



Department  
of Health

AIDS  
Institute

# PrEP for Women: Successes, Challenges & Opportunities

*A Statewide Forum Hosted by the New York State Department of Health AIDS Institute*    **JUNE 8, 2017**



## MEETING REPORT

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*This report was prepared by Mary Beth Hansen, MA, Project Director, Johns Hopkins University HIV Clinical Guidelines Program, September 2017*

## FOREWORD

Lyn Stevens, MS, NP, ACRN

*Deputy Director, Office of the Medical Director, New York State Department of Health AIDS Institute, and Forum Director*

In June 2017, the New York State Department of Health AIDS Institute convened stakeholders from across the state to discuss the unique issues associated with engaging women in pre-exposure prophylaxis (PrEP). With an abundance of topics to address, this discussion is continuing through two events: the June 2017 event, which focused on issues relating to cisgender women, and an event to be held in Spring 2018 to focus on issues unique to transgender women.

For the June 2017 event, we invited PrEP providers and scientific researchers to attend, along with consumers and representatives from community-based organizations and advocacy groups; pharmacies; and family planning, public health, and faith-based agencies. The goal was to glean insights they have gained through their experiences delivering PrEP services to women in diverse settings: challenges unique to implementing PrEP for women, ways to address those challenges, and emerging best practices for engaging women in PrEP statewide. Invited speakers and panelists presented on topics specific to PrEP for women, and then attendees participated in each of three breakout sessions to address key implementation issues: awareness of PrEP, perception of risk among women and their care providers, and women's access to PrEP.

Issues of equity dominated the day's discussions, as did a call for evolution in thinking about risk. With regard to equity, speakers noted that, to date, the primary emphasis in PrEP messaging has been on men who have sex with men. Speakers called for messaging that will reach and speak to women, and especially women of color. Also noted was the need for equity in decision-making related to healthy sex—women must be empowered to engage in sexual health promoting activities. Finally, several speakers emphasized that the greatest risk of HIV exposure appears to be social and geographical, given that women who live in high-risk areas and engage in high-risk social networks are most likely to acquire HIV infection. In recognizing the importance of social and geographical risk, rather than behavioral risk, speakers underscored the need to expand the definition of risk to reach all women who can benefit from PrEP.

All agreed that empowering women to use PrEP, ensuring proper training among providers, and reaching women through diverse methods in diverse settings must be addressed concurrently to ensure New York State's success in delivering PrEP to women who can benefit.

Successes realized to date were acknowledged as well. Agencies reporting on their experiences implementing PrEP described relationship building with female patients, incorporating information about PrEP into all HIV and women's programs and services, and creative community outreach activities as successful methods for increasing PrEP use among women in their service areas.

The success of this forum was made possible by the hard work of many. The people responsible for planning, logistics, materials design and production, venue coordination, registration, note taking, facilitation of and reports on breakout sessions, and transcription of notes included Jennifer O'Connor, Nkechi Oguagha, Marcia Kindlon, Joanna Palladino, Michael McNair, Dora Swan, Richard Cotroneo, Beth Woolston, Mary Beth Hansen, Christina Norwood, and Laura Hatcher. Thank you all for making this day a great success. Special recognition and thanks goes to Laura Duggan Russell who took the lead in both planning and facilitating this event.

We have made great strides in New York State in the fight against HIV, and we have more to do. Sending the clear message to women that PrEP is a proven HIV prevention method that is for them to choose, use, and control will be essential to ending the HIV epidemic in New York State.

## EXECUTIVE SUMMARY

### FORUM ON PREP FOR WOMEN: SUCCESSES, CHALLENGES, AND OPPORTUNITIES

This report summarizes speaker presentations and panel and participant discussions at the first statewide forum on PrEP implementation for women in New York. This meeting was hosted by the New York State Department of Health AIDS Institute (NYSDOH AI) on June 8, 2017.

#### Supporting the New York State Initiative to End the HIV Epidemic

This forum was the third in a series and a continuation of efforts to engage community and policy stakeholders in support of Governor Andrew Cuomo's plan to end the epidemic in New York State. A key component of the governor's plan is to increase access to and uptake of PrEP among people who are at high risk of acquiring HIV infection.

PrEP implementation for adults was addressed on August 26, 2015, when the NYSDOH AI convened a forum, attended by healthcare providers, consumers, community stakeholders, and state and local health officials, to discuss the use of PrEP and PrEP quality of care for adults in New York State. On November 18, 2015, a forum on implementation of adolescent PrEP was convened to address challenges and opportunities specific to the youth population. This forum on PrEP for women focused on identifying challenges that must be addressed to increase women's access to PrEP and their willingness to use it to protect themselves from acquiring HIV.

#### Challenges Unique to Women

Among presenters, panelists, and meeting participants, there was broad agreement that women in New York State are particularly vulnerable to HIV infection due to a mix of social, behavioral, and biological factors. In New York State, in 2015, 20% of new HIV diagnoses were in women, and nearly all reported their transmission risk as heterosexual contact.<sup>1</sup>

In New York, women of color, and particularly Black women, have been disproportionately affected by HIV. In 2015, 59% of all new HIV diagnoses in women were in Black women, who comprise only 16% of the total female population. Research in New York City demonstrated that few women know about PrEP, and very few are using this prevention intervention.

#### Key Issues

All agreed that barriers to PrEP uptake fall into three domains: awareness, attitudes, and access.

- **Lack of awareness:** Neither women nor their care providers know much about PrEP. Care providers who don't know about PrEP, or who don't know how to prescribe it, cannot offer or engage women in discussions of or education about PrEP. Women who don't know about it or who have only seen PrEP marketed to gay men will not know or think to ask about this prevention method. Care providers are also subject to the same messaging as women and may mistakenly believe that PrEP is for gay men, not women.

*Priority for Change:* All agreed that education and training are needed for clinical and non-clinical care providers so that all providers who deliver care to women can inform women about PrEP and provide access.

- **Attitudes:** Many care providers still focus on a "risk assessment" approach to HIV prevention intervention. This focus can be stigmatizing with its emphasis on identifying "risky" or "bad" behaviors that may expose a woman to HIV.

*Priority for Change:* Shifts in attitude are needed among healthcare providers, who must take the first steps toward promulgating a view of PrEP as an essential component of women's health and a routine part of healthcare for women.

- **Access:** Access starts with care providers—a care provider who does not know about PrEP and understand its role in sexual health cannot offer PrEP to women; therefore, access depends on increasing awareness. But access also depends on delivery—PrEP should be made available in as many settings as possible and on demand, and there should be adequate resources available to help women cover the costs of PrEP prescriptions and related expenses.

*Priority for Change:* Expanded education is needed, in a greater number of settings and types of settings where PrEP is prescribed, and expanded resources are needed to provide PrEP to women at reduced or no cost.

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<sup>1</sup> "Female Sex Assigned at Birth, Newly Diagnosed with HIV Infection by Age at Diagnosis and Transmission Risk Category, NYS, 2015". Bureau of HIV/AIDS Epidemiology, AIDS Institute, NYSDOH.

## SUMMARY OF SPEAKER PRESENTATIONS

### OPENING REMARKS

#### Johanne Morne, MS

Director, New York State Department of Health AIDS Institute

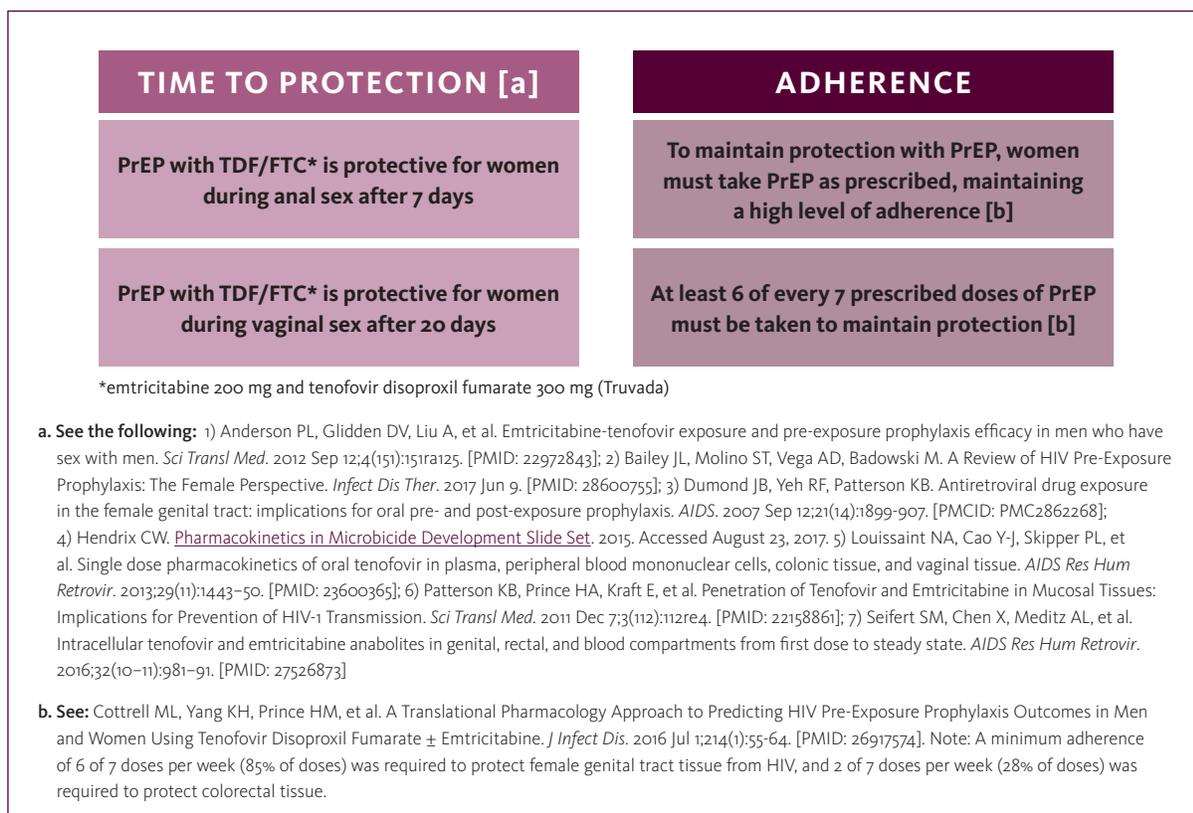
The AIDS Institute Director opened the forum by emphasizing the importance of PrEP to New York State's (NYS) Ending the Epidemic (ETE) initiative. Morne provided an overview of ETE, describing it as a history-making effort grounded in 30 years of work and collaboration among the community, NYS government, the NYS Department of Health, and the New York City Department of Health and Mental Hygiene. In 2014 Governor Cuomo's ETE initiative put forth a 3-point plan to reduce the number of new HIV infections to 750 by the end of 2020 by 1) identifying people with HIV infection and linking them to care, 2) retaining people with HIV infection in care to maximize virus suppression and reduce transmission, and 3) increasing access to pre- and post-exposure prophylaxis (PrEP and PEP). Morne also discussed a fourth area now being implemented—reducing structural barriers to care for individuals across all mission areas to promote a culturally responsive, engaging environment of care.

