



Donor Families
AUSTRALIA

Donor Families Australia NEWS

Autumn 2023, Edition 30

HIGHLIGHTS

Join Donor Heroes
Night 2023!

Donor Family and
Recipient meetings
profiled on TV's SBS
Insight

2022 National
Donation Consent
Rates

LOUISE: BEYOND LOVED ANGEL AND PRINCESS

My "beautiful" wife, Louise, passed away at the age of 44 in April 2014.

Louise would have wanted to help as many people as best she could. Louise was an extraordinary and special woman and the most fabulous mother of two wonderful boys.

One has recently finished university and his younger brother has recently enrolled at Latrobe University. They both adored their mother, and their lives revolved around her. The hugs, joy, laughter, and special moments that we all shared were something to behold. Louise lived for her boys and they were her true joy in life!

*Share
your
story*

Her favourite time of year was Christmas. That special family time, particularly with the boys, was especially important to Louise. The love in our home grew at that time of year. It was as if her love for everyone increased even more.

Louise was a psychologist. She had started her doctorate when she passed away. It was her dream to be called Doctor Louise, but unfortunately it was the one big thing that she was not able to tick off her bucket list.



Helping others as a counsellor was something that Louise enjoyed immensely. She had the ability to see the good in everyone, and at the same time she was able to touch everyone in a very personal and loving way. Louise was a positive influence on so many others she met. She had a gift that is impossible to describe and had a way of touching people that I have never seen before.

Celebrating
10
2013-2023



A life that touches others goes on forever

~continued page 2

~continued from cover

Even the ambulance officers that treated Louise came to the ICU to see how she had fared. They were visibly touched by her in the hour they met her and were noticeably upset when they found out that she was going to pass away. People who met Louise described her as an angel.

Louise was a princess. It was impossible for her to leave the house without makeup, or her hair being done. Her hair dryer was the most used electrical item in the house. The boys were regularly late to school just because Louise took so long to get ready in the morning. She wouldn't even go to the letterbox without being properly dressed. She hated the rain as her hair was naturally curly and the thought of her hair getting wet and all frizzy drove her crazy. Louise carried spare umbrellas everywhere, including at least three in her handbag!

On behalf of Louise, I can ask you only one thing: make your life extraordinary! Be the best that you can be in everything you do. Love and cherish those around you every single day. Tell those that you love how you feel every chance you get. Get out and enjoy everything that this wonderful world has to offer. Travel, live, and experience something new every day that you can. LOVE someone with all your heart and soul.

I do not feel guilt, or anger, or sadness because Louise's donor recipients are alive. They uplift me, and our family, by being here. They give me strength. They give me a reason to go on, to smile and be happy.

We ask that all recipients honour Louise and all other donors by living your life to the fullest. You are alive, so live! Hopefully Louise has made it possible for some of you to live out your dreams, as she did with everyone she met while she was with us. Do not let any guilt stand in your way. There should be no guilt. Live life, smile, be happy, and most importantly, love! Never, ever, stop loving. By loving, you give Louise and all our family love in return.

Donor Families Australia encourages all recipients and their family members to celebrate with us on Donor Heroes Night.

For more information visit:
donorfamiliesaustralia.org/



*Share
your
story*





Social Media Hastags:

- #DonorHeroesNight
- #DonorHeroes
- #DonorFamilies
- #leavealighton
- #forevergrateful

CHAIRMAN'S MESSAGE



Welcome to the Autumn Edition. Our Donor loved ones are always close to our hearts and thoughts. In this edition, we highlight Donor Family Australia's (DFA) and the Organ and Tissue Donation communities' largest display of gratitude to our hero

Donors in the form of Donor Heroes' Night. On 18 May, DFA will call upon the Australian community to turn on a light to show your gratitude to our hero Donors for the wonderful gift of life and life-changing donation to those in need. This evening also raises awareness of Organ and Tissue donation to the wider community.

Once again, Graham Harrison has put together a programme that is hoped to reach hundreds of thousands of Australians. In this, its fourth year, DFA is hoping for the continuation of record numbers reached. Please read our included articles on how you can actively take part and we look forward to seeing your light on the DFA's Facebook page.

Our cover Donor story is about Louise Lowe. John, Louise's husband, has given us the story of beautiful wife and mum, Louise. Her family was everything to her and it shows through her love of her two boys. John tells Louise's Recipients not to feel guilt and to live life to the fullest. Thank you, John, for sharing this story.

