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Fetal Alcohol Syndrome

The TRIUMF Project
&
The Fetal Alcohol Support Network of Toronto & Peel

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Fetal Alcohol Syndrome

An individual's place, and success, in society is almost entirely determined by neurological functioning.

A neurologically injured child is unable to meet the expectations of parents, family, peers, school, career and can endure a lifetime of failures. The largest cause of neurological damage in children is prenatal exposure to alcohol. These children grow up to become adults. Often the neurological damage goes undiagnosed, but not unpunished.

Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Alcohol Related Neurodevelopmental Disorders (ARND), Static Encephalopathy (alcohol exposed) (SE) or Alcohol Related Birth Defects (ARBD) are all names for a spectrum of disorders caused when a pregnant woman consumes alcohol.

More than 10% of children have been exposed to high levels of alcohol in utero. All will suffer varying degrees of effects, ranging from mild learning disabilities to major physical, mental and intellectual impairment. It takes very little alcohol to cause serious damage.



In utero alcohol damage can include:

Loss of intellectual functioning (IQ)	Mild to severe vision problems	Higher than normal to dangerously high pain tolerance
Severe loss of intellectual potential	Mental Retardation	Dyslexia
Serious maxillo-facial deformities	Dental abnormalities	Cleft palate
Immune system malfunctioning	Behavioral problems	Attention deficit disorders
ADD/ADHD	Extreme impulsiveness	Poor judgement
Little or no retained memory	Deafness	Little or no capacity for moral judgement
Little or no capacity for interpersonal empathy	Sociopathic behaviour	Epilepsy
Tremors	Cerebral palsy	Renal (liver) failure
Asthma	Complex seizure disorder	Developmental speech and language disorder
Developmental delay	Height and weight deficiencies	Tight hamstrings
Cognitive perseveration	Echolalia	Autistic traits
Rigidity	Sleep disorder	Developmental coordination disorder
Adaptive esotropia	Tourette's traits	Central auditory processing disorder
Night terrors	Precocious puberty	Social problems
Depression	Reactive outbursts	Suicide
Heart defects	Heart failure	Death

The brain's **Frontal Lobes** control judgement, inhibition, concentration, self-control, conscience, personality and emotional traits as well as cognition and memory, motor speech and movement skills.



Normal Six week-old brains FAS

Alcohol is toxic at all concentrations. Alcohol damage to the fetus occurs over a wide continuum. Damage varies due to volume ingested, timing during pregnancy, peak blood alcohol levels, genetics and environmental factors.

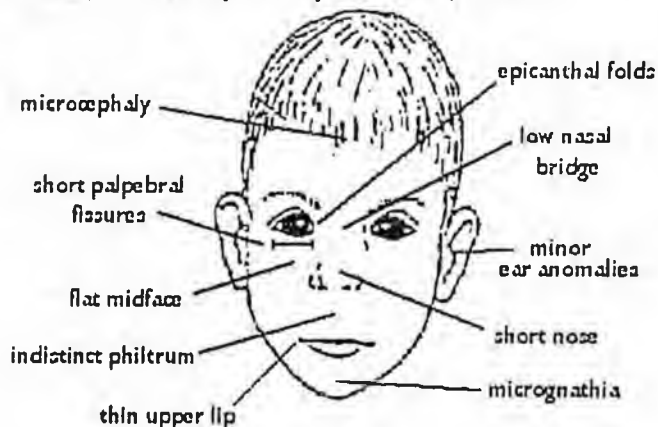
FAS/E is a lifetime disability. It is not curable. A child does not "grow out of it". However, early diagnosis and intensive, and appropriate, intervention can make an enormous difference in the prognosis for the child. There is a small window of opportunity, up to about age 10 or 12, to achieve the greatest potential for an alcohol affected child. That period is when the greatest development of fixed neural pathways occurs. That is when alternative "coping" pathways are most easily built as "work-arounds" to damaged areas of the brain. Time is of the essence.

The Left Hemisphere deals with language based memory - logical interpretation of language, mathematics, abstraction and reasoning, facts and rules (such as safety and social).

The Right Hemisphere deals with holistic functioning - processing of images, sound, touch, for a "holistic" picture. Memory here is visual, auditory and spatial. So, the Left side is logic, facts, rules. The Right side is sensory input and reactive.

The Corpus Callosum connects right and left sides to allow communication between the hemispheres. The Right side senses input, checks with the Left side to see if there are rules to deal with this pattern of input, integrates the stored information and reacts in a modified way. Damage to any of these systems causes very poor, inappropriate response. For example, if the Corpus Callosum cannot access the appropriate information, quickly enough (or at all), then reaction to stimuli will be completely spontaneous, impulsive, based solely on instinct, (if any). Alcohol seriously damages the physical structures, "wiring" and brain chemistry.

FAS (Fetal Alcohol Syndrome) individuals have a distinctive physical appearance and lower IQs, but have lower crime and addiction rates than FAE individuals as they get earlier diagnosis and can be better protected by society and their parents.



While FAE (Fetal Alcohol Effects) individuals may lack the outward physical appearance of alcohol damage, and generally have higher IQ's, the internal damage to the brain and other organs can be just as serious as full FAS. IQ measures convergent fact based thinking. Life skills require divergent adaptive thinking that in FAE individuals will be substantially lower than their IQ. However, because FAE individuals "look normal" they are expected to perform normally. These issues lead to secondary disabilities. Primary disabilities are those the child is born with. Secondary disabilities are those that develop as a result of failure to properly

Costs of FAS/E

On average, each FAS/E individual costs the taxpayer more than \$3 million in his or her lifetime (health problems, special education, psychotherapy and counseling, welfare, crime, and the justice system).

More than 60% of prisoners are likely affected by alcohol in utero. It costs approximately \$120,000/year to "house" a Young Offender and \$82,000 for an adult offender. Punishment does not cure neurological damage.

Add on:

- the FAS/E individual's own lifetime loss of income;
- the high costs to the families (foster, adoptive or biological) who raise and care for FAS/E children and adults;
- the lost income of a parent who must care for the exceptionally high needs of an FAS/E child;
- the costs to families whose FAS/E child is permanently dependent upon them;
- the costs of legal services for defending their child in the courts;
- the cost of stress caused divorce, etc.

deal with the primary disabilities.

