



April 29, 2021

The Honorable Joshua Miller  
Chair  
Senate Health and Human Services Committee  
82 Smith Street  
Providence, RI 02903

**Re: Support for Senate Bill 302**

Dear Chairman Miller and Members of the Senate Health and Human Services Committee:

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) thanks you for adding Senate Bill 302 (SB 302) to the Senate Health and Human Services Committee's meeting agenda. SB 302 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.

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 medications, requiring the patient to "fail first" 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, loss of function and even hospitalizations which may ultimately lead to increases in unnecessary health care costs.

We ask for your support of SB 302 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 SB 302 does not ban the use of step therapy. However, to guarantee patient safety, Rhode Island needs to ensure that step therapy policies do not interfere with appropriate care for rare disease patients and families. SB 302 would protect patients while still enabling health plans to achieve the cost saving benefits of step therapy when appropriate. Given the additional challenges of the COVID-19 pandemic, now is a logical time 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.

Once again, on behalf of the Rhode Island rare disease community, we thank you for bringing SB 302 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](mailto: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 Senate Health and Human Services Committee