Fetal Alcohol Spectrum Disorder

A call to action

te•rat•o•gen stems from the Greek word *teras*, meaning 'monster' - a drug or other substance capable of interfering with the development of a fetus, causing birth defects.

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2/21/14

Prepared for:

The Office of Senator Pete Kelly

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Dear Alaskans,

You are changing the world! Never before has a governmental body with the stature of the Alaska State Legislature, taken on the task of eradicating Fetal Alcohol Spectrum Disorder (FASD). Your commitment to this task will take you on a journey impacting not only your next generation of children, but also the children of the world.

A journey has a starting point and you are at that starting point. Throughout the course of the upcoming years, we will have more accurate information on the teratogenic effects of alcohol, on what works and what doesn't in the field of prevention, who is most at risk, and what this epidemic is doing to our schools, communities, and nation. This document attempts to bring you the most current information possible to give us a common understanding of the task ahead.

The science is compelling. Alcohol is the most powerful teratogen consumed by pregnant women today. It does more damage to the developing fetus than crack, cocaine, or heroin. The damage is lifelong. The brain is particularly effected. FASD, in effect, is an acquired brain damage, occurring before the baby is born and impacting, and in many cases, disabling the individual for the rest of his or her life. Prenatal exposure to alcohol is the leading cause of lowered academic ability and increased social/behavioral issues, overwhelming our schools and communities.

There is very little research on effective strategies for preventing FASD. In the past forty years since Dr. Ken Jones and Dr. David Smith named Fetal Alcohol Syndrome (FAS), the main focus on prevention has been awareness. Studies are finding the rates of drinking when pregnant have not significantly decreased in the past 20 years. The rates of binge drinking by women have increased significantly, now matching rates found in men. Binge drinking and unplanned pregnancies go hand in hand. Binge drinking is particularly dangerous to the developing fetus. Many women, who would never drink when pregnant, expose their developing fetus to alcohol unknowingly before they find out they are pregnant.

We all need to share responsibility in this effort. Men engage in partnership drinking, encouraging their significant other to drink to justify their own drinking, drinking in front of their partner, and, in some cases, forcing the mother-to-be to drink with them. Studies have shown in most cases, when the man was drinking, the woman was drinking. Any effort of prevention needs to include and focus on men, as well as women.

Our systems are overwhelmed with 'multi-million dollar babies', brought on by prenatal exposure to alcohol. Premature FASD babies can cost millions in the first year of life, sadly, in some cases, with the baby dying due to failure of the damaged organs. Ones who live continue to require ongoing medical care, many times for the rest of their lives.

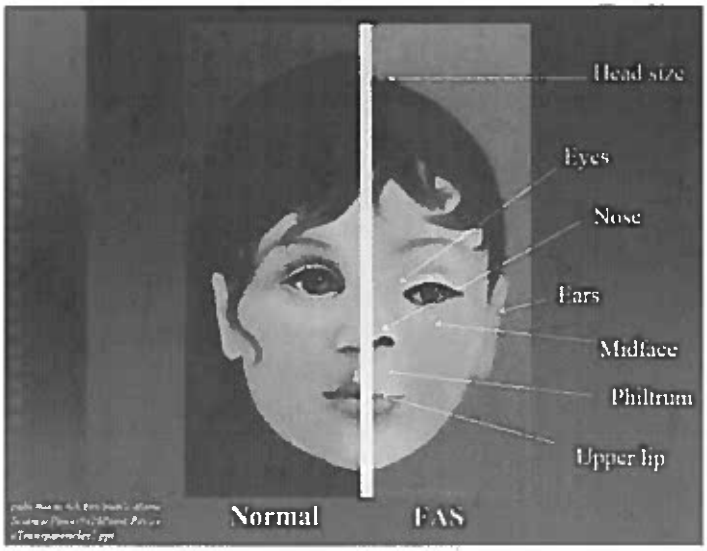
Any discussion about FASD is incomplete without looking at the impact on our criminal system and communities. Emerging research is showing high percentages of prison inmates having been prenatally exposed to alcohol, with the crimes ranging from fraudulent check writing to murder. Juvenile crime is rampant among FASD adolescents. Crimes have victims. Our communities suffer without knowing the root cause is prenatal exposure to alcohol.

