May 20, 2025

Oregon Prescription Drug Affordability Board
350 Winter Salem St NE
Room 410
Salem, Oregon 97309

RE: Proposed Drugs for Affordability Review

Dear Members of the Oregon Prescription Drug Affordability Board:

On behalf of the Alliance for Patient Access (AfPA) I am writing regarding the proposed list of medications to be reviewed for potential inclusion in affordability reviews. As you are considering the spend on prescription drugs, we would encourage you to take a holistic view of the drug pricing ecosystem and ensure that improving the lives of Oregon patients remains a focus.

Founded in 2006, AfPA is a national network of policy-minded health care providers who advocate for patient-centered care. AfPA supports health policies that reinforce clinical decision-making, promote personalized care and protect the provider-patient relationship. Motivated by these principles, AfPA members participate in clinician working groups, advocacy initiatives, stakeholder coalitions and the creation of educational materials.

The proposed list of potential therapies to consider for a potential affordability review is far-reaching and could have a significant impact on Oregon patients across a number of disease states. Similarly structured reviews and evaluations of prescription drugs have already shown concerning unintended consequences. For instance, as a result of the Inflation Reduction Act's Drug Price Negotiation Program, the National Community Pharmacists Association has stated that a third of community pharmacies will not carry or stock drugs that have been negotiated.[1]

While recognizing the need to manage state spending on prescription drugs, it is critical that the board continue to prioritize patient cost and patient access. Throughout the treatment selection and affordability review process, AfPA would encourage the board to incorporate the following provisions:

- Solicit meaningful input from patients, providers and other stakeholders
- Account for individual patient differences and ban the use of discriminatory metrics like the QALY
- Take a holistic approach to the prescription drug supply chain by incorporating the role that other entities, like pharmacy benefit managers, play in driving up patient cost

[1] https://ncpa.org/newsroom/news-releases/2025/01/27/ncpa-cms-third-independent-pharmacies-wont-carry-drugs-negotiated

Patient-centric care is built upon a foundation of trust between the patient and his or her health care provider. Only through open discussion and shared decision making can this relationship effectively develop to provide the patient with the most appropriate care. When treatment options are limited, providers are left to choose from therapies that may not be the best option for that particular patient. Patients are often left with unmet needs and outcomes may suffer as a result. We urge you to consider the above perspective as you are continuing forward with selection and review of these therapies.

Thank you for the opportunity to provide comment and we appreciate your attention to this matter. If AfPA can provide further details or be of assistance, please contact us at 202-951-7097 or cmcpherson@allianceforpatientaccess.org.

Sincerely,

Josie Cooper
Executive Director
Alliance for Patient Access

COMMUNITY ONCOLOGY ALLIANCE

Dedicated to Advocating for Community Oncology Patients and Practices
1225 New York Avenue, NW, Suite 600, Washington, D.C. 20005
(202) 729-8147 | communityoncology.org

May 21, 2025

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

Dear Members,

On behalf of the Community Oncology Alliance (COA) and our members across Oregon, we thank you for the opportunity to provide comments regarding the Oregon Prescription Drug Affordability Board's selection of oncology medications for affordability review. The Community Oncology Alliance represents independent cancer practices across the United States and is dedicated to preserving access to high-quality, affordable, and locally delivered cancer care. We appreciate the state's interest in addressing the cost of prescription drugs and share the state's vision of reducing financial burdens placed on patients.

With this shared vision in mind, we respectfully urge the Board to approach the affordability review process with caution, especially when it involves complex medications that are essential to cancer care. Drugs like Ibrance, Verzenio, and Perjeta are often irreplaceable in a patient's treatment plan. These therapies are selected based on the unique clinical characteristics of the patient and their disease. Even small disruptions in access to these medications can have significant consequences for patients managing a life-threatening illness.

Although the Oregon Prescription Drug Affordability Board does not currently have the authority to implement upper payment limits, the public review process and resulting reports carry influence across the country. Health plans, pharmacy benefit managers (PBMs), and other payers may use PDAB determinations to justify coverage restrictions or apply greater utilization management on patients in need of expedient care. These actors may in turn steer patients toward alternative treatments that are less effective or inappropriate for their specific clinical profile. The result could be delayed care, worsened health outcomes, and increased costs throughout the healthcare system.

In addition, independent oncology practices operate in an already challenging financial environment. These practices often procure, store, and administer complex drugs in-office, offering convenience to patients and better care coordination. However, they must do so at increased financial risk. If affordability reviews prompt changes in reimbursement or acquisition practices that do not account for the full costs of delivering, storing, and administering these medications, practices may be forced to consider significant financial burdens or ultimately succumb to consolidated market pressures. As you may be aware, consolidated markets increase

overall healthcare costs, reduce patient choice, and disproportionately impacting patients in rural and underserved communities who rely on local practices for timely care.

To ensure patient access to local and affordable cancer care is protected, we encourage the Board to incorporate the voices of independent community oncologists into its deliberations moving forward. Our physicians and pharmacists understand firsthand the clinical decision-making and logistical realities involved in administering oncology therapies and how the Board's proposed changes could impact access or disrupt care for patients across the state.

We urge the Board to ensure that any policy recommendations resulting from the review process lead to tangible reductions in patient out-of-pocket costs and do not result in unintended barriers to accessing the best possible cancer treatments available.

Thank you for the opportunity to share these comments. We welcome further dialogue and would be pleased to facilitate connections with our members across the state. If you have any questions, please contact jlee@coacancer.org.

Sincerely,

James Lee
Director, State Regulation & Policy
Community Oncology Alliance (COA)

To: Oregon Prescription Drug Affordability Board
From: Carol Elkins, Aumsville, OR
Re: Ozempic and Mounjaro
Date: 6/3/2025

Hello. Thank you for letting me speak today. My comments are in reference to the cost of weight loss drug prices.

I've been overweight for 40 years and on many diets and programs for weight loss. None have worked for me until Ozempic. I took Ozempic for 1 year and lost 30 pounds. My doctor prescribed Mounjaro to help me continue to lose weight. Then my insurance decided not to cover it. I couldn't afford it without insurance as it was between $300-349/mo. Since I could not afford that, and have had no meds since, I've gained 20 pounds back. This has caused me extreme anguish and depression. I think about my extra weight everyday. I need these medications as they are the only thing that has worked for me. Please consider reducing the cost of these medications. I was prediabetic before the weight loss meds, and since Ozempic helped me to go off these meds. However, I just had a blood test recently and it appears my prediabetes has returned. Weight loss drugs are key to my health, but I need to be able to afford them.

Thank you.

June 9, 2025

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

Dear Chair Bailey and board members,

The high cost of prescription drugs is a significant concern for everyone, and controlling these costs should be a priority. I appreciate that you have a challenging task ahead of you. However, after two years of participating in almost every meeting, I remain unclear about your definition of affordability. What consistent metric will you use when reviewing the extensive list of medications in the five meetings indicated in your calendar? Affordable to whom?

I am glad that you received robust feedback from the patients, caregivers, and other stakeholders through your survey. The agenda for this meeting (at the time of writing my testimony) does not include the report from the patient surveys collected to date. How is the survey data collected before the April 30 deadline going to be used if the Board does not review it before the list is updated? Please share those metrics for each drug under review, so we have a better understanding of the robustness of the patient's feedback.

