Donor Families
AUSTRALIA

# Donor Families Australia NEWS

Autumn 2021, Edition 26

## HIGHLIGHTS

**Donor Heroes' Night on again in 2021 (join us!)**

**An invitation to shop and support Donor Families Australia**

**Groundbreaking legislation comes into effect this month**

**What the amazing gift of sight has really given one inspiring Recipient**

# MY SON, MY LITTLE MATE, MY DONOR HERO

**My son came into this world with a great big bellow. Not because he was just born, but things were just not going his way at 2.17 pm on the 29th September, 1982.**

When cleaning out his windpipe with a suction tube it was found to be blocked. Unfortunately, his windpipe and oesophagus had not formed properly, and the oesophagus was not joined to his stomach. So, at four hours old, he was transferred to Camperdown Children's Hospital for an emergency operation.

*Share your story*

My little mate was still not out of the woods when three months later, while being breastfed, he stopped breathing, turned blue and I had to give him mouth to mouth. Apparently, due to his condition, his trachea only had 15% cartilage, causing it to collapse while being fed. Once again, Ben was taken to Camperdown Children's Hospital, this time to have his chest opened and his aorta sutured to his breastbone to take the pressure off his trachea to breathe normally.

Sadly, Ben had yet a further challenge which would eventuate in him being my Donor Hero. Ben was also born with severe scoliosis where his C7 vertebrae formed a wedge. During his growth spurt at 10 years old, Ben's orthopaedic surgeon informed us that Ben needed major surgery to control the curvature of his spine, or he would be like the "Hunchback of Notre-Dame". The doctor certainly did not pull any punches. It meant once again going to Camperdown

~continued page 2

*A life that touches others goes on forever*

~continued from cover

Children's Hospital (third time lucky) to have his chest opened down his sternum and a section of rib inserted above and below the defective disk to fuse it permanently in position.

In preparation for the operation, Ben needed a polyurethan clamshell moulded around his chest front and back, fitting over his head and velcroed around his waist. This had to be worn for a month before surgery so that Ben would be comfortable wearing it 24/7 for the three months following the operation.

Did he complain? Did he throw a tantrum? No, he was a true champion, wearing it without complaint; he was my Hero. Even when he came home from school one day and said that he had a fight with the school bully, I was horrified, but Ben had a grin from ear to ear. Evidently the bully did not like all the attention Ben was receiving and decided to punch him hard in the stomach. Ben had been wearing his school shirt over his chest plate. The bully gave Ben one almighty wack in the chest, while Ben just looked at him. I was told by Ben's friends that all that Ben said as the bully walked away cradling his hand was, "You can't hurt me because I am protected by my shining armour".

Share your story

As the day for surgery approached, I waved good-bye to Ben not knowing it would be for the last time, as my wife Elayne drove off in the family car taking Ben to Camperdown Children's Hospital for his surgery which was to take place the following day. Meanwhile, I looked after Kyla, Ben's older sister by 18 months.

The following day, Kyla went to school, and I went to work and then headed off to hospital around noon to be with Elayne as Ben was to come out of recovery. Walking into the recovery room, my world fell apart. Elayne was on her own in the room as they had ushered other parents out to allow us to cope privately for what was to unfold.

Elayne's face said it all. In preparing Ben for the operation, the cardiologist cracked open Ben's chest and started to move his aorta to one side to expose his vertebrate ready for fusion. Almost immediately, his aorta tore. One can only imagine the horror that followed within the theatre with doctors being scrabbled across the adjoining two theatres that were operating at the time.

What made matters worse was this outcome was unexpected and they did not have a heart-lung machine on standby. While they tried to maintain his blood pressure, the heart-lung machine had to be filled and primed, and unfortunately that meant Ben went without blood to the brain for twelve minutes before he could be connect.

This resulted in Ben being on a ventilator in ICU from midday Monday with Elayne and I at his bedside, hoping for a miracle. Hope eventually evaporated early on Tuesday morning when the Registrar told Elayne and I, that they believed Ben was brain dead. Elayne and I had lost our only son, our little mate. Doctors then conducted an EEG, dye test and a series of reflex tests to confirm Ben's final prognosis.

By midday Tuesday, we met with the two principal surgeons to be formally told the status of Ben's brain death condition. We both said as one that we wanted to donate Ben's organs and tissue. We would rather do everything we could to spare other families from the grief we were experiencing by donating Ben's organs. We signed the papers to release Ben for organ and tissue donation at 4 pm on Tuesday afternoon. It was a further wait until 6 am, Wednesday morning before we could walk Ben to theatre for the retrieval process. Hours later, we were shown to a quiet room where we were able to cradle Ben and say goodbye to our son, our little mate, Our Donor Hero.

