Submission No 39

Received 23/6/99

Queensland Health

Submission to the Legal, Constitutional and Administrative Review Committee

Transplantation and Anatomy Amendment Bill 1998

Executive Summary

A Legal, Constitutional and Administrative Committee was established by Parliament to consider and report on the Transplantation and Anatomy Amendment Bill 1998. The Committee called for submissions from a wide range of stakeholders involved in transplantation services, including Queensland Health.

The following paper discusses the current issues surrounding donation and transplantation in Queensland and outlines Queensland Health's strategy to improve and/or maintain donation. Rationale for opposing the Transplantation and Anatomy Amendment Bill 1998 and the function of 'Queenslanders Donate' are also discussed.

In response to specific questions raised by the Committee, other topics - legislative barriers to current practice, the relationship to 'Australians Donate', the Spanish and South Australian models of donation, and donor-recipient contact, are also addressed.

Background

A Private Member's Bill regarding organ donor indication on driver's licences was introduced into Parliament by the Member for Thuringowa on 10 November 1998. The Bill is intended to give legal effect to the marking of the organ donor space on driver's licences, thus aiming to increase organ and tissue donation rates in Queensland. In effect, the marking of the "donor" section of a driver's licence would count as "signed in writing" for the purpose of the *Transplantation and Anatomy Act 1979*. There would be no need for designated officers to make any further enquires, or to contact the next of kin about the matter.

The Transplantation and Anatomy Amendment Bill 1998 was debated in Parliament on 14 and 28 April 1999. Subsequently a decision to refer the Bill to a Legal, Constitutional and Administrative Review Committee was supported. The Committee will report to Parliament by 1 August 1999. Submissions from a wide range of stakeholder involved in organ and tissue donation and transplantation have been requested by 10 June 1999.

Queensland Health received $323,000 as new initiative funding in 1998/99 to develop and implement strategies to increase organ and tissue donation in Queensland. These strategies will be implemented through the establishment of 'Queenslanders Donate'.

At a federal level, the Australian Health Ministers Conference endorsed the establishment of 'Australians Donate' on 1 August 1997, to replace the previous organisation ACCORD (Australian Coordinating Committee on Organ Registries and Donation). The new organisation has the key responsibilities of increasing donor rates nationally, improving the coordination and networking of existing donor registries and databases nationally and implementing public and professional education programs to raise awareness and understanding of organ/tissue donation issues. A National Director was appointed in June 1998.

The national body 'Australians Donate' met for the first time in October 1998 to develop a national level framework to improve organ/tissue donation rates across Australia. Queensland Health considered it appropriate to await the outcome of the National Forum ('Australians Donate'), which was held on 11 & 12 April 1999, to ensure that the Queensland direction was consistent with the general principles of 'Australians Donate'.

Therefore 'Queenslanders Donate' has been established to be congruent with the strategic direction of the National body.

Setting the Scene – Donation

Medicine is an evolving science necessitating an ongoing review of the ethical and legal parameters in which it operates. The earliest recorded skin graft dates back to 1869 and corneal graft to 1906 (Porter, 1999). Issues surrounding transplantation and donation of organs and tissues have received increasing attention in the last decade as possibilities in the field have expanded and as the community has become more involved in the debate about the allocation of limited health resources. Transplantation in Australia dates back to the early seventies when renal transplants became a practical tool for the management of end stage renal disease.

Although the community's focus is predominantly on solid organ donation, both regenerative and non-regenerative tissues are important aspects of the total picture. The donation of organs includes heart, lung, liver and kidney. The kidney is the only organ which can be donated by a living donor, due to the body's capability to survive with one healthy functioning kidney.

Tissue donation includes regenerative tissues such as blood, bone marrow, bone, liver segment, sperm and ova. Decisions about the donation of regenerative tissue can be made by living persons.

Decisions about donation of other tissues and organs can be made by an individual prior to death or by and individual's family after death. Due to the time constraints for organ preservation, the donation of a family member's organs is an ethical decision made at a time of great emotional distress.

As discussed in an NHMRC paper 'Donating organs after death' (1997a)
"organ and tissue donation is a decision which will affect those who are left behind after someone has died. Since the issue of organ donation often arises after a sudden and traumatic death, the feelings of the bereaved family are very important"p12.

Respect for the wishes of relatives also decreases the likelihood of negative publicity adversely effecting the community's attitudes to donation. Although written consent is legally sufficient to allow organ donation to take place after death the practice in Queensland is to involve the potential donor's family in the donation decision.

It is necessary to acknowledge that Australia is a multi-cultural nation with diverse religious, ethical and moral beliefs. All of these can affect individual and the community perception and acceptance of organ donation.

Improving health through transplantation needs to acknowledge the continuum and interdependence of the components of donation, retrieval, allocation and transplantation (Brennan 1997).

