

Memorandum of SUPPORT

RI: S2468 (Ujifusa)/H7539(McGaw)

Step Therapy Patient Protections



The National Organization for Rare Disorders (NORD) is proud to share our support for S116 (Ujifusa)/H5119 (McGaw) which establishes categories of exemptions from step therapy protocols and establishes timelines within which health plans must respond to step therapy exception requests.

Background

Step therapy, also known as step protocols or fail first requirements, is a process by which insurers (public or private) require patients to take one or more alternative medications before they can access the medicine initially prescribed by their provider. This is a utilization management practice intended to control health care costs, but step therapy has been increasingly applied to patients with little regard for their medical situation or treatment history. When used inappropriately, step therapy protocols can delay necessary treatment and lead to adverse reactions that ultimately increase health care costs, not lower them.

NORD On the Bill

NORD would like to draw attention to and share our most ardent support for the following provisions of the bill;

1. Establishing Categories for Exemptions from Step Therapy Protocols

To avoid disruptions in care, delays in necessary treatment, increased risk for adverse reactions, and potentially higher out-of-pocket costs to patients, NORD supports the adoption of automatic exceptions from step therapy protocols. Currently, there are no patient protections in place that would provide a basic framework for when it is most appropriate to exempt patients from step therapy. This legislation establishes circumstances where providers can request an exception, including if the medication is contraindicated, has been tried and found to be ineffective, is expected to be ineffective, will delay or prevent medically necessary care or will disrupt treatment currently stable and effective. These are gold-standard exemption categories in effect in states nationwide.

2. Establishing a Timelines for a Response to a Step Therapy Exemption Request

For rare disease patients, delayed responses to step therapy exceptions may lead to more unnecessary tests and procedures and, in some cases, mean a greater risk of experiencing irreversible damage as the disease progresses in the absence of an effective treatment. A clear and expedited timeline, for both emergency and non-emergency situations, is important.

**Get to Know
the Facts About
Rare Disease**

**1 in 10
Americans**
have a rare disease.¹

That is more than
30 million
of our loved ones,
friends, and colleagues.¹

There are more than
10,000
known rare diseases.
Fewer than 5% have an
FDA-approved treatment.²

Rare disease medical
costs are
3–5x higher
than non-rare, totaling
an estimated
\$400B
annually—on par with
cancer and Alzheimer's.³

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This legislation establishes a timeline within which health plans must respond to a provider's request for an exemption from a step protocol. Specifically, the bill requires plans to respond to a healthcare provider's request for an exemption within 72 hours for non-emergency and 24 hours for emergency situations, which will help ensure patients have access to the prescription drugs they need without experiencing any delays in treatment.

3. Prohibition of Step Therapy Protocols for Rare Diseases or Conditions with Limited Treatment Options

For rare disease patients, the use of step therapy protocols is particularly concerning, as it can take years to find a diagnosis and a treatment that works. Many rare disease patients face years of a difficult "diagnostic odyssey" before receiving their correct diagnosis and more than 95% of rare diseases lack an FDA approved treatment. Patients living with a rare condition that does have a safe and effective therapy need access to that therapy to achieve their optimal health and usually have few, if any, alternative treatment options.

To date, 40 states across the country have enacted some form of step therapy protections to help patients access the care and treatment they need in a timely manner. Each year for the last decade, NORD has evaluated how effectively states are serving people with rare diseases across nine issue areas that impact the rare disease community through the publication of [NORD's State Report Card](#). In the area of step therapy, NORD's State Report Card grades states separately across four separate categories: regulation of step therapy protocols, timelines for responses to exemption requests, clarity of the exemption process, and the categories of exceptions guarantee to patients.¹ An overall grade for step therapy is determined by taking the average of these four separate grades.

In the most recent publication of NORD's State Report Card, based upon law in force as of December 2025, Rhode Island received an overall grade of "F" in the step therapy issue area. Should S116/H5119 be enacted, Rhode Island's overall grade in the issue area of step therapy of the NORD State Report Card would be elevated from an "F" to a "B."

With questions, please contact Carolyn Sheridan, Associate Director of State Policy at the National Organization for Rare Disorders (NORD) at csheridan@rarediseases.org.

About the National Organization for Rare Disorders

Founded in 1983, the National Organization for Rare Disorders (NORD®) is a leading independent, nonpartisan, nonprofit and patient advocacy organization dedicated to improving the health and lives of over 30 million Americans living with rare diseases. In partnership with more than 350 disease-specific member patient organizations, NORD drives progress in rare disease research, care, and policy.

Learn more at rarediseases.org

Sources:

¹ [ojrd.biomedcentral.com/articles/10.1186/s13023-018-0936-x](https://www.ojrd.biomedcentral.com/articles/10.1186/s13023-018-0936-x)

² [ojrd.biomedcentral.com/articles/10.1186/s13023-023-02790-7](https://www.ojrd.biomedcentral.com/articles/10.1186/s13023-023-02790-7)

³ [ojrd.biomedcentral.com/articles/10.1186/s13023-021-02061-3](https://www.ojrd.biomedcentral.com/articles/10.1186/s13023-021-02061-3)

¹ NORD's State Report Card® Step Therapy [Grading Methodology](#)