



Donor Families  
AUSTRALIA

# Donor Families Australia NEWS

Winter 2018, Edition 19

## HIGHLIGHTS

### MAKING CONTACT:

- Arrival of the Donor-Recipient Contact Register
- Letter writing on the agenda
- Ethics and gov support in Australia

*Share  
your  
story*

### Remembering Cole

How one recipient has been victorious in life

Our website's "Information Makeover"

## A MOTHER'S MEMORIES - COLE

**Reflecting now on Cole's short life, I truly believe that he had experienced a wonderful, enriching childhood with so many more magical life experiences to look forward to.**

Growing up the youngest of four siblings, he had a hard act to follow, and boy did he give it his best shot trying to keep up in a very busy, energetic home. Growing up on the Sunshine Coast, he spent the majority of his younger life as a passenger, sitting in the car, transporting his older siblings to school and various sporting events. As a young boy, he witnessed firsthand the dedication and achievements of his brothers Billy, Mitchell and Sister Kate. Billy competed for Australia at the 2012 London Olympics in water polo, while Kate also represented Australia in water polo at junior and senior levels. Mitchell became a professional ironman at a young age, competing in the Kellogg's Nutri-Grain Ironman series for four years. Cole was their biggest fan, his love and admiration for them never wavered, he loved them so much — and they him.

During his early adolescent years, he decided that he also wanted to play water polo, and so his own personal journey began. Being a late maturer, he had his disappointments along the way, always trying so hard, and expecting so much of himself. I remember him saying to me numerous times during this period: "Why aren't I good at anything, Mum?" to which I would reply: "You will be Cole; you just haven't found what that something is yet."

Cole was very quiet in nature but also very quietly driven and determined to reach his goals. By this time he was playing competitive water polo in Brisbane on the weekends and cementing some very close friendships. His yearning to live in Brisbane became clear, desperately wanting to attend Brisbane State High



~continued page 2



*A life that touches others goes on forever*

# A MOTHER'S MEMORIES - COLE

~continued from cover

School whilst working towards securing a Queensland Academy of Sport scholarship. It was at this time, towards the end of year nine that I promised him, if I could secure work in Brisbane as a nurse, we would move so that he could live out his dreams. In January 2013, we left his Dad and the family home on the sunshine coast, so he could start year 10 at Brisbane State High School. It was now his time to shine. The new school fitted him like a glove, loving it from day one, making



many wonderful friends and slowly but surely becoming enthusiastic about his school work. By the middle of his senior year in 2015, he had secured his sporting scholarship, and was applying himself academically in order to gain entry to university to undertake a commerce degree. Cole was looking forward to finishing school and of course bursting with excitement to attend "Schoolies' Week" at the Gold Coast with his friends.

I clearly remember the night in December of

2015, after being selected to compete in his first International Water Polo Tournament in Sydney, his coming home from training so excited, to show me his new team bag, togs, towels and uniform. He was so proud.

That was to be the last tournament he would ever play.

On 3 January 2016, Cole attended a friend's 21st birthday party in Brisbane. Whilst walking with one of his

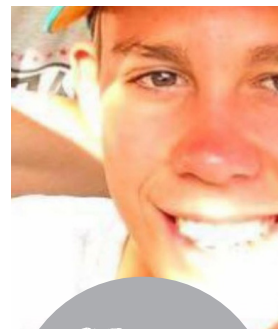
best mates to catch a cab home, he was struck from behind, causing him to fall face first on to the footpath. He sustained a traumatic cerebral brain injury, passing away on 4 January 2016.

Cole was a beautiful, brave young man with his whole life left to be lived-taken from us by an unprovoked "Coward's Punch".

After Cole's death, as a family we searched for answers. What positive message could we share and what action could we take to make this world a better place? There were several decisions made — the first was to donate his organs in order to save other people's lives; secondly we decided to use the colour green in his memory (green is the club colour of his water polo club, The Brisbane Barracudas, and the colour used for organ donation).

