

Hello! My name is Mary Nadon Scott. I am a resident of Northfield, and I am a fierce advocate for rare disease. I am here to ask for your support of an RDAC in Vermont.

Rare isn't so rare. With more than 10,000 known rare diseases, 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 (such as delays in diagnosis, misdiagnosis, lack of treatment options, high out-of-pocket costs and limited access to medical specialists). A Rare Disease Advisory Council (RDAC) acts as an advisory body that gives the rare disease community a stronger voice in state government.

Because each RDAC is tailored to meet the specific needs of that state, decisionmakers working on new laws and regulations that affect the rare disease community can utilize the experts from their state's RDAC to improve policies and ultimately health outcomes for rare disease patients. With the support of NORD (National Organization of Rare Disorders), and other patient organizations and stakeholders in the rare disease community, this important work is accomplished by enabling states to strategically identify and address barriers that prevent individuals living with rare diseases from obtaining proper treatment and care for their condition. In 2015, the first RDAC was created. It would mean a lot to me to see the State of Vermont join the rest of the states that have an RDAC (28). Since 2019 I have been working with the Governor, and his office, to raise rare disease awareness and have been successful in these efforts with the Governor's support of Proclaiming the last day of February to be Rare Disease Day in Vermont.

Thank you for your time, your kindness, your patience with my slurred speech and shortness of breath, and your support of H.573 a bill that will establish an RDAC in Vermont.