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MEMORANDUM

TO: Leadership Team
Executive Directors of Voluntary Agencies
Willowbrook Parties

FROM: Eileen Zibell
Associate Attorney
Counsel's Office

DATE: May 4, 2012

SUBJECT: OPWDD Protocol for Obtaining Informed Consent for HIV Testing

New York State Law regarding HIV testing was amended in 2010 (see Chapter 308 of the Law of 2010). This Chapter mandates that HIV testing be offered to all persons between the ages of 13 and 64 receiving hospital or primary care services. The revision is intended to increase HIV screening and promote prompt treatment of individuals who test positive. Although the new law is intended to make HIV testing a routine part of health care, **written informed consent for testing is still required when a test is offered as part of routine health care in a hospital or as part of primary care services.** More information regarding the new law can be found at www.health.ny.gov/diseases/aids.

In keeping with the intention of this new law, OPWDD will facilitate compliance with the new requirements on behalf of the individuals we serve. Individuals who are at greatest risk for exposure to HIV are a priority for testing. The following factors contribute to an individual's risk for HIV exposure:

- a) A history of unprotected sex including vaginal, oral and anal sex;
- b) A history of IV drug abuse including "street drugs," vitamins, steroids and other injectable medications;
- c) Incarceration in jail or prison;
- d) Body piercing or tattoos; and
- e) Birth to a HIV positive mother.

Although individuals who are at high risk for exposure to HIV are a priority for testing, **all** individuals served by OPWDD should be offered the opportunity to be tested for HIV. Individuals, and the surrogates who provide consent on their behalf, should be educated and encouraged to consent to an HIV test as a part of the individual's routine health care.

Obtaining Consent

Although the HIV test requires only a blood draw and is not an invasive procedure, written informed consent is required by law for routine HIV testing. OPWDD regulations at 14 NYCRR 633.11 must be followed when seeking informed consent from individuals receiving services from OPWDD or from their surrogates.

- a) **Individuals who are self-consenting** - Individuals who are capable of providing consent to HIV testing must be given the opportunity to consent or decline testing. Staff should educate self-consenting individuals regarding this new requirement prior to their appointment with a primary care physician. In addition, if necessary, staff should advise the physician that OPWDD clinicians consider the individual to be capable of consenting. If an individual refuses to consent to an HIV test, staff should document the refusal in the individual's record and continue to educate the individual regarding the benefit of knowing his/her HIV status.
- b) **Individuals with an authorized surrogate** - For those individuals who are not capable of providing consent to HIV testing, but who have a health care agent, a guardian or an actively involved family member who acts as a surrogate pursuant to 14 NYCRR 633.11, consent must be sought from such surrogate. (This includes CAB for Willowbrook class members with full representation). If possible, staff should send the Department of Health's model consent form (or a consent form received from a physician's office) to the appropriate surrogate in advance of the individual's next scheduled medical appointment. If this does not occur, the information and form must be forwarded to the surrogate after the appointment.
- c) **Individuals in need of Surrogate Decision Making Committee (SDMC) Consent** - For those individuals who are not capable of providing consent to HIV testing, and who do not have a health care agent, a guardian or an actively involved family member to act as a surrogate pursuant to 633.11, an SDMC petition should be completed. The 220-A form has been amended for this purpose. Staff should work with individual's primary care physicians to evaluate and prioritize individuals in this category. If possible, several SDMC petitions for different individuals should be submitted together, so that they can be combined into one hearing. OPWDD will be working with SDMC to streamline the process for consent to HIV testing.

Whenever possible, applications for consent to other health care treatment submitted to SDMC should also include a request for consent to HIV testing.

Exceptions to the requirement to offer testing:

Providers are NOT required to offer HIV testing if the individual:

- a. is being treated for a life threatening emergency; or
- b. has previously been offered or has been the subject of an HIV related test (unless otherwise indicated due to risk factors); or
- c. lacks the capacity to consent and no other appropriate person is available to provide consent.

