

## Tennessee

### Tennessee Birth Defects Surveillance System (TNBDSS)

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

**Partner:** Local Health Departments, Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators

**Program status:** Currently collecting data

**Start year:** 2000

**Earliest year of available data:** 1999

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

**Population covered annually:** 80,864

**Statewide:** Yes

**Current legislation or rule:** TCA 68-5-506

**Legislation year enacted:** 2000

#### Case Definition

**Outcomes covered:** 47 major structural birth defects

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Prior to July 1st 2010: 500 grams or more, or in the absence of weight, 22 completed weeks of gestation or more; July 1st 2010 and later: 350 grams or more, or in the absence of weight, 20 completed weeks of gestation or more)

**Age:** Up to 5 years old

**Residence:** In and out of state births to state residents

#### Surveillance Methods

**Case ascertainment:** Passive case-finding with case confirmation, Passive case-finding without case confirmation

**Vital records:** Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate

**Other state based registries:** Newborn hearing screening program, Newborn metabolic screening program, Hospital Discharge Data System

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics

**Other sources:** Midwifery Facilities

#### Case Ascertainment

**Conditions warranting chart review in newborn period:** ICD-10 codes from 26 specific birth defects

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), Cardiovascular condition, Ocular conditions

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

**Database collection and storage:** SAS, REDCap, Birth defects internet case management system (iCMS)

#### Data Analysis

**Data analysis software:** SAS, Arc-GIS

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness

#### System Integration

**System links:** Link to other state registries/databases, Link case finding data to final birth file

#### Funding

**Funding source:** 10% MCH funds, 90% CDC grant

#### Other

**Web site:** [www.tn.gov/health](http://www.tn.gov/health)

**Surveillance reports on file:** Tennessee Birth Defects Registry Report 2014-2018

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## **DATA TABLES**

**Tennessee**  
**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	41 <i>1.5</i>	15 <i>1.8</i>	9 <i>2.4</i>	2 <i>2.0</i>	0 <i>0.0</i>	72 <i>1.8</i>	
Anophthalmia/microphthalmia	39 <i>1.4</i>	11 <i>1.3</i>	7 <i>1.9</i>	1 <i>1.0</i>	0 <i>0.0</i>	58 <i>1.4</i>	
Anotia/microtia	35 <i>1.3</i>	8 <i>1.0</i>	19 <i>5.1</i>	4 <i>4.0</i>	0 <i>0.0</i>	66 <i>1.6</i>	
Aortic valve stenosis	56 <i>2.1</i>	6 <i>0.7</i>	6 <i>1.6</i>	2 <i>2.0</i>	0 <i>0.0</i>	74 <i>1.8</i>	
