

# Guideline for the Prevention of Fetal Alcohol Syndrome (FAS)

This guideline was developed by a working group based on best available evidence and from a province-wide survey of physicians. The development of this guideline was funded as part of the Alberta FAS Initiative and in cooperation with the Prairie Province FAS Initiative.

## DEFINITIONS

- ◆ **FASD (Fetal alcohol spectrum disorder) is an umbrella term used that includes:**
  - Fetal Alcohol Syndrome (FAS) with Confirmed Maternal Alcohol Exposure
  - Fetal Alcohol Syndrome (FAS) without Confirmed Maternal Alcohol Exposure
  - Partial Fetal Alcohol Syndrome (PFAS) with Confirmed Maternal Alcohol Exposure
  - Alcohol-Related Birth Defects (ARBD)
  - Alcohol-Related Neurodevelopmental Disorder (ARND)

## GOALS

This guideline is intended for use by physicians, midwives and other health care professionals to reduce the incidence and disability from FAS by increasing:

- ◆ knowledge about screening for alcohol consumption in pregnancy;
- ◆ awareness about common attitudes regarding alcohol use and FAS; and by
- ◆ promoting productive dialogue and action between healthcare professionals and their patients (and when possible, their partners).

## RECOMMENDATIONS

- ◆ A consistent message must be given to all women of childbearing years and their partners that:
  - a prudent choice for women who are pregnant or who are considering pregnancy is to abstain from alcohol;
  - inform women who consumed small amounts of alcohol occasionally during pregnancy that the risk to the fetus in most situations is minimal; and
  - reducing or stopping alcohol use at any time during pregnancy will reduce the harmful effects of alcohol.
- ◆ Physicians/midwives engage with other health care professionals in basic strategies to prevent FAS in their practices.
- ◆ Given the risk of recurrence is high for women (couples) who have had an FAS child, that they are counselled in recognizing and changing their alcohol use patterns in order to reduce impairments and disabilities in future children.

## PREVENTION STRATEGIES

### Primary Prevention

- Engage in education regarding FAS and the adverse effects of alcohol on the fetus with all women and their partners
- Ask all female patients, of childbearing age, the basic question about their use of alcohol
- Be aware of and use promotional materials in offices and as handouts for patients
- Be aware of and access community resources
- Discuss and enhance access to contraceptive strategies with all women and their partners

### Secondary Prevention

- Identify women who are using alcohol during pregnancy and assess level of risk (refer to Algorithm and Screening Details)
- Counsel pregnant women who are using alcohol about the effects on the fetus and their own health
- Counsel pregnant women regarding the benefits of stopping or reducing the use of alcohol at any time during pregnancy
- Refer women who are using alcohol for appropriate treatment
- Provide contraceptive counselling

### Tertiary Prevention

- Identify those women at high risk in future pregnancies
- Ask the woman why she drinks?
- Refer women at risk, especially pregnant women, for appropriate treatment
- Counsel women about the benefits of stopping or reducing alcohol consumption at any time during pregnancy
- Provide contraceptive counselling

#### **Practice Tip:**

*Alcohol use in pregnancy should be discussed as part of risk reduction counselling.*

## INTRODUCTION

Alcohol is a legal, socially acceptable drug the use of which is part of the daily life of many people in this country. According to one study of 6,000 pregnant women, drinking during pregnancy has increased in the past few years.<sup>1</sup>

In a 1998 Angus Reid survey of Canadians, 75% of women surveyed claimed to be occasional alcohol drinkers, and 25% said they drank frequently.<sup>2</sup> In another 1998 Angus Reid poll done for Alberta Family and Social Services, it was found that 25% of those polled felt that moderate or social drinking is acceptable during pregnancy.

**FAS is the most preventable cause of birth defects.**<sup>3</sup> Although part of the human condition for centuries, this syndrome was first documented in France in 1968,<sup>4</sup> and subsequently defined in 1973 in the United States.<sup>5</sup> Appropriate intervention can prevent FAS; however, it continues to occur in every population where alcohol is consumed.

## SPECTRUM OF DISABILITY RELATED TO FAS

Many terms have been used to describe abnormalities attributed to prenatal exposure to alcohol. Fetal alcohol syndrome (FAS), alcohol related birth defect (ARBD), fetal alcohol effects (FAE), and alcohol related neurological disorders (ARND) are the most commonly used terms.

