T R A N S C R I P T

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Friday 25 August 2023

MEMBERS

Ella George—Chair
Annabelle Cleeland—Deputy Chair
Chris Couzens
Chris Crewther
Gary Maas
Cindy McLeish
Meng Heang Tak

WITNESSES

Lisa Smith, Chief Executive Officer, and

Professor Jeff Szer, Director, Australian Bone Marrow Donor Registry.

The CHAIR: Good afternoon. 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 Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors.

I begin today by acknowledging the traditional owners of the land on which we are meeting, the Wurundjeri Woi Wurrung people of the Kulin nation, and I pay my respects to their elders past, present and future, and extend that respect to First Nations people across Victoria.

I also acknowledge my colleagues participating today: Deputy Chair Annabelle Cleeland, Meng Heang Tak, Chris Crewther, Gary Maas and Christine Couzens. Cindy McLeish will be joining us momentarily.

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, and the Committee will report back no later than 31 March 2024. The Committee has received a number of valuable submissions to date, and we have heard from a number of witnesses. The submissions received to date can be viewed on the Committee's website.

On behalf of the Committee, I would like to take this opportunity to thank you for appearing before us today. We are really incredibly grateful for your time. All evidence given today is being recorded by Hansard and broadcast live. While all evidence taken by the Committee is protected by parliamentary privilege, comments prevented outside this hearing may not be protected by this privilege.

I now invite the Australian Bone Marrow Donor Registry to make a brief presentation to the Committee. This will be followed by questions from Members. Thank you.

Jeff SZER: Thank you, Ella. I am Jeff Szer. I am a clinical haematologist. I work at the Royal Melbourne and the Peter MacCallum Cancer Centre and have the privilege of probably being the oldest still functioning bone marrow transplant physician in the country, let alone the state. I actually established BMT in Victoria at the Alfred hospital in 1984 when I came back from my fellowship in the US, so I have got a long experience and I have seen huge evolution. Whereas in 1984 fewer than one-third of the people that we thought might have benefited from a bone marrow transplant could have one, that has dramatically increased not only in terms of a proportion of people but in fact in eligibility. We used to think 35 was geriatric for bone marrow transplantation. We now have no age limits as such, so we can offer lifesaving therapy to a wide variety of patients. But not everyone gets there still, despite this.

We are talking about a form of therapy that is done with curative intent for patients with life-threatening disorders. Either they have no alternative therapy or the alternative therapies or existing therapies are suboptimal. And from a donation point of view—and my involvement with the ABMDR goes back not quite that long—since the beginning of the foundation of the bone marrow donor registry, we have been able to develop a footprint in Australia and globally. But that footprint is sort of evaporating in the sand with time in terms of our ability to make an impact for Australian, and in this case Victorian, patients as our donor numbers have failed to keep up with requirements and with available technologies.

We see patients clinically all the time who would benefit from a bone marrow transplant, and a large registry of locally available, well-typed donors is very important for their ability to get to transplantation. And you probably are aware by now, I think, from all the submissions that we are dealing with donors who are going to survive the experience and be none the worse for it, which perhaps distinguishes it from solid organ donation and tissue donation. It is a beautiful thing to see donors experience something positive and contribute towards potentially saving a life.

We have ethnic impact on donor suitability. Donors have to be well matched—you will have seen that—by HLA, the human leukocyte antigen, which is done through typing either blood or swabs, which will be the subject, I am sure, of Lisa's discussion with you. And our HLA type, which is used to match with donors, is very much ethnically distinguishable. You can often guess somebody's ethnic origins from their tissue type because things are segregated in communities. And, you know, our population is so diverse. I mean, I am currently trying to find a donor for a patient with a Slovenian parent and—what was the other one?—Chilean. This is very difficult. We have a community that could support an ethnic diversity of appropriate donors if only we had the resources to attract them, keep them, type them and have them available. And, you know, this patient may miss out; we do not know. And unfortunately, there is no way of tracking who has actually suffered

as a result of lack of donor availability. They are there, and I have seen—there is less of it now than there was, but it is still a significant problem.

