

### HIGHLIGHTS

Special Donor Heroes' Night edition (it's nearly here!)

Donor Families Get Together

Transplant Games planning is underway

# Donor Families Australia IN E Model Autumn 2022, Edition 28

## IN LOVING MEMORY OF MUM, PHYLLIS MARY EDWARDS

I am pretty lucky to have retained many memories of my mother *Phyllis.* 

Mum and Dad met via the PMG work, nowadays called Australia Post. Dad used to deliver telegrams and Mum was a telephonist. Moving on several years, and Mum and Dad had married and now lived at the post office in Safety Bay and Roebourne in WA.

We then moved to Killarney where my Dad joined the RAAF, and later to Penrith NSW. It was here that Mum became

Share your story a huge Penrith Panthers fan. She certainly was vocal and to this day I swear that I could hear her cheering even when I was under water at the swimming pool next door. She really enjoyed sports and was very involved in following us in our chosen fields. Mum was very sporty in her youth and enjoyed cross country running. Both her and dad were very graceful on the dance floor and she



used to wear very high heels.

One thing she was NOT was a good cook. She struggled with even basic cooking and OMG, the way she used to do cabbage was indeed different; she would boil it for a couple of hours and then, to add flavour, she would add a teaspoon of vegemite. As kids, we didn't notice cause that was what we were used to.

She adored watching the soap operas and often, the neighbouring women would congregate at our place for the couple of hours between lunch and kids home time,

A life that touches others goes on forever

mesmerised by the stars on the TV. Days of our Lives was a fav of hers along with Coronation Street.

My siblings remember Mum as always having the time to do jigsaws with them, coming to soccer and rugby games, scoring at netball games, and that she was a subtle encourager to all the children. Family was very important to Mum and our house was often filled with laughter as she and our Aunties played darts on the porch and canasta games in our Nanna's sunroom. We loved the closeness she had with her siblings.

The day she died is vivid in my mind. My cousin called me from Fremantle Hospital and told me that Mum was not well. I was in panic mode and lucky for me, my husband had just pulled up in the driveway.

Just as we were approaching Leach Highway, a terrible calm overtook me and I told my husband to slow down as it was too late... Mum was dead. He didn't believe me, but I knew it to be true.

At the hospital she was in intensive care. Cyril, mum's partner, was in the ICU waiting room. Family had started gathering there. I waited outside and paced the hallway waiting for news of mum. I am not sure of the timespan but the next day we were asked what we thought of Organ Donation. It was the only thing that made sense of a senseless death, so Mum donated her heart, lungs, kidney and tissue. I am so glad that her organs could be used to save someone and give them quality of life. The man who oversaw the retrieval of her organs was such a lovely man.



Share your story

I had no idea that emotional pain could go so very deeply or that I could cry so many tears. Never will I feel her arms around me or feel her fingers run through my hair. No more of her loud laughter or late night calls. How can I bring back the past and change the pain we caused each other? We can't but it was so special to be there when I was needed most.

The last couple of years had been difficult for us BUT I know she loved me, and I hope she knows just how very much I love and miss her.

Coral



📿 A life that touches others goes on forever

# **CHAIRMAN'S MESSAGE**

Welcome to our special edition of our Newsletter for the Donor Heroes' Night. This is Donor Families Australia's third night where we celebrate our Organ and Tissue Donor Heroes. Our Donor Heroes are responsible for saving and improving thousands of lives and so many more through the ripple effect. The community can show its appreciation by the simple action of turning on their front porch light on the 18th May.

Donor Families Australia congratulates our hardworking committee member Graham Harrison for getting this evening off the ground. It all came together three years ago when Graham came up with the idea and it was decided to hold this event on his son Ben's anniversary as the date to remember Ben and all Donors, and to help raise awareness of Organ and Tissue Donation.

Every year, we have seen remarkable increase in people taking part. This year has already seen large numbers of people responding to Donor Families Australia's early posts. What makes this all that more remarkable is that Donor Families Australia has been able to do this totally through the voluntary work of its Donor Family and Recipient network. A special thanks to Graham's committee of hard workers, and Dr Leanne Downing from Media Affect.

This year's event has seen such new inovations as the lighting up of the City of Perth Council House in the middle of Perth's CBD with Donor Families Australia's logo. We have spectacular photos and videos of this Light Show in this Newsletter, Donor Families Australia Website, and Facebook pages. A big thank you to the City of Perth for helping us promote the good that Donors do. With the help of Jayden Cummins, filmmaker and Recipient, our videos took on a new professional look.

Please participate with a photo of your front porch light and post the picture on our facebook page as per our flyers. Get your family and friends to join you. Ultimately we want this to be an awareness event where families can have an important discussion on Organ and Tissue Donation and let each other know if they want to be an Organ and Tissue Donor. WA held a picnic for those that wanted to come together and talk about the Donor Hero Night. Living Donors, Donor Families and Recipients were represented.



