CHAIRMAN'S ANNUAL REPORT 2026

Donor Families Australia

Welcome everyone.

Since Donor Families Australia (DFA) was established in 2013, our purpose has been clear: to stand alongside Donors Families, represent our members and advocate for a donation system that treats donors and their loved ones with dignity, respect and compassion. This report proudly reflects what more than a decade of persistence and commitment has achieved—and the work that remains.

I still remember attending an Organ and Tissue Authority (OTA) Board meeting in Canberra to introduce DFA back in 2013. The Board included professors, doctors and senior bureaucrats. One surgeon wished us well but added "they had seen Donor Family organisations before, they never last long". Thirteen years later, DFA is still here: a strong, entirely voluntary organisation receiving no government funding, continuing to make a difference for families and the wider community.

A decade of advocacy and influence

DFA's progress has been built on sustained engagement with politicians, government officials, legal professionals and the community. We have worked to ensure that the experiences and concerns of Donor Families are heard in discussions that shape policy, legislation and practice. Our achievements show what a committed Donor Family voice can accomplish, even when consultation is not readily encouraged.

A significant contribution to the Ethical Guidelines

One of DFA's major achievements has been its substantial input into the Ethical Guidelines for Cell, Tissue and Organ Donation and Transplantation in Australia published in 2025. The guidelines were around ten years in the making, and DFA worked hard to be included in the process. Our involvement helped bring Donor Family perspectives into a national document that guides ethical decision-making.

The published guidelines reflect principles DFA has consistently advocated for:

- *When the relevant people involved agree on the disclosure or exchange of specific information, then information may be shared freely without breaching privacy or confidentiality (1).*

- *As rules that govern many aspects of our society, knowledge of relevant laws is important for appropriate ethical decision-making in donation and transplantation. Failure to follow the law can result in offences being committed or penalties being imposed. This is the case, even if a person does not know about the specific law (2).*

- *Respect for the dignity of donors - including potential donors - means that a donor should never be treated solely as a means to achieve the goal of transplantation for another individual. Treating a donor merely as a source of cells, tissues or organs for transplantation constitutes unethical exploitation (3).*

These principles reinforce the importance of dignity, respect and appropriate consideration of donors and their families.

Helping procure the ALRC review

DFA was instrumental in bringing about the Australian Law Reform Commission's (ALRC) review of Organ and Tissue Donation Legislation in Australia. The issue arose from DFA's efforts to clarify whether donor families could authorise the sharing of their loved one's information. Legal advice obtained from Lavan in Perth indicated that, under Western Australia's Tissue Act, families did not own their loved one's information or have authority to consent to its disclosure. DFA found that similar arrangements applied in most jurisdictions across Australia.

Through persistent advocacy and lobbying, DFA has helped achieve legislative changes in four jurisdictions—New South Wales, the ACT, South Australia and Tasmania—to recognise next of kin of deceased donors in disclosure-of-information provisions. Queensland, Western Australia, Victoria and the Northern Territory have not yet made the same change. With consultation and direction from DFA, the ACT also introduced legislation allowing donation to be acknowledged on the death certificate; at the time of writing, it remains the only Australian jurisdiction to do so.

By lobbying federal politicians, DFA helped secure a much-needed review of Australia's fragmented state and territory laws. As the ALRC recommendations are expected to become public in November 2026, we have continued to engage with jurisdictions and reinforce the importance of recognising families' relationship with their loved one's information. DFA will be ready to contribute when governments consider the recommendations and next steps.

Supporting members and raising awareness

This year, DFA introduced its Brief Communiqué to keep members informed about our work and developments relevant to Donor Families and Recipients. We have also widened our private social media page to include all DFA members, creating more opportunities for people to connect and support one another. With advice from Lani Campbell, a DFA member, we are exploring ways to strengthen our use of social media and reach a wider community.

Committee member, Graham Harrison, has once again placed DFA at the forefront of donation awareness through our annual Donor Hero Night. His work generated impressive engagement and helped make this year's event one of our most successful. Donor Hero Night has become a leading event on the donation awareness calendar, recognising the life-saving and life-improving gift of donation.

Trust and the work ahead

DFA is concerned about the decline in Australia's donation consent rate, reported nationally at 53%, well below the mid-60% levels seen in recent years. We see consent rates as closely connected to trust or lack of in the system. Rebuilding trust requires a willingness to listen to families and the broader community, consider new ideas and address concerns openly and being transparent. Legislative reform and improvements in how the system is managed must be part of that conversation.

The progress made since 2013 has been significant, but our work is not finished. DFA will continue to press for fairer and more consistent laws, greater awareness of the issues affecting Donor Families, and meaningful involvement of families in decisions that affect them. Donor Families

should not be overlooked, and their recognition should not depend on where their loved one lived or died.

To this end DFA will be working for our membership throughout 2026/2027 to make the eight jurisdictions aware of the recommendations within the ALRC's review that matches our expectations for the future. We see the work going forward as being as much a challenge as what the last thirteen years have been. It is so important that Donor Families have a voice and are heard in the future legislative process.

New Organ & Tissue Authority CEO

DFA welcomes Ms Helen Grinbergs as the new Chief Executive Officer of the Organ and Tissue Authority. Our Donor Family membership looks forward to working with Ms Grinbergs as she navigates the challenges and opportunities of ensuring the Australian public receives the best possible outcomes from organ and tissue donation.

Acknowledgements

Thank you to every committee member for your time and commitment, and to our members for your support and for sharing the experiences that give our advocacy its purpose. DFA's achievements belong to the people who have continued to stand up for Donor Families and future Donor Families.

When DFA began in 2013, few could have predicted how far this voluntary organisation would come. Our contribution to the Ethical Guidelines, our role in securing the ALRC review and the legislative changes achieved in several jurisdictions demonstrate the value of persistent advocacy. This report celebrates those achievements and renews our commitment to ensuring Donor Families are heard, respected and recognised.

Thank you for being part of that work.

References

1. Ethical guidelines for cell, tissue and organ donation and transplantation in Australia (EGCTODTA) p 132 (top of page).
2. EGCTODTA p 55 3.5 Laws second para.
3. EGCTODTA p 39 second last para.

Bruce McDowell
Chairman