



**Australian Government**

**Department of Health**

## **Summary Outcomes of Collaborative HTLV-1 Forum Alice Springs, 28-29 August 2018**

### **Day 1 – 28 August 2018**

The Collaborative HTLV-1 Forum (the Forum) commenced at 2pm on 28 August 2018, with the Welcome to Country delivered by Aunty Doris Stuart and the response given by Professor Brendan Murphy.

Professor Murphy delivered the Forum's opening statement by thanking everyone for their attendance and interest, noting that it was fully subscribed. Professor Murphy said HTLV-1 is an enigmatic virus and the Aboriginal Community needs to be front and centre of the response.

Ministers Wyatt, Hunt and Scullion are all very supportive and interested in the outcomes of the Forum. It was also noted the Central Australian Academic Health Science Network and Central Australian Aboriginal Congress were already undertaking work in relation to HTLV-1.

It was acknowledged there is some funding available for emerging communicable diseases but there was still more work to be done before it can be decided how this should be directed.

This Forum has a focus on people in Central Australia with HTLV-1 but we will need to keep informed about international research and responses to HTLV-1.

It is expected the outcomes of the HTLV-1 Forum will result in:

- collaborative approaches to research;
- community engagement to direct culturally-appropriate approaches and priorities; and
- future epidemiological work – noting we are still in the information gathering phase.

Presentations were given on the following topics with some key points included.

## **Professor Damian Purcell**

### *Introduction to the virology of HTLV-1c present in Australia.*

- HTLV-1 is an important but neglected pathogen that infects more cell types than HIV.
- Unlike HIV, HTLV-1 causes T cell proliferation rather than T cell death.
- The percentage of infected T cells (pro-viral load) predicts HTLV-1-associated disease.
- It is thought that recruitment of HTLV-1 infected T cells into an immune response leads to HTLV-1-associated inflammatory diseases.
- The HTLV-1c strain present in Australia has some significant differences in the genes and structure that may contribute to different disease outcomes (e.g. inflammatory disease vs leukaemia).

## **Professor John Kaldor**

### *Epidemiology of HTLV-1 infection in Australia and HTLV-1 infection; all-cause mortality and the development of disease other than HAM/TSP or ATLL: a systematic review.*

- Substantial burden of infection in Central Australia.
- Limited high quality studies for other parts of Australia but prevalence appears to be very low.
- HTLV-1 is associated with certain diseases and mortality, including adult T cell leukaemia/lymphoma (ATLL) and HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP)
- Lifetime incidence of each conditions is 3-5%.
- Not many prospective studies so association or causation is difficult to determine.
- Need for more studies that are able to identify relative contribution of HTLV-1 to burden of important diseases – alongside other contributors.
- Cohort studies should include the range of possible disease outcomes.

## **Dr Vicki Krause**

### *Public Health and Clinical responses on the Northern Territory.*

- 1,200 HTLV-1 notifications since 1994.
- Annual notifications fluctuate with testing rates but range from 20 to 120 notifications per year.
- 4 cases were non-Aboriginal people.
- Most people affected do not have symptoms.
- HTLV-1 sequelae seen after many years of infection.
- There is little or no disease in young people.
- ATLL and HAM/TSP are also notifiable in NT - Only 2 notified to date– 1 HAM and 1 ATLL.
- 20% notifications from WA and SA.
- Definitive population studies needed.
- We need to better explain the disease, especially to pregnant women.

## **Dr Lloyd Einsiedel**

### *Researching HTLV-1 and occurrence and clinical responses in communities.*

- High HTLV-1 sero-positivity rates in remote Australia were first reported in 1988, but only in the last decade has our understanding of the significance of this virus in Central Australia substantially increased.
- Studies within Central Australian communities and with patients from Alice Springs Hospital have consistently report HTLV-1 infection rates exceeding 33% (some as high as ~50%). Dr Einsiedel's studies to date have recruited 823 people to explore the prevalence of HTLV-1 infection and its associated diseases in remote communities.
- In these communities, HTLV-1 significantly increased risk of chronic lung disease and neurological problems.
- Consistent with the biological mechanism of HTLV-1 associated with inflammatory disease, chronic lung diseases, neurological problems, uveitis and infective dermatitis were associated with higher HTLV-1 pro-viral load.
- These findings for chronic lung diseases are similar to those of a large hospital-based case control study which also show increased risk of death among subjects with higher HTLV-1 pro-viral load.

