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