*The consequences of prenatal alcohol exposure fall along a continuum, ranging from subtle neurodevelopmental and behavioral manifestations to FAS.*

It is important to note that abnormalities attributed to prenatal exposure to alcohol occur along a continuum of severity, with miscarriage and stillbirth being the most severe at one end, and various birth defects not sufficient to be classed as FAS at the other end. Even among those diagnosed as FAS, the severity of motor and speech development and behavioral problems varies significantly. The less severe the physical features, the harder it is to make a diagnosis. It is, however, important to address the needs of affected individuals.

The range of disability has been described thoroughly in the literature by various researchers.<sup>6,7</sup> A full description can be found in a report prepared by AADAC.<sup>8</sup>

Results from a 1999 representative survey of Alberta physicians confirmed the need and interest in guidelines on FAS. The survey, with a response rate of 37% (348/930), found that physicians recognized the need for more specific training and information in the area of FAS prevention, diagnosis and management; and 61% noted that clinical practice guidelines would be helpful for them.

## EPIDEMIOLOGY OF FAS

### Alcohol Consumption Patterns

- The prevalence of alcohol consumption amongst women aged 18 to 34 years ranges from 60% to 75% with 4% considered to be alcohol abusers or alcohol dependent.<sup>9,10</sup>
- An estimated 2 to 13% of young women drink heavily. However, few concerted attempts have been made to alter the drinking behavior of young women.<sup>11</sup>
- Lower drinking prevalence has been recorded during pregnancy: 20% less among women in general; among women who are alcohol abusers, the decrease is less than 1%.<sup>4</sup>
- In a national sample, 25% of women reported drinking during pregnancy.<sup>12</sup> No evidence indicates that the heavy drinkers are drinking any less during pregnancy.
- **In 2000, the Centers for Disease Control and Prevention conducted a study of the drinking patterns of pregnant women. The results of that analysis indicated that approximately 10% of pregnant women used alcohol, and approximately 2% engaged in binge drinking or frequent use of alcohol. The results further indicated that more than half of women who did not use birth control (and therefore might become pregnant) reported alcohol use and 12.4% reported binge drinking.** (US Department of Health and Human Services, US Department of Agriculture. Nutrition and your health: dietary guidelines for Americans. 5th ed. Washington, DC: US Department of Health and Human Services, US Department of Agriculture; 2000.)

### Incidence and Prevalence

According to various studies, the worldwide incidence of infants with FAS ranges from **9.1 per 1,000 live births** in high risk populations to **1 - 3 per 1,000 births** in the general population.<sup>14,15,16</sup> (Chavez, Sokol, Sampson, Sampson)

FAS is the leading cause of preventable birth defects and one of the top three leading known causes of mental disability in the western world. Although the ranking of the top three disorders varies from author to author, the literature consistently states that FAS is one of the top three known causes of mental retardation, along with Spina Bifida and Down Syndrome.<sup>17,18,19,20</sup>

The area of prevalence and incidence rate of FAS however, is one of controversy, and study results have noted a wide range of estimates. Some of the contributing factors include, but are not limited to, the following.

- Data has been collected in various ways - including the catchment approach, retrospective studies, and prospective studies - each with its own set of limitations. Consequently, there are difficulties in interpreting and comparing results.
  - Results of some studies have been skewed by the fact that these studies have focused on communities where the target population is known to have a higher alcohol exposure profile.
  - An accurate history of alcohol use in pregnancy is often difficult to obtain, so the true incidence of FAS is often underestimated.
  - There are problems related to diagnosis, including inaccurate diagnosis, missed diagnosis, and lack of knowledge about FAS, leading to unrecognized cases of FAS.
  - Incidence of other conditions within the spectrum of FAS, such as FAE, ARBD and ARND are more poorly defined but are suspected to be higher than that of FAS.
- in households with an annual income greater than \$50,000
  - Other studies note that the incidence rate of FAS appears to be higher among certain populations. For example:
    - Studies conducted in Manitoba indicate higher prevalence rates among Aboriginal populations.<sup>23,24</sup>
    - Higher rates are reported among the Aboriginal population in BC.<sup>25</sup>
    - Other studies suggest that major factors associated with FAS are low socioeconomic status, smoking, poor health, and use of other drugs.<sup>26</sup>
    - The risk of recurrence of FAS appears to be substantially higher for families who already have children affected by FAS. In fact, the estimated risk to younger siblings with FAS is 771 per 1000 live births.<sup>27</sup>

Given these factors, it is difficult to accurately determine incidence and prevalence rates. Although health care professionals are sensitized to look for FAS in certain populations, no woman or target population is exempt. FAS occurs in populations of every race and socioeconomic status.

