

SCR

12

Alaska State Legislature




Interim:
716 West 4th Ave.
Anchorage, Alaska 99501
(907) 269-0199

Session:
State Capitol Building
Juneau, Alaska 99801-1182
(907) 465-4945

Senator Kevin Meyer
Senate District O

TO: Representative Wes Keller, Co-Chair
Representative Bob Herron, Co-Chair
House HSS Committee

FROM: Senator Kevin Meyer 

DATE: February 16, 2010

RE: House HSS Committee Hearing Request for SCR 12

This is a request for a House HSS Committee hearing for SCR 12, "Proclaiming September 9, 2010, as Fetal Alcohol Spectrum Disorders Awareness Day."

The following documents are attached:

- Sponsor Statement
- Current version of the bill
- Fiscal Note
- Back up information
 - 10 Facts about FAS from the SOA, Office of Fetal Alcohol Syndrome website
 - Fetal Alcohol Spectrum Disorders, Pages 33-36 of the "Economic Costs of Alcohol and Other Drug Abuse in Alaska" 2005 Update prepared by the McDowell Group.
 - 4 Letters of Support
- Potential witnesses/testifiers (depending on schedule)
 - Michael Baldwin, Behavioral Health Clinician
 - A representative from Stone Soup Group
 - A representative from HSS or the Advisory Board on Alcoholism and Drug Abuse and the Alaska Mental Health Board
- Staff member assigned to the bill: Christine R. Marasigan, 465-6876

This resolution would observe FASD Awareness Day.

Please contact Christine if you have any questions regarding this legislation.

ALASKA STATE LEGISLATURE

Interim:
716 West 4th Avenue
Anchorage, Alaska 99501-2133
Phone: (907) 269-0199
Fax (907) 269-0197
Senator_Kevin_Meyer@legis.state.ak.us



Session:
Alaska State Capitol
Juneau, Alaska 99801-1182
Phone: (907) 465-4945
Fax: (907) 465-3476
Toll Free: (866) 465-4945

SENATOR KEVIN MEYER
SENATE DISTRICT O

SPONSOR STATEMENT FOR SCR 12

"Proclaiming September 9, 2010, as Fetal Alcohol Spectrum Disorders Awareness Day."

SCR 12 would proclaim September 9, 2010 as Fetal Alcohol Spectrum Disorders Awareness Day (FASD).

Alaska has the highest known incidence of FASD in the United States. This is a condition caused by prenatal exposure to alcohol, which can result in permanent brain damage, birth defects, learning disabilities, behavioral problems and most tragically, the loss of individual potential.

While FASD affects all racial and socioeconomic groups, it is a 100% preventable condition. FASD Awareness Day is observed internationally on September 9th. This serves as a reminder on the ninth day of the ninth month of the year that during the nine months of pregnancy a woman should abstain from alcohol.

SCR 12 would observe FASD Awareness Day by promoting the awareness of the effects of prenatal exposure to alcohol.

FISCAL NOTE

STATE OF ALASKA
2010 LEGISLATIVE SESSION

Fiscal Note Number: 1
Bill Version: SCR 12
(S) Publish Date: 2/10/10

Identifier (file name): _____ Dept. Affected: _____
Title SCR 12 FETAL ALCOHOL SPECTRUM DISORDERS DAY RDU _____
Sponsor Senator Meyer Component _____
Requester (S) Health and Social Services Committee Component Number _____

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

	Appropriation Required	Information						
		FY 2011	FY 2011	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016
OPERATING EXPENDITURES								
Personal Services								
Travel								
Contractual								
Supplies								
Equipment								
Land & Structures								
Grants & Claims								
Miscellaneous								
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0

CAPITAL EXPENDITURES								
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CHANGE IN REVENUES ()								
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FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts								
1003 GF Match								
1004 GF								
1005 GF/Program Receipts								
1037 GF/Mental Health								
Other Interagency Receipts								
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0

Estimate of any current year (FY2010) cost: _____

POSITIONS

Full-time								
Part-time								
Temporary								

ANALYSIS: (Attach a separate page if necessary)

Prepared by: Celeste Hodge, Committee Aide Phone 465-4906
Division: Senate Health & Social Services Committee Date/Time: _____
Approved by: Senator Bettye Davis Date 2/8/2010
Senate Health & Social Services Committee, Chair