I leave you with this parable. There was a village by the river. The river was the lifeblood of the village. It was the source of food, travel, and integral to their spiritual life. All day the villagers expended their energy making a living from the river. One day, a villager saw a baby floating down the river. She pulled the baby out of the river. Soon, more and more babies floated down the river. The villagers were spending most of their time saving and raising the babies that floated down the river. One day, when more babies were sighted in the river, a wise elder was standing on the river bank while others were overwhelmed by the flood of babies. "Help us," the others yelled. "No," the wise one said, "I am going to go up stream and stop the babies from being thrown into the river."

You are going upstream. It is the right thing to do.

Jody Allen Crowe

Fetal Alcohol Spectrum Disorder



Prenatal exposure to alcohol can cause damage exhibited by:

-Smaller head size,
-Anomalies with the eyes,
-Anomalies with the nose,
-Misshapen ears,
-Flat midface
-Indistinct philtrum
-Thin vermillion of the upper lip

as well as up to 61 different physical and psychological disorders[1]

Fetal Alcohol Syndrome is a little used medical diagnosis that requires observable deformity around the eyes, philtrum and upper lip, as well as a psychological assessment, and documented evidence of alcohol consumption by the mother.

- "FAS represents the largest environmental cause of behavioral teratogenesis (causing malformations of an embryo or fetus) yet discovered and, perhaps, the largest single environmental cause that will ever be discovered." Ed Riley, PhD [1]
- "Prenatal Exposure to Alcohol is described as "the most frequently known teratogenic cause of **mental deficiency** in the western world" Sterling Clarren, MD [2]

Fetal Alcohol Spectrum Disorder is a non-medical description of a constellation of conditions related to damage to the brain and body as a result of prenatal exposure to alcohol, without requiring the observable physical features of FAS.

- "Children with and without physical features of fetal alcohol syndrome display qualitatively similar deficits." Ed Riley, PhD [1]

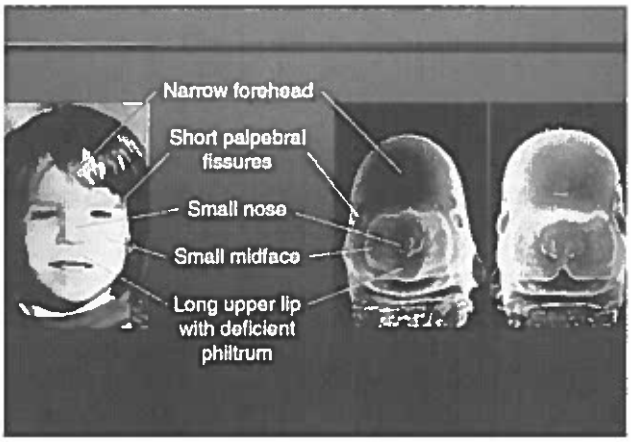
Other terms related to prenatal exposure to alcohol:

Fetal Alcohol Effects, Alcohol Related Neurobehavioral Disorder and Alcohol Related Birth Defects. In 2013, the Diagnostic and Statistical Manual IV introduced Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure as a condition in need of more research. .

When does a woman know she is pregnant?

The human embryo attaches to the uterus at twelve days following conception. At eighteen days following conception, the embryo begins to receive all the nutrition needed for development through the placenta. From this point on, any alcohol in the bloodstream crosses through the placenta and is shared directly with the developing fetus.

