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—Monday 19 June 2023

MEMBERS

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

WITNESSES

Ms Bronwyn Cohen, Quality Manager and Acting Director, and

Dr Heather Machin, Senior Project Manager, Lions Eye Donation Service.

The CHAIR: Good morning. Today we have a public hearing of the Legislative Assembly Legal and Social Issue Committee's Inquiry into Increasing the Number of Registered Organ and Tissue Donors. I welcome our next witnesses. From Lions Eye Donation Service we have Bronwyn Cohen, Quality Manager and Acting Director, and Dr Heather Machin, Senior Project Manager. Thank you so much for appearing before the Committee today.

All evidence being given today is being recorded by Hansard and is broadcast live. While all evidence taken by the Committee is protected by parliamentary privilege, comments repeated outside this hearing may not be protected by this privilege.

Witnesses will be provided with a proof version of the transcript to check. Verified transcripts and other documents provided to the Committee during the hearing will be published on the Committee's website.

I now invite you to make a brief opening statement of approximately 5 to 10 minutes. This will be followed by questions from Members.

Bronwyn COHEN: Thank you, Ella, and good morning, Committee. As you said, my name is Bronwyn Cohen, and I am the Quality Manager and Acting Director of the Lions Eye Donation Service. With me is my colleague Dr Machin. Heather has a wealth of knowledge from the global eye-banking perspective and is our link from the eye donation service to researchers, both domestically and internationally. We greatly appreciate the opportunity to present our ideas for increasing donor registrations, particularly from the eye banking perspective. We would also like to acknowledge and thank our donor families for their consent to eye donation.

We have proudly served the Victorian community for over 30 years, providing quality, evaluated and safe ocular tissue for transplantation by surgeons in Victoria, interstate and New Zealand. We are currently self-sustainable, in that we are able to meet and exceed demand for tissue for transplant, and often assist our neighbouring eye banks with corneas for transplant. Although in Victoria we meet demand, there is always the potential for demand to increase and for us to increase our tissue that we provide to researchers, and therefore we would need to seek additional donors. However, we are at capacity now due to our current outdated facility.

If the aim of the inquiry is solely to increase registrations on the donor registry, the answer is quite simple, and that is with drivers licence registrations and renewal. If, however, the intent is not only to increase donor registrations but to increase the number of actual organ and tissue donations, there needs to be a multifaceted approach. We have five suggested strategies to be employed to raise awareness and encourage more people to register to donate.

The first is to educate the public. Many people are not even aware of eye tissue donation. Through the good work of DonateLife, many people are aware of organ donation. However, I would actually ask the Committee if they had ever heard of eye donation prior to today or to starting this inquiry. We need to provide information about the benefits of eye tissue donation and how it works and dispel any myths and encourage more people to consider donation. It is ethically important that the public are aware of what they are registering for, such that consent is educated consent. As I said, through the good work of DonateLife, many people have heard of organ donation; however, often with eye and tissue donation their first experience is when a loved one is in end-of-life care or indeed if they are requiring a transplant.

Our second idea is to partner with local organisations. Partnering with local organisations such as schools can help spread the message about eye tissue donation to a wider audience. Partnering with professional university and union memberships upon registering for a professional membership—whether it be the CPA, the registered college of practitioners for GPs, the AMA or university student organisations—there would be an opportunity to ask the question, 'Have you considered organ and tissue donation?'

It could also be included in the middle school curriculum. I know DonateLife spoke about this earlier today, but young people only two generations ago were able to drive the change on climate change. We are all aware of climate change now. Two generations ago it was barely spoken of. We have that opportunity to have organ and tissue donation included in the curriculum, potentially in the health sciences field, so people actually become aware that it is possible, it is culturally acceptable and that people can really benefit from such a donation.

Another partner on a national scale would be the national bowel screening program. Eye and tissue donors are predominantly older persons. While older donors are not generally the focus of the solid organ donation, older persons are often ideal eye and tissue donors. Partnering with Lifeblood—so including the organ and tissue donation in the questionnaire—would be a positive, as blood donors already have an altruistic nature and would be more likely to register as organ and tissue donors.

The use of social media—social media can be a powerful tool for raising awareness about eye tissue donation. Creating posts and campaigns, which highlight the need for donations and the positive impact they can have on others, could help reach a wider audience and encourage more people to donate. The next generation have an amazing capacity to connect to enormous numbers of people in a very short space of time. Celebrity influencers are also very powerful message deliverers. The work of Neale Daniher on MND and Olivia Newton-John on breast cancer is quite simply amazing, inspiring and a demonstration of what can be achieved.

We need to make the donation process accessible and convenient so that all hospitals—not just, as you would have heard, the Alfred and the Austin, but all hospitals—have their facility policies in place for end-of-life care to include a discussion with the family for potential organ and tissue donation. The Austin, at their palliative care unit in 8 South, had a tremendous change a number of years ago. A couple of new staff members came in and said, 'Is the conversation happening with families?' And so very often the conversation was not happening. Sheerly having that conversation has incredibly improved the amount of donations, and now 8 South are well and above our greatest referrers for eye tissue.