**“Ensuring that women know about, have access to, and are supported to use PrEP for HIV prevention is crucial to achieving the goals of ETE.”**

Morne identified the purpose of this forum as that of addressing PrEP for women, and she also announced an upcoming forum (Spring 2018) on PrEP for transgender women. Although she applauded the focus on women in general, Morne called for attention to the needs of Black women specifically. She set the stage for much of the discussion that followed by noting the disproportionate burden of HIV infection (59% of new infections in 2015) among Black women in New York, who make up just 16% of the population. Morne also called for scaling up effective interventions already in place and for innovations to expand women's access to PrEP.

In closing, Morne made the point that if any one population in NYS continues to bear the primary burden of new HIV infections after 2020, the epidemic will not be over: “If any one community continues to bear the burden of HIV, then we have not achieved our goal.”

**Figure 1. Time to Protection and Adherence to Maintain Protection with TDF/FTC as PrEP for Women**



**Demetre Daskalakis, MD, MPH**

Deputy Commissioner, Disease Control, New York City Department of Health and Mental Hygiene

**“HIV is an emergency.”**

Dr. Daskalakis began his talk by reminding attendees that HIV is (still) an emergency and should be treated as such. He described the HIV epidemic in NYS as being very similar to the epidemic in the South<sup>2</sup> with significant risk disparities associated with race/ethnicity, age, and sex. Although the number of new HIV diagnoses in New York were historically low in 2015, specific demographics were disproportionately affected, reflecting significant social and health inequities. Specifically, he noted that Black women aged 20 to 29 years comprised the largest proportion of new HIV diagnoses in New York City (NYC) in 2015. Like Morne before him, Daskalakis emphasized that the epidemic in New York will not be ended if new infections are reduced to 750 by 2020 but most of the 750 new diagnoses occur in one group of people.

Daskalakis asserted that the indication for PrEP among women is the same as for men who have sex with men. Despite the equal need, though, the uptake of PrEP among women in New York and nationally is flat. He reported a 332% increase in new PrEP starts nationally between Q1 2014 (530 new PrEP starts) and Q1 2015 (1,761 new PrEP starts). However, it was primarily men who started PrEP during that period: just 13% of new PrEP starts were among women. NYC mirrored the nation: in a 2016 sample of 411 women of color, only a very small number had ever heard of PrEP or discussed it with a care provider, and only two reported using PrEP.

NYC is making great strides in addressing the inequities described by Daskalakis. For example, the city has converted STI clinics to sexual health clinics that take a three-pronged approach to care:

- 1. Biomedical evaluation and intervention:** Instant starts of antiretroviral (ARV) treatment and prevention. PrEP is just one intervention. Identification of people with HIV infection and initiation of antiretroviral therapy (ART) to suppress the virus is also crucial to reducing transmission.
- 2. Social work assessment for social determinants of risk or disease progression and insurance connection:** It has been well-documented that risk of HIV infection can be tied to geographic location, with the highest HIV prevalence occurring in high-poverty neighborhoods in NYC.
- 3. Navigation to longitudinal care for people who are and are not diagnosed with HIV infection:** HIV testing represents an important opportunity to engage people who do have HIV infection in care and get them started on ART to improve and maintain their health and to reduce the risk of transmitting HIV to others. Those who are tested but do not have HIV infection should be engaged in primary care and HIV prevention for health maintenance.

**“If a woman is diagnosed with syphilis or gonorrhea, offer her PrEP immediately.”**

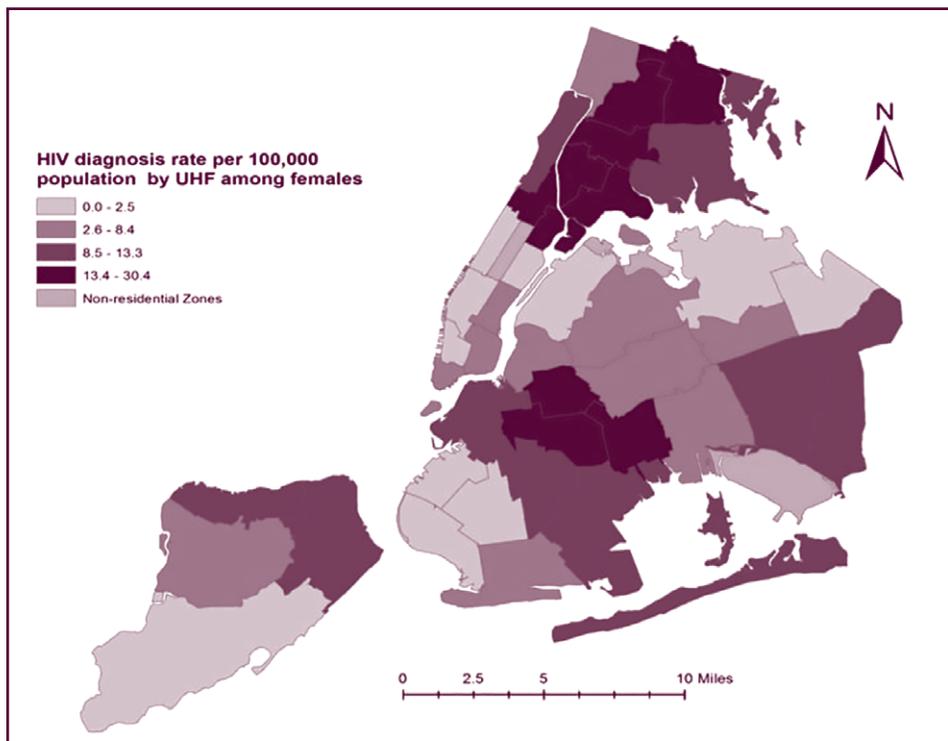
With regard to PrEP specifically, Daskalakis urged the elimination of all barriers to PrEP, stressing that PrEP should be provided to anyone who is having sex without using condoms, to anyone who is diagnosed with an STI, and to anyone who asks for it. And for those who don't ask, PrEP should be offered. He placed the burden on the system to offer PrEP, not on women to know about it and ask. Daskalakis presaged the message delivered by just about all speakers and meeting participants throughout the day when he called for care providers to move away from an emphasis on risk assessment (“interrogation”) and a move toward getting PrEP to women who can benefit. He dismissed criticism regarding over-offering of PrEP. This is an emergency, and over-offering is better than not reaching all women who can benefit from PrEP.

In closing, Daskalakis outlined new and future directions for NYC:

- Development of a PrEP campaign focused on women
- New data analyses to identify biomarkers and epidemiologic characteristics for HIV seroconversion to better focus PrEP provision
- Clear messaging around PrEP and treatment as prevention (TaSP)
- Offer of PrEP at sexual health clinics for any woman requesting this intervention
- Rapid adoption of new female-focused PrEP technologies (e.g., vaginal rings, implants) once they are approved

<sup>2</sup> See, for instance, Villarosa L. America's Hidden H.I.V. Epidemic, *New York Times Sunday Magazine*. June 11, 2017; p. MM38

Figure 2. HIV Diagnosis Rate by United Hospital Fund (UHF) Among Females in New York City, 2015



**Rates of new HIV diagnoses among females are highest in Hunts Point-Mott Haven, East New York, and Crotona-Tremont**

1. Rates calculated using the intercensal 2015 NYC population
2. "Female" includes transgender women
3. As reported to the NYC DOHMH by June 30, 2015

## INVITED SPEAKER PRESENTATIONS

The invited speakers addressed the science of PrEP; the rationale for use of PrEP among women who are trying to get pregnant, who are pregnant, and who are breastfeeding; and the social and political context of PrEP for women.

### Betsy Herold, MD

*Professor of Pediatrics and Microbiology-Immunology; Vice Chair for Research in the Department of Pediatrics; Division Chief, Pediatric Infectious Diseases at Albert Einstein College of Medicine and the Children's Hospital at Montefiore*

**The Conundrum of Topical and Systemic PrEP for Women: How to Deliver the Right Drugs to the Right Place at the Right Time:** Dr. Herold presented data from research on the use of topical (vaginal application) and systemic (oral medications) PrEP regimens for women. She introduced her discussion by observing that clinical study results have, overall, demonstrated that PrEP for women is effective, but not as effective as it is in men. Noting that the differences in efficacy cannot be attributed entirely to issues of adherence, Herold explained that vaginal sex, inflammation, and the gut and vaginal microbiota in females may hold the answers to the conundrum of PrEP for women.

All told, PrEP in women is complicated because the effects of topical PrEP preparations under clinical evaluation have not been predictable. Among women, individual differences are the rule, not the exception, because the vaginal microbiome is highly variable across and influenced by many factors. This variability produces myriad interactions with topical medications.

