

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Monday 24 July 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESSES

Mr Chris Tanti, Chief Executive Officer, and

Mr Andrew Mosley, Head of Government Relations and Policy, Blood Cancer Partnerships,
Leukaemia Foundation.

The CHAIR: Good morning. My name is Ella George, and I am the Chair of the Legislative Assembly's Legal and Social Issues Committee.

I declare open this public hearing of the Legislative Assembly's Legal and Social Issues Committee's Inquiry into Increasing the number of registered organ and tissue donors.

I begin by acknowledging the traditional owners of the land on which we are meeting, the Wurundjeri Woi Wurrung people of the Kulin nation. I pay my respects to their elders past, present and future, and I extend that respect to First Nations people across Victoria. I thank Victoria's First Nations people for their many years of care for this country.

I also acknowledge my colleagues participating today: Deputy Chair Annabelle Cleeland, Member for Euroa; Chris Crewther, Member for Mornington; Cindy McLeish, Member for Eildon; and Meng Heang Tak, Member for Clarinda.

Earlier this year the Legislative Assembly tasked the Legal and Social Issues Committee with an Inquiry into increasing the number of registered organ and tissue donors. The committee will report back no later than 31 March 2024. In calling for public submissions the committee noted that it was particularly interested to hear from the Victorian community about the effectiveness of the current model for registering to be an organ and tissue donor in Victoria, issues impacting organ and tissue donation rates in Victoria, opportunities to improve organ and tissue donation rates in Victoria and national and international models for registering to be an organ and tissue donor.

The committee has received a number of valuable submissions to date which can be viewed on the committee's website, and on behalf of the committee, I would like to take this opportunity to thank all those who provided a written submission, particularly the individuals and families who have bravely shared their own personal stories of organ and tissue donation. The committee held two days of public hearings in June, and today is the first day of two public hearings this week. We will hear from witnesses representing a number of organisations involved in organ and tissue donation. Today we will hear from the Leukaemia Foundation, Monash University Bioethics Centre, the Royal Australian College of General Practitioners, Australia and New Zealand Intensive Care Society Death and Organ Donation Committee, and the Organ and Tissue Donation Team at St Vincent's Hospital, Melbourne.

I would like to take this opportunity as well to acknowledge that it is DonateLife Week. During DonateLife Week people across Australia are encouraged to register to donate to become an organ and tissue donor, and to discuss their decisions with their family. You can register online or find out about events that are happening near you this week at donatelife.gov.au/donatelife-week.

I thank all the witnesses for their time and interest in participating in this important inquiry.

All evidence given today is being recorded by Hansard and will be broadcast live.

While evidence taken by the committee is protected by parliamentary privilege, comments repeated outside this hearing may not be protected by this privilege.

We will now commence hearings with our first witnesses today, and I welcome from the Leukaemia Foundation Chris Tanti, Chief Executive Officer, and Andrew Mosley, Head of Government Relations and Policy, Blood Cancer Partnerships. I invite you now to make a brief opening statement of around 10 minutes and that will be followed by questions from Members. Thank you.

Chris TANTI: Thank you, Ella. I am Chris Tanti. I am the CEO of the Leukaemia Foundation. I am here with Andrew Mosley, who is the Head of Government Relations and Policy, and we would like to thank you for inviting us to speak with you today.

This year nearly 20,000 Australians will be diagnosed with a blood cancer. Over the past 10 years the incidence of blood cancer has increased by 47 per cent, and one in three people diagnosed will not survive five years after their diagnosis.

We are here today to represent patients who need a stem cell transplant to treat or potentially cure their blood cancer now and into the future and for whom the current system is failing. Blood cancer patients receiving stem cell transplants are required to spend substantial time in hospital and stay nearby post transplant. We support many patients through this journey, including in our accommodation villages that are scattered throughout the country. Stem cell transplants, sometimes called bone marrow transplants, are relatively unique to blood cancer. For many, a stem cell transplant may be the last resort which, if successful, provides a long-term cure for their blood cancer.

Every year more than 600 Australians with blood cancer will need donated stem cells for a potentially life-saving donor transplant, but finding a suitable donor can be difficult. Unlike some organ transplants, stem cell transplants need to occur with stem cells that are a close match to the recipient. Some patients luckily find a matching donor within their family; however, more than half will need stem cells from unrelated individuals. This highlights a key issue faced by patients, unfortunately, because there are not enough donors on the Australian registry, and as outlined in our written submission, this has been declining over time. As a result, about three in four of our stem cell donations is sourced from overseas donors, particularly from Germany.