We need to make sure that donor specialist nursing coordinators, who you heard from just before, are in place in as many facilities as possible, especially if they are of a similar ethnicity to the patient population. We have lost donors from the south-east of Melbourne, and we firmly believe that it is because the person having the conversation does not look like you—they are feeling a little more uncomfortable having that conversation. Without those donation specialists or suitably trained health professionals to guide that decision to donate, having a large registration base is essentially ineffectual.

We also need to recognise and honour those who have donated. This can include highlighting their stories and the impact they have had on others as well as recognising their families for their generosity and support. Our donor coordinators at the eye donation service also facilitate a transfer of information, if you will, in that our recipients are encouraged to write to the donor family. It comes via us to ensure that confidentiality is not breached. We will perhaps black out occasionally 'My name is –' and 'I am a –'. That is deleted. But it is really a powerful, powerful tool. If you will just indulge me a little bit here, I do have a letter that came across my desk only last month. It says:

> Dear Donor Family,
>
> I write to you to thank you for your kind donation. I had a cornea transplant a couple of months ago and it has been a great success.
>
> My vision had been badly affected by scarring on the cornea in my right eye. A transplant was my only option to improve my vision. My vision is now greatly improved. My daily quality of life is better and I can enjoy my favourite pursuits – bushwalking, photography and bird-watching.
>
> Nearly 30 years ago my father died of cancer. The only organs of his that were suitable for donation was his corneas. It gave me comfort, at that difficult time, to know that his corneas may help someone.
>
> I can't believe that I have now become the recipient of a similar gift.
>
> Thank you so much for donating your loves ones eyes.
>
> I will always be grateful for this gift.
>
> Kind Regards
>
> Thankful Recipient

If that does not persuade you to donate, I do not really know what else will.

Heather and I are open for your questions. As I said, Heather has a wealth of knowledge when it comes to global eye banking as a member of the global eye-banking association.

The CHAIR: Thank you so much for your presentation to us and also for sharing a very moving letter from a very grateful recipient. We will now move into questions, and I will pass to Christine.

Chris COUZENS: Thank you so much for your time today. We really appreciate it. As Ella said, it was very moving to hear from one of the grateful recipients.

Bronwyn COHEN: It was lovely in that she was both a donor, a consent to donor, and a recipient. It is a very powerful story.

Chris COUZENS: Yes. Thank you for reading that today, I think it really adds to the significance and the value of the work that you do and the important job that we have in preparing this report at the end. You talked about the fact that your organisation meets the demand, I suppose, for donations. We have heard from others that there has been a massive reduction, so have you got a reason for that?

Bronwyn COHEN: We have, and I have got the figures here for the last number of years. There is a definite drop-off in both demand and donation, in that we recover our tissue according to what we have booked ahead for the year. We are licensed by the TGA, which is unlike the organs, so we need to—because we store our tissue. So we will recover the tissue within 24 hours of death; it can extend up to 48 with medical director approval. But then we will recover that tissue, bring it back to the laboratory and store it, you know, preserve it in a nutrient-rich media that we keep in the incubator for up to a month. It is then prepared for transplant according to the transplant surgeon's requests.

Heather MACHIN: But most people—regardless of whether all of the conversations about organs and everybody wants to become an organ donor—at the end, they are more likely to become an eye donor. There are more people who are actually eye donors than anything else purely because of how they died and why they died, which makes them ineligible to do anything else. But it is much easier to donate your eye because there are less things that are wrong with the eye in that respect, and there is no need for matching, like with kidneys or anything like that—any gender, any race or any age can get one or the other, it just depends on that particular cornea's viability. So it is much more diverse in its ability to be shared with a greater amount of people, and it can also be moved easily as well. While we do have, for example, the need for infrastructure, with refrigerators and incubators and all those sorts of things, when we ship it, it is a tiny little jar, which as long as it is kept temperature-proof, can travel to the other side of the world. So it is much more accessible.

We have also had, for the last 30 years, an incredible support from our end users, our ophthalmologists, who have also pushed to make sure that eyes are looked after. And like with everything you see around you, there are eye hospitals—there are no kidney hospitals. So eyes, anything with eyes, we promote, and the users, they have pushed it really hard. So consequently here in Australia, we are one of the few countries where we can say, for a majority of the time, if a surgeon books a request for a cornea, they get that cornea.

Chris COUZENS: And do you have any particular focus on First Nations people or ethnic communities? I think—and you have raised that.

Heather MACHIN: I admit at the moment we do not have a statement on First Nations, and a reconciliation action plan is part of our agenda, both where we work—and we are also part of the Eye Bank Association of Australia and New Zealand—and it is on our to-do list there in the next couple of months. Actually I am trying to convince this one to do it, to be completely honest. So we are completely aware that we do not have one. We do know that we do have First Nation recipients. In fact we have had one recently who actually supported our eye tissue awareness campaign, which we do with DonateLife, and we are incredibly grateful for that. But in terms of statistics and actual strategy, we are lacking.

Chris COUZENS: So will you then set up a database to enable –

Heather MACHIN: We work collaboratively with all the eye banks across Australia. We also work with all of the tissue banks and also the Organ and Tissue Authority through the Eye and Tissue Advisory Committee because we want to make sure our messaging is the same. There is zero point in me putting it on our website if somebody in Queensland is reading it and then realising that it is different in their state. So we try to do everything as a national body in the eye and tissue field to make sure that messaging is clear.

