HCR

52

FISCAL NOTE

STATE OF ALASKA
1992 LEGISLATIVE SESSION

BILL NO. HCR 52

Revision Date: _____ **Department Affected:** Legislative Affairs Agency

Title: Alcohol-Related Birth Defects Awareness Week **BRU:** _____

Component: _____

Sponsor: Rep. Lincoln

Requestor: House State Affairs Committee **COMPONENT SERIAL NO.** [ ][ ][ ][ ]

EXPENDITURES/REVENUES: (Thousands of Dollars)

OPERATING	FY 93	FY 94	FY 95	FY 96	FY 97	FY 98
PERSONAL SERVICES	0	0	0	0	0	0
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	0	0	0	0	0	0
CAPITAL	0	0	0	0	0	0
REVENUE FUND SOURCE:						

FUNDING: (Thousands of Dollars)

GENERAL FUND	0	0	0	0	0	0
FEDERAL FUNDS						
OTHER FUND SOURCE:						
TOTAL	0	0	0	0	0	0

POSITIONS: N/A

FULL-TIME						
PART-TIME						
TEMPORARY						

Estimate of current year impact: 0

ANALYSIS: (Attach a separate page if necessary.)

Prepared By: House State Affairs Committee **Phone:** 465-4859

Division: _____ **Date:** 2/24/92

Approved by Commissioner: Representative Gene Kubina, Chairman

Agency: House State Affairs Committee **Date:** 2/24/92

Distribution (by preparer): Leg. Fin [redacted] **Impacted Agency(ies).**

Rev 10/7/91

FISCAL NOTE

HOUSE COMMITTEE REPORT

(7)

Date Referred: February 19, 1992 FURTHER REFERRALS: 2-28-92 Rules

Date of Committee Action: 2/28/92

The STATE AFFAIRS Committee considered: HCR 52

HOUSE CONCURRENT RESOLUTION NO. 52 ALCOHOL-RELATED BIRTH DEFECTS AWARENESS

Relating to Alcohol-Related Birth Defects Awareness Week.

RECOMMENDATIONS:
be replaced with ______________________ [ ] the same title [ ] a new title

[ ] have attached amendments(s)
[✓] do pass
[ ] do not pass
[ ] no recommendations
[ ] individual recommendations
[ ] additional referral to the ______________________ Committee

ADOPTS: ______________________ letter of Intent

ATTACHES NEW FISCAL NOTE(s): (Dept) APPROVES PREVIOUS: (Dept/Date)

[ ] fiscal impact ______________________ [ ] fiscal note(s) ______________________

[✓] zero fiscal note by the H. STA Cmt for the LAA [ ] zero fiscal note(s) ______________________

SIGNING DO PASS	DP	OTHER RECOMMENDATIONS	DNP	NR	AM
Eugene G. Kuhn	✓				
[signature] Gruenberg	✓				
Mike Miller	✓				
Dave Donley	✓				
[signature]	✓				
[signature]	✓				

Eugene G. Kuhn
CHAIRMAN'S SIGNATURE

STATE OF ALASKA / WALTER J. HICKEL, GOVERNOR

DEPT. OF HEALTH AND SOCIAL SERVICES

DIVISION OF ALCOHOLISM AND DRUG ABUSE

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P.O. BOX 240249
ANCHORAGE, ALASKA 99524-0249
PHONE: (907) 561-42.3

SUMMARY OF STATEWIDE FAS/FAE PREVENTION ACTIVITIES
(since Mother's Day, 1991)

* Dena A Coy, the 18-bed, four bassinet prematernal home for pregnant, substance abusing women, operated by Southcentral Foundation through grants from Department of Health and Social Services (DHSS) and Indian Health Service (IHS), opened July 31, 1991.

* In September, the Centers for Disease Control signed agreements with the DHSS and IHS to accomplish three specific goals:

1. Assist the State of Alaska in developing, implementing, and evaluating FAS surveillance systems;

2. Provide technical and programmatic evaluation of the IHS FAS programs and data;

3. Develop model surveillance, data analysis, and program evaluation methods which could be used to assist other States, communities, Native American populations, Circumpolar and other nations.

* As mandated by SB 409, school district training on the needs of individual students who have alcohol and other drug related disabilities.

* IHS reports FAS coordinators in each of the 12 regions.

* FAS Task Forces have been formed or are on-going in Barrow, Bethel and Fairbanks.

* FAS Parent Support groups have been formed or are on-going in Fairbanks and Anchorage. Barrow will hold first meeting in March.

* High Risk Family Coalitions are active in Anchorage and Juneau.

* The Broken Cord aired on TV on February 3. An 800 number was on the screen for people to call for more information following the broadcast. KYBR, in Barrow, is reading the book over the air.

* Trainings:
- June 3-4, 1991: 250 attended conference sponsoring Dr. Ira Chasnoff, of National Association for Perinatal Addiction and Research.
- June, 1992: Dr. Barry Zuckerman, developmental and behavioral pediatrician, will present in Juneau, Fairbanks, and Anchorage.

* Presentations:
- Alaska Association of School Boards
- State Principals Association
- AAEYC
- Infant Learning Program conference

Celebrate your baby!

If you choose to have a child, there will be many occasions to celebrate. Beginning with your decision to have a baby, the birth itself and on to all the joyous moments involved in raising a child - birthdays, first steps, first words, first day of school - you can look forward to a future full of celebrations. Enjoy each of these special events.

To give your baby the best possible chance for a healthy future:

- **Don't drink, smoke or use other drugs during pregnancy**
- **Seek help if you have a problem with alcohol, tobacco, other drugs or stress**

More information:

Alaska Division of Alcoholism and Drug Abuse
P.O.Box H-05F
Juneau, AK 99811
(907) 586-6201

or

P.O. Box 240249
Anchorage, AK 99524-0249
(907) 561-4213

Alaska Council on Prevention of Alcohol and Drug Abuse
7521 Old Seward Highway, Suite B
Anchorage, AK 99518
(907) 349-6602 or
(800) 478-PREV Outside Anchorage

National Hotline for Domestic Violence
1-(800) 334-SAFE

This brochure provided in accordance with A.S. 18.05.037 and A.S. 25.05.111
PUB 16 (5/91)

Celebrate Your Future

Celebrate your future!

Your future together holds the exciting promise of many plans and choices to make as well as special occasions to celebrate. In the years ahead, you may look forward to celebrating anniversaries, birthdays, new jobs, vacations, a new home, or having children.

If you decide to have children, it will be one of the most important choices you are likely to make in your future. It is a decision that will involve a number of other important choices.

Choices

Every couple who decides to have a baby wants it to be healthy — there are many choices you can make to help ensure yours is, too. In addition to regular prenatal check-ups and a nutritious diet, an expectant mother should be extremely careful about the kinds and amounts of all drugs she takes — including alcohol, illegal drugs and over-the-counter drugs such as aspirin.

When a pregnant woman drinks alcohol or uses virtually any drug, her unborn baby is also exposed to the harmful substance(s). These substances flow directly from the mother's bloodstream through the placenta and cross over to the baby. Harmful chemicals taken during the first three months of pregnancy can affect organ development or cause spontaneous abortion. Continued abuse may affect the baby's brain growth and weight gain or cause premature delivery.