We would like to see the ABMDR restored to its glory. It was once the sixth largest active registry in the world. It is no longer that. And, you know, we would like to punch at least at our weight if not above it—preferably above it. Impact on individual patients is real for what we are here talking about today.

The CHAIR: Thanks, Jeff.

Lisa SMITH: I am Lisa Smith. I am the CEO of the Australian Bone Marrow Donor Registry. ABMDR's charitable purpose is to ensure that people who require this life-saving stem cell transplant have access to suitable unrelated donors, and for over three decades we have provided Australia with a world-class donor registry, as Jeff has just mentioned. We operate very much behind the scenes, matching patients to these volunteer donors anywhere in the world, sourcing the cells from these donors and ensuring that the cells arrive at the patient's bedside. The fact that we are utterly taken for granted is testament really to how well we have done this and to our success.

Every year about a thousand of some of the sickest patients in Australia come to us to find their miracle—that complete stranger who is a perfect genetic match, ideally, with their tissue type and who is willing to donate their stem cells. Patients like four-year-old Kruz Hedderick, who is right now in the Royal Children's Hospital and is awaiting his perfect match, are hoping to undergo what is really an awful treatment, where patients are taken to the brink of death in the hope that they can be saved, because the alternative just does not bear thinking about. These patients are at the centre of everything that we do at ABMDR, and that is why we are here today. For around a decade we have been raising with jurisdictions the problem of underinvestment in Australia's donor recruitment, both in terms of methods and just in terms of total numbers—for so long, in fact, that it seems reasonable to conclude that this problem is becoming a policy position. Either way, it leaves Australians overwhelmingly dependent on the goodwill of people on the other side of the planet. We know that this creates avoidable risks, and we saw firsthand during the pandemic how this dependency made Australian patients especially vulnerable. When those planes stopped flying, we could not get the cells into this country. But worse than that, and as Jeff mentioned, we know that depending on the rest of the world to donate to our patients means that some of our patients have little hope of ever finding their match. We live in a very multicultural country, and your chances of finding a match increase when there are a lot of donors on the registry with the same ethnicity as you. We see patients in Australia from ethnicities that are not well represented overseas—not necessarily all of them as complex as the case that Jeff just mentioned, but Greek, Lebanese, South-East Asian and Indian communities. Imagine also being an Indigenous Australian—there is nowhere else in the world that we can look for you.

Over the past years PwC have been repeatedly engaged to review this problem. Jurisdictions have consulted widely on this problem. They have written a framework document that agrees that it is a problem and also that action must be taken to solve this problem, and yet the problem still remains. We know the solution: sustainably invest in modern donor recruitment methods and significantly increase the number of donors recruited in Australia each year, not by 1,000 or 5,000 but by at least 30,000 donors a year over and above what is currently being delivered. The way to do this is just simply to do what other registries around the world do and have done for the past decade: engage with our young target audience where there are at, which is online and on social media; promote the need for donors; address the myths about donation; develop the trust in the community about our registry; and allow non-blood donors to join by using simple, low-cost and effective cheek swabs. I am happy to pass these around if anybody would like. You can have a look at the kits. They are not that exciting, but there you go.

We have fully costed this solution. We have twice demonstrated that cheek swab recruitment works in Australia. We have identified a readily available source of funding to implement the solution and we have committed the last of our available cash reserves to setting up the solution for success. We have already opened a home-delivered cheek swab recruitment channel, which is the swabs that you see there—they will get posted to you once you register online. Next month we will be rolling out a national awareness campaign. This is all self-funded. We understand that the investment that we require to be made must be agreed to by all states, territories and the Commonwealth and that this takes time, but if you have patients at the centre of your decision-making, the path forward is very clear and the urgency is very obvious. So on this one issue we, and by that I mean all of us involved in this sector, fall far short of the expectations of our patients and the