"The girls get knocked up and the boys get locked up." They are followers, easily misled, with little or no appreciation of consequences. Without intervention, many ride the justice system merry-go-round or become "homeless street people". They are required to compete in society but have been denied the tools to do so.

Of FAE individuals between the ages of 12 and 51:

- 95% will have mental health problems;
- 60% will have "disrupted school experience";
- 60% will experience trouble with the law;
- 55% will be confined in prison, drug or alcohol treatment centre or mental institution;
- 52% will exhibit inappropriate sexual behaviour.

Of FAE individuals between 21 and 51:

- more than 50% of males and 70% of females will have alcohol and drug problems;
- 82% will not be able to live independently;
- 70% will have problems with employment

Early diagnosis can help prevent secondary disabilities such as mental health problems, dropping out of school, trouble with the law and substance abuse. After diagnosis, parents often find that their ability to cope with the child's behavior changes dramatically when they understand that the problems are most likely based on organic brain damage, rather than the child's choice to be inattentive or uncooperative.

Don't Ask My Child to Fly

Bruce Ritchie 1997

Don't ask my child to fly,
for he has not wings.

Don't ask my child to see the glint on the eagle's
beak,
for his vision has been diminished.

Don't ask my child to remain calm amid the din,
for her ability to screen out the noises has been
taken away.

Don't ask my child to be careful with "strangers",
for he is affectionate with everyone and prey for
the unscrupulous.

Don't ask my child to "settle down",
for the clock which works for you and I, does not
exist for her.

Don't ask my child to not play with the toys of
others,
for he has no concept of property.

Don't ask my child to remember you tomorrow,
although you met today.

Don't ask my child to heal your wounds,
for her hands cannot hold a scalpel or sutures.

Don't ask my child to meet the challenges set by
society,
for you have denied her the tools.

Don't ask my child to forgive you for standing
idly by,
while he was being tortured in his mother's
womb,

for he will,

but He should not.



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Anchorage Daily News

Friday, February 11, 2000

Danger for fetus in 1 binge Brain growth spurt called riskiest time

By PAUL RECER
The Associated Press

WASHINGTON - A single drinking binge by a pregnant woman can be enough to permanently damage the brain of her unborn child, according to a study of the effects of alcohol on babies.

Though experiments in the study were conducted on laboratory rats, experts said the findings explain why children born to drinking mothers can suffer learning disabilities and other brain disorders.

The study indicates that rats, and presumably humans, are most susceptible to alcohol-related neurological damage when developing brain cells are furiously building the connections needed for memory, learning and thought. In humans, this brain growth spurt starts in the sixth month of gestation and continues for two years after birth. In rats, it comes in the two weeks after birth.

"We call this a brain growth spurt period," said John Olney, a Washington University School of Medicine researcher and senior author of the study, appearing today in the journal *Science*.

During this spurt, Olney said, a single prolonged contact with alcohol - lasting for four hours or more - is enough to kill vast numbers of brain cells.

"There is a massive wave of cell suicide after the brain is exposed" to alcohol, he said. "The cells die by the millions and millions."

During the spurt, called synaptogenesis, brain cells must receive a balanced signal from two types of neurotransmitter chemicals, glutamate and GABA, he said. If the signal is disrupted, the developing brain cells are programmed to commit suicide. This is the body's way of eliminating surplus cells.

But based on the rat studies, alcohol severely disrupts the glutamate-GABA signals, and that causes nerve cell suicide at about 15 times the normal rate, he said.

Neuron cells that normally die during brain development are about

1.5 percent of the total, but in rat pups exposed to alcohol just days after birth, Olney said, the dead neurons ranged from 5 percent to 30 percent of the total.

"Our study showed that it only requires one round of intoxication of about four hours for this to occur," he said.

The "binge" used in the study gave the rats a blood alcohol level of .20 - 200 milligrams of alcohol per deciliter of blood. Such a level in people is twice the legal standard of drunkenness in many states.

David Lovinger of the Vanderbilt University School of Medicine said in *Science* that the study carries a powerful message: Drinking in late pregnancy "is really unsafe for the brain."

A 1996 study by the Institute of Medicine showed that about 20 percent of women who drink do not stop during pregnancy. About one in every 1,000 babies born in the United States suffers from fetal alcohol syndrome, a disorder caused by exposure to alcohol in the womb. The disorder can cause stunted growth, along with memory and learning problems.

Olney said pregnant women need not be anxious about past, moderate alcohol drinking.

"One glass of wine at dinner is unlikely to cause the damage, but we cannot say that any added intake would be safe," he said. "The most prudent policy would be to have no alcohol during pregnancy."

The connection between brain cell death and disruption of the glutamate-GABA signals also prompts concern about common drugs used on children, Olney said.

Most anesthesia in pediatric surgery, he said, disrupts either glutamate or GABA in the brain. That means surgery using those drugs might increase the risk of brain damage for children under 2.

"It will be important to carefully re-evaluate how these drugs are used in pediatric medicine," Olney said. He suggested the need for studies to establish safety guidelines for use of those drugs on young children.

University of Colorado Health Sciences researcher Boris Tabakoff agrees on the need to evaluate anesthesia used in young children.

"If this study is correct," Tabakoff said in *Science*, "one might need to reassess their safety in (infants) while the brain is still developing."

quoteOne glass of wine at dinner is unlikely to cause the damage, but we cannot say that any added intake would be safe. The most prudent policy would be to have no alcohol during pregnancy.

