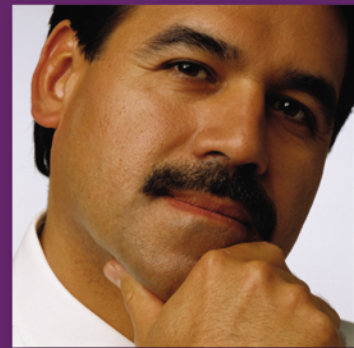
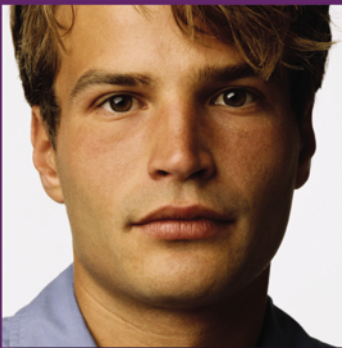


I Just Found Out...



**NORTHEASTERN MASSACHUSETTS
HIV REFERRAL GUIDE**

HIV Referral Guide: NORTHEASTERN MASSACHUSETTS

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Introduction to the Guide

Project Purpose and Background

This binder is designed as a referral guide to accompany the patient booklet, *“I Just Found Out...Frequently Asked Questions About Your HIV Test in Northeastern Massachusetts,”* written for clients receiving a new HIV positive diagnosis in Northeastern Massachusetts. The intent of this referral guide is twofold: to facilitate the provision of high quality referrals to HIV positive clients; and to increase provider use of the rapid HIV test by providing referral resources specific to Northeastern Massachusetts encompassing the North Shore and Merrimack Valley “at the tip of [their] fingers.”

For the past several years JSI Research & Training Institute, Inc. has offered training and technical assistance to reproductive health providers in New England through a CDC cooperative agreement. The overall purpose of the project is to support the integration of HIV prevention services into reproductive health clinical and community settings. Many providers cite the fear of giving a positive HIV result, especially with a rapid HIV test, as a barrier both to increased testing and to implementing rapid HIV testing where they otherwise might want to. Many agencies and providers fear they would not know what to say or where to refer their HIV positive clients and worry about the process disrupting clinic flow.

This resource was developed as a collaborative effort to address this barrier, coordinated by JSI project staff and with representatives from a wide range of disciplines and organizations. The materials were reviewed by specialists in HIV, HIV positive individuals, and a diverse representation of Northeastern Massachusetts in order to ensure medical, technical, and cultural appropriateness (See: Contributors/Review Team and Special Thanks sections).

The Frequently Asked Questions (FAQs) and Referral Guide can be used by anyone doing HIV testing in Northeastern Massachusetts, though both products have been designed to facilitate referrals particularly with the use of the rapid HIV test.

How to Use This Guide

The text from the companion “Frequently Asked Questions” patient booklet are included in this referral guide in black “text boxes” with additional resources listed below them. These pages, which contain relevant resources, can be reproduced and shared with clients to provide tailored information. We hope that you will familiarize yourself with the wide range of resources in this guide before you find yourself sitting face-to-face with an individual receiving a positive HIV result. If you take the time to get to know this guide you should be well-equipped to help a client with a reactive result through the initial delivery of results and to facilitate their referral to the “next steps” of treatment and support. If this seems scary to you, remember that you do not have to be an expert in HIV infection to deliver results. All that is expected is that you provide results with a caring and non-judgmental approach, and that you have the knowledge and understanding in order to lead the client to people who *are* experts in treating and dealing with HIV and AIDS.

CDC HIV/AIDS Science Facts:

CDC Releases Revised HIV Testing Recommendations in Healthcare Settings

September 2006

Effective September 2006, CDC has revised its recommendations for HIV testing in healthcare settings. The *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Healthcare Settings* aim to make HIV testing a routine part of medical care in addition to expanding the gains made in diagnosing HIV infection among pregnant women. The *Recommendations* replace CDC's 1993 *Recommendations for HIV Testing Services for Inpatients and Outpatients in Acute-Care Settings* and they update portions of CDC's 2001 *Revised Guidelines for HIV Counseling, Testing, and Referral* and *Revised Recommendations for HIV Screening of Pregnant Women*.

What is different about the new Recommendations?

Key differences in the *Recommendations* for patients in all healthcare settings are:

- HIV screening (another term for broad-based testing) for patients ages 13 to 64 in all healthcare settings after the patient is notified that testing will be performed unless the patient declines (opt-out screening).
- HIV testing of people at high risk for HIV infection at least once a year.
- Screening should be incorporated into the general consent for medical care; separate written consent is not recommended

- Prevention counseling should not be required with HIV diagnostic testing or as part of HIV screening programs in healthcare settings.

Additional key differences in the *Recommendations* for pregnant women in healthcare settings are:

- Including HIV screening in the routine panel of prenatal screening tests for all pregnant women, unless the patient declines (opt-out screening).
- Repeat screening in the third trimester in certain jurisdictions with elevated rates of HIV infection among pregnant women.

The *Recommendations* emphasize the importance of voluntary testing. Various constituencies have expressed concern that eliminating the recommendation for separate informed consent for an HIV test could result in some patients being tested for HIV without their knowledge. Others have asserted that requiring separate, written informed consent is a barrier that makes HIV screening difficult to conduct in healthcare settings, and that removing this requirement would make widespread HIV screening feasible.

Concerns have also been expressed over the lack of HIV prevention counseling in conjunction with HIV testing. CDC continues to support prevention counseling as an intervention to help people reduce their risks for HIV, but recognizes it can become a barrier to HIV testing in busy healthcare settings.



CDC still recommends that patients receive information about HIV testing, HIV infection, and the meaning of test results.

Why did CDC revise the *Recommendations*?

There are several compelling reasons why CDC has revised the *Recommendations*.

- An estimated one-fourth of the approximately 1 million persons in this country who are living with HIV do not know they are infected. That's approximately 250,000 persons who could be spreading HIV to their partners unknowingly. As HIV screening becomes a more routine aspect of medical care, more people will know they are infected with HIV.
- People living with HIV can receive effective treatment, resulting in improved health and extended life, if their HIV infection is diagnosed earlier. Currently, many people learn of their HIV infection only after they have developed symptoms (in a large study of HIV-infected persons, 65% reported they were first tested for HIV because of illness).
- Most people, after finding out they have HIV, adopt behaviors that reduce HIV transmission. Routine HIV testing may help protect the partners of persons who are living with HIV but do not know it. In theory, new sexually transmitted HIV infections could be reduced more than 30% per year if all HIV-infected persons knew of their infection and adopted changes in behavior similar to those of persons already aware of their infection.
- Routine HIV testing may reduce the stigma associated with an HIV test offered based on the healthcare provider's perception (or knowledge) of risk. When every person gets offered an HIV test at some point in his or her health care, it should take controversy and judgment out of the test and make it a normal part of taking care of oneself.
- Providers reported that requirements for pre-test counseling and written informed consent

were not feasible in emergency rooms and other busy healthcare settings.

For whom are the *Recommendations* intended?

The *Recommendations* are intended for healthcare providers in both the public and private sectors. These include healthcare workers in hospital emergency departments, inpatient services (including labor and delivery), correctional health care facilities, clinics including substance abuse treatment, public health, community, pediatric and adolescent, prenatal, and mental health, and other primary care settings.

These *Recommendations* address HIV testing in healthcare settings only. They do not change existing CDC guidelines on HIV counseling, testing, and referral for persons at high risk for HIV who receive testing in nonclinical settings (e.g., at community-based organizations.)

How did CDC develop the *Recommendations*?

These *Recommendations* are the culmination of a lengthy and deliberate process that began in 1999 when the Institute of Medicine (IOM) recommended adopting a national policy of universal testing of pregnant women with patient notification (opt-out screening), eliminating requirements for extensive pretest counseling, and eliminating requirements for explicit written consent for HIV testing. Adoption of the IOM recommendations led to increased prenatal screening, and, combined with appropriate medical care, contributed to a dramatic 95% decline in perinatally acquired AIDS cases. CDC began exploring the feasibility of adopting a similar policy for the general public, which could bring about reductions in sexually transmitted HIV. Between 1999 and 2006, CDC involved healthcare providers, representatives from professional associations and community organizations, researchers, public health officials, and persons living with HIV to research and refine the

Recommendations in order to expand HIV testing, especially in high-volume, high-prevalence acute-care settings. Through this process, CDC has tried to involve persons most likely to be affected by the *Recommendations* and ensure the resulting *Recommendations* are ethical and fair and would achieve their stated goals.

Conclusion

CDC believes that the adoption of voluntary, HIV screening in healthcare settings will foster the earlier detection of HIV infection, help healthcare workers identify and counsel persons with previously unrecognized HIV infection and link them to clinical and prevention services, and further reduce sexual and perinatal transmission of HIV in the United States.

For more information . . .

CDC HIV/AIDS
<http://www.cdc.gov/hiv>
CDC HIV/AIDS resources

CDC-INFO
1-800-232-4636
Information about personal risk and where to get an HIV test

CDC National HIV Testing Resources
<http://www.hivtest.org>
Location of HIV testing sites

CDC National Prevention Information Network (NPIN)
1-800-458-5231
<http://www.cdcpin.org>
CDC resources, technical assistance, and publications

AIDSinfo
1-800-448-0440
<http://www.aidsinfo.nih.gov>
Resources on HIV/AIDS treatment and clinical trials

Giving Results

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Appendices

- ☒ Reporting HIV Results, Fundamentals of Waived Rapid HIV Testing and Prevention Counseling. Atlanta: Center for Disease Control and Prevention, 2005.
- ☒ Troubleshooting Guide for Confirmatory Testing, Fundamentals of Waived Rapid HIV Testing and Prevention Counseling. Atlanta: Center for Disease Control and Prevention, 2005.
- ☒ HIV Testing Sites in Northeastern Massachusetts. Providence: JSI Research & Training Institute, Inc., 2009.

Giving Results: A Brief Guide

Rapid HIV tests can be conducted with the “Single Session Counseling” model, during which any risk assessment, behavioral counseling, or harm reduction plans are conducted primarily before and/or during the time when the specimen is collected and tested. Then, the plan is adjusted as need be if the result is reactive (also known as “preliminary positive”). Results should ideally be given by the same person that conducts any pre-test counseling who may be the same person conducting the test, or a primary healthcare provider when done in the context of a healthcare visit.

Traditional HIV tests (non-rapid) may also contain risk assessment, behavioral counseling, or harm reduction plans but will be conducted over two sessions. The main difference is that you will know the result before the client returns a second time and can have any necessary referrals prepared accordingly. As this test will be confirmed at the lab, you do not need to re-test; you should simply refer the client on for care. The other difference is the possibility of an indeterminate result, which means a result is inconclusive (could indicate a recent infection or a test reaction to something other than HIV). For an indeterminate result, you will advise the client to return for re-testing in 4 weeks.

Giving a Negative HIV Test Result

1. **Share the result in simple language, making sure they understand.**

A negative result can be given using language such as,

“Your HIV test today was negative, meaning that antibodies were not found in your system today.”

2. **Discuss the 90 day window period and, based on client risk, the need for subsequent testing.**
3. **Reinforce the prevention plan and make referrals and follow-up as necessary.**

Giving a Positive HIV Test Result

1. **Share the result in simple language, making sure they understand.**

For the rapid HIV test, you can use language such as,

“The initial test result is a preliminary positive, indicating that you are likely to be infected with HIV.”

“This must be confirmed with another test to determine whether or not you have HIV infection. We can take some blood today and send it to the lab for that confirmatory test.”

With a traditional or Western Blot confirmatory test, you can use language such as,

“The HIV test result is positive; this means that HIV antibodies have been found in your blood.”

Remember that your primary role at this moment is to attend to their emotional response. It is important to stay with the client both physically and emotionally. Take cues from the client as to what he/she needs from you, knowing that most clients see testing positive for HIV as a crisis in their lives. Clients may be unable to hear or integrate much information during this session.

Offer messages of hope and acknowledge the client’s feelings.

“Take your time, we have plenty of time to talk about the results.”

“How are you feeling about this?”

“What questions do you have?”

“This is hard news to hear. Let me tell you what we can do next.”

The priorities then will be to facilitate or arrange for confirmatory testing (if using a rapid HIV test), assess need for referrals and support for the individual such as mental health support and an HIV specialty care provider, and ensure that you have contact information for follow-up and a plan regarding confirmatory test results. Any discussion of the client’s post-test options such as case management, medical care, partner notification, support systems, etc. should be guided by the client’s ability to attend to it.

2. Facilitate the blood draw for confirmatory test (with the rapid HIV test only).

****INDICATE ON LAB SLIP THAT THE RAPID HIV TEST WAS REACTIVE****

3. Give referrals – at a minimum to an HIV Treatment Center.

If you can, make the telephone calls to set up appointments for HIV medical care or other services right there with the client. Most HIV specialty clinics have someone on-call to speak to someone who is newly diagnosed if needed.

4. Assess need for emotional support.

“It can be difficult dealing with the possibility that you’re infected with HIV. How are you doing? Who can be supportive to you in dealing with this?”

Suicide – Every Counselor’s Fear

A common fear on the part of HIV counselors is that in the face of a positive HIV test, their clients will become suicidal and they will not know how to deal with this or how to help them. First, you should know that this reaction is extremely rare. Many people show no emotion upon being given a positive result – it’s important to be careful not to put our own emotions or preconceived ideas of how we think we would feel onto a client.

That said, any suicidal thoughts or ideas expressed by the client should be taken seriously, and appropriate referrals and support given. If the client does express suicidal thoughts or feelings you can ask, “Is this bothering you so much that you are thinking about killing yourself?” Asking the suicide question is appropriate if the issue comes up. It demonstrates that you are genuinely concerned about the person in distress. Offer to assist in obtaining whatever help he or she would like. If that person is uncomfortable talking to you, or a family member or doctor, tell them they can always call **Samaritans of Merrimack Valley** at (866) 912-HOPE (912-4673), the **National Suicide Prevention Lifeline** at (800) 273-TALK (273-8255), or the mental health resources and hotlines listed in this guide under “Support Groups, Hotlines, and Mental Health.”

5. Prevention plan re: HIV transmission.

Remind the client of the importance of protecting oneself and others to avoid transmitting the virus. Advise the client to adopt the behaviors discussed in the prevention plan (i.e. to act as if he/she is HIV-infected) until a reactive rapid HIV test has been confirmed.

6. Confirm contact information and follow-up plan.

Help your client make a plan:

- Talk about the next few hours, week, two weeks.
- For instance, they may want to call in sick to work.
- Help them think about who they do and do not want to tell (for instance, they may not want to tell their boss).
- Think about who they can go to for support.

7. Take a moment to yourself or to process with a co-worker.

As always, it’s important to maintain boundaries, confidentiality and be professional while taking care of yourself. Remember, all that is expected is that you provide results with a caring and non-judgmental approach, and that you have the knowledge and understanding that will lead the client to people who are experts in treating and dealing with HIV.

Giving a Non-reactive (Negative) Rapid HIV Test Result

Content	Message
Provide test result clearly and simply.	<ul style="list-style-type: none">▪ Your rapid HIV test result is negative.▪ Your rapid HIV test result came back non-reactive.
Explain the meaning of a non-reactive test result.	<ul style="list-style-type: none">▪ This means that HIV antibodies were not found in your blood.▪ This means that the test did not detect HIV antibodies in your blood.
Emphasize that the result is based on exposure that occurred at least 3 months prior to the test.	<ul style="list-style-type: none">▪ This means that you are not infected with HIV, unless you have had a possible exposure within the past 3 months.▪ This result is based on possible exposure you had at least 3 months ago.
Assess the client's emotional reaction to the result.	<ul style="list-style-type: none">▪ How are you feeling about this result?▪ What questions do you have about this result?

Adapted from the Centers for Disease Control and Prevention: Reporting Rapid HIV Test Results
Fundamentals of Waived Rapid HIV Testing and Prevention Counseling

Giving an Invalid Rapid HIV Test Result

Content	Message
Explain that the test must be repeated.	<ul style="list-style-type: none"> ▪ We need to repeat the process from the beginning in order to provide you with an accurate result. ▪ I need to do another test.
Inform the client that the test could not be interpreted.	<ul style="list-style-type: none"> ▪ There was a problem when running your test and it cannot be interpreted. ▪ The test is invalid and cannot be interpreted because there was a problem.
Tell the client the reason(s) why the test could not be interpreted.	<ul style="list-style-type: none"> ▪ Most of the time the problems are related to the process of collecting the specimen or a faulty test kit. ▪ Sometimes problems occur with the test kits or blood collection process. ▪ When this happens, our protocol is to repeat the test.
Assure the client that quality control measures are in place to make sure that the test is conducted correctly.	<ul style="list-style-type: none"> ▪ We have some safeguards in place that help us identify when we have problems running the test. ▪ Our system has detected that there was a problem while running your test. ▪ We have measure in place to determine when problems arise while running the test.
Continue to assess the client's emotional reaction.	<ul style="list-style-type: none"> ▪ How are you feeling? ▪ What questions do you have?

Adapted from the Centers for Disease Control and Prevention: Reporting Rapid HIV Test Results
Fundamentals of Waived Rapid HIV Testing and Prevention Counseling

Giving a Reactive (Preliminary Positive) Rapid HIV Test Result

Content	Message
Provide reactive result to this screening test clearly and simply.	<ul style="list-style-type: none"> ▪ Your screening test result is a preliminary positive. ▪ I have your screening test result and it is reactive.
Explain the meaning of a reactive test result.	<ul style="list-style-type: none"> ▪ This means that the test may have detected HIV antibodies in your blood. ▪ This is a strong indication that you may have been infected with HIV.
Emphasize the need for confirmatory testing.	<ul style="list-style-type: none"> ▪ This result needs to be confirmed with an additional test. ▪ Remember that we talked about the other test that we'll need to do today to confirm the result. ▪ Further testing is always needed to confirm a preliminary positive screening test result.
Assess the client's emotional reaction to the result.	<ul style="list-style-type: none"> ▪ (Counselor: you should allow some silent time for the client to absorb the results.) ▪ How are you feeling about this result? ▪ What questions do you have about this result? ▪ Tell me your thoughts about what I just said.
Advise client to take precautions to avoid transmitting infection to others while awaiting confirmatory testing.	<ul style="list-style-type: none"> ▪ It is important to protect yourself to avoid the possibility of infecting yourself or others. ▪ While waiting for the confirmatory test result, you need to take precautions to avoid the possibility transmitting the virus or acquiring any other infections.

A sample message for conveying this information could be: *"Your screening test result is reactive which means HIV antibodies may have been found in your blood. This result needs to be confirmed with an additional test. While waiting for the confirmatory test result, it is important to take precautions to avoid transmitting the virus. How are you feeling about this result?"*

Adapted from the Centers for Disease Control and Prevention: Reporting Rapid HIV Test Results
Fundamentals of Waived Rapid HIV Testing and Prevention Counseling

Giving an Indeterminate Western Blot HIV Test Result

Content	Message
Provide indeterminate result to this screening test clearly and simply.	<ul style="list-style-type: none"> ▪ Your test result came back indeterminate. ▪ I have your test result and it is indeterminate.
Explain the meaning of an indeterminate test result.	<ul style="list-style-type: none"> ▪ An indeterminate test means that the test could not determine whether you are infected or not. ▪ This is an indication that you may have been infected with HIV very recently, or that something else is reacting with the test to make it look like that; but we will have to repeat the test to determine which one it is.
Emphasize the need for confirmatory testing.	<ul style="list-style-type: none"> ▪ We will need to follow up with an additional test in about 3 weeks. ▪ Further testing will be needed to determine if you are infected with HIV. ▪ Since your risks are high, we'd recommend that you see an HIV specialist who may do some additional testing.
Assess the client's emotional reaction to the result.	<ul style="list-style-type: none"> ▪ (Counselor: you may allow some silent time for the client to absorb the results.) ▪ How are you feeling about this result? ▪ What questions do you have about this result? ▪ Tell me your thoughts about what I just said.
Advise client to take precautions to avoid transmitting infection to others while awaiting confirmatory testing.	<ul style="list-style-type: none"> ▪ It is important to protect yourself to avoid the possibility of infecting yourself or others. ▪ While waiting for the confirmatory test result, you should take precautions to avoid the possibility of transmitting the virus or acquiring any other infections.

Giving a Positive Confirmatory Western Blot HIV Test Result

Content	Message
Provide positive result to this screening test clearly and simply.	<ul style="list-style-type: none"> ▪ Your test result came back positive. ▪ I have your HIV test result and it is positive.
Explain the meaning of a positive test result.	<ul style="list-style-type: none"> ▪ This means that the test detected HIV antibodies in your blood. ▪ This means that the test shows that you have been infected with HIV.
Allow the client time to absorb the test results.	<ul style="list-style-type: none"> ▪ (Counselor: you may allow some silent time for the client to absorb the news) ▪ Had you expected it to come back this way? ▪ Take your time, we have plenty of time to talk about the results and what is next.
Assess the client's emotional reaction to the result.	<ul style="list-style-type: none"> ▪ How are you feeling about this result? ▪ What questions do you have about this result? ▪ Tell me what you are thinking.
Advise client to take precautions to avoid transmitting infection to others.	<ul style="list-style-type: none"> ▪ Let's talk about ways to protect yourself. ▪ How do you plan to prevent getting any other infections? ▪ How do you plan to prevent transmitting HIV to others?
Emphasize the importance of getting linked to specialty medical care.	<ul style="list-style-type: none"> ▪ Let's talk about your medical care. Do you have a doctor or a provider that you would like to stay with, or would you like me to make an appointment with an HIV specialist? ▪ You will need some more tests to determine if you need medications now or not. ▪ They can answer your questions and help you make decisions.

Giving Results: Confirmatory Testing

Where and how can I get confirmatory testing?

Anyone who has a preliminary positive rapid test must get another test to confirm the results. If you have not yet had this second test, ask your doctor for a list of places that offer confirmatory testing, or contact:

- **AIDS Action Committee HIV/AIDS & STD Hotline**
(800) 235-2331 / www.aac.org
M-Th 9am-8pm, F 9am-5pm.
Interpretation services available.
- **Health Quarters**
(800) 892-0234 / www.healthq.org
 - ☐ 19 Broadway, Beverly, MA 01915
(978) 922-4490
 - ☐ 215 Summer St., Haverhill, MA 01830
(978) 521-4444
Spanish spoken.
 - ☐ 101 Amesbury St., Ste. 202, Lawrence, MA 01840
(978) 681-5258
Spanish spoken.
 - ☐ 274 Main St., Reading, MA 01867
(781) 944-8325

Confirmatory Testing for the Rapid HIV Test

- **All patients who have a reactive (preliminary positive) rapid HIV test must be given another test to confirm that the person being tested is infected with HIV.**
- A confirmatory test sample should be collected by you in the same visit after a patient has received a reactive result with a rapid HIV test. If the patient opts to go elsewhere for confirmatory testing, counsel on risk reduction and refer to another testing site.
- Confirmatory testing may be performed on either a whole blood or oral fluid specimen that is sent to the lab.
- All rapid HIV test results must be followed up with a Western blot and/or immunofluorescent assay (IFA) for confirmation.
- **Indicate on the lab sheet that the specimen is from an individual who already received a reactive rapid HIV test result.**
- Most confirmatory test results will be positive, unless in a low prevalence setting.

- If the confirmatory test is negative, however, repeat testing should be performed to rule out specimen mix-up. If an oral specimen was used, repeat testing should be performed with a blood specimen since the oral fluid test is slightly less sensitive than the blood test. The CDC also recommends a sample be sent by the lab to the CDC for further testing for HIV-2, and to re-test in 30-60 days.
- If the confirmatory test is indeterminate, for blood specimens the person should be advised to return for repeat testing in one month. For oral fluid specimens, the Western blot or IFA test should be repeated using a blood specimen. Refer to an HIV specialist for repeat testing.
- Once a patient is confirmed positive, they should be connected to care. Several special blood tests will be run, including an RNA test and CD4 count. This is essential so that the patient and physician can know the extent of virus in their body (number of copies) and how many T cells they have. Both numbers are needed by a physician to recommend treatment.

Troubleshooting Guide For Confirmatory Testing

Problem	Potential Causes	Action
Confirmatory test result does not agree with rapid HIV test result (i.e., RT result is reactive; confirmatory test is negative or indeterminate).	<ul style="list-style-type: none"> ▪ Specimen mix-up. ▪ Testing during HIV window period (varying test sensitivities). ▪ Clients with interfering medical conditions. ▪ Specimens with interfering substances. 	<p>Procedures should describe how to handle discrepancies, as follows:</p> <ul style="list-style-type: none"> ▪ RT result is reactive, confirmatory test is negative. <ul style="list-style-type: none"> ○ <i>Blood specimen</i> – repeat confirmatory testing with new specimen to rule out mix-up. ○ <i>Oral fluid specimen</i> – repeat confirmatory testing using a blood specimen. ▪ RT is reactive, confirmatory test is indeterminate. <ul style="list-style-type: none"> ○ <i>Blood specimen</i> – the client should return for repeat testing in one month. ○ <i>Oral fluid</i> – repeat the Western blot or immunofluorescent assay (IFA) test with a blood specimen. ▪ If the confirmatory testing laboratory performed enzyme immunoassay only, contact the confirmatory testing lab and request a Western blot or IFA test on the same specimen, if it is still available. If the specimen is not available, recall the client and collect a new specimen for confirmatory testing.

RT = rapid HIV test

Fundamentals of Waived Rapid HIV Testing and Prevention Counseling

Adapted from the Centers for Disease Control and Prevention: Providing HIV Test Result

HIV Testing Sites in Northeastern Massachusetts

For more information on HIV testing sites, contact the **AIDS Action Committee HIV/AIDS & STD Hotline at (800) 235-2331** or visit www.aac.org on the web.

Agency	Phone / Website	Address	Hours	Cost/Fees	Appointment Necessary				Special Population(s) Served	Additional Language(s) Spoken
					Confirmatory Testing	Rapid Testing	Confidential Testing	Anonymous Testing		
CAB Health and Recovery Services	(781) 592-4477 www.cabhealth.org/HIV_PROGRAMS.shtml	280 Union St. Lynn, MA 01901	M-F 9am-5pm	Free				✓	Only IDU/Sex Workers	Spanish
Greater Lawrence Family Health Center	(978) 685-7663 ext. 1 www.glfhc.org	11 Lawrence St., Ste. 308 Lawrence, MA 01840	M, T, Th 8am-4pm; W 11am-7pm	Free			✓	✓	IDU	Spanish
Health and Education Services (HES)	(978) 927-4506 (508) 727-8937 (Pager) www.hes-inc.org	156 Cabot St. Beverly, MA 01915	W 2pm-7pm (Free clinic) and by appointment	Free on W 2pm-7pm	✓					Spanish
Health Quarters, Beverly	(978) 922-4490 (800) 892-0234 www.healthq.org	19 Broadway Beverly, MA 01915	M, W-F 8:30am-4:30pm; T 11am-7pm	Sliding fee scale	✓			✓	Teens	
Health Quarters, Haverhill	(978) 521-4444 (800) 892-0234 www.healthq.org	215 Summer St. Haverhill, MA 01830	M 8:30am-4:30pm; T 11am-7pm; W-Th 8:30am-4:30pm	Sliding fee scale	✓			✓	Latinos, Teens	Spanish
Health Quarters, Lawrence	(978) 681-5258 (800) 892-0234 www.healthq.org	101 Amesbury St., Ste. 202 Lawrence, MA 01840	M-F 9am-5pm	Sliding fee scale	✓			✓	Latinos, Teens	Spanish
Health Quarters, Reading	(781) 944-8325 (800) 892-0234 www.healthq.org	274 Main St. Reading, MA 01867	M, F 10am-6pm; W 11am-7pm	Sliding fee scale	✓			✓	Teens	
Latin American Health Institute	(978) 459-3366 www.lhi.org	9 Central St., Ste. 400 Lowell, MA 01852	M 11am-3pm; W 2pm-3pm	Free	✓			✓	Latino	Spanish
Lowell Community Health Center	(978) 322-8655 www.lchealth.org/CARIN_O.shtml	585 Merrimack St. Lowell MA 01854	M, W-F 8:30am-5pm; Tu 8:30am-7:30pm	Free	✓			✓	Latino, Cambodian, and African populations	Spanish, Portuguese, Cambodian, Shona (Zimbabwe)
Lynn Community Health Center	(781) 581-3900 www.lchcnet.org	269 Union St. Lynn, MA 01905	M, W 8:30am-6:30pm; T, Th, F 8:30am-4pm	Free	✓			✓		Spanish, French Creole. Additional interpretation service available via language line
Salem Family Health Center (Part of North Shore Community Health, Inc.)	(978) 744-8388 ext. 6 www.nschi.org	47 Congress St. Salem, MA 01970	M-F 8:30am-5pm							Spanish, Portuguese
Team Coordinating Agency	(978) 373-1181 ext. 21	76 Winter St. Haverhill, MA 01830	M-F 9am-4pm	Free	✓			✓		

Medical Health

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Appendices

- ☒ "Day One: After you've tested positive." Project Inform, May 2008. Web. 27 July 2009.
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- ☒ "What Is Antiretroviral Therapy (ART)?" The AIDS InfoNet, 24 Apr. 2009. Web. 27 July 2009.
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- ☒ "Frequently Asked Questions and Answers About Coinfection with HIV and Hepatitis C Virus." Centers for Disease Control and Prevention. Web. 27 July 2009.
<http://www.cdc.gov/hiv/resources/qa/print/HIV-HCV_Coinfection.htm>.

Medical Health: Treatment Centers

I just learned that I am HIV positive. Do I have AIDS?

AIDS stands for Acquired Immune Deficiency Syndrome. AIDS is the most serious outcome of HIV infection. Being HIV positive is not the same as having AIDS, but it means that you may develop AIDS in the future. HIV attacks your immune system, gradually harming the way it functions. Your immune system protects your body from harmful germs like viruses or bacteria. Over time, if your immune system becomes seriously damaged by HIV, your body loses its ability to fight certain infections and cancers. AIDS occurs once the immune system has been significantly damaged. You will need to have more medical tests to determine how strong your immune system is and if you have AIDS.

Am I going to die?

