PARLIAMENT OF NEW SOUTH WALES

STAYSAFE Committee

BRIEF COMMENTS ON ORGAN AND TISSUE DONATIONS

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TERMS OF REFERENCE

The general terms of reference of the STAYSAFE Committee are as follows:

(1) As an ongoing task, the Committee is to:

(a) monitor, investigate and report on the road safety situation in New South Wales; and

(b) review and report on counter measures aimed at reducing deaths, injuries, and the social and economic costs to the community arising from road accidents.

Without restricting the generality of the foregoing, the following are to be given urgent consideration -

(i) countermeasures aimed at traffic accidents associated with alcohol and other drugs;
(ii) traffic law enforcement measures and their effectiveness;
(iii) a review of human factors affecting traffic accidents, especially those relating to driver and rider licensing requirements and standards;
(iv) the social and economic impact of deaths and serious debilitating injuries resulting from traffic accidents; and
(v) heavy vehicle safety.

RECOMMENDATIONS

RECOMMENDATION 1:
That Medicare Australia, in conjunction with state and territory health departments and motor vehicle authorities, launch ongoing national media campaigns to inform the Australian population about the current low level of enrolment on the National Organ Donor Register.

RECOMMENDATION 2:
That all state and territory government instrumentalities with responsibility for keeping donor registers, including traffic authorities and health departments, adopt uniform guidelines for updating registry information and submitting relevant data for inclusion on the National Register.

RECOMMENDATION 3:
That all states and territories ensure that people enrolling on donor registries be made aware of the requirement for legal informed consent to donate organs and tissue and that current and future participants in all existing registers be contacted to ensure that appropriate consent provisions are complied with.

RECOMMENDATION 4:
That Medicare Australia immediately implement the intention for the National Register to be a consent register, with a mechanism for opting out if an individual does not wish to participate.

RECOMMENDATION 5:
That a national policy be developed concerning the legal age at which informed consent to enrol on the register is allowed.

RECOMMENDATION 6:
That protocols be developed in relation to the role of family members in the decision making process for individual enrolment on the register.

RECOMMENDATION 7:
That hospital procedures be implemented to increase the availability of intensive care beds to other patients, when clinical brain death has been established for consenting donors.

RECOMMENDATION 8:
That the findings and recommendations in this report be forwarded to roads and transport Ministers in other Australian States and Territories for their information, and that issues of indication of consent to organ and tissue donation be brought to the consideration of the Australian Transport Council.

RECOMMENDATION 9:
That the Roads and Traffic Authority revise the form of the drivers licence to show in plain English that the licence holder is or is not a consenting organ and tissue donor.

CHAIRMAN'S FOREWORD

This report of the STAYSAFE Committee provides brief comments on organ and tissue donations. It is intended that this report contribute to the debate around improving current systems for donor registration and developing strategies to increase donor participation.

The STAYSAFE Committee is widely known for its work in the prevention of road trauma. However, its remit to examine road safety matters affecting New South Wales requires the Committee to monitor, investigate and review matters associated with post-crash sequelae, including:

- prosecutions for driving offences (see, e.g., STAYSAFE 25 (1994) which dealt with criminal offences for dangerous driving under the Crimes Act 1900); and
- repairs to crashed motor vehicles (see, e.g., STAYSAFE 66 (2005) which dealt with issues affecting the motor vehicle smash repair industry in New South Wales).

Acknowledgments

I am grateful for the support of my colleagues on the STAYSAFE Committee.

I would like also to acknowledge the friendship and support of the Hon. John Tingle MLC, who retired from Parliament on Tuesday 2 May 2006. At the time of his retirement, John was the longest serving current member of the STAYSAFE Committee, having held membership since 1995.

I wish to thank Mr Bjarne Nordin, Senior Committee Officer for drafting this report assisted by Mr Ian Faulks, Committee Manager, Ms Annette Phelps, Committee Officer, and Ms Millie Yeoh, Assistant Committee Officer, who organised the briefings before the STAYSAFE Committee on organ and tissue donations.

Chapter One—

COMMENTARY

Background

1.1 Hundreds of Australians suffer and die needlessly each year due to a shortage of organ and tissue donors. At the beginning of 2006, 1,716 people were awaiting organ transplants, according to official statistics from Australians Donate, the peak national body for organ and tissue donation for transplantation funded by the Commonwealth, State and Territory governments. By the end of March 2006, 39 people had donated their organs, allowing 152 people to receive transplants. This figure reflects the fact that an average of 3.6 organs are available for transplantation per donor.

1.2 On January 1, 2006, 1,407 people were waiting for kidneys, 123 for livers, 41 for hearts, eight for heart and lungs, 97 for lungs and 31 for pancreases. The organ donation rate is about 10 people a year per million of population, much lower than the roughly 20 per million in Britain and the US. At present, about 2,000 people nationally are on waiting lists and up to 200 people die each year waiting for transplants.

1.3 The New South Wales Department of Health reported to the STAYSAFE committee that, since 1965, 30,000 recipients in Australia have received an organ or tissue transplant. Nationally, in 2005 there were 204 organ donors from which 727 people received a transplant.

1.4 The Federal government, in acknowledging that Australia has one of the highest transplant success rates but one of the lowest donation rates in the developed world, has recently announced a National Collaborative on Organ and Tissue Donation, based on a successful US model, to raise donation rates. In the recent budget statements, the Commonwealth government will support initiatives to encourage Australians to lift the rate of organ donation.
Strategies announced in the budget include the funding of an awareness campaign and the promotion of better liaison and information between states and territories about potential donors and recipients. As part of the package, the Federal government will ask the states to appoint and pay for organ donation coordinators in large hospitals.

1.5 Professor Graeme Russ, an organ donation specialist and chair of the Australia and New Zealand Dialysis and Transplant Registry, is reported as saying that "it is a mystery why the Australian rate is so low". Professor Russ has also said that the most important factor in increasing the rate is to have keen hospital staff, attuned to the need for donors and a supporting network. He suggested that a designated bed should be put aside in intensive care wards for organ donors once brain death occurred, so they were not competing for beds with patients who had a chance of survival.

Donor registration

1.6 Since July 2005, a national Australian Organ Donor Register, administered by Medicare Australia on behalf of the Australian Government, has been operative with 5.6 million potential donors as at April 2006. In January 2005, Australian Health Ministers agreed that the Australian Organ Donor Register would become a register of consent, enabling individuals to record their legal decision to becoming an organ or tissue donor after death. However, due to the disparity of approaches by respective state governments to register donors in their own jurisdictions, of the current 5.6 million participants, 4.8 million have only registered an intention to donate, whereas 800,000 have signed a legal consent.

1.7 The Donor Register attempts to ensure that any consent (or objection) to donating organs and/or tissue for transplantation can be verified 24 hours a day, seven days a week by authorised medical personnel, anywhere in Australia. In the event of a death, information about such a decision will be accessed from the Donor Register and provided to the family concerned. It is therefore recommended that prospective donors talk with their family before registering a decision to participate.

1.8 Previously, each state had its own register and in New South Wales the register was administered via drivers licences downloaded from the Roads and Traffic Authority database. According to NSW Health, there was a move to do away with licences for this purpose in some states, but in New South Wales a decision was made to retain the system. This was stated to be for two reasons. First, because there are three and a half million drivers in New South Wales, resulting in a captive audience to make their intention known. Secondly, licences in New South Wales require an actual consent to be an organ donor, whereas in other states it is merely an expressed intention.

1.9 The intent provision is quite different from legal, informed consent to be an organ donor. There are 194,000 people registered in New South Wales on the organ donor consent register. This is apart from licences and was achieved through a national mail-out by the Health Insurance Commission, as part of the Medicare Donor Register process and provided a mechanism for people who do not drive or have a licence to be able to register their consent.