- **Central Nervous System (CNS) damage can occur starting around the third week (21 days) of the pregnancy.** [3]
- **Classic FAS facial features are a result of heavy alcohol use in a very short window of time between three and six weeks of the pregnancy.** [4]



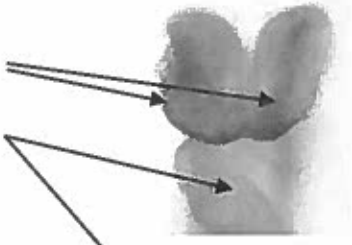
This rat pup (center) was prenatally exposed with one dose of alcohol, resulting in all the FAS characteristics shown on the child on the left. Ed Riley [2][31]

Prenatal alcohol exposure damage is dose related.

- How much alcohol is in the bloodstream?
- When during the pregnancy is alcohol in the bloodstream?
- For how long is alcohol in the fetus?

The damage starts early!

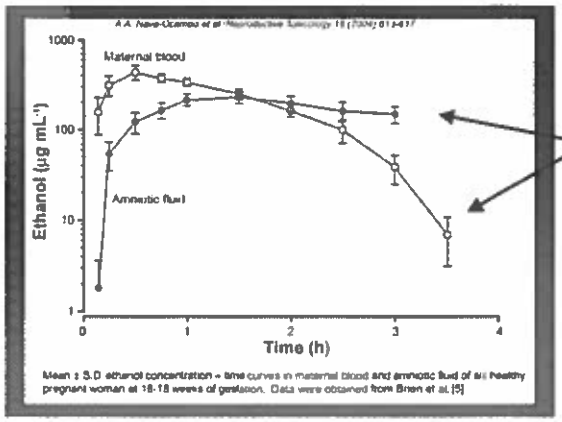
A mouse embryo, at a stage corresponding to a 22-23 day old human embryo, shows dead cells (dark blue) in the developing heart, face and brain 8-12 hours after one exposure to alcohol. [3]



Alcohol is a 'midline teratogen'. Shown are the midline points of the mouse embryo that merge to make the face and brain. This is similar to the stage of a human embryo at 22-28 days.

The arrows point to the midline of the embryo that makes up the face and brain.

"My baby sleeps all week when I get drunk on the weekends." This statement was reported to a teacher by a student who overheard her pregnant aunt laughing about her unborn baby hardly moving during the week after she was drunk on the weekends. [4]



Mean ± S.D. ethanol concentration – time curves in maternal blood and amniotic fluid of six healthy pregnant woman at 16-18 weeks of gestation. Data were obtained from Brien et al.[5]

The blood alcohol level of the pregnant mother rises quickly after one drink and starts to decline in 45 minutes, while the amniotic fluid surrounding the fetus rises and stays constant. The fetus expels the alcohol through urine into the amniotic fluid, then drinks the alcohol-laced amniotic fluid. Studies have shown alcohol can remain in the amniotic fluid for up to twice as long as in the bloodstream of the mother. [6]

Alcohol can cause damage at any time during the pregnancy.

First Trimester exposure could result in, but is not limited to: [3][5]

- Structural damage to the face, body, and brain.
- Damage that results in FAS facial features
- Dis-organization of brain cells and migration of cells to the wrong locations
- Internal organ damage

Second Trimester exposure could result in, but is not limited to:

- Brain damage
- Internal organ damage
- Smaller body and head size

Third Trimester exposure could result in, but is not limited to:

- Lowered IQ (the human brain grows at its greatest rate during the third trimester.)
- Brain cell death due to neural cell damage
- Internal organ damage
- Smaller body and head size.

Prenatal exposure to alcohol greatly increases the risk for: [6][7]

- Miscarriage
- Stillborn
- Pre-term delivery
- Sudden Infant Death Syndrome

Prenatal exposure to alcohol significantly increases the risk for:

- Cerebral palsy [8]
- Epilepsy [9]
- Suicide [10]
- Altered heart function [11]
- 61 medical diagnoses or psychological diagnoses [12]

Cleft palate or cleft lip in 7% of FAS children.

Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."

IOM Report to Congress, 1996

Who is Drinking When Pregnant?

