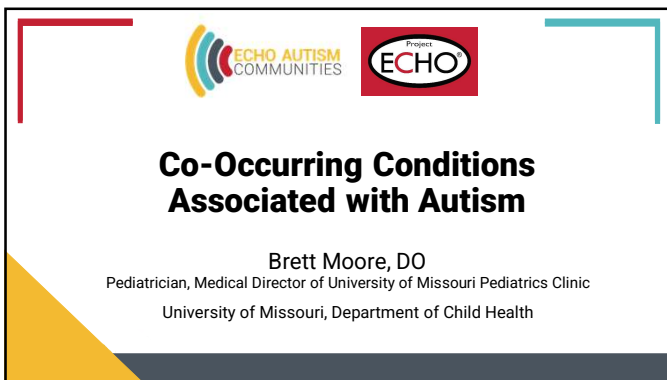




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Date	Topic	Presenter
06/17/2023	Autism/Asperger Therapy	Brett Moore & Lakin Murphy
06/19/2023	Transition to Adult Healthcare	Policy Check Centers
Educational System		
07/07/2023	Overview of the Education System - Birth to 3 years	Black Carter
07/12/2023	Overview of the Education System - 3 to 5 years	Lakin Murphy
08/04/2023	Post-Secondary Options and Employment	Andee Clark
Diagnosis & Funding		
08/14/2023	Overview of the DSM-5B System	Matt Waggoner
09/01/2023	Funding	Matt Waggoner
09/19/2023	Public & Private Insurance	George Mueller
Advocacy Topics		
10/09/2023	Medical Care for the Military Family	Wesley Larson & Mary Turner
10/26/2023	Autism	Wesley Larson, George
11/07/2023	Adult Community Living	De Chapman
11/13/2023	Diagnosis & Healthcare	Andee Clark
Advocacy Skills - Plus		
12/01/2023	Building up your community	De Chapman
12/15/2023	Local Support	De Chapman

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Learning objectives

- Know that those with autism are at higher risk of certain medical conditions
- Understand the are common comorbidities associated with autism
- Know who treats certain conditions
- Be able to give information to families regarding certain conditions



4

More than Meets the Eye



- **Autism is defined as a neurodevelopmental disorder**
 - CDC: "Autism spectrum disorder (ASD) is a [developmental disability](#) that can cause significant social, communication and behavioral challenges"
 - National Institute of Health: "Autism spectrum disorder (ASD) is a developmental disorder that affects communication and behavior. Although autism can be diagnosed at any age, it is said to be a "developmental disorder" because symptoms generally appear in the first two years of life."
 - Autism Speaks: "Autism, or autism spectrum disorder (ASD), refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication."
- **Usually no mention of other conditions**



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People with autism are at increased risk for:

- **More than just autism**
 - Medical concerns
 - Seizures
 - GI problems
 - Sleep Disorders
 - Behavior concern
 - Aggression
 - Anxiety
 - Depression
 - Challenging behavior



6

GI-GI-Ohhhh...

- GI problems, especially constipation, are common in ASD and can continue for years
 - Up to 4 times the general population
 - Associated with increased ASD severity
- Vague symptoms
- Statistically higher incidence in individuals with ASD
 - Can *cause* behavior changes
 - Can also be *caused* by behaviors



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Constipation

- Questions to ask
 - History of stooling (newborn period)
 - Pain or difficulty with stooling
 - Loose stools
 - Frequency of bowel movements
 - Appetite
 - Belly pain



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Constipation


- **Workup/Evaluation**
 - Check growth curve
 - X-ray of abdomen
 - Diet journal
 - Blood work
 - Check for celiac, thyroid disease, inflammatory bowel disease, electrolytes, blood count
- **If nothing serious is found:**
 - Conservative management
 - Possible cleanout followed by maintenance therapy



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Constipation- Treatment


- **Conservative**
 - Timed toileting
 - Increase fiber and water
 - Reward system
 - Social stories
- **Medication**
 - Cleanout
 - Enemas vs oral (think colonoscopy prep)
 - Maintenance with medicine
 - Can last for months



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Constipation and Medication

- **Lactulose**
- **Senna and docusate**
- **Miralax**
 - Generic name: Polyethylene glycol
 - Osmotic laxative
 - Powder- placed in any liquid
 - 6-8 oz no matter the amount
 - Finish within 30 minutes of starting
 - Push fluids
 - Change dose every 2-3 days until desired effect
 - 1-2 pudding stools a day



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Miralax Controversy

- In late 2000's, concern for ethylene glycol and triethylene glycol found in Miralax
 - Ethylene glycol=Antifreeze
- Company bought out
- Petition in 2012 to put warning label for neurologic and psychiatric effects




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Miralax Controversy

- FDA granted Children's Hospital of Philadelphia in 2014 to investigate
 - Unfortunately, the study has not started
- At least a 100 studies have found no link at this time
- Researchers at Nationwide Children's Hospital in 2018 found very low levels of all three compounds in both treated and untreated children. Baseline levels of ethylene glycol and triethylene glycol did not differ between the groups, while diethylene glycol levels were actually lower in the children receiving therapy than in the controls.



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Miralax-bottom line

- Safe initial treatment after conservative management has failed- verified by studies
- Other options are available
- If your child is having problems, discuss with doctor



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GI- Additional Concerns

- Oral Aversion
- Pica
- Restricted diet
- GERD
- Inflammatory Bowel Disease
 - Crohn's
 - Ulcerative Colitis



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Who to see?

