

1 TO THE HONORABLE SENATE:

2 The Committee on Health and Welfare to which was referred House Bill
3 No. 46 entitled “An act relating to the Rare Disease Advisory Council”
4 respectfully reports that it has considered the same and recommends that the
5 Senate propose to the House that the bill be amended by striking out all after
6 the enacting clause and inserting in lieu 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, appointed by the Commissioner of Health;

10 (B) a parent or guardian of a person living with a rare disease,
11 appointed by the Commissioner of Health;

12 (C) the Commissioner of Health or designee;

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

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

17 (F) an academic researcher who conducts rare disease research,
18 appointed by the Commissioner of Health;

19 (G) a physician practicing in Vermont with experience treating a rare
20 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 Vermont
5 Pharmacists Association;

6 (J) a geneticist or genetic counselor, appointed by the Commissioner
7 of Health; and

8 (K) any other persons deemed necessary by the Commissioner of
9 Health.

10 (2) Members of the Advisory Council shall be appointed for staggered
11 five-year terms. Any midterm vacancy shall be filled by the appointing
12 authority for the remainder of the unexpired term. Terms shall begin on
13 January 1 of the year of appointment and conclude on December 31 of the last
14 year of the member’s term. Members of the Advisory Council may serve
15 multiple terms, either consecutively or intermittently.

16 (3) The Advisory Council may collaborate with any other relevant
17 stakeholders it deems appropriate, including the National Organization for
18 Rare Disorders.

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

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

5 (2) provide testimony and comments on pending legislation and rules
6 that impact Vermont’s rare disease community before the General Assembly
7 and other State agencies;

8 (3) in consultation with experts on rare diseases, develop and provide
9 policy recommendations that:

10 (A) identify conditions for the Department of Health to consider as
11 part of appropriate screening guidance and recommendations; and

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

14 (4) any other activities identified by a majority of the Advisory Council.

15 (d) Assistance. The Advisory Council shall have the administrative,
16 technical, and legal assistance of the Department of Health. The Department
17 shall maintain a web page on its website that contains notices of upcoming
18 meetings, meeting minutes, public comments, and reports.

19 (e) Report. As needed, the Advisory Council may submit any
20 recommendations for legislative action to the House Committees on Health

1 Care and on Human Services and to the Senate Committee on Health and
2 Welfare.

3 (f) Meetings.

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

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

8 (3) The Advisory Council shall meet quarterly. Meetings may be held
9 in person or remotely on an electronic platform in accordance with the
10 Vermont Open Meeting Law set forth in 1 V.S.A. §§ 310–314.

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

12 (g) Compensation and reimbursement. The members of the Advisory
13 Council not otherwise compensated for their participation shall be entitled to
14 per diem compensation and reimbursement of expenses as permitted under
15 32 V.S.A. § 1010 for not more than four meetings annually.

16 **Sec. 3. LONG COVID RESOURCES FOR PRIMARY CARE PROVIDERS**
17 **AND PATIENTS**

18 (a) On or before January 1, 2027, the Department of Health shall
19 collaborate with the University of Vermont Medical Center, the Vermont
20 Medical Society, and patients with lived experience of long COVID to:

1 (1) identify existing evidence-informed standards, best practices, and
2 training for primary care providers regarding long COVID and distribute these
3 resources through the Department’s website and to primary care providers; and

4 (2) in collaboration with the Department of Disabilities, Aging, and
5 Independent Living, identify support services for long COVID that include a
6 range of peer and community-based programs, such as long COVID support
7 groups through the University of Vermont Medical Center, the Vermont Center
8 for Independent Living, or another entity, and strategies to support patients
9 who are homebound or at risk of becoming homebound.

10 (b) On or before February 1, 2027, the Department of Health, in
11 collaboration with the Department of Disabilities, Aging, and Independent
12 Living, shall present recommendations to the House Committee on Human
13 Services and the Senate Committee on Health and Welfare on providing long-
14 term disability supports to individuals experiencing long COVID.

15 (c) As used in this section, “long COVID” means postacute sequelae of
16 SARS-CoV-2 infection.

17 Sec. 4. EFFECTIVE DATE

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

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1 (Committee vote: _____)

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Senator _____

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FOR THE COMMITTEE