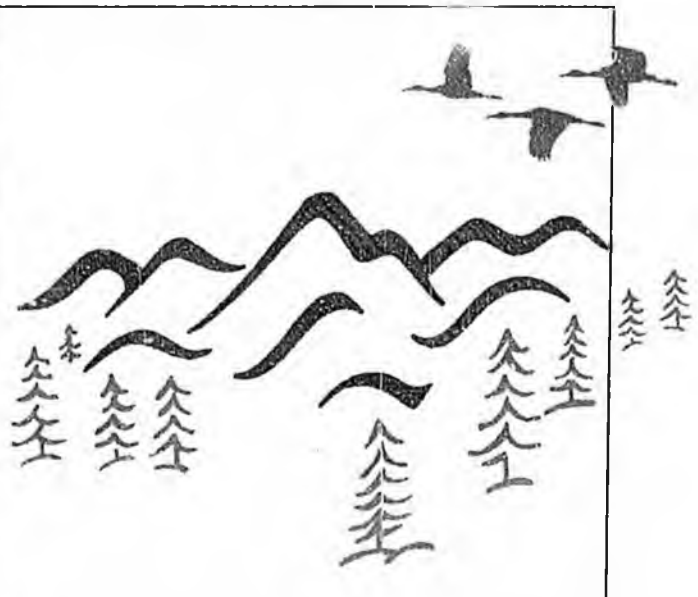
- John Olney, senior author of the study

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Fetal Alcohol Syndrome

Alaska's #1
*Preventable
Birth Defect*



1999 Status Update

Alaska's response to Fetal Alcohol Syndrome

Alaska Department of Health and Social Services

P.O. Box 110601

Juneau, AK 99811-0601

Karen Perdue, Commissioner

L. Diane Worley, Statewide FAS Coordinator



'When spider webs unite, they can tie up a lion.'

~African proverb

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Gov. Tony Knowles proclaimed Sept. 9, 1999, as Fetal Alcohol Syndrome Awareness Day in Alaska:

"To promote awareness of the effects of prenatal exposure to alcohol, to increase compassion for those individuals so affected, to minimize further effects and to ensure healthier communities across Alaska."

Statewide FAS Coordinator
L. Diane Worley
800-478-2072; 907-465-3033

What is Fetal Alcohol Syndrome?

Fetal Alcohol Syndrome (FAS) and other alcohol-related birth defects refer to a group of physical and mental birth defects resulting from a woman's drinking alcohol during pregnancy.

"FAS is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The definition of the fetal alcohol syndrome has changed little since the 1970s when the condition was first described and refined. The condition has been broadly characterized by pre-and /or postnatal growth deficiency, a characteristic set of minor facial anomalies, and evidence of prenatal alteration in brain function such as microcephaly from birth, neurologic problems without postnatal antecedents, or complex patterns of functional disability."

*Dr. Sterling Clarren and Dr. Susan Astley
University of Washington FAS Diagnostic and Prevention Network*

Drinking during pregnancy causes not only FAS, but a wide range of harmful effects to children. These effects can range from a characteristic pattern of physical features and mental impairment to more subtle cognitive and behavioral dysfunction. Other terms often used to define

individuals with prenatal exposure to alcohol that do not meet the medical diagnosis of FAS include fetal alcohol effects (FAE), static encephalopathy, alcohol-related neurodevelopmental disorders (ARND), alcohol-related birth defects (ARBD), and fetal alcohol-related conditions (FARC). While it is often assumed that FAE and these other alcohol-related conditions are less severe than FAS, this is not always the case. The neurological abnormalities, delays in development, intellectual impairments and learning/behavior disabilities that accompany FAE are similar, and sometimes more severe, than with FAS.



Rachel, age 9 and diagnosed with FAS, proudly displays the snails she collected from the stream at Chena Hot Springs Resort during the annual FAS/FAE Family Summer Camp.

Alcohol-related birth defects can occur only when a woman consumes alcohol during pregnancy. It is 100% preventable. Since there is no known safe amount of alcohol consumption during pregnancy, the American Academy of Pediatrics recommends abstinence from alcohol for women who are pregnant or who are planning pregnancy.

Alaska's FAS Agenda

Alaska has the highest documented rate of fetal alcohol syndrome in the nation. Because prenatal exposure to alcohol affects a wide range of social, educational and health services across the state, and because the estimated life-time cost for services to an individual with FAS is \$1.4 million, the state of Alaska is committed to a statewide agenda focused on FAS prevention, intervention and support.

FAS and other alcohol-related birth defects cause permanent, life-long disabilities that require a range of services and supports for the individual and their families.

Research shows that early screening, diagnosis and individualized services reduce the likelihood that affected individuals will develop secondary disabilities associated with FAS and FAE, including mental health problems, problems with employment, school difficulty, involvement with the criminal justice system/incarceration, substance abuse problems and inappropriate sexual behavior.

Because FAS is preventable, one of our top priorities must be primary and secondary prevention programming. Increased efforts to improve service delivery and support to women at-risk for giving birth to an alcohol-affected child are essential to reducing and eventually eliminating this devastating birth defect.

In an effort to address these issues, the state of Alaska has developed a comprehensive, multidisciplinary approach to FAS prevention and intervention with projects, state initiatives and community partnerships across the state.



Scottie and Will, both age 7 and both diagnosed with FAS, enjoy a swim at the FAS/FAE Family Summer Camp in August.

Because FAS is preventable, one of our top priorities must be primary and secondary prevention.

How can we develop an appropriate approach to preventing and treating FAS if we don't know the full extent of the problem?

The Alaska FAS Surveillance Project

The Alaska Fetal Alcohol Syndrome Surveillance Project (AFASSP) is a collaborative effort between the state's Section of Maternal, Child and Family Health and the federal Centers for Disease Control and Prevention (CDC). Through this collaborative effort, Alaska is one of five sites in the United States participating in a 5-year population-based FAS surveillance project funded by the CDC. The other sites are Colorado, Arizona, Wisconsin and New York.

Together, the five sites and the CDC have formed the National FAS Surveillance Network (FASSNet). It is the network's goal to:

- ◆ Determine the number of children with FAS in each state
- ◆ Improve documentation in medical records to increase the potential of finding cases
- ◆ Evaluate the system used to collect the data
- ◆ Provide information to health care providers
- ◆ Serve as a clearinghouse for scientific data related to FAS

In order to address a situation, you need to know what you are dealing with. Currently, we do not have adequate and timely data regarding the rate of FAS births in our state. How can we develop an appropriate approach to preventing and treating FAS if we don't know the full extent of the problem?

