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Mr Bruce McDowell
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By Email: admin@donorfamiliesaustralia.org

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Representing
Western Australians
for more than 120 years

Dear Bruce

Donor Families Australia

Question for advice

- 1 You have asked Lavan to provide you with a letter of advice with respect to legislation surrounding the ability of organ donor families (next of kin of minor/adult deceased donors) to disclose or give to any other person any information or document whereby the identity of "a person" may become publicly known.
- 2 In particular, you asked us to focus on the following pieces of legislation:
 - 2.1 *Human Tissue and Transplant Act 1982 (WA)*, Part III which deals with donations of tissue after death

Statement of the law

- 3 In Western Australia, the primary legislation regarding organ donation is the *Human Tissue and Transplant Act 1982 (WA)* (**HTTA**).

Please notify us if this communication has been sent to you by mistake. If it has been, any privilege between solicitor and client is not waived or lost and you are not entitled to use it in any way.

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Our values:

Lavan respectfully acknowledges the traditional owners of the land on which we live and work.

Organ Donation

Children

- 4 Section 5 of the *Age of Majority Act 1972 (WA)* provides that persons of age 18 years or more are to have full legal capacity. The only potentially relevant caveat in the *Age of Majority Act* is that section 5 does not affect any other 'juristic competence' or capacity attributable to insanity or mental infirmity. This advice does not cover the rights of persons who may not have legal capacity, but who are over the age of 18 years.
- 5 The HTTA defines 'child' as a person who has not attained the age of 18 years.

Living Donors

- 6 Part II, Division 2 of the HTTA provides for donations of tissue by living adults and Division 3 deals with donations from living children.
- 7 With respect to living children, broadly, a parent can consent to the removal of 'specified regenerative tissue' of the child (subject to specific circumstances).¹ There are similar rules with respect to blood transfusions.²

Deceased donors

- 8 Part III of the HTTA deals with donations of tissue after death. There is no explicit provision in Part III relating to children or adults; rather, the 'donor' is referenced as a 'body of a person who has died...'.¹
- 9 However, section 22(2) HTTA provides the situations in which a designated officer for a hospital may authorise the removal of tissue from the body of the person who has died. In this respect, broadly, the designated officer for a hospital may authorise the removal of tissue where:
- 9.1 the designated officer is satisfied that the deceased person had expressed the wish/consent to the removal (and had not withdrawn such consent);³ or
- 9.2 the designated officer has no reason to believe that the deceased person had expressed an objection *and* the senior available next of kin consents to the removal of tissue.
- 10 'Senior available next of kin' is defined, insofar as it relates to children, as:
- (a) in relation to a child, means the first in order of priority of the following persons who is available at the time —

¹ HTTA s13.

² HTTA s19.

³ HTTA s22(2)(a)

(i) if the child has both a spouse, and a de facto partner who has attained the age of 18 years, the spouse or de facto partner with whom the child is living as a spouse or de facto partner;⁴

(ia) the spouse, or de facto partner who has attained the age of 18 years, of the child;

(ii) a parent of the child;

(iii) a brother or sister, who has attained the age of 18 years, of the child;

(iv) a guardian of the child;

11 Accordingly, the consent to the removal of tissue from a deceased child, may, in certain circumstances (and we understand from your instructions, as a matter of practice will always), rest with the spouse/de facto partner/parent/brother or sister/guardian of the child.

Disclosure of Information

12 Section 34 of the HTTA provides:

34. Disclosure of information

(1) Subject to this section, a person shall not disclose or give to any other person any information or document whereby the identity of a person —

(a) from whose body tissue has been removed for the purpose of transplantation or for use for other therapeutic purposes or for medical, teaching or scientific purposes; or

(b) with respect to whom or with respect to whose body a consent or authority has been given under this Act; or

(c) into whose body tissue has been, is being, or may be, transplanted,

may become publicly known.

Penalty: \$500

(2) Subsection (1) does not apply to or in relation to any information disclosed —

(a) in pursuance of an order of a Court or when otherwise required by law; or

(b) for the purposes of hospital administration or bona fide medical research; or

(c) with the consent of the person to whom the information relates; or

⁴ This section recognises that “*It is conceivable that someone could have been married, separated and entered into a de facto relationship before reaching the age of 18*”. See Western Australia, *Extract from Parliamentary Debates*, Legislative Assembly, 11 December 2001, 84 ([https://www.parliament.wa.gov.au/Hansard/hansard.nsf/0/77743d6b5ab88572c8257570001490c0/\\$FILE/A36%20S1%2020011211%20p6798e-6916a.pdf](https://www.parliament.wa.gov.au/Hansard/hansard.nsf/0/77743d6b5ab88572c8257570001490c0/$FILE/A36%20S1%2020011211%20p6798e-6916a.pdf))

(d) when the circumstances in which the disclosure is made are such that the disclosure is or would be privileged.

