WEST VIRGINIA CODE: §16-5CC-3

§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.

WV Legislature