



Donor Families
AUSTRALIA

Donor Families Australia NEWS

Summer 2023, Edition 29

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GRIEF AND LOSS AND THE FESTIVE SEASON

The festive season can be a tough time for anyone who is grieving. It can be a particular trigger that highlights the loss we are facing and person we are missing. They aren't at the table for those family gatherings and we need to 'make merry' because that's what you do at this time of year right?

October was the five-year anniversary after the unexpected loss of my sister, and it hasn't got any easier to face 'special' days including holidays. What has changed is getting used to the idea of festivities without her. It's not easier, but it is more familiar.

*Share
your
story*

Familiarity means fewer of those terrible moments of shock where I kind of forgot she was gone and then realized she had all over again. This familiar path of not having my sister has given me more spaciousness around grieving and brought some change this past year in that I am more focused – once again – on Deanna's life, rather than her death.

Her life was my focus when she was alive. Sharing our kids growing up, the juggle of work and home, life and drama and family and busy-ness. Almost daily messages or emails or calls that were and remain some of the things I miss most with Deanna gone. Picking up



my phone to text her something funny. Calling to complain about our mum buying yet another antique gem.

Living in different states, we'd see each other for a school holiday catch up, or at this time of year for a big family catch up and for me early on it was at those events her absence was most apparent.

But now, as time has moved on, it is the daily things that only she would understand, or that take me 10 minutes to explain to



A life that touches others goes on forever

~continued page 2

~continued from cover

someone else why that thing is particularly hilarious, that I miss. So this past year I have started sending her those texts, laughing out loud at what she would say to that meme, sharing my aggravations at living with teen and teenagers. This has been kind of wonderful. (And all in my head.)

Knowing someone so well – I had the privilege of having her for 43 years as my only sibling – means I know exactly what she would say, when she'd roll her eyes, what advice she would offer, what stories she would want me to share with her son and her nieces and exactly which ones they're a little bit young for just yet...

I know without any doubt she'd be pleased I keep the stories going. She'd be pleased her son and his cousins are chatting with each other just like we did. And she'd be pleased to know I am thinking about her life now rather than her death. Because knowing her so well she would say that's enough now Mel, let me rest and watch you live life to the full.

So this festive season, I will tell stories about the year we were kids living in the country and the sleigh tracks we found on the dry dusty ground along with a pile of reindeer poo. (Father Christmas brought us a trampoline that year and we somersaulted off it all day – no nets back then!) And the year we got bikes and rode them together around that little town and the even littler town we lived in after that. I might tell some stories about the adventures we had (no Mum, we never went near that mineshaft/ swam in that river/ left the gate open, promise!) and the traditions we had that are now part of my own family's traditions. This will be my part in keeping the memory of Deanna alive and letting her live on in the lives of her nieces and son. And in me.

Melanie Cantwell, Donor Sister



*Share
your
story*

A WARM INVITATION TO JOIN US

Share your experience

with similar people to support those making life changing decisions.

Help us to build a caring community
and to shape the future of this caring national network.

If you would like to
find out more about

Donor Families Australia

and how to become a member
please visit our website

**Individually we do great things and affect those around us.
Collectively we do great things and affect a nation!**

www.donorfamiliesaustralia.org

The festive season can bring all kinds of feelings and there are so many different ideas out there on how best to deal with those feelings.



My view is: do whatever you need to. You know You, best. Fireworks and funny videos are what you need? Do it. Quiet introspection, a visit to a special memorial site, curling up in a ball crying? Do it.



There's no one way to grieve and there's no one way to get through festivities while grieving. Giving yourself permission to join in, or not, is important and people who really care about you will understand that this year might be different to last year, or on the day, it just doesn't come together.



There are myriad excellent resources available online about supporting your mental health and wellbeing as much as possible at this time of year when you have lost someone you love. There's practical things to mark the occasion, eg. setting a place, having a photo, etc and mental health support services that remind us we're not alone in feeling like this.

Some reliable sources and useful articles to start you off:

[Managing grief during the festive season | Grief and loss | ReachOut Australia](#)

[Grief Information Sheets](#) for special days at [Australian Centre for Grief & Bereavement](#)

[Tips for managing grief during the holidays](#) from Palliative Care Australia and links to several books about the grief and the festive season

[Griefline](#) ☎ 1300 845 745

[Lifeline](#) ☎ 13 11 14 or text and web chat options

[Beyond Blue](#) has phone, web chat, peer online support options



Talk or chat online to a counsellor

If you're going through a hard time right now, the Beyond Blue Support Service is available 24/7 for brief counselling. Most calls last around 20 minutes.

Our counsellors will listen and help you find the extra mental health help you need.

Get free, confidential counselling (local call costs apply):

[Call a counsellor on 1300 22 4636](#)

[Chat to a counsellor online](#)

Accessibility and language support are available for telephone counselling.

CHAIRMAN'S MESSAGE

Celebrating
10
years
2013-2023

Take a bow, Donor Families Australia (DFA), you have now been operating for ten years and still going strong. When I look back pre-DFA, there was no Donor Family organisation. If you wanted to seek assistance, seek peer to peer support, or let people know things could have been done better, you had nowhere to go. It was easy for the system to ignore you with no repercussions. You were left to sort things out on your own. DFA has brought Donor Families together right around Australia and helped us gain a voice. Over the ten-year period DFA has gone from strength to strength and achieved much.

Looking back on ten years

DFA was formed with the opening of the DFA Donor Awareness Fountain in Geraldton WA, in December 2012. The Fountain, too, is celebrating its ten year anniversary. Earlier this month, we organised a gathering of some of the people that were responsible for the construction of the Fountain, those that wanted to honour the heroes mentioned on the wall, and those that support Organ and Tissue Donation and wished to raise awareness. It was wonderful to see everyone again and celebrate this achievement. DFA, as a fledgling organisation, with the support of a number of individuals, service clubs, business and three levels of government, banded together to build this fountain to raise awareness of Organ and Tissue donation in the Midwest. Anecdotaly, the fountain has saved lives by stimulating the conversation with family members about organ and tissue donation.

From there, a strong committee with representation from around the country was formed. We soon established our goals of supporting each other, advocating on behalf of families, advising those who initiate policy and legislation and promoting organ and tissue donation.

To this end, we were instrumental in achieving the Thank You Day through consultation with then Minister for Organ and Tissue, Minister Nash. DFA hosted seven outdoor Thank You Day events the same year right around the

country.

After consultation with Ernst & Young in its first review where we promoted the importance of having places to remember our loved ones, such as the Geraldton Donor Awareness Fountain, the government funded the Gift of Life Garden in Canberra and the City Beach artwork in Perth. The importance of such places was demonstrated when Minister Nash, visited Geraldton and was able to see firsthand how its presence can affect the community.

Our story is one of persistence and if you don't succeed straightaway, you keep going. An example of this is in our second Newsletter issue's story about the Recognition of Donation on the Death Certificate (April 2013). Almost ten years on, we have success from the ACT Parliament when Tara Cheyne MP successfully introduced this new legislation. This work will continue until we have the same acknowledgement around the country.

Where Donor Families have had little to no profile within the system, DFA has stood tall and made sure our voices were heard. We have been part of media conferences called by politicians and by ourselves. We front the media when it is necessary such as demanding for legislative change in all jurisdictions so that the next of kin is given the authority to give consent for their loved one's information to be made publicly known. Again, the ACT Parliament has, through Minister Rachel Stephen-Smith MP and Minister Tara Cheyne MP, amended the Anatomy Act to include this provision. In the ACT, Donor Families can give Donate Life consent to have families speak at remembrance services. At present, this is the only jurisdiction where this can happen without knowingly contravening legislation.

DFA has been at the forefront of raising awareness with its Donor Awareness Fountain and Thank You Day. Through its committee and members, it has been responsible for



many school talks, service club presentations, conference appearances and training seminars. Over the last few years, we have introduced the Donor Hero Night where you can turn on your porch light to remember those who gave to others. This night has grown every year to where the social media response increases by hundreds of thousands. The last Donor Hero Night was promoted by the City of Perth which lit up its building with the DFA Donor Hero logo for a week. This important event will continue to grow in future years.

One of DFA's most defining Donor Family support service is our anniversary emails. This service also celebrates its tenth year. We know by the response from our members that it's appreciated by those who receive one every year.

