724 Columbia St. NW, Ste. 310 • Olympia, WA 98501 • PHRMA.ORG

March 6, 2025

Oregon Prescription Drug Affordability Board
350 Winter Street NE Salem,
OR 97309-0405
pdab@dcbs.oregon.gov

Re: Oregon Prescription Drug Affordability Board: February 19, 2025 Agenda and Meeting Materials

Dear Members of the Oregon Prescription Drug Affordability Board:

The Pharmaceutical Research and Manufacturers of America ("PhRMA") is writing in response to the Oregon Prescription Drug Affordability Board's (the "PDAB's" or "Board's") meeting materials for its February 19, 2025 meeting, with particular focus on the Board's draft requests for information from individuals with scientific or medical training; manufacturers; patients, caregivers, advocacy groups, and the general public; pharmacy benefit managers ("PBMs"); and safety net providers (collectively, the "Draft Requests for Information" or "Draft RFIs").[1] PhRMA represents the country's leading innovative biopharmaceutical research companies, which are laser focused on developing innovative medicines that transform lives and create a healthier world. Together, we are fighting for solutions to ensure patients can access and afford medicines that prevent, treat and cure disease.

We provide below our comments and concerns with respect to the Draft RFIs. PhRMA is concerned that the RFIs appear to ignore the Board's affirmative statutory duty to protect stakeholder-provided confidential, proprietary, or trade secret information from public disclosure.[2] Additionally, PhRMA is concerned by the inconsistencies across the Draft RFIs and that the Board has not provided clear standards or a transparent process explaining how responses will be considered and used as part of the affordability review process. PhRMA also highlights several specific concerns with respect to the Draft RFIs for Manufacturers and PBMs.

I. Lack of Protections for Confidential Information

The Draft RFIs ask manufacturers and other stakeholders to provide highly confidential, trade secret information for the Board's consideration.[3] However, the Draft RFIs also state that "[a]nswers [to RFIs] are not

[1] Meeting Materials (Feb. 19, 2025), *available at* https://dfr.oregon.gov/pdab/Documents/20250219-PDAB-document-package.pdf. In filing this comment letter, PhRMA reserves all rights to legal arguments with respect to Oregon Senate Bill 844 (2021), as amended by Oregon Senate Bill 192 (2023) (collectively, the "PDAB Statute"), and the Board's implementation of the PDAB Statute. PhRMA also incorporates by reference all prior comment letters to the extent applicable.

[2] *See* PDAB Statute § 646A.694(7)(b).

[3] *See, e.g.*, Meeting Materials at 47 (Draft Request for information: manufacturers per OAR-925-200-0020, #11 and #12) ("Estimated manufacturer net sales or estimated net-cost amounts (including rebates, discounts and price concessions for the prescription drug sold in Oregon in 2023. (OAR-925-200- 0020 2.l)" and "[e]stimated average monetary price concessions (including rebates or discounts) manufacturer provided to health insurance plans in Oregon or is expected to provide to plans in 2023 ... (OAR-925-200-0020 1.d)"); Meeting Materials at 54 (Draft Request for information: safety net providers per OAR-925-200-0020, #11) ("Financial impact to your covered entity from this drug/NDC (savings/revenue)").

confidential and … will be included in the board materials prepared for the affordability review and posted on the website."[4]

PhRMA reminds the Board of its obligation under the PDAB Statute as well as state and federal law to safeguard confidential information from public disclosure.[5] The Draft RFIs, by stating that the Board intends to publish all information submitted in response, appear to be inconsistent with that obligation. If the Board maintains these statements in the finalized versions of its Draft RFIs, it may severely limit the amount of information that stakeholders provide to the Board in response and therefore arbitrarily limit the information available for the Board's consideration. **Consistent with the PDAB Statute, the Board must establish a process to evaluate all information submitted by stakeholders and redact confidential, trade secret, or proprietary information before any such information may be publicly disclosed. In order to support this process, the Draft RFIs should be revised to include a mechanism for stakeholders to designate certain information as confidential.**[6]

PhRMA also notes that publicly posting some of the information provided as part of the Draft RFIs may chill stakeholder participation. For example, the Draft RFI for patients, caregivers, advocacy groups, and the general public asks patients to provide their name, disease state, income range, and insurance status.[7] The Board's indication that it will post this sensitive personal information to its public website may cause a patient or caregiver to decline to participate entirely. **PhRMA requests that the Board revise the draft form for patients and caregivers (and other members of the public) to state that patient names and contact information will not be made public, and that the information provided will be anonymized so that no identifiable patient information is publicly disclosed.**

II. Need for Clear and Consistent Standards

PhRMA remains concerned that the Board has yet to adopt clear and consistent standards governing certain elements of its affordability review process, particularly with respect to the information described in the Draft RFIs. For instance, the Board has not explained how the information provided by stakeholders through the Draft RFIs will be evaluated and used by the Board as part of the broader affordability review process; has not

[4] *See,* Meeting Materials at 45 (Request for information: individuals with scientific or medical training per OAR-925-200-0020), 47 (Request for information: manufacturers per OAR-925-200-0020), 50 (Request for information: patients, caregivers advocacy groups, and general public per OAR-925-200-0020), 52 (Request for information: Pharmacy benefit managers (PBMs) per OAR-925200-0020), 54 (Request for information: safety net providers per OAR-925-200-0020).

[5] PDAB Statute § 646A.694(7)(b) (The Board "*shall* keep strictly confidential any information collected, used or relied upon for the review ... if the information is: (b) [c]onfidential, proprietary or a trade secret []."(emphasis added)). In addition, the Fifth Amendment's prohibition against taking private property without just compensation similarly prohibits the uncompensated disclosure of trade secrets. Courts have made clear that "when disclosure [of pricing information] is compelled by the government," even the "failure to provide adequate protection to assure its confidentiality ... can amount to an unconstitutional 'taking' of property." St. Michael's Convalescent Hosp. v. California, 643 F.3d 1369, 1374 (9th Cir. 1981) (brackets and quotation marks omitted). As the U.S. District Court for the District of Oregon recently ruled, the "public disclosure" of manufacturers' trade secrets violates the Fifth Amendment "[u]nless just compensation is provided" at the time of disclosure. *PhRMA v. Stolfi*, --- F. Supp. 3d ----, 2024 WL 1177999 (D. Ore. Mar. 19, 2024), *appeal pending*, No. 24-1570 (9th Cir., filed Mar. 15, 2024). For further discussion, *see* Letter from PhRMA to Board 4 (June 28, 2024); Letter from PhRMA to Board 1-2 (Aug. 1, 2023).

