

Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: Surveillance, Research

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Legislators

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1996

Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health)

Population covered annually: 9,500

Statewide: Yes

Current legislation or rule: 7 AAC 27.012

Legislation year enacted: 1996

Case Definition

Outcomes covered: Selected major birth defects based on ICD-10-CM code list

Pregnancy outcome: Livebirths (All gestational ages and birth weights)

Age: Birth to third birthday

Residence: In and out of state births to Alaska residents

Surveillance Methods

Case ascertainment: Passive case-finding with limited case confirmation

Vital records: Birth certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Genetics clinics, specialty clinics (heart, cleft lip/palate, neurodevelopmental), Maternal Child Death Review (MCDR), public health nursing, Alaska Dept. of Behavioral Health (AKAIMS)

Delivery hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.

Pediatric & tertiary care hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.

Third party payers: Medicaid databases, Indian health services, Private health insurers

Other specialty facilities: Genetic counseling/clinic genetic facilities

Other sources: Physician reports, Alaska Health Information Exchange, AK AIMS (Alaska Dept. of Behavioral Health)

Case Ascertainment

Conditions warranting chart review in newborn period: All Codes included in the current NBDPN list of birth defects listing (see: http://www.nbdpn.org/docs/Appendix_3_1_BirthDefectsDescriptions2015.pdf) are sampled for review. Other collected conditions/codes will be sampled and reviewed based upon incoming requests and/or need.

Coding: ICD-9-CM/ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database collection and storage: Access

Data Analysis

Data analysis software: R

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Needs assessment, Grant proposals, Education/public awareness

System Integration

System links: Link case finding data to final birth file

System integration: No.

Funding

Funding source: 20% General state funds, 80% MCH funds

Other

Web site:

<http://www.dhss.alaska.gov/dph/wcfh/Pages/mchebi/abdr/default.aspx>

Surveillance reports on file:

Http://www.dhss.alaska.gov/dph/wcfh/Pages/mchebi/abdr/Data_Reports.aspx

Additional information on file: 1)

http://dhss.alaska.gov/dph/wcfh/Documents/mchebi/abdr/Data%20Analysis%20Methods_v2.1.pdf2)

http://dhss.alaska.gov/dph/wcfh/Documents/mchebi/abdr/Data%20Collection%20Methods_v2.1.pdf

Contacts

Alaska Birth Defects Registry

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MCH-Epidemiology

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DATA TABLES

Alaska
Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Anencephalus	<6	<6	<6	<6	<6	7	
						1.6	
Anophthalmia/microphthalmia	6	0	0	<6	<6	9	
	2.6	0.0	0.0			2.0	
Anotia/microtia	<6	0	<6	<6	9	20	
		0.0			8.1	4.5	
Aortic valve stenosis	7	0	<6	0	<6	12	
	3.0	0.0		0.0		2.7	
Atrial septal defect	256	22	44	63	229	630	
	110.3	131.4	134.4	137.5	206.7	141.6	
Atrioventricular septal defect (Endocardial cushion defect)	9	0	0	<6	7	20	
	3.9	0.0	0.0		6.3	4.5	
Biliary atresia	<6	0	0	<6	6	13	
		0.0	0.0		5.4	2.9	
Bladder exstrophy	<6	0	0	0	0	<6	
		0.0	0.0	0.0	0.0		
Choanal atresia	7	<6	0	<6	<6	11	
	3.0		0.0			2.5	
Cleft lip alone	17	<6	<6	<6	17	46	
	7.3				15.3	10.3	
Cleft lip with cleft palate	22	<6	<6	7	20	54	
	9.5			15.3	18.1	12.1	
Cleft palate alone	41	<6	<6	8	45	98	
	17.7			17.5	40.6	22.0	
Cloacal exstrophy	<6	0	0	0	0	<6	
		0.0	0.0	0.0	0.0		
Clubfoot	63	<6	10	21	40	140	
	27.1		30.5	45.8	36.1	31.5	
Coarctation of the aorta	10	0	<6	<6	<6	19	
	4.3	0.0				4.3	
Common truncus (truncus arteriosus)	<6	0	0	0	<6	<6	
		0.0	0.0	0.0			
Congenital cataract	9	0	<6	<6	9	20	
	3.9	0.0			8.1	4.5	
Congenital posterior urethral valves	7	<6	<6	0	<6	15	1
	5.9			0.0		6.6	
Craniosynostosis	31	<6	<6	8	34	84	
	13.4			17.5	30.7	18.9	
Deletion 22q11.2	<6	0	<6	0	<6	8	
		0.0		0.0		1.8	
Diaphragmatic hernia	6	0	0	<6	6	13	
	2.6	0.0	0.0		5.4	2.9	
Double outlet right ventricle	<6	0	0	<6	<6	8	
		0.0	0.0			1.8	
Ebstein anomaly	<6	0	0	0	0	<6	
		0.0	0.0	0.0	0.0		
Encephalocele	<6	0	0	0	<6	<6	
		0.0	0.0	0.0			
Esophageal atresia/tracheoesophageal fistula	7	<6	0	<6	<6	15	
	3.0		0.0			3.4	
Gastroschisis	8	0	<6	<6	21	34	
	3.4	0.0			19.0	7.6	
Holoprosencephaly	21	<6	<6	8	25	60	
	9.0			17.5	22.6	13.5	
Hypoplastic left heart syndrome	<6	0	<6	<6	<6	7	
		0.0				1.6	
Hypospadias	140	12	16	23	45	238	1
	117.3	141.7	95.1	97.7	79.4	104.1	
Interrupted aortic arch	14	0	<6	<6	7	24	
	6.0	0.0			6.3	5.4	

