syndrome

Susan M. Bashinski, Ed.D.

Presenter Information

Susan M. Bashinski has 40 years experience with learners who experience multiple disabilities. She has directed numerous federal and state grants in low-incidence disabilities and deaf-blindness, including: personnel preparation, field-initiated research, model in-service training, and assistive technology. Dr. Bashinski has extensive experience in providing professional development and technical assistance nationally and internationally, particularly in the areas of augmentative and nonsymbolic communication for learners who have low-incidence disabilities, including deaf-blindness and CHARGE syndrome. Her research interests and areas of expertise include early communication and language development, augmentative communication, and cochlear implants, with numerous publications and presentations related to these topics. Dr. Bashinski authored the chapter on assessment of prelinguistic communication for the Hartshorne, Hefner, Davenport, and Thelin 2011 book, CHARGE. She has given both paper and platform presentations at the 2009, 2011, and 2015 CHARGE Conferences.

Presentation Abstract

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



Information Central

The Third Wheel in Marriage

Joan Borton and Jerry Borton

Presenter Information

Joan grew up with friends affected by disabilities from her earliest memories. She has worked in residential care, personal care and community and faith based outreach programs with those affected by physical, intellectual and developmental disabilities. For the last 21 years she has been married to Jerry who was born with a physical disability. Combining her own experiences in marriage and her relationships with many families affected by disability Joan has developed a passion for growing strong marriages in families affected by disability.

Currently Joan lives in suburban Philadelphia with her husband Jerry. She serves on the board of an urban community center in the city of Philadelphia. She is a writer and speaker. You can read her ponderings at www.joaborton.com

Presentation Abstract

Most people marry vowing to love in sickness or health, better or worse; rarely expecting to test that vow. Neither did most of us expect the entrée of disability into our family. Rarely do we consider how disability impacts our marriages. Disability (in a child or spouse) often becomes the largely ignored third wheel in marriage. Learn to identify ways this third wheel impacts your marriage and gain practical tips to recharge your marriage and family.

The Third Wheel in Marriage

Jerry Borton, MS jerryborton@gmail.com

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Most people marry vowing to love in sickness or health, and better or worse; rarely expecting to test that vow. Neither did most of us expect the entrée of disability into our family. Even if we did, rarely do we consider how disability impacts our marriages. Disability (in a child or spouse) often becomes the largely ignored third wheel in marriage.

Identifying the Impact:

1) Becoming a Family affected by disability by choice.

Examples of this include marrying a spouse you know has a disability, marrying someone who has a child with a disability, adopting a child with a known disability.

While this couple knowingly enters into marriage with disability, seemingly with “eyes wide open” the full understanding of the daily relentlessness of disability on the marriage and family is often not realized until further down the road.

2) Becoming a Family affected by disability by surprise

Occurring when a child is born with a disability, a child or spouse encounters an illness or injury that leaves them with a disability, or the process of aging may create an unexpected disability.

Both ways of engaging in family life and marriage affected by disability can bring about a wide variety of impact to each member of the family. Among the couple, experiences may include:

- “Super Hero Complex - I can fix this; they can’t make it without me
- Blame Game - Why did this happen to me/you/us? What did I/you/we do wrong?
- Out of focus care – life revolves around the special needs, ignoring self care, no time or energy left for spouse, rest of the family takes a back seat, exhaustion rules
- Divided parenting - one spouse becomes the parent to the child with a disability leaving the other to parent the typical children.
- Woe is Me – allowing pity (from yourself or others) to reign because your life is so hard
- I’m trapped – resenting spouse because they get out of the house to go to work, and you are living the martyr role
- Increased character - built in each member of the family as they work and live together with some sense of balance.
- Marriage either grows from working together, or falls apart from stress

Why Prioritize Marriage

1) Marriage is foundational to the family and community

Many faith based communities put a strong focus on marriage as the basis for family life. Here are some brief examples from three world religions:

The Third Wheel in Marriage

Christianity – The Bible in Genesis 2:18-25 says, Then the Lord God said, “It is not good that the man should be alone; I will make him a helper fit for him . . . So the Lord God caused a deep sleep to fall upon the man, and while he slept took one of his ribs and closed up its place with flesh. And the rib that the Lord God had taken from the man he made into a woman and brought her to the man. Then the man said, “This at last is bone of my bones and flesh of my flesh; she shall be called Woman, because she was taken out of Man.” Therefore a man shall leave his father and his mother and hold fast to his wife, and they shall become one flesh. And the man and his wife were both naked and were not ashamed.

Pastor John Piper notes: “The most foundational thing to see from the Bible about marriage is that it is God’s doing. And the most ultimate thing to see from the Bible about marriage is that it is for God’s glory. (<http://www.desiringgod.org/messages/staying-married-is-not-about-staying-in-love-part-1> viewed 5/16/17)

Judaism – According to Jewish tradition, the very first recorded marriage was that between Adam and Eve. A great deal of Jewish thought on the significance of marriage takes its cue from this original union. Traditional Biblical interpretation understands the story of Adam as teaching us that human beings are not designed to live alone. Adam was not flourishing in his solitary life, and so God created a partner for him. As Genesis describes it: “It is not good for a person to be lonely”. Marriage is the religiously sanctified state by which our loneliness is alleviated, through which we are supported, and learn to provide support, and without which we cannot live a well-rounded and complete life. It is not merely a social convention or a financial convenience - as we see from the story of Adam, it is essential to our very nature. Thus, the Talmud teaches that it is only through marriage that one becomes a complete person, that it is the ideal state for a person. (http://www.ketubah.com/templates/template28_article.cfm?article=21 Viewed 5/16/17)

Islam - The Holy Quran says, “And marry those among you who are single and those who are fit among your male slaves and your female slaves; if they are needy, Allah will make them free from want out of His grace; and Allah is Ample-giving, Knowing.” (Surah an-Nur, 24:32) The above *ayat* begins with the words *Wa Ankehoo (And marry...)*. The imperative form of the word ‘*nikah*’ implies that either it is obligatory or highly recommended. (Marriage and Morals in Islam, Sayyid Muhammad Rizvi) According to scholars, though marriage is a highly recommended act, it becomes obligatory when there is a chance of falling into sin. (Viewed 5/16/17 on https://www.al-islam.org/islamic-marriage-syed-athar-husain-sh-rizvi/importance-marriage-islam#f_c298e775_1)

Lest one think that only faith based communities hold marriage in high regard consider these words:

“ . . . this belief about the importance of marriage did not only come from the Catholic Church, for it was held even by pagans for centuries before the time of Christ. As Cicero writes in *De Officiis* (On Duties), “The first fellowship exists within marriage itself, and the next with one’s children. . . Indeed, that is the principle of a city and the seed-bed, as it were, of a political community” (54).” Vrom Veronica Arntz published 2/2/206 at <http://truthandcharityforum.org/marriage-and-family-the-fundamental-unit-of-society/>

We welcome your questions, comments and feedback
Jerry Borton, MS jerryborton@gmail.com Joan Borton jjborton@gmail.com

The Third Wheel in Marriage

Marriages benefit society by building and strengthening human relationships within the home (among spouses and children) and beyond (involving relatives, neighbors, and communities). For this reason, the family has long been understood as the fundamental unit of society, the foundation from which religious, civic, and legal organizations naturally develop and flourish. (accessed 5/12/17 at <http://www.usccb.org/issues-and-action/marriage-and-family/marriage/upload/USCCB-FLWY-How-Does-Society-Benefit-From-Strong-Marriages.pdf>)

2) Strength in Numbers

Life, with or without marriage or disability, is hard. Sharing life with another provides strength and companionship for the journey.

King Solomon, referred to as the wisest man who ever lived wrote “Two people are better off than one, for they can help each other succeed. If one person falls, the other can reach out and help. But someone who falls alone is in real trouble.” (Ecclesiastes 4:9-10)

3) Set an Example

Your children watch and learn from you. Your neighbors observe. Investing time in your marriage will lay a foundation for others to follow.

4) Post Traumatic Growth

Your marriage can grow stronger as you walk the path of life affected by disability. There is light and hope at the end of the tunnel if you choose to embrace it.

Consider the following from: <http://www.success.com/article/3-inspirational-stories-of-post-traumatic-growth> (viewed 5/18/17):

Post-traumatic growth as defined by Richard G. Tedeschi and Lawrence G. Calhoun, the University of North Carolina, Charlotte, researchers who coined the term, is “*a positive change experienced as a result of the struggle with a major life crisis or a traumatic event.*” (*italics added*)

Post-traumatic growth doesn’t happen *instead* of post-traumatic stress. It doesn’t make trauma any less traumatic; Tedeschi and Calhoun don’t suggest that trauma is a positive life event. And the road from trauma to growth is hardly a straight line. “It’s not a simple process. We’re not being Pollyannas about it,” Tedeschi says. “Post-traumatic growth doesn’t muscle PTSD aside; PTSD can continue. What post-traumatic growth can do is make some of the symptoms more tolerable, and the person who is expressing these symptoms tends to realize that this is not the whole story.”

Tips to Refresh and Prioritize your Marriage

- ♥ Remember *why* you fell in love. Think back to what drew you to your spouse initially – tell them and look for opportunities to highlight that characteristic and others day to day.

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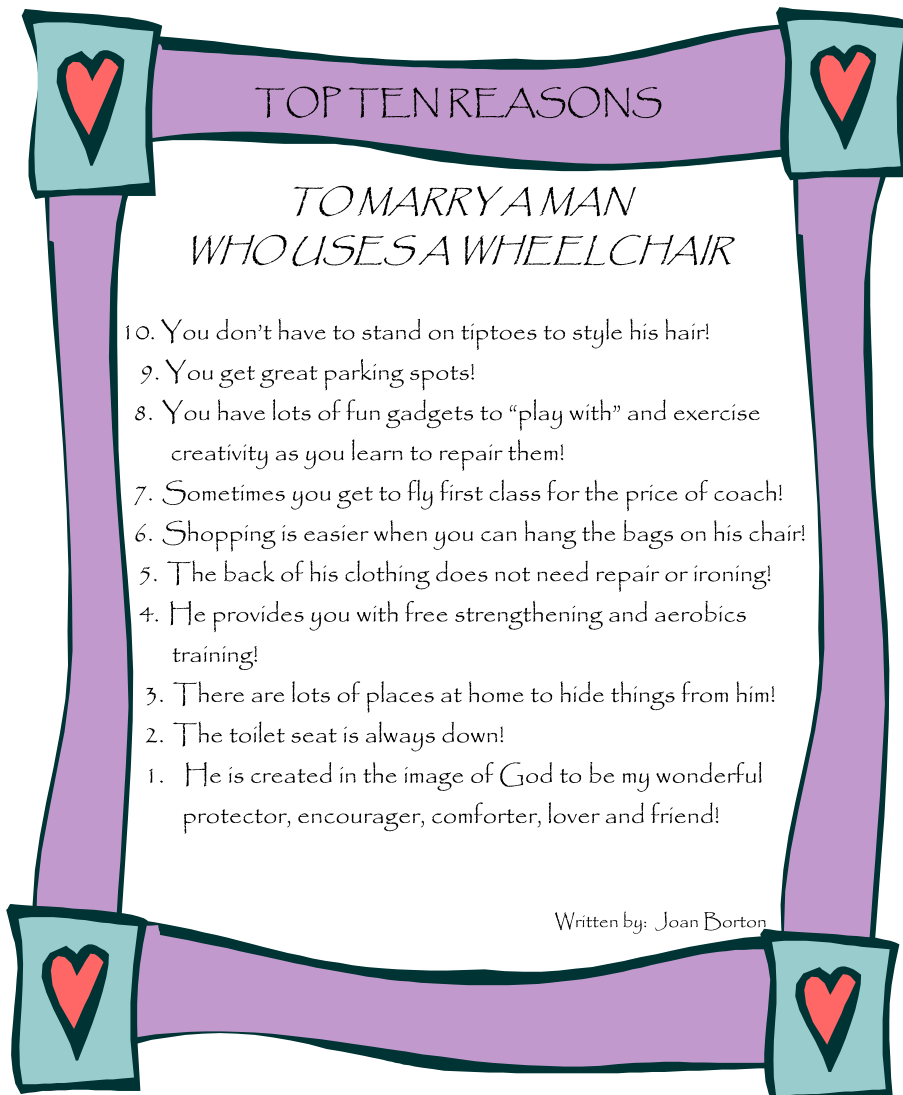
The Third Wheel in Marriage

