

Approved: March 20, 2001
Date

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Garry Boston at 1:30 p.m. on March 20, 2001 in Room 210 Memorial Hall

All members were present except: Representative Geraldine Flaharty, Excused
Representative Nancy Kirk, Excused

Committee staff present: Dr. Bill Wolff, Kansas Legislative Research Department
Renae Jefferies, Revisor of Statute's Office
June Evans, Secretary

Conferees appearing before the committee: Senator James A. Barnett
Charles Wheelen, Kansas Association of Osteopathic
Medicine

Others attending: See Attached Sheet

The Chairperson opened the hearing on **SB 118 - Pilot Program for Fetal Alcohol Syndrome.**

Senator Barnett testified in support of **SB 118**, stating fetal alcohol syndrome is the leading cause of mental retardation in America today. There are about 40,000 live births per year in our state and conservatively there are about 80 live births with the full syndrome per year. About one in 100 live births are born brain-damaged, they don't have the facial damage but have brain damage. Probably, about 400 children are born in our state with brain damage from fetal alcohol syndrome. The key is this: it is all preventative. Each child with fetal alcohol syndrom costs about a million and a half over a lifetime, so 400 times a million and a half is \$600M. Alcohol is the number one drug used today. When a woman is pregnant and uses alcohol the alcohol damages cells and the cells most damaged are the brain. Alcohol goes directly to the fetus. A characteristic face is an important differentiating feature of fetal alcohol syndrom with a narrow forehead, short palpebral fissures, small nose, small midface and long upper lip with deficient philtrum. Children have learning problems, behavior problems and in trouble with the law. Fetal alcohol syndrome is permanent.

The bill creates a new statute under which the Secretary of Health and Environment, within the limits of appropriations, is authorized to establish not more than five fetal alcohol syndrome diagnostic and prevention network pilot programs. Senator Barnett stated if all five pilots could not be done due to money, would be happy with one program. The pilot programs would sunset July 1, 2004 (Attachment 1).

Linda Kenney, Director, Bureau for Children, Youth & Families, KDHE, testified in support of **SB 118**, stating it creates a Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN) in Kansas which is based on a successful model utilized in Washington State. KDHE supports interventions to eliminate substance use during pregnancy and assure, if necessary, early identification of childhood disability due to alcohol and other drugs; however, the Department is unable to recommend funding at this time (Attachment 2).

Charles L. Wheelen, Kansas Association of Osteopathic Medicine, testified as a proponent to **SB 118**, because disease prevention is one of the principal tenets of osteopathic medical practice. Fetal alcohol syndrome is a serious problem that needs to be addressed and the pilot programs envisioned in the bill would likely demonstrate effective methods of preventing FAS. It is a daily challenge to try and educate pregnant patients regarding the harmful effects of tobacco products and alcohol. Any programs the would help educate women more effectively during their childbearing years are welcomed. This is a comparative new diagnosis and the older physicians need to be educated on this. The amendments to **SB 118** by the Senate Public Health and Welfare Committee were adopted at our request. The amendments were asked for principally because we wanted to give all Kansas communities equal opportunity to compete for the state grants that may become available for these fetal alcohol syndrom pilot projects.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES, Room 210, Memorial Hall at 1:30 p.m. on March 20, 2001.

(Attachment 3).

Written testimony supporting **SB 118** received from Trudy Racine, Director, Office of Planning and Policy Coordination, SRS (Attachment 4); Chris Collins, Director of Government Affairs, Kansas Medical Society (Attachment 5); and Leigh Anne Henson, March of Dimes (Attachment 6).

The Chairperson closed the hearing on **SB 118** and stated this was the last day to hold hearings. Normally a bill is not worked the day it is heard but since this is the last day, asked if the committee had any objections to working the bill? The committee was in agreement that the bill should be worked.

Representative Morrison moved and Representative Lightner seconded to move SB 118 out of committee favorably. The motion carried.

The meeting adjourned at 2:30 p.m. and there are no more meetings scheduled at this time.

Fetal Alcohol Syndrome

Presented by: James A. Barnett, MD

- The combined rate of fetal alcohol syndrome (FAS) and alcohol-related neurodevelopmental disorder (ARND) is thus estimated to be at least 9:1/1,000. This conservative rate -- nearly one in every 100 live births -- confirms the perception of many health professionals that fetal alcohol exposure is a serious problem. (Sampson, 1997)

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Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder.

Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, Dehaene P, Hanson JW, Graham JM Jr

Department of Statistics, University of Washington, Seattle 98195, USA.

We critique published incidences for fetal alcohol syndrome (FAS) and present new estimates of the incidence of FAS and the prevalence of alcohol-related neurodevelopmental disorder (ARND). We first review criteria necessary for valid estimation of FAS incidence. Estimates for three population-based studies that best meet these criteria are reported with adjustment for underascertainment of highly exposed cases. As a result, in 1975 in Seattle, the incidence of FAS can be estimated as at least 2.8/1000 live births, and for 1979-81 in Cleveland, approximately 4.6/1,000. In Roubaix, France (for data covering periods from 1977-1990), the rate is between 1.3 and 4.8/1,000, depending on the severity of effects used as diagnostic criteria. Utilizing the longitudinal neurobehavioral database of the Seattle study, we propose an operationalization of the Institute of Medicine's recent definition of ARND and estimate its prevalence in Seattle for the period 1975-1981. The combined rate of FAS and ARND is thus estimated to be at least 9.1/1,000. This conservative rate--nearly one in every 100 live births--confirms the perception of many health professionals that fetal alcohol exposure is a serious problem.

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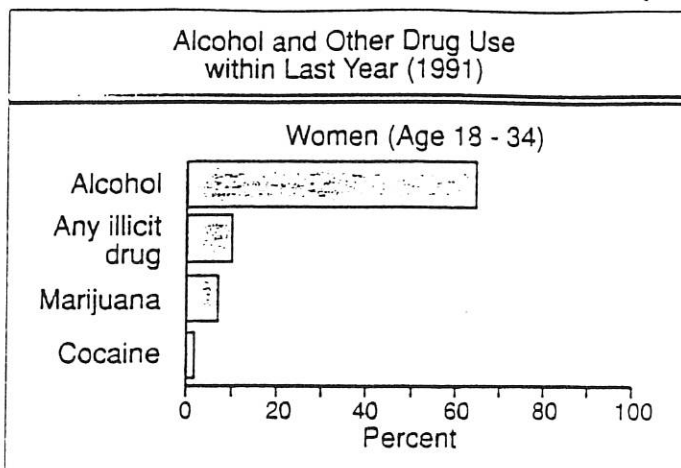
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4. Alcohol and Other Drug Use within Last Year

Drinking is culturally acceptable, and about two-thirds of Americans report drinking alcoholic beverages ⁽¹⁾. More than 86.2 billion dollars was spent on alcoholic beverages in 1990 ⁽²⁾. Using the profits from these sales, the alcoholic beverage industry has developed attractive and persuasive advertising to encourage use of its product.

However, the cost of excessive alcohol use is high: nearly 120 billion dollars in 1983, with about one in every ten adult Americans reporting alcohol abuse or alcoholism ⁽³⁾. In a household survey of women's drinking, young women ages 21 through 34 were more likely to report intoxication and episodic heavy consumption than women in older age groups; they were also more likely to develop signs of problem drinking over a five-year period ⁽³⁾. Nineteen percent of all women drinkers in this survey reported at least two alcohol-related problems ⁽⁴⁾. There is some evidence that the rate of drinking problems among younger women is increasing over time ⁽⁵⁾.

The number of childbearing-age women who use alcohol is notably greater than the number who use cocaine, marijuana, and other illicit drugs. This reflects the legal status of alcohol contrasted to the prohibition of illegal substances and the "War on Drugs" ⁽⁵⁾.

1. National Institute on Alcohol Abuse and Alcoholism. *Seventh Special Report to the U.S. Congress on Alcohol and Health*. From the Secretary of Health & Human Services. U.S. Department of Health and Human Services, January 1990.

2. Distilled Spirits Council of the U.S., January 1990, personal communication.

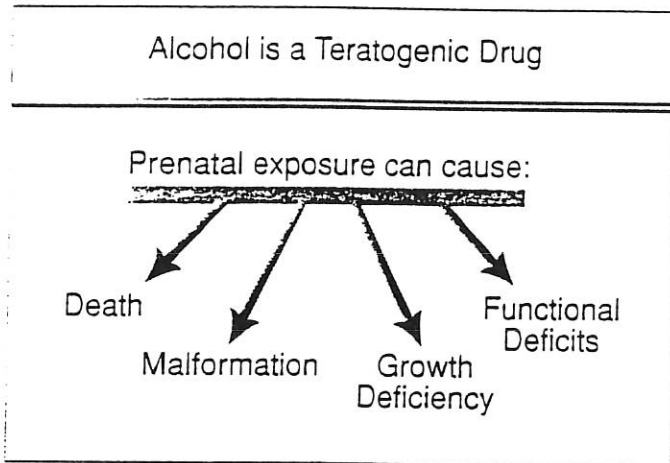
3. Wilsnack SC, Wilsnack RW. Epidemiology of women's drinking. *J Subst Abuse*. 1991; 3:133-157.

