

# Fetal Alcohol Syndrome

## Efforts Underway to Reduce Rates

By Lisa Troshinsky

Closing the Gap, Maternal Health • January/February 2004

For more than 30 years, doctors, nurses and other health care providers have worked to alert women about the dangers of drinking during pregnancy. Yet, prenatal exposure to alcohol is one of the leading causes of mental retardation and preventable birth defects today.

Fetal alcohol syndrome (FAS), a medical term first identified in 1973, describes a lifelong, physically and mentally disabling condition in children whose mothers drank alcohol while pregnant. FAS is characterized by (1) abnormal facial features, (2) growth deficiencies, and (3) central nervous system problems. People with FAS may have problems with learning, memory, attention span, communication, vision and/or hearing. These problems often lead to difficulties in school and problems getting along with others.

### Those Most Affected

FAS affects one in every 500 live births in the United States, the equivalent of 8,000 to 12,000 cases each year. And, the disease disproportionately affects American Indian communities where the incidence of alcoholism is the highest.

The National Organization on Fetal Alcohol Syndrome (NOFAS) says FAS affects American Indian and Alaska Native communities at least 10 times more frequently than it does the broader population. FAS rates vary between different American Indian tribes, but appear to be worse for those located in the southwestern part of the United States.

Though there are no exact statistics, according to a Centers for Disease Control and Prevention (CDC) surveillance study conducted from 1995 to 1997 in four U.S. states, the rate of FAS births for American Indian and Alaska Natives was 3.2 percent, compared with the rate of 0.2 percent for Whites, and a rate of 0.4 percent for the general population. The second highest incidence rate was for African Americans, with a rate of 1.1 percent.

### FAS Not Confronted? Experts Differ

Though FAS is an escalating health concern, related primarily to the rate of alcoholism increasing among women of childbearing ages, experts maintain that the disease has not been taken seriously by the medical community and that there are very few comprehensive programs that exist for its prevention and treatment.

“There isn't really good surveillance data on FAS anywhere in the United States,” said Callie Gass, project director for the

FAS Center for Excellence, a new project started by the Department of Health and Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA).

“We have a mandate from Congress to identify exemplary systems for comprehensive prevention, treatment and appropriate intervention, and we found out there aren't any. We don't know any safe level of alcohol consumption for pregnancy, yet, medical doctors don't routinely tell women not to drink during pregnancy and we don't have intervention programs

“...We don't know any safe level of alcohol consumption for pregnancy...”

Callie Gass, Project Director, FAS Center for Excellence

for women who are drinking.”

One of the main problems in fighting FAS is that it is easily misdiagnosed. Unless a person has the characteristic facial defects, the syndrome can be mistaken for attention deficit disorder, or just plain laziness or intentional “acting out.” A cultural stigma is another barrier to FAS identification and intervention, experts say.

Dr. Kathy Masis, medical officer for behavioral health, Billings Area (Montana), Indian Health Service (IHS), contends that though stigma, embarrassment and resistance associated with FAS exists, there is less of a cultural barrier to facing the problem in American Indian communities.

“IHS was a pioneer in discovering FAS in 1973,” Masis said. “Ascertainment within the American Indian community is better than in other communities; they don't have the level of stigma. American Indians are already stigmatized just for being Indians, for living on a reservation. They don't have the same need to look good for society. There is more of a willingness to talk about FAS and report it.”

But Sharon Asetoyer, executive director of the American Indian Women's Health Education Resource Center, located in South Dakota, says fighting FAS in American Indian communities has a long way to go.

“Some communities have treatment centers, but they are few and far between,” Asetoyer said. “The government spends millions on treatment services, but fails to provide after-care services. Without those, women go back into the same environments and start drinking again.”

“There is a disparity of funding for the American Indian community because we are tucked out here in rural communities and reservations, and we haven't had the voting power in the past,” Asetoyer said. “Luckily, that is starting to change in South Dakota, and now there is a consortium that includes Minnesota, Nebraska, Oklahoma, Arizona, New Mexico, Montana and Idaho, that is dealing with the problem.”





# Fetal Alcohol Syndrome

## Efforts Underway to Reduce Rates

By Lisa Troshinsky

Closing the Gap, Maternal Health • January/February 2004



### Some Hope—More Money, More Initiatives

Efforts by government and private organizations to prevent, identify and treat FAS in American Indian communities are starting to gather steam, say FAS experts. IHS, SAMHSA, CDC, the National Institutes of Health, and NOFAS are among those that have received funding to fight the disease.

“In the last two years, activity around the country toward reducing FAS has been phenomenal,” Masis said. “There is more funding from CDC, IHS recently hired key people, and SAMHSA started the FAS Center for Excellence a few years ago.”

