

ALASKA LEGISLATURE COMMITTEE FILES 1993-1994 8672

7827 HOUSE • HEALTH EDUCATION & SOCIAL SERVICES

1 using some form of regional purchasing group, managed competition, and other mechanisms;  
2 and

3 **WHEREAS** the Health Resources and Access Task Force has submitted a final report  
4 to the Governor and the Legislature in January 1993 and recommended

5 (1) a comprehensive strategy for improving health care for all Alaskans,  
6 including cost containment efforts, health care access improvements, public health or service  
7 delivery system enhancements, and medical malpractice reform;

8 (2) the establishment of regulatory reform measures in the small group health  
9 insurance market;

10 (3) that insurers move toward community rating in establishing premiums in  
11 the small group insurance markets;

12 (4) the establishment of state-sponsored health insurance pooling arrangements;  
13 and

14 (5) that adequate resources be devoted to maintaining a strong health care  
15 infrastructure in the state; and

16 **WHEREAS** the legislature recognizes the need for extensive local involvement and  
17 participation in programs designed to meet their needs and that test or model programs often  
18 are the mechanism to determine long-term statewide programs or agendas;

19 **WHEREAS** the Kenai Peninsula Borough Economic Development District, Inc., has  
20 established a Kenai Peninsula Borough Health Care Advisory Council to develop  
21 recommendations for a health care plan for the Kenai Peninsula Borough residents; and

22 **WHEREAS** the Kenai Peninsula Borough Health Care Advisory Council has  
23 completed extensive surveys of the Kenai Peninsula and produced a report in October 1992  
24 detailing the needs for improved health care for the residents of the Kenai Peninsula Borough;  
25 and

26 **WHEREAS** the Kenai Peninsula Borough Health Care Advisory Council has made a  
27 recommendation that small businesses, large group employers, and government employee units  
28 on the Kenai Peninsula join together to establish a health maintenance organization as  
29 authorized by Title 21 of the Alaska Statutes; and

30 **WHEREAS** the intent of forming this organization for the Kenai Peninsula Borough,  
31 in addition to improving health care and access to same, is to demonstrate implementation of  
32 a successful locally developed, consumer governed, community based payer model for

1 adaptation statewide; and

2       **WHEREAS** the problems and opportunities presented in improving health care and  
3 access to health care of the Kenai Peninsula Borough parallel those found elsewhere  
4 throughout the state and nation; and

5       **WHEREAS** the residents and leadership of the Kenai Peninsula Borough working  
6 through the Kenai Peninsula Borough Economic Development District, Inc., and using the  
7 Kenai Peninsula Borough Health Care Advisory Council have developed a plan of  
8 implementation for this model;

9       **BE IT RESOLVED** by the Alaska State Legislature that, subject to a referendum vote  
10 of the residents, the Kenai Peninsula Borough Health Care Advisory Council be recognized  
11 as a model project relating to health care reform through the establishment of a borough-wide  
12 modified health maintenance organization; and be it

13       **FURTHER RESOLVED** by the Alaska State legislature that the Governor is  
14 respectfully requested to direct the commissioner of health and social services to offer support  
15 and assistance to the Kenai Peninsula Borough Health Care Advisory Council and the Kenai  
16 Peninsula Borough Economic Development District, Inc., in their pursuit of a model region  
17 wide health access and basic care program.

ALASKA STATE

# HOSPITAL & NURSING HOME

ASSOCIATION

April 8, 1993

Representative Cynthia Toohey, Co-Chair  
HESS Committee  
House of Representatives  
State Capitol  
Juneau, AK 99801-1182

Re: Support HCR 17 - Kenai Health Insurance Pool

Dear Representative Toohey:

ASHNHA, representing community hospitals and nursing homes across the state would like to urge your support for HCR 17 recognizing the proposed Kenai health insurance pool as a model demonstration project.

The work of the Kenai Peninsula Borough Economic Council and the Kenai Health Care Advisory Council to provide all citizens in that area basic health insurance can be a model for the country, not just Alaska.

The American Hospital Association is monitoring the plan closely so it can share what is learned there with hospitals across the country.

We urge your support of HCR 17.

Sincerely,



Harlan R. Knudson  
President/CEO

# Kenai takes the lead in health reform

This fall, national experts in the field of health care funding and innovation flew to Alaska. But they didn't go to Anchorage, Fairbanks or Juneau.

Instead, they stayed in Kenai. There, they met with doctors and nurses, labor representatives and municipal officials, among others.

They were in town to help the Kenai Peninsula organize its own health care plan. Their visit is the latest step in an effort that began a year ago when the Kenai Peninsula Health Care Advisory Council was organized to develop recommendations for a health plan for all Kenai residents. It expects to go to the voters in another year to seek formal approval of whatever plan it recommends.

Mike Lockwood, administrator at Central Peninsula General Hospital in Soldotna, says there are two practical reasons why a borough-wide health plan may succeed. "There is a multi-disciplinary group that wants to see it done. It's not just hospitals, or doctors," he says.

"The other reason I think we can succeed is because the Kenai Peninsula is relatively isolated geographically."

In addition to these practical reasons, however, are the people behind the Kenai proposal. They include Stan Steadman, executive director of the Kenai Economic Development District,

Jerry Near, an insurance agent and member of the state task force looking into health care reform, and Lockwood himself.

"I believe strongly that when you identify a problem, it's better to take action yourself rather than wait for someone else to do it. Then you're part of the solution," says Lockwood.

Dr. Bruce Amundson was among the speakers at the Kenai workshop. Amundson has been involved with rural hospitals and community health care reform for several years in Washington.

Amundson told those at the workshop that their work is important because it "represents an attempt to introduce widespread changes to the health care system locally, where cost containment is attainable."

Lockwood agreed, saying "We have an opportunity to increase the health status of the community and by that, lower the cost of health care. I believe that is the solution to high health care costs."

Lowering health care costs is key to the involvement by the Economic Development District, says Kathy Scott, project manager of the health care plan.

"It's humanitarian, but I don't know if that's the striving principle. The overriding principle is to provide services efficiently," says Scott.

The economic impact of having 18 percent of the Kenai Peninsula Borough uninsured is obvious, says Scott.

"Those people may be uninsured, but when they get to the point of needing health services, they're standing in the ER ... and that's one of the most expensive points of contact in our health system," she says.

The health care advisory council also wants to encourage its residents to use local health care resources.

"It makes sense for an economic development district to be involved in containment of services within its region," says Scott, noting that health care in the Kenai borough, as in many other regions of the state, is an important employer.

Lockwood says that, if the Kenai plan does work, it may encourage other areas to find their own solutions using a similar model.

"I think it can translate into the state health care reform process. I don't think a solution for the Kenai Peninsula would be the appropriate solution for Anchorage or Fairbanks," he says.

## The Kenai plan:

The Kenai Peninsula Health Care Plan is patterned in part after proposals from the American Hospital Association, which calls for networks of health care providers, insurers and the community.

Now, the Kenai council is considering a "hybrid" Health Maintenance Organization (HMO), organizing the HMO as a department of the Kenai Peninsula Borough but governing it like a cooperative.

The HMO would be capitalized by local revenue bonds. It is still undecided whether tax revenues would be necessary for operation.

Those eligible for the HMO would be established Kenai Peninsula Borough residents. They would be offered a choice of deductible insurance levels, all of which would include co-pay provisions. The health care program would encourage preventative health care, including dental care.

Families would be charged no more than \$300 a month, and would be allowed to choose their own health service providers.

## Home away ...

*Continued from page 4*

tree that could be knocked down by someone with severe cognitive problems.

These residents may also find the extra activities associated with the holidays disorienting and even frightening.

"We want to keep the people's schedule as static as possible ... but we want to help them enjoy the season too," says Sharma.

She says some of the most popular activities with residents are cooking projects.

"We've had the best stuffing in the world ... and pumpkin pies made from scratch," says Sharma.

In all these nursing homes, community efforts play a large part in ensuring a good holiday season. Carolers from schools and churches, gift donations and people taking seniors into their home for a holiday meal all help make

the time special, say these workers.

"I must say our community has a lot to give at this time of the year," says Stalnaker.

But it is also clear that nursing home workers are the ones that really make holidays a special time for residents. And it's not without a certain cost.

"We end up celebrating most of Christmas here at work. By the time we get home, we're too tired to put up our Christmas tree," says Sharma with a laugh.

She adds, though, that the residents' joy in the season makes it worthwhile.

"It's just heartwarming when you see a resident get a special gift from someone they don't know, or a card from a long-lost friend ... or listen to a story about celebrating Christmas back in the 1930s in Alaska. Those are priceless moments for me with these residents.

"That's a real precious gift that I'm getting from them."

