

A Member of the Roche Group 600 Massachusetts Ave. NW, Suite 300 Washington, DC 20001 Phone: (202) 296-7272 Fax: (202) 296-7290

October 13, 2023

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

### Re: Oregon Prescription Drug Affordability Review

Dear Members of the Oregon Prescription Drug Affordability Board:

We are writing today to share our observations with you regarding the Board's approach to selecting prescription drugs for affordability reviews. Thank you for the opportunity to comment on what we believe to be shortcomings in the data available for the board's consideration during their analysis of the affordability of prescription drugs and patient affordability in Oregon.

Genentech pioneered the biotech industry and revolutionized how we treat some of the world's most complex health problems. Today, as a member of the Roche Group, we remain dedicated to pursuing breakthrough research, developing life-changing medicines, unlocking advances in data and technology, and partnering across society to take on systemic issues that stand in the way of better healthcare for all. We are committed to improving patients' lives through 40 approved medicines and more than 85 potential new medicines in clinical development. Genentech has been proud to manufacture our medicines in Oregon since 2010 at our facility in Hillsboro.

### Limited Data Available for the Board's Use Skew Affordability Review Selection

In deliberations over the last few months, the Board's process has relied almost exclusively on data from Drug Price Transparency carrier reports. The methods for compiling the "DPT Carrier Data - Top Drugs to Review" included in the Board's September 20, 2023 meeting materials are unclear, and we believe this has resulted in an incomplete view of prescription drug spending in Oregon. Without transparent methodologies and complete data, results may be skewed leading to an undue emphasis on a limited number of prescription drugs.

For example, these summarized data suggest Genentech's OCREVUS® is the fourth most costly prescription drug in total annual spending per enrollee. OCREVUS is a therapeutic monoclonal antibody - the first and only FDA-approved disease-modifying therapy for primary progressive multiple sclerosis (PPMS).<sup>1,2</sup> It was the first FDA-approved MS treatment targeting cd20-positive b cells.<sup>3</sup> When OCREVUS launched in 2017, we set the annual wholesale acquisition cost (WAC) at \$65,000 per year – 25% less than interferon beta-1a (our clinical trial comparator) and nearly 20%

<sup>&</sup>lt;sup>1</sup> OCREVUS (ocrelizumab) Prescribing Information. Genentech, Inc. 2016.

<sup>&</sup>lt;sup>2</sup> National Multiple Sclerosis Society. Treating PPMS. Available at

http://www.nationalmssociety.org/What-is-MS/Types-of-MS/Primary-progressive-MS/Treating-Primary-Progressive-MS.

<sup>&</sup>lt;sup>3</sup> OCREVUS (ocrelizumab) Prescribing Information. Genentech, Inc. 2016.

below the average WAC for MS medicines at the time.<sup>4</sup> Now, in 2023, at \$75,102 per year, the WAC for OCREVUS is approximately 28% less than the average price for other MS medications.<sup>5</sup> However, the data in the Board's meeting materials do not include any other MS medicines which have higher annual WAC prices. Additional transparency on the methodologies used to create the "Top Drugs for Review" summary is necessary to understand and verify these results. In addition, the Board should seek to understand a more complete picture of prescription drug spending in Oregon before finalizing the selection of any prescription drug for an affordability review.

Annual costs should be only one consideration when addressing prescription drug spending. It is essential to consider a medicine's lifecycle, pricing history, supply chain economics, total cost of care, overall impact and value of the medicine, as well as the impact of price on patient out-of-pocket costs. In its nearly seven years on the market, OCREVUS pricing has not triggered any state-required price increase notice nor reporting under the state's transparency laws. Between launch in 2017 and 2023, OCREVUS WAC price increases averaged 2.44% per year (cumulative average growth rate, 2017-2023), while annual increases in CPI-U averaged 3.54% per year.<sup>6</sup> Additionally, Ocrevus' Average Sales Price (ASP), which Medicare and some commercial health plans use as the basis for patient cost-sharing for physician-administered drugs, has increased only 1.03% per year<sup>7</sup> (cumulative average growth rate), which supports patient affordability with minimal change in patient out-of-pocket expenses. While the summary data included in meeting materials does include "average year over year price change over the previous five years," these data have not been thoroughly discussed alongside other pricing metrics. Further, the Board has yet to focus on any data related to patient out-of-pocket expenses, which is an essential component of assessing affordability.

Considering these observations, we believe the data used to create the "Top Drugs for Review" list included in the Board's September and October meeting materials is incomplete, denying the Board a true picture of affordability. We urge the Board to further analyze the DPT Carrier Reports and their associated methodologies, and supplement these reports with data from the All Payer Claims Database to ensure a more robust view of prescription drug spending in Oregon, including patient out-of-pocket expenses, before moving forward in your affordability review selection process.

### Use of Limited Data in Drug Selection Omits Critical Context

In addition to the reliance to date on data for a limited number of drugs, the data the Board has been reviewing are devoid of critical context to understand a medicine's value and affordability. In the United States, value has historically been measured by considering the health benefits of a given medicine and the degree to which those benefits justify costs. When assessing the total value of a medicine, it is important to also consider its impact on patients, the healthcare system, and society. One key example of the lack of focus on the broader context of a prescription drug's affordability is the treatment's dosing regimen. OCREVUS appears in the Board's summarized data as one of the drugs identified for "Top Costs" and appeared in 2022 DPT Carrier reports as the most costly drug per prescription in Oregon, citing the "average price per prescription" as \$31,057. However,

<sup>&</sup>lt;sup>4</sup> Genentech (2022 November, 22). Adapting our drug pricing model amidst systemic healthcare challenges. https://www.gene.com/stories/adapting-our-drug-pricing-model-amidst-systemic-healthcare-challenges <sup>5</sup>Genentech (2023 July). OCREVUS® (ocrelizumab) Multiple Sclerosis (MS) WAC Flash Card.

https://www.ocrevus.com/content/dam/gene/ocrevus/resources/ocrevus-ms-wac-price-flashcard.pdf. <sup>6</sup> Bureau Labor Statistics, CPI-U, All items, Unadjusted (Jan 2017 - Jan 2023).

<sup>&</sup>lt;sup>7</sup> CMS ASP Pricing Files,

https://www.cms.gov/medicare/payment/all-fee-service-providers/medicare-part-b-drug-average-sales-price/asp-pricing-files

importantly, OCREVUS is administered by intravenous infusion every six months.<sup>8</sup> This dosing schedule is significantly less burdensome on patients than other MS therapies, which require weekly or monthly injections or infusions. In a real-world study, OCREVUS was found to have an adherence rate of 80% compared to other MS therapies that were on the market on or before 2019 (55%, 35%, and 54% for oral, injectable, and other IV, respectively) over two years.<sup>9</sup> Furthermore, patients with MS who were adherent to medication had substantially lower medical costs compared with those who were non-adherent.<sup>10</sup> Therefore, focusing on a single data point, such as "average cost per prescription," without regard for the dosing regimen or association of the medicine's use in reducing other healthcare costs is inappropriate and may lead to inaccurate assumptions of a medicine's affordability and value.

