HCR

7

FISCAL NOTE

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STATE OF ALASKA
1993 LEGISLATIVE SESSION

Revision Date: —
Dept. Affected: N/A
Title: RELATING TO ALCOHOL-RELATED BIRTH DEFECTS AWARENESS WEEK
BRU:
Component:
Sponsor: REP. NICHOLIA
Requestor:
COMPONENT SERIAL NO.

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	0	0	0	0	0	0
CAPITAL						
REVENUE FUND SOURCE:	0	0	0	0	0	0

FUNDING: (Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 GF						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
TOTAL	0	0	0	0	0	0

POSITIONS:

FULL-TIME						
PART-TIME						
TEMPORARY						

Estimate of current year (FY93) impact: ? 0

ANALYSIS: (Attach a separate page if necessary)

Prepared by:
Phone: 3759
Division: HOUSE HESS COMMITTEE
Date: 3-5-93
Approved by Commissioner: REPRESENTATIVE CON BUNDE CO-CHAIR
Date: 3-5-93
Agency: REPRESENTATIVE CYNTHIA D. TOOHEY, CO-CHAIR

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Health, Education and Social Services Committee
Special Committee on Fisheries

House Concurrent Resolution 7

SPONSOR STATEMENT

HCR 7 relates to the declaration of May 9 - 15, 1993, as Fetal Alcohol Syndrome Awareness Week.

Fetal Alcohol Syndrome (FAS) has been found to be the number one identifiable cause of birth defects accompanied by mental retardation in the United States, and is the only preventable one. Children who are born with FAS suffer disastrous consequences from their mothers' choice to drink alcohol while pregnant. FAS-related birth defects include growth retardation, abnormal facial features, mental retardation, brain deformation, orthopedic and orthodontal problems, and vision loss. All of these effects are devastating to a child; all of them are preventable.

The Department of Health and Social Services, Division of Alcoholism and Drug Abuse is planning a statewide FAS Awareness campaign for Mother's Day Week, 1993. HCR 7 will assist the Division in its efforts to increase consciousness in Alaskan communities about FAS and how to prevent it.

This piece of legislation has the power to help halt the incidence of FAS by raising the awareness of health care providers, schools, and ultimately pregnant mothers. I strongly urge you to support HCR 7.

MY TURN

2-25-93 Empire

Alaska leads the nation in fetal alcohol syndrome

By ERMALEE HICKEL

Did you know that Alaska ranks No. 1 in the nation in the number of babies born each year with fetal alcohol syndrome? It is deeply troubling to me that this tragic problem has reached a crisis level in Alaska, as well as across the nation.

Fetal alcohol syndrome is the No. 1 cause of mental retardation in the western world, and it is also one of the three leading causes of birth defects. Many fetal alcohol syndrome and fetal alcohol effects children have developmental delays, learning disabilities, hyperactivity, attention and behavior problems, physical deformities and severe health problems. These birth defects simply will never go away, and a bay born with FAS or FAE never catches up mentally or physically to normal children.

Drinking any amount of alcohol while a woman is pregnant puts her unborn baby at risk of having FAS or FAE. Why? Because when a woman drinks alcohol, her baby drinks too, because the alcohol passes directly through the placenta to her baby.

Both FAS and FAE are 100 percent preventable. When a woman doesn't drink any alcohol (beer, wine, hard liquor or wine coolers) during pregnancy, her baby will not be at risk for FAS or FAE.

There is no known safe amount of alcohol for a pregnant woman, so she should just not drink alcohol at all.

For women who are planning a pregnancy, the best defense against FAS and FAE is to stop drinking alcohol before trying to conceive. When women who drink and have an unplanned pregnancy should quit drinking as soon as they suspect they are pregnant. It is never too late to stop drinking and get help for you and your baby.

Heavy drinkers should avoid pregnancy until they think they can stay away from alcohol for the nine months from conception to birth, and longer if they plan to breastfeed their babies.

There is no known safe amount of alcohol for a pregnant woman, so she should just not drink alcohol at all. I'd like to suggest that because of the tragic consequences of FAS and FAE, that woman should be free of drinking any alcohol for a year prior to conception in order to give the child the best chance at life.

Researchers are showing that many women inadvertently drink during the first three months of pregnancy because they don't know they are pregnant, and this is very dangerous to the unborn baby.

I know this may be quite a sacrifice, but FAS and FAE are irreversible conditions. Although FAS is totally preventable, once a child has FAS or FAE, they don't grow out of it or get better. They will always have it – the damage is permanent. Babies with FAS or FAE have the disabilities they are born with throughout their lives.

What can we do as a community? One thing that is so important is public awareness. It's not reasonable to wait until women start prenatal care to advise them against drinking alcohol during pregnancy. A woman must be reached before she becomes pregnant and be taught that if she stays away from alcohol entirely during her pregnancy, her baby will not have FAS or FAE.

We can win this battle against FAS and FAE through education, and also by family, friends and communities standing alongside expectant mothers who are struggling with alcohol. A woman battling alcohol can be helped to maintain abstinence through the caring of others.

We must use all of our means to reach women at risk of having babies with FAS and encourage them to believe in themselves and their own worth.

If you need help or know someone who does, please call the Alaska Council on Prevention of Alcohol and Drug Abuse at 1-800-478-PREV. They can refer you to good programs that can help, or you can contact your local alcohol program or health care provider.

Also you may want to contact the Dena A-Coy pre-maternal home in Anchorage at 333-6677. They offer both residential and outpatient treatment programs for pregnant women across the state who are suffering from alcohol and drug addiction. It is a pilot federal/state program that has helped many women have healthy babies.

FAS and FAE can be a thing of the past in just one generation if women just don't drink any alcohol during pregnancy. The choices women make for their lives will affect their babies' lives forever. We must each play our part in encouraging women to have strong, healthy babies.

Economic Impact of Fetal Alcohol Syndrome in Alaska

February 1989

by

Maureen Weeks
Senate Advisory Council

for

Senator Johne Binkley

Alaska State Legislature

Senate Advisory Council

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MEMORANDUM

TO: Senator Johne Binkley
Alaska State Senate

FROM: Maureen Weeks MW
Senate Advisory Council

DATE: February 17, 1989

SUBJECT: Economic impact of Fetal Alcohol Syndrome; IR # 89-100015

An estimated 29 babies with Fetal Alcohol Syndrome (FAS) are born in Alaska annually; of these 26 survive the first year. Two to 15 times this many babies are born with a lesser set of symptoms known as Fetal Alcohol Effects (FAE). Babies exposed to alcohol before birth may be too small when they are born. Just ten years ago al[illegible]all low birthweight babies died at birth. Today, increasingly expensive medical technology saves the lives of four out of five but cannot correct many defects already caus[illegible]d by alcohol. Fifty-eight percent of both FAS and FAE patients have IQ's below 70 (classified as Developmentally Disabled). Conservatively estimated, the lifetime cost per Alaska FAS birth is $1.4 million. Lifetime cost for Alaska FAS babies born each year is $39.8 million.

These are selected medical and social costs only; they do not include, among other things, costs of welfare, the justice system, mild physical problems, mild learning disabilities or loss of a useful member of society.[1]

A table of costs associated with FAS and FAE follows page 18 of this report.

I. BACKGROUND.

Fetal Alcohol Syndrome (FAS) is caused when the alcohol which a pregnant woman drinks damages the brain and body of the fetus as it develops. Until 1973, alcohol was not suspected as toxic to an unborn baby. Respected medical authorities told pregnant women that the placenta protected their fetuses from harmful substances. Today we know these authorities were wrong. Babies who are exposed to alcohol before they are born can be irreversibly harmed for the rest of their lives.

The damage done by alcohol has profound implications for the victim and society. The harmful effects of alcohol on the fetus last a lifetime. A common problem is mental retardation. The average IQ of FAS patients is 66. Almost every child

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[1] Harwood and Napolitano estimate direct average lifetime costs at $405,000 per person and indirect costs at $191,000, in 1980 dollars. Adjustment for inflation and cost of living differences (3 percent per year and 30 percent) yields direct costs of $528,000 and indirect costs of $249,000, for a total of $1,010,000/person, Alaska 1989. Total costs for 29 Alaska FAS births would be $29,290,000. (A 30 percent increase is conservative; the Bureau of Labor Statistics reports that medical services increased by 83.5 percent in Anchorage between 1980 and 1988.) It should be noted that some costs in the Harwood study are much less than Alaska costs. For example, intensive care hospitalization is estimated nationwide at $2,500 per infant v. $120,000/year per infant in Alaska; institutionalization is estimated at $25,000/year nationwide v. $109,000 in Alaska.

or adult with FAS needs lifelong care, supervision or support from family and society. Those most seve.ely affected may spend their lives in institutions. Some suffer physical anomalies such as heart problems, cleft palate, kidney problems, blindness and deafness.

