



Donor Families
AUSTRALIA

Donor Families Australia NEWS

Spring 2020, Edition 24

HIGHLIGHTS

Progress in Letter
Writing Process

New DonateLife
sculpture at Perth's
City Beach

Win an eBike with
the Kurri Mongrels
raffle

Join our next AGM
(via Zoom!)

Social Media lately
Death Certificate
Acknowledgement
in ACT

Thanks again, Pfizer

A DONOR MUM'S THOUGHTS ON THE IMPORTANCE OF LETTER WRITING

My name is Vicki. I lost my 23 year old daughter in a tragic car collision in 2016.

Jess was a nurse on her way to work when a dangerous driver on the wrong side of the road hit her car. We sat by her bedside for four days, watching her slip away from life. Jess was a registered organ donor. We were given the choice to agree to her becoming an organ donor if they were unable to save her.

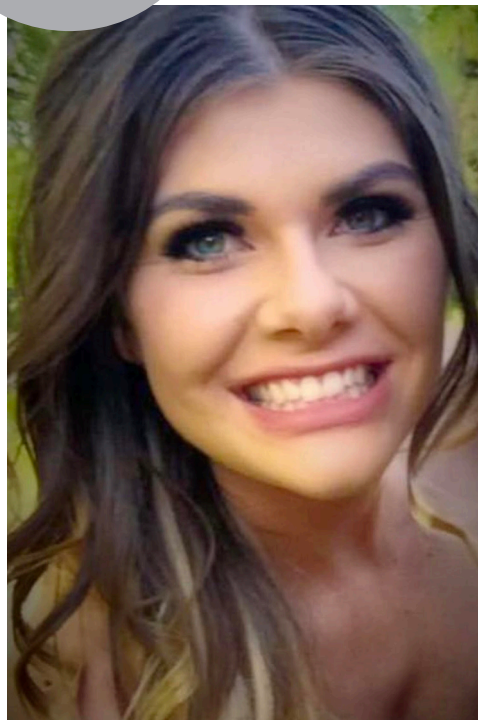
*Share
your
story*

We did agree but I will tell you how difficult the emotions are for a donor family. We tried to put aside our grief for just a moment to understand that our decision will save other families from going through what we were. I tried to imagine a stranger waking after their operation... breathing their first breath with the lungs of my child or feel the beating of my babies golden heart in their chest.

You see: if you have never been through this, I doubt you could understand just how hard it is to walk your child to the theatre doors to become a donor.

I did this from a place in my heart that comes from pure love and kindness for a stranger to live a life taken from my child; after all, I am sharing my beautiful Jess with someone because I believe their life and health are important.

I am in many grief and loss groups on the internet, and learnt so much from recipients



A life that touches others goes on forever

~continued page 2

and how they feel. In all these years, I have only read one person comment they didn't wish to contact their donor family, meaning there are thousands that want to show how grateful they are for a second chance of life. Many have written letters not knowing if they ever reached their donor families, others sharing the joy of hearing back. In return, donor families hoping their letters have been handed on, I have heard from four of the five of my daughter's recipients, and one beautiful lady asking what my child's favourite colour is and favourite flower so she can make a garden in her honour. Letters like this can save the lives of donor families and help with our grief. Even the words "thank you" can help heal our hearts.

Also learning about survivor grief, I know that for many recipients to be able to show their gratitude also helps them mentally cope with their situation.

So I believe it's VERY IMPORTANT that there is a system in place to ensure that letters are passed on in a reasonable time and documented so the writer knows when the letter was delivered. I also believe it's so important for mental health for both parties to agree or decline the passing of letters and the information contained in them, understanding that this information can help people mentally heal and move forwards in their life. I believe that DonateLife can play a huge part in helping this healing process and needs to put this to both sides and let it be the decision of the families involved as no one should have the right to take this opportunity away from them.

I strongly believe that the Organ and Tissue Authority needs to listen to donor families in

relation to the use of first names in the letter writing process. If I can agree to give part of my child to a stranger, I truly believe she deserves the respect of having her first name known to the recipient.

I have spoken to many people about organ and tissue donation and been part of many DonateLife awareness days. From my conversations, I have heard that some people will not sign to be a donor or support their loved ones being an organ donor until the system favours recipients and donor families having more rights to communicate if both parties agree. With a massive shortage of organ donations, I would think this is a huge deal breaker and needs to be taken seriously. The sooner the better because watching people pass away in my groups due to not enough organs, is heartbreaking.