Statutory construction – disclosing information

- 13 In determining what provisions mean, one is required to use principles of statutory construction. The approach to statutory construction is that outlined by the High Court in *SZTAL v Minister for Immigration and Border Protection*⁵ where the Court at [14] stated:

*The **starting point** for the ascertainment of the meaning of a statutory provision is **the text** of the statute whilst, **at the same time, regard is had to its context and purpose**. Context should be regarded at this first stage and not at some later stage and it should be regarded in its widest sense. This is not to deny the importance of the natural and ordinary meaning of a word, namely how it is ordinarily understood in discourse, to the process of construction. Considerations of context and purpose simply recognise that, understood in its statutory, historical or other context, some other meaning of a word may be suggested, and so too, **if its ordinary meaning is not consistent with the statutory purpose, that meaning must be rejected**.*

[emphasis added]

- 14 Accordingly, to interpret the meaning of statute/legislation, we begin with the ordinary meaning of the words.
- 15 Section 34(1) HTTA provides that no person may ‘disclose or give’ to any person, any information or document whereby the identity of (i) a donor, (ii) a person in respect of whom a consent or authority was given under the HTTA, or (iii) a recipient, may become publicly known. Section 34(2) provides exceptions, including, relevantly, “the consent of the person to whom the information relates”. In this section, ‘consent’ is not limited to ‘written consent’.
- 16 According to the ‘Review of the Australian organ donation, retrieval and transplantation system - Final Report - 12 December 2018’ (**the 2018 Review**)⁶, the purpose and context in which the HTTA operates, with respect to disclosure of identifying information, is as follows:

*The respective Human Tissue Acts prohibit the disclosure of identifying information which may result in the identification of an organ donor or transplant recipient. As a result, health professionals are not able to facilitate the meeting of donor families and transplant recipients. While the legislative provisions may vary depending on the jurisdiction, **the purpose remains the same: to protect the identity of those who have donated organs, or received transplantation**.*

[emphasis added]

⁵ *SZTAL v Minister for Immigration and Border Protection* [2017] HCA 34; (2017) 347 ALR 405; 91 ALJR 936 at [14].

⁶ *Review of the Australian organ donation, retrieval and transplantation system* (Final report, 12 December 2018), 106.

Discussion of how the law applies

- 17 On a plain reading of the text of s34(1) HTTA, our view is that the legislation is clear in that it prohibits any person from disclosing information/document(s) from which the identity of (i) a donor, (ii) a person in respect of whom a consent or authority was given under the HTTA, or (iii) a recipient, may become publicly known.
- 18 This is supported by the 2018 Review.
- 19 In our view, the exception noted in s34(2), with respect to 'consent', does not allow for any person, other than the person to whom the information relates, to give the information/document(s).
- 20 In this respect, the 'person to whom the information relates' is (i) the donor, (ii) the person in respect of whom a consent or authority was given under the HTTA, or (iii) the recipient, as identified in s34(1).
- 21 This section seems to imply that, for example, a parent of a child donor cannot say to any other person, words to the effect of 'my son/daughter donated their organ/s', if that identifying information "may become publicly known".
- 22 We have not found any authority on the interpretation of the phrase "may become publicly known".
- 23 It appears highly unlikely (and indeed we have found no instances) that an offence against s34 HTTA would be prosecuted. We cannot, however, discount the theoretical risk.

What if the 'person to whom the information relates' is deceased?

- 24 Whilst we recognise that a person who is deceased will not be able to consent to their identity becoming known (at least insofar as those persons are not able to consent after death), it appears that this is not considered within the legislation. Accordingly, on our interpretation of the legislation, no person may give information/document(s) pertaining to a deceased donor, recipient or person in respect of whom an authority was given, if that person is deceased.
- 25 It is arguable that if the deceased person, prior to their death, had given consent for their identifying details to be disseminated, this would fall into the exception of consent under s34(2)(c).

Rights of next of kin to consent to disclosure

- 26 You raised with us the query as to the rights of the next of kin to consent to disclosure, particularly in the context of the next of kin having substantial rights and powers under the act with respect to organ and tissue donations.⁷

⁷ See, eg, HTTA ss22, 23, 25, 26

- 27 Our view is that next of kin do not fall within any of the express exceptions in s34(2) and as these are the only categories of exception, next of kin are not able, within the scope of the legislation, to provide such details.
- 28 If we are right, that may be an unintended consequence of the legislation and it may be that lobbying is appropriate to cause a change to it.