4. Wilsnack RW, Wilsnack SC, Klassen AD. Women's drinking and drinking problems: Patterns from a 1981 national survey. *Am J Public Health*. 1984; 74:1231-1238.

5. National Institute on Drug Abuse. *Household Survey on Drug Abuse: Population Estimates, 1991*. U.S. Department of Health and Human Services, Publication ADM 92-1887, 1992.

PART III: ALCOHOL AS A TERATOGEN: AN OVERVIEW

This section describes the scientific basis for understanding the impact of alcohol on the developing embryo and fetus. The concept of a continuum of alcohol effects, influenced by dose and timing of exposure as well as the genetic vulnerability of the mother and child, is introduced.



10. Alcohol is a Teratogenic Drug

Teratogenic drugs are those that cause undesirable modifications in the embryo or fetus when consumed during pregnancy. The main types of teratogenic outcomes are: death, malformations, growth deficiency, and functional deficits⁽¹⁾. Alcohol can cause all of these, and this has been demonstrated in both humans and animals⁽²⁻⁴⁾. Fetal effects of prenatal alcohol exposure reflect the dose and pattern of alcohol consumption by the mother, the time during pregnancy that the alcohol was consumed, the genetic susceptibility of the fetus itself, and certain physiologic characteristics of the mother herself such as the rate at which she metabolizes alcohol⁽⁵⁾. As is true of all teratogens, not all offspring who are exposed are affected, but this does not mean that fetal alcohol effects do not occur in others. The variability in severity of alcohol effects among exposed offspring can be high, even in response to the same dose and timing of exposure.

Alcohol is also a neurobehavioral teratogen, which is the name for that class of teratogenic drugs that cause prenatal damage to the Central Nervous System (CNS)⁽⁶⁾. See Section VI.

1. Wilson, JG. Current status of teratology: General principles and mechanisms derived from animal studies. In: JG Wilson, FC Fraser (Eds.) *Handbook of Teratology, General Principles & Etiology*. (Vol. 1, pp. 47-74). New York & London: Plenum Press, 1977.

2. Streissguth AP, Landesman-Dwyer S, Martin JC, Smith DW. Teratogenic effects of alcohol in humans and laboratory animals. *Science*. 1980; 209:353-361.

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4. Randall CL. Alcohol as a teratogen: A decade of research in review. *Alcohol & Alcoholism*. 1987; Supplement 1:125-132.

5. Chernoff GF. The fetal alcohol syndrome in mice: Maternal variables. *Teratology*. 1980; 22:71-75.

6. Riley EP, Vorhees CV. *Handbook of Behavioral Teratology*. New York: Plenum Press, 1986.

Comparison of the effects of drugs on prenatal development

Prenatal alcohol exposure seems to have a more devastating long-lasting effect on the child than other street drugs (that have been studied—ed.). It is often difficult to identify the harm caused by illicit drugs because they are frequently taken in combination with alcohol. (Alcohol the drug is often seen as benign, not as “bad as” other drugs since it is legal. This chart provides a clear visual that this is not true.—ed.)

EFFECT	ALCOHOL	MARIJUANA	COCAINE	HEROIN	TOBACCO
Low Birth Weight	X		X	X	X
Impaired Growth	X				
Facial Malformation	X				
Small Head Size	X				
Intellectual & Developmental Delays	X	X			
Hyperactivity, Inattention	X	X		X	X
Sleeping Problems	X	X	X	X	X
Poor Feeding	X		X		
Excessive Crying	X	X	X	X	
Higher Risk for Sudden Infant Death Syndrome				X	X
Organ Damage, Birth Defects	X				
Respiratory Problems	X			X	x

Alcohol destroys cells in the fetus, causing malformations. (These physical changes contribute to learning and behavioral differences that continue into adolescence and adulthood—ed.) Some effects of cocaine tend to diminish over time, and long-term damage may not be as severe as was originally predicted. Test scores of children exposed to heroin show their physical and psychological development are usually within normal range.

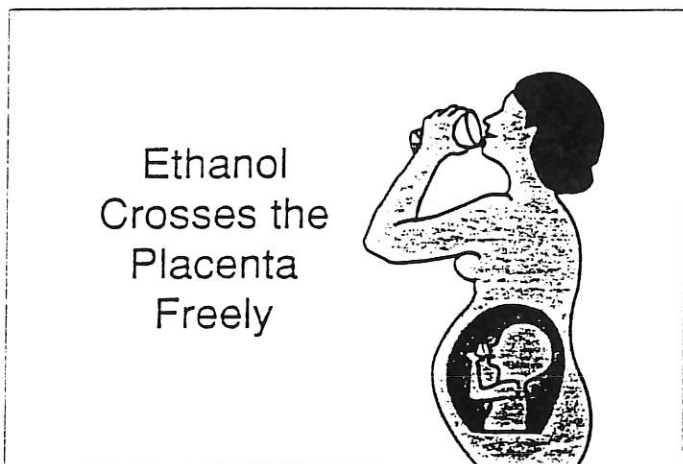
Sources: US Department of Health and Human Services, 1994; Day et al., 1994

Effects of alcohol and other drug use during pregnancy: Additional research

	Alcohol	Amphetamine/ Methamphetamine	Cocaine	Marijuana	Tobacco
Spontaneous Abortion	X		X		
Increased rate of SIDS			X	X	X
Increased rate of stillbirth	X	X	X		
Low birth weight	X	X		X	X
Behavioral problems	X	X			
Learning problems	X	X			

PART II: FETAL AND MATERNAL EXPOSURE

This section addresses special issues with respect to alcohol use during pregnancy and measuring alcohol dose to the fetus.



6. Ethanol Crosses the Placenta Freely

When a pregnant woman drinks, so does her fetus, for alcohol freely crosses the placenta and levels in the fetal and maternal blood are approximately equivalent⁽¹⁾. Shortly after the mother consumes an alcoholic beverage, fetal effects are apparent. In humans, fetal breathing movements were drastically suppressed by the amount of ethanol in one or two drinks^(2,3). In monkeys, a bolus dose of ethanol was followed by collapse of the umbilical vessels within minutes⁽⁴⁾. Other animal studies indicate that there is a direct deleterious action of alcohol on the developing fetus, even in early gestation⁽⁵⁾.

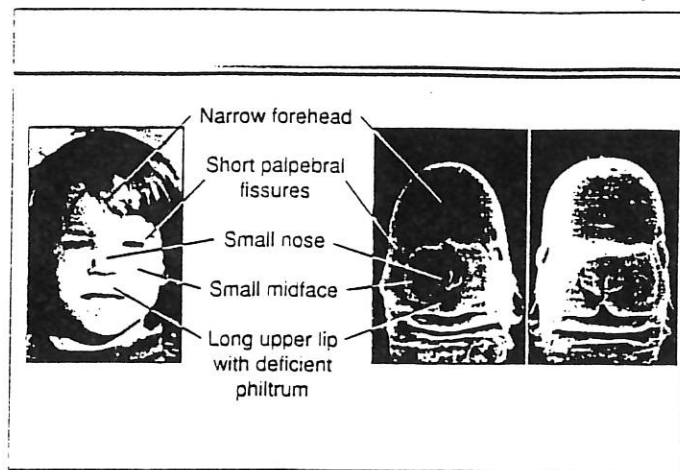
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2. McLeod W, Brien J, Loomis C, Carmichael L, Probert C, Patrick J. Effect of maternal ethanol ingestion on fetal breathing movements, gross body movements, and heart rate at 37 to 40 weeks gestational age. *Am J Obstet Gynecol.* 1983; 145:251-257.

3. Lewis PJ, Boylan P. Alcohol and fetal breathing. *Lancet.* 1979; 1:388.

4. Mukherjee AB, Hodgen GD. Maternal ethanol exposure induces transient impairment of umbilical circulation and fetal hypoxia in monkeys. *Science.* 1982; 218:700-702.

5. Brown NA, Goulding EH, Fabro S. Ethanol embryotoxicity: Direct effects on mammalian embryos in vitro. *Science.* 1979; 206:573-575.



