

Bill introduced on motion by Mrs Jillian Skinner, read a first time and printed.

Second Reading

Mrs JILLIAN SKINNER (North Shore—Minister for Health, and Minister for Medical Research) [4.15 p.m.]: I move:

That this bill be now read a second time.

I am pleased to bring before the House the Human Tissue Legislation Amendment Bill 2012. The bill clarifies a number of processes related to organ donation in New South Wales, which, together with various other policies and strategies this Government will implement, is aimed at increasing rates of organ donation in New South Wales. From 2007 to 2010 there were sustained increases in the New South Wales and national rates of organ donation and transplantation. In 2010 87 people donated their organs and the rate of donors per million population was 12.5. However, in 2011 New South Wales experienced a decline in both of these numbers. The 2011 donor per million population rate of 11 was one of the lowest of any Australian jurisdiction. In 2011 there were 77 solid organ donors in New South Wales. Part of the reason, of course, is that we have been so much better at preventing deaths on the roads and so forth. Any decrease in organ donation, however small, can cause devastating consequences for individuals, and their families, who require a transplant in order to lead full and healthy lives. Unfortunately, people die while they are waiting for a suitably matched organ to be found for transplantation.

In order to look properly at the reasons for the decrease, and canvass strategies aimed at increasing the rates of organ donation, in December 2011 I released a discussion paper titled "Increasing Organ Donation in NSW". The discussion paper canvassed a range of issues including: whether New South Wales should move to a single national register by closing the Roads and Maritime Services register; whether to switch to an "opt-out" model of presumed consent to organ donation; the promotion of advance care directives as a means to indicate consent to organ donation; trialling new models for assisting families to consider donor consent such as designated requestors and dual advocacy; whether to revoke the practice of allowing family members to refuse organ donation in circumstances where the deceased person has consented to it; strategies to better support and raise awareness among Aboriginal and culturally and linguistically diverse community members; and strategies to further enhance the living donor program such as better promotion of financial support options.

Seventy-six submissions were received in response to the discussion paper. The majority of submissions were from members of the community; they were very thoughtful and considered responses. Eleven submissions were received from groups, including clinical and

organ donation advocacy organisations such as Transplant Australia Inc. and ShareLife, the NSW Health Clinical Ethics Advisory Panel, the Medical Services Committee and the Australian Medical Association. Commentary on the proposals was also provided by the Commonwealth's Australian Organ and Tissue Donation and Transplantation Authority. After considering the submissions received, the Government released its "Increasing Organ Donation in NSW: Government Plan 2012", which sets out the Government's plan to increase organ donation rates in New South Wales.

The plan outlines five key outcomes that the Government will pursue. They include enabling peoples' intentions regarding organ donation to be known to their family or significant others, preferably documented and made easily accessible. This is important because evidence has shown that when families understand their loved one has previously consented to organ donation, organ donation goes ahead in nearly all cases. Families often say "no" when it is unknown to them that their loved one has consented to be an organ donor. Another key outcome is addressing information gaps about organ donation, including addressing myths and misperceptions. Identifying all opportunities for organ donation in New South Wales hospitals, supporting clinicians' conversations with families to enable fully informed decisions about proceeding with organ donation and supporting living donor programs are other key outcomes.

The Government's plan will include a number of legislative and non-legislative changes to support the Government's goal to increase organ donation. Many of the Government's goals will be pursued at the front line, led by the NSW Organ and Tissue Donation Service. Information campaigns will target people from culturally and linguistically diverse communities to explain the benefits of organ donation, clarify any misunderstandings, address concerns, and promote family discussions and registration of consent to organ donation. In relation to addressing issues for the various culturally and linguistically diverse families, we acknowledge it is important to understand that it is not just a matter of translating this document into another language, it is about comprehending the cultural attitudes to death and to transplantation, and addressing those attitudes. Education and training programs will also be rolled out for targeted healthcare workers to enhance their capacity to have effective conversations with families of potential donors and the designated requestor model will be trialled in selected New South Wales hospitals. This has worked extremely well overseas.

In addition, to ensure that an individual's views on organ donation are recorded and documented appropriately, the Government will move to a single national register of organ donation intent. New South Wales currently has a stand-alone system for registration of consent to organ donation via the NSW Roads and Maritime Service's [RMS] driver licence application process. However, other States and Territories discontinued their driver licence registers in 2003 and moved to the single Australian Organ Donor Register [AODR] run by Medicare. The move to recording organ donation intention on a single national register that is accessible from anywhere in Australia will assist with increasing organ donation rates by providing a focus on one mechanism for recording organ donation consent of potential

donors. In addition, a single register will reduce the potential for confusion among community members and clinicians about the best way to record consent to organ donation. The single national register will provide benefits that will enable the existing state-based Roads and Maritime Services register to close.

