Annual Legislative Report of the Indiana Birth Defects and Problems Registry
2020

The Indiana Birth Defects and Problems Registry (IBDPR) is a population-based surveillance system established in 1986 to monitor prevalence rates for conditions affecting fetal, infant and child health. The goal of surveillance through the IBDPR is to develop public health initiatives for increased awareness, community education, prevention, and decreased infant mortality. Nationally, it is estimated that about one in every 33 babies is born with a birth defect each year, which correlates to 120,000 babies annually. Birth defects are a leading cause of infant mortality across the United States. In Indiana, birth defects were the second leading cause of infant mortality in 2019. The rate of infant deaths associated with birth defects is 1.6 per 1,000 live births for 2019.

This report covers identified cases from January 2017 through December 2019, including 47 structural and chromosomal birth defects for birth to 3 years, fetal alcohol spectrum disorder through age 5, and pervasive developmental disorders for ages birth to 8 years. **Confirmed or Probable** occurrences for each were as follows:

- Structural and chromosomal birth defects: 7,126
- Fetal alcohol spectrum disorder: 68
- Pervasive developmental disorders: 82

Cardiovascular, genitourinary, and musculoskeletal defects are the most **common structural birth defects** across the United States as well as in Indiana. Of the 7,126 structural birth defects for the reporting period:

- 3,758 were cardiovascular.
- 1,119 were genitourinary.
- 890 were musculoskeletal.

Current Initiatives

The IBDPR team is currently in collaboration with the Centers for Disease Control and Prevention (CDC) and the Maternal and Child Health epidemiology team to surveil pregnant women in the state of Indiana who test positive for COVID-19. This initiative, also named the PILOT Project, is being developed to track pregnancy and neonate outcomes in relation to being diagnosed with a positive COVID-19 test. The purpose of the program is to not only collect data, but also to create awareness and service needs based on the data obtained.

The IBDPR program participates in addressing the opioid epidemic in partnership with the Indiana Perinatal Quality Improvement Collaborative (IPQIC) providing case reviews and follow-up for infants exposed to opioids during pregnancy. This includes utilizing standards of care established by IPQIC to ensure exposed infants have been identified and connected with appropriate healthcare resources to promote healthy growth and development.

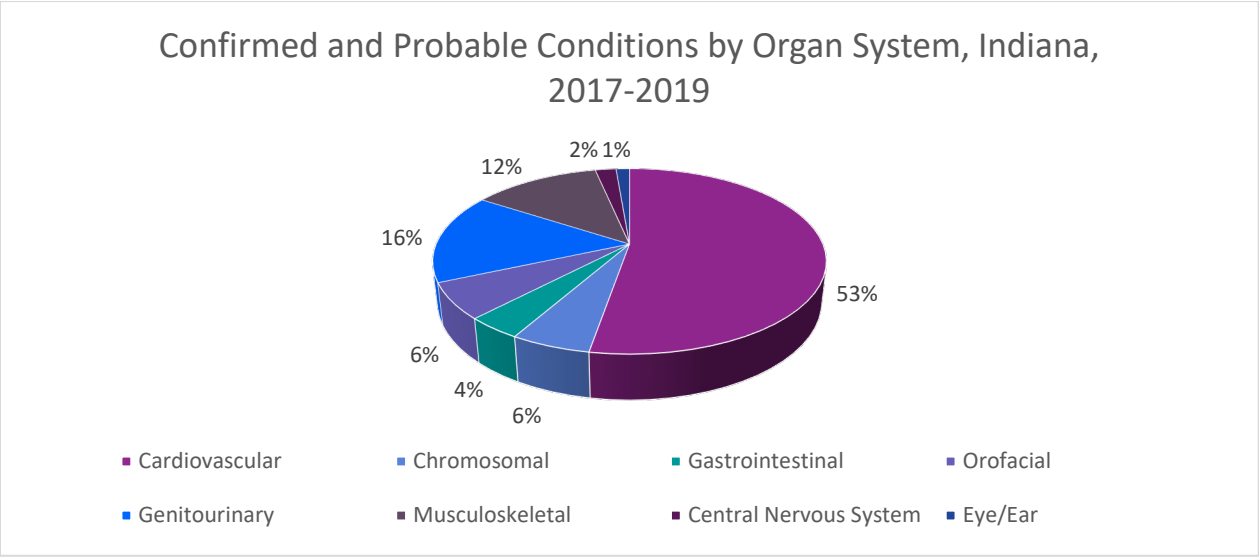
Additionally, an IBDPR subcommittee developed within the IPQIC partnership. Participants in the subcommittee include genetic counselors, geneticists, public health professionals in areas of birth defect surveillance, fatality review and prevention, children and youth with special health care needs, and the Early Hearing Detection and Intervention program. The subcommittee will focus on four specific deliverables including updating the reportable conditions list and creating a process to annually review the list, producing a new data source or methodology for ascertaining conditions diagnosed later after birth, creating communication and education strategies to pinpoint all stakeholders, and creating a new data analysis and reporting plan.

