# Cleft Conditions in Alaska

## AN OVERVIEW OF THE ALASKA BIRTH DEFECTS REGISTRY METHODOLOGY, AND DATA

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# Alaska Birth Defects Registry (ABDR)

- ABDR has existed since 1996

- Passive surveillance

- Multiple reporting sources

- Cases are identified primarily via billing codes

- State Regulation 7 AAC 27.012

# ABDR reporting comes from hospitals, clinics, health insurance companies, diagnostic laboratories and Medicaid

# ABDR asks for reports on specific defects

- Birth defect diagnosed within the first three years of life

- Reporting occurs semi-annually

- Roughly 50 different core conditions

- Over 900 different ICD codes specified in the ABDR reporting guide

- Agencies are ask to include maternal identifiers

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# Maternal identifiers facilitate data linkage with birth certificate records


upserve.com
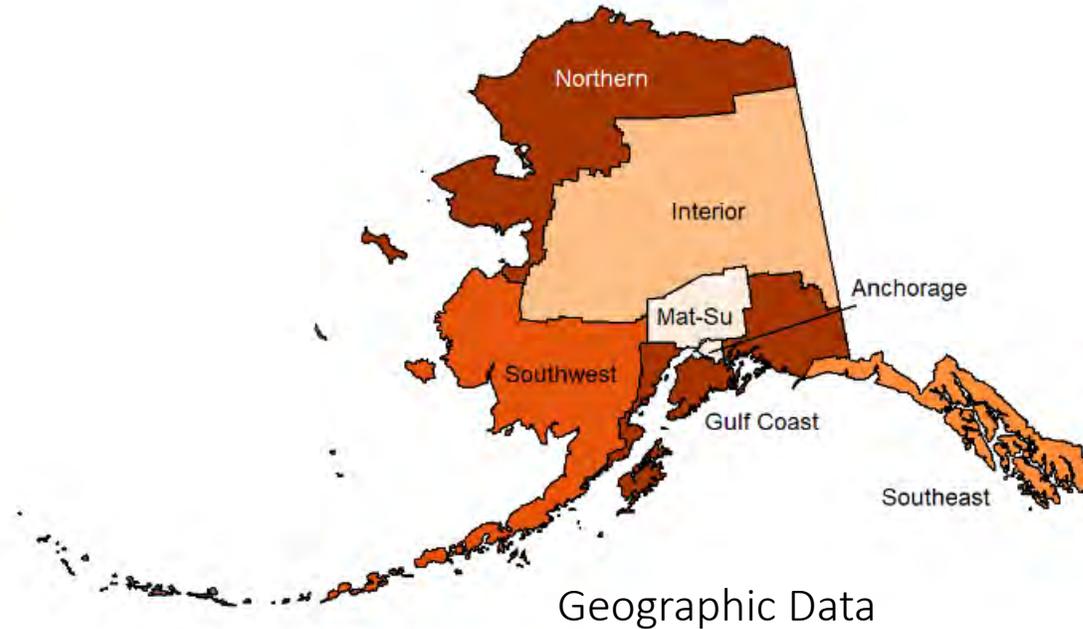
Demographic Data



Geographic Data

# Completely passive surveillance assumes all reports are valid

Cases

Report

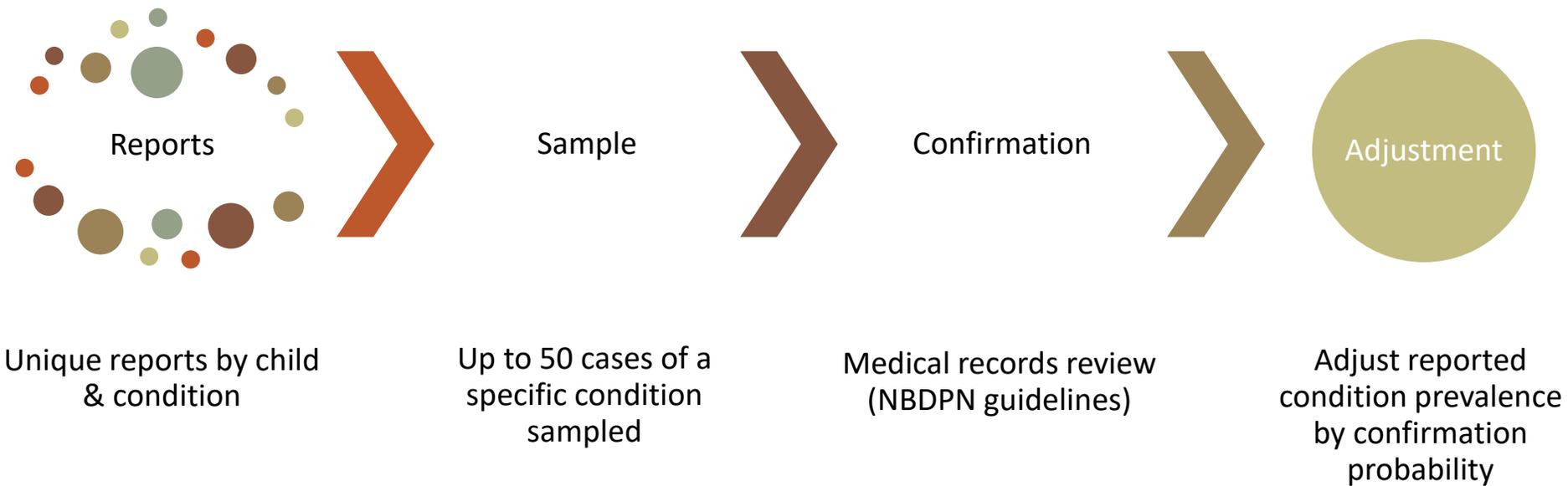Diagnosed cases from various reporting agencies

