

## Wisconsin

### Wisconsin Birth Defect Prevention and Surveillance System (WBDPSS)

**Purpose:** Surveillance, Research, Referral to Services

**Partner:** Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs

**Program status:** Currently collecting data

**Start year:** 2004

**Earliest year of available data:** 2005

**Organizational location:** Department of Health (Maternal and Child Health, Department of Health Services, Division of Public Health, Bureau of Community Health Promotion, Family Health Section, Children and Youth with Special Health Care Needs Unit)

**Population covered annually:** average 69,000

**Statewide:** Yes

**Current legislation or rule:** State statute 253.12 Birth defect prevention and surveillance system. Enacted December 2000. The statute was updated September 2017 and was enacted on July 1, 2018. The original legislation required parent permission to submit identifiers to the registry. The 2017 updated removed that requirement and parents now opt out if they don't want identifiers included in the registry. Department of Health Services rules, Chapter DHS 116 Wisconsin Birth Defect Prevention and Surveillance System. Enacted April 2003.

**Legislation year enacted:** 2000 and update enacted in 2018

#### Case Definition

**Outcomes covered:** A list of 87 specific birth defects are collected. The list may be viewed on our website at <https://www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm>. It is an appendix to the reporting form DPH 40054. The list was developed by the Scientific Committee of the Council on Birth Defect Prevention and Surveillance and is included as an appendix in the rules.

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

**Age:** Up to 2 years after delivery

**Residence:** All children born in and/or receiving services in the state

#### Surveillance Methods

**Case ascertainment:** Passive case-finding without case confirmation, Work with reporters who report batches from EMRs to assure reporting quality and allow manual case entry into the reporting system for reporters with fewer cases who prefer that method.

**Vital records:** Matched birth/death file, compare registry reports to vital records periodically for selected birth defects

#### Case Ascertainment

**Coding:** ICD-9-CM/ICD-10-CM, State created codes assigned to all conditions collected. Reporters combine ICD-9-CM or ICD-10 with text searches to derive defects that share an ICD code.

#### Data Collected

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

**Father:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

#### Data Collection Methods and Storage

**Data collection:** Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Can submit one report on the website or upload multiple reports. A paper form is also available that is entered by state birth defects staff.

