

## Public Administration Committee

---

**From:** Andrew York <ayork@leukaemia.org.au>  
**Sent:** Thursday, 8 May 2014 10:16 AM  
**To:** Public Administration Committee  
**Subject:** Attention Ms Lauren Mesiti, Committee Clerk - Leukaemia Foundation of Australia's Submission in response to the Standing Committee On Public Administration Inquiry into the Patient Assistance Transport Scheme (PATS) in Western Australia.  
**Attachments:** Leukaemia Foundation submission to WA PATS May 2014.pdf

Dear Hon Liz Behjat MLC Chair,

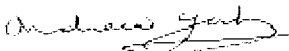
The Leukaemia Foundation welcomes the opportunity to contribute the following submission to the WA Leukaemia Foundation of Australia's Submission in response to the Standing Committee On Public Administration Inquiry into the Patient Assistance Transport Scheme (PATS) in Western Australia. May, 2014.

The Leukaemia Foundation is Australia's peak body for blood cancer, funding research and providing free services to support people with leukaemia, lymphoma, myeloma and related blood disorders.

This submission has been prepared in conjunction with our staff in Western Australia and we would be happy to assist with further information or explanations as required. For any follow up, please contact Andrew York General Manager on the below details.

We look forward to the outcomes of the review and trust that these will ensure a scheme that better meets the needs of eligible patients and carers in Western Australia.

Yours sincerely,



**Andrew York**

General Manager

Leukaemia Foundation | Vision to Cure. Mission to Care.

20 Gibberd Road Balcatta WA 6021 | PO Box 586 Balcatta WA 6914

T 08 6241 1000 | M 0412 297 770 | E [ayork@leukaemia.org.au](mailto:ayork@leukaemia.org.au)

[leukaemia.org.au](http://leukaemia.org.au) | [facebook.com/LeukaemiaFoundation](https://facebook.com/LeukaemiaFoundation) | [twitter.com/LeukaemiaAus](https://twitter.com/LeukaemiaAus)



Please consider the environment before printing this email

Copyright Leukaemia Foundation. This communication is confidential to the named addressee. No one else may read, print, store, copy, forward or act in reliance on all or any of this communication or its attachment without consent. If you have received this in error, please notify the sender immediately or call 1800 620 420.



# Leukaemia Foundation

---

VISION TO CURE  
MISSION TO CARE

---

Submission in response to the  
Standing Committee On Public Administration Inquiry into the  
Patient Assistance Transport Scheme (PATs) in Western Australia.  
May, 2014.

Contact:

Andrew York  
General Manager Leukaemia Foundation in Western Australia  
Leukaemia Foundation  
PO Box 586 Balcatta WA 6021  
Tel 08 6241 1000 3866 4060/Mob 0412 297 770  
Email [ayork@leukaemia.org.au](mailto:ayork@leukaemia.org.au)

Leukaemia Foundation of Australia's Submission in response to the  
Standing Committee On Public Administration Inquiry into the  
Patient Assistance Transport Scheme (PATS) in Western Australia.  
May, 2014.

The Leukaemia Foundation of Australia welcomes the opportunity to contribute this submission to the Western Australia Standing Committee On Public Administration Inquiry into the Patient Assistance Transport Scheme (PATS) within the state. The Foundation is Australia's peak body for blood cancer, funding research and providing services at no charge to support people impacted by blood cancers such as leukaemia, lymphoma, myeloma and related blood disorders.

Each year there are approximately 1,200 West Australians diagnosed with a blood cancer, with around 250 of these people living outside the Perth Metro area. We estimate that over 6,000 West Australians are currently living with a blood cancer; with around 1,250 of these living outside the Perth Metro area. Of those diagnosed we have provided face to face support to just over 3,000 of these people.

In 2012/13, the Leukaemia Foundation in Western Australia managed a patient accommodation service consisting of 19 home away from home apartments where patients were able to stay at no charge for the duration of their treatment. We provided 2,100 nights of accommodation in these apartments, and a further 690 nights of accommodation in commercial properties in a direct effort to meet patient needs.