Chris COUZENS: And obviously education is a big component of organ and tissue donation. Do you see that spreading to the regions as being a key part of that? I know you are specifically eyes, but if you are out there doing eyes, that broader donation information might be really useful too—particularly in, you know, you

have got the Aboriginal health organisations out in the regions, the ethnic communities councils—utilising them, do you see that as of value?

Heather MACHIN: I see all of it as a value. Any time we can get in front of a community or an individual, whether it is somebody who I just met at a party or somebody through the media, is an opportunity to educate about donation. We are basically limited by resources. If we had more staff, we would be out there every day.

Chris COUZENS: So if you had more resources, would you focus that on education and awareness?

Heather MACHIN: Absolutely.

Chris COUZENS: What would your priority be, do you think?

Heather MACHIN: Both.

Bronwyn COHEN: It does need to be, as I say, a multifaceted approach, because while increasing donations would be terrific, we currently meet our demand. Of course in the foreseeable future if there were more ophthalmologists to use the tissue, there would be an increase in demand. We have seen a drop-off in both the public and the private sector since the pandemic, but that is going to, we would assume, rise. We have had a 45% increase since the eye bank started, so we can only assume, with an increase in population, that it is. So it really does need to be that multifaceted approach in that increasing donations would be terrific, but we are at capacity at the moment and we could not do many more in the facility that we are currently in.

Heather MACHIN: There are a couple of points to that. First of all, it would be great to have more regional and remote donors, but the reality is having somebody there who can recover the eye, not just do the consent and the education but with the actual skillset to recover the eye and get that back to the bank in time, is a limitation. In Victoria—thankfully it is a slightly smaller state—we are able to go throughout the state. Other states do not have that luxury, particularly some of the bigger ones—so the proximity to the bank in order to recover or having staff in those regional or remote facilities who can actually recover the tissue. It is basically almost like doing a surgical procedure, so there is a level of training there. It could either be through an ophthalmology registrar or a trained technician, usually a nurse, who can do that and then send it to us. We have that arrangement with Tasmania at the moment. DonateLife Tasmania do consent donors, and there are registrars in Tasmania who send tissue to our eye bank. We process that, and that can go to a Victorian or whoever else is in need.

Chris COUZENS: What is the timeframe?

Heather MACHIN: For recovery?

Chris COUZENS: For collecting the tissue.

Heather MACHIN: Within 24 hours is preferred, though as soon as possible.

Bronwyn COHEN: However, we also do recoveries at the donor tissue bank, and it is 24 hours, for those coroner's cases, since last seen alive. That also will narrow those donors.

Chris COUZENS: Thank you.

The CHAIR: Thanks, Chris. I might hand over to the other Chris now.

Chris CREWTHER: We are all called Chris here. Firstly, thank you again for your submission and for giving evidence here today. As a person who formally did the first 1½ years equivalent of optometry, I am greatly interested in eyes. While I could not see myself in that career, excuse the pun, at least I can ask some questions about it. You have got to have some jokes.

Bronwyn COHEN: I love it.

Chris CREWTHER: You noted that there is I guess perhaps more of an ability to donate eyes, for various reasons, but do you find there is greater reluctance for people to tick the 'corneas, eye tissue' box when they do fill out the donation form?

Bronwyn COHEN: It is a very personal choice. Speaking to my cousin, she said, 'Oh, you can have all my organs, but you can't have my eyes. It's just too personal.' It is a personal choice, and no decision is wrong. We would have liked to have had a conversation and perhaps been able to persuade her, but it is every person's choice, and it is the senior available next-of-kin's choice. That is often what we have difficulty with, in particular with some cultures, as to: who is? It is not just the next of kin but it is the senior available next of kin because we cannot always get in touch with the official next of kin. It just has to be the senior available next of kin, and in some cultures we do not understand what we do not know as to getting to the right person.

Heather MACHIN: Culturally people have a connection—you will know—with their eyes. Again, I will bring in the bones and the kidneys—no-one has an intimate connection with their bones. But the eyes are where we see each other, where we feel each other, where we think about each other and where we see our loved ones, so for a lot of people the eyes are who you are. For people who have that cultural connection with their eyes, that is where that reluctance comes in. However, we have more eye donors in this country than anything else.

Bronwyn COHEN: Yes, you can add up all of the organs altogether –

Heather MACHIN: And tissues.

Bronwyn COHEN: and we still far outweigh—the highest number of transplants is eyes.

Chris CREWTHER: Is that generally, though, also because of the percentage of viability as well?

Heather MACHIN: A little bit, yes. Definitely.

Chris CREWTHER: I guess generally, culturally or not, people want to protect their face and they want to see their loved one's face even in passing and so on. This is sort of a strange question, but –

Heather MACHIN: I think I know what you are going to ask.

Bronwyn COHEN: Yes, I think I know where you are at.

Heather MACHIN: We have heard them all.

Chris CREWTHER: Do you find there is greater registration, say, by the person themselves or assent by families to donations where a person might be nominating, before they die, cremation over burial?

