



Gaining Knowledge About Fetal Alcohol Syndrome

Results from Oregon's
FAS Prevention Program 2005 – 2009



What is Fetal Alcohol Syndrome?

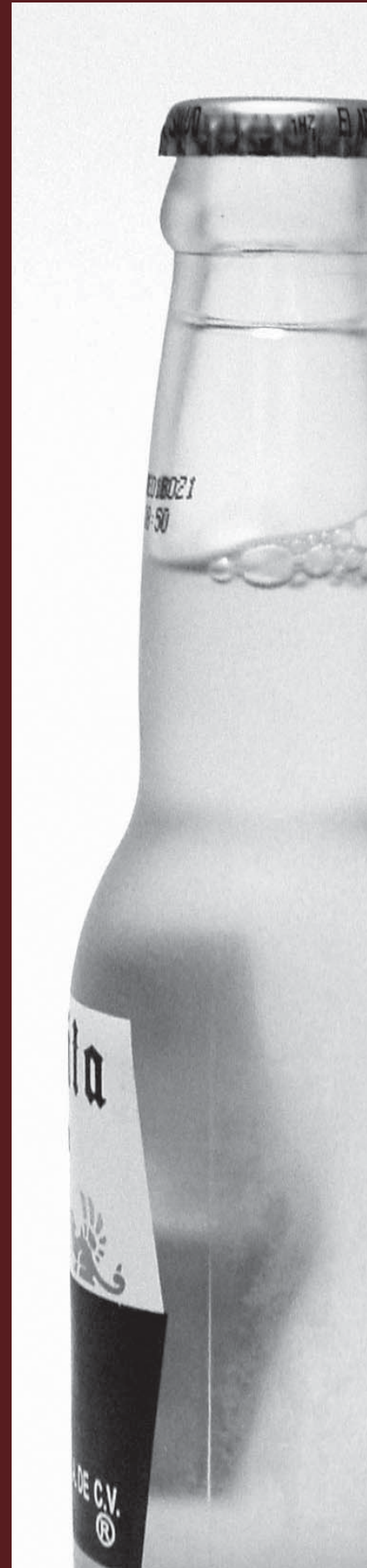
Fetal Alcohol Syndrome (FAS) is a medical diagnosis for the physical and cognitive abnormalities that can result when a fetus is exposed to alcohol during pregnancy. Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that defines the spectrum of disorders, including ARBD (alcohol-related birth defects), ARND (alcohol-related neurodevelopmental disorder), and FAS. FAS is the most severe diagnosis on the spectrum of alcohol-related disorders. FAS was first described in 1972 by Dr. Anne Streissguth and her colleagues. Although much research has been done on FAS, there is still much we do not know. We do know that there is no known safe level of alcohol use during pregnancy. In 2005, the United States Surgeon General issued the following warning: “No amount of alcohol consumption can be considered safe during pregnancy. Alcohol consumed during pregnancy increases the risk of alcohol-related birth defects, including growth deficiencies, facial abnormalities, central nervous system impairment, behavioral disorders, and impaired intellectual development.” FAS is the leading preventable cause of mental retardation and is associated with other cognitive abnormalities. If a woman doesn’t drink during pregnancy, FAS will not occur.

The Centers for Disease Control and Prevention (CDC) has established strict guidelines for the diagnosis of FAS.

Diagnosing FAS

Several methods have been identified for diagnosing FAS. The Institute of Medicine (IOM) developed guidelines in 1996. Researchers Susan Astley and Sterling Clarren developed a model in 2004 that ranks the presence of criteria. A third model, clarifying the IOM guidelines, was developed in 2005. The CDC uses the IOM’s 1996 guidelines for FAS diagnosis as follows:

1. Documentation of three facial abnormalities:
 - Smooth philtrum (the groove that runs from the center of the nose to the upper lip);
 - Thin vermilion border (upper lip);
 - Small palpebral fissures (the distance between the inner corner and outer eye).





2. Documentation of growth deficits:

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

3. Central nervous system abnormalities:

- Head circumference (OFC) at or below the 10th percentile adjusted for age and sex;
- Clinically significant brain abnormalities observable through imaging;
- Neurological problems not due to a postnatal insult or fever, or other soft neurological signs outside normal limits;
- Performance substantially below that expected for an individual's age, schooling or circumstances, as evidenced by:
 - » Global cognitive or intellectual deficits representing multiple domains of deficit performance below the 3rd percentile; or
 - » Functional deficits below the 16th percentile in at least three of the following domains:
 - Cognitive or developmental deficits;
 - Executive functioning;
 - Motor functioning;
 - Attention or hyperactivity;
 - Social skills;
 - Sensory, language, memory, etc.

