

Friday 17 December 2024

Dear GP colleagues,

### **Have you heard of HTLV?**

HTLV (Human T-lymphotropic virus) is a blood borne virus, transmitted via sex, pregnancy, breastfeeding or contaminated blood or needles. There are an estimated 36,000 people living with HTLV infection in the UK and this number is rising.

The National Centre for Human Retrovirology (NCHR), based at St Mary's Hospital, will be reviewing and managing patients living with HTLV and its associated disease complications such as Adult T-Cell Leukaemia/Lymphoma and HTLV associated myelopathy/Tropical Spastic Paraparesis. These complications may affect approximately 5% of patients.

HTLV testing is one of the strategies recommended by the WHO (World Health Organisation) to ensure we mitigate risks of transmission. However, aside from blood donor testing, there is currently no routine testing in antenatal or sexual health clinics.

To limit transmission, partner notification is an important part of our service, with patient contacts and family members advised to seek HTLV testing. Whilst this can be offered within our service, many patients prefer to be seen locally.

Recently, patients and their families have informed us that that they have been unable to access HTLV testing at their GP practice for the following reasons:

1. Confusion about HTLV and HIV. We want to emphasise that HTLV is a different retrovirus to HIV.
2. The GP was unable to find an option for HTLV testing within their system.
3. The recent NHS cyber-attack affected test requests. However, we anticipate this is a temporary issue.

The HTLV test is available universally. To order this blood test, please select HTLV 1&2 antibody screening via ICE.

Please refer any reactive results to our London NCHR Service for ongoing management (email below). We also support satellite HTLV clinics in Birmingham, Manchester and York, and patients may prefer to be seen at these clinics.

If you have trouble requesting HTLV testing, or have any questions, please contact us directly via email or telephone:

- Email: [imperial.hlv@nhs.net](mailto:imperial.hlv@nhs.net)
- Telephone: 0203 312 6604 or 0203 312 1521.

Kind regards,

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