



Donor Families
AUSTRALIA

Donor Families Australia NEWS

Summer 2021, Edition 25

HIGHLIGHTS

Ever heard of a Bank for eyes?

Holly's Insight: hope and healing for Christmas

The mental health ripple effect

A corneal transplant story

The Kurri Mongrels eBike raffle winner

Your 2021 Committee of Management

Sibling loss, the forgotten grief

The #MADDOG100

Leave a light on: Donor Heroes Night 2021

Will South Australia join the ACT?

THIS GENTLE GIANT LIVED LIFE TO THE FULLEST

Noah was a father, a son, a brother, an uncle, and a friend. But most of all, Noah is our hero, a light amongst the dark.

Noah was 24 years old at the time of his passing. A father to Gordon Fellows (3 years), adored son of Rachel Fellows, much loved brother to Amy, Elijah, Meg and Abi Fellows.

Noah was born 15 June 1994, the fourth of five children. The family lived on the Central Coast of NSW before moving to South Brisbane when Noah was three.

*Share
your
story*

Noah shared relationships with his siblings, as individual and unique as *they* were. His oldest sister, Amy, was very much the little mother, nurturing Noah as if her own. Watching their bond take a different shape as they became older was beautiful, with Amy becoming more a counsel and confidant. Noah looked up to only brother Elijah, who taught him everything — from riding motorbikes as kids to welding steel as adults. Both loved fishing and spent many nights together on the Logan river.



Meg, also a little mother, a nurturer, wanting to care for Noah. As she grew, she shared her love of horses, trying to convert Noah from riding motorbikes to horses, even buying him an akubra.

Noah became a big brother at 18 months, when baby sister, Abi, was born. Inseparable, neither would go anywhere without the other. Abi, being taught how to chase snakes and catch tadpoles, soon became a tomboy and Noah's best friend.



A life that touches others goes on forever

~continued page 2

They shared a room for many years, fiercely protective of one another.

The loss of their brother has had a profound impact on them.

At 15, Noah applied for an apprenticeship in a local butcher shop. Once accepted, he left school and worked hard. He had a good work ethic, was well respected in his field. His co-workers speak fondly of him, not only as a colleague but a friend. He was the life of the shop, dancing and singing in the back and charming the customers in the front.



Three days before his 21st, Noah became a father, his greatest achievement. He had truly found his place in the world. To say he loved being a father was an understatement, he relished teaching his son, Gordon, all there was to learn, like how to fish, putting a fish on the line and having him reel in his first catch, to the screams of a delighted little boy, "I caught a fish." Noah loved that Gordon shared his love of snakes and reptiles, never

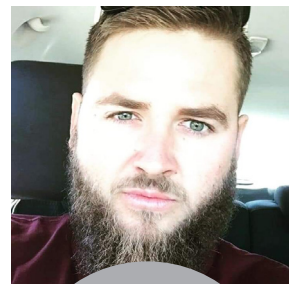
afraid. Cooking was always done with Gordon sitting on the bench and Noah letting him crack eggs, stir batters and flip pancakes. He loved taking Gordon to work, dressing him in a butcher's apron, a knife belt on his waist, showing him off to all his customers, such a proud father.

Noah was the life of the party. Friends say if Noah was going to a party, they were as well. Apparently, if he wore his pineapple singlet, you knew you were in for a good night.

People were drawn to Noah and he loved them, making friends wherever he went. This was evident at his celebration of life — over 600 people, from all ages and walks of life, attended to pay their respects.

On 8 December at 7.30 pm, I received a phone call. Noah had fallen from the fourth floor balcony of his Gold Coast apartment while climbing to gain entry as a flatmate had his keys. Noah survived, however sustained severe brain injury, broken back, pneumothorax and other life threatening injuries. He was taken to Gold Coast University Hospital for emergency brain surgery to remove clots, stop the bleeding and insert drains in his brain. He was put on life support and taken to ICU, for four weeks. The doctors made it clear: if he survived, it was highly unlikely he would regain consciousness, if he did, he would remain in a vegetative state. As the weeks went on, it was clear Noah wasn't making progress. He transitioned into a minimally conscious state. Although his beautiful blue eyes were open, his neurological status remained at around four on the Glasgow Coma Scale. Noah fought hard for 5 months, overcoming many life threatening complications. In late April, he was accepted into a slow stream brain injury rehabilitation facility, we were just waiting for a bed, this was such great news as it gave Noah opportunity to potentially relearn basic living skills.

On 3 May, 2019, things drastically changed. In the early hours, Noah had coded and returned to the ICU. The doctor told us he was



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story*

having uncontrollable seizures. To try one last medication, he had to be intubated, however, change was unlikely and he couldn't survive once taken off intubation.

I asked about organ donation in the event it didn't work. I knew I needed this whole senseless accident and 5 months that followed to have something positive come out of it. I wanted Noah to be remembered for the good he imparted to others, not only in life but in death. Most of all, if Noah could save just one life, if he could stop another person having this same conversation, it was the right decision — one considered without hesitation — should the inevitable occur. Noah was intubated, placed into induced coma and given the medication. Having no effect on the seizures, we were given the weekend to say goodbye.

Watching my two daughters, Amy and Abi, support me in making decisions, being there to comfort their brother in his final hours, something no siblings should ever have to go through, was heartbreaking. To have them stand beside me as young adults, full of resilience, strength and love, supporting me during their loss is a remarkable testimony to their characters. To say I am proud of them both is an understatement.

The weekend was busy with tests to match recipients for Noah's organs. It wasn't lost on me that Noah's heart was so big, there were no matches anywhere in Australia. The donor team, nothing but supportive, made the arduous journey just that little bit easier to bear.



