

## Florida

### Florida Birth Defects Registry (FBDR)

**Purpose:** Surveillance, Research, Educate health care professionals, women of childbearing age and general public about birth defects.  
**Partner:** Local Health Departments, Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators, Federal and state agencies  
**Program status:** Currently collecting data  
**Start year:** 1998  
**Earliest year of available data:** 1998  
**Organizational location:** Department of Health (Epidemiology/Environment), University  
**Population covered annually:** 220,229 in 2018  
**Statewide:** Yes  
**Current legislation or rule:** Section 381.0031(1,2) F.S., allows for development of a list of reportable conditions. Birth defects were added to the list in July 1999.  
**Legislation year enacted:** 1999

#### Case Definition

**Outcomes covered:** Major structural malformations and genetic disorders  
**Pregnancy outcome:** Livebirths (20 week gestation and greater)  
**Age:** Until age 1  
**Residence:** Florida

#### Surveillance Methods

**Case ascertainment:** Passive case-finding with case confirmation, FL has one CDC funded cooperative agreement which use active case ascertainment which is linked to the passive surveillance program.  
**Vital records:** Birth certificates, Death certificates, Matched birth/death file  
**Other state based registries:** Programs for children with special needs  
**Delivery hospitals:** Disease index or discharge index  
**Pediatric & tertiary care hospitals:** Disease index or discharge index

#### Case Ascertainment

**Conditions warranting chart review in newborn period:** Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)  
**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, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications, Family history  
**Father:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

#### Data Collection Methods and Storage

**Data collection:** Electronic file/report submitted by other agencies (hospitals, etc.)  
**Database collection and storage:** Access, Dedicated server for birth defects data

#### Data Analysis

**Data analysis software:** SAS, SQL, dBASE  
**Quality assurance:** Validity checks, Re-abstraction of cases, Comparison/verification between multiple data sources, 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, Capture-recapture analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, 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, Maternal linked file.

**System integration:** The department has created a maternally linked file beginning with 1998. The birth defects data has been included in this linked file. Birth defects data are displayed on the department's Environmental Public Health Tracking Program site ([www.floridatracking.com](http://www.floridatracking.com)) and the Florida Community Health Assessment Resource Tool Set ([www.flhealthcharts.com](http://www.flhealthcharts.com))

#### Funding

**Funding source:** 75% General state funds, 25% CDC grant

#### Other

##### Web site:

<http://www.floridahealth.gov/diseases-and-conditions/birth-defects/index.html>

**Surveillance reports on file:** Publications, procedure manuals, electronic case ascertainment database and educational materials

**Other comments:** CDC/NCBDDD Cooperative Agreement for enhanced surveillance of selected birth defects, referral for services and prevention activities.

