



**Testimony Before the Joint Hearing of the
House Committees on Insurance and Prescription Drug Affordability & Access**

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Thank you, Chairs and members of the Committee. I am John Peller, President & CEO of the AIDS Foundation of Chicago (AFC), and I am honored to be here to testify today on HIV medication pricing, access and coverage issues. These are complex and interrelated issues, and we must find the right solutions to problems that stem from drug manufacturers, pharmacy benefit managers (PBMs) and insurance company practices.

Illinois is seeing dramatic successes in reducing new HIV cases. Over the decade from 2008-2017, new HIV cases dropped by 25% in Illinois and 32% in Chicago. Statewide, Illinois has saved an estimated \$820 million in lifetime health care costs by preventing an estimated 1,839 people from becoming HIV-positive over the same period.¹

These successes have spurred AFC, the Illinois and Chicago Departments of Public Health and over 40 community organizations including Howard Brown Health (and I thank Dr. Cori Blum for joining me today) to develop the Getting to Zero Illinois (GTZ IL) plan, which was released in draft form in December 2018. The draft plan shows that we can end the HIV epidemic in Illinois by 2030. Two key strategies must be implemented to reach this goal.

First, Illinois must increase the number of people who take pre-exposure prophylaxis (PrEP) by 20 percentage points. PrEP is a daily HIV medication (Truvada, made by Gilead) that is nearly 100% effective when taken consistently and correctly. But we estimate that only about 10% of people who are most vulnerable to contracting HIV are actually taking it. Truvada is currently the only drug indicated for PrEP in the United States.

The second goal of GTZ IL is to increase the number of people living with HIV who are virally suppressed by 20 percentage points. Why is viral suppression important? We have a slogan in the HIV world that helps to convey the science – U=U or Undetectable=Untransmittable. The iron-clad science, first proven by the National Institutes of Health, shows us that when a person's viral load is suppressed for at least six months they cannot transmit HIV sexually. In other words, taking HIV medications consistently is an extremely effective form of HIV prevention. But almost half of people in Illinois living with HIV are not virally suppressed. That is about 20,000 people.² Twenty thousand people are not receiving treatment that could benefit their own lives and reduce the spread of HIV in our communities. Furthermore, interruptions in HIV medication access can cause HIV to mutate, making the virus harder to treat and requiring

¹ Estimate by John Peller, AIDS Foundation of Chicago, and Nanette Benbow, Northwestern University, November 2018.

² IDPH HIV Surveillance Section, 12/3/19, slide 18, accessed from https://gtzillinois.hiv/wp-content/uploads/2018/12/GTZ_Dec_3_WAD.pdf 2/27/19.

more complex and expensive medications. Continuous, uninterrupted access to HIV medication is essential for saving lives by maintaining individual health and strengthening communities. Moreover, expanding HIV treatment saves taxpayer dollars.

Despite significant progress in reducing new HIV cases, dramatic and damaging health disparities remain. Gay, bisexual, and other men who have sex with men comprised a majority of people living with HIV in 2017 (IL: 54%; Chicago: 68%) and newly diagnosed people (IL: 60%; Chicago: 77%). Black men the largest share of new diagnoses in this population (IL: 51%; Chicago: 46%). Among heterosexual women, Black women account for more than 73% of HIV cases and new infections.³ Latinx people are also disproportionately impacted by HIV, representing 21% of new HIV diagnoses in Chicago in 2017.⁴ Among certain groups like gay, bisexual, and other MSM, new diagnoses continue to increase. Nationally, over half of black transgender women are HIV-positive.⁵

That's all background to say access to HIV medications is essential if we are to get to zero in Illinois, and the high price of HIV drugs and resulting access challenges are important barriers to overcome for us to be successful.

HIV MEDICATION COST CONCERNS: HIV medications are unquestionably expensive. Drugs recommended by the U.S. Department of Health and Human Services (DHHS)⁶ for most people with HIV range in from \$33,000 TO 40,000.⁷ Nationally, Medicaid spent \$5 billion on antiretroviral medications in 2017, a 47% increase since 2014.⁸ We do not have Illinois-specific Medicaid spending data.

