To: Oregon Prescription Drug Affordability Board
From: Ann DiSalvo
Re: Drug affordability
Date: 3/20/2025

The drug my neurologist prescribed for my condition costs so much that if I had no Medicare or other insurance, after three monthly doses, all of my savings would be gone, and I would be in debt and soon lose my house, having no steady income in my retirement. This is a vulnerable position. My condition has no cure.

To: Oregon Prescription Drug Affordability Board
From: Spencer Scotti
Re: Otezla, Regence Blue Cross, & Accredo
Date: 3/21/2025

4/14/21 Otezla prescription Claim with Walgreens, total amount billed was $3,830.48, copay assistance covered $3,750.00, (no evidence in claim summary) and I paid $80.48 that was applied to my deductible. The co pay assistance amount paid was NOT reflected in this claims summary but later reflected in July and August claims. 6/3/21 Otezla Claim with Accredo, total amount billed $3,703.18, copay assistance covered $2,395.75 (no evidence in claim summary) but total amount billed and applied to my deductible is $3,703.18, as reflected in my claims summary. However, Accredo sent me a bill in September 2021 (AFTER MY LAST FILL) for $3,703.18, and then a corrected bill in February 2022 for $1,307.43. If this had been covered by co pay assistance before covering the next two fills, and similarly reflected in my claims summary, I would NOT have permitted the August 2021 prescription fill, or I might have met my deductible sooner. It is frustrating that this claim seemed to be processed after the next two claims resulting in a large unexpected bill. 7/6/21 Otezla Claim with Accredo, total amount billed $3,703.18, Regence paid $1,549.87, copay assistance covered $2,113.71, this copay assistance amount IS SHOWN in my claims summary as being applied to both my deductible and co pay for the first time. Co pay assistance amount not reflected in the previous two claims but reflected on this claim summary? 8/3/21 Otezla Claim with Accredo, total amount billed $3,703.18, Regence paid $2,952.54, and $740.64 was applied to my copay, which was paid by the copay assistance program. The amount paid by co pay assistance program was reflected on my August claim but not reflected on the April or June claim. If only $80.48 was applied to my deductible in April, but then the full amount of $3,703.18 was applied to my deductible in June, but the full amount of $3,830.48 not applied to my deductible in April? If the April claim amounts were applied like the June, July, & August claim amounts, I believe I might have met my deductible sooner. If the copay assistance program covered the full amount in June like it had in April, and properly reflected in a timely manner, I would NOT have permitted Accredo to fill the August prescription, knowing I might incur a bill for $1,307.43. I have not taken any medication for my condition since September 2021, when I received the original bill from Accredo for $3,703.18.

To: Oregon Prescription Drug Affordability Board
From: Aaron Phelps, Grants Pass
Re: Drug pricing legislation
Date: 4/09/2025

I wonder if this board could advocate for state legislation that would limit the cost of any single medication to be no higher than the lowest price that it is sold for (by its manufacturer) to other countries. I'm not sure if state legislation could actually hold manufacturers/distributors accountable to such legislation especially in programs like Medicare where there are some federal rules/laws in play. In fact, I'd love to see this implemented at the federal level, but perhaps state-based legislation could lead the way?

April 11, 2024

Oregon Prescription Drug Affordability Board
PO Box 14480
Salem, OR 97309

Re: Removal of Dupixent® as an approved orphan drug from subset list of 2023 prescription drugs for affordability reviews

Dear Members of the Oregon Prescription Drug Affordability Board,

Sanofi appreciates the opportunity to submit comments to the Oregon Prescription Drug Affordability Board ("OR PDAB") regarding its subset list of 2023 prescription drugs for affordability reviews. Our product, Dupixent, was selected by the OR PDAB for inclusion on the subset list at the March 19, 2025 meeting. Dupixent is approved to treat six different indications, including eosinophilic esophagitis – a rare disease for which Dupixent was granted an "orphan drug" approval. Given its approved orphan designation, and the prohibition on including such approved products from affordability reviews under the OR PDAB authorizing statute, we respectfully ask that the Board remove Dupixent from any affordability review.[1]

Dupixent, which Sanofi commercializes with its partner, Regeneron, is a biologic medication that blocks the signaling of two key sources of Type 2 inflammation (IL-4 and IL-13) and is currently indicated in the treatment of six conditions: eczema/atopic dermatitis; asthma; nasal polyps; eosinophilic esophagitis (EoE); prurigo nodularis and chronic obstructive pulmonary disease (COPD).

EoE is a rare type 2 inflammatory disease that damages the esophagus and prevents it from working properly. There are approximately 160,000 patients in the U.S. living with EoE who are currently treated, of whom approximately 48,000 have failed multiple treatments. For people with EoE, swallowing the smallest amount of food can be a painful and worrisome choking experience. This disease can also cause narrowing of the esophagus and dilation (physical expansion) of the esophagus may be needed, which is often painful. In severe cases, a feeding tube is the only option to ensure proper caloric intake and adequate nutrition. People with EoE may have poor quality of life and are more likely to experience depression than people without EoE.

Dupixent was granted an orphan designation by the FDA under 21 U.S.C. 360bb for the potential treatment of EoE in 2017. On May 20, 2022, Sanofi received full approval for the treatment of EoE in adult and pediatric patients aged 12 years and

[1] Sanofi reserves the right to supplement this submission with additional information to inform the OR PDAB's decision-making on this important topic.

older. Last year, this indication was extended to cover the treatment of pediatric patients aged one year and older. Included with this letter is copy of the FDA's Orphan Drug Designations and Approvals database entry for Dupixent confirming the approved orphan drug status.

Under the OR PDAB's authorizing statute, "[a] drug that is designated by the Secretary of the United States Food and Drug Administration, under 21 U.S.C. 360bb, as a drug for a rare disease or condition is not subject to review under subsection (1) of this section."[2] Given that Dupixent is approved by the FDA with an orphan designation for the treatment of a rare disease, it should be excluded from review and removed from the list.

Sanofi remains committed – and devotes significant resources – to exploring all of the potential disease states and patient populations that could benefit from Dupixent. Dupixent was recently approved as the first ever biologic product treatment for COPD.[3] We believe that Dupixent will also benefit future patients with other serious diseases and conditions and are currently in clinical trials to pursue several additional indications. In fact, Dupixent is currently being studied in another rare disease orphan indication – bullous pemphigoid.[4]

Dupixent represents precisely the type of innovation and approach to pricing that should be expected from our industry – pursuing first in class or best in class medicines that have the potential to transform the practice of medicine for patients, and pricing those medicines in a manner that reflects the value they provide to patients and society.