Along with our social media pages, our regular newsletter over the ten years has made sure that communication between members is strong. Our Newsletters have always been able to express what is important to our members. Over the years, the main topics discussed with members have been the use of first names of the love one in letters to Recipients and the right of consenting Donor Families and consenting Recipients to meet. This was reflected in a survey DFA conducted of 544 respondents, where 538 said consenting adults should be assisted to meet. DFA presented this to the second Ernst & Young review and Recommendation #26 from the review reflected this by saying consenting parties should be able to meet. We will continue to advocate where our members ask.

A couple of years ago, DFA was presented with a cheque for over \$17,000 from the Kuri Mongrels bike club. It had conducted a fundraising effort topped by a major raffle of an eBike. Thanks to the Kuri Mongrels, DFA has been able to financially support ourselves and is looking at new ways to fund ourselves in the future.

Along with advocating for various members for different reasons, perhaps the biggest act of advocacy came when donor families in NSW realised their letters were not getting through. From further investigation, it was

found that 69 letters had not been passed on through the NSW office. Only through our continual support for these families, was there acknowledgement of this breakdown in the very important communication link between Donor Families and Recipients. DFA was able to link up families and bureaucrats to discuss this at length and work out how this will not happen again.

As a result, DFA was invited to make recommendations to the letter writing policy. This was the first time any consultation has been made with Donor Families regarding this policy — or for that matter any policy that



affected them. An important aspect to come out of this consultation was the need for the letter writer to be notified when their letter has been received by the government agency and then again to confirm the process is complete. Members made it clear to us that they wished to use the first name of their loved one in a letter if they so desired.

One of the major highlights in the last ten

years was the 2019 conference held at the University of Canberra ACT. After months of preparation, delegates came from around Australia — some from overseas. Two days of discussions occurred with people from different interests. Our major achievement would be the Acknowledgement of Donation on the Death Certificate in the ACT put forward by Tara Cheyne MP. There were numerous recommendations made by delegates that have formed DFA's future ambitions.

Perhaps the most important aspect of DFA's first ten years is that when we started, there was little consideration given to the Donor Family; now, policy and lawmakers are very much aware of our presence and the effect

that their decision makes on our lives.

None of the above would have been achieved without the tireless efforts of our past and present committee members and band of volunteers. On behalf of all our members, we thank you. We are very proud of our achievements over this time and we look forward to what can be achieved in the future.

I would personally like to wish everyone all the best with family and friends over the festive season. Please look after yourselves and wishing you every happiness in the New Year.

Bruce McDowell

Chairman

CHAIR'S REPORT AGM 21/22

Celebrating
10
years
2013-2023

It would be fair to say that the last year has been one of Donor Families Australia's (DFA) most important years. DFA has been lobbying strongly to ensure Donor Families rights are acknowledged and respected by the government services and politicians alike. In last year's Chairman's Report, I touched on the fact that DFA had received legal opinion that showed that government departments and Donor Families had been contravening their respective state and territories Human Tissue Acts. Only the person to whom information relates can give consent for that information to become legally publicly known. This means that Donor Families have no legal right to give consent for their loved one's information becoming publicly known. Likewise, government departments cannot legally be involved in sharing this information at events such as remembrance services, websites etc.

As a result, there has been a need for States and Territories to revisit their respective legislation. From that, DFA has unified the nation with the concept that 'it's not in the public's best interest' to prosecute Donor Families. Now we have States and Territories making it known that they have no intention of prosecuting "... *if an individual discloses personal information about an organ donor where consent has*

been provided by the next of kin, where such consent was not able to be obtained before the death of the donor" (Attorney General WA).

During the year, media conferences brought the need for certainty, as to what Donor Families were able to legally do. A WA family created a petition via change.org. This resulted in 17,500 signatures, to date, confirming that, as a human right, Donor Families should own their loved one's information. It was very clear that it's an expectation that deceased donors' next of kin are able to make their information publicly known.

Congratulations to DFA on bringing States and Territories together and providing assurance to Donor Families that they can, with confidence, talk about their loved one in public.

Importantly, because of this work, the World Transplant Games, being held in Perth in April 2023, can now go ahead without a cloud hanging over its head. Now, Donor Families can participate with the confidence that they will not be prosecuted.

Obtaining this unification did not come easily





Donor Families
AUSTRALIA

**Someone* is missing
from our network.**

***is it you?**

~continued from page 6

for Donor Families and for the DFA committee. Where it was thought that it was obvious that Donor Families have the legal authority to give consent for their loved one's information to become publicly known, most states are still reluctant to amend legislation to recognise this. It's hoped that, in future, DFA will be able to report this has been amended around the nation.

This year's Donor Heroes Night (DHN) was by far the most successful conducted. Graham Harrison and his committee put together a memorable evening where our social media was busy displaying lights on porches and windows of people honouring our Donor Heroes.

The total social media involvement was 166% more than the year before. An interesting offshoot to this year's event was the contact from overseas organisations. This would certainly be a great way for us all to recognise the benefits of donation on a global scale. Time will tell where that leads us.

For the first time, Perth City Council 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.

As an add on to this year's DHN, WA held a

DHN picnic for Donor Families. A DFA member provided their beautiful backyard as the setting. All attendees enjoyed the opportunity to meet with other Families. These meetings provide families with an opportunity to mix with likeminded people who can share their unique stories knowing that others understand. Hopefully next year, the idea could spread to other States and Territories.

DFA regularly receives thanks and acknowledgement for its anniversary email to all Donor Family members. A big "thanks" to Philippa Waldron for her continual efforts in this regard. Philippa has now been doing this work for ten years.

I would like to thank the efforts of all the DFA Committee Members in what has been a challenging year for all. I would especially like to thank retiring Karen Garner from Tasmania for all her efforts on the Committee. Karen's input around living donors has opened the eyes of the Committee as to the importance of this form of donation.

I wish the Committee of 2023 all the best with the important work it does on behalf of its membership.

Bruce McDowell

Chairman

19 October 2022

DONOR FAMILIES AUSTRALIA'S FIRST LIFE MEMBER

Since the establishment of Donor Families Australia 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 in 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.

Graham, his wife Elayne and daughter Kyla struggled greatly to cope with Ben's loss in those early days. Graham's approach was to write a story of Ben's life to pass on to Kyla to reflect upon in the future at times when she missed Ben the most. Once finished he felt that there was a story to be shared that would hopefully promote organ donation nationally. The Reader's Digest picked up the story and it was published in the October 1995 edition under the title "Ben's Story". What followed



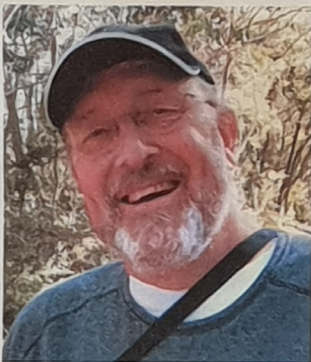
Graham Harrison, Donor Families
Australia's first Life Member

was Graham's involvement in the promotion of organ and tissue donation, both nationally and internationally through to this day.

In the early years, Graham became involved with Mrs Michael McBride of the Australian Coordinating Committee on Organ Registries and Donation (ACCORD) and Alison Barnwell who was a leading Donor Coordinator with the Red Cross that coordinated organ donation with the Eastern States at the time. This association involved Graham giving presentations to medical staff as well as community services and organisation, and in-house workshops. On reflection, Graham felt that Donor Families at this time were better supported in the area of letter writing where the exchange of letters between donor families and recipients were allowed to use first names. This is currently not the case.

During this early period, the "Australian General Practitioners Magazine" contacted the Harrisons to enquire if they would contribute to their article entitled "Who Owns Your Body". The article was published and, to their astonishment, they were contacted 18 months later by Ben's kidney recipient, David Ridoutt, who was able to identify them based on the story content submitted by Graham. This led to a wonderful meeting between both families, which continued for 16 years, until the sad passing of David.

*Ben and David
destine never
to meet*



*David
1943-2009*



*Ben
1982-1993*

*Now together
in spirit
forever*

The relationship between the two families resulted in Graham and David being the “Go-to boys” when it came to public events involving organ/tissue donation and transplantation involving the media and Transplant Australia.

Graham was approached by Transplant Australia (TA) to engage with other Donor Families so that they may be involved and embraced in the forthcoming World Transplant Games to be held in Sydney in 1997. Graham’s speech at the conclusion of the opening ceremony, concluded with David giving a very emotional rendition of “What a Wonderful World”. The Games were a great success, made even better with the involvement of over 80 donor family members involved in most of the medal presentations to each recipient event winner. During Graham’s eight years with TA, he went on to be a TA Board member, established a donor family membership of 650 members, was heavily involved in three National Transplant Games, attended the World Transplant Games in Kobe, Japan, was later invited back to Japan as a guest speaker

on organ donation, managed three major Miracle Dinner events which raised funds for the NSW TA recipients and finally established a contact register between donor family and recipient members which resulted in approximately 10 contacts.

