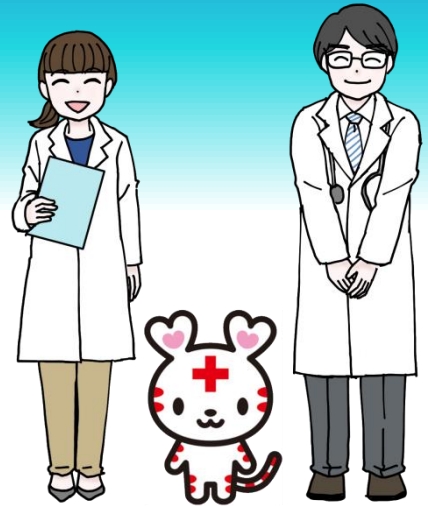


Current Information on HAD

This booklet summarizes current information on 'HTLV-1 and Associated Diseases (HAD) '.

We hope this information will help you live a healthy life and mitigate your anxiety and worries.



Mascot of Japanese Red Cross
Heartora-chan

Contents

This is likely the first time you're learning of your HTLV-1 infection.

HTLV-1 is a virus that can infect humans, similar to the influenza and hepatitis viruses.

HTLV-1 infection has a long history in Japan, and being infected with it does not necessarily mean that you will get sick.

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What is HTLV-1?

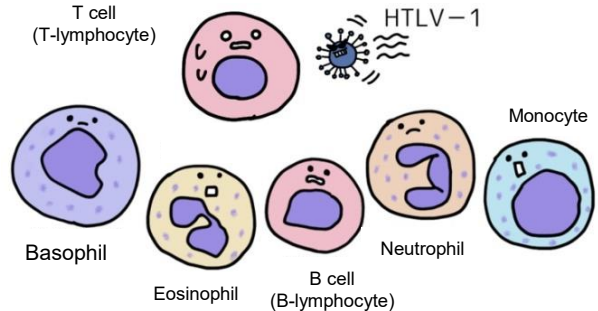


I received a notification telling me I'm infected with HTLV-1. What's that?

HTLV-1 is an infectious agent, and an abbreviation of human T-cell leukemia virus type 1.



HTLV-1 has coexisted with humankind for thousands years and infects T cells, a kind of white blood cell, in the blood.



HTLV-1 carriers



How was my HTLV-1 infection detected?

Japanese blood centers check serum samples from blood donors for antibody for HTLV-1.* An antibody-positive result indicates HTLV-1 infection. Individuals infected with HTLV-1 are called HTLV-1 carriers.



*HTLV-1 testing is mentioned in the 'notification of test result' sheet.

Geographical distribution of the main foci of HTLV-1 infection



Gessain, A and Cassar, O *Front Microbiol* 2012;3:388.

HTLV-1-associated diseases



Will HTLV-1 infection make me sick?

Three diseases have been definitively associated with HTLV-1 infection:
Adult T-cell Leukemia/lymphoma (ATL),
HTLV-1-Associated Myelopathy/Tropical Spastic Paraparesis (HAM/TSP),
and HTLV-1-associated Uveitis (HU).





How often do carriers get sick?

An estimated 3%-5% of carriers will develop ATL, <1% will develop HAM, and HU is even less frequent.



Most HTLV-1 carriers will not develop any disease throughout their lives.

However, if you are concerned about the symptoms described on the following pages, we recommend you visit a medical institution.

Adult T-cell leukemia/lymphoma (ATL)

ATL is a malignancy of HTLV-I-infected CD4+ T-lymphocytes.

Symptoms suggestive of ATL

- Swollen lymph nodes around the body
- Red rashes on the skin or raised rashes that are difficult to cure
- Strong fatigue and high fever that last for days.



If the above symptoms occur without any other diseases, please visit a hematologist immediately.

HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP)

A progressive disease of the central nervous system that causes weakness or paralysis of the legs, lower back pain and urinary symptoms.

Symptoms suggestive of HAM/TSP

- Legs become tangled, making walking difficult
- Easily falling when running.
- Legs are tight or numb.
- Urinary and anal sphincter signs or symptoms can be present.



For cases of HAM/TSP, the early diagnosis and initiation of treatment improve the prognosis.

If any of the above symptoms appear and persist, please visit a neurologist immediately.

Promising protocols for the treatment of HAM/TSP are also being developed.

HTLV-1-associated uveitis (HU)

HU is a disease that causes inflammation in the eyes.

Symptoms suggestive of HU

- Feels like insects and dust are flying in front of you (myodesopsia)
- Hazy vision (nephelopsia)
- Eyes may become red, and eyesight may deteriorate



If any of the above symptoms appear and persist, please visit an ophthalmologist.

HTLV-1 infectivity



If I'm an HTLV-1 carrier,
I must have infected my family.

