

1 TO THE HOUSE OF REPRESENTATIVES:

2 The Committee on Human Services to which was referred House Bill No.
3 46 entitled “An act relating to the Rare Disease Advisory Council” respectfully
4 reports that it has considered the same and recommends that the bill be
5 amended by striking out all after the enacting clause and inserting in lieu
6 thereof the following:

7 Sec. 1. FINDINGS

8 The General Assembly finds that:

9 (1) lack of awareness contributes to common and harmful obstacles that
10 rare disease patients face, such as delays in diagnosis, misdiagnosis, lack of
11 treatment options, high out-of-pocket costs, and limited access to medical
12 specialists; and

13 (2) with the support of the National Organization for Rare Disorders,
14 various patient organizations, and stakeholders in the rare disease community,
15 rare disease advisory councils are enabling states to strategically identify and
16 address barriers that prevent individuals living with rare disease from
17 accessing adequate and effective treatment and care for their condition.

18 Sec. 2. 18 V.S.A. chapter 19 is added to read:

19 CHAPTER 19. RARE DISEASES

20 § 981. RARE DISEASE ADVISORY COUNCIL

1 (a) Creation. There is created the Rare Disease Advisory Council within
2 the Department of Health to provide guidance and recommendations to the
3 public, General Assembly, and other government agencies and departments, as
4 necessary, regarding the needs of individuals living with rare diseases in
5 Vermont.

6 (b) Membership.

7 (1) The Advisory Council shall be composed of the following members:

8 (A) two individuals living with a rare disease, at least one of whom is
9 an older Vermonter, one appointed by the Speaker of the House and one
10 appointed by the Senate Committee on Committees;

11 (B) a parent or guardian of a person living with a rare disease,
12 appointed by the Senate Committee on Committees;

13 (C) the Commissioner of Health or designee;

14 (D) the Commissioner of Disabilities, Aging, and Independent Living
15 or designee;

16 (E) a representative of the Heath Equity Advisory Commission
17 established pursuant to section 252 of this title;

18 (F) an academic researcher who conducts rare disease research,
19 appointed by the Speaker of the House;

20 (G) a physician practicing in Vermont with experience treating a rare
21 disease, appointed by the Vermont Medical Society;

1 (H) a nurse practicing in Vermont with experience treating a rare
2 disease, appointed by the Vermont chapter of the American Nurses
3 Association;

4 (I) a pharmacist practicing in Vermont, appointed by the Senate
5 Committee on Committees; and

6 (J) a geneticist or genetic counselor, appointed by the Senate
7 Committee on Committees.

8 (2) The Advisory Council shall collaborate with any other
9 relevant stakeholders it deems appropriate, including the National
10 Organization for Rare Disorders.

11 (c) Powers and duties. The Advisory Council may conduct the following
12 activities for the benefit of individuals impacted by rare diseases in Vermont:

13 (1) convene public hearings and solicit comments from individuals
14 impacted by rare diseases to assist the Advisory Council with creating a needs
15 assessment identifying gaps in services for individuals with a rare disease in
16 Vermont and the needs of their caregivers and providers;

17 (2) provide testimony and comments on pending legislation and rules
18 that impact Vermont's rare disease community before the General Assembly
19 and other State agencies;

20 (3) consult with experts on rare diseases to develop policy
21 recommendations that:

1 (A) identify conditions to recommend to the Newborn Screening
2 Advisory Committee as part of the Vermont Newborn Screening Program; and

3 (B) support timely patient access to diagnostic services and treatment
4 and enhance quality of services provided by rare disease specialists;

5 (4) maintain a web page on the Department of Health’s website to serve
6 as a resource for individuals with a rare disease that contains notices of
7 upcoming meetings, meeting minutes, public comments, and previous annual
8 reports; and

9 (5) any other activities identified by a majority of the Advisory Council.

10 (d) Assistance. The Advisory Council shall have the administrative,
11 technical, and legal assistance of the Department of Health.

12 (e) Report. As needed, the Advisory Council may submit any
13 recommendations for legislative action to the House Committees on Health
14 Care and on Human Services and to the Senate Committee on Health and
15 Welfare.

16 (f) Meetings.

17 (1) The Commissioner of Health or designee shall call the first meeting
18 of the Advisory Council.

19 (2) Annually, the Advisory Council shall elect a member to serve as the
20 Chair.

1 (3) The Advisory Council shall meet quarterly. Meetings may be held
2 in person or remotely on an electronic platform as determined by the Chair.

3 (4) A majority of the membership shall constitute a quorum.

4 (g) Compensation and reimbursement. The members of the Advisory
5 Council not otherwise compensated for their participation shall be entitled to
6 per diem compensation and reimbursement of expenses as permitted under
7 32 V.S.A. § 1010 for not more than four meetings annually.

8 Sec. 3. EFFECTIVE DATE

9 This act shall take effect on July 1, 2026.

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16 (Committee vote: _____)

17 _____

18 Representative _____

19 FOR THE COMMITTEE