

Testimony

of

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before the

**New York City Council** 

**Committee on Health** 

and

**Committee on Hospitals** 

on

New York City's Efforts to Prevent and Address HIV and Hepatitis

and

Intro 1808 and Resolution 150

December 9, 2019 City Hall – Council Chambers New York, NY Good morning Chairs Levine and Rivera, and members of the committees. I am Dr. Demetre Daskalakis, Deputy Commissioner for the Division of Disease Control at the New York City Department of Health and Mental Hygiene. I am joined by my colleagues from NYC Health + Hospitals, Dr. Nichola Davis, Senior Vice President for Chronic Disease Prevention, and Eunice Casey, Senior Director of HIV Services. On behalf of Commissioner Barbot, I want to thank you for the opportunity to testify today on the Health Department's work to end the epidemics of HIV and viral hepatitis and for the City Council's continued partnership in this work.

The Health Department coordinates New York City's response to the HIV epidemic, including HIV testing initiatives; prevention, care and treatment programming; surveillance; training and technical assistance; administration of federal housing programs; and community engagement. We are also responsible for viral hepatitis programming including prevention, surveillance and outreach activities. The Health Department and Health + Hospitals collaborate closely in this work. Last week, the Health Department announced that New York City has become the first Fast-Track City in the United States to achieve the UNAIDS 90-90-90 targets – 90% of people with HIV know their status, 90% of people diagnosed with HIV on treatment, and 90% of people on treatment virally suppressed. I will share more about this shortly but first some background on how we got to where we are today.

In 2015, Mayor de Blasio announced the NYC Ending the Epidemic Plan (NYC ETE Plan), a \$23 million annual investment to end the HIV epidemic in New York City by 2020. It builds upon the 2015 New York State Blueprint for Ending the Epidemic recommendations from the New York State ETE Task Force, a coalition on which I served alongside government officials, providers and community members from across the state. The NYC ETE Plan is a four-part strategy: increase access to HIV prevention services, including preand post- exposure prophylaxis (PrEP and PEP); promote innovative, optimal treatment for HIV; enhance methods for tracing HIV transmission; and advance sexual health equity for all New Yorkers by promoting comprehensive, affirming sexual health care and supporting community-driven initiatives focused on people disproportionately affected by HIV. Driving this work is a commitment to dismantle the underlying racism, homophobia, transphobia and other identity-based stigmas that lead to health inequities. The New York State and New York City plans have become national and international models for ending the HIV epidemic, including the recently announced federal plan.

In 2016, Mayor de Blasio signed on to the Fast-Track Cities initiative, a global partnership of over 300 municipalities around the world working to achieve UNAIDS 90-90-90 goals. Last week during our World AIDS Day event, Commissioner Barbot announced that as of 2018 in New York City, 93% of people with HIV have been diagnosed, 90% of people diagnosed are on treatment, and 92% of people on treatment are virally suppressed. Not only did we surpass the 90-90-90 goals to achieve 93-90-92, we did it two years early and are the first Fast-Track city in the U.S. to do so.

And that's not all: the annual number of New Yorkers newly diagnosed with HIV fell below 2,000 for the first time since annual HIV reporting began in 2001. According to our 2018 HIV Surveillance Annual Report, 1,917 people were newly diagnosed with HIV in New York City in 2018, down 11% from 2017 and 67% from 2001. These data illustrate the incredible progress we have made over the last several years. Once known for being the epicenter of the HIV epidemic in the U.S., New York City is now leading the country in ending the epidemic. And none of this would have been possible without the support and investment of local and state government. Speaker Johnson and City Council's unwavering support have been critical to our success. It has allowed us to design and implement forward-thinking approaches to ending the epidemic that have put New York City at the cutting edge of public health.

A key element of the NYC ETE Plan is ensuring the widespread availability of comprehensive HIV prevention and treatment services. This begins in the Health Department's eight Sexual Health Clinics, which offer comprehensive, affirming sexual health care, regardless of immigration status, insurance coverage or ability to pay. Following facility upgrades and service enhancements, all eight clinics now offer low- to nocost state-of-the-art services, including STI and HIV testing, emergency PEP, PrEP initiation and navigation and JumpstART, the immediate initiation of HIV treatment with navigation to longer-term care. Recognizing that good sexual health is not just about preventing and treating STIs, the clinics also provide emergency contraception with longer term options available such as pills, patches, rings and injectables; cervical cancer screening; Narcan kits and sterile syringes; short-term counseling services and referrals for continued care; screening and referrals for alcohol and drug use treatment; and assistance in applying for insurance and social services. This summer, we launched the Quickie Lab at Chelsea Express, a cutting-edge laboratory system that tests for chlamydia and gonorrhea within hours instead of days. This means less stressful wait time, quicker treatment initiation and reduced risk of disease transmission, and we have seen a record number of patients since the launch.

Our partners at Health + Hospitals offer comprehensive, compassionate HIV and AIDS care for New Yorkers, including confidential, convenient HIV screening and personalized care and treatment at their hospital-based and community-based federally-qualified health center HIV clinics. As part of the city's commitment to ending the HIV epidemic, Health + Hospitals has been expanding PEP, PrEP and other HIV prevention services, including an innovative program to integrate PrEP access into its primary care and women's health clinics.

Building a sustainable HIV prevention and care model requires the active participation of providers throughout New York City. To this end, the Health Department created the PlaySure Network, a network of HIV testing sites, community-based organizations and clinics, including Health + Hospitals clinics, that promote patient-specific approaches to sexual health and HIV prevention, provide PrEP and PEP and link people who test positive for HIV to care. The PlaySure Network currently has contracts with over 40 organizations across all five boroughs. Our PrEP for Adolescents initiative supports four clinical sites, one of

which is at Health + Hospitals/Gotham Health East New York, engaging 13- to 24-year-olds in biomedical HIV prevention services, including screening and education, PrEP and PEP clinical services and linkage and support services. To more effectively serve young people, the clinics offer co-located services, flexible appointment schedules and personalized communication with PrEP navigators, including by text message. We also support four PEP Centers of Excellence: brick-and-mortar sites, including Health + Hospitals/Elmhurst, utilizing an urgent care model to ensure timely initiation of PEP and patient navigation and support services. The NYC PEP hotline, available 24/7, links people who may have been exposed to HIV to these and other sites with expertise in PEP.

Delivery of HIV prevention services should be the standard of care for preventive medicine and other routine medical visits. Our highly trained, full-time PrEP and PEP detailing teams conduct one-on-one educational visits with providers, with the latest cycle focused on women's health care providers. So far, our detailing campaigns have reached over 5,100 providers at more than 2,900 clinical sites. Our outreach also includes training and technical assistance to clinical and non-clinical providers. Most recently, we've been educating providers and the public on the importance of immediate initiation of antiretroviral therapy on the same day as an HIV diagnosis or first clinic visit, as we have been doing for years in our Sexual Health Clinics.

Much of our programming is focused on specific populations that are disproportionately affected by HIV, such as Black and Latino men who have sex with men (MSM). While there was nearly a 20% decline in new HIV diagnoses among MSM from 2017 to 2018, of all men newly diagnosed with HIV in New York City in 2018, 67% were MSM, and more than three-quarters (78%) of newly diagnosed MSM were Black or Latino. Our Online HIV Home Test Giveaway uses dating apps and social media to reach MSM and transgender and gender nonconforming (TGNC) people who have sex with men. We distributed 12,000 tests, and 16% of participants reported having never been tested previously. The incredible success of this program prompted the New York State Department of Health to adapt it to other parts of the state. Our Project THRIVE initiative involves community-based organizations providing HIV and STI testing and status neutral care navigation to Black and Latino gay and bisexual men and other MSM of color in Brooklyn. And New York City is one of four jurisdictions awarded a CDC demonstration project grant to use molecular HIV surveillance to map possible transmission networks among Latino MSM to implement high-impact HIV prevention services.

We also have expanded services to reach individuals who may otherwise not seek care. Our Re-Charge program is an HIV status neutral and sex-positive harm reduction program focused on MSM who use crystal methamphetamine. It features twice weekly drop-in groups facilitated by a peer support worker and licensed social worker, and a range of individualized services including health education, individual and group counseling and medical and psychiatric visits. Earlier this year, we launched an enhanced home-based care initiative, which brings our services directly to people who are not comfortable engaging in a traditional care setting. We've created a virtual sexual health clinic, whereby nurse practitioners linked through telemedicine and our disease intervention specialists make visits in the community to provide HIV and STI testing,

immediate PrEP initiation, immediate initiation of antiretroviral treatment for people diagnosed with HIV and linkage to continued care with local providers.

We also recognize the essential role of grassroots leadership in HIV prevention efforts. Earlier this year, we announced funding for six small community-based organizations as part of our first ever microgrant initiative, which supports the design and implementation of projects that build resilience, promote sexual health as the essential ingredient in HIV prevention, and develop community leaders. We also continue to offer capacity-building technical assistance to four TGNC-led organizations.

New York City has been a leader in changing the conversation around HIV to reduce stigma, encouraging HIV testing, prophylaxis use, and retention in HIV care. For example, we were the first U.S. jurisdiction to sign on to Undetectable = Untransmittable, or U=U – the evidenced-based finding that people with HIV who are on treatment and maintain an undetectable viral load cannot transmit HIV through sex. Now even the federal government has made U=U a central component of its ending the HIV epidemic plans. Another key message is "status neutrality." In 2016, we released the New York City HIV Status Neutral Prevention and Treatment Cycle that reflects that HIV care does not end with the first undetectable viral load. High-quality care empowers people with HIV to get treatment and remain engaged in care; similarly, high-quality prevention services for people at risk of HIV help keep them negative. A status neutral approach means that whether you are HIV-negative or HIV-positive, there are options to keep you and your partners healthy. These concepts have transformed perceptions about HIV among people living with HIV and in their communities.

These and other messages are at the foundation of our sexual health media campaigns. New York City has become internationally recognized for using dynamic, sex-positive messages and images to educate the public, help reduce stigma and promote our core HIV prevention, care and treatment messaging. Our *Bare it All* campaign, first released in 2017, encourages LGBTQ New Yorkers to talk to their doctors about everything that affects their health, and empowers them to find a new doctor if they cannot have these conversations. *Living Sure*, launched in March 2018, encourages cisgender and transgender women to consider PrEP as part of their sexual health plan. Our 2018 *¡Listos!* campaign encourages Latinos of all genders and sexual orientations to consider PrEP and was the first campaign that we created in Spanish from the start. And our most recent campaign, *Made Equal*, released in June during Pride, promotes U=U and is designed to reduce HIV-related stigma, celebrate healthy sexuality and sexual pleasure and redefine what it means to live with HIV. Like so much of what we do, these marketing campaigns were developed with the direct input of the community. These campaigns encapsulate how we approach our work: science-based, focused on empowerment and sex-positivity and not on stigma, and tailored to resonate with the people we need to reach.

I am incredibly proud of the groundbreaking work we have done, and we have truly served as a model for the nation and the world. We must remain vigilant in our HIV prevention and treatment efforts to ensure that we maintain the ground we have won, conquer new challenges and reach our ultimate goal of ending the HIV epidemic in New York City once and for all.

#### Viral Hepatitis

Now I will turn to the Health Department's comprehensive viral hepatitis work. All New Yorkers living with viral hepatitis should know their diagnosis and receive care to manage or cure their disease. In New York City, there are 230,000 people estimated to be infected with hepatitis B and 116,000 people estimated to be infected with hepatitis C – diseases that lead to cancer and premature death, but are preventable, treatable, and, in the case of hepatitis C, curable. As reflected in our 2018 Viral Hepatitis Annual Report, while the number of reported chronic hepatitis B and C cases has been steadily declining in recent years, there were 6,075 and 4,682 newly reported cases of hepatitis B and C, respectively. Hepatitis B and C continue to disproportionately affect marginalized populations, including people who use drugs, people with a history of incarceration, people living in high or very high poverty neighborhoods and immigrants. We have at our disposal tools to end these epidemics. Hepatitis B can be prevented through vaccination and people who are chronically infected can be treated to prevent liver disease and cancer. Hepatitis C can be prevented through harm reduction and substance use treatment and can be cured. Despite these effective medical interventions, many people at risk for or living with hepatitis B or C in New York City are unaware of their risk or their status and are not in clinical care or prevention services.

The Health Department is a committed partner in national and statewide efforts to eliminate viral hepatitis by 2030. Since 2016, the Health Department has been a member of the New York State Hepatitis C Elimination Initiative, a statewide coalition of providers, advocates and government representatives. We are also a member of the New York State Hepatitis C Elimination Task Force, which developed a comprehensive elimination plan that was submitted to the Governor's Office. Last year, the Health Department developed a New York City-specific strategic plan that defines priorities and goals to address viral hepatitis to guide activities for the next five years. This plan has three goals, which build on our existing clinical and community-based work: identify and share information about trends in viral hepatitis infections to promote citywide improvements in healthcare access and treatment; support healthcare organizations in eliminating hepatitis C and managing hepatitis B; and substantially reduce new viral hepatitis infections in New York City.

The Health Department provides a wide range of viral hepatitis services. This includes promoting the importance of hepatitis A, B and C prevention and screening to people at high risk of acquiring these infections, including people who use drugs; people who have sexual partners with hepatitis A, B or C; MSM; and children born to mothers with hepatitis B or C. Our Sexual Health and Immunization clinics provide hepatitis A and B vaccinations, including to people who are underinsured or uninsured. We provide hepatitis B and C navigation services for people who are out of care, focusing on pregnant and postpartum persons, people living with HIV, people who use drugs, young people with new infection and other priority populations. We have intensive case management for pregnant people with hepatitis B to help ensure infants who were exposed to the virus receive prophylaxis. We also examine surveillance data and perform case investigations to better understand the

epidemiology of the hepatitis B and C epidemics in New York City, prevent new infections and promote linkage to care and treatment. Health + Hospitals is an important source of hepatitis B and C care. Patients diagnosed with hepatitis C are supported through cure; last year, over 1,000 individuals were cured of hepatitis C at Health + Hospital facilities.

An essential component of our viral hepatitis programming is the community navigation contracts we manage for hospitals, health centers, community-based programs serving immigrant communities and syringe service programs. The City Council's support is instrumental in this work. In 2014, the Health Department established the Viral Hepatitis Initiative with funding from the Council. This initiative provides funding for community health organizations to hire and train hepatitis C and hepatitis B navigators, who form the core of the Check Hep B, Check Hep C and Hep C peer navigation programs. Since 2014, an estimated 13,630 people at risk for or living with hepatitis B or C received navigation services, and 5,983 people received hepatitis B or C care and treatment through the Viral Hepatitis Initiative. The 14 syringe service programs provide vaccination, testing and care coordination, overdose prevention and harm reduction education, distribution of sterile syringes and other drug use equipment to prevent the transmission blood-borne diseases, and access to buprenorphine treatment. In 2018, 18,274 people participated in syringe service programs, and over four and a half million syringes were distributed.

Since 2016, we have collaborated with the Empire Liver Foundation to deliver the Hepatitis Clinical Training Program, which aims to increase the number of clinical providers who screen, diagnose, manage and treat hepatitis B and C in accordance national guidelines. Nearly 2,000 providers have been trained as part of this program. Other clinical quality improvement projects include collaborating with health centers to promote hepatitis C screening and treatment, and generating facility-specific dashboards for 40 New York City hospitals, which are shared with hospital leadership and provide information regarding the number of their patients with hepatitis C and the number who have started treatment. We also organize Hep Free NYC, a network of over 200 community organizations working together to build capacity to prevent, manage and treat hepatitis.

One of our most exciting projects is our "micro-elimination" plan to eliminate hepatitis C among people living with HIV in New York City. This work began with Project SUCCEED, a three-year federally funded intervention that aims to improve health outcomes and reduce ethnic and racial disparities among people with coinfection through three main interventions: practice transformation, education and training, and case investigation and linkage to care. The Health Department delivered technical assistance to healthcare facilities with the highest number of patients with hepatitis C and HIV coinfection and provided grants to nine facilities to improve their hepatitis C screening and treatment practices. In addition, Health Department patient navigators reached out to nearly 400 individuals with hepatitis C and HIV coinfection to provide linkage to care services. As of the end of 2017, 62.5% of the estimated 8,988 people in New York City diagnosed with hepatitis C and HIV coinfection had initiated treatment for hepatitis C. Though this federal funding is ending.

it has helped to put the structures in place to continue to achieve hepatitis C elimination among people living with HIV.

#### Intro 1808-2019

Regarding the bills being heard today: Intro 1808 would require the Health Department to conduct a study of all HIV/AIDS-related deaths in the city between 2017 and 2019 to assess the causes and circumstances that led to each death. This bill recognizes the fundamental concept that every HIV-related death is preventable. We have made incredible strides in reducing HIV-related deaths. This has been achieved through early detection, linkage to care and efforts to maintain viral suppression. Every program I just detailed plays a role in reducing HIV-related deaths, and we're happy to talk to you about how we can work together to bring the number of HIV-related deaths down to zero.

#### Resolution 150

While the Administration does not typically comment on Resolutions, Resolution 150, which calls on the U.S. Food and Drug Administration (FDA) to remove blood donation restrictions based on sexual orientation, is particularly relevant to Health Department's work. The FDA's current exclusion of MSM who report having sex in the last 12 months excludes many low risk men who would be excellent candidates for blood donation. This stigmatizes gay and bisexual men as vectors of HIV transmission, suggesting that all sex between men is high-risk regardless of frequency, number of partners and proven protective measures, including condoms and HIV prophylaxis such as PrEP and PEP.

The Health Department has been a national voice to lead efforts to push the FDA to change its stigma-based exclusionary policy. In 2016, the Health Department called on the FDA to change its blood donor deferral policy and replace it with an evidence-based, three-step screening process that does not exclude potential donors based on sexual orientation or gender of their sex partners. This process includes a behavioral risk screening for every potential donor, point-of-care rapid HIV testing for donors who report sexual risk-taking behavior and continued testing of donating blood, per FDA's current recommendation. This screening process is an opportunity to increase HIV testing rates and link more people to care while further improving the safety of the blood supply using science rather than stigma-based exclusions, and would allow thousands if not hundreds of thousands of gay and bisexual men to once again give the life-saving gift of blood. I have personally been involved in efforts at the federal level to change blood donation rules through participation on the FDA's Blood Equality Medical Advisory Board. We are grateful that the City Council, and especially Council Member Dromm, are aligned with us in this fight.

I want to thank Chairs Rivera and Levine for holding this hearing today. I am proud to be your partner in this work. I am happy to answer any questions.

### Missed Opportunities: Adapting the HIV Care Continuum to Reduce HIV-Related Deaths

Sarah L. Braunstein, PhD, MPH, Rebekkah S. Robbins, MPH, and Demetre C. Daskalakis, MD, MPH

Introduction: With advances in HIV care, persons with HIV/AIDS (PWHA) can lead healthy lives, but avoidable HIV-related deaths continue to occur in New York City (NYC).

Methods: We selected PWHA from our surveillance registry who died between 2007 and 2013, resided in NYC, and survived ≥15 months after diagnosis to generate an HIV Mortality Reduction Continuum of Care (HMRCC) describing predeath care patterns among PWHA. We used HIV laboratory test reports to measure care outcomes during an "intervenable period" during which deaths may have been avoided. The continuum was stratified by the underlying cause of death (HIV-related vs. other), and the HIV-related HMRCC was stratified by demographic characteristics.

Results: Eleven thousand one hundred eighty-seven analysis-eligible PWHA died during 2007–2013. Ninety-eight percent linked to care; 80% were retained in care during the intervenable period; 66% were prescribed antiretroviral therapy; 47% had viral load ≤1500 copies/mL; and 40% achieved viral suppression (VS). Half (47%) of the deaths were HIV-related. Retention was higher among HIV-related cause of death (83% vs. 78%) but VS was lower (34% vs. 46%). The HIV-related HMRCC revealed disparities in VS. Despite comparable retention rates, whites had the highest VS (42%, vs. 32% blacks and 33% Latinos/Hispanics), In addition, retention and VS increased with increasing age. People with a history of injection drug use had relatively high rates of retention (88%) and VS (37%).

Discussion: The HMRCC is a novel framework for evaluating predeath care patterns among PWHA and identifying opportunities to reduce preventable deaths. In NYC, reducing mortality will require increasing VS among those already in care, particularly for blacks and Latinos/Hispanics.

Key Words: HIV, mortality, care continuum, viral suppression

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#### INTRODUCTION

Multiple lines of evidence demonstrate that with proper engagement in care and adherence to antiretroviral therapy (ART), persons with HIV/AIDS (PWHA) can lead long, healthy lives. 1-4 However, HIV remains a leading cause of death (COD) in cities with high HIV burden, with HIV infection, and HIV-related deaths disproportionately affecting black and Latino/Hispanic populations. 5-8

Many studies have evaluated HIV care outcomes among PWHA as a measure of the effectiveness of the care delivery and public health system in facilitating the progress of PWHA through stages of care, from diagnosis and linkage through retention and viral suppression (VS). These stages of care are often visualized as a "care continuum" or "cascade" that serves as a surveillance-based snapshot of the care status of the current population of PWHA. The continuum is a tool that estimates the number of undiagnosed persons, persons not linking or engaging in HIV care, and persons not achieving VS. Evaluating points in the HIV care continuum where individuals "fall off" can help identify policies and interventions to improve individual and population health.

Although VS is an important end point for the traditional continuum of care among people living with HIV, a similar methodology could be useful to understand deaths, a critical and often overlooked outcome measure among PWHA. To date, there has been little published work using the same markers of care in the traditional continuum of HIV care to evaluate PWHA who have died.

To address this knowledge gap, we propose the "HIV Mortality Reduction Continuum of Care" (HMRCC), an adaptation of the traditional continuum of HIV care. Our primary objective was to identify "drop-offs" in care during the period preceding death. Such "drop-offs" on the path to VS could be targets for novel or improved strategies to prevent HIV-related deaths. Our secondary objective was to describe the population of PWHA who died, including their care patterns per the HMRCC, to inform programs for people living with HIV who may be at risk of preventable, HIV-related death.

#### METHODS

#### **Data Sources and Study Population**

The New York City Department of Health and Mental Hygiene (NYC DOHMH) conducts HIV surveillance of all newly diagnosed persons and PWHA receiving care in the 5 boroughs of NYC. The HIV Surveillance Registry ("the Registry") contains named reports of all persons diagnosed with HIV/AIDS in NYC, in addition to electronic reports of

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all HIV-related laboratory tests ordered by NYC clinical providers regardless of the type of provider/facility or clinical visit (eg, inpatient vs. outpatient). The registry also tracks patients' vital status, including date of death, COD (when available), and residence at death. This information is updated regularly by matches with local and national death registries.