NOTE: This exception may lead many community providers to assume they do not need to offer HIV testing to individuals served by OPWDD. If surrogate consent has not been obtained prior to the individual's appointment, primary care physicians may not offer the test and will document this exception. However, OPWDD staff are expected to follow up with the appropriate consent giver following the appointment.

Occupational Exposures:

The new law also provides for **anonymous testing of a source patient** in cases of occupational exposure which create a significant risk of contracting or transmitting HIV infection if **all** of the following conditions are met:

- the source person is deceased, comatose or is determined by his or her attending professional to lack mental capacity to consent; and
- the source person is not expected to recover in time for the exposed person to receive appropriate medical treatment; and
- there is no person available or reasonably likely to become available who has legal authority to consent in time for the exposed person to receive appropriate medical treatment; and
- the exposed person will benefit medically by knowing the source person's HIV test results.

As always, a source person with capacity or his/her authorized surrogate may decline testing in the event of an occupational exposure, and an HIV test may not be conducted.

A physician may **only** order an immediate anonymous test when there has been an occupational exposure involving a source patient who is deceased, comatose or otherwise unable to consent. The medical benefit of knowing the source person's test result must be documented in the exposed person's medical record. Moreover, the law requires that the provider order an anonymous test of the source person with results being provided **only** to the attending professional of the **exposed** person and solely for assisting the exposed person in making appropriate decisions regarding post - exposure medical treatment. DOH strongly recommends use of a rapid, HIV test in these situations. The results of the anonymous test **cannot** be disclosed to the **source** person or placed in that source person's medical record.

NOTE: For needle-sticks and other types of occupational exposures in which the source person is an individual served by OPWDD, community providers may assume the person is not capable of consenting and has no surrogate immediately available and seek anonymous testing immediately. If staff are aware that this is occurring, they should make an attempt to contact the individual's authorized 633.11 surrogate by phone to obtain verbal consent prior to proceeding with anonymous testing. If consent is obtained, the results can and should be documented in the source person's medical record.

Written Informed Consent

Use of the DOH model forms (Informed Consent to Perform HIV Testing), or its equivalent is **required** unless the physician's office has provided its own HIV consent form. The model form can be found at <http://www.health.ny.gov/diseases/aids/forms/informedconsent.htm>

DOH requires that individuals receive 7 points of information about HIV before consenting. A description of these points can be found at:

http://www.health.ny.gov/diseases/aids/forms/docs/key_facts_before_testing.pdf

Please address any questions you may have regarding this memo to Vicki Schultz, Director of Nursing and Health Services (Victoria.Schultz@opwdd.ny.gov) or Eileen Zibell in Counsel's Office (Eileen.Zibell@opwdd.ny.gov).



TO: SDMC Volunteer Panelists
FROM: Thomas D. Fisher, SDMC Director
DATE: July 1, 2013
RE: HIV Testing in Surrogate Decision-Making
Committee Cases

In 2010, New York State took steps to make HIV testing a more routine part of health care services.

As of July 30, 2010, New York Public Health Law, Article 27F, requires, with limited exceptions, the routine offer of an HIV test to all patients, ages 13 to 64, in primary care settings, emergency departments and inpatient settings.

Statewide, one third of HIV-positive people learn their status only after reaching advanced stages of infection. Routine testing of individuals will enable earlier diagnoses of those infected and thereby take steps to preserve their own health and help prevent HIV transmission to others, as well as improve health outcomes for people living with HIV.

This law is designed to integrate HIV testing into the provision of routine health care. It also simplifies the process of informed consent, while strictly preserving the longstanding assurance of confidentiality associated with testing and results.

To facilitate implementation of this initiative into the Surrogate Decision-Making Committee process, we modified the "Certification on Medical Need Form SDMC 220-A", to encourage physicians to incorporate a request for HIV testing into an application for consent for other major medical treatment.

Attached to the case is "Say Yes to the Test". This document is issued by the NYS Department of Health and must accompany requests for HIV testing. It is also included for your consideration as supplemental medical information.

