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HIV:

No longer a death sentence

As far as Iris Rivera knew, the clock was ticking.

The doctors said she had maybe five years to live — if she was lucky — and if there was anything that Rivera knew with almost absolute certainty, it was that luck was a complete stranger.

At the time, she was living in a homeless shelter and raising three children virtually on her own. She was married to a drug user, and though her English wasn't great, she said she understood what the doctors were telling her.

She had tested positive for HIV.

Five years.

"It blew my mind," she said. "I thought I was going to die. I asked God to help me because of my children. I wanted to see them grow up."

Back in 1988, when she learned of her condition, five more years of life was a reasonable expectation. But that wasn't good enough for her children, particularly the baby who was then almost three years old and may have been infected during childbirth.

Though she prayed to God, doctors banked on science, and slowly, miracles occurred.

For one of the first times in her life, Rivera started hearing good news.

Her youngest child tested negative. And, more important, she made it past the five-year mark. And then six years. After the seventh, she stopped counting.

"I had to decide whether I wanted to live or die," she said. " I chose to live. HIV lives with me. I don't live with it. I'm in charge here."

> ***"HIV lives with me. I don't live with it. I'm in charge here."***
>
> ***— Iris Rivera***

Rivera's story underscores one of the more remarkable periods in modern day medical history — HIV is no longer a death sentence.

Dr. Valerie Stone, the director of the Women's HIV/AIDS Program at Massachusetts General Hospital, is all too familiar with HIV and AIDS. For the last 20 years, she has specialized in infectious diseases, starting as a fellow at Boston University Medical Center. She was fresh out of Yale Medical School at the time, and was deeply disturbed at the disparate impact HIV/AIDS was having on minority communities.

Iris Rivera contracted HIV from her husband, who used intravenous drugs. She said she had to live for her three children, and fought to overcome the depression, stigma, and stereotyping associated with HIV. Rivera has survived almost 20 years since her diagnosis. She now works with the AIDS Action Committee of Massachusetts as well as other community groups in an effort to educate the public about HIV.

Dr. Stone readily admits that medical advances have come a long way, but are still short in producing a vaccine. "But there has been a real turnaround," Dr. Stone says. "The treatments now are fabulous."

And that is the real story — HIV is treatable.

As retroviruses go, HIV is a particularly nasty one.

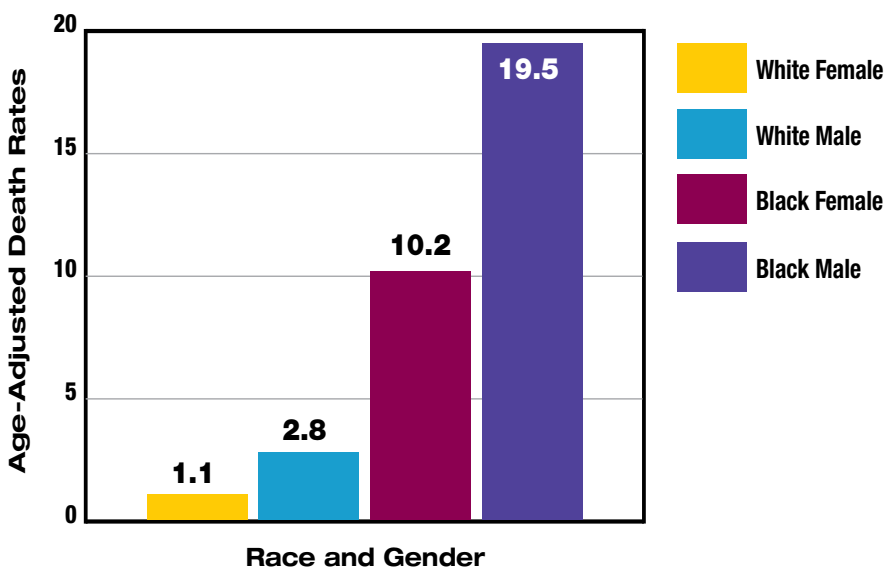
Unable to survive on its own, the virus invades the body's white blood cells and targets the helper T or CD4 cells that are responsible for fending off viruses, bacteria and fungi. HIV multiplies very quickly and overwhelms the helper T cells, leaving the body susceptible to certain types of cancers and opportunistic diseases — infections, such as pneumonia — that a normally functioning immune system could easily overcome. If left unchecked, HIV can eventually result in full-blown acquired immunodeficiency syndrome or AIDS.