To generate the HMRCC, we selected all PWHA who had a recorded date of death from 2007 through 2013 and who were living in NYC at the time of death. To be included in the predeath care continuum outcome analysis, patients must have been alive for at least 15 months after their initial HIV diagnosis. We selected 15 months so that the HMRCC could be used to evaluate the care status of individuals who would have had the opportunity to use NYC's system of HIV-related care. Demographic characteristics (sex at birth, race/ethnicity, age at death, residence at death, and ZIP code-based poverty level of residence at death) and clinical characteristics (HIV diagnosis date, date of death, HIV transmission risk, CD4 and viral load (VL) test results, and COD) were obtained from the registry.

To assess the care and clinical outcomes in the period before death, we included all CD4 and VL tests that were reported to the Registry for these patients in the 15 months before death. Cause of death was based on the underlying cause as recorded in the decedent's death certificate. "HIVrelated deaths" were deaths whose underlying cause was coded with one of 5 ICD codes that represent HIV disease, B20-B24 in ICD-9/-10 nomenclature.<sup>10</sup> These codes correspond with opportunistic infections caused by infectious and parasitic diseases (eg, pneumocystis carinii pneumonia and cytomegaloviral infection), malignant neoplasms (eg, Kaposi sarcoma and Burkitt lymphoma), other specific diseases or infections associated with HIV infection, and with unspecified conditions consistent with HIV disease or AIDS. All other deaths were classified as "non-HIV-related" and included underlying causes, such as cardiovascular diseases, non-AIDS-defining cancers, viral hepatitis, diabetes mellitus, accidents, influenza and pneumonia, and other causes.

#### **Outcome Measures**

We evaluated patient status within 2 time periods in the 15-month predeath period: "the intervenable period (IP)" and the "immediate predeath period." The immediate predeath period was defined as 3 months before the date of death. Primary analyses excluded outcomes from the immediate predeath period to avoid overestimating care engagement and VS secondary to increased care-seeking behavior and access due to deteriorating clinical status and emergent clinical symptoms and events toward the end of life. Exclusion of this immediate predeath period from the 15 months of Registry data analyzed left 12 months before death during which continuum "drop-offs" could have been addressed with clinical or social interventions to prevent HIV-related mortality. This year-long period will be referred to as the "IP."

During the IP, we used definitions for the HMRCC similar to those used in our traditional continuum among people living with HIV/AIDS, using CD4 and VL tests as proxies of HIV medical care.<sup>11</sup> We determined the proportion of patients who: ever linked to care after HIV diagnosis,

defined as the proportion of patients with any CD4 or VL test reported at least 8 days after the date of diagnosis; were retained in care, defined as ≥2 CD4/VL tests ≥90 days apart; were estimated to have been prescribed ART, measured as 95% of those retained in care based on data from the Medical Monitoring Project<sup>12</sup> in NYC in 2013 (New York City MMP, Unpublished data, 2013); had a most recent VL reported in the IP of ≤1500 copies/mL<sup>13</sup>; and were virally suppressed, defined as the most recent VL reported in the IP was ≤200 copies/mL. Care continuum outcomes can fluctuate meaningfully depending on the definition of the various stages of care that are applied. To evaluate the impact of an alternate definition of retention in care, we conducted a sensitivity analysis that included 2 alternative retention definitions. The first was similar to our original definition, but with the added requirement that the 2 care visits signaled by laboratory results reported to the Registry having the same ordering care provider/facility. The second alternate definition incorporated this same requirement, and also required one additional laboratory test ordered by that provider/facility at a later date.

Subgroup analyses in this manuscript focus on HIV-related deaths, given that deaths due to HIV are preventable in the era of effective ART and guidelines supporting universal treatment. We evaluated primary care outcomes among persons with an HIV-related underlying COD stratified by sex at birth, race/ethnicity, age at death, and NYC borough of residence at death, according to data obtained from the Registry. In addition, we measured patients' earliest VL and CD4 count during the IP, as well as their VL and CD4 most proximate to death, by HIV-related vs. non-HIV-related COD. Finally, we compared characteristics of persons with an HIV-related COD who were retained in care by VS status (suppressed/unsuppressed) during the IP.

We quantified disparities in HTV-related age-adjusted death rates among specific demographic and other subgroups by area-based poverty level. 14 We assigned persons to one of 4 ZIP code-level poverty groups ( $<10\overline{\%}$ , 10 to <20%, 20 to <30%, and ≥30% of residents below the Federal poverty level) based on their residence at death, combining HIV-related deaths across all years of the analysis, 2007-2013. We calculated HIVrelated age-adjusted death rates per PWHA alive as of mid-year 2010, using 2010, because it was the middle year of the analytic period (age adjusted to the NYC Census 2010 population). Seven-year death rates were then averaged to create annual death rates. Finally, we calculated a "mortality disparity" metric for each category within the subgroup by subtracting the HIVrelated age-adjusted death rate for the lowest (<10%) poverty group from the HIV-related age-adjusted death rate for the highest (≥30%) poverty group.

#### RESULTS

#### **Analytic Population**

Between 2007 and 2013, 12,010 NYC PWHA died while living in NYC. Among these, 11,187 (93%) died at least 15 months after an initial HIV diagnosis and were eligible for analysis. This population included N=5183 (46%) persons with a reported HIV-related underlying COD and N=6004 (54%)

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TABLE 1. Characteristics of NYC Residents With HIV Who Died During 2007–2013\*

·	Deaths Among Persons With HTV 2007-2013									
	All Deaths 2007— 2013			All Deaths 2007–2013 Eligible for Analysis†						
	Total		· <del></del>		elated Cause of Death	Non-HIV-Related Cause of Death				
	N	%	N	%	N	%	N	%		
Total	12,010	100.0	11,187	100.0	5183	100.0	6004	100.0		
Sex at birth	,		,	200,0		100.0	0004	100.0		
Male	8158	67.9	7573	67.7	3390	65.4	4183	69.7		
Female	3852	32.1	3614	32.3	1793	34.6	1821	30.3		
Race/Ethnicity				,		25	1021	50.5		
Black	6199	51.6	5763	51.5	2803	54.1	2960	. 49.3		
Latino/Hispanic .	4153	34.6	3919	35.0	1852	35.7	2067	34.4		
White	1481	12.3	1364	12.2	472	9.1	892	14.9		
Asian/Pacific Islander	124	1.0	95	0.8	34	0.7	61	1.0		
Native American	34	0.3	33	0.3	16	0.3	17 .	0.3		
Other/unknown	19	0.2	13	0.1	6	0.1	7			
Age group at death, yr		0.2		0.1	J	0.1	,	0.1		
0-12	4	0.0	2	0.0	2	0.0	0	0.0		
13–19	21	0.2	17	0.2	14	0.0	. 3	0.0		
20–29	269	2.2	237	. 2,1	148	2.9		0.0		
30–39	938	7.8	817	7.3	480	9.3	89	1.5		
40–49	3364	28.0	3140	28.1	1716		337	5.6		
50-59	. 4465	37.2	4215	37.7	1832	33.1 35.3	1424	23.7		
60+	2949	24.6	2759	24.7	991		2383	39.7		
Year of HIV diagnosis	2545	24.0	2139	24.7	331	19.1	1768	29.4		
≤1996	5010	41.7	5010	44.0	0252	45.4	0655			
1997–2000	. 2961	24.7	2961 ·	44.8 26.5	2353	45.4	2657	44.3		
2001–2005	2428	20.2	2425		1323	25.5	1638	27.3		
2006–2010	1376 .				1171	22.6	1254	20.9		
2011–2013		11.5	753	6.7	326	6.3	427	7.1		
Area-based poverty level—residence at death‡	235	2.0	38	0.3	10	0.2	28	0.5		
	`\.							*		
Low poverty (<10% below FPL)  Medium poverty (10 to <20% below FPL)	844	7.0	775	6.9	287	5.5	488	8.1		
	2752	22.9	2520	22.5	1068	20.6	1452	24.2		
High poverty (20 to <30% below FPL)	3685	30.7	3416	30.5	1583	30.5	1833	30.5		
Very high poverty (≥30% below FPL)	4674	38.9	4426	39.6	2226	42.9	2200	36.6		
Area-based poverty level not available Transmission risk	<b>55</b> .	0.5	50	0.4	19	0.4	31	0.5		
						•				
Men who have sex with men (MSM)	2026	16.9	1873	16.7	834	16.1	1039	17.3		
Injection drug use history (IDU)	4104	34.2	4032	36.0	1850	35.7	2182	36.3		
MSM-IDU	457	3.8	449	4.0	199	3.8	250	4.2		
Heterosexual§	2254	18.8	2059	18.4	997		1062	17.7		
Perinatal	81	0.7	79	0.7	62	1.2	17	0.3		
Other	38	0.3	38	0.3	18	0.3	20	0.3		
Unknown	3050	25.4	2657	23.8	1223	23.6	1434	23.9		
Median time from last care to death, d (range)	33 (0–4747)		34 (0-474	47)	26 (0-397	8)	43 (0-4747)			
Time from last care to death										
0–1 mo	5673	47.2	5278	47.2	2935	56.6	2343	39.0		
>1–3 mo	3754	31.3	3583	32.0	1567.	30.2	2016	33.6		
>3–6 mo	1350	11.2	1302	11.6	478	9.2	824	13.7		
>6 mo	857	7.1	844	7.5	185	3.6	659	11.0		
Not in care in NYC before death	376	3.1	180	1.6	18	0.4	162	2.7		
Median CD4 count (cells/ $\mu$ L, range): earliest in 15 mo before death	231 (0–6400)	)	235 (0-44	175)	143 (0–44		308 (0-2349)			

(continued on next page)

TABLE 1. (Continued) Characteristics of NYC Residents With HIV Who Died During 2007-2013\*

,	Deaths Among Persons With HIV 2007-2013									
		ths 2007- 013	All Deaths 2007–2013 Eligible for Analysis†							
	Total		Total		HIV-Related Cause of Death		Non-HIV-Related Cause of Death			
	N	%	N	%	N	%	N	%		
CD4 count, cells/µL: earliest in 15 mo before death						•				
≤200	4757	39.6	4515	40.4	2821	54.4	1694	28.2		
201349	2067	17.2	2008	18.0	802	15.5	1206	20.1		
350–500	1559	13.0	1524	13.6	556	10.7	968	16.1		
≥501	2055	17.1	2012	18.0	620	12.0	1392	23.2		
Unknown—no CD4	1572	13.1	1128	10.1	384	7.4	744	12.4		
Median CD4 count, (cells/μL, range): most recent before death	: 136 (0–7315)		143 (0–7315)		78 (0–7315)		215 (0–4984)			
CD4 count before death, cells/μL										
≤200	5518	46.0	5025	44.9	3095	59.7	1930	32.2		
201–349	1556	13.0	1478	13.2	583	11.3	895	14.9		
350-500	878	7.3	843	7.5	293	5:7	550	9.2		
≥501	1076	9.0	1039	9.3	324	6.3	715	11.9		
Unknown-no CD4 in 3 months before death	2982	24.8	2802	25.1	888	17.1	1914	31.9		
Median HIV viral load quantity: earliest in 15 mo before death, copies/mL	799.5 (0-	-750,000)	605 (0-7	750,000)	7760 (0-	750,000)	113 (0-750,00	00)		
HIV viral load: earliest in 15 mo before death						-		•		
≤200 copies/mL	4432	36.9	4398	39.3	1627	31.4	2771	46.2		
>200 copies/mL	5790	48.2	5489	49.1	3084	59.5	2405	40.1		
Unknown—no VL	1788	14.9	1300	11.6	47 <u>2</u>	9:1	828	13.8		
Median HIV viral load quantity: most recent before death, copies/mL	318 (0-750,000)		240.5 (0- 750,000)		1406 (0–750,000)		73 (0–750,000)			
HIV viral load before death										
≤200 copies/mL	3796	31.6	3651	32.6	1522	29.4	2129	35.5		
>200 copies/mL	4160	34.6	3775	33.7	2225	42.9	1550	25.8		
Unknown-no VL in 3 mo before death	4054	33.8	3761	33.6	1436	27.7	2325	38.7		
Cause of death										
HIV-related¶	5661	47.1	5183	46.3	5183	100.0	0	0.0		
Non-HIV-related	6349	52.9	6004	53.7	0	0.0	6004	100.0		
Leading non-HIV-related causes of death (top 3)								•		
Malignant neoplasms (non-AIDS-defining)	1728	27.2			NA	NA	1637	27.3		
Major cardiovascular diseases	1598	25.2			NA	NA	1513	25.2		
Accidents	618	9.7			NA	NA	593	9.9		

Data reported to NYC Department of Health and Mental Hygiene as of September 30, 2014.

with a reported non-HTV-related COD. Although the majority of deaths were due to non-HIV-related causes, a higher proportion of black and Latino/Hispanic decedents had an underlying HIVrelated cause (N = 4655, 48%) compared with white decedents (N = 472, 35%, Table 1). In addition, the median age at death among HIV-related deaths was lower than among non-HIVrelated deaths [51 vs. 54 years (data not shown)].

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#### Stages of the HIV Mortality Reduction Continuum of Care

The HMRCC for all-cause deaths among NYC PWHA from 2007 to 2013 is shown in Figure 1. Although a large proportion of eligible patients were linked to care (N = 11,007, 98%), retained in care (N = 8992, 80%), and prescribed ART (N = 8497, 76%), only 40% (N = 4518) of

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Persons diagnosed at death and those living outside of NYC at the time of death are excluded.
†Persons who died at least 15 months after HIV diagnosis were eligible for analysis.
‡Poverty level based on NYC ZIP code of residence at death. Not available for persons missing ZIP code information or living outside NYC.
§Includes persons who had heterosexual sex with a person they know to be HIV-infected, an injection drug user, or a person who has received blood products. For females only, also includes history of prostitution, multiple sex partners, sexually transmitted disease, crack/cocaine use, sex with a bisexual male, probable heterosexual transmission as noted in medical chart, or sex with a male and negative history of injection drug use.

Last care defined as most recent CD4 or viral load before death.

<sup>#</sup>HIV-related deaths include those whose underlying cause of death was coded with one of 4 ICD codes that represent HIV disease: B20-B24 in ICD-10 nomenclature (Ref. 10). FPL, federal poverty level; NA, not applicable.

decedents achieved VS during the IP. In the sensitivity analysis of alternate definitions of retention in care, the proportion of people considered retained in care dropped to 73% and 44%, respectively, for retention based on 2 and 3 labs ordered by the same provider. Furthermore, applying the more stringent retention in care definition based on 2 labs ordered by the same provider did not lead to higher levels of VS compared with the standard definition (38% vs. 40%, respectively).

Figure 2 presents the HMRCC stratified by the underlying COD. As expected, a higher proportion of persons who died of non-HIV-related COD were virally suppressed compared with persons who died of an HIV-related cause (46% vs. 34%, respectively). Median earliest VL during the IP among persons who died of a non-HIV-related COD was 113 copies/mL (range: 0–750,000) vs. 7760 copies/mL (range: 0–750,000) among those who died of HIV-related COD (Table 1). Median earliest CD4 count during the IP among persons who died of a non-HIV-related COD was 308 cells/μL (range: 0–2349) vs. 143 cells/μL (0–4475) among those who died of an HIV-related COD.

We examined the HMRCC for HIV-related deaths among specific subgroups (Fig. 3). Although most subgroups had similar rates of linkage to care, retention in care, and ART prescription, there were more pronounced differences in VS rates by demographic characteristics. Men had a higher VS rate compared with women (35% vs. 30%); whites (42%) had a higher VS rate compared with blacks (32%) and Latinos/Hispanics (33%). Viral suppression rates increased with increasing age at death: 13% of persons younger than 30 years were suppressed, compared with 15% of those aged 30–39,

22% of those aged 40–49, 40% of those aged 50–59, and 56% of persons aged 60 and older. By major HIV transmission risk categories, persons with a history of injection drug use (IDU) had a higher rate of retention (88%) and VS (37%) compared with men who have sex with men (MSM) (81% and 35%, respectively) and heterosexuals (81% and 28%, respectively). Persons with MSM-IDU transmission risk had the highest rate of retention (92%), but only the third highest rate of VS (29%).

We also saw variability in VS by persons' NYC county (borough) of residence at death, with the highest rate in Manhattan (39%) and the lowest in Queens (30%) (data not shown). There were corresponding differences in other care outcomes by borough, with Queens also having the lowest retention and ART prescription rates. By ZIP code-level poverty, VS decreased as poverty level increased (43% at the lowest poverty level versus 32% at the highest poverty level), but retention was the highest among the higher poverty groups (86% at the highest poverty level vs. 81% at the lowest poverty level, data not shown).

### Characteristics of Persons Achieving Viral Suppression Before Death

Persons in our study with HIV-related COD who were retained in care and achieved VS during the IP were more likely than those who did not achieve suppression to be male (69% vs. 63%), white (11% vs. 7%), and reside in a low or medium poverty area at death (28% vs. 22%), and were less likely to have heterosexual transmission risk (16% vs. 21%) (Supplemental Digital Content Table 2, http://links.lww.com/QAI/B67).

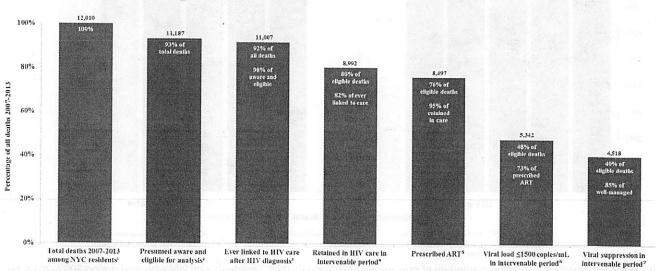


FIGURE 1. HIV mortality reduction continuum of care among New York city (NYC) residents with HIV who died during 2007–2013. ART, antiretroviral therapy. ¹All patients who died in 2007–2013 in NYC and who were not diagnosed at death. ²All patients who died in 2007–2013 in NYC and who died ≥15 months after HIV diagnosis. ³Any CD4 or viral load test ≥8 days after HIV diagnosis. Percentage shown is among eligible deaths. ⁴CD4 ≥2 or viral load tests ≥90 days apart in the IP (the 12 months preceding the immediate predeath period, defined as the 3 months leading up to death). Percentage shown is among deaths eligible for analysis. ⁵Percentage (94.5%) of retained per NYC Medical Monitoring Project, 2013. Percentage shown is among deaths eligible for analysis. ⁶Most recent viral load in the IP was ≤1500 copies/mL. Percentage shown is among deaths eligible for analysis. ³Most recent viral load in the IP was ≤200 copies/mL. Percentage shown is among deaths eligible for analysis.

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#### Mortality Disparities by Subgroup and Area-Level Poverty

We identified a clear gradient in rising age-adjusted mortality rates with increasing area-based poverty level within categories of sex at birth, race/ethnicity, and HIV transmission risk (Fig. 4). By subgroup, females had higher age-adjusted mortality rates across poverty levels than males; blacks and Latinos/Hispanics had higher mortality rates than whites; and by risk, rates were the highest among IDU as compared to heterosexuals and MSM.

We also calculated disparities in age-adjusted mortality rates by poverty level (highest to lowest) within categories of sex at birth, race/ethnicity, and HIV transmission risk (Fig. 4). Males had a higher mortality disparity than females (5.7 vs. 2.9). By race/ethnicity, Latinos/Hispanics (5.5) had the highest mortality disparity, followed by blacks (4.1) and whites (2.0). By major HIV transmission risk categories, MSM-IDU had the highest mortality disparity (9.2), followed by IDU (6.3), MSM (3.8), heterosexuals (1.9), and perinatal (0.8).

#### DISCUSSION

We developed a novel HIV Mortality Reduction Continuum of Care and successfully applied it to persons with HIV who died in NYC during 2007–2013. The NYC HMRCC revealed striking disparities in care outcomes among NYC residents with HIV who died, both overall and for population subgroups. HIV VS rates in decedents with both HIV- and non-HIV-related causes of death were substantially lower than those measured in the NYC continuum of care of people living with HIV: in NYC in 2013, 64% of all persons with HIV were virally suppressed 15; per the HMRCC, only 40% of persons with HIV who died of all causes during 2007–2013 had achieved VS. Furthermore, half of all decedents with an HIV-related COD had a last VL >7760 copies/mL. This finding underscores the need—and opportunity—for more effective clinical management and provision of supportive services to persons with unsuppressed HIV VL.

Looking across the continuum, the largest drop-off was seen in the later stages of care among decedents who seemed to have both linked and remained in care. Among NYC persons living with HIV who were ever prescribed ART, 84% have achieved VS; however, only 53% of persons with HIV who died and were ever prescribed ART achieved this stage of care. This suggests that comorbidities and other psychosocial or structural barriers to treatment adherence may be more prevalent in PWHA at risk of death.

Focusing on preventable, HIV-related deaths reveals high levels of linkage and retention among these individuals.

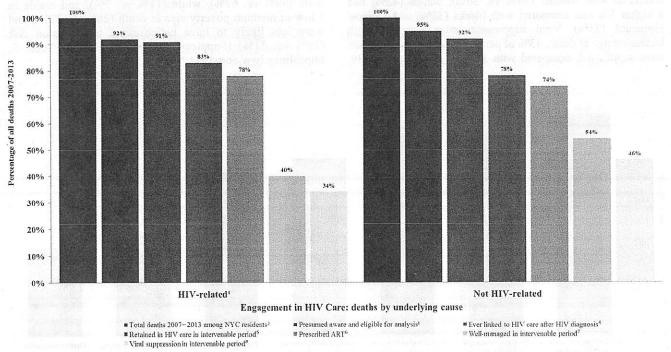


FIGURE 2. HIV mortality reduction continuum of care among New York city (NYC) residents with HIV who died during 2007–2013, by underlying cause of death. ART, antiretroviral therapy.  $^1$ HIV-related deaths include those whose underlying cause of death was coded with one of 5 ICD codes that represent HIV disease: B20-B24 in ICD-10 nomenclature (Ref.10). All patients who died in 2007–2013 in NYC and who were not diagnosed at death. All patients who died in 2007–2013 in NYC and whose deaths were  $\geq 15$  months after HIV diagnosis. Any CD4 or viral load test  $\geq 8$  days after HIV diagnosis. Percentage shown is among eligible deaths. CD4  $\geq 2$  or viral load tests  $\geq 90$  days apart in the IP (the 12 months preceding the immediate predeath period, defined as the 3 months leading up to death). Percentage shown is among deaths eligible for analysis. All of retained per NYC Medical Monitoring Project, 2013. Percentage shown is among deaths eligible for analysis. Most recent viral load in the IP was  $\leq 1500$  copies/mL. Percentage shown is among deaths eligible for analysis.

