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Submission To

Review of Organ and Tissue Donation Procedures

**Select Committee
Legislative Assembly of Queensland**

By

**Ron Simard, Manager
Queensland Bone Bank
Queensland Skin Bank**

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Background

The Queensland Bone Bank and the Queensland Skin Bank are units of the Princess Alexandra Hospital Health Service District. The Queensland Bone Bank (QBB) is a fully TGA licensed Tissue Bank which retrieves, processes and distributes Musculoskeletal tissue for human transplant. In operation since 1987, QBB is one of the largest Musculoskeletal Tissue Banks in Australia providing some 1600 allograft to some 1100 patients annually. In 2007 QBB occupied a Queensland Health developed state of the art facility in Coopers Plains. The Queensland Skin Bank is currently preparing to commence its operations to provide vitally needed human cadaveric skin for transplant for burns victims. Both of these valuable and necessary activities are totally dependent on the Donation of Tissue – our ability to provide Musculoskeletal Allograft and Skin is primarily limited by the number of donations we receive.

This submission will comment on the issue of Consent but will focus primarily on potential means to maximise Tissue Donation under the current arrangements.

Consent

It is my personal and professional view that a system of “opt out” is the preferred approach. The potential that a donation will occur is much more likely where the default position is to donate. International statistics generally support this view (e.g. the Spanish experience) however any system will only be as successful as its implementation and promotion. It is my view that “opt-out” will have its greatest benefit by making donation the “norm” and thus provide one more item to assist a Donor Family in making a decision in a time of great stress.

From a “donation number increase only” point of view, presumed consent should be absolute. However, one does recognise that objection from the Next of Kin and family members in practical terms can effectively negate a donation. In addition, such a draconian position in such a sensitive area is inconsistent with what I perceive as the community standard. I believe that those seeking consent would be strengthened by the concept, but at the end of the day, we are dealing with our fellow citizens and “donation at any cost” is not acceptable.

One must acknowledge that there are individual situations and values (be they religious, cultural or other) which have impact on the possibility of donation in any individual circumstance. There is always a need to balance the individual’s circumstances with the common good.

I believe that one should routinely seek consent for “Research’. A large number of cadaveric donations (some 30% in our experience) are eventually found unsuitable for transplant purposes due to our very stringent screening criteria (tissue has much greater restrictions than organs). There is a continuous need for Research tissue for ongoing process development and validation activities (without which we could not maintain our methodologies to produce allograft) as well as academic research activities.

Improving Donation Rates in Queensland

It is indeed heartening for those in the sector to note the increased interest at the Federal and State level in Organ and Tissue Donation. The commitment of funds federally and the ongoing support in Queensland will hopefully yield more donations and more needs could be met.

Tissue donation is at best treated as a “poor sister” to Organ donation. Tissue donation does not attract the attention or interest that lifesaving organ transplants quite rightly engender. Most Tissue Banking activities are seen as a “life-enhancing” (musculoskeletal) however it is hard to dispute the value of a heart valve tissue and skin allograft as lifesaving. Nevertheless, if the term “Queensland Bone Bank” arises in a discussion in the general public one either encounters a blank stare, a request to repeat, or a comment such as “Which Bank?” Tissue Banks are virtually unknown in the public realm and indeed, our profile in the health setting (outside of Theatre) is only marginally better. A greater awareness of tissue donation and its benefits is needed.

Enhanced Transplant Coordinator Network

I applaud the recent efforts of Queenslanders Donate (QD) to speak on tissue donation and to attempt to enhance its profile. I believe that Queenslanders Donate (which has responsibility to coordinate cadaveric tissue donation on behalf of Queensland Health) should place an even greater emphasis on tissue donation and heartily resist seeing tissue as a secondary activity to organ donation.

To this end, I believe that there should be an increased network of Transplant Coordinators state-wide which would also be responsible to promote cadaveric tissue donations from Hospitals in other scenarios where organ donation is not involved and to support the Living Donor program as well. There are simply not enough local Transplant Coordinators nor the resources to promote tissue donation nor do they I would suggest see tissue donation as a core activity.

Support to the Living Donor Program

The Living Donor Program of the Queensland Bone Bank is a program wherein the Femoral Head removed at a Total Hip Replacement (THR) operation is donated to QBB for conversion into a usable allograft. This removed Femoral Head is otherwise considered as surgical waste and discarded in Theatre. QBB currently receives some 1600 such donations per year. It is widely recognised that there are many more THR operations occurring in the Theatres of Queensland Health Hospitals, let alone the Private Hospitals. QBB has the capacity to process such tissue.

The main reason that these donations do not occur in all instances is simply that participation in the Femoral Head Program is optional. Very busy theatres will carry out tasks that are required, but often optional programs such as this one, are not supported, or if so, when convenient.

It is recommended that participation in the Living Donor (Femoral Head) Program be incorporated as a required and integral part of a Total Hip Replacement Theatre protocol in identified QH facilities and recommended to identified Private Hospitals in Queensland. QD Transplant Coordinators should consider the promotion and support of this program a core responsibility.

Cadaveric Tissue Donation

It is disappointing that the general public are unaware that Tissue donation can occur up to twenty four hours after death. Such information could be disseminated via an expanded Transplant Coordinator network.

