

6 June 1999

Research Director  
Legal, Constitutional and  
Administrative Review Committee  
Parliament House  
George Street  
BRISBANE QLD 4000

Dear Sir/Madam

We submit the attached comments on the proposed Transplantation and Anatomy Amendment Bill.

The opinions are the personal feelings shared by our family members as a donor family. Our views do not necessarily represent the views of other donor families nor donor support groups.

Yours sincerely

Wendy and Dale Nichols

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## **Informed and Definitive Donor Consent**

- Whatever decision is made by the adult, in terms of their body tissue after death, and expressed on the driver's licence, should be final and observed -- be it a "Yes" or a "No".
- Although it is hoped that the decision is an "informed" one, this cannot be guaranteed. Knowledge and consultation cannot be forced upon an adult. However the opportunity should be provided.

## **Availability of Information to Potential Donors**

- To assist the adult make an informed decision a simple explanation of the donation process should be made available to the adult before they are asked to indicate their decision. This may be when they apply for a learner's permit or when notified of renewal of a licence.
- This information could take the form of:
  - a written document and/or
  - a video tape and/or
  - an audio tape, withready access to a contact person for clarification or discussion.

Whatever the mode of presentation, it should be simple, short and factual and in multiple languages.

- The content of the document/tapes could include a short explanation of
  - ♥ the fact that a donor can specify the body tissues to be donated or not donated;
  - ♥ the fact that a potential donor will not be 'let to die' to secure the organs;
  - ♥ the process by which a recipient is selected to allay fears that "some no-hoper doesn't deserve my ..... organs"!
- The adult should then be given the opportunity to discuss their decision with their family/friends.
- Then at the time of indicating their decision, the adult should also be required to:
  - ♥ indicate that they have read/heard/seen information about the donation process.
  - ♥ confirm that they have discussed their decision with family/friends.
  - ♥ nominate a person(s) with whom they have discussed their decision.

### **Accommodation of Relatives' Wishes**

- The adult's decision is final and must be observed.
- If the adult 'dies', then sad as it is, they are dead. It is the surviving family/friends who have to live with the decision. So their feelings have to be taken into account without compromising the 'informed' decision of the deceased.
- Obviously if the donor has discussed the topic with the family/friends then the donation will be made easier for the family/friends.
- If a family/friend has been nominated by the donor, then perhaps the nominee could be invited by the Donor Program Co-ordinator to explain the donor's wishes to the other surviving members.

This means the Donor Co-ordinator would require access to records about the donor and may require previous approval by the nominee to be contacted if the need arose.

- The provision of ongoing support for the donor families is essential. The support may take various forms:
  - ♥ support groups
  - ♥ individual counselling by professionals
  - ♥ opportunity to talk with specially trained individuals from donor families
  - ♥ formal recognition of the Gift of Life eg Thanksgiving Services
  - ♥ some form of 'contact' with the recipients of the donation.

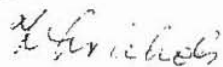
### **Central National Donor Register**

- This just seems so logical and sensible. Why hasn't it been done before? State politics should not be a consideration.
- The practitioners (medical teams, co-ordinators) in the Transplant Programs should be the ones to determine the format of the register; what aspects need to be addressed by it.
- This may be the database that informs the Donor Program Co-ordinator of the donor's specific wishes about organ removal and the nominated family/friend to be contacted.

**Procedures to be followed by relevant authorities**

- Donor Program Co-ordinators need the approval and financial support to educate the public and the medical staff about the procedures and to support donor families.
- Continuous improvement in the procedures should be facilitated by feedback from all stakeholders; not just theoreticians who sit on the relevant committees. For someone not directly affected by the process, it's often a case of "it only happens to other people". It doesn't!

Signed:



Wendy Nichols



(Geoffrey) Dale Nichols