That was back on the 18th of May 1993. A few weeks later, the Red Cross advised us that a middle-aged gentleman had received both Ben's kidneys and a young twelve year old girl in Melbourne received his heart and lungs. Several months later, we received a letter from David, his kidney recipient, and at Christmas, a letter from the parents of the little girl. It was very emotional reading such letters but receiving them meant so much to us. It gave us closure knowing Ben's Gifts saved two lives. It made his short life with us mean just a little more.

In the years that followed, I became involved in promoting organ and tissue donation from a Donor Dad's perspective. Following a number of unusual circumstances, Elayne and I met with Ben's kidney recipient, David Ridoutt, and became good friends of the family. The ABC network's *Australian Story* produced a thirty minute documentary that can be viewed on the DFA website (www.donorfamiliesaustralia.org/videos-Ben's Gift). I also became heavily involved in the National and International Transplant Games, but my real passion was being a founding member of Donor Families Australia and helping support other Donor Families.

Last year's pandemic impacted us all and made 2020 fairly challenging; in particular, more isolated from one another. The DFA website has, for many years, displayed a Virtual Donor Hero's Wall where we now have posted 125 Donor Hero photos and 23 Donor Hero Stories. But we can always have many more!

During 2020, the idea of doing something more in the way of a Donor Heroes' Night came to me based on how the Australian community embraced ANZAC Day during the pandemic. It was so heartening to see the community came out in force to place a lighted candle in one's driveway and play *The Last Post*. So why could we not have a Donor Heroes' Night on the 18th of May? The community would be invited to give recognition, reflection and remembrance to those Australian's that have donated their organs and tissue — an outcome that has saved, or greatly improved, tje lives of many tens of thousands of fellow Australians over the years. All that was requested was for individuals to turn on their porch or balcony light, take a photograph and post it on Facebook, Twitter and/or Instagram, accompanied with a few words of reflection. Our flyer was issued through various eService outlets resulting in approximate 50,000 individuals/families being involved.

DFA is preparing for our second National Donor Heroes' Night event that has the potential to involve hundreds of thousands Australian's that support, or are impacted by, the Gift of Life given by our Donor Heroes. We are also grateful for Affect Media to become involved in our endeavours for our 2021 event.

DFA encourages all members, associate members, and friends of DFA to become involved in spreading the word. Meanwhile, DFA is also encouraging members to submit their Donor Hero photo and story to the DFA website, and join our newly created Facebook Page "Organ and Tissue Donation Support – Donor Families Australia", which is open to all Australian Donor families and Recipients and their families.

Love you mate.

***Graham Harrison (Dad)***

# CHAIRMAN'S MESSAGE

Welcome to new members and thinking of all members who have, or had, anniversaries of their loved ones in recent times.

We at Donor Families Australia (DFA) are extremely excited by the up and coming Donor Hero Night. We would love all our readers and your contacts to turn on your porch light on the 18th May. Let's make this year's message one to remember. Sadly, our consent rates have not moved in over ten years. DFA, through the Donor Heroes' Night, is committed to spreading the message of the importance of Organ and Tissue donation to the community and to keep the conversation going whilst honouring our loved ones who gave this gift to others. Help us to send a message to the community by turning on your light.

Our Donor Hero for this edition, Ben, is the inspiration for the Donor Heroes' Night. Graham and Elayne Harrison's son, has his 28th anniversary coming up on the 18th May. We at DFA celebrate Ben and the work that his Mum and Dad have done for Donor Families over this period. On a personal note I would like to thank Graham and Elayne for all they have done for DFA. They have been the backbone of our organisation right from day one in 2012.

Tara Cheyne's (MLA) new legislation for Acknowledgement of Donation on the Death Certificate in the ACT will commence in May 2021. All Organ and Tissue donations by deceased donors in the ACT will be able to be recorded on the Death Certificate. Read more about this Australian first from Tara in her article.

DFA was proud to be part of the consultative letter writing process. The new systems are now in place. All letter writers should now be receiving notification of receipt of letter and notification of the conclusion of the process. All other improvements can be found on our web page (www.donorfamiliesaustralia.org/resources). I have heard from a recipient letter writer already, to say they did receive the notifications as mentioned. Good start. Please let us know of your experience. DFA will review the system with DonateLife in six months.

