



Donor Families
AUSTRALIA

Donor Families Australia NEWS

Autumn 2020, Edition 23

HIGHLIGHTS

Tips to be kind to yourself

ACT introduces new Bill to recognise Donors

Reflecting on the Ernst & Young Review

Our Social Media platforms lately

Organ/Tissue Donor Hero Night is 18th May

WITHOUT WARNING. REMEMBERING NEILL, AN AMAZING MAN

Dr John “Neill” Openshaw | 10 June 1964 – 1 January 2014

Neill was a 49-year-old Orthopaedic Surgeon, beloved husband of Anthea and an adored and adoring father of four children, Emma (18), Charlotte (17), Kate (14) and Henry (10). His wife, Anthea, shares their family's story.

Neill was a workaholic who loved the work he did. He was a rugby union fanatic who supported the Wallabies and the Western Force passionately. He loved skiing and was obsessed with cars, especially fast ones. And he had the most beautiful bond with his dog, Paddy. Neill was a clever, funny, brilliant, handsome, hardworking, devoted man and we miss him beyond comprehension.

We were married in May 1989 and he died just four months before our 25th wedding anniversary.

Neill collapsed unexpectedly on the morning of New Year's Eve 2013 with, what was later diagnosed as, a cerebral aneurysm. There was no warning. He was on his favourite beach enjoying a sunset with Paddy only 12 hours prior to his death.

Our lives had revolved around our family, our friends and our home. Neill spent most of his free time working on our 12-acre property or with his children at various sports and activities. He spent much of his time with our eldest daughter, Emma, who rode horses competitively and he was usually the medico at the horse events. He became very well known and loved being a part of the horse world with Emma. He also loved skiing holidays with his children,

~continued page 2

*Share
your
story*



A life that touches others goes on forever

~continued from cover

summer holidays spent at Dunsborough and going to every rugby match in Perth.

Organ donation was first mentioned at the hospital not long after we had received the devastating news that he would never recover. In fact, I think I raised it first. We had had a family discussion about organ donation during dinner only months before he died, quite a long discussion and the timing now seems extraordinary. Even though we all agreed that we would want to be organ donors I admit I was not sure I would be able to agree to my beloved family being donors. Yet when that decision had to be made, my four brave children and I did not hesitate.

We were supported every step of the way through those gruelling few days and my children were incredible. No children should ever have to make decisions like this but unfortunately some do and I could not be prouder of how they conducted themselves during this time. I think the decision we made has helped us to heal as we feel strongly that we made the right choice and that at least four other families did not have to suffer losing their loved one as we did.

We have received cards from some of Neill's recipients, which we treasure. I would encourage all recipients to write, even a few words, as it is hard to describe the pleasure it gives to hear that Neill's recipients are happy, healthy and enjoying life because of his gift.

The loss of Neill has been very difficult for us.

Overnight, I became a single mother of four children and have had to learn to manage many aspects of our life that Neill previously had done. My children will always grieve deeply the loss of their beautiful dad. It has been a massive loss. But Neill is and will always be a huge part of our lives. Paddy is still with us, a lot greyer and a bit slower, but still loving an evening on the beach. And my children continue to amaze me with their grace, strength and resilience in facing the loss of their father — Neill would be so incredibly proud of them. They truly make my life worth living as I see him reflected in them in so many ways.

I could never have dreamt that my life would take such an unexpected and unwanted turn. There have been many lessons learned, some good and some more difficult but the opportunity to donate Neill's organs was one of the best. I feel so very proud that at such a devastating time we all chose to donate. It has given us such a sense of comfort that throughout his life and death Neill has made such a difference to so many people's lives. He really was an amazing man and the world is a better place for him being here.

Anthea Openshaw



*Share
your
story*

A WARM INVITATION TO JOIN US

Share your experience
with similar people to support those
making life changing decisions.