We also provided free transport to and from treatment centres in our five vehicles – driving over 110,000kms in the last year alone.

We acknowledge that the PATS service provides a very valuable service to Western Australians assisting regional patients to access life saving, life extending, and quality of life improving services.

The following comments relate to the information detailed in the relevant section of the discussion paper reflecting the Leukaemia Foundation's experience as a NFP service provider within the cancer health sector whose patients utilise PATS:

**1) How adequately PATS delivers assistance to regional people accessing specialist medical care, including:**

Feedback from Leukaemia Foundation patients showed that the PATS scheme was highly valued but could be improved to ensure regional patients are not disadvantaged when accessing medical services. How the PATS rules have been interpreted by various local agencies has made it difficult for us to provide consistent guidance to patients, and we frequently get conflicting feedback from patients who have used the system. Clarity, consistency and transparency around PATS is vital for providing a quality service.

**a) The level of funding applied to the transport and accommodation subsidies provided;**

PATS provides a subsidy towards the costs of travel and accommodation, and we acknowledge it is not intended to meet the full costs of travel and accommodation, or to provide other costs associated with access to specialist appointments.

- However, our rural and regional patients/families face real and genuine difficulties when the primary treatment centres are only located in Perth. The social and family disruption is significant and the PATS assistance only partially recompenses the financial costs involved. Western Australian patients travel the second longest distances in the country (second only

to Northern Territory) to access their cancer services. The allocated funding per kilometre is not adequate for these families with the current travel allocation and the cumulative distances they have to travel during the course of their treatment. We know of several patients who refused treatment due to the difficulty and expenses involved in travelling to Perth. As highlighted in our *Chronic Myeloid Research Report* and *World Lymphoma Awareness Study*, 46% of patients living rurally/regionally were more likely to be very worried about finances and were 77% more likely to have their income reduced. These people could have been much better supported by the system. Through our operations the Leukaemia Foundation has also been made aware of patients who actively avoid pursuing a transport allowance because it was “just too hard” to claim, i.e. the level of stress that they were under did not commensurate to the limited level of funding PATS would provide.

- It is estimated that every two hours, more than one person loses their life to leukaemia, lymphoma, myeloma or a related blood disorder. Blood cancers cause the third highest number of cancer deaths in Australia – after lung cancer and bowel cancer. Haematological cancer can develop in anyone, of any age, at any time. Most blood cancers are incurable and chronic in nature. Treatment for a blood cancer is almost always longer than six months, and should therefore be exempt from the six month re-evaluation rules currently in place. It is an unnecessary burden on this patient group when we know that this timeframe is in line with normal blood cancer treatment protocols.
- The gap for commercial accommodation is prohibitive for most people and the Leukaemia Foundation in Western Australia currently contributes \$163,000 to a hotel stays each year. This is not a long term sustainable option.

#### **b) Eligibility for PATS funding;**

PATS accommodation subsidies are available for people who live 100kms away and whom are required to stay overnight for medical reasons.

- Consideration needs to be given to the 100km limit. Patients who live in towns such as Mandurah, Toodyay, York, Northam or Yanchep are often incapable of making the journey on their own. Treatment times may be delayed, take most of the day, or complications arise causing a tedious journey home. We believe that for blood cancers, a system with identified cumulative kilometres in a period of time should negate the 100km rule. This has been implemented with the NSW IPTAAS fairly successfully. We propose that in Western Australia we implement a rule that if a patient travels 250km in a week to access treatment, they receive PATS.
- There are a number of barriers to clinical trial participation which are often flagged as being protocol related, physician related or patient related. It is important to emphasise the centrality to participation in clinical trials for the rural and regional patient is delineated in their eligibility for PATS. Clinical trials are used to drive medical practice forward and people who access them should not be disadvantaged, they should be supported and ultimately encouraged.
- People participating in clinical trials should have access to PATS. Many people with blood cancers require ongoing support and rehabilitation before, during and after therapy - e.g. people undergoing intensive treatment need to ensure they have full dental services completed before the start of treatment to reduce potentially life threatening infections. People with myeloma suffer bone damage requiring physical therapy

support. These services need to be conducted by people with extensive blood cancer patient experience, which is not readily available in regional areas.