Report the number of unique (by child and condition) defects

# The Bayes Theorem

$$P(A|B) = \frac{P(B|A) \cdot P(A)}{P(B)}$$

# ABDR's modified passive surveillance strategy factors in some case confirmation

**Reports**

Unique reports by child & condition

**Sample**

Up to 50 cases of a specific condition sampled

**Confirmation**

Medical records review (NBDPN guidelines)

**Adjustment**

Adjust reported condition prevalence by confirmation probability

# This methodology requires some important assumptions

- We have the universe of all reported cases of a given defect in Alaska and the reporting completeness is constant by age six.

- The case confirmation probabilities are constant across
  - Age strata
  - Provider
  - Over time

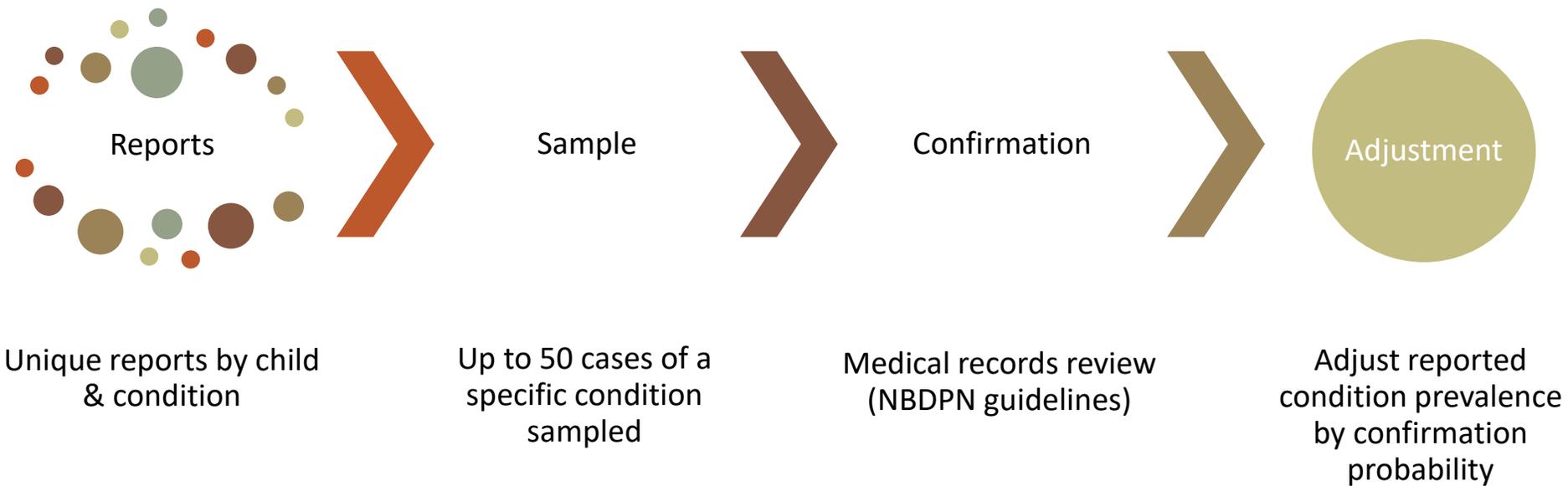ALASKA DIVISION OF
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# Reports outside the reporting age range are also used to infer missing cases

- 2018 ABDR reporting age changed from < 6 to < 3 years old.