As yet, we do not have a clear vision of what our son's legacy will be, but by donating our Cole's organs, we already believe we have left a truly amazing legacy that will live on in generations to come. Cole helped to save six people: a boy received his heart; and a woman a double lung transplant; a little girl and a woman both received liver transplants; whilst two men have each received a kidney transplant. Cole's bone and skin tissue donations help to restore strength and mobility to many people, including people with life threatening burns.

Our love and memories of Cole will live on forever in our hearts, and how proud we are that our son, through his death, made such a profound impact on the lives of many others through his gift of organ transplantation.



Share  
your  
story

 *A life that touches others goes on forever*

# CHAIRMAN'S MESSAGE

Welcome to all our new members since our last Newsletter. Our membership has grown considerably as the Donor Families Australia profile is spreading and people are engaging with other Donor Families and Recipients on mutual topics of concern and interest. One of those being the introduction of our meeting Donor Families and Recipients programme. Please read the included articles for more information on how you too can meet your Donor Family/Recipient if you and they so choose.

The whole issue of letter writing and how to say 'thank you' remains the topic most discussed by Donor Families and Recipients. We have on one hand people who know what they want to say but are blocked by DonateLife's Correspondence Guidelines that state they are bound by 'Legal Requirements'. As a follow up to the so called 'Legal Requirements' I have written to Western Australia's Attorney General who has referred the letter to the State Minister of Health, which was over two months ago. My letter was questioning what laws, if any, have been broken if a Donor Family was to include their loved ones first name in their letter to the Recipient. I have not had a reply at the time of writing this editorial, I can only assume I have asked a difficult question.

I am convinced that the OTA/DonateLife is misleading Donor Families and Recipients as to what the legal requirements are. Confidentiality is about honouring someone's right to privacy, if you have given permission to include your loved one's name in a letter then surely confidentiality has not been breached.

We keep hearing of the terrible handling of letters by those put in charge of acting as the go between. One of the worst cases I have heard recently is a Donor Mum who received a hand written thank you card from, she thought, her child's Recipient. That Mum has since met the Recipient. The Recipient has confirmed he did not write that card. A clear case of someone within the system sending out cards purporting to be a Recipient. If the OTA/DonateLife is so concerned about legal requirements I wonder

if any laws have been broken here. Even worse what are the ethics of such action?

Sadly, this is but one example of complaints we hear of how letters are handled in this country. There needs to be a national

approach involving Donor Families and Recipients to ensure this important contact is handled with dignity and respect for both parties. To this end we call upon the OTA/Donate Life to sort the matter out before any more damage is done. And whilst they are at it, a system should be put in place to cater for those that want to exercise their right of choice to meet their Donor Family/Recipient.

I would strongly recommend all to read National Wave 2 Donor Family Study (Wave 2). It is a study of Donor Families that can be located online at the following location: <http://www.donatelife.gov.au/national-wave-2-donor-family-study>. If you want the complete story, please read the full report, which includes Donor Family quotes.

As mentioned early in the Wave 2 report, Donor Families Australia was consulted along the way. I have been told that Wave 3 and 4 are well progressed. Donor Families Australia was not consulted on either Wave 3 or 4.

I would like to personally thank the Donor Families Australia ommittee who continue to work tirelessly and advocate on behalf of Donor Families and Recipients. At this point I would like to welcome to the committee Blythe Robson from South Australia. We have had the pleasure of having Blythe attend one meeting and know already she will be a great spokesperson and advocate for Donor Families and Recipients in South Australia.

**Bruce McDowell**

Chairman



# ARRIVAL: THE DFA DONOR-RECIPIENT CONTACT REGISTER

During the past year, Donor Families Australia has been involved in a seminar and workshop discussing the issues that surround Donor Family Recipient Contact.

During this same period, a big part of the discussion threads held within the Donor Families Australia Facebook Page (Donor and Recipients Group Australia) revolved around the topic of communication — or the lack of it — between Donor Families and Recipients.

Donor Families Australia Member, Meiling Claus, initially took up the challenge and commenced assisting consenting Donor Families and their Recipient to be able to make direct contact. After numerous successes, assessing Donor Families Australia's legal standing, and increased enthusiasm from members, Donor Families Australia has now established a formal process for both parties to register their consent and provide their personal details to assist in facilitating contact.

