THE LEGISLATIVE COUNCIL SELECT COMMITTEE ON ORGAN DONATION MET IN THE LIBRARY TUTORIAL ROOM, NORTH WEST REGIONAL HOSPITAL, BURNIE, ON FRIDAY 5 OCTOBER 2007.

Ms SUE ROBERTSON, CLINICAL NURSE MANAGER, RENAL UNIT, NORTH WEST REGIONAL HOSPITAL, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Wilkinson) - Thank you for coming along, Sue. We will open it up to you, and then ask you questions.

Ms ROBERTSON - I have a statement prepared that I will read out - I will also hand out copies - and then I am happy to answer any questions.

I am the clinical nurse manager at the North West Renal Unit, which is a satellite dialysis unit of the Launceston General Hospital. At the renal unit we care for people suffering from renal or kidney failure. This may involve conservative management, heomodialysis, peritoneal dialysis or renal transplantation.

As of January this year there were 1 394 people in Australia, of whom 375 were in Victoria and Tasmania, waiting for a kidney transplant, out of some 8 500 of dialysis. There were 385 kidneys retrieved from 201 donors in 2006 and 372 were used Australia-wide. At the North West Renal Unit there are 30 people of dialysis, which is haemo or peritoneal dialysis. Of this number, five are on the waiting list and three others are being worked up.

I am here today to discuss the impact of dialysis on the life of a person with renal failure compared to that of a renal transplant recipient. Someone on haemodialysis has to attend dialysis at least three times a week for four to five hours at a time. This is a minimum requirement to sustain life. They require strict fluid and diet restrictions, they are extremely susceptible to cardiac disease, bone disease and infections and their quality of life is hugely impaired. They are often unable to work, they have stress on their families and cannot enjoy some freedoms that we take for granted. If they are on peritoneal dialysis, they have to perform a sterile procedure to exchange the fluid in the peritoneum four times a day every day or be connected to a machine overnight every night. They also have diet and fluid restrictions. Both modes are dialysis can also have many stressors and complications associated with the access to their blood or their peritoneum needed in order for the dialysis to be performed.

When someone has a renal transplant their biochemical markers return to normal and with it the symptoms of their renal failure resolve. They have to take medication for the rest of their life, however their quality of life improves with the freedom for dialysis and how well they feel. With this improvement life options returns, such as the ability to work, which also has a socioeconomic benefit. Family stress is reduced, which leads to stability within the family unit. As with all procedures, some will experience complications or immediate failure of the kidney, but that is the exception rather than the rule. Kidney transplant is cost-effective, as after the first year the cost of someone with a renal transplant is less than maintaining someone on dialysis. The average waiting time for a kidney is 3.8 years and can extend out to five or six, which is a long time for a person to be on dialysis and increases the risk of developing the complications of renal failure such as cardiac and bone disease.

Patient and graft survival is improving all the time, with patient survival at one and five years, 96 per cent and 87 per cent respectively. Graft survival, which is the kidney survival, at one and five years is 92 per cent and 80 per cent respectively.

Australia has the third-lowest rate of organ donation, with 10 donations per million population, with Spain topping it at 35 donations. In 2001-05 Tasmania had the lowest rates in Australia and also the lowest rate of donors-per-thousand deaths. This improved in 2006 on donations per million population but figures on donations-per-thousand deaths are not yet available.

I believe that the kidney donation rate needs to improve and suggestions that I believe could be looked at are the opt-out legislation for organ donation where rather than opting in to a system it is opting out of it. Emphasis on education programs about discussing wishes with your family to particularly include young people because I believe that society has a taboo about discussing certain things.

The next point is not my area of expertise but when I was looking at a lot of the literature it seems that most of the discussions in ICU are done at the physician level. I believe that possibly senior ICU nurses could be educated more about these discussions. It is often the nurse who has the rapport with the family. Donor coordinators also approach donor families and their background is often nursing. However, in Tasmania the closest donor coordinator is in Melbourne.

Altruistic donation is an area that needs thorough investigation. Another point which can be controversial is for live donors to have, not a payment for the kidney, but a case-by-case individual review of financial support for their lost earnings during the time they are incapacitated. They have relieved the burden on the health system by donating their kidney and they should not have to suffer any financial loss because of that. I have some references in the notes where further information can be found.

Mrs RATTRAY-WAGNER - Sue, you just mentioned that the cost of someone having a renal transplant is less than maintaining someone on dialysis after the first year. Do you have any idea of what the level of saving would be?

Ms ROBERTSON - After that first year - because you obviously have the cost of the surgery and the acute care - for a transplant it is something in the ballpark of $10 000-$15 000, whereas maintaining someone on dialysis is in the ballpark of $30 000-$35 000.

Mrs RATTRAY-WAGNER - So it is a significant saving to the health system, isn't it?

Ms ROBERTSON - Yes, and they are also less likely to further complications, readmissions and all those sorts of things.

Ms FORREST - And those figures are just for the year the operation is conducted?

Ms ROBERTSON - No. I think it is about 1.7 years before it becomes cost-neutral or cost-benefit because in the first year you have the cost of the surgery, the in-patient care, ironing out problems and high levels of medication. But to maintain someone on dialysis is around $35 000 and obviously there can be differences in that, whether they are at home on haemodialysis or home on peritoneal dialysis or in a centre on haemodialysis. Maintaining someone in their second and third year of a renal transplant is cheaper, around the $15 000. I stress that I am very much quoting ballpark, but I can investigate specific figures for you if necessary.

Mrs RATTRAY-WAGNER - Sue, you have quoted the North West Renal Unit and said that there are 30 people on dialysis and five on the waiting list and three others being worked up. Do you know what the complete Tasmanian figure is or not?

Ms ROBERTSON - No, I don't, but I could find that out for you. The 375 in Victoria and Tasmania are counted because, especially with kidney transplant, they work as regions.

Mrs RATTRAY-WAGNER - So, more than likely, that figure is weighted towards Victoria, given that there is only five or eight in the north-west?

Ms ROBERTSON - Absolutely.

CHAIR - Do you know how many donors there were from Tasmania that assisted that figure last year?

Ms ROBERTSON - I have the report in here, but I think it was broken up into Vic/Tas. You can have the report, if you want it. It is the Australian-New Zealand organ donation register, the 2007 report.

Mrs RATTRAY-WAGNER - We have had quite a bit information over the last week.

Ms ROBERTSON - You are welcome to have that, if you want. I got it off the Web.

Ms FORREST - How many people are on home dialysis from your unit?

Ms ROBERTSON - From my unit at the moment there is only one on home haemodialysis and there are seven on peritoneal dialysis, which is also classified as a home therapy.

CHAIR - What is the difference between the two?

Ms ROBERTSON - Haemodialysis is where people have to have some access form to get to their blood, so the blood comes out and goes through the artificial kidney. That is where they have to sit there three times a week for three or four hours. The other type is peritoneal dialysis where they have sterile fluid instilled into their peritoneum and their peritoneum acts as the membrane where waste products transfer into that fluid and then they change the fluid, get rid of the dirty fluid and put fresh fluid in. Either way, they have an access of a tube into their peritoneum, into the belly area, whereas the other people have needles popped into their arm to get direct access to the blood.

Ms FORREST - Do they have a shunt put in?

Ms ROBERTSON - It is a called an 'arteriovenus fistula'; it is a surgical connection between the vein and the artery. We try to avoid them and in some cases they have a tube put directly into the big vessels going to the heart. They have a high risk of infection so we try to avoid those.

Ms FORREST - The people on home dialysis, do they tend to do it overnight generally?

Ms ROBERTSON - Again, if you are talking about PD or haemodialysis, with the peritoneal dialysis most of them would do it overnight; some of them still do the older-fashioned four times a day. That is a personal preference and some people don't like their sleep interrupted. With people on haemodialysis there is a big push, coming from Geelong, of nocturnal haemodialysis. Not everybody has taken that up yet. I think it is fantastic and I am an advocate for it, but we have a lot of problems in the north of the State with home haemodialysis services because we don't have a specific dedicated training nurse or training area to get people to take the machines home. That is a central requirement so the training becomes very ad hoc, when you can fit it in and things like that.

Ms FORREST - What I am hearing is that you may have more people that are coming to the clinic that could potentially be home-dialysis clients -

Ms ROBERTSON - Yes.

Ms FORREST - There has been some talk about having a statewide coordinator for the organ donation side of things. We talked with various people as to how that could work, because of the advantage of having someone on the ground - someone with a nursing background - when an opportunity arises to talk to the family. As it does not happen that often, doing just that would not need to be a full-time occupation. You would need other tasks, I guess, such as educating nursing staff, the medical staff and the public. Do you see that the role could be further expanded to provide that education and support for patients going on home dialysis in that interim period? Do you think that trying to get such a full-time position in both the north and south could work, or is it too different?

Ms ROBERTSON - I think it is too different and I think you would almost get into areas of conflict of interest as well if you have someone promoting organ donation and then you also have people on haemodialysis. I think that those areas should probably be kept separate just like you would never have a renal physician approach somebody in ICU about organ donation because they have a conflict of interest.

Ms FORREST - But do you think the coordinated position, separate then from the renal dialysis side of it, to educate people would be useful?

Ms ROBERTSON - I do not know about a statewide approach. Perhaps if we had a dedicated home haemodialysis nurse - we do have a peritoneal dialysis nurse - but it is always difficult to get more FTEs, and to get space to train these people. We can train them within the unit to take a machine home but it is not an ideal training environment and it takes longer because you have the busy unit happening. Whereas if you had a dedicated space, like a small training unit, you would not have all the distractions of other patients who are not doing things for themselves. You get a lot of human nature attitudes, 'Why do I have to do that because he's not doing it?'. Most of the places on the mainland have a home training unit that you attend to learn to take your machine home. If it is a dedicated space with a dedicated trainer it is a lot more successful.

Ms FORREST - On organ donation, would you want to support and fund a position for that? You mentioned that we need to increase organ donation, particularly for the people who are waiting - and many of those on dialysis are probably potential candidates.

Ms ROBERTSON - I would not say most of them because you have a lot of elderly people who are not appropriate for organ donation because they have other co-morbid conditions that do not make them a candidate. It is a fairly major operation to undergo to have the surgery and then you also have to have all the immunosuppressants. A lot of people with cardiac disease are not suitable.

Ms FORREST - Do you think that the position of the coordinator should promote organ donation, for one thing, but also educate in other areas? Is that important? Do you think that would be a step forward?

Ms ROBERTSON - Yes, I think that absolutely would. I think education is important and, as I said, even in the area of youth. People will say, 'Oh, yeah, I've ticked it on my licence', and if you ask, 'Does your family know?', you will find that they have not discussed it with their family because it has never occurred to them to do so. They will say, 'I was just renewing my licence and I ticked that box', sort of thing. It is a very personal thing. It is not that somebody has to donate organs, it is just that they should inform their families. If they have not discussed it with their family, the family may well withdraw that consent and say, 'They never said anything to me.' But if it is all out in the open, then you can carry out the wishes of that person.

Ms FORREST - So you think a coordinator should target school age kids as well?

Ms ROBERTSON - Yes, I think that there should be something done at a school age. Kids take things home, go back to their families and talk about things. I know some people in some schools might find it a bit morbid or confronting to talk about death and things like that at school, but I think these things should all be out in the open.

Ms FORREST - What age do you think is appropriate for school students? What do you think would be the right sort of approach?

Ms ROBERTSON - I think higher level primary school, but then into secondary, yes.

Ms FORREST - So years 5 and 6 and up, you are suggesting?

Ms ROBERTSON - Yes. There are tactful ways of dealing with children - you do not send them all home having nightmares or anything but if they are just thinking outside the square about all aspects of life I think that that develops thought processes in them extending past organ donation - their minds think about things that we traditionally do not think about.

Ms FORREST - We have sex education from kindergarten in various forms obviously, but with all curriculums there are aspects of health, good eating and living as well. Do you think it should be linked to something like that or does it need to be separate?

Ms ROBERTSON - I think it could be linked in. I have never understood why schools do not mandatorily have, for example, cardiopulmonary resuscitation (CPR) education, so that eventually everybody in the community would know how to do CPR. I think that it could be linked in at those younger levels maybe as a health unit and then it might not be so confronting. When the students get into high school it could be revisited.

CHAIR - I am endeavouring to paint a picture of a person prior to the hardship that they have to go through and the change of lifestyle as a result of having the donation. You talked about their being susceptible to cardiac disease - like what?

Ms ROBERTSON - People do not die of renal failure - it does not happen - they always die of their other complications. The big one is cardiac disease. If somebody has renal failure, because they do not pass water or anything and their toxins build up, the blood vessels in their heart have to cope with great swings in fluid volume in their body. You or I would have a drink and then go to the toilet. These people cannot do that, so the fluid builds up until we can take it off with the dialysis machine or with their home therapy or whatever. They have to stick to fluid restrictions. When I refer to a fluid restriction, I mean 500 mls a day if you are passing no urine. We all know that the patients cannot stick to that as it is very unrealistic; it is like 2.5 cups of coffee and most people have done that by morning tea, let alone the milk on their cereal and so on. This fluid builds up and the only way the heart can cope with that extra fluid is by growing big, which is called cardiomyopathy. Once the heart grows, the muscle grows bigger and it does not go back down again. We tell the patients that they will get big floppy hearts, so that is one of the things.