[6] PhRMA emphasizes that the PDAB Statute imposes an independent obligation on the Board to safeguard *all* confidential, proprietary, or a trade secret information irrespective of whether stakeholders expressly designated the information as such. [7] Meeting Materials at 50-51 (Draft Request for information: patients, caregivers advocacy groups, and general public per OAR-925200-0020).

addressed how the Board will encourage broad stakeholder participation; and has included inconsistent details across the Draft RFI forms for different stakeholder groups. Below, PhRMA highlights a non-exhaustive list of concerns regarding unclear or inconsistent standards in the Draft RFIs.

a. How Collected Information Will Be Used and Evaluated

PhRMA reiterates its previous request that the Board provide concrete details for how it will evaluate and consider the information collected from RFIs in affordability reviews.[8] The information collection process described by the Draft RFIs will involve a diverse set of stakeholders providing voluminous information related to each drug under review. Nevertheless, the Board has not provided details on *how* it will evaluate the information it collects to determine if it is accurate, comparable, and reliable, nor has it established concrete standards for how such information will be considered as part of an affordability review.[9] **PhRMA asks the Board to establish processes and standards that detail how it will evaluate the information it receives and how it will consider such information in affordability reviews.**

b. Lack of Consistent Methodology

The Draft RFIs would request a range of information regarding therapeutic alternatives from multiple different stakeholder groups.[7] PhRMA reiterates its concerns regarding the lack of a specific methodology for how it intends to identify and consider therapeutic alternatives for a particular prescription drug.[8] **We ask that the Board adopt a concrete and consistent methodology for how it intends to identify and consider therapeutic alternatives, including how it will apply greater scrutiny when considering an alternative that is not therapeutically equivalent, as well as in situations where there are special circumstances bearing on whether it is appropriate to use given therapeutic alternatives.[9]**

c. Information of Unclear Relevance to Affordability Reviews

Some of the items in the Drad RFIs request a broad set of informaeon that does not appear to be reasonably relevant to the affordability of the drug under review. For example, the Drad RFIs appear to ask manufacturers to provide the *total* financial assistance provided to various eneees, including pharmacies, providers, consumers, and other eneees, seemingly across their enere drug porholio.[10] The PDAB Statute lists criteria

[7] Meeting Materials at 47, 49 (Draft Request for information: manufacturers per OAR-925-200-0020, #9) ("List any therapeutic alternatives for this drug"); Meeting Materials at 45 (Draft Request for information: individuals with scientific or medical training per OAR-925-200-0020, #6) ("Are there therapeutic alternatives for this drug? (OAR925-200-0020 2.k.B.ii)"); Meeting Materials at 50 (Board, Draft Request for information: patients, caregivers advocacy groups, and general public per OAR-925-200-0020, #5) ("Are there therapeutic alternatives (for example, a different therapeutic agent) for this drug? [citing Board definition of Therapeutic Alternative]").

[8] *See, e.g.*, Letter from PhRMA to Board 2-3 (Oct. 15, 2023).

[9] *Id.* ("e.g., if a drug is used for immunocompromised patients, pediatric patients, the elderly, or individuals who require multiple medications for acute and chronic illnesses"). *Feitelson v. City of Salem*, 46 Or. App. 815, 822 (1980) ("If there is to be any meaningful judicial review, an agency must demonstrate that it has considered the factors prescribed by statute and its own regulations and has not acted in an arbitrary manner or on an ad hoc basis").

[10] Meeting Materials at 48 (Draft Request for information: manufacturers per OAR-925-200-0020, #17-#20). [14] *See* PDAB Statute § 646A.694(1)(a)-(m).

that the Board may consider in an affordability review, all focused on the parecular prescripeon drug under review.[14] Rather than asking for informaeon consistent with those criteria, it appears that the Board is asking for addieonal informaeon on stakeholder praceces that may not have any direct bearing or relevance with respect to the affordability of a parecular drug. **PhRMA urges the Board to narrow these overly broad requests to informaRon reasonably relevant to performing the affordability review of the drug under review, as described in the PDAB Statute and the Board's regulaRons.[11]**

[8] *See* Letter from PhRMA to Board 3 (June 28, 2024).

[9] PhRMA reiterates that the vagueness of the standards adopted to date raises concerns regarding the accuracy of the Board's affordability review decisions and whether (even if UPLs are authorized by the legislature), the Oregon Administrative Procedure Act ("APA") would permit the imposition of UPLs based on such standardless evaluations. The Oregon APA requires agencies to render decisions in a manner that is "rational, principled, and fair, rather than ad hoc and arbitrary." *Gordon v. Bd. of Parole & Post Prison Supervision*, 343 Or. 618, 633 (2007). As such, courts have long held that agencies like the Board must "make policies for even application" across regulated entities and products, which is directly contrary to the use of undefined and unascertainable standards in the affordability review process. *Sun Ray Drive-In Dairy, Inc.*, 16 Or. App. 63, at 72 (1973).

d. Unclear Timelines

The Board has not provided any information on the timelines (1) for the Board to make stakeholders aware of future Requests for Information, (2) for stakeholders to submit their responses to those Requests for Information, or (3) for the Board to compile and review completed responses. **PhRMA asks that the Board specify timelines for requesting, responding to, and considering information through Requests for Information. To allow stakeholders adequate time to provide the detailed information requested, PhRMA also requests that the Board allow stakeholders at least 60 days to respond to any Request for Information.**

e. Proactive Outreach to Stakeholders

The Board has also not detailed how it will encourage broad stakeholder participation in the Request for Information process, particularly from patients, caregivers, and patient advocates. As PhRMA has previously explained, the Board is required to establish a process to conduct outreach to patients and caregivers to provide them an adequate opportunity to share their experiences with each prescription drug under review.[12] PhRMA is concerned that the Board has yet to establish this process, including a mechanism to gather "a diversity of experience among patients from different socioeconomic backgrounds."[17] **Before the Board finalizes the Draft RFIs, it must implement a patient, caregiver, and patient advocate outreach process , as required by Board's regulations.**[13]

III. Draft Manufacturer Request for Information

a. Questions on Therapeutic Alternatives

[11] *See id.*; OAR 925-200-0020(1).

[12] PDAB Statute § 646A.694(3). *See* Letter from PhRMA to Board 3 (Feb. 17, 2024). [17] OAR 925-200-0020(2)(k)(A).