It is clear that the number of drugs under consideration needs to be reduced, or your review time frame needs to be extended. I appreciate the thoughtful conversation around this at the May meeting, but the process remains unclear regarding the metrics that will be used.

As a 26-year advocate for people living with cancer, it is of grave concern to me that three oncology drugs that all target metastatic breast cancer are on the list for review consideration. Cancer therapy is individualized and should involve shared decision-making between the patient and provider. Additionally, these drugs, administered in a medical setting, are combined with other medications. How does a patient tease out all of those variables to answer your survey? Any potential access issue, even if inadvertently caused by this review, could result in significant harm or death. Again, I ask, affordable to whom?

I am concerned that the drugs chosen for review disproportionately target the chronic disease population—the very ones that need innovation to cure their conditions. Yes, innovation comes at a cost, but if a new therapy enables your liver or immune system to function more effectively, allowing you to work and lead a healthier life, what are the cost savings to the system and you?

Unfortunately, you do not have the authority or tools to review the entire healthcare system for opportunities to decrease prescription drug costs. If you are only given a hammer, then that is what you use. However, I implore you to consider all stakeholders' concerns and collaborate with everyone to develop a more effective process. Asking patients and manufacturers to provide personal or proprietary information through non-secure means is not an effective way to garner the critical data points you need to make decisions.

Asking patients to put something in writing on a public website or attending a 3-hour meeting in the middle of the week to testify for 3 minutes, where the Board cannot ask questions or respond, is not patient engagement. Did you know that a 2021 CBS News poll found that about 37% of adults haven't written a letter in over five years, and 15% have never written one? The National Assessment of Adult Literacy Survey also found that 36% of U.S. adults had basic or below-basic health literacy. These statistics make your work much more difficult but underscore the importance of getting it right.

I appreciate you reopening the survey, but it still has a deadline of April 30, so I am unsure who would fill it out for the reviews beginning next month. If you want patient and provider feedback, schedule dedicated listening sessions for each therapy before the review, utilizing providers in our community to help you understand the nuances of the drugs and recruit patients using these drugs. Or, at a minimum, form a stakeholder council representing a broad spectrum of patients.

The Board stopped the reviews once to reorganize and add more definition to "affordability," but I do not see this reflected in the new review process either. Rushing through the process this time around will not help Oregonians.

Sincerely,

Lorren Sandt, Executive Director

Via electronic submission

June 11, 2025

Oregon Prescription Drug Affordability Board (PDAB)
ATTN: Shelley Bailey, Chair
350 Winter St. NE
Salem, OR 97309-0405
pdab@dcbs.oregon.gov

RE: Requesting Removal of IBRANCE® (palbociclib) and NURTEC® ODT (rimegepant) from Oregon Prescription Drug Affordability Board Prioritized Affordability Review Subset List

Dear Members of the Oregon Prescription Drug Affordability Board:

Pfizer appreciates the opportunity to submit comments to the Oregon Prescription Drug Affordability Board (the "Board"). As noted in our letter dated February 28, 2024, Pfizer has significant concerns with ORS 646A.693-697 which we believe takes a narrow view of controlling health care costs and lacks a mechanism to improve insurance plan design, a key driver of high out-of-pocket cost for patients. For this reason and others outlined below, we request that the Board remove IBRANCE® (palbociclib) and Nurtec® ODT (rimegepant) from affordability reviews or determine that they do not pose affordability challenges if the Board continues with such evaluations.

Requests for Exclusions from Affordability Review.
Pfizer Inc. ("Pfizer") is a research-based global pharmaceutical company dedicated to the discovery and development of innovative medicines and vaccines that improve the quality of life for people around the world. A top priority for Pfizer is ensuring that patients can access and afford our medicines and vaccines. We negotiate with insurers and pharmacy benefit managers (PBMs) to help ensure robust coverage for our medicines. We also provide financial assistance for many of our products to help both eligible insured patients for whom high insurance cost-sharing requirements may jeopardize affordability and uninsured patients who lack drug coverage altogether.[1]

We maintain significant concerns about the affordability review process including because ORS 646A.693-697 fails to address determinants of patient affordability including insurance plan design, access to insurer and PBM negotiated discounts, and the role of patient assistance programs. Moreover, the potential unintended consequences of affordability reviews may limit patient access to medicines. For these reasons, we request that the Board exclude IBRANCE® and NURTEC® from affordability reviews or determine that they do not pose affordability challenges if the Board continues with such evaluations.

[1] Pfizer assistance programs can be found at PfizerForAll™, https://www.pfizerforall.com/prescription-assistance#select-medication-section.

Patient affordability depends on insurance plan design.
What patients pay for their medicines is determined by their insurance company or pharmacy benefit manager (PBM). Insurers and PBMs develop formularies, which are lists of drugs that will be covered under different insurance plans. Formularies not only determine if a drug will be covered, but they also determine how much patients must pay out-of-pocket for medicines and if there are any administrative actions required to obtaining coverage (e.g., prior authorizations, fail first policies). The federal government recognized that patient affordability depends on robust insurance coverage and capped Medicare Part D enrollees' annual out-of-pocket cost at $2,000.[2] Similarly, several states have enacted laws or promulgated regulations directly addressing cost-sharing requirements set by insurers or PBMs.[3] However, the affordability review process under ORS 646A.693-697 contains no mechanism for the Board to lower cost-sharing requirements set by an insurer or PBM to improve patient affordability for prescription drugs.

Patients should benefit from negotiated discounts.
Along with determining patients' cost-sharing requirements, PBMs and insurers determine whether patients receive the discounts and rebates they negotiate with pharmaceutical manufacturers. Three PBMs control nearly 80 percent of U.S. prescriptions and medication access for about 270 million Americans.[4] As the PBM market has consolidated, their negotiating leverage with manufacturers has increased. For example, in 2023, manufacturers paid an estimated $334 billion in discounts and rebates.[5] However, unlike other medical services where the patient pays *less* when their insurer negotiates a better price, very few, if any, patients pay less at the pharmacy counter despite billions of dollars in discounts and rebates paid to PBMs and insurers by manufacturers.[6] Instead, most manufacturer discounts and rebates are retained by PBMs as profit or are passed to an insurer, rather than the patient obtaining the medicine.[7]

Oregon law requires PBMs to report how much they collect in rebates and the proportion that is passed to patients in Oregon health benefit plans. The first report, published in 2024, found that, of the over $287 million collected by PBMs, less than $2.3 million went to patients, or less than 1 percent (0.78%) of rebates collected.[7] In addition to investigating the impact of insurance design on patient affordability, we encourage the Board to examine the role that rebates play in what patients pay at the pharmacy counter.

Pfizer's assistance programs support patient access and affordability for IBRANCE® and Nurtec® ODT.

