



STATE OF WEST VIRGINIA
DEPARTMENT OF HEALTH AND HUMAN RESOURCES
Bureau for Public Health
Commissioner's Office

Bill J. Crouch
Cabinet Secretary

Catherine C. Slemp, MD, MPH
Commissioner & State Health Officer (Interim)

December 17, 2018

The Honorable Jim Justice, Governor
Office of the Governor
State Capitol Complex
1900 Kanawha Boulevard, East
Charleston, West Virginia 25305

Dear Governor Justice:

As required by West Virginia Code §16-40-8, enclosed is the West Virginia Birth Defects report for calendar years 2016 and 2017. This report is provided by the West Virginia Department of Health and Human Resources, Bureau for Public Health, through the Office of Maternal, Child and Family Health.

If additional information is needed, you may contact Mr. James (Jim) Jeffries, Interim Director, Office of Maternal, Child and Family Health, at (304) 356-4425 or via e-mail at james.e.jeffries@wv.gov.

Sincerely,

A handwritten signature in cursive script that reads "Catherine C. Slemp".

Catherine C. Slemp, MD, MPH
Commissioner and State Health Officer, Interim

Enclosure



West Virginia Birth Defects

Calendar Years 2016 and 2017
(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 mandate the reporting of infants and minors up to the age of six identified with a birth defect. These laws were implemented to enhance the mechanism in place for timeliness of reports, assurance of confidentiality and verifying reportable diagnostic codes. The purpose of the BDSS is to ensure an effective early identification system, use this information to facilitate intervention, prevention and access to treatment for congenital anomalies, stillbirths and abnormal conditions of newborns, provide public education awareness on prevention of heritable birth defects and create epidemiological studies using the collected data.

Although the process is mandated, no state funds are designated for BDSS. From September 2003 to March 2005 the BDSS received funding from the Centers for Disease Control and Prevention (CDC) and was an active system, i.e. actual chart abstractions were conducted by nurse abstractors and information was entered into the data system. Currently, the BDSS is a passive system, which means data collection relies upon reporting from participating birthing facilities – not actual chart abstractions or diagnostic confirmation. Infants born with birth defects are identified using specific 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 an infant is a West Virginia resident at time of birth. Of the current birthing facilities in the State, only eight facilities reported birth defects to OMCFH during calendar year 2016. Consequently since 2005, there has not been accurate reporting of birth defects across the State due to the lack of consistent participation by all birthing facilities. Beginning with calendar year 2017, a new process was implemented to increase the number of facilities reporting birth defects to the BDSS. The introduction of the Zika virus in the United States and the potential for adverse birth outcomes associated with the virus, including microcephaly,

resulted in CDC recommendations highlighting the need for surveillance of birth defects and efforts to maximize the state's opportunity for early identification and subsequent medical intervention. Efforts to increase surveillance included updating agreements with birthing facilities around the state to provide for the submission of monthly birth defects reports to 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 found 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 reportable conditions that are to be submitted to the BDSS and the number of cases reported by year.

Condition	Code	Number of Cases 2016	Number of Cases 2017
Anencephaly	Q00.0-Q00.1	3	5
Anophthalmia/microphthalmia	Q11.0-Q11.2	2	0
Anotia/microtia	Q16.0, Q17.2	0	3
Aortic valve stenosis	Q23.0	3	1
Atrial septal defect	Q21.1	246	331
Atrioventricular septal defect (AVSD)	Q21.2	2	4
Biliary atresia	Q44.2-Q44.3	1	1
Bladder exstrophy	Q64.10, Q64.19	0	0
Choanal atresia	Q30.0	3	2
Cleft lip with cleft palate	Q37.0-Q37.9	4	9
Cleft lip without cleft palate	Q36.0-Q36.9	3	7
Cleft palate without cleft lip	Q35.1-Q35.9	18	12
Cloacal exstrophy	Q64.12	0	0
Clubfoot	Q66.0, Q66.89	17	36
Coarctation of aorta	Q25.1	8	10
Common truncus	Q20.0	1	0
Congenital cataract	Q12.0	1	4
Congenital posterior urethral valves	Q64.2	0	1
Craniosynostosis	Q75.0	8	11
Dextro-transposition of great arteries	Q20.3	6	4
Diaphragmatic hernia	Q79.0, Q79.1	1	2
Double outlet right ventricle (DORV)	Q20.1	2	4

Condition	Code	Number of Cases 2016	Number of Cases 2017
Ebstein anomaly	Q22.5	2	1
Encephalocele	Q01.0-Q01.9	2	5
Esophageal atresia/tracheoesophageal fistula	Q39.0-Q39.4	3	9
Gastroschisis	Q79.3	6	7
Holoprosencephaly	Q04.2	3	1
Hypoplastic left heart syndrome	Q23.4	3	2
Hypospadias	Q54.0-Q54.9 excluding Q54.4	27	59
Interrupted aortic arch (IAA)	Q25.2, Q25.4	4	0
Limb deficiencies (reduction defects)	Q71.0-Q71.9, Q72.0-Q72.9, Q73.0-Q73.8	6	6
Microcephaly	Q02	35	35
Omphalocele	Q79.2	2	2
Pulmonary valve atresia	Q22.0, Q22.1	2	3
Pulmonary valve atresia and stenosis	Q22.0, Q22.1	10	20
Rectal and large intestinal atresia/stenosis	Q42.0-Q42.9	2	11
Renal agenesis/hypoplasia	Q60.0-Q60.6	4	19
Single ventricle	Q20.4	6	3
Small intestinal atresia/stenosis	Q41.0-Q41.9	7	8
Spina bifida without anencephaly	Q05.0-Q05.9; Q07.01; Q07.03	2	8
Tetralogy of Fallot	Q21.3	5	14
Total anomalous pulmonary venous connection	Q26.2	0	0
Transposition of great arteries	Q20.3, Q20.5	6	4
Tricuspid valve atresia	Q22.4	1	2
Tricuspid valve atresia and stenosis	Q22.4	1	2
Trisomy 13 (Patau syndrome)	Q91.4-Q91.7	0	1
Trisomy 18 (Edwards syndrome)	Q91.0-Q91.3	2	4
Trisomy 21 (Down syndrome)	Q90.0-Q90.9	6	20
Turner syndrome	Q96.0-Q96.9	0	0
Ventricular septal defect	Q21.0	53	94
Total		529	787

There were 19,070 resident births in 2016 and preliminary data for 2017 shows 18,675 resident births. There were 529 reportable birth defects reported to the BDSS in 2016, an estimated rate of 27.7 defects per 1,000 births. There were 787 reportable birth

defects reported to the BDSS in 2017, an estimated rate of 42.1 defects per 1,000 births. As expected, the rate of birth defects reported increased as the number of facilities reporting birth defects increased. The rates are estimated due to the limitations of the passive system as explained previously and defects are counted by condition, not by children. According to the CDC, birth defects affect 1 in every 33 babies, or 3% of all U.S. 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 becoming 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. Since almost half of all pregnancies are unplanned, birth defects prevention measures should be in place at all times to ensure a healthy pregnancy.