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

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

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

www.donorfamiliesaustralia.org



CHAIRMAN'S MESSAGE

Warm welcome to all our new members especially those who have lost a loved one recently and agreed to Organ and Tissue Donation. Your loved one is truly a Donor Hero.

These are indeed very different times. It just goes to show no matter how clever we think we are, there are always greater forces at play. I hope our readers have been able to stay healthy.

COVID-19 has pretty much brought things to almost a standstill, including organ and tissue donation. We understand that transplants have been affected and government staff have been moved around to best suit the fight against this virus. Our thoughts go out to those on the waiting list, waiting for their precious gift of life.

The Donor Families Australia (DFA) committee continues to work and advocate on behalf of its members and even in these difficult times we are still active in promoting organ and tissue donation and providing support to donors and recipients. We encourage you, especially in these times of self-isolation, to use our Facebook pages, Twitter, Instagram and webpage to keep in contact with others in the Organ and Tissue Donation community. This is the time to be reaching out and supporting one another.

At the end of February, DFA represented its members in Canberra. First, it attended (committee members Dr Holly Northam, Barry Mewett and Bruce McDowell), the launching of the Parliamentary Friends of Organ and Tissue Donation. A big thank you to Dr Anne Webster MP and Dr Mike Freelander MP for the invite to attend and speak on behalf of Donor Families. The evening was attended by a large contingent of federal politicians from all sides, as well as public servants and other members of the organ and tissue donation community.

Whilst in Canberra, DFA was granted a meeting with the Minister of Organ and Tissue Donation, the Hon. Mark Coulton MP. DFA took the opportunity to further the discussion on assisting consenting donor families and

recipients meeting. DFA also referred to the letter writing scandal coming out of the Sydney DonateLife office. DFA stressed that its members want the letter writing policy to be overhauled and to be monitored by donor families and recipients. DFA discussed with the Minister that it is so important for letter writers to trust the system that handles their precious communication with each other.

As the Chairman of DFA, I attended OTA/DonateLife's Community Engagement Group meeting in Canberra. DFA members can be assured they are represented on all matters that are raised in our forums.

Our newsletter commences with the wonderful story of Dr Neill Openshaw. His wife, Anthea, has written of how Neill loved his family, his surgical work in the town of Bunbury and spending time with his pet dog Paddy and now to be remembered as a Donor Hero.

Tara Cheyne MLA for the ACT has provided us with her story on how she is wanting to change the ACT legislation so that families are able to have the option to record that their loved one was an organ or tissue donor on their loved one's death certificate. DFA thanks Tara for her efforts and wishes her the best of luck with having the legislation passed. DFA encourages other State and Territory politicians to take on board what Tara has done.

The 18th May will be Organ and Tissue Donor Hero Night. What a wonderful concept. DFA encourages all to show their support for this tribute to our Donor Heroes. Read more about this evening from Graham Harrison's article included in this edition. Remember this date and please share with all your family, friends and networks. Let's light up the night.

Philippa Delahoy provides us with some helpful



tips on how to cope with the new world we are living in.

Nathan Gale introduces himself as a new member on our committee and will be assisting DFA in creating a larger social media presence. Welcome aboard Nathan as our new Queensland committee member.

We also touch on the Ernst & Young newly released Organ and Tissue Donation review and specifically Recommendation No. 26 i.e. "consenting Donor Families and Recipients should be assisted to meet." This

is a major step forward and DFA will eagerly follow the government's progress on this Recommendation.

DFA's thoughts are always with Donor Families especially around anniversaries. We look forward to hearing from our members via our social media outlets so we can know what is important to you and for you to use for peer to peer support. Stay safe over this period.

Bruce McDowell

Chairman

Parliamentary Friends of Organ and Tissue Donation launch



TIME TO BE KIND TO OURSELVES

While we can't deny that this is a time unlike any other for everyone in our community, donor families may be feeling a little more raw than others. When the news is reporting information about ICU beds, ventilators and intubation, I doubt I'm alone in being reminded of the most traumatic time in my life.

