



July 29, 2025

Dear Members of the Colorado General Assembly,

On behalf of Colorado Patients Taking Action, we are writing to share the patient perspective on the implementation of the Colorado Prescription Drug Affordability Board (PDAB).

Colorado is on the cusp of becoming the first state to set upper payment limits (UPLs) on prescription medications. While we support all efforts to lower the cost of health care, we are deeply concerned that the PDAB's current process will fail to deliver savings for Coloradans, and worse, may restrict access to critical medications.

We have closely followed the PDAB's work over the years and have participated in all PDAB meetings. While stakeholder input is permitted, **patient concerns have been consistently overlooked** - with one important exception.

Last year, after repeatedly raising the issue that patients felt their concerns were not being heard, Board Member Dr. Sami Diab proposed adding a **patient voting member** to the PDAB (PDAB Meeting, April 2024). His proposal met resistance and was completely excluded from the PDAB's 2024 report to the legislature. We appreciate that Dr. Diab renewed this call in May 2025, citing the widespread inclusion of patients in clinical review processes. The Board ultimately included a modest recommendation that the General

Assembly “consider the pros and cons” of adding a consumer representative (PDAB Meeting, May 2025).

We strongly urge you to act on this recommendation and ensure that patients have a real seat at the table.

Following another year of diligent patient engagement, we remain alarmed by persistent issues with the PDAB’s process. We have raised — and continue to raise — serious, unresolved concerns that must be addressed before any upper payment limit is implemented. We respectfully submit these concerns for your thoughtful consideration and timely action:

I. No Evidence of Patient Savings

There is currently **no evidence** that a UPL will lower what patients pay at the pharmacy counter.

- In April 2025, the Colorado Division of Insurance released a cost-benefit analysis on applying a UPL to Enbrel. It included **no quantifiable data** and admitted the benefits were "difficult to quantify" due to pharmaceutical supply chain complexity and the absence of a set UPL.¹
- In March 2025, Avalere Health published findings from interviews with senior health plan executives, warning that UPLs could actually **increase patient costs**, disrupt access, and strain benefit design.²
- Importantly, Oregon’s own exploration of this policy space included a meaningful and comprehensive analysis — the Stauffer-Meyer report — demonstrating that a thorough cost-benefit assessment is not only possible but necessary.³
- Oregon’s Stauffer-Meyer report identified significant risks to safety-net providers through the potential erosion of 340B savings and flagged the destabilizing impact that UPLs could have on the Medicaid Drug Rebate Program (MDRP) — which

¹ Colorado Division of Insurance, *PDAB Cost Benefit Analysis* (April 2025),

<https://doi.colorado.gov/sites/doi/files/documents/Cost%20Benefit%20Analysis%20%281%29.pdf>.

² Michael Matthews and Sarah Chen, “Update: Health Plans’ Perceptions of PDABs and UPLs,” *Avalere Health Advisory*, March 2025, <https://advisory.avalerehealth.com/insights/update-health-plans-perceptions-of-pdabs-and-upls>.

³ Oregon Prescription Drug Affordability Board, *Upper Payment Limit (UPL) Analysis: Oregon Educators Benefit Board (OEBB) and Public Employees’ Benefit Board (PEBB), Medicaid FFS and CCO*, prepared by Myers & Stauffer LC (Nov. 2024), included in PDAB Document Package for October 16, 2024 meeting, <https://dfr.oregon.gov/pdab/Documents/20241016-PDAB-document-package.pdf>.

provides critical funding for the state's Medicaid program. Specifically, they noted reduced MDRP value, which is considered the state's share of cost offsets, and concluded that such unintended consequences could outweigh any theoretical benefit.

Recommendations: Before implementing any UPL, the General Assembly should require:

- A meaningful, evidence-based analysis of expected outcomes.
- Assurances from supply chain stakeholders that patient access will not be disrupted.

II. Decisions Based on Flawed and Incomplete Data

We have serious concerns about the data and methodology PDAB is using to make affordability decisions and set public policy.

All Payer Claims Database Inaccuracies: At its April 2025 meeting, the Board acknowledged errors in the **All-Payer Claims Database (APCD)** dating back to 2022.⁴ These errors affected approximately 7% of claims and skew metrics such as:

- Patient counts
- Average Wholesale Acquisition Cost (WAC)
- Average Paid Per Person Per Year (APPY)
- Total payer and patient costs
- The application of inaccurate data calls into question the validity of the unaffordability determinations for Enbrel, Cosentyx, and Stelara.
- The APCD also fails to include denied claims and utilization management barriers which significantly affect patient costs, delays in care, and therapy abandonment.

