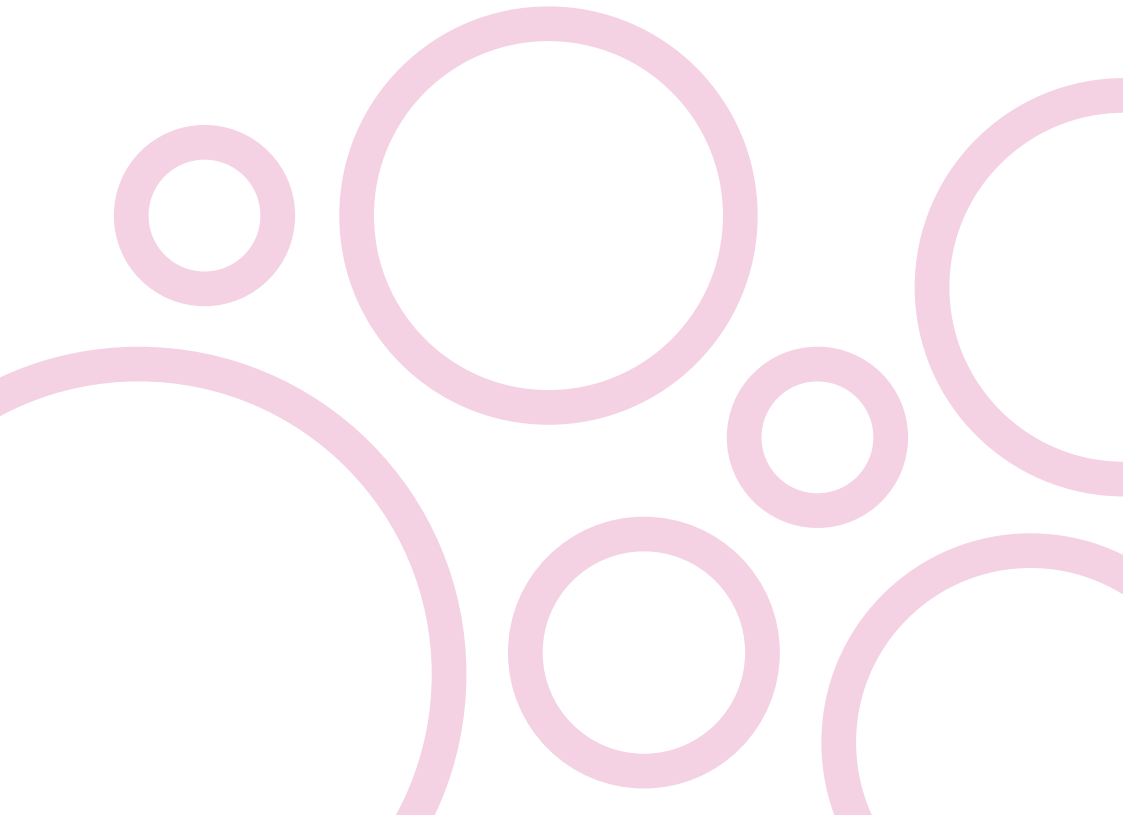




Your guide to

HTLV-2

Information for patients, relatives and carers



What is HTLV-2?

HTLV-2, also known as human T-lymphotropic virus type 2, is a virus that infects a kind of white blood cell called a T-cell or T-lymphocyte, which is important in fighting infections. A virus is a minute organism that can normally be seen when magnified many thousand times by a microscope. Viruses can only survive and replicate by using the life-support system (metabolism) of a living cell.

HTLV-2 infection has been found in Western Africa and may have originated there. It is thought to have migrated during ancient times with native American Indians to North and South America. In modern times HTLV-2 infection has spread among injecting drug users (IDUs) particularly in America, South Vietnam and Europe. The highest rates of HTLV-2 in Europe are found among injecting drug users in Eire, Spain, Italy and Scandinavia.

How would I know if I am infected?