## Panel discussion

The four presenters formed a panel for a question and answer session and broader discussion on the presentations. The key comments arising were:

- Consideration of how additional testing should be done for HTLV-1, especially in pregnancy. This will need more resources in terms of guidelines and advice for both health professionals and for those people who are found to have HTLV-1.
- These additional HTLV-1 resources need to include information for patients in their primary language, pre- and post- test counselling and after care.
- We need more information on the timing and nature of testing and response(s) to address the needs of the individual and the stigma. We need to clarify who should be tested, why and under what circumstances.
- More work is needed to study and understand the strains of HTLV-1, noting type C is the one present in people in Central Australia. We need to better understand how the virus works and in particular its influence on the cell's genes, noting disease causation and association are challenging issues.
- The causes of kidney disease and bronchiectasis in people with HTLV-1 need to be better understood and the impact of lung disease in children and its ongoing impact in later life.
- Most people with HTLV-1 associated inflammatory diseases present with disease in adulthood. This is also true for bronchiectasis: more than 80% of adults with bronchiectasis at Alice Springs Hospital were not admitted with chronic lung diseases in childhood.
- We need true prevalence data and to better understand the trajectory of the disease in Central Australia, noting the current literature doesn't reflect this.
- It was brought to the Forum's attention that patients need to be remembered and their care is a priority. Help needs to be provided to people who are affected by HTLV-1. People who are affected should be told of their diagnosis and supported. Addressing patient needs was identified as a key priority.
- We need longitudinal studies and improved public health awareness and health literacy. We need to address the concerns around breastfeeding, what alternatives are available and how this is communicated to HTLV-1 patients.

- There was broad support of a longitudinal prospective study and access to clinical trials. It was acknowledged translational work was important but it will take some time and we need to do other things in parallel.
- We need to better understand the modes of transmission and the risk of transmission from mother to child via breastfeeding prior to any recommendations on changes to breastfeeding recommendations. This work needs to be based on what the community thinks is appropriate and safe.
- There needs to be greater effort on the prevention of transmission especially via sexual contact and we should consider work done on other BBV and STI disease types to inform communication and guide this work.
- There was a view that it would be helpful if the NDIS<sup>1</sup> recognised bronchiectasis as a disability, which would mean affected people would be able to get physiotherapy. This is of proven benefit for bronchiectasis.
- The issue of co-morbidities needs to be carefully considered and will require a broad collaborative approach, noting we don't know how HTLV-1 impacts individuals' health outcomes and co-morbidities among people without HTLV-1 associated diseases.
- While the immediate focus is on communities in Central Australia, the impacts of HTLV-1 may be evidenced in several jurisdictions and a collaborative cross-jurisdictional approach is needed.
- We need new clinical guidelines which address HTLV-1 specifically.
- It was noted the Australian Government Department of Health will monitor outcomes from the WHO and its work on HTLV-1. It expects to be informed about the work of the HTLV-1 Technical Reference Group and notes the development of vaccines may be considered as part of that work.
- It was agreed a strong partnership with people living with HTLV-1 needs to be established.

Day one ended 6pm 28 August 2018.

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<sup>1</sup> Ref: Section 24 – *Disability requirements of the National Disability Insurance Scheme Act 2013*

## Day 2 – 29 August 2018

### **Community Feedback**

Attendees of the Forum who were associated with or representing local Aboriginal Controlled Health Services and Aboriginal people participating in research, were invited to meet to discuss issues and develop feedback to the larger group. Unfortunately, Aboriginal people from communities where research is being conducted were not comfortable about attending the Forum.

The key outcomes were summarised by Ms Donna Ah Chee, the CEO of Central Australian Aboriginal Congress and Chair of the Aboriginal Medical Services Alliance of the Northern Territory (AMSANT).

