THE FETAL ALCOHOL SPECTRUM DISORDERS:

CAUSES, PREVALENCE, PREVENTION AND TREATMENT

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OBJECTIVES

1. Distinguish between Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders (FASDs)
2. Appreciate how alcohol can devastate a developing baby
3. Describe the risk factors of FASDs
OBJECTIVES

4. Appreciate the pervasiveness of FASDs
5. Identify intervention programs that have been developed
6. Understand the importance of prevention, early diagnosis and treatment

TABLE EXERCISE #1
WHAT IS FETAL ALCOHOL SYNDROME?
• **Growth**
  • Prenatal Growth Deficiency
  • Postnatal Growth Deficiency
  • Microcephaly

• **Face**
  • Short Palpebral Fissures
  • Long, Smooth Philtrum
  • Thin Vermilion Border

• **Neurobehavioral Deficits**

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**WHAT ARE FETAL ALCOHOL SPECTRUM DISORDERS (FASDS)?**
Fetal Alcohol Spectrum Disorder Phenotype
1996

Central nervous system abnormalities
• decreased cranial size
• structural brain abnormalities
• hard or soft neurological signs

and/or
• complex behavioral or cognitive abnormalities
• inconsistent with developmental level
• cannot be explained by familial background or environment alone
HOW WIDESPREAD ARE FASDS?

TABLE VOTE #1
WHAT IS RISKY DRINKING?

“I don’t drink very much. My obstetrician says a glass of wine at night isn’t going to hurt anything...”
ACTUAL RISKY DRINKING IS...

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More than 6 drinks per week for greater than 2 weeks during pregnancy

More than 3 drinks per occasion on greater than 2 occasions during pregnancy

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State-Specific Weighted Prevalence Estimates of Alcohol Use (Percentage of Any Use* Binge Drinking†) Among Women Aged 18–44 Years — Behavioral Risk Factor Surveillance System, 2010

*Any Use: One or more drinks during the past 12 months
†Binge: Four or more drinks on any one occasion during the past 12 months
WHAT CAN WE DO ABOUT FAS AND FASDS?

A LONG TIME AGO, IN A PLACE FAR AWAY

Episode V
THE EMPIRE STRIKES BACK

It is a dark time for the Rebellion. Although the Death Star has been destroyed, imperial troops have driven the Rebel forces from their hidden base and pursued them across the galaxy.

Evading the dreaded Imperial Starfleet, a group of freedom...
PRIOR STRATEGIES FOR REDUCTION OF RISKY ALCOHOL USE IN U.S. WOMEN

- Surgeon General's warning
- Warning labels on containers and where alcohol is sold
- Project Choices
QUICK STRETCH BREAK!

HOW TO MITIGATE OR ELIMINATE THE PRENATAL EFFECTS OF ALCOHOL?

- Successful prevention strategy
- Successful intervention strategy
LET'S STOP THE STIGMA AND MOVE FORWARD

Peggy Combs-Way
SoCal NOFAS

“I AM NOT A PREGNANT WOMAN WHO DRANK.

I AM AN ALCOHOLIC WOMAN WHO GOT PREGNANT.”
Alcohol use and binge drinking among pregnant women aged 18–44 years – United States, 2015–2017

Main Findings

- About 1 in 9 pregnant women reported drinking alcohol* in the past 30 days.
- About one third of pregnant women who reported consuming alcohol engaged in binge drinking.†
- Pregnant women who reported binge drinking in the past 30 days reported an average of 4.5 binge-drinking episodes during that same time period.

UCSD HIGH IMPACT STIGMA STUDY

The group determined focus group participants and developed questions for the focus group that would reveal a better understanding of the existing stigma. The five focus groups included:

- Adults with FASD,
- Birth mothers of children with FASD,
- Other relatives of children with FASD including adoptive parents or siblings,
- Pediatric health providers
- Obstetrical health providers
FOCUS GROUP FINDINGS

The questions asked of the focus groups started with a general question of how you would explain Fetal Alcohol Spectrum Disorders to other people, and then asked more specific questions that revealed people’s attitudes and beliefs about individuals with FASD and their biological mothers.

