

Donor Families Australia EVAS

Summer 2016, Edition 15

HIGHLIGHTS

Thank You Day Round Up Around Australia Herd of Hope is on the Stampede

Deadly Boomerangs

Coping with Christmas -for the bereaved

Peer Support in New York

Ackers Weekend

MY BROTHER, BOOF

My brother Brian (Boof) was born September 10, 1958. He enjoyed everything about life. In high school he followed my Dad into the golfing world, which proved to be an interest he did very well at; he ended up with a handicap of one. He played lots of competition golf winning many awards, including a hole-in-one at our local club. My brother loved many different sports. He played local grade cricket. Boof also loved fishing and in later years, taught himself the guitar. Needless to say any party or gathering, there was a usual sing-a – long.

His love of fishing led to his fateful accident. In August 2015, Boof and his brother-in-law decided to launch his boat at Bonny Hills near Port Macquarie NSW.



Brian, AKA "Boof"

A little while into their trip, a set of rolling swell came through, unexpectedly capsizing their boat. Brian frantically called out to his brother-in-law, in which he held onto the boat, swimming around it and calling out to him. At this point, another lot of swell came through, pushing the boat and my brother into submerged rocks. This broke his leg which was a compound fracture at the ankle and below the knee.

His brother-in-law helped him to shore where witnesses to the event were waiting to assist them.

Brian was taken to Port Macquarie Hospital undergoing theatre to save his leg. At first, the doctors wanted to place a rod through his leg to repair it but were unable to due to him having had a knee replacement in previous years.

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MY BROTHER, BOOF

Over the next few weeks, Brian went to theatre on several occasions to clean the sand and foreign bodies, and infection from his wound.

He was placed in a halo-type brace to secure his leg and after a few weeks came home.

This process of going to theatre continued, even after coming home, as many infections reoccurred.

On January 13 2016, I rang him to say I was going to visit him. His reply was: "My leg is burning again sis.' Don't come; I'd say I'll be going back to hospital."

And yes, he went back to theatre again.

After this operation, a pick line was put in. This allowed him to come home once again.

During all this, my brother and his wife sold their family home at Lake Cathie and purchased a property at Wauchope NSW. This had been a dream of Boof's.

In mid-February, my brother was rushed to hospital, suffering chest pain. This turned out to be clots on his lungs. He was admitted to hospital again and treated to remove the clots.

On Thursday 25 February 2016, I spoke to him about helping him move and his words were: "Don't worry sis,' the mate's got a horse trailer and he and a couple of fellas will do it."

They moved in on 27 February 2016. He was extremely happy and treated himself to a beer on his back deck overlooking his property.

On Sunday afternoon, 28 February, we received a phone call from his sixteen year old daughter saying they had rung an ambulance as something was going on with Brian.

The minutes felt like hours until my sister-inlaw rang stating: "Jann, it's not good. They are preparing him to go to the John Hunter Hospital in the rescue helicopter."

I then had the dreaded task of going to inform my parents (Dad was 85 years old and Mum 82).

We travelled to John Hunter and waited for the helicopter to arrive; we were at the helipad to meet Brian and see him into the hospital.

We waited for what seemed to be an eternity in the Intensive Care Unit waiting room for the doctors to assess him. Eventually we were allowed in to see him. He looked very peaceful but we knew things were not good.

The doctors had a meeting with us, informing us that Brian had suffered a massive brain bleed and was showing no response. The doctors said they would perform more tests the next day to confirm his condition.

We took turns spending time with him until the early hours of the morning, hoping that this was all a dream, that he would wake up and be his normal self. This was not meant to be. On the Monday afternoon, he was pronounced dead, and it was confirmed by our family, that he would be a donor.





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Due to his medical condition, he was able to donate two kidneys and a liver.

At around 3 am Monday 1 March, Brian was taken to theatre. My sister-in-law played his favourite song, "Blackbird" to him.

Brian's donation helped save three people. We have had a letter from one of the kidney recipients who is doing really well. Our dream would be to meet these people one day and tell them stories of my brother.

Brian left a wife, four children and three grandchildren.







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.



ACKERS WEEKEND

On Saturday 12 and Sunday 13 November, we held our very first *James Ackerman Shield* cricket day: Team Ackers V. The Lucky Stars transplant cricket Australia team, raising awareness for organ and tissue donation.

