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BY:

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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

Dear Ms Cawcutt

SUBMISSION TO REVIEW OF ORGAN AND TISSUE DONATION PROCEDURES SELECT COMMITTEE

I refer to the Issues Paper prepared by the Review of Organ and Tissue Donation Procedures Select Committee.

I now **enclose** for your consideration, I submission I have prepared with comments in response to a number of the issues identified in the Issues Paper.

Should you wish to discuss any matter or require any further information please do not hesitate to contact me on my work telephone number or mobile number

Yours faithfully

Margie Kruger

SUBMISSION TO REVIEW OF ORGAN AND TISSUE DONATION PROCEDURES SELECT COMMITTEE

My partner Debbie was on the Queensland Heart Lung Transplant Unit waiting list for just over 2 years and 2 months. Debbie was awaiting a double lung transplant.

Debbie died on 29 October 2007.

Debbie died waiting.

I have prepared some comments as a response to a number of the issues identified in the Review of Organ and Tissue Donation Procedures Select Committee Issues Paper. These comments are a summary of the thoughts of both Debbie and I. I would appreciate your consideration of these comments after reading about Debbie's story.

The investigation and report on organ and tissue donation procedures for some families in Queensland is about life and death.

The issues are complex, the subject matter is emotion provoking, the viewpoints are competing, and those with an interest in organ and tissue donation are varied. It is agreed however that Queenslanders like Debbie are dying awaiting transplant.

My wish is that through stories like Debbie's story, those with the responsibility to make recommendations about organ and tissue donation procedure in Queensland, will be mindful when considering ways to increase donation rates, of the traumatic journey those now awaiting transplant are experiencing. Those awaiting transplant travel this journey with their carers, families, loved ones and friends. The wait is enormously distressing for all these people.

This is Debbie's story...

These are Debbie's words, written in March 2007, about her journey:

> *For the past LONG 18 months, I have been waiting for a life saving double lung transplant. For an even longer 21 months, I have been reliant on supplementary oxygen.*
>
> *Having been diagnosed with Scleroderma in December 1991, I watched as the disease slowly attacked my lungs resulting in severe pulmonary fibrosis. I was referred to the Prince Charles Lung Transplant Unit in July 2005 and was listed for transplant on 18 August 2005. At that time the average wait for lung transplantation in Queensland was 4-6 months.*
>
> *Due to the number of lung transplants performed in Queensland dropping by nearly 50% in 2006, I am still waiting and my condition is worsening daily as I wait.*
>
> *Transplantation which once seemed like a certainty, has now become a race against time.*

> *I will keep fighting for as long as I can. I became a grandmother for the first time 5 months ago and I look forward to the day when I can nurse and play with baby Lachlan without it being a tiring exercise.*
>
> *I have worked as a social worker in the area of child protection in Queensland for the past 20 years and I am confident that there is much more I can do for the community.*
>
> *But any hopes and dreams I might have for the future are totally dependant on the generosity of organ donors and their families.*
>
> *Raising the number of organ donors to meet the needs in Queensland should not be an onerous task. The number of people awaiting lung transplants in Queensland is so small, no one should die waiting….*

Our wait for a life saving transplant was a long and devastatingly sad journey.

Debbie was on supplementary oxygen for 879 days whilst waiting. The hum of oxygen concentrators could be heard 24 hours a day in our home. We also used over 420 cylinders of oxygen. Going out required careful planning, calculating the oxygen needed to keep Debbie alive whilst away from the oxygen concentrators. Electrical storms, power cuts, equipment malfunctions - these all caused enormous practical difficulties and were stressful events to manage as Debbie's life depended on supplementary oxygen 24 hours a day whilst she waited for a transplant.

With an enormous amount of courage Debbie participated in life whilst on the transplant list in the engaging way she had always done. Even though on supplementary oxygen, Debbie continued to work part time in the Department of Child Safety until April 2006.

Debbie's condition however worsened daily as she waited.

Life became so limited for Debbie.

In the last 12 months and particularly the last 6 months, life was a constant challenge. Debbie lived in one room for over a year. She could only walk a few steps before she felt exhausted and some days all of her energy was used just to breathe. Debbie was looking forward to post transplant and taking a breath just as we do.

Each day was a long wait for the call that would provide Debbie with another chance at life.

As Debbie's health deteriorated awaiting transplant, the medical problems she experienced increased, as did her physical discomfort and pain.

Debbie had the most amazing strength, will, tolerance, patience, faith and an unwavering commitment to positive thought. She was determined, courageous, positive and elegant in the way she dealt with her illness.

It is overwhelmingly sad that after Debbie fought so hard, she did not receive the greatest gift one human being can give to another – the gift of life.

Debbie was a registered organ and tissue donor. Debbie was one of the 360 Queenslanders last year who were tissue donors. As a result of her gift, 2 people now have sight.

Debbie was 52 years old when she died, leaving behind a loving family who cherished her. Debbie was uniquely caring, generously giving and interested in others. She had a wonderful sense of fun, she was an awesome friend and she loved her family so dearly. She was truly special.