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## **DATA TABLES**

**Florida**  
**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	44 <i>0.9</i>	22 <i>0.9</i>	26 <i>0.8</i>	<5	0 <i>0.0</i>	96 <i>0.9</i>	
Anophthalmia/microphthalmia	43 <i>0.9</i>	37 <i>1.6</i>	30 <i>0.9</i>	5 <i>1.5</i>	0 <i>0.0</i>	121 <i>1.1</i>	
Anotia/microtia	58 <i>1.2</i>	28 <i>1.2</i>	48 <i>1.5</i>	<5	0 <i>0.0</i>	142 <i>1.3</i>	
Aortic valve stenosis	81 <i>1.7</i>	14 <i>0.6</i>	43 <i>1.3</i>	5 <i>1.5</i>	0 <i>0.0</i>	148 <i>1.3</i>	
Atrial septal defect	4,890 <i>102.2</i>	3,070 <i>129.3</i>	3,928 <i>121.5</i>	304 <i>91.3</i>	17 <i>136.3</i>	12,535 <i>113.2</i>	
Atrioventricular septal defect (Endocardial cushion defect)	168 <i>3.5</i>	135 <i>5.7</i>	87 <i>2.7</i>	9 <i>2.7</i>	<5	414 <i>3.7</i>	1
Biliary atresia	79 <i>1.7</i>	109 <i>4.6</i>	56 <i>1.7</i>	14 <i>4.2</i>	0 <i>0.0</i>	266 <i>2.4</i>	
Bladder exstrophy	15 <i>0.3</i>	<5	5 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	24 <i>0.2</i>	
Choanal atresia	107 <i>2.2</i>	27 <i>1.1</i>	49 <i>1.5</i>	5 <i>1.5</i>	0 <i>0.0</i>	193 <i>1.7</i>	
Cleft lip alone	177 <i>3.7</i>	31 <i>1.3</i>	55 <i>1.7</i>	6 <i>1.8</i>	0 <i>0.0</i>	274 <i>2.5</i>	
Cleft lip with cleft palate	286 <i>6.0</i>	85 <i>3.6</i>	155 <i>4.8</i>	17 <i>5.1</i>	<5	561 <i>5.1</i>	
Cleft palate alone	276 <i>5.8</i>	83 <i>3.5</i>	142 <i>4.4</i>	26 <i>7.8</i>	<5	542 <i>4.9</i>	
Cloacal exstrophy	97 <i>2.0</i>	60 <i>2.5</i>	57 <i>1.8</i>	<5	<5	222 <i>2.0</i>	
Clubfoot	957 <i>20.0</i>	390 <i>16.4</i>	553 <i>17.1</i>	42 <i>12.6</i>	5 <i>40.1</i>	1,996 <i>18.0</i>	
Coarctation of the aorta	328 <i>6.9</i>	122 <i>5.1</i>	158 <i>4.9</i>	19 <i>5.7</i>	0 <i>0.0</i>	644 <i>5.8</i>	
Common truncus (truncus arteriosus)	23 <i>0.5</i>	13 <i>0.5</i>	19 <i>0.6</i>	<5	0 <i>0.0</i>	62 <i>0.6</i>	
Congenital cataract	63 <i>1.3</i>	24 <i>1.0</i>	43 <i>1.3</i>	<5	0 <i>0.0</i>	134 <i>1.2</i>	
Congenital posterior urethral valves	47 <i>1.9</i>	46 <i>3.8</i>	26 <i>1.6</i>	<5	0 <i>0.0</i>	123 <i>2.2</i>	2
Craniosynostosis	239 <i>5.0</i>	55 <i>2.3</i>	126 <i>3.9</i>	8 <i>2.4</i>	0 <i>0.0</i>	439 <i>4.0</i>	
Deletion 22q11.2	17 <i>0.4</i>	8 <i>0.3</i>	15 <i>0.5</i>	<5	0 <i>0.0</i>	44 <i>0.4</i>	
Diaphragmatic hernia	153 <i>3.2</i>	86 <i>3.6</i>	90 <i>2.8</i>	18 <i>5.4</i>	0 <i>0.0</i>	356 <i>3.2</i>	
Double outlet right ventricle	104 <i>2.2</i>	63 <i>2.7</i>	54 <i>1.7</i>	6 <i>1.8</i>	0 <i>0.0</i>	232 <i>2.1</i>	
Ebstein anomaly	47 <i>1.0</i>	9 <i>0.4</i>	21 <i>0.6</i>	<5	0 <i>0.0</i>	89 <i>0.8</i>	
Encephalocele	37 <i>0.8</i>	11 <i>0.5</i>	18 <i>0.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	68 <i>0.6</i>	
Esophageal atresia/tracheoesophageal fistula	122 <i>2.6</i>	52 <i>2.2</i>	85 <i>2.6</i>	12 <i>3.6</i>	0 <i>0.0</i>	281 <i>2.5</i>	
Gastroschisis	233 <i>4.9</i>	62 <i>2.6</i>	107 <i>3.3</i>	5 <i>1.5</i>	0 <i>0.0</i>	416 <i>3.8</i>	3
Holoprosencephaly	90 <i>1.9</i>	71 <i>3.0</i>	66 <i>2.0</i>	6 <i>1.8</i>	0 <i>0.0</i>	240 <i>2.2</i>	
Hypoplastic left heart syndrome	185 <i>3.9</i>	96 <i>4.0</i>	82 <i>2.5</i>	11 <i>3.3</i>	0 <i>0.0</i>	387 <i>3.5</i>	
Hypospadias	2,082 <i>84.7</i>	762 <i>63.3</i>	912 <i>55.0</i>	104 <i>60.5</i>	<5	3,965 <i>69.9</i>	2
Interrupted aortic arch	17 <i>0.4</i>	11 <i>0.5</i>	11 <i>0.3</i>	<5	0 <i>0.0</i>	44 <i>0.4</i>	4

