

# What are the Long-Term Effects and Impacts of Fetal Alcohol Spectrum Disorders (FASD) on Individuals and their Families



National Organization on Fetal Alcohol Syndrome

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# Objectives

By the end of this webinar participants should be able to:

1. Describe some of the possible lifelong developmental, behavioral, and physical effects of fetal alcohol spectrum disorders (FASD).
2. Discuss strategies to reduce the stigma associated with FASD.
3. Describe challenges and resiliency factors within families living with FASD.

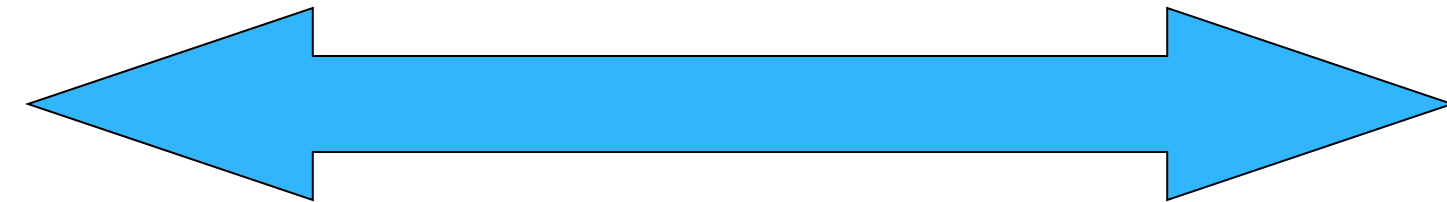
**What recreational drug causes the most long term damage to the developing fetus?**

- a) Heroin**
- b) Cocaine**
- c) Alcohol**
- d) Prescription Opioids**

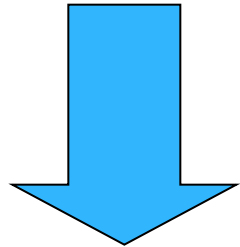
# ANSWER C - ALCOHOL

In 1996, the Institute of Medicine reported “Of all substances of abuse (including heroin, cocaine, marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

# Fetal Alcohol Spectrum Disorders

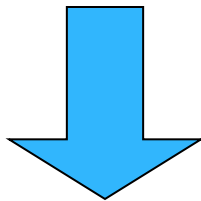


**FAS**



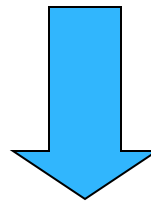
**Fetal Alcohol  
Syndrome**

**PFAS**



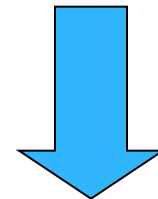
**Partial FAS**

**ARND**



**Alcohol-Related  
Neurodevelopmental  
Disorder**

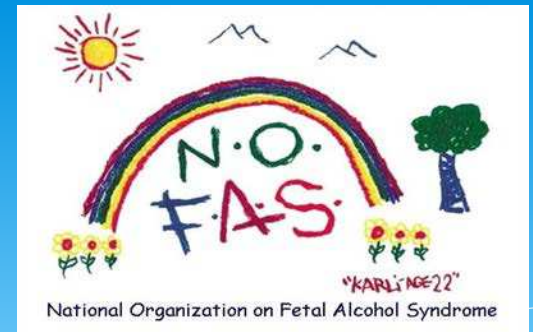
**ND-PAE**



**Neurodevelopmental  
Disorder associated  
with Prenatal Alcohol  
Exposure**

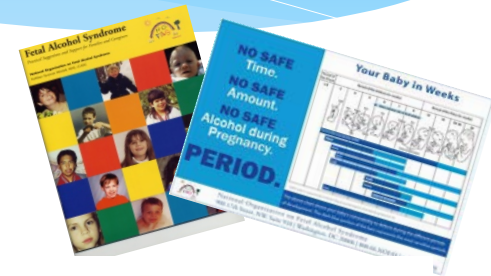
**Fetal and Infant Death**

# NOFAS Clearinghouse nofas.org



## Materials, Resources and FASD Facts

- National Resource/Referral Directory
- Weekly NOFAS Roundup
- K-12 FASD Prevention Curriculum
- Fact Sheets, Books, Posters, DVDs
- Educational webinars/trainings
- Conference presentations
- Facebook
- Twitter @NOFAS\_USA
- YouTube: Alcohol-Free Pregnancy



N.O.  
F.A.S. Weekly Roundup



A photograph of a woman with long dark hair, wearing a white top, sitting and holding her pregnant belly with both hands. The image is overlaid with a semi-transparent blue filter. The text is written in a red, cursive font with a drop shadow effect.

