FETAL ALCOHOL SPECTRUM DISORDER (FASD): FINDING INFORMATION ABOUT PREVENTABLE BIRTH DEFECTS

by Bridget Tierney

INTRODUCTION

A pregnant woman is bombarded with information about diet, exercise, breastfeeding, and options for delivery. Random strangers start giving her advice on coping with morning sickness, and people start asking very personal questions. Everywhere she turns there is a book, magazine, website, or chat room devoted to pregnancy. Surprisingly, however, little information regarding the effects of alcohol on a developing fetus is presented. Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term representing Fetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental disorder (ARND), Alcohol-Related Birth Defects (ARBD), and Fetal Alcohol Effects (FAE). FASD describes the range of adverse effects that can occur in an individual whose mother drank alcohol during pregnancy. These adverse effects may include physical, mental, behavioral, and/or learning disabilities.

FASD is the leading preventable cause of mental retardation and birth defects in the United States. Studies of specific North American populations have shown FASD rates ranging from .03 per thousand to 189 per thousand. A 1988 study of birth defects registries found that 0.03/1000 Asian-American newborns were diagnosed as FAS at birth; while a 1987 study of Northwest Canadian Native Americans found that 120/1000 children had FAS and 69/1000 had other alcohol-related disorders (Institute of Medicine, 1996). Other studies have reported that FAS affects 1.3 to 2.2 children per thousand, and that cases of ARBD and ARND exceed those of FAS by a ratio of 2:1 or 3:1 (Abel and Dintcheff, 1984; Giunta and Streissguth,1988). The National Organization on Fetal Alcohol Syndrome (NOFAS) (2005) estimates that FASD affects one in 100 live births or as many as 40,000 infants each year.

Despite these overwhelming numbers, FASD is rarely in the public eye. In a LEXIS-NEXIS search for newspaper stories on "prenatal AND alcohol," "fetal AND alcohol" and "pregnancy AND alcohol," the author identified only one article in a major American newspaper about Fetal Alcohol Syndrome. That article was, in fact, not about FAS itself, but a review of a novel which has a character that was born to an alcoholic mother.[1]

THE IMPACT OF FETAL ALCOHOL SYNDROME DISORDERS (FASD)

Although pregnant mothers are discouraged from drinking during pregnancy, of all substances known to harm a developing fetus, alcohol has some of the most wide-ranging and devastating effects. As shown in Table 1, alcohol affects a wide range of human functionality. Due to their dramatic withdrawal symptoms, 'crack babies' receive more media attention than alcohol-exposed children, but prenatal exposure to alcohol is actually more damaging to the child than exposure to cocaine. In fact, some of the long-term effects associated with cocaine exposure may be due in part to concurrent use of alcohol during pregnancy (Institute of Medicine, 1996).

An informal study found that a public library in a small city holds 150 to 300 books about pregnancy.[2] The majority of these books are targeted to women who want to improve their chances of having a healthy baby. These books have titles like *What to Expect When You are Expecting, Your Pregnancy Week by Week*, and *The Prenatal Prescription.* The books describe fetal development, explain the physical changes in a woman's body, and offer advice on diet and exercise. One common characteristic these books share is that they are remarkably upbeat, and little is written about the possibility of preventable or genetic birth defects. Most pregnancy guides mention that women should abstain from alcohol during pregnancy, but none dwell on this issue.

In a chapter that focuses on the dietary changes necessary to "grow a baby," *The Complete Guide to Pregnancy after 30* advises that expectant mothers eat 2300 calories a day including 74 to 100 grams of protein and 1200 to 1300 milligrams of calcium. The book continues that a pregnant woman should avoid soft cheeses like feta, brie, and Camembert, and that she should not even consider ingesting herbs like slippery elm, cohosh, pennyroyal, mugwort, or tansy (Winkelman, 2002). No mention is made, however, of the potential dangers of alcohol. In fact, the only mention of avoiding alcohol in the entire book is a paragraph in the "Lifestyle" chapter. When the issue of

Table 1 - Neurobiological Outcome of Prenatal Exposures in Humans or Animals

	Alcohol	Methyl-mercury	Ionizing	Phenytoin	PCBs	Lead	Opoids	Marijuana	Tobacco
Gross neuropathology	•	•	•	--	--	X	X	X	X
Mental retardation	•	•	•	X	?	X	X	X	X
Reduced IQ	•	•	•	•	•	•	X	?	•
Hyperactivity	•	--	--	--	•	?	X	X	•
Attention Deficit	•	--	--	--	--	?	?	•	•
Developmental delays	•	•	--	•	•	--	?	•	•
Gait abnormality	•	•	--	--	X	X	X	•	X
Coordination	•	--	--	--	•	?	?	X	X
Sensory deficits	•	•	--	--	X	•	X	X	•
Neonatal withdrawal	•	--	--	--	--	--	•	?	•

• =effect X=no effect ?=suspected --=not tested
Adapted from: Institute of Medicine, 1996, p. 34.

