



DONOR FAMILIES AUSTRALIA

AGM 16<sup>th</sup> NOVEMBER 2020

## **CHAIRMAN'S REPORT**

**2019/2020**

It gives me great pleasure to be able to present the achievements of Donor Families Australia (DFA) over the last financial year.

The 2020 year can be defined as so much more than just COVID 19. DFA went onto have, perhaps, its most memorable year, so much was achieved in the name of Donor Families.

We started the year with 652 registered families. At June 2020 we had 782, an increase of 20%. This increase in membership is very pleasing and demonstrates the need for our organisation in having a voice to support Donor Families whilst helping to increase the donation rate.

Perhaps the most important single event we have ever held was our first Conference in Canberra on the campus of the University of Canberra. Over 2 days in October 2019 delegates from all over the country came together to talk about Organ and Tissue Donation from a Donor Family perspective. It was 2 full days of talks and group discussions culminating in a call to action by Donor Families to help improve the Donor Family experience. The Conference exceeded all expectations with the feedback from delegates being very positive. A big congratulations to the Conference sub committee for their tireless efforts under the leadership of Holly Northam.

One of the follow up actions from the Conference that stood out was perhaps the achievement of Tara Cheyne MP in having the Acknowledgement of Donation included on the Death Certificate in the ACT. Tara was a guest of our Conference and after discussion with our members took on the task of instigating legislative change. On the 21<sup>st</sup> May 2020, the legislation was passed for Donor Families in the ACT to choose whether they wanted the Death Certificate of their loved one to acknowledge their donation. Tara had achieved much in such a short time for the benefit of Donor Families. On behalf of all Donor Families we congratulate her.

Another action coming from the Conference was to extend our social media reach. We have now instigated our presence on Instagram and Twitter. These new social media platforms now complement our web and facebook pages. This has achieved a far greater reach and has brought in so many more people into the Organ and Tissue conversation. DFA has now moved onto Zoom for holding its monthly meetings. This certainly makes the whole experience so much more personable when you can actually see who you are conversing with.

To further demonstrate DFA's social media reach we embarked on our first Organ and Tissue Donor Hero Night. The community was asked, via our social media platforms, to turn on their porch light the night of the 18<sup>th</sup> May 2020. The posts that followed around this night was overwhelming. People posted photos of their porch light. We had approximately 50 000 reactions over the evening

and the days that followed. The 18<sup>th</sup> May is Graham and Elayne Harrison's son Ben's anniversary. This night is a tribute to Ben and all Donors Heroes. Due to the success of the evening this will now become an annual DFA event.

Last year's Chairman's Report mentioned that DFA had spoken with the consultants from Ernst & Young. They were conducting a Review of the Australian organ donation, retrieval and transplantation system. The Report was completed 12<sup>th</sup> December 2018 and became public in the 2019/2020 year. DFA is very proud to be the reason why the review makes the following recommendation – **Recommendation 26: States and territories establish a nationally uniform process for arrangements for donor families and recipients over the age of 18 to be identified to each other based on the principle of mutual informed consent.** At the time of writing the Chairman's Report DFA has become aware from the Organ and Tissue Authority (OTA) that this recommendation will not be looked at until sometime into 2021, some 2 years after the report has been published. It is indeed very disappointing that the review recommendation has not been followed up. DFA will make sure that it remains on the table.

Perhaps the most damaging single event that DFA has heard of in our eight years was the uncovering, by one of our members in November 2019, of 69 unsent letters in the Donate Life office in Sydney. It was found that some of the letters had been sitting in the office for over 6 months without passing on. DFA sent a formal complaint to the Minister of Organ and Tissue Donation and the Secretary of the Federal Department of Health. The complaint is ongoing with DFA meeting with representatives from the Federal Department of Health. DFA will monitor its progress into the next year. DFA has used member feedback and forwarded ideas to the OTA as to how the letter writing experience between Donor Families and Recipients can be improved upon. DFA will keep members up to date via our social media platforms and Newsletter as to the progress made.

DFA has been very active in representing its members with meetings with the Minister for Organ and Tissue Donation the Hon Mark Coulton, the Federal Department of Health, presenting to the Friends of Organ and Tissue Donation in Canberra at Parliament House, representing its members on the Community Engagement Group in Canberra and lobbying state and territory politicians and public servants.

On behalf of the committee I would like to thank the outgoing committee members, Kelli McDonald and Julie Wilson for their contributions over the period they served on the committee. Their efforts, on behalf of their loved ones has been greatly appreciated.

We manage to produce a regular Newsletter every year. I would like to make special mention of the work done by Samantha Howkins. Sam edits and produces the Newsletter in a very professional way and provides technical support for our web page and membership data base as our community volunteer.

I would also like to thank all the committee members for the work done in the last year. So much was achieved. I look forward to what DFA will be doing next year and into the future to assist Donor Families.

Bruce McDowell

Chairman

16/11/20