Heather MACHIN: Okay, that is not what I thought you were going to ask.

Bronwyn COHEN: No.

Chris CREWTHER: Sometimes, of course, as part of the burial you will have a viewing of the person, and there might be a concern that they might not be seen as they are, whereas in a cremation they are not as worried about that.

Heather MACHIN: All right. So with open caskets, if you want me to get into details, if they are removing a whole eye, they will pack it with something. Also if they are leaving the eye and just taking the cornea, regardless of what they do, they have a little piece of plastic that goes under the eyelid and sticks to the eyelid, so it looks like they are asleep. The viewers will never know that they have had their eyes removed.

Bronwyn COHEN: You would never know. The reconstruction that is done is done very ethically and respectfully, and you would just assume that the donor was asleep. You would never know that the donation has taken place.

Chris CREWTHER: I guess that is part of the educational tools.

Heather MACHIN: Correct. So regardless of whether they want to cremate or bury, or do an open casket or not, it is not really a barrier because at the point of donation we explain that.

Chris CREWTHER: Do you think at the point of registration when a person unticks that box there might be a pop-up or something that can educate them on some of these things?

Bronwyn COHEN: Possibly.

Heather MACHIN: Possibly, yes.

Bronwyn COHEN: It is certainly on our website that a reconstruction is done, and you would never know.

Chris CREWTHER: Now, what question did you think I was going to ask?

Heather MACHIN: I thought you were going to ask that, but it was a little bit around.

Chris CREWTHER: All right. Thank you.

The CHAIR: Thanks, Chris. Gary.

Gary MAAS: Thanks, Ella. Please do speak to Chris Crewther afterwards in terms of the celeb influencer, because I am sure his social media accounts will –

A member: What?

Gary MAAS: All right. Maybe I jest. Thank you for your time today. Can I just ask you a little bit more about Lions Eye Donation Service. Are you a national organisation or are you a state-based organisation?

Bronwyn COHEN: We are a state-based organisation. We are a collaboration between the Centre for Eye Research Australia and the University of Melbourne, with the department of surgery and ophthalmology, and also the Royal Victorian Eye and Ear Hospital. It is a complex Venn diagram. We also get support from the Lions of Victoria and southern New South Wales.

Heather MACHIN: Lions have a long-term history going back to Helen Keller in the USA to support eye care. There are 47 eye banks in nine nations. There are three in Australia, being us, Perth and Sydney.

Gary MAAS: That was going to be my next question, thank you.

Heather MACHIN: We are run separately, but we work with our local Lions clubs. We work with the Lions clubs of Victoria and I think north-west New South Wales, whereas the Lions in Perth work with Lions WA.

Gary MAAS: All right, thank you. I understand you have the connection with the other services. Is there a type of measure that is in place that you all set yourselves against or something that you all try to attain in terms of supply, transplants et cetera?

Bronwyn COHEN: We report to the Australian Organ Donor Register, and we actually compare in that we get a report of how many donors we have, how many were transplanted and our utilisation rate. We do sort of compare a little in that regard, as to making sure that our utilisation rate does not drop considerably, to make sure that we are using our best practice. We are, I am quite proud to say, the leading eye bank of Australia, in that we can supply the greatest range of quality tissue to surgeons, in that the surgeons will ask for tissue to be prepared in different ways and we have the widest range of preparation of tissue.

Gary MAAS: Okay. It has been 30 years that you have been operating in Victoria, is that right?

Bronwyn COHEN: Yes, 32.

Gary MAAS: Thirty-two years—so in terms of the metrics that have been developed over that time, what has changed and improved throughout that time?

Bronwyn COHEN: How long have you got?

Gary MAAS: How long is a piece of string?

Heather MACHIN: I mean, there are quite a lot. Both in Australia and internationally there is a greater awareness of the implementation of things like DonateLife, who have now got things like DonateLife Week, and then two years ago we started the eye and tissue awareness week. So donations have started to increase,

and there is more of an acceptance in the community that they want to donate at the end of life. Those sorts of things have changed. Technologically there are lots of changes too. We implemented—do not quote me on this—probably 15 or 20 years ago a method of storage called organ culture medium, which revolutionised how we were able to recover, store and allocate compared to countries that were using what is called cold storage. So the technology that was available to us, perhaps in comparison to other tissues and organs, accelerated quicker in the early days, which is why, when we are comparing to other tissues, we can say we are meeting need—or meeting demand, I should say. We might not be meeting need, but we are meeting demand.

Gary MAAS: How do we compare to other jurisdictions? Sorry, how does LEDS compare to other jurisdictions?

Heather MACHIN: All jurisdictions in Australia are in relatively the same boat in terms of meeting demand. It is very difficult to determine whether we are all meeting need, because we only know what the surgeons are booking in. So I could not tell you whether there are 50 people in a surgeon's rooms waiting to be booked in, because certain surgeons are more in demand than others or they may have different visiting rights and so on and so forth. But when each of the states are comparing themselves, we compare them based on whether or not we are meeting demand, which means we are meeting the boundaries of our particular health system, and I think across Australia it is relatively similar and we are on a similar par with them on that.

Gary MAAS: How is eye- and tissue-related donation different to other organ and tissue donation?

