FORCE
Facing Hereditary Cancer EMPOWERED

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

On behalf of FORCE (Facing Our Risk of Cancer Empowered) and our Oregon constituents, we appreciate the opportunity to submit comments on the Oregon Prescription Drug Affordability Board's list of drugs selected for affordability review.

FORCE is a national nonprofit organization representing people facing hereditary cancers due to an inherited genetic mutation that increases their risk of cancers including breast, ovarian, prostate, pancreatic, colorectal, endometrial and gastric. As the only national organization representing the unique needs of these high-risk individuals and their families, FORCE serves as a champion, unifying the community and advocating for awareness, affordable access to care, and better treatment and prevention options. Through ongoing engagement with patients, caregivers, and advocacy partners, FORCE collects and synthesizes patient-reported experiences with diagnosis, treatment and caregiving related to hereditary cancers to understand the impact, access challenges, and unmet needs across the hereditary cancer community.

Individuals affected by hereditary cancer are often diagnosed at younger ages than the general population and face an increased risk of multiple primary cancers and recurrence. Access to affordable cancer screening, prevention and treatment options is a primary focus for FORCE. While cost is one factor, the ability to choose from a broad range of interventions and therapies is crucial in facilitating personalized medicine, informed decision-making and successful outcomes. While FORCE supports efforts to improve affordability, we are concerned that Prescription Drug Affordability Board (PDAB) policies—if not carefully designed and implemented—could unintentionally restrict patient access to crucial therapies. This is particularly important in oncology, where treatment decisions are highly individualized and must reflect the unique needs and complexities of each patient's cancer.

Two oncology drugs, Keytruda and Verzenio, are included on the PDAB affordability review list. We appreciate the Board's efforts to solicit stakeholder input on the importance of these medications and the impact of cost on access to care. As the review process moves forward, we urge the Board to ensure that affordability efforts do not create barriers to oncology treatment and that any resulting cost savings directly benefit the Oregon cancer patients who rely on these therapies.

KEYTRUDA
In addition to treating breast cancer, Keytruda is used to treat several other cancers, including a number of rare cancers. Under Medicare, drugs with orphan drug designations, like Keytruda, are ineligible for drug price negotiations because including them may discourage manufacturers from exploring new treatments for rare diseases. For many patients with cancer, especially those with rare cancers, this therapy may be their only treatment option, making it essential to protect access.

Clinical data demonstrate that disease progression in the metastatic setting is cumulative: each recurrence is associated with worsening symptoms, increasing treatment complexity, and fewer remaining therapeutic options. As disease advances, patients report escalating fatigue, pain, gastrointestinal symptoms, and emotional distress, as well as increasing concern about treatment effectiveness and prognosis. FORCE survey respondents with metastatic breast cancer describe ongoing symptom burden and the need to continuously reassess treatment decisions as their disease evolves, reinforcing that progression is not a single event but an ongoing process with profound impact on daily life.

In contrast, delaying or preventing recurrence meaningfully alters the disease trajectory for patients. These outcomes translate into additional time with preserved daily functioning, stability, and the ability to engage in work, family life, and future planning—outcomes that patients consistently identify as critically important.

Recent data from early-stage breast cancer studies indicate that adding ribociclib to standard endocrine therapy reduces the risk of disease recurrence in patients at high risk, reinforcing the importance of earlier intervention to alter long-term disease progression. For FORCE constituents, this reduction in recurrence risk represents more than a clinical endpoint; it directly affects peace of mind and the ability to live without constant anticipation of metastatic disease. Patients consistently describe recurrence as a pivotal turning point that transforms a potentially curable diagnosis into a life-limiting condition. Avoiding recurrence, or meaningfully delaying progression, is therefore viewed by patients as one of the most important outcomes of treatment, particularly when therapies can be administered orally and integrated into daily life with manageable side effects.

VERZENIO

For patients with early-stage hormone receptor–positive (HR+/HER2-) breast cancer, the course of disease is often defined by persistent fear of recurrence, which can extend for many years after initial treatment. Patients with stage II and III disease remain at risk for both early and late recurrence despite standard adjuvant endocrine therapy, contributing to long-term psychological distress and uncertainty about future outcomes. Fear of recurrence is consistently reported by our constituents as one of the most significant and enduring burdens following treatment, affecting emotional well-being, family planning, employment decisions, and overall quality of life.

When breast cancer recurs, it frequently does so as metastatic disease, which is incurable and associated with increasing symptom burden, declining physical function, and shortened survival. For patients and caregivers affected by breast cancer, what matters most is controlling the disease while preserving quality of life, independence, and the ability to engage in everyday life.

We hear from our constituents with early-stage breast cancer that peace of mind—specifically, the reassurance that they are doing everything possible to reduce the risk of recurrence is paramount. The ongoing anxiety around recurrence remains one of the most persistent burdens after treatment and influences how patients think about their future, family responsibilities, and employment. Treatments that meaningfully lower recurrence risk are therefore valued not only for their clinical benefit but for their impact on emotional well-being and long-term quality of life.

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For patients living with advanced or metastatic breast cancer, priorities often shift toward balancing length of life with quality of life. FORCE survey findings and educational programs demonstrate that patients place high value on treatments that provide disease control while minimizing disruption to daily life, preserving autonomy, and reducing cumulative treatment burden. As disease progresses, patients and caregivers report that maintaining independence, managing symptoms, and sustaining normal routines become increasingly important goals of care.

Across disease stages, patients consistently describe oral therapies as an important factor in reducing treatment burden. Oral treatments can limit time spent in medical facilities, reduce travel demands, and lessen reliance on caregivers for transportation and logistical support. The ability to take treatment at home supports continuity of daily life, enables patients to remain engaged in work and family responsibilities, and helps preserve a sense of control during a period often characterized by uncertainty. These benefits are particularly meaningful for individuals managing long-term or chronic treatment regimens.

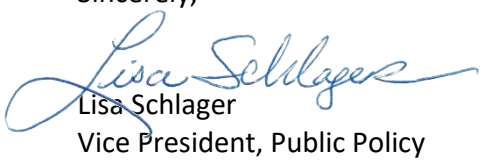
Patient-reported experiences underscore that effective management of cancer requires more than extending survival alone. Patients value therapies that reduce recurrence or progression, preserve function and dignity, support emotional well-being, and can be realistically integrated into daily life. Preserving access to effective treatments such as Kisqali and Verzenio is therefore essential to patient-centered cancer care, as these therapies address both the clinical and lived priorities that matter most to patients and caregivers.

In oncology, few therapies are truly interchangeable, even when they have the same FDA-approved indication. Treatment efficacy can vary by disease subtype, tumor characteristics, prior treatments, side effects, and patient goals. As a result, any determination of a true therapeutic alternative must consider the specific clinical circumstances in which each therapy is used. For example, while Ibrance and Kisqali have been identified as therapeutic alternatives to Verzenio, they should not be considered clinically equivalent or appropriate for every patient.

In addition to ensuring that cost savings reach patients, the PDAB must also preserve access to the most effective therapies for each individual's cancer. Scientific advances have transformed our understanding of cancer at the genetic and genomic levels and have led to the development of targeted therapies that can be life-changing for patients. If affordability policies create access barriers to these innovations, the promise of personalized medicine will not be fully realized. Please consider these factors carefully and ensure that efforts to address drug affordability do not restrict access to essential treatments.

We appreciate your consideration of our perspectives.

Sincerely,



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