TEN THINGS YOU SHOULD KNOW ABOUT FAS

1. Drinking during pregnancy can cause permanent damage to a developing fetus.
2. FAS is one of the most common causes of mental retardation, and is the only cause that is entirely preventable.
3. According to recent State of Alaska DHSS surveillance data, more than 126 children are born at risk for FASD each year in Alaska.
4. Prenatal exposure to alcohol can cause brain damage and other permanent birth defects.
5. Obtaining an FAS diagnosis can improve an individual's ability to function in the world, and may reduce secondary disabilities like depression and school failure.
6. FASD is found in all races and all socio-economic groups – wherever women drink alcohol FASD exists.
7. There is no safe level of alcohol consumption during pregnancy.
8. Women should stop drinking prior to trying to conceive – alcohol can cause damage to a developing fetus even before a woman knows she is pregnant.
9. FASD is 100 percent preventable.
10. With the right diagnosis, support and understanding, many individuals with FASD are living happy and full lives.

**ECONOMIC COSTS OF ALCOHOL
AND OTHER DRUG ABUSE IN ALASKA,
2005 UPDATE**

**PREPARED FOR:
THE ADVISORY BOARD ON
ALCOHOLISM AND DRUG ABUSE
DEPARTMENT OF HEALTH
& SOCIAL SERVICES**

PREPARED BY:



JUNEAU • ANCHORAGE

DECEMBER 2005

Full report is available online:

http://www.hss.state.ak.us/abada/pdf/mcdowell_rept2005_091307.pdf

Fetal Alcohol Spectrum Disorders

Prenatal exposure to alcohol can cause specific birth defects which may include physical, mental, behavioral, and learning disabilities. Many children with fetal alcohol disorders are not identified until they reach school age or later. Individuals with alcohol-related effects may have difficulties with attention, memory, and problem solving. Heart, liver, and kidney defects are also common, as well as vision and hearing problems.¹³ Alcohol-related effects that fall within the broad category of fetal alcohol spectrum disorders (FASD) include:

- fetal alcohol syndrome (FAS),
- partial FAS (PFAS),
- fetal alcohol effects (FAE),
- alcohol-related neurodevelopmental disorder (ARND),
- and other alcohol-related birth defects (ARBD).¹⁴

¹³ National Organization on Fetal Alcohol Syndrome, *What is FAS/FASD?*, www.nofas.org/faqs.aspx?id=9

¹⁴ US Department of Health and Human Services, SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence. *The Language of Fetal Alcohol Spectrum Disorders*.

Full report is available online:

http://www.hss.state.ak.us/abada/pdf/mcdowell_rept2005_091307.pdf

During the past ten years, a number of FAS prevalence rates have been established. Studies by the Centers for Disease Control and Prevention indicate a national rate from 0.2 to 1.5 cases per 1,000 births across various populations.¹⁵ Other studies, including those focusing on specific high-risk populations such as Native Americans, other minorities and families living in poverty have indicated rates from 0.5 to 5.0 per 1,000 live births. Clearly, the data is varied and limited.

In establishing a clear number of infants born each year in the United States with Fetal Alcohol Syndrome, the CDC estimates between 1,000 and 6,000 children will be born with FAS each year - a preventable birth defect and disability.

Beginning in 1997, Alaska was one of five states comprising the CDC's Fetal Alcohol Syndrome Surveillance Network (FASSNet), a program established to provide consistent and comparable FAS prevalence rates. Participating states included Arizona, Colorado, New York, Wisconsin and Alaska (however, FAS rates for Wisconsin are not available). At 1.5 per 1,000 live births, Alaska has a significantly higher rate of children born with FAS than other states in the FASSNet program. In addition, Alaska data showed an estimated FAS prevalence rate of 4.8 per 1,000 live births among Alaska Natives. CDC data indicates FAS prevalence rates ranging from 0.3 per 1,000 in Arizona and Colorado to 0.4 in New York.

CDC estimates that other prenatal alcohol-related conditions, such as ARND and ARBD, occur approximately three times as often as FAS.¹⁶ Within the wider category of FASD (which would include individuals with FAS), the US is estimated to have about 10 cases per 1,000 live births.¹⁷

Alaska's estimated rate of all births impacted by prenatal alcohol exposure is 16.3 cases per 1,000 births, based on the 1995 to 1999 birth years. While these alcohol-related effects are closely associated with FASD, these rates are not directly comparable to national FASD rates of 10 per 1,000 live births due to differences in diagnoses and reporting at the state and national levels. Based on 16.3 cases per 1,000 and the number of live births from 1995 to 1999, approximately 160 infants are born each year in Alaska with FAS and other effects from maternal alcohol use during pregnancy. Of those, approximately 15 are born with Fetal Alcohol Syndrome (FAS).