Low birthweight is one problem commonly seen among babies whose mothers used or abused alcohol or other drugs during pregnancy. Pregnant women who are physically abused also frequently have low birthweight babies. This is serious because it is a major cause of infant death and increases the risk of illness. Low birthweight is associated with mental and physical handicaps, learning disorders and behavior problems.

Since many women do not know they are pregnant until a month or more has passed, **it is best to stop using alcohol and other drugs before becoming pregnant.**

Alcohol

Drinking during pregnancy increases the chance that your baby will be born with Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), or other alcohol-related birth defects (ARBD). These patterns of physical and mental defects are **irreversible, yet totally preventable.** If you choose to drink during pregnancy, your baby may have:

- mental retardation
- malformed facial features
- abnormally small head and brain
- lifelong behavior problems
- severe learning disabilities
- long term and custodial care needs

Tobacco

If you smoke, you inhale nicotine and other chemicals which then pass into your baby's body. The more you smoke, the greater the risks for your unborn child. It's important to stop, especially before the second half of your pregnancy, when smoking is most harmful to an unborn baby's growth. If you choose to continue smoking, your baby may:

- weigh less than normal at birth making it more susceptible to other health problems
- be born premature or be stillborn
- be hyperactive, have learning problems
- be at higher risk for Sudden Infant Death Syndrome (SIDS)

Marijuana

Smoking marijuana during pregnancy can also harm your unborn child. If you choose to use marijuana, your baby may:

- have features similar to FAS infants
- be stillborn
- have nervous system abnormalities
- be born "high" or showing withdrawal symptoms
- be born with low birth weight
- be at higher risk for SIDS

Cocaine

Cocaine, like alcohol, passes freely across the placenta and can seriously harm your unborn baby. While a single dose of cocaine clears out of an adult within 48 hours, an unborn baby is exposed for up to four or five days. If you choose to use cocaine, your baby may have:

- seizures or a brain-damaging stroke
- cerebral palsy and mental retardation
- serious problems with irritability, jumpiness and other nervous system damage
- higher risk for SIDS
- damage to internal organs
- learning disabilities

Physical Abuse

Pregnancy is often a time in your relationship when violence can begin or increase. Just as with drugs, physical abuse of a mother can affect the health and future of the baby. It is important for women facing violence to find immediate safety, either with family, friends or at a local shelter. If you are pregnant and being battered you are:

- two times more likely to miscarry
- four times more likely to have a low birthweight baby

Choices for fathers

Supporting your wife's decision to be alcohol and drug free during pregnancy is one of the most important actions a man can take to have a healthy baby, but fathers have choices of their own to make. While most research relating to alcohol and other drug effects on pregnancy has focused on the mother's use, attention is now being turned to the role of the father. Recent studies indicate that fathers who smoke increase their risk of having children with brain cancer and leukemia. Men who use alcohol near the time of their child's conception risk seriously harming the baby's development in the womb and increase the chances they will father a low birth weight baby. Smoking marijuana is also believed to produce genetic abnormalities in sperm cells.

ALASKA STATE LEGISLATURE

Representative Georgianna Lincoln

HESS Committee, Co-Chair
Resources Committee, Vice-Chair

Budget Subcommittees
Health and Social Services
Revenue

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Stevens Village
Stony River
Takotna
Tanana
Telida
Tuluksak
Tyonek
Venetie
Wiseman

MEMORANDUM

TO: Representative Gene Kubina, Chairman
House State Affairs Committee

FROM: Representative Georgianna Lincoln GL

DATE: February 28, 1992

RE: HCR 52 - Alcohol-Related Birth Defects Awareness Week

HCR 52 recognizes Mother's Day Week, May 10-16 as Alcohol-Related Birth Defects Awareness Week in Alaska.

This resolution is similar to resolutions introduced in past years which asked the public, both individuals and appropriate organizations, to become educated about and involved in awareness campaigns about the dangers of drinking during pregnancy. While we've come a long way in Alaska, we haven't eliminated the threat to the unborn from alcohol and other drugs.

Children born with Fetal Alcohol Syndrome suffer from a multitude of physical, developmental and mental problems. These problems may include permanent growth retardation, central nervous system damage, mental retardation, and abnormal facial features. FAS children may have heart defects, cleft palate, bone deformities, kidney and vision problems. They are never able to lead totally independent lives. The loss of a productive healthy life is impossible to measure, but in terms of medical and other societal costs these individuals conservatively cost society more than $1.4 million over each lifetime.

Data suggests that 29 FAS children are born in Alaska each year. Fetai Alcohol Effects, a less severe form of Alcohol Related Birth Defects which may be caused by as little as one to three drinks per day, affects between two to fifteen that number each year. Some experts believe the number of FAE children in Alaska to be 10 times the number of FAS children. As more is becoming known about the lifelong impacts to children born with FAE, including learning disabilities and

District 24

SPONSOR STATEMENT

behavior problems, that block the individual's "fit" into society, there is a growing suspicion that FAE children may ultimately be even more costly than FAS children in medical and social services.

Having healthy babies was once thought to be the woman's responsibility. Today we know this is a responsibility shared by partners, families, and friends--by each and every one of us. Mother's Day Week is a timely choice to kick off a renewed awarene: of the importance of healthy choices, by the woman who is pregnant and her support system. The State's FAS Coordinator has been working on various activities to promote Mother's Day Week as ARBD Awareness Week. This resolution will complement and reinforce those activities.

HCR 52

HCR 52 declares the week of May 10-16, 1992 as Alcohol Related Birth Defects Week.

This is an annual declaration which is also promoted on a national basis to increase the level of awareness of the dangers of drinking while pregnant. It permits the State of Alaska to easily promote information related to Fetal Alcohol Syndrome (FAS) and other alcohol related birth defects.

Although it was initially identified by medical researchers in 1973, there is evidence that FAS was known since before biblical times. FAS is caused when a pregnant woman drinks alcoholic beverages. It is not known if there is a safe level of alcohol consumption, so the Surgeon General recommends that women who are pregnant or trying to become pregnant do not drink.

An FAS child will be small, have specific facial features, will not grow appropriately, will have central nervous system involvement, and most frequently will be mentally retarded. While some of these characteristics may be ameliorated with time, care and love, these are lifelong disabilities. Mental retardation never goes away.

It is estimated that each child born with FAS costs the state of Alaska a minimum of $1.4 million during his/her lifetime. FAS is totally preventable. This declaration will assist in promoting the message regarding the dangers of drinking while pregnant.

The Division strongly supports HCR 52.

2-25-92
Loren A. Jones Date
Director

24 Feb 92
Theodore A. Mala, MD, MPH Date
Commissioner

DHSS POSITION

July 1981 Volume 11 Number 2

FDA Drug Bulletin

Surgeon General's Advisory on Alcohol and Pregnancy

Information of Importance To Physicians and Other Health Professionals

Surgeon General's Advisory on Alcohol and Pregnancy

The Surgeon General advises women who are pregnant (or considering pregnancy) not to drink alcoholic beverages and to be aware of the alcoholic content of foods and drugs.

A recent report to the President and Congress[1] summarizes current scientific knowledge about health hazards associated with alcohol consumption, including those during pregnancy. The report concludes that alcohol consumption during pregnancy, especially in the early months, can harm the fetus.

