14th February 2007

SUBMISSION on the HUMAN TISSUE (Organ Donation) AMENDMENT BILL

The Health Committee
John Thomson
Secretariat for the Health Committee
Parliament House
WELLINGTON 6001

This submission is from the New Zealand Kidney Foundation, PO Box 139. Christchurch. Phone 03-353-1240

The Foundation requests that the following appear before the committee to speak to our submission.

Associate Professor John Morton, Chairman
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The New Zealand Kidney Foundation is a not-for-profit incorporated society replying on contributions from the public for its operation. We are the national organisation representing New Zealanders with Kidney Disease in close co-operation and consultation with independent local and regional kidney patient societies.
Our role includes:

- funding research into the early detection, prevention and cure of kidney diseases,
- promoting to the public the advantages of early intervention for the treatment of progressive kidney diseases,
- promoting the interests of people with kidney disease and
- Promoting donation of kidneys (at the same time as other organs) for transplantation.

This submission has been prepared by the Executive Committee of the New Zealand Kidney Foundation and is based on informal consultation with kidney patients and their families and the professional experience in clinical transplantation of the members of the Executive – Associate Professors John Morton, Kelvin Lynn and

Richard Robson. This submission is endorsed by the Auckland District Kidney Society Inc. representing renal failure patients in Auckland and Northland.

Summary

The New Zealand Kidney Foundation welcomes and supports any initiatives to enhance the community's awareness of the benefits of organ donation and to increase the low rate of deceased donor organ donation.
The Foundation supports the Bill's aim of encouraging people to make a decision about organ donation in the event of their death and, importantly, to discuss this with their family/whanau.
In our opinion, the establishment of an Organ Donor Register as proposed in this Bill is unlikely to lead to an increase in deceased donor organs for transplantation. In our view such a Register would:

1. be expensive to establish, and maintain with security and accuracy,
2. be inefficient use of resource as expenditure at the low-number potential donor site would be much more effective and efficient than buying registration at the population level,
3. be unlikely to facilitate the work of the health professionals caring for potential organ donors in obtaining agreement to donate,
4. have a low registration rate because of its "opt-in" character and
5. not increase the rate of deceased organ donation.

International experience supports this opinion with most donor registries failing to enlist a significant proportion of the population despite intensive publicity campaigns. Fewer than 20% of the populations in Australia and the UK have signed up and there has been no discernible increase in the rates of organ donation (McCall 2006).

Legally binding directives regarding organ donation in the event of an individual becoming a potential organ donor in an ICU may address the issue of the donor's autonomy but in turn will cause additional anguish and stress for their grieving family/whanau and an additional burden for ICU staff.

Deceased donor organ donation cannot take place without the support and agreement of the donor family. Examples of support for this position are presented below.

1. "Since the transplantation of organs from the deceased depends in a unique way on community understanding and support, it relies on the trust that has been earned by sound practice—a trust that might be diminished if the need for consent is removed." (Morton 2004)

2. The Australian Health Ministers Conference (AHMC) in 2006 recommended the following:

   "Professionals involved in the organ and tissue donation process and who approach donor families should demonstrate a professional commitment to organ and tissue donation and should have received specialised training to provide them with the necessary knowledge and skills."

"When the intentions of the potential donor is known, the family should always remain involved in the process of giving effect to these intentions. They should be asked if they are aware of any changes in the expressed consent of the potential donor."

"A sincerely held objection by the family should be respected even if it is conflict with the known intention of the potential donor."

3. In discussing "Promoting and Facilitating Individual and Family Decisions to Donate" the Committee on Increasing Rates of Organ Donation Board on Health Sciences Policy in the US noted that in overseas studies, families of potential donors provided new information showing that the deceased did not want to donate, or overrode the deceased person's decision, in less than 4% of cases. If the same rates apply in New Zealand making donor wishes legally-binding would only result in between 0 and 1 additional donors per annum. (McCall 2006)

In the Foundation's opinion, organ donation rates in New Zealand are more likely to increase if:

1. There is appropriate investment by the Ministry in public awareness campaigns regarding the benefits of transplantation similar to those mounted for other public health issues such as smoking, obesity and traffic safety. (More New Zealanders start dialysis treatment each year than die in road traffic accidents.)
2. There is informed community discussion of the social and cultural barriers to organ donation for Maori and Pacific Peoples.
3. There is investment in training the health staff whose task it is to discuss organ donation with the families of potential donors and obtain consent for organ donation.

Specific comments on the Bill.

Explanatory note.

a. We support the auditing of requests for organ donation in ICUs in New Zealand. Nevertheless, the reference to "A recent audit shows that only 38 people out of a possible 104 were donors in 1999-2000" requires some comment. We presume this statement refers to the prospective audit carried out by Streat et al in New Zealand Intensive Care Units.
   Our reading of this audit suggests that out of a total of 1,404 deaths there were 522 people with severe brain damage amongst whom 102 potential organ donors were identified. Organ donation was discussed with 69 families, and agreement for organ donation received from 37 families. There were 35 actual organ donors (not **38 donors from 104 potential donors** as stated in the Explanatory Note). Of the 33 families not approached in only 6 instances was this because of a pre-emptive spontaneous refusal.
   That 32 families appear not to have given permission suggests that there is a great need for training in this area.

b. Although 42% of New Zealand drivers are listed as potential donors, the 2005 report of the Australia and New Zealand Organ Donation Registry states that only 25% (10 donors) of actual donors that year had indicated an intention to donate through a signed driver's licence.

c. We understand that organ donor information collected at the time of obtaining a driver licence includes information on specific donations and is available to staff from the NHI database.

Part 1 Preliminary provisions

Section 4(d)
The Foundation seeks clarification that this provision does not apply to living organ donation. Living kidney donors are entitled to financial assistance after donor surgery by way of the Sickness Benefit. Living donor kidney transplants are responsible for an increasing proportion of kidney transplants and living donor liver transplantation is possible in some instances. In 2005 there were 93 kidney transplants carried out in New Zealand and 46 (49%) were from living donors. Live donor-derived kidneys have better outcomes than those from deceased donors. The Foundation believes it is timely for the community to debate the ethics of payment for live organ donors.

Section 5 (1) (b)
The definition of "donor" in the Bill conflicts with established clinical practice. In clinical practice a person who, while alive, consents to the removal of his/her organs is a potential donor and can only become an actual donor under special circumstances e.g. brain death in an ICU or after demanding investigation in the case of a living donor.

Part 2 Removal of organs and registration as donor

Section 7 3C Appointment, functions, and powers of Registrar
Clause (d)
This clause is misleading. With the exception of corneas, bone, heart valves and skin, it is not possible to "bank" solid organs such as kidneys, lungs, liver, heart and pancreas.

Clause (e)
The Foundation does not support the Registrar having the power to "prioritise requests for organs" intended for therapeutic purposes. Allocation of organs is, and must remain, a clinical decision directed by an established prioritisation protocol administered by Organ Donation New Zealand www.donor.co.nz

Section 3H Prohibition on commercial transactions

Clause (1)
Although we agree with the general intent of this clause, we are concerned that it may be in conflict with the current payment of the sickness benefit to living

kidney donors and ignores current international and national debate on the ethics of a state managed payment system for living kidney donors.

Recommendations

1. A Donor Organ Register should not be set up in New Zealand.
2. There should be increased investment in community education regarding the benefits of organ donation and transplantation.
3. There should be public information campaigns to encourage members of the community to make known to their family/whanau their decision regarding organ donation in the event of their death.
4. There should be investment in specialised training for the health staff whose task it is to discuss organ donation with the families of potential donors and obtain consent for organ donation.

References

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