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[2] Kaiser Family Foundation, A Current Snapshot of the Medicare Part D Prescription Drug Benefit. Available at: https://www.kff.org/medicare/issue-brief/a-current-snapshot-of-the-medicare-part-d-prescription-drug-benefit/
[3] California Chapter 619 of 2015; Maryland Chapter 422 of 2014; New Jersey AB 2431 (2019).
[4] U.S. Federal Trade Commission, Office of Policy Planning, Interim Staff Report, Pharmacy Benefit Managers: The Powerful Middlemen Inflating Drug Costs and Squeezing Main Street Pharmacies, Page 7. July 2024. Available at: https://www.ftc.gov/system/files/ftc_gov/pdf/pharmacy-benefit-managers-staff-report.pdf
[5] Drug Channels, PBM Power: The Gross-to-Net Bubble Reached $334 Billion in 2023—But Will Soon Start Deflating. July 7, 2024. Available at: https://www.drugchannels.net/2024/07/pbm-power-gross-to-net-bubble-reached.html
[6] Petersen-KFF Health System Tracker, Price transparency and variation in U.S. health services. January 13 ,2021. https://www.healthsystemtracker.org/brief/price-transparency-and-variation-in-u-s-health-services/.
[7]Oregon Department of Consumer and Business Services, Division of Financial Regulation, Drug Price Transparency Program, Pharmacy Benefit Managers 2024 Data. https://dfr.oregon.gov/drugtransparency/Pages/DPT-pbm-data-2024.aspx

Pfizer recognizes the growing burden of rising insurance deductibles, copayments, and co-insurance on patient access and affordability of medicines, and supports policies that reform insurance benefit design and patient access to negotiated discounts.[8] However, we also recognize that many patients continue to face high cost-sharing requirements under their insurance plans. To help such patients, Pfizer offers copay assistance programs to eligible commercially insured patients for a range of products, including IBRANCE® and Nurtec® ODT. In addition, some government insured patients struggle to afford their cost-sharing requirements. We therefore provide eligible financially insecure, government insured patients access to our therapies for free.[9] Lastly, we also recognize that an estimated 26 million people in the United States lack health insurance.[10] Therefore, we also offer patient assistance programs that offer free medicines to qualified individuals who lack insurance.[11]

Additional considerations for removing IBRANCE® and Nurtec® ODT from the affordability reviews. Pursuant to OAR 925-200-0010, the Board must take into consideration various factors when selecting the subset of prescription drugs to prioritize for an affordability review, including, but not limited to, whether the drug appears on insurer-reported top 25 lists.[12] According to the Oregon PDAB Data Dashboard, *Aggregated Carrier Data*, neither IBRANCE® nor Nurtec® ODT were included on the top 25 drug lists and both ranked well below for the lists on which they were included. IBRANCE® was included on only one list ranked at #66 and Nurtec® ODT was included on only two lists ranked at #63 and #73, respectively.[13]

Additionally, we believe the Board should take into consideration IBRANCE®'s data exclusivity expiration, the timing of the basic patent expiration, and its inclusion in the Medicare Drug Price Negotiation (MDPN) program established under the Inflation Reduction Act.

OAR 925-200-0010(6) requires the Board to consider, when selecting prescription drugs for a prioritized subset list for affordability review, whether a prescription drug has a patent expiration or data exclusivity expiration within 18 months.[14] Basic product patent expiration for IBRANCE® is March 2027 and data exclusivity has already expired. Based on the Board's current affordability review timeline[15], which contemplates identifying drugs that may create affordability challenges in November 2025 and publishing

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[8]Kaiser Family Foundation, 2024 Employer Heath Benefit Survey. https://www.kff.org/health-costs/report/2024-employer-health-benefits-survey/.

[9]PfizerForAll Prescription Assistance. https://www.pfizerforall.com/prescription-assistance.

[10]The Commonwealth Fund, The State of Health Insurance Coverage in the U.S., Findings from the Commonwealth Fund 2024 Biennial Health Insurance Survey. https://www.commonwealthfund.org/publications/surveys/2024/nov/state-health-insurance-coverage-us-2024-biennial-survey.

[11]Pfizer RxPathways. https://www.pfizerrxpathways.com/. The Pfizer Patient Assistance Program is a joint program of Pfizer Inc. and the Pfizer Patient Assistance Foundation™. The Pfizer Patient Assistance Foundation is a separate legal entity from Pfizer Inc. with distinct legal restrictions.

[12]OAR 925-200-0010 Selecting Prescription Drugs for Affordability Reviews. Available at: https://dfr.oregon.gov/pdab/Documents/OAR-925-200-0010.pdf

[13]Oregon PDAB Data Dashboard. Available at: https://app.powerbigov.us/view?r=eyJrIjoiOGM2YjhlMWUtNzE2OC00MmU1LTk2MjktYWUzZGMyNTNmZmQ1IiwidCI6ImFhM2Y2OTMyLWZhN2MtNDdiNC1hMGNlLWE1OThjYWQxNjFjZiJ9

[14]925-200-0010 Selecting Prescription Drugs for Affordability Reviews. Available at: https://dfr.oregon.gov/pdab/Documents/OAR-925-200-0010.pdf

[15]Oregon Prescription Drug Affordability Board, May 21, 2025 Agenda Materials. Pages 9-14. Available at: https://dfr.oregon.gov/pdab/Documents/20250521-PDAB-document-package.pdf

a final report in December 2025, IBRANCE® basic patent and data exclusivity expirations will be within the 18-month timeframe.

The Board has repeatedly discussed and, in 2023, voted to exclude prescription drugs subject to the Maximum Fair Price (MFP) established under the MDPN from the affordability review process due to the unique supply chain and stakeholder difficulties of drugs subject to the MFP. In January 2025, the Centers for Medicare and Medicaid Services (CMS) announced the selection of IBRANCE® for an MFP that will go into effect on January 1, 2027. We urge the Board to maintain the precedent of removing drugs subject to MFP from the prioritized subset list for affordability review.

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Once again, Pfizer appreciates the opportunity to provide comments to the Board. We support efforts to help ensure that patients can access life-saving medicines and look forward to working with Oregon policymakers to find solutions that help patients. If you have any questions, please contact Brandy Flores, Director of Government Relations, at Brandy.Flores@Pfizer.com.

Sincerely,

Tom Brownlie
Vice President
State Policy and Government Relations

EACH PIC COALITION

June 16, 2025

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

RE: Public Comments on Affordability Review Process

Dear Members and Staff of the Oregon Prescription Drug Affordability Board:

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 appreciate your continued efforts to strengthen Oregon's drug affordability review process. This letter provides our recommendations on the RFI process, public engagement mechanisms, and the overall structure guiding the state's cost review efforts.

Ensure a Thorough and Deliberative Process

We remain concerned about the board's lack of clear criteria in developing the subset list of drugs under review. We are also concerned with the length of the list and the drugs that will be subjected to affordability review within the short amount of time the board has allotted to complete its review.

We are encouraged by indications that the board will revise the list during the upcoming meeting. As it does so, we encourage the board to also consider the amount of time that is appropriate to dedicate to the review of each drug.

In Colorado, the PDAB conducted affordability reviews of only five drugs over a time frame of almost a year, and rulemaking considerations to implement upper payment limits are being conducted during three hearings held over three months for each drug. In Maryland, the PDAB selected only six drugs for review and has been developing the affordability review process for a year as well.

In contrast, Oregon's proposal to review 27 drugs and additional insulin products over only four months poses obvious challenges for both the board and the community.

