

**THE LEGISLATIVE COUNCIL SELECT COMMITTEE ON ORGAN DONATION
MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART ON
THURSDAY 30 JANUARY 2008**

PROFESSOR ROBERT JONES, DIRECTOR LIVER TRANSPLANT UNIT, AUSTIN HOSPITAL, MELBOURNE, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED BY TELEPHONE LINKUP.

CHAIR (Mr Wilkinson) - Professor, thank you very much for your time. I know you are obviously flat out and it really is appreciated that you are giving us your time today.

Prof JONES - It is a pleasure.

CHAIR - Are you aware of our terms of reference?

Prof JONES - I am, I read them when they came out and I do apologise for not being there when you were in Melbourne.

CHAIR - I understand. In relation to our inquiry, firstly we were told that there was going to be a Commonwealth report handed down in December last - whether that was going to be a preliminary report or not, I don't know - but we have not seen it and I just wondered whether it was available or not.

Prof JONES - I haven't seen it either. I am not sure whether it is actually out.

CHAIR - We are looking at organ donation and allowing people to understand what it is about. At first we were talking about an opt-out clause. A number of people have said that is not a good idea, what are your views in relation to that?

Prof JONES - Experience around the world is that the opt-out hasn't seemed to make a lot of difference. So I think, just in pragmatic terms, it causes a lot of angst and probably the end result would be not a vast difference in donor rates. So I think just in practical terms it perhaps may not be worth the effort in trying to persuade the public or the parliament that that is the thing we should do. Initially I thought it was an excellent idea but I have come around to the feeling that it probably isn't the key to increasing donation rates.

Mr HARRISS - Notwithstanding the experience in places like Spain?

Prof JONES - I think there are other factors in Spain that make the organ donor rate what it is, and I don't think that's the key one. I certainly would not oppose it but I just think it is a lot of effort to put into that aspect and it might be better if that effort was put into something that is more likely to be productive.

CHAIR - In a utopian world where we are setting up an organ-donation system, what would you do if you were us, as a committee? What recommendations do you think we should make that would help?

Prof JONES - I have not been involved now for about 25 years. We have the wrong end of the horse; if you go and ask anyone do they want to be a donor, not a lot of people want to think about that. But if you actually say to people, 'Do you want to be an organ recipient?', just about everybody agrees. So what we should have on our drivers' licences is, 'Do you want to be an organ recipient?' or something coded along those lines. The implication of course is that if you would be an organ recipient - you, your family or children - then you would be automatically a donor. I think that is a more the concept we should be pushing. So that is one aspect of it. I have been in children's schools and asked, 'Who wants to be a donor?' and about three kids will put their hand up. Then you say, 'Who has a brother or sister? If they got sick and were dying, who would want them to have a transplant?' and of course all the kids put their hands up. So children get that philosophy immediately.

I think the key issue is driven from the intensive-care units in the hospitals and by the handling of the patients and the potential donors by the nursing staff and the medical staff at that level. We know in Australia that for the last 20 years, if you do surveys, about 80 per cent of the public are very onside of our organ donation, and that hasn't changed. So the public attitude over 20 years remains static, basically with most people being pretty supportive. But it is converting that support into being a donor, and that comes down to the very pointy end when the disaster happens, and it is the staff who are involved at that last crucial day or so who often are the ones who make that happen.

You can have the public giving 100 per cent support on surveys, but if the people in the hospitals do not manage it properly, organ donation will not occur. So I think all the effort should go into people who are involved at the crucial end of making the decisions and helping the family make those decisions. You obviously need a background of support in the community for this process, but the key issue will be persuading our intensive care units to do this better.

Ms FORREST - In relation to your comments about asking people whether they want to be a recipient, you are almost implying that if they say yes they will be a donor as well. It is almost like negative consent. Do you think there are issues with that?

Prof JONES - I think the public understand that really. We have this tremendous focus on organ donation, but the whole point of organ donation is to save your life, or your son's or daughter's life if something happens urgently. We are really focusing on the giving in disastrous circumstances - usually sudden death; and no-one likes to think about that - but at the same time those same families that are involved with sudden death and donation, if it was the other way round and they were involved in sudden sickness and needed a transplant, they are the one's who would be on the television saying 'We need a donor.' I think the public understand that. I often say to the families, 'Tomorrow your 20-year-old daughter comes in with acute liver failure out of the blue from something unknown and this young, fit woman has about a week to live unless a donor is available.' That could happen to any of us. I want all Australians to be organ donors because that provides the best chance of saving me or members of my family - we are all in this together. I think it is a big Australian gamble, like betting. I think it is a concept that the public understand, and I think perhaps in a way we are concentrating too much on the donation, almost as a separate, disjointed entity from the reason we are doing it.