Debbie and I spent many hours whilst "waiting", talking about the issues surrounding organ donation and ideas for increasing organ donor rates so people do not die waiting.

The issues that I wish to comment upon are set out below and respond to issues identified for comment in Sections 3 and 4 of the Issues Paper.

SECTION 3. CONSENT TO ORGAN AND TISSUE DONATION – PRESUMED CONSENT AND OTHER APPROACHES TO CONSENT

3.5 Arguments against presumed consent

Issue for comment:
What requirements for consent to organ and tissue donation should apply?

If the current opt-in approach continues, then the following requirements for consent to organ and tissue donation should apply.

1. The consent required for organ and tissue donation should only be the consent of the person during his or her lifetime, to the removal after death of organs and tissue.

2. The recording of a decision on the Australian Organ Donor Register (hereafter referred to as the "AODR") to register as an organ and tissue donor should be the only point of reference for establishing a registered consent.

3. A designated officer should make the inquiry of the AODR to ascertain whether the person during his or her lifetime registered a consent to donation.

4. If a consent to donation was registered, the designated officer should authorise the removal of the organs and tissue.

5. A person with the appropriate skills and experience[1] should inform the next of kin of the registered consent and advise them of the information that the family will require, including information about counselling and supportive services.

6. If the person during his or her lifetime did not register a decision on the AODR, then only in these circumstances, should the consent of the next of kin be sought.

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[1] I refer to the issue of appropriate skills and experience of practitioners in comments on pages 8 and 16 of this Submission.

If the current opt-in approach and the current policy regarding consent requirements continue, then the following should be considered:

1. **The continuation of a National Organ Donor Register**

   It is important that there is one organisation that records the decisions of Australians as to whether or not they wish to be registered as an organ and tissue donor and that this information be readily available to authorised persons.

2. **The re-introduction of the question on the state driver's licence as to whether a person wishes to be an organ donor**

   If this was re-introduced, each time a person renews their driver's licence, they will be required to turn their mind to the question of organ donation.

   Queensland Transport could be provided with the organ donor registration forms from the AODR, which is a booklet containing information about organ and tissue donation, and the registration form is attached to the booklet.

   Queensland Transport personnel need not be involved in providing any information or advice regarding organ donation. They merely need to assume a role of advising people what the process is to register as an organ and tissue donor and provide the information booklet and registration form.

   If a person wishes to complete the registration form at the time of the renewal of their driver's licence, then Queensland Transport could then forward the completed form to the AODR.

   The recording of 'yes' or 'no' on the driver's licence will also assist in circumstances where the issue of organ donation arises, the person has not registered a consent or objection on the AODR and the family are not otherwise aware of the person's wishes.

3. **The organ donor registration form should include a section for the next of kin to complete at the time that a person completes the registration form.**

   Talking with families about the potential of organ and tissue donation at or around the time of death is enormously distressing for families. The discussions happen at a time when people are experiencing shock, trauma and grief. The decision-making capacity of the next of kin at this time is compromised. A more appropriate time for this discussion to occur is during the lifetime of a person when they are registering their consent or objection to organ and tissue donation on the AODR.

   The registration form could include the following information regarding the next of kin –

   - the nature of the relationship between the next of kin and the person registering their consent or objection to organ and tissue donation, with the relationship categories being referred to in the same terms as in the transplantation legislation of the states;

- an acknowledgment that the person has advised them of their wish to register as an organ and tissue donor or register their decision not to be a donor; and

- if the person is registering a consent, an acknowledgement by the next of kin that they will not be asked for consent at a time in the future if the potential of organ and tissue donation arises.

4. **If it is determined that the next of kin must provide consent, then the present process for talking with families must be changed.**

This is our story

Debbie died at The Prince Charles Hospital. There were a number of staff from the hospital that spoke with me after Debbie's death and before I left the hospital. The issue of tissue donation was not raised with me nor was I informed that I would receive a telephone call about tissue donation.

Soon after leaving the hospital after Debbie died, I received a telephone call from the Queensland Eye Bank.

From my recollection, there was no information provided to me about whether Debbie was a registered organ and tissue donor. I knew however that Debbie was.

There was no inquiry as to whether Debbie had spoken of her desire to revoke her consent.

The purpose of the call was to seek my consent to the donation of tissue by Debbie, despite Debbie expressing her consent in writing during her lifetime to be an organ and tissue donor.

The other clear purpose of the call was to gather social and medical information in relation to Debbie by asking a series of questions. I was informed that Debbie's general practitioner would also be telephoned and asked the questions as well.

There was a lengthy series of questions asked of me in a manner that seemed similar to questions asked during a telephone survey.

I was asked questions that for a family are very distressing and seem unwarranted –

> *"Has Debbie worked as a prostitute in the last 12 months?"*
>
> *"Did Debbie use intravenous drugs"*
>
> *"Has Debbie been involved in high risk sexual behaviour".*[2]

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[2] The words used in the questions asked were either these words or words of a similar nature and meaning.