***Always ask all women about their use of alcohol.***

### High Risk Populations

In populations with a high proportion of women who drink alcohol, the incidence of FAS is higher. However, given the research available, it appears that all women need to be screened in pregnancy.

The following sample of research studies illustrates the wide variation of “high risk” groups.<sup>21,22</sup>

- One study notes that the risk of FAS appears to be greater in the presence of the low socioeconomic status, poverty, and lack of education that often accompany abusive drinking; women who drink and have these characteristics appear to be at higher risk of having an FAS child.
- Another recent study indicates that babies born to mothers in the following groups are at highest risk - women:
  - with a college education,
  - who are unmarried,
  - who are students,
  - who smoke,

What we do know for sure is that **alcohol is the common denominator in these high risk populations.**

### MECHANISMS OF ALCOHOL TERATOGENIC EFFECTS

Alcohol is a known teratogen associated with increased pregnancy loss, malformations, growth retardation and neurological dysfunction. The precise mechanism for the teratogenic effect is a combination of toxic effects from ethanol and its metabolites, interference with cell migration, and indirect mechanisms.

The typical features of FAS result from exposure to alcohol throughout the pregnancy with alcohol-related birth defects and alcohol-related neurodevelopmental delay potentially caused by exposure during a critical interval. In addition to excessive regular intake and heavy episodic consumption of alcohol, there is also concern with consistent intake of as little as 2 drinks/day.<sup>28,29, 30</sup>

Malformations generally result from exposure during the first trimester with anomalies commonly of the cardiovascular, skeletal, and genitourinary systems.

Alcohol related neurodevelopmental disorder can manifest as either structural changes such as microcephaly, agenesis of the corpus callosum, or cerebellar hypoplasia; or dysfunction of behavior or cognition.

Exposure to alcohol in the third trimester has a more severe effect on birth weight than exposure earlier in gestation. There appears to be a linear relationship between the amount of alcohol consumed and decrease in birth weight.<sup>31, 32</sup> However, there is growing evidence that reducing heavy alcohol intake, even as late as the third trimester, will result in significantly higher birth weights and significantly fewer infants with alcohol related abnormalities.

## BACKGROUND ON PREVENTION

### Prevention Strategies

The goal of a comprehensive prevention program is to provide overlapping levels of reinforcement (education and persuasion), incentives and interventions to prevent FAS.<sup>1</sup>

### Primary Prevention

Primary prevention involves the elimination of the root causes of a problem by broad-based efforts to promote the health and well-being of a community. These strategies can be applied to the entire population.

In the case of FAS, the goal of primary prevention is to have no fetuses exposed to alcohol, thus eliminating the problems of FAS before they ever develop. Because no safe level of drinking has been identified, ideally all females would cease drinking before conception and during pregnancy.<sup>2</sup> This abstinence would guarantee the primary prevention of all FAS.

### Knowledge and Understanding

To carry out effective prevention strategies, health professionals need knowledge and understanding of the probable etiologic mechanisms of FAS and the factors contributing to the use of alcohol.

Evidence<sup>3-5</sup> shows that information provided by physicians and others in office and prenatal clinic settings is seen as credible and effective in relaying the message.

Clarren<sup>6</sup> suggests that physicians and other health care providers should discuss the notion, prior to conception, that alcohol consumption is potentially harmful to a developing fetus.

### Education

One of the most basic techniques used in primary prevention is public education at all levels.

Information should be directed slightly differently for women and men. It is important to emphasize to women abstinence from alcohol and drugs during pregnancy.<sup>7</sup> For partners and families, the emphasis should be placed on the supportive role that they play in a healthy pregnancy.

**FAS is 100% preventable**

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**A prudent choice for women who are pregnant or who are considering pregnancy is to abstain from alcohol**

### Secondary Prevention

Secondary prevention seeks to reduce the duration and severity of maternal drinking by identification of the person at risk. Thus, strategies would include screening, early intervention programs, and services for pregnant women and women of childbearing potential who may be at risk for having a child with FAS.

### Professional Education

Many physicians are reluctant to inquire about alcohol use. One explanation is that they wouldn't know what to do if they found problems.<sup>8</sup> This attitude may be overcome when physicians learn that patients often appreciate professional concern and when they know how to refer problem patients to community resources for treatment.

