

Private Submission 2 Mr Nicholas Fardell - Inquiry into Organ and Tissue donation in Western Australia.

Cheek Swabbing

Member of the committee – Inquiry into Organ and Tissue Donation in Western Australia.

I recently submitted a submission to your enquiry and look forward to some feedback and to the findings of the committee.

The submission was titled Private Submission Mr Nicholas Fardell - Inquiry into Organ and Tissue donation in Western Australia.

As previously outlined my view and needs have been driven by my recent diagnosis of blood cancer and my submission was based around my own research and assistance from my local MP, the member for Kalgoorlie, Ms Ali Kent. Since the submission was written I have continued research and have now discovered some more information that I urge the committee to look at. I have titled this submission

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As outlined below in the original submission I believed that Blood Donations, Plasma Donations and Bone Marrow donations should work hand in hand with Organ donation as the donors may well be of the same ilk and by asking at the point of donation, we may well increase the number of donors, reduce costs and raise the number of donors, as well increase my chance of a cure in my situation. I believed competition could also play a part but I am cautious of this approach and we should initially only ask PathWest of their availability.

My research has led me to also add some others methods and possible suppliers of these method. The method is the “Cheek Swab” method very similarly administered in the same way as the Covid-19 Mouth Swabs. The actual web site that follows is very informative and I only found it initially by continuing to search for better outcomes. The site has a program “strength to give” and is administered by Australian Bone Marrow Donor Registry, ABMDR. A lot of the following information is straight from their web page <https://www.abmdr.org.au> and is a directly plagiarise. I cannot find where this web page has been updated since 2020. However ABMDR is funded by this and previous state governments.

ABMDR is funded by the Commonwealth, State and Territory governments. Australian governments also contract the Australian Red Cross Lifeblood to recruit blood donors onto ABMDR’s register.

So, there is some competition to Lifeblood. However, that’s not my real concern as it is the outcome we need – more donors.

ABMDR relies on its network to deliver stem cell donations for patient transplants.

Cord blood banks manage the donation, storage and release of umbilical cord blood units to patients in need of a transplant. They operate within a strict Therapeutic Goods Administration (TGA) regulatory framework. There are three public cord blood banks in Australia, in Sydney, Melbourne and Brisbane.

Not having a cord blood bank in WA is another issue this web page brings to light.

Around 80% of Australian patients will find that their best match is an overseas donor. Although we don’t charge Australian patients for our services, when we search overseas registries for a donor, we incur various

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fees. For example, overseas laboratories will charge us to test samples taken from potential donors; or international registries will charge to collect cells from a donor in their country. These costs must be covered, and ABMDR has an agreement with Australian governments to pay these costs for eligible patients, within certain limits.

I have read similar statistic with organ donations as well. This makes your work as committee even more important. Using overseas organs and cells in some cases means we are using tax payer monies while we could be assisting to reduce the cost-of-living crisis in WA and using the valuable monies allocated to go further saving more lives.

*Although the pandemic has temporarily reduced the number of transplants performed, Australia has one of the highest rates (per million inhabitants) of performing blood stem cell transplants globally. Unlike other major transplanting nations, who have on average halved their dependency on foreign donors in the last decade, Australia's dependency has steadily increased to around 8 out of 10 Australian patients relying on an overseas donor. This has posed additional risks and challenges during the pandemic. Significantly more Australian donors need to be urgently recruited. In the last 5 years, global growth in donors aged under 35 was, on average, 188%. Although impressive, major transplanting nations doubled the average global growth rate; except Australia, which grew by just 24%. Between 2012-2021, an average of 5,200 blood donors were recruited to our registry each year. This has led to Australia's increasing dependency on overseas donors. To achieve meaningful improvement, ABMDR has identified that our donor pool should contain 3% of Australia's population of 18-35-year-olds. This can be delivered by the additional recruitment of non-blood donors, with easy-to-use cheek swabs. ABMDR's Strength to Give initiative has proved that cheek swabs are a successful, cost-effective way of recruiting lots of Australian donors. **We are now seeking approval from Commonwealth, state and territory governments to resume Strength to Give's cheek swab program to deliver the donor pool Australian patients deserve.***

I have found the following link to provide the committee more information to consider and would ask that you spend some time perusing this site.