Thank you for the opportunity to provide comments and for considering our concerns. We expect that after considering Dupixent's orphan approval, **the Board will remove Dupixent from the subset list of 2023 prescription drugs for affordability reviews.**

Please feel free to contact me at with any questions at andrea.todd-harlin@sanofi.com or (651) 341-3444.

Sincerely,

Andrea Todd-Harlin
Head, State Government Relations, Sanofi

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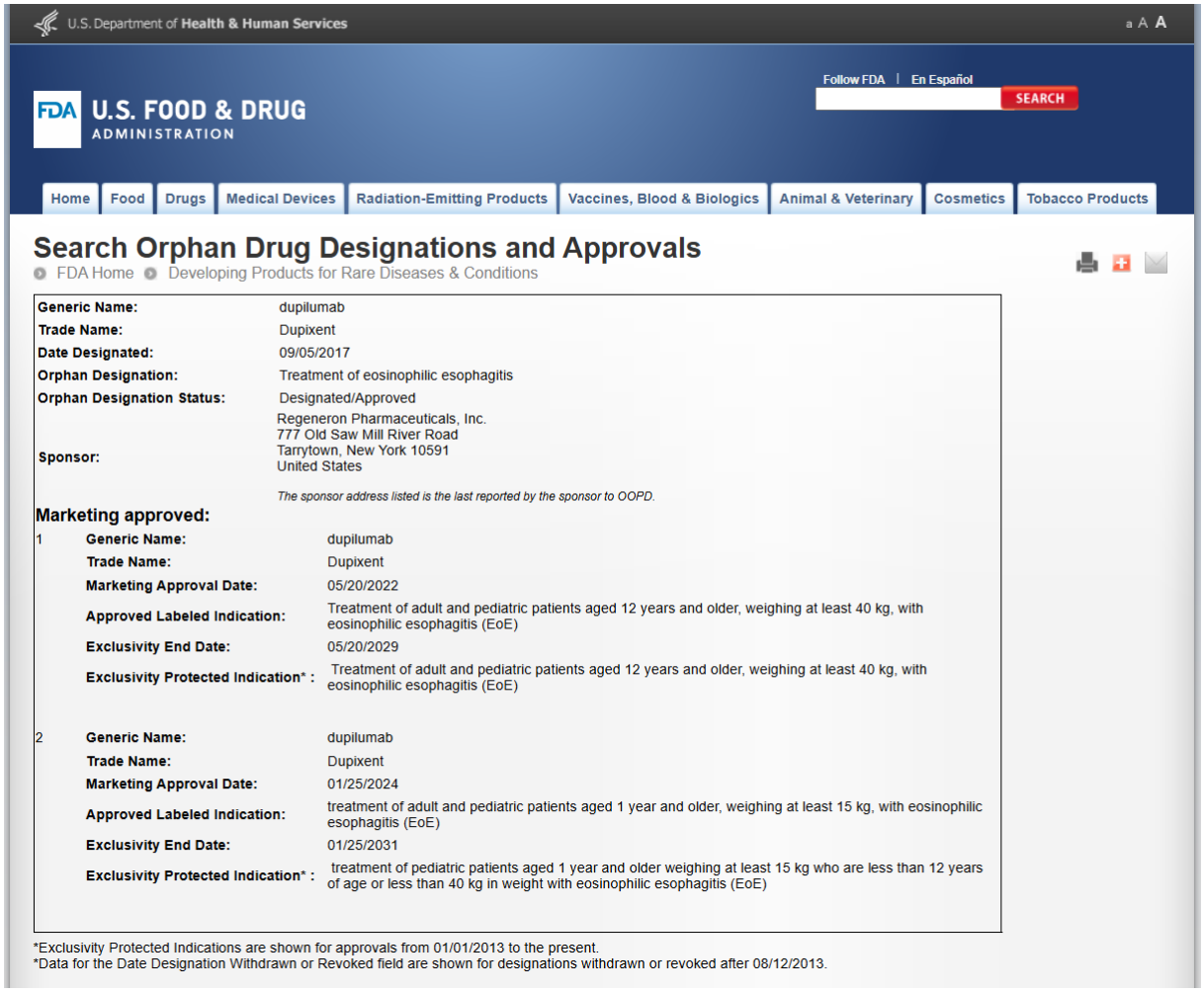
[2] Or. Rev. Stat. § 646A.694(2) (2023).
[3] Sanofi, Press Release, Dupixent Approved in the US as the First-Ever Biologic Medicine for Patients with COPD (Sept. 27, 2024), https://www.sanofi.com/assets/dotcom/pressreleases/2024/2024-09-27-13-35-00-2954551-en.pdf.
[4] Sanofi, Press Release, Dupixent sBLA accepted for FDA priority review for the targeted treatment of bullous pemphigoid, (Feb. 18, 2025), https://www.sanofi.com/en/media-room/press-releases/2025/2025-02-18-06-00-00-3027482.

Attachment A: FDA Orphan Drug Designations and Approvals database entry for Dupixent®



U.S. Department of Health & Human Services

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Generic Name:	dupilumab
Trade Name:	Dupixent
Date Designated:	09/05/2017
Orphan Designation:	Treatment of eosinophilic esophagitis
Orphan Designation Status:	Designated/Approved
Sponsor:	Regeneron Pharmaceuticals, Inc. 777 Old Saw Mill River Road Tarrytown, New York 10591 United States

The sponsor address listed is the last reported by the sponsor to OOPD.

Marketing approved:

1	**Generic Name:**	dupilumab
	Trade Name:	Dupixent
	Marketing Approval Date:	05/20/2022
	Approved Labeled Indication:	Treatment of adult and pediatric patients aged 12 years and older, weighing at least 40 kg, with eosinophilic esophagitis (EoE)
	Exclusivity End Date:	05/20/2029
	Exclusivity Protected Indication* :	Treatment of adult and pediatric patients aged 12 years and older, weighing at least 40 kg, with eosinophilic esophagitis (EoE)
2	**Generic Name:**	dupilumab
	Trade Name:	Dupixent
	Marketing Approval Date:	01/25/2024
	Approved Labeled Indication:	treatment of adult and pediatric patients aged 1 year and older, weighing at least 15 kg, with eosinophilic esophagitis (EoE)
	Exclusivity End Date:	01/25/2031
	Exclusivity Protected Indication* :	treatment of pediatric patients aged 1 year and older weighing at least 15 kg who are less than 12 years of age or less than 40 kg in weight with eosinophilic esophagitis (EoE)

*Exclusivity Protected Indications are shown for approvals from 01/01/2013 to the present.
*Data for the Date Designation Withdrawn or Revoked field are shown for designations withdrawn or revoked after 08/12/2013.