Alaska
Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Limb deficiencies (reduction defects)	24 <i>10.3</i>	<6	<6	6 <i>13.1</i>	14 <i>12.6</i>	47 <i>10.6</i>	
Omphalocele	83 <i>35.8</i>	23 <i>137.4</i>	13 <i>39.7</i>	13 <i>28.4</i>	32 <i>28.9</i>	166 <i>37.3</i>	
Pulmonary valve atresia and stenosis	17 <i>7.3</i>	<6	<6	<6	20 <i>18.1</i>	48 <i>10.8</i>	
Rectal and large intestinal atresia/stenosis	11 <i>4.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	<6	13 <i>11.7</i>	26 <i>5.8</i>	
Renal agenesis/hypoplasia	22 <i>9.5</i>	0 <i>0.0</i>	<6	<6	12 <i>10.8</i>	40 <i>9.0</i>	
Single ventricle	<6	0 <i>0.0</i>	<6	<6	<6	6 <i>1.3</i>	
Small intestinal atresia/stenosis	8 <i>3.4</i>	<6	<6	<6	10 <i>9.0</i>	23 <i>5.2</i>	
Spina bifida without anencephalus	14 <i>6.0</i>	0 <i>0.0</i>	<6	<6	7 <i>6.3</i>	24 <i>5.4</i>	
Tetralogy of Fallot	8 <i>3.4</i>	0 <i>0.0</i>	<6	0 <i>0.0</i>	<6	14 <i>3.1</i>	
Total anomalous pulmonary venous connection	<6	0 <i>0.0</i>	0 <i>0.0</i>	<6	7 <i>6.3</i>	9 <i>2.0</i>	
Transposition of the great arteries (TGA)	<6	0 <i>0.0</i>	0 <i>0.0</i>	<6	<6	12 <i>2.7</i>	
Tricuspid valve atresia and stenosis	<6	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	<6	
Trisomy 13	0 <i>0.0</i>	0 <i>0.0</i>	<6	0 <i>0.0</i>	0 <i>0.0</i>	<6	
Trisomy 18	<6	0 <i>0.0</i>	0 <i>0.0</i>	<6	<6	6 <i>1.3</i>	
Turner syndrome	7 <i>6.2</i>	<6	0 <i>0.0</i>	<6	<6	10 <i>4.6</i>	2
Ventricular septal defect	145 <i>62.5</i>	10 <i>59.7</i>	19 <i>58.0</i>	20 <i>43.7</i>	157 <i>141.7</i>	357 <i>80.2</i>	
Total live births	23,209	1,674	3,274	4,581	11,079	44,498	
Male live births	11,931	847	1,682	2,354	5,670	22,872	
Female live births	11,278	827	1,592	2,227	5,409	21,626	

Alaska**Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)**

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	34 <i>8.8</i>	0 <i>0.0</i>	34 <i>7.6</i>	
Trisomy 13	<6	0 <i>0.0</i>	<6	
Trisomy 18	<6	<6	6 <i>1.3</i>	
Total live births	38,469	6,024	44,498	

Notes

1. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
2. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.

General comments

*Data for totals include unknown and/or other.