At 10.30 am, Monday 6 May, 2019, Noah was taken off ventilation; at 12:48 pm, as we held him in our arms, he took his last breath. I am truly comforted knowing Noah was able to donate his corneas tissue, bone and skin. His donation restored two peoples' sight and his tissue will help many more in the future.

My sweet boy Noah, the world is a darker place without you in it.

Love Mum xo

Rachel Fellows (Mother)

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

We, at Donor Families Australia, would like to let all Donor Families know that they are very much in our thoughts over the festive season. This time of year is another reminder that we are missing someone very special at our table and family gathering. Holly's Insight discusses the approach to Christmas – one of the hardest days of the year for Donor Families. It is an opportunity to reflect even more, at the end of this very arduous year, on the value of our loved ones. It's a reminder to be gentle with ourselves and know that, as she says, we each "wear" our grief in our own different ways. Please read and pass around to your friends and relatives to assist them to provide the comfort and support you may need.

Donor Families Australia very much appreciates Martin Parker, Jann, Billy and Brydee Eastley and the Kurri Mongrels bicycle club for their efforts over the year, culminating in the recent drawing of the winning ticket in their raffle. This club has completed marathon walks and rides, despite the difficult barriers created by COVID 19, in the name of supporting Donor Families whilst raising awareness for Organ and Tissue Donation. Please check later in this newsletter to see who won the e-bike.

Once again, Pfizer has been very generous to Donor Families Australia, providing us with a \$2 000 grant. Not only is Pfizer helping to save the world from the pandemic by producing its vaccine, it's also supporting Donor Families. Thank you Pfizer, for your ongoing support.

Recently, DonateLife conducted its Thank You Day. Donor Families Australia was proud to display "thank yous" and contribute to the day via its social media sites. The history of the Thank You Day goes back to when Minister Fiona Nash and Donor Families Australia discussed how we could raise National Awareness of Organ and Tissue donation and at the same time, thank our loved ones for their contribution. The first Thank You Day saw Donor Families Australia hold successful gatherings around the country to celebrate this day. It is hoped that, as we come out of COVID 19, that something similar can be done in future years.

Donor Families Australia, in the month of

October, conducted its AGM. The Chairman's report on achievements for that year is included. We were able to welcome our first Living Donor, Karen Garner, to the committee. Karen is passionate about helping Living Donors

receive the support they need post donation. We look forward to Karen's input to the committee. Photos and short introductions of all our new committee for this financial year have been included in this edition. Make yourself known to your state or territory representative. Members can contact their state/territory representatives via our Donor Families Australia email: admin@donorfamiliesaustralia.org

Our front page Donor story is of a Tissue Donor Hero, Noah. Noah's Mum, Rachel, has been able to give us a story about Noah's life and contribution and what Noah's sisters have had to endure in honouring Noah's donation.

The effort to have a national rollout of the acknowledgement on the death certificate of donation continues by Donor Families Australia. Read how Jackie Robson is working hard in achieving this in South Australia. If you are a SA Donor Family and would like the choice of your loved one's death certificate acknowledging donation, then let Donor Families Australia or Jackie know. Efforts are under way in other states to achieve the same. We will keep members up to date with our progress.

In this edition, we have an important article by a Donor Sibling, Lani Campbell. She shares the grief she experienced as a sister to her Donor Brother. Lani lets siblings know there are places to go to seek out support.

Mental Health has become a major topic and is finally breaking through the barriers to be recognised as a major area of concern. This can be said for Donor Families who have lost a loved one. Melanie Cantwell from Mental Health Australia gives us some insight into the



Mental Health consequences of experiencing the loss of a love one.

As always DFA works hard to make sure those with influence get to hear about what is important to us. To meet that ends Bruce and Karen McDowell have included the story of their meeting with Senator Patrick Gorman. The Senator was grateful to hear from us and pledged his willingness to help where able.

A warm welcome to all our new members, we

look forward to working with and on behalf of all our members in 2021.

Please enjoy this edition and where possible enjoy having your friends and family around you over the festive season. As we all reflect on a difficult year gone by, hopefully we will all experience a much better year ahead.

Bruce McDowell

Chairman



Trent Gooden is a grateful recipient of a cornea transplant when he was 12 years old.

Trent had a condition called Blepharitis (dandruff of the eyes) from birth. As an infant, he suffered horrid large styes and infections in his eyelashes. He was on steroid drops constantly to try and prevent the cornea from melting.

Unfortunately, it did happen and the condition caused excess red blood veins that encroached on his cornea and weakened it to the point that a simple rub of the eye caused a rupture. Once the tear occurred, there was no other option than temporarily apply a special glue to prevent infection and wait for inflammation to subside. Unfortunately, there was a leak and a second attempt to glue was undertaken. Despite the medical staff efforts, this second attempt wasn't as effective as they had liked and ultimately the transplant had to be done

urgently. Eventually, Trent was able to have a corneal transplant in 2019.

After 5 operations over 2 months, it was a relief to get the transplant completed. It took about 6 weeks for Trent's eye to start feeling like normal.

Trent attends Ridgeview Secondary. His eye transplant has meant he is behind about six months due to missing school. His vision in his affected eye is steadily improving over time.

Trent is very grateful that his eyesight is now so much better. Without Trent's Donor, he would only have vision in one eye. Trent's family said "until one is in the position of need, you don't realise just how important organ and tissue donors are". Trent's future is now much brighter.

Janet – Trent's Mum

ON THE TRACK WITH THE #MADDOG100



Hi I'm Billy Eastley.

On the morning of Friday 30 October, at 6.30 am, I began the #Maddog100 walk, in support of Donor Families Australia.

