

## Florida

### Florida Birth Defects Registry (FBDR)

**Purpose:** Surveillance, Research, Educate health care professionals, women of childbearing age and general public about birth defects.  
**Partner:** Local Health Departments, Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators, Federal and state agencies  
**Program status:** Currently collecting data  
**Start year:** 1998  
**Earliest year of available data:** 1998  
**Organizational location:** Department of Health (Epidemiology/Environment), University  
**Population covered annually:** 220,229 in 2018  
**Statewide:** Yes  
**Current legislation or rule:** Section 381.0031(1,2) F.S., allows for development of a list of reportable conditions. Birth defects were added to the list in July 1999.  
**Legislation year enacted:** 1999

#### Case Definition

**Outcomes covered:** Major structural malformations and genetic disorders  
**Pregnancy outcome:** Livebirths (20 week gestation and greater)  
**Age:** Until age 1  
**Residence:** Florida

#### Surveillance Methods

**Case ascertainment:** Passive case-finding with case confirmation, FL has one CDC funded cooperative agreement which use active case ascertainment which is linked to the passive surveillance program.  
**Vital records:** Birth certificates, Death certificates, Matched birth/death file  
**Other state based registries:** Programs for children with special needs  
**Delivery hospitals:** Disease index or discharge index  
**Pediatric & tertiary care hospitals:** Disease index or discharge index

#### Case Ascertainment

**Conditions warranting chart review in newborn period:** Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)  
**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, 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, 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:** Electronic file/report submitted by other agencies (hospitals, etc.)  
**Database collection and storage:** Access, Dedicated server for birth defects data

#### Data Analysis

**Data analysis software:** SAS, SQL, dBASE  
**Quality assurance:** Validity checks, Re-abstraction of cases, Comparison/verification between multiple data sources, 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, Grant proposals, Education/public awareness, Prevention projects

#### System Integration

**System links:** Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, Maternal linked file.

**System integration:** The department has created a maternally linked file beginning with 1998. The birth defects data has been included in this linked file. Birth defects data are displayed on the department's Environmental Public Health Tracking Program site ([www.floridatracking.com](http://www.floridatracking.com)) and the Florida Community Health Assessment Resource Tool Set ([www.flhealthcharts.com](http://www.flhealthcharts.com))

#### Funding

**Funding source:** 75% General state funds, 25% CDC grant

#### Other

##### Web site:

<http://www.floridahealth.gov/diseases-and-conditions/birth-defects/index.html>

**Surveillance reports on file:** Publications, procedure manuals, electronic case ascertainment database and educational materials

**Other comments:** CDC/NCBDDD Cooperative Agreement for enhanced surveillance of selected birth defects, referral for services and prevention activities.

#### Contacts

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