
WEST VIRGINIA CODE CHAPTER 16
ARTICLE 5CC

WV Legislature

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

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

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

(1) The Secretary of the Department of Health or his or her designee; and

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

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

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

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

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

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

Appointments to the advisory council are for terms of three years.

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

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

§16-5CC-2. Definitions.

As used in this article:

"Department" means the West Virginia Department of Health;

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

"Secretary" means the Secretary of the West Virginia Department of Health.

§16-5CC-3. Duties of the advisory council.

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

- (1) Coordinate statewide efforts for the study of the incidence of rare disease within the state;
- (2) Act as the advisory board to the secretary and the West Virginia Legislature on research, treatment, and education relating to rare diseases;
- (3) Research and identify priorities relating to the quality of, and access to, treatment and services provided to persons with rare diseases in the state;
- (4) Develop, in conjunction and cooperation with the state's medical schools, policy recommendations relating to the quality of, and access to, treatment and services provided to persons with rare diseases in the state;
- (5) Advise, consult, and cooperate with other offices of the department, other agencies of state government, and patient-based organizations in the development of information and programs of benefit to the public and the health care community relating to the diagnosis, treatment, and awareness of rare diseases;
- (6) Identify best practices for rare disease care as implemented in other states and at the national level that will improve rare disease care in the state;
- (7) Develop recommendations for effective strategies to raise public awareness of rare diseases in the state;
- (8) Develop recommendations for best practices for ensuring that health care providers are sufficiently informed of the most effective strategies for recognizing and treating rare disease; and
- (9) Report to the secretary and the Joint Committee on Health not later than January 1, 2021, and annually thereafter on the activities of the advisory council and its findings and recommendations regarding rare disease research and care in West Virginia, including any recommendations for statutory changes and amendments to the structure, organization, and powers and duties of the advisory council. The advisory council shall terminate on June 30, 2025.

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

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

- (1) To pursue and accept gifts, grants, and bequests of funds from individuals, foundations, corporations, federal government, government agencies, and other organizations or institutions to fund the activities of the advisory council;
- (2) To schedule and conduct meetings;
- (3) To the degree that funds are available, publish findings, recommendations, and reports on diagnosis, treatment, research, and education for rare diseases for the use and benefit of the department, other agencies of the state, the medical community, general public, and organizations representing the patients affected.

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

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

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§16-5CC-6. Rare Disease Advisory Council Fund.

There is hereby created a special revenue account in the State Treasury to be known as the Rare Disease Advisory Council Information Fund into which gifts, grants, and bequests may be received for the use of the advisory council to carry out its duties as specified in §16-5CC-3 of this code. The advisory council has the discretion to expend such moneys in this fund from collections as may be reasonable to carry out the duties of the advisory council as are consistent with the terms of the gifts, grants, or bequests providing those moneys. The presence of funds in this special revenue account does not preclude the Legislature from appropriating such funds as it may deem necessary for the use and mission of the advisory council.