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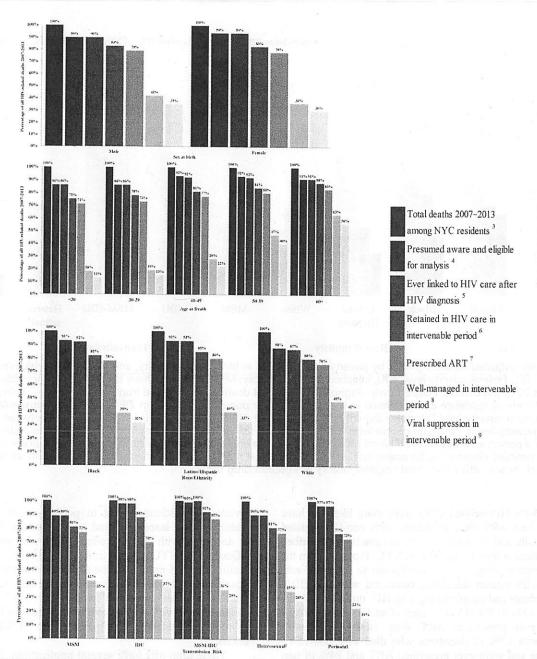


FIGURE 3. HIV Mortality Reduction Continuum of Care among New York city (NYC) residents with HIV who died during 2007–2013 with HIV-related underlying cause of death¹ by: sex at birth, race/ethnicity, age at death, and transmission risk. ART, antiretroviral therapy; IDU, injection drug use history; MSM, men who have sex with men. Persons with other or unknown risk category are not shown in the transmission risk chart. ¹HIV-related deaths include those whose underlying cause of death was coded with one of 5 ICD codes that represent HIV disease: B20-B24 in ICD-10 nomenclature (see reference #10).²Includes people who had heterosexual sex with a person they know to be HIV infected, an injection drug user or a person has received blood products. For females only, also includes history of sex work, multiple sex partners, sexually transmitted disease, crack/cocaine use, sex with a bisexual male, probable heterosexual transmission as noted in the medical chart, or sex with a male and negative history of injection drug use.³All patients who died 2007–2013 in NYC and who were not diagnosed at death. ⁴All patients who died 2007–2013 in NYC and whose death was ≥15 months after HIV diagnosis. ⁵Any CD4 or viral load test ≥8 days post–HIV diagnosis. Percentage shown is among eligible deaths. ⁶ CD4 ≥2 or viral load tests ≥90 days apart in the IP (the 12 months preceding the immediate pre-death period, defined as the 3 months leading up to death). Percentage shown is among eligible deaths. ⁶ Percentage (94.5%) of retained per NYC Medical Monitoring Project, 2013. Percentage shown is among deaths eligible for analysis. ⁶ Most recent viral load in the IP was ≤1500 copies/mL. Percentage shown is among deaths eligible for analysis. ⁶ Most recent viral load in the IP was ≤200 copies/mL. Percentage shown is among deaths eligible for analysis.

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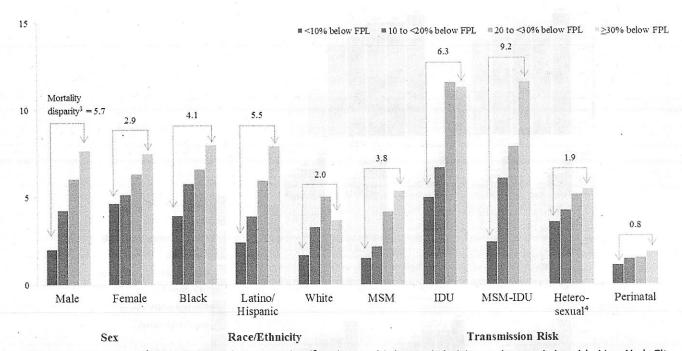


FIGURE 4. Age-adjusted¹ mortality rates by poverty level² and sex at birth, race/ethnicity, and transmission risk, New York City 2007–2013. FPL, Federal poverty level; IDU, injection drug use history; MSM, men who have sex with men. ¹Age-adjusted to the NYC Census 2010 population. People newly diagnosed with HIV at death were excluded from the numerator. ²Poverty is based on NYC ZIP code of residence and is defined as the percent of the population in a given ZIP code whose household income is below the Federal poverty level ³Mortality disparity calculated as the difference in age-adjusted mortality rate between the highest and lowest poverty levels. ⁴Includes people who had heterosexual sex with a person they know to be HIV infected, an injection drug user or a person who has received blood products. For females only, also includes history of sex work, multiple sex partners, sexually transmitted disease, crack/cocaine use, sex with a bisexual male, probable heterosexual transmission as noted in the medical chart, or sex with a male and negative history of injection drug use.

Decedents with HIV-related COD were more likely to have been prescribed ART than decedents with non-HIV-related causes of death, and were more likely to have been prescribed ART than persons living with HIV in NYC. Progress from the ART prescription stage on the continuum to VS was suboptimal in HIV-related decedents compared with non-HIV-related decedents and people living with HIV on the traditional continuum: 43% of PWHA who died of an HIV-related COD and were ever prescribed ART were virally suppressed, compared with 63% of decedents who died of a non-HIV-related cause and were ever prescribed ART and 84% of persons living with HIV and ever prescribed ART.<sup>15</sup>

We found important poverty-related disparities in HIV-related mortality rates among demographic and risk subgroups, with men, Latinos/Hispanics, and IDU experiencing the most dramatic disparities by residential poverty level. These data underscore the role of poverty in influencing variability in death rates due to HIV across and among subgroups. Furthermore, poverty may be a factor underlying suboptimal care patterns and HIV outcomes before death among people with HIV. A number of studies have documented associations between neighborhood poverty and HIV risk, diagnosis, poor care outcomes, and poor treatment outcomes. 16,17

Intervention strategies for improving HIV care outcomes and preventing HIV-related deaths could focus on

alleviating conditions related to poverty, such as housing instability, food insecurity, and substance use. Our finding that decedents with an HIV-related COD who were residing in Queens in NYC at the time of death had the lowest retention, and VS rates could be partially driven by the higher proportion of foreign-born persons among HIV-related decedents in Queens compared with other NYC boroughs. Foreign-born New Yorkers have been shown to have poorer HIV-related outcomes compared with US-born New Yorkers. 18

These drop-offs have several implications. First, standards for clinical follow-up of PWHA with poor health should be rigorous; laboratory monitoring should be done at least quarterly for such patients. Second, patients considered retained under the conventional definition 19-20 that we applied in this analysis may be seeking care only intermittently. True engagement in care means consistent follow-up, not occasional or sporadic encounters with care; "doctor shopping," use of episodic care venues (urgent care and emergency department), and inpatient care would all generate laboratory tests reported to the Registry that would signal retention, but may not actually represent longitudinal care connection. Interventions should seek to improve and promote continuity of HIV care among PWHA to reduce HIV-related mortality. Programs that provide adherence support to

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individuals to achieve and maintain VS are also critical. DOHMH has several ongoing projects that involve sharing HIV-related information from the Surveillance Registry with clinical providers in NYC to improve care outcomes among PWHA.

This study has limitations. Although we limited the analysis to persons who (to the best of our knowledge) were living in NYC at the time of death, patients could have been accessing care at facilities located outside city limits. Because HIV-related tests conducted at such facilities are not reportable to the Registry, our analysis might have underestimated the extent of care patients received during the IP. Although retention in HIV care was relatively high in our study population, out-migration from NYC related to care-seeking did not likely have a large impact on our analysis. Although it is also theoretically possible that resistance to HIV medications could explain, in part, our finding of low VS rates coupled with high retention rates in this cohort, data among newly HIV-diagnosed individuals in NYC during this period show relatively low proportions of transmitted drug resistance (eg, 11.7% in 2009, 15.2% in 2012).<sup>21</sup>

In addition, there is potential for misclassification of the underlying COD in our data. In our analysis, some decedents had an undetectable HIV VL at death and during the IP, but were classified as having HIV as their underlying COD. This could represent disease progression despite VS or potential misclassification of the underlying COD or over reporting of HIV as the underlying COD. Similarly, deaths classified as non-HIV-related (eg, cardiovascular disease and certain malignancies), although not being directly attributable to HIV, may still have been a result of HIV infection. However, although engagement in high-quality HIV care should improve CD4 count and VS, it is less clear to what extent HIV care could prevent death from such HIV-associated conditions. Finally, although our analysis sheds light on the populations that are most at risk of death and should be targeted for intensive outreach services, this analysis excluded persons who died within 15 months of their HIV diagnosis. Given the lateness of their diagnosis, this group is likely an even more difficult population to reach. In the cohort of PWHA who died during 2007-2013 in NYC, there were 823 persons (6.9% of all deaths among PWHA) who died within 15 months of their HIV diagnosis. This is an important area for further analysis.

Although retention in HIV care was high among NYC PWHA who died during 2007–2013, VS was low, at nearly half that among persons living with HIV. High retention coupled with low VS suggests the need to develop strategies to improve suppression and address psychosocial and structural barriers to optimal clinical management. The HIV Mortality Reduction Continuum of Care is a novel framework for evaluating predeath care patterns among PWHA and identifying opportunities for intervention. Future interventions should include strategies to investigate HIV-related deaths as sentinel events. Although disease progression may occur even in the setting of viral suppression, improved medications and guidelines supporting universal treatment of HIV regardless of disease stage should be associated with a significant and durable reduction in the probability of

AIDS-related death.<sup>22</sup> Beyond using data to identify individuals who may be out-of-care, our analysis implies that these data should be used to inspire and support novel strategies to better support the progress of people engaged in care through the latter stages of the care continuum to VS. Like the traditional continuum of care, the observed "drop-offs" seen in the HMRCC represent opportunities to address the barriers to care experienced by people living with HIV to prevent premature death related to their infection.

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# Testimony to be delivered at the New York City Council Committee on Hospitals jointly with the Committee on Health Oversight - The City's Efforts to Prevent and Address HIV and Hepatitis December 9, 2019

Good Morning. My name is Gail Brown. I'd like to thank the committee for conducting this hearing and allowing me to give testimony. I'm here to testify not only as the Director of Advocacy for the Coalition on Positive Health Empowerment, but also as a person living with HIV for 24 years. First, I would like to congratulate NYC for their outstanding job in achieving the 90-90-90 goal as we approach 2020.

The barriers to care that I have faced and that I have witnessed others being challenged with are stigma, lack of insurance, copays, appointments convenient for doctors and clinics and not necessarily for patients, the number of appointments and labs, long waits in the clinic and labs, patients not being able to communicate effectively with their doctors, a lack of information given to patients, and homelessness.

As a consumer, I found it challenging to navigate the health care system. I chose a plan and then had to find a doctor/medical facility and could not find any help and could not get any answers. When I called, I was told to go online and the limited information in the directory with hundreds of doctors was mind boggling. The first I chose had copays that I wasn't aware of. With appointments piling up, the copays for someone on a limited income became overwhelming and ran into hundreds of dollars. It took two years before I was able to find a facility with no copays that I felt comfortable with. Once enrolled, I found the limited availability of appointments to be a problem. I have had to make appointments four and five months in advance. Additionally, the ID doctor in my clinic is only available on Wednesday afternoons. This means I have to take off from work. For others who have young children at home, who have to pick up children from school, who are caretakers, and for those who can't take off from their jobs, they might not be able to get to their doctor. Inevitably, there are always other appointments and lab work that also need to get scheduled where patients have to leave work or drop responsibilities to show up. Then, there are the long wait times to see the doctor.

Coordination among health care providers can be problematic. The pharmacy I use was sending me email reminders for years when it was time to refill a prescription and would automatically send a request to my doctor. Another company took over and the emails stopped. When I realized that I was running low, I called and got the run around for two weeks. I was on the phone every day for hours with customer care and with my clinic. They did not fill my prescription in time and I was without medication for a week. This is unacceptable for a person who relies on this medication to live. Not only didn't I have medication, but the stress was creating more unnecessary complications.



COPE has an education component where we find there are many who are not comfortable communicating with their doctor. Sometimes, the language the doctor is using can be confusing and difficult to understand. Patients are often anxious about the state of their health and feel nervous about asking questions due to stigma, language barriers, or not trusting the system to have their best interests at heart. This is especially true in communities of color where poverty is prevalent. We have found that many patients don't have a thorough understanding of how to maintain their undetectable status. I've heard people say that now that they're undetectable, they don't have to take the medication anymore. Others have said they're cured while others have decided they don't need to take their regimen every day and take weekends off. Patients are not always aware that they have to take medication at the same time every day or if they need to take it with or without food. Medical establishments are responsible for educating the patients they serve.

Homelessness prevents people from keeping to routines and adherent to medications, staying abreast of appointments, and keeping track of their belongings and medications. I applaud housing works for the amazing work they are doing to provide housing for people. And still, homelessness persists especially in this age of of gentrification and rising rents that are unaffordable. Even affordable housing is unaffordable for many. Housing is a right and shelters are not appropriate housing for anyone, especially for those living with HIV.

Lastly, I need to discuss stigma. People are still traumatized by the negative attitudes and have challenges entering special clinics that, whatever they name it, is known as the place for people living with HIV to get medical care. This is such a private matter that is openly known to the whole community causing shame and embarrassment. Care needs to be integrated into the general medical setting for people to feel comfortable that their status is not being revealed. For the active substance using population, stigma is often a barrier to care with medical staff being judgmental and other patients in the waiting area displaying negative attitudes and behaviors. Our success with patients who use drugs is with our provider blocking out a time to see them with little to no waiting time.

#### To improve care;

- Insurance navigators to find the optimal health care coverage and facilities specific to each individual patient
- More patient centered/community-based care with hours that are convenient for parents and for working people.
- The expansion of school health clinics would be ideal for whole family health
- Mobile medical units that travel through the community
- Shorter wait times
- More services available during a single visit to streamline the process.
- Ensuring patients are provided with sufficient information/education is essential to maintaining undetectable status.
- Integrated care
- Coordinating providers



- Blocking time specifically for substance users
- Housing that is truly affordable for everyone

Thank you for the opportunity to testify.

### Testimony of Housing Works Before

#### The New York City Council Committee on Health and Committee on Hospitals

### Regarding Oversight Hearing on The City's Efforts to Prevent and Address HIV and Hepatitis December 9, 2019

Thank you, Chairpersons Levine and Rivera and members of the Committees on Health and on Hospitals, for hearing my testimony today. My name is Norman Archer and I am here representing Housing Works, a healing community of people living with and affected by HIV/AIDS. Founded in 1990, we are the largest community-based HIV service organization in the United States and provide a range of integrated services for low-income New Yorkers with HIV/AIDS – from housing, to medical and behavioral care, to job training. Our mission is to end the dual crises of homelessness and AIDS through relentless advocacy, the provision of life saving services, and entrepreneurial businesses that sustain our efforts.

Housing Works and the End AIDS New York 2020 Community Coalition are greatly encouraged by the 2018 HIV surveillance data showing that the annual number of HIV diagnoses in New York City fell below 2,000, that in 2018 there were no perinatal HIV transmissions reported, and that two years ahead of 2020, New York City became the first city in the US to reach the UNAIDS 90-90-90 goals. We thank the City Council and the Administration for your unwavering commitment to ending our HIV epidemic and believe we should all acknowledge this outstanding progress as a testament to the power of combined efforts of community activists, social service providers, medical facilities, health departments and policy makers.

Like the Committee members and the Department of Health and Mental Hygiene, however, we remain deeply concerned about persistent HIV health inequities and realize we have much work to do. Emboldened by our achievements together, we call for continued and increased efforts to end the epidemic in every population and community by reaching those most vulnerable to HIV infection and to poor HIV health outcomes. As DOHMH reports, the rate of new HIV diagnoses actually increased between 2017 and 2018 for some New Yorkers, including transgender people, people ages 50-59, and men who report both sex with men and a history of injection drug use. Inequities persist as well in linkage to care, viral load suppression and premature mortality—particularly for Black and Latino MSM, women of color and transgender New Yorkers.

Despite increases in the percentages of people newly diagnosed with HIV who are linked to care within one month of diagnosis and virally suppressed within three months, inequities in HIV care outcomes for those newly diagnosed persist, with lower proportions of women and transgender people, Black people and people with a history of injection drug use linked to care and virally suppressed soon after HIV diagnosis.

To address these inequities and further improve our HIV response in order to achieve our 2020 EtE goals, in addition to your sustained support for ongoing initiatives we call for additional City investments, including the following:

We support Int 1808-2019 to examine HIV-related deaths, but also call for funding to establish ongoing systems to declare both AIDS-related mortality and new HIV infections due to injection drug use as sentinel events. Following each sentinel event, DOHMH field services staff would investigate the case with a high degree of attention to determine whether a transmission or mortality could be averted, in order to inform ongoing improvements in our HIV prevention and

care systems. As you know, a sentinel events approach has enabled us to end perinatal transmission, and we believe the same strategy can be used to get to zero AIDS-related deaths and to end transmission via injection drug use.

To protect the most vulnerable New Yorkers, we support the expansion of housing and services for homeless youth and for transgender New Yorkers regardless of HIV status. Safe, stable housing is powerful HIV prevention and care.

We are pleased to report that the HASA Health Care Integration Project pilots are all underway, testing new service delivery models designed to improve HASA outcomes while achieving efficiencies, and employing new data connectivity to support care engagement and coordination. We urge the Council to fully fund the City University of New York evaluation that is essential to your oversight and to inform scale-up.

It is time to require access to PrEP at all harm reduction sites and to fund a program that would provide Syringe Exchange Program Sites with PrEP education peers and offset the cost of colocating harm reduction and health services to provide PEP, PrEP, and HCV testing and treatment.

As you know, New York's Sexual Health Clinics are a critical component of the City's EtE strategy. We call for continued enhancement of Sexual Health Clinics through the addition of services to better address HIV, HCV and sexually transmitted infections. The successful "Dean Street" model implemented at the Chelsea Sexual Health Clinic must be replicated in other heavily impacted communities. The model offers "express," automated and streamlined STI testing based on the Dean Street model out of England. This year DOHMH expanded the Dean Street model to one Sexual Health Clinic in Brooklyn, but further expansion is needed including a location in Queens. We also support the establishment of reproductive health services and transgender health services at all NYC Sexual Health Clinics, including quality reproductive health care, hormone therapy and necessary health care referrals. Services could be further improved by posting greeters at each clinic to facilitate engagement, and by making syringe exchange services available at the clinics.

In tandem to our effort to continue the fight against HIV, we want to reaffirm the importance of eliminating Hepatitis C in NYC. Additional efforts are required to ensure that every New Yorker living with viral hepatitis is aware of their diagnosis and has access to curative treatment. In 2018, there were 4,682 people newly reported with a positive hepatitis C antibody result (RNA positive or RNA unknown), more than twice the number of new HIV diagnoses. Additionally, 50% percent of people reported with chronic hepatitis C in 2015 who had not started treatment by the end of 2018.<sup>2</sup>

By the end of 2017, 62.5% of people living with HIV who ever tested positive for hepatitis C RNA were treated, but 3,372 (more than one-third) remained untreated. Again, inequities persist: Black New Yorkers were less likely than non-Black New Yorkers to have initiated treatment; people living in very high poverty neighborhoods were less likely than those living in lower poverty neighborhoods to have initiated treatment; people with HIV viral load >200 copies/mI were less likely to have initiated treatment than those with a suppressed viral load; people with a history of incarceration were less likely to have initiated treatment than those without a history of incarceration.

We are deeply thankful for the Council's support for the development of overdose prevention centers and urge continued funding for a closely monitored 2-year pilot of 4 Supervised

Consumption Sites in New York City to research the impact of supervised injection services to reduce drug overdose deaths, HIV, and hepatitis C. Provisional data show that in 2018, 1,444 people died from drug overdose in NYC. The Health Department estimates there are more than 10,000 nonfatal overdoses each year. People with a history of nonfatal overdose are at risk for hepatitis B and C and should be tested and connected to care and treatment.

We also thank Chairperson Levine and the Council for your leadership last year in protecting public health programs from the devastating effects of New York State Article 6 cuts, and we stand ready to work with you to advocate for restoration of full State support. As you well know, Article 6 matching funds are essential for City Council discretionary-budget public health programs, such as those that support immigrant health, health education, health insurance access, HIV/AIDS prevention and treatment, child and maternal health, viral hepatitis, and more.

We would like to express our support of the proposed legislation (Int 1808-2019) that would require the Department of Health and Mental Hygiene (DOHMH) to conduct a study of all HIV/AIDS-related deaths in the city between 2017 and 2019 to assess the causes and circumstances that lead to each death. We also support the resolution (Res 0150-2018) calling upon United States Food and Drug Administration to remove any blood donation restrictions based on sexual orientation.

Housing Works, along with organizations, individuals and communities across the City, ask for the Committees' support for ongoing and increased investment in these health priorities. Together, we can push our AIDS epidemic beyond the tipping point by addressing health inequities to end the epidemic for all New Yorkers.

Sincerely,

Norman Archer

Norman Archer Policy & Research Associate Housing Works, Inc. 81 Willoughby Street, 5th Floor Brooklyn, NY 12201 718.408.6069 he/him/his

1. HIV Epidemiology Program, HIV Surveillance Annual Report, 2018, DOHMH, November 2019, available at https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-surveillanceannualreport-2018.pdf

2. New York City Department of Health and Mental Hygiene, Hepatitis A, B and C in New York City: 2018 Annual Report, 2019, available at https://www1.nyc.gov/assets/doh/downloads/pdf/cd/hepatitis-abc-annual-report- 2018.pdf



#### Christina Tsai Site Director 7th Avenue Family Health Center at NYU Langone

December 9, 2019

Testimony before the New York City Council Joint Hearing Committee on Health and Committee on Hospitals Oversight - The City's Efforts to Prevent and Address HIV and Hepatitis

Good morning Chairwoman Rivera, Chairman Levine, and all Council Members present. My name is Christina Tsai and I am the site director at 7th Avenue Family Health Center, a federally qualified health center that is part of the NYU Langone Health system. We are located in Sunset Park, Brooklyn and serve over 5,000 unique patients per year, which generates more than 30,000 visits annually. Over 95 percent of our site's patient population are Chinese immigrants from the southern part of China. Our team of physicians and staff provide primary care services to low-income families in the community, which include migrant workers and undocumented persons. Thank you for giving me the opportunity to testify today about the City's efforts to prevent and address hepatitis, and to speak specifically about the City-funded Check Hep B Program. On behalf of my team at the 7th Avenue Family Health Center at NYU Langone, I hope to convey the importance of the Check Hep B Program and to encourage your support for increased funding for the program.

To provide some background information, Hepatitis B is a liver infection that can be short-term or may develop into a chronic condition. The Hepatitis B virus can be transmitted through sexual intercourse, from infected mothers to their children while giving birth, or via shared used needles. Those living with hepatitis B long-term are at a greater risk for developing cirrhosis, or scarring of the liver, and liver cancer. The Check Hep B program was established in 2014 through funding from the New York City Council and is administered by the NYC Department of Health and Mental Hygiene. The main goal of the program is to coordinate care for those who are chronically infected with Hepatitis B through medical care and treatment. The funding enables organizations like the Family Health Centers at NYU Langone to employ and train patient navigators who help engage patients and provide care coordination for hard to reach and disproportionately affected populations.

