SCR

13

<TARGET><BILL>SCR 13</BILL><SUBJECT>SCR 13</SUBJECT><COMM>HHSS28</COMM></TARGET>

Alaska State Legislature
Senator Pete Kelly

Interim
1292 Sadler Way Ste. 308
Fairbanks, Alaska 99701
Phone - (907) 451-4347
Fax - (907) 451-4348

Session
State Capitol, Rm 516
Juneau, AK 99801
Phone - (907) 465-3709
Fax - (907) 465-4714

Sen.Pete.Kelly@akleg.gov

Sponsor Statement – SCR 13

"Urging the governor to establish and support programs designed to eradicate the occurrence of fetal alcohol spectrum disorder from the state."

Senate Concurrent Resolution 13 calls for a focused, statewide effort to prevent further occurrence of fetal alcohol spectrum disorder in Alaska. Fetal alcohol spectrum disorder (FASD) has been identified as a driver of numerous social challenges in our state. The tragedy of fetal exposure to alcohol continues to negatively impact Alaska's families, communities, and government agencies.

Due to its teratogenic effects, Alcohol creates more damage to the brain of a fetus than cocaine, heroin, or methamphetamine. Unfortunately, the brain damage created by alcohol is irreversible. The state of Alaska currently has the highest documented prevalence of fetal alcohol spectrum disorders in the United States. According to the Alaska Maternal and Child Health Data Book, 112.9 children in 10,000 births in Alaska are born with FASD. The financial cost to the State is tremendous. Best estimates from the Alaska Department of Health and Social Services place the cost per child born with FASD in the range of $860,000 to $4.2 million dollars.

However, fetal alcohol spectrum disorder is completely preventable. This fact highlights the moral and ethical responsibility to take action that all Alaskans share. SCR 13 urges the Governor to establish and support programs designed to eradicate the occurrence of FASD and resolves that the Alaska State Legislature will support programs that will minimize the risk of pre-natal exposure to alcohol. In addition, SCR 13 encourages increasing the State's capability to conduct rapid FASD screening in order to ensure that those experiencing the challenges of living with FASD receive the care and support they rightly deserve as early as possible. Far too often, alcohol addiction and personal trauma fuel the incidence of fetal exposure to alcohol. For this reason, SCR 13 appeals to the Governor to take actions to expand residential substance abuse treatment services for women who are pregnant and concurrently experiencing alcohol and drug addiction challenges. Thus ensuring mother and child receive the care, protection, and healthy environment they both need in order to thrive.

As Alaskans, we all share in the responsibility of ensuring our future generations are healthy and vibrant. The horrible tragedy of fetal alcohol spectrum disorder in Alaska is totally preventable. SCR 13 stands against FASD in Alaska and resolves that the leadership of our State will take actions necessary to safeguard future children from fetal alcohol spectrum disorder.

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Summary of Changes – CSSCR13 (HSS)

"Urging the governor to establish and support programs designed to eradicate the occurrence of fetal alcohol spectrum disorder from the state."

One change was made in Version N of the resolution on Page 2, line 1. The phrase "high quality screening" was replaced with "high quality diagnostic system." This change was made because, Alaska currently does not have a screening tool for FASD, but the state does have a high quality diagnostic system.

Fiscal Note

State of Alaska
2014 Legislative Session

Bill Version: CSSCR 13(HSS)
Fiscal Note Number: 1
(S) Publish Date: 3/3/14

Identifier: SCR13-LEG-SESS-02-24-14
Title: FETAL ALCOHOL SPECTRUM DISORDERS
Sponsor: KELLY
Requester: SHESS

Department: Alaska Legislature
Appropriation: Legislative Operating Budget
Allocation: Session Expenses
OMB Component Number: 782

Expenditures/Revenues

Note: Amounts do not include inflation unless otherwise noted below. (Thousands of Dollars)

	FY2015 Appropriation Requested	Included in Governor's FY2015 Request	Out-Year Cost Estimates				
OPERATING EXPENDITURES	**FY 2015**	**FY 2015**	**FY 2016**	**FY 2017**	**FY 2018**	**FY 2019**	**FY 2020**
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants & Benefits							
Miscellaneous							
Total Operating	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Fund Source (Operating Only)

None							
Total	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Positions

Full-time							
Part-time							
Temporary							

Change in Revenues							

Estimated SUPPLEMENTAL (FY2014) cost: 0.0 *(separate supplemental appropriation required)*
(discuss reasons and fund source(s) in analysis section)

Estimated CAPITAL (FY2015) cost: 0.0 *(separate capital appropriation required)*
(discuss reasons and fund source(s) in analysis section)

ASSOCIATED REGULATIONS

Does the bill direct, or will the bill result in, regulation changes adopted by your agency?
If yes, by what date are the regulations to be adopted, amended or repealed?

Why this fiscal note differs from previous version:

Initial Version

Prepared By: Jessica Geary, Finance Manager — Phone: (907)465-6626
Division: Legislative Affairs Agency — Date: 02/24/2014 09:23 AM
Approved By: Pamela Varni, Executive Director — Date: 02/24/14
Agency: Legislative Affairs Agency

FISCAL NOTE ANALYSIS #1

STATE OF ALASKA
2014 LEGISLATIVE SESSION

BILL NO. CSSCR 13(HSS)

Analysis

This Legislation has zero fiscal impact on the Legislative Affairs Agency.

Bill Hogan
Commissioner
P.O. Box 110601
Juneau, AK 99811-0601
www.hss.state.ak.us

STATE OF ALASKA
DEPARTMENT OF
HEALTH AND SOCIAL SERVICES

Fact Sheet

COMMISSIONER'S OFFICE

FOR IMMEDIATE RELEASE: Feb. 18, 2010

Fact Sheet: Fetal Alcohol Spectrum Disorders

Birth defects from women drinking while pregnant are permanent, preventable

- Fetal alcohol spectrum disorders (FASD) refers to conditions caused by prenatal exposure to alcohol, including fetal alcohol syndrome (FAS).
- FASD are one of the most common causes of developmental disability and the only cause that is entirely preventable.
- FAS is a medical diagnosis defined by the presence of specific growth and nervous system abnormalities and other factors.
- Alaska has the highest rate of FAS in the nation among states that track this data. As many as 180 children are reported to the Alaska Birth Defects Registry each year with a suspected FASD.
- There is no known safe amount of alcohol to consume during pregnancy.
- 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.
- FASD is found among all races and all socio-economic groups – wherever women drink alcohol, FASD can exist.
- FAS and all other birth defects resulting from prenatal exposure to alcohol are permanent.
- Alaska tracks the rate of FAS and FASD to identify risks associated with these conditions and improve prevention programs by targeting groups at risk.
- A state and federally funded Alaska Comprehensive Fetal Alcohol Syndrome Project has expanded the state's diagnostic capability, developed a multimedia public education campaign, and improved training for service providers in Alaska to help them better understand and serve affected individuals and their families.
- Like all disabilities, improvements can be made in how a person adjusts to their disability.
- With a comprehensive diagnosis, parents and providers can identify which services will most help children with an FASD in school and social settings.
- With the right diagnosis, support and understanding, many individuals with FASD can live happy and full lives.

For more information, go to www.hss.state.ak.us/fas/

Contact: Sarana Schell, (907) 269-8041, Cell (907) 398-1480, sarana.schell@alaska.gov
Greg Wilkinson, (907) 269-7285, Cell (907) 382-7032, gregory.wilkinson@alaska.gov

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COACTION

Prenatal alcohol exposure among Alaska Native/American Indian infants

Burhan A. Khan*, Renee F. Robinson, Julia J. Smith and Denise A. Dillard

Southcentral Foundation, Anchorage, AK, USA

Background. Recent reports indicate a decline in rates of Fetal Alcohol Syndrome (FAS) among Alaska Native and American Indian (AN/AI) infants. Nevertheless, AN/AI infants remain disproportionately impacted by the effects of prenatal alcohol exposure.

Methods. AN/AI pregnant women in their 3rd trimester completed a questionnaire on demographic data and the amount and frequency of their alcohol consumption in the month prior to conception and during pregnancy. Differences across demographics and trimesters were tested with the Chi-square, Fisher's exact or McNemar's test as appropriate.

Results. Of the 125 participants, 56% (n = 71) reported no alcohol consumption in the 1st through 3rd trimesters of pregnancy; 30% (n = 38) of the 125 participants also reported no alcohol consumption in the month before pregnancy. Of the 43% (n = 54) who reported consuming alcohol during pregnancy (1st, 2nd and/or 3rd trimester), most (35%) reported alcohol use only in the 1st trimester. Binge drinking in the 1st or 2nd trimester was reported amongst 20% (n = 25) of participants with an additional 18% (n = 29) reporting binge drinking in the month prior to pregnancy. Women who reported pre-conception binge drinking were significantly more likely to report binge drinking during their 1st trimester ($p < 0.0001$) and 2nd trimester ($p < 0.0001$). A history of tobacco use ($p = 0.0403$) and cigarette smoking during pregnancy ($p < 0.0001$) were also associated with binge drinking during pregnancy.

Conclusion. Among study participants, reported use of alcohol was primarily limited to pre-conception and the 1st trimester, with a dramatic decrease in the 2nd and 3rd trimesters. Prevention programmes, such as the Alaska FAS Prevention Project, may have contributed to observed decreases in the 2nd and 3rd trimesters. Additional study and focus on pre-conception, the 1st trimester and binge drinking, as well as tobacco use might augment Fetal Alcohol Spectrum Disorder prevention efforts.

Keywords: *prenatal alcohol exposure*; *fetal alcohol syndrome*; *fetal alcohol spectrum disorder*; *Alaska Native/American Indian infants*

Alcohol use during pregnancy, or prenatal alcohol exposure (PAE), is a national concern, as alcohol use can negatively impact a woman's health and can be passed across the placenta to a developing foetus. Alcohol abuse during pregnancy poses risks to the foetus (including poor growth, decreased muscle tone, delayed development, heart defects, physical/structural problems and mental retardation) known as Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) (1). FAS is the term used to describe growth, mental and physical problems that may occur in an infant when a mother consumes alcohol during pregnancy, whereas FASD is the term used to describe the additional direct and indirect social, physical and emotional effects (2–4).

FAS is one of the most preventable causes of mental retardation in the United States (1,5). Annual long-term economic and societal costs associated with FAS and FASD are in the billions (2–4,6). In 2002, Alaska was assessed as having the highest FAS prevalence rates in states using similar surveillance methodologies (1,7–12). Between 1996 and 1998, FAS prevalence was 15-fold higher in the Alaska Native population than the general Alaska population (13). Though this discrepancy has since decreased, Alaska Native infants still have a disproportionally higher prevalence of FAS with 32 Alaska Native infants with FAS compared to 6 Non-Native Alaskan infants with FAS per 10,000 live births between 2000 and 2002 (14).

This article is based on an article that was featured in the *IHS Primary Care Provider* (September 2011).

Citation: Int J Circumpolar Health 2013, **72**: 20973 - http://dx.doi.org/10.3402/ijch.v72i0.20973
(page number not for citation purpose)

Abstinence from alcohol has been recommended for women who are pregnant or may become pregnant. However, based on studies in the general population, prenatal abstinence from alcohol is estimated to be low ($<20\%$ of pregnant women are abstinent in the 1st trimester) (15). No "safe" level of alcohol use during pregnancy has been established, and prevalence of alcohol use among pregnant and non-pregnant women of childbearing age continues to be a concern. However, larger amounts of alcohol and binge alcohol drinking (currently defined for women as ≥ 4 drinks per sitting) appear to be more harmful than smaller amounts of alcohol ingestion (16,17). Despite increased education and delays in age of conception, drinking behaviours do not appear to have significantly changed (18). During 2001–2005, the highest percentages of pregnant women in the United States reporting any alcohol use were women aged 35–44 years (17.7%) and women with college degrees (14.4%) (19).

Alcohol ingestion in pregnant Alaska Native/ American Indian (AN/AI) women is an even greater public health concern than the general US population (13,20–22). Given high rates of self-reported alcohol use in adults and the high prevalence of FAS and FASD in AN/AI infants, understanding alcohol intake habits of AN/AI pregnant women is vital to develop targeted prevention strategies (1,7–12). As FASD among infants is a direct result of PAE among pregnant women, there is a need to better identify, document and understand alcohol consumption of AN/AI women during pregnancy (e.g. exposure to alcohol through over-the-counter medications, absolute alcohol consumption and occurrence of binge drinking). In this study, we assess self-reported PAE among AN/AI women.

Methods

Setting

Southcentral Foundation's Primary Care Center (SCF-PCC) in Anchorage, Alaska, provides pre-paid primary care services to approximately 45,000 eligible AN/AI people in the urban and remote rural surrounding areas of Anchorage.

Recruitment

Any AN/AI woman ≥ 21 years of age, in her 3rd trimester of pregnancy, and eligible for care at the SCF-PCC was eligible to participate in the study.

Questionnaire

After consent, women were asked to complete a detailed questionnaire on alcohol exposure for each trimester of pregnancy and the month prior to pregnancy. Participants identified both the month in which they found out they were pregnant (received a positive pregnancy test) and the month of their 1st prenatal visit. Based on answers to these questions, the recruiter determined the month prior to pregnancy, 1st trimester, 2nd trimester and 3rd trimester. If consumption of beverages containing alcohol was reported, additional questions about alcohol type, frequency of consumption and amount consumed were asked. Women were also asked about their alcohol consumption during the month before pregnancy and each trimester. The 9 types of alcoholic beverages assessed were beer, malt liquor, wine, sweet wine, fortified wine, wine coolers, hard liquor, mixed drinks and liqueurs. Questions regarding age, height, weight (before pregnancy) and smoking status were also included on the questionnaire.

Data collection and categorisation

De-identified questionnaire data were entered and verified using QDS 2.5 software (Bethesda, MD). Daily absolute alcohol values were calculated from participants' responses to type and volume of alcohol by adjusting reported ounces consumed per day to a number of standardised drinks and multiplying by 0.5 ounces of absolute alcohol per standardised drink. For example, 4 ounces of wine represented a standardised drink and thus represented consumption of 0.5 ounces of absolute alcohol. Categorisation of absolute alcohol consumption was adapted from prior studies with <0.01 fluid ounce (fl. oz.) per day, indicating abstinence from alcohol (i.e. <12 drinks a year), 0.01–0.21 fl. oz. per day indicating light drinking (i.e. <3 drinks a week), 0.22–1.00 fl. oz. a day indicating moderate drinking (i.e. 3–14 drinks per week), and >1.00 fl. oz. a day indicating heavy drinking (i.e. >14 drinks per week) (23,24). At the time of the study, binge drinking was defined as ingesting 5 or more drinks in one sitting, and thus was assessed as such on the questionnaire (16,25–27). It should be noted that since the time this study was conducted, the definition of female binge drinking has been reduced from ≥ 5 drinks to ≥ 4 drinks in one sitting, according to the National Institute of Alcohol Abuse and Alcoholism (NIAAA).

Data analysis

Statistical analyses were performed using SAS 9.2 software (Cary, NC). Associations with reported drinking were investigated with the Chi-square Test of Proportions or Fisher's Exact Test when appropriate. Associations of reported drinking between time periods were tested with McNemar's Test. P-values <0.05 were considered significant.

Results

Demographics

Over the course of the recruiting period, 125 AN/AI pregnant women were enrolled into the study. The average age of participants was 26.8 years of age, with a range of 21–39 years of age.

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Reported drinking during pregnancy

Of the 125 participants, 43% (n = 54) reported drinking alcoholic beverages during pregnancy (1st, 2nd and/or 3rd trimester), with 35% (n = 44) reporting alcohol use in the 1st trimester only. The remaining 8% (n = 10) reported alcohol use in time periods other than the 1st trimester. Of the 80 women who reported alcohol use for the month prior to pregnancy, 59% (n = 47) reported drinking during pregnancy. Of the 71 women that reported no alcohol use during the 1st, 2nd and 3rd trimesters, 54% (n = 38) reported alcohol use in the month prior to pregnancy. Thirty percent (30%) of the total participant pool (n = 38) reported no alcohol consumption from the month before pregnancy through the 3rd trimester. The most prevalent types of alcoholic beverages consumed during pregnancy were beer (23.2%), mixed drinks (21.6%), hard liquor (18.4%) and wine (16%) (Fig. 1).

Absolute alcohol consumption

Daily reported absolute alcohol consumption was compared by trimester and the month prior to pregnancy (Fig. 2). Over the course of the pregnancy, daily values of absolute alcohol consumption decreased heavily between the 1st and 2nd trimesters, with the majority of participants fitting into the abstinence category for the 2nd and 3rd trimesters. Average daily absolute alcohol consumption decreased over the duration of reporting period from 0.371 fl. oz. (month before) to 0.055 fl. oz. (1st trimester) to 0.004 fl. oz. (2nd trimester) to 0.001 fl. oz. (3rd trimester).

Binge drinking

Twenty percent (n = 25) of participants reported at least 1 occurrence of binge drinking during the 1st or 2nd trimester, with an additional 18% (n = 29) reporting binge drinking in the month prior to pregnancy. No women reported binge drinking in the 3rd trimester. Demographics of women reporting binge drinking are detailed in Table I. Although age was not associated with binge drinking during the month before pregnancy ($p = 0.4288$), a higher percentage of women in the youngest age category reporting binge drinking compared to the older categories during pregnancy, though this relationship was not statistically significant ($p = 0.0544$). History of tobacco use ($p = 0.0403$) and smoking tobacco use during pregnancy ($p < 0.0001$) were also associated with binge drinking during pregnancy. However, body mass index was not associated with binge drinking before or during pregnancy. Importantly, women who reported binge drinking during the month before pregnancy were significantly more likely to report binge drinking during their 1st trimester ($p < 0.0001$) and 2nd trimester ($p < 0.0001$, data not shown).

Discussion

In our study, self-reported alcohol use among AN/AI women during pregnancy (~ 50%) continues to be higher than in the general population. Reported drinking was primarily limited to pre-conception and the 1st trimester, with a dramatic decrease in the 2nd and 3rd trimesters. Prevention programmes, such as the Alaska FAS Prevention Project, may have contributed to noticeable decreases, especially in the 2nd and 3rd trimesters; however, alcohol exposure during pre-conception and during the 1st trimester remains high and of concern. Binge drinking pre-conception was also associated with binge drinking in the 2nd trimester and during the entire pregnancy. Thus, additional study focused on pre-conception, the 1st trimester and binge drinking might augment FASD prevention efforts among AN/AI women (7,10,15,28,29). For instance, providers could be encouraged to routinely discuss childbearing plans with women

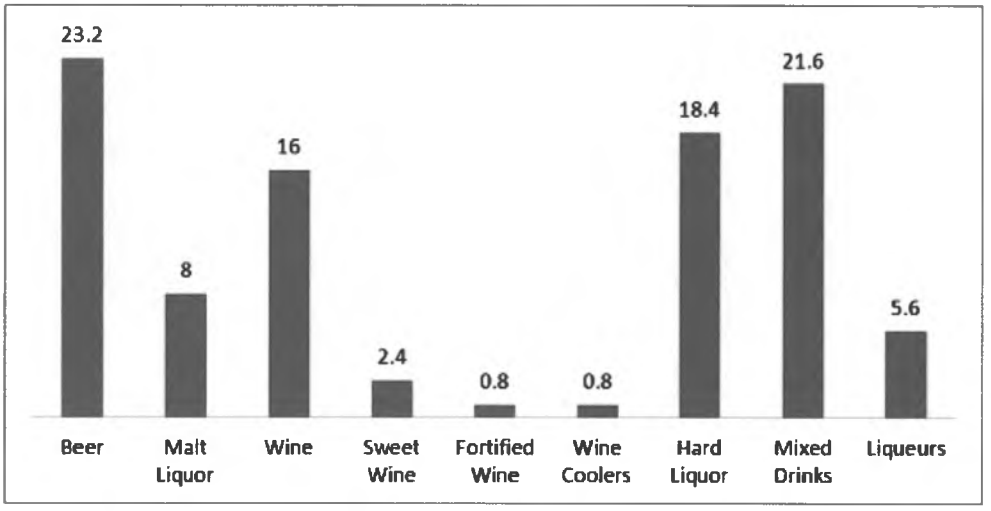

Fig. 1. Type of alcohol ingested during pregnancy (percentages of cohort).

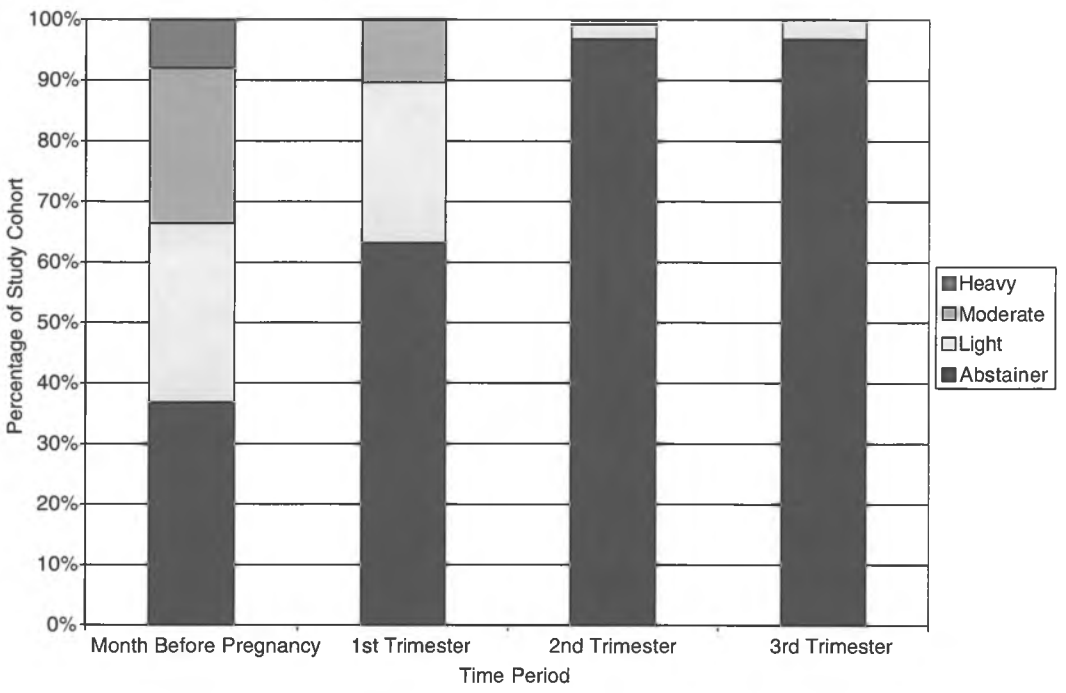

Fig. 2. Daily absolute alcohol consumption categorisations by trimester.

Table I. Demographics and predicative comparisons for binge drinking during pregnancy and the month prior to pregnancy

	Month before pregnancy					Pregnancy[a]				
	Yes		No			Yes		No		
Binge drinking (125 Surveys)	n	%	n	%	p[b]	n	%	n	%	p[b]
Demographics										
Age (16 missing)										
21–25 years	22	42.31	30	57.69	0.4288	15	28.85	37	71.15	0.0544
26+ years	19	33.33	38	66.67		7	12.28	50	87.72	
Smoking during pregnancy or month prior (2 missing)										
Yes	36	59.02	25	40.98	**<0.0001**	22	36.07	39	63.93	**<0.0001**
No	14	21.88	50	78.13		3	4.69	61	95.31	
Body Mass Index (27 missing)										
Underweight/normal weight	11	34.38	21	65.63		6	18.75	26	81.25	
Overweight	8	29.63	19	70.37	0.6198	5	18.52	22	81.48	1.0000
Obese	16	41.03	23	58.97		8	20.51	31	79.49	
Predictive comparisons										
Binge drinking during 1st trimester										
Yes	20	83.33	4	16.67	**<0.0001**					
No	30	29.70	71	70.30						
Binge drinking during pregnancy[a]										
Yes	21	84.00	4	16.00	**<0.0001**					
No	29	29.00	71	71.00						

[a]Includes reported drinking in 1st, 2nd and/or 3rd trimester.
[b]Demographics comparisons used Chi-square test of proportions unless cell counts were too small in which case Fisher's exact test was used. Predictive drinking comparisons used McNemar's Test. Significant p-values in bold.

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they serve and then encourage abstinence from alcohol among women as they try to become pregnant or among sexually active women without effective contraception. Such efforts may potentially attenuate alcohol use very early in the 1st trimester when women may not know they are pregnant.

Since all drinks do not contain the same amount of alcohol, data were collected to identify the type and quantity of beverage ingested. In our study, absolute ethanol consumption was quite variable and ranged from 0 to 237.5 fl. oz. per trimester (Fig. 2) and included a variety of drinks (Fig. 1). Efforts to better identify and understand consumption habits of AN/AI women during pregnancy are vital for targeted PAE prevention strategies. Providers should review with pregnant women the risks associated with ingesting alcohol, making note of the risks associated with different types and volumes of drinks (20,30).

Binge drinking is particularly harmful to foetal brain development (19). In this study, we found significant pre-conception binge drinking, and we found pre-conception binge drinking to be strongly associated with binge drinking during the 1st trimester (Table I). Given the current lowered threshold for binge drinking to ≥ 4 drinks in 1 sitting, estimates of binge drinking we present may be underestimating the prevalence according to current definitions. Younger women were more likely to binge drink (Table I), suggesting a need for more screening and FAS education of women of childbearing age and during early pregnancy. According to a nationwide, postpartum survey, 42.5% of all Alaskan women having a live birth reported the pregnancy was either mistimed (32.4%) or not planned (10.1%). Contraceptive use among these women was reported at 45.3%. Considering these percentages and the prevalence of pre-conception binge drinking in our cohort, healthcare providers should encourage abstinence from alcohol among Alaska Native women who may become pregnant, whether using contraception or sexually active and not using contraception. Efforts can be targeted at younger women, as they were more likely to continue binge drinking into their pregnancy.

Future research to identify Alaska Native women's views regarding pregnancy may help establish appropriate pregnancy planning programmes and further understanding of social and/or cultural characteristics affecting pregnancy. Chang et al. has developed and tested a 4-item alcohol exposure screening tool proven to be more sensitive during pregnancy than typical obstetric staff assessment in ethnically diverse populations (29). Based on our data, this screening tool may be useful to identify women at increased risk in the AN/AI population. In addition, the questionnaire used did not differentiate between alcohol exposure very early in the 1st trimester when women may not know they are pregnant versus alcohol exposure later in the 1st trimester. Furthermore, as women were recruited in the 3rd trimester, recall of alcohol ingestion in the 1st and 2nd trimesters may not have been accurate. Another limitation to our study was sample size. Our study achieved a quarter of the original recruitment goal. A prenatal tobacco exposure study recruiting in parallel with this study enrolled 3-times as many participants. This observation suggests a reluctance of AN/AI pregnant women to enrol into prenatal alcohol-related studies. Social stigma associated with drinking during pregnancy may have been a barrier in achieving the original recruitment goal and thus attaining an even more representative participant population of pregnant AN/AI women. Finally, another limitation to our study was the age of the respondents. Based on the legal drinking age, we decided to look at women aged 21 years and older. This may underestimate the impact of underage drinking on the prevalence of FAS in the AN/AI community.

Conflict of interest and funding

This study was supported by a Native American Research Centers for Health (NARCH) grant U26IHS 300012 from the Indian Health Service with the support of National Institutes of Health/National Institute of Alcohol Abuse and Alcoholism. The authors have not received any funding or benefits from industry to conduct this study.

