

FASD Terminology

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). FASD describes a spectrum or range of clinical conditions associated with prenatal alcohol exposure. 1) FAS with full distinctive facial features; 2) Partial Fetal Alcohol Syndrome (PFAS) with some of the distinctive facial features; 3) ARND with little or no distinctive facial features.

Fetal Alcohol Syndrome (FAS) – FAS is a medical diagnosis for a specific pattern of characteristics resulting from the effects of prenatal alcohol exposure. These characteristics include growth retardation, or being small for age, microcephaly (smaller than normal head), short palpebral fissures (small eye slits), smooth philtrum (vertical groove between the upper lip and nose), a thin upper lip, central nervous system (brain and spinal cord) damage causing behavioral and cognitive (thinking, learning) problems. Evidence of prenatal alcohol exposure is sought but is not necessary for diagnosis to be made.

Fetal Alcohol Effect (FAE) – When a person has central nervous system damage like FAS indicated by behavioral and cognitive problems but without the distinctive facial features, the person may have FAE. Though the term appears in earlier studies and continues to be used by laypersons, some researchers in FAS have requested that the term FAE no longer be used due to the belief by some that FAE is less severe than FAS. THIS IS NOT TRUE. In fact, it may just mean that the child merely doesn't have the facial features or the growth retardation, but the damage to the brain may be just as extensive. Because of the confusion surrounding this term, the following term is now being used more widely.

Alcohol-Related Neurodevelopmental Disorder (ARND) is diagnosed when a child meets the criteria for brain damage but does not have all of the facial features or growth retardation of FAS. Again, ARND IS NOT A LESS SEVERE FORM OF FAS. In many cases, the brain damage in a patient with ARND is as extensive as that in a patient with FAS.

Alcohol-Related Birth Defects (ARBD) are physical abnormalities associated with prenatal alcohol exposure. They include: abnormalities of the eyes and the ability to see and process visual information; the ears and the ability to hear and process auditory information; the structure of the heart and the associated cardiac systems; and abnormalities in the limbs.

FASD Facts

- ◆ Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).
- ◆ Prenatal exposure to alcohol is the leading cause of preventable birth defects in the country.
- ◆ Each year, as many as 40,000 babies are born with an FASD, costing the nation about \$4 billion. (Source: FASD Center for Excellence)
- ◆ According to the Centers for Disease Control and Prevention and the US Surgeon General, there is no known safe amount or safe time to drink alcohol during pregnancy.
- ◆ FASD is an irreversible, lifelong condition that affects every aspect of a child's life and the lives of the child's family – there is no cure for FASD. Although the various effects of FASD are permanent conditions, specific symptoms may be treatable or manageable. People with FASD can grow, improve and function in life with proper support.
- ◆ It has been estimated, the cost of FASD to Ohio taxpayers for providing special services for education, juvenile justice, medical and mental health services, foster care and unemployment is nearly \$300 million every year (Source: Ohio Department of Health).
- ◆ A person with FASD may need multiple services involving numerous agencies in various service systems spread across a number of locations. It is rare to find coordination of services or case management for persons with FASD. Depending on the individual's specific needs, several dozen providers may be involved.
- ◆ Due to a combination of factors, most go undiagnosed. In fact, of the estimated 114,000 Ohioans living with FASD, only 300 have been clinically diagnosed. (Source: Ohio Department of Health)
- ◆ Early diagnosis and treatment for FASD can help children reach their fullest potential, lessen secondary disabilities and problems and help families better understand and cope.
- ◆ Raising a child with FASD is 100 times more expensive than preventing FASD in a child.
- ◆ FASD is 100 percent preventable.
- ◆ Sept. 9 is International Fetal Alcohol Syndrome Awareness Day. All women of child-bearing age need to know not a single drop!

Research

Early Identification/Biomarkers

Bearer, C.F., Stoler, J.M., Cook, J.D., and Carpenter, S.J. (2004). Biomarkers of alcohol use in pregnancy. *Alcohol Research & Health*, 28(1), 38-43.

Screening, Assessment and Diagnosis

Burd, L., Cotsonas-Hassler, T.M., Martsolf, J.T., & Kerbeshian, J. (2003). Recognition and management of fetal alcohol syndrome. *Neurotoxicology and Teratology*, 25, 681-688.

