

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, Fatal 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/LBDMN WWW.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

Contacts

Dionka C Pierce, MPH

LDH/OPH/CCPH/BFH/Data to Action/LBDMN

1450 Poydras St., Suite 2060

New Orleans, LA 70112

Phone: 504-568-5629 Fax: 504-568-7529

Email: Dionka.Pierce@la.gov

Julie A Johnston, BS

LDH/OPH/CCPH/BFH/LBDMN

PO BOX 60630

New Orleans, LA 70160-0630

Phone: 225-342-2017

Fax: 504-568-7529

Email: Julie.Johnston@la.gov

DATA TABLES

Louisiana**Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)**

Defect	Maternal Race/Ethnicity						Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	Indian or Alaska Native, Non-Hispanic	Total*	
Anencephalus	15 1.2	8 0.9	5 3.0	0 0.0	0 0.0	28 1.2	
Anophthalmia/microphthalmia	15 1.2	10 1.1	0 0.0	<5	<5	28 1.2	
Anotia/microtia	23 1.9	11 1.2	9 5.3	<5	<5	46 1.9	
Aortic valve stenosis	27 2.2	7 0.8	<5	0 0.0	0 0.0	38 1.6	
Atrial septal defect	1,043 85.0	970 109.4	123 72.7	30 72.4	17 148.6	2,223 93.1	
Atrioventricular septal defect (Endocardial cushion defect)	85 6.9	83 9.4	11 6.5	<5	0 0.0	186 7.8	
Biliary atresia	7 0.6	9 1.0	<5	<5	<5	19 0.8	
Bladder exstrophy	<5	<5	0 0.0	0 0.0	0 0.0	<5	
Choanal atresia	16 1.3	9 1.0	<5	<5	0 0.0	29 1.2	
Cleft lip alone	50 4.1	16 1.8	<5	<5	<5	71 3.0	
Cleft lip with cleft palate	77 6.3	35 3.9	14 8.3	<5	0 0.0	130 5.4	
Cleft palate alone	135 11.0	53 6.0	17 10.0	<5	6 52.4	216 9.0	
Clubfoot	180 14.7	118 13.3	24 14.2	<5	<5	329 13.8	
Coarctation of the aorta	64 5.2	41 4.6	5 3.0	<5	<5	113 4.7	
Common truncus (truncus arteriosus)	<5	<5	<5	0 0.0	0 0.0	7 0.3	
Congenital cataract	17 1.4	17 1.9	5 3.0	<5	<5	43 1.8	
Congenital posterior urethral valves	22 3.5	19 4.3	<5	0 0.0	0 0.0	44 3.6	1
Craniosynostosis	168 13.7	69 7.8	9 5.3	<5	<5	256 10.7	
Deletion 22q11.2	20 1.6	10 1.1	<5	0 0.0	0 0.0	35 1.5	
Diaphragmatic hernia	29 2.4	13 1.5	8 4.7	0 0.0	0 0.0	52 2.2	
Double outlet right ventricle	33 2.7	20 2.3	<5	<5	0 0.0	57 2.4	
Ebstein anomaly	9 0.7	5 0.6	<5	0 0.0	<5	17 0.7	
Encephalocele	12 1.0	11 1.2	0 0.0	0 0.0	0 0.0	23 1.0	
Esophageal atresia/tracheoesophageal fistula	24 2.0	18 2.0	<5	<5	0 0.0	49 2.1	
Gastroschisis	40 3.3	27 3.0	8 4.7	<5	0 0.0	80 3.4	
Holoprosencephaly	9 0.7	19 2.1	<5	0 0.0	0 0.0	31 1.3	
Hypoplastic left heart syndrome	29 2.4	21 2.4	<5	<5	<5	54 2.3	
Hypospadias	561 89.2	304 68.0	39 45.2	7 33.0	<5	934 76.8	1
Interrupted aortic arch	7 0.6	7 0.8	0 0.0	0 0.0	0 0.0	15 0.6	
Limb deficiencies (reduction defects)	39 3.2	34 3.8	8 4.7	0 0.0	<5	85 3.6	