Participating in the Check Hep B program has enabled our center to link a growing number of identified individuals to care, to provide Hepatitis B screening and testing, and to better educate patients about the disease itself. The 7<sup>th</sup> Avenue Family Health Center is currently the only location in Brooklyn that is providing these crucial services through the Check Hep B program. It is well documented that the populations in our area in Brooklyn are at high risk for Hepatitis B. Hepatitis B is very common in East Asian countries, and Sunset Park, Brooklyn has one of the largest Asian immigrant communities in the NYC area. According to a study that compiled data on liver disease diagnoses between 2014 and 2015, Sunset Park has the highest rate of Hepatitis B in the city, with an infection rate of nearly 744.8 cases per 100,000 people. This is much higher than the rate of Hepatitis B as compared to rest of the country, which is about one case per 100,000 people. Many people currently living with Hepatitis B in these areas are not aware they have the infection, and some realize they are Hepatitis B positive only when symptoms appear, which can be during the later stages of the untreated infection. In



many situations, these individuals do not know where to go for medical care or experience cultural or language barriers. Further, undocumented patients often fear seeking services. The patient navigators funded through the Check Hep B Program help patients overcome barriers to accessing care and treatment.

Since the 7<sup>th</sup> Avenue Family Health Center received funding through the Check Hep B Program, we have enrolled 337 patients. According to data provided by the NYC Department of Health and Mental Hygiene, the 7<sup>th</sup> Avenue Health Center at NYU Langone has had both the highest number of patient enrollments and the highest number of newly enrolled patients every fiscal year to date. Additional funding would allow our site to meet the high need among our patient population in Brooklyn. Our patients would benefit from the addition of another patient navigator to manage an expanding caseload and connect with the most vulnerable individuals who face various impediments to seeking diagnosis and care.

I also wanted to take this opportunity to share a patient case that 7th Avenue Family Health Center helped through the Check Hep B Program. He is a 70 year old male who has been a patient at our site for over 10 years. He has multiple comorbidities, including Type 2 diabetes and renal cancer in 2013. He had kidney surgery to remove the mass and in 2014, our provider identified that the patient had a small mass growing in his liver. It was confirmed later that patient had liver cancer, and he was promptly referred by our primary care team to our NYU innetwork hepatologist for further treatment. Following more advanced treatment, surgery was performed and patient recovered gradually. It has been 5 years post-surgery and the elderly patient is doing well after surviving both kidney and liver cancer. The Check Hep B Program enabled our care team to identify the liver cancer early so treatment could begin promptly, which proved to be life-saving. This is one of many examples reflecting the positive impact that the Check Hep B Program has brought to our growing patient base in providing linkage of care, early detection and treatment of Hepatitis B and overall awareness of the disease in the Sunset Park community.

Again, I greatly appreciate the opportunity to testify. Please feel free to contact me if you have any questions about the Check Hep B Program and the great work that our care team is doing in the Sunset Park community.



## **Enrollment** July 1, 2019 – June 30, 2020

Site name	Newly Enrolled FY2020	Required	Active in program	Required
7th Avenue Family Health Center	19	35	160	50
African Services Committee	13	35	26	75
Apicha Health Center	8	N/A	8	40
H+H Bellevue Hospital	0	50	0	50
BronxCare Health System	9	35	48	50
Charles B Wang - Chinatown	12	27	61	45
Charles B Wang - Flushing	10	27	83	45
Community Health Action of Staten Island	0	N/A	0	40
H+H Elmhurst Hospital	0	35	0	35
Korean Community Services	14	35	42	50
Montefiore Medical Center	6	45	6	75



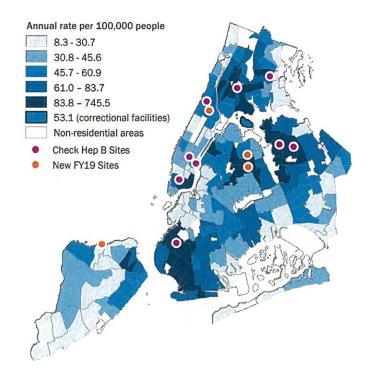
#### HEP B IN NYC AND CHECK HEP B PROGRAM LOCATIONS

The following map shows the rate of newly reported Hep B cases in 2017 by neighborhood tabulation area and the Check Hep B Patient Navigation program locations.

#### **Health Centers and Hospitals** 1. Bellevue Hospital (H+H) 2. BronxCare Health System 3. Charles B. Wang Community Health Center 4. Montefiore Medical Center 5. NYU Seventh Avenue Family Health Center **Community Organizations** 6. African Services Committee 7. Korean Community Services Newly Funded Organizations in FY2019 1. APICHA Community Health Center

- 2. Community Health Action of Staten Island
- 3. Elmhurst Hospital
- 4. Harlem United







#### References:

 $\underline{https://www.hepmag.com/article/new-york-city-reports-extremely-high-hepatitis-b-rates-parts-brooklyn-queens}$ 

Check Hep B Patient Navigation Program – periodic reports provided by NYC Department of Health

Hep Free NYC – 2017 Annual Report



## Brooklyn Community Pride Center Testimony for New York City Council Committee on Hospitals and Committee on Health Monday, December 9, 2019

Thank you for this opportunity to present testimony today regarding the City's efforts to prevent and address HIV and Hepatitis. My name is Floyd Rumohr and I'm the CEO of Brooklyn Community Pride Center, the first and only LGBTQ+ community center located in and serving the residents of Brooklyn.

Our Center is located in Bedford-Stuyvesant and we have exciting plans to open a second location in 2021 in Crown Heights. Those locations were chosen with a purpose - both neighborhoods continue to lead the city in highest rates of new HIV infections. 65% of new infections in 2017 were from men who have sex with men, or MSMs. 45% of new infections were among MSMs of color.

We acknowledge that the City has put many resources into these Brooklyn neighborhoods to help combat the spread of HIV and other STIs. We partner with many of the wonderful organizations on the front lines, including CAMBA, Turning Point Brooklyn, and OASIS, to name just a few. Even as we offer testing and education 7 days a week through these partnerships, we also strive to keep the balance of being a brave space for people to relax and express themselves without feeling like numbers in somebody's grant application or research project.

This is a difficult balance to maintain, because with more than half of all new infections occurring in the MSM community, much of Brooklyn is still sadly lacking in queer-affirming spaces where the population most at-risk will feel comfortable seeking testing, education and advice.

For our black and brown community members, who account for almost half of new infections in 2017, it is especially challenging to be told that accessing HIV and sexual health services in explicitly LGBTQ+ spaces means getting on buses and trains and travelling into predominantly white, predominantly upper-class, gentrified neighborhoods in Manhattan.

As you consider your long-term strategies to combat HIV and STIs in New York City, especially in the outer boroughs, please remember that all the LGBTQ+ competency training and targeted outreach you can fund isn't as effective as having nearby, accessible, explicitly LGBTQ+-affirming brave spaces like Brooklyn Community Pride Center for people to comfortably and organically connect with the life-saving programs and services already in place in neighborhoods where people live.

I invite any and all of you to drop in and visit us at Restoration Plaza, just off the corner of Fulton Street and New York Avenue, to see how we're creating such a space. Thank you.



#### Testimony of

Brian Romero, LMSW
Policy Associate
Gay Men's Health Crisis (GMHC)

Presented to the
New York City Council
Committee on Health and
Committee on Health and Hospitals
Joint Oversight Hearing on
The City's Efforts to Prevent and Address HIV and Hepatitis.

#### COMMITTEE ON HEALTH CHAIR – HON, MARK LEVINE

#### COMMITTEE ON HEALTH AND HOSPITALS CHAIR – HON, CARLINA RIVERA

December 9th, 2019 at 10:00 A.M.

Good afternoon, Chairpersons Levine and Rivera and committee members. My name is Brian Romero (I use he/him/his pronouns) and I am a Policy Associate at the Gay Men's Health Crisis (GMHC . Thank you, for the opportunity to testify on this very timely subject.

At GMHC we are encouraged by the recent 2018 HIV Surveillance report of the New York City Department of Health and Mental Hygiene (DOHMH). For the first time in NYC's history we have achieved less than 2,000 new diagnoses a year since we started recording this data. This does not however yet meet the goal of the Ending the Epidemic task force and blueprint that set a goal of seeing no more than 600 new diagnoses coming from New York City.

We also cannot underestimate the significance of where we have seen an increase in new diagnoses. As was stated in the report, between 2017 and 2018 we saw an increase among transgender people, people between the ages of 50 and 59, men who have sex with men and men who inject drugs. We have also still not seen the reduction in diagnoses among men of color who have sex with men that we have seen in their white counterparts. What can be done in this regard is increasing access to pre-exposure prophylaxis (PrEP) to these populations and to men of color as well.

In addition, without the adequate funding necessary to support these and other initiatives related to healthcare access and provision of services we will not see the outcomes we hope for. Earlier this year in Albany, \$59 million was slashed in Article 6 funding, threatening programs and services in New York City, such as those that support immigrant health, health education, health insurance access, HIV/AIDS prevention and treatment, child and maternal health, transgender health equity, viral hepatitis, and more. Therefore, we strongly urge that the Council do all that it can to advocate for this funding to be restored when it visits Albany during the executive budget. We need Albany to prioritize this in budgetary deals if we are truly going to end the epidemic in New York City and State by 2020.

Finally, as an organization that has worked towards the discriminatory blood ban on men who have sex with me, we urge the Council to pass Resolution 150, which would urge the Food and Drug Administration to discontinue its blood ban based on sexual orientation. The ban is based in homophobia and we cannot afford to continue these restrictions with the blood shortage that exists in this country. Lives are depending on this change. Thank you.

Hearing
New York City Council
Hospitals JOINT Committee Hearing
Monday, December 9th, 2019

Robert Desrouleaux
Program Director The Hepatitis C Mentor and Support Group, Inc.
2525 Hone Ave # 1
Bronx, NY 10469
(347) 886-9558

Thank you for the opportunity to speak to you today. I want to thank Council Member Levine and other council members for supporting the hepatitis community in the past. I am here today as a representative of the Hepatitis C Mentor and Support Group. I have been working for 6 years on the ground in with the underserved communities, providing training on education and supportive services within syringe exchange programs and drop in centers. I work closely with the Founder/ Executive Director Ronni Marks who in addition to being a patient has experience working with both patients and providers.

At HCMSG we provide education and supportive services for people living with Hepatitis C and co-infected with HIV throughout New York City. Educational groups and supportive patient mentoring services have been shown to be important elements of successful and cost effective medical care for patients with Hepatitis C and other chronic health conditions. These services improve the quality of life, as well as medical outcomes for patients.

The training HCMSG provides for healthcare providers help them to have a better understanding of how to work with all patients with an emphasis on high risk populations, such as people with substance use disorder, those co infected with HIV, the LGBTQ community, Youth and Women of child bearing age dealing with Hepatitis C.

<sup>1</sup>Approximately 2.4% of NYC residents 20 years and older have hepatitis C and 1.2% have Hepatitis B. Many are walking around unaware they have it. The rates of liver cancer remain high among NYC residents.

Our Executive Directors, Ronni Marks, serves on the New York State Hepatitis C Elimination task force, and hope to see us provide the model for the entire country, with NY as the first City and State to eliminate Hepatitis C. We need increased services for hepatitis, peer navigators, harm reduction and syringe exchange services.

This is why it is critical that we reduce missed opportunities to screen and diagnose patients who seek care in emergency rooms and hospitals as well as educating providers and staff on the stigma faced by people who use drugs. There are opportunities to move towards elimination by increasing the focus on treating patients who are in the hospital for extended periods of time. Education is needed in overdose prevention, Hepatitis and HIV. People need to understand the syndemic connection between substance use and infectious disease.

As an educator in the field and someone who has witnessed the lack of knowledge in the communities, I can tell you firsthand what an impact this virus has on the lives of those affected. It affects the whole body, not just the liver. Being cured has been the key to having people turn their lives around.

There is such power in having supportive services and patient navigators. It is essential for patients to work with people who understand what they are going through and can help them get through the process, making it easier for patients to adhere to treatment. In many cases it has helped to reduce the feeling of stigma associated with having Hepatitis.

Please help us ensure that all New York City residents have access to Hepatitis C testing, treatment and care regardless of race, gender, or economic status.

Thank You!

#### Reference:

<sup>&</sup>lt;sup>1.</sup> NYC Department of Health; 2016 Annual Report: Hepatitis B and C. www1.nyc.gov/assets/doh/downloads/pdf/cd/hepatitis-b-and-c-annual-report-2016.pdf



December 9, 2019

Testimony: New York City Council Committees on Health, and Hospitals

Government Relations Contact: Lyndel Urbano, Director of Public Policy

lurbano@amidacareny.org, (646) 757-7148

Good morning, my name is Doug Wirth, President and CEO of Amida Care, the largest Medicaid Special Needs Health Plan in New York, serving 8,000 members living with, or at elevated risk for, HIV. Thank you for the opportunity to testify and provide recommendations about how best to address HIV in New York City.

We are encouraged by the news from the New York City Department of Health and Mental Hygiene (DOHMH) that New York City is the first large city to achieve the UNAIDS 90-90-90 HIV goals<sup>1</sup> --two years ahead of schedule—and that new HIV diagnoses in the city have fallen below 2,000 per year for the first time since the beginning of the epidemic.

We are proud that New York continues to be a leader in the fight to End the Epidemic. But there is still much more work that needs to be done. The new DOHMH report shows continued inequities in access to HIV prevention and care. **NYC neighborhoods where most diagnoses** are occurring are the same ones with the highest rates of poverty:

- Nine (9) out of every ten (10) new diagnoses in women are among Black and Latina women;
- Transgender women are seeing increased HIV rates;
- Black and Latino men comprise the majority of all new diagnoses; and
- Pre-exposure prophylaxis (PrEP) uptake to prevent HIV is on the rise, but it isn't reaching many who are at elevated risk for HIV, particularly in black, Latinx, and LGBTQ communities.

New York City must close these gaps and accelerate the momentum to reach our Ending the Epidemic (ETE) goals, and ensure that all New Yorkers have the resources they need to improve and maintain their sexual health. Every person should feel comfortable discussing their sexual health with their health care providers and have ready access to HIV prevention and testing; and,

By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.

<sup>&</sup>lt;sup>1</sup> UNAIDS <a href="https://www.unaids.org/sites/default/files/media">https://www.unaids.org/sites/default/files/media</a> asset/90-90-90 en.pdf

if they test positive, treatment to become undetectable, which lets them lead healthier lives and makes the virus untransmittable to others.

We urge NYC to promote PrEP usage among NYC Medicaid recipients who are at elevated risk for HIV. NYC should also collaborate with New York State to maximize the benefit of Medicaid, by negotiating deeper discounts on this expensive medication as the city and state work together to increase PrEP usage. These discounts would help minimize costs and ensure that Medicaid health insurance plans have adequate rates to support PrEP uptake.

Today, most Medicaid PrEP users are white, but 80% of new HIV diagnoses are among communities of color. PrEP still isn't getting into the hands of those who need it most. The New York State Medicaid ETE goal is to increase the number of Medicaid recipients using PrEP from 6,000 today to 30,000 by 2020. We need to double down on our education and awareness-building efforts, and the outreach, services, and resources we provide, in order to increase PrEP uptake in these communities and ensure that everyone who is HIV negative has the tools to stay negative.

Medicaid health insurance plans like Amida Care, and health care providers can help by making concerted efforts to improve PrEP access. Plans must educate their members about the availability of PrEP, remove administrative barriers such as prior authorization, and cover the medication, as well as follow up laboratory testing and medical appointments to ensure treatment adherence.

At Amida Care, we know this is possible because we've done it. In 2017, NYS expanded eligibility for Amida Care to include people of transgender experience regardless of HIV status; today, 25% of Amida Care's transgender members who are HIV negative are now accessing PrEP. Our PrEP Program is a key component of our HIV Prevention Services. We offer counseling, education, and HIV risk assessment; and we cover all PrEP-related needs, including medications, lab test fees, and follow-up medical appointments. We make sure that our members living with complex conditions like Hepatitis C receive treatment and support, and we have helped over 1,200 of our members get cured of Hepatitis C. We also link our members to supportive services, because folks need affordable housing and to know where their next meal is coming from to be able to take care of their health. Those who are well enough to work need access to livable wage jobs. Only by addressing the needs of the whole person will we be successful in ending the epidemic once and for all.

I'd like to end by thanking City Council for its support for HIV employment programs and ask for increased funding for these services. Having a job is critical to good health and helps address social and economic factors, such as a lack of permanent housing, that drive poor health outcomes. Supporting employment programs for people living with HIV helps them find and keep living wage jobs and move up career ladders.

Amida Care has a long history of helping people with lived HIV, Hepatitis and Substance Use experience to find and keep work, drawing on their lived experience to help others in similar circumstances. We partner with *Housing Works* and the *Alliance for Positive Change* to train and hire our plan members. City Council Ending the Epidemic funding has helped us support 30

consumer workers at 6 Community Health Care providers. To date 20 of them have accepted permanent employment.

Unfortunately, low-income people living with HIV still have difficulty attaining a livable wage. New York City Human Resources Administration (HRA) has done an admirable job of providing support to people living with HIV through its HIV AIDS Services Administration (HASA). However, this support is income based, and when a person starts working, they can quickly earn too much to retain housing and other supports, or may need more than a year to get close to full-time employment.

Amida Care and the *Ending the Epidemic Coalition* are working with the *New York State Office of Temporary and Disability Assistance (OTDA)* and *HRA* to change this. We expect that starting next year, HRA will gain state approval to expand and evaluate an existing income disregard program as a demonstration project. Under the project, HASA will have authority to disregard over 50% of a client's income when calculating eligibility for housing and other supports. The project would be implemented and evaluated over five years instead of the current one year. This project will allow more HASA clients to return to work and earn more without losing housing support. The changes will also realize up to \$18 million in NYC cost savings by flexibly supporting people with HIV as they move from public assistance to greater financial independence and self-support.

Thank you for this opportunity to testify. Amida Care looks forward to working with New York City Council to achieve an end to the HIV epidemic in our city.

#### **About Amida Care**

Amida Care Inc. is a not-for-profit health plan that specializes in providing comprehensive health coverage and coordinated care to New Yorkers with complex conditions, including HIV and behavioral health disorders, and people who are of transgender experience or who are homeless (regardless of HIV status). Amida Care has a wide network of health care providers throughout New York City and is the largest Medicaid Special Needs Health Plan (SNP) in New York State. For more information, visit www.amidacareny.org.



# TRANSGENDER HEALTH SERVICES

# Accessing health services is an important part of living your best life.

At Amida Care, we are committed to improving the quality and access of health services available to transgender, gender non-conforming, and non-binary individuals. We understand that each person's transition and health goals are different, and our specialized **Trans Health Team** will work with you to identify your needs, review your options, and connect you to affirming care and services.

#### **Our Services**

- Gender-Affirming Primary Care
- Gender-Affirming Surgeries
- Hormone Therapy
- HIV services, including PrEP
- Prior Authorization Guidance and Support
- Health Navigation
- Multidisciplinary Care Coordination
- Wellness Activities and Events
- Town Hall Meetings
- Supportive Services
- Advocacy
- And more!

For more information about our plan and if you wish to enroll call 1-800-556-0689 (TTY 711).

Current Amida Care members, contact our Transgender Health Services,

TransgenderHealthServices@amidacareny.org • 646-757-7982 (TTY 711)

if you have any questions.



Follow us on











# SERVICIOS DE SALUD PARA PERSONAS TRANSGÉNERO

El acceso a los servicios de salud es una parte importante de vivir tu vida de la mejor manera. En Amida Care, nos comprometemos a mejorar la calidad y el acceso a los servicios de salud disponibles para personas transgénero, no conformes con el género y no binarias. Entendemos que las metas de transición y de salud de cada persona son diferentes, y nuestro Equipo de Salud Transgénero especializado trabajará contigo para identificar tus necesidades, revisar tus opciones y conectarte con la atención y los servicios de afirmación.

#### **Nuestros servicios**

- · Atención médica para la afirmación del género
- · Cirugías para la afirmación del género
- Terapia de hormonas
- Servicios para el VIH, incluyendo PrEP
- Orientación y apoyo para autorizaciones previas
- · Navegación a través del sistema de salud
- · Coordinación de cuidados multidisciplinarios
- Actividades y eventos de bienestar
- Asambleas públicas
- · Servicios de apoyo
- Abogacía
- · ¡Y más!

Para más información sobre nuestro plan y si deseas inscribirte, llama 1-800-556-0689 (TTY 711).

Miembros pueden comunícarse con Servicios de Salud para Personas Transgénero de Amida Care:

TransgenderHealthServices@amidacareny.org • (646) 757-7982 (TTY 711)

si tienen alguna pregunta.



Síguenos en











#### For Immediate Release:

Shakira Croce, scroce@amidacareny.org, 646 757 7052

#### Amida Care Supports First Ever "PrEP Aware Week" in New York State

PrEP Can Help End the HIV/AIDS Epidemic -

(New York – October 8, 2019) Amida Care is joining the New York State Department of Health (NYSDOH) AIDS Institute, Governor Andrew Cuomo, Commissioner Howard A. Zucker, advocates, New York City elected officials, community organizations, and health care providers from across the state to support and actively promote PrEP Aware Week. Doug Wirth, President and CEO of Amida Care, released the following statement in recognition of PrEP Aware Week, commending Governor Cuomo and the NYSDOH AIDS Institute for their work to increase the number of New Yorkers using pre-exposure prophylaxis (PrEP).

"Increasing the number of New Yorkers taking PrEP is one of our greatest weapons in winning the war against HIV/AIDS. PrEP is a game-changing once-a-day pill that has proven to be 99% effective in preventing HIV transmission. The state just announced another drop in the number of new HIV infections, down 11% between 2017 and 2018. We know that by increasing the use of PrEP, we can get that number down significantly more and really move the needle in ending the HIV epidemic.

"Governor Cuomo has taken a number of important actions to make PrEP accessible for all New Yorkers, including mandating that it be covered by insurance without cost-sharing. But while PrEP usage is on the rise, it isn't reaching many who are at elevated risk for HIV, particularly in black and Latinx communities. In New York, the largest proportion of Medicaid recipients taking PrEP are white men, despite the fact that in 2017 more than 78% of new HIV diagnoses were among people of color. A recent Centers for Disease Control and Prevention report found that doctors are less likely talk to black and Latinx men about PrEP. PrEP Aware Week is designed to help and encourage health care providers to engage all their patients in sexual health conversations that include PrEP. Providers can play an important role in closing gaps in PrEP awareness and access – disparities that must be addressed in order to reach New York's goal of ending the HIV/AIDS epidemic by 2020.

"As New York's largest Medicaid Special Needs Health Plan, designed to serve New Yorkers living with or at elevated risk for HIV, Amida Care has deep expertise in providing sexual health services. We are proud to engage our network of health care providers and staff in supporting PrEP Aware Week. Currently, only about 6,000 New York Medicaid recipients are using PrEP, but the state hopes to increase that number to 30,000 by the end of 2020. We will continue to work with the state to make that goal a reality. Not only will increasing PrEP use improve health outcomes, it will also create significant cost savings. For every 2,000 new HIV infections prevented, \$1 billion in future state Medicaid costs are averted."