A few weeks ago, SBS's *Insight* programme did a story called Transplant Breakthroughs. You can watch it online at: sbs.com.au/ondemand/news-series/insight/insight-2023

DFA members, Linda and Peter Spencer, appeared with their Recipient, Peter, on this *Insight* programme. Please read Linda's account of her and husband, Peter's, experience on the show. I particularly appreciated Peter (Recipient) saying how meeting the Spencers had helped with his survivor guilt.

DFA members again have been well represented in another TV Donation story, ABC's *Compass*.



At this stage we don't know when it will be broadcast but we will let members know when we are advised. DFA members have been interviewed and hopefully our Donor Heroes will be featured.

In collating stories and photos for *Compass*, DFA has been able to put them all together on 'Our Stories' and 'Virtual Donor Wall'. Please click this link to view those photos and stories: donorfamiliesaustralia.org/our-heroes. Our Virtual Donor Wall is a lovely tribute to our loved ones. To submit your story please go to the same link.

As a Donor Family, it's wonderful to see so many Recipients partaking in the World Transplant Games. It's our wish that Recipients are fit and well enough to partake in everyday life. Our loved ones would be happy to see such an example of making the most of the gift that they've received.

Over the period of the Games, we would expect to see a rise in the donation and consent rates because of the high media exposure. The real test will be twelve months after the Games to see if there has been a lasting improvement.

The month of May will mark two years since DFA took Lavan's legal advice to the Labor Government in Perth. Lavan's advice went on to say that the family cannot make their loved one's information publicly known. Since that time, sadly, the Labor government in WA has done nothing other than to let me know that they won't prosecute me if I choose to talk

about my loved one as long as I follow their conditions given. It's probably no surprise that WA has a consent rate of 50%, the lowest of any state. Full marks to the ACT parliament for ensuring Donors and their Families are respected by its amendment to its Anatomy Legislation, allowing Families to speak on behalf of their loved ones.

A demonstration of loss of confidence in the Organ and Tissue Authority (OTA) is the fact that there are currently two inquiries going on around the country into the performance of the sector. The 2022 national consent rates are the worst in the OTA's history.

Perhaps the message here is that governments and bureaucrats need to be listening to Donor Families. The time has come for them to stop blocking and start listening. When your numbers are as bad as they are, you must know that your approach is not working.

DFA will continue to advocate on behalf of its members. We welcome all feedback from our members. I look forward to seeing the Donor Families and the wider community unite on 18 May to acknowledge and celebrate the wonderful gift and legacy our loved ones have made.

Bruce McDowell

Chairman

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

INSIGHT TO DONOR FAMILY EXPERIENCES

Peter and I were invited to participate in the SBS *Insight* program about Organ Transplant breakthroughs, which was aired on Tuesday 28 March. We were there to give our thoughts and experiences as a donor family, explains Donor Mum, Linda Spencer.

The program featured two women who had received a donor uterus, a man from America who had received a penis, another man who had a new hand, and a man who had received a heart in 2018, through the 'Heart in a Box', dead heart transplant breakthrough, first trialed in 2014.

Our son, Bill's, dead heart was the second ever in the world to be used in this experimental trial in October 2014. We met the man who received our son's heart; however, he was unavailable to appear on the SBS show with us.

Also with us on the SBS panel was the man who had received our son's lungs. We tracked this man down on a Facebook site about 14 months after he received his gift of life. He had made a comment on someone else's post which sparked my interest. The post went something like: "Has anyone out there said thank you to their donor family yet, it's been 20 years and I still have not found the words to write a thank you letter".

This man replied with: "I had a double lung transplant just over a year ago and I have received two letters from my donor family, and I've written one to them". This information matched our circumstances. He had mentioned in his letter that he had a grandson born during the time he was having his transplant.

I investigated further on his Facebook page and found a picture of a young woman with a small toddler on her lap. This seemed to match the information in his letter, so I sent him a personal message asking him if he had his transplant on the date that our son died. He replied that it was the correct day. We then compared the letters we had sent to each other through DonateLife, and they matched.

He was so excited to have found us that he and his wife drove from the Blue Mountains to Canberra the following weekend to meet us.