Few, if any, families can pay the enormous costs of supporting an FAS child or adult. Babies born with FAS may need intensive hospital care at birth at an average cost of $2,400 a day. One in eight children born with FAS have cleft palates, requiring surgeries costing up to $75,000 and long term speech therapy twice or three times a week at $96 an hour. Fifty-eight percent of patients with FAS have IQ's below 70 and as such are classified as developmentally disabled. Cost of special education for a severely retarded child is $20,000 a year. Average annual cost for each FAS patient in an institution is $109,000.

Two national studies of the economic impact of Fetal Alcohol Syndrome have been published since the syndrome was discovered in 1973. Harwood and Napolitano in 1985 found the U.S. spends up to $108.8 million a year on FAS births; Abel and Sokol in 1986 found annual costs of $321 million a year. This report adapts the more conservative Harwood and Napolitano study to Alaska.

II. INCIDENCE OF FAS AND FAE

An estimated 29 Alaska babies are born a year with FAS. Experts believe between two and 15 times that many FAE babies are born annually.

A diagnosis of FAS requires signs in three areas:

(1) Pre and/or post natal growth retardation (weight, length, and/or head circumference below the tenth percentile).

(2) Central nervous system problems (neurological abnormality, developmental delay, or intellectual impairment.

(3) Characteristic facial features (including small eyes, crossed eyes, short nose, or abnormalities of the mouth such as cleft palate).

FAS may be difficult to identify, especially among newborns. The identifying facial features may not be easily recognized and mental retardation may not be identified until years after birth.

U.S. researchers speculate that some racial groups, such as certain American Indian tribes, may be at greater risk for FAS than the population as a whole. A 1982-83 study of Indians on 26 reservations in New Mexico, Colorado, Utah and Arizona showed a wide variation in prevalence of FAS among cultural groups. For example, among Navajo Indians, the incidence was 1.4 FAS cases per 1,000 births; among Pueblo Indians it was 2 per 1,000 births and among Plains Indians it was 9.8 per 1,000 births.

Dr. James Berner of the Native Health Service, and Vicki Hild, FAS Coordinator for the Alaska Native Health Board, report statewide incidence of FAS between

1981 and 1988 at 4.2 per 1,000 live births. At an average of 2,700 deliveries annually, this would be about 12 FAS Native births a year.

The estimate comes from an Alaska Area Native Health Service survey of Alaska Native children born between 1981 and 1988. The study shows that the highest recorded FAS rate among any population in the world is in the Copper River area of Alaska: 250 FAS cases per 1,000 births (or one in every four births). Estimated incidence among Alaska Natives in other areas:

Sitka region:	2.1 FAS cases per 1,000 births
Bethel region:	3.5 FAS cases per 1,000 births
Anchorage:	3.8 FAS cases per 1,000 births
Nome region:	4.0 FAS cases per 1,000 births
Tanana Chiefs:	5.9 FAS cases per 1,000 births

It would be a mistake to ignore FAS among non-Native Alaskans. Data shows, for example, that one non-Native woman in Southcentral Alaska has produced seven children with FAS. No one has studied the incidence of FAS among non-Native Alaskans. Indeed, relatively few studies of the incidence of FAS among the general population have been done in the U.S. The literature commonly estimates overall FAS prevalence at from 1 to 3 cases per 1,000 live births (see Sixth Special Report to the U.S. Congress on Alcohol and Health, January 1987). Estimates in U.S. cities show:

Cleveland (1973-79)	.4 FAS cases per 1,000
Cleveland (1979-82)	3.0 FAS cases per 1,000
Seattle (1978)	1.3 FAS cases per 1,000
Boston (1977)	3.1 FAS cases per 1,000
Boston (1983)	2.1 FAS cases per 1,000

Estimates from Europe include:

Sweden (1979)	1.6 FAS cases per 1,000 births
	1.4 cases per 1,000 births
France (1977-79)	1.3 cases per 1,000 births
	2.9 cases per 1,000 births.

Abel and Sokol added together all FAS births reported worldwide in text or by personal communication and found a worldwide incidence of 1.9 FAS cases per 1,000 live births. Rates were higher in North America (2.2 cases per 1,000 live births) than in Europe and other countries (1.8 cases per 1,000 live births). They believe site, economic class and culture affect the reported FAS rate. Hild and Berner place national incidence at 1.7 per 1,000 live births. This study will use that conservative estimate. At an average of 10,000 deliveries annually, this would be about 17 non-Native babies born with FAS in Alaska a year. Added to the estimated 12 Native births, this brings the total Alaska FAS births per year to 29 babies. Of these, 26 babies survive their first year. See Table 1.

In the 16 years since U.S. doctors recognized that alcohol harms the fetus, researchers have concentrated on the more serious illness, FAS. However, patients with FAE have an average IQ of 73 and researchers now believe that in addition to lowered IQ, FAE causes hyperactivity, learning disorders, speech and hearing problems, perceptual problems and short attention span, among other problems. In some cases, these signs may not become evident until the child has trouble in school. Educators faced with a "difficult" child may not associate school problems with prenatal exposure to alcohol.

Researchers disagree on the incidence of FAE. Ann Streissguth of the University of Washington Medical School, an associate of the U.S. discoverers of FAS, estimates that FAE occurs twice as often as FAS. The National Institute on

Table 1

Incidence of FAS births in Alaska, 1988

Native births:	
Deliveries (a)	2,736
Incidence of FAS births (b)	4.2/1000
Number of FAS birt! (2736 x .0042 = 11.	12
Non-Native births:	
Deliveries (a)	10,163
Incidence of FAS births (b)	1.7/1000
Number of FAS births (10163 x .0017 = 17.3)	17
Total FAS births:	29
F rst-year survivors:	
Neonatal mortality rate, Alaska: (c)	5.1%
Neonatal survivors:	28
Postneonatal mortality rate: (c)	5.9%
FAS first-year survivors	26

(a) Alaska Vital Statistics 1985, Department of Health and Social Services, Juneau, 1988.

(b) J.E. Berner, "Update: Incidence of Fetal Alcohol Syndrome (FAS) In Alaska Natives", February 3, 1989.

(c) Alaska Vital Statistics 1985, p. 7.

Alcohol Abuse and Alcoholism reports a ten times increase and Sokol estimates much as a 15 times increase. Hild believes the incidence of FAE in Alaska is ten times that of FAS, or higher. In an effort to be conservative, this report will use the lowest estimate (twice FAS). At this rate, 58 Alaska FAE babies are born a year.

Table 2 shows the number of FAE births per year at each estimate.

Table 2

Incidence of FAE, Alaska 1985 (a)

Estimate of times increase over FAS	Number of FAE born/year (FAS = 29/yr)
2	58
10	290
15	435

(a) Three estimates of the frequency of FAE are quoted in the literature:

* 2 times FAS: Ann P. Streissguth, Ph.d, of the University of Washington Medical School. (Manual on Indian Adolescents and Adults with Fetal Alcohol Syndrome, July, 1986, p. 4)

* 10 times FAS: National Clearinghouse for Alcohol Information at Rockville Maryland. (Fact Sheet, December 1985). V. Hild, FAS coordinator for the Alaska Native Health Board, estimates the FAE incidence in Alaska exceeds 10 times that of FAS.

* 15 times FAS: R.J. Sokol. ("Alcohol Abuse During Pregnancy: An Epidemiologic Study", Alcoholism: Clinical and Experimental Research, April 1980, p. 135-145.

B. Medical costs associated with FAS and FAE.

FAS patients commonly require medical care for cleft palate, heart defects, kidney defects, visual and hearing defects, dental problems and skeletal and postural problems. When estimates of the prevalence of these anomalies are available, this report relies on Abel and Sokol, Harwood and Napolitano and Hild for accurate statistics. Unfortunately, the prevalence for the majority of physical problems has not been established and these costs are not be included in this report. Table 6 shows costs of selected physical disorders. Hospital costs are explained below.

Alcohol can lower birthweight even in babies who do not have FAS. Ruth Little reports that when a pregnant woman drinks one ounce of alcohol a day, birthweight can fall by 160 grams. Alcohol also lowers birthweight in the majority of FAS births. Low birthweight babies are at risk to need intensive care. Just ten years ago almost all low birthweight babies died at birth. Today, newborn intensive care saves the lives of four out of five. This intense early care is increasingly expensive and cannot correct the lifelong and expensive defects already caused by prenatal exposure to alcohol. In some cases, the desperate effort to save a too-small baby's life adds to the irreversible burden of harm the child will carry with it for the rest of its life.

