June 15, 2021

The Honorable K. Joseph Shekarchi  
Speaker of the House  
State of Rhode Island General Assembly  
82 Smith Street  
Providence, RI 02903

Re: Support for House Bill 5704/Senate Bill 302

Dear Speaker Shekarchi:

On behalf of the 1-in-10 individuals living in Rhode Island with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to bring House Bill 5704 (H5704)/Senate Bill 302 (S302) to the floor for swift consideration by the House. H5704/S302 would ensure that, when step therapy is used in Rhode Island, it is safe for patients, clinically grounded, and transparent to patients and health care providers. On May 12th, the Rhode Island Senate unanimously passed this important legislation and we strongly encourage the Rhode Island House of Representatives to do the same this legislative session.

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 forcing patients to try and “fail first” on an alternative medication before accessing 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, and even hospitalizations which can ultimately lead to increases in health care costs.

Therefore, we ask for your support of H5704/S302 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 H5704/S302 does not ban the use of step therapy. H5704/S302 would protect patients while still enabling health plans to achieve the cost saving benefits of step therapy, when appropriate. It is important to reform the state’s step therapy practices to avoid some of the unnecessary burdens on patients, providers and the health care system that could be prevented with appropriate and timely care.

On behalf of the Rhode Island rare disease community, we urge you to allow swift House floor consideration of H5704/S302 and urge its passage. For any questions, please feel free to reach out to Annissa Reed at AReed@rarediseases.org. Thank you for your consideration.

Sincerely,

Heidi Ross
Director of Policy
National Organization for Rare Disorders

Annissa Reed
State Policy Manager, Eastern Region
National Organization for Rare Disorders