*no woman drinks  
because she wants  
to hurt her baby.*



# Old Medical Model: the act of drinking caused the alcoholism

- \* They don't care about their health
- \* Must be shown the destruction so they'll be scared to drink
- \* Withdrawal ends in 3 days, if they drink after that its because they have mental issues
- \* Slow suicide (MH)
- \* If you're young or drink less than your doctor, you can't be an alcoholic



# Disease Model/medical/biological

- \* Most alcoholics don't need psychiatry/AA more effective
- \* Physiological not psychological
- \* Not crazy, immoral, weak-willed, or disgusting

# Differences from male alcoholics:

- \*Women more frequently report a positive family history (denial/fear)
- \*Progression of disease is quicker than men
- \*Woman's partner is more likely to be addicted than a male's partner
- \*Victims of domestic violence
- \*More likely to combine alcohol with RX drugs
- \*More barriers in seeking help
  - \* Financial problems
  - \* child care responsibilities
  - \* family pressures
  - \* social stigma

1977

# Karli, Danny and Erin

## A Happy Little Hippie Family



Karli age 10 (diagnosed with cerebral palsy)



# Alcohol is a Teratogen

Alcohol is a teratogen (*def.* an agent that can cause malformations of an embryo or fetus). Alcohol can cross the placenta and enter fetal circulation, damaging cells and the DNA they contain.



**every single baby reacts  
differently to alcohol.**



**no one can predict how each  
baby will be affected.**

# The Doctors Bag: Prescription Pad

- 90% of women use some form of prescription medication throughout their pregnancy
- Over the last 30 years, first trimester use of prescription medications has increased more than 60% (CDC).
  - About 3.4 of every 1,000 infants born suffer from withdrawal symptoms related to misuse of narcotic prescription medications; that is one newborn every hour.
  - According to the Journal of the American Medical Association, infants suffering from Neonatal Withdrawal Syndrome has more than tripled within the past decade.



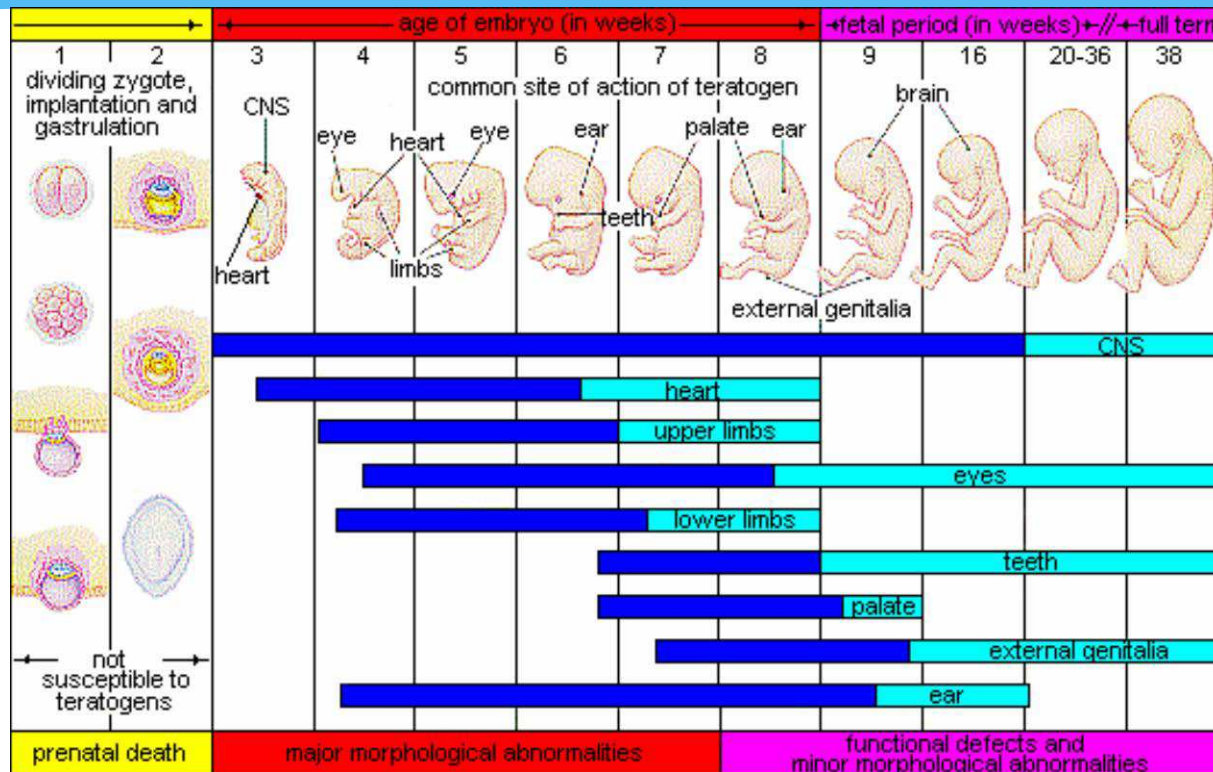
*“Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks”*

