EACH PIC COALITION

March 2025

Dear Member/Senator:

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 share with you the goals of lowering patient out-of-pocket (OOP) costs and ensuring that residents of your state can access the medications they need to maintain their health. We believe prescription drug affordability boards (PDABs) are expensive, ineffective at lowering lower patient costs for prescription drugs, and could ultimately cause more harm by creating added barriers between patients and their medically necessary treatment. Therefore, we urge you to oppose legislation to empower a local PDAB.

We respectfully urge legislators to consider the concerns of patient organizations outlined in this letter. We offer our organization as a resource to any legislator that seeks to connect with patient organizations and patients.

Cost Reviews and UPLs Could Compromise Patient Access to Medications

While we applaud legislators' commitment to supporting patients and lowering the costs of prescription medications, we are concerned that cost reviews and upper payment limits (UPLs) can further complicate an already complex healthcare marketplace and result in worse outcomes for patients.

At their core, cost reviews necessitate selecting individual drugs for review and implementing market interventions for the selected drugs. This alone puts PDABs in a position of creating inequities between patient populations by selecting and reviewing individual drugs, rather than evaluating systemic health costs.

While UPLs are intended to lower costs for patients, the reality is they could create a new incentive structure for payers that could compromise patient access to the selected medications due to increased utilization management or reshuffling of formularies. This eventuality was outlined by the Centers for Medicare and Medicaid Services in their May 3, 2024 Guidance on Medicare Drug Price Negotiation "CMS is concerned that Part D sponsors may be incentivized in certain circumstances to disadvantage selected drugs by placing selected drugs on less favorable tiers compared to non-selected drugs, or by applying utilization management that is not based on medical appropriateness to steer Part D beneficiaries away from selected drugs in favor of non-selected drugs."

Additionally, many of the drugs under cost review are administered directly by physicians under a "buy and bill" model. Physician reimbursement rates are already being squeezed, and UPLs could additionally lower opportunities for treatment costs to be recouped. As a result, it is likely that physicians would adjust treatment recommendations to avoid facing financial deficits, leaving patients with fewer treatment options.

Finally, creating a unique pricing structure in individual states could create state-specific conditions for coverage. We don't know yet how either insurers or manufacturers will react to state-by-state exceptions, but this has potential to cause either of these stakeholders to limit availability in the state and could cause confusion for patients and providers in the state.

Upper Payment Limits Don't Necessarily Translate to Patient Savings

Assuming that UPLs directly translate to lowered costs for patients ignores the complicated nature of our healthcare system. In our system, patients are not responsible for paying the full cost of their prescription medications nor are they allowed to freely select from the full range of treatments medically approved for their condition. Instead, these decisions are determined by their insurance company and pharmacy benefit manager (PBM). It is also these stakeholders that determine if cost-savings realized by the payer are subsequently shared with patients. Unfortunately, in most cases, they are not.

Payers in our health system do not necessarily derive the most value from the lowest cost drugs. According to reporting on PBMs by the New York Times, "Even when an inexpensive generic version of a drug is available, PBMs sometimes have a financial reason to push patients to take a brand-name product that will cost them much more. For example, Express Scripts typically urges employers to cover brand-name versions of several hepatitis C drugs and not the cheaper generic versions. The higher the original sticker price, the larger the discounts the PBMs can finagle, the fatter their profits — even if the ultimate discounted price of the brand-name drug remains higher than the cost of the generic."

Ultimately, this could mean insurers and PBMs place drugs subject to UPLs on higher tiers of the formulary. This could ultimately lead to higher OOP costs for patients who could face higher copay or coinsurance rates to retain access to that drug or alternatively be forced to switch to a more expensive drug that results in higher profits to their PBM. This is also supported by the concern raised by CMS above.

Additionally, non-medical switches in medication can cause unnecessary complications for patients. At a minimum, a switch should require more doctor visits to monitor the efficacy of a new medication. Further, if the switch results in side effects or worsened outcomes, patients could face medical interventions or hospitalization and the additional costs borne out by both.

Patient Access Cannot Be Compromised

Once diagnosed with a chronic condition, patients and their physicians start an often life-long journey to identify the correct treatments to successfully manage their symptoms and improve their health. Many chronic disease patients will ultimately rely on multiple medications to their condition. Some will face multiple chronic conditions or even need additional medications to treat the side effects of either their condition or the medication that keeps their condition manageable.

For these reasons, patients with chronic conditions often rely on a complicated and personalized course of treatment that is not easily altered. Substituting or requiring patients to change drugs based on cost considerations instead of medical needs can disrupt continuity of

care and result in complications and higher overall medical costs. These decisions are better left to patients and their physicians.

Identify and Resolve Patient-Reported Obstacles to Care

While our health system is complicated, one principle is simple: every change and policy we implement should ultimately benefit patients. We urge legislators to keep this principle as a singular focus as it evaluates health reform proposals and new legislation.

Although well-intentioned, UPLs fail to address many of the underlying causes and complicated factors that result in higher prescription drug costs for patients. Therefore, we urge legislators to focus their time on identifying and addressing *patient-reported obstacles* to drug affordability.

Failing to resolve the underlying factors that lead to higher costs for patients can result in short-term relief and uneven benefits – aiding some but potentially leaving others with higher costs and drug accessibility challenges.

PDABs Are Unproven and Expensive

Despite claims that they will lower patient costs, PDABs have so far produced no savings for patients, yet have cost the taxpayers across the nation millions of dollars in operational costs.

The Maryland PDAB, in its sixth year of operation, was projected in its authorizing legislation to cost $4 million and budget requests include another $1.28 million for 2026. The Oregon PDAB is projected to cost over $1 million per year. And the Colorado PDAB was projected to cost $800,000 for its first year, but already requested a supplement of $260,000.

Based on the experiences in each of these early states, it's safe to assume that PDAB operations alone will cost states around $1 million each year. There is no such guarantee that any savings will be realized for states or patients.

Conclusion

In closing, we hope you will forego an ineffective and expensive reform proposal and instead work with our coalition and others to pursue more productive patient-driven reforms. We appreciate an increased focus on issues that impact patient access to care and providing patients every opportunity to have a voice in matters involving our healthcare.

We look forward to working with you in the future on initiatives that can address the broader concerns of patients. Thank you for considering our input and do not hesitate to reach out to the EACH/PIC Coalition Legislative Lead Mark Hobraczk at mark@aiarthritis.org with any questions.

Sincerely,

Ensuring Access through Collaborative Health/Patient Inclusion Council (EACH/PIC Coalition)
AiArthritis

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Alliance for Aging Research
Autoimmune Association
Biomarker Collaborative
California Hepatitis C Task Force
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