- ♥ Celebrate your marriage, not just once a year – but at least monthly. Consider celebrating your “Monthiversary.” That is the day of the month you were married. Example – if you were married on September 25 you celebrate your marriage the 25th of every month. This helps you remember what most call “one of the happiest days” of their lives, and shows the rest of the family that this relationship is important. It may take the form of simply identifying the date and sharing an extra-long kiss or hug, perhaps you make it a date night, or reread your marriage vows to one another each month.
- ♥ Is the idea of a Date Night too stressful? Think instead about a date hour, or a date 15 minutes. The amount of time is not as important as spending time together not talking about the kids.
- ♥ If you are part of a faith community check out marriage enrichment resources they have available to you.
- ♥ Kiss for 10 seconds. Every one of us can find 10 seconds in our schedule. If you make a practice of extending your kisses for 10 seconds you’ll likely be pleasantly surprised at the results.
- ♥ Change your expectations. None of us are going to have a marriage or family life like we see on the big screen. Don’t set yourself up for failure. Put the effort into your marriage in a way that works for your family.
- ♥ Keep short accounts, if you need to discuss something plan a time - don’t go to bed angry or stewing. And don’t talk about your spouse’s shortcomings with your children!
- ♥ Treat your spouse as your spouse, not as another person for you to parent. We were told early in marriage – “remember you can’t make love to your mother/father/child.”
- ♥ Make a commitment to yourself that for one day, week, month (your choice) you will not make a negative comment to or about your spouse. Build on each victory.
- ♥ Acknowledge that both disability and marriage are hard. Face it, but do it together.
- ♥ If you have fallen into the practice of divided parenting (one spouse focused on the person with disability, the other spouse on the typical members), agree to switch roles for a period. Give them the info they will need to succeed (don’t sabotage). You’ll each be encouraged by the time spent with others in your family, and gain an understanding for what the other does.
- ♥ Admit you can’t do it alone and ask for help. Be specific and then accept and thank that help. You may have to relax your standards a bit. It may be true that no one will care for your family member with a disability like you do; but if the care is safe and healthy for all involved, though different than how you would do it, let it be.
- ♥ It is ok to say no to your children sometimes so you can say yes to your spouse. They too need to learn that life is not all about them.
- ♥ Text a positive, loving message to your partner, not just telling them what “their child” did today or the challenge that awaits them at home.

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The Third Wheel in Marriage

- ♥ Exercise Grace (a disposition to show kindness or compassion (<https://www.merriam-webster.com/dictionary/grace>). Assume the best when your spouse says something that may sound otherwise to you.
- ♥ Keep a sense of humor. Sharing chuckles or laughter with your spouse, not laughing *at* them, but rather *with* them. For your enjoyment, here is our top ten list for marriage with a spouse with disability. What would be on the list you would write for the Top 10 reasons to marry your spouse?



***These ideas are shared for those in marriages who need some encouragement and refreshment. If you are in a marriage that is abusive or unsafe seek professional help for yourself and your family immediately.**

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What do I have today? Calendar Systems and Sensory Impairments

Shanti Brown and Timothy S. Hartshorne, Ph.D.

Presenter Information

Shanti Brown is a second year Ph.D. student in a School Psychology program. She is a part of the CHARGE Syndrome research at Central Michigan University. Her current research project is investigating the use of calendar systems as an anxiety intervention for children with multi-sensory impairments.

Presentation Abstract

A calendar system is a tool used to refer to and describe an activity by using objects, pictures, and/or other symbols to communicate a sequential process. This presentation will provide descriptions of several different types of calendar systems, including what they look like and how they are used. Calendar systems have been shown to benefit those who have sensory impairments in many ways by increasing communication, independence, security, and social development.



Information Central

Anxiety in CHARGE Syndrome

Shanti Brown and Timothy S. Hartshorne, Ph.D.

Presenter Information

Shanti Brown is a second year Ph.D. student in a School Psychology program. She is a part of the CHARGE Syndrome research at Central Michigan University. Her current research project is investigating the use of calendar systems as an anxiety intervention for children with multi-sensory impairments.

Presentation Abstract

Anxiety has been found to be a growing concern regarding individuals with CHARGE. This presentation is a synthesis of the current research on anxiety and related behaviors in CHARGE as well as its prevalence in and effect on the population as a whole. The current debate on Obsessive-Compulsive Disorder in individuals with CHARGE will be discussed, as well as the use of interventions aimed at lowering anxiety.



Information Central

Issues Surrounding Fertility and Sexual Function for Families or Individuals Affected by CHARGE Syndrome

R. Matthew Coward, MD FACS

Presenter Information

R. Matthew Coward, MD FACS is an Assistant Professor of Urology and Clinical Assistant Professor of Obstetrics and Gynecology at the UNC School of Medicine, and Director of Male Reproductive Medicine and Surgery at UNC Fertility in Raleigh, NC. He earned his MD with Distinction at UNC, followed by urology residency at UNC, and fellowship in Male Reproductive Medicine and Surgery at Baylor. Dr. Coward's clinical practice focuses in the areas of male reproduction and fertility as well as male sexual dysfunction.

Dr. Coward's second of three children, Ryan, is a 4-year-old who has CHARGE syndrome, a loving little boy who had a congenital heart defect with truncus arteriosus and an interrupted aortic arch, he has a tracheostomy, he feeds through a g-tube, he has a significant balance disorder but is learning to walk, and he has visual deficits and is completely deaf having failed a cochlear implant. He attends preschool, is learning sign language, and enjoys playing with his brother and sister, watching TV, and using his iPad.

Presentation Abstract

Individuals with CHARGE can have numerous difficulties with reproduction and sexual function, in addition to the effects resulting from having multiple severe chronic medical conditions. These issues arise from anatomical abnormalities, hormone deficiencies, and side effects from unrelated problems due to CHARGE. There are many options for individuals with CHARGE to have a family regardless of his or her own reproductive potential. The goal of this session is to understand the sexual and reproductive limitations facing an individual with CHARGE, and how these problems can be assessed and treated.



Information Central

Communication Portfolios: Giving a Voice to Children with Complex Communication Needs

Carol Darrah, M.S. and Christine Spratling, Ed.S

Presenter Information

Carol Darrah is the Early Childhood Coordinator for the Georgia Sensory Assistance Project, which supports children and youth with combined vision and hearing loss. Carol focuses her efforts on early identification and referral, supporting families and early intervention providers, and assisting with transition from early intervention to school services. She earned her Bachelor's and Master's degrees in Child and Family Development from the University of Georgia and has worked in the field of Early Intervention for more than 18 years.

Presentation Abstract

Learn how families and professionals collaborate to create a Communication Portfolio- an easily-used notebook that depicts the child's unique ways of communicating. The Communication Portfolio supports children as they enter new learning settings, participate in community activities, meet new service providers, and interact with family members and friends. It helps others understand and respond to the child's communication more readily and easily and also promotes the consistency of communication strategies used in various settings.

Communication Portfolios

giving a voice to children
with complex communication needs



Abigail's Communication Portfolio

Hi! My name is Abigail. I hope you will use this book to communicate with me.



There are 3 parts to my portfolio. First, there are some tips for communicating with me, and then there is a list of the messages I can give you and pictures of how I communicate it. Finally, there is a list of messages you can communicate to me.

What is a Communication Portfolio?

a portable, easily-accessible notebook that includes photos and descriptions of the child's unique expressive and receptive communication messages

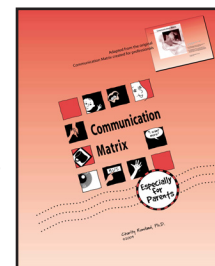
**Every child CAN, WANTS to,
and has the RIGHT to communicate!**

Why make a Communication Portfolio?

- Children with complex communication needs may use unconventional ways to express themselves, and unfamiliar people may have a hard time understanding the child's communication attempts.
- Families are the best source of information about their child's communication skills, and their knowledge should be shared with everyone who interacts with their child.

Families and Professionals Collaborate to Create a Communication Portfolio

- Complete the Communication Matrix or another communication assessment.
- Take or gather pictures of the child using his or her communication skills.
- Organize the information and pictures into the notebook using a template.



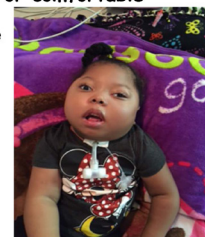
Tips for interacting with me

- ❖ **Greeting:** I am very friendly and like to meet new people. I am learning how to say Hello and Bye-Bye during greeting and leaving routines.
- ❖ **Hearing:** I do not hear with my Left ear, and I have a severe hearing impairment in my Right ear. I wear a hearing aid in my Right ear, and I can hear best on that side. I like to wear my hearing aid; please put it back on my ear if it comes off.
- ❖ **Vision:** I have a significant vision impairment, but I am learning how to use my vision to play and move around. I bring objects close to my Right eye to inspect them. I see simple objects and pictures best with a contrasting background.
- ❖ **Response Time:** I sometimes need extra time (up to 5 seconds) to respond to your question, imitate an action or sound, or follow directions that you've given. Please be patient with me.



"I am content, happy, or comfortable"

I will let you know with my face and body. I will be relaxed when I am comfortable, and will be more attentive to your interactions. I may smile or thrust out my tongue- "licking my tongue". Sometimes I will blink my eyes when people I like talk to me.



Using the Communication Portfolio

- Educators, service providers, family members, and friends use the Communication Portfolio to learn about the child's unique communication skills, so that they are able to understand and respond to the child's communication more readily and easily.
- The Communication Portfolio promotes consistency of communication strategies as children enter new learning settings, participate in community activities, meet new service providers, and interact with family members and friends.
- The Communication Portfolio is updated as the child gains new skills.

Miles, B. (1999). What is communication? In B. Miles & M. Riggio (Eds.), *Remarkable conversations: A guide to developing communication with children and young adults who are deafblind* (pp. 8-19). Watertown, MA: Perkins School for the Blind.

Rowland, C. (2004). Communication Matrix. Portland, OR: Oregon Health & Science University, Design to Learn. www.communicationmatrix.org

Communication is Connection

(Miles, 1999)

"Pay attention to me!"



I may use my most active body movements and grunt vocalizations to get your attention.

When you are busy and I *really* want your attention, I may use gagging behaviors.