A positive HIV test is scary news, but it is not a death sentence. Many people live full lives with HIV, and they are alive and well many years after getting infected. A positive HIV test result is an important medical message. Finding out that you have HIV gives you the chance to get the medical care you need, take control of your health, and slow or prevent some of the possible health effects of HIV.

Where can I get the HIV care I need?

You should find a doctor who specializes in HIV treatment and see this doctor regularly for check-ups of your immune system. Unless you already have an advanced form of HIV disease, this care is mainly preventive—to keep the disease from getting worse. You do not need to stop seeing your regular doctor—they can talk with your HIV doctor about the best ways to take care of your medical needs.

Where to Find HIV Medical Care:

- **Greater Lawrence Family Health Center**
34 Haverhill St., Lawrence, MA 01841
(978) 686-0090 / www.glfhc.org
Spanish, French, Cambodian, Czech, Farsi, German, Gujarati, Hebrew, Indo, Italian, Korean, Lebanese, Lingala, Punjabi, Russian, S-Swa, Taiwanese, and Ukra spoken.
- **Lowell Community Health Center**
585 Merrimack St., Lowell, MA 01854
(978) 937-9700 / www.lchealth.org
Spanish, Portuguese, French, Haitian Creole, Khmer, Lao, Luganda, Swahili, and Vietnamese spoken.
- **Lynn Community Health Center**
269 Union St., Lynn, MA 01901
(781) 581-3900 / www.lchcnet.org
Spanish, French, Arabic, French Creole, Khmer, and Russian spoken.

In addition to the HIV medical care agencies and providers listed, you can also find a directory of additional private providers in your area by searching on the **American Academy of HIV Medicine's** website at www.aahivm.org or the **HIV Medicine Association's** website at www.hivma.org.

More HIV medical care options:

- **Lawrence Kidd, MD**
50 Prospect St., Lawrence, MA 01841
(978) 682-3686
M, W-F 9am-4pm.
- **Karen Mello, MD (Pentucket Medical at RiverWalk)**
500 Merrimack St., Lawrence, MA 01843
(978) 557-8900
M-F 8:30am-5pm.
- **Steven Keenholtz, MD (North Shore Primary Care)**
140 Commonwealth Ave., Danvers, MA 01923
(978) 777-6544
M-F 9:30am-5pm.
- **Peter Sheckman, MD (North Shore Medical Group)**
496 Lynnfield St., Ste. 201, Lynn, MA 01904
(781) 593-3400
M-W 9:30am-5pm.
- **Lucas Wolf, MD**
302 Washington St., Gloucester, MA 01930
(978) 356-5524
M-Th 8am-2pm.
- **Rajaa Nagra, MD**
33 Bartlett St., Lowell, MA 01852
(978) 275-1913
Spanish and Khmer spoken. M-F 8:30am-4:30pm.
- **David Sidebottom, MD (Saints Memorial Medical Center)**
1 Hospital Dr., Lowell, MA 01852
(978) 458-1411

Medical Health: HIV Medications

Do I need to be on HIV medicines now?

You may or may not need to be on HIV medicines now. When to start taking HIV medicines depends on your overall health, the amount of HIV virus in your blood (viral load), and how well your immune system is working. You and your doctor will determine the best time to start taking the medicines. Once you begin taking HIV medicines, you may need to continue taking them for the rest of your life.

HIV/AIDS Basics

What is HIV?

The Human Immunodeficiency Virus (HIV) is the virus that leads to AIDS. HIV belongs to a subset of retroviruses called lentiviruses (or slow viruses), which means that there is an interval—sometimes years—between the initial infection and the onset of symptoms. Upon entering the bloodstream HIV infects the CD4+T cells and begins to replicate rapidly.

Scientists believe that when the virus enters the body, HIV begins to disable the body's immune system by using the body's aggressive immune responses to the virus to infect, replicate and kill immune system cells. Gradual deterioration of immune function and eventual destruction of lymphoid and immunologic organs is central to triggering the immunosuppression that leads to AIDS.

What is AIDS?

Acquired Immunodeficiency Syndrome (AIDS) is the final stage of HIV infection. The Centers for Disease Control establish the definition of AIDS, which occurs in HIV-infected persons with fewer than 200 CD4+T cells and/or persons with HIV who develop certain opportunistic infections. In 1992, the CDC redefined AIDS to include 26 CDC-defined AIDS indicator illnesses and clinical conditions that affect persons with advanced HIV.

Treatment Basics

What is the treatment for HIV or AIDS?

- ➔ **Antiretroviral medicines.** Because HIV is a retrovirus, the drugs used to treat it are called antiretroviral medicines. These powerful medicines control the virus and slow progression of HIV infection, but they do not cure it. These medicines must be taken exactly as the doctor prescribes.
- ➔ **HAART.** The current recommended treatment for HIV is a combination of three or more medicines. This regimen of medicines is called highly active antiretroviral therapy (HAART). How many pills someone will need to take and how often to take them will depend on which medicines the doctor chooses. Remember, each HAART regimen is tailored to each individual patient. There is no one best regimen. You can read more about specific HAART regimens at www.aidsinfo.nih.gov/other/cbrochure/english/04_en.html. HAART may cause some side effects. Patients and their doctors should discuss potential side effects so that they will know if they occur. If they experience any side effects, even those that may seem minor, they should talk about them with their doctor.
- ➔ **Other medicines.** The doctor may also prescribe other medicines, depending on your CD4 cell count and medical needs. Side effects should always be discussed with a doctor. Medicines and the way they are taken should never be changed without first talking with a doctor. Medicines not taken the right way consistently may not be as effective as they should be.
- ➔ **Treating other infections.** If a patient's HIV infection gets worse and the CD4 cell count falls below 200, they are more likely to get other infections. Their doctor may prescribe medicines to prevent particular infections, such as PCP. The most important thing a patient can do after they learn that they have HIV is to work closely with their doctor. Because HIV and HIV-related illnesses vary from person to person, the doctor will design a medical care plan specifically for that individual.

DAY ONE:

AFTER YOU'VE TESTED POSITIVE



getting informed about your status
and taking charge of your health

PUBLISHED BY



MAY 2008



A positive HIV antibody test is scary news but it's not a death sentence. As better therapies continue to be developed, it's entirely possible to live out a normal lifespan after testing positive. The key to living a long life with HIV is availing yourself of health care and suitable therapies.

A positive result is an important medical message that may help you save and extend your life. Whether you took the test or not, sooner or later you would have learned of your HIV status.

If you learn by testing, you have a chance to slow or prevent some of the possible health outcomes. Even if you didn't get tested, HIV would present itself at some point as an infection or damage to your immune system. And, if you had waited for HIV *disease* to present itself, many of your best medical options would already be lost.

Most testing sites provide counseling to help people handle the news. The real work, however, is up to you. Given the right attitude and the right information, most people can live for a long, long time. Getting informed and taking charge of your health will help you make the best of your situation. This publication can help you with the things you need to do:

- › Develop a strategy to adapt to your new situation;
- › Learn more about HIV and how it can affect you;
- › Understand the medical tests you'll use;
- › Find ways to promote and maintain your health; and
- › Learn how to use the services at Project Inform.

Reading this publication is a good first step. It's a little long, but it's worth the time. It's about saving your life.

WHAT'S INSIDE

HIV and your immune system: **2**; Disease progression: **3**; Checking on your immune health: **4–5**; CD4+ cell count tests: **6**; Viral load tests: **7**; Interventions against HIV: **8–10**; When to start treatment: **11**; Available treatments: **11**; The bottom line: **12**.

HIV and your immune system

HIV (*human immunodeficiency virus*) is the virus that causes AIDS (*Acquired Immune Deficiency Syndrome*). Being HIV-positive does not mean that you *have* AIDS, but it does mean that you may *develop* AIDS. HIV attacks your immune system, gradually impairing how it functions.

Your immune system helps keep your body healthy by recognizing and attacking foreign substances, like viruses or bacteria. Over time, if it becomes seriously damaged or weakened by HIV, your body loses its ability to fight certain infections and cancers. These are called *opportunistic infections* (OIs).

AIDS is the most serious outcome of HIV infection. It occurs once your immune system has been significantly damaged. If you have certain OIs, it will lead to an AIDS diagnosis. This is because the presence of these OIs in your

body points to a significantly damaged immune system.

An AIDS diagnosis will also be given if the counts of your immune system cells (called CD4+ T cells or simply CD4s) fall below 200. These cells are the key players in your immune system. Their “normal” range in a healthy HIV-negative person is 500–1,500 cells/mm³.

This gradual destruction of the immune system doesn’t happen the same way in everyone, or even at the same pace. In some, it may not happen at all. In a small percentage of people, HIV destroys their immune systems very rapidly, in just a few years. But others remain well for 10–15 years or longer. On average, without using HIV therapy, most people remain well for about ten years before facing their first serious symptoms.

A number of things are well known about HIV infection:

- *Viral load* tests measure the amount of HIV in the bloodstream. They can generally predict how quickly HIV will damage the immune system. In effect, these tests predict the loss of CD4 cells: the higher the number, the greater the risk of damage to your immune system. Using effective treatments can greatly reduce the level of HIV and slow its rate of disease progression.
- *CD4 cell count* tests measure the level of CD4 cells, a certain type of white blood cell. These tests can measure the decline of your immune health. However, taking HIV therapy can slow the decline of your immune health. In fact, many people who start HIV therapy experience a significant increase in their CD4 counts.
- For long periods, often several years, the body copes effectively with HIV in many people. The number and percentage of CD4 cells fall, but slowly. During this period, most people feel normal and suffer no obvious ill effects. Despite this, most researchers believe that damage is still being done to the immune system. Many scientists believe that early intervention during this time may have the greatest impact, though others remain skeptical. They believe the possible side effects from early treatment might outweigh its benefits.
- Without treatment, the body slowly loses its ability to fight infections. Some infections, like *Pneumocystis jiroveci* pneumonia (sometimes called PCP), become likely when CD4 counts fall below 300 or 200. Minor infections can occur at counts above 300. Other life-threatening infections become more likely when the count falls below 100 or 50.

Disease progression

HIV is a “spectrum” illness: all who are infected have the same disease, but there are different stages to it. AIDS is the name given only to the later most serious stage. In the earlier and less serious stages, people are *HIV-positive*, meaning they tested positive on an HIV antibody test but they have no life-threatening symptoms of illness. If left untreated, most people generally progress along the spectrum toward AIDS.

HIV disease can progress slowly or quickly. Several studies have researched the rate at which it progresses when left untreated. Most conclude that about half of HIV-infected people progress to AIDS if left untreated within about ten years of infection. About three out of four (75%) reach AIDS by the 15th year.

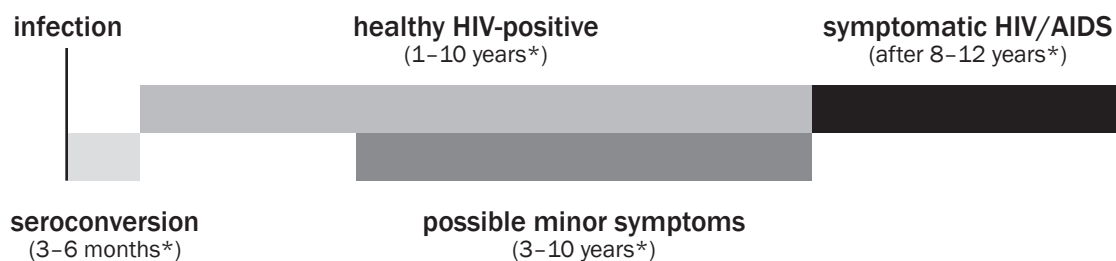
These studies conclude that HIV is a progressive disease that leads to symptomatic illness in most people over time. Children born with HIV and people infected through blood transfusion seem to get sick more quickly. Studies suggest that when women have access to and



seek regular care and monitoring, their progression rates are similar to and perhaps even slower than men. Studies that include people with hemophilia are inconclusive about their rates of progression.

Why people progress at different rates is uncertain. It may be due to differences in the strain of HIV a person gets. Others believe it is influenced by genetic differences in people, while others suspect that lifestyle factors make a difference.

the spectrum of HIV



* average times; actual times may vary greatly from person to person

what happens without intervention*

At which point do you want to do something about your HIV?

Infection and partial recovery

Gradual, stepped CD4+ decline

Risk of serious infection or AIDS

* in roughly 85–90% of HIV-infected people

checking on your immune health

With most illnesses, we wait until a disease shows up before doing anything about it. “If it ain’t broke, don’t fix it.” But in HIV disease, the immune system starts to “break” immediately, not just when OIs show up. So keeping an eye on the health of your immune system is critically important. Two common ways to do this are: (1) noticing when symptoms occur and (2) getting lab tests done. Each can appear to have advantages and disadvantages.

Noticing when symptoms occur

This approach waits for active infections and disease to occur. In HIV, this means watching out for such things as thrush (yeast infections), PCP, Kaposi’s Sarcoma (KS) lesions and so on.

ADVANTAGES

It is easier to believe and take action when we are faced with an obvious illness. People who feel sick usually want to treat the illness as soon as possible.

DISADVANTAGES

HIV disease progresses even before symptoms appear. By the time they do appear, treating the underlying problem may be less effective because your body is left with fewer defenses.

Getting lab tests done

This approach doesn’t wait for symptoms or disease to occur. This means getting routine tests done to check on the different parts of your immune system. These tests include the following:

- › HIV antibody tests
- › CD4 cell counts
- › viral load tests
- › basic blood tests

ADVANTAGES

The laboratory signs of illness usually show up before you actually feel sick. Using these various test results help people and their doctors prevent serious infections *before* they occur. They also help them make treatment decisions based on real numbers and not just guesses.

DISADVANTAGES

Some people find it difficult to act on their test results, since they often feel fine no matter what the lab numbers say. People who feel healthy may be less motivated to start treatment. Test results vary, and they change for many reasons.



Because HIV infection can be a life-or-death matter, it is critical to choose the second approach. Taking a preventive approach makes it possible to:

- ▶ use treatments when they're most effective,
- ▶ prevent the most serious infections, and
- ▶ slow the rate of disease progression and permanent damage to your immune system.

Some people say they hesitate to act before they're sick because today's treatments are not perfect, hoping to wait for something better to come along. However, no one

knows when "perfect" treatments will become available. It is well proven that today's treatments can extend survival time. Although we can't predict the results for every person, we do know what generally happens without treatment.

The purpose of preventive action is to slow the progress of HIV disease. This approach is the one that seems to offer the clearest hope. Once infected, you have one chance to manage your disease correctly. So consider your options carefully and learn how to tell when a therapy is or is not working for you. To learn more, read Project Inform's publicationS, *Making Decisions About Therapy* and *Blood Work: Two Common Tests to Use*.

Project Inform treatment strategy for HIV disease

Have you tested positive for HIV? Yes or no?



Get physical exam(s)
Women: GYN and Pap



Get key tests: CD4
cell count & viral load



Get other blood tests
as needed



Maximize your health support. Consider your treatment options.

Get CD4 cell and viral load tests done every three months.



EARLY STAGE DISEASE

CD4 cell counts: above 500
Viral load: below 5,000

Get tests done every three months.
Consider ways to support your
nutrition and immune system.

MIDDLE STAGE DISEASE

CD4 cell counts: 200–500
Viral load: 5,000–100,000

Consider HIV therapy.
Consider ways to support your
nutrition and immune system.

ADVANCED STAGE DISEASE

CD4 cell counts: below 200
Viral load: above 100,000

Get tests done every three months.
Consider ways to prevent
opportunistic infections.

common blood tests and what they tell you

CD4 cell count tests

For many years, testing the number of CD4 cells was the only lab measure for the effects of HIV disease. Low numbers of these cells (below 200) accurately predict the risk of major infections.

Doctors encourage people to start HIV therapy when their CD4 counts are 200–350. However, these are arbitrary numbers used in studies of HIV drugs. By itself, a CD4 count

doesn't tell us enough about the state of disease. It only shows that the level of CD4 cells is below normal, to varying degrees. Getting the full picture of your HIV disease requires monitoring your general health and additional tests, especially the *viral load* test and CD4 percentage.

It has become common to put people with CD4 counts below 200 or 300 on preventive treatment for

PCP (often using Bactrim/Septra or dapsone), along with all people who have had an initial bout of PCP. Regardless of CD4 count, yearly checking for tuberculosis is becoming increasingly important. Prevention strategies for all of the common OIs are described in Project Inform's publications, *Opportunistic Infections Chart* and *Strategies for Managing Opportunistic Infections*.

CD4 Cell Count Ranges

NORMAL	BELOW NORMAL	LOW
(500 plus)	(350–500)	(under 350)

Normal Range: In general, a CD4 count above 500 suggests no immediate danger. This level is sometimes used as the bottom of the “normal” range, but this can be misleading. While an occasional drop to 500 may be normal, a steady or falling count over time towards 500 or even 600 is not normal and suggests a weakened immune system. At the very least, nutritional counseling, CD4 count monitoring and using other routine tests are recommended in this range, whether or not treatments are used.

Below Normal Range: CD4 counts in this range indicate significant decline of the immune system. However, serious symptoms are uncommon. It is quite rare for a person to die of AIDS with CD4 counts in this range. Some researchers believe this is the best time to begin treatment, especially if your viral load tests also indicate significant viral activity.

Low Range: A CD4 count of 200 or less constitutes an AIDS diagnosis. CD4 counts below 350 indicate the greatest risk for infections. A person with counts below 350 may remain stable for many years, especially with thoughtful health care. While some people have warning signs (symptoms) before major infections occur, this is not always the case. Some progress directly from apparently good health to serious OIs. Generally, people with established HIV infection with CD4 counts in this range are encouraged to start HIV therapy.

drug i.d. chart

TRADE NAME GENERIC NAME

Protease inhibitor

Agenerase	amprenavir
Aptivus	tipranavir
Crixivan	indinavir
Invirase	saquinavir hgc
Kaletra	lopinavir+ritonavir
Lexiva	fosamprenavir
Norvir	ritonavir
Prezista	darunavir
Reyataz	atazanavir
Viracept	nelfinavir

Nucleoside (NRTI) and nucleotide (NtRTI) analogue reverse transcriptase inhibitor

Combivir	3TC+AZT
Emtriva	emtricitabine (FTC)
Epivir	lamivudine (3TC)
Epzicom	3TC+abacavir
Retrovir	zidovudine (AZT)
Trizivir	3TC+AZT+abacavir
Truvada	FTC+tenofovir
Videx	didanosine (ddI)
Videx EC	didanosine enteric-coated (ddI EC)
Viread	tenofovir
Zerit	stavudine (d4T)
Ziagen	abacavir

Non-nucleoside reverse transcriptase inhibitor (NNRTI)

Intelence	etravirine
Rescriptor	delavirdine
Sustiva	efavirenz
Viramune	nevirapine

NRTI + NNRTI

Atripla	Emtriva+Sustiva+Viread
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Entry inhibitor

Fuzeon	enfuvirtide (T20)
Selzentry	maraviroc

Integrase inhibitor

Isentress	raltegravir
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Viral load tests (PCR)

Tests are available that directly measure the activity of HIV in the blood. They provide extra information to describe a more accurate picture of the risk of disease progression.

Viral load tests measure the amount of new HIV being produced and released into your blood. Studies show that higher viral loads are associated with a greater risk of losing CD4 cells and then progressing to symptoms of HIV disease. Ideally, an HIV-infected person should have no detectable level of virus, which means that HIV activity is too low to be measured by the tests.

Current tests measure down as low as 50 copies of virus. This is associated with the best possible medical outcome. Higher levels — ranging from about 30,000 (in women) to 60,000 (in men) to upwards of millions of copies of virus — are linked to higher rates of disease progression. In short, the higher the number, the more rapid the rate of disease progression.

Studies of new drugs use viral load tests to measure the effects of the drugs. A good combination of HIV

drugs can quickly reduce the level of virus at least ten times and often as much as a thousand times. The goal of therapy is to reduce viral load to as low as possible, preferably below the lowest level detected by the test, below 50 copies.

HIV-positive people and their doctors use both CD4 counts and viral load tests to make decisions about if and when to use HIV drugs. These tests also help determine whether a drug is working or not. When HIV levels begin to rise again while using a drug, most doctors believe it is time to switch to another drug or combination of drugs. Also, if your CD4 counts begin falling, reassessing your HIV therapy is warranted.

At the very least, viral load tests provide a rational basis for helping some to decide when or whether to use HIV drugs, as well as a tool for determining whether or not a drug combination is working. For more information, read Project Inform's publications, *Blood Work: A Useful Tool for Monitoring HIV* and *Blood Work: Two Common Tests to Use*.

Final thoughts on testing

No single test gives a total picture of immune health or disease progression, but CD4 count and viral load test results taken together over time are very important. As we learn to manage HIV as a chronic illness, these tests

provide rational guidance about what treatments to use, when and when not to use them, and how well they're working. To help you chart these various blood tests, use Project Inform's publication, *Personal Tracking Charts*.

Interventions against HIV

There are several approaches that you can take against HIV. Many are useful, but using any of them alone is not enough to keep you healthy. Unfortunately, some of these are promoted with extreme passion or as a fad, to the exclusion of the others. The best over-all approach for you may be one that is inclusive, combining the best of each of those explained below that best suits your lifestyle.

1

General health maintenance

This means doing all of the things that are normally recommended for leading a healthy life. These include eating properly with nutritional support; getting enough rest; avoiding alcohol, smoking, drugs and unnecessary stress; and getting exercise and fresh air — in short, all things our doctors recommend. Taken alone, maintaining good health won't prevent you from progressing to AIDS or cure it, but it will give you the best fighting chance you have. A good defense to HIV builds upon a solid foundation of general health. For more information, read Project Inform's publication, *Strategies for General Health Maintenance*.

2

Supportive therapies

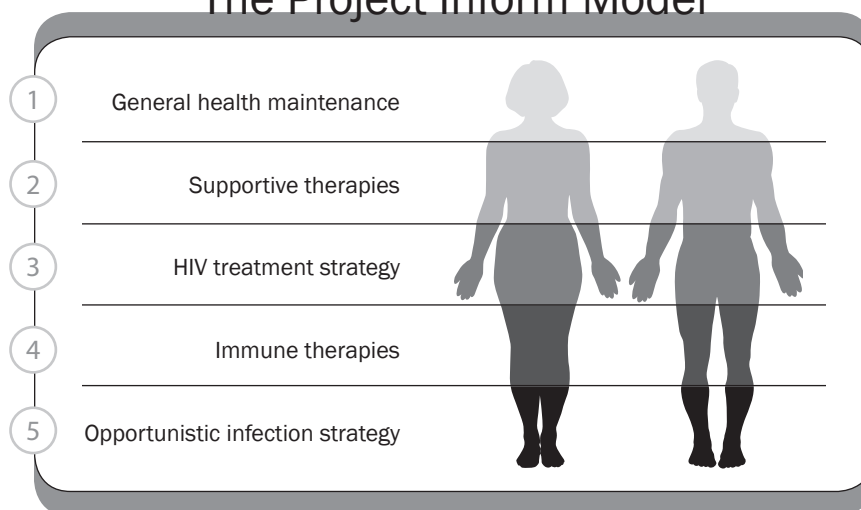
This category, sometimes called a holistic approach, can include various complementary approaches. These include stress reduction; massage; visualization, yoga and relaxation; emotional and spiritual support; natural medicines; and many others. Many of these can help you deal with symptoms of illness, drug side effects and keep your peace of mind. Taken alone, however, they won't solve the problem.

Unfortunately, some promoters of complementary therapy become strict, urging people to use them to the exclusion of all others, even the medicines recommended by doctors. When used in this way, supportive therapies can be harmful and may discourage one from getting necessary medical attention. The best promoters view these therapies as *complementing* other therapies rather than *replacing* them.

For more information, read Project Inform's publication, *Herbs, Supplements and HIV Disease*.



The Project Inform Model



3

4

HIV treatment strategy

HIV attacks and misdirects the immune system, and medicines can help slow its spread. Currently approved HIV drugs are noted in the chart on page 7.

The challenge of using these drugs is knowing when and how much to use, how to combine them, and in what order. Used alone, none of them will work for long. When used together in rational combinations, they can suppress HIV for many years and lengthen your life.

For more information on HIV treatment strategies, read Project Inform's publications, *Strategies for When to Start HIV Therapy* and *Strategies for HIV Therapy*, available at 1-800-822-7422 or www.projectinform.org. You can also ask for information on each of the specific drugs listed on page 7.

Immune therapies

Because the immune system is sometimes suppressed, overactive and misdirected by HIV, it makes sense to seek out medicines that might help correct some of these problems. The goal of using immune therapies is to increase the number or function of lost cells (such as CD4 cells) to restore the balance of the various parts of the immune system or to reduce the harmful activities caused by infected cells. This is easy to describe but difficult to do.

Many researchers feel that we don't yet know enough about the immune system to try to regulate it. Some therapies do influence the immune system. And similar claims have been made about some natural products. There is great popular appeal to the notion that we should somehow "boost the immune system" to help the body naturally regulate itself against HIV.

For the most part, this is little more than an empty advertising slogan. There's little evidence that anyone really knows how to do this. Moreover, the body's natural defenses almost always seem to fail in the fight against HIV. It would be unrealistic to expect that this approach on its own would solve the problems of HIV.

At this point, there's no clear or simple way to address the defects of the immune system in HIV infection. Some of the most complete information on immune therapies is available in Project Inform's publications, *Strategies for Improving Your Immune Health* and *Interleukin-2*.

Interventions against HIV, continued



Opportunistic infection strategy

Once the immune system has failed to a significant degree, it becomes necessary to try to prevent the most common OIs, or prevent them from coming back. OI prevention or *prophylaxis* should be considered when CD4 counts are in or nearing a danger zone. For example, the risk of getting PCP becomes high at CD4 counts of 300 or less. The risk of other infections, like CMV and MAC, increase dramatically when CD4 counts fall below 100.

The careful and timely use of medicine can prevent PCP altogether. As the rate of tuberculosis (TB) rises among HIV-positive people, testing and preventive treatment (if necessary) is recommended. Preventive treatment for other infections, including MAC and recurrent fungal infections, are available as well.

In advanced HIV disease, a person often must try to treat or prevent several OIs at the same time. This can lead to difficult choices, since many medicines can interact with each other. Two publications from Project Inform can help sort this out: *Opportunistic Infections* and *Strategies for Managing Opportunistic Infections*.

The key to successful interventions is comprehensive inclusion — doing all of the things that make sense for you. The biggest mistake is to rigidly choose one approach over the others. HIV is not a political debate or a matter of opinion; it can be a life-threatening illness. Every decision you make about treatment has consequences, and each person has little room for mistakes. So it makes no sense to bet your life on any one philosophy of medicine.

When to start treatment

Getting the earliest possible treatment is generally recommended for treating illnesses. Biologically, there's little reason to think that HIV is any different. In fact, early treatment may be even more important because of the seriousness of the disease. But just what "early" means in the case of HIV disease is not so clear.

When to start HIV medicines is the subject of a great deal of debate and theory. Some people believe that starting treatment is appropriate immediately upon learning of the infection, whether or not your CD4 count is falling, viral load is high or rising, or whether symptoms are evident. Waiting might only let the infection progress and spread to other parts of the body.

A second argument in favor of early treatment is that this may prevent losing critical cells in your immune system. But since we don't know exactly when the loss of these cells occurs, it's still hard to know "when" is the right time to start.

Some researchers prefer to withhold treatment until later in the disease. They believe it is best to save the drugs for later when HIV is more active or when your immune system shows obvious damage. They fear that

treating too early may "use up" the medicines before they're most critically needed. They also fear that people will have long-term side effects from the drugs before they're truly needed.

Since none of the current drugs can be used indefinitely, this argument cannot be casually dismissed. However, even these researchers believe it's wise to start before there's evidence of major damage to the immune system. Just "when" that occurs is unclear. Almost all researchers agree that it's necessary to start anti-HIV therapy when symptoms are present, your CD4 count is falling, or your viral load is high.

We will get clearer answers to these questions as more studies are completed. In the meantime, the question remains a matter of personal choice. For information about HIV therapy, developing a long-term strategy and making decisions about therapies, call Project Inform's Hotline at 1-800-822-7422 or visit www.projectinform.org.



Available treatments

Project Inform provides information on using proven HIV treatments. These and any other treatments should only be used under the care of an experienced doctor. We encourage patients and doctors to enter into collaborative relationships with shared responsibility for reaching and maintaining your health.

Treatment should always occur with monitoring, which evaluates the success or failure of treatment as well as monitors for side effects. Both patient and doctor should be prepared to adjust the strategy based on the results of this monitoring process. This model of flexible, monitored treatment used in the context of a collaborative doctor/patient relationship is the key to managing HIV as a chronic illness.

Complete information on treatments is readily available, along with discussion papers on related topics. Just ask for the basic "treatment package." The latest information on these and other important treatment issues is available through Project Inform's hotline at 1-800-822-7422. Also, there are many other magazines and newsletters for persons with HIV.



the bottom line

- › HIV infection is not a death sentence; you'll be OK for quite some time, no matter what happens.
- › You can gain power over your HIV by learning how it operates.
- › Learn to check on your health and understand the common lab tests.
- › Get acquainted with Project Inform's five-step model (pp 8–10).
- › Get informed about your treatment options.
- › Develop a treatment strategy that makes sense for you.

Project Inform provides more than a hundred publications designed to make information about living with HIV disease, medical therapies, research advances and public policy issues easier to understand. All are available free of charge through Project Inform's National HIV/AIDS Treatment Hotline toll-free at 1-800-822-7422 or online at www.projectinform.org.



Sample treatment information:

PI Perspective
Blood Work: Two Common Tests to Use
Tuberculosis and HIV Disease

Sample health care strategy information:

Dealing with Drug Side Effects
Making Decisions About Therapy
Personal Tracking Charts
Strategies for When to Start HIV Therapy
Strategies for Maintaining Your General Health

Sample information for women:

Positive? How Are You Feeling?
Pregnancy and HIV
Vaginal Candidiasis
Wise Words

Sample public policy information:

TAN (Treatment Action Network) Updates
Grassroots Advocacy 101

Yes, I want to help Project Inform remain at the forefront of HIV treatment information!