Protect Vulnerable Populations

Additionally, we urge the board to evaluate the impact the review process will have on the populations of patients that rely on the drug. The initial subset list of drugs for review in 2025 includes multiple medications used to treat the same condition—for example, Ibrance, Verzenio, and Perjeta are all prescribed for breast cancer. The list also heavily features drugs used to manage autoimmune diseases and migraines, all of which disproportionately affect women.

By including multiple medications that treat the same condition or are relied upon by the same population of patients, the board risks unintentionally creating increased hardship for specific patients. Any unintended consequences of the review process—including increased utilization management or restricted access—may then fall disproportionately on already vulnerable groups and further exacerbate health disparities.

We urge the board to consider the risks to the patients who rely on the medications selected for affordability review as it refines the subset list for 2025. In future years, it is essential to diversify the types of drugs selected for affordability review and to include safeguards that protect vulnerable populations.

Integrate Public Input and Address Patient Needs

We remain concerned that a 30-day public comment period to provide input on 27 medications and insulin products was not adequate. As we continue to note in our outreach to the board, meaningful participation from patients, caregivers, and patient advocacy organizations is critical to ensuring that board actions appropriately address patient needs.

While we are encouraged to hear the board may leave the patient survey open for additional responses, it is unclear how this data will be incorporated into reviews that may already be underway. This raises questions about the weight given to public input and the transparency of the process.

The low survey response rates and lack of transparency into input provided by the public raise doubt into whether the board received enough input to truly understand and address patient needs. We are concerned that reported response rates were insufficient for drawing meaningful conclusions about patient experiences and should prompt further outreach and engagement efforts. To ensure patient experiences are meaningfully reflected, we urge the board to provide individual, unedited submissions with open-ended comments. Authentic stories should be part of the decision-making process—not filtered or reduced to general themes.

We also continue to encourage the board to go beyond three-minute public testimony by creating more robust avenues for patient participation. Patient roundtables or extended listening sessions could provide more substantive insights and help the board better understand the burdens individuals face.

Center the Process on Affordability and Patient Burden

The board's work must be centered on the real-world challenges patients face in affording and accessing their prescribed medications. A narrow focus on systemic or payer-level costs overlooks the most meaningful measure of affordability: whether individuals can obtain and adhere to the medications they need.

We urge the board to take the time necessary to ensure that the affordability review process does not disrupt continuity of care or restrict treatment options. Patients must not bear the burden of unintended consequences stemming from policy decisions that limit access or add new layers of complexity to their care.

To that end, we encourage the board to use its authority to engage directly with a broad range of stakeholders to evaluate the downstream impact of cost reviews. Specifically, we urge the board

to proactively examine how insurers, pharmacy benefit managers, and manufacturers may respond to affordability reviews and whether such responses could limit patient access.

Finally, we invite the board to partner directly with our coalition and its EACH and PIC members. Our organizations represent patients across disease areas and have a deep understanding of the life cycle of disease—from prevention to diagnosis to long-term management. We offer ourselves as a resource to ensure patient perspectives remain at the forefront of this work.

Thank you for your continued commitment to improving drug affordability in Oregon. We appreciate the opportunity to provide this feedback and look forward to continuing our engagement with the board.

Sincerely,

Tiffany Westrich-Robertson
tiffany@aiarthritis.org
Ensuring Access through Collaborative Health (EACH) Coalition Lead

Vanessa Lathan
vanessa@aiarthritis.org
Patient Inclusion Council (PIC) Coalition Lead

PCMA

June 12, 2025

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

Dear Chair Bailey and members of the Oregon Prescription Drug Affordability Board:

On behalf of the Pharmaceutical Care Management Association, I'm writing to express our urgent support for maintaining health plan expertise when selecting the replacement of Robert Judge on the Oregon Prescription Drug Affordability Board (PDAB). Prescription drug affordability is a critical issue affecting individuals, families, and communities across Oregon. Ensuring the Board reflects a diverse range of perspectives – including those from health plans – is vital for achieving balanced and effective policy proposals impacting the cost of prescription drugs.

Health plans play a unique and indispensable role in the healthcare ecosystem. Their expertise in managing drug formularies, negotiating prices with pharmaceutical companies, and implementing cost discounts or copay assistance provides invaluable insights into the financial and operational challenges of delivering affordable medication to Oregon patients. A PDAB board member from a health plan brings firsthand knowledge of how changes to prescription drug pricing affect access, equity, and overall healthcare costs. This perspective is essential for crafting solutions that are practical, equitable, and focused on consumer out-of-pocket costs.

Furthermore, including a board member from the health plan community fosters collaboration among key stakeholders. It creates a bridge between policymakers, pharmacists, and insurance entities, ensuring decisions made by the Board are informed by the realities of implementation. There are currently a majority of pharmacy providers on the Board. While this perspective is also critical, it is paramount to maintain the link between providers, pharmacies, patients, and pharmacy benefit managers (PBMs). Because of their contractual relationships with PBMs, a health plan Board member can provide critical insights into how drug benefits are managed and financed.

As the Board continues its important work of addressing prescription drug affordability, maintaining health plan representation will ensure the interests of patients are upheld. We urge the Board to recognize the value of diverse expertise and retain a health plan member as part of its composition.

Thank you for your attention to this matter and for your ongoing commitment to addressing the affordability of prescription drugs. We are confident your efforts will lead to meaningful improvements in the lives of many Oregon residents.

Sincerely,

Bill Head
Assistant Vice President
State Affairs

Pharmaceutical Care Management Association
325 7th Street, NW, 9th Floor
Washington, DC 20004
www.pcmanet.org

Testimony to the Oregon Prescription Drug Affordability Board

June 12, 2025

Chair Bailey and Members of the Board,

We thank the Prescription Drug Affordability Board (PDAB) for the opportunity to comment today. In the previous two meetings, the board discussed replacing Robert Judge's upcoming vacancy with another clinical perspective. Judge's departure represents the loss of the board's only insurer representative with experience in the complexities of financing prescription drugs. For a board specifically chartered with prescription-drug affordability, proceeding without health plan expertise creates an unnecessary blind spot; any proposals developed without this perspective will fundamentally lack insight into how drugs are actually paid for, compromising the board's core mission and the credibility of its recommendations.

Health plans occupy a unique position in the prescription-drug ecosystem with comprehensive visibility into both medication utilization and overall health care patterns across entire member populations. With prescription drugs now consuming approximately 30% of health care spending, payers' data-driven insights are irreplaceable—revealing which high-cost medications truly reduce total expenses and which simply increase premiums without offsetting benefits. Without payer representation, the board loses access to critical real-world evidence that connects drug-pricing decisions to their actual impact on health care costs.

Additionally, health plans provide practical insight, identifying potential administrative barriers or misaligned incentives before policies are finalized. This forward-looking ability ensures that well-intentioned affordability measures don't inadvertently create new access barriers for vulnerable patients or introduce new loopholes that other stakeholders might exploit to increase prices. Health plan expertise is invaluable for ensuring that reforms achieve their intended outcomes without triggering a cascade of unintended consequences.

The position health plans hold in the market requires them to be pragmatic due to their direct responsibility for health care access and affordability. Insurers navigate the complex intersection of regulatory requirements, market dynamics and economic realities that are paramount when crafting viable solutions. True progress in prescription-drug affordability requires insights from those who must ultimately translate policy concepts into coverage decisions directly affecting patient lives and health care costs. Insurer expertise on the PDAB isn't just beneficial, it's fundamental to developing prescription-drug policies that deliver meaningful affordability improvements for Oregonians.