expectations of donor registries around the world who supply us with their donors, because we continually fail to recruit enough of our own. So we appeal to the Victorian health minister—and all health ministers, but we are here today—to prioritise the needs of patients that look to her and to us to just get on with it. We ask her to make the decision to continue and extend our current cheek-swabbing and awareness-raising activities so that we can recruit that extra 30,000 donors at least that are needed in addition each year. We ask her to champion this with her colleagues around the country and to not let red tape get in the way of what can be done to improve the situation today. Already this inquiry has helped us raise awareness of this issue and this rather perplexing situation that we find ourselves in, so we look forward to assisting you with any questions that you have today.

The CHAIR: Thank you, Lisa and Jeff. I will just start with a general comment, which is that I was quite shocked to hear that three out of four stem cell donations in Australia are coming from Germany and that we do have to look to friends overseas to source that. I think we all agree that we can do better on that front.

Lisa SMITH: It is now over eight out of 10 Australian patients who will have their cells sourced overseas, which is the level that we were at when we went into the pandemic. It decreased during the pandemic because of the difficulties of accessing overseas donors, so instead we saw an increased number of Australian donors used that would not otherwise have been selected, shall we say. They were older, typically, and more females and –

Jeff SZER: No offence.

Lisa SMITH: clinically that is not the preferred choice, but that has since returned to normal. We are back at about 82%.

The CHAIR: Okay. You have said that you think investment is needed to essentially solve this problem. Can you take us through your current funding?

Lisa SMITH: Yes. We have a services contract with the Commonwealth. It is a two-year contract and that is our primary funding source. Jurisdictions all contribute to the funding of those fees. We also receive income from overseas registries. Every time an Australian donor makes a donation in Australia for a patient overseas, we arrange for the export of those cells and then that foreign registry will make a payment to us to basically, you know, recoup the costs. So what we do when we sit down to work out what are the fees we need to charge jurisdictions for our services is we project what we think that income will be from the exports and we deduct that off the fees. So it is like an up-front discount that effectively cancels out. While it is income, it is automatically just included as—it covers part of our operating costs. That is the primary funding that we have available.

Every time an umbilical cord blood unit that has been collected from a newborn is exported, there is a similar fee that is attached; however, when that income comes in, that gets banked into a separate account. Under the terms of our contract with the Commonwealth, in that account, we can not touch that money unless there is jurisdictional approval. And we understand that approval is required from all of the states and territories before we can use that. So that money has been accumulating since about 2001, and that is a sum of about $13 million today. There has been some expenditure of that over the years, typically some of the PwC consultancies, but largely it has just been sitting there accumulating for that entire period.

The CHAIR: Okay. One of the other things you mentioned in your presentation is the requirement, I suppose, of needing donors from different ethnicities and different backgrounds. I am wondering what happens if you cannot find a suitable match for somebody, if you could talk us through what would happen there.

Jeff SZER: Yes. Donor suitability is a moving target and technologies have advanced. If you look down the sequence of what would be an acceptable donor, our ideal donor in most situations is a fully matched sibling from the same parents because they have inherited the same tissue-typing genes from the same parents. They are the best match. With the way we do transplants now, a fully matched unrelated donor—so the genes have come from different places but the important ones happen to be the same as for the patient—is our ideal second donor. We then get faced with choices if we do not have one of those, and it does happen, particularly in the circumstance you are talking about. We can either choose to have a partially mismatched family member or unrelated donor, or the more recent player in this game is what is called a haploidentical family member donor, so this is a parent or a child or a sibling who has inherited half of the genetic information from one parent but

the other half from the other parent. This is something that was not thought possible 20 years ago. It is possible now. It brings with it a whole variety of its own problems and requires a different—but it can be done.