During this same period Graham continued to be heavily involved with the Red Cross and Australians Donate that then became responsible for organ/tissue donation and transplantation at a federal level. During this period both Graham and David continued to be involved with the media involving newspaper & magazine articles and numerous TV interviews involving; Today, 11am News, Sixty Minutes, however the most in-depth presentation was the ABC’s Australian Story title Ben’s Gift that screened in 1999 which can be viewed on the DFA website www.donorfamiliesaustralia.org/media-copy.

In 2005 ShareLife Australia was formed under the stewardship of Marvin Weinman that brought together CEOs from large national

A thousand reasons why it’s great to be alive



corporations for the purpose of identifying “Best Practice” for organ/tissue donation within Australia. Graham was invited onto the Board and worked closely within ShareLife who produced a detailed programme which was taken to Prime Minister Kevin Rudd in 2008. It was sadly noted that between the period of Ben’s death in 1993 and 2008, there had been no improvement in the national donation rate of 13 donors per million of population. The outcome was the establishment of the Organ and Tissue Authority funded by a \$151million grant over several years allocated to improving Australians organ/tissue donation rates.

Meanwhile, Graham continued to be actively engaged in promotion of organ/tissue donation, giving presentations when requested or as guest speaker at many Rotary, Lions and Probus clubs within Sydney and surrounds. One of the most memorable was a presentation to a nurses’ convention centred around organ donation, attended by over 250 nurses. His topic was what he considered as Best Practice in management of a family going through the process of their loved becoming an organ/tissue donor while in the hospital ICU.

The idea of a dedicated Donor Family Association became known in late 2012. With Graham’s background, he was an obvious inclusion. From a phone conversation that followed, Graham was very happy to be involved in establishing such an organisation as he felt it was long overdue. In his view, while OTA/DonateLife had brought about improvements in donation rates, the system itself had become very bureaucratic and distant to those it was designed to support. He felt both Donor Families and Recipients needed to have far greater and broader input into the management and guidance of a system that was meant to support them.

With Graham now having been a DFA Management Committee member of ten years, his enthusiasm has not waned. His experience working within the organ/tissue donation area adds an invaluable perspective of the past, present, and future where DFA can best serve its membership. However, his behind the scenes duties ensures that DFA’s eAdministration is well maintained, including maintaining the membership database,



enhancing and updating DFA website content, managing the Contact Register, and assisting in responding to website enquiries.

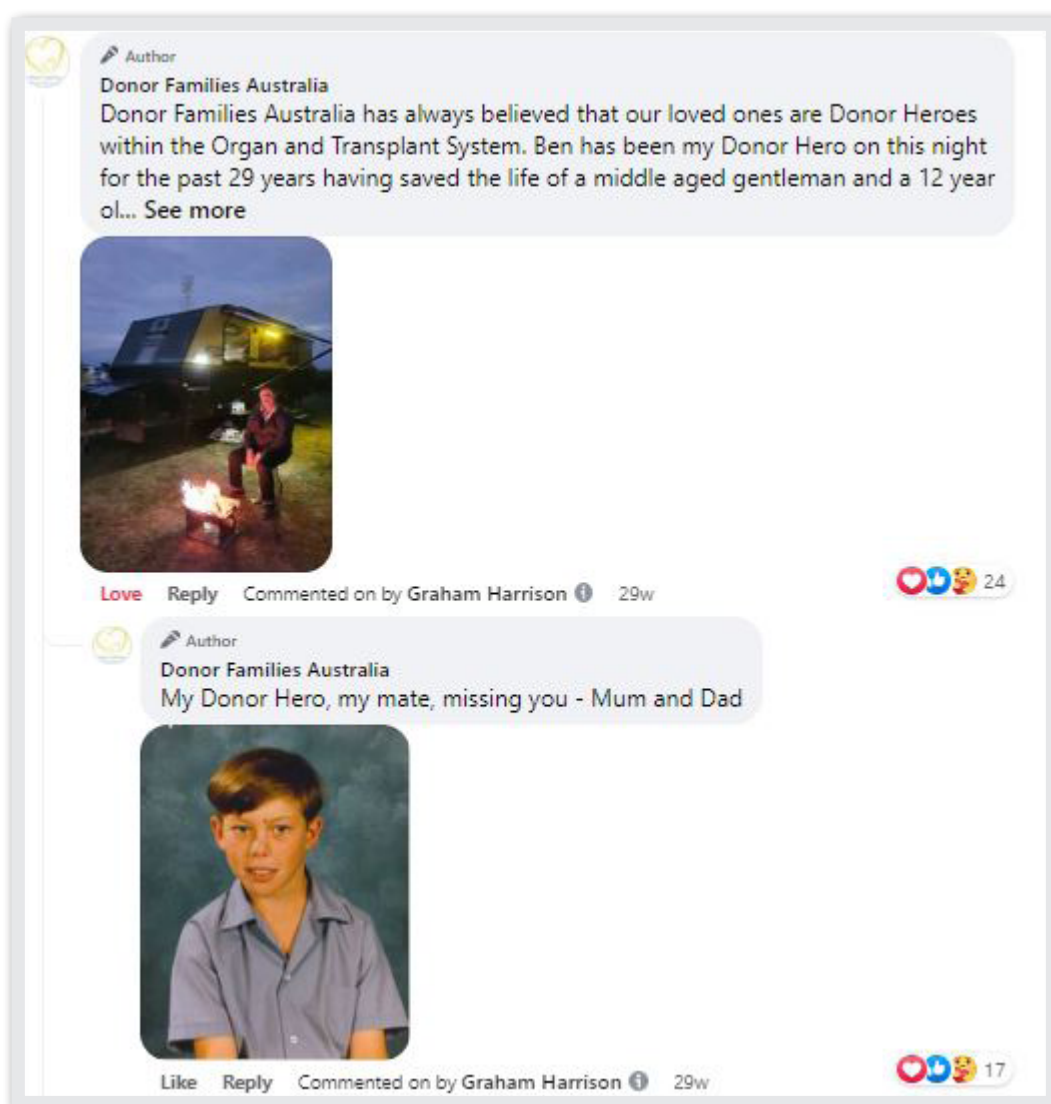
Finally, one of DFA’s major projects, Donor Heroes Night was conceived and is managed by Graham. Initiated in 2020 and held on 18 May each year, the event acknowledges and celebrates all Donor Heroes. The evening encourages donor families, recipients and their families, and general public to post a photo of a lit candle or porch light to the DFA public Facebook page (www.facebook.com/DonorFamiliesAustralia) with a comment. Initially, activity surrounding the lead up and including the night itself generated involvement of approximately 50,000 people across all social media. In 2021, this figure was 125,000 and this year (2022) saw engagement with 260,000. It’s hoped this will continue to grow at a similar rate and even extend internationally in 2023. This single event has demonstrated what impact organ and tissue donation has had on the community over the years and that our loved ones who donated to save others are truly Donor Heroes.

Asked if he had a vision of the future, Graham expressed the hope that both Donor Families and Recipients would be involved directly and equally at all levels within the Organ Tissue Authority and DonateLife at State and Territory level to ensure that these agencies best serve and support those being processed through the system.

Congratulations to Graham for becoming DFA’s first Life Member.

Bruce McDowell

Chairman



Further reference material can be found on the DFA Website

(www.donorfamiliesaustralia.org)

Our Stories / Contact Stories	An outcome not to be denied
Our Stories / Donor Heroes or April 2013	Ben – His Greatest Gift
Latest / Newsletters	DFA News – 2021 cover story “My Son, My Little Mate, My Donor Hero”
Latest / Videos	Ben’s Gift, ABC Australian Story
Latest / Videos	National Donor Awareness Week
Latest / Videos	Harrisons & David contact – The Today Show Ch9
Donor Heroes’ Night	The Event
Donor Heroes’ Night / Donor Hero Stories	Ben & David
Support / Resources	Brain Death from a Donor Father’s perspective
Feedback is welcome on any subjects covered within this article through Contact	

THE LIFESAVING WORK OF DONOR FAMILIES AUSTRALIA



The transformative work of Donor Families Australia (DFA) has been remarkable over the past 10 years in Australian organ and tissue donation practice. This entirely voluntary organisation with no government

funding- uniquely supported and led by Donor Families who share a common goal- a desire to honour their loved ones legacy and to help other families to say 'yes' to save more lives. With that purpose, examples of DFA's achievements 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.
- 'Thank You Day'- a DFA's recommendation to the 2015 EY sector review.
- 'Donor Hero's Night'.
- 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 with Territories and States to enable humane donation legislation that meets contemporary expectations.