People in New South Wales who wish to register their organ donation intent will be referred to the Australian Organ Donor Register. The Australian Organ Donor Register will be promoted via the Roads and Maritime Services website, driver licence and vehicle registration renewal letters and community information campaigns. The promotional activity in New South Wales will complement existing initiatives run via Medicare and the Australian Organ and Tissue Donation and Transplantation Authority. The Government is also investigating transferring consent data from the Roads and Maritime Services register directly to the Australian Organ Donor Register. In the meantime, it is important that information currently stored on the Roads and Maritime Services register is not lost in the short term. For this reason, a snapshot will be taken of the Roads and Maritime Services register and all of the information on it prior to its closure will continue to be used for five years, the equivalent length of time of a drivers licence. Therefore, should the situation arise, the views of a potential donor will be known. This will ensure that the wishes of current licence holders are respected during the transition to the Australian Organ Donor Register.

It needs to be recognised that the snapshot database may not have up-to-date information available about an individual's views on organ donation. This is because information on the Roads and Maritime Services register may only represent the views of the individual at the time of a licence application or renewal and the person's views may have changed over time. It is important that people's most recent views with respect to organ donation are considered and upheld. The ability of an individual to change his or her mind with respect to organ donation is dealt with only partially under the Human Tissue Act. Section 23 of the Human Tissue Act sets out the processes under which a designated officer can authorise the removal of tissue from a deceased person. Under section 23, if a person has given his or her written consent, the designated officer can authorise the removal of tissue, but only if the person in question had not revoked consent during his or her lifetime. However, a person who has not provided written consent to organ donation cannot revoke an initial objection unless donation has been consented to in writing.

Under section 23, if there is no written consent, the designated officer can only authorise the removal of tissue from a deceased person if the officer is satisfied, among other things, that the person in question had not, during his or her lifetime, expressed an objection to organ donation. This means, that if the deceased person had expressed an objection at one point in his or her lifetime, but had later changed his or her mind and was in favour of organ donation at the time of his or her death, a designated officer can authorise the removal of tissue from the deceased. Clearly, the current provision in section 23 may be inadequate in giving effect to the most recent wishes of the deceased. The bill will address this problem. The bill amends section 23 of the Human Tissue Act to provide that, in circumstances when there is no written consent of the deceased, a designated officer can authorise the removal of tissue from a

deceased person who had previously expressed an objection but only when the designated officer is satisfied that, based on the most recent views of the deceased, the deceased person no longer objected to the removal of tissue.

The other requirements in the Act, such as obtaining the senior next of kin's consent, will continue to apply when there is no written consent from the deceased for organ donation. This is an important amendment. Where there is no written consent, it will allow the designated officer to consider the most recent views of the deceased with respect to organ donation and not require a designated officer to rely on historical and out-of-date views of the deceased. The bill also makes similar changes to section 24 of the Human Tissue Act, which relates to authorising the removal of tissue when a person dies in a place other than a hospital. In addition, the bill makes similar changes to the Anatomy Act 1977 to ensure that the most recent views of the deceased can be taken into account in determining whether or not a deceased person's body can be used in an anatomical examination. Another issue that does arise with respect to organ donation occurs when a deceased person had given their written consent, but organ donation does not proceed because the family objects.

The records show that situation occurred in only seven cases last year. Under the Human Tissue Act, if a deceased person had given their written consent to the removal of tissue, a designated officer can authorise the removal of tissue notwithstanding that the deceased's family objects. However, the general practice is that clinicians will not proceed with organ donation against a family's wishes. This is consistent with practice in all other Australian jurisdictions as well as comparable international jurisdictions. In New South Wales there are approximately seven to 10 cases each year in which the deceased person has consented but the family objects and the donation does not proceed. In those rare cases it appears that the main reason clinicians do not proceed is the possibility of causing additional distress to family members when they are already experiencing the grief associated with losing a loved one.

The issue of a family's right to veto organ donation was canvassed in the discussion paper. Some individual community members who made submissions supported overturning family veto. However, the majority of key organ donation community advocacy organisations and clinical or professional organisations supported the current approach. This was because of the concern that removing organs against a family's wishes had the potential to impact on consent because individuals may not want their family to be subjected to additional emotional and psychological distress after their death. The consensus view was that education rather than regulation is the most appropriate means of increasing consent to organ donation. The Government supports this approach and will continue to support community information campaigns that promote family discussion of organ donation wishes, including campaigns that support specific culturally and linguistically diverse and religious communities.