Abel and Sokol report that 79.8 percent of FAS babies are low birthweight (see Table 3). Of 29 Alaska babies born annually with FAS, 23 babies would be low birthweight. Alaska vital statistics records show that 4.6 percent of babies are born low birthweight despite their prenatal care. Thus, one Alaska baby would be low birthweight despite the best prenatal care, leaving 22 Alaska babies whose low birthweight is due to FAS. Abel and Sokol report that 74.3 percent of FAS low birthweight babies are moderately low birthweight, weighing between 1500 and 2500 grams. At this rate, 16 Alaska FAS babies would be

moderately low birthweight. The rest (six babies) are very low birthweight, weighing less than 1500 grams.

The National Institute of Medicine reports that 32.8 percent of moderately low birthweight babies need intensive care (see Table 4). Of the 16 moderately low birthweight Alaska babies, five would need intensive care. All of the very low birthweight babies (six babies) would need intensive care. The total number of FAS low birthweight babies needing intensive care is 11 per year. This estimate is corroborated by Dr. Jack Jacob, Providence Hospital neonatologist, who reports between ten and 15 FAS infants are treated in the intensive care unit each year.

Providence Hospital records show that in 1987, the average length of stay in intensive care for an FAS baby was 27 days and in 1988, it was 65 days.[2] Average FAS hospital costs in 1987-88 were $99,740 per FAS child; average neonatal physician fees for FAS infants were $11,065. These costs include all hospital costs except transport, other physicians and anesthesiology. Total average cost of intensive care for one FAS baby is $110,805 per year. For 11 low birthweight babies, it is $1,218,855 per year.

The Institute of Medicine estimates that 19 percent of all moderately low birthweight babies and 38.3 percent of very low birthweight babies must be rehospitalized during their first year. Streissguth of the University of Washington reports that it is "usual" for FAS babies to be rehospitalized for pneumonia and problems such as hip dysplasia; applying statistics for all low birthweight babies to FAS births may result in conservative estimates.

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[2] To compare, average length of stay for all low birthweight babies in the intensive care unit at Providence was 19.7 days in 1987 and 23.7 days in 1988.

Using the Institute of Medicine averages for all low birthweight babies, one FAS moderately low birthweight baby would be rehospitalized for 12.5 days and two very low birthweight babies would be rehospitalized for 16.2 days. Hospitalization for children not in intensive care was about $900 a day at Providence Hospital in Anchorage in 1988. Rehospitalization for one baby for 12.5 days is $11,250 and for two babies at 16.2 days it is $29,160. Total cost of rehospitalization for low birthweight FAS babies: $40,410. This does not include physicians, surgery, special procedures or transportation. See Table 5.

Table 3

Low birthweight of FAS births,
Alaska 1985

Alaska Low Birthweight Births (under 2500 grams) due to FAS.

FAS births which are Low Birthweight:	
Total FAS births:	29
% FAS births which are under 2500 grams (a)	79.8%
LBW babies in 29 FAS births:	23
(29 x .798 = 22.9)	
Low Birthweight births not due to FAS:	
% Alaska LBW births under 2500 grams not due to FAS (b)	4.6%
4.6% x 23 = 1 LBW birth not due to FAS	
LBW births due to FAS:	22
(23 x .046 = 1.1)	

Weight distribution of Alaska FAS Low Birthweight births:

1500-2500 grams (MLBW):	
% FAS births between 1501-2500 grams (a)	74.3%
FAS MLBW babies:	16
(22 x .743 = 16.4)	
Under 1500 grams (VLBW):	
All other LBW babies are VLBW (under 1500 grams)	6

(a) Abel and Sokol, "Incidence of Fetal Alcohol Syndrome and Economic Impact of FAS-Related Anomalies", Elsvier Scientific Publishers, Ireland, August, 1986, p. 58.

(b) If FAS were eliminated from Alaska, 4.6 percent of all births would still be low birthweight. Although they would still need treatment, the costs of their treatment should not be attributed to FAS. This number is the solution to the following equation: 4.8% x 12,900 births = 79.8% x 24.6 FAS births + p x 12,869 non-FAS births, where 4.8% is low birthweight rate in Alaska; 12,900 is number of Alaska births in 1985; 79.8% is U.S. LBW rate for FAS births; 24.6 is FAS births in Alaska in 1985. Formula devised by J.W. Senner, Oregon State Health Division, "Revised Annual National Cost Estimates" (Portland), p. 2.

Table 4

Costs of intensive care hospitalization for FAS LBW babies
Alaska 1985

Moderately LBW (1500-2500 grams) Intensive Care hospitalization:	
% MLBW babies requiring intensive care (a)	32.8%
MLBW FAS babies requiring intensive care (16 x .328 = 5.4)	5
Very LBW (under 1500 grams) Intensive Care hospitalization:	
% VLBW babies requiring intensive care (a)	100%
VLBW FAS babies requiring intensive care	6
Total	11 babies
Hospital cost for 11 babies at $99,740 (b)	$1,097,140
Physician cost for 11 babies at $11,065 (b)	$ 121,715

(a) The Institute of Medicine reports that 32.8% of LBW infants and 100% of VLBW infants require newborn intensive care. Preventing Low Birthweight, Institute of Medicine, (Washington, D.C.), 1985. This may be an underestimate for FAS babies who show a longer average length of stay in intensive care, an indication that they may be sicker than other low birthweight babies. Providence Hospital reports the following average lengths of stay in the newborn intensive care unit in 1987 and 1988.

	1987	1988
Low Birthweight	19.7 days	23.7 days
FAS Low Birthweight	27 days	65 days

(b) Costs do not include transportation, other physician or anesthesiology fees. Neonatologist Dr. Jack Jacob estimates between 10 and 15 FAS infants a year enter the unit (Lisa Wolf, pers. comm.).

Table 5

Cost of first-year rehospitalization for FAS LBW babies
Alaska 1985

LBW rehospitalization:	
FAS MLBW babies in intensive care	5
Neonatal mortality rate (a)	5.1%
FAS MLBW babies who survive intensive care (5 x .051 = .25)	5
Percent LBW babies rehospitalized (b)	19%
Number of LBW babies rehospitalized (5 x .19 = .95)	1
Cost of rehospitalization: 1 x $11,250 (c)	$11,250
VLBW rehospitalization:	
FAS VLBW babies in intensive care	6
Neonatal mortality rate (a)	5.9%
FAS VLBW babies who survive intensive care (6 x .059 = .35)	6 babies
Percent VLBW babies rehospitalized (b)	38.3%
Number of VLBW babies rehospitalized (6 x .383 = 2.3)	2
Cost of rehospitalization: 2 x $14,580 (c)	$29,160
Total cost of first-year rehospitalization:	$40,410

(a) Alaska 1985 Vital Statistics, Department of Health and Social Services, (Juneau), p. 7.

(b) The National Institute of Medicine reports that 19% of 2500-1500 gram babies are rehospitalized during the first year, as are 32.8% of babies under 1500 grams. Preventing Low Birthweight, National Institute of Medicine, (Washington, D.C.), 1985. This may be an under-estimate for FAS births. Streissguth reports that it is "usual" for FAS babies to be rehospitalized during the first few months of life for pneumonia, failure to thrive, hip dysplasia and other problems. A Manual on Indian Adolescents and Adults with Fetal Alcohol Syndrome, University of Washington Medical School, July 1, 1986.

(c) Providence Hospital charges for pediatric admission, 1988: $900/day (MLBW average length of stay, 12.5 days; VLBW stay. 16.2 days).

C. Costs associated with mental retardation.

Streissguth in a 1986 study of 61 FAS/FAE diagnosed patients between the ages of 12 and 40 shows that more than half (58 percent) of both FAS and FAE patients were developmentally disabled (IQ's below 70). Hild finds the 58 percent estimate likely in Alaska. This report will rely on that estimate. At this rate, 15 FAS first-year survivors and 34 FAE patients have IQ's below 70. (Note that computing the incidence of FAE at 10 times that of FAS, the percentage used by Alaska experts, there would be 336 developmentally disabled FAE patients born every year.) Social service costs for the average moderately to mildly retarded child are $25,000 a year (not including education). For adults, these costs are as high as $45,000 a year (including vocational rehabilitation). About five FAS children currently are part of the Alaska Youth Initiative program for severely troubled youth at an average cost of $90,000 a year each.