National
Multiple Sclerosis
Society

April 11, 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 continue 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 Roadmap and Timeline
The Society has reviewed the document packet for the April 2025 meeting which includes a roadmap and timeline for the pending affordability review processes. We appreciate the Board restarting the affordability review process after a needed pause for public input and refocus on the core goal, which is to strive to understand and lower the costs of vital prescription medications for all Oregonians. The current public commenting and RFI process should give the Board newer and greater insights into the realities faced when Oregonians are confronting the costs associated with utilizing these innovative pharmaceuticals.

The proposed review timeline is ambitions but should provide the needed pathway to fully study the proposed drug list, conduct the affordability reviews, collect and respond to public feedback, and make the legislative amendment recommendations for nine (9) drugs and at least one (1) insulin product which create affordability challenges to Oregon health system and/or patient out-of-pocket costs.

The Society recommends that before any votes are taken to add a drug to the affordability review recommendations to the legislature, all public comment be considered, all drugs be reviewed, and there be a focus on the drugs which would have the largest impact on both state and individual resources. Public comments specific to the identified drugs should be open and ongoing through the process and have multiple rounds of public notice. We look forward to continuing to engage in the process over the coming months as the Board drives towards its legislative recommendations.

Board Accessibility and Public Comment
The Society appreciates the continuing 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 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

OCAP OREGON COALITION FOR AFFORDABLE PRESCRIPTIONS

April 11, 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,

Thank you for your ongoing service to Oregon patients. The Oregon Coalition for Affordable Prescriptions (OCAP) represents individuals and families across the state who are struggling to afford the medications they need. We do not accept funding from the pharmaceutical industry and speak on behalf of Oregon patients.

We appreciate your thoughtful deliberations and vote to identify 27 drugs for potential affordability review at last month's meeting. **As the affordability review process advances, we urge you to prioritize the lived experiences of Oregon patients.** As we've shared in previous testimony, over one in four Oregon adults reported rationing their medications last year—cutting pills, skipping doses, or going without prescriptions due to cost.[1] This is unacceptable.

We were happy to hear about the development of tools and outreach plans that aim to include patient voices more broadly in the affordability review process. But we also want to be clear: **If you hear more from industry representatives than from patients, the process is not working as intended.** Outreach must be robust and inclusive, especially to communities disproportionately impacted by high drug prices.

We strongly urge you to stay the course and resist pressure to delay or weaken the review process. Industry-funded efforts to stall affordability reviews protect profits, not patients. Meanwhile, polling consistently shows that Oregonians—across geography, income levels, and political affiliations—support efforts to rein in excessive drug prices.[2]

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[1] 2024 Poll of Oregon Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey
[2] 2024 Poll of Oregon Adults, Ages 18+, Altarum Healthcare Value Hub's Consumer Healthcare Experience State Survey

OCAP OREGON COALITION FOR AFFORDABLE PRESCRIPTIONS

The stakes are rising. The federal administration has proposed tariffs on at least some pharmaceutical imports[3], which could further drive up prices and deepen drug shortages. This only reinforces the importance of PDAB's work. **Now is the time for bold, patient-centered action.**

Thank you for the opportunity to provide comments. OCAP is more than happy to support the Board's work and help ensure the affordability review process includes as many voices of Oregon patients impacted by high drug costs as possible. 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)
Inga Deckert, (Kaiser Permanente)
Marcus Mundy, (Coalition of Communities of Color)
Odalis Aguilar, (AFSCME Council 75)
Christi Marcotte, (Oregon Health Care Provider)

[3] King, J. (2025, April 09). *Trump To Set Tariffs on Pharmaceutical Products: What We Know*. Newsweek. https://www.newsweek.com/donald-trump-tariffs-pharmaceutical-imports-2057258

HealthHIV

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

202.232.6749 | healthhiv.org

April 14, 2025

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

Dear Members of the Oregon Prescription Drug Affordability Board,

We appreciate the Board's work toward transparency and its ongoing efforts to gather public input as affordability review processes evolve, particularly given that an HIV medication has been identified. As a national organization engaged in HIV, viral hepatitis, STI, and LGBTQ+ health (and as someone whose connections to Oregon's HIV work span decades), we recognize the urgency of addressing prescription drug affordability while safeguarding equitable access to clinically essential—and, in the case of HIV, *life-saving*—medications. These therapies are critical not only for individual care but for public health writ large. We also recognize the complexity of this charge and support a measured, data-informed approach that accounts for both patient-level impacts and broader system effects.

We encourage the Board to continue evaluating review criteria that account for therapeutic class—particularly when the class involves the treatment or prevention of communicable diseases, where individual access directly influences public health, intersects with patient population size, and carries a higher risk of disruption to critical health infrastructure.

While the Board appropriately outlines the three traditional categories of insurance cost-sharing—deductibles, copayments, and coinsurance—we encourage consideration of a fourth, often overlooked mechanism: the system of safety-net facilitation and programmatic access that overlays the commercial market. Programs like the Ryan White HIV/AIDS Program do not function as insurance but instead fill structural gaps by subsidizing premiums, supporting access through 340B reinvestments (across various covered entity entry points, including community health centers, ASOs, and specialty clinics), navigating patient assistance programs, and coordinating non-medical services that enable treatment adherence. These interventions often determine whether patients can obtain and stay on essential medications, particularly in communities with fluctuating insurance status or systemic barriers to coverage. Their exclusion from affordability impact frameworks risks leaving critical access dynamics off the table. Including these products without full consideration of their ecosystem context could unintentionally disrupt care continuity and increase system-level costs.

We appreciate the Board's attention to safety-net provider perspectives and encourage continued efforts to engage a broader range of organizations, including those specific to HIV care, Oregon Health Authority contractors, and related service networks. We urge inclusion of voices from community health centers, rural clinics, and 340B-covered entities, as these providers are often closest to affordability gaps and may face downstream consequences from affordability determinations.

Thank You *all* for your continued and thoughtful deliberations, and for your commitment to a process that centers affordability without compromising access.

Scott D Bertani, MNM, PgMP,

Director of Advocacy for HealthHIV

Johnson & Johnson

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

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

Via Electronic Submission

April 14, 2025

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

Dear Board Chair Bailey:

Johnson & Johnson Innovative Medicines offers comments and questions to the Oregon Prescription Drug Affordability Board ("PDAB" or "Board") on the drug affordability review process and the following Requests for Information ("RFIs"), which were posted on the PDAB's website on March 31, 2025 and are due on April 30, 2025:

- "Request for Information: Manufacturers" ("Manufacturers' RFI");
- "Request for Information: Patients, Caregivers, or Advocacy Groups" ("Patients' RFI"); and
- "Request for Information: Individuals with Scientific or Medical Training" ("Scientific & Medical RFI").

In addition, we have concerns regarding the constitutionality of the statute on which the Board decisions are based. We request that the PDAB respond to our questions during the April 16, 2025 Board meeting.