- Reports among children ages 3-6 years are used to estimate cases missed by our surveillance system.

"THE FIRST TEST WAS FALSE-POSITIVE, THE SECOND TEST WAS FALSE-NEGATIVE. WHAT ARE YOU TRYING TO PULL?"

# ABDR's modified passive surveillance strategy factors in some case confirmation

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Using these adjustments many of our outlier prevalence estimates became much closer to other state and national estimates



towardsdatascience.com
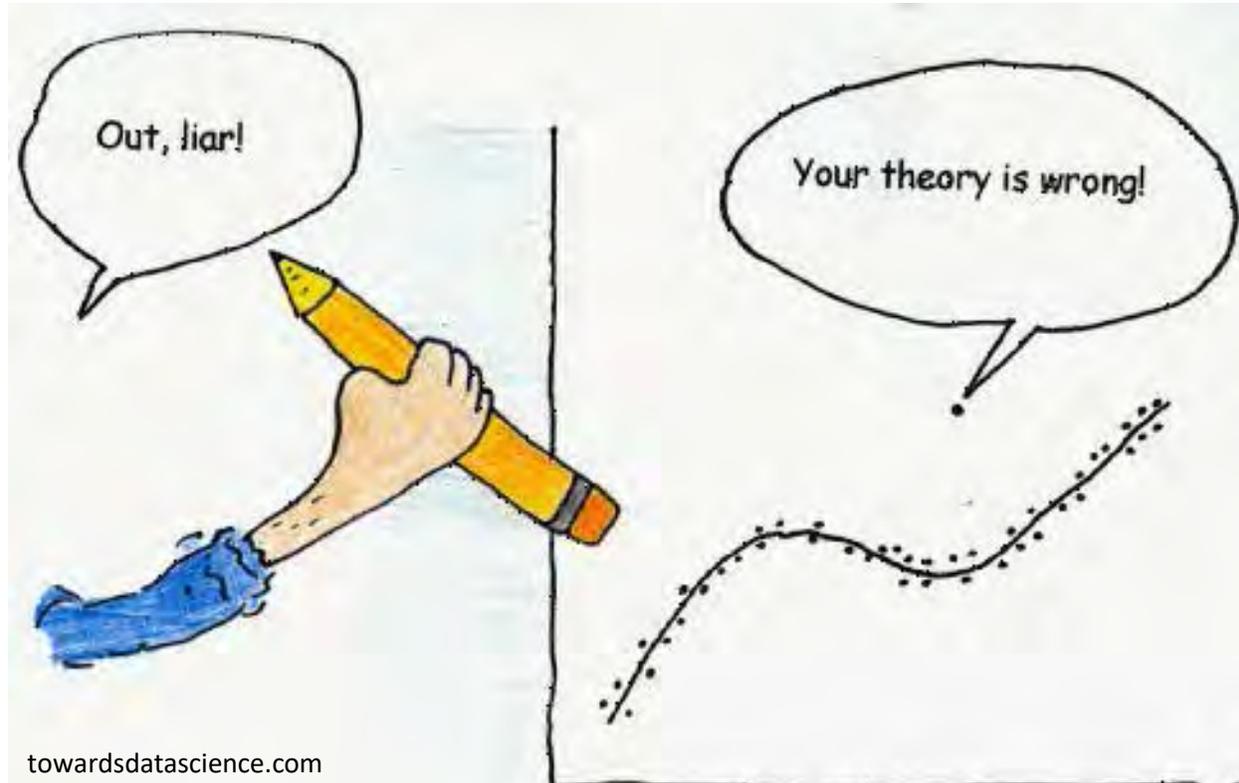
$$P(A|B) = \frac{P(B|A) \cdot P(A)}{P(B)}$$

# Cleft Conditions are birth defects that are characterized by the improper formation of the lip and/or mouth



Cleft Lip



Cleft Palate

# Even after adjustment, estimates of cleft conditions in Alaska remain relatively high

- U.S - The average prevalence rate of all orofacial clefts from 29 U.S States from 2007-2011 was 14.5 per 10,000 live births

- Alaska - The average prevalence rate of all orofacial clefts in Alaska from 2007-2015 was **32.4** per 10,000 live births

| | Reports | Defects | Births | Prevalence (95% CI) |
|---|---|---|---|---|
| Total | 406 | 330.7 | 101978 | 32.4 (29.1, 36.0) |

Notes: 95% CI = 95% Confidence Interval

# All three conditions have prevalence rates higher than national estimates

| Cleft Condition | Alaska Estimated Prevalence 2007-2015 | National Estimated Prevalence 2007-2011 |
|---|---|---|
| Cleft Lip | 4.9 (3.6, 6.4) | 3.1 |
| Cleft Palate | 13.6 (11.5, 16.0) | 5.9 |
| Cleft Lip with Cleft Palate | 14.0 (11.8, 16.4) | 5.6 |