For example, Don from Melbourne had a donor stem cell transplant days before his 71st birthday. His siblings were too old to be donors, although he eventually found a donor in Germany. Three-year-old Larry was diagnosed with aplastic anaemia. His identical twin brother Henry and his older sister Matilda were ruled out as donors. His mum Jess said:

We looked on the Australian registry but couldn't find a match. Larry is part Chinese-Malaysian, and there's not enough ethnic diversity on our registry.

Lauren required not one but two transplants. She says:

... by the time we've come to this relapse and I'm about to get a second transplant and the doctors have told me again, "In the registry, we don't really have many people that are a match to you," ...

Lauren promoted her own story, including on radio and TV, putting her picture on a bus stop around the city. Lauren did find a donor that was a match in Europe. There are various possible reasons for why there are insufficient registered donors. Generally speaking, many people are simply not aware that others may require stem cell transplants, and hence that stem cell donors are needed. There is also little awareness of the bone marrow registry and variable knowledge about how to become a donor.

It is difficult to pinpoint exactly why Germany has a higher number of donors, but some of the features of the German system include: easy availability of kits for cheek swabs; people can register at 17 years of age; the agency there is well resourced; and there seems to be a greater awareness of the need for donation there. The reliance on overseas donors, especially in Germany, raises several problems. Firstly, it creates a security of supply issue, that was underlined by COVID. Secondly, it can cause complications, as donor cells need to travel long distances to reach patients who need to receive the new cells relatively quickly. Delays associated with travel impact the viability of the donor cells, which can result in further complications. Overseas donations also cost significantly more than having local donors. This inadequate donation or donor pool disproportionately and adversely affects minority groups and First Nations people, meaning there are significant equity-of-access issues. First Nations people in particular cannot find matches overseas. Consideration of how to boost recruitment and increase the number of registrees is therefore vital.

We do not believe there is one jurisdiction or entity that can fix the problem by itself, but broadly speaking we think there are several things the Victorian Government could do. Firstly, support the cheek swab campaign. This would help address issues such as inadequate donor numbers, inadequate demographic-specific recruitment and inadequate prioritisation through policy and funding. Effective international models for registering to be a stem cell donor are similar: individuals sign up online or attend a donor drive event, receiving 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 the patient in need of a stem cell transplant. Examples of these programs include Be The Match, a non-profit organisation based in the United States, and DKMS, an international organisation that operates registries in several countries, including Germany, the United States, Poland and the UK. The Australian bone marrow registry has recently relaunched its Strength to Give cheek swab campaign, and the Victorian Government could consider how best to support the campaign in the future.

Secondly, the Victorian Government can help champion further action nationally. While the specifics of the system design and reform are largely outside LF's remit, a report commissioned by government in 2018 found that the current national recruitment approach, which mostly relies on blood donors additionally volunteering to become a stem cell donor, is mismatched to clinical need. 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. The Victorian Government can help champion this at the national health ministers meeting through sustained advocacy for the need to review and update the stem cell donor processes. This could include reviewing current support for donor drives, the collection methods and locations and the funding available to providers of collection services. This already has some recent momentum. Bone marrow transplant funding was discussed at the February national health ministers meeting, and several federal parliamentarians have recently spoken out about the need for stem cell donor reform.

Finally, in May 2022 Nikiya was diagnosed with blood cancer when 17 weeks pregnant and eventually found a donor from Germany. She is a strong advocate for donating blood and encourages others to join the Australian bone marrow registry if they are eligible. She says:

We need more donors ... If there's one thing that I would love, it would be to know that people are out there talking about stem and blood cell donations and going out to join the registry.

This is really important, and I feel strongly about it. I want to do everything I can in my power to raise awareness. There are not many people that know about it unless they're in the industry or know of somebody going through blood cancer.

This inquiry can help raise awareness of the need for people to donate, the challenges faced by patients requiring the stem cell transplant and the need for action to be taken to support the donor drive initiatives. Thanks for your time. We are happy to take any questions.

The CHAIR: Thank you for that excellent opening statement. In reading your written submission, I was really struck by some of the evidence that you provided, including the reliance that Australia has on receiving donations from overseas. I would like to start by asking a couple of questions around the process of becoming a registered bone marrow donor and how to get on that national registry. It seems like it is a very simple process to become a registered organ and tissue donor and it is also a very simple process to sign up, say, with Lifeblood to become a blood donor, but it does look like it is a more complex effort to get on the Australian bone marrow donor registry. I am hoping you can go into the process of becoming a registered donor but also touch on why it is different to the other systems in Australia.

