

**H
I
V**

and
Confidentiality

YOUR LEGAL RIGHTS

UPDATED JANUARY 2009

published by:



**AIDS Legal Council of Chicago
180 North Michigan Avenue, Suite 2110
Chicago, Illinois 60601
(312) 427.8990**

This is one in a series of booklets published by the AIDS LEGAL COUNCIL OF CHICAGO. All are designed to help you understand **YOUR LEGAL RIGHTS** in Illinois. The booklets in this series are:

HIV and Confidentiality

HIV and Discrimination

HIV and Insurance

HIV and Public Benefits

HIV and Undocumented Immigrants

HIV in the Workplace

HIV: Issues for Families with Children

HIV: Issues for Youth and Young Adults

HIV: Returning to Work

HIV: Wills and Powers of Attorney

All of these booklets are free and available at:

AIDS LEGAL COUNCIL OF CHICAGO

180 N. Michigan Ave., Ste. 2110

Chicago, Illinois 60601

(312) 427.8990

www.aidslegal.com

This guide is intended as an overview of HIV-related Illinois and federal law. As with any legal matter, it is always a good idea to consult an attorney concerning the particular circumstances of your case.

HIV AND CONFIDENTIALITY

| | Page |
|--|------|
| Introduction | 4 |
| 1. Getting an HIV Test | 5 |
| 2. Disclosing HIV Test Results | 8 |
| 3. Confidentiality and Your HIV Status | 12 |
| 4. Other Questions | 15 |

INTRODUCTION

When you tested HIV positive, people may have told you that you were required to tell your boss, your dentist, or your family. If you have a child who is HIV positive, you might have heard that you have to tell the principal of your child's school. None of these statements is true. With very few exceptions, **your HIV status is nobody's business but yours.** In addition, your HIV status is confidential according to Illinois law, which means that almost no one can disclose your HIV status without permission from you.

This booklet is designed to answer your questions about confidentiality. If you have more questions after you're done reading, you can call the AIDS LEGAL COUNCIL OF CHICAGO at **(312) 427.8990**. Someone there will be happy to speak with you.

Chapter One

GETTING AN HIV TEST

1) Under Illinois law, am I required to take an HIV test?

Generally, no. HIV testing is not mandatory for the general public in the state of Illinois. In fact, it is not mandatory in any state.

However, there are a few situations in which people are required to be HIV tested. For example, anyone entering the military must be tested for HIV. Anyone convicted of certain sexual crimes must be tested for HIV.

But for private citizens not involved in the military or the criminal justice system, no law requires an HIV test.

2) If I apply for health insurance, can the insurance company require me to get an HIV test?

Yes. Under Illinois law, it is legal for an insurance company to test you for HIV if you are applying for insurance. Of course, no law says that you have to get that HIV test. But if you refuse to take an HIV test, the insurance company can legally refuse to offer you the insurance policy.

3) Do I have to get an HIV test to apply for a marriage license?

No. There was a law in Illinois in 1986 which required people applying for marriage licenses to submit to HIV tests. But that law was repealed a year later when it became clear that testing all marriage applicants was an enormous waste of time and money.

4) Do I have to get an HIV test if I'm pregnant?

The law says your doctor must *counsel* you about HIV, and the doctor must test you for HIV *unless you refuse*. Once your baby is born, the law says that your doctor is supposed to test your baby for HIV within 48 hours *only if your HIV status is unknown*. So if you refuse to get an HIV test yourself, then your baby will be tested.

5) Can I get an anonymous test?

Yes. You have a right to get an HIV test without giving your name. You can get an anonymous HIV test at most public health clinics.

6) What's the difference between an anonymous HIV test and a confidential HIV test?

An **anonymous** HIV test is one that does not have your name attached to it. Sometimes you will give the person taking the test a code to identify yourself, like a string of numbers. But when you test anonymously, your name should not appear on the test result. No one could use that test result to prove your HIV status.

A **confidential** HIV test **does** have your name on it. But the test result must be kept confidential, in accordance with Illinois law. In other words, the test result with your name on it will end up in your medical records, but no one can see your records without legal authorization.

7) I'm 15 years old. Can I get an HIV test without telling my parents?

Yes. In Illinois, anyone **12 or over** can get an HIV test **without** having to tell their parents or guardians. You don't need anyone's permission to get an HIV test, or a test for any sexually transmitted disease. For more information, see the Council's booklet *HIV: Issues For Youth and Young Adults*.

8) Can a doctor test me for HIV without telling me?