That is how we do it. Some places have, particularly during the pandemic, moved towards these half-matched family member donors because of the lack of availability of unrelated donors or inability to get cells here in a timely manner. But it is still regarded by most adult transplants as third tier, and in the adult world, we still have the availability of cord blood transplants. We have not done one in Melbourne for some years now because of the other moving technologies, and it is not an ideal treatment for most adults, although there is still a small bit of activity in paediatric patients.

The CHAIR: Okay, thank you. I will hand over to Committee Members to ask some questions. Would you like to start, Annabelle?

Annabelle CLEELAND: Yes, thank you. That is amazing. Lisa, you have got some frustrations with the level of consulting that has occurred. How many reports or inquiries have you contributed to in this space?

Lisa SMITH: I would say over the past two decades it would be a dozen that are either directly relevant or tangential to this issue. The last published report was a 2018 PwC review. I think it might have been published in January 2019, so I might stand corrected on that, but nevertheless it was conducted in 2018. We contributed to that. There have been subsequent reviews that have not been published that we have contributed to as well. The 2018 review identified the global problem and the fact that the current decision-making process is fragmented and that needed to be reviewed, but we had this big problem with recruitment and the size and the composition of the Australian donor pool. The subsequent reviews that we have contributed to have been into donor recruitment specifically and best practice in terms of donor recruitment and retention, but that one we have not seen come out as yet.

Annabelle CLEELAND: What year was that, sorry?

Lisa SMITH: I think it started in 2020; it was during the pandemic. I think it might have finished in 2021.

Annabelle CLEELAND: And a Victorian or a national –

Lisa SMITH: It is all jurisdictions.

Annabelle CLEELAND: I am going to jump over just from points that you have said. Jeff, you were talking about the Chilean-Slovenian donor that you are looking for. Can you just explain logistically, when you say you are 'looking for' –

Jeff SZER: How does that work? We have a couple of very experienced donor coordinators that work in our department—I am speaking now in a transplant centre, so we have a patient and we need to find a donor. I go to the donor coordinators, they arrange for the tissue typing of the patient if we have not done that already; hopefully we have, and we have. And then they can take a number of steps, but they can do a preliminary search through a global system to see if there is someone that appears to be a match, recognising that not every donor in the world has been fully typed. Often we get a partial match and we say, yes, there is a possibility. Then there is a more formal search that happens directly through the ABMDR—the first bit can be as well, but it is often not—where formal links, both within the Australian registry and our links with the global registries through the World Marrow Donor Association that Lisa and I both work through, can be searched for a donor. Then if you identify someone that appears to be matched, the donor is asked to do confirmatory typing, locally, so that we are sure we are dealing with the right individual with the right tissue type. At that point, once we have a confirmed donor, we can move towards scheduling a transplant. This can take a week or it can take months, or years sometimes, because some of these searches are active while you are trying to keep the patient alive.

Annabelle CLEELAND: Both of you: what would be your thoughts on potentially collaborating with Lifeblood's database and systems? Are there any opportunities to streamline the registration in Australia?

Lisa SMITH: In terms of systems, the systems that we use for the process that Jeff was just talking about are our actual in-house systems and are of our design and our solution. Lifeblood is our most important recruitment partner, clearly, because the existing model is that the only way to join the registry is to be a blood

donor—making a blood donation. There will be posters inside some of those donor centres where you can sign up to our registry, and then they will take the additional blood samples. We have worked very closely for three decades, really, on that particular model, and I see no reason why that needs to change. We are certainly not proposing that. What we are just saying is that the inherent limitations of that model are that you need to be a blood donor, whereas we do not have the same restrictions. We do not care when you had a tattoo, and male-to-male sex is not an issue for us—you can sign up to our registry. We do not have any of those same exclusion criteria. You are automatically cutting yourself off from a significant portion of the population that could sign up, except that because they cannot donate blood, they also cannot join us. Hence the cheek swabs are another way to just directly target that audience.

