

WEST VIRGINIA CODE: §16-5CC-1

§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.