Genentech believes it is essential for the execution of the Board's statutory authorities to ensure broader context is included in the Board's deliberation of affordability in considering specific drugs for selection. To further illustrate the importance of broad context in the selection process, including total cost of care and impact on society, we believe it necessary to highlight two additional findings related to OCREVUS, which would likely not be addressed if the Board continues to rely on limited data generated predominantly by DPT Carrier Reports. First, a recent retrospective claims study demonstrated that initiation of OCREVUS as a first-line treatment reduced patient relapses and healthcare utilization and cost, compared to those who were treated second-line.<sup>11</sup> Second, Genentech was proud to announce new 10-year milestone data earlier this week from open-label extensions of Phase III studies in relapsing MS (RMS) and PPMS that show benefit in slowing long-term disability progression. After ten years of continuous treatment, 77% of patients with RMS were free from disability progression, and 92% were still walking unassisted. In patients with PPMS, 36% were free from disability progression, and 80% of those patients treated continuously with OCREVUS over ten years could still walk.<sup>12</sup>

We thank you again for this opportunity to provide comments and for your consideration of our feedback in your ongoing deliberations. If you have any questions or want to discuss this feedback, please contact Tim Layton, Director of State Government Affairs at <u>layton.timothy@gene.com</u> or (206) 403-8224.

Sincerely,

Mary Wachten

Mary Wachter Executive Director State & Local Government Affairs

<sup>&</sup>lt;sup>8</sup> OCREVUS (ocrelizumab) Prescribing Information. Genentech, Inc. 2016.

<sup>&</sup>lt;sup>9</sup> Pardo G et al. Adherence to and Persistence with Disease-Modifying Therapies for Multiple Sclerosis Over 24 Months: A Retrospective Claims Analysis. Neurol Ther. 2022 Mar;11(1):337-351. *Note, this study was conducted using claims data from April 2016 through December 2019.* 

<sup>&</sup>lt;sup>10</sup> Pardo G et al. The Association Between Persistence and Adherence to Disease-Modifying Therapies and Healthcare Resource Utilization and Costs in Patients With Multiple Sclerosis. J Health Econ Outcomes Res. 2022 Apr 26;9(1):111-116.

<sup>&</sup>lt;sup>11</sup> Geiger CK et al. Real-World Clinical and Economic Outcomes Among Persons With Multiple Sclerosis Initiating First- Versus Second- or Later-Line Treatment With Ocrelizumab. Neurol Ther. 2023 Oct;12(5):1709-1728.

<sup>&</sup>lt;sup>12</sup>Hauser et al. Safety of Ocrelizumab in Multiple Sclerosis: Updated Analysis in Patients with Relapsing and Progressive Multiple Sclerosis Presented at the 9th Joint ECTRIMS-ACTRIMS Meeting. Milan, Italy. 11–13 October 2023.



October 15, 2023

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

## Re: Oregon Prescription Drug Affordability Review: Meeting Materials Related to Affordability Review Rule 925-200-0010

Dear Members of the Oregon Prescription Drug Affordability Board:

The Pharmaceutical Research and Manufacturers of America ("PhRMA") appreciates the opportunity to review and comment on the Board's discussion materials (the "Meeting Materials") for the Oregon Prescription Drug Affordability Board's ("Board's") October 18, 2023 meeting.<sup>1</sup> PhRMA is represents the country's leading innovative biopharmaceutical research companies, which are devoted to discovering and developing medicines that enable patients to live longer, healthier, and more productive lives.

We provide below our comments and concerns with respect to the Board's approach for implementing Rule 925-200-0010 described in the Meeting Materials—including addressing PhRMA's ongoing concerns related to lack of adequate transparency with respect to the specific processes and criteria that the Board will be relying upon. PhRMA appreciates the Board's work to develop potential processes and materials with respect to implementation of its responsibilities under Oregon Senate Bill 844 (2021), as amended by Oregon Senate Bill 192 (2023) (collectively, the "PDAB Statute"). However, PhRMA has concerns on these topics, as outlined in greater detail below.<sup>2</sup>

### I. Transparency on Data Sources for Board Criteria

The Meeting Materials state that the Board will select a "subset of drugs" to prioritize for an affordability review based on consideration of seven enumerated criteria.<sup>3</sup> These criteria encompass broad-ranging categories of information, including insurer reported top 25 lists, manufacturer new specialty drug reports and price increase reports, certain historical data about pricing of drugs, certain Food and Drug Administration ("FDA") approval information (e.g., date of approval, approval pathway), information about therapeutic alternatives, certain patent expiration information, and certain data specifically related to insulin drugs.<sup>4</sup>

Given the diversity of these seven criteria, PhRMA is concerned that the Board has not specified exactly how it will compile, review, and compare these divergent factors. **Specifically, the Board should clarify the exact sources of information it is using for each of these criteria, and how the Board intends to verify the accuracy of such data.** 

Data bearing on these criteria may be drawn from a variety of sources, including reports from insurers, manufacturer data, and various other third-party sources. Certain sources of information may be unreliable or offer only a selective portion of the full picture relevant to the Board's selection of drugs for affordability review. It is

<sup>&</sup>lt;sup>1</sup> See Board, October 18, 2023 Meeting Materials, *available at <u>https://dfr.oregon.gov/pdab/Documents/20231018-PDAB-document-package.pdf</u>.* 

<sup>&</sup>lt;sup>2</sup> In filing this comment letter requesting changes to the Proposed Rules, PhRMA reserves all rights to legal arguments with

respect to the Oregon PDAB statute. PhRMA also incorporates by reference all prior comment letters to the extent applicable.

<sup>&</sup>lt;sup>3</sup> October 18, 2023 Meeting Materials, at 29.