FAS vs. FASD

It is important to remember that the information being used to determine the economic costs of care and service delivery to individuals with Fetal Alcohol Syndrome is only a small portion of the overall impact of prenatal exposure to alcohol and the resulting birth defects and disabilities. Beginning in 2000, the State of Alaska began extensive efforts to improve and expand the ability to appropriately diagnose individuals prenatally exposed to alcohol. In 2005, Alaska has a broad and regionally diverse network of diagnostic teams across the state.¹⁸ Data collected from these teams indicate that from July 2000 through March 2005 teams have conducted

¹⁵ FAS: *Guidelines for Referral and Diagnosis*, CDC, 2004.

¹⁶ CDC, *Tracking Fetal Alcohol Syndrome*, www.cdc.gov/ncbddd/fas/fassurv.htm

¹⁷ National Organization on Fetal Alcohol Syndrome, *What are the Statistics and Facts about FAS and FASD?*, www.nofas.org/faqs.aspx?id=12

¹⁸ For information on available services go to <http://health.hss.state.ak.us/fas/teams/default.htm>.

Full report is available online:

http://www.hss.state.ak.us/abada/pdf/mcdowell_rept2005_091307.pdf

755 FASD diagnostic assessments. Of this number, 76 (10.0 percent) were diagnosed with FAS or atypical FAS; 378 (49.9 percent) were diagnosed with Static Encephalopathy; 251 (32.2 percent) were diagnosed with Neurobehavioral Disorder; and 50 (6.6 percent) were found to have no evidence of organic brain damage.

What this data indicates is that the costs associated with all alcohol-related births are much higher than those estimated just for individuals with FAS. And, as noted in the break-through research of Dr. Ann Streissguth in 1996 (*Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome [FAS] and Fetal Alcohol Effects [FAE]*), individuals with FAE (what is now referred to as FASD) are more likely to develop secondary disabilities and need more services than those with Fetal Alcohol Syndrome and the associated facial dysmorphism. For Alaska and the economic costs associated with all fetal alcohol spectrum disorders, the costs could be as much as 80 percent higher than indicated for FAS alone.

Economic Cost of Fetal Alcohol Syndrome

The cost of caring for and providing appropriate services to a person with FAS can be significant. These costs may include neonatal care for low birth weight to special speech therapy, behavioral management, or residential care for adults with FAS. Lifetime costs for care for children born in 2003 with FAS are estimated below. However, these costs are excluded from the total health care costs for 2003, as the component of that expenditure in 2003 alone cannot be determined.

Methodology

To estimate the economic costs from FAS, the research team first determined the number of live births with FAS in Alaska. The Alaska Department of Health and Social Services has closely monitored incidence of FAS in the state since 1998, as part of a U.S. Centers for Disease Control (CDC) monitoring program called the Fetal Alcohol Syndrome Surveillance Network (FASSNet), the ongoing Alaska FAS Surveillance Project and the Alaska Birth Defects Registry. The development of 13 community-based FASD diagnostic teams across Alaska has also assisted in the collection of data related to both FAS and other alcohol-related disabilities included in the FASD umbrella definition.

The Alaska FAS Surveillance Project data collection system is based on reports to the Alaska Birth Defects Registry, and uses medical chart data points to identify children with FAS or other prenatal alcohol-related conditions. DHSS staff consider the surveillance program to be highly rigorous. Alaska clinicians and case workers use a diagnostic process developed by researchers at the University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network. Reporting of birth defects to the state registry is mandated by Alaska law. While Alaska's FAS surveillance system is believed to capture the majority of prenatal alcohol-related cases, it is possible that underreporting could make the incidence rate even higher.

For birth years 1995 to 1999, the incidence rate of FAS in Alaska is 1.5 per 1,000 live births.¹⁹ This was the highest rate of the five states that were involved in developing

¹⁹ Susan Merrick, FAS Surveillance Project Manager, Alaska Department of Health and Social Services, personal communication, July 2005.

Full report is available online:

http://www.hss.state.ak.us/abada/pdf/mcdowell_rept2005_091307.pdf

the CDC FASSNet system. (The lowest rate was 0.3 FAS cases per 1,000 births.) However, the incidence of all prenatal alcohol-related conditions, including such conditions as alcohol-related birth defects (ARBD) and alcohol-related neurodevelopmental disorder (ARND), as well as FAS, is 16.3 per 1,000 live births. This incidence rate is assumed to be consistent in birth year 2003.

