

# TRANSCRIPT

## LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

### **Inquiry into increasing the number of registered organ and tissue donors**

Melbourne—Tuesday 25 July 2023

#### **MEMBERS**

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

#### **WITNESS**

Mr Allan Turner, Managing Director, Zaidee's Rainbow Foundation.

**The CHAIR:** Good afternoon. We will now recommence the public hearings of the Legislative Assembly Legal and Social Issues Committee's Inquiry into increasing the number of registered organ and tissue donors.

My name is Ella George, and I am Chair of the Committee. I am joined today by Deputy Chair Annabelle Cleeland, Chris Crewther, Meng Heang Tak and Gary Maas.

I welcome our next witness, from Zaidee's Rainbow Foundation, Allan Turner, Managing Director. Thank you very much for being here, Allan, and thank you so much for sharing your family story and experience of organ and tissue donation. It is greatly appreciated.

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 repeated outside this hearing may not be protected by this privilege.

I invite you now to make a brief opening statement of up to 10 minutes, and this will be followed by questions from Members. Thank you.

**Allan TURNER:** Thanks very much, Ella, and I appreciate the invitation to be a presenter at your Committee. On 2 December in 2004 my daughter Zaidee Rose Alexander Turner died suddenly from a burst blood vessel in the brain called an aneurysm at the age of 7 years and 22 days. Zaidee was the only child in Victoria that year to be an organ and tissue donor under the age of 16. Zaidee saved and improved the lives of seven others with the gift of life.

That night while we were waiting for Zaidee's final operation to be a donor I came up with the idea of Zaidee's rainbow shoelaces to be our national symbol—to be a symbol that the community can buy and wear to reflect their support for organ and tissue donation. You see, Zaidee had rainbow shoelaces in her shoes when she was only a tiny tot, hand-me-downs from her big brother Jaz. But that was our inspiration: to get the message out there. Since then we have either sold or given away over 2 million pairs of Zaidee's rainbow shoelaces, or what I like to call messages of hope.

Zaidee's Rainbow Foundation was established in 2005, and in July 2006 I was successful in obtaining a federal government seeding grant via the Department of Health and Ageing out of Canberra for the next six years till 2012, when our funding stopped. We have not to this day received any government funding at any level to help promote and deliver our national campaigns, programs and projects, be it state or nationally. For the past 18 years we have provided the skills and the ability to deliver Zaidee's campaigns in sport at the most elite levels to the grassroots level in all sporting codes, both nationally and locally. Zaidee's was the first charity to engage major elite sporting teams from the AFL, NRL, soccer, basketball, netball and in fact every sporting code to promote organ and tissue donation. This has been done with not one dollar being provided to them for supporting us—in obtaining their support for organ and tissue donation messaging. Now we see a government department taking this over, copying everything we have developed and built—relationships within this space—with huge dollars, and yet we did this for nil cost.

DonateLife is now paying these same sporting codes large sums of grant money to do the same campaign as we did for free—in my opinion doing a lesser job in getting the message out there to support promotions of organ and tissue donation in the community. Why do I think that? They have targeted certain sporting teams that people either like or do not like—in most cases they do not like—which loses community support straight away. For those sporting codes, all they see is an income on their bottom line for supporting a short DonateLife campaign, as they do not have any skin in the sector. Nor will they go forward once the grant money runs out; they simply move onto the next grant, whatever the cause is on the day, for their bottom line—simply to get funding. Sadly, DonateLife have set the bar high now by engaging sporting codes as money-driven campaigns. It is so very hard for Zaidee's to ask for future support at nil cost.

You have even asked for a report on the outcomes, and I would be keen to also see what those reports reflect: the money they spend against outcomes and the increase of the organ donation rate, from these sporting codes. When Zaidee's seeks support from sporting codes, they take ownership of Zaidee's story and why they are supporting us versus having a huge grant provided and then being told to turn up in the media and be part of a campaign which they are getting paid to do. This you cannot fix, but you should be aware of how money is spent in the sector in ways it should never be.

In 2011 Zaidee's launched the first ever schools educational program—the first ever to be written by professional educators covering both primary and secondary school students for many years, until sadly our funding ran out. This program and website have since stopped, as we could not cover the costs to keep it running and updated each year.