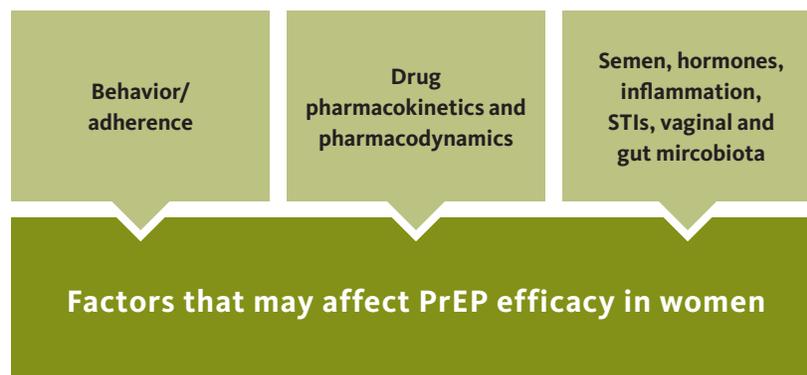
Herold noted that because PrEP has not been studied as extensively in women as it has been in men, the effects of the gut microbiome on oral PrEP are not known. In clinical studies, women have needed higher doses of PrEP medications to achieve protection, and it has been surmised that oral PrEP confers protection through different mechanisms than topical PrEP. It is known that oral PrEP produces very low drug levels in the vagina, but the specific mechanism of protective action conferred by oral PrEP in women has not been defined; it has been theorized that, in women, PrEP works in the lymph nodes.

Herold called for more clinical studies of PrEP in women to shed light on how the drugs act on the cellular level, how they are metabolized, and the effects of intermittent use. She also called for improvement in delivery systems for topical PrEP and for study of the effects of intermittent adherence.

Herold emphasized that, until more is known, patient education is crucial. Women who are using PrEP must be informed about the time to protection with PrEP and about the crucial role that adherence plays in protection from HIV.

### Figure 3: Factors that May Affect Efficacy of Topical and Systemic PrEP in Women

Adapted from Herold's slide 4 "Factors that may impact efficacy"



## Maria Teresa Timoney, CNM

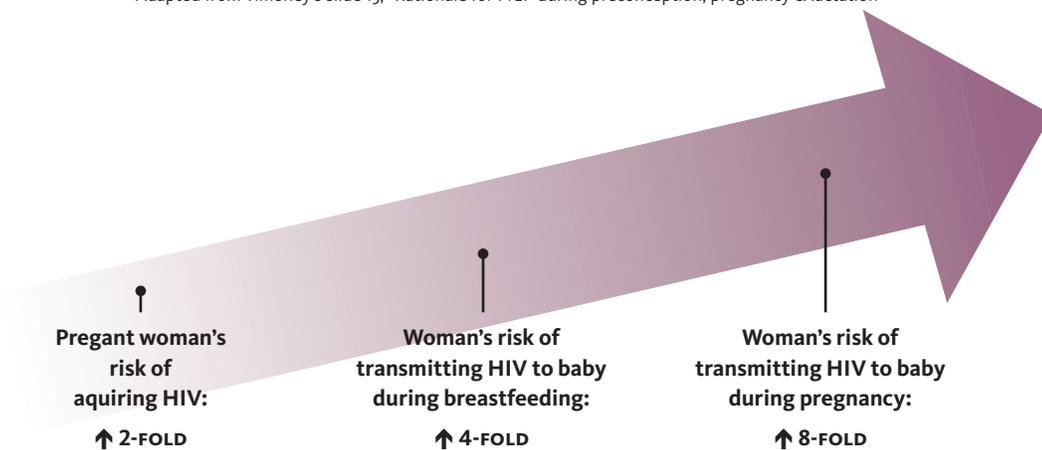
Director, Women's HIV Services, Department of Obstetrics and Gynecology, Bronx Lebanon Hospital Center

**Pre-Exposure Prophylaxis for Women During Preconception, Pregnancy, and Lactation:** In introducing her talk, Ms. Timoney reiterated points made earlier about the documented associations between geography, social networks, and increased HIV prevalence, and about gender disparities in HIV infection in NYC. She then identified the dramatic reduction in mother-to-child transmission (MTCT) of HIV as the greatest success story in the HIV epidemic and described the use of antiretroviral drugs to prevent MTCT as, functionally, the first clinical trial of "PrEP."

After laying this groundwork, Timoney explained the rationale for women's use of PrEP during preconception, pregnancy, and lactation, noting that pregnancy greatly increases a woman's risk of acquiring HIV (2-fold). In turn, higher viral loads associated with acute HIV infection greatly increase the risk of perinatal transmission during pregnancy (8-fold) and the risk of neonatal transmission during breastfeeding (4-fold).<sup>3</sup> The increased risk of HIV acquisition for mothers and their babies can and should be mitigated by use of PrEP.

### Figure 4: Rationale for Use of PrEP during Preconception, Pregnancy, and Lactation

Adapted from Timoney's slide 13, "Rationale for PrEP during preconception, pregnancy & lactation"



However, Timoney asserted that an offer of PrEP should not be tied to risk assessment. She explained, as many would throughout the day, that it is now and always has been difficult to define "high-risk heterosexual." In the past, "high risk" has been defined as multiple sex partners. However, research has demonstrated that most people recently infected with HIV report having just one sex partner within the year prior. "High risk" has also been tied to sex partners' risks, but research has demonstrated that most people are not accurate in their assessment of a partner's HIV risk. In all, risk assessment does not lead to identification of women in need of PrEP because risk itself is so hard to define.

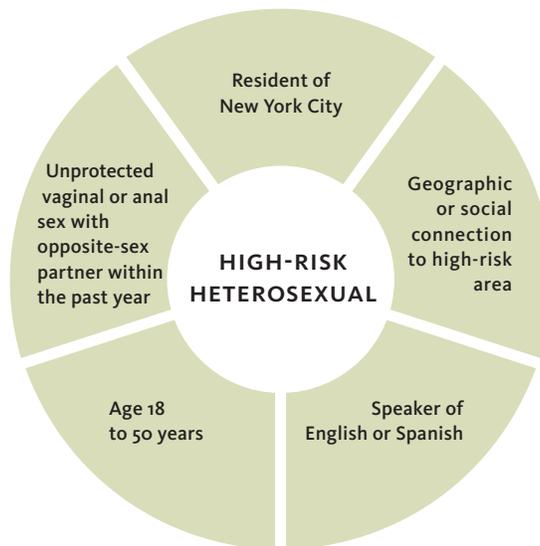
Timoney described newer ideas about risk of HIV acquisition that are beginning to take hold. For instance, it's now known that HIV infection among heterosexual people is clustered in high-poverty New York neighborhoods. Social network mapping has demonstrated that some social and sexual networks have a higher collective risk of HIV infection, even if the risk to individuals in those networks is not higher than the risk to those outside of the network. As a result, Timoney noted, the definition of "high-risk heterosexual" is evolving to include the following elements:

- Geographic or social connection to a high-risk area
- Age 18 to 50 years
- Vaginal or anal sex with opposite-sex partner within the past year
- Resident of NYC
- Speaker of English or Spanish

<sup>3</sup> Cited by Timoney in slide 13: (a) Mugo NR, Heffron R, Donnell D, et al. Increased risk of hiv-1 transmission in pregnancy: a prospective study among African HIV-1-serodiscordant couples. *AIDS*. 2011 Sep 24;25(15):1887-95 [PMID: 21785321]; (b) Drake AL, Wagner A, Richardson B, John-Stewart G. Incident HIV during pregnancy and postpartum and risk of mother-to-child HIV transmission: a systematic review and meta-analysis. *PLOS Med*. 2014 Feb 25;11(2):e1001608. [PMID 24586123]; (c) Humphrey JH, Marinda E, Mutasa K, et al. Mother to child transmission of HIV among Zimbabwean women who seroconverted postnatally: prospective cohort study. *BMJ*. 2010 Dec 22;341:c6580 [PMID 2117735]; (d) Singh S, Lampe MA, Surendera B. et al. HIV seroconversion during pregnancy and mother-to-child HIV transmission: data presented from the enhanced perinatal surveillance projects, United States, 2005-2010. Paper presented at: 20th Conference on Retroviruses and Opportunistic Infections (CROI 2013). Atlanta (GA), March 3-7, 2013 [not available online].

**Figure 5: Evolving Definition of “High-Risk Heterosexual”**

Adapted from Timoney's slide 21, “High-Risk Heterosexual Definition”



Using that type of definition will allow care providers and policy makers to cast a much wider net in identifying women who should be offered PrEP. This is important because, for women who do not have HIV infection but who are trying to conceive with a partner who does, PrEP, combined with suppressive ART for the partner and limited sex without condoms can greatly reduce, if not eliminate, a woman's risk of infection. This type of definition is also important for women who do not have HIV infection but are breastfeeding. Although the safety of PrEP for breastfeeding infants has not been studied extensively, the World Health Organization recommends its use for breastfeeding mothers. Care providers should discuss the potential risks and benefits of PrEP use for women who are breastfeeding so an informed decision can be made. The same holds true for women who are pregnant—clinicians should review the risks and benefits and engage patients in informed, shared decision-making.

When women are using PrEP, they should be counseled about the adherence requirements for PrEP to be effective. Research has demonstrated that PrEP is not quite as effective in women as in men, and women must take the medications every day to maintain protection.

Timoney's most important take-home messages, though, were that all pregnant women should be tested for HIV infection, including during labor and delivery. And, all women should be offered PrEP, but PrEP should be encouraged for women who live in areas that place them at high risk of acquiring HIV.

### **Dázon Dixon Diallo, MPH, DHL**

*Founder and President of SisterLove, Inc.*

**“There is a huge discrepancy between the risk of HIV infection for women and the prevention measures readily available to women.”**

**“Is That for Me?:” Challenging Assumptions about PrEP for Women in the United States:** Dr. Diallo located the issues associated with PrEP for women squarely in the realm of women's struggle against sexual and reproductive oppression. She defined sexual and reproductive oppression as “the control and exploitation of women, girls, and individuals through our bodies, sexuality, labor, and reproduction.”

In contrast, Diallo asserted that sexual and reproductive justice exists “when all people have the social, political, and economic power and resources to make healthy decisions about our gender, bodies, sexuality, and families, for ourselves and our community.”

Diallo discussed the current HIV epidemic in women as a symptom of oppression. She described the struggle to maintain focus on the problem and the needs of women, even though women make up a substantial portion of the U.S. HIV epidemic, and the number of Black women with HIV infection is two to three times higher than in other women. She argued that use of such language as “women make up *only* 20% of HIV cases” is harmful because it diminishes the harm done to women by HIV and the scope of the epidemic in women.