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***Burhan A. Khan**
Southcentral Foundation, Research Department
4105 Tudor Centre Drive, Suite 200
Anchorage, AK 99508
USA
Tel: (907) 729-5491
Fax: (907) 729-5464
Email: bkhan@southcentralfoundation.com

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Fetal Alcohol Spectrum Disorder

A call to action

te·rat·o·gen **stems from the Greek word *teras*, meaning 'monster' - a drug or other substance capable of interfering with the development of a fetus, causing birth defects.**

Jody Allen Crowe, M. S.

2/21/14

Prepared for:

The Office of Senator Pete Kelly

2/21/2014

Dear Alaskans,

You are changing the world! Never before has a governmental body with the stature of the Alaska State Legislature, taken on the task of eradicating Fetal Alcohol Spectrum Disorder (FASD). Your commitment to this task will take you on a journey impacting not only your next generation of children, but also the children of the world.

A journey has a starting point and you are at that starting point. Throughout the course of the upcoming years, we will have more accurate information on the teratogenic effects of alcohol, on what works and what doesn't in the field of prevention, who is most at risk, and what this epidemic is doing to our schools, communities, and nation. This document attempts to bring you the most current information possible to give us a common understanding of the task ahead.

The science is compelling. Alcohol is the most powerful teratogen consumed by pregnant women today. It does more damage to the developing fetus than crack, cocaine, or heroin. The damage is lifelong. The brain is particularly effected. FASD, in effect, is an acquired brain damage, occurring before the baby is born and impacting, and in many cases, disabling the individual for the rest of his or her life. Prenatal exposure to alcohol is the leading cause of lowered academic ability and increased social/behavioral issues, overwhelming our schools and communities.

There is very little research on effective strategies for preventing FASD. In the past forty years since Dr. Ken Jones and Dr. David Smith named Fetal Alcohol Syndrome (FAS), the main focus on prevention has been awareness. Studies are finding the rates of drinking when pregnant have not significantly decreased in the past 20 years. The rates of binge drinking by women have increased significantly, now matching rates found in men. Binge drinking and unplanned pregnancies go hand in hand. Binge drinking is particularly dangerous to the developing fetus. Many women, who would never drink when pregnant, expose their developing fetus to alcohol unknowingly before they find out they are pregnant.

We all need to share responsibility in this effort. Men engage in partnership drinking, encouraging their significant other to drink to justify their own drinking, drinking in front of their partner, and, in some cases, forcing the mother-to-be to drink with them. Studies have shown in most cases, when the man was drinking, the woman was drinking. Any effort of prevention needs to include and focus on men, as well as women.

Our systems are overwhelmed with 'multi-million dollar babies', brought on by prenatal exposure to alcohol. Premature FASD babies can cost millions in the first year of life, sadly, in some cases, with the baby dying due to failure of the damaged organs. Ones who live continue to require ongoing medical care, many times for the rest of their lives.

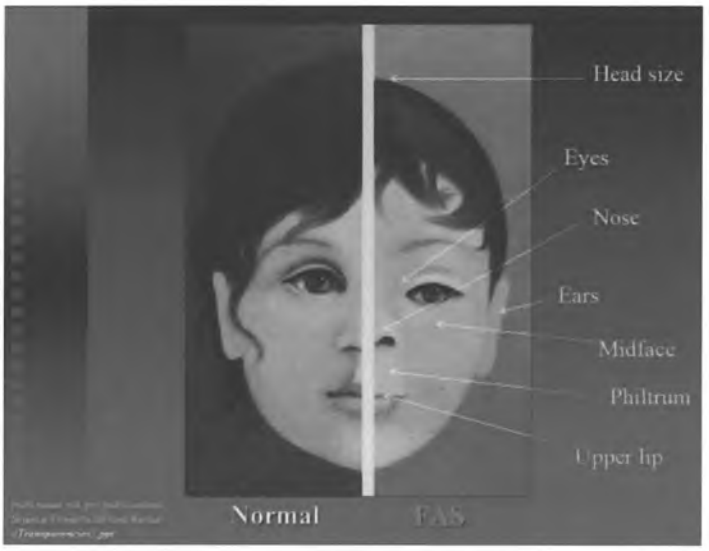
Any discussion about FASD is incomplete without looking at the impact on our criminal system and communities. Emerging research is showing high percentages of prison inmates having been prenatally exposed to alcohol, with the crimes ranging from fraudulent check writing to murder. Juvenile crime is rampant among FASD adolescents. Crimes have victims. Our communities suffer without knowing the root cause is prenatal exposure to alcohol.

I leave you with this parable. There was a village by the river. The river was the lifeblood of the village. It was the source of food, travel, and integral to their spiritual life. All day the villagers expended their energy making a living from the river. One day, a villager saw a baby floating down the river. She pulled the baby out of the river. Soon, more and more babies floated down the river. The villagers were spending most of their time saving and raising the babies that floated down the river. One day, when more babies were sighted in the river, a wise elder was standing on the river bank while others were overwhelmed by the flood of babies. "Help us," the others yelled. "No," the wise one said, "I am going to go up stream and stop the babies from being thrown into the river."

You are going upstream. It is the right thing to do.

Jody Allen Crowe

Fetal Alcohol Spectrum Disorder



Prenatal exposure to alcohol can cause damage exhibited by:
-Smaller head size,
-Anomalies with the eyes,
-Anomalies with the nose,
-Misshapen ears,
-Flat midface
-Indistinct philtrum
-Thin vermillion of the upper lip
as well as up to 61 different physical and psychological disorders [1]

Fetal Alcohol Syndrome is a little used medical diagnosis that requires observable deformity around the eyes, philtrum and upper lip, as well as a psychological assessment, and documented evidence of alcohol consumption by the mother.

- "FAS represents the largest environmental cause of behavioral teratogenesis (causing malformations of an embryo or fetus) yet discovered and, perhaps, the largest single environmental cause that will ever be discovered." Ed Riley, PhD [1]
- "Prenatal Exposure to Alcohol is described as "the most frequently known teratogenic cause of **mental deficiency** in the western world" Sterling Clarren, MD [2]

Fetal Alcohol Spectrum Disorder is a non-medical description of a constellation of conditions related to damage to the brain and body as a result of prenatal exposure to alcohol, without requiring the observable physical features of FAS.

- "Children with and without physical features of fetal alcohol syndrome display qualitatively similar deficits." Ed Riley, PhD [1]

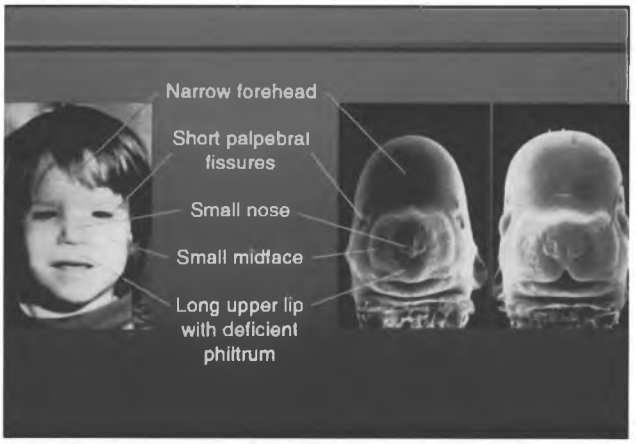
Other terms related to prenatal exposure to alcohol:

Fetal Alcohol Effects, Alcohol Related Neurobehavioral Disorder and Alcohol Related Birth Defects. In 2013, the Diagnostic and Statistical Manual IV introduced Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure as a condition in need of more research. .

When does a woman know she is pregnant?

The human embryo attaches to the uterus at twelve days following conception. At eighteen days following conception, the embryo begins to receive all the nutrition needed for development through the placenta. From this point on, any alcohol in the bloodstream crosses through the placenta and is shared directly with the developing fetus.

- **Central Nervous System (CNS) damage can occur starting around the third week (21 days) of the pregnancy. (3)**
- **Classic FAS facial features are a result of heavy alcohol use in a very short window of time between three and six weeks of the pregnancy. (4)**



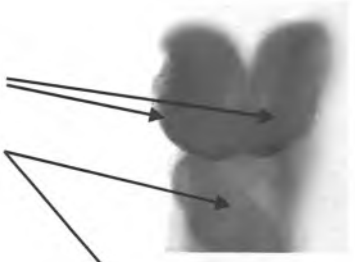
This rat pup (center) was prenatally exposed with one dose of alcohol, resulting in all the FAS characteristics shown on the child on the left. Ed Riley (2)(31)

Prenatal alcohol exposure damage is dose related.

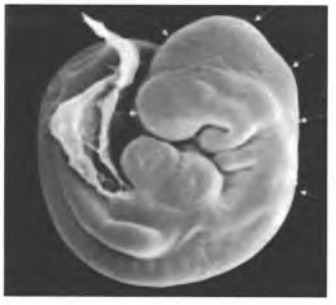
- How much alcohol is in the bloodstream?
- When during the pregnancy is alcohol in the bloodstream?
- For how long is alcohol in the fetus?

The damage starts early!

A mouse embryo, **at a stage corresponding to a 22-23 day old human embryo,** shows dead cells (dark blue) in the developing heart, face and brain 8-12 hours after one exposure to alcohol. (3)

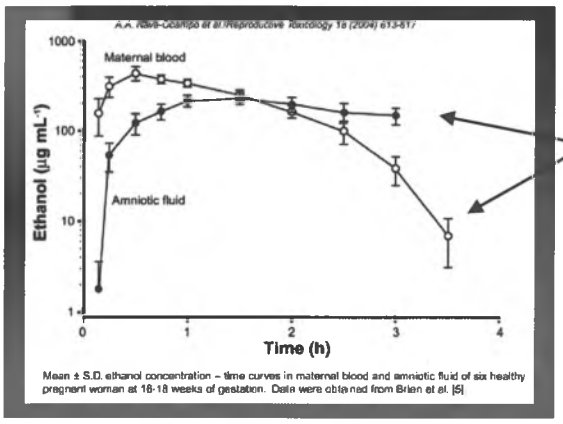


Alcohol is a 'midline teratogen'. Shown are the midline points of the mouse embryo that merge to make the face and brain. This is similar to the stage of a human embryo at 22-28 days.



The arrows point to the midline of the embryo that makes up the face and brain.

"My baby sleeps all week when I get drunk on the weekends." This statement was reported to a teacher by a student who overheard her pregnant aunt laughing about her unborn baby hardly moving during the week after she was drunk on the weekends. (4)



Mean ± S.D. ethanol concentration – time curves in maternal blood and amniotic fluid of six healthy pregnant woman at 16-18 weeks of gestation. Data were obtained from Brien et al. [5].

The blood alcohol level of the pregnant mother rises quickly after one drink and starts to decline in 45 minutes, while the amniotic fluid surrounding the fetus rises and stays constant. The fetus expels the alcohol through urine into the amniotic fluid, then drinks the alcohol-laced amniotic fluid. Studies have shown alcohol can remain in the amniotic fluid for up to twice as long as in the bloodstream of the mother. (6)

Alcohol can cause damage at any time during the pregnancy.

First Trimester exposure could result in, but is not limited to: (3)(5)

- Structural damage to the face, body, and brain.
- Damage that results in FAS facial features
- Dis-organization of brain cells and migration of cells to the wrong locations
- Internal organ damage

Second Trimester exposure could result in, but is not limited to:

- Brain damage
- Internal organ damage
- Smaller body and head size

Third Trimester exposure could result in, but is not limited to:

- Lowered IQ (the human brain grows at its greatest rate during the third trimester.)
- Brain cell death due to neural cell damage
- Internal organ damage
- Smaller body and head size.

Prenatal exposure to alcohol greatly increases the risk for: (6)(7)

- Miscarriage
- Stillborn
- Pre-term delivery
- Sudden Infant Death Syndrome

Prenatal exposure to alcohol significantly increases the risk for:

- Cerebral palsy (8)
- Epilepsy (9)
- Suicide (10)
- Altered heart function (11)
- 61 medical diagnoses or psychological diagnoses (12)

Cleft palate or cleft lip in 7% of FAS children.

Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."

IOM Report to Congress, 1996

Who is Drinking When Pregnant?

Quick facts [13][14][15][16][17][18][19][20]

- 59% of women in the United States 18-44 report drinking alcohol.
- 50% of all pregnancies are unplanned.
- Over 78% of teenage pregnancies are unplanned.
- There is a correlation between teenage drinking and teenage pregnancies.
- 54% of births during the age 22-29 are a result of unplanned pregnancies.
- 31% of births to married women are a result of unplanned pregnancies.
- Binge drinkers have a much higher rate of unplanned pregnancies.
- Unplanned pregnancies are at a high risk for prenatal exposure to alcohol.
- Binge drinking by women is more prevalent in cold climates.
- 60% of women who reported alcohol consumption also reported that they did not learn they were pregnant until after the fourth week of gestation.
- Binge drinking by college-aged women have risen 40% in the past 20 years.
- Up to 40% or more of pregnancies have been exposed to alcohol.
- Canada reports up to 79% of children have been prenatally exposed to alcohol.
    - 79.17% of babies exposed to alcohol
    - 37.20 % of babies exposed to binges in first trimester
    - 15% to 18% continue drinking through the pregnancy
    - 4% heavy drinking throughout the pregnancy
- Self-reporting by the mother is highly unreliable.[21]
- Drinking during pregnancy is <u>under-reported</u> by 300% according to a study done in Sweden. [21]
- The woman most likely to not tell the truth about drinking during pregnancy is the woman who is the heaviest drinker. [21]

The demographics of women most likely to drink during pregnancy in the following order: [22]

- White, single professional female, making more than $50,000 a year in an urban setting
- Low income, blue collar female working in an environment with a majority of men.
- Foster teenagers
- Indigenous women

Men tend to be partnership drinkers, many times putting pressure on their significant other to drink when she is pregnant.

Multi-Million Dollar Babies

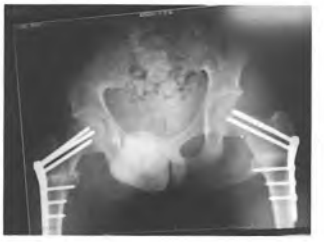
This could be happening in your community! Brady, Rory and Ari tell us the story of the devastation of prenatal exposure to alcohol.

Rory, on the left, lived for 18 months. During that time, she had eleven heart surgeries. Ari, the smaller of the two on the right, is under constant medical care.

Baby Ari was born at 29 weeks gestation. She spent 9 weeks in the NICU with a cost of $732,000. She had heart surgery at 7 days old and this cost was $130,000. She had 2 surgeries on her stomach at a cost of $98,000. She then had 3 hospitalizations which cost another $33,000. She was then back in PICU for over 3 weeks at a cost of $190,000 and a week back on the floor for another $12,000. She then had 4 inpatient stays at a total of $31,000. She had another surgery and inpatient stay for 16 days at a cost of $34,000. She has had special genetic testing to rule out any other genetic condition due to the severity of her issues at a cost of $11,500 dollars. She has a monthly equipment rental cost of $8,000 for the past 31 months. She also has a monthly average medication cost of another $1300 for the past 31 months. She has a medical supply cost per month of an average of $1200 for the past 31 months. She has an equipment cost of $11,000 for wheelchair, standing frame and specialized walker.

Nothing has formed correctly in Ari's physiology. Not her brain, her lungs, her stomach, intestines, or her heart. Her organs are in the wrong place. All genetic testing has come back normal and so the only explanation is her prenatal exposure to alcohol. She is the first child for her mother and it was an unremarkable pregnancy. [4]

Brady's surgeries



Brady is a non-verbal 15 year old who will need adult care for the rest of his life. His diagnoses are FASD, Autism, Seizure Disorder, Scoliosis, and Severe Mental Retardation with the intellect of a one year-old. He has had five surgeries in the past two years on his back, knee, hips, toes, and left leg. His adoptive parents estimate he is already a 2 million dollar baby. [4]

A 20 year study in Germany of hundreds of FAS children revealed: [23]

- 89% had Mental and Motor Retardation
- 80% had speech impediments
- 20% had hearing problems
- 72% were hyperactive
- 20% has Autism/Aggressive/Social Problems
- 29% had heart defects
- 10% had kidney defects
- 46% had genital deformities
- 37% had either a Concave or Pigeon Chest
- 7% had a cleft palate
- 44% had a spinal dimple

A psychologist in Isanti, MN, with four adopted FASD children, reported over

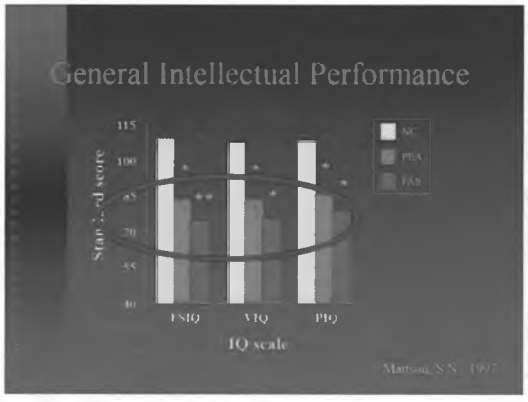
$1,000,000 health cost alone in 2006. [24]

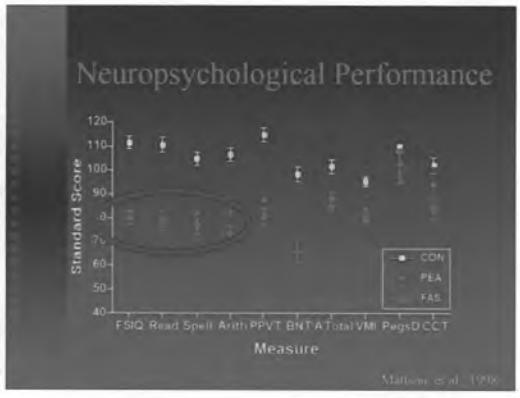
Educational Implications

- Low levels of alcohol consumption during pregnancy can result in mental health issues with adolescents. [25]
- Children exposed to prenatal alcohol experience significantly more mental health problems, including hyperactivity/inattention, and behavioral, emotional and peer relationship problems. [26]
- Math abilities are particularly damaged by prenatal exposure to alcohol. [27]
- Prenatal exposure to alcohol is linked to Autism Spectrum Disorder [28] [29]

....."Some of the children with FASD also meet the diagnostic criteria for an autism spectrum disorder..... It is true, wealthy families are more likely to seek developmental/behavioral evaluation for their children who have neurodevelopmental disorder. Therefore, there are undoubtedly children of wealthy parents who share an autism spectrum disorder diagnosis, who actually have an FASD, based on the reluctance of some medical providers to make an FASD diagnosis..." (see full quote in bibliograhpy)
Dr. Eugene Hoyme, Medical Genetics and Pediatrics, Sanford Health, Rapid City, S.D. [30]

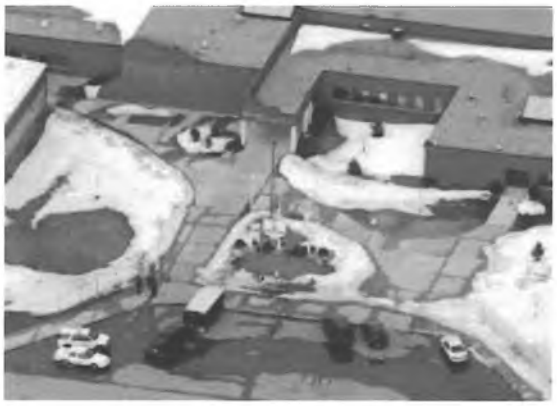
- Autism and FASD have twenty common characteristics. [31]
- Academic performance and information processing is diminished in prenatally exposed children. [32]
- FASD children have lowered ability to coordinate, plan, and execute appropriate responses and to modify behavior flexibly in response to feedback. [33][34]
- Less than one drink a day during the pregnancy can lower language skills. [35]
- IQ, as well as Math, Spelling, and Reading in both FASD (shown on chart as PEA, prenatal exposure to alcohol) and FAS are significantly below normal. [36]





- An estimated 75% or more of Special Education costs are linked to disabilities caused by prenatal exposure to alcohol. [12]

Crime and FASD



Four out of five adolescent school shooters in Minnesota and Wisconsin were heavily prenatally exposed to alcohol. The fifth shooter fit the profile, but the mother denied drinking even when confronted by evidence to the contrary. (37)

- In a macro study of school shooters across the United States, 88% fit the profile of prenatal exposure to alcohol. (37)
- The mother of 1997 school shooter in Bethel, Alaska, lost her parental rights because of her drinking. (37)
- In one study, 93% of the inmates in one county jail at the time of the study had mothers who drank alcohol. (37)
- Jail administrators in Minnesota estimate over 90% of their jail population serve more than one sentence and fit the profile of prenatal exposure to alcohol. (4)
- In one county in Minnesota, over the period of 18 months, seven murders were committed by young male adults who were fit the profile of FASD and were either adopted or had mothers who were heavy drinkers. (37)
- Two police officers in Rapid City, South Dakota were gunned down by a heavily prenatally exposed adult male. (4)
- Adolescents with FASD tend to get into trouble with the law early and often.(38)
- An estimated 35% of individuals with FASD have been in jail at one time or another. (39)
- In Canada, over 60% of people with FASD, over the age of 12, have been charged or convicted of a crime. (39)
- More than 70% of people with FASD have been a victim of crime. (39)
- Depression and suicide tendencies are prevalent in FASD individuals. (9)(40)(41)

Emerging Research

Diffusion Tensor Imaging allows the researcher to see damage not seen before using MRI scans of the brain.

Epigenetics is the study alterations in a cell's genetic information that result in changes in gene expression due to prenatal exposure to alcohol but do not involve changes in the underlying DNA sequence. [42][43]

Prevention is the Answer

Prevention strategies over the past 40 years include, but is not limited to:

- Awareness campaigns
- Labeling alcoholic beverages
- Warning signs posted in establishments that sell alcohol
- Intervention legislation in some jurisdictions
- Training medical personnel on identifying FAS and FASD
- Advocating for inclusion of FASD in the DSM V
- Counseling of women who are at risk for multiple FASD births
- Providing contraceptive counseling for women at risk for FASD births

Emerging prevention strategies:

- The First International Convention on Preventing FASD was held in 2013 Edmonton, Alberta. Representatives from 35 countries attended, with leaders from around the world gathering together to discuss prevention as never before.

- Alaska's initiative will lead the world in prevention.

- Do the PT (Do the Pregnancy Test) – campaign to add PT to responsible drinking along with DD (Designated Driver) for women who are sexually active and drinking alcohol, suggesting the woman take a pregnancy test before partying to protect the unexpected pregnancy. [44]

- Pregnancy test dispensers in women's restrooms in bars, convenience stores, schools, universities, and any place a woman can discretely test for a pregnancy before drinking alcohol. [44]

- Monitored cell phone breathalyzers for monitoring alcohol-involved teenage pregnancies and other alcohol-involved pregnancies with the need determined by parents, caregivers or local social workers within the guidelines of each jurisdiction. [45]

To the Point

- According to the Centers for Disease Control and Prevention (CDC), as well as the U.S. Surgeon General, "There is no known safe amount of alcohol to drink while pregnant. There is also no safe time during pregnancy to drink and no safe kind of alcohol."
- Alcohol is more damaging to the fetus than any other recreational drug.
- Up to 40% or more of our children are prenatally exposed to alcohol. (Canada reports 73%)
- Very few doctors diagnose individuals with FAS and even fewer with FASD.
- FASD is vastly under reported.
- Up to 40% or more of our children have been prenatally exposed to alcohol, many in the critical early pregnancy before the mother knew she was pregnant.
- Even light drinking when pregnant can result in lower math and reading ability and mental illness.
- Every drink a pregnant woman holds in her hand has the potential to take potential from her child.
- Over 60% of the FASD population have been in trouble with the law.
- FASD babies can be multi-million dollar babies with lifelong devastating disabilities.
- The cost to our society for a heavily prenatally exposed individual can reach $1.5 million or more.
- Over 60 medical and mental illnesses can be linked to prenatal exposure to alcohol.
- Over 70% of individual with FASD are victims of crimes.
- An estimated 75% or more of Special Education costs are linked to prenatal exposure to alcohol.

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Alaska Maternal and Child Health Data Book 2012:

BIRTH DEFECTS SURVEILLANCE EDITION

State of Alaska
Sean Parnell, Governor
Department of Health and Social Services
William J. Streur
Division of Public Health
Section of Women's, Children's and Family Health
Maternal and Child Health Epidemiology

ALASKA MATERNAL AND CHILD HEALTH DATA BOOK 2012: BIRTH DEFECTS SURVEILLANCE EDITION

Aulasa Camerlin, Epidemiologist

Contributors
Jennifer Bisson, ABDR* Data Manager
Judy Sharpe, ABDR Lead Medical Records Abstractor
Jennifer Higby, ABDR Medical Records Abstractor
Cara Bergo, ABDR Intern

Acknowledgements
Stephanie Birch, Section Chief
Janine Schoellhorn, Epidemiologist
Yvonne Goldsmith, Unit Manager
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* Alaska Birth Defects Registry

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To find out more about the Alaska Birth Defects Registry (ABDR) and other projects conducted by the Alaska MCH Epidemiology Unit, visit:
http://dhss.alaska.gov/dph/wcfh/pages/mchepi

To find out more about the National Birth Defects Prevention Network (NBDPN) and birth defects surveillance projects in other states, visit:
http://www.nbdpn.org

Introduction

A LETTER TO THE READER

We are pleased to present the second comprehensive analysis of Alaska's birth defects surveillance data in the 2012 birth defects surveillance edition of the Alaska maternal and child health data book.

The *Alaska MCH Data Book 2005: Birth Defects Surveillance Edition*, featured analyses of data from the Alaska Birth Defects Registry (ABDR), including prevalence estimates, trends, regional distributions, and risk factor analyses. The current publication, the *Alaska MCH Data Book 2012: Birth Defects Surveillance Edition*, builds upon the 2005 edition, and provides analyses of ABDR data from 1996-2011. The birth prevalence of major congenital anomalies reported to the ABDR is presented by birth year, region of maternal residence, and demographic characteristics. Univariate analyses provide the user with a comparison of the relative distribution of major congenital anomalies within important maternal and infant subgroups.

The Alaska maternal and child health data book is produced by the Maternal and Child Health Epidemiology Unit of the Section of Women's, Children's, and Family Health. Our purpose is to provide reliable data on maternal and child health issues for use in planning and evaluating programs, preventing poor health outcomes, and guiding public health policy. Through our programs and partners, we collect, analyze, and interpret information on women, children, and families. We hope the *Alaska MCH Data Book 2012: Birth Defects Surveillance Edition* will be a helpful reference for all Alaskans concerned with improving the health and well being of Alaskan families.

Aulasa Camerlin, MA, MPH
MCH Epidemiologist

HOW TO USE THIS BOOK

Birth defects registry data are useful for estimating the burden of congenital anomalies in the state and for identifying service delivery and intervention needs. In this book, we present temporal patterns in the occurrence of major congenital anomalies and the relative frequency of these anomalies among different populations.

The data book is divided into chapters based on the anatomical site of the malformation, a common practice for birth defects reporting. The following information is presented:

- Trends and Geographic Distribution: Because the health care service delivery system in Alaska has agencies that specifically serve the Alaska Native population, we present trend lines for the overall population, Alaska Natives, and non-Natives. We analyzed data by the six labor market regions used by the Alaska Department of Labor and Workforce Development. Sample size limitations prevent analysis by smaller geographical units.
- Epidemiological Characteristics: We evaluated prevalence by sex, birth weight, maternal race, maternal age, trimester of prenatal care, prenatal alcohol use, and prenatal tobacco use. For each characteristic, the tables provide unadjusted relative prevalence estimates and 95% confidence intervals for the estimate.
- Specific Anomalies: For each major anatomical grouping, we present the prevalence of specific anomalies that are designated as "major congenital anomalies" by the National Birth Defects Prevention Network, a coalition of state birth defects registries that works to establish standards for birth defects surveillance and reporting.