The result from collaboration between Meiling, Graham Harrison and the Donor Families Australia Executive has now resulted in the Donor Families Australia Donor-Recipient Contact Registry being made available to all registered Donor Families Australia Members and Associate Members from 1 March 2018.

Information regarding registration is located on the Donor Families Australia website by visiting [donorfamiliesaustralia.org](http://donorfamiliesaustralia.org).

You can either scroll down the Home page to What's New and click on "Australia's First Official Donor/Recipient Contact Registry – visit Latest/Projects" or proceed directly to Latest/Projects from the main menu.

In the Registry's first week, over a hundred application forms were requested and emailed out, which is a good indication of just how strong such a demand for a Contact Registry there is within the Organ and Transplantation Community.



Donor Families Australia Inc.

[Home](#) [About Us](#) [Our Heroes](#) [Latest](#) [Support](#) [JOIN US](#) [Contact](#)



## Projects and Initiatives

Donor Families Australia Inc is involved in a number of projects and initiatives

### Donor/Recipient Contact Registry

WELCOME: The Donor / Recipient community have requested Donor Families Australia act as a 'conduit' to facilitate connections between Donor Families and the beneficiaries of their deceased family member's donation.

Interested Donor Family Members and Recipient Associate Members are invited to place their request to register with the Donor:Recipient Contact Registry.

1. To join the Registry, you must first join as a Member ([click here](#)). To reduce processing times and 'double-ups', please be sure that you are not already a Donor Families Australia Member. If you aren't sure, please just [Contact Us](#) and ask.
2. Once your DFA Membership is confirmed, you can join the Registry
  1. [Click here to open our Contact Form](#)
  2. Add details as requested (your name and email are mandatory fields),
  3. At Subject, select Donor:Recipient Contact Registry
3. We will send you the Contact Registration Form which you should read thoroughly. If you agree with the conditions associated with registration, complete and return to us.

# Joining the Donor-Recipient Contact Register in three easy steps:

## STEP 1

If you are not yet a Donor Families Australia Member, you firstly need to complete the online Membership Application Form

The screenshot shows the 'Donor Families Australia Membership' form. It includes fields for six family members (Family Member 1 to 6), each with 'First' and 'Last' name inputs. Below these is a section for 'Family Member 1 relationship to the Donor' with radio button options: Partner, Parent, Child, Sibling, Other donor family member type, Associate Member (Recipient), Associate Member (Medical), and Other (Neither a donor family member or recipient / medical). To the right, there are fields for 'Donor's Name' (First and Last) and 'Date of Donor's passing or Recipients Transplant' (DD, MM, YYYY).

## STEP 2

Once membership is confirmed, Members and Associate Members seek Donor Family-Recipient Contact registration through the online Contact Us form by selecting "Donor-Recipient Contact Registry."

The screenshot shows the 'Contact Us' form. It includes fields for 'Name' (First and Last), 'Phone Number', 'Email', and 'Website'. The 'Subject' section has radio button options: Media Enquiry, Affiliation, Donor-Recipient Contact Registry (which is selected), and Other. There is a 'Comment' text area at the bottom and a 'Submit' button.

## STEP 3

We will email you the Donor-Recipient Registry onboarding documents for completion and return. Once received, we will let you know when we find a match.

# DFA WEBSITE INFORMATION MAKEOVER

As a result of Donor Families Australia recently advertising the availability of a Donor Family-Recipient Contact Register for consenting parties, there has been an increase members and the public visiting our website at [donorfamiliesaustralia.org](http://donorfamiliesaustralia.org).

Graham Harrison, website administrator, and Sam Howkins Donor Families Australia volunteer, have since been busily updating the website, of which the changes are summarised here.

## Home Page

The “What’s New” links have been updated to go directly to:

- The Donor-Recipient Contact Register
- The latest Donor-Recipient Contact Register Media Release, and
- The latest DFA News issue

## About Us

“Our Board” has been updated to reflect the current Executive Board members and existing vacancies.

