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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;

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

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

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

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

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

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

18           (1) convene public hearings, make inquiries, and solicit comments from  
19           the general public to assist the Advisory Council with an initial needs  
20           assessment of individuals with a rare disease in Vermont and the needs of their  
21           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 rare  
7                   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 2025 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        (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 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.