DATA LIMITATIONS

The Alaska Birth Defects Registry (ABDR) is an enhanced passive surveillance system. While some conditions undergo medical records abstraction and case verification, for the purposes of this publication, prevalence estimates were based on all cases reported under qualifying ICD-9 codes, regardless of case verification status. Previous evaluations have demonstrated that the positive predictive value of reports to ABDR vary substantially by condition.

Birth defects are rare events, and Alaska's population is relatively small. To provide reliable statistical estimates, we used 3-year moving averages to control for erratic yearly changes in prevalence, and categorized birth defects by anatomical groupings, used by most birth defects surveillance projects. Note that within anatomical groupings, specific birth defects may have diverse etiologies and epidemiological characteristics. When less than 5 events occurred within a subgroup, prevalence estimates were not calculated. Except where noted, prevalence estimates included all reported individuals with an anomaly regardless of whether the anomaly occurred in isolation or in association with other anomalies, including as part of a syndrome.

Although birth defects are reportable in Alaska up to age six years, many sources reported birth defects diagnosed in older children. The prevalence estimates presented here include all reports for children born during 1996-2011 that were received before January 1, 2012, regardless of the age at diagnosis or the age at which the child was first reported to the ABDR.

Data were collected from a variety of health care providers and medical records sources and, therefore, were subject to diagnostic bias. For example, the availability of more sophisticated ultrasound machines and clinical specialists in some areas likely resulted in increased diagnoses of anomalies such as asymptomatic ventricular or atrial septal defects. Differences between reporting sources in record keeping and reporting methods may also have affected results.

All risk factor information came from birth certificates linked to ABDR records. Variables from birth certificates may not accurately reflect the true prevalence of some factors such as prenatal care and substance use during pregnancy.

Elevated prevalence estimates within particular risk groups do not imply that a causal relationship existed between the risk factor and the outcome. Associations instead may have occurred as a result of the presence of numerous unmeasured or unanalyzed confounding variables. Nevertheless, these associations may indicate appropriate groups for targeting of services or conducting more thorough evaluations of causal associations.

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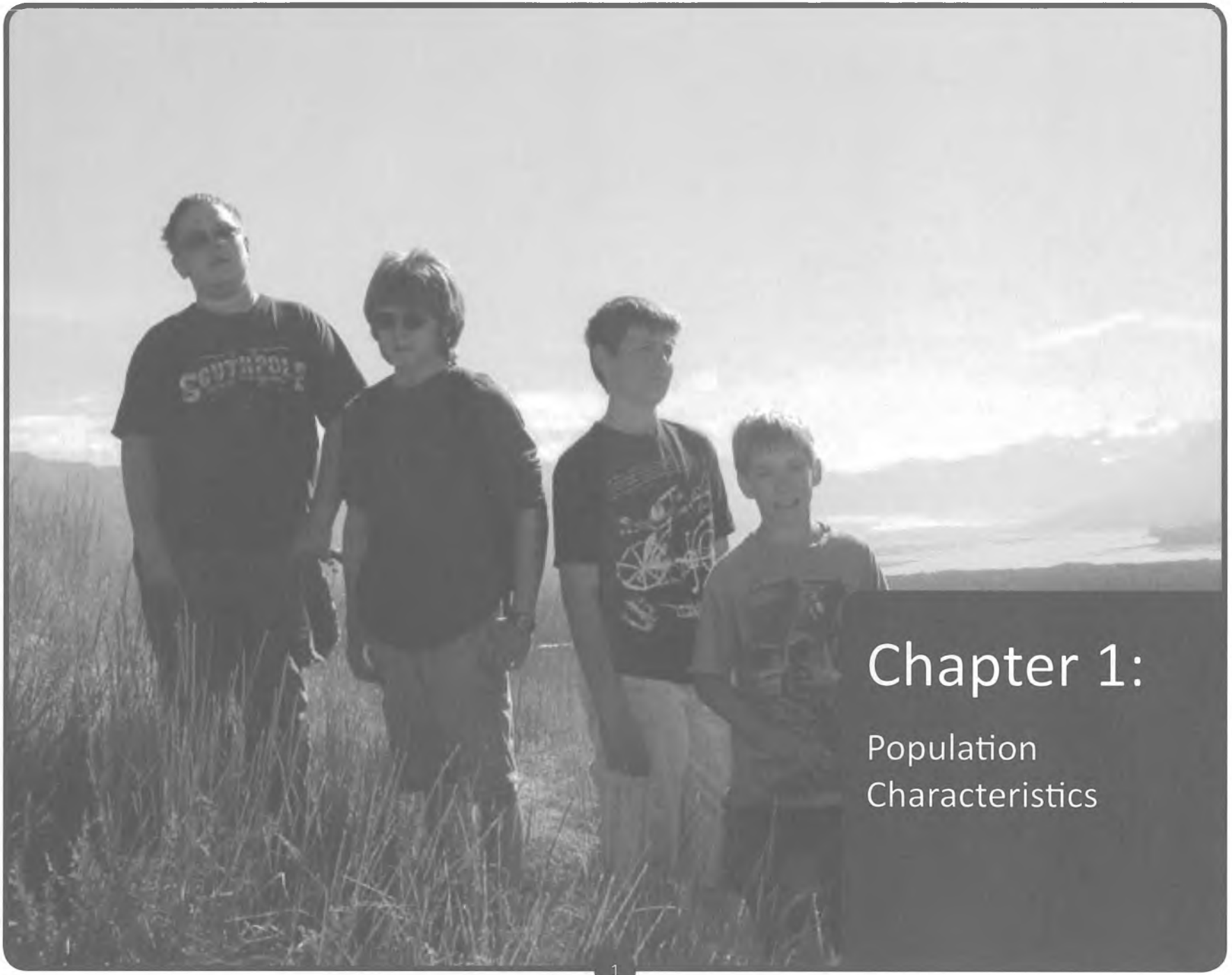


Chapter 1:

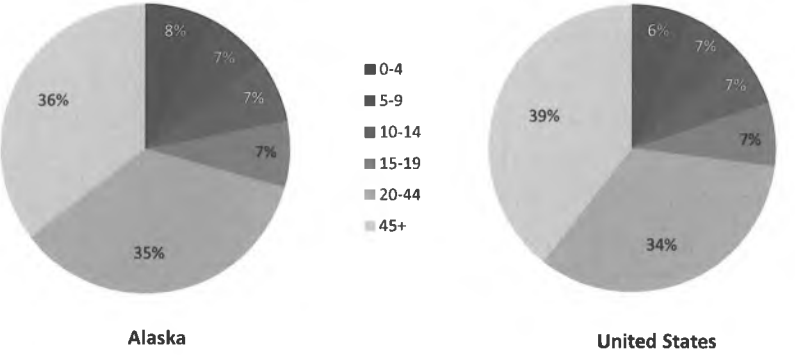
Population Characteristics

Population Characteristics

POPULATION DISTRIBUTION

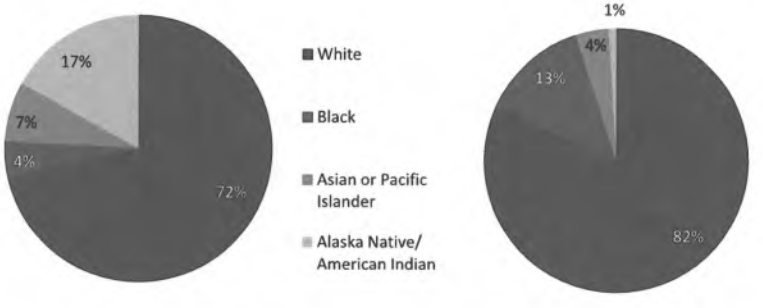
Geographically the nation's largest state, Alaska makes up approximately 16% of the United States land area, but only 0.2% of the population. Alaska's population was 710,231 in 2010, making it one of the least-populated states, ranking 47th. The Anchorage/Mat-Su region is home to 53.6% of Alaska's population. Alaska's population is relatively young. The median age of Alaska's population in 2010 was 33.8 years, less than the national median age of 37.2 years. When reporting race alone or in combination with one or more other races, Whites account for the 79% of the state's population, followed by Alaska Natives (21%), Black or African American (5%), and Asian or Pacific Islanders (10%). Approximately 6% of Alaskans, regardless of race, indicate they are of Hispanic ethnicity. About 55% of the population live in rural areas and of those, 82% are Alaska Natives (1-3).

Population Distribution by Age Group, in Years
Alaska and United States, 2010



Alaska | United States

Population Distribution by Race
Alaska and United States, 2010



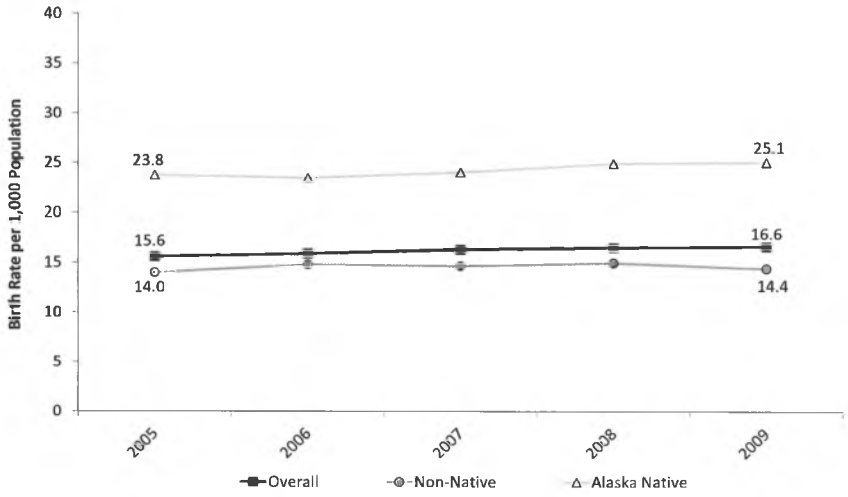
Alaska | United States

Population Characteristics

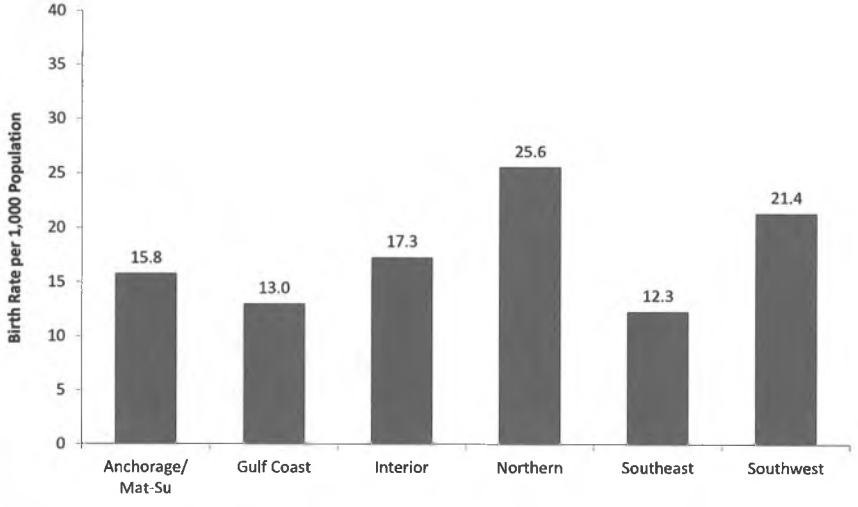
BIRTH RATE

Between 2005 and 2009, the crude birth rate in Alaska remained steady at approximately 16.0 per 1,000 population. Alaska's crude birth rate was consistently higher than that of the nation (16.6 per 1,000 compared to 13.5 per 1,000 in 2009). On any given year in Alaska, approximately 10,900 children are born. Between 2005 and 2009, the Alaska Native crude birth rate was consistently higher than that of non-Natives (25.1 per 1,000 population compared to 14.4 per 1,000 in 2009). While 17% of the state's total population is Alaska Native, one fourth (25%) of the births are Alaska Native. The highest crude birth rates were seen in the Northern and Southwestern regions of the state for years 2005-2009 (25.6 per 1,000 population and 21.4 per 1,000, respectively) (1,2).

Crude Birth Rate by Year and Alaska Native Status, Alaska, 2005-2009



Crude Birth Rate by Region Alaska, 2005-2009



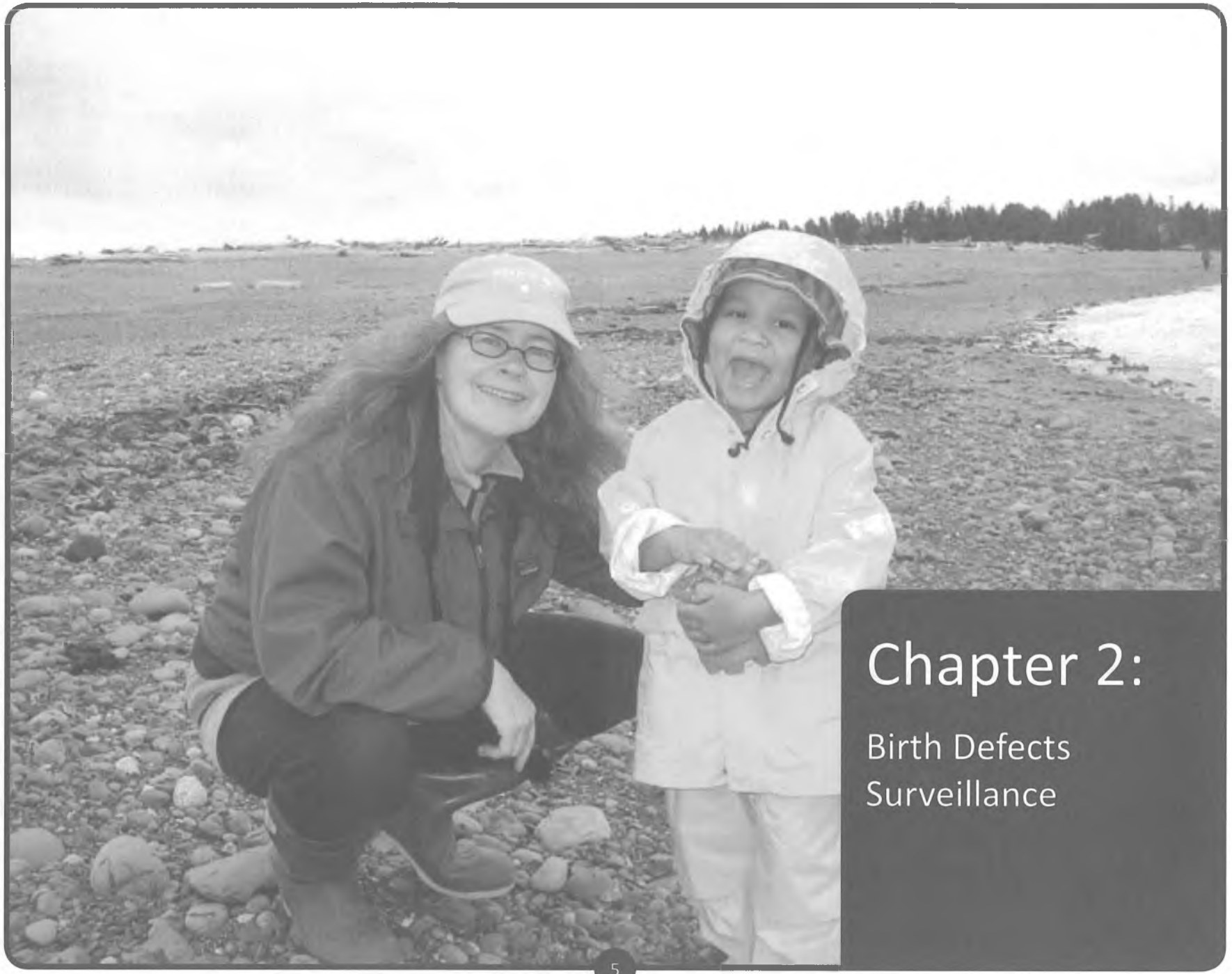
Population Characteristics

BIRTH CHARACTERISTICS

Characteristics of live births are documented on an infant's birth certificate and registered as a vital record with the state of Alaska. These characteristics include details of the infant's birth, as well as demographic, medical, and behavioral factors affecting the pregnancy. Alaska's vital records may be updated as new information is obtained. The data presented on the facing page include complete vital records information as of December 2011 (4). In this data book, we present information on the number of infants reported with birth defects during 1996-2011 by child sex, birth weight, maternal race and ethnicity, maternal age, prenatal care category, reported prenatal alcohol use, and reported prenatal tobacco use. The distribution of these characteristics within the total population of Alaska live births during 1996-2011 is presented on the facing page.

Distribution of Live Births by Selected Birth Characteristics
Alaska, 1996-2011

	n	Percent of Live Births
Child Sex		
Female	81,767	**48.6**
Male	86,602	**51.4**
Birth Weight		
Low and Very Low	9,728	**5.8**
Normal	158,408	**94.1**
Missing	233	**0.1**
Maternal Race		
White	105,081	**62.4**
Alaska Native	42,104	**25.0**
Black	6,995	**4.2**
Asian or Pacific Islander	11,899	**7.1**
Missing	2,290	**1.4**
Maternal Ethnicity		
Hispanic	7,538	**4.5**
Non-Hispanic	149,017	**88.5**
Missing	11,814	**7.0**
Maternal Age		
15-19 years	17,203	**10.2**
20-29 years	94,860	**56.3**
30-39 years	51,493	**30.6**
40-45 years	4,404	**2.6**
Missing or Other	409	**0.2**
Prenatal Care		
First Trimester	102,757	**61.0**
Second Trimester	18,809	**11.2**
Later or None	46,666	**27.7**
Missing or Unknown	137	**0.1**
Maternal Alcohol Use		
Reported	4,836	**2.9**
Not Reported	162,316	**96.4**
Missing	1,217	**0.7**
Maternal Tobacco Use		
Reported	28,242	**16.8**
Not Reported	139,097	**82.6**
Missing	1,030	**0.6**
Total Live Births	**168,369**	**100.0**



Chapter 2:

Birth Defects Surveillance

ABOUT THE ALASKA BIRTH DEFECTS REGISTRY

The Alaska Birth Defects Registry (ABDR) was established in 1996 under Alaska statute 7 AAC 27.012 (5). Health care providers, hospitals, and other health care facilities are required to report to the ABDR when they have cared for a child with a birth defect listed as a *Condition Reportable to Public Health* (6). A list of Alaska's reportable birth defects and their International Classification of Disease Version 9 (ICD-9) diagnosis codes is presented in the facing table.

Public health surveillance systems such as the ABDR provide information on the occurrence and distribution of reportable health conditions within populations. ABDR data are used to:

- Estimate the prevalence of congenital anomalies within populations and identify temporal and geographic trends.
- Investigate unusual patterns of occurrence.
- Monitor the prevalence of birth defects in populations with identifiable or preventable exposures, and determine whether known exposures have increased the risk of birth defects.
- Conduct analytic studies of high prevalence conditions to elucidate possible etiologies and prevention strategies.
- Provide scientific foundation for evidence-based decision making.
- Observe and evaluate the effects of interventions and policy changes.

Complete List of ICD-9 Codes Reportable to the Alaska Birth Defects Registry

237.7-237.72	Neurofibromatosis
243	Congenital hypothyroidism
255.2	Adrenogenital disorders
270.0-270.9	Amino acid metabolic disorders
271.0-271.1	Glycogenosis and galactosemia
277.0-277.9	Other and unspecified disorders of metabolism
279.0-279.9	Disorders involving the immune mechanism
282.0-282.9	Hereditary hemolytic anemias
284.0	Constitutional aplastic anemia
331.3-331.9	Other cerebral degenerations
334.0-334.9	Spinocerebellar disease
335.0-335.9	Anterior horn cell disease
343.0-343.9	Infantile cerebral palsy
359.0-359.9	Muscular dystrophies and other myopathies
362.74	Pigmentary retinal dystrophy
389.0-389.9	Hearing loss: conductive, senorineural and combined
740.0-740.2	Anencephalus and similar anomalies
741.0-741.9	Spina bifida
742.0-742.9	Other congenital anomalies of nervous system
743.0-743.9	Congenital anomalies of eye
744.0-744.9	Congenital anomalies of ear, face and neck
745.0-745.9	Bulbus cordis anomalies and anomalies of cardiac septal closure
746.0-746.9	Other congenital anomalies of heart
747.0-747.9	Other congenital anomalies of circulatory system
748.0-748.9	Congenital anomalies of respiratory system
749.0-749.25	Cleft palate and cleft lip
750.0-750.9	Other congenital anomalies of upper alimentary tract
751.0-751.9	Other congenital anomalies of digestive system
752.0-752.9	Congenital anomalies of genital organs
753.0-753.9	Congenital anomalies of urinary system
754.0-754.89	Certain congenital musculoskeletal deformities
755.0-755.9	Other congenital anomalies of limbs
756.0-756.9	Other congenital musculoskeletal anomalies
757.0-757.9	Congenital anomalies of the integument
758.0-758.9	Chromosomal anomalies
759.0-759.9	Other and unspecified congenital anomalies
760.0-760.9	Fetus or newborn affected by maternal conditions which may be unrelated to present pregnancy
760.71	Alcohol affecting fetus via placenta or breast milk, including fetal alcohol syndrome

Birth Defects Surveillance

SURVEILLANCE METHODS

The Alaska Birth Defects Registry (ABDR) conducts passive surveillance with data collection relying on mandatory reporting by health care providers. Other state-based registries may rely on information reported on the birth certificate or on information gathered by actively searching medical records for cases of reportable birth defects. Differences between states in reported birth defects prevalences might reflect true differences in risk factor prevalence or may be due to differences in surveillance methodologies. Surveillance protocols for the state of Alaska are as follows:

- The reporting facility screens patient records for reportable ICD-9 codes and submits quarterly reports to the ABDR.
- Reports to the ABDR include: child's name, birth and diagnosis date, community of birth, race and ethnicity, sex, community of residence, and diagnosis information.
- From 1996-2005, birth defects were required to be reported up to a child's first birthday, with the exception of alcohol-related birth defects, which were reportable up to a child's 6th birthday. In 2006, ABDR updated its reporting protocol so that all reportable conditions were required to be reported up to a child's 6th birthday. This change allowed for a more standardized and accurate report of birth defects across the state, especially for conditions difficult to diagnose at earlier ages.
- The ABDR is a multiple-reporting source registry that maintains information from all reporting sources for each infant or child reported.
- A single child may be reported to the registry several times, for one or more congenital conditions.
- Data are cross-linked to ensure that each occurrence of a specific defect is tallied only once.
- Data is maintained in a secure, confidential database. Individual data and personal identifiers are not released. Only summarized data are reported.

A copy of the Alaska Birth Defects Registry Reporting Form is presented on the facing page.

State of Alaska
Alaska Birth Defects Registry
Birth Defects Reporting Form

Completion Date: __/__/__ **Person Completing Form:** __________

Medical Facility Name: __________

Patient Last Name: __________

Patient First Name: __________

Patient Middle Name: __________

Patient DOB (month/day/year): __/__/__

Patient Sex:
- ☐ Male
- ☐ Female

Patient Community of Birth: __________

Patient Community of Residence: __________

Patient Race (Check Only One):
- ☐ Alaska Native/American Indian
- ☐ Asian/ Pacific Islander
- ☐ Black
- ☐ Hispanic
- ☐ White
- ☐ Other/Unknown

Medical Record Number: __________

ICD-9 Code	Description of Anomaly	Date of Encounter
___.__		__/__/__
___.__		__/__/__
___.__		__/__/__
___.__		__/__/__
___.__		__/__/__
___.__		__/__/__
___.__		__/__/__

SENTINEL CONDITIONS

Certain sentinel conditions undergo medical records abstractions and case verification. Birth defects are added to the sentinel conditions list if they are found to be reported at unusually high rates in comparison to nationwide rates or rates found in the state for previous years, or for conditions that are of special public health interest (e.g., fetal alcohol syndrome). ABDR's current sentinel conditions include: anencephaly, cleft lip, cleft palate, encephalocele, epispadias, fetal alcohol syndrome (FAS), gastroschisis, Hirschsprung's disease, hypospadias, obstructive genitourinary defect, omphalocele, spina bifida, trisomy 13, trisomy 18, and trisomy 21.

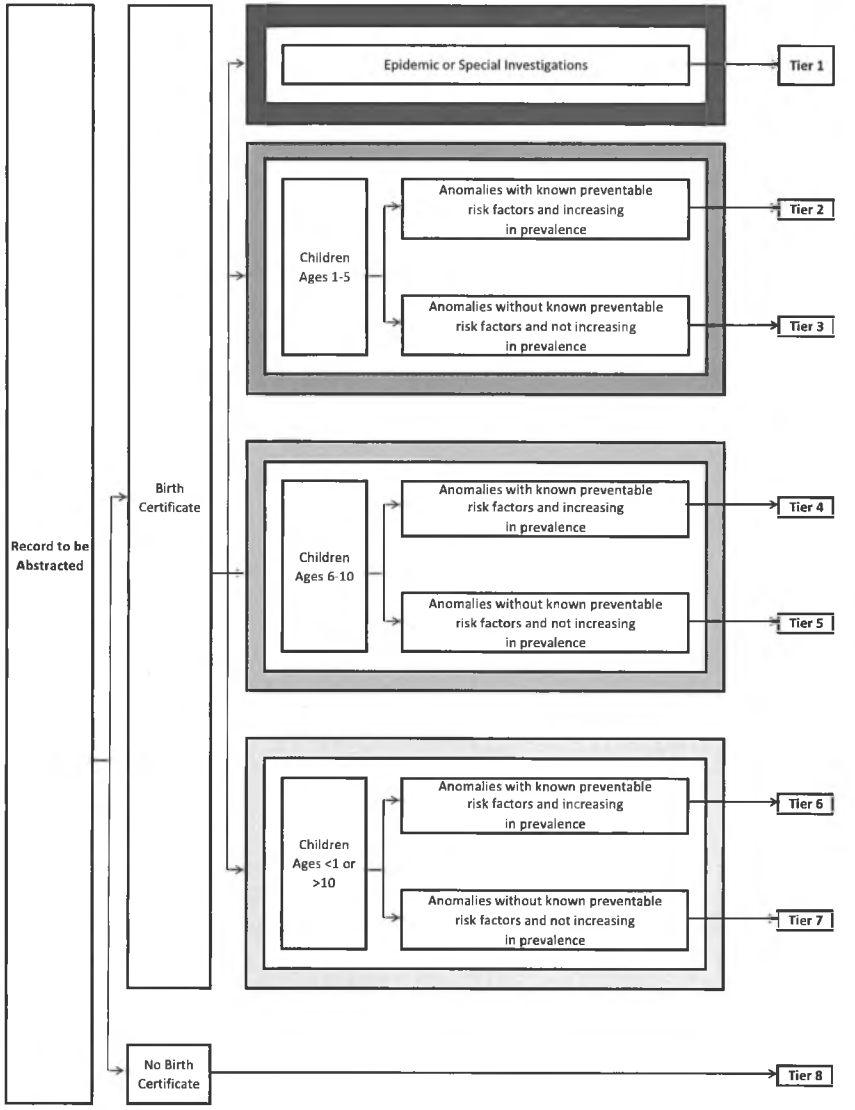
Medical records abstractions are prioritized with the following considerations:

- Responding to current public health needs and changing trends in birth defects.
- Addressing preventable birth defects.
- Making a positive impact in the birth outcomes for the state of Alaska.

