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Industry Advisory Group (IAG)  
National ADAP Working Group (NAWG)

May 18, 2025

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

**RE: Drug List for Affordability Review**

Dear Honorable Members of the Oregon Prescription Drug Affordability Board,

Today, we write with concerns about the drug choices for affordability review.

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.

**Odefsey and HIV Antiretrovirals Should Not be on the List**

Initially, board deliberations discussed not including HIV antiretrovirals for consideration for affordability review. There seemed to be an understanding that in the interest of public health, HIV antiretrovirals should not be up for review, as it is beneficial for all HIV medications to be available without any possible encumbered access that could result from commonly considered price controls like a UPL.

According to the [Oregon Primary Care Association](#), in Oregon, over 200 new cases of HIV are diagnosed annually, with recent increases in rural areas. Additionally, about 1,087 Oregonians may be unaware they are living with HIV. Odefsey is a widely used medication appropriate for newly diagnosed individuals as well as those under care who may need to switch to Odefsey from their current medication.

Community Access National Network (CANN)  
[www.tiicann.org](http://www.tiicann.org)

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There was also understanding that due to patient assistance programs, insurance coverages with low copays, and even the State AIDS Drug Assistance Program (ADAP) - there is no issue of access to HIV antiretrovirals related to patient affordability. As a reminder, the Colorado and Maryland PDABs are not considering HIV antiretrovirals for that reason. Colorado specifically deemed Genvoya as “not unaffordable” due to ample patient assistance.

Yet, Odefsey is currently on the list for consideration for affordability review. It was added to the list when the dashboard was filtered via selecting the number of enrollees and total net carrier spend. The dashboard metric of total net carrier spend is not an indication of patient out-of-pocket affordability. Thus, what affordability concern is being addressed by including Odefsey? If this metric is somehow related to a system cost concern, what is that concern regarding state expenditures, and is that concern worthy of adversely affecting patient affordability and access to Odefsey and other HIV antiretrovirals?


### **Selection Process is Unclear**

Previously, the Board decided to pause the affordability review process in order to reevaluate the best way to explore affordability concerns. However, deliberations utilizing manipulations of the dashboard data do not indicate a clear direction of affordability inquiry. Additionally, the data gathered thus far only comprises a fraction of Oregonians who will be affected by decisions made. Thus, we are concerned that there doesn't seem to be a clear picture of what the affordability concerns are and how the data currently being collected will help inform solutions for those concerns.

Additionally, the current list of drugs for affordability review is heavily skewed towards medical issues affecting vulnerable populations with severe conditions that have few or sensitive treatment requirements. The list contains drugs treating rheumatoid arthritis, Crohn's disease, Cancer, MS, multiple biologics, etc. We would caution you to mindfully consider any actions that could adversely jeopardize patient access to these medications. It is essential to be clear on the desired affordability agenda before taking actions regarding these drugs, as opposed to other medications that may have actual affordability concerns for patients out of pocket that are not expressed by the current data gathered.

We appreciate all of the Board's hard work in trying to figure out solutions for patient drug affordability. However, we urge you to formulate a focused, informed, and replicable process to specify affordability concerns and explain how chosen solutions will rectify those concerns.

Respectfully submitted,



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

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