

## Utah

### Utah Birth Defect Network (UBDN)

**Purpose:** Surveillance, Research, Referral to Prevention/Intervention Services, General Birth Defect Prevention Education

**Partner:** Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Community Health Centers

**Program status:** Currently collecting data

**Start year:** 1994

**Earliest year of available data:** 1994

**Organizational location:** Department of Health (Division of Family Health and Preparedness, Bureau of Children with Special Health Care Needs)

**Population covered annually:** 48,226 for 2018

**Statewide:** Yes

**Current legislation or rule:** Birth Defects and Critical Congenital Heart Disease Reporting Rule (R398-5)

**Legislation year enacted:** 1999

#### Case Definition

**Outcomes covered:** Major structural and genetic defects identified by CDC and NBDPN.

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

**Age:** 2 years based on mandatory reporting

**Residence:** Utah maternal residence, in and out of state births to state residents

#### Surveillance Methods

**Case ascertainment:** Combination of active and passive case ascertainment; population-based

**Vital records:** Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate

**Other state based registries:** Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, CCHD screening program, Autism Registry

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, Champions report live births delivered at their respective hospitals

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, Cardiac catheterization laboratories, Specialty outpatient clinics

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

**Other sources:** Physician reports, Midwives

#### 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 birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatally diagnosed or suspected cases, All fetal death certificates, NICU reports, infant deaths are reviewed

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Auditory/hearing conditions, Any infant with a codable defect

**Coding:** CDC coding system based on BPA, ICD-9-CM/ICD-10-CM

#### 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.), Illnesses/conditions, Family history

#### Data Collection Methods and Storage

**Data collection:** Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff using remote access from office (laptop, web-based, etc.)

**Database collection and storage:** Access

#### Data Analysis

**Data analysis software:** SAS, Access

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness, Logical checks, duplicate check in tracking and surveillance module, case record form checked for completeness, timeliness through system

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Oral Facial Cleft Case-Control Study, UT Center for Birth Defects Research and Prevention, International Clearinghouse for Birth Defects, Local studies

#### System Integration

**System links:** Link to other state registries/databases, Link to environmental databases, Link to Utah genealogic population database, Link to vital records

**System integration:** The database is linked with birth, death, and pulse oximetry screening data. Newborns having failed Pulse Oximetry Screening are integrated with UBDN.

#### Funding

**Funding source:** 7% General state funds, 66% MCH funds, 27% CDC grant

#### Other

**Web site:** <http://www.health.utah.gov/birthdefect>

**Surveillance reports on file:** [Http://ibis.health.utah.gov](http://ibis.health.utah.gov)

**Other comments:** IBIS indicators are online.

#### Contacts

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