If it was not for Zaidee's, Cool Australia, who presented to you recently, would have never got the funding for their schools program. Zaidee's applied for a grant to work with Cool Australia. Instead DonateLife simply cut me out of the grant process and went directly to Cool Australia—another example of them taking good ideas and making them their own.

Zaidee's was the first campaign to launch TV, radio and magazine commercials, bringing in all levels of the media along the way and in fact many times via pro bono support. Zaidee's was the first to engage the Indigenous community on a national scale, with an AFL program back in 2009, developing and designing an educational information brochure with the support of a First Nations artist, which allowed the Rainbow Serpent, a very powerful symbol for First Nations people, to be used in this campaign. This flyer went to over 300 First Nations medical clinics nationally as part of the program. In the brochure there is a simple message to get it out there and to talk about it, and we have some very elite AFL players, from Adam Goodes to Andrew McLeod, supporting it.

Due to no funding at any level, I have spent 80% of the time trying to raise funds to keep the charity running and 20% getting out there talking about the subject. Imagine if this was the other way around how much more impact Zaidee's would have in the community driving education and assisting the increase of the donation rate. The transplantation sector only works if we have donors, and to get donors we need them to say yes before the end of life with full support from family behind them. To do that, we need massive education spelling out the total pathway to becoming a donor and the donation process once they are inside the ICU to save and improve more lives—way before the end of life and ending up in the ICU being asked the question for your loved one to be a donor when your heart has just been torn apart and life for you at this very important moment has stopped and will never be the same again—not just sign up and that will fix everything, which is all we have today as a national campaign. This is what Zaidee's does best and has been doing for the past 18 years. I cannot fix the issues in hospitals. That is above my level. Nor can I change what happens in the process of organ and tissue donation at the end of life. But I can help to get people to say yes to being a donor on the back of a very powerful Zaidee's campaign, projects and programs.

What this little girl has done in the sector has never been done before, and now we have DonateLife copying what we successfully achieved and opening doors in sport and education. They pay others to do their work and yet Zaidee's has not been funded for anything since 2012. Zaidee's is the only full-time national charity of its type working in sport, education and the wider community, with a long list of tools that can be used to engage and inspire others whilst delivering results in getting people to say yes to organ and tissue donation. Yet we watch huge grants being provided to groups that do not or will never care about this space. To them it is income for a short period of time, and once they get the grant and use it they are never heard of again.

From 2017 to 2020 I was privileged to be one of the committee members who sat on the National Health and Medical Research Council for ethical guidelines for organ and tissue donation and transplantation in Australia. These guidelines have not yet been published for use, but I was very proud to have contributed to these guidelines. I have an in-depth understanding of this sector and what needs to change to increase the donation rate to save more lives. For the past 18 years I have been Australia's loudest voice on this subject by far.

When Zaidee died in 2004 there was very little, in fact no, campaigning or marketing in or around organ and tissue donation on a grand scale. There was an organisation called Australians Donate, which DonateLife has since replaced. Australians Donate was closed down by the government of the day due to lack of direction, blown-out budgets and very little return in outcomes during their period of time. I hope we do not see the same happening in outcomes for DonateLife. If that happens, then what? How do things work then going forward in the direction of the sector?

As you have heard from past witnesses and will, I suggest, from future witnesses, you—the state government—have lost full control of what happens in this space in our state. You have heard from parts of the sector that do not even communicate with each other to get the right outcomes to save more lives. In a way, one hand does not know what the other hand is doing at any given time, or has no communication with DonateLife at all. You

have listened to many people in this sector that have given passionate and super ideas to make the sector better. Sadly, unless you take control back at a state level, then these suggestions and ideas to make change happen will never happen. Why? Because I have been part of the sector for 18 years and have been part of many hearings and many reports and yet nothing has been achieved by the recommendations as far as I can ever see.

I wish to provide you with an example of how other health sectors provide work that works and works well. Take the McGrath Foundation, for example, with over 200 specialty breast care nurses in the community nationally supporting those that are going through the worst time of their lives. Now take the organ and tissue donor sector. We have no nurses to do the same theme of work for those that are either post or pretransplant or the donor families at all on a full-time basis. Yes, we offer some small support, but nothing like what McGrath do for their patients. This type of work in this sector is provided by very few nurses and never in regional locations, mostly based in only a few major metro hospitals. Even then their roles are not 100% dedicated to the role. I would like to see the same theme or workload as McGrath nurses do in their sector looking after the same people in a like-for-like manner. Can I ask the question: why don't we have this support in Victoria for people that are on a pathway to die, if they are not going to get a transplant in time?

