



October 19, 2026

Oregon Prescription Drug Affordability Board
Department of Consumer and Business Services
350 Winter Street NE
Salem, OR 97309-0405

RE: Comments on Affordability Reviews, Policy Recommendations and Patient Feedback Form

Dear Members and Staff of the Oregon Prescription Drug Affordability Board:

The Ensuring Access through Collaborative Health (EACH) and Patient Inclusion Council (PIC) is a two-part coalition that unites patient organizations and allied groups (EACH), as well as patients and caregivers (PIC), to advocate for drug affordability policies that benefit patients.

We appreciate the opportunity to provide comments as the board concludes its 2026 affordability reviews and finalizes policy recommendations for its annual report to the legislature. Throughout this process, our coalition has encouraged the board to prioritize policies that directly improve affordability and access for patients, rather than approaches that primarily target prescription drug prices or healthcare system spending. We appreciate the board's continued willingness to explore reforms that address the underlying causes of patient hardship.

Keep Patient Affordability at the Center of Final Drug Reviews

As the board concludes its 2026 affordability reviews, we reiterate our request that affordability determinations focus on patients' actual out-of-pocket costs and experiences rather than the costs incurred by insurers or the broader healthcare system.

As we have previously shared with the board, according to results from our [Patient Experience Project](#), affordability is not determined by drug price alone. Patients experience affordability within the context of what they actually pay, their insurance coverage, cumulative healthcare expenses, access to financial assistance, and their ability to consistently obtain the treatment that works for them. Critically, the research found no single universal price threshold separated an affordable medication from an unaffordable one.

We therefore encourage the board to evaluate whether patients are experiencing affordability challenges, identify what is driving those challenges, and ensure that its determinations reflect the real-world experiences of patients rather than relying primarily on drug pricing or aggregate spending data.

Prioritize Policy Recommendations That Address Patient-Reported Barriers

We appreciate the board's consideration of policy recommendations that move beyond drug reviews and address obstacles patients experience when obtaining and maintaining access to treatment. In particular, EACH/PIC supports three of the proposals under consideration:

- **Strengthening PBM oversight and transparency.** We support the board's recommendation to improve reporting, disclosure, and oversight of PBM practices. Greater transparency into rebates, fees, financial incentives, and payments throughout

the prescription drug supply chain is an important step toward identifying practices that contribute to patient costs and access barriers. We also encourage the board to continue advancing reforms that prohibit spread pricing, delink PBM compensation from drug prices, and ensure negotiated savings benefit patients.

- **Improving commercial health plan continuity of care.** We support policies that make it easier for patients to continue treatments that work for them, including establishing protections that require health plans to honor existing prescription drug authorizations when patients change coverage. Patients who are stable on an effective treatment should not face unnecessary delays, repeated administrative requirements, or treatment disruptions simply because their insurance coverage changes. The proposed transition protections represent a meaningful opportunity to address an insurance-related barrier to care.
- **Broadening the focus of review.** We appreciate the board's recognition that improving patient affordability requires looking beyond the prices of individual prescription drugs. Our research consistently demonstrates that insurance design, coverage restrictions, PBM practices, and other healthcare system factors are often more directly responsible for the affordability challenges patients experience. We therefore support moving away from mandatory annual reviews of individual drug products and toward a more comprehensive examination of these underlying issues.

We also appreciate the board's acknowledgment that broader policy evaluations would be a considerably more complex undertaking, potentially requiring additional expertise, coordination across state agencies, and significant new resources. As legislators consider this recommendation, these practical implications deserve careful attention, particularly the potential budgetary demands and overlap with the responsibilities of existing state agencies.

Preserve Protections for Orphan Drugs

We remain opposed to the board's efforts to review drugs with orphan designations and its proposed amendments to the statutory exemption. Oregon's authorizing statute prohibits the review of orphan-designated drugs, and the board's current practice of reviewing these medications based on individual indications is inconsistent with that prohibition.

These protections exist for important reasons. Patients living with rare diseases frequently have limited or no alternative treatment options and depend on consistent access to therapies that may be critical to managing their conditions. Subjecting these medications to affordability reviews and potentially subsequent cost-control policies risks undermining the very access these statutory protections were intended to preserve.

We therefore oppose both proposed alternatives and urge the board to abandon efforts to weaken or circumvent the existing orphan drug exemption. The board should adhere to the statute as written and preserve the protections established for patients living with rare diseases.

Continue Strengthening Patient Engagement



Finally, we appreciate the board's decision to make its patient feedback form available throughout the year and its willingness to incorporate several of the revisions we recommended in September.

Creating an ongoing opportunity for patients to share their experiences is an important improvement. We encourage the board to continue refining its questions to capture not only whether a medication is affordable, but also why patients experience affordability or access challenges. This information will be particularly valuable as the board considers expanding its work to examine the broader factors affecting patient access.

We appreciate the board's continued attention to prescription drug affordability and its willingness to consider policy approaches that more directly address the problems patients experience. EACH/PIC looks forward to continuing to work with the board to advance reforms that improve affordability while preserving access to necessary treatments.

Sincerely,

A handwritten signature in cursive script, reading "Tiffany Westrich-Robertson".

Tiffany Westrich-Robertson

tiffany@aiarthrititis.org

Ensuring Access through Collaborative Health (EACH) Coalition Lead

A handwritten signature in cursive script, reading "Vanessa Lathan".

Vanessa Lathan

vanessa@aiarthrititis.org

Patient Inclusion Council (PIC) Coalition Lead