



Alone we are rare. Together we are strong.®

April 18, 2024

The Honorable Ann Cummings
Chair
Senate Committee on Finance
115 State St.
Montpelier, VT 05633

The Honorable Mark A. MacDonald
Vice-Chair
Senate Committee on Finance
115 State St.
Montpelier, VT 05633

Re: NORD Responds to Proposed Amendments Offered by Health Plans to Step Therapy Provisions of Vermont H.766 (Black)

The National Organization for Rare Disorders (NORD) writes to thank you for giving [House Bill 766 \(Black\)](#) the opportunity to be heard before your Committee. However, NORD is deeply concerned with attempts by the health insurance industry to water down the proposed patient protections against the utilization management tactic of step therapy that are a critical part of H.766.

NORD is a federation of non-profits and health organizations dedicated to improving the health and wellbeing of people living with rare diseases. NORD was founded over 40 years ago, after the passage of the Orphan Drug Act, to formalize the coalition of patient advocacy groups that were instrumental in passing that landmark law. Our mission has always been, and continues to be, to improve the health and well-being of people with rare diseases by driving advances in care, research, and policy.

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. When used inappropriately, step therapy protocols delay necessary treatment and lead to adverse reactions that ultimately increase health care costs, not lower them. 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.

Preserve the Categories for Exemptions as Proposed

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 five automatic exceptions from step therapy protocols currently included in H.766. NORD is very concerned with amendments proposed by payors to strike circumstances for an automatic exemption where the patient is stable, or the drug comes from same pharmacologic class or has same mechanism of action.

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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. While it may be commonplace for medications to be “switched all the time” that is not the reality for the patients living with a rare disease that we represent.

For many rare disease patients, achieving stability is a multi-year process and partnership with their health care provider trying the different, but often limited treatments available. During the time period where an ideal treatment or disease management protocol is being worked out, providers should be given the trust they deserve to make changes to a patient’s regimen without being forced to try something they already know will not work and explain their rationale to a panel of clinical reviewers who are less likely to know the specifics of a patient’s rare disease or the health care provider’s treatment strategy. Furthermore, it is a recognized challenge that for many rare diseases, data relevant to clinical benefit, therapeutic alternatives, or unmet medical need often does not currently exist in peer-reviewed journals or consensus treatment guidelines. When stability is achieved, it ought to be maintained and protected.

Align with Other States & NORD’s State Report Card

Contrary to testimony that Vermont would be “experimenting with policies that are not being tried anywhere else in the country”—twenty-one states in the country have instituted the same five step therapy exemptions proposed in H.766¹. On an annual basis, NORD evaluates how effectively states are serving people with rare diseases across nine issue areas 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 guaranteed to patients.

In the most recent publication of NORD’s State Report Card, based upon law in force as of December 2023, Vermont received an [overall grade](#) of “F” in the step therapy issue area. Enacting the changes in H.766 would raise Vermont’s overall grade on step therapy from an “F” to a “B” and align the patient protection with those that have been successful in many other states.

We hope you consider NORD a resource for you as this bill moves through the legislative process and urge you to reject any amendments that would reduce the critical patient protections outlined in H.766.

Sincerely,



Carolyn G. Sheridan, MPH
State Policy Manager, Eastern Region

¹ Those states include Arizona, Arkansas, California, Colorado, Delaware, Iowa, Kentucky, Louisiana, Maine, Massachusetts, Nebraska, Nevada, New York, Oklahoma, Pennsylvania, South Dakota, Tennessee, Texas, Washington, West Virginia, and Wisconsin. New Jersey and Rhode Island have bills pending in the current session.