CHAIR - I suppose in some ways you are looking at the end result before you start the journey, aren't you?

Prof JONES - Yes. It is an extraordinary process. When you think on a sudden, unexpected death, it is usually a catastrophe for that family and sometimes the loss involves very young people or children. It is an extraordinary thing when you think that people will allow this donation process to happen - it is really a very fundamental thing. I am always amazed that families are even able to contemplate it at this time of stress. It is an extraordinary process to have families wanting to make this donation. Almost universally they do not care where those organs go. They just have this concept that someone else will be helped. As one parent said to me on Christmas Eve, 'Even though my child has died, at least some other family won't have to go through this.' It is truly a magnificent gesture. In many ways we have an obligation to try to support that activity. By that I mean having our staff in the intensive care units being supported.

When you do an organ donation the nurses in the scrub nurse team are all volunteers. We usually ask, 'Who wants to do this?' because a lot of the nurses don't want to be involved, even though they are professionals. After that program on Channel 9 went to air a couple of our nurses, who previously had taken themselves off those rosters, came and said that having watched that program, their attitude had totally changed and they would be quite happy to be involved in the organ donation team.

Ms FORREST - Do you think the nurses who made the decision not to be involved were just seeing the sadness and the tragedy and not seeing the whole picture? Do you think that is why it changed?

Prof JONES - I think they thought the families were being coerced: in such a tragedy how could families possibly agree to this - that sort of thing. They felt that we were sort of harvesting organs from these people. What the show did demonstrate was that donating was a very positive thing in the donor families' lives. I think that was the key issue. It wasn't doctors and nurses pushing families and driving them to do this; it was really families wanting fundamentally to help someone else. I think that was an aspect that was quite surprising, even for professional nurses.

I think the transplant community has always been regarded as a bit ghoulish. You are in there snatching organs from people. A lot of professional nurses still do not quite like that concept. So I think that program was very helpful in showing that donation processes are sometimes quite beneficial for the donor families.

Mrs RATTRAY-WAGNER - We have had it suggested that there needs to be a social marketing aspect like the 'slip, slop, slap' or the 'bloody idiot drink-driving' concept. Do you believe that that would be a useful tool?

Prof JONES - Yes, I do. I think it is very important that we keep reminding the public, and we have to keep doing these things repeatedly. But I just go back to that information. I think if you look at these surveys over the last 20 to 25 years in Australia it pretty much has not changed. All these millions of dollars have been pumped into lots of publicity campaigns but essentially there are about 60 per cent very strongly positive, 20 per cent sort of positive and about 20 per cent are a bit uncertain about it, and those figures have not changed. So I think what you are probably doing is just reinforcing this public

attitude. I think if we spend hundreds of millions of dollars on public education, it probably is not going to change donor rate much because at the end of the day it is the staff that handle it on the time and the decisions that are made depend very much on the people involved. We have research on that now showing that certain people can achieve very high donation rates and another person can have half that success rate.

CHAIR - Therefore the axle that keeps the wheel revolving in relation to it seems to me to be the people at the coalface in intensive care who are speaking with the families. That seems to be the major indicator as to whether there is going to be an organ donation or not.

Prof JONES - Yes, I agree. I think it is also the nurses, not just the professional doctors or the people who come and ask. It is often the attitude that has been set. A young person may come in and be looked after in the ICU for 48 hours. In that 48-hour period before organ donation is even thought about, the attitude from the relationship with the nursing staff and all of those things are crucial in how the final decision is made. In the Spanish model that clearly is the key issue. They have these professional people who handle this process and the institutions have this targeted as part of the structure of the hospitals. Rather than being an add-on, that you go and ask the families if they want to be donors, these institutions have it as a compulsory part of their hospital vision. Organ donation is a key part. I think there is a structural component as well, that the institution has to see it as important. In our ICU, for example, if somebody dies they say, 'We'll switch the machine off and then we can move that person out and put another person in and it is all very quick, but if they become a donor then we'll have to work hard and keep their heart beating and all of that will add hours to them staying in ICU'. So there is a structural incentive to turn the machines off and not ask as well because it is more work. There are other components in it that perhaps have to be converted over. Maybe intensive care units have to see organ donation as saving a life but it just is not saving the life of someone in their unit at that moment.

Ms FORREST - There are a couple of points there that I would like to follow up. If they have someone in the DEM who needs the bed, that could create a conflict in their minds, I guess. We have had evidence from a number of people that it would be good to have in a State the size of Tasmania one or two dedicated, trained people to be on call and available with this situation arising. Those people would be brought to the ICU where that person is and they could provide a consistent approach, I guess. However from what you have just said, it sounds to me that you need to engage the whole of the ICU staff in every unit where potentially this could occur otherwise a young person could come in who clearly is a potential donor and the attitude of the nursing staff who have received that patient into the ICU may have a bigger impact than the person who comes in later who is experienced and qualified and is going to say all the right things. Is that a fair comment?