The questions seemed to be endless.

Even with the commitment our family has to organ and tissue donation, it was extremely difficult to continue with the questioning process.

It was then also almost impossible to continue in the process when I was informed, without any request for this information, as to the procedure for the "removal of eye tissue from Debbie".

The written communication process that followed in the weeks thereafter was also distressing for our family.

In mid November 2007, I received a letter from the Queensland Eye Bank, thanking me "for the donation from your partner" and requesting I sign a "written authorisation for the removal and use of tissue".[3] There was no acknowledgement that Debbie was a registered organ and tissue donor and that this was her gift.

I then received further correspondence from the Queensland Eye Bank requesting that I consent in writing for "your partner Deborah to donate eye tissue". In this correspondence I was advised that:

> "*While your oral consent is sufficient for the donation procedure to proceed, legislation requires us, the Queensland Eye Bank to make reasonable attempts to obtain written consent for that procedure*".[4]

When I inquired as to what legislation required this course of conduct, I was referred to ss 22 (6)-(8) and (10) of the *Transplantation and Anatomy* Act 1979 (Qld).[5] These sub-sections do not relate to the circumstance where a deceased person, during his or her lifetime, by signed writing, consented to the removal after death of tissue and the consent had not been revoked. The information provided was incorrect in the circumstances where Debbie had registered her wish to be a potential organ and tissue donor.

It is not surprising after participating in the process outlined above that only 360 Queenslanders who died last year were tissue donors and only 39 were organ donors and that anywhere between 40% and 46% of families said NO.

From this experience, I make the following comments:

- hospitals are not speaking with family members about tissue donation at or around the time of death nor before families leave the hospital after their loved one has died;

- families need to be informed that someone will speak with them about tissue donation and be informed about the process for this - it would be helpful if the person who provided this information to families was

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[3] A copy of the letter from the Queensland Eye Bank dated 12 November 2007 is annexed to this Submission and marked with the letter "A".

[4] A copy of the letter from the Queensland Eye Bank dated 17 March 2008 is annexed to this Submission and marked with the letter "B".

[5] A copy of the letter from the Queensland Eye Bank dated 31 March 2008 is annexed to this Submission and marked with the letter "C".

someone from the hospital who had developed even some limited rapport with the family;

- the process for the telephone call should not be a long list of questions unconnected to reflective and responsive dialogue;

- the relevance of each question asked must be reviewed by those with knowledge, skills and experience in communication, trauma and grief and by doctors involved in the transplantation process to ascertain what information sought from the current list of questions is in fact required and accurate enough to be relied upon;

- families can not be regarded as reliable reporters of information about matters forming the purported social evaluation by Queenslanders Donate, for example, if a family member is working as a prostitute or involved in high risk sexual behaviour outside of their relationship, it is unlikely that a spouse or parent would have any knowledge of this;

- there is medical evaluation and testing that occurs prior to any transplant - some of the information attempted to be sought by the questions asked, would be information gleaned as a result of the evaluation and testing conducted by the doctors, and would arguably be more reliable;

- some discretion should be exercised when determining what should be asked of the next of kin - for example, Debbie was on the transplant waiting list at the Prince Charles Hospital for over 2 years, she attended regular outpatient appointments during this time and died at that hospital. Debbie was extremely ill for a long period of time, her medical records at the hospital would have clearly indicated this, her transplant physician was at the hospital after she died and would have easily been able to provide relevant information. It was ridiculous and offensive to ask me if Debbie had been working as a prostitute in the last 12 months of her life;

- in practice, the potential donor's family is not being approached to ascertain whether the deceased person had consented to donation or may have revoked their consent - this is the stated purpose of speaking with the next of kin as referred to in the Act[6] and in the policy of Queenslanders Donate.[7]

- what families are in fact being spoken to about is whether they will give consent for the deceased person to donate organ and tissue even in cases where the deceased person during their lifetime registered as a donor;

- families are saying NO to donation - it is reported that somewhere between 40% and 46% of families say NO.

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[6] *Transplantation and Anatomy Act* 1979 ss 22(5) and 23(3)

[7] Queenslanders Donate Web Site – "How To Register Your Decision To Be A Donor"

People are dying waiting for transplants.

Speaking with families about organ and tissue donation is a crucial matter. The importance of this process must be recognised.

Appropriately skilled and experienced practitioners must be chosen to engage with families. These practitioners must have the necessary skills to assess individual circumstances and ask only relevant questions. They must have the knowledge, skills and experience to effectively engage with the family in a manner that is appropriate in the circumstance of the particular family. The practitioner will need skills that enable them to rapidly build rapport in a most difficult interaction and the ability provide compassion and empathy in the communications.

We need to recognise this as an important communication and have appropriately trained people doing this work, i.e. social workers, psychologists and psychiatrists.

Issue for comment:
Should the role of next of kin or family be different if a person has given written consent to organ and tissue donation?

