

Hello! My name is Mary Nadon Scott. I am a resident of Northfield and a constituent of committee member Representative Anne Donahue, and I am an advocate for rare disease. I am here to ask for your support for H.46, which would establish a Rare Disease Advisory Council in Vermont.

In 2002 I was diagnosed with a rare, genetic, progressive, neuromuscular disease called Friedreich's Ataxia. "Rare Disease" is defined by federal law (Orphan Drug Act) as a condition affecting fewer than 200,000 people in the U.S. When I was first diagnosed, I felt very alone and lost. Although rare disease patients have different diagnoses, the barriers we face are often the same.

Rare isn't so rare. With more than 10,000 known rare diseases, the impact is 1 in 10 Americans—nearly 30 million people Nationwide. It is difficult for state policymakers and government officials to have an in-depth understanding of the needs of the rare disease community. This lack of awareness contributes to common obstacles that rare disease patients face. I have been working with the Governor, and his office, since 2019 to raise rare disease awareness and have been successful in this in many ways; including with the Governor's support of Proclaiming the last day of February to be Rare Disease Day in Vermont.

A Rare Disease Advisory Council (RDAC) would provide an official way for patients to have a voice in state government and inform state leaders about these challenges and potential solutions. 30 states have created an RDAC, which provide policy recommendations and increase awareness of rare disease challenges. RDAC's vary by state in membership, oversight, and responsibilities, but all work to improve healthcare access and resources. Currently there are 10 states considering RDAC bills, reflecting growing national momentum.

Vermont's RDAC bill H.46 creates the Vermont Rare Disease Advisory Council within the Vermont Department of Health to advise lawmakers and agencies on rare disease issues. It ensures that patients, caregivers, healthcare providers, researchers, and policy experts have a voice to help shape better care and support. This is done through annual reports, public hearings, research, and policy recommendations to improve access to diagnosis and treatment.

As a rare disease patient, I feel like having an RDAC in Vermont is prioritizing patients and caregivers to ensure their voices remain central. It would mean a lot to me to see the State of Vermont join the rest of the States that have an RDAC.

I respectfully ask you to support H.46 to help ensure that individuals living with rare diseases in Vermont have a voice in State Health policy. Thank you for your time and dedication to this important issue.