**Database collection and storage:** Oracle

#### Data Analysis

**Data analysis software:** SAS

**Quality assurance:** Validity checks, Comparison/verification between multiple data sources

**Data use and analysis:** Routine statistical monitoring, Grant proposals, Prevention projects

#### Funding

**Funding source:** 100% Other (revenue from birth certificate fees)

#### Other

**Web site:** <https://www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm>

**Surveillance reports on file:** Posted on the website

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## **DATA TABLES**

**Wisconsin**  
**Birth Defects Counts and Prevalence 2015 - 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	23 <i>1.2</i>	1 <i>0.4</i>	5 <i>1.9</i>	4 <i>3.4</i>	0 <i>0.0</i>	33 <i>1.2</i>	
Anophthalmia/microphthalmia	3 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	3 <i>0.1</i>	
Anotia/microtia	28 <i>1.4</i>	4 <i>1.5</i>	5 <i>1.9</i>	2 <i>1.7</i>	1 <i>3.5</i>	40 <i>1.4</i>	
Aortic valve stenosis	13 <i>0.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>3.5</i>	14 <i>0.5</i>	
Atrial septal defect	1,486 <i>76.9</i>	199 <i>75.1</i>	154 <i>59.6</i>	61 <i>51.2</i>	32 <i>112.1</i>	1,932 <i>68.8</i>	
Atrioventricular septal defect (Endocardial cushion defect)	105 <i>5.4</i>	10 <i>3.8</i>	10 <i>3.9</i>	6 <i>5.0</i>	0 <i>0.0</i>	131 <i>4.7</i>	
Biliary atresia	31 <i>1.6</i>	11 <i>4.2</i>	4 <i>1.5</i>	2 <i>1.7</i>	0 <i>0.0</i>	48 <i>1.7</i>	
Bladder exstrophy	6 <i>0.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	6 <i>0.2</i>	
Choanal atresia	30 <i>1.6</i>	7 <i>2.6</i>	2 <i>0.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	39 <i>1.4</i>	
Cleft lip alone	51 <i>2.6</i>	5 <i>1.9</i>	6 <i>2.3</i>	3 <i>2.5</i>	2 <i>7.0</i>	67 <i>2.4</i>	
Cleft lip with cleft palate	160 <i>8.3</i>	14 <i>5.3</i>	19 <i>7.4</i>	4 <i>3.4</i>	3 <i>10.5</i>	200 <i>7.1</i>	
Cleft palate alone	115 <i>5.9</i>	5 <i>1.9</i>	6 <i>2.3</i>	7 <i>5.9</i>	1 <i>3.5</i>	134 <i>4.8</i>	
Cloacal exstrophy	1 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>0.0</i>	
Clubfoot	350 <i>18.1</i>	53 <i>20.0</i>	44 <i>17.0</i>	15 <i>12.6</i>	4 <i>14.0</i>	466 <i>16.6</i>	
Coarctation of the aorta	82 <i>4.2</i>	11 <i>4.2</i>	7 <i>2.7</i>	3 <i>2.5</i>	1 <i>3.5</i>	104 <i>3.7</i>	
Common truncus (truncus arteriosus)	8 <i>0.4</i>	2 <i>0.8</i>	2 <i>0.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	12 <i>0.4</i>	
Congenital cataract	7 <i>0.4</i>	3 <i>1.1</i>	2 <i>0.8</i>	0 <i>0.0</i>	1 <i>3.5</i>	13 <i>0.5</i>	
Congenital posterior urethral valves	7 <i>0.7</i>	1 <i>0.7</i>	2 <i>1.5</i>	1 <i>1.6</i>	0 <i>0.0</i>	11 <i>0.7</i>	1
Craniosynostosis	124 <i>6.4</i>	7 <i>2.6</i>	10 <i>3.9</i>	2 <i>1.7</i>	1 <i>3.5</i>	144 <i>5.1</i>	
Deletion 22q11.2	11 <i>0.6</i>	1 <i>0.4</i>	3 <i>1.2</i>	1 <i>0.8</i>	0 <i>0.0</i>	16 <i>0.6</i>	
Diaphragmatic hernia	81 <i>4.2</i>	10 <i>3.8</i>	7 <i>2.7</i>	5 <i>4.2</i>	0 <i>0.0</i>	103 <i>3.7</i>	
Double outlet right ventricle	60 <i>3.1</i>	6 <i>2.3</i>	5 <i>1.9</i>	6 <i>5.0</i>	0 <i>0.0</i>	77 <i>2.7</i>	
Ebstein anomaly	20 <i>1.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>3.5</i>	22 <i>0.8</i>	
Encephalocele	6 <i>0.3</i>	0 <i>0.0</i>	3 <i>1.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>0.3</i>	
Esophageal atresia/tracheoesophageal fistula	49 <i>2.5</i>	4 <i>1.5</i>	7 <i>2.7</i>	0 <i>0.0</i>	1 <i>3.5</i>	61 <i>2.2</i>	
Gastroschisis	77 <i>4.0</i>	3 <i>1.1</i>	3 <i>1.2</i>	3 <i>2.5</i>	1 <i>3.5</i>	87 <i>3.1</i>	
Holoprosencephaly	17 <i>0.9</i>	0 <i>0.0</i>	2 <i>0.8</i>	1 <i>0.8</i>	1 <i>3.5</i>	21 <i>0.7</i>	
Hypoplastic left heart syndrome	83 <i>4.3</i>	10 <i>3.8</i>	2 <i>0.8</i>	3 <i>2.5</i>	0 <i>0.0</i>	98 <i>3.5</i>	
Hypospadias	591 <i>55.4</i>	65 <i>45.6</i>	41 <i>30.3</i>	12 <i>19.3</i>	3 <i>20.2</i>	712 <i>46.6</i>	1
Interrupted aortic arch	2 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	2 <i>0.1</i>	

