Louisiana Birth Defects Monitoring Network

2019 Annual Legislative Report

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LOUISIANA DEPARTMENT OF HEALTH

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Introduction

Louisiana Birth Defects Monitoring Network (LBDMN) is the only program in the Department of Health responsible for surveillance of birth defects in Louisiana's children. Mandated in 2004, it was the intent of the legislature to "establish a system to collect, analyze, and disseminate data regarding birth defects in the state and to provide information to families of children born with birth defects regarding services available in their community and the development of appropriate prevention programs." (*LA R.S. 40:31.43; and LAC Title 48, Part V, Subpart 55, Chapters 161 & 163 et al.).* See Appendix 1

In addition to fulfilling the annual legislative reporting requirement, the following report details data findings and performance measure assessments for our stakeholders. The categories include:

- Traditional case definition findings from 2013-2015 births;
- Special Project Report: Surveillance of Birth Defects Potentially Associated with Maternal Zika Virus Exposure among 2016-2017 Births; and
- Annual Data Quality Assessment Report Summary for the 2018 calendar year.

Our Mission

The mission of the Louisiana Birth Defects Monitoring Network (LBDMN) is to prevent birth defects and birth defect-related disabilities in Louisiana's children.

What We Do

LBDMN staff conduct active surveillance of birth defects in children born in Louisiana. Monitoring the health status of newborns provides population-based data to help inform policies, educate the public, support efforts of community partners, and prevent new occurrences of birth defects. LBDMN evaluates concerns about unexpected groups of birth defects as well as the effectiveness of preventive interventions. Regionally assigned Data Collection Specialists (DCS) statewide evaluate patient discharge information of newborns until age three years from all birthing hospitals in Louisiana, as well as at Children's Hospital and Tulane University Medical Center in New Orleans. LBDMN maintains a private and confidential database of children affected by congenital structural, functional, and/or genetic birth defects. De-identified medical record data are analyzed statistically for patterns and trends over time.

Who We Serve

LBDMN provides specific birth outcome data for the approximately 63,000 annual births in Louisiana. The program assists:

- Families of infants birth until three years of age with birth defects, by linking them with appropriate medical, educational, public health, and peer support resources;
- Men and women of reproductive age, by providing preventive education regarding birth defects;
- Policy makers, by identifying environmental risk factors and other causes potentially linked to specific birth conditions, and identifying preventive strategies to decrease birth defects;
- Researchers from the Centers for Disease Control and Prevention (CDC), universities, and other states investigating possible causes of specific birth defects.

Total Served

Approximately 1,500 children with specified birth defects are identified annually, which is an average of 300 per 10,000 live births. Since 2005, LBDMN has investigated potential birth defects among 24,737 children (unduplicated) between ages 0-3.

Eligibility Criteria

LBDMN case definition criteria include all of the following:

- The child must have a major structural, functional, or genetic birth defect. Major defects are generally those that can adversely affect the child's health and development. Children who have minor defects posing no significant health or social burdens are excluded.
- The mother's residence at the time of the birth must be the state of Louisiana as determined by the mother's hospital records, or if still in question, by vital records birth registration data.
- Diagnosis of the qualifying condition must be made before the child's third birthday.
- Pregnancy outcomes include only live births with a gestational age at birth of at least 20 weeks. In the absence of an age estimate, the infant must have a birth weight of at least 350 grams.

Services Provided

LBDMN provides:

- Active public health surveillance of hospital discharges of newborns until three years of age for major structural, functional, or genetic birth defects.
- Referral to services for families of children birth until three years of age identified with specified birth defects.
- Prevention of future birth defects through public awareness campaigns in partnership with national, state, and local stakeholders such as CDC, National Birth Defects Prevention Network, Louisiana Chapters of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists, March of Dimes, regional Families Helping Families, and Spina Bifida of Louisiana. Campaigns include education on the importance of management of chronic conditions such as diabetes and hypertension; folic acid consumption; dangers of fetal alcohol, opioid, and tobacco exposure; infection control to prevent risks of associated birth defects.

Funding Sources

Total Annual Federal Funding State Fiscal Year 2018: $638,000 (Title V MCH Block Grant)

Operations

LBDMN operates within the Louisiana Department of Health, Office of Public Health, Bureau of Family Health as one of four programs serving Children and Youth with Special Health Care Needs and their families.

