



Alone we are rare. Together we are strong.®

March 31, 2025

The Honorable Susan R. Donavan
Chair
House Health and Human Services Committee
State House
Providence, RI 02903

Re: NORD Supports S116 (Ujifusa)/H5119 (McGaw) An Act Concerning Step Therapy

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.

With a more than 40-year history, NORD is the leading and longest-standing patient advocacy organization for the estimated 1-in-10 Americans living with a rare disease. An independent 501(c)(3) nonprofit, NORD is dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 355 patient organization members, is committed to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. NORD believes that all individuals with a rare disease should have access to high quality, affordable health care that is best suited to meet their medical needs.

Step Therapy

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.

Establishing Categories for Exemptions from Step Therapy Protocols

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 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, is expected to be ineffective, the patient is stable on the initially prescribed drug, or if it’s not in the patient’s best interest.

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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. This legislation establishes a timeline within which health plans must respond to a patient or 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.

NORD's State Report Card

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 2024, 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."

We hope you consider NORD a resource for you as this bill moves through the legislative process.

Sincerely,



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CC:

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Representative Michelle McGaw, Sponsor H5119
Steve Sepe, Clerk House Health and Human Services
Leah Barber, Director of Grassroots Advocacy, National Organization for Rare Disorders

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