James Ackerman became an organ donor after he lost his life playing the game he loved, rugby league on June 22 2015.

Donor families and recipients travelled from all over Australia to be here for our massive Ackers Weekend, remembering and honouring not only James, but all our donor heroes.

Team Ackers took out the shield and we look forward to doing it all again, bigger and better next year.

The Sunday saw our second annual James Ackerman Memorial Race Day, and for the

second year in a row. it was a sellout. This day means so much to James' family as its all about doing what James loved: having beer and bet with Mayes and family. Again we had a lot of donor families and recipients in attendance and we are truly greatful to have met so many amazing people.



A massive "thank you" to Kevin Green and the

Holyoak family for all their love and support over the two days.



CHAIRMAN'S MESSAGE

I am not sure if it has just been a very busy year or it is just something that happens as you get older but I have hardly had a chance to get used to writing 2016 and now we have to move on to 2017. My wife assures me it is more likely that I am getting older.

I would like to take this opportunity to reflect on the year that was. When I decided to put down some ideas, it became obvious that 2016 will be a year to remember.

To name but a few achievements for Donor Families Australia –

- Increased its membership by 92%. Its facebook page, at the time of going to print, had 1,132 members, where support and advocacy is provided to Donor Families and Recipients. Still the main issue that comes up is consenting recipients and families wanting to meet. Our committee recently watched a 60 Minutes report on this same topic; that TV report was done 16 years ago.
- All states and territories are now represented on its board of management.
- Our committee held its first face-to-face Planning Weekend in Sydney. Our 2016 Strategic Planning paper includes our five year strategic plan. Amongst other recommendations from the weekend our organisation has decided it is time to expand our services and become even bigger. To help with this goal, we need funds and have applied to become a charitable organisation.
- Our members have been busy spreading the message of donation awareness – giving talks to schools and community groups, working with the Indigenous people in the NT and mixing with other donation foundations / organisations and supporting their projects, nationally and internationally.
- Working with the media to publish articles in a medical journal, internet news and newspapers to help further raise awareness.
- During the year, proudly announced the great work done by our committee member

and **ACT** representative, Dr Holly Northam. in receiving her doctorate in Philosophy Health. in Holly's thesis was titled "Hope for



peaceful death and organ donation." DFA recommends this work to anyone wanting to know more about donation from the Donor and their Families' perspective.

- DFA held a Thank You BBQ in Melbourne last year and in this edition 12 months ago, announced that it: "would like to see similar things organised next year around Australia." With the financial backing of the Organ and Tissue Authority (OTA), DFA held seven Thank You Day events: in ACT, NT, Qld, NSW, Vic, SA and WA. Congratulations to all the DFA members involved in putting on these events.
- In more recent times, DFA proudly announced to Australia, the very exciting project being under taken by Megan McLoughlin and her Board, called the "Herd of Hope." Please read our most recent and future editions to keep up with what is happening; you don't want to miss this one.

Our committee has been very busy representing members and as Chairman, I would like to thank them for their tireless efforts in helping to improve the systems experience for Donor Families and to raise awareness of the importance of organ and tissue donation.

On behalf of the committee of DFA, I would like to wish all our members and readers a very peaceful Christmas and please be safe on our roads. We look forward to catching up with our readers next year.

Bruce McDowell





CONNECTING OUR PATHS ETERNALLY

Kevin Green, DFA Committee Member recently went to New York, USA, and met Lilly Julien, an amazing lady who set up the COPE Foundation, in honour of her daughter Michelle. Kevin shares a little about what COPE is all about.

In was in 1996, that Lilly Julien was inspired by a vision of parents also living with the loss of a child, informally gathering in the safety of each other's homes, to find comfort and support through simply being together and freely expressing their grief with others who could understand.

Over time, they found they could impact each other's lives in a meaningful way and remain connected to their children. They then began reaching out to other parents in similar situations and their group became a network with their experiences knitting together and resulting in the creation of COPE, a foundation dedicated to providing emotional support to individuals and families who are struggling to cope with life after loss. Formally recognised in 1999, today it's a support network of over 800 families healing together at COPE House in Eisenhower Park, East Meadow, and on Long Island.