We share the PDAB's goal of improving affordability and access to lifesaving medicines for Oregon patients. However, we oppose the affordability review process because it may result in negative unintended consequences throughout the supply chain, including increased out-of-pocket costs and decreased access for patients.[1] In particular, we seek to raise the following concerns:

- The subset list of drugs was created using flawed, outdated data and inconsistently applied eligibility criteria.
- RFIs on the value of a drug are insufficient.
- RFIs on out-of-pocket costs ("OOP") are inadequate.
- The Manufacturers' RFI requests data that is confidential, unavailable, or is difficult to

[1] Johnson & Johnson, *Influence of Prescription Drug Affordability Boards and Upper Payment Limits on the State Drug Pricing Ecosystem* (2024), https://transparencyreport.janssen.com/influence-of-prescription-drug-affordability-boards-and-upper-payment-limits-on-the-state-drug-pricing-ecosystem (last visited Apr. 11, 2025); Avalere Health, *Update: Health Plans' Perceptions of PDABs and UPLs* (Mar. 28, 2025), https://advisory.avalerehealth.com/insights/update-health-plans-perceptions-of-pdabs-and-upls (last visited Apr. 11, 2025).

provide within 30 days.

- The PDAB's affordability review process lacks transparency; we request clarity on the questions in Section E below during the April 16, 2025 Board meeting.

A. The Subset List of Drugs Was Created Using Flawed, Outdated Data and Inconsistently Applied Eligibility Criteria.

The PDAB's "Subset List of 2023 Prescription Drugs for Affordability Reviews" (List) was developed using flawed and outdated data and inconsistent eligibility criteria. Stakeholders previously noted inaccuracies in the 2025 Affordability Review Data and Dashboard, which was used to create the List, including incorrect WAC average calculations likely based on mistaken assumptions about treatment duration.[2] Despite these issues, the PDAB proceeded to use this flawed data to create the List.

When selecting drugs for the List, the Board used eligibility criteria without clear justification. For instance, last year, drugs subject to the Inflation Reduction Act's "Maximum Fair Price" ("MFP") were excluded. Likewise, in December 2024, the PDAB published its Final UPL Report to the Legislature, which advised that the Board should continue to exclude "MFP" drugs.[3] Yet, this year, "MFP" drugs were included on the List. "MFPs" for the first round of drugs will go into effect in 2026, and initial unintended consequences are already starting to emerge for "MFP" drugs, including constraints on pharmacists and reduced patient access. Therefore, the PDAB should heed its own advice and exclude "MFP" drugs.

Furthermore, the 2025 Affordability Review Data and Dashboard relies on outdated 2023 data, failing to consider that some drugs now have FDA-approved therapeutic equivalents. Irrelevant data, such as whether a drug appeared on last year's affordability review list, was also included, despite the potential to introduce bias. Therefore, we request that the Board pause its RFIs until these issues are resolved.

B. RFIs on the Value of a Drug Are Insufficient.

The RFIs do not sufficiently seek data on the drugs' therapeutic benefit. As stated in a PDAB staff presentation from January 15, 2025, affordability reviews must include information to help the Board determine if price "is justified based on clinical value and the outcome" of the drug.[4]

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[2] BIO, *Comment from the Biotechnology Innovation Organization (BIO) and Oregon Bioscience Association (Oregon Bio) to the Oregon PDAB* (Feb. 12, 2025), https://dfr.oregon.gov/pdab/Documents/20250219-PDAB-public-comments.pdf.

[3] *Prescription Drug Affordability Board (PDAB) Upper Payment Limit (UPL) Report to the Legislature* (Dec. 2024), https://dfr.oregon.gov/pdab/Documents/reports/PDAB-upper-payment-limit-report-2024.pdf (last visited Apr. 8, 2025).

[4] Cortnee Whitlock, *Prescription Drug Affordability Board, Affordability Review*, (Jan. 15, 2025) https://dfr.oregon.gov/pdab/Documents/20250115-PDAB-document-package.pdf#Page=44 (last visited Apr. 8, 2025).

Yet, only the Medical and Scientific RFI solicits input on clinical benefits.[5] The Scientific and Medical RFI is extensive, and some of the drugs on the List are within the same therapeutic class. Individuals with scientific and medical training may not have time to complete the RFI for all drugs on the List that are within the same class by the April 30 deadline. Additionally, given the format of the Scientific and Medical RFI, it is unclear how they could submit scientific data, such as peer reviewed studies. As such, there may be a small response pool and anecdotal data rather than scientific evidence on a drug's value.

Moreover, Oregon law prohibits the PDAB from using cost-effectiveness data that employs quality-adjusted life-years (QALYs) or similar formulas due to concerns about discrimination based on age, health, and disability.[6] It remains unclear how the Board will ensure that the data collected does not rely on QALYs and similar formulas, whether the Board will gather additional data to supplement the RFIs, or how the Board will be able to define value in an objective and consistent way. Therefore, we request that the PDAB clarify its approach to accurately assessing drug value at the April 16, 2025 Board meeting.

C. RFIs on Out-Of-Pocket Costs Are Inadequate.

The RFIs are unlikely to result in accurate or sufficient assessments of patient cost-sharing. Oregon law requires the PDAB to identify nine drugs that may either "create affordability challenges for health care systems ***OR high out-of-pocket costs for patients in the state***" (emphasis added).[7] As noted in J&J's previous comments, patient affordability challenges often stem from high out-of-pocket (OOP) costs, as determined by health plans and pharmacy benefit managers (PBMs)—not manufacturers.

The Patients' RFI is the only RFI requesting data on patient OOP costs. Yet, responses are likely to be anecdotal and may not accurately reflect average OOP costs for Oregon patients. For example, that RFI asks for the "most recent monthly, out-of-pocket cost" for the drug.[8] Yet, out-of-pocket costs may vary widely due to factors such as dose, treatment duration, type of health plan, deductible status, utilization management, tier placement, copay assistance, or use of copay accumulators, maximizers, or alternative funding programs. As such, there may be significant variations in coverage and cost-sharing.

The extent to which the PDAB is engaging in stakeholder outreach is also unclear. Previous attempts to seek patient, caregiver, and advocacy group input have resulted in low response rates. Insufficient responses and selection bias may result in a sample that does not accurately reflect the characteristics of the target population.