Imagine you visit the doctor tomorrow as you or your child are feeling unwell. The doctor turns to you and tells you you need an organ transplant soon or you will die. Then what? What happens after that? The stress is placed on individuals, families and the community at large and yet we do not have the same support as we provide breast care nurse patients in this state. Imagine if we had Zaidee's organ and tissue support nurses for people going through stages of their life that need direction, advice, support and a shoulder to cry on. How good would that be in helping to reflect that this sector is grown up and not left behind today?

In 2015 I launched the opt-out campaign to change the system from an opt-in to an opt-out, as I believe we have run out of ideas and incentive to grow the rates in Australia as they are doing around the world. I now call this Zaidee's law. Recently when England campaigned to go opt-out they used two children to head up their national campaign and they called it Max and Keira's law—Max, who needed a heart, and Keira, who donated it to him—which greatly helped the community to engage with the subject and be inspired by that idea that being a donor is the greatest gift anyone can provide at the end of life, a reflection on what my daughter did.

The opt-out system has many levels to it and moving parts. What this does is it allows the subject to be talked about with every person in this state no matter what the age. It provides the opportunity to bring this subject to the top of the media's attention for many years, not just a week as we have now, and the discussion in homes. It will have the ability to change our culture forever, and this is what we need. Just look at the countries above us in the world rankings that run the opt-out system and you will see results that we struggle to achieve. It is time we have the next tool in the box, as we have run out of just asking people to register, that this is everything. Well, I tell you, it never has been and never will be—DonateLife will never change their direction unless you people in front of me legislate that this is the way to go and do it now, before tomorrow. More people will be waiting for a transplant today, tomorrow and in the future—dying waiting.

The harsh reality is that if we did increase the donation rate, which I believe an opt-out system will do over time, we would not be able to handle the total amount of operations for transplants due to lack of support and theatre staff in the hospital system as it is currently today—one major reason why the sector is pushing back on running an opt-out system, I believe.

Many have sat here and reflected on what has happened in the past and the reasons why we are so bad at providing you with strong leadership and direction and ideas to produce a better outcome going forward. Zaidee has a bag full of tools that are needed when it comes to engaging the community in Victoria. Zaidee can provide these tools, our skill and our passion in a partnership with the state government that will allow you the opportunity on a grand scale—and I must say, at low budgets—for Victoria to be Australia's leading donation state if this is what you wish to achieve. Imagine if it was your son or daughter that needed a transplant today: the system cannot provide for that to happen and the wait is long and the education in the community is weak. An opt-out system provides hope, guidance and a way forward to help increase the donation rate, rather than just asking people to sign up—this does not fix the rates; it never has and never will. A change of system is needed so your child has the best hope of a second chance in life.

Zaidee's strongly suggests that you brave politicians have the ability to list your names down in history by amending the legislation that will forever change the culture and direction of organ and tissue donation in

Victoria for decades ahead. You will not be remembered for cutting the ribbon or opening a sports stadium or funding provided for that local dog park or the years of service that you have given when you are gone, but you will be remembered as the politicians that passed legislation to save and improve the lives of more Victorians that need a transplant today, tomorrow and into the future by having an opt-out system for all Victorians to be inspired and to have a new direction and hope for organ and tissue donation like the best countries in the world currently provide today. If Nova Scotia have now gone opt-out as the first breakaway state in Canada, so can Victoria lead the way, and let us now show the rest of the country how it is done. I strongly suggest taking back control, as if you do not, nothing will change going forward, and history reflects that. Thank you and good luck with the direction you take come March 2024. As I always say, if a seven-year-old girl called Zaidee can be a donor, anyone can.

**The CHAIR:** Thank you, Allan. That was a really remarkable and moving opening statement. We are so grateful. On behalf of the Committee, thank you for sharing Zaidee's story and Zaidee's remarkable gift.

**Allan TURNER:** Thank you.

**The CHAIR:** Thank you for all of the work that you have done over the past 18 years in raising awareness. There must be thousands more people who are registered organ and tissue donors because of your work, so thank you.

