A stylized graphic of a plant with several leaves and a stem, rendered in shades of blue and white, positioned on the left side of the slide.

Fetal Alcohol Spectrum Disorders (FASDs)

Common, Complex and Unrecognized

AMERSA 47th Annual Conference

November 3, 2023

Washington DC

Agenda

- **Overview**.....*Daniel P. Alford, MD, MPH*
- **Personal Experience***Susan Terwey, MS*
- **The State of the Science***Jeffrey Wozniak, PhD*
- **Clinical Presentation & Treatment**.....*Vincent C. Smith, MD, MPH*
- **Prevention, Resources & Advocacy**.....*Kendra Gludt, MPH*
- **Final Thoughts**.....*Susan Terwey, MS*

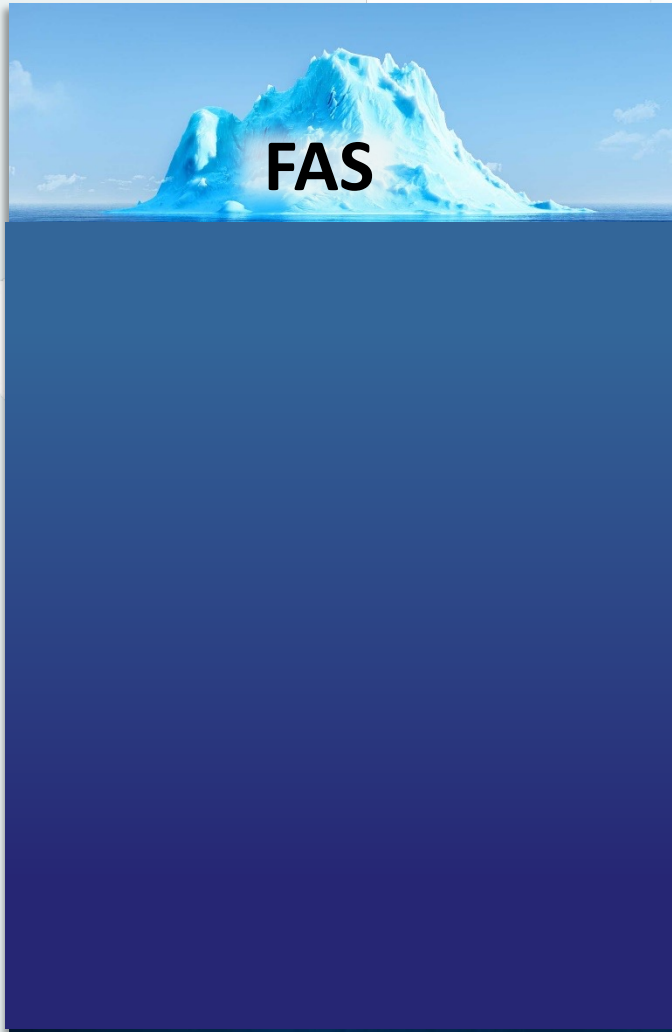
Learning Objectives

- Describe the full spectrum and prevalence of FASDs
- Summarize the neuropathology of prenatal alcohol exposure (PAE)
- Discuss stigma and shame as it relates to PAE
- Describe clinical presentations and evidence informed care of individuals with an FASD
- Name prevention efforts and national resources that support individuals and families affected by FASDs

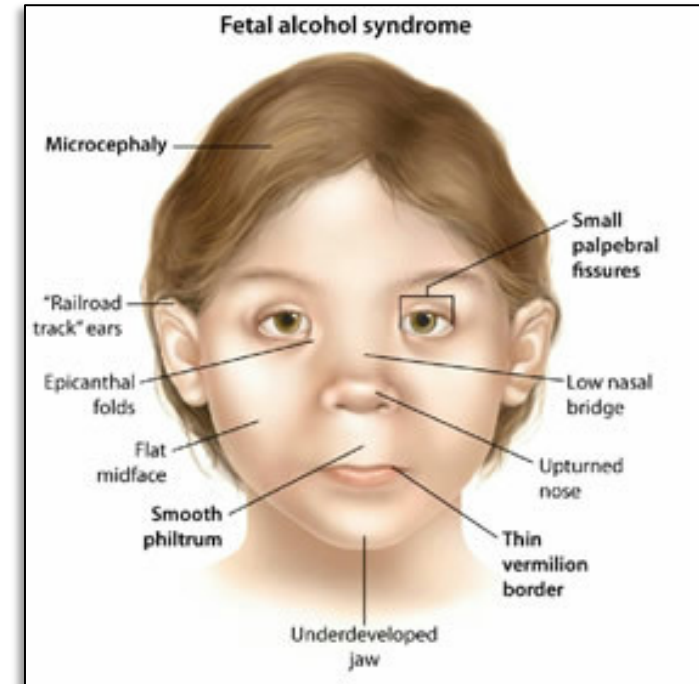
Fetal Alcohol Toxicity

- Experimental and clinical studies demonstrate alcohol is a teratogen
- Prenatal alcohol exposure can impair brain development throughout all stages of gestation
 - Alcohol quickly equilibrates between the maternal and fetal compartments and rapidly reaches the fetus
 - The amniotic sac serves as a reservoir for alcohol, prolonging fetal exposure
 - Approximately 1 in every 13 infants prenatally exposed to alcohol will develop FASD
- Variables leading to fetal damage are complex and interrelated
 - Maternal and fetal genetics, maternal health and nutrition
 - Alcohol dose, pattern and timing of exposure
 - Binge drinking (4+ drinks/occasion) is associated with more severe effects

Fetal Alcohol Spectrum Disorders (FASDs)



- **FAS:** Fetal Alcohol Syndrome



Fetal Alcohol Spectrum Disorders (FASDs)

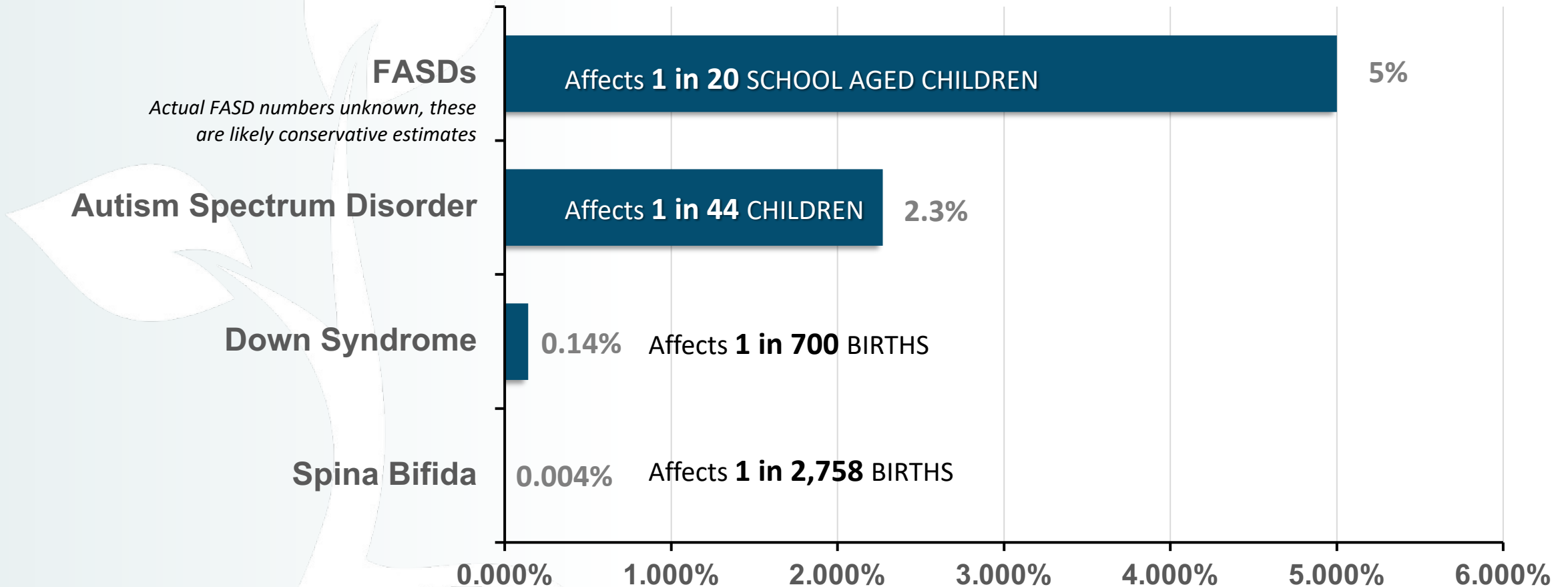
- FASDs are a range of conditions attributable to prenatal alcohol exposure that include behavioral, learning, and physical problems
- In the US, FASDs are the most common **preventable** developmental disabilities
- FASDs are **permanent**
- In the US, an estimated 1-5% of 1st grade children may have an FASD¹
- FASDs occur in all socioeconomic and ethnic groups²

1. May PA et al. *JAMA*. 2018

2. Popova S et al. *BMC Public Health*. 2019



Comparison of FASDs and Other Conditions



May JA, et al. *JAMA*. 2018

Popova S, et al. *Lancet Glob Health*. 2017

Williams JF, et al. *Pediatrics*. 2015

www.healthline.com/health/birth-defects

www.cdc.gov/ncbddd/autism/data.html

www.ndss.org/about-down-syndrome/down-syndrome/

www.cdc.gov/ncbddd/spinabifida/data.html

Prevention Challenge

Non-Pregnant Women of Reproductive Age

- 54% report alcohol use in previous 30 days¹
- 18% report binge drinking in previous 30 days¹

Unintended Pregnancies

- 49% of pregnancies are unplanned¹
- Pregnancy may not be known for up to 6 weeks or later into the pregnancy²

Pregnant Women

- 13.5% report alcohol use in previous 30 days³
- 5% reported binge drinking in previous 30 days³

1. Tan CH, et al. *Morb Mortal Wkly Rep*. 2015

2. Green PP, et al. *Morb Mortal Wkly Rep*. 2016

3. Gosdin LK et al. *Morb Mortal Wkly Rep* 2022

Reasons for Alcohol Use During Pregnancy

4 Themes

Theme 1: *Influence of individual beliefs*

- Belief alcohol has beneficial properties
- Belief alcohol is harmful only in specific types and quantities
- Belief alcohol is less harmful than other prenatal exposures (e.g., smoking)

Theme 2: *Influence of culture*

- Social acceptability and pressure for alcohol consumption
- Alcohol consumed as part of tradition and custom
- Alcohol consumed based on intuitive decision making influenced by personal/peer experiences in the community

Reasons for Alcohol Use During Pregnancy

4 Themes

Theme 3: *Influence of knowledge and advice*

- Consumed alcohol for other health conditions (e.g., nausea)
- Lack of awareness/knowledge of the adverse impacts of alcohol on the fetus
- Insufficient or mixed advice from medical practitioners

Theme 4: *Influence of pregnancy circumstances*

- Consumed alcohol as a coping mechanism for adverse events during pregnancy
- Unplanned or unwanted pregnancy
- Alcohol use disorder

Education Gaps & Mixed Messaging

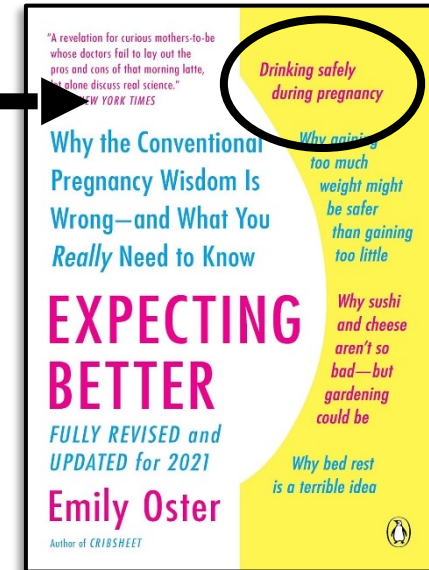
- **Lack of education and awareness among health care providers**
 - Only 16% of pregnant persons with known past 30-day alcohol consumption were advised by a health care provider to quit or reduce their alcohol use (Luong J, et al. *MMWR* 2023)

- **Mixed messaging...**



“more than the occasional drink is likely perfectly fine,...Specifically, one to two drinks a week in the first trimester, and up to a drink a day in the second and third trimester, is likely safe”

Expecting Better by Emily Oster



- Campaigns that use blaming and shaming language, such as “FASD is 100% preventable”, can stigmatize and isolate pregnant individuals who use alcohol

Personal Experience

Susan Terwey, MS

Atypical?



- Caucasian
 - Middle class
 - Master Level education
 - Professional in the FASD Field – 13 years
 - Social Drinker
 - Infertility issues - adoptions, unplanned pregnancy
-

Parenting History



- Foster mom to kids with FASD and prenatal alcohol exposure
 - Infertility issues - adoptions, unplanned pregnancy
 - Prenatal care
-

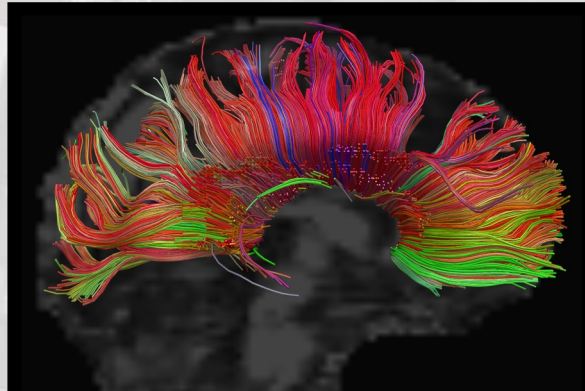


Realizing I was a “Birth Mom”

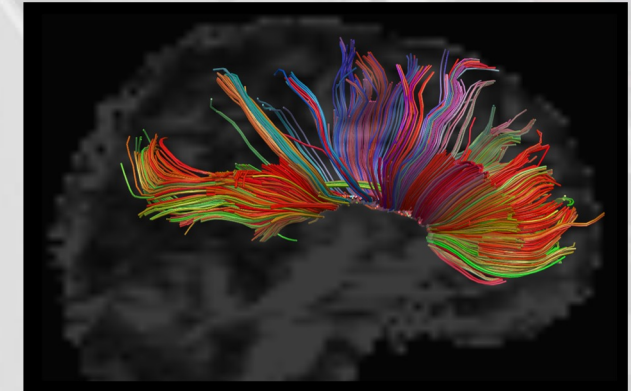
- Bio son was the most challenging of all: sensory, high risk, refusals/hiding, behavior room, learning gaps
- School Special Ed assessments (504), Psych eval - no questions about prenatal alcohol exposure
- Anger management, 2 school changes
- Neighborhood alcohol use
- FASD lightbulb flickers
- 1st detox at age 14 – intake interview
- Juvenile court charges – County social worker, FASD Assessment
- Adult detox interview
- Awareness of adults with SUD dealing with undiagnosed FASD issues



The state of the science of Fetal Alcohol Spectrum Disorders



Jeffrey R. Wozniak, Ph.D.
Professor
Department of Psychiatry &
Behavioral Sciences
University of Minnesota

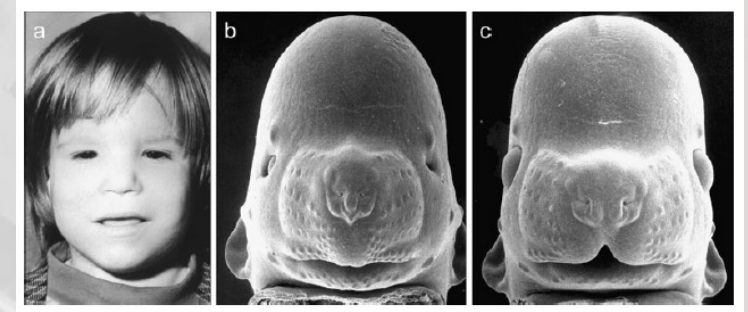




How and when does alcohol disrupt neurodevelopment?

