WEST VIRGINIA SECRETARY OF STATE

KRIS WARNER

ADMINISTRATIVE LAW DIVISION

eFILED

7/29/2026 12:32:05 PM

Office of West Virginia Secretary Of State

NOTICE OF AGENCY APPROVAL OF A PROPOSED RULE AND FILING WITH THE LEGISLATIVE RULE-MAKING REVIEW COMMITTEE

AGENCY: Health

TITLE-SERIES: 64-81

RULE TYPE: Legislative

Amendment to Existing Rule: Yes

Repeal of existing rule: No

RULE NAME: 64-81 Birth Defects Information System

PRIMARY CONTACT

NAME: Virginia M PayneWVa Code 16-1-4 and 16-40-7

ADDRESS: 321 Capitol Street

Charleston, WV 25301

EMAIL: virginia.m.payne@wv.gov

PHONE NUMBER: 304-389-9183

CITE STATUTORY AUTHORITY: W.Va. Code §16-1-4

EXPLANATION OF THE STATUTORY AUTHORITY FOR THE LEGISLATIVE RULE, INCLUDING A DETAILED SUMMARY OF THE EFFECT OF EACH PROVISION OF THE LEGISLATIVE RULE WITH CITATION TO THE SPECIFIC STATUTORY PROVISION WHICH EMPOWERS THE AGENCY TO ENACT SUCH RULE PROVISION:

W.Va. Code §16-40-7

IS THIS FILING SOLELY FOR THE SUNSET PROVISION REQUIREMENTS IN W. VA. CODE §29A-3-19(e)? No

IF YES, DO YOU CERTIFY THAT THE ONLY CHANGES TO THE RULE ARE THE FILING DATE, EFFECTIVE DATE AND AN EXTENSION OF THE SUNSET DATE? No

DATE eFiled FOR NOTICE OF HEARING OR PUBLIC COMMENT PERIOD: 6/25/2026

DATE OF PUBLIC HEARING(S) OR PUBLIC COMMENT PERIOD ENDED: 7/25/2026

COMMENTS RECEIVED: No

(IF YES, PLEASE UPLOAD IN THE COMMENTS RECEIVED FIELD COMMENTS RECEIVED AND RESPONSES TO COMMENTS)

PUBLIC HEARING: No

(IF YES, PLEASE UPLOAD IN THE PUBLIC HEARING FIELD PERSONS WHO APPEARED AT THE HEARING(S) AND TRANSCRIPTS)

RELEVANT FEDERAL STATUTES OR REGULATIONS: No

WHAT OTHER NOTICE, INCLUDING ADVERTISING, DID YOU GIVE OF THE HEARING?

N/A

SUMMARY OF THE CONTENT OF THE LEGISLATIVE RULE, AND A DETAILED DESCRIPTION OF THE RULE'S PURPOSE AND ALL PROPOSED CHANGES TO THE RULE:

This rule establishes and implements a statewide birth defects information system for the collection and reporting of congenital anomalies and abnormal conditions. Amendments to the rule include technical cleanup and updates to diagnostic codes.

STATEMENT OF CIRCUMSTANCES WHICH REQUIRE THE RULE:

The rule is being amended to include updated diagnostic codes.

SUMMARIZE IN A CLEAR AND CONCISE MANNER THE OVERALL ECONOMIC IMPACT OF THE PROPOSED LEGISLATIVE RULE:

A. ECONOMIC IMPACT ON REVENUES OF STATE GOVERNMENT:

None

B. ECONOMIC IMPACT ON SPECIAL REVENUE ACCOUNTS:

None

C. ECONOMIC IMPACT OF THE LEGISLATIVE RULE ON THE STATE OR ITS RESIDENTS:

None

D. FISCAL NOTE DETAIL:

Effect of Proposal	Fiscal Year		
	2026 Increase/Decrease (use "-")	2027 Increase/Decrease (use "-")	Fiscal Year (Upon Full Implementation)
1. Estimated Total Cost	0	0	0
Personal Services	0	0	0
Current Expenses	0	0	0
Repairs and Alterations	0	0	0
Assets	0	0	0
Other	0	0	0
2. Estimated Total Revenues	0	0	0

E. EXPLANATION OF ABOVE ESTIMATES (INCLUDING LONG-RANGE EFFECT):

N/A

BY CHOOSING 'YES', I ATTEST THAT THE PREVIOUS STATEMENT IS TRUE AND CORRECT.

Yes

Virginia M Payne -- By my signature, I certify that I am the person authorized to file legislative rules, in accordance with West Virginia Code §29A-3-11 and §39A-3-2.

TITLE 64
LEGISLATIVE RULE
DEPARTMENT OF HEALTH
BUREAU FOR PUBLIC HEALTH

SERIES 81
BIRTH DEFECTS INFORMATION SYSTEM

§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. -- ~~April 29, 2004~~.