Andrew MOSLEY: Sure. I would probably start by saying one of the main ways that people get on the registry is through the Lifeblood program. Generally, when people go and donate blood we encourage people at that point to talk to Lifeblood about possibly becoming a stem cell donor as well. That is the main mechanism. There are other initiatives that have been put into place, particularly recently with the Strength to Give campaign, and that is run by the registry themselves. That is a newer thing. It was rolled out a couple of years ago. The registry have just refreshed that, and they are running a drive at the moment. They are some of the main ways that people get on the registry. There has been discussion over the past couple of years about different ways to try and make it as easy as possible, and I think it is fair to say that some of those conversations are ongoing.

The CHAIR: Do you have any suggestions about how to make it easier?

Chris TANTI: I think that one of the challenges in this space is visibility. There is very limited awareness of the issues. I think if you are affected personally, you are more likely to seek the opportunity to do this. I think the other challenge is that we are after relatively younger people. So 18 to 35 years of age is probably the optimum, and in terms of raising awareness we are not targeting that group. There is a really interesting group in Victoria called Tackling Leukaemia, who have started to work with football clubs, and First Nations people and Pacific Islanders specifically, to recruit stem cell donations. They have done a lot of work in those clubs. So they are very connected into the sports area, and the reason they do that is because the guy who was in charge of it had leukaemia, and a coach also had leukaemia. The coach died from his leukaemia. He was not able to receive a stem cell transplant whereas the CEO of that group did, so he has made it his mission to recruit people.

I think most people are aware of the idea of an organ donation, and it occurs after you have died, generally, and so people will opt in to that arrangement. Stem cell is a completely different thing, and I think we just need to make some noise about it.

Andrew MOSLEY: One of the patients that we cited in our opening statement today—her experience very much mirrors that. I do not think that she was necessarily as familiar either, and she went through that process of that understanding. That is one of the things that we are trying to highlight today, only for those that are not necessarily aware, that this is a really important thing for many people.

Chris TANTI: I mean, the other thing I would highlight is that, you know, you are diagnosed with these illnesses, and you are end stage when you are looking for a stem cell transplant. So you are absolutely desperate, and to not have a pool of people that you can call on would just be devastating, I imagine, for those people.

The CHAIR: The committee understands that the Australian Government restricts the number of donors that can join the register. Is that accurate?

Andrew MOSLEY: Some of those national arrangements are probably best put to those that are more closely involved in the collection and donation than we are. There have been some ongoing conversations at that national level. There was a report by PwC in 2018 that was released a little bit after that, and then there have been some ongoing conversations at that national level. I do not think we are as familiar as perhaps others would be in terms of some of those conversations, but it did come into the national arena again in February where it was discussed at the national health ministers meeting. I believe some of those conversations are ongoing, but we do not really have any more specific information than that.

The CHAIR: Are you aware of any costs associated with adding someone to the registry?

Andrew MOSLEY: From a donor perspective I believe there is no cost. I think the registry themselves are funded up to a certain amount for different people. I would suggest that the registry would be best placed to answer that, though.

The CHAIR: Okay, thank you. I might just ask one more question before I hand over to my Committee Members. Just in terms of governance arrangements, are you able to speak to those and how the registry sits separately to, say, the Australian Organ Donor Registry and the work of the Organ and Tissue Authority and just explore that governance a little further for us?

Andrew MOSLEY: Sure. There is the 1982 tissue Act, and stem cells are essentially exempted. They are defined within the Act, but then they are exempted from the regulation of that. So what that has meant in practice and with subsequent acts is that the OTA has got, I guess, responsibility for organ and tissue donation and the registry, the Australian Bone Marrow Donor Registry, manages the stem cells. And there are various contracts with Lifeblood and DonateLife across the country to help enable that, but they essentially sit separately.

The CHAIR: Great, thank you. Annabelle, would you like to ask some questions?

Annabelle CLEELAND: I am almost replicating a similar question, but going a little bit deeper, I think.

The CHAIR: Great.

Annabelle CLEELAND: Is there an opportunity for a national registration where it integrates both the sort of Lifeblood donor and stem cells?

Chris TANTI: Is there an opportunity to do that?

Annabelle CLEELAND: Yes.

Chris TANTI: It is probably difficult for us to say. Would that be a good idea? I would think that would be a very good idea. I think what we have is a really complex system that is not well known, and particularly from a patient perspective it is potentially under-utilised, I would think. And navigating that, just in terms of the conversations that I have had around the traps, is difficult, and there is a lot of frustration. I think it needs to be

looked at. What the end result is is difficult to say. The groups that I talk to about this constantly talk about the challenges, so I think that it does need a review.

Annabelle CLEELAND: Just from looking at your submission and recommendations, it seems like it could address a lot of the barriers that you are experiencing and that you have raised. If you could hope for recommendations out of the inquiry, what would be your top two to overcome the major barriers?

