HCR

52

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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MEMORANDUM

TO: Senate House Health, Education and Social Services Committee

FROM: Representative Georgianna Lincoln georg

DATE: March 27, 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. Fetal 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 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

Theodore A. Mala — 26 Feb 92

Theodore A. Mala, ~~MD~~, MPH — Date
Commissioner

DHSS Position

STATE OF ALASKA

WALTER J. HICKEL, GOVERNOR

DEPT. OF HEALTH AND SOCIAL SERVICES

DIVISION OF ALCOHOLISM AND DRUG ABUSE

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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

State FAS/FAE Activity

NATIONAL COUNCIL ON ALCOHOLISM AND DRUG DEPENDENCE, INC

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]

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. [illegible] (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.

WHAT IS NCADD?

NCADD is a national nonprofit organization combating alcoholism, other drug addictions and related problems through its national office, 200 state and local Affiliates, and thousands of volunteers in communities throughout America. Founded in 1944, NCADD's primary mission is education, prevention and public policy advocacy.

NCADD provides education about alcoholism and other drug addictions as treatable diseases, offers prevention programs for schools, organizations and communities, dispenses medical/scientific information, answers questions from the public, legislative bodies and the media, and distributes a variety of publications. NCADD also offers information and referral services to children, teenagers, and adults seeking help with alcoholism, other drug dependencies, and related problems.

NCADD conducts, as it has every year since 1952, a prestigious national conference where leaders in the field convene to report their latest findings and to discuss emerging trends and issues of concern. NCADD also sponsors National Alcohol Awareness Month in April and National Alcohol-Related Birth Defects Awareness Week beginning on Mother's Day each year.

People seeking more information and/or referral can contact an NCADD Affiliate in their area or use NCADD's national toll-free help line: 1-800-NCA-CALL.

NATIONAL COUNCIL ON ALCOHOLISM
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Revised 1/90

National Geographic
February 1992

THE PREVENTABLE TRAGEDY

FETAL ALCOHOL SYNDROME

Text and photographs by GEORGE STEINMETZ

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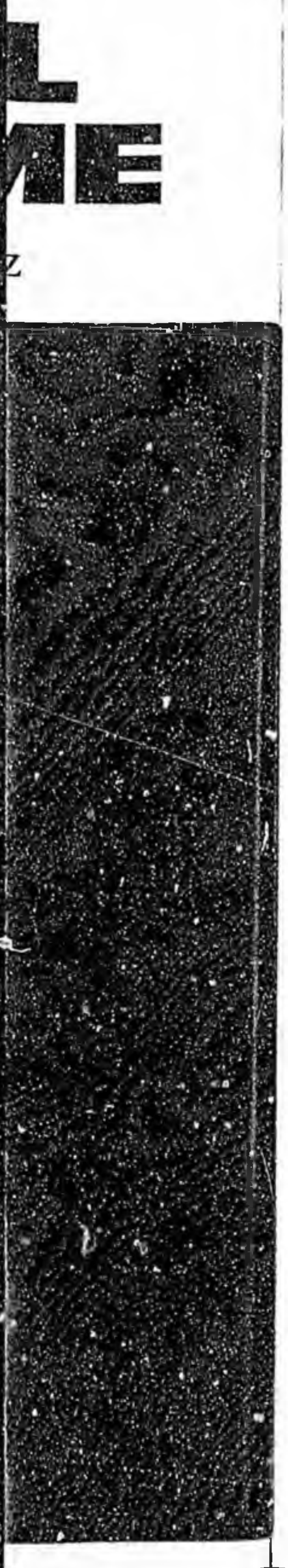


“When Malcolm was born, I thought my heart would break,” she said. “And, oh my God, the guilt. . . .”

Ellen O’Donovan* was losing her fight against alcoholism when she discovered she was pregnant. Months later her son was born with fetal alcohol syndrome, and his battles began.

I met them both in Dublin, where my photographic coverage had brought me. Ellen and her three-year-old son, Malcolm (left), live in a small town on Ireland’s north coast; they had ridden a bus for six hours to visit Malcolm’s doctor, a specialist who is treating the boy for severely defective vision, one of his many alcohol-related disabilities.

First identified about 1970, fetal alcohol syndrome (FAS) is a term used to describe the damage some unborn children suffer when their mothers drink during pregnancy. Alcohol in the mother’s bloodstream can be toxic to the developing fetus depending on the stage of pregnancy and how much she drinks. Damage can range from subtle to severe, causing clumsiness, behavioral problems, stunted growth, disfigurement, mental retardation.

Ellen’s doctor had told her that an American journalist wanted to photograph her with her son. She consented in hopes that others could learn from her mistake, but when I began unpacking my cameras, she hesitated. Then she took a deep breath and began to talk.

“I was drinking a bottle of vodka a day that December,” she said grimly, “so out of touch that I didn’t even know I was two months pregnant. When I found out, I quit there and then, but the damage was done.”