It was emotional and exciting for both sides. He told us about being attracted to horses after the transplant whereas, before, he had hated them. He told us his grandson that was born while he was having his transplant was named Logan and we told him Bill owned a horse named Logan.

We listened to him describe his feelings of survivor guilt and were able to assure him that we were happy for him to be alive because of our son's gift. Our son was not going to survive and didn't need his organs anymore. He was going to the grave, with or without his organs. It made so much sense to us to try and help others at death's door; to give them a second chance at life. Something our son, Bill, didn't get.

He found our meeting to be very helpful in processing his feelings of survivor guilt and we were all amazed at the horse connection.

We have kept in contact over the years. He and his wife have visited Canberra on several occasions to participate in the Gift of Life Walk around Lake Burley Griffin with us. We have met them at the Arboretum where there is a Gift of Life memorial garden that we visit. We have visited them at their home in the Blue Mountains and spent a couple of nights caravan camping with them at the South Coast of NSW. Finding each other has been beneficial for all of us.

The SBS program can be watched in full on SBS On Demand, or the cut down version just relating to dead heart transplant, us, and the lung recipient can be viewed on the Facebook site "[Be Like Bill, Be a Hero](#)".

Linda Spencer



The Spencers with Bill's Recipients and SBS Presenter



View SBS *Insight* "Transplant Breakthroughs" episode:
[sbs.com.au/ondemand/news-series/insight/insight-2023/
insight-s2023-ep6/2179498563752](https://sbs.com.au/ondemand/news-series/insight/insight-2023/insight-s2023-ep6/2179498563752)



Bill Spencer, Donor Hero



Thursday 18 May 2023

As Donor Families Australia's Donor Heroes Night draws closer, the event — now in its fourth year — looks set to surpass all previous records across all social media channels, nationally, and for the first time, internationally.

Donor Families Australia has long recognised that Australia's Organ and Tissue donors are our Heroes within the Organ and Tissue transplantation community. Donor Heroes Night enables Donor Families, Recipients, and the Australian community to celebrate, commemorate, and acknowledge all Organ and Tissue Donors who have given the Gift of Life. A gift that has saved or greatly improved the lives of tens of thousands of Aussies over the past four decades.

This year's event also seeks to raise the profile of Organ and Tissue Donation across the broader Australian community.

Following the nation's highest yearly donation rate of 22.2 donors per million population (dpmp) back in 2018, we've seen a drastic decline with the rate dropping by 22% in 2022, to 17.34 dpmp. This is even less than the 18.3 dpmp achieved in 2015.

In 2022, many developed countries achieved record numbers of donations; sadly not so in Australia.

Donor Heroes Night also provides the opportunity for families to have the all important conversation when a family member wishes to become a Donor — and to register with the Australia National Organ and Tissue Donor Register.

Donor Families Australia is, therefore, calling on all supporters of Organ and Tissue Donation to become involved by promoting Donor Heroes Night, wherever and however possible, by posting your support on Facebook, Twitter, Instagram, and YouTube.

This year, Donor Families Australia, is encouraging both national and international participation in Donor Heroes Night. As a result, 18 international organisations and associations have been sent invitations.

If any members have international contacts that you think may be interested in being involved in Donor Heroes Night, please email the Donor Heroes Night team at: admin@donorfamiliesaustralia.org

To assist you in advertising the event, our **Donor Heroes Night Flyer** pdf can be downloaded from our website at donorfamiliesaustralia.org/donor-heroes-night

Donor Families Australia invites you to

Leave a light or candle on for Donor Heroes' Night 18 May 2023

Turn on a light:

- for all donor heroes
- if you are a donor family
- if your mate was a donor hero
- if you know of a donor hero
- if you are a recipient
- if you are a recipient family
- if you need a transplant
- if you have signed the National Organ/Tissue Donor Register
- if you support Organ/Tissue Donation.



Celebrating Organ and Tissue Donors

Donor Families Australia

proudly invites you to join thousands of Australian households who will be leaving their light on for **Donor Heroes' Night**.

Held on the evening of **18 May 2023**, Donor Heroes' Night is a dedicated event which honours and commemorates all organ and tissue donor heroes as well as highlighting the importance of organ/tissue donation within the community.

Your involvement means a great deal to all Donor Families

Donor Heroes are the 25,000 men, women and children who have given the gift of life and or improved life by donating their organs and tissue.

