

TO: Senate Committee on Health and Welfare

FROM: Ilisa Stalberg, Director, Division of Family and Child Health

DATE: April 8, 2026

SUBJECT: H. 46 – Rare Disease Advisory Council

Thank you for the opportunity to discuss this important effort to support the rare disease community with the Committee.

Today's testimony will focus on a walk-through of the Department of Health's mark-up and suggested revisions to H. 46.

- Revisions to the appointment process (proposed 18 V.S.A. § 981(b)) – Our suggested revisions provide the Commissioner of Health and other professional organizations with the authority to appoint members of the Rare Disease Advisory Council (RDAC) instead of the Legislature. These suggested edits will help ensure that the work of the RDAC is well coordinated with other efforts at the Department and also respond to concerns expressed by the Committee about the Legislature's ability to make these appointments.

The suggested revisions also include language to clarify the appointment process, including term lengths, how vacancies would be filled, and the removal of appointed members. This is typically provided in statute for other advisory committees and we recommend similar language be included here.

- Revision to provide flexibility to the RDAC to collaborate with others (proposed 18 V.S.A. § 981(b)(3)) – Current language in the bill requires the RDAC to collaborate with any other relevant stakeholders it deems appropriate. We suggest revising this to allow for, but not require, collaboration with others in order to provide flexibility to the RDAC.
- Revisions to clarify RDAC's role in making recommendations to the Department of Health (proposed 18 V.S.A. § 981(c)(3)) – Our suggested revisions would allow RDAC to make recommendations beyond the Newborn Screening Program and would clarify that any recommendations from the RDAC would be considered by the Department of Health in the context of existing programs, requirements, and processes.



- Revisions to clarify the Department of Health’s administrative support of the RDAC (proposed 18 V.S.A. § 981(d)) – Our suggested revisions move the requirement to maintain a web page from the “Powers and Duties” section to the “Assistance” section in the bill. Maintaining a web page that contains notices of upcoming meetings, meeting minutes, public comments, and reports is a task that is better suited to the Department of Health, rather than the RDAC.

The Department wants to stress that our role would be limited to basic support of the RDAC. As we noted in previous testimony, the Department can provide the legal, technical, and administrative assistance required in the bill, but this assistance would be limited to tasks such as sharing information about open meeting laws, scheduling assistance, maintaining a webpage, and providing access to virtual meeting platform software and physical meeting locations. The Department would not be able to perform research, analysis, or policy and legal work on behalf of the RDAC.

- Revisions to clarify meeting requirements (proposed 18 V.S.A. § 981(f)) – Our suggested revisions would require meetings to be held in accordance with Vermont’s Open Meeting Laws. This is typically included in statute for other advisory committees and we recommend similar language be included here.

