

Fetal Alcohol Spectrum Disorders Understanding Effects Improving Outcomes



John Kellerman at age 5 (left), 12 (centre) and 19 (right): "I just want to keep him out of prison and out of the morgue."

Part 1: The Faces of FASD
Presentation by Teresa Kellerman
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Arizona Division of Developmental Disabilities

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Teresa's Background

- Director of Fetal Alcohol Resource Center, AZ DES Division of Developmental Disabilities
- State FASD Coordinator for So. AZ through the SAMHSA FASD Center For Excellence
- Certified trainer for FASD Center For Excellence
- Certified trainer for The Arc
- Co-founder of FASD Awareness Day
- Parent of children with prenatal exposure
- 35 years experience in the field of FASD

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Sources

The sources for information in this training include March of Dimes, National Institute on Alcohol Abuse and Alcoholism, the FASD Center for Excellence, the National Organization on Fetal Alcohol Syndrome, and the Institute of Medicine. Most of the citations can be found on the web site of the FAS Community Resource Center at

www.fascrc.com

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Today We Will Learn About

- The faces of FASD
- FASD Facts, Definitions, and Statistics
- Recognition of FASD Symptoms
- Diagnostic criteria

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The Faces of FASD

- **All photos and stories in this presentation are used with permission of the parents**
- **Stories about John are told with his permission.**
- **The ideal life situation for John is not the common experience of most children.**

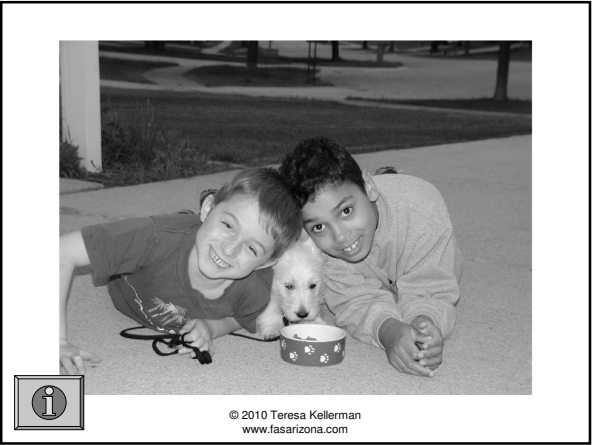
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More babies are born with Fetal Alcohol Disorders than with Autism.



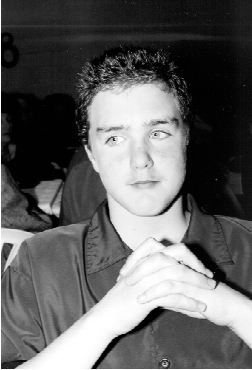
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Chris
(deceased)

For more photos
and stories, Google

fasstars



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Baby Born Free

Babies have a better chance of being born healthy when they are protected from alcohol during pregnancy.

Mobile web site:
www.babybornfree.com/

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Definitions and Diagnostic Terms

FASD = Fetal Alcohol Spectrum Disorders

FASD is an umbrella term, not a diagnosis

FASD includes the following diagnoses:

- **FAS = Fetal Alcohol Syndrome**
- **pFAS = Partial Fetal Alcohol Syndrome**
- **ARND = Alcohol Related Neurodevelopmental Disorders (formerly called Fetal Alcohol**



Effects or FAE)

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What Does FASD Look Like?

There may or may not be

- physical symptoms
- birth defects
- facial features
- developmental delays

In most cases, the child with FASD looks just like any other child.

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Diagnostic Criteria for Full FAS

- Low birth weight/height
- Microcephaly (small head circumference)
- Facial characteristics
- CNS (brain) damage
- History of prenatal exposure to alcohol



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Facial Characteristics in Infancy



- Small eye openings
- Smooth philtrum
- Thin upper lip
- Less than 10% of children with FASD have distinctive FAS facial features



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FASD Diagnostic Guidelines



Fig 1. Left: Child with FAS. Short palpebral fissures, a smooth philtrum, and a thin upper lip are evident. Center: "Hooky stick" configuration of the upper palmar crease, a minor anomaly common among children with FAS. Right: "Rat tail" ear.