Then you also have your vessel diseases. With all the toxins build up and everything, you will have various cascades of inflammatory responses happening in the body leading to plaque build up and so on in their heart so the blood vessels to their heart are being impaired as well. Eventually, where a normal body might eject a certain percentage of blood with each contraction of the heart these people might only be ejecting 40 per cent or less in some cases from their heart. Hypertension is a big issue as well - high blood pressure with renal failure.

CHAIR - So you are looking at a heart attack or stroke as a result?

Ms ROBERTSON - Yes.

Ms FORREST - Heart failure too.

Ms ROBERTSON - And heart failure yes, where the fluid will build up and it will tip over into their lungs and then they end up drowning in their own fluids.

CHAIR - What about the bone disease, the same reason, infections build up?

Ms ROBERTSON - The bone disease comes about because calcium and phosphate balance in renal failure is a very delicate balance. Normally your kidneys would get rid of the extra phosphate in your food, but in renal failure that does not happen. It is one of the biochemical markers that are more difficult to remove with dialysis. Therefore, the phosphate level builds up. Calcium and phosphate do a balancing act in our bodies, so if the phosphate builds up and the calcium drops you will get a high turnover of the bone with the calcium coming out of the bones. Also you have little glands in your neck called parathyroid glands and these become overactive because they are trying to get this balance all right all the time. People often end up needing a parathyroidectomy which is again another major surgery removing these glands. They become hyperactive and what we call 'hypertrathy', they just become bigger and bigger and make more and more and so it becomes this vicious cycle and that has an effect on the bones as well.

Mr FORREST - You have to look after your kidneys.

Ms ROBERTSON - There is renal osteodystrophy and adynamic bone disease. There are about three types of bone disease which renal patients can get, so they are more susceptible to fractures and stuff.

CHAIR - In your position as the critical nurse manager, have you had to speak with the family and had to speak with the individuals themselves who are donating their organs?

Ms ROBERTSON - No, I have never been in that position because I am at the other end of the situation, so I have only been in the situation where people are receiving the organs, never in the other end - which is more the ICU end of things. Going back a step, I have from a live donor point of view. From a live donor point of view we deal with people all the time, like where the husband or wife or the adult child is donating to the mother or the mother to the child.

CHAIR - What is the situation with that because we were told that if I wanted to give one of my kidneys to my best mate, I could not do that.

Ms ROBERTSON - If you have a relationship with that person you can. We have had friends donating to each other.

CHAIR - You can?

Ms ROBERTSON - Yes.

CHAIR - And families?

Ms ROBERTSON - Families can give to each other. Usually the initial test is on blood type, however in December last year the Royal Melbourne did a different blood group donation as well. So donations from families members, absolutely, and they will get the social worker to talk to you and do a psychosocial review to make sure there is a relationship and that you are not actually paying off an old debt and that type of thing. The only odd one is this altruistic situation where someone just wants, out of the goodness of their heart, to give to someone and there is not some other motive there.

CHAIR - What is the difference really? We spoke with a girl a few days ago who had to go to America to donate one of her kidneys.

Ms ROBERTSON - I guess the difference is that relationship. Society accepts that if you have a relationship with someone you are going to want to relieve them of that burden. If it is your husband you want to relieve them of that burden and give them a kidney, whereas with altruistic donation I think society probably struggles with questions of, 'What's in it for you? What's really going on in your head? Is it some guilt trip from something that you have experienced in the past and you feel like you are repaying society?' I think society finds it hard to accept that there could be such people out there who want to do something just because they are good people and do not want anything in return. It is going to be a very rare exception that this happens anyway.

CHAIR - Sure.

Ms FORREST - Theoretically a husband or wife could give their kidney to each other or a good friend but there is always the chance of falling out after that.

Ms ROBERTSON - Absolutely.

Ms FORREST - Just because you have a relationship now that is good and strong does not necessarily mean it is going to be the same in five or 10 years' time, but one would hope it would be. So when you are saying 'altruistic', where there is no relationship, it potentially has the same risk.

Ms ROBERTSON - Yes.

Ms FORREST - I am not quite sure what the objection is and that is what we are trying to find out. Is it because there is no relationship so you are doing it for the wrong reasons, or because there is no relationship so you might be doing it for the right reason - you want to make a gift? It is a bit hard to know what the problem is.

CHAIR - Is it a legal issue? In other words, if they come along to you, you would probably say, 'Go and have a chat to LifeGift'.

Ms ROBERTSON - I am not actually sure whether there is a legal issue around that. I could not say. I have an inkling that there might be some legal thing because the lady you referred to on the television otherwise would have found someone in Australia, I would imagine. Perhaps it is just that the surgeons shy away from it because they haven't done that before.

Mrs RATTRAY-WAGNER - She did indicate that there was no way that she could get it done in Australia.

Ms ROBERTSON - Yes.

Ms FORREST - But that was on talking to the hospitals, so there may not be a legislative restriction; it could just be that none of the members of staff are happy to take it on, for whatever reason.

Ms ROBERTSON - Perhaps that is because of the risk to them if something then happens to her, that you have caused someone harm who doesn't have a relationship with that person.

Ms FORREST - The same could be said if I donate to a friend and then we had a falling-out a few years later.

Ms ROBERTSON - Yes.

CHAIR - The average waiting time for a kidney is 3.8 years; is that within Tasmania or Australia-wide?

Ms ROBERTSON - Australia.

CHAIR - Within Tasmania/Victoria is it about the same?

Ms ROBERTSON - I don't know. There is a different agreement with kidneys than for hearts and lungs because people can stay alive on haemodialysis and there are more kidneys - because you have two kidneys. There is a different system where you match for HLA typing, a specific matching. Six things are matched other than blood group and there are exchange systems between the States. So if you had someone in Western Australia that had a perfect match with someone in Tasmania, then they would get that kidney rather than it be used in Western Australia. That setup is unique to kidneys.

CHAIR - I understand that in Tasmania there are 375 from Victoria and Tasmania waiting for a kidney. We do not know the exact numbers for Tasmania but in the north-west there are 30 people on dialysis and five on the waiting list.

Ms ROBERTSON - The average on dialysis is about 17 to 19 per cent who are waiting.

CHAIR - If you heard today that there was a kidney available for one of these five on the waiting list, what happens?

Ms ROBERTSON - We would organise patient transport to get them to Melbourne as soon as possible. We would check out when they last had dialysis; we might have to give them one last run of dialysis or that may be done in Melbourne. We always have everybody ready, so they have tests up-to-date, but a lot of those get repeated in Melbourne as a last-minute check. So people are always ready and fit to go now, even in the middle of the night. If we can get them on a commercial flight, that is what happens. When they take the kidney out there can only be a certain amount of cold ischemic time - how long the kidney is out.

CHAIR - What is the time limit there?

Ms ROBERTSON - I do not have that information on the tip of my tongue. It is more generous than it is for hearts and lungs; I think they are only for eight or so hours.

So if we can we get them on a commercial flight, but if for some reason they have to have them sooner then they will organise a specific flight - but that is extremely rare.

If somebody dies here who is going to donate, the retrieval team comes over here to retrieve the organs. They are on special flights and they take the organs back with them.

CHAIR - So the retrieval team is from Melbourne?

Ms ROBERTSON - Yes.

CHAIR - There is no retrieval team in Tasmania?

Ms ROBERTSON - No.

CHAIR - Should there be?

Ms ROBERTSON - I would not imagine we would have enough. It is a specialty area.

CHAIR - Are they all done at the Alfred?

Ms ROBERTSON - No, the ones we have done have been at the Royal Melbourne. If we wanted someone to be on the kidney-pancreas list - if they have diabetes as well and we are looking at the pancreas - then they will be on the list at Monash Medical Centre. We have done a couple in Adelaide when they were trialling laparoscopic surgery.

CHAIR - As I think I might have said, 24 000 people have properly consented and filled in the consent form that you can get from Medicare. Another 150 000 out there have given their intention, but that is all it is; it is not a valid consent. What is the best way to pass the information on to those 150 000-odd out there willing, it would seem, to consent but maybe not knowing that they have not consented properly?

Ms ROBERTSON - With the opt-in legislation it comes down to education. But, again, it is one of those things where people think it will not happen to them.

CHAIR - We are looking at 174 000 approximately who have put their hand up and said, 'Yes, I'm willing', even though only 24 000 of those are done correctly, our intention rate is extremely good. It has been 40-odd per cent for people that can do that - I think 46 per cent - which is second in Australia.

Ms ROBERTSON - Right, okay. Then it is education about talking to their families so that their families know their intentions.

Ms FORREST - These are the people who have ticked their licence - that is an intent and not a consent?

Ms ROBERTSON - Yes.

Ms FORREST - If you do it through Medicare, it is a consent?

Ms ROBERTSON - Yes.

Ms FORREST - Do you think that people do not know there is a difference?

Ms ROBERTSON - Possibly. I think that if people tick their licence they just think it is going to happen.

Ms FORREST - Yes.

Ms ROBERTSON - They say, 'Oh, but I've ticked my licence'.

Ms FORREST - Yes, and that is an intent?

Ms ROBERTSON - Yes, and I am not saying that in every circumstance if the licence is ticked or the consent has been given that the family should agree. It might just not be appropriate - it might tip that family over the edge. Although that person wants their organs donated, there might be certain situations where it is just not appropriate.

CHAIR - We have heard evidence that if the families do not agree, even though there has been the consent, normally it does not occur, and that is a good point that you just made; it might tip the family over the edge. What type of things are you talking about?

Ms ROBERTSON - I guess on a emotional level, if it is something that that family cannot cope with - it is a controversial issue because then you have the intent of the person and respecting their wishes but then you do not want to place anyone else in harm's way either.

Probably most of those issues can be addressed by good communication with counselling and the one-on-one stuff.

CHAIR - Sure.

Ms FORREST - Looking at the issue of the consent, one of the criticisms that has been made about an opt-out process is whether that really is informed consent and those people do not get around to it; people might be a bit complacent, perhaps, or might not get around to making a commitment either way. They think, 'I will think about that at another time'. So if it is an opt out, you are in unless you opt out. Do you think that is informed consent and would that be an issue with that process?

Ms ROBERTSON - It is a valid point that you raise. However, I guess I think that the people that are passionate about it, that do not want to donate their organs, will be the ones that make sure that they opt out and you will not have - that terrible phrase - 'wasted opportunities'.

Ms FORREST - I am trying to think of a difficult situation that might arise that might make it not work. If someone arrived from a country that did not have a consent program or had a different system, perhaps, and if we put in an op-out system, without being informed of that on entry to the country, they could -

Ms ROBERTSON - Yes, I would imagine that you would have to be an Australian. I am not sure with all those legal things.

Ms FORREST - The whole issue around informed consent seems a bit tricky.

Ms ROBERTSON - Yes, and I am not sure how other countries have addressed that. I am guessing that Spain does because they have the highest rate but I am not certain. It would be interesting to find out how they deal with those types of issues.

CHAIR - Have you received any education at all about organ donation?

Ms ROBERTSON - I have had pamphlets at times.

CHAIR - Has any of the hospital staff that you know of, in the north-west or anywhere you have worked, had any education about organ donation?

Ms ROBERTSON - The ADAPT program, which is the Australasian Donor Awareness Program for Transplantation, was held recently in the Burnie hospital and that is aimed at people like ICU staff. I sent one of my nurses along to get the other flip side of the coin to have that awareness.

CHAIR - Sure. Do you think there are any missed opportunities as a result of people not being properly educated within the hospital and the medical staff?

Ms ROBERTSON - Of actual potential donations?

CHAIR - Yes.

Ms ROBERTSON - Not working in ICU, I do not think I can really comment on that because I am not sure. I think that would be something for ICU to answer.

CHAIR - In relation to getting that type of evidence, would the best person be the chief of the intensivist ward or something like that?

Ms ROBERTSON - Yes.

CHAIR - Okay.

Ms ROBERTSON - And given that it is mostly physicians that talk at this stage, in that report it will show you who approached the patients each time and in a percentage of cases it was the family that approached the doctors, which is quite a positive thing really, so I would suggest talking to an intensivist, like the medical head of ICU, but I think the nursing side of ICU should be more heavily involved but I could be speaking out of turn because it is not my area of expertise.

CHAIR - It is still your belief?

Ms ROBERTSON - Yes, because I think it is the nurse who has the greatest rapport with the patient and if you are looking after someone for seven days straight then you are going to have developed a pretty good rapport with them.

Mrs RATTRAY-WAGNER - And the family as well.

Ms ROBERTSON - Yes, with the family.

Ms FORREST - Sue, in those sort of circumstances and particularly if the patient has just arrived basically and it seems that he is going to be a potential donor, because obviously the staff are very active in trying to save that person's life and do what they can, do you think it would be helpful to have someone who is specially trained to come in and assist with the relatives?

