



THE COUNCIL OF  
THE CITY OF NEW YORK  
CITY HALL  
NEW YORK, NY 10007

COREY JOHNSON  
SPEAKER

TELEPHONE  
(212) 788-7210

**Testimony Submitted for the Record  
U.S. House Committee on Oversight and Reform  
Hearing: "HIV Prevention Drug: Billions in Corporate Profits after Millions in  
Taxpayer Investments"  
Corey Johnson  
Speaker, New York City Council  
May 16, 2019**

Chairman Cummings, Ranking Member Jordan, and members of the House Committee on Oversight and Reform, thank you for the opportunity to submit testimony for the record on HIV prevention drugs. This issue is of critical importance to me, to New York City, and to the entire country, and I thank you for your leadership in addressing this issue at this hearing today. I am submitting testimony today both in my role as Speaker of the New York City Council, the legislative body of the largest city in the United States, and on a personal level, as an HIV-positive citizen of the United States of America.

The affordability and accessibility of HIV-preventing drugs could not be a more personal issue to me. When I was 22 years old, I seroconverted. Less than two weeks later, I lost my job and my health insurance. At the time, I lived with a tremendous amount of shame, fear, and anger at myself, and with remorse for testing HIV-positive. I turned to alcohol and drugs to self-medicate through the devastation of my diagnosis. Now, 15 years later, I am struck by the fact that we can save millions of Americans from having to go through this painful experience, from expensive medical care, and from life-changing diagnoses. We have the ability to improve and save the lives of millions of Americans, but

we're being blocked from making real progress by the unconscionable prices of PEP and PrEP.

PEP, or post-exposure prophylaxis, is an HIV prevention drug which HIV-negative people take after coming into contact with HIV to reduce their risk of HIV infection. PrEP, or pre-exposure prophylaxis, is a medication intended to prevent HIV infection for people who do not have HIV, but who are at substantial risk of becoming infected. When taken consistently, PrEP has been shown to reduce the risk of HIV infection in people who are at high risk by up to 92 percent. But among the estimated 1.1 million people nationwide who are potential candidates for PrEP, only eight percent are receiving it. In addition, use of PrEP remains largely limited to white gay or bisexual men, meaning that groups with the highest risk of infection – including, men who have sex with men, transgender individuals, women of color, sero-discordant couples (HIV negative partner), and injection drug users – are not benefiting from this life-saving drug. And while much of the focus of the conversation around PrEP has centered on sexually active men, sexually active women are also at risk of contracting HIV.

Currently, Truvada is the only brand of PrEP medication available in the United States until at least 2021, when the first generic version of the medication becomes available, and 2024, when all generic versions will be available for sale. The United States government, through the National Institutes of Health (NIH), and by extension its taxpayers, paid for almost 100 percent of the research that went into the development of Truvada, and has exclusively licensed the patent and the right to manufacture Truvada to Gilead Sciences.

Since brand-name Truvada was approved for HIV prevention six years ago, its average wholesale price has increased by approximately 45 percent. Now, the drug — which accounts for billions of dollars in annual global revenue for Gilead Sciences — carries a list price of approximately \$2,000 for a 30-day supply, with an average monthly cost of approximately \$6 to produce. The monthly cost charged by Gilead means that Truvada continues to remain out of reach for too many New Yorkers and Americans across this country. Access to PrEP for every person who is at risk of HIV infection could be one of the most important steps in continuing New York City's work to end the epidemic.

In New York City in 2017, there were 2,157 new HIV diagnoses and 1,239 new AIDS diagnoses, according to the New York City Department of Health and Mental Hygiene (DOHMH). This means that as of the end of 2017, 125,884 New Yorkers were presumed to have been living with HIV/AIDS. As of March 31, 2018, there were 1,343 deaths reported among people with HIV in 2017. HIV/AIDS also disproportionately affects communities of color in New York City, with the HIV diagnosis rate among black males at 1.4 times higher than the rate among Latino/Hispanic males and over 3 times higher than the rate among white males as of 2017. For women, these numbers are even more jarring: in 2017, the HIV diagnosis rate among black females was 2.7 times higher than the rate among Latina/Hispanic females and over 10 times higher than the rate among white females. And yet, according to DOHMH, in 2016, “only 21 percent of sexually active black and/or Latina women were aware of PrEP.”

