



THE BRIEF

DONOR FAMILIES AUSTRALIA

Member Update — THE BRIEF No. 2

Hello members,

Welcome to our 2nd Edition of THE BRIEF, where we try and keep you up to date with important organ and tissue matters.

Donor Families Australia (DFA) a few years ago asked a legal firm for its opinion on the Human Tissue Act's confidentiality clause. They concluded that, legally, families after saying "yes" to donation can not refer to their loved one in the context of organ and tissue donation. To further back this up the Australian Law Reform Commission (ALRC), as part of its recent review process into organ and tissue donation, redacted from personal submissions, all reference to loved ones information such as name, use of the word his/her and any words that could possibly identify the deceased donor.

Because of DFA's lobbying for law reform, especially where Families should own their loved one's information, the Federal Attorney General ordered a review of Federal, State and Territory Human Tissue Acts.

Please find included the link of ALRC's Discussion Paper –

<https://www.alrc.gov.au/publication/review-of-human-tissue-laws-discussion-paper-2025/>

DFA's full submission to the Discussion Paper can be found at –

<https://www.alrc.gov.au/inquiry/review-of-human-tissue-laws/submissions/>

The ALRC's review will put forward its recommendations in August/September 2026. Thank you to all those members who contributed with their own submissions or provided input to DFA letting us know what was important to them.

Included in THE BRIEF is –

- A summary of DFA's submission to the ALRC
- Information about our Donor Heroes Night 18th May 2026 and
- The introduction of our new facebook page for members.

As always DFA encourages members to make comment on any of these topics or anything they would like to be included in future THE BRIEF's.

Bruce McDowell
Chairman

Honouring Donors, Supporting Families. Strengthening Ethical Donation in Australia



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Donor Families Australia (DFA) Submission Summary

Australian Law Reform Commission – Review of Human Tissue Laws (2025 Discussion Paper)

Key Themes	Summary
Purpose of Submission	Donor Families Australia (DFA), representing over 1,000 donor families nationally, provided a response to ensure that Human Tissue laws are humane, transparent, and trusted by the community . DFA emphasises that increasing donation rates depends on public trust and respect for donors and families .
Primary Principle: Public Trust	DFA strongly argues that “ promoting and upholding public trust ” must be the first and central principle of any reform. Without trust, donation systems cannot function effectively.
Humanising the Law	The review must go beyond harmonisation and modernisation to humanise human tissue laws , recognising the lived experiences of donor families and ensuring dignity, respect, and transparency.
National Regulatory Framework	DFA supports uniform Commonwealth legislation with: • A single independent national regulator • Mandatory adoption by all States/Territories • Alignment with NHMRC Ethical Guidelines (2025)
Independent National Regulator	DFA calls for a new Independent Regulator , separate from existing bodies, with powers to: • Oversee all donation and transplantation activities • Monitor, audit, and enforce compliance • Establish binding standards and codes • Investigate complaints
Concerns with Existing Systems	DFA expresses serious mistrust of current Institutions , citing: • Lack of accountability • Poor communication with families • Inconsistent application of laws • Exclusion of donor family voices
Ombudsman Role	A dedicated independent Ombudsman is recommended to: • Address complaints • Ensure transparency • Reduce conflicts of interest
Inclusion of Lived Experience	Donor families and recipients must be actively involved in governance , policy development, and regulatory processes through transparent selection methods.



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Ethical Priorities & Rights	Summary
Respect for Donor Dignity	Laws must prioritise the principle that Donors are never to be treated merely as a source of tissue . Any such treatment is considered unethical and exploitative .
Alignment with Ethical Guidelines	The NHMRC Ethical Guidelines (2025) must underpin all legislation. Ethical principles should take precedence where inconsistencies arise.
Voice of Donors and Families	DFA advocates for legal recognition of the right of Donor Families to speak about their loved ones , own their loved ones information, including sharing stories and, where mutually agreed, connecting with recipients.
Informed Consent	“Valid consent” must be clearly defined and include: <ul style="list-style-type: none"> • Full disclosure of how tissue will be used • Clarity on commercial aspects (if any) • Understanding of risks and processes, do not use the terms like ‘Nature and Effect’ as meaningless to the community • Consideration of literacy, language, and emotional capacity.
Concerns with Current Consent Practices	DFA highlights issues such as: <ul style="list-style-type: none"> • Lack of transparency prior to consent • Distress caused by “cold call” donation requests • Potential coercion or inadequate information • Over-reliance on donor registers without fully informed consent
Role of Families in Decision-Making	Families must: <ul style="list-style-type: none"> • Be consulted and involved in all decisions • Retain a meaningful role in consent processes • Be protected from coercion or distress
Designated Officers	DFA strongly supports retaining and strengthening independent Designated Officers to: <ul style="list-style-type: none"> • Ensure legal compliance • Confirm valid consent • Provide independent oversight
Equity and Accessibility	Legal reforms must address inequities by ensuring: <ul style="list-style-type: none"> • Accessible information for all communities • Clear definitions of “informed consent” • Education for both the public and health professionals
Transparency and Accountability	DFA calls for: <ul style="list-style-type: none"> • Mandatory public reporting • Oversight of financial practices (cost recovery) • Clear regulation of tissue use, storage, and



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	research • Independent investigation of breaches
Commercialisation Concerns	Human tissue must never be treated as a commodity. DFA opposes: • Financial incentives driving donation • Lack of transparency in tissue use or sale
Consenting Adults Meeting	DFA supports consenting Donor Families and consenting Recipients to be assisted to meet.
Final Position	DFA supports reform but insists it must: • Be values-based and ethically grounded • Restore community trust • Protect Donor dignity and Family rights • Ensure independent oversight and accountability

Conclusion

DFA's submission emphasises that **trust, dignity, and transparency are foundational** to a successful human tissue donation system. Legal reform must prioritise **people over process**, ensuring that Donors and their Families are respected, informed, and central to all decision-making. Without these reforms, public confidence—and therefore consent rates—will remain at risk.



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Donor Heroes Night on 18th May 2026

Save the date!!! This is the 7th year the event when DFA members can acknowledge and celebrate our Donor Hero loved ones. Post your photo and message of your Hero at www.facebook.com/DonorFamiliesAustralia.

Spread the word with family and friends and encourage all Australians to get involved. More information to follow in the coming weeks.

Graham Harrison, DHN Coordinator.

Donor Families Australia Membership (Facebook) Group

DFA is in the process of developing and making available a PRIVATE Facebook Group open to all Members (Donor Families) and Associate Member (Recipients and their families). The Facebook Group will enable our membership to become more involved and able to communicate on all topics, issues and events that are impacting on the DFA membership.

Over the course of the next few months our membership of 1,000+ will be issued a personal invitation to join this PRIVATE Group through your membership email. So please be patient as it will take some time to process you all.

Some examples of items of discussion can involve; Legislative issues being reviewed by government as they pertain to Donor Families, forthcoming events, issues of service provided by DonateLife that can be improved, seeking personal support, comments that can improve the DFA website, opportunities as to how you can be more involved with DFA and its Executive etc to name a few.

We look forward to your involvement.



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Donor Heroes Night



18th May 2026

An Event of Reflection and Remembrance of Organ and Tissue Donors that have given the Gift of Life to those with the greatest need. Celebrate with us by lighting a candle or leaving your porch light on during the evening of 18th May 2026 and post a photo and comment on

www.facebook.com/DonorFamiliesAustralia

Your involvement will help raise awareness across Australia. For more information visit www.donorfamiliesaustralia.org