Certainly the awareness campaign that we are putting out is very much targeted to young men, particularly diverse young men, and it is showing a full representation of all of the spectrum of diversity out there that can sign up to us. But at the end of the day, a donor has to actually join our registry. They need to give their consent to us in order for us to be able to add them into this search process and in order for us to be able to collect samples from them and share their information and register it with Jeff's team and hospitals around Australia but also registries around the world. This is another aspect of why stem cell transplantation is so different from organ and tissue transplant—because we are global. It really does not matter. It is mathematically impossible for Australia to meet 100% of patient demand, or for any country to do that, for that matter. We will always have a need to have that global connection and exchange of cells and relationships and agreements and systems that support that. Having said that, having an 80-plus per cent dependency is not acceptable, but there will always be some degree.

Jeff SZER: There was some rationale at the very beginning for trying to restrict the donor pool to blood donors. Victoria was a great example of how things can go wrong if you do not do it correctly. There was this massive campaign by what became the Bone Marrow Donor Institute to create a registry as a result of the father of a patient of mine getting very active. They went to football clubs and all sorts of people, so we had thousands of people signed up to be donors, none of whom had any idea what they were signing up for, and they became unavailable people. So we had a registry that was bloated by unavailable donors, which actually delays the process for patients. You find someone who is a match, or a potential match, you go to find them and then you exert an enormous amount of energy trying to contact them and explain to them what they signed up for during that raffle. That is why we went that way—that was an active decision—but we have moved on from then I think.

Lisa SMITH: Yes. In fact we still encounter that very issue, because a lot of blood donors do not realise what they have signed up for and that we are a separate organisation. Many of them actually think that they did donate when they gave their blood—'Wasn't that the donation?' We still have issues today where if we contact a donor, we have had people very angry: 'Who are you? How did you get my number? Remove me off your list.' It really is just that. You know, although it is solely responsible for the 140,000 donors that we have with us today—and we are obviously extremely grateful for that—it does come with its own challenges, so that is part of the communication challenge we have got, and it has created a fair degree of confusion that does need to be overcome. For us a much cleaner method is just direct, and then we can build that relationship directly, because at the end of the day we are the ones who will be collecting their consent to actually donate and we are talking them through that process.

Annabelle CLEELAND: I have got a question, but I will pass to my colleagues and we will see if we have time.

The CHAIR: Thanks, Annabelle. Just before we hand over to colleagues, a reminder to speak into your microphones, if that is okay, so everyone can hear us okay. Chris.

Chris CREWTHER: My question sort of relates to your Chilean-Slovenian example. With a growing multiethnic community with increasing diversity in families—mine is one example, but my brother's partner, for example, is a quarter Native American, a quarter Indigenous Australian, a quarter Dutch and a quarter something else—are you finding it increasingly troublesome to find matching donors, particularly for people like my brother's partner if she would ever need a donation?

Jeff SZER: Yes. There would be remarkably few people like that—

Chris CREWTHER: If any.

Jeff SZER: who not only fall into that same ethnic mix but actually have—there are multiple tissue types within any ethnicity. I mean many, many. And it is worth saying that modern typing technology is very different to what it was in the 1990s or even 20 years ago. Most of the donors we found that we thought were matched back then probably were not matched by modern criteria, so it gets harder and harder, not easier and easier to identify, so you need a much bigger donor pool. For some of these ethnic subsets you will never find an adequate number of donors, but that does not mean we should not try. It is a bit like the rare blood groups for the sickle cell anaemia patients we have got around the place. There are some people that have got a single donor in the whole country for them for a required blood transfusion, or some with none. It sometimes creates real problems of numbers, but again it does not mean we should not try and go and look and find as many appropriate donors as can be done appropriately.

Lisa SMITH: We know that around 22% of Australian patients when they start their formal search—which is the point at which we have produced the ranked reports and then Jeff's team have gone through and picked and said, 'Look, these are the ones that we want to now proceed to further blood sampling'—will only be proceeding with one donor because that is who they can find.

Jeff SZER: Clinically we ideally like to have a backup, because things fall over.