- ☐ Enclosed is my donation of: ☐ \$50 ☐ \$100 ☐ \$250 ☐ \$500 ☐ \$1,000 ☐ Other \$ _____
- ☐ Enclosed is my pledge of: \$ _____ per month for _____ months.
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☐ This is a new address.

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Circle One: **CHECK AMEX MC VISA DISCOVER**

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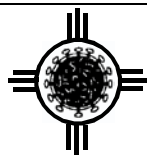
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FACT



WHAT IS ANTIRETROVIRAL THERAPY (ART)

WHAT IS ART?

ART means treating retroviral infections like HIV with drugs. The drugs do not kill the virus. However, they slow down the growth of the virus. When the virus is slowed down, so is HIV disease. Antiretroviral drugs are referred to as ARV. ARV therapy is referred to as ART.

WHAT IS THE HIV LIFE CYCLE?

There are several steps in the HIV life cycle. (See Fact Sheet 400 for a diagram.)

1. Free virus circulates in the bloodstream.
2. HIV attaches to a cell.
3. HIV empties its contents into the cell.
4. The HIV genetic code (RNA) is used by the reverse transcriptase enzyme to build HIV DNA.
5. The HIV DNA is inserted into the cell's DNA by the integrase enzyme. This establishes the HIV infection in the cell.
6. When the infected cell reproduces, it activates the HIV DNA, which makes the raw material for new HIV viruses.
7. Packets of material for a new virus come together.
8. The immature virus pushes out of the infected cell in a process called "budding."
9. The immature virus breaks free of the infected cell.
10. The new virus matures: raw materials are cut by the protease enzyme and assembled into a functioning virus.

APPROVED ARV DRUGS

Each type, or "class", of ARV drugs attacks HIV in a different way. The first class of anti-HIV drugs was the **nucleoside reverse transcriptase inhibitors** (also called NRTIs or "nukes".) These drugs block Step 4, where the HIV genetic material is used to create DNA from RNA. The following drugs in this class are used:

- Zidovudine (Retrovir, AZT)
- Didanosine (Videx, Videx EC, ddl)
- Stavudine (Zerit, d4T)
- Lamivudine (EpiVir, 3TC)
- Abacavir (Ziagen, ABC)
- Tenofovir, a nucleotide analog (Viread, TDF)
- Combivir (zidovudine/lamivudine combination)
- Trizivir (zidovudine/lamivudine/abacavir combination)
- Emtricitabine (Emtriva, FTC)
- Truvada (combination of emtricitabine and tenofovir)
- Epzicom (combination of abacavir and lamivudine)

Another class of drugs blocks the same step of the life cycle, but in a different way. These are the **non-nucleoside reverse transcriptase inhibitors**, also called **non-nukes** or **NNRTIs**. Four have been approved:

- Nevirapine (Viramune, NVP)
- Delavirdine (Rescriptor, DLV)
- Efavirenz (Sustiva or Stocrin, EFV)
- Etravirine (Intelence, ETR)

The third class of ARV drugs is the **protease inhibitors or PIs**. These drugs block Step 10, where the raw material for new HIV virus is cut into specific pieces. Ten protease inhibitors are approved:

- Saquinavir (Invirase, SQV)
- Indinavir (Crixivan, IDV)
- Ritonavir (Norvir, RTV)
- Nelfinavir (Viracept, NFV)
- Amprenavir (Agenerase, APV)
- Lopinavir/ritonavir (Kaletra or Aluvia, LPV/RTV)
- Atazanavir (Reyataz, ATZ)
- Fosamprenavir (Lexiva, Telsir, FPV)
- Tipranavir (Aptivus, TPV)
- Darunavir (Prezista, DRV)

A newer class of ARV drugs is **entry inhibitors**. They prevent HIV from entering a cell by blocking Step 2 of the life cycle. Two drugs of this type have been approved:

- Enfuvirtide (Fuzeon, T-20)
- Maraviroc (Selzentry or Celsentri, MVC)

The newest type of ARV drug is the integrase inhibitor. It prevents HIV from inserting its genetic code into the human cell's code in step 5 of the life cycle. The first drug of this type is:

- Raltegravir (Isentress, RGV)

HOW ARE THE DRUGS USED?

Antiretroviral drugs are usually used in combinations of three or more drugs from more than one class. This is called "Combination Therapy." Combination therapy works better than using just one ARV alone, It also helps prevent drug resistance.

Manufacturers of ARVs keep trying to make their drugs easier to take, and have combined some of them into a single pill. See Fact Sheet 409 for more information on combination medications.

WHAT IS DRUG RESISTANCE?

When HIV multiplies, most of the new copies are mutations: they are slightly different from the original virus. Some mutations keep multiplying even when you are taking ARV drugs. When this happens, the drug will stop working. This is called "developing resistance" to the drug.

If only one ARV drug is used, it is easy for the virus to develop resistance. For this reason, using just one ARV drug (monotherapy) is not recommended. But if two drugs are used, a

successful mutant would have to "get around" both drugs at the same time. And if three drugs are used, it's very hard for the right mutations to show up that can resist all three drugs at the same time. Using a triple-drug combination means that it takes much longer for resistance to develop.

CAN THESE DRUGS CURE AIDS?

At present, there is no known cure for HIV infection or AIDS. ARVs reduce the viral load, the amount of HIV in your bloodstream. A blood test measures the viral load. People with lower viral loads stay healthier longer. They are also less likely to transmit HIV infection to others.

Some people's viral load is so low that it is "undetectable" by the viral load test. This does **not** mean that all the virus is gone, and it does not mean a person is cured of HIV infection. See Fact Sheet 125 for more information on viral load.

WHEN DO I START?

There is not a clear answer to this question. Most doctors will consider your CD4 cell count and any symptoms you've had. ARV therapy is usually started if your CD4 cell count is dropping to near 350, if you are pregnant, need treatment for hepatitis B, or have symptoms of HIV-related disease. See fact sheet 404 for more information on treatment guidelines. This is an important decision you should discuss with your health care provider.

WHICH DRUGS DO I USE?

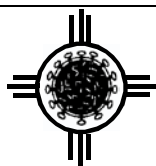
Each ARV drug can have side effects. Some may be serious. Refer to the fact sheet for each individual drug. Some combinations of drugs are easier to tolerate than others, and some seem to work better than others. Each person is different, and you and your health care provider will have to decide which drugs to use.

The viral load test is used to see if ARV drugs are working. If the viral load does not go down, or if it goes down but comes back up, it might be time to change ARV drugs.

WHAT'S NEXT?

New drugs are being studied in all of the existing classes. Researchers are also trying to develop new types of drugs, such as drugs that will block other steps in the HIV life cycle, and drugs that will strengthen the body's immune defenses. See fact sheets 470 and 480 for more information on newer classes of drugs.

Revised April 24, 2009



U.S. ANTIRETROVIRAL THERAPY GUIDELINES

WHY DO THE GUIDELINES KEEP CHANGING?

We keep learning more about the best way to fight HIV. In 1998, the US Department of Health and Human Services created a panel of physicians, researchers, and consumers to develop treatment guidelines. They constantly review AIDS research results. The guidelines are updated about once each year. The panel released the latest guidelines in November 2008.

NOTE: These are guidelines, not rules. Patients should receive individualized care from a health care provider with experience treating HIV infection. **The full text of these guidelines is available on the Internet at <http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf>**

VIRAL LOAD AND CD4 CELL TESTING

Viral load and CD4 cell tests provide critical information for decisions on antiretroviral therapy (ART). Before changing treatment, the tests should be repeated to confirm the results. Fact Sheet 124 has more information on CD4 cell tests and Fact Sheet 125 covers viral load testing.

Viral load should be tested:

- Before starting or changing medications. This provides a reference value;
- About 2 to 8 weeks after starting or changing medications. This shows whether the new drugs are working;
- Every 3 or 4 months. This helps make sure the medications are still working. For patients who haven't started taking medications, it helps decide when to start.

CD4 cell counts should be done:

- When someone first tests HIV-positive
- Every 3 to 6 months to monitor the strength of the immune system

RESISTANCE TESTING

Viral resistance testing helps health care providers choose the most effective drugs. See Fact Sheet 126 for more information. Resistance testing is recommended for patients starting therapy, when viral load is not controlled by new medications, or when it "breaks through" a regimen that used to work. The guidelines recommend resistance testing before starting antiretroviral treatment (ART.) It can also make sense for people who don't need to start ART yet. This can show if the person got infected with drug-resistant virus.

OTHER LABORATORY TESTS

The guidelines recommend using a viral tropism test (see fact sheet 129) before starting therapy with a CCR5 inhibitor. They also suggest using a genetic test, HLA-B*5701 before starting abacavir (see fact sheet 416).

WHEN TO START TREATMENT

Patients with symptoms of HIV disease or with less than 350 CD4 cells should be treated.

Regardless of CD4 count, treatment is recommended for all pregnant patients, and patients with HIV-associated nephropathy (a kidney disorder) or patients who need treatment for hepatitis B

Some experts would treat patients with higher CD4 counts.

GOALS OF THERAPY

The guidelines list the following goals for HIV therapy. Treatment goals are the same for people starting therapy and those who have been on therapy for a long time:

- Reduce viral load as much as possible for as long as possible
- Restore or preserve the immune system
- Improve the patient's quality of life
- Reduce sickness and death due to HIV

The following tools are suggested to help achieve these goals:

- Maximize adherence. Help the patient take medications correctly.
- Think about future regimens when choosing drugs. Keep future options open
- Use resistance testing when it will help.

WHAT DRUGS SHOULD BE USED FIRST?

The guidelines list several preferred regimens for people starting anti-HIV treatment. They include atazanavir (Reyataz), darunavir (Prezista), fosamprenavir (Lexiva), or lopinavir (Kaletra), each boosted with ritonavir, or efavirenz (Sustiva.) These should be taken with Truvada (emtricitabine + tenofovir). Many other combinations are listed as "alternative regimens." Other combinations are listed for use only when a preferred or alternative regimen cannot or should not be used.

Several drugs or combinations are listed as "Not Recommended." Some are not recommended for initial therapy due to low anti-HIV activity or inconvenience. Others are not recommended at any time. These include any nuke or non-nuke by itself (monotherapy) or just two nukes because these treatments generally have only limited benefits for a short

period of time. Also, the guidelines recommend **not using** the triple-nuke regimens.

There are special considerations for the treatment of pregnant women, adolescents, drug users, people also infected with hepatitis B or C or with tuberculosis.

INTERRUPTING TREATMENT

A patient may need to interrupt treatment for several reasons: side effects are intolerable, there's a drug interaction, if they run out of any of their medications, or if they have surgery scheduled. Treatment interruptions are **not** recommended in response to treatment failure.

ART should only be stopped if your health care provider recommends it. Two large studies showed that people who interrupted treatment had a higher rate of HIV-related health problems or death. For more information see fact sheet 406, Treatment Interruptions.

WHEN TO CHANGE

Treatment should be changed due to treatment failure, or intolerance of current drugs.

Treatment failure: Within 6 months after starting a treatment, the viral load should drop below 400 copies. Within 1 year, it should be less than 50 copies. If the viral load does not drop this much, change the treatment. Other signs of treatment failure include:

- An increase in viral load from undetectable to detectable levels
- Failure to increase CD4 cells by 25 to 50 during the first year; or
- A new AIDS-related illness.

Intolerance: If a patient cannot take the prescribed drugs because of their side effects or interactions with other needed medications, the drugs should be changed.

WHAT TO CHANGE TO?

Decisions to change ART should include a review of prior treatments, physical exam, resistance testing, adherence and side effects. Ideally, three drugs that the virus will respond to can be identified and used in a new regimen.

If there are few options for change, and viral load was reduced, it may make sense not to change medications. Another option is to use combinations that are more experimental. Treatment interruptions are not recommended.

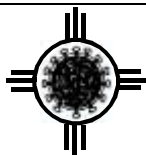
Revised April 28, 2009

Medical Health: Clinical Trials

Clinical Trials: Clinical trials are health research studies. They are an option for people who are interested and who medically qualify. These studies often pay for HIV medicines and HIV medical care in full. Ask your doctor about this option or visit:

- **AIDS Clinical Trial Information Service**
(800) 874-2572; TDD: (800) 243-7012 / www.aidsinfo.nih.gov
- **Community Research Initiative of New England (CRI)**
23 Miner St., Boston, MA 02215
(617) 502-1700; (888) 469-6577; TTY: (617) 778-5460 / www.crine.org

In addition to the two resources listed above, the **National Institutes of Health** also have information on clinical trials. To find out more, visit www.clinicaltrials.gov on the web.



PARTICIPATING IN A CLINICAL TRIAL

WHAT IS AN AIDS CLINICAL TRIAL?

Before new drugs can be sold to treat HIV disease, they must be proved to be safe and effective. The Food and Drug Administration (FDA) approves new drugs and other treatments based on the results of laboratory tests, animal tests, and tests in humans (clinical trials).

New treatments are tested in humans only if there were good results from laboratory tests and animal studies. In the first clinical trials, the treatment is tested for safety in a small group of people. Later trials with many more participants test how well the treatment works. InfoNet Fact Sheet 105, How HIV Drugs Get Approved, has more information on the phases of clinical trials.

A clinical trial is a carefully planned medical experiment. The guidelines for a clinical trial are called a protocol. The protocol is a document that describes exactly how the trial will be carried out.

WHO CAN PARTICIPATE IN A CLINICAL TRIAL?

The protocol explains the rules for participation in a clinical trial. Each trial is different. For example, some trials require certain viral loads or CD4 cell counts.

You normally cannot participate in a clinical trial if you have any opportunistic infections, or are using any treatments that might make it difficult to measure how well the test treatment is working. You also cannot participate if the study treatment might harm you. For example, women sometimes cannot participate in trials during the first three months of pregnancy, because of the risk of birth defects for their newborn child.

Trials are carried out at different hospitals and clinics throughout the world. Some hospitals participate in

many clinical trials. Others may not offer any. Some trials will reimburse your travel costs to a study center.

WHAT ARE THE BENEFITS OF PARTICIPATING?

- You could get a new treatment before it is available by prescription.
- Your health will be watched very carefully.
- You might get some or all of your medications paid for. You might also get some lab tests or other care for free.
- You will be helping others by contributing information about new treatments.

WHAT ARE THE RISKS?

- In trials, new treatments are compared to the best available medication or to a dummy medication (a "placebo"). **You might not get the new treatment.** Patients and health care providers in these trials are not told who is getting the new treatment.
- You might have to stop taking other medications during the trial.
- Study treatments might not work.
- Study treatments might have serious side effects.
- Participating in a study might take a lot of time. It could require special record-keeping or many trips to the study location.

HOW ARE PARTICIPANTS PROTECTED?

There are strict laws on research using human participants. The main tool to protect you is called "Informed Consent." You will be given a full, written description of the clinical trial to read and sign before you agree to participate. Take your time to review the Informed Consent before you sign it. If you need an interpreter to help you understand it, ask for one. If you have questions, be sure you get the answers before you sign.

There are also local and national boards that review and monitor each clinical trial before it starts and while it is in progress. Trials can be stopped early if they are harming participants.

You can decide to drop out of a clinical trial **at any time, for any reason.**

SHOULD I PARTICIPATE?

You and your health care provider should discuss the possible benefits and risks of taking part in a clinical trial. Here are some of the questions you should consider:

- What is the purpose of the study?
- How long will it last?
- Where is it being conducted?
- How will I take the medication (pills, shots, intravenous infusion, other)?
- What else do I have to do (records to keep, office visits, etc.)?
- What will I have to pay for?
- Can I be reimbursed for travel expenses?
- Is childcare available?
- Will I be able to stay on the study treatment after the trial is over? Who will pay for it?
- What was learned in previous studies of this treatment?
- Will I have to stop any drugs or other treatments I am now using?
- Will taking part in this study exclude me from other clinical trials?

TO FIND OUT MORE ABOUT CLINICAL TRIALS:

For information about participating in clinical trials or trials availability throughout the US, call the **AIDSinfo Service** at 1-800-448-0440 or visit their Internet web site at <http://aidsinfo.nih.gov>

The FDA website has information on the drug development process at <http://www.fda.gov/Drugs/DevelopmentApprovalProcess/HowDrugsareDevelopedandApproved/default.htm>

Revised June 30, 2009

Medical Health: Co-infections

Are there any other things I need to get tested for, such as hepatitis?

It's important for people who test positive for HIV to be tested and/or vaccinated for hepatitis. Testing and vaccinations are provided at many locations across the state. It is also recommended for people who test positive for HIV to be tested for tuberculosis and STDs, such as syphilis, gonorrhea, and chlamydia. Please ask your health care provider for more information on where to go for hepatitis testing and vaccines or contact:

- **AIDS Action Committee Hepatitis Hotline**
(888) 443-4372 / www.aac.org
- **North Shore Health Project, HIV/AIDS & Hepatitis C Case Management**
67 Middle St., Gloucester, MA 01930
(978) 283-0101 / www.healthproject.org

According to the Center for Disease Control, about one quarter of HIV-infected persons in the United States are also infected with hepatitis C virus (HCV). HCV and the hepatitis B virus (HBV) are among the most important causes of chronic liver disease in the United States and HCV/HBV infection progresses more rapidly to liver damage in HIV-infected persons. HCV/HBV infection may also impact the course and management of HIV infection. In Northeastern Massachusetts, the following centers also offer treatment specifically for HIV/HCV/HBV co-infection:

- **MGH Chelsea Health Center, HIV Department**
151 Everett St., Chelsea, MA 02150
(617) 887-4330 / www.massgeneral.org
Spanish spoken.
- **Boston Medical Center**
One Boston Medical Center Place, Boston, MA 02118
(617) 638-8000 / www.bmc.org
Spanish, Portuguese, French, German, and Haitian Creole spoken.
- **Fenway Community Health**
1340 Boylston St., Boston MA 02215
(617) 927-6000 / www.fenwayhealth.org
Spanish spoken.

Frequently Asked Questions and Answers About Coinfection with Hepatitis C Virus

Why should HIV-infected persons be concerned about coinfection with HCV?

About one quarter of HIV-infected persons in the United States are also infected with hepatitis C virus (HCV). HCV is one of the most important causes of chronic liver disease in the United States and HCV infection progresses more rapidly to liver damage in HIV-infected persons. HCV infection may also impact the course and management of HIV infection.

The latest U.S. Public Health Service/Infectious Diseases Society of America (USPHS/IDSA) guidelines recommend that all HIV-infected persons should be screened for HCV infection. Prevention of HCV infection for those not already infected and reducing chronic liver disease in those who are infected are important concerns for HIV-infected individuals and their health care providers.

Who is likely to have HIV-HCV coinfection?

The hepatitis C virus (HCV) is transmitted primarily by large or repeated direct percutaneous (i.e., passage through the skin by puncture) exposures to contaminated blood. Therefore, coinfection with HIV and HCV is common (50%-90%) among HIV-infected injection drug users (IDUs). Coinfection is also common among persons with hemophilia who received clotting factor concentrates before concentrates were effectively treated to inactivate both viruses (i.e., products made before 1987). The risk for acquiring infection through perinatal or sexual exposures is much lower for HCV than for HIV. For persons infected with HIV through sexual exposure (e.g., male-to-male sexual activity), coinfection with HCV is no more common than among similarly aged adults in the general population (3%-5%).

What are the effects of coinfection on disease progression of HCV and HIV?

Chronic HCV infection develops in 75%-85% of infected persons and leads to chronic liver disease in 70% of these chronically infected persons. HIV-HCV coinfection has been associated with higher titers of HCV, more rapid progression to HCV-related liver disease, and an increased risk for HCV-related cirrhosis (scarring) of the liver. Because of this, HCV infection has been viewed as an opportunistic infection in HIV-infected persons and was included in the 1999 USPHS/IDSA Guidelines for the Prevention of Opportunistic Infections in Persons Infected with Human Immunodeficiency Virus. It is not, however, considered an AIDS-defining illness. As highly active antiretroviral therapy (HAART) and prophylaxis of opportunistic infections increase the life span of persons living with HIV, HCV-related liver disease has become a major cause of hospital admissions and deaths among HIV-infected persons.

The effects of HCV coinfection on HIV disease progression are less certain. Some studies have suggested that infection with certain HCV genotypes is associated with more rapid progression to AIDS or death. However, the subject remains controversial. Since coinfecting patients are living longer on HAART, more data are needed to determine if HCV infection influences the long-term natural history of HIV infection.

How can coinfection with HCV be prevented?

Persons living with HIV who are not already coinfecting with HCV can adopt measures to prevent acquiring HCV. Such measures will also reduce the chance of transmitting their HIV infection to others.

Not injecting or stopping injection drug use would eliminate the chief route of HCV transmission; substance-abuse treatment and relapse-prevention programs should be recommended. If patients continue

to inject, they should be counseled about safer injection practices; that is, to use new, sterile syringes every time they inject drugs and never reuse or share syringes, needles, water, or drug preparation equipment.

Toothbrushes, razors, and other personal care items that might be contaminated with blood should not be shared. Although there are no data from the United States indicating that tattooing and body piercing place persons at increased risk for HCV infection, these procedures may be a source for infection with any bloodborne pathogen if proper infection control practices are not followed.

Although consistent data are lacking regarding the extent to which sexual activity contributes to HCV transmission, persons having multiple sex partners are at risk for other sexually transmitted diseases (STDs) as well as for transmitting HIV to others. They should be counseled accordingly.

How should patients coinfectd with HIV and HCV be managed?

General guidelines

Patients coinfectd with HIV and HCV should be encouraged to adopt safe behaviors (as described in the previous section) to prevent transmission of HIV and HCV to others.

Individuals with evidence of HCV infection should be given information about prevention of liver damage, undergo evaluation for chronic liver disease and, if indicated, be considered for treatment. Persons coinfectd with HIV and HCV should be advised not to drink excessive amounts of alcohol. Avoiding alcohol altogether might be wise because the effects of even moderate or low amounts of alcohol (e.g., 12 oz. of beer, 5 oz. of wine or 1.5 oz. hard liquor per day) on disease progression are unknown. When appropriate, referral should be made to alcohol treatment and relapse-prevention programs. Because of possible effects on the liver, HCV- infected patients should consult with their health care professional before taking any new medicines, including over-the-counter, alternative or herbal medicines.

Susceptible coinfectd patients should receive hepatitis A vaccine because the risk for fulminant hepatitis associated with hepatitis A is increased in persons with chronic liver disease. Susceptible patients should receive hepatitis B vaccine because most HIV-infected persons are at risk for HBV infection. The vaccines appear safe for these patients and more than two-thirds of those vaccinated develop antibody responses. Prevaccination screening for antibodies against hepatitis A and hepatitis B in this high-prevalence population is generally cost-effective. Postvaccination testing for hepatitis A is not recommended, but testing for antibody to hepatitis B surface antigen (anti-HBs) should be performed 1-2 months after completion of the primary series of hepatitis B vaccine. Persons who fail to respond should be revaccinated with up to three additional doses.

HAART has no significant effect on HCV. However, coinfectd persons may be at increased risk for HAART-associated liver toxicity and should be closely monitored during antiretroviral therapy. Data suggest that the majority of these persons do not appear to develop significant and/or symptomatic hepatitis after initiation of antiretroviral therapy.

Treatment for HCV Infection

A Consensus Development Conference Panel convened by The National Institutes of Health in 1997 recommended antiviral therapy for patients with chronic hepatitis C who are at the greatest risk for progression to cirrhosis. These persons include anti-HCV positive patients with persistently elevated liver enzymes, detectable HCV RNA, and a liver biopsy that indicates either portal or bridging fibrosis or at least moderate degrees of inflammation and necrosis. Patients with less severe histological disease should be managed on an individual basis.

In the United States, two different regimens have been approved as therapy for chronic hepatitis C: monotherapy with alpha interferon and combination therapy with alpha interferon and ribavirin. Among HIV-negative persons with chronic hepatitis C, combination therapy consistently yields higher rates (30%-40%) of sustained response than monotherapy (10%-20%). Combination therapy is more effective against viral genotypes 2 and 3, and requires a shorter course of treatment; however, viral genotype 1 is the most common among U.S. patients. Combination therapy is associated with more side effects than monotherapy, but, in most situations, it is preferable. At present, interferon monotherapy is reserved for patients who have contraindications to the use of ribavirin.

Studies thus far, although not extensive, have indicated that response rates in HIV-infected patients to alpha interferon monotherapy for HCV were lower than in non-HIV-infected patients, but the differences were not statistically significant. Monotherapy appears to be reasonably well tolerated in coinfecting patients. There are no published articles on the long-term effect of combination therapy in coinfecting patients, but studies currently underway suggest it is superior to monotherapy. However, the side effects of combination therapy are greater in coinfecting patients. Thus, combination therapy should be used with caution until more data are available.

The decision to treat people coinfecting with HIV and HCV must also take into consideration their concurrent medications and medical conditions. If CD4 counts are normal or minimally abnormal ($> 400/\mu\text{l}$), there is little difference in treatment success rates between those who are coinfecting and those who are infected with HCV alone.

Other Treatment Considerations

Persons with chronic hepatitis C who continue to abuse alcohol are at risk for ongoing liver injury, and antiviral therapy may be ineffective. Therefore, strict abstinence from alcohol is recommended during antiviral therapy, and interferon should be given with caution to a patient who has only recently stopped alcohol abuse. Typically, a 6-month abstinence is recommended for alcohol abusers before starting therapy; such patients should be treated with the support and collaboration of alcohol abuse treatment programs.

Although there is limited experience with antiviral treatment for chronic hepatitis C of persons who are recovering from long-term injection drug use, there are concerns that interferon therapy could be associated with relapse into drug use, both because of its side effects and because it is administered by injection. There is even less experience with treatment of persons who are active injection drug users, and an additional concern for this group is the risk for reinfection with HCV. Although a 6-month abstinence before starting therapy also has been recommended for injection drug users, additional research is needed on the benefits and drawbacks of treating these patients. Regardless, when patients with past or continuing problems of substance abuse are being considered for treatment, such patients should be treated only in collaboration with substance abuse specialists or counselors. Patients can be successfully treated while on methadone maintenance treatment of addiction.

Because many coinfecting patients have conditions or factors (such as major depression or active illicit drug or alcohol use) that may prevent or complicate antiviral therapy, treatment for chronic hepatitis C in HIV-infected patients should be coordinated by health care providers with experience in treating coinfecting patients or in clinical trials. It is not known if maintenance therapy is needed after successful therapy, but patients should be counseled to avoid injection drug use and other behaviors that could lead to reinfection with HCV and should continue to abstain from alcohol.

Infections in Infants and Children

The average rate of HCV infection among infants born to women coinfectd with HCV and HIV is 14% to 17%, higher than among infants born to women infected with HCV alone. Data are limited on the natural history of HCV infection in children, and antiviral drugs for chronic hepatitis C are not FDA-approved for use in children under aged 18 years. Therefore, children should be referred to a pediatric hepatologist or similar specialist for management and for determination for eligibility in clinical trials.

What research is needed on HIV-HCV coinfection?

Many important questions remain about HIV-HCV coinfection:

- By what mechanism does HIV infection affect the natural history of hepatitis C?
- Does HAART affect the impact of HIV on the natural history of HCV infection?
- Does HCV affect the natural history of HIV and, if so, by what mechanism?
- How can we effectively and safely treat chronic hepatitis C in HIV-infected patients?
- How can we distinguish between liver toxicity caused by antiretrovirals and that caused by HCV infection?
- What is the best protocol for treating both HIV and chronic hepatitis C in the coinfectd patient?

The following sources may also helpful in understanding HCV and HCV/HIV coinfection.

Publications

1. Centers for Disease Control and Prevention. [Recommendations for prevention and control of hepatitis C virus \(HCV\) infection and HCV-related chronic disease](#). MMWR 1998;47(No. RR-19):1-39.
2. Centers for Disease Control and Prevention. [1999 USPHS/IDSA guidelines for the prevention of opportunistic infections in persons infected with human immunodeficiency virus: U.S. Public Health Service \(USPHS\) and Infectious Diseases Society of America \(IDSA\)](#). MMWR 1999;48(No. RR-10):32-4.
3. National Institutes of Health. Chronic hepatitis C: current disease management (NIH Publication No. 00-4230). DHHS, 1999. (See web version below).
4. Sulkowski MS, Mast EE, Seeff LB, Thomas DL. Hepatitis C virus infection as an opportunistic disease in persons infected with human immunodeficiency virus. Clinical Infectious Diseases 2000 Apr;30 Supplement 1:S77-S84.

Internet Resources

1. [CDC HIV/AIDS Home Page](#)
2. [Division of Viral Hepatitis, CDC](#)
3. [National Institutes of Health](#)
4. [CDC National Prevention Information Network](#)
5. [Expert Perspectives: Strategies for the Management of HIV/HCV Coinfection](#)

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[Divisions of HIV/AIDS Prevention](#)

[National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention](#)

Source: www.cdc.gov/hiv/resources/qa/print/HIV-HCV_Coinfection.htm



Medical Health: Health Insurance and Financial Support

I hear that HIV care and medicines are expensive, and I don't have health insurance. Does that mean I cannot get the care I will need to stay healthy?