## Our Heroes

- Our Virtual Donor Wall has received a large number of new Donor Heroes, submitted by their Donor Families, now numbering 31 photos in all (so far).
- The Hero Stories have also generated great interest with 14 stories now displayed.



A new feature has been added where visitors can now select from the displayed “character” and all stories with that first name starting with that letter will be displayed. This will make it a lot easier to locate individual stories when the number of stories increases.

## Latest

- Videos have now been separated from Media and a number of new videos have since been added
- Projects have been changed to only reflect projects which are current. The only one at present is the Donor-Recipient Contact Registry which as one would expect is generating a lot of interest (see article in this issue!)

## Support

- Resources: a number of existing support documents developed by DonateLife are available for download and they make interesting reading. Even more interesting is that DonateLife have sought comment from Donor Families Australia on the current content which Members are invited to do through “Contact Form.”



Home About Us Our Heroes Latest Support JOIN US Contact

## WELCOME

HELP US BUILD A CARING COMMUNITY  
AND SHAPE THE FUTURE

Trust your Family – Have the conversation



Updated Home Page menus and items

## Join Us

This is the new title used to become a member, volunteer to provide support, and make a donation.

## Website Forms

We have added more relationship categories to the Membership Application Form to specifically include:

- Other donor family member type,
- Associate Member (Recipient),
- Associate Member (Medical), and
- Other (neither a donor family member or recipient/medical).

The Contact Form used as part of the Donor/Recipient Contact Registry now also displays a specific “Subject criteria” for the Donor/Recipient Contact Registry.

A Complaints Form has also been added to allow constructive comments of Donor Families Australia and can also be used as an avenue to raise concerns or issues arising within the organ donation and transplantation system which Donor Families Australia may choose to take-up on your behalf.

If you are community-minded and/or belong to a company who is, please approach us by using the Corporate Supporter contact form and talk with us about how we can honour your commitment to our mission and support you in return.

So in conclusion, the Donor Families Australia website can only be as dynamic, interesting and supporting in response to content submitted. I therefore encourage all members and associate member to browse the site and consider how you can support this online community - perhaps by submitting photographs and Hero Stories, or providing website feedback, or something that is important to you.

**Graham Harrison**

DFA Website Administrator



Donor Families Australia Inc.

A screenshot of the Donor Families Australia website. At the top, there is a navigation bar with links for Home, About Us, Our Heroes, Latest, Support, JOIN US, and Contact, along with a Facebook icon. Below the navigation bar, there are two video thumbnails. The first video shows three women smiling together, with the title "Donor Families and Recipients connecting by Robyn McCanna" and the date "10th June 2018". The second video shows a group of people in a studio setting, with the title "The Today Show interviewing the Harrison's and their son's Kidney Recipient David" and the date "2000". To the right of the second video, there is a short text snippet: "Graham and Elayne Harrison together with David Ridout, their son's Kidney recipient talk with Liz Hayes on the morning Today Show about the meeting and what it has meant to them both."

More Videos available

A screenshot of the Donor Families Australia website's Media Releases section. The page has a teal header with the text "Media Releases". Below the header, there are two news items. The first item is titled "Australia's First Official Donor/Recipient Contact Registry" and is dated "11 March 2018", with a "Read More" button. The second item is titled "DFA Donor/Recipient Contact Registry" and is dated "28 February, 2018", also with a "Read More" button.

Separate Media section

# NOT A VICTIM BUT A VICTOR

Born in the country town of Narrabri in 1980 to Mum (Kim), and Dad (John), joining big brother, John or Johnny as we all knew him, life as a little one was full of exploration.

I was three when we moved to the city; Johnny had become ill and we needed be closer to medical specialists. It was a sea change moving to the beachside suburbs of Wollongong, then Coogee, and there seemed to be an adventure around every corner – the beach, Wileys bathes and so many fond memories.

In 1986, I started at Coogee Public School, and it was here that I developed my love and enthusiasm for all things running that eventually set me on my path for Little Athletics.

