Creating a Circle of Hope: FASD Prevention & Advocacy

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National Organization on Fetal Alcohol Syndrome

About NOFAS

Mission

NOFAS works to prevent prenatal exposure to alcohol, drugs, and other substances known to harm fetal development by raising awareness and supporting women before and during their pregnancy, and supports individuals, families, and communities living with Fetal Alcohol Spectrum Disorders (FASDs) and other preventable intellectual/developmental disabilities.

Vision

A world where all children are born free of exposure to alcohol, drugs, and other substances known to harm fetal development.

Purpose

NOFAS educates the public, practitioners, and policymakers about the risk of prenatal exposure to alcohol, drugs, and other substances known to harm fetal development including tobacco, marijuana, heroin and other opioids, cocaine, and methamphetamine, recognizing that these substances are often used simultaneously. NOFAS supports individuals and families living with FASDs through referrals, advocacy, training for professionals, information dissemination, and a wide range of diverse initiatives and resources.
33 NOFAS State Affiliates

Speaking and Training Requests
- Curriculum Development & Dissemination
- Students and professionals
- Crisis calls & questions
- Media Outreach

International and State Resource Directory
- Policy and Advocacy
NIH Study Finds as Many as 1 in 20 First-Graders Are Affected by Prenatal Alcohol Exposure
FETAL ALCOHOL SPECTRUM DISORDERS MIGHT BE AT LEAST TWICE AS COMMON AS AUTISM


Fetal Alcohol Spectrum Disorders

FAS  PFAS  ARND  ND-PAE

Fetal Alcohol Syndrome  Partial FAS  Alcohol-Related Neurodevelopmental Disorder  Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure

Fetal and Infant Death
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 judgments and stigma.

Kathy Mitchell, NOFAS 2014

Alcohol use among US women, 2011-2013

Behavioral Risk Factor Surveillance System (BRFSS)

State-based, random-digit–dialed telephone survey of 206,481 women aged 18–44 years, 8,383 were pregnant

A multi-stage nationally representative sample of households

In-person interviews 5,601 women aged 15–44 years, including 4,303 nonpregnant, nonsterile women

1 in 10 pregnant women reports alcohol use*

3 in 4 women who want to get pregnant as soon as possible report drinking alcohol


Why do some people become addicted to alcohol and other drugs, while others do not?

**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.
Opioid Abuse Skyrockets

* Addiction from opioid prescriptions is the fastest rising public health problem in the United States.
* Over 2,000 deaths per week have been attributed to opioid abuse.
* Most of the fatalities are due to **Oxycontin**
* Over 100 people die every day in US from drug overdose.
* Americans consume 99% of the world's supply of hydrocodone.

History of FAS

* Judges; Old Testament, "Behold, thou shalt conceive and bear a son and now drink no wine or strong drink!"

* In ancient Carthage and Sparta there were laws prohibiting the use of alcohol by newly married couples in order to prevent conception during intoxication.

* 1720's, "gin epidemic" the Royal College of Physicians reported to the Parliament that parental drinking was a cause of "weak, feeble and distempered children."

* 1860's, House of Commons came out with a paper entitled "Effects of Drunkenness on the Nation", which also contained a report on the effects of maternal alcohol consumption on the newborn: "They tend to be born starved, shrunkeled and imperfect in form"

* 1973, U.S., Dr Kenneth Lyon Jones and Dr David Smith coined the term Fetal Alcohol Syndrome (FAS), which has since become a clearly established clinical entity.
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.

Impact of Alcohol Use on the Developing Fetus

Adapted from Moore and Persaud, 1993.
Comparison: Child with FAS and mouse fetus with fetal alcohol exposure

Child with FAS
- Small head
- Short palpebral fissures
- Small nose
- Small midface
- Long philtrum; Thin upper lip

Mouse fetuses
- alcohol-exposed
- normal

Photos courtesy of K. Sulik

The developing embryo is vulnerable to alcohol even when it is small enough to fit inside the zero on a penny
an unborn baby’s blood alcohol concentration will be the same as mom’s but for a longer period of time

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

Example of extreme brain damage resulting from prenatal alcohol exposure

Brain Mapping

Gray Matter Density Increase
- Sowell et al., 2001a

Shape Distortion in Frontal and Parietal Lobes
- Sowell et al., 2001b
Role of frontal lobes