Many recipients, not knowing what to say or how to start a letter in fear of upsetting their donor family, also need some assistance. I have only ever seen total respect shown between recipients and donor families in my groups and helping each other heal and the wonderful stories of new friendships and families finding each other gives us all hope that soon DonateLife will join in helping the healing process for thousands of families and giving them the choices they deserve.

Vicki McLennan (Denniss) and my sweet Jess McLennan (7th March 1993 - 4th June 2016)



*Share
your
story*



CHAIRMAN'S MESSAGE

For as long as I have been involved with Donor Families Australia (DFA), 8 years, the main topic of conversation and source of disappointment has been the handling of letters between Donor Families and Recipients and the block placed on consenting Donor Families and Recipients meeting. As an organisation, we have done our best to improve the communication access between Donor Families and Recipients. We have been able to establish that there is no legal reason why communications in any form can't be established.

I am very pleased to report that the Organ and Tissue Authority (OTA) has actively sought DFA's, along with our members', input into the review of the two Letter Writing Guidelines brochures and Policy Document relating to letter writing exchange. DFA was able to pass on a very comprehensive list of recommendations as provided by its membership. DFA would like to thank all those that gave feedback on the letter writing review. All responses were collated and passed onto the OTA for consideration.

Since our submission, DFA has received a number of updates from the OTA. We have been advised that an important policy improvement will be the introduction of an initial point of contact advising the writer of the letter that the correspondence has been received and forwarded. This inclusion should ensure that writers of letters will know if their letter has been dealt with in a timely manner. In case there is still a problem, the DonateLife web page will be updated with links to the contact details of DonateLife agencies for follow up on the status of correspondence. In this way, we will have a tracking type facility available.

Probably the most important change that Donor Families want to see is the ability to use their loved one's first name in a letter. At this stage, I have been told that this will go to the national group of DonateLife agencies to discuss. Again, there is no law that says this cannot be done; it will just come down to DonateLife policy. As updates come through, DFA will keep members informed with any

changes to the letter writing process.

In this edition of our newsletter, we have a heartwarming story from a Donor Mum on the importance of letter writing for Donor Families. We at DFA will continue to work on behalf our members to help facilitate a letter exchange process that meets the needs of our Donor Families and Recipients.

DFA has been very much at the forefront of getting acknowledgement of our loved ones' donation on the Death Certificate. Our readers will be aware from past newsletters that this has been legislated in the ACT. We are lobbying to get all States and the NT to legislate similarly. We do know that the national group of Births, Deaths and Marriages Registrars have discussed the implementation of acknowledgement on the Death Certificate at their fortnightly meetings.

We have included the DonateLife ACT details for all ACT Donor Families to seek a letter of evidence to present to the ACT Registrar.

Since our last newsletter, the DFA Management Committee held a Planning Workshop via Zoom to prioritise areas to work towards for our members. We also are promoting our eBike raffle that has been organised by the Kurri Mongrels in NSW. A big "thank you" for those members of this club who did a "COVID ride" to help fundraise for our organisation whilst promoting Organ and Tissue donation to the community. More about this and how our readers can purchase a ticket in this raffle is included in this edition.

Congratulations to the City of Cambridge and DonateLife WA on the commissioning of the new statue in City Beach. This is another wonderful way to acknowledge the importance of Organ and Tissue donation to the community



whilst promoting the importance of having a discussion on Organ and Tissue donation with your loved ones.

DFA supported the Organ and Tissue Authority in running a campaign on social media during DonateLife week. It was pleasing to see the number of reaches our message achieved to promote Organ and Tissue donation.

DFA will be holding its AGM on Monday 16 November. We encourage our members to consider nominating where there are vacancies

to fill if they wish to have an active role in supporting other Donor Families.

Our thoughts go out to all our members who have been affected by COVID-19. We wish our members good health.

We hope that when life returns to some semblance of normality, the community's generosity returns to past levels and our Recipient friends can benefit from it.

Bruce McDowell

Chairman

WHAT HAPPENED WHEN DONOR FAMILIES AUSTRALIA MET WITH THE COMMONWEALTH DEPARTMENT OF HEALTH

In August, our Chairman, Bruce McDowell, DFA Committee Member, Philippa Delahoy, and Donor Mum, Tania Teelow, met with two key policy makers at the Department of Health to discuss the importance of letter writing to donor families (and recipients) and the harms felt when the process fails.

Tania beautifully articulated the emotional strength needed to sit down and write letters to her child's recipients and the all-too-familiar toll this has on donor families. She spoke about her fresh grief and damage on discovering her letters hadn't been forwarded by the DonateLife office.