**KEY CONCEPTS UNDERLYING  
AHA'S NATIONAL HEALTH CARE REFORM STRATEGY**

Approved by AHA Board of Trustees  
January 25, 1992

1. Universal access to a package of basic health care benefits should be guaranteed for everyone residing in the United States.
2. Health care should be financed by a pluralistic system that relies on both government and private sources of payment.
3. Cost control should be accomplished primarily through a restructuring of the health care delivery and health care financing systems so that underlying incentives are consistent for all parties involved, while supporting the efficient use of resources to promote good health. Development and dissemination of practice parameters, medical liability tort reforms, and antitrust reforms should be pursued simultaneously.
4. Health care delivery should be restructured by establishing community care networks, formed via regulated competition and held accountable for:
  - improving the health status of the community served,
  - providing a comprehensive range of high quality health care services,
  - managing the continuity of care across providers and over time,
  - simplifying patient interactions with care deliverers, and
  - efficiently producing and using services.
5. Payments by purchasers should be based predominantly on capitated fees to community care networks in order to align the incentives among providers to conserve resources through collaboration and to focus on keeping people well. Provider payment within networks should be based on negotiations among each network's participants, governed by broad regulatory parameters designed to avoid the undesirable effects of unfettered competition.
6. Cost shifting should be avoided, in favor of a balancing of needs for cost containment and fair payment, by establishing an independent body to set the capitated rates paid to networks by purchasers, including establishment of a structure to appropriately adjust those rates to reflect the underlying risk of the population covered and the geographic conditions under which services are delivered.
7. Maximum flexibility should be employed throughout the approach used to achieve these concepts in order to:
  - recognize appropriate community variations,
  - preserve latitude for local decision making,
  - preserve a measure of consumer choice,
  - allow innovation and demonstration of new delivery and financing models, and
  - provide for appropriate involvement of state and local governments.
8. Formation of networks should be promoted in the public sector by encouraging the Medicare and Medicaid programs to use networks and by providing financial incentives for beneficiaries to choose networks. In the private sector, network use should be encouraged by offering tax or other incentives aimed at employers, employees, insurers, and providers.

For More Information: Harlan Knudson, Alaska State Hospital & Nursing Home  
Association - Juneau - 586-1790

# FISCAL NOTE

STATE OF ALASKA  
1993 LEGISLATIVE SESSION

BILL NO. HCR 17

Revision Date: \_\_\_\_\_ Dept. Affected: All Agencies  
 Title: "Relating to a health insurance pool established for residents of the Kenai Pen." BRU: \_\_\_\_\_  
 Sponsor: REP. GARY DAVIS Component: \_\_\_\_\_  
 Requestor: \_\_\_\_\_ COMPONENT SERIAL NO. \_\_\_\_\_

**Expenditures/Revenues:**

(Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
<b>TOTAL OPERATING</b>	<b>-0-</b>	<b>-0-</b>	<b>-0-</b>	<b>-0-</b>	<b>-0-</b>	<b>-0-</b>

CAPITAL						
---------	--	--	--	--	--	--

REVENUE FUND SOURCE:						
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**FUNDING:**

(Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 GF						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
<b>TOTAL</b>	<b>-0-</b>	<b>-0-</b>	<b>-0-</b>	<b>-0-</b>	<b>-0-</b>	<b>-0-</b>

**POSITIONS:**

FULL-TIME						
PART-TIME						
TEMPORARY						

Estimate of current year (FY93) impact: -0-

**ANALYSIS:** (Attach a separate page if necessary)

Prepared by: Lynda Giguere, Aide  
 Division: House Labor and Commerce  
 Approved by Commissioner: Bill Hulse - Chair L+C  
 Agency: \_\_\_\_\_

Phone: 465-6827  
 Date: 4-6-93  
 Date: 4-6-93

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## SPONSOR STATEMENT

HCR 17

"Relating to a health insurance pool established for residents of the Kenai Peninsula Borough".

The Legislature established a Health Resources and Access Task Force in 1991. That Task Force submitted a final report with recommendations to the Governor and the Legislature in January 1993. The recommendations can be found on page 2 of this resolution.

The Kenai Peninsula Borough Economic Development District has established a Kenai Peninsula Borough Health Care Advisory Council to develop recommendations for a health care plan for the Kenai Peninsula Borough. This plan is a step in the right direction to address health care reform issues. They would like to have the plan implemented as a model for other areas statewide. The Kenai Peninsula Borough Health Care Advisory Council would like to be recognized as a model regional area for pooling insurance requirements, for establishing community rating for insurance premiums, for developing small group insurance regulatory reform measures, and for establishing a health maintenance organization.

HCR 17 requests that the Governor direct the Commissioner of Health and Social Services assist the Kenai Peninsula Borough Health Care Advisory Council in their pursuit of a model region wide health access and basic care program.

*Sponsor Statement*

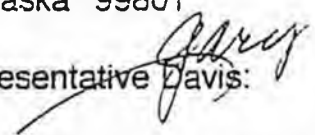
Kenai Peninsula Borough

# Health Care Advisory Council

Kenai Peninsula Borough Economic Development District, Inc. 110 S. Willow St., Suite 106 Kenai, Alaska 99611 (907) 283-3535 Fax: (907) 283-3913

January 25, 1993

Representative Gary Davis  
Alaska Legislature  
Juneau, Alaska 99801

Dear Representative  Davis:

You have undoubtedly heard about the grassroots effort on the Kenai Peninsula to show that local people are willing to take their share of responsibility in the national health care crisis. With a little seed money from the State, local financial participation and a lot of public participation, much ground has been covered in the last year toward establishing a borough-wide health care plan. The Council's mission, as empowered by the Kenai Peninsula Borough Assembly, is to:

**Submit a report to the Borough Assembly making finds and recommendations as to options for the establishment of a Borough-wide insurance program which would make affordable health insurance available to all residents and thereby increase access and utilization of the local health care system.**

Soon, the Council will ask the Legislature to recognize its accomplishments and provide critical financial input. Should our mission be accomplished, we expect our plan to serve the State and Nation as a model for community based health care. Recognizing the impact of such a request, the Council and staff are preparing a formal proposal for consideration by the State as a key local initiative health care demonstration project. Council member Jerry Near has energetically represented the insurance industry on the State's Health Resources and Access Task Force and his meeting this week in Juneau provides a perfect opportunity to introduce the concept of a State demonstration project to you. We will be following up Jerry's remarks with a detailed proposal in just a few weeks.

As a Kenai Peninsula legislator, we know you share our concerns for accessible and affordable health care not only for Peninsula residents, but for all Alaskans. We look forward to working closely with you to achieve that end:

Sincerely

  
Kathleen F. Scott  
Project Manager

Enclosures

KPB - Health Care Advisory Council - Background Info

**KENAI PENINSULA BOROUGH  
HEALTH CARE ADVISORY COUNCIL**

Lottie Bogard  
Sterling

Jeanne Berger, M.A., PHN  
Hope

Brenda O'Brien  
Seward

Margaret French  
Homer

Dr. Jon Godfrey, DC  
Homer

Jerry Near  
Soldotna

Dr. Vickey Hodnik, DDS  
Homer

Dr. John Kobylarz, DDS  
Soldotna

Mike Lockwood  
Soldotna

Dr. James Zirul, DO  
Soldotna

Ken Hepner  
Sterling

Robert Roth  
Kenai

Linda Hutchings  
Soldotna

Judy Charpentier  
Kenai

Ray Zagorski  
Soldotna

Emery Thibodeau  
Kenai

Jim Heim  
Soldotna

Karen Moore  
Soldotna

Jon McMichael  
Soldotna

Bonnie Heimbuch  
Soldotna

George Carnahan  
Kenai

Burt Anderson  
Homer

Ross Kendall  
Nikiski

James Krasnansky  
Seward

Rich Underkoffler  
Soldotna

Marion Nelson  
Nikiski

Dick Swamer  
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Lorin MacKay  
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Kenai, Alaska 99611

Bruce Amundson, M.D.  
18454 -16th Ave., N.Y.  
Seattle, Washington 98177

## **Kenai Peninsula Borough Health Plan**

### **Operating Principles & Assurances**

The Kenai Peninsula Health Care Advisory Council has generally operated under these principles and assurances while crafting the draft proposal for a borough-wide health plan. The sponsors commit to:

- \* Providing health services which meet the needs and expectations of Borough resident.
- \* Supporting and developing the broadest range of services possible and appropriate in each community of the borough.
- \* Keeping as much health care as possible and feasible within the borough boundary.
- \* Developing an organizational framework for the plan's administration that represents all parties sharing responsibility for high quality and cost-effective health services.
- \* Providing innovative - creative strategies and programs to
  - reduce the cost of health care
  - support early intervention
  - emphasize preventive care
  - reduce unnecessary use of hospitals, emergency rooms and surgery
  - develop and use case management for complex patients and families
  - encourage greater responsibility for health choices
  - effect coordination among providers
- \* Recognizing that the resources and innovation already exist in our borough to develop a national model health care program.

HEALTH CARE ADVISORY COUNCIL  
PROPOSED HEALTH CARE REFORM PROJECT  
Overview

KENAI PENINSULA, ALASKA

February 1993

Kenai Peninsula Borough Health Care Advisory Council

Sponsored by  
Kenai Peninsula Borough Economic Development District, Inc.  
Community Health Services Development Grant  
through the University of Alaska, Fairbanks

*Health Care Advisory Council Proposed Health Care Reform Project*

## Introduction

The Kenai Peninsula Health Care Advisory Council, operating under authority of the Kenai Peninsula Borough, is pleased to present this health care reform project proposal for consideration. The solutions offered in this regional initiative address primary health care issues facing the entire nation through

- insurance pooling
- community based, consumer managed health care
- use of a community rating system
- attractive incentives for wellness health care

If this project is modeled, health care becomes accessible to all individuals who qualify for the Alaska Permanent Fund Dividend. Small businesses, large group employers and government employee units are joined together through the establishment of a Health Maintenance Organization (HMO). Already authorized by Title 21 of the Alaska Statutes, the project proposes to demonstrate implementation of a successful consumer governed, community based payer model for adaptation statewide.

