

West Virginia

West Virginia Birth Defects Surveillance System

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

Partner: Hospitals, Universities, Early Childhood Prevention Programs

Program status: Currently collecting data

Start year: 1989

Earliest year of available data: 1989

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

Population covered annually: 18,000

Statewide: Yes

Current legislation or rule: WV State Code 16-5-12a

Legislation year enacted: 1991; updated 2002

Case Definition

Outcomes covered: ICD-10 Codes Q00–Q07, Q10–Q18, Q20–Q28, Q30–Q34, Q35–Q37, Q38–Q45, Q50–Q56, Q60–Q64, Q65–Q79, Q80–Q89, Q90–Q99

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

Age: 0-6 years

Residence: In-state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation

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

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Infant and Maternal Mortality Review Panel

Delivery hospitals: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries

Other sources: Pediatric referrals

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Infants with low birth weight or low gestation (<2500 grams or <37 weeks), All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Developmental delay, GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, 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.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database collection and storage: Access

Data Analysis

Data analysis software: Access

Quality assurance: Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Needs assessment, Service delivery, Referral, 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

Funding

Funding source: 100% MCH funds

Other

Web site: <http://wvdhhr.org/omcfh>

Additional information on file: Legislative reports on file with State Legislative Library

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DATA TABLES

West Virginia
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	12 <i>1.5</i>	1 <i>3.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	13 <i>1.5</i>	
Anophthalmia/microphthalmia	3 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	3 <i>0.4</i>	
Anotia/microtia	5 <i>0.6</i>	1 <i>3.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	6 <i>0.7</i>	
Aortic valve stenosis	10 <i>1.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	10 <i>1.2</i>	
Atrial septal defect	1,225 <i>156.1</i>	57 <i>206.2</i>	26 <i>159.9</i>	6 <i>86.7</i>	3 <i>361.4</i>	1,333 <i>158.1</i>	
Atrioventricular septal defect (Endocardial cushion defect)	14 <i>1.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	14 <i>1.7</i>	
Biliary atresia	9 <i>1.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>1.1</i>	
Bladder exstrophy	2 <i>0.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	2 <i>0.2</i>	
Choanal atresia	11 <i>1.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	11 <i>1.3</i>	
Cleft lip alone	26 <i>3.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	26 <i>3.1</i>	
Cleft lip with cleft palate	44 <i>5.6</i>	0 <i>0.0</i>	1 <i>6.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	45 <i>5.3</i>	
Cleft palate alone	58 <i>7.4</i>	1 <i>3.6</i>	1 <i>6.2</i>	1 <i>14.5</i>	1 <i>120.5</i>	62 <i>7.4</i>	
Cloacal exstrophy	8 <i>1.0</i>	2 <i>7.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	10 <i>1.2</i>	
Clubfoot	131 <i>16.7</i>	6 <i>21.7</i>	1 <i>6.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	138 <i>16.4</i>	
Coarctation of the aorta	35 <i>4.5</i>	1 <i>3.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	36 <i>4.3</i>	
Common truncus (truncus arteriosus)	5 <i>0.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>120.5</i>	6 <i>0.7</i>	
Congenital cataract	12 <i>1.5</i>	1 <i>3.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	13 <i>1.5</i>	
Congenital posterior urethral valves	6 <i>1.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>23.8</i>	0 <i>0.0</i>	7 <i>1.6</i>	1
Craniosynostosis	122 <i>15.5</i>	3 <i>10.9</i>	1 <i>6.2</i>	1 <i>14.5</i>	0 <i>0.0</i>	127 <i>15.1</i>	
Deletion 22q11.2	3 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	3 <i>0.4</i>	
Diaphragmatic hernia	9 <i>1.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>1.1</i>	
Double outlet right ventricle	12 <i>1.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	12 <i>1.4</i>	
Ebstein anomaly	10 <i>1.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	10 <i>1.2</i>	
Encephalocele	13 <i>1.7</i>	1 <i>3.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	14 <i>1.7</i>	
Esophageal atresia/tracheoesophageal fistula	20 <i>2.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	20 <i>2.4</i>	
Gastroschisis	26 <i>3.3</i>	2 <i>7.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	28 <i>3.3</i>	
Holoprosencephaly	17 <i>2.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	18 <i>2.1</i>	
Hypoplastic left heart syndrome	16 <i>2.0</i>	1 <i>3.6</i>	0 <i>0.0</i>	1 <i>14.5</i>	0 <i>0.0</i>	18 <i>2.1</i>	
Hypospadias	228 <i>56.8</i>	8 <i>58.1</i>	4 <i>45.7</i>	3 <i>71.3</i>	0 <i>0.0</i>	246 <i>57.0</i>	1
Interrupted aortic arch	7 <i>0.9</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>120.5</i>	8 <i>0.9</i>	