Prof JONES - I think that is a very good summary. I think you still need that professional person who does the asking, who is very good at that and sees that as a key part of their job, but the groundwork has to be set by an ICU that is very much supportive and onside. If you have a lot of your nurses there who are very negative about it then those feelings are picked up by the families well before the coordinators arrive. But interestingly families, because they have built up a relationship with those nurses, will often come

back and ask the nurses, 'What do they think, because you are looking after my son.' So I think both of those aspects are critically important.

If you are spending money, I think it could be very targeted on intensive care units and maybe workshops and showing them programs like *The Gift*, with the donor family's side of the story because I found that interesting too. Even as a surgeon who has been involved for a long time, hearing donor families months or years later talking about the process was really moving and something that none of us really see because we are all just involved on the day.

Ms FORREST - I am not sure if there are situations but I imagine there could be some families who still struggle with the whole concept, even though they have agreed to a donation. Are there families who still struggle and have their stories been heard in this process, or are we just hearing the good stories?

Prof JONES - I agree with that. It is almost universal that not everyone in the family is onside because often it can be a big extended family of 10 or a dozen people. Usually you find there is one key person - the mother, father, or somebody - who leads the family decision-making. But it is quite common to find that the grandmother opposed - older people are very much opposed to it - but the person who is the key decision-maker for this person who has died will often then persuade them.

But it also interesting that people who are often very opposed to it later on, a month or year later, have changed their mind, it is just at that crucial moment they cannot dream of this going ahead when someone they love has just died, but their attitudes often change. So it is very rare to find someone later on in the family who doesn't have a positive attitude. If that has happened, it is probably because it has been a very chaotic donation process or very dysfunctional. That is where that professional person who comes into the ICU, handling that complex family arrangement and following up that family later on, is very important in terms of coping with the outcome and the fall out later. But I think it is almost universal to find that in most families it is very common not to have everyone in agreement with it. The trick is converting those members because often the people who are most outspoken are those who are not in favour, whereas the people who are positive about it aren't positively positive, they are saying, 'Oh well, okay'. So you only need one really strongly-spoken family member to be negative to influence everyone. The ability to handle that is for those professional people who can do that well. Very few people can do that really well.

CHAIR - I noted the report of the Department of Human Services and LifeGift, the Victorian Organ Donation Service, *The potential for organ donation in Victoria: an audit of hospital deaths*, which was an inquiry which went from January 2002 until October 2004. Obviously you are aware of it -

Prof JONES - Yes I am.

CHAIR - but can't remember the conclusions without them in front of you. The actual conclusions to me seem to sum up what should be our recommendations. Can I go through them and dwell on them as we go through them.

Prof JONES - Certainly.

CHAIR - The first one says:

'Ensuring that the clinical governance framework in Victorian hospitals includes an explicit accountability for the organ and issue donation performance achieved within our health services.'

Prof JONES - Yes, I agree with that entirely.

CHAIR - Has that been happening since this report has come out?

Prof JONES - It has not happened formally but it is gradually happening, I think, this realisation that organ donation is part of the structural makeup and part of the service delivery. We are seeing transplantation, which was a cottage industry by a few eccentrics on the margins of medicine, moving into the mainstream, being regulated and being regarded now as part of the official process of caring. I think that process is happening slowly but certainly it could be sped up.

CHAIR - Therefore should there be a vision statement? Is that what you are saying of each hospital with ICUs to say that it is a focus that they have to give attention to?

Prof JONES - It could be stronger; I think it should be a mandatory part of their auditing and performance indicators. It is very easy to sit around and have a wishy-washy vision statement, but I think it should be built in. We know from Australian reference figures that a hospital such as the Royal Melbourne should be achieving a certain number of donors and if not, there something dysfunctional. So I think I would be tougher about it.

CHAIR - So that's what it should be? The hospital is to achieve x number of organ donors for 2008?

Prof JONES - Well, it is a bit hard to be that specific. In the major head injury trauma unit you have 50 deaths of young people a year. We know that probably 30 of those 50 could be donors, so you would expect that kind of number. It is sort of built-in in a way that if there are only 10 donors out of 50, you know they are not doing it very well. You can almost put a figure on it.

Ms FORREST - We have a neuro-surgical unit in Hobart, but the number of suitable donors we would get in a year is very variable because of our population. Would it be more appropriate to have an expectation requirement of the intensive care unit to be a unit where all the staff have a like-minded approach to how they deal with it? Is there a political pathway - for want of a better word - for a patient who comes in that way?