I'm talking about the 13 days I spent by my husband Scott's bed in ICU. Scott contracted swine flu in 2011 and he was placed into a drug-induced coma and progressed onto more and more interventions to keep him alive, before succumbing to a brain haemorrhage. Even after nine years, it's a memory that I try to block out and coronavirus is making this seem a little like 'groundhog day'.

At this time, as a donor family community I think it's really important that we take care of ourselves and that is often easier said than done, so I thought I'd share some tips that I've been using.



Limiting my consumption of the news to two times in the day, first thing in the morning for 30 mins and early evening for 30 mins. I'm deliberately avoiding the news at end of the day, as I don't want to think about this while I'm winding down to sleep.



Allowing myself to acknowledge that this is an uncertain time and that being apprehensive is normal. But I also remind myself that Australia has world-class healthcare and that as a society, we do appear to be flattening the curve.



Using the 5-4-3-2-1 trick to focus on the present, if I'm starting to panic:

- Name five things that you can see around you
- Name four things that you can hear around you
- Name three things that you can feel around you, e.g. the seat you're sitting on, your clothes, your watch etc.
- Name two things that you can smell around you
- Name one thing that you're proud of yourself for achieving



Listening to my favourite music; it's amazing how a song can transport you to a happy place.



Walking in my local neighbourhood; as someone wise once said, no-one feels worse after a walk.



Drinking plenty of water and get 20 mins of sun every day; we are basically house plants with more complex emotions

@donor_families



/DonorFamiliesAustralia



@donor_families_australia



Please feel free to share your tips with Donor Families Australia's social media...

Above all, be kind to yourself!

Philippa Delahoy

BEHIND THE SCENES OF DONOR FAMILIES AUSTRALIA

Behind Donor Families Australia there is a band of hard working volunteer members that keep the organisation's wheels turning.

The DFA News and overall content is managed by Bruce McDowell and Sam Howkins compiles each issue which can be a daunting task at times when running into ten pages or more. If you'd like to contribute a Donor Family or Recipient story, article concerning organ donation and transplantation, or provide feedback to the editor, please contact us: www.donorfamiliesaustralia.org/contact (Newsletter).

DFA Membership Database duties are shared between Philippa Waldron and Graham Harrison. Philippa is DFA's welcoming host who sends receipts to new members, (full Donor Family Members or Recipient/Others Associate). Philippa also issues remembrance emails to Donor Family Members prior to the date of their Donor Heroes passing.

Graham is involved with maintaining the Membership Database, used primarily for issuing newsletters and identifying members' needs. If you need to update your membership contact details, please contact us through: www.donorfamiliesaustralia.org/contact (Contact). *Note you don't need to re-register.

The DFA Donor-Recipient Contact Register is also managed by Graham. It's open to all DFA Donor Family and Associate Recipient Members, so if you wish to register, join DFA first. Only when both parties have consented, and a definable connection has been established, is initial contact made. Meanwhile, personal details are kept confidential. To find out more, please visit: www.donorfamiliesaustralia.org/contact-process-conditions. It's easy to register online at: www.donorfamiliesaustralia.org/contact-register.

For Members: Donor Families Australia has a closed (private) Facebook page for Donor Families only. It's noted that a few members are both Donor family Member and Recipient. The Facebook group is for exchanging stories and providing support between Donor Families.



DFA Members are invited to join once they've registered as a DFA Member.

We invite you to browse our website (www.donorfamiliesaustralia.org), which provides information about our organisation, stories from Donor Families and Recipients, a Virtual Donor Wall, latest news and support information. Graham is a busy boy providing general administration tasks while Sam is credited with the design and build of the site. If you have comments regarding the website please go to: www.donorfamiliesaustralia.org/contact (Website Feedback)

DFA has newly created social platforms on Instagram (@donor_families_australia) and Twitter (@Donor_Families_Australia). Please follow and feel free to contribute.

