



October 8, 2019

The Honorable John Mahoney
Chair, Joint Committee on Public Health
Room 130, Massachusetts State House
24 Beacon St.
Boston, MA 02133

The Honorable Joanne Comerford
Chair, Joint Committee on Public Health
Room 70-C, Massachusetts State House
24 Beacon St.
Boston, MA 02133

Re: Support for H.1934 – an Act to Create a Rare Disease Advisory Council

Dear Chairman Mahoney and Chairman Comerford,

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 the opportunity to submit testimony in support of H.1934, legislation that would establish a Rare Disease Advisory Council. We look forward to working with you and members of your committee to swiftly pass this 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 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.

The Massachusetts Rare Disease Advisory Council will give rare disease patients a unified voice in our state government by providing them a forum to make recommendations to elected officials and other state leaders about pressing health care issues. From providing information on the provider-patient relationship to identifying best practices throughout the nation, the council will coordinate with legislators and other government leaders to improve public policy for the entire state. What is more, because this legislation requires broad participation from the different health care sectors present in Massachusetts— 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.

In creating this council, Massachusetts will join eight other states that have already enacted similar legislation in support of their rare disease community: Alabama, Connecticut, Illinois, Kentucky, Minnesota, Missouri, New Hampshire, North Carolina, and Pennsylvania.

We hope you consider the incredible support a Rare Disease Advisory Council can provide to the rare disease community in Massachusetts. We must give a voice to residents in the Commonwealth living with rare diseases – many of whom are too young or too sick to speak for themselves.

Thank you for the opportunity to comment on this legislation and for your support of H.1934. For further questions, please do not hesitate to contact me at ddelcarlo@rarediseases.org.

Sincerely,

/s/

Danielle Del Carlo
Director of State Policy

CC: Members of the Joint Public Health Committee