



Sunday, August 4, 2019

Breakout Session E28 • 10:45-11:45 am • Chantilly Ballroom East

“CHARGE Syndrome Is Only a Part of You!”: How and When To Tell Your Child They Have CHARGE Syndrome

Haley Grant, Mississippi State University

Mary Aultman Hurley, Mississippi State University

Kasee Stratton-Gadke, PhD, Mississippi State University

Presenter Information

Haley Grant is a first-year educational specialist graduate student in the School Psychology program at Mississippi State University. She has been involved in the Bulldog CHARGE Research Lab since 2016 as an undergraduate and is excited to continue research with CHARGE throughout her graduate studies. Haley attended the 2016 International CHARGE Conference in Orlando, FL, presenting research. She hopes to expand her research within the field of school psychology regarding Individualized Education Plans and crisis management. She is currently working on campus as a graduate assistant in Disability Support Services serving students directly providing organizational and time-management advice. Haley also is a secondary clinician at the Autism and Developmental Disabilities Clinic on Mississippi State University's campus.

Mary Aultman Hurley is a first year Educational Specialist Student in the School Psychology program at Mississippi State University. She received her bachelor's degree in special education at Mississippi State University and received a concentration in Severe and Profound Special Education. During an internship, Mary was able to work with a student with CHARGE focusing on adaptive and educational skills. Mary continues to work with the Bulldog CHARGE Syndrome Research Lab at MSU, and maintains clients at the Autism and Developmental Disabilities Clinic. Ms. Hurley also works in Disability Support Services as a Graduate Assistant.

Dr. Kasee Stratton is an assistant professor in School Psychology at Mississippi State University, as well as a licensed psychologist and nationally certified school psychologist. Dr. Stratton has been involved with the CHARGE community and conducting research for 15 years and is the director of the Bulldog CHARGE Syndrome Research Lab at Mississippi State University. Dr. Stratton's clinical work has been with children and adolescents with a wide range of developmental disabilities and significant behavioral concerns. She is currently the Co-Director of the Autism and Developmental Disabilities Clinic at Mississippi State University where she supervises and provides services from an applied behavior analytic perspective enhancing skills (i.e. communication, social, behavioral, adaptive skills) and minimizing problem behaviors.

Presentation Abstract

When and how do I tell my child they have CHARGE syndrome? While each family will decide when the time is right for them, it is never too early or too late to learn how to begin this discussion. This presentation will cover the benefits of letting your child know about CHARGE and will address specific talking points. Child- and family- friendly strategies for introducing the diagnosis to your child and continuing the conversation will be presented. Dr. Stratton has worked with many families introducing this topic and will share examples and things to avoid when discussing this topic.

Learning Objectives

- To provide an opportunity for parents/caregivers to learn how to begin the discussion of the diagnosis of CHARGE with their child.
- To raise awareness about the benefits of each child with CHARGE understanding their diagnosis.
- To equip parents/caregivers with the tools necessary to teach their child about CHARGE.

“CHARGE Syndrome Is Only A Part of You!” How and When to Tell Your Child They Have CHARGE Syndrome

Haley Grant, Mary Aultman Hurley, &
Kasee Stratton Ph.D., NCSP



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Fears, Worries, and Thoughts

He/she has to know how to
take care of themselves

I don't want to scare them.

They cannot fully comprehend
this, so how can I say it on
their level?

Since they go from doctor to
doctor, I want them to be
aware of what is going on.

How do I even start this
conversation?

My child has realized he/she is
different. What now?



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6 Reasons Why You Should Tell Your Child About the Disorder

1. Self-advocacy skills are a must
2. If you don't tell them, someone else might
3. As a parent, you should be in control of the first conversation
4. Keeping it a secret may assume that this is a bad/negative thing
5. Most kids know there are difference and will be relieved
6. Not knowing the diagnosis doesn't change the diagnosis



What Do We Know?

- There is no current research regarding disclosure of CHARGE Syndrome
- Little research in general about disclosure
 - The most commonly disclosed disorders in the literature are ADHD and Autism Spectrum Disorder (Williams, 2014)
 - DiGeorge Syndrome (Faux et al., 2012), common barriers were not knowing what words to use or how to initiate the discussion
 - Minimal guidance on how to navigate the conversation
 - Disclosure occurred in stages



Building Blocks of Conversation

- When do you begin?
 - There is no specific age
 - This is personal to your child, not a general understanding
 - Seek normalcy. *What would you do if your child was adopted?*
- Considerations
 - Your child's development
 - YOUR understanding on CHARGE
 - Their comprehension of information
 - Any additional diagnosis such as depression or anxiety
 - Will you or your child need help from a professional?

How and when, not if!



