# Preventing Fetal Alcohol Spectrum Disorders (FASD)

Broadcast Date: March 2, 2006



# **Faculty**

Kathleen Mitchell, MHS, LCADC
Vice President and National Spokesperson
National Organization on Fetal
Alcohol Syndrome (NOFAS)
and
Consultant to Emory Regional Training Center

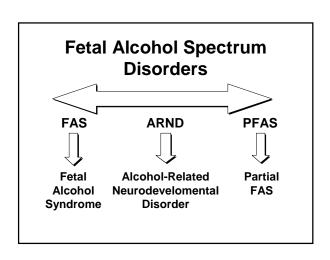
Atlanta, Georgia

# **Program Objectives**

- Identify the specific criteria for diagnosis of Fetal Alcohol Syndrome (FAS) and understand how timing and dosing of prenatal alcohol can affect fetal development.
- Gain knowledge of behaviors and disorders that are consistent with individuals with Fetal Alcohol Spectrum Disorders (FASD).

# **Program Objectives**

- Gain knowledge of biological, social and environmental differences in identifying and treating substanceabusing women.
- Identify techniques for assessing, intervening and engaging addicted women into the healing process.
- Discuss how families that give birth to children with FASD are affected.



# 40,000 New Cases of FASD Annually Estimated Cases Each Year HIV (91) Muscular Dystrophy (1,004) SIDS (2,295) Spina Bifida (2,813) Down Syndrome (5.024) FASD 10,000 20,000 30,000 40,000 50,000

### **Costs of FAS**

- FAS costs U.S. \$5.4 billion annually.
- An FAS birth carries lifetime health costs of \$860,000, although can be as high as \$4.2 million.
- Including quality of life, FAS prevention may be "cost effective" at up to \$850,000 per child.
- 1 in 100 births in the U.S. will have effects from exposure to alcohol.

# National Organization on Fetal Alcohol Syndrome Vision Statement

A global community free of alcohol-exposed pregnancies and a society supportive of individuals already living with

Fetal Alcohol Spectrum Disorders (FASD)

### What Does NOFAS Provide?

- Public Awareness
  - Media Outreach
  - -PSA
  - Awareness Campaigns
  - -Youth Education
- · Professional Education
  - -Curricula
  - Provider training www.nofas.org

### What Does NOFAS Provide?

- Advocacy
  - -Government Affairs
  - -Advisory
- Constituent Services
  - Affiliate Network
  - -Birth Mom Network
  - -Support Groups
  - -Consultation
  - -Referral

www.nofas.org

# Website, Newsletters, PSA's, Posters & Fact Sheets



www.nofas.org



# Circle of Hope

Sponsored by SAMHSA, FASD Center for Excellence



Warrior Mom





**Mission Statement** 

The mission of the Circle of Hope is to increase understanding and support and strengthen recovery for women who drank during their pregnancy(s), and their families.

### 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.

# Substance Use in **Pregnancy**

- · Overall rates of alcohol use among pregnant women have declined since 1995. But rates of frequent and binge drinking remain at high levels.
- More than 130,000 pregnant women per year in the U.S. consume alcohol at risk levels.

# Substance Use in Pregnancy

- 1 in 30 women who know they are pregnant reports "risk drinking".
- 1 in 7 women of childbearing age engage in "risk drinking".
  - -Birth defects associated with alcohol exposure can occur before a woman knows she is pregnant.
  - -Nearly 50% pregnancies are unplanned.

# 2 Things **Necessary for Life:**

- Water
- Women

### · Myth:

- -An addict will not go into treatment until they have hit bottom.
- Truth:
  - -An addict lives on an emotional bottom, we just need to take the time to tell them.

# Women Identify the **Top Three Barriers to Addiction Treatment**

- · 39% said the inability to admit the problem is severe enough to warrant treatment (denial).
- 32% said the lack of emotional support for treatment from family members.
- · 28% inability to provide adequate care for children.

### **Women and Treatment**

- Women receive the most benefit from treatment programs that provide comprehensive services for meeting their basic needs including access to:
  - -Food, clothing, shelter
  - -Transportation
  - -Employment/vocational counseling
  - -Legal assistance
  - Literacy training and educational opportunities
  - -Child care
  - -Social services

# **Progression of Alcoholism**

| Stage 1 -<br>Tolerance                                       | Stage 2 - Physical<br>Dependency                                                              | Stage 3 - Major<br>Organ Change                             |
|--------------------------------------------------------------|-----------------------------------------------------------------------------------------------|-------------------------------------------------------------|
| high tolerance<br>with occasional<br>use                     | increased<br>tolerance/possible a.m.<br>use                                                   | possible daily or<br>maintenance use<br>(reduced tolerance) |
| occasional<br>hangovers                                      | withdrawal:<br>headaches/nausea<br>(anorexia, high BP, loss<br>of concentration,<br>weakness) | migraines<br>vomiting<br>rapid pulse, BP<br>disorientation  |
| disrupted sleep patterns                                     | sleeplessness                                                                                 | insomnia                                                    |
| Colds/ infections                                            | disease pathology developing                                                                  | major organ damage                                          |
| Irritability-mood<br>swings-mild<br>depression-<br>isolation | MH diagnosis<br>(depression, anxiety,<br>panic) institutions and rx                           | suicidal ideation or<br>attempts  K. Mitchell, 2004         |

