

May 2023

Parliament of Victoria
Legislative Assembly Legal and Social Issues Committee
Parliament House, Spring Street
EAST MELBOURNE VIC 3002

Via email: registereddonorsinquiry@parliament.vic.gov.au

Dear Legislative Assembly Legal and Social Issues Committee

Re: Inquiry into increasing the number of registered organ and tissue donors

Thank you for the opportunity to provide a submission to the *Inquiry into increasing the number of registered organ and tissue donors*.

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.

While acknowledging some of the challenges and opportunities are national issues, this submission addresses all four Terms of Reference:

1. The effectiveness of the current model for registering to be an organ and tissue donor in Victoria
2. Issues impacting organ and tissue donation rates in Victoria
3. Opportunities to improve organ and tissue donation rates in Victoria
4. National and international models for registering to be an organ and tissue donor.

As Australia's second-most populous jurisdiction, and as home to some of the nation's leading treatment centres, Victoria has both the opportunity and imperative to help lead positive change that increases Australia's donor pool and in doing so, decreases Australian patients' reliance on overseas donors.

Context: The imperative to improve blood cancer outcomes

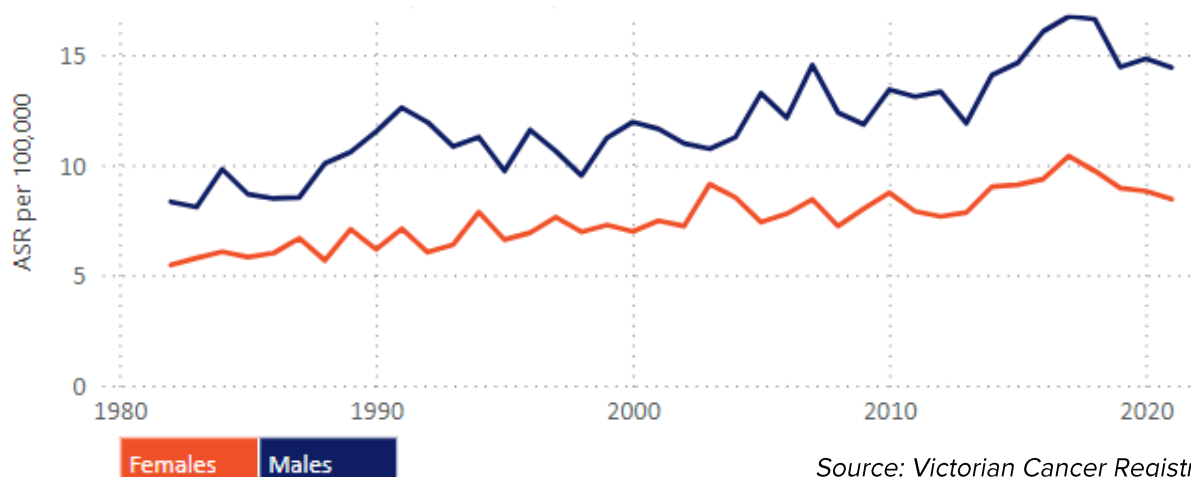
Stem cell (bone marrow) transplants are relatively unique to blood cancer. Despite being potentially curative, stem cell transplants are associated with serious mortality and morbidity risks. Patients receiving transplants are required to spend substantial time in hospital and stay nearby post-transplant.¹

For many blood cancer patients, a **stem cell transplant is the 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

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.

Figure 1: Victorian age-standardised leukaemia incidence rate per 100,000



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.

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. Government holds the key to being able to make this happen.