13. Formation of FAS Face in the Mouse from 2 Doses of Alcohol

A characteristic face is an important differentiating feature of fetal alcohol syndrome. This mouse study of Sulik and colleagues demonstrates how brief prenatal alcohol exposure, at a critical moment in development, can produce major defects in the developing brain that are manifest in the face^{1,2}. (See slide 20 for a description of the characteristic FAS face and references 4 and 5 for more additional studies.) Two doses of ethanol were administered on day 7, the embryos developed craniofacial malformations closely resembling those seen in the human fetal alcohol syndrome. "Striking histological changes occurred in the developing brain within 24 hours of exposure,"³. Not all exposed fetuses were affected, and some were much more severely affected than others from the same dose and timing of ethanol. Two of the 72 fetuses were exencephalic or anencephalic while 30 of 72 had eye malformations, including coloboma of the iris, microphthalmia, and apparent anophthalmia. The primary growth deficiency of the eye was reflected in shortened palpebral fissures. Short palpebral fissures are a primary facial feature of FAS. This range of eye defects in children with FAS/FAE has also been described clinically^{6,7}. This study demonstrates that chronic or regular alcohol use was not necessary to produce changes in brain development. In humans, this exposure would be equivalent to heavy or binge drinking during the third week of pregnancy.

1. Sulik KK, Johnston MC, Webb MA. Fetal Alcohol Syndrome: Embryogenesis in a mouse model. *Science*. 1981; 214: 936-938.

2. Sulik KK, Johnston MC. Sequence of developmental alterations following acute ethanol exposure in mice: Craniofacial features of the Fetal Alcohol Syndrome. *Am J Anat*. 1983; 166:257-269.

3. Kotch LE, Dehart DB, Alles AJ, Chernoff N, Sulik KK. Pathogenesis of ethanol-induced limb reduction defects in mice. *Teratology* 1992; 46:323-332.

4. Kotch LE, Sulik KK. Patterns of ethanol-induced cell death in the developing nervous system of mice; neural fold stages through the time of anterior neural tube enclosure. *Int J Devl Neuroscience* 1992; 10:273-279.

5. Kotch LE, Sulik KK. Experimental fetal alcohol syndrome: Proposed pathogenic basis for a variety of associated facial and brain anomalies. *Am J Med Genetics* 1992; 44:168-175.

6. Stromland K. Malformations of the eyes in fetal alcohol syndrome. *Acta Ophthalmol*. 1981; 59: 445-446.

7. Rabinowicz M. New ophthalmic findings in fetal alcohol syndrome. *JAMA*. 1981; 245(2): 108.



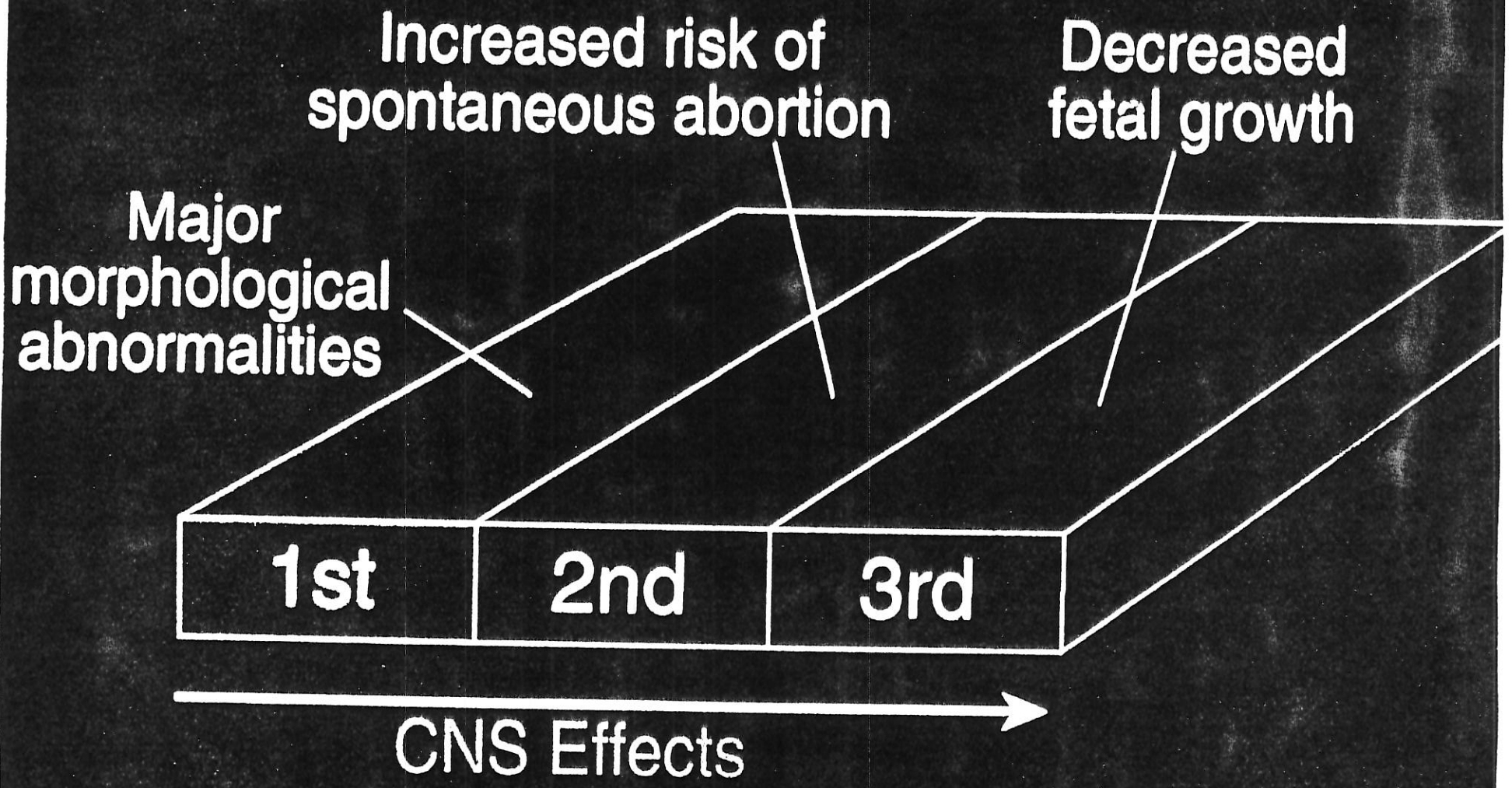
11. Animal Models of FAS: Ethanol Exposed Pup Compared to Normal

When fetal alcohol syndrome was first identified, many scientists believed that it was caused not by maternal alcohol use, but by poor diet, other drugs of abuse, or by some other unidentified factor. Animal studies have since shown that even in the absence of these other factors, alcohol exposure is correlated with decreased growth, and increased morphologic abnormalities, central nervous system involvement, and embryo/fetal death. Poor diet and other health hazards may alter the risk of fetal alcohol effects, but they are not the primary cause.

For example, consider the pups shown on this slide. Ethanol (2.1 g/kg) was given orally twice daily, throughout pregnancy, to the mother of the smaller animal; this is roughly equivalent to 10.5 oz 100-proof vodka twice daily for a 60 kg human. (Mean peak blood ethanol concentrations of 205 mg/dl were obtained in the groups of animals given this dose.) Mothers of the control pups received isocaloric amounts of sucrose in place of the ethanol. Amounts of food and water ingested were the same for both experimental and control animals. At this dose of ethanol, rates of stillbirth and early mortality were sharply increased and the number of offspring per litter decreased. The weight, crown to rump length, and head circumference of surviving ethanol-exposed pups were significantly lower than controls, as is clearly evident from the slide. Fetal alcohol effects have been demonstrated in many other types of experimental animals, including mice, rats, hamsters, monkeys and chickens (see slide 12).

1. Ellis FW, Pick JR. An animal model of the fetal alcohol syndrome in beagies. *Alcohol Clin Exp Res.* 1980; 4:123-134.

Major Effects of Ethanol by Trimester of Pregnancy



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FACT SHEET

Fetal Alcohol Syndrome

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The consumption of alcohol during pregnancy is one of the leading preventable causes of birth defects and childhood disabilities in the United States.¹ The adverse effects associated with fetal alcohol syndrome (FAS) range from growth deficiency, brain structure and function anomalies, and abnormalities of the head and face.² It is estimated that in 1992 the cost of treating FAS-affected infants, children, and adults was over \$1.9 billion.³ The lifetime cost per child affected with FAS is estimated to be \$1.4 million.⁴

FAS and Public Awareness

- In 1981 the Surgeon General first advised that women should not drink alcoholic beverages during pregnancy because of the risk of birth defects.
- Public law 100-690 was implemented in 1989, requiring warning labels on all alcoholic beverages sold in the United States.
- Since 1990 the Dietary Guidelines for Americans have stated that women who are pregnant or planning to become pregnant should not drink alcohol.
- As of 1998, 19 states require the posting of alcohol health warning signs where alcoholic beverages are sold.