It was critical for the Department to understand the firsthand experience of donor families who have experienced breaches of the letter writing process and the needless pain caused to families who have given so much and deserve every respect and support.

Bruce and Philippa stated that donor families deserve a letter writing process that is well-organised, transparent and predictable, one which is quality-assured and closely monitored to provide donor families (and recipients) with confidence their correspondence is forwarded and received.

All three attendees felt the Department listened to our concerns and more clearly understood the impact of failures in the letter writing process, with a renewed commitment to listening to donor families and DFA in developing an improved process.

The OTA are currently finalising a revised letter writing process, to which DFA has made significant contributions. Thank you to our many members who have contributed their ideas and suggestions to improve certainty in the letter writing process.

Philippa Delahoy



Striking new statue at Perth's City Beach commemorates lives made possible through organ and tissue donation

21 AUG, 2020, CATE TWEEDIE

DFA wish to acknowledge SCOOP Perth for permission to reprint this article:

<https://scoop.com.au/striking-new-statue-at-city-beach-commemorates-lives-made-possible-through-organ-and-tissue-donation/?view=grid>

Take a trip to the City Beach foreshore and you'll notice a new addition to the beachfront: a brand-new sculpture by local artist Simon Youngleson, commissioned by DonateLife as part of their wider social media awareness campaign, the Life Project, with the tag #makethisthemoment. This campaign is designed to encourage community discussion around organ and tissue donation, and to increase the number of registrations on the Australian Organ and Donor Register.

Artist Simon Youngleson with his piece. Images courtesy of Steve Wise from 27Creative.

North of the City Beach Surf Club, the sculpture features three larger-than-life human figures, measuring up to three metres tall and weighing over 400 kilograms. The artist, Simon Youngleson has designed the artwork with the aim to connect visitors and the community space, encouraging people to touch and interact with the piece.

"The three figures are meant to represent

anyone enjoying the spectacular seascape and delighting in the joy of life. They could be family, friends or strangers – anyone. We cannot help but create meaning when we look at human figures in the landscape. What are they looking at? What can they see? What might they say if they could talk? It is my hope that as people interact with the sculpture, it will remind us to celebrate life and reflect on the selfless generosity of organ and tissue donors."

Whilst most Australians are in support of organ donation, only 1 in 3 are currently registered as organ donors. Simon Towler, the acting State Medical Director of DonateLife, said "It is our hope that this unique sculpture will become a discussion point and a catalyst for action. No one should die waiting for a transplant, and we encourage West Australians to make this the moment to register as an organ donor. We acknowledge that this can often be a difficult conversation to have one's family, but we hope it is one that people will choose to have."



"The outdoors and the ocean are intrinsic parts of life in WA, and this iconic position overlooking City Beach is a fittingly beautiful space for the 'Life Project' sculpture."

The sculpture is available for viewing at City Beach any time of day, and if you feel so inclined, it takes 60 seconds to register for organ and tissue donation, through this website.

KURRI MONGRELS RIDE FOR DONOR FAMILIES AUSTRALIA

The Kurri Mongrels Bike Association bike ride for 9th and 10th September, was based at Moonan Flat NSW.

Due to Covid restrictions, only 10 people were allowed.

The boys had some serious tracks to get through, as well as some picturesque countryside. After a hard day riding, The Moonan Flat Pub was very accommodating for the boys.

The money raised from this ride goes to Donor Families Australia. Thank you to the boys who participated.

Jann Eastley



THE KURRI MONGRELS eBIKE RAFFLE

Win a fabulous Cannondale Montera 2 eBike

(\$9,499 value)



GET YOUR TICKETS:

Visit The Station Hotel, Cessnock Bicycle Company or your favourite Mongrel, OR

Purchase via bank transfer:

1. Transfer funds

Name: Brydee Eastley

BSB: 650 000

Account No: 5057 45518

Reference: [Your name]

**Don't forget to enter your name in the reference box!*

2. Once you've transferred funds (Step 1), SMS Brydee, our charity ambassador, on 0421 319 477 (include your name, mobile number and number of tickets required) for cross-referencing.

3. We'll SMS a reply with details of your purchased tickets.

Prize Drawn: 11 December 2020 at the Kurri Mongrels Awards night

Every dollar raised: goes directly to Donor Families Australia

Thanks to: Station Hotel and Cessnock Bicycle Company

DEATH CERTIFICATE ORGAN AND TISSUE DONATION ACKNOWLEDGEMENT

DFA thanks the assistance given to Donor Families in the ACT by Donate Life ACT.

The way the legislation reads in the ACT, for the acknowledgement of donation on the death certificate, it is necessary for the Next of Kin to present evidence to Birth, Deaths and Marriages office of their loved one's donation.