#### **About Amida Care**

Amida Care Inc. is a not-for-profit health plan that specializes in providing comprehensive health

coverage and coordinated care to New Yorkers with complex conditions, including HIV and behavioral health disorders; and people who are of transgender experience or who are homeless, regardless of HIV status. Amida Care has a wide network of health care providers throughout New York City and is the largest Medicaid Special Needs Health Plan (SNP) in New York State. For more information, visit <a href="https://www.amidacareny.org">www.amidacareny.org</a>.



https://www.gaycitynews.nyc/stories/2019/25/ending-epidemic-2019-11-27-gcn.html

November 27, 2019 / News / Health

# Accessibility, Affordability Key to Ending Epidemic

Recent declarations of victory in New York come with key caveats



DONNA ACETO

Amida Care CEO Doug Wirth said there must be a massive boost in Medicaid recipients who use PrEP by next year and cited the importance of getting tested for HIV.

BY MATT TRACY Community News Group



NEW YORK CITY COUNCIL/ JEFF REED

Out gay Councilmember Ritchie Torres said "HIV has become a disease of poverty disproportionately affecting communities of color."

The fight to eradicate HIV/ AIDS in New York has progressed in recent years, but health experts and elected officials are highlighting areas that must be addressed in order for the state to end the epidemic.

The state, the city, and a broad array of HIV groups embarked several years ago on a campaign to end the AIDS epidemic, which was defined as lowering new infections in the state to 750 annually by 2020 (and to 600 in the city). Questions have surfaced about the viability of the goal, however: While Governor Andrew Cuomo recently appeared to declare victory in the state's campaign, officials told The New York Times that new diagnoses — a figure that is different than new infections, since not all HIV transmissions are detected promptly — were only on pace to be lowered to "a little more than 1,500 per year by 2020." Health department spokespeople still voiced confidence that new infections would drop to 750 by next year, but the state has not yet released new infection data for calendar year 2018.

According to out gay Bronx Councilmember Ritchie Torres and Amida Care CEO Doug Wirth, the remaining challenges largely boil down to accessibility and affordability.

"To an extent not seen before, HIV has become a disease of poverty disproportionately affecting communities of color," Torres told Gay City News. "The Bronx alone is home to 24 percent of New Yorkers living with HIV. The focus of public policy should be on breaking down the barriers to accessing PrEP that continue to plague communities of color."

While the use of PrEP — which when used consistently is effective at preventing infection in HIV-negative people — is on the rise, it is not reaching men of color the way it is reaching white men. CDC data from 2014 to 2017 showed that PrEP awareness and use were lower among both Latinx and Black men compared to their white counterparts.

"Part of the challenge around PrEP is that 80 percent of new HIV diagnoses are among people of color, but 80 percent of PrEP uptake among Medicaid recipients has been among white men," said Wirth, whose organization provides services to Medicaid-eligible HIV-positive individuals and those at risk for acquiring HIV. "We've got to increase conversations within social networks, healthcare providers, churches, faith communities, and bodegas."

Wirth stressed that it also remains important for folks to continue getting tested for HIV. Knowing one's status and staying virally suppressed if HIV-positive are crucial to the emerging U=U (undetectable = untransmittable) campaign to spread awareness that a person whose viral load is undetectable cannot transmit the virus to others. That campaign gained mainstream exposure when CNN's Anderson Cooper explained U=U to viewers during an LGBTQ-focused Democratic presidential town hall in October.

Many of the remaining hurdles toward ending the epidemic in New York pertain to healthcare quality. Torres cited a lack of cultural competency among too many providers. There are providers, he said, who are not even aware of how to properly advise on the use of PrEP.

"There needs to be proactive outreach to men who have sex with men and who might face an elevated risk of HIV," he said.

The absence of culturally competent providers also adds extra hurdles to the existing challenge of erasing stigma around healthcare services for men who have sex with men. Torres said an overall lack of access to preventative care in the Bronx and the persistence of homophobia among providers makes accessing healthcare even more of an obstacle.

https://www.nytimes.com/2017/10/02/opinion/aids-prevention-medicine.html

#### **AIDS Prevention Medicine**

October 2, 2017

# The New Hork Times

To the Editor:

Re "Why Anti-H.I.V. Medicine Isn't for Me" (Sunday Review, Sept. 24):

Rampant stigma concerning H.I.V. and sexuality in our health care system makes it difficult for the L.G.B.T.Q. community and people of color to obtain competent and respectful care. Pre-exposure prophylaxis, which is more than 90 percent effective in preventing the transmission of H.I.V., has been particularly stigmatized.

It is essential for the medical community to address barriers to care. H.I.V. specialist primary-care providers at community health centers make pre-exposure prophylaxis accessible through outreach.

For those who decide to take the medication, care coordination provides a support system to encourage them to stick with their medication. The health care field needs to hire, promote, train and retain staff who understand the communities they serve.

Making those who inquire about pre-exposure prophylaxis feel uncomfortable and shamed will only hold us back.

DOUG WIRTH, NEW YORK

The writer is president and chief executive of Amida Care, a special-needs health plan for people with chronic conditions.



https://brooklyneagle.com/articles/2019/10/24/for-the-first-time-new-york-state-initiative-focuses-on-hiv-prevention/

# Bresklyn Daily Eagle

HEALTH BROOKLYN BORO

# For the first time, New York state initiative focuses on HIV prevention

October 24, 2019 Kelly Mena



Octavia Kohner, who uses PrEP, advocates for access to the drug at Brooklyn Borough Hall. Eagle photo

A new statewide initiative aimed at increasing education and prevention methods around HIV/AIDS launched for the first time this year, highlighting a once-a-day pill that reduces the transmission of the disease.

<u>"PrEP Awareness Week."</u> which runs from Oct. 20 to Oct. 26, aims to boost public awareness of <u>PrEP</u> (pre-exposure prophylaxis), a once-a-day pill taken by people who are HIV-negative to reduce their risk of infection if they're exposed to HIV.

The pill has proven to be 99 percent effective in preventing HIV transmission when taken regularly, according to city officials. Truvada is the only form of PrEP currently approved by the FDA.

"Increasing access to PrEP is one of our greatest weapons in winning the war against HIV," said Doug Wirth, president and CEO of Amida Care, a provider of PreP. "PrEP is a game-changing

pill, so tell your friends, talk to your family members, have conversations at work and when you go to your house of worship, whether that is a church, mosque or synagogue, or another house. You need to talk about sex, and we need to talk about taking care of each other."

Wirth went on to note that usage of the drug is on the rise across the state, with the largest portion of new users being cis-gendered white men.

Amida Care provides the drug free through Medicaid to anyone who is eligible, but for those whose insurance plans don't cover the medication, prescriptions can run up to \$1,000 monthly, Wirth said.

The state offers a <u>program</u> for those who need financial assistance accessing the drug, which reimburses enrolled patients for certain services, including HIV testing, adherence counseling, and STD testing and treatment.

"I've been on PrEP a while, but the issue is access to it can be very difficult," said Octavia Kohner, a transgender woman who has been using the drug since 2012. "Taking it everyday can be very difficult. So I think mobile clinics are really important, to sort of bridge the gap between people who are aware and people who are actively taking it."

As part of the awareness week, <u>events have been running throughout the back</u> to promote safe sex — like a condom giveaway on Friday evening.

Places that currently offer PrEP in Brooklyn include SUNY Downstate, The Brooklyn Hospital Center, Housing Works and Brightpoint Health or Community Healthcare Network, according to Wirth.

The statewide effort comes as Brooklyn recently experienced a spike in new HIV cases. In 2017, the borough saw an uptick of more than 10 percent in new HIV diagnoses, a significant change from 2016. The increase was the only one citywide, compared to an overall decrease of 11 percent across New York City in the same year.

The neighborhoods of Bedford-Stuyvesant and Crown Heights were among the hardest hit, accounting for a quarter of the new diagnoses in the borough, according to city date.

"We want to increase the usage of PrEp, to educate people on how important it is to use PrEp and also to empower young people to take the initiative in having safer sex practices," said Brooklyn Borough President Eric Adams.

http://www.brooklyndowntownstar.com/view/full\_story/27676221/article-Awareness-week-stresses-effectiveness-of-PrEP



#### Awareness week stresses effectiveness of PrEP

by Salvatore Isola Oct 29, 2019



PrEP Awareness Week ended Saturday, but for many Brooklynites the lifesaving drug and crucial step in the fight against HIV has year-round effects.

The week attempted to increase public awareness of PrEP (pre-exposure prophylaxis), a daily pill that people who are HIV-negative take to reduce their risk of contracting the disease.

Borough President Eric Adams and representatives from Amida Care, who provide PrEP, say the drug has proven to be 99 percent effective in prevention.

"We took on this conversation to let people know that HIV and AIDS is not a death sentence, as long as you take the proper precautions," said Adams,

DrED is accounted through Medicaid and Amida Coro massides DrED to these alicilia without

PrEP is covered through Medicaid, and Amida Care provides PrEP to those eligible without cost. Treatment costs about \$1,000 a month.

"People will likely need access to PrEP for anywhere between six months to five years, and we're willing to pay for the cost of that medication and help people to stay HIV negative," CEO Doug Wirth said. "Increasing access to PrEP is one of our greatest weapons in winning the war against HIV."

PrEP user Octavia Wheeler spoke of the struggle to find the drug and use it daily, but called it "literally a life-saving drug."

"Because of PrEP, I did not have to worry about a positive diagnosis," she said.

In 2017, Brooklyn saw over 600 new HIV diagnoses, the only borough that saw an increase. Crown Heights and Bedford-Stuyvesant were among the hardest hit.

"There's much more we need to do to make sure that every Brooklynite knows about PrEP," Wirth said.

https://mysocialgoodnews.com/brooklyn-borough-president-eric-l-adams-amida-care-and-national-black-leadership-commission-on-health-recognize-prep-aware-week/



## Brooklyn Borough President Eric L. Adams, Amida Care, and National Black Leadership Commission on Health Recognize PrEP Aware Week

Published October 24, 2019 | By Api Podder

Pre-exposure Prophylaxis is a Crucial Component of New York State's Blueprint to End the HIV/AIDS Epidemic by 2020



Press Release – BROOKLYN, NY (October 23, 2019) – On the afternoon of Wednesday, October 23rd, Brooklyn Borough President Eric L. Adams, Amida Care, and the National Black Leadership Commission on Health (NBLCH) gathered at Brooklyn Borough Hall with health care providers, advocates, and members of the community to support and promote PrEP Aware Week. The inaugural PrEP Aware Week, which runs from October 20 through October 26, has been organized by the New York State Department of Health's AIDS Institute to increase awareness and uptake of pre-exposure prophylaxis (PrEP).

"Brooklyn has become, unfortunately, the epicenter of not only the current crisis but also new infection rates. We want to be proactive in stopping the spread of AIDS and HIV by distributing information," said Brooklyn Borough President Eric L. Adams. "Solutions start with information and communication. In this borough alone, 30,000 of our neighbors are living with HIV, and we want to send a loud message that this does not have to be a death sentence. The conversation must start here."

PrEP is a game-changing pill that is highly effective in preventing HIV transmission when taken daily. New York State recently announced that the number of new HIV infections was down 11% from 2017 to 2018. Increasing PrEP usage can reduce that number even further and move us closer to ending the epidemic.

"Increasing the number of New Yorkers taking PrEP is one of our greatest weapons in winning the war against HIV. As New York's largest Medicaid Special Needs Health Plan, Amida Care has deep expertise in providing sexual health services, including our ground-breaking PrEP program. We're proud to join Borough President Adams, the National Black Leadership Commission on Health and the providers, community members, and advocates here today to support PrEP Aware Week. While PrEP usage is on the rise, it isn't reaching many who are at elevated risk for HIV, particularly in black and Latinx communities. That's why PrEP Aware Week is so important. We look forward to continuing to work to help reach the state's goal of having 30,000 New Yorkers using PrEP by the end of 2020," said Doug Wirth, President and CEO of Amida Care.

Brooklyn bears a disproportionate burden of the HIV epidemic, with more than 30,000 people living with HIV. In 2017, Brooklyn experienced 640 new HIV diagnoses, representing a 10.15% increase in new diagnoses from the previous year — making Brooklyn the only borough with an increase. Bedford-Stuyvesant and Crown Heights are among the hardest-hit neighborhoods citywide, accounting for a quarter of new diagnoses in the borough.

"It is important to point out that PrEP is for persons who are HIV-negative, in order for them to remain HIV-negative. HIV is still alive, and it is very much alive right here in the borough of Brooklyn," said C. Virigina Fields, President and CEO, National Black Leadership Commission on Health. "We're here because African Americans and Latinos are still disproportionately impacted. And, we are here because we want to get the message out –especially to these populations, who may have fear out of a lack of information about what PrEP is, what the costs are, and how it works – so that we can educate."

In New York, the largest proportion of Medicaid recipients taking PrEP are white men, despite the fact that in 2017, more than 78% of new HIV diagnoses were among people of color and people of trans experience. A recent Centers for Disease Control and Prevention report found that doctors are less likely to talk to black and Latinx men about PrEP.

"We find out, from taking surveys, that young people actually do know about PrEP. What they don't know about is how to walk into a doctor's office, how to feel comfortable, where to go for a place that is safe and how does this get paid for," said Dr. Jeffrey Birnbaum of SUNY Downstate Medical Center. "People do know about PrEP but making the connection between what they know and how to get in the door is where we have a lot of work to do."

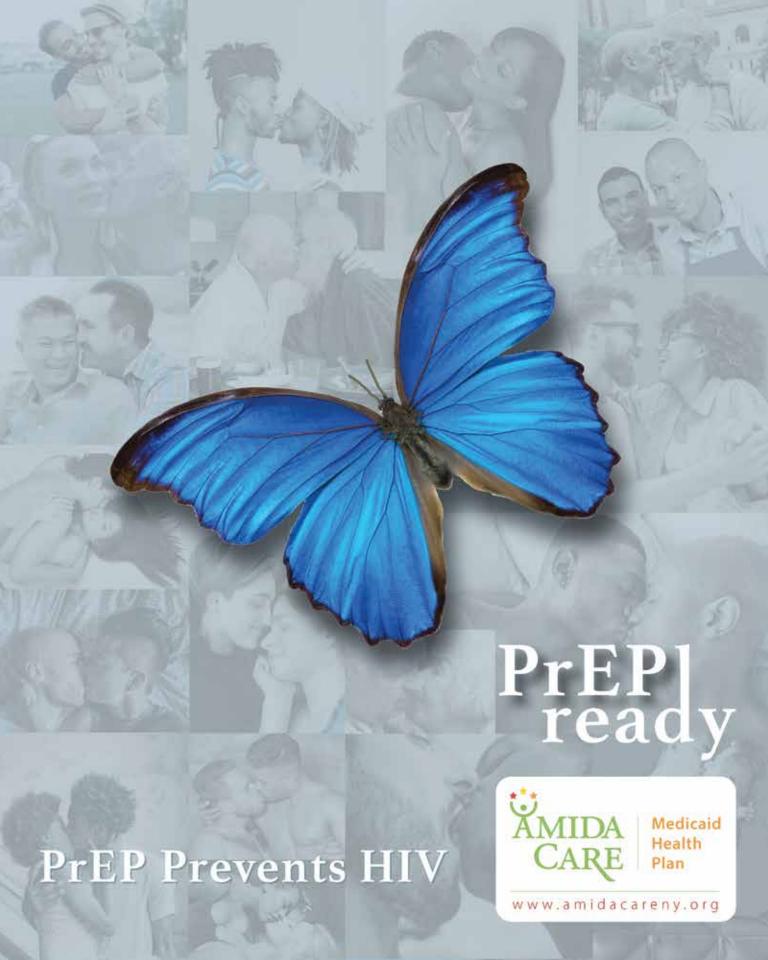
Octavia Leona Kohner, a Brooklyn community member who uses PrEP said, "PrEP radically changed my life for the better. I can live a vivid, vibrant life, but I still need support. Some of that comes from media and culture. Some of that comes from my family, chosen or otherwise. And, an essential part of that is health care. Hormones have enabled me to fully live in my body with joy. PrEP is equally important to me."

#### **About Amida Care**

Amida Care Inc. is a not-for-profit health plan that specializes in providing comprehensive health coverage and coordinated care to New Yorkers with complex conditions, including HIV and behavioral health disorders; and people who are of transgender experience or who are homeless, regardless of HIV status. Amida Care has a wide network of health care providers throughout New York City and is the largest Medicaid Special Needs Health Plan (SNP) in New York State. For more information, visit <a href="https://www.amidacareny.org">www.amidacareny.org</a>.

#### About the National Black Leadership Commission on Health

The National Black Leadership Commission on Health (NBLCH) champions the promotion of health and prevention of diseases to reduce disparities and achieve equity within the black community. Founded as the National Black Leadership Commission on AIDS, NBLCH now has an expanded focus that includes HIV/AIDS, Hepatitis C, cardiovascular disease, breast cancer, prostate cancer, sickle cell, diabetes and mental health. Championing black health through advocacy, policy and action is the main goal of the newly expanded organization.











# BE YOURSELF

The health plan for individuals

When you're part of the Amida Care community, you can be yourself. We see each member as a whole person, with physical, emotional, and social needs. We want to help you improve your health and live your most authentic, best life.



**1-855 GO-AMIDA** (1-855-462-6432) (TTY 711)

www.AmidaCareNY.org 🔞 🕑 🛗









# PrEP Helps End the HIV Epidemic!

**Welcome to our latest community publication – all about PrEP**. Taken as directed, this game-changing pill is 99% effective in preventing HIV. We invite everybody in our diverse communities to learn more about PrEP and educate others about its benefits.

Increasing the number of New Yorkers taking PrEP is one of our greatest weapons in winning the war against HIV/AIDS. Amida Care strongly advocates for **greater access to PrEP**, particularly among people in our Black and Latinx communities, who accounted for 78% of new HIV diagnoses in our state in 2017. There is less access to and uptake of PrEP in these communities, despite the fact that PrEP usage is on the rise overall. This gap in access must be addressed for New York to reach its goal of ending the HIV/AIDS epidemic.

We applaud Gov. Andrew Cuomo's mandate for statewide expansion of PrEP insurance coverage. Starting in 2020, New York State insurers must cover all PrEP treatment costs, including screenings and co-pays. This will help more people take control of their sexual health and could avert as much as \$1 billion in future state Medicaid costs spent treating HIV.

As we continue Amida Care's mission to provide comprehensive care for those living with HIV, let's get PrEP-ready and continue to partner with other community organizations and the New York State Department of Health to reach our goal of ending the epidemic.

- Doug Wirth, President and CEO, Amida Care









# What Is PrEP?

PrEP is a once-a-day pill that can lower the risk of getting HIV. Currently, two antiretroviral treatments are approved for PrEP: Truvada and Descovy.

#### **Truvada for PrEP**

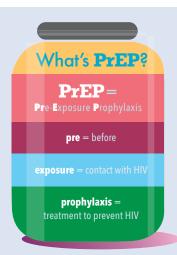
Truvada for PrEP has been available since 2012. When taken daily, Truvada has been shown to reduce the risk of HIV infection during sex by up to 99%. Truvada should be taken daily for at least one week to block transmission through anal sex, and for at least three weeks to block transmission through vaginal sex for women.\*

Among people who inject drugs, Truvada taken daily reduces the risk of getting HIV by up to 74%.

## **Descovy for PrEP**

Descovy for PrEP was approved in October 2019. Descovy works similarly and is as effective as Truvada, but has only been approved for people at risk for HIV from having receptive anal sex (being penetrated anally.) Descovy has NOT been approved for people at risk from vaginal sex. More research is needed to fully determine how effective Descovy is in preventing HIV infection during vaginal sex or from sharing needles.

\*Truvada has not been studied in trans women with neovaginas who are at risk for HIV from vaginal sex. A neovagina is a vagina constructed surgically.



# Where to Get PrEP

You can consult your doctor, primary care provider, or a sexual health clinic to get a prescription for PrEP, if it's appropriate for you.

To learn more about PrEP, to find out if it's right for you, or to find a doctor or provider that prescribes PrEP, visit **www.prepforsex. org** or text **GETPREP** to 69866 for personalized advice on PrEP.

For more information, go to our website at www.AmidaCareNY.org/our-plans/prep-pep/

# Is **PrEP** Right for YOU?

Talk to your doctor or health care provider about PrEP if you answer YES to ANY of these questions:

- Are you HIV-negative?
- Do you sometimes forget or choose not to use condoms for anal or vaginal sex?
- Are your sexual partners HIV-positive or of unknown status?



- Have you been diagnosed with sexually transmitted infections (STIs) in the past six months?
- Do you and/or your partner(s) exchange sex for money, housing, drugs, or other needs?
- Do you use intravenous drugs, even occasionally?
- Have you been on postexposure prophylaxis (PEP) in the past year?
- Are you trying to get pregnant with an HIV-positive partner?



# What **PrEP** Is Not:

**PrEP** does NOT protect you from other STIs;

PrEP is NOT a cure for HIV;

PrEP does NOT prevent pregnancy.





# **PrEP: What to Expect**

Getting on PrEP means visiting a doctor or health care provider, taking some lab tests, filling the prescription, and going to follow-up visits with your doctor every three months.

Remember, PrEP is MORE than just a prescription. PrEP is a program – and a key piece in the HIV prevention toolbox.



# At Your First PrEP Consultation

To assess your risk, your doctor will ask about your sex life and drug use. Talking about this could feel a bit uncomfortable, but it's necessary to determine your sexual health needs.

## Your doctor will test you for:

- HIV (to ensure that you're HIV-negative)
- Other sexually transmitted infections (STIs): gonorrhea, syphilis, chlamydia
- Hepatitis B
- Kidney function

# At Your Quarterly PrEP Check-Ups (Every Three Months)

## Your primary doctor will test you for:

- HIV (to check that you're still HIV-negative)
- Other STIs: gonorrhea, syphilis, chlamydia
- Kidney function



# The Importance of Adherence

 Truvada for PrEP is 99% effective when taken daily for anal or vaginal sex. For maximum protection, make sure not to skip a dose.

 Your body needs to build up a high enough concentration of HIV-fighting medication to keep you protected.
 These levels differ for anal and vaginal sex.
 For the greatest protection during anal sex,

For the greatest protection during anal sex, you need to have taken the pill every day for at least a week. For vaginal sex, you won't start being protected against HIV until you've taken Truvada daily for at least three weeks.





# **Peace of Mind**

Taking PrEP is a way to empower yourself. It provides more control over your sexual health and helps reduce stress and anxiety.

"I feel much more relaxed about sex now. Before PrEP, I would get so stressed out and panicky..."