Bronwyn COHEN: We can recover tissue from a much wider range of potential donors. In that, for me, I have breast cancer, so I would be excluded from donating my organs; however, I can still donate my eyes. So again, that is why the palliative care unit at the Austin is such a valuable resource for us, in that they have a conversation with so many people in palliative care. We also have a much wider age group. I just did some figures this morning. Over 70% of our donors are over 50. Now, that would not be the case for organs. The majority of our donors are in their 60s and their 70s. Our surgeons actually ask for tissue sometimes from a donor who is over 70. We have one surgeon who has a patient whose cornea is over 100 years old, because 30 years ago she was in her 40s and received tissue from a donor in their 70s. She is now in her 70s, so the tissue is over 100 years old, and it is still working perfectly fine and she is still able to see, which is just fantastic. Again, that is another reason why we have got a much wider range for a donor pool. With something like the bowel screening program, it would be fantastic to say, 'Have you considered?' It may not be that, you know, the organ –

Gary MAAS: I was about to go there actually.

Bronwyn COHEN: It may not be for an organ donor, but it would be perfect for an eye and tissue donor.

Gary MAAS: I was about to move into—some of the evidence we have heard so far is about targeting younger people in terms of registration and also older people in terms of registration. When you mentioned the age of 50 years, I was about to bring in the bowel screening. Do you want to elaborate on that a bit more?

Bronwyn COHEN: It is really, really useful for us to have the older donors. They are donors that are very useful for us. In particular a donor over the age of 60 without diabetes is a perfect donor for us. And also one donor can help multitudes of people. There are some cases where even eye donation is excluded, and that is haematological malignancies—so any sort of leukaemia, myeloma, and any neurological disorders. So MND and, dare I say it, at the moment CJD—we cannot accept any donors with that sort of history at the moment. We did, however, facilitate recently a voluntary assisted dying case in the region of an MND patient who gave their consent as a first person—gave their consent as an organ and eye tissue donor. We could not accept the eye tissue for transplant, but we were able to pass that on to a researcher who is looking at early diagnosis for MND. So that person may not have saved the sight of two people but may yet save the sight of hundreds of MND people.

Heather MACHIN: Sorry, Gary, I have just written here 'Circle back to Gary.'

Gary MAAS: Yes.

Heather MACHIN: So you wanted to know what the main difference was with tissues in comparison to organs. Two big things: first of all, we bank. So generally speaking with an organ, give or take, it will go directly –

Gary MAAS: Short period of time.

Heather MACHIN: Yes. It goes directly from the donor—and as the Alfred team were saying, they need an operating theatre—straight to the operating theatre. That might be in the same building or at another facility. We bank, so we take it to a facility where it goes through a process, and those process steps may include the testing and the preparation. Different tissues require different types of preparation. And I know you have got VIFM talking on Friday, so they will talk about theirs. But we may do things like preparing. The cornea has got five layers, so a surgeon may only need to change one of the diseased layers, not all five. Eye bankers will strip—it is called 'stripping', which is a terrible name—the tissue so that the surgeon gets that one piece of tissue. So our coordinator is not just going and doing the surgery themselves, they are preparing the tissue for the surgeon. So that banking is the big difference.

The second biggest difference is we are regulated and organs are not. And so we have an additional burden, but thankfully we have got a lovely Quality Manager. We have an additional burden with the TGA, and they consider it a product. We do not like the language 'product' because we see it as a gift, but we have to work with the TGA under a regulatory biologicals framework—organs do not. We have that financial burden, organs do not.

Gary MAAS: Okay. And as unaccustomed as I am to asking Dorothy Dixer questions, is reintroducing driving licence registrations for organ and tissue donation in Victoria the most effective way to increase registrations? And, depending on your answer, are there any other—or better—alternatives?

Bronwyn COHEN: If it is just about registrations, that is a no-brainer, in that South Australia is the only state that still has that, and it is not surprising they have the highest registration rate. It is in front of every adult who goes for a drivers licence, which would have to be 90% of the population. It is in front of them, and it gets renewed every 10 years. So that would be the easiest, simplest way—to get VicRoads to be able to talk to the organ donor registry—for sure.

Gary MAAS: Okay. Thanks very much. No further questions for me.

The CHAIR: Thank you, Gary. Annabelle.

Annabelle CLEELAND: Thank you. I want to say thank you and congratulations on everything you have achieved in the last 30 years. It is quite impressive to see what you have presented today as well, so keep up the good work. I have got some questions. I want to home in on the tissue research element. Can you just explain to me what tissue research achieves and goes towards and the community benefit of that?

Bronwyn COHEN: We have fabulous researchers here at the Centre for Eye Research Australia who collaborate with eye banks and institutions internationally. Heather mentioned the different layers of the cornea and just replacing the layer that is required. The researchers are looking at ways to bioengineer that layer that is required. So potentially one donor could then have those cells made from not just one person, but they could actually translate to many people. The researchers will say that they are not just looking at saving the sight of the recipient but looking at changing the sight of many recipients.