Should you have any questions or concerns please contact me at (518) 549-0328.

State Health Commissioner Urges All New Yorkers to Get an HIV Test

Approximately 30,000 infected persons in New York State have not been diagnosed

ALBANY, N.Y. (June 27, 2013) - In recognition of National HIV Testing Day on Thursday, June 27, State Health Commissioner Nirav R. Shah, M.D., M.P.H., today urged all New Yorkers to get tested for HIV, the virus that causes AIDS. An estimated 30,000 New Yorkers carrying the HIV virus are unaware they have it.

"Recent advances have greatly enhanced the treatments available to people who have HIV infections," Commissioner Shah said. "That is why it is important for people who may have the HIV virus and do not know, to get diagnosed and treated as soon as possible. New York State's HIV testing law provides a convenient and accessible way to get tested while visiting your health care provider."

Approximately 156,000 New Yorkers are infected with HIV, and 18 percent of them--nearly 30,000---are unaware they have the virus. Early diagnosis is critical to slowing the spread of the HIV virus. More than 30 percent of new HIV cases are considered "late diagnoses," defined as diagnosed with AIDS at the same time or within 12 months of the initial HIV diagnosis. Many of these individuals are immunologically compromised and pose a much higher transmission risk than those who are diagnosed early and receiving appropriate care and HIV medications.

Under the State's HIV testing law, which went into effect in September 2010, HIV testing must be offered to all individuals ages 13 to 64 who receive hospital or primary care services. The HIV test must be offered to inpatients, people seeking services in emergency departments, and people receiving primary care as outpatients at clinics or from physicians, physician assistants, nurse practitioners or midwives.

While everyone should know their HIV status, testing is particularly important for those who have:

- Injected drugs or steroids with others or used shared equipment (e.g. syringes, needles, works) currently or any time in the past;
- Been diagnosed with or been treated for hepatitis, tuberculosis (TB), or a sexually transmitted disease such as gonorrhea, Chlamydia or syphilis;
- Had unprotected vaginal, anal, or oral sex with multiple partners, anonymous partners, or men who have sex with men; or
- Had sex with a partner they located on the Internet.

Where to get an HIV test in your area:

In New York City:

Call: 1-800-TALK HIV or dial 311.

Rest of State:

| | |
|-------------------------------------|----------------|
| Albany Region | 1-800-962-5065 |
| Buffalo Region | 1-800-962-5064 |
| Lower Hudson Valley Region | 1-800-828-0064 |
| Rochester Region | 1-800-962-5063 |
| Long Island Region (Nassau/Suffolk) | 1-800-462-6786 |
| Syracuse Region | 1-800-562-9423 |

The New York State Department of Health (DOH) has a toll-free confidential AIDS Hotline, where individuals can call to learn more about HIV and get information about free HIV testing opportunities in their communities.

| | |
|---------|-----------------------|
| English | 1-800-541-AIDS (2437) |
|---------|-----------------------|

New HIV Testing Practices in New York Will Improve Screening and Early Diagnosis

- Versión español

ALBANY, N.Y. (September 14, 2010) – Under a new law that took effect this month, changes to New York State's HIV testing practices will increase opportunities for people to be screened for the virus and improve linkages with care and treatment services for individuals diagnosed with HIV.

"HIV/AIDS continues to be a major health concern for New Yorkers, and this important change in the law will make HIV testing more routine, while maintaining key patient privacy protections," said State Health Commissioner Richard F. Daines, M.D. "The law brings New York's testing practices more in line with guidelines issued by the federal Centers for Disease Control and Prevention and strengthens our efforts to combat HIV and AIDS."

An estimated 20 percent of HIV-positive New Yorkers are unaware they are infected, and 33 percent of persons newly identified with HIV have been infected long enough that they are diagnosed with AIDS within one year. Earlier testing would have linked these individuals to health care that could prevent the onset of AIDS and encourage them to take measures that would avoid transmitting the virus to others.

