

# Chairman's Report 2023

Donor Families Australia (DFA) celebrated its 10-year Anniversary within this reporting year. The importance of this organisation to its members and the wider community has never been stronger. Over the ten years we have maintained a strong committee of dedicated members across the nation which continue to meet our goals of Care, Support, Advocacy and Awareness for Donor Families and the wider Community.

DFA is an entirely voluntary organisation with no government funding, uniquely supported and led by Donor Families who share a common goal, the desire to honour their loved one's legacy and to help other families to say 'yes' to save and improve more lives. With that purpose, examples of DFA's achievements over the past ten years include:

- Fighting for visibility of the people whose final legacy was to save and improve lives.
- Establishing and improving Donor memorials, for example, Geraldton, Canberra, and Perth - a DFA recommendation to the 2015 EY sector review.
- Promotion and creation of the 'Thank You Day'.
- Creation of the 'Donor Hero's Night'.
- Providing ongoing advocacy for:
  - Respectful, compassionate Donor / Recipient letter writing processes.
  - Enabling respectful meetings between consenting adult Donor Families and Recipients.
  - Lobbying and co-creation guidance to support organ donation within Territories and States to enable humane donation legislation that meets contemporary expectations.
  - Efforts to bring about amendments to legislation in State/Territory and Federal jurisdictions to ensure that Donor Families own their loved one's information without conditions.

The most recent national transplant consent rates during this reporting period are the lowest in the history of the Organ and Tissue Authority

(OTA), with a national rate of 54% and with WA recording the lowest consent rate of 50%. A demonstration of loss of confidence in the OTA is the fact that there were two inquiries going on around the country into the performance of the sector during this reporting period.

When DFA commenced ten years ago the rate of family consent, when the family knew what their loved one wanted, was 95%. As mentioned by the Medical Director of WA Donate Life during the WA inquiry into Organ and Tissue Donation, that rate over the last ten years has now slipped to 80%. As a statistic it probably does not mean too much but when you think about the hundreds, if not thousands of lives that have been lost/or affected because of this decline it does bring it to mind especially if your loved one passed away waiting for a lifesaving organ or tissue. This is a clear indication of the lack of trust in the system by the community. Despite this being a gradual trend, the public sector overseeing Organ and Tissue Donation has done nothing other than to exacerbate the situation with its denial that there is a problem.

We appreciate that change does not happen overnight, but nevertheless it has been over two years since DFA first brought to the attention of the OTA and government the Legal firm Lavan's advice, that both the OTA and Donor Families were restricted in what they could say about our loved one's donation, which absurdly could attract penalties and fines.

To this end DFA has been working tirelessly over the past twelve months with State/Territory and Federal governments to amend the wording of the relevant legislations. During this reporting period some inroads have been achieved.

Donor Families in the ACT are now legally authorised to give consent for their loved one's story to be told at Donate Life remembrance services as of 24 November 2022. This was brought about after DFA questioned the lawfulness of the ACT and other jurisdictions being able to share the stories of those who have donated organs or tissue, even if the families have consented. This has been distressing and frustrating for families and has limited the way in which DonateLife ACT has been able to raise awareness of or acknowledge this gift of life. The passing of the amendments to the Bill in the ACT Legislative Assembly made it clear that, with families' consent, DonateLife can share the stories of the families'

loved ones. The legislation in the ACT has now made it plain that the family does own and control their deceased loved one's information unconditionally. DFA was acknowledged by Hon. Tara Cheyene MLA ACT for bringing this issue to their attention. On behalf of the DFA Committee and its members we wish to recognise the support shown by the Hon Tara Cheyene and the Minister of Health of the ACT, Hon Rachel Stephen-Smith in instigating this amendment.

Following on from this work the Hon Nicola Centofanti MP SA has also been lobbying for changes to the SA legislation. Nicola has had passed her bill on Acknowledging Donation on the Death Certificate, through the Upper House in SA. We now are waiting to see what the Labor Party in SA will do in the Lower House. This was largely achieved through the work done by our SA committee member Jackie Robson on behalf of DFA.

Despite being the organisation that raised the issue of families not owning their deceased loved one's donation information, in May 2023 DFA became aware that the OTA had drafted an amendment to the Federal legislation. It was presented to the Federal parliament with NO consultation with DFA or any Donor Families despite the legislation directly affecting Donor Families. DFA had legal advice saying that families around the country did not own their deceased loved one's donation information and as such they do not have the authority for their loved one's donation information to be passed on. This meant that the Donate Life offices had been holding remembrance services contrary to their jurisdiction's legislation. It also meant that families could not give consent to hospitals to pass their loved one's donation information on.

The OTA's solution was to surreptitiously amend Federal legislation so that it could override all States and Territories to ensure that their own staff will not be penalised or fined. They gave no consideration for the families. In all jurisdictions other than the ACT families still do not own or control their loved one's information.

DFA lobbied intensely over this period to have the amendment changed to include consideration for families. Whilst we were unsuccessful with our efforts, we did manage to have our message conveyed to all Federal politicians, that the wording of this Bill –

- was done with NO Consultation,

- confirms the lack of ownership/control of our loved one's information,
- demonstrates the heavy handedness of having two levels of government now controlling what families can say and do in relation to their loved one's donation information.
- needs to be passed onto the families at the time of being asked to consent to retrieval of organs/tissues of their loved ones, in the interest of the families making an informed consent.

