



March 26, 2018

Chairperson Joshua Miller
Senate Health & Human Services Committee
41 Talbot Manor
Cranston, RI 02905

Vice Chairperson Gayle Goldin
Senate Health & Human Services Committee
P.O. Box 2722
Providence, RI 02906

Re: Impact of Prescription Drug Benefit Legislation (SB 2532) on Access to HIV and Hepatitis C Medications

Dear Senators Miller and Goldin:

We are writing on behalf of the HIV Health Care Access Working Group (HHCAWG) – a coalition of over 100 national and community-based HIV service organizations representing HIV medical providers, public health professionals, advocates, and people living with HIV who are all committed to ensuring access to critical HIV- and hepatitis C-related health care and support services. **We write to share our strong concerns regarding parts of Senate Bill 2532.**

Specifically, we oppose the provision in the bill that would allow health plans to prohibit the use of manufacturer drug discount cards and coupons from being applied towards beneficiaries out of pocket maximum. We believe, if passed, it would severely restrict patient access to HIV and hepatitis C (HCV) medications. This would endanger people's lives and have significant individual and public health consequences. **We urge you to reject this provision from the bill.**

Importance of Access to HIV Medications

While we recognize drug prices are increasing and need to be addressed, access to medications is critically important for people living with HIV, and now, for people who are at higher risk of HIV. If a person living with HIV has access to antiretroviral drugs and is adherent to their medication regimen, that individual can live a long, healthy life largely unaffected by this disease. Furthermore, if an individual living with HIV is on antiretroviral treatment, their HIV can be suppressed to such a level that the possibility of transmitting the virus is essentially non-existent. Therefore, HIV treatment is also effective HIV prevention.

Additionally, people who do not have the virus, but are at higher risk of contracting HIV, can take a medication to prevent infection. This medication regimen is known as pre-exposure prophylaxis (PrEP). PrEP is a Food and Drug Administration (FDA)-approved medication that when taken consistently, reduces the risk of HIV infection by between 92 and 99 percent.

Suitable generic alternatives are currently not available for HIV prevention and for the treatment of HIV and HCV. While some generic alternatives are available for HIV treatment regimen components recommended for most patients in the *Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents Living with HIV* maintained by the Department of Health and Human Services, these require breaking up single-tablet regimens widely considered important to adherence and still involve at least one brand-name drug with no generic equivalent.¹ Without the co-pay assistance, most people living with HIV will be unable to afford their treatment, and individuals trying to protect themselves from HIV will be left at greater risk of acquiring the virus.

High Beneficiary Cost-sharing Limits Access

Today, one of the greatest obstacles facing HIV-positive people, and those who would like to access PrEP, is the patient cost of medications. Even for people covered through the private and employer insurance market, the financial burden of increasingly high deductibles and high co-insurance reduces the affordability, and thus the adherence rates, to these drugs. This is particularly true given that the vast majority of medications used to treat HIV and the only drug currently approved for PrEP are not available in generic form and, when covered by insurance plans, are often on the highest cost-sharing tiers. While in the past, many plans had first dollar coverage for prescription medications, more plans today are requiring individuals and families to first meet a deductible that can be several thousand dollars, with co-insurance rates as high as 50 percent after the deductible is met. High deductibles, coupled with high cost-sharing, prohibit many people from being able to afford their critically necessary medications and treatments.

- According to the Kaiser Family Foundation (KFF) 2017 Employer Health Benefits Survey, the average deductible for people with employer-sponsored coverage was \$303 in 2006, rising to \$1505 in 2017².
- In the same report, KFF found that more employees are enrolled in high-deductible plans—up to 28% in 2017—as compared to five years ago when 19% of people were enrolled in a high-deductible plan offered by an employer.

¹ HHS Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents Living with HIV. 2017 Oct 17. <https://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-arv/37/>

² <https://www.kff.org/report-section/ehbs-2017-section-8-high-deductible-health-plans-with-savings-option/>

- For plans offered in the individual marketplace, Avalere’s analysis found that the national average for the popular silver-tier plan deductible increased from \$2,658 to \$3,937 between 2015 and 2018³.

Co-pay Cards Enable Beneficiaries to Access Drugs

To assist people living with HIV or people on PrEP in affording their prescriptions and adhering to them, pharmaceutical manufactures have offered co-pay assistance programs. This assistance reduces the amount the beneficiary pays for their medication and helps them meet their deductible and maximum out-of-pocket spending limit. The availability of this assistance has enabled people living with HIV to remain alive and healthy, prevents transmission of HIV to others, and the acquisition of HIV for people taking PrEP. This ultimately lowers costs for health plans by eliminating the high costs of care for every transmission prevented. Without the copay assistance programs beneficiaries would not be able to afford their medications, daily adherence would be endangered, and the public health jeopardized.

