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Thank you for the opportunity to return 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.

As noted in previous testimony, 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 of Health also supports the important legislative intent of H. 46 – to give the rare disease community a platform to strategically identify and address barriers that prevent individuals living with rare diseases from accessing adequate and effective treatment and care for their conditions.

Since our previous testimony, the Department has begun to explore ways to ensure that a rare disease advisory council could be meaningful and productive, especially during these times of great uncertainty. We have made attempts to engage with UVM to explore opportunities for collaboration but understand from their testimony that they too may have significant resource constraints. We also recognize there may be much to learn from what other states are doing. As this work will continue next session, we appreciate the opportunity for further discussion with stakeholders that can help shape this effort and maximize its impact.

In its current form, the Department is concerned that the deliverables presently specified in H. 46 are not realistically achievable for a volunteer-based Council within the framework of the bill as written, and that the Department cannot currently volunteer the support necessary to complete these deliverables on the Council's behalf.

H. 46 requires the advisory council to produce several deliverables: 1. Convene and conduct public hearings; 2. Create a needs assessment; 3. Provide testimony and comments on pending, relevant legislation and rules; 4. Consult with experts on rare diseases and develop policy recommendations, including recommendations related to newborn screening, quality of care, access, and affordability; and 5. as needed, draft a report to committees of jurisdiction – all within four meetings a year.

This is a lot of work requiring a high level of policy, medical, and clinical expertise. 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 Council, composed of volunteers, many of whom are professionals in fields already dealing with time constraints and access issues, would be charged with accomplishing these tasks during its quarterly meetings and on their own time.

Given the uncertainty regarding the stability of federal funding sources that currently support a significant portion of the Department of Health's work, including much of the work already dedicated to rare disease monitoring, it is critical for the Department to prioritize its existing efforts to protect and support the health of all Vermonters at this time.

However, the Department believes that the goals of H.46 can be met without the required activities currently listed in the bill. The Department recommends making the list of activities for the Council a set of options ("may") rather than requirements ("shall") (Sec. 981(c), p. 3, line 11 of draft 1.1). This will allow the Council to have a voice while working at the pace its resources allow. The Department will offer technical, administrative, and legal assistance to support the Council as it works through these efforts.

The Department supports the legislative intent to establish an advisory council whose work in this important space can be meaningful and productive. This recommended change would allow more time for stakeholders to identify efforts that best fit Vermont's needs and empower the advisory council to articulate its own goals and resource requirements in due course as well.

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.

Again, due to the current uncertainty around federal funding, the Health Department needs to ensure its role would be limited to basic support, so the expectations of the legislature and community can be met.