Donate Life ACT "will happily provide Donor Families with evidence required (via letter) ... to amend their loved ones' death certificate to reflect their generous gift."

DFA encourages all ACT Donor Families who wish to amend their loved one's death certificate to contact:

Wendy Barber | Administration Officer
Phone: 02 5124 5625 | Email: wendy.barber@act.gov.au
DonateLife ACT | Canberra Health Services | ACT Government
Building 6 Level 1, Canberra Hospital, Garran | PO Box 11 Woden ACT 2606
www.health.act.gov.au



2,000 REASONS TO THANK PFIZER AUSTRALIA



Donor Families Australia thanks Pfizer Australia for their generous Pfizer CARES community collaboration grant of \$2,000, as part of their corporate social responsibility activities.

For 2020, Pfizer Australia engaged with a number of activities to raise awareness of organ and tissue donation and transplantation and we'd like to acknowledge one of our committee, Philippa Delahoy, for her advocacy within Pfizer.

Donor Families Australia will use this grant to support our members and to advocate for your needs with policy makers and key decision makers.

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

SOCIAL MEDIA ENGAGEMENT

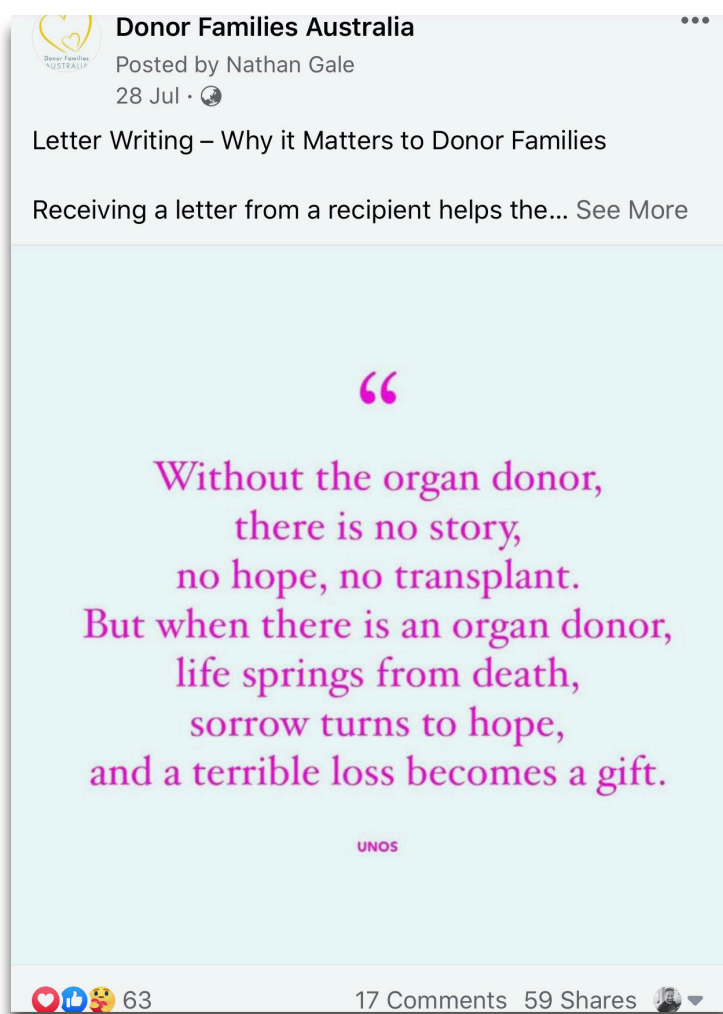
Donor Families Australia was very active during DonateLife Week this year (26 July-2 August) posting daily articles, memes and memoirs to our social platforms and webpage.

We placed strong emphasis on the need to *'Have the conversation'* with loved ones about your desire to register as an organ and tissue donor, along with the impacts to organ and/or tissue donor family members, and the benefits associated with letter writing between family members and recipients.

DFA also promoted the recent success of our inaugural 'Light the Night' event in May, commemorating the loss of loved ones who generously gifted life to others in need.

DFA's campaign during DonateLife Week was a huge success. We estimate DFA's posts reached in excess of 13,000 people, with more than 2,000 engagements (comments, likes and shares). We plan to continue active participation in future DonateLife Weeks, promoting donor family member impact awareness and 'Having the conversation' to register as a donor.