Some key changes enacted under the law signed by Governor David A. Paterson on July 30, 2010, that are now in effect include:

- HIV testing must be offered to all persons between the ages of 13 and 64 who receive hospital or primary care services, with limited exceptions noted in the law. The offering must be made to inpatients, persons seeking services in emergency departments, and persons receiving primary care as an outpatient at a clinic or from a physician, physician assistant, nurse practitioner or midwife.
- Consent for HIV testing can be part of a general durable consent to medical care, although specific opt-out language for HIV testing must be included.
- Consent for rapid HIV testing can be made verbally and noted by the health care provider in the medical record.
- Prior to being asked to consent to HIV testing, patients must be provided with information about HIV as required by the Public Health Law.
- Providers authorizing HIV testing must, with the patient's consent, arrange an appointment for care and treatment for persons confirmed positive.

Humberto Cruz, Director of the Department of Health's (DOH) AIDS Institute, said, "New York State continues to be an epicenter of the HIV epidemic. Over 120,000 people are living with HIV in New York, more than any other state in the country. We need to be working aggressively with all health care providers to ensure people who are infected are found early and offered the life-saving treatments that are available."

More information is available on the DOH website at http://www.nyhealth.gov/diseases/aids/testing/hiv_testing_law.htm

Resources have been posted, including model consent forms and answers to Frequently Asked Questions.

Revised: September 2010

How New York State's New HIV Testing Law Affects Consumers

Questions and Answers for NYS Residents

How has the law changed?

On July 30, 2010, Governor David Paterson signed an amendment to the New York State law that governs HIV testing. The amended law, which took effect on September 1, 2010, makes testing more readily available in health care settings, while also making it easier for patients to give their consent (permission).

How does the new law affect me as a health care consumer living in New York State?

With limited exceptions, the new State law requires health care professionals to offer all patients between the ages of 13 to 64 a voluntary HIV test. The law applies to anyone receiving treatment for a non-life-threatening condition in a hospital, a hospital emergency department or a primary care setting, such as a doctor's office or outpatient clinic.

Under the state's old law, patients could not receive HIV tests unless they first provided specific written consent. Under the new law, you can consent to a rapid HIV test by signing a general consent for medical care or by telling the provider that you agree to be tested. Rapid tests produce results within an hour. The provider must make a note of this conversation in your medical record. Though written consent is still required in some circumstances, the new law simplifies the process for providing it.

Why was the law changed?

HIV infection can spread more readily - and kills more readily - when people don't know they're infected. By integrating HIV testing into routine health care, the new law makes it easier to learn your current HIV status. If you find you are HIV-negative, you can take steps to stay negative. If you learn you are HIV-positive, your health care provider is now legally required to help link you to follow-up medical care, with your consent.

Is HIV testing mandatory?

No. HIV testing remains voluntary. Your health care provider cannot test you without first getting your consent. The provider also must inform you before conducting or ordering the test. You have the right to decline an HIV test before being subjected to one. If you are signing a general consent for medical services, you can decline testing by signing the opt-out section on the form.

If I refuse an HIV test, will the decision affect my care?

No. You will still be seen and treated for whatever condition brought you to seek health services. Health care services and treatment cannot be denied if you decline an HIV test.

Where can I get an HIV test?

The New York State Department of Health offers anonymous HIV testing (you don't give your name) throughout the state. These facilities will test anyone age 12 years or older, without charge, regardless of their health insurance coverage or immigration status. HIV testing is also available in hospitals, doctors' offices and community clinics. To find an HIV testing site near you, go to:

- Anonymous HIV Testing Sites

Does health insurance cover HIV testing?

Most managed care plans now cover HIV screening. It is also covered by New York State's Medicaid and Medicare programs.

How often should I be tested for HIV?

The U.S. Centers for Disease Control and Prevention (CDC) recommends getting re-tested for HIV if you have ever engaged in any of the following behaviors (even once) that might increase your risk:

- Injecting drugs or steroids with shared equipment (such as needles, syringes, or works)
- Having unprotected anal, vaginal, or oral sex
- Exchanging sex or drugs for money
- Having unprotected sex with anyone who has engaged in any of the activities above or whose HIV status you do not know

If you continue with any of these behaviors that increase your risk of HIV transmission, you should be tested every year. Talk to a health provider about an HIV testing schedule that is right for you.

