

Hawaii

Hawaii Birth Defects Program (HBDP)

Purpose: Surveillance

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Early Childhood Prevention Programs, Iowa Registry for Congenital and Inherited Disorders

Program status: Currently collecting data

Start year: 1988

Earliest year of available data: 1986

Organizational location: Department of Health (Children with Special Health Needs Branch)

Population covered annually: 19,000

Statewide: Yes

Current legislation or rule: Hawaii Revised Statutes - sec. 321-421 through 426 Hawaii Revised Statutes - sec. 324-41 through 44

Legislation year enacted: 2002

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: Up to one year after delivery

Residence: All in-state births

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, 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

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), 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 selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

Coding: CDC coding system based on BPA

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, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

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: Access

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Double-checking of assigned codes, Clinical review

Data use and analysis: Public health program evaluation, Rates by demographic and other variables, Epidemiological studies (using only program data)

Funding

Funding source: 100% Other (State Special Funds)

Other

Web site: <http://health.hawaii.gov/genetics/programs/hbdhome/>

Contacts

Jonathan B. Kimura, MSCP

**Hawaii Birth Defects Program, Hawaii State Department of Health
741 Sunset Avenue**

Honolulu, Hawaii 96816

Phone: 808-733-9065

Fax: 808-733-9068

Email: jonathan.kimura@doh.hawaii.gov

Sylvia Mann, MS, CGC

Genomics Section, Hawaii State Department of Health
741 Sunset Avenue

Honolulu, Hawaii 96816

Phone: 808-733-9063

Fax: 808-733-9068

Email: sylvia.mann@doh.hawaii.gov