Jones, K.L. & Smith, D.W. (1973). Recognition of the fetal alcohol syndrome in early infancy. *The Lancet*, Nov 3;2(7836), 999-1001.

Sampson, P.D., Streissguth, A.P., Bookstein, F.L., & Barr, H.M. (2000). On categorizations in analyses of alcohol teratogenesis. *Environmental Health Perspectives*, 108 Sup 3, 421-428.

Neuropsychological and Physiological Impact

Church, M.W. & Kaltenbach, J.A. (1997). Hearing, speech, language, and vestibular disorders in the fetal alcohol syndrome: A literature review. *Alcohol Clinical and Experimental Research*, 21(3), 495-512.

Coggins, T.E., Olswant, L.B., Olson, H.C. & Timler, G.R. (2002). On becoming socially competent communicators: The challenge for children with fetal alcohol exposure. *International Review of Research in Mental Retardation*, 2. Retrieved 2/14/06 from <http://depts.washington.edu/fasdpn/pdfs/irrmr.pdf>.

Coles, C.D. (2001). Fetal alcohol exposure and attention: Moving beyond ADHD. *Alcohol Research & Health*, 25(3), 199-203.

Kelly, S.J., Day, N. & Streissguth, A.P. (2000). Effects of prenatal alcohol exposure on social behavior in humans and other species. *Neurotoxicology and Teratology*, 22, 143-149.

Streissguth, A.P. & O'Malley, K. (2000). Neuropsychiatric implications and long-term consequences of fetal alcohol spectrum disorders. *Seminars in Clinical Neuropsychiatry*, 5(3), 177-190.

Streissguth, A.P., Aase, J.M., Clarren, S.K., Randels, S.P., LaDue, R.A., & Smith, D.F. (1991). Fetal alcohol syndrome in adolescents and adults. *Journal of the American Medical Association*, 265(15), 1961-1966.

Longitudinal Studies

Streissguth, A.P., Barr, H.M., Bookstein, F.L., Sampson, P.D., & Olson, H.C. (1999). The long-term neurocognitive consequences of prenatal alcohol exposure: A 14-year study. *Psychological Science*, 10(3), 186-189.

What We Can Do - Response

Johnson, C.L. & Lapadat, J.C. (2000). Parallels between learning disabilities and fetal alcohol syndrome/effect: No need to reinvent the wheel. *Exceptionality Education Canada*, 10(3), 65-81.

Olson, H.C., Burgess, D.M., & Streissguth, A.P. (1992). Fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE): A lifespan view, with implications for early intervention. *Zero to Three: National Center for Clinical Infant Programs*, 13(1), 24-29.

Watson, S.M.R. & Westby, C.E. (2003). Prenatal drug exposure: Implications for personnel preparation. *Remedial and Special Education*, 24(4), 204-214.

What We Don't See—The Impact of Prenatal Alcohol Exposure

A. Mechanisms of Prenatal Alcohol Damage

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.

Wei-June, A. C., Maier, S.E., Parnell, S.E., & West, J.R. (2003). Alcohol and the developing brain: Neuroanatomical studies. *Alcohol Research & Health*, 27(2), 174-175.

B. Possible Mitigation Treatments

Thomas, J.D., La Fiette, M.H., Quinn, R.E., & Riley, E.P. (2000). Neonatal choline supplementation ameliorates the effects of prenatal alcohol exposure on a discrimination learning task in rats. *Neurotoxicology and Teratology*, 22, 703-711.

Vink, J., Auth, J., Abebe, D.T., Brenneman, D.E., & Spong, C.Y. (2005). Novel peptides prevent alcohol-induced spatial learning deficits and proinflammatory cytokine release in a mouse model of fetal alcohol syndrome. *American Journal of Obstetrics and Gynecology*, 193(3), 825-829.

C. Brain Imaging

Mattson, S.N., Schoenfeld, A.M., & Riley, E.P. (2001). Teratogenic effects of alcohol on brain and behavior. *Alcohol Research & Health*, 25(3), 185-191.

D. Paternal Impact

Cicero, T.J. (1994). Effects of paternal exposure to alcohol on offspring development. *Alcohol Health & Research World*, 18(1), 1994.

Randall, C.L. (2001). Alcohol and pregnancy: Highlights from three decades of research. *Journal of Studies on Alcohol*, 62, 554-561.