If I am younger than 18 years old, do I need my parents' permission to get tested?

No. People under age 18 do not need parental consent to be tested for HIV or other sexually transmitted infections. Under the new HIV testing law, the test should be offered to you starting at age 13.

Are your test results kept confidential (private)?

Yes. Healthcare providers and laboratories are required to report positive HIV test results to the New York State Department of Health. But HIV test results - whether positive or negative - are kept strictly confidential in accordance with the law.

Revised: March 2011

Informed Consent to Perform HIV Testing

My health care provider has answered any questions I have about HIV/AIDS. I have been provided information with the following details about HIV testing:

- HIV is the virus that causes AIDS and can be transmitted through unprotected sex (vaginal, anal, or oral sex) with someone who has HIV; contact with blood as in sharing needles (piercing, tattooing, drug equipment including needles), by HIV-infected pregnant women to their infants during pregnancy or delivery, or while breast feeding.
- There are treatments for HIV/AIDS that can help an individual stay healthy.
- Individuals with HIV/AIDS can adopt safe practices to protect uninfected and infected people in their lives from becoming infected or being infected themselves with different strains of HIV.
- Testing is voluntary and can be done anonymously at a public testing center.
- The law protects the confidentiality of HIV test results and other related information.
- The law prohibits discrimination based on an individual's HIV status and services are available to help with such consequences.
- The law allows an individual's informed consent for HIV related testing to be valid for such testing until such consent is revoked by the subject of the HIV test or expires by its terms.

I agree to be tested for HIV infection. If the results show I have HIV, I agree to additional testing which may occur on the sample I provide today to determine the best treatment for me and to help guide HIV prevention programs. I also agree to future tests to guide my treatment. I understand that I can withdraw my consent for future tests at any time. If I test positive for HIV infection, I understand that my health care provider will talk with me about telling my sex or needle-sharing partners of possible exposure.

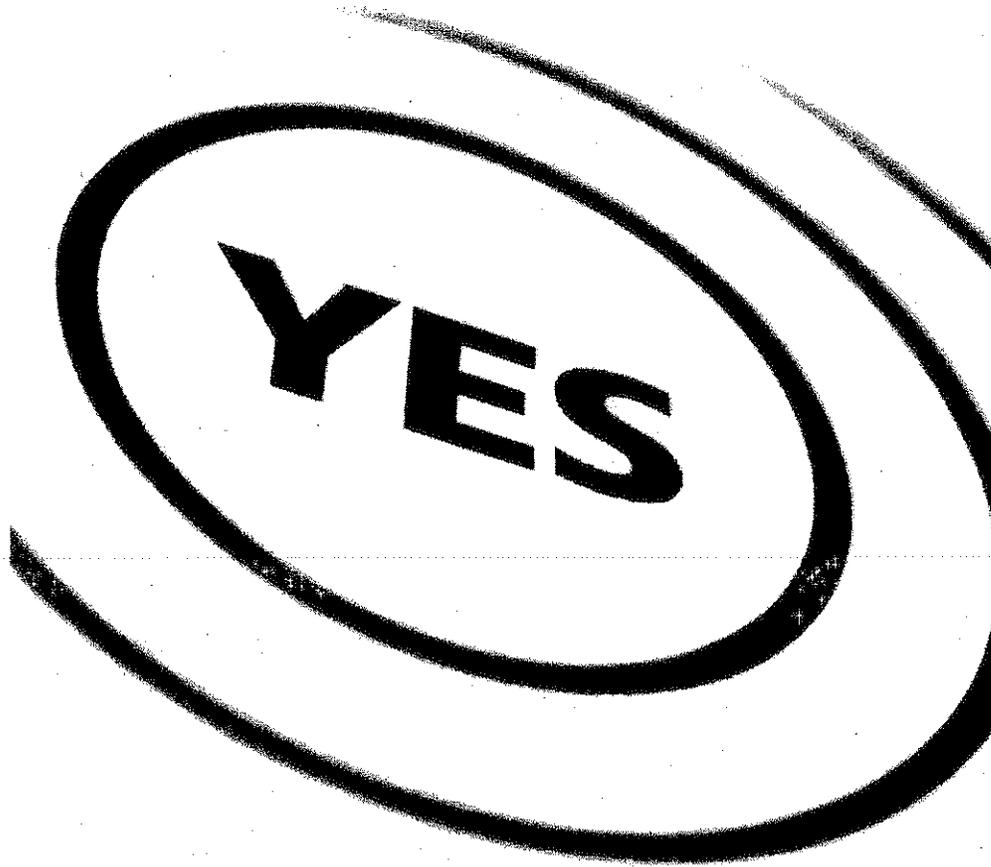
I may revoke my consent orally or in writing at any time. As long as this consent is in force, my provider may conduct additional tests without asking me to sign another consent form. In those cases, my provider will tell me if other HIV tests will be performed and will note this in my medical record.