Ms ROBERTSON - Yes, and that is what a donor coordinator would do.

Ms FORREST - So you think that is important?

Ms ROBERTSON - Yes.

Ms FORREST - Do you think one person covering the whole State would be enough?

Ms ROBERTSON - Yes. There might be cases where two are happening at the same time but it would be unlikely and you still have the intensivists if there are two happening at the same time, but you can get someone within four hours within the State and they are not going to make a decision in four hours. You can keep someone ventilated for those extra four hours and that is not a problem, so I think that a statewide one would be absolutely appropriate.

Ms FORREST - If there was more than one at one time, they would most likely be in the same place anyway.

Ms ROBERTSON – Possibly, yes, from the same incident.

CHAIR - Sue, thanks very much for coming along and giving us your expertise.

THE WITNESS WITHDREW.

Mr MIRKO MARKOTA WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Wilkinson) - Thank you very much for coming along to speak with us today.

Mr MARKOTA - About 12 years ago I lost a kidney from amyloidosis. I was on perineal dialysis for four years and four years on haemodialysis. Four years ago I was lucky and received a kidney. I now feel a lot better and different. When you are tied to a machine for five-and-a-half hours it is not fun and when you get home you are tired. Now I feel normal, as I did 15 years ago. I can do a lot of things with the kids, sport and work. I have started working again. I know it is grief to someone who lost a kidney but it is a happiness to some other family, like it was to mine.

CHAIR - Can you give me a picture of your life on dialysis?

Mr MARKOTA - Life on dialysis is not very easy. You are tied for five hours on a machine every second day.

CHAIR - Where is the machine - at your place or at the hospital?

Mr MARKOTA - I was in the renal unit. I went to Launceston for four months and after pushing through and talking to the media we had the renal unit in Burnie, so I was three years at Burnie. Life on dialysis is not easy; it doesn't matter if you are young or old. Maybe it is harder on the younger ones.

CHAIR - Why is that? Because you have five hours every second day on dialysis?

Mr MARKOTA - Five hours with your blood going up and down. If you put on too much weight it would take too much off and make you very miserable and tired. You have to keep the level right so you cannot eat or drink what you want; you have to limit liquids. I was limited to half a litre a day. Twice in the fours years I put too much weight on and I fainted. When you take too much liquid off your blood pressure goes right down and you don't feel very well.

CHAIR - Are you married with children?

Mr MARKOTA - Yes, I have six children: one married, another one close to it, one in the army, one at uni and two girls in high school.

CHAIR - Did it affect your general lifestyle with them because of the tiredness you were feeling?

Mr MARKOTA - Yes, because you can't do what you want with your family. You are tired all the time; you don't feel very well and when you go out you want to go back home to sit down. It is not pleasant.

CHAIR - Does it put stresses on your family life?

Mr MARKOTA - Yes, a lot of stress. Why did it happen to me? Why not somebody else? Then you are going to the hospital and see other people and you think, 'It's all right. There are a lot of people worse than I am'.

CHAIR - Leading up to the transplant, obviously you didn't know when it was going to happen?

Mr MARKOTA - No, I was told it was from now to five years, and I was waiting eight years. I didn't think I would get it because eight years was too long. At 3 o'clock in the morning, I had the call from the doctor and he said, 'You have a kidney'. I said, 'Oh, you're bull-shitting'.

Laughter.

Mr MARKOTA - I said, 'It can't be'. It was Saturday morning and they said, 'We've booked your flight'.

CHAIR - So you got the phone call at 3 o'clock and went straight to Melbourne. Which hospital did you go to?

Mr MARKOTA - The Royal Melbourne. They were already waiting for me. As soon as I came through the door at the renal unit and told them my name they said, 'A bed is ready for you, and we have a few tests'. At 2 o'clock I was in theatre.

CHAIR - At 3 o'clock in the morning you received a call and at 2 o'clock that afternoon you were in theatre.

Mr MARKOTA - Yes, and I woke up at midnight.

CHAIR - Obviously there is the rehabilitation process that you have to go through after having the transplant; was that difficult?

Mr MARKOTA - Immediately I felt a lot different when I woke up from the anaesthetic. I saw a lot of tubes hanging from me and the nurse said, 'You're already passing urine'. I had never passed it for eight years. I said, 'It can't be', and they said, 'Yes'. On the second day I went to shower with help and the third day I went by myself.

Mrs RATTRAY-WAGNER - To the shower on the third day?

Mr MARKOTA - Yes, and in one week, the following Saturday, I went out. I had to stay months in Melbourne next to the hospital to check my blood every 24 hours. I had to go at 8 o'clock in the morning to check the blood. After months I came back home and every second day for two weeks I went to Launceston to see Dr Fassett and his assistant. That gradually became longer and longer and now I see him every three months to check my blood and things.

CHAIR - When did you start getting back to what you thought you were like prior to getting the illness?

Mr MARKOTA - When I came home from Melbourne I started to feel a lot better, and started feeling very normal in about a month.

CHAIR - How long did it take you to get back to work?

Mr MARKOTA - Twelve months after that I felt a lot better. I talked to my doctors and asked them if I could go back to work and they said 'Yes, if you wish', so I went. I never felt better, definitely. I know people are giving up and maybe if I did not have family I might have too. It was very hard staying on dialysis for so long.

Ms FORREST - Was there ever any discussion or consideration of a family member donating one of their kidneys for you?

Mr MARKOTA - Yes. My two sons went for a test but I was not really happy taking from the kids. If my other kids lost theirs I would push them to give one to the other.

Ms FORREST - How old were they at the time?

Mr MARKOTA - One was 18 but I was told they had to be 25 to be a donor.

Ms FORREST - The age of 25?

Mr MARKOTA - Yes, I think so.

Ms ROBERTSON - Eighteen is legal but the Royal Melbourne might impose their own age limit.

Mr MARKOTA - One boy was not compatible and one boy was about 40 per cent compatible, so I had to wait.

Ms FORREST - Is amyloidosis passed on in families? Are you worried about your children having it?

Mr MARKOTA - No; amyloidosis cannot be passed on to anybody. It is due to infection, stress or whatever. I had an infection in the leg and that is why my kidney failed. I cannot pass it on to any other member of the family. That is the one good thing.

Ms FORREST - It would have been an even more difficult situation if that was the case.

Mr MARKOTA - I asked about that straight away. I know exactly when my kidney started going downhill. It deteriorated slowly. I asked a lot of doctors and a lot of people, and checked the Internet to see whether it could be passed on to the next generation or not, but no, my sickness is not one that passes from generation to generation.

Ms FORREST - Do you think it has made you and your family perhaps more aware of organ donation and the importance of looking after the organs you have to start with, I guess?

Mr MARKOTA - Yes, my family was tested straight away, but the tissue was not compatible and that was why I had to wait so long. Someone else could get it a lot quicker than I did, but I had to wait a bit longer.

Ms FORREST - You had to wait eight years, which is a long time. If there were more organ donations available because people made their intentions known, do you think that would help?

Mr MARKOTA - Yes, because then there would be more organs available. In Australia I reckon there are about 2 000 - 3 000 people waiting on the list and not enough organs.

Ms FORREST - So how do you think we could encourage more people to be organ donors?

Mr MARKOTA - I reckon start talking to them and give them a bit more information about what is happening and how people feel. I know it is very hard for someone who has lost a family member to give that person's organ to someone else, you know, but that brings happiness to the other family. You can look at that either way.

Ms FORREST - So do you talk to people about it?

Mr MARKOTA - Yes, I talk; I am not hiding anything. I am talking all the time and I am not really keeping it to myself. I tell everybody who wants to know and I talk to the people who are on dialysis, how they are feeling and so on. I stress that it is a good thing donating organs to somebody else.

Ms FORREST - So do you think that as a result of your talking to other people out in the community, they are more likely to go and sign up?

Mr MARKOTA - Yes, I think some do. If you talk to them and they understand what you want and how you feel, you know -

Ms FORREST - Do you tell them how to register? Do you know how to register?

Mr MARKOTA - Yes, I know how to register, I tell them. After registration, you still have to get the family to sign the intention. There have to be more talks to the families - a lot of people are ticking a box on their licence, but that is not good enough.

Ms FORREST - So do you think the Medicare system where you register with Medicare is a good enough system? You have seen the way that Medicare -

Mr MARKOTA - If they are registered - just the registration is all right but you have to, I reckon, put it to the people to understand why it is good to donate something.

Ms FORREST - We need more education.

Mr MARKOTA - More education or more teaching directly or indirectly. I know that the renal unit people are doing those things, but is anybody else doing it - you know, approaching people and so on? I reckon it should be more open and even on the TV. I saw on TV the other day a lady from Hobart donating to an American and that was very nice; but definitely in Australia there is a lot of red tape to go through before you donate to somebody else. I think they should cut that red tape, you know.

Mrs RATTRAY-WAGNER - I think a lot of people would agree with you - too much red tape. It is our understanding that the lady from Hobart would have liked to donate within Australia, but it was not possible.

Mr MARKOTA - It was not possible because of too much red tape - that is what she said anyway - and I believe that there is. She gave her kidney to an American - good luck to the American citizen.

CHAIR - How did you feel, in your mind, after your received it? Did you have to have any counselling to accept the fact that you had somebody else's kidney inside your body?

Mr MARKOTA - Not really, no. I learnt a lot about donation before the event and I was really happy to receive it. I never needed counselling; I was already very knowledgeable about things. I know about injections and that you have to keep yourself in good health to keep them. I don't want to lose them.

Ms FORREST - Who and where did you get information from?

Mr MARKOTA - I got information from the doctor and now I get it from the Internet. Dr Fassett was very nice and he talked about it. I know a few doctors and they are lovely to talk to.

Ms FORREST - Did you talk to other people who had had kidney transplants?

Mr MARKOTA - Yes, but I never talked much. I know that with a few people their family donated and I talked to them. Like somebody else, I never actually met them. As soon as people get a kidney they don't come back - only to see the doctor. They don't want to go back. When you come back you feel different, when you see people attached to the machines. I was there for eight years.

Mrs RATTRAY-WAGNER - You're not involved in any organisation, any support group here?

Mr MARKOTA - No.

Mrs RATTRAY-WAGNER - Do you know if there is one locally?

Mr MARKOTA - There is one in Launceston but it was too far too travel. There have been a few people on dialysis in Burnie and we could start one.

Mrs RATTRAY-WAGNER - It would probably feel that you were having a little meeting when you are all together on your dialysis.

Mr MARKOTA - The renal staff are very nice to talk to, too.

CHAIR - Mirko, thank you very much for coming along and telling us your story, before and after.

THE WITNESS WITHDREW.

Ms PATRICIA TURNER WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Wilkinson) - Thanks for coming along, Patricia. I understand you wanted to read something out to us, and then we can take it into evidence.

Ms TURNER - Yes. I am an organ recipient. I had a double lung transplant and this is my point of view. I am against the proposal that people have to register that they do not wish to donate their organs. It paves the way for people who do not wish to donate to have their organs harvested. I had a double lung transplant three years ago and was on the waiting list three years before that. It is abhorrent to me to think that the lungs that I received were not voluntarily given. As it is, I am blessed to have received a gift from the donor and his family. An opt-out option could be overriden by the family anyway, as is the case with the driver's licence yes/no system. I ask why is this when the donor has made his intentions clear.

It is difficult for families of a deceased person to come to terms with brain death after people believing for thousands of years that death occurs when the heart stops. I felt the same. When I had my interview, after I was accepted, I said, 'Could the patient who is donating have the machine switched off, heart stop, bring them back to life?' - so that they did die and then have the organs taken out. That was not an option. What they do is switch it off momentarily and there is a reflex action that can tell whether the heart will start again or not. I was fairly happy with that, that they did test the heart to see whether it would start again. I became very incapacitated during my wait for a transplant and I was looked after wonderfully by the transplant team.

CHAIR - You are against the opt-out option, as I understand it, on the basis that you would feel uncomfortable knowing that you had some working lungs inside you that were donated by a person who may not voluntarily donated them?

Ms TURNER - Yes. There are people who probably couldn't really opt out themselves - someone alone or someone who couldn't cope with doing it.

Ms FORREST - Are you thinking of someone with, say, a mental incapacity who isn't able to make a decision?

Ms TURNER - Yes, maybe, or a person living a normal life who doesn't think about it or doesn't have family around to talk about it with.

Ms FORREST - Do you think that if there was a really good education program, from the school stage and through our lives, whether it was an advertising campaign for a week, a year or whatever, to raise awareness so people become more aware of it then it might be easier for people to make that choice?

Ms TURNER - I think the best thing to do is to find out what people have against it. What are they scared of when their family member died? What would make them not give consent? I am against having schoolchildren hassled about dying, it is not part of their life, or worry about sex before they are 12 years old. I think late high school is the time to educate them and raise it. I do not think young children should be subjected to it.

CHAIR - Did you have to have any counselling after the transplant to help you get used to the fact that some other person's organs were helping you to stay alive?