Among the findings of the report are the following:

- Significantly decreased birth weight has been observed among the children of some women who average only one ounce of absolute alcohol (two standard drinks) per day during pregnancy.[2]
- Sizeable and significant increases in spontaneous abortions have been observed at reported alcohol consumption levels as low as one ounce of absolute alcohol twice a week.[3,4]
- A woman who consumes alcohol at amounts consistent with a diagnosis of alcoholism risks bearing a child with a specific cluster of severe physical and mental defects known as the fetal alcohol syndrome (FAS) (See September-October 1977 *Drug Bulletin*). This syndrome of birth defects is frequently associated with mental retardation, and is also characterized by central nervous system disorders, growth deficiencies, specific cluster of facial abnormalities and other malformations, particularly skeletal, urogenital and cardiac. Many of these characteristics are individually subtle but are readily apparent to trained dysmorphologists.
- Even if she does not bear a child with full FAS, a woman who drinks heavily is more likely to bear a child with one or more of the birth defects included in the syndrome. Microcephaly, which is associated with mental impairment, is one of the more common of these defects.

The reported effects on pregnancy outcome appear to be independent of potentially confounding variables including nutrition and smoking.

In addition, it has been demonstrated that alcohol readily enters breast milk and thus is transmitted to the nursing infant. Heavy alcohol consumption is known to decrease the mother's milk.

Research to establish the mechanisms by which alcohol consumption affects fetal and neonatal growth and development is underway.

Health professionals are urged to inquire routinely about alcohol consumption by patients who are pregnant or considering pregnancy. This information should be included in their medical records.

Each patient should be told about the risk of alcohol consumption during pregnancy and advised to not drink alcoholic beverages and to be aware of accurate drinking information from patients, as well as written material for pregnant patients, by contacting the National Clearinghouse for Alcohol Information (NCALI).[5,6]

References:

1. *Report to the President and Congress on Health Hazards Associated with Alcohol and Methods to Inform the General Public of these Hazards.* U.S. Department of the Treasury and U.S. Department of Health and Human Services, Nov. 1980. Available for $4.25 from Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.
2. Little RE. Moderate alcohol use during pregnancy and decreased infant birth rate. *Am J Public Health*, 67: 1154, 1977.
3. Kline J, Shrout P, Stein Z *et al.*: *Lancet*, 2: 176, 1980.
4. Harlap S and Shiono PH: Alcohol, smoking and incidence of spontaneous abortions in first and second trimester. *Lancet*, 2: 183, 1980.
5. Sokol RJ and Miller SI: Identifying the alcohol abusing obstetric/gynecologic patient: a practical approach. In *Alcohol Health and Research World*, 4: 36-40, 1980. Available as document OPO 258 from NCALI, P.O. Box 2345, Rockville, MD 20852.
6. *Alcohol and Your Unborn Baby*, Pub. No. PH-90, NIAAA, 5600 Fishers Lane, Rockville, MD 20857.

NCADD FACT SHEET: ALCOHOL-RELATED BIRTH DEFECTS

DEFINITIONS

- Fetal alcohol syndrome (FAS) is one of the top three known causes of birth defects with accompanying mental retardation—and the only preventable cause among those three. FAS can be prevented by abstaining from alcohol consumption during pregnancy.[1]

  FAS is characterized by a cluster of congenital birth defects that develop in the infants of some women who drink heavily during pregnancy. These defects include prenatal and postnatal growth deficiency; facial malformations such as a small head circumference, flattened midface, sunken nasal bridge and flattened and elongated philtrum; central nervous system dysfunction; and varying degrees of major organ system malformations.[2]

- Fetal alcohol effects (FAE), a less severe version of FAS, is characterized by milder or less frequent FAS signs. Low birthweight, subtle behavioral problems or a partial display of physical malformations, for example, may be seen in the newborns of women who consumed less alcohol during pregnancy than women with FAS newborns.[3]

INCIDENCE AND RISK FACTORS

- Nearly 5,000 babies – one in every 750—are born with FAS every year. (FAS prevalence rates range from one in 1,000 to one in 200.) Comparatively, FAE may affect 36,000 newborns each year.[4]
- One in six women in the peak childbearing years of 18-34 may drink enough, either chronically or episodically, to present a hazard to an unborn infant.[5]
- Alcoholic women are at highest risk of bearing children with FAS. Alcoholism is a chronic, progressive and potentially fatal disease characterized by tolerance and physical dependency or pathologic organ changes, or both.[6]
- FAS is prevalent in 9.8 of every 1,000 American Indians from a particular high risk culture. Other American Indian populations have rates ranging from 1.3 to 10.3 for every 1,000.[7]
- An average of one to two reported drinks daily is linked to decreased birthweight, growth abnormalities and behavioral problems in the newborn and infant. Increased risk of spontaneous abortion has been found at an even lower dose: one to two drinks twice weekly.[8]
- The probability of having a child with FAS or FAE increases with the amount and frequency of alcohol consumed. Whenever a pregnant woman stops drinking, she reduces the risks of FAE and the consequences of alcohol exposure.[9]
- There is no known safe dose of alcohol during pregnancy, nor does there appear to be a safe time to drink during pregnancy. Although 90 percent of the public is aware that drinking during pregnancy may damage the fetus, one study showed that one-third of women interviewed believed that drinking more than three drinks a day during pregnancy was safe.[10]

"GOVERNMENT WARNING: (1) According to the Surgeon General, women should not drink alcoholic beverages during pregnancy because of the risk of birth defects..."

—Warning label required by federal law on beer, wine, hard-liquor and wine-cooler containers, effective November 1989.

ECONOMIC FACTORS

- Assuming a conservative estimate of one FAS newborn for every 1,000 live births in 1980, it cost approximately $14.8 million to treat them; $670 million to treat the 68,000 FAS children under 18; and $760 million to treat 160,000 FAS adults. Plus, indirect productivity losses were $510.5 million.[11]
- Women are now heavily targeted for marketing of alcoholic beverages. (Women will spend $30 billion on alcoholic beverages in 1994, up from $20 billion in 1984.)[12]

PUBLIC HEALTH RECOMMENDATIONS

- The best advice for pregnant women is to abstain from alcohol consumption during pregnancy. There is no evidence to establish an alcohol consumption level free of risks to the fetus.[13]
- Women who breastfeed should continue to abstain from drinking alcohol until their babies are weaned. Alcohol readily enters breast milk and heavy alcohol consumption has been shown to reduce lactation.[14]
- As of January 1990, nine states and 17 cities/counties require that signs warning of the dangers of drinking during pregnancy be posted wherever alcoholic beverages are served or sold.[15]