Heather MACHIN: We do research, as Bronwyn said, with the researchers here, but we also help researchers at Monash, at Uni Melb—basically any research team who is ethics approved can apply. But the main benefit of allocating into research, if we are looking at it from the corneal perspective, is to reduce the long-term burden on the end-of-life field. The one that Bronwyn has just mentioned—if we can turn one cornea into 70, we can improve access to tissue to reduce global blindness, and there are 12.7 million people waiting for a cornea around the world. That is just in corneas.

If we move the entire eye into research, we can help things like macular degeneration, glaucoma and all the leading causes of blindness, which I will quiz Chris on later. At the moment we have researchers who are seeking access to tissue from people who have had Parkinson's disease, because they are doing Parkinson's research. We have got researchers who are looking at the connection between the brain and the eye to see if

they can detect Alzheimer's through ocular visions with our optometrists in the community. This will revolutionise prevention and the acceleration of eye care into a wide range of eye care and affiliated fields, like diabetes, to just name one. Through that, the whole intent is to then reduce healthcare costs through prevention, rather than where we are, at the transplant side, where it is kind of too late. If we can prevent the progression of disease, we are not only preventing the disease but we are also preventing or reducing the demand for the tissue, which as we are discussing today is a problem.

Annabelle CLEELAND: With the donations you receive, what portion would go to towards research? And is that the portion beyond the living demand, I guess?

Bronwyn COHEN: Yes, 100% our priority is tissue for transplant. It only goes to research if for some reason it is excluded from transplant, whether it be from a quality perspective—perhaps the cornea was not of a sufficient cell number or it was seen to have some scarring or something like that, so it would not be suitable for transplant from a quality perspective. Then there is also a risk perspective. So if they were found to have had hep B or HIV or anything like that, again it would not be suitable for transplant. It would be excluded, and then it would be offered for research.

Heather MACHIN: By offering donors the opportunity to be research donors, we are also giving those who would otherwise be excluded from transplant the opportunity to donate. That is incredibly important, particularly as we are already meeting demand most of the time. If we go out and start saying no, we are reversing all the hard work that you are doing today and all the hard work that the DonateLife field are doing by telling people to become a donor, because when they get to the point of donating, we say, 'No, we don't need it.' But by offering the opportunity to donate towards research, we are keeping that momentum alive, not necessarily for our transplants but for everybody else in the organ and tissue field who are not meeting demand and need to keep that positive conversation going. So we are trying to also make sure that if we do not need it for transplant, we are giving them that opportunity to still become a donor because they very much want to.

Annabelle CLEELAND: Have you had to decline an eye or tissue donation because of your current facilities and your capabilities of storage?

Bronwyn COHEN: Yes.

Annabelle CLEELAND: What sort of percentage are you declining at the moment?

Bronwyn COHEN: It does fluctuate because the supply can never be guaranteed. We do not really know when we are going to be given a lot of referrals, a lot of opportunities, and there is also a logistical point in that we cannot get to the regions a lot of the times. A donor in Mildura—we just cannot facilitate that unless we get a seat on the plane with the multi-organ team. So we just cannot facilitate that, purely through logistics, but we also cannot facilitate the donation from a logistical point of view and the number of staff that we have. It would be great to have more staff, but we cannot fit them in.

Annabelle CLEELAND: What about storage? Are there limitations on your ability to store eye and tissue donations that has led to decline?

Bronwyn COHEN: We can only store for one month. That was the change that Heather spoke about, in that previously it was stored first for seven days in cold storage in the fridge. We now have organ culture, which allows us to store in an incubator for up to 30 days, which gives us a lot more flexibility with allocation of tissue. We allocate ethically and evenly across all of our surgeons; however, we have a terrific relationship with our surgeons and they will say, 'Look, the recipient is in their 90s. Probably don't send me a 20-year-old cornea. Send me an older one'—it does not need to be the quality of a recipient who is a young recipient. So we do try, and having that 30-day storage allows us to try and match the recipient a little more with the donor.

Annabelle CLEELAND: Okay. And you mentioned regional barriers, so what is your presence in regional Victoria?

Bronwyn COHEN: Primarily we send tissue to Ballarat. We have not done as many for Ballarat this year, but Geelong, there is a surgeon in Geelong that does quite a lot of surgeries, and again along the peninsula as well. We have partnered with a fabulous group of volunteers called Bloodbikes, and they deliver our tissue for us. We have the three donor coordinators. These coordinators have the most amazing spectrum of skills, in that

they will talk to families to gain consent; they need to talk medical to be able to talk to doctors about why a patient died or what was the reasoning behind things, any medical and social history. They will then do the surgery, as in do the recovery, come back to the laboratory and be scientists, do the actual technical side of the evaluation—again the technical side of preparing the tissue—and then they were getting in their car and driving the tissue to Ballarat and back, which took 30% of our workforce out, and the only car. So we have now partnered with Bloodbikes, and they come in and deliver the tissue for us. They have been fantastic and have revolutionised us, because that just takes that burden out, in that they do the deliveries for us. We are in very early stages of discussion with a facility at Bendigo where perhaps the tissue could be recovered locally and then a Bloodbiker could deliver it from Bendigo down to Melbourne so that that donation could be facilitated. But we have had to say no to quite a lot of regional donors purely on logistics.