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[5] Oregon PDAB, *RFI Surveys*, https://dfr.oregon.gov/pdab/Pages/affordability-review.aspx (last visited Apr. 11, 2025).
[6] OR Rev. Stat. § 646A.694(4).
[7] OR Rev. Stat. § 646A.694(1).
[8] Oregon PDAB, *Request for Information: Patients, Caregivers, or Advocacy Groups*, https://forms.office.com/pages/responsepage.aspx?id=Mmk_qnz6tEegzqWYytFhz9y8eINey1hChuhr1FkbA3pURUJXOVpCSDNUMFFaUVdEQTFRNVlGOTNYOSQlQCN0PWcu&route=shorturl

Additionally, patients and caregivers who do respond may not understand the terminology used in the RFI or accurately gage cost-sharing responsibilities. A 2023 survey from KFF found that half of insured adults have at least some difficulty understanding their insurance, including their coverage, what they owe out of pocket, and common health insurance terms.[9] Another study published in 2022 noted that only 16% of survey respondents could calculate their out-of-pocket costs.[10] Consequently, self-reported, anecdotal evidence from a limited number of respondents is unlikely to accurately portray patient affordability. Therefore, the PDAB should gather this information from entities that directly control OOP costs—health plans and PBMs.

D. The Manufacturers' RFI Requests Data that Is Confidential, Unavailable, or Is Difficult to Provide within 30 Days.

The Manufacturers' RFI presents several challenges, including requests for confidential, unavailable, or hard to obtain data. The PDAB lacks a process to ensure the confidentiality of manufacturer-submitted data. The RFI states that only personal contact information will be protected from public disclosure.[11] Yet, much of the requested information is confidential or unavailable in the public domain.

Additionally, the RFI asks manufacturers to provide information on ***competitors'*** therapeutic alternatives (requests for ***competitors'*** estimated net sales, net costs, and average price concessions, discounts, and rebates). Manufacturers do not have access to such information. Additionally, indications can vastly differ between products, creating ambiguity as to which products would fit within the therapeutic alternative classification. Finally, collecting much of the requested information is burdensome and may not be feasible as manufacturers may not currently collect certain requested data. It is significantly challenging, and may be outside of manufacturer's control some cases (e.g., competitors' pricing data), to provide all the requested data within the 30-day timeframe. The Board should revise its requests and extend its submission deadline.

E. The PDAB's Affordability Review Process Lacks Transparency; We Request Clarity During the April 16, 2025 Board Meeting.

Due to a lack of transparency, it is unclear how the PDAB will conduct its affordability reviews,

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[9] Karen Pollitz, et al., *KFF Survey of Consumer Experiences with Health Insurance*, KFF (June 15, 2023), https://www.kff.org/private-insurance/poll-finding/kff-survey-of-consumer-experiences-with-health-insurance/#:~:text=Among%20the%2058%25%20of%20insured,availability%20of%20mental%20health%20providers (last visited Apr. 11, 2025).

[10] Rishtya Kakar, et al, *Health Insurance Literacy Perceptions and the Needs of a Working-Class Community*, Health Lit. Res. Practice (Mar. 31, 2022) https://pmc.ncbi.nlm.nih.gov/articles/PMC8973763/#:~:text=A%20large%20nationally%20representative%20survey,et%20al.%2C%202014) (last visited Apr. 11, 2025).

[11] Oregon PDAB, *Request for Information: Manufacturers*, https://forms.office.com/pages/responsepage.aspx?id=Mmk_qnz6tEegzqWYytFhz9y8eINey1hChuhr1FkbA3pUNUZTSDJBMFFET0dLMUdJMzFOMjEyMjRSUyQlQCN0PWcu&route=shorturl (last visited Apr. 11, 2025).

what scientific processes will be used, or whether such processes will be evidence-based. The Board must collect and analyze data for 27 drugs and selected insulin products, narrow the list to nine drugs and one insulin product, and prepare a report to the Legislature by year-end. It appears that the Board is planning to review all 27 drugs as well as any selected insulin products between June and October, meaning six or more drugs may be reviewed at each Board meeting.[12] It is unclear how the Board will ensure 1) adequate stakeholder outreach and engagement; and 2) thorough analysis for each drug. The affordability review process and engagement opportunities are not clearly outlined. Therefore, we request answers to the following questions during the Board meeting on April 16, 2025:

- Will the Manufacturers' RFI be the only opportunity for manufacturers to provide input?
- Will each of the 27 drugs under review receive public hearings with stakeholder input?
- Will the Board narrow the List further before it begins its affordability reviews?
- How will the Board ensure that its processes are evidence-based and scientific?
- How will the PDAB assess the data it receives from stakeholders and develop its final list? Will this information be in the public domain with opportunity to provide corrective feedback where applicable?

As one of the nation's leading healthcare companies, J&J has a responsibility to engage with stakeholders in constructive dialogue to address these gaps in affordability, access and health equity as well as protect our nation's leading role in the global innovation ecosystem.

We know that patients are counting on us to develop and bring medicines to market. 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.

Sincerely,

Michael Valenta
Vice President, Value, Access & Pricing, Strategic Customer Group
Johnson & Johnson Services, Inc.

[12] Oregon PDAB, *Agenda for April 16, 2025 Board Meeting*, https://dfr.oregon.gov/pdab/Documents/20250416-PDAB-document-package.pdf (last visited Apr. 11, 2025).

EACH PIC COALITION

April 14, 2025

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

RE: Public Comments on Subset List RFI, Cost 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. We write to offer feedback on the current Request for Information (RFI) process, public engagement opportunities, and the overall direction of the cost review framework.

RFI Process and Public Comment Timeline

We commend the board for accepting and integrating stakeholder input on the RFI forms, particularly efforts to make the patient form more accessible and relevant. While not all patient-suggested changes were incorporated, this responsiveness to community feedback is an important step forward and reflects the board's stated commitment to transparency and inclusiveness. We also would like to thank the Board for including patient organizations as a stakeholder group invited to provide information on behalf of patients and caregivers. However, the published survey as designed is only usable for individuals (i.e., requests for dosage, how long on the drug, etc.) We do appreciate acknowledgement of this issue and the suggestion for patient organizations to submit patient and caregiver data through written comments.

We are concerned that the current 30-day comment period to provide feedback on 27 medications is not sufficient. More time is required to ensure patients, caregivers, and organizations can meaningfully contribute to the review process and provide feedback on the medications included in the subset list. We respectfully urge the board to extend the public comment period to a minimum of 60 days to allow meaningful participation from patients, caregivers, and patient organizations.

We also request additional transparency around how the comment period is being publicized and whether a minimum threshold of responses is required before moving forward with review decisions. Public awareness and engagement are critical to the legitimacy and success of the review process.

We look forward to the upcoming April board meeting, where we hope additional clarity will be provided on how data collected via the RFI will be shared with the public and board members. The agenda notes that a "report" will be provided to board members. We would like to note that a staff summary of RFI responses is not adequate for board members or for the public. For

transparency purposes, we request that patient responses redact personal identification, but include individual submissions with unedited, open-ended comments, so authentic patient experiences can be referenced during review processes.

