EACH PIC COALITION

January 14th, 2025

Virginia House of Delegates
Labor and Commerce Committee
General Assembly Building
201 North 9th Street
Richmond, Virginia 23219

Dear Chair Ward, Vice-Chair Herring, and Members of the Labor and Commerce Committee:

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 the goal of lowering patient out-of-pocket costs so that they can more easily maintain their health.

We urge you to oppose legislation to empower a prescription drug affordability board (PDAB) in Virginia because we believe a PDAB is the wrong approach to effectively lower patient costs for prescription drugs and could ultimately cause more harm by creating added barriers between patients and their medically necessary treatment.

Existing PDABs Have Not Lowered Costs for Patients
EACH has been actively working with PDABs in multiple states and has seen firsthand the limitations of the PDAB model. Based on what we have seen, we believe that PDABs are ineffective in identifying and solving the actual problems patients with chronic conditions face when attempting to access their medications.

The PDAB model provides a board of unelected officials the authority to review prescription drug costs and set Upper Payment Limits (UPLs) for them. Contrary to the claims of PDAB supporters, UPLs do not directly lower patient out-of-pocket costs and will have little impact on overall patient costs. In reality, setting UPLs for drugs might endanger patient accessibility or limit appropriate reimbursement for the physicians who administer them.

Additionally, UPLs will 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. Insurers and PBMs could place drugs subject to UPLs on higher formulary tiers or implement other utilization management tactics to steer patients away from these drugs. This could lead to higher out-of-pocket 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 which results in higher profits for their PBM.

These plan-prompted changes are collectively known as non-medical switching. Non-medical medication switches can also cause unnecessary complications for patients. At a minimum, a switch in medication will 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.

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Focusing solely on the price of drugs ignores the many complicated factors that ultimately drive costs up for patients and oversimplifies a very complex process. Instead, we strongly urge the Commonwealth of Virginia to focus on patient-reported issues and address the causes of their affordability and access challenges - including prior authorization, alternative funding programs, and PBM reform.

Patient & Caregiver Testimonies (Patient Inclusion Council)[1]

Direct input from patients also bears out that alternative reforms would be more advantageous for patients and address their reported concerns related to affording and accessing their prescription medications.

For example, patient testimonies provided to the PDAB in Colorado demonstrated how access and affordability issues commonly stem from the utilization management policies of insurers. In fact, many patients with chronic diseases pay little to nothing for biologics due to charitable or manufacturer assistance programs.

We have found similar testimonies from residents of Virginia (two examples provided below), who either did not report struggling with drug affordability because manufacturer assistance programs are available to them or those who did cite costs as a barrier report being subject to high coinsurance or other insurer policies that inhibit access.

We agree that a focus on addressing healthcare barriers to patient access and affordability is necessary, but choosing to establish a high-cost program, with no demonstrated positive outcomes for patients, is not the best use of time and resources.

> ***Stephanie, VA resident.*** *I have been on biologic infusions for 24 years. Through a variety of insurance plans I have paid different amounts, however, because of manufacturer assistance programs, most of the time it is zero. Even for a brief time when I had a high deductible plan I used the manufacturer patient assistance program so I paid nothing other than $100 for my first infusion of the year then met my out of pocket max and the entire rest of the year everything was free.*
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> *Prior to starting this biologic, I was 22 and recommended for full disability. This drug keeps me working, parenting, and living a mostly normal life! If access was pulled, especially given it's completely affordable to me, I would be devastated.*
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> *After learning a bit more about the new government appointed boards that could be established to review certain high cost drugs, I would be alright with this if the board consisted of doctors (who understand our diseases), researchers, and patients. If politicians or those supporting the insurance companies were part of the decision makers, no way.*
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> ***Bree, mother of Tenley, VA residents****. Tenley is living with Juvenile Idiopathic Arthritis (JIA) with Uveitis (inflammatory eye disease, a result of JIA). She is 11 and has been on*

[1] Testimonies provided have not been edited.

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Humira for 3 years now. Both the Uveitis and JIA have been under control for almost 2 years now, thanks to this medication.

We got a new insurance plan in 2024, but with the same carrier. I started calling to get the ball rolling to fill her Humira on January 4th, 2024. It was not "approved" and sent to fill until January 21st. We then received the medication on the 23rd, almost 3 whole weeks when we already had the prescription and a Prior Authorization on file.

In the past with the manufacturer copay assistance plan, we only paid $5 out of pocket. Our new insurance plan charges us 30% out of pocket until the deductible is met (up to the max out of pocket) and has no copay plan included. So we had to pay initially $2,285.12 to fill January's prescription and the assistance card was credited $3,500 (so a total cost of $5,785). So after paying, we submitted our payment directly to the manufacturer of Humira, who reimbursed us everything but the $5. This model would be very problematic for families who cannot afford to spend this money and then, due to insurance protocols, ask the assistance program for a refund.

She is currently in an active flare and ended up being a few days late on her injection due to the delay in the refill. If we couldn't get this medication for her, I would worry that the ongoing joint damage would become permanent and cause damage that could lead to blindness in her eyes.

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 me at mark@aiarthritis.org with any questions.

Sincerely,

Mark Hobraczk
Director of Public Policy, AiArthritis
Legislative Lead, EACH/PIC Coalition
Person living with Ankylosing Spondylitis