Annabelle CLEELAND: I am just keen to understand your funding model and some of the opportunities. You are obviously very separate but collaborate with DonateLife. Are there any limitations to being a standalone and operating separately, or would there be greater unity if DonateLife was more of an umbrella organisation to you?

Bronwyn COHEN: We work terrifically with DonateLife and at the VIFM as well—the Institute of Forensic Medicine—and DonateLife will populate the EDR, as it is known, the electronic donor record, and that is a national database. We can only see what is useful for us, for the eyes, but all the conversations get documented in there, and they are terrific supporters of ours and are aware that if the donor is not suitable for organs, they will still refer to us for eyes, and they are fantastic supporters. We will get a referral via DonateLife or via hospital direct.

Annabelle CLEELAND: Where do you receive your funding from?

Bronwyn COHEN: We are a not-for-profit, and any recipient is not out of pocket for the cost of the service of the tissue. So we do not charge for the tissue; we recover the costs that we incur to recover that tissue. Within the private sector that is covered by the private health insurance, and within the public sector that is part of the hospital budget, with state government funding for what goes into the hospital that gets claimed back to us for the tissue. And there is a prosthesis list. To get any increase in charge we need to establish the reason for cost increases, and so there is a standard charge that we charge and each eye bank and tissue bank charges across Australia.

Annabelle CLEELAND: Sorry, let me catch up. Is there an opportunity to sell tissue? I understand there is a growing market for selling tissue globally as well.

Heather MACHIN: It is illegal to sell tissue.

Annabelle CLEELAND: Illegal?

Heather MACHIN: Yes, and it is widely frowned upon. There are parts of the world—let us call them unscrupulous folk—that do do that. In eyes in Australia, we have no for-profit eye banks. There is one in another country, but it is not in Australia, and that has actually not had much traction, I should say, in comparison to the non-profits. One of the biggest barriers for them, the reason why they have not been able to get much traction, is because there is so much evidence to indicate that the non-profit eye banks, like the model we have, are meeting demand, and we are also accelerating new technologies and keeping up with what is going on. So we do not really need to have a for-profit entity to be providing money to shareholders and things like that when the non-profit is working in this field.

Annabelle CLEELAND: That is fascinating. Did you want to add a supplementary question to that?

Chris CREWTHER: Is it correct that unlike other organs, there are more donations than there are requests?

Heather MACHIN: This is really fascinating. It is my PhD area. There is a big difference between need and demand, so the need is always there, but the demand is what changes. The demand is shaped by how many surgeons we have, how many operating theatre lists they have, how many nurses they have and the coffers at the end of the day. So while there may be need, unless a surgeon has the ability to get a booking in a theatre –

Chris CREWTHER: Capacity.

Heather MACHIN: Yes. We do not look at it as 'Are we meeting need?' because it is not our role as the provider of the tissue to do that. That is up to the surgeons and the operating theatres and people working in that area of health to bring that capacity. We can only look at it as the providers of the tissue—'Are we meeting demand?' meaning 'Every time a surgeon books in a recipient, are we meeting that need?' And the answer is yes.

Chris CREWTHER: Do you have any waste of donations in terms of getting towards the 30-day mark?

Heather MACHIN: Yes.

Chris CREWTHER: Do you have to dispose of it, or do you have other means—that you partner with say, developing nations, to export items?

Heather MACHIN: Yes, we do. It depends.

Bronwyn COHEN: It primarily depends on consent, in that 'Has the person consented to research?' So if it is getting near the end of its 30-day storage, we will look to see if it is considered for research and perhaps offer it for research. We also help out New Zealand quite considerably, in that we are well in advance already to date this year of donation. While we are self-sustainable, New Zealand is not yet self-sustainable, whereas the US are huge exporters of tissue. So they will export to other countries to assist the global demand for eyes.

Chris CREWTHER: Do we do that—like, with Fred Hollows? I know in your career you have done a lot of work with Fred Hollows. Is that something we do?

Heather MACHIN: You have googled me! Fred Hollows does not do that, but around the world there are about 116,000 corneal transplants done globally. 25% of those are done with tissue that is moved from one country to another, and 45% of that is done through the USA, so we are an incredibly small fish in the context of exportation. We have in the past provided—not our eye bank, but in the 90s some banks provided tissue to Japan and to Korea on an ad hoc basis. Today we have eye banks that do provide humanitarian tissue to Noumea and also a little bit to Nepal. But in terms of having an entire strategy, Australia, nor any eye bank or tissue bank in Australia, has a strategy in place on the exportation of tissue. It is not illegal. There is nothing in the legislation to prevent it. It is all based on the ethics. As long as you have an export licence from the TGA, we can move tissue to another country. This is my PhD subject. It is not based on the consent. However, we have implemented on our consent form a line that says we may move your tissue not only internationally but also to other parts of Australia, so that covers us if we are sharing. We feel it is important to tell them, and it is on our website publicly because that needs to be transparent. On the import side there is no tissue for eye transplantation imported into Australia. There is tissue imported for research but not for transplantation. Bone, however, is imported into Australia, and VIFM can talk to you more on that. We are receiving bone in this country from other countries.

Annabelle CLEELAND: Finally—thank you, Ella, for your patience—just going back to your facility: what exactly are your needs to suit forecast demand?