Medical records that demonstrate the following characteristics are prioritized and differentiated into tier groups (the higher the tier group, the higher the priority for abstraction):

- Conditions undergoing epidemic or special investigation.
- Records linked to an Alaska birth certificate (to prevent the abstraction of possible duplicate records among non-birth certificate-matched reports).
- Records for birth years for children ages 1-5 years, followed by ages 6-10, and ages >10 (to ensure the most current trends in birth defects are verified). Please note that this age prioritization is slightly different for investigations of fetal alcohol syndrome (FAS) due to possible difficulty in diagnosing this condition at early ages. FAS records are abstracted in the following priority order: birth years for children ages >6 and <8 (higher priority); birth years for children ages >8 and <10 (medium priority); children ages 0-5 or >10 (lower priority).
- Conditions with known preventable risk factors that are also increasing in prevalence.
- Records that cannot be linked to birth certificates, older birth years, and birth defects with currently unknown methods of prevention are still abstracted, but at a lower priority level.

Sentinel Conditions Priority Tiers



CASE ASCERTAINMENT

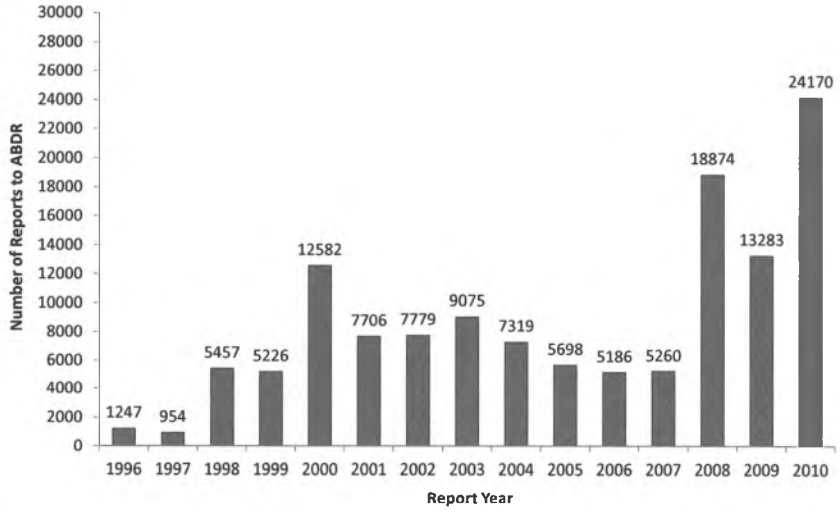
Surveillance issues such as incomplete case ascertainment, late or delayed case ascertainment, variation in diagnostic techniques, over- and under-reporting, coding errors, and differences in methodology may influence the reliability of prevalence estimates derived from surveillance data. The Alaska Birth Defects Registry (ABDR) regularly conducts surveillance evaluations to quantify, address, and minimize biases associated with these effects.

The completeness of case ascertainment is an important consideration in selecting which birth cohorts to include in an analysis of surveillance data. For this data book, it is important to keep in mind that providers may report children whom they have cared for with a birth defect up to the age of 6. Therefore, case ascertainment for birth years after 2006 may be incomplete and exhibit under-reporting.

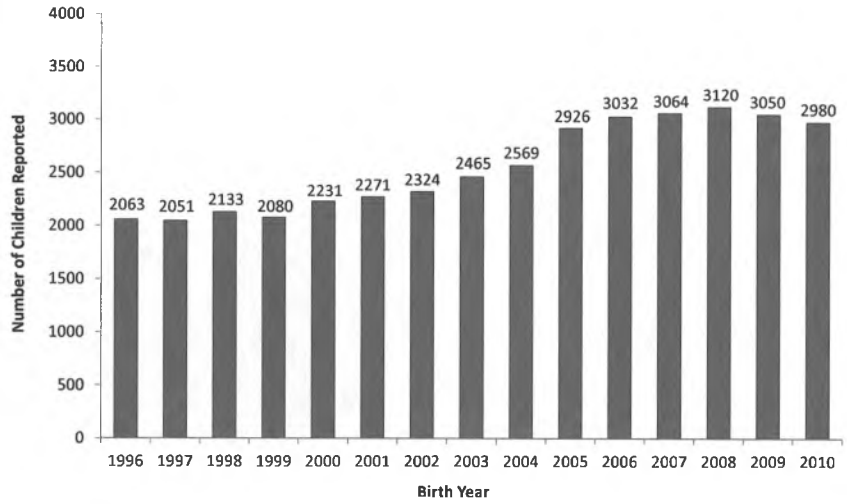
Efforts to improve reporting and educate providers about ABDR reporting requirements are most apparent in the late 2000's when the number of reports received by the ABDR increased from just over 5,000 in 2007 to nearly 19,000 in 2008, and over 24,000 in 2010. This is a reflection of aggressive outreach efforts instituted by ABDR staff to collect both current and retrospective data from as many providers as possible. As outreach efforts continue and new reporting sources are added, we expect the number of reports to ABDR to increase by year until optimal reporting is attained.

During 1996-2010, the ABDR received an average of 8,654 reports per year, and identified an average of 2,557 children who were born each year with a reportable birth defect. These figures includes both major congenital anomalies and non-major congenital anomalies.

Number of Reports to ABDR by Year of Report
Alaska, 1996-2010



Number of Children Reported to ABDR by Birth Year
Alaska, 1996-2010



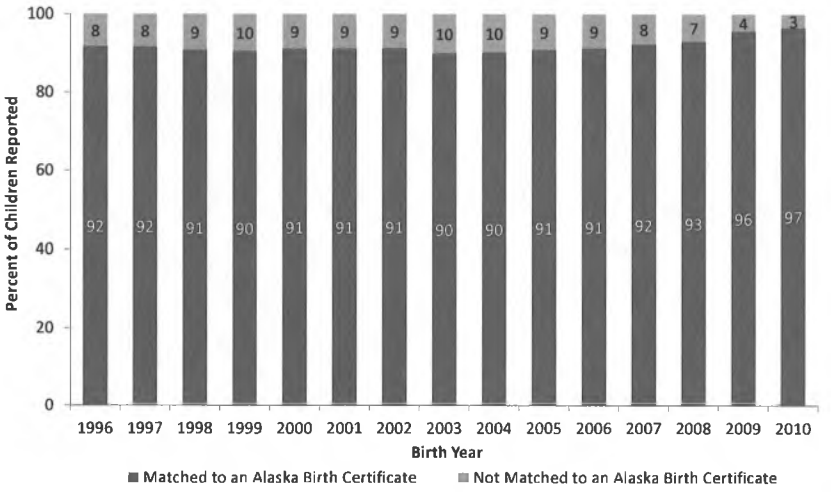
BIRTH CERTIFICATE MATCHING

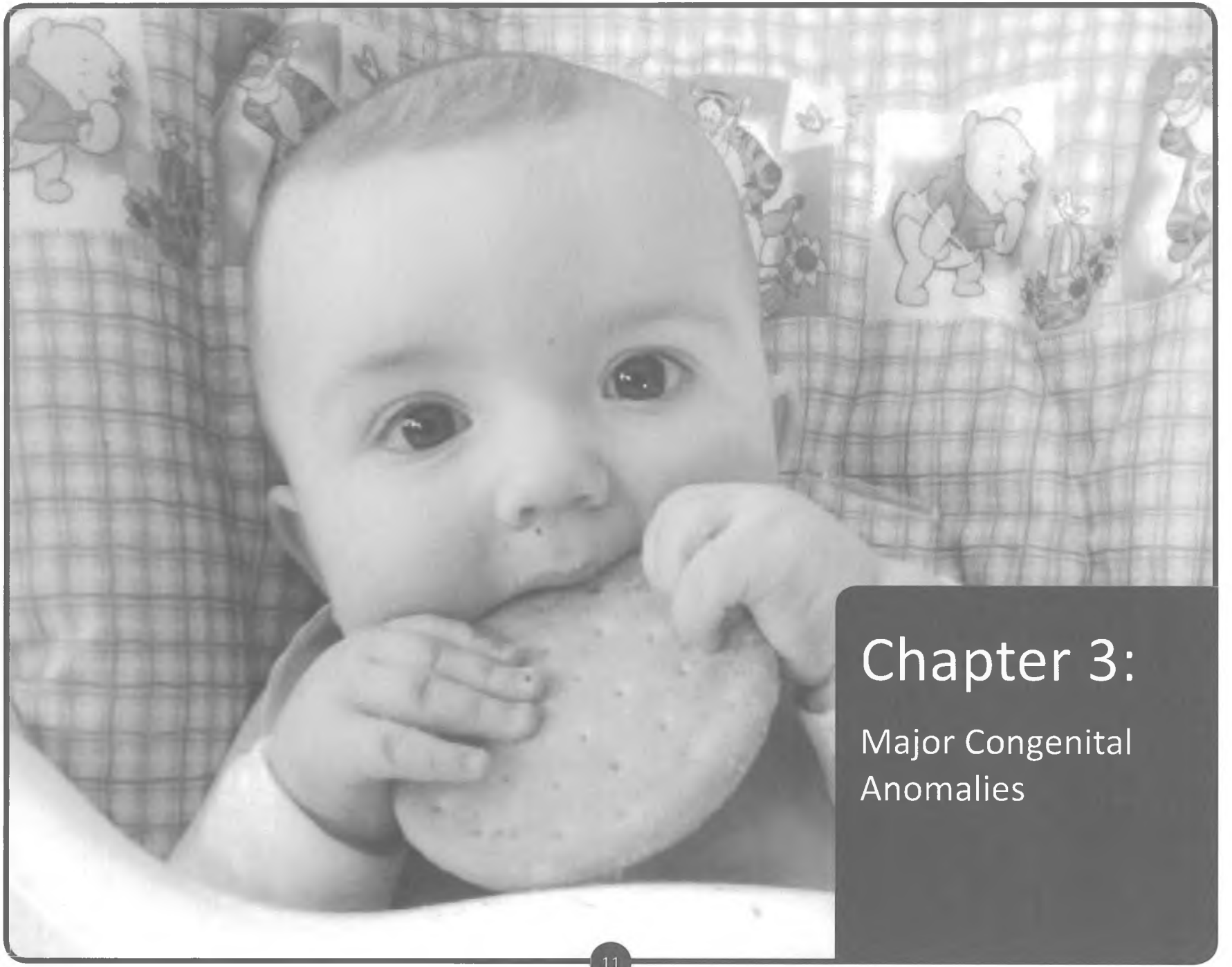
Children who cannot be matched to an Alaska birth certificate were, and have been historically, excluded from analyses. This purpose of this exclusion is to protect against duplication of counts of major congenital anomalies.

The Alaska Birth Defects Registry's (ABDR) goal is to ensure at least 90% of all children reported to the ABDR are matched to an Alaska birth certificate. For every year of the study period, this goal was either met or exceeded. This success of birth certificate matching can be attributed to aggressive matching methodologies employed by the ABDR Data Manager. Exact and probabilistic matching strategies have relied upon cross-linking ABDR data with data from the Bureau of Vital Statistics, Medicaid, the Permanent Fund Dividend, and other statewide databases. Probability matching has been utilized on a case-by-case basis where multiple key variables have shown agreement.

Despite the high percentages of birth certificate matching during this study period, an average of 8% of children reported to the ABDR were still excluded from analyses for every birth year cohort. The majority of children who could not be matched to an Alaska birth certificate were determined to be out-of-state births. Despite whether a child was born in Alaska or out of state, the exclusion of children who could not be matched to an Alaska birth certificate could result in incomplete prevalence estimates for major congenital anomalies or biased risk factor analyses. Further epidemiological investigation of this excluded group of children is needed to examine public health impact and need.

Percent of Children Reported to ABDR by Birth Year and Birth Certificate Matching Status, Alaska, 1996-2010





Chapter 3:

Major Congenital Anomalies

Major Congenital Anomalies

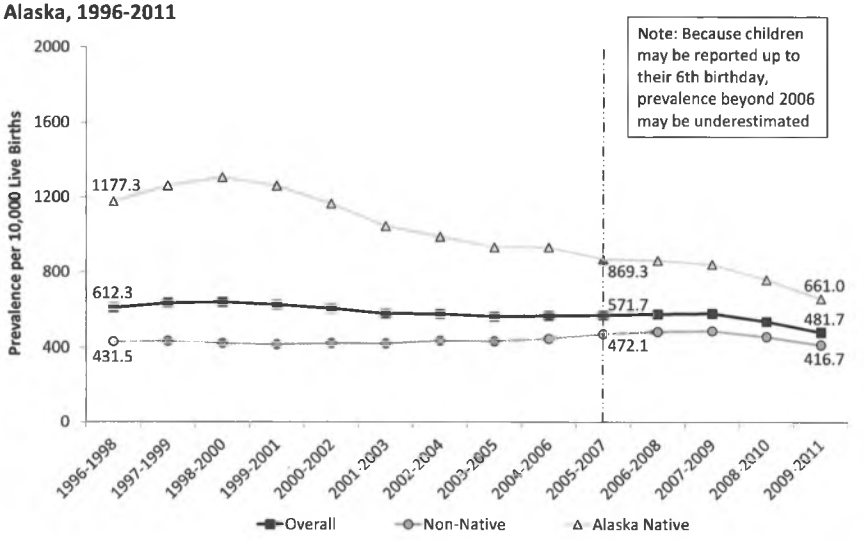
TRENDS AND DISTRIBUTION

The National Birth Defects Prevention Network (NBDPN), an organization that works to promote birth defects research and integrate information collected by state birth defects registries, has defined 45 birth defects that are considered major congenital anomalies (7). This data book presents epidemiological information on these congenital anomalies, including alcohol-related birth defects and not including amniotic bands.

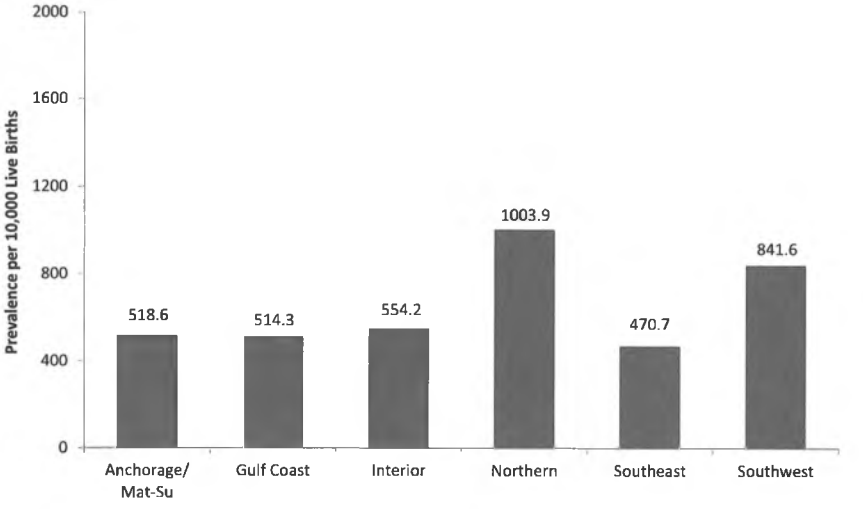
During birth years 1996-2011, the following trends and distributions were observed:

- Major congenital anomalies affected approximately 6% of Alaska live births annually. This is twice the national average.
- The overall prevalence of major congenital anomalies decreased among both Alaska Native and non-Native children.
- The prevalence of major congenital anomalies was higher among Alaska Native children when compared to non-Native children.
- The prevalence of major congenital anomalies was highest in the Northern and Southwest regions (10% and 8% of live births, respectively).

Prevalence of Major Congenital Anomalies by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Major Congenital Anomalies by Region
Alaska, 1996-2011



Major Congenital Anomalies

EPIDEMIOLOGICAL CHARACTERISTICS

Birth defects are one of the most common causes of death among infants and newborns. The cause of most birth defects is currently unknown. Epidemiological information on the occurrence of birth defects may elucidate etiologies and assist in identifying needs for resource allocation and public health efforts.

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with a major congenital anomaly for birth years 1996-2011:

- Males were more likely to be reported with a major congenital anomaly when compared to females.
- Children with low birth weights (< 2500 grams) were 4.8 times more likely to be reported with a major congenital anomaly when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were more than twice as likely to deliver a child with a major congenital anomaly when compared to white mothers.
- Mothers of Hispanic ethnicity were less likely to deliver a child with a major congenital anomaly when compared to mothers who were not Hispanic.
- Mothers ages 30-39 years were the least likely of all age groups studied to deliver a child with a major congenital anomaly, and teenage mothers and mothers 40-45 years were the most likely.
- Mothers who received prenatal care beginning in the second trimester or no prenatal care at all were more likely to deliver a child with a major congenital anomaly when compared to mothers who received prenatal care in the first trimester.
- Mothers who reported alcohol use during pregnancy were 3.6 times more likely to deliver a child with a major congenital anomaly when compared to mothers who did not report alcohol use during pregnancy.
- Mothers who reported tobacco use during pregnancy were 2.2 times more likely to deliver a child with a major congenital anomaly when compared to mothers who did not report tobacco use during pregnancy.

Prevalence of Major Congenital Anomalies by Selected Birth Characteristics
Alaska, 1996-2011

	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**508.4**	ref	-
Male	**632.5**	1.3	(1.2 - 1.3)
Birth Weight*			
Low and Very Low	**1750.5**	4.8	(4.5 - 5.1)
Normal	**418.7**	ref	-
Maternal Race			
White	**438.1**	ref	-
Alaska Native	**970.2**	2.3	(2.2 - 2.5)
Black	**473.1**	1.1	(1.0 - 1.2)
Asian or Pacific Islander	**411.4**	0.9	(0.9 - 1.0)
Maternal Ethnicity			
Hispanic	**465.8**	0.8	(0.7 - 0.9)
Non-Hispanic	**578.9**	ref	-
Maternal Age			
15-19 years	**716.5**	1.4	(1.3 - 1.5)
20-29 years	**561.1**	1.1	(1.0 - 1.1)
30-39 years	**525.3**	ref	-
40-45 years	**728.9**	1.4	(1.3 - 1.6)
Prenatal Care			
First Trimester	**519.4**	ref	-
Second Trimester	**692.4**	1.4	(1.3 - 1.4)
Later or None	**641.1**	1.3	(1.2 - 1.3)
Maternal Alcohol Use			
Reported	**1694.5**	3.6	(3.3 - 3.9)
Not Reported	**535.5**	ref	-
Maternal Tobacco Use			
Reported	**995.0**	2.2	(2.1 - 2.3)
Not Reported	**483.9**	ref	-

*1255 infants with patent ductus arteriosus were excluded from birth weight analysis because the surveillance case definition for patent ductus arteriosus specifies that only infants ≥2500g are counted.

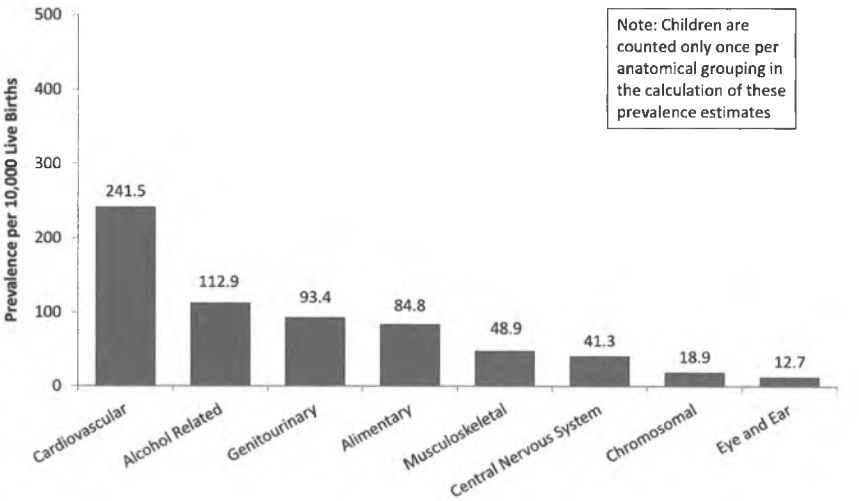
ANATOMICAL GROUPINGS

Major congenital anomalies are categorized into eight groupings – fetal alcohol spectrum disorders, also referred to as alcohol related birth defects, and seven anatomical groupings: cardiovascular, genitourinary, alimentary tract, musculoskeletal, central nervous system, chromosomal, and eye or ear anomalies. Children may be reported with isolated or multiple birth defects, both within and across these anatomical groupings. Prevalence estimates for anatomical groupings are provided on the facing page for all *children* reported with at least one anomaly per grouping (each child is counted only once per anatomical grouping), as well as all *reports* received for each anatomical grouping (children may be counted more than once for multiple defects within each anatomical grouping).

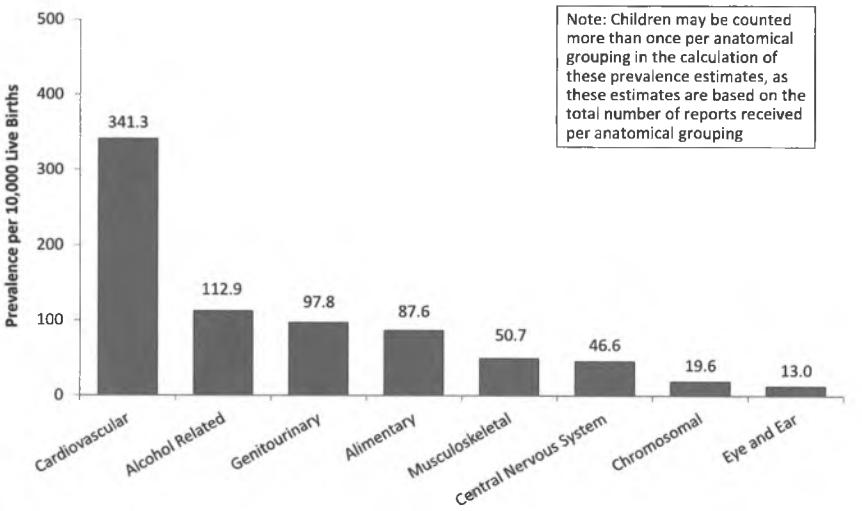
In summary, from 1996-2011:

- It was not uncommon for children to be reported for multiple major congenital anomalies within and across anatomical groupings.
- Cardiovascular birth defects were the most frequently reported major congenital anomalies in Alaska.
- Alcohol related birth defects and genitourinary birth defects were the second and third most commonly reported birth defects, respectively, with approximately 1% of all live births reported for each grouping.

Prevalence of Children Reported with Major Congenital Anomalies by Anatomical Grouping, Alaska, 1996-2011



Prevalence of Reports of Major Congenital Anomalies by Anatomical Grouping Alaska, 1996-2011



CASE FATALITY RATES

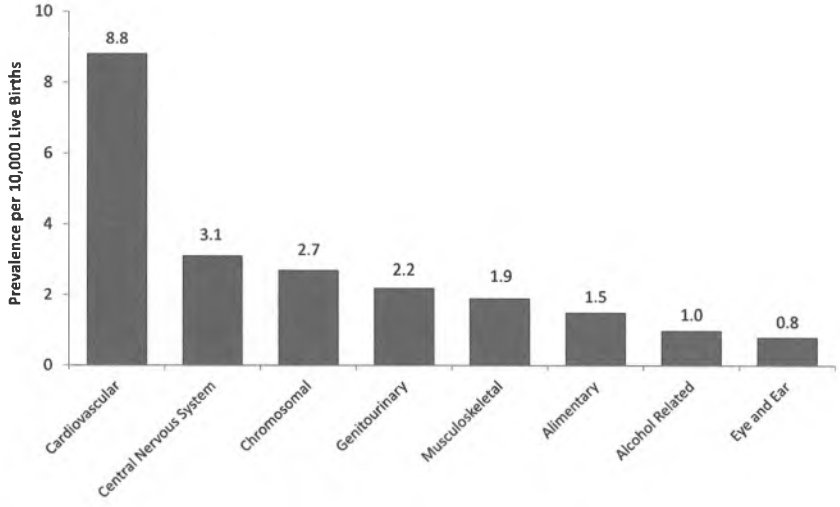
Both the national infant mortality rate and the Alaska infant mortality rate are approximately 67 per 10,000 live births. Major congenital anomalies account for more than 20% of these deaths, making major congenital anomalies the leading cause of infant death throughout the country (8,9).

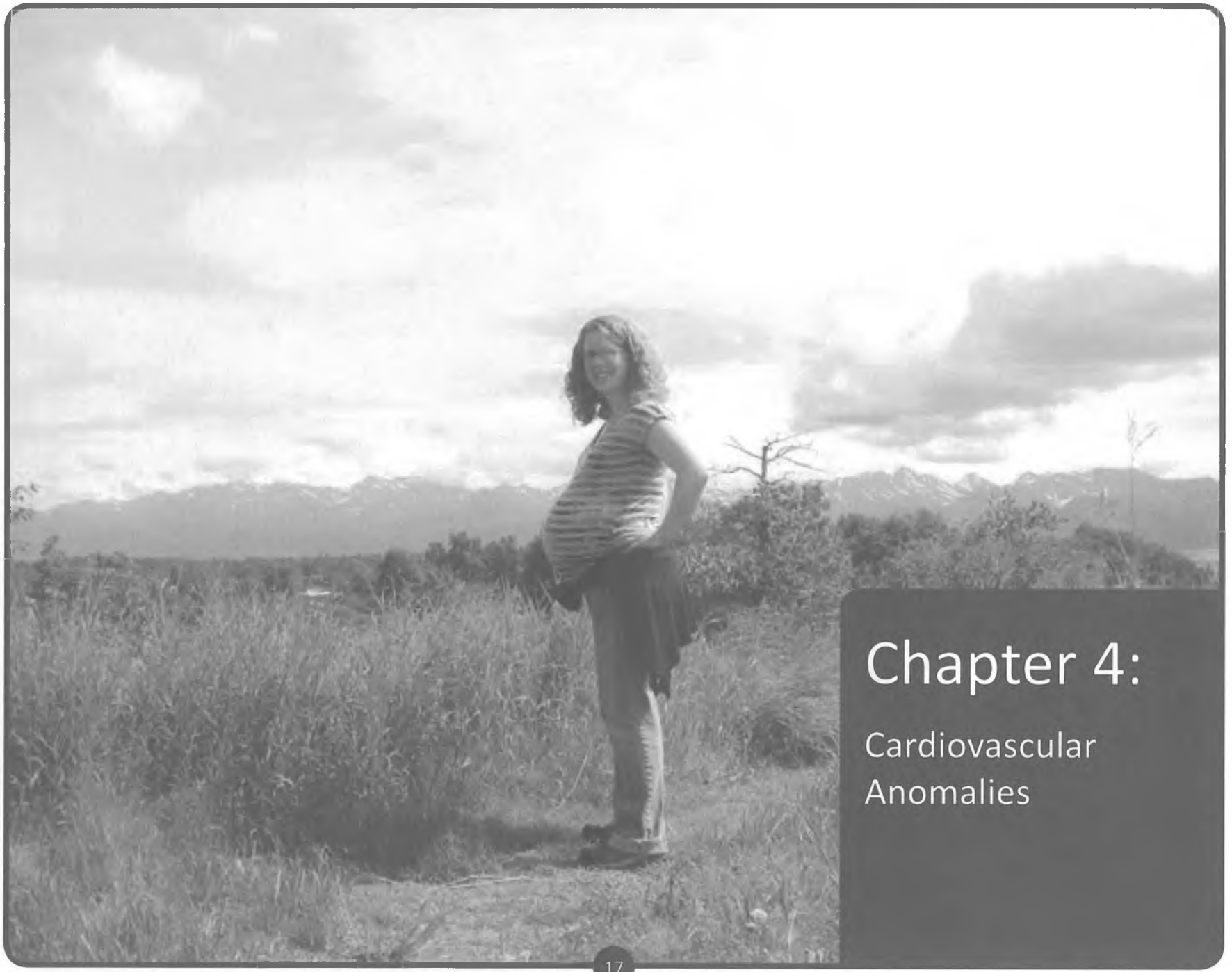
In Alaska, the case fatality rate among children reported to the Alaska Birth Defects Registry (ABDR) with a major congenital anomaly was 244 per 10,000 live births for birth years 1996-2009. Children reported with a major congenital anomaly were 3.6 times more likely to die before their first birthday when compared to children who were not reported with a major congenital anomaly, and children who were reported with multiple congenital anomalies were at an even higher risk for infant death.

