NATIONAL CENTRE FOR HUMAN RETROVIROLOGY

Your guide to HTLV-1

Information for patients, relatives and carers

What is HTLV-1?

HTLV-1, also known as human T-lymphotropic virus type I, 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.

The HTLV-1 virus has been around for thousands of years. It has gradually spread through the human population but is more common in certain parts of the world including West and Southern Africa, the Caribbean, South America, Japan and Iran. In some of these areas more than one percent of the population carry the virus. With the exception of Romania, HTLV-1 is uncommon in Europe and is mainly found among people who have originated from the areas listed above. The rates of infection in migrants are similar to those seen in the regions that they migrated from.

How would I know if I am infected?

Most people with HTLV-1 infection are perfectly well, have no symptoms or signs of disease, and are therefore completely unaware that they are carrying this infection. This is called asymptomatic carriage. We have estimated that 36,000 people in the UK have HTLV-1 infection. The majority are asymptomatic carriers and just over 1,000 patients in the UK are aware that they are carrying the infection.

HTLV Prevalence

A special blood test can easily identify if you have this virus. If the infection has occurred, your body will respond by producing antibodies to fight it. The absence of HTLV-1 antibodies excludes HTLV-1 infection unless the infection has just occurred and the test was done before the body has produced antibodies to HTLV-1. If your doctor suspects a recent infection, he/she will recommend that you should repeat the antibody test three months later.

Please note that HTLV-1 infection does not show up in routine blood tests such as those requested by your GP or in most hospital tests.

How does HTLV-1 infection occur?

HTLV-1 can be transmitted from person to person in four ways:

1) **From a mother with infection to her baby**. This happens in 25% (or one in four) of cases. As most infections occur through breastfeeding we recommend it should be avoided. It will reduce the risk that the baby acquires the infection to five percent (or one in 20). The risk of infection through breastfeeding seems to be low during the first three months. However, the longer you breastfeed, the greater the risk of infection.

2) **Between sexual partners through unprotected sex**. The best information indicates that in a heterosexual relationship there is a seven percent chance of transmission over five years. The risk of transmission from an infected man seems to be four times greater than from an infected woman. We recommend the use of condoms to protect against HTLV-1 transmission. When a couple are trying to have a baby we recommend a further discussion with an expert about how to minimise the risk of transmission through sex.

3) **Through transfusion of blood from from a donor with HTLV-1**. The risk may be as high as 85 percent from an infected donation but depends on how the blood is processed and how long it is stored for. People with HTLV-1 infection should not donate blood, organs or sperm and should not carry an organ donor card. In the UK, and in many but not in all other countries, blood is screened for HTLV-1 infection.

4) **Through sharing or reusing needles and syringes to inject drugs, or during some religious practices such as self-flagellation (also known as zanjeer or tatbir).** The use of disposable equipment for injections prevents infection, as does avoiding the sharing of blades in other practice.

Please note that HTLV-1 infection is not passed from person to person by coughing, sneezing, kissing, cuddling or daily social contact.

Does HTLV-1 cause any disease?

HTLV-1 does not cause disease in the vast majority of people infected with the virus. It appears to remain in the body throughout life without causing any harm at all. However, about five percent of (or one in 20) people will develop disease due to HTLV-1 but this usually occurs only after several decades of infection.

There are two main types of disease caused by HTLV-1:

- **Adult T-cell leukaemia/lymphoma (ATL)**. This is a rare form of cancer of the blood seen in fewer than 20 patients per year in the UK. It is usually treated with anti-cancer drugs.
- **HTLV-1-associated myelopathy (HAM)**. This is an inflammation of nerves in the spinal cord that causes stiffness and weakness of the legs, backache, a weak bladder and constipation. Not all of these symptoms may be present, especially at the beginning. The disease often starts very slowly and the initial symptoms may be attributed to arthritis or an aging process. The damage to the nerves is thought to be caused by proteins released by the immune cells fighting the infection. In the UK about 12 people are diagnosed with HAM each year. Clinical trials of new therapy for HAM are being conducted through the National Centre for Human Retrovirology (see patient's guide to HAM). At the moment different medicines in combination with physiotherapy are available to treat various symptoms, such as stiffness, pain, weak bladder, etc. We may also recommend some drugs to reduce the amount of the virus in the blood or decrease inflammation.

