



Public Health
England

HTLV National Register Newsletter

Issue 11, June 2017
htlvregister@phe.gov.uk

Welcome to the 11th edition of the HTLV National Register Newsletter!

New register coordinator

Hello! My name is Bhavita Vishram and I am the new co-ordinator of the Human T-cell Lymphotropic Virus (HTLV) National Register replacing Katy Davison. I am excited and thrilled to be part of this team; in my new role, I have been given the challenge of increasing the number of participants recruited and improving engagement of those already taking part. The more individuals we have participating in our long term follow up, the more we can learn about HTLV associated disease. For me to meet this challenge, I need YOUR help. Please read on to find out more about how you can help and why participation matters. Thank you to everyone involved in the HTLV National Register for their continued support.

Bhavita Vishram

Recruitment is everything

- Our UK register is one of only two HTLV registers still recruiting in the world. To take part, you must be diagnosed with HTLV virus – but asymptomatic – i.e. symptom free. Please speak to your clinic to find out more.
- In 2017, the register reached its 14th year. There are now 249 individuals affected by HTLV who have given consent to participate, these were recruited by the four HTLV specialist clinics and NHS Blood and Transplant.

Follow up 6 is coming your way!

- This summer, we will be undertaking **the 6th follow up** by sending follow up questionnaires to everyone who has been on the register for at least one year.
- Follow ups are done every two years. The information you provide about your health helps us to understand more about the possible signs and symptoms of HTLV associated diseases.
- Your engagement in follow up is crucial – so if you receive a questionnaire PLEASE complete and return it. The more responses we get, the more likely we can determine if our findings are statistical significant observations and not chance findings.
- Don't hesitate to contact us if you need help completing the form.

Support is out there

- The National HTLV Patient Forum offers support to anyone affected by HTLV. If you want to talk with other patients about HTLV, come along to the meetings held at St. Mary's Hospital, London. For more information please contact HTLVpatientforum@gmail.com. I presented at the patient forum in January of this year and I will be presenting at more dates in the future.



Attending the HTLV
Conference, Japan

Please do look out for me and my colleagues – it's an opportunity to ask questions and for you to learn more about the register.

- You can find more information about HTLV in general at the following websites:
<http://www.htlvaware.com/>
<http://www.htlv1.eu>

Events - HTLV International Conference

- In March 2017, the global conference was held in Tokyo. HTLV is endemic in Japan.

International patient support groups

- There were two guest of honour speeches by the president of the Japanese (President of the Patient Association NPO Smile Ribbon) and Brazilian (Todos Juntos na Prevenção do HTLV) patient groups. The Japanese patient group has been important in lobbying about the importance of HTLV to the Japanese government. (<https://www.smile-ribbon.org/>)

Science

- We presented a scientific poster titled 'Prevalence of HTLV attributable symptoms in the UK asymptomatic cohort'. From your responses to our questionnaires, we found that over 12 years the presence of symptoms appeared to change over time. However, when analysing the data statistically, we found that the change was not significant and may have occurred by chance. This could be partly due to the small number of questionnaires returned to us, which is why every follow up is very valuable, so please return follow up 6 questionnaire if you receive it.
- There were some interesting presentations on studies on HTLV prevalence conducted in blood donors in Japan and the US. In the US the prevalence is higher among younger blood donors with ongoing transmission through sexual contact and injecting drug use. In Japan, the prevalence is higher among older blood donors with mother to child an important route of transmission.

Finding more about HTLV in the UK

- Public Health England monitors HTLV in the UK. In England and Wales there are around 90 new diagnoses each year.
- Although there are two types, most patients were diagnosed with HTLV-1 (86%).
- Women are more affected than men, and most infections were associated with endemic countries.

Contact us

If you have something you would like us to report in the newsletter that you don't think we are covering, please send your suggestions to the HTLV register email address below and we will be happy to consider them:

The HTLV National Register NHSBT/PHE Epidemiology Unit. Public Health England. 61 Colindale Avenue. London NW9 5EQ. htlvregister@phe.gov.uk



Smile ribbon badge sold at 500 yen (£3.50) have made a major contribution to the patient group campaign.



NPO smile Mascot – who travels all around the country with the aim of bring joy and smiles to people.