<sup>&</sup>lt;sup>4</sup> See id.



therefore important that the Board provide clarity on the different information sources that it intends to rely upon as part of its prioritization process. Use of erroneous or incomplete data would impact the reliability of the Board's assessments, and it is therefore critical that the Board provide transparency as to its intended data sources—as well as its intended processes for weighing and comparing the Board's criteria.<sup>5</sup>

PhRMA requests that the Board provide clear definitions and sources for each of the data elements it intends to use in its drug selection and affordability review processes, including the elements in its "top drugs to review" table.<sup>6</sup> The elements for which definitions and sources should be provided include (but are not limited to):

- Carrier-reported spending: The Meeting Materials do not specify whether plan-reported costs are gross or net of rebates. Data elements such as "total amount of spend" and "average cost per prescription" are not adequately defined, and staff discussion at the August 23<sup>rd</sup> meeting included contradictory statements about whether these data were reflective of rebates or not.<sup>7</sup> As we have previously stated, the impact of rebate amounts on actual costs (compared to gross spending) should not be dismissed or minimized in the Board's determinations.<sup>8</sup> PhRMA is increasingly concerned that the substantial rebates and discounts paid by pharmaceutical manufacturers, approximately \$236 billion in 2021, do not make their way to offsetting patient costs at the pharmacy counter.<sup>9</sup> Rebates lower the price that plans are actually paying for medication an average of 49% and any data reported without that information may unintentionally lead the Board to make incorrect assumptions about the magnitude of medicine spending in Oregon.<sup>10</sup>
- **Newly-added metrics:** Over the past two meetings the Board has added new metrics to its "top drugs to review" table ("Drug List") each month<sup>11</sup> However, the Board has not supplied clear definitions of these metrics or provided data sources (and where applicable, methodology) that the Board is relying upon to compile and analyze them.
- Therapeutic Alternatives: The Board has not yet provided any clarity with respect to how it intends to identify and consider therapeutic alternatives for a given prescription drug. PhRMA strongly recommends that the Board use caution when considering information regarding "therapeutic alternatives" for particular medications.<sup>12</sup> Drugs within a particular therapeutic class will often have significant differences, including in their chemical formulas, mechanism of action, and safety and effectiveness profiles, even though the drugs treat a similar clinical indication. A patient who can safely and effectively use one drug in a therapeutic class may experience increased risk of negative outcomes (e.g., drug interactions, side effects, treatment failures) with another drug in the class. Patients also respond differently to treatment because of a number of factors, such as genetics, age, sex, socioeconomic status, drug-drug interactions, diet, environment, and co-morbidities. This means that treatments that are the best option for some

<sup>&</sup>lt;sup>5</sup> See also Letter from PhRMA to Board (Apr. 16, 2023), at 2.

<sup>&</sup>lt;sup>6</sup> October 18, 2023 Meeting Materials, at 39-40.

<sup>&</sup>lt;sup>7</sup> August 23, 2023 Meeting Minutes, at 3.

<sup>&</sup>lt;sup>8</sup> See also Letter from PhRMA to Board (Apr. 16, 2023), at 2.

<sup>&</sup>lt;sup>9</sup> Drug Channels Institute. The 2021 Economic Report on U.S. Pharmacies and Pharmacy Benefit Managers. March 2022.

<sup>&</sup>lt;sup>10</sup> IQVIA. Use of Medicines in the US.: Spending and Usage Trends and Outlook to 2026, April 2022.

<sup>&</sup>lt;sup>11</sup> September meeting materials added 7 new criteria (Total annual spend per enrollee, Avg YoY price change (over past 5 years), Brand or generic, Drug has a therapeutic equivalent or biosimilar, First FDA approval date, Drug part of IRA CMS negotiation list, Number of carriers, Percent of carriers) and the October meeting materials added 6 new criteria (Beginning 2022 package WAC, End 2022 package WAC, WAC price change % 2022, Drug approved through an expedited pathway, Patent expiration date within 18 months, Exclusivity expiration date within 18 month).

<sup>&</sup>lt;sup>12</sup> See also Letter from PhRMA to Board (Feb. 11, 2023), at 6.



individuals are not as effective for others.<sup>13</sup> The Board's process should include greater scrutiny when considering an alternative that is not therapeutically equivalent, as well as when there are special circumstances bearing on whether it is appropriate to use given therapeutic alternatives (e.g., if a drug is used for immunocompromised patients, pediatric patients, the elderly, or individuals who require multiple medications for acute and chronic illnesses).<sup>14</sup>

**PhRMA also recommends that the Board create a process for permitting manufacturers and other stakeholders to provide input where information may be inaccurate or incomplete.** Because of the voluminous and complex nature of the data considered by the Board and the variety of sources it is drawn from, the Board should give impacted stakeholders a reasonable opportunity to review and provide written responses.<sup>15</sup>

The Board's processes should also incorporate mechanisms by which manufacturers and other stakeholders can safely provide confidential information, which should be protected against improper disclosure or use as required in light of the confidentiality obligations imposed on the Board by federal and state law.<sup>16</sup> In some cases, manufacturers may provide sensitive information detailing issues regarding data bearing on specific drugs, and it is important that the Board take appropriate steps to independently safeguard such information. Consistent with its prior comment letters, PhRMA emphasizes that the Board's statutory obligation is to "keep [statutorily protected information] strictly confidential," and this requirement applies to all such information, even if a submitter does not specifically mark the information for protection.<sup>17</sup> This is especially true here because the Board's reports may include recommendations that, if implemented, would have significant repercussions for Oregonians' access to prescription medicines.

### II. Transparency in Methodology and Process Related to "Top Drugs to Review" Table.

PhRMA is also concerned about the continuing lack of transparency with respect to the methodology underlying the Board's Drug List. Among other things, the Board should clarify its processes and methodology surrounding how products are placed on the Drug List for review. Over the course of the past several months, certain products have been placed on the Board's Drug List, removed from later iterations of the list, and then re-inserted back on the list. For example, in August, the Board stated it would remove drugs with orphan-only designations, yet these orphan-only designated drugs appear to have been re-included on the October Drug List without explanation.<sup>18</sup> Similarly, other new drugs have been added to the list based on "staff recommendation," but without any detailed explanation or narrative as to the specific reasons for the staff recommendations that resulted in inclusion on the Drug List.

The Board should clarify its process for choosing the metrics included on its Drug List, explain why each metric is relevant to the Board's prioritization process, and provide stakeholders adequate time to review and comment on

<sup>&</sup>lt;sup>13</sup> See McRae, J., Onukwugha, E., Why the Gap in Evaluating the Social Constructs and the Value of Medicines?, 39 PharmacoEconomics 1365 (2021), available at https://doi.org/10.1007/s40273-021-01075-w.

<sup>&</sup>lt;sup>14</sup> As PhRMA has previously explained, the Board should also adopt an appropriately nuanced definition of therapeutic alternative. PhRMA recommends defining "therapeutic alternative" in a manner that requires a drug to have been shown through peer-reviewed clinical studies to have similar therapeutic effect, a similar safety profile, and expected outcome when administered to patients in a therapeutically equivalent dose in order to be considered a therapeutic alternative. Letter from PhRMA to Board (Feb. 11, 2023), at 6. <sup>15</sup> The Board should, however, ensure that any disclosures are consistent with the confidentiality requirements imposed by federal and state law, as described below.

<sup>&</sup>lt;sup>16</sup> See, e.g., Letter from PhRMA to Board (Feb. 11, 2023), at 7-8 (outlining PhRMA's confidentiality concerns in additional detail, and explaining the confidentiality obligations of the Board under state and federal law). See also Letter from PhRMA to Board (June 23, 2023), at 3.

<sup>17</sup> ORS § 646A.694(7).