<https://strenghtogive.org.au>

I urge this committee to look into the swab methods which has operated overseas for in excess of 10 years. I cannot find more information at this point in time. But if we increase the donors across all registries then you committee will be a success.

Which brings me to the point of this second submission a story on the ABC network. This story outlines the important work that ABMDR funds and supports. They actually are selling Cord Blood to fund check swabbing test.

<https://www.abc.net.au/news/health/2023-03-27/bone-marrow-donation-cheek-swab-blood-cancer-registry/102130254#:~:text=Cheek%20swabs%20aren't%20new,to%20recruit%20another%206%2C00%20donors.>

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Bone marrow registry to fund cheek swab collection as families seek donors overseas

[ABC Health & Wellbeing](#)

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By [Shelby Traynor](#) for [the Health Report](#)

Posted Mon 27 Mar 2023 at 3:00am Monday 27 Mar 2023 at 3:00am



Joining a bone marrow registry requires a sample of cells, usually from the inside of your cheek, which is used to match with people who need a transplant. *(Getty Images: Hyoung Chang/The Denver Post)*

Help keep family & friends informed by sharing this article

abc.net.au/news/bone-marrow-donation-cheek-swab-blood-cancer-registry/102130254

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Murray Foltyn was diagnosed with a rare form of blood cancer in 2014.

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Key points:

- In Australia, potential bone marrow donors must sign up to the registry via the blood donation service
- People in other countries such as the UK and US can register by submitting a cheek swab
- The Australian bone marrow donation registry is funding a renewed national cheek swab program

He found out he would need a bone marrow transplant in January this year, when the medication he was on stopped working.

But finding a suitable donor soon proved tricky.

"I did expect [the search] to go faster," Murray says.

Despite initially being told that finding a match wouldn't be an issue, he hasn't found one with similar ancestry to his own.

So a month ago, Murray's wife Claudia decided to take the search overseas.

"As we learnt more it became clear that we weren't going to achieve too much in Australia, with the limited testing capabilities," she says.

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Claudia and Murray expanded their search for a suitable bone marrow donor overseas. *(Supplied: Claudia Foltyn)*

This may change, as Australia's Bone Marrow Donor Registry (ABMDR) starts a cheek swab program to recruit local donors.

But the registry is paying for this itself as it awaits government funding.

Local donor shortage

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The program aims to expand the pool of bone marrow donors in Australia, which is small compared to other countries.

In the four years to 2020, donor pools of [comparable nations almost quadrupled in size](#), while Australia's increased just 24 per cent.

Currently, the only way to join Australia's bone marrow donor registry is through Australian Red Cross Lifeblood.

This means people unable or ineligible to donate blood also can't register as a bone marrow donor.

But overseas, cheek swabs — a quick and simple way of collecting cells to match with transplant recipients — have been widely used for over a decade.

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Murray and Claudia collected 25 cheek swabs every 15 minutes at one swabbing event. (Supplied: Claudia Foltyn)

The chief executive of the ABMDR, Lisa Smith, says this has resulted in "an explosion" of overseas donors during that time — which Australia has become reliant on.

"Going into the pandemic, 80 per cent of people needing a bone marrow transplant were not able to find one in Australia," Ms Smith says.

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But overseas donations aren't a plausible option for everyone, especially Indigenous and Torres Strait Islander peoples, as well as patients with ethnicities that are common in Australia, but not in the global donor pool.

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Ms Smith says Australia is lagging behind the rest of the world and "it's ultimately harming patients".

The [Health Minister Mark Butler acknowledged the issue in February](#), and has indicated funding is in the works, but Ms Smith says the situation is urgent.

"Patients need us to act at lightning speed."

And patients don't just need to find a bone marrow match to get a transplant — they also need to be healthy enough to have the procedure.

For people with cancer and others with life-threatening conditions, the search for a donor can take months, putting them in a precarious situation.

Simplicity of swabs

With the help of family members overseas, Claudia has set up mass swabbing events in several countries to recruit as many potential donors as possible.