Support organ and tissue donation and take part by simply adding a photo of your light/candle and/or your donor hero supported with a comment on the DFA Facebook page and tagging **Donor Families Australia** or via the internet at Facebook.com/DonorFamiliesAustralia



DFA is celebrating 10 years of service to Donor Families and their recipients

For more information, head to: www.donorfamiliesaustralia.org/donor-heroes-night or contact Graham Harrison or Bruce McDowell at admin@donorfamiliesaustralia.org

Donor Families, recipients and the supporting public are welcome to join DFA
Donor Families Australia Incorporated, Charity Registered, ABN 54426172274
Donations to DFA for the support of its donor family membership is available through the DFA website

www.donorfamiliesaustralia.org

[Get the Flyer \(pdf\)](#)

Australians urged to have family conversation for Organ/Tissue Donation



While the event revolves around celebrating our Donor Heroes, the aim is also to raise organ and tissue donation awareness within the Australian community. Mr Graham Harrison, Event Coordinator of Donor Heroes Night, stated that: "As a result of this event, Australians may be more inclined to consider becoming an organ and tissue donor following their passing."

The need is currently far greater as a result in the decline in donor/ transplant activity. According to data released in 2022 by the Department of Health, Australia has recorded a 22 per cent drop from its highs in 2018 in the donation rate. In the same release, 2022, we see a national consent rate of 54%, possibly the lowest ever in the history of the Organ and Tissue Authority at a time that other developed countries are achieving record donation rates.

For Graham, the task of raising awareness about the importance of tissue and organ donation hits close to home. Graham donated the organs of his ten year old son, Ben, in 1993 after Ben died unexpectedly during surgery. To commemorate the contribution that Ben and tens of thousands of other organ and tissue donors have made to the lives of their recipients, Graham leads a team from Donor Families Australia which runs the annual Donor Heroes Night event on May 18 each year – the anniversary of his son's passing.

Donor Heroes Night is a great opportunity for Australians to get behind tissue and organ donation by sharing stories of their donor heroes. Each year, many hundreds of participants head online to facebook.com/DonorFamiliesAustralia with the intention of 'leaving a light on' for our Donor Heroes. All visitors are encouraged to upload a picture of their porch light or candle and add a note of remembrance or gratitude for their Donor Hero. Last year, the campaign had 260,000 active supporters, and Graham hopes for an even better turnout this year.

Graham and other Donor Heroes Night supporters are buoyed by recent reports that organ donation registrations are now increasing. "I want to offer a sincere 'thank you' to everyone who says yes to tissue and organ donation as over 1,750 Australians are currently waitlisted.

"I encourage everyone to have a conversation with their loved ones about their wishes to donate, take the time to understand the process and be sure to register your intent on the national organ donor registry," he said.

Further information on Donor Heroes Night and the benefits of organ and tissue donation can be found online at: donorfamiliesaustralia.org/donor-heroes-night

Associated hastags:

#DonorHeroesNight #DonorHeroes #DonorFamilies #leavealighton #forevergrateful

This is the first of a series of three Donor Heroes Night Media Releases, all available from our website at: donorfamiliesaustralia.org/donor-heroes-night

HOW TO: Posting on Donor Heroes Night

The following steps provide some guidance in posting a photo and comment on Facebook for Donor Heroes' Night:

Step 1.

Once your photo of your porch light or candle is taken, transfer it onto your computer. If using your phone to post, this step is not required.

Step 2.

Log into DFA's Facebook Page (facebook.com/DonorFamiliesAustralia) from your internet browser OR if you're already logged into Facebook, enter "Donor Families Australia" in the Facebook search field.

Step 3.

Having completed Step 2, you'll see the following Donor Families Australia Facebook header which confirms you're at the correct Facebook page.



Step 4.

Proceed our post inviting all participants to post their photo and commemoration comment. Note: the heading pictured will be "pinned" to the top of the page for easy location.

DONOR HEROES NIGHT
18th May 2023
Post your Photo and
Commemoration comment below

Step 5.

Click **Comment** under the Post heading above to initiate your donor hero post, then click on the camera icon to add your photo, and complete your comment.

Step 6.

To add an additional photo (eg: your donor hero loved one) under your own post, click **Reply** to add your own personal photo.