We started at Polkolbin in Hunter Valley wine country NSW, with our destination being some 100+ kilometres to the white sands of Newcastle. There were two teams taking on the challenge: eight men and six ladies. Numbers were down due to the COVID virus, with mainly locals filling the two teams.

The day started out nicely with a beautiful sunrise walking through leafy vineyards. This soon changed with a steep rise to Bimbadeen Lookout. Morning tea was served with a fill of water bottles, sandwiches and banana bread delivered by our support team. Onwards to Millfield, Paxton and along the Congewai Valley, the 30 kilometre point, with several stops on the way to replenish supplies.

We were following the Great North Walk and a quick left turn off the dirt road into some scenic bush tracks seemed too good to be true. The terrain quickly changed with an unrelenting climb into the Watagan Ranges. Heart rates were redlining, everyone giving encouragement to reach the summit. A quick break at the top of the hill and on through forestry roads to Heaton Lookout. Light rain started to fall and we donned our raincoats.



From Heaton Lookout, we descended into The Gap with nightfall upon us. It was here we were greeted by a large support crew, Jann Eastley cooking up a storm for all involved. (Jann is my wife and a representative with Donor Families Australia, NSW).

We walked through the night with another deluge hitting us on the way down to Lake Macquarie. We walked along the edge of the lake to Warners Bay, a stop on the way to tape 'Workshirts' deteriorating feet. 80 kilometres with 20 kilometres to go.

The last 20 kilometres were a real struggle. After our short rests, we resembled old men walking off, only to straighten and march on. Our second-to-last stop was Glenrock Reserve Newcastle, where you can nearly smell the salt air. Once again, we were treated to a hearty feed at 5 am by our trusty support team.

From there on, we reached Burwood Beach on daybreak which really lifted our spirits, the finish line in reach. Sand under our feet, we

walked the beach to Merewether. We were inundated with well wishers along the coastal walk with one young lad and his dog asking if we were the Kurri Mongrels walking and if we had been walking all night.

From Merewether, we walked on towards Newcastle Harbour with heads held high and a spring in our step. We reached the harbour at approximately 7.30 am, had some celebratory refreshments, 25 hours and 115 kilometres under our belt.

Through the whole ordeal, when things were tough, I would think of all the donor families out there and this would lift my spirits.

Thank you to the Kurri Mongrels, our support crew and Donor Families Australia for the chance to participate in this event. Also a big shoutout to our sponsors, Station Hotel Kurri Kurri and Cessnock Bicycle Company.

Cheers, Billy

CHAIR'S REPORT AGM 19/20

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

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

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

Perhaps the most important single event we have ever held, was our first Conference in Canberra on the campus of the University of Canberra. Over two days in October 2019, delegates from all over the country came together to talk about Organ and Tissue Donation from a Donor Family perspective. It was two full days of talks and group discussions culminating in a call to action by Donor Families to help improve the Donor Family experience.

The Conference exceeded all expectations with the feedback from delegates being very positive. A big congratulations to the Conference sub-committee for their tireless efforts under the leadership of Holly Northam.

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

Another action coming from the conference was to extend our social media reach. We have now instigated our presence on Instagram and Twitter. These new social media platforms now

complement our web and facebook pages. This has achieved a far greater reach and has brought in so many more people into the Organ and Tissue conversation.



Donor Families Australia has now moved onto Zoom for holding its monthly meetings. This certainly makes the whole experience so much more personable when you can actually see who you are conversing with.

To further demonstrate Donor Family Australia's social media reach, we embarked on our first Organ and Tissue Donor Hero Night. The community was asked, via our social media platforms, to turn on their porch light on the night of 18th May 2020. The posts that followed around this night was overwhelming. People posted photos of their porch light. We had approximately 50,000 reactions over the evening and days that followed. The 18th May is Graham and Elayne Harrison's son, Ben's, anniversary. This night is a tribute to Ben and all Donors Heroes. Due to the success of the evening, this will now become an annual Donor Families Australia event.

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

the review recommendation has not been followed up. Donor Families Australia will make sure that it remains on the table.

Perhaps the most damaging single event that Donor Families Australia has heard of in our eight years was the uncovering, by one of our members in November 2019, of 69 unsent letters in the DonateLife office in Sydney. It was found that some of the letters had been sitting in the office for over six months without passing on. Donor Families Australia sent a formal complaint to the Minister of Organ and Tissue Donation and the Secretary of the Federal Department of Health. The complaint is ongoing with Donor Families Australia meeting with representatives from the Federal Department of Health. Donor Families Australia will monitor its progress into the next year.

Donor Families Australia has used member feedback and forwarded ideas to the Organ and Tissue Authority as to how the letter writing experience between Donor Families and Recipients can be improved upon. Donor Families Australia will keep members up to date via our social media platforms and newsletter as to the progress made.

Donor Families Australia has been very active in representing its members with meetings with the Minister for Organ and Tissue Donation, the Hon. Mark Coulton, the Federal Department

of Health, presenting to the Friends of Organ and Tissue Donation in Canberra at Parliament House, representing its members on the Community Engagement Group in Canberra, and lobbying state and territory politicians and public servants.

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

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

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

Bruce McDowell

Chairman

16 November 2020



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

***is it you?**

SPRINGS OF HOPE AND HEALING IN THE APPROACH TO CHRISTMAS



This year has brought great suffering, loss and despair to many in our beautiful but increasingly ravaged world. I do not wish to revisit this, other than to reflect that these experiences of uncertainty, fear

and grief may have brought many of us to a new realisation of the gifts of family and community that surround us on a daily basis—previously taken for granted... no more.

