August 7, 2026

Dear Members of the Colorado General Assembly,

On behalf of Colorado Patients Taking Action and the undersigned partner organizations, we respectfully submit our Second Annual Patient Perspective Report on the Colorado Prescription Drug Affordability Board (PDAB).

Five years after SB 21-175 became law, the Colorado Prescription Drug Affordability Board has failed to save a single Coloradan even $1 on a prescription. The Board has spent millions of dollars in public funds to adopt an upper payment limit on Enbrel, which the federal government had already negotiated a year earlier. And as of July 1, enforcement of the Enbrel UPL is on hold due to a federal injunction issued after the court found it likely conflicts with federal patent law. Five years, millions spent, zero results.

Colorado's rush to impose the nation's first Upper Payment Limit (UPL) is not earning the state any credibility with leaders working to lower drug costs. It is making us a cautionary tale. As Virginia Governor Abigail Spanberger stated in her reasoning for vetoing her own state's board earlier this year, "evidence from other states clearly shows that Prescription Drug Affordability Boards (PDABs) do not achieve this goal. They are expensive undertakings that other states have either repealed or are considering repealing due to costs and ineffectiveness." New Hampshire in particular, repealed its PDAB at the urging of a legislator who was a member of the board. Notably, after robust deliberation, Oregon's PDAB officially voted not to recommend UPLs to its legislature for inclusion in its recent annual report, citing non-UPL options as more effective solutions.

We urge you to apply the same scrutiny to the Prescription Drug Affordability Board that you would apply to any multi-year, multi-million-dollar investment that has yet to benefit a single Coloradan. Colorado's PDAB should not move forward simply because years and millions of dollars have already been spent. We ask the General Assembly to determine whether the PDAB delivers genuine patient savings without jeopardizing access, continuity of treatment and health outcomes.

I. No Patient Savings Despite Years of Work and Millions of Dollars Spent

The Board's record illustrates the gap between activity and outcomes. Between 2023 and 2024, the PDAB completed affordability reviews of five medications: Enbrel, Genvoya, Cosentyx, Stelara, and Trikafta. The board declared three unaffordable. Yet only one determination has produced a UPL: the $600-per-dose limit on Enbrel, adopted in October 2025 after repeated delays and four separate rulemaking hearings. The processes for Stelara and Cosentyx have produced nothing to date.

Even if a UPL takes effect, meaningful patient savings are far from expected. The upper payment limit caps what insurers and patients collectively pay, but the Board has not explained whether savings captured by insurers and pharmacy benefit managers will ever reach patients through lower cost-sharing or premiums. The PDAB has failed to publish any projection of patient-level savings for any drug it has reviewed.

Consider what the Board's signature action actually amounts to. The Enbrel UPL was set at the Maximum Fair Price that the federal government negotiated under the Medicare drug price negotiation program, then rounded up to the nearest hundred dollars. This benchmark was produced through federal negotiation, not the Board's own analysis of the specific needs of Coloradans and the state's complex healthcare system. We hope you will ask what affordability gains the Board has delivered that would not have occurred without it.

Recommendations:

- Adopt patient out-of-pocket savings as the explicit measure of the Board's success.
- Publish a projected patient-savings estimate before any UPL takes effect.
- Establish mechanisms to ensure that savings realized by insurers and PBMs are passed through to patients at the point of sale.
- Demonstrate that any projected savings are attributable to the Board's own actions rather than to federal Medicare negotiation or biosimilar competition already underway in the market.

II. Decisions Based on Flawed and Incomplete Data

Capping the price of a medication that thousands of patients rely on demands analytical rigor. The data and methods behind the Board's decisions have not met that standard.

Most significantly, PDAB staff disclosed in 2025 that claims data from the All Payer Claims Database, which served as the justification for unaffordability determinations for Enbrel, Cosentyx, and Stelara, had been miscategorized by a reporting pharmacy benefit manager. The error surfaced only after the Board had already declared all three drugs unaffordable and begun UPL rulemaking. Rather than conducting new reviews, the Board corrected the tables through addenda and reaffirmed its original conclusions. **If the data underlying a determination was wrong, on what basis are the conclusions drawn from it presumed correct?**

The Board's analyses also rest on an incomplete picture of what patients pay. The claims and list-price data it relies on do not fully capture manufacturer rebates, discounts, or patient assistance, and so do not reflect the net prices actually paid in the market. Conclusions about access have been drawn in part from small, unscientific survey samples that cannot reasonably be considered representative of the broader patient population.

The Board has further applied its own criteria inconsistently. It excluded Humira, initially ranked first among eligible drugs, because biosimilar alternatives existed, yet advanced Stelara to UPL rulemaking after the FDA approved multiple interchangeable biosimilars and an unbranded biologic priced as much as 90 percent below the brand. **Applying an exclusion criterion to one drug but not another undermines confidence that these determinations rest on consistent, principled analysis.**

Recommendations:

- Commission an independent, third-party audit of the data and methodology behind each completed affordability review before any UPL takes effect
- Establish minimum data-quality and validation standards that must be met before any unaffordability determination or UPL.
- Base affordability determinations on net prices and verified patient out-of-pocket data.
- Adopt and consistently apply written criteria for drug selection and exclusion, including the treatment of drugs with generic, biosimilar, or therapeutically equivalent alternatives.