Generally, no. The Illinois AIDS Confidentiality Act says that no physician may order an HIV test without first obtaining the **documented, informed consent** of the test subject. In other words, the laws say that the person testing you for HIV must first ask for your consent, and document the fact that you agreed to have any HIV test. Without that consent, the doctor is not supposed to test you for HIV.

However, there is a big exception to this law. The exception says that if a doctor believes it is necessary to test you for HIV in order to diagnose and treat your symptoms, then he can test you without your consent. The AIDS Legal Council believes this exception is bad public policy. The Council believes that a doctor should **always** get consent from a patient before testing for HIV, so long as the patient is able to consent. Unfortunately, the exception to the law gives physicians permission to test a lot of people for HIV without telling them.

So if you go to the doctor and you do not want an HIV test, make sure to tell your doctor so. It would be a good idea to tell your doctor **in writing** that you don't want an HIV test.

9) Can anyone ever legally test me for HIV against my will?

Yes, but only in a few certain circumstances:

- ◆ If you have been involved in a blood accident with a health care worker, police officer or paramedic.
- ◆ If you are convicted of a sex crime
- ◆ If you are entering the military

Chapter Two

DISCLOSING HIV TEST RESULTS

1) If I test positive for HIV, who will know the results?

The answer depends on whether you test **anonymously** or **confidentially**.

If you test **anonymously**, that means your name is not written on the test result. So the only person who knows your test result is the health care worker who informs you. There is no other record of your HIV test. No one else will be informed.

If you test **confidentially**, that means your name is written on your test results. That will create a permanent record of your HIV status. In that case, your doctor may have to disclose your HIV status to certain people, like the Department of Health or, if you are a student, the principal of your school. The rest of this chapter will discuss these and other situations in detail.

2) If I test positive, does my doctor have to give my name to the Department of Health?

Yes. Illinois law requires that doctors report the names of their patients who test HIV-positive to the Department of Health.

3) If I am a high school student and I test HIV positive, is my school informed?

Yes. Under current Illinois public health code, the public health department must inform the principal of your school that you are HIV positive if you are:

- ◆ enrolled in elementary, middle or high school and
- ◆ are between the ages of 3 and 21.

If you are a student at a public school, the principal must then disclose the identity of the student to the district superintendent.

The principal **may** also disclose your identity to:

- ◆ the school nurse
- ◆ your classroom teachers
- ◆ those persons who are required to decide placement or educational programs for you.

But the principal may only tell these people if they need to know.

In addition, the principal may tell other people who work in the school that there is an HIV positive child enrolled there, so long as the principal does not reveal the name of the child.

We think this law is bad public policy, and we are working to get this law changed.

The principal **cannot** disclose the identity of an HIV positive student to other students in the school, or to the parents of the other students.

4) If I test HIV positive, does my doctor have to tell my spouse or sexual partner?

No. The only sexual partner your doctor is allowed to tell is your legal husband or wife. Even then, the doctor must first give you a chance to tell your husband or wife yourself. If you don't tell your husband or wife, then your doctor can tell

them. But even then, he is **not required** to tell them. If you are afraid you will be hurt or homeless if your husband or wife finds out you are HIV+, be sure to tell your doctor.

The law does **not** allow your doctor to inform any sexual partner except your legal spouse.

5) If I test HIV positive, does my doctor have to tell my family or my roommate?

No. In fact, your doctor would be in violation of the law if he told your family or your roommate that you were HIV positive without getting permission from you first. It is **your** decision whether or not to tell your family or roommate about your HIV status.

6) If I test HIV positive, does my doctor have to tell my employer?

Absolutely not. Most people who test HIV positive do not want their employer to know, because they are worried that their employer might discriminate against them. **Your doctor has no right to disclose your HIV status to your employer without your permission.** For more information on your rights as an employee, see the Council's booklet *HIV in the Workplace*.

7) If I test HIV positive, do I have to tell anyone when I have sex or share needles?

Yes. Illinois law says that any HIV positive person who does something which **could** transmit HIV is committing "criminal transmission of HIV." **You don't have to actually infect someone to break this law.** Just putting someone at risk is enough. If you do not inform sexual or needle-sharing partners that you are HIV positive before you have sex or share needles, then you are breaking Illinois law.

To protect yourself legally, you should always disclose your HIV status before engaging in any sexual or needle-sharing behaviors.

This is even true if you are going to engage in safer sexual behaviors. Under Illinois law, if you wear a condom during intercourse but don't tell your sexual partner your HIV status, you might still be committing an illegal act.