## Background

The Kenai Peninsula Borough Assembly authorized the formation of the Kenai Peninsula Health Care Advisory Council to determine the feasibility of a borough-wide health insurance program. The Health Care Advisory Council (HCAC) is composed of nearly thirty peninsula residents representing labor, government, health service providers, health insurance providers, education, small and large businesses, non-profit organizations, clergy, the media and general public. Enabled and established fifteen months ago, the group first adopted the project's developmental phase mission statement.

### Mission Statement

Submit a report to the Kenai Peninsula Borough Assembly making findings and recommendations as to options for the establishment of a borough-wide insurance program which would make affordable health insurance available to all residents and thereby increase access and utilization of the local health care system.

provider services by offering a community based, cooperatively managed system.

- cost accountability through the traditional third party system but with pro-active consumer participation.
- removing the vulnerability of health service providers to medical malpractice suits by establishing arbitration as the means for dispute resolution.
- small business employers who have previously been unable to supply health care benefits because small group exposure increases the underwriter's risk resulting in higher premiums.
- individuals who are self-employed and have no option for health care coverage by providing access to a large pool.
- curbing spiraling government and private enterprise labor costs with reduced premiums by applying a community rating system.
- hospital emergency rooms used to deliver clinical health care services at a disproportionate rate for the service needed by charging for inappropriate use.

## Solution

To adequately address Alaska's health care crisis, action must be taken first on a local level. The Kenai Peninsula Health Care Project proposes to deliver health services to Kenai Peninsula Borough residents through a Health Maintenance Organization (HMO) as authorized under Alaska Statutes Title 21. Once health powers are adopted by the Kenai Peninsula Borough, a consumer governing board of not more than nine members will initiate the implementation phase of the project through a contracted insurance partner.

The Kenai Peninsula Health Care Plan proposes benefits parallel to those offered to large group employers like the Kenai Peninsula Borough. Through reduced co-payment percentages, use of local service providers is rewarded. Enrollee cost will vary depending on the level of risk exposure to the plan determined by the participants' selection of variable deductible level. Here are key elements proposed by the Plan:

### Organizational Structure. . .

Effective health care reform occurs through this proposal because costs are controlled at a community level. Only community residents and health professionals have the ability to identify specific barriers to local health delivery system cost containment. The

The proposal uses the "gatekeeper" concept of managed care where enrollees choose their primary care physician. The physician becomes the manager for the patient's health care on a fee for service basis. Selection of local health care services is rewarded through lower patient co-payment cost. Plan participants may change their selected "gatekeeper" physician at anytime.

All state board certified health care providers on the Kenai Peninsula may participate in the HMO. Access to the system for health service providers outside the Kenai Peninsula Borough will occur through a selection process in which quality of care is stressed over cost. Non-participating provider services may still be used, however co-payment costs are increased to the patient.

The plan charges patients for non-emergency use of hospital emergency rooms.

#### Plan/Project Funding . . .

Payment of premiums by enrollees will fund the plan's operation. For example, an average \$350 per month premium for 4,000 enrollees will generate \$16,800,000 in plan premiums. Preliminary actuarial review comments, due in March, 1993, will provide approximate premium costs for each deductible level as well as estimated losses, administrative costs and claims levels for years one, two and three of the plan. It is our belief that the plan will generate sufficient funds to adequately meet operational costs.

These avenues are actively being pursued for capitalization of the plan:

- 1) Funding based on pre-sold contracts with large group employers like UNOCAL, Tesoro, Homer Electric Association, Kenai Peninsula Borough General Government and School District, Peninsula city governments, and VECO for example.
- 2) Application for government and foundation grants with principle interest in health care reform such as the Ford Foundation, the Robert Wood Johnson Foundation, and the U.S. Department of Health and Social Services Rural Health Outreach Grant Program.
- 3) Establishing the foundation to receive municipal revenue bonds repaid through premium receipts.

Since April 1992, the Kenai Peninsula Borough Economic Development District has sponsored the activities of the council through a small Community Health Services Development grant administered by the University of Alaska, Fairbanks. The grant is nearly exhausted, but has stretched far beyond what was originally planned because the work of the council has been done by volunteers and many expenses have been donated.

## Conclusion

- Will the plan provide affordable and accessible health care to all Kenai Peninsula Borough residents?
- Have we sufficient evidence to establish that a cooperative consumer driven organization applied regionally to the delivery of health care will effect cost containment?
- Will the increased use of local health services stimulate economic growth on a regional and state level?
- Does demonstrating the project first on a smaller scale, make sense in finding practical solutions to often overwhelming health care reform issues?

The men and women of this community effort, the Kenai Peninsula Health Care Advisory Council, feel this proposal answers these questions and provides effective solutions for local, State and National health care reform.

Will we meet the need of the "gap group" ( those who have no insurance and do not qualify for any state or federal program)? If accessibility is the problem, then undoubtedly this plan is immediately responsive. If affordability is the issue, we will not solve the problem without identifying a funding mechanism to subsidize health care for welfare recipients and the unemployed. This Council stands ready to continue developing effective solutions to health care issues. The reward, of course, is the satisfaction of providing access to quality health care for our residents at an affordable cost.

**Kenai Peninsula Health Care Advisory Council**  
Kenai Peninsula Borough Economic Development District, Inc.  
110 South Willow Street, Suite 106  
Kenai, Alaska 99611  
Phone (907) 283-3335/Fax (907)283-3913  
Project Manager Kathleen Scott  
Phone (907) 283-5130/Fax (907)283-5918

# HOUSE COMMITTEE REPORT

(7)

Date Referred: March 24, 1993

FURTHER REFERRALS:

HESS  
Finance

Date of Committee Action: 4/06/93

The LABOR AND COMMERCE Committee considered:

HCR 17

HOUSE CONCURRENT RESOLUTION NO. 17

KENAI PENINSULA INSURANCE POOL

Relating to a health insurance pool established for residents of the Kenai Peninsula Borough.

- RECOMMENDATIONS: [ ] the same title  
 be replaced with \_\_\_\_\_ [ ] 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): \_\_\_\_\_ (Dep't)  
 [ ] fiscal impact \_\_\_\_\_

APPROVES PREVIOUS: \_\_\_\_\_ (Dep't/Date)  
 [ ] fiscal note(s) \_\_\_\_\_

zero fiscal note All Agencies

[ ] zero fiscal note(s) \_\_\_\_\_

SIGNING DO PASS	DP	OTHER RECOMMENDATIONS	DNP	NR	AM
<i>Brian D. Porter</i>	✓				
<i>Amy Mal...</i>	✓				
<i>Edon...</i>	✓				
<i>W.S. William</i>	✓				
<i>...</i>	✓				
<i>Bill Hudson</i>	✓				

*Bill Hudson*  
 CHAIRMAN'S SIGNATURE

House 492 Committee Report

HCR

31

# HOUSE COMMITTEE REPORT

(9)

Date Referred: February 2, 1994

FURTHER REFERRALS:

Date of Committee Action: 2/14/94

The HEALTH, EDUCATION AND SOCIAL SERVICES Committee considered: HCR 31

HOUSE CONCURRENT RESOLUTION NO. 31

ALCOHOL-RELATED BIRTH DEFECTS AWARENESS

Relating to Alcohol-Related Birth Defects Awareness Week.

RECOMMENDATIONS:  the same title  
 be replaced with \_\_\_\_\_  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 H+SS

zero fiscal note(s) \_\_\_\_\_

SIGNING DO PASS	DP	OTHER RECOMMENDATIONS	DNP	NR	AM
<i>[Signature]</i>	✓				
<i>[Signature]</i>	✓				
<i>[Signature]</i>	✓				
<i>[Signature]</i>	✓				
<i>[Signature]</i>	✓				
<i>[Signature]</i>	✓				
<i>[Signature]</i>	✓				

*[Signature]*  
CHAIRMAN'S SIGNATURE

# FISCAL NOTE

STATE OF ALASKA  
1994 LEGISLATIVE SESSION

BILL NO. HCR 31

Revision Date: \_\_\_\_\_ Dept. Affected: Health and Social Services  
 Title: Relating to Alcohol-Related Birth Defects BRU: Alcohol & Drug Abuse  
Awareness Week. Component: Administration  
 Spc 180r: Representative Nicholia  
 Requestor: \_\_\_\_\_ COMPONENT SERIAL NO. 302

**Expenditures/Revenues:** (Thousands of Dollars)

OPERATING	FY95	FY96	FY97	FY98	FY99	FY00
PERSONAL SERVICES	0.0	0.0	0.0	0.0	0.0	0.0
TRAVEL	0.0	0.0	0.0	0.0	0.0	0.0
CONTRACTUAL	0.0	0.0	0.0	0.0	0.0	0.0
SUPPLIES	0.0	0.0	0.0	0.0	0.0	0.0
EQUIPMENT	0.0	0.0	0.0	0.0	0.0	0.0
LAND & STRUCTURES	0.0	0.0	0.0	0.0	0.0	0.0
GRANTS, CLAIMS	0.0	0.0	0.0	0.0	0.0	0.0
MISCELLANEOUS	0.0	0.0	0.0	0.0	0.0	0.0
<b>TOTAL OPERATING</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

<b>CAPITAL EXPENDITURES</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>
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<b>CHANGES IN REVENUES</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>
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**FUND SOURCE** (Thousands of Dollars)

1002 Federal Receipts	0.0	0.0	0.0	0.0	0.0	0.0
1003 GF Match	0.0	0.0	0.0	0.0	0.0	0.0
1004 GF	0.0	0.0	0.0	0.0	0.0	0.0
1005 GF/Program Receipts	0.0	0.0	0.0	0.0	0.0	0.0
1006 GF/MHTIA	0.0	0.0	0.0	0.0	0.0	0.0
Other	0.0	0.0	0.0	0.0	0.0	0.0
<b>TOTAL</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**POSITIONS:**

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY94) cost \$ \_\_\_\_\_

**ANALYSIS:** (Attach a separate page if necessary)

This HCR has no fiscal impact on the department.