⁴ Partnership for Safe Medicines. "PDAB Activity – April 2025 Update." *SafeMedicines.org*, April 2025. <https://www.safemedicines.org/2025/04/pdab-activity-apr-2025.html>.

Flawed Survey Design: As raised by Tiffany Westrich-Robertson of the EACH Coalition and Patient Inclusion Council in written testimony to the PDAB, the Board's patient survey design used in affordability reviews is deeply flawed and inaccurate ⁵:

- Responses included non-Colorado residents, violating the statutory requirement for Colorado-specific input.
- Medicare beneficiaries were included, despite the fact that UPLs do not apply to Medicare-covered drugs. Colorado cannot legally impose UPLs on Medicare plans, as they are federally regulated under the Centers for Medicare & Medicaid Services (CMS). Any attempt to do so risks federal preemption and legal challenge — and highlights the need for PDAB to distinguish clearly between state-regulated commercial plans and federally regulated Medicare coverage.
- As a result, the data does not reflect the real affordability landscape for the population PDAB is meant to impact.

Ongoing Use of Discriminatory QALYs: Despite clear statutory and federal prohibitions, PDAB continues to reference **Quality Adjusted Life Years (QALYs)** in its evaluations.

- QALYS measures inherently devalue the lives of people with disabilities or chronic illnesses and violate the General Assembly's directive that such methodologies not be used in affordability decisions.

Recommendations: Halt implementation of UPLs until the Board can:

- Demonstrate that their decisions are based on complete, reliable, Colorado-specific data.
- Employ a transparent and evidence-based process.
- Redesign patient surveys to exclude Medicare data and out-of-state responses and reanalyze prior surveys with corrected methodology.
- Strengthen and enforce the prohibition on QALYs in all PDAB decisions.

⁵ Colorado Division of Insurance, *Written Testimonies to the Prescription Drug Affordability Board*, May 23, 2025,

https://doi.colorado.gov/sites/doi/files/documents/Written%20Testimonies_5.23.25.pdf.

III. Lack of Implementation Planning:

We are deeply concerned that the Board has not conducted a meaningful implementation analysis. Specifically:

- How are supply chain actors — including pharmacies, PBMs, and insurers — supposed to distinguish between commercial and Medicare claims in order to comply with a UPL?
- The PDAB has failed to adopt any monitoring metrics to evaluate whether UPLs impact patient access or affordability post-implementation.
- Without tracking outcomes, the Board cannot credibly claim to be protecting patient interests — or even measure whether its actions are having any effect at all.

Recommendations: Prior to implementing UPLs, require the PDAB to:

- Provide a detailed implementation plan that clarifies compliance pathways for supply chain actors.
- Commit to measuring and reporting on patient access and affordability outcomes after a UPL is implemented.

IV. No Results After \$2 Million Spent

On July 1, PDAB issued an 11-page report claiming Colorado is "leading the nation" in addressing drug affordability. As patient stakeholders, we challenge that assertion. Over the past four years, the Board has cost taxpayers more than \$2 million and has not saved patients a single dollar at the pharmacy counter.

This year we watched as you, our legislators, struggled to cut \$1.2 billion dollars in spending to address Colorado's budget deficit. As you know, these cuts will affect school meals, early intervention for children with disabilities, and transportation safety. At a time when we are cutting vital health and safety services, it is irresponsible to continue spending on a board that has failed to deliver on its core promise to make prescription drugs more affordable.

The New Hampshire Legislature recognized this failure. They cut all funding for the state's PDAB and repealed the Board entirely.⁶ Colorado should consider doing the same.

⁶ New Hampshire Medical Society. *Legislative Updates – May 27, 2025*.
<https://www.nhms.org/news/legislative-updates-52725>

Recommendation: We urge you to stop funding a failed experiment and instead invest our limited public dollars in programs that produce measurable results for Coloradans.

Sincerely,

ACT Now

Biomarker Collaborative

The Bonnell Foundation: Living with Cystic Fibrosis

Colorado Springs Special Needs Families

Community Access National Network

Cystic Fibrosis United

Epilepsy Foundation of CO & WY

Exon 20 Group

Global Coalition on Aging

ICAN, International Cancer Advocacy Network

Lupus and Allied Diseases Association, Inc.

Lupus Colorado

Mamas Facing Forward

MET Crusaders

National Infusion Center Association

PDL1 Amplifieds

Spondylitis Association of America