HTLV-1 can also cause inflammation of the eye (uveitis), joints (arthritis), muscles (myositis), thyroid, lung (alveolitis and bronchiectasis) and skin (dermatitis). These conditions are even less common than ATL and HAM and the skin condition is usually only seen in tropical climates.

Can HTLV-1 infection be cured?

At present there is no treatment available to cure the infection. 95 percent of all infected people go through life without developing any HTLV-1-associated diseases.

Is everyone infected with HTLV-1 at equal risk of developing an HTLV-1-associated disease?

HAM seems to be less common among Japanese with HTLV-1 infection than among other populations.

If mothers with HTLV-1 can be advised not to breastfeed, ATL can be prevented in the next generation as ATL is unlikely to develop following infection acquired during adulthood.

The risk of disease also relates to the amount of virus in the blood of the person with HTLV-1 infection.

Contacting partners and family members

Since most people with HTLV-1 infection do not know they have it, the virus can unknowingly spread to others.

This can be prevented by testing for the presence of the virus, and then using precautions to stop further spread.

If you test positive, we advise that you inform your sexual partners to have a blood test for HTLV. If you feel unable to inform them, do talk to us about this. We will be able to support you and notify them on your behalf.

If your children need to be tested, we can also arrange this. This is usually done in the children's department.

Other members of your family may also benefit from testing, and we shall discuss this with you.

Should I inform my partners and family members to get tested if I am found to have HTLV-1?

Since most people infected with HTLV-1 do not show any symptoms, the virus can unknowingly spread through generations via sexual contact and breastmilk. Transmission to future generations can be prevented if individuals are aware of their HTLV-1 status.

The HTLV clinic at Imperial College Healthcare NHS Trust, St Mary's Hospital

This is the National Centre for managing HTLV infection. We have established satellite clinics in Birmingham, Manchester and York.

The clinic was first established in 1991 to:

- Provide a centre for the diagnosis, treatment, management, counselling and care for people with HTLV-1 infection and their families
- Investigate why and how some people with HTLV-1 infection develop disease
- Study and improve the treatment of HTLV-1 associated disease

The clinic was developed into the National Centre for Human Retrovirology in 2002 by the Department of Health. It works in partnership with Imperial College London.

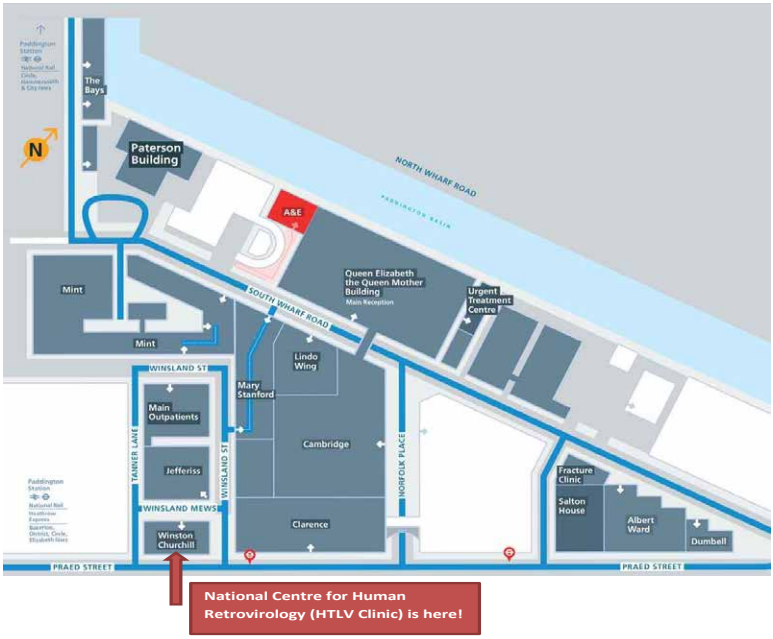
Where to find HTLV services in the UK

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. Limited parking for those with disability 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