While we are making progress in the fight against HIV and AIDS in New York City, this progress is not coming quickly enough, and this is largely due to the cost-prohibitive expense of HIV-preventing drugs, PEP and PrEP. While it is true that many private insurance plans and New York State Medicaid cover the cost of PEP and PrEP

medication, changes in insurance coverage have put a heftier financial burden on patients. As drug prices continue to climb, many private health plans are making patients responsible for a larger share of drug costs with many restricting the use of copay coupons that pharmaceutical companies have used to shield patients from out-of-pocket expenses. Gilead provides a co-pay coupon, but as stated earlier, many health plans are no longer allowing the co-pay coupon to count towards their prescription drug deductible. This has placed PrEP out of reach for many New Yorkers who have long enjoyed coverage through their health plan in combination with the co-pay coupon.

New York State and New York City are taking tremendous steps to make progress despite the barriers imposed by cost and access. In 2014, New York Governor Andrew Cuomo outlined the *Ending the Epidemic (ETE)* Initiative to end the AIDS epidemic in New York State. The goal is to reduce the number of new HIV infections to just 750 (from an estimated 3,000) by 2020. On December 1, 2015, New York City, using the New York State blueprint, launched ETE with the goal of reducing the number of new infections in the city to fewer than 600 in 2020. DOHMH, in conjunction and in collaboration with local stakeholders, community advocates, City Hall and the City Council developed a four-part strategy to end the City's HIV epidemic:

1. Increase access to HIV prevention services;
2. Promote innovative, optimal treatment for HIV;
3. Enhance methods for tracing HIV transmission; and
4. Improve sexual health equity for all New Yorkers.

Additionally, in Fiscal Year 2019, the New York City Council allocated nearly \$7 million to the ETE Initiative, building on the \$6.3 million allocated in Fiscal 2018. The initiative funds prevention, education, outreach, and support services that align with the

ETE framework, helping to connect clients to healthcare and medication, including PrEP and PEP. This Initiative works in conjunction with Mayor Bill de Blasio Administration's \$23 million annual investment in the ETE Blueprint. The ETE Initiative funds more than 50 community-based organizations throughout the five boroughs. In addition to robust outreach and education programs, the Initiative funds viral suppression labs, PrEP education at needle exchange sites, and PEP Centers of Excellence in Brooklyn and Queens, among other services. The ETE Initiative supports some of the City's most vulnerable and marginalized populations, providing PrEP screening and navigation, and HIV testing to high-risk Transgender And Gender Non-Conforming (TGNC) people. Other programs address the needs of substance users, deploying peer-based outreach teams in non-traditional venues in order to increase access to HIV testing and medical care.

In addition to the ETE Initiative, the New York Council supports HIV/AIDS prevention and support services provided by religious institutions and community-based organizations through the \$1.1 million HIV/AIDS Faith-Based Initiative. The Viral Hepatitis Prevention Initiative, funded at nearly \$2 million in Fiscal Year 2019, funds programs and services intended to combat the spread of Hepatitis B/C and HIV as passed through intravenous drug use. In addition to Hepatitis B/C testing, services include addiction treatment, care coordination, overdose prevention, mental health assessments, and sterile syringe access.

I am incredibly proud of all of the work that we've done in New York City to increase access to PEP and PrEP and to make these life-saving medications more affordable for New Yorkers. But it is unconscionable and immoral that Gilead continues to make massive profits off of a drug that was researched and funded by American tax-payer dollars. The burden of subsidizing the cost of these drugs should not also fall onto the shoulders of

cities and taxpayers, who are currently receiving very minimal return on their investments into these drugs. We have within our power the ability to end the HIV/AIDS epidemic once and for all, to improve the lives of all Americans, and to save on expensive medical care. The only thing that is standing in our way is unethical profiteering by large drug companies. I urge the Committee to hold Gilead accountable, and to question them about how they plan to make these drugs accessible and affordable to the Americans who paid for the research that made their profits possible.

I thank you for this opportunity, and I look forward to working with the Committee on this issue.

In service,

A handwritten signature in black ink, appearing to read 'CJ', with a long horizontal stroke extending to the right.

**COREY JOHNSON**  
Speaker