HIV can lie silent for many years — up to ten or more — before the infected person begins to show symptoms. The initial infection with HIV is relatively innocuous and may seem more like the flu – fever, headache, sore throat, swollen lymph nodes. Like many other life-threatening diseases, HIV/AIDS requires a test to determine its presence. Without proper

Iris, *continued to page 4*

The Disparity of HIV Diseases

Although death rates from HIV diseases have fallen for all groups over the past few years, blacks in Massachusetts bear a disproportionate share of the state's deaths. The age-adjusted death rates for HIV diseases in Massachusetts in 2005 for black males is twice that for black women, seven times that for white men, and almost 18 times that for white women.



Figures are age-adjusted to the 2000 U.S. standard population, per 100,000.

Source: Massachusetts Deaths 2005, Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health, March 2007.

Two tales of living with HIV/AIDS

When it comes to HIV/AIDS, Catherine duBois Gaynes doesn't mince words.

"Sex is fantastic," she says, "especially when it's done with that right loving feeling. But please, please, please protect yourself."

Gaynes was 51 years old when she learned that her HIV test came back positive. She is now 61, and, the Good Lord willing, she will talk and preach about the disease until the day she dies.

"I found out on a Monday," she said. "And it's a good thing I didn't get paid until that Friday, because I know I would have tried to kill myself. But it made me stop and take a real hard look at how I was living my life."

Gaynes said she thought she was too old to contract the disease, but given the way she lived her life — drinking and drugging and having unsafe sex — she said she now knows that it was just a matter of time.

"I don't regret my life," she said. I mean, it wasn't terrible. I had a good time. And if I could, I'd wish that HIV/AIDS wasn't in the world. But this is reality, and we must deal with reality."

Catherine duBois Gaynes learned that there is no age limit for HIV. She lived a fast life and became infected at the age of 51. Gaynes is pictured at the AIDS Action Committee's AIDS Walk last year.

Reality has changed a lot for those still living.

Gaynes recalls her first regimen of medications — 22 pills in all, some of which were as large as her thumbnail. "It was horrible," she said.

These days, Gaynes is taking just two pills a day. The most bothersome side effect is that, for whatever reason,

Gaynes, *continued to page 4*

June 27 is National HIV Testing Day

From initial infection to AIDS: The progression of HIV

AIDS has been one of this nation's leading health problems since the first reported case in the United States in 1981. The Centers for Disease Control and Prevention (CDC) report that 1.2 million people are currently living with HIV/AIDS, and roughly 40,000 new cases of HIV are diagnosed annually. According to a 2005 CDC report, of those diagnosed with AIDS, 29 percent were white, 19 percent were Hispanic/Latino and a startling 50 percent were black.

It is important to understand HIV/AIDS, its symptoms, progression and treatment options, especially given its prevalence among the black population in America.

AIDS starts as HIV, or human immunodeficiency virus, which is contracted when an infected individual's bodily fluids (such as blood, sperm, or vaginal secretions) come in contact with an uninfected person's broken skin or mucous membrane. In 2005, the most common form of transmission of the virus was through sexual contact, while 20 percent were the result of the use of injection drugs. Transmission of the virus is also possible from a pregnant woman to her fetus or through breast milk. However, a treatment is available that can reduce by two-thirds the risk of transmission to the baby.

Once contracted, HIV begins to attack the white blood cells that fight disease. With fewer white blood cells, a person is more susceptible to sickness, and his or her body has a more difficult time fighting off infection. For some, it takes years for HIV to develop into AIDS. A person is considered to have AIDS, or acquired immune deficiency syndrome, once his or her white blood cell count gets below a certain level — usually about 200. At this point, the body is nearly incapable of fighting off sickness.