Chris TANTI: Well, I think there is an issue around cheek swabs. Those seem to be well accepted overseas, but we seem to have some trouble with them here. At least that is how I understand it. I think it is probably the easiest way to engage people, particularly young people, in the process of stem cell donation. I think a starting point, though, has to be—I mean, there are a number of systems at the government's disposal—raising awareness around the issues. My background has largely been in mental health all my life, and I remember when we were setting up Headspace the push into education and educating young people and teachers on the identification of mental health issues. We could do very similar things in schools, so people have an awareness of stem cell transplants and what is involved in that, in a very simple way, but it would raise awareness around the issues at a very young age. It is the younger group that we are trying to tackle. There is no point marketing to people like me because I am past my use-by date in this space.

Andrew MOSLEY: I think with the schools that the other opportunity there is that it helps normalise it as well.

Chris TANTI: Correct.

Andrew MOSLEY: One of the things we are talking about is a lack of awareness, and by socialising it at that school level I think it helps normalise it as a process.

Annabelle CLEELAND: With the Strength to Give cheek swabbing campaign, can you explain to me when the cheek swabs are actually conducted?

Chris TANTI: My understanding is that they are conducted anywhere. Tackling Leukaemia, for example, will do it on a football field, and then it gets sent off and is part of the registry. It does not need to be an incredibly—you know, people do not need to go into a clinic, for example. It can be done pretty much anywhere. It is a fairly simple process. Actually, one of the questions that I have raised is, 'Okay, so once they've done that, what is their obligation? How does their obligation continue?' I do not think there is enough discussion around what the process is from getting your cheek swabbed to what commitment you have to make beyond that.

Annabelle CLEELAND: And—pardon.

Andrew MOSLEY: Sorry. I was just going to say you can also sign up on the web and a cheek swab kit can be sent to you.

Annabelle CLEELAND: Okay. And so have you been in contact with, say, Lifeblood as a point of contact to conduct those cheek swabs and formalise the results and communication?

Chris TANTI: We do not specifically do that sort of work. We are contacted by people who are trying to do that sort of work and who are trying to influence the process. We do not ourselves do any of that. The majority of our work that we do is psychosocial support for patients, accommodating them when they are coming in from rural or regional areas and are getting treatment in the cities, and then financial assistance and a whole range of other things. It is not part of the repertoire of things that we do.

Annabelle CLEELAND: Is that because it should fall under the advocacy of a different body? Sorry to ask simple questions.

Chris TANTI: No, no, no. It is not a simple question, and it is one of the questions I keep—'Why are we not in this space?' is a question for me. I think 'because it's a pretty crowded space' would be my view, and could we do more in this space? Potentially, yes. But I think it is complex, and my sense is and my advice is that we would actually muddy the waters if we got involved. It is already complex enough, and so to your question about a review or a consolidation of things, I would agree with that. We create these complex systems in health that actually do not need to be that complex.

Andrew MOSLEY: I think Strength to Give is at the moment being driven by the registry. Oops, it is not us. We are certainly trying to support that, and we give support in terms of communications and things. I think when it goes to that next sort of level about some of those covenants and funding and contractual arrangements, that is where you would probably be best placed to speak to those that are involved in the implementation of it.

Annabelle CLEELAND: So it is not necessarily a financial or resourcing limitation, but it is that you are kind of staying in your lane, effectively?

Chris TANTI: Yes.

Annabelle CLEELAND: I am keen to understand the rise in diagnoses, which is extraordinary. Is that going to continue—47 per cent in the last decade? What is behind that? Then my supplementary would be: how many people would lose their life because they are unable to source stem cells if that was their final opportunity?

Chris TANTI: The first question is complex to answer, and I get asked this question all the time. The simple answer or the answer I can give you simply is that we are an ageing population. Blood cancers generally affect people who are older, even though we are mostly aware of children with leukaemia and there is a whole lot of interest in that. But we are an ageing population, and it does affect people over the age of 60. So that is one explanation for it. But we are not clear why it is on the rise, we just know that it is on the rise and it is forecast to double again, so it will be a significant burden.

Your second question I have already forgotten, because I am sleep deprived. But I am happy to take it again.

Annabelle CLEELAND: Just on the 19,000 Australians diagnosed each year, how many of those would potentially lose their lives because—I know this is a really ‘how long is a piece of string’ question—the number is limited by sourcing stem cells because of the challenges?

Andrew MOSLEY: Not really. There are about 600 a year that need it. We do not have the numbers in terms of exactly how many of those might really need it and would pass if they did not. It is a little difficult to collect that data as well. There might be other agencies that are better placed and are closer to the stats, particularly because some of those things occur in different parts of the health system. It is a bit difficult for us to answer.