The original aims of Donor Families Australia remain, 'To provide care and support to families who have donated their loved ones organs and tissues; To advocate on behalf of these families and give them a voice in all aspects of organ and tissue donation; To educate the wider community about the benefits of organ and tissue donation whilst emphasising the very important role of the donor families in this

process.' For ten years, DFA has worked to create a credible and responsive organisation that appropriately reflects the views and wishes of its membership. The idea of co-creation and the rights of the 'consumer' were emerging ideas in Australia when DFA commenced. Now governments, policy makers and practitioners recognise that the voices and knowledge of consumers are critical for effective healthcare. Surprisingly, despite DFA's clear mission, values, and relevance, it continues to be excluded from many sector discussions.

Sadly, the good will and desire to support and enhance organ donation practice held by members of DFA are often unrecognised. Many early efforts at dialogue with the OTA were sadly rejected or DFA and its representatives dismissed by institutional leadership as a group of people who would 'disappear'— suggestions were made that the organisation would collapse — people would 'get over' their grief and 'move on', or, if they stayed, were probably grieving inappropriately. The relationships with governing organisations that DFA hoped to establish failed to eventuate. DFA presented authentic, critical, and independent views when offering consumer experiences and sought to share expert knowledge of donation to help improve practice. It is interesting to compare the successful advocacy work DFA have been involved in from 'outside' the OTA 'tent' and to highlight ongoing challenges governing institutions 'inside' the 'tent' face to ensure people waiting for transplant receive one revealed by the data.

One of DFA's first activities in 2013 was to collaborate with ShareLife in a media panel to voice the fact that more needed to be done to achieve 'best practice' in organ donation. The expert panel argued that the voices of Donor Families and other consumers should be integral in ensuring best practice in Australian organ donation. ShareLife is the Non-Government Organisation that was instrumental in creating the international best practice business case

**Holly's
Insight**

used by then Prime Minister Rudd to establish the OTA in 2009. Rudd announced \$150M in funding over a three-and-a-half-year period to enable Australia to lead the world in organ donation stating, "...roll the clock on three years and we're out there as world leaders...". Since 2009 the Federal Government have spent over \$650M with a goal to increase annual donation rates from 12 donors per million population (dpmp) to the then world benchmark of 35 dpmp. Today, Australia is still less than halfway to that target, at 16.4 dpmp, ranking 16th in the world of transplants per capita behind comparable countries.

Many problems with Australian practices have related to a failure to translate public support for organ donation to consent to donation at death. The 'consent rate' has effectively 'flatlined'. In 2009, the Australian organ donation consent rate was 55%; in 2021: 56%. The extraordinary focus by the OTA on the Australian Organ Donor Register statistics have obscured the truth, that the consent rate is extremely poor. For example, Spain do not have an organ donation register and yet have over 85% of families consent to donate. The efforts are reserved for the care of the family by experts in donation who work very carefully with the media to educate the public about donation. DFA continues to advocate that by listening to families who are expert in the experience and by being open to Donor Families' knowledge, the national donation consent rate could be over 85%, saving many more lives.

Barriers to consent identified in my research, and mentioned regularly by families, include terminology and how organ donation is discussed with the family; the relationship between the family, the doctor caring for their loved one and nursing staff; the perceptions of suffering that the family may have if care is not delivered well; and importantly in Australia, the length of time from death to donation continues to lengthen. In 2021, the time from confirmation of death until the donation surgery ranged from three hours to three days — with an average of just over a day. This is a very long time for families to be at the hospital with their deceased loved one, and for ICU's to support the care of the deceased Donor and their family. These perceptions of prolonged suffering and the staffing required for the care

can influence the way the healthcare team asks the families to donate, and impact families' decisions. It is interesting to note in 2013, when DFA started, there were more donors (302) than in 2021 (295), and the time taken from brain death confirmation to donation surgery was only 5-32 hours (average 19.5 hours).

It is impossible to look at Australia's statistics and not realise that something is wrong. The US, despite a disproportionate impact from Covid in their hospitals this year, had its highest donation rate ever. Clearly there is more that can be done for the community to say 'yes' to organ and tissue donation to improve Australian patients' opportunities to receive a transplant. People with organ failure have an over 90% chance of surviving more than five years if they receive a transplant. It is time for DFA to be seen as a valued partner to the national organ donation organisations and for authentic co-creation of legislation, policies and practices to enable system transformation.

For those in need of a transplant, it is sobering to realise that at the end of 2020, approximately 14,500 people with kidney failure required dialysis, and like so many others in organ failure, because our rates are perceived by doctors as so low, most will never be offered a waiting list place.

Australia ranks 39th in the world for people on dialysis who are also on the kidney transplant waiting list. In 2020, only 8.6% of people experiencing kidney failure and dialysis were waiting for a transplant compared to 1999 when 26% of dialysis patients were on the waiting list.

DFA understands these metrics and the importance of excellent end of life care to enable organ and tissue donation to be normalised. Let's hope that we achieve the metric we are capable of in Australia. I challenge Australia to have an 85% consent rate or greater in the next 5 years — it is possible utilising DFA's expert guidance.

Dr Holly Northam, Faculty of Health, University of Canberra Pudandam

References: available on request.

Acknowledgement: Thanks to Brian Myerson (Sharelife) for contribution to this article. Holly has spent many years as a Sharelife Director.

10th ANNIVERSARY OF THE DFA DONOR AWARENESS FOUNTAIN

Ten years ago, on 15 December 2012, the DFA Donor Awareness Fountain was opened by Geraldton Mayor, Mr Ian Carpenter, and Mr Derryn Hinch.

It was a beautiful day with over 200 people in attendance. Along with various speeches there was a duo playing and singing, How to Save a Life by the Fray.

Donor Families, representing their loved one honoured with a plaque on the wall, all received a white rose.

Ten years on, a gathering of 20 people came together to commemorate that special day. Donor Families, the Hon. Lara Dalton MLA, WA Centre

for Rural Health Director, Sandra Thompson, who provided the Administration Management for the project, Architectural firm Eastman, Poletti and Sherwood, who designed and project managed represented by Craig Poletti, local tradies who gave of their time during construction, and supporters of Organ and Tissue Donation, all came along.

Bruce McDowell talked about the beginnings of the project with the draft design and then as to how the funds were raised from governments and community. He told of how the floating ball artist, Richard Williamson, generously donated much of his time and material. Bruce recognised the fantastic work done by the local tradies free of charge. Bruce mentioned how the Fountain has done its job with providing a place of reflection and creating awareness., saying: "Anecdotaly we know that lives have been saved with families being prompted to have a conversation about donation and sadly, later having to make that decision".

The group represented the generational effect donation has, with a one month old baby present who has an aunty honoured with a plaque on the wall.

A perfect way to honour and remember our loved ones.

Connecting Donor Families

Derryn Hinch Opens Donor Awareness Fountain

DFA was officially first launched on the 15/12/12 at the opening of the Donor Awareness Fountain in Geraldton WA. Derryn Hinch, along with the Geraldton Mayor, Mr Ian Carpenter officially opened the Fountain. It was a fine Saturday afternoon, perfect for unveiling the fountain which is located in a park over looking the ocean nestled under the trees. The group of dignitaries addressed the hundreds of people that attended this very special occasion. The guests of honour were the Donor Families of the 28 Donors listed on the wall.

Mr Bruce McDowell welcomed all and thanked those that gave of their time and money to build this tribute to the heroes of organ and tissue donation. He took this opportunity to introduce Donor Families Australia. The DFA logo was proudly displayed on the day and the organisation has its name on one of the plaques as a major contributor to the project.

It is hoped that other tributes to Donors can continue so that Donors around Australia are properly honoured as the heroes that they are.

Share your experience with similar people to support those making life changing decisions. Help us to build a caring community and to shape the future of this new and exciting network.