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

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

There are not enough local donors

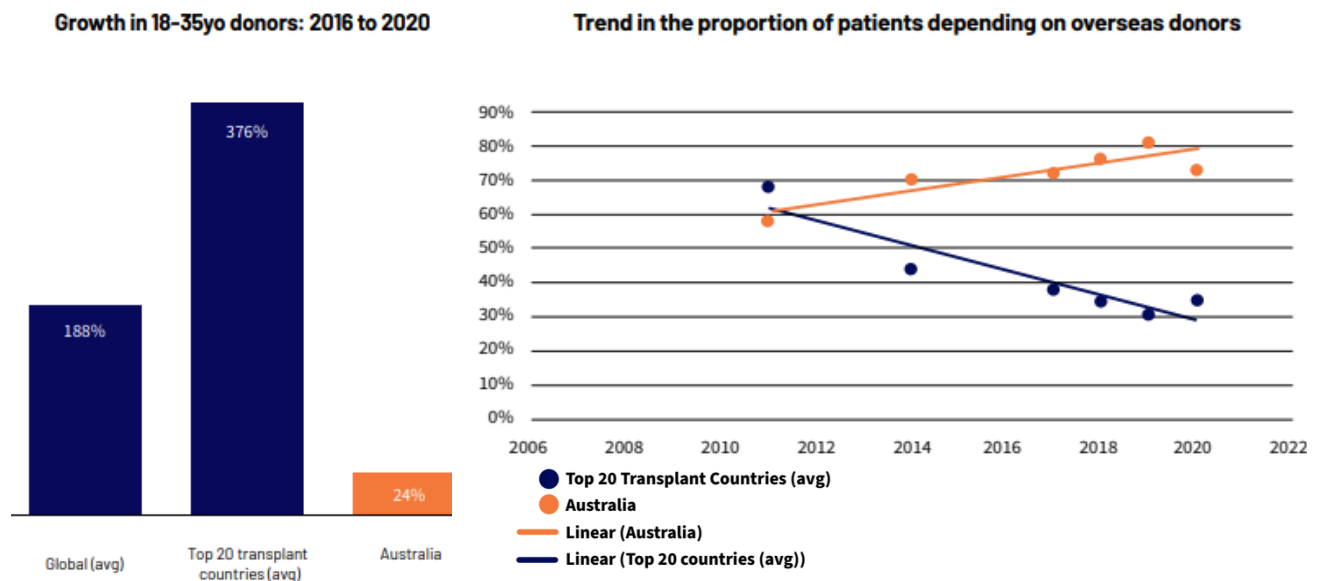
Every year, more than 600 Australians with blood cancer will need donated stem cells for a potentially life-saving allogeneic transplant.

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.

Figure 1: Australia's increasing dependence on international donors, in contrast to international peers³



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.

The COVID-19 pandemic also highlighted the risk of this inadequate local donor pool to patients, with reduced access to overseas donors and increased risk of transport delays and damage.

Inadequate demographic-specific recruitment is reinforcing inequitable outcomes

Relying on overseas donations also means patients from various ethnic backgrounds are not well represented on international registries, like First Nations people and Pacific Islanders, and find it more difficult to find a suitably matched donor.

The National Strategic Action Plan for Blood Cancers, endorsed by the Federal and all State and Territory Governments in 2020, identifies the need to improve access for Indigenous and CALD people (Actions 1.6 and 1.7) to the stem cell register as part of actions required to support high-risk groups.⁴

³ Australian Bone Marrow Donor Registry, *Annual Report 2021-22*, p.5.

⁴ <https://www.leukaemia.org.au/national-action-plan/>

Similarly, one of the six Strategic Objectives in the draft new Australian Cancer Plan is "Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander People."⁵

These Government-endorsed visions for equitable outcomes through access to stem cell transplants for vulnerable groups will not be realised without targeted donor recruitment campaigns.

Stem cell donations have not been prioritised through policy and funding settings

There is considerable room to better optimise current stem cell donor processes and funding, both in Victoria and across the country.

Government support for donor programs has been intermittent. There is also an opportunity to have a significant impact on stem cell donor levels by looking at where (i.e. which sites) blood products are collected in Australia, and the incentives for providers to progress and process stem cell donations as well as other blood products.

These issues cannot be solved by one jurisdiction alone.

As recognised by the "Health Ministers' Meeting" in February 2023, increasing the stem cell donor pool requires a national effort. This is in part due to the challenges and probabilities in finding a match, and because of the complex funding and delivery arrangements across the country.

As Australia's second-most populous jurisdiction, and as home to some of the nation's leading blood cancer treatment centres, Victoria has both the opportunity and imperative to take a leadership role at the national level to help improve Australia's stem cell donor architecture and funding arrangements.

The Victorian Government can do this at the Health Ministers' Meeting through sustained advocacy for the need to review and update stem cell donor processes, including reviewing current support for donor drives, the collection methods and locations, and the funding available to providers of collection services.