Advisory Board

As mandated in the establishing law, *LA R.S. 40:31.43*, LBDMN is guided by an advisory board of volunteer stakeholders appointed by the secretary of LDH including the following:

(1) One pediatrician from a list of names submitted by the Louisiana State Medical Society
(2) One board-certified clinical geneticist from a list of names submitted by Ochsner Clinic

(3) One board-certified clinical geneticist from a list of names submitted by Tulane University Medical Center
(4) One board-certified clinical geneticist from a list of names submitted by Louisiana State University Health Sciences Center- New Orleans
(5) One board-certified clinical geneticist from a list of names submitted by Louisiana State University Health Sciences Center- Shreveport
(6) One maternal/fetal medicine physician from a list of names submitted by the March of Dimes
(7) One parent representative from a list of names compiled from various parent groups or by individual application
(8) One consumer representative from a list of names compiled from various consumer groups or by individual application
(9) One epidemiologist employed by or contracted to the department

The role of the LBDMN advisory board as prescribed in the law is *"to make recommendations on the implementation and continuing operation of the surveillance system."* The advisory board meets in person annually. Other contacts throughout the year are via email or teleconference as necessary.

Staff

LDH-OPH Bureau of Family Health contributes staff time to support LBDMN operations, including the Principal Investigator (10%) and direct supervisor of the LBDMN Program Manager; a CDC-funded Senior Epidemiologist (5%); and the LBDMN Staff Epidemiologist (60%). Surveillance staff contracted through the Louisiana Public Health Institute at 100% time commitment to LBDMN include the Program Manager, RN Case Review Clinical Coding Specialist, and six regional DCS. See Appendix 2 for Organizational Chart.

Methodology

LBDMN has conducted birth defects surveillance in Louisiana since 2005 using active case ascertainment methodologies. This means multiple data sources are used to identify potential cases of interest, which may fit within the case definition. Once potential cases are qualified, these sources are reviewed to abstract data, validate abstractions, and track children with birth defects who meet case definition at any time from birth up to their third birthday. Hospital medical records are the primary source for data collection. DCS obtain discharge indices from hospitals to identify potential cases by billing codes (ICD code). Other secondary data sources include Medicaid, Hospital Inpatient Discharge Data (LAHIDD), as well as birth, death, and fetal death record data from the Louisiana Vital Records Electronic Event Registration System (LEERS).

All abstracted data are reviewed for completeness and coding accuracy by a Registered Nurse Case Review Clinical Coding Specialist and/or the LBDMN Program Manager before data are accepted into the Registry and are available for reporting. The surveillance data are stored and managed in a custom web-based database integrated with LEERS birth and death certificates as well as Early Hearing Detection and Intervention (LA-EHDI) data.

For each case, ICD billing codes are converted into CDC clinical coding system, based on the British Pediatric Association and Classification of Diseases and the ICD-9/10-CM, which is used to classify birth defects for data analyses and reporting. Prevalence rate of birth defects is calculated as the number of

children with birth defects per 10,000 total live births. There is an exception for hypospadias and Turner Syndrome, which is limited to males and females respectively and interpreted as the rate among live born males and females, respectively. The 95% confidence interval (CI) is calculated with the assumption that the number of children with birth defects followed a Poisson Distribution. Please refer to Appendix 3 for the Case Ascertainment\Review\Quality Assurance flow chart.

Findings

Not all defects are evident at birth; therefore, LBDMN follows children until three years of age allowing adequate time for proper diagnosis. The data is finalized every 3.5 years to more accurately present the number of birth defects that have occurred within a calendar year.

Traditional Case Definition Findings

The following tables represent data from births in 2013-2015 calendar years. Only live births with birth weight >= 350 grams or gestational age >= 20 weeks were included. The data in this report are limited to children born to Louisiana residents and birth occurrence in state. Of 180,641 children born between 2013 and 2015, 5,016 children were diagnosed with at least one birth defect, yielding an overall prevalence of 277.7 per 10,000 live births or 2.8 % (annual average is 300/10,000). Among children with birth defects, cardiovascular system defects (about 48%) are the most common followed by defects of the genitourinary, musculoskeletal, chromosomal, orofacial, gastrointestinal, central nervous, eye, and ear, face, and neck systems. (Table 1)

Table 1: Distribution (%) of total birth defects by organ and chromosome system among children born with birth defects, 2013-2015 birth cohort (n = 5,016)

