

# THE FETAL ALCOHOL SPECTRUM DISORDERS:

## CAUSES, PREVALENCE, PREVENTION AND TREATMENT

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SCHOOL OF MEDICINE

## 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



# 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**

WHAT ARE FETAL  
ALCOHOL  
SPECTRUM  
DISORDERS  
(FASDS)?



INSTITUTE OF MEDICINE  
OF THE NATIONAL ACADEMIES

## Fetal Alcohol Spectrum Disorder Phenotype 1996

ALCOHOL RELATED  
NEURODEVELOPMENTAL  
DISORDER (ARND)

### 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

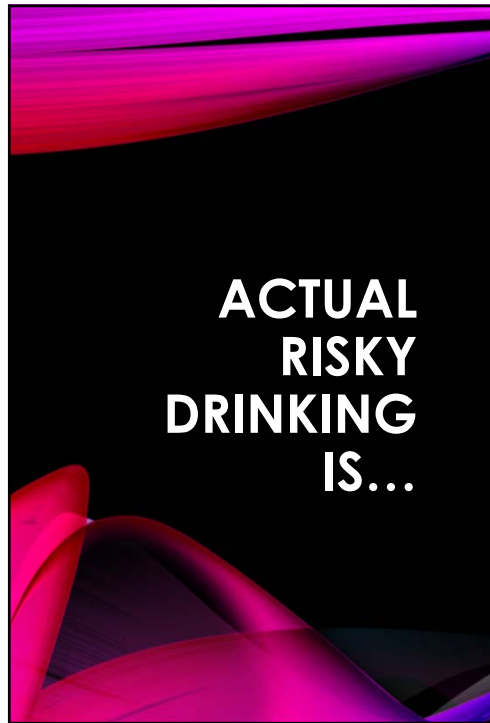
# HOW WIDESPREAD ARE FASDS?



## 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..."





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





# WHAT CAN WE DO ABOUT FAS AND FASDS?

A LONG TIME AGO, IN A PLACE FAR AWAY



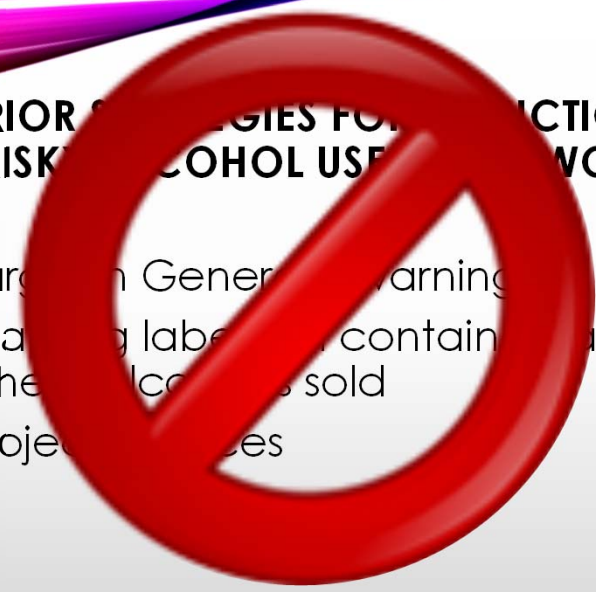
Episode V  
**THE EMPIRE STRIKES BACK**

*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.*

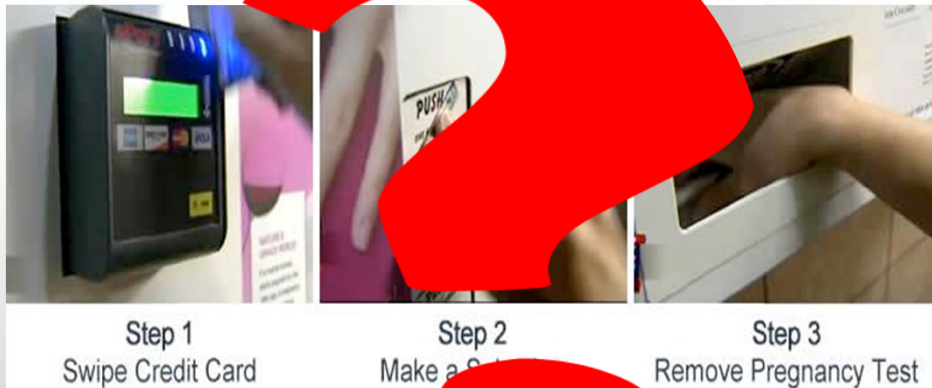
***Evading the dreaded Imperial  
Starfleet, a group of freedom***