- Most GI issues can be taken care of by the primary provider
- May need help from a gastroenterologist, who specializes in the whole GI system (intestines, stomach, liver, gallbladder, colon)
- Sometime patients will need to be in a hospital for further workup



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Seizures

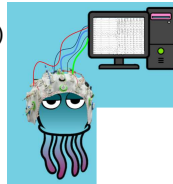
- **Common in autism and persist into teen and adult years**
 - Higher incident than general population
- **First seizure can occur in adult years**
- **Epilepsy: neurologic disorder with abnormal brain activity that causes seizures or periods of unusual behaviors, sensations or loss of awareness**
 - Cause of early premature death in autism



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Seizures



- Can come in many different forms
- Shaking episodes (tonic-clonic)
- Eye flutter
- Loss of muscle tone
- **Staring episode**
 - Sometimes seen with autism as a behavior, so important to distinguish



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Seizures- Questions to ask


- Stiffening of muscles
- Fainting
- Staring- does not respond to snapping finger in front of eye, dilated pupils
- Jerking movements (not able to stop)

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Seizures- What to do


- **Have family keep dairy**
 - How long
 - Seemed tired after incident, how long before normal self
 - Loss of bowel or bladder
 - Family history
 - Anything that happened right before
 - Any new medications



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Seizures- Treatment

- Will likely need an EEG
- Will likely need head imaging at some point
- Likely be placed on medication
- Seizure precautions
 - Never alone by fire, bath, heights, etc.



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Who to see?

- May need to see primary provider first for a referral
- If needed, referral to a neurologist



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Sleep

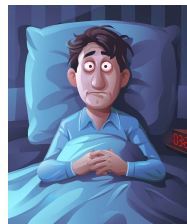
- 50-80% of children with autism
- Persists into the teenage years
- Can cause challenging daytime behaviors
- Parental stress is related to poor sleep in children
 - Which happened first?



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Insomnia

- Trouble falling asleep
- Trouble staying asleep
- Early morning awakenings
- Causes
 - Natural nature of autism (over arousal)
 - Medication
 - Sleep apnea (snoring loudly, pauses in breathing)
 - Sleep hygiene (screens, caffeine, limited exercise)



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Sleep- Questions to ask

- Night time/bedtime routine
- How long to fall asleep
- Waking in the night
- Snoring (how loud)
- Restless sleep (legs moving a lot)
 - Check diet (iron)



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Sleep-evaluation and treatment

- Sleep log
- Sleep habit intervention
- Monitor snoring, seizures or other medical conditions (eczema)
- Sleep study
- Check iron or ferritin (iron stores in body)
- Treatment- after ruling out other causes
 - Melatonin (can cause vivid dreams)
 - Other medications (prescription)



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Who to see?

- Start of with primary provider to see what the biggest concerns are
- There are sleep specialists who see patients as well as look over the sleep study (also called polysomnograms or PSG)



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Behavior Concerns

- Aggression/challenging behavior
 - Is this new, has something changed
- Anxiety
 - Can present as behavior "problems" in all children
- ADHD
 - Vanderbilt forms
- Depression
 - Maybe hard to determine, especially if non-verbal
 - Increased rate of suicide in those with a



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Behavior concerns- How to Address

- Discuss with PCP
 - Write down in changes recently (school, home life, medications)
 - Review medical conditions
 - Are they controlled, have then changed recently
- May need more information
 - Vanderbilt forms for ADHD
 - Screen for Child Anxiety Related Disorders (SCARED) for anxiety
- Referral to specialist



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Who to see?


- Autism center
- Psychiatrist (medical doctor who evaluates and prescribes medicine)
- Psychologist (usually a PhD who analyzes, discusses treatment plan, may provide therapy, may not prescribe medicine)
- Behavioral pediatrician
- Neurologist



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Standard of Care


- All of these conditions should be reviewed with physician
 - Done yearly or when seen by their doctor for follow up for conditions
- ACN (Autism Care Network)
 - Helping to make this routine so all autism providers are aware of best care
- Families and advocates can help promote



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Resources:


- [Autism's Clinical Companions: Frequent Comorbidities with ASD | Children's Hospital of Philadelphia \(chop.edu\)](#)
- [Autism and Health: A Special Report by Autism Speaks | Autism Speaks](#)
- [Medical Conditions Associated with Autism | Autism Speaks](#)
- Your Friendly Neighborhood Physician



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References

- Kolves, K., Fitzgerald, C., Nordentoft, M., Wood, S. J., & Erlangsen, A. (2021). Assessment of suicidal behaviors among individuals with autism spectrum disorder in Denmark. *JAMA Network Open*, 4(1), e2033565. doi:10.1001/jamanetworkopen.2020.33565
- Madra M, Ringel R, Margolis KG. Gastrointestinal Issues and Autism Spectrum Disorder. *Child Adolesc Psychiatr Clin N Am*. 2020 Jul;29(3):501-513. doi: 10.1016/j.chc.2020.02.005. Epub 2020 Apr 2. PMID: 32471598; PMCID: PMC8608248.
- Wang LW, Tancredi DJ, Thomas DW. The prevalence of gastrointestinal problems in children across the United States with autism spectrum disorders from families with multiple affected members
- *Pediatr Rev* (2021) 42 (7): 360–374. <https://doi.org/10.1542/pir.2020-000547>



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