Ms TURNER - No. I waited so long and I was in touch with all the people involved.

CHAIR - Was that from here that you received assistance from North West Regional?

Ms TURNER - Yes, I saw specialists here every three months. The Alfred team came to Tasmania every three months and I saw them every three months. They monitored my condition from the time I was on it until the time I received my transplant. Even though it was for five minutes I had to go down to Hobart because they wanted to know what condition I was in. If people were sicker than I was they got the lung. I had a fairly unusual blood group and you had to go by your blood group, but if people were sicker than I was then they got the lung. Young people always had a lung, from what I gather. Young cystic fibrosis people never wanted for a lung, which is fair enough, because I was an older transplant. My condition got worse and worse.

CHAIR - What condition did you have?

Ms TURNER - I had emphysema, bronchitis and asthma.

CHAIR - The lungs you have now have you nearly back to normal?

Ms TURNER - Yes, nearly back to normal. I could do nothing and was going downhill. The carbon dioxide levels in my blood were rising. I staggered down to Hobart, they saw me and within two months I had a transplant. I got a phone call on Sunday afternoon and they flew me over in a small private plane. I had the transplant at 2 o'clock on 20 September 2004.

The way I have been treated has been wonderful. I haven't wanted for anything - and I haven't any money either. I am incredibly grateful for everything.

Mrs RATTRAY-WAGNER - You shouldn't have to rely on money.

Ms TURNER - I am in a country where that did not matter, which is a good thing.

CHAIR - Patricia, thank you very much for coming along and thanks for telling us your story.

THE WITNESS WITHDREW.

<u>SENATOR STEPHEN PARRY</u> WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Wilkinson) **-** Thank you for coming. We just want to have a brief overview and then we can start firing questions.

Senator PARRY - That sounds great. Thank you very much, Chair and Councillors. I want to address a couple of things but first of all qualify why I am here, apart from the fact that I am representing the people of Tasmania in one capacity. Some would know that I am a former funeral director and had a lot to do with organ donation and dealing with families who had donated organs and also dealing with the bodies after death, and there is a couple of issues I want to talk to about regarding that. Secondly, I was a lecturer in embalming and mortuary science and funeral service ethics around Australia so this came up on quite a few occasions there.

I also want to declare upfront that I am very supportive of organ donation and everything we can do to increase that awareness because of a number of issues which I will discuss.

I would like to table three documents. The first one I would like to table is a speech I gave in the Parliament on 7 February this year about organ donation to support Organ Donation Week. Secondly, I would like to table a Letter to the Editor in the *Advocate* newspaper and that was on 26 June this year and just again to follow up from organ donation in responding to other comments in the local newspaper, so I will not speak to those. The third document that I wish to table also I will speak to in a moment also.

One of the things I want to discuss is basically the perception that the community has about organ donation and how people think it arrived. I have canvassed people in public forums and private discussions over a number of years, most recently at the Liberal Party State Convention in Launceston a few months ago. I raised the matter on the floor and we debated the issue of the reversal of onus, having everyone accepted as an organ donor unless you indicate otherwise which, I understand, Chair, is a passionate part of your involvement in this.

CHAIR - We have had some interesting evidence in the last few days.

Senator PARRY - I am looking forward to reading some of it after the committee has presented the report.

I have discussed this a lot and there is overwhelming ignorance - people do not comprehend that less than 1 per cent of people are in a position to ever donate an organ. People think that if you die naturally in your sleep tonight and you are healthy, your organs can be harvested which, as you would now know, is totally incorrect. An education prong would have to be the first aspect, indicating to people that we need everyone to consent and do everything they possibly can to inform people in their family and people who will be making decisions post-death that it is such a rarity that you die in the right circumstances that your organs can be used for organ donation. I think that is the greatest ignorance within the community and if we can get that issue through first, I believe that is going to go a long way towards getting people to volunteer.

The second issue is the decision-making process. I am not familiar with the legislative aspects in each State - I also understand some acts in some States in relation to the governance of human tissue may affect organ donation - but generally most people are not aware of their legal rights in relation to organ donation. Your will is the last place you would put it because quite often, from a funeral director's perspective, the will is read after the body is in the ground, so it is absolutely too late to place it in a will. That is a useless avenue. The main thing is discussion, talking about it at home, talking about it with your loved ones. As Ruth would know, my kids and I have spoken openly over the last 20-odd years about what happens after any of us die and all of us know that all of us would be willing organ donors, which is the first hurdle. People have to make the decision currently as it exists in Tasmania and mostly elsewhere. It happens usually around the bedside of the person whose organs have been ventilated for the purposes of potential harvesting. I think that is a second issue in education, advising people exactly what happens at the time of death and who makes that decision. On your driver's licence is not the guarantee because if you haven't discussed it with mum and dad and it is on your driver's licence, mum and dad are most likely going to say no.

CHAIR - We have found out from information that all up there are about 174 000 people within Tasmania who have either expressed their intention or filled out the proper consent form. When you look at the proper consent form, there are about 24 000 who have filled that out, and the rest are on driver's licences or people have signed some intent to donate. That means that there are 150 out there who are willing and yet, because they haven't signed the consent form, they are not properly registered.

Senator PARRY - That is exactly right. And even if they have signed it and are registered, all that is is an indication to the next of kin. You can go through the whole process of filling in the forms and registering, but if your next of kin doesn't know and do not consent, it is a waste of time. I think that needs to be another strong avenue of education if there is no other change in legislation.

The final thing I want to address in my opening remarks is what happens to the body after death. Again, this is another misconception. People assume that the body is unsuitable for viewing and for other aspects post death. I will quote from Mr Peter Lyons - and I think he had a go at you, Chair - on 19 July this year. I will table it, but I want to read a salient point:

> 'When the proposal was first aired, a mature-aged friend of mine who has had extensive experience in hospitals and has even assisted in transplant operations was appalled.'

And this is referring to your statement about organ donation.

> 'Her contention was that the body, be it mother, father, sister, brother or whatever, does not belong to the State but is the precious possession of the family. She has seen bodies that have been virtually stripped internally and then filled out using paper and other items, including sawdust, and sewn up so they appear intact when ready for burial. This has been done in the interests of science as it has enabled doctors and nurses to actually "operate" on actual human organs.'

I was so incensed I did not write back to him straight away because it would have been a very terse letter. Look, this is the misconception that we have, and I will table that as well. That is the extract of that article. This is the problem we have: people assume that the body is going to be unsuitable for a viewing, which is a very important phase after any death, and especially when the death has been more sudden and more traumatic. Where organ donation is consented to, it is usually in a case of a death that has been more traumatic or sudden.

Just to be put clearly on the record, human bodies, after organ harvesting, are totally rendered normal again by qualified funeral directors. In fact it is easier to prepare a body after organ harvesting than it is after a full autopsy for forensic purposes because there has been no cranial invasion and that makes the job a little easier. The body itself will retain shape and there is no sawdust, sand or newspaper or anything placed into the human cavities after the harvesting operation. It is simply like an autopsy where there is an incision - a high thoracic - through the low abdominal and the rib cage is cut, as it would normally be in an autopsy, the organs are removed and then the body is usually resutured. If we have to treat the body we have to unsuture and arterially inject the body from the internal cavities. But that presents no problem to body preparation at all so I think families need to understand that there are no huge gaps and that you are not going to see a sunken chest. There are many different myths that I constantly dispel when I am talking to people about it.

So with those few words, that is all I wish to say in the opening remarks. In summing up, I think education needs to be really stepped up and more factual to highlight the things I mentioned earlier. In relation to being a presumed donor, my feeling in Tasmania is that most people are against having a legislative presumption that you are an organ donor unless you have formally indicated otherwise. I do not see our changing that - that is my feeling of the perception of the mood of the people of Tasmania but -

CHAIR - That is the evidence you are getting.

Senator PARRY - Yes, and I am probably of the opinion that I would not mind it being compulsory unless you indicate otherwise, but I think we would have to respect the wishes in that sense. I am not strongly of that opinion, but that would have eased our situation because I can only see the benefit and the value; others see the fear and mystique. Maybe after we have overcome the fear and the mystique of it all, we might be able to run that again.

So Chair and councillors, that is my brief evidence and I am very happy to answer any questions.

CHAIR - Thank you, do you write back to Peter in the end?

Senator PARRY - No.

Laughter.

Senator PARRY - It has required a lengthy dissertation and I wanted it to get out and into the public arena as well but it was too hard - too complex to do. You need to engage people, eye-to-eye, when you talk about these issues, I think, rather than write because people will turn off if it gets too nasty or ghoulish in that sense.

CHAIR - You must have spoken with some people in your time, Steve, in your position - both now and also before politics - who have experienced their loved ones dying. Have you ever spoken with anybody who has agreed to their family or one of their family donating their organs and those organs having been donated?

Senator PARRY - Definitely. I have dealt on a personal basis with six families in Tasmania who have had organs harvested from a family member after death. In all of those cases the donors were young people - when I say young, probably sub-50; only one was over 50 - and they all died in the circumstances where they were basically hospitalised, brain dead and then organ oxygenated. All of the families, without exception, have felt a great sense of worth about their loved ones' organs being donated.

The maximum number of organs utilised in any one of those, I think, was five, so that is five individuals who have benefited from one person's death. Simon and Ruth would aware of some of the families - I do not want to place their names on record - but some of them here locally have been willing participants in speaking in favour of organ donation.

There is a strong protocol, as you would probably be aware, governing the making of contact with recipients and, if protocols can be met, some have been in touch and some have received letters back anonymously. It is a great feeling of wellbeing after that has taken place so the death has not been totally in vain and I have seen just positive healing. I have not seen a family grieving in any negative or difficult way because or organ donation.

In north-west Tasmania in the last 25 years that I have been involved in the funeral industry up until today, only eight families have had organ donations. Just so you are aware what usually happens, the body has either been here or down at the old hospital and the organ team will usually fly in from Victoria in the evening; they harvest the organs - the ventilation equipment is switched off during that process obviously - and the organs are whisked straight back across by charter with the team and they are distributed around the country - or indeed in Tasmania, if that is the case.

Ms FORREST - Does the body normally go from the theatre to the morgue?

Senator PARRY - Yes.

Ms FORREST - The next time that the family see the body is usually -

Senator PARRY - After we have prepared it. Generally, the family say goodbye within the context of the intensive care unit or the operating suite and the body is still intact. Once the harvesting team move in they then do what they have to do and the family have no further contact until after we have attended to preparing the body.

CHAIR - Those families have seen the body after the organs have been retrieved?

Senator PARRY - Yes. In fact in one case probably about 80 or 90 people viewed the body of one young fellow with the family's permission. The family were very happy with that.

CHAIR - So the misconception that was in the paper was wrong again?

Senator PARRY - Yes, rubbish. I do not even know where that comes from. There is a mixture of scientific donation, which is totally different to organ donation, within this article and the article has been written, in my view, based upon ignorance. There is no thorough research in that at all.

CHAIR - With the education, what type of thing do you think is needed to educate?

Senator PARRY - It has to start at school, like a lot of things have to start at school. Do not ask me to give you a list of what you should do, but on this particular topic it has to start at school at an age where comprehension of these issues is important. I think grade 10 or thereabouts and that needs to be the first issue, amongst a number of life issues that need to be discussed at school. This is one of those life issues. I have been involved in talking to grade 6 and grades 10 and 11 and 12 mixes over a period of 20-odd years and this topic will come up and I am always keen to talk about it when they ask. I do not introduce it because that has never been part of the mandate of when I have been asked to go to schools to address schools on issues about bereavement, but when it does come up I am very happy to talk about it and the kids engage. They want to know.

I think that is where it has to start and then it just has to be a community awareness program generally across every age band in every possible way we can do that. We are having people who are dying in the right circumstances and consent is not forthcoming and that is the concern.

Ms FORREST - Is that because the families are not consenting or it was not considered?

Senator PARRY - I think it is a combination of two things. I think the families obviously are not consenting because they do not know. 'We don't know whether Jimmy would like this or not. We're not sure. It's too hard and too complicated. We will have to say no'.

CHAIR - He has gone through enough.

Sen. PARRY - Exactly and/or there are strong emotional and psychological issues of 'Our son has died but there is a person out there walking around with his heart'. I do not want to get on to the recipient side, but that is a big issue for the recipients walking around with someone else's heart knowing the circumstances of death. So there is some of that. There are some people who do not think they can cope with that and that is a legitimate reason if they maintain that that is going to make their life unbearable. But the main issue is that they have never discussed it at the level that they should have discussed it - around the dinner table. We were talking about prepaid funerals earlier, before we came in - a lot of people do not talk about prearranging or what they want to do when they die and you get to the situation where I go to a family home and families will say, 'We don't know whether dad wanted to be cremated or buried'. That is the first hurdle, but if it had been discussed four years ago or yesterday or whenever, there is a great comfort knowing 'Dad wanted to be buried so let's bury dad' and there is a big comfort and you know you are making the right decision.