FAS Statistics

- In 1995, four times as many pregnant women frequently consumed alcohol as in 1991.⁵ Researchers speculate that the increase in alcohol consumption by pregnant women may be attributed to widespread reports on the health benefits of moderate drinking.⁶
- 51% of women of child-bearing age between 18-25 and 53% between 26-34, report the use of alcohol within the past month.⁷
- 17% of women of child-bearing age between 18-25 and 13% between 26-34, report binge drinking (five or more drinks on one occasion) within the past month.⁸
- A national survey found that more than half of women age 15-44 drank while pregnant.⁹
- Of the women who reported drinking during their pregnancy, 66% reported drinking in their first trimester; 54% reported drinking in their third trimester.¹⁰
- FAS is estimated to occur in 1 to 2 live births per every 1,000 in the United States each year.¹¹
- Fetal Alcohol Effects (a less severe set of alcohol-related abnormalities) is estimated to occur in 3-5 live

irths per every 1,000 in the United States each year.^{2, 11}

- According to the birth defects monitoring program, FAS rates among American Indians are 3.0 per 1000 live births compared to a rate of 0.6 per 1000 live births among Blacks and 0.1 per 1000 live births among Whites.¹²
- FAS is not just a childhood disorder,¹³ exposure to alcohol as a fetus can cause a wide range of lifelong physical and mental disabilities.¹⁴
- Fetal alcohol exposure may increase the risk for later alcohol, tobacco, and drug dependence in adults.¹⁵

Possible Solutions: Treatment, Education, & Higher Taxes

- Studies have shown that FAS is completely preventable and that the consumption of alcohol can result in lifelong physical and mental impairments on the fetus. Research suggests that all pregnant women should be screened for alcohol use during prenatal visits. Women who test positive, or prove to be at-risk, should be identified early by physicians and referred for counseling and treatment.¹⁶
- A recent survey illustrated the need for physician education on "how much" alcohol consumption is "too much" during pregnancy. 41% of physicians placed the threshold for FAS at one to three drinks per day while 38% placed the threshold at one or fewer drinks per day.¹⁷ Both opinions directly contradict the Surgeon General's advice that women not consume any alcoholic beverages during pregnancy because of the risk of birth defects.
- Research by Abel suggests that the most effective public health strategy for reducing FAS is a combination of public health messages that target alcohol abuse, coupled with higher taxes on alcoholic beverages. Abel states that recent studies have shown that heavy drinking and binge drinking are sensitive to price changes, and that price elasticities are relatively high for heavy drinkers who are aware of the consequences of their drinking.¹⁸
- Studies have shown that alcohol beverage warning labels have increased awareness of the risks involved with alcohol consumption during pregnancy.¹⁹ However, over time the alcohol warning labels have become commonplace, with the message often being overlooked. Changing the appearance (i.e., size, color, etc.) and rotating different warning labels on alcoholic beverage containers may help prolong awareness while eventually decreasing the number of women who expose their fetuses to alcohol.

References

1. Centers for Disease Control and Prevention. (1995). Update: Trends in fetal alcohol syndrome—United States, 1979-1993. *MMWR*, 44:249-251.
2. Abel, E., and Sokol, R. (1987). Incidence of alcohol syndrome and economic impact of FAS-related anomalies. *Drug and Alcohol Dependence* 19:51-70.
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15. Yates, W. R., Cadoret, R. J., Troughton, E. P., Stewart, M., & Giunta, T. S. (1998). Effect of fetal alcohol exposure on adult symptoms of nicotine, alcohol, and drug dependence. *Alcoholism: Clinical and Experimental Research*, 22(4):914-920.
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18. Abel, E. L. (1998). Prevention of alcohol abuse-related birth effects—II. Targeting and pricing. *Alcohol*, 33(4):417-420.
19. Greenfield, T., & Kastutas, L. A. (1993). Early impacts of alcoholic beverage warning labels: National study findings relevant to drinking and driving behavior. *Safety Science*, 16:689-707.

For more information on Fetal Alcohol Syndrome contact:

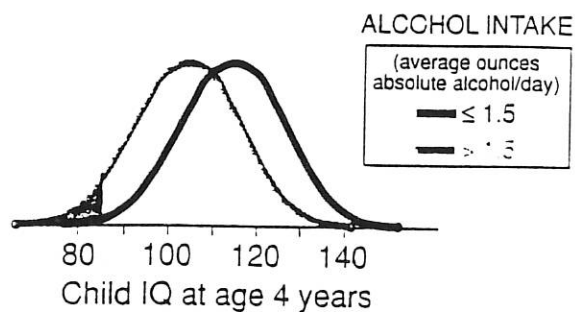
The National Organization on Fetal Alcohol Syndrome (NOFAS)
<http://www.nofas.org>

The ARC of the United States (A National Organization on Mental Retardation)
<http://www.thearc.org>

The Fetal Alcohol and Drug Unit (University of Washington)
<http://depts.washington.edu/fadu>

[\[Booze News\] \[CSPI Home Page\]](http://www.cspsinet.org/booze/fas.htm)

Effects of Social Drinking on the IQ of a Population



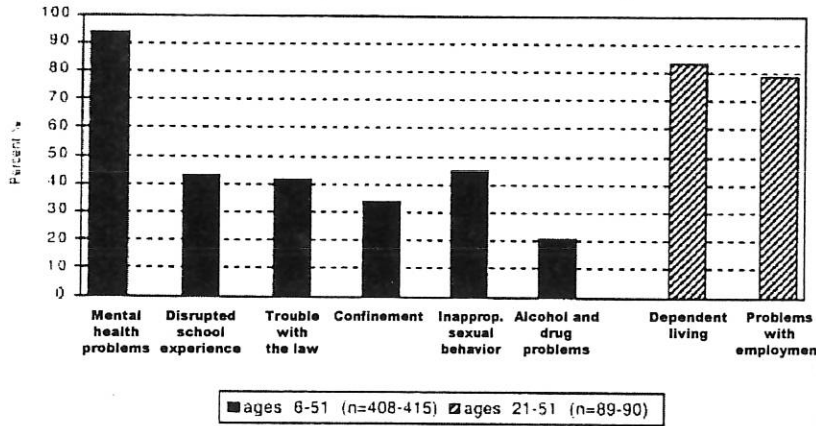
61. Effects of Social Drinking on the IQ of a Population

Seemingly subtle individual effects of prenatal alcohol exposure can have a significant collective impact on society. One longitudinal prospective study of a large group of pregnant women from a well-educated, middle-class community was begun before it was general knowledge that women should not drink during pregnancy. Women whose self-reported alcohol-use scores averaged over 1.5 ounces of absolute alcohol per day (3 drinks per day, on average, of beer, wine and/or liquor) had children whose IQ scores averaged 5 points lower than the children of the rest of the mothers, even after statistically adjusting for maternal and paternal education, race, prenatal nutrition, aspirin and antibiotics exposure, child's sex and birth order, mother-child interactions and preschool attendance. The accompanying slide shows normal distributions picturing the effect of a 5-point mean IQ decrement on the overall average profile of the community. This level of prenatal alcohol exposure would be expected to significantly increase the proportion of children with low IQ scores (below 85) and to significantly decrease the proportion with IQ scores in the superior range.

1. Streissguth AP, Barr HM, Sampson PD, Darby BL, Martin DC. IQ at age four in relation to maternal alcohol use and smoking during pregnancy. *Dev Psychol.* 1989; 25: 3-11.

