Feb 29, 2024

Chair Deb Patterson
Senate Committee on Health Care
900 Court St. NE, S-411,
Salem, Oregon 97301

Chair Rob Nosse
House Committee on Behavioral Health and Health Care
900 Court St. NE, H-472
Salem, Oregon 97301

Dear Chair Patterson and Chair Nosse:

As organizations representing patients, people with disabilities and older adults, we are writing with regard to our concerns about the implementation of the State Prescription Drug Affordability Board and the need for oversight from legislators. When the bill creating the board passed, we were assured that its processes would be transparent, provide for robust engagement of patient and disability stakeholders and avoid reference to discriminatory evidence related to the effectiveness and value of treatments being evaluated. We have been very disappointed. At this stage, it is now clear that our efforts to engage the board members and staff in addressing our concerns are not working. As you know, the board itself is not operating at full capacity and is trying to recruit new members.[1] Therefore, we urge the legislature to pause the board's activities and initiate legislative oversight of the board's implementation.

On December 4, 2023, several organizations reached out to the board to ask it to address our concerns about board representation, the lack of engagement opportunities for expert advisors living with a condition treated by the selected drugs for review, the transparency of its deliberations, including its use of measures such as the quality-adjusted life year (QALY) and equal value of life year gained (evLYG) to measure the effectiveness and value of treatments, and finally the need to emphasize patients in affordability reviews. To date, we have not received a response or been given an opportunity to meet. In fact, their processes have only gotten worse. Our prior letter to the board is provided to you as an addendum to this letter.

We continue to be concerned that the board's meetings do not welcome patient input. The board's agenda does not provide any guidance on the information being sought from patients to help in their deliberations. The time allotted for patient input is very limited and does not provide for a robust back and forth discussion between the board members and concerned patients and people with disabilities. It is not clear to us what information is being considered by the board and on which patients and people with disabilities could be providing input. The affordability review timeframes for each treatment under consideration are very short during the meetings with little engagement opportunity. There is not a separate dedicated engagement opportunity for patients and

[1] https://dfr.oregon.gov/pdab/Documents/20240131-PDAB-applicant-summary.pdf

and people with disabilities related to each drug being reviewed, which is highly inconsistent with the process in other states. In summary, the board process is confusing and instills little confidence that its conclusions will accurately represent the effectiveness and value of treatments under consideration.

The lack of public testimony to-date is a strong indicator that the current process is not working. In the December meeting, public comment was limited to 1 minute per person.

The legislation creating the board, SB 844, stated, "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." The legislation also listed several criteria focused on the patient experience of accessing drugs being evaluated, including "health inequities for communities of color," "impact on patient access" and "estimated average patient copayment or other cost-sharing," yet the affordability review seems less focused on patient affordability than costs borne by the state. We share concerns about health system costs, but do not want the board's work to be at the expense of patients for whom existing therapeutic alternatives may not be the most clinically effective. We want to understand how the board is defining existing therapeutic alternatives and whether they are as effective as the treatments being reviewed. It is insufficient for the state to conclude less expensive alternatives are just as effective without hearing from patients. The goal of this process should be to ensure patients have access to the treatment that is most effective to treat their disease or condition. This requires a robust feedback loop and dedicated time to engaging patients and people with disabilities, including time for the board to respond, ask questions and solicit additional information.

Additionally, when the legislature passed SB 844, patients and people with disabilities were assured that QALYs and similar measures were barred from the board's consideration. Yet, the Institute for Clinical and Economic Review (ICER), an entity that calls QALYs the gold standard and that has developed the similar evLYG measure, as well as associated pro-QALY entities such as the Program on Regulation, Therapeutics, and Law (PORTAL), are deeply engaged in the board's work. Therefore, it is of the utmost importance for the evidence under consideration by the board to be transparent to the public to allow for patients and people with disabilities to weigh in with the board if consideration of certain evidence may be in conflict with its statute. We have shared these concerns with the board, yet we continue to be kept in the dark about the underlying evidence that may support its decisions.

In closing, we hope that the legislature will consider our concerns, pause the board's implementation, and conduct much-needed oversight of its activities. Thank you for your consideration and efforts to advance a health system that is equitable and allows for patients to affordably access the most clinically effective treatment.

Sincerely,

Organizations:
AiArthritis
ALS Northwest
Biomarker Collaborative

Caring Ambassadors Program
Cystic Fibrosis Research Institute
Exon 20 Group
ICAN, International Cancer Advocacy Network
MET Crusaders
National Bleeding Disorders Foundation
Pacific Northwest Bleeding Disorders
Partnership to Improve Patient Care
PD-L1 Amplifieds
The Bonnell Foundation: Living with cystic fibrosis
The ALS Association
The Coelho Center for Disability Law, Policy and Innovation
The Headache and Migraine Policy Forum

Individuals:
Laura Bonnell
Mary Canton
Lance Christian
Joy Krumdiack
Robbie Thurman-Noche

cc: Governor Kotek
Members of the Oregon Legislature
TK Keen, DCBS
Ralph Magrish, DCBS
PDAB committee