



WEST VIRGINIA BIRTH DEFECTS

Calendar Years 2018 and 2019
(January - December)

West Virginia Birth Defects

The West Virginia Birth Defects Surveillance System (BDSS) is administered by the West Virginia Department of Health and Human Resources, Bureau for Public Health, Office of Maternal, Child and Family Health (OMCFH) to monitor the occurrence of birth defects among the State's children. West Virginia Code §16-40-1 *et seq.* and West Virginia Code of State Rules §64-81 require reporting of birth defects in infants and minors up to the age of 6.

The purpose of the BDSS is to identify and describe congenital anomalies, stillbirths and abnormal conditions of newborns; detect trends and epidemics in congenital anomalies, stillbirths and abnormal conditions of newborns; quantify morbidity and mortality of congenital anomalies and abnormal conditions of newborns; stimulate epidemiological research regarding congenital anomalies, stillbirths and abnormal conditions of newborns; identify risk factors for congenital anomalies, stillbirths and abnormal conditions of newborns; facilitate intervention in and prevention of congenital anomalies, stillbirths and abnormal conditions of newborns; facilitate access to treatment for congenital anomalies and abnormal conditions of newborns; and inform and educate the public about congenital anomalies, stillbirths and abnormal conditions of newborns.

At its inception in 2003, the BDSS received funding from the Centers for Disease Control and Prevention (CDC) and was able to implement an active system. An active system utilizes actual chart abstractions conducted by nurse abstractors and information entered into a data system. Because CDC funding ended in 2005, the BDSS became a passive system in which data collection relies upon reporting from participating birthing facilities, and actual chart abstractions or diagnostic confirmation are not performed.

Infants born with birth defects are identified using specific International Classification of Diseases—ICD 10 codes—and reported to the BDSS by various methods on a monthly basis by participating birthing facilities. Demographic information from the birth certificate is used to verify that an infant is a West Virginia resident at time of birth.

The 2017 introduction of the Zika virus to the United States highlighted the need for surveillance of birth defects, due to the likelihood of increased potential for adverse birth outcomes, including microcephaly, and an increase in efforts to maximize the opportunity for early identification of birth defects and subsequent medical intervention. Thus, OMCFH has implemented a new process in order to increase the number of facilities reporting birth defects to the BDSS, including updated agreements with birthing facilities to provide for the submission of monthly birth defects reports to the BDSS. Currently, all birthing facilities in the state provide monthly discharge reports for inclusion in the BDSS.

A birth defect is a condition that occurs during the baby's development. It could affect how the body looks, works or both. It may be identified during pregnancy, at birth or a few years after birth. Some birth defects are easily recognized, while others can only be identified by specialized testing. The abnormality can range from mild to severe or even result in death.

The following table lists the congenital anomalies that are submitted to the BDSS and the number of cases reported for 2018 and 2019.

