STATE OF WEST VIRGINIA
DEPARTMENT OF HEALTH AND HUMAN RESOURCES
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Jim Justice
Governor

Bill J. Crouch
Cabinet Secretary

January 20, 2017

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

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

Dear President Carmichael and Speaker Armstead:

As required by West Virginia Code §16-40-8, regarding birth defects surveillance, please find enclosed the report for January through December 2013. This report is provided by the West Virginia Department of Health and Human Resources 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/vc

Enclosure

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

West Virginia
Birth Defects

Calendar Year 2013
(January –December)

Office of Maternal, Child and Family Health
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Charleston, WV 25301
Melissa Baker, MCH Epidemiologist
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WEST VIRGINIA
Department of
Health & **Human**
Resources
BUREAU FOR PUBLIC HEALTH

The West Virginia Birth Defects Surveillance System (BDSS) is administered by the 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. with rules and regulations West Virginia Code of State Rules §64-81 mandates 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, meaning 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. Infants born with birth defects are identified using specific ICD9 codes and reported to the BDSS (by various methods) on a monthly basis by participating birthing facilities. Also, information regarding infants with an identified birth defect at the time of delivery that is indicated on the birth certificate are electronically imported into the BDSS. Of the current 27 birthing facilities in the state, only 8 facilities report birth defects to OMCFH. With the existing process, there is not accurate reporting of birth defects in 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 CODE	DIAGNOSIS All Congenital Anomalies (740-759) (Reports would include 4th and 5th digit attachments, i.e. 740.0 or 743.30.)
740	Anencephalus and similar anomalies
741	Spina Bifida
742	Other congenital anomalies of nervous system
743	Congenital anomalies of eye
744	Congenital anomalies of ear, face and neck
745	Bulbus cordis anomalies and anomalies of cardiac septal closure
746	Other congenital anomalies of heart
747	Other congenital anomalies of circulatory system
748	Congenital anomalies of respiratory system
749	Cleft palate and cleft lip
750	Other congenital anomalies of upper alimentary tract
751	Other congenital anomalies of digestive system
752	Congenital anomalies of genital organs
753	Congenital anomalies of urinary system
754	Certain congenital musculoskeletal deformities
755	Other congenital anomalies of limbs
756	Other congenital musculoskeletal anomalies
757	Congenital anomalies of the integument
758	Chromosomal anomalies
759	Other and unspecified congenital anomalies

There were 20,829 resident births in 2013 and 519 reportable birth defects collected in the BDSS, a rate of 24.9 defects per 1,000 births. Table 2 lists the conditions and the number of cases reported to the BDSS for 2013 resident births.

Table 2: Birth Defects by Condition Reported to the West Virginia BDSS 2013	
Condition	**Number of Cases**
Anencephalus	4
Spina bifida without anencephalus	5
Encephalocele	1
Holoprosencephaly	6
Congenital cataract	0
Anotia/microtia	0
Aortic valve stenosis	3
Common truncus	24
Transposition of great arteries	7
Dextro-transposition of great arteries	7
Tetralogy of Fallot	6
Ventricular septal defect	56
Atrial septal defect	199
Atrioventricular septal defect (AVSD)	4
Pulmonary valve atresia and stenosis	6
Pulmonary valve atresia	1
Tricuspid valve atresia and stenosis	0
Tricuspid valve atresia	0
Ebstein's anomaly	2
Hypoplastic left heart syndrome	2
Coarctation of aorta	14
Single ventricle	2
Interrupted aortic arch (IAA)	0
Double outlet right ventricle (DORV)	5
Cleft palate without cleft lip	21
Cleft lip without cleft palate	0
Cleft lip with cleft palate	7
Choanal atresia	2
Esophageal atresia/tracheoesophageal fistula	4
Rectal and large intestinal atresia/stenosis	5
Biliary atresia	2
Small intestinal atresia/stenosis	8
Renal agenesis/hypoplasia	6
Hypospadias	50
Cloacal exstrophy	5
Diaphragmatic hernia	4
Limb deficiencies (reduction defects)	3
Clubfoot	35
Trisomy 13 (Patau syndrome)	1
Trisomy 21 (Down syndrome)	8
Trisomy 18 (Edwards syndrome)	4
Total	519

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.