March 28, 2024

Vermont Senate
ATTN: Committee on Health and Welfare
115 State St
Montpelier, VT 05633

Re: H 766, An act relating to prior authorization and step therapy requirements, health insurance claims, and provider contracts

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of the prior authorization provisions in H 766. The EveryLife Foundation is a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

Inappropriate utilization management requirements burden patients living with chronic illness, including the 1 in 10 people nationwide impacted by one or more of the 10,000+ rare diseases. We support the provisions in H 766, including those listed below, that would set reasonable and appropriate standards for insurance prior authorization processes.

Ensure Timely Review of Prior Authorization Requests and Appeals
Time is a precious commodity in the rare disease community because many individuals face progressive diseases with limited life expectancies. Navigating a rare disease diagnosis can require more than 6 years, on average, after symptoms begin.[i] In many cases, once a patient is diagnosed, inefficient prior authorization processes can further delay their treatment. We support the provisions of this bill that would implement time-bound standards to ensure plans respond to prior authorization requests in a reasonable amount of time.

Eliminate Unwarranted Prior Authorization Requirements
While 95% of rare diseases do not yet have an FDA-approved treatment, for those patients who do have an available therapy, prior authorization requirements create hurdles in accessing the treatments that many have fought for decades to exist.[ii] In some cases, insurers may deny coverage altogether, leaving rare disease patients with few options. This is especially true for rare disease patients whose treatments often do not have alternatives. We appreciate the provisions in this bill that require that prior authorization approval be valid for the duration of the prescribed or ordered treatment, service, or course of medication or one year whichever is longer. We also appreciate the provisions that, for treatment, services, or course of medications that that continues for more than one year, renewal not be required more frequently than once every five years.

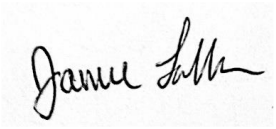
Delays or lapses in care caused by unnecessary prior authorization requirements or inappropriate determinations can yield irreversible disease progression[iii] and catastrophic healthcare costs. The EveryLife Foundation's seminal 2022 study revealed the impact of rare disease to be nearly $1 trillion dollars in 2019.[i] A stunning 60% of those costs are absorbed by families and by society. In addition to direct medical expenses, indirect costs associated with rare diseases such as lost productivity, absenteeism and forced early retirement are a significant financial burden on the economy and on rare disease families[2] and inappropriate use of prior authorization requirements only serve to add to these impacts.

A rare disease patient, Sara, from Bellows Falls, Vermont, shared with us her experience seeking prior authorization for her medication.

> *"I started having symptoms at the age of 7 - fevers, headaches, abdominal pain. The attacks would last from 3 to 4 days every month on the dot. It went on like this for 5 years till […] I got the confirmed diagnosis at the age of 12. I'm 28 and still dealing with flares often as we're trying to find a biologic to help. With my insurance, I've tried several different biologics and I've been denied several times. They also denied one medication that's crucial for my condition and my doctors have had to make multiple calls to my insurance company saying we tried all other options."*

It is important for insurance companies to facilitate timely and appropriate care for patients, including those with rare diseases. We support the provisions in H 766 that would set reasonable and appropriate standards for insurance prior authorization processes. Thank you for the consideration of H 766.

Sincerely,



Jamie Sullivan
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CC:
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[i] *The National Economic Burden of Rare Disease Study, EveryLife Foundation for Rare Diseases, everylifefoundation.org/burden-landing/*

[ii] *Fermaglich, Lewis J, and Kathleen L Miller. A Comprehensive Study of the Rare Diseases and Conditions Targeted By Orphan Drug Designations and Approvals Over the Forty Years of the Orphan Drug Act." Orphanet journal of rare diseases vol. 18,1 163.*

[iii] In this recent national survey of physicians, almost half of the physicians reported that prior authorization policies led to urgent or emergency care for patients, and one-third of the physicians reported that prior authorization led to a serious adverse event for a patient in their care, including hospitalization, permanent impairment, or death. *2022 AMA Prior Authorization (PA) Physician Survey, American Medical Association*