HIV care and treatment are expensive and are necessary to stay healthy, but there are services to help people who don't have insurance. There are ways to get free or low-cost care. You might be eligible for MassHealth or Commonwealth Care. Visit www.mahealthconnector.org on the web or talk to a case manager listed under "Support Services" to help you find the right help. Some options for support are:

- **Financial Advocates for Patients:** Hospitals and clinics have financial advocates—people who can help you explore your payment options. If you do not have any insurance, they can help you apply for state assistance (MassHealth or Commonwealth Care). If you don't qualify for any of those, most hospitals offer financial assistance based on income.
- **Massachusetts HIV/AIDS Drug Assistance Program (HDAP) and Comprehensive Health Insurance Initiative (CHII):** This program helps to cover the cost of HIV medicines if you are uninsured or underinsured. To find out if you qualify, contact **HDAP/CHII** at (800) 228-2714, M-F 8:30am-5pm / www.atdn.org/access/states/ma/ma.html. Spanish spoken.
- **Clinical Trials:** Clinical trials are health research studies. They are an option for people who are interested and who medically qualify. These studies often pay for HIV medicines and HIV medical care in full. Ask your doctor about this option or visit:
 - **AIDS Clinical Trial Information Service**
(800) 874-2572; TDD: (800) 243-7012 / www.aidsinfo.nih.gov
 - **Community Research Initiative of New England (CRI)**
23 Miner St., Boston, MA 02215
(617) 502-1700; (888) 469-6577; TTY: (617) 778-5460 / www.crine.org

Dental Assistance

There is also dental assistance for those living with HIV. In Massachusetts, the HIV Dental Treatment Fund pays for dental care for eligible persons with HIV/AIDS who are uninsured or underinsured. Massachusetts has over 200 participating dental practices. To find out more, you can contact:

- **The HIV Dental Treatment Fund (Boston Public Health Commission)**
774 Albany St., 2nd Floor, Boston, MA 02118
(617) 534-4717 ext.1 / www.bphc.org (Search for HIV dental enrollment)

Information for Providers on the Massachusetts AIDS Drug Assistance Program (ADAP)

*The text below is printed from the website of the **Community Research Initiative of New England**. It can be accessed at www.crine.org/index.php?id=56.*

“The Massachusetts HIV Drug Assistance Program (HDAP) provides access to critical HIV-related medications for residents of the Commonwealth of Massachusetts who are otherwise unable to obtain these life-saving drugs. A program of the Office of HIV/AIDS of the Massachusetts Department of Public Health funded through federal and state sources, HDAP is administered by CRI.

HDAP is designed to provide access to medications to clients in need. In order to be eligible for HDAP, an individual must be HIV-positive and living in Massachusetts. To enroll, an individual must also meet income eligibility guidelines, set at a level that recognizes both the high cost and number of HIV-related medications an individual with HIV/AIDS may need, as well as the high cost of living in Massachusetts.

HDAP is among the nation’s most complete drug assistance programs for people living with HIV. HDAP can pay for medications and drug co-pays, private non-group health insurance premiums and premium co-pays, HIV resistance testing (genotype and virtual phenotype lab tests), and post-exposure prophylaxis (“PEP”) for potential non-occupational exposures to HIV.

By law, HDAP is a “payer of last resort;” this means that program enrollees must show that they have applied to other entitlement programs (such as Medicaid/MassHealth, Medicare, etc.) at the time of their HDAP application. Undocumented Massachusetts residents are eligible for HDAP.

HDAP plays a crucial role in providing resources to a diverse population who may otherwise lack access to HIV-related medications. More than half of HDAP enrollees are from communities of color; approximately three-quarters of HDAP clients have incomes of less than 200% of the federal poverty level.

This program is supported by funds from the U.S. Public Health Service/Health Resources and Services Administration, the Massachusetts Department of Public Health, and the Boston Public Health Commission AIDS Program through Title I of the Ryan White CARE Act, and is administered by Community Research Initiative of New England (CRI).”

For more information, contact:

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Sexual and Reproductive Health

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Appendices

- ☒ "Sex and prevention concerns for positive people." Project Inform, Sept. 2002. Web. 27 July 2009.
<<http://www.projectinform.org/info/sex/index.shtml>>.
- ☒ "Population Reports, Series L, Number 15 – Family Planning Choices for Women With HIV." Johns Hopkins Bloomberg School of Public Health: The INFO Project. Web. 26 Aug. 2009.
<<http://www.infoforhealth.org/pr/115/table1.shtml>>.
- ☒ "Pregnancy and HIV." The AIDS InfoNet, 15 Jan. 2009. Web. 27 July 2009.
<http://www.aidsinfonet.org/fact_sheets/view/611>.
- ☒ "Pregnancy and HIV." The AIDS InfoNet, 15 Jan. 2009. Web. 27 July 2009.
<http://www.aidsinfonet.org/fact_sheets/view/611>.
- ☒ "Children and HIV." The AIDS InfoNet, 16 Nov. 2008. Web. 27 July 2009.
<http://www.aidsinfonet.org/fact_sheets/view/612>.

Sexual and Reproductive Health: Safer Sex and Prevention for Positive People

What can I do to keep HIV from spreading?

HIV is spread through contact with blood, semen, vaginal fluid, or breast milk. The most common ways that people get infected with HIV are unprotected sex or sharing of needles for drug use. HIV can also be passed from mother to infant at birth or through breastfeeding.

To prevent spreading the virus to others:

- Use a condom every time you have sex.
- Do not share needles or syringes.

HIV is NOT spread through everyday casual contact with people at school, work, home, or anywhere else. HIV cannot be spread through contact with tears, sweat, or saliva, or by sharing objects like cups, phones, or toilet seats. HIV is not spread through mosquito bites, coughing, or hugging someone with HIV.

If I am HIV positive, can I have sex with another HIV positive person with no risk?

Even if both partners are HIV positive, there is still some risk. You or your sex partner could pass on other sexually transmitted diseases, including other forms of HIV that make it more difficult for the doctors to treat you. It is extremely important that you protect yourself and your partner (HIV positive or not) by practicing safer sex.

Safer Sex Basics

HIV is spread through blood, semen, and vaginal fluid. Any activity that doesn't allow blood, semen, or vaginal fluids to enter a person's body is safe.

- Use a new latex condom and water-based lubricant like K-Y Jelly or Astroglide every time you have vaginal or anal sex. (This is not risk-free as a condom may break or come off.)
- Don't use oil-based lubricants with condoms. Oils in hand lotions, massage oils, Vaseline, etc. can cause the condom to leak or break.
- People who are allergic to latex can use plastic (polyurethane) condoms. These come in both male and female styles. Condoms made from animal skin do **NOT** protect against HIV.
- Lubricants containing Nonoxynol-9 (N-9) may increase the risk of HIV transmission. Do not use them.
- For oral sex use a barrier such as a latex condom, dental dam, or plastic food wrap.
- Don't share sex toys. If you do share, wash them well and cover them with a fresh condom each time.
- The surest way to avoid spreading sexually transmitted diseases (STDs), including HIV, is not to have sexual intercourse.

To find additional information and topics on safer sex, contact **Project Inform** at (800) 822-7422 or visit www.projectinform.org on the web.

What about birth control and family planning?

If you are HIV positive and are not yet ready to have a baby, birth control and family planning can help you:

- Enjoy a healthy sex life while reducing the chance you will transmit HIV to your partner or children.
- Prevent unintended pregnancy and avoid the stress of an unplanned pregnancy.
- Plan desired pregnancies while minimizing the risk of HIV transmission.

Some HIV drugs and medications affect how well birth control pills or other birth control methods work, so it is important to talk to your doctors about your HIV medicines, the birth control method you are currently using, and what other methods might be available to you. This way, you can figure out which birth control method will work best for you.

To find out more about birth control and family planning, contact:

- **Health Quarters** at (800) 892-0234 or visit www.healthq.org on the web.

How do I talk to my partner or a future partner about HIV and safer sex?

Telling a partner you have HIV or that you want to have safer sex can be scary, confusing, and embarrassing. You may fear being rejected or left alone. But sooner or later, it will be important to talk about HIV with your partner. The longer you wait, the harder it gets. If you talk with your partner before you get into a situation where HIV could be spread, then you and your partner can make choices together about safer sex.

Here are some things to think about before you tell someone that you're HIV positive:

- Think about how you would like to have this information told to you, if you were the partner.
- Get support and advice on talking to partners from your HIV doctor, counselor, peer leader, or case manager.
- Telling your partner you have HIV may bring on a strong reaction. Be sure that you have support regardless of how your partner responds.
- If you are going to be in a situation where HIV could be spread, practice safer sex. This is the single most important thing you can do.
- If you feel unsafe telling your partner, talk to your HIV doctor, counselor, or case manager. Contact one of the agencies in the Support Services section of this Guide.
- For assistance contact a **Disease Intervention Specialist (DIS)** in the Northeast Region at (978) 851-7261 ext. 4036. This is a state program that will inform the individuals at risk, without telling them your name.

- For more information about Partner Services, contact **Lowell Community Health Center** at (978) 937-9700.
- You can also contact:
 - **The Gay & Bi Men's Health Program (GBMHP)**
156 Cabot St. Beverly MA 01915
(978) 927-4506 ext. 219 / www.gbmhp.org
Provides one-on-one and couple education around safer sex and sexual health.

Lowell Community Health Center can be reached at (978) 937-9700, and the agency offers services in Spanish, Portuguese, French, Haitian Creole, Khmer, Lao Luganda, Swahili, and Vietnamese. The agency's website is www.lchealth.org.

SEX AND PREVENTION CONCERNS FOR POSITIVE PEOPLE

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Safer sex and prevention messages are often targeted solely to HIV-negative people. Yet, preventing HIV and other infections remains an important issue for people living with HIV as well. Whether your partner is HIV-positive, HIV-

negative, female, male or transgendered, there are many reasons to be concerned about safer sex and prevention. This publication explores some of the most common sexual transmission concerns for people living with HIV.

WHAT'S INSIDE

What are the risks of passing HIV to my HIV-negative partner?: **2**; What kinds of infections can I protect myself from getting?: **3**; You can prevent getting common infections at home: **4-5**; We're both positive. What are our concerns?: **6**; The reality of safer sex: **6**; Preventing your risk of infections: **7**; Transmission of multi-drug resistant HIV: **7**; HIV and STDs: woman-to-woman: **7**; Safer sex guidelines: **8**.

what are the risks of passing HIV to my HIV-negative partner?

A concern of many people living with HIV is passing HIV to their uninfected partner(s). While much evidence suggests that men transmit HIV more easily than women, women can still pass HIV to uninfected partners—both male and female. This is because HIV is present in blood (including menstrual blood), vaginal secretions and in cells in the vaginal and anal walls. In fact, high levels of HIV can be found in these areas even if there's a low amount of HIV in your blood.

For women, HIV levels in vaginal fluids greatly increase when you have gynecological (GYN) conditions, like yeast infections or inflammation. Several studies in test tubes show that some sexually transmitted infections (STIs), like chlamydia, increase HIV reproduction. Vaginal inflammation, a common symptom of these infections, causes tiny scrapes and cuts on the delicate skin of the vaginal area that can then harbor HIV. HIV levels can also temporarily increase after treating some of these conditions.

Likewise, men with active STIs, especially active herpes lesions, etc., are more likely to both acquire and transmit HIV. Less is known about whether HIV levels are actually higher in blood and semen

during an active STIs in men, but certainly any infection that causes a lesion, like herpes, provides a portal for HIV to pass through and makes transmission more likely. Studies do show that even when a man has undetectable levels of HIV in his blood, there are sometimes detectable HIV levels in semen and pre-cum fluid. HIV transmission from men with undetectable HIV levels in their blood has been documented several times.

In short, if you're not practicing safer sex, there's no way to know when you're more or less likely to pass HIV to your partner(s). Exposure to vaginal or anal secretions, semen or other blood with high

levels of HIV increases your risk of transmission. The risk further increases when one's partner has an infection or inflammation. It's also possible to have active infections or GYN conditions without having symptoms or knowing it. (For general guidelines on safer sex practices, see page 8.)

Finally, a number of known cases have shown multi-drug resistant HIV being passed from people living with HIV to their partners. What this means is that the newly infected partners have a form of the virus difficult to treat with anti-HIV drugs, leaving them with limited options to treat their infections.

IN SHORT, IF YOU'RE NOT PRACTICING SAFER SEX, THERE'S NO WAY TO KNOW WHEN YOU'RE MORE OR LESS LIKELY TO PASS HIV TO YOUR PARTNER(S).

what kinds of infections can I protect myself from getting?

Prevention isn't just about protecting someone else from getting HIV; it's also about protecting yourself from other harmful infections. You can do something about many common and serious infections. The risks of unsafe sex are numerous because many STIs can cause serious harm in people living with HIV.

Cytomegalovirus (CMV) is such a condition. While most adults are infected with CMV, it doesn't cause disease in healthy, HIV-negative people. Therefore, most people carry the virus but don't have active CMV disease. However, once CMV becomes an active infection, it's the leading cause of blindness and among the major causes of death in people with AIDS. Ways to prevent CMV infection include practicing safer sex.

CMV prevention is probably much more relevant to women than to men, particularly adult gay men. The rate of CMV infection among women is generally lower (40% among women living with HIV) than what's seen among adult gay men (80–90% of whom are already infected with CMV, regardless of HIV status). The bottom line is that if you're not infected with CMV, safer sex remains a potent tool in helping to prevent CMV disease.

Like CMV, human papilloma virus (HPV) is another STI. HPV is the virus that causes genital warts in some people. These warts may or may not be visible by external examination, yet might be present in the anus or cervix. As one of the major causes of anal and cervical cancer, HPV is common and difficult to treat among people living with HIV. Some types of HPV are more likely to develop into cancer than other types.

Both men and women are at risk for anal cancer associated with HPV. Some studies suggest that a woman living with HIV is more at risk of developing anal cancer as opposed to cervical cancer associated with HPV infection. Unlike other conditions associated with HIV



disease, the rate of anal and cervical cancer associated with HPV infection does not appear to be dramatically declining with increased use of anti-HIV therapy. Unfortunately, condom and other barrier protections may not protect you from HPV infection and transmission, but they might decrease the risk of transmission.

Hepatitis, cryptosporidiosis, parasites and other infections can also be passed during sexual activity. Every condition described above can be deadly in anyone living with HIV, especially with a weakened immune system. (For more information on how to prevent these infections, see pages 4–5.)

It's important for people living with HIV to protect themselves from these unwanted and possibly dangerous infections. Lab tests can detect these infections, but your medical coverage may not pay for them. You can ask your doctor about possibly getting these tests. Then, use the results to build a prevention plan that helps protect you from getting new infections.



For more
treatment
information, call
Project Inform's
toll-free National
HIV/AIDS
Treatment
Information
Hotline at
1-800-822-7422.

You can prevent getting

Bartonella (Cat Scratch Fever)

A bacterial infection that can cause fevers, headaches and a marked reduction in red blood cells (i.e. anemia).

Put on the flea collar!

- › Avoid adopting kittens or cats under one year old.
- › Avoid cat scratches or allowing cats to lick open cuts or wounds. Promptly wash all cat scratches or wounds.
- › Use flea control for cats.



Campylobacter

A bacterial infection that can cause diarrhea, abdominal pain and vomiting.

When Fluffy has the runs, run!

- › Avoid contact with animals that have diarrhea.
- › In general, get someone else to handle potty duties for pets.

Coccidioidomycosis (Valley Fever)

A fungal infection that causes fevers, difficulty in breathing and night sweats.

On your next archeological dig, bring Endust!

- › Although there are areas of the country such as the deserts of the Southwest where it may be impossible to avoid exposure to this pest, you can still reduce the risk of exposure by avoiding excavation sites and dust storms.

Cryptococcosis

A fungal infection that primarily infects the brain resulting in headaches, fevers and altered mental behavior.

Don't feed the birds!

- › Avoid areas that may be heavily contaminated with the pest that causes the infection (called Cryptococcus), including areas with a lot of pigeon droppings. Avoid handling birds, even those kept as pets.

Cryptosporidiosis

A parasite that can cause diarrhea.

Put down the baby, and move away from the goat!

- › Wash hands after fecal contact (like after changing a baby's diaper) and after gardening or other contact with soil.
- › Avoid contact with young farm animals or animals with diarrhea (including pet stores and animal shelters).
- › Wash hands after handling pets and avoid contact with pet feces.
- › Boil water for at least one minute. If possible, install a water filter system that can filter out Cryptosporidium.
- › Avoid swimming in water that may be contaminated by Cryptosporidium. Some lakes, rivers, swimming pools and salt water beaches may be contaminated with human or animal waste that contains Cryptosporidium.

For more information on preventing infection with crypto, call Project Inform's Hotline.

Cytomegalovirus (CMV)

A virus that infects the entire body. (Left untreated, CMV can cause diarrhea, blindness, inflammation of the brain, etc.)

Safer sex is hot sex (and it's not just about HIV infection)!

- › Wash hands after fecal contact.
- › Follow safer sex practices.
- › If blood transfusions are required, only CMV antibody negative or leukocyte-reduced blood products should be used.

Hepatitis A, B and C Virus (HAV, HBV and HCV)

Viral infections that can cause liver damage, failure and sometimes cancer.

- › Talk to your doctor about the appropriateness of vaccination (for HAV and HBV).
- › Follow safer sex practices.
- › Learn about particular risks for HAV and traveling in areas where threat for exposure is great and vaccination prior to travel highly recommended.

common infections at home!

Herpes

A viral infection that can cause ulcer lesions around the mouth, genitals and rectum.

- › Follow safer sex practices.

Histoplasmosis

A fungal infection that can cause fevers, reduction in red blood cells and difficulty in breathing.

Put down the mop and move away from the chicken coop!

- › Although it may be impossible to avoid exposure to this organism in areas of the country like the Midwest river valleys, people can still reduce their risk by not cleaning chicken coops, disturbing soil under bird roosting sites or exploring caves.

Human Papilloma Virus

A viral infection that can cause warts, which can become cancerous.

- › Follow safer sex practices. Condoms cannot wholly prevent HPV transmission.

Listeriosis

A bacterial infection that can cause meningitis, an inflammation in the brain.

- › Avoid eating any non-pasteurized dairy products, such as soft cheeses like Brie and goat cheese.
- › Heat ready-to-eat foods like hot dogs and ensure that they're steaming hot before eating them.



Microsporidiosis

A parasite that can cause diarrhea.

- › Wash hands frequently and follow other good personal hygiene measures.

Salmonella

A bacterial infection that can cause food poisoning and diarrhea.

- › Avoid Caesar salads or anything that may contain raw eggs.
- › Avoid eating under-cooked eggs and poultry.
- › Avoid contact with animals that have diarrhea.
- › Avoid contact with reptiles like snakes, lizards, iguanas and turtles.

Toxoplasmosis

A parasite that mostly infects the brain resulting in confusion and delusional behavior.

These recommendations only apply to people who are NOT antibody positive to Toxoplasma.

- › Avoid eating raw or under-cooked meats. (Cook to an internal temperature of 150°F or 65.5°C.)
- › Wash hands after contact with raw meat and after gardening or other contact with soil.
- › Wash fruits and vegetables in filtered water or in a .05% bleach solution before eating raw.
- › Wash hands after changing a cat's litter box or preferably have an HIV-negative person change it.
- › Cats should be kept indoors and be fed canned or dried commercial cat food and not raw or undercooked meats.

Tuberculosis

Primarily infects the lungs and can cause cough, weight loss and fatigue.

- › If possible, avoid working or volunteering in facilities considered high risk for tuberculosis, such as healthcare and correctional facilities and homeless shelters.

Varicella-Zoster

A viral infection commonly known as chicken pox and shingles.

- › People who have NOT had chicken pox or shingles should avoid direct contact with people with active chicken pox or shingles.

we're both positive. what are our concerns?

For people whose partner(s) also live with HIV, prevention messages and reasons to practice safer sex sometimes become unclear. A common question is: "If I'm positive and my partner is positive, then why do we have to practice safer sex?" Simply put, safer sex remains important among positive partners. This is because in addition to preventing new infections as discussed above, other factors place positive sex partners at risk.

One of these factors is re-infection with HIV. While the issue of re-infection remains unclear, some new evidence shows that it can and does happen. If you're on therapy that HIV has become resistant to, it's possible for you to transmit the drug-resistant strain to your partner, possibly crippling the benefits of those therapies for your partner. On the other hand, if your partner is on anti-HIV therapy, you could become infected with his or her drug-resistant strain(s) and have decreased benefits from therapy. (For more information on drug-resistant virus, see page 7.)

Finally, it's important to remember that your partner's viral load (amount of HIV in blood) may not relate to the level of virus in semen or vaginal or anal fluids. Therefore, while HIV levels in blood may be undetectable by a lab test, they still may be present in high levels elsewhere. (Note: Standard viral



load tests do not measure HIV in semen or vaginal or anal fluids. Also, in studies, even when viral load tests of semen came back undetectable, HIV-infected cells could still be found in the semen. These cells are believed important for passing HIV from person to person.)

When both partners live with HIV, consider these points when discussing safer sex:

- ▶ Infections like CMV, HPV, herpes, hepatitis (B and C) among others, remain major concerns. All these are potentially deadly infections in people living with HIV, but they can be prevented, to some degree, through practicing safer sex.
- ▶ Re-infection with drug-resistant or more aggressive strains of HIV remains a theoretical possibility. It must be considered when negotiating safer sex between positive partners.

the reality of safer sex

You put yourself at risk for infections through unprotected sex with a partner—activities that expose you to your partner's blood, blood products, urine, feces, semen or vaginal or anal fluids. In some cases these infections may never harm your partner, but they might be life-threatening to you should your immune system weaken as a result of HIV.

If your partner(s) is also living with HIV, neither of you is immune

to new infections. Be aware of both the real and theoretical risks as you discuss and negotiate safer sex. Every sexual behavior or activity carries some level of infection risk. It's generally believed that some activities are less risky than others, but low risk obviously doesn't mean no risk.

Negotiating safer sex and using risk reduction to prevent passing or getting HIV or other infections is not

easy. Safer sex requires the involvement of willing partners. This is especially difficult for women because safe and low-cost woman-initiated methods of HIV prevention do not currently exist. For people in situations where domestic violence occurs, this willing involvement can be almost impossible. In this case, seeking family violence prevention services is probably the safest and smartest plan of action.

preventing your risk of infections

People living with HIV must consider taking precautions to avoid exposing themselves to common infections, which are possibly deadly in people with a weakened immune system. Although safer sex is usually thought of in regards to preventing HIV infection, exposure to many major infections and STIs can be reduced if safer sex is followed. Avoiding oral-anal contact can greatly reduce the risk of getting parasites that can cause diarrhea and other symptoms. (Examples of parasites include tape worms, scabies and more common among people with HIV are Toxoplasma and Cryptosporidium.)

Safer sex is not the only way to prevent exposure to infections, however. There are a number of things you can do to decrease your risk of potentially harmful infections.

In general, people with HIV should not eat raw or undercooked meats, poultry or seafood. Avoid unpasteurized dairy products, which may contain parasites, bacteria or viruses that in turn can cause severe illness. For example, eating raw shellfish can result in hepatitis A infection. Risks can be reduced further by following guidelines for “safer” food preparation.



transmission of multi-drug resistant HIV

There is increasing concern over the transmission of drug-resistant virus and multi-drug resistant HIV. People infected with multi-drug resistant HIV are unlikely to optimally benefit from most, if not all, of the available anti-HIV therapies. While many known cases of AZT-resistant HIV transmission have occurred in the past, transmission of multi-drug resistant virus is being seen increasingly. These observations underscore the importance of including safer sex in your life, even when you and your partner(s) are both living with HIV.

HIV and STDs: woman-to-woman

Woman-to-woman sexual activity has generally been associated with a lower risk of passing HIV, although a number of cases have been reported. The risk of passing HIV and other STIs between women has not been thoroughly studied. But the few studies to date note that many women who have sex with women engage in a number of high-risk behaviors that may increase their risks of both getting and passing HIV and other STIs (including the types of HPV associated with cervical and anal cancer). So in the meantime, it's best to play safe and refrain from making easy assumptions about HIV and STI transmission during woman-to-woman sex.

Safer sex guidelines

In addition to protecting from HIV infection and transmission, practicing safer sex also reduces the risk of passing or contracting other diseases, like chlamydia, gonorrhea, herpes and hepatitis. These can be especially troublesome in people with weakened immune systems. A few tips on how to protect yourself and your partner during sex are found below.

One word: Plastics!

Use latex condoms and plenty of water-based lubricant (K-Y Jelly, Astroglide, Probe) for vaginal and anal sex. If you're sensitive (allergic) to latex, try polyurethane condoms (Avanti). The female condom (Reality) is also made of polyurethane. However, polyurethane condoms may have higher breakage problem than latex.

Protect the environment and your condoms!

Don't use oil-containing lubricants like Crisco, Vaseline, baby oil, lotion or whipped cream as they can destroy latex. (Note: Oil-based lubes can be safely used with polyurethane condoms.) Good water-based lubricants last longer and often feel better anyway.

Read the label!

Many people avoid products with the spermicide, Nonoxynol-9. Some studies now show it can cause irritation that may promote STIs, including HIV.

Wrap it to go!

For oral sex with a man, it's safest to use a condom. For oral sex with a woman or oral-anal sex (rimming), it's safest to use a dental dam (latex square), plastic food wrap, or a condom or latex glove cut to make a flat sheet.

Try a breath mint instead!

Avoid brushing or flossing your teeth up to two hours before or after oral sex to minimize small cuts. Be aware of bleeding gums, cuts or sores on or in the mouth.

Let your fingers do the walking!

Use latex gloves for hand jobs (sex with your hands) or fisting. Try powder-free latex or polyurethane gloves for folks who are sensitive to latex.

Good clean fun!

If you share sex toys (like dildos or vibrators), put on a fresh condom for each user and/or when going to or from the anus and vagina. Clean toys with bleach, alcohol or soap and water between uses.

On the wild side!

Avoid contact with blood, semen and vaginal and anal fluids. Sex toys like whips or knives can break the skin and should not be used on another person until they're disinfected with bleach or cleaning solution.



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Sexual and Reproductive Health: Family Planning and Reproductive Health

If I am HIV positive, does this mean that I can never have children?

HIV positive people can have children, but having a baby is a decision to make very carefully. HIV can be passed to the baby during pregnancy, at birth, or after birth through breastfeeding. For HIV positive people with HIV negative partners, having unprotected sex can put both the partner and the baby at risk for becoming infected with HIV. If you are an HIV positive woman who wants to have a baby, it is very important to take all the steps to ensure that the amount of HIV virus in your body is as low as possible before birth. If you are an HIV positive man, there are special techniques to remove HIV from the sperm. Seeing an obstetrician (pregnancy doctor) who specializes in HIV care is the most important thing you can do to increase the chance that your baby will be born healthy and free of HIV. Visit www.womenchildrenhiv.org on the web to learn more.

To find out more about birth control and family planning, contact:

- **Health Quarters** (800) 892-0234 or visit www.healthq.org on the web.

Is there special advice for women with HIV?

Women with HIV should be seen regularly for gynecological services to check for STDs, receive family planning counseling, and get a Pap test at least once a year. Women with HIV are more likely to have abnormal Pap test results, which, if left untreated, can lead to cervical cancer. Infection with HIV means your body is less effective in controlling all types of viruses. The human papilloma virus (HPV) is a specific virus that can infect cervical cells (the cells that the Pap test looks at). If the Pap test result is abnormal, the doctor may need to repeat it or do other tests. Ask your healthcare provider if the HPV vaccine is right for you.

Family Planning Choices for Women With HIV

How providers can help women with HIV make reproductive decisions






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Table 1. Comparing Contraceptive Methods for People with HIV





www.infoforhealth.org/pr/l15/table1.shtml

Providers can use the information in this table as they help women or men with HIV choose a contraceptive method. Important points:

- All methods are safe for people who are infected with HIV, have AIDS, or are taking ARV medications, except as specifically noted.
- Except for male and female condoms, none of these methods helps to prevent transmission of STIs, including HIV.
- Dual method use—that is, using condoms and another method of contraception together—helps to protect against STIs and provides more protection against pregnancy than condom use alone.

Method	Considerations for Women With HIV
Male and female condoms 	<ul style="list-style-type: none"> • The only method that helps protect against both pregnancy and STIs, including HIV. • Must be used correctly every time to be fully effective. • Maintaining consistent and correct use can be difficult.
Combined oral contraceptives (COCs) 	<ul style="list-style-type: none"> • Not known if certain ARVs decrease effectiveness of COCs. In case they do, condoms provide extra contraceptive protection. • Taking pills every day, without missing pills, is particularly important to compensate for any possible decrease in effectiveness when on ARVs.
Progestin-only pills (POPs) 	<ul style="list-style-type: none"> • Not known if certain ARVs decrease effectiveness of POPs. In case they do, condoms provide extra contraceptive protection. • Particularly appropriate for breastfeeding women who want pills. Exclusive breastfeeding, which is the safer breastfeeding option to reduce risk of HIV transmission to the infant, provides additional protection against pregnancy. • For women who are not breastfeeding, taking pills every day, without missing a pill or pills, is particularly important in order to compensate for any possible decrease in effectiveness when on ARVs.

Progestin-only and combined injectable contraceptives 	<ul style="list-style-type: none"> • Not likely that ARVs reduce effectiveness of injectable contraceptives. Still, women using ARVs should be especially careful to return on time for injections. • Condoms could be used for additional protection from pregnancy, especially as the time of the next injection approaches or if a woman is late for her next injection. • It is not necessary to have the next injection early or to shorten the injection interval.
Implants 	<ul style="list-style-type: none"> • Not known if certain ARVs decrease effectiveness of implants. In case they do, condoms provide extra contraceptive protection.
Emergency contraceptive pills (ECPs) 	<ul style="list-style-type: none"> • It is thought that ARVs do not reduce the effectiveness of ECPs. • No evidence for increasing the ECP dosage for women on ARVs.
Copper-bearing intrauterine device (IUD) and levonorgestrel intrauterine device 	<ul style="list-style-type: none"> • A woman who is at risk of HIV infection or who is infected with HIV can generally have an IUD inserted. • A woman who has AIDS, is taking ARVs, and is clinically well can generally have an IUD inserted. • A woman should usually not have an IUD inserted if she has AIDS and is not taking ARVs, or if she is taking ARVs, but is not clinically well. • If a woman develops HIV or AIDS while she has an IUD in place, it generally does not need to be removed. • A woman who has gonorrhea or chlamydia should not have an IUD inserted. • IUD users with AIDS should be monitored for pelvic inflammatory disease.
Female sterilization and vasectomy 	<ul style="list-style-type: none"> • Delay sterilization and vasectomy if currently ill with AIDS-related illness. • Special arrangements are needed to perform female sterilization on a woman with AIDS and a vasectomy on a man with AIDS. The procedure should be undertaken only in settings with experienced staff and sufficient equipment and support. • Female sterilization and vasectomy do not prevent transmission of HIV.