The symptoms of HIV vary by stage. When first infected, the symptoms are similar to those of a common cold or flu. Then, for a period of time — up to ten years or more — a person can be relatively symptom free. That is why it's important to be checked regularly if you are sexually active. When symptoms do appear, they can include:

- **Low energy**
- **Weight loss**
- **Frequent fevers and sweats**
- **Persistent or frequent yeast infections**
- **Persistent skin rashes or flaky skin**
- **Short-term memory loss**
- **Sores from herpes infections**

As the disease progresses to AIDS, the symptoms also begin to change. The symptoms of AIDS can include:

- **Cough and shortness of breath**
- **Seizures and lack of coordination**
- **Difficult or painful swallowing**
- **Mental symptoms, such as confusion and forgetfulness**
- **Severe and persistent diarrhea**
- **Fever**
- **Vision loss**
- **Nausea, abdominal cramps, and vomiting**
- **Weight loss and extreme fatigue**
- **Severe headaches with neck stiffness**
- **Coma**
- **Susceptibility to certain cancers**

Fortunately, there are several treatment options for people with HIV or AIDS. While there is no cure or vaccine, there are drug plans that can slow the rate of the disease and improve the quality of life for those living with HIV or AIDS.

It is important to be tested regularly if you fall in a group at risk for contracting HIV. The CDC now encourages voluntary HIV testing as a routine part of medical care for all adolescents and adults ages 13 to 64 regardless of risk. It is also important to understand that there are many treatment options available for people who test positive.

MythBusters: Know the facts about HIV

10 HIV/AIDS Myths

1. HIV and AIDS are the same.

HIV is a virus that causes AIDS. A person infected with HIV may not develop AIDS for years, if at all, depending on the progression of the infection. A person is considered to be infected with AIDS when his or her white blood cell count reaches such a low level that the body cannot adequately fight infection.

2. You can get HIV from working with someone who is infected.

You cannot get HIV from shaking hands, using the same toilet seat, sharing pens, or speaking in close proximity. It can be contracted only by coming in contact with infected bodily fluids through an open wound or mucous membrane.

3. You can get HIV from a mosquito or other insect bite.

Mosquitoes inject only their saliva, not the blood of others they have bitten.

4. You can get HIV from kissing or being sneezed on.

You cannot get HIV from being sneezed on and there is no risk in closed-mouthed kissing. With open-mouth kissing there is a slight risk if there are open sores or blood in both parties' mouths.

5. There's a cure for HIV/AIDS.

There is no cure for HIV/AIDS. There are drug therapies that allow people to live with the disease, but there is no cure.

6. You can't get HIV if you're on the pill, or use a diaphragm, a sponge, spermicide, or other similar birth control methods.

These birth control methods are not intended to prevent the transmission of STDs (sexually transmitted diseases) and will not provide protection against HIV infection.

7. HIV can't be transmitted through breastfeeding.

There is a risk of passing HIV to a breastfeeding baby through the breast milk.

8. You can't have a baby if you have HIV.

HIV does not interfere with becoming pregnant. Additionally, there are currently drug therapy options to reduce the risk of transmitting HIV to a new child.

9. You'll know if you get infected with HIV.

HIV symptoms show up in individuals at different times. There is no way to know for sure if you are infected except through a blood test, which is why it is important to be tested regularly if you are at risk for contracting HIV. The CDC encourages voluntary HIV testing as a routine part of medical care for all adolescents and adults ages 13 to 64.

10. HIV is a death sentence.

More than one million people in America are living with HIV due to many advances in drug therapy. HIV and AIDS are diseases that you can live with given the right treatment.

An open discussion on violence

The Urban League of Eastern Massachusetts, in collaboration with the Boston Public Health Commission and a host of community partners, invites you to join in a series of community conversations on violence as it affects our mental, physical and spiritual health. Admission is free and open to the public.

When:

June 11, 5:30 – 8:00 p.m. Dorchester House Multi-Service Center

June 26, 5:30 – 8:00 p.m. To be announced

To RSVP e-mail: kcprmail@aol.com (617.427.0997)

HIV

Questions & Answers

Joseph R. Betancourt, M.D.
Director of the Disparities Solutions Center, Massachusetts General Hospital

1. Viruses are very common and, to a large extent, harmless, such as the common cold. What makes HIV so different and dangerous?