## PRIOR STRATEGIES FOR REDUCTION OF RISKY ALCOHOL USE IN WOMEN

- Surgeon General's Warning
- Warning labels on containers and when alcohol is sold
- Project ...



## Minnesota Pay Wending Machine





Step 1  
Swipe Credit Card

Step 2  
Make a Selection

Step 3  
Remove Pregnancy Test



**HOW TO  
MITIGATE OR  
ELIMINATE  
THE  
PRENATAL  
EFFECTS OF  
ALCOHOL?**

-  Successful prevention strategy
-  Successful intervention strategy

A slide with a white background and a black vertical bar on the left side. The black bar contains the text "HOW TO MITIGATE OR ELIMINATE THE PRENATAL EFFECTS OF ALCOHOL?" in white, bold, sans-serif font. To the right of the black bar, there are two light gray rounded rectangular boxes. The top box contains a purple checkmark icon followed by the text "Successful prevention strategy". The bottom box contains a purple target icon followed by the text "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."**




**THE FACTS:  
ALCOHOL USE  
AND  
PREGNANCY**

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




## MOVING FORWARD

- 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.**

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American Academy of Pediatrics

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American Academy of Family Physicians

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American College of Obstetricians and  
Gynecologists

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Association of Women's Health Obstetrics, and  
Neonatal Nurses (AWHONN)

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National Association of Pediatric Nurse  
Practitioners

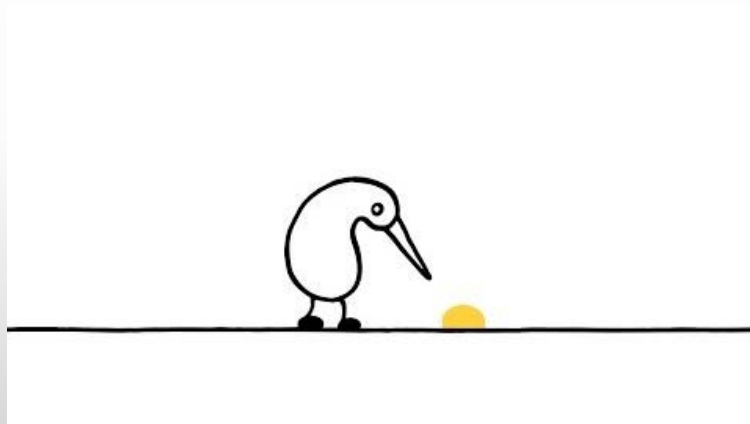
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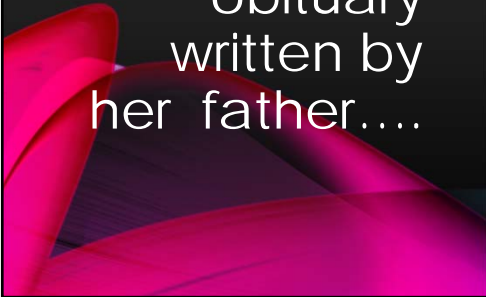
National Organization on Fetal Alcohol  
Syndrome

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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

# EVOLVING INTERVENTION PROGRAMS

**FASD  
INTERVENTIONS  
FOR CHILDREN**

**A. Families Moving Forward**

- goals are 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 year 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

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Concrete

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Consistency

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Repetition

---

Routine

---

Simplicity

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Specific

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Structure

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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





# 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



## **CONTACT US ANYTIME**

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