SOURCES

[1]H.J. Harwood et al., Economic Costs to Society of Alcohol and Drug Abuse and Mental Illness—1980 (Research Triangle Park, N.C.: Research Triangle Institute, 1984), p. B-3. [2]"Fetal Alcohol Syndrome," Alcohol Topics in Brief, National Institute on Alcohol Abuse and Alcoholism (NIAAA), April 1985, p. 1; K. Warren, "Alcohol-Related Birth Defects: Current Trends in Research," Alcohol Health and Research World, NIAAA, Vol. 10, No. 1 (Fall 1985), p. 4. [3]R. Little and C. Ervin, "Alcohol Use and Reproduction," eds. S. Wilsnack and L. Beckman, Alcohol Problems in Women (New York: The Guilford Press, 1984), p. 158. [4]Harwood et al., op. cit., p. B-3; H.J. Harwood and D.M. Napolitano, "Economic Implications of the Fetal Alcohol Syndrome," Alcohol Health and Research World, NIAAA, Vol. 10, No. 1 (Fall 1985), p. 41. [5]"Behavior Risk—Factor Surveillance—Selected States," Morbidity and Mortality Weekly Report, February 1983, pp. 32 – 155. [6]NIAAA, Fourth Special Report to the U.S. Congress on Alcohol and Health, ed. J.R. DeLuca, DHHS Pub. No. (ADM) 82 – 1080, 1981, p. 36. [7]P. May, et al., "Epidemiology of Fetal Alcohol Syndrome among American Indians of the Southwest," Social Biology, Vol. 30 (1983), pp. 374 – 387. [8]Little and Ervin, loc. cit., p. 162. [9]J. Funkhouser and R. Denniston, "Preventing Alcohol-Related Birth Defects," Alcohol Health and Research World, NIAAA, Vol. 10, No. 1 (Fall 1985), p. 56. [10]Ibid., p. 54. [11]Harwood et al., Economic Costs to Society, p. B-11 and B-15. [12]"Betty Briefcase Buys More Bottles," Advertising Age, Thursday, September 12, 1985; Impact, Vol. 19, No. 15 (August 1, 1989). [13]NIAAA, Sixth Special Report to the U.S. Congress on Alcohol and Health: from the Secretary of Health and Human Services, DHHS Pub. No. (ADM) 87-1519, 1987, p. 93. [14]R. Niven, "Alcoholism—A Problem in Perspective," Journal of the American Medical Association, Vol. 249 (1983), pp. 2029-2033. [15]NCADD Office for Public Policy, Washington, D.C.

NATIONAL COUNCIL ON ALCOHOLISM AND DRUG DEPENDENCE, INC

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Revised 1/90

Ideas for Community Activities on the Prevention of Alcohol-Related Birth Defects

- Adopt a pregnant woman and be her support person throughout the pregnancy and postpartum period.
- Make a written contract with a pregnant patient not to drink during the pregnancy.
- Offer pregnant patient $$$ off their total prenatal and delivery bill if they do not drink during the pregnancy.
- Offer pregnant patients a gift, such an infant safety seat, if they do not drink during the pregnancy.
- Work with local taverns and restaurants to offer free non-alcoholic drinks to their pregnant customers.
- Work with local school board and teachers to incorporate a class on Alcohol-Related Birth Defects in junior and senior high schools.
- Work with schools to have special ARBD presentations made in the schools by the health aide, community health representative, public health nurse, or doctor.
- Arrange to have ARBD presentations made to the PTA.
- At local health fairs, have an ARBD display.
- Encourage Native Health Corporations, Indian Health Service and State Alcohol Programs to develop preven tion and intervention programs for pregnant women.
- Launch an ARBD media campaign, including television, radio and newspapers, in your area.
- Contact local childbirth educators (LaMaze Childbird Association) in hospitals and family planning clinics, and encourage and support their efforts by providing them with information on Alcohol-Related Birth Defects.
- Develop a on-hour ARBD presentation targeted to youth that can be presented to youth groups and clubs.
- Conduct ARBD presentations to women's groups in your community.
- Conduct ARBD presentations to men's groups in your community.
- Work with AA to have ARBD presentations made at regular AA meetings, and also at Al-Anon and Al-A-Teen meetings.
- Prepare educational display on ARBD for local clinic.
- Develop an ARBD prevention network in your own community by identifying persons who are interested in working to prevent Alcohol-Related Birth Defects.
- Work with local government to develop ordinances regarding drinking while pregnant; and on displaying warnng signs at point of purchase.
- Set up a support group for pregnant women that would not only provide prenatal and parenting education, but social activities.
- Work with local stores to do promotional display on non-alcoholic beverages, focusing on pregnant women.
- Conduct ARBD presentations at prematernal homes.
- Encourage your local Medical Association to promote education on ARBD for medical professionals.
- Sponsor a poster contest in the schools on the topic of prevention of ARBD.

Courtesy of Alaska Native Health Board

Vol. 1, No. 4 Fall 1991

ICEBERG

AN EDUCATIONAL NEWSLETTER FOR PEOPLE CONCERNED ABOUT FETAL ALCOHOL SYNDROME (FAS) AND FETAL ALCOHOL EFFECT (FAE) . . . BECAUSE THE PROBLEMS WE READILY SEE ARE ONLY THE *TIP OF THE ICEBERG*

JAMA ARTICLE ON FIRST MAJOR STUDY OF LONGTERM CONSEQUENCES OF FAS

Fetal Alcohol Syndrome in Adolescents and Adults

by Ann Streissguth

Most of the patients with Fetal Alcohol Syndrome or Fetal Alcohol Effect (FAS/FAE) described in the medical literature have been young children. Only isolated case reports of adolescents and adults have appeared. In the March, 1991 issue of the Journal of the American Medical Association, researchers from the University of Washington Medical School (in collaboration with others from New Mexico and British Columbia) published the first major study of the long-term consequences of FAS.

In this report, 61 patients are described, who range in age from 12 to 40 years. Their average age was around 17 years. Seventy-four percent of the sample were American Indian, because the study involved a follow-up of earlier research carried out on several Indian reservations in the southwest. This report also included patients referred to dysmorphologists for diagnostic evaluations.

Physical Features Less Distinctive After Puberty

One important finding was that the physical features of FAS are less distinctive after puberty. The faces of the patients were not as characteristic as they had been in childhood.

Growth deficiency for weight was not as remarkable as in infancy and childhood. The majority remained short, and had microcephaly (small heads). This helps explain why the initial identification of persons with this disability is more difficult as they mature, and points up the importance of early identification.

Intellectual Level Varied

Intellectual development was extremely varied. Some patients were very mentally retarded and others had normal intelligence. The average intellectual level for the patients with FAS was in the mildly retarded range. Almost half of them, however, had an IQ of 70 or above, so would not be technically classified as mentally retarded.

This has important implications for obtaining community services. Many persons with FAS are not automatically eligible for programs designed for the mentally retarded. Although the average academic functioning of these patients was at the 2nd to 4th grade level, some did read and spell at a 5th grade level or above. In general, arithmetic skills were the most limited, probably representing difficulty with abstract thought.

Impaired Adaptive Functioning

This study carried out systematic evaluations of the patients' level of adaptive functioning in three skill areas: daily living, socialization, and communication. This subgroup had an average chronologic age of 17 years but their average age of adaptive functioning was at a 7-year level.

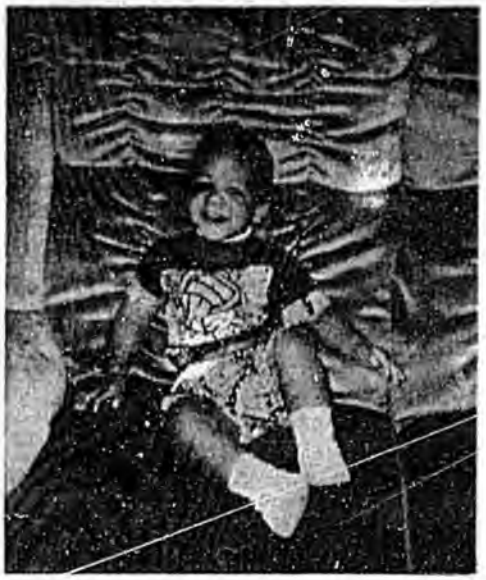
The group performed best on daily living skills (at an average 9-year level) and most poorly on socialization skills (at approximately the 6-year level). Although one or two patients had age-appropriate daily living skills, none were age-appropriate in terms of socialization or communication skills. Even the patients who were not *technically* retarded failed to accomplish several specific types of adaptive behaviors such as: failure to consider consequences of action, lack of appropriate initiative, unresponsiveness to subtle social cues, and lack of reciprocal friendships.