Publications by Donate Life

- 29 You raised with us a query as to the rights of 'Donate Life' to publish information about donors and recipients in their 'Book of Life', in which the donor and/or recipient's identities may become known.
- 30 As a preliminary matter, we note that as we are not privy to any Donate Life information (save for what is publicly available), we cannot categorically state whether Donate Life is operating within the scope of the HTTA or not.
- 31 However, on our preliminary view, it appears that by publishing stories referring to deceased donors and recipients (wherein in the identity of the donor/recipient may become publicly known), the Book of Life may be in breach of the HTTA.
- 32 It is possible (though we recognise unlikely) that the people referred to in the publication had consented to their personal identifying information being used.

Rights of donor families/next of kin to be aware of legislative limitations

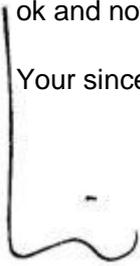
- 33 You have raised with us whether donor families/next of kin should be made aware of the provisions and limitations under the HTTA before consenting to organ donation, particularly insofar as they relate to the rights of donor families to disclose information in respect of the donor (and/or recipient).
- 34 From a legal perspective, there are no requirements in the HTTA that donors and/or their families/next of kin must be informed of their rights after consenting to organ donation. Consent can only be given if *medical advice* (not legal advice) has been given.
- 35 From an ethical perspective, this is certainly an issue which we can understand would be close to the heart of many donor families and accordingly, you may choose to lobby around this issue and the wording and workings of the legislation.

Use of this letter, and waiver of privilege

- 36 We note that the information and advice provided in this letter is for the use of Donor Families Australia. If you share this advice with any other parties/persons, any legal professional privilege will be lost.

We set out in Annexure 1, some scenarios and our interpretation of what the legislation says is ok and not ok in each situation.

Your sincerely

A handwritten signature in black ink, appearing to be "Iain Freeman".

Iain Freeman
Partner

Annexure 1 - FAQs/Practical Examples

Deceased child donor

- 37 A child under the age of 18 has died. The child's parents attend at the hospital (the child is not in a serious relationship). At the hospital, the designated officer has asked the child's parents if they consent to the child's organ/s being donated. The parents agree and the child becomes an organ donor.

Can the parents 'spread the word' about their child being an organ donor?

- 37.1 No. On our interpretation of the legislation, the parents, even as next of kin, cannot disclose any information about their child, where the identity of that child may become publicly known. If a parent says to a person 'my son/daughter chose to be an organ donor', then the identity of that child is known. Whether the identify of the child 'may become publicly known' will depend on the circumstances. It may be arguable that the parents could tell select people about their child and their child's donation, if telling those people did not mean that the information 'may become publicly known'.

- 37.2 We recognise it is highly unlikely that parents/next of kin would be prosecuted for a breach of disclosure of identifying information about their son/daughter being an organ donor.

Can the parents/next of kin consent to identifying information about the child being disclosed?

- 37.1 No. Only the 'person to whom the information relates' can consent to the disclosure of the identifying information.

Can the child consent to information being published about them/their donation, whilst they are alive?

- 37.2 Unclear. In theory, if a donor has consented to their own identifying information being disclosed, then such disclosure is not in breach of the Act. However, for a person under the age of 18, the consent may be required to have been given by their parent/guardian. The legislation is not clear on this point.

- 37.3 It is possible that, in line with provisions such as those relating to donations of tissue by living children, the child would not be able to provide consent unless they had received advice with respect to the nature of the consent, implications of consent, and so on. However, it appears highly unlikely that an (otherwise healthy) child would ever be in a position to seek advice regarding such information. It is much more likely that this would be a 'dinner table conversation'.

Deceased adult donor

- 38 An adult has died. At the hospital, the designated officer has asked the adult's next of kin (in this case, their spouse) if they consent to the adult's organ/s being

donated.⁸ The spouse knew the deceased wished to be an organ donor, and agrees and the deceased adult becomes an organ donor.

Can the spouse publicise that the deceased spouse's was an organ donor?

- 38.1 No, not if the donor's identify 'may become publicly known'. Not unless the deceased spouse had consented to the disclosure of their information. This would likely be difficult to demonstrate.

Living adult donor

- 39 An adult has consented to donating an organ whilst they are alive, and donates a kidney to their spouse.

Can the recipient spouse publicise their gratitude for the donor?

- 39.1 Only if the donor is not identified, or if the donor consented to being identified (or any gratitude was such that the identity of the donor would not become publicly known).

⁸ We note that you have instructed us that it is a matter of practice that the donor's next of kin is asked whether they consent; accordingly, our examples do not address situations where the designated officer is satisfied that the deceased person, during their lifetime, expressed a wish/consent to the removal of tissue, and the officer has then not sought input from the next of kin.