<sup>&</sup>lt;sup>18</sup> See generally PDAB, August 23, 2023 Meeting Minutes 3 (noting discussion about removal of orphan drugs), available at <a href="https://dfr.oregon.gov/pdab/Documents/20230823-PDAB-approved-minutes.pdf">https://dfr.oregon.gov/pdab/Documents/20230823-PDAB-approved-minutes.pdf</a>.



the metrics *before* they are finalized and *before* any decision or vote is taken by the Board. To this end, PhRMA recommends that the Board: (1) expressly propose its tentative final list of metrics, (2) provide an opportunity to comment on these metrics, and then (3) finalize the metrics to be included on its Drug List at least one meeting in advance of the Board taking votes to select any eligible drugs included on the Drug Lists. This will provide opportunity for comment on the metrics before they are finalized and before the Board renders any decisions based on such metrics, consistent with the Board's due process and Oregon Administrative Procedures Act ("APA") obligations to provide meaningful opportunity for notice and comment.<sup>19</sup>

PhRMA also has concerns about the apparent weight given to metrics that are not among the seven criteria that the Board has said it will consider for purposes of prioritizing among eligible drugs for affordability reviews. Notably, for example, the Board's new "drug also on the CCO list" metric is not related to any of the Board's seven prioritization criteria, yet the Board appears to be including it on its Drug List and giving it significant weight when determining which drugs to prioritize for affordability review.<sup>20</sup> The Board should clarify the source of this metric and why it is being included, including the metric's relevance in light of the Board's enumerated prioritization criteria.<sup>21</sup>

As we have discussed in prior letters, greater transparency is needed to ensure that manufacturers and other stakeholders have clear insight into how the Board is operationalizing its decision-making.<sup>22</sup> This is necessary both to facilitate informed notice of the Board's methodology, as well as for purposes of allowing stakeholders to assist the Board in identifying any inadvertent errors or oversights as the Board implements an inherently complex and multi-faceted process of identifying drugs eligible for affordability reviews. Most importantly, greater specificity is also a vital safeguard against arbitrary decision-making, as clear and transparent standards, policies, and methodologies are necessary to ensure consistent and appropriate implementation of the requirements of the PDAB Statute.<sup>23</sup>

\* \* \*

We thank you again for this opportunity to provide comments and feedback, and for your consideration of our concerns. Although PhRMA has concerns with the Meeting Materials, we stand ready to be a constructive partner in this dialogue. Please contact <u>dmcgrew@phrma.org</u> with any questions.

Sincerely,

Dharia McGrew, PhD Director, State Policy

Snot

Merlin Brittenham Assistant General Counsel, Law

<sup>&</sup>lt;sup>19</sup> See discussion of the Board's obligations under the APA in Letter from PhRMA to Board (Feb. 11, 2023), at 2.

<sup>&</sup>lt;sup>20</sup> See, e.g., October 18, 2023 Meeting Materials, at 5-7 ("Shelley Bailey made a motion to combine the top drugs

to review from the DPT carrier list, filter it by percent of carriers impacted, add the top 20 drugs from the CCO list, flush out duplicates, and choose the top 30 drugs from there ... Recommendation [by the Chair]: combine total cost and carrier cost. Look at the DPT drug data to mesh with top 25 of the CCO data.")

<sup>&</sup>lt;sup>21</sup> See Or. Admin. R. 925-200-0010.

<sup>&</sup>lt;sup>22</sup> See Letter from PhRMA to Board (Apr. 16, 2023), Letter from PhRMA to Board (June 23, 2023)

<sup>&</sup>lt;sup>23</sup> As PhRMA has explained in prior comment letters, the APA requires the Board to render all decisions in a manner that is "rational, principled, and fair, rather than ad hoc and arbitrary." *Gordon v. Bd. of Parole & Post Prison Supervision*, 343 Or. 618, 633 (2007). *See, e.g.*, Letter from PhRMA to Board (Feb. 11, 2023), at 2.



# Submissions: Proposed policy recommendations

The following letters and emails were submitted by the public for board review.

**Background**: At the 9/20/2023 board meeting, the PDAB announced it was seeking policy recommendations from the public. The board will consider these proposals for possible inclusion in the board's 2023 recommendations to the Oregon Legislature. PDAB is charged with making recommendations that are solution based that will make prescription drugs more affordable for Oregonians. The board accepted submissions until 5 pm Friday, October 6. The board received six submissions. In addition, the board received policy recommendations from four groups who gave presentations at board meetings this past year.

| From:        | Carissa Kemp  |
|--------------|---|
| To:          | PDAB * DCBS   |
| Cc:          | Molly McGrew; MAGRISH Ralph M * DCBS; WHITLOCK Cortnee * DCBS |
| Subject:     | ADA Insulin Affordability Policy                              |
| Date:        | Wednesday, September 6, 2023 1:24:25 PM                       |
| Attachments: | image001.png  |
|              | Oregon Insulin Policy .pdf                                    |

You don't often get email from ckemp@diabetes.org. Learn why this is important

Chair Akil Patterson and Executive Director Ralph Magrish,

Thank you for the opportunity to share the American Diabetes Association's policy priority related to addressing the Oregon insulin copay cap. Please see the attached document which outlines two opportunities to address:

- 1. Removing the requirement that the copay cap be tied to the CPI. As a result of this language, the copay cap has increased twice and is now \$85.
- 2. Lower the copay cap amount to \$35 in alignment with Medicare and other states across the country.

We appreciate the opportunity to present this critical issue. Please do not hesitate to reach out if you have any questions.

Carissa Kemp



#### Carissa Kemp

Director, State Government Affairs (AK, CO, ID, MN, MT, ND, NV, OR, SD, UT, WA, WY)

Phone: 703-299-2053 ext. 2053 Mobile: 715-573-1234 diabetes.org 1-800-DIABETES (800-342-2383)





### Leading the Fight for Insulin Affordability

Insulin saves lives. That's why we're fight to make it more affordable. Through tireless advocacy and powerful partnerships with health organizations and insulin manufacturers, we're breaking down barriers to affordable care. Together, we can ensure all of the 8.4 million Americans who rely on insulin can access and afford it.

### Burden of Diabetes in Oregon<sup>1</sup>

- Approximately 306,000 people in Oregon, or 9.5% of the adult population, have diagnosed diabetes.
- An additional 93,000 people in Oregon have diabetes but don't know it, greatly increasing their health risk.
- There are 1,097,000 people in Oregon, 33.5% of the adult population, who have prediabetes.
- Every year an estimated 20,000 people in Oregon are diagnosed with diabetes.

