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(HEAL) Group
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National ADAP Working Group (NAWG)

June 16, 2025

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

RE: Subset List/Board Goals

Dear Honorable Members of the Oregon Prescription Drug Affordability Board,

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

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

Changes Made to Updated Subset List Are Encouraging Yet Concerning

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

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

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

Survey Response Data Does Not Present a Clear Picture

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

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

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

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

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

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

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

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

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

Respectfully submitted,



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

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