Bronwyn COHEN: We need a bigger and better facility. Our facility is about the size of that little space there. Ideally where the tissue comes in would be considered a dirty room—the tissue that we have is not sterile in that the eyes are open to the environment, so it is not sterile. It would come into that room, and then once we have all of the assessments that are done—the communicable diseases have come back negative and everything else, all the other checks—and it has been cleared, then it can be processed in another clean room so there is less risk of contamination. We have done the microbiological checks, so everything is actually known to be clear. That is what we need.

We also have our donor coordinators. We have one coordinator that works in an open plan office, and on her screen is private and confidential information. She is taking phone calls from GPs and trying to find out a medical history for a donor in an open office. Yes, all of our researchers have signed confidentiality waivers, but for the respect of our donor families we really believe that should be done in a much more confined and more private space. But just at the moment we do not have that space.

Heather MACHIN: And futuristically, the way that the eye and the tissue sectors are moving is to things such as bioengineered technologies, so as we move in the next 5, 10 or 15 years towards biotechnologies our

labs in eyes and tissues will need to be prepared to advance to process tissue for bioengineered technologies. That is an additional space that all eye and tissue banks in Australia will be faced with developing in the years to come.

Bronwyn COHEN: The environmental monitoring that we need to meet, from the TGA perspective, so that it is a pharmaceutical grade clean room—we have only got this one little space to have that clean room for human tissue at the moment. Ideally, we would have more space that is then that ISO standard clean room.

Annabelle CLEELAND: Thank you.

The CHAIR: We have run over time. I do have a few more questions for you. I am very happy for you to take these on notice if that is your preference, but I am also happy to have a short answer. Firstly, and this is one for notice, today you have provided a lot of different data about things taking place in Victoria and nationally and internationally. Is that something you would be happy to share with Members in a written format?

Heather MACHIN: I can send you whatever you want.

The CHAIR: That would be fantastic.

Heather MACHIN: Everything I have presented today is publicly available in the literature.

The CHAIR: I think that would be incredibly helpful for our inquiry, and we will provide you with a transcript so you can refer back to the data that you provided. Also, if there are other things that you think would be beneficial for us to know, you are more than welcome to include that in that pack too. One of the clear themes that has come out of your presentation is the stark differences between eye and eye tissue donations and other organ donations, and in particular we are very focused on raising awareness around registering to become a donor. I am wondering if you are aware of any best-practice awareness campaigns either from Australia or internationally that specifically speak to becoming an eye and eye tissue donor?

Heather MACHIN: Yes. The gentleman who was sitting in the seat for the Alfred brought up, I think it was called, Billy, the US Billy. It is actually quite hilarious. It is a really good campaign, and it gets right to the heart of the fact that people who are mean can become donors. When he mentioned it, I was like, 'It's a great one.' The USA are really advanced in all organs but also in eyes and tissues, but there are other countries like India who also do incredible donor awareness weeks and donor awareness months. They are probably the main ones. And then there are individual ones in Germany and places like that. But it is basically about figuring out what is culturally appropriate. What works in Germany might not work here and vice versa. So they are out there, but it is hard to give you an exact one.

In terms of campaigns, I think something that we need to do here is anytime the word 'organ' is mentioned the word 'tissue' needs to follow. There is a real misconception in just general dialogue that it is all about organs, and it is not. The fact that we do more transplants for eyes than organ speaks to that, and yet we get zero attention, and that makes it very difficult in trying to then get funding to support things or even make sure donors are provided with the correct information. That narrative around organs versus organs and tissues really needs to change. I do congratulate the Organ and Tissue Authority. Two years ago we started working with them. We did launch the first eye and tissue awareness week last year, and we did the second one here in May. It is the start of something beautiful, but we need to keep going with that.

The CHAIR: Great. And referencing that campaign as well—the US campaign with somebody who people might not have considered a suitable donor—I think there are a lot of misconceptions as to who is and who is not a suitable donor. I would not consider myself a suitable eye donor because I cannot see past here –

Heather MACHIN: Fine.

Bronwyn COHEN: And see—that is absolutely fine.

The CHAIR: But if you have any suggestions as to how we can bring that awareness to the community about how you might wear glasses but you can still be an eye donor, I think that would be an important message to hear.

Bronwyn COHEN: Absolutely.

Heather MACHIN: We would love to partner with anybody who would like to have that conversation, and because we are connected with the eye care community, including the optometrists, the orthoptists, the ophthalmologists and the ophthalmic nurses, doing that as a collaborative is something we would love to do, and again do that with OTA and DonateLife. But it is resource-based, and if there are resources to do it, we will be there front and centre to do anything like that.

The CHAIR: Great. All right. Well, thank you so much, Bronwyn and Heather, for appearing before the Committee today and for your contributions. I think they have really in particular highlighted some of the differences between organ donation and eye tissue donation, so thank you for providing that information to us. The Committee is incredibly grateful for your time and effort in preparing your evidence.

Bronwyn COHEN: We thank you for the opportunity, because it needs to be a collaborative, multifaceted approach if we are going to improve the lives of so many more people.

The CHAIR: Thank you. The Committee will now take a 45-minute break. I declare this hearing adjourned.

Witnesses withdrew.