Most people who are infected with HTLV-2 are perfectly well, have no symptoms or signs of infection (they are called asymptomatic carriers), and are completely unaware that they are infected. We cannot estimate the number of people infected with HTLV-2 in the UK. However, we know it is less than the number infected with HTLV-1. For example, only one in 200,000 blood donors was found to carry HTLV-2 compared with one donor in 20,000 for HTLV-1. It is sometimes difficult to find out how these people became infected with HTLV-2 because they may have no obvious risk factors.

HTLV-2 infection is diagnosed by testing for antibodies to HTLV-2 in the blood. The body responds to all kinds of infections by producing antibodies that recognise only that particular infection. Therefore, the absence of HTLV-2 antibodies excludes HTLV-2 infection unless

the infection has just occurred and the test was done before the antibodies appeared in the blood. If a recent infection is suspected, the antibody test should be repeated three months later.

Please note that HTLV-2 infection does not show up in routine blood tests such as those requested by your GP or in most hospital tests.

You may have been tested or wish to be tested because:

- You are a blood donor and are being screened for HTLV-2 and other infections
- A family member or your partner is infected with HTLV-2
- You have developed symptoms associated with the virus (please see ‘Does HTLV-2 cause any disease?’)
- You have another viral infection with similar routes of transmission, for example hepatitis C virus

How does HTLV-2 infection occur?

HTLV-2 can be transmitted from person to person in four ways:

- 1) From an infected mother to her baby. As most infections occur through breastfeeding we recommend it should be avoided. According to research from Brazil and Argentina, around 30 percent of breastfed infants become infected. The longer an infected mother breastfeeds her baby, the greater the risk of infection.
- 2) Between sexual partners through unprotected sex. The use of condoms protects against many other infections and is likely to prevent most sexual transmission of HTLV-2.

- 3) Through transfusion of blood from an HTLV-2 infected donor. People with HTLV-2 infection should not donate blood, organs or sperm and should not carry an organ donor card. In the UK blood is screened for HTLV-1 infection and the screening test also detects antibodies to HTLV-2.
- 4) Through sharing or reusing needles and syringes to inject drugs. The use of disposable equipment for injections prevents infection.

Please note that HTLV-2 infection is not passed from person to person by coughing, sneezing, kissing, cuddling or daily social contact.

Does HTLV-2 cause any disease?

HTLV-2 does not cause any disease in the vast majority (99 percent) of people infected with the virus. It appears to remain in the body throughout life without causing any harm at all.

In rare cases the virus can cause HTLV-2-associated myelopathy (HAM2). This is an inflammation of nerves in the spinal cord that causes stiffness and weakness of the legs, backache, a weak bladder and constipation. Much less is known about HAM2 than about HTLV-1-associated myelopathy but the damage is probably caused by proteins released from immune cells fighting the infection, which harm the nerves.

A study of blood donors in North America shows that people infected with HTLV-2 have an increased risk of bacterial infections, particularly of the chest and bladder.

Can HTLV-2 infection be cured?

At present there is no treatment available to cure the infection. Asymptomatic patients do not require any treatment and they are usually followed up in the clinic annually.

What is the difference between HTLV-1 and HTLV-2?

HTLV-1 and HTLV-2 are closely related viruses but they tend to affect different populations. They are also associated with different diseases and different rates of disease. Even though both can cause a myelopathy, an inflammation of the spinal cord, this is much more common with HTLV-1. HTLV-1 can also cause leukaemia, a blood cancer, but this is not found with HTLV-2 infection.

The screening tests detect both HTLV-1 and HTLV-2 antibodies. Further tests are then performed to distinguish between the two viruses.

What is the difference between HTLV-1/2 and HIV?

HTLV-1 and HTLV-2 should not be confused with the human immunodeficiency virus (HIV). Tests for HTLV do not detect HIV and vice versa.

The diseases associated with HTLV are very different from HIV. However, both HIV and HTLV are transmitted in the same way. Therefore, the same things help to protect against infection. Laboratory studies have shown that one of the treatments for HIV, when combined with another anti-viral treatment, is useful for treatment HTLV-1-associated leukaemia.