Likewise, dad wanted his organs donated, our son wanted his organs donated so then it is a huge burden off your shoulders knowing you are complying with a dead man's wish. That is still a very strong issue in society today; you do not want to do anything against the wishes of a person who has just died. The first issue really is the lack of consent or known consent from the potential donor by the people who are left to make the decision. Secondly, it has to be made in a time of great emotional upheaval, stress, rushed, in the hospital setting, so it is very difficult for them to make that decision.

Ms FORREST - Do you think that we are missing some who are potential donors because the medical nursing staff do not consider it, particularly because it is a fairly rare event?

Senator PARRY - That could be a case, Ruth. I could not comment and say, 'Yes, I know of case A, B, C and D'. I am not aware of them but that would not surprise me. I am aware of some people who have died and organ donation was a potential but it did not happen because of those circumstances. They were not sure whether he or she would have liked their organs donated - and the pressure of making a decision at a very difficult time in life. It is a combination of the two reasons.

Ms FORREST - As far as getting consent, education is the first thing probably, so you have to have some sort of form that makes it easy for people to do. We have the Medicare avenue at the moment. Do you think that could be better? Do you think there is another way that it could be done? Do you think we should be looking at advance directives because that does not cover organ just donation? That can cover whatever else you want or do not want.

Senator PARRY - Perhaps you do what some nursing homes do now. When you sign up to a nursing home you have to say, 'In the event of my death please call Joe Blogg's funeral directors'. When people are admitted to hospital you might say, 'In the event of my death' - because there would be circumstances within the hospital environment where this would happen - 'I do wish to have my organs donated and I have discussed it with my next of kin'. That might be the only way on a formal, procedural basis within the hospital environment to gain additional organ donation. I still maintain that it comes back to education and discussion, I think. You have to discuss it with your next of kin well prior to any event, when you are fit and healthy and when none of this is around.

Ms FORREST - I am not of the stats -

Senator PARRY - There are some statistics in my speech that I have tabled about our rates compared to other rates around the world.

Ms FORREST - I guess it is how and where people die. The majority of people who come into ICU are obviously critically ill from a car crash, a stroke or whatever. They are treated for four or five days before they die - or do most come in and the decision is that they are brain dead on arrival or soon afterwards? That is where the difficulty is, I guess, because these are the ones most likely to be good candidates for donation but they are not going to be able to sign anything.

Senator PARRY - No, it is the next of kin who make the decision.

Ms FORREST - So the next of kin would have to sign that piece of paper?

Senator PARRY - Absolutely, but if the next of kin knew that there was a consent prior to the eventuality then I think that is the first basis. That would just relieve so much pressure on the next of kin, knowing that 'My son said he was very happy to be an organ donor'.

Ms FORREST - If it were my son who was critically injured and unconscious, I came into the hospital soon after he arrived and they asked me to sign a form saying that I am happy to have his organs donated, but he is not dead yet -

Senator PARRY - It is difficult. You are going to feel terrible whenever this happens.

Ms FORREST - As a nursing staff member, I would be reluctant to hand that form to the parent.

Senator PARRY - Even after death, or when the person is in a clinically dead situation but with oxygenated organs, that is another time to do that but you hang on until the last minute - 'Don't talk to me about that now. I don't want to discuss it. That's the last thing we want to think about'. It is a very awkward time and it has to be handled sensitively by staff, which I know it has been in the past. There may be a reluctance on the part of some staff in some hospitals to approach a family at a critical part in that process but I have no direct evidence of that.

Getting back to the mode of how the eventuality of death arrives, only having dealt with six or so, two have been attempted suicides and were under manual resuscitation upon arrival at the hospital and died shortly thereafter or after the resuscitation has ceased. Two have been in hospital in a critical condition - both from accidents. I cannot recall the other two over a 20-odd year period. That gives you an idea; there is not a lot of scope. If we had hundreds we could say, 'This is the most common entry route'. Thankfully it is not a common occurrence but we have to make every occurrence count; that is the bottom line.

CHAIR - Steve, have you ever been a party to conversations within the family in relation to organ donation from a person who is in hospital, critically injured and has every likelihood of dying?

Senator PARRY - Yes, I have on one occasion that I can vividly remember. It was discussed in a very pragmatic way - 'This is a very useful and important thing to do'. That was the basis of the discussion.

CHAIR - How did it come about? Did the nurses or the doctor come to the family and say, 'This is the situation; there's no likelihood that she or he is going to be resuscitated. He's brain dead'.

Senator PARRY - I cannot recall how the decision or information was imparted to the family because I was involved prior to their making the decision and prior to the ventilation equipment being switched off and the harvesting team coming in. That was only a few hours beforehand, but they were a very resolute, strong family. They are still here and still in this community and they have had no adverse effects from that. They were obviously asked before they left the hospital and went home to consider before they went back.

CHAIR - How long did it take for them to make a decision?

Senator PARRY - Within hours; it wasn't a day or half a day.

CHAIR - Did they struggle over any particular point, such as, 'I don't know whether I can live with the fact that another person might be walking around with his kidneys or lungs'?

Senator PARRY - No. I cannot remember the conversation within that family context, but I am aware of other people who have been organ recipients in other families whom I have dealt with and they have spoken to me about it since. In that particular case, no, I do not think that was an issue raised - but I know it is of concern.

CHAIR - So the major thrust of their decision-making was, 'We believe it is an appropriate thing to do; we believe it's going to give real assistance to keep alive others and therefore we will do it.'

Senator PARRY - Correct - and a purpose and a value for a life taken so young; I think that was an added thrust.

Mr HARRISS - I have no questions, just an observation which appears to be coming through consistently with various witnesses. It's a personal choice - you refer to 'harvesting' and our report will refer to 'retrieval'.

Senator PARRY - Yes, a much better word.

Mr HARRISS - It is, and I think that can go a long way to communicating a sensitive and soft message.

Senator PARRY - I have adopted the medical terminology because when you move within a system, particularly a system such as this, you used the terminology of the day. I would endorse that. I think 'harvesting' is a fairly harsh term, albeit technical. It would be nice to find something even softer than 'retrieval', but retrieval is one step better.

Ms FORREST - I think the term 'harvesting' is also linked with the black market and organ trading. If you read any articles, 'harvesting' is the term that is always used in connection with the black market.

Senator PARRY - There is another protocol which I know organ donation teams adhere to. If the organ is not utilised or it becomes unsuitable because of longevity out of the body or because of transportation issues, then the organ cannot be just disposed of or utilised for any other means without going back to the family for further consent. I think that is another important issue to come across in the education process. People think, 'Are they going to end up in China or Africa'.

Ms FORREST - Or in the rubbish.

Senator PARRY - Or in the rubbish; yes, just discarded.

CHAIR - What does normally happen with those organs that cannot be used for whatever reason?

Senator PARRY - I think they are being used for research purposes, but with the consent of family. We have had one case - I don't think it was through organ donation - where an organ was returned to us from pathology because the family refused to allow the organ to be utilised for whatever purpose it was going to be utilised for after an autopsy. We had to exhume the body and replace the organ into the correct cavity and re-bury the body, at government expense. I think that would probably be going a bit too far when you have consented for organ donation, but that would be a possibility. The organ could be cremated or re-buried - even buried in the same grave above the coffin. That is not an issue either. There would be many practical solutions to organs not being used other than for the specific donation purpose.

CHAIR - Can I run you quickly through the terms of reference?

Senator PARRY - Yes. I know I haven't addressed them completely.

CHAIR - No, you have because you have touched on them as we have been going through. The first one is whether the present systems established within Tasmania and Australia that enable a person to register a legally, valid consent to become an organ donor are adequate. It would seem in summary that you would be saying, 'No, they're not adequate because there is not enough education and therefore people really don't know what to do'. Is that a fair summation?

Senator PARRY - I think the words 'the present systems established' is correct; it is not adequate. We certainly need to increase that, in particular the awareness campaign.

Ms FORREST - Just going one step further, Stephen, it says on the form that you get from Medicare, 'I have discussed this decision with my family, partner or friend'. Do you think there is any value in getting a family member to sign it, saying you are next of kin? You would think if someone is willing to sign it, they would have at least discussed it and that would be an indication that they are not just saying that.

Senator PARRY - I think it is excellent that that dot point is even on there. That is brilliant. I wasn't aware of that. I would have no problem with that, getting someone else to sign it. But then are you going to turn people off? I went to register a long time ago and I didn't have my Medicare number, so I didn't bother doing it. It doesn't really matter anyway because, quite frankly, I think this is a waste of time. Unless your family is going to consent, unless legislation changes, that is really saying, 'Okay, I consent to have my name on the list'. It might sway your family by them saying, 'Oh yes, he has put his name on the organ donor list so he must have agreed'.

Ms FORREST - But if a next of kin had to sign this as well, you would think that at least they would know what they were signing.

Senator PARRY - I think you might tend to turn people away from registering. That would be my only concern because it is very private. They don't want to rush out and say, 'I'm an organ donor' and run around and tell everyone. Especially kids not wanting to tell their parents necessarily, unless it is discussed in the right environment at home. I don't know. My gut feeling would be you would deter some from doing it and make it one step more complicated. I think that should be bolder, that 'I have discussed this decision'. That is probably as far as you could push that.

CHAIR - We can only get those at Medicare. Shouldn't we be able to get them at other places - Service Tasmania et cetera?

Senator PARRY - You can download them, and I think everyone is capable of downloading nowadays. The target audience for this would be the younger people who are more Internet savvy.

Ms FORREST - But if you have brochures in uni cafes and things like that, they might say, 'Oh, I hadn't really thought about that'. They may need something to jolt them and then they can go to the web site. They may need some sort of a trigger. Why would you go to the Medicare web site as an 18-year-old?

Senator PARRY - No, you wouldn't unless you specifically went for that purpose. I think wider distribution would certainly achieve a greater registration.

CHAIR - What about term of reference 2: the adequacy of Tasmania's approach in identifying potential donors and facilitating the donation and procurement process?

Senator PARRY - Well, everyone is a potential donor. I don't think we can do better - we have identified them all. The facilitation of the procurement process really comes back to consent. Whether it be within the ambulance system, the hospital emergency and intensive care and high-dependency sections, provided there is knowledge there that when these circumstances present family need to be offered the opportunity for their next-of-kin to become a donor, that is about the only improvement that could be made. But my understanding is the awareness is fairly high within that regime but I do not have any direct evidence that it is not. That would be the only thing I could think of.

Ms FORREST - There have been some suggestions from other witnesses that a State-based coordinator for the organ donations might help to educate the nursing and medical staff. We only have a few a year. As an ICU nurse, you might never see it.

Senator PARRY - Yes, exactly.

Ms FORREST - A State-based coordinator, whether it be one for the whole State or two part-timers or whatever, could educate staff, the public, schoolkids – whatever.

Senator PARRY - Yes, I think that would a good idea. I think a full-time education officer or coordinator would be great to do exactly that, starting at the key aspects of ambulance, critical care areas and then a wider community education program. You could occupy a full-time person doing that quite easily.

Ms FORREST - The other comment about that person is that person could actually be the person who is called to assist the families at the time because they would have a lot of knowledge and they could answer their questions with a fairly sensitive approach. We all know that some people, under stress, do not always do things well.

Senator PARRY - Correct, and it is nearly a semi-chaplaincy role as well as many others. You would have to have a knowledge of things like what happens after death, to answer all those questions at a critical moment. I think that would be ideal, without wishing to micro-manage or get into detail but you would probably need two working part-time so you would have relief. You would not want one person on call 24 hours a day, seven days a week. You have to have someone available 24/7 to go anywhere within the State or to any of the major hospitals within the State, whether that be three or four I will not debate today.

Laughter.

CHAIR - We have touched on three and five. Regarding the impact that uncertainty amongst family members regarding an individual's donation wishes has on their decision, we have touched on that. You would be saying that if the families do not know, they often do not want to visit the decision because of what they have just been through.

Senator PARRY - Yes. Again, I think it comes back to education, it comes back to who talks to the family at the time and the family's own beliefs and understanding. The more ignorant that people are, the harder this issue is going to be so I go back to my opening remarks of the education on two fronts.

CHAIR - Are there any other questions?

Mrs RATTRAY-WAGNER – No. I think the member for Murchison grilled him fairly well.

Laughter.

Mrs RATTRAY-WAGNER - It was interesting from a personal perspective. I had quite often wondered about the viewing of a body afterwards so I am really enlightened by that. I can actually talk about it to other people now because I know.

Senator PARRY - Even with eyes - that is a fairly important part and I did not touch upon that - if there is a corneal donation or any other form, even sometimes the whole eye might be taken for a particular reason, that still will not preclude viewing because with the techniques, the qualifications of embalmers, in particular, you can restore the body so that the eye looks normal.

Mrs RATTRAY-WAGNER - That is really significant information that we have obtained out of that.

Senator PARRY - Myth busters, that is what it seems to be, yes.

Ms FORREST - But it is also almost like a superstitious thing that if you talk about dying you might die.

Senator PARRY - Correct, yes.

Ms FORREST - It is a bit like prepaid funerals.

