

## Maryland

### Maryland Birth Defects Reporting and Information System (BDRIS)

**Purpose:** Surveillance, Referral to Services

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

**Program status:** Currently collecting data

**Start year:** 1983

**Earliest year of available data:** 1984

**Organizational location:** Department of Health (Epidemiology/Environment, Prevention and Health Promotion Administration Maternal Child Health Bureau)

**Population covered annually:** 75,000

**Statewide:** Yes

**Current legislation or rule:** Health-General Article, Section 18-206; Annotated Code of Maryland

**Legislation year enacted:** 1982

#### Case Definition

**Outcomes covered:** Selected birth defects - anencephaly, spina bifida, hydrocephaly, cleft lip, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper or lower limb, congenital hip dislocation, and Down syndrome until 2009, then all significant birth defects

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Or  $\geq$ 500 grams weight; reports accepted on fetal deaths  $<$ 500 grams or  $<$ 20 weeks gestation if sent to us.), Elective terminations (Reports accepted on terminations  $<$ 500 grams or  $<$ 20 weeks gestation if sent to us. BDRIS has no specific legal authority to collect information on terminations. Maryland does not require that any certificate be filed with Vital Records for a termination unless the body is transported for burial.)

**Age:** Newborn

**Residence:** All in-state births

#### Surveillance Methods

**Case ascertainment:** Passive case-finding with case confirmation

**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, Sickle Cell Disease, Critical Congenital Heart Defect follow Up Program

**Delivery hospitals:** Primary source: sentinel birth defects hospital report form; electronic reporting began 5/1/13

**Pediatric & tertiary care hospitals:** transfers from delivery hospitals, if screening not done at delivery hospital.

**Other sources:** Midwifery Facilities

#### Case Ascertainment

**Conditions warranting chart review in newborn period:** Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All fetal death certificates

**Coding:** 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, 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.)

#### 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.)

**Database collection and storage:** Access, Mainframe, Visual dBASE, SAS, ASCII files; as of 5/1/13 data stored on vendor server

#### Data Analysis

**Data analysis software:** SAS

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, 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, Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness

#### System Integration

**System integration:** As of 5/1/13, the birth defects data collection is integrated into the same electronic system in which we collect hearing and CCHD screening data.

#### Funding

**Funding source:** 100% General state funds

#### Other

**Web site:** <http://phpa.dhmd.maryland.gov/genetics/SitePages/bdris.aspx>

**Surveillance reports on file:** All reports submitted to CDC

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