Congenital Anomaly	Code	Number of Cases 2018	Number of Cases 2019
Anencephaly	Q00.0-Q00.1	2	4
Anophthalmia/microphthalmia	Q11.0-Q11.2	0	1
Anotia/microtia	Q16.0, Q17.2	3	1
Aortic valve stenosis	Q23.0	5	4
Atrial septal defect	Q21.1	320	357
Atrioventricular septal defect (AVSD)	Q21.2	4	3
Biliary atresia	Q44.2-Q44.3	1	3
Bladder exstrophy	Q64.10, Q64.19	0	0
Choanal atresia	Q30.0	1	5
Cleft lip with cleft palate	Q37.0-Q37.9	12	4
Cleft lip without cleft palate	Q36.0-Q36.9	9	6
Cleft palate without cleft lip	Q35.1-Q35.0	12	16
Cloacal exstrophy	Q64.12	0	0
Clubfoot	Q66.0, Q66.89	48	51
Coarctation of aorta	Q25.1	9	8
Common truncus	Q20.0	1	0
Congenital cataract	Q12.0	3	1
Congenital posterior urethral valves	Q64.2	2	1
Craniosynostosis	Q75.0	23	8
Dextro-transposition of great arteries	Q20.3	1	0
Diaphragmatic hernia	Q79.0, Q79.1	1	4
Double outlet right ventricle (DORV)	Q20.1	2	1
Ebstein's anomaly	Q22.5	4	3
Encephalocele	Q01.0-Q01.9	4	2
Esophageal atresia/tracheoesophageal fistula	Q39.0-Q39.4	5	4
Gastroschisis	Q79.3	2	11
Holoprosencephaly	Q04.2	4	3
Hypoplastic left heart syndrome	Q23.4	6	1
Hypospadias	Q54.0-Q54.9 excluding Q54.4	67	51
Interrupted aortic arch (IAA)	Q25.2, Q25.4	0	0
Limb deficiencies (reduction defects)	Q71.0-Q71.9, Q72.0-Q72.9, Q73.0-Q73.8	7	9
Microcephaly	Q02	28	54
Omphalocele	Q79.2	3	2
Pulmonary valve atresia	Q22.0	6	1
Pulmonary valve atresia and stenosis	Q22.0, Q22.1	23	10

Congenital Anomaly	Code	Number of Cases 2018	Number of Cases 2019
Rectal and large intestinal atresia/stenosis	Q42.0-Q42.9	8	9
Renal agenesis/hypoplasia	Q60.0-Q60.6	13	11
Single ventricle	Q20.4	4	0
Small intestinal atresia/stenosis	Q41.0-Q41.0	3	4
Spina bifida without anencephaly	Q05.0-Q05.9; Q07.01; Q07.03	4	7
Tetralogy of Fallot	Q21.3	11	10
Total anomalous pulmonary venous connection	Q26.2	0	1
Transposition of great arteries	Q20.3, Q20.5	1	0
Tricuspid valve atresia	Q22.4	4	2
Tricuspid valve atresia and stenosis	Q22.4	4	2
Trisomy 13 (Patau syndrome)	Q91.4-Q91.7	0	0
Trisomy 18 (Edwards syndrome)	Q91.0-Q91.3	4	2
Trisomy 21 (Down syndrome)	Q90.0-Q90.9	18	16
Turner syndrome	Q96.0-Q96.9	1	1
Ventricular septal defect	Q21.0	75	98
Total Birth Defects Reported per ICD-10 Code		768	792
Total Children with at Least One Birth Defect		572	615

According to West Virginia Vital Statistics data, there were 15,990 resident occurrence births at West Virginia facilities in 2018 and preliminary data for 2019 show 15,878 resident occurrence births at West Virginia facilities. In 2018, there were 768 reportable birth defects affecting 572 births reported to the BDSS, an estimated rate of 35.7 reportable defects per 1,000 births or 3.5% of West Virginia resident occurrence births. In 2019, there were 792 reportable birth defects affecting 615 births were reported for an estimated rate of 38.7 per 1,000 births or 3.8% of West Virginia resident occurrence births. Because the Bureau for Public Health is financially unable to implement an active surveillance system, rates of birth defects are estimated, and the numbers reflected above are most likely underestimated because some birth defects are not evident at birth. Nationally, the CDC estimates that birth defects affect 1 in every 33 babies, or 3% of all US births (<https://www.cdc.gov/ncbddd/birthdefects/data.html>).

Many birth defects occur before a woman even realizes she is pregnant. While not all birth defects can be prevented, a woman can increase her chance of having a healthy baby by visiting a doctor before getting pregnant, controlling existing medical concerns such as obesity and diabetes, not smoking, not using alcohol or illegal drugs and taking 400 mg of folic acid daily. West Virginia Pregnancy Risk Assessment Monitoring System (PRAMS) data for 2018 show 22.8% of pregnancies were unintended (wanted later or not at all) and 21% of women were not sure how they felt about their pregnancy intention. Therefore, birth defects prevention measures should always be in place to ensure a healthy pregnancy.