

# American Academy of Pediatrics

## Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

Presented by:



American Academy  
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN®



# Acknowledgments

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- David Wargowski, MD, Kenneth L Jones, MD, Prachi Shah, MD, Yasmin Senturias, MD, Vincent C Smith, MD, MPH FAAP, H. Eugene Hoyme, MD, and Miguel Del Campo, MD (Screening, Assessment, and Diagnosis)
- Yasmin Senturias, MD, FAAP (ND-PAE)
- Yasmin Senturias, MD, FAAP, Vincent C Smith, MD MPH FAAP, and Prachi Shah, MD (Treatment Across the Lifespan for Person with FASD)

# Learning Objectives

1. Describe diagnosis of ND-PAE
2. Explain the importance of obtaining prenatal alcohol exposure information on *EVERY* patient
3. Describe ND-PAE across development



# The Umbrella of FASDs



- Fetal Alcohol Syndrome (FAS)

- Alcohol Related Birth Defects (ARBD)

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

- Partial Fetal Alcohol Syndrome (pFAS)

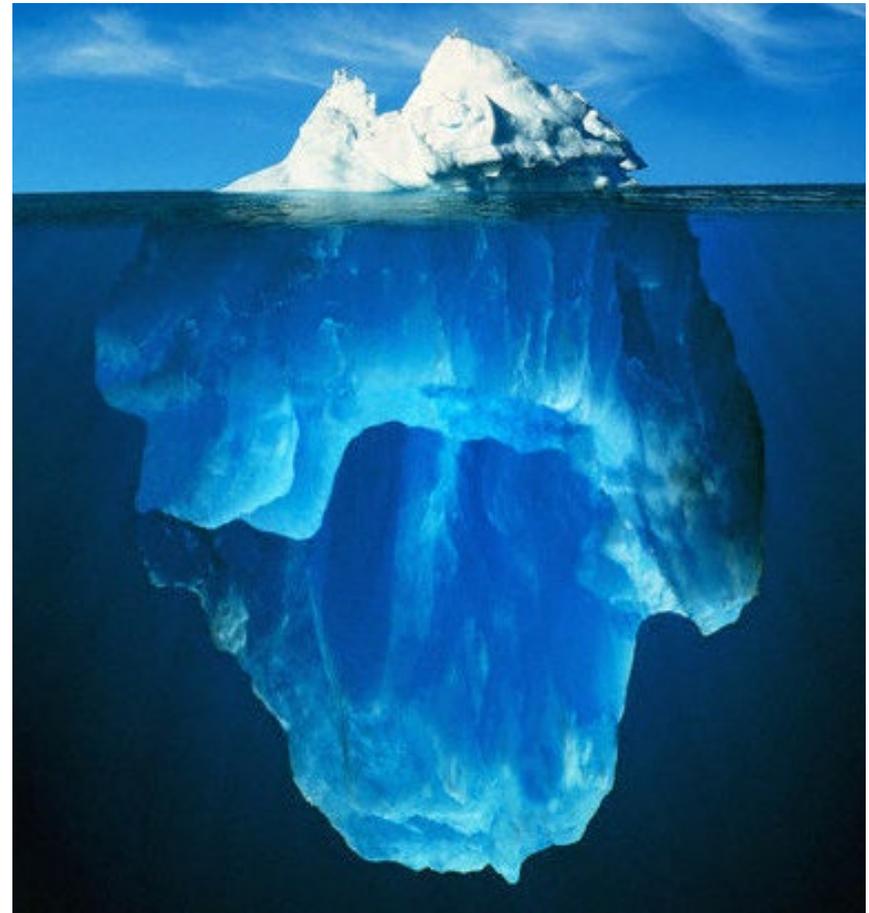
- Alcohol Related Neurodevelopmental Disorder (ARND)

# Diagnoses Resulting from In Utero Exposure to Alcohol

**ARBD** – Congenital anomalies only  
(very rare)

**FAS & pFAS** – Most widely known  
of the FASDs with physical and  
neurodevelopmental characteristics  
(rare)

**ARND/ND-PAE** –  
Neurodevelopmental/behavioral  
effects w/o physical features  
(extremely common)



# ARND & ND-PAE

## VERY SIMILAR

Diagnoses that reflect adverse effects of prenatal alcohol exposure w/o physical features