Senator PARRY - Yes.

Ms FORREST - If I go and prepay my funeral, does that mean that I am going to die next week? Kids probably think that a bit until they realise what it is all about so, again, you have to come back to educating people about what it is about and why we need to talk about it now rather than waiting until you are dead, obviously.

Mrs RATTRAY-WAGNER - But yet we take out car insurance and life insurance, and we think nothing of it - house insurance, all those things.

Senator PARRY - Talking about death, it is deeper and there is the spiritual aspect, there is a strong emotional aspect, and talking about it with either your parents or your children is difficult because you are talking about an eventuality that you are not looking forward to in any way, shape or form. So it is a hard one to broach and I think that is part of it, Ruth, that people are reluctant to discuss.

Ms FORREST - It reminds you of your mortality and we all like to think, 'I'm immortal'.

Senator PARRY - Correct, yes, in a very poignant way.

Ms FORREST - Unfortunately none of us is.

Senator PARRY - I turn it around occasionally and I say, 'If you don't discuss your funeral you might die and things might not go the way you want them. If you're insured nothing will happen but if you're not insured things will happen'. It seems to be one of those Murphy's laws now; you cannot throw them to any scientific analysis but that is how I view it.

CHAIR - Steve, I would like to thank you for coming in and giving your submission, which was more than helpful, thanks.

Senator PARRY - Thank you for the opportunity. I think it is a very worthwhile thing you are doing as you are raising the awareness by merely holding this inquiry. I am very keen to see your final submission.

CHAIR - The Commonwealth is having a look as well, as you probably know. They are, I believe, going to come back with some conclusions and recommendations in December and it would seem a pity to go off on a tangent to them because it should be dovetailed as much as possible. The committee will wait and see what they arrive at and then proceed from there, so hopefully we can built on what has already been done.

Senator PARRY - Well done. Thank you.

THE WITNESS WITHDREW.

Ms JACQUALINE WATCHMAN WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Wilkinson) - This is an informal gathering to get your views in relation to organ donation to assist us with making recommendations. We will allow you to start and then ask some questions, if appropriate. It is being transcribed which means that what you say is going to be taken down. If there is something that is a bit precious to you that you do not feel you can say openly, that you would rather keep to within the committee, please let us know and we can have that in camera, as it is called, so it is just between you and the committee. We have you listed from between three o'clock and 3.30 p.m.. Do not feel that you have to watch the clock all the time.

Ms WATCHMAN - I feel very honoured to be asked to come and speak to you. It is something that I have been very aware of for a long time. I worked in Canberra hospital as a nursing aide, became a registered nursing aide and I have worked looking after people. Then I joined the Victorian Police Force and death then became quite a reality in another way. We all think we are immortal and you suddenly turn 60 and you think, 'Oh my goodness'. It is something that I have read up on a lot. I lost my sister to cancer. She was only 36 and she had five children. We talked about that a lot a long time ago. I know it started in about 1954. I think today there could be more done and more people informed about both life and deceased donor organs. I really hope that Australia gets behind it and we are able to find the way to do it.

We go back to people who are suddenly struck with a terminal illness, and that happens to young people. I met a young man at the airport two weeks ago and he has bone cancer. He shared part of his life with me and I think for young people to have to face that is quite difficult when they have young brothers and sisters, and mum and dad are still alive. Once they are on that journey often it become quite educational for all the people involved in the family.

CHAIR - We will go through the terms of reference one by one.

Ms WATCHMAN - I think people have to give consent after the person is deceased. There has to be something else that could perhaps be put in place so that when the person is alive there is something for the family - a document or something - so that they know your wishes. Say I go home today and something happens, my family do know my wishes, but that is not the case with many people. You certainly aren't expecting that to happen, so perhaps there could be some document so that when you do your will it could be done at the same time so that you could state what your wishes are.

CHAIR - Do you realise there is already a form that you can collect at Medicare?

Ms WATCHMAN - Yes, I do, but a lot of people still don't know.

CHAIR - Should you be able to access those from other areas?

Ms WATCHMAN - Yes. Today we have the Internet and there is some great information on there if you look at the sites - organ donation et cetera. With the Internet and SMS messaging, if the Government could see it could be done that way you would reach a much wider group of people.

Ms FORREST - Are you talking about educating people that way or getting consent?

Ms WATCHMAN - Both. I think the Internet is a pretty special place to be able to do that. All our young people are very au fait with it, very IT-literate. SMS messages can be sent, as they are for other things, without it being offensive - 'Have you ever thought about this?'

Ms FORREST - So you're not suggesting they give consent with an SMS?

Ms WATCHMAN - No, just to highlight to people that there is a need, that people are waiting, or if something happens to little children.

CHAIR - So podcasts?

Ms WATCHMAN - Yes. It is becoming such a big thing now and it has happened fast.

CHAIR - What about the second term of reference - the adequacy of Tasmania's approach in identifying potential donors and facilitating their donation?

Ms WATCHMAN - I haven't worked inside the hospitals here so I don't know. What I have put in my statement is that I do know that staff are extremely stressed in their work cases in all the hospitals. They are working double shifts. People have to wait a long time and unless they are on a medical or surgical ward and their wishes are known, the staff literally don't have time to talk about those things. Every time I go in they are so busy delivering services, so there just isn't time. We have such a diverse cultural mix in Australia. Unless it is directly talked about among all the professionals in the hospitals, then the doctors who come to work here from overseas may not quite understand what our law is here. It varies in every country. Some of them might be able to contribute in a very positive way from what they have experienced but, once again, there is no time. They are flat out trying to deliver the service.

CHAIR - What about medical education for doctors and nurses?

Ms WATCHMAN - I would hope that that is delivered in a really big way.

CHAIR - Was it delivered to you at all?

Ms WATCHMAN - No. I found out everything myself. Schools could broach this in the senior grades, certainly in high school, because children have to deal with death in a high school, even in primary school but particularly in high school, and I think they are very sensible. They are able to be talked to by the right team of people. They are getting their licences at high school, they are driving cars in years 11 and 12, so I think it is all very important.

CHAIR - What about in the police force?

Ms WATCHMAN - I actually got to see lots of babies born in Canberra hospital and then you get to see people at the other end. You come in the same way and we all leave the same way. It is tragic when you see someone who was asphyxiated in a truck. You think, 'What an awful waste', particularly now that we have the opportunity to do so much with tissues, corneas and everything else. You could educate the truckies and various groups; there is a huge potential.

Ms FORREST - The issue with someone who suicides is that they are generally not found soon enough to donate organs.

Ms WATCHMAN - Yes, that is really hard because they are usually deceased.

Ms FORREST - And most people when they do that sort of thing go away somewhere private to do it.

Ms WATCHMAN - They still cannot take any tissue at all from those people?

Ms FORREST - It depends. Corneas maybe, but it depends on how long. Often those people are found considerably later.

Ms WATCHMAN - I understand; that is difficult. To put people in the ICU if they want to donate is really a consideration. Even if it is one bed I think it is very worthwhile to do that. I watched a little girl being given her liver last week on TV. Somebody had just decided to give a part of their lobes and I think that is just magic. In five days she was really well. Although she has problems to face it is something that would not normally have happened to her.

Ms FORREST - That was a live donor.

Ms WATCHMAN - Yes. The media has been doing some good stories. There was one in this morning. I just happened to put it on while I was having my cup of tea. There was a very well known athlete and she has had live tissue donation for her knee. She said she had three options and she took the third one because she wants to win the gold next year. She said her coach was very opposed to it. They showed her knee and she is going well. I think it is four months and she is breaking the barriers and she is getting back to where she wants to be. It is fantastic that you can do that today. If she had not been talked to and it had not been explained to her she perhaps would not have known. She said, 'Now I would like to tell everybody out there that as a result all my family are now organ donors. We've all put our name down'.

CHAIR - This was for what?

Ms WATCHMAN - She had a terrible problem with her knee.

CHAIR - What are the impediments, if any, causing Tasmanians to have the lowest organ donor rates in the nation?

Ms WATCHMAN - I really do not know. I have lived in this State for six years and it is a unique culture of people. They are a caring and close people. I really do not know whether it is spiritual or whatever.

CHAIR - I can indicate that people who have signed a consent form by ticking it on the licence comes to around about 174 000 people, which is an extremely good percentage -

Ms WATCHMAN - Yes, that is.

CHAIR - but the consent form has only 24 000, so we are missing out on the 150 000 balance between ticking the licence and actually making the effort to sign the consent form, because they do not know about it.

Ms WATCHMAN - That possibly is the loophole. Put it out there and really broadcast it. There are all different ways to get that message across, and not just with the ads or the campaigns. I think the human approach and the stories are very important because once people know, they all talk. It is a very close community and they talk.

CHAIR - Have you talked to any family members that have either had a family member donating or, alternatively, family members or siblings within the family, themselves?

Ms WATCHMAN - My own daughter - she cannot have any more children - decided last year to donate eggs so that is like organ donation. She thought, 'What a waste'. She is 34, so she decided to do that for a couple in Sydney and went through IVF in Sydney. They would never have had children. This is an older couple and the grandparents have a little grand-daughter. She was born this year. There are two frozen embryos that she will give to science or to stem cell research and it is really quite special.

So, from that perceptive, there are things you can give. We have talked about what our wishes are if something ever happened to any of us. I know that children are a separate identity and what has to happen there but all those things today are significant. Even 10 years ago I had a very different view about it but reading and keeping up with it and seeing technology advance and the teams that put so much care and compassion into it, it is all part of the big picture.

CHAIR - For an education program or promotional program, what do you believe would be the most effective?

Ms WATCHMAN - I have watched various things be delivered and I do think the media is the best way, but it is how it is done. It is the concept, that people think, 'What are they going to do when the body goes through there?'. That part is very sensitive for people and I think that if you get a great team of people, you get all the right doctors and the staff that do that work, you could do a really good job and that you could work in with television, radio and newspapers. But the media that do the stories - the human stories - are probably the most effective.

I watched a policeman in Sydney who just lost his life after six months. They found a donor and it was too late. He was in intensive care for six months and you think, 'Oh, he has little children'. I am sure that those sorts of stories would be very helpful.

CHAIR - Tell me if I am wrong, but when you said 'goes through there', are you talking about in the funeral parlour when you see the coffin go behind the curtains?

Ms WATCHMAN - Yes.

CHAIR - Are you saying that you could have an advertisement showing that and then on the other side you could have an advertisement showing the family playing with their children, gong about their normal everyday life?

Ms WATCHMAN - Yes. I think that if you got an advertising person who is very sensitive to this together with the funeral director - a whole team of people - you could do a really good job. I believe it is possible. We have such extremely realistic TV today that there aren't a lot of things that people do not see at the right time slots. Yes, I do believe that some people never face their mortality and never face death but for other people who become informed, it is a huge journey for them - they talk about it.

Mrs RATTRAY-WAGNER - Jaqualine, it has been suggested that it would probably be a fairly useful thing to have a specified organ donation day. We are aware that there is a week but, unfortunately, a lot of people are not aware of the week, so perhaps we could have a day as we have done with the cancer day, the breast cancer day, the police day and that type of thing. Do you think that would be fairly valuable?

Ms WATCHMAN - Yes, I do and you have to get all the media in the State to get right behind you and do it. Make it more a celebration. Tracey Wickham's daughter has been buried at the Sunshine Coast. She passed away with cancer and her mum is going to make something positive out of the negative, and I think that is the way. I think it could be really good.

CHAIR - Thank you very much, Jaqualine, that was very informative.

THE WITNESS WITHDREW.

Mr JOHN YEATS AND **Mrs JANE YEATS** WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR (Mr Wilkinson) - John and Jane, thank you very much for coming along and being prepared to give us some evidence in relation to the select committee's investigation into organ donation. As you have probably heard me say, it is transcribed and therefore anything you say will be taken down unless you say to us that there a couple of things that you want to say in private and then we can arrange for that. What we normally do is give you the ability to give your presentation in 10 or so minutes and then we can ask you some questions.

Mr YEATS - The first thing I would like to do, if I might, is to congratulate you because I had so many things I wanted to say in the past hour but I managed to shut up so you have done a very good job of keeping me quiet.

Laughter.

Mr YEATS - I wandered outside when Stephen finished his submission to congratulate him on what he had to say, and I speak as a donor family and as a person that is currently waiting for a lung transplant. I have been associated with the Alfred Hospital Transplant Unit for just over four years now and I can totally concur with everything Stephen had to say. He was a mouthpiece for me and you had better believe that everything he said was absolutely spot-on in every respect. That is the first thing I want to say.

Do you want to hear the story so far as a donor family is concerned? A lot of things were brought up when you were speaking -

CHAIR - That would be good thanks, John, because I know Rudie Sypkes suggested -

Mr YEATS - We are meeting with Rudie in about two weeks' time.

CHAIR - we make contact with you. As he said, you tragically lost a daughter at the age of 18 in a car accident and you lost a son and you are awaiting a lung transplant. You donated an organ six years ago, is that right?

