Act No. 98 (H.46). An act relating to the Rare Disease Advisory Council

Subjects: Advisory council; health; rare diseases

This act establishes the Rare Disease Advisory Council 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. The Advisory Council may convene public hearings and solicit comments from individuals impacted by rare diseases; provide testimony and comments on pending legislation and rules that impact Vermont's rare disease community; identify conditions for the Department of Health to consider as part of appropriate screening guidance; support timely patient access to diagnostic services and treatment and enhance quality of services provided by rare disease specialists; and any other activities identified by a majority of the Advisory Council.

This act also requires the Department of Health to collaborate with stakeholders and patients with long COVID to identify existing evidence-informed standards, best practices, and training for primary care providers regarding long COVID and to 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. It further requires the Department of Health to present recommendations on providing long-term disability supports to individuals experiencing long COVID by February 1, 2027.

Effective Date: July 1, 2026