All such factors create a huge discrepancy between the risk to women and the prevention measures available and delivered to women. With regard to the well-documented poor uptake of PrEP among women, Diallo named many factors that hinder or slow women's access to PrEP, including the following:

- Lack of information for women and their care providers, prevailing myths and misperceptions about PrEP, and lack of expertise among care providers
- Discrimination, bias, and stigma in healthcare
- Negative bias against women's sexuality and their expression of sexuality
- Limited or withheld family planning options
- Insufficient research on PrEP use and efficacy in women
- Lack of respect for women's agency and self-determination
- Emphasis on risk assessment, which is a challenge for women and their care providers
- Media coverage and messaging about PrEP that is focused on gay men and excludes women
- Lack of PrEP availability in the settings where women most often get healthcare, such as family planning and STI clinics
- Limited options for PrEP administration, which limit women's control of HIV prevention
- Cost and lack of information about payment assistance

Despite the challenges, though, Diallo suggested remedies to the current situation and ways to overcome the challenges of increasing use of PrEP among women who can benefit. Specifically, she named the following actions as essential to removing barriers and increasing access to PrEP for women:

- More research on PrEP in women and new delivery systems that make PrEP easier to take or use
- Stronger public health commitment to PrEP for women specifically
- Grants targeted to expansion of PrEP programs for women and greater integration of PrEP services into all services for women
- Routine bundling of PrEP education and PrEP access with HIV testing and counseling
- Scaled up training of care providers across as many clinical settings as possible
- Completion of the SHIPP study, the goal of which is "To learn lessons about how best to incorporate the delivery of daily oral PrEP into the services provided by health centers serving sexually active adults at high risk of acquiring HIV infection. The pilot study will initiate data collection at federally-qualified health centers or look-alikes in four U.S. cities." [[CDC Foundation](#)]
- Scale up provision of PrEP—make PrEP readily available (e.g., online) and available on demand
- Develop and disseminate positions on PrEP policy and administration

## PANEL DISCUSSION: EXPERIENCES IMPLEMENTING PREP FOR WOMEN

### PANELISTS:

- **Jamie Morrill**, PrEP Specialist, Trillium Health
- **Debra Lesane**, Program Director, Caribbean Women's Health Association, Inc.
- **Kate Collier, PhD, MPH**, Director of Research and Evaluation, Planned Parenthood of New York City

Panelists were invited to discuss their experiences in implementing PrEP for women in three different clinical settings and were asked to describe the following aspects of their programs:

- **Utilization:** Number of patients served, demographics, unique characteristics, and recruitment
- **Service model:** Support team, providers, special training, linkages, funding, and unique issues (e.g., adherence, social services, medical services)
- **Metrics:** Performance data, quality measures, and outcomes
- **Successes:** Key achievements and unique aspects of the program
- **Challenges:** Key challenges to PrEP implementation

An overview of panelists' presentations is presented in Table 1.

**Table 1: Overview of Three PrEP Implementation Programs**

<b>TRILLIUM HEALTH</b> Jamie Morrill, PrEP Specialist	
<b>Utilization</b>	<ul style="list-style-type: none"> <li>• Approximately 350 patients on PrEP; 27 (7.7%) are women</li> <li>• Age distribution among women on PrEP: 26% aged 22 to 29 years; 41% aged 30 to 39 years; 33% aged 40 to 59 years</li> <li>• Race distribution among women on PrEP: about 48% Black; 37% White; 15% other</li> </ul>
<b>Service Model</b>	<ul style="list-style-type: none"> <li>• Multidisciplinary; eight on-site PrEP providers</li> <li>• Patients see PrEP Specialist and provider at every visit and have access to a team that includes a clinical pharmacist, behavioral health specialist, and care manager</li> <li>• PrEP patients are seen on intake, at 1 month follow-up, at 3 month follow-up, then quarterly or as-needed ongoing</li> <li>• PrEP on demand is available</li> <li>• Direct PrEP phone line</li> </ul>
<b>Best Practices</b>	<ul style="list-style-type: none"> <li>• All care providers at Trillium know about PrEP</li> <li>• Team of PrEP specialists who focus on the following: <ul style="list-style-type: none"> <li>- Linking patients and care providers</li> <li>- Patients' sexual history</li> <li>- Risk assessment</li> <li>- Education and counseling—PrEP, safer sex, HIV, STIs</li> <li>- Insurance and assistance program navigation</li> <li>- Linkage to additional services, such as care management, behavioral wellness, housing, transportation, and food</li> <li>- Follow-up</li> <li>- Outreach</li> </ul> </li> <li>• PrEP-specific marketing and social media campaign</li> </ul>
<b>Successes</b>	<ul style="list-style-type: none"> <li>• Trillium has four female PrEP/PEP care providers and one female PrEP Specialist to increase comfort among women who want to work with female care providers</li> <li>• PrEP on demand: Intake and prescription on same day; no wait for appointment</li> <li>• Improved health outcomes as a result of taking time to address patients' other medical and socioeconomic needs and build trust</li> <li>• Women who present for pregnancy or STI care are linked to PrEP</li> <li>• Use of messaging that equates PrEP with birth control and PEP with Plan B</li> <li>• Outreach to women where they are: college campuses, coffee shops, straight bars, and church and religious communities</li> </ul>
<b>Challenges</b>	<ul style="list-style-type: none"> <li>• Need for more marketing and community messaging with focus on PrEP</li> <li>• Need to expand social messaging to focus on PrEP (not just pregnancy prevention)</li> <li>• Bridging the knowledge gap between OB-GYN care providers and primary care providers</li> <li>• Stigma of PrEP use among women</li> <li>• Intimate partner violence</li> <li>• Identifying and meeting needs of sex workers</li> <li>• PrEP services are time consuming</li> </ul>
<b>Priorities for Change</b>	<ul style="list-style-type: none"> <li>• Marketing to/for women</li> <li>• Increased collaboration with women's health organizations</li> <li>• Increase and promote women's health services overall</li> <li>• Increase outreach to women</li> <li>• More research with women</li> <li>• Create support group for women</li> <li>• Identify and implement incentives</li> <li>• Address childcare needs</li> </ul>

**Table 1: Overview of Three PrEP Implementation Programs, continued**

<b>CARIBBEAN WOMEN'S HEALTH ASSOCIATION, INC. Debra Lesane, Director of Programs</b>	
<b>Utilization</b>	<ul style="list-style-type: none"> <li>• 457 women received HIV prevention services (FY 2015-16)</li> </ul>
<b>Service Model</b>	<ul style="list-style-type: none"> <li>• Maternal and child health support services</li> <li>• Immigration legal assistance</li> <li>• HIV testing, counseling, and community prevention education</li> <li>• Six AIDS Institute funded programs</li> </ul>
<b>Best Practices</b>	<ul style="list-style-type: none"> <li>• Develop resources and maintain relationships with PrEP clinical providers</li> <li>• Encourage discussion of PrEP in all discussions of HIV testing and prevention</li> <li>• Identify points of PrEP intersection with all programs and services for women</li> </ul>
<b>Successes</b>	<ul style="list-style-type: none"> <li>• PrEP education incorporated into all HIV prevention interventions—with everyone who comes for HIV testing and counseling</li> <li>• “We take people to services—we don't just send them; we need to know who is providing PrEP in the community”</li> </ul>
<b>Challenges</b>	<ul style="list-style-type: none"> <li>• Women do not acknowledge their HIV risk</li> <li>• Women think PrEP is for men who have sex with men (MSM)</li> <li>• Not enough inclusion of women of color in marketing and educational materials</li> <li>• Separation of pregnancy services and HIV services, with no intersection—information about HIV prevention and PrEP has to be incorporated into all services for women</li> </ul>
<b>Priorities for Change</b>	<ul style="list-style-type: none"> <li>• Creation of educational materials for women specifically</li> <li>• Increased collaboration between community-based organizations and PrEP clinical providers to improve education of and outreach to women</li> </ul>

**Table 1: Overview of Three PrEP Implementation Programs, continued**

<b>PLANNED PARENTHOOD OF NEW YORK CITY</b> Kate Collier, PhD, MPH, Director of Research and Evaluation	
<b>Utilization</b>	<ul style="list-style-type: none"> <li>In 2016, across five health centers, 60,000+ clients were served, more than 104,000 STI screenings were provided, and 32,700 HIV tests were performed</li> <li>95% of clients are women, 70% of whom are younger than 30 years</li> <li>The majority of clients (60%) were insured by Medicaid, paid reduced rates, or received free care</li> <li>Race ethnicity distribution: 32% Latino; 28% Black; 25% White; 6% Asian</li> </ul>
<b>Service Model</b>	<ul style="list-style-type: none"> <li>In 2016, PrEP services were implemented in health centers in Manhattan, Staten Island, Brooklyn, and the Bronx</li> <li>On an initial visit, patients are seen by a clinician, social worker, and financial counselor</li> <li>HIV testing and a prescription for PrEP are provided at a 2-week follow-up visit</li> <li>Patients are seen at 12-week follow-up for repeat HIV test, STI screening, and assessment for PrEP continuation</li> </ul>
<b>Metrics</b>	<ul style="list-style-type: none"> <li>Initial visits for PrEP:               <ul style="list-style-type: none"> <li>- 81.5% cisgender men; 17.5% cisgender women; 1% transgender women</li> <li>- 48.5% White; 30% Latino; 14% Black</li> <li>- 36% aged 18 to 24 years; 55% aged 25 to 34 years; 11% aged 35 years and older</li> <li>- 71% return rate for 2-week PrEP follow-up visit</li> </ul> </li> </ul>
<b>Successes</b>	<ul style="list-style-type: none"> <li>PrEP services are in demand</li> <li>Can be integrated into sexual and reproductive health services</li> <li>Well-tested messages and materials to raise PrEP awareness, improve HIV risk perception, and increase PrEP knowledge among women</li> </ul>
<b>Challenges</b>	<ul style="list-style-type: none"> <li>Women do not acknowledge their HIV risk</li> <li>Women think PrEP is for MSM</li> <li>Not enough inclusion of women of color in marketing and educational materials</li> <li>Separation of pregnancy services and HIV services, with no intersection—information about HIV prevention and PrEP has to be incorporated into all services for women</li> </ul>
<b>Priorities for Change</b>	<ul style="list-style-type: none"> <li>Implementation of PrEP prescription on initial visit (began June 2017)</li> </ul>

## PANELISTS' SHARED SUCCESSSES, CHALLENGES, AND PRIORITIES

“We need to approach our work with INDIGNATION: the people who are getting infected with HIV now are from the same groups as those who have been getting infected for all 30 years of this epidemic.” — *D. Lesane*

The three programs presented by panelists were more different than alike; consequently, the number of shared successes and challenges were few. That said, all noted that one of the greatest challenges is that women are not especially aware of their risk of acquiring HIV. Compounding that challenge is what all perceive as women's tendency to prioritize the needs of their families and others in general over their own needs, so that even if women are aware of threats to their health, they may not be able or willing to address those threats.

