March 2019

Dear Colleague:

Reverend Dr. Martin Luther King, Jr. once said, “Faith is taking the first step even when you don’t see the whole staircase.” We have come a long way since the beginning of our effort to end the AIDS epidemic (ETE) in June of 2014. Now, as our ETE programming is implemented and we continue to make refinements to improve outcomes, I believe we have an opportunity to make 2019 truly epic!

The 2018 Ending the Epidemic (ETE) Summit held in Albany on December 4-5 was a great success, featuring more than 70 community-driven presentations and posters describing the innovative work being done across our state. It was also an opportunity to celebrate our ongoing success, as demonstrated by the latest epidemiological data from the end of 2017. These data indicate:

- Continued decreases in new HIV cases, with 2,769 new diagnoses in 2017, a 20% drop from 2014 and a 4% drop from 2016;
- Continued increases in linkage to care within 30 days, meeting our 2017 target metric of 81%;
- Significant increases in PrEP utilization, with more than 24,000 people taking advantage of PrEP; and,
- Strong evidence that we are indeed “bending the curve” of the epidemic, as outlined in the initial ETE announcement in 2014.

If you were not able to attend the ETE Summit, you can still take advantage of the great resources by visiting 2018 Ending the Epidemic Summit.

This letter outlines priorities that build upon the three points addressed in my January 2018 Call to Action letter. Since issuing that call to action, we have made strides on each of the three points, as indicated by data from our Quality of Care Program and NY Links, where facility-level cascades show increases in the percent of newly diagnosed persons entering care within three days and increases in rates of viral suppression among people engaged in any care. There is also good reason to believe that we are making significant facility-level progress addressing the long-standing problem of HIV stigma.

In addition, AIDS Institute-funded clinical sites and community-based organizations (CBOs) providing care coordination activities are required to enter client-level viral load data into the AIDS Institute Reporting System (AIRS). This allows the AIDS Institute to review rates of viral load suppression across different initiatives as well as other demographic considerations. These efforts help facilitate “real-time” monitoring of our progress, which is required as we work to promote viral suppression for all people living with HIV (PLWH).

In 2019, I ask that we continue our commitment to promote rapid access to treatment, increase rates of viral suppression, and eliminate stigma as we fine-tune our efforts to address the following additional priorities:

**Additional Priority # 1: Address the issue of concurrent HIV/AIDS diagnosis.**

Our ultimate goal is early identification of HIV, but according to 2017 data, 20% of new HIV diagnoses were accompanied by a diagnosis of AIDS. This means that these individuals were living with HIV and unaware of it
for some time. Based on these data, it is likely that the same is true for a significant percentage of the approximately 11,000 New Yorkers who are living with HIV but remain unaware of their status. In some cases, these individuals are interacting with the health care system and are not being offered HIV testing, representing a missed opportunity and a likely significant departure from both the standard of care and state regulation. In other cases, these individuals may be actively avoiding the health care system due to fear of being diagnosed and the stigma associated with HIV. To address the problem of concurrent HIV/AIDS diagnosis, we must:

- **Make routine HIV testing truly routine:** In 2018, the Department of Health (DOH) disseminated guidance regarding updated HIV testing regulations. The removal of the requirement to obtain consent in writing or orally helped to streamline the offer of HIV testing and increase testing rates at regulated settings. In the *HIV Testing, Reporting and Confidentiality in New York State: 2017-18 Update*, it was noted that the DOH will require “corrective action plans as needed to ensure implementation of the testing law standards.” Primary care providers, urgent care facilities, hospital inpatient and emergency departments, and other regulated facilities and providers must act now to implement the routine offer of HIV testing as a part of health care.

- **Fine-tune recruitment efforts of testing programs:** In 2018, the AIDS Institute offered training to assist HIV testing programs in fine-tuning recruitment efforts to best reach those living with HIV who are unaware of their status. Our ability to address concurrent HIV/AIDS diagnoses depends largely on the success of these programs using data and partnering within their communities to guide testing efforts to reach those who are living with HIV and are not aware of their status.

- **Ensure that all individuals with a concurrent AIDS diagnosis are afforded rapid initiation of HIV treatment:** Whenever a newly diagnosed person presents with an opportunistic infection (OI) or initial lab work indicates a CD4 count below 200, rapid initiation of an effective ART regimen is a must, along with adherence support and needed wrap-around services. The only exceptions to rapid ART initiation would be individuals diagnosed with tuberculosis, tuberculosis meningitis or cryptococcal meningitis, due to concerns of overlapping toxicities. Consultation with a clinician experienced in managing ART with acute OIs is recommended. For more information, visit *Initiating ART Following Acute OIs*.

