State of Alaska Epidemiology

Bulletin

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Alaska Birth Defects Registry, 2018–2022

The Alaska Birth Defects Registry (ABDR) monitors birth defects among Alaska resident births using a modified passive surveillance system. This system collects data from multiple sources, including hospitals, specialty clinics, public and private health insurers, diagnostic laboratories, and medical record aggregators.[1] For each reported condition, a sample of cases is selected for detailed review, and case confirmation is completed through medical record abstraction. A confirmation rate derived from this sample is then applied to all reported cases to estimate the overall prevalence of each condition. To ensure comprehensive case ascertainment, the ABDR accepts reports for birth defects diagnoses occurring in children up to 3 years of age. The table below presents reported case counts and estimated prevalence among Alaska births during 2018–2022 for 25 of the 47 nationally defined core and recommended birth defects, specifically, those with validated confirmation rates.[2] Although directly comparable national data are not available, national prevalence estimates for the most recent period (2016–2020) are provided for context.[3]

Table. Selected Birth Defect Counts and Prevalence (per 10,000 live births), Alaska (2018–2022) and U.S (2016–2020)[3]

Condition	# of Alaska Reports	Alaska Estimated Prevalence (95% CI)	U.S. Estimated Prevalence (95% CI)	Alaska Reports 5-Year Trend†
Coarctation of the aorta	31	3.7 (2.4, 5.9)	5.8 (5.7, 6.0)	
Common truncus	4	0.2 (0.0, 0.8)	0.6 (0.6, 0.7)	--
Double outlet right ventricle	3	0.3 (0.1, 1.2)	2.4 (2.3, 2.4)	--
Ebstein anomaly	5	0.9 (0.3, 2.1)	0.8 (0.7, 0.8)	--
Hypoplastic left heart syndrome	2	0.4 (0.1, 1.5)	2.5 (2.5, 2.6)	--
Pulmonary valve atresia and stenosis	87	13.1 (10.2, 16.7)	10.3 (10.1, 10.4)	*
Single ventricle	3	0.1 (0.0, 0.8)	0.7 (0.6, 0.7)	--
Teratology of Fallot	13	1.7 (0.9, 3.3)		
Total anomalous pulmonary venous	7	1.2 (0.5, 2.4)	1.3 (1.3, 1.4)	
Transposition of the great arteries	7	1.0 (0.3, 2.1)	3.0 (2.9, 3.1)	
Tricuspid valve atresia and stenosis	3	0.3 (0.1, 1.2)	1.8 (1.7, 1.9)	--
Anencephalus	9	0.7 (0.2, 1.8)	1.9 (1.8, 2.0)	
Spina bifida without anencephalus	27	3.1 (1.9, 5.1)	3.5 (3.4, 3.6)	
Encephalocele	3	0.3 (0.1, 1.2)	1.0 (0.9, 1.0)	--
Holoprosencephaly	37	1.4 (0.6, 2.7)		
Trisomy 13	5	0.5 (0.1, 1.5)	1.4 (1.4, 1.5)	--
Trisomy 18	6	0.7 (0.2, 1.8)	3.0 (2.9, 3.1)	
Trisomy 21 (Down syndrome)	77	14.0 (10.9, 17.6)	15.6 (15.4, 16.7)	
Anophthalmia / microphthalmia	8	0.3 (0.1, 1.2)	2.0 (1.9, 2.0)	
Clubfoot	134	8.5 (6.3, 11.5)	18.6 (18.5, 18.8)	
Craniosynostosis	169	11.9 (9.1, 15.3)		
Diaphragmatic hernia	22	3.7 (2.4, 5.9)	3.1 (3.0, 3.2)	
Gastroschisis	31	4.4 (2.9, 6.6)	4.1 (4.0, 4.2)	
Limb deficiencies	43	5.6 (3.7, 7.9)	4.8 (4.7, 4.9)	
Omphalocele	76	2.9 (1.7, 4.9)	2.5 (2.4, 2.6)	*

*Ref: 95% CI = 95% Confidence Interval, * Indicates a significant trend,*
-- Indicates there were <6 reported cases and suppressed due to statistical instability.

- Alaska estimates are based on the most recent 5 years of available data, accounting for the 3-year reporting lag; national estimates reflect the most recent data available.
- Five-year trend analyses enhance monitoring by identifying longitudinal patterns and emerging shifts not otherwise apparent in cross-sectional 5-year period prevalence estimates. During 2018–2022, Alaska experienced a statistically significant increase in the prevalence of pulmonary valve atresia and stenosis and a statistically significant decrease in the prevalence of omphalocele (Table).
- Because Alaska and U.S. estimates are derived using different statistical methods and case ascertainment approaches, nonoverlapping confidence intervals should not be interpreted as evidence of statistically significant differences. Clinical misdiagnosis, medical coding misclassification, incomplete surveillance ascertainment, small population size, and the rarity of many of these conditions can further contribute to unstable estimates. Accordingly, these data should be interpreted as descriptive and used to inform further evaluation and research.
- All organizations that collect or maintain medical records or diagnosis codes for children aged <3 years are required to report qualifying conditions semiannually (see 7 AAC 27.012).[1]
- Please review the ABDR reporting guide and contact the ABDR at hssbirthdefreg@alaska.gov with questions.[1]

References
1. Reportable defects and conditions are available at: https://health.alaska.gov/en/resources/reporting-guide-alaska-birth-defects-registry-abdr/
2. Case definitions are available at: https://nbdpn.org/wp-content/uploads/2024/07/SGSC_-_Ch3_Case_Definition_-_final_draft_2016DEC20.pdf
3. Stallings EB, et al. NBDPN. National population-based estimates for major birth defects, 2016-2020. *Birth Defects Res*. 2024 Jan;116(1):e2301.

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