Additionally, we would like more detail on the May 21 public meeting. We ask whether patients will be given designated time or accommodations to speak and how this meeting will differ in structure or purpose from standard board meetings. Early information about format and participation opportunities will help ensure robust engagement.

Ensuring Meaningful Public Input During Cost Reviews

We understand that the cost review process includes a public comment component once the nine drugs and one insulin product are selected. We urge the board to ensure these comment periods are clearly announced in advance and that at least 45 days are provided for input. Comment periods should be accompanied by broad outreach from the board and state agencies to ensure patients and organizations are aware of their opportunity to weigh in.

It is essential that patient input be prioritized throughout this process. The individuals who rely on these medications every day must be seen as subject matter experts, and their insights should shape the outcome of these reviews.

Centering the Process on Patient Burdens and Affordability

We continue to encourage the board to center cost reviews around the lived experiences of patients and the real-world affordability challenges they face. A review that focuses solely on systemic or payer-level costs risks overlooking the most meaningful aspect of affordability: the context behind affordability concerns, including the impact on people's ability to access and adhere to their prescribed medications.

We encourage the board to take the necessary time and care to ensure this process supports, not disrupts, continuity of care. Patients must not face unintended consequences from policy decisions that limit treatment options or impose additional burdens.

To that end, we strongly urge the board and staff to utilize the authority of the board to fully explore with all healthcare stakeholders how cost reviews will be implemented and identify in advance any potential adverse impact to patients.

Finally, we invite the board to utilize this organization and its EACH and PIC members as a direct conduit to understanding and incorporating patient and caregiver perspectives, as we have the best understanding of the life cycle of disease from the lens of prevention, diagnosis, and disease management.

We appreciate your commitment to this work and offer our coalition as a continued resource in elevating patient voices and informing thoughtful, patient-centered policymaking.

Sincerely,

Tiffany Westrich-Robertson

Tiffany Westrich-Robertson
Ensuring Access through Collaborative Health (EACH) Coalition/Patient Inclusion Council

April 14, 2025

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

Dear Chair Bailey and Members of the Prescription Drug Affordability Board,

Ahead of the Board's April 19 meeting, the Oregon Society of Medical Oncology (OSMO) and the Association for Clinical Oncology (ASCO) would like to express our concern that upper payment limits (UPLs) for cancer drugs could disproportionately impact Oregon patients with cancer.

OSMO is a professional organization whose mission is to facilitate improvements for Oregon physician specialties in both hematology and oncology. OSMO members are a community of hematologists, oncologists, advanced practice providers, and other physicians who specialize in cancer care. ASCO is the world's leading professional society representing physicians who care for people with cancer. With over 50,000 members, our core mission is to ensure that patients with cancer have meaningful access to high-quality cancer care.

Oncologists do not set or control drug prices; they offer each patient the most appropriate, evidence-based treatment that will ensure the best outcome for an individual patient with cancer and his or her specific disease. The subset list of 2023 prescription drugs for affordability review targets three drugs used to treat cancer, including a drug administered by infusion or injection in a physician's office.

Physician-administered therapies are not limited to cancer; treatment for many chronic conditions such as multiple sclerosis, rheumatoid arthritis, and macular degeneration includes their use. An upper payment limit for a physician-administered drug could impact how health plans design benefits and tiering for drugs under the medical benefit, which could impact a physician's ability to use the right medication at the right time. We are concerned that reimbursement for a physician-administered drug with a UPL will fail to cover costs incurred for procuring, storing, and handling highly toxic agents. Medicare and private market reimbursement for physician-administered drugs includes payment to cover costs associated with drug treatments in physicians' offices. Without such payment for drugs subject to a UPL within state regulated plans, oncology practices could face a financial burden that puts them at risk of closure and patients could face delays in care or have to travel further for treatment.

As the Board conducts affordability reviews, we urge you to consider the type of drug and whether it is administered through a clinic or physician's office, as outlined on page 39 of the 2024 PDAB Upper Payment Limit Report. We appreciate the opportunity to provide comments and offer ourselves as a resource. Please contact Sarah Lanford at sarah.lanford@asco.org if you have any questions or if we can be of assistance.

Sincerely,

Holly Almond, NP, MSN, RN, BA
President
Oregon Society of Medical Oncology

Eric P. Winer, MD, FASCO
Chair of the Board
Association for Clinical Oncology

HIV+HEP
POLICY INSTITUTE

April 14, 2025

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

Re: Public Comment for April 16, 2025 Board Meeting

Dear Members of the Oregon Prescription Drug Affordability Board:

The **HIV+Hepatitis Policy Institute** is a leading advocate for equitable and affordable healthcare for individuals living with or at risk of HIV, hepatitis, and other serious or chronic health conditions. As the Board finalizes its list of prescription drugs to review, we want to reiterate our concerns about the inclusion of any HIV medications and encourage the Board to reconsider their inclusion. We believe that affordability reviews of HIV medications fail to fully account for the intricacies of the existing HIV safety net, which makes lifesaving HIV treatments affordable for most people. We also want to highlight numerous factors in the global HIV drug ecosystem that would be difficult for a state to effectively consider.

Since the onset of the AIDS crisis in the 1980s, our community has tirelessly fought for access to effective treatments, leading to the establishment of vital safety net programs that ensure HIV care and medications remain affordable. Programs such as the Ryan White HIV/AIDS Program provide $2.5 billion annually to ensure HIV treatments and care to low-income people living with HIV[i]. The Ryan White Programs generates $2.8 billion in drug purchases through the 340B program[ii] enabling crucial wraparound services and provide care and treatment to those who cannot afford it. Additionally, drug manufacturers contribute over $1 billion in rebates directly to state AIDS Drug Assistance Programs-all to help with affordability of HIV drugs.[iii]

For example, Oregon's ADAP, known as CAREAssist, operates with a diverse funding stream totaling approximately $50 million, sourced from Part B funding, rebates, and program income. This funding covers essential medications and services for people living with HIV[iv]. Further affordability is achieved through additional rebate programs, such as Medicaid drug rebates, which help reduce the financial burden on public programs.

Pharmaceutical manufacturers also play a key role, contributing billions through copay assistance, free medication programs, and global initiatives like PEPFAR, which expand access to affordable HIV treatments worldwide. While gaps in coverage remain, this robust safety net has

been instrumental in ensuring people living with HIV receive the care and medications they need at an affordable rate.

Federal policies have further reinforced this safety net, helping to expand access to preventive care. For instance, the Affordable Care Act (ACA) and recommendations from the U.S. Preventive Services Task Force (USPSTF) have eliminated financial barriers by mandating that PrEP (pre-exposure prophylaxis) be available at no cost to most insured individuals. This policy ensures that those vulnerable to HIV can access lifesaving preventive treatments, complementing safety net programs and helping to reduce the spread of the virus-for free.