2. Opportunities to improve organ and tissue donation rates in Victoria (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.⁶

The Leukaemia Foundation wants to see Australia's reliance on overseas donors decrease, by 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.⁷

⁵ <https://engage.australiancancerplan.gov.au/>

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 *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

To achieve this target, the *Strength to Give* program has attempted to promote greater enrolment; however, funding support has varied across time, and there also remains limited community awareness of the need for bone marrow (stem cell) donors.⁸

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:⁹

- 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."¹⁰

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.¹¹

The Victorian Government, in partnership with other State and Territory Governments and the Federal Government, can take action by:

- 1) promoting awareness of the need for donors
- 2) taking further action on bone marrow registry funding arrangements, building on the recent Health Ministers' Meeting declaration.

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

⁹ 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

¹⁰ <https://www.health.gov.au/sites/default/files/2023-02/health-ministers-meeting-communique-24-february-2023.pdf>

¹¹ *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

3. National and International Models (ToR 4)

International models

Generally speaking, effective international models for registering to be a stem cell donor are similar. Individuals sign up online or attend a donor drive event, receive a swab kit in the mail, and complete the swab kit to provide a sample of their DNA. This DNA sample is then used to determine if they are a match for a patient in need of a stem cell transplant. If they are a match, they may be contacted to donate their stem cells.

Examples of these programs include:

- *Be The Match* – A non-profit organization based in the United States that operates the largest and most diverse registry of potential stem cell donors in the world.
- *DKMS*: An international organization that operates registries in several countries, including Germany, the United States, Poland, and the UK.
- *Canadian Blood Services Stem Cell Registry*
- *Anthony Nolan* – a UK-based charity that operates the country's stem cell donor registry.

A cheek swab campaign would help address issues identified earlier in this paper, including inadequate donor numbers, inadequate demographic-specific recruitment, and inadequate prioritisation through policy and funding settings.

Australia's opportunity

Australia is well-placed to quickly mobilise a campaign to increase donors, given the pre-existing presence of the "Strength to Give" campaign, which the Leukaemia Foundation has supported.

"Strength to Give" is a cheek swab-based enrolment program run by the Australian Bone Marrow Donor Registry to grow and diversify Australia's donor pool.

It has already demonstrated its effectiveness. The campaign has been running since 2019, and has reached millions of Australians through various channels, including social media, TV, and radio.

Scaling up and sustaining this program around the country would see a significant increase in the availability of relevant Australian stem cell donors.

The Leukaemia Foundation remains committed to increasing the number of stem cell donors in Victoria and throughout Australia, including promotional support for Strength to Give.

Further, as part of our self-funded services for patients and families affected by blood cancer and related disorders, we support patients through provision of information and resources about stem cell donation and transplantation, as well as the financial assistance, accommodation/travel for treatment and the emotional support they need.

However, leadership and sustained support from all governments and agencies engaged in blood and stem cell collection is required to increase Australia's stem cell donor pool, and support for a cheek swab campaign is one achievable way of doing so.

Thank you for your consideration of the issues highlighted above. We would be happy to discuss further – Tim Murphy, General Manager (Blood Cancer Partnerships), can be contacted at tmurphy@leukaemia.org.au. We would also welcome the opportunity to speak directly to the Committee and/or give evidence at a public hearing.

Sincerely,



Chris Tanti
Chief Executive Officer

About the Leukaemia Foundation

The Leukaemia Foundation is the only national organisation that represents all Australians living with blood cancer – including leukaemia, lymphoma, myeloma, myeloproliferative neoplasms (MPN), myelodysplastic syndromes (MDS) and amyloidosis.

We provide the following free services to patients:

- Personalised information and support from highly trained Blood Cancer Support Coordinators for patients and their loved ones alongside a range of health and wellbeing services
- Accommodation near major hospitals around Australia and help getting to and from the many appointments that come with a blood cancer diagnosis
- Trusted information to empower people to navigate the road ahead, including critical education, support groups, booklets, newsletters, and online information

The Leukaemia Foundation's research program drives rapid advancements in blood cancer treatments, encourages the careers of promising scientists, and helps give Australians access to global clinical trials.

We advocate for better policies, better access to new and innovative treatments, better diagnostics and, ultimately, better outcomes so that more people live through blood cancer and live well.

Blood cancer in Australia

In Australia, when taken together, blood cancers are the third-most diagnosed cancers and the second-most common cause of cancer death. Today more than 135,000 Australians are living with a blood cancer and sadly 1 in 3 people will have died within five years of their diagnosis. We know the number of people being diagnosed with blood cancer is on the rise with the incidence of blood cancer increasing 47 per cent over the past 10 years and predicted to double by 2035.