Obtaining specific data on FAS is a complex process with many challenges that must be addressed. For example, at this time:

- ◆ The method of diagnosing the syndrome is not standardized
- ◆ The diagnosis code (ICD-9) for reporting the syndrome is not specific to FAS
- ◆ Characteristics associated with the syndrome vary from child to child
- ◆ Characteristics of the syndrome may change as the child gets older
- ◆ Documentation in the medical record may be incomplete
- ◆ Availability of medical providers to evaluate and report children is limited
- ◆ Reviewing records statewide requires many resources (travel, personnel, etc.)

The state FAS Surveillance Project has just entered its third year of a five-year project. A summary of preliminary data is included in this publication.

Alaska Birth Defects Registry

Because birth defects are the leading causes of infant mortality and morbidity in the United States, the *Alaska Birth Defects Registry* (ABDR) was created in 1996 as a tool for tracking and analyzing data to assist in making improvements in our state's public health programs. The registry is a passive surveillance system. Hospitals, physicians, early intervention programs, pediatric clinics and other health care providers serving children from birth through age six are required to report contacts involving the diagnosis of a congenital anomaly.

The specific purposes of the Alaska Birth Defects Registry are to:

- ◆ Perform epidemiological surveillance-monitoring to learn more about the occurrence of birth defects in Alaska
- ◆ Prevent secondary disabilities by making recommendations concerning special services needed in local communities
- ◆ Provide an accurate, unduplicated count of children with birth defects to other programs and agencies
- ◆ Provide statistics to other researchers studying the causes/risks of birth defects
- ◆ Identify potential areas of unmet need

To be included in the registry, a child must have been born to a woman who was a resident of Alaska at the time of the child's birth, and be diagnosed as having one of the eligible conditions. Guidelines for reporting are available in the booklet, "Conditions Reportable to Public Health," available through the Division of Public Health.

Currently, 22 out of 24 Alaska hospitals are reporting, representing approximately 92% of 1997 births. In addition, there are seven physician/health clinics reporting, which represents approximately 65 physicians statewide. All information collected is kept confidential. Employees involved in the registry are subject to Alaska Administrative Code 27.890: "Confidentiality of Required Reports and Medical Records." Identity of individuals is not used in any report or publication. The *Alaska Birth Defects Registry* is a program of the Section of Maternal, Child and Family Health within the Division of Public Health.

"FAS is a reportable condition in Alaska. Reportable birth defects associated with maternal alcohol consumption or other noxious substances include: Fetal Alcohol Syndrome, Alcohol-related Neurological Deficits, Fetal Alcohol Effects, Possible/Suspected Fetal Alcohol Effects, microcephaly, and any other conditions which may have been caused by alcohol or drug use during pregnancy. This means that hospitals, physicians, surgeons, and other health care facilities or practitioners diagnosing or providing treatment to a patient less than six years old affected by maternal consumption of alcohol or other noxious substances are legally required to report information about the patient to the Alaska Department of Public Health."

7 Alaska Administrative Code (AAC) 27.012

'Once an individual is diagnosed with FAS/FAE, family members and social services workers can customize developmental approaches and goals to ensure that the individual reaches his or her personal potential. Diagnosis provides visibility, and visibility prompts solutions.'

Dr. Ann Streissguth
University of Washington
Fetal Alcohol & Drug Unit



Ardyce Turner is one of six team members from the Yukon Kuskokwim Fetal Alcohol Syndrome Multidisciplinary Community Team. Ardyce and 17 other Alaskans traveled to Seattle to attend a 3-day training at the University of Washington FAS Diagnostic and Prevention Network. Ardyce is the FAS Coordinator for the Yukon Kuskokwim Health Corporation in Bethel.

Multidisciplinary Community Team Network

In a 1996 study, Dr. Ann Streissguth, University of Washington Fetal Alcohol and Drug Unit, found that being diagnosed with an alcohol-related birth defect before the age of six years was a key 'protective factor' helping to minimize secondary disabilities and improving long-term outcomes. One of Alaska's major challenges has been to improve and increase the state's capacity to identify, screen and diagnose fetal alcohol syndrome and other alcohol-related birth defects. The lack of diagnostic services has also hampered our ability to improve service delivery for affected individuals and their families.

Working toward the goal of increasing our state's FAS diagnostic capacity, the state has developed a *Network* of statewide *FAS Multidisciplinary Community Teams*. With funding provided by the Alaska Mental Health Trust Authority, community teams are being developed and selected for training in identification, screening, diagnosis and service planning at the University of Washington's FAS Diagnostic and Prevention Network. Selection to receive this training is through a competitive statewide RFP process. Selected communities must indicate a clear understanding of the problem in their community, readiness to begin screening and diagnosis of FAS/FAE, and a true collaborative/multidisciplinary approach to addressing the problem in their community.

The *Network* currently consists of three teams that received training last May. Those teams represent the Bristol Bay Area (Dillingham); the Copper Valley Region (Glennallen/Copper Center); and the Yukon Kuskokwim Area (Bethel). Since returning from the training, each team has developed a "model" that best meets the needs of their individual community. Each model includes a process for both identification/diagnosis and the development of an individualized service plan for the affected individual and their family. Developing a service plan based on the availability of local resources is key to the success of this project. Each model also includes a strong parent advocacy component, utilizing a parent navigator/parent advocate model, like that developed through the Stone Soup Group in Anchorage. Ongoing support, coordination and consultation for the network of teams is provided through quarterly teleconferences, annual in-service training and an internal network for consultation and support.

Three additional teams will be selected for training in February of 2000, with a final 3 teams selected and trained in 2001. Information on how to contact a team for a diagnostic referral is listed in the FAS Diagnostic Resources section of this booklet.

Surveillance project releases preliminary data

The number of children born with fetal alcohol syndrome and other alcohol-related birth defects, in Alaska and nationwide, remains somewhat a mystery. Most of the available data is based on estimates, limited data pools, and inconsistent diagnostic and surveillance criteria.