I want to be clear that HIV drug manufacturers somewhat mitigate the impact of these high prices with strong patient assistance programs that provide free medications to people who are uninsured and co-pay coupons to help people afford the out-of-pocket costs of HIV medications. HIV drug manufacturers also make generous charitable contributions to support the work of AIDS Service Organizations, including AFC. HIV drug companies say they give supplemental rebates to Medicaid programs, the AIDS Drug Assistance Program, and 340B covered entities, often beyond what is mandated by law. However, the dollar value of those rebates are confidential, so the public has no knowledge about the amount of these rebates.

³ Getting to Zero Illinois Draft Plan, Dec. 3, 2018, p. 8. Accessed from www.gtzillinois.hiv/draft-2/27/19.

⁴ Chicago Department of Public Health, HIV/STI Surveillance Report 2018, December 2018, p. 24.

⁵ CDC, HIV among Transgender People, <https://www.cdc.gov/hiv/group/gender/transgender/index.html> accessed 2/27/19.

⁶ Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents Living with HIV. Department of Health and Human Services. Available at <http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>. Accessed 2/27/19.

⁷Wholesale acquisition cost (WAC) from Fair Pricing Coalition ARV Pricing Table, 2018.

⁸ Kaiser Family Foundation, Utilization and Spending Trends in Medicaid Outpatient Prescription Drugs, Figure 4, accessed from <http://files.kff.org/attachment/Issue-Brief-Utilization-and-Spending-Trends-in-Medicaid-Outpatient-Prescription-Drugs-2/28/18>.

Therefore it is impossible to assess what impact supplemental rebates have on patients' access to these medications.

Because of the high price of HIV medications, HIV is the one of the only diseases in America that has a dedicated program that pays for medications. The AIDS Drug Assistance Program, or ADAP, is run by the Illinois Department of Public Health and funded by state general revenue and federal funds. ADAP is a vital program that covered nearly 7,500 Illinoisans with HIV in 2016, and it covers premiums and out-of-pocket costs for over 4,200 people who otherwise wouldn't be able to afford them.⁹ While our state's ADAP makes sure no low-income Illinoisan goes without HIV medications, it is a part of a patchwork system that may not be sustainable long-term because of the high costs of medications. Illinois also has a program, PrEP4Illinois, that offers free Truvada for people who are vulnerable to HIV but have access challenges; this is another example of a patchwork program.

Here are some examples of concerns about HIV drug pricing practices.

In 2018, Janssen released Symtuza, a single-tablet regimen that contains four drugs in one pill. The wholesale acquisition price (WAC) at introduction was nearly \$42,000 a year, a record for a single-tablet regimen. This is roughly \$5,000 more than competitor single-tablet regimens. (Note that these are list prices and actual prices are confidential but may be much lower.) While Janssen isn't charging more than the price of the four component drugs included in this single tablet regimen, the original development costs have been recovered many times over. These were existing drugs that were put into one tablet. Of course, the clinical trials to get the new single tablet cost money, which Janssen is entitled to recover, but the cost of this drug is extraordinary and excessive. Because of the high price, it is the only HIV drug not covered by Illinois ADAP.

Second, HIV drug manufacturers, like most drug companies, routinely increase prices by more than the rate of medical inflation. Gilead has increased the price of Truvada by 157% between its introduction in 2004 and 2018, compared to medical inflation of 56% over the same time period and overall inflation of 33%. The price of Triumeq, by ViiV, has increased 31% since 2014, compared to 13% medical inflation and 7% overall inflation over the same period.¹⁰ It's important to note that some of this increase is driven by demands by pharmacy benefit managers for rebates, but the rebate amounts are confidential so we don't know to what extent this drives the increases.

Third, HIV drug manufacturers may also engage in questionable practices to lengthen the life of their patents and monopolies. Truvada is the only drug approved in the U.S. for PrEP and a widely-used HIV treatment option. It has been alleged that Gilead has a pay-for-delay agreement with a generic manufacturer to postpone the availability of a generic form of

⁹ [2018 National Ryan White Part B ADAP Monitoring Project Annual Report](#), National Alliance of State and Territorial AIDS Directors, accessed 2/27/19.