Prepared by: Suzanne Perry  
 Division: Alcohol & Drug Abuse  
 Approved by Commissioner: Margaret P. Lowe, M.Ed., Ed.S.  
 Agency: Department of Health & Social Services

Phone: 465-2071  
 Date: 02/08/94  
 Date: 2/9/94

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# Alaska State Legislature

House of Representatives  
 COMMITTEE ON HEALTH, EDUCATION  
 AND SOCIAL SERVICES

DATE: 2/14/94

PLACE: Capitol Room 106

SUBJECT OF MEETING:  
 \* HCR 31: ALCOHOL RELATED BIRTH DEFECTS AWARENESS  
 \* HB 361: Approp: EDUCATION FUNDING FOR FY 95

NAME	REPRESENTING	BUSINESS/PERSONAL MAILING ADDRESS	ZIP	(H) PHONE	(W) PHONE	DO YOU WANT TO TESTIFY?	WHAT SUBJECT/ WHICH BILL?
DOROTHY GARRETT	AEA ✓	Inlet View 1219 "P."	99501	333-7891	277-7681	(Y) N	HB361
Duane Guiley	DOE				5-8679	Y N	AVAILABLE TO ANSWER QUESTIONS HB361
Suzanne Perry	DHSS			465-2071 →		Y N	Ans Ques if necessary HCR 31
Loren Jones	Div Ale & Dry Ale				465-2071	Y (N)	<del>HB</del> HCR 31
Janis Cooksey						(Y) N	<del>CS HB 361</del> <del>HB 361</del>
Carol Rose	APSB				6-1083	(Y) N	CS HB 361
Claudia Douglas	NEA-Alaska					(Y) N	CS HB 361
Deborah Smith	ANA HB			465-3071 →		(Y) N	CS HB 361
						Y N	
						Y N	
						Y N	

Fetal Alcohol Syndrome (FAS) is a birth defect caused by a woman drinking during her pregnancy.

44-50% of women who drink heavily during pregnancy will have children with FAS.

11% of women who drink moderately during pregnancy will have children with FAS.

Alcohol passes freely through the placenta to the baby. The baby's blood alcohol level is the same as the mother's. The baby drinks with the mother - drink for drink.

No amount of alcohol during pregnancy is safe for the baby.

Children with FAS have:

#### 1. Abnormal, Deformed Facial Features

- \* small, widely spaced eye openings
- \* small head
- \* short upturned nose
- \* indistinct or no groove between the nose and upper lip
- \* thin upper lip
- \* flat midface
- \* small jaw



#### 2. Growth Retardation

- \* at birth they are smaller than normal children in weight, length and/or head circumference
- \* FAS children do not "catch-up", they will always be below normal



FAS CHILD      NORMAL CHILD

#### 3. Poor Brain Development

- \* mental retardation
- \* small, incompletely formed brain
- \* developmental delays
- \* learning disabilities
- \* poor fine and gross motor coordination
- \* seizures



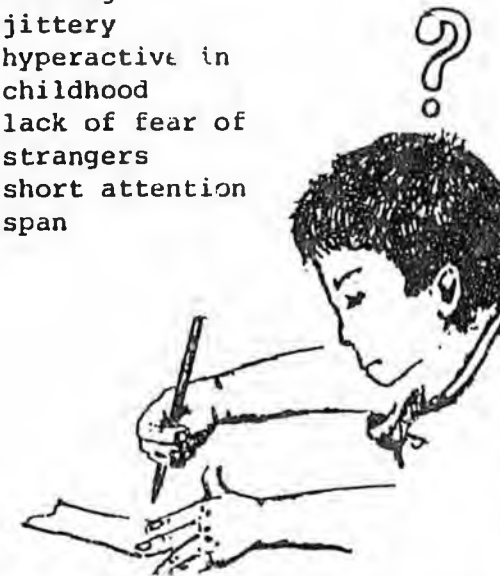
#### 4. Physical Deformities

- \* heart defects needing surgery
- \* vision and hearing defects
- \* kidney defects
- \* abnormal liver functioning
- \* cleft lip or cleft palate
- \* joints (fingers, toes, hips, elbows, knees, etc.) that do not work right
- \* immune deficiencies - are sickly children
- \* failure to thrive



#### 5. Behavior Problems

- \* irritable in infancy
- \* poor mother-child bonding
- \* jittery
- \* hyperactive in childhood
- \* lack of fear of strangers
- \* short attention span







Health, Education and  
Social Services Committee  
Special Committee on Fisheries

House District 36  
Alatna  
Allakaket  
Aniak  
Anvik  
Arctic Village  
Beaver  
Bettles  
Birch Creek  
Canyon Village  
Central  
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Chicken  
Chistochina  
Chitina  
Chuathbaluk  
Circle  
Copper Center  
Crooked Creek  
Dot Lake  
Eagle  
Evansville  
Fort Yukon  
Gakona  
Galena  
Grayling  
Gulkana  
Healy Lake  
Holy Cross  
Hughes  
Huslia  
Igugig  
Iliamna  
Kakhonak  
Kalskag  
Kaltag  
Kenny Lake  
Koyukuk  
Lake Minchumina  
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Minto  
Nabesna  
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Nikolai  
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Tanacross  
Tanana  
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Telida  
Tetlin  
Tik  
Tonsina  
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## Representative Irene K. Nicholia

State Capitol • Juneau, Alaska 99801  
Phone: 465-4527 FAX: 465-2294

### House Concurrent Resolution 31

### SPONSOR STATEMENT

HCR 31 recognizes Mother's Day week of May 8 - 14, 1994 as Fetal Alcohol Syndrome Awareness Week.

Fetal Alcohol Syndrome (FAS) related birth defects include **permanent** growth retardation, physical malformations, and permanent central nervous system damage, including developmental delays, learning disabilities, behavioral problems, and mental retardation.

Following are some additional FAS/FAE Facts:

- FAS is the number 1 known cause of **mental retardation** in the United States, and one of the three leading causes of birth defects.
- Each year over **40,000 American children** are born with defects because their mothers drank alcohol when pregnant.
- **The effects of FAS never go away.** People with FAS have the disabilities they are born with, including mental retardation, throughout their lives.
- There is **no known safe amount of alcohol** for a pregnant woman. When a woman drinks, her baby drinks because the alcohol passes directly through the placenta to the baby.
- Conservatively estimated, the lifetime cost per Alaska FAS birth is **\$1.4 million.**

Attached is additional information regarding FAS. I would encourage you to read the enclosed Economic Impact of Fetal Alcohol Syndrome in Alaska Report and "The Preventable Tragedy, Fetal Alcohol Syndrome," which appeared in the February, 1992 edition of *National Geographic*.

Today we have the opportunity to make an impact in the area of FAS by both improving quality of life and by promoting cost effective prevention. Fetal Alcohol Syndrome and Fetal Alcohol Effects are 100% preventable. Let's work together to send a message to the public about the dangers of drinking alcohol during pregnancy.

I strongly urge you to support HCR 31.

Sponsor Statement

*National Geographic*  
*February 1992*

THE PREVENTABLE TRAGEDY

# FETAL ALCOHOL SYNDROME

Text and photographs by GEORGE STEINMETZ



THE PREVENTABLE TRAGEDY, FETAL ALCOHOL SYNDROME - NATIONAL GEOGRAPHIC

**“W**hen 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. Month 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, 'hank 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*



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

*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.*

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 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." □



# dispatch



## INTERNATIONAL

### What We Can Do About Fetal Alcohol Syndrome

Ann Pytkowicz Streissguth, PhD

When a pregnant woman drinks alcohol, within minutes the blood alcohol level in the fetus becomes about the same as that in the mother. The embryo and fetus are growing and changing so rapidly that their development can be altered by exposure to certain toxic drugs, like alcohol. Amounts of alcohol that have no perceptible long-term effect on the mother can produce long-lasting effects on the offspring.

The birth defect caused by heavy prenatal exposure to alcohol *in utero* is called Fetal Alcohol Syndrome (FAS). FAS is the most common known cause of mental retardation in the western world. Yet FAS is entirely preventable.

Lemoine, a French pediatrician, noted a characteristic appearance and behavior among children of alcoholic mothers. He concluded in a 1968 paper that the characteristics were so distinctive that alcoholism in the mothers could be diagnosed by observing the children. In 1973 Jones, Smith, and colleagues independently made similar observations and termed this characteristic pattern of physical abnormalities *Fetal Alcohol Syndrome*.<sup>1, 2</sup> Since then, hundreds of reports of patients from all racial groups have been published.

Fetal Alcohol Syndrome (FAS) is a specific birth defect manifest by a cluster of specific features in each of three categories: (1) facial abnormalities; (2) growth deficiency; and (3) central nervous system effects.