Many years ago – with a clarity that seems like ‘just yesterday’, I remember the joy I felt when attending the midnight Christmas eve carol service at our local church – my daughters, husband, parents, brother, dear friends and their children. I remember the joy of that evening, it had been a hot day of frantic preparations – cooking, cleaning and wrapping. My memory was of cool summer dresses, happy voices, children giggling and boisterous renditions of carols that filled me with joy and hope for Christmas period and future.

It was whilst settling down on the pew following a joyous carol that I heard my phone ringing. The shock ran through me with the realisation that it was the hospital number. I had not silenced the phone, never imagining that I would be called out at this time on Christmas eve. It had not occurred to me as a novice organ donation co-ordinator nurse that I would be alerted to an imminent death at this sacred moment... I froze briefly then silenced the phone.

Quickly easing myself outside to hear the words of tragedy from the specialist doctor. “We have a young woman who is dying. She has received catastrophic and unsurvivable brain injury. We will need you to be available at the right time to talk to her family.”

The reality that death is not selective to time or place when it strikes, and that a family would be hearing, seeing and feeling the gut wrenching and inconceivable events of impending death at that moment tore at my heart – and I prayed for that family – a family I was yet to meet.

The day that followed, Christmas Day, was a rollercoaster of the work of supporting the

**Holly's
Insight**



health care team to ask for donation from a grieving family. The family had brought in their presents for her and opened them at her bedside. I remember in the days that followed, the meaning held by a wombat.

The extraordinary grace and love that I was privileged to witness from that family, and others subsequently transformed my person, and strengthened my commitment to advocate on behalf of donors and their families, and the people who care for them.

The deep hope, beyond death, that somehow enabled a devastated, grieving family to commit to saving and improving the lives of others is an extraordinary power, the focus of my PhD, and a power that is most evident at Christmas with the celebration of love, hope and future.

This Christmas I reflect — Christmases past — on the family and friends who were with me that first Christmas when I was called to witness the unthinkable grief of a deeply loving family as they lost their daughter, sister and wife. Deep in my heart, I remember another Christmas in Darwin when my family and I were torn from our home as it was destroyed around us in Cyclone Tracy. We had sung carols as we clung to each other through the night. And yet, in the bleak light of Christmas morning we looked out from where we huddled, fearful for our neighbours and friends, yet feeling so totally blessed to be alive.

We remember and celebrate our loved ones at Christmas — especially the ones who have left their souls implanted in ours. This Christmas is the first Christmas that my family and I will celebrate without many of the people who were standing with me, singing, when I received that call to enable my first organ donation. 2020 has been a harsh year for so many, and our losses have been great. There are many triggers that cause tears to unexpectedly well up. For me, yesterday was hearing a carol that my father Tim loved to sing. This will be our first Christmas without him and other loved ones.

Things that I wish to share, that I know are important at this time of remembering and

creating new, happy memories, is to ensure I do things that honour the memories and ongoing impact in our lives of those who we still love but cannot be with: saying their names out loud; making time and space in our hearts to reflect.

A podcast that lifted my heart this week is by actor, comedian Rob Delaney, about how his conception of hope and death changed following the death of his two year old son, Henry, from a brain tumour, and how he sees his love now for his other children:

“I don’t know if Henry’s death made me love his brothers more, but it certainly made me love them better. Because when I hold them now, I know what they really are. They’re temporary gatherings of stardust, just like Henry”, he says.

Each one of us travels the journey of grief at different times and in different ways... some at the beginning and some deeply experienced. We need to care for each other with compassion and kindness and not judge the other on our experience and practice of managing our grief. We need to lift each other up in our hearts and through the year. Self-compassion, and compassion for others, allows us to recognise that we each ‘wear’ our grief differently. Please reach out for support if you feel it would be helpful. The ability to have someone to listen and hear our stories to heal is so important. Love and loss don’t disappear; our experiences of it just change over time.

Sending my love and hopes to you, your friends and family. Go gently over the festive season and into the future.

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

References:

1. @robdelaney podcast on BBC radio 4. <https://twitter.com/bbcr4today/status/1336234113813127170?s=12>

Support services:

- Compassionate friends: 1300 064 068
- Donatelife: https://donatelife.gov.au/sites/default/files/final_ndfss_publicoverview_jul2020_02_ota20_12725.pdf
- Lifeline: 13 11 14
- Beyond Blue: 1300 22 4636

YOUR DONOR FAMILIES AUSTRALIA COMMITTEE

Helen Day
Treasurer (NT)



Nathan Gale
(QLD)



Philippa Delahoy
Secretary (NSW)



Philippa Waldon
(WA)



Holly Northam
(ACT)



Barry Mewett
(ACT)



Graham Harrison
(NSW)



Bruce McDowell
Chair (WA)



Jackie Robson
(SA)



Leanne Campbell
Vice Chair (VIC)



Jann Eastley
(NSW)



Rebecca Free
(TAS)



Karen Garner
(TAS)



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.

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.

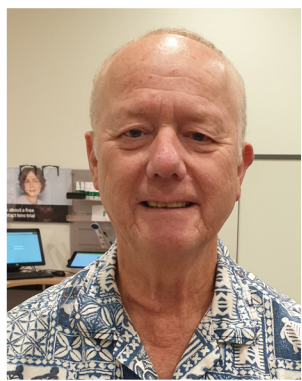
Helen Day — Treasurer (NT)



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.

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.

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.

Jann Eastley (NSW)



Jann joined the DFA committee after losing her brother in 2016 from a boating accident. His donation saved three people.

She's passionate about promoting organ donation and supporting other donor families and recipients.

Nathan Gale (QLD)



Nathan's triplet brother, Adam, died suddenly in January 2014. Adam was a registered organ donor and donated various organs to five recipients, saving five lives. Nathan and his family attended the inaugural Donor Families Australia conference in Canberra, October 2019 where he became a member of

Donor Families Australia. He is now Social Media Co-ordinator, promoting DFA's campaign to Have the Conversation with loved ones once you've registered to become an organ and tissue donor — to ensure your family are aware of your desire to donate and save lives.