<p>Lactational amenorrhea method (LAM)</p> 	<ul style="list-style-type: none"> • Women who are infected with HIV or who have AIDS and choose to breastfeed their infant can use LAM. • Exclusive breastfeeding (without introducing any other foods, liquids, or water) for the first six months of a baby's life is the safer breastfeeding pattern to minimize the risk of HIV transmission through breastmilk. This pattern of breastfeeding is compatible with LAM. • If a woman's monthly bleeding returns before six months, she will need another contraceptive method while continuing to breastfeed exclusively. • Women with HIV and their health care providers need to consider the infant feeding options available and to weigh their various risks and consequences.
<p>Fertility awareness methods</p> 	<ul style="list-style-type: none"> • Calendar-based fertility awareness methods rely on regular menstrual cycles. For women with advanced HIV (low CD4+ cell count), irregular cycles may be common and make these methods difficult to use. • For most people, fertility awareness methods are less effective than are other modern methods of contraception.
<p>Spermicides</p> 	<ul style="list-style-type: none"> • Women at high risk of HIV infection and who have very frequent intercourse should not use spermicides. • Women with HIV infection, including AIDS, should not use spermicides.
<p>Diaphragm</p> 	<ul style="list-style-type: none"> • Diaphragms may help keep infectious organisms from reaching the cervix, however a recent study found that diaphragms do not protect against HIV infection. • Because diaphragms are used with spermicide, they are not generally recommended for women at high risk for HIV infection or women who are infected with HIV.

Dual Protection Strategies Help Prevent Pregnancy and STIs

www.infoforhealth.org/pr/115/8.shtml

By practicing dual protection, women with HIV take steps to prevent unplanned pregnancy, prevent transmission of HIV to an uninfected partner, and protect themselves against STIs. For women with HIV, these strategies include:

- **Consistent and correct use of male or female condoms.** One method, condoms, when used consistently and correctly, can protect against both pregnancy and STI transmission during vaginal sex. As typically used, however, pregnancies occur among 15 per 100 women in the first year that their partners use male condoms. This is less protection against pregnancy than hormonal methods or intrauterine devices typically provide. As female condoms are typically used, pregnancies occur among 21 per 100 women in the first year of use.

Condoms protect best against STIs spread by discharge, such as HIV, gonorrhea, and chlamydia. They also protect against STIs spread by skin-to-skin contact, such as herpes and human papillomavirus. On average, male condoms are 80% to 95% effective in protecting people from HIV infection when used consistently and correctly with every act of sex. Evidence on female condoms is not as extensive as male condoms, and it is not certain whether they provide the same level of protection against HIV and other STIs as male condoms.

- **Use of condoms along with another contraceptive method** (also called “dual method use”). Using condoms and another contraceptive method together provides extra protection against pregnancy beyond what condom use alone provides. (Male and female condoms should not be used together; friction may lead to slipping or tearing of the condoms.) This strategy may be a choice for women who want to be sure to avoid pregnancy but cannot always count on their partners to use condoms.
- **Condoms and emergency contraception.** Emergency contraceptive pills can be used as back-up protection against pregnancy in the event that a condom fails, is used incorrectly, or is not used. Emergency contraception does not help to prevent STIs.
- **Avoiding all types of penetrative sex.** Abstaining from penetrative sexual contact is the only certain way to prevent both pregnancy and sexual transmission of HIV and other STIs, but in fact it is often difficult to maintain abstinence. Abstinence is not feasible for many women, particularly those who are married or cohabitating.

Correct and Consistent Use of Condoms Can Be Difficult

While many people use condoms more often after learning that they have HIV infection, correct and consistent use of condoms, with or without another method, is often difficult. A study in Burkina Faso, for example, found that nearly 40% of women who had tested positive for HIV during pregnancy started using hormonal contraceptives after they gave birth, but only 8% consistently used condoms.

There are various reasons that women and couples do not use condoms consistently. The cost or lack of availability of condoms may preclude their use. Whether or not they have HIV, many women have little control over condom use, when they have sex, or, in some circumstances, even with whom they have sex. Some women with HIV may fear disclosing their HIV status to their partners. Some women with HIV report that their partners refuse to use condoms, despite the risk that these men may face. Some women with HIV may feel there is no need to use condoms if they know or think that their partner also is infected with HIV.

Thus, pressing condom use on all women may not be helpful and could be counterproductive. When condom use is not an option, assuring effective contraception with a different method may be more realistic. The best strategy is the one that a woman with HIV is able to practice effectively in the situation that she faces.

Pregnancy rates during typical use reflect how effective methods are on average, including people whose use of the method is not consistent or always correct. Pregnancy rates during consistent and correct use reflect the best observed effectiveness rates among people who say they have followed instructions for proper use.

Sexual and Reproductive Health: OB/GYN Care

I am HIV positive and already pregnant. Will my baby be positive?

No one can tell for sure if your baby will be born with HIV. There is always a chance. Take the following steps to minimize the risk. Get medical care for HIV in addition to your regular OB/GYN care.

- You will need to take certain medicines to get the amount of HIV as low as possible in your body before delivery.
- Your baby will need to be on HIV medicines for the first few weeks/months of its life and see a specialist in an HIV pediatric clinic listed below.
- You should not breastfeed if you are HIV positive, as HIV can be passed through breast milk.

Women, Children, and HIV: Resources for Prevention and Treatment

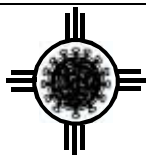
(www.womenchildrenhiv.org) offers additional information on best practices in preventing mother-to-child transmission of HIV and caring for infected children.

For Specialty HIV OB/GYN care contact:

- **Perinatal HIV Provider Information Line at Brigham and Women's Hospital**
75 Francis St., Boston, MA 02115
(800) 742-2211

For Specialty HIV Pediatric care contact:

- **Greater Lawrence Family Health Center**
34 Haverhill St., Lawrence, MA 01841
(978) 686-0090 / www.glfhc.org
Spanish, French, Cambodian, Chezyk, Farsi, German, Gujarati, Hebrew, Indo, Italian, Korean, Lebanese, Lingala, Punjabi, Russian, S-Swa, Taiwanese, and Ukra spoken.
- **Lowell Community Health Center**
585 Merrimack St., Lowell, MA 01854
(978) 937-9700 / www.lchealth.org
Spanish, Portuguese, French, Haitian Creole, Khmer, Lao, Luganda, Swahili, and Vietnamese spoken.
- **Children's Hospital Boston, Infectious Diseases Program**
300 Longwood Ave., Boston, MA 02115
(617) 919-2900 / www.childrenshospital.org
- **MGH Chelsea Health Center, HIV Department**
151 Everett St., Chelsea, MA 02150
(617) 887-4330 / www2.massgeneral.org
Spanish spoken.



PREGNANCY AND HIV

HOW DO BABIES GET AIDS?

The virus that causes AIDS can be transmitted from an infected mother to her newborn child. Without treatment, about 20% of babies of infected mothers get HIV.

Mothers with higher viral loads are more likely to infect their babies. However, no viral load is low enough to be "safe". Infection can occur any time during pregnancy, but usually happens just before or during delivery. The baby is more likely to be infected if the delivery takes a long time. During delivery, the newborn is exposed to the mother's blood. Drinking breast milk from an infected woman can also infect babies. Mothers who are HIV-infected **should generally not breast-feed their babies**. To reduce the risk of HIV infection when the father is HIV-positive, some couples have used sperm washing and artificial insemination.

HOW CAN WE PREVENT INFECTION OF NEWBORNS?

What if the father is infected with HIV? Recent studies have shown that it is possible to "wash" the sperm of an HIV-infected man so that it can be used to fertilize a woman and produce a healthy baby. These procedures are effective but very expensive.

Use antiretroviral medications: The risk of transmitting HIV is extremely low if antiretroviral medications are used. Transmission rates are only 1% to 2% if the mother takes combination antiretroviral therapy (ART.) The rate is about 4% when the mother takes AZT during the last six months of her pregnancy, and the newborn takes AZT for six weeks after birth. See Fact Sheet 411 for more information on AZT.

Even if the mother does not take antiretroviral medications until she is in labor, two methods cut transmission by almost half.

- AZT and 3TC (See Fact Sheet 415) during labor, and for both mother and child for one week after the birth.
- One dose of nevirapine (See Fact Sheet 431) during labor, and one dose for the newborn, 2 to 3 days after birth.

Combining nevirapine and AZT during labor and delivery cuts transmission to only 2%. However, resistance to nevirapine can develop in up to 40% of women who take the single dose. This reduces the success of later ART for the mother. Resistance to nevirapine can also be transmitted to newborns through breast feeding. However, the shorter regimens are more affordable for developing countries.

Keep delivery time short: The risk of transmission increases with longer delivery times. If the mother uses AZT and has a viral

load (see Fact Sheet 125) under 1,000, the risk is almost zero. Mothers with a high viral load might reduce their risk if they deliver their baby by cesarean (C-) section.

Feeding the Newborn

Up to 14% of babies may get HIV infection from infected breast milk. Breast feeding is controversial, especially in the developing world. Most transmission from breast feeding occurs within the first two months after birth. On the other hand, replacement feeding can create additional risks for infant mortality from various diseases.

A recent study showed that it is possible for a newborn to become infected by eating food that is chewed for it by an infected mother. This practice should be avoided.

HOW DO WE KNOW IF A NEWBORN IS INFECTED?

Most babies born to infected mothers test positive for HIV. Testing positive means you have HIV antibodies in your blood. Fact Sheet 102 has more information on HIV tests. Babies get HIV antibodies from their mother even if they aren't infected.

Another test, similar to the HIV viral load test (See Fact Sheet 125, Viral Load Tests), can be used to find out if the baby is infected with HIV. Instead of antibodies, these tests detect HIV in the blood. This is the only reliable way to determine if a newborn is infected with HIV.

If babies **are** infected with HIV, their own immune systems will start to make antibodies. They will continue to test positive. If they **are not** infected, the mother's antibodies will eventually disappear. The babies will test negative after about 12 to 18 months.

WHAT ABOUT THE MOTHER'S HEALTH?

Recent studies show that HIV-positive women who get pregnant do not get any sicker than those who are not pregnant. Becoming pregnant is not dangerous to the health of an HIV-infected woman. This is true even if the mother breast-feeds her newborn for a full term (2 years). In fact, a study in 2007 showed that becoming pregnant was good for a woman's health.

However, "short-course" treatments to prevent infection of a newborn are not the best choice for the mother's health. If a pregnant woman takes ART only during labor and delivery, HIV might develop resistance to them. This can reduce the future treatment options for the mother. See Fact Sheet 126 for more information on resistance.

A pregnant woman should consider all of the possible problems with antiretroviral medications.

- Pregnant women should not to use both ddI (Videx, see Fact Sheet 413) and d4T (Zerit, see Fact Sheet 414) in their ART due to a high rate of a dangerous side effect called lactic acidosis.
- Do not use efavirenz (Sustiva) during the first 3 months of pregnancy.
- If your CD4 count is more than 250, do not start using nevirapine (Viramune).

Some doctors suggest that women interrupt their treatment during the first 3 months of pregnancy for three reasons:

- The risk of missing doses due to nausea and vomiting during early pregnancy, giving HIV a chance to develop resistance
- The risk of birth defects, which is highest during the first 3 months. There is almost no evidence of this, except with efavirenz.
- ART might increase the risk of premature or low birth weight babies
- **However, current guidelines do not support treatment interruption for pregnant women.**

If you have HIV and you are pregnant, or if you want to become pregnant, talk with your health care provider about your options for taking care of yourself and reducing the risk of HIV infection or birth defects for your new child.

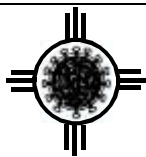
THE BOTTOM LINE

An HIV-infected woman who becomes pregnant needs to think about her own health and the health of her new child. Pregnancy does not seem to make the mother's HIV disease any worse.

The risk of transmitting HIV to a newborn can be virtually eliminated with "short course" treatments taken only during labor and delivery. But short treatments increase the risk of resistance to the drugs used. This can reduce the success of future treatment for both mother and child.

The risk of birth defects caused by ART is greatest during the first 3 months of pregnancy. If a mother chooses to stop taking some medications during pregnancy, her HIV disease could get worse. Any woman with HIV who is thinking about getting pregnant should carefully discuss treatment options with her health care provider.

Revised January 15, 2009



CHILDREN AND HIV

HOW SERIOUS IS HIV FOR CHILDREN?

Where antiretroviral medications (ARVs) and good medical care for pregnant women are available, new infections of children are rare. There were about 2 million children around the world living with HIV in 2007.

Anyone age 13 or younger is counted as a child in US health statistics. In 1992, almost 1,000 children were infected. By 2002, there were just 92 new infections. African-American newborns are much more likely to be infected than children of other races. Most children with HIV were born to mothers with HIV. Others got a transfusion of infected blood. In the developed world, blood for transfusions is screened and most pregnant women are taking ARVs. See fact sheet 611 for more information on pregnancy and HIV.

Infected mothers can pass HIV to their newborns. This happens where mothers do not get good medical care while they are pregnant. It also happens where ARVs are not available, or where blood for transfusions is not always screened.

HOW ARE CHILDREN DIFFERENT?

Children's immune systems are still developing. They have a different response to HIV infection. CD4 cell counts (see fact sheet 124) and viral load counts (see fact sheet 125) are higher than in adults. An infant's viral load usually declines until age 4 or 5. Then it stabilizes.

Children also respond differently to ARVs. They have larger increases in CD4 cell counts and more diverse CD4 cells. They seem to recover more of their immune response than adults.

Infants have more fat and water in their bodies. This affects the amount of medication available. Children have a very high rate of metabolism. This gradually slows as they mature.

The liver processes drugs and removes them from the body. It takes several years to mature. As it matures, drug levels in children can change a lot.

Bones develop quickly during the early years of life. ARVs can weaken bones in adults. This was also seen in children. See

Fact Sheet 557 for more information on bone problems in HIV.

RESEARCH ON CHILDREN

The US government supported the Pediatric AIDS Clinical Trials Group to study AIDS in children. In Europe, the Pediatric European Network for Treatment of AIDS does similar work.

It is very difficult to recruit children into HIV clinical trials. In the US, many children with HIV have already been in more than one research study. With falling infection rates, there are very few new cases of pediatric HIV. The US has considered ending support for its pediatric trials network. Important research questions may be studied in adults.

A recent study found that children with HIV who were doing well on treatment had more behavioral problems and lower developmental scores than normal.

TREATMENT FOR CHILDREN

HIV-infected children should be treated by a pediatrician who knows about HIV.

Antiretroviral therapy (ART) works very well for children. The death rate of children with AIDS has dropped as much as for adults. However, manufacturers were not required to study their products in children until very recently in the US. As a result, very few ARVs have been studied in children. Still, 12 ARVs are approved for use by children.

The correct doses are not always known. Children's doses are sometimes based on their weight. Another method is body surface area. This formula considers both height and weight. As mentioned above, several factors affect drug levels in children. Dosing may have to be adjusted several times as a child develops.

The doses of some medications for infants and very young children can be individualized. They come in liquid or powder form. Others come in a granular form. Some pills can be crushed and added to food or liquids. Some clinics teach children how to swallow pills. Children who can swallow pills have more medication options.

Doctors sometimes try to cut adult tablets into smaller pieces for children. However, this can result in doses that are too low.

Some tablets are difficult to cut. Also, the medication may be unevenly distributed in the tablet

It is difficult to know when to start treatment for children. Immediate treatment might prevent immune system damage. Delayed treatment may provide better quality of life for several years. However, HIV-related diseases show up much faster in untreated children than in adults. Without treatment, about 20% of children die or develop AIDS within one year. Most HIV-infected children in the US start ART before they are 3 months old. US Guidelines for ART in children were last updated in November 2005. They can be found on the Internet at <http://www.aidsinfo.nih.gov/Guidelines/>

CHILDREN AND ADHERENCE

Adherence (see fact sheet 405) is a major challenge for children and infants. Both the child and the parents may need extra help. Many children do not understand why they should put up with medication side effects.

Their parents are usually HIV-positive. They may have their own difficulties with adherence. Their children may take different medications, on a different schedule. Many ARVs taste bad or have a strange texture. A feeding tube directly into the stomach may be necessary if an infant refuses to swallow medications.

THE BOTTOM LINE

Where ARVs and good medical care for pregnant women are available, new infections of children are rare. Treatment of HIV-infected children is complicated. Not all ARVs are approved for use by children. The correct dosing is not always known. Children may have a difficult time tolerating medications and taking every dose as scheduled.

However, because children's immune systems are still developing, they might have a better chance of fully recovering from damage caused by HIV.

Children with HIV should be treated by a pediatrician with experience in HIV.

Revised November 16, 2008

Living Well with HIV

V. Living Well with HIV

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Appendices

- ☒ Lewis, Jim, and Michael Slocum. "Just Diagnosed Resource Center - Creed - You Are Not Alone." *The Body: The Most Comprehensive HIV/AIDS Resource*. 31 Dec. 1982. Web. 27 July 2009. <<http://www.thebody.com/content/art30259.html>>.
- ☒ "Nutrition." The AIDS InfoNet, 12 June 2009. Web. 27 July 2009. <http://www.aidsinfonet.org/fact_sheets/view/800>.

Living Well with HIV: Taking Care of Yourself

How do I take care of myself?

There are many things you can do for yourself to stay healthy. Here are some of the most important:

- See a doctor who specializes in HIV treatment.
- Follow your doctor's instructions. Talk to your doctor about your questions and concerns.
- If your doctor prescribes medicine for you, take the medicine just the way he or she tells you. Taking your medicine incorrectly gives your HIV infection more chance to fight back. If you have side effects from your medicine, call your doctor for advice—don't change how you take your medicine on your own or because of what friends tell you.
- Get immunizations (shots) to prevent pneumonia and flu.
- If you smoke or use drugs not prescribed by your doctor, consider reducing or quitting.
- Eat healthy foods. Eating well is very important because it keeps you strong, your energy up, and your weight stable.
- Practice safer sex.
- Exercise regularly. Exercise helps you stay strong and relieve stress.
- Get enough sleep and rest.
- Take time to relax. Many people find prayer or meditation, along with exercise and rest, helps them cope with the stress of living with HIV.

You can also find additional **wellness support programs** through these organizations listed below:

- **Strongest Link Cornerstone Wellness Center**
156 Broad St., Ste. 205, Lynn, MA 01901
(781) 581-2393 (Contact: Kathy Day) / www.strongestlink.org
Provides case management, nutrition, holistic therapies, and peer support.
Spanish spoken.
- **North Shore Health Project**
67 Middle St., Gloucester, MA 01930
(978) 283-0101 / www.healthproject.org
Provides case management, consultation about hepatitis C, hepatitis A and B vaccines, peer support, acupuncture, massage, substance abuse and general counseling. Portuguese spoken.
M-F 9am-5pm.
- **Lowell Community Health Center**
585 Merrimack St., Lowell, MA 01854
(978) 937-9700 / www.lchealth.org

Lowell Community Health Center can be reached at (978) 937-9700, and the agency offers services in Spanish, Portuguese, French, Haitian Creole, Khmer, Lao, Luganda, Swahili, and Vietnamese. The agency's website is www.lchealth.org.

BODY POSITIVE

December 31, 1982 (Revised January 12, 2009)

Creed – You Are Not Alone

There are nearly a million of us in the United States. Don't isolate yourselves.

By Jim Lewis and Michael Slocum

Maybe you have tested HIV-positive very recently; maybe you've known it for some time, but this is the first time you've reached out for information or support. You need to know that you are not alone. There are an estimated 1 million HIV-positive people in the United States.

Testing positive for HIV does not mean that you have AIDS, but HIV is probably the greatest threat to your life you have ever faced. This virus may remain inactive in your body for a long time, but it may not. If you are healthy now, you may still go on to develop some sort of health problems related to HIV. You may develop AIDS. There remain many uncertainties surrounding HIV, and though there is currently no "cure" for HIV infection, there are treatments. You need to learn what information is available and make informed choices about your health.

Many HIV-positive people now live fulfilling and happy lives. Many are healthy and show no symptoms of disease. Many choose to take treatments and drugs that promise to lengthen their lives. So, as serious as this is, there is hope. You do not have to look at testing HIV-positive as if you've been given a death sentence.

It's a good thing you found this out. As upsetting as testing positive may have been for you, you are better off knowing, so you can learn about HIV and decide what you want to do about it. The fact that you cared enough about yourself to get the HIV test and the fact that you are reading this magazine show that you are concerned about your health. So give yourself some credit. You have taken important first steps to take care of yourself, and you should be glad about it.

Years ago, those who tested HIV-positive had few places to turn for support. These people felt like they were hanging in limbo. Fortunately, much has changed. We know more about HIV now and many organizations have formed around the world to offer support and information to people living with this virus. Many have already faced the questions inherent in living with HIV, and many will follow. You don't have to face this by yourself. There are lots of hands reaching out to assist you.

Your Emotional Health

Finding out that you are infected is usually overwhelming. Even if you had suspected it for some time, learning that you are can be a very traumatic experience. Testing HIV-positive has led some people to quit their jobs, quickly write out their wills, and say goodbye to their friends and family, only to discover that they aren't sick and will probably live for many years to come. It's common to perceive these results as an immediate death sentence, but this is simply not true.

What you are feeling now is perfectly normal. Anger, fear, confusion, numbness, depression -- all are completely natural reactions to the kind of news you've heard. If you've known for even several weeks, you may find yourself having a normal day, then suddenly remember that you are HIV-positive. It's very common for this kind of realization to just "hit you in the face" out of nowhere over and over again. You are not going crazy if this happens to you. Your moods may swing from profound sadness one moment to extreme anger the next. That's normal, too.

The first step to getting through this emotional turmoil is to acknowledge what you are feeling. Don't be surprised to find yourself going through the day in a state of shock. Allow yourself to feel nothing. Your emotions will come rushing back in soon enough. This is merely a way that your mind "turns off" to allow you to cope with a problem.

If you are feeling angry, that's fine. You have every right to be angry and a lot to be angry about. This virus is threatening your very existence. It's okay to express this anger. If you're frightened, acknowledge your fears. You are thinking about things that would make anyone fearful. You are allowed to feel the way you do. Don't be hard on yourself or think you have to be strong. You don't have to be anything.

Fear of Sickness and Death

Almost everyone is afraid of getting sick and dying. If you're young, you may never have had to face the death of someone close to you. We often think of dying as something that happens only when we're old. You may never have really considered the reality of your own death before. Now, suddenly, you are HIV-positive and your mortality becomes very real. You may be afraid of pain, of hospitals, or of becoming unattractive to others through an illness.

Your reaction to the idea of getting sick or dying could go one of two ways. You may decide that you are definitely going to live and that there is no way that this virus is ever going to "get" you. This is a form of what's called denial -- refusing to face some of the possibilities of living with HIV. If you find yourself feeling this way, try to keep in mind that having hope to go on with your life is good. However, it can become dangerous if it keeps you from taking care of yourself.

The other way you might choose to deal with the subject is by deciding that you are absolutely going to die of this and there is nothing you can do about it. If you go this way, you may find yourself fantasizing about your own sickness and death. You have to keep in mind that there are many people who are HIV-positive who are living productive, happy lives, and you can be among them if you choose. It's good to face up to the possible consequences of this infection, but not to the point that living today becomes less important than your fear of the future. It helps to remind yourself that everyone will die, but that doesn't prevent most people from living today.

Starting Over

One of the truths of testing HIV-positive is that once you know, you can **never not know** again. For better or worse, your life will always be different now. You may be experiencing great feelings of loss about this. You may feel that certain areas of your life are now in the hands of doctors, insurance companies, or symptoms. This can make you feel as though you have less control over your own life and may cause you incredible anxiety.

Know this -- you do not have to give up control of your life. By arming yourself with information and deciding what is right for you, you will soon realize that you are still the same person you were. It is your life, your body, your health, and no matter how well-meaning your family, your friends, or your doctor may be, they have no right to take control of your life. Allow yourself to take time to decide what you want to do. Then go do it.

You may find that many of the priorities in your life change rapidly. If you are considering making major changes in your life, just make sure that you think them through carefully. Many HIV-positive people have made huge changes in the way they live. Many have broken bad habits, such as drinking too much or smoking. Some have gotten out of bad relationships or quit jobs they really hated. Facing the

possibility of getting sick or dying has made many of our lives much better because it has made us take action in areas we have previously ignored or repeatedly put off. Mortality can be a great motivator.

Some people blame themselves for being HIV-positive. This kind of guilt and self-hate is very destructive. Regardless of how you were infected, you did not go somewhere or do something with the intention of infecting yourself -- so why beat yourself up about it? You are facing enough right now; you don't need to punish yourself for testing HIV-positive also.

Grief, or extreme sadness, is one of the emotions that most HIV-positive people face at some point. You may be grieving for yourself, facing the possibility of your own death. For many of us, the virus is not only affecting our lives, but the lives of those we love. Many have lost friends and loved ones to HIV, or have many people in their lives who are also HIV-positive. Allow yourself to express grief and fear in some way. Permit yourself to cry. These feelings are valuable and normal; ignoring them will not make them go away.

You may also feel that you are now damaged in some way -- that no one will want to touch you or love you or that you are less desirable because you are HIV-positive. You may feel that you will never be able to love again, that no one would want to be with you if they knew that you were HIV-positive. These feelings will pass. You are not "damaged goods." You are still a valuable person, as capable of giving and receiving love as ever. You can make your own decisions, relax, and enjoy each day. This may be a struggle and you may have to find new ways of coping with daily life, but it's worth it.

Getting Support

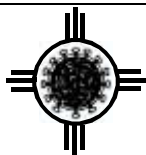
Many of us have been raised with the idea of "rugged individualism," that we must face things on our own, that this is what "strength" is all about. Asking for help or reaching out for support are often considered weaknesses. Consequently, a very common response to testing HIV-positive is withdrawal. We isolate ourselves, hiding the news of our status. This can be very painful.

Your life does not have to be doom and gloom. It is possible to have a very positive attitude as a person living with HIV -- millions are doing it right now -- but it is much more difficult to get on with your life and live happily if you're trying to do it alone.

There's no need for you to handle this by yourself, and it's probably a mistake even to try to do it. You are not the only person facing this. Learn who the others are and what they have to offer. Just hearing how someone else has adjusted to living with the virus can be enough to help you realize that life is still good, that you can still have love and laughter. And you may also be surprised to learn that your own sharing can help others. In sharing the issues that concern us, each of our voices lends strength to the others.

Support groups are a powerful means of learning to cope with this new beginning. There are support groups offered by HIV/AIDS organizations across the country. If you don't know of an HIV/AIDS organization in your area, call the U.S. Centers for Disease Control Healthline at 1-800-232-4636. If there's no support group in your area, you may be just the person to get one started. Just remember: those millions of people living successfully with HIV are people who've reached out to get the help they needed. Wherever you are, you can find support, or the means to create it. It just doesn't make sense for us to face the same issues without helping each other out. We are not alone. And neither are you.

Michael Slocum and Jim Lewis were editors of Body Positive. HIV/AIDS organizations around the world have reprinted "You Are Not Alone" in their own languages.



NUTRITION

WHY IS NUTRITION IMPORTANT?

Good nutrition means getting enough macronutrients and micronutrients. Macronutrients contain calories (energy): proteins, carbohydrates, and fats. They help you maintain your body weight. Micronutrients include vitamins and minerals. They keep your cells working properly, but will not prevent weight loss.

Good nutrition can be a problem for many people with HIV. When your body fights any infection, it uses more energy and you need to eat more than normal. But when you feel sick, you eat less than normal.

Some medications can upset your stomach, and some opportunistic infections can affect the mouth or throat. This makes it difficult to eat. Also, some medications and infections cause diarrhea. If you have diarrhea, your body actually uses less of what you eat.

When you lose weight, you might be losing fat, or you might be losing lean body weight like muscle. If you lose too much lean weight, your body chemistry changes. This condition is called wasting syndrome or cachexia. Wasting can kill you. If you lose more than 5% of your body weight, it could be a sign of wasting. Talk to your doctor.

NUTRITION GUIDELINES FOR PEOPLE WITH HIV

First, **eat more**. Extra muscle weight will help you fight HIV. This is very important. Many people want to lose weight, but for people with HIV, it can be dangerous.

Make sure you eat plenty of protein and starches, with moderate amounts of fat.

- **Protein** helps build and maintain your muscles. Meats, fish, beans, nuts, and seeds are good sources.
- **Carbohydrates** give you energy. **Complex** carbohydrates come from grains, cereals, vegetables, and fruits. They are a "time release" energy source and are a good source of fiber and nutrients. **Simple** carbohydrates, or sugars, give you

quick energy. You can get sugars in fresh or dried fruit, honey, jam, or syrups.

- **Fat** gives you extra energy. You need some — but not too much. The "monounsaturated" fats in nuts, seeds, canola and olive oils, and fish are considered "good" fats. The "saturated" fats in butter and animal products are "bad" fats.

A moderate **exercise** program will help your body turn your food into muscle. Take it easy, and work exercise into your daily activities.

Drinking enough **liquids** is very important when you have HIV. Extra water can reduce the side effects of medications. It can help you avoid a dry mouth and constipation. Remember that drinking tea, coffee, colas, chocolate, or alcohol can actually make you lose body liquid.

PRACTICE FOOD SAFETY

It's very important to protect yourself against infections that can be carried by food or water.

Be sure to wash your hands before preparing food, and keep all of your kitchen tools and work areas clean. Wash all fruits and vegetables carefully. Don't eat raw or undercooked eggs or meat, and clean up juices from raw meat quickly. Keep leftovers refrigerated and eat them within three days. Check the expiration date on foods. Don't buy them or eat them if they're outdated.

Some germs are spread through tap water. If your public water supply isn't totally pure, drink bottled water.

WHAT ABOUT SUPPLEMENTS?

Some people find it difficult to go shopping and prepare meals all the time. Supplements can help you maintain your body weight and get the vitamins and minerals you need. Don't use a product designed to help you lose weight, even if it says it contains everything needed for good nutrition! Your health care provider can help you choose a supplement that's right for you.

Vitamin and mineral supplements can be very helpful. They are discussed in Fact Sheet 801.

THE BOTTOM LINE

Good nutrition is very important for people with HIV. When you are HIV-positive, you will need to increase the amount of food you eat and maintain your lean body weight.