In summary, from 1996-2009:

- Case fatality rates were highest among children reported with cardiovascular anomalies (8.8 per 10,000 live births), followed by central nervous system anomalies (3.1 per 10,000 live births), chromosomal anomalies (2.7 per 10,000 live births), genitourinary anomalies (2.2 per 10,000 live births), musculoskeletal anomalies (1.9 per 10,000 live births),and alimentary anomalies (1.5 per 10,000 live births).
- Case fatality was not as frequent among children reported with alcohol related birth defects (1.0 per 10,000 live births) and eye and ear anomalies (0.8 per 10,000 live births).

Case Fatality Rates for Major Congenital Anomalies by Anatomical Grouping Alaska, 1996-2009





Chapter 4:

Cardiovascular Anomalies

Cardiovascular Anomalies

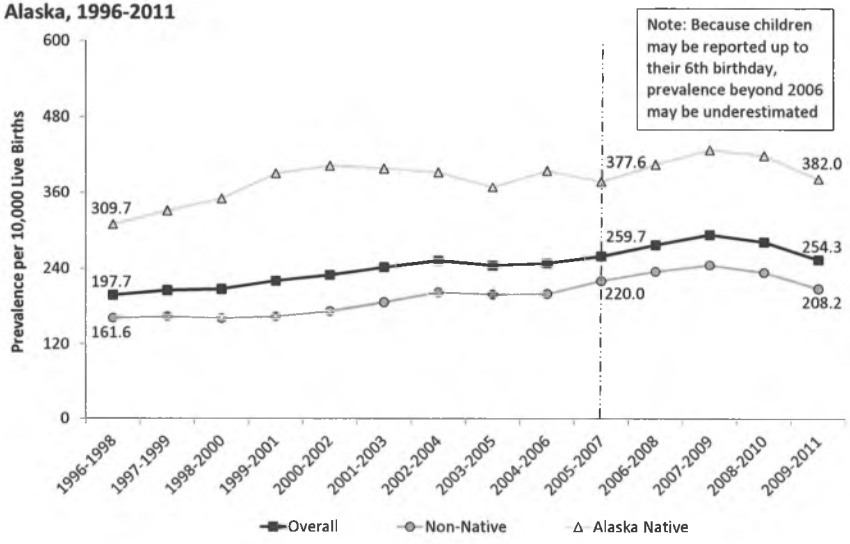
TRENDS AND DISTRIBUTION

Cardiovascular birth defects affect the heart or blood vessels surrounding the heart. Cardiovascular defects are estimated to be present in about 1% of live births nationwide, and are the most commonly diagnosed congenital anomalies. Prevalence estimates for cardiovascular anomalies are highly influenced by the availability of modern diagnostic techniques. Cardiovascular anomalies usually result in either obstructed or abnormal blood flow to or from the heart, and range in seriousness from minor self-correcting anomalies to fatal conditions (10).

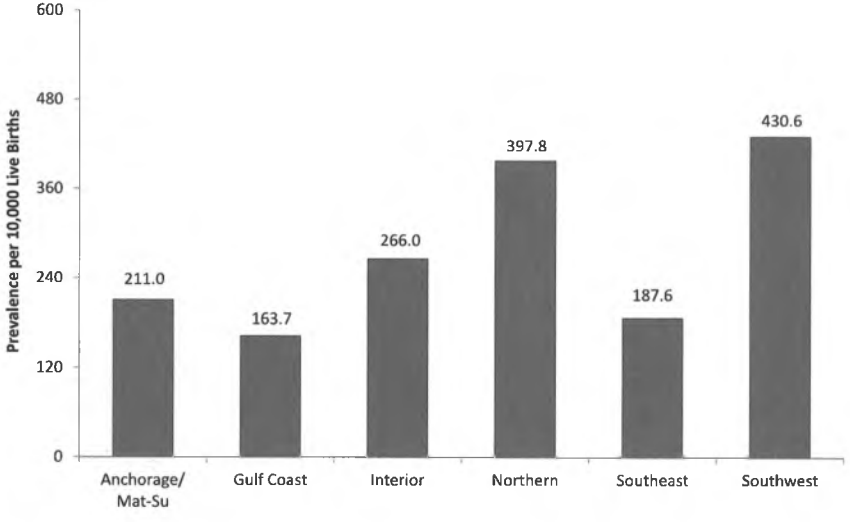
During birth years 1996-2011, the following trends and distributions were observed:

- Cardiovascular anomalies affected nearly 2.5% of Alaska live births annually. This is more than twice the national average.
- The overall prevalence of cardiovascular anomalies increased among both Alaska Native and non-Native children.
- The prevalence of cardiovascular anomalies was higher among Alaska Native children when compared to non-Native children.
- The prevalence of cardiovascular anomalies was highest in the Northern and Southwest regions (4% of live births).

Prevalence of Cardiovascular Anomalies by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Cardiovascular Anomalies by Region
Alaska, 1996-2011



Cardiovascular Anomalies

EPIDEMIOLOGICAL CHARACTERISTICS

The cause of most cardiovascular birth defects is unknown. Cardiovascular defects are believed to have a multi-factorial etiology with both genetic and environmental components. Studies have shown links between cardiovascular defects and chromosomal aberrations, somatic mutations, gene-environment interactions, environmental contaminants, and maternal characteristics such as diet, medication use, and smoking. Family history increases the risk of having a child with a cardiovascular anomaly (10-12).

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with a cardiovascular anomaly for birth years 1996-2011:

- Males were slightly less likely to be born with a cardiovascular anomaly when compared to females.
- Children with low birth weights (< 2500 grams) were nearly 9 times more likely to have a cardiovascular anomaly when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were twice as likely to deliver an infant with a cardiovascular anomaly when compared to white mothers.
- Mothers ages 40-45 years were 1.7 times more likely to deliver a baby with a cardiovascular birth defect when compared to mothers ages 30-39 years.
- Mothers who received prenatal care beginning in the second trimester or later or no prenatal care at all were 1.2 times more likely to deliver a baby with a cardiovascular anomaly when compared to mothers who received prenatal care in the first trimester.
- Mothers who reported alcohol or tobacco use during pregnancy were more likely to deliver a baby with a cardiovascular anomaly when compared to mothers who did not report alcohol or tobacco use during pregnancy.

Prevalence of Cardiovascular Anomalies by Selected Birth Characteristics
Alaska, 1996-2011

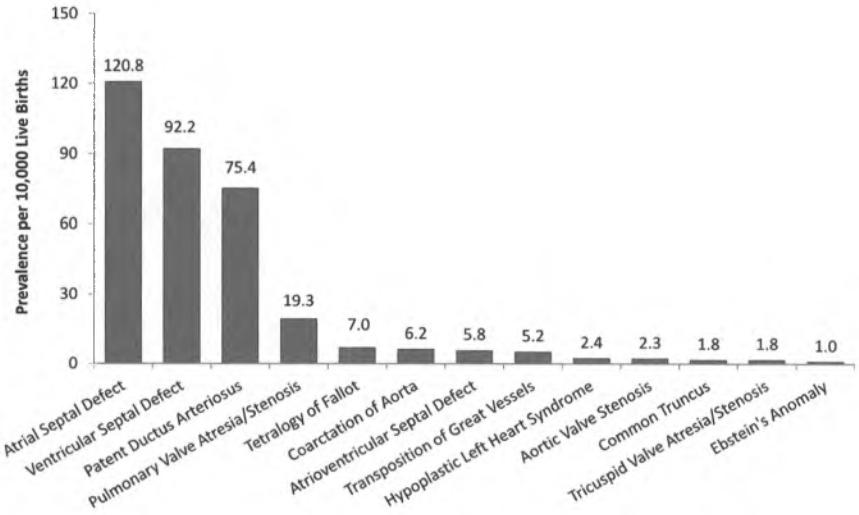
	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**250.1**	ref	-
Male	**233.4**	0.9	(0.9 - 1.0)
Birth Weight*			
Low and Very Low	**942.2**	8.7	(8.0 - 9.4)
Normal	**117.5**	ref	-
Maternal Race			
White	**191.9**	ref	-
Alaska Native	**376.9**	2.0	(1.9 - 2.1)
Black	**219.9**	1.1	(1.0 - 1.4)
Asian or Pacific Islander	**209.5**	1.1	(1.0 - 1.3)
Maternal Ethnicity			
Hispanic	**228.2**	0.9	(0.8 - 1.1)
Non-Hispanic	**240.9**	ref	-
Maternal Age			
15-19 years	**270.5**	1.2	(1.1 - 1.4)
20-29 years	**239.3**	1.1	(1.0 - 1.2)
30-39 years	**223.4**	ref	-
40-45 years	**370.2**	1.7	(1.4 - 2.0)
Prenatal Care			
First Trimester	**223.2**	ref	-
Second Trimester	**263.8**	1.2	(1.1 - 1.3)
Later or None	**273.0**	1.2	(1.1 - 1.3)
Maternal Alcohol Use			
Reported	**381.4**	1.6	(1.4 - 1.9)
Not Reported	**235.6**	ref	-
Maternal Tobacco Use			
Reported	**342.3**	1.6	(1.5 - 1.7)
Not Reported	**219.5**	ref	-

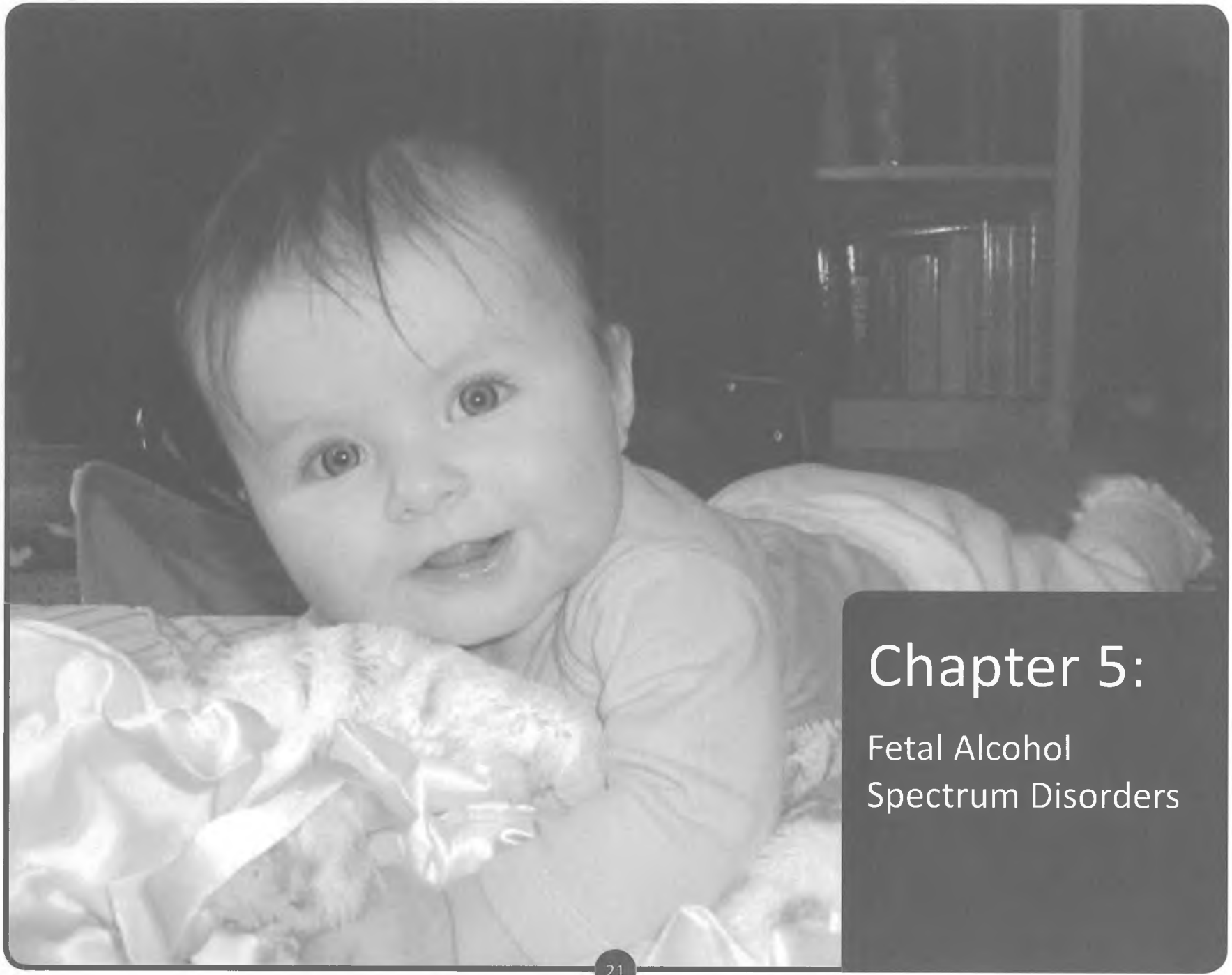
*1255 infants with patent ductus arteriosus were excluded from birth weight analysis because the surveillance case definition for patent ductus arteriosus specifies that only infants ≥2500g are counted.

SPECIFIC ANOMALIES

The most common cardiovascular anomalies in Alaska for birth years 1996-2011 were atrial septal defects (1.2% of live births) and ventricular septal defects (0.9% of live births), followed by patent ductus arteriosus (0.8% of live births) and pulmonary valve atresia/stenosis (0.2% of live births). These four conditions together comprised over 90% of the cardiovascular birth defects during the specified time period.

Prevalence of Specific Cardiovascular Anomalies
Alaska, 1996-2011





Chapter 5:

Fetal Alcohol Spectrum Disorders

Fetal Alcohol Spectrum Disorders

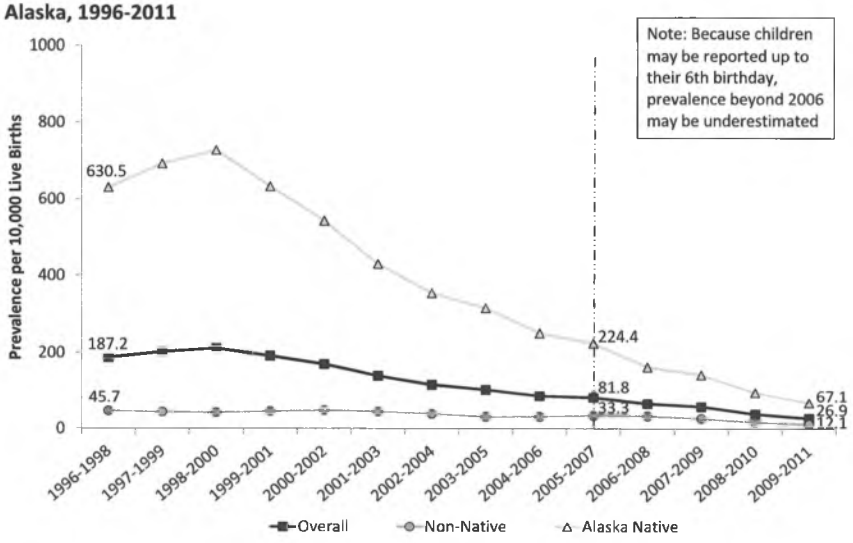
TRENDS AND DISTRIBUTION

Fetal alcohol spectrum disorders (FASD) include the collective conditions that can occur as a result of a person being exposed to alcohol in utero. FASD is estimated to be present in approximately 0.2-1.5 per 1,000 live births nationwide, though estimates are highly variable and most likely underestimated. The Institute of Medicine has defined four diagnostic categories in the FASD continuum, including fetal alcohol syndrome (FAS), partial FAS (PFAS), alcohol-related neurodevelopmental disorders (ARND), and alcohol-related birth defects (ARBD). Effects of FASD range from mild to severe, and may impact growth, facial appearance, central nervous system structure and function. Secondary conditions that may result from FASD include mental health problems, disrupted school experience, trouble with the law, inappropriate sexual behavior, and dependent living and problems with employment over the age of 21 years (10,13).

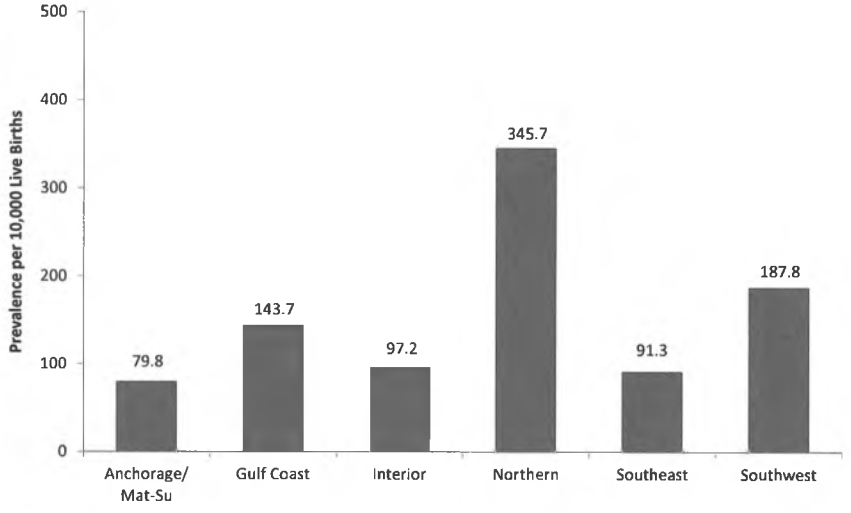
During birth years 1996-2011, the following trends and distributions were observed:

- FASD affected approximately 1% of Alaska live births annually.
- The overall prevalence of FASD decreased dramatically among Alaska Native children.
- The prevalence of FASD was higher among Alaska Native children when compared to non-Native children.
- Prevalence of FASD was highest in the Northern region (3.5% of live births), followed by the Southwest region (1.9% of live births).

Prevalence of Fetal Alcohol Spectrum Disorders by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Fetal Alcohol Spectrum Disorders by Region
Alaska, 1996-2011



Fetal Alcohol Spectrum Disorders

EPIDEMIOLOGICAL CHARACTERISTICS

The cause of Fetal Alcohol Spectrum Disorders (FASD) is exposure to alcohol in utero. According to the Centers for Disease Control and Prevention (CDC), there is no known amount of alcohol that is safe to drink while pregnant, and there is no safe time to drink during pregnancy. The CDC recommends that pregnant women abstain from drinking for the duration of their pregnancy, as well as prior to pregnancy if planning to become pregnant or not utilizing an effective method of birth control (10).

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with a fetal alcohol spectrum disorder for birth years 1996-2011:

- Males were slightly more likely to be reported with FASD when compared to females.
- Children with low birth weights (< 2500 grams) were 3.6 times more likely to be reported with FASD when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were more than 10 times more likely to deliver a child with FASD when compared to white mothers.
- Mothers who reported Hispanic ethnicity were less likely to deliver a child with FASD when compared to mothers who did not report Hispanic ethnicity.
- Overall, teenage mothers were most likely to deliver a child with FASD; however, this was not true for Alaska Native mothers. Alaska Native mothers ages 15-19 years were less likely to deliver a child with FASD when compared to Alaska Native mothers of any other age group.
- Mothers who received prenatal care beginning in the second trimester or no prenatal care at all were more likely to deliver a baby with FASD when compared to mothers who received prenatal care in the first trimester.
- Women who reported tobacco use during pregnancy were over 9 times more likely to deliver a child with FASD when compared to mothers who did not report tobacco use during pregnancy.

Prevalence of Fetal Alcohol Spectrum Disorders by Selected Birth Characteristics
Alaska, 1996-2011

	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**107.5**	ref	-
Male	**118.0**	1.1	(1.0 - 1.2)
Birth Weight			
Low and Very Low	**343.9**	3.6	(3.2 - 4.0)
Normal	**98.5**	ref	-
Maternal Race			
White	**35.1**	ref	-
Alaska Native	**350.5**	10.3	(9.2 - 11.6)
Black	**47.7**	1.4	(1.0 - 1.9)
Asian or Pacific Islander	**8.6**	0.2	(0.1 - 0.5)
Maternal Ethnicity			
Hispanic	**38.9**	0.3	(0.2 - 0.5)
Non-Hispanic	**120.0**	ref	-
Maternal Age			
15-19 years	**147.9**	1.3	(1.1 - 1.5)
20-29 years	**103.9**	0.9	(0.8 - 1.0)
30-39 years	**115.7**	ref	-
40-45 years	**105.8**	0.9	(0.7 - 1.2)
Prenatal Care			
First Trimester	**81.8**	ref	-
Second Trimester	**212.4**	2.6	(2.3 - 3.0)
Later or None	**141.2**	1.7	(1.6 - 1.9)
Maternal Alcohol Use*			
Reported	-	-	- -
Not Reported	-	-	- -
Maternal Tobacco Use			
Reported	**425.3**	9.1	(8.3 - 10.0)
Not Reported	**48.5**	ref	-

*Maternal alcohol use during pregnancy is part of the case definition for FASD and is not analyzed as a risk factor.

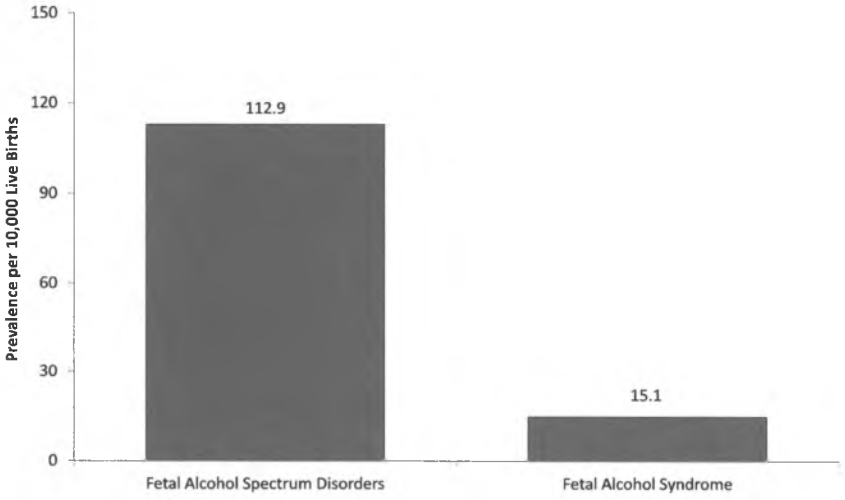
Fetal Alcohol Spectrum Disorders

SPECIFIC ANOMALIES

Of the Fetal Alcohol Spectrum Disorders (FASD), Fetal Alcohol Syndrome (FAS) is the only condition maintaining Centers for Disease Control and Prevention (CDC) established diagnostic protocol. However, a promising model with proven specificity and sensitivity for diagnosing FASD has been developed by the Center of Human Development and Disability at the University of Washington in Seattle. A diagnosis of FAS requires all three of the following findings: abnormal facial features, growth deficits, and central nervous system problems (a person may meet the central nervous system criteria for FAS diagnosis if there is a problem with the brain structure, even in the absence of apparent functional problems). This case definition is used by the state of Alaska (14,15)

The Alaska Birth Defects Registry (ABDR) reviews the medical records of children reported with FASD to determine FAS case status. Only a fraction (13.4%) of children reported with FASD meet the case definition for FAS. The nationwide prevalence estimate for FAS is approximately 1-3 per 1,000 live births. Alaska's prevalence estimate for FAS is 1.5 per 1,000 live births.

Prevalence of Specific Fetal Alcohol Spectrum Disorders
Alaska, 1996-2011



Chapter 6:

Genitourinary Anomalies

Genitourinary Anomalies

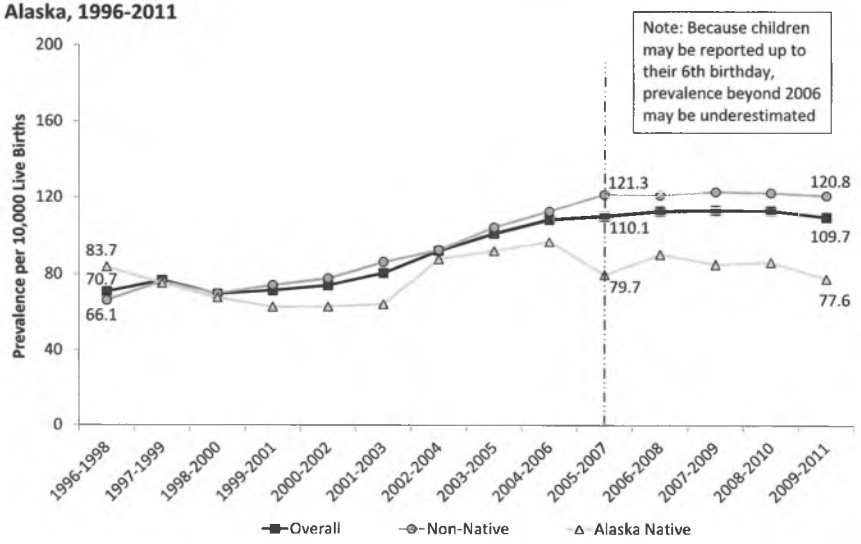
TRENDS AND DISTRIBUTION

Genitourinary anomalies are congenital malformations of the urinary tract and reproductive system. As a group, these anomalies are relatively common and include both rare, life threatening anomalies and less severe but more common anomalies that may be corrected surgically.

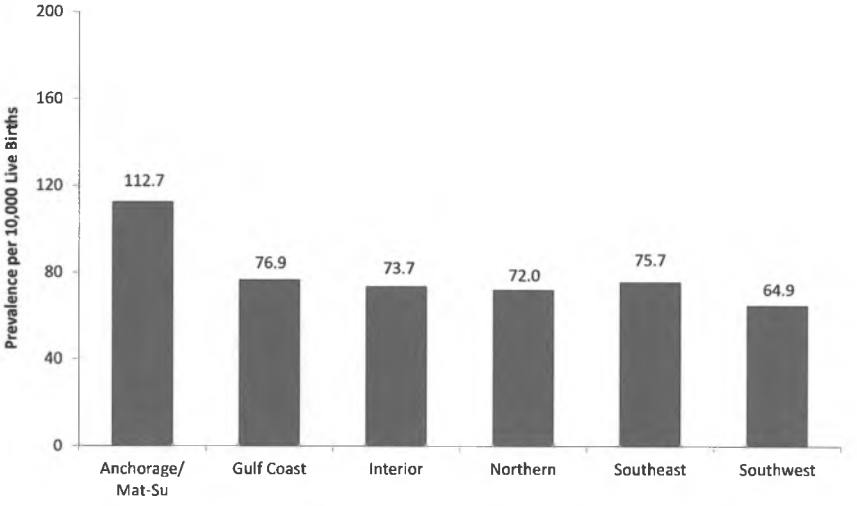
During birth years 1996-2011, the following trends and distributions were observed:

- Genitourinary anomalies affected nearly 1% of Alaska live births annually.
- The prevalence of genitourinary anomalies increased dramatically among non-Native children, and decreased slightly among Alaska Native children.
- The prevalence of genitourinary anomalies was higher among non-Native children when compared to Alaska Native children.
- The prevalence of genitourinary anomalies was highest in the Anchorage/ Mat-Su region (1.1% of live births).