Another shared challenge is PrEP messaging and marketing to date. All observed that PrEP messaging has largely focused on reaching MSM, and mostly White MSM. This was not presented as statistical fact, but as an observation made by women served by these programs. To that point, the presenter from Planned Parenthood of New York City noted that their client base for PrEP was predominantly White, cisgender men with private insurance, which is very different from their overall client base of women of color who do not have private insurance. All observed that marketing and messaging that allows women, and especially women of color, to recognize themselves in the messages and ads are needed. Because marketing and messaging have not focused on women, many/most women in the experience of these presenters don't know about PrEP. As a result, all the programs represented by the panelists are directing effort and resources toward marketing and social media campaigns designed specifically to reach women in general and women of color specifically.

Finally, another challenge shared by all is stigma associated with taking PrEP. Women who take PrEP are reluctant to acknowledge it and talk about it out of fear of being judged harshly for engaging in behavior that could make PrEP a necessity. The stigma associated with PrEP prevents or greatly limits the use of peer-to-peer outreach and support groups that have been instrumental in addressing so many other health issues. The presenter from Trillium Health noted that the program has four female PrEP care providers and one female PrEP Specialist to make sure that women have access to female care providers.

All reported the priority of expanding PrEP services, including counseling, education, outreach, and direct provision of PrEP.

Meeting participants echoed and expanded upon many of the observations made by panelists, agreeing that women's health services tend to be siloed. Many stressed that services need to be provided in multiple settings to reach women who are receiving treatment for addiction or mental illness, who are incarcerated, or who are sex workers. In addition, a wider array of social services are needed to address women's most pressing needs so that health, HIV prevention, and PrEP can receive the necessary attention. In all, participants called for more creative and strategic thinking and work to reach women who need PrEP.

**Figure 6: Successes, Challenges, and Priorities Shared by Three Programs Currently Implementing PrEP for Women in New York State**

SHARED SUCCESSSES	SHARED CHALLENGES	SHARED PRIORITIES
PrEP services have been implemented	Complexity of women's lives	Outreach and education to increase women's knowledge of PrEP
PrEP services are in demand	Stigma associated with PrEP use	Counseling to help women understand their risk of HIV
Response to PrEP outreach has been good	General perception that PrEP is for gay White men	Expanded services for women

## SUMMARY OF BREAKOUT SESSIONS AND REPORT OUT

Meeting participants were divided into three groups and invited to rotate through three breakout sessions, each of which addressed topics identified in advance as important to any discussion of PrEP implementation for women. Group discussions were facilitated by AIDS Institute staff, who then reported on the groups' responses to questions about the following:

- Awareness of PrEP among women and their care providers
- Perception of risk among women and their care providers
- Women's access to PrEP

### SESSION 1: AWARENESS OF PREP AMONG WOMEN AND THEIR CARE PROVIDERS

**Figure 7: Participants' Responses to Breakout Session 1 Discussion Questions**

<b>QUESTIONS:</b> Given that healthcare settings are places where women are likely to hear about PrEP, which care delivery settings should be prioritized for PrEP education? In which settings are care providers best positioned to reach women, and how should education be accomplished?			
Correctional Healthcare Settings	STI and Sexual Health Clinics	Family Planning Services, All Settings	Substance Use Treatment, All Settings
<ul style="list-style-type: none"> <li>• Focus education efforts on discharge planners</li> <li>• Educate inmates so they know to ask about PrEP</li> <li>• Set the standard of offering PrEP at intake and at discharge</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure that care providers educate all patients who seek care and services, regardless of risk assessment results</li> <li>• Ensure that care providers are able to offer PrEP on-site and on demand or have partnerships for referral</li> </ul>	<ul style="list-style-type: none"> <li>• Train all levels of care providers</li> <li>• Encourage care providers to bundle PrEP education with contraception education as a standard of care</li> <li>• Provide patient education materials and make sure they are readily available so patients can ask care providers about PrEP</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure that care providers who work in detox settings are able to educate their patients about PrEP</li> <li>• Make provision of PrEP education in detox settings a standard of care</li> </ul>
<ul style="list-style-type: none"> <li>• Provide incentives for clinicians: Award CME credits for participation in PrEP-related training</li> <li>• Make PrEP training and PrEP proficiency a requirement for licensure</li> <li>• Ensure adequate funding for training</li> <li>• Include PrEP training in NYSDOH curriculum for care providers and front-line staff in all settings</li> </ul>			

Figure 7: Participants’ Responses to Breakout Session 1 Discussion Questions, continued

QUESTION: Given the epidemiological evidence that women of color are disproportionately affected by HIV, how can we raise awareness of PrEP as a prevention option among Black women?			
Strategic Marketing, with Clear Messaging	Respect for Sensitivities	Relate PrEP to Sexual Health	Strategic Outreach
<ul style="list-style-type: none"> <li>• Use women who represent the audience as messengers so women can see themselves in the ads and public service announcements</li> <li>• Emphasize not just skin color, but all types of diversity: age, community, ethnicities</li> <li>• Messengers should speak with an array of accents, or in array of languages</li> <li>• Avoid unnecessarily complicated messages</li> <li>• Consider using well-known celebrities</li> </ul>	<ul style="list-style-type: none"> <li>• Respect and address a pervasive suspicion of drugs that are “supposed to be good for us”</li> <li>• Reassure women that PrEP does not affect fertility</li> </ul>	<ul style="list-style-type: none"> <li>• Make clear that PrEP affords women power and control over HIV prevention</li> <li>• Help women see that effective prevention of HIV is essential to the healthy sex life they deserve</li> <li>• Focus on the positive (PrEP as self-protection) instead of on “wrong” behaviors that make PrEP necessary</li> <li>• Use a positive approach to make messages easier to hear and to help combat the stigma associated with PrEP</li> </ul>	<ul style="list-style-type: none"> <li>• Take PrEP education and messaging to women</li> <li>• Deliver PrEP messaging in women-centered spaces</li> <li>• Package PrEP for women specifically create and distribute total prevention toolkits for women that include PrEP</li> </ul>
QUESTION: Is it possible to identify strategies for raising awareness of PrEP among women and their care providers globally—regardless of care setting or specialty areas of practice?			
Training	Messaging	Policy	Funding
<ul style="list-style-type: none"> <li>• Educate and train all clinical and non-clinical care providers who interact with patients or clients</li> <li>• Educate consumers to empower them to seek, ask about, and access PrEP</li> <li>• Deliver education as broadly as possible, making effective use of multimedia and all possible channels</li> </ul>	<ul style="list-style-type: none"> <li>• PrEP is affordable and payment assistance is available</li> <li>• PrEP is easy—one pill, once per day</li> <li>• PrEP is for sexual health and protection</li> <li>• Messengers should look and sound like their audiences</li> <li>• Women who are using PrEP can be powerful messengers—engage them</li> </ul>	<ul style="list-style-type: none"> <li>• Require inclusion of PrEP in quality of care activities and measures—use client risk ratio measure to set goals for numbers of patients on PrEP</li> <li>• Promote and support capacity-building among organizations that have access to and can reach target populations</li> <li>• Build PrEP into schools’ sex education curriculum</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure that adequate funding is provided to organizations that are providing PrEP services</li> <li>• Ensure that funding is available for traditional and non-traditional organizations that are effective in reaching target populations</li> </ul>

## SESSION 2: PERCEPTION OF RISK AMONG WOMEN AND THEIR CARE PROVIDERS

Figure 8: Participants' Responses to Breakout Session 2 Discussion Questions

<p><b>QUESTION:</b> Given that women do not often perceive themselves to be at risk of acquiring HIV, and that care providers' assumptions about risk are often incorrect, how can/should care providers assess women's risk?</p>
<p><b>Don't focus on risk assessment:</b> Clinicians should offer PrEP in response to a woman's sexual activity. The offer should not depend on "proof" of risk.</p> <p>Instead of asking about risk, care providers should ask open-ended, non-stigmatizing questions about sexual activity. Questions such as "Tell me about your ideal sex life" and "Tell me your concerns about HIV" convey sex positivity and a care provider's commitment to helping women have healthy sex and stay healthy.</p>
<p><b>Inform and educate; don't interrogate:</b> Instead of asking a woman "How many sex partners do you have?" a care provider can provide information: "Did you know that the more sex partners you have, the greater your risk of exposure to HIV?" and talk about why that's the case. Or, instead of asking a woman "Do you have anal sex?" a care provider can educate: "Did you know that when you have anal sex . . . ?"</p> <p>Instead of questions, care providers can describe possible scenarios, the risk involved, and ways for a woman to reduce risk, including use of PrEP, if she ever has a similar experience.</p>
<p><b>Make the offer of PrEP routine:</b> Care providers should build the discussion and offer of PrEP into <i>all clinical encounters</i> with all sexually active women as a routine part of health maintenance.</p> <p>Clinicians should encourage women to prioritize their sexual health and help them see HIV prevention as essential to healthy sex.</p>
<p><b>Do not deny PrEP:</b> There are only two absolute contraindications to PrEP—HIV infection and inadequate renal function. Offer PrEP to any woman who is sexually active, does not have HIV infection, and has adequate kidney function.</p> <p>Offer PrEP immediately to any woman who is diagnosed with an STI.</p>
<p><b>Make it easier for women to ask about PrEP:</b> Having enticing information available in the waiting room, in restrooms, and in treatment rooms will convey that PrEP is a welcomed topic of discussion.</p>