Patient Name: _____ Date: _____

Signature: _____
Patient or person authorized to consent

Medical Record #: _____

Say yes to the HIV test.



**We're asking everyone.
It's the law.**

Key Facts to Know Before Getting an HIV Test:

- HIV is the virus that causes AIDS. It can be spread through unprotected sex (anal, vaginal, or oral sex) with someone who has HIV, through contact with HIV-infected blood by sharing needles (piercing, tattooing, drug equipment, including needles), or by HIV-infected pregnant women to their infants during pregnancy or delivery, or by breastfeeding.
- There are treatments for HIV/AIDS that can help a person stay healthy.
- People with HIV/AIDS can use safe practices to protect others from becoming infected. Safe practices also protect people with HIV/AIDS from being infected with different strains of HIV.
- Testing is voluntary and can be done at a public testing center without giving your name (anonymous testing).
- By law, HIV test results and other related information are kept confidential (private).
- Discrimination based on a person's HIV status is illegal. People who are discriminated against can get help.
- Consent for HIV-related testing remains in effect until it is withdrawn verbally or in writing. If the consent was given for a specific period of time, the consent applies to that time period only. You may withdraw your consent at any time.

HIV testing is especially important for pregnant women.

- An infected mother can pass HIV to her child during pregnancy, child birth, or through breastfeeding.
- It is much better to know your HIV status before or early in pregnancy so you can make important decisions about your own health and the health of your baby.
- If you are pregnant and have HIV, treatment is available for your own health and to prevent passing HIV to your baby. If you have HIV and do not get treatment, the chance of passing HIV to your baby is one in four. If you get treatment, your chance of passing HIV to your baby is much lower.
- If you are not tested during pregnancy, your provider will recommend testing when you are in labor. In all cases, your baby will be tested after birth. If your baby's test is positive, it means that you have HIV and your baby has been exposed to the virus.

If you test positive for HIV:

Your tester will schedule, with your permission, a follow-up appointment with a health care provider.

- If you test positive for HIV, every effort will be made to link you directly to primary care, prevention, support, and partner services.
- It is not enough for a tester to give you contact information for a Designated AIDS Center (DAC) or an HIV experienced provider. They must actively link you to primary care.
- The health care professional who conducted the test must schedule, with your permission, a follow-up medical appointment for HIV care. The appointment is voluntary.

Your health provider will talk with you about notifying your sex partners or needle-sharing partners.

- Your partners need to know that they may have been exposed to HIV so they can get tested and treated (if they have HIV).
- If you are uncomfortable notifying your partners on your own, your health care provider can notify them (either with you or without you being present).
- Health Department counselors (Partner Services Specialists) can also help notify your partners without ever telling them your name.
- If your health care provider knows the name of your spouse or other partner, he or she must report the name to the Health Department.
- To ensure your safety, the Partner Services Specialist or your health care provider will ask you questions about the risk of domestic violence for each partner to be notified.
- If there is any risk, the Partner Services Specialist or your health care provider will not notify partners right away and will assist you in getting help.