Organ and chromosome system	Number	Percent*
Cardiovascular	2,407	48.0
Genitourinary	1,438	28.7
Musculoskeletal	534	10.6
Chromosomal	479	9.5
Oro-facial	298	5.9
Gastrointestinal	277	5.5
Central Nervous	253	5.0
Eye	57	1.1
Ear, Face, Neck	30	0.6

**Because one child may have more than one birth defect, the total percents are greater than 100% when totaled*

The four most common birth defects with a prevalence greater than 10 per 10,000 live births among children born in 2013-2015 included atrial septal defect (81.3), hypospadias (75.8), ventricular septal defect (48.1), and Down Syndrome (12.0). Stratified by organ and chromosome system, the most common birth defects were: cardiovascular: atrial septal defects and ventricular septal defects; genitourinary: hypospadias; central nervous: microcephalus, spina bifida, and hydrocephalus; eye: congenital cataract and anophthalmia/microphthalmia; ear, face, and neck: anotia/microtia; orofacial: cleft lip and cleft palate; gastrointestinal: rectal/large intestinal atresia or stenosis; musculoskeletal: clubfoot, craniosynostosis, and gastroschisis; and chromosomal: Down syndrome (Table 2).

Table 2: Distribution (%) and prevalence (per 10,000 live births) of specific birth defects by organ and chromosome system, 2013-2015 birth cohort (N = 180,641)

System	Birth defects	Number	%	Rate	CI95%
Central Nervous (n = 253)	Microcephalus	109	43.1	6.0	5.0, 7.3
	Spina bifida (without anencephalus)	67	26.5	3.7	2.9, 4.7
	Hydrocephalus (without Spina Bifida)	42	16.6	2.3	1.7, 3.1
	Anencephalus	21	8.3	1.2	0.7, 1.8
	Encephalocele	15	5.9	0.8	0.5, 1.4
Eye (n = 57)	Congenital cataract	33	57.9	1.8	1.3, 2.6
	Anophthalmia/microphthalmia	24	42.1	1.3	0.9, 2.0
Ear, face, neck (n = 30)	Anotia/microtia	26	86.7	1.4	0.9, 2.1
Cardiovascular (n = 2407)	Atrial septal defect	1468	61.0	81.3	77.2, 85.5
	Ventricular septal defect	869	36.1	48.1	45.0, 51.4
	Atrioventricular septal defect (Endocardial cushion defect)	125	5.2	6.9	5.8, 8.2
	Pulmonary valve atresia and stenosis	110	4.6	6.1	5.0, 7.3
	Tetralogy of Fallot (TOF)	100	4.2	5.5	4.5, 6.7
	Coarctation of the aorta	92	3.8	5.1	4.1, 6.2
	Transposition of the great arteries (TGA)	55	2.3	3.0	2.3, 4.0
	Hypoplastic left heart syndrome	47	2.0	2.6	1.9, 3.5
	Dextro-transposition of great arteries	36	1.5	2.0	1.4, 2.8
	Aortic valve stenosis	22	0.9	1.2	0.8, 1.8
	Tricuspid valve atresia and stenosis	14	0.6	0.8	0.4, 1.3
	Total anomalous pulmonary venous connection	6	0.2	0.3	0.1, 0.7
	Ebstein anomaly	14	0.6	0.8	0.4, 1.3
	Common truncus (truncus arteriosus)	7	0.3	0.4	0.2, 0.8
Gastrointestinal (n = 277)	Rectal and large intestinal atresia/stenosis	84	30.3	4.7	3.7, 5.8
	Esophageal atresia/tracheoesophageal fistula	39	14.1	2.2	1.5, 3.0
	Small intestinal atresia/stenosis	42	15.2	2.3	1.7, 3.1
	Biliary atresia	16	5.8	0.9	0.5, 1.4
Oro-facial (n = 298)	Cleft palate without cleft lip	132	44.3	7.3	6.1, 8.7
	Cleft lip with cleft palate	94	31.5	5.2	4.2, 6.4
	Cleft lip without cleft palate	50	16.8	2.8	2.1, 3.6
	Choanal atresia	25	8.4	1.4	0.9, 2.0
Genitourinary (n = 1438)	Hypospadias*	698	48.5	75.8	70.3, 81.7
	Renal agenesis/hypoplasia	72	5.0	4.0	3.1, 5.0
	Congenital Posterior Urethral Valves*	60	4.2	6.5	5.0, 8.4
Musculoskeletal (n = 534)	Clubfoot	160	30.0	8.9	7.5, 10.3
	Craniosynostosis	136	25.5	7.5	6.3, 8.9
	Gastroschisis	76	14.2	4.2	3.3, 5.3
	Diaphragmatic hernia	44	8.2	2.4	1.8, 3.3
	Limb deficiencies (reduction defects)	66	12.4	3.7	2.8, 4.6
	Omphalocele	43	8.1	2.4	1.7, 3.2
Chromosomal (n = 316)	Trisomy 21 (Down Syndrome)	216	45.1	12.0	10.4, 13.7
	Trisomy 18	37	7.7	2.0	1.4, 2.8
	Deletion 22 q11	27	5.6	1.5	1.0, 2.2
	Trisomy 13	16	3.3	0.9	0.5, 1.4
	Turner Syndrome**	14	2.9	1.6	0.9, 2.7