[13] *See id.*

PhRMA is concerned by the sections in the draft manufacturer RFI that request information on therapeutic alternatives. Questions 14 and 15 ask for manufacturers to provide the estimated "manufacturer net sales or estimated net-cost amounts" and "manufacturer net sales or estimated net-cost amounts" for therapeutic alternatives.[14] Manufacturers may not have access to this type of information about other manufacturers' products, including the pricing- and sales-related information for drugs considered by the Board to be therapeutic alternatives. **PhRMA asks the Board to revise the RFI to remove the request for sales or cost data for other manufacturers' products.**

b. Distinguishing Between Price Concessions to Plans and PBMs

In queseons 12 and 13 of the drad manufacturer RFI, the Board asks manufacturers to provide the "[e]semated average monetary price concessions ... provided to health insurance plans in Oregon" and the "[e]semated average monetary price concessions to PBMs registered in Oregon."[20] As PhRMA has explained

in prior comments, this disenceon incorrectly characterizes how rebates and other price concessions flow across the supply chain, risking erroneous reporeng and misleading data.[21] PBMs contract with pharmaceuecal manufacturers to negoeate rebates on behalf of the PBMs' health plan clients. Manufacturers generally pay rebates directly to PBMs, which then pass them on, in whole or in part, to health plans or employers according to the terms of the client's agreement with the PBM.[22] **PhRMA requests that the Board revise the RFI to clarify which price concessions it considers to be provided "to PBMs" and how it intends to disRnguish between those price concessions and others provided by manufacturers in the affordability review process.[15]**

IV. Draft PBM Request for Information

PhRMA is concerned that the draft PBM RFI does not include responses that would show how patients are ultimately impacted by PBM and health plan practices.[16] These practices, which directly drive patient out-ofpocket costs, include benefit design choices (e.g., cost-sharing requirements such as coinsurance and deductibles, alternative funding programs (AFPs), and copay accumulator adjustment and maximizer programs) and fees, rebates, and other price concessions paid by drug manufacturers to PBMs and plans that are not shared directly with patients at the point of sale.[17]

[14] Meeting Materials at 48 (Draft Request for information: manufacturers per OAR-925-200-0020, #14 and #15). [20] Meeting Materials at 47-48.

[15] PDAB Statute § 646A.694(7)(b).

[16] For example, asking for "estimated total amount of price concessions, discounts or rebates PBM received from manufacturers and labelers in 2023 for the prescription drug under review, expressed as a percentage of the prices" will not provide any insight into whether these price concessions, discounts, and rebates are ultimately passed on to patients. Meeting Materials at 52-53 (Board, Draft Request for information: Pharmacy benefit managers (PBMs) per OAR-925-200-0020, #8).

[17] *See* Letter from PhRMA to Board 2 (Apr. 13, 2024). As stated previously, accumulator adjustment programs ("AAPs") block manufacturer cost-sharing assistance from counting towards cost-sharing requirements, including deductibles and maximum outof-pocket limits. Maximizers involve inflating patients' cost-sharing to fully deplete available cost-sharing assistance before insurance coverage kicks in. AAPs utilize third-party vendors, sometimes in partnership with smaller PBMs, to convince employers to drop coverage of some or all specialty medicines, and assist patients in getting access to those medicines through patient assistance programs intended for uninsured or underinsured patients instead. AAPs are a type of cherry-picking strategy to avoid individuals with higher health risks, such as individuals with pre-existing conditions. Letter from PhRMA to Board 8 (Sep. 15, 2024). [26] *See, e.g.,* Letter from PhRMA to Board 5 (Nov. 1, 2024). "There is growing public interest in assessing the role, value of, and significant power

PhRMA has discussed these issues at length in previous letters, and concerns with PBM practices have similarly been raised by the Oregon Secretary of State.[26] **PhRMA encourages the Board to revise the draft PBM RFI to gather information on how PBMs and health plans are affecting drug affordability for Oregon patients. Consistent with the Board's policy recommendations to the legislature in December 2024,[18] PhRMA reiterates its request that the Board ask whether a PBM (or its affiliated plans) restricts third party payments from applying toward patient out-of-pocket requirements (e.g., deductible or cost-sharing obligations).[28]**

Additionally, the Board should revise the draft PBM RFI to request the dollar amount of price concessions, discounts, and rebates the PBM received from manufacturers and retained, rather than passed on to health plans or patients for each drug under review. The Oregon Drug Price Transparency Program already collects this information on an aggregate basis, but requesting this information through its PBM RFIs would provide the Board with a more direct understanding of how these practices may impact the affordability of a particular prescription drug.[19]

* * *

On behalf of PhRMA and our member companies, thank you for consideraeon of our comments. Although PhRMA has concerns about the Drad RFIs, we stand ready to be a construceve partner in this dialogue. Please contact dmcgrew@phrma.org with any queseons.

Sincerely,

Dharia McGrew, PhD
Director, State Policy

Merlin Brittenham
Assistant General Counsel, Law

21 *See* Letter from PhRMA to Board 3 (Jan. 11, 2025) (commenting on this distinction in the Draft Carrier Data Cell Template).

22 PhRMA, *Follow the Dollar: Understanding How the Pharmaceutical Distribution and Payment System Shapes the Prices of Brand Medicines*, *available at* https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/D-F/Follow-the-DollarReport.pdf.

and influence held by third-party organizations known as pharmacy benefit managers." Oregon Health Authority, *Pharmacy Benefit Managers: Poor Accountability and Transparency Harm Medicaid Patients and Independent Pharmacies* (Aug. 2023).

18 Policy recommendation #5 suggesting that PBMs and insurers should report to the state on their usage of copay accumulators and maximizers. https://dfr.oregon.gov/pdab/Documents/reports/2024-PDAB-Annual-Report.pdf 28 *See* Letter from PhRMA to Board 4 (Aug. 1, 2023).

19 Oregon Division of Financial Regulation Prescription Drug Price Transparency, Pharmacy benefit managers 2024 data, *available at* https://dfr.oregon.gov/drugtransparency/Pages/DPT-pbm-data-2024.aspx.

Sacramento, CA

Washington, DC

State legislatures want to chalk up the passage of prescription drug affordability boards (PDABs) as a victory for patients and a political win to address the cry of high drug prices. However, years after many of these boards were established, we're getting a clearer picture of what these boards are failing to accomplish.

