

## Indiana

### Indiana Birth Defects & Problems Registry (IBDPR)

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

**Partner:** Hospitals, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 2002

**Earliest year of available data:** 2003 birth data is available in 2006

**Organizational location:** Department of Health (Maternal and Child Health)

**Population covered annually:** 83,000

**Statewide:** Yes

**Current legislation or rule:** IC 16-38-4-7Rule 410 IAC 21-3

**Legislation year enacted:** 2001

#### Case Definition

**Outcomes covered:** Major birth defects, genetic disease, fetal alcohol syndrome, neonatal abstinence syndrome, pervasive developmental disorders, metabolic disorders, hearing loss, congenital blood disorders, and certain eye disorders.

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Less than 20 weeks gestation, 20 weeks gestation and greater, We only capture if mom had a past stillbirth or spontaneous abortion, not for the current child. For spontaneous abortions we quantify it as less than 20 weeks gestation, and for stillbirth we quantify it as 20 weeks gestation or greater. Data is not delineated by birth outcome.)

**Age:** 0-3 for core, recommended, and extended conditions; up to 5 years for FAS; up to age 8 with Autism Spectrum Disorders

**Residence:** In- and out-of-state (as reported to IBDPR) births to state residents

#### Surveillance Methods

**Case ascertainment:** Passive case-finding with case confirmation, case confirmation for hospital discharge data; w/o case confirmation for direct physician reporting

**Vital records:** Birth certificates, Death certificates

**Other state based registries:** Newborn hearing screening program, Newborn metabolic screening program, Developmental Disabilities Surveillance

**Delivery hospitals:** Discharge summaries

**Pediatric & tertiary care hospitals:** Discharge summaries

**Other specialty facilities:** Genetic counseling/clinic genetic facilities

**Other sources:** Midwifery Facilities, Physician reports

#### Case Ascertainment

**Conditions warranting chart review in newborn period:** Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), We collect all cases with codes Q00-Q99, but only perform chart reviews on core, recommended, extended NBDPN conditions, plus FAS, NAS, and Autism Spectrum Disorder.

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**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, Prenatal care, Pregnancy/delivery complications

#### Data Collection Methods and Storage

**Data collection:** Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

**Database collection and storage:** Oracle

#### Data Analysis

**Data analysis software:** SAS, SQL, Excel

**Quality assurance:** Double-checking of assigned codes, Data/hospital audits, Review by IBDPR staff, non-clinician

**Data use and analysis:** Routine statistical monitoring, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, 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, The birth defects registry is linked to other program databases (see below).

**System integration:** The database is linked with birth, death, newborn hearing screening, newborn metabolic, and pulse oximetry screening data.