Affordability reviews of HIV medications may fail to fully capture the complexity and interdependence of safety net programs, which not only ensure affordability for patients but also sustain the broader HIV care infrastructure. Pricing interventions, such as the imposition of upper payment limits (UPLs), could destabilize this ecosystem, jeopardizing access to care and disincentivizing pharmaceutical manufacturers from continuing the research and development that has driven remarkable progress. The transformative innovations enabled by this investment—including longer-acting treatments, preventive therapies, vaccines, and the hope of an eventual cure—could be at risk if the delicate balance of these systems is disrupted.

The impact of these advancements cannot be overstated. Antiretroviral therapy (ART) has drastically changed the prognosis and quality of life for people living with HIV. When the first highly effective ART became available in 1996, a 20-year-old newly diagnosed with HIV had a life expectancy of just 10 years. Today, thanks to modern therapies, individuals with HIV enjoy lifespans comparable to the general population, with improved tolerability and far fewer side effects. These innovations have transformed HIV from a terminal illness into a manageable chronic condition for millions.

Importantly, high out-of-pocket costs for patients often stem from systemic issues unrelated to drug pricing, such as insurer practices and pharmacy benefit manager (PBM) strategies. Policymakers should focus on addressing these barriers through targeted reforms, such as regulating PBMs, capping out-of-pocket expenses, and ensuring that copay assistance counts toward deductibles. These solutions can improve affordability for patients without undermining the infrastructure and progress that have revolutionized HIV care.

We strongly believe that affordability reviews of HIV medications are unnecessary, given the comprehensive safety net programs that effectively ensure access to lifesaving treatments. Any future pricing interventions, such as the imposition of UPLs, could destabilize this well-established network, threatening access to care for people living with HIV. Programs like the Ryan White HIV/AIDS Program, the 340B program, and manufacturer copay assistance are critical to sustaining the progress and innovation that have transformed HIV treatment.

As we look to the future, it is essential to protect and strengthen these systems that have saved and transformed countless lives. Policymakers must prioritize targeted solutions that enhance affordability without compromising the stability of the infrastructure that has been pivotal in

the fight against HIV. By preserving this delicate balance, we can continue to provide hope and care for millions living with HIV while advancing toward the ultimate goal of ending the epidemic.

Thank you for your consideration of these comments. We urge the Board to carefully weigh the potential consequences of including HIV medications in the affordability review process and to recognize the vital role existing programs play in ensuring access to care. We welcome the opportunity to serve as a resource as the Board continues its important work to advance affordable and equitable healthcare for all Oregonians. If you have any questions or need any additional information, please do not hesitate to reach out to our Government Affairs Manager, Zach Lynkiewicz, at zlynkiewicz@hivhep.org.

Sincerely,

Carl E. Schmid II
Executive Director

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[i] Ryan White HIV/AIDS Program Funding: FY 2015–FY 2024 appropriations by program
[ii] 2023 340B Covered Entity Purchases
[iii] 2024 National RWHA Part B ADAP Monitoring Project Annual Report
[iv] KFF: Distribution of ADAP Budget by Source

April 14, 2025

Re: Oregon PDAB Draft Generic Drug Report and Process for Affordability Review Determinations

Honorable Members of the Oregon Prescription Drug Affordability Board,

The Alliance for Health Innovation (Alliance) is a group of cross-sector stakeholders representing patients, providers, caregivers, academia, biopharmaceutical innovators, and business communities. Led by the Global Coalition on Aging (GCOA), the Alliance is committed to establishing the importance of innovation in achieving healthy aging. We advocate for state policy solutions that support a thriving innovation sector, enabling Oregon residents and other communities to live longer and healthier lives.

We thank the Board for the opportunity to comment on the draft of the "Generic Drug Report" and how this will be utilized to conduct affordability reviews of the current list of 27 identified drugs, potentially subjecting them to an Upper Payment Limit (UPL) in the future.

We write today to express significant concern about the drugs included on the draft list for review, particularly considering the current federal policy landscape, including cuts to public health infrastructure, and HIV research. [1,2] These changes, many of which were noted in the Generic Drug Report, stand to negatively impact both patient affordability and access. Should the Board proceed with an affordability review of the named drugs, they would be contributing to the uncertainty patients and communities are experiencing during these troubling times, which could further harm patient access and future innovation of life-saving therapeutics.

Furthermore, questions of concern related to the PDAB's data reliability threaten to exacerbate challenges around access to care and deepen disparities. Based on the Oregon Drug Price Transparency (DPT) reports, only about 25% of the lives in Oregon are accounted for in the PDAB's analysis.[3] When healthcare determinations are built on a foundation of inaccurate or incomplete data, communities and sub-populations that are underrepresented will experience the most harm, further exacerbating inequities and access challenges in the state.

Many diseases that once burdened aging populations have evolved into manageable chronic conditions due to modern, safer, and more effective treatments, allowing many patients to live longer, healthier lives. This is especially true in Oregon, where, by 2034, according to the most recent State Plan on Aging, adults over 65 will be a larger age demographic than those 18 and under. Further, people of color are projected to comprise 45% of the state's older adult population by 2050.[4]

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[1] (April 1, 2025) The Associated Press. Here's where jobs and programs are being cut at the nation's top health agencies. https://apnews.com/article/trump-hhs-cdc-fda-nih-cms-layoffs-5aba829b829d9e1a0167c4a0d968aadb
[2] (March 25, 2025) CNN. 'People will die based on these decisions': Trump administration cuts funding for dozens of HIV studies. https://www.cnn.com/2025/03/25/health/hiv-research-funding-cut/index.html
[3] Oregon Division of Financial Regulation (DFR). Prescription Drug Price Transparency. https://dfr.oregon.gov/drugtransparency/Pages/insurers.aspx
[4] (October 2023) Oregon State Plan on Aging. Oregon Department of Human Services. https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/de-9397a_23.pdf

HIV serves as a strong example of the impact that innovation can have to change the course of a disease and how price-setting policies could derail progress for aging populations. Thanks to years of biomedical investment and innovation, a person with HIV who starts treatment soon after their diagnosis can expect to live the same lifespan as a person without HIV. By 2030, over 70% of the population of people with HIV in the US will be over the age of 50.[5]

While there have been significant strides to discover new treatments in recent decades, there remains a vast unmet patient need for new solutions to complex, age-related health challenges. And, as people with HIV live longer, these age-related health challenges can become compounded due to the development of comorbidities that affect health-related quality of life. People living with HIV are more likely to develop additional health issues as they age and tend to develop them earlier than people who do not have HIV. Due to concerns with the complexity of polypharmacy and drug-drug interactions, if not managed appropriately, healthcare costs have the potential to be significant. In Oregon, the prevalence of HIV is highest among those aged 45 and older, a statistic that should give the PDAB pause as to the impact of their decisions across a patient's continuum of living with and managing a chronic condition.[6] Everybody should have the opportunity for a better quality of life and healthier aging.