**Figure 8: Participants' Responses to Breakout Session 2 Discussion Questions, continued**

<p><b>QUESTION:</b> How should a care provider respond when a woman appears to be at risk of HIV acquisition but refuses PrEP?</p>
<p><b>Help women recognize indicators of risk:</b> A care provider can provide information about HIV prevalence in a woman's community and what that means for her.</p> <p>Discuss and explain the significance of "high-risk area" and "high-risk social networks."</p> <p>Help women understand the risk to her if a sex partner has any type of STI or if a partner has sex with others, whether she knows about it or not.</p>
<p><b>Support women's agency in healthcare decisions:</b> When a woman declines PrEP, her care provider should continue to provide information that will build knowledge and understanding about sexual health and the array of available risk reduction options, including PrEP.</p> <p>If a woman declines PrEP, her care provider should revisit the topic on more than one occasion not to nag, but to check in over time, as a woman's knowledge evolves and life circumstances change.</p>
<p><b>Make PrEP part of health maintenance list:</b> Care providers should make the discussion of HIV prevention and PrEP a topic of discussion during every clinical care visit.</p> <p>If a woman declines PrEP at one point, give her multiple opportunities to learn more and reconsider her decision. Readiness changes over time, as do priorities.</p>
<p><b>Offer more than one viable option for reducing risk:</b> Share all available resources in the HIV prevention tool-kit, and keep the door open to PrEP in the future.</p> <p>Resources offered to women should include the names and phone numbers of PrEP providers in the community.</p> <p>Engage other types of care providers, including peer educators when possible, in educating women about PrEP.</p>
<p><b>Avoid stigmatization:</b> A move away from risk assessment will help avoid the stigmatization of specific activities (e.g., any women who is sexually active should be offered PrEP, not just women who say they engage in anal sex).</p> <p>PrEP should be discussed as a part of sexual health, not as an antidote to undesirable behavior.</p>

## SESSION 3: WOMEN'S ACCESS TO PREP

“PrEP is like birth control: It prevents HIV like contraception prevents pregnancy.  
PEP is like the Plan B pill: It works when prevention doesn't.” — *Meeting participant*

**Figure 9: Participants' Responses to Breakout Session 3 Discussion Question**

<b>QUESTION: What barriers prevent women from accessing PrEP and how can they be overcome?</b>	
<p><b>HEALTHCARE BARRIERS:</b></p> <ul style="list-style-type: none"> <li>• Care providers who are not educated about PrEP or who have and act on misconceptions about PrEP</li> <li>• Not enough sources of PrEP services, especially in rural areas</li> <li>• Lack of PrEP on demand</li> <li>• Restrictions on care providers' time hinder development of the trust that fosters discussion of sexual health</li> </ul>	<p><b>SUGGESTED REMEDIES:</b></p> <ul style="list-style-type: none"> <li>• Make PrEP the domain and responsibility of multiple medical specialties, and train care providers across specialties and practice settings.</li> <li>• Divorce PrEP from the risk continuum.</li> <li>• Develop and deliver PrEP education to front-line staff in medical care settings, correctional settings, CBOs, hospitals, and schools.</li> <li>• Develop scripts to help care providers recognize how to build PrEP into many different types of patient encounters.</li> </ul>
<p><b>STRUCTURAL BARRIERS:</b></p> <ul style="list-style-type: none"> <li>• Cost of PrEP</li> <li>• Limited resources to help women with child care, employment, housing, and transportation</li> <li>• Immigration status</li> <li>• Lack of education</li> </ul>	<p><b>SUGGESTED REMEDIES:</b></p> <ul style="list-style-type: none"> <li>• Help women access PrEP payment assistance.</li> <li>• Help women meet the demands that compete for attention to their own health and link them to resources to help with essential needs.</li> <li>• Make it easy for women to get started by providing PrEP on demand.</li> </ul>
<p><b>PERSONAL AND SOCIAL BARRIERS:</b></p> <ul style="list-style-type: none"> <li>• Stigma</li> <li>• Mistrust of drug companies' motives and of PrEP effectiveness</li> <li>• Ageism (care providers often do not talk with older women about sex)</li> <li>• Fear of partner's discovery</li> </ul>	<p><b>SUGGESTED REMEDIES:</b></p> <ul style="list-style-type: none"> <li>• Help community-based PrEP champions come forward to help educate their peers.</li> <li>• Offer women multiple options for HIV prevention and improve topical PrEP delivery systems.</li> <li>• Make PrEP education widely available, including in secondary schools, so adolescents can learn where and when they're ready.</li> </ul>

## CONCLUSIONS:

### PRIORITIES FOR CHANGE TO EXPAND ACCESS TO AND IMPLEMENTATION OF PrEP FOR WOMEN IN NYS

Women in NYS are particularly vulnerable to HIV infection due to a mix of social, behavioral, and biological factors. Women accounted for 20% of new HIV diagnoses in 2015 in NYS, and nearly all (94%) of these women reported their transmission risk as heterosexual contact.<sup>4</sup>

In New York, women of color, and particularly Black women, have been disproportionately affected by HIV. In 2015, 59% of all new HIV diagnoses in women were in Black women, who comprise only 16% of the total population of women. Research in NYC demonstrated that few women know about PrEP and very few are using this prevention intervention.

## KEY ISSUES

This forum convened stakeholders from throughout New York to identify factors that impede PrEP uptake in women throughout the state. Many problems and barriers, with multiple sources, were identified. However, the key issues identified throughout the day fall into three main categories: awareness, attitudes, and access.

- **Awareness:** Neither women nor their care providers know much about PrEP. Care providers who don't know about PrEP, or who don't know how to prescribe it, can't offer PrEP or educate women about it. Women who don't know about PrEP or who have only seen PrEP marketed to gay men won't ask about it.
- **Attitudes:** Many care providers still focus on a "risk assessment" approach to HIV prevention interventions. This focus can introduce stigma because it centers on identifying "risky" or "bad" behaviors that a woman needs protection from. Care providers are also subject to the same messaging as women and may mistakenly believe that PrEP is for gay men, not women.
- **Access:** Women's lack of access to PrEP is a multifaceted problem with roots in lack of research on PrEP in women, inadequate funding, and limited availability. Researchers know the questions that still need to be answered about PrEP for women—where in a woman's body does it work and how? What can be done to improve topical PrEP? How can PrEP be made as easy as possible for women to use? PrEP services for women need to be funded at higher levels so PrEP can be provided to women in as many possible settings as possible and can be provided on demand.

## PRIORITIES FOR CHANGE

Attendees agreed on the following top priorities for change to help expand PrEP uptake among women in NYS:

### 1. Increase Awareness

- Teach care providers that PrEP should be a routine part of healthcare and teach them how to help women adopt that point of view.
- Develop and deliver effective messaging about PrEP for women, and especially women of color. Develop and deliver compelling educational materials and make them available in as many settings as possible. Provide PrEP education for women at all points of contact with the healthcare system and in all appropriate non-medical settings.
- Fund and vastly expand outreach to women.
- Make the idea of PrEP accessible to care providers and to women: Education and discussion of PrEP should be a routine part of health maintenance. Help women and their care providers to internalize this analogy: PrEP is like birth control (protection) and PEP is like "Plan B" (backup if protection fails).

### 2. Change Attitudes

- HIV is still an emergency and must be treated as such. Heterosexual women, and especially women of color, are disproportionately affected by HIV in New York. The risk to women is great, and the need to prevent HIV acquisition in women is urgent. This is a responsibility for all care providers in all settings.
- Encourage care providers to focus less on risk behavior assessments that may not identify all indicators for PrEP in women. PrEP should not be tied to risk behavior assessments; it should be given to any woman who requests it. PrEP should be offered to anyone who is tested for HIV or any other STI. PrEP is for protection against HIV and for healthy sex, and so it should be routinely offered to any woman who is sexually active.

<sup>4</sup> "Female Sex Assigned at Birth, Newly Diagnosed with HIV Infection by Age at Diagnosis and Transmission Risk Category, NYS, 2015". Bureau of HIV/AIDS Epidemiology, AIDS Institute, NYSDOH.

- Focusing on risk reinforces stigma. Focusing on sexual health helps eliminate stigma. Care providers must shift their perspective away from emphasizing risk and fear and toward sexual health and health maintenance. PrEP should be promoted as a key to good health.
- Focusing on individual risk behavior places undue pressure on individuals and their care providers. Individual women may or may not know, for instance, whether a sex partner has HIV infection or is monogamous. But every woman will know if she is having sex. Care providers may not know whether a woman is remembering or reporting all possible risky behaviors and will not be able to tell a woman's risk by looking at her. But care providers will be able to ask a woman whether she is sexually active and will be able to describe scenarios that may place her at risk and provide information about protective actions. Care providers can also learn about geographic areas with high HIV prevalence, inquire about where a woman lives, and offer PrEP based on geography.
- PrEP is an integral part of women's healthcare and should be treated as such—discussion of PrEP and education about PrEP should be as common as discussion of blood pressure, diet, and exercise.

### **3. Expand Access**

- Access starts with care providers—a care provider who does not know about PrEP and understand its role in sexual health cannot offer PrEP to women. Care providers must be educated about PrEP.
- Expand support for PrEP—train non-clinical care providers about PrEP. Make sure that everyone who can talk about PrEP with women and who can provide education and information is able to do so.
- Expand points of access—make PrEP available in as many settings as possible—and make PrEP available on demand.
- Increase awareness of payment mechanisms available to help cover the costs of PrEP prescriptions and related costs.

**Figure 10: Summary of Top Priorities for Increasing Uptake of PrEP among Women in New York**

**PrEP for Women Forum attendees agreed that the top priorities for change to ensure success in expanding uptake of PrEP among women in NYS in the next 3-5 years should be:**

### **1. Increase Awareness**

- Greatly expand education about PrEP to care providers across multiple specialties and practice settings.
- Promote PrEP as a routine part of women's healthcare.
- Develop and deliver effective messaging about PrEP for women, especially to women of color.