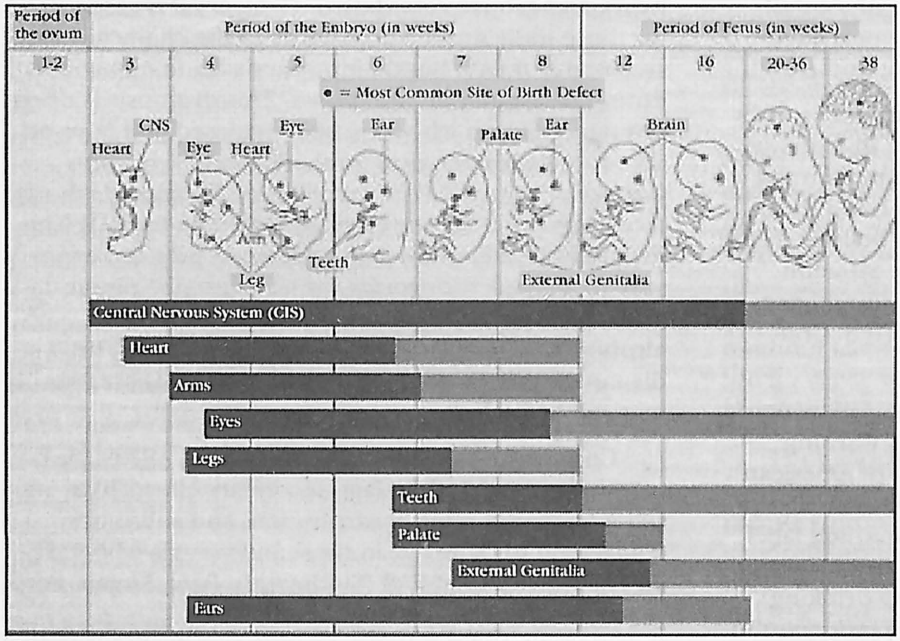
drinking alcohol is raised, the information is often dangerously inaccurate. *Pregnancy for Dummies* (2004) claims that organ systems form in the first trimester, during which alcohol intake should be reduced. In direct contrast, however, scientific evidence indicates that damage to the fetus can occur throughout the pregnancy. Figure 1 shows how alcohol affects various organ systems throughout the course of pregnancy. Although the first trimester is the stage of greatest vulnerability, drinking later in pregnancy can still have profound effects.

Additionally, a study of over five hundred women and their offspring at Wayne State University demonstrated that women who drank as little as one alcoholic beverage per week gave birth to children who were more than three times as likely to display aggressive and delinquent behaviors. Children of "social drinkers" also had poorer attention spans than the control group (Mattson and Riley, 1997, p. 10).

The most sound advice may come from pre-pregnancy guides like *Before Your Pregnancy* and *The Twelve Month Pregnancy* which advise quitting alcohol *before* you are pregnant. *Before Your Pregnancy* recommends that women abstain from alcohol as soon as they begin to think about getting pregnant. The authors warn that even a woman who has had a recent period may in fact be pregnant – she may have mistaken "spotting" for her period (Ogle & Mazzullo, 2002, p. 32).

Other pre-pregnancy guides are blunt with their advice. In *Conception, Pregnancy, and Birth*, Stoppard explains that "Research suggests that the effect of alcohol is variable: some heavy drinkers get away with it, while some women who drink only a small amount don't. The only certainty is that there will be no effect if alcohol is avoided" (Stoppard, 1993, p. 17). *Your Pregnancy Week by Week* puts it even more simply: "Why take chances? For the health and well-being of your developing baby, abstain from alcohol during preg-

Figure 1



The dark portions of the bars represent the periods of greatest vulnerability, the lighter portions represent periods of time in which alcohol could cause minor structural abnormalities.
Source: Centers for Disease Control and Prevention

nancy. Responsibility for preventing these problems rests squarely on your shoulders!" (Curtis and Schuler, 2000, p. 41). Nevertheless, expectant mothers will only benefit from this sage advice if they actually read these books.