Annabelle CLEELAND: Do you know how many of the 600 that require it receive it? Maybe rather than being so dark in my questioning, do you know how many are able to source stem cells of the 600?

Andrew MOSLEY: My understanding is it is about 600 a year. On top of that, how many are still waiting I am not sure.

Annabelle CLEELAND: Okay. Thank you for your time. My time is up.

Meng Heang TAK: Thank you, Chair. Thank you both. In terms of what the Chair opened with in terms of increased registration, and I guess it is also to do with receiving the donation, in terms of multicultural, diverse cultures, First Nations people and Pacific islanders, what has been the strategy to increase that and to make it easier for those diverse cultures or First Nations to have access to that?

Chris TANTI: Shall I give the R-rated answer? Not much. I think we are incredibly negligent in this space, because I think what we say is that we can rely on donations from overseas, but of course that is not going to help a whole lot of First Nations people or people from diverse ethnic backgrounds. That is a significant challenge, and for us, we are about to fund an epi study for First Nations people. We will get a bit more information on that, but the Tackling Leukaemia program is specifically targeting Pacific Islanders and First Nations people because there is nothing—there was nothing.

Andrew MOSLEY: That is right.

Chris TANTI: That is the R-rated answer. We need to do a lot more in this space if we are going to have an impact on the survival disparity, which is fairly significant.

Meng Heang TAK: Just a follow-on, sorry. Would you think it is the language issue or just an understanding of the issue?

Chris TANTI: I think it is –

Meng Heang TAK: Or awareness?

Chris TANTI: I think it is a structural systems issue, but I do think there are issues around language potentially and fear and a whole range of things that we have to debunk, but again, if people are not aware of these things in their own community—I have just spent a bit of time with a Torres Strait Islander community in Cairns, and initially the view was ‘Well, it doesn’t affect our community,’ but it does affect their community. People do not know how they can support their communities through a stem cell donation or a swab. So raising awareness in a way that is culturally appropriate for those communities in a language that they can understand is critical, and we do not do enough of that in Australia. We do not think enough about that.

Andrew MOSLEY: Look, we are not the only country that is working out how best to do that. Canada are going through some similar things, and I know they have got an initiative around black donor lives matter. There have been various community-led campaigns to try and fix that same problem, but as Chris said, the short answer is that it has mainly been about trying to increase awareness but we need to do more.

Meng Heang TAK: Okay. All right. Thank you, Chair. Thank you, both.

The CHAIR: All right. Great, thank you. Cindy.

Cindy McLEISH: Thank you. Thanks very much for coming in. I have got lots of questions, and I hope that I can keep them short so I can get through them all.

Just first of all, with the process—many years ago one of my friends was a bone marrow donor for her brother. Her family were tested, and she and her sister were both able to go ahead with it, and the process of the donation was extremely painful and difficult. Is that still the same?

Andrew MOSLEY: It has been changing with time. So about 90 per cent of donations now are peripheral blood, whereas it used to be a bit more skewed towards the injection in the hip. So things have been changing a lot.

Cindy McLEISH: So that is not really something that would deter people? Because it is all well and good to go on the registry. When you actually get called up or you realise what it needs, is that something that might turn people off?

Andrew MOSLEY: It can be, and I think one of the important things is that education, partly to ensure people are aware of the need for stem cell donors and that people are aware of what the process is. Part of being aware of what the process is, I think, is about knowing the process now can be that peripheral blood, which is essentially taking out the blood and then an apheresis process, which takes a couple of hours but is much more comfortable than the injection. I think there is a chance for us to communicate that it is not what it was, that it is now much easier.

Cindy McLEISH: I was quite surprised to read that only 50 per cent of people, I think it was, are compatible with a family member. And I guess that really threw me because anyone that I had heard of going down this path had always just gone to family members rather than going externally. And I was just having visions, with the cheek swabs when you were talking about, you know, of just someone taking them into work and saying, ‘Hey, will everybody just do a quick cheek swab and see if anyone is compatible with me?’ So what is the link? Why isn’t it just familial that makes you compatible, and a random stranger is?

Chris TANTI: Well, I am not medically qualified, so I will not give you all of that.

Cindy McLEISH: That is okay.

Chris TANTI: But if your family is out of your age range, if your family is not within that 18 to 35, for example, then it is not going to be something that you would harvest; it is not something that is useful. So you would look for the most compatible, I imagine, and you would probably need to talk to experts about this. You

would look for the most compatible. Having said that, even if you find that there is compatibility, there are risks associated with that. So people develop graft-versus-host disease, which is incredibly complex and debilitating and, you know, still is not covered under the NDIS, and people really struggle with surviving their blood cancer as a result.