We feature a recipient, Martin Parker, in this edition who was responsible, along with his fellow mongrels (Kurri Mongrels Mountain Bike Club), for raising an incredible $17,224 for DFA to carry on its work. Read how Martin has made the most of his precious gift to thank his donor.

DFA has been given an opportunity to help fund its future projects via a great online shopping site, Better That. If you use this link (https://bit.ly/3wvulei) and nominate Donor Families Australia as your cause, we will receive a portion of the sales. We invite you to check out the products on offer and their prices. Read more about it in this edition.

DFA and the Organ and Tissue Authority/DonateLife have set in place regular meetings every two months. DFA's committee will attend via Zoom. We have had our first meeting which covered a large range of topics. We look forward to future meetings and the outcomes that relate to Donor Families and the OTA/DonateLife through these communications. Let us know what is important to you and we will follow it up.

We would like to remind Donor Families that they can communicate with other Donor Families on our facebook page Members:Donor Families Australia. And also catch up with DFA news on our facebook page Donor Families Australia and web page by the same name. You can also follow us on Twitter and Instagram.

We hope you enjoy this edition.

***Bruce McDowell***

Chairman

*Connect with us*

@donor_families

/DonorFamiliesAustralia

@donor_families_australia

# Leave your porch light on for Donor Heroes' Night

## 18 May 2021

**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.

### Donor Families Australia

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

Held on the evening of **18 May 2021**, Donor Heroes' Night is a dedicated event which honours and commemorates all organ and tissue donor heroes.

**In 2020 we reached 50,000 participants. Let's see if we can reach 500,000 in 2021!**

**Donor Heroes** are the 10,000 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 porch light to your Facebook, Instagram or Twitter page and tagging **@DonorFamiliesAustralia**.

Donor Families
AUSTRALIA

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

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www.donorfamiliesaustralia.org

# WHAT MARTIN HAS SEEN

**"Granular Stromal Dystrophy is a bugger of a thing," says Martin Parker. But "knowing that Donor Families Australia are there to offer recipients and donors support when it's needed is a great comfort."**

About 25 years ago, I found that I was suffering from an unusual hereditary disease, Granular Stromal Dystrophy. It wasn't an immediate issue but the prospect was that my sight would gradually decline and I might face functional sight impairment in the future.

The saving grace was that corneal transplants could restore my sight.

But, eyes are delicate and the number of times I could recieve transplants over my whole life was limited. Being younger, the longer I could delay surgery, the better vision prospects I had later in life. These were the facts, and I just had to accept them.

Sure enough, by 2004, I was "legally blind", unable to drive, read or work. I still had enough vision to live a great life with assistance so I decided to delay surgical intervention and get on with life and "see" how things turned out.

That was fine for a while. I walked the Kokoda Track, rode a push bike from Perth to Newcastle, and focussed on what I could do, rather than what I couldn't. Life was pretty good; I was doing lots of things.

That was great for a while. I was really enjoying life and my wonderful family. But this disease of gradual onset was creeping up on me. I was less able to function, some of the things I was doing became unsafe. It was time to sort out one or both eyes.

With the help of a fantastic team at the Sydney Eye Institute and a cornea donor, I had my first transplant/graft in 2006. The surgery was expertly performed, my recovery good and the very next day, I took off my eye patch and experienced a visual clarity and a depth of colour that had to be seen to be believed.

The gift that that donor made to me had transformed me. I hadn't realised how much vision I had lost; having it restored overnight was extraordinary. I was quickly able to drive again, and I could read efficiently (something I loved). I became a bit safer to be around. I could do more.

We kept a gap between the surgery to my left eye to better manage the recurrence of the condition. Thanks to another wonderful donor, I had my second successful corneal transplant in 2010. Again, the restoration of clear vision was really exciting. I could do lots of stuff, so I did.

With a great team of friends, I've riden a bike across Australia five times now, ridden around New Zealand, South Africa, from Zimbabwe to Zambia, trekked a fair bit and seen a lot of the world.

In November, some friends and I completed the Mad Dog 100 for Donor Families Australia, 115 kilometres over the Great North Walk in 25 hours to raise awareness for their cause. It was a big day out. Combined with a few other events, we raised over $17,200 for DFA.

Granular Stromal Dystrophy is a bugger of a thing. It's creeping back. We monitor it, consider any risks that it might present, and make decisions on the long term future, knowing that there are generous donors and their families out there who are willing to help.