ERNST & YOUNG REVIEW RELEASED

A national reform program for Australian organ donation, and transplantation was introduced in 2009 by the (then) Rudd Government and was led by two objectives:

1. Increase the capability and capacity within the health system to maximise donation rates, and
2. Raise community awareness and stakeholder engagement across Australia to promote organ and tissue donation.

As detailed on the [DonateLife website](#) (accessed: 23 April 2020): “In April 2018 the Australian Government proposed an independent review of deceased organ donation, retrieval and transplantation to ensure the national health system has the capacity and capability to optimise donation opportunities and access to transplantation for more Australians.”

The review carried out by Ernst & Young (EY), available on DonateLife’s website in February 2020, was specifically designed to look at Objective 1 only.

Of the list of 199 Stakeholders Consulted, (refer page 151) Donor Families Australia was the only donor family organisation interviewed. At this meeting, we were able to put across matters of importance to Donor Families; opening up communication between parties was stressed.

The review contains 57 recommendations. One recommendation in particular — number 26 — if implemented, will make a huge difference to thousands of Donor Families and Recipients.

Recommendation 26 provides that: *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.*

DFA applauds EY for acknowledging that this is a basic right of consenting individuals. EY recognised what this issue is about, that of freedom of choice and the exercising of our human rights.

So many times, we have heard this debate focusing on whether individuals want to meet, when in fact the debate should be about individuals having the right to make the choice to meet. DFA knows Donor Families and Recipients who don’t necessarily want to meet. However, they have told DFA they recognise the right of those who do want to meet.

In recent times, WA has legalised Voluntary Assisted Dying. The WA public were overwhelmingly in favour citizens’ rights in having the choice (80% for; 20% against). It was interesting that the medical association in WA lobbied hard against legislation and the want of the general public.

From stories in the media of meetings between Donor Families and Recipients, it is clear that both sides have a lot to gain. It also shows how the community further benefits from Organ and Tissue Donation by raising awareness.

DFA will be following closely the progress of Recommendation 26 through the Organ and Tissue Donation sector and will keep our members informed.



INTRODUCING NATHAN

As one of a set of triplets (Brian, Adam, and I) with an older brother, Scott, I was never lost for company as a child. We all learned to be competitive and to fight for our lot, but also how to share and support each other during tough times, in and out of school hours. Our mother encouraged the three of us to be independent, and to develop our own personalities and interests. We were spilt into different school classes, and took up separate sports and extracurricular activities - I played tennis and the violin, Adam and Brian both played baseball and soccer, but whereas Brian loved athletics, Adam was our artist.

We weren't always the closest of triplets, but we always supported each other. As we grew older, our separate circles of friends merged together into one enormous group and, to the delight of our parents, we would often host pool parties and 'hang outs' at our house for dozens of our friends.

Adam was always the centre of this group. He was gregarious and playful and compassionate and kind ensured that he was naturally popular (especially with all of the girls). Adam and I had a very close bond after high school, and ended up living together in Brisbane for a few years and really getting to know each other as adults.

It didn't surprise me at all when, in our late 20s, Adam told me that he and his lovely new wife, Lee, had had a heartfelt conversation in which they had both decided to enrol in the Organ Donor registry. They both felt it was a responsible and noble thing to do — the right thing to do — especially as they had decided to try to have children.

It's always horrible and shocking to get "that

call". The day after his daughter's first birthday party, Adam collapsed outside in the Brisbane summer heat, and was rushed to hospital. A brain aneurism had ruptured and caused swelling on the brain, and there was no chance of survival. I remember sitting next to his bed, with Lee and the rest of our family, hoping for a miracle, but knowing, deep down, that my brother and closest friend was going to leave us.



Triple threat: Brian, Adam and Nathan

Adam gave the opportunity of life to five people with the donation of several organs including his heart, liver, kidneys, lungs and pancreas. His departing generous gift to the world filled me with pride in my brother and provided comfort during that incredibly painful time. I enrolled myself on the organ donor registry later that month.