**Studies<sup>9, 10</sup> indicate that a supportive counselling and/or case management program can result in 60 to 80 percent of pregnant women reducing their alcohol intake before the third trimester and 35 to 50 percent stopping "heavy" drinking**

### Screening

The pregnant woman who consumes alcohol cannot be identified by appearance or by socioeconomic characteristics therefore a systematic drinking history is essential and should be obtained from all patients during the initial history and in subsequent prenatal care.

In response to this clinical need several screening tools have been developed such as the T-ACE screening questionnaire.<sup>11</sup> Although it is understood that many physicians currently use the CAGE screening tool, this committee finds the T-ACE to have higher sensitivity and specificity when used to assess periconceptual heavy drinking. (Refer to the Screening Algorithm).

### Intervention

Pregnancy is an ideal time for the physician to identify drinking problems and to intervene. It is reported that alcohol consumption often decreases spontaneously during pregnancy.<sup>12</sup>

*Once alcohol consumption has been identified, physicians should discuss the fetal risks with the woman and her family in the same way that other risks are discussed. Everything possible should be done to discourage drinking during the pregnancy to prevent harm to the fetus*

In several clinical trials, intervention as a part of prenatal care has been successful in reducing alcohol consumption. Approximately 50 percent of heavy drinkers were able to reduce their drinking to the moderate or rare category and these women had infants with higher birth weights and fewer characteristics of FAS.<sup>13</sup>

**Practice Tip:**

- *Disulfiram should not be used during pregnancy.*<sup>14,15</sup>
- *Special care in detoxification procedures during pregnancy are needed.*

### Tertiary Prevention

Tertiary prevention is aimed at reducing the complications, impairments, and disabilities caused by FAS, and includes activities that prevent recurrence of the condition in subsequent children. Strategies should be designed and reserved specifically for children with FAS and their caregivers.

### Treatment/Therapy

It is important to assist the mother (couple) to recognize and change their alcohol consumption pattern. Specific education and advice for voluntary referral to therapy for alcohol and drug misuse should be pursued with the couple who have an FAS child. This advice should be offered empathically but firmly. A more direct approach is needed if change is not evident over a reasonably short period of time.<sup>16</sup>

**AADAC has available resources in the Alberta communities that are easily accessible.**

### Future Pregnancies

Once a diagnosis of FAS has been made, aggressive measures are needed to reduce the injury to future children. This is best accomplished by helping the mother (and partner) in changing their alcohol abuse pattern.<sup>17</sup> Studies indicate **that women who have had one definite FAS child and continue to drink will have equally or progressively more severely damaged children in subsequent pregnancies.**<sup>18</sup> Both parity and age are contributing factors. In such cases, isolating the experience of pregnancy from alcohol and substance abuse is the logical and safe course of prevention.

Intensive case management of women who have borne one or more FAS children has been shown to help protect against future FAS children, allow for the care of the specific social and medical needs of the woman and her family, and improve the future health of the mother.<sup>16</sup>

## REFERRAL SOURCES

Contact your Regional Health Authority, AADAC, or the College of Physicians and Surgeons of Alberta for a list of current resources.

## AREAS FOR FURTHER RESEARCH AND DEVELOPMENT

Although there has been much research regarding FAS and other disorders associated with fetal exposure to alcohol, there are a number of issues that require further study and clarification. These include the need for:

- accurate data on **incidence and prevalence rates** of FAS within Alberta;
- discussion and confirmation of appropriate **terminology** around FAS, FAE, and ARBDs;
- multidisciplinary teams with specialized training and experience in the area of FAS and diagnosis of the same;
- examination of the effect of **paternal alcohol consumption** on disorders with FAS;
- research into the **effects of the use of pharmaceuticals and other drugs and solvents;**
- **providing physicians with the necessary knowledge, skills, and tools** to properly screen women and provide accurate information about the effects of alcohol use on the development of the fetus;
- development of **specialized interventions** for women at risk of having an FAS child;
- examination of the **role and outcomes of various interventions** for FAS affected individuals; and
- development of specialized **detoxification methods for pregnant women.**

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## **TOWARD OPTIMIZED PRACTICE PROGRAM**

The successor to the Alberta Clinical Practice Guideline (CPG) program, TOP is an initiative directed jointly by the Alberta Medical Association, Alberta Health and Wellness, the College of Physicians and Surgeons, and Alberta's Health Regions. The TOP Program promotes appropriate, effective and quality medical care in Alberta by supporting the use of evidence-based medicine.

## **TO PROVIDE FEEDBACK**

The Working Group for FAS is a multidisciplinary team composed of family physicians, obstetricians, pediatricians, geneticists, Community Medicine specialists, midwives, representatives from AADAC, Alberta Family and Social Services, Health Canada, the Alberta CPG Program, the Committee on Reproductive Care, the Nechi Institute and the public.