One day, maybe soon, I will be looking for help again. Knowing that Donor Families Australia are there to offer recipients and donors support when it's needed is a great comfort.

See you soon.

***Martin Parker***

# ON BREAKING GROUND WITH DONOR FAMILIES

**Tara Cheyne, MLA, tells us what being a key part of the introduction of ground breaking organ and tissue donor legislation (Acknowledgement of Donation on the Death Certificate in the ACT) means to her, as it comes into effect.**

Later this month will be an historic occasion. Legislation will come into effect in the Australian Capital Territory so that families are able to have the option to record that their loved one was an organ/tissue donor on the death register – and, in turn, have this reflected on their loved one's death certificate. Families will also have the option to request a formal letter from the Chief Minister of the ACT acknowledging the gift. We believe that the ACT will be the first Australian state or territory to provide these options to families.

This legislation had its genesis at the inaugural Donor Families Conference held in Canberra in 2019. While there are a number of ways in which organ and tissue donation is acknowledged, it was at this conference that families 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.

And so, with help from DFA, Gift of Life ACT and donor families, I set about drafting this legislation. It was introduced in February 2020 and then passed in late May. Key principles guiding the legislation are that these acknowledgements are 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.

By not being time-limited, this removes any urgency in needing to decide about the acknowledgement and recognises 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 these reforms come into effect will have this option available to them, too. If at any time a death certificate has been previously issued and a family requests that it be amended to include the acknowledgement, there will be no extra cost.

While the legislation passed in May 2020, a commencement date of up to a year later was inserted at that time. This was because, being the first of its kind, we wanted to take the time to design a process that was simple and straightforward. In November 2020, I was delighted to become the Minister responsible for overseeing this legislation and can assure you that officials have been working hard to ensure that the process is smooth. That said, once it commences, I very much welcome and encourage any feedback about how it is working and any improvements that might be able to be made. As I write this, we are making the final tweaks before it goes live.

While the responsibility for death registration and certificates, as well as organ donation, sits with each state and territory, the legislation is similar in each jurisdiction. It may be, then, that the ACT legislation could serve as a template for other jurisdictions if they wish to adopt this. I welcome engagement from other jurisdictions.

It has been an immense privilege and very humbling for me to work so closely with DFA and so many donor families in driving this reform. Thank you to all of those who have advocated, answered my many questions, and shared their very personal stories.

*Tara Cheyne, MLA*

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# I AND YOU by Lauren Gunderson

**A moving story about legacy through ORGAN DONATION, and from America's most produced and popular living playwright, Lauren Gunderson, comes the WA premiere of the award-winning I and You; an ode to youth, life, love and the strange beauty of human connectedness, 8-29 May at Burt Hall.**

Presented by THEATRE 180 and featuring two of the hottest young performers in WA – Sophia Forrest and Darius Williams, I and You burns with humanity amid a poetical call to arms for living your best life. Exploring the sensitive topic of organ donation, the ending respectfully leaves audiences breathless with a twist they were not expecting.

Caroline (Sophia Forrest) hasn't been at school for months – sick at home, she's trapped in her bedroom with only Facebook, Twitter and Insta for company. When classmate Anthony (Darius Williams) arrives unexpectedly, spouting Walt Whitman's Leaves of Grass and brandishing an unfinished English Lit project he urgently needs her help with, she is less than impressed and rejects this intrusion into her damaged life. As they come together and reveal themselves through Whitman's electric poetry and over waffle fries, they discover a connection far deeper than either of them could ever have imagined.

"…enjoyable, tender study of youth: Gunderson is good at capturing both that soft-centre earnestness, and the hard, self-protective casing around it…" TimeOut London

Suitable for ages 14 years upwards.

**I and You is part of THEATRE 180's Double Bill program with The Children**

**Where:** Burt Hall, 38 St Georges Tce Perth

**When:** 8-29 May, 2021

**Bookings:** www.theatre180.com.au

Generous fundraising options are also available for your group. If you would like to discuss options, please contact: info@theatre180.com.au

**In February, Donor Families Australia proudly became a good cause partner with the sensational new online shopping platform, Betterthat.com.**

Better That are on a mission to make shopping better for everyone by giving back to good causes with every purchase!

As a good cause partner with Better That, DFA receive up to 25% of their net rate in sales as a donation. All you have to do to assist DFA receive these benefits is to register as a shopper and to nominate DFA as your preferred good cause! From fashion, footwear, jewellery, accessories, homewares and electronics, Better That are an innovative way to shop where everyone benefits. Plus, for their launch, we get an extra $1 for every sign-up! (up to the first 5,000 registrations).

