



Donor Families
AUSTRALIA

Donor Families Australia NEWS

Summer 2022, Edition 27

HIGHLIGHTS

Rural location
impacts on living
donors

Surviving Christmas
without your loved
one

DonateLife
Correspondence
Flowcharts

Reflections on 2021
(AGM Report)

PlusLife Managing
Director retires

ANGEL FROM HEAVEN JUST ON LOAN

“I now look at every person differently, just wondering,” says David Reynolds as he remembers his wife, Neralie.

Neralie was born at Wahroonga New South Wales on 7 July, 1957.

It was only in the last eight years that I found out unfortunately Neralie had endured a very difficult and unfortunate early life, of which she had never complained, which would affect her in later years.

As a young girl, Neralie became a very talented classical pianist and unfortunately had her hand badly damaged before her biggest concert at the Sydney Conservatory (courtesy of her father). Neralie still managed to achieve ‘Honours’.

After completing school at Sylvania High School in 1973, Neralie moved to Glen Waverley.

Neralie found the Victorian attitude to surfing not to her liking. One day she waggled school and went to

Frankston to find there was no surf which she craved for.

At age 16, she made a submission to the NSW Nursing Board to seek approval to study nursing at the Sutherland Hospital in Caringbah. After much deliberation, she was told she had been accepted but they expected her to fail as she had no family support. To Neralie that was, in itself, a challenge. Neralie left home to travel without any family support and trekked to Sydney to commence training on 22 January 1975.

Three years later, after suffering

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A life that touches others goes on forever

~continued page 2

some illness in the week of her final exams, she graduated with High Distinction in every facet of her nursing studies.

Neralie returned to Glen Waverley whereby, lucky for her, she met me, (Dave), an out of work professional cyclist. (What a catch).

Our first date was one whereby she took me to see an unregistered neurosurgeon whose speciality was wart removal. After the procedure, we ventured up Mount Dandenong to take in the view. I took a bottle of Ben Ean. (She did like Ben Ean). Without a cork screw, we managed to open the bottle spilling most of it in the front of my Holden Statesman. About four hours later, I drove Neralie home and she looked so gorgeous in her white nurses' uniform. Unfortunately, the dressing had come off my hand and her surgical white uniform had many red hand prints over most of it. I called back the next day to be greeted by hostile parents at the door. Neralie was standing behind them laughing. I think that was then they decided they did not like me.

We dated for three weeks from about 6 pm to 4 am. On the third week, we were chatting and simultaneously said, "We might as well get married." We could not believe we spoke the exact same words. The next night we informed her parents that we were to be married. As expected, it did not come with any blessing (surprise surprise). I overheard her mother say one night, "It will never last." 42 years later: how wrong were they!

We were married in March 1979 at Mount Dandenong with her mother missing the wedding.

Over the next 42 years, we lost our first child, had the four most amazing children, Chris, Belinda, Heidi and Mark and lived a dream life.

We are the proud grandparents of fifteen living grandchildren and four special sons and daughters-in-law. We have bred sheep with Neralie having a natural ability to prepare sheep to the highest standard — culminating in winning Supreme Champion Ram on sixteen consecutive occasions. She became an Australian Sheep Judge for Royal Shows.

Neralie continued nursing and, until her passing, was still a Registered Nurse.

At age sixteen, Neralie was a champion swimmer in four strokes. At age 31, she started swimming again, winning every event she competed in some by 30 meters against girls aged 16 years and up. Aged 60, she competed once more with the same result. She did it so easily.

In 2013, Neralie decided to paint. She said she wanted to paint watercolours; I painted the house. A year later, she held her own exhibition, selling several to Melbourne buyers. In 2015, she decided to restore furniture at which again she was so talented. During Covid, she decided to restore a broken down rocking horse.

Whatever Neralie decided to do, she did it well, very very well. She could not be denied. There were no shortcuts. Neralie was a perfectionist; it seemed easy for her. I had no idea of the demons she was harbouring.

In 2018, Neralie decided to show her dog Tully. Again with absolute dominance, she exhibited in Victoria, Alice Springs, Tennant Creek and Wagga Wagga. No one had ever taken a pure white Maltese to the red centre of Australia to Royal Shows and won, only Neralie Reynolds. Tully not only won but became National Champion.

In the last few years, we travelled Australia widely punctuated by bouts of serious illness and treatment. In a short period of time, Neralie had lost both her parents, both my parents and my brother Lloyd, our groomsman.

In 2019, we were at Mareeba FNQ shopping at the supermarket. In front of us, there was an elderly lady searching her purse for cash to pay for her groceries which were all staple No Name brand. She broke down in tears; she had lost her money. Without stopping, Neralie leant over and said, "We'll get this." It was \$78. The lady began to cry. We put her in the car and took her home. Neralie went inside to find her demented husband sitting in a chair. They were destitute. Neralie came out and I said "Thanks darling, we have done our duty for the day."



*Share
your
story*

Three days later, Neralie told me she left them with \$300 as that's how much money Neralie had in her purse. In hindsight, it was the most expensive home brand shopping I have ever done. Neralie was happy and that's the sort of thing she did.

For the last seven years, Neralie had suffered a severe illness of which she did not disclose to many people, except family. She struggled every day and night. At times it was insurmountable but still she fought. She did not know the word quit! In early November, she announced to our family she had beaten the illness. She was finally back to her old self. It was better than winning Tatts. It took so much toll on her getting there. Her recovery came after meeting Doctor Neeraj Sareen, a very progressive specialist, who embraced Neralie's illness, incorporating ground breaking techniques and some very old treatments saving Neralie's life. Our family and Neralie will be always grateful for his dedication and help in treating her.

In November, a young guy backed into my Mercedes Benz in Wonthaggi. We got out and chatted and Neralie found he was down helping his mum as his father had died and she wanted him to drive the car. Neralie found the car was not registered and decided that we would pay to have it repaired ourselves as they had a recent loss and were under the pump. The guy was so relieved. She just said "Pay the

favour forward". Little did we know what was around the corner.

Late last year, she decided she wished to become involved once again with horses and purchased several, one of which she fell from on the fateful evening.

Prior to her accident, Neralie registered as an Organ Donor. After 21 days in ICU, two massive brain operations and absolute fighting spirit, we acceded to her wish and Neralie became an Organ/Tissue Donor, which resulted in two young children receiving her pulmonary valves within 24 hours, thereby giving them a second chance at life.

That's Neralie. Every time I see a child walk along the street, I will look at them differently just wondering!! It was the hardest decision we have ever had to make as a family.

We, as a family, would like to thank all the nursing and medical staff at the Royal Melbourne Hospital.