PDABs have wasted millions in taxpayer dollars and threatened access to crucial treatments and the stability of the supply chain — all while delivering zero savings to patients, disincentivizing biomedical innovation, and potentially harming healthy aging. For the sake of patients and taxpayers, state legislators must look elsewhere for solutions that address affordability issues.

Numerous states have established a PDAB, and several more are actively considering, or will consider, bills that establish these boards or expand their authority during 2025 legislative sessions. Years after some of these boards were established, we better understand their costly implementation process, which does not include meaningful public input and is ineffective in reducing patient costs.

Four states are prime examples of the cost of standing up and managing these boards. In Colorado, the PDAB cost taxpayers $700,000 in its first year, totaling $2 million in taxpayer costs to date. The Maryland PDAB has spent more than $3 million since 2019, with substantial continuing expenses — a previous job posting for the board's executive director listed an annual salary range reaching more than $151,000. Legislation to establish a PDAB in New Jersey appropriated $1.5 million for board expenses, while the Oregon PDAB was appropriated $1.7 million. Collectively, state PDABs have generated zero dollars in patient savings.

The primary tool at PDABs' disposal is upper payment limits (UPLs), which cap reimbursement rates for specific drugs for pharmacists and clinicians.

Unfortunately, pharmacists and the trade associations representing them continue to tell PDABs that reduced reimbursement rates will affect whether they can carry a drug with a UPL, raising the alarm that the reduction in reimbursement will affect their financial stability and patient access to care, particularly in small communities with limited

healthcare resources. Nearly half of healthcare stakeholders in Oregon expressed concerns that UPLs would adversely affect their organizations financially. A survey found that five out of six healthcare payers do not expect patients to directly benefit from UPL-related savings.

Patients, advocates, providers and other stakeholders have voiced concerns about the effects PDABs and UPLs could have on patient access to affordable prescription medications. Many patients feel excluded from board processes due to a lack of representation and limited opportunities for input. Despite this, PDAB members and staff have spent little time investigating these concerns — lending credence to the idea that these boards are not intended to increase access for patients but to check a popular political box.

The implications of establishing PDABs extend beyond direct costs to taxpayers and a lack of patient savings. UPLs often interfere with existing rebates or drug discount programs, leaving patients and their providers with marked-up drug prices. Many of these safety-net programs find value in the margin between reimbursement rates and the cost of medicine after rebates. If a PBAB sets a UPL that limits the amount that can be reimbursed for the purchase of a drug, safety-net providers may only break even or lose money — limiting these programs from supporting patients who rely on them for care. UPLs are a misguided and blunt instrument that will cause systemic harm to the healthcare safety net that serves vulnerable people.

In addition to the millions spent on these boards, taxpayers will almost certainly be asked to backfill the funding losses caused by the financial harms of UPLs. This “solution” will cost more than the problem it fails to solve. These measures threaten healthy aging as patients who rely on these medicines to treat chronic conditions throughout their lives will be worse off than they are now.

PDABs are a failed experiment that does not deserve the attention of state legislatures. Our aging population increasingly faces chronic conditions that require consistent and reliable access to medications. PDABs threaten the availability of these essential treatments by destabilizing pharmacies’ financial viability and discouraging the development of new drugs. Ensuring patients can access their prescribed medications without interruption is critical for their health and well-being.

Rather than implementing or expanding PDABs, lawmakers must, instead, pursue strategies that save people money when they pay for their prescriptions at the pharmacy counter. Banning copay accumulator adjustment programs and increasing regulations around pharmacy benefit managers would represent meaningful progress toward ensuring patients receive the financial relief they deserve. A first step would be for state lawmakers to listen to the patients, caregivers, advocates and other stakeholders telling them that PDABs are not the solution to any of the problems facing our healthcare system.

Received on 3/11/2025 from Peter Pitts, Center for Medicine in the Public Interest

OCAP OREGON COALITION FOR AFFORDABLE PRESCRIPTIONS

March 14, 2025

Oregon Prescription Drug Affordability Board
350 Winter Street NE
Salem, OR 97309-0405
pdab@dcbs.oregon.gov

Dear Chair Bailey, Vice Chair Burns, and PDAB Board Members,

We are the Oregon Coalition for Affordable Prescriptions (OCAP), a diverse group of health care providers, labor organizations, community advocates, and everyday Oregonians who believe prescription drugs should be affordable and accessible. Since 2017, we have worked to rein in skyrocketing drug prices and hold the unregulated pharmaceutical industry accountable for exploiting Oregon seniors, individuals with chronic conditions, and their families. Our mission is to amplify the voices of those impacted by out-of-control drug pricing and to support policies that promote transparency, accountability, and lower prescription costs.

Thank you for your service on the Prescription Drug Affordability Board. Your role is critical in ensuring that Oregonians are no longer burdened by excessive and unsustainable medication prices.

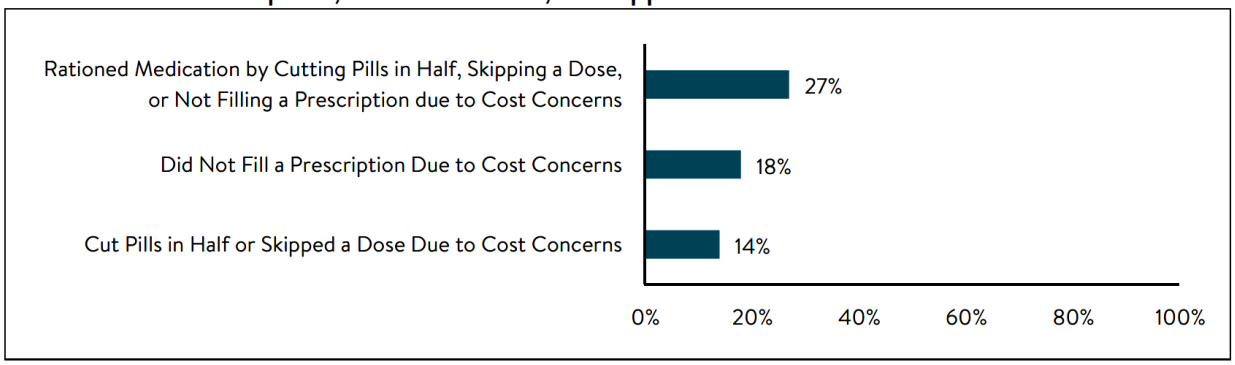
The Oregon PDAB was created with a clear mission: *to protect Oregonians and the state's health care system from the high costs of prescription drugs*.[1] We urge you to fulfill that mission by taking bold, decisive action to finalize the necessary processes for affordability reviews—including requests for information, carrier data call templates, data sets, and criteria for affordability review selection.