**Wisconsin**  
**Birth Defects Counts and Prevalence 2015 - 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)	48 2.5	7 2.6	9 3.5	3 2.5	1 3.5	68 2.4	
Omphalocele	36 1.9	5 1.9	0 0.0	2 1.7	0 0.0	43 1.5	
Pulmonary valve atresia and stenosis	144 7.4	12 4.5	14 5.4	6 5.0	4 14.0	180 6.4	
Pulmonary valve atresia	31 1.6	0 0.0	2 0.8	0 0.0	0 0.0	33 1.2	
Rectal and large intestinal atresia/stenosis	60 3.1	9 3.4	7 2.7	2 1.7	1 3.5	79 2.8	
Renal agenesis/hypoplasia	102 5.3	15 5.7	14 5.4	0 0.0	1 3.5	132 4.7	
Single ventricle	23 1.2	2 0.8	3 1.2	0 0.0	0 0.0	28 1.0	
Small intestinal atresia/stenosis	32 1.7	5 1.9	2 0.8	0 0.0	0 0.0	39 1.4	
Spina bifida without anencephalus	84 4.3	9 3.4	7 2.7	3 2.5	1 3.5	104 3.7	
Tetralogy of Fallot	84 4.3	12 4.5	3 1.2	5 4.2	0 0.0	104 3.7	
Total anomalous pulmonary venous connection	18 0.9	1 0.4	2 0.8	0 0.0	0 0.0	21 0.7	
Transposition of the great arteries (TGA)	115 5.9	5 1.9	11 4.3	6 5.0	1 3.5	138 4.9	
Dextro-transposition of great arteries (d-TGA)	102 5.3	5 1.9	11 4.3	6 5.0	1 3.5	125 4.5	
Tricuspid valve atresia and stenosis	20 1.0	4 1.5	1 0.4	1 0.8	0 0.0	26 0.9	
Trisomy 13	9 0.5	1 0.4	2 0.8	2 1.7	0 0.0	14 0.5	
Trisomy 18	33 1.7	7 2.6	3 1.2	1 0.8	0 0.0	44 1.6	
Trisomy 21 (Down syndrome)	280 14.5	36 13.6	38 14.7	14 11.7	4 14.0	372 13.3	
Turner syndrome	12 1.4	5 4.1	4 3.3	1 1.8	0 0.0	22 1.7	2
Ventricular septal defect	739 38.2	93 35.1	97 37.5	31 26.0	13 45.6	973 34.7	
<b>Total live births</b>	<b>193,358</b>	<b>26,485</b>	<b>25,835</b>	<b>11,920</b>	<b>2,854</b>	<b>280,671</b>	
<b>Male live births</b>	<b>106,676</b>	<b>14,258</b>	<b>13,544</b>	<b>6,211</b>	<b>1,482</b>	<b>152,914</b>	
<b>Female live births</b>	<b>86,682</b>	<b>12,227</b>	<b>12,291</b>	<b>5,709</b>	<b>1,372</b>	<b>127,757</b>	

**Wisconsin**  
**Birth Defects Counts and Prevalence 2015 - 2018 (Prevalence per 10,000 Live Births)**

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	18 <i>3.6</i>	2 <i>5.1</i>	114 <i>4.1</i>	
Trisomy 13	3 <i>0.6</i>	2 <i>5.1</i>	21 <i>0.7</i>	
Trisomy 18	15 <i>3.0</i>	6 <i>15.3</i>	59 <i>2.1</i>	
Trisomy 21 (Down syndrome)	62 <i>12.3</i>	19 <i>48.6</i>	476 <i>17.0</i>	
<b>Total live births</b>	<b>50,449</b>	<b>3,912</b>	<b>280,671</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.