Tools for Screening & Diagnosis

Physicians are often considered the front line of prevention with FASD. Brief interventions are delivered as part of clinical care visits. Effective brief interventions to reduce alcohol misuse include:

- ◆ Assessment
- ◆ Advice
- ◆ Agreement on goals
- ◆ Assistance to stop drinking
- ◆ Arrangement of follow-up
- ◆ Referral for additional assistance.

Good evidence shows that assessment or screening, brief intervention and followup with non-dependent alcohol drinkers at risk of alcohol-related health consequences can reduce alcohol consumption. Evidence on the effectiveness of brief intervention for pregnant women is more limited but is sufficient to recommend it. Screening and brief interventions also can identify pregnant women for more intensive intervention.

The main goals of the following tools are to increase the identification of individuals with fetal alcohol syndrome (FAS) and to improve the delivery of appropriate services to those individuals and their families. The following tools are also provided to assist physicians with working with women of childbearing years, pregnant and nursing women.

Preventing Fetal Alcohol Spectrum Disorders Intervention Guides and Resources

Guidelines for Referral and Diagnosis of Fetal Alcohol Syndrome

Centers for Disease Control and Prevention 2004. Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis. Atlanta, GA. Department of Health and Human Services. www.cdc.gov/ncbddd/fas/documents/FAS_guidelines_accessible.pdf

Fetal Alcohol Syndrome TUTOR, CD

This comprehensive tool distributed by the March of Dimes helps health professionals screen and diagnose children with fetal alcohol syndrome. The CD-ROM uses descriptive text, video clips, animations and illustrations to assist users. For Windows and Macintosh. For more information about ordering a copy go to: <http://depts.washington.edu/fasdnpn/htmls/order-forms.htm>

Double Arc

Double ARC is a non-profit organization founded by the Sisters of Notre Dame in 1992. The focus of Double ARC is addressing the needs of children whose behavior and academic challenges put them at risk of failure. Double ARC also specializes in children with FASD who are challenged in academic areas.

SAMSHA Center for Fetal Alcohol Spectrum Disorder, Center for Excellence

Links to publications and research concerning screening and brief clinical interventions to reduce alcohol use of pregnant women can be found on their website: <http://www.fasdcenter.com/resource/interventionPreventingFASD.cfm#brief>

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

Links to publications and research concerning screening and brief clinical interventions to reduce alcohol use among various population can be found on NIAAA's website: <http://www.niaaa.nih.gov/>

Evidence-Based Practice

Screening and Brief Clinical Interventions To Reduce (Prevent) Alcohol Use

Brief interventions are delivered as part of clinical care visits. Effective brief interventions to reduce alcohol misuse include assessment, advice, agreement on goals, assistance to stop drinking, and arrangement of follow up or referral for additional assistance.

Screening for Alcohol Use and Problems

Centers for Disease Control and Prevention. 2004. Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis. Atlanta, GA. Department of Health and Human Services. (Pages 30–33).

www.cdc.gov/ncbddd/fas/documents/FAS_guidelines_accessible.pdf

National Institute on Alcohol Abuse and Alcoholism. 2002. Screening for Alcohol Problems—An Update. Alcohol Alert, No. 56. Bethesda, MD. National Institutes of Health.

pubs.niaaa.nih.gov/publications/aa56.htm

Babor, T.F.; Higgins-Biddle, J.C.; Saunders, J.B.; and Monteiro, M.G. 2001. AUDIT-The Alcohol Use Disorders Identification Test: Guidelines for Use in Primary Care. Second Edition. Geneva. World Health Organization.

whqlibdoc.who.int/hq/2001/WHO_MSD_MSB_01.6a.pdf

Chang, Grace. 2001. Alcohol screening instruments for pregnant women. Alcohol Research and Health 25(3):204-209. pubs.niaaa.nih.gov/publications/arh25-3/204-209.htm

Cherpitel, C.J. 1997. Brief Screening Instruments for Alcoholism. Alcohol Health and Research World. 21:348-351. pubs.niaaa.nih.gov/publications/arh21-4/348.pdf

Also see below, "Screening and Behavioral Counseling Interventions in Primary Care To Reduce Alcohol Misuse: Recommendation Statement" and "Helping Patients With Alcohol Problems."