People increasingly use the Internet for information to supplement and to replace traditional books. Fortunately, there a number of excellent FASD and prenatal health resources on the Web, including the Centers for Disease Control and Prevention's Fast Facts <*http://www.cdc.gov/ncbddd/fas/*>, the National Organization on Fetal Alcohol Syndrome <*http://www.nofas.org*>, and a comprehensive report from the National Institute on Alcohol Abuse and Alcoholism <http://www.niaaa.nih.gov/publications/10report/chap05b.pdf>.

Unfortunately, these sites are not the first retrieved by a typical Google search. For example, a Google search for "can I drink beer while pregnant?" retrieved 116,000 records. Although none of the top results came from authoritative sources like the Centers for Disease Control, most of the advice seems reasonable. The danger comes, however, when people look for advice on anonymous forums, bulletin boards, and chat rooms. One of the top-ranked results in Google was a forum at *babycenter.com* where a pregnant woman asked for advice on how to 'deter dirty looks' when she orders beer at a restaurant (Baby Center, 2004). Responses to her query ranged from 'My Russian great grandmother was a firm believer that every pregnant woman should drink one glass of beer a day in order to insure a healthy pregnancy' to 'I drank an occasional beer during all of my pregnancies and my children are perfectly healthy' to 'Order an O'Douls!' to 'Do some research and you'll find that ANY amount of alcohol crosses the placenta easily.' There is no expert advice on a forum like this – the advice is pure opinion.

Information from books and web sites only comes to those that actively seek it, but for those that do not seek out information on the effects of alcohol on the fetus, there is a reminder every time they buy a drink. Since November 1989, each bottle of alcoholic beverage sold in the United States must display the Surgeon General's warning that pregnant women should not drink because of the risk of birth defects (U.S. Congress, 1988).

Gallup surveys conducted in the years following the implementation of the Surgeon General's warning label, however, show that fewer than half of American adults are aware of the label (Hankin, 1996). In 1990, 37% of adults surveyed knew about the warning label, 49.8% in 1991, and 45.6% 1992. Studies conducted on the effectiveness of the label in preventing drinking during pregnancy do indicate, however, a reduction in self-reported drinking, but only among non-high-risk drinkers (Hankin, 1996). This conclusion is supported by another study conducted by the Institute of Medicine (1998) which found that universal prevention methods appear to have the most impact on women who consume low to moderate amounts of alcohol, but little to no impact on women who abuse alcohol.

For those who are truly interested in finding information about FASD, there is a tremendous amount of information available. Bibliographies in scholarly articles run into the tens of pages, covering everything from animal studies to psychological case studies. For those new to the subject, an excellent starting place is the National Organization on Fetal Alcohol Syndrome <*http://www.nofas.org*>, which offers lists of books, links tailored to specific audiences, and a database of journal articles written about prenatal alcohol exposure.

Those who wish to investigate FASD should note that related terminology has changed over time. The label 'Fetal Alcohol Spectrum Disorders' was only coined in April 2004, when representatives from the National Organization on Fetal Alcohol Syndrome, Centers for Disease Control, National Institutes of Health, Substance Abuse and Mental Health Services Administration, and Health Canada agreed on common terminology. Before that time, the condition was commonly referred to as 'Fetal Alcohol Syndrome' or other labels.

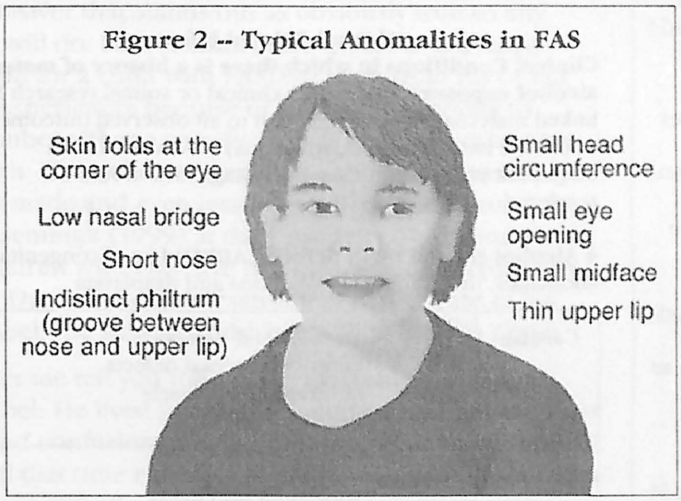
Similarly, in 1996, the Institute of Medicine charged a committee to supply a set of diagnostic criteria. They settled on five categories of Alcohol-Related Effects: *Category 1* is Fetal Alcohol Syndrome with confirmed maternal alcohol exposure.