If 58 percent of FAS and FAE patients are developmentally disabled, an estimated 42 percent have minimal brain dysfunction. In this report, costs for this portion of patients are estimated at $4,000 each, the additional cost of special education for mildly disabled persons (above regular education operating costs). State officials caution that FAS/FAE patients with IQ's between 70 and 100 may actually be more expensive than those with lower IQ's because of added counselling, legal and corrections costs. This is not reflected in this report.

Streissguth's study of 61 FAS/FAE patients from the Southwest U.S., Seattle and Vancouver, B.C. showed the following patient characteristics:

(1) IQ's ranged from a score of 20 to 105. Average IQ of patients with FAS was 66 and of patients with FAE, 73. No patient with FAS showed

an IQ above 90. Streissguth concludes it is impossible to predict from a diagnosis alone how handicapped an individual patient with FAS/FAE will be as an adolescent or adult.

(2) 58 percent of both FAS and FAE patients had IQ's below 70, (generally classified as developmentally disabled).

(3) The average reading, spelling and arithmetic level of these patients (ages 12 to 40) was 4th grade, 3rd grade and 2nd grade, respectively.

(4) Average level of general adaptive functioning was 7 years 5 months. (Median age of those tested was 16 years 5 months.)

(5) There was no indication of general improvement in IQ, achievement or adaptive living scores as patients got older.

(6) None of the patients were able to live independently.

Vicki Hild of the Alaska Native Health Board has tabulated living situations for 118 Alaska Natives with FAS. She found that 20 percent had been adopted and 10 percent had died. The remaining children shuttled back and forth between their biological parents and state custody. It is state policy to keep children with their biological parents if possible; children move in and out of state custody as a parent's condition improves or worsens. Among biological parents of the 118 children in the Hild study, only three mothers appeared "reasonably" stable.

Hild cites as an example of "ping-ponging" custody, the case of one Alaska FAS child who had lived in seven foster homes by the time she was three.[3]

D. Costs not included in this estimate.

Medical researchers have not yet determined a reliable rate of incidence for the majority of physical defects common to FAS victims and these costs have not been included in this estimate. These physical anomalies include visual problems, kidney and genital tract problems, and dental and skeletal defects (more frequently found in adolescents and adults), including club foot and scoliosis and neurotube defects such as spina bifida. Also not included are on-going lifelong medical costs associated with the ill health of patients with these problems. (Despite their illnesses, however, FAS patients are expected to live a normal life span.) Transportation, anesthesiology and some physician costs for first-year hospitalization and costs of FAE babies with physical damage are also not included.

Many social costs are also not included in this estimate. FAS children and adults are at high risk for physical and sexual abuse. They may exhibit signs of depression; some may be suicidal; a few may become violent. As they grow into adulthood, some may exhibit increasingly inappropriate sexual behavior.

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[3] Streissguth believes stability is important to the well-being of FAS patients. "We usually find great improvement in emotional development and social functioning when children with both full and partial FAS have stable and supportive living arrangements. Improved behavior which often occurs, even in the absence of changes in IQ, should not be ignored simply because it is more difficult to measure and quantify." "Psychological and Behavioral Effects in Children Prenatally Exposed to Alcohol", Alcohol Health and Research World, Fall 1988, p. 10.

Many of the costs of welfare, child abuse, sexual abuse, psychiatric care, incarceration, stress on the care-giver and loss of a useful member of society are not included in this report. Hild has stated that "without early intervention, all FAS and most FAE patients will be on welfare." In addition, this report does not consider what may be the enormous, but still unrecognized, costs of learning disabilities suffered by children afflicted with FAE.

TABLE I

LIFETIME COST ESTIMATES OF SPECIFIC BIRTH DEFECTS IN FAS BIRTHS -- ALASKA

	Birth Defect	Annual Cost per Patient	Number of Times or Years	Lifetime Cost per Patient	Prevalence	Number Per Yr (% x 26)	Lifetime Cost: All Born 1988
	ANNUAL FAS BIRTHS (29 BIRTHS; 26 SURVIVORS)						
1	Neonatal Unit/Providence	99,740	1	99,740		11	1,097,140
2	Neonatal Physician	11,065	1	11,065		11	121,715
3	First Year Rehospitalization	13,470	1	13,470		3	40,410
4	Initial Audio Screening	100	1	100	52%	15	1,500
5	Audio Check-up	100	4	400	100%	26	10,400
6	Otitis Media Surgery	1,224	1	1,224	56%	15	18,360
7	Hearing Aid	1,260	14	17,640	33%	9	158,760
8	Hearing Aid Mold	50	65	3,250	33%	9	29,250
9	Heart Surgery	75,000	1	75,000	5%	1	75,000
10	Cleft Palate Surgery	65,000	1	65,000	12%	3	195,000
11	Infant Learning Program (HSS)	2,513	3	7,539	100%	26	196,014
12	H/C Child: phys defect (HSS)	8,700	18	156,600		7	1,096,200
	H/C Child: devel delay (HSS)	8,700	3	26,100	58%	15	391,500
13	Minimal Special Eductn (DOE)	4,000	15	60,000	42%	11	660,000
14	Child Mental Retardation (DOE)	20,000	15	300,000	58%	15	4,500,000
15	DD Child (HSS)	25,000	18	450,000	58%	15	6,750,000
16	Alaska Youth Initiative (HSS)	90,000	12	1,080,000		1/2	540,000
17	DD Adult Initial Training(HSS)	45,000	3	135,000	58%	15	2,025,000
18	DD Adult Supervised Work (HSS)	22,500	44	990,000	58%	15	14,850,000
19	Institution	109,000	65	7,085,000	3%	1	7,085,000
	Lifetime Costs for FAS Births: 1988						39,841,249
	Lifetime Costs per FAS Birth			1,373,836			
20	ANNUAL FAE BIRTHS AT TWICE FAS RATE (58)						
21	Infant Learning Program (HSS)	2,513	3	7,539	58%	34	256,326
22	DD Child (HSS)	25,000	18	450,000	58%	34	15,300,000
23	Child Mental Retardation (DOE)	20,000	15	300,000	58%	34	10,200,000
24	DD Adult Initial Training(HSS)	45,000	3	135,000	58%	34	4,590,000
25	DD Adult Supervised Work (HSS)	22,500	44	990,000	58%	34	33,660,000
	Lifetime Costs for FAE Births: 1988						64,006,326
	Total FAS/FAE Births						103,847,575

NOTES TO FAS COST TABLE

Numbers refer to line numbers on the table.

1. Neonatal Unit. Charges per FAS patient in the Providence Hospital Neonatal Intensive Care Unit were $68,910 in 1987 and $130,570 in 1988, for an average of $99,740. Average length of stay of FAS infants in the Neonatal Intensive Care Unit more than doubled between 1987 and 1988. It was 27 days in 1987 and 65 days in 1988 (v. 19.7 and 23.7 days for all low birthweight babies in the unit). Statistics provided by Lisa Wolf of Providence Hospital.

2. Neonatal Physician. Physician costs per FAS child were $6,130 in 1987 and $16,000 in 1988, for an average of $11,065. Estimates by Sharon Lee of Alaska Neonatal-Perinatal Associates.

3. First-year rehospitalization. Cost estimate is based on 1988 Providence Hospital pediatric charges of $900/day. The number of infants and average length of stay (12.5 days for moderately low birthweight infants and 16.2 days for very low birthweight babies) are from the National Institute of Medicine and are for all low birthweight infants. Applied to FAS births, these may be underestimates. Streissguth reports it is "usual" for FAS babies to be rehospitalized in the first few months of life.

4. Initial Audio Screening. The state audiologist, Communicative Disorders Program, Anchorage, reports all FAS children need a workup. This report estimates that 11 infants receive a workup in intensive care; the 15 remaining surviving infants are counted in this entry.

5. Audio Check-up. FAS children need three to four follow up checks. The $100 charge is from the Alaska Treatment Center in Anchorage; the check-up estimate is from the state audiologist.

6. Otitis Media Surgery. Estimate is from the Geneva Woods Ear Nose and Throat Associates. Source of 56% prevalence is Harwood and Napolitano. These costs do not include less severe ear problems common to 93 percent of FAS patients (Alaska Treatment Center). Twenty-nine percent of FAS patients have permanent hearing loss.

7. Hearing Aid. A hearing aid for a baby costs $1,260; it is replaced once every five years for life at this cost. Cost estimate from Alaska Treatment Center.

8. Hearing Aid Mold. A $50 ear mold must be replaced annually. Estimate from Alaska Treatment Center.

9. Heart Surgery. Up to 70 percent of FAS patients have heart problems (Streissguth reports the portion at 30-40 percent; Hild reports 70 percent). Harwood and Napolitano report 10 percent require heart surgery, but reduce the estimate to 5 percent to reflect cases actually having surgery. Cost estimates from Vicki Hild, Alaska Native Health Board FAS coordinator.