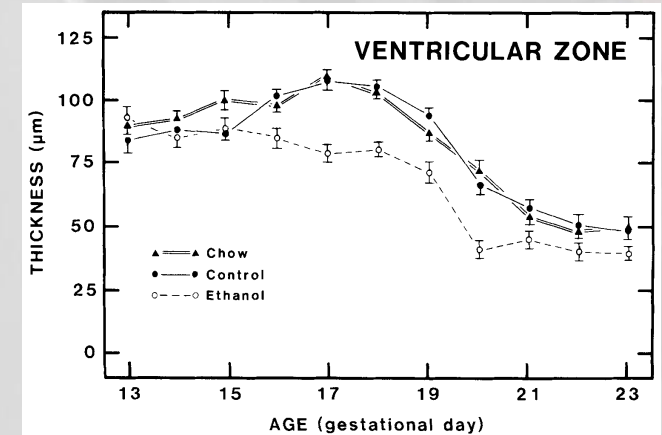
1. First trimester (gastrulation):

- Pregnancy loss
- Impact on the neural tube
- Small brain, eye defects, facial dysmorphology



2. Second trimester (neurogenesis):

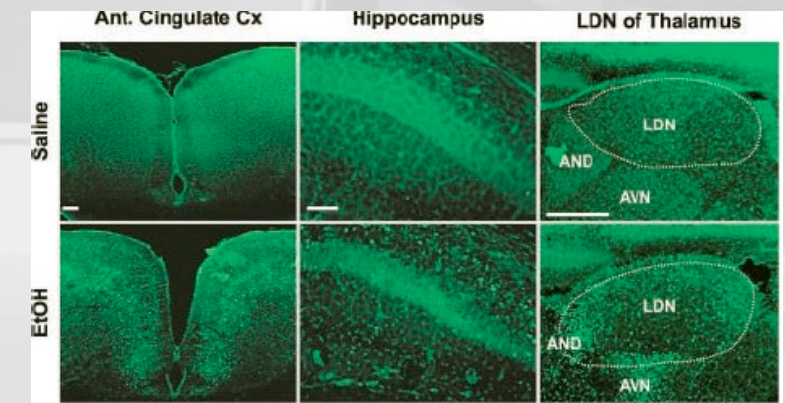
- Impact on cell multiplication
- Abnormal migration of neurons



Miller et al. (1989), *J. Comp Neurol.*, 287, 326-338

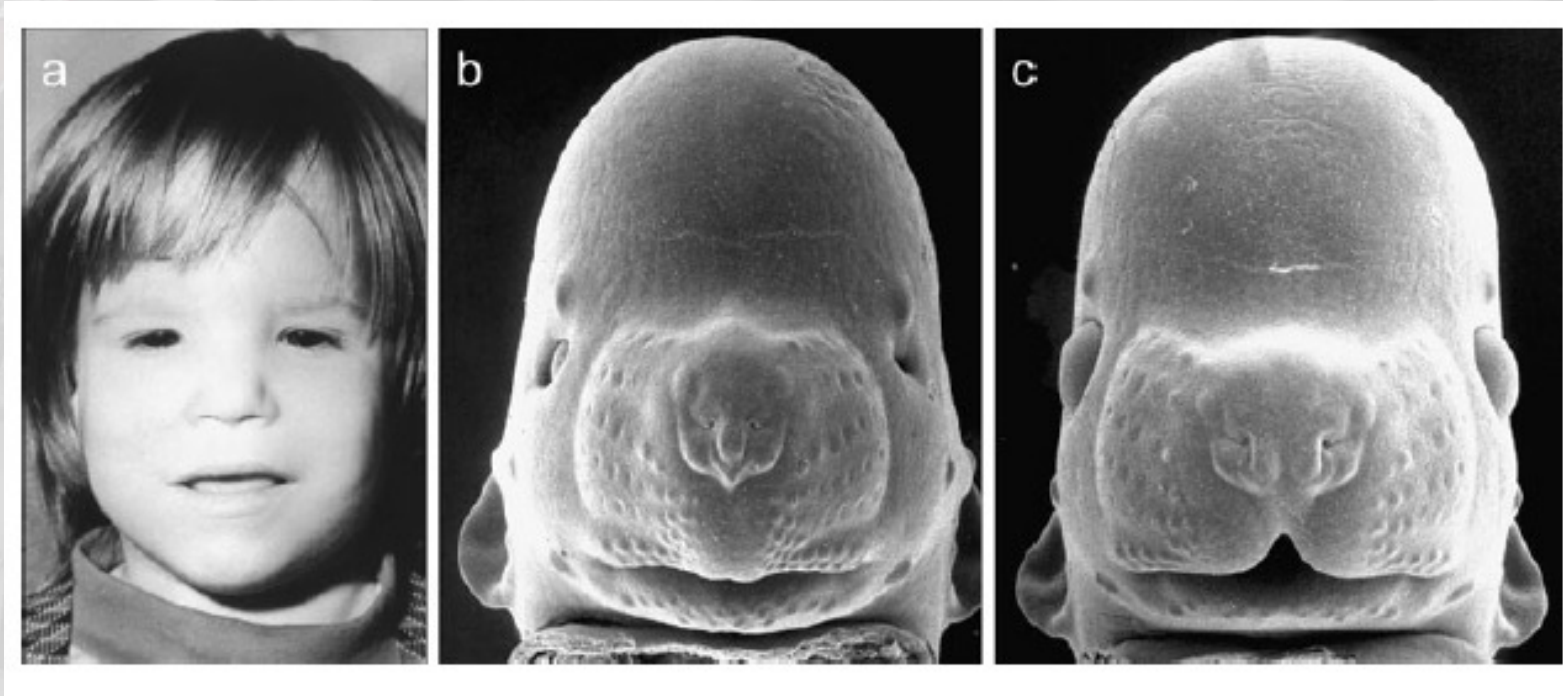
3. Third trimester (synaptogenesis):

- Impact during the brain's growth spurt
- Effects on synaptogenesis / long lasting impacts on plasticity



Ieraci & Herrera (2006), *PLoS One*

Sulik et al. 1981: Gastrulation model



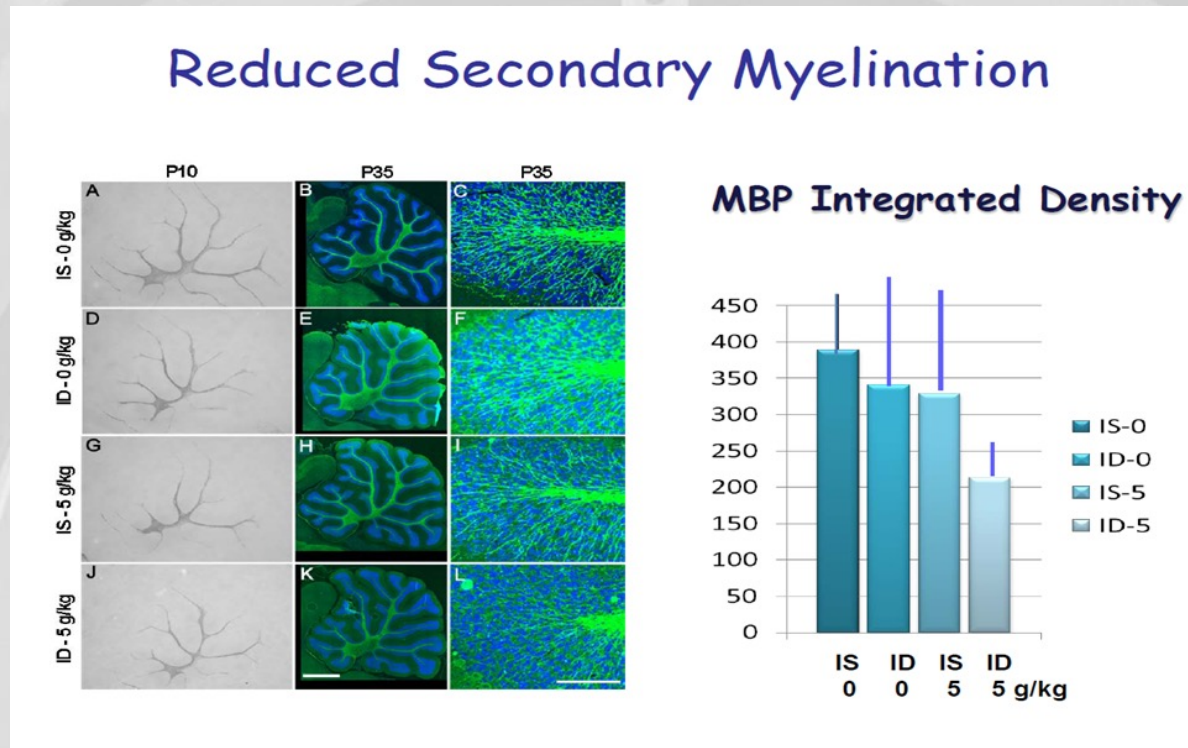
- **Day 7** (day 17 or 18 in human); 0.2 BAC (5-6 drink equiv. two doses)
- Craniofacial effects
- Forebrain, midline brain anomalies, callosum, hippocampus, basal ganglia
- **Day 8.5**: equivalent to week 4 (day 21-24) in humans -> different pattern of anomalies

Apoptosis from ethanol exposure (single “binge” model)

- Third-trimester model (brain growth spurt; 7-day-olds)
- Millions of neurons are signaled to self-destruct (apoptosis)
- Significant behavioral and learning deficits



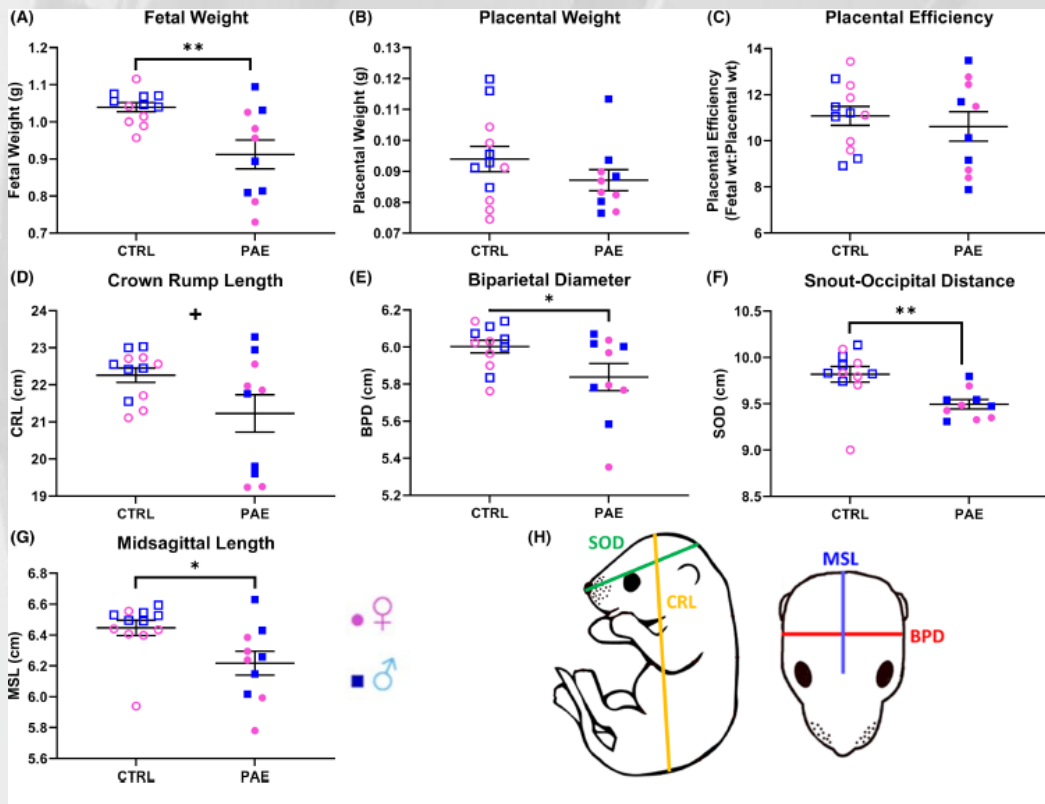
An example of co-occurring risk factors in PAE



Third-trimester model in rats: **Iron deficiency exacerbates damage** from alcohol (myelination, in this case); In humans, myelination occurs from week 14 into adolescence.

Prenatal alcohol exposure contributes to negative pregnancy outcomes by altering fetal vascular dynamics and the placental transcriptome

Marisa R. Pinson¹ | Alexander M. Tseng¹ | Amy Adams¹ | Tenley E. Lehman¹ |
Karen Chung¹ | Jessica Gutierrez² | Kirill V. Larin² | Christina Chambers^{3,4} |
Rajesh C. Miranda^{1,5,6} | Collaborative Initiative on Fetal Alcohol Spectrum Disorders



- Mouse model - single exposure
- Disruption in fetal blood flow
- Altered gene expression in the placenta
- Intrauterine growth restriction
- Ethanol-exposed fetuses were shorter and weighed less

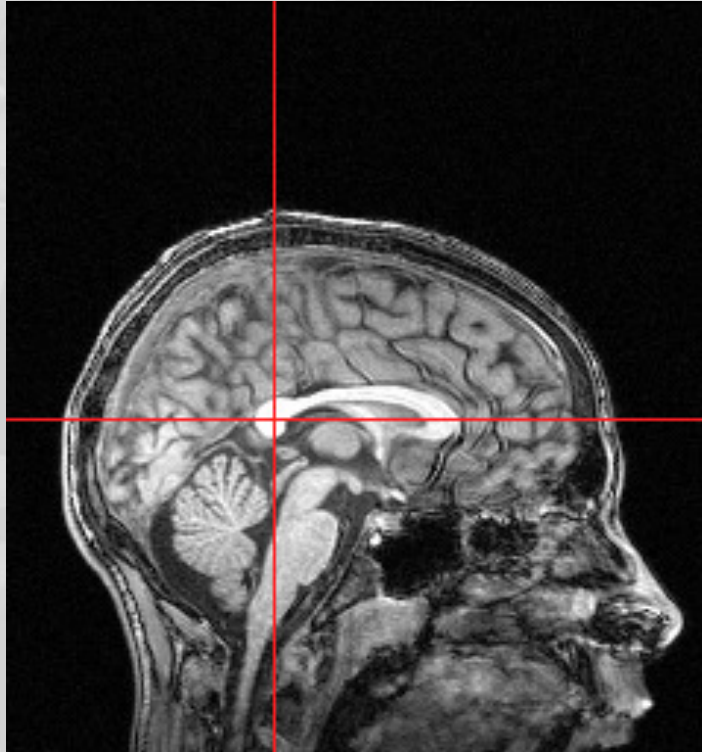
The influence of paternal alcohol consumption on offspring

- In large human cohort: association between father's drinking and child behavior (anxiety & aggression)
- Animal studies have shown:
 - Paternal peri-conception alcohol consumption is associated with offspring hyperactivity (Abel et al. 1993)
 - Histone modifications (epigenetic effects) (Cambiasso et al. 2022)



What have we learned about neurodevelopmental impacts of alcohol from people with FASD?