DONOR HEROES NIGHT 2022


Here's a small sample of the many beautiful and heartfelt posts on our Facebook page from Donor Heroes Night 2022



 **Rebecca Louise Free**
My light shines bright for my beautiful Mum Maureen, who gave the gift of life to five others on 4.3.2010. We love you so much Mum and miss you each and every day xxx





Love Reply Hide 41w 



 **Author**
Donor Families Australia
Donor Families Australia has always believed that our loved ones are Donor Heroes within the Organ and Transplant System. Ben has been my Donor Hero on this night for the past 29 years having saved the life of a middle aged gentleman and a 12 year old girl at the time. On behalf of all Donor Families I say "Our Donor Heroes will never be forgotten". Donor Heroes Night is for you Ben and the approximate 25,000 organ and tissue donor that have given the "Gift of Life" over the past 40 years.



Love Reply Commented on by Graham Harrison  41w 

 **Author**
Donor Families Australia
My Donor Hero, my mate, missing you - Mum and Dad



Like Reply Commented on by Graham Harrison  41w 



Robyn McCanna

My porch lights are on shining pink in loving memory of our beautiful daughter/sister/sister in law & Aunt Sally McCanna who gave the gifts of her heart, kidneys, pancreas & liver on the 12th May 2014 ❤️❤️
Also remembering Lui Polimeni, Julia Kovacs, Bill Spencer, Harry Laurie & Andrea Dotta, all beautiful hero's who gave the ultimate gift when they couldn't stay xxxx



Love Reply Hide 41w



Robyn McCanna

Steven & Maria honouring his sister & SIL with their pink porch light. My beautiful grandchildren Lucas, Sally & Ava showing their love & support of their angel Aunty Sally McCanna ❤️❤️❤️❤️❤️