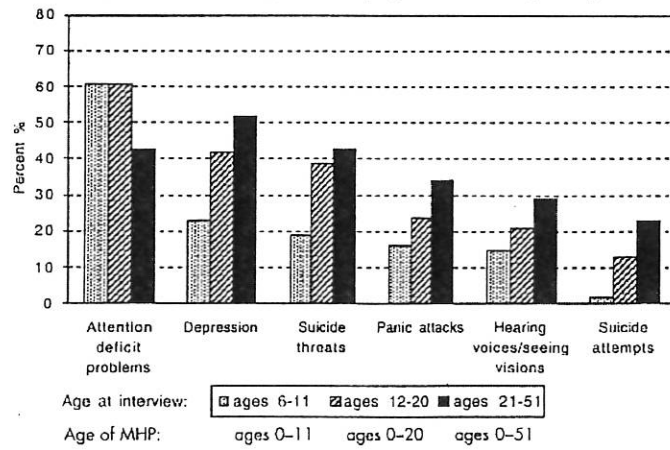
Secondary Disabilities

7.1 Prevalence of Secondary Disabilities across the Life Span



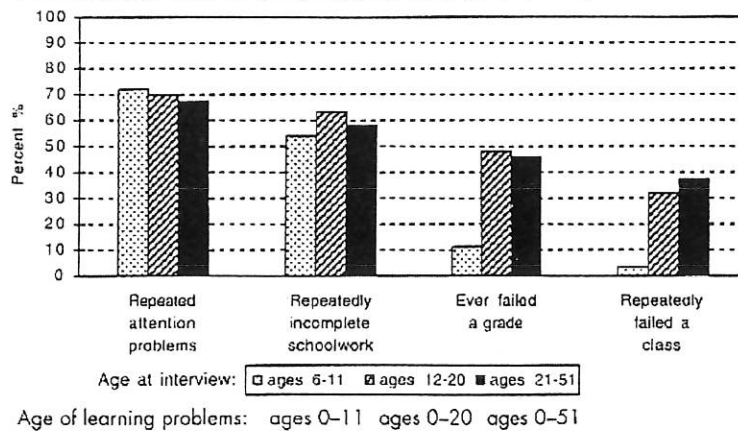
Mental Health Problems

8.4 History of mental health problems by age at interview (n=415)



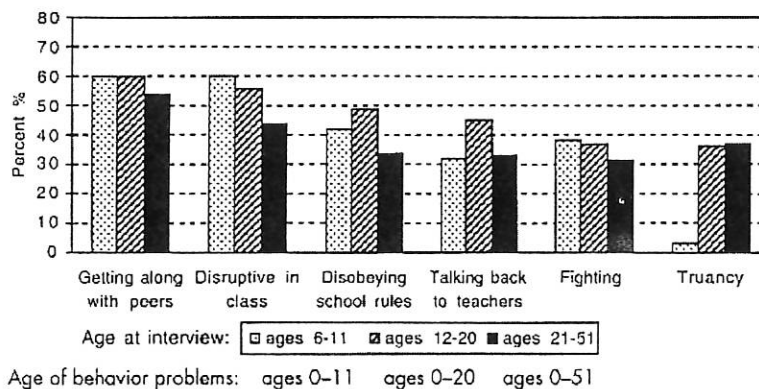
Learning Problems by Age

9.4 Learning problems by age at interview (n=395-407)



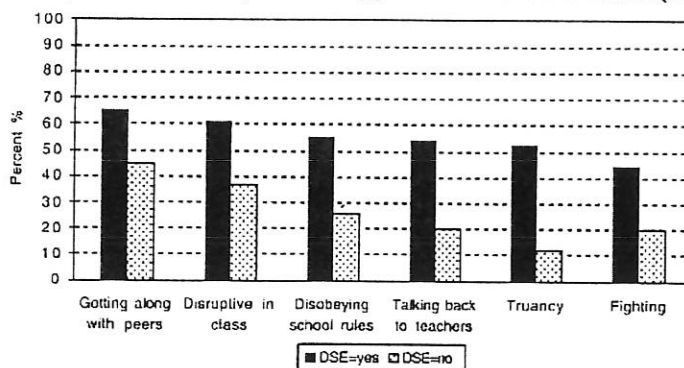
Behavior Problems by Age

9.5 Repeated behavior problems by age at interview (n=403-408)



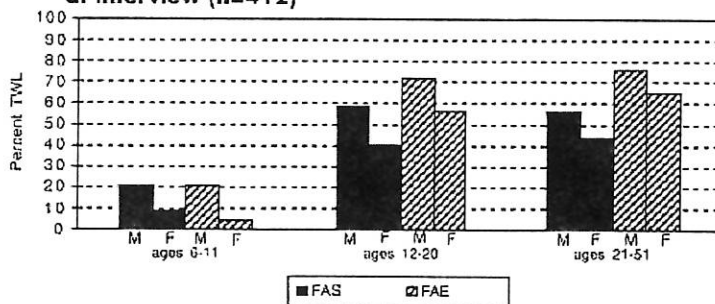
Repeated Behavior Problems

9.8 Repeated behavior problems by presence or absence of DSE (n= 240-245)



Trouble with the Law

10.1 History of Trouble With the Law (TWL) by sex, diagnosis and age at interview (n=412)

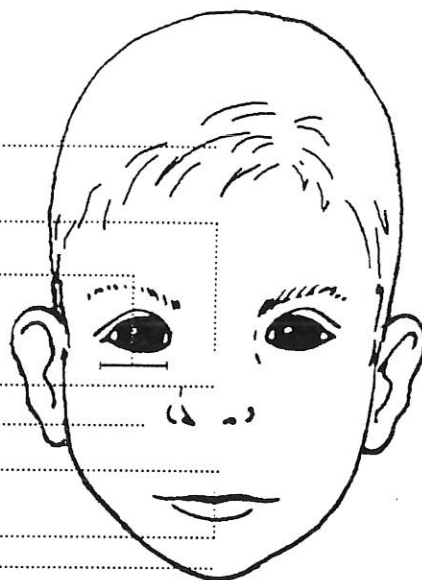


FETAL ALCOHOL SYNDROME IS PERMANENT

Children with fetal alcohol syndrome have three characteristics: abnormal facial features, stunted growth and brain injury. Fetal alcohol effects has been used to describe individuals who have a history of prenatal alcohol exposure but not all the physical or behavioral symptoms of fetal alcohol syndrome. Although not all fetal alcohol syndrome symptoms occur in children with fetal alcohol effects, both disabilities are devastating.

The irreversible damage caused by prenatal alcohol use is, in my opinion, the most significant factor in the cycle of poverty in the inner city.

DR. LYDIA CAROS
PEDIATRICIAN,
MINNEAPOLIS



Source: Streissguth et al., 1988

EFFECT OF ALCOHOL ON THE BRAIN

SUFFER THE
CHILDREN:
THE
PREVENTABLE
TRAGEDY OF
FETAL ALCOHOL
SYNDROME

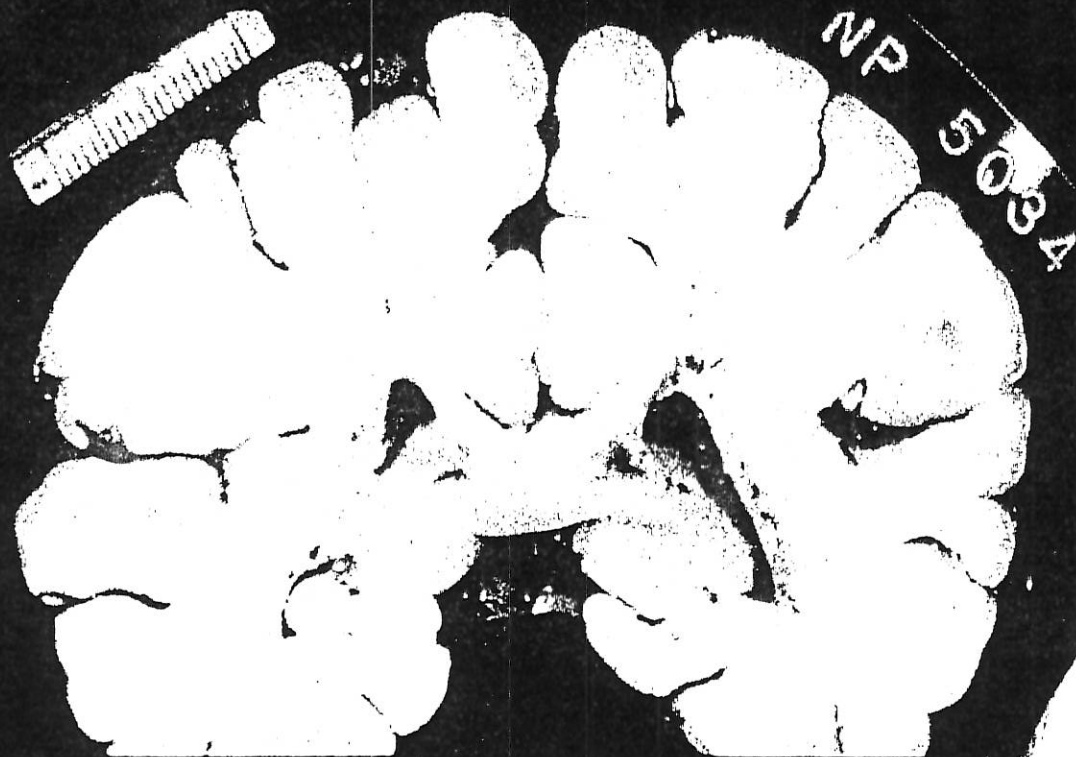
**NEWBORN BABY'S BRAIN
DAMAGED BY ALCOHOL** →
> DECREASED SIZE
> NOT FULLY DIVIDED INTO LEFT
AND RIGHT HEMISPHERES
> SMOOTH SURFACE AND FEWER
FOLDS INDICATE LACK OF
DEVELOPMENT