Why is donation an important issue?

For an ever increasing number of Australians with life threatening illnesses, transplantation of organs or tissues provides the best chance of preserving life or achieving some quality of life (Pearson & Chapman, 1999). Australia has one of the highest rates of successful transplantation in the world with over 15,000 Australians receiving donated tissues and organs since the 1940s. However each year 20% of Australians on organ transplant waiting lists die before a suitable donor organ is found.

Diseases which can be assisted by organ transplant are increasing. For example, in Queensland the incidence of end stage renal failure is increasing both as a per capita rate and in absolute terms as the population increases. Although renal failure can be assisted by dialysis the waiting list for renal transplant is increasing as donor rates fail to meet the demand for organs. Renal dialysis is one of the ten most frequent treatments in major Queensland hospitals (Health Information Centre, QH 1999).

Donation Rates.

The Australian and New Zealand organ donation rate between 1993 and 1997 remained relatively unchanged at 10/11 donors per million of population (dpmp). However Australia has a smaller rate of organ donation than other developed countries. In 1997 International Donor rates for percentage of Multiple Organ Donors were led by Spain with 29 dpmp, 20.6 in the USA and 20.5 in Portugal.

In 1997, in Australian States with a sufficient population to make figures meaningful, the range for donation was 17 DPMP in South Australia to 4 DPMP in Western Australia. Nevertheless, the proportion of donors in Queensland is greater than all other states, except South Australia.

In Queensland the donation rate from 1993 –1998 (DPMP) was:

1993	14
1994	12
1995	10
1996	10
1997	11
1998	12

Interstate and international comparisons of donation rates are not always meaningful due to the influences of factors such as better surgical management, changes in clinical practice, improvements in lifestyle, and advances in technology and pharmacology, contributing to fewer deaths.

In Queensland, the organ and tissue donor rate began to significantly decrease during the early 1990s. There are a number of possible reasons for this including the reduction in the road toll, the decrease in drowning rates via the introduction of compulsory pool fences and the introduction of mandatory bicycle helmets. Better

surgical management and advancements in the treatment of hypertension, and subsequent reduction in strokes, have also been identified as contributing to this decrease. Other impacts on the rate of organ donation, such as those linked to social trends or general hospital administrative procedures, are less identifiable as the organ donation process takes place on an ad hoc basis and is largely due to the goodwill of the next of kin of donors and the hospitals involved.

Therefore it is proposed by some stakeholders that actual the number of deaths, and potential donors is a more useful method of comparing donation rates. The current data shows there has been a consistent reduction in donors per thousand deaths in Queensland and Western Australians and a steady increase in South Australia.

In examining 1996 figures for donors per thousand deaths in 1996 Queensland's rate was comparable with other States at 1.56, except South Australia (2.15) and the Northern Territory (3.89) (Australian and New Zealand Organ Donation Registry 1998 Report).

In the 1995/96 financial year, 11,527 people died in hospital in Queensland. Approximately 0.5% of these became organ donors. A benchmark of 1% has been identified as the ideal target rate for organ donation. Most of the population, whatever their age, can potentially donate tissues or organs. Exceptions would include individuals who are HIV positive and those with gross infections. For example, corneas can be donated up until donors are 90 years of age.

It also needs to be appreciated that all donors are not accepted because the organs/tissues cannot be retrieved within the short time that organ viability can be maintained (refer to attachment A). A further restriction is that organ/tissue retrieval can only be performed by qualified staff who work within a Therapeutic Goods Authority (TGA) approved centre.

Brain Death

Death is defined in the *Transplantation and Anatomy Act (1979)* as having occurred when there is –

- Irreversible cessation circulation of blood in the body of the person or
- Irreversible cessation of all funtion of the brain of the person.

In circulatory death rapid deterioration of vascular organs occurs due to lack of oxygen (ischaemia) thus rendering the organs unsuitable for transplantation. Tissue is less susceptible to this ischaemic damage and may be suitable for transplantation for up to 2 hours if the body is refrigerated soon after death.

In brain death the circulation remains intact therefore both vascular organs and tissues are able to be removed for transplantation. However potential donors must be kept ventilated to preserve oxygen supply to the body. This can make the acceptance of 'death' difficult for family members.

'Brain death' can only be determined after a series of clinical criterion are met and must be certified by two experienced doctors who are not involved in the transplantation services. This definition assists in understanding why organ donation

can only be carried out in hospital settings, and usually follows a sudden incident such as a motor vehicle accident, drowning or cerebrovascular accident (stroke).

The South Australian Model

Mr Bruce Lindsay, Executive Director, 'Australians Donate' and Professor Geoffrey Dahlenburg, Director South Australian Organ Donation Agency and Council Member 'Australians Donate' propose that there are two main contributing factors to South Australia's relatively high rate of donation.