These findings underscore the critical importance of keeping adolescents with FAS/FAE in the school setting. They certainly do

(continued on p. 7)

A FAS Success Story

LANCE *by Connie Moss, Anchorage, Alaska*



He came into our lives when he was just 24 hours old. That was 21 months ago. He has changed our lives in so many ways. Most professionals ask us "How do you do it?". I was so thankful when Dr. Streissguth did not ask me that, during our phone conversation in May.

> When he blows me kisses I get a knot in my throat.

Lance has several medical problems, let me name a few. He is diagnosed as FAS, he is a cocaine baby, he is microcephalic , he has Myoclonic Jerks (a form of Epilepsy), he is still on Pregestimil (a predigested formula) due to his rumination, he is developmentally delayed (at 21 months he is functioning at a 10 months level), he has a severe allergy to all wheat products, he has a sleep disorder, and was diagnosed at 6 months as hyperactive.

But we prefer not to dwell on the negative. We are in the process of adopting him - an energetic, lovable toddler. We have loved him since the day he came to us as a foster baby at one day old. We are also adopting his 3 year old sister, who is FAE, and also a cocaine baby. She came to live with us when she was 6 months old.

> We laugh so hard he forgets he's angry

Lance is a daily challenge, but the love he has brought to our home is immeasurable. The first time he said "mama", he got hugged so tight he jumped with surprise. Every milestone is embedded in my memory. To me he is the cutest child ever born. When he blows me kisses I get a knot in my throat. We've been through the trenches together, and we have survived.

The reason we have survived is Dr. Ann Steissguth! The first real information I received on FAS was at a symposium in Anchorage. I must admit that when she stepped up on the platform, I thought, "How can this tiny woman, in her tailored suit, know anything about what I face daily?", but from the moment she opened her mouth to speak, I was spellbound. She was describing "my" children!

I took notes till my hand was cramped. That day changed the way I dealt with my children. I credit our success with Lance to her. After the symposium, I read everything I could get my hands on about FAS children, most of it written by Dr. Streissguth. It works, it really works and I am much more relaxed and encouraged about the future of my children.

We have provided tight structure in our home. It is of the utmost importance. Second is consistency in everything possible. Third comes repetition. I find myself repeating things to everyone, because I am so used to doing it with the kids. Fourth is teaching appropriate behaviors; no one wants to be around a child that is constantly "in your face" .

> He has learned to say "please".

Also, you must be an advocate for your child. Lance is seen weekly by the Anchorage Infant Learning Program, once a week he goes to occupational therapy and will soon be starting physical therapy. All of these things now come to us as second nature, but it was really difficult and frustrating in the beginning.

We have always been a family that loves to laugh. Lance has provided us with free entertainment. He just recently "learned" to throw a temper tantrum from our younger foster child.

First he would kick, and forget to lay down. Then he learned to lay down and scream, but forgot to kick. This went on for several weeks, (different variations) with Lance never quite getting it all together. We laugh so hard over this display that he forgets he's supposed to be angry. It does ease the tension.

In May we were faced with the dilemma of placing Lance on Ritalin. We had serious reservations about doing that. I made several phone calls for advice and wound up putting in a call to Dr. Streissguth. I was certain she would be too busy to speak to me, but I thought maybe someone on her staff would be able to take the call. You can imagine my surprise when I actually got put through to her. It was the most wonderful experience!

I felt she truly understood how I was feeling. She was so uplifting, so encouraging, so warm, and so helpful that I felt like I was on a "high" after our conversation. We decided not to put Lance on Ritalin, and feel very confident with our decision. I now have renewed strength to continue with our children.

Dr. Streissguth also gave me some excellent ideas on getting Lance to eat real foods. It is working, slowly but surely. We are creating in him a "desire" to eat. He is offered one small bite at every meal. If he eats it fine, if he chooses not to, fine. If he wants another bite, we distract him and do not give it to him. He is now becoming interested in more "bites". This is in just one week. It has taken an enormous burden off our shoulders. We were beginning to wonder if he would still be on the bottle at age 18! The bonus is that he has learned to say the word "please".

We have many wonderful stories I could tell you about our children but let me just end by telling you this. There is a reason for our children being in our lives and I have finally realized, thanks to Dr. Streissguth, that it is NOT to drive me crazy!

Fetal Alcohol Syndrome - A letter from a 16 year old

by Sidney Helbock

When I first found out that I had the symptoms of Fetal Alcohol Syndrome I was confused and angry. I thought that I was different from everyone else and that I would be known for what I have. Since then I have learned that the symptoms vary from individual to individual. It depends on during what stage of the pregnancy the mother drank, and the amount of alcohol consumed.

> I used to think
> I was different from
> everyone else

One of my symptoms is trouble understanding instructions. When a teacher shows us a certain topic, I can understand. Visual contact is a very important way of learning for me. Instructions sometimes confuse me. Following instructions is hard. When I'm asked or told to do something (like "take out the garbage") I won't understand, or the words will get mixed up in my mind.

> Most of the time
> I worry a lot

Some other symptoms are: not being able to follow oral instructions as well as written ones (example - Teacher

giving assignment instructions orally - not being able to remember or follow them correctly); not hearing exactly what was said to me (example - My stepfather giving me a command to do, and not hearing him clearly, even in the same room. It's like I don't catch some words or phrases.); being impulsive, doing or acting on excitement, not able to focus on reality if disaster strikes.

Most of the time I worry a lot, and make problems seem impossible to handle. When I worry, I make myself sick. At school sometimes I get sick to my stomach, or get a fever and feel awful.

These symptoms are very small compared to some symptoms I've

> this is to help me
> guide myself
> and others

heard of. Some people find it impossible to believe when I explain my problem, since they can't see the signs of FAS.

This letter is to help me guide myself and others. I want to help people learn about FAS, help parents who have kids who have it, and let other people who have it understand themselves better.

Sincerely, Sidney Age 16

DECLARATION OF WAR

WHEREAS: Alcoholism is maiming and killing our loved ones, and

WHEREAS: Fetal Alcohol Syndrome is the number one cause of mental retardation,and

WHEREAS: Fetal Alcohol Syndrome is TOTALY PREVENTABLE,and

WHEREAS: We can no longer stand idly by and watch our families and friends decimated by this enemy,

THEREFORE BE IT RESOLVED: that we, the undersigned, hereby make a DECLARATION OF WAR

against alcoholism and Fetal Alcohol Syndrome, and,

BE IT FURTHER RESOLVED: that we, the undersigned,

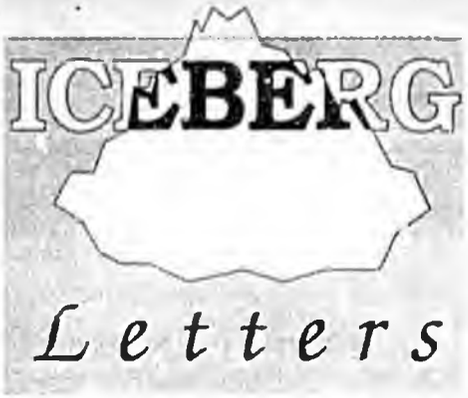
"CALL THE WARRIORS TO BATTLE".