Prof JONES - When you start putting absolute figures on it it becomes very ghoulish. But there is a compromise of building it into the structure of how the place is working - not just a vision statement.

Ms FORREST - Is it a care plan to the people that present?

Prof JONES - Yes - and maybe auditing. You have a death and the family doesn't agree, you have some auditing process to work out why, and whether we could have done anything to change the situation.

Ms FORREST - That could be easily incorporated into a review of any unexpected death in the hospital anywhere, couldn't it?

Prof JONES - I guess it could.

Ms FORREST - Even in a hospital where the facility may not be there? Say it was one of our rural hospitals, even identifying why that patient wasn't transferred quickly enough to the Royal Hobart or wherever could be an issue that could be followed up as a mandatory process that occurs.

Prof JONES - Yes, I think that would be another excellent idea of maintaining a balance without being demanding or pushy about it. I think you are right, and I think the public and the hospitals would accept that because I think it is gradually being accepted that transplantation is a key part of service delivery and donation is obviously a crucial part of that.

CHAIR - The report's second conclusion went on to say:

'Ensuring that intensive care units take a leadership role within their hospitals in managing potential donors, including confirming any known wishes of any potential organ and tissue donor regarding donation and discussion of organ donation with families. Development of this leadership role would be assisted by the appointment of an intensivist part-time with responsibility for directing a program of activities to optimise the identification and management of potential organ donors within their hospital.'

That is a bit wordy, but it is pretty well what we have been saying, isn't it?

Prof JONES - I think that is a pretty good summary. I guess that report was written by two intensivists, but I think they are right. I do not think it is just self-interest. In some ways, when you are talking to intensivists, another intensivist is more likely to pay attention. It probably has to be driven by the intensive care units themselves.

CHAIR - The next conclusion really fits in with what you were saying about the main issue that needs to be looked at and improved. It says:

'Ensuring that all staff discussing organ donation with families have appropriate experience and the requisite skills. One model for training is the Medical Adapt workshop.'

Is that still an appropriate model for training?

Prof JONES - I think it is. It is probably the only model, the only training program around. Even with that program - and people who go through it do much better - just because you have done it doesn't make you a good person to go and talk to families. Some people

seem to have that natural ability. Selecting the right person is absolutely crucial in terms of the outcome. It is not just a matter of sticking someone in the program and expecting them to get a good result.

CHAIR - One of the key findings was that a higher rate of consent was noticed when senior specialists, rather than junior medical staff, managed the discussions.

Prof JONES - When you think about it, it is an extremely difficult thing looking after someone whose son has died. At a time you are letting them know that there is no chance, you are also raising this issue of helping someone else. It is an extremely difficult thing to do and it is so easy to find a reason not to do it - the family is upset and it is all too stressful. It is such a key part of the job.

Ms FORREST - How do you address the issue of taking the senior intensivist, for example, away from the bedside if you are still trying to save this person's life or to potentially make them suitable as a donor? How do you deal with that and how would we deal with that in a smaller unit so that we do not have intensivists coming out our ears?

Prof JONES - It is a problem and I think it is a slight conflict of interests where you are meant to be working to save the person's life and then you are suddenly switching roles to say, 'It's all over now. How about helping someone else?' That is where I think having that independent person coming in at that point to do the asking is good. But it has to be supported by the people the family already trust because when you walk out there and say, 'This is your son. He looks pink, he's on a ventilator but he's brain dead and we're going to turn the machine off', it is a real act of faith and you have to trust those doctors and nurses that this is what is happening. Families will turn back to the people who are looking after their family member and ask them their opinion but maybe that is where this independent person comes in, even if it is just another intensivist who has not been looking after that family and just raises the issue and is the person who handles the consent process.

It is an interesting problem. There is a realisation very early on that the transplant surgeons on the recipient side should not be involved in asking the organ donors because obviously they have a vested interest in the recipient and I think it is slowly dawning that maybe the intensivists who are looking after the donor have a slight conflict of interests when they start thinking about whether this person can be a donor. I think the public would find that easier as well, that the person who is looking after them is not responsible for asking about donation.

Ms FORREST - So you really have to have that separate person. Again, when you have small numbers it makes it hard to have that person available at the right place at the right time and it is likely that that person would have had no direct contact with the patient or their family and it would make it harder to gain their confidence. The family would say to the nurses caring for them, 'What would you do? If it was your son in that bed, what would you do?' How do you get around those issues with an independent person coming in?