I represented the school at multiple State and National events including athletics and cross country. I was a handy swimmer too – making it through to regionals – but I didn't enjoy the sport so never really pursued it.

In 1988 after multiple unexplained illnesses, I was diagnosed with Idiopathic Cryptogenic Cirrhosis – chronic liver failure – and told that like my brother, I would have to undergo a liver transplant within the year to save my life. I felt fine, so I did not accept the doctor's prognosis and chose instead to keep myself fit and healthy, throwing myself into Little Athletics and quickly becoming a state and national representative race walker and distance runner.

I was 12 when my brother passed, following complications post liver transplant. This was a tough time for me, not only for the loss of

my brother who I was extremely close to but knowing that one day I would also face the same surgery. I resolved that I was going to be as fit as I could be for the surgery and ready to face the battle ahead.

By the age of sixteen, I had won several state and national titles with Randwick Botany Little Athletics Club and South Sydney Seniors – all with Chronic Liver Failure. I had, however, started to get noticeably sicker and was encouraged to leave school to focus on my health.

Not many know that during this time, I had told my parents that I was not sure if I would go ahead with any surgery, should I get a call. I was sixteen or seventeen years old, rebellious, and had figured that I would live life in the fast lane for as long as my body allowed, rather than face what Johnny did. I can't honestly say what made me change my mind but it was like a flick of a switch. I got up one Monday morning, told Mum I wasn't fit enough for this surgery, and caught the bus to the local gym where I signed up for twelve months (out of my own money) and completed a 2 hour physical assessment with a personal trainer. I then wandered over to the Hensley Athletics field and joined up with my coach for a session where I ran some of the best times of my athletics career.

Little did I know that in less than an hour following this, on a normal Monday afternoon in late January 1998, I would receive my lifesaving call. It was the 19th. All doubt was quickly erased from my mind by this stage,





and while I didn't feel physically ready, I was 100% mentally committed.

We headed to the Royal Prince Alfred Hospital and the next few hours were all about the preparation. From the neck to knees shave and enema, to the countless doctors, nurses and surgeons doing their final checks, and us making sure that all the family and close friends knew what was happening.

I am not sure what time I finally went to theatre – it was either really, really late or really really early. I remember a lot of that time, like it was yesterday in fact, the smells, the lights the sounds and the naughty jokes my Transplant Co-ordinator was telling me...and the bet. The bet he made that I would not be able to make it to compete at the Australian Transplant Games that would be held in Ballarat, Victoria, in August that year.

After a three month hospital stay and three months home nursing, I put the many hiccups behind me as set out to win my bet with the Transplant Co-ordinator: I was going to race at the Australian Transplant Games held in August the same year, in Ballarat.

I did make it to those Games, and I did pretty well, setting a few new Australian records and meeting so many other wonderful transplant recipients.

Fast forward several years and my rap sheet reads pretty well: an Australian representative at the World Transplant Games, gold medal winner, World and Australian record holder at the World Transplant Games, sub four hour marathon runner, and more recently an Australian representative at the Obstacle Course World Championships.

Truth be told I had no idea what OCR (obstacle course racing) was until my gym manager asked if I'd be keen to give it a go. My first event was a seven kilometre Spartan race at Peak Crossing, Queensland. I finished in eighteenth position and had a grin from ear to ear – I smiled so much that I had mud all through my teeth, and right there and then, without any other experience, I signed up for



the Ultra Beast event – a 42 kilometre Spartan event a few months later.

I have since become classed as an Elite Obstacle Racer competing in events from seven kilometre to 24 hour events and have been lucky enough to have achieved several podiums and become an Australian Representative at the World Obstacle Racing Championships, where recently I recently placed nineteenth in my age group and first in the open women's team with a couple of legendary Ninja Warriors.

My donor and their family gave me a chance, a chance at a life, that I would otherwise not have been afforded, had it not been for their selfless gift. Not only have I been able to achieve in the athletic arena, I was able to marry the love of my life, step foot on every continent and experience things many only ever dream about. I have a lot to be thankful for, and yes I am lucky. But I also get up every day and work my butt off. I have, and always will, comply with the tests, medications and advice from the doctors.