This declaration was produced by the attendees at the Inchelium Fetal Alcohol Syndrome Conference, in Inchelium Washington on August 20, 1991.

The Battle to Protect Our Children

Are we not our ancestors' people? Were our people not great warriors: When an enemy threatened them, did they not come together and fight as one to protect their families? Why do we turn away from our enemy today? Why do we dishonor our ancestors by cowering like dogs in the face of our enemy, "alcoholism"? Can we not come together as one to fight our enemy? An enemy who is killing and disabling our children. An enemy who has already killed many of our brothers and sisters. An enemy who has killed most of our parents and even some of our grandparents. NOW is the time for us to "Call our Warriors" to battle. Let us prepare for battle. Let us prepare our minds, our souls and our bodies for the greatest battle of our lives...the battle to protect our children.

by Virginia LeaderCharge
Presented at the Inchelium FAS Conference, August 20, 1991



FROM OVERSEAS

Dear Mrs. Leuthold,

Ann Streissguth sent me the first issue of "the Iceberg", your very remarkable newsletter. I congratulate you!

In France we have a lot of children, adolescents and adults with FAS/FAE problems. In our next workshop about FAS, I'll talk about your campaign to fight pregnant women's alcoholism.

"Iceberg", I think, can bring overseas many answers to our problems.

Yours sincerely,
Dr. Philippe Dehaene
Centre Hospitalier de Roubaix, France

EDITORS NOTE: I have sent Dr. Dehaene a packet of several copies of past issues to share with his colleagues. He included copies of his research and promotional materials they have been using for some time aimed at pregnant women (in French of course). The brochures have a photograph of a pregnant woman ala Demi Moore, and are very attractive.

BIBLIOGRAPHY AVAILABLE

Editor,

Did you know that a bibliography is available on Alcohol and Pregnancy with hundreds of items from the past 2 years? It was compiled in May of 1991 by the NIAAA Office of Scientific Affairs, and is available from the National Clearinghouse on Alcohol and Drug Information. (P.O. Box 2345, Rockville, MD 20852) There is no charge for this. They can be reached at 1-800-729-6686 or (301) 468-2600. Please let people know about this.

A Reader
Seattle, WA

EDITORS NOTE: I encourage all readers to make use of this valuable resource to educate themselves. This bibliography can also be shared with the professionals you deal with in your life, and help them get accurate and valid information on FAS/FAE issues.

Parents' Support Group

Connecting with others who really *do* understand !

The enthusiasm and sense of belonging generated at Parents' Support Group meetings is testimony to the existence of unmet needs in families with FAS/FAE affected children.

Many parents have experienced frustration, anger, grief, anxiety and other feelings in relation to the challenges of dealing with their children. Families or helping professionals who do not face some of the problems FAS/FAE families do, may not believe, and/or understand this intensity. Sometimes they discount or minimize the reality faced by affected parents because they just don't face such issues in their own family.

In the support group, it is often a new experience for these parents to meet with and talk to a whole roomful of people who can truly share their feelings. What a healing and supportive environment. How wonderful to know their own anguish is validated by the understanding and acceptance of many other parents. The past sense of isolation vanishes as they connect with others who share their life experience.

In addition, there has been an outpouring of wonderful, creative ideas to help support families and educate the community and professionals about FAS/FAE issues.

Some suggestions for parents:

- Leave a paper trail. Accumulate reports, letters and comments on incidents and events. These documents will be valuable to help you justify a safe, appropriate solution for your child if/when things accelerate.
- Talk to professionals. Reach out to your own doctors, teachers, and counselors with information. Leave the Iceberg in their offices. Communicate your experiences to them so they see the gut impact as well as the facts. Be clear about what you and your children need.
- Share your feelings. Take good care of yourself by regularly attending support groups, and working on your own support network.
- Share your ideas. Check out your perceptions and evaluations with other parents who experience the same reality. Listen to how other parents solve problems and try what seems to fit your own circumstances. Tell others how you solve problems, and share your successes.
- Maintain perspective. Our FAS/FAE children take an inordinate amount of our time and energy. Focus on the family as a whole. Recognize your obligations to your own self care, and to others in your family. Aim for balance.

The Parents' Support Group in Seattle meets at 7:30 PM every other Monday, at the Aurora Church of the Nazarene, North 175th and Meridian North, Room 209. Call Roberta Wright (206) 546-6226 for dates and other pertinent information.

The next few meetings will be used to plan long range goals and decide on a name for the group. All parents are invited to come and participate. Parents from other areas will be assisted in setting up support groups in their own communities.

I C E B E R G

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Adoptive Families and the "Search" Movement

How to Get the Medical Information You Need About your Adopted Children

by Sally Graves

I was watching my 18-month-old grandchild blowing soap bubbles in the yard last month, and it occurred to me that soap bubbles provided a visual symbol for the way we spread information around among counselors, researchers and parents in the field of FAS/FAE.

Foster parents, adoptive parents, caseworkers, therapists, birth parents, and teachers all tend to move around within their special "bubbles", reflecting the area of interest closest to them. Too often, our bubbles are closed and they float past each other. Sometimes they barely touch and then bounce away. Often they are solitary and never touch at all. But, when I watched the toddlers playing with their bubbles, I noticed something. When you are working close to someone else, the bubbles can stick together and merge into one big bubble, or integrate into a cluster with innumerable little ones attached.

For example, I'm an adoptive parent of "special needs" children. I also have biological children. Years ago my bubble focused on my kids and the ways that everyone in our family was affected by the dynamics that adoption created for us. I've had to learn a lot about the psychological and developmental impacts of adoption. As our children became adults, we learned a great deal about resources for searching out birth families (the "Search Movement"). Now we are connected with a new network (a new bubble?) of adult adoptees and birth parents that we barely knew existed five years ago.

Recently I was speaking with another adoptive parent who had become an expert on the disabilities caused by FAS, but had no idea how to begin asking and searching for birth parent information. "I guess I'll have to hire a private detective...", she sighed. "Oh no, that's not necessary," I assured her. "Let me tell you about W.A.R.M., and the triad support groups, and the volunteer search consultants..." Our bubbles had bumped against one another and merged into a larger bubble. We each shared knowledge and resources and were strengthened to work for change.

Birth parents need support in dealing with the grief they feel about their children. Adoptive and foster parents need to connect with birth parent information in order to do their parenting jobs. Medical professionals need to hear the experiences of the parents (adoptive, foster or birth) doing the actual child rearing, so that all of us working with FAS/FAE children can do the best possible job.

These are some important resources for those interested in birth parent search information and support. The American Adoption Congress (ACC) maintains a "hotline" for the purpose of offering search and support referrals at (505) 296-2198. In Washington State, the affiliate of AAC is the Washington Adoption Rights Movement (W.A.R.M.). Contact W.A.R.M. at 5950 6th Ave. S. (#107), Seattle, WA 98108, (206) 767-9510.

Sally Graves is an adoptive parent in Seattle, and co-coordinator of the Adoptive Parents Support Group of the Seattle Interracial Family Association. She is Assistant Director of the Social Work Continuing Education Department at the University of Washington.