Major structural anomalies sometimes occur in FASD

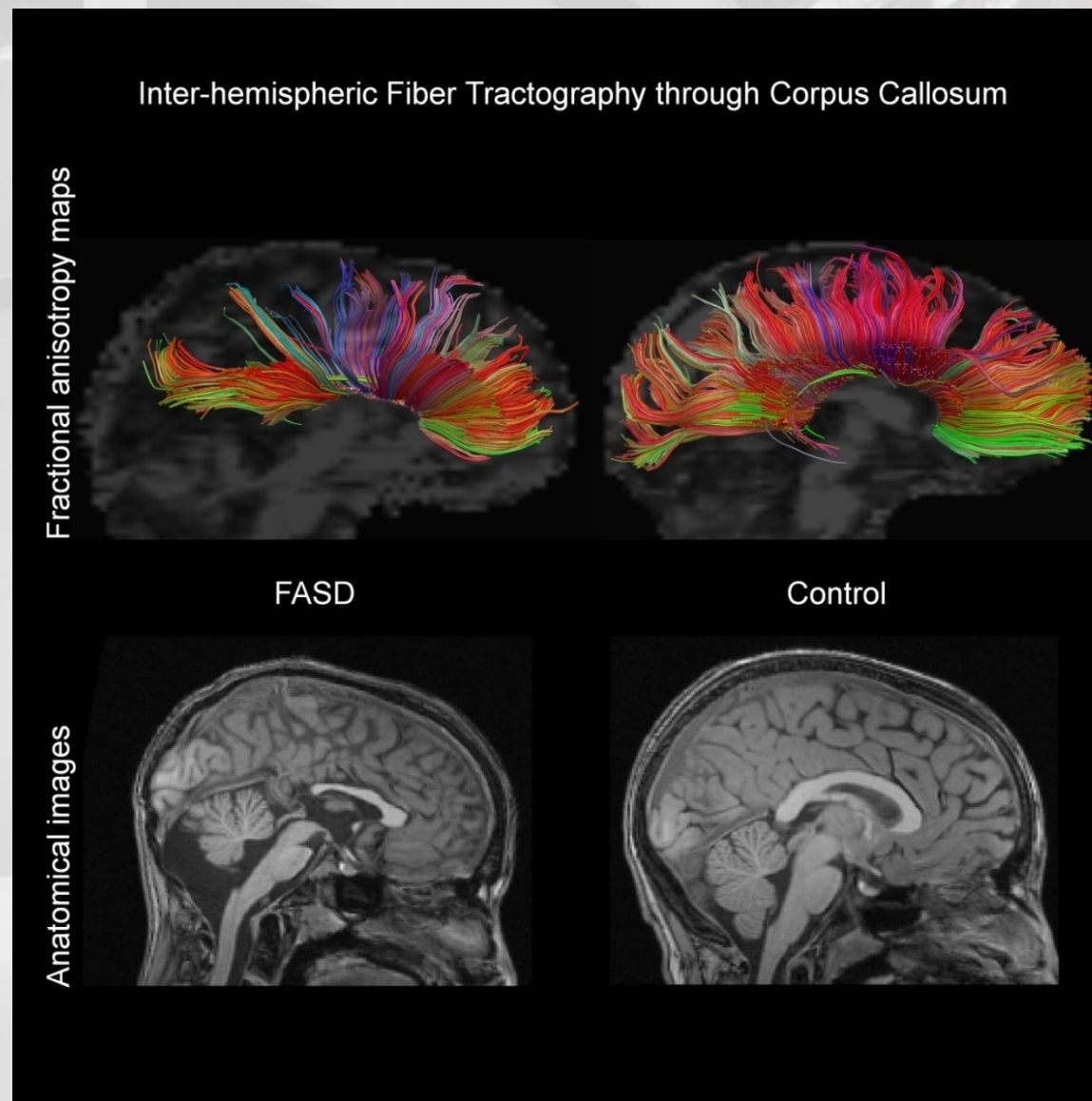
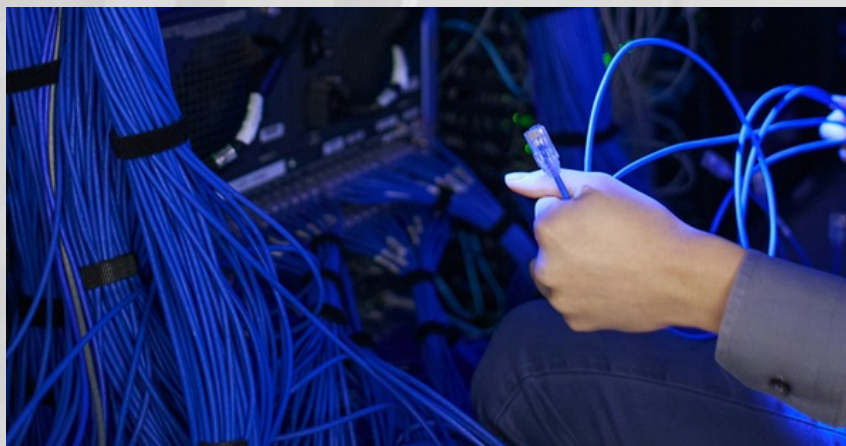


Typical Development



Fetal Alcohol Syndrome

Diffusion imaging reveals white matter anomalies in FASD



Wozniak, J.R. & Muetzel, R.L. (2011). What Does Diffusion Tensor Imaging Reveal About the Brain and Cognition in Fetal Alcohol Spectrum Disorders? *Neuropsychology Review*, 21(2), 133-147.

Inter-Hemispheric Functional Connectivity Disruption in Children With Prenatal Alcohol Exposure

Jeffrey R. Wozniak, Bryon A. Mueller, Ryan L. Muetzel, Christopher J. Bell, Heather L. Hoecker, Miranda L. Nelson, Pi-Nian Chang, and Kelvin O. Lim

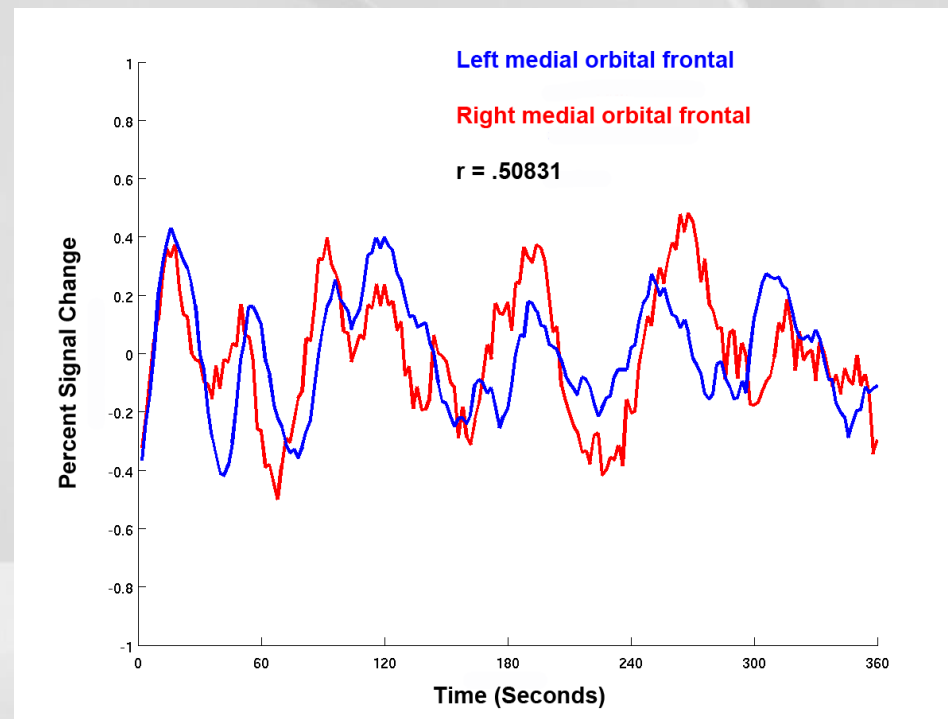
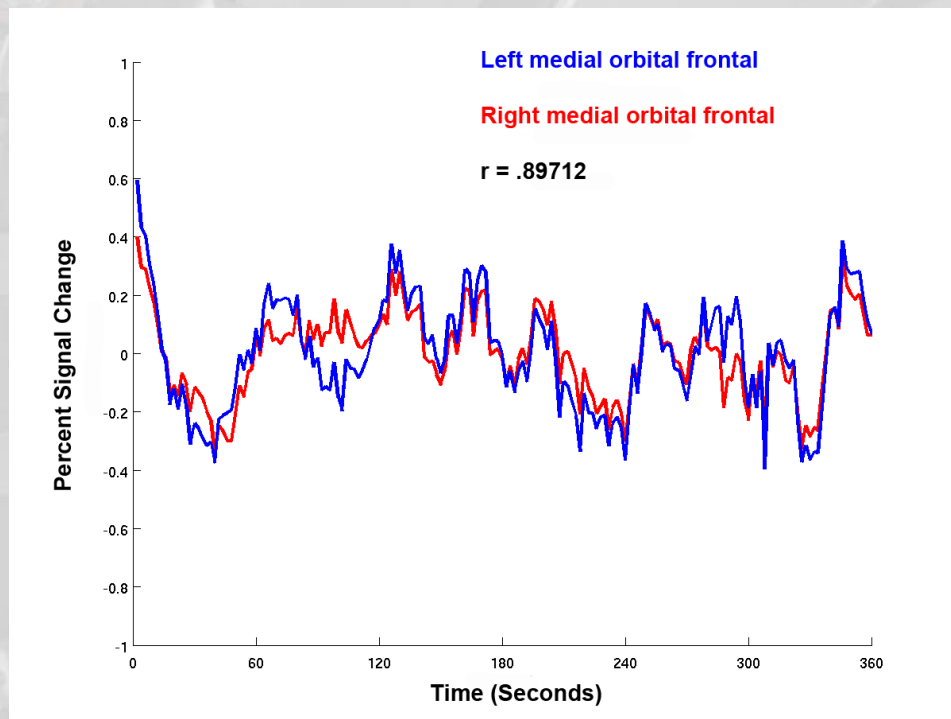
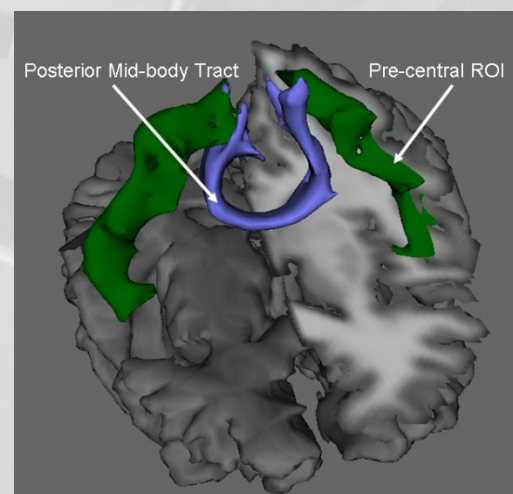
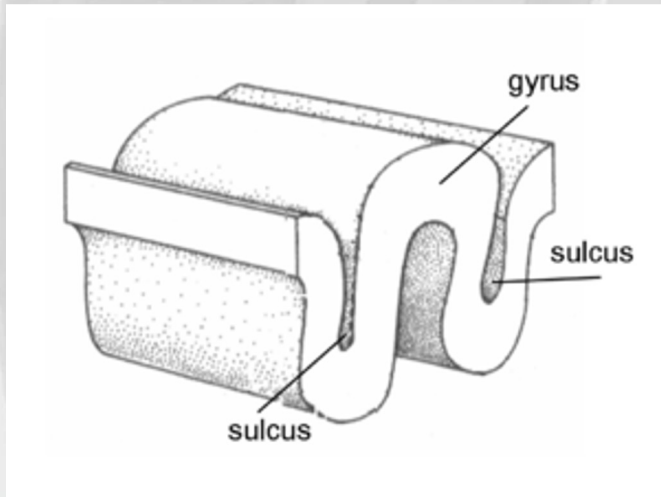


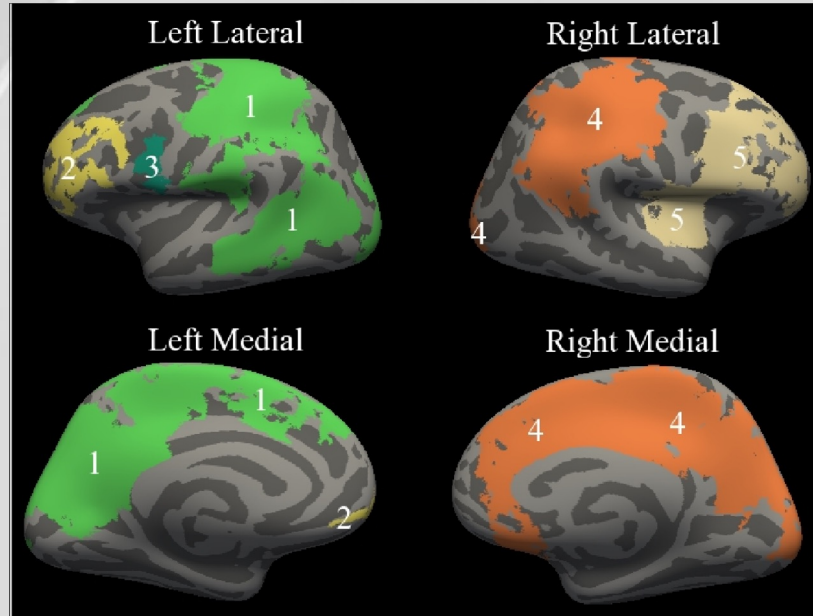
Figure 1. fMRI time-series from one control subject illustrating **high correlation** between BOLD signal change in right and left medial orbital frontal cortex.

Figure 2. fMRI time-series from one FASD subject illustrating **low correlation** between BOLD signal change in right and left medial orbital frontal cortex.