Yes - In these circumstances:-

1. The next of kin should not be asked whether they will give consent for the deceased person to be an organ and tissue donor.
2. The next of kin should be informed that the deceased person, during his or her lifetime, registered a consent on the AODR to be a donor and did not register a change to that consent.
3. Only an appropriately qualified practitioner[8] should engage with the next of kin and provide this information - this practitioner should also provide information about counselling and supportive services as is assessed as appropriate in the particular circumstances of that family.

Like other Australian states, we have a legislative framework in Queensland that provides for the removal of tissue from the body of a deceased person who during their lifetime by signed writing, consented to the removal after death of tissue[9] and the consent was not revoked by the deceased person.[10]

In these circumstances, no further authority is required for the removal of tissue from the body of the deceased. There is no legislative requirement for the next of kin to consent to the removal of tissue in these circumstances.

The *Health Legislation Amendment Act 2001* amended Section 22(5) of the *Transplantation and Anatomy Act* 1979 to provide for the provision that continues in

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[8] I refer to my comments on pages 8 and 16 of this Submission regarding "appropriately qualified practitioners

[9] Tissue is defined in s 4(1) of the *Transplantation and Anatomy Act* 1979 to include an organ, blood or part of a human body

[10] *Transplantation and Anatomy Act* 1979, s22(5)

force today. In the Explanatory Notes, the purpose and effect of the amendment was to:

> *"tighten the consent regime by providing that a designated officer can rely on the following consents in order to authorise the removal of tissue and organs for transplantation or use for other therapeutic, medical or scientific purposes:*
>
> * *the written consent of the deceased (given during life);* *OR* (emphasis added)
>
> * *the consent of the senior available next of kin (where the deceased had not expressed an objection during life and there is no objection from any other senior available next of kin).*[11]

The Explanatory Notes provide that the written consent of the deceased given during life is all the consent that is required and this was considered to be appropriate in circumstances where the Act was amended to "tighten the consent regime".

It was the intention that the authority for the removal of organs and tissue be the written consent of the deceased given during their life. The legislation now in force provides for this. It is the policy that has changed this. The policy should reflect the intention of the legislation and the effect of the legislation. If the person has given written consent to donation during life, the next of kin should not be asked for consent.

The AODR provides for a process for people to record their decision about becoming an organ and tissue donor for transplantation after their death.

The AODR also provides for people to change or remove their details from the AODR. Thus, a process for the revocation of consent is provided for by the AODR.

There does not appear to be any suggestion that the AODR is conducted in a manner that would compromise the integrity of the information recorded on that register.

As at 30 June 2008, 1,152,668 Australians had recorded a legally valid consent registration including intent registrations of 16 and 17 year olds.[12] The resident population of Australia was projected to be 21,391,325 as at 13 August 2008.[13] Thus approximately 5% of the Australian population have recorded a legally valid consent registration.

It may be argued that given the low rate of registered donors in Australia, the people who have recorded a legally valid consent registration have a commitment to being an organ and tissue donor in the event of their death.

It may also be argued that the 5% of Australians who have registered a consent, have an understanding of the registration process, including registering a change. The "Statement" part of the registration form refers to a request to "register" or a request to "change/remove" the person's details on the AODR. This statement is immediately above the signature part of the form that the person must have signed for their consent to be registered.

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[11] Health Legislation Amendment Bill 2001, Explanatory Notes, p.3

[12] AODR Statistics, Medicare Australia

[13] Australian Bureau of Statistics

To develop a policy around the proposition that the 5% of Australians committed enough to record a legally valid consent registration may revoke this consent and therefore the next of kin must be consulted, is flawed in a many ways.

Firstly, to involve next of kin in the consent process in circumstances where a person during his or her lifetime recorded a legally valid consent registration, undermines the self-determination of those who have registered to be donors.

As a community, we promote self-determination. We have provisions for people to record in writing how they wish to deal with their estate upon their death and these wishes are only disturbed in the smallest number of cases by a court of competent jurisdiction.

During a person's adult lifetime, the ethical principles that guide doctors in their relationships with patients, include respect for the patient's autonomy regarding the management of their health, including the refusal of treatment.[14]

To ask the next of kin to consent or object to organ donation for a deceased person who during their lifetime by signed writing, consented to donation, takes away a fundamental right of the deceased person.

To speak with the next of kin under the guise of ensuring that these registered donors had not changed their mind since recording their decision on AODR is also unnecessary. These people have demonstrated an understanding of the registration process and have signed a document that refers not only to registration but a process for revocation.

There is no data offered to support the proposition that a deceased person who during their lifetime registered a legally valid consent, may have decided to change that consent and done nothing to record the change.

There is however evidence that:

- in Queensland, family members are always asked for their consent for organ and tissue donation from the potential donor regardless of whether or not the person registered as a donor during life;
- between 40% and 46% of families say NO;
- people, like Debbie, are dying waiting for transplants; and
- 40% to 46% of further potential donors would give those waiting for transplantation better odds of another chance at life.

The process for asking the next of kin for consent for organ and tissue donation of a loved one occurs at a time that I would describe as the most devastatingly sad and heart wrenching moment of my life. In circumstances where a person has given written consent to organ and tissue donation, it is overly burdensome for the next of kin to be asked for a consent that has already been provided.