### ARND

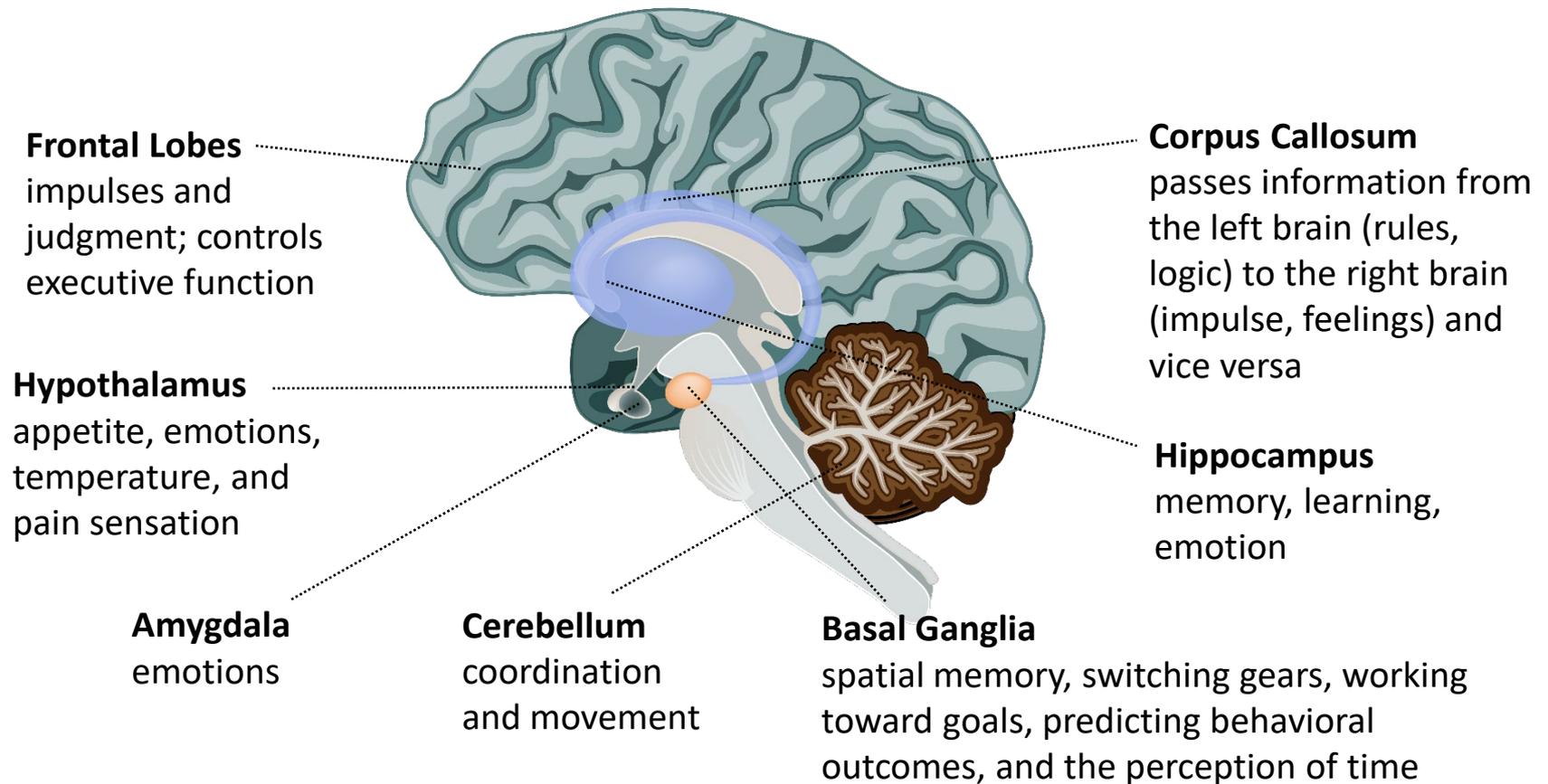
- Primarily a research operational definition adapted to clinical settings
- Requires standardized testing

### ND-PAE

- Clinical diagnosis in the framework of other mental health diagnoses delineated by APA
- Dx can be comorbid with FAS or pFAS

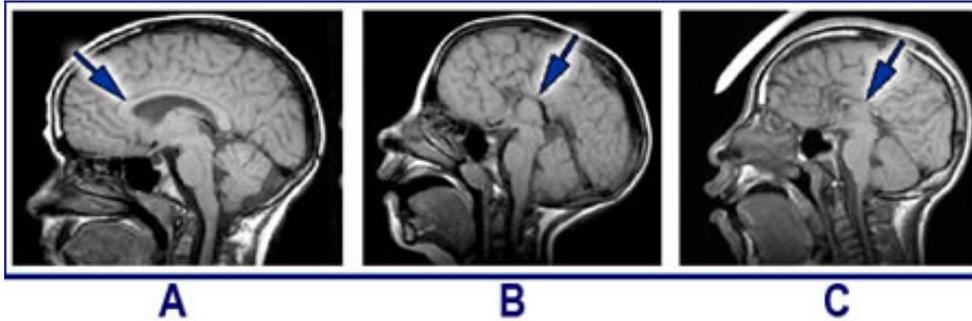
**Both diagnoses require confirmed in utero exposure to alcohol**