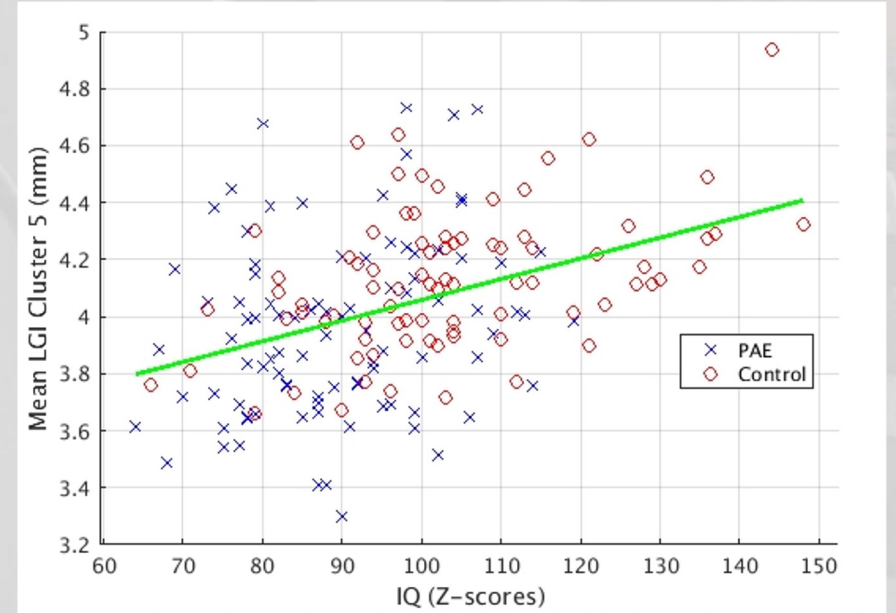
Cortical complexity is altered in FASD



Typical cortical folding



Alcohol's impact on cortical folding



Cortical folding and cognition



Full Length Article

Hippocampal subfield abnormalities and memory functioning in children with fetal alcohol spectrum disorders

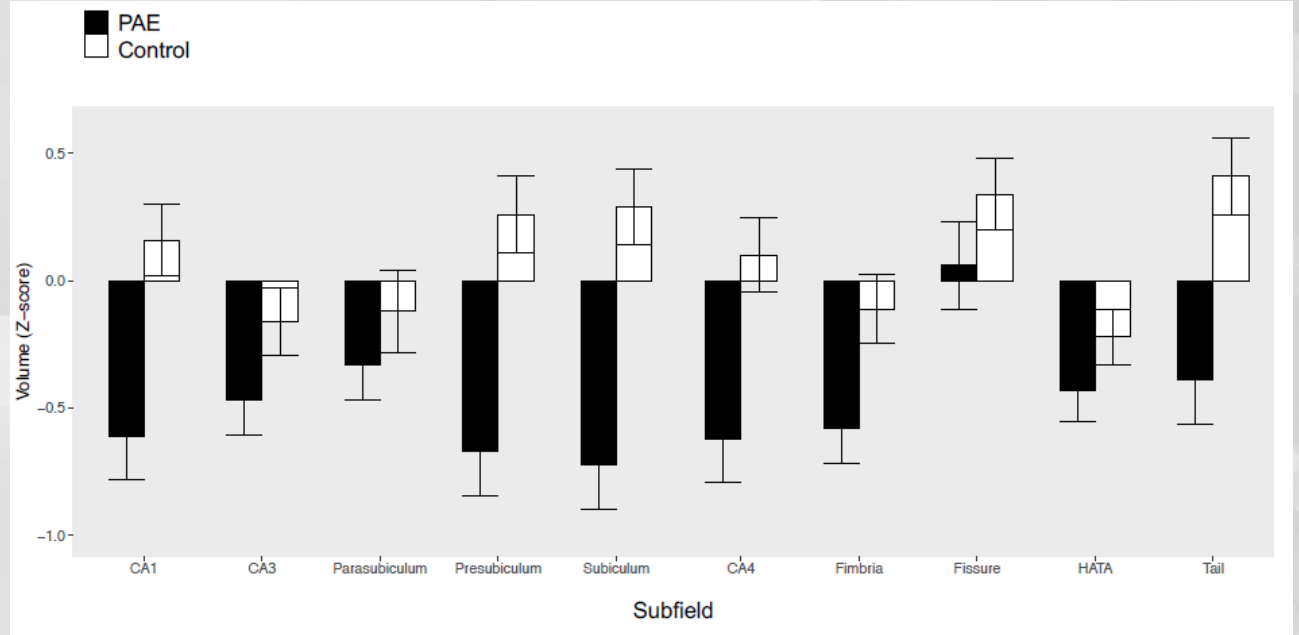
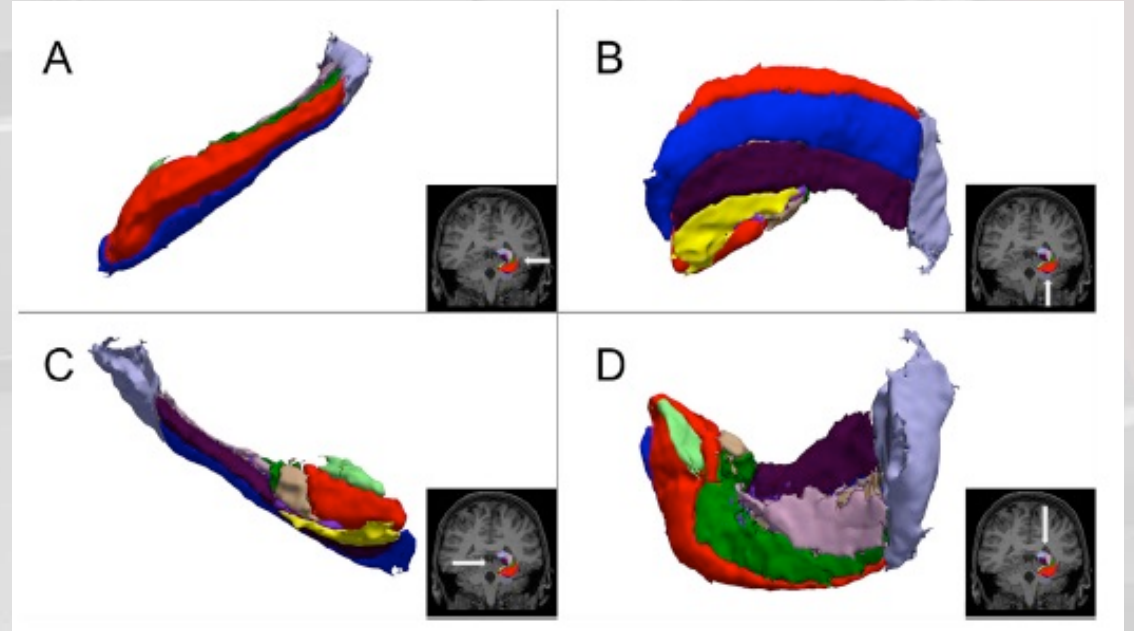
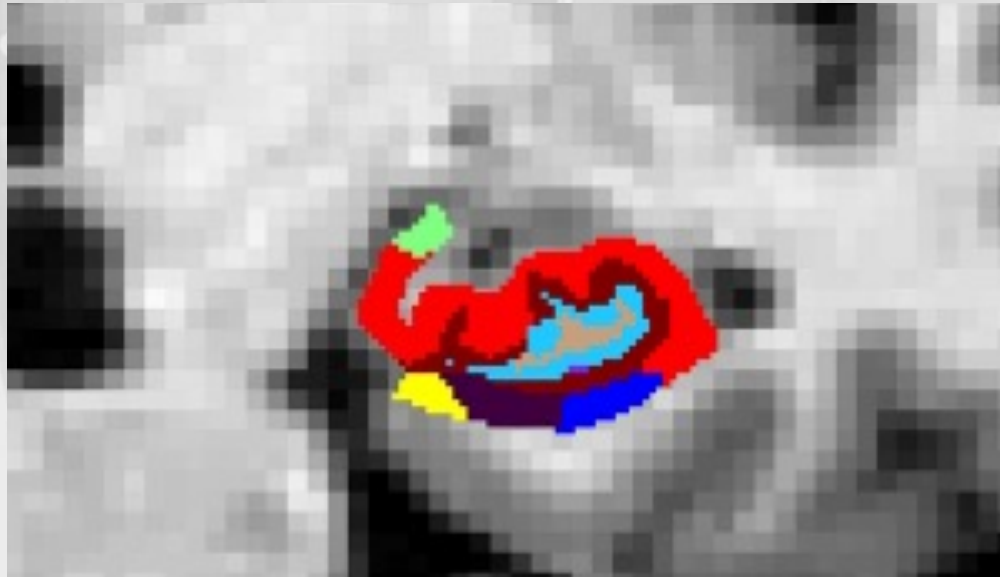
Donovan J. Roediger^c, Alyssa M. Krueger^c, Erik de Water^c, Bryon A. Mueller^c, Christopher A. Boys^c, Timothy J. Hendrickson^c, Mariah J. Schumacher^c, Sarah N. Mattson^a, Kenneth L. Jones^b, Kelvin O. Lim, CIFASD^c, Jeffrey R. Wozniak^c✉

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<https://doi.org/10.1016/j.ntt.2020.106944>

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An example from a non-clinical sample

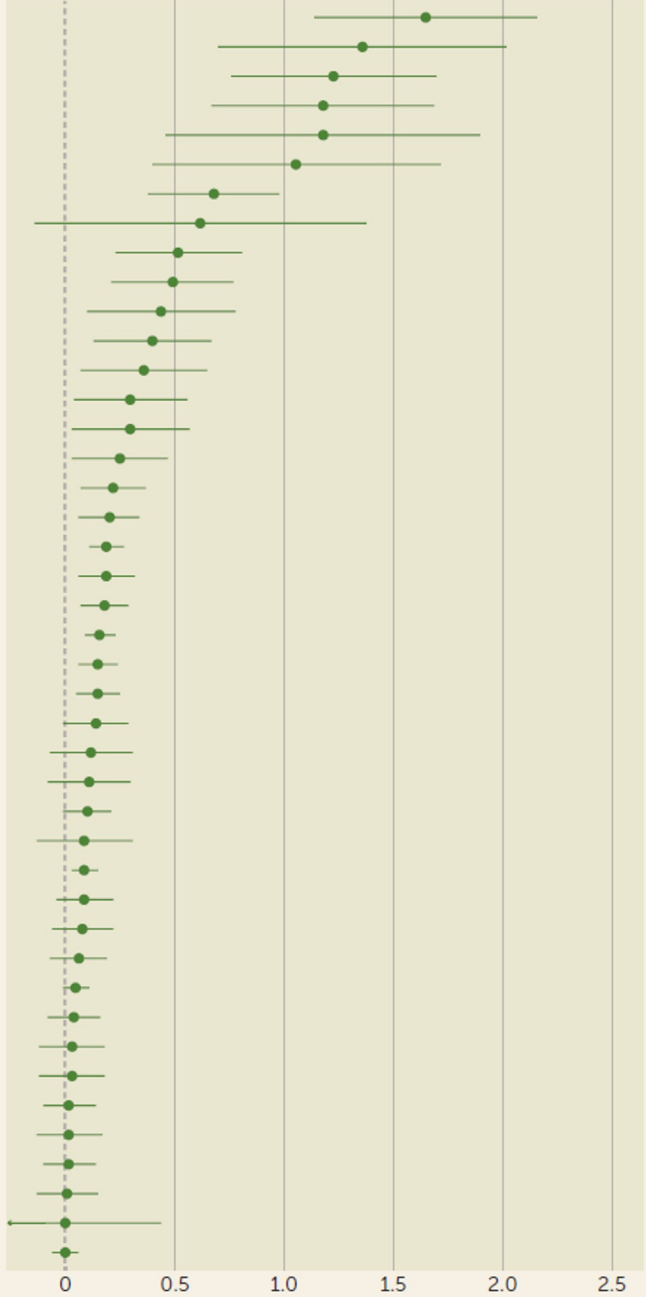
Adolescent Brain Cognitive Brain Development (ABCD) Birth Cohort Study:

- 7201 unexposed
- 2518 exposed

Figure shows relative behavioral and cognitive deficits for exposed vs. unexposed children

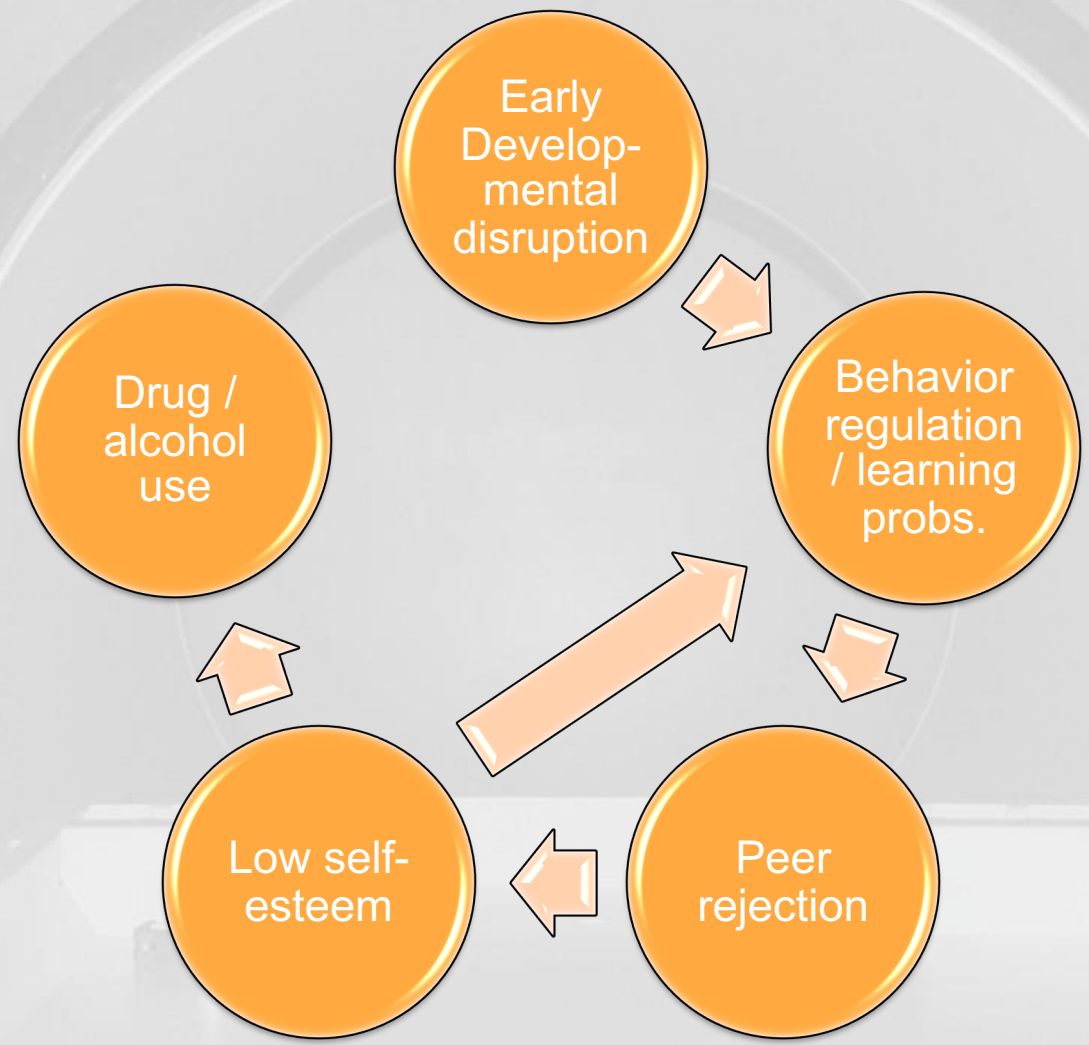
A. Psychological, Behavioral, and Cognitive Outcomes