Oregonians cannot afford further delays. Every day without action means more patients forced to choose between life-saving medications and other basic necessities. A recent Altarum survey of more than 1,400 Oregon adults found that *27% had to ration their medication in the last year*—cutting pills, skipping doses, or not filling prescriptions due to cost.[2] That is *27 percent too many.*

[1] Oregon Legislative Assembly. ORS 646A.693 – Prescription Drug Affordability Board; membership and qualifications of members; terms of office; duties; conflicts of interest; rules.
[2] 2024 Poll of Oregon Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

OCAP OREGON COALITION FOR AFFORDABLE PRESCRIPTIONS

Figure 2
Did Not Fill a Prescription, Cut Pills in Half, or Skipped a Dose Due to Concerns About Cost



2024 Poll of Oregon Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

Industry groups benefiting from high drug prices and those they fund are attempting to slow your processes. We urge you to consider the source and resist efforts to maintain the status quo. The vast majority of Oregonians—across political and economic lines—support measures to cap prescription drug costs.[3] They are counting on you to act.

You have both the authority and the responsibility to challenge excessive drug pricing. This is your opportunity to deliver real relief to Oregon patients, especially the most vulnerable in our communities. **We urge you to move forward now—without hesitation.**

Thank you for the opportunity to provide feedback, and please know as you move forward, OCAP will always be here as a resource and eager to work in partnership to tackle this critical issue. You can contact us at info@affordablerxnow.org or through BethAnne Darby at Strategies 360 or Charlie Fisher at OSPIRG. Together, our work can build a better and healthier Oregon for all!

Sincerely,

The Oregon Coalition for Affordable Prescriptions Board

John Mullin, Board Chair (Seanduine, and health and human service advocate)
Richard Blackwell, Board Treasurer (Pacific Source)
Emerson Hamlin, Board Secretary (Oregon Nurses Association)
Inga Deckert, (Kaiser Permanente)
Marcus Mundy, (Coalition of Communities of Color)
Odalis Aguilar, (AFSCME Council 75)
Christi Marcotte, (Oregon Health Care Provider)

[3] 2024 Poll of Oregon Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

National
Multiple Sclerosis
Society

March 19, 2025

Oregon Division of Financial Regulation
Oregon Prescription Drug Affordability Board
350 Winter St. SE
Salem, OR 97309

RE: National Multiple Sclerosis Society Comments Affordability Review Criteria and Review RFI

Members of the Oregon Prescription Drug Affordability Board:

Thank you for the opportunity to submit comments on the Oregon Prescription Drug Affordability Board. The National Multiple Sclerosis Society (Society) is pleased that the State of Oregon and the Prescription Drug Affordability Board (Board) are seeking public comments and input throughout each step in this process. The Society has been actively involved in the creation and implementation of Prescription Drug Affordability Boards nationwide, as we believe they provide important information regarding the high cost of prescription medications. The Board and the Society share a common goal in ensuring affordable access to medications for all Oregon residents.

Background
Multiple sclerosis (MS) is an unpredictable disease of the central nervous system. Currently there is no cure. Symptoms vary from person to person and may include disabling fatigue, mobility challenges, cognitive changes, and vision issues. An estimated 1 million people live with MS in the United States. While there is not yet a cure, we do know that early diagnosis and treatment are critical to minimizing disability. Significant progress is being made to achieve a world free of MS.

Costs of Living with MS
People with MS have a variety of healthcare needs including but not limited to addressing neurological symptoms, emotional and psychological issues, rehabilitation therapies to improve and maintain function and independence, and long-term care. These needs vary dramatically from person to person and can change year on year as the disease progresses. Prescription medications, known as disease-modifying therapies (DMTs), are central to most treatment regimes.

MS is a highly expensive disease, with the average total cost of living with MS calculated at $88,487 per year[1]. MS may impact one's ability to work and can generate steep out-of-pocket costs related to medical care, rehabilitation, home & auto modifications, and more. For individuals with MS, medical costs are an average of $65,612 more than for individuals who do not live with this disease. Disease-modifying treatments are the single largest component of these medical costs. As of July 2024, the median annual brand price of MS DMTs is more than $107,000. Five out of seven of the

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9109149/

National
Multiple Sclerosis
Society

DMTs that have been on the market for at least 13 years are priced over $100,000 annually and continue to see regular price increases.

Affordability Review Criteria
The Society again restates that when undertaking an affordability review, in addition to the requirements in Oregon Administrative Code § 925-200-0010, the Board also consider additional factors which could influence affordability including:

- Average monetary price concessions, discounts, or rebates the manufacturers provide to health plans and PBMs (expressed as a percentage of WAC),
- Average cost to state health plans based on typical patient access to a drug,
- Impacts on patient access resulting from the cost of the drug and insurance benefit design,
- Average ACTUAL patient out-of-pocket costs, copays, and/or any other cost-sharing amounts.

The current Board discussion around the stakeholder RFI outreach will provide answers and data to some of the above points and the Society anticipates reviewing all such data when made publicly available.

The Society knows that the price of the medication is but one aspect of what makes access to these high-cost prescriptions out of reach for many people with MS and other conditions. The Society will continue to look at the entire healthcare system and encourages legislatures and entities like the Oregon Prescription Drug Affordability Board to do likewise.

Affordability Review RFI forms, additional comments: Patients, Caregivers, Advocacy Groups
The Society recognizes and appreciates the board's continued solicitation of expertise, experience, and input from affected stakeholders. The Society thanks the Board for the opportunity to make initial comments on the RFI form during the February meeting. The Society would like to offer additional comments based on the edits to the patients, caregivers, or advocacy groups RFI form.

- Question 1 identifying which entity is responding offers clarity, however, the Society again highlights that patients and caregivers are far different entities from patient advocacy groups and separate, targeted forms for patients/caregivers and advocacy groups would likely provide better insight and stronger data.
- The terminology employed continues to read as directed towards a medical provider to answer with continued and numerous references to "patient", clarifications may be needed or warranted depending on intended respondent.
- Question 10 could be answered both subjectively and clinically, clarification may be needed to parse out actionable data.
- Page 6 of the PDAB Agenda Packet.pdf is corrupted obscuring the statutory reference, the disclaimer, and questions 1-3. We assume they are similar to the other forms but ask for clarification moving forward.
- Question 13 patient assistance figures asked for could be widely interpreted or speculated, rendering any such data collected of limited use.