**Allan TURNER:** Thank you.

**The CHAIR:** All right. We have got some time for questions now, and I would like to start. In your statement and your submission you have touched on a range of different areas, and one thing that we have heard a lot about is education, so education in helping to drive the number of people who become registered donors, but also education around understanding organ and tissue donation so that when the time comes for that difficult conversation, families are informed as to what it means. You mentioned that you have previously delivered some education programs, and I would love to hear a bit more about that.

**Allan TURNER:** Well, my wife is a kindergarten teacher, and we all started back when Zaidee died—my wife set up a Zaidee Day, a rainbow day at the kindergarten for four-year-olds. Even to this day, going in 18 years on, we still have that day at kindergarten. These kids are four years of age, and what better time to have that conversation. These four-year-olds at the kindergarten get what happened to Zaidee, because my wife explains that to them—that she died and she donated parts of her body. And these kids, they understand where the heart is and they get to understand what a cornea is, and then they trot off home in all the excitement about the rainbow day and they say to mum and dad, 'God, we had a great day today, we all got dressed up in rainbow gear, we had rainbow cake and we spoke about Zaidee's story.' They learn about what organ and tissue donation is all about at the age of four. And then we go to primary schools, and we sit in front of primary schools and we tell Zaidee's story and we tell them what she gave and how she died and all that, and the questions that we get all the time are—more and more, kids get death. Kids are not scared of death and dying. It is we the parents that do not want to talk about it; we do not think of our child dying.

Bata school shoes years ago came to me and we said, 'How about we do a black school shoe called Zaidee shoe and we put rainbow laces in it?' Every year they sell a couple thousand of these pairs right around the country and have done for the last, I think, 17 years. So when you go out to buy your black school shoes for your kids, you can buy a Zaidee shoe and start the conversation. We also have a kindergarten project—I do not know where the shoe is—and we give school shoes to kindergartners to teach children to tie the shoelaces up when they go from kindergarten to school, because most children go from kindergarten and have shoelaces in their shoes. And with that comes a flyer about how to do your shoelaces up, and on the back of the flyer that mum and dad have to read, it is about what organ and tissue donation is about—about a little girl. And so the conversation starts.

I think school education is the key to really changing the system and the culture for the generations above. Here we have DonateLife, who have an educational program through Cool Australia, and all they are concentrating on is 16- and 17-year-olds. When we approached them for decades about driving school education at primary school, secondary school and university, they were not interested. They are all just worried about 16- and 17-year-olds. If you look at the 16- and 17-year-olds market in schools, it is the worst age to try to drive the education because these kids are going through HSC or going into the next year of HSC. They do not have time

for optional subjects. You know, they are all about the curriculum and are not worried about optional subjects. Optional subjects are something that the teachers will not throw upon them leading into HSC or whatever the higher educational level is.

Back in 2005 the federal government changed the law to say that children cannot register under the age of 16. We fought that. We went to the government and said, 'That's a silly law. You should not do that.' They said, 'Well, that's what we're doing,' so children under 16 cannot register. So the following year we came up with the idea of Zaidee's kids donor cards. On the back of that you write your name and your address and your parents sign it, and then they have a conversation. We have given away over 640,000 or 650,000 of these cards to schoolchildren so they can go home and have a conversation with their mums and dads. They cannot register, but they have a little Zaidee card in their purse or in their side table.

Education is the crux of going forward with all sorts of different ways and manners. I mean, we had a school educational program. I had a full-time school educator going to schools with dummies with torsos and hearts and livers and all that, and they would take them out and put it back together. We ran out of funding, so I had to sack him, and we do not have that educational program anymore because we have lost all of our funding. With the ideas and the concepts that we have come up with, we wanted to work with Cool Australia. We wanted to be the grant provider delivering the information to them, but unfortunately we got pushed out of the picture and they have done it the DonateLife way, not the way that we think it needs to be done in the school education system for both primary and secondary.

**The CHAIR:** Okay. Thank you for that. Just very quickly with regard to the funding, was that the funding that you previously received through the Organ and Tissue Authority?

**Allan TURNER:** It started off with the Department of Health and Ageing back in 2006, and then it was a couple of years after that when DonateLife were formed. They then took over the funding, and they controlled the funding for four years of that last six-year period that we had. You know, each year that was cut backwards until it got to a point that they said, 'There's no more funding going forward,' and we thought, 'Here we are, we're the most proactive, loudest charity foundation out there trying to deliver results, and you're cutting our funding.' We had three different meetings with DonateLife board members up in Canberra, and we were on bended knees to see if we could get more funding, but it was not to be.