Louisiana**Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)**

Defect	Maternal Race/Ethnicity						Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	Indian or Alaska Native, Non-Hispanic	Total*	
Omphalocele	25 2.0	27 3.0	0 0.0	0 0.0	<5	54 2.3	
Pulmonary valve atresia and stenosis	71 5.8	67 7.6	9 5.3	<5	<5	154 6.5	
Pulmonary valve atresia	5 0.4	8 0.9	<5	0 0.0	0 0.0	15 0.6	
Rectal and large intestinal atresia/stenosis	60 4.9	36 4.1	6 3.5	<5	0 0.0	106 4.4	
Renal agenesis/hypoplasia	51 4.2	30 3.4	7 4.1	<5	<5	91 3.8	
Single ventricle	10 0.8	7 0.8	0 0.0	<5	0 0.0	18 0.8	
Small intestinal atresia/stenosis	39 3.2	35 3.9	10 5.9	0 0.0	<5	88 3.7	
Spina bifida without anencephalus	42 3.4	29 3.3	<5	<5	0 0.0	76 3.2	
Tetralogy of Fallot	66 5.4	40 4.5	12 7.1	<5	<5	124 5.2	
Total anomalous pulmonary venous connection	7 0.6	8 0.9	<5	<5	0 0.0	18 0.8	
Transposition of the great arteries (TGA)	29 2.4	16 1.8	9 5.3	<5	<5	57 2.4	
Dextro-transposition of great arteries (d-TGA)	25 2.0	15 1.7	8 4.7	<5	<5	50 2.1	
Tricuspid valve atresia and stenosis	10 0.8	8 0.9	0 0.0	0 0.0	0 0.0	20 0.8	
Tricuspid valve atresia	9 0.7	5 0.6	0 0.0	0 0.0	0 0.0	16 0.7	
Trisomy 13	7 0.6	10 1.1	0 0.0	0 0.0	<5	18 0.8	
Trisomy 18	22 1.8	19 2.1	<5	0 0.0	0 0.0	43 1.8	
Trisomy 21 (Down syndrome)	129 10.5	105 11.8	28 16.5	6 14.5	<5	275 11.5	
Turner syndrome	<5 1.8	8 1.8	<5	0 0.0	0 0.0	14 1.2	2
Ventricular septal defect	624 50.8	378 42.6	110 65.0	19 45.8	5 43.7	1,158 48.5	
Total live births	122,752	88,659	16,922	4,145	1,144	238,758	3
Male live births	62,901	44,703	8,633	2,124	572	121,536	
Female live births	59,850	43,956	8,289	2,021	572	117,221	

Louisiana**Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)**

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	76 3.6	<5	80 3.4	
Trisomy 13	15 0.7	<5	18 0.8	
Trisomy 18	26 1.2	17 6.5	43 1.8	
Trisomy 21 (Down syndrome)	178 8.4	97 37.3	275 11.5	
Total live births	212,737	26,019	238,758	3

Notes

1. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.

2. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.

3. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

-Data for conditions exclude births that occurred in a military birth hospital or were covered by a military insurance payer source.

-Data for conditions from 2014 are final and include only live births to Louisiana residents that occurred in 45/53 birth hospitals and covered 93% of total births.

-Data for conditions from 2015 are final and include only live births to Louisiana residents that occurred in 50/52 birth hospitals and covered 97% of total births.

-Data for conditions from 2016 are provisional and include only live births to Louisiana residents that occurred in 49/51 birth hospitals and covered 92% of total births.

-Data for conditions from 2017 are provisional and include only live births to Louisiana residents that occurred in 49/50 birth hospitals and covered 96% of total births.

-Data for conditions include probable cases.