Senate Authorizes $2 Million Plus for FAS — Will the House?

Senator Brock Adams: Activist for FAS Programs

Brock Adams is one of the strongest supporters of alcohol research in general, and FAS programs in particular. This past year he has spearheaded significant legislation.

Adams has worked closely with Senators Tom Daschle, Tom Harkin, and Edward Kennedy on S1306. One goal of this Senate bill is to reorganize the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA). Adams recommended ADAMHA Institutes should focus more attention on FAS and other alcohol-related birth defects. He named the University of Washington in Seattle as a national leader of FAS research.

Adams obtained authorization in the Senate for $2 million for the Centers on Disease Control to begin a program to assist states in FAS prevention, evaluation, and improvement of data on the number of infants born diagnosed with FAS.

Adams made American Indian governing units and agencies eligible to apply for Federal grants. The areas covered include a variety of mental health services, demonstration projects, substance abuse prevention and treatment projects, and community grants.

Adams included American Indians as one of the focus groups for the new Office of Special Populations. This office will develop and coordinate plans to prevent substance abuse and mental illness, and to counteract discrimination.

Now it is vital to get the House to keep the same level of appropriations for FAS in their cooresponding versions of these bills. Time is of the essence! Let the House members know how you feel, or send your letters of support to Senator Adams, 915 2nd Avenue, Seattle, WA 98104

N O F A S - Healing the Broken Cord

New Organization Dedicated to Eradication of All Alchol Related Birth Defects

The first annual meeting of the National Organization for Fetal Alcohol Syndrome (NOFAS) will be held in Minneapolis on October 21-23, 1991. The conference, titled "Healing the Broken Cord", will feature Rodney A. Grant from "Dances with Wolves". Grant will speak on how to focus on healing the Indian community as a whole. The conference is coordinated by the American Indian Institute of the University of Oklahoma. Each presentation will be followed by a talking circle session led by a trained facilitator.

Contact sponsor Patti Munter at (202) 785-4585, NOFAS, 1815 "H" St. NW, Suite 750, Wash., DC for information — or the conference coordinator for the American Indian Institute, University of Oklahoma at (405)325-4127.

NOFAS has been organized with specific goals and objectives.

- To reduce the rate of alcohol related birth defects in the United States through increased public awareness and education.

- To establish an annual conference on FAS/FAE aimed primarily at the Indian community which will address medical, educational and community issues.
- To assist in the promotion of preventative education and community empowerment through a media campaign aimed at the Indian community.
- To train health care professionals, educators and community members in issues of FAS/FAE and addressing the specialized needs of FAS/FAE children.

Promotional materials from NOFAS further explain the factors that motivate their organization.

FAS/FAE is the leading known cause of mental retardation. It can be prevented. If women didn't drink when pregnant there would not be another case of FAS.

Recent data estimates that 2.7 out of every 1,000 babies born in this country are afflicted with FAS/FAE, and in some Indian communities one out of four babies born are affected by alcohol. Mental retardation, low IQ, organ dysfunction and hyperactivity are just some of the problems these children must bear. **— all are irreversible.**

Alcohol related birth defects are a national problem and require a national program that will provide all women and families access to information on alcohol and prenatal care for the health and life of their children. NOFAS will establish a central source of information on FAS/FAE prevention, intervention and treatment.

An Adult Has Been Diagnosed as FAS or FAE - Now What?

by Diane Davis

An adult with FAS is often a child in an adult body. Physically, that body may appear to be completely normal, or it can have definite malformations. The range is wide, as is true of what tasks these adults can easily perform, how much information they can retain, how well they can manage even the simplest of daily living skills. There is great variety in how they respond to the world socially and emotionally. Some common factors are:

-Their academic skills are limited.
-They have poor judgement and little concept of what is right or wrong.
-They are often victims because others take advantage of them.
-They have little or no ability for handling money appropriatly.
-They may have a normal sex drive but little or no impulse control and a limited ability (if any) to care for a child of their own.
-They may become depressed and isolated easily, and few have normal friendship patterns with peers.

In our society, there is the expectation that adults who look "normal" will act like adults, not children. There is very little tolerance for the type of acting out that FAS/FAE adults may do.

Because they are like children, these adults need primary caretakers who can look after them. They need to be protected. They need consistency and routine, especially in a job setting. They need tasks that they can succeed at, and bosses and other adults who are patient and understanding.

Providing supervised social activities is also important. Often FAS/FAE children and adults excel in art, music and certain sports. Activity provides a valuable outlet and brings fun into a life that can be frustrating and lonely.

Adequate medical/dental care is another area of importance. Just as young children don't always know that they need a doctor's attention or that it is time for a dental or eye examination, neither do FAS/FAE adults. They need responsible others who will follow through with seeing that they get to their appointments.

Counseling that has just begun to become available for FAS/FAE affected children and their families. Sometimes the family needs strengthening emotionally before it can begin to adapt to the changes that need to be made. Parents and siblings may need to open up and express their feelings, disappointments, fears and frustrations. They may need to become more educated about FAS/FAE. Affected children can also benefit from counseling. They can be introduced to specific, concrete ideas and ways of dealing with things. They also can respond in a positive way to the one-on-one attention and a person who can be objective and give them the emotional support they need.

Diane Davis is a therapist in private practice. She specializes in issues related to chemical dependency, FAS and FAE. She can be reached at (206) 323-9097.

Longterm Study *(from p.1)*

not have the adaptive living skills to survive well outside of a structured environment. Our research also points up the necessity of schools taking a broad functional approach to education, and the importance of job-skills training and work experience. It is of interest to note that of those patients on whom information was available, only 6% were in vocational programs, 2% were working, and none were entirely independent.

Family History

Family environments of these patients with FAS/FAE had been remarkably unstable. On average, they had lived in five different principal homes in their lifetimes. Only 9% were with both biologic parents; 3% with their biologic mothers. For those for whom accurate data could be obtained, 69% of their biologic mothers were known to be dead. This statistic demonstrates the severe impact of alcoholism in women (they died not only of cirrhosis, but of many other types of alcohol-related accidents and violent deaths).

This information leads to the conclusion that an early diagnosis of FAS in a child is important from the standpoint of both mother *and* child. Mothers (who have given birth to children with FAS) are clearly at risk for alcohol-related disability and premature death. Diagnosis of FAS in the child can not only help the child receive proper services early in life, but can help the mother be recognized as needing support and services for her own alcoholism.

Maladaptive Behaviors Present Greatest Challenge

This article concludes "Fetal Alcohol Syndrome is not just a childhood disorder; there is a predictable long-term progression of the disorder into adulthood, in which maladaptive behaviors present the greatest challenge to management."

As we point out in the article, however, the outcomes that we have documented represent the interactive influences of biology and environment.

Most of these patients were born before mothers were generally aware that drinking during pregnancy was harmful. Most of these patients were undiagnosed as infants and young children, or if they were, this diagnostic information was not carried along with them through life. Thus, most were raised by caretakers who were unaware of their diagnosis and taught by teachers who had no knowledge that they had a life-long disability.

Home, School and Community Interventions

It is our hope that with more widespread diagnosis of FAS, and with clearer understanding of the long-term consequences of FAS, that more reasonable and appropriate environmental interventions can be developed, at home, in the school, and in the broader community. Out of this realization can come the help for each child to develop to his or her own best potential, in an environment that is ultimately the most enhancing for that individual.

