



Transplant Australia Ltd
Suite 2/188 Pacific Highway
North Sydney NSW 2060

Postal Address
PO Box 592
North Sydney NSW 2059

+61 2 9922 5400/Phone
+61 2 9954 6412/Fax
www.transplant.org.au
contactus@transplant.org.au

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Research Director
Review of Organ and Tissue Donation Procedures Select Committee
Parliament of Queensland
Corner George and Alice Streets
BRISBANE QLD 4000

Transplant Australia Submission to the Review of Organ and Tissue Donation

Dear Sir/Madam

Transplant Australia wishes to make the following submission to the Select Committee. On behalf of our National Board and Queensland Branch we wish to applaud your Government for its commitment to improving organ and tissue donation rates in Queensland.

By way of background Transplant Australia is a national community organization of transplant recipients, those awaiting transplantation, donor families, living donors, doctors, nurses and supporters. Our vision is for Australia to lead the world in organ and tissue donation and transplantation – saving lives, improving quality of life and providing much needed care and support.

Transplant Australia works in the areas of advocacy, awareness and support. Our objectives are to increase the rate of organ and tissue donation through sector reform; improve the community's understanding of transplantation; and to provide our members with support, education and guidance to improve their health and quality of life.

Transplant Australia played a key role on the National Clinical Taskforce on Organ and Tissue Donation and its CEO, Christopher Thomas, is the Community Nominee on the National Cognate Committee on Organ and Tissue Donation and Transplantation.

We therefore support without qualification the recommendations of the Clinical Taskforce and the current work of the Cognate Committee. This work has formed the basis of the Reform Package announced by the Federal Government last month. This package undoubtedly represents the most significant opportunity to reform the sector and increase organ donor rates in Australia.

Importantly it addresses and proposes fundamental changes in the areas most likely to yield sustainable results over the long term.

Transplant Australia believes it is crucial that all Governments in Australia support this reform package as the past has been beset by individual jurisdictions at both Federal and State level all attempting their own activities without reference to a consistent national approach.

That said, we believe there are a number of areas that the Queensland Government could focus on in order to achieve best practice in Australia.

South Australia has consistently shown that organ donor rates can be influenced at the state, regional and hospital level. Its rate of donation has traditionally been at times more than twice the national average.

Equally, Spain is often referred to as a world leader in organ and tissue donation. However at the recent summit in Adelaide, it was explained that in this country of 40 million people, there is a significant variance in the rate of organ donation in different regions. This also demonstrates that while a nationally consistent approach works, it is possible to achieve best practice on a smaller scale.

In South Australia we would argue that the most significant factors influencing the level of donation are most probably the 'soft' measures – the influence that a number of senior individuals within the hospital setting have to ensure that donor opportunities are maximized.

In other words, Queensland, while supportive of the national effort, can implement a range of state or hospital-based reforms and programs which can ensure that your state's rate of donation is maximized.

Importantly, no state should be complacent and believe that the status quo is good enough. Nor should we accept that the job is now complete since the Federal Government has released its Reform Package. Organ donor rates can be maximized. Potential donors are being missed; the refusal rate by families is too high. All of this can be positively influenced.

With this in mind, Transplant Australia offers the following comments and recommendations on the Committee's Terms of Reference:

Consent Issues

Transplant Australia, in representing those most affected by transplantation, will always view positively, reforms which have the potential to increase organ and tissue donation rates. We naturally view presumed consent with some favour. However it is clear that it is not a panacea to Australia's challenges and the time is not right for one state of Australia to proceed with such a fundamental change in isolation to the rest of the country.

The most significant barriers to donation lie in the hospital system. Consumer surveys demonstrate that Australians view donation extremely positively. The imposition of a presumed consent model on Australians without their explicit involvement could turn what support we currently have into a negative environment.

We welcome the debate and believe that Australia should explore all opportunities to increase donation rates. However it is important to first ensure that our systems within the hospital and transplant co-ordination sectors are reviewed, streamlined and improved. This is the purpose of the Reform Package.

If, however, Australia does not see a significant increase in donation rates over the next three years following the implementation of the package, it would be appropriate to re-examine legislative reform, including the issue of presumed consent.

That is not to say that there are not other reforms that can be implemented to improve consent issues.

Queensland's rate of registration on the Australian Organ Donor Register is considerably short of the national average. Medicare Australia's data shows that 27.25 per cent of eligible Queenslanders are registered. The national average is 33.49 per cent of eligible Australians. Queensland would need another 198,340 resident to register just to equal the national average. This should be a priority.

Next of kin understanding of an individual's registration could also be strengthened by the inclusion of an optional family witness section on the registration form to demonstrate that an individual has discussed their decision with their family.

Through this method, the role of next of kin in confirming a potential donor's decision, should be more of a formality because the issue will have been previously discussed.

Transplant Australia also believes a family consent form – an adaptation of the current registration form – would help strengthen whole-of-family support for donation. This could be implemented without change to existing legislation in the following manner:

- Family members 18 years and over would be able to consent on the form as currently allowed.
- Family members aged 16 and 17 would be able to register their intent and agree to receive a consent form when they turned 18.
- Family members under the age of 16 would indicate their agreement to receive a consent form when they turned 18.

Through this method a family could show their support for donation and importantly create an environment in which opting-in to donation became just another life decision that a young person considered when they turned 18 (such as enrolling to vote, getting a driver's licence, etc).

We acknowledge that these types of initiatives should ideally be implemented at a national level and we are hopeful that the Select Committee may embrace some of these recommendations to further advance our position.