You will not infect family or acquaintances with HTLV-1 through your daily routine at home, school or the office.



HTLV-1 has only a very weak infectivity, so you needn't worry about passing the infection through your daily activities, aside from breastfeeding and having sex without condoms.



HTLV-1 infection has not been reported through casual contact via clothes, tableware, public baths, or swimming pools. Furthermore, you will not pass the infection by sneezing or coughing.

HTLV-1 transmission



How and why did I get infected?

HTLV-1 transmission occurs by exposure to a large amount of living infected cells. There are three major routes of transmission.



Major routes of transmission of HTLV-1

- ◆ Mother-to-Child through breastfeeding
- ◆ Sexual contact without condoms
- ◆ Blood transfusion and organ transplant

In Japan, all donated blood is screened for HTLV-1 infection to prevent transmission by transfusion. At present, HTLV-1 transmission mainly occurs from mothers to children and by sexual contact without condoms.

Mother-to-Child transmission of HTLV-1



I breastfed my children.
Are they infected?



What should I do to prevent
the newborn from getting
infected?

Infants may be infected with
HTLV-1 via breast milk from
HTLV-1-carrier mothers.



Refraining from breastfeeding
suppresses HTLV-1 infection
by up to 97%.



According to reports, approximately 20% of infants breastfed for a long period acquire infection in HTLV-1-endemic areas.

Please consult your obstetrician to choose a nursing method.

HTLV-1 transmission between partners



Did I transmit HTLV-1
to my husband?



Did I transmit HTLV-1
to my wife?

Around 4,000 new infections occur annually in Japan, and the number of new infections in women is about 3 times as high as that in men. However, viral exposure does not necessarily result in infecting your partner, and HTLV-1 infection will not immediately cause health problems.





How can we prevent infection between partners?

Can we have children?

Sexual intercourse does not always result in infection. Sexual transmission can be prevented by using condoms, and HTLV-1 has not been reported to be transmitted through kisses or saliva.

If you wish to give birth, please engage in normal sexual intercourse.

In cases of sexual transmission, the onset of adult T-cell leukemia/lymphoma is rarely observed.

[For adult T-cell leukemia/lymphoma (ATL), see the following pages.]



Request to decline blood donation



Can HTLV-1 carriers continue to donate blood?

Unfortunately, blood from HTLV-1 carriers cannot be used for blood transfusions in order to prevent transmission to recipients.



We thank you for your kind offer, but please refrain from donating blood in the future.

Consultation counter for HTLV-1



I want to know more about HTLV-1.
Is there anyone I can talk to?

Consultation desk for Blood Donors at the Kyushu Block Blood Center

E-mail: hinshitsu-chikushino@qc.bbc.jrc.or.jp

Only available in Japanese or English

The blood center has a consultation desk.
Please send an e-mail to the right
address. In addition, the attached sheet
includes a list of medical institutions that
accept consultations.



Please refer to the MHLW website for detailed explanations.

HTLV-1 MHLW

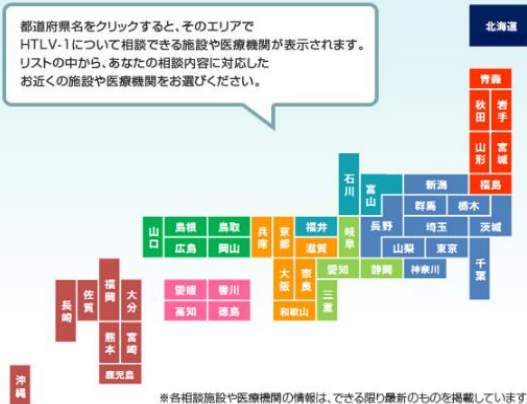
Search

You can find a consultation desk by clicking on the prefecture where you live.



HTLV-1相談・医療機関検索

都道府県名をクリックすると、そのエリアでHTLV-1について相談できる施設や医療機関が表示されます。リストの中から、あなたの相談内容に対応したお近くの施設や医療機関をお選びください。



※各相談施設や医療機関の情報は、できる限り最新のものを掲載していますが、更新の状況によって必ずしも最新でない場合もありますこと、ご了承ください。

(Source: Ministry of Health, Labor and Welfare website)

If you still have questions or concerns, please use one of these consultation services.

Comments from donors received positive notification

When I was 20 years old, I was notified of a positive HTLV-1 result after donating blood. I was worried, but now I have two kids and am living in good health. (Woman, 30s)

After receiving the notification, I was worried. However, I went to the hospital to undergo an examination and felt relieved. I was told that I should undergo an examination once a year. (Man, 50s)

I felt conflicted when I was told I was HTLV-1-positive. Now, I'm swaying between feelings of relief and anxiety. If I get sick, I intend go to the hospital and tell the doctor that I am an HTLV-1 carrier. (Woman, 50s)

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