8) I don't think I can bring myself to tell my sexual partners that I'm HIV positive. But I'd feel better if someone told them to get tested. Is there any way this can happen without using my name?

Yes. Your local department of health can notify your sexual and needle-sharing partners that they may be at risk for HIV, but they won't disclose your name. If you want the department of health to do this for you, you should call your local office and tell them you want to cooperate with their **voluntary partner notification program**. You will go down to the health department office and meet with a worker who will talk to you about your sexual and needle-sharing history. That worker will determine which of those people should be notified about the risk of HIV infection, and will contact those people. **But the worker will not disclose your name.**

Chapter Three

CONFIDENTIALITY AND YOUR HIV STATUS

1) My boyfriend and I had a big fight. Now he's threatening to tell my family and neighbors that I'm HIV positive. Can he do that?

Legally, he cannot. The Illinois AIDS Confidentiality Act states that no **person** can disclose your HIV result without permission from you. So if your boyfriend starts telling people that you are HIV positive, and you have not given him permission to do so, he is breaking the law.

2) What can I do to stop someone from telling other people I'm HIV positive?

One thing you can do is make it very clear to that person that any unauthorized disclosure of your HIV status is a violation of the law. The Illinois AIDS Confidentiality Act says that each time someone intentionally discloses your HIV status, that person can be fined \$10,000 by the courts. If this person is threatening to tell five people about your HIV status, he might be liable for \$50,000 in damages!

3) I have insurance through work. If I file an HIV-related claim, can the insurance company tell my employer I'm HIV positive?

Your employer should not find out about your HIV status. A federal law called HIPAA generally prohibits an insurance company from disclosing confidential information to your employer. However, the insurance company will probably disclose the claims history to your employer. This means your employer will be told what types of health conditions people have who are insured under the

group policy – without being told who those specific people are. So if you work for a small company, and your employer finds out that one person on the group health insurance plan has HIV, your employer may guess who that person is.

4) I tested HIV positive in my doctor's office, and I don't want my insurance company to know. Is there a way I can hide my HIV status from my insurance company?

The only way to prevent an insurance company from knowing your HIV status is to test anonymously. That way your name is never associated with the test result.

But if you don't test anonymously, and your HIV result ends up in your medical records, then you cannot hide your positive status from your insurance company. If your insurance company reviews your medical records at some point, your HIV status will be disclosed.

5) I have to fill out an insurance form for my employer that asks me questions about my health. What do I say?

If you work for a very large company (say over 1000 employees), you should be okay, because they probably have other employees with serious health problems and their Human Relations Department probably knows the rules about keeping medical information confidential. But if you have any doubts, or you work for a smaller company, here are three ways that you might handle this.

- ◆ Put a big circle around the whole section that lists all the health conditions and write “various pre-existing conditions – full details available from my doctor” and give the doctor’s name and phone number. Sign a form at your doctor’s office that it’s okay to tell the insurance company about your HIV, but not your employer.
- ◆ Tell your employer, “I know I’ll be in trouble if I leave anything out on this form so I’m just going to take it to my doctor’s office and have them fill it in.”

My doctor is a nut about privacy, though, and he'll want to fax it directly to the insurance company. Could you give me their fax number?" Then, whether or not you give it to your doctor, fax the completed form to the insurance company yourself with a note that they must not share the information with your employer (which they already should know).

- ◆ Call the insurance company yourself and tell them your situation. Tell them you are going to fill out two forms – one for them with all the truthful answers, and one for your employer that leaves out your HIV and anything else you might be worried about disclosing (for example, mental illness). Get their fax number. Then tell your employer you need an extra form because you messed up on the first one. Fax the form with the true information to the insurance company. Turn the other one in to your employer.

Chapter Four

OTHER QUESTIONS

- 1) I'm worried that my girlfriend may be HIV positive, but she refuses to get an HIV test. How can I make her get tested?**

You can't. Legally, she is not required to take an HIV test simply because she is in an intimate relationship. If she does not want to take an HIV test, she does not have to.

- 2) I know someone who is HIV positive, and he is having a lot of unsafe sex. Can I have him arrested?**

Your local State's Attorney's office makes the decision whether to prosecute cases under the criminal transmission law. You can contact them if you think there is a case they should prosecute. You should know, though, that you may be violating the AIDS Confidentiality Act if you give a person's name to the State's Attorney's office. It may also be hard to prove the details of another person's sexual practices.