Finally I would like to thank my beautiful family for their undying help, care and love.

Neralie, you were my strength, you are my strength and anything I have achieved, I attribute to you. I shall never be able to repay you. Love today, tomorrow and forever.

David Reynolds

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

CHAIRMAN'S MESSAGE

2021 has brought with it many new challenges with COVID still affecting us all. Sadly, for many families, those grieving were further impacted with restrictions on visitors in ICU and funerals. I know this time of the year can also be very challenging for Donor Families. It is never easy not having our loved one with us but even more so at the times when we like to celebrate with all our family. There is always someone missing... The Executive of DFA extends its warmest wishes at this time of year to all our members and especially for those who have experienced a loss in the past twelve months. Included in this edition is a special section on coping in the festive season without a loved one.

Our AGM in October saw four new members to our committee. Welcome to Donor Families, David Reynolds and Anthea Openshaw and Recipients, Warwick Duncan and Janelle Colquhoun. Having two Recipients on our committee will allow us to become more involved and informed as to what is important to Recipients. We really look forward to their input. Both Anthea and David will be strong advocates for Donor Families in their respective states of WA and Vic. The Executive looks forward to working with these new committee members who bring with them new experiences and skill sets to further enhance our work we do on behalf of Donor Families, Living Donors and Recipients. Bios on our committee members are available on our website. Find out who is your state/territory representative.

As much as we welcome our new committee members, we also say goodbye to Philippa Waldron, Jann Eastley and Nathan Gail. To those members we thank them for their tireless efforts. Philippa is an inaugural member of our committee. The good news is she is not going too far, the role of sending out anniversary emails to our members will still be done by Philippa. Thanks to Jann and her husband, Billy, for the great job done in raising funds for Donor Families Australia to continue doing its work into the future. We look forward to the time

when we can all get together and have a Donor Family Dinner. A big "thank you" to Nathan for setting us up in the world of social media. We now appear on all the platforms, thanks to Nathan.

Our cover story in this edition is from one of our new committee members. David Reynolds and his family share their memories and experiences of living with Neralie. Not only did Neralie live a full and busy life but now she has become a Donor Hero as well.

In recent times, we have seen confusion come into what Donor Families can and can't do in relation to disclosure of information legislation (i.e. what can we say about our loved ones in public according to the law?) This is a very important area that all Donor Families and Recipients need to become aware of. Please read the article on the need to change legislation NOW, included in this edition. If families wish to follow up on any concerns raised in this story, they should contact Donor Families Australia by email.

Looking back on the year, we can see the important work done by Donor Families Australia. We were able to implement and review the new protocol for correspondence between Donor Families and Recipients. Donor Families and Recipients have come to us to assist with their individual letter writing experience. Donor Families Australia has been able to let them know how their correspondence has progressed.

Our Donor Families Australia Donor Hero Night, co-ordinated by Graham and Elayne Harrison, was a resounding success and more is included in this edition.

Despite not being able to travel as easily due to COVID, Donor Families Australia has been



able to reach out to its members through its social media platforms to provide ongoing support and keep our members informed. It was wonderful that in the West we were able to have a gathering of Donor Families for an inaugural morning tea catch up. Those that attended enjoyed the opportunity of talking to others that have had a similar experience. All voted for another catch up in Coral and Ivor's garden in 2022. Hopefully, Donor Families Australia can replicate this in other states/territories for next year. More information is included in this edition. For more detail of the work done by Donor Families Australia, please read the Chairman's Report included.

Donor Families Australia would like to congratulate Sam and Brad on the birth of their first child, Arthur. Sam is a valued member of our team and the reason we can produce our professional newsletter on a regular basis. Sam has been a volunteer for many years and we appreciate her involvement, especially given her busy life, and even more so now that Arthur has arrived.

On behalf of all the committee at Donor Families Australia, we would like to wish everyone a very happy festive season and all the best in the New Year.

Bruce McDowell

Chairman

Connect with us



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@donor_families_australia



Sam and Brad take four month old Arthur for his first meeting with a special certain Christmas friend.

CHAIRMAN'S REPORT

Chairman, Bruce McDowell, presented his report from the Donor Families Australia Annual General Meeting (20 October 2021), reflecting on the year that was, and our many achievements.

It has been a year of many achievements and it gives me great pleasure to be able to present them here tonight.

Over the last financial year, Donor Families Australia has been instrumental in advocating, supporting, and raising awareness for all in the donation and wider community.

Our Donor Families Australia community continues to grow: at 30 June 2020, we had 782 registered families; as at 30 June 2021, we had 904 registered families – an increase of 16%. The fact that membership continues to grow shows the need for our organisation.

The flow-on effect of the previous year's conference continues. It was from the conference that Tara Cheyne's Acknowledgement of Donation on the Death Certificate was born. To Tara's credit, her new ACT legislation was enacted in this year. Donor Families in the ACT can now present to their Birth, Death and Marriage Government Department to have their loved one's Death Certificate amended to acknowledge that they were a donor. What a wonderful achievement by Tara, especially in Covid 19 times, and a great way to help honour our loved one's selfless gift to those in need of organs and tissues.

The conference also highlighted the importance of letter exchange between Donor Families and Recipients. This year saw Donor Families Australia take its role to a new level in advising on how this process should be managed. Members have made it clear to Donor Families Australia that there were many flaws in how letters are handled. This was made glaringly obvious when 69 letters were left unsent in the DonateLife office in Sydney. What followed this occurrence was a first, where the Organ and Tissue Authority (OTA) consulted with Donor Families Australia on how its letter writing procedures should be improved. Members will be aware of the information and requests for

ideas from the committee to help put together our recommendations for improvements. Over the course of working with the OTA, we were satisfied that, in principle, the measures implemented from our engagement would help all Donor Families and Recipients.

The only recommendation Donor Families Australia presented not taken up was that of Donor first names being allowed in the Donor Families' letter. The OTA explained to Donor Families Australia that this would contravene legislation around the country and potentially place health workers in a position of being fined and/or face a penalty. Donor Families Australia decided to test this against the Human Tissue Act of WA, seeking legal advice from Lavan Legal in Perth WA. Donor Families Australia is still reviewing the advice as this report is being written, but it would be fair to say it is a revelation and throws into question what this legislation specifically means and how it affects Donor Families, Recipients and government department practices. We have taken this advice to politicians and public servants and will keep the membership informed of how this advice plays out in the future.

My Chairman's Report from last year mentioned 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") from the Ernst and Young review and that it would be brought before a national body. Unfortunately, this still has not happened. Donor Families Australia continues to lobby in this area and hopes that a positive outcome for Donor Families and Recipients will eventuate. We will update the membership.