In Alaska, there is considerable interest in knowing the number of children with FAS and FAE and the characteristics associated with these conditions. National FAS prevalence rates range from 0.1 to 0.7 per 1,000 live births (CDC, 1995). In Alaska, a previous study found FAS prevalence among children age 0-17 years to range from 0.5 to 0.8 per 1,000 births (Egland, et al, 1998).

Preliminary data from the Alaska FAS Surveillance Project suggests an estimated FAS Prevalence rate of 1.0 – 1.4 cases per 1,000 live births for children age 0-3 years. *This estimate is based on reviews of children born between 1995-1997, and include those with a confirmed or probable case of fetal alcohol syndrome according to the FAS surveillance case definition. It does not include other fetal alcohol-related conditions.*

How FAS Surveillance Works in Alaska

The FAS Surveillance Project works hand-in-hand with the Alaska Birth Defects Registry. Once a potential case has been reported to the registry, the registry coordinator notifies the FAS Surveillance Project and provides the necessary information for identification. Potential cases include any children that have been reported with the ICD-9 diagnosis code "760.71." This code refers to any alcohol-related conditions including FAS, ARND, FAE, etc. The surveillance coordinator is responsible for reviewing and collecting information from each identified medical record to determine if they meet the case definition.

Limitations and Biases of the FAS Surveillance Project

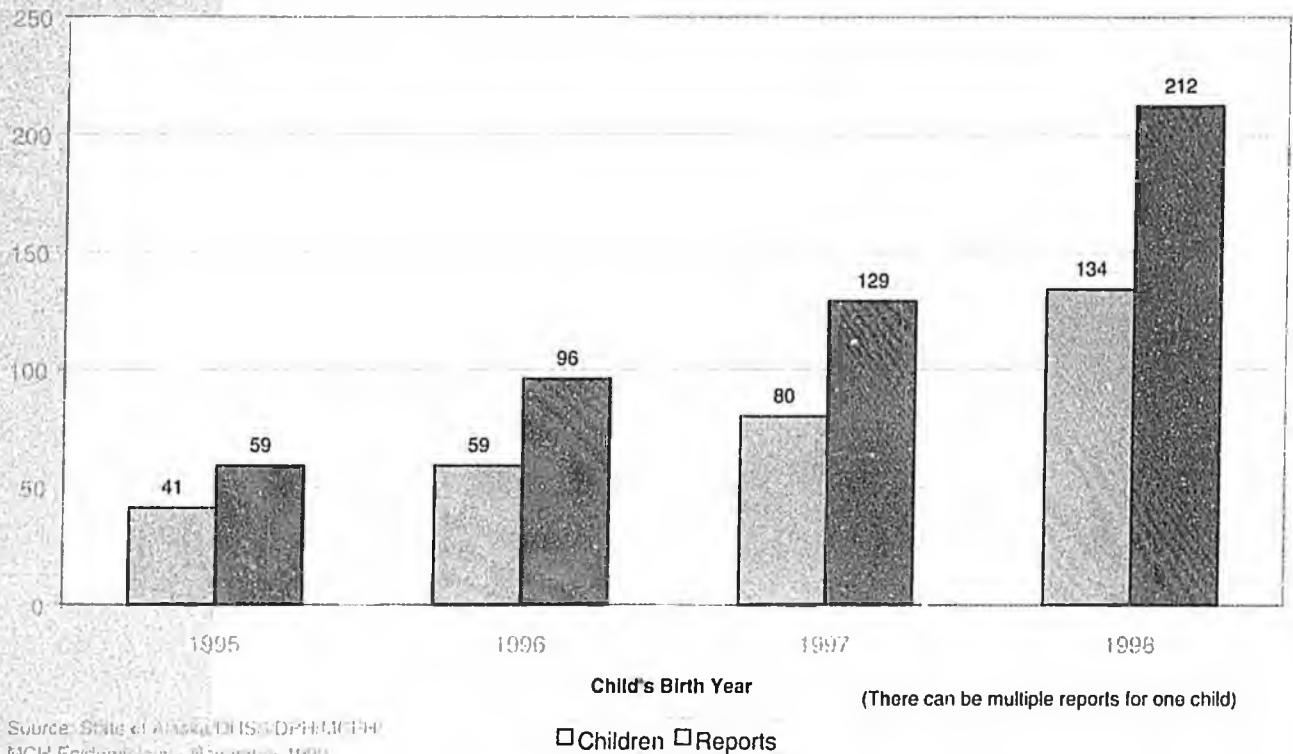
Potential cases are referred from those that have been reported to the Alaska Birth Defects Registry with the ICD-9 diagnosis codes 760.71. The definition of the 760.71 code is "Fetus or newborn affected by alcohol" and it is used to describe fetal alcohol syndrome, fetal alcohol effects, alcohol-related birth defects, and any other alcohol-related conditions. After reviewing records of children reported with this code, it is apparent this code is also used to report drinking during pregnancy, even when there is no documented effect to the child.

FAS Surveillance Case Definition

The diagnosis of FAS is subjective, with a wide range of physical and functional features. *No standard definition of FAS exists.* This makes it very difficult to compare numbers between different regions across the State and even medical facilities within the same community. Surveillance case definitions are used to standardize information. Currently the Alaska surveillance project is using a case definition developed by a multi-state surveillance network so that Alaska's numbers can be compared to other states.

Continued on Page 8

**Figure 1:
Reports of Alcohol-Related Conditions or Maternal Alcohol Use
to the Alaska Birth Defects Registry**



For this reason, it cannot be assumed that every child reported with 760.71 has an alcohol-related birth defect. However, the code may be used to identify children who *potentially* have alcohol-related conditions.

There are limitations inherent in the methods used to identify cases. These include not receiving reports from all medical facilities/providers statewide, and having differences in the way providers across the state evaluate and report cases. The limitations are addressed in part because there is the potential for multiple facilities/providers to report the same child.