- JUDGES 13:7

## **Use of Ethanol in Threatened Premature Labor**

- \* View on the absolute safety of alcohol in pregnancy continued into the 1960's when the alcohol drip was introduced in obstetrics.
- \* One of few medical uses of ethanol.
- \* Involved I.V. ethanol infusion for 6–10 hours, reaching BAC as high as 160 mg/dl
  - \* First report — Fuchs, F., et al., *Am. J. Obstet. Gynecol.*, 99:627 (1967)

# Impact of Alcohol Use on the Developing Fetus



Adapted from Moore and Persaud, 1993.

# Alcohol & SIDS

“Alcohol use while pregnant is a leading causal factor in both fetal and infant death.”

\* Ken Warren, PhD, Acting Director, NIAAA  
NOFAS interview, [www.nofas.org](http://www.nofas.org)

# The facial features of Fetal Alcohol Syndrome can be seen in both a child and a mouse fetus that were exposed to alcohol during development

child with FAS



Narrow forehead

Short palpebral  
fissures

Small nose

Small midface

Long upper lip  
with  
deficient philtrum

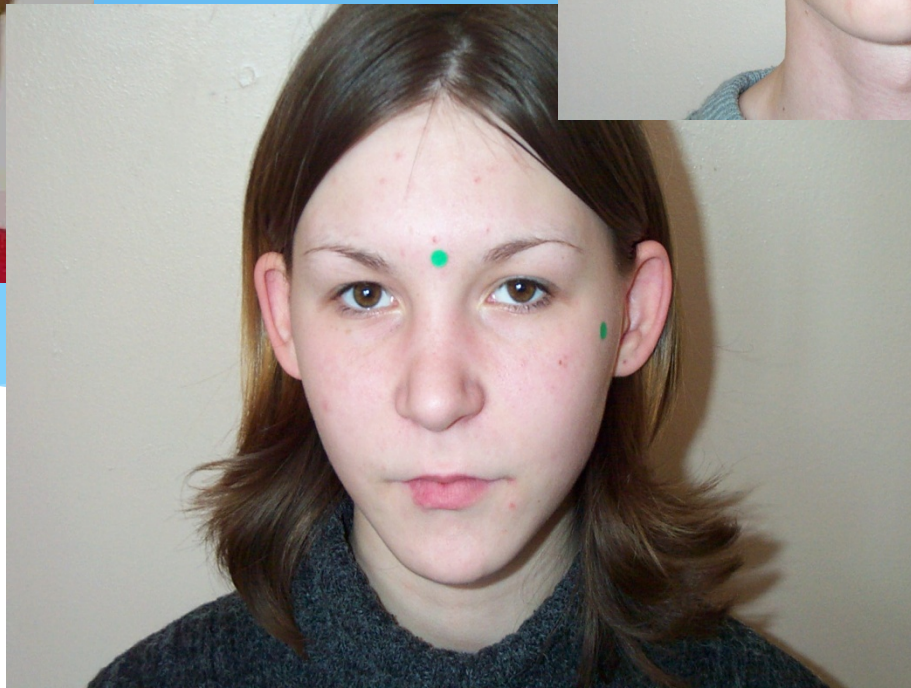
mouse fetuses



alcohol-exposed

normal

The facial features of FAS are not always obvious.



