WEST VIRGINIA BIRTH DEFECTS

2018-2024

(January-December)

West Virginia Department of HEALTH

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 in collaboration between the West Virginia Department of Health, Bureau for Public Health, Office of Maternal, Child and Family Health (OMCFH) and West Virginia Office of Shared Administration, Management Information Services (MIS) 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 the occurrence of birth defects; detect trends and epidemics; quantify morbidity and mortality; stimulate epidemiological research; identify risk factors associated with birth defects; facilitate interventions that prevent birth defects; facilitate access to treatment; 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. Zika virus infection during pregnancy can increase the potential for adverse birth outcomes, including microcephaly. However, through health surveillance of birth defects, early identification and subsequent medical intervention can improve outcomes. With the emergence of Zika virus , 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 18 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, 2021, 2022, 2023, and 2024. In earlier published reports some ICD- 10 codes were combined, leading to aggregated data rather than true counts for specific birth defects. Data published in this report has been updated and represents all birth defects tracked by the CDC as represented by the specific ICD-10 codes from 2018-2024.

Congenital Anomaly	Code	2018	2019	2020	2021	2022	2023	2024
Anencephaly	Q00.0-Q00.1	3	4	1	0	1	2	1
Anophthalmia/microphthalmia	Q11.0-Q11.2	1	1	0	7	1	2	2
Anotia/microtia	Q16.0, Q17.2	3	1	3	2	3	1	1
Aortic valve stenosis	Q23.0	5	4	4	4	2	1	1
Atrial septal defect	Q21.1	332	394	393	354	154	0	0
Atrioventrical septial defect (AVSD)	Q21.2	5	4	7	6	8	0	0
Biliary atresia	Q44.2-Q44.3	2	4	2	1	1	0	2
Bladder exstrophy	Q64.10, Q64.19	0	0	0	1	1	0	1
Choanal atresia	Q30.0	1	6	4	1	6	3	3
Cleft lip with cleft palate	Q37.0-Q37.9	12	7	16	12	8	10	11
Cleft lip without cleft palate	Q36.0-Q36.9	9	6	9	5	5	5	5
Cleft palate without cleft lip	Q35.1-Q35.9	16	27	24	17	9	9	17
Cloacal exstrophy	Q64.12	0	0	0	0	0	0	1
Clubfoot	Q66.0, Q66.89	50	53	56	41	35	37	31
Coarctation of aorta	Q25.1	10	8	13	14	13	12	13
Common truncus	Q20.0	1	0	1	0	0	1	1
Congenital cataract	Q12.0	3	1	1	3	4	0	0
Congenital posterior urethral valves	Q64.2	2	1	3	2	2	0	3
Craniosynostosis	Q75.0	28	15	24	19	13	9	0
Dextro-transposition of great arteries	Q20.3	1	1	11	7	7	8	7
Diaphragmatic hernia	Q79.0-Q79.1	1	5	7	2	2	3	4

Congenital Anomaly	Code	2018	2019	2020	2021	2022	2023	2024
Double outlet right ventricle (DORV)	Q20.1	3	1	2	10	3	4	8
Ebstein's anomaly	Q22.5	4	3	1	1	2	1	2
Encephalocele	Q01.0-Q01.9	4	3	2	2	1	1	1
Esophageal atresia/tracheosophageal fistula	Q39.0-Q39.4	5	5	5	8	6	3	2
Gastroschisis	Q79.3	2	11	5	9	1	7	5
Holoprosencephaly	Q04.2	5	7	2	4	1	1	2
Hypoplastic left heart syndrome	Q23.4	7	1	4	6	12	14	5
Hypospadias	Q54.0-Q54.3, Q54.5-Q54.9	70	53	69	61	50	68	74
Interrupted aortic arch (IAA)	Q25.2, Q25.4	0	0	0	0	0	0	0
Limb deficiencies (reduction defects)	Q71.0-Q71.9, Q72.0-Q72.9, Q73.0-73.8	0	1	0	0	0	0	0
Microcephaly	Q02	33	67	74	53	43	66	67
Omphalocele	Q79.2	3	2	9	3	6	0	2
Pulmonary valve atresia	Q22.0	6	1	0	5	3	2	1
Pulmonary valve atresia and stenosis	Q22.1	17	14	21	17	18	16	16
Rectal and large intestinal atresia/stenosis	Q42.0-Q42.9	8	13	24	17	12	3	7
Renal agenesis/hypoplasia	Q60.0-Q60.6	24	19	18	12	17	11	4
Single ventricle	Q20.4	4	1	3	4	12	8	6
Small intestinal atresia/stenosis	Q41.0	3	3	0	2	5	3	3

Congenital Anomaly	Code	2018	2019	2020	2021	2022	2023	2024
Spina bifida without anencephaly	**Q05.0-Q05.9, Q07.01, Q07.03**	**9**	**14**	**7**	**6**	**8**	**9**	**8**
Tetralogy of Fallot	**Q21.3**	**13**	**15**	**11**	**10**	**6**	**3**	**13**
Total anomalous pulmonary venous connection	**Q26.2**	**0**	**1**	**7**	**2**	**4**	**3**	**4**
Transposition of great arteries	**Q20.5**	**0**	**0**	**0**	**2**	**2**	**0**	**1**
Tricuspid value atresia	**Q22.4**	**4**	**5**	**0**	**1**	**6**	**0**	**2**
Tricuspid value atresia and stenosis	**See Q22.4**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Trisomy 13 (Patau syndrome)	**Q91.4-Q91.7**	**0**	**1**	**1**	**3**	**0**	**1**	**2**
Trisomy 18 (Edwards syndrome)	**Q91.0-Q91.3**	**4**	**2**	**9**	**5**	**0**	**1**	**3**
Trisomy 21 (Down syndrome)	**Q90.0-Q90.9**	**32**	**25**	**40**	**22**	**27**	**35**	**23**
Turner syndrome	**Q96.0-Q96.9**	**1**	**1**	**8**	**4**	**6**	**6**	**5**
Ventricular septal defect	**Q21.0**	**83**	**116**	**112**	**104**	**100**	**119**	**117**
Total Code Count		**829**	**927**	**1013**	**871**	**626**	**488**	**487**
Total Children with at least one birth defect		**629**	**716**	**807**	**664**	**474**	**410**	**396**

Table 1. Congenital Anomalies identified by ICD-10 codes, 2018-2024

Year	Number of Resident Births	Number of Birth Defects	Rate (per 1000 births)	Percentage of West Virginia Resident Births
2018	18243	629	34.5	3.4
2019	18090	716	39.6	3.9
2020	17327	807	46.6	4.6
2021	17189	664	38.6	3.8
2022	16929	474	27.9	2.7
2023	16606	410	24.6	2.4
2024	17022	396	23.2	2.3

Table 2. Rates and percentages for congenital anomalies from children with at least one birth defect, 2018-2024. Number of resident births source: CDC Wonder.

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 one 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 attending prenatal care visits, controlling existing medical concerns, such as obesity and diabetes, not smoking, reframing from alcohol or illegal drugs, and taking 400 mg of folic acid daily. West Virginia Pregnancy Risk Assessment Monitoring System (PRAMS) data for 2023 show 21.42% of pregnancies were unintended (wanted later or not at all) and 20.64% of women were not sure how they felt about their pregnancy intention. Therefore, birth defect prevention includes appropriate family planning education, early prenatal care, and maternal health optimization prior to and during pregnancy.