

H.46

Introduced by Representatives Donahue of Northfield, Noyes of Wolcott, and

Stone of Burlington

Referred to Committee on

Date:

Subject: Health; rare diseases; advisory council

Statement of purpose of bill as introduced: This bill proposes to establish the  
Rare Disease Advisory Council.

An act relating to the Rare Disease Advisory Council

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

~~Sec. 1. 18 V.S.A. chapter 19 is added to read:~~

CHAPTER 19. RARE DISEASES

§ 981. RARE DISEASE ADVISORY COUNCIL

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

~~(b) Membership.~~

1 ~~(1) The Advisory Council shall be composed of the following members~~  
2 with members potentially fulfilling multiple roles if the member meets  
3 qualifications of more than one subdivision:  
4 (A) the Commissioner of Health or designee;  
5 (B) the Commissioner of Vermont Health Access or designee;  
6 (C) the Commissioner of Financial Regulation or designee;  
7 (D) the Director of the Office of Racial Equity or designee;  
8 (E) two individuals living with a rare disease, one appointed by the  
9 Speaker of the House and one appointed by the Senate Committee on  
10 Committees;  
11 (F) a representative of an academic research institution in the State  
12 that receives grant funding for rare disease research, appointed by the Speaker  
13 of the House;  
14 (G) a caregiver of a person living with a rare disease, appointed by  
15 the Senate Committee on Committees;  
16 (H) a physician practicing in Vermont with experience treating a rare  
17 disease, appointed by the Vermont Medical Society;  
18 (I) a nurse practicing in Vermont with experience treating a rare  
19 disease, appointed by the Vermont chapter of the American Nurses  
20 Association,

(D) a geneticist or genetic counselor, appointed by the Senate

Committee on Committees;

(K) a representative of health insurance companies serving  
Vermonters, appointed jointly by Blue Cross Blue Shield of Vermont and MVP  
Health Care;

(L) a representative of the biopharma industry doing business in  
Vermont, appointed by the Speaker of the House; and

(M) a representative of a rare disease patient organization  
operating in Vermont, appointed by the Governor.

(2) In event there is an even number of members on the  
Advisory Council after the appointments are made pursuant to  
subdivision (1) of this section, the Governor shall appoint one  
additional member, provided the member aligns with the Advisory  
Council's purpose and prioritizes representation of patients and  
caregivers.

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

(1) convene public hearings, make inquiries, and solicit comments from  
the general public to assist the Advisory Council with an initial needs  
assessment of individuals with a rare disease in Vermont and the needs of their  
caregivers and providers,

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

4 (3) consult with experts on rare diseases to develop policy  
5 recommendations that:

6 (A) improve patient access to and quality of services provided by  
7 rare disease specialists;

8 (B) advance affordable and comprehensive health care coverage;

9 (C) provide relevant diagnostic services and improve programs such  
10 as the State's newborn screening program; and

11 (D) ensure timely treatment and other needed services;

12 (4) publish a list of existing, publicly accessible resources on research,  
13 diagnosis, and treatment, including education resources for health care  
14 providers, relating to rare diseases on the Advisory Council's website;

15 (5) review the Department of Health's January 2023 presentation  
16 describing the public health impact of rare diseases in Vermont and the  
17 Department's role in addressing rare diseases statewide as required by 2024  
18 Acts and Resolved No. 164, Sec. 2; and

19 (6) any other priorities identified by the Department of Health or a  
20 majority of the Advisory Council.

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

3 (e) Report. Annually, on or before December 15, the Advisory Council  
4 shall submit a written report to the House Committees on Health Care and on  
5 Human Services and to the Senate Committee on Health and Welfare with its  
6 findings and any recommendations for legislative action, including:

7 (1) a description of the activities and progress of the Advisory Council  
8 during the previous year; and

9 (2) an update on the status of the Advisory Council's funding needs.

10 (f) Meetings.

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

13 (2) The Commissioner of Health or designee shall serve as the chair.

14 (3) During the first year of enactment, the Advisory Council shall meet  
15 on at least a monthly basis and thereafter by the call of the Chair. Meetings  
16 may be held in person or remotely on an electronic platform as determined by  
17 the Chair.

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

19 (5) The Advisory Council shall maintain a web page on the Department  
20 of Health's website containing notices of upcoming meetings, meeting  
21 minutes, public comments, and previous annual reports.

1 ~~(c) 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 12 meetings annually. These payments  
5 shall be made from monies appropriated to the Department of Health.

6 Sec. 2. EFFECTIVE DATE

7 ~~This act shall take effect on July 1, 2025.~~

*Sec. 1. FINDINGS*

*The General Assembly finds that:*

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

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

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

*CHAPTER 19. RARE DISEASES*

*§ 981. RARE DISEASE ADVISORY COUNCIL*

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

(b) Membership.

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

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

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

(C) the Commissioner of Health or designee;

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(f) Meetings.

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

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

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

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

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

*Sec. 3. EFFECTIVE DATE*

This act shall take effect on July 1, 2026.