1.10 Legally, in New South Wales, families do not have to be consulted once donor consent has been established but the reality of the donation process is that NSW Health still consults the families. The Director of Clinical Policy, NSW Health, told STAYSAFE:

> "It is an extremely difficult time for families and when you are approaching them for one of their loved ones who has just been declared brain dead to be an organ donor and to have them agree to proceed with the organ donation process there is still a lot of argument around that. But at present the policy is that we would still go to the family so that we do not create a whole host of other patients from the process, because it can be quite traumatic for the relatives as well. But where we have a registered consent or intent on a register it is most unusual for a family to refuse. But where we do not know the intent or whether there is consent the family refusal rate can be as high as 50 per cent in a year. Where the family

> knows the intent of the person who has died we usually do not have a problem. There is the odd one but it is very rare. But on the reverse of that, if the family does not know the intent or consent of the relative it can be as high as 50 per cent. It ranges from 30 to 50 per cent in a given year."
> (Evidence before STAYSAFE, Monday 1 May 2006)

1.11 While Health Ministers have agreed that the Australian Organ Donor Register would be the only national register for organ and/or tissue donation, one of the challenges for the new Register is to ensure the cooperation of states where they have intent registers, as opposed to the situation in NSW where there has been a consent register for a number of years. Strategies involving Medicare Australia and state and territory government instrumentalities must be devised to ensure that the national Donor Register reflects the wish of donors to consent to the reuse of their organs under appropriate circumstances.

Increased donor participation

1.12 The encouragement of greater enrolment on the national consent register must involve elements of education, awareness and appeals to greater community involvement. In addition, it can also include the possibility of incentive schemes and legislated automatic inclusion unless permission is refused by the potential donor. Incentive schemes are complicated by the provisions of the Human Tissue Act 1983. Under Part 6 (Section 32), Prohibition of trading in tissue, the following extract refers:

> 32 Trading in tissue prohibited
>
> (1) Maximum penalty: 40 penalty units or imprisonment for 6 months, or both. A person must not enter into, or offer to enter into, a contract or arrangement under which any person agrees, for valuable consideration, whether given or to be given to any such person or to any other person:
>
> (a) to the sale or supply of tissue from any such person's body or from the body of any other person, whether before or after that person's death or the death of that other person, as the case may be, or
>
> (b) to the post-mortem examination of any such person's body after that person's death or of the body of any other person after the death of that other person.
>
> (2) Subsection (1) does not apply to or in respect of the sale or supply of tissue if the tissue has been subjected to processing or treatment and the sale or supply is made for the purpose of enabling the tissue to be used for therapeutic purposes, medical purposes or scientific purposes.
>
> (3) Subsection (1) does not apply to or in respect of a contract or arrangement providing only for the reimbursement of any expenses necessarily incurred by a person in relation to the removal of tissue in accordance with this Act.
>
> (4) Where the Minister considers it desirable by reason of special circumstances so to do, the Minister may, by instrument in writing, approve the entering into of a contract or arrangement that would, but for the approval, be void by virtue of subsection (5),

and nothing in subsection (1) or (5) applies to or in respect of a contract or arrangement entered into in accordance with such an approval.

(5) A contract or arrangement entered into in contravention of this section is void.

1.13 Therefore, under this Act, it is illegal for people entering into or offering to enter into a contract or arrangement under which people agree to the sale or supply of tissue for personal gain or "valuable consideration". In relation to a suggestion that a rebate could be offered for drivers' licences to anyone giving donor consent, the committee was told that legal advice provided to NSW Health is that this is currently unlawful.

1.14 On the question of automatic inclusion on the Donor Register, this would mean that everybody, upon brain death, would be a potential donor. Such a legislated system applies in Spain, France and Belgium and ensures that every citizen is a donor, unless he or she objects strongly to inclusion on the register. A change in current arrangements would have to be extensively promoted in the community with appropriate public education campaigns in order to potentially increase the number of donors available. New South Wales performs the majority of transplants in the whole country, nearly equal to the rest of the country, and could lead in this area.

1.15 However, such a change to the current system requires further policy development in relation to formulating a national approach to deemed consent, including addressing such issues as: age of consent; mechanisms for opting out of the system; and the practicalities of state and territory government commitments to operating the uniform donor register.

1.16 On the question of age of consent, the current Donor Register has a provision for registering intent at age 16 and 17, but legal consent cannot be obtained until a person is 18 years of age. A further issue is that in most states, a majority of current registered donors who have indicated their intention to provide organs as part of the driving licence process are not aware that they need to provide additional legal consent in order for their wishes to be carried out. This will require an extensive effort to inform and educate everyone on the current register, as well as those intending to donate in the future.

1.17 In view of the identified shortage of available consenting organ and tissue donors, a concerted effort is required to improve the operation of the Australian Organ Donor Register. Whereas New South Wales has operated a consent register for some years, it is up to the Federal government and the other states and territories to adopt uniform and collaborative policies and mechanisms to enable the 2,000 people currently awaiting organs to be assisted, thereby reducing the number of fatalities directly resulting from the current shortage of suitable organs.

1.18 This process should be driven by the Australian Health Ministers Advisory Council, in conjunction with Medicare Australia and Australians Donate and involve all state and territory health departments and traffic authorities, in order to take advantage of data already captured by these lead agencies in the pursuit of a comprehensive Donor Register. A national approach should incorporate the objectives outlined in the recent Federal budget and incorporate the following components:

- increased community awareness of organ and tissue donation through ongoing campaigns;

- expanded access to registration on the Australian Organ Donor Register;
- enhanced clinical data on organ and tissue donation and transplantation;
- national consistency in transplantation waiting lists; and
- improvements in the quality and safety of organs and tissues for transplantation.

1.19 STAYSAFE proposes that the findings and recommendations in this report be forwarded to roads and transport Ministers in other Australian States and Territories for their information, and that issues of indication of consent to organ and tissue donation be brought to the consideration of the Australian Transport Council.

1.20 Finally, STAYSAFE notes that the current practice of indicating donor status on the New South Wales drivers licence is ambiguous—for example, donor consent is indicated by the letter A. STAYSAFE recommends that the Roads and Traffic Authority revise the form of the drivers licence to show in plain English that the licence holder is or is not a consenting organ and tissue donor (i.e., by the words Yes or No).

Chapter Two—
PROCEEDINGS BEFORE JOINT STANDING COMMITTEE UPON ROAD SAFETY, BRIEFING ON ORGAN AND DONATION, MONDAY 1 MAY 2006

Professor EARL OWEN, Microsurgeon, and

Mr WILLIAM HEILER, Director, Clinical Policy, Population Health, New South Wales Department of Health,

before the Committee:

Mr GIBSON (CHAIRMAN): Professor Owen and Mr Heiler, thank you for coming to brief the Committee today. I invite either of you to tell us about organ donation and transplants.

Mr HEILER: Thank you for the invitation to give you a presentation on organ donation, tissue donation and transplantation. I will go over the management arrangements nationally, give an overview of what we do nationally plus what we do at State level and some statistics on organ donation, transplantation and the logistics of that. Since 1965 in Australia there have been 30,000 recipients that have received an organ or tissue transplant. Nationally, in 2005 there were 204 organ donors and from those 204 organ donors nationally 727 people received a transplant. Currently, an average of 3.6 organs are transplanted per donor.

At national level, there is a peak national body, Australians Donate, which is funded by all governments of Australia. It is a non-profit incorporated association. A current initiative is a national collaborative involving 20 hospitals across Australia. It will be looking at different methodologies for the identification of potential organ donors and how that works within each of the hospitals. It will be run through what we call the breakthrough collaboratives. People will be brought together. We will compare the different ways they are doing it and looking at donation rates from within those hospitals. There is a range of hospitals, some poor performing hospitals in terms of donors and also some that we know that are quite good at it.

Another national project was the national schools project. Some educational material has been prepared—a video, a booklet—and provided to secondary schools throughout Australia. At a national level there is the Australian Organ Donor Register, which has operated since July 2005. Previous to this each State had its own register, and in New South Wales our register was through the RTA. This is where your licence came in. Back in 2005 there was a move to do away with licences for this purpose in some States but in New South Wales we made the decision that we would not. There are a couple of reasons. One is that we have three and a half million drivers in New South Wales, a captive audience to make their intention known.