To estimate FAS costs in Alaska, the research team relied on data published in Health Professions Education Partnership Act of 1998 (Senate Bill 1754). The cost of treating an individual with FAS over his or her lifetime was estimated to be at least \$1.4 million in 1995. These costs could include neonatal intensive care, medical and surgical services (not related to neonatal care), special speech therapy, behavioral management, and residential care. Medical and surgical service might include rectifying or monitoring hearing loss or cleft palate surgery. Residential services include special education, home care, speech therapy or institutional care. The 1995 data was adjusted for inflation using the Bureau of Labor Statistics Consumer Price Index for medical care. Additionally, costs of providing care were adjusted by the Alaska differential for cost of living (65 percent in 2003). The resulting total lifetime costs (in 2003 dollars) for providing services to an individual with FAS are estimated at \$3.1 million.

The total cost for providing services to an individual with FAS born in Alaska during 2003 was estimated by multiplying the lifetime costs by the number of FAS births during that period.

Results

Table 18 presents estimated costs for FAS births in Alaska during 2003. During that period, Alaska had about 15 FAS births. Total economic costs resulting from services to all individuals with FAS in Alaska totaled approximately \$47.0 million.

Table 18
Lifetime Costs of Medical and Residential Services
for Children Born with FAS in 2003

	Incidence and Costs
Alaska births in 2003	10,084
FAS incidence per 1,000 live births	1.5
FAS births	15
Lifetime FAS cost	\$47,037,000

Source: Birth data from the Alaska Bureau of Vital Statistics. McDowell Group, based on FAS data from Alaska Department of Health and Social Services; and Health Professions Education Partnership Act of 1998, S. 1754, 108d Congress (1998).

Senator Kevin Meyer
Alaska State Capitol
Juneau, AK 99801-1182

February 8, 2010

RE: SCR 12 Fetal Alcohol Spectrum Disorders Awareness Day Proclamation

Dear Senator Meyer,

I am writing this letter in support of Senate Concurrent Resolution No. 12 proclaiming September 9, 2010, as Fetal Alcohol Spectrum Disorders Awareness Day. I was planning to provide testimony by phone, but unfortunately, I am unable to break away from work.

Over the past 22 years as a behavioral health clinician I have witnessed firsthand the devastating consequences of prenatal alcohol and FASD for Alaska's families and communities.

Alaska unfortunately has the highest known rates of FAS/FASD in the United States. As you know, Alaska also ranks high in many other statistics such as domestic violence, sexual assault, and suicide. One of the secondary consequences of prenatal alcohol is that those with an FASD without adequate support often experience significant mental health problems, are at greater risk for suicide, and are frequently exploited and victimized.

Your efforts towards keeping FASD awareness active, and on the forefront of people's minds, will make a difference for Alaska's families and communities. This will happen by communicating the importance of awareness and taking action to prevent future FASD, as well as provide interventions for those who are already impacted.

Thank you for your efforts. If I can answer any questions, or be of help, please let me know.

Respectfully,



Michael Baldwin

5340 Tudor Top Circle
Anchorage, AK 99507
907-250-7736

Anchorage Council on Fetal Alcohol Spectrum Disorders

The Anchorage Council on FASD is a cooperative network of individuals and organizations committed to advocacy for people impacted by prenatal alcohol exposure and to the prevention of FASD.

February 5, 2010,

Members:

Alaska Center for Resource Families

Alaska Injury Prevention Council

Alaska Pacific University

Anchorage School District STRP Center

Covenant House Alaska

Good Samaritan Counseling Center

Nine Star Enterprises

Northern Educational Consulting

Pioneer Consulting

RURAL GAP

Southcentral Foundation Alaska Women's Recovery Project

Southcentral Foundation Dena A Cay Program

Southcentral Foundation FASD Diagnostic Team

State of Alaska Office of Children's Services

Stone Soup Group

Volunteers of America, AK Inc.

To the members of the Alaska State Senate HSS Committee,

I am writing on behalf of the agencies, programs and community members that participate in the Anchorage Council on FASD asking the committee to support passage of SRC 12, relating to FASD Awareness Day, September 12, 2010.

Our council has been involved in FASD prevention, education and support activities for many years. One of our most intensive community outreach activities has been the annual International FASD Awareness Day events taking place each year on September 9 at 9:09 am for the last 10 years.

With Alaska having the highest know rate of Fetal Alcohol Spectrum Disorders in the United States, we believe it is imperative that prevention activities such as that proposed in this resolution be actively encouraged whenever possible.