- a young gay man from Callen-Lorde Community Health Center

# **PrEP:** Costs and Insurance Coverage

Medication, Doctor Visits, and Lab Tests

**Amida Care Prep Coverage**: Amida Care members receive 100% coverage for Prep. We offer counseling, education, and HIV risk assessment. If you are a member and have questions about taking Prep, contact your doctor or Amida Care Member Services at **1-800-556-0689**, TTY 711.

# **Medicaid/ Private Insurance**

Medicaid covers PrEP in New York State, and most private insurance plans cover part or all of the costs of taking PrEP.



#### No Health Insurance?

Through PrEP-AP, our state's PrEP Assistance Program, all uninsured or underinsured NY residents can apply for coverage of PrEP medication and other costs by calling 1-800-542-2437 or online at on.ny.gov/34yxKtR.

# Gilead's Advancing Access

If you need PrEP but lack insurance coverage, Gilead, the maker of Truvada and Descovy, offers a patient assistance program called Advancing Access. Go to www.gileadadvancing access.com or call 1-800-226-2056 Monday-Friday, 9 a.m.-8 p.m. EST.

"At first, we practiced safe sex using condoms while Sabastian spoke to his medical provider and got on PrEP. Since then, we've been trying to have children together, so we are both great examples of Undetectable = Untransmittable (U=U) and PrEP care."

-lailani, transgender woman, in mixed-status relationship

**-Lailani**, transgender woman, in mixed-status relationship with Sabastian, transgender man, both members of Amida Care





Taking PrEP **daily** to prevent HIV is the only dosing schedule currently approved by the U.S. Food and Drug Administration (FDA). The NYC Department of Health and other experts have also endorsed an alternative "on-demand" or intermittent approach to taking PrEP – but **only** for people who have receptive anal sex.

This on-demand dosing schedule calls for four pills a week, so it's sometimes called **2-1-1**. Here's how it works:

- Take two PrEP tablets 24 hours before sex. You can take the first dosage up to 2 hours before sex, but taking them closer to 24 hours is better.
- After sex and 24 hours after your first dose, take another tablet.
- Finally, 24 hours later, take one more PrEP tablet.

Follow this schedule every time you have sex.

If you have sex again before you finish this 2-1-1 PrEP-taking schedule, then you should take one PrEP tablet every 24 hours for 48 hours after your final sexual contact.

**If you already took PrEP at some point during the previous week**, then you should take just one tablet (instead of two) as your pre-exposure dose. Next, follow the rest of the on-demand dosing by taking one more PrEP tablet 24 hours later, then your final PrEP tablet after another 24 hours.

On-demand PrEP is endorsed only for people who have receptive anal sex and don't have sex that often — or those who would rather not or can't afford to take daily PrEP. This **2-1-1** dosing schedule should be followed carefully, **with guidance from your medical provider**.

On-demand PrEP has **not** been studied in people who inject drugs. Current research suggests that taking PrEP on this **2-1-1** schedule to prevent HIV from vaginal sex is **not** likely to be effective.



# What Is PEP?

PEP is a medication that can protect you if you take it after a known or suspected exposure to HIV. Like PrEP, PEP is an important tool in your sexual health toolbox. Made from a combination of anti-HIV medications, PEP can prevent you from getting HIV. You need a prescription from a doctor or health care provider to obtain PEP.

# Is **PEP** Right for YOU?

If you answer YES to any of these three questions, PEP may be right for you:



1 Did you have sex without a condom or did a condom break during sex with someone who is HIV-positive or whose HIV status you don't know?



3 Were you forced into sex against your will?



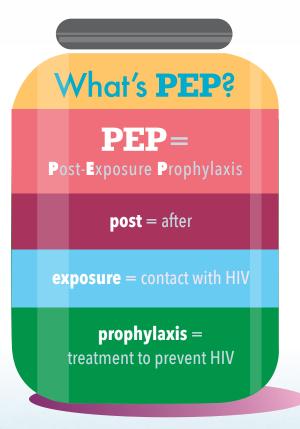
# How to Take **PEP**

If you know or suspect that you've just been exposed to HIV from sex or sharing needles, start taking PEP as soon as possible – and no later than 72 hours after possible exposure! PEP then must be taken every day for four weeks (28 days).



# Where to Get **PEP**

If you think you've just been exposed to HIV, call the NYC PEP Hotline at (844) 3-PEPNYC (844-373-7692) or go immediately to an emergency room or clinic and ask for PEP.



"As soon as I realized I could've been exposed to HIV, my friend told me about getting PEP, and that's why I'm here."

- a young gay man from Callen-Lorde Community Health Center

WHY DO I HAVE TO TEST FOR

**HEPATITIS B?** 

Before starting PrEP, it's important to get tested for Hepatitis B (Hep B) virus. That's because Truvada and Descovy work against Hep B, as well as HIV. For some people, these drugs may **not** be strong enough to control an active Hep B infection, so they could cause drug resistance.

If you test negative for Hep B, ask your doctor whether you should get vaccinated. There's no cure for Hep B, but **the vaccine can prevent it**.

If you test positive for active Hep B disease, ask your doctor to check on the health of your liver and prescribe the right treatment for you. If a person stops taking PrEP without realizing they also have Hep B, the Hep B virus could grow very quickly. Their liver could become dangerously inflamed.

You can still take PrEP if you have Hep B, but you need to work very closely with your doctor or medical providers to work out the best ways for you to start and stop taking PrEP.

THERE'S NO CURE FOR HEP B, BUT THE VACCINE CAN PREVENT IT.



# Gay and Bisexual Men: PrEP Use

Although PrEP use in the United States has increased among gay and bisexual men at risk for HIV, greater PrEP awareness and access is needed. This need is especially true for Black and Latino men. Research shows their communities are hardest hit by new HIV diagnoses, yet PrEP awareness and use is lower than among Whites.

"My partner has HIV, so taking PrEP helps me manage my anxiety. I'm doing what I can to protect myself from HIV..."

- Raoul, young, gay Latino, Bronx

## **Highest Infection Rates**

The most recent U.S. data (2016) shows that the populations most affected by HIV are gay and bisexual men, with Blacks and Latinos in this community accounting for a disproportionately high number of new HIV diagnoses. This population experiences homophobia, stigma, and lack of access to care that can increase risk behaviors and pose barriers to getting HIV prevention services.

#### Social Issues

Creating culturally appropriate programs that increase PrEP awareness and use in this population, especially among Latinos and Blacks, will prevent the spread of HIV and foster wellness.

Gay and bisexual men experience homophobia, stigma, and lack of access to care that can increase risk behaviors and pose barriers to getting HIV prevention services.







# **Trans**

There is currently no known scientific reason why PrEP and hormone therapy cannot be taken at the same time.

## **Transgender Women**

Transgender women are disproportionately affected by HIV, with an estimated 14% diagnosed HIV-positive. PrEP and PEP are important tools to prevent more cases of HIV in this community.

Many transgender women are at risk for HIV through receptive anal sex (being penetrated anally). PrEP has been proven 99% effective in blocking HIV through anal sex, when taken









# Community

## **PrEP and Hormone Therapy**

While more research is needed on PrEP and hormone therapy, the Centers for Disease Control and Prevention (CDC) currently reports no known drug interactions between hormone therapy and the medicines contained in PrEP. Therefore, there is currently no known scientific reason why PrEP and hormone therapy cannot be taken at the same time.

If you are worried that PrEP will affect your hormone therapy, ask your doctor or health care provider to check your hormone levels.

People who use PrEP should see their doctor every three months for a follow-up visit that includes HIV testing and prescription refills. This medical appointment could be combined with check-ups on hormone therapy.

## **Neovaginas: More Research Needed**

In transgender women, the risk to those having neovaginal sex is unknown. A neovagina is constructed during gender-affirming surgery. More research is needed to determine the efficacy of PrEP for transgender women having sex vaginally.

"PrEP has helped me feel confident to be sexually active again. Now I feel less stressed about my sexual health" - trans woman, Bronx

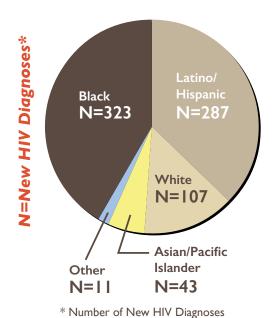


Trans men who have receptive anal or vaginal sex can also benefit from taking PrEP to lower their risks of HIV.



# PrEP for Youth More Access Is Needed

The latest available research from the NYC Department of Health shows that in 2017, new HIV diagnoses among Black and Latino males aged 13 to 29 were more than five times that of White males in their age group. Yet statistics show that most New Yorkers who take PrEP are White people. We must close this gap.



among Men 13 to 29 in NYC, 2017

### **Meeting Youth Where They Are**

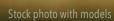
Organizations like NYC's **Ali Forney Center** (which annually serves 400+ LGBTQ homeless and runaway youths) provide PrEP and other HIV-risk reduction services at their on-site clinic. In addition to medications and careful monitoring, Ali Forney Center offers their young clients comprehensive support services including warm meals, MetroCards, therapists, job/school opportunities, safe shelter, and housing placement.

Without such services, PrEP adherence – taking the medication as prescribed and going to follow-up medical visits – is difficult, and clients are left vulnerable to HIV infection and drug resistance. To meet the pressing needs of our young Black and Latino gay and bisexual men at high risk, more supportive services are badly needed.

"My partner is HIVpositive. We talked about it and decided we'd both feel safer if I started PrEP. It works for us."

– a young Black gay man





**PrEP** for Black Women and Latinas

The most common way women get HIV is through sex with a male partner who has HIV. When taken daily for at least three weeks, Truvada for PrEP is 99% effective at preventing HIV from both vaginal and anal sex. That makes PrEP an important prevention strategy for women – one that doesn't depend on your sexual partners. You are in control!

## **A Greater Impact**

Black and Latina women in the United States get HIV at a lower rate than men, but they are impacted more heavily by HIV than White women. In 2017, 90% of all women who tested positive for HIV in NYC were Black or Latina.



# LOVE YOUR LIFE

## I'm PrEPed. Are you?

Learn about PrEP, a once-a-day pill that can help you stay HIV-negative.

Loveyourlife.org | 908.561.5057

funded in part by THE ROBERT | Silver | VIIV

# "I'm PrEPed. Are you?" New PrEP Campaign at Iris House

Iris House, the nation's first organization to provide services to Black women and Latinas affected by HIV/AIDS, has long been working to empower and support women with HIV. In August 2019, Iris House launched a new PrEP awareness campaign called "I'm PrEPed. Are you?" This campaign targets women in New Jersey communities, including Elizabeth, Plainfield, and Westfield.

"Using PrEP has definitely improved my sex life! I still use condoms with my partner, but I feel so much more relaxed and comfortable because I trust that PrEP is giving me an extra layer of protection, in case the condom breaks. Now I'm able to enjoy myself and my partner without worrying about getting HIV!" -Lucia, a client of Iris House



Amida Care makes the first move, contacting our members and starting conversations about PrEP and PEP. By taking an active role, we reduce stigma and take the burden off our members.

Our organization's innovative PrEP Program, a key element in Amida Care's HIV Prevention Services, was launched in January 2018. We are now working to screen all of our HIV-negative members and help them gain access to PrEP or PEP, if appropriate.

# Making It Easier for Members

Our program builds awareness of PrEP and PEP among Amida Care's members and staff. We make the first move, contacting our members and starting conversations about PrEP and PEP. By taking an active role, our team reduces stigma and takes the burden off our members.

Someone starting a conversation can really open doors, and help people to talk about their needs and desires.

# Expert Pharmacy Advice

Every Amida Care member who starts taking PrEP is contacted by our Pharmacy Department staff and provided with "first-fill" support.

This includes professional advice on proper dosage, adhering to treatment, possible side effects, prescription refills, and necessary follow-up, such as medical visits with lab tests every three months. If a member needs PEP, our team provides counseling and makes sure they can pick up their medication the same day it's prescribed.

#### **Advocacy**

When it comes to PrEP and PEP research, we advocate for more studies on the effectiveness of PrEP use in the trans community, especially by trans women of color and women with neovaginas (who have undergone gender-affirming surgery). We also note that more testing could be done with cis women and other groups, beyond the studies on cis men who have sex with men.

## The Future

# Educating members, staff, and health care providers

In the next year or so, Amida Care's PrEP Program plans to:

- host a PrEP summit and trainings for our providers, and
- train every Amida Care staff member on the benefits of PrEP and PEP.

#### New technologies

Talking about sex could be a little embarrassing for some. We are looking into new, improved methods and technologies like online self-assessments, so members will have more privacy when discussing sexual health.

For more information about our PrEP Program, call Member Services at 1-800-556-0689 (TTY 711) and go to our website at www.AmidaCareNY.org/our-plans/prep-pep/

# We offer



Counseling



**Education** 



HIV risk assessment

# We cover all PrEP-related needs



**Medications** 



Lab test fees



Follow-up medical appointments

# **Prep resources**

## In NewYork City

NYC SEXUAL HEALTH CLINICS – PrEP, PEP, and STI treatment. For locations and hours for all eight of NYC's low-to-no-cost Sexual Health Clinics, call 311 or go to on.nyc. gov/2PnkZy9.

COMMUNITY HEALTHCARE NETWORK
NYC – PrEP/PEP and sexual health
programs, via www.chnnyc.org or call
1-347-534-8424. Health centers in Bronx,
Brooklyn, Manhattan, and Queens, as well
as a mobile van.

CALLEN-LORDE Community Health
Centers – Comprehensive sexual health
care via www.callen-lorde.org, by calling
their PrEP/PEP specialists at 1-212-2717293, or visiting their walk-in clinics in
Manhattan or the Bronx.

HARLEM UNITED – Email prep@ harlemunited.org to contact PrEP navigators for more information or make an appointment. At www.harlemunited. org, view the PrEP Conversations video series and PrEP educational campaign called SWALLOW THIS.

HOUSING WORKS – Email BePrEPared@ housingworks.org or call 347-236-7925. HW's Community Healthcare PrEP Services offer patient education, comprehensive medical visit, help with insurance enrollment, and more.

MOUNT SINAI – Call 800-MD-SINAI (637-4624), go online at www.mountsinai.org, or visit locations of Mount Sinai Health System throughout New York City for their HIV/AIDS Services, Men's Sexual Health Project, walk-in HIV testing, and more.

#### For LGBTQ Youth

**ALI FORNEY CENTER** – PrEP/PEP counseling, housing, and other social services for homeless and runaway LGBTQ youth (ages 13-29). Go to **www.aliforneycenter.org** or call **1-212-206-0574**.

#### For Women and Families

IRIS HOUSE – HIV prevention (including PrEP counseling), support, and other services for women, families, and the underserved affected by HIV/AIDS, visit www.irishouse.org, or call 1-212-423-9049. Offices in Harlem and Plainfield, NJ.

#### For LGBTQ Elders (Over 50)

**SAGE** (Services & Advocacy for LGBTO Elders) – For PrEP seminars and their SAGEPositive Program, go to **www. sageusa.org**, email **info@sageusa.org** or call **1-212-741-2247**. Also offered: HIV and STI testing.

AMIDA CARE – For more resources and information on PrEP/PEP, if you belong to (or would like to join)
Amida Care, call Member Services at 1-800-556-0689 (TTY 711) and go to our website at www.AmidaCareNY.org/our-plans/prep-pep/



**Across New York State** 

To learn more about PrEP and to find a medical provider to prescribe PrEP near you, go to **www.prepforsex.org**.

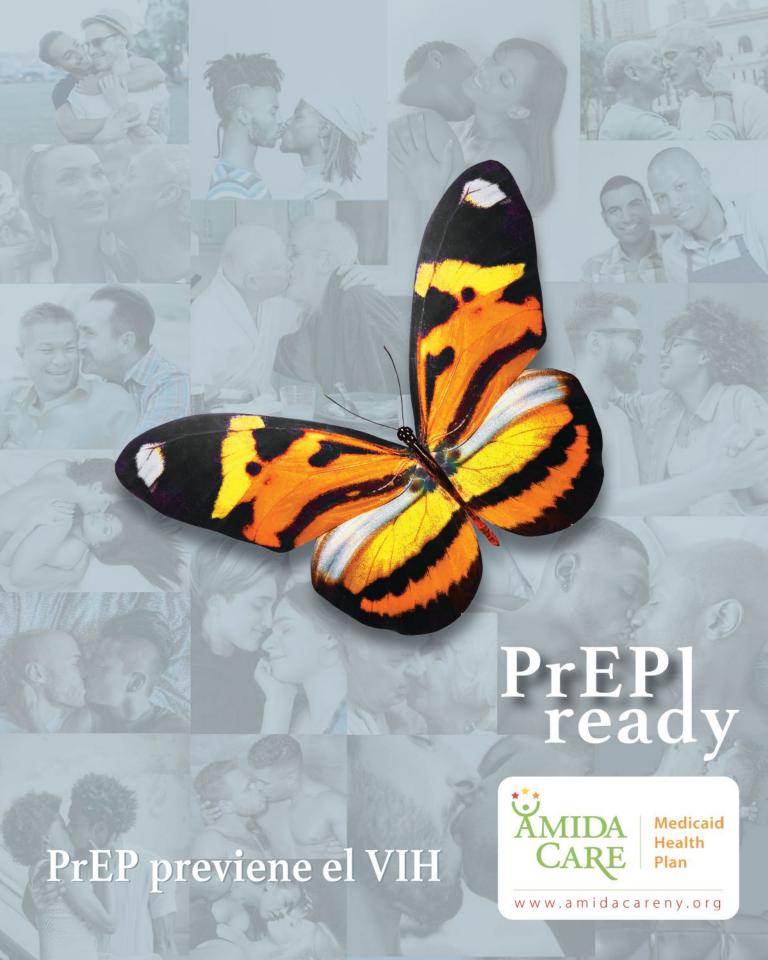
# Across the United States and U.S. territories

To access the National Prevention Information Network, a detailed online directory of PrEP providers nationwide, go to: **npin.cdc.gov/preplocator**.





20 Stock photo with models











# SÉ TÚ MISMA

El plan de salud para individuos

Como miembro de la comunidad de Amida Care, puedes ser tú misma/o. Nosotros vemos a cada socio como personas completas, con necesidades físicas, mentales, emocionales y sociales que deben ser atendidas para mejorar su salud y vivir una vida más auténtica y mejor.



1-855 GO-AMIDA (1-855-462-6432) (TTY 711)

www.AmidaCareNY.org 🖪 📵









# PrEP ayuda a acabar la epidemia del VIH!

**Bienvenidos a nuestra más reciente publicación comunitaria:** todo sobre PrEP. Esta píldora cambia el juego y es 99% efectiva en la prevención del VIH, cuando se toma según se indica. Invitamos a todos en nuestras diversas comunidades, a conocer más sobre PrEP y educar a otros sobre sus beneficios.

Una de nuestras mejores armas para ganar la guerra contra el VIH/SIDA, es aumentar el número de neoyorquinos que toman PrEP. Amida Care aboga firmemente por **un mayor acceso a PrEP**, particularmente entre las personas en nuestras comunidades negras y latinas, que representaron el 78% de los nuevos diagnósticos del VIH en nuestro estado, en 2017. Hay menos acceso y aceptación de PrEP en estas comunidades, pese al hecho de que el uso de PrEP está en aumento en general. Esta brecha en el acceso debe abordarse para que Nueva York alcance su objetivo de acabar la epidemia del VIH/SIDA.

Aplaudimos el mandato del gobernador Andrew Cuomo para la expansión estatal de la cobertura de seguro para PrEP. A partir del año 2020, las aseguradoras del Estado de Nueva York deberán cubrir todos los costos del tratamiento de PrEP, incluyendo pruebas de diagnóstico y los copagos. Esto ayudará a que más personas tomen el control de su salud sexual y podría evitar hasta \$1000 millones en gastos futuros estatales de Medicaid, por costos para tratar el VIH.

A medida que continuamos la misión de Amida Care de brindar atención integral a las personas que viven con el VIH, preparémonos con PrEP y continuemos colaborando con otras organizaciones comunitarias y el Departamento de Salud del Estado de Nueva York, para alcanzar nuestro objetivo de acabar la epidemia.

- **Doug Wirth**, Presidente y CEO, Amida Care









## ¿Qué es PrEP?

PrEP (siglas en ingles) es una píldora que se toma una vez al día, que puede reducir el riesgo de contraer el VIH. Actualmente, dos tratamientos antirretrovirales están aprobados para la PrEP: Truvada y Descovy.

#### Truvada para PrEP

Truvada para PrEP ha estado disponible desde el año 2012. Cuando se toma diariamente, Truvada demostró que reduce el riesgo de infección por VIH durante el sexo, hasta en un 99 por ciento. Truvada debe tomarse diariamente por al menos una semana para bloquear la transmisión a través del sexo anal, y durante al menos tres semanas para bloquear la transmisión a través del sexo vaginal para la mujer.\*

Entre las personas que se inyectan drogas, Truvada tomada diariamente, reduce el riesgo de contraer el VIH hasta en un 74%.

#### **Descovy para PrEP**

Descovy para PrEP acaba de ser aprobada en octubre de 2019. Descovy trabaja de manera similar y es tan efectiva como Truvada, pero sólo fue aprobada para personas en riesgo de contraer el VIH teniendo sexo anal receptivo. Descovy NO fue aprobada para personas en riesgo de sexo vaginal. Se necesita más investigación para determinar completamente qué tan efectiva es Descovy para prevenir la infección por VIH durante el sexo vaginal o cuando se comparten agujas.

★Truvada no ha sido estudiada en mujeres trans con neovaginas que están en riesgo de contraer el VIH a través del sexo vaginal. Una neovagina es una vagina construida quirúrgicamente.



### Donde conseguir **PrEP**

Puedes consultar a tu médico, proveedor de atención primaria, o una clínica de salud sexual para obtener una receta de PrEP, si es apropiado para tí.

Para obtener más información sobre PrEP, y averiguar si es adecuada para tí, o para encontrar un médico o proveedor que recete PrEP, visita **www.prepforsex.org** o envía un mensaje de texto al 69866 con el mensaje **GETPREP** para obtener asesoramiento personalizado sobre PrEP.

Para obtener más información, visita www.AmidaCareNY.org/our-plans/prep-pep/

## ¿Es **PrEP** bueno para Tí?

Habla con tu doctor sobre PrEP si respondes SÍ a CUALQUIERA de estas preguntas:

- ¿Eres VIH negativo/a?
- ¿A veces olvidas o eliges no usar condones para sexo anal o vaginal?
- ¿Son tus parejas sexuales VIH positivas o de estado desconocido?



- ¿Te han diagnosticado infecciones o enfermedades de transmisión sexual en los últimos seis meses?
- ¿Tú y/o tu(s) pareja(s) intercambian sexo por dinero, vivienda, drogas u otras necesidades?
- ¿Usas drogas intravenosas, incluso ocasionalmente?
- Has estado en PEP en el último año?
- ¿Estás tratando de quedar embarazada de un compañero VIH positivo?
- ¿Tu pareja te ha amenazado o forzado para que tengas sexo contra tu voluntad?