The first possible factor is improved communication within hospitals. Most staff in the South Australian Tertiary and major Secondary hospitals are well aware of the importance of a proactive organ/tissue donation system.

The second contributing factor is more proactive and aware Intensivists. In South Australian Tertiary hospitals Intensivists have a role in promoting organ/tissue donation through actively encouraging and supporting families of 'brain dead' relatives in Intensive Care Units to consider organ/tissue donation. Once the medical team has identified a potential donor the donor coordinators work with families to encourage an informed consent for the potential donation. The medical staff work in a part time capacity to perform duties in addition to their existing Intensive Care responsibilities, for which the Intensive Care Unit is remunerated by the South Australian Organ Donation Agency. This issue is further discussed below in comments on the European Consensus Document.

In comparison, in Queensland knowledge concerning organ/tissue donation varies in Queensland hospitals staff. Those in hospitals that house the present Donor Coordinators - Princess Alexandra Hospital and The Prince Charles Hospital - have higher levels of knowledge, however the donation rates remain low. The level of awareness in Intensivists also varies

Another essential factor to consider in analysis of the Queensland situation when compared to South Australia, is the size and decentralised nature of the State. In 30 minutes it is possible to fly out of the borders of South Australia. In contrast 30 minutes flying in Queensland reaches Bundaberg in the north. In addition South Australia's four major Tertiary Hospitals are located in Adelaide, in relatively close proximity to most donors and secondary hospitals.

Queensland's major Tertiary hospitals are all located in the southeastern corner of the State and not within easy reach of donors or secondary hospitals. The major Provincial hospitals are a considerable distance from Brisbane. As previously stated, time is of the essence in organ/tissue retrieval and a potential donor must be kept on a ventilator until such time as retrieval and consent can be organised.

The Spanish Model

The 'Spanish Model' of donation has created a great degree of interest internationally for those involved in donation and transplantation. In 1989 Spain established the Organization Nacional de Tranplantes (ONT) to take responsibility for co-ordinating and recording of organ donation throughout Spain. The rate of organ donation rose from 14 donors per million population (pmp) in 1989 to 27 in 1995.

Components of the Spanish model included:

- Decentralisation of responsibility and accountability to provincial and local levels
- Donor cordinators located in local hospitals
- Co-operation of regional and National levels
- Transplant coordinators working closely with other agencies (police, media and justice)

The key is to identify all potential donors, to professionalise and optimise the way in which consent is sought and to follow – up families after the initial meeting. Doctors are involved in directly requesting donation of organs and tissues.

The major differences for Queensland are that Spain has the highest doctor to population ratio in developed countries and can therefore afford to employ medical coordinators. Also the country has a more religiously homogenous population which is accepting of transplantation. Australia is a more multi-cultural nation with a range of ethnic backgrounds and religious beliefs. The Brennan Report (1997) acknowledges the need for a special approach to ethnic and Indigenous populations in Australia.

The lessons to be learned from the Spanish model are decentralisation, local accountability, measures of performance, and professionalism in managing donor families before, during and after the consent and donation process (Brennan 1997). The procurement rate mainly results from efforts to overcome obstacles such as untrained staff, unidentified donors and reluctance to approach grieving families. The key issue identified is not just a lack of donors but the failure to turn potential donors into actual donors (Matesanz & Miranda, 1997)

The principles of the Spanish model have been incorporated in the structure of 'Queenslanders Donate', whilst acknowledging the different factors influencing Queensland.

"Meeting the Organ Shortage – Current Status and Strategies for Improvement of Organ Donation" European Consensus Document

The Legal, Administrative and Constitutional Committee sought Queensland Health's response to the above paper, which had been submitted by Dr Rafael Matesanz.

The paper contains principals which are generally supportive of Queensland Health's direction to improve organ donation. However there are elements of the above paper which are not supported by Queensland Health

Specifically the Spanish model employs full time medical staff as donor coordinators, which is not feasible in Queensland. Spain has a relative over supply of medical staff, which is not applicable in Australia The most recent Australian Medical Workforce Advisory Committee estimates that the current intensive care workforce is 398 specialists and that there will be a requirement for 464 specialists nationally by the year 2008. The South Australian model incorporates part time medical coordinators. The Annual Report of the Activities of SODA (South Australian Organ Donation Agency) (1998) states that medical donor coordinators are all senior Intensive Care Consultants who have extra duties including:

- To identify within the intensive Care Unit and other areas of the hospital any potential organ donors
- To discuss with relatives, in conjunction with the Donor Coordinators the option of organ donation
- To provide medical assistance to the Donor Coordinator in the initial stage of the donation process
- Responsibility of the clinical management of the donor
- To identify issues that influence (that is assist or limit) donor procurement in general or with the specific hospital
- The provision of education within the hospital and providing the Intensive Care perspective of organ donation in policy making committees.