I'm learning to use more positive ways to get attention. Preparing me for some "alone" or "wait" time can help me, like giving me a toy, talking to me, or playing music.

"I feel overwhelmed"

I put my hands over my eyes like this to let you know that I am feeling shy or overwhelmed, that I don't understand what you're saying to me, or that I would like for you to leave me alone.



Families and practitioners share their experiences...

- A parent explains that the Communication Portfolio "has helped our transition into the school system... because a lot of times, people don't quite understand why our kids do what they do or what it means."
- A parent uses the Communication Portfolio to help others "get to know and understand" her daughter and to "know what to do and what not to do" with her.
- "I saw [the parent] be involved and feel validated...to me that was worth it all in itself," relates an early intervention service provider who supported a family during transition.
- "It was extremely helpful for us during diagnostics to understand, prior to meeting her and prior to evaluating her, what we were looking for in terms of communication and how she was responding..." shares a member of the educational team.
- "It was really nice to pull out [the Communication Portfolio] in the session and know immediately what to do with her," relates a speech-language pathologist.
- A parent explains the benefit of the small Communication Portfolio notebook, "she has a bag on the back of her wheelchair, so she takes the actual notebook with her to school...because, of course, the paperwork and files are kept in the office, but she has a copy physically with her."



"I am unsure of that" or "I don't like that texture"



I make this face when I am unsure of a new situation.

If you push me to feel a texture or taste a food with a new texture, I will cough and then my tummy will get sick.

Please read my expressions carefully ☺

"It's time to do this..."

It is really nice if you will let me know what is about to happen to me so that I can learn the names or object symbols for some of my routines. My family gives me a combination of auditory, visual, and tactile cues during our routines.

Here are some routines that I'm learning...

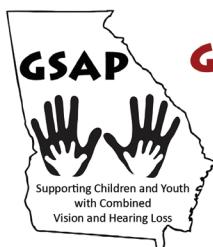
Activity	Words you can use	Cues that you can use
Diaper	Time for your diaper	Let me see and feel the clean diaper, tap my bottom.
Tasting food	Time to taste food	Let me smell the food, let me see and touch the spoon, and help me make the sign for "eat."
Reading	Time to read a book	Let me see and touch the book, help me make the sign for "book."
Sit up / pick up	Time to sit up / get up	Clap your hands and make an upward motion that I can see. Move my arms up before picking me up or pulling me to sitting.
Stander	Time to go in the stander	Let me see the stander, tap my feet.
Glasses	Time to put your glasses on	Let me see and feel the glasses, tap my forehead (just above my eyes) before putting them on.



College of Education

Department of Communication
Sciences and Special Education

UNIVERSITY OF GEORGIA



GEORGIA
SENSORY
ASSISTANCE
PROJECT

For information:

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Office of Special Education Programs
U.S. Department of Education

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1. Carol Darrah, M.S.
2. Georgia Sensory Assistance Project
3. 570 Aderhold Hall, UGA, Athens, GA 30602-7152
cdarrah@uga.edu
(706) 542-2433
4. Carol Darrah is the Early Childhood Coordinator for the Georgia Sensory Assistance Project, which supports children and youth with combined vision and hearing loss. Carol focuses her efforts on early identification and referral, supporting families and early intervention providers, and assisting with transition from early intervention to school services. She earned her Bachelor's and Master's degrees in Child and Family Development from the University of Georgia and has worked in the field of Early Intervention for more than 18 years.
5. No
6. Poster Session
7. Educational Issues
8. Families with young children; families whose children have complex communication needs; professionals in early intervention or special education; family engagement coordinators
9. Communication Portfolios: Giving a Voice to Children with Complex Communication Needs
10. Christine Spratling, Ed.S, Technical Assistance Specialist, Georgia Sensory Assistance Project
11. Learn how families and professionals collaborate to create a Communication Portfolio- an easily-used notebook that depicts the child's unique ways of communicating. The Communication Portfolio supports children as they enter new learning settings, participate in community activities, meet new service providers, and interact with family members and friends. It helps others understand and respond to the child's communication more readily and easily and also promotes the consistency of communication strategies used in various settings.
12. This session will highlight the creation and use of a Communication Portfolio to support children with complex communication needs. Communication is

connection, and it is through these connections that children learn and develop (Miles & Riggio, 1999). Children with multiple or significant disabilities, including combined vision and hearing loss, often face challenges in developing communication. They often have unique ways of communicating their wants, needs, and preferences, including facial expressions, body movements, vocalizations, or sign approximations, and unfamiliar people are likely to have difficulty in understanding the child's attempts to communicate (DeCaluwe, McLetchie, Peters, Luiselli, & Mason, 2005). Families are a rich source of information about their child's unique communication skills, and it is essential to share this information with others who interact with the child.

Families and professionals collaborate to create a Communication Portfolio. First, we complete a communication assessment to gather information. We like to use the Communication Matrix (Rowland, 2004), an assessment for early communicators; however, you can use another preferred assessment tool. Next, we gather and/or take pictures of the child using his/her communication skills. Then, we organize the information into a portable notebook, which makes it easily-accessible for everyday use.

Educators, service providers, family members, and friends can use the Communication Portfolio to learn about the child's unique communication skills, so that they are able to understand and respond to the child's communication more readily and easily. The Communication Portfolio supports children as they enter new learning settings, participate in community activities, meet new service providers, and interact with family members and friends. Additionally, using the Communication Portfolio promotes consistency of communication strategies across people and settings.

This session will be organized with an interactive PowerPoint presentation, hand-on activities, and video clips.

13. Learning Objectives:

- Participants will review the process of organizing assessment information and pictures to create a Communication Portfolio;
- Participants will examine strategies for sharing and using the Communication Portfolio with family members, educators, and related service providers.

- Participants will identify benefits of using the Communication Portfolio in home, school, and community settings to enhance children's participation in activities.

References

- DeCaluwe, S.M., McLetchie, B.A., Peters, M.H., Luiselli, T.E., & Mason, B. (2005) Communication and connecting with learners who are deafblind. Developing communication portfolios (books and videos). Watertown, MA: New England Center Deafblind Project.
- Miles, B., & Riggio, M. (1999). Remarkable conversations. A guide to developing meaningful conversations with children and young adults who are deafblind. Watertown, MA: Perkins School for the Blind.
- Rowland, C. (2004). Communication matrix. Portland, OR: Oregon Health & Science University, Design to Learn.



Information Central

Neurological issues in CHARGE syndrome: our experiences so far

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

Presenter Information

Christa de Geus is a medical doctor in training to become a clinical geneticist. Within clinical genetics she has a particular interest in neurology and neuroradiology.

In 2014 she joined the research group of prof. Conny van Ravenswaaij as a PhD student. Her PhD focuses on neurological symptoms in CHARGE syndrome.

Conny van Ravenswaaij is a clinical geneticist with a long-lasting experience in genetic and clinical studies on CHARGE syndrome. Since her group discovered CHD7, the gene responsible for CHARGE syndrome, in 2004, she coordinates a multidisciplinary clinic and supervised several PhD research projects dedicated to the syndrome. Her research is mostly based on questions raised by the parents and often results in clinical guidelines. Thus far she has published over 30 papers and four book chapters on CHARGE syndrome.

Presentation Abstract

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

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



Information Central

Growth in CHARGE syndrome

Dieuwerke Dijk, MD

Presenter Information

Dieuwerke Dijk is a resident in training to become a physician for people with intellectual disability. Apart from her clinical work at a health care centre for people with intellectual disability, she participates in the CHARGE research at the University Medical Centre Groningen. Scope of her research is growth in CHARGE syndrome.

Presentation Abstract

Growth is a strong indicator of the well-being of children. Although growth retardation is one of the main characteristics of CHARGE syndrome, at present little is known about normal growth in children with CHARGE syndrome. We want to find out more about normal growth in CHARGE syndrome by making growth charts and assessing body proportions in children with CHARGE syndrome.



Information Central

Dissecting the causes of frontal cortex abnormalities in a mouse model for CHARGE syndrome

Alex P A Donovan

Presenter Information

Alex Donovan is a first-year PhD student at King's college London studying the developmental origins of executive functioning deficits in CHARGE syndrome. Alex has a neuroscience bachelor's degree from KCL, and is now working under Dr. Albert Basson, focusing on the role of the chromatin remodeling factor CHD7 in the development of the frontal cortex, and the consequence of its disruption in CHARGE syndrome.

Presentation Abstract

Many individuals with CHARGE syndrome have been reported to have deficits in executive functioning, often associated with a diagnosis of an autism spectrum disorder. The neurodevelopmental and neuroanatomical underpinnings of these deficits are not yet known. However, functional studies have identified the prefrontal cortex as the primary brain region governing executive functions. I report studies on a Chd7^{+/-} mouse model to investigate the impact of Chd7 heterozygosity on the development and function of the frontal cortex.



Information Central

CHARGE Syndrome and the IEP: What do parents think?

Whitney Driskell, Liddie McPhail, Hailey Ripple, Tierra Kilbert, Kasee Stratton

Presenter Information

Whitney Driskell is a graduate student at Mississippi State University in the School Psychology Program. Whitney has been a member of the Bulldog CHARGE Syndrome Research Lab at Mississippi State University since January of 2015. Under the advisement of Dr. Kasee Stratton, Whitney serves on the IEP research team. Whitney plans to attend internship and graduate from the school psychology program where she hopes to gain employment in a public school setting and become an advocate for individuals with low incidence disabilities.

Presentation Abstract

Limited research has been conducted on educational accommodations in CHARGE. Additionally, parents have frequently expressed frustration with navigating their child's Individualized Education Plan (IEP). This study aimed to identify parental 1) perceptions of the IEP process, 2) understanding of their child's goals and accommodations and 3) satisfaction with the IEP and the IEP team. The researchers will present their research and how this investigation will advance future educational research.



Information Central

The Able Act: EnABLE Savings for Life

Mary Anne Ehlert

Presenter Information

Mary Anne Ehlert, CFP®, is a financial professional and sister to an individual with disabilities. She is highly regarded as a specialist in working with families of individuals with disabilities and the elderly and speaks to conferences and television audiences on financial planning. Mary Anne's journey began in senior management positions within the banking industry, including Deutsche Credit Corp, Heller Financial and Citicorp. For over 20 years she was a leader in the corporate world leaving in 1990 to create Ehlert Financial Group, a business driven to assist individuals and families develop both short and long term financial strategies to help them find peace of mind. Over the years, she found that many individuals and families were receiving transactional advice, rather than overall planning, and thus she set about to become a true personal advisor to her clients. The mission to become that needed resource to her clients has driven the overall purpose and strategy of the firm. In addition, she also found herself focusing on families like her own, families of individuals with special needs. Her sister, Marcia, helped her understand that families with special needs must plan differently. Since that time, she has focused a division of her practice on working with these families.

Presentation Abstract

The presentation will be uplifting and educational, as well as provide a good basic understanding of some important facts. Mary Anne Ehlert will tell you all you need to know about the Able Act...The Able Act which amends section 529 of the IRS Code and allows for Tax Free savings and investment accounts for individuals with disabilities. If you are ready to save tax free for expenses for your loved one with a disability, without losing government benefits, then attend this seminar!



Information Central

CHARGE Syndrome in Brazil

Debora Ferreira and Timothy S. Hartshorne, Ph.D.

Presenter Information

Debora Ferreira is a senior at Central Michigan University who work in the CHARGE Syndrome Research Lab. As a dual citizen with Brazil, she is interested in how to support individuals with CHARGE in that country.

