

26 November 2013

Secretary  
National Commission of Audit  
Australian Government  
Parliament House  
CANBERRA ACT 2600

By email: [submissions@ncoa.gov.au](mailto:submissions@ncoa.gov.au)

Dear Secretary,

The Leukaemia Foundation welcomes the opportunity to make a submission to the National Commission of Audit with a view to identifying areas of Government activity which impact people affected by blood cancers and with ideas for improvement.

The Leukaemia Foundation is the peak body for blood cancers, funding research and providing free services to support people with leukaemia, lymphoma, myeloma and related blood disorders. Our organisation provides a suite of support services including, information, education programs, emotional support, and referral to expert services, accommodation, transport, and practical assistance including financial assistance. Through our National Research Program, we fund talented researchers with the best ideas to improve blood cancer treatment and to develop novel approaches to improve our understanding of these cancers and with a long term view of finding new cures.

We believe that there are opportunities to improve the impact of some government services and schemes, in particular, we submit that

1. **Regional Development of Australia Fund** – the Leukaemia Foundation partnered with the Australian Government to fund the building of a state of the art patient and family accommodation centre in Adelaide. Partnership schemes like the RDAF, makes establishing a significant facility feasible for a medium tier charity like the Leukaemia Foundation. It is within our capacity to operate and maintain an accommodation facility provided we can secure the funds to establish the facility. Without the RDAF scheme, this would have been beyond our means. We strongly encourage the Australian Government to maintain this or similar scheme to
2. **Patient Assisted Travel Scheme (PATS)** – this is a national scheme which is implemented by health services in the states and territories according to national guidelines. We would like to see this scheme standardised with common core benefits regardless of

where a person lives in Australia. It is an important scheme for rural and regional patients and their carer/family. The community would be better served if this service was provided through an existing national service like Centrelink or Medicare, with provision for online applications with a 24/7 helpline. Assistance should match duration of treatment and enable participation in clinical trials.

### **3. Pharmaceutical Benefits Scheme**

The TGA/PBS provide key services to the Australian community, ensuring that Australians have access to best quality, safe and effective medicines that are cost effective for the management of illness. These regulatory processes were developed in an era before molecular and genetic medicine and need streamlining and synchronisation to ensure that they continue to be fit for purpose and deliver the most cost effective, timely access to therapies for people with blood cancers. There is scope to improve evidence requirements appropriate for cancer, including quality of life measures, to better manage therapies for rare cancer subgroups and to recognise the trend to personalised medicines. Alternative arrangements should be considered for the reimbursement of oncology medicines with timely and transparent reporting. Ideally and wherever possible, our regulatory systems should be harmonised with international criteria to reduce red tape and cost barriers to new medicines and to ensure that Australia remains an attractive country for drug research and development as well as clinical trials.

Yours sincerely,



Chief Executive Officer