Donor Families Australia conducted its second Donor Heroes Night in May this year. This event grew enormously by comparison

to its first year. Through the efforts of Graham and Elayne Harrison, in honour of their son Ben and all Donors, this year's effort had a final reach of over a million people. Graham and Elayne put together a very professional media campaign that culminated in porch lights being turned on. 18 May 2021 was a very memorable evening. Donor Families Australia applied for an OTA grant for this event but amazingly, it was rejected on the basis it did not meet the criteria of raising awareness.

This year saw our single biggest fundraising event. The Kurri Mongrels, an organisation of cyclists from the NSW Newcastle area, took on Donor Families Australia as its charity for the year. Despite COVID 19 restrictions, it still managed to conduct cycling events through the local area, raising awareness along the way. The Mongrels conducted a major ebike raffle that raised over \$17,000. A big "thank you" to Jann and Billie Eastley for their efforts in getting this off the ground. For the second time, Pfizer has been kind enough to include Donor Families Australia in its grant allocations with a \$2,000 payment. Well done to Philippa Delahoy for her efforts in making this happen. Donor Families Australia is a charitable organisation that relies on community generosity to support our objectives. We will continue to look at new avenues of sponsorship.

This year saw some major IT and social media improvements through the efforts of Graham Harrison, Nathan Gale and Sam Howkins. The Donor Family Australia public facebook page has 2,295 followers. The Donor Families Australia website had 1,853 new unique visitors this year. The largest activity was our Donor Hero Night. Our database collection system had a huge revamp that allows quick reference to our membership per state and territory. We would like to thank the members for their response to our recent data survey.

Again, Donor Families Australia has been very active in representing its members with bi-monthly meetings with the OTA and being part of the OTA's Community Engagement Group.

Committee members are constantly attending meetings outside the monthly Donor Families Australia meeting with politicians, public servants and community members to advocate on behalf of its membership.

On behalf of the committee, I would like to thank the outgoing committee members, Philippa Waldron and Nathan Gale. Philippa has been a member of the committee since its inception in early 2013. She has done a great job in sending out our anniversary remembrance emails to all Donor Families, a service, I know, which is greatly appreciated by the membership. Philippa receives a lot of thank you's around the country for what she does. The good news is that even though Phillipa will no longer be a committee member, she has agreed to continue this role of sending out anniversary remembrance emails to our membership. A big "thank you" also to Nathan. Nathan has helped bring us into the current world of social media. Many of our social media posts are generated by Nathan. Similarly, to Philippa, Nathan, as a non-committee member will continue to post into the future.

I would also like to thank all the committee members for the work done in the last year. Every year has its new challenges, and the committee took them on and achieved great things in the name of our members. I would also like to formally welcome our newly elected committee members who, I'm sure will bring with them valuable experience to their new role. I look forward to what Donor Families Australia will be doing next year and into the future to assist Donor Families.

Bruce McDowell

Chairman

20 October 2021

BEAUTIFUL DAY FOR MORNING TEA

A beautiful morning tea was held recently in Perth, in the wonderful garden of Coral and Ivor.

It didn't take long for new friendships to be formed with a common bond of our immense pride in our loved ones' altruistic gift. It was a great opportunity for local Donor Families to get together and share stories of their loved ones in a relaxed and supportive environment.

The morning tea catering was made possible by the support and generosity of the IGA Preston Street Grocer. A lovely spread was provided and neverending cups of tea were enjoyed by all.

Everyone in attendance was keen to repeat next year and we'll ensure we will let our WA members know the details for the next one.

If Donor Families in other states would like to have a similar event organised, please contact us and we'll try to arrange further gatherings of Donor Families around the country.

Once again, a big "thank you" to Coral and Ivor for generously opening up your garden for the event; it was a lovely space for us to enjoy a lovely morning together!





THE NEED FOR LEGISLATIVE CHANGE THAT AFFECTS DONOR FAMILIES AND RECIPIENTS

How many times over the years have we heard: “We need to change Legislation”?

I have heard it, and seen it written, many times.

Well Donor Families Australia agrees! The law around disclosure of information within the states/territories needs amending—and soon. The ambiguity around this clause potentially has those that deliver the service and Donor Families, unwittingly contravening the law.



Please read Lavan Legal’s opinion on our website:

https://www.donorfamiliesaustralia.org/_files/ugd/8a154b_bb3b32dffdba42ffa7a7b615495cf251.pdf

Those that have read Lavan’s opinion have been surprised with what it says. Some of the questions we need clarification on are:

- What can a Donor Family and a Recipient say, legally, when they deliver a speech at a remembrance service?
- Can they even deliver a speech at this service?
- What authority has the Donor Family to be able to give consent to disclose their loved ones information in relation to their donation?
- For fear of breaking the law by making our loved one publicly known, as per legislation, what can a Donor Family say to anyone in relation to the donation?

It is evident that this law needs to be amended to give Donor Families and Recipients the comfort of knowing that they are safe from penalties and fines when discussing their loved one’s donation.

If you would like to make comment or find out more about this issue, please email us at admin@donorfamiliesaustralia.org



Save the Date: 18 May 2022

Donor Heroes Night gives the entire Australian community an opportunity to express their gratitude to all Organ and Tissue Donors for their lifesaving and life-improving gifts to fellow Aussies needing transplants.

In 2021, Donor Families Australia achieved over 122,000 Donor Heroes Night Facebook engagements with more than 500 photos and comments posted to our page (facebook.com/DonorFamiliesAustralia).

In 2022, with your assistance, we're hoping to double participation, making Donor Heroes Night 2022, our biggest ever event.

We're seeking membership participation to help spread the word and get involved.

Your level of involvement can be as much as you wish. Here's how you can take part:

1. Spread the word by publicising the event on your social media channels (Facebook, Twitter, Instagram etc), via your email network, and through family and friends
2. Send us personal Donor Hero Story which we'll post on our Donor Heroes Night page (donorfamiliesaustralia.org/donor-heroes-night)
3. Add your Donor Hero to our Donor Virtual Heroes Wall (donorfamiliesaustralia.org/the-virtual-donor-wall)
4. Share your story with your local newspaper(s) or other media outlets
5. Turn on your porch light (or similar) on the night (Wednesday 18 May 2022)
6. Post a photo of your porch light, along with your donor hero or a general comment of gratitude to all our Donor Heroes on your social media channels.

Over the next few months, the Donor Heroes Night Team will prepare an updated Donor Heroes Night flyer, background reference sheet, and suggested story format, which we'll be distributing during January/February 2022.

Local State and Territory Representatives will be available for further assistance if required in the New Year.