Presentation Abstract

This poster is based on information from parents and professionals in Brazil who have a connection to someone with CHARGE syndrome. They are working to learn more and make others aware of this diverse syndrome. Not only do they want to raise awareness and support each other, they are working towards getting more professionals to understand CHARGE so they can better the lives of the ones they know with this syndrome.



Information Central

You Asked, We Listened: What's missing on the IEP for students with CHARGE?

Matthew Ferrigno

Presenter Information

Matthew Ferrigno is a first year School Psychology doctoral student at Mississippi State University. He joined the Bulldog CHARGE Syndrome Research Lab at Mississippi State University in the fall of 2016. Matthew has been assisting a research team examining individualized education plans (IEP) for students with CHARGE. Due to the lack of specific accommodations and outlines for IEP's, Matthew plans to promote a better understanding of what needs to be placed on an IEP.

Presentation Abstract

Parents often face many complications obtaining special education services and developing IEPs for their children with CHARGE. The Texas Deafblind Outreach has developed a set of IEP quality indicators. Quality indicators not only serve as a guide for those developing IEPs, but they also increase the likelihood of appropriate provision of services. This study will review how IEPs for students with CHARGE compare to the quality indicators provided by the Texas Deafblind Outreach.



Information Central

Radiological Imaging Findings in CHARGE Syndrome

**Lauren Fogarty, MD Candidate 2020,
Kim Blake MD, Pierre Schmit MD**

Presenter Information

Lauren is a first year medical student at Dalhousie University. She is working with Dr. Kim Blake and Dr. Pierre Schmit researching radiological imaging in children with CHARGE syndrome at the IWK Health Centre in Halifax, Nova Scotia. Prior to beginning her medical degree, Lauren completed her MSc studying molecular signaling throughout neural development.

Presentation Abstract

Individuals with CHARGE Syndrome often have complex medical needs requiring multiple radiological investigations from birth through to adulthood. CHARGE characteristics affect multiple organ systems and can vary significantly from one individual to another. Here, we have reviewed the literature and outlined common imaging findings in children with CHARGE syndrome integrating cases from the IWK Health Centre to illustrate these findings.



Information Central

Variables that Impact Walking in Individuals with CHARGE Syndrome

Dr. Elizabeth (Beth) Foster, CAPE

Presenter Information

Dr. Beth Foster is a Certified Adapted Physical Educator. She worked as an Elementary Adapted Physical Educator in Pennsylvania for 6 years then was an APE consultant in Texas for 4 years. During her time teaching in Pennsylvania, Beth was named the 2012 adapted physical education teacher of the year. Beth has been involved in Camp Abilities, a developmental sports camp for individuals who are blind, visually impaired, or deafblind for the past 12 years. She is currently the assistant director for Camp Abilities in Pennsylvania and Texas. From her experience at Camp Abilities, she developed a passion and determination to be knowledgeable within the field of deafblindness. Beth has presented on various topics about deafblindness across the U.S. She completed intervener training at the Minnesota Deafblind Project. Beth has been involved with the Texas Chargers for the past 3 years providing physical activities for individuals with CHARGE Syndrome at their annual retreat and has directed the Camp Abilities at the past two International CHARGE Conferences. Beth received her PhD in May 2016 by completing research related to children with CHARGE Syndrome and walking. Currently Dr. Foster is an assistant professor at Cal Poly Pomona in California in adapted physical education.

Presentation Abstract

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



Information Central

The Sensory Base of Unusual Behaviors in Children with CHARGE

Aaron Hartshorne and Timothy S. Hartshorne, Ph.D.

Presenter Information

Aaron Hartshorne is a first year student at Central Michigan University where he is a member of the CHARGE Syndrome Research Lab. He will be transferring to Alma College in the Fall. He is the sibling of a young adult with CHARGE syndrome.

Presentation Abstract

Children with CHARGE syndrome display an array of behaviors that some may consider problematic. However, many times these behaviors are sensory based in nature, and serve to help the child self-regulate and orient his or her body in space. This poster suggests the most probable sensory function of these behaviors.



Information Central

The Behavior Triangle for CHARGE Syndrome

Timothy S. Hartshorne, Ph.D.

Presenter Information

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

Presentation Abstract


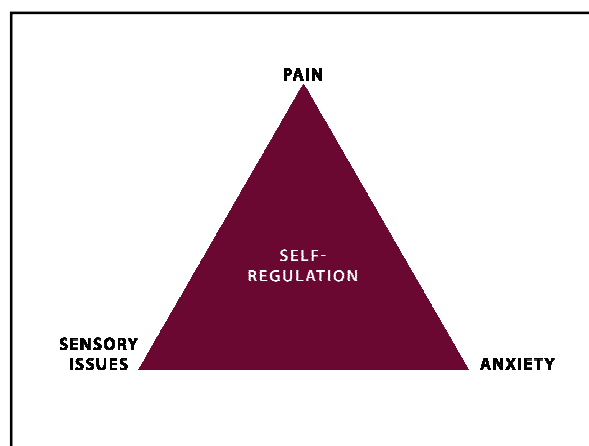
Having considered issues around challenging behavior in individuals with CHARGE for many years, I have come to the conclusion that the behavior has three primary sources: pain, sensory issues, and anxiety. This presentation will address what we know about each of these, and then discuss the development of self-regulation skills as a prime intervention.

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Understanding Behavior in CHARGE Syndrome

Timothy S. Hartshorne, Ph.D.
Central Michigan University

Sources of Pain in CHARGE

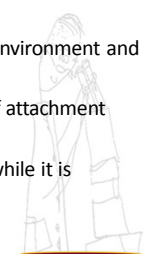
- Otitis Media¹
- Sinus infections
- Migraines¹
- Abdominal Migraines^{1,2}
- Gastroesophageal reflux disease (GERD)²
- Gas
- Constipation^{1,2}
- Muscle pain²
- Tactile defensiveness
- Stoma pain
- Oral pain/teeth
- Surgery¹



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Why pain is so important


- Can affect normal brain and neurological development
- Can affect sleep
- Can interfere with exploration of the environment and learning
- Can interfere with the development of attachment and trust
- Once tolerated may be ignored even while it is affecting health and behavior
- Is communicated through behavior



CHARGE
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Sensory Issues

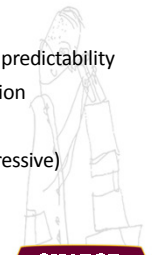
- Hearing – sensorineural hearing loss
- Vision – coloboma
- Smell – anosmia
- Taste – prefer strong tastes
- Tactile – defensiveness
- Vestibular – balance issues
- Proprioceptive – awkwardness
- The loss of each sensory system multiplies the impact on the child and the child's development



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Sensory Processing Disorder

- Missing, partial, distorted, fragmented information
- Over-sensitivity or Under-sensitivity
- Processing time may be longer
- Confusion & the need for consistency & predictability
- Idiosyncratic behaviors & misinterpretation
- Movement and postural differences
- Communication issues (receptive & expressive)
- Developmental delay
- Fatigue



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Anxiety

- “A feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome.”



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- *Pessimism and negative thinking patterns
- *Anger, aggression, restlessness, irritability, tantrums, defiance
- *Constant worry about things that might happen or have happened
- *Crying
- *Physical complaints such as stomachaches, headaches, fatigue
- *Avoidance behaviors
- *Sleeping difficulties
- *Perfectionism
- *Excessive clinginess and separation anxiety
- *Procrastination
- *Poor memory and concentration
- *Withdrawal from activities and family interactions
- *Eating disturbances

<http://www.kathyeugster.com/articles/article004.htm>

Self-Regulation

The primarily voluntary regulation of cognition, behavior, emotion and physiological states for the purpose of goal-directed actions

But it needs to be developed and learned

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Self-regulation of pain

- Pain anxiety and pain catastrophizing
- Tension, distress, nervousness, irritability
- The role of stress
- Changing one's thoughts and expectations
- Meditation
- Distraction

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This is self-regulation of sensory systems



HOW?

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Help with self-regulation

- Making life more regulated
 - Routine
 - Predictability



Thanks to my Lab

- Megan Schmittel
- Bree Kaufman
- Shanti Madhavan-Brown
- Shelby Muhn
- Anna Weatherly
- Gretchen Imel
- Rebecca Jokinen
- Debora Ferreira
- Rachel Wilson
- Blair Tiseo
- Aaron Hartshorne

www.chsbs.cmich.edu/CHARGE

Like us on facebook!!





Information Central

The CHARGE Syndrome Research Lab at Central Michigan University

Timothy S. Hartshorne, Ph.D.

Presenter Information

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

Co Presenters: Megan Schmitt, Bree Kaufman, Shanti Madhavan-Brown, Anna Weatherly, Shelby Muhn, Rachel Wilson, Gretchen Imel, Blair Tieso, Aaron Hartshorne


Presentation Abstract

The CHARGE Lab at Central Michigan University began about 1999 when Tim Hartshorne began to study behavior in children with CHARGE. This presentation provides a bit of history, and then describes the research of the current lab members.



Trying to understand the behavior


- It's because they are deafblind
- It's because they have communication problems
- It's because of vestibular difficulties
- It's because of early experiences
- Early research on
 - Executive function
 - Autistic like behaviors
 - Attachment
 - Sleep disturbances
 - Psychiatric diagnoses and medication



CHARGE
Research Lab

Current Projects

- Development of Play
- Recreation
- Medicine side effects
- Fun Chi
- Profiles of ability in CHARGE
- Anxiety and calendar systems
- Restorative Environments
- Headaches




Scottsdale CHARGE conference

CHARGE
Research Lab

Current Lab

Maria Ramirez
Ben Kennert
Megan Schmittell
Bree Kaufman
Shanti Brown
Shelby Muhn
Anna Weatherly
Lily Slavin
Gretchen Imel
Becca Jokinen
Debora Ferriera
Rachel Wilson
Blair Tiseo
Aaron Hartshorne



<https://www.cmich.edu/colleges/chsbs/Psychology/charge>
Facebook: CHARGE syndrome research lab



Information Central

Milestones in CHARGE Syndrome

Meg Hefner, MS, Saint Louis University
Emily Fassi, MS, Washington University in St. Louis
Kevin Ballard

Presenter Information

Meg is a genetic counselor with 35 years of experience with CHARGE syndrome. She was a founding Board member of the CHARGE Syndrome Foundation and remains active as an Advisor to the Board. She has written extensively on CHARGE for families (Management Manual for Parents), geneticists (American Journal of Medical Genetics special issue on CHARGE syndrome), and professionals working with children with CHARGE (CHARGE Syndrome, Plural Publishing). Awards for CHARGE syndrome work include the first Stars in CHARGE award and the Diane Baker Alumni Award from the University of Michigan. She has presented at every CHARGE Syndrome Conference and actively answers genetic and medical questions by email and on several CHARGE Facebook pages. Meg's most recent endeavor is the CHARGE syndrome database (CSCDP), created to facilitate research by providing baseline information on individuals with CHARGE to researchers around the world.

Presentation Abstract

CHARGE Syndrome Clinical Database Project is a web-based, parent-completed database and registry with more than 1000 data items of medical and developmental features. Participants may upload photographs and limited medical records. Data are exported to Excel for analysis. More than 150 participants have entered relatively complete data. Although some participants are young and therefore have not yet reached milestones, we have data on around 100 for most milestones. Multiple milestones will be presented.