Thank you for your time and consideration,

moda HEALTH

cigna healthcare

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OCAP OREGON COALITION FOR AFFORDABLE PRESCRIPTIONS

June 13, 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,

The Oregon Coalition for Affordable Prescriptions (OCAP) deeply appreciates your continued service to Oregon patients. We represent Oregonians across the state who struggle to afford prescription medications. One in four adults in Oregon reported rationing or going without their prescription medications last year due to high costs[1]. We advocate on their behalf and we do not accept funding from the pharmaceutical industry.

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*[2]. **We urge you to stay true to this mission by avoiding further delays in the affordability review process.**

Pharmaceutical companies and the organizations they fund are actively working to stall this process. This is a familiar tactic, used in state after state, to block transparency and accountability[3]. You've heard their claims that your affordability reviews could lead to loss of access, but this is a well-worn scare tactic. The reality is that manufacturers are highly unlikely to stop selling medications in a state simply because a drug is deemed unaffordable by PDAB.

In fact, pharmaceutical companies continue to operate in countries with strong price controls, because even a regulated market is preferable to no market at all. Profit, even when reduced, is still profit.

We appreciate your thoughtful approach to affordability reviews planned starting next month. We understand that adjustments to the list of medications may be necessary. However, **we are concerned about the exclusion of all orphan-designated drugs from the subset list.**

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[1] 2024 Poll of Oregon Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey
[2] Oregon Legislative Assembly. ORS 646A.693 – Prescription Drug Affordability Board; membership and qualifications of members; terms of office; duties; conflicts of interest; rules.
[3] Patients for Affordable Drugs. (2025, February). PhRMA's false claims about "unintended consequences" of the Inflation Reduction Act. https://www.patientsforaffordabledrugs.org/wp-content/uploads/2025/02/P4AD-PharmaFalseClaimsReport-FINAL1.pdf

OCAP OREGON COALITION FOR AFFORDABLE PRESCRIPTIONS

While orphan drugs are intended to treat rare conditions (one that has a patient population under 200,000), the financial incentives of this designation have resulted in drug companies increasingly seeking this status for existing medications used to treat common diseases[4]. Drugs with an orphan drug designation, benefit from generous federal benefits and protections and have been shown to have reduced investment risk and cost due to expedited approval reviews, shorter trials, and proxy outcomes. Today, six of the ten top-selling drugs[5] have orphan designation[6], and over half of orphan drug spending is for non-orphan conditions[7].

The PDAB declaring a drug unaffordable simply means the Oregon legislature will consider whether or not regulation is needed. It is highly unlikely that any drug makers would abandon the Oregon market as a result.

We urge you to continue to ensure that the affordability review process includes the voices of Oregon patients most affected by high drug prices. **Please act boldly and do not allow industry-driven fear tactics to derail your efforts.**

Oregon families, seniors, and veterans across the state are counting on you.

Thank you for the opportunity to submit these comments. Our board is available to support your work in any way we can. You can reach us at info@affordablerxnow.org or through BethAnne Darby at Strategies 360 or Charlie Fisher at OSPIRG.

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)
Marcus Mundy, (Coalition of Communities of Color)
Odalis Aguilar, (AFSCME Council 75)
Christi Marcotte, (Oregon Community Registered Nurse)

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[4] Optum, Inc. (2023, May 18). *Orphan drugs are sweeping the market — but can we afford them?* https://business.optum.com/en/insights/orphan-drugs-market-can-we-afford-them.html
[5] Manalac, T. (2025, March 5). *10 best-selling drugs of 2024 rake in billions amid exclusivity threats*. BioSpace.https://www.biospace.com/business/10-best-selling-drugs-of-2024-rake-in-billions-amid-exclusivity-threats
[6] Oregon Prescription Drug Affordability Board. (2025, May 2025). *2023 Preliminary Aggregated Carrier Data.* *https://app.powerbigov.us/view?r=eyJrIjoiOGM2YjhlMWUtNzE2OC00MmU1LTk2MjktYWUzZGMyNTNmZmQ1IiwidCI6ImFhM2Y2OTMyLWZhN2MtNDdiNC1hMGNlLWE1OThjYWQxNjFjZiJ9*
[7] Optum, Inc. (2023, May 18). *Orphan drugs are sweeping the market — but can we afford them?* https://business.optum.com/en/insights/orphan-drugs-market-can-we-afford-them.html

HealthHIV

1630 Connecticut Avenue, NW, Suite 500
Washington, DC 20009

202.232.6749 | healthhiv.org

June 16, 2025

Subject: Stakeholder Comment on Odefsey Affordability Review – Treatment Access and Ecosystem Considerations

Dear Members of the Prescription Drug Affordability Board,

Thank you all (again) for the opportunity to comment on the inclusion of Odefsey in Oregon's affordability review schedule. As someone actively involved in both national HIV and Oregon health policy, and someone who's been living with HIV for nearly thirty years, I want to highlight why continued access to Odefsey matters and how recent FDA trial halts, other state formulary disruptions, and 340B pressures make this moment especially critical. Moreover, we appreciate the Board's commitment to ensuring Oregon residents can access necessary medications while balancing broader concerns about system-wide costs. As an organization engaged in HIV policy and access across the country—and with longstanding collaboration in Oregon—we write to raise concerns about how affordability determinations for HIV medications must account for their unique ecosystem context.

Odefsey's Crucial Place within the HIV Treatment Ecosystem:

As it stands, Odefsey remains an important treatment option for many Oregonians living with HIV. It's often chosen for its tolerability, its fit with certain comorbidities/conditions, and adherence patterns it supports, especially when patients and providers have relied on it as part of a long-standing individualized care or service plan. And for those taking it, it still represents a viable (albeit older) alternative to regimens like Biktarvy, which—although more widely used—has itself raised concerns when listed for PDAB affordability reviews in states such as Maryland.

The affordability review of Odefsey also comes at a time of recent announcements in the oral small-molecule HIV treatment pipeline. Just this month, the FDA placed a clinical hold on trials involving Gilead's next-generation oral small-molecule candidates, GS-1720 and GS-4182, part of its WONDERS-1 / WONDERS-2 trials. These agents were being studied as potential long-acting oral therapies and considered likely successors to existing "newer" regimens (like Biktarvy). However, the trials were halted due to CD4+ T-cell depletion—echoing the same safety concerns that paused development of Islatravir (Merck) for both HIV treatment and Pre-Exposure Prophylaxis (PrEP). These developments are not just setbacks in R&D—they shift the burden *back* onto maintaining the viability of <u>existing</u> HIV treatment options, like Odefsey.

Ongoing Access Challenges for Odefsey:

But access to Odefsey depends on how commercial plans or Medicaid Managed Care Organizations (MCOs) structure their formularies and utilization management policies. In Washington, for example, a 2021–2022 budget proviso led to the creation of an HIV Medication Access Workgroup to examine the effects of prior authorization, step therapy ("fail first"), and rebate strategies on access and public health. Although the proviso didn't require changes to formularies, it opened the door for the Health Care Authority (HCA) to remove HIV antivirals from managed care in 2023, citing the prior authorization repeal. HCA described the move as compliance-driven, but many stakeholders (like me) argued that it went beyond what the proviso in practice required. Internally, the change was tied to HCA's desire for more predictable budgeting and centralized oversight, even though other solutions could have addressed the same issues. The Washington State Hospital Association and safety-net providers—including Ryan White clinics, FQHCs, and DSH hospitals—opposed the move, noting that it was implemented without advance notice or consultation. They warned that the policy could offset 340B program income used to fund outpatient care, case management, and services for vulnerable populations in the context of communicable disease care.