I digress to inform the House and anyone listening to this debate that at 11.30 a.m. tomorrow Transplant Australia will be available in the Fountain Court of Parliament House to register anyone who wants to become an organ donor. Even those who are already registered should

come along to show their support. I will also be launching the Transplant Games, which will be held in Newcastle later this month. The Government wants everyone to understand organ donation and to continue to discuss it. NSW Health has found that in situations when the wishes of the deceased person are known and/or recorded families rarely refuse organ donation. That is why the Government wants to educate the community about the importance of family discussion and to educate clinicians so that they have the skills to discuss organ donation with families and to support families to make decisions about it.

As I speak, training is being provided to clinicians to help them to understand how to have those conversations. While there are clear reasons that clinicians do not proceed with organ donation in the face of family objection, it is not clear why families are refusing to comply with the deceased person's wishes. This is due to limited information available to NSW Health about the reasons a small number of families do not accede to their family member's expressed wishes. This is important information because it would allow NSW Health to review the small number of cases in which this occurs. That information would also allow NSW Health to determine whether any additional processes can be put in place to ensure that, where possible, a deceased person's wishes are acted upon.

As such, the bill amends the Human Tissue Act to create a new section 27A to allow the Director General of NSW Health to issue guidelines in respect of organ donation to ensure information is recorded setting out the reasons for not proceeding with organ donation where the deceased had given his or her consent but the family objected. This provision will ensure that clinicians involved in organ donation can adequately document the reasons it did not proceed, notwithstanding that the deceased consented. Such documentation will support analysis of the reasons for family refusal and will assist in developing awareness campaigns that focus on addressing the concerns that lead to family refusal. In addition to the guidelines, the Government will expand specialist training for clinicians in conducting consent conversations and will trial a new model for approaching families for consent. The model will involve specially trained designated requesters who are independent from the treating team.

Due to their specialised role and training, the designated requestors will develop the skills and expertise to work appropriately and sensitively with a family when the question of organ donation arises. Specialised knowledge and skill are also appropriate and necessary when it comes to the removal of tissue. The final amendment in this bill relates to the procedures involved in that process. Under the Human Tissue Act, tissue can be removed after a person has died provided that valid consents and authorities have been obtained. Under section 27, normally once a valid consent and authority has been given to remove the tissue, the authority authorises a medical practitioner to remove the tissue. However, it is not always necessary for a medical practitioner to remove tissue for transplantation purposes. Medical practitioner skills are not necessary to remove tissue for transplantation in a way that maintains its viability.

Appropriately trained non-medical clinicians can remove tissue. Use of non-medical

clinicians is more cost-effective and also enables tissue to be retrieved more frequently and in a more timely way because the process is not competing with the clinical service delivery demands on a medical practitioner's time. Tissue retrieval occurs most frequently in a post-mortem setting and it is done by people with a background in science rather than untrained, unskilled personnel. For this reason, section 27 (1A) allows for certain tissue—that is, musculoskeletal and corneal tissue—to be removed by a person other than a medical practitioner if the person is appointed by the director general of NSW Health. Persons appointed by the director general to remove musculoskeletal and corneal tissue are persons specifically trained to remove tissue and such persons are usually from a nursing, scientific or a pathology or mortuary assistant background.

In addition to musculoskeletal and corneal tissue, in certain cases cardiovascular tissue can also be adequately removed from a deceased person by a non-medical practitioner. This occurs when the entire heart is not viable for transplantation but heart valves and other tissue can be used to benefit another person. In order to address this situation, the bill amends section 27 to allow a non-medical practitioner to remove cardiac tissue if the person is appointed by the director general. This amendment will bring the removal of cardiovascular tissue into line with that of musculoskeletal and corneal tissue, and ensures that a more flexible and effective approach can be utilised in removing cardiovascular tissue, particularly heart valves. This bill is part of an important and key Government goal of increasing organ donation and will support the vital policy and procedural changes that are occurring at the community and health service level in order to increase our rates of organ donation. Organ donation can save and transform lives and should be supported by both this Parliament and the community as a whole—and I believe it is. I commend the bill to the House.

Debate adjourned on motion by Dr Andrew McDonald and set down as an order of the day for a future day.