**Prevalence limited to males (92,029); **Prevalence limited to females (88,612)*

Prevalence of specific birth defects by organ and chromosome system and race/ethnicity are presented in Table 3.

Table 3: Prevalence of specific birth defects by organ and chromosome system and race/ethnicity, 2013-2015

Defects	White/Non-Hispanic		Black/Non-Hispanic		Hispanic		Other- Non-Hispanic	
	n	Prevalence, CI95%	n	Prevalence, CI95%	n	Prevalence, CI95%	n	Prevalence, CI95%
Central nervous system								
Anencephalus	11	1.2, 0.6-2.1	9	1.3, 0.6-2.5	-		0	
Spina bifida without anencephalus	38	4.1, 2.9-5.6	25	3.7, 2.4-5.4	-		-	
Hydrocephalus without Spina Bifida	19	2.0, 1.2-3.2	22	3.2, 2.0-4.9	-		0	
Encephalocele	9	1.0, 0.4-1.8	5	0.7, 0.2-1.7	0		-	
Microcephalus	44	4.7, 3.4-6.3	55	8.1, 6.1-10.6	-		6	4.8, 1.8-10.4
Eyes								
Anophthalmia/microphthalmia	12	1.3, 0.7-2.3	10	1.5, 0.7-2.7	0		-	
Congenital cataract	19	2.0, 1.2-3.2	12	1.8, 0.9-3.1	0	-	-	
Ears, face, and, neck								
Anotia/microtia	15	1.6, 0.9-2.7	7	1.0, 0.4-2.1	-		-	
Cardiovascular system								
Transposition of the great arteries (TGA)	26	2.8, 1.8-4.1	19	2.8, 1.7-4.4	9	7.2, 3.3-13.6	-	
Tetralogy of Fallot (TOF)	48	5.2, 3.8-6.8	39	5.8, 4.1-7.9	10	8.0, 3.8-14.7	-	
Ventricular septal defect	460	49.4, 45.0-54.1	297	43.8, 39.0-49.1	72	57.4, 44.9-72.3	40	31.9, 22.8-43.5
Atrial septal defect	668	71.8, 66.4-77.4	664	97.9, 90.6-105.6	79	63.0, 49.9-78.6	57	45.5, 34.4-58.9
Atrioventricular septal defect (Endocardial cushion defect)	60	6.4, 4.9-8.3	53	7.8, 5.9-10.2	7	5.6, 2.2-11.5	5	4.0, 1.3-9.3
Pulmonary valve atresia and stenosis	53	5.7, 4.3-7.4	48	7.1,5.2-9.4	6	4.8,1.8-10.4	-	
Tricuspid valve atresia and stenosis	8	0.9, 0.4-1.7	5	0.7, 0.2-1.7	0		-	
Ebstein anomaly	9	1.0, 0.4-1.8	-		0		-	
Aortic valve stenosis	18	1.9, 1.1-3.1	-		0		0	
Hypoplastic left heart syndrome	23	2.5, 1.6-3.7	22	3.2, 2.0-4.9	-		0	
Coarctation of the aorta	50	5.4,4.0-7.1	31	4.6, 3.1-6.5	7	5.6, 2.2-11.5	-	
Dextro-transposition of great arteries	16	1.7, 1.0-2.8	13	1.9, 1.0-3.3	7	5.6, 2.2-11.5	0	
Pulmonary valve atresia	-		-		0		0	
Orofacial system								
Cleft palate without cleft lip	78	8.4, 6.6-10.5	34	5.0, 3.5-7.0	13	10.4, 5.5-17.7	7	5.6, 2.2-11.5
Choanal atresia	13	1.4, 0.7-2.4	9	1.3, 0.6-2.5	-		-	
Cleft lip without cleft palate	40	4.3, 3.1-5.9	6	0.9, 0.3-1.9	-		-	
Cleft lip with cleft palate	53	5.7, 4.3-7.4	33	4.9, 3.3-6.8	6	4.8, 1.8-10.4	-	
Gastrointestinal system								
Esophageal atresia/tracheoesophageal fistula	18	1.9, 1.1-3.1	12	1.8, 0.9-3.1	-		5	4.0, 1.3-9.3
Rectal and large intestinal atresia/stenosis	42	4.5, 3.3-6.1	34	5.0, 3.5-7.0	5	4.0, 1.3-9.3	-	
Biliary atresia	7	0.8, 0.3-1.5	6	0.9, 0.3-1.9	-		-	
Small intestinal atresia/stenosis	14	1.5, 0.8-2.5	19	2.8, 1.7-4.4	8	6.4, 2.8-12.6	-	
Genitourinary system								
Renal agenesis/hypoplasia	41	4.4, 3.2-6.0	26	3.8, 2.5-5.6	-		-	
Congenital Posterior Urethral Valves	34	7.1, 4.9-9.9	25	7.3, 4.7-10.8	0		-	
Hypospadias	421	88.0, 79.8-96.9	229	67.0, 58.6-76.3	26	40.9, 26.7-60.0	22	59.5, 37.3-90.1
Musculoskeletal system								
Gastroschisis	35	3.8, 2.6-5.2	28	4.1, 2.7-6.0	10	8.0, 3.8-14.7	-	
Omphalocele	19	2.0, 1.2-3.2	21	3.1, 1.9-4.7	0		-	
Diaphragmatic hernia	21	2.3, 1.4-3.4	15	2.2, 1.2-3.6	6	4.8, 1.8-10.4	-	
Limb deficiencies (reduction defects)	37	4.0, 2.8-5.5	22	3.2, 2.0-4.9	-		-	
Craniosynostosis	91	9.8, 7.9-12.0	40	5.9, 4.2-8.0	0		5	4.0, 1.3-9.3
Clubfoot	88	9.5. 7.6-11.6	57	8.4, 6.4-10.9	12	9.6, 4.9-16.7	-	
Chromosomal system								
Trisomy 13	8	0.9, 0.4-1.7	6	0.9, 0.3-1.9	-			
Trisomy 21 (Down Syndrome)	113	12.1, 10.0-14.6	65	9.6, 7.4-12.2	26	20.7, 13.6-30.4	12	9.6, 4.9-16.7
Trisomy 18	18	1.9, 1.1-3.1	15	2.2, 1.2-3.6	-		-	
Turner Syndrome	-		7	2.1, 0.8-4.3	-		-	
Deletion 22 q11	15	1.6, 0.9-2.7	9	1.3, 0.6-2.5	-		0	

