March 25, 2025

Alaska Senate
ATTN: Committee on Commerce & Labor
120 4th Street,
Juneau, AK 99801

Re: SB 133 – Regarding Prior Authorization

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of SB 133. 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 treatment[i], 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. We support the provisions in SB 133, including those listed below, that would set reasonable and appropriate standards for insurance prior authorization processes.

Promote Clinically Appropriate Decision Making
Too often, prior authorization determinations are not based on medical science and can undermine a physician's medical expertise. We commonly hear from rare disease patients who tell us that the people who review their prior authorization requests have no expertise on their condition or, perhaps even worse, don't know what their condition is. Given the complex nature of individual rare diseases, it is important that the appropriate medical experts are involved in reviewing prior authorization requests on behalf of an insurer. We support the section of the bill that allows health care providers the opportunity to request a clinical peer review of a prior authorization request from a qualified specialist.

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.[ii] 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.

Reduce Interruptions in Treatment Caused by Prior Authorization Requirements
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.[iii] When authorizations are valid for longer periods of time, patients can focus on managing their health rather than navigating procedural hurdles. We appreciate the provisions in this bill that require prior authorizations for the treatment of chronic conditions remain valid for at least 12 months.

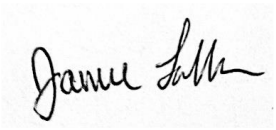
Promote Transparency and Accountability
Requiring insurers to report prior authorization data and trends helps patients, advocates, and policymakers to identify patterns and potential disparities in access to care. This transparency allows us to better understand the challenges faced by rare disease patients and work towards more equitable and

effective policies. We support the provisions of this bill that require insurers to make key aggregate data and metrics publicly available.

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.[ii] 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 SB 133.

Sincerely,



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

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

[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*