Brief Interventions: Evidence and Guides

U.S. Preventive Services Task Force. 2004. Screening and Behavioral Counseling Interventions in Primary Care to Reduce Alcohol Misuse. Rockville, MD: Agency for Healthcare Research and Quality (Selected chapters are listed below).

Whitlock, E.P.; Polen, M.R.; Green, C.A.; Orleans, C.T.; and Klein, J. 2004. Behavioral counseling interventions in primary care to reduce risky/harmful alcohol use by adults. Originally in Ann Intern Med 2004;140:558-69. www.ahrq.gov/clinic/3rduspstf/alcohol/alcomisum.htm

Screening for Alcohol Misuse. www.ahrq.gov/clinic/uspstf/uspdrin.htm

Screening and Behavioral Counseling Interventions in Primary Care to Reduce Alcohol Misuse: Recommendation Statement. www.ahrq.gov/clinic/3rduspstf/alcohol/alcomisrs.htm

Task Force Ratings: Strength of Recommendations. www.ahrq.gov/clinic/3rduspstf/ratings.htm

National Institute on Alcohol Abuse and Alcoholism. 2005. Helping Patients Who Drink Too Much: A Clinician's Guide. Rockville, MD. National Institute on Alcohol Abuse and Alcoholism. pubs.niaaa.nih.gov/publications/Practitioner/CliniciansGuide2005/guide.pdf

Babor, T.D.; and Higgins-Biddle, J.C. 2001. Brief Intervention for Hazardous and Harmful Drinking: A Manual for Use in Primary Care. Geneva: World Health Organization. whqlibdoc.who.int/hq/2001/WHO_MSD_MSB_01.6b.pdf

Handmaker, N.S.; and Wilbourne, P. 2001. Motivational interventions in prenatal clinics. Alcohol Research and Health 25(3):219-299. pubs.niaaa.nih.gov/publications/arh25-3/219-299.htm

National Institute on Alcohol Abuse and Alcoholism. 1999. Brief Intervention for Alcohol Problems. Rockville, MD. National Institute on Alcohol Abuse and Alcoholism. pubs.niaaa.nih.gov/publications/aa43.htm

National Institute on Alcohol Abuse and Alcoholism. 2000. The Tenth Special Report to the U.S. Congress on Alcohol and Health: Chapter 8: Treatment of alcohol dependence with psychological approaches. Rockville, MD: National Institute of Alcohol Abuse and Alcoholism. pubs.niaaa.nih.gov/publications/10report/chap08b.pdf

Parent-Child Assistance Program (P-CAP)

The Parent-Child Assistance Program (P-CAP) uses a paraprofessional home visitation model to reduce risk behaviors in women with substance abuse problems. The program uses a case management approach, which is an effective complement to traditional substance abuse treatment. The focus is not simply on reducing alcohol and drug use, but also on reducing other risk behaviors and addressing the health and social well-being of mothers and their children.

Parent-Child Assistance Program (P-CAP). 2002. SAMHSA Model Programs: Parent-Child Assistance Program, Brief Program Description. modelprograms.samhsa.gov/template_cf.cfm?page=promising&pkProgramID=134

Project CHOICES

Project CHOICES targets women at risk of having an alcohol-exposed pregnancy before they become pregnant. A large proportion of women do not realize they are pregnant until well into the first trimester, and many drink alcohol during this time. The project focuses on reducing drinking and postponing pregnancy through contraception with women 18 to 44 who are sexually active and drinking alcohol.

Centers for Disease Control and Prevention. 2003. Motivational Intervention to Reduce Alcohol-Exposed Pregnancies—Florida, Texas, and Virginia, 1997-2001. Washington, DC: Government Printing Office. www.cdc.gov/mmwr/preview/mmwrhtml/mm5219a4.htm

Project CHOICES Intervention Research Group. Reducing the risk of alcohol-exposed pregnancies: A study of a motivational intervention in community settings. Pediatrics 2003;111(5):1131-1135. (This article references information from the CHOICES feasibility study. Table 1 describes all the components of the counseling sessions.) pediatrics.aappublications.org/cgi/content/full/111/5/S1/1131

Surgeon General's Advisory on Alcohol Use in Pregnancy

Thirty-two years ago, United States researchers first recognized fetal alcohol syndrome (FAS). FAS is characterized by growth deficiencies (or, decreased growth), abnormal facial features (specific facial features), and central nervous system (or, brain) abnormalities. FAS falls under the spectrum of adverse outcomes caused by prenatal alcohol exposure called Fetal Alcohol Spectrum Disorders (FASD). The discovery of FAS led to considerable public education and awareness initiatives informing women to limit the amount of alcohol they consume while pregnant. But since that time, more has been learned about the effects of alcohol on a fetus. It is now clear that no amount of alcohol can be considered safe.

