WEST VIRGINIA BIRTH DEFECTS

**Calendar Years 2018, 2019, 2020 and 2021
(January - December)**

Office of Maternal, Child and Family Health
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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 64CSR81 requires reporting of birth defects in infants and minors up to the age of 6.

The purpose of 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, 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 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.

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 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 implemented a new process in order to increase the number of facilities reporting birth defects to BDSS, including updated agreements with birthing facilities to provide for the submission of monthly birth defects reports to BDSS. Currently, all birthing facilities in the state provide monthly discharge reports for inclusion in BDSS.

The following table lists the congenital anomalies that are submitted to BDSS and the number of cases reported for 2018, 2019, 2020 and 2021.

Congenital Anomaly	Code	# of Cases 2018	# of Cases 2019	# of Cases 2020	# of Cases 2021
Anencephaly	Q00.0-Q00.1	2	4	1	2
Anophthalmia/microphthalmia	Q11.0-Q11.2	0	1	0	1
Anotia/microtia	Q16.0, Q17.2	3	1	2	2
Aortic valve stenosis	Q23.0	5	4	3	3
Atrial septal defect	Q21.1	320	357	257	388
Atrioventricular septal defect (AVSD)	Q21.2	4	3	4	7
Biliary atresia	Q44.2-Q44.3	1	3	1	1
Bladder exstrophy	Q64.10, Q64.19	0	0	0	1
Choanal atresia	Q30.0	1	5	3	1
Cleft lip with cleft palate	Q37.0-Q37.9	12	4	8	13
Cleft lip without cleft palate	Q36.0-Q36.9	9	6	8	5
Cleft palate without cleft lip	Q35.1-Q35.9	12	16	18	18
Cloacal exstrophy	Q64.12	0	0	0	0
Clubfoot	Q66.0, Q66.89	48	51	40	49
Coarctation of aorta	Q25.1	9	8	8	16
Common truncus	Q20.0	1	0	1	0
Congenital cataract	Q12.0	3	1	1	2
Congenital posterior urethral valves	Q64.2	2	1	2	3
Craniosynostosis	Q75.0	23	8	10	24
Dextro-transposition of great arteries	Q20.3	1	0	5	4
Diaphragmatic hernia	Q79.0, Q79.1	1	4	3	3
Double outlet right ventricle (DORV)	Q20.1	2	1	2	6
Ebstein's anomaly	Q22.5	4	3	1	1
Encephalocele	Q01.0-Q01.9	4	2	1	2
Esophageal atresia/tracheoesophageal fistula	Q39.0-Q39.4	5	4	3	10
Gastroschisis	Q79.3	2	11	3	9
Holoprosencephaly	Q04.2	4	3	2	3
Hypoplastic left heart syndrome	Q23.4	6	1	1	10
Hypospadias	Q54.0-Q54.9 excluding Q54.4	67	51	51	70
Interrupted aortic arch (IAA)	Q25.2, Q25.4	0	0	0	0
Limb deficiencies (reduction defects)	Q71.0-Q71.9, Q72.0-Q72.9, Q73.0-Q73.8	7	9	5	8
Microcephaly	Q02	28	54	46	51
Omphalocele	Q79.2	3	2	6	3
Pulmonary valve atresia	Q22.0	6	1	0	4
Pulmonary valve atresia and stenosis	Q22.0, Q22.1	23	10	12	18
Rectal and large intestinal atresia/stenosis	Q42.0-Q42.9	8	9	16	15

Congenital Anomaly	Code	# of Cases 2018	# of Cases 2019	# of Cases 2020	# of Cases 2021
Renal agenesis/hypoplasia	Q60.0-Q60.6	13	11	11	16
Single ventricle	Q20.4	4	0	1	2
Small intestinal atresia/stenosis	Q41.0-Q41.0	3	4	4	6
Spina bifida without anencephaly	Q05.0-Q05.9; Q07.01; Q07.03	4	7	2	5
Tetralogy of Fallot	Q21.3	11	10	9	7
Total anomalous pulmonary venous connection	Q26.2	0	1	4	4
Transposition of great arteries	Q20.3, Q20.5	1	0	5	4
Tricuspid valve atresia	Q22.4	4	2	0	1
Tricuspid valve atresia and stenosis	Q22.4	4	2	0	1
Trisomy 13 (Patau syndrome)	Q91.4-Q91.7	0	0	1	3
Trisomy 18 (Edwards syndrome)	Q91.0-Q91.3	4	2	5	3
Trisomy 21 (Down syndrome)	Q90.0-Q90.9	18	16	18	23
Turner syndrome	Q96.0-Q96.9	1	1	6	3
Ventricular septal defect	Q21.0	75	98	66	100
Total Birth Defects Reported per ICD-10 Code		**768**	**792**	**656**	**931**
Total Children with at Least One Birth Defect		**572**	**615**	**513**	**706**

According to West Virginia Vital Statistics data, there were 18,243 resident occurrence births at West Virginia facilities in 2018, 18,090 resident occurrence births at West Virginia facilities in 2019 and preliminary data shows 17,327 resident occurrence births at West Virginia facilities in 2020 and 17,955 resident occurrence births in 2021. In 2018, there were 768 reportable birth defects affecting 572 births reported to BDSS, an estimated rate of 31.4 reportable defects per 1,000 births or 3.1% of West Virginia resident occurrence births. In 2019, there were 792 reportable birth defects affecting 615 births reported to BDSS for an estimated rate of 33.9 per 1,000 births or 3.3% of West Virginia resident occurrence births. In 2020, there were 656 reportable birth defects affecting 513 births reported to BDSS for an estimated rate of 29.6 per 1,000 births or 2.9% of West Virginia resident occurrence births. In 2021, there were 931 reportable birth defects affecting 706 births reported to BDSS for an estimated rate of 39.3 per 1,000 births or 3.9% of West Virginia resident occurrence births. Rates of birth defects are estimated based upon the monthly reports received from facilities with no follow-up for confirmation or exclusion. 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 2020 show 17.9% of pregnancies were unintended (wanted later or not at all) and 18.5% 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.