If you're seeking further information, please contact the Donor Heroes Night Team via email (admin@donorfamiliesaustralia.org)

TIPS FOR SURVIVING CHRISTMAS WITHOUT YOUR LOVED ONE

“I’ve been asked to write this article in my capacity as a qualified counsellor,” advises Helen Day, “but I find myself leaning towards my own lived experience in the things that I have found that has personally helped me.”

Everyone, naturally, is different, and what may work for one person, may not work for another. We’re all individuals, and I hope what I write can help all readers in their own personal way.

Christmas can be an incredibly difficult time of year for anyone who has lost a loved one. It doesn’t matter how many years have passed; you never stop feeling a strong sense of loss and sadness with the lead up to Christmas, which is like any other anniversary when they fall throughout the year. In preparation for Christmas, here are some coping strategies that I’ve found helpful to navigate your way through Christmas without your loved one.

Write a support list

Write a list of family or friends who you can contact or spend time with, so that you’re not alone. Some may love to be on their own through most of the year, but I’ve found when it’s an anniversary or especially at Christmas, it’s best not to go through it alone.

Never ever feel guilty about feeling sad during these times. You have every right to feel sad because the person you loved is no longer physically here and where you may cope daily without them during the year, you won’t feel that strong in the lead up to Christmas or a significant anniversary time.

If you have a support list of names already written, it won’t be hard during your time of grief to think of who to call.

Set a place at the table

People have often found at Christmas or during an anniversary period, to set a place at the table for your loved one.

Alternatives are to light a candle, raise a glass in their honour and share some stories. You’ll be surprised just how much their presence will be felt and how comforting that can feel.

Do something creative

One year I was on my own for Mother’s Day. It was incredibly hard as I always do my best to be with my children or people I know can provide me with some support and comfort.

That year, I found all the pictures of my children from when they were born to then, and included pictures of my grandchildren. Putting a collage together of all these pictures, I made a video with Coldplay’s “The Scientist” playing in the background. It occupied my time and gave me great comfort when I watched the video I created of so many special memories.

I have often found writing poems has also helped me and I was able to share one of them with my son’s recipients so that they could learn a little more about him.

Playing my son’s favourite music has been comforting and if you have small children, you could ask them to create a Christmas card for your loved one.



Places to visit

You could go to a place where your loved one used to go. Take someone with you who also may be struggling so that you can share the moment together and remember all the good times.

You could go to church or even visit their grave and take some flowers.

You could plant something in their memory such as a rose bush or a tree.

Or organise a special gathering where you could release butterflies, birds, or balloons.

You could take a yoga or meditation class or learn to do something your loved one enjoyed.

It can just be the littlest things that you do that can make all the difference at Christmas and help you feel their presence and know that you are not alone. Don't be afraid to cry if that helps and remember to be kind to yourself. You deserve to do something special for yourself that will honour your loved one's memory.



Above: Helen's much loved and missed son, Stewart.



Donor Families
AUSTRALIA

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

***is it you?**



THE EXPERIENCES OF RURAL LIVING KIDNEY DONORS

Alison Barrett, Health Researcher at the University of South Australia discusses the impacts of being a living donor when living in a rural location.

Donating an organ as a living organ donor is a major life event and may result in additional burdens for people living in rural, regional or remote regions, due to the concentration of specialist services in major metropolitan hospitals.

Limited research has been undertaken about the emotional, medical, social, financial and practical impacts of this experience for

around the world. We did not find any studies that exclusively explored the experiences of living organ donors from rural regions, nor any that explored the experiences of rural living liver donors.

Some studies explored the experiences of both rural and urban living kidney donors. From these studies, we found that rural living kidney donors may experience a financial

burden as a result of their geographical location of residence. Additionally, the further a donor lives from the transplant centre, the greater their likelihood of not receiving sufficient follow up care after the donation surgery.

Both of these findings are very important in terms of recovery and longer-term outcomes for rural living kidney donors.

We then interviewed seventeen living kidney donors from rural, regional and remote parts of Australia between January and August 2019

rural people, and due to the important role living organ donors play, it warrants further exploration.

With my supervisory team, I undertook a masters by research project at the University of South Australia to explore and gain a better understanding of the experiences of living kidney donors from rural, regional, or remote locations. We also wanted to find out what could be done to support them and help them navigate the donation process.

Firstly, we completed a systematic review to find any information that had been published about rural living liver or kidney donors from

to further explore their emotional, medical, social, practical and financial experiences.

The key things we learnt from the interviews are that the transplant recipient's health and wellbeing have an impact on the living kidney donor and was a strong motivator for them to donate. The interviews also highlighted that donors are generally willing to do whatever it takes to be a donor, including undergoing tests and preparation to make themselves as healthy and compatible as possible.

In rural areas, living kidney donors have varied levels of access to medical support and other important services (such as transport). This



means extensive travel is often required to access specialist and medical support, which may take a toll on time, finances and emotional wellbeing. It is important to note that strategies and support options to minimise the burden of travel and time away exist.

Donors have concerns about medical issues, including the side-effects from the surgery and other medical procedures, and required changes in lifestyle as a result of living with one kidney.

Some rural living kidney donors experience financial concerns, others do not; this seems to depend on what state or territory the donor lives and when the donation occurred. For example, more financial support is available now than there was 15-20 years ago.

The emotional and social impact of donating can be made worse by other life events occurring at the same time. Support from friends, family and local health professionals is very important.

Some donors highlighted having a good understanding of living kidney donation at the start of the process, while others knew less. Similarly, some sources of information are hard to find and are overwhelming, but helpful sources of information also exist.

Many lessons were learnt from the donation experience and highlighted through the interviews, as the donors provided advice to share with potential rural LKDs.

Overall, though, despite challenges and concerns, donors consistently expressed that it was a worthwhile experience. The opportunity to help save a life, or improve someone's quality of life, was viewed to outweigh any risks or challenges associated with the surgery.

The research highlighted a unique group of individuals who each helped someone in need of a life-saving kidney transplant, and their experiences were shaped by their rural location of residence. While most recovered well and experienced no major complications from surgery or long-term outcomes, it highlighted that additional educational, practical and emotional support to help them more easily manage the process would be welcomed.



VALE, MEGAN: NOW YOU FLY WITH ANGELS

Helen Day, Donor Families Australia committee member, fondly farewells and remembers her son's kidney/pancreas recipient, Megan

On 14 November 2021, one of my son's recipients passed away peacefully with her family and friends beside her.

My son, Stewart, lived life to the full and achieved so much in his nearly 24 years life.