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.

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.

Philippa Waldon (WA)



I am from Perth (Joondalup).

My husband, Peter, died very suddenly from a brain aneurysm nearly 11 years ago. I was so lucky to have had such a beautiful man in my life for 38 years. I have been privileged to have met only one of Peter's recipients

which has helped me cope with the loss of a loved one. I understand how important it is to many of us to receive that special letter and I thank and encourage all recipients to keep writing that special "thank you" as it can be the best medicine for a Donor Family.

Let's hope 2021 is a good one for all of us.

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

WHEN WILL SOUTH AUSTRALIA JOIN THE ACT IN ACKNOWLEDGING DONOR HEROES ON DEATH CERTIFICATES?

The short answer is: soon, if Donor Families Australia's Jackie Robson's efforts have anything to do with it.

During the year, I became aware of the very important legislation that passed in the ACT Legislative Assembly.

This legislation gives organ and tissue donor families the option to have their loved one's donation recognised on their death certificate, regardless of whether it was given while they were alive or following their death, and receive a letter of acknowledgement from the chief minister — an Australian first.

Requests for a letter from the Chief Minister, or for changes to the death register, would only be able to be made by the family, with the provision of verifying information.

The intention is that the legislation applies whether the person was a donor while living or a donor on the occasion of their death.

There are a number of existing avenues for recognition of organ donation, including the Gift of Life Walk and the annual services of remembrance. However, apart from an acknowledgment letter from the hospital via DonateLife (in the case of organ and tissue donations on the occasion of death), there are few formal, tangible avenues for families to see the significance of the donation acknowledged.

I decided to contact local politicians here in South Australia to try and have SA become the first state in Australia to pass this same legislation. I first contacted my local member and did receive acknowledgement from the Minister of Health that the government is currently seeking input from the ACT and other jurisdictions about this important issue. This was occurring during COVID, so to receive a reply was positive.

I have since had a meeting with the Shadow Minister for Health, and the Labor government is very interested in ensuring this legislation is discussed in Parliament. I did have interview times set up with Channel 10 and the Shadow Minister for Health but on each occasion, COVID has intervened and the meeting has had to be postponed. I am hoping that in the new year, I shall have a chance to highlight this initiative in the media. This is something my family and I feel passionate about so I will continue to work to try and have this legislation passed in SA.

If you are a South Australian Donor Family and want the option of having your loved one acknowledged as a donor on their death certificate, please let Donor Families Australia know and we will pass the numbers onto the SA politicians.

Jackie Robson

Donor Families
Australia Committee
Member, South
Australia



Donor Heroes Night

In May 2020, Donor Families Australia held a spontaneous evening event of recognition, reflection and remembrance of all Australians that have donated their organs and/or tissue, saving or greatly improving lives of many tens of thousands of fellow Australians over the years.

The evening resulted in responses from 50,000 individuals turning on a porch or balcony light to commemorate the evening.

In 2021, the aim is to DOUBLE the participation, and more!

To achieve this goal, Donor Families Australia has established a Project Team and planning has already commenced to make the evening of 18 May 2021, a truly memorable event.

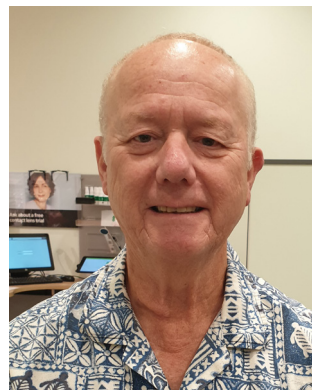
Donor Families Australia is calling on all members, both Donor Families and Recipients to provide a brief article of 300-400 words, commemorating their Donor Hero, from either perspective. We'd also like you to include a photo of your Donor Hero or, if you're a Recipient, yourself.

We publish these articles on our website and display them throughout the Australian community in the month leading up to 18 May. We'd also like to hear from you if you're available for media interviews (TV, radio and print) and would feel comfortable discussing what Donor Heroes Night means to you.

You can submit your story online at:
<https://www.donorfamiliesaustralia.org/our-heroes>.

Members that have indicated they are available to be involved with the media will be first contacted to confirm their availability closer to May 2021.

For further information, please contact Graham Harrison, Event Team Leader through our website:
<https://www.donorfamiliesaustralia.org/contact> (General)



DONOR HEROES NIGHT

Save the Date

18 May 2021

DONATE FOR LIFE, HOPE AND A POSITIVE MENTAL HEALTH RIPPLE EFFECT

“In a world where we often, and sadly, only celebrate life when there is death, over Christmas, I plan to celebrate and remember my sister, and focus on the many lives her death has helped save and improve” writes Melanie Cantwell, Deputy CEO of Mental Health Australia.

Three years on from her unexpected death at 43, our decision to donate her organs has changed the lives of many people, including mine.

Her liver went to a man who wrote the most beautiful letter about how grateful he is.

His partner wrote to me about how her first partner had died, and what it meant that her second partner is now living and not facing death.

Deanna’s corneal donation means a young boy can now see. A grandfather can now breathe, two women are off dialysis, and numerous people have benefitted from her skin and bone tissue.

Confronting? Yes, it is. But hope for others at a time we had none? Undoubtedly.

Many profound messages of hope fulfilled, because that’s what organ and tissue donation can do.

When we talk about the theme of mental health at Mental Health Australia where I work, I actually wonder ‘what does organ donation have to do with mental health?’ When I wrote about this in our own newsletter, I wondered whether I was blurring two issues I’m so passionate about – mental health and organ donation. But my team quickly remind me of the positive ripple effects of hope through organ donation, and its impact on physical and mental wellbeing.