In October 2019, my father decided to attend the Donor Families Australia Conference in

Canberra to honour his lost son, and be part of the community of like-minded Organ Donor family members, and Scott and I went with him. Hearing similar stories from other family members as well as from several recipients brought a sense of camaraderie, knowing there was an organisation dedicated to providing support and understanding.

I am grateful to have been invited to assist DFA as its Social Media Co-ordinator, in order to provide updates to followers and the public regarding DFA's media releases, social events and conferences, and legal and political advances for donors and their families.

Nathan Gale, Social Media Co-ordinator

[See next page for an overview of DFA's social platforms]

OUR SOCIAL MEDIA PLATFORMS



Facebook

[@DonorFamiliesAustralia](#)

General enquires, media releases, upcoming events etc

[@Members:Donor Families Australia](#)

A forum for family members of organ donors to discuss personal events and current political movements associated with Organ Donation



Instagram

[@donor_families_australia](#)

Quick posts of DFA updates, media releases, photos of DFA and affiliates activities etc



Twitter

[@Donor_Families_Australia](#)

Quick posts of DFA updates, media releases, photos of DFA and affiliates activities etc



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

***is it you?**



ON RECOGNITION AND AGENCY

MLA Tara Cheyne describes her recent process in the introduction of new legislation in the ACT — it's a bold and welcome move which DFA hopes is passed into law, and that politicians around Australia take it on board.

On 19 February 2020, I had the privilege of introducing into the ACT parliament the Births, Deaths and Marriages Registration (Tissue Donor Acknowledgement) Amendment Bill 2020. The title of the Bill might be a mouthful, but the premise is straightforward: changing the legislation so that families are able to have the option to record that their loved one was an organ or tissue donor on their loved one's death certificate.

In the ACT there are a number of ways in which organ and tissue donation is acknowledged and recognised, including the annual DonateLife walk, the annual service of remembrance, and the Gift of Life garden at the National Arboretum. However, donor families and advocates—both in the ACT and across the country—have raised with me that, apart from an acknowledgement letter, there are few formal, tangible avenues where the significance of the donation is acknowledged in a personal way. While for some families the acknowledgement they receive is enough, other families have reported that they feel that the significant decision and the significant gift of organ donation are under-recognised. This was really crystallised for me at the inaugural Donor Families Conference in Canberra in October 2019, where I was able to speak to many families who consistently suggested how valuable it would be to have the option to have the act of donation acknowledged on their loved one's death certificate.

Hearing from so many people firsthand was the push I needed to investigate how it could be done—and then do something about it.

Death registration



and certificates—and the legislation and regulations which sit behind them—are the responsibility of each state and territory. I set about drafting a Bill to amend the existing legislation to give families this opportunity, guided by three principles: that the opportunity be optional, entirely up to the family and not-time limited. My aim was to give each family control and agency in deciding if, how and when they wish to have their loved one's donation recognised. I believe the Bill achieves this.

This is how it will work: the next of kin of a deceased person will be able to make a request in writing, together with verifying information, to the Registrar-General that the death register reflect that the person was a donor. Only information that is in the death register can be included on a death certificate issued by the Registrar-General. So, once the Registrar-General has entered this information into the death register, families will then be able to apply for a death certificate which reflects that their loved one was a tissue donor.

I am aware the information that verifies the donation and the donor may change depending on the time and nature of the donation, so I have deliberately not defined what "verifying information" is. However, an example would be an official acknowledgement letter.