# Areas of the Brain Affected By Prenatal Alcohol Exposure



# Alcohol Effects on the Brain

## Corpus callosum



- A. Control child age 14 y with normal corpus callosum
- B. Child age 12 y with FAS and a thin corpus callosum
- C. Child age 14 y with FAS and agenesis of the corpus callosum

Source: Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1): 49-52.



Brain of baby with no exposure to alcohol compared to the brain of baby with heavy exposure to alcohol

Photo courtesy of Sterling Clarrrens, MD

# Prenatal Alcohol Exposure/ND-PAE: Relevance to Pediatric Practice

- Most common *preventable* cause of intellectual disability and behavior disorder
- Lifelong effects
- More serious effects than other drugs or teratogens

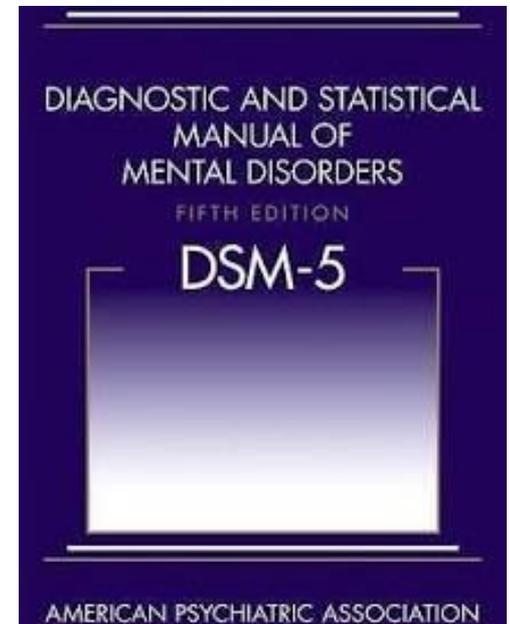
*“Of all the substances of abuse, including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”*

- Institute of Medicine, 1996

# Overview: Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

## DSM 5 Diagnostic Criteria

- 3 domains of impairment
  - Neurocognitive deficits
  - Problems with self-regulation
  - Delayed adaptive skills
- Known prenatal exposure to alcohol at more than minimal level
  - 13+ drinks in one month
  - With no more than 2+ drinks consumed on any occasion





# Prenatal Alcohol Exposure History in Context of Routine Care

- Part of all well child assessments
  - Ideally before a development/behavior problem arises
- Review all potential exposures
- Review family, social and pregnancy histories
- Explain that alcohol is commonly consumed, often before pregnancy is recognized



# Prenatal Alcohol Exposure History in Context of Routine Care

- Use open-ended questions
  - EXAMPLE:** “Tell me about your alcohol use in the 3 months prior to finding out you were pregnant.”
  - NOT:** “You didn’t drink while pregnant, did you?”
- Ask about partner’s drinking habits
- Provide assurance that to provide the best care possible it’s important to know all of the facts about the pregnancy



# 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.

# AAP Bright Futures

## Suggested contact points:

- All prenatal visits
- The earliest well child visits
- All new patient visits
- Whenever a related concern is observed or raised





# 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”

# ND-PAE

## Neurocognitive deficits

- Low IQ or developmental delay
- Executive functioning deficits
- Impaired learning (esp. math)
- Memory impairment
- Problems of visual-spatial reasoning

# ND-PAE

## *Self-regulation problems*

- Difficulty managing mood and/or behavior management issues
- Attention problems (esp. shifting attention)
- Poor impulse control

# ND-PAE

## *Difficulty learning/Delayed adaptive skills*

- Communication deficits in language acquisition or comprehension
- Problems with social communication or interactions especially social communications (e.g., understanding idioms or jokes)
- Problems with self care/daily living skills
- Motor issues in younger children

# ND-PAE Across Development: Neonatal & Infancy

- **NEUROCOGNITIVE**
  - Developmental delay
- **SELF-REGULATION**
  - Difficulty with self soothing – easily overstimulated (affects sleep)
  - Poor habituation irritability – avoid overstimulation
- **ADAPTIVE SKILLS**
  - Poor suck, poor motor skills – will need therapy



