



Alone we are rare. Together we are strong.®

January 29, 2025

The Honorable Representative Mary-Katherine Stone
Vermont House of Representatives
115 State St.
Montpelier, VT 05633

Re: NORD Supports H.46 (Stone) – Establishing the Vermont Rare Disease Advisory Council

Dear Representative Stone,

The National Organization for Rare Disorders (NORD) is thrilled to express our support for your bill, [H.46](#), and thanks you for your unwavering commitment to Vermont's rare disease community. This legislation represents a critical step toward addressing the unique challenges faced by Vermonters living with rare diseases by creating a Rare Disease Advisory Council (RDAC).

A rare disease is defined federally in the Orphan Drug Act as any condition affecting 200,000 or fewer Americans. Individuals living with rare diseases often encounter delayed diagnoses, limited treatment options, and barriers to accessing specialized care. An estimated 1-in-10 Americans are living with a rare disease - a striking figure that underscores the urgency of addressing gaps in care for these patients. By establishing Vermont's RDAC within the Department of Health, H.46 creates a vital mechanism to address these challenges through expert collaboration, community input, and targeted policy recommendations.

For over 41 years, NORD has represented the collective voice of rare disease patients, caregivers, and advocates. With a network of more than 350 member organizations, we work to advance research, improve access to care, and shape policies that enhance the lives of those living with any of over 10,000 known rare diseases. Through our [Project RDAC](#) initiative, we aim to establish effective RDACs in every state to address the specific needs of rare disease communities at the state level.

NORD is eager to welcome Vermont to the community of 30 states that have given their rare disease patients a stronger voice in state government by creating a Rare Disease Advisory Council (RDAC). Those states include all of Vermont's neighbors, New York, New Hampshire, and Massachusetts, as well as Alabama, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Vermont's proposed Rare Disease Advisory Council (RDAC) aligns closely with efforts across New England to improve health care access, raise awareness, and advocate for individuals living with rare diseases. Similar to RDACs in states like Maine, Massachusetts, and New Hampshire, Vermont's council will reside within the Department of Health, ensuring integration with the state's public health initiatives. The council's purpose mirrors regional goals, focusing on providing guidance to policymakers, engaging with the public, and addressing barriers to care and treatment through collaborative expertise.

Vermont's council will bring together a diverse membership of patients, caregivers, healthcare providers, researchers, and industry representatives, along with designees from key state agencies. Regular

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monthly meetings and public engagement efforts, such as surveys and open forums, will ensure that rare disease stakeholders have a meaningful voice in shaping Vermont's health care landscape.

What sets Vermont's RDAC apart is its focus on equity, flexibility, and actionable outcomes. The council will strengthen programs like Vermont's Newborn Screening Program to enable early and accurate diagnoses, provide expert testimony on legislation impacting the rare disease community, and develop publicly accessible resources on research, diagnosis, and treatment. Structural flexibility, such as allowing members to fulfill multiple roles and enabling the governor to appoint an additional member to achieve a voting majority, ensures that the council can adapt and function effectively.

By creating the Vermont RDAC, the state will demonstrate its commitment to equity, innovation, and community well-being. This council represents a powerful opportunity to improve health outcomes and support a population that has historically been underserved.

Thank you for championing this critical legislation. NORD remains a committed partner as this bill progresses. Please feel free to contact me at csheridan@rarediseases.org for any questions or assistance.

Sincerely,



Carolyn G Sheridan, MPH
State Policy Manager, Eastern Region
National Organization for Rare Disorders

CC:

Leah Barber, Director of Grassroots Advocacy, National Organization for Rare Disorders



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