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National Organization for Rare Disorders Testimony in Support of H.573 (Stone)

State of Vermont House of Representatives
House Committee on Human Services

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Good afternoon, Chair Wood, Vice-Chair Brumsted, Representative Stone, and Members of the Vermont House Committee on Human Services.

I am so excited to be here alongside a few of our Vermont coalition members to express the support of NORD for H.573 and to provide you all with a bit more information about Rare Disease Advisory Councils and the one H.573 seeks to establish here in the Green Mountain State.

My name is Carolyn Sheridan, and I am one of two State Policy Managers at the National Organization for Rare Disorders, or NORD. I am responsible for the development and implementation of NORD's policy efforts which support the rare disease community on the state level within the eastern region of the United States.

For those not familiar with our organization, NORD is the leading independent advocacy organization in the United States, representing the more than 30 million people living with any one of the over 10,000 known rare diseases.

In the United States, a rare disease is defined federally within the Orphan Drug Act, as any condition that affects fewer than 200,000 people.

When NORD talks about RDACs we tend to describe them as independent, state-established advisory bodies that provides a platform for the rare community to have a stronger voice in state government.

RDACs are organized differently in each state. Some of the distinguishing features include the type of entity that houses the RDAC, the composition and size of the Council, the duties and accountability requirements of the Council.

The average number of council members is 16 with a range of 11 to 28.

I am very excited to share that due to Mississippi signing their RDAC into law just last week, we now have a total of 28 states that have enacted one of these councils!

We have seen such enormous value come out of the 22 RDACs up-and-running in other states across the country in elevating the needs of rare disease patients on the state level. For example,

Councils throughout the country, such as Pennsylvania, Colorado, South Carolina, and Massachusetts have conducted surveys to better understand common challenges rare disease patients and caregivers face. They use this data to help identify the needs of their state's rare disease community. Some states have collected thousands of responses.

Colorado has established a relationship with the State's Prescription Drug Affordability Board (PDAB) as drugs with orphan designations/indications have come up for discussion.

Minnesota and Connecticut have directly engaged with the legislature in support of legislation that would impact the rare community – in fact, the RDAC in Minnesota was instrumental in



passing HF384/SF1029 to secure robust network access to rare and potentially rare patients in the state.

Some states are working with their medical schools to help them develop curriculum that teaches medical students about rare diseases and unique needs that patients and their families often have.

Vermont's RDAC would be housed within the Department of Health and have a diverse body of membership made up of individuals in the rare disease community including patients, caregivers, providers, researchers, industry representatives, health plan representatives, and patient advocacy organizations. Their task would be to provide guidance and recommendations to the public, General Assembly, and other governmental bodies regarding the needs of individuals living with a rare disease in Vermont.

The scope of proposed duties of Vermont's RDAC in H.573 would make it a stand-out in the region. Of note include; convening public hearings, making inquiries and soliciting comments from the public to assist the Council with a population survey of the needs of the rare community in Vermont; requiring the Council to provide testimony & comments on pending relevant legislation and rules and advise on policy matters related to patient access and affordability, diagnostic and treatment service accessibility, and drug affordability and utilization management strategies by health plans; and the evaluation and issuing of recommendations to improve existing policies and programs such as the State's newborn screening program and Medicaid.

NORD is eager to welcome Vermont to the community of 28 states who have elevated the voice of the rare community by creating one of these councils and we will be working hard over the summer to continue to build up our already phenomenal group of supporters!

I thank you for your time today and I hope you will join us in this effort!

Sincerely,



Carolyn G. Sheridan, MPH
State Policy Manager, East

NORD'S Project RDAC

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