# ND-PAE Across Development: Toddler to Pre-K

- **NEUROCOGNITIVE**
  - Difficulty following/understanding instructions
- **SELF-REGULATION**
  - ADHD picture
  - Prolonged tantrums
  - Sleep problems
- **ADAPTIVE SKILLS**
  - Delays in gross/fine motor and adaptive skill



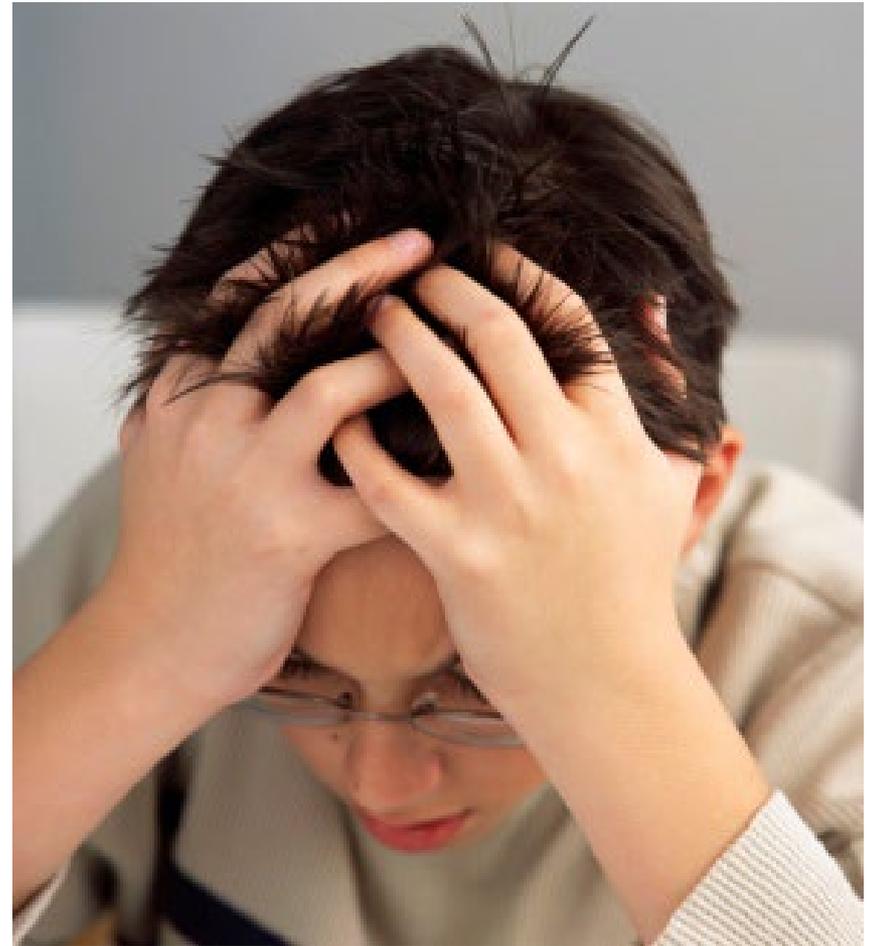
# ND-PAE Across Development: Kindergarten to 6<sup>th</sup> Grade

- **NEUROCOGNITIVE**
  - Delayed overall development
  - Learning
- **SELF-REGULATION**
  - Inattention
  - Tantrums, with low frustration tolerance
- **ADAPTIVE SKILLS**
  - Naïve, easily influenced, difficulty reading social cues
  - Seems to act younger than their age, immaturity



# ND-PAE Across Development: Middle School and Beyond

- **NEUROCOGNITIVE**
  - Cognitive problems, poor organizational skills/executive functions
  - Academic difficulties – math and reading comprehension
- **SELF-REGULATION**
  - Behavioral outbursts
- **ADAPTIVE SKILLS**
  - Naïve, easily influenced by others – needs parent to help make good choices





# Potential Differential and Comorbid Diagnoses

## *Behavioral disorders examples*

- ADHD
- Intellectual disability
- Early trauma
- Conduct disorder/oppositional defiant disorder
- Parenting issues



# Delivering the Diagnosis

- Show compassion
- Use active listening
- Be sensitive to the possibility of stigma
- Discuss treatment options, better parent-child interactions



# When to Consider a ND-PAE Diagnosis?

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



# Why Pediatricians Do Not Routinely Screen for ND-PAE

- Insufficient training
- Discomfort in making the diagnosis
- Stigma

# Pathway to a Diagnosis

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

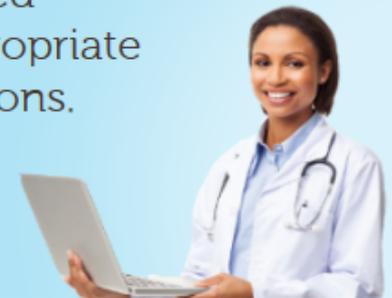


## Toolkit

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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.