- PATS should be made available for people to access allied health services – which will help improve their quality of life and maintenance of their overall health which will reduce the fiscal burden of the patient on the state healthcare system. Services should be inclusive of dental, physiotherapy, psychotherapy, occupational therapy, speech therapy as well as mental health services.

**c) The administration process;**

The Leukaemia Foundation in Western Australia currently deals with eight regional PATS offices and 67 different referral email/contacts. This is a time consuming exercise in providing immediate care to patients.

- The Leukaemia Foundation believes a centralised electronic processing system would be welcomed by all stakeholders. Any issues could be resolved at the initial application stage and would not need to be revisited, e.g., incorrect completion of forms by referring GPs/specialists/social workers and would outline clear guidelines for completion and submission of documentation. Electronic forms are now available in NSW and will be implemented in South Australia. We would welcome this initiative in Western Australia.
- The PATS needs some formal mechanism to allow appeals against the decisions of the Scheme's administrators. For a majority of our patients living with a blood cancer, treatments in Perth can go between six months and in the worst case scenario up to two years. The triggering of a PATS review for special extension after six months places undue strain on patients and families. The Leukaemia Foundation would support a process for haematology patients to be granted an extension of PATS based on specialist opinion at time of application. The question of eligibility would not rest with PATS staff but with a medical panel qualified to make such judgements. PATS staff should not have liberty to question medical staff recommendations for a scheme aiming to assist needy people to access treatment. Information about the appeal process needs to be more accessible, and patient friendly.
- PATS staff training needs improvement. Patients report bad phone manners, rudeness, lack of knowledge around rules, inflexibility, and receive different outcomes depending on whom they speak with at the office. Some patients know the names of PATS staff that they will not deal with due to poor and inconsistent service delivery. A training program to help administration staff understand the need for empathy, and a customer care focus will make a huge difference to patients and their experience of the Scheme.
- Many patients have reported that they did not know about PATS, or that they are eligible to receive PATS. A more concerted effort to ensure all patients are made aware of their PATS entitlements is very important. Several patients have identified to us that they endured unnecessary hardships due to this lack of information available to them.

It is important for the Leukaemia Foundation to work in collaboration with PATS offices to improve communication and to ensure the health outcomes of people living with a blood cancer are improved.

**d) Whether there is consideration of exceptional circumstances; and**

- As discussed under point c limitations with the scope of the Scheme. The present six month limitation is inflexible and unrealistic for haematology patients. Treatment regimens often last 12 months or longer, e.g. Acute Leukaemia – up to a three-year protocol.

Under the current PATS there is no provision for a family member/legal guardian to accompany an adult patient for inter-hospital patient transfer, or when the patient has been primarily evacuated (eg. Via a RFDS flight).

**2) Any incidental matter**

The definition of a carer in the PATS Policy could be expanded to include clear guidelines around the eligibility of a carer/escort for the purpose of PATS when the patient is unable to manage their treatment alone.

- The Leukaemia Foundation sees the quality of data as an area that needs addressing. This review and any further reviews would be greatly assisted by access to information gathered by all stakeholders. Consultation prior to and during any review would provide a broader view of the effectiveness of the Scheme. For example, the Foundation has also been advised previously by PATS that it does not have the ability to segment data by disease/condition type, meaning that eligibility criteria cannot currently be changed to take disease type into consideration.
- An improvement in the PATS guide under the Further Information section could include the listing of further services providers that provide comprehensive support and or information.
- The Leukaemia Foundation in Western Australia is willing to appear before the Committee to further explain or elaborate on our submission if any questions arise.