10. Cleft Palate. Costs include an average of four surgeries, dental and orthodontics work. They do not include long term speech therapy at $96/session twice or three times a week. Estimates from Vicki Hild. The 12% estimate is average of Abel and Sokol (11.5%) and Harwood and Napolitano (12.5%).

11. Infant Learning Program. Mary Diven of the state division of Maternal and Child Health reports these figures are "deceptively low", under estimating the true cost of rural service. Infant Learning Program costs as much as $6,000/year in some rural areas.

12. Handicapped Children's Program. Cost estimates include averages for children with heart problems, cleft palate and developmental delay. Children with physical problems can be on the program for 21 years; children with developmental delays may be on the program for as few as three years. Cost estimates by Kathy Robinson, Maternal and Child Health, Alaska Department of Education. This report estimates that one child per year has heart problems (a low estimate in view of the 30 to 70 percent with heart problems); three have cleft palates; and three more have other physical problems such as spina bifida, progressive scoliosis or severe visual and hearing loss.

13. Minimal Special Education. Costs cover only $4,000/year for additional special education for learning disabled children, above normal operating and capital education costs (Tom Buckner, Department of Education). Christine Hagmeier of the Department of Health and Social Services cautions that patients with IQ's above 70 and below 100 "may well be more expensive than those with lower IQ's" because they an become involved in counselling, corrections and the law. These costs are not reflected in this report. The 42 percent prevalence estimate is from Streissguth.

14. Child Mental Retardation. Cost of special education for severely retarded children is $20,000 - $23,000/year, in addition to normal operating and capital education costs. Estimates from Tom Buckner, Department of Education.

15. Developmentally Disabled Child (HSS). Cost estimate by Christine Hagmeier of the Department of Health and Social Services. Costs can include foster care, in-home care, shared care, respite care, in-home training, advocacy and family support. Hagmeier reports that severely disabled children can cost between $35,000 and $85,000 with average cost of $55,000.

16. Alaska Youth Initiative. Cost estimate from John Van Den Berg, Department of Health and Social Services. This is a program for 52 severely troubled youths. The average age is 15.8 years; the average number of failed housing placements is 16. Currently five FAS youths are in the program. This report estimates children remain on the program an average of 12 years (based on Van Den Berg's report that "absolute minimum lifetime costs per child are $1 million".) It further assumes that one FAS child would enter this program every two years. Streissguth reports that aggressive behavior may be a problem for about 40% of the boys. Those from a less structured and protected environment may be "quick to anger when crossed and quick to strike out impulsively".

17. Developmentally Disabled Adult Initial Training. Costs include $25,000 residential care (example: foster care and independent living) plus initial vocational rehabilitation costs of $20,000, for a total of $45,000. Initial vocational rehabilitation costs average between two and five years. Estimate by Christine Hagmeier.

18. Developmentally Disabled Adult Supervised Work. After initial rehabilitation costs (see #17 above), costs can "fade" to between $10,000 and $25,000 for lifetime residential care plus $5,000 lifetime vocational rehabilitation care (Hagmeier). The average of this $15,000 to $30,000 range is $22,500.

19. Institution. Estimate by Ellen Ganley, Governor's Council for the Handicapped and Gifted.

20. FAE Births. Annual FAE births are calculated in this report at twice that of FAS births. This is a conservative estimate. Hild believes the actual number of FAE births annually is ten times the FAS births (or 290 FAE births and 168 developmentally disabled FAE persons.) In this report, cost estimates for FAE births are limited to mental retardation. They do not include costs associated with mild learning disabilities, physical anomalies, child abuse, sexual abuse or the justice system.

21. See #11.
22. See #15.
23. See # 14.
24. See # 17.
25. See # 18.

SOURCES

Ernest L. Abel and Robert J. Sokol, "Incidence of Fetal Alcohol Syndrome and Economic Impact of FAS-Related Anomalies", Department of Obstetrics and Gynecology, Wayne State University, Drug and Alcohol Dependence, Vol. 19, 1987, pp. 51-70.

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Henrick J. Harwood and Diane M. Napolitano, "Economic Implications of the Fetal Alcohol Syndrome", Alcohol World Health & Research, National Institute on Alcohol Abuse and Alcoholism. Fall 1985.

Ruth Little, "Moderate Alcohol Use During Pregnancy and Decreasing Infant Birthweights", American Journal of Public Health, Vol. 67, 1977.

Ann P. Streissguth, A Manual on Indian Adolescents and Adults with Fetal Alcohol Syndrome, University of Washington Medical School, July 1, 1986.

PERSONS CONSULTED

James Berner, M.D., Chief, Area Community Health Services Branch, Alaska Area Native Health Service.

Tom Buckner, Special Education, Alaska Department of Education.

Mary Diven, Infant Learning Program, Alaska Department of Health and Social Services.

Ellen Ganley, Governor's Council for the Handicapped and Gifted.

Robert Gregovich, formerly with Mental Health and Developmental Disabilities, Alaska Department of Health and Social Services.

Christine Hagmeier, Mental Health and Developmental Disabilities, Alaska Department of Health and Social Services.

Henrick Harwood, National Institute of Medicine, Rockville, Md. (202-334-3017)

Vicki Hild, FAS Coordinator, Alaska Native Health Board.

Kathy Robinson, Handicapped Children's Program, Alaska Department of Health and Social Services.

Sandra Randalls, R.N., University of Washington Medical School, Seattle (Ann Streissguth was out of town).

John Van Den Berg, Mental Health and Social Services, Alaska Department of Health and Social Services.

Lisa Wolf, Providence Hospital.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

Infant with full FAS This child died shortly after birth.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

CRITERIA FOR FETAL ALCOHOL SYNDROME

- **Prenatal or postnatal growth retardation in weight, height and/or head circumference**