Furthermore, the IBDPR team is currently applying to a grant funded by the CDC titled "Advancing Population-Based Surveillance of Birth Defects." This three-component grant focuses on improving data quality, improving primary and secondary prevention strategies, developing interoperability capacity between electronic health records and birth defect surveillance, and the linkage of congenital heart defect results to surveillance data. The potential awarding of this grant will allow the IBDPR team to expand its services beyond collecting the data. Educational resources, trainings, and prevention campaigns are needed to spread awareness of birth defects to medical providers and Hoosier families.

Indiana Structural Birth Defect Rates, 2017-2019

The IBDPR monitors 47 structural birth defects categorized into eight organ systems along with fetal alcohol spectrum disorder and pervasive developmental disorders. The eight organ systems include: central nervous system, eye and ear, orofacial, cardiovascular, gastrointestinal, genitourinary, musculoskeletal, and chromosomal. Between January 2017 and December 2019, there were 7,126 confirmed or probable structural birth defects, 68 fetal alcohol spectrum disorders, and 82 pervasive developmental disorders. Cardiovascular, genitourinary, and musculoskeletal conditions remained the top three organ systems for birth defects. The figure below depicts the percentage of birth defects by category. Of the 7,126 structural birth defects, 3,758 were cardiovascular; 1,119 were genitourinary; and 890 were musculoskeletal. Atrial septal defect, ventricular septal defect, and hypospadias had the highest number of cases in years 2016-2018 and again in years 2017-2019. There were 1,632 cases of atrial septal defect followed by ventricular septal defect at 1,249, and hypospadias with 928. The figure below depicts the percentage of birth defects by category.

Figure 1. Structural Birth Defects by Category, Indiana, 2017-2019



Use of Indiana Birth Defects and Problems Registry Data

This year the National Birth Defects Prevention Network did not ask for data from the previous five years as requested in most years due to a shift in resources and the fact that the 1998 Birth Defects Prevention Act does not stipulate the national report on birth defects be completed annually but rather biennially. The National Birth Defects Prevention Network will still have a special issue in Birth Defects Research Journal for January 2021. The requested data for the special issue is on Trisomy 21 (Down syndrome) and co-occurring defects.

Internally, data from the IBDPR is used to detect statewide trends in birth defects and emerging outbreaks impacting mothers and babies, such as COVID-19. The Indiana Department of Health uses the information collected to identify epidemiological factors associated with birth defects; prepare for the next emerging threat to mothers and babies; address community concerns about the environmental effects on adverse birth outcomes; evaluate education, screening, and prevention programs; and establish efficient referral systems that provide special services for the children with birth defects and their families.

Proposals for Prevention of Birth Defects and Problems in Indiana

Birth defects and birth problems occur for various reasons, including inherited genetic conditions; new (or *de novo*) genetic mutations; perinatal exposure to infectious disease, toxic chemicals, and drugs; limited nutrients available to the developing fetus; and poor health behaviors exhibited by the mother both before and during pregnancy. While not all birth defects and problems can be prevented, the Indiana Department of Health is committed to promoting prevention methods to decrease the rate of infant morbidity and mortality across the state.

In response to the opioid epidemic, the Indiana Perinatal Quality Improvement Collaborative (IPQIC), an advisory board to the state Department of Health, recommended adding the codes for neonatal abstinence syndrome (NAS) and perinatal substance use as reportable conditions to the IBDPR. This effort would help identify both exposure to substances as well as actual diagnosis of NAS. Monitoring these conditions through the IBDPR allows for statewide data, reporting, and education. Current work of this initiative is focused on improving the data collection for NAS. Future objectives of this initiative include follow-up of identified cases to ensure connection to appropriate healthcare resources based on established standards of care.

The IBDPR team partnered with the Division of Fatality Review and Prevention at the state Department of Health to further understand the causes of fetal and infant deaths from the Fetal and Infant Mortality Review programs. The underlying outcome of this collaboration is to create and provide supplemental programs based on demographic need. One initiative involves implementing a folic acid campaign in counties that are reporting a higher rate of newborn born with anencephaly and spina bifida. This partnership will allow the IBDPR team to provide educational resources to communities based on their specific needs and decrease the overall rate of infant mortality throughout Indiana.

Additionally, the IBDPR team is currently in the planning stage of creating birth defect prevention trainings to be made available to primary care physicians, obstetricians, social workers, and more. The web-based trainings will be available on the IN-TRAIN Network, which is a platform that provides training and learning opportunities to public health professionals. The primary goals are to spread awareness of birth defects and improve overall quality of care.

