

WEST VIRGINIA LEGISLATURE

2017 REGULAR SESSION

Introduced

Senate Bill 670

BY SENATORS TAKUBO AND STOLLINGS

[Introduced March 20, 2017; 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 §16-5Z-1, §16-5Z-2, §16-5Z-3, §16-5Z-4 and §16-5Z-5, all relating to
 3 establishing the West Virginia Advisory Council on Rare Diseases; setting forth its
 4 composition; establishing terms of members; defining terms; establishing the powers and
 5 duties of the council; setting forth duties of the Secretary of the Department of Health and
 6 Human Resources; and setting a sunset date.

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 §16-5Z-1, §16-5Z-2, §16-5Z-3, §16-5Z-4 and §16-5Z-5, all to read as follows:

ARTICLE 5Z. THE WEST VIRGINIA ADVISORY COUNCIL ON RARE DISEASES.

§16-5Z-1. Definitions.

1 The following words have the following meaning:

2 “Council” means the West Virginia Advisory Council on Rare Diseases.

3 “Department” means the West Virginia Department of Health and Human Resources.

4 “Rare disease” means any disease which affects fewer than two hundred thousand people
 5 in the United States. Rare diseases are sometimes called orphan diseases.

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

§16-5Z-2. Establishment and composition of West Virginia Advisory Council on Rare
Diseases.

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

3 (b) The council consists of ten members designated as follows:

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

6 (2) The remaining nine members shall be appointed by the secretary:

7 (A) Three physicians licensed and practicing in the state with experience researching,
8 diagnosing or treating patients with rare diseases. One of these physicians is to be a pediatrician
9 who provides care to children with rare diseases;

10 (B) Three persons over the age of eighteen who either have a rare disease or are a
11 caregiver of a person with a rare disease;

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

14 (D) A person with an advanced degree in public health or other health-related field who
15 also has experience in medical research and analytical review of medical literature, preferably
16 with experience in the diagnosis, treatment or physiology of rare diseases; and

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

18 (c) The chairperson and vice-chairperson of the council shall be elected from the council's
19 membership by a simple majority vote.

20 (d) Members serve without compensation but will be reimbursed by the department for
21 reasonable and necessary expenditures incurred in the performance of their duties as members
22 of the advisory council.

23 (e) Appointments to the advisory council are for terms of three years each, except that in
24 the initial appointments, one physician and one patient or family member are to be appointed for
25 a term of one year, and one physician and one patient or family member are to be appointed for
26 a term of two years, and the registered nurse or advanced practice registered nurse will be initially
27 be appointed for a term of two years. To bring greater diversity of knowledge of illnesses
28 represented, the representative of a patient-based organization or advocacy group may only
29 serve one term. All other members appointed to the advisory council may be reappointed for
30 additional terms.

31 (f) The advisory council may consult with entities and person with a particular expertise as
32 they deem necessary in the fulfillment of their duties.

§16-5Z-3. Powers and duties of the advisory council.

1 The advisory council may:

2 (1) Pursue and accept gifts, grants and bequests of funds from individuals, foundations,
3 corporations, the federal government, governmental agencies and other organizations or
4 institutions to fund the duties of the advisory council;

5 (2) Schedule and conduct meetings;

6 (3) Publish findings, recommendations and reports on diagnosis, treatment, research and
7 education for rare diseases for the use and benefit of the department, other agencies of the state,
8 the medical community and the general public.

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

11 (5) Act as the advisory board to the Secretary and the West Virginia Legislature on
12 research, diagnosis, treatment and education relating to rare diseases;

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

15 (7) Develop, in conjunction and cooperation with the state’s medical schools, policy
16 recommendations on relating to the quality of and access to treatment and services provided to
17 persons with rare diseases in the state;

18 (8) Advise, consult and cooperate with other offices of the department and other agencies
19 of state government in the development of information and programs of benefit to the public and
20 the health care community relating to the diagnosis, treatment, and awareness of rare diseases;

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

23 (10) Develop recommendations for effective strategies to raise public awareness of rare
24 diseases in the state;

25 (11) Develop recommendations for best practices for ensuring that health care providers

26 are sufficiently informed of the most effective strategies for recognizing and treating rare diseases;

27 and

28 (12) Report to the Governor, secretary and the Legislature not later than January 1, 2018,

29 and annually thereafter, on the activities of the advisory council and its findings and

30 recommendations regarding rare disease research and care in West Virginia, including any

31 recommendations for statutory changes and amendments to the structure, organization and

32 powers and duties of the advisory council.

§16-5Z-4. Powers and duties of the secretary.

1 In addition to the powers set forth in section two of this article, the secretary may:

2 (1) Provide the advisory council with administrative support reasonably necessary for the
3 advisory council to carry out its duties; and

4 (2) Make and sign any agreements and may perform any acts that are necessary to
5 receive, accept or secure gifts, grants and bequests of funds in the name of the advisory council.

§16-5Z-5. Sunset date.

1 Unless continued by act of the Legislature, the counsel shall cease to exist on December
2 31, 2022.

NOTE: The purpose of this bill is to establish the West Virginia Advisory Council on Rare Diseases. The bill sets forth its composition. The bill establishes terms of members. The bill defines terms. The bill establishes the powers and duties of the council. The bill sets forth duties of the Secretary of the Department of Health and Human Resources. The bill sets a sunset date.

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