

## Louisiana

### Louisiana Birth Defects Monitoring Network (LBDMN)

**Purpose:** Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services

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

**Program status:** Currently collecting data

**Start year:** 2005

**Earliest year of available data:** 2005

**Organizational location:** Department of Health (Maternal and Child Health, LDH/OPH/CCPH/BFH/Title V CYSHCN Programs)

**Population covered annually:** 62,000

**Statewide:** Yes

**Current legislation or rule:** Law: LA R.S. 40:31.41 - 40:31.48, 2001. LDH Rule: LAC 48:V. Chapters 161 and 163

**Legislation year enacted:** 2001

#### Case Definition

**Outcomes covered:** Major structural birth defects and selected genetic conditions specified by NBDPN in core, recommended, and expanded lists including an additional list of interest to LBDMN.

**Pregnancy outcome:** Livebirths (greater than or equal to 20 weeks gestation or greater than or equal to 350 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Added Fetal Deaths for 2016 births)

**Age:** Up to third birthday

**Residence:** In and out of state births to state residents at the time of birth

#### Surveillance Methods

**Case ascertainment:** Active Case Finding, 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:** Newborn hearing screening program

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

**Third party payers:** Medicaid databases

**Other sources:** Louisiana Hospital Inpatient Discharge Data (LAHIDD)

#### 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 birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)

**Conditions warranting chart review beyond the newborn period:** 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.), 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:** Custom built web-based database.

#### Data Analysis

**Data analysis software:** SAS, ArcGIS

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, 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, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, 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, Link case finding data to final death file

**System integration:** Integrated with Louisiana Electronic Event Registration System (LEERS) birth and death records and Louisiana Early Hearing Detection and Intervention (LA-EHDI) Program database.

#### Funding

**Funding source:** 100% Other (MCH Title V Block Grant/State Matching Funds)

#### Other

##### Web site:

WWW.LDH.LA.GOV/LBDMNWWW.LDH.LA.GOV/LBDMN

**Surveillance reports on file:** Louisiana Morbidity Report, May-June 2009, Vol 20, No 3; Results from 2006-2008 Birth Defects Surveillance System; Presentations of analysis using 2006-2008 data concerning ASD Reporting; Cleft Lip/Palate and Hearing Loss; and Age and Racial Disparities

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