



July 9, 2021

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

The Honorable John J. Lawn, Jr.
Chair
Joint Committee on Health Care Financing
24 Beacon Street
Room 445
Boston, MA 02133

Re: Support for Senate Bill 756 (S.756)/House Bill 1311 (H.1311)

Dear Chair Friedman, Chair Lawn, and Members of the Joint Committee on Health Care Financing:

On behalf of the 1-in-10 individuals living in Massachusetts with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for adding Senate Bill 756 (S.756)/House Bill 1311 (H.1311) to the Joint Committee on Health Care Financing's meeting agenda. S.756/H.1311 would ensure that when step therapy is used in Massachusetts, it is safe for patients, clinically grounded, and transparent to patients and health care providers. It is safe for patients, clinically grounded, and transparent to patients and health care providers.

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. NORD believes strongly that all patients deserve the medical care that is best suited for their medical situation and will give them the best results.

Step therapy policies, also known as fail first, are used in an attempt to control costs by requiring a patient to "fail first" on an alternative medication before being granted access to the medication that was originally prescribed to them by their provider. This process of prolonging ineffective treatment and delaying access to the right treatment – especially for patients living with serious or chronic illnesses – can lead to medical setbacks, disease progression, loss of function and even hospitalizations, which may ultimately lead to increases in unnecessary health care costs.

We ask for your support of S.756/H.1311 to allow patients better access to the most appropriate treatments prescribed by their healthcare providers. This would be accomplished by:



- Ensuring that step therapy protocols are based on widely accepted medical and clinical practice guidelines;
- Creating a clear and expeditious process to request a medical exception and requiring a response by the patient's health plan within 72 hours for non-emergency and 24 hours for emergency situations; and
- Providing certain circumstances for a patient to override the step therapy protocol when the drug required under the step therapy protocol is contraindicated or will likely cause an adverse reaction of physical or mental harm.

It is important to note that S.756/H.1311 does not ban the use of step therapy. However, to guarantee patient safety, Massachusetts needs to ensure that step therapy policies do not interfere with appropriate care for rare disease patients and families. S.756/H.1311 would protect patients while still enabling health plans to achieve the cost saving benefits of step therapy when appropriate.

Once again, on behalf of the Massachusetts rare disease community, we thank you for bringing S.756/H.1311 before your Committee for consideration and urge its swift passage. For any questions, please feel free to reach out to Annessa Reed at 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 Joint Committee on Health Care Financing