¹⁰ Private communication from Paul Arons, Fair Pricing Coalition Member, 2/27/18. WAC prices shown.

Truvada, which is now scheduled to go generic in 2021.¹¹ A lower-cost generic form of Truvada would be an essential development that could improve access to HIV medications for prevention.

The following bills that the Prescription Drug Affordability & Access Committee will review offer promising solutions to some of these pricing issues:

- [HB 2880](#) (Guzzardi), which would establish a tax on drug prices that exceed the Consumer Price Index (CPI)
- [HB 2882](#) (Guzzardi), which would hold drug companies accountable when they raise prices by an amount that exceeds medical CPI in a year,
- [HB 3492](#) (Guzzardi), which would create a prescription drug review board, and
- [HB 53](#) (Flowers), which would require disclosures to state government and payers before price increases

In addition, I urge the committee to examine the role the PBMs play in drug pricing and annual increases, and to improve the transparency of PBM practices.

It's important to note that acceptable generic forms of HIV medications are increasingly available. Expanding the use of generics is one way to lower HIV drug spending. In fact, three of the four DHHS-recommended drug regimens for initial treatment can use a generic component. There are many people with HIV for whom generic forms of treatment may be appropriate, and as the costs of branded regimens continue to rise, health care providers, patients, payers and advocates must come to consensus on when it is acceptable to encourage the use of a generic drug. Note that step therapy is never acceptable for people with HIV because of the risk of drug resistance; it can also reduce an individual's quality of life and increase pill burden.

ENSURING ACCESS TO ONCE-DAILY SINGLE TABLET REGIMENS: I want to turn next to single-tablet regimens (STRs), one pill taken once a day that contains a complete HIV treatment of between two and four separate drugs. The alternative is to take two or more pills once or more times a day. STRs play a vital role in adherence, something with which many people with HIV struggle. However, many commercial and marketplace plans place STRs on the highest cost-sharing tiers, require the use of specialty pharmacies to obtain them, or require prior authorization (which increases the administrative burden on providers and increases the risk of medication lapses, reducing adherence and viral suppression). As of January 2019, fee-for-service Illinois Medicaid covered just 3 of 11 STRs, compared to an average of 9 for the state's Medicaid managed care plans.¹²

¹¹ https://www.vice.com/en_us/article/xw875w/the-fda-has-approved-generic-prepbut-access-may-remain-difficult

¹² AIDS Foundation of Chicago, Comparison of Medicaid Fee-for-Service and Managed Care HIV Formularies, January 1, 2019, unpublished.

Payers implement these cost-containment strategies because of the high prices of HIV medications, but evidence suggests such restrictions are not cost-effective when looking at overall health care costs (not just pharmacy costs). In fact, an analysis from Express Scripts released in November 2018 showed that one-pill once-daily drugs significantly improve adherence. In fact, 74.5% of patients on STRs are adherent versus only 64.9% of patients taking several HIV pills daily.¹³ That's almost a 10-percentage point improvement. Moreover, HIV health care costs were \$5,427 higher for patients on multi-tablet drugs per year.¹⁴ Multiplied by the estimated 20,000 people with HIV on treatment in Illinois, that adds up.

As we work towards the goal of ending the HIV epidemic in Illinois, increasing access to STRs is essential. However, paying the high cost for HIV medications is not sustainable, which is why we see access restrictions for STRs. I urge you to advocate for HFS to increase the number of STRs that are covered under fee-for-service, and to closely monitor access to STRs under Medicaid managed care plans. This includes making sure drug companies are lowering their prices or offering substantial supplemental rebates to increase access, and monitoring HFS to ensure that they are accepting the offers of supplemental rebates.

