



**Australian Government**

**Department of Health**

On August 28 and 29 in Alice Springs a Collaborative Forum on HTLV-1 was convened by the Central Australian Academic Health Sciences Centre and the Australian Government Chief Medical Officer. The forum included Aboriginal leaders, community and patient representatives, researchers, representatives from Aboriginal community-controlled health services, clinicians, public health officials, and representatives from Commonwealth and state and territory health departments. The forum reaffirmed the importance of Aboriginal leadership in this process and agreed on the following statement.

### **HTLV-1 in Central Australia**

Human T-cell Lymphotropic Type-1 (HTLV-1) is a virus that occurs in diverse communities around the world and has been present among Aboriginal people in Central Australia for thousands of years. The type of the virus found in Central Australia, type C, is unique to our part of the world. Preliminary data suggests high rates of this virus in some communities in Central Australia.

Current evidence shows that infection with this virus is not likely to cause disease in a majority of people. International research shows that, in a small proportion of people after many decades, HTLV-1 causes a rare form of leukaemia and/or a spinal cord disease. Studies have suggested associations with other diseases but it is not yet known whether it causes those diseases or not. The true burden of disease of HTLV-1 in our communities needs further research.

HTLV-1 can be prevented in adolescents and adults by safe sex and not sharing needles. The significant health benefits of breastfeeding are well established and, whilst transmission through breastfeeding can occur, current evidence does not yet warrant a change in practice in Central Australia.

Once acquired, HTLV-1 is present for life, but there are management options for most of the diseases that may arise from it. Further treatment options are being investigated.

There needs to be a major long-term study, developed in partnership with the affected communities, to work out exactly what impacts this virus is having on people in Central Australia.

We will be working to develop better access to effective testing options together with clinical guidelines for HTLV-1 associated conditions. Although the forum did not recommend widespread testing at this stage, more research needs to be done to understand where the virus occurs.

We will continue to work collaboratively to integrate community priorities, research findings, and clinical and public health guidelines into a coordinated approach to HTLV-1 in Australia.

Considering the wide range of health concerns of Aboriginal people in Central Australia we need to continue to strengthen primary health care, address the broader social determinants of health and enable healthy lifestyles.

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