Licences in New South Wales have an actual consent to be an organ donor whereas in other States it was an intent. That is quite different in terms of legal consent, informed consent to be an organ donor. There were 194,000 people registered in New South Wales on the organ donor register. This is apart from the licences. This was achieved through a national mail-out

by the Health Insurance Commission. That provided another mechanism for people who do not drive or have a licence to be able to get on a register to register their consent.

Mr GIBSON (CHAIRMAN): Every time you renew your licence do you have two renew your consent?

Mr HEILER: Yes.

Mr GIBSON (CHAIRMAN): Do you lose many? People may be thinking that they have given consent—

Mr HEILER: Not as a rule. I would have to get the statistics on that. The numbers on the licences do not seem to change too much in terms of consent. At the moment 4.8 million Australians are on the register. Legally we do not have to go to families once we have a consent but the reality of the donation process is that we still go to the families. It is an extremely difficult time for families and when you are approaching them for one of their loved ones who has just been declared brain dead to be an organ donor and to have them agree to proceed with the organ donation process there is still a lot of argument around that.

But at present the policy is that we would still go to the family so that we do not create a whole host of other patients from the process, because it can be quite traumatic for the relatives as well. But where we have a registered consent or intent on a register it is most unusual for a family to refuse. But where we do not know the intent or whether there is consent the family refusal rate can be as high as 50 per cent in a year. Where the family knows the intent of the person who has died we usually do not have a problem. There is the odd one but it is very rare. But on the reverse of that, if the family does not know the intent or consent of the relative it can be as high as 50 per cent. It ranges from 30 to 50 per cent in a given year.

Mr GIBSON (CHAIRMAN): Should there be presumed consent?

Mr HEILER: That is where we get into the issue of how to approach the family. We do that. We still approach the family. It depends how far you want to push relatives when they are traumatised. That becomes a real issue.

Mr GIBSON (CHAIRMAN): That is true but on the other side of it you have 4.8 million that are willing to be organ donors and we still have a huge waiting list for organ recipients. Last year only a handful of organs were transplanted.

Professor OWEN: We will get on to that later.

Mr GIBSON (CHAIRMAN): Is the system working? That is what I am asking.

Professor OWEN: We do not think so.

Mr MAGUIRE (STAYSAFE): Going back to the licensing and the intent and consent, you said all the other States had intent and New South Wales operated on consent. Would that not require a simple change in legislation in New South Wales? Has that been advocated?

Mr HEILER: It is not an issue in New South Wales. The new Australian Organ Donor Register is a consent register. The problem is in other States, where they have intent registers. But we have had a consent register here for a number of years. That is being addressed nationally through the Health Insurance Commission and the new Australian Organ Donor Register. We need a single register, a single point of contact within Australia. But how people actually get on that register is another issue. We are looking at a range of ways that people can register.

Mr MAGUIRE (STAYSAFE): At the moment it is done through Medibank?

Mr HEILER: Yes, but in New South Wales we download the Roads and Traffic Authority register onto the national database.

Mr SOURIS (STAYSAFE): Was everybody sent a letter or sent something?

Mr HEILER: From the Health Insurance Commission, yes. But the response is varied.

Mr SOURIS (STAYSAFE): I would have filled it in. I must have got it, I suppose, but I just cannot remember it.

Mr HEILER: It was mailed to everyone with a Medicare card. At a State level, in 1997 we created a statewide infrastructure for organ and tissue donation. It is currently with the Australian Red Cross blood service. That is where the State donor co-ordinator role is. At an area health service level we have the area donor co-ordinators. These are nurses with intensive care backgrounds. They work closely with the intensive care units within an area health service around the donation process at the hospital. Once a donor is identified at the hospital a whole process is gone through. The Red Cross then, with the State donor co-ordinators—they are the ones that organise. They take over at the end of the process at the hospital and organise the retrieval and transport of organs and the notification to the transplant surgeons and hospitals and get in touch with them about recipients that have gone through a process where the recipient is selected. But primarily the Red Cross also runs our tissue typing laboratories. The tissue typing is done there and a register is kept there. The whole process happens fairly quickly.

A big thing—we have just touched on it—is to ensure that families of potential donors get the correct information, or as much information as they would like. We can actually give the family too much information, and that could turn them away from agreeing to the donation, or you cannot give them enough. The people approaching the families are trained how to approach the families and go about asking for their consent to proceed with the organ donation from the relative. It is quite an involved process. It can take quite a deal of time and it is very emotional. This is a really difficult task. NSW Health has the Transplant Advisory Committee. It is made up of transplant clinicians, intensivists, representatives from NSW Health, and the organ donation network, which includes both the area had donor co-ordinators and the State donor co-ordinators situated within the Red Cross. Because we work closely with the Australian Capital Territory they have a representative on the Transplant Advisory Committee. It advises NSW Health on organ and tissue donation policy.

Recent policies that we have developed cover altruistic kidney and liver donations. This is where live people make it known that they wish to donate a kidney to someone. You can imagine that this has brought up a lot of ethical issues for transplant surgeons when they are

contacted by these people because they have a vested interest. They want the kidney: they want to give it to their patients. Their patients want the kidney. A whole process has been developed to ensure that anyone who is willing to donate an altruistic kidney goes through a proper process of assessment. It is done in the best way. Altruistic kidney and liver donations are different from directed donations. Nearly half the kidney transplants in New South Wales are now directed donations. These are usually from a relative or a very good friend. They make up a considerable amount of the activity. Altruistic donation is something different; that is donating it to the community.

The Hon. IAN WEST (STAYSAFE): Are there geographical boundaries on it?

Mr HEILER: No.

Professor OWEN: It also applies to skin.

The Hon. IAN WEST (STAYSAFE): Is it international?

Mr HEILER: Organs are allocated by State first—an organ is offered in the State where it is donated—and if there is no-one suitable within that State, the organ is then offered around Australia.

Mr MAGUIRE (STAYSAFE): You mentioned donating a liver altruistically. Are you talking about a part of the liver for grafting?

Mr HEILER: Yes. There are two distinct lobes in the liver. They can take the smaller lobe from a live donor and implant that into someone else. It will grow to the correct size for the patient and function quite well. I do not think we done have one in New South Wales yet. This procedure is very new. It is being done in the United States. We can transplant to two people from a brain-dead donor because we can split the liver. An adult will get the larger lobe and a child will get the smaller lobe.

Mr HUNTER (STAYSAFE): Does that mean a person who is healthy could donate his smaller lobe and continue to function normally with the larger one?

Professor OWEN: Yes.

Mr HEILER: If the smaller lobe is transplanted into an adult, that organ will grow.

Mr HUNTER (STAYSAFE): Does the larger part grow a second smaller lobe?

Professor OWEN: No.

The Hon. IAN WEST (STAYSAFE): What is your definition of "altruistic"?

Mr HEILER: It refers to someone who wants to donate an organ to the community for allocation to anyone as opposed to a directed donation from a relative to a relative.

The Hon. IAN WEST (STAYSAFE): Does altruistic donation involve cash in any way?

Mr HEILER: Absolutely not.

Mr HUNTER (STAYSAFE): How long have we known about this breakthrough or advance in transplant technology regarding the smaller lobe?

Professor OWEN: About 15 years.

Mr HUNTER (STAYSAFE): Is there a waiting list for liver transplants?

Mr HEILER: Yes.

Mr HUNTER (STAYSAFE): So the word is not out in the public domain that one can donate part of a healthy liver to another person?

Professor OWEN: That is correct; it is not really generally known. It is in other countries.

Mr HEILER: These two policies were developed by the New South Wales Transplant Advisory Committee. I sit on an inter-governmental committee set up by the Australian Health Ministers' Advisory Council to deal with organ and tissue donations. We took those policies to that group and I believe it they are just about to come out as national policies. We try to do these things at a national level because it is a national resource and it is managed in that way.