The facial abnormalities include a cluster of characteristics: small eyes; thin upper lip; flat midface; short upturned nose; small chin; other eye problems, including drooping eyelid and crossed eyes; and some minor abnormalities of the

external ear. Not all of these are found in all cases of FAS, and the individual characteristics have no diagnostic significance when found in isolation. A higher frequency of major congenital malformations (heart defects, cleft lip and palate, and so forth) occurs in children with FAS, but no particular major malformation is necessary for the diagnosis.<sup>3</sup> Malformations of the fingers, toes, and other joints and limbs also occur with increased frequency. Auditory problems (primarily inflammation of the ear) and vision problems (primarily nearsightedness) are also frequently observed, along with malformed and misaligned teeth.

Growth deficiency for height and/or weight is present at birth and continues during childhood. The low birth weight and short birth length show a direct effect of alcohol on fetal growth. Except in unusual circumstances the continuing growth deficiency is a permanent condition arising from the prenatal trauma, and usually not the result of postnatal nutritional status. Hormonal changes may result in weight gain among females, so the characteristic thin appearance may not be observed after puberty. Shortness of stature remains characteristic into adulthood in most patients.

**FAS is the most common known cause of mental retardation in the western world.**

Central nervous system manifestations usually include some degree of mental handicap, ranging from mild to severe. Small head circumference is usually present and it reflects smaller brain size. Large head circumference may be present. In infancy, tremulousness and jitteriness, poor sucking reflex, high or low muscle tension, and/or delayed development are often observed. Childhood manifestations include hyperactivity, short attention span, borderline to moderate mental retardation, and/or learning and behavioral problems.

Certain postpubertal changes should be considered in diagnosing FAS in adolescents and adults.<sup>4</sup> After puberty the general appearance may not be as striking. Growth of the nose and chin may increase; growth deficiency for weight may no longer be relevant (particularly in females), although small head circumference and/or short stature may remain as

12501 OLD COLUMBIA PIKE, SILVER SPRING, MD 20904

markers. Hyperactivity and short attention span may become less prominent, although specialized memory deficits, difficulty with adaptive behavior, and poor judgment become increasingly noticeable.

In general, the older the child, the less distinguishing are the physical features associated with FAS. Diagnosis is easiest within the first two or three years of life. Not all newborns are readily diagnosed, although by eight or nine months the diagnostic picture is usually clear.

FAS, or the effects of prenatal alcohol in general, do not diminish as the child grows older. Different aspects, however, are conspicuous at different ages. The newborn shows effects on growth and development and subtle central nervous system abnormalities. During the pre-school years, hyperactivity and language and motor problems are noted. The school-age years show learning and behavior problems, and attentional and memory deficits. In adolescence psychosocial problems and aggressive anti-social behavior are often observed. Adults exhibit difficulties with adapting and self-sufficiency. Intellectual deficits associated with FAS remain fairly constant into adulthood in most patients.

*Fetal Alcohol Effects (FAE)* is a term used when a child has had prenatal alcohol exposure and some characteristics of FAS, but not enough for diagnosis of the full syndrome.<sup>3</sup> FAS is clearly defined and known to be caused by heavy *in utero* alcohol. FAE covers a wide range of disabilities and aberrations from which prenatal alcohol exposure can only be inferred. With FAE, symptoms are less specific to alcohol.

The impact on the child can be just as debilitating whether the diagnosis is FAS or FAE. All such children should be considered at risk for developmental problems, particularly at key ages such as the onset of normal schooling, the onset of puberty, and the end of formal schooling. Although children diagnosed with FAS, as a group, have lower IQ scores than those with FAE, they may be equally at risk as adolescents and adults for learning disability, behavioral problems, mental illness, and psychosocial disorders as adolescents and adults.

Children with the full FAS are usually born to women who clearly consumed a lot of alcohol during pregnancy. One problem with research on the effects of alcohol on the fetus, however, is that assessment of exposure comes primarily from self-report.

The duration of maternal alcoholism is highly related to severity and frequency of FAS among offspring. Women are more vulnerable to alcohol than men, developing cirrhosis and dying from alcoholism after fewer years of and much less lifetime alcohol consumption. Gynecologic problems increase with increasing drinking levels. Miscarriage or stillbirth, premature birth, birth defects, and infertility are all associated with

higher levels of alcohol consumption.<sup>5,6</sup>

Prenatal alcohol exposure is associated with a continuum of risks. At the heaviest exposure end are children who are clinically abnormal and diagnosed FAS. At the lighter end effects may not be observed in individual offspring but are detected by epidemiologic studies of more or less normal individuals in population-based studies.

Amounts of as low as two drinks per day increase risk of spontaneous abortion, lowered birth weight, and neurobehavioral effects on offspring as old as seven years. Three or more drinks per day increase risk of stillbirths, reproductive system disorders, and neurobehavioral deficits.

One recent study shows an association between drinking one or two drinks per day during lactation and a decrease in psychomotor function in year-old babies, even after adjusting for variables. Advice to breast feeding mothers may also need to be modified.


Much information on long-term neurobehavioral effects of social drinking in pregnancy has come from the 15-year Seattle Longitudinal Prospective Study on Alcohol and Pregnancy.<sup>7,8</sup> Starting on the first day of life, alcohol-related deficits were observed on neurobehavioral tests and on physical examination. Subtle alcohol-related decreases were also noted on mental and motor development at eight months. By four years statistically significant IQ deficits were observed, as well as decreases in fine and gross motor function (mostly balance), and sustained attention. Poor reaction time was one of the strongest deficits at the four-year exam.

Of course these studies do not indicate that drinking during pregnancy is the *only* cause of these outcomes. But after other known causes have been statistically adjusted for, prenatal alcohol exposure remains a significant predictor of later neurobehavioral effects in children. These

studies on the children of social drinkers confirm that there is no known safe level of alcohol exposure *in utero* and no known safe time for exposure during gestation.

The prevalence of FAS is about one in 600 to 750 live births in studies conducted in northern France; Gothenburg, Sweden; and Seattle, Washington. The risk of FAE is about twice that of FAS.

The cost to the United States of Fetal Alcohol Syndrome has been conservatively estimated at \$321 million per year for only some of the disabilities associated with it.<sup>9</sup> Many patients with FAE are unable to live independent productive lives even though they may not technically be classified as mentally retarded. Current residential and support services for mentally retarded persons in the United States are about \$11.7 billion per year; 11 percent of these costs are estimated to be from FAS alone.<sup>9</sup> These are probably underestimates as the extent of disability in adolescents and adults with both FAS



Advice to breast feeding  
mothers may also need to be  
modified.

and FAE is only now being recognized.

In the Seattle Longitudinal Study on Alcohol and Pregnancy; "blind" clinical examinations were given to newborn infants whose mothers' alcohol use had been previously measured by self-report during pregnancy. The higher the mother's drinking during pregnancy, the higher the risk of having a baby with fetal alcohol effects (defined here as growth deficiency, small head circumference, and minor physical abnormalities). The risk for an offspring with FAE was 10 percent for those reporting one to two ounces of absolute alcohol per day, and 19 percent for those averaging over two ounces (over four drinks of wine, beer, or hard liquor per day, on the average).<sup>10</sup>

At four years of age, children classified FAE at birth on these criteria had IQ scores over 2/3 of a standard deviation (10.5 IQ points) below the rest of the sample after adjusting for the other known influences on IQ in this population.<sup>11</sup> These subtle newborn characteristics of FAE were good predictors of children who were clearly at risk for long-term neurobehavioral deficits. Irrespective of neonatal FAE characteristics, mothers who had three or more drinks per day on the average had children with an average of five IQ points lower than the rest of the group at four years.<sup>11</sup> Mothers who reported a binge pattern of alcohol (five or more drinks per occasion) had more children at risk for learning disabilities. By the second grade of school, 24 percent of their children were already in special programs or classes, versus 14 percent for the rest.

The harm alcohol causes to the fetus has been established with hundreds of studies on laboratory animals where alcohol, as the primary cause, can be separated from the other factors that may vary with alcohol in the human condition and which in human studies must be statistically controlled. These include smoking, use of illicit drugs, poor nutrition, poverty, and adverse child-rearing conditions. Prenatal alcohol, in the absence of these variables, has been shown to produce growth deficiency, physical malformations, and disruptions in the central nervous system in a variety of animal species ranging from rodents to nonhuman primates. The studies of perhaps the greatest interest are those documenting alcohol-related disruptions in brain development *in utero*. Early work in this area documents alcohol-related disruptions in several regions of the brain.<sup>12</sup> Several more recent studies extend this work to low-dose effects of alcohol, showing behavioral and neurochemical effects at doses too low to produce deviations in physical structure or growth that last well into adulthood. Noble reports evidence that prenatal alcohol exposure alters activity of excitatory amino acids (EAAs) in the brains of adult rats.<sup>13</sup>

The behavioral problems observed in animal models of FAS may derive in part from brain disruption *in utero*, the

lifetime consequences of which are played out as the offspring develops.<sup>12</sup> A wide variety of lifetime behavioral deficits of the rat that are produced by prenatal alcohol exposure have been documented. These behaviors—also observed in patients with FAS and/or documented in the Seattle social drinking study—include: early sucking difficulty, weak reflexes, early gait problems, difficulty with response inhibition, increased activity, learning problems, and visual spatial problems. Animal and human studies show fairly good agreement when compared in terms of estimated blood alcohol levels (BALs), and both show a dose response relationship.