National
Multiple Sclerosis
Society

- Questions 17 and 18 collect qualitative data. What is the boards intended use for such data and how will such qualitative statements be utilized for and impact reviews?
- Questions 19-22 relate to demographic data and must be optional, be kept strictly confidential and, have a clear, stated need and purpose for the collection and retention.
- Improvements in that overall, the form reads more patient friendly with limited industry jargon employed.
- Again, the Society recommends that a separate form be created for patients/caregivers and the patient advocacy community.

The Society would appreciate any opportunities to hear more about outreach plans, intended audiences, timeframes, and other ways the Board hopes to distribute, collect, and utilize the data from this RFI and subsequent processes.

Board Accessibility and Public Comment
The Society appreciates the efforts in public transparency and accountability that the Oregon Board has demonstrated since its establishment. The Board has made their meetings accessible to all Oregonians via online broadcasts and shared materials, as well as by providing multiple forms and points of outreach to interested and concerned stakeholders.

The Society would like to thank the board for the release of the agenda materials a full week prior to the March 2025 meeting. We will however continue to ask for the agenda packet and other materials to be posted as early as possible, preferably two weeks prior to any Board meeting, to allow for full consideration and review both the public and other interested parties. This could increase stakeholder engagement, active participation, and greater understanding of the process.

The National Multiple Sclerosis Society again thanks the Board for the opportunity to provide comments on the drug selection review criteria and draft stakeholder review RFI. The Society welcomes the opportunity to work with the Board on the implementation of their legislative charge to improve affordability and access to prescription medications for all Oregonians. Should you have any questions, please contact Seth Greiner, Senior Manager of Advocacy, at seth.greiner@nmss.org.

Sincerely,

Seth Greiner
Senior Manager, Advocacy

Oregon Prescription Drug Affordability Board
350 Winter Street NE, Salem, OR 97309-0405
pdab@dcbs.oregon.gov

March 12, 2025

Dear Members of the Oregon Prescription Drug Affordability Board,

On behalf of HealthHIV, we appreciate the Board's thoughtful approach to affordability reviews and its February discussions on balancing cost containment with maintaining access to critical medications—including HIV treatments.

A strong affordability framework must focus on patient-centered relief, prioritizing high-cost drugs that impose significant out-of-pocket burdens. Addressing real-world affordability challenges—such as cost-sharing barriers, prior authorization hurdles, and formulary exclusions—ensures that affordability measures reflect the realities patients face.

The Board's consideration of public input on HIV medications underscores its broader commitment to balancing cost evaluation with access preservation. Excluding HIV medications remains a crucial safeguard for safety-net programs such as ADAPs, 340B reinvestments, and Medicaid rebates, which are integral to sustaining HIV care. Maintaining transparency around these exclusions will help ensure policy stability for providers and patients.

When reviewing drugs with therapeutic alternatives, it is essential to account for clinical differences, side effect profiles, and adherence challenges to prevent substitutions that could compromise care. These real-world concerns, frequently raised by patient organizations and the public, highlight the need for a nuanced approach that prioritizes treatment continuity and patient well-being.

Additionally, expanding access to structured, Oregon-specific data will allow patients, providers, and community advocates to engage meaningfully in the affordability review process. Engaging safety-net providers, public health experts, and affected communities before final affordability determinations will help prevent disruptions in care access.

We *commend (and thank)* the Board's commitment to balancing affordability with access and look forward to ongoing collaboration to ensure cost containment strategies strengthen Oregon's public health infrastructure.

Respectfully,

Scott D Bertani, MNM, PgMP

Director of Advocacy HealthHIV

COMMUNITY ACCESS NATIONAL NETWORK

Mailing Address:

Attn: Jen Laws
PO Box 3009
Slidell, LA 70459

Chief Executive Officer:

Jen Laws
Phone: (313) 333-8534
Fax: (646) 786-3825
Email: jen@tiicann.org

March 17, 2025

Oregon Prescription Drug Affordability Board
Department of Consumer and Business Services
350 Winter Street NE
Salem, OR 97309-0405

RE: Ongoing Affordability Review Development

Dear Honorable Members of the Oregon Prescription Drug Affordability Board,

The Community Access National Network (CANN) is a 501(c)(3) national nonprofit organization that focuses on public policy issues related to HIV/AIDS and viral hepatitis. CANN's mission is to define, promote, and improve access to healthcare services and support for people living with HIV/AIDS and/or viral hepatitis through advocacy, education, and networking.

Today, we write with commentary and support of the affordability review efforts.

Exclusion of ARVs and Vaccines is Prudent

We support the Board's affordability review approach of removing vaccines and HIV medications from review consideration. This move acknowledges the Board's understanding of CANN's concerns regarding continuous access and the dangers of needlessly exposing patients and entities to potential adverse effects of rate setting when evidence shows these medications do not pose affordability issues to patients.

Changes to RFI Drafts

We support the confidentiality update made to the RFI Draft for patients, caregivers, or advocacy groups. Explicitly stating that patient contact information will remain private and not public will make patients more amenable to participating in the survey, which will garner more meaningful responses in terms of both the number and quality of feedback.

We would also suggest not soliciting feedback for medications with utilization of less than 100 patients and removing those medications from the dashboard to support the need for patient confidentiality. The Colorado PDAB recognized this issue. Therein, Colorado decided not to consider drugs with very low utilization in soliciting comments via surveys because it could risk patient confidentiality.

We also applaud the inclusion of safety-net providers in the RFIs. Understanding how rate-setting mechanisms can affect and harm these entities is pertinent to any decision-making. We urge the Board to seek out a diversity of safety-net provider types for the survey responses. Hospitals, such as DSHs, do not operate in the same manner or serve the same populations as FQHCs, rural critical access hospitals, and community health centers.

We thank you for all your ongoing hard work to help patients. We appreciate and recognize your careful deliberations and efforts to seek meaningful data to make evidence-based decisions.

Respectfully submitted,

Ranier Simons
Director of State Policy, PDABs
Community Access National Network (CANN)

On behalf of
Jen Laws
President & CEO
Community Access National Network

March 17, 2025

Oregon Prescription Drug Affordability Board
c/o Department of Consumer and Business Services
350 Winter Street NE
Salem, OR 97309-0405

TO: Members of Oregon Prescription Drug Affordability Board

I am writing to share my concerns regarding the Oregon Prescription Drug Affordability Board's process for selecting medications and conducting affordability reviews. As a physician, my primary focus is the well-being of my patients, and I am deeply troubled that the current approach to affordability reviews may jeopardize access to essential medications.