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Building Blocks

- Make your tone unique and open in your home
- This is not a one-time conversation, this conversation can be over time depending on your child's comprehension
- Include siblings in this conversation, they want to know and might have just as many questions
- Be thoughtful of your responses
 - The more uncertain or tense you appear, the greater concern your child will have (possibly siblings as well!)
 - Role play can sometimes help 😊



Building Blocks

- Be simple, HONEST, and to the point → avoid false hope
- Be CONCRETE
 - Your child doesn't need to know the latest research on CHARGE Syndrome, be mindful of their age and what they can understand
- This will likely be more difficult for you than your child
- Be open to them having questions or thoughts afterwards
- Listen, Listen, Listen!
- Acknowledge your child's feelings
- Open the door for the conversation to continue



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How to Keep the Conversation Open and Continuous

- Use the words "CHARGE Syndrome"
- Keep your child informed about health and medical plans
- Encourage them to have questions and comments
- Provide alternative options



How will this Benefit your Child?

- Better understanding
- Independence
- Self-advocacy
- Self-awareness
- Realistic expectations
- Safety
- Positivity about their medical conditions



Peer Groups

- Allowing your child to understand their diagnosis will give them the power to have conversations with others
- A part of our role is informing group, but at the same time allowing your child to have a voice
 - Peers who are knowledgeable of disabilities or different diagnoses become allies



Positives of CHARGE

- Second language (ASL, Cued Speech, etc.)
- Greater knowledge of medical terminology impact career paths
- Meet other families and peers you wouldn't have met otherwise
- Strong and powerful and have defied most odds
- Great personality
- No sense of smell means you don't have to smell your stinky brother or sisters socks



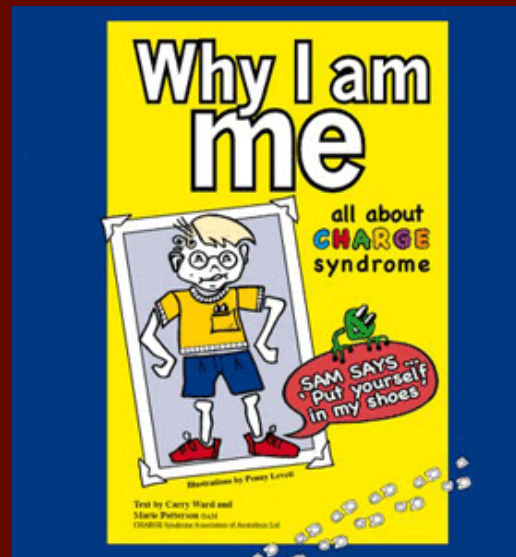
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Strengths and Areas of Improvement for Everyone

- Emphasize that everyone has strengths and areas of improvement (Williams, 2014)
- Tie this conversation to your child's strengths



Resources, Resources, Resources



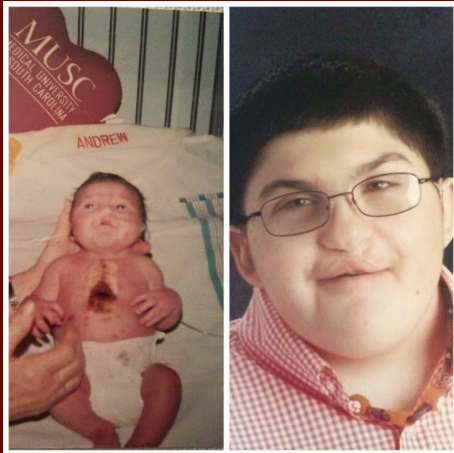
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Story Book

- You want your child to see how far they have come!
- Make a story book of their life to show them how strong they have been throughout this journey
- Make a fun and friendly title such as “****’s Adventure!”
- Gather photos from their life and have fun captions to chronologically tell their story
- Use strong words such as powerful, super-kid, and fighter



Andrew's Story



From then to now, you have been so strong! You were born fighting and that made you into who you are today.



At the beginning, things were really scary, and sometimes they still are!



Even though some things were harder for you, you kept a smile on your face!



It didn't stop you from having fun and making the best out of every situation!



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You're always willing to try new things including riding in a helicopter and changing schools and meeting new friends!



Let's not forget one of your most favorite things to do. Can you name some more?



Not every kid has experienced what you have which makes you super unique and one of a kind!



Sometimes you need extra support, but you are always able to find enjoyment in what you do! And to teach us valuable skills to help you.



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Just because life has thrown you some curve balls, doesn't keep you from being the life of the party. You're awesome!



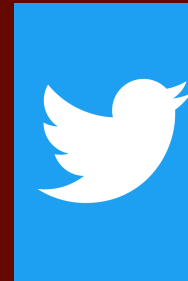
Mississippi State University

Haley Grant
Mary Aultman Hurley



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BulldogCHARGE Lab/](https://www.facebook.com/BulldogCHARGE Lab/)

Dr. Kasee Stratton-Gadke
kstratton@tkmartin.msstate.edu
662-325-5461
Mississippi State University
Director, Bulldog CHARGE Syndrome Research Lab



<https://twitter.com/BulldogCHARGE>



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