Be sure to eat a balanced diet, including plenty of protein and whole grain foods, with some sugar and fat. An exercise program will help build and maintain muscle.

Drink plenty of liquids to help your body deal with any medications you are taking.

Practice food safety. Keep your kitchen clean, wash foods, and be careful about food preparation and storage. If your tap water isn't pure, drink bottled water.

If you feel you need to use nutritional supplements, be sure to get some expert advice from your health care provider.

FOR MORE INFORMATION

You can get more information on nutrition and HIV from the following:

A Clinician's Guide To Nutrition In HIV and AIDS, by Cade Fields-Gardner and others, published by the American Dietetic Association, \$26 plus \$5 shipping and handling: The American Dietetic Association, P.O. Box 97215, Chicago IL 60678-7215; or 800-877-1600, ext. 5000.

Eat Up! Nutrition Advice and Food Ideas for People Living with HIV and AIDS by Charlie Smigelski, RD, \$10.00, <http://www.eatupbooks.com/hivbooks.html>

Nutrition and HIV: A New Model for Treatment by Mary Romeyn, MD, \$18.95, published by Jossey-Bass, Inc, telephone 415-433-1740.

Fact sheets on HIV nutrition are available at <http://www.larklands.net>

Reviewed June 12, 2009

Support Services

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Support Services: AIDS Service Organizations and Case Management

I just learned that I am HIV positive. Where can I get support?

Studies have shown that people who have support from others do better with living with HIV. Support can come in different ways for different people. Some people turn to a family member for support. Others tell a close friend. Other people get support from their HIV doctor or social worker.

A good person to ask for support and help is an **HIV case manager**. A case manager can help you to find the services you need, not just medical care but housing, transportation, nutrition, legal services, and mental health care. Talk to your doctor or social worker, or contact any of the agencies below, to discuss whether case management might be a good option for you.

Case Management Services:

- **Strongest Link AIDS Services**
5 Federal St., Ste. 250, Danvers, MA 01923
(978) 777-5885; (800) 887-0036 / www.strongestlink.org
Provides case management services for individuals infected with HIV throughout Essex County.
Spanish spoken. M-F 9am-5pm
- **Greater Lawrence Family Health Center**
34 Haverhill St., Lawrence, MA 01841
(978) 686-0090 / www.glfhc.org
Provides case management, peer support, and nutrition services.
- **Lowell Community Health Center**
585 Merrimack St., Lowell, MA 01854
(978) 937-9700 / www.lchealth.org
Provides case management, acupuncture, peer support, Directly Observed Therapy (DOT), and nutrition services.
- **Lynn Community Health Center**
269 Union St., Lynn, MA 01901
(781) 581-3900 / www.lchcnet.org
Provides case management services.
- **North Shore Health Project**
67 Middle St., Gloucester, MA 01930
(978) 283-0101 / www.healthproject.org
Provides case management, consultation about hepatitis C, hepatitis A and B vaccines, peer support, , acupuncture, massage, substance abuse and general counseling. Portuguese spoken. M-F 9am-5pm.

Housing Support:

- **AIDS Housing Corporation (AHC)**
(617) 927-0088 / www.ahc.org
Publishes directory of HIV/AIDS supportive housing programs in Massachusetts. Website includes comprehensive list of HIV/AIDS housing programs in MA and other housing resources.
- **Greater Lawrence Family Health Center** can be reached at (978) 686-0090, and the agency offers services in Spanish, French, Cambodian, Chezik, Farsi, German, Gujarati, Hebrew, Indo, Italian, Korean, Lebanese, Lingala, Punjabi, Russian, S-Swa, Taiwanese, and Ukra spoken.
- **Lowell Community Health Center** can be reached at (978) 937-9700, and the agency offers services in Spanish, Portuguese, French, Haitian Creole, Khmer, Lao Luganda, Swahili, and Vietnamese.
- **Lynn Community Health Center** can be reached at (978) 937-9700, and the agency offers services in Spanish, French, Arabic, French Creole, Khmer, and Russian spoken.

These agencies offer case management and will be able to either offer or direct you to financial emergency assistance, nutritional supplements educational seminars on HIV, support groups, and counseling.

A Note about Housing

The agencies listed above can all help with answering questions about housing and making referrals. Alternatively, you or your client can also contact these additional housing agencies listed below:

- **North Shore Community Action Program - Housing Opportunities for People with AIDS (HOPWA)**
98 Main St., Peabody, MA 01960
(978) 531-0767 / www.northshorecap.org/hopwa.html
Provides housing case management, eviction prevention, financial support, and utility assistance.
- **Serenity Supportive Housing**
9 Nike Village, Topsfield, MA 01983
(978) 887-0833 (Contact: Lucinda Nolet) / www.hes-inc.org/scp_ssh.htm
Serves GLBT and drug and alcohol recovery clients.

Support Services: Support Groups, Hotlines, and Mental Health

For support, referrals, and information in Massachusetts, contact the **AIDS Action Committee HIV/AIDS & STD Hotline** at (800) 235-2331; TTY: (617) 437-1672; e-mail: hotline@aac.org. M-Th 9am-9pm, F 9am-7:30pm. Spanish also spoken. Additional interpretation services available.

Who can I talk to about this?

Finding out you have HIV is a life-changing event. You may feel anxious, irritable, jumpy, or scared. It is normal to be angry—at yourself for taking risks; at the person you believe may have infected you; at the world. One of the most important things you can do is to find someone to talk to. Here are some options:

- **Support groups** of people living with HIV are helpful for many people. Being with others who are dealing with the same things can help you feel less alone. You may also learn new information about treatments and services. Refer to the list below to find a support group.
- **Talk with a counselor.** This is a safe way to share your feelings, and it may help you see the issues more clearly. To find a counselor, see the list below.
- **Call a hotline (telephone help service).** Hotline calls are confidential and anonymous. You can talk to them about everything without them even knowing who you are. For hotline phone numbers, see the list below.

Support Groups:

- **Strongest Link's Cornerstone AIDS Services**
156 Broad St. Ste 205, Lynn, MA 01901
(781) 581-2393 (Contact: Emily Levine) / www.strongestlink.org
Provides peer support, case management, nutrition, and holistic therapies.
Spanish spoken.
- **North Shore Health Project, Women's Group**
67 Middle St., Gloucester, MA 01930
(978) 283-0101 (Contact: Christine Bobek) / www.healthproject.org
- **Family Service, Inc.**
430 North Canal St., Lawrence, MA 01840
(978) 327-6600 / www.familyserviceinc.com
- **Team Coordinating Agency**
76 Winter St., Haverhill, MA 01830
(978) 373-1181 ext. 21

- **Lowell Community Health Center**
585 Merrimack St., Lowell, MA 01854
(978) 937-9700 / www.lchealth.org
Provides individual and group peer support.

Counselors and Mental Health Services:

- **Health & Education Services**
131 Rantoul St., Beverly, MA 01915
(978) 927-4506 ext. 216 / www.hes-inc.org
Serves MSM.
- **South Bay Mental Health Center**
15 Union St., Lawrence, MA 01843
(978) 688-4830 / www.southbaymentalhealth.com
Limited Spanish spoken.
- **Lowell Community Health Center, Behavioral Health Services**
17 Warren St., Lowell MA 01852
(978) 937-9700; (978) 937-9448 / www.lchealth.org/behavioralhealth.shtml
- **Lynn Community Health Center**
269 Union St., Lynn, MA 01901
(781) 581-3900 (ask for Behavioral Health) / www.lchcnet.org
- **North Shore Emergency Services, Mental Health/Substance Abuse**
41 Mason St., Salem, MA 01970
(978) 524-7107 / www.hes-inc.org/scs_nses.htm
Interpreters in multiple languages available.
- **Family Continuity, Beverly Mental Health Clinic**
72 Rear Cabot St., Beverly, MA 01915
(978) 232-9600 / www.familycontinuity.org

Hotlines (Telephone Help):

- **AIDS Action Committee HIV/AIDS & STD Hotline**
131 Clarendon St., Boston, MA 02116
Hotline: (800) 235-2331 (M-Th 9am-9pm, F 9am-7:30pm); Client services directory: (617) 450-1250; TTY: (617) 437-1672 / www.aac.org
Provides information and referrals for HIV, hepatitis, STDs, and legal services.
Spanish spoken. Interpretation services available.
- **CDC Information Hotline**
(800) CDC-INFO (232-4636); TTY: (888) 232-6348 / www.cdc.gov/hiv
Staff will review health data with callers, answer health-related questions, and provide necessary referrals.
Spanish spoken. Service available 24/7.
- **Fenway Health - Peer Listening Line**
(617) 267-2535; (800) 399-PEER (399-7337) / www.fenwayhealth.org
Provides callers 25 and under with information, referrals, and support. Line is staffed with GLBT volunteers 25 and under. 5pm-10pm.

- **Trevor Project**
(800) 850-8078 / www.thetrevorproject.org
Serves gay, lesbian, transsexual, bisexual youth.

If you ever feel at a complete loss and don't know what to do, go to an Emergency Room or call:

- **Samaritans of Merrimack Valley, Inc.**
Regional hotline: (866) 912-HOPE (912-4673); Teen Hotline: (888) SOS-TEEN (767-8336); Greater Lawrence area: (978) 688-6607

The list below contains a collection of other regional as well as national helplines:

- **AIDS Treatment Information Service**
(800) 448-0440; TTD: (800) 243-7012 / www.aidsinfo.nih.gov
This hotline provides contact with an information specialist for information about clinical trials.
Spanish spoken.
- **American Social Health Association**
(800) 227-8922 / www.ashastd.org
Provides STD related information, referrals, and materials.
- **Healing Abuse Working for Change (HAWC)**
27 Congress St., Salem, MA 01970
(978) 744-8552 / www.helpabusedwomen.org
Spanish, Portuguese, and French spoken. Serves Latino and GLBT populations.
- **YWCA of Greater Lawrence Rape Crisis/Sexual Assault Hotline**
(877) 509-YWCA (509-9922); TTY: (978) 686-8840 / www.ywcalawrence.org
Spanish and Portuguese spoken.
- **Gay, Lesbian, Bisexual, and Transgender Helpline**
(617) 267-9001; (888) 340-4528 / www.fenwayhealth.org
Provides callers with information, referrals, and support. 6am-11pm, but subject to volunteer availability.
- **Massachusetts Substance Abuse Information & Education Helpline**
(800) 327-5050; TTY: (617) 536-5872 / www.helpline-online.com
Provides information and referrals for drug and alcohol abuse problems and related concerns including referrals for detox facilities, shelters, and methadone clinics.
Spanish spoken.
- **Massachusetts Organization for Addiction Recovery (MOAR)**
c/o Boston ASAP, 30 Winter St., 3rd Floor, Boston, MA 02108
(617) 423-6627 / www.moar-recovery.org
MOAR's mission is to organize recovering individuals, families, and friends into a collective voice to educate the public about the value of recovery from alcohol and other addictions.

- **Samaritans of Boston, Inc.**
24-hour crisis hotline: (617) 247-0220; Statewide Teen Hotline: (800) 252-8336 / www.samaritansofboston.org
- **National Suicide Prevention Lifeline**
(800) 273-TALK (273-8255) / www.suicidepreventionlifeline.org
Spanish spoken.
- **Covenant House Youth Crisis Line (“Nine Line”)**
(800) 999-9999 / www.nineline.org
Spanish spoken. Additional translation services available via phone translation service.
- **CrisisLink**
(800) 273-TALK (273-8255); (703) 527-4077 / www.crisislink.org
- **Boys Town National Crisis Hotline**
(800) 448-3000; TDD: (800) 448-1833 / www.girlsandboystown.org
A 24-hour crisis, resource, and referral line.
Spanish spoken.
- **National Hopeline Network**
(800) SUICIDE (784-2433) / www.hopeline.com
The Hopeline Network helps make appropriate and critical services available to all.
Spanish spoken.
- **National Runaway Switchboard**
(800) TO-BE-SAF (862-3723) / www.1800runaway.org
Provides confidential crisis intervention and local and national referrals through a 24-hour hotline.
Spanish spoken.
- **Suicide and Crisis Helplines Around the World**
www.befrienders.org
Provides access to suicide and crisis helplines in over 40 countries. The site is available in over 10 language

Support Services: Domestic Violence Hotlines and Support

Who can I talk to if I don't feel safe at home?

Domestic violence programs and hotlines provide support and assistance to anyone who faces violence, threats, or abuse at home or from a partner. These programs can help with crisis intervention, safety planning, information about domestic violence, and referrals to local service providers. Domestic violence programs and hotlines in Massachusetts are listed below. All services are confidential, and there are services available to everyone, including people in same-sex relationships, males, people with disabilities, and immigrants.

- **Healing Abuse Working for Change (HAWC)**
27 Congress St., Salem, MA 01970
(978) 744-8552 / www.helpabusedwomen.org
Spanish, Portuguese, and French spoken. Also serves Latino and GLBT populations.
- **YWCA of Greater Lawrence**
38 Lawrence St., Lawrence, MA 01840
(978) 687-0331; TTY: (978) 686-8840 / www.ywcalawrence.org
- **Jane Doe, Inc. - Massachusetts Coalition Against Sexual Assault and Domestic Violence**
(877) 785-2020; Spanish: (800)223-5001 / www.janedoe.org
Spanish, French, German, and Haitian Creole spoken.
- **Health & Education Services**
131 Rantoul St., Beverly, MA 01915
(978) 927-4506 ext. 216 / www.hes-inc.org
Serves MSM.
- **Lowell Community Health Center, SAFVE Program**
17 Warren St., Lowell MA 01852
SAFVE assists individuals in ensuring their safety, offers facilitated referrals to shelters and legal services, and provides counseling and social services.
(978) 937-9700; (978) 441-1700 / www.lchealth.org/CARE.shtml

Additional domestic violence/intimate partner violence and sexual assault resources:

- **Gay Men's Domestic Violence Project**
955 Massachusetts Ave., PMB 131, Cambridge, MA 02139
(800) 832-1901 / www.gmdvp.org
Spanish spoken.
- **North Shore Rape Crisis Center**
(800) 922-8772 / www.hes-inc.org/scp_nsrcc.htm
Spanish spoken.
- **Jeanne Geiger Crisis Center 24-Hour Hotline**
2 Harris St., Newburyport, MA 01950
(978) 388-1888; Office: (978) 465-0999 / www.jeannegeigercrisiscenter.org

- **Rape Crisis of Greater Lowell**
(800) 542-5212
- **SafeLink (Toll free 24-hour statewide domestic violence hotline)**
c/o Casa Myrna Vasquez, PO Box 180019, Boston, MA 02118
(877) 785-2020; TTY: (877) 521-2601 / www.casamyrna.org
Spanish, Portuguese, and Cape Verdean Creole spoken. Staff also has access to a language line with 150 language translations available.
- **Llamanos y Hablemos**
799 West Boylston St., Worcester, MA 01606
(800) 223-5001; TTY/TTD: (508) 852-7600 / www.llamanos.org
Spanish sexual assault helpline provides crisis intervention, referrals, education and training, and outreach.

Support Services: Substance Abuse

I think I have a substance abuse problem. What should I do?

The important thing is to find the right level of care for you. Massachusetts has teen and adult substance abuse treatment programs and many levels of care, including detox, residential, intensive outpatient, and partial hospital programs. Call any program for a telephone screening to see if the program is the right level for you. If not, they will refer you to another program that can better meet your needs.

Even if you don't have health insurance, you may be able to get care. You might be eligible for MassHealth or Commonwealth Care. Visit www.mahealthconnector.org on the web to get more information about these programs. Also, many programs are funded by the Massachusetts Department of Health to provide services to all who are eligible based on income. Ask your HIV case manager or social worker about other programs that may be able to help you pay for substance abuse treatment.

Here are some options for substance abuse information and services:

- **Massachusetts Substance Abuse Information & Education Helpline**
(800) 327-5050; TTY: (617) 536-5872 / www.helpline-online.com
Information and referrals for drug and alcohol abuse problems and related concerns including referrals for detox facilities, shelters, and methadone clinics.
Spanish spoken.
- **CAB Health and Recovery Services**
Zero Centennial Dr., Peabody, MA 01960
(978) 968-1700; (800) 323-2224 / www.cabhealth.org
- **Team Coordinating Agency**
76 Winter St., Haverhill, MA 01830
(978) 373-1181 ext. 21
- **Project COPE**
181 Union St., Lynn, MA 01902
(781) 581-9270 / www.projectcope.com

Additional substance abuse programs:

- **Lowell Community Health Center, Behavioral Health Services**
555 Merrimack St., Lowell, MA 01854
(978) 937-9700; (978) 459-8656 ext. 24 / www.lchealth.org/behavioralhealth.shtml
Provides inpatient and outpatient behavioral health services.
Outpatient services: M, W, Th, F 8:30am-5pm
- **North Shore Emergency Services, Mental Health/Substance Abuse**
41 Mason St., Salem, MA 01970
(978) 524-7107 / www.hes-inc.org/scs_nses.htm
Interpreters in multiple languages available.

- **Turning Point Inc. Safe Recovery Program**
(978) 388-6600
- **Substance Abuse & Mental Health Services Administration (SAMHSA) 24-Hour Helpline**
(800) 662-HELP (662-4357); Spanish: (800) 662-9832; TDD: (800) 228-0427
<http://findtreatment.samhsa.gov/facilitylocator.doc.htm> (Treatment Facility Locator)
- **Massachusetts Organization for Addiction Recovery (MOAR)**
c/o Boston ASAP, 30 Winter St., 3rd Floor, Boston, MA 02108
(617) 423-6627 / www.moar-recovery.org
- **Alcoholics Anonymous**
12 Channel St., Boston, MA 02210
(617) 426-9444 / www.aaboston.org
- **Al-anon, Alateen Infoline**
(508) 366-0556
- **Habit OPCO**
www.habitopco.com
 - ❑ 99 Topeka St., Boston, MA 02118
(617) 442-1499
 - ❑ 11 Circle Ave., Lynn, MA 01905
(781) 595-2413
 - ❑ 650 Suffolk St., Lowell, MA 01854
(978) 452-5155

How can I prevent the spread of HIV infection if I use needles?

Always use clean needles; the safest thing is never to share your needles with others and not to reuse needles. If you must share, clean your needles with bleach and water.

The purpose of needle exchange programs is to prevent the transmission of HIV, hepatitis C, and other blood-borne diseases by giving people harm reduction tools to lower the risk. Harm reduction tools include:

- Clean syringes (needles can also be bought at pharmacies in Massachusetts without a prescription).
- Bleach.
- Alcohol swabs, cookers, and cotton.
- Condoms and other safe sex materials.

You may trade-in your used needles at these sites and receive a voucher to purchase new ones:

- **Center for Addictive Behaviors (CAB) Health and Recovery Services**
 - ❑ 280 Union St., Lynn MA 01901
(781) 592-4477
M-F 9am-5pm.
 - ❑ 42 Washington St., Gloucester, MA 01930
(781) 592-0243
M, W, F 9am-5pm.

For additional information on needle exchange programs:

- **AHOPE (Formerly Boston Public Health Commission Needle Exchange Program)**
723 Massachusetts Ave., Boston, MA 02118
(800) 383-2437; Outreach: (617) 592-7828; Office: (617) 534-3963 / www.bphc.org
Provides HIV/hepatitis care, NARCAN distribution, and overdose prevention education
Spanish spoken.
- **Cambridge Cares About AIDS (CCAA) Needle Exchange Program (NEP)**
17 Sellers St., Cambridge, MA 02139
(617) 599-0246 / www.ccaa.org
M, W-F 10am-6pm, T 12 noon-6pm.

Prevention/Education for injection drug users:

- **Center for Addictive Behaviors (CAB) Health and Recovery Services**
27 Congress St., Ste. 105, Salem, MA 01970
(978) 740-1572 (Contact: Paula Shevinelle) / www.cabhealth.org
Prevention, education for IDU, and substance abuse users.

- **Greater Lawrence Family Health Center**
 34 Haverhill St., Lawrence, MA 01841
 (978) 686-0090 / www.glfhc.org
 Spanish, French, Cambodian, Czech, Farsi, German, Gujarati, Hebrew, Indo, Italian, Korean, Lebanese, Lingala, Punjabi, Russian, S-Swa, Taiwanese, and Ukra spoken.
- **Latin American Health Institute (LHI)**
 9 Central St., Ste. 400, Lowell, MA 01852
 (978) 459-3366 / www.lhi.org
 Serves Latino MSM, IDU. Spanish spoken.
- **Team Coordinating Agency**
 76 Winter St., Haverhill, MA 01830
 (978) 373-1181 ext. 21

Support Service: Additional Specialty Support

How do I find support specific to me?

Anyone can become HIV positive. There are many, many different “me’s”—HIV affects people of all genders, all skin colors, all sexualities, with any amount of money, from all countries, and of all ages. You can talk to your doctor, a social worker, a case manager, or any of the agencies listed in this guide to help you find the support you need.

Where can I find more information about HIV?

You can go to your local library for free internet access. The internet has a huge amount of HIV information, some good and some not-so-good. Here are some websites and phone numbers that may be helpful to you:

- **HIV/AIDS resource site for positive people**
www.thebody.com
- **Massachusetts AIDS Action Committee**
(800) 235-2331 / www.aac.org
M-Th 9am-9pm, F 9am-7:30pm. Spanish spoken and additional interpreters available.
- **Federal HIV/AIDS information and resources**
www.aids.gov
- **CDC Information Hotline**
(800) CDC-INFO (232-4636); TTY: (888) 232-6348 / www.cdc.gov/hiv
Staff will review health data with callers, answer health-related questions, and provide necessary referrals. Service available 24/7. Spanish spoken.
- **POZ Magazine and HIV Meds Online**
www.poz.com
- **The Gay and Lesbian National Hotline**
(888) THE-GLNH (843-4564) / www.glnh.org
M-F 4pm-12 midnight, Sat noon-5pm.
- **National Minority AIDS Council**
(202) 483-6622 / www.nmac.org or write to info@nmac.org
M-F 8:30am-5pm. Spanish spoken.
- **PatientsLikeMe: Patients Helping Patients Live Better Every Day**
www.patientslikeme.com
Social network and information for HIV positive people.
- **The Massachusetts Department of Health HIV/AIDS Bureau**
(617) 624-5300; (800) 443-2437 / www.mass.gov/dph

More Massachusetts-based support resources:

- **Gay, Lesbian, Bisexual, and Transgender Help Line**
(617) 267-9001 / www.fenwayhealth.org

- **Latin American Health Institute (LHI)**
9 Central St., Ste. 400, Lowell, MA 01852
(978) 459-3366 / www.lhi.org
Serves Latino MSM, IDU. Spanish spoken.
- **Health & Education Services (HES), Gay and Bi-Men's Health Program**
(978) 927-4506 ext. 219 / www.hes-inc.org
Serves MSM.
- **Tri-City Mental and Retardation Center**
181 Union St., 2nd Floor, Ste. B, Lynn, MA 01901
(781) 581-8412
Serves Latino MSM, MSM/IDU population.

More national and web-based support resources:

- **AEGIS (AIDS Education Global Information System)**
www.aegis.com
AEGIS offers a comprehensive web site that provides information on the basics of HIV treatment and links to a wide variety of organizations and media sources.
- **AIDS Info (US Department of Health and Human Services)**
(800) 448-0440 / www.aidsinfo.nih.gov
- **AIDS Treatment Data Network**
www.atdn.org
- **AIDS Vaccine Advocacy Coalition**
www.avac.org
- **The Black AIDS Institute**
www.blackaids.org
- **The Centers for Disease Control (CDC)** maintains a database of over 19,000 service organizations in the United States dealing with HIV/AIDS, tuberculosis, and sexually transmitted diseases. You can search this database by visiting www.cdcnpin.org/scripts/search/orgSearch.aspx on the web.
- **Henry J. Kaiser Family Foundation**
www.kff.org/hivaids
The Kaiser Family Foundation (KFF) is a non-profit, private operating foundation focusing on the major health care issues facing the nation. The Foundation is an independent voice and source of facts and analysis for policymakers, the media, the health care community, and the general public.
- **HIV General Info**
www.yourttotalhealth.ivillage.com/hiv-aids.html
- **HIV Vaccine Campaign**
<http://bethethegeneration.nih.gov>

- **HIV InSite (University of California at San Francisco)**
<http://hivinsite.ucsf.edu>
The HIV InSite, operated by the University of California at San Francisco (UCSF), has sections on the medical, prevention, policy, and statistics related to HIV and AIDS. Its AIDS Knowledge Base is an online textbook on AIDS.
- **Informational site for a wide range of HIV/AIDS questions**
www.aidsinfonet.org
- **International Foundation for Gender Education (IFGE)**
(781) 899-2212 / www.ifge.org
- **National Association of People with AIDS (NAPWA)**
(240) 247-0880 / www.napwa.org
- **National Centers for Disease Control and Prevention**
(800) CDC-INFO (232-4636); TTY: (888) 232-6348 / www.cdc.gov/hiv
- **National HIV/AIDS Treatment Infoline**
(800) 822-7422
- **National Minority AIDS Council**
(202) 483-6622 / www.nmac.org or write to info@nmac.org
- **National Native American AIDS Prevention Center (NNAAPC)**
(510) 444-2051 / www.nnaapc.org
- **Project Inform**
(800) 822-7422 / www.projectinform.org
Spanish spoken.
- **Social Security Administration, Benefits for People living with HIV/AIDS**
www.ssa.gov/pubs/10019.html
Text also available in Spanish.
- **Statehealthfacts.org (Kaiser Family Foundation)**
www.statehealthfacts.org
This resource allows site visitors to compare HIV/AIDS state statistics on new and cumulative AIDS cases, AIDS case rates, persons living with AIDS, AIDS deaths, HIV infections, HIV testing statistics and policies, additional AIDS-related state policies, Ryan White funding and funding for HIV prevention, and AIDS Drug Assistance Programs, including budget, client, and expenditure data.
- **Women Responding to Life-Threatening Diseases (WORLD)**
(510) 986-0340 / www.womenhiv.org

Rights and Responsibilities

VII. Rights and Responsibilities

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- ☒ "Telling Others You are HIV Positive." The AIDS InfoNet, 13 Apr. 2009. Web. 27 July 2009. <http://www.aidsinfonet.org/fact_sheets/view/204>.
- ☒ "HIV Partner Notification." Office of Health and Human Services. Web. 27 July 2009. <<http://www.mass.gov>>.
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- ☒ "HIV Reporting in Massachusetts for Health Care Providers." Office of Health and Human Services. Web. 27 July 2009. <<http://www.mass.gov>>.
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- ☒ "Rights & Resources - Massachusetts." HIV Testing and Privacy in Massachusetts. GLAD: Equal Justice Under Law. Web. 26 Aug. 2009. <<http://www.glad.org/rights/massachusetts/c/hiv-testing-and-privacy-in-massachusetts/>>.
- ☒ Ferri, Janice, Richard R. Roose, and Jill Schwendeman. "A Note to Teens Who Have Just Learned They Are HIV-Positive." The Body: The Most Comprehensive HIV/AIDS Resource, 1994. Web. 27 July 2009. <<http://www.thebody.com/content/art12754.html>>.
- ☒ "HIV/AIDS and Immigrants: A Manual for Service Providers - Basic Rules of Working with Noncitizens Living with HIV/AIDS." National Immigration Project of the National Lawyers Guild and SF AIDS Foundation. Web. 27 July 2009. <<http://www.nationalimmigrationproject.org/HIV/2004HIVManual/2004hivmanual/page4.html>>.
- ☒ "HIV & Immigration: The Basics." Lambda Legal and Immigration Equality. Web. 27 July 2009. <<http://data.lambdalegal.org/pdf/447.pdf>>.

Rights and Responsibilities: Disclosure, HIV Testing, and the Law

Are my HIV test results confidential?

Under Massachusetts law the privacy of your HIV test results is protected. HIV is a reportable illness, and your name will be shared with the Department of Public Health—but your name will only be shared with the HIV/AIDS surveillance program, where your information is carefully protected and kept confidential.

Massachusetts General Law, Chapter 111, Section 70F (MGL C111, SEC 70F) protects the confidentiality of an individual's HIV status and states that a physician, health care provider, or health care facility must get a person's written informed consent before:

- Testing a person for HIV.
- Telling a third party that a person took the HIV test.
- Telling someone else the results of a person's HIV test.

Who do I have to tell?

Telling someone else that you are HIV positive can be very difficult, and there are many things to consider when telling another person. Wait until you feel ready before you tell others you have HIV. Whoever you do tell, be sure that you trust them to support you. It's a good idea to remind them that it is up to you to tell others (not them). It may take people time to accept the news.

For anyone who may have been unknowingly put at risk (for example, previous or current sexual partners) it is important to inform them so that they can get tested. Here are some options for doing this:

- **Tell the person yourself.** Your social worker or doctor can give you some ideas for how to do this.
- **Bring the person to your doctor's office.** You can tell them there, and your social worker or doctor can answer questions.
- **Contact a Disease Intervention Specialist.** Disease Intervention Specialists (DIS) are state employees trained to interview, counsel, and locate sexual and/or drug using partners of individuals with HIV and notify them of their possible risk of exposure. Partner Notification is a voluntary service. Notification is in private to assure that the person being informed is the same as the person who was named by the partners. All information is confidential. The DIS worker is not notified of the client's name, and his/her information is never revealed or acknowledged. Call **HIV/STD Partner Notification, Northeast Region** at (978) 851-7261 ext. 4036.
- **If you face domestic violence,** telling a partner your HIV status may put you at even greater risk. Talk to your doctor about this issue. For more information about keeping yourself safe, contact **Domestic Violence SafeLink** at (800) 785-2020; TTY: (877) 521-2601.

- **The SAFVE Program at Lowell Community Health Center** also offers help for individuals who face domestic violence. To get in touch with this program, call (978) 937-9700 or (978) 441-1700.

Do I have to tell my employer? Landlord? School teacher?

No, you do not have to tell your employer, landlord, or teacher—it's up to you. Take your time to decide who to tell and how you will approach them. Be sure you're ready and that you have support, whatever the person's reaction is. There are laws that protect people with HIV from discrimination in employment, housing, and education.

