NORD®
National Organization
for Rare Disorders

RARE MA

August 5, 2020

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

Re: Support for Establishing a Rare Disease Advisory Council in Final Health Care Bill

Dear Chair Friedman,

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) urges you to support including provisions creating a rare disease advisory council in Massachusetts in the final comprehensive health-related legislative package (H.4888/S.2796) being negotiated by the conference committee. Last month, over 25 patient advocacy groups joined a letter of support for House Bill 4268 (H.4268), legislation that would create a rare disease advisory council (RDAC). We are grateful that an amendment adding the language of H.4268 into H.4888 was adopted in the House-passed version of H.4888. NORD urges you, in your role as a conferee, to ensure language creating an RDAC be retained in the final health bill being negotiated by the Senate and House conferees.

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 communities and have 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, we urge you to ensure that the final health bill negotiated by the conference committee give a voice to your constituents living with rare diseases by creating a rare disease advisory council in Massachusetts. 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