I do everything to not let my past define me but instead use it to my advantage. I purposely try not to tell people about my transplant until I have proven myself in any arena, be it work or sport – I am not a victim but a victor and I owe it to my donor and their family to be the best version of me I can be.

**Kate**

# Upcoming Events



DFA News is distributed throughout Australia each quarter.

If you have a public event planned in relation to organ and tissue donation, please let us know and we can publish your event details.\*\*

To advertise an event, contact us: <http://donorfamiliesaustralia.org/contact-us>



Donor Families  
AUSTRALIA

## AROUND AUSTRALIA

Donor Families Australia is a nationwide independent support and advocacy network comprising families who have donated their loved ones' organs and tissue.

Membership is free and gives donor families a voice:

- To speak with and to support each other;
- To let those who formulate organ and tissue donation policy know what is important to Donor Families; and
- To connect the community to a group that knows the experience of donation so they might come to a true understanding of what it is all about.



*A life that touches others goes on forever*

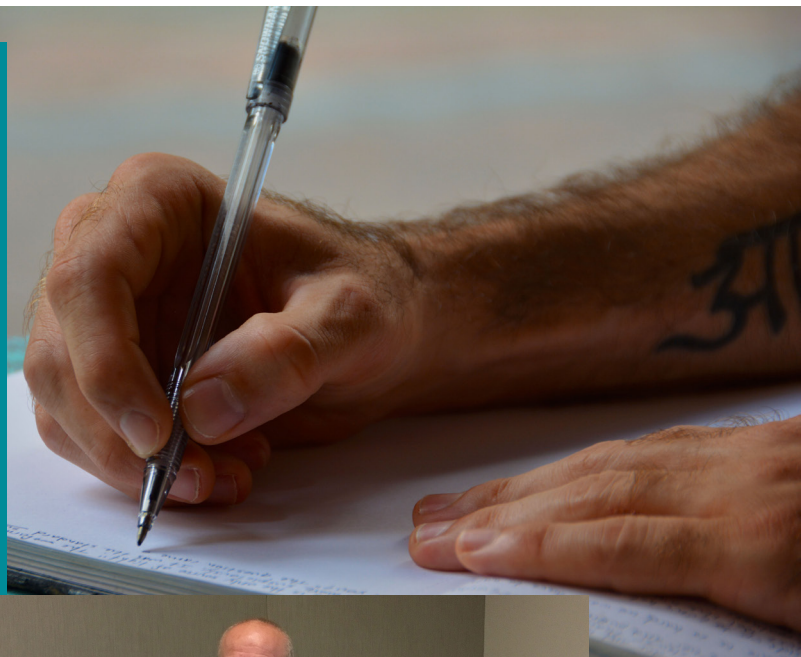
# ON LETTER WRITING

On 9 March 2018, four members of Donor Families Australia: Jann Eastley, Graham Harrison, Kevin Green and Bruce McDowell, made their own way from different parts of Australia to a meeting in Sydney with Lucinda Barry, CEO Organ and Tissue Authority (DonateLife) and Harry Burkett OTA Project Officer.

The topic was Letter Writing.

The discussion flowed and we all had a good chance to air our thoughts on how letter writing is done and how it should be done.

We look forward to hearing from the OTA as to what the outcomes from our meeting are.



## 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](http://www.donorfamiliesaustralia.org)



Donor Families  
AUSTRALIA

# Donor Families Australia

*is here to:*

## Care

and support families who have donated their loved ones' organs and tissue

## Educate

the wider community about the benefits of organ and tissue donation whilst emphasising the very important role of Donor Families in this process

## Advocate

and give donor families a voice in all aspects of organ and tissue donation

## Share

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

**Donor Families Australia is a place for Donor Families to go**  
**We want to hear all our Donor Families' stories and experiences**  
**We want to assist all Donor Families with what they are going through**  
**We will always act as a voice for our membership**

**Help us build a caring community  
and shape the future**



[www.donorfamiliesaustralia.org](http://www.donorfamiliesaustralia.org)