COPE's programs include Camp Erin NYC – a free weekend bereavement camp for children and teens ages 6-17 grieving the death of someone close to them, and the Teen General Loss Bereavement Group. Their monthly healing workshops offer yoga, meditation, Reiki, art, movement, music, breath work and more. COPE also holds special events and workshops, professional forums, a grief support line and an extensive website, ongoing support group meetings and the one-on-one support of peer mentors.

LiveOnNY

Web: www.copefoundation.org



MY TIME WITH THE DEADLY BOOMERANGS

On 23 September 2016, I flew from Perth to Townsville to meet "The Deadly Boomerang's" mum, Vivien... I will explain.

My husband Peter died very suddenly in February 2009 in Perth. The loss and shock was indescribable.

On the transplant waiting list for a new liver was Tony David who was very, very sick. The transplant was a success and we eventually met years later and discovered we only lived five minutes apart in Perth. Tony has a nickname of the "Deadly Boomerang," given to him as he is the only World Champion Aussie Darts player (you can "google" his life). In Townsville, I met and was made so welcome by all Tony's family and friends. His mum, Vivien, is a lovely person - as is his son Alex.

That particular weekend, there was a darts competition named after Tony, called "The Boomerang Classic." Players came from all over Australia. I was introduced to so many of Tony's friends, all of whom thanked me for saying "yes" on behalf of my husband.

I am sure many of you will understand just

what it means to others when your "hero" has affected so many lives; it is very comforting and makes us very proud of our loved ones who are no longer with us.

Tony, after having the transplant, was able to marry his long time sweetheart, Natalie, who is also a darts player: ranked second in Australia and eleventh in the World. She is off to Japan soon to contest the Masters. Tony's son, Alex, is also an up-and-coming player and partnered his dad in the Boomerang Classic. The whole family did exceptionally well.

My trip to Queensland was beautiful. To meet Vivien (Tony's mum) and his friends confirmed that decision, made more than seven years ago, was the right one.

I strongly believe that there should be a better system in place to bring donor families and recipients together if they want to meet, as I know firsthand what a difference it makes and unites new families forever.

Philippa Waldron

Donor Families Australia, Perth



THANK YOU: DONORS AND THEIR FAMILIES

Holly's Insight This edition, *Holly's Insight* is an extract from her speech presented at the Canberra Thank You Day function.

I am deeply honoured to represent Donor Families Australia today-an extraordinary group of people who lead by example in saving life through transplantation. My name is Dr Holly Northam I am a Senior Lecturer at the University of Canberra and a Director on the Board of Donor Families Australia (DFA) and also Share Life Australia. Today I speak on behalf of DFA.

DFA are a national independent grass roots organisation comprising families who have donated their loved ones' organs and tissues-Increasingly live donors and recipients are also reaching out to this new organisation for

support and voice. Established in 2013, it is the only organisation in Australia specifically dedicated to organ and tissue donors and their families and specifically seeks to give voice to this vulnerable group of people who have often been hidden by regulatory practices.

Most importantly the organisation seeks to continue the gift of donors to save the lives of suffering people in our community. The organisation does this through its aims which are to provide care and support to all families who have donated their loved ones organs; to advocate for and give donor families a voice; to educate the community about the benefits of donation, whilst respecting, acknowledging and supporting those touched by donation decisions.

Thanks to a grant from Donatelife, DFA are staging numerous events today across Australia to give visibility to donor families and to encourage healing relationships across the donation transplantation community.

The ACT has many, many organ and tissue donors and their families to thank- and many others who would have donated

if they could have-we thank these wonderful people. Importantly we are also aware that for some, not donating has complicated their personal experience of grief- and we thank them for their wish to donate.

The high rate of donation in the ACT compared with the rest of Australia is indicative of our generous community- but evidence shows that the care and support provided to dying patients and their families in hospital by skilled doctors, nurses and the donation team is the greatest predictor of donation proceeding regardless of location. The ACT rates of donation are a tribute to our health care teams -and using internationals comparators can be compared with world's best. The ACT experience backs up evidence from Spain where there is no register, but instead a focus on expert care of donors and families at end of life when offering the choice of organ donation.