**The CHAIR:** Okay. Thanks, Allan. Heang.

**Meng Heang TAK:** Thank you so much, Allan. Thank you very much for all the work that you have done. I am very sorry to hear about your daughter.

**Allan TURNER:** Thank you.

**Meng Heang TAK:** In terms of education and training, which are very important parts of your campaign, how does that connect to the multicultural community? Has there been any?

**Allan TURNER:** Well, we go to schools that are full of multicultural people. I do not think we treat them separately. Years ago, DonateLife came up with brochures—I think there were about eight or nine different brochures—that were all written in different languages, and they sent them out. I am not too sure if they are still available today, but that was what they did, and they did a good job on that for sure. I talk about this a lot, and I think we get a bit too wrapped up with multicultural community education and what we are asking them to deliver. I say to people, people in the multicultural sector, that they can go and get a passport, they can go and buy a car, they can go and buy a house and they can go and do all sorts of different things, but we struggle with thinking that they can come up with a yes or no or understand what organ and tissue donation is all about. I do not think that is correct. I think that they are provided with the right information in their language, and the heads of these multicultural organisations support it. I do not think it is a real issue out there at all. I think a lot of people are trying to make it an issue, but I cannot see it. I have been doing this for a long time, and I speak to a lot of different multicultural people. Shepparton, where I live, is full of multicultural communities. I do not struggle with communicating with them and them understanding what organ and tissue donation is all about—whether it be a yes or a no.

**Meng Heang TAK:** Speaking to the multicultural community, like you said, has there been a notable change in terms of getting from that understanding to signing up?

**Allan TURNER:** Look, I think there is. But I think if you look at the percentage, it is a very low percentage of people in the multicultural sector that are actually registered today. I think that is an issue where we go, 'Is it important or is it non-important?' But at the end of the day, as I say, more people donate that are not registered than those that are, and they have for decades. So in a way we ask people to register, and we communicate to them. But even for those that are registered, I mean, the second time they talk about organ and tissue donation is when they are in ICU and they get tapped on the shoulder and someone says, 'Hey, we'd like to talk about organ and tissue donation.' You would do a lot of the preplanning beforehand and education beforehand, but the crux of it is the end-of-life discussion between the families and what happens then. So it is hard to predict how much information you provide and how much education you give, because it could be all washed out the door when somebody says no.

**Meng Heang TAK:** Thank you. Thank you, Chair.

**The CHAIR:** Thanks. Chris.

**Chris CREWOTHER:** Thank you. Well, firstly, especially as a father myself of a seven-year-old daughter at the moment, I definitely congratulate you and your family and particularly Zaidee on her gift of life for seven others and for your advocacy over so many years, particularly in the face of not having much government funding or other support. So I particularly congratulate you on your dedication.

In terms of an opt-out system, you talk about a hard opt-out and a soft opt-out in your documentation. Do you think that an opt-out system does need to be accompanied by rules to stop family members giving their consent except for in exceptional circumstances or do you think they should maintain it?

**Allan TURNER:** No, I do not, Chris. I am totally against having a family member being blocked from any discussion. The way I explain it is: you are in the ICU, there is lots of family—some are going to say yes, some are going to say no, but you have that discussion. Most countries around the world have a soft approach, and that is what I am applying for: a soft approach or a soft opt-out, not a hard opt-out. You have got to imagine that that person laying there cannot speak, cannot communicate. They may have signed a form, but if the family make a decision to say no, you have got to respect that because they are dead. They are not going to come back, but you have got to live the rest of your life with the decision, be it yes or no. And at that time, which is the worst time in one's life, if it is a no and they do not want to proceed, you have got to respect that. No-one is going to go against that. You cannot walk in and say, 'Sorry, he signed the form; we don't care what you say, we're going to wheel him in.' That happens in America. It does not happen anywhere else in the world.

**Chris CREWOTHER:** Now, you also noted that in 2005 the federal government changed the laws for children nationally, passing laws that no child 15 years and under can be a registered organ or tissue donor. Do you know why they took that approach, and can you explain further the current system for children at the moment? Where do you see that going and what things do you think should be changed for children to be able to donate?