| Stage 1<br>Tolerance               | Stage 2<br>Physical<br>Dependency | Stage 3<br>Major Organ<br>Change    |
|------------------------------------|-----------------------------------|-------------------------------------|
| memories of<br>how nice use<br>was | preoccupation/<br>craving         | use despite consequences            |
| one-two<br>gateway drugs           | variety of drug use               | multiple drug addictions            |
| mild tremors                       | intentional tremors               | seizures or D.T's                   |
| sexual pleasure                    | sexual problems                   | impotence                           |
| family<br>problems                 | school & work<br>problems         | loss of family, job<br>& school     |
| trouble with the law (close calls) | DWI-DUI /<br>possession           | incarcerations<br>K. Mitchell, 2004 |

# Women Can and Do Recover From Addictive Disease; Treatment Needs To Include the Following:

- · Biological differences
- · Social differences
- · Co-dependency issues
- Communication problems
- · Shame and secrets
- · Incorporate spirituality

# Moving from Victim to Warrior Mom!



# Our Families Journey Through Addiction, Denial and Recovery



# 1977 - Karli, Danny and Erin A Happy Little Hippy Family



# Karli age 10 (diagnosed with cerebral palsy)



# **Our Family Process:**

- Years of frustration and misdiagnosis.
- Years of believing that Karli was not trying her best.
- Believing that Karli would "grow out of it".
- Received Diagnosis of FAS for Karli (16 years of age).

## **Acceptance Phase**

- · Survival: Do or Die!
- · Catapulted into Process of Recovery.

# Karli at 16 Receives Diagnosis of FAS New House Rules:

No discussing what Karli cannot do! The focus changed to what Karli could do:

- · Great artist!
- Friendly to everyone.
- Wants to be helpful.
- Everyone likes Karli.
- 100% pure of heart, Holy.
  Would not hurt another person-ever!
- · Really wants your approval.
- Great with the elderly and individuals with severe handicapping conditions.

# Karli Possessed a Natural Ability for Spiritual Simplicity!

- Maybe she was here to teach us??...
- The glass was now half full!!

"We are not human beings having a spiritual experience, rather spiritual beings having a human experience."

Pierre Teihard de Chardin

Support and Understanding From My Family Was the Key to My Recovery



# Individuals With FASD Make Powerful Advocates!



"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)

# **Fetal Alcohol Syndrome**

- Specific pattern of facial features.
- Pre- and/or postnatal growth deficiency.
- Evidence of central nervous system dysfunction.
- Maternal Alcohol Exposure
  - -Confirmed alcohol exposure or
  - -Unknown alcohol exposure

# Increased Sibling Mortality in Children with FAS

- Study compared the rate of all-cause mortality in siblings of children diagnosed with FAS with the siblings of matched controls.
- The siblings of children with FAS had increased mortality (11.4%) compared with matched controls (2.0%), a 530% increase in mortality.

# Increased Sibling Mortality in Children with FAS

- Siblings of children with FAS had increased risk of death due to infectious illness and SIDS.
- A diagnosis of FAS is an important risk marker for mortality in siblings even if they do not have FAS.
- Maternal alcoholism appears to be a useful risk marker for increased mortality risk in diagnosed cases and their siblings.

· Authors: Burd L.; Klug M.; Martsolf 2004

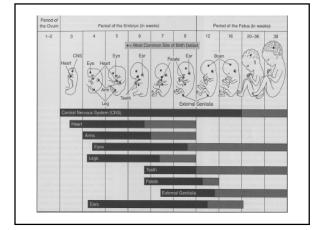
# 2005 Surgeon General's Updated Recommendations

- Women who are pregnant should not drink.
- A woman who has already consumed alcohol during pregnancy should stop to avoid further risks.
- Women who are at risk for or are trying to become pregnant should not consume alcohol.
- Health professionals should work with all women of child bearing age to reduce risk.

### Introduction

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.





### **Research in Animal Models**

- Effects of moderate blood alcohol prenatally:
  - Poor sensory motor development, poor suckling, increased hyperactivity, learning and behavioral problems.
- Effects 1-2 binge episodes:
  - FAS, physical anomalies, neurochemical alterations in brain.

## **University of Washington School of Medicine 2000**

- Brain growth spurt period:
  - -The sixth month of pregnancy through the second year of life.
- · Findings: 1 binge (4 hours of intoxication) exposure to alcohol can permanently damage the developing brain; neurological connections essential for memory learning and thought are developed during this period. - Dr. John W. Olney



- · Small palprebral fissures
- · Smooth philtrum
- Thin vermillion

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

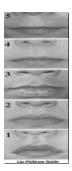
mouse fetuses





# Lip - Philtrum Guide

- ABC Scores
- C-5
- C -4
- B -3
- A 2
- A -1
- · Smooth philtrum and thin vermillion must rank 4 or 5



### Growth

- Confirmed prenatal or postnatal height or weight, or both, at or below the 10th percentile, documented at any one point in time.
  - -(adjusted for age, sex, and race or ethnicity.)