**Florida**  
**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)	159 3.3	93 3.9	119 3.7	5 1.5	<5	382 3.4	
Omphalocele	105 2.2	91 3.8	53 1.6	<5	0 0.0	261 2.4	3
Pulmonary valve atresia and stenosis	365 7.6	278 11.7	365 11.3	12 3.6	<5	1,066 9.6	
Pulmonary valve atresia	25 0.5	21 0.9	19 0.6	<5	0 0.0	72 0.7	5
Rectal and large intestinal atresia/stenosis	191 4.0	80 3.4	118 3.6	18 5.4	0 0.0	422 3.8	
Renal agenesis/hypoplasia	270 5.6	135 5.7	177 5.5	17 5.1	<5	618 5.6	
Single ventricle	67 1.4	48 2.0	35 1.1	<5	0 0.0	155 1.4	
Small intestinal atresia/stenosis	183 3.8	114 4.8	101 3.1	12 3.6	0 0.0	419 3.8	
Spina bifida without anencephalus	131 2.7	48 2.0	78 2.4	<5	0 0.0	269 2.4	
Tetralogy of Fallot	262 5.5	123 5.2	140 4.3	14 4.2	<5	562 5.1	6
Total anomalous pulmonary venous connection	38 0.8	14 0.6	35 1.1	<5	0 0.0	90 0.8	
Transposition of the great arteries (TGA)	148 3.1	56 2.4	77 2.4	<5	0 0.0	292 2.6	
Dextro-transposition of great arteries (d-TGA)	133 2.8	53 2.2	75 2.3	<5	0 0.0	272 2.5	
Tricuspid valve atresia and stenosis	38 0.8	32 1.3	18 0.6	<5	0 0.0	92 0.8	7
Trisomy 13	38 0.8	44 1.9	19 0.6	<5	0 0.0	106 1.0	
Trisomy 18	70 1.5	77 3.2	54 1.7	10 3.0	0 0.0	215 1.9	
Trisomy 21 (Down syndrome)	577 12.1	338 14.2	405 12.5	38 11.4	<5	1,404 12.7	
Turner syndrome	60 2.6	10 0.9	34 2.2	6 3.7	0 0.0	111 2.1	8
Ventricular septal defect	2,807 58.7	1,399 58.9	2,115 65.4	163 48.9	7 56.1	6,656 60.1	9
<b>Total live births</b>	<b>478,339</b>	<b>237,472</b>	<b>323,306</b>	<b>33,308</b>	<b>1,247</b>	<b>1,107,528</b>	<b>10</b>
<b>Male live births</b>	<b>245,819</b>	<b>120,336</b>	<b>165,750</b>	<b>17,199</b>	<b>656</b>	<b>567,141</b>	
<b>Female live births</b>	<b>232,517</b>	<b>117,130</b>	<b>157,554</b>	<b>16,108</b>	<b>591</b>	<b>540,371</b>	

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	404 <i>4.4</i>	12 <i>0.6</i>	416 <i>3.8</i>	3
Trisomy 13	68 <i>0.7</i>	38 <i>2.0</i>	106 <i>1.0</i>	
Trisomy 18	103 <i>1.1</i>	112 <i>5.8</i>	215 <i>1.9</i>	
Trisomy 21 (Down syndrome)	685 <i>7.5</i>	719 <i>37.3</i>	1,404 <i>12.7</i>	
<b>Total live births</b>	<b>914,597</b>	<b>192,871</b>	<b>1,107,528</b>	<b>10</b>

**Notes**

1. Data for this condition include canal type atrioventricular septal defect.
2. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
3. Data for this condition may differ from previous reports due to ICD-9-CM coding system changes.
4. Data for this condition are based on code Q25.21.
5. Data for this condition exclude cases with a co-occurring ventricular septal defect.
6. Data for this condition include cases of pulmonary atresia that co-occurred with ventricular septal defect.
7. Data for this condition include congenital tricuspid stenosis.
8. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
9. Data for this condition include probable cases.
10. Data for total live births include unknown gender.

**General comments**

\*Data for totals include unknown and/or other.  
 -Data for conditions include live births only.