Information Central

CHARGE syndrome: the importance of inner ear MRI and CHD7 testing for diagnosis as the dysmorphology is not always obvious

Meg Hefner, MS

Presenter Information

Meg is a genetic counselor with 35 years of experience with CHARGE syndrome. She was a founding Board member of the CHARGE Syndrome Foundation and remains active as an Advisor to the Board. She has written extensively on CHARGE for families (Management Manual for Parents), geneticists (American Journal of Medical Genetics special issue on CHARGE syndrome), and professionals working with children with CHARGE (CHARGE Syndrome, Plural Publishing). Awards for CHARGE syndrome work include the first Stars in CHARGE award and the Diane Baker Alumni Award from the University of Michigan. She has presented at every CHARGE Syndrome Conference and actively answers genetic and medical questions by email and on several CHARGE Facebook pages. Meg's most recent endeavor is the CHARGE syndrome database (CSCDP), created to facilitate research by providing baseline information on individuals with CHARGE to researchers around the world.

Presentation Abstract

CHARGE syndrome (CS) is a complex and extremely variable genetic condition, most often caused by mutations in the CHD7 gene. The diagnosis still remains primarily clinical. Baby A is a subtle case where the diagnosis would likely have been greatly delayed without MRI and CHD7 testing. At birth, she did not have unusual ears or any of the other dysmorphic features typical of CHARGE.



Information Central

A new feeding scale for use in CHARGE syndrome

Alexandra Hudson, MD Candidate 2018
Dr. Kasee Stratton and Dr. Kim Blake

Presenter Information

Alexandra is a medical student at Dalhousie University in her third year of study. Prior to attending medical school, she completed my Honors Bachelor of Science at the University of Toronto in human biology, physiology, and psychology. She is currently studying CHARGE syndrome and its associated eating and gastrointestinal issues, under the supervision of Dr. Kim Blake at the I.W.K. Hospital in Halifax, Nova Scotia.

Presentation Abstract

Feeding issues are a major cause of morbidity and mortality in CHARGE syndrome. The feeding difficulties are unique and are not accurately captured with current validated feeding scales. This study designed a new feeding scale specific for CHARGE syndrome, and tested its validity and reliability in 100 individuals. This new scale can be used to assess an individual's current severity of feeding difficulties, track their oral feeding progress, and can alert to areas of concern that need clinical intervention.

Feeding Assessment for CHARGE Syndrome (FACS) Scale

Date: _____

Name of Individual with CHARGE Syndrome: _____

Age: _____

Gender (Circle one): Male

Female

Not Disclosed

Completed By (Circle one): Mother

Father

Feeding Therapist

Nurse/Physician

Other: _____

What percentage of your child/adult's daily fluid/nutrition intake is by G/J tube feeding? (Circle one percentage):

0%	25%	50%	75%	95%
----	-----	-----	-----	-----

Circle one number on the scale:		Never	A Little	Sometimes	A lot	Always
1	He/she will refuse food when eating orally.	0	1	2	3	4
2	He/she takes longer than 45 minutes to eat orally.	0	1	2	3	4
3	He/she takes less than 15 minutes to eat orally.	0	1	2	3	4
4	He/she needs close supervision when eating orally.	0	1	2	3	4
5	He/she needs someone in the room when eating orally.	0	1	2	3	4
6	He/she has problems cutting food when eating orally.	0	1	2	3	4
7	He/she has problems feeding him/herself when eating orally.	0	1	2	3	4
8	He/she chokes or coughs when eating orally.	0	1	2	3	4
9	He/she has trouble chewing food.	0	1	2	3	4
10	He/she has trouble swallowing food.	0	1	2	3	4
11	He/she has to be told or reminded to chew.	0	1	2	3	4
12	He/she has to be told or reminded to swallow.	0	1	2	3	4
13	He/she does not like to mix food textures when eating (e.g. mixing puree and solid food).	0	1	2	3	4
14	He/she accidentally loses food out of his/her mouth during eating.	0	1	2	3	4
15	He/she will over-stuff his/her mouth with food during eating.	0	1	2	3	4

Circle one number on the scale:		Never	A Little	Sometimes	A lot	Always
16	He/she has difficulty moving food around with his/her tongue during eating.	0	1	2	3	4
17	He/she has a hard time feeling food or anything touching the inside of his/her mouth.	0	1	2	3	4
18	He/she dislikes oral eating.	0	1	2	3	4
19	He/she lets food sit in his/her cheeks or palate during eating (on purpose or not).	0	1	2	3	4
20	He/she will have food hidden in his/her cheeks or palate after the meal has ended (on purpose or not).	0	1	2	3	4
21	The Parent/Caregiver gets worried about their child/adult's ability to eat orally.	0	1	2	3	4
22	The Parent/Caregiver has difficulties feeding their child/adult. (e.g. preparing food the right way, getting enough information about helping them eat/drink)	0	1	2	3	4
Does the child/adult have problems with:		No		Yes		
23	Cold foods	0		1		
24	Room temperature foods	0		1		
25	Warm foods	0		1		
26	Thin liquids (e.g. water)	0		1		
27	Pureed foods (e.g. applesauce)	0		2		
28	Mashed lumpy food (e.g. mashed potatoes or mashed vegetables)	0		2		
29	Soft chewable foods (e.g. bread, crackers)	0		2		
30	Tough chewable foods (e.g. meat)	0		1		
31	Hard vegetables and fruit (e.g. raw apples)	0		1		

Total Score (sum of all items)	/100 total points
---------------------------------------	--------------------------

Questions (1-4)

1. Which description best describes your child/adult's **current** feeding difficulties? (Circle one)

0 – **Very mild.** (E.g. Feeding difficulties are not an issue, doesn't need any feeding therapy, can handle all foods, can eat while alone, no trouble with chewing or swallowing)

1 – **Mild.** (E.g. Can handle most food, may have some feeding difficulties once in a while)

2 – **Mild to moderate.** (E.g. Can handle most food, may have some chewing or swallowing difficulties, may need some feeding therapy)

3 – **Moderate.** (E.g. Needs supervision sometimes when eating, has trouble chewing or swallowing certain foods, has feeding difficulties most of the time)

4 – **Severe.** (E.g. needs feeding therapy, needs assistance when eating, needs supervision when eating, has trouble with many food textures,)

5- **Very severe.** (E.g. Has a lot of feeding difficulties, needs feeding therapy, has trouble chewing and swallowing, has trouble with lots of food textures, chokes when eating, pockets food in cheeks, overstuffing mouth when eating)

2. How well do you think your child's score on this questionnaire describes the severity of their **current** feeding difficulties?

0 – Not at all.

1 – Poorly.

2 – Only a little bit.

3 – Well

4 – Very well

5 – Extremely well

3. Do you have any suggestions for improvement of these questions in this questionnaire? (Please describe)

4. Do you think this questionnaire has missed any important questions about feeding problems in CHARGE syndrome? (Please describe)



Information Central

Overview of Sexuality Education

Chathuri Illapperuma, Jordan Parker, Emily Mathis, Mallory Eddy, Alex Clarke, Kasee Stratton

Presenter Information

Chathuri Illapperuma, Jordan Parker, Emily Mathis, Mallory Eddy, and Alex Clarke are graduate students in the school psychology program at Mississippi State University and have been active members in the Bulldog CHARGE Syndrome Research Lab led by Dr. Kasee Stratton since September 2015. As a group, we research sexuality education for CHARGE in order assist and educate those individuals closely associated with the syndrome.

Presentation Abstract

The quality of sexuality education for students receiving special education has been an area of concern. Absence of federal regulations and a universal, accessible curriculum and learning outcomes may leave some individuals with inadequate knowledge. Limiting access to sexuality education increases risk for vulnerable, unhealthy sexual activities, and lack of knowledge on safe and healthy relationships including intimate relationships. This poster aims to highlight the trend in sexuality education and the need for a consistent and holistic approach.



Information Central

Trends in and Barriers to Recreation Participation in CHARGE Syndrome

Gretchen Imel and Timothy S. Hartshorne, Ph.D.

Presenter Information

Gretchen Imel is a senior with a dual major in therapeutic recreation and psychology at Central Michigan University. She has been a member of the CHARGE Syndrome Research Lab for three years.

Presentation Abstract

Participation in recreational activities is a component of an optimal quality of life. However, individuals with CHARGE face many barriers to recreation. This study found that individuals with CHARGE are actively participating in a wide range of recreational activities with walking, swimming, and listening to music having the most participation and swimming, listening to music, and walking being rated as the top favorites. Barriers were identified as expense of activity and adaptive recreation equipment.



Information Central

**10 years of support and activities for people
with CHARGE Syndrome in Germany and
German speaking areas**

Claudia Junghans and Dr. Julia Benstz

Presenter Information

Claudia is 1st President of CHARGE Syndrome e.V. (German CHARGE Family Support Group) and mother of an 13 year old son with CHARGE syndrome. She regularly lectures on the CHARGE syndrome from the point of view of an affected mother. She also heads the office of the German CHARGE Family self-support group.

Presentation Abstract

CHARGE Syndrom e. V. is a German self-support group, founded by parents of children with CHARGE Syndrome in 2006. The group is based in Germany but includes all German speaking countries like Austria, Switzerland, Luxembourg, France and German speaking people who are living in Italy. Currently it has 255 members including families, professionals, relatives and friends.

CHARGE Syndrome in German-speaking countries

Background:

CHARGE Syndrom e.V. is a self-help group, founded in 2006 by parents of children with CHARGE syndrome. The group is based in Germany but welcomes people from all German-speaking countries. Families from Austria, Switzerland, Luxembourg, Italy (South Tyrol) and France are represented.

In 2016, the group celebrated its 10th anniversary, which also means

- currently 261 members
- 10 German CHARGE Conferences
- 2 Professional days
- 43 themed family-weekends in total
- 400.211,02 € donated money in total from 2006 to 2016 from health insurances (special support of self-help groups) and the foundation Aktion Mensch

Main focus: themed family weekends covering special topics

- **Annual German CHARGE Conference – in particular the anniversary German CHARGE Conference in 2016**
All CHARGE-families were invited, as well as national and international experts and professionals with different backgrounds. The program included lectures on relevant topics, one-to-one interviews with experts, discussion groups, CHARGE-simulation experiments (to enable a better understanding of what CHARGE feels like), a kids and youth program etc. Also a professional day took place. In 2016 we had 500 participants in total.
- **Workshop “Communication and behavior” -**
This workshop is aimed at a small group of participants. Exchange and mentoring about the wide spectrum of communication issues encountered in CHARGE, including development of individual strategies. Special auxiliary materials are also provided. Group discussions as well as individual counseling with specialists (supported by video analysis) are made available according to demand. Seminars are offered at three levels of detail and complexity: basic, advanced, and booster sessions.
- **Workshop for young people with CHARGE**
The participants are young people (14+ years) with CHARGE-Syndrome. They are encouraged to be self-aware and to move independently among a group of like-affected people, without their parents. Special challenges designed to improve self-confidence are offered. A particular highlight for the young CHARGE participants has proven the making of a movie entitled “We are CHARGE, so what!”

- **Workshop for mothers of a CHARGE-child**

This highly successful workshop is designed to create an oasis of relaxation in recognition of the conditions of extreme stress the mother of a CHARGE child lives under. The aim is to enable the mother to attend to her own needs and create an atmosphere in which she can exchange experiences, meet other mothers in the same situation, and take on new information. This demonstrably helps ease the pressure on the mothers and also helps them simplify their everyday life.