In making an FAS diagnosis, the documentation of alcohol exposure in utero is not a requirement, as often this information is unknown.

The Burden of FAS

Clearly, FAS is a serious life-long disorder, and as the most severe condition in the spectrum of disorders, incurs a significant burden for families and communities. These children require specialized services in health care, education, and social services.^{vi} However, even children who are diagnosed with ARND or ARBD, milder forms of the disorder, require extra care and attention. Below an estimate of the cost burden of FASD in Oregon is shown.

2009 Cost of Fetal Alcohol Spectrum Disorders (FASD):

FAS incurs a considerable cost burden, because these children require long-term care and special education. In Oregon, annual health care expenditures associated with FAS total almost \$80 million. All of these costs are preventable.

Number of Oregonians with FASD**	29,518
Number of children under 18 with FASD	8,854
Number of children under 18 with FAS	520
Annual cost of FASD* in Oregon	\$77,780,496
Total per/person annual cost of FASD***	\$2,635

FASD means Fetal Alcohol Spectrum Disorder and includes children and adults diagnosed with full-blown Fetal Alcohol Syndrome and children diagnosed with Alcohol-Related Neurodevelopmental Disorder (ARND).

** Includes children and adults w/FASD; based on an estimate of prevalence at .5 per 1000 for FAS in Oregon population and 8 per 1000 for ARND.

*** Includes children and adults w/FASD.

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Fetal Alcohol Syndrome Surveillance Project

The mission of Oregon’s Fetal Alcohol Syndrome Surveillance Project was to develop and implement a surveillance system for FAS throughout the state. The purpose of conducting FAS surveillance was to assess the burden of FAS in Oregon, provide data for the planning of FAS–related services, and create awareness of the risks of alcohol-exposed pregnancies, both in the professional and public communities. The project also aimed to create the groundwork for improved provider capacity to diagnose FAS.

The Fetal Alcohol Syndrome Surveillance Project is a cooperative agreement with the Centers for Disease Control and Prevention (CDC) and seven other states. The project collected, reviewed and analyzed data on children in Oregon born between 2001 and 2006, who were either diagnosed with FAS or who fit other criteria for FAS. Because there is no simple blood test — or any other kind of simple test — to determine if a child has FAS, many children who have FAS are not identified or are mis-identified. Many service providers, including pediatricians and other types of doctors, receive various levels of training to diagnose for FAS, and it may often get documented as a behavioral disorder or other type of disability, such as ADHD (attention deficit hyperactivity disorder) or a learning disability. By estimating the prevalence of FAS within Oregon using one consistent set of criteria, plans for better services and communication between providers can be improved. In addition, surveillance of FAS can lead to improved education for health care providers, foster care providers, teachers and other professionals, and set a goal for preventing future FAS babies and children.





Oregon was one of seven states that participated in the CDC Fetal Alcohol Syndrome Surveillance Project. The project combined information from birth certificates, Medicaid records, hospital birth and maternity records, and records from pediatric clinics for 768 children in Oregon who were identified as high risk for FAS. Information was requested from 60 birth hospitals and was combined with records from 168 pediatric clinics. Medical information was gathered from 2,677 records.

What was learned?

Prevalence of FAS, 2001 – 2006, Oregon

Total Oregon live births, Jan 1, 2001 – Dec 31, 2006	276,692
Confirmed and Probable Cases	96
Prevalence per 1000 Live Births	0.347

Source: Oregon Birth Certificates and Oregon FASSLink Database

Prevalence of FAS by year[♦], 2001 – 2006, Oregon*

2001	0.508
2002	0.487
2003	0.370
2004	0.372
2005	0.280
2006	0.082

♦ FAS diagnosis occurs over time. The criteria emerges as a child ages. Children born in the earlier years (2001 - 2002) were more likely to have received a final diagnosis of FAS because more opportunities occurred for assessment.