Mr YEATS - Our son, David, and that was 13 years ago. He donated organs. He died from a disease known as Marfan Syndrome. In very simple layman's terms, Marfan Syndome is one whereby the body grows but the internal organs and the arteries and one thing and another do not. At 13 David was 6 feet 7 inches. Unfortunately the internal organs and arteries did not keep up with that spurt of growth and as a result he was 20 when the phone call came through one night that the main artery to his brain had just literally pulled off like a hose from a tap. He would have been dead within moments, I would say. That is how we became involved with the donor situation.

Mrs YEATS - We were confronted with the situation that Stephen was discussing with you at the hospital.

Ms FORREST - You son was in hospital at the time when that happened?

Mr YEATS - If you would like me to tell you the story, then you can ask me questions. But I hope you will not ask me similar questions to those that you asked of Stephen. Strangely enough, it was Friday 13 January 1995 when we received the call. I might add at this stage that it was from my ex-wife - Jane and I had been together for 120 years or something but David was the second son with my first wife. Janette rang us up at I think just after midnight on Friday 13 December 1995. We were living in the Blue Mountains outside of Sydney at the time. She said, 'I think you'd better come down to the Nepean Hospital. David's in hospital and things aren't real good'. I can remember asking, 'When you say "not real good", what does that mean?' and she said, 'It means it's as bad as it gets'. I thought, 'What's going on?' We got straight in the car and drove down the mountains, which took roughly an hour, to get to the Nepean Hospital. At that stage he was on life support in the ICU. People were running around everywhere and we were in a state of shock anyway, but I realised before too long that David was no longer with us. Even though the nurses and sisters there at the time wouldn't say exactly that, I did manage to find one who said, 'Things are real bad. He won't be coming back'. I suppose we were in the hospital for half an hour or maybe an hour when we were approached. He was on life support and virtually brain dead at that point in time. You can imagine that with the main artery to your brain not providing blood to the brain, you wouldn't survive very long. At this stage I have to compliment the way in which we were approached by, I think it was a doctor in charge of ICU and one or the nursing sisters. It was done in a very compassionate, delicate, sensitive way. Prior to this we had never given thought to organ donation because like a typical Australian, it happens to everybody else; it never happens to me. It is like to road deaths; it is never going to happen to my kids. Well, we have had both.

They approached us in a very tasteful way. They explained to us the procedure, what brain death meant, how they checked there was brain death, and we had absolutely no hesitation in donating organs. To this day, I am very glad we did because it really cushions the blow. As Stephen said, you get a great feel of worth from the way it does soften the blow of such a traumatic time in your life. Let's face it, it is a very traumatic time. I think the way in which a family of a potential donor is approached is so very important. You have to have a very compassionate person doing it. I think we covered this. Ruth, I think you were saying that we could have a coordinator who could do it. I think somebody else suggested someone with a bit of chaplaincy experience or certainly with the empathy of a chaplain.

CHAIR - What went through your mind at that stage - obviously thousands of things, but what was the major thing

Mr YEATS - So far as donating was concerned?

CHAIR - Yes. So far as saying Yes.

Mr YEATS - I'll be quite honest with you, the very first question I asked after we had been approached - they took us to a quiet room away from all the clatter of the hospital and I was probably in shock and I didn't think - was, 'Do we have a choice as to where it goes?' Obviously you don't, but that was the first thing that came to mind.

CHAIR - And then other things such as, 'This is tragic for us, but I can assist other lives'?

Mr YEATS - Personally, it meant that David's death was not going to be in vain. Somebody else was going to gain life through David's death. I can't remember how many of his organs were used - I think it was three or four.

Mrs YEATS - Everything except the eyes. I think you were a bit hesitant about the eyes.

Mr YEATS - Yes, they were welcome to have anything at all, but we were reluctant to give the eyes because he had beautiful eyes. In hindsight, I know so much more about donating and transplanting now, but it was just the eyes.

CHAIR - Do you know how many other people have benefited?

Mr YEATS - It was a minimum of three. We did have a little bit of contact with one of them afterwards, only through the transplant coordinator with the Red Cross.

Mrs YEATS - One thing I found a little disappointing, though, is that it is a big thing when you are donating organs and you really only had a response from one recipient. We didn't hear a thing from the others. To me, just a little thank-you would be so nice, a little bit of acknowledgement, but we didn't get that. I don't think we prompted the letter, I think it came automatically.

Mr YEATS - I responded to it and then the following Christmas I sent a card and a letter through the transplant unit to this person but there was no response. It would have been nice to get something back. I don't mean going to meet the person physically. My first reaction back in those days was, 'I'd love to meet the recipient'. If the recipient walked in here today I would be overjoyed, but now I realise there are problems involved with that sort of situation. It is a very delicate situation and I can understand some of the ramifications that could crop up if that were to happen. That is how we became involved as donors.

Ms FORREST - Did you have many questions at the time about what was going to happen to David and were they adequately addressed?

Mr YEATS - Regarding the clinicians we spoke to - the doctor or the nurse we spoke to - to be quite honest, at that particular time you are in a state of shock. I think they addressed everything perfectly well. I really didn't have any questions at that time.

Ms FORREST - You might not be able to remember this, but did they give you the opportunity to come back at some later stage and talk to them again if you needed to?

Mr YEATS - I can't say it was offered, but I am sure they would have been there had we chosen to do so. All I can remember - and we are going back 12 years now - was the fact that it was handled in such a wonderful way that it was hard to say no.

CHAIR - As you said, some people are dealt a bad hand, to say the least, and you have had to go through it again with a motor vehicle accident.

Mr YEATS - That was Jane's daughter.

Mrs YEATS - That was my daughter and it wasn't even mentioned because she was dead within five minutes at the scene. Obviously her organs would not have been used anyway. At that time it was never discussed; people never talked about organ donation. This is going back about 25 years.

Mrs RATTRAY-WAGNER - So you lost your daughter before -

Mrs YEATS - I think David went a couple of years after that, so we had two blows in a short time. This is the third blow, but that's life.

Mr YEATS - We retired to beautiful Tasmania and five minutes after retiring here we found that I have pulmonary fibrosis and the only thing that can fix it is a lung transplant. But on the bright side, and I look on the bright side, I think David Read - he is our pulmonary man - was saying that usually after diagnosis you have an average of 27 months without transplantation. I have had six years, so I am doing all right. I was a bit slow being diagnosed because I thought, 'There's nothing wrong with me, I'm just getting fat and old'.

Laughter.

Mr YEATS - I had had the symptoms of fibrosis for probably 13 or 14 years, so I am well past my use-by date. If I turn blue while I am sitting here, just turn the oxygen up a little bit.

CHAIR - How has it affected your life, John?

Mr YEATS - My situation or that of my son?

CHAIR - First, your son.

Mr YEATS - I think it is one of those things that until you go through it, it is hard to understand what it is like. It will never leave you, it will never be out of your mind, but you put it on the backburner, otherwise it gets to you. Everybody has different ways of dealing with this sort of trauma, different ways of grieving. Some people grieve for the next 20, 30, 40 years or for the rest of their life. Other people get on with their life.

Mrs YEATS - We grieved in different ways. John grieved quite well but it really flattened me. I think I was walking around in a daze for about two years. Everything was just grey, black; I had no feelings. I ended up with chronic fatigue. John seemed to cope really well, considering he had the business.

Mr YEATS - Yes, but I am not sure that this might not be a by-product of all the stress and the worries.

CHAIR - Your situation, John, has obviously affected your life markedly.

Mr YEATS - Very much so, to the point I was in the supermarket the other day and an elderly lady knocked half-a-dozen tins of baked beans onto the floor and my first reaction was to help her. I didn't have the oxygen on at the time and I thought, 'I can't', because if I leant down to pick up three or four tins of baked beans I would be puffing, so I had to apologise to her for not getting down. She thought, 'He's a big fellow, what's wrong with him?'. Fortunately one of the lasses in the supermarket was there and I asked her to give her a hand to pick them up - I was not able to do that.

I cannot garden any more. I cannot chop wood. I can wash the dishes; I can do very little.

Mrs YEATS - He is such a contrast in comparison to what he used to be like. He was such a physical go-go sort of person.

Mr YEATS - I have never sat still for five minutes. We arrived at the hospital here today and we always have to allow plenty of time. I cannot hurry doing anything anymore. We arrived here very early and I said to Jane, 'I hope there's a spot in the disabled car park for us', which there was right outside the door. So I have really had my wings clipped but it has been a very gradual process. Until I get a new set of lungs I don't think I will realise just how bad I was. With this particular disease, it can go like that over a period of years or months or it can just go - gotcha. Sometimes it might get to there and then just stabilise.

Ms FORREST - So how long have you been on the waiting list?

Mr YEATS - Just on 12 months. I was assessed four years ago, but I was not quite bad enough for a lung transplant.

Ms FORREST - So how do you keep your fitness up? You have to have a certain degree of wellness, otherwise they will take you off the list, I understand.

Mr YEATS - You are exactly right in what you say there.

Ms FORREST - So how do you manage that?

Mr YEATS - I had a good physiotherapist who sorted out this routine for me which used to take me 15 minutes and now takes me 35 or 40 minutes, and over the last week I have reneged on doing that each day as well. It is neck, arm and leg exercises and twisting and turning. I walk the dog every morning. What used to be a five or six-kilometre walk is now about one kilometre on the flat.

Mrs YEATS - For what it is worth, he does tend to push himself to exhaustion in trying to take a lot off me.

Mr YEATS - After the physio I am exhausted.

Mrs YEATS - That goes on all the time but in the last week he has got to the point now where he cannot extend himself anymore. He has realised now that this is it. There is a line there and he has to stay within that line now.

Mr YEATS - I mowed the lawns while Jane was not at home on Tuesday, which took me three and half hours and should have taken me 20 minutes. I like to take the load off her, so I am really a saint underneath it all.

Laughter.

Mr YEATS - It took me two days to get over it. I spent yesterday virtually in bed or lying in front of the fire because I was totally flat and exhausted. I thought seriously about even ringing up if I was not going to come good to cancel the arrangement here today, but I am so glad I came and heard what has been said today. I am absolutely tickled pink with what Stephen had to say. He was a mouthpiece for me, he really was.

CHAIR - What percentage of your lungs do you have now?

Mr YEATS - I could not give you the figure because every time I speak to David he throws all these different figures at me. Usually I understand it when he says, 'Good morning', and that is about all. Possibly my lung capacity is not too bad but the alveoli, which take the oxygen in and give the carbon dioxide out, are the problem because there was a lot of scar tissue there. I am just not getting the oxygen I should be getting. The actual lung capacity probably is not too bad.

Ms FORREST - So what sort psychological preparation have you had, because the call could come tonight - you never know.

Mr YEATS - We have somebody organised to house-sit for us, to look after the animals and the house.

Ms FORREST - But how is your mental health?

Mr YEATS - You mean mentally?

Ms FORREST - Yes. Have you been to see a social worker, psychologist and those sort of people to help you prepare?

Mr YEATS - Only those that you see with the transplant team in Melbourne, which is a pretty quick five-minute chat, but other than that -

Mrs YEATS - We do it all on our own.

Mr YEATS - Yes, we are pretty good. We do it ourselves. We have had a lot to do with people that have had transplants and with the transplant team. We know what is ahead of us.

Mrs YEATS - We have made it our business to be aware.

Ms FORREST - So if a call came tonight you would hop on the plane and you would feel quite confident going over?

Mr YEATS - We would be in big trouble because we forgot to bring our bags with us today.

Ms FORREST - Where do you live?

Mr YEATS - Near Port Sorell. We realise that the call could come while we are sitting here. Everything is organised, bags are packed and ready to go at a moment's notice.

Mrs RATTRAY-WAGNER - You said that you knew Patricia Turner and you said you have made yourself aware about what is required.

Mrs YEATS - Anything in this line, whether it is my health or John's health, we make it our business to learn all about it. Read about it, get onto the net, talk to people - it is the only way to cope with it all. You have to fill your head with all this information, sort it all out and away you go and continue on with life as best you can.

Mr YEATS - I am a technological dyslexic but I have learned to operate the computer to the point of being able to pull down things about this particular disease on the Internet, as I have the statistics about Australian donor organisation from the ANZ data organisation, and particularly Tasmanian donations.

CHAIR - Is the present system established within Tasmania and Australia that enables a person to register a legal and valid consent to become an organ donor adequate? What do you say about that?

Mr YEATS - They are probably quite adequate if people knew about them. I say that because I have addressed a number of people or spoken to a number of people, most of whom think it is still a matter of putting a tick on your drivers licence application. They are all wrong. Other people I have spoken to, and quite recently, have suggested that they have done all sorts of things to try to find out what they do now, but nobody was able to say, 'Just go to Medicare offices'. Two people actually went to Service Tasmania to say, 'I have signed my driver's licence but I believe that's no longer a valid way to do it, so what do I do?' They don't know. People are simply just not aware, and perhaps that is reflected in the figures you are talking about concerning people having not gone further with the Medicare thing. I personally think that the system is adequate. If you say to people they can go to a Service Tasmania office or the local police station or Medicare then it suddenly becomes too hard. I think it is quite adequate just as it is.

