

# **WEST VIRGINIA LEGISLATURE**

**2023 REGULAR SESSION**

**Committee Substitute**

**for**

**House Bill 3164**

By Delegates Summers, Tully and Walker

[Originating in the Committee on Health and Human

Resources; Reported on February 2, 2023]

1 A BILL to amend and reenact §16-5CC-3 of the Code of West Virginia of 1931, as amended,  
2 relating to modifying the West Virginia Advisory Council on Rare Diseases; changing the  
3 entities to which said Council reports; changing the termination date of said Council.

*Be it enacted by the Legislature of West Virginia:*

**ARTICLE 5CC. WEST VIRGINIA ADVISORY COUNCIL ON RARE DISEASES.**

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

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

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

5 (2) Act as the advisory board to the secretary and the West Virginia Legislature on  
6 research, treatment, and education relating to rare diseases;

7 (3) Research and identify priorities relating to the quality of, and access to, treatment and  
8 services provided to persons with rare diseases in the state;

9 (4) Develop, in conjunction and cooperation with the state's medical schools, policy  
10 recommendations relating to the quality of, and access to, treatment and services provided to  
11 persons with rare diseases in the state;

12 (5) Advise, consult, and cooperate with other offices of the department, other agencies of  
13 state government, and patient-based organizations in the development of information and  
14 programs of benefit to the public and the health care community relating to the diagnosis,  
15 treatment, and awareness of rare diseases;

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

18 (7) Develop recommendations for effective strategies to raise public awareness of rare  
19 diseases in the state;

20 (8) Develop recommendations for best practices for ensuring that health care providers are  
21 sufficiently informed of the most effective strategies for recognizing and treating rare disease; and

22 (9) Report to the ~~Governor, secretary, and West Virginia Legislature~~ secretary and the Joint  
23 Committee on Health not later than January 1, 2021, and annually thereafter on the activities of the  
24 advisory council and its findings and recommendations regarding rare disease research and care  
25 in West Virginia, including any recommendations for statutory changes and amendments to the  
26 structure, organization, and powers and duties of the advisory council. The advisory council shall  
27 terminate on ~~January 1, 2023~~ June 30, 2025.

NOTE: The purpose of this bill is to extend the termination date of the West Virginia Advisory Council on Rare Diseases due to a delay in beginning its duties and to change the entities to which said council reports.

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