As a board-certified pediatrician and rheumatologist, I have spent my career caring for children and young people with chronic or disabling conditions. Many of my patients, including those with juvenile idiopathic arthritis and lupus, rely on specialized, innovative, yet often expensive therapies.

Unfortunately, the current data sets and the OAR 925-200-0010 criteria used to select a subset of drugs for the Oregon affordability reviews rely on aggregated insurer and manufacturer information that is not easily accessible or understandable to the public who depend on access to these therapies. Given the complexity and importance of these issues, before the Board votes more transparency describing how the drugs are being selected for review and what factors are influencing affordability determinations are critical data that should be made more apparent for all stakeholders involved.

The criteria for this data set, which includes insurer-reported top 25 drug lists, manufacturer pricing reports, historical price increases, and the presence of generic or biosimilar alternatives, prioritize financial and market-driven factors. While these are important considerations, they do not sufficiently account for the clinical necessity of these therapies or the complexities of providing individualized patient care. They also do not incorporate the realities and complexities of the drug supply and pricing ecosystem that ultimately decide patients' drug costs.

This concern is further heightened by the fact that therapeutic alternatives are not the same as therapeutic equivalents and the lack of a clear definitions and guidelines for selecting the "affordable" medications. The board does not acknowledge these differences, how these therapeutic differences are defined or how this information would be utilized in decision-making. Many individuals living with chronic disease are treated with therapies that have similarities, but this decision to try one therapy over the other should be determined by the patient and their doctor. We are particularly concerned about the potential misuse of selecting drugs for the UPL without clear guidelines and definitions as to how the varying therapeutic differences will be considered and used going forward.

While I enthusiastically support your efforts to address prescription drug costs, the current process and lack of adequate definitions and transparency on how these drugs are selected risks limiting access to essential medications for Oregonians with rare and chronic conditions. Physicians and patients are eager to collaborate with the Board to ensure its affordability decisions reflect real-world patient needs and realities, but this requires a more thoughtful, patient-centered approach. As it stands now, the Board's actions are potentially imposing yet another intermediary int the patient-physician relationship and decision-making and could inadvertently restrict access to medications for those who need them most in Oregon.

Thank you for your attention to this critical issue.

Sincerely,

Harry L. Gewanter, MD, FAAP, MACR
President, Virginia Society of Rheumatology
Board Member, Let My Doctors Decide Action Network

Public Comment

to: The Oregon Prescription Drug Affordability Board (PDAB)

from: Anne Kiley-Pellechia
1403 NE Holman St.
Portland, OR 97211
607 769 5665

Thanks for giving me the opportunity to make a public comment.

Drug prices in this country are impossibly inflated due to lack of national government regulations. The same drug that is affordable in Canada and in Europe, is not affordable in the US. Strange, considering that so many drugs are developed in the US, by US companies which receive government funding to research these drugs, and more government funding to produce them.

If you are the Drug Affordability Board, why haven't you restarted affordability reviews after your pause nine months ago?

How many Oregonians right now are facing that Big Choice: take a lifesaving drug that will bankrupt you and your family, or refuse the treatment and die, so that your family will not become homeless. If my husband loses his VA benefits, which he may based on the insanity that has currently deranged the government, his cancer will kill him because we cannot afford the treatment that is keeping him alive.

To: Oregon Prescription Drug Affordability Board
From: Gracie Campbell, retired graphic designer
Re: Drug pricing
Date: 3/14/2025

My friends and relatives with medical conditions all face tremendous financial hardship to pay USA drug prices. Several of my friends have elected not to take the prescribed drug because it would bankrupt them. We are all aware of the cash exchange between manufacturers and insurers that serves to keep the profits high.

Oregon can do better. Let's bring a sense of reason that can reset the role of drugs for Oregonians as medicine, equal to its role as profit-making.

Pharmaceutical companies are contributing enormously to the morality/ethical and humanism crisis we're suffering globally.

To: Oregon Prescription Drug Affordability Board
From: Kip S, Voices of Health Care Action
Re: Resume drug affordability reviews
Date: 3/14/2025

I have multiple relatives who rely on expensive monthly prescriptions to treat chronic illnesses including Multiple Sclerosis and Type 2 Diabetes. These medications are so costly that my relatives often have to choose between taking their prescribed medications or being able to see their doctors, even foregoing healthy foods due to lack of funds. I urge you to resume drug affordability reviews and reduce costs so that my friends and family can get the medications they need to thrive. Thank you for your time.

To: Oregon Prescription Drug Affordability Board
From: Ms. Laura Hanks, Portland Street Medicine
Re: Drug Affordability
Date: 03/16/2025

Dear PDAB,

I am a retired PA and I urge you to restart your drug affordability reviews ASAP. Oregon patients, families, and health care providers need lower drug prices now. Patients in Oregon continue to struggle with high drug costs every day. With the current uncertainty around federal funding and legislation, the time to protect Oregonians is now!

Sincerely,

Laura Hanks, PA

To: Oregon Prescription Drug Affordability Board
From: Rebecca Schneider
Re: Rifaximin
Date: 3/14/2025

I suffer with Small Intestine Bacterial Overgrowth (SIBO). Have had for over a decade. The only pharmaceutical that provides relief is Rifaximin. In the U.S. my meds are out of my financial reach and insurance will not cover, at $2k for a two week supply. Doctor would prefer three rounds of treatment which would cost me $6k. I choose to have my prescriptions filled in Canada where I pay less than $200. for a two week supply. Would love to keep that money in the US but I can’t afford my health care at those prices.

To: Oregon Prescription Drug Affordability Board
From: Vicki Wares
Re: Eloquis
Date: 03/15/2025

I am 82 years old, on Medicare A & B but have no Part D drug coverage. I have been on warfarin for about 40 years now and am having issues with maintaining a stable warfarin level in my blood. My primary care giver has prescribed Eloquis but the cost is exorbitant! What I fear most is having a debilitating like my mother had. I was her caregiver and loved her very much but what happened to her is terrifying. I live alone in the house my father built for his family and hope I will be able to spend the rest of my remaining days here. Please assist your people to afford the medicines that will aid us to live as healthily as possible. We need your commitment and ACTION.