West Virginia
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)	26 3.3	1 3.6	0 0.0	0 0.0	0 0.0	28 3.3	
Omphalocele	11 1.4	1 3.6	0 0.0	0 0.0	0 0.0	12 1.4	
Pulmonary valve atresia and stenosis	70 8.9	4 14.5	1 6.2	0 0.0	0 0.0	75 8.9	
Pulmonary valve atresia	18 2.3	1 3.6	1 6.2	0 0.0	0 0.0	20 2.4	
Rectal and large intestinal atresia/stenosis	30 3.8	2 7.2	1 6.2	0 0.0	0 0.0	33 3.9	
Renal agenesis/hypoplasia	47 6.0	1 3.6	0 0.0	0 0.0	0 0.0	49 5.8	
Single ventricle	16 2.0	1 3.6	0 0.0	0 0.0	0 0.0	17 2.0	
Small intestinal atresia/stenosis	28 3.6	1 3.6	0 0.0	0 0.0	0 0.0	29 3.4	
Spina bifida without anencephalus	15 1.9	0 0.0	0 0.0	0 0.0	0 0.0	15 1.8	
Tetralogy of Fallot	46 5.9	1 3.6	0 0.0	0 0.0	1 120.5	48 5.7	
Total anomalous pulmonary venous connection	2 0.3	0 0.0	0 0.0	0 0.0	0 0.0	2 0.2	
Transposition of the great arteries (TGA)	17 2.2	0 0.0	0 0.0	0 0.0	0 0.0	17 2.0	
Dextro-transposition of great arteries (d-TGA)	16 2.0	0 0.0	0 0.0	0 0.0	0 0.0	16 1.9	
Tricuspid valve atresia and stenosis	10 1.3	0 0.0	0 0.0	0 0.0	0 0.0	10 1.2	
Trisomy 13	3 0.4	0 0.0	0 0.0	0 0.0	0 0.0	3 0.4	
Trisomy 18	14 1.8	0 0.0	0 0.0	0 0.0	0 0.0	14 1.7	
Trisomy 21 (Down syndrome)	58 7.4	3 10.9	0 0.0	1 14.5	0 0.0	65 7.7	
Turner syndrome	1 0.3	1 7.2	0 0.0	0 0.0	0 0.0	2 0.5	2
Ventricular septal defect	328 41.8	11 39.8	0 0.0	2 28.9	2 241.0	346 41.0	
Total live births	78,470	2,764	1,626	692	83	84,318	
Male live births	40,170	1,377	875	421	44	43,164	
Female live births	38,300	1,386	751	356	40	41,154	

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	26 <i>3.5</i>	2 <i>2.2</i>	28 <i>3.3</i>	
Trisomy 13	2 <i>0.3</i>	1 <i>1.1</i>	3 <i>0.4</i>	
Trisomy 18	8 <i>1.1</i>	6 <i>6.5</i>	14 <i>1.7</i>	
Trisomy 21 (Down syndrome)	42 <i>5.6</i>	23 <i>24.9</i>	65 <i>7.7</i>	
Total live births	75,085	9,233	84,318	

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.