Quick facts [13][14][15][16][17][18][19][20]

- 59% of women in the United States 18-44 report drinking alcohol.
- 50% of all pregnancies are unplanned.
- Over 78% of teenage pregnancies are unplanned.
- There is a correlation between teenage drinking and teenage pregnancies.
- 54% of births during the age 22-29 are a result of unplanned pregnancies.
- 31% of births to married women are a result of unplanned pregnancies.
- Binge drinkers have a much higher rate of unplanned pregnancies.
- Unplanned pregnancies are at a high risk for prenatal exposure to alcohol.
- Binge drinking by women is more prevalent in cold climates.
- 60% of women who reported alcohol consumption also reported that they did not learn they were pregnant until after the fourth week of gestation.
- Binge drinking by college-aged women have risen 40% in the past 20 years.
- Up to 40% or more of pregnancies have been exposed to alcohol.
- Canada reports up to 79% of children have been prenatally exposed to alcohol.
    - 79.17% of babies exposed to alcohol
    - 37.20 % of babies exposed to binges in first trimester
    - 15% to 18% continue drinking through the pregnancy
    - 4% heavy drinking throughout the pregnancy
- Self-reporting by the mother is highly unreliable.[21]
- Drinking during pregnancy is <u>under-reported</u> by 300% according to a study done in Sweden. [21]
- The woman most likely to not tell the truth about drinking during pregnancy is the woman who is the heaviest drinker. [21]

The demographics of women most likely to drink during pregnancy in the following order: [22]

- White, single professional female, making more than $50,000 a year in an urban setting
- Low income, blue collar female working in an environment with a majority of men.
- Foster teenagers
- Indigenous women

Men tend to be partnership drinkers, many times putting pressure on their significant other to drink when she is pregnant.

Multi-Million Dollar Babies

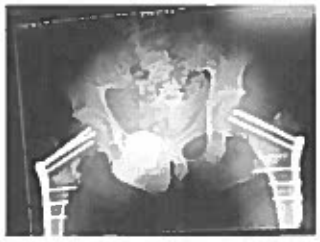
This could be happening in your community! Brady, Rory and Ari tell us the story of the devastation of prenatal exposure to alcohol.

Rory, on the left, lived for 18 months. During that time, she had eleven heart surgeries. Ari, the smaller of the two on the right, is under constant medical care.

Baby Ari was born at 29 weeks gestation. She spent 9 weeks in the NICU with a cost of $732,000. She had heart surgery at 7 days old and this cost was $130,000. She had 2 surgeries on her stomach at a cost of $98,000. She then had 3 hospitalizations which cost another $33,000. She was then back in PICU for over 3 weeks at a cost of $190,000 and a week back on the floor for another $12,000. She then had 4 inpatient stays at a total of $31,000. She had another surgery and inpatient stay for 16 days at a cost of $34,000. She has had special genetic testing to rule out any other genetic condition due to the severity of her issues at a cost of $11,500 dollars. She has a monthly equipment rental cost of $8,000 for the past 31 months. She also has a monthly average medication cost of another $1300 for the past 31 months. She has a medical supply cost per month of an average of $1200 for the past 31 months. She has an equipment cost of $11,000 for wheelchair, standing frame and specialized walker.

Nothing has formed correctly in Ari's physiology. Not her brain, her lungs, her stomach, intestines, or her heart. Her organs are in the wrong place. All genetic testing has come back normal and so the only explanation is her prenatal exposure to alcohol. She is the first child for her mother and it was an unremarkable pregnancy. [4]

Brady's surgeries



Brady is a non-verbal 15 year old who will need adult care for the rest of his life. His diagnoses are FASD, Autism, Seizure Disorder, Scoliosis, and Severe Mental Retardation with the intellect of a one year-old. He has had five surgeries in the past two years on his back, knee, hips, toes, and left leg. His adoptive parents estimate he is already a 2 million dollar baby. [4]