**NEWBORN BABY'S
NORMAL BRAIN** →



Source: Dr. Sterling Clarren, University of Washington

Coronal Sections of Brain



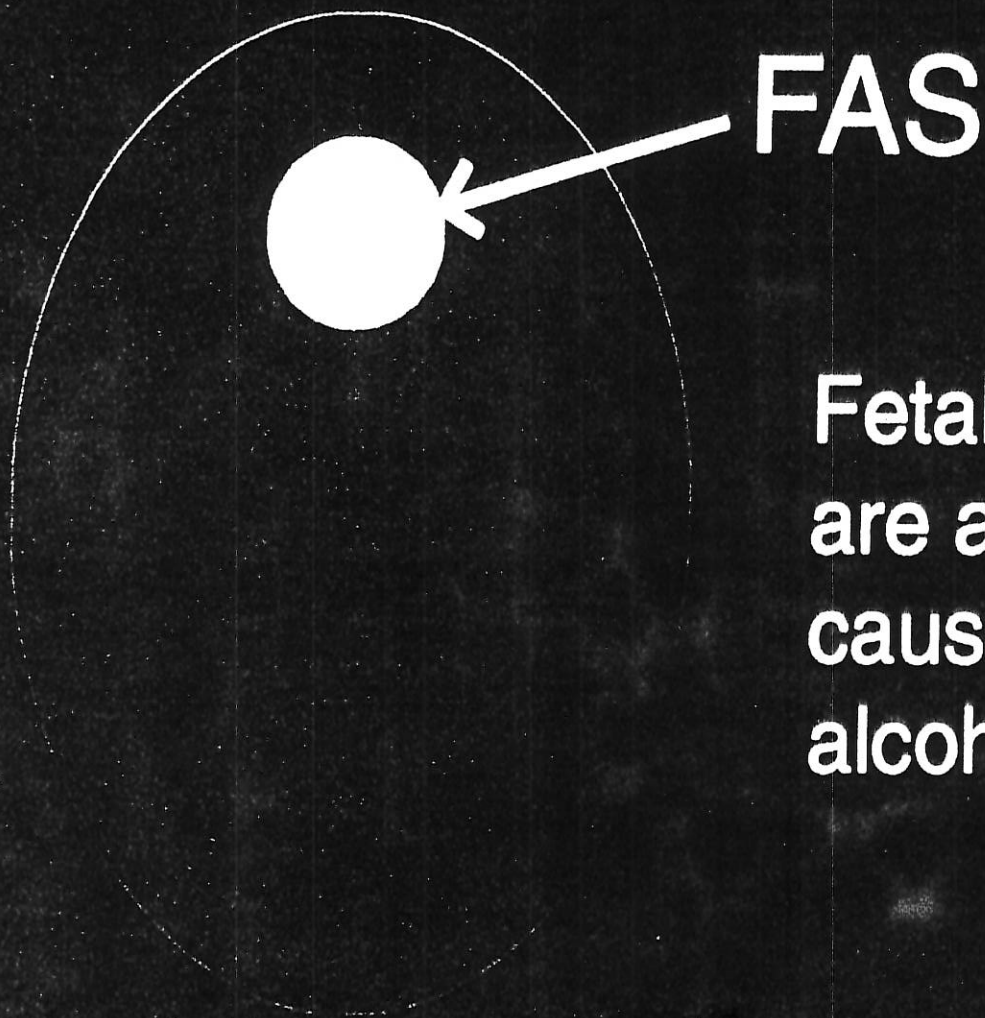
Normal

FAS



FAS is Part of FAE

(A very small part)



Fetal Alcohol Effects
are all of the effects
caused by prenatal
alcohol exposure

Comparison of House, Senate Budgets

(For fiscal year 2001, figures in millions)

AGENCY/PROGRAM	HOUSE	SENATE	DIF
Dept. of Education	\$2,552.4	\$2,559.7	\$7.3
SRS, State Hospital	\$1,683.4	\$1,695.9	\$12.5
State Universities	\$1,475.6	\$1,475.8	\$0.2
Dept. of Transportation	\$923.3	\$923.3	\$0.0
Dept. on Aging	\$357.4	\$359.3	\$1.9
Prison System	\$223.5	\$226.7	\$3.2
Dept. of Human Resources	\$218.8	\$218.8	\$0.0
Dept. of Health, Environment	\$169.7	\$173.8	\$4.1
Kansas Lottery	\$140.0	\$140.0	\$0.0
State Treasurer	\$111.9	\$111.9	\$0.0
Dept. of Commerce, Housing	\$86.6	\$85.7	(\$0.9)
Juvenile Justice	\$76.8	\$83.8	\$7.0
Dept. of Revenue	\$77.0	\$78.4	\$1.4
Court System	\$83.7	\$83.4	(\$0.3)
Other Agencies	\$470.0	\$473.2	\$3.2
ALL AGENCIES	\$8,650.1	\$8,689.7	\$39.6

- Living in a stable and nurturant home for over 72% of life
- Being diagnosed before the age of 6 years
- Never having experienced violence against oneself
- Staying in each living situation for an average of more than 2.8 years
- Experiencing a good quality home from age 8-12 years
- Having applied for and been found eligible for division of developmental disabilities services
- Having a diagnosis of FAS rather than FAE/ARND

**Twelve points regarding Fetal Alcohol Syndrome/
Alcohol-Related Neurodevelopmental Disorder (FAS/ARND)**

1. People with FAS have an invisible, underdiagnosed, and under served disability. Recognition of FAS is synonymous with recognition of brain damage
2. FAS/ARND is a 'hidden' population, not recognized in the DSM IV, and is often a subset within other diagnoses (e.g. ADD/ADHD, LD, ED, PDD, ODD)
3. FAS/ARND includes a wide continuum of physical and behavioral effects
4. The most at-risk people are those with ARND. They may have none of the observable physical characteristics associated with FAS
5. FAS/ARND is an invisible **physical** handicapping condition whose only manifestation may be in presenting behaviors
6. Neurodevelopmental characteristics of people with this physical disability are incompatible with learning theory-based assumptions about brain function
7. Interventions based on principles of learning theory are incompatible with neurodevelopmental characteristics, or differences in brain function
8. Inappropriate and ineffective traditional interventions implemented over time have been associated with chronic frustration and the development of debilitating secondary characteristics
9. An alternative explanatory theory linking neurodevelopmental characteristics with presenting behaviors expands understanding and provides a shift in perceptions, reframing interpretations of presenting behaviors: From "won't" to "can't"
10. This shift dictates providing environmental adaptations for those with FAS/ARND to assure adequate supports are available, prevent deterioration, and maximize realization of developmental potential. The principle of providing environmental adaptations is the same as for *other* physical handicapping conditions
11. Children, parents and professionals, all strata of communities and cultures benefit from this shared knowledge and a development of a common language to facilitate implementation of appropriate continua of care, over time
12. Adequate adaptations are required at home and in the community to provide appropriate levels of support over time. This suggests the need for information and support for parents and professionals to develop and implement coordinated, appropriate and effective services. Change is indicated at the level of individuals, families, institutions, policy and law.

INTERNAL MEDICINE

James M. Geitz, M.D.
James A. Barnett, M.D., FA.C.P.
W. Brock Kretsinger, D.O.
W. Timothy Duncan, M.D.
Rachel A. Duncan, M.D.

**Emporia Area Fetal Alcohol Syndrome
Diagnostic and Prevention Network**

CARDIOLOGY

M. Usman Sheriff, M.D.

1. Team: Physician - (family physician, pediatrician).
Speech therapist.
Occupational therapist.
Public health nurse.
Social worker.
Family advocate.
Psychologist.

EMERITUS

Phillip W. Morgan, M.D.
(1928-1966)
Edward J. Ryan, M.D.
(1947-1979)
John L. Morgan, M.D.
(1949-1984)
Gould C. Garcia, M.D.
(1964-1999)

2. State support \$10,000.00-15,000.00 per site.
3. Community support.
4. Training venues:
 - a) 3 days in Seattle at \$700.00 per person plus travel.
 - b) Telephone contact with Seattle to discuss clients (15-20 minutes) during the first 6-12 months.
 - c) Share dossiers.
 - d) On-call assistance for the Seattle team to be accessible - \$3,000.00 per year.

SERVICES

Bone Densitometry
Ultrasonography
Mammography
In-Office Laboratory
Nuclear Cardiology
Echocardiography
Cardiac Catheterization
Diagnostic
Interventional
Holter Monitor
Exercise Testing
Pacemaker Clinic

Fetal Alcohol Syndrome Diagnostic and Prevention Network



Susan J. Astley, Ph.D. and Sterling K. Clarren, M.D., Directors
University of Washington (206) 526-2206 <http://depts.washington.edu/fasdpn>

What is FAS?