Prevalence of Genitourinary Anomalies by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Genitourinary Anomalies by Region
Alaska, 1996-2011



Genitourinary Anomalies

EPIDEMIOLOGICAL CHARACTERISTICS

The cause of genitourinary birth defects is still uncertain. Studies have shown possible links between genitourinary birth defects and environmental exposures such as pesticides, herbicides, fungicides, insecticides, industrial by-products and end products, and living in close proximity to hazardous waste sites; however, these studies are not conclusive. Other possible risk factors include maternal characteristics such as white race, older age (≥ 40 years), tobacco/alcohol use during pregnancy, low income, overweight/obesity, pre-existing diabetes, and diet. Low birth weight, gestational age ≤ 37 weeks, family history of genitourinary birth defects, and certain risk genes have also been linked in some studies to increased risk (16-27).

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with a genitourinary anomaly for birth years 1996-2011:

- Males were 5 times more likely to be reported with a genitourinary anomaly when compared to females.
- Children with low birth weights (< 2500 grams) were nearly 3 times more likely to be reported with a genitourinary anomaly when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were less likely to deliver a child with a genitourinary anomaly when compared to white mothers.
- Mothers ages 40-45 years were more likely to deliver a baby with a genitourinary anomaly when compared to mothers ages 30-39 years.

Prevalence of Genitourinary Anomalies by Selected Birth Characteristics
Alaska, 1996-2011

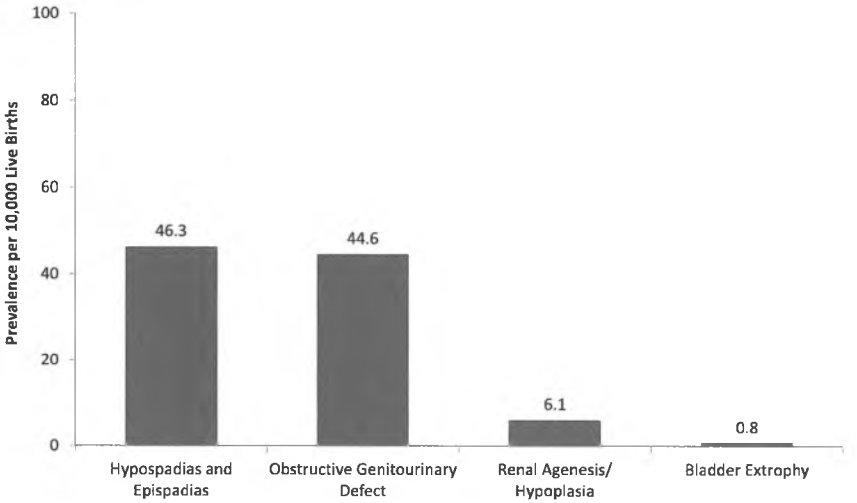
	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**30.4**	ref	-
Male	**152.9**	5.1	(4.4 - 5.8)
Birth Weight			
Low and Very Low	**234.8**	2.8	(2.4 - 3.2)
Normal	**84.8**	ref	-
Maternal Race			
White	**97.7**	ref	-
Alaska Native	**79.3**	0.8	(0.7 - 0.9)
Black	**107.1**	1.1	(0.9 - 1.4)
Asian or Pacific Islander	**95.8**	1.0	(0.8 - 1.2)
Maternal Ethnicity			
Hispanic	**76.5**	0.8	(0.6 - 1.1)
Non-Hispanic	**93.5**	ref	-
Maternal Age			
15-19 years	**97.4**	1.1	(0.9 - 1.3)
20-29 years	**93.9**	1.1	(0.9 - 1.2)
30-39 years	**88.8**	ref	-
40-45 years	**119.6**	1.4	(1.0 - 1.8)
Prenatal Care			
First Trimester	**93.5**	ref	-
Second Trimester	**87.6**	0.9	(0.8 - 1.1)
Later or None	**96.0**	1.0	(0.9 - 1.2)
Maternal Alcohol Use			
Reported	**95.9**	1.0	(0.8 - 1.4)
Not Reported	**93.1**	ref	-
Maternal Tobacco Use			
Reported	**84.0**	0.9	(0.8 - 1.0)
Not Reported	**95.0**	ref	-

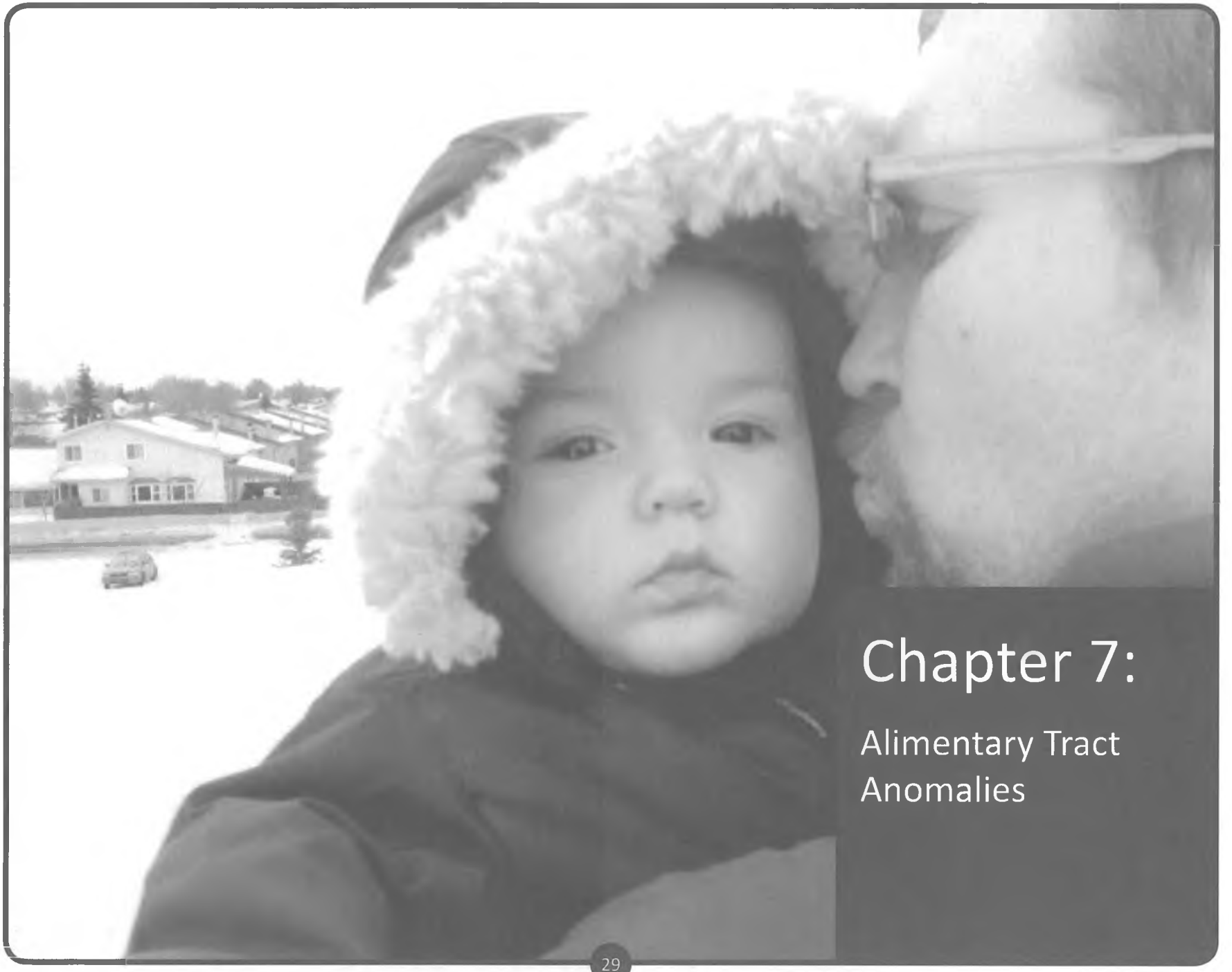
Genitourinary Anomalies

SPECIFIC ANOMALIES

The most common genitourinary birth defects in Alaska for birth years 1996-2011 were hypospadias/epispadias (0.5% of all live births) and obstructive genitourinary defects (0.4% of live births). These conditions together comprised 93% of the genitourinary birth defects reported during the specified time period. Because of the unusual increase from 1996 to 2011 in the prevalence of genitourinary birth defects overall, primarily composed of hypospadias/epispadias and obstructive genitourinary defects, the Alaska Birth Defects Registry (ABDR) is currently conducting an investigation in collaboration with subject matter experts for these specific anomalies.

Prevalence of Specific Genitourinary Anomalies
Alaska, 1996-2011





Chapter 7:

Alimentary Tract Anomalies

Alimentary Tract Anomalies

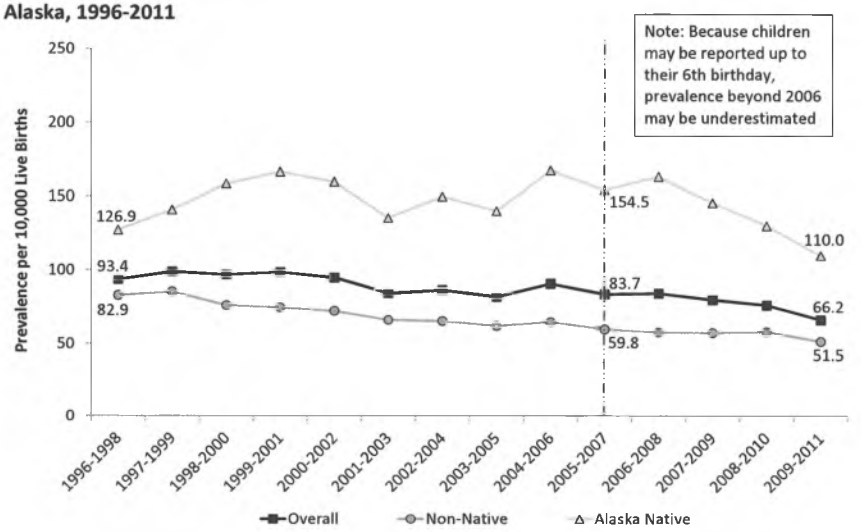
TRENDS AND DISTRIBUTION

Alimentary tract anomalies involve the oral cavity, pharynx, esophagus, stomach, and intestine. These birth defects are often referred to as orofacial and gastrointestinal anomalies. As a group, alimentary tract anomalies are some of the most common birth defects, often occurring in conjunction with other congenital anomalies. Birth defects may occur at multiple sites along the alimentary system and can be severe.

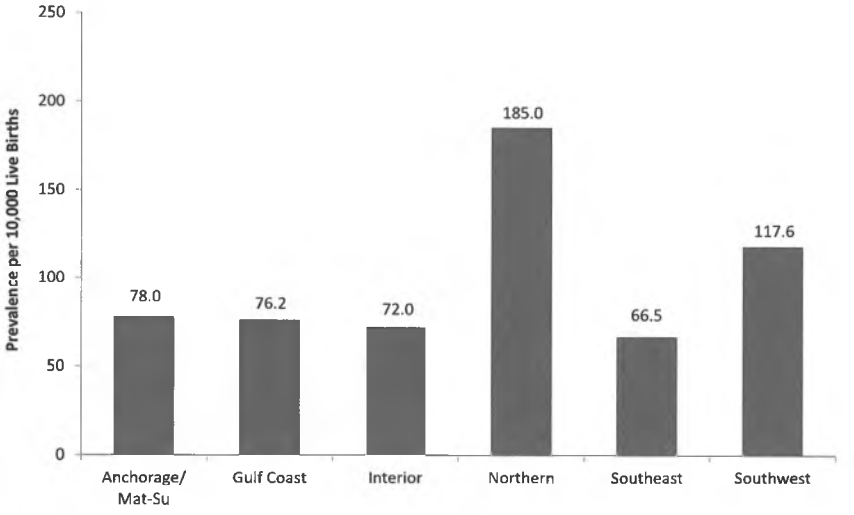
During birth years 1996-2011, the following trends and distributions were observed:

- Alimentary tract anomalies affected nearly 0.9% of Alaska live births annually.
- The overall prevalence of alimentary tract anomalies decreased among both Alaska Native and non-Native children.
- The prevalence of alimentary tract anomalies was higher among Alaska Native children when compared to non-Native children.
- The prevalence of alimentary tract anomalies was highest in the Northern region (1.9% of live births), followed by the Southwest region (1.2% of live births).

Prevalence of Alimentary Tract Anomalies by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Alimentary Tract Anomalies by Region
Alaska, 1996-2011



Alimentary Tract Anomalies

EPIDEMIOLOGICAL CHARACTERISTICS

The cause of most alimentary tract anomalies is unknown. Alimentary tract anomalies are believed to have a multi-factorial etiology with epigenetic components. Studies have shown links between alimentary tract anomalies and genetics, gene-environment interactions, environmental exposures, and maternal characteristics such as diet, medication use, and smoking. Oral clefts, the most common alimentary tract anomalies, were recently associated with use of topiramate, an anticonvulsant used to treat epilepsy, during pregnancy (10,28).

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with an alimentary tract anomaly for birth years 1996-2011:

- Males were 1.5 times more likely to be reported with an alimentary tract anomaly when compared to females.
- Children with low birth weights (< 2500 grams) were 2.6 times more likely to be reported with an alimentary tract anomaly when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were more than twice as likely to deliver a child with an alimentary tract anomaly when compared to white mothers.
- Teenage mothers and mothers ages 20-29 years were the most likely to deliver a baby with an alimentary tract anomaly.
- Mothers who reported alcohol or tobacco use during pregnancy were more likely to have a child with an alimentary tract anomaly when compared to mothers who did not report alcohol or tobacco use during pregnancy.

Prevalence of Alimentary Tract Anomalies by Selected Birth Characteristics
Alaska, 1996-2011

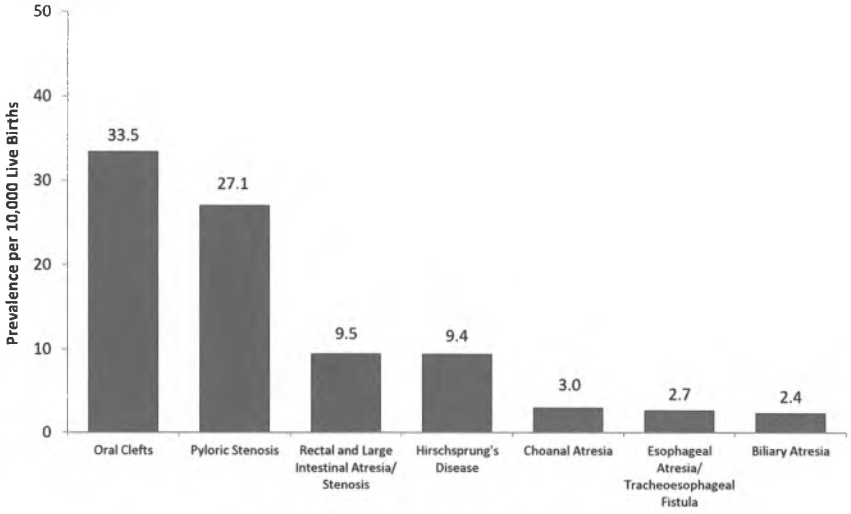
	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**66.4**	ref	-
Male	**102.1**	1.5	(1.4 - 1.7)
Birth Weight			
Low and Very Low	**199.5**	2.6	(2.2 - 3.0)
Normal	**77.7**	ref	-
Maternal Race			
White	**67.5**	ref	-
Alaska Native	**141.6**	2.1	(1.9 - 2.4)
Black	**53.5**	0.8	(0.6 - 1.1)
Asian or Pacific Islander	**56.4**	0.8	(0.6 - 1.1)
Maternal Ethnicity			
Hispanic	**64.4**	0.7	(0.6 - 1.0)
Non-Hispanic	**85.9**	ref	-
Maternal Age			
15-19 years	**127.9**	1.9	(1.6 - 2.2)
20-29 years	**85.5**	1.2	(1.1 - 1.4)
30-39 years	**69.0**	ref	-
40-45 years	**80.5**	1.2	(0.8 - 1.7)
Prenatal Care			
First Trimester	**82.1**	ref	-
Second Trimester	**97.3**	1.2	(1.0 - 1.4)
Later or None	**85.9**	1.0	(0.9 - 1.2)
Maternal Alcohol Use			
Reported	**131.3**	1.6	(1.2 - 2.0)
Not Reported	**83.3**	ref	-
Maternal Tobacco Use			
Reported	**138.8**	1.9	(1.7 - 2.1)
Not Reported	**73.9**	ref	-

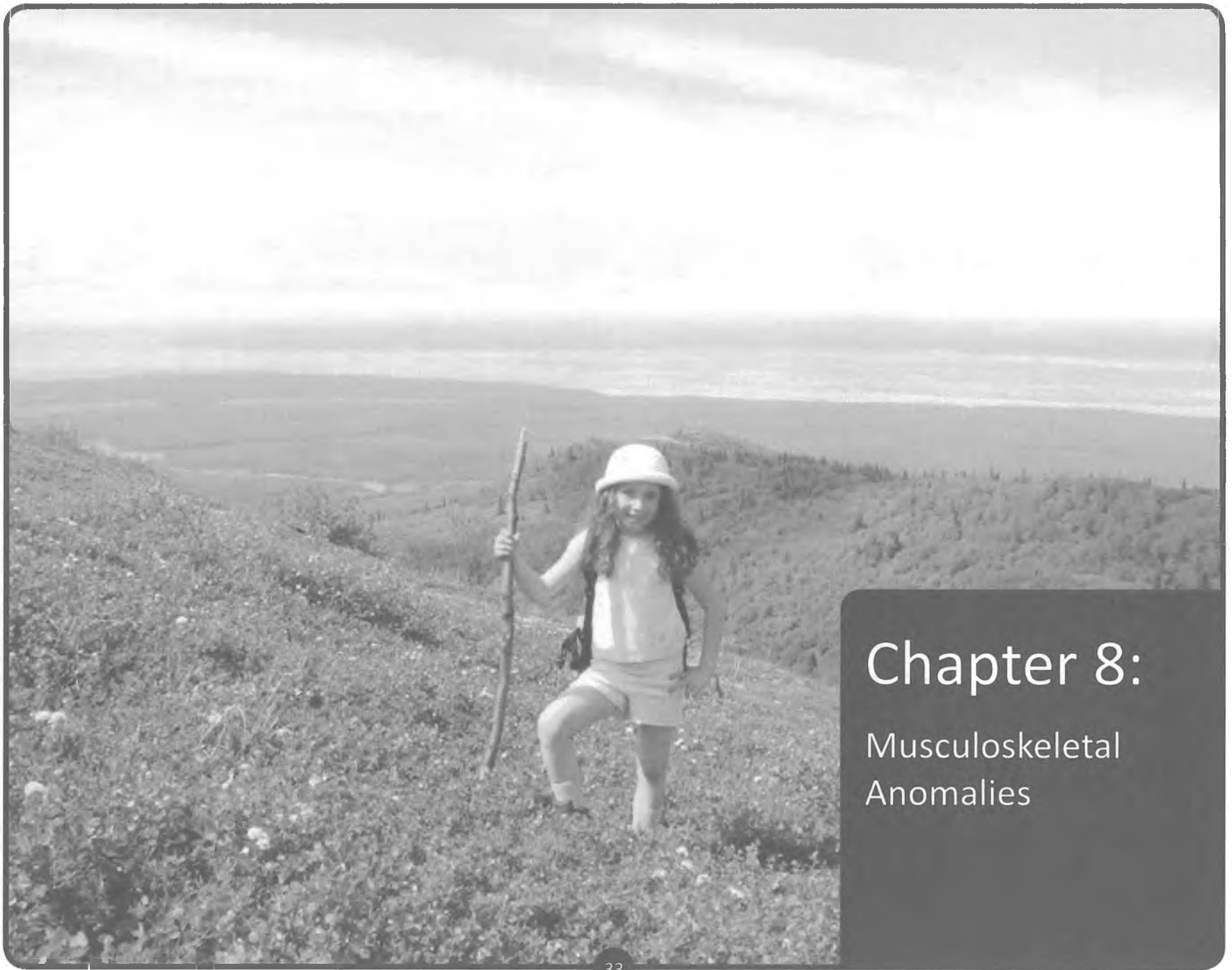
Alimentary Tract Anomalies

SPECIFIC ANOMALIES

The most common alimentary tract anomalies in Alaska for birth years 1996-2011 were oral clefts and pyloric stenosis (each condition representing approximately 0.3% of live births). These conditions together comprised nearly 70% of all alimentary tract anomalies reported during the specified time period.

Prevalence of Specific Alimentary Tract Anomalies
Alaska, 1996-2011





Chapter 8:

Musculoskeletal Anomalies

Musculoskeletal Anomalies

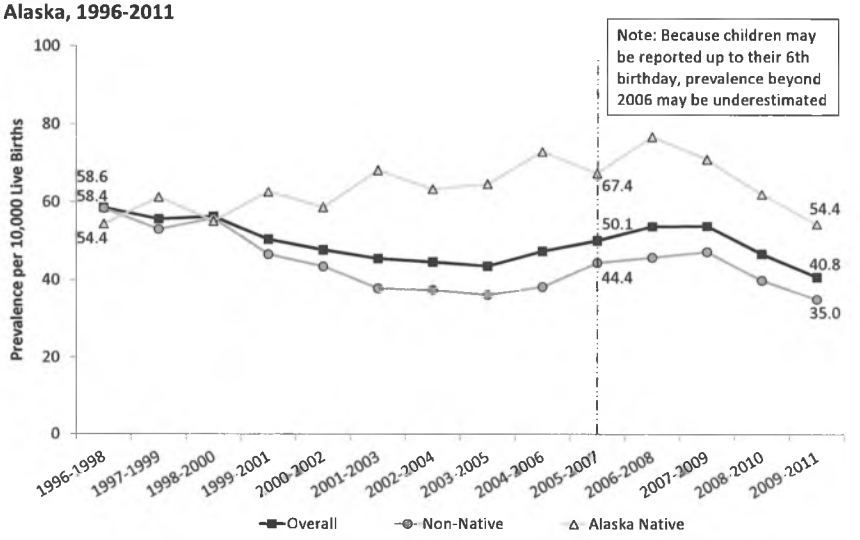
TRENDS AND DISTRIBUTION

Musculoskeletal anomalies include diverse congenital anomalies of the limbs, abdominal wall, and diaphragm. Major skeletal anomalies occur when one or more parts of a limb are missing or abbreviated (reduction deformities of the arms and legs) or when the hip joint capsule is so relaxed that it dislocates at birth (congenital hip dislocation). Abdominal wall anomalies are formed early in gestation when the wall fails to close properly, causing part of the gut to protrude outside the abdomen (gastroschisis or omphalocele). A diaphragmatic hernia occurs when there is an incomplete separation of the thorax (containing the heart and lungs) from the abdomen (containing the gastrointestinal organs).

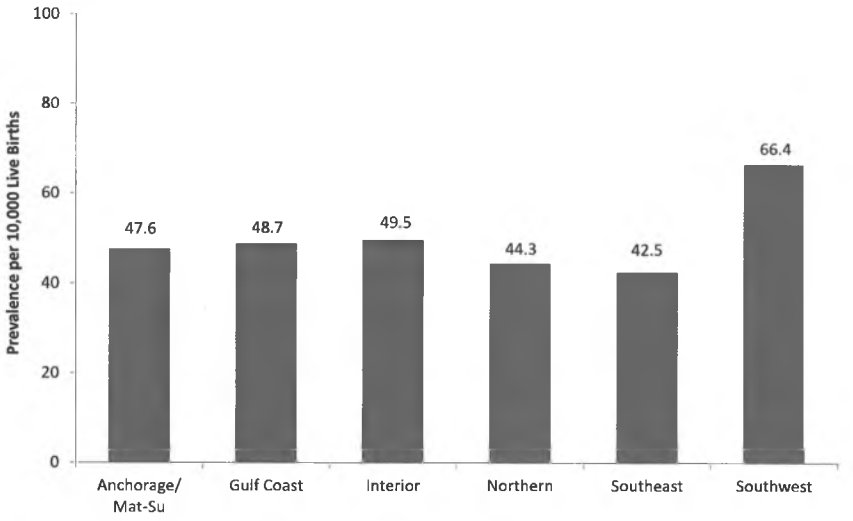
During birth years 1996-2011, the following trends and distributions were observed:

- Musculoskeletal anomalies affected nearly 0.5% of Alaska live births annually.
- The prevalence of musculoskeletal anomalies decreased among non-Native children, and remained steady among Alaska Native children.
- The prevalence of musculoskeletal anomalies was higher among Alaska Native children when compared to non-Native children.
- The prevalence of alimentary tract anomalies was highest in the Southwest region (0.7% of live births).

Prevalence of Musculoskeletal Anomalies by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Musculoskeletal Anomalies by Region
Alaska, 1996-2011



Musculoskeletal Anomalies

EPIDEMIOLOGICAL CHARACTERISTICS

There is a broad diversity of etiologies among the various musculoskeletal anomalies. For example, intrauterine position is an important factor in hip dysplasia. Gastroschisis and omphalocele, defects of the abdominal wall, have been associated with younger maternal age, alcohol and tobacco use, certain medications, infections, and overweight/obesity. Limb deficiencies have been associated with maternal diabetes, vascular compromise by amniotic bands or other constrictive forces, and exposure to certain medications (thalidomide was implicated in 5800 limb defects between 1958 and 1963). Chromosomal abnormalities can also cause musculoskeletal defects (10,29).

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with a musculoskeletal anomaly for birth years 1996-2011:

- Males were less likely to be reported with a musculoskeletal anomaly when compared to females.
- Children with low birth weights (< 2500 grams) were 4 times more likely to be reported with a musculoskeletal anomaly when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were 1.4 times more likely to deliver a child with a musculoskeletal anomaly when compared to white mothers.
- Teenage mothers were more likely to deliver a baby with a musculoskeletal anomaly when compared to mothers ages 30-39.
- Mothers who reported tobacco use during pregnancy were more likely to deliver a child with a musculoskeletal anomaly when compared to mothers who did not report tobacco use during pregnancy.