- Executive function
- Judgment
- Difficulty in interpreting feedback from the environment
- Risk taking
- Non-compliance with rules
- Impaired associated learning
- Spontaneity
- Memory
- Social and sexual behavior
- Some aspects of language

The Basal Ganglia and other Subcortical Structures

- Relays information to frontal lobes
- Organize and prioritize information
- Filters information
- Category learning
- Emotional gating
- Working memory
Executive Functioning

Cognitive functions involved in planning and guiding behavior in order to achieve a goal in an efficient manner:

- The ability to organize and plan
- Focus and maintain attention
- Be able to store memories and retrieve them
- Issues related to affect and inhibition, e.g. preventing anger from getting out of control
- Self-awareness
- Initiating and ending activities

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).

Images courtesy of Dr. S. Mattson
Lamination of Brain

- From 6 weeks of gestation on
- The way cells go together to form the brain
- The most important part of brain development is how the brain is organized: brain stem-midbrain-limbic-cortex

Screening for FASD: Lifelong Problems Appear Across a Continuum of Severity

<table>
<thead>
<tr>
<th>Mild</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognition</td>
<td>Reduced IQ, Learning Disabilities, poor insight and judgment, executive functioning, attention, short term memory and processing speed</td>
</tr>
<tr>
<td>Behavior</td>
<td>Aggression, temper outbursts, impulsivity</td>
</tr>
<tr>
<td>Social Skills</td>
<td>Poor boundaries, difficulty reading facial expressions or body language</td>
</tr>
<tr>
<td>Speech and Language</td>
<td>Pragmatic speech, receptive and expressive language</td>
</tr>
<tr>
<td>Emotion</td>
<td>Anxiety, depression, mood disorders</td>
</tr>
<tr>
<td>Motor Skills</td>
<td>Fine, gross motor skills impairment</td>
</tr>
</tbody>
</table>

Lockhart, P. 2006
Common disorders identified with FASD

- Autism/Asperger'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

FASD is a Systemic Disability

Animal Studies (Joanne Weinberg, 2008)
- Study examines how alcohol exposure affect neurological systems in an animal model and implications for intervention.
  - Altered hormonal, immune, and behavioral function
  - Special emphasis on stress
Preventing FASD may prevent many other health consequences

35 Year Old Woman (PAE)

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

Not all babies born to mothers who drink alcohol are affected by the alcohol to the same degree – other factors, such as mother’s nutrition may be important in modifying alcohol’s effect on the child’s learning ability and growth

Pregnant women who drink alcohol tend to have LOWER levels of nutrients that are essential for the development of the baby:

- ↓ zinc
- ↓ copper
- ↓ iron
- ↓ folate
- ↓ B12
- ↓ Vitamin D
Not every woman who drinks heavily during pregnancy will give birth to a child with an FASD.

Not all children with an FASD have exactly the same defects or deficits.

Many biological and environmental factors influence the effects of alcohol on the developing fetus.

Behavior is not purposeful
Paradigm Shift:

- Person with a developmental disability
- Can’t not Won’t
- Need support (External Brain)
There is a great interest in the topic of pregnant women that drink

In January 2016 the Washington Post article on NOFAS Vice President Kathy Mitchell. The article was featured on the front page of the Health section and was the most widely read article. On day 3 the post reported that it had been read by 7.7 million people and led FASD to trend on Facebook as the 6th most talked about topic in the days that followed publication of the article. Other media had feature articles and talk shows on the topic including the Daily News, Self Magazine, CBS; The Doctors, and NPR Radio.

NOFAS Circle of Hope
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* International Groups
* Peer mentoring Support
* Speakers Bureau
* Newsletters
* Private Facebook site for birth moms
* Webinars
Take Away Message:

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

Resources

- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
- https://findtreatment.samhsa.gov
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Clearinghouse for Alcohol and Drug Information (NCADI): ncadi.samhsa.gov
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
American Academy of Pediatrics

- Professional education materials to inform pediatricians about prevention, identification, and treatment of children with FASDs
  - PediaLink online training course
  - AAP FASD Toolkit – www.aap.org/fasd

Contact me ANYTIME!
Thank You!

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