NORD®
National Organization
for Rare Disorders

RARE MA

July 14, 2020

The Honorable Aaron Michlewitz
Chair, House Ways and Means Committee
Room 243
24 Beacon St.
Boston, MA 02133

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

Dear Chairman Michlewitz,

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 your work during COVID-19 and urges you to swiftly move House Bill 4268 (H.4268) through your committee. H.4268 establishes a rare disease advisory council (RDAC) within the state, which if passed, would help to give a voice to the rare disease community within Massachusetts's government.

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 considered 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 in Massachusetts will give rare disease patients a unified voice in Massachusetts state government. Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, 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. What is more, because this legislation requires broad participation from the different health care sectors present in Massachusetts– patients, caregivers, doctors, hospitals, insurers, manufacturers, and researchers are all represented on the council – it will also serve as an educational resource to all stakeholders about the ways in which rare disease patients interact with our health care system.

To date, fourteen other states have already enacted similar legislation in support of their rare disease community and proven that the RDAC can be an invaluable resource. Those states include: 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 considering the creation of a Rare Disease Advisory Council. Please support this legislation to give a voice to Massachusetts residents living with rare diseases. For any questions, please feel free to contact Heidi Ross via email at hross@rarediseases.org. Thank you for your consideration.

Sincerely,

Heidi Ross

Heidi Ross
Director of Policy
National Organization for Rare Disorders

Alan R. Holbrook

Alan Holbrook
Massachusetts Rare Action Network Volunteer State Ambassador

CC: Members of the House Ways and Means Committee