

Formed Families Forward Webinar

Fetal Alcohol Spectrum Disorders: Diagnosis and Beyond

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Disclosures

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I do not intend to discuss an unapproved/investigative use of a commercial product/device in our presentation.

Overview

Overview of FASD and the diagnostic criteria for diagnosis and role of screening.

Discuss the physical and behavioral characteristics for children with an FASD.

Describe referrals and the role of the medical home for a children with an FASD.

Have fun and learn!



FASD: Prevalence

- Prevalence in a Midwestern city (May, 2014)
 - FAS: 6-9/1000 children
 - All FASD: 24-48 /1000 children (2.4% to 4.8%)
- Increased prevalence among children in child welfare (Lange, 2013)
 - FAS: 60/1000 children (6%)
 - All FASD: 169/1000 children (16.9%)

FASD: Perspectives on Prevalence

Birth defect	Prevalence
Down syndrome	1.2/1000 births
Cleft lip +/- palate	1.2/1000 births
Spina bifida	1/1000 births
Autism	12.5-14/1000*
Fetal Alcohol Syndrome (FAS)	6-9/1000*
All FASDs	24-48/1000* (May, 2014)

*per 1000 school age children

Prenatal Alcohol Exposure: Relevance to Maternal and Child Health

- Most common *preventable* cause of intellectual disability and behavior problems – likely seen in most pediatric practice.
- Effects can be *lifelong*.
- Effect development and function more so than other drugs or teratogens. Can contribute to a range of growth deficits and structural anomalies (FASD)

The Umbrella of FASD



Fetal Alcohol
Syndrome (FAS)

Partial Fetal Alcohol
Syndrome (pFAS)

Alcohol Related
Birth Defects
(ARBD)

Alcohol Related
Neurodevelopmental
Disorder (ARND)

Neurobehavioral
Disorder-associated
with Prenatal Alcohol
Exposure (ND-PAE)

FASD Terminology and Acronyms

- **PAE: Prenatal Alcohol Exposure**
- **FASD: Fetal Alcohol Spectrum Disorders**
 - Umbrella term for a range of effects that can result from prenatal alcohol exposure (not a diagnosis)
 - Encompasses a group of specific disorders (more on these later), including:
- **FAS: Fetal Alcohol Syndrome**
 - The most widely known diagnosis in the spectrum
- **ARND: Alcohol Related Neurodevelopmental Disorder**
 - Used in some dx schemes for individuals without physical characteristics
- **ND-PAE: Neurobehavioral disorder associated with prenatal alcohol exposure.**
 - New category in DSM-5 Section III: Emerging Measures and Models
 - Defines more precisely the developmental and behavioral manifestations associated with PAE

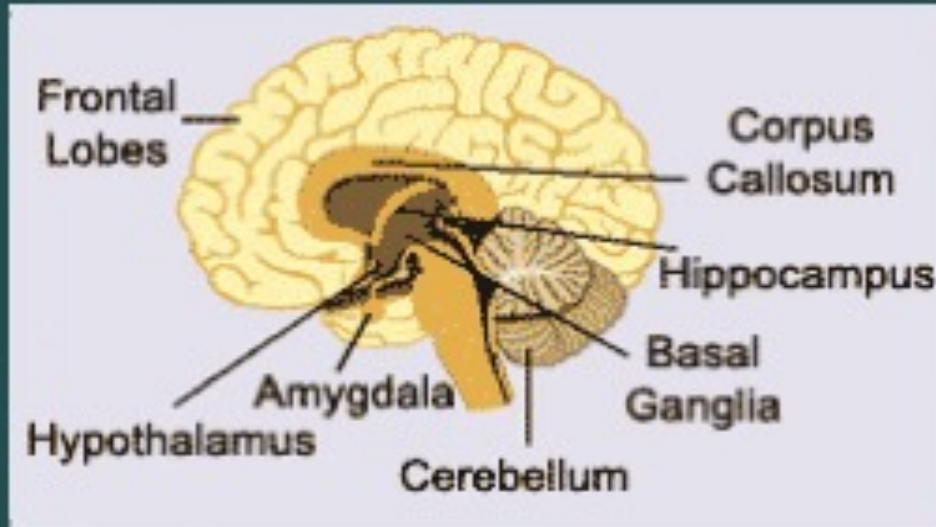
When to Consider a FASD Diagnosis?

- Developmental, cognitive, or behavioral concerns
- Complex medical concerns (e.g. cardiac)
- Growth deficits
- History of maternal alcohol or drug use
- A sibling diagnosed with a FASD
- Dysmorphic facial characteristics associated with FAS are present

Areas of the Brain Affected By Prenatal Alcohol Exposure

Frontal Lobes – impulses and judgment; controls executive function

Hypothalamus - appetite, emotions, temperature, and pain sensation



Corpus Callosum- passes information from the left brain (rules, logic) to the right brain (impulse, feelings) and vice versa.