### **2. Change Attitudes**

- Remind care providers in all practice settings that HIV remains an emergency and preventing HIV among women is a responsibility shared by all who provide healthcare services to women.
- Encourage a move away from the current focus on risk assessment and risk-based interventions. PrEP is for sexual health.
- Promote widespread understanding of PrEP as an integral part of women's healthcare so that discussion of PrEP and education about PrEP become as common as discussions of blood pressure, diet, and exercise.

### **3. Expand Access**

- Utilize training and education to increase the numbers of clinical care providers who are able to prescribe PrEP.
- Train non-clinical care providers about PrEP to ensure that every health professional and paraprofessional who is in a position to talk about PrEP with women and provide education and information is equipped to do so.
- Expand points of access—make PrEP available in as many settings as possible—and make PrEP available on demand.
- Increase awareness of payment mechanisms available to help cover the cost of PrEP prescriptions and related expenses.

## APPENDIX A: MEETING AGENDA

- 9:30 AM–9:40 AM **Welcome and Introductions:**  
Laura Duggan Russell, MPH, Senior Program Coordinator, Office of the Medical Director, NYSDOH AIDS Institute
- 9:40 AM–9:50 AM **Opening Remarks:**  
Johanne Morne, MS, Director, NYS DOH AIDS Institute
- 9:50 AM–10:00 AM **Opening Remarks:**  
Demetre Daskalakis, MD, Deputy Commissioner, Disease Control, NYC DOHMH

### PART I: INVITED SPEAKERS

- 10:00 AM–10:30 AM **The Conundrum of Topical and Systemic PrEP for Women: How to Deliver the Right Drugs to the Right Place at the Right Time**  
Betsy C. Herold, MD, Professor of Pediatrics and Microbiology-Immunology, Vice Chair for Research in the Department of Pediatrics, and Division Chief, Pediatric Infectious Diseases at Albert Einstein College of Medicine and the Children's Hospital at Montefiore, Bronx, NY
- 10:30 AM–11:00 AM **Beyond Condoms: Pre-Exposure Prophylaxis for Women During Preconception, Pregnancy, and Lactation**  
Maria Teresa Timoney CNM, Director, Women's HIV Services, Department of Obstetrics and Gynecology, Bronx Lebanon Hospital Center
- 11:00 AM–11:30 AM **"Is That for Me?": Challenging Assumptions about PrEP for Women in the U.S.**  
Dázon Dixon Diallo, MPH, DHL, Founder and President of SisterLove, Inc.
- 11:30 AM–12:00 PM **Questions & Answers**

### PART II: WORKING LUNCH WITH PANEL DISCUSSION

- 12:15 PM–1:00 PM **Real-World Experiences in Implementing PrEP for Women**  
  - Jamie Morrill, PrEP Specialist, Trillium Health
  - Debra Lesane, Program Director, Caribbean Women's Health Association, Inc.
  - Kate Collier, PhD, MPH, Director of Research & Evaluation, Planned Parenthood of New York City
- 1:00 PM–1:15 PM **Questions & Answers**

### PART III: ROUND-ROBIN BREAKOUT SESSIONS

- 1:15 PM–2:45 PM **Participant Discussions:** Attendees will circulate through three 25-minute breakout sessions to discuss their experiences with the following key topics in PrEP implementation for women: awareness of PrEP, perception of risk for HIV, and access to PrEP. After 25 minutes of discussion in one session, participants will be directed to the next session until everyone has had the opportunity to participate in each of the three sessions. After a short break, we will gather to report out and identify priorities for policy and change.

### PART IV: PRIORITIES FOR POLICY AND CHANGE: REPORTS FROM BREAKOUT SESSIONS

- 3:00 PM–3:45 PM **Report Out: Successes, Challenges and Priorities for Change:** Session leaders will report out to the whole group with the goal of identifying the top 3-5 items in each of the following areas:  
  - Issues and challenges unique to PrEP implementation for women
  - Keys to success, including best practices for engaging women
  - Policies needed to increase PrEP uptake among women
  - Priorities for change to guarantee success in the next 3 years
  - Based on concerns and solutions identified are there suggested policy changes/program changes/interventions?
- 3:45 PM–4:00 PM **Next Steps and Closing Remarks:** Laura Duggan Russell

## APPENDIX B: SPEAKER BIOS

### Kate Collier, MPH, PhD

Dr. Collier is the Director of Research and Evaluation at Planned Parenthood of New York City. In this role, she conducts research to support new agency initiatives and serves as the evaluator for PPNYC's Project Street Beat program. Kate has previously worked for the HIV Center for Clinical and Behavioral Studies at Columbia University and the NYS Psychiatric Institute, the Columbia University Mailman School of Public Health, and Gay Men's Health Crisis. She holds a PhD in social sciences from the University of Amsterdam.

### Demetre Daskalakis, MD, MPH

Dr. Daskalakis is the Deputy Commissioner for the Division of Disease Control at the New York City Department of Health and Mental Hygiene. Dr. Daskalakis directs the public health laboratory and all infectious disease control programs for New York City, including HIV, tuberculosis, STIs, vaccine-preventable diseases, and general communicable diseases. His division is one of the largest in the Department, employing more than 1,000 staff, managing >\$350 million, and operating 17 clinical facilities. He received his medical education from NYU School of Medicine and completed his residency training in 2003 at Beth Israel Deaconess Medical Center in Boston. He also completed Clinical Infectious Disease fellowships at the Brigham and Women's/Massachusetts General Hospital combined program. He received his master's degree in public health from the Harvard School of Public Health. He has been a career-long physician-activist in the area of HIV treatment and prevention among LGBTQ+ people.

### Dázon Dixon Diallo, MPH, DHL

Dr. Diallo is a advocate in the struggle for women's human rights and reproductive justice, and the fight against HIV/AIDS, on behalf of communities of women living with HIV and those at risk of HIV and STIs. In 1989, Diallo founded SisterLove, Inc., the first women's HIV/AIDS and RJ organization in the southeastern United States. She is a member of In Our Own Voice: The National Black Women's Reproductive Justice Agenda, where she advocates for sexual and reproductive justice in public health and prevention policies and programs. Diallo is a member of the Board of Directors of the National Women's Health Network, is a founding member of the 30 for 30 Campaign for Women in the National HIV AIDS Strategy, serves on the Fulton County HIV Advisory Board and is a co-chair for the Act Now End AIDS national coalition. She was recently appointed to the National Institutes of Health Office on AIDS Research Advisory Council. Dr. Diallo holds a master's degree in public health from the University of Alabama at Birmingham and bachelor's degrees from Spelman College. In 2012, Diallo received an honorary Doctorate of Humane Letters from her alma mater, Spelman College. She convenes the only national coalition of women focused on HIV and biomedical prevention, the US Women & PrEP Working Group.

### Betsy C. Herold, MD

Dr. Herold is Professor of Pediatrics and Microbiology-Immunology; Vice Chair for Research in the Department of Pediatrics; and Division Chief, Pediatric Infectious Diseases at Albert Einstein College of Medicine and the Children's Hospital at Montefiore in the Bronx, NY. Dr. Herold graduated from the University of Pennsylvania Medical School, completed a residency in pediatrics, clinical fellowship in pediatric infectious diseases, and postdoctoral fellowship in herpes virology at Northwestern University. She leads a translational research program focused on understanding HSV entry and pathogenesis, the HIV-HSV syndemic, and exploiting that knowledge to develop safe and effective antiviral therapies including vaccines and PrEP. Her team is studying intravaginal rings to protect women from HIV and HSV.

### Debra Lesane

Ms. Lesane has more than 30 years of experience in the following areas of healthcare: strategic planning, program planning and development, and community affairs and advocacy. Ms. Lesane has worked in a variety of healthcare settings, including hospitals, mental health treatment organizations, and community-based organizations. Her career focus has been to develop health education programs and support services to underserved communities and to contribute to the overall elimination of health disparities in NYC. Ms. Lesane is the Director of Programs at the Caribbean Women's Health Association, Inc. (CWAHA), which is located in the Flatbush section of Brooklyn. CWAHA provides a variety of services throughout NYC, including HIV testing and counseling, maternal and child health support programs, immigration legal assistance, and Medicaid/health insurance enrollment services. Ms. Lesane has recently been very involved in promoting community engagement in the implementation of the Delivery System Reform Incentive Payment Program in Brooklyn.

**Johanne Morne, MS**

Ms. Morne serves as Director of the NYS Health Department's AIDS Institute, where she directs policy and program development related to HIV, hepatitis C, STDs, drug user health, and LGBTQ+ health. She has worked closely with community stakeholders in implementing the governor's plan to end the AIDS epidemic in NYS by the end of 2020. Ms. Morne has bachelor's degrees in psychology and social work and holds a master's degree in education and counseling from the College of St. Rose. Before joining the Health Department, Ms. Morne directed community-based services at Whitney M. Young, Jr. Health Center, serving as clinical supervisor of chemical dependency services and program director of community outreach, mental health, and HIV services. At Albany Medical Center, Ms. Morne served as quality manager of psychiatry, behavioral health, and HIV services. She served as adjunct professor in the Sociology Department at the University of Albany for two years. Ms. Morne's professional and clinical experience is in public health and behavioral health, particularly within communities of color.

**Jaime Morrill**

Ms. Morrill is a PrEP Specialist from Rochester, New York. For the last year and a half she has worked at Trillium Health, first as a Retention and Adherence Specialist, and now, for almost a year, as a PrEP Specialist. Trillium Health is a neighborhood health center that specializes in LGBTQ+ services. While completing her bachelor's degree in social work from SUNY Brockport, Jaime spent a year in Vietnam working with veterans and victims of Agent Orange. She then came to Trillium Health where her passion for helping others directed her at ETE 2020.

**Maria Teresa (Tess) Timoney, CNM**

Ms. Timoney is the Director of Women's HIV Services for the Department of Obstetrics and Gynecology at Bronx Lebanon Hospital Center, where she has been providing obstetric and gynecological care for women with HIV infection since 2001. She has been actively involved in HIV prevention efforts throughout her career, from her role as a colposcopist for the HIV Prevention Trials Network Vaginal Microbicide Trials, to her current role as an investigator for IMPAACT. In 2016, she completed the Greater New York Hospital Association United Hospital Fund Clinical Quality Fellowship. She is currently working to implement expanded PrEP eligibility screening across the Bronx Lebanon Ambulatory Care Network. She attended the Columbia University School of Nursing and Barnard College. Before becoming a midwife, Ms. Timoney worked for many years as an artist and curator in New York City. She is most grateful to the women she has met and cared for in her practice at Bronx Lebanon.