	B (95% CI)
CBCL total problems score	1.65 (1.14, 2.16), p<0.001
Working memory	1.36 (0.69, 2.02), p<0.001
CBCL externalizing factors	1.23 (0.75, 1.70), p<0.001
CBCL internalizing factors	1.18 (0.67, 1.68), p<0.001
Executive function and cognitive flexibility	1.18 (0.46, 1.90), p=0.001
Executive function, attention, and inhibition	1.06 (0.41, 1.72), p=0.001
Processing speed	-0.68 (-1.74, 0.38), p=0.21
Episodic memory	0.62 (-0.14, 1.38), p=0.11
CBCL somatic complaints	0.52 (0.23, 0.82), p<0.001
CBCL thought problems	0.49 (0.21, 0.77), p<0.001
K-SADS hallucinations score	0.44 (0.11, 0.78), p=0.19
CBCL attention problems score	0.40 (0.13, 0.67), p=0.004
CBCL anxious or depressed score	0.36 (0.07, 0.64), p=0.01
CBCL aggressive behavior score	0.30 (0.04, 0.55), p=0.02
CBCL withdrawn or depressed score	0.30 (0.03, 0.57), p=0.03
CBCL rule breaking behavior score	0.25 (0.04, 0.55), p=0.02
RAVLT long delay (30 minutes)	0.22 (0.06, 0.37), p=0.005
K-SADS unspecified bipolar and related disorder	-0.20 (-0.34, 0.05), p=0.18
K-SADS separation anxiety disorder	0.19 (0.10, 0.27), p=0.03
UPPS-P sensation seeking score	0.19 (0.06, 0.32), p=0.004
UPPS-P lack of planning score	0.18 (0.06, 0.29), p=0.002
K-SADS oppositional defiant disorder	0.16 (0.09, 0.23), p=0.03
K-SADS obsessive-compulsive disorder	0.15 (0.07, 0.24), p=0.08
RAVLT learning score	0.15 (0.06, 0.25), p=0.001
RAVLT immediate delay	0.14 (0.00, 0.29), p=0.05
K-SADS delusions score	0.12 (-0.07, 0.31), p=0.52
K-SADS posttraumatic stress disorder	-0.11 (-0.30, 0.08), p=0.57
UPPS-P lack of perseverance score	0.1 (-0.01, 0.21), p=0.06
CBCL social problems score	0.09 (-0.13, 0.30), p=0.43
K-SADS attention deficit hyperactivity disorder	0.09 (0.02, 0.15), p=0.17
UPPS-P negative urgency score	0.09 (-0.04, 0.22), p=0.19
BIS/BAS behavioral inhibition score	0.08 (-0.06, 0.22), p=0.24
BIS/BAS fun seeking score	0.06 (-0.07, 0.19), p=0.36
Cash Choice Task	0.05 (0.00, 0.11), p=0.30
K-SADS social anxiety, selective mutism disorder	-0.04 (-0.16, 0.07), p=0.73
K-SADS major depressive disorder	-0.03 (-0.18, 0.13), p=0.85
K-SADS conduct disorder	0.03 (-0.12, 0.18), p=0.84
K-SADS generalized anxiety disorder	-0.02 (-0.14, 0.10), p=0.85
UPPS-P positive urgency score	0.02 (-0.12, 0.17), p=0.73
BIS/BAS reward responsiveness score	-0.02 (-0.14, 0.09), p=0.70
BIS/BAS drive score	0.01 (-0.14, 0.15), p=0.93
K-SADS panic disorder	0.00 (-0.44, 0.44), p=1.0
K-SADS specific phobia	0.00 (-0.06, 0.06), p=0.98



Lees et al. 2021
 Association of prenatal alcohol exposure with psychological, behavioral, and neurodevelopmental outcomes in children from the ABCD study;
 American Journal of Psychiatry,
 177:11

Example of the cycle of secondary disability



FASD and predisposition for substance use?

Those with FASD are at high risk for substance use from:

1. Genetic / early life adversity
2. Physiological change (GABA receptor sensitivity; Dopamine)



Is medication effective for FASD?

Medications for FASD

- Animal studies – prenatal ethanol exposure leads to hyper-sensitivity to methylphenidate later in life
 - Means et al. (1984)
 - Ulug & Riley (1983)
- Human studies:
 - Oesterheld et al (1998): stimulants treated hyperactivity, but not attention deficits in those with FASD
 - Poor responsivity to stimulants:
 - O'Malley & Hagermann (1998)
 - O'Malley & Nanson (2002)
 - Snyder et al. (1997)

Psychotropic medication algorithm for FASD

(Mansfield Mela, MBBS; U. Saskatchewan: canfasd.ca/algorithm)

- Consensus-based comprehensive decision-tree addressing four common symptom clusters in FASD:
 - Hyperarousal
 - Emotion dysregulation
 - Hyperactivity / inattention
 - Cognitive inflexibility
- First and second line medications recommended



Mela M, et al. (2018). The utility of psychotropic drugs on patients with Fetal Alcohol Spectrum Disorder (FASD): a systematic review. *Psychiatry and Clinical Psychopharmacology*. 2018:1-10)

Mela et al. (2020). Treatment algorithm for the use of psychopharmacological agents in individuals prenatally exposed to alcohol and/or with diagnosis of fetal alcohol spectrum disorder (FASD). *J. Popul Ther Pharmacol*, 27(3):e1-e13.



**How do we target neurodevelopment
in FASD?**

Example: Choline is an essential nutrient for humans

- Classified as essential nutrient
- Cells die by apoptosis without it
- Multiple needs:
 1. Cell membrane
 1. Lipid metabolism
 2. Precursor to acetylcholine
 3. Gene expression (development)
- Deficiency -> neural tube disorders



2009 Phase 1 study: delivery system development

- Two arms: 500 mg. choline vs. placebo per day
- Based on adequate intake of 200-250 mg. per day
- Fruit-flavored drink mix
- 9 month duration



Choline supplementation in children with fetal alcohol spectrum disorders: a randomized, double-blind, placebo-controlled trial^{1,2}

Jeffrey R Wozniak,^{3*} Anita J Fuglestad,³ Judith K Eckerle,⁴ Birgit A Fink,³ Heather L Hoecker,⁶ Christopher J Boys,⁴ Joshua P Radke,⁷ Maria G Kroupina,⁴ Neely C Miller,⁴ Ann M Brearley,⁵ Steven H Zeisel,⁸ and Michael K Georgieff⁴

Elicited Imitation (memory) performance

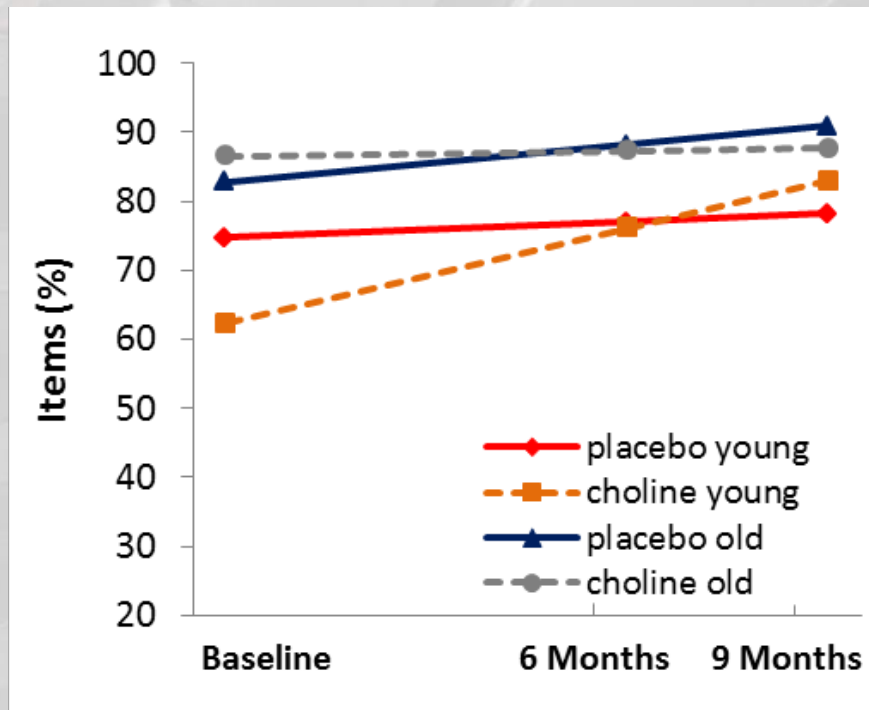


Fig 1. EI items after short delay

- **21 point increase for young choline**

RESEARCH

Open Access

Four-year follow-up of a randomized controlled trial of choline for neurodevelopment in fetal alcohol spectrum disorder



Jeffrey R. Wozniak^{1,2*}, Birgit A. Fink¹, Anita J. Fuglestad³, Judith K. Eckerle¹, Christopher J. Boys¹, Kristin E. Sandness¹, Joshua P. Radke⁴, Neely C. Miller¹, Christopher Lindgren¹, Ann M. Brearley¹, Steven H. Zeisel⁵ and Michael K. Georgieff¹

Variables	Choline (n = 15)	Placebo (n = 16)	t or χ^2	p
Gender (male %)	53.3	52.943.8	0.27	.60
Baseline				
Age, M (SD)	3.81 (0.823)	3.95 (0.75)	0.51	.62
IQ	84.53 (12.57)	78.59 (21.48)	0.98	.332
Follow Up				
Age, M (SD)	8.57 (1.01)	8.59 (0.99)	0.05	.97
Height, M (SD)	128.84 (7.95)	129.61 (8.05)	0.28	.78
Weight, M (SD)	28.73 (11.36)	29.23 (7.07)	0.15	.89

Table 3 Stanford–Binet Intelligence Scale—Fifth Edition group comparison results

EMMean (SE)	Placebo (n = 16)	Choline (n = 14) ^a	Statistic	Significance	Effect size
Verbal IQ	88.3 (2.8)	90.6 (3.1)	$F(1, 28) = 0.29$	$p = 0.60$	$PE^2 = 0.01$
Non-Verbal IQ	85.6 (2.1)	92.9 (2.4)	$F(1, 28) = 5.17$	$p = 0.03^*$	$PE^2 = 0.17$
Fluid Reasoning	88.1 (3.7)	90.3 (4.1)	$F(1, 28) = 0.15$	$p = 0.70$	$PE^2 = 0.01$
Knowledge	85.0 (2.3)	87.5 (2.6)	$F(1, 28) = 0.50$	$p = 0.49$	$PE^2 = 0.02$
Quantitative Reasoning	93.1 (2.1)	92.7 (2.3)	$F(1, 28) = 0.02$	$p = 0.90$	$PE^2 = 0.00$
Visual-Spatial Processing	91.3 (3.0)	98.3 (3.3)	$F(1, 28) = 2.38$	$p = 0.14$	$PE^2 = 0.08$
Working Memory	84.0 (2.5)	94.4 (2.8)	$F(1, 28) = 7.74$	$p = 0.01^*$	$PE^2 = 0.23$
Full-Scale IQ	86.1 (2.4)	91.1 (2.7)	$F(1, 28) = 1.86$	$p = 0.19$	

Summary

- Alcohol has numerous negative impacts on the developing brain
- Even single episodes can be harmful
- Cognitive & behavioral effects are often present, even when the craniofacial elements are not
- We've learned a great deal by collaborating with individuals with lived experience of FASD who contribute to research
- New interventions may take advantage of windows of neuroplasticity and opportunities to optimize remaining brain development

FASDs Clinical Presentation and Evidence-Informed Treatment

Vincent C. Smith, MD, MPH

Division Chief of Newborn Medicine

Boston Medical Center

Professor of Pediatrics

Boston University Chobanian & Avedisian School of Medicine



A large, light blue, stylized graphic of a plant with three leaves and a wavy base, positioned on the left side of the slide.

Clinical Presentation

Brain Areas Affected By Prenatal Alcohol Exposure

Frontal Lobes

impulses and judgment; controls executive function

Hypothalamus

appetite, emotions, temperature, and pain sensation

Amygdala

emotions

Cerebellum

coordination and movement

Basal Ganglia

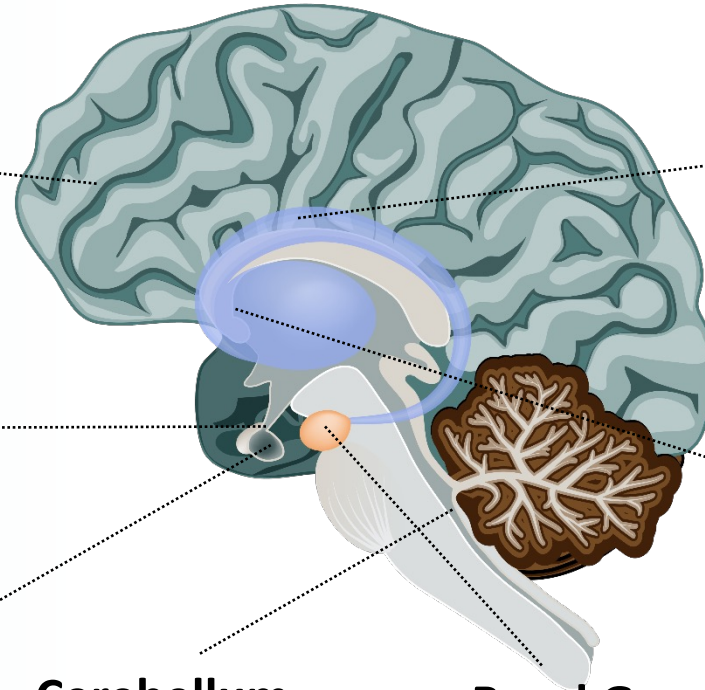
spatial memory, switching gears, working toward goals, predicting behavioral outcomes, and the perception of time

Corpus Callosum

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

Hippocampus

memory, learning, emotion



Neurobehavioral Disorder

Neurobehavioral Characteristics

- **Neurocognition**
Learning, memory, math, executive functioning, visual-spatial, IQ/DD
- **Self-regulation**
Attention, impulsivity, emotional lability, outbursts
- **Adaptive Functioning**
Communication, social, daily living skills, motor

Physical Characteristics

- **~20% of children affected**
- Growth restriction
- Facial features:
 - Smooth philtrum
 - Thin upper lip
 - Short palpebral fissures

Facial Features

It's a common myth that all people with an FASD have a specific set of facial features

The fact is, only a small percent of people with FASD have these facial features; for the vast majority of individuals with an FASD, their disability is invisible

Copyright Susan Astley Hemingway 2012.
<https://depts.washington.edu/fasdnp/htmls/fas-face.htm>



Examples of facial phenotypes across race and age

A large, light blue, stylized graphic of a plant with several leaves, positioned on the left side of the slide.

Diagnosis of FASD

FASD Diagnostic Schema Available

Currently available guidelines:

- Updated Clinical Guidelines for Diagnosing FASD (Hoyme et al, *Pediatrics*, 2016)
- Canadian guidelines for FASD diagnosis (Cook et al, *CMAJ*, 2015)
- National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (CDC 2004)
- FASD 4-digit diagnostic code (Astley and Clarren, *Alcohol*, 2000)

Historically available guidelines:

- A practical clinical approach to diagnosis of FASD: clarification of the 1996 Institute of Medicine criteria (Hoyme et al, *Pediatrics*, 2005)
- FASD: Canadian guidelines for diagnosis (Chudley et al, *CMAJ*) 2005
- Fetal Alcohol Syndrome (The Lancet, 1973)

The Diagnostic and Statistical Manual version 5 published by the American Psychiatric Association also proposes criteria for neurobehavioral disorder associated with prenatal alcohol exposure.