CHARGE Syndrom e.V / Germany

+++ www.charge-syndrom.de

+++ info@charge-syndrom.de

Claudia Junghans / 1st president



Information Central

Profiles of Ability in CHARGE Syndrome

Bree Kaufman, M.A. and Timothy S. Hartshorne, Ph.D.

Presenter Information

Bree Kaufman is a 4th year doctoral student in school psychology at Central Michigan University. She works with Dr. Tim Hartshorne in the CHARGE Syndrome Research Lab. Her current research focuses on degrees of functioning within CHARGE syndrome.

Presentation Abstract

Parents often wonder if their child's CHARGE is mild, moderate, or severe. The ABILITIES Index provides a way to profile the functional ability of persons with disability in 9 major domains: audition, behavior and social skills, intellectual functioning, limbs, intentional communication, tonicity, integrity of physical health, eyes, and structural status. The purpose of this research was to explore the usefulness of the ABILITIES Index for CHARGE.



Information Central

Effective Positioning Interventions to Facilitate Fine Motor Skills in School-Aged Children with CHARGE Syndrome and/or deafblindness

Samantha Kublin, OTD, OT/s, Sarah Bis, MS, OTR/L, C/NDT, Diane Smith, Ph.D., OTR/L, FAOTA

Presenter Information

Samantha Kublin is an occupational therapy doctoral student studying at the MGH Institute of Health Professions in Charlestown, MA. Currently, Samantha is completing her doctoral research project at Perkins School for the Blind's Deafblind Program in Watertown, MA. She is working with students with CHARGE Syndrome (CS) and/or deafblindness ages 3-22 in the school setting. Samantha has education and experience with evaluation and treatment of fine motor skills in children with motor delays and is conducting a research study to determine the most effective position for students with CS to increase fine motor skills.

Presentation Abstract

In the article, The Forgotten Sense-Proprioception (2006), David Brown explains that children with CHARGE Syndrome can benefit from positioning that addresses their proprioceptive sense in order to best utilize other senses for functional activities. We tested this hypothesis by adapting the position of children with CHARGE Syndrome and/or deafblindness when performing fine motor tasks. We will discuss the trends discovered in the research study. Participants will leave the session with increased knowledge on adaptive positioning that may be implemented at home or in the school setting.



Information Central

Teaching Gross Motor Skills and Balance to Children with CHARGE Syndrome

Lauren J. Lieberman Ph.D., Pamela Haibach-Beach Ph.D., Beth Foster Ph.D.

Presenter Information

Dr. Lauren J. Lieberman is a Distinguished Service Professor in the kinesiology department of The College at Brockport, State University of New York (SUNY). She earned her undergraduate degree from West Chester University in Pennsylvania, her master's degree at the University of Wisconsin at LaCrosse, and her PhD in Movement Studies in Disability at Oregon State University. She taught in the deafblind program and coached three sports at the Perkins School for the Blind. She teaches undergraduate and graduate courses in adapted physical education. She codirects the Institute on Movement Studies for Individuals with Visual Impairments (IMSVI) at The College at Brockport and is the founder and director of Camp Abilities, an educational sports camp for children with visual impairments.

Dr. Beth Foster is an assistant professor at Cal Poly Pomona in California in the area of adapted physical education. She is also a nationally Certified Adapted Physical Educator. She worked as an Elementary Adapted Physical Educator in Pennsylvania for 6 years then was an APE consultant in Texas for 4 years. During her time teaching in Pennsylvania, Dr. Foster was named the 2012 Pennsylvania State Association for Health, Physical Education, Recreation and Dance adapted physical education teacher of the year. Beth has been involved in Camp Abilities, a developmental sports camp for individuals who are blind, visually impaired, or deafblind for the past 12 years. She is currently the assistant director for Camp Abilities in Pennsylvania and Camp Abilities Texas.

Dr. Pamela Haibach-Beach is an Associate Professor at the State University of New York, College at Brockport. She earned her Ph.D. at the Pennsylvania State University in kinesiology with a specialization in motor behavior and a minor in gerontology. Her two main areas of research are 1) postural control and balance and 2) motor development, more specifically, the influence of sensory modalities in human populations including healthy and special populations ranging from children to older adults.

Presentation Abstract

Children with CHARGE Syndrome are behind their peers in balance, motor skills and developmental milestones. The purpose of this demonstration is to show parents, caregivers and professionals a variety of ways to teach basic gross motor skills. In this demonstration children will have the opportunity to throw, kick, run, jump, challenge their balance, and develop core strength. Attendees will be given a hand-out with the list of modified motor skills and equipment used.



Information Central

Modelling hypoventilation and anesthetic recovery in a zebrafish (*Danio rerio*) model of CHARGE syndrome

Jessica MacLean

Presenter Information

Jessica is a first year medical student at Dalhousie University and is working on a project investigating adverse events following anesthesia administration in individuals with CHARGE syndrome using a zebrafish animal model. Her research is supervised by Dr Kim Blake and Dr Jason Berman and is conducted in the Berman lab which has a zebrafish model of CHARGE syndrome. Jessica completed a Master's in Science during which she conducted research in the area of cardiovascular pharmacology before entering medical school. She is interested in both the clinical and research aspects of CHARGE syndrome, and is looking forward to being able to take what is seen clinically and model it in the lab in hopes of furthering the understanding of the mechanisms of CHARGE.

Presentation Abstract

CHARGE patients commonly experience both minor and severe adverse events following anesthesia and sedation administration. There can be increased mortality and morbidity resulting from abnormal heart rate and decreased respiratory rate. Zebrafish that have been genetically engineered to lack *chd7* exhibit features of CHARGE. We will examine responses to anesthetic agents in this zebrafish model in an attempt to investigate causative factors. We will also investigate the regulation of *phox2b*, a gene involved in controlling respiration.



Information Central

What should we be looking for? Child-centered and capacity-building assessment approaches

**Julie Maier, Educational Specialist
California Deafblind Services**

Presenter Information

Julie Maier is an Educational Specialist for California Deafblind Services and provides technical assistance to families of children with deafblindness and their school teams. She has served many children and teens with CHARGE syndrome. Julie also serves as the Program Coordinator for an OSEP funded personnel preparation project "Specialization Program in the Education of Learners who are Deafblind" at San Francisco State University. Julie has been involved in the in the field of special education in the area of moderate-severe disabilities since 1987, including as a faculty member of SFSU Special Education Department since 1999. Julie has presented at numerous conferences on the topics of meaningful assessment for children with deafblindness and training providers in effective educational practices, including 2015 International TASH Conference, 2015 International CHARGE Syndrome Conference, and 2016 German CHARGE Syndrome Conference. She has written or co-authored several published articles on assessment, self-determination, social supports, collaborative partnerships between families and school teams during the transition process.

Presentation Abstract

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



Information Central

Moving forward with the transition to preschool through collaborative planning

Julie Maier, Educational Specialist
Myrna Medina, Family Engagement Specialist for California Deafblind Services

Presenter Information

Julie Maier is an Educational Specialist for California Deafblind Services and provides technical assistance to families of children with deafblindness and their school teams. She has served many children and teens with CHARGE syndrome. Julie also serves as the Program Coordinator for an OSEP funded personnel preparation project "Specialization Program in the Education of Learners who are Deafblind " at San Francisco State University. Julie has been involved in the field of special education in the area of moderate-severe disabilities since 1987, including as a faculty member of SFSU Special Education Department since 1999. Julie has presented at numerous conferences on the topics of meaningful assessment for children with deafblindness and training providers in effective educational practices, including 2015 International TASH Conference, 2015 International CHARGE Syndrome Conference, and 2016 German CHARGE Syndrome Conference. She has written or co-authored several published articles on assessment, self-determination, social supports, collaborative partnerships between families and school teams during the transition process.

Myrna Medina has served as CDBS Family Engagement Specialist since 2000 supporting families of children with deafblindness. She is the parent of two children, one of whom is deafblind as a result of an unknown etiology. Myrna is a native of Mexico and fluent in English and Spanish. She has been instrumental in ensuring linguistic and cultural sensitivity of all CDBS Spanish language services and products. Myrna serves as the coordinator and as an active regional participant of the CDBS Network of Family Support Providers and is currently serving her second term as Secretary of the Coalition of Parents and Educators Deaf-Blind, a statewide family organization on behalf of children who are deafblind. Myrna also plays a leadership role in numerous organizations throughout the state, including Unidad y Fuerza (the FRC at Miller Children's Hospital in Long Beach), Centro de Niños y Padres at California State University Los Angeles, Birth-to-Five Vision Network, Junior Blind of America, and Dicapta, an OSEP-funded accessible communication development project. Myrna presents on numerous topics including: improving team collaboration and partnerships; sibling issues; working with Spanish speaking families; and communication between home and school. She presented at the Cal-TASH 2005, CEITAN, Fiesta Educativa and International CHARGE Syndrome Conferences 2013 and 2015. She has written and co-authored fact sheets and published articles on the importance of maintaining collaborative relationships between home and school, transition, and team work. She is also the coordinator for the national monthly CHARGE calls, and she acts as the co-presenter for the quarterly Spanish Webinars sponsored by NCDB, NFADB and CDBS.

Presentation Abstract

Times of transition can be one of the most anxious and stressful periods in a family's life, especially that first transition from early intervention services to preschool. We will share suggestions, tips, and resources families can use to be actively involved in the transition assessment process and strategies which early interventionists, educators and service providers can employ to encourage and support the family's involvement and ensure a smooth and successful transition to preschool services.

Moving forward with the transition to preschool through collaborative planning

***Julie Maier & Myrna Medina,
California Deafblind Services***

***13th Annual International CHARGE Syndrome Conference
Orlando, FL July, 2017***

“Planning a transition takes time, communication, patience, and sensitivity to the needs and emotions of the family and their child. Planning in advance will minimize the stress caused by changes the family will experience, reduce fears of the unknown, help families to build new relationships with staff and become involved in the new program, support the child during the transition process and help him or her adapt to the new environment”
(Lavada Minor, 1997).

Problem/Issues: The transition from home-based early intervention services to preschool services can be stressful, confusing, and scary for many families of children with intensive support needs, such as CHARGE syndrome. This transition often lays the foundation for successful partnership between school service providers and families over the years. It's critical to ensure families are informed, respected, and involved during this important transition process. It is also important that the preschool team receives all of the essential information about a child with CHARGE and their support needs in preparation for this successful transition.

Why the transition to preschool can be difficult

- Every transition brings up memories of past transitions, and some may have been very difficult.
- Uncertainty and fear about leaving early intervention services in the home or day care setting for larger school setting.
- The Individualized family Support Plan (IFSP) changes to Individualized Educational Plan (IEP) and this change from a focus on family supports and

services to services and supports for child may be scary and difficult to understand.

- Issues of trust and fear, especially if the assessment period or transition is rushed or the school team doesn't take time to reach out to provide information and answer family's questions.
- Communication between families and school's assessment team and new teachers and services providers may be challenging due to language and/or cultural differences.
- Assessment process focuses on deficits or delayed milestones rather than the child's skills, interests, and family's goals for child.
- Child might have many medical or specialized health care needs and likely has very unique support needs.
- Difficulty finding an appropriate program that fits the child's unique educational needs especially in the areas of sensory losses and communication.