Lisa SMITH: Of the other 78% of Australian patients, they average five—taking five donors through that process. So yes, it is very much not a position to be in.

Chris CREWTHER: Thank you.

The CHAIR: Thank you. Cindy.

Cindy McLEISH: Thank you. I too had questions about that, but we have covered them all. One of the things that I noted is that we are talking about the best chance of success if the donor is young—18 to 35—and ideally male. Is that to do with female reproduction, or—

Lisa SMITH: Yes.

Jeff SZER: Yes. So nulliparous females—that is, females who have never been pregnant—are pretty close to males in the same age group in terms of suitability, but when you are pregnant you get exposed to paternal antigens with the developing fetus and can develop antibodies and cells against those markers, so it becomes a statistically riskier transplant to use a female who has been pregnant.

Lisa SMITH: In terms of age, the research shows that patient outcomes decrease by about 3% for every decade of an adult donor's age.

Cindy McLEISH: I think you might take that.

Lisa SMITH: Certainly we do see 50-odd-year-old donors donating, but if you have your preference, you will want the youngest possible donor, and that is why we have put in place the age restrictions. It is largely because, you know, obviously there is expense associated with joining the registry and the sampling and all the rest of it. You are on the registry until you are 60. Expending that money recruiting, say, a 58-year-old, who is very much unlikely to be chosen unless they are one of those rare exceptions where they are the only match, and then two years later retiring them—it is not economically rational to do that, and it is unlikely to actually lead to any improved patient outcomes. That is why we have the age limits that we do.

Cindy McLEISH: Just the other question that I have: you mentioned earlier that there has been $13 million that has accumulated. Whose books is that sitting on?

Lisa SMITH: Ours.

Cindy McLEISH: Yours. Thanks.

The CHAIR: Annabelle, I think we are good for questions over here if you had some more thoughts.

Annabelle CLEELAND: Jeff—sorry, I just wanted to hone in—you said we were once the sixth-largest registry, and we are no longer that. Where do we sit on our performance, and what were the main factors behind us slipping?

Lisa SMITH: In terms of the size of the donor pool, using it as a percentage of the population—that is the way we do comparisons—when we look at comparable nations, which is nations that transplant at similar rates that we do in Australia, we are last. We are bottom of a list of about 20 countries. If you are only recruiting about 5500 donors a year, which is what the average has been over the last decade or two, then that is the inevitable result. I know that you have heard from our colleagues from ZKRD—Joannis. Between Germany and America they recruit millions of donors a year, and it is largely because of the low cost and ease of these cheek swabs that they been able to do that. Most other nations are recruiting very significant proportions of their population onto the registry. When we are looking at the most desirable donors, 18- to 35-year-olds, in terms of the numbers that sit on our registry, it is 0.2% of the population. If you are looking at overseas countries, it is up to 5% of their population.

Jeff SZER: Or more.

Lisa SMITH: Just in terms of the 18- to 35-year-olds, so it is not even counting the total size of their donor pool. If you just look at how many of their donors are 18 to 35 and measure that as a percentage of the population, it is orders of magnitude.

Jeff SZER: The last trip I took before the borders closed down in 2020 was to a country that had just celebrated their millionth stem cell donor on their national registry. The total population of that country is 9 million. That is where we sit.

Annabelle CLEELAND: If you had one major recommendation, it would be to support cheek swabs?

Lisa SMITH: We need to substantially increase the number of donors, and that cannot be achieved through constraining your donor pool to just blood donors, so therefore you need another way for people to get on. So, yes, it has to be cheek swabs. We do need to make sure that it is clear that this is a substantial increase. We have done a couple of the demonstration projects, and that brought 5,500–6,000 donors. The current conversation that we are in with jurisdictions relates to half a million dollars funding into cheek swabs, which is actually a lower amount of funding than what we had during the demonstration projects. It is all great, but it is not enough, and we need to make that significant investment now.