To celebrate Mother's

Day, we have Coral's tribute to her Donor Hero Mum. Read what Coral's Mum meant to her and her siblings.

Anthony Cignarella PhD Candidate has been contacting many of our members regarding his study – The relationship between organ donor families and transplant recipients: An exploration of societal perspectives. This is very important work, and we encourage all those who have put themselves forward to complete Anthony's interview process.

The following hyperlink is to a news article recently published in Canada:

#### https://news.westernu.ca/2022/04/organdonation-anonymity/

It talks about where Canada is at with consenting Donor Families and Recipients meeting. It also includes a very interesting video. It would seem the world is changing, and it could be time for Australia to catch up.

We also have a Facebook post from Tara Cheyne MLA for the ACT. Tara has been responsible for some of the most significant legislative changes in Australia on behalf of Donor Families. In reading this post, Tara is continuing her advocacy for Donor Families. Hopefully we will see jurisdictions around Australia amend their Human Tissue Acts so that Donor Families can freely speak about what their Donor heroes have done without fear of prosecution. Thank you, Tara, for your ongoing support.

I look forward to celebrating our Donor Heroes' Night with our membership and the wider community on 18 May.

#### Bruce McDowell

Chairman



# A BEAUTIFUL DAY FOR MORNING TEA

We were blessed with beautiful weather for our special Donor Hero Get Together.

Thanks to the generosity of Ivor and Coral who once again hosted an event for Donor Families Australia in their magnificent garden.

It was lovely to see some old faces and new faces come together to acknowledge this up and coming special event the Donor Hero Night.

Those in attendance were recipients, living donors and donor families welcoming the opportunity to celebrate the Donor Heroes that have made such an impact on others through their gifts of organ and tissues.

It is always special to bring together those that have been touched by organ and tissue donation together and we hope that we can continue to catch up in the future.



Wednesday 18 May 2022

Donor Family Members, Recipient Associate Members, and Friends of Donor Families Australia...

#### To assist with the marketing of this event:

Please inform your family, friends, neighbours, work colleagues and the general community

in your location area of Donor Heroes' Night in recognising, commemorating and celebrating the approximate 25,000 Organ and Tissue Donors over the past 40 years that have given of themselves in the hope of improving or saving the lives of those that seek the "Gift of Life".

It's also an opportunity to raise organ and tissue donation awareness following a drop in 2021 by 24% to 421 in the nation's donation rate — from a high of 554 in 2018.

On the night of 18 May, we're asking that you "leave on a light" or "light a candle" for all Donor Heroes, and post a photo and leave a comment via Donor Families Australia's Facebook Page (www.facebook.com/DonorFamiliesAustralia), as well as your Twitter and Instagram accounts if you have one.

For more information visit: https://www.donorfamiliesaustralia.org/

#### The Team behind Donor Heroes' Night

This year we are fortunate to have the services of a dynamic team of DFA members;

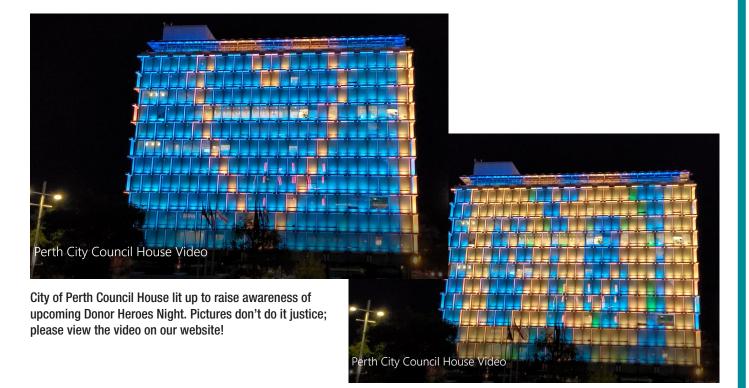
- Graham Harrison, Co-ordinator and founder of Donor Heroes Night
- Bruce McDowell, Chairman of DFA and donor dad from WA
- Anthea Openshaw, Donor partner from WA
- Warwick Duncan, Recipient from VIC
- Jenelle Colquhoun, Recipient from QLD
- Jayden Commins, Recipient from NSW and film producer in TV and advertising,
- Robert Manning, Recipient from NSW with a marketing and media strategist.

#### Just look at us grow!

As a result, this year's Event has undergone change and much growth:

- Donor Families Australia website has been restructured allowing navigation to Donor Heroes' Night from the main menu
- Donor Heroes' Night event web page enhanced now includes how to post a photo
- Online Media information sheet now available online
- New dynamic video(s) being produced
- Twitter, Instagram (and hopefully YouTube) will be embraced this year
- We've expanded on our Stories, where possible

And finally, DonateLife, Transplant Australia, Kidney Australia and other organisations are having greater involvement in displaying the event on their social services.