Hippocampus – memory, learning, emotion

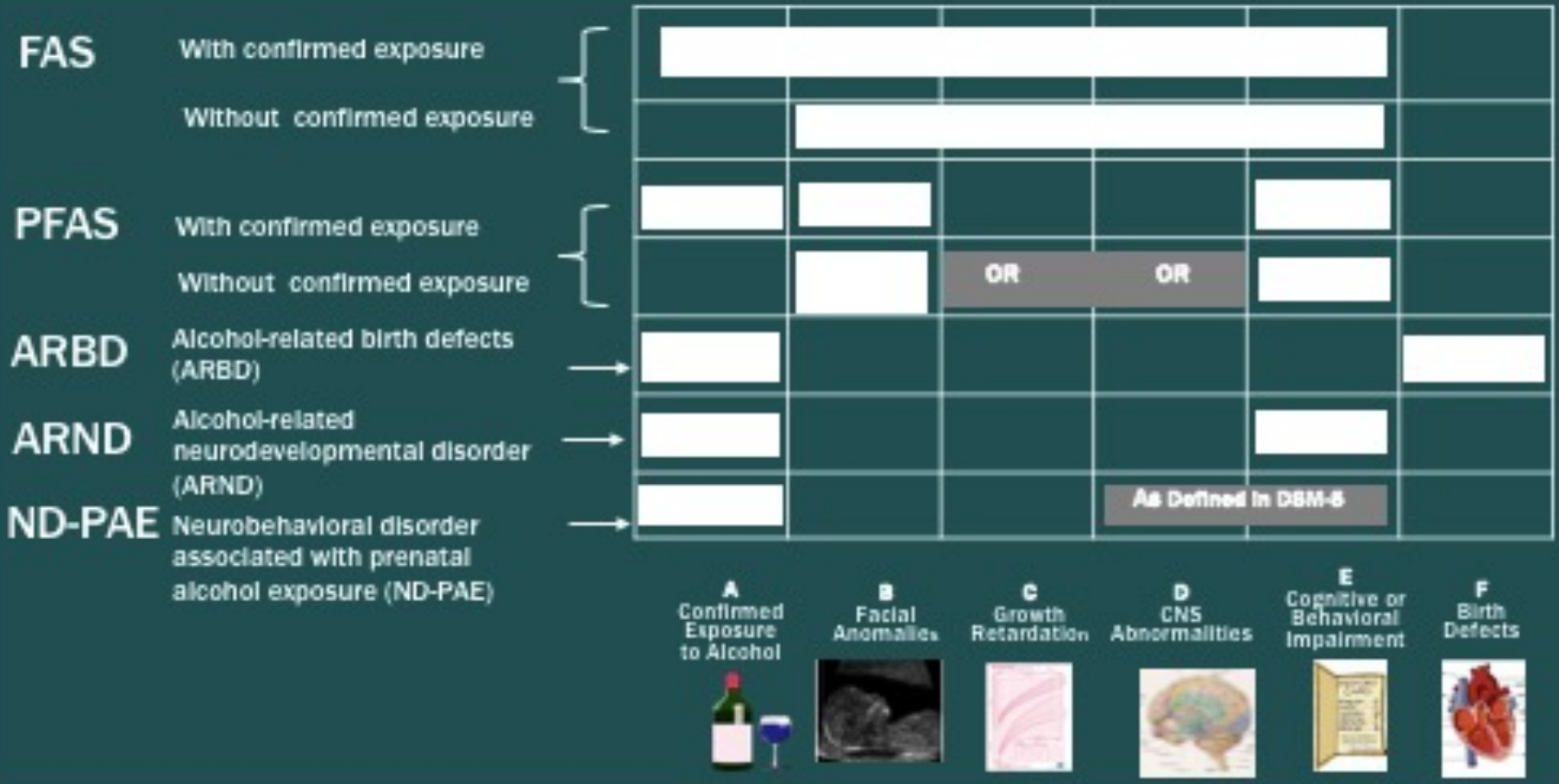
Amygdala - emotions

Cerebellum - coordination and movement

Basal Ganglia - spatial memory, switching gears, working toward goals, predicting behavioral outcomes, and the perception of time

Source: Dr. Sarah Mattson, University of San Diego

Spectrum of FASD



Potential Benefits of a Diagnosis

- Parental relief
- Access to evidence-based interventions
- Avoids unnecessary testing, referrals, and interventions
- Reduce recurrence

Why Pediatricians Do Not Routinely Screen for FASD

- Insufficient training
- Discomfort in making the diagnosis
- Stigma
- Don't ask.....don't tell

Record Review & History

- Prenatal Alcohol Exposure History
- Birth records (weight, length, head circumference)
- Medical history/records (birth defects?, exposures?)
- Postnatal growth records
- Developmental/behavioral history
- Psychological testing, including cognitive and behavioral assessments

Conversations with Mothers: Practice Compassion (NOFAS.org)

- Be gentle, ask questions, and listen
- Stick to the facts
- Be non-judgmental, avoid stigmatizing language
- Remind her that you care about her child, her, and their family
- Use person first language, e.g. “child with a FASD”

AAP's Bright Futures

AAP's Bright Futures suggest three screening questions for the pediatric situation:

- How often do you drink beer, wine or liquor in your household?
- In the 3 months before you knew you were pregnant, how many times did you have 4 or more drinks in a day?
- During your pregnancy, how many times did you have 4 or more drinks in a day?