The research project found that all participants, including physicians, have hidden stigma and negative attitudes towards mothers that have children with an FASD.

The collective focus groups reported the following stereotype beliefs about birth mothers of children with FASD:

- They are ignorant
- They are very unstable
- They are selfish people
- They are uneducated
- They are child abusers.
- They are addicts/alcoholics.
- They are unable to change.
My story is filled with:
Broken pieces,
Bad decisions,
And some ugly truths.

But, it's also filled with:
A major comeback,
Peace in my soul,
And a Grace that saved my life.
~anonymous

WHAT I DIDN'T KNOW:
- The impact of alcohol on the developing fetus
- That I couldn't stop drinking and using
- That there was help available
- That I suffered from a disease called addiction
- That I was an alcoholic
WHAT I WOULD LIKE YOU TO KNOW:

- I am not a monster
- I never wanted to harm my child
- I couldn’t stop
- I needed help
- I was scared
- I loved my baby

• 1984 – Gave birth
• 1986 – Preliminary diagnosis & official diagnosis
• 1992 – Research studies
• 1996 – Entered the foster care system
• 1997 - Began my 12-step journey
• 2003 – Became an FASD advocate
• Doctors need to stop telling women it is ok to drink; “an occasional glass of wine is ok”

• Providers need to be able to offer resources to women with suspected alcohol use disorder

• Providers need to be comfortable talking to women about alcohol use AND women need to feel safe talking to their doctor about their drinking

Talking to women about their alcohol/drug use during pregnancy

• Screening for prenatal alcohol exposure can be incorporated into a standard script to help ease potential discomfort and provide reassurance to the caregiver when discussing topics that may be sensitive.

• During birth history, anticipatory guidance, or any other appropriate portion of the parent interview, after asking standard guidance questions (eg, about medications, tobacco, home environment), one can ask about prenatal alcohol exposure.

• The following are examples of questions to screen for prenatal alcohol exposure:
  How far along were you before you found out you were pregnant?
  Before you knew you were pregnant, how much alcohol (beer, wine, or liquor) did you drink?
  After you found out you were pregnant, how much alcohol did you drink?
The Dependency system (foster care system) is overrun with children who were prenatally exposed to alcohol. Everyone needs to work with the mothers so they can get their children home.

Judges, social workers, attorneys, and foster families can help end the stigma by encouraging mom in her recovery.

STOP THE BLAMING AND SHAMING

We will continue to have families impacted by prenatal alcohol exposure as long as there is a stigma against the women who drink alcohol while pregnant.
THE MESSAGE IS SIMPLE:

"THERE IS NO KNOWN SAFE AMOUNT OF ALCOHOL TO DRINK WHILE PREGNANT.

American Academy of Pediatrics
American Academy of Family Physicians
American College of Obstetricians and Gynecologists
Association of Women’s Health Obstetrics, and Neonatal Nurses (AWHONN)
National Association of Pediatric Nurse Practitioners
National Organization on Fetal Alcohol Syndrome
Society for Physician Assistants in Pediatrics

UNDERSTANDING ADDICTION: NUGGET - A SHORT VIDEO
An excerpt from a young woman’s obituary written by her father:…

“I encourage enhanced funding for treatment in general and using Department of Social Services as a gateway for mothers with addiction to get help. Because, as one would guess, once the mother is separated from her children, desperation sets in, even with the brightest and most determined of mothers.”

INCREASE PUBLIC AWARENESS

• FASD
  • is NOT rare
  • does NOT occur only in low income, uneducated women
  • CAN occur in all three trimesters
  • Number 1 cause of intellectual disability in North America
INCREASE PUBLIC AWARENESS

- NO safe level of drinking during pregnancy
- Alcohol has the GREATEST impact on fetal development
- Totally Preventable

INNOVATION
INSTITUTE FOR FETAL ALCOHOL SPECTRUM DISORDERS DISCOVERY

• Multidisciplinary Diagnostic Clinic
  • Dysmorphologist and Clinical Geneticist
  • Developmental Pediatricians
  • Education Specialist
  • Psychologists

INSTITUTE FOR FETAL ALCOHOL SPECTRUM DISORDERS DISCOVERY

• Intervention programs
• Screening of special populations
• Public Outreach
• Research Registry
• Parent Support Group
FASD INTERVENTIONS FOR CHILDREN

A. Families Moving Forward
- Goals: to support parents and help them better understand their children who are affected by alcohol. It is a Positive Parenting Program designed for children 3-13 years of age.