Structural head circumference at or below 10th percentile, abnormalities observable through imaging **Neurological Functional** 



# Prenatal Exposure to Alcohol Can Cause Permanent Changes in the Brain

- These changes in the brain are not due to poor postnatal environments, being in foster care, or a host of other possibilities.
- Knowing what brain areas are involved might enable us to develop better treatment strategies.

Visualization of the brain of a normal individual (A) and two with FAS (B,C) shows permanent loss of the tissue indicated by the arrows (portions of the corpus callosum).





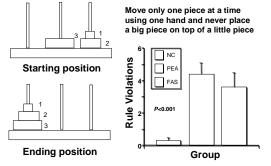


Normal

**FAS/ARND** 

FAS

# Executive Functioning Deficits



# Summary of Neuropsychological Findings

- Heavy prenatal alcohol exposure is associated with a wide range of neurobehavioral deficits including visuospatial functioning, verbal and nonverbal learning, attention, and executive functioning.
- Children with and without physical features of the fetal alcohol syndrome display qualitatively similar deficits.

# Common Disorders Identified with FASD

- Autism/Aspergers' 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

# Fetal Alcohol and Drug Unit

**University of Washington** 

In a study that examined 415 persons with FASD between the ages 6-61, Dr. Ann Streissguth found:

# Potential "Secondary Disabilities"

- Mental health problems (90%)
- Disruptive school experience (60%)
- Trouble with law (60%)
- Confinement (50%)
- Inappropriate sexual behavior (50%)
- Alcohol/drug problems (30%)
- Dependent living (80%)
- Employment problems (80%)

# **Systems Impacted by FASD:**

- Healthcare, insurance, HMO, MCO
- Education, (alternative/special ed)
- Justice, juvenile justice (recidivism)
- · Shelters/housing
- Mental health and addiction (recidivism)
- · SSI and disability
- Public assistance

# Early diagnosis can help prevent secondary disabilities





## Prevention of FASD Assessment of Mothers and their Children

- Screening
- Intervention
- Diagnosis
- Treatment



# **Key Clinical Practices**

- · Ask:
  - All women of childbearing age about alcohol use.
  - All pregnant women about alcohol use.

# **Opportunity**

- Pregnancy is an opportunity for change.
- Women who are pregnant are more receptive to intervention programs and treatment than women who are not currently pregnant.

# Discuss Birth Experiences with Women

- · Red Flags:
  - -Two or more miscarriages?
  - -Stillbirths?
  - -Infant/child deaths (SIDS)?
  - Children with LD, ADHD, MH or behavioral disorders?
  - -Children diagnosed with FASD?
- Positive response to any of the above questions should warrant a screening of all children for possible FASD (where substance use is known or suspected).

## **During Screening**

- Follow up the screening questions with probes.
- · Be non-judgmental.
- Listen attentively to her concerns.
- Refrain from negative comments or reactions.
- Focus on your patient as well as her baby.

### **Women with Addictive Disease**

Many have lost their voice; have turned off their "inner wisdom".

- · Have low self-esteem.
- · Have little self-confidence.
- Feel powerless.
- Majority have been physically and/or sexually abused.
- Are co-dependent.
- · Have been living in secrecy.

# Identify or Create "Natural" Connections

- Re-connecting Women:
  - Women Circle's/Clubs/Meetings
    - Artist way meetings, inner child groups, quilting.
  - Spiritual communities.
  - Social activities.
  - Health club/physical Activities/county recreation.
    - · Art or yoga classes.

# Help Women to Change Their Belief Systems: Maybe I Could Experience Good Things in Life?

• Encourage her to nourish, giggle, hug, create, take risks, massage and to sit and listen and you will witness a Beautiful Soul Bloom!

**Hello SOUL-SELF!** 

# **Community Prevention**

- Disseminate NOFAS brochures.
- Display NOFAS posters.
- Conduct educational and training workshops.



# **Take Away Message:**

- Identify women and/or their children with FASD.
- Pursue an assessment and diagnosis when signs of FASD are evident.
- Incorporate mind, body, and spiritual healing strategies for treating mothers of children with FASD.

- Take Away Message:
   Ensure that healthcare professionals
  - -Trained to educate their clients on the effects of alcohol use during pregnancy on the developing fetus.
  - -Competent in their ability to identify and appropriately pursue an assessment.
  - Understand possible treatment referrals for patients with possible
  - Discussing reproductive health options with women.

Together we can prevent FASD and create systems of care to Support individuals with FASD.

For a complete list of upcoming programs, go to the

Alabama Public Health Training Network web site at

www.adph.org/alphtn

Produced by the **Video Communications Distance Learning Division Alabama Department of Public Health** (334) 206-5618 alphtn@adph.state.al.us March 2, 2006

