

WEST VIRGINIA LEGISLATURE

2016 REGULAR SESSION

Introduced

House Bill 4526

BY DELEGATES ROHRBACH, STANSBURY, FAIRCLOTH,

B. WHITE, WAXMAN, CAMPBELL, SUMMERS AND

ELLINGTON

[Introduced February 12, 2016; referred to the
Committee on Health and Human Resources then
Finance.]

1 A BILL to amend the Code of West Virginia, 1931, as amended, by adding thereto a new article,
 2 designated §16-5Y-1, §16-5Y-2, §16-5Y-3, §16-5Y-4, §16-5Y-5 and §16-5Y-6, all relating
 3 to establishing an advisory council on rare diseases; creating the advisory council and its
 4 composition; setting terms of members; defining words and phrases; defining the duties
 5 and the 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:

1 That the Code of West Virginia, 1931, as amended, be amended by adding thereto a new
 2 article, designated §16-5Y-1, §16-5Y-2, §16-5Y-3, §16-5Y-4, §16-5Y-5 and §16-5Y-6, all to read
 3 as follows:

ARTICLE 5Y. WEST VIRGINIA ADVISORY COUNCIL ON RARE DISEASES.

§16-5Y-1. Establishment and composition of West Virginia Advisory 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 ten 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) Nine 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 disease;

9 (B) Three persons over the age of eighteen 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 who

14 also has experience in medical research and analytical review of medical literature, preferably
15 with experience in the diagnosis, treatment or physiology of rare diseases; and

16 (E) A representative from a patient-based organization or advocacy group for rare disease.

17 Appointments to the advisory council shall be for terms of three years each, except that in
18 the initial appointments, one physician and one patient or family member shall be appointed for a
19 term of one year, and one physician and one patient or family member shall be appointed for a
20 term of two years, and the registered nurse or advanced practice registered nurse shall initially
21 be appointed for a term of two years. In order to bring greater diversity of knowledge of illnesses
22 represented, the representative of a patient-based organization or advocacy group may only
23 serve one term. All other members appointed to the advisory council may be reappointed for an
24 additional term.

25 (c) In addition to the ten voting members of the council, the President of the Senate shall
26 designate a senator from the West Virginia Senate and the Speaker of the House shall designate
27 a delegate from the West Virginia House of Delegates, to serve on the advisory council at the will
28 and pleasure of the presiding officer of each respective house of the Legislature in the capacity
29 of an advisory member of the council.

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

32 (e) Members shall serve without compensation but shall be reimbursed by the department
33 for reasonable and necessary expenditures incurred in the performance of their duties as
34 members of the advisory council, except for the designated members of the Legislature who shall
35 be reimbursed by the Legislature for their reasonable and necessary expenditures.

§16-5Y-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 two hundred thousand people

4 in the United States and is known to be substantially under diagnosed and unrecognized as a
5 result of lack of adequate diagnostic and research information, including diseases known as
6 "orphan diseases" for research purposes; and

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

§16-5Y-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 of the Department of Health and Human
5 Services and the West Virginia Legislature on research, diagnosis, treatment and education
6 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 on 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 of Health and
13 Human Resources and other agencies of state government 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 diseases;
22 and

23 (9) Report to the Governor, secretary and West Virginia Legislature not later than January
24 1, 2017, 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.

§16-5Y-4. Powers of the advisory council.

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

3 (1) To pursue and accept gifts, grants and bequests of funds from individuals, foundations,
4 corporations, the federal government, governmental 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 and the general public.

§16-5Y-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.

§16-5Y-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 section three

4 of this article. 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 shall 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.