Families will be able to make the written request at any time. This removes any urgency in needing to make a decision about it and takes into account



Left and above: Tara Cheyne, MLA

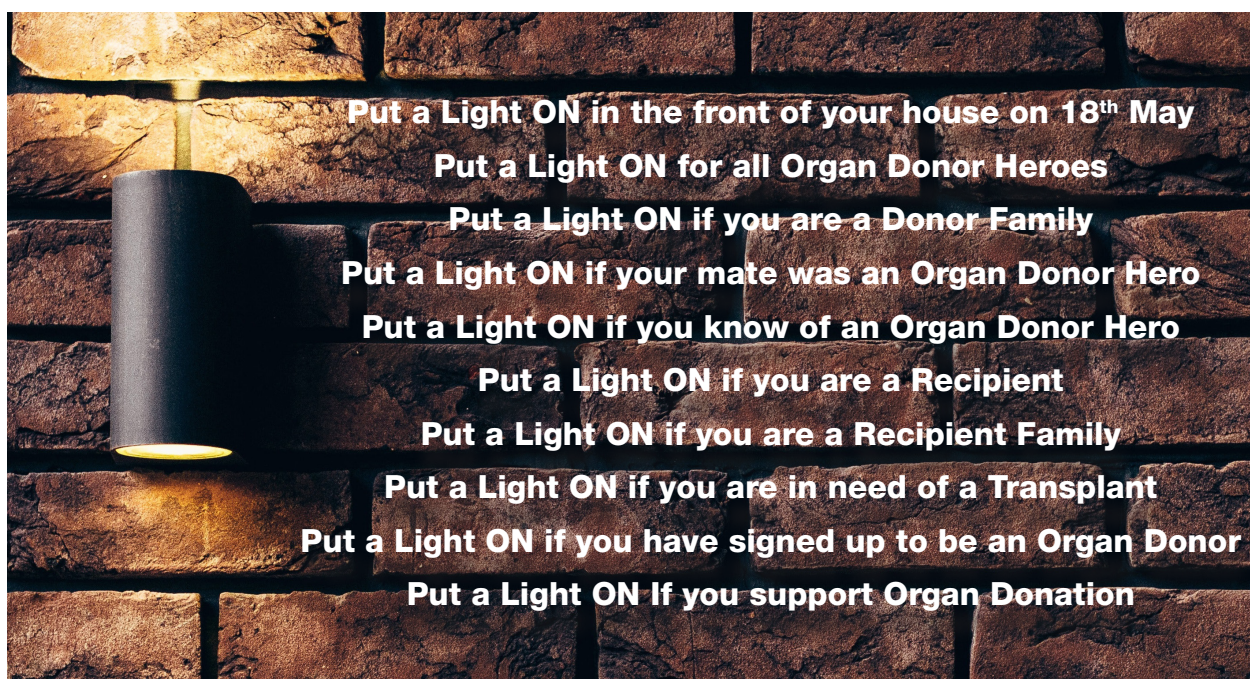
that what might be right for each family can change over time. It also means that families whose deceased loved one was an organ or tissue donor before this comes into effect will have this opportunity, too.

I am incredibly grateful for the support and advice I've received, particularly from families who have advocated, answered my many questions, and shared their very personal stories. Thank you especially to Professor Holly Northam, who is unfailingly generous and responsive with her time and expertise. It was also an honour to have Marjorie and Michael Taylor present in the gallery when I introduced the Bill.

While the pandemic has disrupted our usual parliamentary sitting pattern, I remain hopeful that the Bill will be debated before the end of year—and hopeful that it will be passed. If successful, it may be a template for other states and territories to follow.

Tara Cheyne, MLA

Organ/Tissue Donor Hero Night: 18th May



Following the national campaign to celebrate ANZAC Day with a candle vigil at 6 am, I thought it would be a wonderful opportunity to do the same for our Organ and Tissue Donor Heroes at sunset.

And as my son's anniversary is the 18th May, that's as good a date as any.

So, come the 18th May from sunset, turn on your front porch light or a light in your window or balcony, in recognition of our Heroes who have given the Gift of Life — the greatest gift of all.

Spread the word and come the 18th May, "Put a Light ON".