AND

- **Altered morphogenesis, especially a characteristic facial dysmorphology**

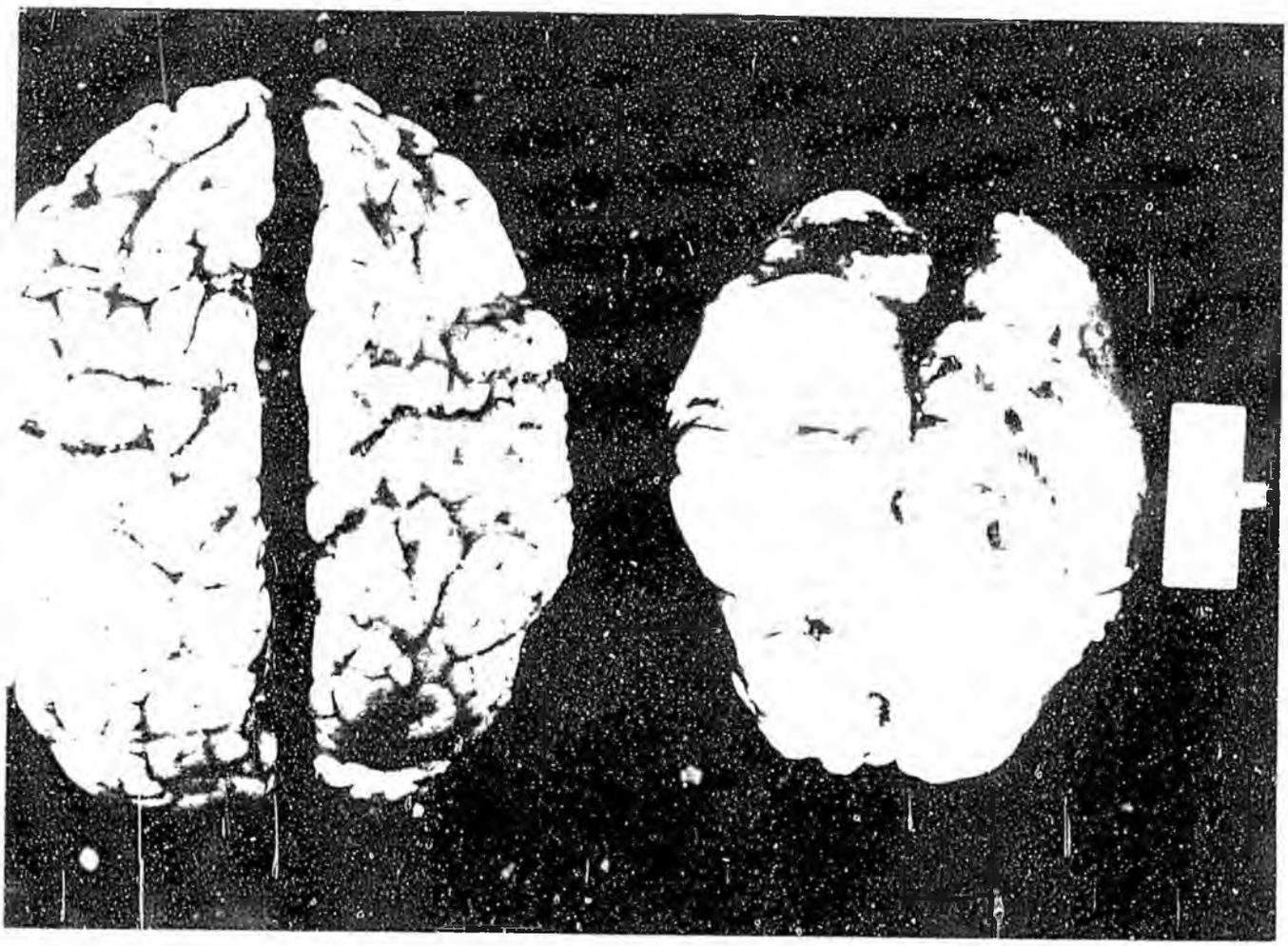
AND

- **Central nervous system involvement, often with mental retardation**

Criteria for FAS

• growth retardation • abnormal facial features • mental retardation

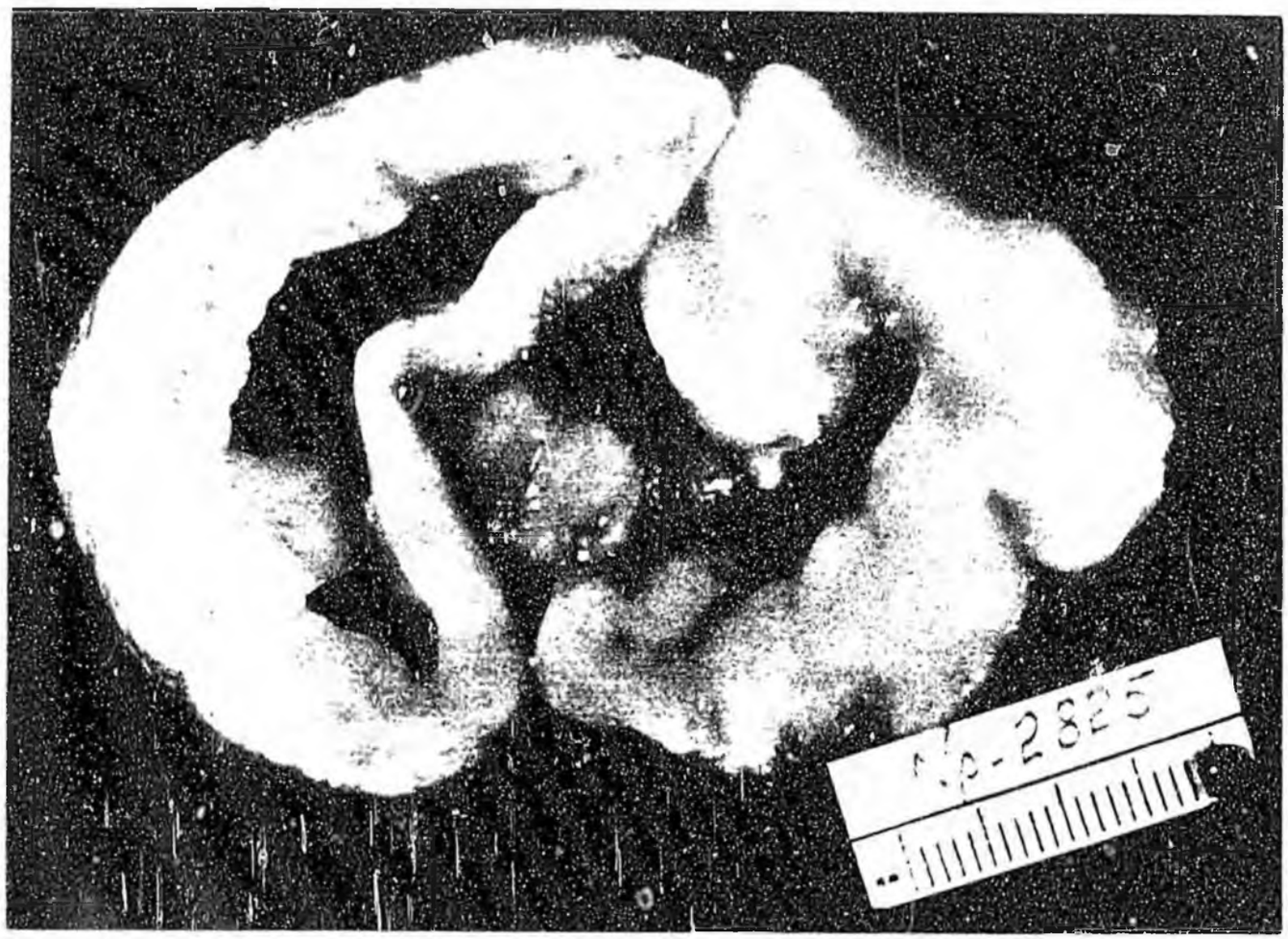
ALCOHOL-RELATED BIRTH DEFECTS



Brains from two infants who died at 5 days.
One brain is normal, the other FAS damaged.

The FAS brain is smaller, and deformed.

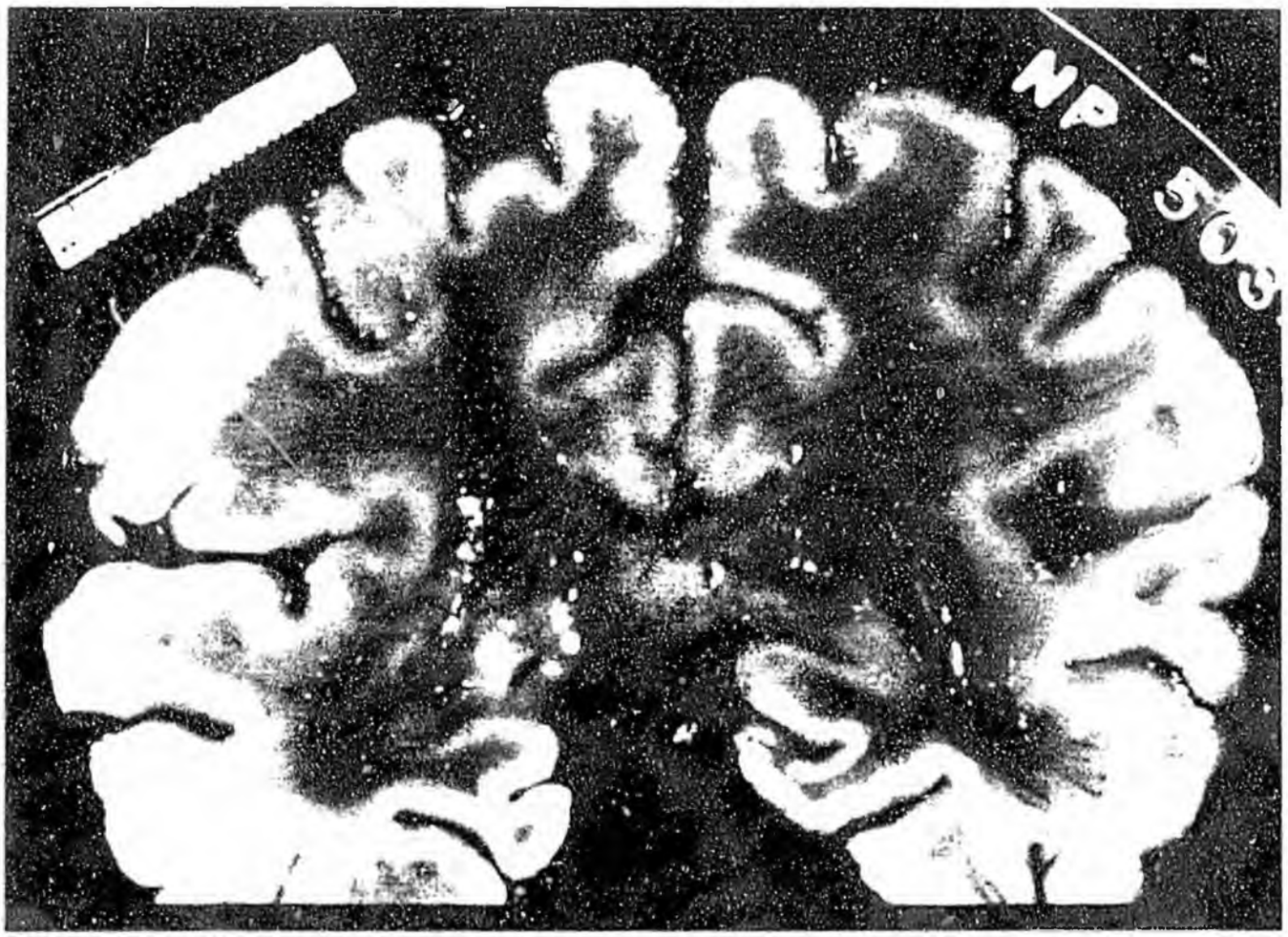
ALCOHOL-RELATED BIRTH DEFECTS



A cross section of the FAS brain.

