

1 H.532

2 Introduced by Representative Till of Jericho

3 Referred to Committee on

4 Date:

5 Subject: Health; public health; Rare Disease Advisory Council

6 Statement of purpose of bill as introduced: This bill proposes to establish the

7 Rare Disease Advisory Council.

8 An act relating to the Rare Disease Advisory Council

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

10 Sec. 1. RARE DISEASE ADVISORY COUNCIL

11 (a) Creation. There is created the Rare Disease Advisory Council for the
12 purposes of:

13 (1) coordinating statewide efforts to study the incidence of rare diseases
14 within the State and the status of the rare disease community; and

15 (2) providing advice to the General Assembly, public, and relevant
16 public and private agencies that provide services to, or are charged with the
17 care of, individuals with rare diseases.

18 (b) Membership. The Advisory Council shall be composed of the
19 following members:

20 (1) the Commissioner of Health or designee;

1 (2) the Commissioner of Finance and Management or designee;

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

3 (4) the State Epidemiologist for Infectious Disease;

4 (5) the State Epidemiologist for Environmental Health;

5 (6) two physicians licensed pursuant to 26 V.S.A. chapter 23 or 33 who

6 have expertise in the diagnosis and management of patients with rare diseases,

7 including one pediatrician who provides care to children with rare diseases,

8 appointed by the Vermont Medical Society;

9 (7) two nurses licensed pursuant to 26 V.S.A. chapter 28 who have

10 expertise in providing care to patients with rare diseases, appointed by the

11 Vermont chapter of the American Nurses Association;

12 (8) two representatives of geographically distinct hospitals in the State,

13 one of which is a research hospital, appointed by the Vermont Association of

14 Hospitals and Health Systems;

15 (9) a representative of the health insurance industry, appointed jointly by

16 health insurers with 10,000 or more covered lives in Vermont for

17 comprehensive major medical health insurance;

18 (10) a representative involved in the biopharmaceutical industry,

19 appointed by the Vermont Biosciences Alliance;

20 (11) a representative of the scientific community who is engaged in rare

21 disease research, appointed by the Governor;

1 (12) two Vermont residents with a rare disease, appointed by the
2 Speaker of the House; and

3 (13) two parents residing in Vermont, each of whom has a child with a
4 rare disease, not from the same family, appointed by the Committee on
5 Committees.

6 (c) Powers and duties. The Advisory Council shall study the prevalence
7 and treatment of rare diseases in Vermont, including:

8 (1) determining the most appropriate method to collect rare disease data
9 and information concerning Vermont residents with rare diseases in a manner
10 that both protects patient privacy and ensures interoperability with similar data
11 collected by federal and state governments;

12 (2) identifying priorities relating to access, quality, and cost-
13 effectiveness of treatment and other services provided to Vermont residents
14 with rare diseases and developing policy recommendations related to identified
15 priorities;

16 (3) identifying best practices used in other states and at the national
17 level for rare disease management, monitoring and surveillance, education,
18 detection, diagnosis, information, and care to improve these functions and
19 capabilities relative to rare diseases among Vermont residents; and

20 (4) developing effective strategies to raise public awareness of rare
21 diseases within Vermont.

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

3 (e) Report. On or before January 1, 2024 through January 1, 2026, the
4 Advisory Council shall submit a written annual report to the House
5 Committees on Health Care and on Human Services and the Senate Committee
6 on Health and Welfare with its findings and any recommendations for
7 legislative action.

8 (f) Meetings.

9 (1) The Commissioner of Health or designee shall call the first meeting
10 of the Advisory Council to occur on or before September 1, 2022.

11 (2) The Advisory Council shall select a chair from among its members
12 at the first meeting.

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

14 (4) The Advisory Council shall cease to exist on January 1, 2026.

15 (g) Compensation and reimbursement. Members of the Advisory Council
16 shall be entitled to per diem compensation and reimbursement of expenses as
17 permitted under 32 V.S.A. § 1010 for not more than four meetings per fiscal
18 year. These payments shall be made from monies appropriated to the
19 Department of Health.

20 Sec. 2. EFFECTIVE DATE

21 This act shall take effect on July 1, 2022.