

California*

California Birth Defects Monitoring Program (CBDMP)

*Last updated 2019

Purpose: Surveillance, Research

Partner: Local Health Departments, Hospitals, Universities

Program status: Currently collecting data

Start year: 1983

Earliest year of available data: 1983

Organizational location: Department of Health (Genetic Disease Screening Program/ Center for Family Health/ California Department of Public Health)

Population covered annually: 70,000

Statewide: No, CBDMP currently monitors a ten-county subset of California births that are demographically similar to the state as a whole and whose birth defects rates and trends have been reflective of those throughout California. Furthermore, CBDMP has statutory authority to conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.

Current legislation or rule: California Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 1996

Legislation year enacted: 1982

Case Definition

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)

Age: One year

Residence: In-state births to residents of counties monitored by CBDMP

Surveillance Methods

Case ascertainment: Active Case Finding

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories

Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All elective abortions, All neonatal deaths, All prenatally diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codable defect

Coding: CDC-modified BPA codes, further modified for use in CA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

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

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

Data Collection Methods and Storage

Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database collection and storage: SQL server

Data Analysis

Data analysis software: SAS

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

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, link registry to final vital records birth, fetal death, death and birth cohort files

Funding

Funding source: 100% Other (Fee-based Special Funds)

Other

Web site:

<https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/cbdmp/default.aspx>

Surveillance reports on file: California-specific birth defect data available: select defect-specific data sheets, annual surveillance report, and county-level estimates

Additional information on file: Please send inquiries to gdspcbmdmp@cdph.ca.gov

Contacts

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California
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	162 <i>6.1</i>	<5	167 <i>5.4</i>	
Trisomy 13	28 <i>1.1</i>	13 <i>2.9</i>	41 <i>1.3</i>	
Trisomy 18	47 <i>1.8</i>	42 <i>9.5</i>	89 <i>2.9</i>	
Trisomy 21 (Down syndrome)	237 <i>8.9</i>	275 <i>62.1</i>	513 <i>16.5</i>	
Total live births	265,904	44,301	310,281	4

Notes

1. Data for this condition include cases with congestive heart failure, confirmation by catheterization or surgery, or, beginning in 2018, confirmation by echocardiogram when the case was 6 weeks of age and the case had a minimum gestational age of 37 weeks.
2. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
3. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
4. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.