Assessment Domains for Diagnosis

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



Screening Concepts or Information Needed to Understand Potential PAE

- General alcohol use in the home
- Amount and type(s) of alcohol consumed **before** finding out they were pregnant
- Amount and type(s) of alcohol consumed **after** finding they were pregnant
- Occurrence of binge drinking (4 or more drinks in one sitting)
 - Women more likely to disclose this behavior
 - Indicative of general drinking
 - Most harmful to the fetus



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
- History of adoption or child welfare involvement
- A sibling diagnosed with a FASD
- Dysmorphic facial characteristics associated with FAS are present



Diagnostic Dilemmas



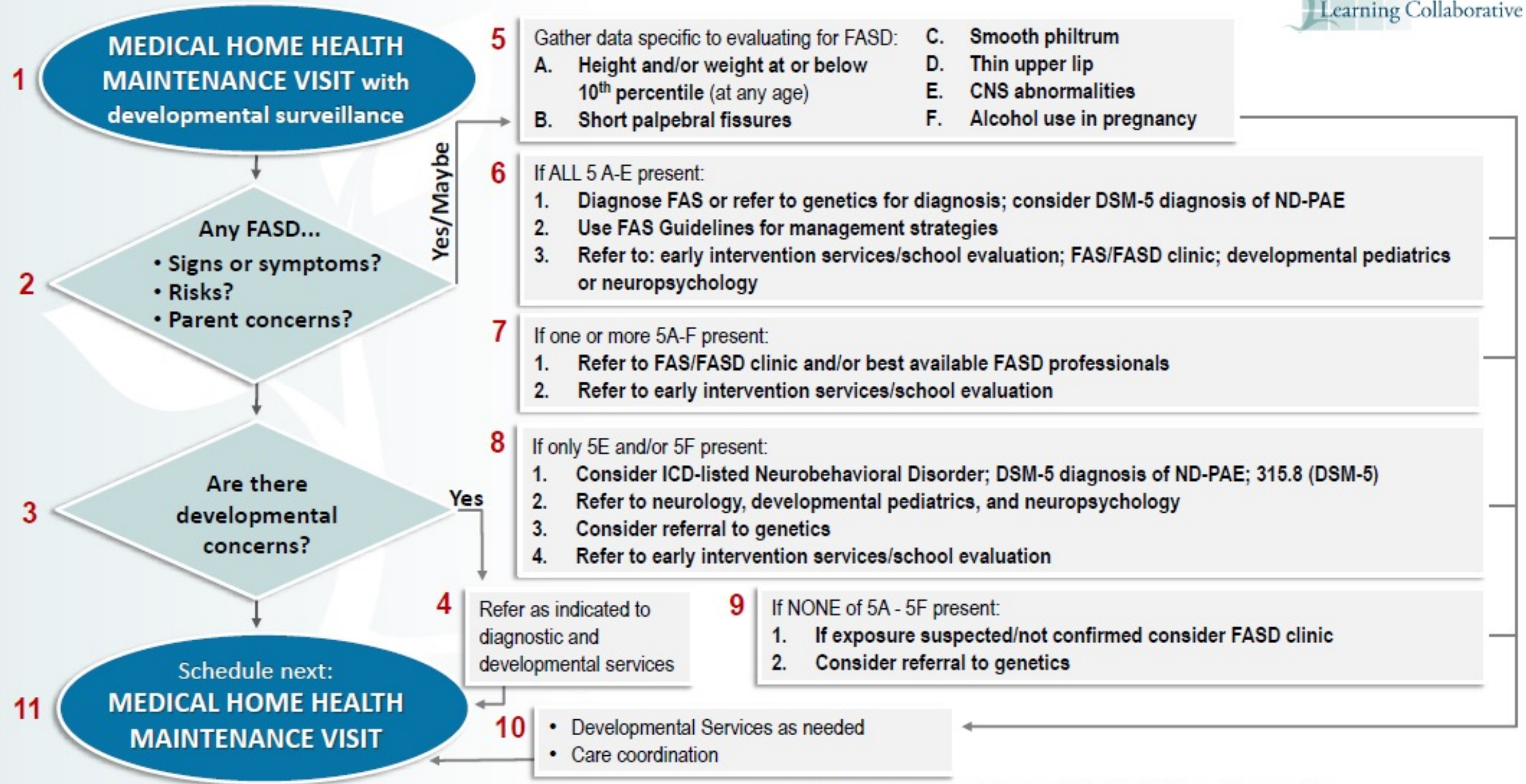
FASDs Resources

- The AAP FASD Toolkit:
aap.org/fasd
- Comprehensive, one-stop resource



The screenshot shows the American Academy of Pediatrics (AAP) website. At the top left is the AAP logo with the text "American Academy of Pediatrics" and "DEDICATED TO THE HEALTH OF ALL CHILDREN®". To the right is a search bar labeled "Search All AAP". Below the logo is a navigation menu with "Home" selected, and other options: "News", "Membership", "Career Resources", "Research", "Philanthropy", and "About the AAP". The main heading is "Fetal Alcohol Spectrum Disorders" in white text on a blue background. Below the heading is a breadcrumb trail: "Home / Patient Care / Fetal Alcohol Spectrum Disorders". The central image shows a doctor in a white coat and stethoscope, wearing blue gloves, looking at a clipboard while talking to a woman and a young girl. To the right of the image is a text block: "We've assembled resources related to Fetal Alcohol Spectrum Disorders (FASD) to raise awareness of individuals with an FASD, promote screening for prenatal exposure to alcohol and encourage referral for diagnostic evaluations for an FASD. The goal is to build the capacity of pediatricians, nonphysician clinicians, and allied health professionals to ensure that all individuals with an FASD, and their families, receive a diagnosis and care in their medical home for any condition along the FASD continuum." At the bottom of the page is a button labeled "Fetal Alcohol Spectrum Disorder Overview" with an upward-pointing arrow icon.

Flow Diagram for Medical Home Evaluation of FASDs



Potential Benefits of a Diagnosis

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



A large, light blue, stylized graphic of a plant with several leaves, positioned on the left side of the slide.

Non-Pharmacologic Treatments

Evidence Informed Programs for FASD

- Zones of Regulation (late preschool thru adulthood)
- Math Interactive Learning Experience (MILE)
- Go FAR
- Parents and Children Together (PACT)
- Families Moving Forward
- Good Buddies

Access to some of these programs remains limited in many communities

A fundamental element is teaching parents how to interact with their children at home

The Zones of Regulation

Zone of Regulation (modified for children with FASDs)

- Zones of Internal states
 - **Blue** = low/under arousal
 - **Green** = optimal
 - **Yellow** = increased arousal
 - **Red** = high arousal, low emotional control
- Practical skills and strategies provided for each Zone

- Teaches skills & strategies
- Includes parent education and skill building
- Teaches children in group settings
- Can be modified for the pediatric setting
 - *Created by an occupational therapist, Leah Kuypers*
 - *Zones of regulation: systematic, cognitive-behavioral approach to teach how to regulate feelings, energy & sensory needs*

Math Interactive Learning Experience (MILE)

Ages: 3-9 years

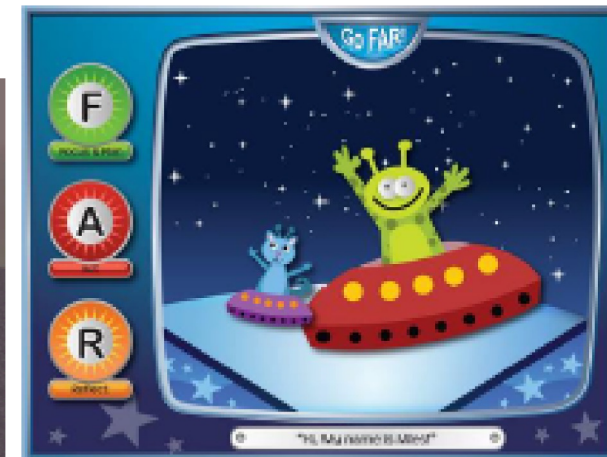
- 6-week intervention
- Improves math skills and handwriting
- Improves behavior per parent report
- Educate parents and teachers about FASD
- 1:1 instruction for children

GoFar



Ages 5-10 years

- FAR: “F” Focus/Plan, “A” Act, “R” Reflect
 - Improves behavioral and educational outcomes in FASD
- Parents/Caregivers learn parenting strategies
- Incorporates a computer game to teach children to control impulsive and problematic behavior
- 10 weekly sessions



Parents and Children Together (PACT)

Ages: 6-12 years

- 12-week group therapy intervention
 - Equal time spent training parent & child separately, parent & child together
- Parent goals:
 - Understand brain changes due to PAE
 - Prevent/intervene in child's behavioral difficulties
- Child goals:
 - Improve executive function
 - Improve emotional regulation

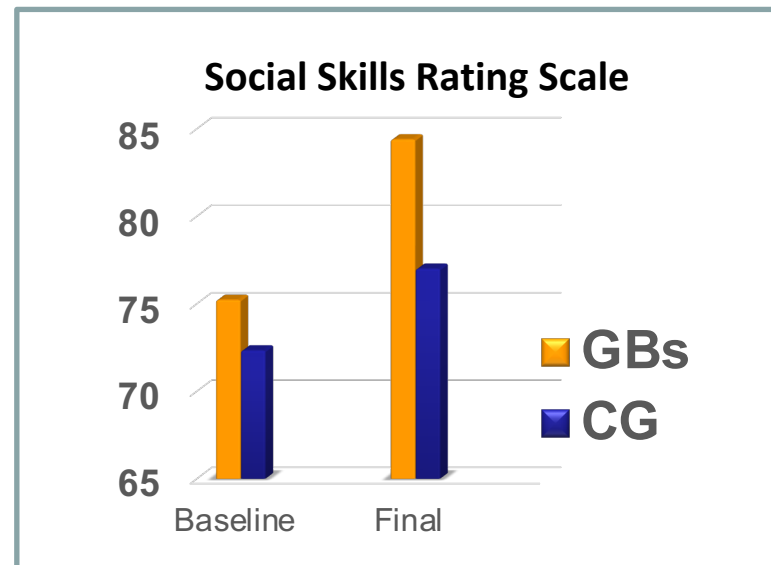
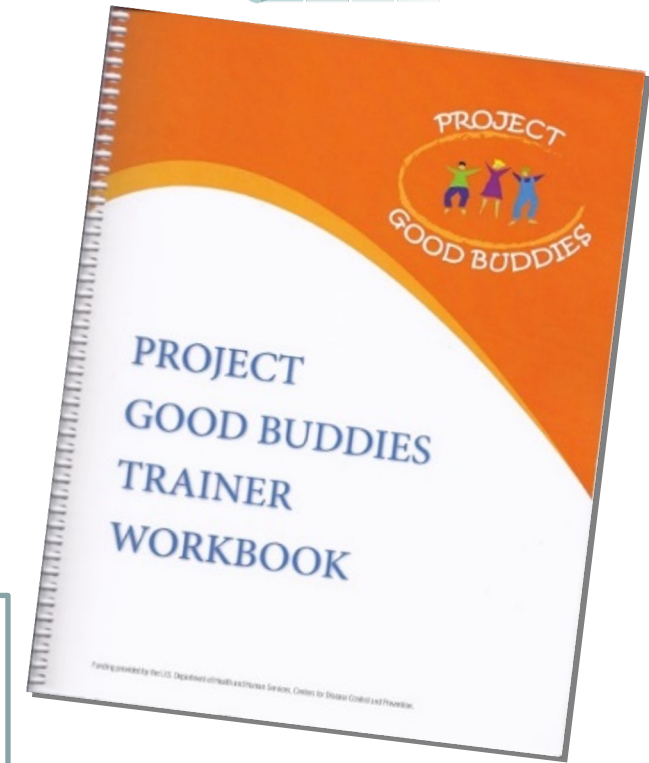
Families Moving Forward

Ages: 3-12 years

- Caregiver support and coaching
 - Education about PAE effects
 - Teaching proactive parenting strategies
- School/provider consultation
- Community resource linkage
- Training and support provided through Seattle office

Good Buddies

- Teaches social skills
- 12-week group sessions for child and parents
- Instruction + practice + homework
- Build a play date
- Explicit, “in-your-pocket”



Evidence Informed Programs for Child Behavior Problems *(not specific for FASD)*

- Parent/Child Interaction Therapy (PCIT)
- Parenting through Change
- Incredible Years
- Attachment and Biobehavioral Catch-up (ABC)
- Guided Growth

Parent-Child Interaction Therapy (PCIT)

- For young children with emotional/behavioral disorders
- Improve quality of parent-child relationships and interaction patterns
- Live-coaching model (parents in room with child, therapist watching by one-way mirror or video, coaching through an earpiece)

Parenting Through Change

Target: parents of 2-18 yo

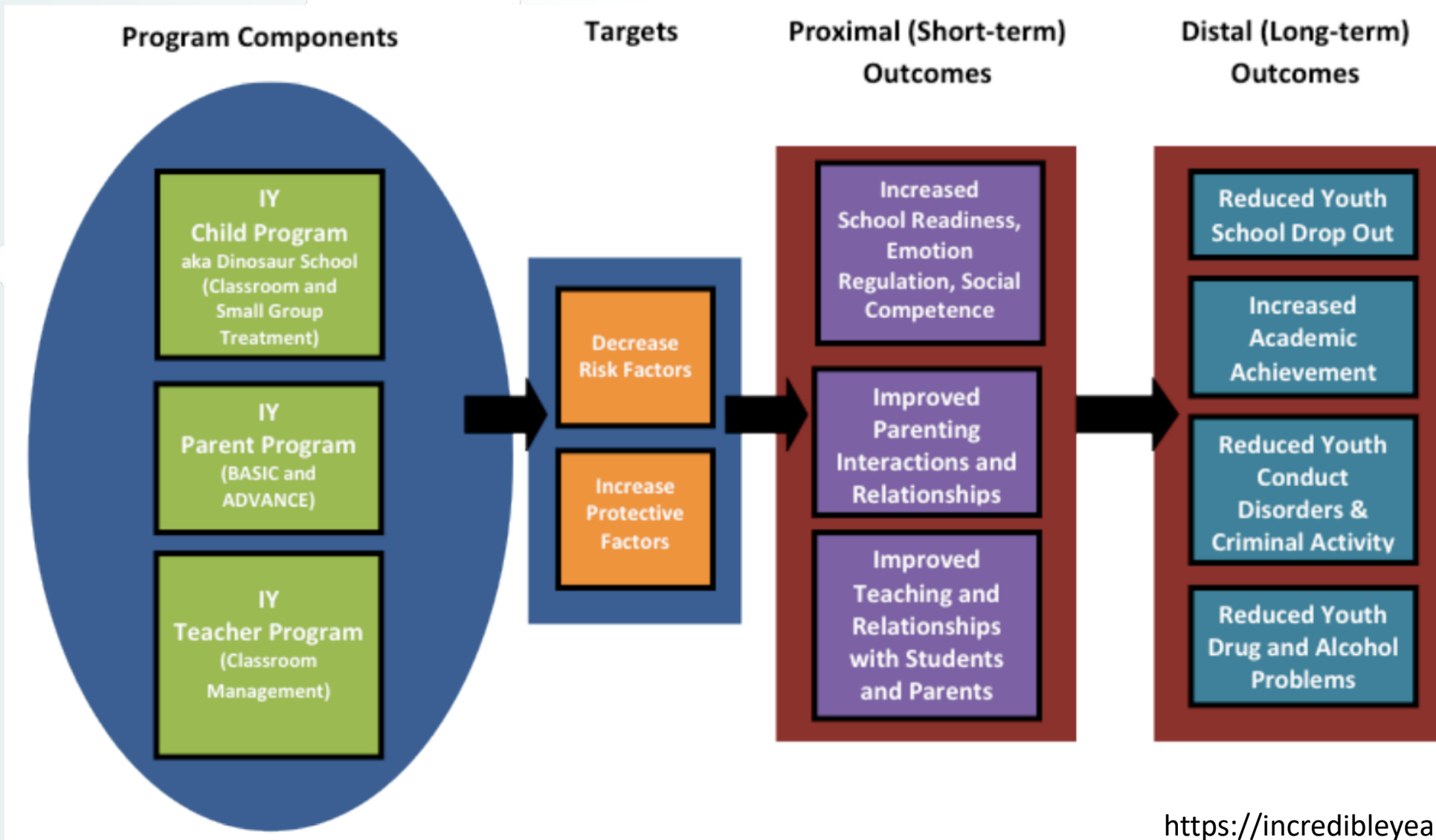
- Group parenting intervention
 - weekly lessons (10, 12, and 14 week formats)
- Oppositional/defiant, conduct problems
- ADHD symptoms
- Delinquency, deviant peer associations
- Substance use
- Depression
- Academic problems