The Agency reimburses the Intensive Care Unit for these services and this is reported to be within the range of $20,000 - $40,000 per annum depending on the size of the hospital. Such a system would have significant resource implications for Queensland health with 25 donor hospitals, both in terms of workforce planning and recurrent costs.

The Australian and New Zealand Intensive Care Society, the professional body for Intensivists, in a report on Organ and Tissue Donation, state that "*enquiring about the stated wishes of the patient and requesting consent to organ donation from the family are ethical and professional responsibilities of the intensive care specialist*" – Principle 2.1 (ANZIC 19998).

Therefore Queensland's model will encourage more active involvement of intensivists through - facilitation of evidenced based practice by analysis of the results of death audits, education about organ donation and support from 'link nurses'.

Although there is no doubt that the Spanish Model has increased organ donation there are definitional differences in the paper when compared to Queensland's definitions. "Effective Donor" is defined in the document as "a person from whom at least one solid organ (or tissue) has been retrieved for transplantation". In Queensland the donor rate is calculated on donated and transplanted organs. The transplantation rate post retrieval is high in Queensland – for example 97% of

retrieved kidneys are transplanted. It is extrapolated that under similar definitions the donation rate for Spain would be more similar to the United States figure of 23 pmp rather than 31.5 pmp.

The paper discusses 'The Six Steps' (4.1.2) including donor identification, donor screening, donor management, consent/authorisation, organ retrieval and organ allocation. It is the view of the donor coordinators in Queensland that the first two steps are the barriers to increasing organ donation rates in tis State and that the remaining four steps work efficiently and well. Once consent is obtained the potential of donation is maximised through effective national allocation systems, and cooperative retrieval procedures. For example the Australian donor rate is approximately half of that of the United States, however the transplantation rate of lungs is approximately 30-40% higher pmp.

Issues raised in the paper which are supportive of Queenslanders Donate are:

- The development of a system to detect the gap between potential donors and actual donors in each hospital /area (which has been termed 'death audits' in this submission) (2.1.iii)
- The importance of discussing one's wishes concerning organ donation and transplantation with relatives (2.1.xiii)
- That "the deceased's wishes and the sentiment of his/her family have to be treated with respect. The communication established with the deceased's family and the consideration given to their wishes are essential elements in the process of procurement itself" p19. This is one of the key issues for Queensland Health and the rationale for rejection of the Anatomy and Transplantation Amendment Bill (1998). This is further discussed below.

Why the Bill is not supported

As discussed above there is no doubt that increasing the rate of organ donation has the potential to impact positively on the lives of chronically ill Queenslanders. Therefore the *intent* of the Bill to increase donation rates is acknowledged and supported.

The Private Members Bill advocates that indication of organ donation on a driver's licence should become legal consent

Queensland Health does not support this proposal for the following reasons:

- Irrespective of the legal situation the family should be involved in the decision
- Only 9% of drivers have the licence with them in an ICU situation
- A group of potential donors are missed who are either not drivers or are too young to have a licence
- There is a degree of error in recording the decision to be a donor on the drivers licence
- People often make the decision at the transport Customer Centre when renewing the licence. This is not the ideal situation to be making important decisions about donation.

The Private Member's Bill will not effectively address the shortage of donor organs since the issue of declining organ and tissue donation is complex and it is unlikely that the consent procedures under the *Transplantation and Anatomy Act 1979* are a major reason for the insufficient number of donor organs available

It is Queensland Health's view that other strategies should be implemented to increase the rate of organ/tissue donation and that the proposal to enable driver's licence indication to be legally binding is not supported.

Community Attitudes

Community and other surveys show that a conservative figure of 60% of Australians would be willing to donate their organs after death (Pearson & Chapman,1999). The acceptance of donation as a worthwhile practice is also high in Queensland. A recent Queensland Health survey (April – July 1998), which included questions on organ donation provides the following information regarding community attitudes to donation (refer to Table 1). Additionally giving consent for the use of a relative's organs or tissues can benefit grieving families. In a 1995 survey by the Princess Alexandra Hospital, more than 80% of Queensland donor families indicated that organ donation provided them with some comfort in their time of loss.