1.4. Effective Date. -- ~~April 29, 2004~~.

1.5. Sunset. -- This rule shall terminate and have no further force or effect on August 1, 2032.

§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.

All terms contained in this rule shall have the same meaning as set forth in W. Va. Code §16-40-1. This section sets forth definitions for terms that are not otherwise defined, but that appear through this rule

~~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.~~ 3.1. 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.~~ 3.2. 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.~~ 3.3. 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.~~ 4.1.1. 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.~~ The ICD-10-CM Codes, and the type of cases that are reportable to the information system, as set forth in this section, are non-inclusive, and may be modified to meet national standards

~~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~~
	~~Specified Conditions in the Perinatal Period (760-763) (including 4th and 5th 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~~

ICD-10-CM Code	
Chapter Q00-QA0 – Congenital malformations, deformations, chromosomal abnormalities, and genetic disorders; select codes listed below:	
Q00.0-Q00.1	Anencephaly
Q01.0-Q01.9	Encephalocele
Q02	Microcephaly
Q04.2	Holoprosencephaly
Q05.0-Q05.9, Q07.01, Q07.03	Spina bifida without anencephaly
Q11.0-Q11.2	Anophthalmia/microphthalmia
Q12.0	Congenital cataract
Q16.0, Q17.2	Anotia/microtia
Q20.0	Common truncus
Q20.1	Double outlet right ventricle (DORV)
Q20.3	Dextro-transposition of great arteries
Q20.4	Single ventricle
Q20.5	Transposition of great arteries
Q21.0	Ventricular septal defect

Q21.1	Atrial septal defect
Q21.2	Atrioventrical septial defect (AVSD)
Q21.3	Tetralogy of Fallot
Q22.0	Pulmonary valve atresia
Q22.1	Pulmonary valve atresia and stenosis
Q22.4	Tricuspid value atresia
Q22.4	Tricuspid value atresia and stenosis
Q22.5	Ebstein's anomaly
Q23.0	Aortic valve stenosis
Q23.4	Hypoplastic left heart syndrome
Q25.1	Coarctation of aorta
Q25.2, Q25.4	Interrupted aortic arch (IAA)
Q26.2	Total anomalous pulmonary venous connection
Q30.0	Choanal atresia
Q35.1-Q35.9	Cleft palate without cleft lip
Q36.0-Q36.9	Cleft lip without cleft palate
Q37.0-Q37.9	Cleft lip with cleft palate
Q39.0-Q39.4	Esophageal atresia/tracheosophageal fistula
Q41.0	Small intestinal atresia/stenosis
Q42.0-Q42.9	Rectal and large intestinal atresia/stenosis
Q44.2-Q44.3	Biliary atresia
Q54.0-Q54.3, Q54.5-Q54.9	Hypospadias
Q60.0-Q60.6	Renal agenesis/hypoplasia
Q64.10, Q64.19	Bladder exstrophy
Q64.12	Cloacal exstrophy
Q64.2	Congenital posterior urethral valves
Q66.0, Q66.89	Clubfoot
Q71.0-Q71.9, Q72.0-Q72.9, Q73.0-73.8	Limb deficiencies (reduction defects)
Q75.0	Craniosynostosis
Q79.0-Q79.1	Diaphragmatic hernia
Q79.2	Omphalocele
Q79.3	Gastroschisis
Q90.0-Q90.9	Trisomy 21 (Down syndrome)
Q91.0-Q91.3	Trisomy 18 (Edwards syndrome)
Q91.4-Q91.7	Trisomy 13 (Patau syndrome)
Q96.0-Q96.9	Turner syndrome
Chapter P00-P96 – Certain conditions originating in the perinatal period; select codes listed below:	
P00-P04	Newborn affected by maternal factors and by complications of pregnancy, labor, and delivery
P05-P08	Disorders of newborn related to length of gestation and fetal growth
P09	Abnormal findings on neonatal screening
P10-P15	Birth trauma
P19-P29	Respiratory and cardiovascular disorders specific to the perinatal period
P35-P39	Infections specific to the perinatal period
Chapter H00-H59 – Diseases of the eye and adnexa; select codes listed below:	

H47.03	Optic nerve hypoplasia
Chapter H60-H95 – Diseases of the ear and mastoid process; select codes listed below:	
H90.0-H90.8	Conductive and sensorineural hearing loss
H91.0-H91.9	Other and unspecified hearing loss
H90.A	Conductive and sensorineural hearing loss with restricted hearing on the contralateral side

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.~~ 4.4.1. The commissioner shall remove all identifying information from the record, but leave the case in the system for reporting purposes; and

~~4.4.b.~~ 4.4.2. 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 §16-1-18.