### **Research**

There is support for a longitudinal prospective research model on the two following conditions:

- i. This was **not** to be just talking about HTLV-1.
- ii. It **has to be** about the person with a positive test result and what happens next. This approach must include being able to answer the questions of that person (whatever they may be).

There is support for determining the true prevalence and understanding the impact of the viral load of HTLV-1.

There is also support for using existing serum banks (noting this is the least disruptive to community).

HTLV-1 testing outside of clinical research projects should only be offered if there is treatment for any associated conditions – which should be provided.

We need to differentiate between testing for research or for patient care at a population level and at a clinical level. Population level testing/screening is not supported.

May do more harm talking to community if we don't know enough.

### **Pregnancy**

We know some women who test positive for HTLV-1 are being told not to breastfeed and this needs to be addressed. Pregnant women should not be targeted for HTLV-1 testing, as many of their situations are stressful enough without adding to the burden. We need to do more in the primary health care system and undertake actions and give advice on, for example, how to strengthen the immune system. We need to promote breastfeeding along with messages about the importance of good nutrition.

### **Information Sharing**

There was discussion about how to tell someone about HTLV-1 without causing undue concern. It is important to keep “do no harm” at top of mind in

responding to HTLV-1 (noting some people have been told it's a serious virus for life).

There is a need to correct the misinformation that is in some communities about HTLV-1. The key message should be that the virus is thousands of years old and that for the most part, it is not a problem to a person's health.

### **Other points**

It would be highly beneficial to have a group statement from the Forum (this was released on Friday 31 August 2018).

The Central Australian Academic Health Sciences Network (CAAHSN) must be the lead organisation in the collaborative response.

There are issues around the sexual transmission of HTLV-1 as there is a lack of evidence on who has the virus and its implications. This impacts on the provision of appropriate advice about the virus, noting that there is already a lot of material and guidance on safe sex. This aspect will need further discussion in the future.

Following this, presentations were given by:

#### **Joel Liddle**

##### *Working with communities with HTLV-1*

- Community members are provided information on risks of transmission, what having HTLV-1 means, and how to look after yourself/family if you/they have HTLV-1.
- Messages need to be in the primary language of the community and this usually requires onsite translation.
- Oral and visual aids are valuable as not everyone is familiar with the written words (flip charts/ipads).
- Familial, cultural and language connection credited to the success of the study.
- People now want to know their results and they need the right support and counselling when they are given a positive result.
- People want to talk about their holistic state of health.
- Long term intergenerational support is needed.
- Some factors that may be contributing to the impacts of HTLV- in these communities:
  - Environmental health, housing, lack of autonomy over their health.
- Mobility of people from Central Australian to other regions may result in spread of HTLV-1.

## **Associate Professor Kerry Taylor**

### *Developing an HTLV-1 health literacy program*

- Community information is needed in accessible formats.
- Resource development should involve community members and health professionals.
- Preventative and health promotion messages – posters, flip charts, short DVDs, art works.
- Principle-based messages that relate to a variety of health concerns.
- Links should be made to what is already in place.
- Development of a shared vocabulary.
- Goal is to inform not alarm, through culturally safe engagement.
- All people have the right to make informed decisions.

Questions were responded to during the presentations along with a facilitated discussion. Some key comments were:

- When planning community engagement the language needs to be specific for the community where the research is being done.
- Currently HTLV-1 test results show a positive or negative result but do not test for pro-viral load.
- The language also needs to be made contextual, as similar words can have different meanings in different communities.
- Each community will need its own strategy and the goal is to inform people not alarm them. This is where the development of shared vocabulary will be very useful.
- This discussion highlighted the need for very clear messaging to individual Aboriginal communities as well as the wider community.

Break out groups were formed to discuss 3 main topics – the development of clinical and public health guidelines, research and community messaging.