### The problem

In 2021, the Oregon legislature passed House Bill 2623 to cap copayments for insulin. At the time, the legislation capped copayments at \$75 for a one-month supply of insulin for people on state-regulated plans. At the time, Oregon was the 18<sup>th</sup> state to address cost-sharing for insulin. Today, 25 states plus the District of Columbia have passed similar legislation. We applaud Oregon's steps to address insulin, but we can do better:

- Remove the requirement that the copay cap on insulin be adjusted with the consumer price index. Since 2021, the copay cap has increased and will now be \$85. People are having to make difficult choices between paying their bills, rent, and paying for their prescription medication. When the cost-of-living increases, it makes it more challenging for people to afford their medication and tying the copay cap to the CPI only puts the life-saving medication further out of reach. The ADA supports legislation to remove this requirement.
- 2. Lower the copay amount to \$35 in line with Medicare and other states across the country. **The ADA supports legislation to lower the copay cap amount**.

If you have questions please contact Carissa Kemp, Director of State Government Affairs, <a href="mailto:ckemp@diabetes.org">ckemp@diabetes.org</a>.

<sup>&</sup>lt;sup>1</sup> http://main.diabetes.org/dorg/docs/state-fact-sheets/ADV\_2020\_State\_Fact\_sheets\_OR.pdf

From: Nathaniel Brown <nathaniel@chronicdiseasecoalition.org>
Sent: Thursday, September 28, 2023 1:18 PM
To: PDAB \* DCBS <PDAB@DCBS.oregon.gov>
Subject: Re: Policy considerations for 2024
Hi Melissa,

If I might add one more request for Board consideration: A recent Oregon Secretary of State audit of PBMs found that Oregon's regulation of PBMs is "limited and fragmented."

### https://sos.oregon.gov/audits/Pages/audit-2023-25-Pharmacy-Benefit-Managers.aspx

I would love to see PDAB discuss ways to shine a light on PBM practices by enhancing transparency requirements and ensure that savings negotiated by PBMs are passed on to patients. I can be more specific if needed, but the link above will take you to recommendations from OHA and SOS.

Thanks,

Nathaniel Brown | Director of Advocacy | Chronic Disease Coalition 6605 S Macadam Avenue, Suite 200 | Portland, OR 97239 971-219-5561



From: Nathaniel Brown <<u>nathaniel@chronicdiseasecoalition.org</u>>
Sent: Tuesday, September 26, 2023 11:47 AM
To: PDAB \* DCBS <<u>pdab@dcbs.oregon.gov</u>>
Subject: Policy considerations for 2024
Importance: High
To whom it may concern,

Given the Oregon PDAB's charge to recommend solutions-oriented policy proposals that help reduce costs for patients, the Chronic Disease Coalition would welcome your consideration of a copay accumulator ban in 2024. We have been advocating on this bipartisan issue for many years, as have other patients and patient advocacy groups. Please see attached testimony from 2023 session for more context, and if you'd like to discuss further, I am happy to do so.

Many thanks,

Nathaniel Brown | Director of Advocacy | Chronic Disease Coalition 6605 S Macadam Avenue, Suite 200 | Portland, OR 97239 971-219-5561



Oregon Senate Committee on Health Care 900 Court St. NE Salem, OR 97301

March 6, 2023

Chair Patterson and members of the committee:

On behalf of the Chronic Disease Coalition, thank you for the opportunity to provide support for SB 565, a bipartisan bill that would ban harmful copay accumulator programs that impact thousands of Oregon chronic disease patients.

Based in Portland, the Chronic Disease Coalition is a nationwide nonprofit organization dedicated to protecting the rights of chronic disease patients against discriminatory policies and practices. The coalition was founded in 2015 and has since worked to advocate for people living with long-term or lifelong health conditions such as diabetes, kidney disease, multiple sclerosis, psoriasis, cancer, and other chronic diseases.

We are pleased to support this legislation, which would ensure that all payments, including those by third parties, count toward insured Oregonians' total cost-sharing requirements. Many chronic disease patients and their families rely on various types of copay assistance to afford the medications they need to manage their conditions.

Unfortunately, insurers continue implement programs that ban all third-party copay assistance – real dollars paid to the insurer – from counting towards patients' out-of-pocket costs. This forces chronic disease patients to pay twice (or more), while dissuading charitable assistance for future patients.

Many pharmaceutical manufacturers support patient assistance programs by providing funds for what are commonly known as copay coupons or manufacturer copay cards. Previously, payments using funds from these programs counted towards a patient's deductible, helping them afford coverage until the copay assistance is utilized and the benefits from insurance coverage begin.

Copay accumulator programs or accumulator adjustment programs maximize the use of copay assistance without assisting in the patient's deductible, leaving chronic disease patients with exorbitant out-of-pocket costs on top of the many other challenges that come with their diagnoses.

Simply put, if money is put into the system to benefit a patient, it should. As health care leaders in Oregon, we urge you to join the Chronic Disease Coalition in supporting this bipartisan legislation. This is an important step that will lead to better patient outcomes across the state.

Thank you,

Nathaniel Brown, director of advocacy nathaniel@chronicdiseasecoalition.org 971.219.5561 From: BethAnne Darby <bethanned@strategies360.com>
Sent: Thursday, October 5, 2023 1:34 PM
To: PDAB \* DCBS <PDAB@dcbs.oregon.gov>
Cc: Inga Deckert <inga@proxygr.com>
Subject: Policy Recommendation from OCAP

Dear PDAB Board – On behalf of the Oregon Coalition of Affordable Prescriptions (OCAP) we submit a policy recommendation on biosimilars as follows:

We suggest changes to current statute that would better align the substitution of biosimilars with that of generic drugs, allowing for more widespread substitution of biosimilars and lowering drugs prices for consumers. Suggested changes to current statute are in redline below. Thank you for your consideration.

**689.522** Substitution of biological products for prescribed biological products; rules. (1) A pharmacy or pharmacist filling a prescription order for a biological product may not substitute a biological product for the prescribed biological product unless:

(a) The substitute biological product has been <u>determined licensed</u> by the United States Food and Drug Administration to be as a biosimilar to or interchangeable with the prescribed biological product;

(b) The prescribing practitioner has not designated on the prescription that substitution is prohibited;

(c) The patient for whom the biological product is prescribed is informed of the substitution in a manner reasonable under the circumstances; and

(d)(c) The pharmacy or pharmacist retains a record of the substitution for a period of not less than three years.

(2) The State Board of Pharmacy shall, on a website maintained by the board, maintain a link to the current list, if available, of biological products determined by the United States Food and Drug Administration to be interchangeable.

(3)(2)(a) For purposes of this section, the board shall adopt by rule definitions for the terms "biological product," <u>"biosimilar"</u> and "interchangeable."

(b) The rule defining the terms "biological product" and "biosimilar" must be consistent with 42 U.S.C. 262(i)(1) and (2).

