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### **Submission to the Health Select Committee on the Human Tissue (Organ Donation) Amendment Bill**

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 38 nationally organised societies. It has 31 branches throughout the country attended by representatives of those societies and some 150 other societies. NCWNZ also represents a number of individual women. The Council's function is to serve women, the family and the community at local, national and international levels through research, study, discussion and action.

The main provisions of this Bill were circulated for discussion to the membership through our monthly Circular and via e-mail. Responses were received from 15 Branches, three Nationally Organised Societies, and five individual members. Of these, few disagreed with the fundamental concept of human tissue or organ donation. This submission has been prepared by the Public Issues Standing Committee based on those responses.

We wish to make specific comments on the following sections of the Bill:

#### **Part 2 Removal of organs and registration as donor**

##### **Clause 7 New sections 3A to 3I inserted**

##### **3A Organ donor register**

##### **(2)**

There was widespread support for this structure of responsibility. It was felt that the register must be available on-line 24 hours to be accessed from all hospitals through a secure web-site by authorised personnel who have signed a confidentiality agreement. It was emphasised that good communication and clear guidelines are essential for the register to be used effectively. However, the suggestion from one Branch was that instead of a new register being established, use should be made of the National Health Index (NDI). It was also suggested that with the medical potential of life-support systems combined with fast electronic access, meeting the intent of the Register would be practical and efficient.

##### **3C Appointment functions and power of Registrar**

These conditions are supported by NCWNZ

##### **3D Registration**

These provisions were supported by the majority of respondents and it was widely agreed that sensitive public education was needed to prepare the community. However, there were some concerns about how wishes are expressed during a last illness. One group strongly maintained that if the wishes were conveyed orally, at least one witness should not be a family member. Another group suggested that anyone on the register who wished to amend their instructions



during a final illness should do so in writing, with a JP or two or more witnesses who are not family members, witnessing the signature. It was felt that if the next of kin did not want the donation of organs they might exert pressure on the person who would be unable to counteract in their weakened state. Others felt that the requirement for such formal witnessing could be a further pressure in an already stressful situation.

**(1) (a)**

The majority of respondents supported registration for people aged 18 years and over with several commenting that it fits well with the voting age. However, a small number felt that allowing a young person aged 15 years and older to give their own consent is appropriate if they were given sufficient information and understood the implications of their decision. Others considered that the ability of next of kin to authorise removal of organs for those under 18 already covers the situation adequately.

**(1) (c)**

One Nationally Organised Society with experience in caring for people with intellectual disabilities believed that there were some people with intellectual disabilities who would be capable of making an informed decision over this matter. Their response asked for some distinctions to be included in the definition of the term 'intellectual disability' so that those with a mild disability could take individual responsibility to register if they wished.

**3G Withdrawal of registration or consent**

**(2)**

Although the majority of respondents supported this, several dissenters commented that they could foresee situations when this could be very stressful for next of kin.

**GENERAL COMMENTS**

The survey of the NCWNZ membership also asked for comment on the 'opt-on' concept of the proposed legislation which requires donors to register or to re-confirm their registration if they have already indicated on their driver's licence their wish to be a donor. The alternative would be the assumption that all deceased persons have consented to organ removal for therapeutic or anatomical use unless they have applied to have their name removed from the register i.e. the 'opt-off' concept.

The 'opt-on' concept was strongly favoured by a large majority of respondents. Supporting comments indicated the recognition for appropriate publicity and informed consent, much easier administration of an 'opt-on' register and the potential for distress and dispute among surviving relatives and for the violation of human rights if some people were unaware of the register and their inclusion on it.

The minority who supported the 'opt-off' concept did so because they felt there would then be greater availability of organs and a much better chance of the best possible match.

While good publicity and education were recurring themes in these additional comments from the NCWNZ membership, there was also the message that this must be accompanied by a readily accessible and user-friendly path to the registration process. Suggested ways in which registration could be facilitated included registration forms accompanying the electoral roll registration, publicity in warrant of fitness reminder letters, and opportunities to register at doctors and lawyers offices or appropriate community centres.



The importance of discussing the issue with close relatives and friends and of leaving an unambiguous written record of the deceased's wishes which cannot be overturned was also emphasised by many of our members. One respondent who works in palliative care said that she is always conscious of how important it is for people to be encouraged, and also supported, in this sometimes difficult process of letting their wishes be known. She commented that it is very frustrating for staff members when they know that the patient's wishes are being ignored.

Objective and clear but brief explanations of how organs are harvested and used would be reassuring, and make it easier for the next-of-kin to accept the donor's intentions if the time came for this to be actively considered. It was also suggested that those dealing with the recently bereaved should be alert to the need for appropriate support and counselling for the shocked and grieving next of kin in these situations, especially if the death is sudden, or there are cultural or religious conflicts.

In addition to the medical factors, NCW NZ sees this issue as having important and far-reaching implications for the social and cultural well-being of New Zealand.

Thank you for the opportunity to comment on this Bill.

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**Convener, Public Issues Standing Committee**