



Alone we are rare. Together we are strong.®

Testimony in Support of H.46 (Stone)

State of Vermont Senate Committee on Health and Welfare
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Presented by:

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Good morning, Chair Lyons and members of the committee.

I am so grateful and excited to be invited back before each of you today — this time to speak more specifically on **H.46 and efforts to establish a Rare Disease Advisory Council** here in the great state of Vermont. The last time I was with you, we spoke about Rare Disease Day and the rare disease community as a whole. I am going to build on that foundation.

This is a community of 30 million Americans living with any of over 10,000 known rare diseases.

Applying the NIH estimate of 1-in-10 Americans living with a rare disease to 2025 U.S. Census data, we are talking about approximately 64,466 Vermonters living with a rare disease today.

Just about one year ago today — on Wednesday, April 16, 2025 — the Vermont Department of Health gave a presentation before the House Committee on Human Services, fulfilling a statutory reporting requirement under Act 164 of 2024. That act asked the Department of Health to come before the committee to describe the public health impact of rare diseases in Vermont and to describe the Department's role in addressing rare diseases statewide. Here's what we learned:

Vermont's Department of Health is already doing critical work for our community. **The Newborn Screening Program** flags rare conditions in newborns early so families can access support and care. The **Birth Information Network** collects data on over 115 conditions — many but not all of which are rare — drawn from medical claims, newborn screening, and vital records — and from 2018 to 2022, 4% of Vermont infants had one or more monitored conditions. The state's **Cancer Registry** and **ALS Registry** capture additional rare disease populations. This infrastructure is genuinely valuable and deeply appreciated.

It produces data and services. **What it cannot do on its own is translate that knowledge into coordinated policy action** — identifying gaps, elevating the patient voice, and giving lawmakers a trusted expert body to consult. That is exactly what the RDAC is designed to do. H.46 doesn't ask Vermont to start from scratch; it **activates** what's already there.

The council's newborn screening function deserves particular attention. **Nearly 80% of rare diseases are genetic in origin** — which means the geneticist or genetic counselor seat built into this council's membership isn't just good practice, it's essential to the council's ability to do this work well. **The expertise needed to make sound screening recommendations has to be at the table, and this bill puts it there.** The newborn screening landscape at the federal level is also in flux right now, which makes having that in-state expertise formalized through this council all the more valuable.

The national evidence for RDACs is compelling. An analysis of NORD's Annual State Report Card data shows that **70% of states scoring an overall A or B have an RDAC.** States with an RDAC show statistically significant improvements in overall health policy outcomes, roughly **the difference between a C+ and a B-**. In practice, councils are resolving medication coverage disputes, supporting patient

insurance navigation, launching IRB-approved state-specific population surveys, and being pulled directly into legislative processes

Vermont is the final state remaining in the New England region to establish one of these councils, and the process here has truly been a joy to be a part of. This has been a patient coalition-driven effort from the start, and experiencing Vermont's community-minded approach firsthand makes me genuinely optimistic about what this council could accomplish here. I believe it could become a high-value, trusted space where Vermont's rare disease community solves shared challenges in ways that improve the system for everyone.

I also want to briefly address why this needs to be legislation rather than an administrative action. Of the 33 states that have established RDACs, 30 did so through an act of the legislature — precisely because **statutory authority provides the strongest foundation for sustained impact and long-term stability.** An administratively created body can be dissolved or deprioritized with a change in administration. A legislatively established council cannot.

Thank you so much for allowing me to come before you again today. I have been following the bill discussions, including those related to amendments addressing typographical corrections and tweaking the reporting language to add an "as requested" component, both of which NORD would support.

I am happy to take any questions.

Respectfully submitted,

A handwritten signature in black ink, appearing to read 'C. Sheridan', with a long horizontal flourish extending to the right.

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