Other mechanisms that may show the harm alcohol causes to the fetus have included prenatal oxygen deficiency from alcohol-induced constriction of fetal circulation; alcohol-induced inhibition of essential amino acids across the placenta and blood/brain barrier; direct toxic effects of acid aldehyde or other primary metabolites of alcohol; disruption of prostaglandin synthesis; and/or disruption of the hypothalamic-pituitary-ovarian-adrenal axis.


The 1985 National Household Survey on Drug Abuse found that 89 percent of women in the childbearing years had had alcohol in their lifetimes, 61 percent in the past month. The 1987-88 National Adolescent Student Health Survey showed that 50 percent of 10th grade girls were using alcohol and 50 percent thought it was acceptable to have sex with a steady friend. In Seattle, recent studies at the University Hospital revealed that 52 percent of women had used alcohol during pregnancy and 13 percent had an alcohol use pattern involving five or more drinks per occasion.

Organized prevention activities are clearly warranted. The best start is a pronouncement from a country's public health officer, recommending that women abstain from alcohol during pregnancy and when planning a pregnancy.

The next step is to get that message to the entire community, not just pregnant women. Although it may be difficult for an individual woman on her own to overcome alcohol use, the support from family and friends can help her attain and maintain abstinence.

Strategies for raising public awareness about abstinence during pregnancy can include warning labels on alcohol beverage containers; signs at places where people purchase alcoholic beverages; brochures distributed throughout the community; continued media coverage; and a crisis line for information and referral. The crisis phone line becomes the link between the information transmitted in the public awareness campaign and the services available in the community. One without the other will not solve the problem.<sup>14, 15</sup>

Increasing professional education about alcohol-related birth defects (ARBD) is another important activity. Medical schools, nursing schools, psychology departments, schools



Children classified FAE at birth had IQ scores 10.5 points below the rest of the sample.

of education and social welfare, schools for public administration and policy—all training programs for human services personnel should have specific curriculum materials on alcohol-related birth defects. But to prevent alcohol related birth defects, we will have to rely on a broader campaign than one just oriented to public health nurses, obstetricians, and midwives. It should be a community activity, and a broad range of community service professionals need to be trained at two levels: curriculum additions for those currently in training, and on-going in-service training for those who are already operating as professionals in the field.

Teachers without knowledge of FAS/FAE are often annoyed at the behaviors of such children in the classroom and frustrated by their inability to help them. When the cause of these problems is not recognized, they are often expected to perform to unrealistic expectations, often find school frustrating and unrewarding, often develop undesirable behaviors, and often end up dropping out of or being expelled from school. They are usually even less well-equipped for survival outside of school. Use of alcohol and other drugs and a life on the streets often awaits them once they leave institutional supports.

All women in prenatal care should be asked about their use of alcohol before and during pregnancy, told about the risks associated with such drinking, and advised to stop drinking. Although the best outcome is obtained by abstaining throughout pregnancy, stopping during pregnancy is related to better outcome than drinking throughout pregnancy.

Routine screening of all delivering mothers for alcohol use and of all newborns for FAE is extremely important to target these high-risk families. Appropriate services are needed not only for women who are using alcohol during pregnancy, but also for intensive post-delivery follow-up for mothers and babies. The range of services should include both inpatient and outpatient services, oriented to the special needs of alcohol-dependent women and dealing with the myriad of associated problems, including social support, financial support, self-image and job-skills training, as well as the obvious detoxification and alcohol treatment aspects.

Finally, it is important to properly educate learning-disabled individuals about ARBD and the risks of alcohol use and to provide concrete help with appropriate methods of birth control and treatment for alcohol and drug abuse problems, particularly among the handicapped. Pregnancy has been a frequent problem among adolescent girls with FAS. Although FAS is not genetically transmitted, it can occur in successive generations when women who themselves have ARBD drink heavily during pregnancy. Even in the absence of drinking during pregnancy, these developmentally-disabled mothers are clearly at high risk for parenting difficulties.

Safeguarding the future generation should be a primary goal for public health officials and for private citizens. Our children are our most precious resource.

*Ann Pytkowicz Streissguth, PhD, is professor of psychiatry and behavioral sciences at the University of Washington School of Medicine in Seattle.*

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# Symptoms of Fetal Alcohol Syndrome

For more information on Fetal Alcohol Syndrome call the Information Center for New Mexicans with Developmental Disabilities at 1-800-552-8195.

Fetal Alcohol Syndrome (FAS) is a group of physical and mental birth defects resulting from a mother's alcohol consumption during pregnancy. Although more and more cases of the syndrome are being diagnosed in the U.S. every year (approximately 5000 per year), medical personnel are often unfamiliar with FAS, which was only identified as a birth defect in 1973. A complete diagnosis of fetal alcohol syndrome in children involves the identification of as many as 38 characteristics. Here are a few of the most common features of babies born with FAS.

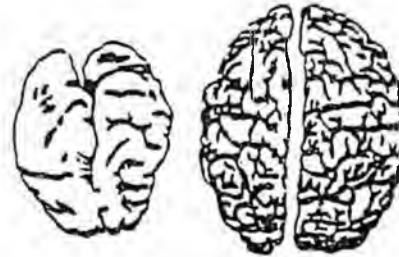
FAS  
8 year old



Normal  
8 year old

## Slow growth before and after birth

- Birthweight of newborns is usually in the lowest 5%
- Growth remains slow throughout childhood
- Small head circumference (microcephaly) persists throughout adult life



FAS brain

Normal brain

Brain damage resulting in a smaller and abnormally developed brain. This results in low IQs (average FAS child's IQ is low 70s) and mental retardation as well as behavioral problems.



## Abnormal facial features

- flat facial profile
- small eye openings
- small nose with nostrils which are often aimed forward
- poorly developed nasal bridge
- abnormal ears with "railroad track" ridges
- long and flattened upper lip



A  
pregnant  
woman  
never  
drinks  
alone.

New Mexico's  
Campaign to Stop  
Fetal Alcohol  
Syndrome

A project of the N.M.  
Developmental Disabilities  
Planning Council  
435 Saint Michael's Dr.  
Building D  
Santa Fe, NM 87501

505 827 7590

Additional Information

**Bodies are hairy at birth, although the hair disappears**

**Joint abnormalities in the hands, elbows and hips**

**High risk for congenital heart disease, cleft lip, cleft palate & seizures**

**Braces often required for misaligned teeth**

**Poor eyesight requiring glasses**

As FAS children grow, the syndrome is less visible but behavioral difficulties are apparent. Among the most common behavioral difficulties are:

**delayed toilet training**

**irritability**

**hyperactivity**

**attention deficits**

**poor coordination**

**poor judgement & logic**

**temper tantrums & disobedience**

**easily manipulated**

**failure to understand consequences of actions**

**anti-social behavior**

FAS is completely preventable if a woman abstains from drinking during pregnancy, while nursing or attempting to conceive. Therefore, it's important for doctors, nurses and other medical personnel to discuss alcohol consumption with pregnant patients. While most FAS babies are born to women who drink enormous quantities of alcohol, it is not clear whether there is a threshold amount of alcohol that must be consumed before damage occurs. Even moderate amounts of alcohol, or a pattern of binge drinking, can lead to low birthweight babies, depressed IQs, behavioral problems and other symptoms of Fetal Alcohol Effect (FAE), a less severe version of FAS.

A pregnant woman never drinks alone. Until more data are available, it's best to advise patients to follow the Surgeon General's advice and avoid alcohol during pregnancy.

# Fetal Alcohol Fact Sheet

"If women didn't drink anymore during pregnancy, there would **never** be another baby born with Fetal Alcohol Syndrome or Fetal Alcohol Effect."

— Ann P. Streissguth, Ph.D., University of Washington

## What are FAS and FAE?

When mothers drink alcohol while pregnant, their babies could have **Fetal Alcohol Syndrome (FAS)** or **Fetal Alcohol Effect (FAE)**. FAS and FAE are a group of birth defects that have no cure. People with FAS and FAE have a range of problems as severe as being mentally retarded to less visible problems like difficulty paying attention in school. Alcohol might cause a child to:

- ...be slow or mentally retarded
- ...look different than other children
- ...be small for his or her age
- ...have learning problems, with a lower IQ
- ...be hyperactive, with a short attention span
- ...have many health problems

## Facts...

- ♦ FAS is the #1 known cause of mental retardation in the United States, and one of the three leading causes of birth defects.
- ♦ Each year over 40,000 American children are born with defects because their mother drank alcohol when pregnant.
- ♦ The effects of FAS never go away. People with FAS have the disabilities they are born with, including mental retardation, throughout their lives.

## Can FAS and FAE be prevented?

**Yes, they are both 100% preventable!** When a woman stays away from alcohol (beer, wine, hard liquor and wine coolers) during pregnancy, her baby will not have FAS or FAE.

- ♦ Women **planning** a pregnancy should stop drinking alcohol before trying to conceive and should not drink throughout pregnancy and breast feeding.
- ♦ Women who drink and have an **unplanned** pregnancy should quit drinking as soon as they suspect they are pregnant.
- ♦ **Heavy** drinkers should avoid pregnancy until they think they can stay away from alcohol for the nine months from conception to birth, and longer, if they plan to breast feed their babies.

## How much is too much?

There is no known safe amount of alcohol for a pregnant woman. When a woman drinks, her baby drinks because the alcohol passes directly through the placenta to the baby.