# Growth (CDC Diagnostic Guidelines):

- Confirmed prenatal or postnatal height or weight, or both, at or below the 10<sup>th</sup> percentile, documented at any one point in time

(adjusted for age, sex, and race or ethnicity)

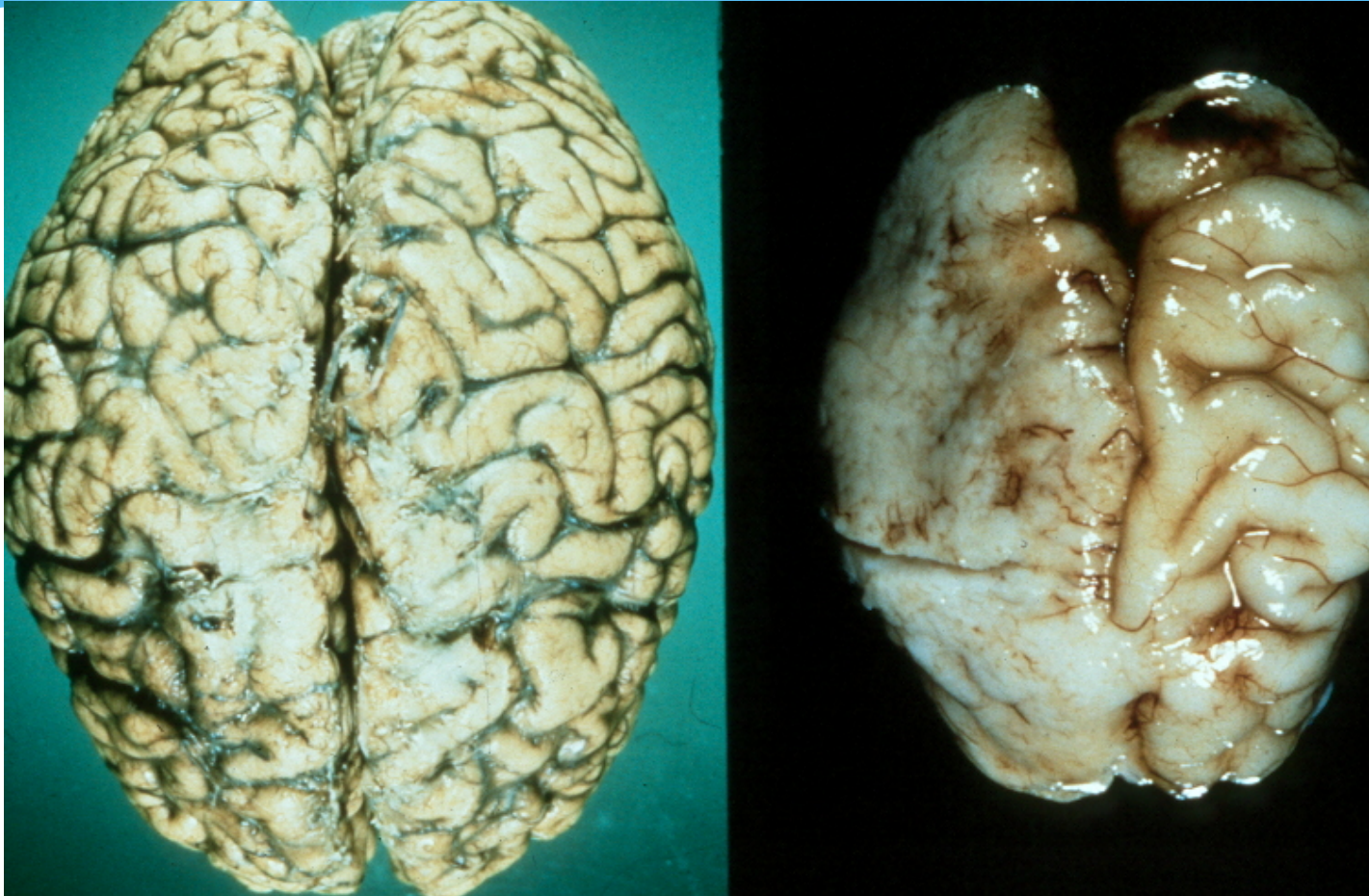
# Preventing FASD may prevent many other health consequences