If you test negative for HIV, the health provider giving you the negative test result will share the following important information with you:

If you received a negative HIV antibody test result, this almost always means you are not infected with HIV. However, you should understand what an HIV test result means and that you may need to be re-tested.

Why you may need to be re-tested for HIV.

The period between the time of exposure and the time that a test can detect HIV infection is called the "window period." During this period, an infected person has HIV and can pass it to other people, even if his or her HIV test is negative. If you engaged in any risk behaviors for HIV during the three months prior to your HIV test, you should be tested again three months after your last possible exposure. Your provider will answer any questions you may have about re-testing.

You still have to protect yourself from HIV infection.

Even though you tested negative for HIV, keep protecting yourself from HIV infection. Do not have unprotected sex or share needles, syringes, or other drug injection equipment with anyone who has HIV or whose HIV status you don't know. Do not share needles for ear piercing, body piercing, or tattooing. You could get HIV if someone with HIV used the needle before you.

If you have sex:

Use a latex male condom or a female condom. Condoms work to prevent HIV if you use them the right way, every time you have sex. You can buy condoms at grocery stores, drugstores and online. In New York City, condoms are free at certain stores, businesses, community organizations and clinics. For a list of participating organizations, go to nyc.gov/condoms.

If you shoot drugs:

- Use new needles and equipment each time you shoot up.
- Never share needles, syringes or works.
- Never buy needles on the street, even if they look new.
- If you are 18 or older, you can buy new needles at many drugstores.
- Syringe exchange programs provide needles free of charge. See 'More Information and Help' to find out more about syringe service programs in NYC and NYS.

If you are drunk or high, you are less likely to think about protecting yourself and others from HIV. Using any drug lowers your ability to make decisions about safer sex and using clean needles and works.

More Information and Help:

New York State Department of Health Website:

www.health.ny.gov/diseases/aids/publications

New York State HIV/AIDS Hotlines (Toll-Free):

English: 1-800-541-AIDS

Spanish: 1-800-233-SIDA

TDD: 1-800-369-2437

Voice callers can use the New York Relay System 711 or

1-800-421-1220 and ask the operator to dial 1-800-541-2437

Free, Anonymous Testing:

For HIV information, referrals or information on how to obtain a FREE HIV test without having to give your name and without waiting for an appointment, call the regional program closest to the county you live in:

Capital District Region Anonymous HIV Testing Program:

1-800-962-5065

Western Region (Buffalo Area) Anonymous HIV Testing Program:

1-800-962-5064

Lower Hudson Valley Region Anonymous HIV Testing Program:

1-800-828-0064

Western Region (Rochester Area) Anonymous HIV Testing Program:

1-800-962-5063

Long Island (Suffolk/Nassau) Region Anonymous HIV Testing Program:

1-800-462-6786

Central New York Region Anonymous HIV Testing Program:

1-800-562-9423

New York City: 311 for information on DOHMH STD Clinics

More Information and Help:

New York City HIV/AIDS Hotline:

1-800-TALK-HIV (825-5448)

National Centers for Disease Control STD Hotlines:

English/Spanish 1-800-232-4636, TTY 1-888-232-6348

New York State HIV/AIDS Counseling Hotline:

1-800-872-2777

New York State Partner Services:

1-800-541-AIDS

New York City Contact Notification Assistance Program:

1-212-693-1419

Confidentiality:

New York State Confidentiality Hotline: 1-800-962-5065

Legal Action Center: 1-212-243-1313 or 1-800-223-4044

Expanded Syringe Access Program (ESAP):

English: 1-800-541-2437

Spanish: 1-800-233-7432

Human Rights/Discrimination:

New York State Division of Human Rights: 1-718-741-8400

New York City Commission on Human Rights: 1-212-306-7500

health.ny.gov/aids
nyc.gov/health

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