You may want to tell your employer if your HIV illness or treatments interfere with your job performance. If you want to tell your employer, but are worried about their reaction or your job security, talk to your provider or case manager first. If you do decide to tell your employer, make sure they understand that they must keep your HIV status confidential.

If you apply for a new job, employers are not allowed to ask about your health or any disabilities. Legally, they can only ask if you have any condition that would interfere with the main job tasks.

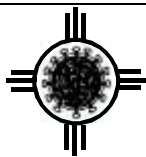
If you have legal questions related to your HIV, you can contact:

- **Massachusetts Commission Against Discrimination**
One Ashburton Place, Boston, MA 02108
(617) 727-3990 / www.mass.gov/mcad
Spanish spoken.
- **AIDS Action Committee**
131 Clarendon St., Boston, MA 02116
Hotline: (800) 235-2331 (M-Th 9am-9pm, F 9am-7:30pm); Client services directory: (617) 450-1250; TTY: (617) 437-1672 / www.aac.org
Provides information and referrals for HIV, hepatitis, and STDs. AAC Access Line provides free or reduced fee legal services for people with HIV who meet the income eligibility guidelines. Spanish spoken. Interpretation services available.
- **Gay & Lesbian Advocates & Defenders (GLAD), AIDS Law Project**
30 Winter St., Ste. 800, Boston, MA 02108
(617) 426-1350; (800) 455-GLAD (455-4523) / www.glad.org
- **JRI Health Law Institute**
25 West St., 5th Floor, Boston, MA 02111
(617) 988-8700 / www.jri.org

To get additional information on legal questions related to HIV, you can also recommend your client to contact any of the agencies listed below:

- **Massachusetts AIDS Discrimination Initiative**
95 Berkeley St., Room 651, Boston, MA 02116
(617) 426-5665
Publishes a comprehensive directory of legal resource agencies.

- **Harvard Legal Aid Bureau**
23 Everett St., Cambridge, MA 02138
(617) 495-4408 / www.law.harvard.edu/students/orgs/hlab
Spanish and Portuguese spoken. Additional interpretation services available.
- **Massachusetts Office on Disabilities**
One Ashburton Pl., Room 1305, Boston, MA 02108
(617) 727-7440 / www.mass.gov/mod
- **Disabilities Law Center, Inc.**
11 Beacon St., Ste. 925, Boston, MA 02108
(617) 723-8455; (800) 872-9992; TTY: (617) 227-9464; TTY: (800) 381-0577 / www.dlc-ma.org
Free legal assistance or representation for individuals.
Spanish, Portuguese, French, and Russian spoken.
- **Equal Employment Opportunity Commission**
One Congress St., Boston, MA 02114
(617) 565-3200
- **MDPH Division of Health Care Quality, Department of Public Health**
Division of Health Care Quality - Intake Unit
99 Chauncy St., 2nd Floor, Boston, MA 02111
(800) 462-5540 / www.mass.gov/dph/dhcq/hcqske.htm
Monitors the quality of health care services provided in Massachusetts by nursing homes, hospitals, ambulance services, labs, blood banks, home health agencies, state schools, and community based programs for the mentally retarded. Also addresses rights of Medicare beneficiaries.
- **Massachusetts Correctional Legal Services**
8 Winter St., Ste. 11, Boston, MA 02108
(617) 482-2773 / www.mcls.net
For HIV+ people in Massachusetts Correctional Institutions who need legal assistance around HIV issues.
- **Legal Action Center**
225 Varick St., New York, NY 10014
(212) 243-1313 / www.lac.org or write to lacinfo@lac.org



TELLING OTHERS YOU'RE HIV-POSITIVE

WHAT ARE THE ISSUES?

When you test positive for HIV, it can be difficult to know who to tell about it, and how to tell them.

Telling others can be good because:

- You can get love and support to help you deal with your health.
- You can keep your close friends and loved ones informed about issues that are important to you.
- You don't have to hide your HIV status.
- You can get the most appropriate health care.
- You can reduce the chances of transmitting the disease to others.
- In many states, you can be found guilty of a felony for not telling a sexual partner you are HIV-positive before having intimate contact.

Telling others may be bad because:

- Others may find it hard to accept your health status.
- Some people might discriminate against you because of your HIV.
- You may be rejected in social or dating situations.

You don't have to tell everybody.

Take your time to decide who to tell and how you will approach them. Be sure you're ready. **Once you tell someone, they won't forget you are HIV-positive.**

GENERAL GUIDELINES

Here are some things to think about when you're considering telling someone that you're HIV-positive:

- **Know why** you want to tell them. What do you want from them?
- **Anticipate** their reaction. What's the best you can hope for? The worst you might have to deal with?
- **Prepare** by informing yourself about HIV disease. You may want to leave articles or a hotline phone number for the person you tell.
- **Get support.** Talk it over with someone you trust, and come up with a plan.

- **Accept** the reaction. You can't control how others will deal with your news.

SPECIAL SITUATIONS

People You May Have Exposed to HIV:

It can be very difficult to disclose your status to sexual partners or people you shared needles with. However, it is very important that they know so they can decide to get tested and, if they test positive, get the health care they need. The Department of Health can tell people you might have exposed, without using your name.

Employers: You may want to tell your employer if your HIV illness or treatments interfere with your job performance. Get a letter from your doctor that explains what you need to do for your health (taking medications, rest periods, etc.). Talk with your boss or personnel director. Tell them you want to continue working, and what changes may be needed in your schedule or workload. Make sure they understand if you want to keep your HIV status confidential.

People with disabilities are protected from job discrimination under the Americans with Disabilities Act (ADA). As long as you can do the essential functions of your job, your employer cannot legally discriminate against you because of your HIV status. When you apply for a new job, employers are not allowed to ask about your health or any disabilities. They can only legally ask if you have any condition that would interfere with essential job functions.

Family Members: It can be difficult to decide whether to tell your parents, children, or other relatives that you are HIV-positive. Many people fear that their relatives will be hurt or angry. Others feel that *not* telling relatives will weaken their relationships and may keep them from getting the emotional support and love that they want. It can be very stressful to keep an important secret from people you are close to.

Family members may want to know how you were exposed to HIV. Decide if or how you will answer questions about how you got infected.

Your relatives may appreciate knowing that you are getting good health care, that you are taking care of yourself, and about your support network.

Health Care Providers: It's your decision whether or not to tell a health care provider that you have HIV. If your providers, including dentists, know you have HIV, they should be able to give you more appropriate health care. All providers should protect themselves from diseases carried in patients' blood. If providers are likely to come in contact with your blood, you can remind them to put gloves on.

Social Contacts: Dating: can be very threatening for people with HIV. Fear of rejection keeps many people from talking about their HIV status. Remember, every situation is different and you don't have to tell everybody. If you aren't going to be in a situation where HIV could be transmitted, there's no need to tell. Sooner or later in a relationship, it will be important to talk about your HIV status. The longer you wait, the more difficult it gets.

An HIV-Positive Child's School: It is best to have good communication about your child's HIV status. Meet with the principal and discuss the school's policy and attitude on HIV. Meet with the nurse and your child's teacher. Be sure to talk about your child's legal right to confidentiality.

GETTING HELP

You can get help with telling others about your HIV status from the counselors at the HIV anonymous test sites, or your HIV case manager.

Reviewed April 13, 2009

HIV Partner Notification

Reaching people who have been exposed to disease, and then providing an appropriate intervention, is at the very core of public health practice. With STDs, the sexual or needle-sharing partner is identified by the infected individual, informed of his/her exposure, and offered services to prevent, cure or manage the infection. The Division of STD Prevention has been using PN as a tool to limit the number of cases of syphilis and gonorrhea for the past 50 years. We have extended this tool to HIV prevention for the past five years.

Reaching infected persons and providing them with counseling and education are critical elements of an HIV prevention program. PN provides for this on an individual and personalized basis, while providing feed-back on the effectiveness of broader, community-based efforts. As a prevention tool, PN can help fine-tune and target the messages for those at greatest risk.

Tenets of Partner Notification

- **PN IS ALWAYS VOLUNTARY** - No one is forced to use the service.
- **STD INTERVIEWERS DO NOT NEED TO KNOW THE CLIENT'S NAME** - we only need the counselor or other professional to assure us we are interviewing an HIV infected person.
- **NOTIFICATION IS ALWAYS FACE-TO-FACE, IN PRIVATE** - this assures to the greatest extent possible that the person being informed is the same as who was named by the partner.
- **PARTNERS ARE NOTIFIED OF POSSIBLE EXPOSURE**, not that they are infected.
- **THE SOURCE OF INFORMATION IS NEVER REVEALED OR ACKNOWLEDGED.**
- **NO RECORDS ARE KEPT ON HIV-INFECTED PEOPLE USING PN** - notes kept by the STD interviewer with names of partners are shredded and burned after notification is performed.

Advantages of PN for the HIV-Infected Person

- safety - many HIV-infected people, particularly women, fear the possibility of emotional or physical abuse. PN provides a safe way to reach partners and minimize risk of harm to the infected person.
- selective notification - an infected person who fears for his/her safety from a particular partner need not name that person, but there may be other partners who could be named without the same concern for safety.
- empowerment - the HIV-infected person is taking an active role in their own care and in the care of those important to them.

Advantages of HIV-PN for Partners

- Partners are informed of risks of which they may not be aware.
- HIV-PN provides personalized education to those at highest risk of infection, i.e., partners of HIV-infected people, with advice on how to continue expressing their sexuality while reducing future risks of exposure and infection.
- Partners are informed of risks to which they may be exposing other partners.
- Partners are offered counseling/medical care/social services to help determine whether they're infected and to help cope with such news - thus, HIV-PN is a gateway to services for those at highest risk of infection.

Protecting the Infected Person

- The STD interviewer does not need to know the infected person's name; the person notifying the partner(s) may not be the one who interviewed the infected person, so there's little chance of inadvertently providing any identifying clues.
- Pronouns (he, she) regarding the infected person are avoided.
- Partners are directed away from dwelling on "Who named me?" and focus instead on learning about HIV and the need to deal with the possibility of being infected.
- Partners are informed only that the person naming them was a contact during the past 10 years.

To Obtain Services or Ask Questions

PN notification services are offered through anyone who works with HIV-infected people, e.g., clinicians, counselors, social workers, etc. The provider can call the STD Prevention Division whenever their client decides to use the service and can arrange a meeting between the client and the STD representative. By working through the provider, the client's identity is not divulged and the STD representative will have the provider's assurance that the person requesting PN services is actually HIV-infected. This protects against false notifications perpetrated against other people.

Call the Division of STD Prevention to receive further information.

Greater Boston: (617) 983-6940

This information is provided by [Communicable Disease Control](#) within the [Department of Public Health](#).

http://www.mass.gov/?pageID=eohhs2terminal&L=6&L0=Home&L1=Consumer&L2=Prevention+and+Wellness&L3=Disease+Prevention&L4=Sexually+Transmitted+Diseases&L5=Partner+Services&sid=Eeohhs2&b=terminalcontent&f=dph_cdc_c_std_partner_notification&csid=Eeohhs2

Massachusetts

Introduction and Table of Contents

January 27, 2009

To the Reader:

The *Compendium of State HIV Testing Laws* describes key state HIV testing laws and policies. Each state's HIV testing laws are unique and many have undergone revision or supplementation since the release of the [CDC's 2006 HIV testing recommendations](#). The *Compendium* is designed to help clinicians understand HIV testing laws and to implement sound HIV testing policies. It should not, however, be used as an official legal document.

The NCCC provides clinical consultation for healthcare providers as part of the HRSA [AIDS Education and Training Centers](#) program. Clinicians with questions about HIV testing are encouraged to call the **National HIV Telephone Consultation Service (Warmline)** at **(800) 933-3413**. The Warmline also provides advice on HIV management, including antiretroviral treatment. Other NCCC consultation services include: the National Clinicians' Post-Exposure Prophylaxis Hotline (**PEPline**) at **(888) 448-4911** for advice on managing occupational exposures to HIV and hepatitis; and the National Perinatal Consultation and Referral Service (**Perinatal HIV Hotline**) at **(888) 448-8765** for consultation on preventing mother-to-child transmission of HIV.

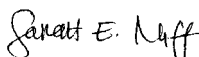
We update the *Compendium* periodically, but it is beyond the scope of the project to perform ongoing verification of every section frequently. We encourage readers to send comments, corrections, and updates (with citations when possible) to Sarah Neff at neffs@nccc.ucsf.edu.

Thank you,



Ronald H. Goldschmidt, MD
Director

&



Sarah E. Neff, MPH
Director of Research and Evaluation

National HIV/AIDS Clinicians' Consultation Center (NCCC)
San Francisco General Hospital
University of California, San Francisco

The Warmline, PEPline, and Perinatal Hotline are part of the National HIV/AIDS Clinicians' Consultation Center (NCCC) based at San Francisco General Hospital/ UCSF. The NCCC is a component of the **AIDS Education and Training Centers (AETC) Program** funded by the Ryan White CARE Act of the **Health Resources and Services Administration (HRSA)** HIV/AIDS Bureau in partnership with the **Centers for Disease Control and Prevention (CDC)**.

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Definitions and Helpful Resources

January 27, 2009

Definitions Commonly Used Nationally

- **Anonymous Testing** – Patient's name is not recorded with test results.
- **Confidential** – Patient's name is recorded with test results.
- **HIV Prevention Counseling** – Refers to an interactive process of assessing risk, recognizing specific behaviors that increase the risk for acquiring or transmitting HIV and developing a plan to take specific steps to reduce risks.¹
 - **Pre-test counseling** can include: (1) discussing HIV, risk factors and prevention methods; (2) explaining the meaning of positive and negative test results and their implications; (3) assessing the patient's personal and social supports; (4) determining the patient's readiness to cope with test results; (5) discussing disclosure of test results to others; and (6) advising the patient if reporting positive test results to health authorities is required.
 - **Post-test counseling** can include: (1) informing the patient of the results and meaning of the test results; (2) providing education about avoiding risks of sexual and injection drug exposures; and, for patients who test positive, (3) assessing the impact of test results for the patient and family; (3) explaining treatment options; (4) discussing partner counseling and disclosure of test results to others; and (5) initiating a support and treatment plan.
- **General Consent** – Consent for HIV screening is included in the general medical consent.
- **HIV** – Human Immunodeficiency Virus.
- **Informed Consent** – A process of communication between patient and provider through which an informed patient can choose whether to undergo HIV testing or decline to do so. Elements of informed consent typically include providing oral or written information regarding HIV, the risks and benefits of testing, the implications of HIV test results, how test results will be communicated, and the opportunity to ask questions.¹
- **Name-based reporting** – Cases are reported by patient name (required in all states except HI and VT).
- **Opt-in** – Patients typically are provided pre-HIV test counseling and must consent specifically to an HIV-antibody test, either orally or in writing.²
- **Opt-out** – Performing HIV screening after notifying the patient that: the test will be performed; and the patient may elect to decline or defer testing. Assent is inferred unless the patient declines testing.¹
- **Routine Testing** – HIV screening that is performed routinely during health-care encounters.
- **Rapid Testing** – Testing with any of the six FDA-approved rapid HIV tests that produce results in 30 minutes or less.³
- **Specific Consent** – Consent for the HIV screening is separate from the general medical consent.

Helpful Resources

CDC Recommendations and Guidelines: <http://www.cdc.gov/hiv/topics/testing/guideline.htm>

Emergency Department Implementation Guide: <http://edhivtestguide.org/>

Prenatal HIV Testing Website: <http://www.cdc.gov/hiv/topics/perinatal/1test2lives/>

For questions or comments about the compendium, contact NCCC: NCCCTemp@nccc.ucsf.edu

Clinicians with questions about HIV testing can call the Warmline at 800-933-3413.

¹ Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings. MMWR Recomm Rep. 2006 Sep 22;55(RR-14):1-17; quiz CE1-4. <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm>

² <http://www.cdc.gov/mmwr/PDF/wk/mm5145.pdf>

³ <http://www.cdc.gov/hiv/topics/testing/resources/factsheets/rt-lab.htm>

Massachusetts

A Quick Reference Guide for Clinicians to Massachusetts HIV Testing Laws

January 27, 2009

This Quick Reference Guide for clinicians is a summary of relevant Massachusetts state HIV testing laws. Note that if a section in this Quick Reference Guide reads “no specific provisions were found,” provisions actually might exist for this topic within the state’s statutes, codes, or rules and regulations, but probably are not essential to clinicians.

For a more complete synopsis of Massachusetts HIV testing laws, please refer to the section of the Compendium that follows this Quick Reference Guide.

Informed Consent

- Specific informed consent required; must be in writing (see *State Policies Relating to HIV Testing, 2009*, below, for exceptions).

Counseling

- Counseling of all HIV/AIDS patients to modify high-risk behavior is required.

Provisos of Testing

- **Anonymous**
 - Anonymous testing is available at designated anonymous testing sites.
- **Rapid**
 - No specific provisions regarding rapid testing were found.
- **Routine**
 - No specific provisions regarding routine testing were found.

Disclosure

- No specific provisions regarding the notification of partners or contacts were found.

Minor/Adolescent Testing

- Minors may consent to venereal disease testing and treatment, HIV not explicitly included.
- Physicians may, but are not required to, notify the parents of the HIV test result.

Massachusetts

Perinatal Quick Reference Guide:

A Guide to Massachusetts Perinatal HIV Testing Laws for Clinicians

January 27, 2009

This Perinatal Quick Reference Guide for clinicians is a summary of relevant Massachusetts perinatal state HIV testing laws. Note that if a section in this Quick Reference Guide reads “no specific provisions were found,” provisions actually might exist for this topic within the state’s statutes, codes, or rules and regulations, but probably are not essential to clinicians.

For a more complete synopsis of Massachusetts HIV testing laws, please refer to the corresponding section of the *State HIV Testing Laws Compendium* (www.nccc.ucsf.edu), “Testing of pregnant women and/or newborns.”

Prenatal

- **Initial visit**
 - No specific provisions regarding initial visit prenatal testing were found.
- **Third trimester**
 - No specific provisions regarding third trimester prenatal testing were found.

Labor & Delivery

- No specific provisions regarding labor & delivery testing were found.

Neonatal

- No specific provisions regarding neonatal testing were found.

Other

- N/A

Massachusetts

State Policies Relating to HIV Testing, 2009

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General Laws of Massachusetts [MGL]

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Title 105: Department of Public Health..... Pages 8-11

	Policy Category	Type	Section Code(s)
RESTRICTIONS/ MANDATES	Restrictions on use of HIV test	Testing prohibited for employment/hiring purposes at health care facilities	16 MGL c. 111, § 70F
	Mandatory testing within the criminal justice system	Correctional institutions must check for presence of venereal diseases of each inmate incarcerated for 30 days or more	18 MGL § 16
	Mandatory testing outside of the criminal justice system	No related laws found	
PRE-TESTING	Mandatory offering of HIV/AIDS information and/or testing	Education of individuals receiving counseling/treatment in drug rehabilitation treatment programs	105 CMR 300.300
		Education of those receiving counseling/treatment at an STD clinic	105 CMR 300.300
		Education of those receiving Family planning/prenatal services	105 CMR 300.300
		Educational materials given to all individuals applying for a certificate of intention of marriage	105 CMR 300.300
	Informed consent	Specific informed consent required – written	16 MGL c. 111, § 70F
		Consent of exam and treatment by parent of a minor may be overlooked in an emergency	16 MGL § 12F
	Counseling requirements	HIV/AIDS cases shall receive counseling to modify sexual/ high-risk behavior	105 CMR 300.200

	Anonymous testing	Anonymous (at anonymous testing sites) and confidential testing available	16 MGL c. 111, § 70F 16 MGL c. 111, § 117 MA Dept. of Health
POST-TESTING	Disclosure/confidentiality	HIV reports confidential	16 MGL c. 111, § 70F 105 CMR 300.120
		Partner notification Disease Intervention Specialists	105 CMR 340.300
	Reporting	Name-based reporting	105 CMR 300.180
OTHER	Testing of pregnant women and/or newborns	Prenatal testing not required (Clinical Advisory sent to health care providers recommending that all women be offered testing in the first trimester of pregnancy)	105 CMR 300.300
	Testing of minors/adolescents	Minors may consent to treatment for venereal disease	16 MGL c. 111, § 117 16 MGL c. 111, § 12F
		Physician may, but is not required to, notify parents or guardians	16 MGL § 12
	Rapid HIV testing	DPH issued written guidelines in October 2005	105 CMR 300.180 (B), (C)
	Training and education of health care providers	No related laws found	

Recommended Resources**The General Laws of Massachusetts**

<http://www.mass.gov/legis/laws/mgl/>

Massachusetts State Legislature

<http://www.mass.gov/legis/>

Code of Massachusetts Regulations – Reportable Diseases

<http://www.mass.gov/Eeohhs2/docs/dph/regs/105cmr300.pdf>

Massachusetts Department of Public Health

<http://www.mass.gov/dph/>

Massachusetts HIV-AIDS Bureau

http://www.mass.gov/?pageID=eohhs2terminal&&L=5&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=Department+of+Public+Health&L4=Programs+and+Services+A+-+J&sid=Eeohhs2&b=terminalcontent&f=dph_aids_g_aids_landing&csid=Eeohhs2

Massachusetts HIV/AIDS Surveillance Program

<http://www.mass.gov/dph/cdc/aids/aidsprog.htm>

Massachusetts DPH – Reportable Diseases

http://www.mass.gov/dph/cdc/surveillance/reporting_and_surveillance.htm

HIV Reporting in Massachusetts for Health Care Providers

The Massachusetts Department of Public Health (MDPH) is changing how cases of HIV infection must be reported. Starting January 1, 2007 all cases of HIV infection will be reported by name. AIDS reporting, which has always been by name, will remain the same.

- Starting January 1, 2007, HIV infection cases must be reported by name to the Massachusetts HIV/AIDS Surveillance Program at the MDPH. This is the same way that AIDS cases have been reported to MDPH since 1983. Although our previous name-based code system was performing well, the U.S. Centers for Disease Control and Prevention (CDC) now require name reporting. Federal funding for Massachusetts will be based on reported cases of AIDS and HIV infection, but CDC will count only those cases that are reported to MDPH by name. No names are reported to the federal government.
- All patients diagnosed with HIV infection who are receiving medical care at your facility should be reported by name starting January 1, 2007. If individuals currently in care have been previously reported using the code, the Department expects these individuals to be re-reported by name prior to December 31, 2007.
- This reporting change also serves as a reminder to review your facility's current HIV testing and medical care consent forms to be certain they are accurate about reporting by name to MDPH. A new consent to care form may need to be signed if the previous consent to care stated that the patient's name would not be reported to DPH.
- State regulations (105 CMR 300) identify AIDS and HIV as reportable diseases and mandate that physicians and other health care providers report HIV and AIDS cases which they diagnose. Because persons with HIV infection often receive treatment from several of these entities at the same time, the primary medical care provider and/or the facility where care is provided are considered the principal source of HIV case reports. Facilities with large HIV case loads should develop a coordinated reporting plan and designate an individual responsible for reporting. Patients who are not Massachusetts residents are not reportable. Likewise, providers and facilities located outside Massachusetts are not subject to the reporting regulation.
- According to state regulation, at no time can the names of people with HIV or AIDS be shared with the federal government, any state or local department, or with any other program in the state health department. All public reports based on these data will remove names or other identifying information, and will group HIV statistics in order to protect individual privacy.

The Department's priority is for all individuals diagnosed with HIV and AIDS to access and maintain quality clinical care. Please make every effort to explain the new reporting system in a manner that preserves the continuity of patient care.

To Obtain Case Report Forms and Other Materials Contact

The Massachusetts HIV/AIDS Surveillance Program
Massachusetts Department of Public Health
(617) 983-6560

Additional information is available at www.mass.gov/dph/aids.

[HIV/AIDS Surveillance](#)

[DPH Provider Information](#)

This information is provided by the [HIV/AIDS Bureau](#) within the [Department of Public Health](#).

http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Provider&L2=Reporting+to+the+State&L3=Diseases+%26+Conditions&L4=HIV%26%2347%3BAIDS&sid=Eeohhs2&b=terminalcontent&f=dph_aids_c_reporting_providers&csid=Eeohhs2

HIV Reporting in Massachusetts for Consumers

What is changing January 1, 2007?

The Massachusetts Department of Public Health (MDPH) is changing how cases of HIV will be reported to the Department. Starting January 1, 2007, all cases of HIV infection will be reported by name instead of by code.

What was the previous reporting system?

Since 1999 HIV cases have been reported using a code that cannot be tracked back to your name. This code is sent to the Massachusetts HIV/AIDS Surveillance Program of the Massachusetts Department of Public Health. Cases of AIDS have been reported by name since 1983. Under no circumstances are names ever reported to the federal government.

Why is the state health department making this change now?

Massachusetts has collected HIV cases by code since 1999 through a system that has worked well. However, federal law is changing the way the state receives funding for HIV/AIDS services. In order to avoid losing millions of dollars in federal funds that support these services, Massachusetts must change its reporting system. This change will also allow the federal government to better understand the HIV/AIDS epidemic at the national level and target funds since HIV cases in addition to AIDS cases will now be counted. No names, however, will be reported to the federal government.

Who reports HIV?

Under state regulation, any diagnosing physician who provides primary care for an individual with HIV infection or AIDS is required by law to report this case to the state health department. Usually this is a person's primary medical care provider. Counseling and testing providers who are not diagnosing physicians are not required to report HIV or AIDS.

How is the reported information used?

Information from HIV and AIDS reporting is used to monitor the HIV/AIDS epidemic and to help plan and carry out programs to prevent HIV infection, treat HIV disease, and provide support for people living with HIV/AIDS. For example, the information is used to:

- Determine the number of people living with HIV/AIDS in Massachusetts
- Plan HIV prevention programs
- Direct funds and other resources for HIV/AIDS programs to areas where they are most needed
- Qualify for funding which is distributed based on the number of cases of HIV/AIDS.

Who is able to see my information?

The names of individuals reported living with HIV are sent directly to the HIV/AIDS Surveillance Program. State regulations prohibit names to be shared with anyone else

Mass.Gov

including the state or federal government. The privacy of reported persons will be strictly protected. This is the same system that has been in place for reporting of individuals living with AIDS since 1983. According to state regulation, at no time can the names of people with HIV or AIDS be shared with the federal government, any state or local department, or with any other program in the state health department. Public reports based on these data never include names or identifying information and group statistics to protect individual privacy.

How will my privacy be protected?

The HIV/AIDS Surveillance Program has developed strong security measures to protect the safety of HIV/AIDS information. Only members of the surveillance program who sign an oath of confidentiality have access to HIV/AIDS data. High level security measures protect these data, including a guarded entrance to the building that houses the data, a locked room holding all HIV/AIDS data that only surveillance program staff may enter, and a surveillance program computer which is protected by password and not connected to the Internet or any other computer network. Since MDPH has collected named AIDS cases since 1983, these data have been securely held without incident.

I have already been reported by code. Will I be reported again by name?

All people living with HIV in Massachusetts who are in medical care will be reported by name starting January 1, 2007. If you were previously reported, your health care provider will send a new report to the health department that adds your name to the earlier report.

Will anonymous HIV testing still be available?

Yes, free, anonymous HIV testing will continue to be available at sites throughout the state. Results of anonymous tests are not reported to the Department by anonymous testing sites.

For a complete listing of testing sites in your area please view the Counseling and Testing area at www.mass.gov/dph/aids.

For More Information

Call	or
Massachusetts HIV/AIDS Surveillance Program	AIDS Action Committee Hotline
Massachusetts Department of Public Health	1-800-235-2331
1-617-983-6560	

For a complete list of Massachusetts resources, go to www.mass.gov/dph/aids.

[HIV Surveillance](#)

This information is provided by the [HIV/AIDS Bureau](#) within the [Department of Public Health](#).

http://www.mass.gov/?pageID=cohhs2terminal&L=6&L0=Home&L1=Consumer&L2=Physical+Health+and+Treatment&L3=Diseases+%26+Conditions&L4=HIV%26%2347%3BAIDS&L5=HIV%26%2347%3BAIDS+Reporting&sid=Ecohhs2&b=terminalcontent&f=dph_aids_c_reporting_nonproviders&csid=Ecohhs2

Rights and Responsibilities: Children and Legal Issues for Minors

I'm under 18 years old. What's different for me?

If you are under 18 and test positive for HIV, you or your doctor should contact:

- **Greater Lawrence Family Health Center**
34 Haverhill St., Lawrence, MA 01841
(978) 686-0090 / www.glfhc.org
- **Lowell Community Health Center**
585 Merrimack St., Lowell, MA 01854
(978) 937-9700 / www.lchealth.org
- **Children's Hospital Boston, Infectious Diseases Program**
300 Longwood Ave., Boston, MA 02115
(617) 919-2900 / www.childrenshospital.org
- **MGH Chelsea Health Center, HIV Department**
151 Everett St., Chelsea, MA 02150
(617) 887-4330
Spanish spoken.

Neither you nor your doctor has to tell your parents at this time. If you are worried that telling your parent or guardian that you have HIV will put you in danger at home, talk to your doctor, a case manager, or contact: **Domestic Violence SafeLink** at (800) 785-2020; TTY: (877) 521-2601.

In addition, the **SAFVE Program at Lowell Community Health Center** also offers support and assistance; the agency can be reached at (978) 937-9700 or (978) 441-1700.

If I have children do they need to be tested?

It's very hard and frightening to think that your child might be HIV positive. Whether or not your children need to be tested for HIV depends on a number of different things, including your children's ages and at what point you were exposed to HIV. Talk to your HIV doctor about whether your children may have been infected and whether they should be tested. The doctor can help you figure out options to get the test done and any support services you may need. Even if you think your child was probably not exposed to HIV, you may still choose to get them tested for peace of mind.

Questions & Answers (Accurate as of January 01, 2005)

<http://www.glad.org/rights/massachusetts/c/hiv-testing-and-privacy-in-massachusetts/>

Minors and Informed Consent

Can minors give informed consent?

Under Massachusetts law, minors (persons under the age of 18) are generally considered to lack the legal capacity to consent to medical treatment. However, given the importance of making HIV testing available to adolescents, there are two sources of law that authorize a minor to consent to medical treatment or testing, such as an HIV test, without the consent of a parent or legal guardian.