## Patients Health Chart at (35 years old)

- Systemic lupus
- Idiopathic thrombocytopenia purpura
- Chronic migraine
- Antiphospholipid syndrome
- Fibromyalgia
- Hiatal hernia
- Pituitary microadenoma
- \* Hysterectomy
- \* Prolapsed bladder
- \* Depression
- \* Anxiety
- \* Learning disabilities
- \* Poor executive functioning

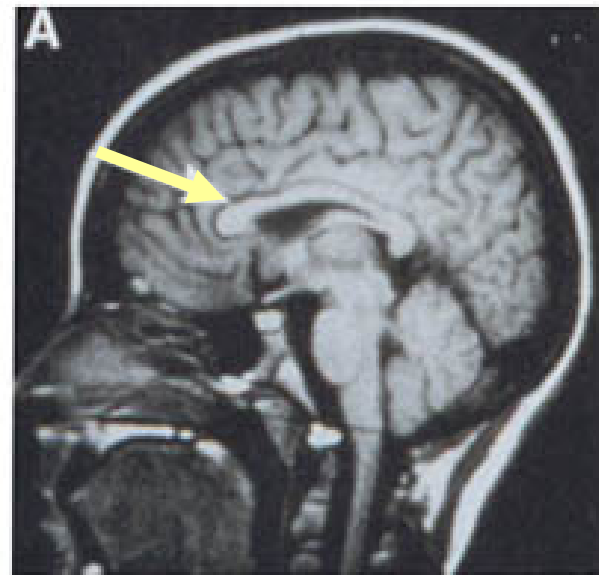


# *A severely affected prenatally-exposed brain*

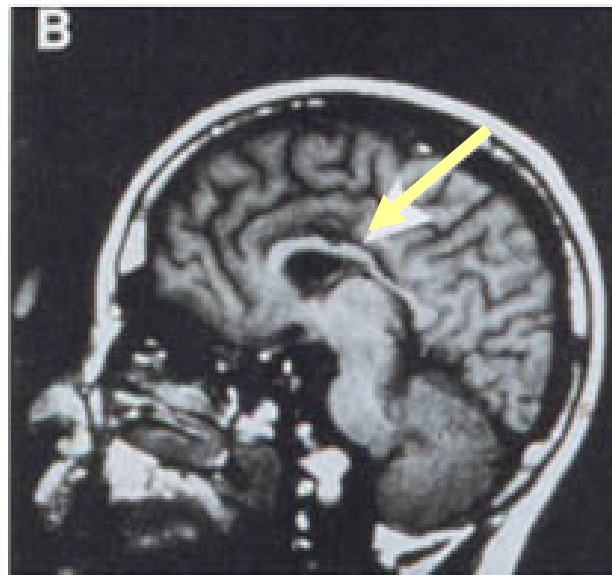


*- from Sterling Clarren*

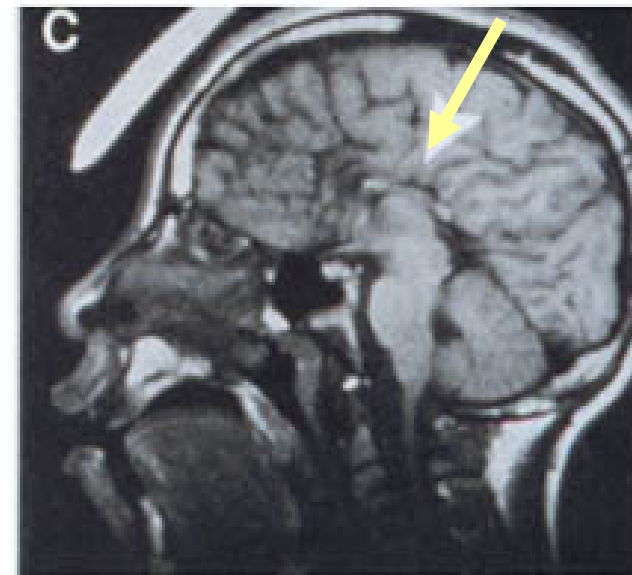
**Visualization of the brain of a typical (A) and two children exposed to alcohol (B,C) shows permanent loss of the tissue indicated by the arrows (portions of the corpus callosum).**