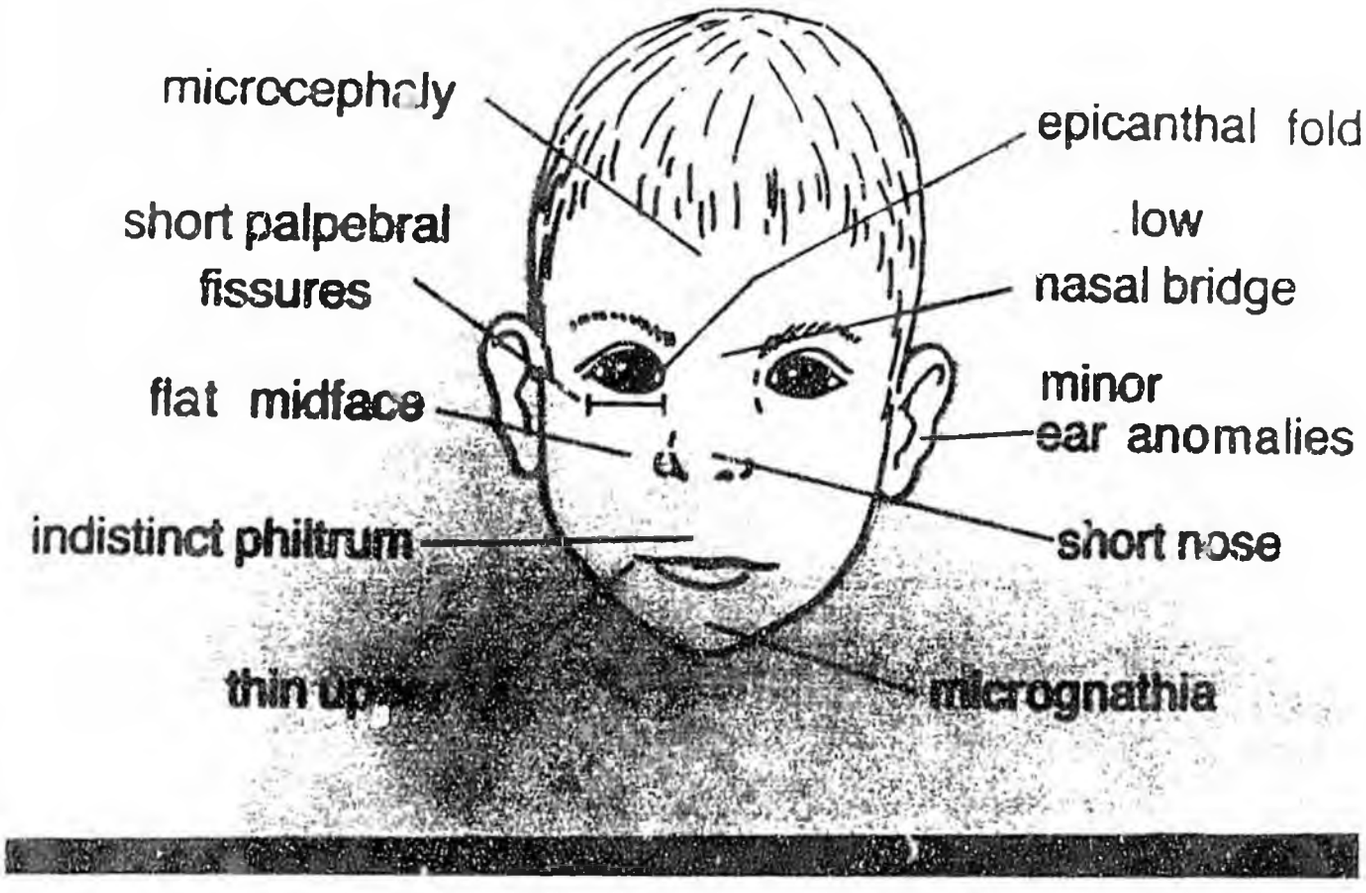
ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE



A cross section of a normal brain.

ALCOHOL-RELATED BIRTH DEFECTS



Common facial characteristics of a child with FAS.

Not all children have all abnormalties.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

Kenny at 8 months.

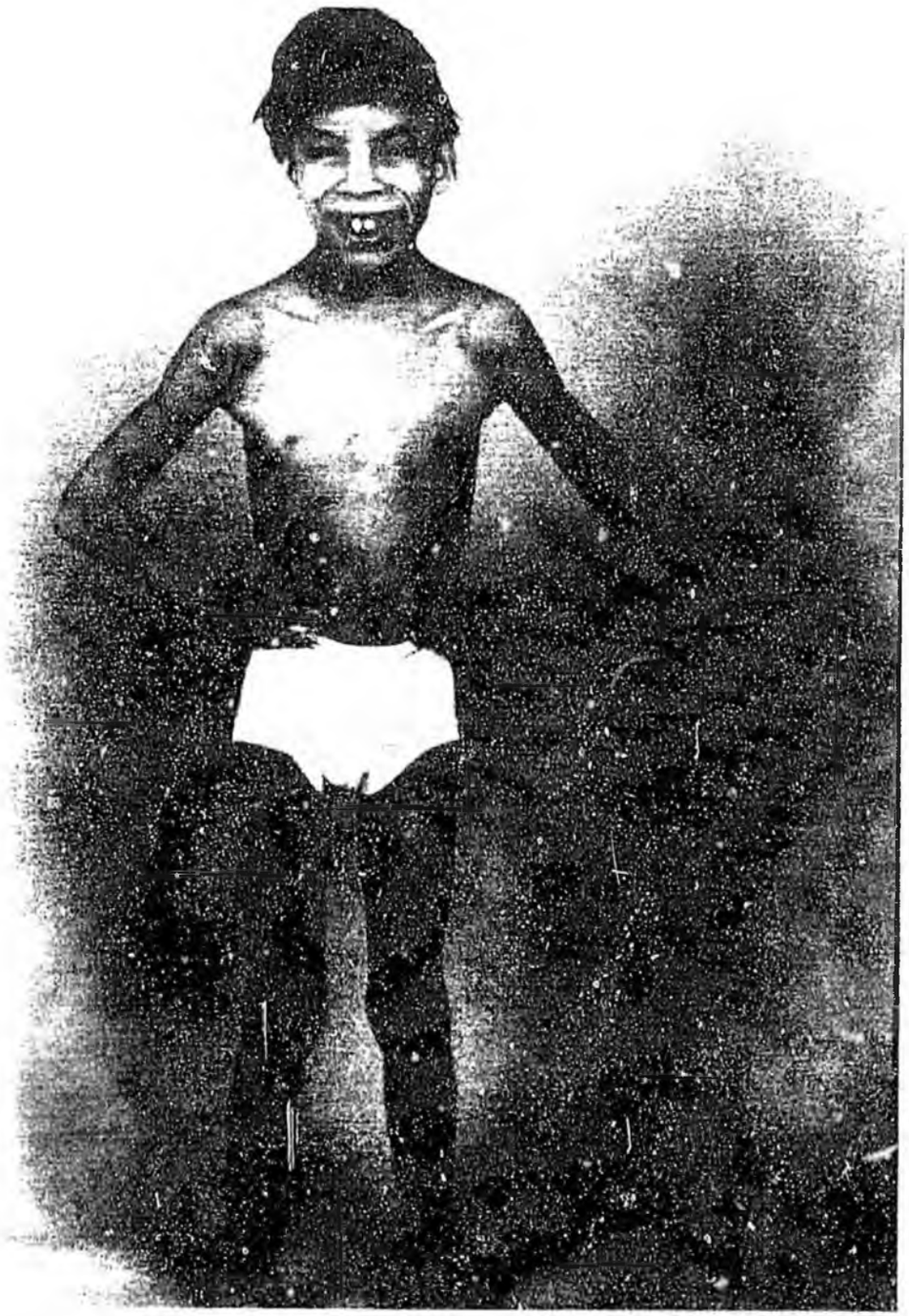
ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

Kenny at 5 years.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effect FAE



Kenny at 8

Kenny has severe mental retardation, orthopedic problems, orthodontal problems, and vision problems.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

Four sisters. The girl in red is normal. The other three have FAS.