People who fit into this diagnostic have characteristic facial anomalies (Figure 2), nervous system impairment, and growth retardation. *Category 2* is reserved for those individuals who have all of the characteristic symptoms of FAS, but their mother's drinking habits during pregnancy are unknown. This diagnosis is often given to children who have been adopted and have no access to their biological mother's medical history. *Category 3*, 'Partial FAS' describes an individual who fits most, but not all of the diagnostic criteria for FAS. This diagnosis is only given with confirmed prenatal exposure to alcohol. *Categories 4 and 5* describe physical and neurological impairments linked to prenatal alcohol exposure outside of the scope of FAS. The diagnostic criteria for each category of FASD are summarized in Table 2.

Contrary to popular belief ARBD and ARND are not milder forms of FAS. In fact, secondary effects like school dropout rates, incarceration, and substance abuse tend to be worse in those individuals who have an FASD other than FAS (Streissguth, Barr, Kogan, and Bookstein, 1999).

Because of its distinct facial anomalies, FAS is diagnosed confidently and consistently. Other forms of FASD, however, are less obvious and therefore more

Figure 2



difficult to diagnose. Even an expert may have difficulty confirming the diagnosis of FAS when the facial anomalies are incomplete or atypical. Other disorders such as Aarskog syndrome, William's syndrome, and maternal PKU (phenylketonuria) have been confused with FAS (Institute of Medicine, 1998). Since other types of FASD are manifested in behavioral and learning disabilities, children may often be diagnosed as having a conduct disorder, borderline personality disorder, attachment disorder, or attention deficit hyperactivity disorder (McCreight, 1997).

The risk factor for development of alcohol-related birth defects is still not certain. While some children of alcoholic mothers may develop a severe case, other infants who experienced the same amount of prenatal alcohol exposure may exhibit relatively minor symptoms. In fact, one study found a situation concerning twins where one twin had profound FAS while the other had only minor symptoms (see Figure 2) (Abel, 1998). It is estimated that between 10% and 40% of children of mothers who drink heavily during pregnancy exhibit the characteristics required for a FAS diagnosis (Mattson & Riley, 1997). A number of factors affecting the risk for FASD include maternal weight, fetal weight, cell development at the time of alcohol exposure, age of mother, overall health of mother, maternal use of cigarettes and/or other toxic substances, paternally derived factors, genetic susceptibility, and other factors as yet undetermined by researchers (Abel, 1998).

FASD has far-ranging effects on families with affected members. FAS educator and mother of an alcohol-affected son, Brenda McCreight describes the moment at which she finally understood the depth of her son's condition. Jason and his family lived in a constant state of tension because they tried to control him instead of working with his condition. Moments after a fight with his sister had escalated to the point of near-violence

> Jason sat down and started to cry. It was not a normal cry, it was a cry of the deepest despair I had ever heard. "Oh Mommy" he said, "I don't know what's wrong with me. I'm just an animal and I belong in a cage. Why don't you put me in a cage so I can't hurt anybody?" (McCreight, 1997, p. 48)

In a study of 415 individuals with FASD, Streissguth, et al. found that 90% had been to a psychotherapist or counselor for a mental health problem; 60% had been suspended, expelled, or dropped out of school; 60% had been charged with or convicted of a crime; 50% had experienced confinement in a prison or mental health facility; 50% had engaged in inappropriate sexual behavior; and 30% had been in treatment for substance abuse. Only 20% of those over twenty-one years old lived independently, and 80% described problems with employment (Streissguth, et al., 1999).

Studies show that prenatal alcohol exposure results in significant damage to intellectual capacity. Although there is no set IQ score in the diagnosis of FAS or FASD, the IQ of the average person with FAS falls in the borderline range of mental retardation. A 1996 study by Mattson and Riley of FAS case reports found a mean IQ of 65.73 with a range of 20 to 120. A review of retrospective studies reported a mean IQ of 72.26 with a range of 47.4 to 98.2 (Mattson and Riley,1996). This effect is not limited to individuals with FAS. When the IQs of a control group, a group with FAS and a second group with a condition called PEA (individuals with confirmed prenatal exposure to alcohol who do not have the facial anomalies characteristic of FAS) found that the PEA group had significant cognitive deficits, and that many of these individuals had IQs in the mental retardation range. The average IQ for the PEA group was in the low 80s (1996).

Even those individuals with IQs in the normal range may struggle in school due to a variety of learning disabilities from dyslexia to aphasia to spatial disorders (McCreight, 1997). Attention Deficit Disorder is also common for people with FASD, but the stimulant drugs often prescribed for Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) tend not to be as effective for those with FASD as they are for those with "pure" ADD or ADHD (Snyder, Nanson, Snyder, and Block, 1999).