Specific concerns for families of children with CHARGE syndrome may include:

- Medical and health issues
- Child does not yet communicate effectively or their communication skills are still emerging.
- Physical safety concerns
- Need for intensive instructional support or services of an intervener
- Uncertainty about what the team knows about educating and supporting children CHARGE syndrome and/or deafblindness.

Essential Practices

Three key practices to utilize at this important transitional point in a child's life to develop comprehensive plans to assist with successful transitions:

1) **Discover the family's story**, which will reveal a lot of important information about the child as well;

- 2) **Use a collaborative assessment approach** in order to gain the most complete and accurate profile of this child and their needs;
- 3) **Engage in interactive discussion about child's development, skills and support needs** with other team members, important members of the child's family, and current early intervention service providers.

Specific Practices to Utilize

Early intervention providers (sending team)

- Let families know what to expect during the transition process to preschool and start planning together about key information to share with school team.
- Give information to families about upcoming trainings about IEP process or preparing for transition to preschool.
- Assist the family with connecting to local support services (e.g. family support groups, family resource centers, service providers you may know in the child's local school district, state deafblind project staff).
- Share with the family the ways their participation in their child's program and services may differ in a center or school based program rather than a home program. Offer strategies for ways they can get involved at their child's new school or program and effective ways to communicate between home and school.
- Share the most recent assessments and progress reports with receiving team.
- Assist the family in putting together a packet of information, or a personal passport about their child and family.

School district (receiving team)

- Consider and appreciate the enormity of the transition for this family.
- Provide clear verbal and written explanation of the assessment process and IEP meeting and service placement discussion.
- Strive to collaborate with the other service providers completing assessments so that the final assessment report provides an accurate, strength-based portrait of this child, their current and emerging skills and specific support needs.
- Hold family-centered training activities (e.g., "Learning About the IEP Process") and make strong efforts to reach the families with children under the age of 3.
- Contact and consult with local deafblind specialists or service providers with experience serving children who are deafblind during the initial assessment process and the transition into a new school program.
- Don't forget to gather input from the family. Ask them about their family, their child, and their hopes and goals for their child.
- Conduct assessments in natural settings that are familiar to the child.
- Provide the family with information about programs and services and supports that are available, including visits to see programs that are offered.

Family

- Develop a personal passport or “All About Me” book/packet about your child and family.
- Attend family training activities on the IEP process and roles and responsibilities of families.
- Talk to other parents who have already gone through this transition for support and suggestions.
- Ask district staff to consult with deafblind specialists and the child’s current intervention service providers.
- Reach out to local deafblind specialists for advice and support. Contribute as much information as you can to the specialists conducting the assessments. The receiving school agency will likely ask you to complete written questionnaires or they may want to interview you in person. Let each specialist know what you have shared with the other specialists.
- Write up a list of the services and supports you think your child needs and be prepared to present it at the meeting. Prepare a statement to make at the beginning of the meeting about your child and family and what you hope to gain from the meeting.
- Visit the receiving school or program, possibly with your child and one of early intervention service providers.
- Remember YOU are the expert on your child.
- It often helps to bring a photo of the child to the meeting to keep everyone focused on this unique child.

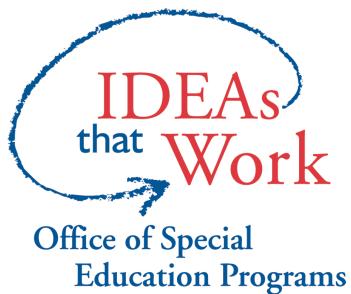
“This first transition is difficult for our children, but it I think it is even harder on parents. We are leaving behind an environment that was cozy and that welcomed us as a family. We are now moving onto a school that is bigger in size, includes more children, longer school hours and definitely more student focused. It is one of the biggest events in our child’s life and the life of our family. As parents we need to start this transition knowing as much information about the process as possible to make this scary move as smooth as possible. The basic information that we know at the beginning will grow with our experience. The more prepared we are, the smoother the transition. There are many strategies parents will learn and use over the years, and some of them will work and some of them won’t work. It is important always to remember that we are talking about our child, their needs and well-being... Finally, during any transition or any time we are discussing our child’s rights or our own parental rights, we need to play the role of an “advocate”. We become our child’s voice,

but we have to remember that the most important role we have to play is to be our child's advocate and not forget the focus is our child's education."

~ Myrna Medina, parent and Family Engagement Specialist for CDBS, 2016

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Project Officer, Jo Ann McCann.



KEEP ON TOP

TWO PAGE TIPS TO HELP YOU THINK WHEN PREPARING FOR THE TRANSITION OF OUR CHILDREN WITH DIFFERENT ABILITIES



Think about their ...

- ❖ **Strengths** Qualities, likes, things that make your child happy or she/he enjoys
- ❖ **Weaknesses** Things that make her/him uncomfortable, frustrated, dislikes
- ❖ **Skills** Motor and cognitive
- ❖ **Level of performance** Things she/him can do with and without support, environment that will affect performance (e.g. familiar or unfamiliar places or people)
- ❖ **Accommodations** Things that will help your child use all his/her potential (observed by you, or suggested by a specialist)
 - Consistency
 - Better lighting
 - Amplifications
 - Repetition
 - Assistive technology
 - Adequate materials
 - One-to-one support
- ❖ **Hopes and dreams** What would you like your child to do, what are your immediate and future goals
- ❖ **Concerns** Any thing that you can think of that might affect your child's well being, learning and performance

~Myrna Medina, California Deafblind Services, 2017



1. Write down a list of questions before each meeting.
2. Don't wait to the last minute before the meeting to prepare.
3. Maintain a collaborative attitude.
4. Have realistic expectations.
5. As much as possible speak with your head not with your heart.
6. Make sure to get all your questions answered.
7. Know that you are an equal partner and you have a say on any decision-making.
8. Create a binder to keep all school records and paperwork.
9. Remember you can sign the IEP, parts of the IEP that you are in agreement, or not sign it at all, and take it home to read it over then sign it.
10. You have the right to invite whomever to accompany you to the IEP meeting.

~Myrna Medina, California Deafblind Services, 2017

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Information Central

Decision-making in the removal of gastrostomy tubes or buttons in CHARGE syndrome

Rachel Malta and Timothy S. Hartshorne, Ph.D.

Presenter Information

Rachel Malta recently completed her specialist degree at Central Michigan University, and is employed as a school psychologist in Charlotte, Michigan. While at CMU she was a member of the CHARGE Syndrome Research Lab.

Presentation Abstract

Gastrostomy tubes are often used to maintain adequate nutrition, but within the CHARGE population many parents eventually decide to have the tube removed. A survey was distributed addressing parental support needs and decision reasoning regarding removal. Results suggested a trusting, collaborative relationship between medical professionals and parents of the child, and clear, published guidelines regarding the process and timeline would be useful. Parents reported consulting a variety of professionals and parents with similar situations.



Information Central

Let's Talk About Sex: Implications for Future Research in Sexuality Education

Emily Mathis, Alex Clarke, Mallory Eddy, Chathuri Illapperuma, Kasee Stratton

Presenter Information

Emily Mathis, Alex Clarke, Mallory Eddy, Chathuri Illapperuma are second year School Psychology graduate students at Mississippi State University and members of the Bulldog CHARGE Syndrome Research Lab. Collectively, they work on the Sexuality Research Team. Sexuality education is crucial for teaching safety and relationship knowledge and this team was formed in response to the lack of sexuality education for individuals who have CHARGE or are deaf-blind. They hope to bring awareness and education to families and individuals with CHARGE, while working to develop a comprehensive sexuality education appropriate for individuals who are deaf-blind.

Presentation Abstract

Current literature on Comprehensive Sexuality Education (CSE) programs for individuals who are deafblind indicates CSE is beneficial. Such programs increase awareness of sexually transmitted diseases, promote safety, and improve general knowledge of development. However, there is limited research and resources available for individuals who have multisensory impairments. This poster aims to provide areas for future research by addressing deficits in the literature. A study proposal to expand sexuality education for CHARGE will also be presented.



Information Central

Recently recognized late emerging medical issues in an eighteen-year-old with CHARGE syndrome: a case report

Angus Morgan, BSc

Presenter Information

Angus Morgan is a third year medical student studying at Dalhousie University in Halifax, Nova Scotia, Canada. Angus has a longstanding history of working with children who have developmental differences, beginning more than 10 years ago. From facilitating summer camps and extra-curricular programming for children with developmental differences, to eventually contributing to the medical literature under that same umbrella, his interest in improving the well-being of children has continued to grow. He was introduced to CHARGE syndrome in the winter of 2016 while doing an elective in general pediatrics with Dr. Kim Blake, who has keen academic and clinical interest in the syndrome. From here, he hopes to pursue pediatrics in his residency training, and to continue contributing to the literature on CHARGE syndrome.

Presentation Abstract

It is coming to light that CHARGE related issues once thought to only arise in childhood, can in fact emerge for the first time in adolescence or even adulthood. Here we report an 18-year-old female who was diagnosed with CHARGE syndrome as a neonate, but in her teenage years, developed late dumping syndrome, and overactive bladder. This is the first case report outlining the presentation of these late manifestations of CHARGE syndrome.



Information Central

Post-Traumatic Growth in Parents of Children with CHARGE

Shelby Muhn and Timothy S. Hartshorne, Ph.D.

Presenter Information

Shelby Muhn is a first-year school psychology doctoral student at Central Michigan University. She has been a member of the CHARGE Syndrome Research Lab at Central Michigan University since April of 2016.

Presentation Abstract

Having a child with a severe medical and physical disability can be a traumatic event for families to face. They may feel isolated, guilty, and have moments of discouragement as they experience challenges. Although they face these encounters many parents begin to demonstrate considerable strength. The current research is looking to see what contributes to the phenomenon of post-traumatic growth in parents of children with CHARGE. Future goals include interventions and therapies to facilitate growth in parents.



Information Central

Reach & Match®: Children With Sensory Impairments Play With Peers.

Tristan Pierce, MIA

Presenter Information

Tristan Pierce has over 30 years of experience working in educational publishing, the last 16 years as the Multiple Disabilities Project Leader at the American Printing House for the Blind (APH). Her job involves research and design, creative direction, product management, writing, editing, and field testing.

Tristan holds a BA in Advertising and French, and an MIA in Intercultural Management. She has worked with scholar athletes from around the world; developed art activities for international children's events; and managed a toddler house in a Haitian orphanage, where many children with disabilities live. Tristan coached the Kentucky School for the Blind swim team for 14 years. She works part time with adults who have intellectual disabilities at Day Spring Community Living.

Designing products for learners with multiple disabilities requires knowledge of many diagnostic conditions. Tristan collaborates with specialists who have education and experience in specific areas of impairment. Using this team approach, Tristan has guided many products from concept to production.

Tristan's interest in nutrition and physical education resulted in a new category of products available from APH. Tristan works with experts in the field of physical education to create health and fitness products.

Presentation Abstract

This poster outlines field test results of 35 preschool children playing with the Reach & Match, an innovative system for students with sensory impairment and other special needs to learn and engage with peers. The double-sided sensory play provides distinctive modes of individual learning and group play. The front side provides toddler training for manual dexterity and identifying tactile patterns. The reverse side provides preschoolers with braille/print learning, motor development, direction, and spatial training.



