

21 February 2007
SUBMISSION on the HUMAN TISSUE BILL

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.

(Please note we have also requested the same for the Human Tissue (Organ Donation) Amendment Bill)

Associate Professor John Morton, Chairman Telephone number 03 364-0640 Ext 89680
Associate Professor Kelvin Lynn, Medical Director Phone 03 364-0655
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 on behalf of the New Zealand Kidney Foundation by the Foundation's Medical Director – Associate Professor Kelvin Lynn.

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 intention of balancing the wishes and needs of potential donors and their families. We ask you to note that in spite of clearly stated and recorded directions being given by potential donors in regard to organ donation, their families' wishes regarding organ donation after their death may differ. Resolution of such conflict requires appropriately trained clinical staff. Investment is needed in training such staff to work in New Zealand's Intensive Care Units.

While the Foundation understands the Government's wish to rationalise the regulatory framework in regard to human tissue it asks the Committee to note that there is an efficient and effective voluntary system for the retrieval and allocation of deceased donor organs and for the assessment of potential living donors. Any regulatory framework resulting from the present legislation should not put this successful system at risk. The Foundation believes that setting up an effective National Organ and Tissue Donor Register may prove difficult and expensive. At least in regard to organ donation, such

Registers in other countries have not resulted in an increase in the rate of organ donation. (McCall 2006, Childress and Liverman 2006)

The Foundation supports the Government's current policy of allowing welfare assistance for living donors. The Foundation believes that the shortage of donor organs will not be met by increases in deceased organ donation and thus considers that there should be community discussion on the desirability of compensating living donors as is occurring in other developed countries. (Freidman and Freidman 2006)

Specific comments on the Bill.

Clause 3

The Foundation supports the purpose of the Act.

Clause 7

The Foundation supports the intent of this clause but asks the Committee to note that informed consent in regard to deceased organ donation may be problematic because of the context and timing of any recorded consent.

Clauses 28 and 29

Notwithstanding the comments above regarding informed consent the Foundation believes that these clauses provide useful guidance to clinical staff charged with the task of discussing organ donation with the deceased's family.

Clause 45

In spite of this clear statement indicating the binding nature of "appropriate consent" it is inconceivable that organs would be removed from a deceased person for transplantation without the agreement of the grieving family. To do so would be to add to the burden of the bereaved and to damage the public's faith in the integrity of deceased organ donation. (Morton 2004)

References

- Childress JF, Liverman CT (editors). Organ Donation: Opportunities for Action. Committee for increasing rates of organ donation. Washington DC: Board on Health Sciences Policy, Institute of Medicine of the National Academies, National Academies Press; 2006.
- McCall J. Organ donation and legislation. NZ Med J 18 August 2006, Vol 119 No 1240
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