If you would like to find out more about Donor Families Australia and how to become a member please visit our website:
www.donorfamiliesaustralia.com

become A MEMBER

The first edition of DFA News in May 2013 reports DFA's official launch at the Donor Awareness Fountain Opening event



Ten years on, another group came together to celebrate the opening of the DFA Donor Awareness Fountain in Geraldton, WA.

**For the full story on the DFA
Donor Awareness Fountain
please visit:**

**[https://www.flipbookpdf.net/web/
site/35b860ad90ba3255e227020
24aef8e57c654e7a4202212.pdf.
html#page/1](https://www.flipbookpdf.net/web/site/35b860ad90ba3255e22702024aef8e57c654e7a4202212.pdf.html#page/1)**

A MESSAGE TO PHILIPPA WALDRON, DFA COMMUNICATOR EXTRAORDINAIRE - THANK YOU!

“Thank you for your lovely message. It means the world to me that someone cares.” (Donor Family)

For ten years, our DFA community has grown, connected, and built strong and enduring threads of care. Most of this relationship building has happened through shared experiences of grief and healing – and through remembering our loved ones well. One of the most remarkable members of DFA, a gentle, quiet, skilful healer and connector has been Philippa Waldron, a cherished and indispensable supporter of DFA’s work since its inception.

“Thanks so much for your kind thoughts again. It never goes unnoticed, and is very much appreciated” (Donor Family).

Philippa has contributed in the most effective way over the years motivated by the memory of her husband Peter, using love, compassion, critical thinking, and care in all her activities. Initially Philippa helped with the newsletter, bringing knowledge and skills from her professional life. Philippa actively contributed to our Board– enhancing its work and tirelessly advocating to support the West Australian Donor Family community- and ultimately people in need of transplantation.

“Thank you to you all for thinking of me and my family ” (Donor Family).

Philippa’s most important and enduring role was to volunteer to welcome new members and send each Donor Family an email of recognition, remembrance, and care on the anniversary of their loved ones’ death. We believe that Philippa shaped this role modelling and exemplifying the DFA values, ‘Care, advocate, educate, share’. We believe this role is unique – never done before, a volunteer donor family member, supporting and caring for Donor Families. Philippa shaped it in a deeply committed manner, and shared extraordinary empathy along the way. This work continued for the past 10 years as our membership has steadily grown. It is important to note, that DFA understand that remembering and honouring Donors and their families is critically important for community trust and increased

acceptance of donation. Philippa worked to ensure DFA practice is to remember and recognise every anniversary every year with an email drawing from Donor Family personal experience.

“Thank you so much. That is very kind to keep the records of these dates xx” (Donor Family).

Philippa’s experience of the death of her husband of 38 years, Peter, who tragically died at 61, helped her to understand the donation decision experience. Drawing from her own situation and knowledge of the stories of others, she has listened, shared respect, empathy, kindness and care with many individuals, and families over the past 10 years. Philippa believes herself fortunate to have met one of Peter’s recipients and believes “every donor family member and recipient family member given the right to meet if they mutually wish,” and has advocated strongly for a greatly improved Donor Family and Recipient process of correspondence. In Philippa’s words, “Letters should not be opened and names crossed out if a Donor and Recipient agree to receive such letters... it is their very personal choice.”

“That is very nice of you to acknowledge Stephen’s special gift” (Donor Family).

There have been many responses to Philippa’s messages over the years, the title is one, those sprinkled through this article others. What we do know is that the correspondence is valued by many, “Thankyou for the lovely message it means a lot to me”

Thank you, Philippa, for all you have contributed, on behalf of the Board of DFA we are so pleased you will remain connected, but now have much more time to spend with your beautiful family and do things that celebrate all that is good in our world. Thank you.



ACT DOUBT HAS ENDED

Donor Families are now legally authorised to give consent for their loved one's story to be told at Donate Life remembrance services in the ACT as of 24 November 2022.

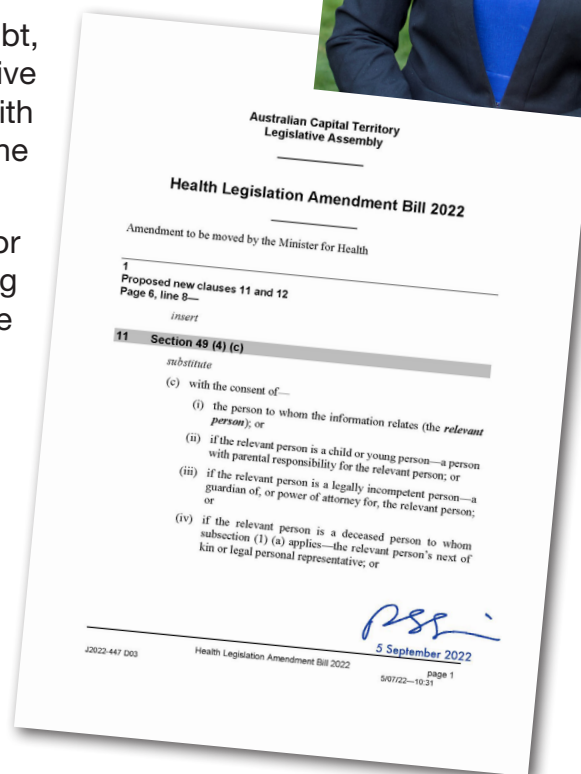
Since legal advice was received over a year ago, there has been a live question about the lawfulness of the ACT and other jurisdictions being able to share the stories of those who have donated organs or tissue, even if the families have consented.

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.

Today the ACT Government ended this doubt, with amendments passing in the Legislative Assembly today which make clear that, with families' consent, DonateLife can share the stories of the families' loved ones.

Thank you to Donor Families Australia for bringing this to our attention and ensuring we were able to address this regrettable situation.

Hon. Tara Cheyne MLA ACT



TISSUE DONATION STATEMENTS IN SOUTH AUSTRALIA

Following ACT legislation change, South Australia has introduced a Bill relating to Tissue Donation Statements. Hon. Nicola Centofanti explains the background, and provides more detail.

Firstly, I would like to acknowledge all donor families this Christmas. The decision to donate is an incredible gift of life. The generosity of those families, to make such a selfless decision at a time of huge loss, is remarkable.

In November of this year, after consultation, I introduced The Births, Deaths and Marriages Registration (Tissue Donation Statements) Amendment Bill 2022 into the Legislative Council in South Australia. This Bill will amend the Births, Deaths and Marriages Registration Act 1996 to allow the next of kin of a deceased person to request a tissue donation statement be included on any certificate issued under the Act certifying the death of a person.

Organ and tissue donations transform and save many lives across the country each year.

The lives of 1,174 Australians were changed last year as a result of receiving an organ transplant, thanks to the generosity of 421 deceased organ donors and their families. That is 1,174 fathers, mothers, grandparents, children, partners and friends.

Whilst being registered on the organ and tissue donor register helps inform a family of their loved one's desire, it is ultimately the decision for the family.

There are a number of ways in which organ and tissue donation can be acknowledged.

Donor families and those who have received a transplant can write anonymous letters to each other. (The letters must be anonymous because it is a confidential program).

A national DonateLife Service of Remembrance is held online each year to commemorate the generosity of donors and their families. Other annual events include Thank You Day, the DonateLife SA Rose Planting Ceremony and the National Donor Heroes' Night. The donor

family lapel pin has been specially designed for families to wear to commemorate their loved one's donation.

Whilst all these events are incredibly important and have

a vital role in commemorating the generosity and importance of organ and tissue donors in our community, there is still something missing. Formal acknowledgement.

In recognition of the significant contribution that organ and tissue donors provide to the community, the ACT government passed legislation in May 2020 to provide the opportunity for this to be formally acknowledged in the death register and/or in a letter from the Chief Minister.

The ACT was the first jurisdiction in Australia to provide this opportunity as well as to apply to have the statement: *'The deceased gave a gift of life, generously donating organs/tissue'* added to the certificate.

The Births, Deaths and Marriages Registration (Tissue Donation Statements) Amendment Bill 2022 (the Bill) I have introduced into South Australian Parliament is modelled on the ACT legislation.

The Bill will allow the next of kin of a deceased person to request a tissue donation statement be included on any certificate issued under the Act certifying the death of a person.

It will also enable the next of kin of a deceased person to request an 'intended tissue donation statement' be included on any certificate issued under the Act certifying the death of a person.

