



December 4, 2023

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

Subject: Consumer Engagement

Dear Members of the Oregon Prescription Drug Affordability Board:

On behalf of 25 community-based organizations and people living with challenging health conditions, we are writing to express our concern about the Prescription Drug Affordability Board's (PDAB) process for engaging people with disabilities and chronic conditions, depriving it from incorporating their experiences and voices in its decisions. Therefore, we would like to provide the following comments and recommendations:

- **Board representation:** There is no representation of patients or people with disabilities on the Board. While the statute creating the PDAB did not require inclusion of patients and people with disabilities on the board, it also did not exclude from the board people with the required expertise who also identify as people living with a chronic condition or disability. Therefore, we urge efforts to identify people to serve as board members that are qualified people with disabilities or chronic conditions. Also, we urge the current board to recommend to the legislature that seats be explicitly added to the board for patients and people with disabilities.
- **Engagement Opportunities:** We are concerned that the PDAB meeting agendas have not formally involved expert advisors living with a condition treated by the selected drugs for review, nor have the meetings to date given priority to hearing their testimony. For example, Colorado held separate meetings for each of the 5 drugs selected for review, with one meeting specifically for patients and one meeting for clinicians treating the specific population of patients and researchers. Colorado also has an advisory council that reports to the board, which includes patients and people with disabilities. We request that the board work with patients and people with disabilities to schedule engagement opportunities, one for patients and one for clinicians and researchers, as part of its deliberations related to affordability. These engagement sessions should provide an opportunity for communication between the board and stakeholders, consistent with state law.

- **Transparency of Deliberations:** During Oregon’s legislative debate creating the PDAB, it was a priority for many in the patient and disability communities to ensure that its process did not rely on evidence that is discriminatory or biased, which would exacerbate existing health inequities. Therefore, many of our organizations supported provisions barring the use of quality-adjusted life years (QALYs) or similar formulas. Yet, the board is engaged with the Program on Regulation, Therapeutics, and Law (PORTAL), which has presented to the board options for considering comparative cost and benefit that explicitly includes 1) using existing health technology assessments which historically rely on QALYs or similar measures such as the equal value of life year gained (evLYG), 2) referencing the evidence rating from the Institute for Clinical and Economic Review (ICER), an entity which calls QALYs the “gold standard,” and 3) directly using QALYs and evLYG as part of reviews. Therefore, we urge the Board to publicly disclose for comment the evidence under consideration from third parties related to clinical effectiveness, cost effectiveness, and any comparators used in judgements of therapeutic benefit. This step is essential to protect the process from being undermined by considerations of evidence that is biased, discriminatory, or unlawful. Similarly, the board should avoid using a flawed comparator to judge whether a treatment is affordable or effective.
- **Emphasis on Patients in Affordability Review:** The statute creating the PDAB allows for the selection of treatments that the board determines “may create affordability challenges for health care systems or high out-of-pocket costs for patients.” We are concerned that the Board has brought in third parties to advise their process such as PORTAL, a third party whose work is focused on achieving savings for payers as opposed to achieving lower out-of-pocket costs for patients. As the process moves forward, we urge the board to work closely with organizations representing patients and people with disabilities to ensure that their real world affordability concerns are driving the board’s determinations.

It will be important for the board to balance input from patients, people with disabilities, providers, and researchers. For example, at the most recent PDAB meeting on November 15, we appreciated a guest physician's excellent presentation on the various ways she prescribes insulin to her patients. However, the board did not ask questions to the provider that would have been useful such as whether the drug worked in some populations and not others or whether one easier to adhere to than another? Also, the patient’s experience was missing from the presentation. For real communication, we would have preferred the board elicit the patient experience by asking targeted questions such as whether one drug caused the patient to access the emergency room more frequently than the other, or which was cheaper for overall out-of-pocket costs or had fewer side effects resulting in more productivity. This kind of nuanced information could be elicited as part of engagement opportunities for impacted stakeholders.

We respect you have been given an enormous task and would like to work with the committee to develop a more robust process for community engagement. The statute does not prohibit the board from directly engaging patients and people with disabilities. In fact, the law states, "The board shall accept testimony from patients and caregivers affected by a condition or disease that is treated by a prescription drug under review by the board and from individuals with scientific or medical training with respect to the disease or condition." Additionally, the statute conveys an expectation that the evidence under consideration will be disclosed to the public as long as it is not a trade secret or otherwise prohibited from being shared.

Oregon's goal of increased health equity demands the inclusion of patients and people with disabilities in this process. Thank you for your vital work in reducing the cost of prescription drugs for all Oregonians. We look forward to hearing from you.

Sincerely,

ALS Northwest, Portland, OR
Answer2Cancer Inc., Portland, OR
Caring Ambassadors Program, Oregon City, OR
Cystic Fibrosis Research Institute, Palo Alto, CA
Disability Rights Oregon, Portland, OR
Eastern Oregon Center for Independent Living, Pendleton, OR
HIV Alliance, Roseburg, OR
ICAN, International Cancer Advocacy Network, Phoenix, AZ
National Bleeding Disorders Foundation, New York, NY
National Psoriasis Foundation, Portland, OR
Pacific Northwest Bleeding Disorders, Corvallis, OR
Partnership to Improve Patient Care, Washington, DC
Project Access Northwest, Seattle, WA
The Community for Positive Aging, Portland, OR

Individuals

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Respectfully submitted by Lorren Sandt, Caring Ambassadors Program