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) The Advisory Council shall be composed of the following members, with members potentially fulfilling multiple roles if the member meets qualifications of more than one subdivision:~~

~~(A) the Commissioner of Health or designee;~~

~~(B) the Commissioner of Vermont Health Access or designee;~~

~~(C) the Commissioner of Financial Regulation or designee;~~

~~(D) the Director of the Office of Racial Equity or designee;~~

~~(E) two individuals living with a rare disease, one appointed by the Speaker of the House and one appointed by the Senate Committee on Committees;~~

~~(F) a representative of an academic research institution in the State that receives grant funding for rare disease research, appointed by the Speaker of the House;~~

~~(G) a caregiver of a person living with a rare disease, appointed by the Senate Committee on Committees;~~

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

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

~~(J) 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;~~

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

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

~~(C) provide relevant diagnostic services and improve programs such as the State’s newborn screening program; and~~

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

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

~~(5) review the Department of Health’s January 2025 presentation describing the public health impact of rare diseases in Vermont and the Department’s role in addressing rare diseases statewide as required by 2024 Acts and Resolved No. 164, Sec. 2; and~~

~~(6) any other priorities identified by the Department of Health or 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. Annually, on or before December 15, the Advisory Council shall submit a written report to the House Committees on Health Care and on Human Services and to the Senate Committee on Health and Welfare with its findings and any recommendations for legislative action, including:

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

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

(f) Meetings.

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

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

(3) During the first year of enactment, the Advisory Council shall meet on at least a monthly basis and thereafter by the call of the Chair. 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.

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

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

Sec. 2. EFFECTIVE DATE

~~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 Heath 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.*~~

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, appointed by the Commissioner of Health;

(B) a parent or guardian of a person living with a rare disease, appointed by the Commissioner of Health;

(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 Commissioner of Health;

(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 Vermont Pharmacists Association;

(J) a geneticist or genetic counselor, appointed by the Commissioner of Health; and

(K) any other persons deemed necessary by the Commissioner of Health.

(2) Members of the Advisory Council shall be appointed for staggered five-year terms. Any midterm vacancy shall be filled by the appointing authority for the remainder of the unexpired term. Terms shall begin on January 1 of the year of appointment and conclude on December 31 of the last year of the member's term. Members of the Advisory Council may serve multiple terms, either consecutively or intermittently.

(3) The Advisory Council may 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) in consultation with experts on rare diseases, develop and provide policy recommendations that:

(A) identify conditions for the Department of Health to consider as part of appropriate screening guidance and recommendations; and

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

(4) 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. The Department shall maintain a web page on its website that contains notices of upcoming meetings, meeting minutes, public comments, and reports.

(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 in accordance with the Vermont Open Meeting Law set forth in 1 V.S.A. §§ 310–314.

(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. LONG COVID RESOURCES FOR PRIMARY CARE PROVIDERS AND PATIENTS

(a) On or before January 1, 2027, the Department of Health shall collaborate with the University of Vermont Medical Center, the Vermont Medical Society, and patients with lived experience of long COVID to:

(1) identify existing evidence-informed standards, best practices, and training for primary care providers regarding long COVID and distribute these resources through the Department's website and to primary care providers; and

(2) in collaboration with the Department of Disabilities, Aging, and Independent Living, identify support services or other resources for long COVID that include a range of peer and community-based programs, such as long COVID support groups through the University of Vermont Medical Center, the Vermont Center for Independent Living, or another entity, and strategies to support patients who are homebound or at risk of becoming homebound.

(b) On or before February 1, 2027, the Department of Health, in collaboration with the Department of Disabilities, Aging, and Independent Living, shall present recommendations to the House Committee on Human Services and the Senate Committee on Health and Welfare on providing long-term disability supports to individuals experiencing long COVID.

(c) As used in this section, "long COVID" means postacute sequelae of SARS-CoV-2 infection.

Sec. 4. EFFECTIVE DATE

This act shall take effect on July 1, 2026.