(c) The rule defining the term "interchangeable" must:

(A) For biological products licensed under the Public Health Service Act, define the biological products that may be substituted for other biological products as having been determined by the United States Food and Drug Administration as meeting the standards in 42 U.S.C. 262(k)(4); and

(B) For biological products approved by the United States Food and Drug Administration under the Federal Food, Drug, and Cosmetic Act, 21 U.S.C. 301 et seq., define the biological products that may be substituted for other biological products as having been determined by the United States Food and Drug Administration as therapeutically equivalent as set forth in the latest edition or supplement of the Approved Drug Products with Therapeutic Equivalence Evaluations. [2013 c.342 §2; 2013 c.342 §4; 2016 c.43 §§1,2]



C 503.510.3153 PORTLAND, OR

STRATEGIES360.COM

Submitted by email to: <u>PDAB@dcbs.oregon.gov</u>

October 6, 2023

Dear Members of the Oregon Prescription Drug Affordability Board,

At Johnson & Johnson (J&J), for more than 130 years, cutting-edge technologies and expert insight have helped us understand and address the serious health problems of today and unlock the potential medicines of tomorrow. We apply rigorous science and compassion to confidently address the most complex diseases of our time. We also recognize these innovative medicines can only have an impact if patients can access and afford them.

We welcome the opportunity to provide to the Oregon Prescription Drug Affordability Board (PDAB) J&J's policy recommendations to offer to the Oregon legislature, with the following principles in mind: 1) patients should have affordable and timely access to the most appropriate, effective treatment options and sites of care now and in the future, and 2) treatment decisions belong in the hands of patients and their healthcare providers, not commercial payers with no accountability for patient outcomes due to misaligned incentives.<sup>1</sup>

## I. Any focus on drug list price to make policy recommendations would be misguided in addressing prescription drug affordability.

Achieving patient affordability must include an examination of the complexity of the entire drug supply chain ecosystem, including insurance benefit design, and patient OOP costs. The list price of a medicine is a starting point that is ultimately reduced to a net price, the amount a manufacturer receives after negotiating and providing rebates, discounts and/or fees to different parts of the healthcare system. These include negotiations with private insurance companies, Pharmacy Benefit Managers (PBMs) and entities where medications are dispensed or administered (e.g., hospitals, clinics and private physician practices). In addition, there are mandatory or statutory price reductions provided through government programs. Government programs (e.g., Medicare, Medicaid, etc.) receive prices reduced by both private negotiations and statutory discounts. Vigorous private market negotiations throughout the system result in lower net prices for commercial payers and government programs.

While commercial insurers pay lower net prices, many patients do not directly benefit from these lower prices and continue to pay higher out-of-pocket (OOP) costs. Manufacturers do not have input into insurance benefit design that dictates patient OOP costs. Patients pay higher OOP costs because their cost-sharing amount, set by their insurance plan benefit design, is often based on the initial list

<sup>&</sup>lt;sup>1</sup> https://transparencyreport.janssen.com/#what-we-believe-section

### Johnson&Johnson

price, not the negotiated lower net price the commercial insurer pays. The difference between the list price and net price has grown significantly, with one analysis putting the total at more than \$200 billion in 2021 for the entire healthcare system.<sup>2</sup> Some states have implemented solutions by enacting legislation requiring PBMs share the savings with the patients.<sup>3,4,5</sup>

<u>Policy Recommendation: Require that PBM rebates and discounts be directly</u> <u>shared with patients at the pharmacy counter.</u>

## II. Patients should not face restrictive utilization management programs that interfere with access, affordability, and treatment choice.

Policy goals will not be met by establishing price controls, which may have longterm negative impacts across benefit design, patient access, pricing, contracting, and future innovation. Furthermore, patients may experience limited treatment choice and have little to no reduction in their OOP costs as a result of price control policy.

Policy solutions should be sought to alleviate patient access and affordability challenges that result from increasingly restrictive utilization management programs, and which interfere with medical decision-making.

Utilization management is the use of administrative mechanisms (e.g., prior authorization) and financial mechanisms (e.g., patient cost sharing), which commercial insurers and PBMs implement to control or restrict patient access to healthcare. One such example is the increasing use of exclusion lists, which are designed to block patients from accessing a medicine that their own doctor has prescribed. Since 2014, these exclusion lists have grown more than 961% to include more than 1,156 unique products.<sup>6</sup> Exclusion lists are also being leveraged with specialty drugs, which could disproportionately affect patients with very serious and specialized treatment needs. Additionally, utilization management programs include expanded tiered lists with varying cost sharing, prior authorization, non-medical switching and step therapy. De-escalation in utilization management has the potential to improve patient accessibility and affordability towards medically necessary treatments, and research indicates a reduction in systemic costs.<sup>7</sup>

<sup>2</sup> https://www.drugchannels.net/2022/03/warped-incentives-update-gross-to-net.html

<sup>3</sup> https://www.wvlegislature.gov/Bill\_Status/bills\_text.cfm?billdoc=HB2263%20SUB%20ENR.htm&yr=2021&s esstype=RS&billtype=B&houseorig=H&i=2263

https://iga.in.gov/pdf-documents/123/2023/senate/bills/SB0008/SB0008.06.ENRH.pdf

<sup>5</sup>https://www.arkleg.state.ar.us/Home/FTPDocument?path=%2FACTS%2F2023R%2FPublic%2FACT333.pdf <sup>6</sup> https://www.xcenda.com/-/media/assets/xcenda/english/content-assets/white-papers-issue-briefs-

studies-pdf/xcenda\_pbm\_exclusion\_may\_2022.pdf

https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2021.00036

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The American Medical Association found prior authorization (PA) to be a burdensome process that can lead to negative patient outcomes.<sup>8</sup> An AMA physician survey on prior authorization in 2022 found that 91% of respondents reported that PA can lead to negative clinical outcomes; 82% reported that PA can lead to patients abandoning their course of treatment, and 34% reported PA has led to a serious adverse event for a patient in their care.<sup>9</sup> Prior authorization should not create unnecessary burdens on health care providers, nor should it result in delayed care for patients in need.

In addition, any policy approach should recognize the significant difference of transformative cell and gene therapies in their potential to be curative. Consideration should be given to innovative therapies that involve a complex patient journey across sites of care in the health care system, leading to unique affordability challenges for patients based on their insurance plan's benefit design.

Legislative solutions should ensure that patients have timely, predicable, patientcentered, and straight-forward access to care. Medical decision-making should remain between a provider and the patient, and coverage policies should facilitate patient access to the most medically appropriate care.

Policy Recommendation: Examine the use of utilization management tools and evaluate how best to regulate them in the interest of patient access and minimizing OOP costs.

#### III. Patients should benefit from cost-sharing assistance that is intended to count towards their cost-sharing burden.

Insurers may negotiate with manufacturers for rebates to reduce the plan's overall expenses, but these rebates are often not directly shared with patients. When patients are left with high out of pocket costs, they may look to manufacturer patient assistance programs for additional support but often face the growing threat of patient assistance diversion programs, which are schemes implemented by commercial insurers, PBMs or other third-party intermediaries that divert patient assistance money away from patients to the financial benefit of non-patient third parties. These programs have numerous, deceptive names (e.g., accumulators, maximizers, optimizers or Alternative Funding Programs); yet, they all have the same purpose – to make it harder for patients to access and afford needed healthcare in order that the program operators may financially benefit.