Table 1: Attitudes to Donation – Queensland Population Estimates
N= 5,594

In the event of your death would you be willing for one or more of your organs or tissues to be donated for transplantation? Yes 71.7 % ; No –17% Don't know – 10.3%

Are *your immediate family aware of your decision to donate*? Yes 79.9 % No – 15.6% don't know 4.4%

94% *of respondents indicate that they would provide consent for donation if an immediate family member died and had indicated willingness to donate their organs*

Of the 27.3% or were either unwilling or unsure about donation of their organs the following reasons were provided:
against my religion - 9.4 %
don't know enough about it – 5.9%
may upset the family – 5.7%
too old to be a donor – 17.3%
doctors may not try as hard to save a donor – 4.2%
concerned may not really be dead - 4%
don't want body to be cut up – 20%
don't know why – 33.4%
other reason – 33.4%
A further 20% said that they would agree to donation for a relatives organs in consultation with the rest of the family

Source: Statewide Health Survey 1998; Health Information Centre; Queensland Health

The falling rates of organ donation thus run counter to the views of Queenslanders collected in the above survey.

However the data confirms the value of encouraging discussion with family members to increase the awareness of an individual's wishes. One of the keys is to educate the public to discuss organ donation with their friends and relatives to increase awareness of an individual's wishes and any changes in this since formally recording intent.

Recording of wishes can be done by:

- drivers licence indication – ticking yes, no or undecided on the application form
- written consent (this could be stored with a legal will)
- a donor card
- completion of a donation form distributed by Transplant Coordinators on request

There is no capacity to indicate wishes for donation in an Advance Health Directive made under the *Powers of Attorney Act 1998*. The transplant coordinators at the Princess Alexandra Hospital have devised a form to enable people to indicate their wishes, including the specifics of which tissue/organs they wish to donate. This is a variable which can affect consent to donation.

It is Queensland Health's view that multiple strategies need to be implemented due to individual preferences and the limitations of the current licence indication system.

The Current Legal Situation

The *Transplantation and Anatomy Act 1979* authorises the use of a deceased person's body for transplant and related purposes in a number of circumstances. These are:

- where a deceased person, during his or her lifetime, by signed writing consented to the removal after death of tissue from his or her body (for organ transplant or related purposes) and the consent had not been revoked by the deceased person

- where a designated officer in a hospital after making reasonable inquiries believes that the deceased person, during his or her lifetime, orally expressed the wish for, or orally consented to, the removal after death of tissue from his or her body (for organ transplant or related purposes) and the consent had not been revoked by the deceased person

- where the designated officer in a hospital does not have sufficient evidence that the deceased orally expressed the wish for, or orally consented to the removal after death of tissue from his or her body, and the deceased had not expressed an objection to the removal of tissue from his or her body, the senior available next of kin of the deceased person is able to consent to the removal of tissue from the body of the deceased person.

Although Queenslanders may indicate a preference to donate organs on their driver's licence, the Crown Solicitor has advised that the mere indication of this preference does not constitute a valid consent for the purposes of the *Transplantation and Anatomy Act 1979*, as it does not expressly provide that the removal of tissue is for any of the purposes referred to in section 22(1) of the *Transplantation and Anatomy Act 1979*.

Organ and tissue donation is an emotive issue and while there is no legal requirement to consult with the relatives about organ/tissue donation if the wishes of the deceased are known, as a matter of policy, consultation is routinely undertaken with relatives. Processes have been designed to ensure that relatives are approached by only one transplant team.

Legislative Barriers

Queensland Transport has historically provided a service to the organ donation program by offering people the opportunity to indicate their preference about organ donation on their driver's licence.

Currently, under privacy constraints, the *Traffic Act 1949* (Sect 14A), prohibits information being transferred from the Department of Transport to Queensland Health. It is Queensland Health's belief that the general public is unaware that indication of willingness to become a donor on a driver's licence is not available to those who require the information.

Of the 2.2 million driver licence holders on Queensland Transport's database, approximately 50% have indicated "Yes" as their preference to donate organs in the case of their death. A high proportion of the other 50% of drivers selected "Undecided".

Medical practitioners and transplant coordinators report that, knowing a person's preference assists them in approaching the next of kin for the necessary approval to proceed. If the person has indicated "yes" it is uncommon for the family to oppose this wish.

Nevertheless, the driver's licence or an organ donor card is only sighted in about 9% of organ donation situations. It should also be noted that many young persons and non-licence holders may also be potential donors.

In summary the legislative barriers to the release of information could be overcome by:

a) amendment to the Traffic Act (1949)
The Department of Transport have indicated that there is no intent to amend the Traffic Act (1949) at this time.

b) including a question on the drivers' licence application form asking people to authorise the transfer of information to QH. The latter option would involve a periodic down load of information from Queensland Transport to Queensland

Health so that medical staff and transplant coordinators could access this information on a database.

To assist Queensland Health to increase the rate of organ/tissue donation, Queensland Transport has been investigating new or additional mechanisms to assist people in recording their decision and to make that information available to medical practitioners when needed. The value of this information is to be able to say to family members that a relative had indicated that they did want to be a donor, or that undecided had been ticked. If a person had indicated "no" it is still worthwhile asking the family if the person had discussed the issue with the family and had indicated their preference. It is possible for opinion to change during the 5-year period in which a licence is valid. Nevertheless, the family's final decision will always be respected.