# Diagnosis Established

## *What now?*

- Counsel re: risk of neurodevelopmental manifestations over time, need to intervene to avoid secondary conditions.
- Medical home: [aafp.org/practicemanagement/transformation/pcmh.html](https://www.aafp.org/practicemanagement/transformation/pcmh.html)
- AAP toolkit: [aap.org/fasd](https://www.aap.org/fasd)

# Interprofessional Care for Patients with FASD

## Health Care is Changing

- Move towards outcomes-based, value-based and **team-based** care.
- Reimbursement with the Medicare Access & CHIP Reauthorization Act of 2015 (MACRA) will support values-based care and reimburse **team-based** care.

More information on potential team members is available in the AAP FASD Toolkit

## Interprofessional Care

- Create and develop a team from different specialties to collaborate in planning & care.
- Establish a common goal
- Care should be interdependent, complimentary, coordinated.
- The patient and family should be considered team members if practicable.



# Why ND-PAE Diagnosis and Evaluation Matter

- It helps facilitate understanding of the child's strengths and challenges as it relates to neurobehavioral functioning
- It helps provide the framework for the parents and teachers to provide the environment necessary for the child to succeed
- It helps provide the developmental and educational interventions that could lead to better outcomes

# Take Homes

- ND-PAE is more common than recognized and may be easily missed or mis-diagnosed
- You most likely have children in your practice with ND-PAE

# Take Homes (Continued)

- Obtaining history of prenatal exposure to alcohol is good practice and should be routine for all patients
- Issues indicative of ND-PAE can arise at any point in development
- Diagnosis of ND-PAE can facilitate better child and family outcomes

# Review

The diagnosis of ND-PAE (DSM-5) requires:

- Confirmed alcohol exposure,
- Neurocognitive impairment,
- Self-regulation impairment, and
- Deficits in adaptive functioning



# Review

Traditional behavioral therapies may not work best for children with a ND-PAE.

- Recommended for children diagnosed with ND-PAE:
  - Regularly scheduled follow-up in the medical home
  - Evaluation by a psychologist to assess neurocognition and behavior
  - Medication management for co-occurring conditions if necessary

# References

- Mattson, S.N, et al (1997). MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1): 49-52.
- DSM-5, American Psychiatric Association, 2013, p.799.
- Hagan JF, Balachova T, Bertrand J, et al. Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure. *Pediatrics*. 2016;138(4): e20151553.
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# Questions?



# Comparing and Contrasting Alcohol Use and Opioid Use During Pregnancy

	Opioid Use During Pregnancy	Alcohol Use During Pregnancy
<b>Prevalence of use</b>	1.6%-8.5% of pregnant women use opioids; however, it's on the rise. <sup>1</sup>	Approximately 8.5% of pregnant women drink alcohol at some point during pregnancy. <sup>1</sup>
<b>Likelihood of developing</b>	NAS is seen in 30-80% of infants born to women who used opioids in the third trimester. <sup>2</sup>	2-5% of school age children may have FASDs. <sup>3</sup>
<b>Negative effects/ disabilities</b>	Neonatal Abstinence Syndrome (NAS) <sup>4</sup>	Fetal Alcohol Spectrum Disorders (FASDs) <sup>1</sup>
<b>Duration of effects</b>	Unknown <sup>4</sup>	FASDs last a lifetime <sup>5</sup>

# Comparing and Contrasting Alcohol Use and Opioid Use During Pregnancy (Continued)

	Opioid Use During Pregnancy	Alcohol Use During Pregnancy
<b>Cost of care</b>	Average of \$90,000 per case of NAS <sup>6</sup>	Estimate \$1.2-2.5 million per case of FAS <sup>7</sup>
<b>Screening and brief intervention</b>	Universal screening using the 5 P's tool, and brief intervention <sup>8</sup>	Universal screening using the AUDIT (US) tool, and brief intervention <sup>9</sup>
<b>Ethics</b>	Avoid separation of mother and child <sup>10</sup>	Avoid separation of mother and child <sup>10</sup>
<b>Treatment</b>	Medication-assisted therapy (MAT) <sup>2</sup>	Appropriate treatment referral for alcohol use disorder*