Love Reply Hide 41w



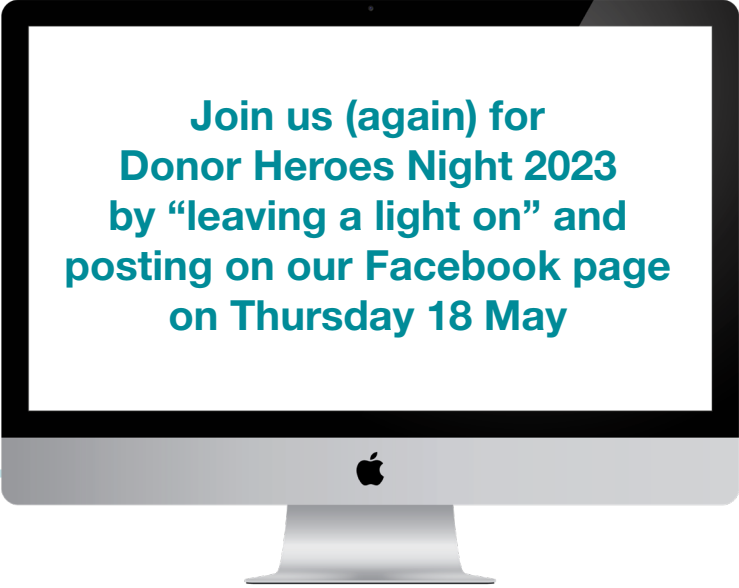
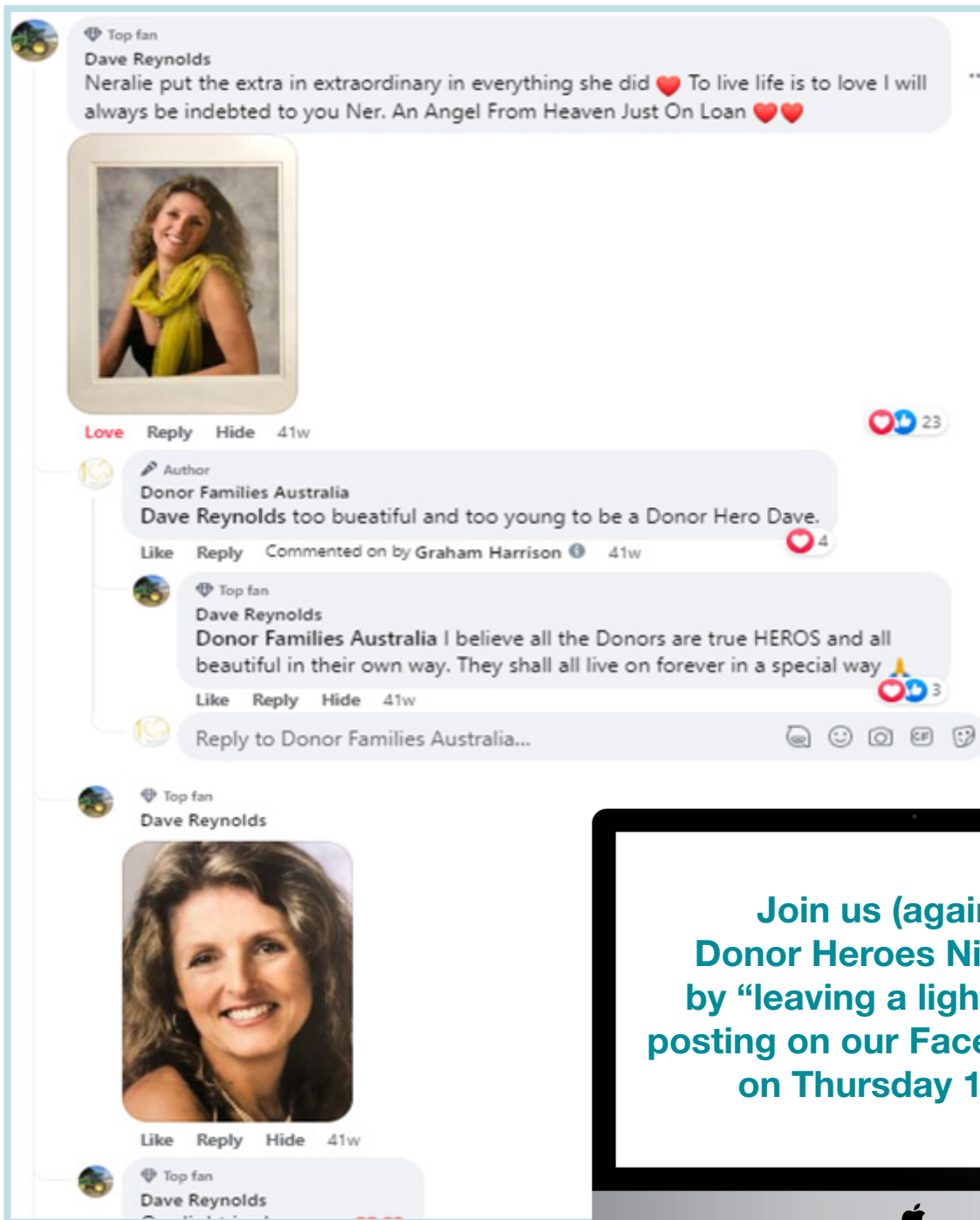
Janelle Colquhoun

Tonight, on Donor Heroes' Night, I'm commemorating the living and deceased people who have saved so many lives by donating organ and tissue. I've lit a candle in honour of my anonymous donor hero, who was 27 when she passed away, but has given me so far an additional 14 years of life. Thank-you to my Donor Hero for this incredible gift, and to her amazing family who made the decision to donate at such a terrible time in their lives.