Prof JONES - I think you are right; you certainly have to have the people who have looked after the person who has died being very supportive and I think you have to be realistic with what is available with the resources. It obviously works very well. When I was in

England there was an intensivist who was crucially involved in the issue of brain death and getting it through Parliament in the UK. He was an ICU intensivist in Reading. He was completely onside about organ donation and was responsible for one of the key decisions in how to determine brain death. He retired from this hospital while I was working there and even though the young guy taking over was very supportive of transplantation, the number of organ donors in that hospital dropped by 80 per cent. So it went from someone who was not only supportive but very actively engaged to someone who was supportive but not actively working on it. And this was an intensive care unit where this guy looked after the patients - it was a small intensive care unit - and did the asking. So I think it can be done well by the right person and there are some advantages in it by the family knowing that person. But it certainly has to be seen as very much a secondary issue after you have made that decision that that person is no longer going to live.

CHAIR - Have each of the intensive care hospitals in Victoria provided for a regular feedback to anybody who wishes to know in authority on the key organ and tissue donation performance indicators?

Prof JONES - No, at the moment there is not. For example, at my own hospital here, the Austin, we have a surgical audit which the intensivists come to and the questions are routinely raised in that because we look at all the surgical deaths every week and all the potential donors. So it is usually raised but it is an informal process that is just built into our working week. But at the moment I think that is probably an exception.

CHAIR - Yes. Should it be better and, if so, how?

Prof JONES - Yes. Again, I think it comes back as being part of that perhaps governance process, auditing and discussing. Everyone starts to think, 'Could we have done better? Could we have turned that death into a donor? Is there something that we didn't do that imperilled that?' So I think we should be building that into the governance and the structure and the auditing process.

It is interesting, auditing in the hospitals is only just getting off the ground. Hospitals that don't audit anything are going to struggle to suddenly start auditing this aspect. But if you are already auditing surgical complications, it makes it very easy to tack this on as part of the process. It is happening and I think the quality assurance component of it is gaining ground in most hospitals in most hospitals throughout Victoria. There is a lot of rhetoric supporting it but it actually costs money and takes time and is quite hard work.

Ms FORREST - We could also save a lot of money.

Prof JONES - I think you are right. At the end of the day you are actually measuring quality and it does keep people on their toes, there is no doubt about that, and when there is a disaster there is a formal mechanism of looking at everything as it happens.

CHAIR - How do you register within Victoria?

Prof JONES - People keep asking that and that is the problem. It is terribly easy. You can call the LifeGift - there is a number you can ring - and fill out a form, or you can go online and do it. People like to fill out a form, there is no doubt about that, and then they

like to give it to someone. So I think there is a mechanical process that people like to do - fill out a form, sign it and hand it in and somebody says, 'Thank you'. Filling it out online often does not seem quite as rewarding. People often still do not know where to ring and that is why those numbers are put up every time in the paper and on television.

I think the registry is useful because people expect there to be somewhere you register but in practical terms it is probably not the most important thing. So if you only had a certain amount of dollars to spend I am not sure I would pump it into getting people onto the registry, it would be much better that they are just talking about it and thinking about it, and maybe have discussed it with their families. But having said that, I think it is part of the component of raising public awareness and it gives people a formal mechanism of doing it formally because I think people think it is such a key decision 'that I will donate my organs', you don't think it is something you'd tell your wife, you think it is something you should have to write down and make legal. So often people don't regard just talking to someone about it as very concrete.

CHAIR - In relation to the registration, it would seem, and from the evidence we have as well, that it expresses an intention at the time but it could be 20 years ago when you made your wishes known and who knows what has occurred over the last 20 years. So therefore we are getting back again to informing the family, letting the family know, and then having your expert specialists speak with the family and also perhaps with one of the nurses or other people involved in the process, to speak with the family to ensure that that wish is going to be abided by.

Prof JONES - Yes, and I think that is where the registry is useful. If someone can say, 'Your son has signed the register and said he wanted to be a donor', it often influences the family dramatically. So I think it is very useful but it is certainly quite hard updating it and keeping it relevant and a lot of money goes into that, so I guess you're balancing the costs of doing that.

CHAIR - With an update it could be done fairly easily, could it not, with your licence. Your licence in Tasmania, if necessary, can go for five years, and if you put it on the licence that seems to me to be a fairly good way of keeping it updated without any real cost involved.

Prof JONES - Yes, I think that is right. It is interesting, I have been involved now for a long time and I used to have a very passive view about all this but I think having seen the demand now outstripping the supply of organs, you start getting more hardnosed and think you have families who will not contemplate being a donor, or won't even think about it and certainly haven't signed on, but those same families tomorrow desperately begging for someone to be a donor for them. So I think we could be much tougher in the community. I like the idea, harking back, 'Would you be an organ recipient?' The implication of course if you say, 'No', that you would go to the bottom of any waiting lists, or something like that, there would be a negative connotation. You would find that just about every Australian would sign on just on the gambling chance that they might need it one day, or their children might.