Prevalence of Musculoskeletal Anomalies by Selected Birth Characteristics
Alaska, 1996-2011

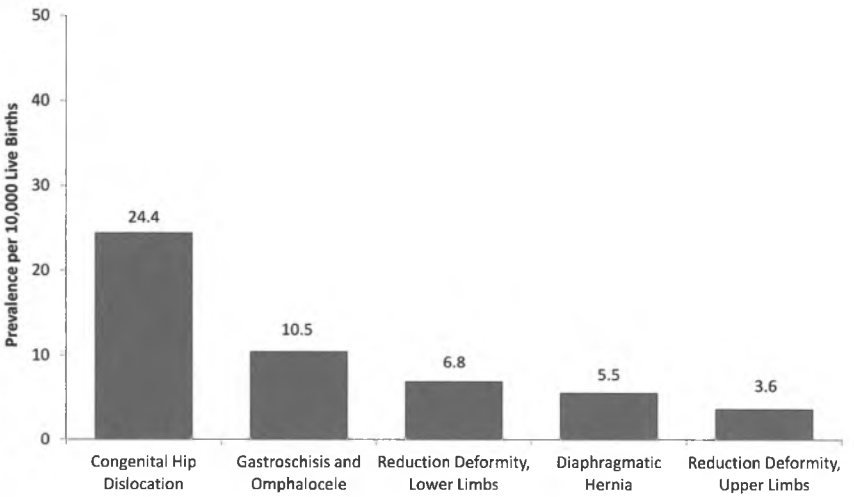
	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**57.5**	ref	-
Male	**40.8**	0.7	(0.6 - 0.8)
Birth Weight			
Low and Very Low	**165.2**	4.0	(3.4 - 4.8)
Normal	**41.7**	ref	-
Maternal Race			
White	**45.2**	ref	-
Alaska Native	**62.5**	1.4	(1.2 - 1.6)
Black	**34.7**	0.8	(0.5 - 1.2)
Asian or Pacific Islander	**35.9**	0.8	(0.6 - 1.1)
Maternal Ethnicity			
Hispanic	**60.4**	1.3	(0.9 - 1.7)
Non-Hispanic	**48.2**	ref	-
Maternal Age			
15-19 years	**65.7**	1.4	(1.2 - 1.8)
20-29 years	**48.1**	1.1	(0.9 - 1.2)
30-39 years	**45.6**	ref	-
40-45 years	**36.8**	0.8	(0.5 - 1.3)
Prenatal Care			
First Trimester	**47.3**	ref	-
Second Trimester	**56.8**	1.2	(1.0 - 1.5)
Later or None	**49.5**	1.0	(0.9 - 1.2)
Maternal Alcohol Use			
Reported	**45.9**	0.9	(0.6 - 1.4)
Not Reported	**48.8**	ref	-
Maternal Tobacco Use			
Reported	**54.7**	1.2	(1.0 - 1.4)
Not Reported	**47.4**	ref	-

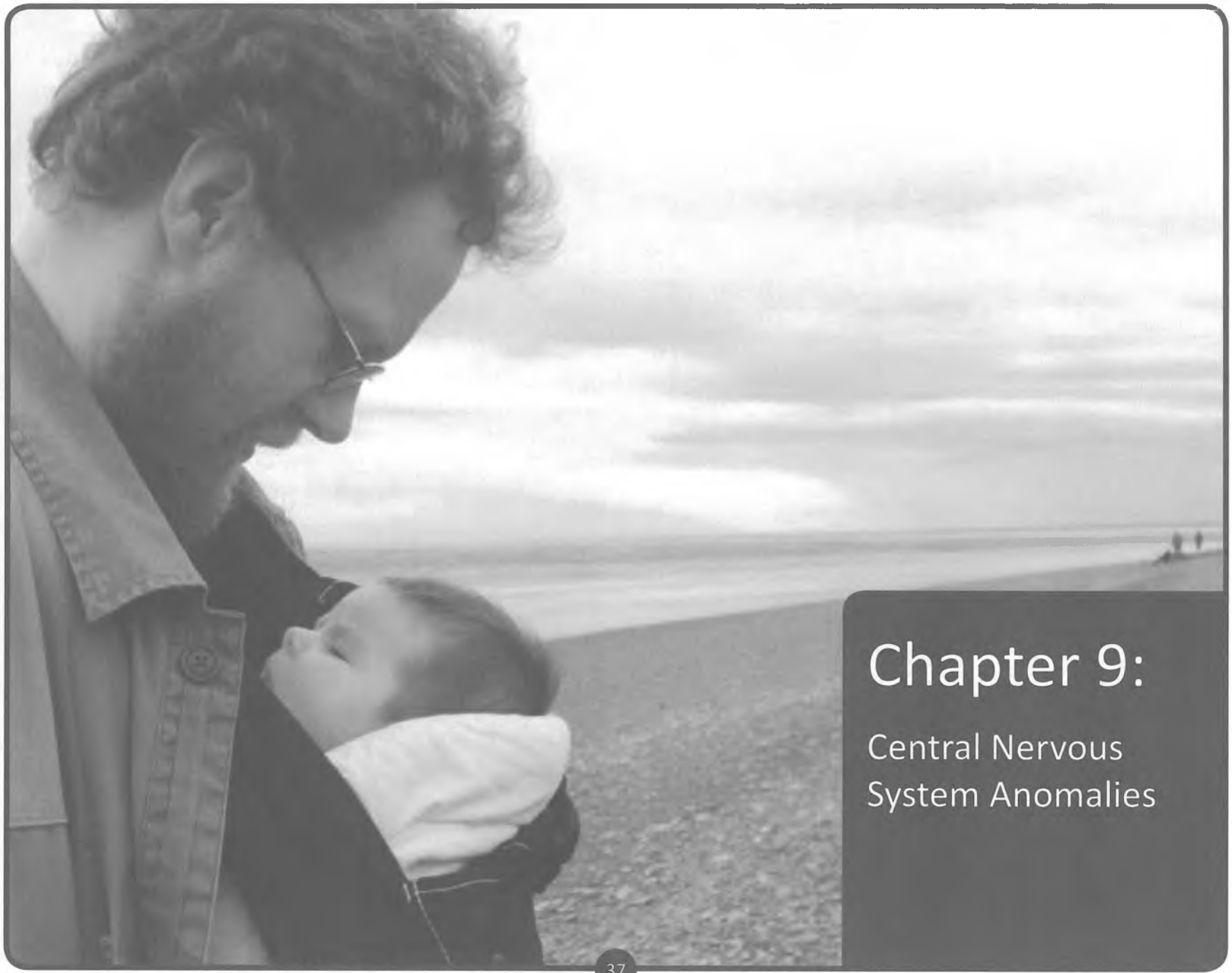
Musculoskeletal Anomalies

SPECIFIC ANOMALIES

The most common musculoskeletal anomalies in Alaska for birth years 1996-2011 were congenital hip dislocations (0.2% of live births) and gastroschisis and omphalocele (0.1% of live births). These conditions together comprised approximately 69% of all musculoskeletal anomalies reported during the specified time period.

Prevalence of Specific Musculoskeletal Anomalies
Alaska, 1996-2011





Chapter 9:

Central Nervous System Anomalies

Central Nervous System Anomalies

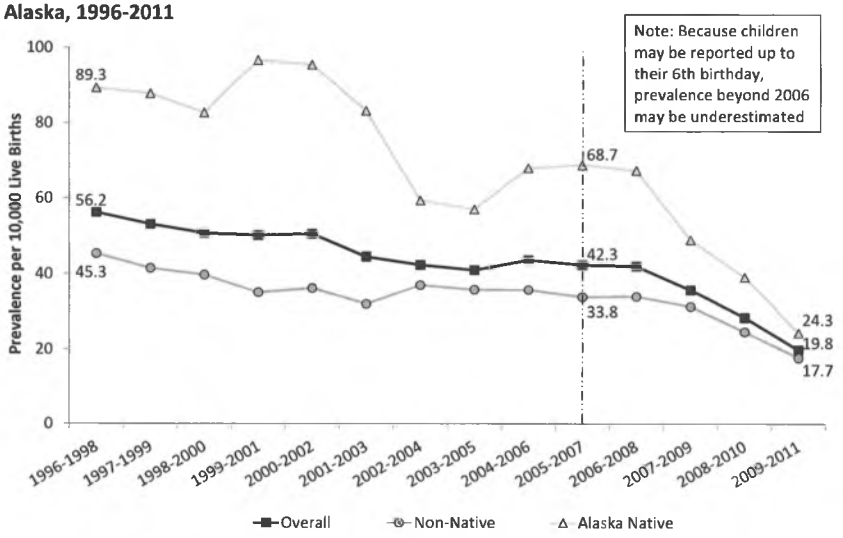
TRENDS AND DISTRIBUTION

The brain and spinal cord make up the central nervous system. Structural anomalies of the central nervous system are typically severe, and many result in death of the child. Because of the severity of these anomalies, some infants are not carried to term and, therefore, estimates of birth prevalence may underestimate the frequency of central nervous system anomalies.

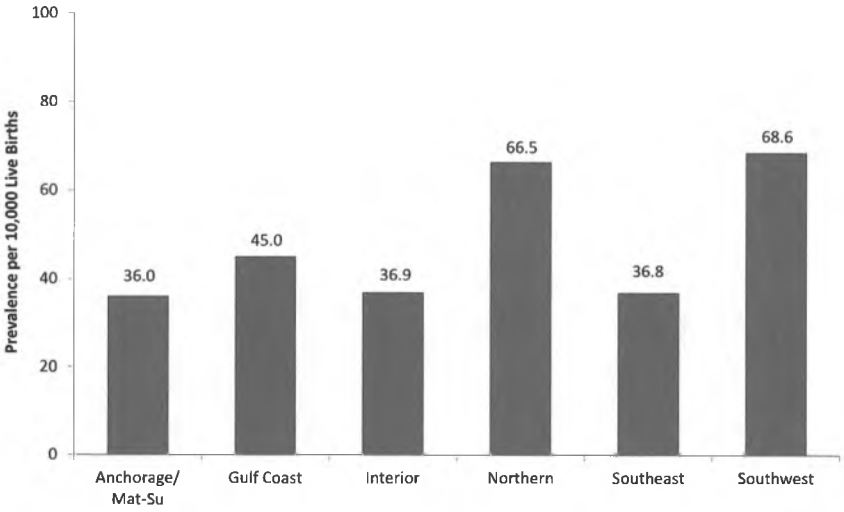
During birth years 1996-2011, the following trends and distributions were observed:

- Central nervous system anomalies affected approximately 0.4% of Alaska live births annually.
- The prevalence of central nervous system anomalies decreased overall, and most dramatically among Alaska Native children.
- The prevalence of central nervous system anomalies was higher among Alaska Native children when compared to non-Native children.
- The prevalence of central nervous system anomalies was highest in the Northern and Southwest regions (0.7% of live births).

Prevalence of Central Nervous System Anomalies by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Central Nervous System Anomalies by Region
Alaska, 1996-2011



Central Nervous System Anomalies

EPIDEMIOLOGICAL CHARACTERISTICS

Birth defects of the central nervous system are thought to be caused by interacting genetic and environmental factors. The exact role that these factors play in causing central nervous system defects is still unknown. Low intake of folic acid prior to pregnancy and in early pregnancy has been shown to increase the risk of having a child born with a neural tube defect (a subset of central nervous system anomalies). The Centers for Disease Control and Prevention (CDC) recommends 400 micrograms of folic acid every day for women who are pregnant or planning to become pregnant to reduce the risk of neural tube defects (10).

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with a central nervous system anomaly for birth years 1996-2011:

- Males were slightly more likely to be reported with a central nervous system anomaly when compared to females.
- Children with low birth weights (< 2500 grams) were nearly 8 times more likely to be reported with a central nervous system anomaly when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were twice as likely to deliver a child with a central nervous system anomaly when compared to white mothers .
- Teenage mothers and mothers ages 40-45 years were the most likely to deliver a baby with a central nervous system anomaly.
- Mothers who reported alcohol and tobacco use during pregnancy were more likely to deliver a child with a central nervous system anomaly when compared to mothers who did not report alcohol and tobacco use during pregnancy.

Prevalence of Central Nervous System Anomalies by Selected Birth Characteristics
Alaska, 1996-2011

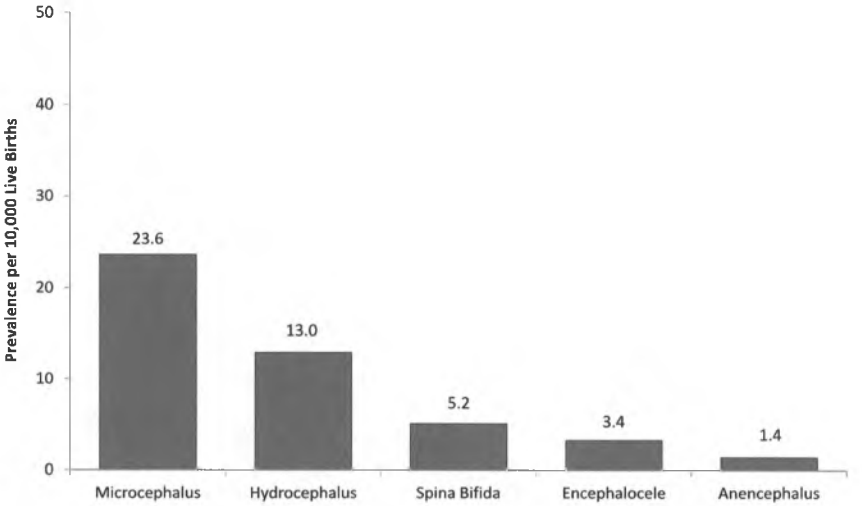
	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**38.6**	ref	-
Male	**43.9**	1.1	(1.0 - 1.3)
Birth Weight			
Low and Very Low	**226.5**	7.8	(6.6 - 9.1)
Normal	**29.7**	ref	-
Maternal Race			
White	**32.6**	ref	-
Alaska Native	**65.6**	2.0	(1.7 - 2.4)
Black	**40.5**	1.2	(0.8 - 1.8)
Asian or Pacific Islander	**35.1**	1.1	(0.8 - 1.5)
Maternal Ethnicity			
Hispanic	**28.2**	0.7	(0.4 - 1.1)
Non-Hispanic	**40.9**	ref	-
Maternal Age			
15-19 years	**61.0**	1.7	(1.4 - 2.2)
20-29 years	**38.9**	1.1	(0.9 - 1.3)
30-39 years	**35.6**	ref	-
40-45 years	**57.5**	1.6	(1.1 - 2.5)
Prenatal Care			
First Trimester	**35.7**	ref	-
Second Trimester	**53.0**	1.5	(1.2 - 1.6)
Later or None	**49.3**	1.4	(1.2 - 1.6)
Maternal Alcohol Use			
Reported	**129.2**	3.4	(2.6 - 4.4)
Not Reported	**38.7**	ref	-
Maternal Tobacco Use			
Reported	**74.0**	2.1	(1.8 - 2.5)
Not Reported	**34.6**	ref	-

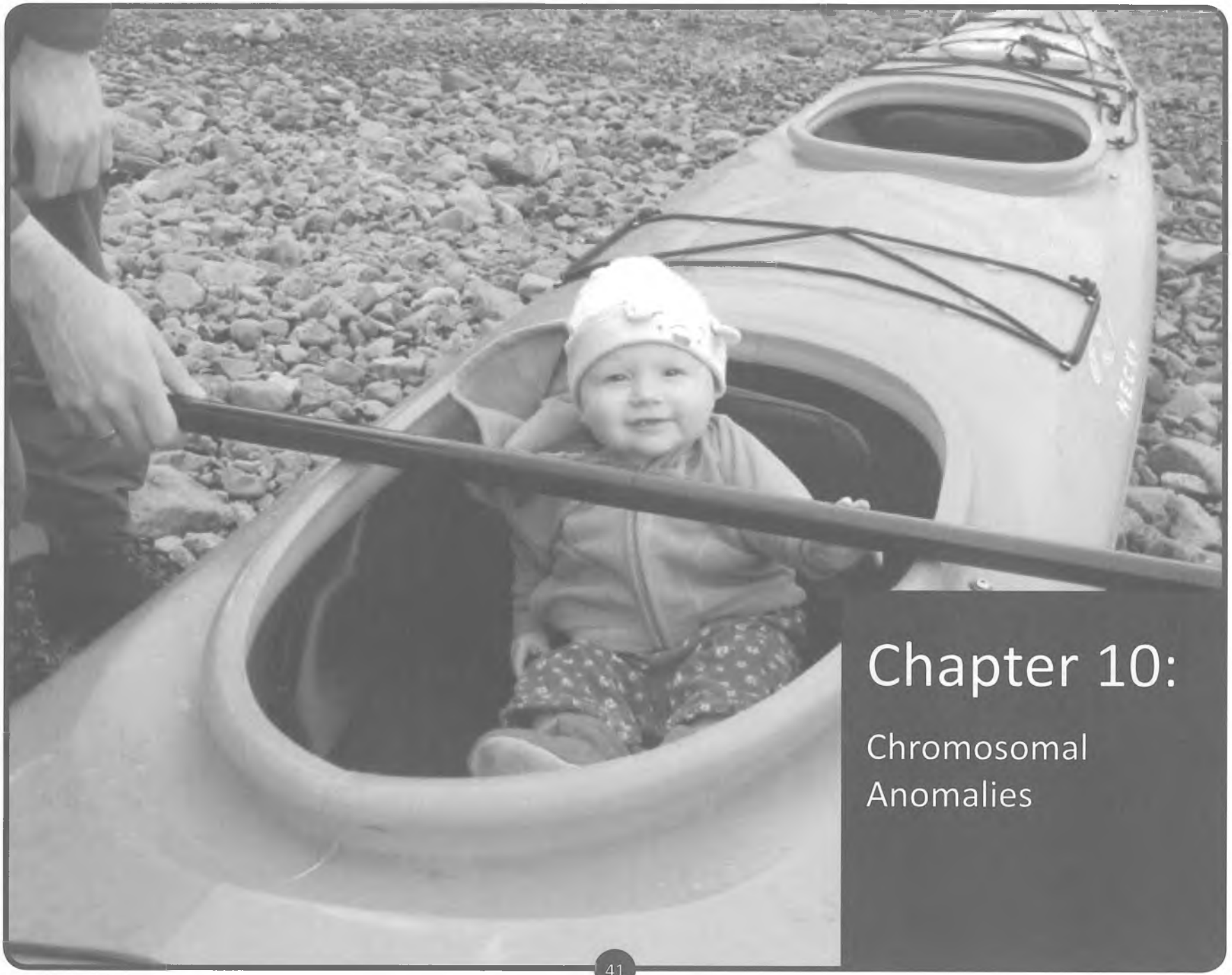
Central Nervous System Anomalies

SPECIFIC ANOMALIES

The most common central nervous system anomalies in Alaska for birth years 1996-2011 were microcephalus (0.2% of live births) and hydrocephalus (0.1% of live births). These two conditions together comprised approximately 79% of all central nervous system anomalies reported during the specified time period. Neural tube defects, which include spina bifida, encephalocele, and anencephalus, accounted for the remaining 21% of central nervous system anomalies.

Prevalence of Specific Central Nervous System Anomalies
Alaska, 1996-2011





Chapter 10:

Chromosomal Anomalies

Chromosomal Anomalies

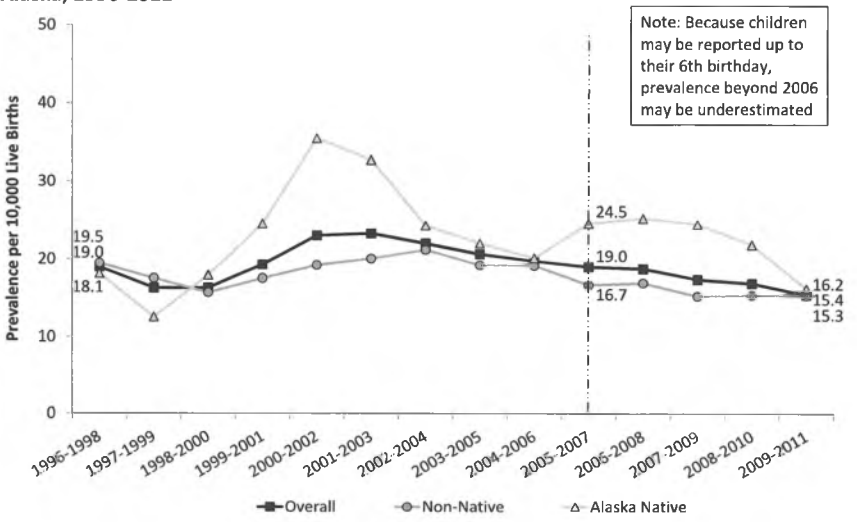
TRENDS AND DISTRIBUTION

Birth defects categorized as chromosomal anomalies refer to those that are caused by abnormal numbers of chromosomes, or deletions or damage to the structure of the chromosome. A trisomy is a common type of chromosomal anomaly, and occurs when an infant has an extra copy of a chromosome, forming a triad instead of a pair. A characteristic syndrome results, depending on which chromosome pair was affected, and may be life threatening.

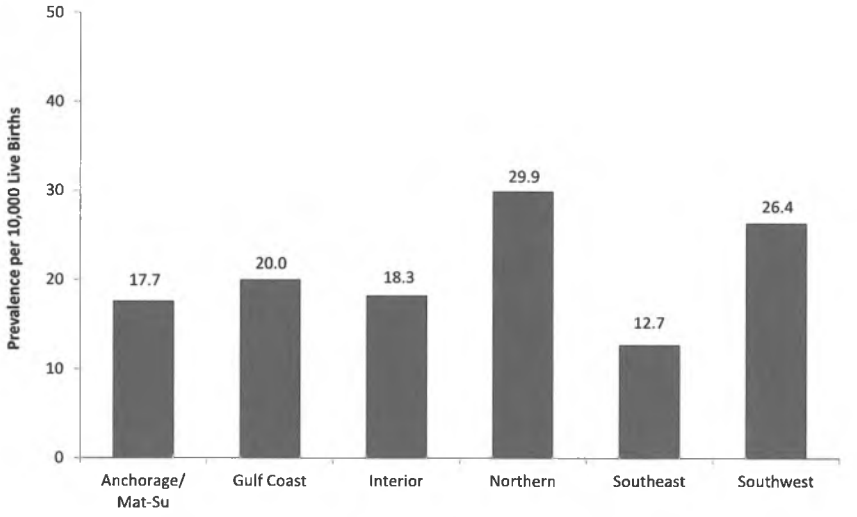
During birth years 1996-2011, the following trends and distributions were observed:

- Chromosomal anomalies affected approximately 0.2% of Alaska live births annually.
- The overall prevalence of chromosomal anomalies remained relatively consistent among both Alaska Native and non-Native children.
- The prevalence of chromosomal anomalies was highest in the Northern and Southwest region (0.3% of live births).

Prevalence of Chromosomal Anomalies by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Chromosomal Anomalies by Region
Alaska, 1996-2011



Chromosomal Anomalies

EPIDEMIOLOGICAL CHARACTERISTICS

Most causes of chromosomal anomalies, including trisomy, are unknown. No studies have successfully identified behavioral or environmental risk factors, but risk has been associated with older maternal age. Though there is currently no known way to prevent chromosomal anomalies, the Centers for Disease Control and Prevention (CDC) recommends optimizing conditions for a healthy pregnancy, such as taking a daily multivitamin with at least 400 micrograms of folic acid, not smoking, and not drinking during pregnancy (10).

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with a chromosomal anomaly for birth years 1996-2011:

- Children with low birth weights (< 2500 grams) were more than 6 times more likely to be reported with a chromosomal anomaly when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were slightly more likely to deliver a child with a chromosomal anomaly when compared to white mothers.
- Mothers ages 40-45 years were more than 5 times more likely to deliver a child with a chromosomal anomaly when compared to mothers ages 30-39.

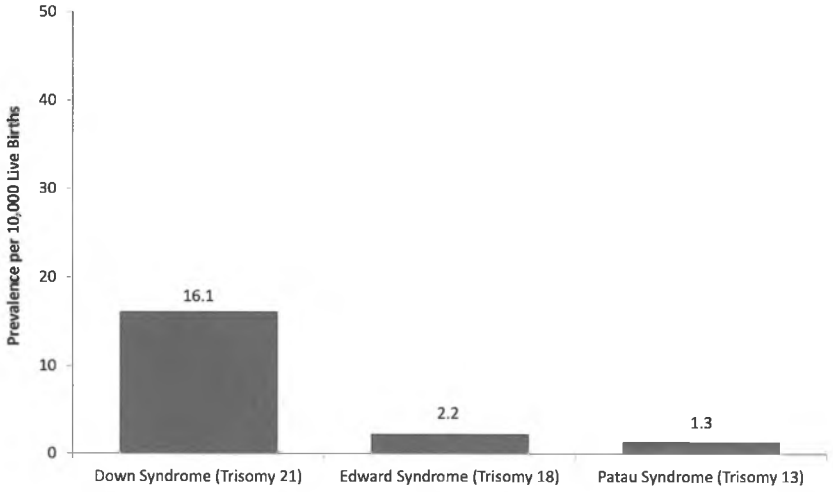
Prevalence of Chromosomal Anomalies by Selected Birth Characteristics
Alaska, 1996-2011

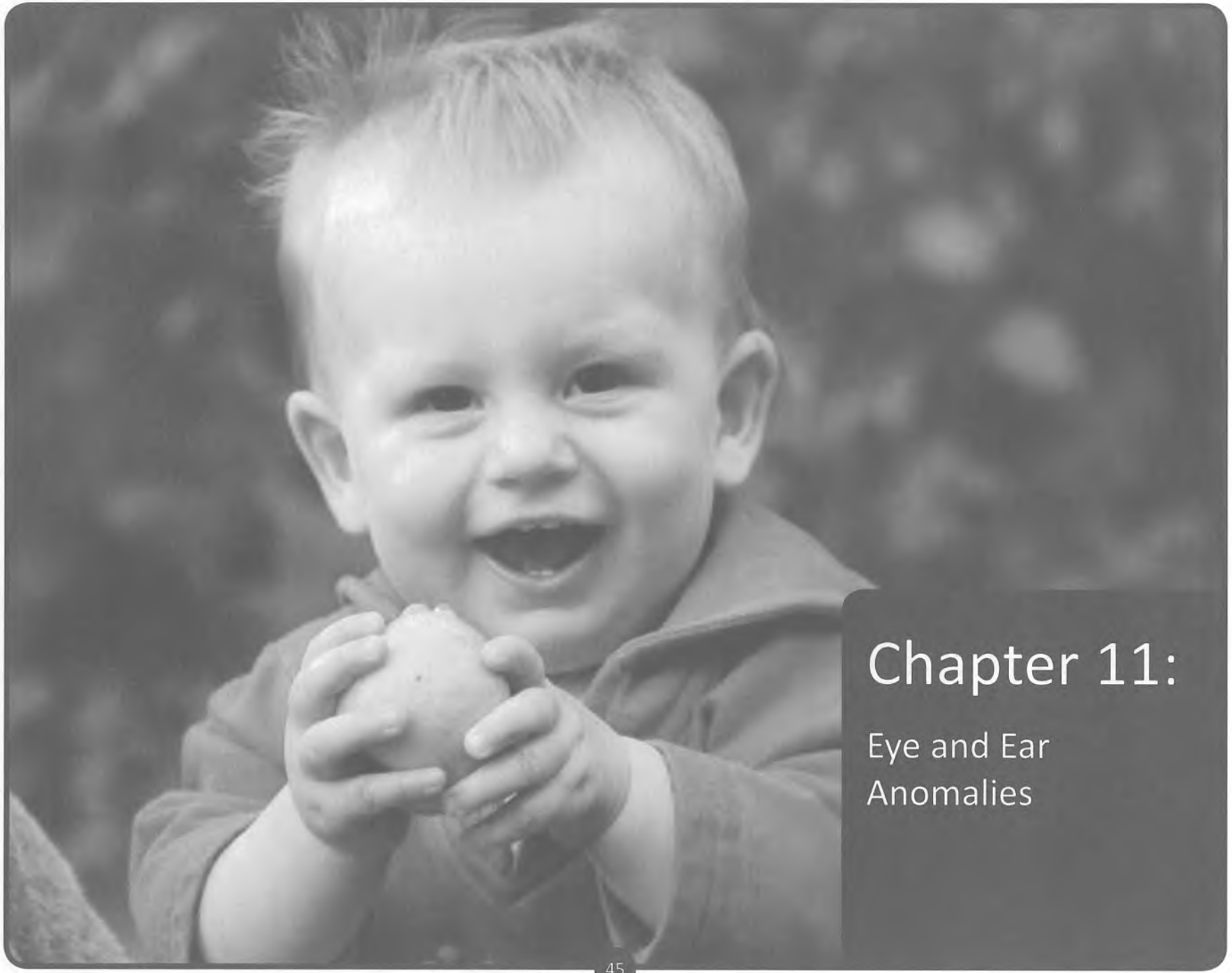
	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**20.2**	ref	-
Male	**17.8**	0.9	(0.7 - 1.1)
Birth Weight			
Low and Very Low	**91.4**	6.4	(5.0 - 8.2)
Normal	**14.3**	ref	-
Maternal Race			
White	**17.7**	ref	-
Alaska Native	**22.4**	1.3	(1.0 - 1.6)
Black	**17.4**	1.0	(0.5 - 1.8)
Asian or Pacific Islander	**18.8**	1.1	(0.7 - 1.7)
Maternal Ethnicity			
Hispanic	**21.5**	1.2	(0.7 - 2.0)
Non-Hispanic	**18.1**	ref	-
Maternal Age			
15-19 years	**13.5**	0.6	(0.4 - 0.9)
20-29 years	**11.9**	0.5	(0.4 - 0.6)
30-39 years	**23.8**	ref	-
40-45 years	**124.2**	5.3	(3.8 - 7.3)
Prenatal Care			
First Trimester	**17.9**	ref	-
Second Trimester	**22.7**	1.3	(0.9 - 1.8)
Later or None	**19.7**	1.1	(0.9 - 1.4)
Maternal Alcohol Use			
Reported	**27.1**	1.5	(0.8 - 2.6)
Not Reported	**18.4**	ref	-
Maternal Tobacco Use			
Reported	**17.5**	0.9	(0.7 - 1.3)
Not Reported	**19.0**	ref	-

SPECIFIC ANOMALIES

Three trisomies are classified as major anomalies. These are trisomy 13 (Patau syndrome), trisomy 18 (Edward syndrome), and trisomy 21 (Down syndrome). The most common chromosomal anomaly in Alaska for birth years 1996-2011 was trisomy 21 (0.16% of live births). Trisomy 21 accounted for 82% of all chromosomal anomalies reported during the specified time period. Trisomy 18 and trisomy 13 occurred in less than 0.03% of all live births.