Most viruses are harmless. They attack the body, our body identifies them and neutralizes them, and we get better. However, HIV — the human immunodeficiency virus — causes AIDS, or the acquired immunodeficiency syndrome. HIV is a different and very dangerous virus because it attacks the immune system — the body's primary method of fighting infections. Not only can the body not neutralize HIV, but HIV destroys our ability to fight infections gradually until we can be harmed by infections that we would usually be able to handle.

2. Is there a time when an HIV-positive person is no longer infectious?

Once you have HIV, you can always spread it and are always considered infectious. Some of the new medications bring the amount of HIV in the body — the viral load — to very low levels. Having an "undetectable viral load" does not mean, however, that a person is no longer infectious. Patients with undetectable blood levels may still have enough HIV in their semen or vaginal fluids to transmit infection. This is very, very important to know. Once you have HIV, you absolutely need to have safe sex, no matter what the circumstance.

3. Should people who are low risk for HIV get tested?

Anyone who has ever had unprotected sex should get tested for HIV. If you have unprotected sex between HIV exams, you should get tested again and get tested routinely. It is impossible to know if a sexual partner has HIV just by looking at them, or by assuming that they don't have it because they haven't had many sexual partners. If you engage in high-risk behaviors, such as frequent unprotected sex, or use intravenous drugs, you should get tested routinely as well.

For women who plan to become pregnant, testing is even more important. If a woman is infected with HIV, medical care and certain drugs given during pregnancy can lower the chance of passing HIV to her baby. All women who are pregnant should be tested during each pregnancy.

4. Can women with HIV infect men?

Absolutely, without a doubt. Vaginal secretions, and menstrual blood from an infected woman can contain HIV and infect a man during intercourse.

5. Is it possible for a person to be unaware that he or she has HIV?

One of the biggest challenges in tackling HIV infection locally and around the world is encouraging people who have no symptoms to get tested. The reason it is important that people get tested is because you can have HIV for many years and not know it, as you may have no symptoms at all. If you have HIV and don't know it, not only are you at risk of infecting others during this time, but you are missing precious time when you could be getting treatment to slow down the progression of the disease to AIDS.

6. Can HIV survive outside the body?

HIV is a fragile virus. It cannot live for very long outside the body. As a result, the virus is not transmitted through day-to-day activities such as shaking hands, hugging, or a casual kiss. You cannot become infected from a toilet seat, drinking fountain, doorknob, dishes, drinking glasses, food, or pets. You also cannot get HIV from mosquitoes.

Maria-Pamela Janairo of the Disparities Solutions Center assisted in the preparation of these responses.

HIV Prevention 101

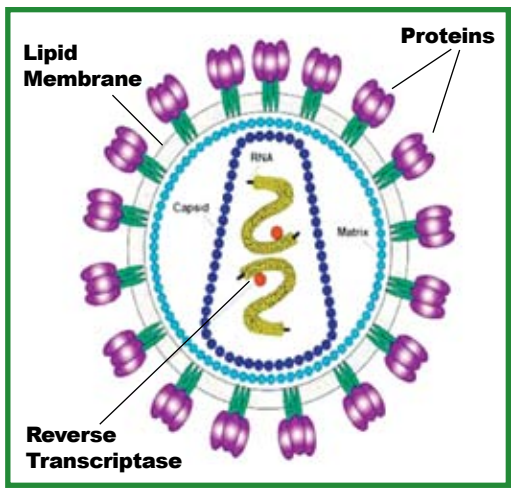
There is no cure or vaccine for HIV, but it is preventable.

- Don't engage in unprotected sex (sex without use of a latex condom) unless you are absolutely sure of the HIV status of your partner.
- Use a latex condom each time you have sex if you don't know the HIV status of your partner or if your partner is HIV-positive.
- If you are an intravenous drug user, use a new needle each time you inject. Do not share needles, syringes, cookers, cotton or water. Contact the Needle Exchange Program at (800) 383-2437 to exchange used syringes for new ones.
- Do not become complacent. Although medications have reduced deaths from opportunistic diseases, HIV/AIDS remains a very serious infection.