Megan received the gift of over 9 years. However, over the past 11 months, she was not able to live it as well as she had in previous years since receiving my son's gift of kidney and pancreas.

In January 2021, Megan suffered a major stroke and fought so hard to regain the life she once had.

In September, she fulfilled another dream of being able to buy her own home when she was finally released from hospital.

She had so much fight for life that began from the age of ten, when she was diagnosed with Type 1 Diabetes. Eventually, this would affect her kidneys, regularly spending time on dialysis, and was close to death prior to receiving the phone call that would change her

life. I first spoke to Megan on 29 April 2016, my son's fourth anniversary, when Megan came across a social media post I had put up. She knew that the other kidney recipient had met me, so she gave her a call to confirm if Stewart was their donor hero.

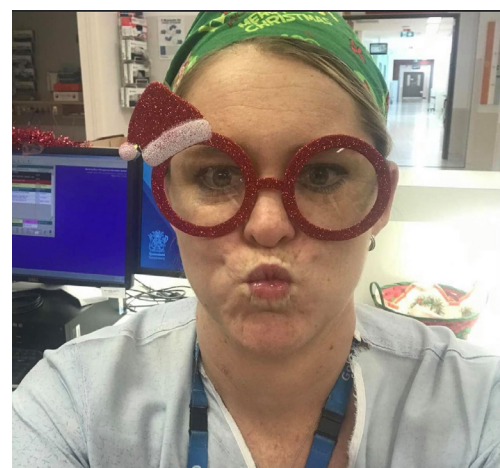
Eventually, I was honoured to meet Megan and her family as I was flying through Brisbane to Melbourne for a Donor Families Dinner. From the moment I spoke to Megan, I could feel a very special connection. This was only more confirmed when I met her beautiful family later that year.

Megan was very similar to my son in that she had so much strength and was a fighter. They both appreciated the life they had been given and fulfilled it every day that they had been given.

Megan was able to fulfil her lifelong dream of travelling to Paris. During the extra nine years she was given, she was able to travel to different destinations around the world including New York, Indonesia, and Hawaii. She had a great love of Fifty Shades of Grey and even met the author! I was so jealous when she went to see Pink in concert as that is on my bucket list and am hoping one day that I will get to see her live.

It was such an honour to be a part of Megan's life over the past five years. Her greatest achievement was to complete her degree and become a nurse where she could help people like my son did.

Although I did feel the natural grief knowing that a part of my son was gone, I would eagerly do it all again with any of his other recipients. To personally see the amazing life that Megan lived because of the gift my son gave her has been such an honour.



I hope one day to meet more of my son's recipients. Even just to hear from them how their lives have changed would mean so much. On 29 April 2022, it will be ten years since I lost my son. The remaining recipients celebrate ten additional years from my son's gift. I pray they have been as fulfilling as Megan's. I'm very proud of all she achieved during her additional years, and I know Stewart would've been stoked to know how much his gift meant to his recipients.

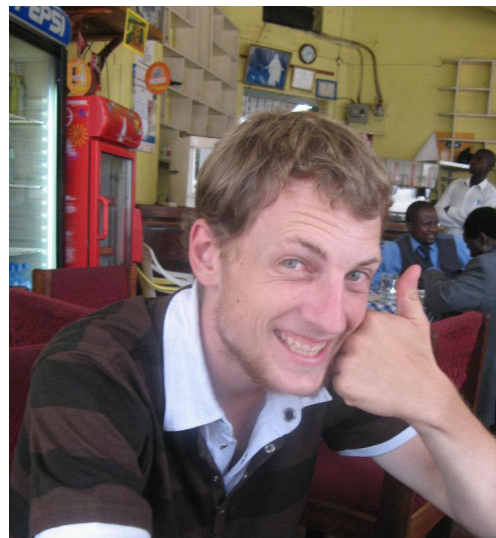
I know I'm not the only donor parent blessed to meet a recipient. I know I'm not the only one who's experienced the loss when a recipient dies. I do know that even when a recipient dies, the donor families who have been blessed to meet their loved one's recipient have felt no regrets.

It saddens me that Australian legislation tries to prevent Donor Families and Recipients from meeting, when it's their choice to. It upsets me even more when this legislation tells me I cannot share that my son was a donor hero on social media. I'm a strong advocate for organ donation, and I fear it's rules like these that put some families off deciding to donate their loved one's organs to recipients desperately needing these lifesaving procedures. It's a timely reminder that sometimes it's better to talk first to donor families and recipients about their personal wishes before making restrictive decisions preventing a donor family from proudly sharing on social media how their loved one's life made a difference to recipients through organ donation.

In early November, Megan developed a blood clot to the brain that could not be operated on. Although she was such a fighter, she was no longer able to live the fulfilling life she once had and knew that her time was over; there was no fight left in her. During Megan's service, two candles were lit by her family. One for Megan, the other one for my son, Stewart. I cried a lot; it was such a beautiful thing to do. I know my son is a guardian angel for all his recipients and knew that when Megan let go of her last breath, he was there to guide her up to heaven.

RIP Megan! May you now fly with the angels and be set free!