The CHAIR: I have got a couple more questions I would like to finish with if that is all right. We have heard a little bit about some of the misconceptions when it comes to bone marrow and stem cell donations, and we would love to essentially get on the record some of that. If you could explain some of the differences between the processes for collecting bone marrow and stem cell donations and what processes are common in Australia, that would be great.

Jeff SZER: It is all bone marrow; it is just a question of where you get it from. That is a little bugbear of mine. Peripheral blood-derived haematopoietic stem cells are collected by a process called apheresis, which involves stimulating the bone marrow stem cells to escape from their normal space, get into the bloodstream and then be collected on a machine, which is sort of akin to dialysis but not, where a donor is hooked up to a machine for a few hours. The blood washes through it and the stem cell fraction is removed, and everything else is given back. That is a one- or two-day exercise for a few hours on a machine and four or five days of being injected with a blood-promoting hormone called filgrastim, or G-CSF. That is all done in the ambulatory setting most of the time. A bone marrow donation was the traditional way we collected things until the discovery of filgrastim, which happened in Melbourne at the Walter and Eliza Hall Institute of Medical Research, so it is a very Melbourne-based thing. We did the original studies that showed you could actually get cells into the circulation to collect them in Melbourne.

Bone marrow donation is an inpatient procedure. It is an overnight stay in hospital, but not always, and involves a general anaesthetic and multiple needle passes into the bone marrow space at the back of the pelvis and the collection of up to a litre, or sometimes a little bit more, of bone marrow, which is sort of a blood-filled but bone-marrow-enriched product. That is a bit tougher for people. There is some post-operative pain and it does require an inpatient stay, but there is also a bit of mobilisation pain in the stem cell patients; it is just front loaded rather than rear loaded. It is not a completely benign procedure, and a general anaesthetic is a general

anaesthetic. But they are now a minority of collections, both in the family member and the unrelated donor, not only for convenience—the nurses do the collections on the machines and doctors have got to collect the stuff, and we are inherently lazy, or busy or something. So the majority is blood cell collection. It does alter the pattern of transplant, but they are essentially getting the same cells, just in different proportions and different mechanisms. No donor has died in Australia from either procedure. There are adverse reactions to anything that happens, and I in fact chaired for a long time and still sit on a committee of the World Marrow Donor Association, which looks at every adverse event that is reported. We filter the Australian ones through to the ABMDR scientific committee, and we are increasingly looking at family member donors in that context as well. So it is a very detailed examination of donor safety.

Lisa SMITH: Nine out of 10 donors will be donating through that apheresis method. Some patients, their outcomes are better if there is marrow. Typically those patients are infants, and we find that when donors appreciate that they are donating to an infant—we have babies that are weeks old, and in fact we have some unborn babies on our books—that does mean that they find it is not actually that scary a procedure after all. It is certainly not as scary as what that baby has got to go through.

The CHAIR: And the technology for the donation through blood cells, that was developed in Melbourne?

Jeff SZER: It was an adaptation of existing technology—no, it was actually developed as a result of a joint research project between the Royal Adelaide Hospital, the Alfred and Westmead Hospital in Sydney. We showed that you could collect these cells from autologous donors—that is, people who are donating for themselves. That could be done after chemotherapy recovery before we had the availability of stimulating stem cells in normal individuals. So the technology predated the availability of getting cells out of normal individuals. That is why we could only use bone marrow prior to that. So no, we cannot claim that we invented apheresis. I wish we could, but we cannot. We might have the best apheresis nurses in the country here, but I am not –

The CHAIR: That is on the record now. Well, we should claim some credit.

Jeff SZER: Yes.

The CHAIR: Great. Were there any further questions from Committee Members? In that case, we might wrap that up there. Jeff and Lisa, thank you so much for appearing before the Committee today and for your written submission to the inquiry. The Committee greatly appreciates the time and effort that you have taken to appear before us. You will be provided with a proof version of today's transcript to check, and verified transcripts will be published on the Committee's website. Thank you again, and I declare this hearing adjourned.

Committee adjourned.