Structure of HIV

HIV is a retrovirus that invades the body's white blood cells, incorporates its own genome, and commandeers the body's immune system. HIV targets CD4 or helper T cells that are responsible for fending off viruses, bacteria and fungi that cause disease. HIV multiplies very quickly and overwhelms the helper T cells leaving the body susceptible to certain types of cancers and opportunistic diseases — infections, such as pneumonia, that a normally functioning immune system can easily overcome.

If left unchecked, HIV can eventually result in full-blown acquired immunodeficiency syndrome or AIDS, the final stage of HIV infection.

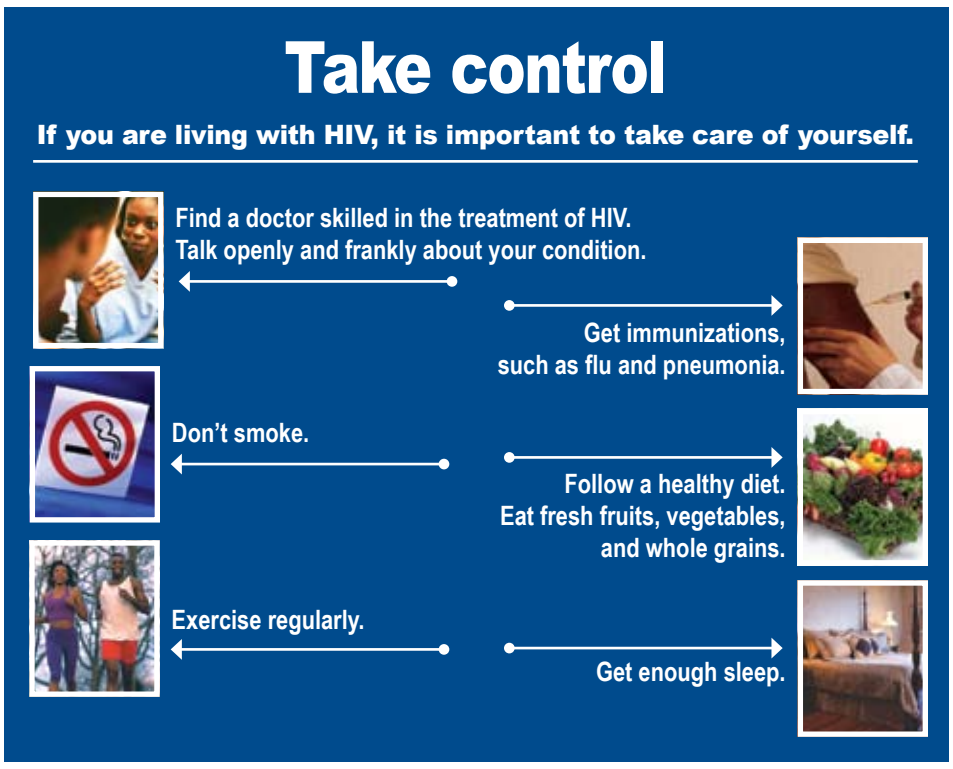


Source: National Institute of Allergy and Infectious Diseases

Risk Factors and Causes

Contrary to common beliefs and stereotypes, any person of any age, race, gender, or sexual orientation can become infected with HIV. Rather, it is certain behaviors and conditions that cause infection. You are at higher risk if you:

- Have unprotected sex (vaginal, anal, and oral) with multiple partners or a partner who is HIV-positive. Unprotected sex is sex without use of a latex condom every time.
- Share or reuse needles during intravenous drug use.
- Have another sexually transmitted disease, such as syphilis.
- Received an accidental needle stick, which happens infrequently to health care workers.
- Received a blood transfusion prior to 1985 before standard testing for HIV began.
- Were born to an infected woman. An HIV-positive woman can transmit the virus to her child during childbirth or through breast-feeding. If a woman receives treatment for HIV during pregnancy, she reduces her baby's risk by two-thirds.



