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Senate Standing Committees on Community Affairs  
PO Box 6100  
Parliament House  
Canberra ACT 2600

National Heart Foundation  
of Australia  
ABN 98 008 419 761

Level 2, 850 Collins St  
Docklands VIC 3008  
T: 13 11 12

### **Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023**

Thank you for the opportunity to put forward a submission to the Senate inquiry into the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 (the Bill). The Heart Foundation supports the Bill as it will help increase community awareness of organ donation, which is crucial to increasing the number of people willing to become organ donors.

For those living with severely damaged or diseased hearts, a heart transplant can be the last avenue of hope in terms of treatment options. In 2020–21, there were 129 heart transplants performed – 84 (65%) for males and 45 (35%) for females.<sup>i</sup> In 2021, 117 deceased organ donors (28%) had a heart retrieved. From these heart donors there were 112 heart transplant recipients.<sup>ii</sup>

In general, for medical reasons organs can only be used from willing donors who die in hospital and who meet other eligibility criteria. Of those eligible to donate, only 54% of families provided their consent, which further reduces the number of available organs that can be used.<sup>iii</sup> This means that inevitably there are more people in need of donor organs than there are organs available.

The Heart Foundation favours policies that will help increase the number of eligible donors by showing the community the positive impact that organ donation can have. Increasing the rate of organ donation and transplantation will assist in improving heart health outcomes, in particular for people with severe forms of heart failure and coronary heart disease, and save the lives of donor recipients.

It is the Heart Foundation's understanding that the Bill will enable increased awareness of organ and tissue donation by more easily allowing the Australian Organ and Tissue Authority (OTA), DonateLife agencies, grant recipients and "authorised family members" to publish, disseminate or disclose information about deceased organ or tissue donors or recipients.

The key change is allowing a slightly broader range of close family members to provide permission for information about the deceased's organ donation. On balance, the Heart Foundation views this as appropriate as the dissemination of this knowledge will hopefully help inspire other people to register as potential organ donors.

The impact of the Bill on donor privacy is relatively small, but in the view of the Heart Foundation strikes the right balance between respecting the privacy of the donor individual and their family, and the importance of showing the positive impact that organ and tissue donation can have.

The other additional privacy safeguards in the existing legislation will continue to operate, and there are no changes proposed in the Bill that would allow any party to identify links between organ donors and recipients. Furthermore, there are no changes proposed in the Bill that would affect organ recipient privacy.

Thank you for the opportunity to put forward a submission to the committee.

Kind Regards,

David Lloyd  
Chief Executive Officer

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<sup>i</sup> AIHW. *Heart, stroke and vascular disease: Australian facts*. 2023. Available at: [www.aihw.gov.au/reports/cvd/092/hsvd-facts/contents/treatment-and-management/hospital-care-and-procedures](http://www.aihw.gov.au/reports/cvd/092/hsvd-facts/contents/treatment-and-management/hospital-care-and-procedures)

<sup>ii</sup> AIHW. *Heart, stroke and vascular disease: Australian facts*. 2023. Available at: [www.aihw.gov.au/reports/cvd/092/hsvd-facts/contents/treatment-and-management/hospital-care-and-procedures](http://www.aihw.gov.au/reports/cvd/092/hsvd-facts/contents/treatment-and-management/hospital-care-and-procedures)

<sup>iii</sup> Australian Organ and Tissue Donation and Transplantation Authority. *Australian Donation and Transplantation Activity Report*. 2022. Available at: [www.donatelife.gov.au/all-about-donation/statistics-in-australia](http://www.donatelife.gov.au/all-about-donation/statistics-in-australia)