Mr HUNTER (STAYSAFE): I am sure there would be many people prepared to donate.

Mr HEILER: There is a risk. There is a lot more experience in the United States with altruistic liver donations, but the donor death rate is higher. There is a substantial risk to the liver donor and to a lesser extent to kidney donors—it is much lower. There is not only the risk of death from being an altruistic donor, but also the fact that it takes several months for a kidney donor to recover and get back to work. There is a considerable cost involved in terms of being an altruistic donor in addition to the risk to life. It is still seen as a breakthrough procedure, especially with livers.

Professor OWEN: The skin can also be altruistically donated by a relative. If someone is very badly burnt—50 to 60 per cent of his body is damaged—he does not have enough skin to replace the burnt skin and may well die. We ask family members to donate skin and we get a very good response.

Mr BARTLETT (STAYSAFE): Are the survival rates better with the skin donors?

Professor OWEN: There is no death rate.

Mr HEILER: Skin is also harvested from cadavers. As at January 2006, 1,716 people were on an organ transplant waiting list. Approximately 813, or 47 per cent, of those waiting live in New South Wales. That is a 3.18 per cent increase since January 2005. By the end of March 2006, 39 people will have donated organs, allowing 152 people to receive transplants. A quote I rather like states:

The human face of organ transplantation is a waiting list of patients who come into our clinics every day who are desperate to receive a transplant to save their lives.

In fact, the largest organ waiting pool is for a kidney. Of the 813 patients waiting for a transplant in New South Wales, 699 are waiting for a kidney. Approximately 1 in 10 people in the transplant waiting pool are children. The average waiting period for a kidney is 3.8 years; heart, 2.2 years; pancreas, 1.7 years; liver, 1.5 years; and lung 1.2 years. Organ donation can occur only after someone dies of trauma to the brain in a hospital and while attached to a ventilator. This is does not occur very often. A typical organ donor in Australia is 42 and male. We do audits across New South Wales and Australia on deaths within intensive care units to ensure that we are not missing the identification of those people who are suitable to be an organ donor.

An exponential growth in tissue demand is expected due to new technology and the impact of the ageing population. The St George Bone Bank has done a deal with a company that makes bone paste. The technology for the glue belongs to the company, but we harvest the bone from donors—usually cadavers, not brain-dead donors—and in a joint venture they make this bone paste for orthopaedic surgery. It is a breakthrough for Australia. It promotes better bone growth, the join is stronger and the length of stay in hospital is reduced dramatically. We have a decreasing supply of donors. The chance of being a suitable donor is 1 in 100. Only 1 per cent of the Australian population who die of brain injury die in a hospital. In addition, Australia has become more aggressive in surgery and our health system is quite successful in this area. That also limits the donor pool.

Mr HUNTER (STAYSAFE): Can you explain why a donor must die while in hospital and on ventilation for the organ to be suitable for transplant?

Mr HEILER: That is the only way that the organ can be kept alive.

Mr HUNTER (STAYSAFE): We see movies depicting people running from one hospital to another with organs in an Esky. Is that fiction?

Mr HEILER: No, that is how they transport them. However, when the organs are removed to be transported, they are removed in a viable state and placed in ice, which slows down the degradation. If a person is killed in a car accident and dies on the side of the road and it takes an hour for the body to be transported to hospital, the organs are not viable.

Mr HUNTER (STAYSAFE): What about if they die in the ambulance on the way to hospital?

Professor OWEN: They can be kept alive but still be brain dead.

Mr HUNTER (STAYSAFE): So it is part of ambulance officer training to keep people alive in this circumstance?

Professor OWEN: Yes.

Mr HEILER: Cause of donor deaths from cerebral vascular accident or stroke is 48 per cent; cerebral tumour, 2.5 per cent; road trauma, 26 per cent—that is where this other group comes in; and other trauma, 11.5 per cent. The vast majority result from stroke of some

description. Brain death occurs in only 1 per cent of the deaths. Two specialists must do separate tests to determine that brain death has occurred. A number of procedures are undertaken to determine this. The main point is that there must be no brain function and no blood flow to the brain. A decreasing number of deaths satisfy these criteria. There is pressure on the health system to consider maintaining a patient who may progress to brain death. This involves families and clinicians and it is complex. It can also be traumatic. We have another document that refers to advanced care directives for patients. It is a very difficult time for families. There is pressure from families to get it over with.

Mr BARTLETT (STAYSAFE): So if the family wants a loved one taken off the ventilator, it is not good in terms of supply for you?

Mr HEILER: If the patient is identified as a potential organ donor, that is the point at which the family would be approached. It is a difficult period because to approach a family we must diagnose brain death. If someone is on a ventilator in an intensive care unit but has not progressed to brain death, but we think that will occur, do we keep them there for another week explicitly to become an organ donor when the family is going through the trauma? It is a very delicate balance and call by the people in the intensive care unit.

Mr BARTLETT (STAYSAFE): They might need the bed.

Mr HEILER: That is another issue. Do you keep someone who is brain dead on a ventilator in intensive care when there is a young person in the emergency department who needs that bed? How do you make that decision weighing the need for the organs and that person's need for the bed? There are many dynamics in the hospital that impact on that decision. Reasons why donations do not proceed include hepatitis C and coronial issues. We have arrangements with the Coroner. It is rare for the Coroner to refuse permission to go ahead with an organ donation. Cardiac arrest in the operating theatre is an issue. Potential non-beating heart is a new policy we are trying to introduce. With some organs, like the kidney, if we can get to a non-beating heart donor within a very short period we may be able to salvage the kidneys for donation and transplantation. High-risk behaviour can put people out. We also look at hepatitis C positive patients. We cannot give them hepatitis C again if we give them a liver from a donor who has hepatitis C, but the liver is still fine.

There are ethical issues around that as well. Key issues include the low probability of brain death, opt in versus opt out. This has been a topic around for a number of years now. The Spanish model, which is held up as being a good model, is an opt-out system. But it is interesting that, whether you have an opt in or are an opt-out system—and this is around the consent—you actually have to register to opt out of being a donor instead of registering to opt in. But in Spain where they have this model and in other countries, the policy is still to go to the families, and the families still have the last say with either on opting in or opting out. Family refusal we have spoken about, and we are starting to do some work around rural and regional areas to try to capture or ensure that we are not missing potential donors out in those areas.

Mr GIBSON (CHAIRMAN): Would it be better with your licence and what have you to only sign it if you do not want to be a donor?

Professor OWEN: Absolutely. I will bring that up later.

Mr HEILER: That is a debate that is going on. Future initiatives include public consultation, of course. Organs are the property of the community. Donor registry and promotion is ongoing. The family education strategy is coming out and we are also trying to do some work with the private hospitals around organ donation through the private sector. Tissue donation features greater eligibility across deaths because the time factor is not as critical. No constant blood supply is required for tissue donation. Tissues that can be donated include corneas, heart valves, skin and bone, cartilage, tendons, bone marrow, veins—quite a number of things.

Regarding drivers licence statistics from Australia, the bulk of those statistics are ours because the other States have actually gone away from the driver's licence, but I believe that they are looking at reintroducing it in some of the other States. Drivers licence rebates—I know this Committee has been looking at this—is a very contentious issue. Recently you may have seen articles around China and the sale of organs in China. We have actually had residents in New South Wales that have gone to China and have had transplants there with outcomes that have been far less than desirable. I believe there is only one that has been successful that had gone over, and other people have died.

But China has said that they are going to put a stop to it now and it will be illegal in China shortly. In New South Wales, the Human Tissue Act 1983 Section 32 contains provisions that aim to stop people entering into or offering to enter into a contract or arrangement under which people agree for valuable consideration to the sale or supply of tissue. An offer of a rebate licence or registration fees is not legal in New South Wales, and that is our legal advice at the present time.