Helen Day



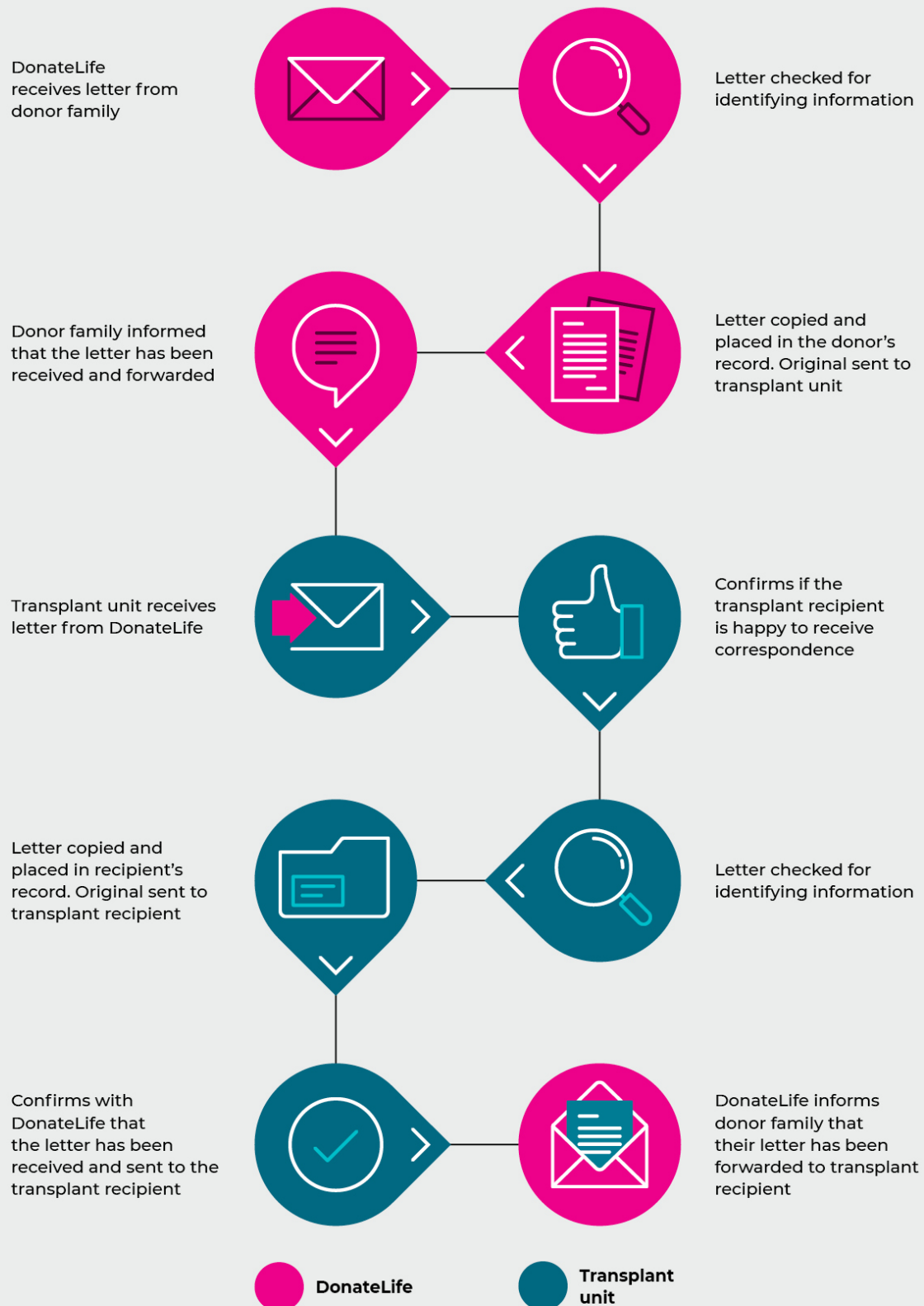
Top: Stewart, Donor Hero, whose gift gave Megan another ten years of life

Middle: Megan fulfils another dream, travelling to Paris

Bottom: Candles lit for Stewart and Megan at her memorial service

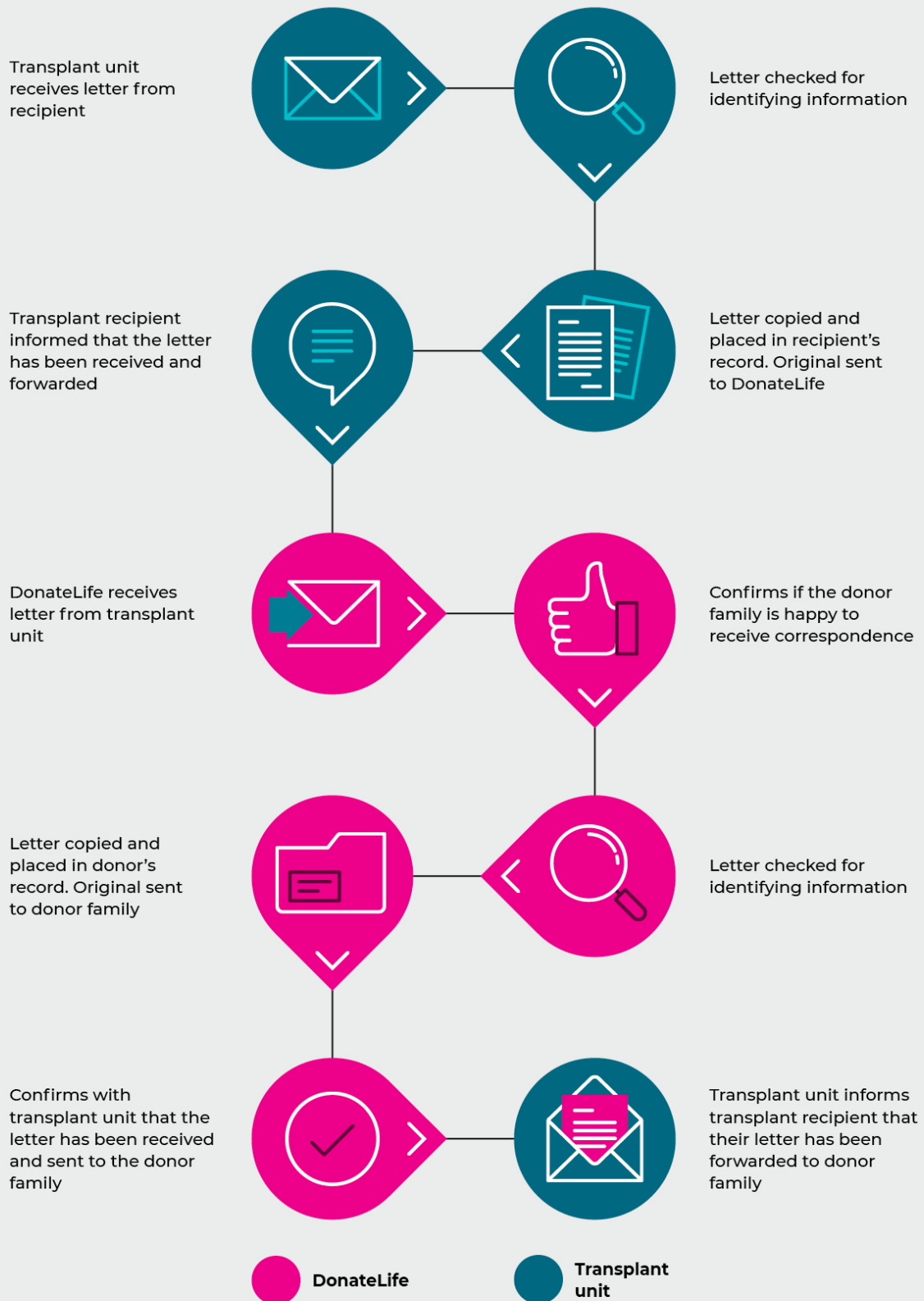
CORRESPONDENCE FLOWCHARTS

Correspondence process for donor family to transplant recipient



For more information about the correspondence process, please see the **Correspondence Guidelines for Donor Families** at www.donatelife.gov.au/resources/donor-families/contact-between-donor-families-and-recipients

Correspondence process for transplant recipient to donor family



For more information about the correspondence process, please see the **Correspondence Guidelines for Transplant Recipients** at www.donatelife.gov.au/resources/donor-families/contact-between-donor-families-and-recipients

ANNE COWIE RETIRES

PlusLife Managing Director Anne Cowie retires after 28 years at the helm of Western Australia's only bone and tissue bank.