**Allan TURNER:** To my understanding—we made inquiries about why they have taken children off the national database—it was to do with legalities and security of children's names on lists. I think one state was against it, and in this federal system if one state is against it, then they all have to follow. That was the case. I think Queensland said, 'No, we don't support having children listed on any kind of database, so we're not going to support children under the age of 15 being registered.' Children under 15 still need parental consent—so does a 25-year-old, a 30-year-old, a 55-year-old. They still need family consent by the time they are in a situation to be a donor. So at the end of the day, I say children under the age of 15 work in the opt-out system already, because they cannot sign on and they cannot sign off. You hope they have had a conversation. You hope that they have been in a situation of being on the hypothetical side of things to say, 'If we're in a situation to be a donor, is it a yes or a no?' And if it is a yes, great, and if it is a no, you know. That is what is going to happen at the end of life in that discussion in the ICU.

**Chris CREWOTHER:** But the families still can give consent for a child, say if—

**Allan TURNER:** Definitely, yes.

**Chris CREWOTHER:** Many other witnesses have spoken about the licence system and South Australia as a stand-out maintaining the links between registration as an organ and tissue donor and the licences, whereas

everywhere else is not, and you can see the differences in registration. Do you think that is something that we need to look at again—linking our licence system with registration?

**Allan TURNER:** Definitely, Chris. We campaigned vigorously when they decided to take it off the list. We spoke to many politicians, wrote many an email, and the feedback was: ‘Bad luck. No hope. You’re not going to get there.’ To my understanding it was a clash of egotistical heads of departments saying, ‘We own the list’, ‘No, you own the list’. Well, if you own the list, you control it, you do it. And one said to the other, ‘Get stuffed.’ That is why the drivers licence tick was taken off the box, simply because they could not work out who owned the list and who controlled the list. When you have got two departments—I am sure you have seen that before—if they argue with each other, you are better off to walk away and leave it at that. And that is what they did: they took it off. To South Australia’s credit, you can get your drivers licence at 16 in South Oz, and they have got the highest rate of registrations in the country and have ever since. So it was one state that supported it, and they did not budge.

**Chris CREWTHER:** If we move to an opt-out system, do you think that the licence or any other touchpoint where you renew your licence or get a card –

**Allan TURNER:** Definitely do it.

**Chris CREWTHER:** should be utilised under an opt-out system to give you a chance to opt out?

**Allan TURNER:** You do as many touchpoints as possible to encourage the wider demographic out there, whether it be the multiculturalists or whether it be the age group of people over 50 that all still think that they have got a tick on the licence. I do many presentations to older groups—Probus clubs, Rotary clubs—and they still say, ‘Yeah, it’s on my licence.’ I say, ‘Well, bring it out and show me’, and they bring it out and it is not. So again, education out there—they did not have it when they took it off, and they certainly will have it when they bring it back on. As part of the documentary *Dying to Live* we interviewed the head honcho out of the USA, and we said, ‘Why is the USA one of the very few countries in the top 10 that still work in the opt-in system?’ He said, ‘Because the drivers licence is a major key of getting donors.’ The single major factor of getting donors is it is ticked on their licence in the USA—simple fact.

**Chris CREWTHER:** Thank you. Thank you, Chair.

**The CHAIR:** Thanks, Chris. Gary.

**Gary MAAS:** Thanks, Ella. Thanks very much, Allan, for your presentation today and your passionate advocacy as well. What do you think is the best way to encourage Victorians to register on the Australian Organ Donor Register?

**Allan TURNER:** There are many ways, Gary. There are many ways, and we have been doing this for many, many years. We use a lot of tools to engage those specific areas in the community. For example, cricket—we came up with the idea of Zaidee’s rainbow cricket grip and we thought that could be the go. I thought I would never do it because McGrath Foundation had the pink cricket grip and I did not want to step on his toes. Then one year they brought out pink shoelaces, and I said, ‘Stuff it, I’m bringing out rainbow grips.’ We brought out the rainbow grip, and we sold or gave away over 36,000 of these grips to children and young adults—36,000 were sold nationally. Everybody in a cricket team wanted one because we had Aaron Finch as an ambassador. Every time he was out in the MCG he held his bat up for a 50, and they said, ‘I’ve got to get one of those grips.’

