

# Getting tested for HTLV

You find out if you carry HTLV by having your blood tested for HTLV antibodies. Ask your doctor for more information.

- **HTLV negative** means your body has not encountered HTLV & has not developed antibodies against HTLV. You do not carry HTLV.
- **HTLV positive** means your body has encountered HTLV & has developed antibodies against HTLV. You carry HTLV.
- **HTLV indeterminate** means your body might have encountered HTLV. You need an additional blood test to check for the virus DNA directly. Most results come back as negative.

Doctors don't routinely check for HTLV when doing blood tests so please ask them if you would like to know more or if you want to be tested.

## Treatment for HTLV-1

### Is there a cure for HTLV infection?

Unfortunately, currently there is no known cure for HTLV infection. There is also no vaccine against HTLV.

### Is there treatment for HAM/TSP?

Although there is no cure for HAM/TSP a number of treatments are available. There are two approaches to treatment:

- **treatment of the cause:** i.e. the inflammation in the spinal cord
- **treatment for the symptoms:** weakness, stiffness, pain etc

### ATLL Treatment

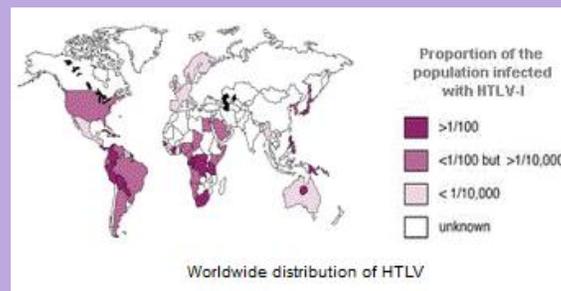
Treatment for ATLL varies depending on the sub-type and stage of disease as well as geography. Basically different countries have different treatment guidelines for the different ATLL subgroups.

## HTLV-2,-3 and -4

Very little data is available on the natural history of HTLV-2, which is commonly seen in North and South Americas. Disease is less commonly associated with HTLV-2. The HOST study showed that people infected with HTLV-2 have a small increased risk of bacterial infections, particularly of the chest and bladder.

There is very little information available about HTLV-3 and HTLV-4, which was discovered in West Africa. Nobody knows how many individuals are infected with these viral subtypes or if they cause illness.

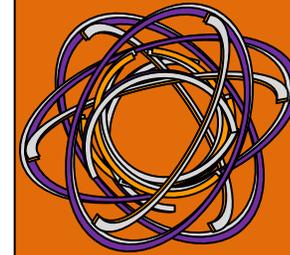
However, given the fact that a related virus, HTLV-1 is known to cause serious diseases, it is imperative to monitor the possible spread of these viruses and to determine their disease potential.



## Find out more

Want to find out more information about HTLV? Do you have questions or want to find out about ongoing research? Try some of the following websites or research centres:

- North East Retrovirology Referral Centre (NERRC), York
- National Centre for Human Retrovirology (NHRC), London
- [www.HTLVaware.com](http://www.HTLVaware.com)
- [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)
- [www.htlv.allenpress.com](http://www.htlv.allenpress.com)
- [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)



# HTLV

Human T cell Lymphotropic Virus

What is HTLV?

How is it passed on?

How do I get tested?



# What is HTLV?

HTLV stands for Human T cell Lymphotropic Virus. It is a retrovirus that infects a type of white blood cell called Tcell or T lymphocyte.

HTLV-1 is a very old virus, which appears to have infected humans for hundreds, if not thousands of years

There are four subtypes of HTLV: HTLV-1, HTLV-2, HTLV-3 and HTLV-4. They are retroviruses. HTLV is endemic (common) in the Caribbean, Japan, South America, and parts of Africa. Interestingly, it has also been observed in Iran and Romania. Most patients just carry the virus and may transmit the virus, but will never become ill. Only 5% of people might ever become ill and disease is most commonly seen in those people who are infected with HTLV-1.

HTLV-2 is often found in West Africans, Native Americans and people who have injected drugs.



Most people who develop HAM/TSP will have been infected with HTLV-1 for months, years or even decades.

Nobody knows what triggers the inflammation to start.

Luckily only 3 to 5 out of 100 people infected with HTLV-1 ever develop ATLL. Only persons infected with HTLV-1 get ATLL.

Many HAM/TSP patients work very hard at staying mobile and active. Physical exercise is like drug therapy, it must be done daily and regularly.

**Please join us!** Follow us on Twitter and tweet.

**'HTLVaware'**



## How is HTLV passed on?

HTLV-1 can be passed on through infected blood, semen, vaginal fluids, rectal secretions, breast milk and organ transplants. The most common ways HTLV-1 is passed on are:

- Sex without a condom
- Sharing used needle or other injecting drug equipment
- Mother to child (the risk of transmission can be reduced if breast feeding is avoided)
- Blood Transfusion/Organ Transplants (blood and organs should not be donated if infected with HTLV. Blood and organs are screened in the UK)

## Does HTLV-1 cause any diseases?

The great majority of people infected with HTLV-1 do not develop any related disease.

A small minority of individuals, about 1 in 20 of these infected, will develop disease due to HTLV-1, but this usually occurs after several decades of infection.



It is important to know if you are HTLV positive as even if you are not ill you can still pass it on to others.

HTLV-1 can cause a type of blood cancer or inflammatory disease.

**ATLL(Adult T-cell Leukaemia/Lymphoma)** is a rare form of cancer of the blood, divided into four subtypes.

**HAM/TSP (HTLV-1-Associated Myelopathy/Tropical Spastic Paraparesis)** is an inflammation of the cells in the spinal cord that can cause stiffness and weakness of the legs, lower leg and backache, a 'weak' bladder, constipation and erectile dysfunction.

**HTLV-1 may also cause** inflammation of the eye (uveitis), joints (arthritis), muscles (myositis), lung (alveolitis) and skin (dermatitis).

## Asymptomatic Carriers

Asymptomatic carrier, also referred to as AC, is a person who has antibodies against HTLV but does not have any problems caused by HTLV.

Luckily most people, 95 out of 100 people, who carry HTLV do not become ill. This means that the immune system of the body is able to prevent disease from developing.

### How is an AC diagnosed?

An AC carries HTLV antibodies in the blood. In most cases, a HTLV proviral load can be measured in the blood cells if not too low.

### How does an AC develop disease?

The exact mechanism, which allows an HTLV associated disease to develop in an AC is unknown.

**Please join us!** Follow us on Twitter and tweet.

**'HTLVaware'**