**Normal**

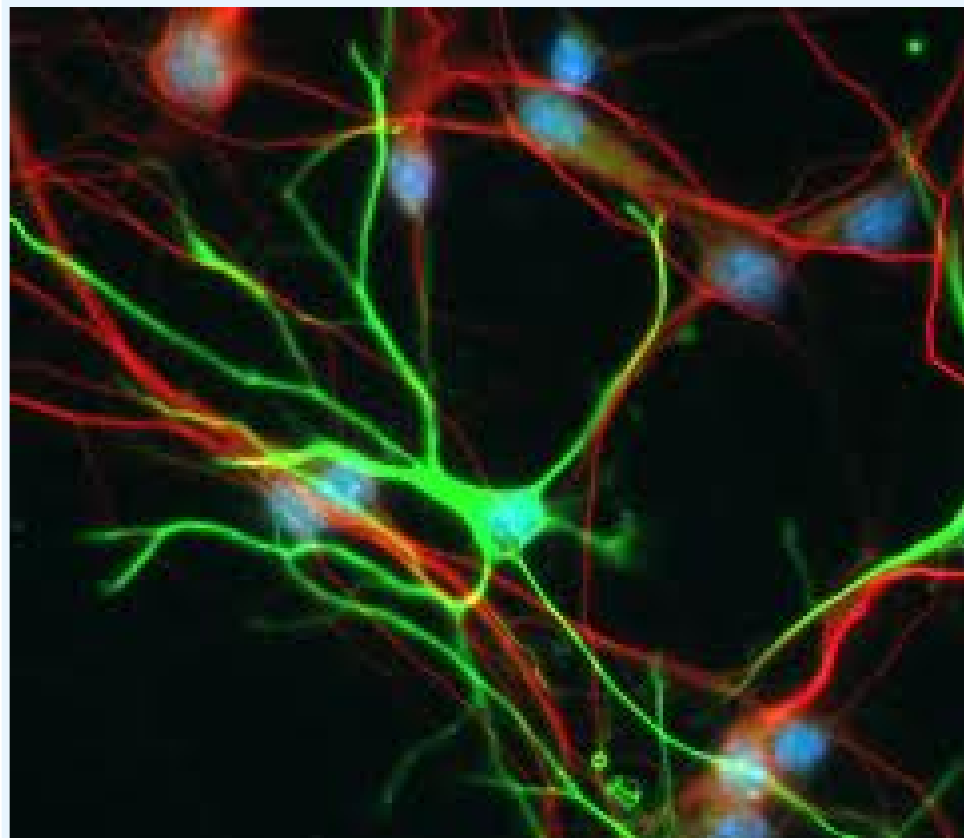


**FAS/PEA**



**FAS**

*Prenatal exposure to alcohol  
causes the brain to actually  
be “built” differently ...*



# Learning Theory

*assumes that the student/adult is capable of:*

- \* Learning a rule or principle*
- \* Understanding the underlying concepts of that principle*
- \* Remembering these concepts*
- \* Generalizing this learning to many different situations*

# Alcohol during pregnancy can result in a brain that:

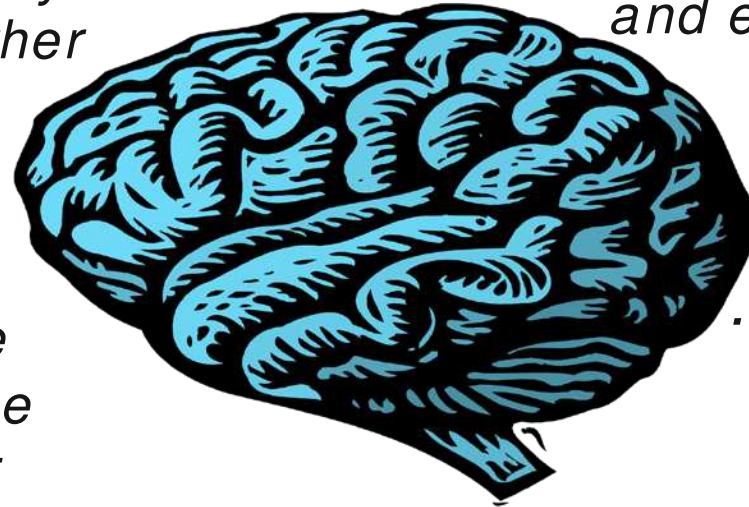
*...can't read the emotions or body language of other people*