Prevalence rates are all per 10,000 live births



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Prevalence rates are all per 10,000 live births

# Distribution of **cleft palate** prevalence in Alaska by Public Health Region of maternal residence at the time of birth shows the highest prevalence in Northern and Gulf Coast Regions

2007-2015
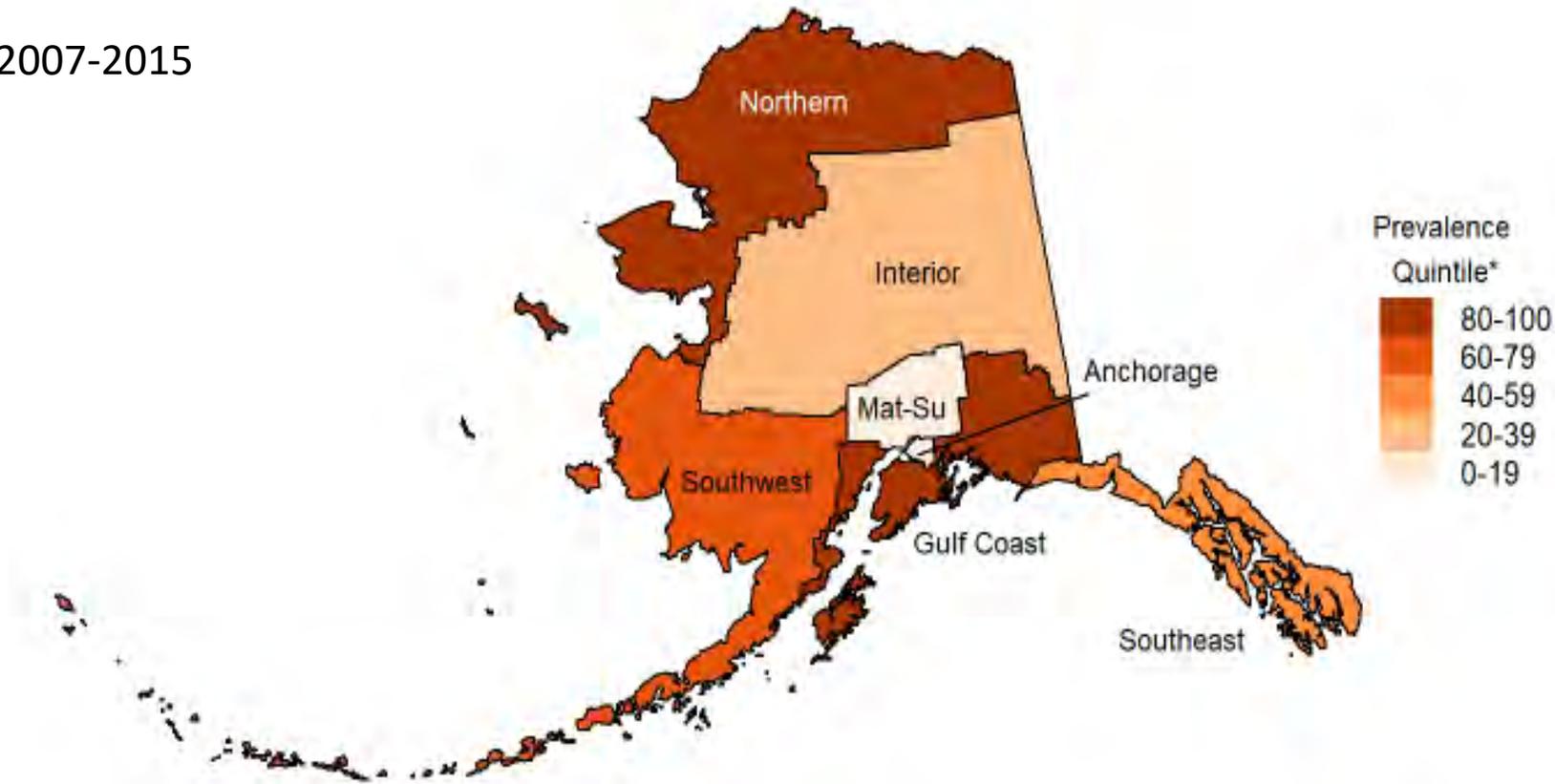
# Large variation within regions sometimes makes geographic comparisons difficult

