

## **Chairman's Report 2024**

Welcome everyone

In the 2021 Chairman's Report it was mentioned that Donor Families Australia (DFA) had sought the legal advice from the Legal firm Lavan, as to whether the family of the Organ and Tissue Donor owned their loved ones information.

On testing the advice of the Organ and Tissue Authority (OTA) Lavin confirmed that families did not own their loved ones information, and as such, did not have the authority to give consent for their loved ones information to be shared. The ramifications of this advice from Lavan meant that the along with Donor Families the OTA was acting outside of the various state and territory legislations.

Three years on, and DFA is pleased to report that we, through our ongoing lobbying, have been instrumental in having a review announced by the Attorney-General, Mark Dreyfus and the Minister of Organ and Tissue Donation, Ms Ged Kearney, on the various Human Tissue Acts across all states and territories. The aim of this review is to help harmonise state and territory legislations relating to Organ and Tissue Donation and to fix the obvious short comings of the current legislations.

This review is to be conducted by the Australian Law Reform Commission (ALRC) and will go for approximately 12 months. This is an important milestone for DFA to provide an importable voice for Donor Families. The Federal Minister of Organ and Tissue Donation, Ms Ged Kearney, instructed her Federal Health Department to invite DFA to take part in a meeting to discuss the setting up of such a review with the staff of the ALRC. Much was discussed around the various legislations and DFA was able to contribute especially where the Donor and their Families were affected. The Minister is to select the Commissioner for the task and with the possible start of the review process in early 2025. The review workforce will travel around the country to speak to all stakeholders and those wanting to contribute to the process. A review such as this This has never been conducted before and is an opportunity for all Australians to have a say.

On the 19<sup>th</sup> February 2024 the WA government enacted an amendment to its Human Tissue Act. It made it legal for tissue retrieval to be performed by non medically qualified employees.

At the time of implementing this legislation the WA government had not consulted with one Donor Family. DFA is aware that families will not be informed of this prior to consenting for retrieval of tissues.

The legislation was put through to satisfy government and industry and no consideration given to the Donor or their family. This situation is an ongoing discussion with those who have implemented this legislation.

DFA held a two day workshop for our committee in May. The workshop was held in Canberra at committee member Dr Holly Northam's home. We had a full turn out of members with a couple needing to attend via zoom. The committee invited two special guests in Felicity McNeil and Paul Cross. Felicity brought with her experience and knowledge as the past CEO of the OTA and Paul his experience with the Canberra political scene and legal understandings of legislation. We had two great days of workshops and discussion and fellowship given some of the committee were meeting face to face for the first time.

It has been a year of intense advocating for Donor Family by DFA. Soon after dealing with the OTA over the amended Federal Human Tissue act DFA was fighting hard for Donor Families to be heard with the draft Organ and Tissue Donation Ethical Guidelines.

DFA was aware of the efforts being made over recent years to update the Ethical Guidelines. For the last three years DFA has made contact with the relevant government body that had the task of putting this Draft together. They advised us that DFA would be consulted and we were to be included on the stakeholder list of those to be invited to respond to the draft. Unfortunately this did not happen and DFA made a complaint with the Minister of Organ and Tissue, Ms Ged Kearney . As a result DFA was able to acquire a seven week extension to respond to the draft. DFA did an extensive consultation process with its membership. We held Zoom meetings and forwarded out a survey for members to respond to draft proposals. We had a very vocal and active response that DFA was able to compile a lengthy comprehensive paper to put before the main ethical body in Australia. Thank you to all those who partook in the consultation process and to Holly Northam for compiling the report. We are still waiting to hear what changes our efforts have made to the draft.

I am pleased to report that DFA, through its SA committee member Jackie Robson, has been successful in the SA government putting forward draft amendments that closely replicate those implemented by the ACT two years ago. This legislation established that the Donor Family owned their loved ones information, and as such, could give consent to others to pass on their loved ones information. Unfortunately this principle is still not an established one with the other jurisdictions around the country. It is eventually hoped that the review being conducted by the ALRC will rectify this.

DFA conducted its fifth Donor Hero Night in May. This night is our major focus to help raise awareness of the importance of Organ and Tissue donation whilst honouring the donor. DFA thank all those that honoured and acknowledged our Organ and Tissue Donor Heroes and showed their support in Organ/Tissue Donation and Transplantation. It was encouraging to see such a large number of Organ/Tissue donation and transplantation organisations and support groups, both nationally and international get involved. The importance of conducting Donor Heroes' Night is highlighted by the fact that 21 organisations were engaged this year; 10 from Australia, 6 from Canada, 5 from United Kingdom and 2 from Europe. It is even more incredible when one realises that a total of 186,888 followers had the potential to participate. The power of social media services across the platforms involving; Facebook, Instagram, X (Twitter) and YouTube during the six weeks of marketing leading up to and including the evening Event, amounted to over 42,500 known hits recorded.

On the evening of Donor Heroes' Night, in conjunction with Donor Families Australia, both Donor and Recipient Group Australia and DonateLife (Australia) combined, achieved 26,005 Reaches 3,780 Likes, 469 Comments, 323 Photos and 1,116 Shares amounting to a total of 31,693 hits. This outcome acknowledges just how important it is to enable those involved in Organ/Tissue donation the ability to honour our Donor Heroes, for where would all those that have received a transplant around the world be without them. I would encourage you all to follow the link <https://www.facebook.com/DonorFamiliesAustralia> and read some of the many comments posted.

DFA wants to thank all our volunteers, Sam Howkins our Newsletter editor and production manager, all our committee members who work tirelessly in the background advocating for change. Graham Harrison for organising the wonderful Donor Hero Night.

The past year has especially highlighted the need for an organisation such as DFA. If we weren't there the voices representing the Donors and Families would not only not be heard but would actively and intentionally be left out of all the conversations around Organ and Tissue Donation by the public sector and the politicians. Hopefully now those who contribute most, the donor and their family, to this sector will be represented in all the various legislative changes and the important document the ethical guidelines so that the Australian public will be fully informed with how this sector conducts itself.

It would be fair to say that this year has seen more change than the ten years before it. Governments are finally recognising that legislation is out dated and not suited to today's world. We just need that to flow over to our public sector. We look forward to next year and the years to follow to see how far the Human Tissue Acts and the Ethical Guidelines go to honouring our loved ones.

Bruce McDowell  
Chairman  
Donor Families Australia