Since starting as the founding staff member of PlusLife in 1993, Mrs Cowie has steered the organisation to significant growth, increasing the not-for-profit from two staff – herself and an administration role – to a workforce of 34, managing hundreds of bone and tissue donations each year.

“While organ donation has a high community profile, many people are not aware that tissue donation is actually possible, or that the decision to donate tissue and bone can be life-changing for patients,” Mrs Cowie said.

“One deceased tissue donor has the potential to improve the wellbeing, sight and mobility of up to 60 people through the donations of bones, tendons, corneas, heart valves and skin.

“We are proud that PlusLife grafts are produced from bone and tissue donated by Australian donors and not sourced from overseas. We stand by our onerous and thorough screening practices that ensure we are continually offering only the best quality donations to the community.

PlusLife Board Chairman, Mr Bart Boelen, also paid tribute to Mrs Cowie, saying PlusLife may not be what it is today without her hard work and influence.

“I would like to acknowledge the dedicated work of Anne Cowie to PlusLife over the past 28 years. Her commitment to the cause has been unwavering and her determination and hard work has seen the Perth Bone and Tissue Bank grow from extremely humble beginnings to the successful enterprise it is today,” he said.

“But the road has not been without challenge. Just a few years ago, PlusLife faced the threat of closure when a suitable location could not be found for its operations and, more recently, the COVID-19 pandemic has impacted heavily on the number of tissue donations to PlusLife at a time when demand for allograft is at record levels.

“Successfully navigating these challenges is testament to Anne’s dedication and commitment to the cause and overwhelming desire to help others. We thank her for her hard work and wish her all the very best for the future.”

PlusLife is a not-for profit and the only bone bank in WA. It manages bone and tissue donations through its two donor programs.

Like organ donation, bone, tendons and ligaments can be donated after death with consent from next-of-kin. Living patients having hip replacement surgery can donate the ball part of their hip.



Dear Donor Family,

I am one of the many extremely grateful recipients who has benefited through your loved one's incredibly altruistic gift.

Due to laws and policies, you are unknown to me, as I am to you, but I wanted to tell you how thankful I am for the wonderful gift you gave me, and how much I would love to meet you.

I would love to tell you personally of what an enormous difference to my life you have made, and how I reflect daily on your loved one, whose organs/tissue I have now custodianship of.

I always feel so sad thinking about the loved one you lost, and what a remarkable decision you made at what must have been one of the worst times in your life. I hope it is of some comfort to know that I am making the most of the life-saving gift you gave to me. I have gone from struggling to get out of bed, to re-pursuing my career, supporting my family and friends, inspiring others, travelling, being a positive influence in my community, and competing in sports.

It cannot be understated, but I owe my life to my donor, and my donor's amazing family.

Please know that I am thinking of you, particularly at Christmas when I realise it is one of the times of year you will be missing your loved one most.

Janelle Colquhoun

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 (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)



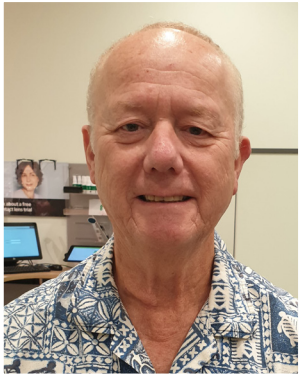
Philippa is a donor wife, following the sudden passing of her husband Scott in 2011.

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 has 30 years' experience as a nurse and midwife.

Her Churchill Fellowship and PhD study, "*Hope for a peaceful death and organ donation*" identified more must be done to help families making donation decisions.

Holly is head of Nursing at University of Canberra, and part of Donor Families Australia, Sharelife Australia and the Coalition to End Organ Harvesting in China.

YOUR DONOR FAMILIES AUSTRALIA COMMITTEE

Janelle Colquhoun



Living with Type 1 diabetes since age 10, Brisbane-born Janelle studied opera at the Queensland Conservatorium of Music, and in her Post-Graduate year, sang at World Expo'88 as a street entertainer before a successful career as an opera singer with the

Australian and Frankfurt Opera companies.

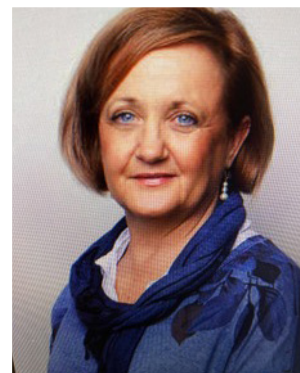
At 29, she went blind from the complications of diabetes, and subsequently experienced further complications including chronic renal failure leading to three year's home dialysis. In July 2008, Janelle received the life-saving gift of a simultaneous pancreas kidney transplant at Westmead Hospital.

A health system frequent flyer, and passionate health consumer advocate and lobbyist, Janelle has served on 26 non-profit and government committees and was a Health Stream delegate at the 2020 Summit in Canberra, suggesting opt-out organ donation. She's an award-winning writer and professional speaker, having given concerts and spoken on diabetes, blindness, disability arts, kidney failure and organ donation.

Since 1999, she runs an entertainment and production agency specialising in professional artists with disability, producing over 1400 events. She also still sings and in 2017, took up blind archery.

When Covid-19 is under control, she hopes to travel again and continue singing and speaking at festivals and events, making the most of the amazing gift she received.

Anthea Openshaw



I have lived in Bunbury, in the south west of WA since 2005 when Neill and I moved here with our four children. I became a donor wife in January 2014 after Neill died following a cerebral aneurysm.

Since Neill's death, I have changed my career and retrained as

a social worker which included writing an Honours thesis on the subject of donor families meeting the recipients of their loved ones' organs. I passionately believe it should be the right of every donor family and recipient to meet if mutual consent is provided.

I also believe that donor families and recipients should be informed of the existence of Donor Families Australia as I was unaware until several years after Neill's donation. Being a part of such a supportive organisation of people with shared experiences and having the opportunity to attend the 2019 Donor Families Australia conference in Canberra has been incredibly rewarding for me and I look forward to working to promote and grow Donor Families Australia into the future.

Warwick Duncan



In July 1989, with a young family of three boys, Warwick was stricken with a rare hepatic virus which required a liver transplant. He received that second chance due to the selfless decision by a family that didn't want another family to

go through the hell that they were going through.