#### Funding

**Funding source:** 14% Service fees, 86% Genetic screening revenues

#### Other

**Web site:** [www.birthdefects.in.gov](http://www.birthdefects.in.gov)

**Surveillance reports on file:** Progress Report to the Indiana Legislature

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## **DATA TABLES**

**Indiana**  
**Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)**

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Anencephalus	26 <i>0.8</i>	3 <i>0.6</i>	4 <i>1.7</i>	2 <i>1.8</i>	0 <i>0.0</i>	35 <i>0.9</i>	
Anophthalmia/microphthalmia	31 <i>1.0</i>	3 <i>0.6</i>	3 <i>1.3</i>	1 <i>0.9</i>	0 <i>0.0</i>	40 <i>1.0</i>	
Anotia/microtia	47 <i>1.5</i>	6 <i>1.2</i>	4 <i>1.7</i>	7 <i>6.2</i>	0 <i>0.0</i>	65 <i>1.6</i>	
Aortic valve stenosis	56 <i>1.8</i>	2 <i>0.4</i>	5 <i>2.2</i>	4 <i>3.6</i>	0 <i>0.0</i>	67 <i>1.6</i>	
Atrial septal defect	2,359 <i>74.3</i>	471 <i>97.3</i>	211 <i>91.6</i>	76 <i>67.7</i>	4 <i>97.8</i>	3,164 <i>77.4</i>	
Atrioventricular septal defect (Endocardial cushion defect)	121 <i>3.8</i>	26 <i>5.4</i>	10 <i>4.3</i>	2 <i>1.8</i>	0 <i>0.0</i>	160 <i>3.9</i>	
Biliary atresia	20 <i>0.6</i>	8 <i>1.7</i>	3 <i>1.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	32 <i>0.8</i>	
Bladder exstrophy	11 <i>0.3</i>	3 <i>0.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	14 <i>0.3</i>	
Choanal atresia	41 <i>1.3</i>	3 <i>0.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	45 <i>1.1</i>	
Cleft lip alone	105 <i>3.3</i>	6 <i>1.2</i>	5 <i>2.2</i>	2 <i>1.8</i>	0 <i>0.0</i>	119 <i>2.9</i>	
Cleft lip with cleft palate	209 <i>6.6</i>	16 <i>3.3</i>	24 <i>10.4</i>	5 <i>4.5</i>	0 <i>0.0</i>	259 <i>6.3</i>	
Cleft palate alone	249 <i>7.8</i>	28 <i>5.8</i>	14 <i>6.1</i>	3 <i>2.7</i>	0 <i>0.0</i>	296 <i>7.2</i>	
Cloacal exstrophy	31 <i>1.0</i>	4 <i>0.8</i>	1 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	36 <i>0.9</i>	
Clubfoot	444 <i>14.0</i>	66 <i>13.6</i>	31 <i>13.5</i>	6 <i>5.3</i>	0 <i>0.0</i>	559 <i>13.7</i>	
Coarctation of the aorta	181 <i>5.7</i>	16 <i>3.3</i>	14 <i>6.1</i>	5 <i>4.5</i>	0 <i>0.0</i>	218 <i>5.3</i>	
Common truncus (truncus arteriosus)	16 <i>0.5</i>	2 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	18 <i>0.4</i>	
Congenital cataract	20 <i>0.6</i>	7 <i>1.4</i>	3 <i>1.3</i>	1 <i>0.9</i>	0 <i>0.0</i>	31 <i>0.8</i>	
Congenital posterior urethral valves	34 <i>2.1</i>	6 <i>2.4</i>	1 <i>0.9</i>	2 <i>3.4</i>	0 <i>0.0</i>	44 <i>2.1</i>	1
Craniosynostosis	367 <i>11.6</i>	43 <i>8.9</i>	25 <i>10.9</i>	4 <i>3.6</i>	0 <i>0.0</i>	445 <i>10.9</i>	
Deletion 22q11.2	18 <i>0.6</i>	2 <i>0.4</i>	1 <i>0.4</i>	1 <i>0.9</i>	0 <i>0.0</i>	22 <i>0.5</i>	
Diaphragmatic hernia	111 <i>3.5</i>	18 <i>3.7</i>	16 <i>6.9</i>	3 <i>2.7</i>	0 <i>0.0</i>	151 <i>3.7</i>	
Double outlet right ventricle	64 <i>2.0</i>	15 <i>3.1</i>	7 <i>3.0</i>	2 <i>1.8</i>	0 <i>0.0</i>	90 <i>2.2</i>	
Ebstein anomaly	12 <i>0.4</i>	3 <i>0.6</i>	1 <i>0.4</i>	1 <i>0.9</i>	0 <i>0.0</i>	18 <i>0.4</i>	
Encephalocele	27 <i>0.9</i>	3 <i>0.6</i>	2 <i>0.9</i>	0 <i>0.0</i>	0 <i>0.0</i>	33 <i>0.8</i>	
Esophageal atresia/tracheoesophageal fistula	75 <i>2.4</i>	7 <i>1.4</i>	8 <i>3.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	93 <i>2.3</i>	
Gastroschisis	108 <i>3.4</i>	20 <i>4.1</i>	17 <i>7.4</i>	2 <i>1.8</i>	0 <i>0.0</i>	148 <i>3.6</i>	
Holoprosencephaly	51 <i>1.6</i>	6 <i>1.2</i>	5 <i>2.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	66 <i>1.6</i>	
Hypoplastic left heart syndrome	69 <i>2.2</i>	4 <i>0.8</i>	8 <i>3.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	81 <i>2.0</i>	
Hypospadias	1,218 <i>74.7</i>	166 <i>67.5</i>	55 <i>47.0</i>	47 <i>79.9</i>	2 <i>101.0</i>	1,502 <i>71.7</i>	1
Interrupted aortic arch	22 <i>0.7</i>	3 <i>0.6</i>	3 <i>1.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	28 <i>0.7</i>	