I now wish to emphasize to prospective parents, healthcare practitioners, and all childbearing-aged women, especially those who are pregnant, the importance of not drinking alcohol if a woman is pregnant or considering becoming pregnant. Based on the current, best science available we now know the following:

- 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.
- No amount of alcohol consumption can be considered safe during pregnancy.
- Alcohol can damage a fetus at any stage of pregnancy. Damage can occur in the earliest weeks of pregnancy, even before a woman knows that she is pregnant.
- The cognitive deficits and behavioral problems resulting from prenatal alcohol exposure are lifelong.
- Alcohol-related birth defects are completely preventable.

For these reasons:

1. *A pregnant woman should not drink alcohol during pregnancy.*
2. *A pregnant woman who has already consumed alcohol during her pregnancy should stop in order to minimize further risk.*
3. *A woman who is considering becoming pregnant should abstain from alcohol.*
4. *Recognizing that nearly half of all births in the United States are unplanned, women of child-bearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure.*
5. *Health professionals should inquire routinely about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy, and advise them not to drink alcoholic beverages during pregnancy.*

Background

In the United States, FAS is the leading preventable birth defect with associated mental and behavioral impairment. There are many individuals exposed to prenatal alcohol who, while not exhibiting all of the characteristic features of FAS, do manifest lifelong neurocognitive and behavioral problems arising from this early alcohol exposure. In the United States,

the prevalence of FAS is between 0.5 to 2 cases per 1,000 births. It is estimated that for every child born with FAS, three additional children are born who may not have the physical characteristics of FAS but still experience neurobehavioral deficits resulting from prenatal alcohol exposure that affect learning and behavior.

The outcomes attributable to prenatal alcohol exposure for the children of women whose alcohol consumption averages seven to 14 drinks per week include deficits in growth, behavior, and neurocognition such as problems in arithmetic, language and memory; visual-spatial abilities; attention; and deficits in speed of information processing. Patterns of exposure known to place a fetus at greatest risk include binge drinking, defined as having five or more drinks at one time, and drinking seven or more drinks per week.

Despite public health advisories and subsequent efforts to disseminate this information, including a Surgeon General's advisory in 1981, recent data indicate that significant numbers of women continue to drink during pregnancy, many in a high-risk manner that places the fetus at risk for a broad range of problems arising from prenatal alcohol exposure including fetal alcohol syndrome. For example, data suggest that rates of binge drinking and drinking seven or more drinks per week among both pregnant women and non-pregnant women of childbearing age have not declined in recent years. Many women who know they are pregnant report drinking at these levels.

In addition, recent analysis of obstetrical textbooks suggests that physicians may not be receiving adequate instruction in the dangers of prenatal alcohol exposure. The American College of Obstetricians and Gynecologists advises against drinking at all during pregnancy. Nevertheless, only 24 percent of obstetrical textbooks published since 1990 recommended abstinence during pregnancy, despite 30 years of research since the first publications proposed a link between alcohol exposure and birth defects. Scientific evidence amassed in these decades has fortified the rationale for the original advisory against alcohol consumption during pregnancy. Continuing research has generated a wealth of new knowledge on the nature of fetal alcohol-induced injury, the underlying mechanisms of damage, concurrent risk factors, and the clinical distinction of alcohol-related deficits from other disorders.

Alcohol-related birth defects are completely preventable. A number of resources are available to assist healthcare and social services professionals in advising their patients to reduce and refrain from alcohol in pregnancy. These resources include the National Institute on Alcohol Abuse and Alcoholism, NIH (www.niaaa.nih.gov), the Centers for Disease Control and Prevention (www.cdc.gov/ncbddd/fas/), and the Substance Abuse and Mental Health Services Administration (www.fascenter.samhsa.gov/).