III. Lack of Patient Safeguards Prior to Implementation

Most concerning, the Board has devoted little attention to patient safeguards even though Colorado's first UPL takes effect in less than six months. Enormous effort has gone into setting the payment limit, and almost none into protecting patients if something goes wrong.

The Board has identified no process for monitoring access disruptions, responding to shortages, addressing formulary restrictions, or providing relief when patients encounter new barriers to their treatments. It has not addressed patient notification, appeals, or emergency-access mechanisms. Nor has it offered guidance on how pharmacies, PBMs, wholesalers, manufacturers, and insurers are to operationalize and comply with UPLs, including the basic question of how they will distinguish state-regulated commercial claims from Medicare claims subject to different legal and reimbursement rules. They merely proverbially "throw up their hands" and claim that enforcement and compliance are the purview of the Attorney General and the Department of Insurance.

The Board has likewise not evaluated the administrative burden, compliance costs, or market disruptions that UPLs may create across a complex and interconnected supply chain. There is no process to identify, report, or correct unintended consequences such as care delays, reduced access, pharmacy network disruptions, or new utilization-management hurdles. **Colorado patients should not be subjected to a large-scale policy experiment without a clear implementation roadmap and meaningful safeguards to protect access to medically necessary treatments.**

Recommendations:

- Prior to implementing any UPL, require the PDAB to publish a detailed implementation plan setting out compliance pathways, operational responsibilities, enforcement mechanisms, and stakeholder obligations across the pharmaceutical supply chain.
- Conduct an implementation-readiness assessment of operational challenges, administrative costs, and risks to patient access.
- Establish and measure patient-centered metrics, including out-of-pocket savings at the pharmacy counter, continuity of access to medications, health outcomes and treatment adherence, and pharmacy participation
- Monitor patient-centered metrics after implementation through a formal process with corrective action and annual reports to the General Assembly.

IV. No Expansion Without Demonstrated Results

The Board is already discussing additional affordability reviews and new drug selections, even though two of the three drugs it declared unaffordable have not been through UPL rulemaking, and the UPL for the third cannot be implemented due to the federal preliminary injunction finding it likely violates patent law. Expanding the PDAB's scope before evaluating the results of its initial actions puts process ahead of results and raises legitimate concerns about oversight and accountability.

This matters at a moment of real fiscal strain. As lawmakers make painful choices affecting school meals, early-intervention services for children with disabilities, public health programs and transportation safety, every public dollar should be accompanied by clear accountability and demonstrable results. After more than $3 million and five years, the Board has not produced measurable savings at the pharmacy counter, nor any system-level savings for the state. That record should inform any decision to commit additional resources to this program.

Limited public dollars should be directed toward programs that demonstrate clear, measurable benefits for Colorado patients and families. To date, the PDAB has not produced any substantive cost-benefit analysis despite multiple requests from stakeholders and the Department of Insurance.

Recommendation:

- Pause any expansion of the PDAB's activities and require a comprehensive, independent evaluation of the Board's effectiveness, costs, and patient impacts before committing additional public resources.

V. Inadequate Patient and Stakeholder Engagement

Policies that affect access to life-sustaining medications require genuine stakeholder engagement. Too often, the PDAB's process has felt procedural rather than substantive:

- Public comment was briefly moved to the start of meetings so members could hear from patients before deliberating, but the comment period has since been returned to the end of meetings. Because agendas shift and discussions run long, stakeholders wait hours to speak and often lose the chance to speak altogether.
- Holding substantive deliberation before public testimony creates the appearance that decisions are formed before stakeholder input is considered.

- The Prescription Drug Affordability Advisory Council (PDAAC) was created to advise the Board, yet there is little transparency about whether or how its recommendations are reflected in Board decisions.
- Patients, caregivers, providers, and advocates have invested hundreds of hours in meetings, testimony, and comments, with no mechanism to track how that input influences Board actions.

Recommendations:

- Restore public comment to the beginning of every Board meeting, before substantive deliberation occurs.
- Require the Board to document stakeholder and PDAAC recommendations and report publicly how each was considered, accepted, or rejected.
- Adopt a stakeholder-engagement framework ensuring patient, caregiver, and provider input is meaningfully incorporated throughout decision-making.

As legislators, you have the prerogative to insist the PDAB deliver evidence, meaningful safeguards, and demonstrated patient savings before any Upper Payment Limit takes effect. The decisions the General Assembly makes in the coming session will determine whether the PDAB delivers real relief for patients or simply expands its reach without accountability or impact. We are grateful for your attention to these concerns and welcome the opportunity to work with you to get this right.

Respectfully submitted by,

Advocates for Compassionate Therapy Now

AiArthritis

Biomarker Collaborative

Center for African American Health

Colorado Rare Disease Coalition

Community Access National Network

ICAN – International Cancer Advocacy Network

Lupus Colorado

Mamas Facing Forward

MET Crusaders

NRG1 Energizers

PDL1 Amplifieds