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[14] AMA Code of Ethics – 2004, Editorially Revised 2006

The process of requesting consent of the next of kin may:

- further traumatise them;
- deprive a person waiting for transplant of a chance of life; and
- result in an enormous loss for those who love the people who die waiting.

Issue for comment:
What is the best way to use a donor register in connection with consent when donation is being considered?

1. The AODR provides for the recording of:

    (a) consent to donate organs and/or tissue;

    (b) a decision not to be an organ and/or tissue donor; and

    (c) a change or the removal of a person's details on the AODR.

    Authorised persons may access this information and be informed about these matters.

    The AODR seems to adequately record the information listed above.

    In relation to a change or the removal of a person's details on the AODR, the terminology used should be changed to reflect the terminology used in the state legislation, i.e. the "revocation of consent".

2. The information recorded on the AODR should include a record of confirmation that the next of kin was made aware at the time of the registration, of the decision the person registers. The organ donor registration form should include a section for the next of kin to complete at the time that a person completes the registration form[15].

Issue for comment:
Do you support introduction of an opt-out or presumed consent system?

<u>Yes</u>

An opt-out system if <u>introduced together with</u> programs to increase public awareness and educate people about organ and tissue donation, should increase donor rates. This system should reduce waiting times and save the lives of people who are now dying waiting for a transplant, people just like Debbie.

Research shows that about 90% of Australians support organ donation in principle. Some suggest that the rate of support amongst Australians for organ donation is as high as 97%[16].

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[15] For further details, please refer to the comments on pages 4 and 5 of this Submission regarding the inclusion of information in relation to the next of kin on the AODR.
[16] David Hookes Foundation Web Site

If this is the case, then for those who argue that a presumed consent system removes the ability of the individual to choose, the percentage of the population that this applies to is small. Further, if the opt-out system is introduced together with an education program and mechanisms to increase public awareness, then the small percentage of the population who do not wish to be a donor, may opt-out and will understand the process to do this.

Some argue presumed consent would change the altruistic nature of organ donation. If a presumed consent system is introduced, people will still have a decision to make – "should I opt-out?". The decision not to opt-out is a decision to give life – the greatest gift one human being can give to another.

The low rates of organ donation in Australia must be considered in the context of our present opt-in system.

The consequences of a system that results in low organ donation rates as is occurring in Queensland, is **death**.

We talk of Australia as having fewer organs available for transplantation than people waiting for an organ transplant and speak of reducing waiting times for transplantation to saves lives.

We need to talk about death - that is what not improving donor rates means for those awaiting transplantation.

As a community, we generally avoid talking about the hard things. To talk about death and dying is confronting, difficult, sad and produces anxiety and fear.

When speaking about organ and tissue donation, we need to talk about death and about how organ donation can provide hope for life.

We need to use strong language so the public understand the pressing need for organ donors.

The Issues Paper identifies that opponents see it as far worse for a deceased person's organs to be retrieved against their wishes than for organs of a willing donor to not be retrieved under the current system. Perhaps these opponents would consider the matter differently if their spouse, parent or child needed a transplant for another chance at life. For Debbie, the non-retrieval of organs of a willing matching donor may have led to her death. For Debbie and our family, this is far worse!

Issue for comment:
What role should a deceased person's family or next of kin have in consent of organ and tissue donation?

If the opt-in system continues, then a deceased person's family or next of kin should only have a role in consent of organ and tissue donation if the deceased person during their lifetime:

1. did not record a legally valid consent registration on the AODR; or

2. did not record an Intent Registration on the AODR.

Where a deceased person during life recorded on the AODR a legally valid consent registration or registered an intention to donate organs and tissue, the family or next of kin have no role in the consent process. In these cases, the family or next of kin should be informed of the decision the deceased person registered. They should also be provided with information about organ and tissue donation upon request and be provided with a referral for counselling and supportive services as assessed as appropriate for the particular family.

If the deceased person during life did not register a decision on the AODR, only then should the family or next of kin be approached about the issue of consent for organ and tissue donation.

The role of the next of kin in these cases should initially only focus upon their understanding of the deceased person's beliefs and wishes regarding organ and tissue donation.

If the next of kin is not aware of the deceased person's wishes, then communications should be focused upon:

- what it means to give life;
- what living is like for those waiting for transplantation;
- what another chance at life means for the people on the waiting lists; and
- whether their loved one would have wished to help others.

Only after these communications should the next of kin be asked whether they consent to organ and tissue donation.

The provision of information to next of kin about the donation process and attempting to dispel the myths about donation, in my submission is unhelpful. The next of kin should be welcomed to ask any questions they may have. To provide families however, with information about how organs and tissue are removed when this information is not requested is from my experience, enormously upsetting and may be contributing to families saying NO.

If an opt-out system is introduced, the best chance those waiting for a transplant have of life is for a strong presumed consent system. In this system, there is no role for family or next of kin in the consent process.