*responds slowly*

*...can't link cause and effect*

*...thinks in a disorganized way*

*...thinks like the brain of someone much younger*



*...has trouble moving information from one situation to another*

*...forgets information*

*...has difficulty with time and money*

*...uses poor judgment*

# Common disorders identified with FASD

- \* Autism/Aspergers' s Disorder
- \* Attention Deficit Hyperactivity Disorder (ADHD)
- \* Borderline Personality Disorder
- \* Attachment-Bonding Disorder
- Depression
- Learning disability
- Oppositional-Defiant Disorder
- Post Traumatic Stress Disorder (PTSD)
- Receptive-Expressive Language Disorder
- Conduct Disorder

# FAS TIMELINE

Actual age of individual: 18

Skill	Developmental age equivalent
Expressive Language	=====> 20
Comprehension	=====> 6
Money, time concepts	=====> 8
Emotional maturity	==> 6
Physical maturity	=====> 18
Reading ability	=====> 16
Social skills	=====> 7
Living skills	=====> 11

**Adapted from: Research findings of Streissguth, Clarren et al. Diane Malbin 1994**



# 5

## Types of concerns that may lead to an assessment for an FASD

1. Developmental or behavioral concerns
2. Dysmorphic facial features associated with prenatal alcohol exposure (PAE)
3. Growth deficiency at or below 10<sup>th</sup> percentile for head circumference, height, weight at any time, including prenatally
4. History of confirmed or suspected PAE
5. Self-reported or family concern about possible

# Families raising a child with an FASD face many challenges

- Most cases of FASD are never diagnosed. Symptoms of FASD are identified and addressed. But rarely is alcohol identified as the causal factor.
- Few physicians, healthcare professionals, disability professionals, psychologists, therapists, etc. are trained in how to identify FASD.
- \* Birth mothers can face incarceration in some states.
- \* Birth families can live with painful judgements and stigma.



# Helping Families to COPE

Change Perception:

linear to circular

Acceptance is a  
process, not an event

One day at a time



# Traits of Healthy & Resilient Families

- \* Commitment
- \* Time Together
- \* Respect
- \* Spirituality
- Connectedness
- Adaptability
- Communication
- Cohesion



# *Family in Recovery*

- \* Learns that addiction is a disease-not self-inflicted.
- \* Discovers hope for self & user.
- \* Has peace of mind/serenity.
- \* Helps others.
- \* Can discuss and work out problems.
- \* Has support network and can identify and discuss feelings.
- \* May assume prior family roles.
- \* Learns not to personalize behaviors of FASD



# ***My Child Has FAS: The Scarlet Letter***

**A lifetime of public shaming, judgment  
and blaming:**

**(individuals living with FASD, mother, father, sisters,  
brothers, grandmother, grandfather, granddaughters,  
grandsons, nieces, nephews, aunts, cousins,  
son-in-laws, daughter-in-laws, their in-laws, etc.)**

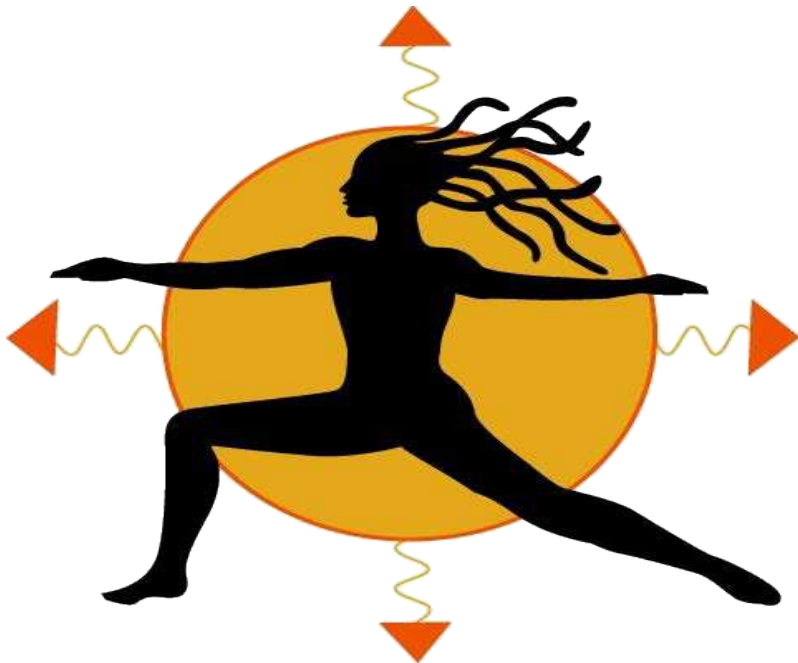
# NOFAS Circle of Hope Birth Mothers Network