## APPENDIX C: PREP PAYMENT OPTIONS IN NEW YORK STATE

Payment Assistance Options	Coverage or Services	Eligibility
<p><b>Private Insurance</b></p>	<ul style="list-style-type: none"> <li>• Most plans cover PrEP</li> <li>• Coverage varies based on plan, and there may be deductibles and co-payments</li> </ul>	
<p><u>Medicaid</u>  <b>HELPLINE: (800) 541-2831</b></p> <p><b>AIDS Drug Assistance Program (ADAP) Provider Relations:</b></p> <p><b>In state, toll free: (800) 542-2437</b>  <b>Out of state: (518) 459-1641</b></p> <p><b>E-mail: <a href="mailto:ADAP@health.ny.gov">ADAP@health.ny.gov</a></b></p>	<ul style="list-style-type: none"> <li>• PrEP prescription costs, medical appointments, and lab tests</li> </ul>	<ul style="list-style-type: none"> <li>• Prior approval that must be renewed every 3 months</li> </ul>
<p><u>PrEP Assistance Program (PrEP-AP)</u></p> <p><b>AIDS Drug Assistance Program (ADAP) Provider Relations:</b></p> <p><b>In state, toll free: (800) 542-2437</b>  <b>Out of state: (518) 459-1641</b></p> <p><b>E-mail: <a href="mailto:ADAP@health.ny.gov">ADAP@health.ny.gov</a></b></p>	<ul style="list-style-type: none"> <li>• Doctors' visits and lab tests</li> <li>• HIV and STI/STD testing, counseling, and supportive primary care services consistent with PrEP clinical guidelines</li> <li>• PrEP medications obtained through manufacturer patient assistance programs (PAP)</li> </ul>	<ul style="list-style-type: none"> <li>• There is no age limitation, but to be eligible, a patient must be: <ol style="list-style-type: none"> <li>1) Not HIV-infected</li> <li>2) At risk acquiring of HIV</li> <li>3) A resident of NYS</li> <li>4) Uninsured or underinsured</li> <li>5) At 435% of the Federal Poverty Level (FPL) or lower with annual income</li> </ol> </li> <li>• To be eligible, providers must be: <ol style="list-style-type: none"> <li>1) Enrolled in the NYS Medicaid Program</li> <li>2) Responsible for assisting patients with the PAP application to receive Truvada as indicated for PrEP</li> </ol> </li> </ul>
<p><u>Gilead Advancing Access Co-Pay Program</u></p> <p><b>Phone: (877) 505-6986</b></p>	<ul style="list-style-type: none"> <li>• Up to \$300/month in prescription co-payments</li> </ul>	<ul style="list-style-type: none"> <li>• To be eligible, patients must: <ol style="list-style-type: none"> <li>1) Be 18 years of age or older</li> <li>2) Have private insurance</li> <li>3) NOT be enrolled in Medicare or Medicaid</li> </ol> </li> </ul>
<p><u>Gilead Truvada for PrEP Medication Assistance Program</u></p> <p><b>Phone: (855) 330-5479</b></p>	<ul style="list-style-type: none"> <li>• Prescription costs</li> </ul>	<ul style="list-style-type: none"> <li>• There is no age limitation, but to be eligible, patients must: <ol style="list-style-type: none"> <li>1) Have insurance and coverage for prescription medications</li> <li>2) Have an annual income less than 400% of FPL</li> </ol> </li> </ul>

PrEP PAYMENT OPTIONS AVAILABLE IN NYS, CONTINUED		
Payment Assistance Options	Coverage or Services	Eligibility
<p><a href="#">Patient Advocate Foundation Co-Pay Relief Program</a></p> <p>Phone: (866) 512-3861</p> <p>Applications may be submitted <a href="#">online</a> or by phone: (866) 512-3861, M-F 8:30 AM to 5:30 PM, EST, by patients or by their medical care provider or pharmacist</p>	<ul style="list-style-type: none"> <li>Up to \$5,000 in assistance toward pharmaceutical expenses related to prevention, treatment and management of HIV or AIDS</li> </ul>	<ul style="list-style-type: none"> <li>There is no age limitation, but to be eligible, patients must:               <ol style="list-style-type: none"> <li>1) Have insurance and coverage for prescription medications</li> <li>2) Have an annual income less than 400% of FPL</li> </ol> </li> </ul>
<p><a href="#">Partnership for Prescription Assistance (PPA) Program</a></p> <p>Phone: (888) 477-2669</p>	<ul style="list-style-type: none"> <li>Helps uninsured and underinsured Americans get prescription medications and access to clinics at no or low cost</li> </ul>	<ul style="list-style-type: none"> <li>Visit the website, enter drug names, and complete an online questionnaire to learn of available options</li> </ul>
<p><a href="#">Gilead Advancing Access</a></p> <p>Phone: (800) 226-2056</p> <p>Applications may be submitted <a href="#">online</a> or by phone: (800) 226-2056. Counselors are available M-F, 9 am to 8 pm EST; confidential messages may be left at any time</p>	<ul style="list-style-type: none"> <li>Matches patients to a Gilead assistance program based on eligibility criteria</li> </ul>	

## APPENDIX D: RESOURCES

### PrEP/PEP Directories

- NYS Department of Health PrEP/PEP Voluntary Provider Directory: [http://www.health.ny.gov/diseases/aids/general/prep/provider\\_directory](http://www.health.ny.gov/diseases/aids/general/prep/provider_directory)
- NYS Department of Health PrEP-AP Participating Provider Directory: [http://www.health.ny.gov/diseases/aids/general/prep/docs/prep-ap\\_directory](http://www.health.ny.gov/diseases/aids/general/prep/docs/prep-ap_directory)
- Please PrEP Me – National PrEP Provider Directory: <https://www.pleaseprepme.org/>

### Online Resources

- HIVE Blog “Share Your Story”: <https://www.hiveonline.org/share-your-story/>
- PrEPforSex.org: <https://www.prepforsex.org>
- Project Inform–PrEP: <https://www.projectinform.org/prep>
- SisterLove, Inc.: <http://www.sisterlove.org>
- U.S. Women & PrEP Working Group: [uswomenprepworkinggroup@gmail.com](mailto:uswomenprepworkinggroup@gmail.com)

## APPENDIX E: MEETING PARTICIPANTS

### **Bisrat Abraham, MD**

New York City Department of Health  
and Mental Hygiene (NYC DOHMH)

### **Jessica Atrio, MD, MSc, FACOG**

Albert Einstein College of Medicine

### **Ofelia Barrios**

Iris House

### **Oni Blackstock, MD, MHS**

Albert Einstein College of Medicine,  
Montefiore Medical Center

### **Erin Bortel, MSW**

New York State Department of Health  
(NYSDOH) AIDS Institute

### **Gina Brown, MD**

National Institutes of Health

### **Kate Collier, PhD, MPH**

Planned Parenthood of New York City

### **Richard Cotroneo**

NYSDOH AIDS Institute

### **Melissa Creighton, CNM, IBCLC**

North Central Bronx Hospital

### **Erica Crittendon**

NYC DOHMH

### **Demetre Daskalakis, MD, MPH**

NYC DOHMH

### **Dázon Dixon Diallo, MPH, DHL**

SisterLove

### **Laura Duggan Russell, MPH**

NYSDOH AIDS Institute

### **Zoe Edelstein, PhD**

NYC DOHMH

### **Tracie Gardner**

The Legal Action Center

### **Charles Gonzalez, MD**

NYSDOH AIDS Institute

### **Jessica Gourdet-Murray**

NYSDOH AIDS Institute

### **Sharon Griffith, MD**

Community Healthcare Network

### **Linda Hakim, MS**

Westchester County Department  
of Health

### **Mary Beth Hansen, MA**

Johns Hopkins University (JHU)  
HIV Clinical Guidelines Program

### **Julie Harris**

NYSDOH AIDS Institute

### **Betsy Herold, MD**

Albert Einstein College of Medicine

### **Marcia Kindlon**

NYSDOH AIDS Institute

### **Beryl Koblin, PhD**

NY Blood Center

### **Michael Lecker, MD**

Trillium Health

### **Debra Lesane**

Caribbean Women's Health Association

### **Deborah Levine, LCSW**

ACRIA, Love Heals

### **Nathan Levitt, MSN, FNP-BC**

Community Healthcare Network

### **Michelle Logan**

NYSDOH AIDS Institute

### **Lissette Marrero, MSW**

U.S. Department of Health and  
Human Services

### **Jaime Martin, MPH**

NYC DOHMH

### **Mike McNair**

NYSDOH AIDS Institute

### **Bethsy Morales, MA**

Hispanic Federation

### **Johanne Morne, MS**

NYSDOH AIDS Institute

### **Jaime Morrill**

Trillium Health

### **Christina Norwood, MS, ELS**

JHU HIV Clinical Guidelines Program

### **Jennifer O'Connor**

NYSDOH AIDS Institute

### **Nkechi Oguagha**

NYSDOH AIDS Institute

### **Joanna Palladino**

NYSDOH AIDS Institute

### **Margaret Reneau, EdD, MA, MS**

National Black Leadership Conference  
on AIDS

### **Peggy Rivera**

Planned Parenthood Nassau County

### **Roberta Ross**

Caribbean Women's Health Association

### **Lena Saleh**

NYC DOHMH

### **Julia Siren, D., NP.**

CrescentCare Health

### **Cheryl Smith, MD**

NYSDOH AIDS Institute

### **Lyn Stevens, MS, NP, ACRN**

NYSDOH AIDS Institute

### **Dora Swan**

NYSDOH AIDS Institute

### **Maria Teresa Timoney, CNM**

Bronx Lebanon Hospital Center

### **Amanda Wahnich**

NYC DOHMH

### **Terri Wilder, MSW**

Mount Sinai Institute for  
Advanced Medicine

### **Beth Woolston**

NYSDOH AIDS Institute

### **Ashley Zuppelli, RPh,**

PharmD, AAHIVP

Trillium Health