<sup>8</sup> American Medical Association, *What is Prior Authorization?* July 12, 2022, https://www.ama-assn.org/practice-management/prior-authorization, July 21, 2022 (citing 2021 AMA Prior Authorization

Physician Survey, https://www.ama-assn.org/system/files/prior-authorization-survey.pdf). <sup>9</sup> See AMA Prior Authorization (PA) Physician Survey, https://www.ama-assn.org/system/files/prior-authorization-survey.pdf, 2021.

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Prohibiting diversion of assistance funds away from patients would require legislative solutions that ensure that payments made by or on behalf of enrollee count towards costs of prescription drugs when calculating enrollee's contribution to OOP maximum, deductible, copayment, coinsurance, or other cost-sharing for drugs. Currently, nineteen states and Puerto Rico have passed legislation to prohibit diversion of cost-sharing assistance. Analysis has shown that state laws that have protected patient assistance by prohibiting diversion practices has not resulted in premium increases.<sup>10</sup>

Policy Recommendation: Prohibit diversion of cost-sharing assistance to ensure payment made by or on behalf of patients counts towards their cost-sharing burden.

As one of the nation's leading healthcare companies, we have a responsibility to engage with stakeholders in constructive dialogue to address these gaps in affordability and access, and to protect our nation's leading role in the innovation ecosystem.

We recommend that the Oregon PDAB and Legislature seek to advance sound policy solutions that would support patient access to innovative medicines, improve patient affordability, and allow for treatment decisions to remain in the hands of patients and their healthcare providers. If you have any questions, I can be reached at tsweat@its.jnj.com.

Sincerely,

Terrell Sweat Director, US State Government Affairs

<sup>&</sup>lt;sup>10</sup> https://ghlf.org/copay-assistance-protection/



October 6, 2023

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

### **Re: Oregon Prescription Drug Affordability Review: Call for policy recommendations that will make prescription drugs more affordable for Oregonians.**

Dear Members of the Oregon Prescription Drug Affordability Board:

PhRMA appreciates the opportunity to provide potential policy recommendations for the Board's consideration as part of the Board's 2023 policy recommendations to the Oregon Legislature. We believe that the Board's policy recommendations should focus on the factors that impact consumer affordability of prescription drugs, specifically focusing on patient out-of-pocket costs. There are a full range of factors driving such out-of-pocket costs, including benefit design (e.g., cost-sharing requirements such as coinsurance and deductibles, and accumulator adjustment and copay maximizer programs) and rebates, discounts, and other price concessions and reductions paid by drug manufacturers to pharmacy benefit managers ("PBMs") and health insurance plans that the PBMs and plans are not sharing directly with patients at the point-of-sale.

As an industry, we believe that patients need lower out-of-pocket costs without a reduction in health care choice, quality, or access. Biopharmaceutical companies continue to pay billions in rebates and discounts negotiated with insurers and PBMs, while at the same time premiums and patient out of pocket costs continue to rise.<sup>1</sup> There is a flaw in the system when rebates and discounts continue to grow without any meaningful benefit directly to patients taking those medicines. PhRMA proposes the following policy solutions to help make medicines more affordable and the system work better for patients:

### Policy Solutions to Make Medicines More Affordable for Oregonians

### Rebate Passthrough at the Point-of-Sale

The net price of a medicine reflects the final price paid by the PBM and the plan sponsor. Yet in the majority of cases, the net price is not the price available to patients with insurance at the pharmacy counter. Instead, PBMs and insurers typically require patients with deductibles and coinsurance – who pay a percentage of the cost of their medicine rather than a fixed copayment – to pay based on the undiscounted list price, rather than the discounted net price paid by the PBM. In contrast, health plans typically base patient out-of-pocket spending for care received from doctors and hospitals within the plan's provider network on the discounted rates negotiated by the plan on patients' behalf. Requiring PBMs and health plans to share the savings they receive on medicines directly with patients at the pharmacy counter would lower patient out-of-pocket costs and help realign payer incentives.

<sup>&</sup>lt;sup>1</sup> Fein AJ. "The 2023 Economic Report on U.S. Pharmacies and Pharmacy Benefit Managers." Drug Channels Institute. March 2023.



In the commercial market, actuaries estimate that sharing negotiated rebates directly with patients at the point-of-sale would increase premiums by an average of 1 percent or less.<sup>2</sup> Recognizing that lower cost sharing can improve patient access to medicines, some PBMs have already adopted point-of-sale passthrough programs for their commercial market customers. Within two months of implementing such a program for fully insured group health plans, OptumRx observed up to a 16 percent improvement in medication adherence.<sup>3</sup> Similarly, CVS Health recently noted that "Not only do [point-of-sale] rebates save employees money, they also make prescription purchases more transparent."<sup>4</sup> In 2021, West Virginia became the first state in the nation to require PBMs to pass through manufacturer rebates at the point-of-sale.<sup>5</sup> In 2023, Arkansas and Indiana passed legislation to share the savings with patients.<sup>6</sup>

### Delinking Compensation from the Price of a Medicine

"Delinking" policies require that PBMs and other supply chain entities receive a fixed fee based on the value of the services they provide, rather than receiving compensation based on the price of a medicine. This would disrupt the misaligned incentives in the current system that encourage PBMs to prefer higher prescription drug prices over lower ones.<sup>7</sup> Industry experts have noted that the current compensation model has propelled PBMs to adopt business practices that systematically drive up prescription drug prices.<sup>8</sup>

### Duty of Care

In August, the Oregon Secretary of State's Audit Division released an audit entitled "Oregon Health Authority, Pharmacy Benefit Managers: Poor Accountability and Transparency Harm Medicaid Patients and Independent Pharmacies."<sup>9</sup> That report found that,

Certain PBM practices create risks for private insurers and federal and state health programs. PBMs have merged with other entities to remain competitive and to increase their revenue streams ... PBMs have considerable influence on which drugs are covered by insurers and can require consumers to get certain prescriptions filled at a specialty or mail order pharmacy, which the PBM may own ... Vertical integration in the pharmaceutical system poses risks of decreased

<sup>&</sup>lt;sup>2</sup> Milliman. "Measuring the Impact of Point of Sale Rebates on the Commercial Health Insurance Market," July 2021.https://www.milliman.com/en/insight/measuring-the-impact-of-point-of-sale-rebates-on-the-commercial-health-insurancemarket

<sup>&</sup>lt;sup>3</sup> UnitedHealth Group. "Successful Prescription Drug Discount Program Expands to Benefit More Consumers at Point-of-Sale." March 12, 2019. https://www.unitedhealthgroup.com/newsroom/2019/2019-03-12-prescription-drug-program-expands-tobenefit-consumers-point-of-sale.html

<sup>&</sup>lt;sup>4</sup> "Prescription Coverage: CVS/Caremark." Indiana State Personnel Department. Accessed March 12, 2022. https://www.in.gov/spd/benefits/prescription-coverage/

<sup>&</sup>lt;sup>5</sup> Kelly C. "Rebate Reform: West Virginia Law Requires PBMs to Share the Savings." Pink Sheet. April 29, 2021.

https://pink.pharmaintelligence.informa.com/PS144231/Rebate-Reform-West-Virginia-Law-Requires-PBMs-To-Share-The-Savings

<sup>&</sup>lt;sup>6</sup> Arkansas House Bill 1481 (Act 333 of 2023) and Indiana SB 8, 2023.

