

H.46 – An act relating to the Rare Disease Advisory Council

As recommended by the House Committee on Human Services, Draft 2.1¹¹

Bill Summary

The bill proposes to establish 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 would be composed of 11 members. Meetings may be held in person or remotely on an electronic platform. Members of the Advisory Council not otherwise compensated for their participation would be entitled to per diem compensation and expense reimbursement under 32 V.S.A. § 1010 for not more than four meetings annually. Finally, the Advisory Council would have the administrative, technical, and legal assistance of the Department of Health (VDH).

Fiscal Impact

As many as eight of the 11 members could be eligible for per diem compensation and expense reimbursement. Nonetheless, the fiscal impacts to VDH would be nominal. Further, the cost of any activities the Advisory Council may conduct, such as convening public hearings, maintaining a website, etc. would also be minimal and could be covered within VDH's proposed fiscal year 2026 budget. As such, no further appropriations would be required.

ⁱ The full fiscal note history is available on the fiscal tab of the bill page on the General Assembly website and can be pulled up through a bill number search on the JFO page.

¹ The Joint Fiscal Office (JFO) is a nonpartisan legislative office dedicated to producing unbiased fiscal analysis – this fiscal note is meant to provide information for legislative consideration, not to provide policy recommendations.