- skill encouragement
- limit setting
- monitoring
- problem solving
- positive involvement
- active communication
- emotional regulation
- academic promotion

<https://www.cebc4cw.org/program/parenting-through-change/detailed>

<https://www.generationpmtto.org/>

The Incredible Years (Programs for 0-18 y)



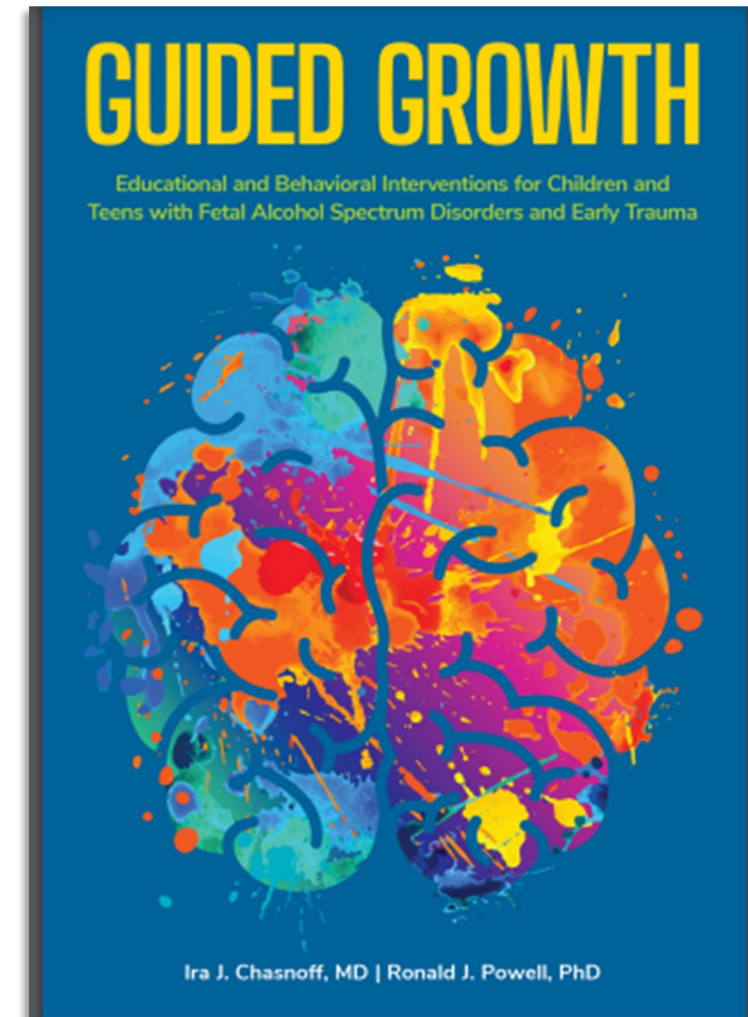
Attachment and Biobehavioral Catch-up (ABC)

6-24 months

- Home visiting program
- Caregiver intervention to help caregivers nurture infants and toddlers, foster their development, and form strong and healthy relationships
- Adapted for telehealth
- ABC team provides training for parent coaches.

Guided Growth: Educational and Behavioral Interventions for Children and Teens with FASDS and Early Trauma

- Interactive training and prerecorded webinars, videos, books
- Leadership Institute – technical assistance for creating system of care for families at risk for/affected by prenatal substance exposure



FASD Tools for Parents

EIGHT MAGIC KEYS
PLANNING FOR STUDENTS WITH FETAL ALCOHOL SPECTRUM DISORDER

- CONCRETE**: TALK IN CONCRETE TERMS. AVOID ABSTRACT LANGUAGE.
- CONSISTENCY**: PARENTS & EDUCATORS USE THE SAME WORDS & INTERPRETS.
- REPETITION**: REPEAT MANY TIMES TO ENGRAIN IN LONG-TERM MEMORY.
- ROUTINE**: HELP REDUCE ANXIETY.
- THE MASTER KEY**: KEEP IT SHORT & SWEET.
- SIMPLICITY**: THE GLUE.
- SPECIFIC**: DON'T BEARLY WANT TO HEAR. GIVE STEP BY STEP DIRECTIONS.

LEGAL CHECK-UP
A Resource for Parents of Children with Disabilities from Birth to 21 in Minnesota
January 2020

Fetal Alcohol Spectrum Disorder: an Australian toolkit for parents, caregivers and families

fasd australia

All About Me!
A Book About:

(Put ME Here!)

PR%F Alliance
Parent Advocacy Toolkit

Created in partnership with the Minnesota Disability Law Center and made possible by the Minnesota Department of Health and the American Bar Endowment.

LEGAL AID
MID-MINNESOTA LEGAL AID
MINNESOTA DISABILITY LAW CENTER
Duluth Ferlie Mankato Minneapolis

mi DEPARTMENT OF HEALTH
ABE
American Bar Endowment
Empowering your life needs.
Advancing your life work.

Proof Alliance Parent Advocacy Toolkit 2019

LET'S TALK FASD
PARENT DRIVEN STRATEGIES IN CARING FOR CHILDREN WITH FASD

VON

FAS
Parenting Children Affected by Fetal Alcohol Syndrome
A Guide for Daily Living

Ministry for Children and Families Edition

BRITISH COLUMBIA
Ministry for Children and Families
Parent Support Services
SOCIETY OF CHILDREN'S ADVOCATES

Take Home Points

- Prenatal alcohol exposure is the most common *preventable* cause of intellectual disability and behavior disorder
- The effects of prenatal alcohol exposure are lifelong
- Documentation of prenatal alcohol exposure is often a limitation of in the diagnosis of FASD
- There are benefits to making a FASD diagnosis
- There are evidence-informed programs to support individuals, families, and providers affected by FASD



PR%F
Alliance

**FASD Prevention,
Resources, and Advocacy**

Kendra Gludt, MPH
Director of National Programs

PROF

Alliance

Our mission is to prevent fetal alcohol spectrum disorders (FASD) and to support all impacted.



FASD Resources

Identification of FASD:

- Screening
- Diagnosis

**FASD
Informed
Professionals
and Parents**

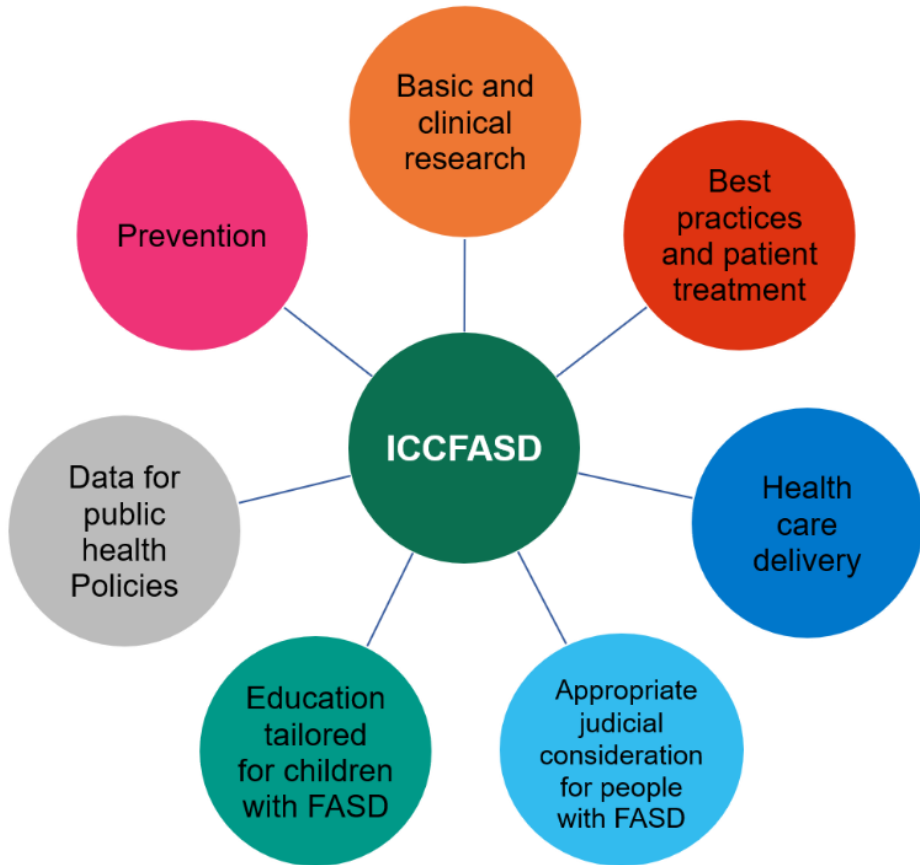
**Prevention of
Prenatal
Alcohol
Exposure**

**Culturally
Responsive
Programs**

Policy Change

Interagency Coordinating Committee on FASD

FASD-Related Work of the ICCFASD Agencies



CDC Centers for Disease Control and Prevention

IHS Indian Health Service

HRSA Health Resources and Services Administration

NIH National Institutes of Health

ACF Administration for Children & Families

CMS Centers for Medicare & Medicaid Services

DOJ United States Department of Justice

SAMHSA Substance Abuse and Mental Health Services Administration

FASD Research: Collaborative Initiative on FASD



CIFASD | Collaborative Initiative on
Fetal Alcohol Spectrum Disorders

HOME

ABOUT US

RESEARCH

PUBLICATIONS

NEWS

PARTICIPATE

EDUCATION

RESOURCES

CONTACT

DATA SHARING



The purpose of this consortium is to inform and develop effective interventions and treatment approaches for Fetal Alcohol Spectrum Disorders (FASD), through multidisciplinary research involving basic, behavioral and clinical investigators and projects. We hope to develop an infrastructure to foster collaboration and coordinate basic, clinical and translational research on FASD.



National Institute
on Alcohol Abuse
and Alcoholism

CIFASD is supported by NIAAA

CDC FASD Communication Materials

LET'S TALK

ALCOHOL AND
PREGNANCY

For more information, visit
WWW.CDC.GOV/FASD



LET'S TALK

ABOUT ALCOHOL USE
DURING PREGNANCY.



For more information, visit
WWW.CDC.GOV/FASD

ALCOHOL USE DURING PREGNANCY
IS ASSOCIATED WITH AN
INCREASED RISK OF

MISCARRIAGE STILLBIRTH
SIDS PRETERM BIRTH

AS WELL AS A RANGE OF
LIFELONG BEHAVIORAL, INTELLECTUAL,
AND PHYSICAL DISABILITIES, KNOWN AS
FETAL ALCOHOL
SPECTRUM DISORDERS (FASDs).

DURING PREGNANCY,
ALCOHOL CAN

PASS FROM THE
PREGNANT PERSON

To

THE FETUS
AND AFFECT
ITS DEVELOPMENT.



<https://www.cdc.gov/ncbddd/fasd/partners-tools.html>

CDC FASD Project: Building FASD Surveillance

Understanding Clinical Data and Pathways to Inform Surveillance of Children with FASD

A feasibility project that will

- Characterize information accessible within health-related data systems for children suspected of or diagnosed with FASD.
- Describe the referral, evaluation, and diagnosis processes.

Findings will be used to inform the development of future public health surveillance activities.

Recipients:

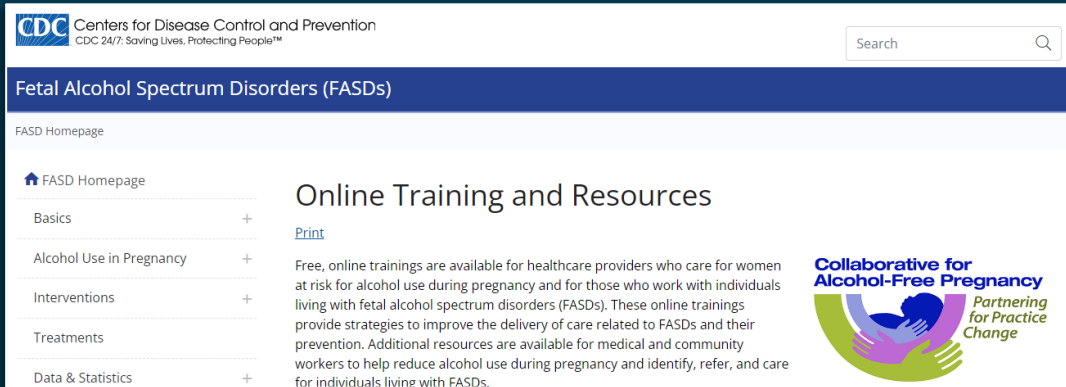
Emory University

Minnesota Department of Health and Proof Alliance

Period of Performance: 9/1/2022 – 8/31/2025

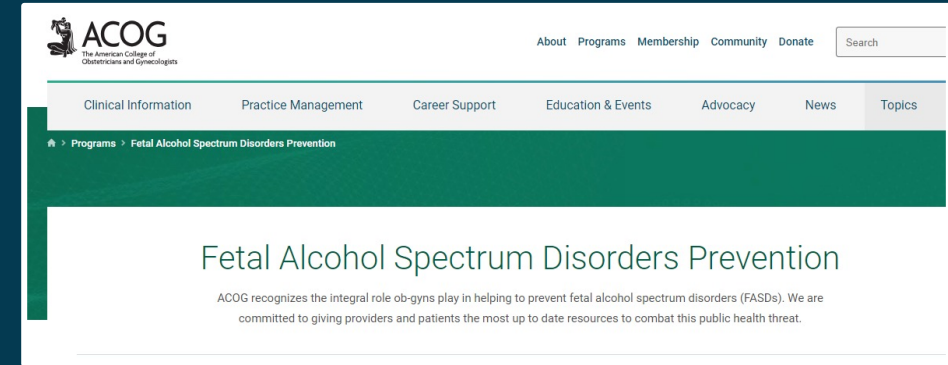
Online Training and Resources for Medical Professionals

Collaborative for Alcohol-Free Pregnancy



www.cdc.gov/ncbddd/fasd/searchable-training/index.html

ACOG FASD Champions

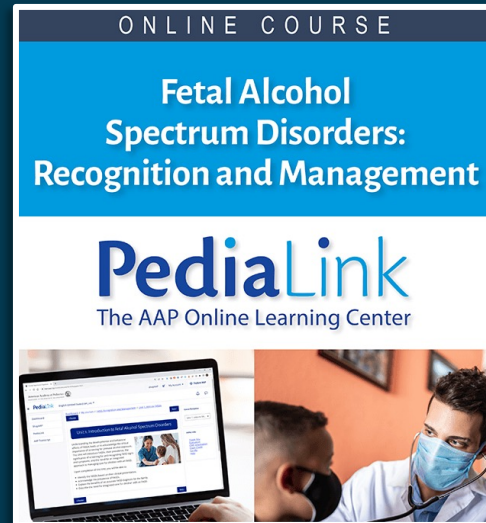


www.acog.org/programs/fasd

AAP FASD Toolkit and Resources



www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/



B-SMART Podcast on FASD



www.bmc.org/addiction/training-education/b-smart

Prevent FASD and care for children affected by it

- HRSA funded virtual ECHO® sessions for pediatric and prenatal practices, 2020-2024.
- Collaboration between Proof Alliance and Boston Medical Center.
- Teaches healthcare teams how to screen for prenatal alcohol exposure, counsel on FASD, and care for patients impacted by FASD.
- Free Continuing Education Credits.
- Since it started three years ago, 57 clinic practices participated across 15 states.
- Currently recruiting for prenatal practices to enroll, starts in February 2024.