The HTLV clinic at Imperial College Healthcare NHS Trust, St Mary's Hospital was developed into the National Centre for Human Retrovirology in 2002 by the Department of Health. It works in partnership with Imperial College London and provides a national referral service for patients with HTLV infection to regional centres.

The clinic offers:

- Information for people with HTLV-1/2 infection and their families
- Diagnosis of HTLV-1 and HTLV-2 infections
- Investigation and treatment of HTLV-1/2-associated diseases

If you are an asymptomatic carrier, we will offer you an appointment in the clinic once or twice a year to check your blood tests.

If you are found to have health problems related to HTLV-2 infection, we may see you more often, depending on the severity of your symptoms.

We have also an active research programme to:

- Investigate factors (for example immune, genetic, lifestyle) which may influence why some carriers develop virus-associated disease and some do not
- Learn about the immune (body protection) response to these viruses and how it may prevent disease
- Develop effective treatments for those who have HTLV1/2 associated disease

If you wish to discuss or participate in this research, please contact the clinic on 020 3312 6604.

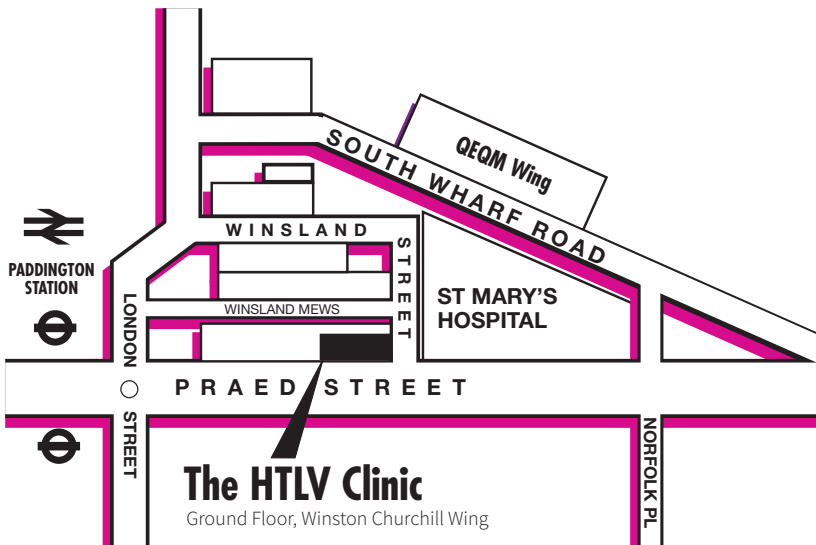
Where to find HTLV services in the UK

Our HTLV clinic is situated on the ground floor of the Winston Churchill Wing at St Mary's Hospital.

You are advised to travel, if possible, by public transport when visiting the clinic. Car parking is very limited and you may find it difficult to find a place to park near the hospital. Disabled parking is available on Winsland Street. The nearest tube station is Paddington (Bakerloo, District, Circle and Hammersmith & City lines), which is also a railway station. Buses that stop on Praed Street are numbers 7, 15, 23, 27 and 36.

If you or your family wish to know more about HTLV, ATL, HAM/TSP, or participate in research, please contact:

The National Centre for Human Retrovirology
Ground floor, Winston Churchill Wing
St Mary's Hospital, Praed Street, London W2 1NY
Tel: 020 3312 6604
Email: imperial.htlv@nhs.net
More information can be found at: www.htlv.eu



There are also HTLV Clinics in Birmingham, Manchester and York
– see addresses and contact details below:

Manchester HTLV Clinic

Pennine Acute NHS Trust, Department of Infectious Diseases,
North Manchester General Hospital, Crumpsall, Manchester M8 5RB
Tel: 0161 720 2734

Birmingham HTLV Clinic

University Hospitals Birmingham NHS Foundation Trust
Queen Elizabeth Hospital Birmingham, 3rd Floor East Block,
Main Drive, Edgbaston, Birmingham B15 2TH
Tel: 0121 371 6954

York HTLV Clinic

York Teaching Hospitals NHS Foundation Trust
Monkgate Health Centre, 31 Monkgate, York YO31 7WA
Tel: 01904 725423