Queensland Health has been negotiating with Transport to include consent for the information to be provided to QH when consent for donation is indicated on the driver's licence. Renewal information is sent to driver's six weeks prior to the renewal date, and educational material could be included at this point to encourage prospective donors to discuss donation with their families. Another strategy would be to provide a "freecall" phone at Transport Customer Centres to enable people to discuss any concerns or questions with qualified staff. This would reduce the onus on counter staff to be answering donation questions, which would be an unfair expectation.

Queensland Health's Approach To Increase Organ Donation

Queensland Health is currently committed to a range of strategies aimed at increasing the rates of organ and tissue donation. In the 1998/99 Budget an amount of $332,000 was provided to establish "'Queenslanders Donate'", a comprehensive and coordinated approach to organ donation within the State's hospitals

In May 1997 the Transplant Services Advisory Committee (TSAC) was constituted with the objectives of providing advice to the General Manager (Health Services) on:

- the present situation and how services can be enhanced with a focus on benchmarking
- New developments/treatment
- Strategic directions of services, role delineation, planning
- Human resource issues particularly workforce planning.

Mr Graham Hyde, District Manager, Bayside District Health Service as Chair of the TSAC, is Queensland Health's representative on the National Council of 'Australians Donate' and also the Management Committee of 'Australians Donate'. A Policy Consultative Group has been formed, which aims to bind national level projects to State level projects. Dr John Scott is the Queensland Health representative on this committee but it is envisaged that the newly appointed Manager of 'Queenslanders Donate' will replace Dr Scott. These arrangements facilitate congruence of strategy at a state and national level.

The TSAC also saw a role in developing a framework which would enhance the organ/tissue donation rate in Queensland. In February 1998, the TSAC endorsed the Discussion Paper "Queenslanders Donate - a new way forward".

Since that time several submissions regarding the allocation of the funding were submitted to the General Manager (Health Services). These proposals encapsulated the expertise and experience of a wide range of stakeholders involved in donation and transplantation issues. The structure currently being implemented, 'Queenslanders Donate', combines the strengths from several proposals, whilst maintaining a degree of autonomy for individual donation and transplantation services.

In essence 'Queenslanders Donate' will:

- Provide a structured and consistent approach to donation aimed at ensuring the key elements of donation are met.
- Work with participating hospitals to maintain/increase the number of organ/tissue donors.
- Work more closely with the John Tonge Centre to maintain/increase the number of tissue donations.
- Establish a single point of contact for referral when a death occurs.
- Provide a 24 hour referral evaluation and consent service
- establish quality assurance and audit mechanisms.

'Queenslanders Donate' will be complimentary to and supportive of the objectives of 'Australians Donate'.

Interstate data also indicates that there needs to be effective liaison between hospitals, particularly Intensive Care Units and Intensivists, and Donor Coordinators and that coordination is a vital ingredient in ensuring success. A recent American study demonstrated the value of implementation of in-house coordinators in hospitals and routine notification of all deaths in increasing organ donation rates (Shafer et al. 1998). This was achieved by identifying potential donors and facilitating an organ donor awareness program, which are elements of the Queensland model.

Nevertheless, as has been discussed, when comparing the Queensland system for organ donation with interstate models, it is essential to consider the decentralised nature of Queensland and the timeframes for successful negotiation and retrieval of donated organs.

'Queenslanders Donate' has been established to create a network of staff involved in organ and tissue donation, retrieval and transplantation. The Manager has a key role in coordinating this group of services which previously have not functioned as a cohesive network of services.

This will be achieved by:

- working with the newly formed Transplant Clinical Advisory Committee whose prime role will be to oversee the service and to provide policy direction for the service
- Working closely with 'Australians Donate'

- Gaining access to the Queensland Transport data base on potential donors and managing a Queensland Health Donor Registry
- Providing education material on organ/tissue donation to all participating hospitals District Health Services and Queensland Transport for distribution with driver's licence renewals.