Love Reply Hide 41w





Additional References



WEBSITE: donorfamiliesaustralia.org



TWITTER: @donor_families



WEBSITE: donorfamiliesaustralia.org/donor-heroes-night



FACEBOOK: /DonorFamiliesAustralia

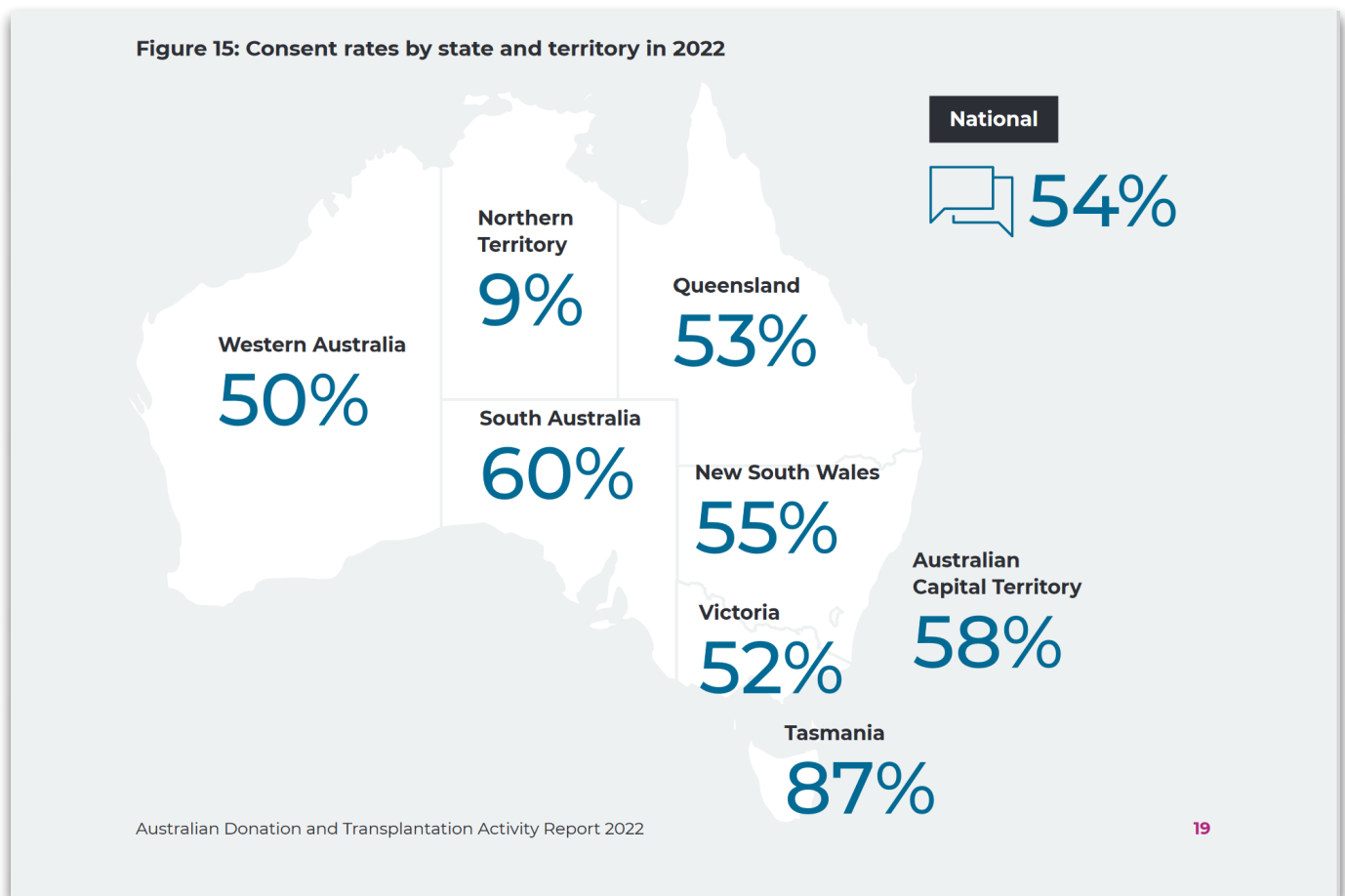


WEBSITE: donorfamiliesaustralia.org/the-virtual-donor-wall



INSTAGRAM: @donor_families_australia

AUSTRALIAN DONATION AND TRANSPLANTATION ACTIVITY REPORT 2022



Australian Organ and Tissue Donation and Transplantation Authority. (2022). *Australian Donation and Transplantation Activity Report 2022*. Canberra, Australia.

The *Australian Donation and Transplantation Activity Report 2022* was released on 20 February 2023 by the Minister responsible for DonateLife.

These figures are nothing short of disturbing. (Donor Families Australia would like to point out that Tasmania is a standout with its high consent rate and deserves to be congratulated). The national figure is the lowest in the history of the Organ and Tissue Authority (OTA).

Whilst other developed countries such as America and Italy are recording record numbers of donations in 2022, Australia is languishing far behind. Sadly, these low numbers translate into lives lost.

It really is time for governments and bureaucrats to start thinking of other strategies to increase consent rates. For the ten years that Donor Families Australia has been operating, we have only heard one strategy from the OTA: increasing registration rates. It is clearly not working. It's time to start reinvesting the millions of dollars spent on promoting the need to register into other strategies.