**Indiana**  
**Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)**

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Limb deficiencies (reduction defects)	103 3.2	11 2.3	11 4.8	0 0.0	0 0.0	126 3.1	
Omphalocele	66 2.1	13 2.7	7 3.0	5 4.5	0 0.0	93 2.3	
Pulmonary valve atresia and stenosis	244 7.7	31 6.4	35 15.2	5 4.5	1 24.4	317 7.8	
Pulmonary valve atresia	29 0.9	4 0.8	6 2.6	1 0.9	0 0.0	40 1.0	
Rectal and large intestinal atresia/stenosis	141 4.4	22 4.5	15 6.5	3 2.7	0 0.0	183 4.5	
Renal agenesis/hypoplasia	165 5.2	27 5.6	17 7.4	5 4.5	0 0.0	217 5.3	
Single ventricle	26 0.8	6 1.2	5 2.2	0 0.0	0 0.0	37 0.9	
Small intestinal atresia/stenosis	114 3.6	22 4.5	4 1.7	11 9.8	0 0.0	152 3.7	
Spina bifida without anencephalus	98 3.1	13 2.7	13 5.6	2 1.8	0 0.0	126 3.1	
Tetralogy of Fallot	106 3.3	14 2.9	5 2.2	6 5.3	0 0.0	135 3.3	
Total anomalous pulmonary venous connection	37 1.2	7 1.4	5 2.2	1 0.9	0 0.0	51 1.2	
Transposition of the great arteries (TGA)	11 0.3	1 0.2	2 0.9	1 0.9	0 0.0	15 0.4	
Dextro-transposition of great arteries (d-TGA)	82 2.6	8 1.7	9 3.9	3 2.7	0 0.0	103 2.5	
Tricuspid valve atresia and stenosis	17 0.5	7 1.4	2 0.9	2 1.8	0 0.0	28 0.7	
Trisomy 13	19 0.6	1 0.2	1 0.4	1 0.9	0 0.0	22 0.5	
Trisomy 18	40 1.3	10 2.1	5 2.2	3 2.7	0 0.0	59 1.4	
Trisomy 21 (Down syndrome)	415 13.1	63 13.0	56 24.3	15 13.4	0 0.0	551 13.5	
Turner syndrome	33 2.1	1 0.4	1 0.9	0 0.0	0 0.0	36 1.8	2
Ventricular septal defect	1,345 42.4	215 44.4	177 76.8	53 47.2	0 0.0	1,812 44.3	
<b>Total live births</b>	<b>317,334</b>	<b>48,412</b>	<b>23,036</b>	<b>11,219</b>	<b>409</b>	<b>408,728</b>	
<b>Male live births</b>	<b>163,004</b>	<b>24,586</b>	<b>11,690</b>	<b>5,886</b>	<b>198</b>	<b>209,589</b>	
<b>Female live births</b>	<b>154,330</b>	<b>23,826</b>	<b>11,346</b>	<b>5,333</b>	<b>211</b>	<b>199,139</b>	

**Indiana****Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)**

<b>Defect</b>	<b>Maternal Age (Years)</b>		<b>Total*</b>	<b>Notes</b>
	<b>Less than 35</b>	<b>35+</b>		
Gastroschisis	148	0	148	
	<i>4.1</i>	<i>0.0</i>	<i>3.6</i>	
Trisomy 13	14	8	22	
	<i>0.4</i>	<i>1.6</i>	<i>0.5</i>	
Trisomy 18	32	27	59	
	<i>0.9</i>	<i>5.5</i>	<i>1.4</i>	
Trisomy 21 (Down syndrome)	294	257	551	
	<i>8.2</i>	<i>52.0</i>	<i>13.5</i>	
<b>Total live births</b>	<b>359,252</b>	<b>49,459</b>	<b>408,728</b>	

**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. Prevalence is calculated per 10,000 female live births.

**General comments**

- \*Data for totals include unknown and/or other.  
 -Data for conditions include probable cases.