INSURANCE AND PBM ISSUES: I want to highlight several access issues related to insurance company and PBM practices that impact people who take HIV medications for treatment or prevention, as well as people who take expensive medications for any chronic condition. These include:

- **Co-Pay Accumulators:** Insurance companies are increasingly using co-pay accumulator policies that do not allow co-pay coupons to count towards a member's deductible for private insurance. While the drug coupon covers the cost of the drug during the deductible, it does not defray the deductible. When the value of the coupon runs out, the consumer must keep paying out-of-pocket until they meet their deductible. Essentially, co-pay accumulator policies require consumers to meet their deductible twice, and the insurance company keeps the double payment. Insurance companies are implementing these policies because they want members to use generics, but there are not always suitable generic alternatives for people with HIV and other costly chronic diseases. Look for a bill to be introduced in the coming weeks that will ban co-pay accumulators.
- **Specialty pharmacy requirements:** Pharmacy benefit managers – and especially Medicaid managed care PBMs – often require patients to get HIV medications from mail-order, specialty pharmacies when there is no medically necessary reason for this requirement. This means people with HIV have to get some drugs from their corner drug store and others by mail. Consumers who cannot get single-tablet regimens may run out of one of their three drugs, but keep taking the rest, a dangerous practice that can lead to resistance. Again, look for legislation that will address this practice in the coming weeks.

¹³ Express Scripts, Viral Signs: Understanding HIV Medication Use, Nov. 28, 2019, p. 3, accessed from <http://lab.express-scripts.com/lab/publications/viral-signs-understanding-hiv-medication-use> 2/28/19.

¹⁴ Express Scripts p. 14.

- **High deductibles:** The high cost of HIV medications and the rise of high-deductible health plans mean patients often have to pay thousands of dollars before they meet their deductible. [HB 2174](#) (Rep. Kathleen Willis, D-Northlake) would address this by requiring at least one-quarter of insurance carriers' plans to have a flat co-pay for prescriptions. This would be in lieu of more expensive deductibles and co-insurance amounts that apply to services covered in the rest of the plan.
- **Monitoring Marketplace plans for discriminatory practices:** Finally, I urge you to pressure the Department of Insurance to closely monitor HIV medication coverage and pricing under Marketplace plans. In the past in Illinois, a marketplace plan put every HIV drug in the highest cost-sharing tier – which could require paying 50% of the cost of the drug out of pocket, or \$1,000 or more a month. This deters people with HIV from enrolling in the plan and is a form of discrimination against people with disabilities. Again, in addition to monitoring insurance plans, we must call out drug companies for high costs that are driving insurance companies to make these coverage decisions.
- **Maintain the 340 B program:** The 340 B program is an often unrecognized yet critical funding source of healthcare, support services, and treatments for uninsured people affected by HIV/AIDS. The HIV service delivery sector depends on manufacturer discounts and savings made possible by 340B program. It helps reduce outlays by government entities and helps low-income and uninsured patients gain access to a full continuum of care. Despite charges by the pharmaceutical industry to the contrary, 340B does not drive the high cost of medications; in fact, the discount helps lower costs for those who are most vulnerable and the health systems caring for them.

FLAWED MEDICAID REDETERMINATION PROCESS CREATES BARRIERS TO HIV MEDICATION

ACCESS: Finally, a significant problem impacting continuity of medication access for people with HIV in Illinois is the number of Medicaid recipients who are removed from the program because of the flawed redetermination process. As a result, people with HIV churn between Medicaid, ADAP and drug company assistance programs. The people who are trying to do everything right – to manage their health and stay on meds – face barriers erected by the state of Illinois Medicaid program that conspire to interrupt their access to life-saving meds. The stress, disruption and time wasted by clinicians, case managers, and pharmacists is immeasurable. The committees can easily fix this by supporting SB 2021 (Sen. Heather Steans – D-Chicago) when it comes over from the Senate.

CONCLUSION: Illinois can end the HIV epidemic by 2030 by increasing access to HIV medications for prevention and treatment. The combination of high HIV drug prices plus payer and PBM practices result in deadly barriers to treatments and increase costs to our state. Addressing high drug prices is a key component of ending the HIV epidemic.

Thanks to Tim Horn and Paul Arons of the Fair Pricing Coalition for their assistance with this testimony. Learn more at www.fairpricingcoalition.org.