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Supporting the HIV, Viral Hepatitis and Sexual Health Workforce

# 2016 HTLV-1 Round Table – Outcomes and recommendations.

Tuesday 15 November 2016, 4:00 – 7:30pm

The 2016 HTLV-1 roundtable came to the clear conclusion that there are high rates of HTLV-1 infection, morbidity and mortality in Indigenous remote communities. Ongoing studies are essential to prevent multiple modes of transmission including culturally sensitive practices and mother-to-child transmission. This research must be led by appropriate Central Australian Indigenous community representatives. This requires the development of a research model in which central Australian Indigenous communities and other stakeholders, such as the Tangentyere council and Aboriginal Medical Services, are engaged in primary language to develop an Indigenous controlled program which interfaces with well-resourced biomedical research centres in capital cities.

Two local Indigenous people (one man and one woman, as dictated by cultural practices) who are skilled in Aboriginal Languages and able to communicate with non-Indigenous researchers are required to facilitate the development of this structure. Each Indigenous Research Officer will be able to communicate in two to three local Indigenous languages. Coverage of language groups further from Alice Springs will require additional staff. A critical component of this will be to provide extensive training to these individuals in all relevant aspects of HTLV-1 infection in order to improve the health literacy of community members in this area. These individuals will be extensively trained in the medical aspects of HTLV-1 infection and when ready they will be able to train a new contingent of community. This will ensure that a virtual research community is built that respects the Indigenous ownership of research into HTLV-1, an infection that contributes to the substantial burden of disease and premature mortality in Indigenous communities.

Recommendations: Establishing an HTLV-1 community interface that will form the central leadership of a research initiative that connects community to a research consortium of primary health providers, infectious disease clinicians, virologists, drug and vaccine researchers, diagnostic laboratory scientists, public health specialists and epidemiologists.

**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