



March 27, 2025

Oregon House of Representatives
ATTN: Committee on Behavioral Health and Health Care
900 Court Street, NE,
Salem, OR 97301

Re: HB 3134 – Regarding Prior Authorization

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of HB 3134. 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. While 95% of rare diseases do not yet have an FDA-approved treatmentⁱ, 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. 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.

For rare disease patients, stability and continuity of care are paramount. Frequent reauthorizations can lead to interruptions in treatment, increased stress for patients, and irreversible disease progression.ⁱⁱ When authorizations are valid for longer periods of time, patients can focus on managing their health rather than navigating procedural hurdles. We appreciate efforts to reduce the quantity of prior authorizations by providing exceptions when certain circumstances are met that are in the best interest of the patient and are clinically appropriate. We also appreciate the provisions in this bill that require prior authorizations for the treatment of certain conditions remain valid for a given length of the treatment.

Delays or lapses in care caused by unnecessary prior authorization requirements or inappropriate determinations can also yield catastrophic healthcare costs. The EveryLife Foundation's seminal 2022 study revealed the impact of rare disease to be nearly \$1 trillion dollars in 2019.ⁱⁱⁱ 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 and inappropriate use of prior authorization requirements only serve to add to these impacts.

It is important for insurance companies to facilitate timely and appropriate care for patients, including those with rare diseases. Please support HB 3134.

Sincerely,

Jamie Sullivan
Vice President of Policy

Emily Stauffer
Associate Director of State Policy

EveryLife Foundation for Rare Diseases

EveryLife Foundation for Rare Diseases

CC:

Michael Pearlmutter, Chief Executive Officer, EveryLife Foundation for Rare Diseases

Annie Kennedy, Chief of Policy, Advocacy and Patient Engagement, EveryLife Foundation for Rare Diseases

Vicki Seyfert-Margolis, Chair, Board of Directors, EveryLife Foundation for Rare Diseases

ⁱ *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.

ⁱⁱ 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*

ⁱⁱⁱ *The National Economic Burden of Rare Disease Study, EveryLife Foundation for Rare Diseases, www.everylifefoundation.org/burden-landing/*