A 20 year study in Germany of hundreds of FAS children revealed: [23]

- 89% had Mental and Motor Retardation
- 80% had speech impediments
- 20% had hearing problems
- 72% were hyperactive
- 20% has Autism/Aggressive/Social Problems
- 29% had heart defects
- 10% had kidney defects
- 46% had genital deformities
- 37% had either a Concave or Pigeon Chest
- 7% had a cleft palate
- 44% had a spinal dimple

A psychologist in Isanti, MN, with four adopted FASD children, reported over

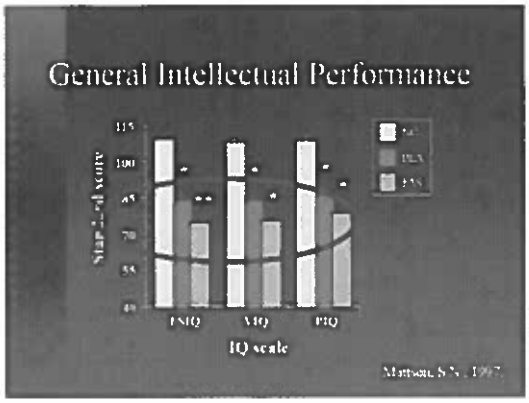
$1,000,000 health cost alone in 2006. [24]

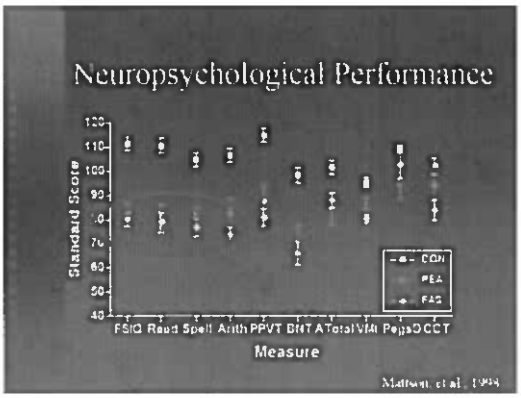
Educational Implications

- Low levels of alcohol consumption during pregnancy can result in mental health issues with adolescents. [25]
- Children exposed to prenatal alcohol experience significantly more mental health problems, including hyperactivity/inattention, and behavioral, emotional and peer relationship problems. [26]
- Math abilities are particularly damaged by prenatal exposure to alcohol. [27]
- Prenatal exposure to alcohol is linked to Autism Spectrum Disorder [28] [29]

.....“Some of the children with FASD also meet the diagnostic criteria for an autism spectrum disorder..... It is true, wealthy families are more likely to seek developmental/behavioral evaluation for their children who have neurodevelopmental disorder. Therefore, there are undoubtedly children of wealthy parents who share an autism spectrum disorder diagnosis, who actually have an FASD, based on the reluctance of some medical providers to make an FASD diagnosis...” (see full quote in bibliograhpy) Dr. Eugene Hoyme, Medical Genetics and Pediatrics, Sanford Health, Rapid City, S.D. [30]

- Autism and FASD have twenty common characteristics. [31]
- Academic performance and information processing is diminished in prenatally exposed children. [32]
- FASD children have lowered ability to coordinate, plan, and execute appropriate responses and to modify behavior flexibly in response to feedback. [33][34]
- Less than one drink a day during the pregnancy can lower language skills. [35]
- IQ, as well as Math, Spelling, and Reading in both FASD (shown on chart as PEA, prenatal exposure to alcohol) and FAS are significantly below normal. [36]





- An estimated 75% or more of Special Education costs are linked to disabilities caused by prenatal exposure to alcohol. [12]

Crime and FASD

Four out of five adolescent school shooters in Minnesota and Wisconsin were heavily prenatally exposed to alcohol. The fifth shooter fit the profile, but the mother denied drinking even when confronted by evidence to the contrary. [37]