Special Project:
Surveillance of Birth Defects Potentially Associated with Maternal Zika Virus Among 2016-2017 Births

In response to the emerging public health concern surrounding Zika virus exposure, in August 2016 LBDMN received CDC grant funding to conduct rapid surveillance of birth defects known to be associated with maternal Zika exposure and referrals to coordinated care for children born with those birth defects.

Funding enabled LBDMN to accomplish infrastructure enhancements in collaboration with the Louisiana Bureau of Vital Statistics and Louisiana Newborn Hearing Screening and Early Hearing Detection and Intervention (LA-EHDI) programs. These improvements include the following:

- Addition of Zika Virus to the list of Congenital Infections as a risk factor for Congenital or Late-Onset Hearing Loss on the LA-EHDI Newborn Hearing Screening Report Form;
- Addition of Zika Virus to the list of Infections Present and/or Treated During This Pregnancy on the Louisiana Birth Certificate application (LEERS);
- Addition of Microcephaly, Other Central Nervous System Anomalies, Microphthalmia, and Arthrogryposis to the list of Congenital Anomalies on LEERS;
- Integration of LA-EHDI and LEERS databases into the LBDMN database for data accessibility. These administrative data sources broaden and speed case ascertainment activity.

Zika Birth Defects Surveillance (ZBDS), through LBDMN, tracked specified birth defects *regardless of viral exposure* in order to determine baseline prevalence rates. Note: The Zika Pregnancy Registry in the Infectious Disease Epidemiology Section within the Bureau of Infectious Diseases tracks cases of mothers and infants with exposure to Zika virus.

