



April 30, 2020

The Honorable Cindy F. Friedman
Chair, Joint Committee on Health Care Financing
Room 208, Massachusetts State House
24 Beacon St.
Boston, MA 02133

The Honorable Harriette L. Chandler
Vice-Chair, Joint Committee on Health Care Financing
Room 333, Massachusetts State House
24 Beacon St.
Boston, MA 02133

The Honorable Daniel R. Cullinane
Vice-Chair, Joint Committee on Health Care Financing
Room 236, Massachusetts State House
24 Beacon St.
Boston, MA 02133

Re: Support for H.4268 – an Act to Create a Rare Disease Advisory Council

Dear Chairman Friedman, Vice-Chair Chandler, and Vice-Chair Cullinane,

On behalf of the 1-in-10 individuals in Massachusetts with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for all your dedication and efforts during the COVID-19 pandemic on behalf of the Commonwealth of Massachusetts. Today, we write to ask for your support of House Bill 4268, an act to create a Rare Disease Advisory Council (RDAC). We look forward to working with your committee to advance this important piece of legislation.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

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.



Creating an RDAC will give rare disease patients a unified voice in Massachusetts state government. The RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, and identifying best practices for the care of those with rare diseases. It will also be tasked with evaluating the current system of rare disease treatment and available resources and then develop recommendations to increase the survival rates and quality of life for rare disease patients. This council would include broad participation from the different health care sectors representing the Massachusetts rare disease community including patients, caregivers, physicians, nurses, academic researchers, and hospital administrators. As a result of the diverse membership on the council, it will also serve as an education resource to all stakeholders about the ways rare disease patients interact with our health care system.

In creating this council, Massachusetts will be joining fourteen other states who have already enacted similar legislation in support of their rare disease community: Alabama, Connecticut, Illinois, Kentucky, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Pennsylvania, Tennessee, Utah, and West Virginia.

Once again, on behalf of the Massachusetts rare disease community, we thank you for your consideration of H. 4268 and urge for its swift reporting out of the Health Care Financing Committee ahead of the June 19th deadline. For any questions, please feel free to contact NORD's Director of State Policy, Heidi Ross (hross@rarediseases.org).

Sincerely,

Heidi Ross
Director of State Policy
National Organization for Rare Disorders

Alan Holbrook
Massachusetts Rare Action Network Volunteer State Ambassador

CC: Members of the Joint Health Care Financing Committee