How best to help families within such a system should be considered. Governments must provide appropriate levels of funding so families receive the necessary interventions at the time of donation and during the bereavement process if further supportive services are required. The importance of continuing education and public awareness is crucial to the community managing a strong presumed consent system.

3.6 Opting out of presumed consent

Issue for comment:
If a presumed consent system was to be introduced, what mechanisms should be introduced for people to opt-out?

If a presumed consent system was introduced either nationally or in Queensland only, the AODR could be used for people who wish to opt-out, to register their decision to opt-out.

This would be a cost effective way to record the decisions of people who wish to opt-out.

The introduction of education programs and public awareness campaigns would provide people with the necessary information as to what steps they need to take to opt-out.

If it is correct that somewhere between 90% and 97% of people in Australia support organ and tissue donation, then it is only a small percentage of the population that will utilise the system to opt-out.

There is a disparity between the number of Australians who support organ and tissue donation and the number of registered consents. Some suggest this is evidence that people do not take the step of adding their name to a register. Some argue that this could apply if an opt-out system is introduced. We need to be mindful however that the current disparity is numbers is occurring in an opt-in system. The consequences of not recording a decision in the current system are entirely different to not recording a decision to opt-out in a presumed consent system.

Issue for comment:
How could simple and reliable access to an opt-out mechanism be ensured?

It seems that the AORD has a reliable way of recording decisions. There are no issues identified regarding the integrity of the information recorded by the AODR and no issues identified in relation to designated officers accessing information from the AODR.

The disparity in the numbers of the adult population who support organ donation and the number of registered consents may simply be about the lack of knowledge and understanding of people as to how to register their consent to be a donor rather than any difficulty with the AODR. A clear example of confusion about registration of consent is the belief that an indication on a driver's licence as to willingness to be a donor is effective in recording a registered consent. Whilst this question currently does not appear on licence renewal applications, there are many driver's licences that are not yet expired that contain this information.

The use of a reliable system already in place is a cost effective way to record decisions to opt-out.

The AODR is readily accessible to people and there is no cost for a person to record a decision.

The current system of the AODR appears to be simple and reliable. The difficulty seems to be that the public are not well informed as to what steps they need to take to register a legally valid consent on the AODR.

The information as to how to access the AODR needs to be the focus of a public awareness campaign and education process.

Access to an opt-out mechanism will only be reliable if the public are well educated about what they are required to do to record their decision to opt-out.

3.10 Implications of introducing an opt-out or presumed consent system

Issue for comment:
If an opt-out or presumed consent is not introduced, is the current system of consent appropriate?

Yes

The AORD is an effective way to record consent to donate, a decision not to donate or a revocation of consent.

The issue does not seem to be whether the current system of consent is appropriate, the issue appears to be that the public do not understand what the current system is.

Education and public awareness is one of the key answers to improving donor rates in Queensland.

4. OTHER OPTIONS TO IMPROVE ORGAN AND TISSUE DONATION IN QUEENSLAND

4.10 Incentives – financial and other

Issue for comment:
What action should be taken to improve organ and tissue donation in Queensland?

Queensland should introduce an opt-out system.

If the opt-out system is introduced in Queensland before any national opt-out system, the AODR would still be an appropriate register for people to record a decision to opt-out.

It is important that if Queensland does have a different procedure in place for organ and tissue donation that the registration of decisions is still recorded by a national system. This is particularly important given that it is reported that organs are exchanged between Australian states.

Whilst the matter of national co-operation is referred to in the Issues Paper, for those waiting urgently on the Queensland Lung Transplant Unit list, they are informed that there is someone just as sick in the other states also waiting for that match. Seeking organs for a lung transplant from another state was specifically excluded as an option, even when the race against time was drawing near.

The issue of national co-operation should form part of any federal government review as the stated aims of co-operation may not be being applied across all areas of transplantation. This is also an issue for the Queensland government to consider, specifically in lung transplantation.

Issue for comment:
Are there particular hospital based strategies that should be considered in Queensland to improve organ donation rates?

To improve the rate of organ and tissue donation, hospitals must accurately identify potential organ donors.

Appropriately trained persons must speak with families prior to death in the case of organ donation, and in the case of tissue donation, either before or immediately after the death, but in any case, prior to the family leaving the hospital.

What is an "appropriately trained person" to speak to families about organ and tissue donation must be carefully examined. Matters to consider include –

- the professional framework for practice that would best achieve the stated goals of the defined intervention;
- a consideration of the knowledge and skills the practitioner needs so they can competently communicate with families; and
- what demonstrated experience is necessary of the practitioner to effectively and compassionately interact with families.

Issue for comment:
What action should be taken to promote better public awareness of organ and issue donation?

Promoting better public awareness of organ and tissue donation issues will require a significant financial commitment by the government to achieve the desired outcomes.

We need to invest in a public awareness campaign and we need to find a champion who will hold the organ and tissue donor banner high. We need to engage those most talented in developing campaigns to increase public awareness. We need to do this NOW.