In memory of his donor, Warwick strikes something off his 'Bucket List' on the anniversary of his transplant every year. This has led him to achieve all sorts of adventures including skydiving, hot air ballooning, white water rafting and gliding. On the 25th anniversary of his donor's passing, he climbed the world's highest free-standing mountain Mt Kilimanjaro in Tanzania.

YOUR DONOR FAMILIES AUSTRALIA COMMITTEE

Karen Garner (TAS)



I have lived in Hobart, Tasmania, for the last 19 years.

I donated a kidney to my partner, David, in 2013 and we married in 2014. We travelled to Melbourne for the operations and spent about a month for recovery. At the time, we had a 4 year old son

and were fortunate my mother could come from Queensland to look after him.

I recognised the need for additional support for living donors during my donation. Whilst I understand the need for vigorous testing, physical and mental, to ensure the full implications of donating are explored, and there will be no detrimental outcomes for the donor, the sometimes onerous testing whilst having a partner needing dialysis four times a week made this time quite stressful.

I am passionate about ensuring support required for living donor, not only leading up to the point of donation, but immediately after and ongoing, irrespective of outcome and relationship between donor and recipient. The Supporting Living Organ Donors Program is a welcome financial support mechanism but I feel support needs to extend further than just financial.

I am looking forward to bringing the unique perspective of living donors as the first appointed to the committee.

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.

Dave Reynolds



I am proud to say I am a donor husband, a position I never expected to be in. In January 2021, Neralie, my beautiful wife of 42 years, suffered a tragic accident on our farm in South Gippsland. In February 2021, after a 22 day heroic struggle, Neralie became a Donor.

Within three days, Neralie's pulmonary valve had been modified with one recipient being in New Zealand and the other in New South Wales.

Our four children and their partners and fifteen grandchildren now respectively view all children differently.

During our stay in the ICU, there were serious disconnects between the Donor, Donor Families, and the system which must be improved. I aim to make the most difficult phase in a Donor and Donor Families life more respectful, informative, less painful and more inclusive.

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



SAY THEIR NAME

Say Their Name, A Podcast, will launch in early 2022, with the aim of educating families about the process of organ and tissue donation in Australia.

We are seeking individuals who are comfortable in sharing their story within an hour episode.

We encourage participants from all States and Territories, and culturally and ethnically diverse backgrounds, to apply.

If you are interested in participating or simply would like further information prior to making your decision, please email Lani at:

lrcampbell00@gmail.com

Instagram: **[@saytheir name_apodcast](https://www.instagram.com/saytheirname_apodcast)**



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



Donor Families AUSTRALIA

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

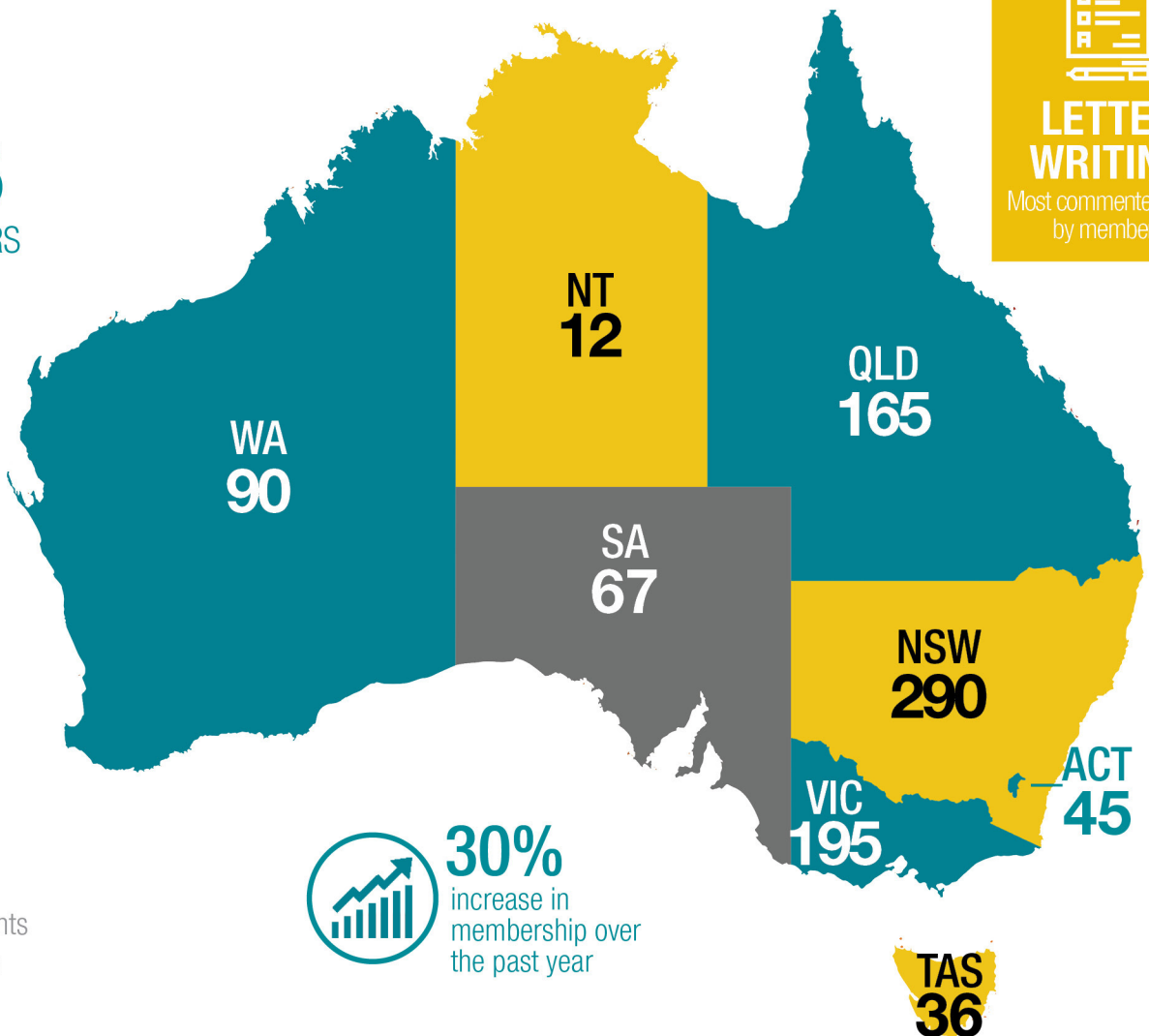
...in 2021

918
TOTAL MEMBERS



LETTER WRITING

Most commented topic by members



3,514

Facebook Donor and Recipients Group Members



30% increase in membership over the past year

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