Atrial septal defect	4,978 <i>183.8</i>	2,259 <i>273.5</i>	594 <i>159.1</i>	147 <i>148.0</i>	11 <i>198.9</i>	8,046 <i>198.4</i>	
Atrioventricular septal defect (Endocardial cushion defect)	158 <i>5.8</i>	58 <i>7.0</i>	20 <i>5.4</i>	3 <i>3.0</i>	0 <i>0.0</i>	239 <i>5.9</i>	
Biliary atresia	108 <i>4.0</i>	46 <i>5.6</i>	15 <i>4.0</i>	6 <i>6.0</i>	0 <i>0.0</i>	176 <i>4.3</i>	
Bladder exstrophy	8 <i>0.3</i>	3 <i>0.4</i>	3 <i>0.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	14 <i>0.3</i>	
Choanal atresia	66 <i>2.4</i>	17 <i>2.1</i>	11 <i>2.9</i>	1 <i>1.0</i>	0 <i>0.0</i>	95 <i>2.3</i>	
Cleft lip alone	83 <i>3.1</i>	14 <i>1.7</i>	8 <i>2.1</i>	6 <i>6.0</i>	0 <i>0.0</i>	111 <i>2.7</i>	
Cleft lip with cleft palate	210 <i>7.8</i>	35 <i>4.2</i>	33 <i>8.8</i>	4 <i>4.0</i>	1 <i>18.1</i>	284 <i>7.0</i>	
Cleft palate alone	224 <i>8.3</i>	38 <i>4.6</i>	21 <i>5.6</i>	4 <i>4.0</i>	0 <i>0.0</i>	288 <i>7.1</i>	
Cloacal exstrophy	71 <i>2.6</i>	24 <i>2.9</i>	7 <i>1.9</i>	1 <i>1.0</i>	1 <i>18.1</i>	104 <i>2.6</i>	
Clubfoot	622 <i>23.0</i>	184 <i>22.3</i>	67 <i>17.9</i>	10 <i>10.1</i>	1 <i>18.1</i>	892 <i>22.0</i>	
Coarctation of the aorta	238 <i>8.8</i>	68 <i>8.2</i>	39 <i>10.4</i>	8 <i>8.1</i>	0 <i>0.0</i>	359 <i>8.9</i>	
Common truncus (truncus arteriosus)	23 <i>0.8</i>	8 <i>1.0</i>	4 <i>1.1</i>	1 <i>1.0</i>	0 <i>0.0</i>	36 <i>0.9</i>	
Congenital cataract	71 <i>2.6</i>	20 <i>2.4</i>	8 <i>2.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	99 <i>2.4</i>	
Congenital posterior urethral valves	32 <i>2.3</i>	26 <i>6.3</i>	4 <i>2.1</i>	3 <i>5.8</i>	0 <i>0.0</i>	66 <i>3.2</i>	1
Craniosynostosis	387 <i>18.0</i>	45 <i>6.9</i>	43 <i>14.2</i>	7 <i>8.7</i>	0 <i>0.0</i>	488 <i>15.1</i>	2
Deletion 22q11.2	8 <i>0.3</i>	3 <i>0.4</i>	1 <i>0.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	12 <i>0.3</i>	
Diaphragmatic hernia	114 <i>4.2</i>	37 <i>4.5</i>	13 <i>3.5</i>	4 <i>4.0</i>	0 <i>0.0</i>	170 <i>4.2</i>	
Double outlet right ventricle	84 <i>3.1</i>	30 <i>3.6</i>	11 <i>2.9</i>	4 <i>4.0</i>	0 <i>0.0</i>	129 <i>3.2</i>	
Ebstein anomaly	44 <i>1.6</i>	5 <i>0.6</i>	10 <i>2.7</i>	3 <i>3.0</i>	0 <i>0.0</i>	62 <i>1.5</i>	
Encephalocele	40 <i>1.5</i>	14 <i>1.7</i>	4 <i>1.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	58 <i>1.4</i>	
Esophageal atresia/tracheoesophageal fistula	79 <i>2.9</i>	21 <i>2.5</i>	8 <i>2.1</i>	3 <i>3.0</i>	0 <i>0.0</i>	112 <i>2.8</i>	
Gastroschisis	142 <i>5.2</i>	34 <i>4.1</i>	15 <i>4.0</i>	2 <i>2.0</i>	0 <i>0.0</i>	202 <i>5.0</i>	
Holoprosencephaly	97 <i>3.6</i>	30 <i>3.6</i>	13 <i>3.5</i>	4 <i>4.0</i>	0 <i>0.0</i>	145 <i>3.6</i>	
Hypoplastic left heart syndrome	97 <i>3.6</i>	34 <i>4.1</i>	13 <i>3.5</i>	2 <i>2.0</i>	0 <i>0.0</i>	149 <i>3.7</i>	
Hypospadias	1,639 <i>117.8</i>	439 <i>105.6</i>	121 <i>63.5</i>	43 <i>83.8</i>	1 <i>35.8</i>	2,263 <i>109.1</i>	1
Interrupted aortic arch	50 <i>1.8</i>	18 <i>2.2</i>	10 <i>2.7</i>	1 <i>1.0</i>	0 <i>0.0</i>	79 <i>1.9</i>	