CHAIR - What about the adequacy of Tasmania to identify potential donors?

Mr YEATS - I think this gets back to exactly what Stephen and Jacqualine were saying. I doubt whether the staff in our hospitals here today have the time to worry about it, quite frankly. It is go, go, go. I think there should probably be an empathic, compassionate coordinator, for the want of a better title, one north and one south, because you have to be available 24 hours a day, seven days a week. These things do not wait for you. Somebody is going to be taken off life support at 3 o'clock this morning so the family wants somebody to speak to now, not tomorrow morning. I really do not think there is an adequate approach in identifying potential donors in Tasmania at the present time. I think that is perhaps reflected in the figures. This year since December we have had one donor in Tasmania, according to my figures. We have had only 25 since 2000. Something is not right. I cannot understand why Canberra, with a similar population to Tasmania, have figures that are just as abysmal.

Mrs YEATS - And the Northern Territory.

Ms FORREST - The Northern Territory you can understand because of the distances if there is a motor vehicle accident in the outback.

Mr YEATS - One donation this year from Tasmania for two kidneys to me is sad.

CHAIR - That takes us down to the next term of reference, when you say there is only one this year.

Mr YEATS - That is according to the figures that were released to me anyway.

CHAIR - That term of reference is the impediments, if any, causing Tassie to have the lowest organ donor rates in the nation.

Mr YEATS - Yes, that marries in with number 2.

CHAIR - It could be a number of things. One could be that we are not having the deaths -

Mrs YEATS - Good point.

CHAIR - which amount to being able to retrieve organs or, alternatively, it could be the fact that we are missing that window of opportunity to get them, which goes back to hospital awareness, doesn't it?

Mr YEATS - Yes, exactly, and the criteria to retrieve the organs. A lot of people think that because a car hit a tree at 10 o'clock they should be able to have the organs at four o'clock tomorrow morning. It just doesn't work like that, as you are all well aware anyway.

Ms FORREST - Unfortunately we have had a very high road-death rate this year. Could it be that people who can be saved are being saved, that those who die at the scene were going to die anyway? Any others maybe are being saved because of advances in medical treatment. There is more sophisticated treatment for people who have suffered a stroke and some of those other occurrences that occur that make people potential donors. Is that a factor or do you think we are not picking them up in the hospitals?

Mr YEATS - I really can't answer that. I don't know; I haven't been close enough to it.

Mrs YEATS - We haven't been close enough to the medical side of things to understand it.

Mr YEATS - I take your point, but a donor-per-million basis is what they liked to work on. Our figures are still very sad. If we really knew what the answer was we probably wouldn't be here today; we would be out recruiting all the organ donors. It is a hard one, Ruth.

Mrs YEATS - None of us really ever knows when we might need an organ, do we?

Mrs RATTRAY-WAGNER – No, Jane, we don't.

Ms FORREST - Do you think enough people talk to their families about it?

Mrs YEATS - I would say probably not. People don't discuss these things until it happens to them, a family member or a friend and then the subject comes up. Other than that, they get with life. I don't think they even think about it. TV and other media is exposing a lot of that sort of thing now, which is probably making people more aware, as Jacqualine pointed out.

Mr YEATS - There was a big spike in it, too, when David Hookes, the cricketer, died two or three years ago. There was a huge spike. I think Channel 9 or WIN has a new program starting next Wednesday night called *The Gift*, which will make people aware. This probably gets on to the next term of reference whereby I think you really need some well-accepted, high-profile person pushing for it within Tasmania.

CHAIR - Often what you have, it seems to me, is that spike when something happens to someone like David Hookes. Close friends and family shed a tear over what happened but then they can see the benefits to other families as a result of the tragedy that occurred to David Hookes. But again it gets down, I suppose, to term of reference 4: the impact that uncertainty amongst family members regarding an individual's wishes is concerned. In other words, his family obviously realised that he was passionate about donating his organs and therefore there didn't appear, on the face of it, to be any problem with him immediately being able to donate the organs. Was their any uncertainty in your mind with your son? Did you have any discussion with him, or any of the family?

Mr YEATS - Absolutely no uncertainty whatsoever, other than the fact that my ex-wife did say that David had said during the previous 12 months that if he ever died they could do what they liked with his body. If they wanted his organs they could have them because they would be no good to him anymore. He was a pretty pragmatic sort of kid. So there was absolutely no uncertainty whatsoever. Once again, Jim, I think it comes back to the way in which we were approached. I keep coming back to that bottom line: the way in which we were approached about it.

CHAIR - So that is even more important, isn't it, than knowing a person's wishes. I do not know why you have to know their wishes but over and above that is how you are approached at the time.

Mr YEATS - Sure. Had we not known David's wishes, it would not have made any difference because of the way that we were approached. That was probably the paramount thing so far as our decision to donate was concerned. Getting back to what we were discussing earlier, I do not think families do talk about it because it is just something that will happen to someone else up the street; it is not going to happen to us.

Ms FORREST - A comment was made by at least one other witness that that particular person thought it was important that the people who approached the families of potential donors were not the same people that were caring for the person in ICU because there was this fear that the patient would not be given the best care because they might think that there are organs to be donated here. I am not saying this is right or wrong but I am just asking you whether you think that would have been issue. It sounds to me, from what you have said, that the people who came and talked to you were people who actually were caring for your son, although you did not know whether they were or not.

Mrs YEATS - I think there was a doctor involved.

Mr YEATS - I am sure there was a doctor. He might have been the chief surgeon in charge of ICU.

Ms FORREST - So he might not have been caring for your son at the time, but do you think that is important or is it more the approach and how it is done rather than that separation?

Mr YEATS - It could be an individual thing, Ruth. To us that was not important. I think it was important to me knowing that some good was going to come from David's death. Somebody was going to benefit in a very positive way from it. That, to me, was the important thing, but then that is me. Other people would hardly give a damn.

Ms FORREST - We know that David had Marfan Syndrome. Were you expecting that he would die at a young age?

Mr YEATS - David had had an accident 12 months before and at that stage he was told that he had Marfan Syndrome but I think it was too late to go through the procedure whereby you stunt the growth with some sort of injection. I do not know whether it is hormones.

Ms FORREST - Anti-growth hormones.

Mr YEATS - It was too late for that. I think David might have been aware that he did have Marfan Syndrome but he was not probably aware of what the ramifications of that were. I had never heard of Marfan Syndrome and nobody I have ever spoken to has heard of Marfan Syndrome, and the week after David died our next-door neighbour's son died of exactly the same thing, strangely enough.

Mrs YEATS - Ruth, you have been in the nursing fraternity and now they can actually do operations to extend that - what is it?

Ms FORREST - The brain stem?

Mrs YEATS - Yes. They can actually operate on that now to extend it, can't they?

Ms FORREST - I am not really sure. That is a bit advanced for my knowledge and field. It is amazing what can be done now, too. It is about picking the condition up early.

Mr YEATS - Sure, but not once you have gone to 6 foot 7 inches when you are 13 years of age.

Mrs YEATS - He did grow very fast.

Mr YEATS- Or he might have been 14 years of age.

Mrs YEATS - It was all very sudden.

Ms FORREST - I cared for a woman with Marfan Syndrome who was having a baby.

Mr YEATS - I bet she was tall.

Ms FORREST - She was.

Mr YEATS - I bet she had long fingers and I bet she had a thin neck.

Mrs YEATS - That is a bad sign.

CHAIR - Do I take it that in relation to a suitable education and promotion program you are saying not really at the moment, it is improving, but there is still not a suitable education and promotion program in place to ensure that the community appreciates the need for organ donation?

Mr YEATS - To me, there certainly is not at the present time. Programs like this that are coming up next week will probably do a lot for it, particularly on the mainland, but I think Tasmanians are very parochial, too, and we want to do something in Tasmania. The other thing, too, is that possibly a lot of people in Tasmania think, 'Why should we worry? That all happens on the mainland. It doesn't happen down here. They don't do transplants in Tasmania so it really doesn't affect us'. It really is an education-type process.

Mrs YEATS - They probably also think that you can get organs from all over Australia and New Zealand and there would be plenty of organs so why worry? Maybe they think that way as well.

Ms FORREST – Do you think it would help if you had a Tasmanian education promotion rather than an education campaign that people like yourselves and others who have been recipients and donor families were involved in in some way to say, 'We're these people that you don't think exist and we are the ones'?

Mrs YEATS - I think that is a good point. I think that probably would have a good impact.

Mr YEATS - Yes, I still believe that people prefer to relate themselves to that high profile sportsman or politician or whatever, rather than some retired old geek from Port Sorell.

Ms FORREST - But you are a real person, though, and now a real Tasmanian.

Mr YEATS - Yes, I know that. I cut my teeth in the television industry 100 years ago when TV began in Australia at Channel 7 in Sydney but I really do not know how to overcome this, to publicise the need for organ donation in Tasmania. It has to be an ongoing thing; I do not know there is a lot of value in having a donation day today.

Ms FORREST - If you did it every year, though, would it be a benefit?

Mr YEATS - I do not know; there seem to be days for everything now.

Mrs RATTRAY-WAGNER - So you think they have lost a bit focus, or a bit of momentum?

Mr YEATS - Yes; you want something that is going to tug the heart strings on the 6 o'clock news tonight. I know it is not cheap.

Mrs YEATS - But then look at the pink ladies with this breast cancer awareness; look at the impact they are making at the moment with all their publicity. People are starting to be aware of it.

Mr YEATS - We were very interested at the time of David's death about the way in which brain death is established, how it is not just one doctor who comes along, taps him on the toes and says, 'Oh, he's dead'. It is a lot more involved than that of course.

CHAIR - Can you tell us the problems that you had with that because we have heard a bit of evidence to say that until your heart stops they don't think any person is dead.

Mr YEATS - Obviously they are on life support and anybody walking past the bed would not think there is nothing wrong with the guy. I had earlier taken one of the nursing sisters aside and she virtually told me that David had passed away, but I think there might be three doctors that have to certify the fact that the patient is brain dead. They do it in a number of different ways to prove that there is no brain function whatsoever. I forget, at this stage, the rigmarole that went on but I know we were quite satisfied that, yes, David had passed away before they went about retrieving the organs.

CHAIR - So once you heard that, that was enough for you. You realised that even though the heart was still pumping -

Mr YEATS - It was only by mechanical means that it was still pumping. I might add too that David's heart and lungs were unable to be used.

Mrs YEATS - That could be a worry with a lot of people - 'What if they carve me up when I am still alive'.

Mr YEATS - There are all sorts of myths, as our friend, Mr Lyons, wrote about in the paper, regarding organ donation and organ transplant.

Mrs YEATS - People need to be educated.

Mr YEATS - Yes, people do need to be educated but can you educate people that are not really interested because they feel it is not going to affect them.

Ms FORREST - What about a program in schools, grades 9 or 10? Kids are receptive to life and death issues; they want to learn about contraception and they want to learn about -

Mr YEATS - I agree, yes. I think it is probably a good starting point, yes, but then it is going to take some years before it -

Mrs YEATS - It is long-term thing.

Mr YEATS - Yes, I want to see some action today to see that donation rate up overnight.

Ms FORREST - But if 30 grade-10 kids went home tonight and talked to their parents, and then their parents talked at their next dinner party to their friends and suddenly it became an issue, then it might catch on.

Mr YEATS - Particularly if it was backed up with some sort of media promotion campaign so that the kid can go home from school and say, 'Mum, guess what we did at school today? We saw something on television about that last night'.

Mrs YEATS - It really is not a bad idea.

Ms FORREST - Kids in schools cut up sheep lungs, eyes and hearts and all sorts of things so there are opportunities to bring it up.

Ms YEATS - It certainly wouldn't do any harm.

Mr YEATS - I would like to think that whatever is done is going to be the most effective way of getting action, but I am the sort of bloke who wants it yesterday. I don't want it five years up the track.

CHAIR - John, is there anything else you wanted to say ?

Mr YEATS - I think I have covered everything. I was absolutely busting when you were speaking to Stephen; I wanted to back up what he was saying. I can honestly say that everything he said was absolutely spot-on.

Mr YEATS - Looking back on it I often say to John, 'I wonder if we could have saved David's lungs cryogenically and you could have used them today'.

Mr YEATS - In Hobart, did you have any other donor families represented?

CHAIR - Yes.

Mr YEATS - Did they speak along similar lines to what I had to say?

CHAIR - Probably to date we have had two witnesses talking more about the spiritual side of things.

Mr YEATS - There was an outfit in New South Wales called 'Silent Hearts', a group of donor families who supported each other over the years. I believe it has now faded into oblivion. There were quite a few people involved with it - some hundreds - but it has gone by the board now for some reason or other.

CHAIR - Fiona Coote was the face of it, wasn't she?

Mr YEATS - Yes, she was the first heart transplant.

I hope we have been of some assistance to you this afternoon. We certainly appreciate the opportunity to have spoken with you.

THE WITNESSES WITHDREW.