Once a woman has a FAS child, and if she keeps drinking during her other pregnancies, these children will have FAS, and each one more severe.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

FAS child with ear anormaly and flat-midface.

Hirsutism (abnormal hair growth) is the only characteristic that does go away.

ETHANOL ENTERS BREAST MILK

Concentration of ETOH in milk
≈ concentration in maternal blood

A nursing mother who drinks can also cause growth retardation and brain damage in her baby.

The alcohol level in breast milk is the same as the mother's blood alcohol level.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome: FAS
Fetal Alcohol Effects: FAE

Many have vision problems.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

Many have serious heart problems.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

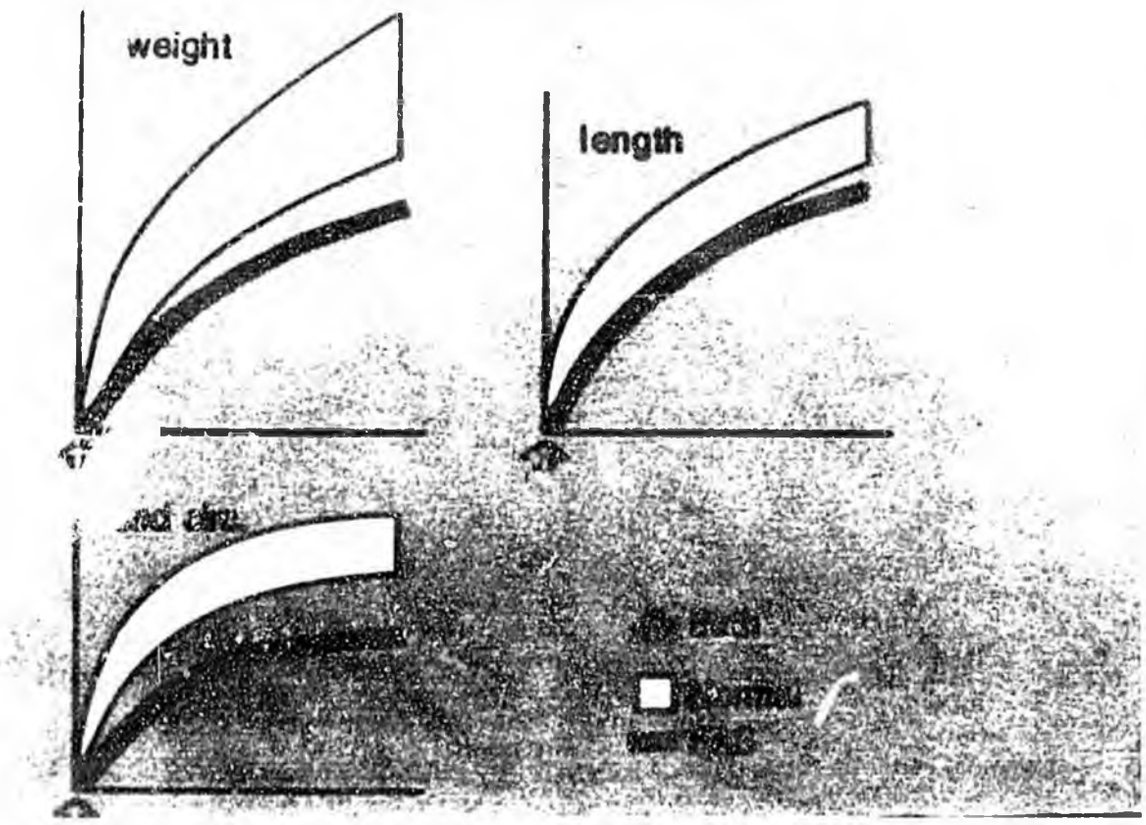
FAS children have central nervous system damage, learning disabilities, mental retardation, and behavior problems.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

FAS children are also often the victims of physical abuse and sexual assault.

GROWTH DEFICIENCY IN FETAL ALCOHOL SYNDROME



FAS children never catch up to normal children.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

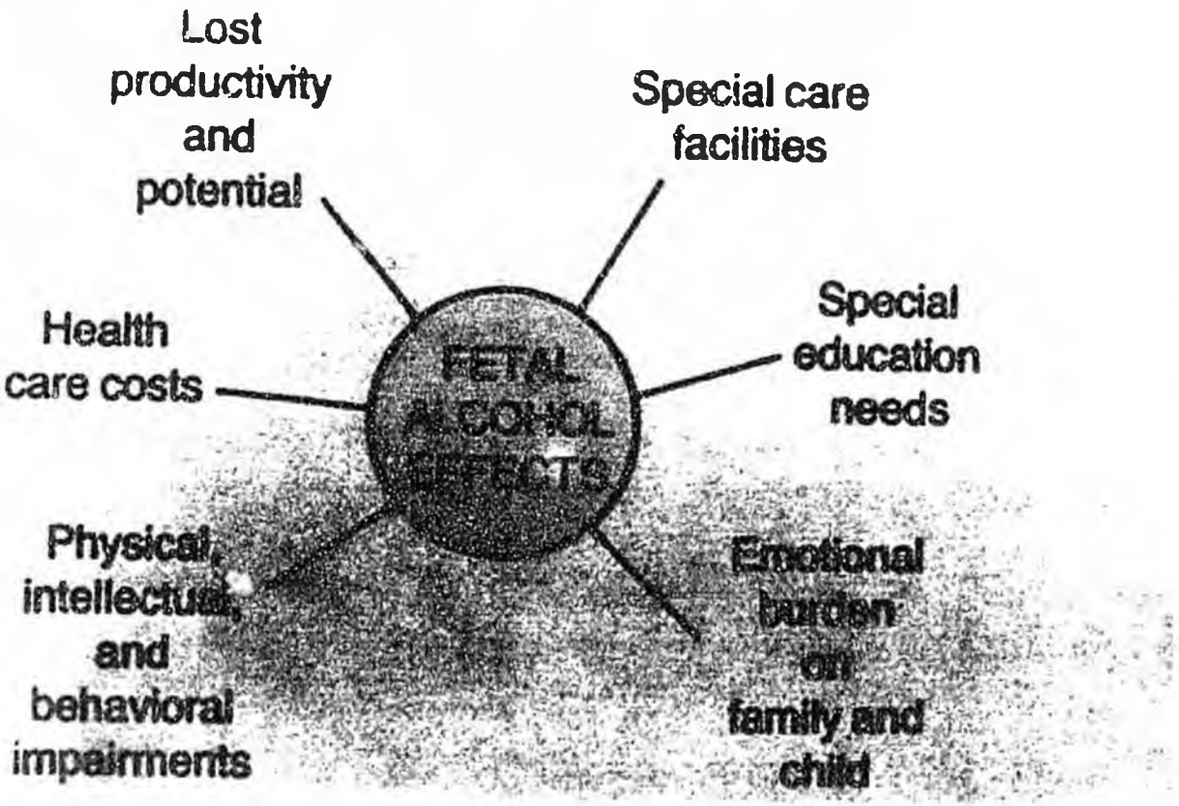
Julie

At 10 months of age she was not yet up to what should have been her normal birth weight, birth length, and head circumfrances.

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effect FAE

TOTAL COSTS TO SOCIETY OF FETAL ALCOHOL EFFECTS



Fetal Alcohol Effects

FAE is more difficult to identify, but the effects of alcohol on these children also takes its toll.

How do you measure quality of life?

ALCOHOL-RELATED BIRTH DEFECTS

Fetal Alcohol Syndrome FAS
Fetal Alcohol Effects FAE

Diagnosis of FAS is easier at early ages; some of the facial differences appear more normal as the child grows.

Learning problems continue, and as adults FAS children never lead totally independent lives.

Official Business

COMMITTEE:

SENATE HESS

DATE: March 22, 1993

SIGN-IN

Subject of meeting:

HCR 7 - ALCOHOL-RELATED BIRTH DEFECTS AWARENESS

PLEASE PRINT!

NAME	ADDRESS (MAILING) & (ZIP)	PHONE	REPRESENTING	DO YOU WANT TO TESTIFY?
Suzanne Perry		465-2071	DHSS Div Alcohol + Drug Abuse	YES
Pat Jackson	Rep. Nicholia	4527		yes