**Tennessee**  
**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)	122 <i>4.5</i>	34 <i>4.1</i>	15 <i>4.0</i>	3 <i>3.0</i>	0 <i>0.0</i>	176 <i>4.3</i>	
Omphalocele	68 <i>2.5</i>	33 <i>4.0</i>	12 <i>3.2</i>	3 <i>3.0</i>	0 <i>0.0</i>	120 <i>3.0</i>	
Pulmonary valve atresia and stenosis	250 <i>9.2</i>	87 <i>10.5</i>	29 <i>7.8</i>	9 <i>9.1</i>	1 <i>18.1</i>	379 <i>9.3</i>	
Pulmonary valve atresia	29 <i>1.1</i>	6 <i>0.7</i>	4 <i>1.1</i>	1 <i>1.0</i>	0 <i>0.0</i>	40 <i>1.0</i>	
Rectal and large intestinal atresia/stenosis	127 <i>4.7</i>	43 <i>5.2</i>	28 <i>7.5</i>	6 <i>6.0</i>	0 <i>0.0</i>	205 <i>5.1</i>	
Renal agenesis/hypoplasia	195 <i>7.2</i>	44 <i>5.3</i>	22 <i>5.9</i>	3 <i>3.0</i>	0 <i>0.0</i>	267 <i>6.6</i>	
Single ventricle	38 <i>1.4</i>	11 <i>1.3</i>	7 <i>1.9</i>	2 <i>2.0</i>	0 <i>0.0</i>	59 <i>1.5</i>	
Small intestinal atresia/stenosis	127 <i>4.7</i>	55 <i>6.7</i>	22 <i>5.9</i>	2 <i>2.0</i>	1 <i>18.1</i>	209 <i>5.2</i>	
Spina bifida without anencephalus	131 <i>4.8</i>	31 <i>3.8</i>	16 <i>4.3</i>	6 <i>6.0</i>	0 <i>0.0</i>	188 <i>4.6</i>	
Tetralogy of Fallot	182 <i>6.7</i>	64 <i>7.7</i>	13 <i>3.5</i>	4 <i>4.0</i>	0 <i>0.0</i>	263 <i>6.5</i>	
Total anomalous pulmonary venous connection	28 <i>1.0</i>	4 <i>0.5</i>	9 <i>2.4</i>	1 <i>1.0</i>	0 <i>0.0</i>	42 <i>1.0</i>	
Transposition of the great arteries (TGA)	96 <i>3.5</i>	22 <i>2.7</i>	16 <i>4.3</i>	2 <i>2.0</i>	0 <i>0.0</i>	137 <i>3.4</i>	
Dextro-transposition of great arteries (d-TGA)	91 <i>3.4</i>	22 <i>2.7</i>	13 <i>3.5</i>	2 <i>2.0</i>	0 <i>0.0</i>	129 <i>3.2</i>	
Tricuspid valve atresia and stenosis	36 <i>1.3</i>	10 <i>1.2</i>	4 <i>1.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	50 <i>1.2</i>	
Trisomy 13	30 <i>1.1</i>	11 <i>1.3</i>	6 <i>1.6</i>	2 <i>2.0</i>	0 <i>0.0</i>	49 <i>1.2</i>	
Trisomy 18	45 <i>1.7</i>	20 <i>2.4</i>	14 <i>3.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	79 <i>1.9</i>	
Trisomy 21 (Down syndrome)	374 <i>13.8</i>	89 <i>10.8</i>	85 <i>22.8</i>	15 <i>15.1</i>	0 <i>0.0</i>	572 <i>14.1</i>	
Turner syndrome	33 <i>2.5</i>	10 <i>2.4</i>	4 <i>2.2</i>	2 <i>4.2</i>	0 <i>0.0</i>	51 <i>2.6</i>	3
Ventricular septal defect	1,333 <i>49.2</i>	403 <i>48.8</i>	211 <i>56.5</i>	41 <i>41.3</i>	4 <i>72.3</i>	2,006 <i>49.5</i>	
<b>Total live births</b>	<b>270,907</b>	<b>82,602</b>	<b>37,328</b>	<b>9,934</b>	<b>553</b>	<b>405,499</b>	<b>4</b>
<b>Male live births</b>	<b>139,137</b>	<b>41,579</b>	<b>19,067</b>	<b>5,134</b>	<b>279</b>	<b>207,343</b>	
<b>Female live births</b>	<b>131,768</b>	<b>41,022</b>	<b>18,260</b>	<b>4,800</b>	<b>274</b>	<b>198,152</b>	

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	189 <i>5.3</i>	10 <i>2.0</i>	202 <i>5.0</i>	
Trisomy 13	38 <i>1.1</i>	11 <i>2.2</i>	49 <i>1.2</i>	
Trisomy 18	50 <i>1.4</i>	29 <i>5.8</i>	79 <i>1.9</i>	
Trisomy 21 (Down syndrome)	320 <i>9.0</i>	246 <i>49.0</i>	572 <i>14.1</i>	
<b>Total live births</b>	<b>355,207</b>	<b>50,223</b>	<b>405,499</b>	<b>4</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 begin in late 2015.
3. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
4. Data for total live births include unknown gender.

**General comments**

\*Data for totals include unknown and/or other.