No Inevitable Conclusions

Wide variation in intellectual levels in this group of patients confirms what we have known since the beginning, namely that the diagnosis of FAS does not carry with it any particular guarantees, or inevitabilities about IQ, or about academic achievement levels. Diagnosis of FAS does not mean that a person cannot graduate from high school or even attend college. It does mean that some degree of brain damage *has been sustained* and that the results of this will be apparent in the persons' adaptive behaviors.

This article further suggests that the more serious manifestations of FAS may well be experienced at that time in life when the expectations for independent functioning are the greatest. It is our hope that the result of this knowledge will be better program development, more widespread help and support for parents and teachers, and more realistic and helpful expectations for the patients themselves.

Unrealistic expectations can led to frustration, despair, and hopelessness. Public knowledge about this disability should garner support for the disabled persons and lead to hope for a happier, more fulfilling future.

Fetal Alcohol Syndrome in Adolescents and Adults. A. P. Streissguth, J. M. Aase, S. K. Clarren, S. P. Randels, R. A. LaDue, D. F. Smith. Journal of the American Medical Association. April 17, 1991, Vol. 265, No. 15, pp. 1961-1967.

SUBSCRIPTION FORM (Prepaid subscriptions only. Enclose check or money order. ICEBERG, P.O. Box 4292, Seattle, WA 98104)

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Yes, I ALSO wish to help support the goals of the Iceberg with a contribution.

Enclosed please find a contribution of_____ to promote education about FAS/FAE.

CONTACTS

THANK YOU FROM SEA TO SHINING SEA

We wish to thank our generous readers. From all over the US and Canada they have sent money to help support our efforts to educate about FAS/FAE. Some contributions were small — others were very substantial. Every one is valued for the commitment it represents, as well as for the financial support offered.

Heart felt thanks to you all. Together we can make a difference. THANKS! to these recent contributors:

Ann Alton
Nancy Anderson
Elizabeth Bagshaw
Mrs. Wm. Cameron
Maureen E. DeLapp
Josie DeVries
Sylvia W. Epstein
Barry A. Feder
Dean M. Franzen
Sally Graves
Jean Haas
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Kouying Morovan
Julie S. Parker
Belle K. Rosenbloom
Jackie Steil
Vera Sullivan
Rick Teboe
Pat Vavrick
John & Mary Wegmann

Adolescent Task Force Reports

FAS is a developmental disability issue. By changing state law to recognize this, FAS/FAE families would become eligible for many services. This will not happen without active participation and advocacy. Contact Josie DeVries at (206) 778-4048 to add your voice to the team effort. This is vital!

COMING EVENTS

Oct. 18, 91 Wash. State School Directors Assessment Committee. Presentation on FAS/FAE by Sandra Randels and Heather Carmichael-Olson. Call Cindy Lonnborg, program coord. (206) 493-9231, 221 College St. NE, Olympia, WA 98506-5313

Oct. 21, 91 (+ Every other Monday evening) Seattle Parent's Support Group. Call Roberta Wright at (206) 546-6226 for location and more information. All parents/other caregivers are wecome. Groups are forming in other areas.

Oct. 21, 91 (+ Every Monday) 6-7:30 PM Grandmothers Group at Central Seattle Recovery Center, 1401 E. Jefferson - third floor. Free child care provided. Call Connie Gaines (206) 322-2970 for more info.

Oct 23, 91 (+ Every Wed. from 1-2:30 PM) Support Group for Grandmothers/Caregivers of Alcohol/Cocaine Affected Children (Columbia Health Center, 4400 37th South, Seattle) Call: Gwen Browne (206) 296-4650

Oct. 21-23,'91 The First Annual Meeting of the National Organization for Fetal Alcohol Syndrome (NOFAS) is planned for Minn, MN. "Healing the Broken Cord". Contact sponsor Patti Munter, (202) 785-4585, NOFAS, 1815 "H" St. NW, Suite 750, Wash., DC for info. or American Indian Institute, University of Oklahoma, (405)325-4127.More on p.6.

Nov. 1, 1991 FAS Conference. Educational Service District 189. Speakers Sandra Randels, Donna Burgess, and Marceil Vadheim. Call Karen Small (206) 424-9573, 205 Stewart Rd., Mt. Vernon, WA 98273.

Nov. 15-16, 91 Conference on "Prenatally Exposed to Alcohol & Drugs: Medical, Psychosocial, & Educational Issues for the Child, Family & Community". Contact Donna Nimec, MD at Children's Hosp..(303) 861-8888, 1056 E. 19th Ave., Denver, CO 80218. Speakers: Sandra Randels, Donna Burgess, and Robin LaDue.

Dec. 11-12, 91 Casey Family Program Training Conference-FAS Workshop. Speakers: Sandra Randels, Heather Carmichael-Olson. Contact Mary Liz Callan, Conf. Coord., (206) 448-4620, 2033 6thAve. (Suite1100), Seattle, WA 98121-2536

Readers are invited to submit events of interest for publication in "Coming Events" as a community service. Publication does not imply endorsement. Mail to P.O. Box 4292, Seattle, WA 98104

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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

P.O. Box V
State Capitol
Juneau, Alaska 99811
Phone: (907) 465-3114

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 almost 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 caused 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 severely 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 births (2736 x .0042 = 11.5)	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
First-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 at 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 1500-2500 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.

James Berner, M.D., Letter to George Brenneman, M.D., February 10, 1988 and Letter to Chief, Area Community Health Services Branch, Alaska Area Native Health Service, February 3, 1988.

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.

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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.

House State Affairs Committee
Representative Gene Kubina, Chair

DATE: February 28, 1992

PLACE: Capitol Room 102

SUBJECT OF MEETING:

*HB 506 - Relating to PF Dividend Check-Off for ANWR Support
*HCR 51 - Relating to Organ and Tissue Donation Week
*HCR 52 - Relating to Alcohol-Related Birth Defects Awareness

NAME	REPRESENTING	BUSINESS/PERSONAL MAILING ADDRESS	ZIP	(H) PHONE	(W) PHONE	DO YOU WANT TO TESTIFY?		WHAT SUBJECT/ WHICH BILL?
Carol Reed	C/BJ DHSS High Risk Families Coalition	CDD - 3406 Glacier Hwy	99801	789-3867	586-1470	(Y)	N	HCR 52
Rod Mourant	Revenue				x 2330	Y	(N)	HB 506
Bob Stalwakker	Retirement Benefits				x 4470	Y	N	SB 381
Tom Williams	PFD Division	Revenue			x 2323	(Y)	N	HB 506
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	

House State Affairs Committee
Representative Gene Kubina, Chair

DATE: February 28, 1992

PLACE: Capitol Room 102

SUBJECT OF MEETING:

*CSSB 381 - Relating to Health Insurance Info for PERS Retirees
HB 404 - Relating to Deadline for Certain Candidates
HB 327 - Relating to Primary Elections

NAME	REPRESENTING	BUSINESS/PERSONAL MAILING ADDRESS	ZIP	(H) PHONE	(W) PHONE	DO YOU WANT TO TESTIFY?		WHAT SUBJECT/ WHICH BILL?
Paula Terrel	Sen Kelly	P.O. Box V	99811		465 1200	(Y)	N	SB 381
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	