Indiana County Data for 47 Structural Birth Defects and Two Disorders for Years 2017-2019

IBDPR collects data on 49 conditions, 47 of which are structural anomalies designated nationally by the National Birth Defects Prevention Network. Indiana also collects data on pervasive developmental disorders and fetal alcohol spectrum disorders as mandated. The prevalence rate for the 49 targeted conditions in Indiana for 2017-2019 was 305.31 per 10,000 live births. The county prevalence rates are listed below in Table 1. Counties with fewer than 20 cases do not have stable rates and should not be compared. Counties near Cincinnati, Dayton, Louisville, and Chicago may be underreported due to families seeking care in large healthcare facilities across state lines (eg. Cincinnati Children's Hospital, Dayton Children's Hospital, Norton Children's Hospital, and Lurie Children's Hospital, respectively). The counties with the five highest stable rates were Putnam (539.08 per 10,000), Sullivan (527.95 per 10,000 live births), Noble (481.74 per 10,000 live births), Greene (454.11 per 10,000 live births), and Fulton (450.07 per 10,000 live births). In years 2016-2018, Noble, Greene, and Fulton counties were not part of the highest five county rates. Putnam County increased from second highest rate to first highest rate in 2017-2019 compared to 2016-2018. Floyd, Clark, Adams, Jasper, and Lagrange counties had the lowest stable rates, with 111.17, 123.42, 167.36, 194.81, and 209.47 per 10,000 live births, respectively. Floyd, Clark, and Lagrange counties were in the lowest five counties for years 2016-2018. Some counts are suppressed for confidentiality due to small numbers. Unstable rates have been suppressed indicating a numerator less than 20.

Table 1. Structural Birth Defects, Fetal Alcohol Syndrome, and Pervasive Developmental Disorder Rates by County, Indiana, 2017-2019

County	Confirmed or Probable Counts	Prevalence Rate per 10,000 Live Births
Adams	32	167.36
Allen	581	370.87
Bartholomew	82	264.18
Benton	11	†
Blackford	17	†
Boone	75	313.81
Brown	13	†
Carroll	13	†
Cass	50	376.51
Clark	41	123.42
Clay	41	425.75
Clinton	53	407.38
Crawford	*	†
Daviess	45	265.33
Dearborn	*	†
Decatur	21	222.46
De Kalb	55	345.91

County	Confirmed or Probable Counts	Prevalence Rate per 10,000 Live Births
Delaware	113	348.12
Dubois	34	211.71
Elkhart	268	292
Fayette	18	†
Floyd	22	111.17
Fountain	20	380.95
Franklin	*	†
Fulton	32	450.07
Gibson	43	360.13
Grant	57	245.80
Greene	47	454.11
Hamilton	339	302.57
Hancock	87	352.37
Harrison	11	†
Hendricks	175	351.26
Henry	34	243.20
Howard	98	330.97
Huntington	44	355.13
Jackson	60	328.05
Jasper	21	194.81
Jay	29	348.56
Jefferson	24	228.35
Jennings	27	280.37
Johnson	178	321.76
Knox	30	243.51
Kosciusko	96	318.94
Lagrange	46	209.47
Lake	339	213.07
La Porte	95	258.93
Lawrence	49	323.43
Madison	138	327.48
Marion	1362	321.58
Marshall	56	340.63
Martin	12	†
Miami	47	406.22
Monroe	92	257.85
Montgomery	54	403.29
Morgan	79	342.73
Newton	8	†

County	Confirmed or Probable Counts	Prevalence Rate per 10,000 Live Births
Noble	91	481.74
Ohio	*	†
Orange	17	†
Owen	20	301.66
Parke	23	395.19
Perry	7	†
Pike	8	†
Porter	115	237.85
Posey	20	252.84
Pulaski	14	†
Putnam	60	539.08
Randolph	23	291.14
Ripley	25	252.78
Rush	11	†
Scott	6	†
Shelby	44	300.34
Spencer	14	†
St. Joseph	327	314.60
Starke	24	300.75
Steuben	44	404.78
Sullivan	34	527.95
Switzerland	4	†
Tippecanoe	187	291.28
Tipton	8	†
Union	7	†
Vanderburgh	247	387.94
Vermillion	13	†
Vigo	138	391.60
Wabash	36	378.55
Warren	10	†
Warrick	77	418.71
Washington	18	†
Wayne	68	306.17
Wells	28	280.84
White	32	355.16
Whitley	45	390.96
Indiana	**7276**	**305.31**

Notes:
* Count suppressed for confidentiality.
† Numerator less than 20, therefore, the rate is unstable. We do not recommend comparing unstable rates.