Swimming—you cannot wear laces in swimming, so we came up with the budgie smugglers, Zaidee’s rainbow budgie smugglers, and we have them in ladies costumes as well. So you look at the different sectors. I mean, we did stuff in the horse racing industry where all the jockeys wore rainbow breeches, and we had bibs for the strappers and we had the logo on the saddle. It is looking at the sector and saying, ‘How can we encourage people and inspire people in that different sector to think and talk about organ and tissue donation?’ We have done so much over the years.

Rainbow socks and netball—we have a huge amount of netball players who wear rainbow socks. Soccer players and football players wear Zaidee’s rainbow socks. We look at what we can do in that sector and we go, ‘Let’s develop something up and drive it hard’, and we do and we have and we have been successful. There are not too many sporting teams out there in Victoria that probably have not worn a pair of Zaidee’s rainbow

shoelaces, from the under 12s to the seniors, at some point in time. But with extra funding imagine how much more we could do if we gave these away to every single football player in Victoria. How many hundreds of thousands of those would there be?

Zaidee's books—I wrote Zaidee's book in 2018. Called *Chasing Rainbows*, it is a basic storybook about how Zaidee started off at school and her journey through school, her collapse in my wife's arms, then being rushed off to hospital and flown down from Shepparton in the aeroplane. Then the back of the book is about the myth busters, about 'I'm not too old. I'm not too young. I drink too much', all that sort of stuff—breaking the myths about what organ and tissue donation is all about. There are various ways of going about it. You do not have to spend \$250,000 on an AFL team to do a one-week campaign for you. Imagine if I had \$250,000—I could do a year's program nationally on that, quite simply. So I think you have got to target certain markets and drive something that interests them and captures their attention rather than a one-off.

**Gary MAAS:** You described the education element through all the various tools there to get into the different segments of the community. What about procedurally into registration? Is there something that you would suggest in terms of encouraging people to register? Is there anything procedurally that you would like to see change?

**Allan TURNER:** Well, Gary, I am not encouraging people to register, I am encouraging people to run an opt-out system. As part of the opt-out system we do want them to register like they are doing in England, the same thing, so it is a two-pronged attack. But I think, you know, just getting people to register is not enough. I think we have got to get away from this idea that registration is the be-all and fix-all. It is not. We can get 8 million people to register. How many people are going to die next week, next month, next year that are actually on the register? If we had an opt-out system, instead of having 7 million people registered now we would have 18 million people, if not more, that would support an opt-out system. I know in our surveys 95% of people support an opt-out system. Over 90% of people support organ and tissue donation but only 36% of the people are registered. So it is not only a numbers thing, it is the way you go about it. Kids between 18 and 29 are bulletproof: 'Nothing is going to happen to me.' Life just goes on. They are the lowest registration target market. But how do we convince them? There are lots of incentives out there that you could do. We have got a couple of apprentices up in Shepparton that do not have to pay rego because they are an apprentice. You know, there could be different ways of encouraging and inspiring people to talk about it, to think about it and hopefully one day, if they are in a situation as Zaidee was, to be an organ and tissue donor.

**Gary MAAS:** Okay. Thanks very much.

**The CHAIR:** Thanks, Gary. Annabelle.

**Annabelle CLEELAND:** Thanks, Ella. We are running out of time so I will skip through quickly. We have read your book as well and had the conversation. It was tough for me, not for the kids. Just talk me through your advocacy in the 2006 to 2012 period and the grants. Was there a KPI attached to an engagement level with that investment?

**Allan TURNER:** Yes, there sure was. Every year we had to do a report and run on KPIs. We had to do a presentation on what we were trying to achieve for the next 12 months for the funding, and we were very successful. Every KPI we met, everything we said we were going to do we did. In fact we did probably more than what we were funded to do. Simply on the fact of Zaidee's powerful story, people wanted to engage with us. They wanted to support us. It was not hard to ring up sporting teams and tell Zaidee's story, and that cost nothing. It cost my salary as part of the funding, but we were not spending major money on major campaigns out there as they are doing now. So, yes, we achieved our KPIs. If we had not, we would not have got funding every six years. But at the end of the time I think they said, 'Well, no, we're going in a different direction,' and we were cut.