[www.nofas.org/coh](http://www.nofas.org/coh)

Mitchell@nofas.org

## Peer Mentoring Support:

- \* Improve and strengthen the lives of birth families
- \* Provide peer support for birth families
- \* Decrease the stigma, blame and shame that birth families may experience





# Words Can Perpetuate Stigma:

- \* **Avoid blaming language**
  - **FASD occurs when a fetus is exposed to alcohol NOT FASD occurs when a pregnant woman drinks**
  - **A child who has an FASD versus an FASD child (person first language)**

# Conversations with mothers:

- \* Be gentle, non-judgmental, ask, then listen to their story.
- \* Stick to the facts by providing information and education on alcohol/drug use, dependency or addiction in a matter of fact manner.
- \* You may be the only person that CAN help move them to change.
- \* To provide the best care possible it's important to know all of the facts about the pregnancy including any exposures.
- \* Remind her that you care about her child and HER and want the best health possible for the entire family.

# Stamp Out Stigma Campaign

Join the campaign!  
[www.nofas.org/stigma](http://www.nofas.org/stigma)

Join NOFAS and the NOFAS Circle of Hope to stop the stigma of birth mothers of children with FASD and the stigma of all individuals and families living with the disorders.



National Organization on Fetal Alcohol Syndrome

**STAMP OUT  
STIGMA**

# Take Away Message:

- ❧ **Identify women with SUD and get them the support they need**
- ❧ Addiction and FASD affects the entire family; all family members need support and counseling
- ❧ Treatment and support can come in many ways for women and their families
- ❧ Consider the possibility of FASD or other developmental disabilities in clients and their children

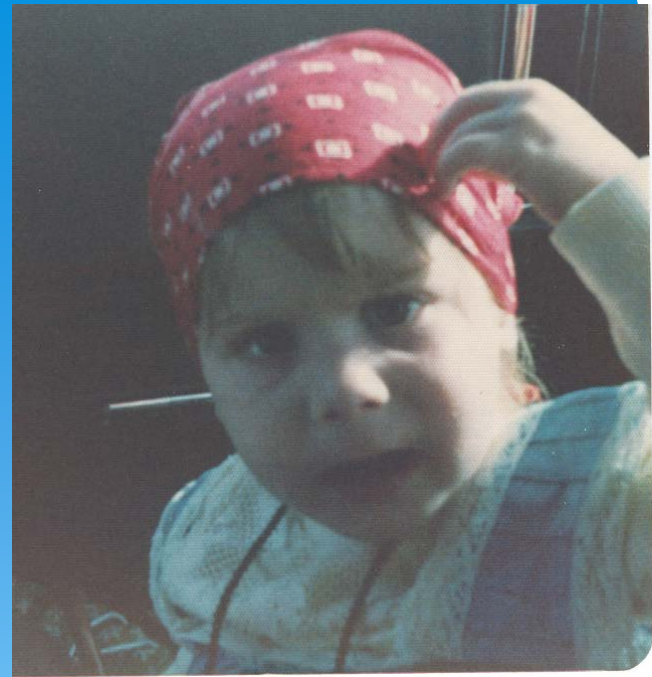
# Resources



**Nofas.org**

- ❑ **ACOG Webpage on alcohol and women:**  
[www.womenandalcohol.org](http://www.womenandalcohol.org)
- ❑ **AAP FASD Toolkit** – [www.aap.org/fas](http://www.aap.org/fas)

Contact me  
**ANYTIME!**  
Thank You!



*Kathy Mitchell*  
**NOFAS.org**  
**Washington, DC**

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