EACH PIC
COALITION

May 18, 2026

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

RE: Public Comments on 2026 Cost Review

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

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

As the board makes final deliberations on the structure for the 2026 affordability review process, we respectfully resubmit our letter submitted for the April meeting and urge the board to carefully assess how their determinations on the drugs selected for 2026 review could impact patient affordability AND patient access in the future.

We stand ready to work with the board in developing an approach that better assesses patient needs and better address patient-identified barriers to care.

Thanks for your time and consideration.

Sincerely,

Tiffany Westrich-Robertson

Tiffany Westrich-Robertson
tiffany@aiarthritis.org
Ensuring Access through Collaborative Health (EACH) Coalition Lead

Vanessa Lathan

Vanessa Lathan
vanessa@aiarthritis.org
Patient Inclusion Council (PIC) Coalition Lead

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April 13, 2026

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

RE: Public Comments on 2026 Cost Review

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

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

We appreciate the opportunity to provide comments as the board continues its work on the 2026 drug affordability review process. We share the board's goal of improving affordability for Oregonians and believe there is a critical opportunity to strengthen the process by more fully centering patient experience and ensuring that policy approaches align with how patients actually experience affordability challenges.

Centering the 2026 Review Process on Patient Experience

As the board begins the 2026 review cycle, we strongly encourage a more deliberate focus on patient-reported experiences as the foundation for affordability determinations and policy development.

Our Patient Experience Project: Patient-Reported Affordability & Unaffordability Survey 2.0 found that affordability is not defined by the price of a drug alone, but by whether patients can consistently access their medications within the context of their overall financial and health circumstances. Patients repeatedly identified insurance coverage, cost-sharing structures, and access to financial assistance as the primary drivers of affordability and access.

Specifically, patients who reported stopping or not initiating treatment overwhelmingly cited insurance-related barriers, including coverage denials, utilization management, and high or unstable out-of-pocket costs, rather than drug price alone. In addition, many patients experienced significant variability in their out-of-pocket costs for the same medication over time, contributing to "affordability shifting" and, in some cases, loss of access altogether.

These findings reinforce a consistent theme we have raised in prior comments: patient affordability is largely determined by insurance design and access-related factors, not directly by the price of a medication. As a result, policy approaches that focus primarily on price are unlikely to resolve the challenges patients report and may fail to improve real-world affordability.

Statutory Considerations Regarding Orphan Drugs

We also wish to raise concerns regarding the board's inclusion of drugs with an orphan drug designation in its 2026 cost review. Not only is the board circumventing its own statute with this action, but it is also circumventing the intent behind the measure, which is to protect rare disease patients by preventing actions that could compromise their access to needed treatments.

Patients using orphan-designated therapies often have limited or no alternative treatment options and depend on stable access to maintain their health. Policies that risk disrupting access to these treatments carry significant consequences for these patient populations.

We therefore strongly urge the board not to proceed with the review of drugs with orphan drug designations and to adhere to both the letter and intent of the statute.

Improving Patient Engagement and Data Collection

To support a more effective and patient-centered 2026 review process, we encourage the board to strengthen its approach to patient engagement and data collection. Without these improvements, there is a significant risk that the board's analysis will continue to lack the context needed to identify effective policy solutions.

Traditional survey methods that rely on closed-ended or yes/no questions do not capture the context necessary to understand affordability. As our research demonstrated, it is essential to understand *why* patients report a medication as unaffordable, including the role of insurance barriers, cumulative healthcare costs, and disruptions in financial assistance. Equally important is investing in developing patient-facing questions that are designed for clarity and opportunities to share their full experiences.

In addition to enlisting help from Patient Research Partners (PRPs) to assist with question design, our survey incorporated open-ended questions that allowed patients to describe their experiences in their own words, which proved critical in identifying the true drivers of affordability challenges.

We encourage the board to adopt the questions and similar approach from our most recent survey as a model when designing your surveys. , To assist, the PIC will lead efforts to launch a Patient-Facing Data Collection Best Practices Toolkit. It will include:

- Tested model questions
- Focus group style questions for use when conducting patient listening sessions or roundtables
- Lessons learned regarding question design that resulted in challenging analysis

EACH/PIC will also offer complimentary services to the OR PDAB to assist writing any additional patient-facing questions to discover endpoints not included in our existing tool.

We also welcome the board and staff to partner with patient organizations from EACH to support outreach and ensure diverse participation.

Conclusion

As the board moves into the 2026 review cycle, ensuring that patient experience is central to both data collection and policy development will be essential to achieving meaningful improvements in affordability.

Policies that address the root causes of affordability challenges that patients themselves have identified are far more likely to reduce real-world affordability challenges than approaches focused solely on drug price.

Sincerely,

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