

WEST VIRGINIA LEGISLATURE

2023 REGULAR SESSION

ENROLLED

Committee Substitute

for

House Bill 3164

BY DELEGATES SUMMERS, TULLY AND WALKER

[Passed February 20, 2023; in effect from passage.]

1 AN ACT 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
21 are sufficiently informed of the most effective strategies for recognizing and treating rare disease;
22 and

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

The Clerk of the House of Delegates and the Clerk of the Senate hereby certify that the foregoing bill is correctly enrolled.

.....
Clerk of the House of Delegates

.....
Clerk of the Senate

Originated in the House of Delegates.

In effect from passage.

.....
Speaker of the House of Delegates

.....
President of the Senate

The within is this the.....
Day of, 2023.

.....
Governor