There are three sources of cadaveric donation: Hospital deaths, Multi-Organ Donation and the Coronial system. All could be enhanced with a shift in view: tissue donation when considered is seen as an “add-on; a “nice extra” but not a core value.

Hospital Deaths

Currently, the Queensland Eye Bank screens Hospital deaths in certain QH facilities. There is a notification system via HBCIS which provides email and a SMS message when time of death information is entered. The system does not assess all deaths because

- there is no expectation to report deaths to Tissue Banks
- the event is not necessarily entered in a timely manner and retrieval times may become compromised
- the screening service is not 24/7
- Retrieval activities are geographically limited

In some overseas jurisdiction, all deaths are reported to a Tissue Bank Call Centre. Compliance is assured via including such a requirement in Accreditation standards and, by extension, not reporting can have serious repercussions to a facility. As for the Femoral Head program noted above, unless there is some kind of onus or obligation placed upon participation, the activity will not occur as there are a vast number of competing obligatory activities. Such a Call Centre could theoretically serve an area much larger than Queensland.

All areas in identified QH hospitals wherein there is a potential for a retrieval of tissue to occur should notify a Call Centre within one hour of death of a patient. We would anticipate that the Transplant Coordinators would facilitate this activity as well.

Multi Organ Donor

During the period July 1 2007 to June 30 2008, some 10 Multi Organ Donors also became Musculoskeletal Tissue Donors. We are grateful for each and every one of these donations, but are disappointed that this represents less than one-quarter of Organ donations. We acknowledge that tissue donation has significantly expanded screening criteria and this eliminates a number of Organ Donors. We do recognise that arranging organ donation is quite complex and can generate significant impact on resources and will delay the release of the cadaver as compared to an organ – only donation. We are disappointed that it would appear that tissue donation is considered “expendable” and not pursued if the impact on resources (i.e. theatre time) is a concern: it feeds the view that tissue donation is a lesser activity, and, a “nice to have” but not sufficiently important.

We appreciate the dilemma when the family wishes to have the loved one’s remains returned expeditiously, and the particular quandary that a Transplant Coordinator faces when seeking a possible further 4 to 6 hours of delay. Nevertheless, we are hopeful that the Transplant Coordinator would be sufficiently committed to Tissue Donation to encourage the donation.

Coronial Lodgements

The largest source of cadaveric donations is via the Forensic Mortuaries operated by QH Forensic and Scientific Services (FSS).

FSS openly states that they “support” Tissue Banking, but they are quite clear and straightforward that Tissue Banking is “always” secondary to the Coronial process. Numerous presentations I have attended clearly place Tissue Banking in the second tier of activity. It has been frequently stated without apology (and indeed with no malice whatsoever) that Tissue Banking is an add-on, and will always be forgone if donation interferes with the Coronial process. This is an ingrained view which has been the “modus operandi” it appears since the beginning of Cadaveric donation via Forensic Services. Anecdotal comments also regularly arise that some involved have personal objection to donation in particular situations (such as a young child).

It is within this “corporate culture” that the screening and evaluation of lodgements is conducted. There is a significant screening resource provided via Queenslanders Donate, support to mortuary activities and support to Coronial Counselling to attempt to offset the additional burden created by screening for tissue donation. In spite of these resources, Tissue donation continues to be devalued and it appears that some would be content to see Tissue donation simply “go away”.

There is a definite respect and commitment to tissue donation at more senior levels, but this does not appear to transcend to all levels. One could suggest that since the activity is secondary and when competing demands arise, the secondary activities lose out. There is a need to have Tissue Donation recognised by FSS as a core value, that Donation is assumed and then eliminated (in the same sense as opt-out consent to donate), and that personal values cannot transcend corporate values. If donation “impedes” the coronial activity, then donation should not proceed. However, if a donation is “inconvenient”, this should not in itself preclude donation.

Summary

The “presumed consent” option is held to be likely to provide more tissue donors insofar that it declares donation as the norm. There are numerous complications and each case should be considered in its own right, with the caveat of “do no harm” weighed against the benefit to the many.

The current existing opportunities to donate tissue suffer from a lack of public awareness in general and a comparable situation within Queensland Health itself. The yield of donations from existing activities could be increased with an expanded network of Transplant Coordinators supporting cadaveric and femoral head donation in identified areas coupled with QH policy making tissue donation a core activity. A change in perception towards tissue donation in the coronial setting could significantly enhance donations.

Summary of views

- presumed consent (Opt-out) is supported as a means to potentially increase donations
- an increased network of Transplant Coordinators who would be responsible to:
 - support and promote Tissue donation as a core value akin to Organ donation
 - promote cadaveric tissue donations from Hospitals in other scenarios where organ donation is not involved
 - promote the Living Donor (Femoral Head) program
- participation in the Living Donor (Femoral Head program) should be mandatory in identified QH facilities and recommended to Private Hospitals
- All areas in identified QH hospitals wherein there is a potential for a retrieval of tissue to occur should notify a Call Centre within one hour of death of a patient
- Forensic and Scientific Services should recognise Tissue Donation as a core value and service