Andrew MOSLEY: I think the really short answer as well is that for a stem cell transplant the match has to be really, really close, which can be a bit different to some organs. And the reality is that humans are very complicated and that is why it does take a big search to try and find an appropriate stem cell match.

Cindy McLEISH: So why is it, then, that First Nations are looked at differently? I mean, if it is not, you know, related to family and if it is just in the wider population, how come that is a specific problem?

Andrew MOSLEY: Generally speaking, a good match generally comes from the same sort of ethnic group.

Cindy McLEISH: Yes, okay. And the 18 to 35 being optimal, where is that data from? Why isn't it 18 to 40, or 16 to 40?

Andrew MOSLEY: Clinicians would probably be the best placed to answer that, but there has been quite a bit of research into it. Generally speaking, 18 to 35 is the accepted group, and that is partly because it has been associated, through research, with better outcomes. There are some countries that I think have a slightly different age group, sometimes up to about 40. That is for those countries to talk to. I believe you are speaking with the NHS tomorrow, and it might be interesting hearing their perspective on that as well.

Cindy McLEISH: I was going to ask about other countries, so it is interesting that you mentioned it. Earlier we talked about getting donors from Germany. Are we the only country relying on Germany?

Andrew MOSLEY: No. There are other countries that go to Germany as well. There are registries that are operated by international groups. In short, Germany does this very well.

Cindy McLEISH: Really?

Andrew MOSLEY: And there are other countries that go to Germany, and there are other countries that are probably at different stages of having a donor registry at all as well.

Chris TANTI: So they have a greater pool of donors as a result of their system.

Cindy McLEISH: You also mentioned earlier that through Lifeblood there is a bit of advocacy about, you know, signing up to being stem cell donors. What success rate is that?

Andrew MOSLEY: I am not sure what that success rate is.

Chris TANTI: No, neither am I. You have to ask the difficult questions.

Cindy McLEISH: I have got lots of them here.

Chris TANTI: You asked some difficult questions too. We would have to take that one on notice, I suspect. But look, you talk to most people in the community and most people have not heard of stem cell donation, so I mean, it is just not something that we are educated about. I think of one of my first meetings when I first joined the foundation—recruitment was incredibly difficult, but there is no campaign around any of that, so of course it is going to be difficult. How are people going to volunteer to do that?

Cindy McLEISH: Yes, because you usually hear about a family member.

Chris TANTI: Correct. That is exactly what happens.

Cindy McLEISH: That is what you assume. And then to hear that that is only 50 per cent really was quite a surprise.

Andrew MOSLEY: We had an example earlier of that young boy. He had a twin brother, and even in that case his brother was not an appropriate match. It can be quite a difficult process.

Cindy McLEISH: Just with the German situation, is there a cost comparison? Is it easy for them to do it? Is it cheap for them to do it? Is it expensive? Do they put more resources in it?

Chris TANTI: Well, it is more expensive for us to not do it. Yes, so it is a higher cost.

Cindy McLEISH: And so what is the process? When we get something from Germany, does it have to be frozen? Does it have to be just kept on ice? What is the situation then to get it to Australia? What is the time period that is required to get it from A to B and used?

Chris TANTI: I am not sure of the process, but I know that the time period is pretty tight. You would need to move pretty quickly.

Andrew MOSLEY: They even acknowledge that on their website. They talk about their speedy processes, and they sort of mention some other countries that they send the stem cells to, particularly Australia. I believe it has to be within a couple of weeks.

Cindy McLEISH: A couple of weeks—that is longer than I thought it might have been. How do things go in the UK? Are they self-sufficient in terms of this? Are there other countries that do not need to rely on Germany, for example, for supply?

Chris TANTI: I think there are many countries that are self-sufficient.

Andrew MOSLEY: I think that is correct, yes.

Chris TANTI: Yes.

Cindy McLEISH: It just surprises me that Germany has got such an excess that they can shoot it all around the world.

Andrew MOSLEY: I think one thing to remember is that finding a stem cell match is difficult. It might be that they have a lot of people but it might still be that they need to import because individual A might need a match from individual B that might be in a different country, even if Germany themselves have a lot of donors.

Cindy McLEISH: Yes, okay. I think that is me for the minute. Thanks.

The CHAIR: Great, thanks. Chris.

Chris CREWITHER: Thank you, Chair. Firstly, thank you for your submission once again and your time today. You talk about further action on the bone marrow registry and you talk about the Be the Match program and DKMS in Germany and elsewhere. Do you see that the Be the Match program is something that we could replicate and expand upon here in Australia, and could you elaborate a bit more on that program and whether you think it is something that we could look at further here in Victoria and indeed Australia?

