Blood Systems

HTLV-I/II INFORMATION SHEET

What is HTLV-I/II?

The human T-cell lymphotropic viruses type I and type II (HTLV-I/II) are closely related but distinct retroviruses that can infect humans. These viruses have nothing to do with HIV or AIDS. HTLV-I and HTLV-II viruses infect specific cells in the body known as lymphocytes, a type of white blood cell. White blood cells are involved in the immune response and help the body fight infection. Although HTLV-I and HTLV-II are rarely associated with disease, United Blood Services tests for these viruses because they can be transmitted through blood transfusion.

What are the signs and symptoms of HTLV-I/II infection?

The majority of people infected with HTLV remain asymptomatic.

HTLV-I infection

- Adult T-cell leukemia (ATL)
  - ATL is a disease that involves a specific group of blood cells. About 2 – 4 % of people infected with HTLV-I infection develop ATL. The infection may be dormant for decades. The clinical picture may include skin lesions and pulmonary involvement.
- HTLV-I associated myelopathy/tropical spastic paraparesis (HAM/TSP)
  - HAM/TSP is a disorder of the nervous system and is characterized by progressive and permanent lower-extremity weakness, numbness and stiffness of the legs and difficulty walking. 2% - 4% of people with HTLV-I infection develop HAM/TSP.

HTLV-II infection

- HTLV-II associated myelopathy/tropical spastic paraparesis (HAM/TSP)
  - HAM/TSP is a disorder of the nervous system and is characterized by progressive and permanent lower-extremity weakness, numbness and stiffness of the legs and difficulty walking. About 1% of people with HTLV-II infection develop HAM/TSP.

How is HTLV-I/II spread?

HTLV-I/II can be spread through close contact with an infected individual or their body fluids, including:

- Sharing of needles and syringes among intravenous drug users
- Breast milk from an infected mother
- Sexual contact with an infected partner
- Blood transfusions prior to 1988

*You **cannot** spread HTLV-I/II by casual contact, such as shaking hands, hugging, and sharing homes and workplace, including bathrooms.*

What are the risk factors for HTLV-I/II?

HTLV-I

- Originate from or live in an area of the world where HTLV-I is commonly found:
  - Southern Japan
  - Several Caribbean countries
  - Some parts of Africa and South America (Brazil, Columbia, Peru, Chile, Guiana and French Guiana)
  - Papua New Guinea, South America
  - The Middle East
  - Melanesia
- Injection drug use (past or present) or sex with an injection drug user
- Unprotected sex with an HTLV-I infected partner or with people from an area known to have high rates of HTLV-I
- Breastfed by an HTLV-I infected mother or wet nurse
- Blood transfusion (prior to 1988 in the United States)

HTLV-II

- Injection drug use (past or present)
- Unprotected sex with an HTLV-II infected partner or sex with an injection drug user (past or present)
- Breastfed by an HTLV-II infected mother or wet nurse
- Blood transfusion (prior to 1988 in the United States)
- American Indian (North, Central or South America) or African Pygmy ethnicity

Can HTLV-I/II be treated and prevented?

- There is no medication available that can eliminate the virus from the body.
- There are some medications that reportedly improve or relieve some of the symptoms of HTLV associated diseases.
- There is no vaccine to prevent HTLV.
- It is not known why a few people with HTLV-I/II develop disease while most do not, and there are no tests that can determine which people will become ill.
- There is no known way to reduce the risk of developing any of the associated diseases.
- You can prevent spreading or acquiring HTLV by avoiding intravenous drug use, unprotected sexual contact, and breastfeeding by an infected mother.

How is blood tested for HTLV-I/II?

All donated blood is tested for HTLV-I/II before it is transfused to a patient. A sample of the donor's blood is tested using a screening test called chemiluminescent immunoassay (ChLIA) that detects antibodies to HTLV. If the screening test is reactive, more specific supplemental testing (LIA) is performed to determine if the screening test results are indicative of true infection or are false-positive test results. If the supplemental test results are negative, the HTLV screening tests are considered to be false-positive, therefore the person is not truly infected with HTLV. If the supplemental test results are positive, the person is more than likely truly infected with HTLV and consultation with a physician is strongly recommended. An indeterminate supplemental test result can have a few different meanings and may necessitate more testing to determine the true result. The person may not be infected with HTLV but it is advisable that the individual follow up at a later time with another HTLV test. All blood from donors who test repeatedly reactive (positive) on the ChLIA test is destroyed and is NOT used for transfusion.

What if I test confirmed positive for HTLV I or HTLV II?

If you test positive on both a screening test and a supplemental test, you should consider yourself infected with HTLV. We strongly recommend that you see your doctor for a periodic medical evaluation so you can be provided with the best health care and new information, as it becomes available. For HTLV-I, an annual history and physical with periodic blood tests and lymph node and neurological exams are recommended. For HTLV-II, an annual neurological exam is recommended. Appropriate laboratory testing should also be performed.

Should a person with a positive HTLV I or HTLV II test donate blood?

NO. You are also advised not to donate plasma, bone marrow, organs, semen/sperm or breast milk for others.

What is meant by a false-positive test result?

A false-positive test result means that the initial screening test was reactive, but a more precise supplemental test was negative. Almost all false-positive test results occur because of interference with the test and are not due to infection. They are not testing errors. Receiving a false-positive test result can be worrisome and upsetting, but tests that are falsely positive really mean that infection is not present in the blood. Therefore, a person with a false-positive result does not have the disease and has not exposed a partner, children or friends to the infection or disease. If you have any additional concerns, you may speak to your physician who can give you medical advice. Repeat testing may also be discussed with your doctor.

What should I do if I am infected with HTLV-I/II?

If your supplemental test is positive for HTLV, there are several important steps you should take to protect your health and the health of others:

DO see a doctor for medical evaluation, even if you do not feel sick.

DO use condoms when you have sex and inform your sexual partner.

DO tell anyone with whom you have had sex or shared needles or syringes that you are (and they may be) infected with HTLV.

DO avoid breastfeeding.

DO maximize your chances of remaining in good health by eating a healthful diet, exercising regularly, avoiding stress and getting adequate rest.

DO NOT DONATE BLOOD, PLASMA, BONE MARROW, ORGANS, SEMEN/SPERM OR BREAST MILK FOR OTHERS.

DO NOT share needles or syringes with anyone.

It is important to keep in mind that most people with HTLV-I/II will never develop any disease associated with these viruses.

For additional information, access the International Retrovirology Association web site. http://htlv.net