If a positive response is obtained, additional questions about amount, frequency and timing may be appropriate for diagnostic purposes.

ASSESSMENT DOMAINS FOR DIAGNOSIS

- History of Prenatal Alcohol Exposure
- CNS (structural, neurologic, functional)
- Growth
- Dysmorphic Facial Features

Best Definition of Cognition and Behavior in FASD: ND-PAE

- DSM-5 emerging diagnosis
- Criteria describes impairment in *neurocognition, self-regulation and adaptive function,*
- Diagnosis is made in the context of confirmed prenatal alcohol exposure,
- Criteria do not require the presence of physical features

Neurobehavioral Effects

Neurocognitive deficits

- Low IQ or developmental delay
- Executive functioning deficits
- Impaired learning, memory or specific learning problems (esp. visual-spatial and math)
- Motor functioning delays for younger children



Neurobehavioral Effects

Self-regulation problems

- Self-soothing, sleep
- Difficulty managing mood
- Behavior management issues
- Attention problems (esp. shifting attention)
- Poor impulse control

FASD: Role of the Medical Home

Role of the pediatrician:

- ❖ Initial Developmental screening
- ❖ Close monitoring
- ❖ Provide patient and family centered care
- ❖ Care coordination in the medical home with needed providers (e.g. mental health, education, social services)
- ❖ Referral for diagnosis, specialty assessments (e.g., mental health, occupational therapy, family counseling, etc.)
- ❖ Documentation
- ❖ Develop care plan & coordination for children with FASD and families
- ❖ Provide, and help digest, scientific as well as other reference materials

Pathway to a Diagnosis

- The AAP FASD Toolkit (www.aap.org/fasd) is a comprehensive resource for identification, diagnosis and medical home management on patients with a FASD
- Toolkit includes information on common diagnostic approaches and tools, a flow diagram for evaluation of FASDs, and guidelines for referral and diagnosis.



a program to enhance the health & development of infants & children

Fetal Alcohol Spectrum Disorders Program

A program of the American Academy of Pediatrics in cooperation with the Centers for Disease Control & Prevention

Toolkit

The Fetal Alcohol Spectrum Disorders (FASD) Toolkit was developed to raise awareness, promote surveillance and screening, and ensure that all affected children receive appropriate and timely interventions.

This toolkit is designed to ensure that all affected children receive appropriate and timely interventions.



CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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The Role of Integrated Care in a Medical Home for Patients With a Fetal Alcohol Spectrum Disorder

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Referrals

- For diagnosis: If uncertain whether findings satisfy criteria, depending on available resources:
 - FASD diagnostic clinic
 - Genetics and dysmorphology clinic
 - Neurodevelopmental/behavioral pediatrician
 - Neuropsychologist or behavioral psychologists for ND-PAE or ARND
- For treatment/care needs and care planning or management:
 - Neuropsychologist, clinical or school psychologist, early intervention
 - SLP, OTR or PT as indicated
 - Social work
 - Medical specialists as indicated (e.g., Otolaryngologist to address frequent ear infections)

Alcohol use during pregnancy can lead to lifelong effects.

Up to **1 in 20** US school children may have FASDs.



People with FASDs can experience a mix of the following problems:

Physical issues

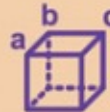
- low birth weight and growth
- problems with heart, kidneys, and other organs
- damage to parts of the brain



Which leads to...

Behavioral and intellectual disabilities

- learning disabilities and low IQ
- hyperactivity
- difficulty with attention
- poor ability to communicate in social situations
- poor reasoning and judgment skills



These can lead to...

Lifelong issues with

- school and social skills
- living independently
- mental health
- substance use
- keeping a job
- trouble with the law



Drinking while pregnant costs the US **\$5.5 billion** (2010).



SOURCES: CDC Vital Signs, February 2016. American Journal of Preventive Medicine, November 2015.

Resources

- American Academy of Pediatrics (AAP): [aap.org/fasd](https://www.aap.org/fasd)
- Centers for Disease Control and Prevention (CDC): [cdc.gov/ncbddd/fasd](https://www.cdc.gov/ncbddd/fasd)
- National Organization on Fetal Alcohol Syndrome: [nofas.org](https://www.nofas.org)
- National Institute on Alcohol Abuse and Alcoholism: [niaaa.nih.gov](https://www.niaaa.nih.gov)

Take Home Messages

FASD are more common than recognized. You most likely know/meet children with an FASD.

Obtaining history and screening prenatal exposure to alcohol is good practice and should be routine for all patients.

Behavioral issues are variable and warrant referral and intervention.

FASD is 100% preventable. Let's work together.

Questions?



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