While the carve-out may have streamlined payer-level access, it introduced unforeseen billing and care coordination challenges across pharmacies, prescribers, and case managers. That experience is exactly why there's concern in Oregon—that an affordability review of Odefsey could lead to similar barriers and disruptions here. And as the PDAB

looks to other states for ways to address pricing challenges for patients, please also consider the disruptions our neighboring state experienced, where a single policy shift had ripple effects across the entire HIV care system.

The Tangible Consequences of HIV Care Disruptions:

For those on the frontlines of HIV care, especially Ryan White–covered entities, these disruptions can have tangible and immediate consequences. Odefsey access is not just a therapeutic matter—it's an operational linchpin to HIV treatment strategies across the country, including in Oregon. Ryan White entities are statutorily obligated to reinvest 340B savings directly into patient care. But when access is changed, as was the case in WA, the fallout hits bottom lines, and therefore also funding for case management, adherence support, and viral suppression almost directly. This stands in (outright) contrast to many hospital-based entities, where reinvestment of 340B savings is often discretionary and lacks the same accountability requirements that govern HIV programs like Ryan White.

If Odefsey is subject to an affordability review and potential upper payment limit (UPL) imposition in Oregon, there is a serious risk that it may be dropped from formularies or placed under burdensome utilization management (UM). This would shift costs to HIV case managers (public and private), ADAPs (AIDS Drug Assistance Programs), Title XIX Medicaid targeted providers, and HIV specialty clinics that must scramble to support payer-driven medication switches, often in pharmacy deserts or under restrictive PBM networks. PDAB affordability listings—when interpreted by plans and pharmacy benefit managers (PBMs)— may result in additional barriers to access, such as tiering, step therapy, or utilization review policies (UPLs). For HIV specialty clinics navigating restrictive PBM networks, these compounding pressures threaten prescribing autonomy and financial viability.

Conclusion:

As seen in Washington State, these policy shifts may yield spreadsheet savings — but even when framed as temporary or compliance-based, they can destabilize HIV care ecosystems in practice. And the immediate desire (or illusion) of cost containment too often masks real-world service degradation. For these reasons, we continue to urge the Board to consider not just the cost burden of medications like Odefsey, but the systemic pricing structures that drive those burdens, and to engage with contractors and the Oregon Health Authority, which administers the ADAP program, and publicly report those findings back to the PDAB. Affordability interventions must not shift responsibility away from manufacturers, leaving patients and providers to navigate the resulting challenges on their own; or shift more financial and operational burden onto adherence staff and case managers simply because a formulary changed.

Given the state of the small-molecule, HIV oral-formulation treatment pipeline and the *critical* role Odefsey *still* plays in care, we ask the Board to weigh carefully the issues that could come from this particular affordability review. At a time when states are reevaluating PBM practices and formulary controls, PDAB decisions should avoid reinforcing payer-driven disruptions that undermine care access, clinical stability, and cost-effective outcomes.

Thank you, once more, for your time, effort, consideration, and continued leadership.

Sincerely,

Scott D. Bertani

Director of Advocacy, HealthHIV

scottb@healthhiv.org

Johnson & Johnson Health Care Systems, Inc.
1125 Bear Tavern Road
Titusville, NJ 08560

T +1-800-526-7736
jnj.com

Via Electronic Submission

June 16, 2025

Shelley Bailey, Board Chair
Oregon Prescription Drug Affordability Board
pdab@dcbs.oregon.gov

Dear Board Chair Bailey:

Johnson & Johnson Innovative Medicine ("J&J") thanks the Oregon Prescription Drug Affordability Board ("PDAB" or "Board") for its open dialogue and for requesting that staff confirm the accuracy of its prescription drug data in response to our oral testimony at the May 21, 2025 Board meeting. We also thank staff for updating the Prescription Drug Data Spreadsheets ("Spreadsheets") and the Oregon PDAB Data Dashboard ("Dashboard") to include the FDA-approved generics of Xarelto (rivaroxaban). We further respectfully request that the Board **remove TREMFYA and XARELTO from the "Subset List of 2023 Prescription Drugs for Affordability Reviews" ("Subset List") because neither drug meets eligibility criteria required by Oregon law or criteria that the PDAB has prioritized.**[1]

As noted in our previous comment, when selecting drugs for affordability reviews, the Board is required by Oregon law to prioritize drugs appearing on the following lists and reports:[2]

- Three Carrier-Reported Top 25 Lists:
    1. Top 25 most frequently prescribed drugs ("MP")
    2. Top 25 most costly drugs as a portion of total annual spending ("MC")
    3. Top 25 drugs that have caused the greatest increase in total plan spend ("GI")

- Two Oregon Drug Price Transparency ("DPT") Program Reports:
    1. Manufacturer New Drug Report
    2. Manufacturer Price Increase Report

As shown in Image 1, ***TREMFYA is not on any of these Lists or in either Report.*** TREMFYA is listed as #47 on the GI list, #46 on the MC list, and #92 on the MP list—***not within the Top 25***. TREMFYA is #159 on the additional category of "Most Expensive" drugs, a category created and prioritized by the PDAB. Image 1 also shows that TREMFYA does not appear on either of the two DPT reports. Therefore, we believe that TREMFYA does not meet the criteria for the Subset List and request that it be removed.

Likewise, Image 1 below shows that XARELTO is #47 on the GI list, #60 on the MP list, and #321

[1] OR Admin Reg 925-200-0010; OR. Rev. Stat. 646A.689; OR Rev. Stat. 743.025; *OR PDAB Agenda - January 15, 2025 Meeting*, *Agenda* (Jan. 15, 2025), https://dfr.oregon.gov/pdab/Documents/20250115-PDAB-document-package.pdf#Page=44 (last visited June 12, 2025).
[2] OR Admin Reg 925-200-0010; OR Rev. Stat. 743.025; OR. Rev. Stat. 646A.689.

on the Most Expensive list—***not within the Top 25***. XARELTO also does not appear on either of the two DPT reports. While XARELTO is now shown as #23 on the MC list, it is a drug for which CMS has set a "Maximum Fair Price," and it has FDA-approved generics—two additional factors that the Board has prioritized. Therefore, XARELTO does not meet the criteria for the Subset List, and we request that it be removed.

Image 1. "Top 25 List" and "DPT Report" Columns for TREMFYA and XARELTO in the "2023 Subset List Aggregated Information v04" Spreadsheet.