* Per 1000 live births

Source: Oregon Birth Certificates and Oregon FASSLink Database

Prevalence of FAS by race, 2001 – 2006, Oregon*

White	0.26
Black	0.89
Native American	1.23
Asian	0.00

* Per 1000 live births

Source: Oregon Birth Certificates and Oregon FASSLink Database

Primary, secondary and tertiary prevention of FAS

Clearly, primary prevention of FAS through education for pregnant women and women of childbearing age is the ultimate goal. However, once significant alcohol exposure has occurred, secondary prevention through early screening and diagnosis of FAS is critical, as early intervention can result in significant reductions in morbidity. Unfortunately, the characteristic symptom cluster that definitively identifies FAS emerges only slowly in the first years of life, and this presents a challenge to practitioners who provide pediatric care. Increased awareness of syndrome characteristics and referral sources could eventually lead to a shorter time until diagnosis, and better outcomes. For families with children who are already diagnosed with FAS, tertiary prevention should be the goal, through the provision of supportive services to prevent further complications of the disorder.

Primary prevention: education for pregnant women and women of childbearing age

- Encourage and/or provide contraception for sexually active women who drink.
- Provide in-service training on FASD for providers and staff. The CDC offers training through the Frontier FASD Regional Training Center, and the American College of Obstetricians and Gynecologists (ACOG) provides FASD Prevention tool kits and screening instruments for women's health care providers. Links to these resources are below.
- Make FASD materials (brochure, posters and videos) available in office waiting rooms and clinics. The National Organization for Fetal Alcohol Syndrome (NOFAS) provides many materials for providers.

Secondary prevention: early screening

- Screen all women of childbearing age for alcohol-use disorders to identify those at risk, and then use appropriate counseling techniques, such as motivational interviewing, to discourage drinking during pregnancy.
- Inquire about alcohol use among all female patients contemplating pregnancy or who are pregnant. This is particularly important for patients who are clinically depressed, or have a history of substance abuse, domestic violence, or childhood sexual abuse. Identify women who are at risk by using screening tools such as T-ACE and TWEAK, which ask specific questions about drinking habits.^{vii, viii}
- Recognize the importance of timely identification of child development problems and early intervention through screening and assessment.





Tertiary prevention: preventing complications

- Identify a developmental pediatrician or clinic for assessment and a treatment plan by a multiple service provider team.
- Encourage parents to keep a complete copy of their child's medical and education records, as well as other documentation, to assist in streamlining the coordination of care.
- Provide parents with information on services and resources to meet the child's needs, including eligibility for Medicaid (www.oregon.gov/DHS/healthplan/app_benefits/ohp4u.shtml).
- Assist parents in reducing the effects of the child's biological risks by encouraging them to provide a nurturing, positive, structured, home environment.
- For children who exhibit behavior or learning problems, coordinate with the school system to provide psychoeducational testing and supportive services.

Other resources:

www.cdc.gov/ncbddd/fas

www.nofas.org

www.cdc.gov/mmwr/preview/mmwrhtml/rr5411a1.htm

http://pubs.niaaa.nih.gov/publications/DrinkingPregnancy_HTML/pregnancy.htm

www.oregon.gov/DHS/ph/wh/fas.shtml

http://www.cdc.gov/ncbddd/fasd/acog_toolkit.html

Information compiled by DHS Public Health Division, Office of Family Health, Women's and Reproductive Health Section, Oregon FAS Prevention Program, 2009.

- i U.S. Department of Health and Human Services; HHS ST: District of Columbia; www.niaaa.nih.gov and www.cdc.gov/ncbddd/fas
- ii *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment. National Academies Press. 1996.*
- iii *Astley, Susan, and Clarren, Sterling. Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-digit diagnostic code. FAS Diagnostic and Prevention Network, University of Washington. Third edition, 2004.*
- iv *Hoyme, H. Eugene, et al. A Practical Clinical Approach to the Diagnosis of Fetal Alcohol Spectrum Disorders: Clarification of the 1996 Institute of Medicine Criteria. Pediatrics. American Academy of Pediatrics. 2005;115;pp.39-47.*
- vi *Lupton, C.; Burd, L.; and Harwood, R. Cost of Fetal Alcohol Spectrum Disorders. American Journal of Medical Genetics, Part C (Seminar in Medical Genetics). 127C:42-50 (2004).*
- vii *Alvik, A.; Haldorsen, T.; and Lindemann, R. 2005. Consistency of reported alcohol use by pregnant women: Anonymous versus confidential questionnaires with item nonresponse differences. Alcoholism: Clinical and Experimental Research 29(8):1444-1449.*
- viii *Moraes, C.L.; Viellas, E.F.; and Reichenheim, M.E. 2005. Assessing alcohol misuse during pregnancy: Evaluating psychometric properties of the CAGE, T-ACE and TWEAK in a Brazilian setting. Journal of Studies on Alcohol 66(2):165-173.*



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