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/

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