'Queenslanders Donate' comprises the following positions:

- **Manager** - the primary role of the manager will be to establish and manage 'Queenslanders Donate', and to liaise and negotiate with Queensland Health Service Districts, the John Tonge Centre* and private hospitals. The position will coordinate a network which aims to maximise organ and tissue donation. Ms Tina Cooper has been appointed to the position and is expected to commence in June. Ms Cooper is currently one of the transplant coordinators at the Princess Alexandra Hospital Organ and Transplantation Service.
- **Social Worker** - based at the John Tonge Centre*, as part of the Prince Charles Hospital staff establishment. The position aims to increase tissue donation through contact with families of deceased persons at the John Tongue Centre. The position would also provide follow up for donor families and offer bereavement support.
- **Retrieval Technician** - a temporary 12 month position based at the John Tonge Centre, as part of the Prince Charles Hospital establishment. This position would assist in the retrieval of all tissues at the John Tonge Centre*. **Mortuary Technician** - a temporary 12 month position at the John Tonge Centre to assist in the efficient performance of autopsies.
- **Project Officer** - a temporary 6 month position to investigate and analyse the potential to increase tissue donation through the implementation of more flexible working arrangements at the John Tonge Centre*.
- **Intensive Care Coordinating Nurses** - 7 positions functioning one day/week (and backfilled) distributed in metropolitan and provincial hospitals; the role of these positions is to educate and increase awareness of intensive care unit staff and to conduct audits of deceased persons to determine the causes for missed potential donors. The nurses will be a link between the hospital and the donor coordinator centre.

(* The John Tonge Centre is a component of Queensland Health Scientific Services which conducts forensic scientific services and is responsible for performing coronial autopsies).

This structure will facilitate a unified approach to consent, identification of potential donors, hospital and public education, quality care and follow up of donor families.

The outcome of establishing 'Queenslanders Donate' will be evaluated within a 12 month period to ascertain:

- whether organ/tissue donation rates have increased
- if consent to donate organs and tissues has increased
- the results of death audits which measure the number of available donors vs actual donors
- whether cost savings have been achieved through more efficient processes and the replacement of expensive artificial prostheses with human tissue (eg, heart valves)

- whether public attitudes to organ donation have changed (by repeating the Health Information Centre survey)

Donor-Recipient Contact

The issues surrounding contact between donor families and recipients and their families are complex. Historically organ donation and transplantation centres have felt a strong obligation to protect the confidentiality and interests of donor families and recipients (Albert, 1998).

To address this issue a draft policy has been developed by the Transplant Coordinators at the Princess Alexandra Hospital, which is currently undergoing evaluation by the Legal and Administrative Law Unit, Queensland Health.

The proposed model would be similar to that for parties involved in adoption ie future contact requires consent from both parties.

Databases

'Australians Donate' is developing a proposal whereby the Transplant Promotion Council (TPC) would be the holder of a national database. A potential element of the strategy is to include donation options on application and renewal forms for large and national organisations. The objective of this database is to create a single and national database to enable 24 hour access to information for transplant coordinators and Intensive Care Units.

As a precursor to contribution to a National donor database Queensland would need to develop and refine a State database. Having access to information about people's intent to donate as indicated on their driver's licence would assist the establishment of such a database. The information technology issues surrounding the establishment of such a database have not been explored in this paper, however it is acknowledged that considerable resources would be required in establishing and managing a database.

Other Resource Issues

The Committee asked representatives of Queensland Health to identify other financial barriers to increasing donation rates in Queensland.

Three possible areas have been identified:

The first is the establisment and ongoing management of a donor register both at a State and National level. The development and ongoing management of such a register will be resource intensive.

The second issue is that of financial support for living donors in terms of loss of time from employment and family care during periods of hospitalisation and recovery. Medical care is provided through the public health system and assistance for travel

and accommodation is provided through the Queensland Health Patient Travel Subsidy Scheme. Nevertheless other associated costs that can contribute to financial difficulties are not recompensed at this stage.

The third area where increased funding may be warranted is in the expansion of the number of coordinating nurses in Intensive Care Units throughout the State. Early evaluation of the implementation of 'Queenslanders Donate' would assist in determining if increasing resources in this area would be beneficial.

Conclusion

Organ and tissue donation should be based on the dual pillars of organs and tissues being freely gifted and subject to the consent of the donor and/or their family (Brennan 1997).

The Private Member's Bill, while meritorious in intent, is a simplistic approach to a very complex issue. The key elements of successful donation systems are the ability to ensure that all potential donors are identified; that the option of donation is offered to all eligible families; that the option is offered in a systematic and appropriate way; and that the donation is utilised to the maximum extent. The Bill attempts to partially address one element – identification of some donors.

'Qucenslanders Donate' has been developed following wide consultation with experts in the field of transplantation and is based on the strengths of interstate and overseas models. 'Queenslanders Donate' should be implemented and evaluated against specific performance criteria to assess its effectiveness. Modification and refinement can then occur in accordance with gathered information and results.

The implementation of 'Queenslanders Donate' offers an opportunity to maintain or increase the current organ/tissue donation rates in Queensland. Underlying principles are that increasing donor rates can be achieved by raising awareness and improving hospital communications and by supporting the relationships between 'Queenslanders Donate' and the Intensive Care Unit staff.