Impact of Proposed Legislation

Enacting new legislation that will prevent co-pay assistance contributions from counting towards a beneficiary’s deductible and maximum out of pocket spending limits leaves individuals at risk for discontinuing HIV or HCV treatment. By doing so, it will allow insurance companies to create an environment that will lead to poorer health outcomes and increased rates of new infections, and higher costs for health plans. This practice is particularly concerning when applied to medications for which there is no generic alternative, which is the case for the vast majority of drugs used to treat HIV, and all drugs used to treat HCV and prevent HIV. In those cases, failing to count co-pay assistance cards toward a consumer’s deductible and out-of-pocket maximum leaves the consumer with no affordable coverage option.

The financial impact of these changes is significant. Unaware of the change, many consumers find themselves facing a “cost cliff” mid-year. After hitting the maximum on their co-pay card assistance, they pick up their prescription only to discover that the co-pay card has not been counted toward the deductible and they now will owe over a thousand dollars per refill to continue their medication. This likely will cause dangerous treatment disruptions mid-year as medication becomes prohibitively expensive without warning.

In addition to the financial upheaval related to dramatically increased patient cost-sharing, beneficiaries are shocked by the abrupt change in their insurance coverage. In instances where these practices have already been implemented, insurance plans have not adequately notified their beneficiaries of this change, leading people to continue to engage in their health care and financial planning in the new year just as they have in the previous years, unaware that the circumstances have changed. This change in coverage has been difficult for patients to learn about and to understand. Finally, the impact of the change is not felt until several months into

³ <http://avalere.com/expertise/managed-care/insights/silver-exchange-premiums-rise-34-on-average-in-2018>

the year, and beneficiaries have no idea how much this change will cost them until they pick up their prescriptions at the pharmacy.

Given the high number of people living with HIV who are co-infected with hepatitis C virus (HCV), we are concerned that instituting this policy for curative HCV drugs will make access to these drugs out of reach to most people living with HCV. This will not only endanger their personal health but increase future medical costs and lead to future HCV infections.

Some have stated that the existence of co-pay cards steer beneficiaries to particular brand name medications and away from generic medications. However, as stated above, there are few generic substitutes for HIV treatment and for PrEP and HCV treatment, there are no generic alternatives. The co-pay cards clearly assist beneficiaries in accessing their medications at a price they can afford for medications that are costly and life-saving.

For the reasons stated above, we urge you to reject this provision of SB 2532.

Should you have any questions or need additional information, please feel free to contact Carl Schmid with The AIDS Institute at cschmid@theaidsinstitute.org, or HHCAWG co-chairs Robert Greenwald with the Treatment Access Expansion Project at rgreenwa@law.harvard.edu, Amy Killelea with the National Alliance of State and Territorial AIDS Directors at akillelea@NASTAD.org, or Andrea Weddle with the HIV Medicine Association at aweddle@hivma.org

Respectfully submitted by:

ADAP Educational Initiative | AIDS Action Baltimore | AIDS Alabama | AIDS Alliance for Women, Infants, Children, Youth & Families | AIDS Foundation of Chicago | AIDS Healthcare Foundation | The AIDS Institute | AIDS Project Rhode Island | AIDS Research Consortium of Atlanta | AIDS Resource Center of Wisconsin | AIDS United | American Academy of HIV Medicine | APLA Health | Bailey House, Inc. | Bronx Lebanon Family Medicine | Cascade AIDS Project | Center for HIV Law and Policy | Clare Housing | Coalition on Positive Health Empowerment | Communities Advocating Emergency AIDS Relief (CAEAR) | Community Access National Network (CANN) | Fair Pricing Coalition | Georgia AIDS Coalition | Harm Reduction Coalition | HealthHIV | HIV Dental Alliance | HIV Medicine Association | Housing Works | Legal Council for Health Justice | Michigan Positive Action Coalition | Minnesota AIDS Project | National Alliance of State and Territorial AIDS Directors | Nashville CARES | National Latino AIDS Action Network | National Working Positive Coalition | NMAC | Positive Women's Network - USA | Prism Health | Project Inform | Rocky Mountain CARES | San Francisco AIDS Foundation | SisterLove | Southern AIDS Coalition | Southern HIV/AIDS Strategy Initiative | Treatment Access Expansion Project | Treatment Action Group

cc: Members, Senate Health and Human Services Committee