Continuity of care in HIV is of utmost importance, ensuring viral suppression and reducing the risk of drug resistance. Reducing the risk of transmission is paramount to ending the HIV epidemic in Oregon. The Medicare program has recognized the value of unimpeded patient access to provider-recommended treatments for HIV, including antiretrovirals on a list of six "protected classes" where "all or substantially all" such treatments are required to be covered by Part D plans.[7] Despite this, changes to funding at the federal level have strongly impacted HIV surveillance and research, leaving people living with HIV even more at risk from decisions made at the state level.[8] Moreover, cuts to federal DEI programs and those supporting care for transgender individuals could further complicate treatment access for people living with HIV.

Recognizing that the board currently does not have the authority to set Upper Payment Limits (UPLs) or a similar type of price-setting mechanism on medicines deemed to be unaffordable, the threat of these policies is being actively explored by Oregon policymakers. Policies such as UPLs typically dampen the environment which has enabled innovations that have allowed individuals with chronic and complex conditions to live longer and healthier lives.

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[5] (2017) Transactions of the American Clinical and Climatological Association vol. 128 "The Aging Population with HIV Infection." https://pmc.ncbi.nlm.nih.gov/articles/PMC5525433/
[6] Oregon Public Health Division – HIV, STD & TB Section. (2024) The Oregon HIV Epidemic. https://public.tableau.com/app/profile/oregon.health.authority.public.health.divison/viz/HIVinOregon/HomePage
[7] Centers for Medicare and Medicaid Services. Medicare Prescription Drug Benefit Manual. Chapter 6 – Part D Drugs and Formulary Requirements. https://www.cms.gov/Medicare/Prescription-Drug-Coverage/PrescriptionDrugCovContra/Downloads/Part-D-Benefits-Manual-Chapter-6.pdf
[8] (April 8, 2025) Kaiser Family Foundation. What Do Federal Staffing Cuts and HHS Restructuring Mean for the Nation's HIV Response? https://www.kff.org/policy-watch/what-do-federal-staffing-cuts-and-hhs-restructuring-mean-for-the-nations-hiv-response/

These policies also lead to significant access restrictions over time that, ironically, disproportionally affect the disadvantaged populations they intend to help. If, as noted in the Generic Drug Report, federal decisions such as tariffs impact the availability of generic and name-brand drugs, the access to life-saving medications could be further constricted, leading to devastating health and economic consequences.

UPLs can inadvertently restrict patient access to essential medications and treatments.[9] When reimbursement caps are imposed, there is a risk that the availability of necessary medicines may become limited. If PDABs and UPLs lead to lower reimbursement rates for programs and clinics that provide safety-net services, they threaten access to critical HIV treatments for patients and the ability of these providers to keep their doors open at the very time patients should be most protected, due to policy changes at the federal level. This especially impacts individuals with chronic or complex conditions who rely on specific treatments to manage their health effectively. Such restrictions can lead to delayed access to treatments or the necessity to resort to less effective or alternative therapies, ultimately compromising short- and long-term patient health outcomes.

The healthcare sector thrives on innovation, driven by the need to develop new treatments and technologies that improve patient care. Financial constraints imposed by UPLs deter pharmaceutical companies and researchers from investing in research and development efforts to discover and bring to market groundbreaking and more effective therapies. The prospect of lower returns on investment may lead to decreased funding for these critical R&D efforts, stifling the progress that is necessary to address unmet medical needs and advance healthcare solutions.

Lastly, UPLs are unlikely to reduce patients' out-of-pocket costs. Research from the Partnership to Fight Chronic Disease (PFCD) explored payer perspectives on UPLs, which revealed the potential impacts of PDABs using these tools to set price limits on prescription medicines. Most surveyed payers (five of six) did not anticipate that UPL-related savings would be passed on to patients through lower premiums, deductibles, or cost sharing.[10] All payers interviewed noted that drugs subject to a UPL and competitors in the same therapeutic class are likely to see increased utilization management should the UPL restructure new benefit designs. To date, there have been zero dollars worth of patient savings as a result of PDAB activities across states.[11]

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[9] (September 2024) Global Coalition on Aging. Policy Brief: The Risks of Prescription Drug Affordability Boards and the Importance of Innovation for Healthy Aging and Health Equity. https://globalcoalitiononaging.com/wp-content/uploads/2024/09/GCOA-Policy-Brief-The-Risks-of-Prescription-Drug-Affordability-Boards-and-the-Importance-of-Innovation-for-Healthy-Aging-and-Health-Equity_09.18.2024.pdf

[10] (April 2, 2024) PFCD. (New Insurer Perspectives Highlight Considerable Patient Challenges Anticipated from Prescription Drug Affordability Boards. *PFCD*. https://www.fightchronicdisease.org/latest-news/new-insurer-perspectives-highlight-considerable-patient-challenges-anticipated

[11] (September 2024) Global Coalition on Aging. Policy Brief: The Risks of Prescription Drug Affordability Boards and the Importance of Innovation for Healthy Aging and Health Equity. https://globalcoalitiononaging.com/wp-content/uploads/2024/09/GCOA-Policy-Brief-The-Risks-of-Prescription-Drug-Affordability-Boards-and-the-Importance-of-Innovation-for-Healthy-Aging-and-Health-Equity_09.18.2024.pdf

Global Coalition on Aging

While PDABs are already costly for states in terms of establishing and managing these boards, with the uncertainty surrounding HIV programs at the federal level, the Oregon PDAB likely would have to invest additional time and resources to meaningfully engage with patient concerns around the implications of selecting a treatment for HIV for an affordability review.

The concerns detailed in this letter and the Generic Drug Report present overwhelming challenges for individuals impacted by and aging with HIV in Oregon. As such, we urge the Oregon PDAB to exclude HIV treatments from the board's cost review process. Care delivery ecosystems are intricate and interconnected, making it impossible to evaluate them in isolation.

While controlling healthcare costs is a critical objective that we support, the board must recognize the potential consequences to Oregon's fragile safety-net services that connect patients to critical treatments and explore alternative approaches that balance cost control with the need to ensure patient access to essential treatments and foster ongoing medical advancements, including in HIV. The Oregon PDAB must consider these consequences in the context of the current health policy landscape, including decisions at the federal level that may impact pricing and access.

Thank you for allowing us to share our concerns and for your commitment to finding solutions to the affordability challenges that Oregon patients face. We would be happy to discuss these concerns further or answer any questions.

Sincerely,

Michiel Peters

Head of Advocacy Initiatives, Global Coalition on Aging