The O’Donovans are not alone. Thousands of babies are born with alcohol-related defects each year, ranking FAS as one of the leading known causes of mental retardation.

According to his doctors, Malcolm was undersized at birth, with kidneys and a stomach that didn’t work properly; he had to be tube-fed until he was 14 months old.

His head is smaller than normal, and he also has facial abnormalities typical of FAS children—small wide-set eyes, a thin upper lip, a short upturned nose, and a receding chin. He was born with damaged corneas, and his eyelids drooped. Surgery later gave him limited sight in his right eye.

FAS is irreversible, and during our session it became clear to me that Ellen has dedicated her life to caring for her son. “He doesn’t seem retarded, thank God,” she said. “He’s even starting to talk a little. I’m working with him every day, helping him learn to do the things normal kids do.”

I was moved by the way she held him and comforted him in Gaelic when he started to cry. “If this little boy hadn’t come along, I might have drunk myself to death,” she said quietly. She hasn’t taken a drink, she added, in three and a half years.

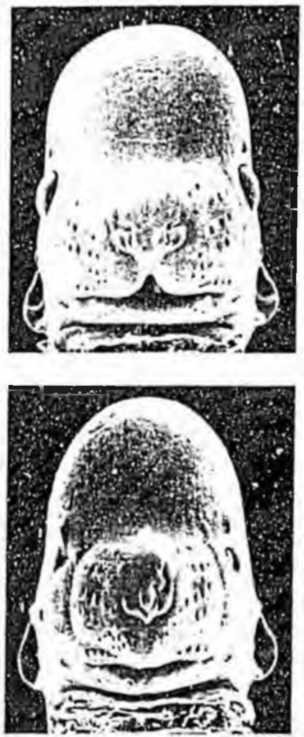
Still, it isn’t going to be easy. Unemployed and living with her mother, Ellen plans each day around Malcolm and the frequent trips they make to his doctors in Dublin. When I offered to reimburse her for the bus fare, she declined. “Just tell women out there that if they want to have a baby, leave the drink out of it,” she said. Then she kissed her son on the top of his head and they were gone.

**Real names are not used*

A large dose of alcohol given to a pregnant mouse produced severe abnormalities in the developing fetus (bottom), according to doctors at the University of North Carolina studying effects of alcohol in early pregnancy.

Compared with a normal fetus (top), the one exposed to alcohol suffered eye damage, a stunted brain, and facial deformities similar to human babies with FAS, particularly those affected during the first trimester, when bones and organs are forming.

Blood-alcohol levels reached during the experiment approximate those that could occur in a woman of average size if she drank a quart of vodka within a 24-hour period.



K. K. SULIK, UNIVERSITY OF NORTH CAROLINA, CHAPEL HILL

I met them in every country I visited—some with tiny, twisted bodies, others with faces tragically skewed. Some were agitated, while others seemed quite normal. Each encounter was disturbing, for few things compare to the sadness of a child stunted by FAS, or made miserable by a group of more subtle abnormalities known as fetal alcohol effect (FAE).

"What's really sad is how many FAS and FAE kids go through life undetected," says Ann Streissguth of the University of Washington, a specialist in FAS behavior. "It takes a trained eye to spot FAS, even in the severely retarded. And in FAE, mildly retarded kids are often misjudged because they tend to be talkative and outgoing. No one dreams their nervous systems are impaired."

As the FAE child grows, such positive traits are often muted by alcohol-related shortcomings—impaired memory, brief attention span, poor judgment and capacity to learn from experience. Some victims drop out of school in frustration or wind up on the margins of society.

Fetal alcohol damage shows itself differently in every child. In the Soviet Union I met a boy, a teenager, who was continually trying to stab his playmates with scissors; in Sweden I met a wonderful little girl who was so sweet and beautiful that I felt I was photographing an angel.

Little is known about the


FRATERNAL TWIN GIRLS, FIVE MONTHS OLD; FRANCE


FIFTEEN-YEAR-OLD BOY WITH FATHER; SWEDEN


THREE-YEAR-OLD GIRL; SWEDEN


TEN-YEAR-OLD GIRL; CHICAGO


SIX-YEAR-OLD BOY; SEATTLE


FOUR-YEAR-OLD


SEVENTEEN-YE

TLE

FOUR-YEAR-OLD GIRL; GERMANY

SEVENTEEN-YEAR-OLD BOY, SEATTLE

thresholds of alcohol that cause FAS. Genetics may also be a factor. Even with fraternal twins one might have severe FAS, while the other is mildly affected. Not all mothers who drink have FAS babies. Some doctors believe that any alcohol puts the baby at risk, while nearly all agree that binge drinking is perilous, especially during the first 12 weeks, when signs of pregnancy are few. As Ellen O'Donovan lamented, "I didn't even know I was pregnant. That's the tragedy of it." ☐

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

> this is to help me guide myself and others

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

ICEBERG Letters

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 Dehoene
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.

ICEBERG

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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: Activis[illegible] 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 recom-mended 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 autho[illegible] 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.

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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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Louise G. Harper
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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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