# 1. The Development of Clinical and Public Health Guidelines

## PUBLIC HEALTH GUIDELINES

We need to:

- Underpin this work with community involvement and input.
- Look at existing guidelines which include reference to HTLV-1 and see how these can be updated and or consolidated.
- Review and update blood screening, organ transplant, communicable diseases and breastfeeding guidelines. Note any testing for HTLV-1 in pregnancy will require a research project to inform how and when to advise on breastfeeding, including when to stop. It will also need to consider the availability and feasibility of interventions to inform testing regimes.
- Note that guidelines will not be developed in the short term until more is known about HTLV-1. Close monitoring of activities can inform the process and deliver clear messages about HTLV-1 and what it means for the patient.
- Recommend that HTLV-1 not be routinely tested along with other STIs until there is an appropriate way to assist those people with a positive test to understand, and receive counselling, on what this means for them. This approach can be changed in the future to a test and treat model of care once more information becomes available.
- Ask the Communicable Diseases Network Australia (CDNA) to advise on national notification of HTLV-1.
- Consider biohazard (occupational exposure) guidelines for HTLV-1.
- Consider clinical guidelines for others who may be at risk and consider consolidating a number of guidelines for associated diseases in collaboration with community for addressing HTLV-1.
- Note there are issues of skin health, lung disease, neurological disorders and leukaemia all manifesting in communities and in people with and without HTLV-1.
- It was also noted in Dr Einsiedel's presentation, rates for lung diseases and neurological diseases are higher in adults with higher HTLV-1 pro-viral load.
- GPs want advice. PHN liaison through the Health Pathways project should be considered.
- Any person with a confirmed diagnosis must be offered treatment for any associated conditions, where available.
- Guidelines should be able to accommodate health professionals work settings noting primary health care in the field is delivered differently to that in a hospital setting.
- The guidelines need to be clear on treatment priorities.

## **CLINICAL GUIDELINES**

There is a need to:

- Ensure that the Northern Territory guidelines include HTLV-1 in biohazard exposure protocols.
- Consider other at-risk populations (Needle and Syringe Programs, prisons and other intravenous drug users).
- Consolidate existing clinical guidelines directed at optimum treatment of associated diseases of HTLV-1 and follow-up for bronchiectasis, skin health and other infections.
- Include testing on HTLV-1 associated diseases.
- Update for remote use, which include Central Australian Rural Practitioners Association manuals.

## **2. Research**

We need to:

- Conduct a longitudinal prospective study which looks at risk factors (clinical, immunological); disease progression and associations, and viral and host factors and involve control/comparison groups. This work needs to start in Central Australia through special collections and quantitative research.
- Undertake prevalence studies in other locations and to utilise the lessons learned in Central Australia.
- Where possible, use stored serology samples and also consider other options.
- Consider establishing pro-viral load validation/comparison testing, regulatory endorsement and options for scaling-up.
- Better understand mother to child transmission rates and broader transmission rates and transitioning from breastfeeding to solid foods;
- Better understand sexual transmission and prevention.
- Develop a consensus approach to research via partnerships with communities via consortia.
- Consider new treatments or preventions (e.g. vaccine), including those from overseas and those available through clinical trials.
- Translate research into primary health care and community-appropriate language.

## **3. Community Messaging**

We need to:

- Describe a shared understanding of where we are now and where we are going. This includes both for the community and in the research and there needs to be consensus about these approaches.
- Disseminate the message that this is an ancient virus and people have survived for a long time.

- ✓ Noting there is no one to blame for this virus and this is not just a disease in Aboriginal people.
- ✓ It is mostly preventable and can be managed if people acquire it.
- ✓ Messages should be integrated into holistic health messaging.
- Ensure that information provided to the community is in the primary language for each region (there are differences for each) and use social media to get messages out to people.
- Use plain English in government and other types of communication.

**Meeting close:**

Professor Murphy thanked everyone for their participation and sharing some diverse views. He concluded that we have a clear path forward supported by community leadership.

The draft communique was formulated and agreed. It was noted a plain English version may also be required for dissemination to communities.

**Next Steps:**

- Researchers and clinicians present will develop a longitudinal prospective study proposal, led by CAAHSN, for consideration by the Australian Government Department of Health. This will be done in a partnership (consortium) model between different research institutions.
- The communique to be published on the Department of Health website once finalised. This was published on 31 August 2018, available at: <http://www.health.gov.au/sexual-health>
- The Department of Health will report back to Ministers on the Forum outcomes.

Day two ended at 5:10pm.