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Birth Defects among Infants and Children in Alaska

Birth defects are a leading cause of mortality – accounting for approximately 20% of deaths to infants in Alaska and the U.S. as a whole. Genetic, environmental, and maternal illness during pregnancy are factors that can cause birth defects, however, the causes for about 70% of birth defects are unknown.

Seriousness

Healthy People 2010 Targets and National Data

Indicator	Alaska	Nation	Healthy People 2010 Goals*
Infant mortality due to birth defects per 1,000 live births	1.4 (2002-04)†	1.4 (2002-04)^	1.1
Incidence of spina bifida and other neural tube defects (NTDs) per 10,000 live births	6.7 (1999-2002) [2]	7.3 (1999-2001) ¥	3

- The rate of infant mortality due to birth defects is 29% higher than the Healthy People 2010 (HP2010) goal for both Alaska and the nation.
- The prevalence of spina bifida and other neural tube defects (NTDs) in Alaska was more than 2 times that of the HP2010 goal (1999-2001). However, Alaska now has a lower prevalence than most states.
- Compared to the nation, the incidence of NTDs is approximately 9% lower in Alaska.

Severity

Birth defects are the leading cause of infant mortality and contribute substantially to illness and long-term disability.

A neural tube defect occurs when the neural tube fails to close properly, leaving the developing brain or spinal cord exposed to amniotic fluid. The two most common NTDs are anencephaly and spina bifida. Spina bifida can result in paralysis of the infant's legs, loss of bowel and bladder control, water on the brain (hydrocephalus), and learning disabilities. Approximately 80%-90% of infants born with spina bifida live. Anencephaly is a fatal condition, often resulting in miscarriage. Infants that are born alive die shortly after birth.[1]

Urgency

During 1996-2002, the Alaska Birth Defects Registry (ABDR) identified an average of 556 children who were born each year with a reportable major anomaly birth defect. This represents about 6% of an annual Alaska birth cohort. Major congenital anomalies are those that are defined and monitored by the National Birth Defects Prevention Network.

- During 2002-2004, among Alaskan infants that died before their first birthday, 46% died as a result of a birth defect.[†]
- During 1996-1998, an annual average of 10 neural tube defect-affected infants were born in Alaska. In 2000-2002, the annual number of neural tube defect cases declined to six.[2]
- Cardiovascular defects are the most common major anomalies reported to the ABDR. Two percent of Alaskan infants are reported with a cardiovascular birth defect.[2] Taken individually, three of the most frequently reported birth defects classified as major defects are cardiovascular defects: atrial septal defect, ventricular septal defect, and patent ductus arteriosus (91.8, 84.6, 59.9 per 10,000 live births, respectively, 1996-2002).[2]

Disparities

The prevalence of major congenital anomalies was highest in the Northern and Southwest regions (11% and 9% of live births, 1996-2002, respectively) and the lowest in the Southeast and Interior (approximately 4% to 5%). Male infants were more likely to be reported with a major congenital anomaly than females. Alaskan infants with low and very low birth weights were 3.7 times more likely to be reported with a major anomaly than infants of normal birth weight.[2] There are racial disparities as well. The prevalence of major congenital anomalies among Alaska Natives was about 2.5 times that of other race groups. When children reported with fetal alcohol spectrum

Fifteen Most Frequently Reported Major Anomalies
Alaska
Birth Years 1996-2002

Congenital Anomaly	Rate per 10,000 live births	n
Atrial Septal Defect	91.8	641
Ventricular Septal Defect	84.6	591
Patent Ductus Arteriosus	59.9	418
Hypospadias and Epispadias	36.4	254
Microcephalus	30.5	213
Obstructive Genitourinary Defect	30.4	212
Pyloric Stenosis	30.1	210
Cleft Lip and Cleft Palate	29.4	205
Pulmonary Valve Atresia/Stenosis	27.9	195
Congenital Hip Dislocation	27.1	189
Fetal Alcohol Syndrome *	16.5	66
Down Syndrome (Trisomy 21)	15.3	107
Hydrocephalus	13.6	95
Hirschsprung's Disease	13.3	93
Neural Tube Defects	7.7	54

* Fetal Alcohol Syndrome data are for birth years 1996-1999

Data Source: *Alaska Birth Defects Registry from:*
Schoellhorn J, Wiens HN, Perham-Hester K. Alaska Maternal and Child Health Data Book: 2005: Birth Defects Surveillance Edition. Anchorage, AK: Maternal and Child Health Epidemiology Unit, Section of Maternal Child and Family Health, Division of Public Health, Department of Health and Social Services. p 30 May 2006.

disorder are excluded from the analysis, the probability of an Alaskan Native infant having a major congenital anomaly was still over twice that of any other race group.[2]

Economic Loss

Surgery and other medical procedures can mediate some anomalies, but treatment is often long lasting, painful and expensive. The total lifetime cost for a person with Fetal Alcohol Syndrome in Alaska is estimated to be $5.2 million[3]. The average total lifetime cost for each infant born in the U.S. with spina bifida is approximately $520,000 per child, for cerebral palsy $890,000, and for ventricular septal defect, $893,000.[4] These estimates are adjusted to 2006 dollars.