Andrew MOSLEY: I think there are a couple of things that we could sort of consider from those other examples. There are things that happen overseas that we do not do routinely here. The cheek swab is the obvious one. There has been, again, ongoing conversations about being able to do a cheek swab campaign, and we would suggest that governments broadly do consider how best to support a proper cheek swab campaign. There are other things that we could consider that happen in some of those other programs. For example, and we mentioned this before, thinking about how we can raise the issue of stem cell donations a little bit earlier. We cannot take their donations before 18, but some of those other countries and some of those other programs you mentioned, sometimes they do the registering at 17. That could be another way as well. And ongoing resourcing I think for increasing awareness would be something else that some of those other countries do that we could look at.

Chris CREWITHER: Are there ways that we can increase umbilical cord blood stem cell donations here in Victoria as well? Is that something that you would recommend we do more around, or are there particular things that we can do in that regard?

Andrew MOSLEY: I would suggest that that is something where you would need to talk to those on the front line of obtaining donations. There are a couple of organisations that are involved broadly in that specific space that might be, I think, better placed to talk about exactly what we could do there.

Chris TANTI: Having done this with my own children, I think one of the challenges there is the expense. It is not cheap. And then you are—my kids are now 20 and 18—still getting notes from them and you are not clear about whether the donation is viable any longer. There is a huge up-front cost, or there is a significant up-front cost, and then there are ongoing costs. You know, I think most people would find that really, really difficult.

Chris CREWITHER: Yes. You talk about the cryopreservation of international stem cell donations. Can you explain that process a bit more, and is that something that Australia or Victoria needs to invest in more? I know we have a lower number of donations than, say, in Germany, but it may be that a donation here may not be suitable for a recipient in Australia but may be suitable overseas. Is that something that we need to invest in more heavily here in Victoria?

Andrew MOSLEY: I think one of the features—we have touched on this a couple of times. It is difficult to find a stem cell match, so as a country we are connected in that sense. I do not think it is ever going to be up to one specific state to try and solve the problem itself. In terms of the logistics of exporting and importing stem cells, because we are a reasonable distance from many other countries, and particularly Europe where some of this is done quite well, ultimately we do not want to continue that sole reliance. I think the more we can do within Australia the better, and the better Victorians will be and the better others around the country will be as well.

Chris TANTI: I think we have clearly got some unique populations here. You look at the United States or you look at the UK—they are both very multicultural societies, but we have our First Nations people and then Pacific Islanders, so we have a population here that is quite unique to this country, and we do not cater for them. Given the complexity around matching, the only solution is to increase the pool and to invest in doing that, and that investment needs to occur at a number of different levels, particularly around raising awareness. Given that people have to be age 18 to go through the process, I do think a campaign in schools, and not necessarily part of a health curriculum, around what it is and what the options might be on leaving, without getting people to commit or, you know, having parents beat teachers up—I think there is an opportunity for us to educate students about this and the possibilities of donating in the future.

Chris CREWITHER: I must admit that it was educational for me. When you hear about organ donations generally you are not often thinking of ethnicity being a factor, whereas with stem cells it is. Obviously, I do not understand the science behind that, not being a scientist myself, but given that complexity as compared with regular organ and tissue donations, what more can we do to target CALD communities or Indigenous communities or others that are under-represented in addition to what, I guess, you have already raised within your submission?

Chris TANTI: I think the PwC report talked about patient-facing organisations like the Leukaemia Foundation playing a role in that. I mean, we could certainly play a role in working with these communities to raise awareness et cetera. The medical system is designed to kill the cancer—that is what they are there for—and there is not a lot of work that occurs from a public health perspective. I think organisations like ours could probably do a lot more in that space. Given that we rely pretty much solely on the donations of the general public to do that, it is pretty hard with limited funds, but our organisation has its heritage in rural, regional and remote communities. There is a significant opportunity for us, and we are doing a bit more in the First Nations space because we realise there is a survival disparity. There is a lot of work that we could potentially do. We could lend support to those sorts of initiatives quite easily.

Chris CREWITHER: And in your view, is there a lot Victoria can do as well to help to scale up the Strength to Give program that you mentioned in there, or Australia generally? What can be done in that regard?

Chris TANTI: I think Victoria could do more in terms of working with everybody else. I think the thing that COVID highlighted for me was how—when I was living in the United States, I got a very clear sense that it was not they were not united states at all, it was 50-odd countries—and COVID highlighted for me the sort of

differences between the states and the fact that we are not as necessarily well joined up in this space, and I think Victoria could lead the way in helping us join up a bit more, because we certainly need to.