Information Central

Examining the Measurability and Attainability of IEP Goals for Individuals with CHARGE Syndrome

Hailey E. Ripple, Johnna Dowdy, Olivia Kesler,
Katherine Johnson, Kasee Stratton

Presenter Information

Hailey is a doctoral student in the school psychology program at Mississippi State University and has been an active member in the Bulldog CHARGE Syndrome Research Lab led by Dr. Kasee Stratton. Hailey's research interests related to CHARGE include researching IEPs and parent perceptions of the IEP process, behavior, and strategies to raise awareness for CHARGE. Hailey was also one of the first Davenport Fellows.

Presentation Abstract

In order for an individual with a special education ruling to make appropriate educational and social progress in school, it is critical that the goals included in their individualized education programs (IEP) are measurable and attainable. The current study aims to examine the previously mentioned variables in IEPs written for individuals with CHARGE Syndrome. IEPs for individuals of various ages are included in results. Best practice in writing IEP goals will be included.



Information Central

IEP Transition Plans for Individuals with CHARGE Syndrome

Hailey E. Ripple, Elizabeth Struna, Matthew Ferrigno, Katherine Johnson, Kasee Stratton

Presenter Information

Hailey is a doctoral student in the school psychology program at Mississippi State University and has been an active member in the Bulldog CHARGE Syndrome Research Lab led by Dr. Kasee Stratton. Hailey's research interests related to CHARGE include researching IEPs and parent perceptions of the IEP process, behavior, and strategies to raise awareness for CHARGE. Hailey was also one of the first Davenport Fellows.

Presentation Abstract

Transition plans included on individual education programs (IEPs) can be an unfamiliar topic for families when it comes time to plan for an individual's future after school. Transition plans aim to guide individuals towards opportunities for further education, employment, and independent living (Trainor, Morningstar, & Murrar, 2016). Current data on transition plans for individuals with CHARGE syndrome will be presented. Researchers aim to educate parents about necessary components of transition plans and ways to ensure that post-school goals are achieved.



Information Central

Social Play in Children with CHARGE Syndrome

Megan C. Schmittell and Timothy S. Hartshorne, Ph.D.

Presenter Information

Megan Schmittell is a fourth year graduate student in the school psychology doctoral program at Central Michigan University. She is a member of The CHARGE Syndrome Research Lab at Central Michigan University, and her research is focused on social play in children with CHARGE syndrome.

Presentation Abstract

Play is a fundamental aspect of development. As children age, they progress through different stages of social play supporting their social, emotional, and cognitive development. There is little information on how children with CHARGE syndrome develop social play. The current poster reports results from a study documenting the stages of social play in which a sample of children with CHARGE syndrome are functioning, as well as, information regarding their play preferences, as reported by parents.



Information Central

Research on Headaches in Children with CHARGE Syndrome

Lily Slavin and Timothy S. Hartshorne, Ph.D.

Presenter Information

Lily Slavin is a recent graduate of Alma College with a psychology major. Through a summer research program and independent study she worked in the CHARGE Syndrome Lab at Central Michigan University during the summer and fall of 2016.

Presentation Abstract

This poster will summarize the results of our study on the presence and incidence of headaches in CHARGE syndrome. We looked for associations between the presence or absence of CHARGE characteristics and headaches. We also looked at the presence of headaches and sleep, hormone replacement therapy, and eating. Finally, we investigated the behaviors used by parents to identify headaches.



Information Central

Working Together to Support Families

**Sheri Stanger, MA, Ed.M. and
Megan Cote, MS Ed.**

Presenter Information

Sheri Stanger has worked in the disability field for 26 years and is currently the Director of Outreach for the CHARGE Syndrome Foundation. She also runs a national CHARGE tele-support group. Sheri received her Master's Degrees from Teachers College, Columbia University in Psychological Counseling. Prior to becoming Director of Outreach for the Foundation, she worked as a rehabilitation counselor and school counselor and as a consultant for the NY State Deaf-Blind Collaborative. She is a past president for the National Family Association for Deaf-Blind and a board member for 18 years. She started the agency's Affiliate Network. Sheri is the mother of a 23-year-old daughter with CHARGE syndrome.

Megan Cote is the Initiative Lead at the National Center on Deaf-Blindness (NCDB) for the Center's Early Identification and Referral and Family Engagement Initiatives. In her 23-year career in special education, she has been a classroom teacher, educational consultant, and director of the Kansas Deaf-Blind Project, and has worked on multiple grant projects. Megan earned her Master's degree at the University of Kansas in Special Education. In her current role at NCDB she has collaborated with the CHARGE Syndrome Foundation to help expand and shape the CHARGE State Liaisons program and the outreach services they provide to families.

Presentation Abstract

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



Information Central

The Bulldog CHARGE Syndrome Research Lab at Mississippi State University

Kasee Stratton, Ph.D., NCSP

Presenter Information

Dr. Kasee Stratton is an assistant professor of school psychology at Mississippi State University. She is also a licensed psychologist and nationally certified school psychologist. She directs the Bulldog CHARGE Syndrome Research Lab at MSU. Dr. Stratton has been researching and presenting about CHARGE since 2005. She is an author of two chapters in the book, CHARGE Syndrome, the developer of the CHARGE Non-Vocal Pain Assessment, and has presented in the U.S., Australia, New Zealand, and Denmark on CHARGE. Dr. Stratton specializes in challenging behavior and improving adaptive skills.

Presentation Abstract

The Bulldog CHARGE Syndrome Research Lab at Mississippi State University conducts research and helps to spread awareness of CHARGE. The lab is composed of undergraduate students and graduate students in school psychology. The lab is under the direction of Dr. Kasee Stratton. Our goal is to investigate areas that are important to families, professionals, and individuals with CHARGE. Additionally, the lab seeks to create a diverse group of advocates and future professionals who are well informed of CHARGE syndrome.



Information Central

The CHARGE IEP: What Accommodations and Rulings are Common?

Elizabeth Struna, Hailey Ripple, Amanda Cosgriff, Whitney Driskell, Savannah Trice, Tierra Kilbert and Kasee Stratton

Presenter Information

Elizabeth Struna is a first year Doctoral student in the School Psychology program at Mississippi State University. Elizabeth has been a member of the Bulldog CHARGE Research Lab since the Fall Semester of 2016. Since joining the Lab, she has aided with the research of Individualized Education Plans (IEPs) in CHARGE. Elizabeth has always shown an interest in school compliance with IEPs. By assisting with this study, Elizabeth hopes to bring together educators and parents.

Presentation Abstract

Although CHARGE syndrome has a diverse presentation, little is known about the common educational accommodations or services provided for students with CHARGE. Yet, many children with CHARGE share a common special education category—deafblind. This poster will review the most frequent special education accommodations and services, as well as highlight the special education categories by which students are served. This information should assist professionals and parents in advocating for students with CHARGE and will also serve to identify any underserved educational areas.



Information Central

What makes up a family in CHARGE: Family Dynamics and Demographics

**Madison Sully, Megan Anderson,
Kasee Stratton,**

Presenter Information

Madison Sully is an educational specialist graduate student in the School Psychology program at Mississippi State University (MSU). Madison is interested in family dynamics and relationships in CHARGE families. Madison joined the Bulldog CHARGE Syndrome Research lab at MSU upon her first year of graduate school in 2014. CHARGE quickly became an interest of Madison's due to the limited information available. As a researcher on the family dynamics and relationships team, Madison is interested in understanding the dynamics of families who have a child with CHARGE Syndrome. In 2015, Madison attended her first CHARGE Conference in Chicago. The experience of meeting many individuals with CHARGE and their families has brought her back to her second conference with more research to share.

Presentation Abstract

Our research is intended to understand the make up and dynamics of families that include a child with CHARGE Syndrome. At present, no research has reviewed the family demographics or parental relationships in CHARGE Syndrome. The researchers seek to understand the differences and similarities between families with a child with CHARGE. Additional research questions addressed will include the number of children with CHARGE, birth order, and divorce rates.



Information Central

Social Skills of Individuals With CHARGE Syndrome

Lori A. Swanson, Ph.D., Meg Hefner, M.S.,
Bridget Leukuma, B.S.

Presenter Information

Dr. Swanson is a former board member of the CHARGE Syndrome Foundation. She was co-chair of the Education Committee with Kathy McNulty. She sponsored many of the educational webinars for the CHARGE Syndrome Foundation. She also contributed to the CHARGE Accounts newsletter. She is the author of a chapter on Communication in the CHARGE Syndrome book (Hartshorne, Hefner, Davenport, & Thelin, Eds.). She is co-author of a chapter of Forms and Functions in Communication in the CHARGE Syndrome book. Dr. Swanson's primary research interest is the communication skills of individuals with CHARGE syndrome. She is a professor in the Department of Communication Sciences and Disorders and a practicing speech-language pathologist.

Presentation Abstract

Five individuals with CHARGE syndrome were assessed using the Social Skills Improvement System (SSIS) Rating Scales (Gresham & Elliot). The ability of the participants to evaluate their own social skills varied. Parent and student ratings of individual behaviors often differed. The social profile of individuals with CHARGE will be described and the utility of SSIS for this population will be discussed.



Information Central

Adverse Effects and Behavioral Analysis of Psychotropic Drug Use with Children with CHARGE Syndrome

Blair Tiseo and Timothy S. Hartshorne, Ph.D.

Presenter Information

Blair Tiseo is a senior studying neuroscience at Central Michigan University. She has been in the CHARGE research lab for one year and focuses on psychotropic medications in those with CHARGE syndrome. Blair is planning to go to graduate school in spring of 2018 to become a Physician's Assistant.

Presentation Abstract

The use of psychotropic medications in the CHARGE population is understudied in relation to adverse effects, outcomes, and usage. A single-subject design will be used to study individuals with CHARGE syndrome who are beginning a psychotropic medication prescribed by their physician. The results will show the relationship between adverse effects and symptoms before starting the regiment. This study will show the adverse effects specific to those with CHARGE syndrome and whether or not the medications are effective.



Information Central

Restorative Environments

Anna Weatherly and Timothy S. Hartshorne, Ph.D.

Presenter Information

Anna Weatherly is a first-year school psychology doctoral student at Central Michigan University. She has been a member of the CHARGE Syndrome Research Lab at Central Michigan University since August of 2016. She also holds a Master's Degree in Environmental Psychology from the University of Surrey.

Presentation Abstract

Mental fatigue, or the reduced ability to block distractors and attend to important stimuli, has many cognitive and behavioral consequences, such as, difficulties in problem solving, a tendency to act rashly, being irritable, less patient, uncooperative, and problems making and following plans. According to Attention Restoration Theory, spending time within a restorative environment is the best way to recovery from mental fatigue. Beginning to understand how individuals with CHARGE Syndrome experience mental fatigue and restorative environments may be beneficial.



Information Central

Issues in Psychotropic Medication Use for Children with CHARGE Syndrome

Rachel Wilson and Timothy S. Hartshorne, Ph.D.

Presenter Information

Rachel is a junior at Central Michigan University. Currently, she is working on finishing a degree in psychology and is involved in the CHARGE lab on campus led by Tim Hartshorne. Her project is focused on psychotropic medications used on children with CHARGE syndrome.

Presentation Abstract

Psychotropic medications are often prescribed to children with CHARGE as a way to reduce challenging behaviors. Issues concerning prescribing children with CHARGE psychotropic medications include lack of prospective research done on long term effects of these medications, off-label prescribing, side effects, and the effect these drugs have on the child's ability to communicate.