Whether a presumed consent system is introduced in Queensland or nationally or whether the current system remains, the public must become informed.

They need to know that people are dying waiting for transplants.

They need to know we are leaders in transplant medicine in Australia.

They need to know about the pressing need for donors.

They need to know that one day someone in their family may need a transplant to have a chance at life.

We need an action plan that identifies people with the skills, energy and commitment to develop a strategy to educate Queenslanders about organ and tissue donation. We need to find a public face for organ and tissue donation.

There are many and varied entities and persons with an interest in organ and tissue donation. They are contributing in various ways to creating greater community awareness about donation in the hope of increasing donor rates.

The David Hookes Foundation was "*established to inspire more Australians to register as organ donors and to discuss their decision with family and friends*". Through Zaidee's Rainbow Foundation and the national message, this foundation "*aim to assist in the increase of organ and tissue donation*". We as a family, through Do it for Debbie, "*are dedicated to improving donation rates so people awaiting transplant do not die waiting. We want to increase the number of registered donors in Australia and get these people talking to their families and friends about their decision to "give life*".

We need to identify these entities and individuals and coordinate their efforts to achieve the common goal.

We need to:

- harness the interest and commitment of both the state and federal government to this important issue;
- advocate for and effectively utilise the financial commitment that government is making to the issue of organ and tissue donation;
- coordinate the efforts of community agencies; and
- encompass the energy and dedication individuals and families have to effect change.

Many people do not currently understand the issues about organ and tissue donation, how to register a consent or that their family will decide about donation, even if they have registered a consent to donation. We need to educate people about all of the issues surrounding organ and tissue donation.

The state and federal government must continue with their financial commitment to this important issue. An increase in donor rates for some will mean life not death.

The costs to the community of declining donors numbers currently includes:

- the under-utilisation of transplant units;
- the loss of skilled transplant surgeons;
- the cost of providing health care to those waiting whose need for medical intervention increases as they wait due to the deterioration of their health; and

- the emotional cost for those dying, their carers and their loved ones.

In this context, the commitment of funds to developing and implementing a strategy to increase public awareness about the issues surrounding organ and tissue donation in the hope of increasing donor numbers is a positive investment in our future.

Other issues for comment:

Data Collection

We must improve data collection about organ and tissue donation issues.

Only then with confidence may an issue be identified as a matter impeding the organ and tissue donation procedure or a matter that is helpful in effecting the change needed to increase donor numbers. For example, what data is there that supports the notion that a person who has registered a consent during their lifetime may change their mind and have not revoked the consent. To develop policies around propositions not supported by data is dangerous in an area like organ donation where the stakes are high for those waiting.

The Queensland organisation that co-ordinates organ and tissue donation

We need to review the organisation in Queensland that co-ordinates organ and tissue donation to ensure that the structure and framework for the provision of services best meets the desired aims.

We need to ask these questions:

- Has the organisation been able to maximise the opportunity for organ and tissue donation?
- Has the organisation been able to adequately increase education and awareness in the community about the benefits of organ and tissue donation for transplantation?
- Are they able to provide the necessary support for donor families?
- Why does the organisation that has a mission to maximise donation rates to promote a healthier Queensland, not refer to the needs of those waiting and their families?
- Why are donor rates so low in Queensland?
- Queensland Health decided not to participate in The National Organ Donation Collaborative in 2006 to "enable Queenslanders Donate to prioritise implementation and evaluation of new initiatives for state-wide organ and tissue donation process" – since July 2006 what achievements have been made in relation to the implementation and evaluation of new initiatives? What are these initiatives?

- Why have the organisation initiated a project to develop curriculum materials for Queensland schools to educate students about organ donation and transplantation when financial resources are limited and the education of the adult population who may register as donors is so poor?

- Why do the organisation say they do not have accurate statistics on how many family members refuse to consent to donation?

- Why do the organisation suggest that the estimated 5% to 10% of next of kin who override a known wish of a potential donor to donate are "small numbers"?

  Last year in Queensland there were only 39 organ donors?

  A 10% increase in donor rates would have meant approximately 4 more donors in Queensland and approximately 12 more organ transplant recipients.

  The small numbers matter! They mattered to Debbie.

Finally

The commitment by the Queensland government to the review of organ and tissue donation procedures should be applauded.

The Select Committee should be congratulated on the informative Issues Paper prepared by the committee that identifies the pertinent issues surrounding organ and tissue donation.

Increasing donor rates in Queensland so people do not die awaiting transplant is such a important issue for our community.

The hard work that needs to be done about organ and tissue donation has commenced.

The hard decisions must now follow.

For all the Debbie's in our community and their families, I encourage the Select Committee to make recommendations that provide those waiting with the best chance at life.

I also ask that the government swiftly respond to recommendations made by the Select Committee and swiftly implement the changes so desperately needed to increase donor rates and SAVE LIVES.

