

April 14, 2025

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

Re: Public Comment for April 16, 2025 Board Meeting

Dear Members of the Oregon Prescription Drug Affordability Board:

The **HIV+Hepatitis Policy Institute** is a leading advocate for equitable and affordable healthcare for individuals living with or at risk of HIV, hepatitis, and other serious or chronic health conditions. As the Board finalizes its list of prescription drugs to review, we want to reiterate our concerns about the inclusion of any HIV medications and encourage the Board to reconsider their inclusion. We believe that affordability reviews of HIV medications fail to fully account for the intricacies of the existing HIV safety net, which makes lifesaving HIV treatments affordable for most people. We also want to highlight numerous factors in the global HIV drug ecosystem that would be difficult for a state to effectively consider.

Since the onset of the AIDS crisis in the 1980s, our community has tirelessly fought for access to effective treatments, leading to the establishment of vital safety net programs that ensure HIV care and medications remain affordable. Programs such as the Ryan White HIV/AIDS Program provide \$2.5 billion annually to ensure HIV treatments and care to low-income people living with HIV.<sup>1</sup> The Ryan White Programs generates \$2.8 billion in drug purchases through the 340B program<sup>11</sup> enabling crucial wraparound services and provide care and treatment to those who cannot afford it. Additionally, drug manufacturers contribute over \$1 billion in rebates directly to state AIDS Drug Assistance Programs-all to help with affordability of HIV drugs.<sup>111</sup>

For example, Oregon's ADAP, known as CAREAssist, operates with a diverse funding stream totaling approximately \$50 million, sourced from Part B funding, rebates, and program income. This funding covers essential medications and services for people living with HIV.<sup>iv</sup> Further affordability is achieved through additional rebate programs, such as Medicaid drug rebates, which help reduce the financial burden on public programs.

Pharmaceutical manufacturers also play a key role, contributing billions through copay assistance, free medication programs, and global initiatives like PEPFAR, which expand access to affordable HIV treatments worldwide. While gaps in coverage remain, this robust safety net has

been instrumental in ensuring people living with HIV receive the care and medications they need at an affordable rate.

Federal policies have further reinforced this safety net, helping to expand access to preventive care. For instance, the Affordable Care Act (ACA) and recommendations from the U.S. Preventive Services Task Force (USPSTF) have eliminated financial barriers by mandating that PrEP (pre-exposure prophylaxis) be available at no cost to most insured individuals. This policy ensures that those vulnerable to HIV can access lifesaving preventive treatments, complementing safety net programs and helping to reduce the spread of the virus-for free.

Affordability reviews of HIV medications may fail to fully capture the complexity and interdependence of safety net programs, which not only ensure affordability for patients but also sustain the broader HIV care infrastructure. Pricing interventions, such as the imposition of upper payment limits (UPLs), could destabilize this ecosystem, jeopardizing access to care and disincentivizing pharmaceutical manufacturers from continuing the research and development that has driven remarkable progress. The transformative innovations enabled by this investment—including longer-acting treatments, preventive therapies, vaccines, and the hope of an eventual cure—could be at risk if the delicate balance of these systems is disrupted.

The impact of these advancements cannot be overstated. Antiretroviral therapy (ART) has drastically changed the prognosis and quality of life for people living with HIV. When the first highly effective ART became available in 1996, a 20-year-old newly diagnosed with HIV had a life expectancy of just 10 years. Today, thanks to modern therapies, individuals with HIV enjoy lifespans comparable to the general population, with improved tolerability and far fewer side effects. These innovations have transformed HIV from a terminal illness into a manageable chronic condition for millions.

Importantly, high out-of-pocket costs for patients often stem from systemic issues unrelated to drug pricing, such as insurer practices and pharmacy benefit manager (PBM) strategies. Policymakers should focus on addressing these barriers through targeted reforms, such as regulating PBMs, capping out-of-pocket expenses, and ensuring that copay assistance counts toward deductibles. These solutions can improve affordability for patients without undermining the infrastructure and progress that have revolutionized HIV care.

We strongly believe that affordability reviews of HIV medications are unnecessary, given the comprehensive safety net programs that effectively ensure access to lifesaving treatments. Any future pricing interventions, such as the imposition of UPLs, could destabilize this well-established network, threatening access to care for people living with HIV. Programs like the Ryan White HIV/AIDS Program, the 340B program, and manufacturer copay assistance are critical to sustaining the progress and innovation that have transformed HIV treatment.

As we look to the future, it is essential to protect and strengthen these systems that have saved and transformed countless lives. Policymakers must prioritize targeted solutions that enhance affordability without compromising the stability of the infrastructure that has been pivotal in

the fight against HIV. By preserving this delicate balance, we can continue to provide hope and care for millions living with HIV while advancing toward the ultimate goal of ending the epidemic.

Thank you for your consideration of these comments. We urge the Board to carefully weigh the potential consequences of including HIV medications in the affordability review process and to recognize the vital role existing programs play in ensuring access to care. We welcome the opportunity to serve as a resource as the Board continues its important work to advance affordable and equitable healthcare for all Oregonians. If you have any questions or need any additional information, please do not hesitate to reach out to our Government Affairs Manager, Zach Lynkiewicz, at <a href="mailto:regonians.">regonians.</a> If you have any questions or need any additional information, please do not hesitate to reach out to our Government Affairs Manager, Zach Lynkiewicz, at <a href="mailto:regonians.">regonians.</a> If you have any questions or need any additional information, please do not hesitate to reach out to our Government Affairs Manager, Zach Lynkiewicz, at <a href="mailto:regonians.">regonians.</a> If you have any questions or need any additional information, please do not hesitate to reach out to our Government Affairs Manager, Zach Lynkiewicz, at <a href="mailto:regonians.">regonians.</a> If you have any questions or need any additional information, please do not hesitate to reach out to our Government Affairs Manager, Zach Lynkiewicz, at <a href="mailto:regonians.">regonians.</a> If you have any questions or need any additional information, please do not hesitate to reach out to our Government Affairs Manager, Zach Lynkiewicz, at <a href="mailto:regonians.">regonians.</a> If you have any questions or need any additional information, please do not hesitate to reach out to our Government Affairs Manager, Zach Lynkiewicz, at <a href="mailto:regonians.">regonians.</a> If you have any questions or need any additional information.

Sincerely,

Carl E. Schmid II
Executive Director

Ryan White HIV/AIDS Program Funding: FY 2015–FY 2024 appropriations by program

<sup>&</sup>quot; 2023 340B Covered Entity Purchases

iii 2024 National RWHA Part B ADAP Monitoring Project Annual Report

iv KFF: Distribution of ADAP Budget by Source