Iris

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testing, most don't know they have it, and unknowingly can spread it to unsuspecting partners. The Centers for Disease Control and Prevention (CDC) estimate that 25 percent of those living with HIV are unaware of their infection.

Such was the case with Rivera.

Five years before she was actually tested, she had an appointment with her gynecologist. She had chills, fatigue, and a cold "that wouldn't go away." Her doctor suspected HIV at the time, but Rivera refused to take the test.

After the appointment, Rivera said she talked with her husband about the possibility that she or he might have HIV or worse.

His response was typical. Even though he was an intravenous drug user, she said he claimed to use his own needles and never shared them.

Valerie E. Stone, M.D., MPH
Director, Women's HIV/AIDS Program
Massachusetts General Hospital

Rivera's husband went on to explain that he was "too healthy" to have that disease. The implication was clear. He was not gay.

"He told me that he was a 190-pound muscular man," she said, "and that there was no way that he could have AIDS."

He further told her to look at herself and that she looked very healthy.

In hindsight, Rivera concedes that she was in denial. It wasn't until five years later, while living in a homeless shelter, that she developed the nerve to get tested.

The shelter had sponsored a workshop on HIV, and as she listened, she said "my heart started beating faster." Knowing that she could possibly have HIV, she got tested at Martha Eliot Health Center in Jamaica Plain.

The initial treatments were horrid. Her regimen of AZT pills caused most of her hair to fall out. She also developed thrush, a fungus that attacked her esophagus and trachea and left white lesions on her tongue and throat. Under normal circumstances, her body's immune system would have been able to defend itself. With HIV, she couldn't.

"It was awful," she said. "I wouldn't wish that on my enemy."

She now takes only three medications once a day, and so far so good. For the most part, she has overcome the stigma, stereotyping and depression. She still has her moments, but she is happy to be alive and living, volunteering a lot of her time with the AIDS Action Committee. Her husband was finally diagnosed with AIDS. After a two-year bout, he died in 1993.

So widespread is the epidemic of HIV that last year CDC revised its recommendations for testing for HIV to include adults, adolescents, and pregnant women in health care settings. The revised recommendations were meant to expand testing to low-risk people in addition to those considered high-risk.

The good news is that medications have been developed that can help keep HIV at bay, preventing the onset of symptoms or progression to AIDS. Highly active antiretroviral therapy, or HAART, was introduced in 1995. HAART is a combination of antiretroviral medications that attack HIV on several fronts to prevent the virus from reproducing by interfering with it at different stages of its lifecycle. The drugs slow the progression of the disease and allow people infected to live longer.

In its infancy, HIV was considered a white gay male disease, but time has changed that description. Incidence of the virus has increased in blacks, females, and heterosexuals at an alarming rate. Nationally, blacks constitute more than half of HIV/AIDS cases, and women account for 26 percent. The incidence among heterosexuals is one of the fastest growing categories of HIV-positive people due largely to intravenous drug and unprotected sex with HIV-positive partners.

In Boston, the typical HIV/AIDS case is a black male between the ages of 40 and 49. The incidence is lowest among Asians and those under the age of 20 and above 50. The death rates from HIV diseases in Massachusetts show a marked disparity by race. Black males are hardest hit. The death rate from HIV diseases in black men is twice that of black females, seven times that of white males and 18 times that of white females.

Dr. Stone says that one of remaining hurdles is still overcoming the stigma. Unlike other chronic diseases, such as cancer or strokes, where it's considered a test of courage to survive or beat it, living with HIV/AIDS has little public sympathy. "Even with all of the successful treatments and longer life spans," Dr. Stone says, "people still feel ashamed to admit that they have HIV because of this persistent stigma. Hence, they often keep it a secret. Yet, one of the worst things that we can do is remain silent."

The CDC encourages voluntary HIV testing as a routine part of medical care for all adolescents and adults ages 13 to 64. Yearly testing is recommended for people at high risk of infection.