#### **MEDIA RELEASE**

# SHINE A LIGHT FOR ORGAN AND TISSUE 'DONOR HEROES' AT 6 PM ON MAY 18!

#### FOR IMMEDIATE RELEASE

Australian households are reminded to light a candle or shine a porch light in support of the thousands of donor heroes who have changed a person's life through their generous act of organ and tissue donation. Commencing at 6pm on the evening of May 18, 2022, Donor Heroes' Night is a free online event designed to commemorate and celebrate the lives of approximately 25,000 Australian organ and tissue donors who have given the ultimate gift so that others may live.

Donor Families Australia has a broad selection of 'donor hero' family members who are happy to share their stories with the media. Approximately 1,850 Australians are currently waitlisted for an organ transplant, and an additional 13,000 people are on dialysis – some of who may need a kidney transplant one day. In 2021, 200 people received a kidney from a living donor, more than 2,400 people had their eyesight restored through a corneal transplant, and over 10,000 people received tissue (e.g. musculoskeletal, heart, skin) transplants – all thanks to the life-changing gift of donation.

Donor Heroes' Night organiser, Mr. Graham Harrison, lost his 10-year-old son Ben in 1993, and May 18 marks the anniversary of Ben's passing. As an organ donor, Ben's heart and lungs went to a 12- year-old girl, and his kidneys saved a 50-year-old man.

The Donor Families Australia website has a dedicated event page with downloadable flyers and donor hero stories to help journalists, schools and interested organisations spread the word about the event. They also have family members who are willing to speak to the press.

Donor Heroes' Night starts at 6pm on May 18 and participants are asked to upload their photos of either lit candles or porch lights to the Donor Families Australia Facebook page at <u>https://www.facebook.com/DonorFamiliesAustralia</u>.

Further information can be found at: <u>https://www.donorfamiliesaustralia.org/donor-heroes-night</u> and a downloadable poster is available on the page or via this link here.

#### Associated hashtags:

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

#### **MEDIA ENQUIRIES**

Bruce McDowell // Chairman and Media Contact // Mobile: 0427 645 262

Graham Harrison // Media Contact // Mobile: 0421 697 048

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BOILERPLATE: Donor Families Australia is a national member-based independent support and advocacy group comprising families who have donated their loved ones' organs and tissue. It's the only organisation of its kind in Australia specifically dedicated to Donor Families.

# Leave a light or candle on for Donor Heroes' Night 18 May 2022

#### 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 2022**, Donor Heroes' Night is a dedicated event which honours and commemorates all organ and tissue donor heroes.

#### 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 tissues.

If you support organ and tissue donation, you can take part by simply adding a photo and comment of your light to your Facebook, Instagram or Twitter page and tagging **DonorFamiliesAustralia**.



For more information, head to: www.donorfamiliesaustralia.org/donor-heroes-night or contact Warwick Duncan or Graham Harrison at admin@donorfamiliesaustralia.org All Donor Families and Recipients are welcome to join DFA Donor Families Australia Incorporated, Charity Registered, ABN 54426172274

#### www.donorfamiliesaustralia.org

#### Connect with us



@donor\_families

/DonorFamiliesAustralia

@donor\_families\_australia

Thanky Tapa!



**Tara Cheyne MLA** is in **Canberra**, **Australian Capital Territory**. 4 May at 10:21 · ③

The significance of the decision to donate organs and tissue, and the significance of these gifts themselves, cannot be overstated. They are gifts of life.

The ACT Government recognises technical barriers have recently been identified in Transplantation and Anatomy Acts across the country which have limited families' abilities to have their loved ones' donation stories shared publicly.

The Government intends to bring amendments later this year, following consultation with the Organ and Tissue Authority and the Government Solicitor, to remove this limitation.

This may then be the blueprint for other jurisdictions to follow suit in amending their own Acts.

Thank you to the families, carers, loved ones and advocates who have raised this with us.

DonateLife

Donor Families Australia



#### **Transplantation and Anatomy Act 1978**

A1978-44

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Republication No 17 Effective: 14 November 2019

Republication date: 14 November 2019

Last amendment made by A2019-42

Families Australia for identifying the legislative restrictions for Donor Families, and for prompting governments to make the necessary legislative changes so that Donor Families can truly own their loved one's information. Thanks to Tara Cheyne for moving on these changes with the ACT government. Let's hope the other jurisdictions do the same.

Well done to Donor

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5 comments 8 shares

A Share

Comment

# **TRANSPLANT GAMES PLANNING UNDERWAY**

Mark this date in your calendar!



For more information and to register, visit www.worldtransplantgames.org



## 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

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