## For more information about...

Alcohol use: National Council on Alcoholism and Drug Dependence Helpline: 1-800-622-2255  
or: 1-800-475-4673

Drug use: National Clearinghouse on Alcohol & Drug Information: 1-800-729-6686

Birth Defects: March of Dimes, Washington State Chapter 1-800-345-5188

If you want to talk to someone about a problem with alcohol or other drugs call 1-800-662-4357

## 10 COMMON MISCONCEPTIONS ABOUT FETAL ALCOHOL SYNDROME (FAS) AND FETAL ALCOHOL EFFECTS (FAE)

Ann P. Streissguth, Ph.D.

Fetal Alcohol & Drug Unit, Department of Psychiatry & Behavioral Sciences  
School of Medicine, University of Washington  
Seattle, WA 98195

1. **That FAS means mental retardation.**
  - \* Some people with FAS are mentally retarded, others are not.
  - \* People with FAS can have normal intelligence.
  - \* They are brain damaged and have specific areas of strengths and weaknesses.
    - It's more like people who have sustained brain injury from an auto accident.
2. **That the behavior problems associated with FAS/FAE are all the result of poor parenting or a bad environment.**
  - \* No, being brain damaged can lead to behavior problems because brain damaged people don't process information the same way that other people do, so they don't always behave like others expect them to.
  - \* Brain damaged children are hard to raise in the best environments.
  - \* Their parents need help and support, not criticism.
3. **That they will outgrow "it" when they grow up.**
  - \* Unfortunately, they do not. FAS lasts a lifetime, but the manifestations and type of problems change with each age.
  - \* It takes a longer period of sheltered living for brain damaged children to grow up.
4. **That to admit they are brain damaged is to give up on them.**
  - \* Have we given up on children with other defects?
  - \* We need research to understand the needs of patients with FAS and how to help them. We haven't invested in that area yet. We will learn how to help them when we decide to invest in the problem.
5. **That diagnosing them will brand them for life.**
  - \* A diagnosis tells you what the problem is, helps you figure out how to treat the problem and relieves the person of having to meet unrealistic expectations.
6. **That they are unmotivated when they don't keep appointments or act in a way that we consider responsible.**
  - \* Probably the explanation lies in memory problems, inability to problem solve effectively, or simply being overwhelmed.
  - \* Sometimes they misconstrue reality.
7. **That one agency can solve any or all of the problems alone.**
  - \* The multiple needs of patients with FAS/FAE require multiple fronts of intervention and intense interagency cooperation.
8. **That this problem will be solved with existing knowledge.**
  - \* Research is desperately needed, and the magnitude of the problem will necessitate.
9. **That the problem will go away.**
  - \* FAS is preventable, but alcohol is so much a part of our culture and so aggressively marketed to those least able to resist, that active prevention activities must continue on all fronts to safeguard our children's future and the future of our people.
10. **That their mothers had an easy choice not to drink during pregnancy, and through callousness or indifference, permanently damaged their children.**
  - \* Biologic mothers of children with FAS need help with their alcoholism and/or with birth control.
  - \* Pregnancy is an excellent time for alcohol abusing mothers to stop drinking, but they need help.

## WHAT YOU CAN DO TO MAKE A DIFFERENCE

### Suggested Steps to Take to Address FAS in Your Community

- Educate yourself. Learn all you can about FAS. Be sure you understand the facts. Remember that FAS is multi-faceted. There are persons with FAS in every age group and every age has different needs. In addition there is the whole area of prevention. No one strategy will address all the needs.
- Educate the community. The following are 2 examples of how communities have done this in Washington:
  - Woodinville had a town meeting sponsored by the Woodinville Kiwanis Club and the March of Dimes.
    - The meeting was widely advertised. Notices went home with every child in the school district.
    - They arranged for a panel of speakers including:
      - The FAS Coordinator for the state Department of Health who gave an overview of FAS.
      - The biological mother of a child with FAS from Woodinville who talked about her experience as a parent of a 9 year old with FAS and what support she needs.
      - The teacher of the above child, who talked about how she deals with him in the classroom.
      - A counselor who works with children with FAS in a grade school, who talked about techniques she uses with them.
      - An adoptive parent who talked about her experience as the parent of an adolescent with FAS and what support she needs.
      - A probation counselor supervisor who talked about how the criminal justice system is beginning to recognize clients with FAS.
    - A sign-up was available for persons interested in pursuing the issue. The plan was to get a working group formed.
    - The meeting was in the evening in the school gym and about 80 people were in attendance.
  - In Chehalis the Lewis County Hotline and C.A.R.E. Services coordinated with the Lewis County Health Department and set up an informational evening meeting on FAS.
    - The state FAS Coordinator for the Department of Health gave a 45 minute talk describing FAS.
    - An adoptive mother spoke about being the parent of a 9 1/2 year old with FAS.
    - A local parent who has adoptive and foster children with FAS spoke about her experiences.
    - A panel of local people was present to speak about their interest in FAS, what they know, and what they are trying to learn. The panel included:

- Talk to your legislator and senator. Are they knowledgeable about FAS? One way to educate them is to have parents in their district with children with FAS tell them their story.
- Get in touch with the FAS Adolescent Task Force, Jocie DeVries, (206) 778-4048, to learn about what they are doing. They may be involved in testifying before the legislature or any number of other activities. They welcome active support.
- Subscribe to ICEBERG, a quarterly newsletter for parents and professionals who care about persons with FAS.
- Be an advocate for one family or one child.

Prepared by: Sandra P. Randels, Coordinator  
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Washington State Department of Health  
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May 29, 1992

Economic Impact of  
Fetal Alcohol Syndrome  
in Alaska

February 1989

by

Maureen Weeks  
Senate Advisory Council

for

Senator John Binkley

# Alaska State Legislature

Senate Advisory Council



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Juneau, Alaska 99811  
Phone: (907) 465-3114

## MEMORANDUM

TO: Senator John 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.<sup>1</sup>

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

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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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<sup>1</sup> 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.

Senator Johne Binkley  
February 17, 1989  
Page 3

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.

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## 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

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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

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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 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.<sup>2</sup> Average FAS hospital costs in 1987-88 were \$99,740 per FAS child; average neonatal physician fees for FAS infants were \$11,065. These costs include all hospital costs except transport, other physicians and anesthesiology. Total average cost of intensive care for one FAS baby is \$110,805 per year. For 11 low birthweight babies, it is \$1,218,855 per year.

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

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<sup>2</sup> 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.

Senator John Binkley  
February 17, 1989  
Page 11

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.

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Table 3  
Low birthweight of FAS births,  
Alaska 1985

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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

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(a) Abel and Sokol, "Incidence of Fetal Alcohol Syndrome and Economic Impact of FAS-Related Anomalies", Elsevier 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:  $4.8\% \times 12,900 \text{ births} = 79.8\% \times 24.6 \text{ FAS births} + 0 \times 12,869 \text{ non-FAS births}$ , 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

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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

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(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.

	<u>1987</u>	<u>1988</u>
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

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LBW rehospitalization:

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

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(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.

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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.

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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.<sup>3</sup>

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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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<sup>3</sup> 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.

Senator Jonne Binkley  
February 17, 1989  
Page 18

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 Educatn (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			
ANNUAL FAE BIRTHS AT TWICE FAS RATE (58)						
20 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 can 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.

Senator John Binkley  
February 17, 1989  
Page 24

#### 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.
- Ruth Little, "Moderate Alcohol Use During Pregnancy and Decreasing Infant Birthweights", American Journal of Public Health, Vol. 67, 1977.
- Ann P. Streissguth, A Manual on Indian Adolescents and Adults with Fetal Alcohol Syndrome, University of Washington Medical School, July 1, 1986.

#### PERSONS CONSULTED

- James Berner, M.D., Chief, Area Community Health Services Branch, Alaska Area Native Health Service.
- Tom Buckner, Special Education, Alaska Department of Education.
- Mary Diven, Infant Learning Program, Alaska Department of Health and Social Services.
- Ellen Ganley, Governor's Council for the Handicapped and Gifted.
- Robert Gregovich, formerly with Mental Health and Developmental Disabilities, Alaska Department of Health and Social Services.
- Christine Hagmeier, Mental Health and Developmental Disabilities, Alaska Department of Health and Social Services.
- Henrick Harwood, National Institute of Medicine, Rockville, Md. (202-334-3017)