Eligibility Criteria/Case Definition:

- This project included births from January 1, 2016-June 30, 2017.
- Pregnancy outcomes included live births and fetal deaths occurring in Louisiana with one of 26 categories of birth defects associated with Congenital Zika Syndrome as specified by the CDC's ZBDS Case Inclusion Guidance.
- Louisiana residents as determined by the mother's hospital records, or if unclear, by vital records birth registration forms.
- Diagnosis of the qualifying condition must have been prior to the child's first birthday.
- Neither the mother nor the baby need to have been tested positive or exposed to Zika virus for inclusion.

Cases were ascertained from the following datasets: Louisiana State Bureau of Vital Statistics records including births, deaths, and fetal deaths, Medicaid, and 49 of 51 eligible reporting hospitals. Among these births and fetal deaths, LBDMN reported 254 qualifying birth defects to CDC (3 fetal deaths and 251 live births) ***none of which had maternal exposure to Zika.***

Table 4: Zika associated birth defects, Louisiana January 2016 - June 2017

Birth defects	Number
Brain abnormalities with and without microcephaly	***141***
Confirmed or possible congenital microcephaly	45
Intracranial calcifications	20
Cerebral/cortical atrophy	14
Abnormal cortical gyral patterns	37
Corpus callosum abnormalities	15
Cerebellar abnormalities	14
Porencephaly	10
Hydranencephaly	14
Ventriculomegaly / hydrocephaly	43
Fetal brain disruption sequence	24
Other major brain abnormalities	72
Neural tube defects (NTDs) and holoprosencephaly	***63***
Anencephaly / Acrania	16
Encephalocele	9
Spina bifida	25
Holoprosencephaly/Arhinencephaly	14
Structural eye abnormalities	***25***
Microphthalmia / Anophthalmia	7
Coloboma	3
Cataract	13
Intraocular calcifications	2
Chorioretinal anomalies involving the macula	2
Optic nerve atrophy, pallor, and other optic nerve abnormalities	4
Congenital contractures and joint	16
Congenital deafness	27

The impact of Zika virus exposure has been low to non-existent in Louisiana resulting in no live births or fetal deaths of children affected by Congenital Zika Syndrome to follow beyond birth. Although rapid surveillance of Zika associated birth defects has ended, LBDMN continues to track a select few of these birth defects as part of its traditional case definition surveillance activities.

Data Quality Assessment Summary for 2018 Calendar Year

CDC monitors national birth defects surveillance through a branch called the National Center for Birth Defects and Developmental Disabilities (NCBDDD). NCBDDD coordinates standards for state birth defects programs through the National Birth Defects Prevention Network (NBDPN). The NBDPN Standards Workgroup produces an annual assessment report summary on Data Quality for population-based birth defects surveillance systems.

Performance standards are used to improve and standardize operations, outcomes, and surveillance functions across state programs, thereby making data comparable at the state, multi-state, and national levels. Eleven data quality measures around completeness, timeliness, and accuracy are associated with three performance levels (1) Rudimentary, (2) Essential, or (3) Optimal.

In 2018, Louisiana met level 1 criteria, rudimentary, in both measures of timeliness. Improving in this quality measure has been the aim of the program since 2015. In order to see consistent improvements, LBDMN has made systemic changes in workflow processes including:

- Implementation of a web-based LEERS integrated database in 2015;
- Adding 3 supplemental datasets for case ascertainment in 2017;
- Securing electronic submission of monthly discharge reports from 49 of 51 eligible reporting facilities in 2017/18;
- Securing remote access for abstracting medical records in 39 reporting facilities in 2017/18;
- Expanding the case definition to include fetal death; and
- Adopting a tiered abstraction strategy approach beginning in 2019 for future data cohorts.

See Appendix 4 for complete 2018 NBDPN Data Quality Assessment Report Summary.

Conclusion

Of 180,641 children born in Louisiana between 2013 and 2015, 5,016 children were diagnosed with at least one birth defect, yielding an overall prevalence of 277.7 per 10,000 live births or 2.8 % (annual average is 300/10,000). Among children with birth defects, cardiovascular system defects (about 48%) are the most common followed by defects of the genitourinary, musculoskeletal, chromosomal, orofacial, gastrointestinal, central nervous, eye, ear, face, and neck systems.

Louisiana Birth Defects Monitoring Network incorporates evidence based best public health surveillance practices including current technology and advanced methodologies to improve systems and data quality to identify, understand, and prevent birth defects and to make referrals to improve quality of life of families in Louisiana.

Section 2 – Appendix

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