2007-2015

| | Reports | Defects | Births | Prevalence (95% CI) |
|---|---|---|---|---|
| Anchorage | 72 | 49.5 | 41815 | 11.8 (8.9, 15.5) |
| Gulf Coast | 20 | 12.6 | 6313 | 20 (11, 33.2) |
| Interior | 34 | 23.1 | 18534 | 12.5 (8.3, 18.6) |
| Mat-Su | 12 | 9.4 | 12081 | 7.8 (4, 14.1) |
| Northern | 22 | 13.9 | 7114 | 19.5 (10.8, 31.2) |
| Southeast | 13 | 8.7 | 6375 | 13.6 (6.5, 24.7) |
| Southwest | 29 | 18.4 | 9746 | 18.9 (11.7, 29.2) |

Prevalence rates are all per 10,000 live births

# Demographic data from the birth certificate provides some descriptive epidemiology of specified maternal, birth, and child characteristics.

Cleft Palate 2007-2015

| | Reports | Defects | Births | Prevalence (95% CI) |
|---|---|---|---|---|
| **Sex** | | | | |
| Female | 94 | 63.5 | 49462 | 12.8 (10.0, 16.3) |
| Male | 108 | 72.1 | 52516 | 13.7 (10.9, 17.3) |
| **Birth weight (grams)** | | | | |
| <2500 | 29 | 17.6 | 5925 | 29.6 (18.0, 45.9) * |
| 2500+ | 173 | 118.0 | 95890 | 12.3 (10.3, 14.7) |
| **Maternal age** | | | | |
| 12-19 | 23 | 14.7 | 8043 | 18.2 (10.4, 29.2) |
| 20-24 | 53 | 35.9 | 28015 | 12.8 (9.0, 17.4) |
| 25-29 | 57 | 38.7 | 30852 | 12.6 (9.0, 16.9) |
| 30-34 | 43 | 29.0 | 22480 | 12.9 (9.0, 18.5) |
| 35-39 | - | - | 10015 | 13.9 (7.6, 22.2) |
| 40+ | - | - | 2543 | - |

Notes: Prevalence reported per 10,000 live births; Data suppressed for # of reports < 6; 95% CI = 95% Confidence Interval

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# Demographic data from the birth certificate provides some descriptive epidemiology of specified maternal, birth, and child characteristics.

Cleft Palate 2007-2015

|  | Reports | Defects | Births | Prevalence (95% CI) |
|---|---|---|---|---|
| **Maternal race** | | | | |
| Alaska Native/American Indian | 95 | 58.9 | 25801 | 22.8 (17.4, 29.1) |
| Asian/Pacific Islander | 12 | 8.8 | 9399 | 9.3 (4.4, 16.8) * |
| Black | 6 | 4.3 | 4134 | 10.3 (3.9, 24.8) |
| White | 87 | 62.2 | 61287 | 10.2 (7.9, 13.0) |
| **Maternal education (years)** | | | | |
| <12 | 28 | 17.8 | 9778 | 18.2 (10.9, 27.8) |
| 12 | 93 | 60.2 | 36724 | 16.4 (12.7, 21.0) |
| 12+ | 74 | 53.0 | 52380 | 10.1 (7.6, 13.0) |
| **Marital status** | | | | |
| Married | 99 | 69.6 | 64510 | 10.8 (8.5, 13.5) * |
| Unmarried | 102 | 65.3 | 37078 | 17.6 (13.8, 22.3) |

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Cleft Palate 2007-2015

| | Reports | Defects | Births | Prevalence (95% CI) | |
|---|---|---|---|---|---|
| **Maternal smoking use** | | | | | |
| Reported smoking | 53 | 32.9 | 14467 | 22.7 (15.7, 31.2) | * |
| Reported not smoking | 140 | 97.3 | 85927 | 11.3 (9.3, 13.8) | |
| **Medicaid (mother or child)** | | | | | |
| Medicaid | 147 | 93.7 | 51554 | 18.2 (14.7, 22.1) | * |
| non-Medicaid | 55 | 41.9 | 50311 | 8.3 (6.0, 11.1) | |
| **Father on birth certificate** | | | | | |
| None | 16 | 10.2 | 5559 | 18.3 (9.9, 33.1) | |
| Present | 186 | 125.4 | 96419 | 13.0 (10.9, 15.4) | |

Notes: Prevalence reported per 10,000 live births; Data suppressed for # of reports < 6; 95% CI = 95% Confidence Interval

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# In conclusion

- ABDR reporting comes from multiple agencies

- ABDR utilizes a modified passive surveillance strategy to improve prevalence estimates and timeliness

- Even after adjustment, estimates of cleft conditions in Alaska remain relatively high

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# Thank You

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