Senator John Binkley  
February 17, 1989  
Page 25

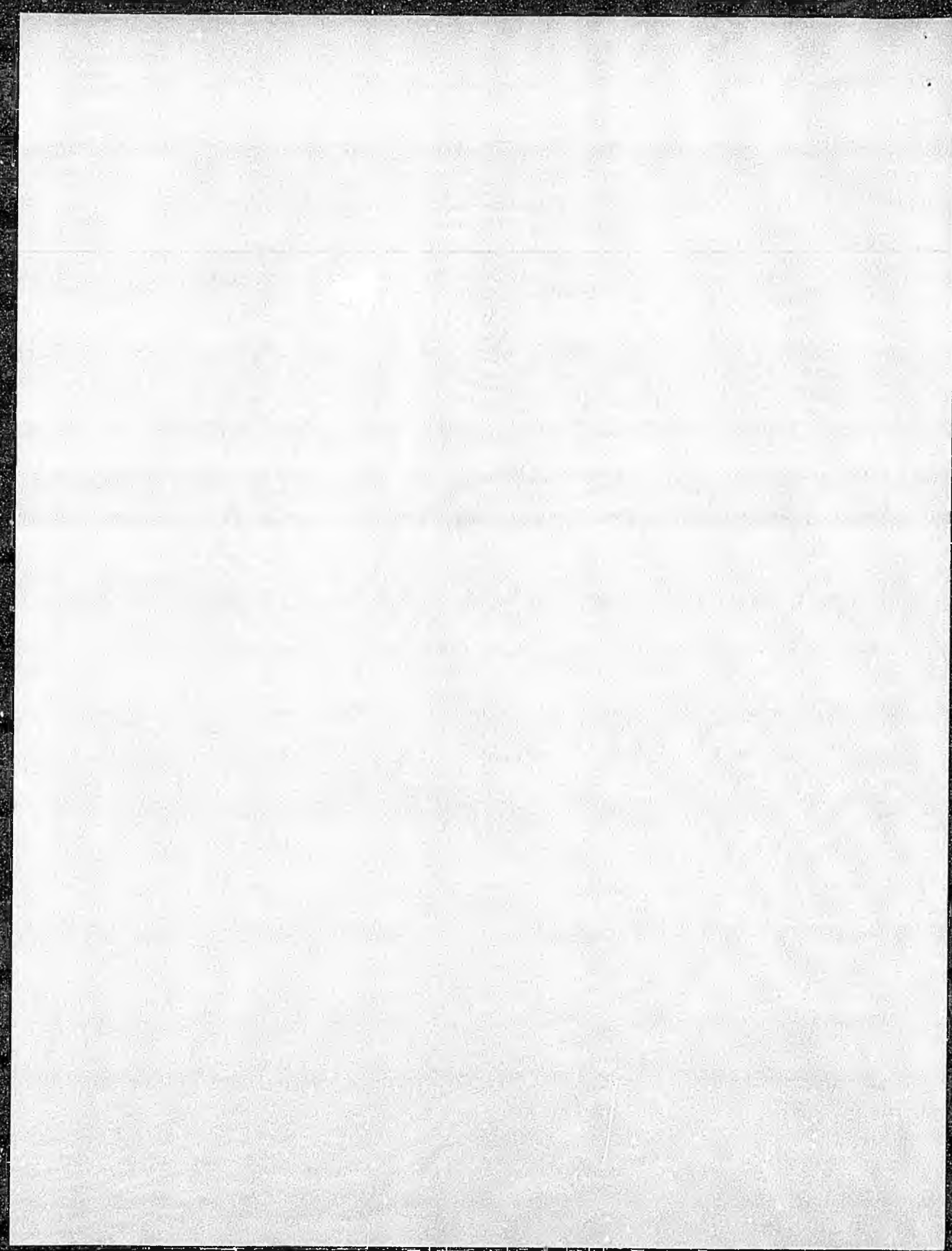
Vicki Hild, FAS Coordinator, Alaska Native Health Board.

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.



## ASTF Final Project Report

**Name:** Steven Jacquier

**Project Title:** "Demonstrating Fetal Alcohol Syndrome in Laboratory Mice: An Interdisciplinary Multi-Grade Classroom Project."

**Contact Info:** Rampart School

Rampart, AK 99767

Tel: 907-358-3112 [Home and School]

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### **Project Description:**

In this project students learn and apply scientific concepts and laboratory skills through participation in a socially relevant and meaningful hands-on project. By adapting several classic studies investigating the effects of maternal alcohol consumption on offspring in laboratory mice and then implementing this experiment in the public school, students learn valuable content area knowledge as well as important industrial skills. Data collection and use of statistical analysis in the interpretation of project data enhance the mathematics learning of students. Higher order thinking skills are fostered not only by direct involvement with the scientific method and use of applied mathematics, but also when the results and realizations of the experiments are related to the context of human health and welfare for the individual as an organism and as a citizen in the larger community. A key feature of this multi-grade interdisciplinary project is that it repeatedly exposes students to important material and involves them directly with the experiment through kinesthetic learning approaches. Students also gain organizational skills and public speaking skills via developing demonstrations and presenting their findings to peers and adult community members.

**What worked?** The project was successful in repeatedly exposing students to the content area material and requisite lab skills through direct kinesthetic involvement. Large increases in knowledge were measured by use of pre and post testing; student statements reflecting awareness, attitude, and behavior also reflected a significant positive impact by involvement in the project. Finally, the lab experiment portion of the project was actually successful: fetal alcohol syndrome was indeed demonstrated in lab mice in the classroom by students.

**What was good about the project?** Being able to incorporate portions of science, math, social studies, and language arts instruction for grades 5 through 12 into a single project focus made for more effective instruction in the context of a small multigrade rural classroom. The hands-on approach empowered students to take ownership of the project and become personally invested in the outcome. Their success in mastering the requisite theory and skills was demonstrated by actually producing FAS in lab mice in the classroom, by writing articles which were published in the district newsletter, and by the demonstrations which they produced for peers and community members.

**What spin-offs resulted from the project?** Students who worked directly with the project went on to become peer educators. Travelling to other schools, athletic meets, and a regional youth leadership conference the students presented what they had learned to other students and with community

members as well. Public speaking skills, organizational skills, and effective peer education were spin-offs.

**What needs to be changed for greater success?** Language Arts and Social Studies applications could be exploited to greater advantage with more careful planning beforehand. Some technical details (such as detection of seminal plugs) need to be worked upon as well. Finally, some special equipment design would be useful, e.g., developing a classroom cabinet for the project which would allow students to see what is going on at all times with the mice yet control mouse dander odor at the same time.

**Methods:** Please call or write for specific details, some of which are still in development. In brief, males and females of a special strain of lab mice are bred at an age of approximately 60 days. After insemination the female is weighed each day; in 9 days she will usually increase 3 grams in weight. On the 9th day, 10th day, or on both the 9th and 10th days of gestation the female is force-fed a specific dose (taken from a body weight table) of 20% ETOH solution equivalent to 5.8 ml of alcohol per Kg body weight. The mouse becomes inebriated, demonstrates loss of control and then loss of consciousness, and remains intoxicated for about 6 to 8 hours. Eight days later the experimental and control dams are sacrificed either by cervical dislocation or CO<sub>2</sub> inhalation; the pups are removed by caesarian section and compared for count, length, weight, and anatomical deformities. Parallel to the lab effort students study FAS/E and produce papers, presentations, and products in Language Arts and Social Studies (e.g., book reports on The Broken Cord by Michael Dorris, Brave New World by Huxley, economic and legal analysis of newspaper articles and court cases related to the monetary and social cost of FAS/E).

**Equipment:** Please call or write for a complete list, which is still in development. In brief, the essential equipment for performing this project could be condensed down to the mice [the C57BL/6J mouse strain, available from Jackson Laboratory, 1-800-422-MICE], mouse cages [expensive at around \$150.00 each yet essential for good control and cleanliness; available from any science supply house], Purina Mouse Chow [local feed supply store], Everclear or other ethanol alcohol [liquor store or scientific supply house], feeding needle [Cat. #7902, 20G @\$86.00 from 516-248-0300 ], 1.0 ml syringe [Fisher Scientific], a pair of surgical scissors and forceps [Cat. #RS-5960 @\$35.00 and #RS-8254 @\$17.00 from 202-393-1234, ]. A balance capable of weighing to 0.1 grams is necessary; a top-loading electronic model (such as those available for around \$300 from Edmund's Scientific) works best. Learning was greatly enhanced, however, by having realistic models of developing human fetuses [Nasco Cat. #WA8849M @\$400 from 1-800-558-9595], colorful charts and booklets [Anatomical Products, 1-800-621-7500; Health Edco, 1-800-299-3366 ext 295; Denoyer-Geppert, 1-800-621-1014]. Without a video microscope and monitor (available from Carolina Biological, 1-800-334-5551, for around \$2,000.00) only two or three students can see what is going on during a dissection, whereas with the video display on a large monitor an entire roomful of students can see small detailed structures and complex operations. Another highly useful resource is the Dartmouth Medical School's Project Cork Institute

slideshow "Pregnancy and the Fetal Alcohol Syndrome" [\$100 from 800-432-8433].

**Time lines:** The full project works well as a two-semester activity for a small rural school with a multi-grade classroom. It would probably work well as a semester class meeting two or three times a week at an urban high school or even at a junior high. Peer educators can produce an interesting and powerful presentation of their projects in as little as 45 minutes, although 90 minutes is better if a c-section is performed. Peer educators found avid audiences with students as young as 1st grade and all the way to adult groups.

**Students touched:** This project involved 15 students from grades 5 through 12 directly in the day-to-day investigation. These students in turn peer-educated roughly 400 other students from 1st grade through 12th grade, and about 50 adults. The instructor also reached perhaps an additional 100 students and 100 adults at the ASTF Conference in Juneau, was a speaker on a Prevention panel addressing perhaps 200 adults at a statewide FAS Conference held in Nome (the conference was broadcast live via public radio throughout the bush), and recorded a 15 minute TV interview with Mrs. Ermalee Hickel which was broadcast throughout Alaska on the Rural Alaska Television Network (it will be repeated a number of times this year). Most of those who have seen the project are members of severely FAS/E impacted rural communities.

**Community involvement:** The project received widespread support from the community of Rampart, from the Yukon Flats community at large, and from the leadership of the Doyon region Native community. A resolution from the Rampart Student Council was introduced at the Tanana Chiefs Conference Youth Delegation which supports introducing this project to schools throughout rural Alaska; the resolution was adopted.