

California Birth Defects Registry Data: Technical Notes

Data timeframe

Birth defects reported among deliveries during the 5-year span, 2012 through 2016.

Geographic coverage

Maternal residence in the 8-county ascertainment region shown in the map below, which includes: Fresno, Kern, Kings, Madera, Merced, San Joaquin, Stanislaus, and Tulare, which constitute about 30% of annual births in California.



Case Definition

Although the Program monitors over 200 conditions, many are quite rare. These Birth Defects Data Sheets highlight fourteen birth defects or birth defect groups below. Many are common, serious, and have substantial public health impact.

Cases included in these Birth Defects Data Sheets met the following criteria:

- Live born, stillborn < or >= 20 weeks of gestational age, or medically terminated
- Diagnosis made through one year of age; hypospadias made until the age of two.
- Met the diagnostic criteria for birth defects in the following categories:
 - Anophthalmia/Microphthalmia
 - Anotia/Microtia
 - Cleft Lip/Cleft Palate
 - Craniosynostosis
 - Esophageal Atresia/Tracheoesophageal Fistula
 - Gastroschisis
 - Heart
 - Hypospadias
 - Limb Deficiencies
 - Neural Tube Defects
 - Omphalocele
 - Trisomy 13
 - Trisomy 18
 - Trisomy 21
- [List of the diagnostic codes used to define these defects](#)

Multiple Birth Defects in the Same Case

A person can have more than one birth defect. Cases with multiple defects are counted separately for each defect (i.e., a child with cleft lip and trisomy 13 will be counted as a case of cleft lip, and again as a case of trisomy 13). Therefore, the defect data do not necessarily represent mutually exclusive cases. It is important to recognize that adding up the number of defects will not yield the number of babies with defects.

Demographic characteristics

CBDMP registry cases are linked to live birth certificate data from California Department of Public Health Vital Records¹.

Mother's Age at Delivery:

The mother's age (in years) categories used:

- Less than 20
- 20-24
- 25-29
- 30-34
- 35-39
- 40 and above

Mother's Race/Ethnicity:

The mother's race/ethnicity classifications used in this report uses CA Vital Statistics reporting standards:

- White: White/Non-Hispanic
- Hispanic: Any Race/Hispanic; includes Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, Central or South American, other Spanish or Hispanic origin
- Black: African-American/Non-Hispanic
- Asian/Pacific Islander: Asian/Non-Hispanic, (Chinese, Japanese, Korean, Vietnamese, Asian Indian, Cambodian, Laotian, Hmong, Thai, Filipino, other Asian origin) Pacific Islander/Non-Hispanic, (Hawaiian, Guamanian, Samoan, other Pacific Islanders)
- American Indian or Alaska Native: American Indian/Non-Hispanic, Alaska Native/Non-Hispanic (Aleut, Eskimo)
- Other: Other/Non-Hispanic

¹ Data sources: Births: 2012-2016, Birth Statistical Master File, California Department of Public Health, Center for Health Statistics and Informatics.

Data Analysis

Small numbers

Small numbers of cases can create analysis problems, such as unstable rate estimates. In case of a rare defect or areas with a small population, the issue of small numbers can arise. The addition of a single birth defect will make the rate for a particular year appear much higher than usual. The fluctuation over time may not be statistically significant. Since a small change in the number of cases reported can result in a relatively large change in rates, caution should also be used in comparing annual rates for a specific defect.

Birth Prevalence Rate

When examining data, a birth prevalence rate better reflects occurrences in a population than does the number of cases. Birth prevalence was calculated as follows:

$$= \frac{\text{number of birth defect cases}}{\text{total number of live births}} \times 10,000$$

Prevalence rates were calculated per 10,000 live births by mother's age and race/ethnicity.

Confidence Intervals:

The birth prevalence rate for a specific defect is the best estimate of the true prevalence. To understand the range of possible values for the true prevalence, we also calculate the 95% confidence interval in the *Summary Birth Defect Prevalence Table*. From a practical viewpoint, confidence intervals are particularly useful when dealing with small numbers of cases or where the birth defect prevalence for one group are compared with that of other groups. It helps minimize reader concern about prevalence values that appear high or different when in fact it is most likely due to random fluctuation. We calculate 95% confidence interval using Clopper-Pearson Method and SAS software version 9.4.

Limitations

These data are subject to several limitations. First, the registry includes birth defects diagnosed in the first year of life, so birth defects detected after the first birthday and diagnoses that are refined after the first birthday may not be recorded in the registry. Second, due to some high-volume referral facilities being outside of ascertainment counties some patients may be transferred outside of our ascertainment region. Due to this, we perform surveillance activities at some facilities outside ascertainment counties, however some diagnoses that are made outside of an ascertainment county or in facilities that our staff do not access, such as prenatal diagnostic facilities and private physicians' offices, may not be captured. Third, data are collected from medical records and as such are subject to differences in clinical practice. And, finally, we perform ascertainment in a subset of California counties (mentioned above). Although this subset is demographically similar to the state's population as a whole, we are unable to provide statewide population-based data at this time.