CHAIR - A bit like insurance?

Prof JONES - Yes. I think the community would understand it in the same way that when you have waiting lists of patients and you say to the community, 'How are we going to rank these patients?' The general feeling around the world is that you put the sickest first, but if you have two people equally sick and it's a toss up of whom you choose, the community expects you to choose the person who has been waiting the longest. So I think people do understand these very pragmatic issues of practical issues of ethics.

CHAIR - Let us say a person in Tasmania dies, donates their organs - it doesn't occur here, they have to go to Victoria for that to occur - some may argue that they want those organs donated within Tasmania as opposed to their going to another Australian State. That can be an issue with some, maybe. How do you cope with that?

Prof JONES - I think it is a recurring issue. But we have discovered that pooling those resources is so much more useful and Tasmanians, for example, benefit far more by having access to the Victorian donor pool. For example, a 25-year-old Tasmanian can come into a Hobart hospital tomorrow with only a week to live with end-stage liver failure from a viral infection. The chances of there being a Tasmanian donor in that week are very low, but the chances of there being a Victorian donor are much higher. Having access to the bigger pool means that you are much more likely to get the best outcome. I think we have to push that point. We could probably argue that a national pool would be even better, but running that would be impractical. Certainly the Victorian-Tasmanian link benefits both very much.

Mr HARRISS - Professor Jones, could you put your finger on any underlying reason why other countries perform better in donors per million than Australia? Is it just that they allocate lots more dollars to the program and therefore the intensive care area is well staffed and well equipped to facilitate the process?

Prof JONES - I think there is a little money involved, but it is not crucial. For example, we have in Australia nationally about 60 different groups who have a registered interest in organ donation - all of them doing their own thing and spending money and totally not coordinated in any way. Spain has just one group that coordinates everything. You cannot be involved in organ donation unless you are part of this national overview. I think that is crucially important. The Spanish arm has five or seven branches to it, but it is all centrally run. Australia has this totally disjointed group of people - lots of people with their fingers in the pie. That is a crucial part of it.

Mr HARRISS - How do we change direction because there are sensitivities there, where all these groups believe - quite rightly most likely - that they are doing a good job and have done so for a long time.

Prof JONES - That is where you guys come in!

Laughter.

CHAIR - But we don't want to do anything!

Mrs RATTRAY-WAGNER - I think you just handballed that nicely, Professor!

Prof JONES - It is interesting. I worked in the United States for quite a long time and the US has double, treble our donor rate. The US is this vast country of different attitudes, but it is interesting that even they have a much better donor rate than we do here. I think our problem in Australia has been that organ donation and transplanting has been literally a cottage industry, totally outside the mainstream of medicine - so much so that we in the last 20 years get on aeroplanes, travel to New Zealand, operate over there, return to Australia with human organs, and it is totally outside everything. There is no registration, no importation, nothing. Where else could you do that? You couldn't go over there and bring back an animal. Yet we can travel over there, retrieve human tissue, operate in hospitals where they do not even know who we are, and bring those New Zealand organs back here. There is no way the structure copes with it. Nothing is in place. It gradually dawned on governments, who are now trying to do something about it, but I think the problem is that we have just been a cottage industry outside the mainstream and no-one has really taken any real interest. I was absolutely delighted to have a parliamentary select committee take an interest - that is extraordinary, and I congratulate Tasmania for doing it.

Ms FORREST - I think part of that possibly comes back to cost. Would it be a fair comment to say that not enough money has been invested at the front end, in the ICUs of Australia, who are facing these situations? If it is a cottage industry, there is not a great focus and you are not staffed or equipped to keep a person alive until their organs can be collected when you have other patients waiting for those beds. Is that an issue that needs to be addressed as a main focus? I guess, in that if you do not resource your ICUs, if you don't adequately train your staff and you don't provide them with enough resources to keep someone in a bed for another day. I am not sure how long it takes, it probably varies - from the time you decide that patient is not going to survive until you actually can take them out to the operating theatre and free up the bed for the next person, so to speak.

Prof JONES - That is very much the case. About eight years ago Victoria did institute an extra payment for someone who became a donor. So if you had someone sitting in a bed a lot longer than they otherwise would have, because I think there is a payment of \$1 500 that ICUs can apply for once a year and get that money rebated. So I think there is a bit of recognition of that but I think that again is a very crucial part of building it into the structure of the ICU -

Ms FORREST - Under your DIGs and case-mix models, does it not rate there?