The Hon. IAN WEST (STAYSAFE): Is that world's best practice, is it, in the global economy in which we live?

Mr HEILER: That it is illegal to offer financial incentives?

The Hon. IAN WEST (STAYSAFE): Yes.

Mr HEILER: That is around the world. Recently there were some entrepreneurial surgeons in South Africa who were flying over Third World country donors from South America and providing transplants to the middle European area. They will go to gaol.

The Hon. IAN WEST (STAYSAFE): For how long?

Mr HEILER: It remains to be seen.

Mr MAGUIRE (STAYSAFE): You mentioned the word "valuable". What is the meaning of "valuable" in your statement?

Mr HEILER: Under the law?

Mr MAGUIRE (STAYSAFE): Yes.

Mr HEILER: That is any consideration that could have a value, no matter what it is—goods, cash, services, anything—valuable consideration.

Mr HUNTER (STAYSAFE): Is the legislation that we have passed based on something that has come from the United Nations? Is there some kind of international agreement that our national government has signed up to?

Mr HEILER: I am not 100 per cent sure of that. I do not know whether you know, do you?

Professor OWEN: No, there is no such thing.

Mr HEILER: But there is a convention around the world in developed countries. You see, where this has started, it is always the people from the Third World who are exploited, so there is a convention around the world that we will not enter into the trade of organs, human tissue.

Professor OWEN: If you get the English papers—downstairs you can get them—there has been a controversy lasting about a year now because so many of the British people do not get heart transplants and they are going to die otherwise, and they have been shipping them off to China. China has hundreds and hundreds of transplants being done and paid for with mixed results, but people will accept anything. If you are going to die, you really will go anywhere that can help you, if you can afford it, or if you cannot afford it, your relatives will help you.

Mr GIBSON (CHAIRMAN): How about the situation with the good friend of a lot of us here, Kerry Packer? What are your thoughts on that?

Professor OWEN: Do you mean the donation from his driver?

Mr GIBSON (CHAIRMAN): Yes, his pilot.

Mr HEILER: As far as I was aware, there was no financial valuable consideration.

Mr GIBSON (CHAIRMAN): You would be the only person in Australia that would think that way. But that is all right?

Mr HEILER: No, it is a directed donation, yes.

Professor OWEN: Absolutely.

Mr MAGUIRE (STAYSAFE): What about religious views? How does that impact on donations?

Professor OWEN: Every single religion—and I had gone to nine religions before doing the first hand transplant just to check—not a single religion objects in any way to transplantation of organs or tissues.

Mr HEILER: There are some issues around, though, being a donor.

Mr MAGUIRE (STAYSAFE): What about the Jehovah's Witness?

The Hon. IAN WEST (STAYSAFE): That is blood.

Professor OWEN: No, that is blood. That is not an organ.

Mr MAGUIRE (STAYSAFE): So they support the donation of organs, not blood?

Professor OWEN: Some of them say it will not, but the leaders say, yes, it is all right, when you point out that they may die.

Mr HEILER: And my dealings with those particular groups is to say, "Leave it to the judgment call, to the individual."

Professor OWEN: That is right. Well, what is religion anyway?

The Hon. IAN WEST (STAYSAFE): Maybe that is not for this Committee.

Mr BARTLETT (STAYSAFE): Would there be some suggestion you would like to make to the Committee regarding the direction of New South Wales policy in this area?

Mr HEILER: I think the system in New South Wales between organs and tissues has been a little bit fragmented and we have been doing some work around trying to get a co-ordinated network under the umbrella of one organisation to co-ordinate those organs and tissues. If you look to cost and benefit to the community, tissue is probably going to provide far more to the community than organ transplantation. Organ transplantation is probably more to the individual whereas tissue is relatively cheap to procure and process and distribute and to use, and the benefits to the community are far greater, as a whole. That is not to take away from the individual with the organs, either, and I would like to see us develop that in New South Wales. Certainly at New South Wales Health, that is what we are working towards at the present time.

Mr HUNTER (STAYSAFE): Considering the number of people who pass away brain dead in a hospital on a ventilator, what is the proportion of families who have a say in how you cannot harvest at all?

Professor OWEN: About 50 per cent.

Mr HUNTER (STAYSAFE): What is that in numbers in New South Wales?

Mr HEILER: Maybe 50—maybe. You have to be careful here because we had the intention of the donor being known to the family. There is no family refusal.

Mr HUNTER (STAYSAFE): I am saying when the intention is not known you have the family refusing, and that is about 50 a year. If there was some other way and if all of those people had given permission, you would still get a few rejections from the family and you would not go ahead, but you say you would probably get about 45 additional organ donors a year.

Professor OWEN: I can give you the figures for France.

Mr HUNTER (STAYSAFE): I am just wondering whether you would cut into this waiting list.

Professor OWEN: Yes, you would.

Mr HEILER: Yes, you would—no doubt.

Professor OWEN: Absolutely.

Mr HUNTER (STAYSAFE): Have we looked at maybe health funds? Has it been talked about with Medicare that all Australians are asked whether they are prepared to donate organs? Is there some other way we can make contact with people to seek their agreement, or is adjusting the driver's licence donor clause the better way to go?

Professor OWEN: Legislation is the way to go.

Mr HUNTER (STAYSAFE): So everyone would be deemed to be in?

Professor OWEN: Yes. This occurs in Spain, France and Belgium. It has been going for 24 years in France and it is very successful. I could not have done the first hand transplant, the first double hand transplant and the first face transplant with our team here in New South Wales. We could have led the world in it, but we did not because we cannot do it here. It is tissues, and it is composite tissues. But it is expected that with the changes that we are all working towards, that will become possible.

Mr GIBSON (CHAIRMAN): We have never talked about buying an organ or selling an organ, but we have talked about some form of recognition for people who are donors. Tell me the difference: if I go to Woolies or Coles and spend $100, I get a voucher for 4¢ a litre off my fuel. So where is the difference? By giving an incentive, whether it be a cheaper licence or whatever, just as recognition—

Professor OWEN: You could give a medal and you could give public recognition, but if you start paying for them you are going to have a lot of problems.

Mr GIBSON (CHAIRMAN): No, I would never say pay for them, no.

Professor OWEN: Yes. But that sort of thing is a very generous offer from the politicians, to give a medal to people who do donate.

Mr HEILER: The issue around recognition is that every year there is an organ donation awareness week. During that week, one of the focuses within that week every year is the recognition of past donors and their families and the gift that they have made to the community. That is done.

Professor OWEN: But you have not heard of it because it is not being pushed enough.

Mr HEILER: It is very difficult to get the coverage within the media to these events and that takes a lot of work. There is a lot of effort gone into it.

Mr GIBSON (CHAIRMAN): Can I be blunt? You tell me if I am right or wrong. The system does not seem to be working.

Professor OWEN: That is correct.

Mr GIBSON (CHAIRMAN): If you look at 4.5 million people wanting to be donors, and we are picking up 50 or 60 a year.

Professor OWEN: It is pathetic.

Mr HEILER: No, that is only in New South Wales.

Mr GIBSON (CHAIRMAN): But even in New South Wales.

Professor OWEN: Yes, that is right.

Mr HEILER: We do the audits. I am not saying it is 100 per cent great, but the audits in New South Wales show us that we do not miss those deaths within intensive care units. That is what it suggests.

Professor OWEN: There are a not enough intensive care units. There are not enough doctors making decisions. There is a lot wrong with the system of health, but we are not talking about that. We are talking about the 50 or so that we missed that we could get that are sitting in hospitals but we cannot use, whereas in countries like France you look at the population and the percentage and it is very much higher for donations.

Mr MAGUIRE (STAYSAFE): What about the mobility of recovery teams? Are they centrally based, or can a recovery team operate outside major hospitals?

Professor OWEN: Again, that is a very good question. They are not as organised as they are in other countries in Europe. They are organised as well as we can, and there is no criticism of the committee trying to do it. But when I get to tell you about the French system, you will see how they have organised it really well.