References

Albert P (1998) Direct contact between donor families and recipients: crisis or consolation? *Journal of Transplant Coordination*, 8; 3, Sept; 139-144.

Australian and New Zealand Intensive Care Society (1998) – Recommendations Concerning Brain Death and Organ Donation; Working Party on Brian Death and Organ Donation Report, 2nd edition. ANZIC.

Brennan PJ (1997) Review of the Australian Coordinating Committee on organ tissue and Donation – summary report.

NHMRC (1997) *donating organs after death: ethical issues*. Ethical Issues in Organ Donation. Discussion paper no. 1. Commonwealth Department of Health and Family Services, Canberra

Matesanz R & Miranda B (1997) *The Spanish Experience in organ donation*. In Organ and Tissue Donation for Transplantation. Ed Chapman, Deierhoi M and Wight C. Arnold, Sydney.

Pearson IY & Chapman JR (1999) Improving organ donor rates. *Medical Journal of Australia* (170), 17 May; 463-464.

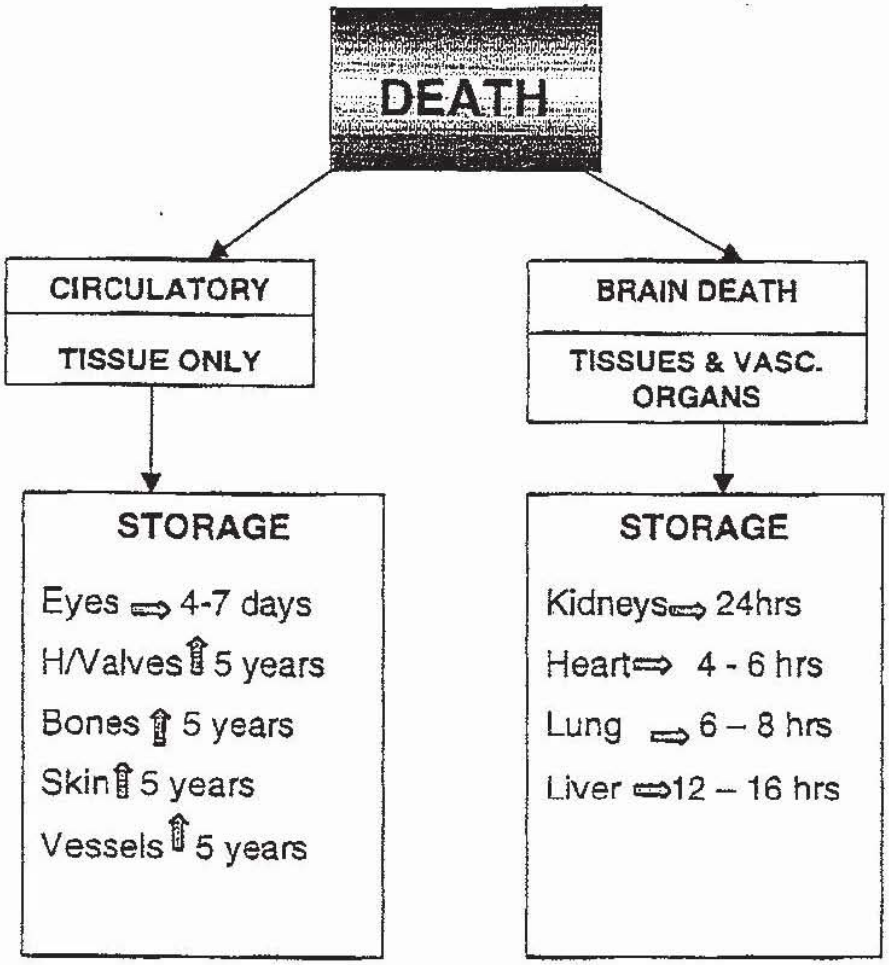
Porter R (1999) The Greatest Benefit to Mankind. A Medical History of Humanity from Antiquity to the Present. Fontana Press, London

Queensland Health (1998) Statewide Health Survey. Total Queensland Population Estimates, Health Information Centre.

Shafer T, Hueneke MJ, Wolf WS, Davis KD, Ehrie RN, Van Buren CT, Orlowski JP, Reyes DH, Gruenfelder RT & White CK (1998) Texas non-donor hospital project: a program to increase organ donation in community and rural hospitals. *Journal of Transplant Coordination*, (8) 3, September; 146 – 152.

South Australian Organ Donation Agency (1998) - Annual Report of the Activities of SODA.

Attachment A



STORAGE METHODS – TISSUES

Bones	- fresh - 70°c dried - freeze dry → shelf
Eyes	- 4°c in solution
Skin	- 4°c liquid N_2
Heart Valves	- 4°c liquid N_2
Vessels	- 4°c liquid N_2