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H.573

Introduced by Representative 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. The Advisory Council shall be composed of the
following members:

(1) the Commissioner of Health or designee;

1 (2) the Commissioner of Vermont Health Access or designee;

2 (3) the Commissioner of Financial Regulation or designee;

3 (4) the Director of the Office of Racial Equity or designee;

4 (5) two individuals living with a rare disease, one appointed by the

5 Speaker of the House and one appointed by the Senate Committee on

6 Committees;

7 (6) a representative of an academic research institution in the State that

8 receives grant funding for rare disease research, appointed by the Speaker of

9 the House;

10 (7) a caregiver of a person living with a rare disease, appointed by the

11 Senate Committee on Committees;

12 (8) a physician practicing in Vermont with experience treating a rare

13 disease, appointed by the Vermont Medical Society;

14 (9) a nurse practicing in Vermont with experience treating a rare

15 disease, appointed by the Vermont chapter of the American Nurses

16 Association;

17 (10) a representative of health insurance companies serving Vermonters,

18 appointed jointly by Blue Cross Blue Shield of Vermont and MVP Health

19 Care;

20 (11) a representative of the biopharma industry doing business in

21 Vermont, appointed by the Speaker of the House;

1 (12) a member of the scientific community in Vermont who is engaged
2 in rare disease research, such as a medical researcher with experience
3 conducting research on rare diseases, appointed by the Governor; and

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

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

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

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

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

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

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

20 (C) provide relevant diagnostic services; and

1 (D) ensure timely treatment and other needed services, including to
2 the State’s newborn screening program;

3 (4) research and make recommendations to State agencies and health
4 insurers that provide services to persons with a rare disease regarding the
5 impact of prior authorization, cost-sharing, tiering, or other utilization
6 management procedures on the provision of treatment and care to individuals
7 with rare diseases;

8 (5) evaluate and make recommendations to implement improvements to
9 Vermont’s newborn screening programs;

10 (6) evaluate and make recommendations to improve Medicaid coverage
11 for drugs used by individuals with rare diseases, including engagement with
12 the Drug Utilization Review Board to improve coverage of diagnostic services
13 and to facilitate access to necessary health care providers with expertise in the
14 treatment of rare diseases;

15 (7) publish a list of existing, publicly accessible resources on research,
16 diagnosis, treatment, and education relating to rare diseases on the Advisory
17 Council’s website;

18 (8) identify and distribute educational resources for health care
19 providers to foster recognition and optimized treatment of rare diseases in
20 Vermont; and

1 (9) research and identify best practices to reduce health disparities and
2 achieve health equity in the research, diagnosis, and treatment of rare diseases
3 in Vermont.

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

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

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

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

13 (f) Meetings.

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

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

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

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

1 (5) The Advisory Council shall maintain a webpage on the Department
2 of Health's website containing notices of upcoming meetings, meeting
3 minutes, public comments, and previous annual reports.

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 12 meetings annually. These payments
8 shall be made from monies appropriated to the Department of Health.

9 Sec. 2. EFFECTIVE DATE

10 This act shall take effect on July 1, 2024.