Mr GIBSON (CHAIRMAN): That is a good cue to change and to thank you, Mr Heiler, for your information this morning. It has opened our eyes anyway, so thank you very much for that. We look forward to hearing from Professor Owen.

Mr Ian FAULKS: Professor Owen, we are not quite sure which file we should be opening.

Professor OWEN: It is marked PowerPoint, so find PowerPoint and it is the first one on the left that we want to go to, but not just yet. While you are doing that—thank you for inviting me to come along. As the Senior Children's Surgeon at the Prince of Wales Hospital in 1972, I went to the Minister in New South Wales who was concerned with health and safety. Eventually I met Mr Wran and we stopped eye injuries occurring in children to a large extent by banning the sale of fireworks—disappointing all of you who were fathers at the time because you could not have them in your letterboxes, blowing them up, or your kids blowing their fingers off or injuring their eyes.

The Government was very good and listened to me when I told it about all the eye injuries that were coming into the children's hospitals, and it banned the sale of fireworks. Every year with Channel 9 we held a fireworks night at the showground. We had a lot of fun doing it and we raised a lot of money for research. In 1973 I went to another Minister for Health, because by then the Minister had changed, with pictures of all the fingers, hands and limbs that had come off since I started putting on fingers and hands in the world in 1970.

For your information, I have a picture of the first boy—the first human ever—who, at the age of two, had his finger replanted. This picture of him was taken two weeks ago, 36 years later, and he is now 38. He is a New South Wales boy and he has his index finger back perfectly. I went to the Minister with a whole lot of pictures showing people who had had their hands, arms, penises and ears off, and we had put them back on. That went to a safety and workplace committee, very much like this committee, and WorkSafe was eventually brought up as a result. That is history.

Right now very efficient organisations are trying to do their best because organ donations and transplants are the same thing. You cannot do a transplant if you have not got a donor. We cannot use pigs or monkeys yet. We have not crossed the Zeno transplant barrier sufficiently to do that, otherwise people would be suggesting farming animals for appropriate organs. Wonderful pioneering work is being done in Melbourne and, to some extent, in Sydney, on tissue growth—growing parts of your own body from a biopsy, growing your own kidney and heart tissue from stem cells.

The Federal Government has put a lot of money into that and we are proud of it. We are getting a chance to do it but the medical profession needs a lot more money. Since you cannot have organ transplants without donors it is an easy thing for the Government to think about. Everybody, upon brain death, should be a donor. That does not mean that a lot of people who do not seem to have a brain should be donors. In this country voting is compulsory. It is easy. Everybody, upon brain death, should be a donor. If you had that, like they have had it in Spain, France and Belgium for years, you would have much more people.

France is where I go. I have been going there since 1970. I am an honorary French citizen and I go there every year. I have just come back from France. We conduct workshops and we teach them how to do this. There are nearly 70 million people there. Anyone who is about to die and who is near a hospital is on a register. How do they do it? Let me explain it to you. I have here copies of the colour pictures that are put out around the country. I will hold them up for you so that you can see them. In France all over the country in a week—we do not advertise like this—coloured brochures are issued.

Why graft? You cannot do a graft on somebody's heart. It is not possible to use other forms of treatment otherwise you will have a death. The same thing applies to heart, liver, lungs, and so forth. So there is a big coloured brochure for people to see. Another brochure headed, "All citizens are organ and tissue donors", explains it to them. France is divided up into seven sections. I am giving this as an example. The same thing occurs in Belgium, et cetera, and there are about 10 million people in each. They are organised by government, which has a big department and it is all done by computer.

Those computers are mixed with European computers and we now have Eurograft. That has been in place for 20 years. If they do not want the organ in France it can be shipped

immediately to another country. The same thing works in England, France and Belgium and Spain. Some of the other countries do not have any collection services whatsoever. Basically, it is a question of whether the Government really wants to push this at a Federal level. New South Wales should always lead in these things anyway, which is why you are interested in it. If they are going to do it, it must be done properly. That is my way of thinking.

To prevent the traceable reasons why you do not want to be a donor you can have another of these brochures sent to you. If you do not want to be a donor, because everybody is, you write in and officially disqualify yourself. That is the clause that the Chair was asking for earlier. This brochure refers to voluntary live bone marrow donors, which Mr Heiler did not quite mention but which he would have mentioned if he had had the time. You can donate your bone marrow, which again is a transplant. So add that to the skin that you can donate and the corneas. However, you cannot donate corneas while you are still alive.

You can donate bone marrow, and skin for burns. One brochure explains to people that they can donate skin. This brochure is all about "La mort cérébrale", or brain death, what it means, what precautions must be taken and what tests have to be done to prove that somebody is brain dead. The public are fully aware, and continue to be made aware, of these things every year. What steps do you take if you do not want to be a donor? That is very important. A lot of people think twice about donating. You can donate blood vessels voluntarily. There are some vessels and nerves in your body that you can donate that you do not need. Kidneys, of course, are the most common one. There are a large number of kidney donors in a number of countries.

Brochures are issued for heart, liver, pancreas and lung donors. Another brochure is issued for lung and heart donors. Another one is issued which answers questions that people ask about donation, and so it goes on. People want information about rejection. They want to know what that is, so a beautiful coloured supplement on that is prepared. Another brochure is issued about how to co-ordinate the seven regions and how to co-ordinate in hospitals. They go to a lot of trouble and they spend a lot of money. It is worth it for the people who eventually get the organs. It is well organised in France.

I would say that you should seriously consider making it compulsory—without using the word "compulsory"—to ensure that every citizen is a donor, unless he or she objects strongly to the registry. That would be widely circulated and it would immediately double, at least, the number of donors we get. It is a big State—it has 4.5 to 5 million people that we know about. When they die the hospitals have a way of telling whether or not they are brain dead. Does anyone have any questions about that? It would be a big advance if you came to a decision only to consider it. New South Wales does the majority of transplants in the whole country, nearly equal to the rest of the country, and we should be leading. I have always thought that New South Wales was ahead of Victoria at least, and specially in this area. I have lots of pictures to show you, if you have the time.

Mr HUNTER (STAYSAFE): Is it possible to get copies of the relevant legislation in these countries?

Professor OWEN: That is a very good idea.

Mr HUNTER (STAYSAFE): I know it would probably be in a different language, but we might be able to get it translated.

MR GIBSON (CHAIRMAN): Last year I note that the number of heart and lung transplants was zero. Is that because none were available, or does the cost factor come into that?

Professor OWEN: I would say that at least three factors come into that. One is that when people are in extremis they tend to be on some form of a pump, either keeping their hearts alive with stimulation, or a tracheostomy is done and their lungs are expanded. But the lungs fill up with fluid and they are hard to manage. To get a donor who has a good heart and a good lung at the same time is difficult. That is one of the factors. Another factor is that there is a huge amount of tissue and families are not happy about that. You probably have another reason.

Mr HEILER: The incidence of heart-lung transplants at the same time is not great.

Mr BARTLETT (STAYSAFE): The success rate?

Mr HEILER: No, the success rate is fine. They are not done all that often.

Mr HUNTER (STAYSAFE): In the past did you not have to have both done?

Professor OWEN: No, separately. You can have your own heart taken out and another heart put into the space where the heart was, or you can have an auxiliary heart like the recent case when the auxiliary heart took over from the main heart.

Mr HUNTER (STAYSAFE): I thought in the past in order to have a successful lung transplant you needed the same heart?

Professor OWEN: No.

Mr HUNTER (STAYSAFE): So why do we do heart-lung transplants? You are only implanting organs from another body.

Mr HEILER: If the patient needs a heart and a lung they will do a heart-lung transplant. That is what I am saying. There are not many of those.

Mr HUNTER (STAYSAFE): So really there are two donors?

Mr HEILER: Yes.

Professor OWEN: Then the recipient can become a donor. If they have a heart and a lung, they might not use the heart and that will go on to someone else. So it can actually go on to a third person. It depends what is wrong and what transplants they do.

