STATE OF WEST VIRGINIA
DEPARTMENT OF HEALTH AND HUMAN RESOURCES

Bill J. Crouch
Cabinet Secretary

February 9, 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 please find the West Virginia Birth Defects report for calendar years 2014 and 2015. 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 Christina Mullins, Director, Office of Maternal, Child and Family Health, at (304) 356-4392 or e-mail at Christina.R.Mullins@wv.gov.

Sincerely,

Bill J. Crouch
Cabinet Secretary

BJC:tm

Enclosure

cc: Rahul Gupta, MD, MPH, FACP
Anne Williams
Christina Mullins
Steve Harrison
Lee Cassis
Legislative Library

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The Honorable Mitch Carmichael, Chair
Joint Committee on Government and Finance
State Capitol Complex
Room 229M, Building 1
Charleston, West Virginia 25305

The Honorable Tim Armstead, Chair
Joint Committee on Government and Finance
State Capitol Complex
Room 228M, Building 1
Charleston, West Virginia 25305

Dear President Carmichael and Speaker Armstead:

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West Virginia Birth Defects

Calendar Years 2014 and 2015
(January–December)

WEST VIRGINIA
Department of
Health & Human Resources
BUREAU FOR PUBLIC HEALTH

Office of Maternal, Child and Family Health
350 Capitol Street, Room 427
Charleston, WV 25301
Melissa Baker, MCH Epidemiologist

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 State 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. This legislation was implemented to enhance the mechanism in place for timeliness of reports, assurance of confidentiality and verifying reportable diagnostic codes.

Although the process is mandated, no state funds are designated for the program. During a short period of time (September 2003 to March 2005), the BDSS received funding from the Centers for Disease Control and Prevention (CDC) and was an active system where actual chart abstractions were conducted by nurse abstractors, and the information was entered into the data system. Currently, the BDSS is a passive system, which means data collection relies upon reporting from facilities – not actual chart abstractions or diagnostic confirmation. Infants born with birth defects are identified using specific ICD 9 and ICD 10 codes and reported to the BDSS by various methods on a monthly basis by participating birthing facilities. ICD 9 codes were used until October 2015 and then transitioned to ICD 10 codes; these codes are listed in Table 1. Also, 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 report birth defects to OMCFH. With the existing process, there is not accurate reporting of birth defects across the State due to the lack of consistent participation by all birthing facilities.

The purpose of the BDSS is to ensure an effective early identification system, use this information to enrich the quality of life for those affected by special conditions, provide public education awareness on prevention of heritable birth defects and create epidemiological studies using the collected data.

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. Table 1 lists the reportable conditions that are to be submitted to the BDSS.

Table 1: Conditions Reportable to the West Virginia BDSS		
ICD 9 CODE	**ICD 10 CODE**	**DIAGNOSIS** All Congenital Anomalies (740-759) (i.e. 740.0 or 743.30.)
740	Q00.0 - Q00.2	Anencephaly and similar anomalies
741	Q05.0 - Q05.9 Q07.01 and Q07.03	Spina Bifida
742	Q01.0 – Q04.9 Q06.0- Q07.00 Q07.02 and Q07.08 – Q07.09	Other congenital anomalies of nervous system
743	Q10.0 – Q15.9	Congenital anomalies of eye
744	Q16.0 – Q18.9	Congenital anomalies of ear, face and neck
745	Q20.0 – Q21.9	Bulbus cordis anomalies and anomalies of cardiac septal closure
746	Q22.0 – Q24.9	Other congenital anomalies of heart
747	Q25.0 – Q28.9	Other congenital anomalies of circulatory system
748	Q30.0 – Q34.9	Congenital anomalies of respiratory system
749	Q35.1 – Q37.9	Cleft palate and cleft lip
750	Q38.0 – Q40.9	Other congenital anomalies of upper alimentary tract
751	Q41.0 – Q45.9	Other congenital anomalies of digestive system
752	Q50.01 – Q56.4	Congenital anomalies of genital organs
753	Q60.0 – Q64.9	Congenital anomalies of urinary system
754	Q65.00 – Q65.6 Q66.0 – Q68.5 Q71.40 – Q71.43 and Q68.8, Q74.3, Q76.3,	Certain congenital musculoskeletal deformities

