

**WEST VIRGINIA  
SECRETARY OF STATE  
JOE MANCHIN, III  
ADMINISTRATIVE LAW DIVISION**

Form #4 ■

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2003 DEC -8 P 2: 21

OFFICE WEST VIRGINIA  
SECRETARY OF STATE

**NOTICE OF RULE MODIFICATION OF A PROPOSED RULE**

AGENCY: DHHR - Bureau for Public Health TITLE NUMBER: 64

CITE AUTHORITY: WV Code §§ 16-1-4 & 16-40-7

AMENDMENT TO AN EXISTING RULE: YES  NO

IF YES, SERIES NUMBER OF RULE BEING AMENDED: \_\_\_\_\_

TITLE OF RULE BEING AMENDED: \_\_\_\_\_

IF NO, SERIES NUMBER OF RULE BEING PROPOSED: 81

TITLE OF RULE BEING PROPOSED: Birth Defects Information System

THE ABOVE PROPOSED LEGISLATIVE RULES, FOLLOWING REVIEW BY THE LEGISLATIVE RULE MAKING REVIEW COMMITTEE, IS HEREBY MODIFIED AS A RESULT OF REVIEW AND COMMENT BY THE LEGISLATIVE RULE MAKING REVIEW COMMITTEE. THE ATTACHED MODIFICATIONS ARE FILED WITH THE SECRETARY OF STATE.



Authorized Signature

**TITLE 64**  
**WEST VIRGINIA LEGISLATIVE RULE**  
**BUREAU FOR PUBLIC HEALTH**  
**DEPARTMENT OF HEALTH AND HUMAN RESOURCES**

**FILED**

2004 JAN 16 A 11:58

**SERIES 81**  
**BIRTH DEFECTS INFORMATION SYSTEM**

OFFICE WEST VIRGINIA  
SECRETARY OF STATE

**§64-81-1. General.**

1.1. Scope. – This rule establishes and implements a statewide birth defects information system for the collection and reporting of congenital anomalies and abnormal conditions. This rule should be read in conjunction with W. Va. Code §§16-1-18 and 16-40-1 et seq. The W.Va. Code is available in public libraries and on the Legislature's web page, <http://www.legis.state.wv.us/>.

1.2. Authority. – W.Va. Code §§16-1-4 and 16-40-7.

1.3. Filing Date. –

1.4. Effective Date. –

**§64-81-2. Application and Enforcement.**

2.1. Application. – This rule applies to all infants born in West Virginia and to the health care providers caring for children at birth and up to the age of six (6) that are diagnosed with a congenital anomaly or abnormal condition based upon national standards.

2.2. Enforcement. – This rule is enforced by the commissioner of the bureau for public health.

**§64-81-3. Definitions.**

3.1. Advisory Council. – The committee appointed pursuant to W. Va. Code §16-40-6 to advise on the establishment and implementation of the birth defects information system.

3.2. Birth Defects Information System - The data base that contains individual case demographic and diagnostic information maintained by the Office of Maternal, Child and Family Health within the Bureau for Public Health.

3.3. Congenital Anomaly and Abnormal Condition. - An abnormality of the body's structure or inherent function present at birth, whether the abnormality is detected at the time of delivery or becomes apparent at a later date.

3.4. Freestanding Birthing Center. – A health care facility in which births routinely occur, that is not licensed under W. Va. Code §16-5B-1 et seq.

3.5. Health Care Providers. – A physician, or his or her designee, at any medical facility including, but not limited to private clinics, health departments and hospitals.

3.6. Hospital. - A facility licensed as a hospital pursuant to W. Va. Code §16-5B-1 et seq. and Welch Emergency Hospital.

3.7. Nurse-Midwife. – An individual authorized under W.Va. Code §30-15 to practice nurse-midwifery.

**§64-81-4. Reporting Requirements.**

4.1. Each physician, nurse-midwife, hospital and freestanding birthing center shall provide information to the birth defects information system on all patients up to the age of six (6) that have been diagnosed with a congenital anomaly or abnormal condition.

4.1.a. The commissioner may not require the reporting of personal identifying information or enter into the system any personal identifying information regarding congenital anomalies or abnormal conditions of a child whose parent or legal guardian objects on the basis of religious beliefs according to W. Va. Code §16-40-2.

4.2. The information shall be provided on forms obtained from the Office of Maternal, Child and Family Health in the Bureau.

4.3. Cases to be included in the information system shall consist of the International Classification of Diseases (ICD) diagnoses. After the information is submitted, the advisory council shall recommend the following types of cases that are reportable to the information system based on national standards.

ICD CODE	DIAGNOSIS
All Congenital Anomalies (740-759) (Reports would include 4 <sup>th</sup> and 5 <sup>th</sup> 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
	Specified Conditions in the Perinatal Period (760-763) (including 4 <sup>th</sup> and 5 <sup>th</sup> digit attachments, i.e., 765.2 or 765.20)
760.71	Fetal Alcohol Syndrome
764	Slow fetal growth and fetal malnutrition
765	Disorders relating to short gestation and low birthweight
766	Disorders relating to long gestation and high birthweight

4.4. If a child's parent or legal guardian wants information concerning the child removed from the birth defects information system for religious reasons:

4.4.a. The commissioner shall remove all identifying information from the record, but leave the case in the system for reporting purposes; and

4.4.b. A form for the parent or legal guardian to complete for the removal of the child's identifying information shall be mailed to all birthing facilities and made available upon request at the Bureau for Public Health office and on the Bureau's web page: <http://www.wvdhhr.org/>.

**§64-81-5. Confidentiality.**

5.1. Only those persons employed by the Bureau for Public health dealing specifically with the birth defects registry shall have access to the database. All others requesting data from the registry shall complete a request form detailing what information is requested and how it shall be used. The person requesting the information then shall be given compiled data with no identifying information attached.

5.2. Anyone who obtains confidential information while implementing W.Va. Code §16-40-1 et seq. may disclose it only to reporting sources, persons demonstrating a need that is essential to health related research or care of persons with congenital anomalies and abnormal conditions, or as required or permitted by law.

5.3. Anyone who obtains confidential information while implementing W.Va. Code §16-40-1 et seq. shall provide a written statement to the commissioner that he or she fully understands the confidentiality of the information and will maintain it.

5.4. The commissioner may publish reports with statistical data relating to birth defects and other adverse birth outcomes that do not in any manner identify individual patients or individual sources of information are permissible, provided that the data is not for such small geographic areas or in categories with few entries that together with other publicly available information, the patients could be identified.

**§64-81-6. Penalties.**

6.1. Anyone who violates the provisions of W.Va. Code §16-40-1 et seq. or this rule is subject to the penalties in W.Va. Code §16-1-17 and -18.

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