Lo que No es PrEP:

PrEP NO protege de otras infecciones de transmisión sexual (ITS);

PrEP NO es una cura para el VIH;

PrEP NO previene el embarazo.





## PrEP: Qué Esperar

Empezar a tomar PrEP significa visitar a un médico o proveedor de atención médica, hacerte algunas pruebas de laboratorio, obtener la receta y visitas de seguimiento con tu médico cada 3 meses.

Recuerda, PrEP es MÁS que sólo una receta. PrEP es un programa - y una pieza clave en la caja de herramientas de prevención del VIH.



## En tu primera consulta de PrEP

Para evaluar tu riesgo, tu médico te preguntará sobre tu vida sexual y el uso de drogas. Hablar sobre esto podría ser un poco incómodo, pero es necesario determinar tus necesidades de salud sexual.

#### Tu médico te examinará para:

- VIH (para asegurarse de que eres VIH negativa/o)
- Otras ITS (infecciones de transmisión sexual): gonorrea, sífilis, clamidia
- Hepatitis B
- Función renal.

#### En tus visitas trimestrales de PrEP (cada 3 meses)

#### Tu médico te examinará para:

- VIH (para asegurarse de que sigues siendo VIH negativo/a)
- Otras ITS: gonorrea, sífilis, clamidia
- Función renal.



## La importancia de la adherencia

 Truvada como PrEP es 99% efectiva al tomarse diariamente cuando se practica sexo anal o vaginal. Para máxima protección, asegúrate de no omitir una dosis.

 Tu cuerpo necesita acumular una concentración suficientemente alta del medicamento contra el VIH para mantenerte protegido/a. Estos niveles difieren para el sexo anal y vaginal. Para la mayor protección durante el sexo anal, necesitas tomar la píldora todos los días por al menos una semana. Para el sexo vaginal, tú no estarás protegida/o contra el VIH hasta haber tomado Truvada diariamente durante al menos 3 semanas.





### **Tranquilidad**

Tomar PrEP es una forma de empoderarte a tí mismo. Proporciona más control. sobre tu salud sexual, ayuda a reducir el estrés y la ansiedad.

"Ahora me siento mucho más relajado sobre el sexo. Antes de PrEP, me ponía muy estresado y en pánico..."

– jóven gay, cliente de Callen-Lorde Community Health Center

## PrEP: Costos y Cobertura de Seguro Médico

#### Medicamento, Visitas Médicas y Laboratorios

**Cobertura PrEP de Amida Care**: Los socios de Amida Care reciben cobertura 100% para PrEP. Ofrecemos asesoramiento, educación y evaluación de riesgo de VIH. Si tienes preguntas acerca de tomar PrEP, contacta a tu médico o Servicios para Socios de Amida Care, 1-800-556-0689, TTY 711.

#### Medicaid/Seguro Médico Privado

Medicaid cubre PrEP en Nueva York y la mayoría de los planes privados de salud cubren parte o todos los costos de tomar PrEP.



#### ¿No Tienes Plan Médico?

A través de PrEP-AP, el Programa de Asistencia de PrEP del estado, todo residente de NY sin seguro o con seguro insuficiente puede solicitar cobertura de medicación de PrEP y otros costos llamando al 1-800-542-2437 o en línea en on.ny.gov/34yxKtR.

#### **Advancing Access de Gilead**

Si necesitas PrEP pero no tienes cobertura de salud, Gilead, el fabricante de Truvada y Descovy, ofrece un programa de asistencia al paciente llamado "Advancing Access". Visita www. gileadadvancingaccess.com o llama al 1-800-226-2056, lunes a viernes, 9am-8pm EST.

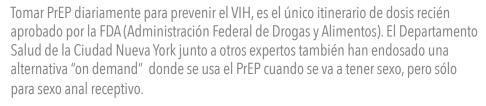
"Al principio, practicábamos sexo seguro usando condones mientras Sabastián consultaba con su proveedor de cuidado médico y comenzó a tomar PrEP. Desde entonces, hemos estado tratando de tener hijos juntos, así que somos un gran ejemplo del cuidado de salud PrEP y de Indetectable = Intransmisible (I=I)" -Lailani, mujer transgénero en una relación de estatus del VIH mixto

con Sabastian, un hombre transgénero, ambos socios de Amida Care.



Fotos de archivo con modelos

# Dosis de PrEP "On Demand"



Este itinerario de dosificación "on demand" exige tomar cuatro pastillas por semana, por lo cual a veces se conoce como **2-1-1.** 

#### Así es como funciona:

- Toma dos tabletas de PrEP 24 horas antes del sexo. Puede tomar la primera dosis hasta 2 horas antes del sexo, pero es mejor tomarlas más cerca de las 24 horas.
- Luego del sexo y 24 horas después de tu primera dosis, toma otra tableta
- Finalmente, 24 horas después, toma una tableta PrEP más.

Sique este itinerario cada vez que tenga relaciones sexuales.

**Si vuelves a tener sexo antes de terminar este enfoque PrEP 2-1-1.** Entonces deberás tomar una tableta de PrEP cada 24 horas por 48 horas, luego de tu último contacto sexual.

#### Si ya tomaste PrEP en algún momento durante la semana anterior.

Entonces deberás tomar sólo una tableta (en lugar de dos) como tu dosis previa al sexo. Luego, continúa la dosis "on demand" tomando otra tableta PrEP 24 horas después del sexo, y luego tu tableta PrEP final después de las siguientes 24 horas.

La PrEP "on demand" es endosada sólo para personas que tienen sexo anal receptivo y que no tienen relaciones sexuales con tanta frecuencia, y que prefieren, o no pueden tomar PrEP a diario. Esta dosis 2-1-1 debe seguirse cuidadosamente, con la orientación de tu médico.

La PrEP "on demand" no ha sido estudiada en personas que se inyectan drogas. La investigación actual sugiere que tomar PrEP en esta dosis con itinerario **2-1-1** para prevenir el VIH en sexo vaginal, pudiese no ser efectivo.

9

## ¿Qué es PEP?

PEP (siglas en ingles) es un tratamiento que puede protegerte del VIH si lo tomas después de exponerte al virus, o sospechar que has estado expuesto. Igual que PrEP, PEP es un instrumento importante en tu caja de herramientas para la salud sexual. Compuesto por una combinación de medicamentos anti-VIH, PEP puede prevenir que contraigas el VIH. Para obtener PEP necesitas la receta de un médico o proveedor de cuidado de salud.

### ¿Es **PEP** Bueno Para Tí?

Si respondes SÍ a cualquiera de estas tres reguntas, PEP podría ser adecuada para tí:



Tuviste sexo sin condón o se rompió el condón durante el sexo con alguien que es VIH-positivo o cuyo estatus del VIH no conoces?



3 ¿Fuiste forzado a tener sexo contra tu voluntad?



### Cómo Tomar PEP

¡Si sabes o sospechas que has estado expuesto/a al VIH a través del sexo o compartiendo agujas, comienza a tomar PEP lo antes posible - y no a más tardar de 72 horas! Entonces, tienes que tomar PEP todos los días por cuatro semanas (28 días).



## Dónde conseguir **PEP**

Si crees que acabas de estar expuesta/o al VIH, llama a la **Línea Informativa del PEP** en NYC al **(844) 3-PEPNYC (844-373-7692)** o acude inmediatamente a una sala de emergencias o clínica, y pide PEP.

### ¿Qué es PEP?

PEP del inglés
Post-Exposure Prophylaxis =
profilaxis post exposición

post = despues

**exposición** = contacto con HIV

profilaxis = tratamiento para prevenir el VIH

"Tan pronto me di cuenta de que pude estar expuesto al VIH, mi amigo me dijo acerca de tomar PEP, y por eso estoy aquí"

- joven gay, cliente Callen-Lorde Community Health Center

¿POR QUÉ TENGO QUE HACERME LA PRUEBA DE LA

**HEPATITIS B?** 

Antes de comenzar PrEP, es importante hacerte la prueba de Hepatitis B (Hep B). Esto es porque Truvada y Descovy trabajan contra la Hepatitis B, al igual que contra el VIH. Para algunas personas, estas drogas podrían no ser lo suficientemente fuertes como para controlar una infección activa de Hep B, así que podrían causar resistencia a los medicamentos.

Si tu prueba de Hepatitis B es negativa, pregúntale a tu médico si debes vacunarte. No existe cura para la Hepatitis B, pero **la vacuna puede prevenirla**.

Si tu resultado es positivo para la enfermedad activa de la Hepatitis B, pide a tu médico que verifique la salud de tu hígado y que recete el tratamiento adecuado para tí. Si una persona deja de tomar PrEP mientras que también tiene una infección por Hep B sin diagnosticar, el virus de la Hepatitis B podría replicarse muy rápidamente y tu hígado podría inflamarse peligrosamente.

Puedes tomar PrEP si tienes Hepatitis B, pero debes trabajar muy de cerca con tu médico o proveedores médicos, para identificar las mejores formas para comenzar y dejar de tomar PrEP.

NO HAY CURA PARA LA HEPATITIS B, PERO LA VACUNA PUEDE PREVENIRLA.



## Hombres gay y bisexuales: Uso de PrEP

Aunque el uso de PrEP en los Estados Unidos ha aumentado entre hombres gays y bisexuales en riesgo de contraer el VIH, se necesita una mayor concientización y acceso a PrEP. Esta necesidad es especialmente grande entre los hombres negros y latinos. Los estudios demuestran que estas comunidades son las más fuertemente afectadas por nuevos diagnósticos del VIH, sin embargo, el conocimiento sobre PrEP y su uso es menor que entre los Blancos.

"Mi pareja tiene VIH, así que tomar PrEP me ayuda a manejar la ansiedad. Estoy haciendo lo que puedo para protegerme del VIH.."

- Raoul, joven, gay Latino, Bronx

#### Las tasas más altas de infección

Los datos más recientes de Estados Unidos (2016) demuestran que las poblaciones más afectadas por el VIH son los hombres gay y bisexuales, donde los negros y latinos en esta comunidad representan un número desproporcionalmente alto de nuevos diagnósticos del HIV. Esta población experimenta homofobia, estigma y falta de acceso a la atención de salud, lo que podría aumentar los comportamientos de riesgo y presentar barreras para conseguir los servicios de prevención del VIH.

#### **Asuntos sociales**

La creación de programas culturalmente apropiados que aumenten el entendimiento y el uso de PrEP en esta población, especialmente entre los latinos y los negros, evitaría la propagación del VIH y fomentaría el bienestar.

Hombres gay y bisexuales experimentan homofobia, estigma y falta de acceso a la atención de salud, lo que podría aumentar los comportamientos de riesgo y presentar barreras para conseguir los servicios de prevención del VIH.













## **Comunidad Trans**

#### PrEP y la terapia hormonal

Si bien se necesita más investigación sobre PrEP y la terapia hormonal, la CDC (Centro para el Control y Prevención de Enfermedades) actualmente informa que no se conocen interacciones farmacológicas entre la terapia hormonal y los medicamentos contenidos en la PrEP. Por lo tanto, no se conoce ninguna razón científica por la cual actualmente la PrEP y la terapia hormonal, no se puedan tomar al mismo tiempo.

Si te preocupa que la PrEP afecte tu terapia hormonal, pide a tu médico o proveedor de atención médica que verifique tus niveles hormonales.

Las personas que toman PrEP deben visitar a su médico cada tres meses para un chequeo de seguimiento que incluya la prueba del VIH y reabastecimiento de los medicamentos. Estas citas médicas pueden ser combinadas con chequeos a tu terapia hormonal.

#### Neovaginas: Se necesita más investigación

En las mujeres transgénero, se desconoce el riesgo para quienes tienen relaciones sexuales neovaginales. Una neovagina es construida durante una cirugía de afirmación de género. Se necesita más investigación para determinar la eficacia de la PrEP para mujeres transgénero que tienen sexo vaginalmente.

"PrEP me ha ayudado a sentir la confianza para estar sexualmente activa otra vez. Ahora me siento menos estresada sobre mi salud sexual"

– mujer trans, Bronx



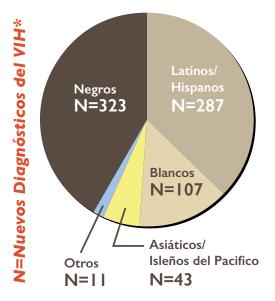
Los hombres transgénero que tienen sexo anal o vaginal receptivo también

pueden beneficiarse de tomar la PrEP para reducir su riesgo del VIH.



## PrEP para la Juventud Más acceso es necesario

Los últimas investigaciones disponibles del Departamento de Salud de la Ciudad de Nueva York demuestran que los nuevos diagnósticos del VIH en hombres negros y latinos entre las edades de 13 a 29 años en 2017 fueron más de 5 veces que la cantidad de hombres blancos dentro de ese mismo grupo. Aún así, las estadísticas demuestran que la mayoría de los neoyorquinos que toman PrEP son blancos. Debemos cerrar esta brecha.



\* Número de nuevos diagnósticos del VIH entre hombres de 13 a 29 años en Nueva York, 2017

#### Encontrando a los jóvenes en donde estén

Organizaciones como el **Ali Forney Center** de la Ciudad de Nueva York (que sirve anualmente a más de 400 jóvenes LGBTQ sin hogar y fugados) proporcionan PrEP y otros servicios de reducción de riesgo del VIH, en las clínicas ubicadas en sus oficinas. Además de medicamentos y monitoreo cuidadoso, el Ali Forney Center ofrece servicios completos de apoyo a sus clientes jóvenes, lo cual incluye comidas calientes, MetroCards, terapeutas, oportunidades de estudio y trabajo, albergue seguro y ubicación en viviendas.

Sin tales servicios, la adherencia al PrEP (tomar el medicamento según recetado e ir a visitas médicas de seguimiento) sería muy difícil, y los clientes quedarían vulnerables a infectarse con VIH y la resistencia a los medicamentos. Para llenar las necesidades apremiantes de nuestros hombres jóvenes, homosexuales y bisexuales, negros y latinos en alto riesgo, se necesitan urgentemente más servicios de apoyo.

"Mi compañero es VIH positivo. Hablamos sobre eso y decidimos que ambos nos sentiríamos más seguros si yo comienzo con PrEP. Funciona para nosotros"

- joven afroamericano gay



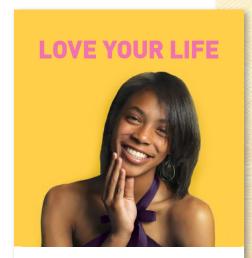
**PrEP** para Mujeres Negras y Latinas

La forma más común en que las mujeres contraen el VIH es a través del sexo con un compañero masculino con VIH. La PrEP es 99% efectiva para prevenir el VIH tanto con el sexo vaginal, como con el anal, cuando se toma diariamente por al menos tres semanas. Esto hace de PrEP una estrategia de prevención importante para las mujeres y es una que no depende de sus parejas sexuales. ¡Tú estás en control!

#### **Un gran impacto**

Las mujeres negras y latinas en los Estados Unidos se infectan con VIH en una tasa más baja que los hombres, pero son impactadas más fuertemente por el VIH que las mujeres blancas. En 2017, en la Cuidad de NY el 90% de todas las mujeres que dieron positivo al VIH eran negras o latinas.





#### I'm PrEPed. Are you?

**Learn about PrEP**, a once-a-day pill that can help you stay HIV-negative.

loveyourlife.org | 908.561.5057

funded in part by THE ROBERT | 1 VIIV

## "Estoy en PrEP. ¿Y tú?" Nueva campaña de PrEP en Iris House

Iris House, la primera organización de la nación en proporcionar servicios a mujeres negras y latinas afectadas por el VIH/SIDA, lleva mucho tiempo trabajando para empoderar y apoyar a las mujeres con VIH. Con oficinas en Harlem y Plainfield, NJ, Iris House se mantiene a la vanguardia promoviendo PrEP y PEP para mujeres, para ayudar a acabar la epidemia.

En agosto del 2019, Iris House lanzó una nueva campaña de orientación pública sobre la PrEP llamada "Estoy en PrEP. ¿Y tú?". Esta campaña está dirigida a mujeres en las comunidades de Nueva Jersey, incluyendo Elizabeth, Plainfield y Westfield.

"¡Usar PrEP definitivamente ha mejorado mi vida sexual! Todavía uso condones con mi pareja, pero me siento mucho más relajada y cómoda porque confío en que PrEP me está dando una capa de protección extra, en caso de que el condón se rompa. Ahora puedo disfrutar de mí y de mi compañero, sin preocuparme por contraer el VIH!"

—Lucia, clienta de PrEP por Iris House



Linnovador programa PrEP de nuestra organización, un elemento clave en el servicio de Amida Care para la prevención del VIH, fue lanzado en enero de 2018. Ahora trabajamos para realizar la prueba del VIH a todos nuestros socios VIH negativos, para ayudarlos a tener acceso a PrEP o PEP, según corresponda.

#### Más Fácil para los Socios

Nuestro programa crea conciencia sobre PrEP y PEP entre los socios y el personal de Amida Care. Hacemos nuestro primer acercamiento llamando a nuestros socios e iniciando conversaciones sobre PrEP y PEP. Tomando un papel activo, logramos reducir el estigma y hacer sentir más comodos a nuestros socios. Cuando se comienza una conversación honesta, se abren puertas que pueden ayudar a las personas a hablar sobre sus necesidades y deseos.

#### Asesoramiento Experto en Farmacia

Todos los socios de Amida Care que comienzan a tomar PrEP son contactados por nuestro personal del Departamento de Farmacia, y provistos con asesoramiento para su "primer abastecimiento".

Esto incluye asesoramiento profesional sobre la dosis adecuada, adherirse al tratamiento, posibles efectos secundarios, reabastecimientos de recetas y seguimiento necesario, como visitas médicas con pruebas de laboratorio cada tres meses.

Hacemos nuestro primer acercamiento a nuestros socios e iniciando conversaciones sobre PrEP y PEP. Tomando un papel activo, logramos reducir el estigma y hacer sentir más comodos a nuestros socios.

Si un socio necesita PEP, nosotros proporcionamos asesoramiento y nos aseguramos de que pueda recoger su medicamento el mismo día en que se lo recetaron.

#### Activismo

Cuando se trata de investigación médica sobre PrEP y PEP, abogamos por más estudios sobre la efectividad del uso de PrEP en la comunidad trans, especialmente por mujeres trans de color y mujeres con "neovaginas" (que han sido sometidas a cirugía de afirmación de género). También notamos que se podrían hacer más pruebas con mujeres cis y de otros grupos, más allá de los estudios en hombres cis que tienen sexo con hombres.

#### El Futuro

Educando a socios, proveedores y trabajadores de servicios de salud

Para el próximo año el Programa PrEP de Amida Care planea:

- organizar una cumbre de PrEP y capacitaciones para nuestros proveedores, y
- capacitar a todo nuestro personal sobre los beneficios de PrEP v PEP.

#### Nuevas tecnologías

Hablar sobre relaciones sexuales podría ser un poco vergonzoso para algunos. Estamos buscando nuevos y mejores métodos y tecnologías, como autoevaluaciones a través del Internet, de modo que los socios tengan más privacidad al momento de hablar sobre la salud sexual

Para más información sobre nuestro Programa de PrEP, llama a Servicios para Socios al **1-800-556-0689 (TTY 711)** o visita nuestro portal **www.AmidaCareNY.org/our-plans/prep-pep/** 

#### **Ofrecemos**



Consejería



Educación



Evaluación de riesgo del VIH

## Cubrimos todas las necesidades relacionadas al PrEP



Medicamentos



Cuotas de pruebas de laboratorio



Citas médicas de seguimiento

### **RECURSOS de PrEP**

#### En la Ciudad de Nueva York

#### CLÍNICAS DE SALUD SEXUAL DE NYC -

Tratamiento de PrEP, PEP, e ITS (infecciones de transmisón sexual). Para horarios y localidades de las ocho Clínicas de Salud Sexual, con servicios gratis o a bajo costo, llama al 311 o visita el portal **on.nyc.gov/2PnkZy9**.

RED COMUNITARIA PARA EL CUIDADO DE SALUD NYC – Programas de PrEP/PEP y salud sexual, a través de www.chnnyc.org o llamando al 1-347-534-8424. Hay centros de salud en El Bronx, Brooklyn, Manhattan y Queens, y también una unidad móvil.

Centros Comunitarios de Salud CALLEN-LORDE – Cuidado de salud sexual completo a través de www.callen-lorde.org, llamando a sus especialistas de PrEP/PEP al 1-212-271-7293, o visitando sus clínicas que atienden sin citas previas en Manhattan o El Bronx. HARLEM UNITED – Envía un correo electrónico a prep@harlemunited.org para comunicarse con los navegadores de PrEP para obtener más información o concertar una cita. En www. harlemunited.org, ve la serie de videos de conversaciones de PrEP y la campaña educativa de PrEP llamada SWALLOW THIS.

HOUSING WORKS – envae un correo electrónico a BePrEPared@housingworks. org o llame al 347-236-7925. Los servicios de PrEP de atención médica comunitaria de HW ofrecen educación al paciente, visitas médicas integrales, ayuda con la inscripción al seguro y más.

MOUNT SINAI – Llama al 800-MD-SINAI (637-4624), ingrese en línea en www. mountsinai.org, o visite las ubicaciones del Sistema de Salud Mount Sinai en toda la ciudad de Nueva York para obtener sus servicios de VIH / SIDA, Proyecto de Salud Sexual para Hombres, pruebas de VIH y más.

#### Para jóvenes LGBTQ

CENTRO ALI FORNEY – Orientación sobre PrEP/PEP, vivienda y otros servicios sociales para los jóvenes LGBTQ (13 a 29 años de edad) que no tienen hogar o que se han fugado de sus hogares: visita www.aliforneycenter.org o llama al 1-212-206-0574.

#### Para mujeres y familias

IRIS HOUSE – Prevención del VIH (incluyendo orientación sobre PrEP), apoyo y otros servicios para la mujer, familias y las personas marginadas que son afectadas por el VIH/SIDA. Visita www.irishouse.org, o llama al 1-212-423-9049. Oficinas en Harlem y Plainfield, NJ.

#### Para los LGBTQ mayores (más de 50 años)

SAGE (Servicios y Defensa para las Personas Mayores LGBTQ, por sus siglas en inglés) – Para seminarios acerca de PrEP y su programa SAGEPositive, visita www.sageusa.org, escribe al correo electrónico info@sageusa.org o llama al 1-212-741-2247. También se ofrecen pruebas de diagnóstico del VIH e infecciones de transmisión sexual (ITS).

AMIDA CARE – Para más recursos e información sobre PrEP/PEP, si eres socio de Amida Care (o quisieras unirte como socio), llama a Servicios para Socios al 1-800-556-0689 (TTY 711) o visita nuestro portal www.AmidaCareNY.org/our-plans/prep-pep/





#### **Estado de Nueva York**

Para conocer más sobre PrEP y encontrar a un proveedor de cuidado médico que recete PrEP cerca de ti, visita **www.prepforsex.org**.