To: Oregon Prescription Drug Affordability Board
From: Lisa A. Read
Re: Prescription drugs
Date: 03/15/2025

Voices of Healthcare sent me an email requesting that I make a comment.

To: Oregon Prescription Drug Affordability Board
From: Brook B DeCamp
Re: Prescription Drug Reviews
Date: 03/16/2025

My husband is a chronic pain patient. It is very difficult for him to receive prescriptions for pain relief medication due to illegal prescription drug access and abuse. He is generally limited to Buprenorphine which does not completely eliminate his pain. Insurance does not cover his prescription. It is important for unbiased individuals such as your board continue to evaluate Oregon's prescription drug programs.

To: Oregon Prescription Drug Affordability Board
From: Donna Bonetti
Re: Prescriptions
Date: 3/14/2025

I stopped taking an asthma medication when it became too expensive. I also reduced my use of a prescribed estrogen cream I need but fortunately my gynecologist suggested an off label way to use it more efficiently, so I now use less of this prescription.

To: Oregon Prescription Drug Affordability Board
From: Chris Jensen
Re: Advair 500/50
Date: 3/14/2025

I have COPD. I can not afford the drugs I need to help me live a regular life. The drugs I need are at a cost of $400 - $700 per 30-day supply. That allows me to breathe and move through a typical day. I have to settle for a lesser dosage and a cheaper generic brand that is shipped from another country. The results are NOT the same.

To: Oregon Prescription Drug Affordability Board
From: Jessi Presley-Grusin
Re: Restart affordability hearings
Date: 3/14/2025

Please restart prescription drug affordability hearings. It's wonderful that your review produced improvements in the process but delaying the restarting of the hearings doesn't help patients afford their medications, which is what the review was intended to do. Please restart the hearings so that more Americans will be able to afford the prescription drugs they need to stay well. Thank you for your time.

To: Oregon Prescription Drug Affordability Board
From: Joel Nista
Re: Medicare Schedule D
Date: 3/14/2025

Insurance companies do not belong between health and healthcare. Physicians for A Single Payer Healthcare, Nurses for Medicare for All and thousands of people like you and me want Medicare for all.

To: Oregon Prescription Drug Affordability Board
From: Keith Kreger, an individual
Re: Call For Action
Date: 3/14/2025

Please I urge PDAB to restart drug affordability reviews, because delaying doesn't help patients afford their medications. Big Pharma and their allies are working hard to slow PDAB down--but we know that Oregon patients, families, and health care providers need lower drug prices now.

To: Oregon Prescription Drug Affordability Board
From: Kimberly Prieur
Re: All
Date: 03/15/2025

I watch my parents pay way too much for prescriptions that firstly a doctor has been pushed to push onto every patient and secondly that are needed life saving medications. We are the richest nation and big pharma drains every citizen's livelihood and health.

To: Oregon Prescription Drug Affordability Board
From: Kathy Hanavan
Re: Submitting a comment
Date: 3/14/2025

Hello,

I urge you to start drug affordability reviews. Many patients are unable to afford their meds and a delay only makes this worse.

Kathy Hanavan

To: Oregon Prescription Drug Affordability Board
From: Tanya Maria Pritt, Family Recovery Inc.
Re: Drug affordability
Date: 3/14/2025

Please address the high cost of medications. I tend to pay different prices each month when I pick up my medication. I do not have a choice. Costs seem to be at the whim of insurance companies. I pay because I need them, and I am resentful of the cost and lack of consistency in pricing.

To: Oregon Prescription Drug Affordability Board
From: Linda Spencer-Blackledge
Re: Advair
Date: 3/13/2025

I haven't been able to afford Advair since the beginning of 2023. It went off my formulary. It costs over $100 per month now. As I am a senior and a widow on SSI and a pension, that is too high for just one medication. It's for my asthma. I am allergic to steroids, so I can't use rescue inhalers. So my asthma is now uncontrolled.

To: Oregon Prescription Drug Affordability Board
From: Patricia Pomeroy, Padala Farms
Re: Several
Date: 3/14/2025

I am 75 years old and, like millions of people in the USA, I take several medications that keep me functional. Please don't take away a program that does so much for so many. Thank you for your attention to this vital program. Thank you for your support.

To: Oregon Prescription Drug Affordability Board
From: Stacey Gehrman, individual
Re: Review and action by PDAB
Date: 3/13/2025

PDAB is for the benefit of the people of Oregon. They need to do their job and provide the information. If not, then dissolve this board and form another as these individuals are not providing the service.

To: Oregon Prescription Drug Affordability Board
From: Joy C Thomson
Re: Insulin
Date: 3/13/2025

I am a concerned Oregonian. My husband is on several medications, including insulin. I urge PDAB to restart affordability reviews because delaying only benefits pharmaceutical companies, not patients.

To: Oregon Prescription Drug Affordability Board
From: Marna Herrington, Rich Earth Organic Skin Care Studio
Re: Prescription prices
Date: 03/14/2025

Please restart drug affordability reviews, because delaying doesn't help patients afford their medications.

Thank you.

To: Oregon Prescription Drug Affordability Board
From: Ann Clark
Re: Lower drug expense
Date: 3/14/2025

I’m a retired psychologist on a fixed income.

To: Oregon Prescription Drug Affordability Board
From: Bea Momsen
Re: Simbicort
Date: 3/14/2025

To: Oregon Prescription Drug Affordability Board
From: Dan Morgan
Re: PDAB should restart affordability reviews
Date: 3/14/2025

To: Oregon Prescription Drug Affordability Board
From: Heath Rakes
Re: Resume assessments
Date: 3/13/2025

To: Oregon Prescription Drug Affordability Board
From: Maria Nazzaro
Re: review and lower drug prices
Date: 3/14/2025

To: Oregon Prescription Drug Affordability Board
From: Tita Husted
Re: Carbaglu
Date: 3/14/2025

To: Oregon Prescription Drug Affordability Board
From: Victoria Eills, private citizen
Re: Prescription drug affordability
Date: 03/15/2025

To: Oregon Prescription Drug Affordability Board
From: Rebecca Humble, Findourway
Re: Cymbalta
Date: 3/14/2025

To: Oregon Prescription Drug Affordability Board
From: Walter Roce, voting public
Re: PDAB
Date: 3/13/2025

To: Oregon Prescription Drug Affordability Board
From: Harriet Ellen Bing, private citizen
Re: Prescriptions
Date: 3/13/2025