Free and Confidential Walk-in HIV Testing and Counseling

Date	Organization	Address	Time	Tel. No.
6/9	Boston Public Health Commission	Gay Pride Block Party Cor. Berkeley & Chandler	2 - 8 PM	617-534-2295
6/12	Boston Public Health Commission	Maverick Square Station E. Boston	9:30 AM - 12:30 PM	617-534-2295
6/26	Boston Public Health Commission	Central Square E. Boston	1 - 4 PM	617-534-2295
6/27	Boston Public Health Commission	Mozart Park Centre St., Jamaica Plain	12:30 - 4:30 PM	617-534-2295
6/27	Fenway Community Health	7 Haviland Street, Rooms 201 A & B, Boston	10 AM - 6 PM	617-927-6229
Mon-Fri	Boston Medical Center Project Trust	721 Mass. Avenue	8:30 AM - 5 PM	617-414-4495
Mon-Fri	Cambridge Cares about AIDS	17 Sellers St., Cambridge	10 AM - 5 PM	617-661-3040
Mon-Fri	Martha Eliot Community Health Center	75 Bickford St. Jamaica Plain	8:30 AM - 5 PM Thur: 8:30 AM - 7 PM	617-971-2349
Mon-Fri	Mattapan Community Health Center	1425 Blue Hill Ave. Mattapan	8:30 AM - 5 PM	617-296-0061
Mon-Thur	Neponset Health Center	398 Neponset Ave Dorchester	5:30 - 8:30 PM	617-282-3200 x 115
Mon	Family Van	Dudley Square	1:30-4:30 PM	617- 442-3200
Tu & Thur	Geiger Gibson Health Center	250 Mount Vernon St. Dorchester	5:30 - 8:30 PM	617-282-3200 x 115
Wed	Fenway Community Health	7 Haviland Street, Rooms 201 A & B, Boston	4:30 - 6 PM	617-927-6229
Thur	Family Van	Codman Square	9 AM - 12 noon	617-442-3200
Fri	Family Van	Upham's Corner	9 AM - 12 noon	617-442-3200
Fri	Family Van	Mattapan Square	1:30-4 PM	617-442-3200

For additional testing sites and information, call the HIV Hotlines

AIDS Action Committee of Massachusetts
(800) 235-2331 • M-Th 9 AM – 9 PM • F 9 AM – 7:30 PM

Centers for Disease Control and Prevention
(800) 232-4636 • 24 hours/day

Gaynes

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her hip size has shrunk and her stomach has grown. "Let me tell you, for a black woman not to have any hips is a problem," she joked. "I'm very uncomfortable with my body shape right now."

One thing is clear. She has become much more comfortable accepting the fact that she has a disease that carries a stigma.

"It can be emotionally devastating," she said. "It hasn't become less difficult on that level. But there are a lot of services to help deal with the devastation. Because of them, I am a HIV success story."

greg-eugene is another.

An entertainer by profession, he volunteers his spare time with the Boston Living Center, AIDS Action Committee, and Multicultural AIDS Coalition, to name a few. He holds educational workshops and gives advice on positive thinking and how to live with HIV/AIDS.

"You ain't through until you're through," is one of his mantras.

He too knows of the emotional turmoil associated with having AIDS. He also knows the value of protection.

"It is the responsibility of the positive person to tell a partner that he or she has HIV disease," he said. "[It's also up to] the non-infected person to take responsibility and protect him or herself regardless of who the partner is. That includes married people."

As a gay man, greg-eugene readily admits he was in denial. His partner had contracted AIDS and eventually died. greg-eugene didn't get tested until he experienced a sharp pain in his leg. He went to a doctor and a biopsy was taken. He was diagnosed with Kaposi's sarcoma, an opportunistic disease that is common in AIDS.

Shortly after learning that he tested positive, greg-eugene became depressed and began living a reckless lifestyle. The good news is that behavior was short-lived. Instead of living in denial, he has taken control of his life. He now goes in for testing every three months. So far, his numbers are good.

"It's about immediacy and the now," he said. "It's about being true to self and friends." That's what keeps him going.

greg-eugene has lived with AIDS for 11 years. He remains centered by focusing on the positive and being true to himself and friends. He volunteers with several organizations, including the Boston Living Center and the AIDS Action Committee.