#### **Estados Unidos y sus territorios**

Para tener acceso a la Red Nacional de Información para la Prevención, un directorio detallado de todos los proveedores de PrEP a nivel nacional, visita: **npin.cdc.gov/preplocator**.









## Testimony of Planned Parenthood of New York City Before The New York City Council Committee on Health and Committee on Hospitals Regarding Efforts in New York City to Prevent HIV and Hepatitis Infections

December 9th, 2019

Good Morning. My name is Sarah Zuercher and I am a Nurse Practitioner and the Director of Mobile Health Services at Planned Parenthood of New York City. Thank you Committee Chairs Carlina Rivera and Mark Levine for holding this important oversight hearing to explore prevention measures to address the incidence of HIV/AIDS and Hepatitis in New York City.

Planned Parenthood of New York City (PPNYC) has been a leading provider of sexual and reproductive health services in New York City for more than 100 years, conducting over 90,000 patient visits per year. PPNYC provides a wide-range of sexual and reproductive health services. We are a trusted name in health care because of our commitment to comprehensive, inclusive care. With our Project Street Beat (PSB) mobile health center, PPNYC brings most of the services provided in our health centers to communities in the Bronx, Brooklyn, Northern Manhattan and Queens that face barriers accessing care in traditional settings. PSB services include sexually transmitted infection screening and treatment, Pre-Exposure Prophylaxis (PrEP), Post-Exposure Prophylaxis (PEP), clean syringe distribution and syringe disposal, narcan and overdose prevention counseling, birth control counseling, wellness exams, gynecologic care, health insurance enrollment, HIV testing and counseling and Hepatitis C screening and linkage to treatment. In addition to our mobile health center, PSB has two offices--one in the Bronx and one in Brooklyn-- from which staff provide resources and support to individuals that are at an increased risk for HIV or are living with HIV. These resources include individual case management, support groups, health care coordination, harm reduction counseling and linkage to PrEP navigators.

The PSB program is committed to centering the health care needs of people who face barriers to health care and are disproportionately impacted by health inequity including: black and latinx women, people who are unstably housed, young people navigating the health care system on their own for the first time, people who use drugs, people who are undocumented or have recently arrived in this country and LGBTQ people of color. We believe that in order to support patients, we must remove barriers to access including bringing health care directly to people in the community. This means acknowledging the totality of the patient's circumstances and understanding what measures can be taken to remove barriers including not requiring ID, providing free care and medication for uninsured individuals, providing sufficient medication during the visit to reduce the need for pharmacy navigation and providing care during hours outside of the traditional work day to allow for flexible scheduling.

PSB's services are a reflection of PPNYC's commitment to providing accessible care to all and providing the resources necessary to reduce the incidence of HIV and support individuals that are currently living with HIV.





#### **HIV and Hepatitis Interventions**

PPNYC recognizes the important measures the City Council is taking to prevent HIV and hepatitis infections with today's proposed legislation. However, we recommend a holistic approach and recognition of the realities and barriers New Yorkers face when accessing care. Our city's plan to prevent HIV and Hepatitis infections must center the health care needs of the people most marginalized by our healthcare system and by our society. We should respond to the real life reasons that people continue to get HIV and do more to make PrEP an easy and convenient HIV prevention option for people who have the most complex circumstances that place them at risk.

Recently, the United States Preventative Task Force's draft gave PrEP an "A" grade, which will help make PrEP more accessible for many, especially those with private health insurance. However, we need to do more to ensure that PrEP is accessible to those who face the highest risk and the most significant barriers to care<sup>2</sup>. PrEP should be as easy to get as any routinely prescribed medication like birth control pills or antibiotics. But for people who are homelessness, have mental health issues, use substances, are undocumented, are under their parents insurance and worried about confideniality, and/or who do not have health insurance, the process of getting PrEP and staying on it can be incredibly difficult if not impossible.

The city should also fund health care providers to dispense PrEP/PEP medication. Navigating pharmacies is a barrier for many and for those without health insurance, the requirements for free services/ insurance enrollment are unfairly burdensome to certain populations like individuals who live or work on the street. The ability to get medication directly from a trusted health care provider cuts down the steps people have to take in order to start PrEP. Health insurance companies should also be required to reimburse providers who dispense PrEP directly to patients.

Additionally, the city should invest in safe consumption sites and do more to make substance use treatment available to all. Safe consumption sites are integral and can reduce harms associated with drug use like HIV and Hepatitis infections, overdose deaths, and use of substances in public<sup>3</sup>. These facilities offer clean needles and promote proper disposal of used needles, which greatly reduce the transmission of HIV and Hepatitis reduce the risk of bacterial infections. Safe consumption sites serve as an access point for continued care and a referral source for individual's needs.<sup>4</sup> The city should also require providers to adopt risk assessment tools to help determine the likelihood that an individual will be exposed to HIV or Hepatitis. PPNYC uses risk assessments to explore a person's history with substance use, intimate partner violence,

<sup>&</sup>lt;sup>1</sup>https://www.uspreventiveservicestaskforce.org/Page/Document/draft-recommendationstatement/prevention-of-human-immunodeficiency-virus-hiv-infection-pre-exposure-prophylaxis

<sup>&</sup>lt;sup>2</sup>https://www.nytimes.com/2018/11/20/well/live/hiv-aids-prevention-prep.html?smid=nytcore-ios-share

<sup>&</sup>lt;sup>3</sup> https://www.medpagetoday.com/hivaids/hivaids/75871

<sup>&</sup>lt;sup>4</sup> https://www.medpagetoday.com/hivaids/hivaids/75871



homelessness, and number of sexual partners. This assessment allows us to holistically address the specific needs of our patients and provide them with an array of care options.

### <u>Int 1808-2019: Examining the causes and conditions surrounding HIV/AIDS-related deaths in NYC</u>

PPNYC supports Int 1808-2019, which will require the Department of Health and Mental Hygiene (DOHMH) to conduct a study of all HIV/AIDS-related deaths in New York City between 2017 and 2019. Though there are extensive studies conducted on death among HIV positive individuals and the incidence and risk factors of HIV, there is very little data that is specific to New York City. In 2018, there were 1,917 new cases of HIV and 1,683 deaths among individuals that were HIV positive in New York City<sup>5</sup>. However, there is little data identifying common factors, risks or patterns that exist<sup>6</sup>. At PPNYC, we understand that New York City is unique and that the experiences of individuals living with HIV in New York City may not be reflected in national studies. Given this, we believe that it is extremely important for DOHMH to conduct a study to understand this population. Furthermore, we encourage the New York City Council and DOHMH to use the findings of the study to inform legislative and public health responses to ensure that we can continue to combat the HIV epidemic.

### Reso 0150-2018: FDA to remove any blood donation restrictions based on Sexual Orientation

During the 1980s, the United States Food and Drug Administration (FDA) implemented a ban on blood donations from men who had sex with men (MSM). This ban, which was implemented in 1985, was based on data that suggested that HIV incidence among MSM was higher than the general population. The ban was intended to be an emergency measure and precaution against contamination of the U.S. blood supply in the absence of adequate and accurate screening methods<sup>7</sup>. Despite recent advances in screening technology, the FDA continued to enforce a lifetime ban on MSM from donating blood until 2015, at which point they reduced the ban to a 12 month deferral beginning from the most recent sexual contact<sup>8</sup>. Though the change in policy is a step in the right direction, the current MSM blood donation deferral is based on outdated practices and perpetuates a stigma against LGBTQ individuals, while also limiting the sources of blood supply in the United States. PPNYC understands that the original ban and the recent deferral were developed as a safety measure, intended to safeguard the blood supply in the United States. However, we urge the FDA to reevaluate these requirements in light of recent technological advances.

Presently, the FDA takes a "Five Layers of Safety" approach, intended to minimize the risk of transmitting infectious diseases, while maintaining an adequate supply in the United States. This

<sup>&</sup>lt;sup>5</sup>https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-surveillance-annualreport-2018.pdf

<sup>&</sup>lt;sup>6</sup>https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-aids-overall.pdf

<sup>&</sup>lt;sup>7</sup>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5554671/

<sup>8</sup>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5753789/





five-step approach consists of initial donor screening, maintaining donor deferral lists, testing collected blood for transfusion-transmitted infections, properly storing blood prior to testing results to minimize the spread of infections if the blood is contaminated, and investigation, when necessary<sup>9</sup>. Despite encouraging donors to screen themselves and opt out of donating if risks are present, the FDA requires laboratory testing and screening for Hepatitis B; Hepatitis C; HIV; Human T-cell lymphotropic viruses; Treponema pallidum, which causes syphilis; West Nile Virus; Trypanosoma cruzi (Chagas disease); and the Zika virus.

We believe that instead of relying on risk factors developed from antiquated understandings of disease, the FDA should incorporate rapid HIV screening into the first step of the Five Layer of Safety Protocol. Implementing rapid HIV testing will ensure a layer of screening that would accurately detect the presence of infectious disease before it enters the blood supply without discriminating against one group of people.

In addition to stigmatizing a group of individuals based on sexual orientation the MSM deferral is contributing to a larger blood shortage. According to the Red Cross, a critical blood shortage exists today: blood and platelets are being distributed at a higher rate than donations are being made and the Red Cross has less than a five-day supply of blood on-hand 10. Blood scarcity of this magnitude poses a public health concern and we believe that it can be addressed if the FDA reevaluated donation requirements and implements safe and reliable screening measures.

We encourage the FDA to reevaluate restrictions based on sexual orientation, and instead implement screening methods that are scientifically reliable. Doing so will ensure that we are moving away from stigmatizing practices and have access to an increased supply of blood from individuals that are presently excluded.

#### **Conclusion**

We want to emphasize the importance of considering the realities New Yorkers faces when accessing care when exploring rates of HIV and Hepatitis infections. People lead complex lives and individuals from marginalized communities are often met with judgement and neglect when seeking care. We applaud the City Council for its efforts to explore how our health systems are providing care and find comprehensive solutions. We look forward to working collectively with the City Council and other providers to ensure health access is available to all. Thank you.

#### ###

Since 1916, Planned Parenthood of New York City (PPNYC) has been an advocate for and provider of sexual and reproductive health services and education for New Yorkers. Through a clinical services, education, and advocacy, PPNYC is bringing better health and more fulfilling lives to each new generation of New Yorkers. As a voice for sexual and reproductive health

<sup>&</sup>lt;sup>9</sup>https://www.fda.gov/consumers/consumer-updates/have-you-given-blood-lately

<sup>&</sup>lt;sup>10</sup>https://www.redcrossblood.org/local-homepage/news/article/critical-blood-shortage-3A-red-cross-urges-blood-and-platelet-donors-to-give-now-1.html



26 Bleecker Street New York, NY 10012 p: 212.274.7200 · f: 212.274.7276 www.ppnyc.org

Planned Parenthood of New York City

equity, PPNYC supports legislation and policies to ensure that all New Yorkers will have access to the full range of sexual and reproductive health care services and information

400 Broadway / New York, NY 10013 o 212 334 7940 /f 212 334 7956 apicha.org

Contact: Phillip Miner, pminer@apicha.org, 646-884-5384

## Testimony of Apicha Community Health Center Before the New York City Council Committee on Health and Committee on Hospitals Oversight Hearing regarding the City's Efforts to Prevent and Address HIV and Hepatitis December 9, 2019

Thank you Chairperson Levine and members of the Committee on Health and the Committee on Hospitals for this opportunity to testify on the City's efforts to prevent and address HIV and Hepatitis. Apicha Community Health Center (CHC) welcomes the Committee's attention to these issues at a time when New York City and State share a plan to end the AIDS epidemic (EtE) by the year 2020.

Apicha CHC is a Federally Qualified Health Center that has demonstrated an ability to reach and provide care to some of the most marginalized people in New York City for nearly 30 years. Apicha CHC's provision of HIV/AIDS-related services since its inception, from street outreach to HIV primary care, has resulted in a patient-centered service delivery model that has created both a safe space and safety net for People Living with HIV/AIDS, Lesbian, Gay, Bisexual and Transgender (LGBT) individuals, Asian & Pacific Islanders (A&PIs) and individuals from other communities of color (COCs). These communities face many barriers to care including poverty, language isolation and lack of health insurance. To overcome these barriers, Apicha CHC offers informed, high-quality culturally and linguistically appropriate primary care, sexual health and robust enabling services.

This past week, New York City announced significant progress toward achieving that goal. We achieved 90-90-90, which means 90 percent of people with HIV who know their status, 90 percent of people who have HIV on treatment and 90 percent of people with HIV whose viral load is suppressed. As of 2018, New York City had diagnosed 93 percent of people living with HIV, 90 percent are being treated, and 92 percent of those on treatment are virally suppressed. New York City is the first major city to accomplish this goal. Additionally, the City's health department released its 2018 HIV surveillance report that indicated new HIV diagnoses have dropped below 2,000 -- which is the lowest since the city began its reporting since 2001.

With this announcement, there is no doubt that we have the tools to bring down new infections and extend the lives of those living with HIV/AIDS. The impact made by the City's investment in the EtE goals is clear. To continue this momentum, we must ensure the resources necessary to increase access to PrEP and PEP in the communities who have yet to benefit from these powerful biomedical HIV prevention tools to achieve health equity. The most recent HIV/AIDS surveillance data reveals some vulnerable communities are not experiencing equivalent benefits from the current EtE efforts: A&PI, Native Americans, the transgender community, and African-American and Hispanic/Latina women. Serving these communities requires understanding their unique needs and cultures.

For example, statewide, A&PIs have only seen a three percent decrease in new infections since the beginning of EtE. We know that the people becoming infected are men who have sex with men, they are young, they are immigrants, many are linguistically isolated, and they are poor. Complicating successful outreach, A&PIs are a very diverse group, hailing from many countries, bearing unique cultures, and speaking a multitude of languages. Formerly named Asian and Pacific Islander Coalition on HIV/AIDS, Apicha CHC has addressed the HIV/AIDS-related unmet needs of A&PIs in NYC since 1989 and understands that providing outreach and health education to these communities requires linguistic and cultural competence to address the stigma surrounding both HIV and LGBT status within these communities.

If barriers like stigma are unaddressed and inconsistent or inadequate resources are allocated to reach these linguistically and culturally isolated populations, improvements will be hard to achieve. In worst case scenarios, spikes in the rate of infection can occur. We have seen this scenario played out since the beginning of the EtE initiative. In 2017, there were 7 new infections within the Thai population, a community who had not seen that number of new infections in years.

Although the number of new infections in the A&PI, Native American, and Transgender populations are small in comparison to other groups, it is critical to note that the total size of these populations are also relatively small. As a result, the number of people in these populations who are infected may not look significant when viewing the HIV surveillance data as a whole, but the proportion of people infected within these communities can be devastating. For this reason, when talking of expanding access to PrEP and PEP, resources must be commensurate to the proportion of a community infected. Providing access to health care must not leave New York City's small communities behind.

Additionally, the historical lack of resources and attention to women of color, transgender, and immigrant communities have left them far behind in their knowledge of biomedical prevention tools like PrEP and PEP and knowledge of their risk of contracting HIV. As a result, many are unaware of the value of PrEP/PEP and the resources available to them. Data shows this is a pervasive issue affecting these groups. In 2016, despite reaching a record-low number of new HIV diagnoses in New York City, there was a 5 percent increase in new diagnoses among women compared to 2015, and Black and Latina women made up over 90 percent of all women who were newly diagnosed. From 2014-2018, transgender folks represented 2.8 percent of all new infections in New York City, most of them transgender women.

Despite these challenges, we have the tools and experience to end the epidemic and achieve health equity for all New Yorkers. Apicha CHC knows from experience that, with adequate funding and resources, these barriers can be overcome, new HIV diagnoses can be reduced, and quality of life for everyone living with HIV/AIDS can be improved. We look forward to Ending the Epidemic in partnership with the New York City Council.

Sincerely,

Teresita R. Rodriguez Chief Executive Officer

Serenta Rodrigue



## TESTIMONY BEFORE THE NEW YORK CITY COUNCIL Committee on Health and Committee on Hospitals December 9, 2019

#### Submitted by Kimberleigh Joy Smith, MPA Senior Director for Community Health Planning & Policy

Good Afternoon. Thank you Chairs Levine and Rivera for the opportunity to submit written testimony for today's Oversight Hearing on the City's Efforts to Prevent and Address HIV and Hepatitis. Callen-Lorde would like to extend its gratitude to Councilmember Danny Dromm, as well.

**Callen-Lorde Community Health Center** is a growing community health center with a mission to reach lesbian, gay, bisexual and transgender communities and people living with HIV in New York City and beyond. As a vital part of the city's dynamic healthcare infrastructure, Callen-Lorde provided a patient-centered medical home for nearly 18,000 patients in 2018, 24% of whom are patients living with HIV. In 2018, we provided 91,887 tests for sexually transmitted infections and 3,705 PrEP prescriptions. Callen-Lorde was an early adopter of PrEP and we remain one of the largest PrEP practices in the country. We are busy clinic that is challenged every day to keep pace with the demand for our quality, culturally and community competent services.

For the record, Callen-Lorde supports **Resolution 0150-0218** as well as this Committee's efforts to examine the causes and conditions surrounding HIV/AIDS-related deaths in New York City.

As a member of the Ending the Epidemic 2020 Coalition, Callen-Lorde endorses the full budget recommendations of the New York City Plan to End the AIDS, as well as the community's request for the New York City Council to baseline Hepatitis C Funding.

With our allies, we are encouraged by the news from the New York City Department of Health and Mental Hygiene (DOHMH) that New York City is the first US city to achieve the UNAIDS 90-90-90 HIV goals<sup>1</sup> -- two years ahead of schedule—and that new HIV diagnoses in the city have fallen below 2,000 per year for the first time since the beginning of the epidemic. But our optimism is cautious. We know there is a lot more work to be done in order to ensure that the end of the epidemic reaches ALL communities.

As you heard earlier, HIV diagnoses rates are disproportionately higher among people of color than their white counterparts in New York City. Just a few examples: In 2018, HIV diagnoses rates among Black women were 11 times higher than among white women. Similarly, higher proportions of transgender people diagnosed with HIV were Latino/Hispanic in 2018.<sup>2</sup>

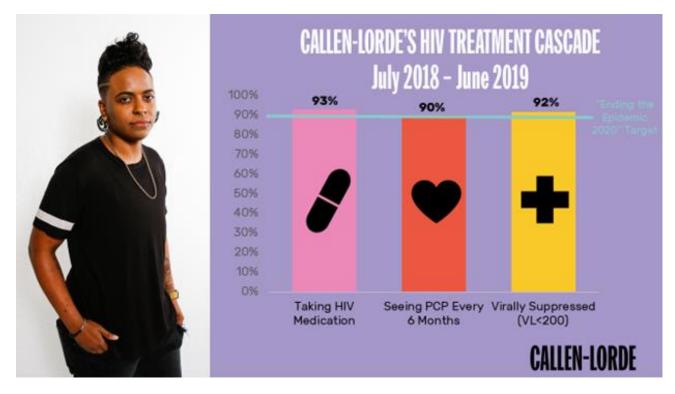
<sup>&</sup>lt;sup>1</sup> UNAIDS <a href="https://www.unaids.org/sites/default/files/media">https://www.unaids.org/sites/default/files/media</a> asset/90-90-90 en.pdf

By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.

<sup>&</sup>lt;sup>2</sup> HIV/AIDS 2018 Surveillance Report, New York City Department of Health and Mental Hygiene. https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-surveillance-annualreport-2018.pdf, accessed December 8, 2019.

## **ECALLEN-LORDE**

More than six years after approval by the FDA, the utilization of PrEP – the treatment that can prevent HIV – remains very low. Disparities in access and utilization are exacerbating overall disparities in the HIV epidemic in New York City and across the country.



At Callen-Lore, we consider ourselves to be at the forefront of the efforts to end the HIV epidemic. Our integrated, stigma-free, sex positive model of high quality medical care – and care coordination – engages patients in a whole-body approach to their health care. Further, we are able to track clinical measures and create clinical and social service interventions that address disparities.

In 2017, an assessment we conducted of our transgender women patients revealed that 42% were HIV positive and that these patients were less likely to be compliant with medical visits and while 76% took antiretrovirals, only 31% had detectable viral loads, indicative of medication non-adherence. Even after deploying funding and instituting initiatives designed to end the HIV epidemic three years, we observed that our trans female patients still were holding a disproportionate HIV viral load burden – meaning they were less likely to be virally suppressed<sup>3</sup> than TGNB patients overall and non-TGNB patients. We designed the **It's About Me Program**, a viral suppression incentive program tailored to transgender and gender non-binary patients. In the last year, we've increased our rates of HIV screening by 29% for TGNB patients, and recent rates of viral suppression among trans women is about 80 percent.

We are able to achieve successes around viral suppression by making sure that our staff represents the community we serve-meaning having TGNB staff that are able to be peer educator and lead initiatives to support major outcomes. In addition our promotional and education materials mirror the community at large, showing that healthcare is for everybody.

<sup>&</sup>lt;sup>3</sup> Viral suppression is defined as, literally, suppressing or reducing the function and replication of a virus. "Viral load" refers to the number of copies of HIV per mL of blood. In other words, it's the amount of virus in the blood.



Even with these great strides, we are exploring disparities in PrEP usage. Last year 83% of PrEP-eligible white patients were prescribed PrEP. During the same time period, only 68% of Black eligible patients were prescribed PrEP.

At the same time, we are observing another disconcerting trend: Sexual transmission of HCV among men who have sex with men is increasing and associated with crystal meth use, condomless anal intercourse, HIV and STIs. Over a one-year period in 2018-19, we diagnosed 21 cases of acute HCV infection in MSM, most who had multiple risk factors. Ninety percent were MSM and 76% were HIV positive.

Though we are working hard and making great progress in ending the HIV epidemic and eliminating Hep C; the disparities in PrEP usage and the uptick in sexual transmission of HCV signal to us the need for increased investment in access, education and awareness.

As you start to prepare for the next City budget, please fully fund the ETE budget requests and baseline Hep C funding. Specifically,

- Expand the streamlined "Dean Street" model for sexual health clinics. NY's Chelsea Sexual Health Clinic is now offering "express," automated and streamlined STI testing based on the Dean Street model out of England. NYC should expand this model.
- Expand the Women's ETE Services and extend Live Sure, PEP and PrEP Awareness Campaigns for Women
- Establish Reproductive Health Services and Transgender Health Services at NYC Sexual Health Clinics.
- Allocate funding for prevention efforts that focus on MSM communities to provide education as part of comprehensive prevention strategies including harm reduction and increased screening.

Thank you for the opportunity to submit testimony today.

For more information, please contact Kimberleigh J. Smith at 212-271-7184 or ksmith@callen-lorde.org



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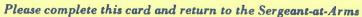
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