Both lawmakers and the courts have acknowledged the importance of minors being able to make independent decisions about their health care in certain circumstances.

What laws govern minors and informed consent?

Massachusetts law¹⁴ provides that a minor may give consent to medical or dental care if he or she is:

- Married, widowed or divorced;
- A parent of a child;
- A member of the armed forces;
- Pregnant or believes herself to be pregnant;
- Living separate and apart from his parents or legal guardian and is managing his own financial affairs; or
- “Reasonably believes himself to be suffering from or to have come in contact with any disease defined as dangerous to the public health [by the Department of Public Health] pursuant to Chapter 111.” The list of such diseases includes HIV. The minor may only consent to care relating to the diagnosis or treatment of that disease.

A physician or dentist is not liable for performing a procedure without informed consent if the physician relied in good faith on the patient’s statement that he or she is over 18 years of age.

Medical or dental records and other information about a minor who consents to treatment are confidential and may not be released except with the consent of the minor or upon a judicial order. The statute, however, creates an exception to the confidentiality of a minor’s medical information when the physician or dentist “reasonably believes” that the minor’s condition is “so serious that his life or limb is endangered.” In this case, the physician or dentist must notify the parents or legal guardian of the minor’s condition.

What do the courts say about minors and informed consent?

In addition to the provisions of Chapter 112, Section 12F, courts have held that minors can provide informed consent for medical treatment if they are sufficiently intelligent and mature to understand the risks and benefits of treatment, regardless of financial independence or living situation. This is known as the “mature minor” rule.

Courts will typically assess the minor’s age, experience, education, training, judgment, conduct and demeanor to assess whether under a particular circumstance the minor has the ability to appreciate the nature and consequences of treatment.

Courts will give particular weight to how close the person is to majority (18 years of age), the benefits of the treatment or test (which are significant in the case of an HIV antibody test), and the complexity of the treatment or test.

¹⁴ M.G.L. c. 112, § 12F

A Note to Teens Who Have Just Learned They Are HIV-Positive

1994

This is an excerpt from There is Hope: Learning to Live with HIV, 2nd Edition, written by Janice Ferri, with Richard R. Roose and Jill Schwendeman, a publication of The HIV Coalition.

If you're a teenager who's just learned you're HIV-positive, you may face some stress that adults and children don't have. You aren't little anymore, but you're not quite an adult yet, either. You may not be very comfortable with your body, your family, your friends, or your sexuality. There can be a lot of pressure, both from inside yourself and from people around you. It can be hard to relate to people you've just met, and to those who've known you a long time but aren't quite sure how to approach you now.

The news that you're HIV-positive can feel like one big thing too many on your plate. It's very common for young people who learn they are infected to try and make the news "go away" by ignoring it. It can be good not to let something get to you when you need to be busy living your life. Unfortunately, ignoring HIV can leave you feeling lonely and depressed; it can also keep you from getting medical attention that can help you live longer.

A key thing to remember is, you are not alone! There are many other people your age who are going through the same thing. Telling a friend who will respect your privacy can be a big relief. If you're not ready to tell anyone you know personally, try talking anonymously to someone at a hotline or HIV service agency, at the numbers listed throughout this book. There also are support groups out there strictly for teens or people in their 20's. They're a great place to get information, vent strong emotions, and make new friends.

It may not be as comfortable to approach an adult. However, if you do, you could be very glad you did. An older person can be your advocate, or help you solve practical problems by lending you money, giving you a ride or a place to stay, helping you find services that cater to youth, or just being there when you need to talk.

The most important thing is finding someone to hook up with, at least for basic medical care. If you're worried about the word getting around, make your contact by phone instead of in person. Make sure and ask whether you can be assured of confidentiality. Your life and future are very precious. Do something good for yourself by making that first connection.

This article was provided by HIV Coalition (HIVCO). You can find this article online by typing this address into your Web browser: <http://www.thebody.com/content/art12754.html>

General Disclaimer: The Body is designed for educational purposes only and is not engaged in rendering medical advice or professional services. The information provided through The Body should not be used for diagnosing or treating a health problem or a disease. It is not a substitute for professional care. If you have or suspect you may have a health problem, consult your health care provider.

Rights and Responsibilities: Legal Issues for Non-Citizens

What are the legal aspects of being HIV positive for immigrants? Will I be deported?

The U.S. Department of Homeland Security (DHS) can keep HIV positive noncitizens out of the United States, keep you from coming back in if you leave, or keep you from changing your immigration status (to become a permanent resident). DHS can also remove noncitizens if you entered without government permission. However, DHS can choose to waive (set aside) some of these rules. To apply for and receive a waiver you must in be medical care and carefully follow all treatment recommendations. DHS will request records of all this and will ask your doctor to rate the level of health risk a person is to citizens of the United States. If you have questions about your citizenship status or about applying for a waiver, contact an immigration expert. The following non-profit immigration agencies can help guide you:

- **Greater Lawrence Family Health Center**
34 Haverhill St., Lawrence, MA 01841
(978) 686-0090 / www.glfhc.org
- **Lowell Community Health Center**
585 Merrimack St., Lowell, MA 01854
(978) 937-9700 / www.lchealth.org

More immigration resources:

- **Latin American Health Institute (LHI)**
9 Central St., Ste. 400, Lowell, MA 01852
(978) 459-3366 / www.lhi.org
Serves Latino MSM, IDU. Spanish spoken.
- **Team Coordinating Agency**
76 Winter St., Haverhill, MA 01830
(978) 373-1181 ext. 21
- **Neighborhood Legal Services**
www.neighborhoodlaw.org
 - ❑ 37 Friend St., Lynn, MA 01902
(781) 599-7730
 - ❑ 170 Common St., Ste. 300, Lawrence, MA 01840
(978) 686-6900Spanish, Khmer, Russian, and Vietnamese interpreters available.

Basic rules of working with noncitizens living with HIV/AIDS

Treat noncitizen, HIV positive clients like you would any other client. Get them the services they need. Assure them that everything they tell you will be kept confidential and that you will not call the Department of Homeland Security. **The difference:** Be aware that being a noncitizen may make it risky for them to get services and do things that a US citizen can do without risk.

Cultural barriers may make it harder to help noncitizens. Noncitizen clients may not feel comfortable discussing HIV or sexual orientation with anyone, let alone a stranger. Explore ways to ask questions about HIV or sexual orientation that allow clients to be more open and trusting. Some advocates may be homophobic or fear people with HIV/AIDS. Make sure the immigration advocates working with your clients are comfortable dealing with HIV/AIDS and sexual orientation or transgender issues. Clients may not realize you will not turn them over to DHS. Assure your clients that you do not work for DHS and will keep everything they tell you confidential. Clients may not be able to communicate their fears or concerns in English. Interview them in a language they speak fluently, using an interpreter who is not related to them.

Ask them whether they have explored all routes to immigration status, including asylum petitions based on persecution because of HIV status or sexual orientation.

Never tell clients to go to the Department of Homeland Security by themselves. No one should speak to DHS or go to DHS before talking to an immigration law expert. If noncitizens go to DHS by themselves, DHS may arrest them and remove them from the United States before they have the chance to talk to a lawyer.

Noncitizens with HIV should not contact DHS without first discussing their options with an immigration advocate.

Inform clients that DHS may arrest and detain them. Although it is unlikely that DHS will make arresting HIV positive noncitizens a high priority, it will remove noncitizens if they entered the country without permission. DHS may also try to deny returning noncitizens with legal status from reentering the United States if the agent suspects the noncitizens are HIV positive. Tell your client to be prepared.

Being Prepared

- Carry copies of any immigration documents you have at all times.
- Carry with you the name and phone number of an immigration advocate who will take your call from DHS detention.
- Before traveling outside the United States, check with an immigration advocate about whether you will be able to get back in.
- If DHS detains you, demand your right to call your immigration advocate.
- Never sign any DHS documents without first talking to an immigration advocate.
- If DHS turns you back from the border, call your immigration advocate right away. Unless you challenge the DHS decision, DHS may criminally prosecute you if you enter the United States again.

Work with local immigration advocates. Although this manual will give you some basic information about immigration status and HIV, you should only use this information to explore your clients' options. Do not tell your clients you *know* what their immigration status is or how they can change that status. The consequences of providing inaccurate advice can be severe. The severe consequences of the immigration law mean it is very important that you establish a working relationship with a local immigrants' rights agency or practitioner. *Your noncitizen clients always should carry with them the name and telephone number of an immigration advocate or agency that they can call from DHS detention.*

Many immigration advocates do not know how HIV can affect immigration status and may never have had a client with HIV. They may lack sensitivity to clients with HIV and be unaware of all the options available to noncitizens with HIV. After reading this manual, *you may know more than local immigration advocates about HIV and immigration.* Share this manual with the immigration advocates you consult. If you do not know immigration advocates in your area who are sensitive to HIV/AIDS issues and know the options for noncitizens with HIV, call the National Immigration Project of the National Lawyers Guild (see back cover). Be aware that some fraudulent immigration practitioners prey on the hopes and desperation of noncitizens.

Tell noncitizens to talk to an immigration expert before they leave the United States. Anyone who is not a US citizen may be prevented from coming back into the United States if a DHS border official suspects he or she has HIV. This includes some lawful permanent residents

(people with "green cards") and applicants for lawful permanent residence who go abroad to pick up their visas. Some noncitizens - whether or not they are HIV positive - who have been in the United States without Government permission also may be permanently barred from reentering or gaining legal status in the United States. See the section on *Travelers with HIV* for more information.

Inform all noncitizens that they should never falsely claim to be a US citizen. False claims to US citizenship can lead to a variety of problems, including deportation or removal, the inability to ever legalize one's status, or even prosecution. If you or your client believes that he or she has already made a false claim to US citizenship, consult an immigration legal advocate. There is one extremely limited exception for children of citizens who were lawful permanent residents and reasonably believed that they also were citizens at the time they claimed to be a citizen. There may also be other considerations that would help your client.

Every noncitizen should get counseling on HIV that assures confidentiality or anonymity or both. Before undergoing a DHS medical examination, a noncitizen should get tested at a local clinic. Most testing centers will ensure results are confidential, meaning they will share them only with the person taking the test. Despite this assurance, however, some states require doctors and medical practitioners to turn over the names of people who test positive for HIV or those with an AIDS diagnosis to state or federal agencies. If this occurs in your state, noncitizens should only take tests anonymously. Call the National AIDS Hotline (1-800-342-2437) or contact a local AIDS office or health department to find out where your client can get an anonymous or confidential HIV antibody test.

Work to ensure noncitizens get necessary public benefits. Under the 1996 federal welfare reform law, state and local governments decide who receives many public assistance benefits. Work with other state advocates to ensure state and local public assistance is available to all your noncitizen clients, regardless of immigration status. Since Congress eliminated numerous forms of federal public assistance for noncitizens, this local support becomes vital, both for individual clients and for public health concerns in general. *Your efforts to convince state and local governments that noncitizens should receive public assistance are crucial.*

Be aware that some people administering public benefits hold racist, homophobic, and/or anti-immigrant ideas and stereotypes. Before sending noncitizens to another agency, including an HIV/AIDS agency, find out that agency's policies on reporting people to DHS. Ask them if they believe they can help noncitizens and if they feel they must report undocumented immigrants to DHS. Although many local benefits administrators are not required to report people they suspect are undocumented to DHS, many may believe think they are. Moreover, unsympathetic service providers may call DHS if they suspect a noncitizen is undocumented or HIV positive or has AIDS. Sympathetic benefits providers, in contrast, may wish to help challenge the legality, morality, and practicality of reporting applicants to DHS. It is unlikely noncitizens in the United States will be removed for being HIV positive, but they could end up in immigration court if DHS learns of their HIV status. Make sure you do not refer clients to service providers who will report them to DHS. **The best you can do for your clients is to help them understand their choices, and provide them with whatever support you can find.**



Lambda
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Lambda Legal is a national organization committed to achieving full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people, and those with HIV through impact litigation, education and public policy work.

Lambda Legal's publications are made possible through donations from people like you. To make a difference today visit www.lambdalegal.org.

Lambda Legal Defense & Education Fund
www.lambdalegal.org

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120 Wall Street, Suite 1500
New York, NY 10005-3904
tel. 212-809-8585
fax 212-809-0055

Western Regional Office
3325 Wilshire Boulevard, Suite 1300
Los Angeles, CA 90010-1729
tel. 213-382-7600
fax 213-351-6050

Midwest Regional Office
11 East Adams, Suite 1008
Chicago, IL 60603-6303
tel. 312-663-4413
fax 312-663-4307

Southern Regional Office
1447 Peachtree Street, NE, Suite 1004
Atlanta, GA 30309-3027
tel. 404-897-1880
fax 404-897-1884

South Central Regional Office
3500 Oak Lawn Avenue, Suite 500
Dallas, TX 75219-6722
tel. 214-219-8585
fax 214-219-4455

corbis.

HIV

& Immigration:

THE BASICS



IMMIGRATION EQUALITY

A PUBLICATION BY LAMBDA LEGAL AND IMMIGRATION EQUALITY

HIV-POSITIVE PEOPLE from other countries are almost completely banned from entering the United States. Fortunately, with special permission (known as an HIV waiver), you can get around this severe policy.

This kit provides an overview of the basic options available if you are an immigrant or a visitor to the U.S. who is living with HIV. Use this kit to learn about your rights, and then contact a good immigration attorney using the resources provided.

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Visiting the United States

If you hold a nonimmigrant visa (because you plan to stay in the U.S. for a limited period of time), immigration officials have the power to require you to take an HIV test only if they have any reason to suspect that you are HIV-positive.

While you are traveling (on a plane, for example), you will be asked to fill out a Form I-94, which asks if you have a communicable disease of public significance. If you don't know your HIV status, you can truthfully answer no to this question, but knowing your HIV status can be important to your overall health care.



When you arrive in the U.S., you will be questioned — an immigration officer will look at your Form I-94, ask you questions about why you are coming to the U.S. and make sure that your reason for coming matches the kind of visa you have in your passport.

Later, a U.S. customs official will inspect your luggage. If HIV-related medication is found in your luggage, the customs official may notify an immigration official, and you may be sent home unless you were granted an HIV waiver. It is not legal to carry unmarked prescription medication, so carrying unlabeled medication in your luggage could also pose a problem.

If an immigration official requires you to take an HIV test, a doctor selected by the U.S. Citizenship and Immigration Services (USCIS) must administer the test.

The doctor chosen by the USCIS may not be sensitive when disclosing your test results.

Are You Eligible for an HIV Waiver?

If you are applying for a nonimmigrant visa, and you are HIV-positive, you may qualify for an HIV waiver (special permission to enter the U.S.) if you plan to stay in the U.S. for 30 days or less and you can show that you:

1. are currently asymptomatic;
2. are able to cover your medical bills if you become sick while in the U.S.; and
3. don't pose a danger to public health in the U.S.

VISA BASICS

Gaining entry into the United States is a two-step process.

First, you must apply for a visa, a stamp in your passport that allows you to board a plane or take other transportation to the U.S. You can apply for a visa from the U.S. consulate in your country. You will also need a passport.

Second, a U.S. immigration official must admit you into the country at the airport or at a border. A visa does not guarantee that you will be allowed to enter the U.S. — that permission is granted by U.S. immigration officials.

Citizens of certain countries (mostly in Western Europe) who want to visit the U.S. for a short period of time **and who can present a machine-readable passport** do not need a visa. These countries are known as visa-waiver countries. The U.S. began enforcing the machine-readable-passport requirement for citizens of visa-waiver countries on October 26, 2004. If you do not have a machine-readable passport, you will need a visa to enter the U.S., regardless of whether you are from a visa-waiver country.

For more information about whether your country is a visa-waiver country and what makes a passport machine readable, check with the

OR

You plan to visit the U.S. for a “designated event” (for example, an AIDS conference or the Gay Games).

Immigrating to the United States

You can apply for legal permanent residence at the U.S. consulate in your country (“consular processing”) or from within the U.S. (“adjustment of status”). The rules governing who can apply for adjustment of status are complex, and if you are in the U.S., you will need to consult with an attorney to determine whether you are eligible.

U.S. consulate in your country or visit http://www.travel.state.gov/visa/tempvisitors_novisa_waiver.html. Your country's passport-issuing agency may be able to help you determine if your existing passport is machine readable or tell you how to apply for a new passport if necessary.

There are two types of visas — immigrant and nonimmigrant:

☐ An immigrant visa — also known as a green card or legal permanent residence — allows you to stay in the U.S. permanently, subject to certain conditions.

☐ A nonimmigrant visa allows you to stay in the U.S. for a limited period of time and for a specific reason (for example, to attend school or to be a tourist).

The State Department is the U.S. government agency responsible for administering the laws and regulations for people who apply for visas from outside the U.S.

The Department of Homeland Security is the U.S. government agency responsible for administering the laws and regulations regarding non-U.S. citizens entering and remaining in the U.S.

If you are HIV-positive, your application for permanent immigration will be denied unless you are given an HIV waiver.

The likelihood of obtaining an HIV waiver is much lower through consular processing than through adjustment of status, in part because it is very difficult to secure private health insurance in the U.S. from abroad.

U.S. law requires anyone interested in immigrating to the country to take an HIV test, so you should learn your HIV status before starting the immigration process. If you are HIV-positive, consult an immigration lawyer familiar with HIV issues before applying for permanent immigration status. (See the resource section at the end of this booklet for suggestions.)

HIV waivers are available only for applicants with specific established family relationships with U.S. citizens or permanent residents.

You can apply for an HIV waiver if you are the legally married husband or wife, the unmarried son or daughter, or the unmarried lawfully adopted child (under 18) of a U.S. citizen or permanent resident. You can also apply if you have a son or daughter who is a U.S. citizen or permanent resident.

To obtain a waiver, you must also file a special application with the signatures of your treating physician and the local or state health officer to show that:

—The danger to the public health of the U.S. created by your admission is minimal (generally a letter from your treating physician stating that your health is stable and that you have received counseling about how HIV is spread).

—The possibility of the spread of infection created by your admission is minimal (generally a sworn statement from you explaining that you have received counseling, you understand how HIV is spread and you do not engage in high-risk behavior).

—No U.S. government agency will incur an expense because of your admission, without its consent (generally proof that you have private health insurance that will cover the cost of your HIV treatment).

Even if you have an employer who wants to sponsor you for legal permanent residence, or if you win the green card lottery (where applicants are randomly selected for a visa), you cannot get a green card if you are HIV-positive unless you have a relative who qualifies you for a waiver.

Although all applicants for legal permanent residence must show that they can support themselves without government assistance, applicants with HIV face extra scrutiny and must convince the USCIS that they can support themselves.

Applying for Asylum

If you fear persecution in your home country because of your HIV status, you may be eligible for asylum in the U.S. To find out more about what is considered persecution, consult an immigration lawyer familiar with HIV issues. (See the resource section for suggestions.)

All asylum applications are completely confidential, meaning your home country will not be told about your application.

To claim asylum, you must be physically present in the U.S. or at an airport or border crossing.

You must prove that you are unable or unwilling to return to your home country due to past persecution or well-founded fears of future persecution due to your HIV status.

You can claim asylum on more than one ground at the same time, for example, fear of persecution because you are gay and because you are HIV-positive. You must be prepared to show that in your home country people with HIV are targeted as a group and subject to persecution. Persecution is different from discrimination or hardship.

You must file an application for asylum within one year of your last entry into the U.S. or show an extraordinary reason for missing the deadline. If you have just learned that you are HIV-positive and fear returning to your country as a result, this may qualify you for an exception to the one-year filing deadline.

An application for asylum is considered filed on the date it is received by the USCIS.

Undocumented Applicants

If you are undocumented, you can still apply for asylum. However, information that you provide on the asylum application will be used as evidence to begin removal (formerly known as “deportation”) proceedings if your application for asylum is denied.

If you are granted asylum, you can apply for legal permanent residence one year after your asylum approval. You can then obtain a “humanitarian” HIV waiver and you won’t need to have a relative who is a U.S. citizen or holds a green card to do so.

Contact an immigration attorney with experience handling HIV and asylum cases to assist you.

Becoming a U.S. Citizen

Permanent residents interested in becoming U.S. citizens do not have to take an HIV test. There is no requirement that legal permanent residents applying to naturalize must take a medical exam, nor is there a ban on people who are HIV-positive becoming citizens.

Be sure to speak with an immigration attorney before applying for citizenship. A couple of the issues you will discuss are any length of time you were outside the U.S. while a permanent resident or whether you have a criminal record.

Most applicants (unless they are elderly and have been in the U.S. for a long time) must pass an English test and a civics test. A waiver is available for these tests if your doctor can certify that you have a disability that prevents you from learning the information on the tests. Being HIV-positive alone would not qualify you for the waiver, but having dementia, other neurological problems or severe side effects from your medication might.

If you are approved to become a U.S. citizen (through “naturalization”), you will be required to attend a swearing-in ceremony to complete the process. If you have obtained a medical waiver for the English and civics tests, it is important that your doctor state that you are competent to understand the oath of allegiance to the U.S.

Due to overwhelming numbers of immigrants applying for citizenship and understaffing at the USCIS, in some locations it can take two to three years to become a U.S. citizen.

Once you are a U.S. citizen, it can be much easier to sponsor family members (parents, opposite-sex spouse, children) to get their green card.

Photo courtesy of Corbis

Traveling Outside the United States

If you are HIV-positive, and aren't a U.S. citizen, consult an attorney familiar with HIV and immigration issues before traveling outside the U.S.

Immigration officers have the power to ask all non-U.S. citizens about their HIV status every time they pass through a port of entry (for example, at airports or border crossings).

You may be denied entry to the airport or be kept from crossing the border if an immigration officer finds out that you are HIV-positive.

Traveling with Medication

If HIV-related medication is found in your baggage at the airport, you may be detained and sent back to your country unless you have obtained an HIV waiver. It is not legal to carry unmarked prescription medication, so carrying unlabeled medication in your luggage could also pose a problem.

If you hold a nonimmigrant visa, immigration officials have the power to require that you take an HIV test if they suspect that you are HIV-positive.

Permanent Residents

If HIV-related medication is found in your baggage, it is possible that you will be put through removal proceedings.

Consult an immigration attorney if you are planning to leave the U.S. for more than six months or if you have ever been arrested (even if you did not serve time in jail and even if the arrest happened long ago).



Photo courtesy of Corbis

Taking an HIV Test

Knowing your HIV status is an important part of taking care of your health.

U.S. law does not require health or testing facilities to ask the immigration status of people taking an HIV test. You do not have to tell anyone at a test site if you are undocumented, even if you are asked.

Testing facilities are not required to inform the USCIS of your HIV status. However, most states require that testing facilities report the names of persons who test positive to certain state or federal agencies.

Contact the National HIV/AIDS Hotline (800-342-2437) to get a listing of clinics that offer anonymous testing for HIV in your state.

Anonymous testing is not the same as confidential testing. Anonymous testing guarantees that your results will not be reported to anyone.

Confidential test results may be reported to state agencies, under court orders, etc. Free HIV tests are available throughout the country.

Receiving Medical Assistance

If you hold a nonimmigrant visa you may be able to apply for Emergency Medicaid; each state has its own rules about eligibility and coverage. Contact the national Medicaid hotline (877-267-2323, menu option #5) to obtain information on coverage and phone numbers for state Medicaid offices.

AIDS Drug Assistance Programs (ADAP) in some states will provide medications and services for immigrants, including those who are undocumented. To find out about ADAP coverage in a specific state, visit the AIDS Treatment Data Network's website at www.atdn.org/access/states/index.html.

Resources

Lambda Legal

120 Wall Street, Suite 1500
New York, NY 10005
212-809-8585
www.lambdalegal.org
legalhelpdesk@lambdalegal.org
Lambda Legal is a national organization committed to achieving full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people and those living with HIV through impact litigation, education, and public policy work. During the Help Desk hours, Lambda Legal staff respond directly to members of the community who are seeking legal information and assistance with sexual orientation, gender identity and expression and HIV-related discrimination.

Immigration Equality

350 West 31st Street, Suite 505
New York, NY 10001
212-714-2904
www.immigrationequality.org
info@immigrationequality.org
Immigration Equality, formerly LGITF, addresses the widespread discriminatory impact of immigration laws on the lives of lesbians, gay, bisexual, transgender and HIV-positive individuals through education and outreach, advocacy and the maintenance of a nationwide resource and support network. Immigration Equality provides advice and technical assistance to LGBT and HIV-positive immigrants and their attorneys via email and telephone. Immigration Equality

also operates a pro bono asylum program for LGBT and HIV-positive asylum seekers.

EAST

Center for Civil Rights Legal Clinic

1211 Chestnut Street, Suite 605
Philadelphia, PA 19107
215-731-1447
www.center4civilrights.org
c4crinfo@center4civilrights.org
Provides legal advice to LGBT communities in Pennsylvania. Provides direct representation for low-income LGBT clients.

Gay Men's Health Crisis

119 West 24th Street
New York, NY 10011
212-367-1000 and 800-AIDS-NYC
www.gmhc.org
Provides direct representation to HIV-positive residents in New York City in immigration matters.

Greater Boston Legal Services

197 Friend Street
Boston, MA 02114
617-371-1270
www.gbls.org
Immigration clinic that offers free and low-cost services.

HIV Law Project

161 William Street, 17th Floor
New York, NY 10038
212-577-3001
www.hivlawproject.org
Provides free legal services and advocacy to low-income people living with HIV.

International Gay and Lesbian

Human Rights Commission

350 Fifth Avenue, 34th Floor
New York, NY 10118
212-216-1814
www.ighrc.org
ighrc@ighrc.org
Provides support services to immigrants and their advocates.

Latino Health Institute

95 Berkeley Street
Boston, MA 02116
617-350-6900
www.lhi.org
Provides immigration advice and assistance. Services are free, but there is often a waiting list.

Safe Horizon Immigration Law Project

2 Lafayette Street, 3rd Floor
New York, NY 10007
212-577-7700
www.safehorizon.org
info@safehorizon.org
Provides free and low-cost legal services to immigrants.

Whitman-Walker Clinic

1407 South Street, NW
Washington, DC 20009
202-797-3500
www.wwc.org
wwcinfo@wwc.org
Provides free legal services to people living with HIV.

MIDWEST

Illinois Coalition for Immigrant and

Refugee Rights

36 South Wabash, Suite 1425
Chicago, IL 60603
312-332-7360
www.icirr.org
Provides information and referrals to appropriate legal services.

Legal Assistance Foundation of

Metropolitan Chicago

111 West Jackson Boulevard
Chicago, IL 60604
312-341-1070
www.lafchicago.org
Provides legal advocacy to low-income residents.

Midwest Immigrant and Human

Rights Center

208 South LaSalle Street,
Suite 1818
Chicago, IL 60604
312-660-1370
www.heartland-alliance.org
moreinfo@heartland-alliance.org
Provides immigration assistance, deportation defense and asylum representation to low-income immigrants.

Minnesota AIDS Project

1400 Park Avenue South
Minneapolis, MN 55404
612-341-2060
www.mnmaidsproject.org
info@mnmaidsproject.org
Provides legal services, direct representation and referrals to a network of volunteer attorneys for HIV-related legal matters.

Photo courtesy of Corbis

SOUTH

Florida Immigrant Advocacy Center
3000 Biscayne Boulevard, Suite 400
Miami, FL 33137
305-576-6273
www.flacfla.org
Provides free direct legal services.

SOUTH CENTRAL

AIDS Law of Louisiana, Inc.
144 Elk Place, Suite 1530
New Orleans, LA 70112
504-568-1631 or 800-375-5035
aidslaw@bellsouth.net
Provides free legal services and referrals to a statewide network of cooperating attorneys. Must meet state eligibility.

Human Rights Initiative of North Texas
2501 Oak Lawn Avenue, Suite 850
Dallas, TX 75219
214-855-0520
www.hrionline.org
hriinfo@hrionline.org
Provides free legal representation for those seeking asylum in the U.S. for various reasons. Must meet financial eligibility requirements.

Texas Human Rights Foundation
3400 Montrose, Suite 207
Houston, TX 77006
713-522-0636
www.thrf.org
thrf@thrf.org
Provides education and legal assistance to the LGBT community and people impacted by HIV.

WEST

ACLU of Southern California
1616 West Beverly Boulevard
Los Angeles, CA 90026
213-977-9500
www.aclu-sc.org
Advocates for individual rights and equal justice, and against unwarranted government interference and abuse.

ACLU of Washington
705 Second Avenue, Suite 300
Seattle, WA 98104
206-624-2184
Complaint and Referral Line:
206-624-2180
www.aclu-wa.org
Advocates for individual rights and equal justice, and against unwarranted government interference and abuse.

El Rescate Legal Services
1313 West 8th Street, Suite 200
Los Angeles, CA 90017
213-387-3284
www.elrescate.org
Offers free legal representation and basic civil and immigration rights education.

Immigration Law Project
Los Angeles Gay & Lesbian Center's Legal Clinic
1625 North Schrader Boulevard
Los Angeles, CA 90028-6213
323-993-7670
www.laglc.org/section04/So402.htm
Offers immigration advice and advocacy. No direct legal service.

National Center for Lesbian Rights

Immigration/Asylum Project
870 Market Street, Suite 570
San Francisco, CA 94102
415-392-6257
www.ncnlrights.org/projects/immigration.htm
info@ncnlrights.org

Provides support and information to immigrants. Offers a free legal clinic.

Northwest Immigrant Rights Project
401 Second Avenue South, Suite 407
Seattle, WA 98104
206-464-1519 or 888-201-1012
www.nwjustice.org
njp@nwjustice.org
Provides legal representation and community education to low-income refugees and immigrants.

Additional online resource:

The National Lawyers Guild
"HIV and Immigrants,"
<http://www.nationalimmigrationproject.org/HIV/HIV.htm>.

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Immigration Equality
350 West 31st Street, Suite 505
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info@immigrationequality.org

Immigration Equality (formerly LGIRTF) addresses the widespread discriminatory impact of immigration laws on the lives of lesbian, gay, bisexual, transgender and HIV-positive individuals through education outreach, advocacy and the maintenance of a nationwide resource and support network.

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