



**ashm**

Supporting the HIV, Viral Hepatitis and Sexual Health Workforce

## HTLV-1 Special Interest Group Roundtable 2

8/11/17

National Convention Centre, Canberra

HTLV-1 is demonstrably causing significant disease in Central Australia, and must be addressed as a national priority. Much of the work required will need funding and investment, and any funded response must be led by Indigenous groups. Many solutions are already available, but require culturally appropriate implementation, while other areas require significant research.

### Priorities for work:

- Define the epidemiology of HTLV-1 in a wider fashion across Australia
- Guidelines for the testing and clinical management of HTLV-1 are required, both for Australia and internationally
- Identify, validate and write guidelines on ongoing monitoring required for a HTLV-1 positive person, including a mechanism to identify people with early disease e.g. spirometry, time to walk, HTLV-1 proviral load
- A literature review on the use of HTLV-1 proviral load as a clinical monitoring tool should be prepared as background for the above
- Treatment research on HTLV-1 is required, for both PrEP and treatments for those already positive
- Culturally appropriate public health guidelines and a public health response to HTLV-1 should be developed – breastfeeding advice at least for women known to be positive. Partner notification should also be considered as a priority
- Dr Genoveffa Franchini has a developed vaccine in the freezer of her lab. She was previously unable to generate interest from drug companies to develop this further, but is happy to collaborate to continue the development. Australia is very well positioned to lead vaccine development including potential clinical trials in the future.
- Information available on HTLV-1 from the WHO needs to be updated
- Advocacy for wider access to HTLV-1 proviral load testing is required, including a submission to the PBAC
- Strong community engagement on HTLV-1 is required. This should include a yearly feedback meeting for affected communities, including public health, clinical and basic science topics, to inform them about how research conducted in their communities has been used. This could be run by the Australian Academic Health Research Translation Centre, among others

**Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM)**

Locked Bag 5057 Darlinghurst NSW 1300 | Level 7, 46-56 Kippax Street Surry Hills NSW 2010

T +61 2 8204 0700 | F +61 2 9212 2382 | E [ashm@ashm.org.au](mailto:ashm@ashm.org.au) | W [www.ashm.org.au](http://www.ashm.org.au)

ABN 48 264 545 457 ACN 139 281 173 CFN 17788