Fetal Alcohol Syndrome:

Guidelines for Referral and Diagnosis

National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Department of Health and Human Services

in coordination with

National Task Force on
Fetal Alcohol Syndrome and Fetal Alcohol Effect

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

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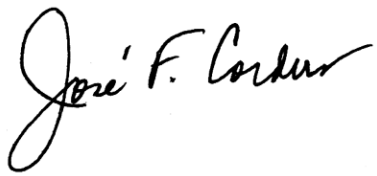
Foreword

The National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, in collaboration with the National Taskforce on Fetal Alcohol Syndrome and Fetal Alcohol Effects, is pleased to present ***Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis.*** This document represents the deliberations of clinicians, researchers, parents, and representatives of governmental and non-governmental organizations, whose main goals were to increase the identification of individuals with fetal alcohol syndrome (FAS) using uniform criteria, and to improve the delivery of appropriate services to those individuals and their families. These new guidelines will help achieve those goals by educating medical and allied health professionals about FAS.

In 2003, we, in the FAS research and practice communities, celebrated the 30th anniversary of the first reports describing fetal alcohol syndrome. Since that time we have learned a great deal about this preventable condition. We now recognize that FAS represents the tip of the iceberg and that there is a continuum of outcomes associated with prenatal exposure to alcohol. These guidelines were undertaken, in part, as an effort to facilitate further identification, understanding, and study of all conditions resulting from prenatal exposure to alcohol. They build on previous work and incorporate important scientific and clinical knowledge that has been obtained in recent years. CDC is pleased to provide continuing support for the expansion and refinement of scientific descriptions for FAS and other disorders related to prenatal exposure to alcohol through its ongoing work with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect and the federal Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS).

Preventing all adverse outcomes associated with prenatal alcohol exposure remains a primary goal of CDC, as well as the entire U.S. Department of Health and Human Services. CDC is committed to working with other federal agencies, organizations in the private sector, relevant partners, and the public to achieve this goal. Similarly, CDC is committed to enhanced early identification of individuals with FAS and related disorders to ensure their access to appropriate services. These latest guidelines for referral and diagnosis are an important step towards that goal. Together we will ensure all persons with FAS and related disorders develop optimally and reach their full potential.



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Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis

EXECUTIVE SUMMARY

As part of the fiscal year 2002 appropriations funding legislation, the U.S. Congress mandated that the Centers for Disease Control and Prevention (CDC), acting through the National Center on Birth Defects and Developmental Disabilities (NCBDDD) Fetal Alcohol Syndrome (FAS) Prevention Team and in coordination with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE), other federally funded FAS programs, and appropriate non-governmental organizations, would:

- Develop guidelines for the diagnosis of FAS and other negative birth outcomes resulting from prenatal exposure to alcohol,
- Incorporate these guidelines into curricula for medical and allied health students and practitioners, and seek to have them fully recognized by professional organizations and accrediting boards, and
- Disseminate curricula to and provide training for medical and allied health students and practitioners regarding these guidelines.

Through the coordinated efforts of CDC, the NTFFAS/FAE, and a scientific working group (SWG) of experts in FAS research, diagnosis, and treatment, the following diagnostic criteria were developed over a 2-year period:

Facial dysmorphia
Based on racial norms, individual exhibits all three characteristic facial features:
- Smooth philtrum (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Thin vermillion (University of Washington Lip-Philtrum Guide rank 4 or 5)
- Small palpebral fissures (at or below 10th percentile)

Growth problems
Confirmed prenatal 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).

Central Nervous System Abnormalities

I. Structural

1) Head circumference (OFC) at or below the 10th percentile adjusted for age and sex.
2) Clinically significant brain abnormalities observable through imaging.

Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis

Substantial empirical and clinical scientific evidence has shown that prenatal exposure to alcohol causes damage to the developing fetus. Such exposure is commonly cited as the leading preventable cause of birth defects and developmental disabilities (1-3). Children* exposed to alcohol during fetal development can suffer multiple effects. While the number and severity of negative effects can range from subtle to serious, the negative consequences are lifelong. The effects of prenatal exposure to alcohol and basic diagnostic features of fetal alcohol syndrome (FAS) were first described in the United States (U.S.) medical literature 30 years ago (4-8). In 1981, the U.S. Surgeon General issued a public health advisory warning that alcohol use during pregnancy could cause birth defects (9). Further, mandated labeling of alcohol products was established in 1989 (10). Despite the known adverse effects of prenatal exposure to alcohol, many children who experience these adverse effects do not receive proper diagnosis due to the absence of current diagnostic guidelines. These current guidelines, which were federally mandated of the Centers for Disease Control and Prevention (CDC) in the U.S. Department of Health and Human Services (DHHS) 2002 Appropriations Bill, seek to update and refine diagnostic and referral criteria in light of the scientific and clinical advances in the understanding of this disorder during the past 30 years.

These guidelines are organized into several sections. Background information and a history of the development of these guidelines are presented. Next, revised and refined diagnostic and referral criteria for FAS are described, including the empirical and clinical evidence that support each criterion. Comparison of these guidelines with other diagnostic methods currently in use is provided. Because diagnosis is not the endpoint for most clinicians who see children with FAS, a discussion of the essential services for affected individuals is included. Likewise, prevention of FAS by reducing the number of alcohol-exposed pregnancies is inherent in dealing with the disorder. Therefore, a discussion focused on identifying and intervening with women at risk for an alcohol-exposed pregnancy is provided. Finally, a discussion of future needs and efforts related to FAS and other prenatal alcohol-related disorders conclude this report.

BACKGROUND

Prevalence. Studies by CDC have reported FAS prevalence rates from 0.2 to 1.5 cases per 1,000 births across various populations (11-14). Other studies reflecting a variety of ascertainment methodologies have produced estimates ranging from 0.5 to 2.0 cases per 1,000 live births (15-16). Such rates are comparable with or above other common developmental disabilities such as Down syndrome or Spina Bifida (17). Using the CDC FAS estimates, among the approximately 4 million infants born each year, an estimated 1,000 to 6,000 will be born with FAS. Studies of particularly vulnerable populations yield prevalence estimates that far exceed those of other common disabilities. Disadvantaged groups, Native Americans, and other minorities have been documented to have

* Although referral and diagnosis for FAS can be made throughout the lifespan, the majority of individuals are referred and diagnosed in childhood. Thus, the terms "child" or "children" as used in these guidelines are not intended to preclude referral, assessment, and diagnosis of older individuals.

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To learn more about Fetal Alcohol Syndrome, contact:

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Http://www.cdc.gov/ncbddd/fas

Order materials:
Http://www.cdc.gov/fas/faspub.htm

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