Mr HUNTER (STAYSAFE): I do not quite understand why you would pull out someone's healthy heart.

Professor OWEN: No, you do not. It is not healthy.

Mr HUNTER (STAYSAFE): It might be useful?

Professor OWEN: I cannot think of an instance. Can you?

Mr HEILER: No.

The Hon. IAN WEST (STAYSAFE): You have had experience in France. To put it in the crudest terms—I wish there were better words—and referring to supply and demand could you give us your expert advice on this method? In France you have a larger supply.

Professor OWEN: There are 70 million people and they are worse drivers than we are.

The Hon. IAN WEST (STAYSAFE): Is the demand being met?

Professor OWEN: No. The demand is not being met. Being in a foreign country and despite the fact that we were taking the donor and doing the hand transplant, we still believe we should have asked the relatives because they may have been against it. So we got knocked back several times. In November last year the team did a face transplant, which has made all the front pages. That patient is brilliant now. She has full feeling in the rest of her face. I have pictures to show just how good she is. The movement has come back completely on one side of her face and the other side is missing just a bit of movement, but that is coming good. It is a beautiful result.

To get a donor for that without asking for the permission of the person who is dead to me seems incomprehensible. They do turn you down. I was in France twice last year because we had donors that were suitable. Their tissue type was done. We checked their full history to ensure they did not have cancer. Donors have to deal with a huge number of issues. You say, "Why are there not enough donors?" There might be heart disease in a person or a form of communicable disease. You do not lay it all out because you think they know that, but they do not. Their lungs may be hopeless. They might have had hepatitis, or they might have severe diabetes—Type 1 or Type 2 diabetes.

You do not transplant these people's organs, even if the family wants you to, because they are not suitable. You need almost pristine organs. That does not mean to say it cannot be an old person like me, because my heart is still working very well and so forth. You know what I am talking about. So you will get fewer donors if you ask. However, you get a lot more donors if it is compulsory. We then asked the elder of the family in France who did not sign a form that he was against it and he said, "It is my desire and I give consent that any part of my body can be used—tissue and organs." If it was not tissue we could not do a face transplant or a hand transplant, as they are not considered organs. There is not time to show you all the pretty pictures that I would like to show you. I can show you the latest pictures of the face transplant. Pass these around. You can see how well she is doing. It will be on television soon. In May 2006 there will be a program about the complete operation and result.

Mr GIBSON (CHAIRMAN): Was that somebody else's face?

Professor OWEN: Absolutely.

Mr SOURIS (STAYSAFE): Did you not see it on television?

Mr GIBSON (CHAIRMAN): I did.

Mr SOURIS (STAYSAFE): It is fantastic.

Professor OWEN: The first double hand transplant is probably the best example of a massive amount of tissue called composite tissue because it is skin, which is the hardest to immunosuppress; it is very difficult. The skin is there to protect you. It is the biggest organ you have got. It is hard to take a piece of skin from a cadaver and put it on somebody else. You need to do a lot of tissue modifying with deep ray therapy or atomic washing, if you like, sterilisation and so forth. Otherwise it will reject very quickly. You have got muscle, tissue, bones, fat and so forth.

Mr SOURIS (STAYSAFE): I cannot help feeling that we are missing out. I am in favour of your compulsory policy but I feel that we are missing out on many potential donors because of the regional thing. I think I saw that only 20 hospitals do transplants. So you have to be taken to one of the 20 hospitals as a trauma victim. Is that right?

Mr HEILER: No. The 20 hospitals are part of a collaborative approach to look at different methodologies for procurement.

Mr SOURIS (STAYSAFE): If I am taken to Singleton hospital my wish to be a donor will not be fulfilled.

Professor OWEN: It can be if you are going to survive more than 10 hours after you are taken there.

Mr GIBSON (CHAIRMAN): If you are on life support.

Professor OWEN: Without life support even. But with life support with our wonderful system of helicopter air ambulances we can take care of your desire by all means.

Mr HEILER: One of the reasons that we do not get a lot of donors in the rural and regional areas is that when someone gets sick or is injured in those areas they come to the intensive care units in the major cities, such as Sydney. That is where they become brain dead. So it is not that you are missing donors from the country; it is just that they are declared brain dead in the city not in the country. You have got to be careful just how you look at those statistics.

Mr SOURIS (STAYSAFE): But a trauma patient would probably go to a district hospital and then a helicopter might take them to John Hunter Hospital in the Hunter. But that is a lot of hours.

Professor OWEN: Yes, it could be.

Mr SOURIS (STAYSAFE): Sometimes the helicopter goes to the scene and the patient is taken to a teaching hospital within an hour.

Professor OWEN: Obviously the better donation of the organ or the tissue is as fast as you can get it in. But you can preserve things considerably. Any organ or tissue has a blood supply—that is how it is alive—and you can perfuse it. There are means of mobile perfusion. In France you can go hundreds of miles to pick up your donor after he is dead and bring him in very quickly to the hospital where the organ is needed because of the system of dividing the country into seven sections and having a fabulous systems that is run by doctors in charge and nursing staff who are programmed and trained to ask the right questions, to be in the hospitals and to soothe the problems—the very big problems—that the families have. They have been doing it for a long time now and they are very efficient. The public are getting more and more aware, especially in times of crisis, that anybody can die from a bomb or something like that. But maybe they are just shocked and not dead and they could be revived with a donation of some sort.

Mr SOURIS (STAYSAFE): But the donor still has to reach the hospital where the specialist team is located.

Professor OWEN: No, the donor does not have to, the organ or the tissue has to. In France we go out and get just a kidney or a heart.

Mr HEILER: We do that here too.

Mr SOURIS (STAYSAFE): The team goes out and gets the organ.

Professor OWEN: Yes.

Mr HEILER: We have two retrieval teams—one is at Westmead and one is at RPA. The air ambulance or CareFlight—

Professor OWEN: They are all organised.

Mr SOURIS (STAYSAFE): They would not go to Singleton. It would only be when the donor got to John Hunter, for example.

Mr HEILER: If the patient was in Singleton they could do it there. They can do it anywhere.

Professor OWEN: If a person dies suddenly—they have no heartbeat—and they are sure that they do not have any brain function then they will call straightaway to Royal Prince Alfred—

Mr SOURIS (STAYSAFE): They would do that?

Mr HEILER: Yes. Absolutely. But the majority of people who meet the criteria to be an organ donor die in major Sydney hospitals and not in rural areas.

Mr HUNTER (STAYSAFE): So they could remove the relevant organs and transport them to wherever.

Mr SOURIS (STAYSAFE): I have another question about policy. I hope I am right in this assessment. The list of potential recipients is prioritised so if you are younger you are more likely to be higher up the list and so on.

Professor OWEN: Not necessarily.

Mr HEILER: Not necessarily, no.

Mr SOURIS (STAYSAFE): I know some people who have been told, "You are too old. You are 70 and you are going to be beaten every time by another recipient."

Professor OWEN: Not true.

Mr SOURIS (STAYSAFE): Therefore, my question is: Would not older donors be suitable for these older patients?

Professor OWEN: That is one factor. It always amuses us doctors when we hear stories about someone saying, "I've got cancer and the doctor says I've only got four weeks to live so I'm going on a binge." Doctors do not say that. We do not know how long you have got to live. But if you are 70, you have heart failure and you really are in need of a heart and you are a young kid who has got a series of heart defects that are going to kill you within the next 10 years, if there is a heart available obviously the older person will get it.

Mr SOURIS (STAYSAFE): Would an older person's donor heart go to a kid?

Professor OWEN: Yes, that is okay if the heart is fine.

Mr HEILER: It is more likely to be a kidney. I think we had one instance—I am not sure of the actual ages—where it was an elderly donor and the kidney went to a child.

Mr SOURIS (STAYSAFE): There is a misconception in the community that older donors are useless and that younger recipients will always beat an older potential recipient.

