The HTLV-1 Longitudinal Study

Why this research is needed:

The human T-cell leukaemia virus type 1 (HTLV-1) is a retrovirus that establishes life-long infection. While the majority of people with HTLV-1 do not appear to manifest symptoms, in a small proportion the virus causes (up to 10%) an aggressive form of leukaemia, adult T-cell leukemia (ATL), and a debilitating progressive neurological disease, designated HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP)[1,2]. HTLV-1 has also been associated with a number of inflammatory and infectious conditions[3]. Significant advances in our knowledge of HTLV-1c infection in central Australia have been made during the past decade, which indicate that the adult prevalence of HTLV-1 infection is among the highest ever reported, and that infection is associated with several diseases, of which the most clinically significant is lung disease[4-6]. Hospital-based seropositivity rates suggests that HTLV-1 infection is also common in Western Australia (WA)[7]; however, there has been no epidemiological research in WA communities to determine prevalence of HTLV-1 infection or associated diseases. During the 2018 HTLV-1 Forum held in Alice Springs, a consensus was reached that priority be given to a longitudinal study to establish the impact of HTLV-1 infection on the burden of disease in remote central Australian communities.

What this research will do: This study will engage central Australian communities where significant HTLV-1 prevalence has been discovered, and extend this baseline cohort through a prevalence study in several communities in the Ngaanyatjarra Lands, in preparation for commencing a longitudinal study with these communities. Our field research team will visit study communities in the Ngaanyatjarra Lands and around Alice Springs for consultation and to develop health literacy resources in primary language. Local Aboriginal workers/ representatives will be invited to work with the research team, participating in the initial consultation sessions with their communities and support recruitment and study activities.

In the Ngaanyatjarra Lands, field research teams will make a series of visits to participating communities to collect clinical samples and observations, data which will be analysed and findings fed back to communities. With appropriate consents, participants in the Ngaanyatjarra study will join those from communities around central Australia as the baseline cohort for the larger longitudinal study in preparation.

How this research will be used: This study will provide important information regarding the HTLV-1 epidemiology in remote WA communities at the Ngaanyatjarra Lands, which will in turn be useful for determining HTLV-1 endemic area in the central desert area that will inform national strategies to control HTLV-1 infection. It will also establish the baseline cohort for planned HTLV-1 longitudinal study in central Australia.

Project details

Lead partner: Baker Heart and Diabetes Institute
Collaborating partners: Ngaanyatjarra Health Service
Key contact: Dr Mohammad Radwanur Talukder
Email: radwan.talukder@baker.edu.au
Phone: 08 89590105

Australian Government
National Health and Medical Research Council

NHMRC

NHMRC accredited
Centre for Innovation
in Regional Health

References

1. Murphy EL, Hanchard B, Figueroa JP, et al. Modelling the risk of adult T-cell leukemia/lymphoma in persons infected with human T-lymphotropic virus type I. *Int J Cancer* 1989; **43**(2): 250-3.
2. Gessain A, Mahieux R. Tropical spastic paraparesis and HTLV-1 associated myelopathy: clinical, epidemiological, virological and therapeutic aspects. *Rev Neurol (Paris)* 2012; **168**(3): 257-69.
3. Schierhout G, McGregor S, Gessain A, Einsiedel L, Martinello M, Kaldor J. Association between HTLV-1 infection and adverse health outcomes: a systematic review and meta-analysis of epidemiological studies. *Lancet Infect Dis* 2020; **20**(1): 133-43.
4. Einsiedel L, Woodman RJ, Flynn M, Wilson K, Cassar O, Gessain A. Human T-Lymphotropic Virus type 1 infection in an Indigenous Australian population: epidemiological insights from a hospital-based cohort study. *BMC public health* 2016; **16**: 787.
5. Einsiedel L, Pham H, Wilson K, et al. Human T-Lymphotropic Virus type 1c subtype proviral loads, chronic lung disease and survival in a prospective cohort of Indigenous Australians. *PLoS neglected tropical diseases* 2018; **12**(3): e0006281.
6. Einsiedel L, Cassar O, Goeman E, et al. Higher Human T-Lymphotropic Virus Type 1 Subtype C Proviral Loads Are Associated With Bronchiectasis in Indigenous Australians: Results of a Case-Control Study. *Open Forum Infectious Diseases* 2014; **1**(1): ofu023-ofu.
7. Grivas, R., Freeman, K., & Baird, R. (2014). Human T-lymphotropic virus-1 serology in the Northern Territory: 2008–2011. *Pathology*, *46*(7), 644-648.