

March 2023

Standing Committee on Public Administration
Parliament House
4 Harvest Tce
West Perth WA 6005

Via email: lcpac@parliament.wa.gov.au

Dear Standing Committee on Public Administration

Re: Inquiry into organ and tissue donation in Western Australia

Thank you for the opportunity to provide a submission to the *Inquiry into organ and tissue donation in Western Australia*.

The Leukaemia Foundation is the only national organisation representing all Australians with blood cancer. For over 45 years we have provided a variety of supports and services, and funded life-changing research. We provide evidence-based policy advice and amplify the voices of those affected by blood cancer.

When stem cells in someone's bone marrow get damaged or destroyed because of blood cancer, a life-saving stem cell transplant from a health donor is often necessary to rebuild the body's blood and immune systems.

However, not enough suitable Australians are registered as a donor.

We welcome the World Transplant Games being held in Perth in April, and hope it will build awareness of this issue. The LF is supporting stem cell donor recipients who are competing, including Lauren, who's search for a second bone marrow donor was shared on C7, C9 & ABC and on bus stop ads around Perth in 2012/13. A donor was found in Europe. Now 33, Lauren is celebrating her achievements at the Games.

While acknowledging some of the challenges and opportunities are relevant nationally, this submission addresses the first three Terms of Reference:

- Effectiveness of, and issues with, organ and tissue donation (ToR 1 & 2)
- Opportunities to improve organ and tissue donation rates in Western Australia (ToR 3)

Context: The imperative to improve blood cancer outcomes

This year 19,403 Australians will be newly diagnosed with a blood cancer. This is equivalent to **53 people every day** or one person every 27 minutes.

Over the past 10 years, the **incidence of blood cancer has increased by 47%**, and 135,000 Australians are now living with a blood cancer. Sixteen Australians will lose their life to blood cancer each day and 1 in 3 people diagnosed with a blood cancer will not survive five years after their diagnosis.

Blood cancers require, in many instances, highly specialised and complex care throughout the treatment period. Many blood cancers can have repeated acute episodes of treatments, remission and relapse.

Some blood cancers can become refractory to current treatments, leaving patients with very limited options. Treatments are often aggressive, highly toxic and can result in debilitating lifelong side effects.

Stem cell (bone marrow) transplants are relatively unique to blood cancer. Despite being potentially curative, stem cell transplants are associated with serious mortality and morbidity risks. Patients receiving transplants are required to spend substantial time in hospital and stay nearby post-transplant.¹

For many patients, a stem cell transplant is a last resort therapy which, if successful, provides a long term cure for their blood cancer. A patient must be matched with an appropriate Haemopoietic Progenitor Cell (HPC) donor, just as a blood transfusion can only be received from a person with a matching blood type.²

The Leukaemia Foundation is financially supporting the CAST study funded at the Centre for Blood Transplant and Cell Therapies at Westmead Hospital, focused on the prevention of graft versus host disease (GVHD), a complication of allogeneic stem cell transplants.

However, significant action is needed to increase the broader donor pool, with government being able to take a key role.

1. Effectiveness of, and issues with, stem cell donation (ToR 1 and 2)

Every year, more than 600 Australians with blood cancer will need donated stem cells for a potentially life-saving allogeneic transplant.

Some patients find a matched donor in their family, but more than half will need stem cells from a matched but unrelated individual.

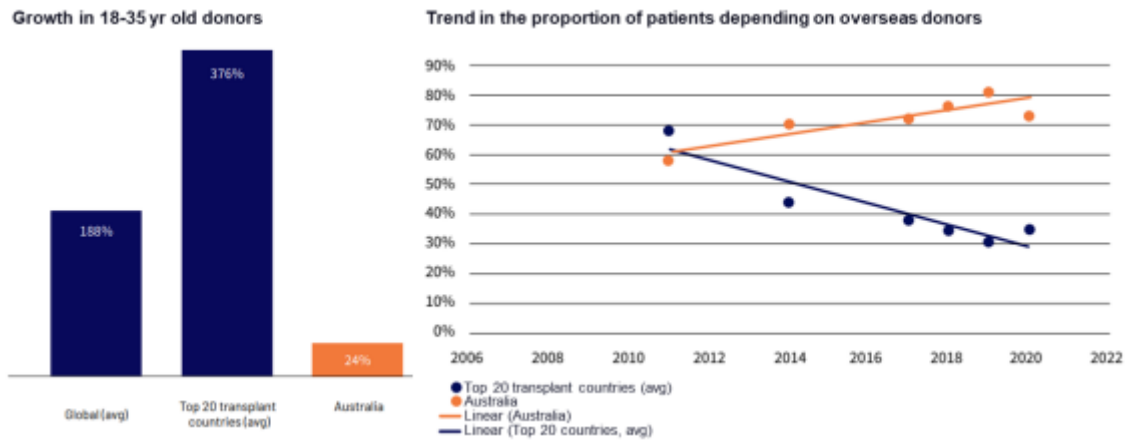
However, not enough suitable Australians are registered as a donor, and this has been declining over time.