So why not get online and see what the site has to offer? Prices are very competitive, and you'd be doing us a favour with every purchase.

Just follow this link: https://bit.ly/3wvulei

Thank you and happy shopping!

*Donor Families Australia*

# 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

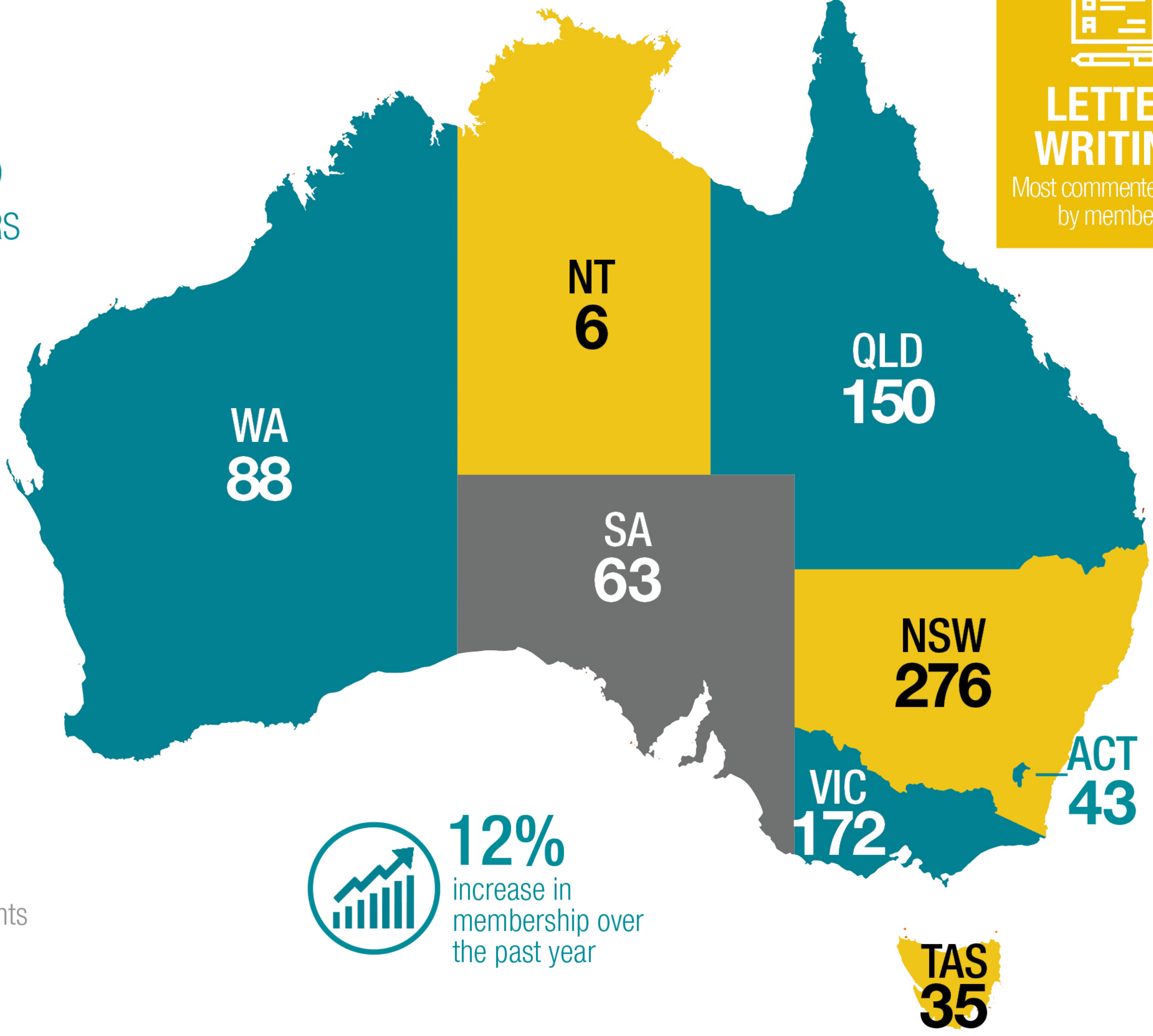
Advocate and give donor families a voice

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

## ...in 2021

**853**
TOTAL MEMBERS

**LETTER WRITING**
Most commented topic by members



**3,430**
Facebook
Donor and Recipients
Group Members

**12%**
increase in membership over the past year

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