Table 1: Conditions Reportable to the West Virginia BDSS		
ICD 9 CODE	**ICD 10 CODE**	**DIAGNOSIS** All Congenital Anomalies (740-759) (i.e. 740.0 or 743.30.)
	Q76.411 and Q76.425 – Q76.429	
755	Q65.81 – Q65.9 Q66.3, Q66.89, Q68.2, Q68.6 – Q74.2 Q74.8 - Q74.9 and Q76.49	Other congenital anomalies of limbs
756	Q75.0 – Q76.419 Q76.49 – Q79.9	Other congenital musculoskeletal anomalies
757	Q80.0 – Q84.9	Congenital anomalies of the integument
758	Q90.0 – Q99.1 Q99.8 – Q99.9	Chromosomal anomalies
759	Q85.1 – Q85.9, Q86.8, and Q87.0 – Q89.9	Other and unspecified congenital anomalies

There were 20,303 resident births in 2014, and 442 reportable birth defects collected in the BDSS, an estimated rate of 21.8 defects per 1,000 births. There were 19,778 resident births in 2015, and 517 reportable birth defects collected in the BDSS, an estimated rate of 26.1 defects per 1,000 births. The rates are estimated due to the limitations of the passive system as explained previously. It is approximated that birth defects occur in 3% of all U.S. births. Table 2 lists the conditions and the number of cases reported to the BDSS for 2014 and 2015 resident births.

Table 2: Birth Defects by Condition Reported to the West Virginia BDSS		
Condition	**Number of Cases**	
	2014	**2015**
Anencephaly	0	1
Spina bifida without anencephaly	3	0
Encephalocele	0	1
Microcephaly	17	36
Holoprosencephaly	10	3
Anophthalmia/microphthalmia	1	0
Congenital cataract	0	2
Anotia/microtia	1	0
Common truncus	1	3

Table 2: Birth Defects by Condition Reported to the West Virginia BDSS		
Condition	Number of Cases	
	2014	2015
Transposition of great arteries	2	3
Dextro-transposition of great arteries	1	3
Tetralogy of Fallot	12	13
Ventricular septal defect	57	73
Atrial septal defect	189	244
Atrioventricular septal defect (AVSD)	1	5
Pulmonary valve atresia and stenosis	12	14
Pulmonary valve atresia	4	2
Tricuspid valve atresia and stenosis	1	1
Tricuspid valve atresia	1	1
Ebstein anomaly	1	2
Aortic valve stenosis	1	2
Hypoplastic left heart syndrome	4	5
Coarctation of aorta	6	5
Total anomalous pulmonary venous connection	1	1
Single ventricle	1	2
Interrupted aortic arch (IAA)	1	0
Double outlet right ventricle (DORV)	3	1
Cleft palate without cleft lip	10	4
Cleft lip without cleft palate	4	1
Cleft lip with cleft palate	6	9
Choanal atresia	2	2
Esophageal atresia/tracheoesophageal fistula	3	2
Rectal and large intestinal atresia/stenosis	7	6
Biliary atresia	3	1
Small intestinal atresia/stenosis	3	7
Renal agenesis/hypoplasia	7	1
Bladder exstrophy	1	0
Hypospadias	24	20
Congenital posterior urethral valves	1	2
Cloacal exstrophy	7	4
Diaphragmatic hernia	2	4
Limb deficiencies (reduction defects)	2	4
Clubfoot	17	14
Trisomy 13 (Patau syndrome)	0	2
Trisomy 21 (Down syndrome)	9	9
Trisomy 18 (Edwards syndrome)	3	2
Total	442	517

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. Since almost half of all pregnancies are unplanned, birth defects prevention measures should be in place at all times to ensure a healthy pregnancy.