The Working Group encourages your feedback. If you need further information or if you have difficulty applying this guideline, please contact:

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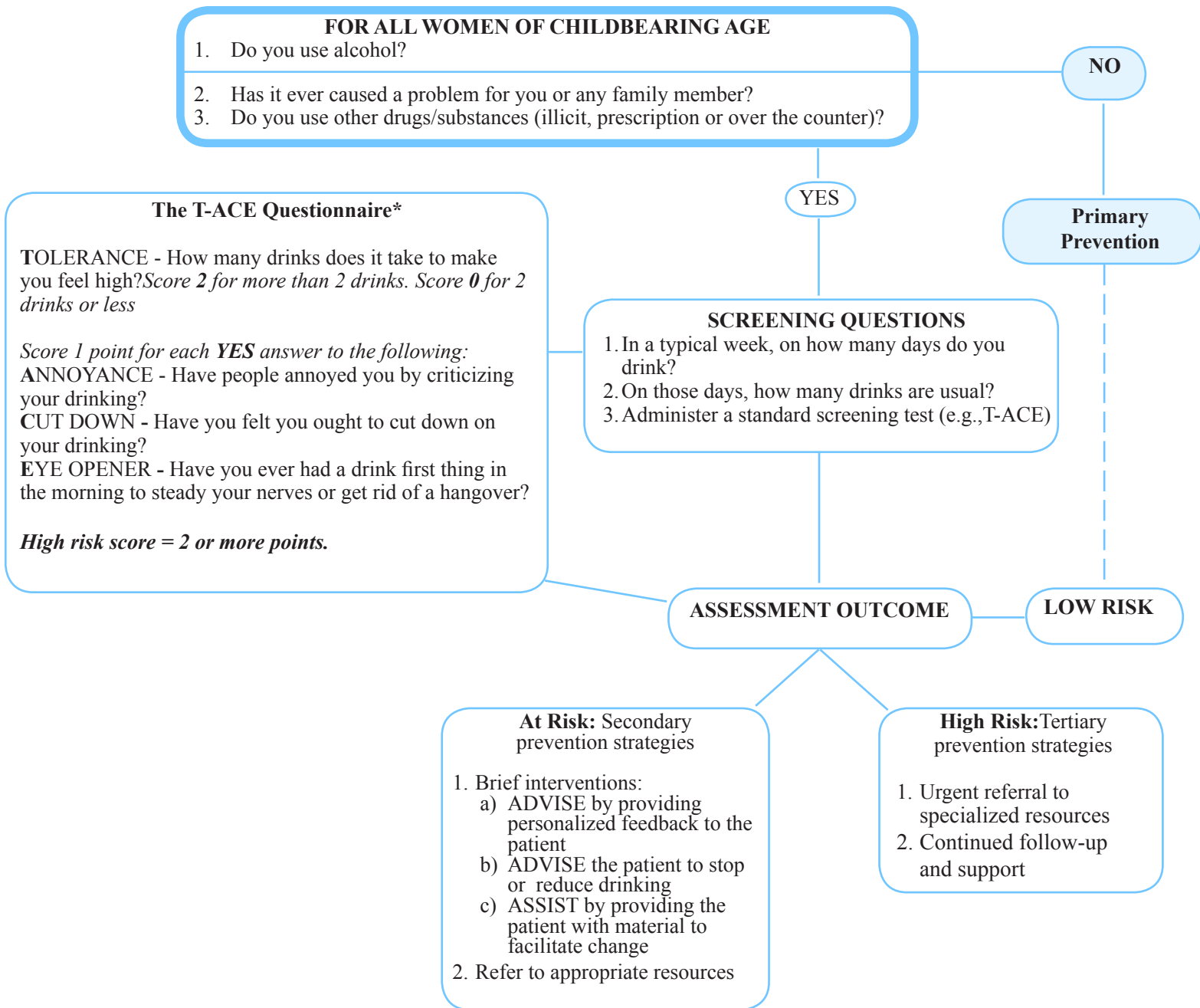
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# ALGORITHM: SCREENING FOR ALCOHOL USE



\* The T-ACE questionnaire is an example of one systematic approach to alcohol screening. Reference: Sokol R. et al. The T-ACE Questions, practical prenatal detection of risk drinking. American Journal of Obstetrics and Gynecology, April 1989; 160(4).