

1 H.46

2 An act relating to the Rare Disease Advisory Council

3 It is hereby enacted by the General Assembly of the State of Vermont:

4 Sec. 1. FINDINGS

5 The General Assembly finds that:

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

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

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

16 CHAPTER 19. RARE DISEASES

17 § 981. RARE DISEASE ADVISORY COUNCIL

18 (a) Creation. There is created the Rare Disease Advisory Council within
19 the Department of Health to provide guidance and recommendations to the
20 public, General Assembly, and other government agencies and departments, as

1 necessary, regarding the needs of individuals living with rare diseases in
2 Vermont.

3 (b) Membership.

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

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

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

10 (C) the Commissioner of Health or designee;

11 (D) the Commissioner of Disabilities, Aging, and Independent Living
12 or designee;

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

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

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

19 (H) a nurse practicing in Vermont with experience treating a rare
20 disease, appointed by the Vermont chapter of the American Nurses
21 Association;

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

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

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

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

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

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

17 (3) consult with experts on rare diseases to develop policy
18 recommendations that:

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

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

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

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

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

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

14 (f) Meetings.

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

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

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

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

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

5 Sec. 3. EFFECTIVE DATE

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