Poor short-term memory is also common in individuals with FASD. According to McCreight (1997), memory problems can lead to lying because these children, under pressure to produce an answer, cannot recall what they did or did not do and therefore give the first answer that comes to mind. They keep doing so until the adult is satisfied and the pressure is removed. To the adult who wants an answer, the behavior seems to be deliberate lying. To the child with

Table 2 -Diagnostic Criteria for Fetal Alcohol Syndrome (FAS) and Alcohol-Related Effects

Fetal Alcohol Syndrome

1 FAS with confirmed maternal alcohol exposure

A Confirmed maternal alcohol exposure

B Evidence of a characteristic pattern of facial anomalies that include features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface)

C Evidence of growth retardation including at least one of the following:

- Low birth weight for gestational age
- Decelerating weight over time not due to nutrition
- Disproportional low weight to height

D Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:

- Decreased cranial size at birth
- Structural brain anomalies (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- Neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor hand-eye coordination

2 FAS without confirmed maternal alcohol exposure

B, C, and D as above

3 Partial FAS with confirmed maternal alcohol exposure

A *as above*

B Evidence of some components of the pattern of characteristic facial anomalies

Either C, D, or E

C *as above*

D *as above*

E Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment

Alcohol-Related Effects

Clinical Conditions in which there is a history of maternal alcohol exposure, and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. There are two categories, which may co-occur. If both diagnoses are present, then both diagnoses should be rendered:

4 Alcohol-related birth defects (ARBD) List of congenital anomalies, including malformations and dysplasias

Cardiac	Artrial septal defects Ventricular septal defects Aberrant great vessels Tetralogy of Fallot
Skeletal	Hypoplastic nails Shortened fifth digits Radioulnar synostosis Flexion contractures Camtodactyly Clinodactyly Pectus excavatum and carinatum Klippel-Feil syndrome
Ocular	Hemivertebrae Scoliosis
Renal	Aplastic, dysplastic, hypoplastic kidneys Horseshoe kidneys Ureteral duplications Hydronephrosis
Auditory	Strabismus Refractive problems secondary to small globes Retinal vascular anomalies

5 Alcohol-related neurodevelopmental disorder (ARBD)

Presence of:

A Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:

- Decreased cranial size at birth
- Structural brain anomalies (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- Neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor hand-eye coordination

And/or:

B Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment

Source: Institute of Medicine, 1998, p. 4-5

FASD, when the memory will not cooperate; there is no one answer that stands out as obviously true so any reply will do. Poor memory also makes it extremely difficult for a child with FASD to learn from his or her own experiences because of a frequent inability to remember either a specific behavior, its consequences, or both. The link between action and consequence is rarely made and even less frequently remembered. As Dr. Kaemingk (1999) at the University of Arizona puts it, children with FAS "live in a new world everyday" (p. 204). Dorris echoes this sentiment in a tribute to his son Abel, the subject of the bestselling *Broken Cord:*

> Let me tell you the most remarkable thing about Abel: He lived for 23 years, endured daily loneliness and confusion and hardship and frustration, and in all that time never once did he do anything that was intentionally cruel or hurtful to another living creature. He was maddening in his inability to learn from experience, to grasp the larger picture, but he was also sweetness distilled... If only he had been able to learn how to cross the street in accordance with a green light (Dorris, 1999, pp. xxi-xxii).

Abel's inability to connect action with consequence resulted in his death. On his way home from work one dark night, he crossed a busy state highway against a traffic light. Even at age 23, he was not always capable of crossing a street on his own.

There are no known cures for FASD, but it is entirely preventable. Children who are not exposed to alcohol in the womb do not get FASD. Readily accessible, accurate information is a first step in preventing thousands of needless birth defects each year.

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ENDNOTES

[1] An August 2004 search in LexisNexis Academic retrieved a review of Louise Erdich's novel *Four Souls* in the July 25, 2004 *Seattle Times*. Louise Erdich is the adoptive mother of two sons and a daughter with varying degrees of FASD.

[2] Using a browse search for the subject "pregnancy," I searched the web OPACs of five public libraries which serve cities with populations of 75,000 to 150,000. The Saint Joseph County Public Library in Indiana holds 153 items; the Greater Manchester InterLibrary Cooperative System in New Hampshire holds 217; the Merrimack Valley Library Consortium in Massachusetts holds 350; the Eugene Public Library in Oregon holds 294; and the Parmly Billings Library in Montana holds 157.

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