**Annabelle CLEELAND:** How many inquiries or reports have you been involved in in this space in recent years?

**Allan TURNER:** Quite a few. I mentioned the report back in 2011 where I actually sat in front of the committee and said that I do not support an opt-out system; I do not want to have the government dictating to us what we do with our bodies at the end of life. Four years later I changed my mind and launched the opt-out campaign. Why? Because I looked at what is happening around the world. I looked at what had happened

between 2011 and 2015. I looked at the recommendations that were provided back in the 2012 report. Nothing has been achieved from that report.

I hate to think that whatever you guys do in March 2024, any recommendations you make, will not actually get carried through, because I have done so many different inquiries and so many different reports and interviews with people but I have never seen any of the outcomes or recommendations being carried through to 100%. Sadly, this happens.

**Annabelle CLEELAND:** Hopefully we all accept that as a challenge and prove you wrong. We are putting a lot of effort into this. I have just got two quick questions. How many grants have you applied for and who are you applying to and how many have you had declined in recent years—say in the last decade?

**Allan TURNER:** Dozens and dozens and dozens. I have lost count of how many I have applied for. Every time I have applied for a grant from DonateLife since 2012 it has been knocked back, and there are lots of reasons behind that, because they see us as competition. They see the Zaidee brand as being in opposition to the DonateLife brand. When you look at the DonateLife brand, they want to be out there full on. They do not want to see the Zaidee logo anywhere near it. So no matter how many grants I have applied for to DonateLife over the years, every one—great ideas—has been knocked back for different reasons I cannot fathom. Unfortunately, we are not one of the sexiest subjects out there in the community, organ and tissue donation. The corporates do not see the value in putting money into this sector, because it does not get the exposure that cancer or MND or any other of those major subjects out there get.

I wish I had played one AFL game or played one game of cricket for Australia and had a name behind it; that would have helped. Look at what happened with the Glenn McGrath foundation; here is a guy who played a lot of cricket, his wife unfortunately died, and they made a successful and fantastic charity out of that. They get paid \$17 million, \$18 million a year from the government to drive these breast care nurses around the country. Sadly, the organ and tissue donation sector gets paid little, or gets funded very little. The money that comes out of DonateLife does not even tick all the boxes, it does not have much impact at all, and given that ad campaign is 52 weeks of the year and theirs is this one week of the year, you have got to go figure where the money should be spent.

**Annabelle CLEELAND:** I have run out of time, sorry, Allan. But just finally, just around some of those barriers with paediatric organ donors, it is an area that is really, really hard to get into at the moment. Zaidee had an extraordinary story with you, and in having that conversation with her, phenomenal beforehand, what is your advice to break through some of the barriers, and what do you see as the barriers and some of the solutions?

**Allan TURNER:** I think it is just talk. I think it is just information. It is providing information to parents and children, and to say that this is the conversation you need to have. We are a classic example of the hypothetical, the normal family: the two kids, the dog, mum and dad living in Shepparton; you know, we are bullet-proof, nothing is going to happen to us—until the day that Zaidee died. That statistic that she had, the only child to be a donor, it is always going to be someone else. It is always that other person on the news. It is always that person on page three. In fact, we were the news, we were the front page, we were the people on page three for 12 months. And I guess you have got to think that—do not only just think about what happens to you, but what you could do for another family. My brave wife was the one who said at the time that Zaidee was going to donate. There could have been a child down the hospital corridor that was waiting for a kidney or part of Zaidee's body to live a life again, and that is what happened. You have got to think of others. You have got to think that, through your worst nightmare, you have given hope and life to someone else that you probably will never meet, never see, never hug, never write to.

But I think it is one of those things, that we need to get more education out there. We need to show the grief of what families like ours go through, the impact. I have always said that to put someone out that has had a transplant is good, but it does not cut through. Show the emotion. Show the heartache and what a donor family has had to do and go through to inspire someone else to think this is what you could do, this is what could happen at the end of life.

**The CHAIR:** Thank you, Allan. Thank you very much for appearing before the Committee today and for your contribution to this inquiry, and to your contribution to inquiries all across the country and the ongoing

work that you are doing with Zaidee's Rainbow Foundation. Thank you so much to you and your family for bravely sharing Zaidee's story and your experiences with us. The evidence that you have provided to the Committee is invaluable, so thank you.

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.

The Committee will now take a 10 minute break, and I declare this hearing adjourned.

**Witness withdrew.**