Physically, we know it helps severely sick people to live, and to go on and thrive when they may not have previously, but the lifesaving donation of an organ or tissue is much more than a physical fix.

The hope that organ donation conveys, and what that can do for someone’s mental health and that of their carers, family and loved ones is immeasurable.

Hope for potential recipients to keep waiting and fighting. Hope for eventual recipients to keep living. And hope for the families and friends of many who share the journey, as well as the distress and anxiety of it all.

If hope is the primary mental health benefit for organ donation recipients and their loved ones, then for the families of donors perhaps knowing that such hope exists can help provide meaning and sense at an extremely difficult time.

Melanie Cantwell’s much loved and missed sister, Deanna, with son, Zac, (2017)



Acknowledgement of the donor's contribution is also important to donor families, who supported last May's tabling in the ACT Legislative Assembly of a Private Business Bill to recognise organ and tissue donation on a death certificate, a national first. As a Canberra resident, I also personally supported this and made contact with Tara Cheyne who tabled the Bill.

Each year, I attend the Donate Life ACT Service of Remembrance and Thanksgiving in Canberra to celebrate those impacted by organ and tissue donation. Each state holds these services throughout the year.

My family attend the Gift of Life Walk around Lake Burley Griffin, to raise awareness in support of organ and tissue donation and promote registration on the Australian Organ Donor Register.

Of course, like so many others in 2020 I have attended a range of virtual events instead.

To find out more about the events in Canberra or to register to donate please contact with the ACT DonateLife office. After all it only takes a minute to register as an organ and tissue donor, a minute to help maintain hope and cause a positive ripple effect.

I miss my sister terribly. But it's a wonderful experience to receive a letter from her recipients and feel proud about what she has done, and continues to do after she has gone. This genuinely helps my mental wellbeing on those days grief is almost unbearable. An experience I know many of you share. Particularly at times like a festive season...

For me personally, knowing that our loss has in some way benefited others is a small and calming comfort to not having my sister here with us today, and if nothing else that fact has to be good for my own mental health.

Melanie Cantwell

Deputy CEO & Company Secretary, Mental Health Australia and Donor Sister

DONOR FAMILIES AUSTRALIA WEBSITE RECEIVES FURTHER UPGRADE

Due to our website builder and host, Wix, undergoing a major upgrade, Donor Families Australia has once again drawn on the services of Sam Howkins from The Streamlined Desk. This involved undertaking a complete review of our website design and styles, and modifying some elements and functionality. It's meant many hours of Sam's time and Donor Families Australia remains ever grateful for the time she commits in maintaining the functionality of the website as well as being our newsletter designer and editor.

That being said, the day to day uploading of photos and data is managed on a volunteer basis and in some cases, it can take upwards of day to a week or so for some items to be published on the website.

I encourage you all to visit our website and become more involved as follows:

Virtual Heroes Wall

Post a photo of your Donor Hero on our virtual Wall. There are now 98 Donor Heroes displayed on the Heroes Wall.

<https://www.donorfamiliesaustralia.org/the-virtual-donor-wall>

Submit your Story

There are currently 19 Donor Stories, 2 Contact Stories and Recipients can contribute.

<https://www.donorfamiliesaustralia.org/our-heroes>

Contact Register

This is available for both Donor Family members and Recipient associate members that wish to make their detail available for possible contact between both parties. Although approximately 50% of our membership have indicated on registration that they have a desire to make direct contact, they are still required to complete the Contact Register before DFA can undertake further action. Currently there are 171 registrations.

<https://www.donorfamiliesaustralia.org/contact-register>



Visit: [donorfamiliesaustralia.org](https://www.donorfamiliesaustralia.org)

Contact Us

Our Contact page has also been enhanced which provides the membership the opportunity to be more interactive:

- Become a member
- Complaints and Suggestions
- Volunteer with us
- Become a corporate supporter
- Newsletter contributions
- Website feedback
- General contact

<https://www.donorfamiliesaustralia.org/contact>

Latest

This topic group has also been enhanced providing the latest News, Newsletters, Events, Holly's Insight & Videos

<https://www.donorfamiliesaustralia.org/latest>

Connect with us



@donor_families



/DonorFamiliesAustralia



@donor_families_australia

A BANK HOLDING FAR GREATER RICHES



Donor families and recipients may well be aware through personal experience that there are banks for eyes. Lisa Buckland, Manager at Lions Eye Bank, gives us a quick overview of how the bank works and what it does.

Established in 1986 the Lions Eye Bank is the only facility in WA that coordinates the collection, processing and distribution of eye tissue for transplantation. In addition to corneal transplants, scleral tissue is used in other surgical procedures.

All donor tissue is utilised either for transplantation or, if unsuitable, for ethically approved research or surgical training with the consent of the donor's family. This tissue is crucial to advancing research and developing surgical techniques.