<sup>&</sup>lt;sup>7</sup> Frier Levitt, LLC and Community Oncology Alliance. "Pharmacy Benefit Manager Exposé: How PBMs Adversely Impact Cancer Care While Profiting at the Expense of Patients, Providers, Employers, and Taxpayers." February 2022. https://communityoncology.org/wp-content/uploads/2022/02/COA\_FL\_PBM\_Expose\_2-2022.pdf

<sup>&</sup>lt;sup>8</sup> PBM Accountability Project, "Understanding the Evolving Business Models and Revenue of Pharmacy Benefit Managers", 2021. https://b11210f4-9a71-4e4c-a08f-cf43a83bc1df.usrfiles.com/ugd/b11210\_264612f6b98e47b3a8502054f66bb2a1.pdf

<sup>&</sup>lt;sup>9</sup> Oregon Health Authority, Pharmacy Benefit Managers: Poor Accountability and Transparency Harm Medicaid Patients and Independent Pharmacies, https://sos.oregon.gov/audits/Pages/audit-2023-25-Pharmacy-Benefit-Managers.aspx



consumer access to medications and affordability to everyone, not just those receiving Medicaid benefits.

To address the concerns raised by the Secretary of State's report, the Board could recommend PBMs be subject to a duty of care. Expressly imposing a duty or standard of care on PBMs and requiring these companies to act in the best interest of patients, providers, and their clients (health plans)—and when in conflict, the patient first—would be an important step for the Oregon Legislature to take so that PBMs act in a transparent manner and place their duties to patients, providers, and their clients before their own financial interests.

### Anti-Steering

The Oregon Secretary of State's audit report also found concerning PBM practices as it relates to community pharmacies. The report found that, "independent pharmacies are more likely to be reimbursed less for prescriptions than national chain pharmacies ... On average, the estimated profits for national chain and specialty/mail order pharmacies are more than twice the amount independent pharmacies receive."<sup>10</sup> Prohibiting PBMs from directing patients to affiliate pharmacies can improve competition and reduce incentives for PBMs to self-deal, allowing independent pharmacies a chance to compete and providing patients with access and choice for fulfilling their prescriptions.

\* \* \*

We thank you again for this opportunity to provide comments and feedback, and for your consideration of our proposed policy solutions. We stand ready to be a constructive partner in this dialogue and help identify solutions that will help Oregon patients better afford their medicines. Please contact dmcgrew@phrma.org with any questions.

Sincerely,

Dharia McGrew, PhD Director, State Policy

<sup>&</sup>lt;sup>10</sup> Oregon Health Authority Pharmacy Benefit Managers: Poor Accountability and Transparency Harm Medicaid Patients and Independent Pharmacies, https://sos.oregon.gov/audits/Pages/audit-2023-25-Pharmacy-Benefit-Managers.aspx

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Mr. Akil Patterson Chair Prescription Drug Affordability Board PO Box 14480 Salem, OR 97309

Ms. Shelley Bailey Vice Chair Prescription Drug Affordability Board PO Box 14480 Salem, OR 97309

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

We greatly appreciate the willingness of the Oregon Prescription Drug Affordability Board to consider recommendations from patient advocacy groups on ways to help lower the costs of drugs to patients.

ICAN, International Cancer Advocacy Network, is a 501(c)(3) non-profit organization (EIN 86-0818253), based in Phoenix, Arizona. During the past 27 years, we have helped more than 17,500 Stage IV cancer patients in all 50 states—including Oregon—and in 72 foreign countries.

Our goal for each patient is to extend life with the highest achievable quality of life. We deal with all cancers and connect patients with brilliant oncologists, find clinical trials, help interpret molecular profiling reports, and arrange preapproval access and compassionate use/Right to Try requests.

We have been active participants in several of the discussions regarding prescription drug pricing issues and have had several of our Oregon patients testify along with ICAN's Director of Governmental Relations.

First, some areas of agreement:

1) We all share the goal of lowering prescription drug costs (and health care costs in general) for both health care systems and for patients.



2) We greatly appreciate that Quality Adjusted Life Years ("QALYs") will <u>not</u> be used as a metric as the Board carries out its important work.

3) There are areas where great savings can be made without the negative impacts on the drug discovery pipeline that price controls create.

One of the areas where broad agreement could be created is in reform of Pharmacy Benefit Managers (PBMs).

If the Members of the Board have not seen it, we would like to strongly recommend the recent report of the Audits Division of the Secretary of State entitled: *Oregon Health Authority Pharmacy Benefit Managers Poor Accountability and Transparency Harm Medicaid Patients and Independent Pharmacies August 2023 Report 2023-25* which can be found at this link: <u>https://sos.oregon.gov/audits/Pages/audit-2023-25-Pharmacy-Benefit-Managers.aspx</u>

The Report lays out, in meticulous, well-researched detail, exactly how the PBM system is failing patients. We will not belabor that failure and those details here as we are sure the Members know that just three PBMs control 80% of the market, and that patients pay considerably more for drugs than they should because of PBM practices.

Rather, we wish to endorse the recommendations of the Report (page 31) and especially to draw your attention to the areas where Oregon has fallen behind other states in requiring PBM transparency. Indeed, of nine specific areas of transparency reform, Oregon only requires PBMs to be transparent on four (see page 23 of the Report). That is in contrast to states ranging from Michigan to Texas that require substantially more transparency than does Oregon.

This is the great opportunity for the PDAB Board to make recommendations to the legislature for prompt consideration and passage of a bill requiring PBM transparency in these areas.

On the federal level, Senator Wyden, as Chair of the Senate Finance Committee, has been leading the way on PBM reform. The state legislature should do likewise.

We urge consideration of these and other cost-reducing measures that promise much more direct impact on prices, and on a greater number of drugs, than price controls on a handful of drugs. These reforms have the advantage of preserving (and indeed, increasing) access to drugs for patients.

Please do not hesitate to contact me at <u>marcia@askican.org</u> or at (602) 618-0183 if you need any additional information. Thank you for your consideration.

Respectfully submitted,

Marciafor

Marcia K. Horn, JD President and CEO ICAN, International Cancer Advocacy Network 27 West Morten Avenue Phoenix, AZ 85021-7246

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