Preliminary Information Gathered

As shown in Figure 1, the reports of alcohol-related conditions and maternal alcohol use increased steadily between 1995 and 1998. This may indicate:

- ◆ An increase in the awareness of medical providers to note alcohol-related conditions or exposure in the medical record
- ◆ An increase in the awareness of medical facilities and providers to report to the Birth Defects Registry

Of children born between 1995-97, 180 with alcohol-related conditions or exposure were reported to the Alaska Birth Defects Registry as of September 1999

(see Table 1). Of these, 133 medical records were reviewed, representing 96 children (multiple records at different facilities were reviewed on several children in order to get a more complete picture). Of the children whose charts were reviewed, 21 (22%) met the FASSNet Surveillance Case Definition for Confirmed or Probable FAS.

Because only 53% of the 1995-1997 births reported with maternal alcohol exposure have been reviewed to date, FAS prevalence among children in this age group cannot be directly calculated. However, FAS prevalence can be estimated if the

assumption is made that cases abstracted to date are representative of all cases reported with alcohol-related conditions or maternal alcohol use. Using the percentages associated with the Confirmed, Probable and Combined values shown in Table 1, an estimated number of cases per birth year was calculated (see Table 2).

The estimated number of confirmed FAS cases and number of total estimated cases was applied to the actual number of Alaska live births, giving an estimated FAS prevalence rate of 1.0 - 1.4 per 1,000 births. *It is important to note here that this is an estimate made using small and possibly unstable numbers. These are preliminary rates; however they are consistent with previously published rates and more reliable rates will be calculated once reporting to the Alaska Birth Defects Registry is complete, and all medical records have been reviewed.*

Data from the records reviewed also provided information about

Table 1: Potential FAS Cases, Charts Abstracted, and Case Status as of September 1999

Child's Birth Year	Reported w/Alcohol-Related Condition or Exposure	# Children Whose Charts Were Reviewed	Abstracted				Confirmed & Probable % of Abstracted Records
			Confirmed FAS Case ¹		Probable FAS Case ²		
			# Children	% of Total	# Children	% of Total	
1995	41	18	4	22%	2	11%	33%
1996	59	35	6	17%	1	3%	20%
1997	80	43	6	14%	2	5%	19%
Total	180	98	16	17%	5	5%	22%

¹Confirmed FAS Case = Met all four of the categories defined by FASSNet Surveillance Case Definition.

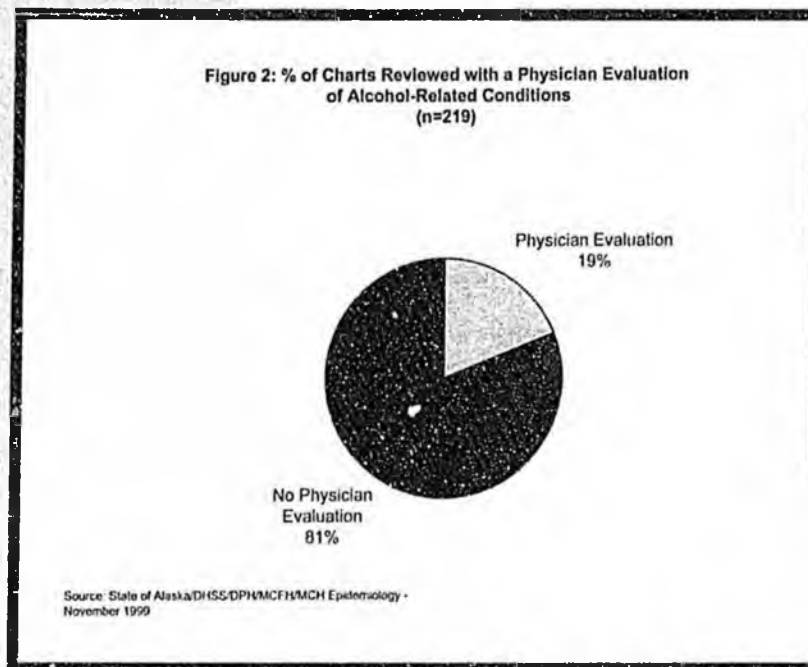
²Probable FAS Case = Met facial feature and alcohol criteria defined by FASSNet Surveillance Case Definition and at least 1 of the other 2 categories (CNS anomaly or growth delay)

Source: State of Alaska/DHSS/DPH/MCFH/MCH Epidemiology - November 1999

Table 2: Estimated Prevalence of FAS Among Alaskan Children, Age 0-3, Based on Extrapolating Information from Abstracted Records

Birth Year	Estimated # of Confirmed FAS Cases	Estimated # of Probable FAS Cases	Total # Estimated Cases	Alaska Live Births	Estimated Prevalence Rate per 1,000 Births
1995	9	5	14	-	-
1996	10	2	12	-	-
1997	11	4	15	-	-
Total	30	11	41	30,219	1.0 - 1.4

Source: State of Alaska/DHSS/DPH/MCFH/MCH Epidemiology - November 1999



documented alcohol use during pregnancy and physician diagnosis of alcohol-related conditions. Ninety-seven percent (97%) of the children had records documenting maternal alcohol use, and 29% showed alcohol use during at least 2 trimesters of the pregnancy. Only 19% of the records reviewed had a physician evaluation of alcohol-related conditions (see Figure 2). This was lower than expected, but is consistent with the knowledge that medical diagnosis

of FAS and other fetal alcohol-related conditions is not readily available in Alaska.

Future Goals of the FAS Surveillance Project

Over the remaining 3-1/2 years of this project, all records that have been reported to the Alaska Birth Defects Registry (for children born in 1995 forward with alcohol-related conditions or maternal alcohol use) will be reviewed. Once a larger sample of these records has been reviewed, information will be available, including:

- ◆ How Alaska FAS prevalence rates compare to other states
- ◆ How the FAS prevalence varies by race and maternal age
- ◆ How the FAS prevalence varies between geographic regions in Alaska
- ◆ Who the children with FAS are living with
- ◆ How many mothers of children with FAS used other drugs and/or smoked during pregnancy
- ◆ What types of services are children with FAS referred to

For further information about the Alaska FAS Surveillance Project contact Danise Podvin, FAS Surveillance Coordinator at 907-269-3406. For information about the Alaska Birth Defects Registry contact Lisa Durham, Birth Defects Registry Coordinator at 907-269-3443.

