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Agency of Human Services

MEMORANDUM

TO: Senate Committee on Health and Welfare

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

DATE: April 1, 2026

SUBJECT: H.46 Rare Disease Advisory Council Testimony

Thank you for the opportunity to discuss this important effort to support the rare disease community with the Committee. The Department recognizes the significant impact rare diseases have on individuals and families in Vermont and the importance of rare disease monitoring and research.

The Department is enthusiastic to continue its work to sustain the many efforts currently undertaken to help address rare diseases through screening and data collection, partner collaboration, and disease prevention and health promotion. The Department also supports the important legislative intent of H. 46 – to elevate the voices of individuals and families living with rare diseases and work to strategically identify and address barriers to adequate and effective identification, treatment, and support.

The House made several edits to the bill as introduced to address concerns the Department shared about resources and the ability of a volunteer-based Council to realistically achieve the activities identified in the bill.

The current version of the bill includes a list of activities that provides a set of options to the Council, which will allow the Council to have a voice while working at the pace its resources allow. It will also allow more time for partners and individuals with lived experience to identify efforts that best fit Vermont's needs and empower the Council to articulate its own goals and resource requirements in due course.

Given the uncertainty regarding the stability of federal funding sources that currently support a significant portion of the Department of Health's work, the Department needs to ensure its role would be limited to basic support of the Council.

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 Council.

The Department welcomes the opportunity to continue conversations with the legislature and other stakeholders to find the most appropriate and impactful way to support the rare disease community in Vermont. We would appreciate the opportunity to follow up with minor edits to the bill to help improve coordination between the proposed Rare Disease Advisory Council and existing efforts at the Department as well as enable the Council to achieve its important objectives given limited resources.

Answers to Potential Committee Questions

What revisions to the bill is the Department contemplating?

Minor changes to address the role of the Department in appointing members to the Committee and clarifying the powers and duties of the Council.

Can the Department of Health help identify potential members to appoint to the Committee?

If the legislature is not prepared to appoint members to the Council, the Department can take on that responsibility.

What would the Rare Disease Advisory Council's role be in recommending conditions for inclusion on the newborn screening panel?

- While the Council could make recommendations to the Department of Health, several factors need to be considered before a condition is added, including evidence on the net benefit of screening, the ability of the state to screen for the condition, and the availability of effective treatments or interventions. Vermont typically relies on a federal advisory committee (the Advisory Committee on Heritable Disorders in Newborns and Children) for this evidence review and once a condition is recommended by this committee, the Department considers it for addition to the state newborn screening panel. Vermont does not have the ability to conduct such an extensive evidence review and there are concerns about using a different standard for approving conditions than what is used nationally.
- The Department also is required to conduct rulemaking before a condition can be added to the panel.

Would the Department consider bringing the NBS Advisory under the RDAC?

- The proposed powers and duties for the RDAC include identifying conditions to recommend to the Department for potential addition to the state newborn screening panel. This activity overlaps with how the Department currently seeks input from the Newborn Screening Advisory Committee when considering the addition of conditions to the state newborn screening panel.

- The Department is open to bringing the NBS advisory committee under the RDAC to streamline the process for making recommendations to the Department and advising the Department on the addition of conditions.
- Any recommendations made by the RDAC would be reviewed and considered by the Department. The Department is also required to conduct rulemaking before a condition can be added to the panel.
- Most likely the NBS Advisory would be a subcommittee to the RDAC needing specific pediatric clinical and laboratory expertise.