

WEST VIRGINIA LEGISLATURE

2020 REGULAR SESSION

Introduced

Senate Bill 269

BY SENATORS STOLLINGS, RUCKER, AND ROBERTS

[Introduced January 10, 2020; referred
to the Committee on Health and Human Resources;
and then to the Committee on Government
Organization]

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 and
 5 powers of the advisory council; setting out particular duties of the Secretary of the
 6 Department of Health and Human 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 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

18 term of one year, and one physician and one patient or family member shall be appointed for a
 19 term of two years, and the registered nurse or advanced practice registered nurse shall initially
 20 be appointed for a term of two years. In order to bring greater diversity of knowledge of illnesses
 21 represented, the representatives of a patient-based organization or advocacy group may serve
 22 more terms after not being on the council for at least one year. All other members appointed to
 23 the advisory 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 Senator from the West Virginia Senate and the Speaker of the House of Delegates
 26 shall designate a Delegate from the West Virginia House of Delegates , to serve on the advisory
 27 council in 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 but shall be reimbursed for reasonable and
 31 necessary expenditures incurred in the performance of their duties as members of the advisory
 32 council, except for the designated members of the Legislature who shall be reimbursed by the
 33 Legislature for their reasonable and necessary expenditures.

§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, including, but not limited to:

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

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

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

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

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

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

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

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

22 (9) Report to the Governor, secretary and West Virginia Legislature not later than January
23 1, 2021, and annually thereafter on the activities of the advisory council and its findings and
24 recommendations regarding rare disease research and care in West Virginia, including any
25 recommendations for statutory changes and amendments to the structure, organization, and
26 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, foundations,
4 corporations, the 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 publish findings, recommendations, and reports on diagnosis, treatment, research,
8 and education for rare diseases for the use and benefit of the department, other agencies of the
9 state, the medical community, general public, and organizations representing the patients
10 affected.

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

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