To: Oregon Prescription Drug Affordability Board

From: Erin Daugherty, RN, BSN | Redmond, OR

Re: Testimony given at the Oregon Prescription Drug Affordability Board community forum in Redmond, May 6, 2026

Date: Revised edition submitted by email June 1, 2026

Good evening. My name is Erin Daugherty. I am a Redmond resident, a registered nurse of 25 years, and a board member of the rare disease advocacy non-profit, **ElevateRare**. I am here tonight as a professional and a patient living with a complex, rare disease: Ehlers-Danlos Syndrome. By estimation, 420,000 Oregonians live with a rare or complex disease and manage a slew of debilitating complications.

Because I am on SSDI, I am required to have Medicare Part A, which provides no prescription drug coverage. This triggers the **Federal Anti-Kickback Statute**, which legally bars me from manufacturer co-pay assistance when my primary insurer, Moda PEBB PPO, denies a drug. I am "double-insured," yet functionally blocked from the financial relief available to others, leaving me to face astronomical costs alone. I currently manage 15 routine and 6 as-needed medications.

Point I: Denial of Treatment – The "OTC" Inconsistency and Clinical Safety

(talk about how loperamide is covered, the prescription capsules for about $4, Moda pays for this prescription and it is the exact same dose at OTC)   My prescription for 40mg Esomeprazole—necessary for biopsy-proven erosive esophagitis—is denied by Moda due to "OTC availability." However, the 20mg OTC version is FDA-approved for short-term use only (14 days). Moda’s policy forces me to either pay hundreds of dollars out-of-pocket or engage in a dangerous "pill burden" of doubling up OTC pills. As a nurse, my greatest concern is the message these denials send: that specialist oversight is optional. This policy ignores **ORS 743A.062**, which requires coverage for treatments supported by medical literature and FDA-approved drugs.

The "Ghost Pricing" Glitch: During the recent PDAB meeting in Redmond, I tested the ArrayRx site. I entered ‘omeprazole 40 mg #60’ and was shocked to see quotes of $10,000 to $15,000. I have learned this is a "ghost pricing" glitch: when PBMs update contracts, the system temporarily loses its connection to the actual negotiated rate and defaults to an inflated, arbitrary placeholder. To a computer, it is a glitch; to a patient, it is a financial emergency. Apps meant to save time are failing silently, leaving patients to believe this is the current cash price and either look elsewhere or not fill the prescription.

Then I looked up the omeprazole 40 mg #60 a month on Cost Plus Drugs. The same medication total cost to fill is $6.72 and this site also lists the cost of the drug itself: $1.50. There is full transparency on this site: The cost of the drug, a very low profit for the drug company, the cost of pharmacy services and shipping. Where does the money go when insurance pays $100-$1000s of dollars for a drug that costs $1.50 to make! This much is totally clear: The $600–$900 retail costs are not reflective of value—they are a hidden tax on the sick. **Full transparency, as demonstrated by Cost Plus, is the only way forward.**

Point II: Denial of Prevention (Zepbound & Xolair)

I live with Mast Cell Esophagitis and Mast Cell Enteritis. Both Zepbound and Xolair are supported by published literature for mast cell stabilization, yet both are denied.

- **Zepbound:** My physician prescribed Zepbound for weight management and Obstructive Sleep Apnea. Moda denied this, citing "Diabetes Only" criteria. Personally, I sought Zepbound for Mast Cell stabilization. Since starting it, I have had zero episodes of anaphylaxis and zero ER visits.
- **Xolair:** I am currently unable to access Xolair due to an insurance denial. Its mechanism—the direct downregulation of mast cells—is well-documented in peer-reviewed literature. This is not a "wild" experiment; it is a targeted therapy backed by objective clinical data.

The ultimate irony: Insurance companies prefer to pay for the catastrophe—the surgery or the lifetime of enteral nutrition—rather than the treatment or prevention.

Point III: The "Off-Grid" Survival Crisis

These denials force rare disease patients into "fragmented survival mechanisms." When we are forced "off-grid" to find affordable meds, we destroy the integrity of Oregon's healthcare data. My Electronic Medical Record (EMR) is inaccurate because insurance companies have no record of the drugs they deny, and out-of-country fills never hit the state's prescription monitoring systems. This dangerous gap bypasses the interoperability goals of the **21st Century Cures Act**.

Closing

Oregon law requires medications to be covered if they are an accepted standard of care. Yet, the burden of enforcement falls entirely on the consumer. Until there is a route to report these denials that result in immediate fines higher than the cost of the drug, insurers will continue to operate as financial entities rather than healthcare partners. One denial letter should be all the evidence needed for action.

Thank you.