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.