Fetal Alcohol Consultation and Training Services (FACTS)

Alcohol-related birth defects have a major impact on an individual's ability to learn and to control their behavior. Students with FAS or FAE are impulsive, hyperactive, and over stimulated. They have difficulty with abstract concepts, memory, cause and effect, and social skills.

All of these deficits lead to difficulty in school—difficulty in learning, socializing and controlling daily behavior. Yet, many individuals with FAS or FAE have normal intelligence, they are exceptionally verbal, and eager to please so their resulting behavior *appears* to be deliberate, non-compliant, and out-of-control.

Fetal alcohol syndrome is a medical diagnosis. Other alcohol-related birth defects [FAE, ARBD and ARND] are not official diagnoses. FAS is not identified specifically as a developmental disability, is not a specific mental health category or a behavioral disorder. For these reasons, it is often difficult for schools to identify and provide appropriate services for children and youth with FAS or FAE. These individuals often fall through the cracks, leaving teachers, administrators, families and affected individuals frustrated and without adequate support.

The *Fetal Alcohol Consultation and Training Services (FACTS)* project was developed to address this need. The goal of *FACTS* is to provide statewide assistance through training, technical assistance and support to schools, individuals, families and communities working with children and youth affected by FAS and other alcohol-related birth defects.

The question being addressed is “what is needed to improve and maximize the educational potential of children and youth impacted by birth defects related to prenatal exposure to alcohol?”

Services include consultation, education and training for developing effective methods and strategies to teach and maximize learning in children prenatally exposed to alcohol. Services are available to public schools, private schools, preschools and parents who home-school their children. In addition, services are available to other community agencies and individuals who work directly with affected children in settings outside, but in collaboration with, the school arena. This includes programs such as Infant Learning, mental health counselors, child protective services, respite care and others.

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Sixty-eight percent of the children served through the Division of Family and Youth Services' subsidized adoption and guardianship program are affected by FAS or prenatal drug or alcohol exposure.

Division of Family and Youth Services

Efforts to reduce alcohol consumption among teenagers and young women may benefit from concerted programs focusing on family planning and the prevention of polydrug use and sexually transmitted diseases.

CDC Study on Binge Drinking in Women

The long-term goal of the *FACTS* project is to build community capacity to support children with FAS and other alcohol-related birth defects both in the schools and in their communities.

FACTS is a program of the University of Alaska Fairbanks, Northern Studies Department. During fiscal year 2000 the project will target six communities for intensive on-site consultation, training and support. These communities are Bethel, Barrow, Fairbanks, Glennallen/Copper Center, Dillingham and Ketchikan. In addition, statewide services will be available in the form of training, resource materials, phone consultation, a web site and a computer listserver for ongoing discussions about educating children with prenatal exposure to alcohol.

Motivational Interviewing/ Services for High-Risk Women

The Fetal Alcohol Syndrome Motivational Interviewing Project was developed to help special populations at risk of having children with fetal alcohol syndrome. Through the Section of Maternal, Child and Family Health within the Division of Public Health and in cooperation with the Department of Corrections, this project focuses on the "high turn-around" population of women who enter and exit the Hiland Mountain Correctional Facility in Anchorage.

The goal of the project is to intervene with female offenders who are released from Hiland Mountain Correctional Facility into the community offering family planning services and referral to other appropriate services such as substance abuse treatment. The project is being carried out as a pilot project in Anchorage with the intent of expanding the project in the future.

Women in prison have been identified as a population at risk for producing children with fetal alcohol syndrome. The *Assessment of the Needs of Women Offenders in Custody of the Alaska Department of Corrections, Final Report, March 31, 1998*, indicates that 66% of women offenders who responded to their survey were under the influence of drugs or alcohol at the time they committed their offense. Aggregate information available in the report reflects that 45% of the respondents felt that their female health needs were not being met. It is unknown whether they would have sought medical care for these conditions if not incarcerated; however, these figures point to a population potentially in need of health and substance abuse treatment services.

The Motivational Interviewing Project will fund a health care provider to be the site of family planning and other supportive services. It is anticipated that the provider will offer the needed health care services, focusing on family planning methods. Additionally, a case manager within this health care setting will provide ongoing assistance to the women, including referral to substance abuse treatment services through a motivational interviewing process.

The Motivational Interviewing process is an approach designed to help people build commitment and reach a decision to change. It draws on strategies from client-centered counseling, cognitive therapy, systems theory and the social psychology of persuasion. From a theoretical perspective, motivational interviewing lies in two areas: it draws heavily on the construct of ambivalence and the conflict between indulgence and restraint (Miller & Rollnick, 1991). This approach will be piloted through this project on a variety of issues that are pertinent to the intended population. It is anticipated that motivational interviewing will contribute to an increase in enrollment in substance abuse treatment services when appropriate. The project is currently in the contract solicitation process. Project start-up is expected in early January 2000.

Consumer Boards Respond to FAS Agenda

In Alaska's planning and advocacy system, responsibility for children and youth with neurological disorders are shared by the Governor's Council on Disabilities and Special Education, the Advisory Board on Alcoholism and Drug Abuse and the Alaska Mental Health Board. All three consumer boards have taken an active role in developing a long-term, comprehensive FAS agenda for the state of Alaska.

Governor's Council on Disabilities and Special Education

The mission of the Governor's Council on Disabilities and Special Education is to create change that improves the lives of Alaskans with disabilities. This year the Council is focused on a number of major initiatives in planning, evaluating and promoting services that will benefit people with FAS/FAE.

The council is working to streamline the Developmental Disability Home and Community-Based Services Waiver. This will make it easier to use the system and to assist individuals and families in being better consumers of services funded through the DD waivers.

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Brandon, age 12 and diagnosed with FAE, loves baseball. This year Brandon and his team, the Ketchikan All Stars, won the Alaska State Championship in Sitka and went on to San Bernadino, Calif., for the Western Regional tournament. While he is the tiniest kid on the team he is often referred to as "the kid with the biggest heart."