Thankyou to Phillipa Delahoy, Dr Holly Northam, Felicity McNeil and Paul Cross for their tireless efforts over this period of lobbying. DFA did have several politicians who worked hard to have our message heard – Hon Linda Reynolds, Hon Perin Davey, and Hon David Pocock to mention some.

DFA celebrated its fourth year of hosting our Organ and Tissue Donor Heroes Night. Our Donor Heroes are responsible for saving and improving thousands of lives and so many more through the ripple effect. The community are encouraged to show its appreciation by the simple action of turning on their front porch light on the 18<sup>th</sup> of May. This year the total social media involvement was up 66% more than the year before. An interesting offshoot to this year's event was the contact from overseas organisations. Perth City Council once again lit up their building in the Perth CBD, brightly displaying the DHN and DFA logo. Next year, we hope to have more cities involved in bringing attention to our Donor Heroes. DFA wish to acknowledge all the work that Committee member Graham Harrison puts in each year to make this an ongoing success.

Since the establishment of DFA in early 2013, many individuals have contributed towards making the organisation what it has become today. As a founding member, Graham Harrison has been effectively contributing to various facets of DFA. However, most would not be aware that his involvement within the organ donation and transplantation environment commenced 29 years ago in May 1993, when his son passed away and became an organ donor at the age of ten. Congratulations to Graham for becoming DFA's first Life Member.

In November 2022 the DFA Committee held its annual Planning Day. The Committee met to discuss several important topics for us to tackle in the

new year. This was a lively meeting with many topics covered and most importantly mapped out the direction DFA would like to tackle as a priority. Some of the topics included:

- Continued advocacy in ownership of our loved one's information including helping to facilitate changes to the relevant legislation.
- Across all States and Territories, roll out recognition on the Death Certificate of organ and tissue donors, as achieved in the ACT.
- Call upon all areas of Organ and Tissue donation to be more transparent in the donation process to assist families when agreeing to organ and tissue donation and keeping them informed post donation.
- Assisting consenting Donor Family adults and consenting Recipient adults to meet.
- Continue to grow DHN not just in Australia but further afield.

Donor Families and Recipients wanting to be assisted to meet is an ongoing issue for our members. In March 2023 SBS aired a programme on Breakthroughs in Organ and Tissue Transplants. It was evident from those in the audience that finding the match of Donor to Recipients was very beneficial to the Donor Families and the Recipients. DFA will continue to support our members to have relevant laws and OTA policies amended to ensure that respectfully consenting Donor Families and consenting Recipients are supported to meet.

The DFA committee often has the discussion on which is the best model opt in or opt out and the need for the committee to get a unified DFA position. Discussion was held at committee meetings about the pros and cons of each approach. The committee agreed that the opt in opt out is a distraction to the actual issues which is the need for better education of the public (i.e., registering does nothing to prepare families for the conversations that occur in the hospital) and that there needs to be transparency and accountability at the hospital level. It is our opinion that the opt In or opt out models won't change the size of the patient pool. Looking at new innovative ways of raising awareness and gaining information from those with the "lived experiences", Donor Families, would help contribute to improving the donation rate. DFA will continue to lobby in these areas for our members.

There are several people I wish to acknowledge and thank on behalf of the committee and its members. Firstly, to our outgoing committee members: Donor Family Representatives Anthea Openshaw and Helen Day. Anthea has offered sage insights over her time on the committee and stood up to take over the anniversary emails to our members. Thankfully Anthea has agreed to carry on this important work of anniversary emails to help provide support to our Donor Family members. Helen Day had been an inaugural member of our committee and took on the role of Treasurer for several years which is most appreciated. Thank you both for your efforts and support shown to Donor Families. Further to this we say goodbye to our two Recipient Representatives Janielle Colquhoun and Warrick Duncan. It is always important to have the insights from a Recipients point of view. Both their inputs have been invaluable. We wish all the outgoing committee members all the best for the future.

As the Chairman I wish to thank the Committee for all their efforts over the past twelve months it has been a very active year, and they all make my job so much easier with their ongoing support and input. A special thank you to Sam Howkins who, despite having her second child recently, provides ongoing support to DFA by providing editorial and publication expertise for our newsletter. I would also like to acknowledge our members who graciously provide their loved one's stories for our newsletters. The sharing of our stories is an important part of the healing process and a wonderful way of honouring our Donor Heroes. It is great to read the input on our closed and open facebook page. It also gives families an opportunity to support each other. Thank you to those members who have represented DFA at various media presentations to help raise awareness in the community. Thank you also to local governments who have contributed with ongoing upkeep of the Donor Awareness Fountain in Geraldton (with the help of Nagle Catholic College) and lighting up the CBD Council building in Perth to acknowledge DFA's Donor Hero Night.

We look forward to our next twelve months with determination to achieve the Human Right amendment to our legislations to give all Donor Families the unconditional ownership of their loved one's donation information. We also look forward to supporting our members in any way we can.

Chairman

Bruce McDowell

15/11/23