“I think more attention has been put on fighting FAS in the American Indian communities because of Congressional support,” said Kathleen Mitchell, NOFAS program director and national spokesperson.

One piece of significant legislation, the Children’s Health Act of 2000, requires the HHS Secretary to make awards to public, nonprofit and private organizations to establish up to four centers for excellence to study techniques to prevent FAS and alcohol-related birth defects.

As a result of that legislation, for the purpose of combating FAS, SAMHSA was appropriated approximately \$12 million for fiscal year (FY) 2001, \$11 million for FY 2002, \$9.7 million in FY 2003, and \$10 million is expected for FY 2004, Stone said.

“Before these appropriations, SAMHSA was getting nothing for FAS,” Stone said.

“There have been some funding increases within CDC for state-based grants for FAS awareness and training,” said Candice Jalonen, a health scientist at the CDC National Center on Birth Defects and Developmental Disabilities.

“For FY 2003, CDC received \$12.4 million, and for FY 2004, \$12.5 million was appropriated for FAS prevention. CDC also heads up a federal FAS Task Force, and contracts non-profits and community organizations to conduct FAS prevention.”

“NOFAS also has grown due to increased investment for this issue over the last three-year-period,” said NOFAS executive director Tom Donaldson.

### Projects are Beginning

“The SAMHSA FAS Center for Excellence is still in its research stage,” said center project director Callie Gass. “We’re going around the country conducting town hall meetings to identify what the American Indian communities need regarding FAS, particularly in the southwest. We’re developing a strategic plan—trying to figure out how to get around lack of resources in those areas, and discovering which best practices and models are required.”

Gass went on to say, “We want to increase recognition of women at risk, and after someone is diagnosed with FAS, we want to encourage early intervention, which could

include occupational, speech, and behavior therapy.”

NOFAS recently received \$175,000 from the Weinburg Foundation for a three-year Indian youth project to fight FAS, and \$150,000 from the CDC for a Cherokee Nation project in Oklahoma, Donaldson said.

“The goal of the Cherokee Nation project is to conduct prevention and intervention work,” said Mitchell. “The Cherokee Nation will form an advisory committee that will drive our activities, and we will develop a public awareness campaign to serve women and children and develop workshops for health clinics and addiction treatment centers.”

NOFAS just completed a similar three-year, public awareness campaign in Washington, D.C., funded by the National Institutes of Health that targeted African Americans. NOFAS also is continuing to increase FAS awareness in the medical community.

“We’ve had an FAS curriculum at several medical institutions, including Northwestern and Georgetown, for more than 13 years, and we’re working with the CDC to develop a general FAS curriculum for medical students and practitioners,” Mitchell concluded.

*For more information on the Substance Abuse and Mental Health Services Administration Fetal Alcohol Spectrum Disorders Center for Excellence, go to <http://www.fascenter.samhsa.gov>*

Number and Prevalence Rate\* of Fetal Alcohol Syndrome Cases • Fetal Alcohol Syndrome Surveillance Network, 1995-1997

Race/ethnicity	Alaska			Arizona			Colorado			New York			Total		
	Births	Cases	Rate	Births	Cases	Rate	Births	Cases	Rate	Births	Cases	Rate	Births	Cases	Rate
White, non-Hispanic	19,007	5	.3	114,851	15	.1	63,653	11	.2	68,932	18	.3	266,443	49	.2
Black	1,341	0	-	7,054	4	**	5,508	5	.9	13,455	21	1.6	27,358	30	1.1
Hispanic	1,287	0	-	80,626	16	.2	21,579	8	.4	3,635	0	-	107,127	24	.2
Asian/Pacific Islander	1,493	0	-	4,371	1	**	2,556	0	-	1,693	0	-	10,113	1	**
AI/AN++	7,117	40	5.6	15,685	39	2.5	1,744	1	**	627	1	**	25,173	81	3.2
Other/Unknown	39	0	0	456	0	-	96	0	-	447	0	-	1,038	0	-
<b>Total</b>	<b>30,284</b>	<b>45</b>	<b>1.5</b>	<b>223,043</b>	<b>75</b>	<b>.3</b>	<b>95,136</b>	<b>25</b>	<b>.3</b>	<b>88,789</b>	<b>40</b>	<b>.4</b>	<b>437,252</b>	<b>185</b>	<b>.4</b>

\* Per 1,000 population/\*\* Rates were calculated when the number of cases was <5/ ++American Indian/Alaska Native  
Source: *Morbidity and Mortality Weekly Report (MMWR)* May 24, 2002 / 51(20):433-5