Screening & treatment services for women
Between FY 98 and FY 2000, Alaska increased funding of treatment services for women by 40 percent -- from \$1.3 million to \$2.2 million.

Both residential and outpatient treatment services specifically for women and their children are now available in Anchorage, Fairbanks, Mat-Su, Dillingham, Sitka and Juneau. During FY 99, nearly 3,000 women received such services.

On-site substance abuse screening services are available for high-risk women through state child protection and public assistance offices in Anchorage, Fairbanks and Mat-Su. This increases timely and appropriate referrals.

In early development and education, the council is incorporating the concepts of the Individual Family Service Plan used to provide Infant Learning Program services into the Individual Education Plan in school-based special education. Expanding statewide Fetal Alcohol Consultation and Training Services that collaborate with school districts, school personnel, parents, and community resources to deliver appropriate education of students with FAS/FAE is also a top priority.

The council is attempting to increase employment opportunities for individuals with disabilities through economic development and small business ownership. With resources provided by a five-year federal grant, the council is designing a system of Alaska-specific employment incentives for people with disabilities to get and keep jobs.

Advisory Board on Alcoholism and Drug Abuse

As part of its overall mission to combat alcohol abuse, the Advisory Board on Alcoholism and Drug Abuse is committed to the elimination of FAS/FAE births in Alaska. The board:

- ◆ Advocates for funding that provides education, early intervention and treatment to pregnant women and those of child-bearing age who abuse alcohol.
- ◆ Advocates for expanding transitional housing capacity for women and women with children who have completed substance abuse treatment and are working toward successful transition back to their communities.
- ◆ Collaborates in the sponsorship of FAS/FAE forums and summits.

In addition, the board included numerous references to FAS initiatives in "Results Within Our Reach", the State Plan for Alcohol and Drug Abuse Services, 1999-2003. Each of the 18 strategies offer practical support for reducing fetal alcohol syndrome and other alcohol-related birth defects.

Alaska Mental Health Board

In an effort to focus on the needs of individuals with FAS or FAE, the Alaska Mental Health Board (AMHB) has become involved in several collaborative projects. These coordinated approaches will help ensure that children and youth with FAS/FAE receive appropriate early diagnosis, support and treatment.

The *Transition Services Task Force* is a subcommittee of the AMHB Children's Workgroup. The workgroup has selected three priorities for

action—out-of-state placements, transition services for children entering the adult mental health system and integration and collaboration within the department. The goal for this group is to develop an effective system that brings together the youth, their family, friends, natural supports, service providers and the legal system to actively support the youth in meeting developmental challenges, achieving personal goals and establish supportive relationships.

The *Mental Health Stabilization Homes* are a collaborative effort by several DHSS agencies to provide a five-bed, short term residential facility that will serve children with mental health issues, who are in state custody. This service will allow families, communities and providers time to prepare a child's permanent placement in a therapeutic environment that is less restrictive than hospitalization or an institute.

The *Young Child Behavioral Health Initiative* has three components aimed at addressing prevention and early intervention. Those components are: training and support for providers of services to families of young children; parenting resources and support; and coordination of and access to systems that impact young children and their families.

What's next?

Alaska in line for \$5.8 million federal FAS grant

Thanks to the support and efforts of Sen. Ted Stevens, Alaska is in line to receive \$5.8 million in federal funds to increase state efforts to prevent and treat fetal alcohol syndrome and other alcohol-related birth defects.

Increased funding will provide Alaska with the opportunity to develop a more coherent, integrated and comprehensive state agenda on fetal alcohol syndrome. Strategies to strengthen Alaska's response to FAS include:

- ◆ Create a comprehensive, community-based approach to preventing fetal alcohol-related birth defects.
- ◆ Establish statewide data collection, analysis and research related to substance abuse and pregnancy so we can better measure improvements in our prevention and service efforts.
- ◆ Establish a statewide system to identify, screen and diagnose individuals affected by prenatal exposure to alcohol.
- ◆ Prevent FAS by increasing our state's existing system of care for substance-abusing women at risk of pregnancy.
- ◆ Increase services to meet the needs of individuals impacted by prenatal exposure to alcohol.

**Governor's Council on
Disabilities & Special
Education**
269-8990

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**Advisory Board on
Alcoholism & Drug
Abuse**
465-8920

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**Alaska Mental Health
Board**
465-3071

Fetal Alcohol Syndrome: Alaska's most preventable birth defect

FAS/FAE Resources in Alaska

FAS Diagnoses

Alaska Genetics & Birth Defects Clinics
1-800-799-7570 (statewide)
907/269-3430 (Anchorage)

Alaska Native Medical Center—Pediatrics
907/729-1000 (Anchorage)

Alaska Neurodevelopmental Clinics
1-800-799-7570 (statewide)
907/269-3460 (Anchorage)

Bristol Bay Area FAS Community Team
Joy Crow at 907/842-4139 or
1-800-478-4139 ex. 356

Copper Valley Region FAS Community Team
Gay Wellman at 907/822-5241

Providence Pediatric Neurodevelopmental Clinic
907/562-9212

Yukon Kuskokwim FAS Community Team
Dr. Eric Noble at 907/543-6300

University of Washington
FAS Diagnostic & Prevention Network
206/526-2000

FAS/FAE Parent Support

Alaska Foster Parent Training Center
1-800-478-7307

Anchorage Parent Education Group (PEG) for
Families of Children with FAS/FAE
907/694-6644 or 907/345-4808

Bethel FAS Parent Support Group
907/543-6486

Fairbanks FAS/FAE Parent Support Group
907/479-6584

Fetal Alcohol Consultation and Training Services
(FACTS)
1-877-393-2287 (statewide)

PARENTS, Inc.
1-800-478-7678 (statewide)
907/337-7678 (Anchorage)

Parents Resource Network
1-877-786-7327 (statewide)
907/344-1997 (Anchorage)

Stone Soup Group
907/561-3701



Fetal Alcohol Syndrome

Alaska's #1 Preventable Birth Defect

Visit us online at www.hss.state.ak.us/fas



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