Overseas registries — in Europe, the UK, the US, South Africa, Israel and the Netherlands — have treated Murray "as one of their own", she says.

Murray says people "we've never met, that we don't know" have also offered to run swabbing drives in their local community.

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A cheek-swabbing event hosted in a North London home involved more than 200 participants on each of two evenings. *(Supplied)*

Cheek swabs aren't new to Australia.

In 2019, the [ABMDR ran a pilot program of mail-out cheek swabs](#) called "Strength to Give" and recruited around 5,000 new donors.

Governments funded a small extension of the program in 2020-21, allowing ABMDR to recruit another 6,000 donors.

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But funding dried up in mid-2021, and Ms Smith says the registry has been in limbo since.

It's clear people are still interested in becoming bone marrow donors. Earlier this month, Murray's family was given special dispensation for a single cheek-swabbing event in Sydney, where they collected 270 swabs.



A mass cheek-swabbing event in a hall in Rose Bay. *(Supplied)*

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They've also organised blood test drives, but those have more constraints. In Melbourne they were told they could not exceed 50 tests, despite more than 150 people expressing interest.

Claudia says it's striking how easy the process has been overseas compared to Australia.

"Now that we're in it, we get a full sense of the frustration that 'Strength to Give' has felt for years."

A question of funding

The reliance on overseas donors isn't saving the Government any money.

Laboratories charge for test samples. If a match is found, [the Government picks up the bill](#) for the collection and transportation of overseas donations, or travel expenses for a related donor to come to Australia.

But matching local donors with local patients won't just cut costs. It will also reduce certain transplant risks, and ensure self-sufficiency during a crisis.

Ms Smith says Australia's bone marrow donor registry is ready to roll out nationwide cheek-swabbing.

It even has enough money to do it — the registry has accumulated \$12.8 million from exporting umbilical cord blood — but can't access the funds.

While Health Ministers have approved the release of only \$1 million to the ABMDR for blood testing and cheek swabbing, Ms Smith says it's not enough.

So, over the next several months, the registry will be using capital reserves to fund its "Strength to Give" program.

[Eligible people can sign up online](#) and request swabs in the post. They can also join the registry when they next donate blood.

Another important part of the ABMDR's program will be helping patients run cheek swabbing events, like Murray's family has done here and overseas.

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The more registered, the better

Murray says he feels "extreme gratitude" towards his wife and his family for taking charge in a difficult situation.

Whether they're a match for Murray or not, the people who turn up to these swabbing events will be added to the global donor registry. Claudia says it's the "cherry on top" of the situation.

"Our drive is Murray, of course, but those people can save anyone's life," she says.

"We want every eligible 18 to 35 year old in Australia to swab and get themselves onto the registry — for Murray, for everyone."

Murray is positive he will find a match. In the meantime, he's looking forward to governments and donor services working together to expand the registry.

"I think it will make a big difference to others in similar situations."

Posted 27 Mar 2023

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Conclusion:

- If possible, to prove the support for the number of regional candidates that are unable to participate in donating I would like the committee to assist me to find the funding to conduct a cheek swabbing drive in "The Goldfields". Special dispensation is available and the registry achieved over 270 donors at one event it was given special dispensation to run. Which if we have the committee support and Ms Kent is agreeable, I will be asking Ms Kent to help organise and support along with local Identity Mr Doug Daws. Ms Kent as I stated previously assist myself and provided some contacts to start this journey in parallel to her efforts to resume blood donation services to the Goldfields. Mr Daws amongst his many hats is invested in returning Blood Donations services and his contacts and support will be immense.
- If possible, for the committee to urge the Federal Health Minister, Mr Mark Butler to free up the \$12.8 million dollars which ABMDR has accumulated from exporting umbilical cord blood, to perform more Cheek Swabbing Testing. This may also involve our own WA health Minister and I urge the committee to discuss this with the state health minister. The ultimate goal would be for the premier to raise it at national cabinet.

I thank the committee for your work and reading my 2 submissions, I hope they help in this vital work you're completing.

If any questions arise around this submission, please do not hesitate to contact myself.

Nicholas Fardell