Fetal alcohol syndrome (FAS) is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. FAS is characterized by growth deficiency, permanent brain damage and a unique cluster of minor facial anomalies. Not all children exposed to alcohol during gestation are born with FAS. Many are born with the same level of brain damage but do not have the facial anomalies that permit a discrete diagnosis of FAS. These children need the same social, educational and healthcare services as children with FAS and far outnumber children with FAS.

How does FAS fiscally impact Washington State?

It costs Washington State only \$200,000 per year to support the Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN). It costs Washington State an estimated \$1,500,000 in lifetime social and health care services for every child born with FAS. Preventing just one FAS birth will pay for over seven years of the FAS DPN operating costs. The FAS DPN has the opportunity to prevent 10-20 FAS births per year. It costs Washington State 30 times more to raise a child with FAS than to prevent FAS in a child.

FAS facts.

- FAS is 100% preventable.
- FAS is the leading known cause of mental retardation.
- An estimated 200 children are born with FAS in Washington State each year. An additional 400 to 1,000 children are born each year with permanent brain damage associated with prenatal alcohol exposure.
- FAS is not just a health care issue. Its primary impact is on schools, foster and adoption services, the justice system, and mental health services.
- Less than 10% of adults with FAS live independently or remain employed.

What is the Washington State FAS Diagnostic and Prevention Network?

- The Washington State FAS DPN was established in 1995 and is the first program of its kind in the nation.
- It consists of six clinical sites (Spokane, Yakima, Whitman, King, Snohomish, and Pierce counties) and one core-training site (University of Washington) linked by a statewide database. See our website [<http://depts.washington.edu/fasdpn>].
- The WA State FAS DPN is currently recognized as a national model for FAS Diagnosis and Prevention demonstrating an invaluable partnership between academic research and public health through interagency collaboration. Several states and provinces have requested and received training by the FAS DPN to establish similar networks in their communities.

What does the FAS DPN do for children, families and health care professionals in Washington State?

- **Diagnostic Program**
 - We provide accurate diagnoses and comprehensive care plans for individuals with prenatal alcohol exposure statewide. To date we have evaluated over 1,500 patients statewide. 87% of families report they received help from us they could not receive elsewhere. 99% would recommend our diagnostic services to other families in similar need.
 - We have developed a comprehensive Diagnostic Guide for FAS that is being distributed and used worldwide.
- **Training Program**
 - We provide FAS training to community health care, educational, correctional and social service providers statewide. We have trained over 1,000 professionals to date.
 - We developed a FAS medical training CD-ROM that is distributed nationally by the March of Dimes.
- **Primary Prevention Program**
 - We identify women at highest risk to give birth to children damaged by prenatal alcohol, namely the birth mothers of children diagnosed with brain damage and prenatal alcohol exposure at our FAS DPN clinics. We provide the women with referrals to appropriate community-based programs including the Parent-Child Assistance Program to help them reduce their use of alcohol and practice effective family planning.
 - Through our research we have identified factors that significantly enhance and hinder a woman's ability to stop drinking and practice effective birth control. We conducted interviews with 80 women who gave birth to children with FAS in WA State. A key finding: women who receive mental health treatment are significantly more likely to succeed in stopping drinking.
- **Screening Program**
 - We developed a highly accurate, computerized, FAS photographic screening tool that is now used world-wide.
 - We provide medical screening for FAS in high-risk populations (foster care and juvenile rehabilitation) to identify children at risk. Early accurate diagnosis reduces secondary disabilities. To date, our screening program has demonstrated that the prevalence of FAS in foster care is 10 times higher than in the general population.



KANSAS
DEPARTMENT OF HEALTH & ENVIRONMENT
BILL GRAVES, GOVERNOR
Clyde D. Graeber, Secretary

KDHE Testimony

Testimony on SB 118
to
House Health and Human Services Committee
Presented by Linda Kenney, Director
Bureau for Children, Youth & Families

March 20, 2001

Chairperson Boston and members of the House Health and Human Services Committee, I am honored to appear before you today to discuss Senate Bill 118.

This bill establishes not more than five pilot projects to address fetal alcohol syndrome at the community level. It creates a Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN) in Kansas which is based on a successful model utilized in Washington State. The Kansas Department of Health and Environment supports interventions to eliminate substance use during pregnancy and to assure if necessary early identification of childhood disability due to alcohol and other drugs. This is a very worthwhile bill. However, there are a number of competing priorities facing the Department this session so that we are unable to recommend funding at this time.

Thank you for the opportunity to appear before your Committee. I will stand for questions.



Testimony
House Health and Human Services Committee
Regarding
Senate Bill 118
By Charles L. Wheelen
March 20, 2001

The Kansas Association of Osteopathic Medicine supports the provisions of SB118 because disease prevention is one of the principal tenets of osteopathic medical practice. Fetal alcohol syndrome is a serious problem that needs to be addressed and the pilot programs envisioned in SB118 would likely demonstrate effective methods of preventing FAS.

Most of our members are primary care physicians who specialize in family medicine and some of our members specialize in obstetrics and gynecology. It is a daily challenge to try and educate pregnant patients regarding the harmful effects of tobacco products and alcohol. We welcome any programs that would help us educate women more effectively during their childbearing years.

The amendments to SB118 by the Senate Public Health and Welfare Committee were adopted at our request. We asked for the amendments principally because we wanted to give all Kansas communities equal opportunity to compete for the state grants that may become available for these fetal alcohol syndrome pilot projects.

We also requested that the requirement for local matching funds be deleted because we are aware of testimony to the Health Care Reform Legislative Oversight Committee by numerous local health departments. The Committee's report to the 2000 Kansas Legislature regarding local health departments stated that, "Most reported they are stretched to the maximum and, in some instances, have had to implement reductions in staff, in staff training, and even in services delivered. All conferees identified unmet needs in the areas served."

In addition, we were concerned that the original language now contained in lines 42-43 on page one and line one on page 2 might be interpreted to mean that local funding would have to be credited to a state fund and then be appropriated by the Legislature; a procedure that could unnecessarily delay implementation of the projects. Despite our concerns about the availability of local resources, the language was restored by the Senate Ways and Means Committee.

Thank you for considering our comments. We respectfully request your favorable action on SB118.

H & HS
3-20-01
Atch # 3

Kansas Department of Social and Rehabilitation Services
Janet Schalansky, Secretary



Docking State Office Building
915 SW Harrison, 6th Floor North
Topeka, Kansas 66612-1570

for additional information, contact:

Operations
Diane Duffy, Deputy Secretary

Office of Budget
J.G. Scott, Director

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Trudy Racine, Director

phone: 785.296.3271 *fax:* 785.296.4685

House Health and Human Services Committee
Tuesday, March 20, 2001, 1:30 PM

**SB 118: An act relating to fetal alcohol syndrome; establishing a
diagnostic and prevention network pilot program**

Janet Schalansky, Secretary of Kansas Department of Social and
Rehabilitation Services
785-296-3271

HaHS
3-20-01
Atch#4

**Kansas Department of Social and Rehabilitation Services
Janet Schalansky, Secretary**

House Health and Human Services Committee
Tuesday, March 20, 2001, 1:30 PM

**SB 118: An act relating to fetal alcohol syndrome;
establishing a diagnostic and prevention network pilot program**

Thank you, Mr. Chairman and Committee members, for this opportunity to provide written testimony regarding SB 118. Although this bill does not impact SRS directly, we would like to speak to the importance of the issue it addresses.