B. Go FAR - developed by Claire Coles Ph.D and Julie Kable Ph.D of Emory University
- Includes a computer game that teaches children to control impulsive and problematic behavior. The intervention focuses on improving adaptive functioning and developing metacognitive control.

C. MILE Math Interactive Learning Experience - developed by Emory University
- Parent Training Component
- FASD, behavior regulation, advocacy, MILE teaching methods
- One-on-One sessions with child to address learning and behavior (6-12 sessions)
FASD INTERVENTIONS

- FASD Informed
  - Focus on strengths based approaches
  - Adapt existing interventions to meet the needs of individuals with FASD
- Peer Social Skills Groups
- Behavioral interventions
- Regional Center (not automatically qualified)
- 504 and IEP plans in education
- Alternative therapeutic interventions: Animal Assisted Therapy, Music Therapy, Art Therapy, Equine Therapy etc.
- Parent and Caregiver Support Groups, Educational Websites
  Proof Alliance Minnesota, NOFAS

EIGHT MAGIC KEYS FOR DEVELOPING SUCCESSFUL INTERVENTIONS FOR FASD

Concrete
Consistency
Repetition
Routine
Simplicity
Specific
Structure
Supervision
HOPEFUL OUTCOMES WITH DIAGNOSIS

- Educating professionals and caretakers about diagnosis to develop effective treatment plans (Collaborative Care)
- Normalizing the frustrations
- Rule out other factors such as trauma, identify specific neurobehavioral profile patterns
- Creating empathy and understanding which decreases frustrations for everyone involved
- Strength based approaches to increase self esteem and outcomes

SCREENING OF SPECIAL POPULATIONS

- Kearny Mesa Juvenile Detention Facility 2013-2016
  - only 44% of the juveniles who screened positive were ever evaluated
  - Help from probation, parents and caregivers!
SCREENING OF SPECIAL POPULATIONS

- KidSTART
  - developmental/behavioral needs ages 0-5
    - Screen and refer
    - 65% of those referred to clinic diagnosed FASD
    - 29% of those screened diagnosed FASD

TABLE EXERCISE #2
TODAY’S REALITY

Early diagnosis and intervention are CRITICAL and lead to much better outcomes.

PULUNSKY UNIT
TEXAS DEPT. OF CRIMINAL JUSTICE

- Texas Death Row
- 290 men awaiting Execution
- We have evaluated 15 men for possible diagnosis of FAS
- At 12 different prisons throughout the US
- All men sentenced to death for murder whose lawyer wanted to use diagnosis of FASD to change their sentence from death to life in prison without the possibility of parole
TODAY’S REALITY

We are missing many cases of FASD in the system right now

2019 FEDERAL LEGISLATION

The Advancing FASD Research, Prevention, and Services Act, S. 2879

- Provides a structure to develop well-informed public policy on FASD and creates a clear, ongoing societal commitment to advancing research and ensuring essential services for persons with FASDs and their families
  - Creates an “Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders”
  - US Health and Human Services to establish research agenda for FASD
  - Directs the NIAA to research promising avenues for FASD diagnosis, intervention, and prevention
  - Develop standard, evidence based clinical diagnostic guidelines and criteria for all other fetal alcohol spectrum disorders.
  - Authorizes FASD grant programs for medical experts, children, and their families
SUMMING UP

1. Alcohol can devastate a developing baby
2. Fetal Alcohol Spectrum Disorders (FASD) are common
3. Effective prevention is critical
4. Early diagnosis and intervention is critical

LEADERSHIP
GOOD LUCK AND CONTACT US ANY TIME!

CONTACT US ANYTIME

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