Prof JONES - No. I might be out-of-date but certainly it was an ex gratia payment outside the DIG. You wrote in once a year and said, 'We've had five donors' and they give you a cheque.

Ms FORREST - So effectively you are operating over budget to do it?

Prof JONES - Correct, yes. It is very much a cottage industry. I think it is a very good concept. It is really a bunch of amateurs and I often sit down with people and am amazed that it works at all; it is really just the enthusiasm of a lot of committed people. It has been outside of regulation in the most fundamental way, much less in subtle things like remunerating the bed costs.

Ms FORREST - So purely that is something that needs to happen as a matter of priority, I would suggest, to actually look at including it in those funding models. The opportunity is there and that it is not a cost factor that might be one of the inhibiting factors.

Prof JONES - Yes, I agree entirely. I think it does subtly influence decision-making. It is too difficult to ask and it is going to cost money and all these things add up to make it -

Ms FORREST - And you are already over budget.

Prof JONES - Yes, why bother? I agree.

CHAIR - Is there any document that you can point us to - and it goes hand-in-hand with the organ recipient - to show how the families have reacted as a result of an organ being donated to one of their own? In other words, they have come back or written letters saying, 'This is terrific, I've now been able to live the life that I wanted to live. I'm able to jog around the oval, swim laps of the pool' - all those types of things. Is there any document where we can show the public the benefits? I know you can talk about it but it is never really as good as if you get the words from the horses' mouths.

Prof JONES - Is this a recipient of any organ?

CHAIR - Yes, any organ, just to show how that family's life has changed as a result of obtaining -

Prof JONES - Yes, there is a lot of data showing that the quality of life for the individual and for the family has dramatically changed. There aren't many times in medicine where you can reverse a sick person's quality of life - they could be dying and five months later they are back mowing the lawn. It really is an extraordinary transformation both in life but also quality of life and treating people who are desperately sick and can't do anything and the next thing you know they are leaping out of aeroplanes and parachuting. So there is plenty of data on that.

CHAIR - We have some.

Prof JONES - I can certainly track down some of the quality-of-life stuff. It is not all roses; there is a side to transplantation that doesn't work so well. We use a simple formula. We say of our very sick patients a third will often do exceptionally well, a third do very well but still have a few problems and often a third may end up with some significant problems which mean they don't get back to 100 per cent. So I think we have to balance it.

Ms FORREST - When the other option is death, it is probably still okay.

Prof JONES - But they are still alive, that's right. There are some wonderful stories to fulfil those things you are talking about in terms of getting back to raising a family from being one step away from dying.

CHAIR - That is what I would personally like to put in the report, a number of those personal life stories to show how much benefit it has been.

Prof JONES - There are some studies but they get a bit academic and boring - percentages and things. I wonder if the best thing would be if we could track down some actual families who could give you a statement of what it has meant to them. Often they will write things for us - they will send in notes or put out a newsletter for other families.

CHAIR - Something like that rather than tracking them down would be terrific. We have a couple of comment from people who have been involved and they are really helpful, but it gets back to taking the focus off the organ donor to the organ recipient.

Prof JONES - There would be no problem in getting our coordinators to ask a few families, and then perhaps we could e-mail you.

CHAIR - That would be terrific, thank you. We don't want to hold you up, we know you are frightfully busy.

Prof JONES - No, no. This is very important, I think.

Ms FORREST - I have just one other question: you touched on it earlier. You said that having people sign up to a register is probably not all that important because at the end of the day it comes down to the bedside, pretty much. In your experience, have you found that where there has been a discussion at least - maybe not a consent provided - that it is an easier and more straightforward process? Or the fact that it has been discussed at all not really have any impact?

Prof JONES - I think it does make it very much easier if it has been discussed in the family. If that person has also signed that registry, it would be very unlikely that the family would then go against those decisions. Once someone has signed a document, even if the family is opposed - and we have seen instances where someone in the family is strongly opposed, but because that young person signed that registry, the family acknowledges that that is what he wanted.

Ms FORREST - What stage and age do you think it should be brought up initially? Should it be a six-year-old, a 10-year-old, an 18-year-old or what?

Prof JONES - That is a really interesting question. Obviously for the registry, that is driving-licence age, but it is interesting how many children have been involved when families discuss it. We have one case where an eight-year-old expressed an interest in being a donor. It is extraordinary that very young children are very aware of this issue. We do transplant children, so they are aware of it. I had a discussion last Friday with a little boy from Hobart who came to the Royal Hobart and we had a video link-up. He is eight years old, he has to have a liver transplant and he is very aware of the risk. The hidden question is, of course, how dangerous is this? Finally, this little boy, who was sitting there with his three brothers, asked, 'Could I die?' He was very aware, at eight, that not only could he die, but also that the organ was coming from someone who was going to die. It is amazing. Children are extraordinarily robust and often need to know. It is much better to discuss the fact that the donor organ will come from someone who has died.