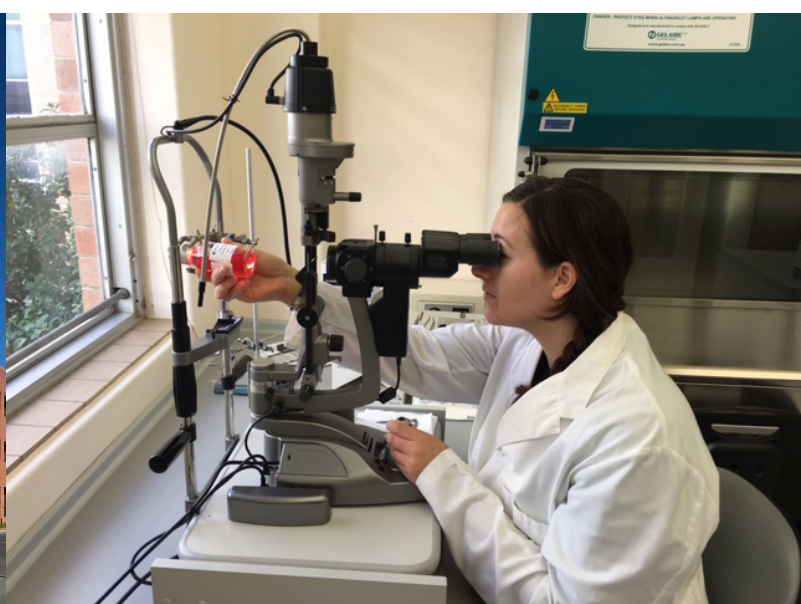
The new organ culture storage method introduced in April 2011 enabled the eye bank to schedule patients, negating the previous practice of managing a long two year waiting list. Patients only have to wait around 2-3 weeks for a graft now, which includes a quarantine period to allow for testing and evaluation of the tissue.

As a member of the Eye Bank Association of Australia and New Zealand (EBAANZ), the Lions Eye Bank works collaboratively with other eye banks to maintain consistently high levels of quality, safety, proficiency and ethics. Excess tissue is shared when appropriate and emergency requests for tissue are always supported.

As an independent organisation, the Lions Eye Bank is self-funded through cost recovery and is supported by the Lions Save-Sight Foundation WA.

Lisa Buckland

Manager, Lions Eye Bank



FROM ONE SIBLING TO ANOTHER

I felt the inner turmoil within my mother before I saw it in her eyes, as I retrieved my backpacking bag for my next adventure. Fighting her maternal instinct to stop me, especially after the loss of my brother, Brett. But she selflessly saw me off, as she knows that travel provides me solace.

Many ask, don't you fear travelling alone? But I'm never truly alone, because he always shows me a sign that he is watching over me.

Ten years have now gone by since my brother passed, but I still reflect on how at times, I yearned to connect with those who had lived my experience. Often, we as siblings downplay our grief as to not concern our parents, but it is just as important for us to grieve naturally. Just as there is no comparison for the love of a parent to their child, there is no other bond like that of siblings. One of the great losses in life is the death of a brother or sister, yet we know this is one of the most neglected types of grief, especially in adulthood.

In grief literature, siblings are often referred to as the forgotten mourners. "The focus of grief, they told me, was on their parents. Furthermore, they noted that they held the double weight of their own and that of their parents' grief. One of their [siblings'] laments was that none of them ever had the opportunity to read about sibling loss, or share their stories and their siblings with others who had also experienced this type of loss" (Davidson, 2018, Sibling Loss - disenfranchised grief and forgotten mourners, Bereavement Care, Volume 37(3), 124-130).

The Compassionate Friends of Victoria (TCFV) want to change that!

With the recent creation of a new sibling division, we have launched an online peer based social and emotional chat support program for bereaved siblings aged 18-30 years, residing in Victoria, Australia.

We understand your loss, we are walking the very same journey you are but you need not suffer in silence!

So when you need to chat with someone who just gets it, we are here for you:

Online Chat Service

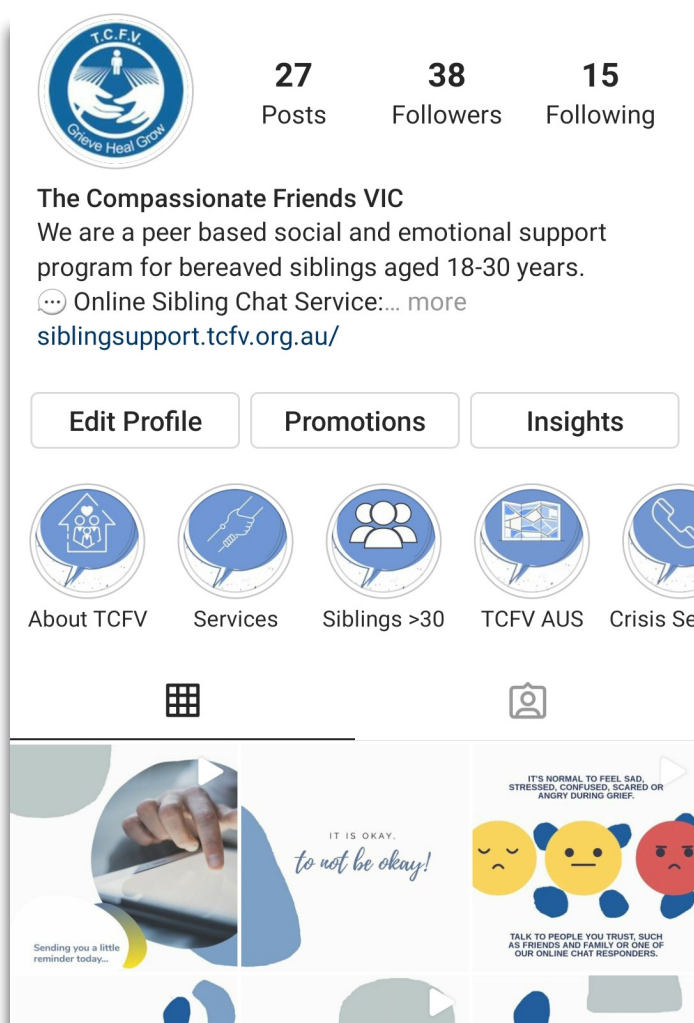
3 pm-12 am, daily

www.siblingsupport.tcfv.org.au

The Compassionate Friends of Victoria also support parents and grandparents who have lost a child, via in person support groups or our dedicated 24hr support hotline on 1300 064 068.