The inclusion of this provision will enable acknowledgement of a deceased person who was an intended tissue donor to also be captured. For example, where a family says



'yes' to donation, but for a range of reasons, the deceased tissues were unsuitable for donation. Again, this is recognition of the incredibly important decision that families and next of kin make in saying 'yes' to organ donation. A technical reason for a loved one to then not be able to donate shouldn't stand in the way of this intent and this recognition.

The intent is that the Tissue Donation Statement is optional. It is entirely up to the family to determine if they want the donation recognised on a loved one's death certificate. For some families, the acknowledgement they receive currently may well be sufficient.

The Tissue Donation Statement is also not time limited. It is intended that families will have control to determine when, if and how they wish to have their loved one's donation recognised. This removes any urgency to

make a decision about the acknowledgement and recognises that what might be right for each family can change over time. It also means that families whose deceased loved one was an organ or tissue donor before this change comes into effect will have these acknowledgement options available to them — with a death certificate reissued at no extra cost. The request can only come from the next of kin.

I will look to progress this legislation when Parliament returns in the new year.

Ensuring that families of organ and tissue donors can seek formal recognition of their loved one's life saving gift is a small change that those of us in this chamber can make, that will make a big difference to many.

Hon. Nicola Centofanti MLC

**Individually, we do great things
and affect those around us.
Collectively, we do great things
and affect a nation!**

DONOR FAMILIES AUSTRALIA PLANNING DAY NOVEMBER 2022



On 19 November 2022, our Committee met to discuss a number of 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. The topics included:

- Continue our important advocacy work in the area of ownership of information legislation around the Human Tissue Act (State/Territories governments).
- Facilitate changes to legislation. Committee members agree that change to legislation is our ultimate goal and, for example, a letter from the WA Health Minister to donor families with the promise not to prosecute donor families is not good enough. We need a dedicated and aligned national change and we know that States and Territories are watching ACT 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.
- Legally there is nothing to prevent recipients from talking about themselves, their hospital and their transplant date, however, we believe that DonateLife offices may be misleading recipients about this. In so doing they are not making the donor publicly known.
- Increase support to our membership.
- Formulate our position on the important topic of Opting In versus Opting Out. This will be based on informed decision using best practices from around the world.
- Continue to grow Donor Hero Night in importance as a vehicle to honour the Donor and raise awareness of organ and tissue donation, not just in Australia, but further afield.
- Continue and improve the important work that DFA does by exploring new ways to attract funding and donations.
- Hold a second DFA conference in 2024 following the success of the first.
- Support the World Transplant Games in WA in 2023.
- Increase our social media presence for the benefit of our membership and reaching a wider audience to promote our information and to provide support to donor families.
- Increase membership through making our organisation more prominent in OTA materials provided to Donor Families.
- Formalise a Donor Families Australia Five Year Plan.

We all look forward to returning from our summer breaks and continuing on with our important work.

WHAT DOES IT TAKE TO BE HEARD?

This article does not apply to the ACT, they have heard.

Our daughter is a donor hero, yet we have no legal right to say her name when sharing her donation story.

A petition has been set up through Change.org. It is to bring about legislative change in WA and other States and Territories in Australia to give us and other donor families the legal right to:

- Show our daughter's photo, say her name with pride and tell people she is a Donor Hero. This in turn will help promote the benefits of organ/tissue donation and help increase the current lagging consent rate.
- Have her donation recorded on her death certificate to formally recognise her gift to others. The law in WA and every other Australian state prohibits this from happening.
- Have total control of our daughter's donation information to use as we choose.

Here in WA, we are not legally allowed to tell you that our daughter helped many other people when she died. Additionally, we don't have the legal right to give consent to others to pass on our daughter's donation details. No one told us that we could be prosecuted in WA for telling people that our daughter was a Donor Hero.

WA legislation prohibits donor families from publicly identifying their deceased loved ones as organ/tissue donors. This is an intrusion of our human rights.



Legally being able to tell our daughter's story is such an important part of our grieving process. Sadly, relevant state and federal government departments that support organ/tissue donation have shown little appetite to change the legislation.

We are proud members of the national support body for donor families, Donor Families Australia (DFA).

As a priority and as an act of compassion and decency, we, along with DFA, call on the WA Health Minister to initiate an amendment to the Human Tissue and Transplant Act 1982 WA, that would give donor families unconditional control of their loved ones' information.

This is a petition on Change.org: <https://chnng.it/QzyswJ2gPC>

17,517 have signed. Let's get to 25,000!

At 25,000 signatures, this petition becomes one of the top signed on Change.org

Comments from the Petition



"People who participate in the ultimate act of generosity should not become invisible by doing so... quite the contrary. WA needs to catch up to the rest of the nation."

"I absolutely support this petition. It's purpose is to change a badly constructed law which fails ordinary human rights."

"I think donor heroes should be recognised as it helps their life live on in a new form. Families should be allowed to discuss their loved one's as a part of their grieving process."

"Such ridiculous and oppressive legislation must not be allowed to continue and donor families must be allowed to tell the story of their loved ones who have chosen to donate their organs."

"This law is non sensical. I was appalled to hear families can't share the name of the donor. This law needs to change."

"I think it's worth doing because tremendous benefits can come from donor's families being able to share their stories and hear of the people their family member's donation has affected. It is not something to be hidden it is something to be cherished and celebrated."

"Donating your loved ones organs and tissues is the last and most powerful thing you can do at the end of life and you should be allowed to be proud and share the wishes of your loved one to help with the grieving and say it out loud if you want to."

"I'm signing because of a number of reasons. Firstly, I had no idea that this legislation existed and just assumed that there would be a process in place for the organ donor and their family to have their sacrifice and amazing gift acknowledged."

"I have seen a number of videos / photos from the USA that show the organ donor and their loved ones walking with them as they take their final trip to the operating

theatre. It also seems to be common practice that the donor and their family have been given a "guard of honour" by Doctors, Nurses and family as a sign of respect for that person's last amazing gift that they are giving to someone they don't even know. Those videos are very emotional but also amazing and must give the donor's family a sense of pride and a small glimmer of positivity in what is probably the worst day of their lives."

"I can also see absolutely no reason why the donor's death certificate cannot acknowledge their status as an organ donor."

"I think all of these things would dramatically increase the number of people who register to be an organ donor."

"Let's be prepared to get down and dirty and work through the issues. Otherwise donations are likely to continue to decrease."

"I'm signing this petition as a heart transplant recipient (2/8/2018)."

"Apart from a thank you letter I wrote but delivered anonymously by social worker I have had no contact with the donor family! The donation of a life saving heart is such a major event in my life and the donor family, the denial of contact seems absurd."

"Well done Bruce for putting the spotlight on this very important issue. I doubt many would have been aware of this situation and equally most would not be surprised at the behaviour of our bureaucracy. Personally, I would do what you feel is right, and if really concerned about litigation do it in an election year."

"My son recently received donor tissue and bone during surgery and I would have liked the opportunity to thank his donor's family for it, rather than just sending in a basic, standard, unfeeling letter of thanks."

"I had no idea about this restrictive law (which I note was created in 1982!) until reading this petition. Come on law makers...it's 40 years down the track. We know so much more about grief and mental health since this law was made. High time to do better for the grieving families of donor heroes. Please, to all States...do better than this and get this changed."

"The position by State & Territory Govt's across the country makes no sense and in some ways shows great disrespect to the donor and their families. Being able to acknowledge, and in a way celebrate, the amazing gift to help others in desperate need should not be a criminal offence."

"I am a transplant recipient and donor families should have every right to disclose the details of their donor heroes. What a ridiculous law to prevent that."

"I'm signing because my husband (& our sons Dad) is a donor hero & there shouldn't be threatening legal BS standing in our way of proudly acknowledging & sharing with pride & love the tremendous gift of life that he has given. This life changing gift absolutely needs to be recognised on all donors death certificates as its their final document of their life. Come on decision makers.. its time for change.. all Families go through so much pain & suffering when their loved one passes.. then to work through the donor process at THE worst time of their lives..& you get through it because its their dying wish, to help others if they can & the very least we ask is to proudly & freely have the right to openly share our loved ones story & display their photo & talk about them by name... its time !!!"

"Our children, our hero's, other lifesavers deserve to have their names recognised. It was good enough for the powers that be to ask us in our times of despair to say yes, recognition by using their names is a small request."

"Prohibiting donor families from publicly identifying their deceased loved ones as organ/tissue donors is an intrusion of human rights. Please change the legislation."

"We lost our son 5 yrs ago and he was an organ donor. I would love to be able to honour him by using his name with pride if I ever feel the need in correspondence with recipients."

