April 1, 2026

Testimony of the Rare & Ready Coalition in Support of SB26-140

Dear Committee Chair and Members,

On behalf of the Rare & Ready Coalition, we respectfully urge your support for SB26-140, which would exempt rare disease and plasma-derived therapies from Prescription Drug Affordability Board (PDAB) review.

There are approximately 10,000 known rare diseases, but **only 5% have an FDA-approved therapy**. There are only **552 drugs and biologics** on the market having an orphan designation and **75% of those treat just a single rare disease**.[1] Unlike traditional medicines, orphan drugs serve extremely small patient populations and have limited clinical use, only **10%, about 60 drugs,** are approved for multiple indications.[2]

SB26-140 recognizes this reality. By exempting rare disease and plasma-derived therapies from PDAB review, the bill helps ensure that patients can maintain access to the only treatments designed for their conditions. For these patients — many of whom are children — these treatments are not optional; they are often the only available lifeline.

PDAB policies, while well-intentioned, can have serious unintended consequences for the rare disease community. These boards can restrict access to medications, deter future research and development, and weaken longstanding orphan drug protections. Most importantly, they can put patients at risk of losing access to the only therapies that sustain or extend their lives.

PDABs do not lower out-of-pocket costs at the pharmacy counter or reduce insurance premiums. Instead, they can create access barriers by limiting the ability of insurers and pharmacies to obtain therapies priced above state-imposed thresholds.

Other states, including Oregon and Washington, have already recognized these risks and taken action to exempt rare disease treatments from PDAB review. Colorado now has the opportunity to follow their lead and protect its most vulnerable patients.

For individuals living with rare diseases, access to treatment is essential to survival, quality of life, and hope for the future. **These therapies are not widely used, broadly interchangeable drugs—they are highly specialized treatments, often designed for one condition.** SB26-140 ensures that these patients are not unintentionally harmed by policies that were never designed for them.

Respectfully,
Rare & Ready Coalition

[1-2] "Orphan Drugs in the United States: An Examination of Patents and Orphan Drug Exclusivity," available at www.rarediseases.org/rareinsights