Each year, members of more Alaskan communities get together to plan and conduct FASD prevention and education events on September 9. It will be wonderful to have the support of our legislature as we continue our work on this serious health issue.

We look forward to joining many other Alaskan communities putting on community - based FASD educational activities next 9/9 and encourage the members of the Senate HSS committee to approve SRC 12.

Sincerely,

Cheri Scott, facilitator

Anchorage Council on FASD

Advisory Board on Alcoholism
and Drug Abuse



Alaska Mental Health Board

ALASKA MENTAL HEALTH BOARD
ADVISORY BOARD ON ALCOHOLISM AND DRUG ABUSE
431 NORTH FRANKLIN STREET, SUITE 200
JUNEAU, ALASKA 99801
(907) 465-8920

February 8, 2010

Senator Kevin Meyer
Alaska State Capitol
Juneau, Alaska 99801

Re: SCR 12 — FASD Day

Dear Senator Meyer,

The Advisory Board on Alcoholism and Drug Abuse and the Alaska Mental Health Board express their appreciation and support for your resolution declaring September 9, 2010 Fetal Alcohol Spectrum Disorders Day. As you know, fetal alcohol spectrum disorders are 100% preventable. Raising awareness and recognition of this fact will help prevent more Alaskan children from being born affected by prenatal alcohol exposure.

Even more importantly, it will raise awareness of the special, and often very individual, needs of individuals diagnosed with fetal spectrum disorders. Too often the services and supports they need to thrive – at home, at school, and in their communities – are not available. By designating a day to focus on the unique issues of fetal alcohol spectrum disorders and their impact on Alaska, we can not only support Alaskans with FASD but also prevent future Alaskans from experiencing FASD.

Thank you for your continued work on this important issue.

Sincerely,

Debi Keith, Chair
AMHB

James Duncan, Chair
ABADA



Supporting families who care for children and youth with special needs

February 8, 2010,

To the members of the Alaska State Senate HSS Committee,

I am writing to ask the members of the Senate HSS committee to support passage of SRC 12, relating to FASD Awareness Day, September 12, 2010.

I manage the FASD Family Support Program housed at Stone Soup Group. This program provides FASD focused training to family members and service providers, information and referral services and support to families of children and adults who experience FASD.

I am also the adoptive parent of a young man who was severely affected by prenatal exposure to alcohol. We are one of the lucky families – our son is so impaired that he qualifies for many services and supports. Many of my friends and the families I work with every day are not so lucky. Their children look typical and so the world expects them to be able to function as if they didn't have organic brain damage from their prenatal alcohol exposure.

Our family has been proud to be part of the annual International FASD Awareness Day events taking place each year in Alaska on September 9 at 9:09 am for the last 10 years. We see it as an excellent opportunity to help educate the community about the needs of individuals living with FASD and the importance of preventing prenatal damage to future members of our community.

As both a service provider that works with families dealing with the issues of FASD everyday and as the parent of a wonderful child with FAS, I want to encourage the members of the Senate HSS committee to approve SRC 12 proclaiming September 9, 2010 Fetal Alcohol Spectrum Disorders Awareness Day, and continue to identify ways to assist our state in combating this terrible disorder that impacts every area of our state budget in one way or another.

Best Wishes,

A handwritten signature in black ink that reads "Cheri Scott".

Cheri Scott, Manager

FASD Family Support Program

Stone Soup Group

Liz Clement

From: Liz Clement
Sent: Thursday, March 11, 2010 12:33 PM
To: 'Kathleenmtil@aol.com'
Subject: RE: (no subject)

Ms. Tilton,

Thank you for the email. I will place a copy of your message on each of the House Health and Social Services Committee members' desks at the hearing this afternoon. That way they will all be able to see it as they listen to testimony and talk about SCR 12.

Sincerely,

Liz Clement
Staff to Rep. Herron
Alaska State House District 38
t: (907) 465-6576
f: (907) 465-4589

From: Kathleenmtil@aol.com [mailto:Kathleenmtil@aol.com]
Sent: Thursday, March 11, 2010 12:26 PM
To: Liz Clement
Subject: (no subject)

Liz,

I would like to be heard. I am currently a Foster Parent with a beautiful Cognitively Disabled 12 year old who has introduced me to FASD. I want to learn as much as I can & being able to attend public functions would be a safe cooperative to do just that. I am hoping this e-mail will be considered a voice as I have an appointment this afternoon and am unable to speak by phone.....

Thank you for your time & efforts involving this very important matter.

Sincerely,

Kathleen M. Tilton