- In a macro study of school shooters across the United States, 88% fit the profile of prenatal exposure to alcohol. [37]
- The mother of 1997 school shooter in Bethel, Alaska, lost her parental rights because of her drinking. [37]
- In one study, 93% of the inmates in one county jail at the time of the study had mothers who drank alcohol. [37]
- Jail administrators in Minnesota estimate over 90% of their jail population serve more than one sentence and fit the profile of prenatal exposure to alcohol. [4]
- In one county in Minnesota, over the period of 18 months, seven murders were committed by young male adults who were fit the profile of FASD and were either adopted or had mothers who were heavy drinkers. [37]
- Two police officers in Rapid City, South Dakota were gunned down by a heavily prenatally exposed adult male. [4]
- Adolescents with FASD tend to get into trouble with the law early and often.[38]
- An estimated 35% of individuals with FASD have been in jail at one time or another. [39]
- In Canada, over 60% of people with FASD, over the age of 12, have been charged or convicted of a crime. [39]
- More than 70% of people with FASD have been a victim of crime. [39]
- Depression and suicide tendencies are prevalent in FASD individuals. [9][40][41]

Emerging Research

Diffusion Tensor Imaging allows the researcher to see damage not seen before using MRI scans of the brain.

Epigenetics is the study alterations in a cell's genetic information that result in changes in gene expression due to prenatal exposure to alcohol but do not involve changes in the underlying DNA sequence. [42][43]

Prevention is the Answer

Prevention strategies over the past 40 years include, but is not limited to:

- Awareness campaigns
- Labeling alcoholic beverages
- Warning signs posted in establishments that sell alcohol
- Intervention legislation in some jurisdictions
- Training medical personnel on identifying FAS and FASD
- Advocating for inclusion of FASD in the DSM V
- Counseling of women who are at risk for multiple FASD births
- Providing contraceptive counseling for women at risk for FASD births

Emerging prevention strategies:

- The First International Convention on Preventing FASD was held in 2013 Edmonton, Alberta. Representatives from 35 countries attended, with leaders from around the world gathering together to discuss prevention as never before.

- Alaska's initiative will lead the world in prevention.

- Do the PT (Do the Pregnancy Test) – campaign to add PT to responsible drinking along with DD (Designated Driver) for women who are sexually active and drinking alcohol, suggesting the woman take a pregnancy test before partying to protect the unexpected pregnancy. [44]

- Pregnancy test dispensers in women's restrooms in bars, convenience stores, schools, universities, and any place a woman can discretely test for a pregnancy before drinking alcohol. [44]

- Monitored cell phone breathalyzers for monitoring alcohol-involved teenage pregnancies and other alcohol-involved pregnancies with the need determined by parents, caregivers or local social workers within the guidelines of each jurisdiction. [45]

To the Point

- According to the Centers for Disease Control and Prevention (CDC), as well as the U.S. Surgeon General, "There is no known safe amount of alcohol to drink while pregnant. There is also no safe time during pregnancy to drink and no safe kind of alcohol."
- Alcohol is more damaging to the fetus than any other recreational drug.
- Up to 40% or more of our children are prenatally exposed to alcohol. (Canada reports 73%)
- Very few doctors diagnose individuals with FAS and even fewer with FASD.
- FASD is vastly under reported.
- Up to 40% or more of our children have been prenatally exposed to alcohol, many in the critical early pregnancy before the mother knew she was pregnant.
- Even light drinking when pregnant can result in lower math and reading ability and mental illness.
- Every drink a pregnant woman holds in her hand has the potential to take potential from her child.
- Over 60% of the FASD population have been in trouble with the law.
- FASD babies can be multi-million dollar babies with lifelong devastating disabilities.
- The cost to our society for a heavily prenatally exposed individual can reach $1.5 million or more.
- Over 60 medical and mental illnesses can be linked to prenatal exposure to alcohol.
- Over 70% of individual with FASD are victims of crimes.
- An estimated 75% or more of Special Education costs are linked to prenatal exposure to alcohol.

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