Therapy class	Proprietary name(s)	Non-proprietary name	Number of prescriptions	Number of enrollees	List type	Total lists	GI rank	MC rank	MP rank	ME rank	Drug on 2023 Manufacturer reporting under ORS 646A.6
ANTICOAGULANTS	Xarelto	Rivaroxaban	7746	2160	GI / MC	2	47	23	60	321	No
DERMATOLOGICALS	Tremfya	guselkumab	1092	229	GI / MC	2	47	46	92	159	No

As one of the nation's leading healthcare companies, J&J has a responsibility to engage with stakeholders in constructive dialogue to address gaps in affordability and access as well as protect our nation's leading role in the global biopharmaceutical innovation ecosystem. We know that patients are counting on us to develop, bring to market, and support access to our medicines. We live this mission every day and are humbled by the patients who trust us to help them fight their diseases and live healthier lives. We thank you in advance for taking our recommendations into account.

Sincerely,

Michael J. Valenta

Michael Valenta

Vice President, Value, Access & Pricing, Strategic Customer Group
Johnson & Johnson Healthcare Systems, Inc.

OREGON STATE PHARMACY ASSOCIATION
19363 Willamette Drive #260 • West Linn, Oregon 97068
(503) 582-9055 • www.oregonpharmacy.org • info@oregonpharmacy.org

June 14, 2025

Dear Members of the Oregon Prescription Drug Affordability Board,

Oregon is facing a prescription drug access crisis that demands urgent, decisive intervention. On behalf of pharmacists and pharmacies across the state, the Oregon State Pharmacy Association (OSPA) submits these comments to urge the Oregon Prescription Drug Affordability Board (PDAB) to **recommend a comprehensive ban on Pharmaceutical Benefit Managers (PBMs) operating in Oregon.** Incremental reforms have failed. To protect patients, pharmacies, and the sustainability of Oregon's healthcare system, a bold shift is necessary.

Oregon ranks last in pharmacy access among the contiguous United States, with over 200 pharmacy closures since 2008 and a 56% increase in pharmacy deserts in just four years. **This is not simply an economic issue—this is a public health emergency.** PBMs are at the center of this crisis, using opaque, profit-driven models that restrict access, inflate costs, and undermine independent pharmacies. These practices directly contradict the PDAB's mission to protect consumers and improve drug affordability.

PDAB was established to identify high-cost drugs, conduct affordability reviews, and recommend policies to the legislature that will increase drug affordability. PBMs' lack of transparency, predatory reimbursement models, and formulary control create systemic barriers to these goals.

An audit by the Oregon Secretary of State found PBM transactions in Medicaid to be too complex and opaque to ensure accountability. If the PDAB is to fulfill its purpose using real-world evidence, the underlying structure that blocks transparency must be addressed. A comprehensive ban on harmful PBM practices is not outside the scope of PDAB—it is essential to its success.

The Core PBM Practices Undermining Affordability and Access

1. Vertical Integration and Market Manipulation:
PBMs now own or are owned by insurers and pharmacies, enabling them to steer patients to PBM-owned outlets, squeezing out independent providers. This anti-competitive behavior reduces choice, convenience, and access—particularly in underserved communities. Attorneys General in 39 states and territories have called for a national ban on PBM-owned pharmacies. Oregon must lead where federal action lags.

2. Opaque Pricing Structures:
PBMs often retain significant portions of manufacturer rebates rather than passing them on to consumers or payers. **This creates a financial incentive to favor high-cost drugs with larger rebates, driving up list prices.** Efforts to mandate transparency have failed, as PBMs find ways to circumvent reporting requirements. Transparency alone is no longer sufficient—structural change is needed.

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3. Predatory Reimbursement Tactics:
Practices such as spread pricing, below-cost reimbursements, and clawbacks jeopardize pharmacy sustainability. OSPA's analysis found that 75% of Medicaid reimbursements to independent pharmacies didn't cover basic labor and drug costs. Oregon pharmacies are being forced to operate at a loss—an unsustainable reality that contributes directly to pharmacy closures and reduced access.

4. Formulary Control and Patient Restrictions:
PBMs restrict access to lower-cost or clinically preferred drugs in favor of those yielding higher rebates. Patients face delays and denials due to non-medical switching, prior authorization, and step therapy. These practices erode clinical autonomy and compromise patient outcomes.

The Human and Financial Toll in Oregon

- Over 200 pharmacy closures since 2008
- 35 closures in the last year alone
- 56% growth in pharmacy deserts over four years
- Dead last in pharmacy access (contiguous U.S.)
- Disproportionate impact on rural, Black, Latino, and underserved communities
- $1.9 million in excess taxpayer spending on a single MS drug in 2021 due to PBM markups (3 Axis Advisors)

States across the nation are acting. Arkansas has already banned PBMs from owning or operating pharmacies, effective 2026. Ohio's Medicaid program saved $140 million by removing large PBMs. Louisiana, Iowa, Florida, and others have enacted reforms that include rebate pass-throughs, NADAC reimbursement, and spread pricing bans. Oregon must build on its own progress with HB 3212 and HB 4149 and push further.

Recommendations to the PDAB
1. Recommend a Comprehensive Ban on Harmful PBM Business Practices:
The PDAB should formally advise the legislature to enact a ban that includes:

- Prohibiting vertical integration and ownership of pharmacies
- Eliminating spread pricing and opaque reimbursement models
- Requiring 100% rebate pass-through to payers and patients
- Restricting formulary practices that prioritize PBM profit over patient care

2. Frame the Ban as a Pathway to a Healthier System:
This is not just a prohibition—it is an opportunity to build a more transparent, equitable, and affordable drug system. It would:

- Restore fair competition and support community pharmacies
- Reduce patient out-of-pocket costs
- Improve access, especially in rural and underserved areas

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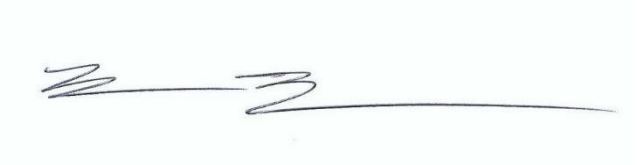
- Align Oregon's healthcare market with the PDAB's mission

3. Recommend a Phased Transition and Alternative Models:
PDAB can advise the legislature on how to implement a managed transition—mirroring Arkansas's timeline—to develop alternative payment models, state-managed formularies, and robust oversight frameworks.

The current PBM system is structurally incompatible with Oregon's goals of transparency, affordability, and access. The PDAB has both the authority and the responsibility to recommend systemic change. Oregonians cannot wait for federal reform. The time for bold, state-level action is now.

We urge the Board to recommend a comprehensive legislative ban on harmful PBM operational models and help chart a new, patient-centered future for Oregon's drug supply chain.

Sincerely,



Brian Mayo
Executive Director

COMMUNITY ACCESS NATIONAL NETWORK

Mailing Address:

Attn: Jen Laws
PO Box 3009
Slidell, LA 70459

Chief Executive Officer:

Jen Laws
Phone: (313) 333-8534
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June 16, 2025

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

RE: Subset List/Board Goals

Dear Honorable Members of the Oregon Prescription Drug Affordability Board,

The Community Access National Network (CANN) is a 501(c)(3) national nonprofit organization focusing on public policy issues relating 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.

While CANN is primarily focused on policy matters affecting access to care for people living with and affected by HIV, we stand in firm support of all people living with chronic and rare diseases and recognize the very reality of those living with multiple health conditions and the necessity of timely, personalized care for every one of those health conditions. State Prescription Drug Affordability Boards are of profound importance to our community.

