



Welcome to the 14th HTLV National Register Newsletter

Thank you for your continuing contribution to the HTLV National Register, which is now in the 22nd year of recruitment. With your support, we have 301 people consented and helping us learn more about HTLV and the impact it has on people's lives. Register participants have provided valuable information on symptoms, wellbeing, quality of life and recently their views on antenatal screening for HTLV. The Register is a collaboration between UK Health Security Agency, NHS Blood and Transplant and Imperial College Healthcare NHS Trust.



Many people on the Register (81%) have HTLV infection but were free of symptoms at recruitment. Of these, 125 (51%) were identified by blood transfusion services and 118 (49%) by specialist clinics. From the health information they provided in up to 8 follow up questionnaires between 2005 and 2022, we found some potential HTLV-associated symptoms came and went, and the onset of severe 'HAM-like' symptoms was 1%. Also, most people responding to the 8th follow up perceived their quality of life was good despite living with HTLV.



UK National Screening Committee (NSC) is reviewing a recommendation for targeted HTLV antenatal screening

Having not accepted the recommendation to screen all pregnant people for HTLV infection, a recommendation to test those from areas considered to have high prevalence of infection has now been submitted to the NCC for review. The outcome is awaited.

In the 8th follow up for the Register, we found that participants supported antenatal screening for HTLV being available in the UK. Among the 99 respondents who shared their views on antenatal screening, 95% indicated support for screening despite acknowledging it would cause moderate anxiety, as is the case for other antenatal screening tests.



However, we acknowledge that most who responded were positive for HTLV infection, and none were pregnant at the time of completing the questionnaire, which means these views may not reflect wider opinion. Further research is important to better understand how pregnant people may feel about this topic. We are considering how we might be able to do this.

Feedback from HTLV European Research Network Conference, 2023

Many researchers shared their work at the recent HERN conference and updated our understanding of how people are affected by HTLV in Europe, as well as their experiences developing improved testing and treatments options for HTLV. It was especially exciting to hear about potential vaccines for HTLV. One study showed promising signs, and researchers are seeking approval for clinical trials.



There were also talks on potential therapies, with clinicians sharing their experiences and case studies. A summary of the conference is available: <https://www.degruyter.com/document/doi/10.1515/nipt-2023-0025/html>.

HTLV Conference 2024 in London

The next international HTLV conference is in London from 2nd to 5th of June 2024. There will be sessions on many aspects of HTLV with talks and workshops from researchers and clinicians from a variety of countries and specialisms from basic science to public health and policy. You can read more here: <https://www.hntl2024.org/>

Progress is also being made internationally

While lots of exciting research is happening in the UK, there has been progress on improving HTLV prevention globally. The Pan American Health Organisation (PAHO) has been working on guidance for diagnosis and the expansion of HTLV antenatal screening and hosted a workshop on this topic. You can read more about the workshop here: <https://iris.paho.org/handle/10665.2/59463>



New tests for HTLV in final stages of development

There are new HTLV tests in development in Brazil and Japan that are showing promise as better options for diagnosis. These are rapid point-of-care screening tests that detect antibodies for HTLV without requiring expensive instruments and laboratory equipment. This could make testing easier and cheaper globally, increasing diagnostic opportunities and supporting our understanding of HTLV around the world.

For those affected by HTLV - support is out there



If you are finding your diagnosis daunting, confusing or feel that you are alone, please speak to your clinical team. They can put you in contact with other people with HTLV, who are part of a growing peer-to-peer support network.

You can find more information about HTLV at The National Centre for Human Retrovirology <http://www.hntl.eu/> or HTLV Aware website <https://www.hntlaware.com/>

Other upcoming events

- International HTLV Awareness Day on 10 November 2024



Links

- International Retrovirology Association, IRVA, found here: <https://htlv.net/what-is-irva>
- HTLV Guidance on the Government website, located here: <http://www.gov.uk/guidance/human-t-cell-lymphotropic-virus-htlv-national-register>

Contact Us

If you have suggestions on what you would like to see in future newsletters, please send us an email or write to the address provided below – we are always looking for ways to improve the information we provide you:

The HTLV Register htlvregister@ukhsa.gov.uk