



June 28, 2021

The Honorable Cathy Breen  
Chair  
Committee on Appropriations and Financial Affairs  
15 Falmouth Ridges Drive  
Falmouth, ME 04105

The Honorable Teresa Pierce  
Chair  
Committee on Appropriations and Financial Affairs  
6 Waites Landing Road  
Falmouth, ME 04105

**RE: Support for Legislative Document 972 - Maine Rare Disease Advisory Council**

Dear Chair Breen, Chair Pierce, and Members of the Committee on Appropriations and Financial Affairs:

On behalf of the 1-in-10 individuals in Maine with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for considering Legislative Document 972 (LD 972). LD 972, sponsored by Representative Margaret Craven, establishes clear membership and duties for a Rare Disease Advisory Council (RDAC), which if passed, would help to give a voice to the rare disease community within Maine's state government. NORD respectfully urges you to support and adequately fund LD 972 as it moves through your Committee.

Creating an RDAC in Maine will give rare disease patients a unified voice in Maine state government. Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, convening public hearings and soliciting comments from the public related to rare diseases, and best practices for the care of those with rare diseases. It will also be tasked with creating a rare disease plan for the state and developing methods to publicize the profile of the social and economic burden of rare diseases to ensure health care providers are informed.

Rare diseases are present across a broad spectrum of medical conditions. For example, there are more than 500 types of rare cancers, and all forms of pediatric cancer are rare. For patients suffering from these and numerous other rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well-understood, with most not receiving sufficient attention or funding for research.



In creating this council, Maine would join nineteen other states that have already enacted similar legislation in support of their rare disease community and proven that the RDAC can be an invaluable resource. Those states are Alabama, Connecticut, Florida, Illinois, Kentucky, Louisiana, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, Virginia, and West Virginia.

Once again, on behalf of the Maine rare disease community, we thank you for considering LD 972, and urge its swift passage with adequate appropriations. For any questions, please feel free to contact Annessa Reed via email at [areed@rarediseases.org](mailto:areed@rarediseases.org). Thank you for your consideration.

Sincerely,

Heidi Ross  
Director of Policy  
National Organization for Rare Disorders

Annessa Reed  
State Policy Manager, Eastern Region  
National Organization for Rare Disorders

CC: Members of the Committee on Appropriations and Financial Affairs