Chris CREWETHER: Thank you. I better go back to the Chair for the last five minutes.

The CHAIR: Thank you, Chris. Annabelle, did you have any further questions to ask?

Annabelle CLEELAND: That is a perfect segue, actually, from Chris's comments and your comments just then. Dissecting Australia's performance at a state level, is there any state that is performing higher or better? What is the comparison when it comes to stem cell registration?

Andrew MOSLEY: I believe it roughly correlates to the population of the states, so New South Wales has got the highest. Victoria does have the second highest, I believe. I think it is about 21 per cent—20.8 maybe. In that sense I do not think Victoria is necessarily not doing a good job, it is just that collectively and as a country we need more.

Annabelle CLEELAND: Okay. I am just sneaking one in really quickly because that was a quick answer. Should the awareness and promotion fall under the Organ and Tissue Authority and DonateLife?

Andrew MOSLEY: As things are currently set up, it would come under, I think, the Australian Bone Marrow Donor Registry, which is an independent charity, working with Lifeblood. In terms of exactly how they would work together, that is probably a conversation for them.

Annabelle CLEELAND: Until I get yelled at—on the blood cancer treatment centre, if they turn to the bone marrow registration and there is not the supply or the stem cell donation in the register, is that the end of the investigation, or are there other opportunities? I was surprised that there was a patient who undertook her own campaign in this space. Once the hospital or treatment centre cannot find that donation, is that the end of the investigation?

Andrew MOSLEY: I think you will find that patients doing their own campaign is actually not incredibly unusual.

Chris TANTI: No.

Annabelle CLEELAND: Sure.

Andrew MOSLEY: That person was in Perth, but there are lots of other examples. There was a more public example earlier in the year where someone really needed a donation and it became a campaign, particularly in Queensland. But it is not that uncommon, and the harsh reality is that the people involved in the process and the registry do absolutely all they can to try and find a donor for that person. If you are that person in that situation, it is almost a matter of life and death that you can find someone, so obviously you are going to do everything that you can as well to maximise the opportunity and the chances of finding a match somewhere in the world.

Chris TANTI: Yes, I agree. Patients will do extraordinary things to stay alive for their families. One of our advocates, when CAR T was not so available here, was flying to the UK every couple of months, at a huge expense to her and her family, just to stay alive—and it worked, actually. We see patients really working very, very hard to try and stay alive. Most of them will not accept a no, and they will try and find alternatives. Whether an alternative exists is another thing. I guess this is why we had a bigger pool; we would inspire a bit more confidence. But it is hard to inspire confidence when we are lagging.

Cindy McLEISH: I have just got a really quick one. Is there a greater prevalence of blood diseases in any particular ethnicity?

Andrew MOSLEY: Blood diseases generally? I think it probably depends on the disease. For stem cells—I could be misquoting here, but I think for Anglo populations it might be higher, as in the conditions for which a stem cell transplant is relevant. But we would probably have to take that on notice, I think, in terms of getting that correct.

Cindy McLEISH: Would you mind? Thanks. Thanks, Ella.

The CHAIR: Great. Just to wrap up, just one final question from me. You have spoken today about the role that the Victorian Government can play in advocating to the national health minister, perhaps through the national health ministers meetings. I am wondering if you can just elaborate on that a little bit further about what Victoria can be advocating for at a national level.

Andrew MOSLEY: There have been conversations over the course of a couple of years that have sort of started looking at our system broadly in terms of stem cell donations and some of the things that can be done to help further improve them. As Chris mentioned, there was the PwC report, and there was a national response to that. It was mentioned and it was discussed by, I should say, not just the one health minister but all health ministers nationally in February in terms of the need to perhaps do more, and certainly there were a number of parliamentarians that noted that perhaps we can and should be doing more. I believe the health ministers met again last week. As far as I am aware, at least in terms of the public communiqué, it was not discussed. I guess what we would be suggesting is that, now that particularly this year it has been put back on the agenda, Victoria and the other governments could continue to talk with each other about what some of those governance changes perhaps could look like, which we sort of started touching on here, because ultimately as the funders they are probably in the best position to think about what new arrangements could look like.

The CHAIR: Okay. Thank you, Chris and Andrew, for appearing before the Committee today and for your contribution to this inquiry. The Committee greatly appreciates the time and effort you have taken to prepare your evidence, both your written submission and the evidence you have provided today. You will be provided with a proof version of today's transcript to check, together with the questions taken on notice. Verified transcripts and responses to any questions taken on notice will then be published on the Committee's website.

The Committee will now take a 15-minute break, and I declare this hearing adjourned.

Witnesses withdrew.