"OMG you're kidding. This sounds like one of those laws from the dark ages that they've held onto, just because it's there. It's the exact opposite of everything that organ donation is all about and accordingly it needs to be changed NOW!!"

"This is critical to improve Australia's organ donation rate. Let donor families tell their story and honour the legacy of their deceased loved one. Let organ/tissue donor families "say their loved ones' name.""

"If you keep such a negative attitude towards the "HEROS FAMILIES", others may not want to donate their loved one's organs due to secrecy laws."

"My son was an organ donor and I should be able to shout his name out without fear of recrimination."

"As a support person of a transplant recipient, we want to honour those who are organ donors and their families who are happy to share this information."

"I'm a recipient and without selfless donors I would not be here. If they choose to share their details that should be their choice. Government butt out, this is NOT your journey & you've not felt the pain."

"This law is having the impact of blocking the community from receiving information about the positive benefits of organ and tissue donation for people who agree to donate. It is cruel in the it silences and makes invisible the people who are most critical in the organ donation process- thus creating mistrust and fear. It disregards bereaved families basic human right to grieve and to appropriately honour the life of their loved one. It is not consistent with community expectations in the 21st century and its effects cast a negative light on donation."

"I have signed. A very generous donor family made a decision in a time of great sorrow 33 years ago that has gifted me life since then. I have been speaking about my experiences promoting organ donation since then and the thought that politicians and bureaucrats having control of what can be said chills me to my core."

"As a donor my family should be allowed to say this without fear or prosecution, clearly this legislation is outdated and needs changing."

"Those who donate are incredibly kind. The family members of those who donate have to live with the decision and that cannot be easy. The ability to publicly recognise the gifts that donors give may be one more thing that helps them through their grief."

"Because I am a Donor Mother and my son gave the gift of life to three people who now have a chance of a better life. Please let me and my family tell the world about my hero son and his precious and unique gift of life. "

"My Son (21) and my Brother (23) are Donor Heroes. They deserve to be recognised, together they saved 9 lives. We should be allowed to say their names LOUD AND PROUD!!! My niece is also a recipient and she should get a voice as well if she wants to know who her hero was then no one should stop her!!!!"

"I lost a nephew in 1991... his organs were successful to 8 people.. his mum, my sister and his dad were notified of the success but it would have been more meaningful to say His name in the thank you!"

"This law is insanely wrong. My 15 year old's organs saved the lives of 6 people and the eye sight of 2 others. To not be able to legally talk about his life saving legacy would be absolutely unbearable."

LETTER WRITING PROCESS

The left is for Donor Families and the Right for Recipients. The important thing to remember is that Donor Families send their correspondence to their State/Territory Donate Life office and Recipients, to their Transplant Unit within their hospital.

At the start of the process, you should be informed that your letter has been received and you should also be informed at the conclusion of the process. All up you should be notified twice by the respective agency. In this way, there should be no doubt as to 'what has happened to my letter?'

Donor Families Australia knows how important these letters are to both the Donor Family and the Recipient. If you have any questions or you feel as though your letter has not received this attention, either make contact with the agency you gave the letter to, or let us know and we will follow up on your behalf.



Correspondence process for donor family to transplant recipient

DonateLife receives letter from donor family.



DonateLife checks letter for identifying information.



Letter copied and placed on donor's record. Original sent to transplant unit.



Donor family informed that the letter has been received and forwarded.



Transplant unit receives letter from DonateLife.



Transplant unit confirms if the transplant recipient is happy to receive correspondence



Transplant unit checks letter for identifying information



Letter copied and placed on recipient's file. Original sent to transplant recipient.



Transplant unit confirms with DonateLife that the letter has been received and sent to the transplant recipient



DonateLife informs donor family that their letter has been forwarded to transplant recipient



Correspondence process for transplant recipient to donor family

Transplant unit receives letter from recipient.



Transplant unit checks letter for identifying information.



Letter copied and placed on recipient's file. Original sent to DonateLife.



Transplant recipient informed that the letter has been received and forwarded.



DonateLife receives letter from transplant unit.



DonateLife confirms if the donor family is happy to receive correspondence.



DonateLife checks letter for identifying information.



Letter copied and placed on donor's record. Original sent to donor family.



DonateLife confirms with transplant unit that the letter has been received and sent to the donor family.



Transplant unit informs transplant recipient that their letter has been forwarded to donor family.

YOUR DONOR FAMILIES AUSTRALIA COMMITTEE



Helen Day
Treasurer (NT)



Janelle
Colquhoun (QLD)



Philippa Delahoy
Secretary (NSW)



Holly Northam
(ACT)



Barry Mewett
(ACT)



Graham Harrison
(NSW)



Bruce McDowell
Chair (WA)



Jackie Robson
(SA)



Anthea Openshaw
(WA)



Dave Reynolds
(VIC)



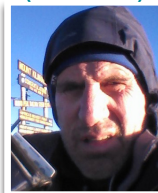
Leanne Campbell
Vice Chair (VIC)



Rebecca Free
(TAS)



Warwick Duncan
(social media)



YOUR DONOR FAMILIES AUSTRALIA COMMITTEE

Bruce McDowell — Chair (WA)



I live in Perth WA with my wife Karen, having previously resided in Geraldton for the past 30 years, whilst raising our family of three children. After our 19 year old daughter Alysha passed away in 2008, I became a Donor Dad. I could not be prouder of Alysha for becoming a Donor Hero.

I am now retired after a working life that included a degree in Health Administration and 20 years in the public hospital sector. I moved on to gain a Masters in Accounting and a CPA Public Practice. I enjoyed my remaining working years in my own accounting practice, supporting the community of Geraldton.

At the time of becoming a Donor Family, there was no organisation that supported and or advocated for Donor Families. With like-minded families, Donor Families Australia was established in 2013. It is very pleasing to see this group grow, going from strength to strength.

I would like to see greater openness and transparency within the Organ and Tissue Authority/DonateLife when supporting Donor Families. Through the ongoing work of the Donor Families Australia Committee, I hope that we will be able to help facilitate better communication between consenting Donor Families and Recipients. I would also like to see all States and the Northern Territory follow the ACT lead and have Donors acknowledged on their Death Certificate as recognition of their final altruistic act.

Helen Day — Treasurer (NT)



Helen, mother of four, (26 to 34), with three grandchildren and resides in Darwin. In 2012, Helen's son, Stewart, was killed in a freak motorbike accident, just before turning 24. He'd always put others first and it was a blessing he saved six lives. Helen would like to see more support

for donor families and to support families in the Northern Territory.

Leanne Campbell — Vice Chair (VIC)



Diamond Creek has been home for my husband Rick and I, for 36 years, where we raised our three children. It's a town with a natural bush setting and a strong sense of community. We lost our 21 year old son Brett in December 2009, and became a donor family. Whilst he was not a registered organ

donor, we chose to uphold his decision to give the gift of life. Lack of support, during and after our donation experience, compelled me to speak up for positive change and become involved with the inception of Donor Families Australia. The need to connect with others who had walked this journey was imperative.

Philippa Delahoy — Secretary (NSW)



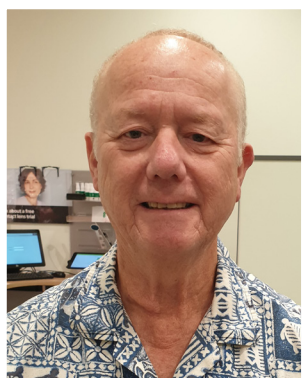
Philippa is a donor wife, following the sudden passing of her husband Scott in 2011.

His kidneys freed two young people from a lifetime of dialysis and his corneas went to medical research. Scott, a huge sci-fi fan, would be amused by his organs living on long after him.

Philippa became involved in Donor Families Australia in 2017.

YOUR DONOR FAMILIES AUSTRALIA COMMITTEE

Graham Harrison (NSW)



Graham became heavily involved in supporting and promoting Donor Families following the passing of his 10 year old son Ben in 1993 due to failed surgery. Having been involved in many organ donation and transplantation organisations throughout the years that followed, it has

become Graham's passion as a founding member with Donor Families Australia in 2013 to assist in supporting and help grow the national organisation. In his role as eAdministrator, he is responsible for uploading data into the Membership Database, the DFA Website, the DFA Contact Register and is an administrator for the DFA Members Facebook Group.