Supported by Donor Families Australia – Graham Harrison

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

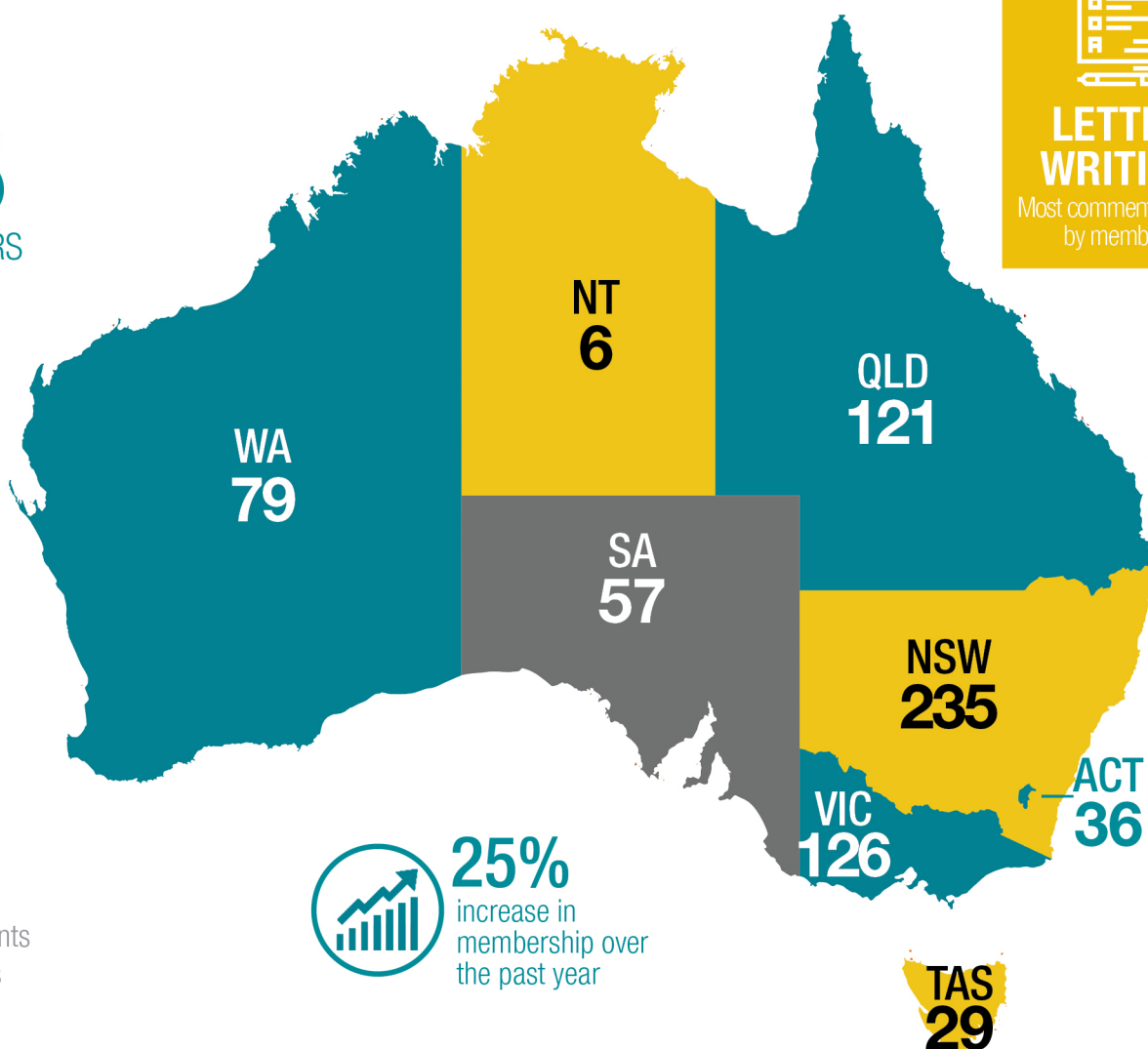
...in 2020

715
TOTAL MEMBERS



LETTER WRITING

Most commented topic by members



3,193

Facebook
Donor and Recipients
Group Members



25%
increase in
membership over
the past year

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