Nathan Gale



Please connect with us:



@donor_families



/DonorFamiliesAustralia



@donor_families_australia



AGM

Annual General Meeting

Time/ 8 pm Australian Eastern Daylight Time (Sydney)

Date/ Monday 16 November, 2020

Venue/ via Zoom (RSVP to get the link)

Committee Nominations/ To nominate for a committee position, please email us: admin@donorfamiliesaustralia.org

RSVP/ Email: admin@donorfamiliesaustralia.org
by Monday 9 November, 2020



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

***is it you?**

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

Support

Advocate

Educate

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

Advocate and give donor families a voice

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

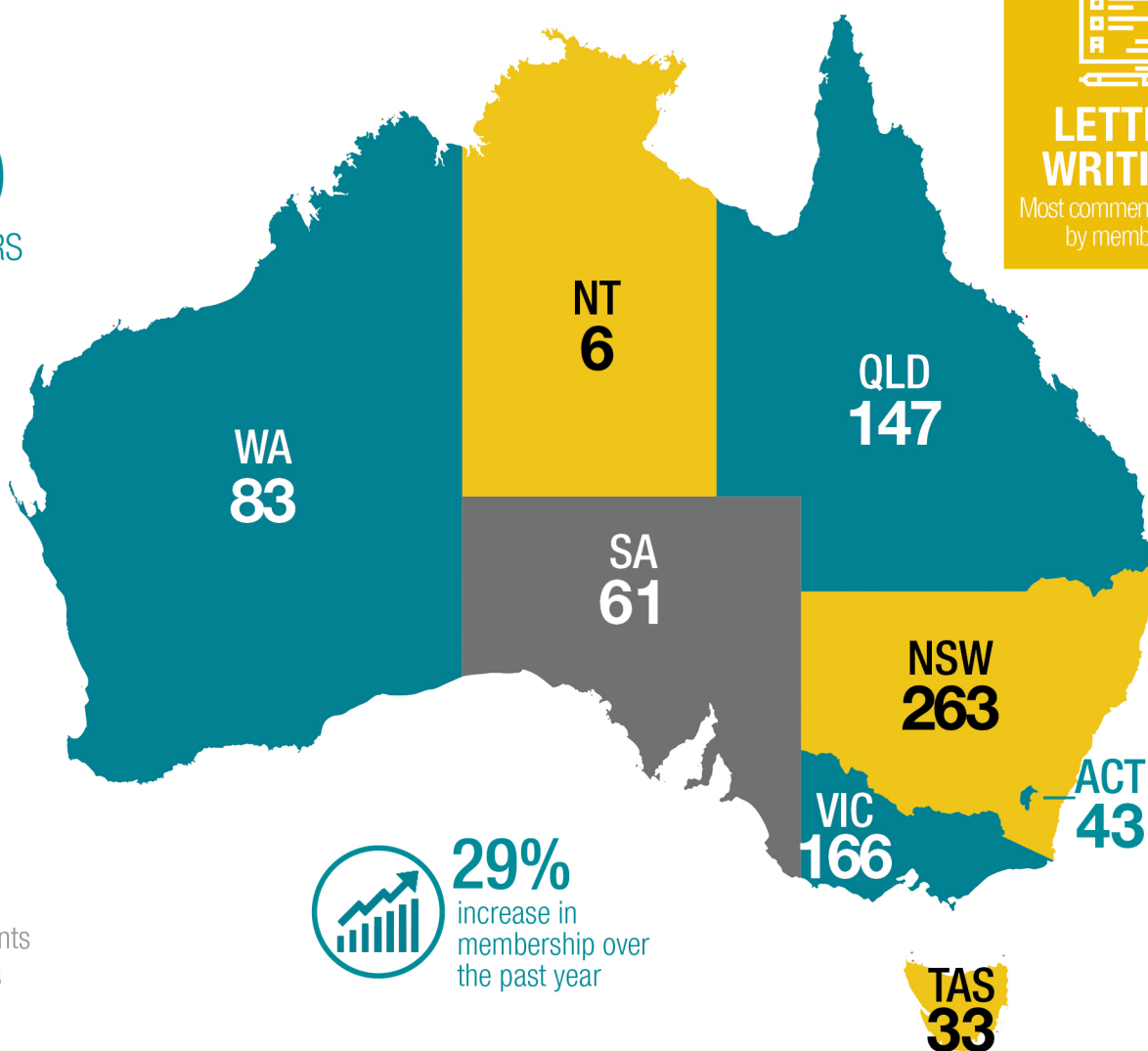
...in 2020

829
TOTAL MEMBERS



LETTER WRITING

Most commented topic by members



3,359

Facebook
Donor and Recipients
Group Members



29%

increase in
membership over
the past year

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