Jackie Robson (SA)



My husband of 34 years and beautiful dad to our 3 children became a donor after his very sudden death in 2016. He saved the lives of 3 people and his pancreas went to medical research. We as a family are passionate about spreading the word about organ donation and we would like to

see donor families and recipients given the right to meet if they both wish.

Barry Mewett (ACT)



Barry became a donor husband following the sudden death of his wife, Jean, in 2005.

Multiple organs were donated, enabling a number of people to be restored. Jean would've been amazed and profoundly grateful to know so many people were assisted.

Holly Northam (ACT)



Dr Holly Northam OAM, (PhD, RN, RM, M CritCareNurs) is Associate Professor in Nursing at the University of Canberra (UC), Churchill Fellow (2006); 2022 Senior Fellow of the Higher Education Academy of the United Kingdom; and the inaugural international visiting fellow at the

Restorative Research, Innovation and Education Lab, Schulich School of Law, Dalhousie University, Nova Scotia, Canada.

Previously Head of Discipline for Nursing at UC (2018- 2021), Holly served as elected academic representative UC Council and Academic Board (2018-2020). She is a Director on boards of ShareLife Australia and Donor Families Australia.

Holly played an instrumental role in setting up and running the ACT Organ and Tissue Donation Service. Her PhD study, 'Hope for a peaceful death and organ donation' identified that more must be done to alleviate suffering caused by communication failures in healthcare. In 2021, she took over the role of convening the Canberra Restorative Community and transitioned it to the UC.

She brings her years of clinical experience to her research and teaches units such as Indigenous Health. Holly has a strong social justice focus.

Janelle Colquhoun



Living with Type 1 Diabetes since age 10, Brisbane born Janelle studied opera at the Queensland Conservatorium of Music. At 29, she went blind and experienced chronic renal failure with three years of home dialysis. In 2006, she received the gift of a simultaneous pancreas

kidney transplant. Today, she still sings and is an award winning archer.

Anthea Openshaw (WA)



Anthea has lived in Bunbury, south west WA since 2005 when she and Neill moved there with four children. She became a donor wife in 2014 after Neill died following a cerebral aneurysm.

Since his death, she retrained as a social worker (her Honour's

thesis was donor families meeting recipients of their loved one's organs). She passionately believes it's the right of every donor family and recipient to meet if mutual consent is provided, and that each should be informed about DFA.

Dave Reynolds (VIC)



Dave is proud to say he's a Donor Husband, a position he never expected to be in. In 2021, Neralie, his beautiful wife of 42 years, suffered a tragic accident on their South Gippsland farm. Within three days of her donation, Neralie's pulmonary valve had been modified, and

gifted to two recipients — in New Zealand and New South Wales. Their four children and their partners, and fifteen grandchildren, now respectively view all children differently, 'just wondering'.

During their ICU stay, there were serious disconnects between the Donor, Donor Families and system which must be improved. He aims to make the most difficult phase in a Donor and Donor Family's life more respectful, informative, and inclusive, and less painful.

Rebecca Free (TAS)

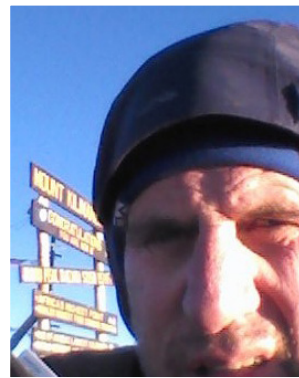


Rebecca is proud donor family member in Tasmania after sadly losing her beautiful Mum to a brain aneurysm in 2010. From this complete tragedy, they witnessed many times the power of donation.

The journey is unique, and she enjoys meeting and assisting other

families in the same situation.

Warwick Duncan (social media)



In 1989, with a young family of three boys, Warwick was stricken with a rare hepatic virus, requiring a liver transplant. He received that second chance due to the selfless decision by a family that didn't want another to go through the hell they were.

In his Donor's memory, Warwick strikes something off his 'Bucket List' on each anniversary of his transplant. This has led to all sorts of adventures like skydiving, hot air ballooning, white water rafting and gliding. On the 25th anniversary of his donor's passing, he climbed Mt Kilimanjaro, the world's highest freestanding mountain.

OUR VISION

To continue the gift of donors to save the lives of suffering people in our community and to care for those who have donated



Care

Provide care and support to families who have donated their loved one's organs and /or tissues

Support

Advocate

Advocate and give donor families a voice

Educate

Educate the community about the benefits of donation, whilst respecting, acknowledging and supporting those touched by donation decisions

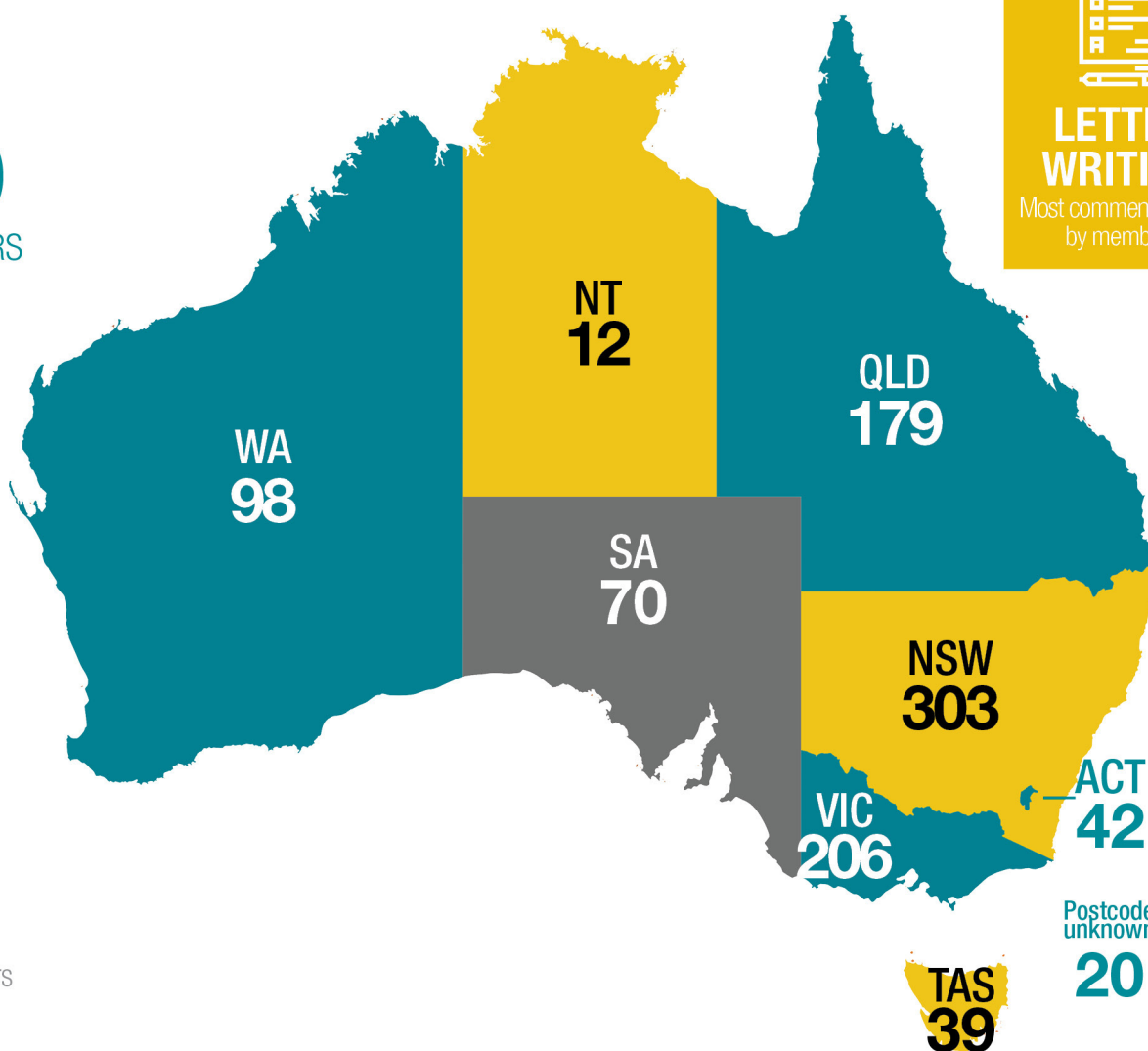
...in 2022

969
TOTAL MEMBERS



LETTER WRITING

Most commented topic by members



2,739

Facebook
Donor Families
Australia followers

To find out more and to become a member please visit our website at donorfamiliesaustralia.org