You'll never walk alone!

Lani Campbell



BRUCE & KAREN MEET PATRICK GORMAN

Member for Perth, Patrick Gorman MP made time recently to meet Bruce and Karen McDowell at his Perth City office where he is based.

Mr Gorman listened to the Donor Family Australia story and what its main issues are currently.

Bruce and Karen were able to let Mr Gorman know how important it is for Donor Families and Recipients to meet. He was shown the Ernest and Young Review, highlighting Recommendation 26 that states "consenting Donor Families and Recipients should be assisted to meet" and was very responsive to the idea of Donor Families and Recipients having the right of choice to do so.

The importance of Letter Writing and Donor Families wanting the choice to be able to use their loved one's first name was discussed. Bruce and Karen were able to express how important it is to many Donor Families to be able to refer to their loved one by their first name in correspondence.

Mr Gorman heard how Donor Families Australia is lobbying all States and the Northern Territory to introduce Acknowledgement of Donation on the Death Certificate for those families that would like to do so. Now that the Australian Capital Territory has introduced the legislation, Donor Families Australia is keen for the same to be rolled out around the country. Mr Gorman said he would talk to the Western Australian Attorney-General to help promote the progress of this legislation through the WA parliament.

Donor Families Australia would like to thank Mr Gorman for his time and for listening to what is important to Donor Families.



KURRI MONGRELS RAFFLE WINNER

And the winner of the fabulous Cannondale Montera 2 eBike is...

Richard Short from Mulbring NSW

Every dollar raised came directly to Donor Families Australia.

Thanks, Kurri Mongrels, and everyone, for your support!



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

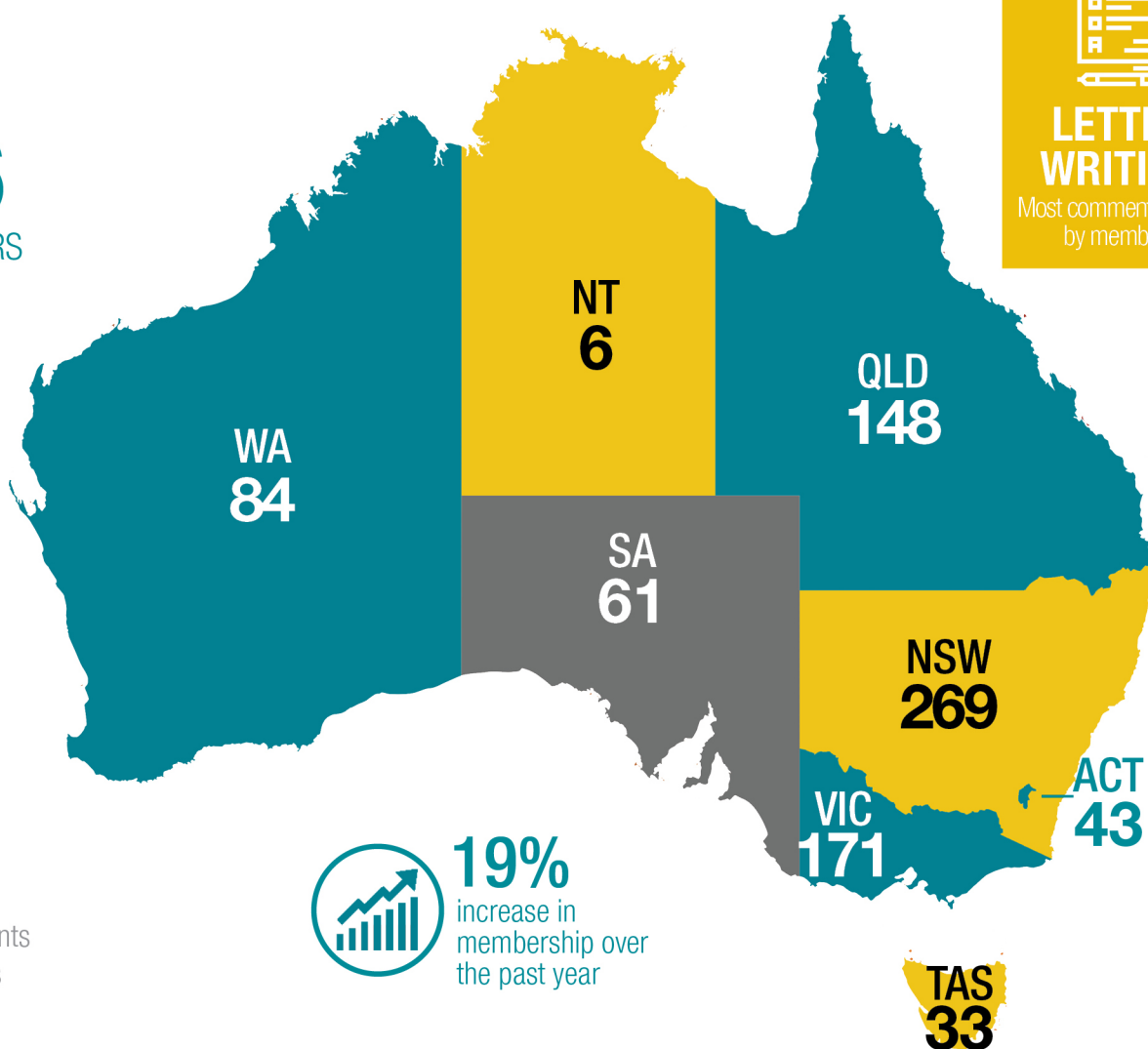
...in 2020

836
TOTAL MEMBERS



LETTER WRITING

Most commented topic by members



3,359

Facebook
Donor and Recipients
Group Members



19%

increase in
membership over
the past year

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