Mr HEILER: If an older person died or was pronounced brain dead in the intensive care unit, regardless of the age, the clinicians would make a decision as to the suitability of that person becoming an organ donor. They are clinical decisions.

Mr HUNTER (STAYSAFE): So if they are 70 years of age their heart could still live for another 30, 40 or 50 years in a younger recipient.

Professor OWEN: Yes. It is just a pump.

Mr HEILER: Clinically, providing the organ is of a suitable quality for transplant.

Mr SOURIS (STAYSAFE): I saw a Foxtel program about a doctor who was waiting for a transplant. An older donor made it work for him. That older donor would not have been suitable for others so he was the recipient.

Professor OWEN: That was an American program.

Mr SOURIS (STAYSAFE): Yes. The recipient was an American doctor.

Professor OWEN: We do not have the same criteria for life as other countries do.

Mr SOURIS (STAYSAFE): They flew the organ by Lear jet for six hours.

Mr HUNTER (STAYSAFE): I have two questions. You mentioned cancer. If someone has lung cancer or liver cancer, for example, are they able to have a transplant or do we not transplant to people with cancer because cancer cells could have spread to other parts of their body?

Mr HEILER: That would be the usual case, yes.

Professor OWEN: Yes.

Mr HUNTER (STAYSAFE): If we were flush with organs for transplant would cancer patients then start to be considered for transplant?

Professor OWEN: If they did not have secondaries in vital places, yes—prostate cancer, for instance.

Mr MAGUIRE (STAYSAFE): Professor, what is the rejection rate of organ transplants?

Professor OWEN: That was one of my slides. The more experienced the transplantation unit is, the more it can gauge what dose to start on a person of a specific weight in kilograms. We know the drugs that will keep rats alive for their entire life of up to four or five years—rats usually die about one to two. We can organise to go and look at all the doses given all around the world and find the dose for a person your size who has a heart transplant. We then gradually lessen it over the years until either a form of tolerance to that organ has developed—possibly because the lining of the inside of the blood vessels is taken over by the person who has received it; the recipient. There are these considerations. But you try to give enough immunosuppressive drugs to stave off the inexorable rejection of that organ or tissue. You are on a constant adjustment if you are part of the team that is doling out the doses of these drugs to the recipients.

The big advance happened when we did the first hand transplant because we had a dreadful patient—Clint Hallam—who we did not know was an escapee from a prison in New Zealand. He was a naughty boy and did not like taking his pills. He did not like doing his physiotherapy either. He found out that if he stopped taking his immunosuppressants little red marks appeared on the skin of the transplanted hand. If he started taking his drugs again to the normal dose they went away within 48 hours. He did not tell us this, of course, until he ran out of pills because he was not the sort of patient who did what he was told. We found that was terrific. So now when we do hand transplants, and with the face transplant, we transplant with the organ a bit of donor skin to an area where it will not show—under an arm or something—and we look at that and see when the little red spots occur. That helps us to adjust the dose long before a biopsy will tell you that it is rejecting, which is a big advance. It gives us a window into a heart transplant where otherwise you would have to biopsy, and it is not easy to biopsy a heart or a liver.

Mr MAGUIRE (STAYSAFE): And accidents can occur with biopsies.

Professor OWEN: Yes, of course they can. You have got to understand that the people who do transplants are really aware of people's feelings—relatives' feelings, wives' and husbands' feelings and especially the feelings of parents of children—about what is going on. They take enormous trouble in this country and in France, Belgium and so forth to live up to the highest standards that you would apply yourself. But we are desperate to get better and more donors. I come back to the point—it is past our time—that it would be very nice if the Commonwealth Government would allow us to have everybody a donor. After all, we are all voters. We do not even think about that but there was a huge controversy about compulsory voting.

Mr HUNTER (STAYSAFE): Is that an area of Federal Government legislation?

Mr HEILER: No, at the present time it is covered by individual State human tissue Acts. They are based on draft legislation from the Australian Law Reform Commission from about the late 1980s.

Mr BARTLETT (STAYSAFE): I think there is general consensus around the table about what you are advising. It is just a matter of bringing down the report and hoping that someone listens to us.

Mr HUNTER (STAYSAFE): Of the people who are on your waiting list for a transplant, do you state why they need a transplant—what has caused them to need a liver transplant, for example?

Mr HEILER: I am not aware of that.

Mr HUNTER (STAYSAFE): The type of disease or whether it is self-inflicted. I am trying to work it out.

Professor OWEN: If it is a liver it is usually liver damage due to self-abuse, drugs or whatever.

Mr HEILER: Haemochromatosis.

Professor OWEN: But there are many diseases that affect the liver because the liver is the only thing you have got that makes all the products and keeps everything else alive. So the answer is yes. But we are more meticulous, I think, with checking up on the donor than we are with the patient.

Mr GIBSON (CHAIRMAN): Thank you very much. It has been a great pleasure to meet you today, Professor Owen. You have the admiration of everyone here for being such a great Australian. I say that without trying to embarrass you. You are a genius.

(Professor Owen and Mr Heiler withdrew)

Appendix A – RELEVANT EXTRACTS FROM THE MINUTES OF THE STAYSAFE COMMITTEE REGARDING ORGAN AND TISSUE DONATION

No. 53/45

STAYSAFE

PROCEEDINGS OF THE JOINT STANDING COMMITTEE ON ROAD SAFETY

9:30 A.M., MONDAY 1 MAY 2006 AT PARLIAMENT HOUSE, SYDNEY

MEMBERS PRESENT

Legislative Council	*Legislative Assembly*
Mr West	Mr Gibson
	Mr Souris
	Mr Hunter
	Mr Maguire
	Mr Bartlett

Also in attendance: Mr Faulks, Manager of the Committee, Mr Nordin, Senior Committee Officer, Ms Phelps, Committee Officer, and Ms Yeoh, Assistant Committee Officer.

The Chairman presiding.

1. Apologies

Apologies were received from Mr Tingle, Mr Colless, Ms Hay and Mr Barr.

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6. Briefing on organ and tissue donations and transplants

The Committee received a briefing on organ and tissue donations and transplants.

Professor Earl Owen
Mr Bill Heiler, New South Wales Health

appeared before the Committee.

The Chairman and Members examined Professor Owen and Mr Heiler.

The briefing concluded, and Professor Owen and Mr Heiler withdrew.

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9. General business

There being no further business, the Committee adjourned at 12:50 p.m..

Chairman Committee Manager

STAYSAFE

PROCEEDINGS OF THE JOINT STANDING COMMITTEE ON ROAD SAFETY

10:00 A.M., THURSDAY 29 JUNE 2006 AT PARLIAMENT HOUSE, SYDNEY

MEMBERS PRESENT

Legislative Council	*Legislative Assembly*
Mr West	Mr Gibson
Mr Brown	Mr Souris
Mr Colless	Mr Hunter
	Mr Maguire
	Mr Barr

Also in attendance: Mr Faulks, Manager of the Committee, Mr Nordin, Senior Committee Officer, and Ms Phelps, Committee Officer.

The Chairman presiding.

1. Apologies

Apologies were received from Mr Bartlett and Ms Hay.

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7. Consideration of Chairman's draft report: 'Brief comments on organ and tissue donations'

The Chairman presented the draft report: 'Brief comments on organ and tissue donations'.

The draft report was accepted as being read.

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On the motion of Mr Souris, seconded Mr West:

> That the draft report: 'Brief comments on organ and tissue donations', be read and agreed to.

Passed unanimously.

On the motion of Mr Souris, seconded Mr West:

> That the draft report: 'Brief comments on organ and tissue donations' be accepted as a report of the STAYSAFE Committee, and that it be signed by the Chairman and presented to the House.

Passed unanimously.

On the motion of Mr Souris, seconded Mr West:

> That the Chairman and Committee Manager be permitted to correct any stylistic, typographical and grammatical errors in the report.

Passed unanimously.

8. General business

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There being no further business, the Committee adjourned at 11:20 a.m..

Chairman Committee Manager