



“We don’t represent the patient voice, we *are* the patient voice.”

February 7, 2024

Maryland Senate
Finance Committee
3 East
Miller Senate Office Building
Annapolis, Maryland 21401

Re: SB388

Dear Committee Chair Beidle, Vice Chair Klausmeier, and Committee Members:

The International Foundation for **Autoimmune & Autoinflammatory** Arthritis (**AiArthritis**), a patient organization led by people affected by **AiArthritis** diseases, has been actively engaged with the Maryland Prescription Drug Affordability Board (PDAB) and look forward to assisting as they explore the barriers patients with chronic disease face as they seek out treatments to maintain their health.

We have been impressed with the board’s methodical approach to undertaking the work with which they have been tasked and integrating patients and stakeholders throughout the process. However, given the outsize impact policies implemented by the board can have on patients, we urge the committee to vote against efforts to broaden the board’s oversight before the board has even completed their original undertaking.

AiArthritis has been actively involved in other states that have recently implemented local PDABs, including Colorado and Oregon, and have seen firsthand the limitations of the PDAB model in those states. Based on what we have seen, we believe that PDABs are an untested model and have so far been ineffective in identifying and solving the actual problems patients with chronic conditions are facing when attempting to access their medications. For example, in Colorado, testimonies from patients using Enbrel, Cosentyx, and Stelara repeatedly demonstrated access and affordability issues largely stem from the utilization management policies of insurers. In fact, many patients with chronic disease pay little to nothing for biologics due to manufacturer assistance programs.

Some of the risks that we have seen with the PDAB model in other states:

- 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.
- Reviewing only a handful of medications positions PDABs to create further inequities, picking winners and losers among patients and patient populations.
- Setting upper payment limits (UPLs) for drugs might endanger their accessibility in the state or limit appropriate reimbursement for the physicians that administer them. UPLs will not lower prescription drug costs for patients because they do not lower out of pocket costs.
- PDABs create another bureaucratic barrier and require chronic disease patients, who are often already overtaxed trying to maintain their own health and manage their care, to monitor additional government bodies and advocate to protect their healthcare.



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Patients with complex and chronic conditions often spend years identifying treatments that work for them. Additionally, treatments can also work for years but then become less effective, forcing patients to change therapies. There is no “one size fits all” health solution; therefore, it is critical that health policies do not impede access to treatments or lead to fewer options for patients.

Proposals that come out of PDABs often target the most innovative medicines, disproportionately impacting patients with diseases where there is high unmet need and where low-cost treatment options are not available (e.g. rare diseases), running counter to the aims of personalized medicine and availability of new treatments.

To employ a healthcare analogy, some PDABs are seeking to address a symptom rather than the underlying condition. We are working with the Maryland PDAB to mitigate some of the shortfalls we have seen in other states. At the same time, we also urge you as legislators to pursue other reforms that would be more beneficial for patients including:

- Focus on the existing and pressing affordability and access issues that most impact patients, many of which originate from payers (insurance companies and pharmacy benefit managers (PBMs)).
- Address the broader healthcare industry when considering reforms and identify long-term solutions rather than short-term relief for a limited few.
- Ensure transparency and accountability to patients and citizens by keeping policymaking in the hands of legislators that are accountable to voters, not unelected boards.

In closing, we appreciate the committee’s focus on issues that impact patient access to care and every opportunity given to patients that enables us to have a voice in the matters involving our healthcare. We hope you will give due consideration to the shortfalls that we have identified with the PDAB model and instead work to address the broader concerns of patients. Thank you for considering our input and do not hesitate to reach out to me at tiffany@aiarthritis.org with any questions.

Sincerely,

Tiffany Westrich-Robertson
Chief Executive Officer
Person living with non-radiographic axial spondyloarthritis
International Foundation for **Autoimmune & Autoinflammatory** Arthritis