

AIDS and HTLV III : HTLV III antibody : to test or not to test / The Terrence Higgins Trust.

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Terrence Higgins Trust

Publication/Creation

1986.

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THE
TERRENCE HIGGINS TRUST

AIDS and **HTLV III**

**HTLV III
ANTIBODY;**

**To test or not
to test?**

3rd Edition: April 1986

FREE

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Introduction

Blood tests to detect the presence of antibodies to HTLV III virus, the cause of AIDS, are now widely available. We must all decide whether to ask for testing and whether to accept it if offered. Some people may be tested without their knowledge or consent, with or without adequate reason.

The medical and social issues are complex and the facts are often hazy. What follows are some of the questions which we think you should consider before making up your mind. Only you know your personality and circumstances — so only you can make the final decision.

How is the test done?

The test is done on a small sample of blood taken from a vein in the arm in the usual way. The results usually take about two to four weeks.

What does the test show?

The test shows the presence or absence of antibodies to HTLV III virus (also known as LAV or ARV), now widely accepted to be the cause of AIDS. If antibodies are found then it means that the virus has been present in the body at some time and has caused the body to react to it.

How reliable is the test?

The test method used in laboratories is now very reliable and positive tests will usually be double checked.

What does a negative test mean?

This probably means that you have not been exposed to infection with the virus.

There is however a big problem. It can take up to three months — and very occasionally longer — to produce antibodies after the virus has entered the body. During this time the antibody test will be negative but you are likely to be infectious and the test will later become positive. You can place more faith in a negative test if you haven't had 'unsafe sex' (or shared injection needles and syringes) for more than three months.

What if the test is positive?

1. *Am I still infectious?*

Most probably — but no one knows for certain. Some people undoubtedly are, as they can be shown to have passed the disease on to others. The virus has been found in up to 90% of people with a positive antibody test. At present it *must* be assumed that anyone who is antibody positive is infectious.

2. *Will I develop AIDS?*

Probably not. Over a two year period, about 10% of healthy gay men found to be antibody positive develop AIDS. About another 15% will develop Persistent Generalised Lymphadenopathy (PGL), AIDS Related Complex (ARC) or other "AIDS related" illnesses. About 75% stay healthy. No one knows whether more of these will become ill in years to come. Figures from different reports vary considerably and we will have to wait for reliable long term tests on large numbers of people before we can be more precise.

3. *Who will know the test results?*

If you attend an STD clinic of your own accord, the result should stay within the clinic. Some clinics may wish to notify your GP. *Ask* beforehand whether they intend doing so. If you are sent to other departments within the hospital, the specialists there will probably be told your result. This is then likely to go into your general hospital notes which tend to be less confidential than those kept in the STD clinic. The result may then be available to any doctor, nurse or anyone else who sees your case notes. Even if you know that a positive test does not equal AIDS, they may not. It will probably be essential that a few people know of your result in order to take the necessary precautions but it may be wise to make sure that a senior staff member — doctor or sister — is fully aware of the implications. In units used to dealing with such cases no problems should arise.

4. *Should my GP know my result?*

If you are ill, there is no doubt that your

G.P. should — indeed must — know. If you become ill they should be told immediately to prevent any dangerous delay in diagnosis. Again try to make sure that they are aware of the need for confidentiality and are sufficiently well informed to know that a positive test does not mean that you have AIDS.

If your GP does know, what will he or she do with the information? Some may be prepared to keep the information secret and separate from your routine records. Otherwise ensure that they are confident about the security of these records. Even if they give you assurances, what happens if you have to see their partners or locum? Or if you change doctors, when your notes are transferred to your new doctor? Will the result be mentioned in medical reports for employers and insurance companies? At present no major insurance company will accept anyone who is antibody positive for any type of life insurance.

5. Should I tell anyone else?

While it is very important to have someone to talk to, think carefully about which of your friends you can really trust. Try to decide before you get the result who you want to confide in. A positive result is always a shock and there is often a temptation to tell people who you would later prefer not to know.

There is *no* need for your employer or work colleagues to know that you are having the test — far less that the result is positive. Even knowing that you are at risk can make people react badly because of ignorance or prejudice.

Ideally, your dentist should know of a positive result to make sure that he takes a few basic precautions. It must be said though that many may then refuse to treat you. If you have problems ask the clinic who tested you to help arrange alternative treatment.

Once the test is done you may lose control of what happens to the result. Consider before you have it done whether the benefits are worth the risks. Discuss confidentiality with the doctor doing the test.

How do I decide?

The final decision depends greatly on your own personality and situation but the following points may help.

If a doctor experienced in dealing with HTLV III infection considers the test to be a useful part of his investigations then the potential value of the result in terms of treatment almost always outweighs the risks.

If your partner has evidence of HTLV III infection, knowing your own antibody status may be important in deciding how to continue your sex life together. If both partners are positive many doctors feel that there is little to be lost by having sex together as before. If only one partner is positive, most would recommend that you have safer sex. It is quite possible for the regular partner of an antibody positive person to remain antibody negative.

If you are particularly anxious about the possibility of HTLV III infection, it may improve your quality of life to have the test done, especially if your risk seems very low. You must however be prepared to accept the possibility, however remote, that it might be positive, with all that this entails. People inclined to worry can find a positive test difficult to cope with.

Some people feel that they have to know their result to enable them to behave with greater social responsibility. Whether you are positive or negative you should consider safer sex but some people can only change their lifestyle if they know their test result.

Finally, the issues are in some respects different — and more difficult for bisexual men or heterosexual men and women who may be at risk. They must consider the danger to any children they or their partners may have in future. Antibody positive women seem more likely to develop AIDS if they become pregnant.

You should feel free to discuss these or any other points with our Helpline or with a doctor in a clinic dealing with the problem before you decide.

Some Practical Advice

* Don't be pressurised into having a test done until you have had time to decide whether it is the best thing for you.

* We think that an STD/special clinic/dept. of genito-urinary medicine is the best place to have the test done, as they are usually more accustomed to the concept of absolute confidentiality.

* Unless you are prepared to tell people your result when they ask, don't tell them you are having the test done.

* It can be very important to have someone to talk to about your fears and worries. Some people you tell may react badly because of their own worries. Try to decide beforehand who you can trust and think twice before telling anyone else.

* Your clinic should be prepared to help you deal with a positive result. You can also phone the Trust Helpline for support and advice.

* Do NOT tell your employer.

* Whether you are positive, negative or don't know, you must consider safer sex: if you are negative to protect yourself, if you are positive to protect others and to avoid catching other diseases.



The Terrence Higgins Trust Limited

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