TO THE HOUSE OF REPRESENTATIVES:

The Committee on Human Services to which was referred House Bill No. 46 entitled “An act relating to the Rare Disease Advisory Council” respectfully reports that it has considered the same and recommends that the bill be amended by striking out all after the enacting clause and inserting in lieu thereof the following:

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 shall 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 that should be screened for as part of the Vermont Newborn Screening Program;

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

(C) advance affordable and comprehensive health care coverage;

(D) provide and improve relevant diagnostic services and improve programs such as the Vermont Newborn Screening Program; and

(E) ensure timely access to treatment and other needed services;

(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 shall 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.

(Committee vote: ___________)

____

Representative ___________

FOR THE COMMITTEE