- **Combat HIV stigma in every venue and with every tool we have so that people will not be afraid to have an HIV test, engage in HIV care or take advantage of PrEP:** Excellent work was done in 2018 as HIV clinical sites undertook efforts to combat stigma as part of the NYS Quality of Care Program. The HIV Quality of Care Program will continue this focus in 2019. The AIDS Institute’s new training, “*From Stigma to Affirmation,*” helps non-clinical providers identify concrete steps that can be taken to address stigma. The ETE Summit was the perfect venue to unveil our state’s new U=U campaign: “*Community Stepping Forward: I Won’t/Can’t Transmit HIV to Anyone.*” The AIDS Institute is supporting a statewide multi-level campaign on billboards, in subway cars, health care sites, pharmacies, social media platforms/dating sites, and TV spots. It is our great hope that this campaign, along with all of your efforts, will move the needle on stigma such that every individual will feel comfortable coming forward for an HIV test, HIV treatment, or PrEP. Along with this campaign, the AIDS Institute has disseminated a *U=U FAQ*, which clarifies the definition of undetectable as viral load remaining below 200 copies/mL, in accordance with NYS Clinical Guidelines and CDC guidelines.

**Additional Priority # 2: Address the unique needs of older adults living with HIV.**

By the end of 2020, it is estimated that 70% of PLWH in NYS will be over the age of 50. An important ETE goal is the elimination of HIV-related mortality; 2018 saw the creation of a new methodology for assessing the extent to which individuals are dying from HIV-related causes. The new methodology involved performing a detailed medical chart review on a representative sample of 2016 NYS deaths among PLWH. The review was completed by IPRO in the fall of 2018. In addition to producing the state’s best estimate of HIV-related death, the results of the review are expected to help advance HIV-related care and prevention efforts in 2019 and beyond. Promoting positive health outcomes for PLWH now means addressing co-morbidities, such as
cardiovascular disease, liver disease, cancer, and other conditions associated with aging. It also means promoting smoking cessation and addressing behavioral health issues such as substance use, mental health, recovery from trauma, adherence burn-out and social isolation. This necessitates a high level of coordination between clinical providers and support services programs. New York’s Medicaid Health Homes, grant-funded programs, and other community partners have a critical role to play supporting older adults living with HIV. A comprehensive set of recommendations for addressing HIV among older adults was developed by the ETE Older Adults Advisory Group, and I encourage all providers to review these recommendations to identify concrete steps that can be taken in your community.

Additional Priority # 3: Ensure that Certified Peer Workers (CPWs) interested in working full-time have access to a salaried, livable wage. A recent survey of CPWs indicated that 74% of CPWs are compensated either on an hourly basis or through stipends. CPWs interested in full-time employment should have access to a salaried, livable wage and benefits comparable to other employees. Providing practicum opportunities for individuals interested in certification is also important for ensuring a pipeline for future CPWs as we work to determine the optimal size of the state’s peer workforce. CPWs have an important role to play in our ETE efforts, and the value of their work should be compensated accordingly.

Additional Priority # 4: Expand access to PrEP to all eligible individuals/populations. Significant progress is being made to ensure that PrEP is affordable and available. Effective 12/1/2017, all insurance plans in NYS that offer prescription drug coverage are required to cover PrEP. On December 26, 2018, the United States Preventive Services Task Force closed its public comment period on a draft recommendation that “clinicians offer pre-exposure prophylaxis (PrEP) with effective antiretroviral therapy to persons who are at high risk of HIV acquisition,” and afforded PrEP the highest possible grade. If the A-grade recommendation is adopted, it will set a new standard for clinical providers and insurers and will help to fully open the door to PrEP. Enrollment in PrEP-AP, the NYS financial assistance program that covers medical appointments and lab work associated with PrEP, is continuing to increase, covering 2,585 people since its inception on 1/1/2015. In 2015, 2017 and 2018, the AIDS Institute sponsored statewide forums to outline strategies for expanding access to PrEP to adolescents, women and women of transgender experience, respectively. The Latino Gay and Bisexual Men Advisory Group and Black Men Who Have Sex with Men Advisory Group also outlined implementation strategies to ensure gay and bisexual men of all races and ethnicities have equal access to PrEP. PrEP has also shown to be an important HIV prevention intervention for people who use drugs, affording protection for both sexual and needle-sharing behaviors. Just as our commitment to ending the epidemic will not be realized unless it extends to all populations, so too we must ensure that all populations have equal access to PrEP.

Early in the epidemic, AIDS took the lives of far too many young people. In 2018, we were sorely reminded of this as we lost several dear members of our Young Adult Consumer Advisory Committee. These losses remind me that, at its roots, our work is about building community and promoting self-worth and human dignity. In closing, I would like to thank each of you for your day-to-day efforts to meet each person you serve with compassion and kindness. I believe that together, by combining compassion and kindness with the power of HIV testing, ART, and PrEP, we will make 2019 epic indeed.

Sincerely,

Johanne E. Morne, MS
Director
AIDS Institute