Creating a positive environment to change behaviour

Australia's rate of organ and tissue donation awareness is, according to most surveys, extremely high. However this does not always lead to a change in behaviour and family refusal rates vary amongst state jurisdictions of between 30 and 60 per cent.

If the rate of consent is to be improved two areas of reform need to be addressed. Challenges and potential solutions in the hospital sector will be addressed later in this paper.

Queensland needs to create an environment in which the public understand the tangible benefits of donation. It needs to create an environment where the need for organ and tissue donation ranks alongside other health awareness areas such as breast cancer or heart disease.

Transplant Australia is already closely engaged with the Queensland Government in staging the world's largest awareness event for organ and tissue donation – the World Transplant Games – in August 2009.

The Queensland Premier Anna Bligh recently launched these games and became an ambassador to promote organ and tissue donation leading up to and during the Games.

The Queensland Government has a wonderful and unique opportunity to maximize the staging of these Games in Queensland to leave a lasting impression and legacy on Queensland and its residents. Transplant Australia urges the Queensland Government to complement its already significant support of these Games through additional public awareness activities including:

- Ensuring there is a whole-of-government support for organ and tissue donation by declaring this important public health initiative its number one health priority for 2009.
- Encouraging all Queensland Departments to include a donation message on their corporate materials, including letters, invoices, websites, etc.
- Transplant Australia has already invested significant resources and time into developing a Community Engagement Program to deliver a consistent and professional message about donation at the grassroots level to schools, community groups and businesses. The Queensland Government could support this work by providing funding for a volunteer in Queensland to co-ordinate local activities to ensure this message is delivered professionally throughout the State.
- This Program could also be delivered in the undergraduate medical and nursing environments and this volunteer position could co-ordinate the delivery of this program to our future doctors and nurses, leaving them with a lasting and positive impression of the success of transplantation.

- Transplant Australia also acknowledges the culturally-sensitive issue of donation amongst Australia's indigenous community and would be prepared to work with the Queensland Government on developing an outreach program to help understanding of donation amongst this significant population in Queensland.
- Joining with Transplant Australia to deliver a number of highly visible public awareness activities during 2009 such as a dedicated State of Origin match focused on donation and other sporting events of great interest to the public.

The importance of public awareness activities which are evidence-based and designed to change consumer behaviour should not be under-estimated and will play a significant role in creating an environment in which donation is viewed positively and becomes an accepted and natural decision for the community.

Challenges and potential solutions in the hospital sector

Transplant Australia acknowledges that while programs designed to change public awareness and understanding are important, the most significant reforms need to occur within the hospital setting.

The National Reform Package has been designed to address some of the fundamental blockages in the hospital sector and we urge the Queensland Government to work within this framework to ensure a consistent approach.

Activities which could complement this national approach yet at the same time be delivered locally and are strongly recommended by Transplant Australia include:

- Ensuring the adequate availability of intensive care beds in each hospital. A review of the availability of intensive care beds in Queensland could be undertaken now and does not have to wait for the implementation of the National Reform Package.
- Ensuring there is a dedicated medical coordinator focused on organ and tissue donation in each Queensland hospital.
- Ensuring high level support for donation throughout the hospital system. This could include a meeting of all hospital administrators where the latest evidence could be delivered by donor and transplant experts to make sure that this important component of the sector understands the emphasis being placed on donation.
- South Australia, as previously discussed, has succeeded in raising donation rates partly because of the individual senior champions within the hospital setting who ensure donation remains a high priority and happens. The Queensland Government is urged to undertake an audit or review of the personnel working within the hospital sector to identify and nurture those 'champions'.
- Paired donation. Transplant Australia acknowledges the growing importance of live donation and believes the Queensland Government should encourage innovative programs such as paired donation.
- In addition live donors often suffer significant economic and financial hardship during the donation and recovery process. We recommend that the Queensland Government could examine the establishment of a fund to assist those donors in their out-of-pocket and health expenses and loss-of-wages. Although full reimbursement would not be viable it would be viewed considerably positively by these donors whose generous decision has not only saved or greatly improved their life of a loved one but has in turn saved the health budget a significant amount of costs for on-going care and dialysis of these patients.

Financial Incentives

Your review also asked for comment in regard to financial incentives. Transplant Australia does not support any proposal to offer financial incentives to potential donors with the exemption of helping to support live donors with their out-of-pocket and health care costs as described above. Financial incentives would undermine the public's confidence in the system and overseas have shown to prey on the poor and vulnerable in our society.

We do however acknowledge that many families waiting for a loved one to be transplanted face significant hardship. Many face loss of income and relocation expenses as they move to be near a transplant centre to wait for a suitable organ.

Transplant Australia believes the Queensland Government could assist these families significantly by providing subsidized accommodation and living away from home subsidies. This would be seen extremely positively by many people suffering financial hardship. Transplant Australia would be more than prepared to work with the Government on developing a proposal in this area.

Summary

Transplant Australia in this submission has not attempted to address all of the challenges and opportunities in the hospital sector as we anticipate that the Queensland Government will embrace many of the proposals recommended in the Reform Package.

We applaud your Government's commitment to this area and the establishment of this Select Committee. We have been impressed by the professionalism and understanding of this issue shown by the Committee's Chair, Ms Karen Struthers MP, and research staff.

Transplant Australia would be more than prepared to address this submission with the Committee if further information or comment is sought.

Yours sincerely,

A handwritten signature in dark ink, consisting of a long horizontal stroke followed by a stylized, looped flourish.

Christopher Thomas
Chief Executive Officer