Ms FORREST- Having said that, do you think there is a place for some sort of targeted program - just to raise awareness, not to try to get consent from kids - in school or at that level, so that the matter is discussed?

Prof JONES - That is an interesting point.

Ms FORREST - Sex education is a big topic, but you will get people saying, 'I don't want my kid told how to do that!' Is this an area that could have potential or would it cause conflict?

Prof JONES - Perhaps you could ask the teaching community what they think about it. I have certainly been into schools where we have discussed transplantation. Kids love that sort of thing because it is scary and ghoulish! I guess it is seen very much as something that families are involved in and talk about it. Children will be dragged along by mum and dad or older brothers and sisters. It is a very interesting point. Children are often very good vehicles to change attitudes of families.

Mrs RATTRAY-WAGNER - Could I just ask you, with your discussions with children in the classroom, was it more because of your profession, or because you were discussing potential organ donation?

Prof JONES - I was dragged along to my kids' school - you know, 'take your dad along to talk about his job'.

CHAIR - Were you asked not to come back?

Laughter.

Prof JONES - The kids were really interested - they loved it.

Ms FORREST - I am not suggesting that the teaching staff should do it, because I do not think teachers generally should do sex education either. It is not a comfortable thing for people to talk about and if the teacher's position on organ donation was ambivalent or negative then the people we talk about, these specialist staff who would attend the bedside or go down to ICU to talk about families, would be the people who could perhaps undertake that sort of program as well in a small State.

Prof JONES - Yes. I guess high schools would not be controversial in any way. Whether parents would be upset if you had eight-year-olds or 10-year-olds, I do not know. Certainly in high schools you could imagine it being incorporated in like driver education and that kind of thing.

Ms FORREST - It is about normalising it, isn't it. Rather than making it an unknown, fearful thing, it is about normalising the process.

Prof JONES - Yes, I agree entirely and I think that is why those TV shows that show the good and the bad are very beneficial. They are not Hollywood glamourising it.

CHAIR - I understand it is not in the medical course at the university; they do not talk about it there until, I understand, they become interns - this is within Tasmania - and likewise

in the university course for nursing it is not really spoken of. Should it become, not probably a subject, but spoken about at university and then when people get out into practice in their early stages?

Prof JONES - Absolutely. Again, I think it is a sign of this sort of cottage industry. It is not mainstream; it is not seen as legitimate; it is kind of all these eccentric, weird people.

CHAIR - In what area would it be discussed?

Prof JONES - It is like a lot of the intern stuff; a lot of the real issues are only discussed when they start working. A lot of the residents or nurses would only hit it when they have a patient or they have been closely involved. A lot of it is one of these things that you learn on the job and you are then very much picking up attitudes that are those of your colleagues around you, and that is a bit hit and miss, of course. If you work with nurses who are very emotionally opposed to it then you often pick up on it.

CHAIR - Sure. I know in law you had the moots and you had two people who were qualified, judging you on that moot and telling you how you could improve or how you could speak in a different way. Should there be that type of thing in a university course with medical students and nursing students - in other words, putting them in a real-life situation, even though it is not real life, but getting them in that moot-type situation, asking them how they would do it and running them through the process?

Prof JONES - It is a fabulous idea. As a little aside to that, once at a meeting I went to an intensivist got up and put up a video he had made about how to ask. It was a Monty Python-type situation about how to go and ask a family.

CHAIR - I feel at home with that, Professor. I have been likened to John Cleese on a number of occasions.

Laughter.

Prof JONES - It illustrated everything you should not do if you are asking a family if they want to be a donor. It was incredibly instructive and I think it would be a wonderful idea for students. It is a great idea - and for nurses as well.

CHAIR - Professor, thank you very much. It really is appreciated. We have quite a bit of material before us and hopefully we will be able to come down with our report as soon as possible. I say 'as soon as possible' because we want, if we can, to dovetail with the Commonwealth proposals. It seems silly for Tasmania to go in one direction and the rest of the Commonwealth to go in the other. A lot will depend on when the Commonwealth one comes down but really the evidence seems to be fitting into pretty obvious pieces, to us anyway, as to what should occur. It is as a result of information such as yours that we really are able to I think make our views more concrete. Thank you very much.

Prof JONES - It is great and I congratulate the Tasmanian Government. It really is a sign, I think, that things are moving away from a cottage industry and I think everyone is to be congratulated.

CHAIR - Thank you.

THE WITNESS WITHDREW.