

# **WEST VIRGINIA LEGISLATURE**

**2020 REGULAR SESSION**

**Committee Substitute**

**for**

**Senate Bill 269**

SENATORS STOLLINGS, RUCKER, ROBERTS, CLINE, AND

JEFFRIES, *original sponsors*

[Originating in the Committee on Health and Human

Resources; reported on January 31, 2020]



1 A BILL to amend the Code of West Virginia, 1931, as amended, by adding thereto a new article,  
2 designated §16-5AA-1, §16-5AA-2, §16-5AA-3, §16-5AA-4, §16-5AA-5, and §16-5AA-6,  
3 all relating to establishing an advisory council on rare diseases; creating the advisory  
4 council and its composition; setting terms of members; defining terms; defining duties,  
5 subject to the availability of resources; defining powers of the advisory council; setting out  
6 particular discretionary duties of the Secretary of the Department of Health and Human  
7 Resources; and establishing a special revenue account.

*Be it enacted by the Legislature of West Virginia:*

**ARTICLE 5AA. WEST VIRGINIA ADVISORY COUNCIL ON RARE DISEASES.**

**§16-5AA-1. Establishment and composition of the West Virginia Council on Rare Diseases.**

1 (a) There is hereby established the West Virginia Advisory Council on Rare Diseases to  
2 advise state agencies on research, diagnosis, treatment, and education relating to rare diseases.

3 (b) The council shall consist of 12 voting members, constituted as follows:

4 (1) The Secretary of the Department of Health and Human Resources or his or her  
5 designee; and

6 (2) Eleven members who shall be appointed by the Governor as follows:

7 (A) Three physicians licensed and practicing in the state with experience researching,  
8 diagnosing, or treating rare diseases;

9 (B) Three persons over the age of 18 who either have a rare disease or are a family  
10 member of a person with a rare disease;

11 (C) A registered nurse or advanced practice registered nurse licensed and practicing in  
12 the state with experience treating rare disease;

13 (D) A person with an advanced degree in public health or other health-related field; and

14 (E) Three representatives from a patient-based organization or advocacy group for rare  
15 disease, with preference given to organizations based in West Virginia.

16 Appointments to the advisory council are for terms of three years each, except that in the  
17 initial appointments one physician and one patient or family member shall be appointed for a term  
18 of one year, one physician and one patient or family member shall be appointed for a term of two  
19 years, and the registered nurse or advanced practice registered nurse shall initially be appointed  
20 for a term of two years. In order to bring greater diversity of knowledge of illnesses represented,  
21 the representatives of a patient-based organization or advocacy group may serve more terms  
22 after not being on the council for at least one year. All other members appointed to the advisory  
23 council may be reappointed for additional terms.

24 (c) In addition to the 12 voting members of the council, the President of the Senate shall  
25 designate a member of the West Virginia Senate and the Speaker of the House of Delegates shall  
26 designate a member of the West Virginia House of Delegates to serve on the advisory council in  
27 the capacity of an advisory member of the council.

28 (d) The chairperson and vice-chairperson of the council shall be elected from the council's  
29 membership by a simple majority vote of the total membership of the council.

30 (e) Members serve without compensation. Travel expenses may only be reimbursed if  
31 travel is related to activities provided for under a grant or private donation.

**§16-5AA-2. Definitions.**

1 As used in this article:

2 “Department” means the West Virginia Department of Health and Human Resources;

3 “Rare disease” means any disease which affects fewer than 200,000 people in the United  
4 States and is known to be substantially under-diagnosed and unrecognized as a result of lack of  
5 adequate diagnostic and research information, including diseases known as “orphan diseases”  
6 for research purposes; and

7 “Secretary” means the Secretary of the West Virginia Department of Health and Human  
8 Resources.

**§16-5AA-3. Duties of the advisory council.**

1           The advisory council shall exercise the following duties to the degree that resources are  
2 available, including, but not limited to:

3           (1) Coordinate statewide efforts for the study of the incidence of rare disease within the  
4 state;

5           (2) Act as the advisory board to the secretary and the West Virginia Legislature on  
6 research, treatment, and education relating to rare diseases;

7           (3) Research and identify priorities relating to the quality of, and access to, treatment and  
8 services provided to persons with rare diseases in the state;

9           (4) Develop, in conjunction and cooperation with the state's medical schools, policy  
10 recommendations relating to the quality of, and access to, treatment and services provided to  
11 persons with rare diseases in the state;

12           (5) Advise, consult, and cooperate with other offices of the department, other agencies of  
13 state government, and patient-based organizations in the development of information and  
14 programs of benefit to the public and the health care community relating to the diagnosis,  
15 treatment, and awareness of rare diseases;

16           (6) Identify best practices for rare disease care as implemented in other states and at the  
17 national level that will improve rare disease care in the state;

18           (7) Develop recommendations for effective strategies to raise public awareness of rare  
19 diseases in the state;

20           (8) Develop recommendations for best practices for ensuring that health care providers  
21 are sufficiently informed of the most effective strategies for recognizing and treating rare disease;

22 and

23           (9) Report to the Governor, secretary, and West Virginia Legislature not later than January  
24 1, 2021, and annually thereafter on the activities of the advisory council and its findings and  
25 recommendations regarding rare disease research and care in West Virginia, including any

26 recommendations for statutory changes and amendments to the structure, organization, and  
27 powers and duties of the advisory council.

**§16-5AA-4. Powers of the advisory council.**

1 In order to carry out the duties described in this article, the advisory council has the  
2 following powers:

3 (1) To pursue and accept gifts, grants, and bequests of funds from individuals,  
4 foundations, corporations, federal government, government agencies, and other organizations or  
5 institutions to fund the activities of the advisory council;

6 (2) To schedule and conduct meetings;

7 (3) To the degree that funds are available, publish findings, recommendations, and reports  
8 on diagnosis, treatment, research, and education for rare diseases for the use and benefit of the  
9 department, other agencies of the state, the medical community, general public, and  
10 organizations representing the patients affected.

**§16-5AA-5. Duties and powers of the secretary.**

1 The secretary at his or her discretion may provide the advisory council with administrative  
2 support reasonably necessary for the advisory council to carry out its duties. In addition, the  
3 secretary may make and sign any agreements and may do and perform any acts that are  
4 necessary to receive, accept, or secure gifts, grants, and bequests of funds in the name of the  
5 advisory council.

**§16-5AA-6. Rare Disease Advisory Council Fund.**

1 There is hereby created a special revenue account in the State Treasury to be known as  
2 the Rare Disease Advisory Council Information Fund into which gifts, grants, and bequests may  
3 be received for the use of the advisory council to carry out its duties as specified in §16-5AA-3 of  
4 this code. The advisory council has the discretion to expend such moneys in this fund from  
5 collections as may be reasonable to carry out the duties of the advisory council as are consistent  
6 with the terms of the gifts, grants, or bequests providing those moneys. The presence of funds in

- 7 this special revenue account does not preclude the Legislature from appropriating such funds as  
8 it may deem necessary for the use and mission of the advisory council.

NOTE: The purpose of this bill is to create an advisory council to educate the public and the medical community in the recognition, diagnosis, treatment, and research of rare diseases.

Strike-throughs indicate language that would be stricken from a heading or the present law and underscoring indicates new language that would be added.