As a result, about three in four of all stem cell donations are sourced from overseas donors.

¹ *State of the Nation: Blood Cancers in Australia Report 2023*: https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf

² *State of the Nation: Blood Cancers in Australia Report 2023*: https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf

Figure 1: Australia's increasing dependence on international donors, in contrast to international peers



This can cause complications as donor cells need to travel far distances to reach patients who need to receive the new stem cells quickly. Delays associated with travel can impact the viability of the donor cells, which can result in further complications. Overseas donations also cost significantly more than having local Australian donors.

Relying on overseas donations also means patients from ethnicities not well represented on international registries, like First Nations peoples, may be more difficult to find a suitable matched donor.

The COVID-19 pandemic also highlighted more risk to patients, with reduced access to overseas donors and increased risk of transport delays and damage.

2. Opportunities to improve organ and tissue donation rates in Western Australia (ToR 3)

The sector has come together to find short-term solutions such as cryopreservation of international stem cell donations, however, ongoing and longer-term solutions must be found.³

The Leukaemia Foundation wants to see Australia's reliance on overseas donors decrease with having more suitable Australians on the Australian Bone Marrow Donor Registry (ABMDR). The Foundation is calling on all Australians, and especially those from diverse ethnic backgrounds, to become stem cell donors and join the ABMDR's register.

In 2021, federal and state governments recognised the need for Australia to become more donor self-sufficient in their National HPC Framework report. The ABMDR estimates that 100,000 new HPC donors must be recruited within the next five years.⁴

To achieve this target, the Strength to Give program has attempted to promote greater enrolment; however, support has varied across time, and there remains limited awareness of the need for bone marrow (stem cell) donors.⁵

³ National Strategic Action Plan for Blood Cancers, 2020, https://www.leukaemia.org.au/wp-content/uploads/2020/09/National-Strategic-Action-Plan-for-Blood-Cancer_June-2020.pdf

⁴ State of the Nation: Blood Cancers in Australia Report 2023: https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf

⁵ State of the Nation: Blood Cancers in Australia Report 2023: https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf

The National Strategic Action Plan for Blood Cancer (National Action Plan) outlines recommendations to support the enrolment of underrepresented populations on the Australian Bone Marrow Donor Registry. Specifically, it states:⁶

- To help power and support high-risk patient groups, governments and the sector need to ensure access for Indigenous people to safe and effective stem cell transplants and increase the representation of Aboriginal and Torres Strait Islanders on the Australian Bone Marrow Donor Registry (Recommendation 1.6.5).
- To help harmonise evidence development and regulatory applications, governments and the sector should engage to develop a strategy to optimise supply of suitable stem cell donors for Australian and international patients and to ensure equity of access to cellular and emerging therapies, including CAR T-cells (Recommendation 4.3.1)

At the Health Ministers Meeting on 24 February 2023, the Federal Health Minister and State and Territory Health Ministers agreed that:

- "Bone Marrow – Health Ministers approved immediate release of \$1 million from the Cord Blood Export Revenue fund to increase bone marrow donation recruitment, through both blood testing and cheek swabbing. Proposals for scaling bone marrow donation recruitment nationally are currently being considered. Health Ministers gave provisional approval for the release of further funds from the Cord Blood Export Revenue fund with details to be finalised following clinical advice, due in April 2023."⁷

The WA Government, in partnership with other State and Territory Governments and the Federal Government, can take action by promoting the need for people to become donors. Further action on funding arrangements, building on the recent Health Ministers Meeting declaration, would also be welcome.

As identified in the Leukaemia Foundation-funded *State of the Nation: Blood Cancers in Australia Report 2023*, new, proactive strategies are needed for the recruitment, education and retention of ideal donors (young, male and ethnically diverse) to meet contemporary clinical trends and growing demand, so that the needs of Australian patients are met and Australia's reliance on internationally sourced donors is reduced.⁸

Thank you for your consideration of the issues highlighted above. We would be happy to discuss further and can be contacted at ctanti@leukaemia.org.au.

Sincerely,



Chris Tanti
Chief Executive Officer

⁶ National Strategic Action Plan for Blood Cancers, 2020, https://www.leukaemia.org.au/wp-content/uploads/2020/09/National-Strategic-Action-Plan-for-Blood-Cancer_June-2020.pdf

⁷ <https://www.health.gov.au/sites/default/files/2023-02/health-ministers-meeting-communiqué-24-february-2023.pdf>

⁸ *State of the Nation: Blood Cancers in Australia Report 2023*: https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf