



Welcome to the 12th edition of the HTLV National Register Newsletter!

New register coordinator

My name is Zoë Gibney and I am the new HTLV National Register coordinator! I am proud and excited to be part of one of the only two actively recruiting registers in the world and I hope to help bring more attention to HTLV in both the general population and the research community.

Follow up 7 is on its way to you

- We will be conducting our 7th follow up this Autumn by sending out an updated self-completion questionnaire to everyone who has been on the HTLV register for at least 12 months. We conduct follow-ups every 2 years to understand more about possible signs and symptoms of HTLV-associated diseases and to construct a clearer and more comprehensive picture of how HTLV affects people.
- The questionnaire takes 5-10 minutes to complete and your participation is vital for the success of the register and our research into HTLV.
- Please complete the questionnaire even if you have **no symptoms** as it is just as important to know if you do **not** have symptoms as it is to know that you do.
- 2019 marks the 16th year of the register and currently, we have 261 people living with HTLV enlisted on our register.
- Since the register began, we have found the following reassuring findings: **none** of the register participants have developed Adult T-cell Leukaemia/ Lymphoma (ATLL), but some have reported symptoms suggestive of HTLV-1 Associated Myelopathy (HAM).

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 clinician. They can put you in contact with other HTLV patients who are part of a growing peer-to-peer support network. The networks are supported by personnel from the Clinical Trials Centre at St Mary's Hospital and are a great way to discuss life with HTLV, outside the medical world.
- You can find more information about HTLV on the new HTLV website www.htlv.eu and also at www.htlvaware.com.

Research Virology Conference, Belfast: April 2019;

NHS Blood & Transplant Consultant Virologist, Dr Heli Harvala presented on the identification of HTLV in blood donors and testing procedures for HTLV at the UK Clinical Virology Network meeting. Her talk was given to

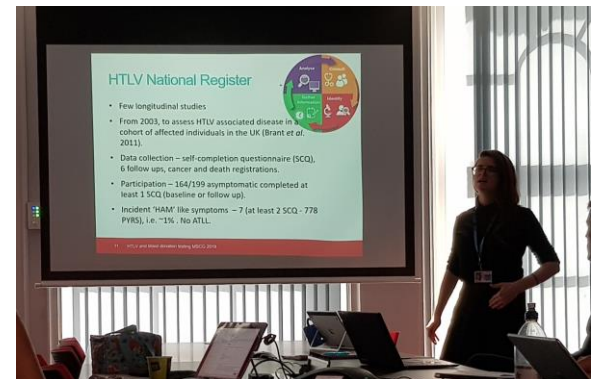


Fig. 1 Presenting on HTLV at NHS Blood & Transplant clinical meeting

improve awareness of how to detect and diagnose HTLV infections and spread general awareness of HTLV within the clinical community.

19th Conference of the International Retrovirology Association: HTLVs and associated viruses, Lima: April 2019 :

The conference stressed the importance of screening all tissue donors for HTLV, provided an update on treating HAM patients with Mogamulizumab and how early diagnosis is important because patients with early disease show best response to treatment, and described the high rates of lung disease in HTLV-1 patients in Australian Aborigines and HTLV-1 patients in Belem in northern Brazil.

Finding more about HTLV in the UK

- Although there is no cure for HAM, treatments for inflammation of the spinal cord and symptomatic treatments for weakness, stiffness and pain are available.
- There are various lines of treatment for ATLL depending on the stage and sub-type of the disease – more information can be found at www.htlv.eu.
- Currently, there is no treatment to eradicate the HTLV-1 virus, however, 90% of people infected with HTLV-1 don't develop any HTLV-1-associated complications.

How is HTLV passed on?

HTLV can be transmitted from mother to child, through sex, and through the use of unsterilised blood and tissue. However, new research has shown that the religious practice of Matam and Tatbir (https://wwwnc.cdc.gov/eid/article/25/4/18-0984_article), which involves cutting or whipping oneself with blades (see figure 2), practised by some Shia Muslims, was the probable source of transmission of HTLV-1 in 11 men in the UK, identified since 2014. During the ritual, men sometimes share blood-stained blades and although dipped in antiseptic solution, this measure is not adequate to prevent HTLV transmission. Recent guidelines, written with the involvement of local community leaders, stress the importance of not sharing equipment, of ensuring that blood is not splashed onto other men's wounds during the practice, and of getting an HTLV test.



Fig.2 Matam and Tatbir

Important dates!

- **World HTLV day: November 10th, 2019** – only the 2nd ever - <https://htlv.net/whatsnew>
- **Public and Patient Involvement Event, London: November 20th, 2019.** Please email imperial.htlv@nhs.net for details and attendance information.
- **The first World Health Organisation (WHO) HTLV burden of disease meeting, Tokyo: November 13th-14th, 2019.** A consultation to help the WHO better understand the impact of HTLV infections globally.

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:

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