Proof Alliance Online Training

PR%F
Alliance

[Home](#) [Courses](#) [Contact](#) [Login](#) 

Proof Alliance Online Training

Proof Alliance is your source for the most comprehensive, customizable training and education on fetal alcohol spectrum disorders (FASD). Increase your knowledge, gain a better understanding of the impact of prenatal alcohol exposure and learn more effective approaches to treating and preventing FASD with our on-demand training courses.

Featured Courses



learn.proofalliance.org

Trainings available for:

- Caregivers and foster caregivers
- Social service providers
- Medical professionals
- Substance use treatment providers
- People in treatment for substance use disorders
- Justice and corrections professionals
- Educators, paraprofessionals, after-school programs
- Middle/ high school students
- College students
- General Population

Creative FASD Prevention: Being in Unexpected Places

Not just pregnancy related spaces, not just women.

- Liquor stores
- College campuses
- Beer tasting events
- Special Olympics
- Pride festival

Going where people are getting their information.

- Social media
- Influencers





Social Media Campaign:

PROOF

How much alcohol is safe to drink during pregnancy?

Is red wine safer than beer? Is drinking during the first trimester more harmful than the third trimester? Use this tool to find out.

Let's find out

Pregnancyalcoholcalculator.org

Drinkingwhilepregnant.org

Fasdproof.org

Proof Alliance FASD Communication Materials

Busting the Myths about Drinking During Pregnancy

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Alliance

Drinking alcohol during pregnancy can cause birth defects, brain injury, and fetal alcohol spectrum disorders (FASD). There is no known amount of alcohol that can be considered safe during pregnancy. All major health groups advise that if a person is pregnant or may become pregnant, they should abstain from alcohol.

There are many myths surrounding alcohol use during pregnancy.

MYTH	MYTH	MYTH
Wine is safe to drink during pregnancy. Wine is safe to drink especially if it's just one or two glasses here and there.	FASD is only common in certain communities.	It's safe to drink alcohol at the end of the pregnancy.
FACT	FACT	FACT
All types of alcohol contain chemicals known as teratogens. These are harmful to a developing baby. Drinking any kind of alcohol can impact the baby's development. The safest choice is to not drink any	In the United States, 1 in 7 pregnancies are exposed to alcohol. As many as 1 in 20 children have an FASD. FASD affects people from all races, all ethnicities and all income levels.	The baby's brain develops throughout the entire pregnancy. Drinking at any time during pregnancy can cause permanent brain injury. The safest choice is to not drink if you're pregnant.

Understanding Behaviors of FASD

PR%F
Alliance

Fetal alcohol spectrum disorders (FASD) include brain injury and disabilities caused by prenatal alcohol exposure.^{1,2} Drinking alcohol during pregnancy can cause changes to brain size, structure and functioning.³ This type of brain injury can lead to issues with behavior.⁴

Without an understanding of the challenges faced by people with FASD, typical behaviors may be seen as purposefully misbehaving or acting out; however, it is often just the opposite. When it seems like a child won't do something, it might be that they can't do it – at least not without support.⁵

Remember that everyone with an FASD has the ability to succeed.

Strategies, support and interventions can help improve outcomes, behavior and overall well-being for people with FASD.⁶

Challenges and Strategies

It is important to note that each person with FASD is unique and has different strengths and challenges. Not every person with FASD will demonstrate all of the effects below. More so, this is not a complete list of all the possible behavioral effects of FASD.

Due to brain injury, people with FASD may have difficulty with:

<https://www.proofalliance.org/article/fact-sheets-and-strategy-guides/>

A TREATMENT IMPROVEMENT PROTOCOL

Addressing Fetal Alcohol Spectrum Disorders (FASD)

TIP 58



A TREATMENT IMPROVEMENT PROTOCOL

Addressing Fetal Alcohol Spectrum Disorders (FASD)

TIP 58

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Substance Abuse Prevention

1 Choke Cherry Road
Rockville, MD 20857



Support for Families, Youth, and Caregivers

- Support groups
- Retreats
- Social events
- Life skills
- Advocacy
- Caregiver conference
- Online support spaces
- Panel presentations
- Podcasts
- Resource navigation

Proof Alliance Family Support

PR%F Alliance

The Fresh Start Forum

SUPPORT FOR PEOPLE WHO USED ALCOHOL DURING PREGNANCY

EVERY OTHER MONDAY
5:30 P.M. TO 7:30 P.M. CST
VIRTUAL: REGISTER FOR LINK
IN-PERSON: PROOF ALLIANCE



Register



PR%F Alliance

Second Saturdays

AN IN-PERSON SUPPORT GROUP FOR YOUTH AGES 16-21 WITH AN FASD

SECOND SATURDAYS
12:00 P.M. TO 1:30 P.M. CST
1876 W MINNEHAHA AVE,
ST PAUL, MN 55104




Proof Alliance

FAMILY NIGHT

Connect with other families in our programming and enjoy fun, family-friendly activities!

FREE PIZZA!

DETAILS:
📅 November 17, 2022
🕒 6:00 - 8:30 p.m.
📍 Proof Alliance
1876 Minnehaha Ave W., St. Paul

YOUTH (AGE 15+)
Meet in the large conference room for a movie on the big screen
*Supervised by PA staff

CAREGIVERS
Meet in the family support lounge for crafts, conversation and respite



PR%F Alliance

FASD and Me

A VIRTUAL SUPPORT GROUP FOR PEOPLE AGED 17-23 WITH AN FASD.
LAST WEDNESDAY OF THE MONTH
6:00 P.M. TO 7:30 P.M. CST
REGISTER FOR ZOOM LINK

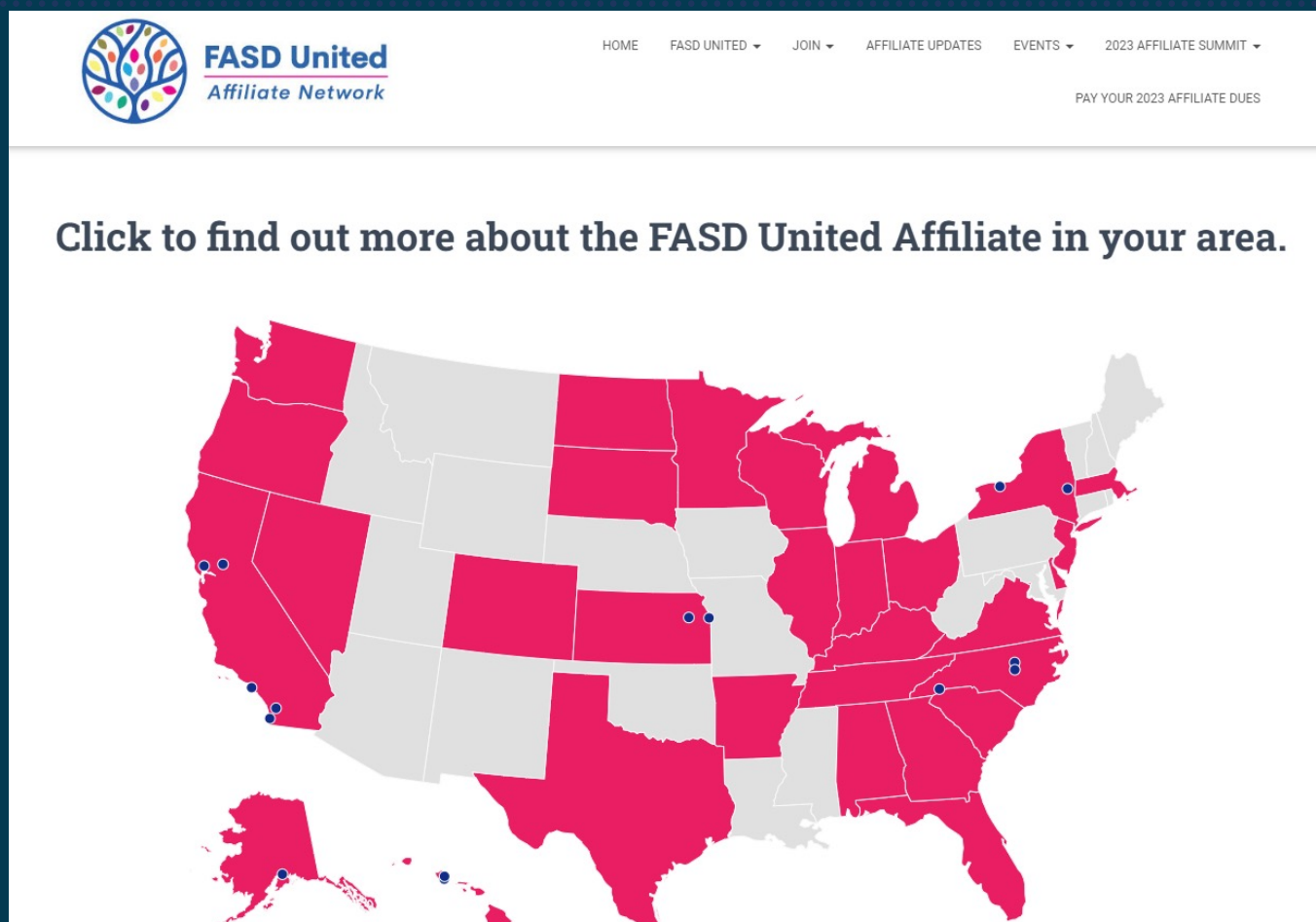


Register



Visit Events Calendar: proofalliance.org/events

FASD United Affiliate Network



FASD United
Affiliate Network

HOME FASD UNITED JOIN AFFILIATE UPDATES EVENTS 2023 AFFILIATE SUMMIT

PAY YOUR 2023 AFFILIATE DUES

Click to find out more about the FASD United Affiliate in your area.

fasdunited.org

Recovering Mothers Anonymous



recoveringmothers.org

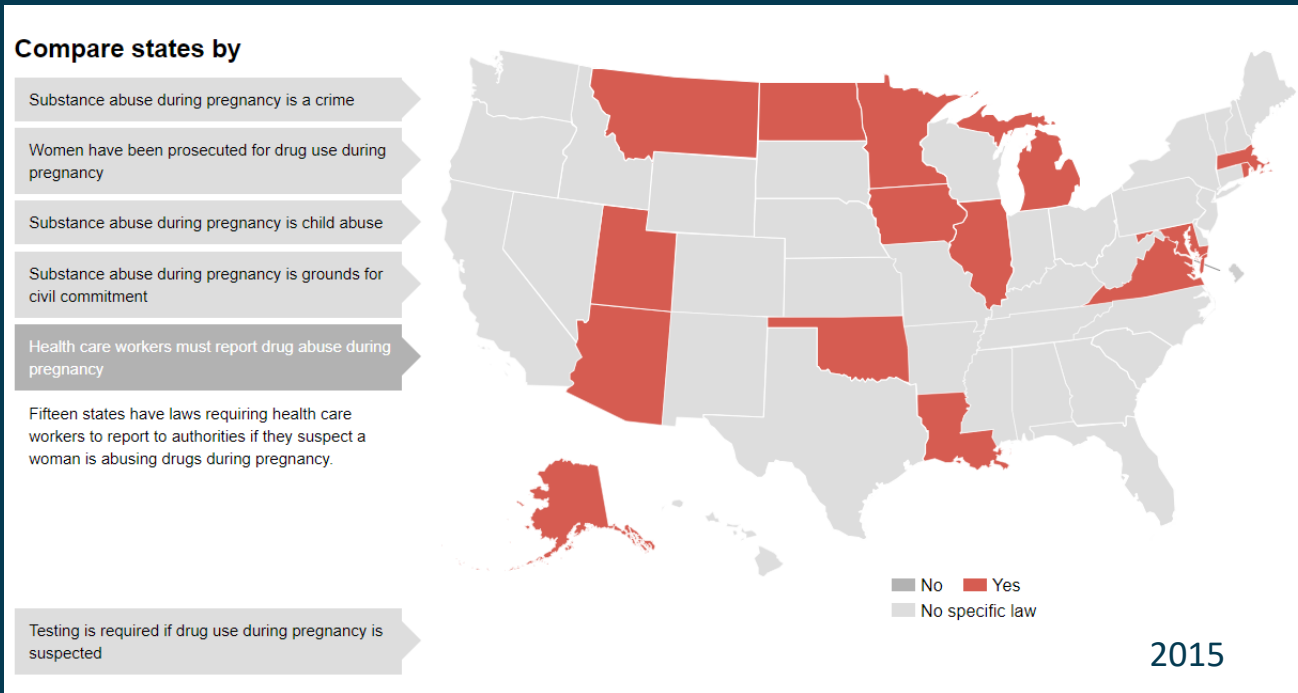


The ***Our Children Are Sacred*** app is your resource for ***FASD information*** and ***returning to culture.***



Mandated Reporting: Alcohol Use During Pregnancy

Policy changes are happening all the time and vary from state to state.



HHS Public Access

Author manuscript

Womens Health Issues. Author manuscript; available in PMC 2020 May 01.

Published in final edited form as:

Womens Health Issues. 2019 ; 29(3): 213–221. doi:10.1016/j.whi.2019.02.001.

State policies targeting alcohol use during pregnancy and alcohol use among pregnant women 1985-2016: evidence from the Behavioral Risk Factor Surveillance System

Sarah C.M. Roberts, DrPH¹, Amy A. Mericle, PhD², Meenakshi S. Subbaraman, PhD, MS², Sue Thomas, PhD³, Ryan D. Treffers, JD³, Kevin L. Delucchi, PhD⁴, and William C. Kerr, PhD²

Conclusions: "Most policies targeting alcohol use during pregnancy do not appear to be associated with less alcohol consumption during pregnancy."

<https://projects.propublica.org/graphics/maternity-drug-policies-by-state>

National Policy Advocacy: FASD RESPECT ACT

The FASD Respect Act (H.R. 3946/S.1800) is legislation addressing FASD on a national level.

Bi-partisan legislation:

- Co-sponsored in the Senate by Senator Amy Klobuchar (D-Minnesota) and Senator Lisa Murkowski (R-Alaska)
- Co-sponsored in the House of Representatives by Representative Betty McCollum (D-Minnesota, 4th District) and Representative Don Bacon (R-Nebraska, 2nd)



<https://nofaspolicycenter.org/the-fasd-respect-act/>

National Policy Advocacy: FASD RESPECT ACT

The FASD Respect Act (H.R. 3946/S.1800) would allow the US Department of Health and Human Services to provide:

- Funding for education, awareness, and services across community agencies and systems of care for infants to adults
- Provide funding to state and tribal systems for FASD services throughout the lifespan
- Create Centers for Excellence to guide states and other systems of care in
 - Expanding diagnostic capacity
 - Public awareness and outreach about FASD
 - Training and technical assistance on prevention
 - Supports and interventions for people diagnosed with FASD



FASD Resources:

Identification of FASD:

- Screening
- Diagnosis

FASD
Informed
Professionals
and Parents

Prevention of
Prenatal
Alcohol
Exposure

Culturally
Responsive
Programs

Policy Change

All of these improve when we increase awareness and decrease stigma.

Closing Comments

Susan Terwey, MS



Closing Comments

- Biggest regret of my life
 - Typical? Yes – a lightbulb may be going off for some of you - Clear message, no message, inaccurate message
 - Biases often based on class and culture
 - Uncomfortable asking – “don’t want to damage the relationship”
 - We don’t disclose unless asked – repeatedly
 - “Make it okay” – your openness may open the door for disclosure
 - Kids don’t blame their moms, we shouldn’t either.
-