Prevalence of Specific Chromosomal Anomalies
Alaska, 1996-2011





Chapter 11:

Eye and Ear Anomalies

Eye and Ear Anomalies

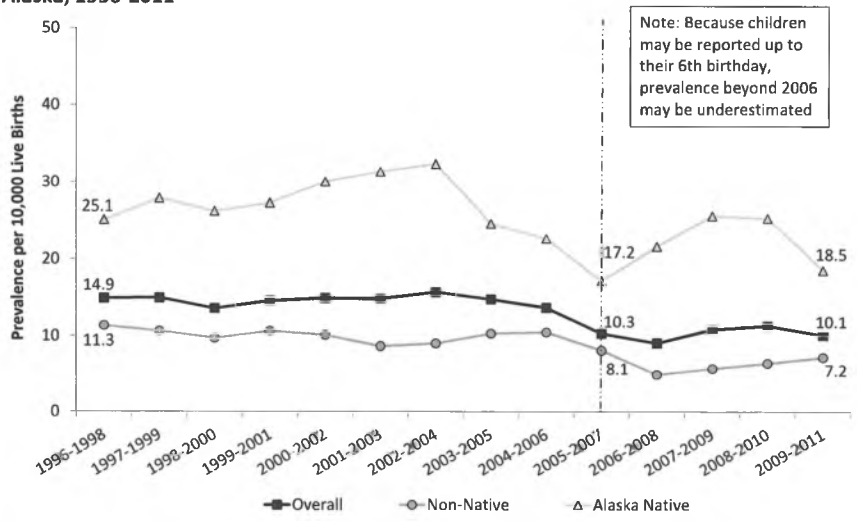
TRENDS AND DISTRIBUTION

Major birth defects of the eye and ear include: aniridia, absent or incomplete iris; anophthalmia, the absence of the eye (specifically, the absence of the globe and ocular tissue from the orbit); microphthalmia, an abnormally small eye; congenital cataract, an opaque lens of the eye; anotia, the absence of an ear; and microtia, an abnormally small ear.

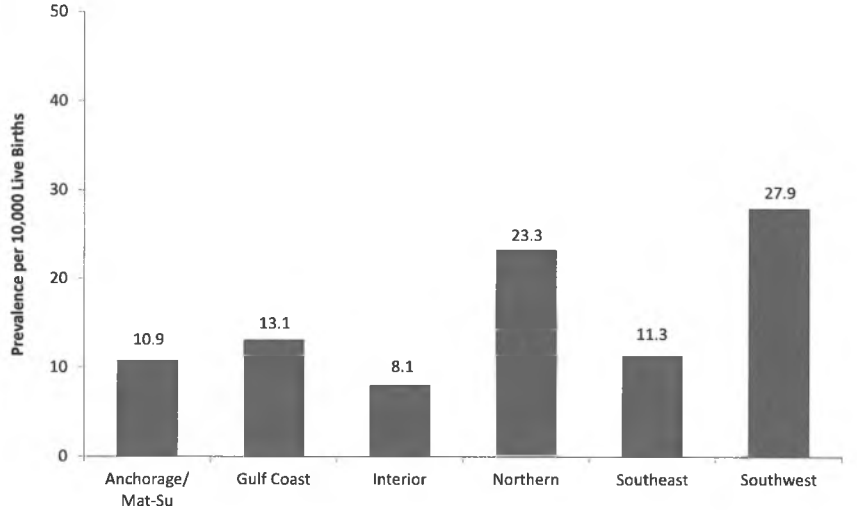
During birth years 1996-2011, the following trends and distributions were observed:

- Eye and ear anomalies affected approximately 0.1% of Alaska live births annually.
- The overall prevalence of eye and ear anomalies decreased slightly among both Alaska Native and non-Native children.
- The prevalence of eye and ear anomalies was higher among Alaska Native children when compared to non-Native children.
- The prevalence of eye and ear anomalies was highest in the Southwest region (0.3% of live births), followed by the Northern region (0.2% of live births).

Prevalence of Eye and Ear Anomalies by Birth Year and Alaska Native Status
Alaska, 1996-2011



Prevalence of Eye and Ear Anomalies by Region
Alaska, 1996-2011



Eye and Ear Anomalies

EPIDEMIOLOGICAL CHARACTERISTICS

Eye and ear anomalies may occur in isolation or as part of a syndrome, and many have a genetic etiology. Eye anomalies can affect the normal appearance of the eye or result in poor vision. Ear anomalies can affect the external, middle, or inner ear. Fetal exposure to the rubella virus (German measles) can lead to congenital rubella syndrome, which, along with cardiovascular anomalies and developmental delay, is associated with eye and ear anomalies such as cataracts and hearing impairment (10,29).

Unadjusted risk factor analysis revealed the following epidemiological characteristics for Alaskan children reported with an eye or ear anomaly for birth years 1996-2011:

- Children with low birth weights (< 2500 grams) were nearly 9 times more likely to be reported with an eye or ear anomaly when compared to children with normal birth weights (between 2500 and 4500 grams).
- Alaska Native mothers were twice as likely to deliver a child with an eye or ear anomaly when compared to white mothers.
- Mothers ages 40-45 years were nearly twice as likely to deliver a child with an eye or ear anomaly when compared to mothers ages 30-39 years.
- Mothers who reported alcohol or tobacco use during pregnancy were 1.6 times more likely to deliver a child with an eye or ear anomaly when compared to mothers who did not report alcohol or tobacco use during pregnancy.

Prevalence of Eye and Ear Anomalies by Selected Birth Characteristics
Alaska, 1996-2011

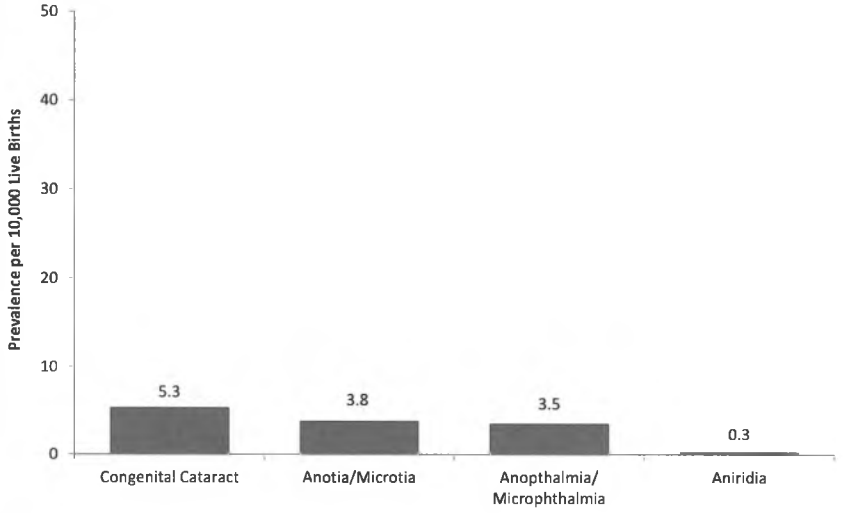
	Prevalence per 10,000 Live Births	Prevalence Ratio	95% CI
Child Sex			
Female	**250.1**	ref	-
Male	**233.4**	0.9	(0.9 - 1.0)
Birth Weight			
Low and Very Low	**942.2**	8.7	(8.0 - 9.4)
Normal	**117.5**	ref	-
Maternal Race			
White	**191.9**	ref	-
Alaska Native	**376.9**	2.0	(1.9 - 2.1)
Black	**219.9**	1.1	(1.0 - 1.4)
Asian or Pacific Islander	**209.5**	1.1	(1.0 - 1.3)
Maternal Ethnicity			
Hispanic	**228.2**	0.9	(0.8 - 1.1)
Non-Hispanic	**240.9**	ref	-
Maternal Age			
15-19 years	**270.5**	1.2	(1.1 - 1.4)
20-29 years	**239.3**	1.1	(1.0 - 1.2)
30-39 years	**223.4**	ref	-
40-45 years	**370.2**	1.7	(1.4 - 2.0)
Prenatal Care			
First Trimester	**223.2**	ref	-
Second Trimester	**263.8**	1.2	(1.1 - 1.3)
Later or None	**273.0**	1.2	(1.1 - 1.3)
Maternal Alcohol Use			
Reported	**381.4**	1.6	(1.4 - 1.9)
Not Reported	**235.6**	ref	-
Maternal Tobacco Use			
Reported	**342.3**	1.6	(1.5 - 1.7)
Not Reported	**219.5**	ref	-

Eye and Ear Anomalies

SPECIFIC ANOMALIES

Eye and ear anomalies are some of the least common major congenital anomalies. There are four specific eye or ear anomalies that are classified as major anomalies: congenital cataract (0.05% of live births), anotia/microtia (0.04% of live births), anopthalmia/microphthalmia (0.04% of live births), and aniridia (less than 0.01% of live births).

Prevalence of Specific Eye and Ear Anomalies
Alaska, 1996-2011



Appendices

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GLOSSARY

Active Surveillance: Surveillance system in which project staff make periodic field visits to health care facilities such as clinics and hospitals to identify new cases of a health outcome.

Alaska Birth Defects Registry (ABDR): A surveillance program that was established in 1996 under Alaska statute 7 AAC 27.012 requiring health care providers, hospitals, and other health care facilities to report to the ABDR when they have cared for a child with a birth defect listed as a *Condition Reportable to Public Health.*

Alaska Maternal and Child Health Data Book: A recurring publication produced by the Maternal and Child Health Epidemiology Unit of the Section of Women's, Children's, and Family Health of the State of Alaska Department of Health and Social Services' Division of Public Health that provides reliable data on maternal and child health issues in the state of Alaska.

Alaska Native: For the purposes of this data book, "Alaska Native" refers to Alaska Native and American Indian people who reside in Alaska, as identified by maternal race reported on the birth certificate.

Alcohol Related Birth Defects (ARBD): Collective health outcomes that can occur as a result of a person being exposed to alcohol in utero.

Alimentary Tract Anomalies: Congenital anomalies involving the oral cavity, pharynx, esophagus, stomach, and intestine.

Anencephalus: Congenital absence of the skull and brain.

Aniridia: Congenital absence of the iris of the eye.

Anopthalmia: Congenital absence of the eye globe.

Anotia: Congenital absence of the ear.

Aortic Valve Stenosis: Congenital heart defect characterized by aortic valve narrowing reducing the flow of blood.

Association: State in which two attributes occur together either more or less often than expected by chance. Association does not necessarily indicate causation.

Atrial Septal Defect: Congenital heart defect characterized by one or more openings in the atrial septum.

Atrioventricular Septal Defect (formerly termed Endocardial Cushion Defect): Congenital heart defect characterized by a combined atrial and ventricular septal defect, and common atrioventricular valve (instead of distinct tricuspid and mitral valves).

Bias: Deviation of results or inferences from the truth, or processes leading to such systematic deviation. Any trend in the collection, analysis, interpretation, publication, or review of data that can lead to conclusions that are systematically different from the truth.

Biliary Atresia: Congenital absence of the ducts in the biliary tract.

Birth Year: The year in which a child was born (versus "Report Year").

Bladder Extrophy: Congenital exposure of the bladder mucosa caused by incomplete closure of the anterior bladder wall and the abdominal cavity.

Cardiovascular Anomalies: Congenital anomalies of the heart or great vessels present at birth.

Case Fatality Rate: The percentage of people diagnosed as having a specified health outcome who die within a certain time after diagnosis.

Case Verification: A form of active surveillance in which program staff make periodic field visits to health care facilities such as clinics and hospitals to confirm cases of a reported major congenital anomaly by analyzing medical records. Also "Medical Records Abstraction."

Causation: An identified exposure that directly affects a specified health outcome (versus "Association").

Central Nervous System Anomalies: Congenital anomalies of the brain and spinal cord.

Choanal Atresia: Congenital absence of the passageway between the nose and pharynx due to a thick bone or thin "membranous" bone.

Chromosomal Anomalies: Congenital anomalies resulting from abnormal numbers of chromosomes, or deletions or damage to the structure of the chromosome.

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Coarctation of the Aorta: Congenital heart defect characterized by narrowing of the descending aorta.

Cohort: For the purposes of this data book, a group of people born during a particular period or year is called a birth cohort.

Common Truncus: Congenital heart defect characterized by a single great arterial trunk instead of a separate aorta and pulmonary artery. Commonly known as truncus arteriosis.

Confidence Interval: A range of values for a variable of interest constructed so that if the procedure is used over and over, a certain percentage of the intervals will contain the true parameter value. For purposes of this data book, 95% confidence intervals were used alongside prevalence ratios.

Confounding Variable: An exposure or other characteristic that may influence a determination of causality. A confounding variable can be both a risk factor for the health outcome as well as associated with the exposure in question.

Congenital Cataract: Congenital clouding of the lens of the eye.

Congenital Hip Dislocation: Congenital dislocation of one or both hips.

Crude Birth Rate: The number of live births occurring among the population of a given geographical area during a given year.

Demographic/Epidemiological Characteristic: An exposure or other characteristic being observed or measured that is hypothesized to influence a health outcome. Also "Risk Factor."

Diaphragmatic Hernia: Congenital defect of the muscular diaphragm resulting in herniation of the abdominal contents into the chest.

Down Syndrome: Distinctive and common chromosome abnormality syndrome caused by an extra copy of chromosome 21. Can be complete (Trisomy 21), attached to another chromosome (translocation), or mixed with cells containing normal chromosomes (mosaic). Also "Trisomy 21."

Ebstein's Anomaly: Congenital heart defect characterized by downward displacement of the tricuspid valve into the right ventricle.

Edwards Syndrome: Chromosomal abnormality caused by an extra chromosome 18. Also "Trisomy 18."

Encephalocele: Congenital defect of the skull resulting in herniation of the brain.

Epispadias: Congenital defect of the genitals where the opening of the urethra is located on the upper side of the penis in boys and between the clitoris and labia in girls.

Esophageal Atresia/Tracheoesophageal Fistula: Congenital discontinuity of the lumen of the esophagus. Usually associated with a tracheoesophageal fistula, which is an abnormal connection between the esophagus and trachea.

Etiology: Source or cause of a specified health outcome.

Exposure: A risk factor or characteristic that can affect a specified health outcome.

Eye and Ear Anomalies: Congenital anomalies affecting the eyes or ears.

Frequency: The pattern of health-related characteristics and events in a population.

Gastroschisis: Congenital opening of the abdominal wall with protrusion of the abdominal contents. Can be distinguished from omphalocele by location usually to the right of the umbilicus.

Genitourinary Anomalies: Congenital anomalies of the urinary tract and reproductive system.

Geographic Distribution: The six labor market regions designated by the Alaska Department of Labor and Workforce Development that includes Anchorage/ Matanuska-Susitna, Gulf Coast, Interior, Northern, Southeast, and Southwest regions of Alaska. Also "Region."

Health Outcome: For purposes of this data book, the health outcome being analyzed is birth defects.

Hirschsprung's Disease (Congenital Megacolon): Congenital aganglionic megacolon (enlarged colon) due to absent nerves in the wall of the colon.

Hydrocephalus: Accumulation of fluid within the spaces of the brain. Can be congenital or acquired.

Hypoplastic Left Heart Syndrome: Congenital heart defect characterized by extreme smallness of left-sided structures. Classically, aortic valve/mitral valve atresia or marked hypoplasia, ascending aorta, and left ventricle hypoplasia.

Hypospadias: Congenital defect of the penis in which the urethral opening is on the underside of the penis.

Low Birth Weight: Less than 2500 grams.

Major Congenital Anomaly: A birth defect of serious medical and cosmetic consequence to the child. The major congenital anomalies under surveillance by the Alaska Birth Defects Registry follow guidelines established by the Centers for Disease Control and Prevention.

Medical Records Abstraction: A form of active surveillance in which program staff make periodic field visits to health care facilities such as clinics and hospitals to confirm cases of a reported major congenital anomaly by analyzing medical records. Also "Case Verification."

Microcephalus: Small head, with corresponding smallness of the brain.

Micropthalmia: Congenital smallness of the eye globe.

Microtia: Congenital smallness or maldevelopment of the external ear, with or without absence or narrowing of the external auditory canal.

Musculoskeletal Anomalies: Congenital anomalies of the limbs, abdominal wall, and diaphragm.

Normal Birth Weight: Between 2500 and 4500 grams.

Obstructive Genitourinary Defect: Congenital narrowing or absence of the urinary tract structure at any level. Severity often depends upon the level of the obstruction.

Omphalocele: Congenital opening of the abdominal wall with protrusion of the abdominal contents. Can be distinguished from gastroschisis by location within umbilical ring.

Oral Clefts: Includes cleft lip (congenital defect of the upper lip in which there is incomplete closure) and cleft palate (congenital defect in the closure of the palate; the structure which separates the nasal cavities and the back of the mouth. May involve the soft palate, hard palate or alveolus).

Passive Surveillance: Surveillance system in which either available data on reportable conditions are used or reporting is mandated or requested with the responsibility for the reporting falling on the health care provider.

Patau Syndrome: Chromosome abnormality caused by an extra chromosome 13. Also "Trisomy 13."

Patent Ductus Arteriosus: Congenital heart defect characterized by persistence of the fetal blood vessel connecting the pulmonary artery and the aorta.

Positive Predictive Value: The probability that a child truly has the health outcome being reported.

Prenatal: The entire period of pregnancy.

Prenatal Care: Health care services provided to a woman between conception and delivery that are pregnancy-related. Prenatal care, for purposes of this study, were categorized as beginning in the first trimester (first 3 months of pregnancy), second trimester (months 4-6 of pregnancy), third trimester (months 7-9 of pregnancy), or none at all/not reported.

Prevalence: The number of affected persons present in the population at a specific time divided by the number of persons in the population at that time (i.e., the proportion of the population that is affected by a health outcome for a specified period of time).

Prevalence Ratio: A comparison of two prevalences in order to determine a prevalence ratio of a specified health outcome among the exposed versus unexposed.

Pulmonary Valve Atresia/Stenosis: Congenital heart defect characterized by absence (or narrowing) of the pulmonary valve or pulmonary artery itself.

Pyloric Stenosis: A congenital narrowing of the opening of the stomach into the small intestine.

Rectal and Large Intestinal Atresia/Stenosis: Congenital absence, closure or constriction of the large intestine, rectum or anus.

Reduction Deformity Upper(Arms)/Lower (Legs): Congenital absence of a portion or entire limb.

Region: The six labor market regions designated by the Alaska Department of Labor and Workforce Development that includes Anchorage/Mat-Su, Gulf Coast, Interior, Northern, Southeast, and Southwest regions of Alaska. Also "Geographic Distribution."

Renal Agenesis/Hypoplasia: Congenital absence of the kidney.

Report Year: The year in which a child was reported to the Alaska Birth Defects Registry (versus "Birth Year").

Risk Factor: An exposure or other characteristic being observed or measured that is hypothesized to influence a health outcome. Also "Demographic/ Epidemiological Characteristics."

Sentinel Condition: A condition of special interest to the Alaska Birth Defects Registry that undergoes medical records abstraction and case verification.

Spina Bifida: Neural tube defect with protrusion of the spinal cord and/or meninges.

Syndrome: A set of health outcomes occurring together.

Temporal Pattern: Pattern or occurrence over a period of time, generally years or decades. Also "Trend."

Tetralogy of Fallot: Congenital heart defect composed of ventricular septal defect, pulmonary stenosis or atresia, displacement of the aorta to the right, and hypertrophy of right ventricle.

Transposition of Great Vessels: Congenital heart defect in which the aorta arises from the right ventricle, and the pulmonary artery arises from the left ventricle (opposite of normal).

Trend: Pattern or occurrence over a period of time, generally years or decades. Also "Temporal Pattern."

Tricuspid Valve Atresia/Stenosis: Congenital heart defect characterized by the absence (or narrowing of) of the tricuspid valve.

Trisomy 13: Chromosome abnormality caused by an extra chromosome 13. Also "Patau Syndrome."

Trisomy 18: Chromosomal abnormality caused by an extra chromosome 18. Also "Edwards Syndrome."

Trisomy 21: Distinctive and common chromosome abnormality syndrome caused by an extra copy of chromosome 21. Can be complete (Trisomy 21), attached to another chromosome (translocation), or mixed with cells containing normal chromosomes (mosaic). Also "Down Syndrome."

Unadjusted Analysis: Analysis of risk factors without adjustment for possible confounding variables. Also "Univariate Analysis."

Univariate Analysis: Analysis of risk factors without adjustment for possible confounding variables. Also "Unadjusted Analysis."

Ventricular Septal Defect: Congenital heart defect characterized by one or several openings in the ventricular septum.

Very Low Birth Weight: Less than 1500 grams.

TECHNICAL NOTES

Significance
All statistical analyses were performed at a significance level of alpha=.05.

Trend Analyses
Trend analyses were performed using Mantel Haenszel Chi-square for trend analysis. Because birth defects are rare events, trends for major congenital anomalies are graphed as three-year moving averages. However, all trend analyses are performed on the single year data, not moving averages data. Although the graphs of trends may show what appears to be a declining trend, it should be noted that these are moving averages and the decline may not be statistically significant since the analysis is performed on single year data, not the averaged data.

Moving Averages
Moving averages are overlapping sequences of time periods that are used to smooth out the year-to-year variability that is often observed when dealing with small numbers. A general formula for calculating the first and second time periods using the moving average method is as follows:

$$MA = \frac{\sum_{P_i-(w-1)}^{P_i} events}{\sum_{P_i-(w-1)}^{P_i} pop} \times 10^n, \quad \frac{\sum_{P_{i+1}-(w-1)}^{P_{i+1}} events}{\sum_{P_{i+1}-(w-1)}^{P_{i+1}} pop} \times 10^n$$

where P_i = time period of interest
w = width of interval
n = base for multiplier
pop = population

so $w = 3$ would be a three-year moving average
$n = 3 \Rightarrow 10^3$ would give a rate per 1,000

Percent Change
Percent change between two time periods is calculated as follows:

$$PC = \frac{(P_n - P_o)}{P_o} \times 100$$

where P_n= later time period
P_o = earlier time period

Prevalence Ratios
Prevalence ratios, the ratio of two prevalence estimates, are used to compare the prevalence for two populations and are similar to rate ratios. Relative prevalence was calculated as follows:

$$RP = \frac{(E_1/P_1)X10^n}{(E_2/P_2)X10^n} = \frac{Rate_1}{Rate_2}$$

where RP = relative prevalence
E_1 = number of events occurring in population 1
E_2= number of events occurring in population 2
P_1 = number of people in population 1 at risk of an event
P_2 = number of people in population 2 at risk of an event
n = base for multiplier
$Rate_1$ = rate (prevalence) for population 1
$Rate_2$ = rate (prevalence) for population 2

so $n = 3 \Rightarrow 10^4$ would give a rate per 10,000

Note: The multiplier, 10^n, must be the same for both rates. A prevalence ratio of 1.0 indicates that there is no difference in the race-specific or age-specific rates for the two populations being compared. It is customary for the group of interest to be labeled as population 1 and the reference group as population 2, so, the group of interest is always in the numerator.

Case Fatality Rates

Case fatality rates, the percentage of people diagnosed as having a specified health outcome who die within a certain time after diagnosis, are used to measure the severity of that health outcome. Case fatality rates for infants diagnosed with a major congenital anomaly were calculated as follows:

$$CFR = \frac{MCA_d}{MCA_t} \times 10{,}000$$

where *CFR* = case fatality rate
MCA_d = number of children diagnosed with a specified major congenital anomaly who died
MCA_t = total number of children diagnosed with a specified major congenital anomaly

so *CFR* would give a rate per 10,000

Appendices

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Section of Women's, Children's, and Family Health, Division of Public Health,
State of Alaska Department of Health and Social Services in Anchorage, Alaska.

State of Alaska
Sean Parnell, Governor

Department of Health and Social Services
William J. Streur, Commissioner

Division of Public Health
Ward B. Hurlburt, Chief Medical Officer
Kerre Fisher, Acting Director

Section of Women's, Children's, and Family Health
Stephanie Birch, Chief

Maternal and Child Health Epidemiology Unit
Yvonne Goldsmith, Manager

December 2012

OUSE COMMITTEE REPOR

(7)
Date Referred to Committee: March 18, 2014 **FURTHER REFERRALS:**

Date of Committee Action: 4/1/2014

The HEALTH AND SOCIAL SERVICES Committee considered: **CSSCR 13(HSS)**

CS FOR SENATE CONCURRENT RESOLUTION NO. 13(HSS)
Urging the governor to establish and support programs designed to eradicate the occurrence of fetal alcohol spectrum disorder from the state.

SCR 13-FETAL ALCOHOL SPECTRUM DISORDERS

Recommends it be replaced with [ ] HCS *or* **[ ] CS** *for* _____ (_____)
For Senate Bills with new title: [ ] Technical Title [ ] New Title: HCR_____ **[ ] Same Title [ ] New Title**

[ ] attach amendments
[ ] add new referral to _____Committee
[ ] Letter of Intent_____Committee

List of Abbrev for Depts.:
ADM
CED
COR
CRT
EED
DEC
DFG
GOV
DHS
LWF
LAW
LEG
MVA
DNR
DPS
REV
DOT
UA

NEW FISCAL NOTES
*FN# is assigned by Chief Clerk's Office

*FN#	List by Dept(s):	Fiscal	Indet.	Zero

PREVIOUS FISCAL NOTES

FN#	List by Dept(s):	Fiscal	Indet.	Zero
1	LEG			✓

Signing with recommendations	Printed Last Name	DP	DNP	NR	AM
Paul Seaton	SEATON	X			
	Reinbold	X			
	Pratt	X			
	Keller	X			
	NAGEAK	X			
	TARR	X			
Chair:	Higgins	✓			
Chair:					