Margie Kruger

A

Queensland
Government

Queensland **Health**

COPY

Ms Margie Kruger
43 Prospect Street
WYNNUM QLD
4178

Ref: CAP/5256/

12 November 2007

Dear Ms Kruger,

May I express my condolences on behalf of the Queensland Eye Bank staff on the death of your partner. I would like to thank you for consenting to eye donation at this difficult time.

I hope you will find some consolation in your loss with the knowledge that the donation has helped towards restoring sight to others.

The donation was a wonderful way to help others; it is a generous gift that shows great compassion.

On behalf of the Queensland Eye bank we would like to thank you for the donation from your partner Deborah. Her corneas were successfully transplanted into a man in his thirties and a man in his sixties.

I would be grateful if you could sign and return the official record of your consent for the hospital records; a reply paid envelope is enclosed for this purpose.

If you would ever like to talk to the Eye Bank staff about the donation, then please feel free to contact us by telephone on (07) 3240 2104, or you can write to the above address.

Thank you again.

Yours sincerely,

Cheryl Pascual
Donor Family Liaison Officer
Queensland Eye Bank

Encs:
Consent Form
Reply paid Envelope

The Queensland Eye Bank, recipients of eye tissue and donor families acknowledge the wonderful gift that was made to help others in a non-denominational Service each year. The Brisbane Service is normally held on the last Sunday in May. Please telephone (07) 3240 2350 if you would like further details. We will write to you closer to the date to give you details of the Service. If you do not wish to be contacted by us again then please can you tick the box below and return this with your consent form.

☐ ***Tick here if you do not wish to be sent details of the Service and return to us.***

A

Queensland Government

Queensland **Health**

SENIOR AVAILABLE NEXT OF KIN WRITTEN AUTHORISATION FOR REMOVAL AND USE OF TISSUE

IN ACCORDANCE WITH THE QUEENSLAND TRANSPLANTATION AND ANATOMY ACT 1979

I, ...
(name)

of..
(address)

being the .... (Senior Available Next of Kin)
(relationship to the donor)

of..
(donor name)

hereby consent upon his/her death to the removal

of ....EYE.......................... **tissue**
(and sample of blood/tissue for disease screening)

(i) **from his/her body for the purposes of transplantation to the body of a living person,**

(ii) ***or, in the event of the above named tissue not being suitable for transplantation into a living person, it may be used for medical or scientific research into tissue disease.** *(delete if not applicable)

(iii) **I also consent to the use and disclosure of the medical information that is retained by health providers for use for these purposes.**

To the best of my knowledge, the donor has not expressed an objection to the removal of tissue for these purposes.

14/11/2006

APPROVED

....
(Signature of senior available next of kin) *(Date)*

Senior available next of kin means the person who is the first reasonably available relative of the deceased in the following order of priority: (i) spouse (including a married or de facto partner of the same or opposite sex); (ii) son/daughter 18 years and over, (iii) parent, (iv) brother/sister 18 years and over. If the deceased is a child (ii) is not applicable and Guardian is added at end of list.

B

Princess Alexandra Hospital
Health Service District

Queensland
Government

Queensland **Health**

Enquiries to:	Queensland Eye Bank
Telephone:	07 3240 2104
TTY:	07 3240 7737
Facsimile:	07 3240 5299
Our Ref:	5256
Date:	17 March 2008

Ms Margie Kruger
43 Prospect Street
Wynnum Qld 4178

Dear Ms Kruger

We recently wrote to you regarding giving consent for your partner Deborah to donate eye tissue. While your oral consent is sufficient for the donation procedure to proceed, legislation requires us, the Queensland Eye Bank to make reasonable attempts to obtain written consent for that procedure.

Please would you complete the attached form and send it back in the enclosed envelope. This will allow us to complete our records.

If you have any questions about this process please do not hesitate to contact me on at the Eye Bank on 32402104.

Thank you again for being part of this Tissue donation program where your partner has been able to improve the quality of life for others.

Yours sincerely

Nichalas Nuttall
Clinical Coordinator
Queensland Eye Bank

Office	**Postal**	**Phone**	**Fax**
Princess Alexandra Hospital Health Service District	Ipswich Road Woolloongabba Q 4102	61 7 3240 2111	61 7 3240 5657

c

Princess Alexandra Hospital
Health Service District

Queensland
Government

Queensland **Health**

Enquiries to:	Queensland Eye Bank
Telephone:	07 3240 2104
TTY:	07 3240 7737
Facsimile:	07 3240 5299
Our Ref:	5256
Date:	31 March 2008

Ms Margie Kruger
43 Prospect Street
Wynnum Qld 4178

Dear Ms Kruger

Thank you for your letter which we received on Friday 26th.

The relevant legislation is the Transplantation and Anatomy Act 1979 (Qld), specifically Part 3 Section 22 sub-section 6-8 and 10. The link to the relevant website is

http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/T/TranspIAAnatA79.pdf

I have enclosed the consent form for Deborah. I would appreciate it if you could sign it and send it back to me in the enclosed envelope.

If you would like to discuss any aspect of the consent process or, indeed, anything regarding Deborah's donation, I would be happy to assist.

Yours faithfully

Nick Nuttall
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