Interventions & Recommendations

Primary prevention: The causes of most birth defects are not known. Preventable birth defects include those that result from drug, alcohol, chemical exposure, and conditions due to vaccine-preventable infections (varicella, rubella). Furthermore, the U.S. Public Health Service and the Institute of Medicine recommend that all women of childbearing age consume 0.4 mg of folic acid daily to reduce the risk of an NTD-affected pregnancy.[5] By consuming the recommended daily intake of folic acid, the risk of an NTD-affected pregnancy is reduced 50%-70%.[6]

The Alaska Pregnancy Risk Assessment Monitoring System found that overall knowledge of folic acid benefits among mothers of newborns increased from 63% in 1996 to 81% in 2001.[7] A countrywide survey in 2004 found that 82% of respondents who were currently pregnant or had been pregnant within the previous two years knew about folic acid.[8]

Secondary prevention: This includes voluntary prenatal diagnosis, genetic counseling, and selective termination of pregnancy. These activities require that women seek prenatal care and that high quality diagnostic services are available. The Alaska Genetics Clinics offer specialty clinics for diagnosis and genetic counseling for individuals with inherited conditions, chromosomal disorders, or birth defects. The genetics counselor provides information on diagnosis, causes, treatment, reproductive risks, carrier testing, and prenatal diagnosis.

Tertiary Prevention: Many congenital anomalies, such as cardiac defects and oral clefts, can be surgically treated preventing adverse outcomes (including death) associated with the anomaly.

The Alaska Infant Learning Program (ILP) includes several reportable birth defects among the screening criteria used to identify children needing its support. About 20% of the children reported to the ABDR from 1996-2004 received ILP services. The per patient cost of care for ILP is about $4,200.

Intervention Effectiveness

The benefits of secondary and tertiary prevention measures have been shown. Primary prevention measures are less quantifiable.

Capacity

Propriety

Monitoring the prevalence of birth defects and identifying adverse outcomes associated with birth defects fall within the overall mission of the Women's, Children's, and Family Health Section. National initiatives have been set forth to address this issue (HP2010).

Economic feasibility

Some birth defects are amenable to therapeutic intervention. Primary and secondary prevention, however, are more cost-effective measures. Emphasis should be placed on effective primary prevention measures, such as folic acid awareness.

Acceptability
Primary prevention and therapeutic intervention are well accepted. Secondary prevention is more problematic because of the controversies surrounding abortion, even when a fetus has a fatal congenital anomaly. Surveillance using the ABDR is well accepted by the community.

Resources
Alaska Birth Defects Registry; FAS Surveillance Project; Alaska Infant Learning Program; Alaska Folic Acid Coalition.

Title V funding provides the foundation for the genetics and specialty clinics and the State's involvement in recruiting needed pediatric subspecialists. The Infant Learning Program is supported by a combination of state general funds and federal program dollars. The ABDR was previously funded by a grant from the Centers for Disease Control and Prevention (CDC). However, with CDC funding no longer available, ABDR needs to find a more stable funding source.

Legality
Physicians, hospitals, and other health care facilities and providers must report children from birth up to one year of age who have any of the reportable birth defects under the Alaska Administration Code (7 AAC 27.012).

References

[1] Centers for Disease Control and Prevention. National Center on Birth Defects and Developmental Disabilities: Folic Acid Now Fact Sheet. 2004.
[2] Schoellhorn J, Beery AL. Alaska Maternal and Child Health Data Book 2005: Birth Defects Surveillance Edition. Anchorage, AK. Maternal and Child Health Epidemiology Unit, Section of Women's, Children's and Family Health, Division of Public Health, Department of Health and Social Services. p 29, May 2006.
[3] Lupton, C. The Financial Impact of Fetal Alcohol Syndrome. SAMSHA FASD Center for Excellence. Electronic publication retrieved 2/22/2007 from http://www.fascenter.samhsa.gov/publications/cost.cfm
[4] Centers for Disease Control and Prevention. Economic Costs of Birth Defects and Cerebral Palsy—United States, 1992. MMWR 44(37), September 22, 1995.
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[6] CDC. Recommendations for the Use of Folic Acid to Reduce the Number of Cases of Spina Bifida and Other Neural Tube Defects. MMWR; 41(RR-14): 2-3. 1992.
[7] Perham-Hester KA, Wiens HN, Schoellhorn J. Alaska Maternal and Child Health Data Book 2005: PRAMS Edition. Anchorage, AK. Maternal and Child Health Epidemiology Unit, Section of Women's, Children's and Family Health, Division of Public Health, Department of Health and Social Services. p 29, May 2006.
[8] The Gallup Organization. Folic Acid and the Prevention of Birth Defects: a National Survey of Pre-Pregnancy Awareness and Behavior among Women of Childbearing Age, 1995 – 2004. September 2004.

Data Sources

[†] Alaska Bureau of Vital Statistics, 2002-2004 Data: State of Alaska, DHSS, DPH. January 2005.

[¥] Canfield, MA, Honein, MA, et al. National Estimates and Race/Ethnic Specific Variation Of Selected Birth Defects In The United States, 1999-2001. Birth Defects Research (Part A); 76 (11); 747-755 (2006).

[^] National Center for Health Statistics (NCHS) Vital Health Statistics System, 2002-2004 Data in: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS). Feb 2007. http://webappa.cdc.gov/sasweb/ncipc/leadcaus10.html

[*] Healthy People 2010. U.S. Department of Health and Human Services. Healthy People 2010. 2nd ed. With understanding and improving health and objectives for improving health. 2 Vols. Washington, DC: U.S. Government Printing Office. 2000.

Notes

Estimates of spina bifida and other neural tube defects include spina bifida, anencephaly, and encephalocele.

Findings from the Alaska Birth Defects Registry presented here are based on passive reporting to the ABDR and not verified by case chart review.

Cost estimates were adjusted to 2006 dollars using the medical care component of the Consumer Price Index.