Changes Made to Updated Subset List Are Encouraging Yet Concerning

The survey response infographics posted in the meeting materials for the June 18, 2025, meeting do not list Odefsey, which would indicate it is no longer being considered. We thank you for that decision as it indicates you listened to, understood, and thoughtfully considered the concerns multiple stakeholders raised concerning it and HIV medications overall.

We also applaud the efforts made to investigate Botox, Rinvoq, Humira, and Dupixent to remove them from the subset list due to FDA orphan designation. However, even though the biologics Dupixent and Humira were removed, multiple biologics remain on the list. Some of the biologics also have no biosimilar. Additionally, Ibrance, which helps the body fight cancer, is on the list. Access to biologics, cancer medications, and other drugs that affect vulnerable patients with delicate and serious disease states is a matter of life and death. We encourage the Board to engage in a thorough analysis of drugs like these

to ensure that decisions made do not adversely affect access to the medications and significantly improve whatever affordability challenges you identify.

Survey Response Data Does Not Present a Clear Picture

The current number of survey responses presented vary significantly in the number of respondents, depending on the drug. Even so, in the infographics regarding patient out-of-pocket cost ranges, there is wide variation in reported patient costs within the ranges of several of the drugs. We encourage continued efforts to get more patient feedback to bolster insight. We also ask that your deliberations consider why and how there are so many different out-of-pocket costs for each medication. For example, there could be patients who are not aware of the assistance they qualify for but have not been utilizing. Additionally, there may be plan dynamics that need to be addressed to better serve patients. Given the information gathered thus far, it would be helpful for the public to understand how the Board plans to utilize this data to identify potential affordability concerns. This also applies to the information regarding prescription coverage by insurance type.

Regarding survey data being gathered to inform the PDAB's actions, we would like to highlight the importance of distinguishing between and appropriately assessing the data, limiting the analysis to plan types in which the PDAB has the power to enact or suggest regulatory actions. Collecting affordability-related information from Medicare enrollees is important, especially to assist the Oregon legislature in presenting resolutions urging action to the federal government. Nevertheless, just like ERISA plans, Medicare is not subject to state regulatory actions imposed by a PDAB, as it is governed by federal law. Thus, data related to Medicare, ERISA plans, and any other federally regulated plans should be excluded from PDAB determinations.

We Encourage the Board to Ensure Its Goals Stay at the Forefront

The Board has been tasked with the noble and arduous task of effectuating positive change to improve affordability for Oregonians. This requires the utilization of staff, including the solicitation of information from various subject matter experts, a range of consulting services, and multiple categories of data sources and interpretations. Moreover, in the national PDAB landscape, states are looking to one another to find ways to best assist their constituents. This includes communication among various state PDAB staff groups, along with the manner in which they monitor various state PDAB meetings.

We encourage the Board to be mindful of ensuring its desires are explicitly acted upon and that its endeavors are not inadvertently steered by influences not clearly beneficial to Oregonians. Various state PDABs have their own challenges they are working through, including fleshing out how the extraordinarily complex drug supply chain, payer mechanics, and entities providing care to patients all interact. What the PDAB is tasked with is new, very necessary, but cautiously speculative in the effects decisions may impart.

It is essential to ensure that every consideration is based on meaningful data and analysis and approached with an open mind to the nuances involved. There is independent data that explains the very real possibility of cost-control decisions resulting in increased costs to patients. Consistently evolving data includes direct commentary from payers. When advocacy groups and individual patients raise various concerns, those concerns are valid. The pharmaceutical industry is not a monolithic big bad wolf. High-cost interventions are still valuable because of their significant benefits, just as some lower-cost interventions are not as valuable or effective. Analysis indicating how improper affordability actions can affect Medicaid and other programs is real.

It is disheartening that Executive Director Magrish is quoted as making statements such as, “It literally is Chicken Little, the sky is falling. It’s a fairy tale trying to create a hysterical or mistaken belief that disaster is imminent should upper payment limits occur”. Such sentiments continue to be propagated across states. We encourage the Board to examine the background of entities such as PORTAL and ICER in the same manner as advocacy groups and other organizations, with their motivations and funding being scrutinized.

While affordability concerns are universal, the needs of Oregonians are specific. The inquiries you desire and the discourse you generate should remain under your guidance and not be inadvertently improperly informed.

We thank you for all of your ongoing hard work and thoughtful deliberations.

Respectfully submitted,

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

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

National
Multiple Sclerosis
Society

June 18, 2025

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

RE: National Multiple Sclerosis Society Comments on Updated Data Subset List of Prescription Drugs and Insulin Products pursuant to OAR 925-200-0010

Members of the Oregon Prescription Drug Affordability Board,

Thank you for the opportunity to continue to submit comments to the Oregon Prescription Drug Affordability Board. The National Multiple Sclerosis Society (Society) thanks the Prescription Drug Affordability Board (Board) as they continue to work to lower the cost of prescription medications for all Oregonians. The Society will continue to be involved as we believe Boards such as these provide important information and transparency regarding the high cost of prescription medications.

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.

MS Disease-Modifying Therapies and Ocrevus®
As the Board undergoes the winnowing of the subset of prescription drugs and insulin products for affordability review consideration the Society respectfully reminds the board to continue to actively utilize both the most up-to-date science and the lived experience of people with MS. As mentioned in previous correspondence, there is consensus that early diagnosis and early treatment with an MS disease-modifying therapy (DMT) improves long-term health outcomes for people with relapsing forms of MS by reducing the number of relapses, slowing disease progression and delaying irreversible neurological damage. There is growing scientific consensus that the strategy of early treatment with a high efficacy DMT is best for people with MS.[1]

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9489547/

Today there are more than 20 DMTs, both brand name and generic, approved by the FDA for treatment of relapsing forms of MS. Ocrevus®, approved by the FDA in 2017, is considered to be in the category of high efficacy treatments and remains the first and only medication approved for primary progressive multiple sclerosis (PPMS). Approximately 10-15% of people with MS have PPMS and experience gradually worsening neurologic symptoms and an accumulation of disability without relapses. Ocrevus® utilizes an anti-CD-20 action which specifically reduces nerve damage which can lead to irreversible disability progression.

The Society best estimates based on claims data is that from 2023-2024 almost 1,100 Oregonians living with MS utilized the DMT Ocrevus® out of an estimated MS population of just over 11,000, representing approximately 10% of Oregonians living with MS[2].

Additional Commentary
As highlighted in previous correspondence, there are other factors which influence the shared decision-making of a patient and doctor's choice of DMT. Some of the top factors in those conversations include efficacy, tolerance of side effects, dosage frequency and route of administration- all of which can affect adherence to treatment. Ocrevus® is administered by infusion every six months and has an often-appealing treatment regime for people with MS as they may have increased quality of life due to the dosing infrequency.

***

The National MS Society thanks the Board for their work and dedication and for the opportunity to provide comments throughout the drug review process. Should you have any questions, please contact Seth Greiner, Senior Manager of Advocacy, at seth.greiner@nmss.org.

Respectfully,

Seth M. Greiner
Senior Manager, Advocacy

[2] Komodo Health. (2025, April 29). *Oregon Ocrevus Multiple Sclerosis Utilization 2023-2024* [Data set]. Komodo Prism.