A Practical Clinical Approach to Diagnosis of Fetal Alcohol Spectrum Disorders: Clarification of the 1996 Institute of Medicine Criteria - *Pediatrics* 2005;115:39-47

by H. Eugene Hoyme, MD, Philip A. May, PhD, Kenneth Lyons Jones, MD, and Luther K. Robinson, MD et al



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Most Cases of FASD are Invisible

- Only 11% of children with FAS or ARND receive a diagnosis by age 6 --1996 Streissguth
- The facial features of FAS are not always easily recognized during the early years
- Facial features of FAS result from drinking during brief period, 3rd week after conception.

--Goodlett, C.R., and Horn, K.H. 2001. Mechanisms of alcohol-induced damage to the developing nervous system. *Alcohol Research & Health*25(3):175-184.

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FASD and Developmental Disabilities

- The causes of most cases of cognitive disabilities remain unknown
- **Alcohol during pregnancy is the leading preventable cause of birth defects, cognitive disabilities, and neurobehavioral disorders**
- Only 15% of people with FASD qualify for developmental disability services

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Alcohol is a Toxic Substance

- Alcohol is a toxin
- Alcohol is a carcinogen
- Alcohol is a teratogen
- Alcohol causes more damage to the developing baby's brain than any other substance, including marijuana, cocaine, meth, and heroin.

-- Institute of Medicine Report to Congress

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Neurological signs in early years

- Poor habituation
- Irritability – intense response to stress
- Longer time to recover from stress
- Sensitivity to external stimuli
- Feeding problems
- Disrupted sleep cycles
- Developmental delays

These symptoms may or may not be present.

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Neurological signs during childhood

- Difficulties with bonding and attachment
- Inappropriately affectionate to strangers
- Inability to form healthy relationships
- Memory deficits (forget the rules)
- Poorly formed conscience (lying/ stealing)
- Stubborn, compulsive, perseverate, tantrums
- Arrested social development (“Think Young”)
- Poor judgment, lack of impulse control

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The most troublesome symptoms are perceived as behavior problems:

- Willful misconduct
 - Manipulation
 - Trying to get attention
 - Lazy
- “It's not that they won't, they **can't**.”

-Diane Malbin www.fascets.org

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ADHHH- HHHD

Only 60% of children with FASD have ADHD with hyperactivity



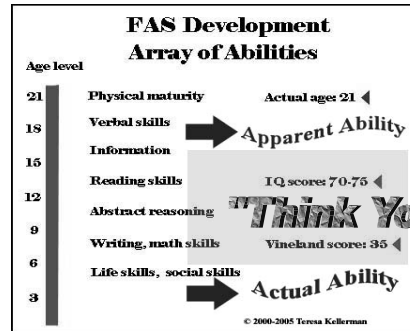
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Conscience Development Stunted at 6-Year-Old Level



“Think Young”

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One person – many levels of function

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Common Challenges Across the Spectrum

Most children with FASD have

- Memory deficits
- Lack of impulse control
- Poor judgment
- Emotional dysmaturity

“Think Young”

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The healthiest babies...

...are those whose mothers and fathers are alcohol-free...
before conception,
during pregnancy,
and throughout the
child's growing years.

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Prevent Fetal Alcohol Disorders

Share the message:

“If you are pregnant,
Don't drink...
If you drink,
Don't get pregnant.”

...

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Review

- FASD = Fetal Alcohol Spectrum Disorders
- FASD is not a diagnostic term
- FASD includes Fetal Alcohol Syndrome (FAS), partial FAS, and Alcohol Related Neurodevelopmental Disorder (ARND)
- Most symptoms are invisible
- The most important thing to remember is to “Think Young”

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