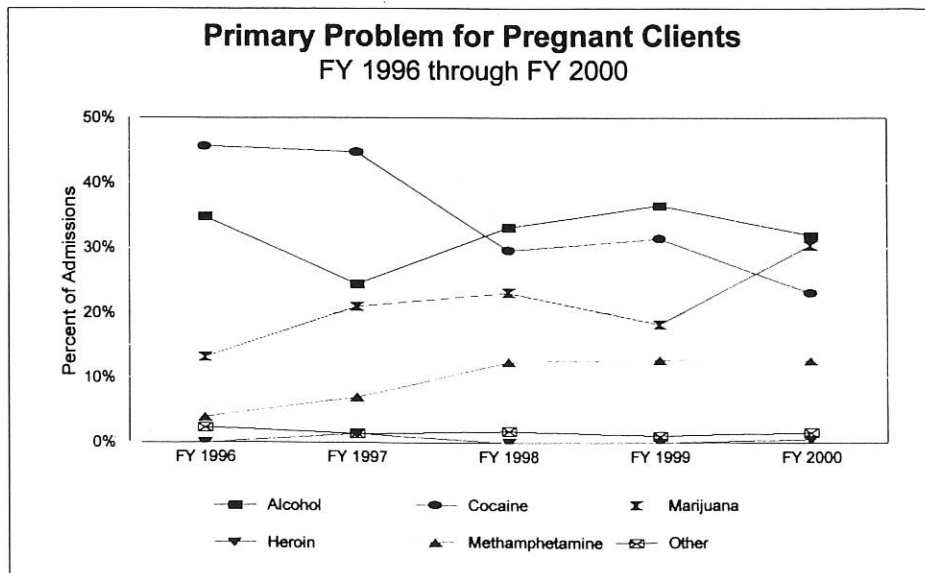
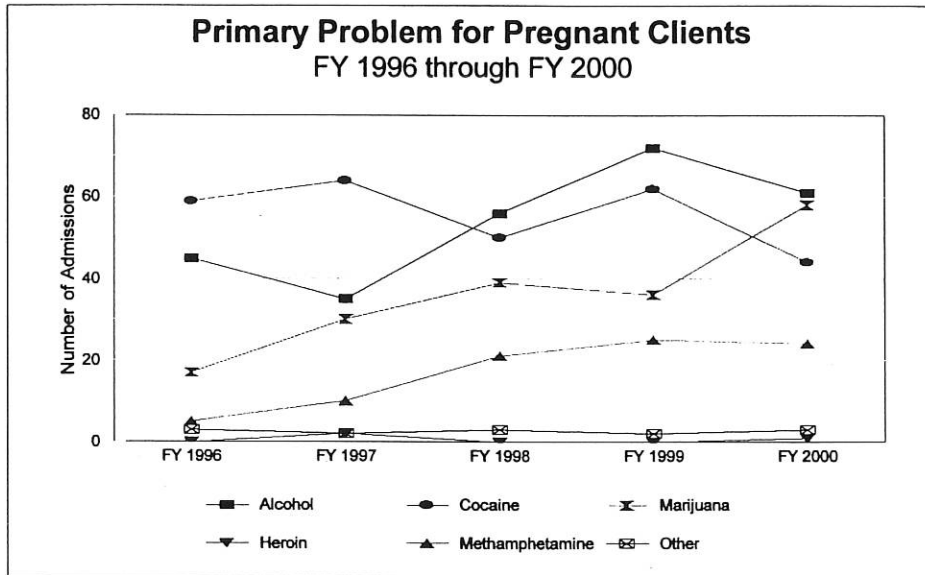
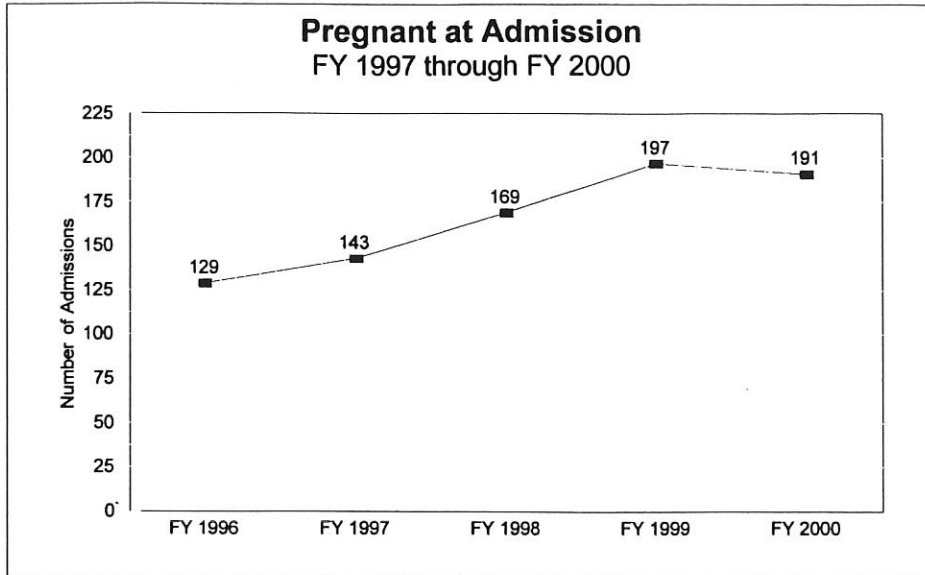
Fetal Alcohol Syndrome and Alcohol-Related Neurodevelopmental Disorders (FAS/ARND) is a new term for most people. It was not until 1973 that the diagnostic term FAS was developed. Since 1973 thousands of articles have been written about FAS/ARND. Most describe the physical effects of alcohol and other drugs on pregnancy outcomes. Until recently little information on the practical implications of FAS/ARND has been available for parents, professionals and people with FAS/ARND.

Fetal Alcohol Syndrome is one of many adverse conditions that can result from substance abuse. SRS is constantly reminded of the pervasiveness of substance abuse and its effects on individuals and their families. We deal with those effects in both childrens' and adult programs. As Secretary Schalansky sometimes says, SRS (and other social service agencies) all too often represent the ambulance at the bottom of the hill, rather than the fence at the top of the hill that would prevent people from falling. Accordingly, we are continuing to increase our emphasis on prevention efforts, and particularly on those community-based prevention efforts that have been shown to decrease substance abuse and other negative behaviors while increasing positive outcomes for children and their families.

SRS also provides substance abuse treatment services to low income Kansans, including services that are specifically targeted to women. The attached information shows that 191 pregnant women were admitted to substance abuse treatment in state-funded programs during FY 2000. This represents about 5 percent of the 4,100 women of all ages who received those services. Approximately one-third of the 191 pregnant women admitted to treatment, or 60 individuals, indicated that alcohol was their primary drug of choice, a percentage that was followed closely by marijuana. This represents a shift from the past two years' data, which showed that cocaine was the second most prevalent drug of choice. Methamphetamine use by this population grew during the mid-90s but has remained stable at around 12 percent for the past two years. Use of heroin and other substances was very infrequent among this population, a trend that tends to be true overall for Kansans.

Although the number is relatively small, each of those 60 pregnant women who are abusing alcohol is at risk, as are their children. Far greater numbers of women who are abusing alcohol, but who either do not access state-funded treatment or do not receive treatment at all, may also be affected by FAS. This bill focuses on prevention by establishing a diagnostic and prevention network pilot program which would apply the best research and knowledge to the problem of FAS/ARND in Kansas.

Pregnant Client Trends FY 1997 through FY 2000



4-4



KANSAS MEDICAL SOCIETY

TO: House Committee on Health and Human Services

FROM: Chris Collins *Chris Collins*
Director of Government Affairs

DATE: March 20, 2001

RE: SB 118: Fetal Alcohol Syndrome Pilot Program

Mr. Chairman and Ladies and Gentlemen of the Committee:

Thank you for the opportunity to present written testimony to you today in support of SB 118. The Kansas Medical Society respectfully urges the committee to pass this bill.

SB 118 presents a reasoned and practical approach to reducing the prevalence of Fetal Alcohol Syndrome. FAS is an illness that creates a significant burden on all members of society, not only those afflicted with it. You have already heard convincing testimony from Senator Barnett, M.D., regarding the daunting challenges faced by its victims and you have heard about the enormous cost to all Kansans for providing educational, social and correctional services for these individuals.

This bill requests a modest appropriation that will be matched by local funds or services, ensuring community commitment to the program's success. It relies on existing public health infrastructures, instead of creating entirely new entities. Its sunset provision creates accountability for those involved because they must report their progress to the legislature before seeking additional funding. Alleviating the burden that Fetal Alcohol Syndrome presents to all members of our society is the right thing to do. Creating and funding pilot programs under SB 118 is the smart way to do it.

For the foregoing reasons, KMS respectfully urges passage of SB 118. Thank you for the opportunity to submit testimony on this important matter.



March
of Dimes
Saving babies, together

March of Dimes
Birth Defects Foundation

Kansas/Western Missouri Chapter
4050 Pennsylvania #141
Kansas City, Missouri 64111
Telephone (816) 561-0175
Fax (816) 531-2484

March 20, 2001

To: Chairman Boston and members of the House Health & Human Services Committee
From: Leigh Anne Henson, March of Dimes
Re: SB 118

Chairman Boston and members of the House Health & Human Services Committee:

The March of Dimes would like to provide its support for SB 118, which establishes fetal alcohol syndrome diagnostic and prevention network pilot programs in the state of Kansas.

As the premier advocate for both the unborn and newborn infants, the March of Dimes' mission is to reduce and eliminate the incidence of disease at the time of birth. The pilot program established by SB 118 would increase awareness of fetal alcohol syndrome, and would drastically reduce its existence throughout the state.

Thank you for allowing us to provide our support of SB 118.

Sincerely,

Leigh Anne Henson
March of Dimes

H & HS
3-20-01
Atch # 6