



## Welcome to the 13<sup>th</sup> Edition of the HTLV National Register Newsletter!

My name is Ruth Wilkie and I am the new HTLV National Register coordinator! I recently joined the team having previously worked on Coronavirus (COVID-19) and malaria. I have a particular interest in viruses and communicating science in ways people can easily understand. I'm really excited to join the ongoing HTLV research being done in the UK!



From Friday 1 October 2021, a new organisation, the UK Health Security Agency (UKHSA) became fully operational and has taken on board the responsibilities of Public Health England (PHE) relating to infections, including the HTLV National Register.

## World HTLV Day webinar: 10 November 2021 at 11am GMT



Join us in a virtual meeting on World HTLV Day organised by Carolina Rosadas and help us develop a plan to tackle HTLV. This interactive online meeting "Webinar HTLV World Day: International health policy forum for the elimination of HTLV" is brought to you by HTLV Channel and Pan-American Health Organization, with the support of the National Centre for Human Retrovirology (NCHR), Imperial College Healthcare NHS Trust, London. The webinar will discuss public health policies aimed at people living with HTLV. Experts from different countries will share experiences and good practice and we will be able to discuss

strategies for stopping the virus from spreading. Your input as someone living with HTLV would really help our discussions. We hope to see you there!

### Register

[English](#)

[Portuguese](#)

[Spanish](#)

## Follow up 8 is on its way to you

- we will be sending the eighth National HTLV follow up out to you soon
- we have also included some questions on COVID-19 this year
- almost 300 people affected by HTLV are on board and your feedback is helping us gain a better understanding of HTLV infection
- the good news is that after 18 years of the register we have seen very few go on to develop HTLV-related symptoms
- at the last follow up 65% said there was no impact on pain, anxiety, mobility, and ability to do normal everyday activities without help.

Please do complete the survey, even if you have **no symptoms** - it is just as important to know if you do **not** have symptoms as it is to know that you do. This year we hope to give you the opportunity to complete the form electronically.

## World Health Organization publishes recommendations on a strategy to tackle HTLV infection globally

The World Health Organization now officially recognises HTLV infection and in April 2021 published 12 recommendations. The report acknowledged how important HTLV testing is for monitoring how

many people have the infection and providing support for those affected. It made suggestions on several aspects of research, and also advised incorporating the management of HTLV into existing clinical guidelines of practice.

### **Feedback on Public and Patient Involvement Event - Adine Adonis; Clinical Specialist Neurophysiotherapist, NCHR, Imperial College Healthcare NHS Trust**

We wanted to hear about peoples' experiences living with HTLV and what their healthcare concerns were. We successfully obtained funding to explore, develop and have this conversation. This year we have been hosting a series of engagement workshops to explore people's experiences of living with HTLV, the issues they wanted to focus on and what they wanted from healthcare providers. We have gathered so many rich stories and information that people wanted to make sure we heard. There are 2 more sessions planned on the **15 December 2021 at 1:30pm via Zoom and March 2022.**

We are analysing this information and developing plans on how to tackle these areas. The overwhelming messages from the participants are that this is the start of the conversation, not the end, and that meeting up with others who have HTLV infection had many benefits including making people feel less isolated.

*"We can add our voices together for change...change happens when people collectively make it so, that was the turning point for me, to know that there are other people who can add their voice to mine. and push for research."*

*"It has been really useful in terms of knowing that I'm involved in change."*

### **Our advice about COVID-19 vaccination for those with HTLV infection from the NCHR**

- Most will require an initial 2 doses of vaccination AND a booster dose six months later.
- Some people will require a third dose during their vaccination course and a booster dose at a later stage. This group will be contacted separately by the clinic.
- See your GP or visit the NHS COVID-19 vaccination website to arrange a vaccination. If you do not have a GP or are experiencing difficulty arranging vaccinations, please contact your clinic who may be able to arrange this for you.
- If you have concerns about the vaccine that you would like to discuss, please contact the NCHR and discuss this with the clinical team.

### **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 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](#) or [HTLV Aware website](#).

### **Important upcoming events:**

- World HTLV Day Webinar on 10 November 2021
- [HTLV 2022 Virtual Conference](#), Melbourne 8 to 11 May 2022
- HTLV European Research Network conference – TBC



### **Links**

[International Retrovirology Association, IRVA](#)  
[HTLV Guidance on the Government website](#)

### **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**, NHSBT/UKHSA Epidemiology Unit. 61 Colindale Avenue. London NW9 5EQ. [htlvregister@phe.gov.uk](mailto:htlvregister@phe.gov.uk)