What's interesting is that two states have called for inquiries into how they can get consent rates up. Donor Families Australia looks forward to being involved in these and any future reviews to help in this area.

OUR VISION

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



Donor Families AUSTRALIA

Care

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

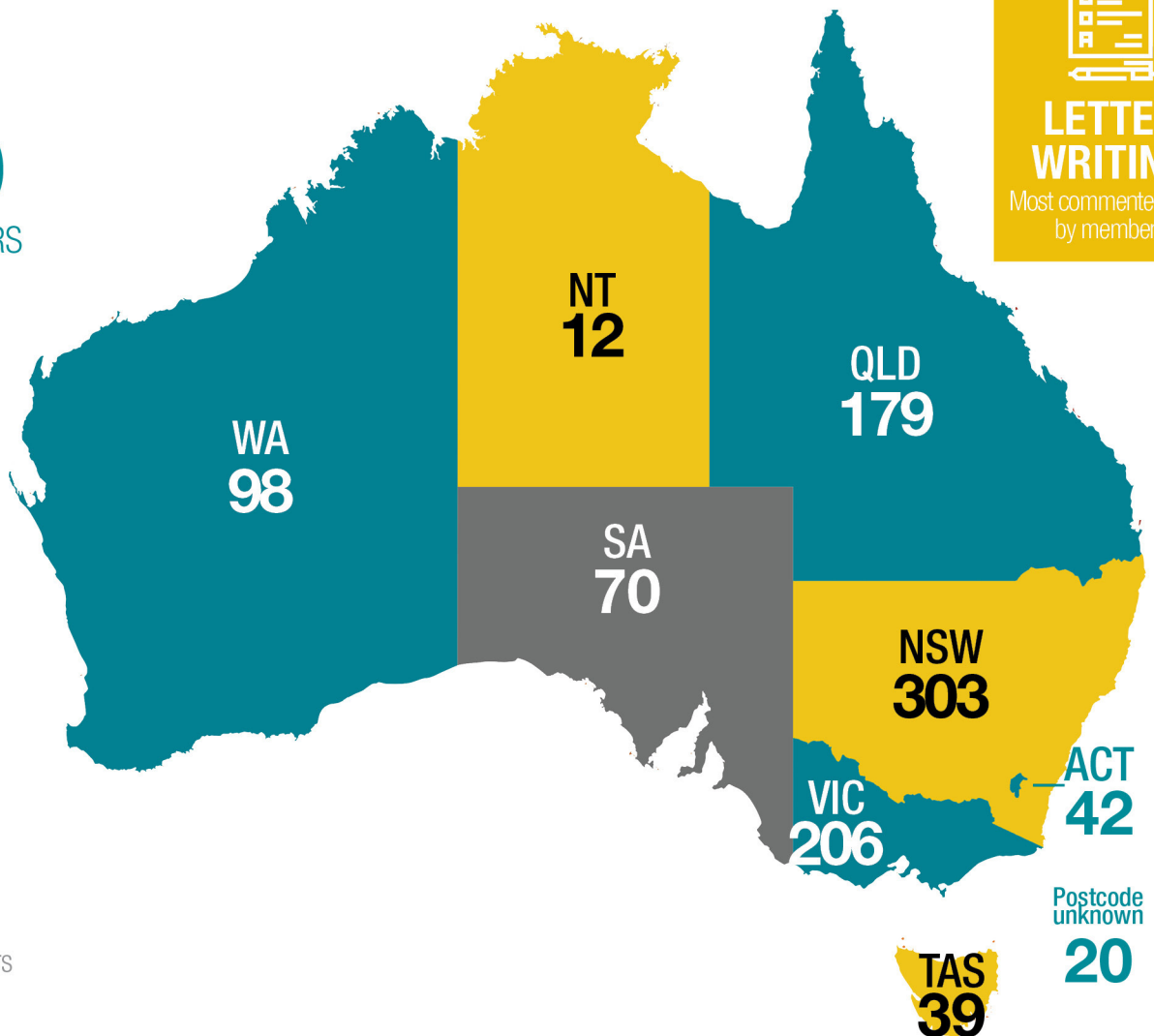
...in 2022

969
TOTAL MEMBERS



LETTER WRITING

Most commented topic by members



2,780

Facebook Donor Families Australia followers

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