Dr Holly Northam with Hon. Minister Ken Wyatt

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The current ACT experience of low registrations compared to the rest of Australia shows that although the organ donor register is a useful tool to support organ donation decisionsto be effective it must be backed up by compassionate, respectful and accountable care of donors and their families in hospital and afterwards. In reality the donation is not a simple box to tick- the experience and consequence of making organ donation decisions can lead to significant suffering for the families involved- especially when staff are unfamiliar with what is required. The onus of responsibility must always fall to those involved to provide expert supportive care for as long as it is required- DFA help to address this need in our community.

There have been more than 7000 organ donors and an unknown number of tissue donors since 1989, but the people who agreed to donation and their courage and generosity are often invisible. Evidence that bereaved family decision-makers and the community perceive

donor families as invisible and unrecognised is a barrier to donation. Thank youday helps to address this possible barrier and I thank you all for supporting this initiative.

DFA seeks to address this and other barriers to donation arguing that grieving families should not be blamed if they choose not to donate, especially if information and communication are insensitive to the patient and their family's needs. Over the coming two years we will roll out a number of strategies to ensure that donation becomes a respected and normal part of end of life care in Australia- and donors and their families are visible, heard and honoured.

The ACT Chief Minister, Mr Andrew Barr, recently promised an organ and tissue donor reflection garden here at the Arboretum- this is just one goal that we will be delighted to support in the coming year. It must be remembered that making an organ or tissue donation decision is a decision that impacts on the lives for those involved forever. Thank you to the donors and their families...



"HOW DO I COPE WITH CHRISTMAS? IT IS SUCH A DIFFICULT TIME ALWAYS."

"This question is often asked by bereaved families," explains Diane Murphy, DonateLife Queenland's Familly Support Co-ordinator, "so I'd like to talk about practical ways to assist with coping at Christmas."

A resurgence of deep sorrow in response to the Christmas period is a normal experience for bereaved individuals. It is difficult because sorrow and pain are paramount for us; the season highlights our grief and loss and the absence of the person we love. Others seem unaffected by the absence of our loved one who seems forgotten and irrelevant to the world. They are full of anticipation of a happy time, when for us (the bereaved) there is a sense of dread. Feelings of sadness and vulnerability predominate.

The lead-up

Bereaved people describe the lead-up as often more difficult to cope with than the actual day. It is accompanied by feelings of anxiety and fear, regardless of whether the grief is recent or informed by the experience of previous years. Invitations may arise for social events and handling those can be tricky. One of the most difficult things even if we attend a function is that others don't mention our loved one any

more.

Alan Wolfelt says to be "bereaved" in part means "to have special needs." Pose the question to yourself,... "What are my needs?"

Are we trying to please others, or can we do what would be healthy and promote closeness to the person who died? How would I like to spend this day? Would a walk on the beach or the place where they loved to go help me?

Am I expecting others to read my mind and know what I need? Figuring out what you want is the hard part and communicating that to someone else can go a long way.

If I need to acknowledge or talk about my loved one at Christmas lunch or dinner, it's okay. In fact, if I honour the loved one by saying something or doing something, it could make it easier for others by expressing something they cannot find the words for.

How could I honour them and my own need to mourn them on this day?

The plan

It may be difficult to make a plan at all! A plan though can help to give structure to the day. It can also organise our thoughts and feelings which enhances our sense of mastery. It can be a very private plan (such as visiting the grave



or plaque site, saying a prayer) or something you would like to ask a friend or family member to share with you.

We can learn from the year before about when the most difficult time is. It may be Christmas Eve or Christmas Day, so that planning to do something specific or different for that time is essential. The plan can range from doing something formally to remember and honour the loved one or informally such as dedicating time to reflect. Even if we make a plan, it is okay to change the plan if you want. It may be very helpful to view changing as normal and not a failure.

Traditions and downscaling

Downscale – don't feel you have to do any tasks usually done. Ask for assistance with tasks usually done on your own. Identify what practices you would like to retain.

For many years after my mother died, I felt very guilty NOT making the plum pudding (which was a tradition loved and valued by her) and much to my relief, I found that other members of my family readily accepted that task. Explain to children this year is different. The tree is going to be a table decoration instead of the usual. Lunch will be a salad and not a roast this year. Family don't mind; it's the togetherness that matters. Giving yourself permission to make changes is the start of coping.

Prepare for the holiday period

Include in the plan, something that will help to get through the weeks. It may be a project such as reorganising the photograph album, creating a memory box, or writing a letter to the loved one acknowledging an aspect of the relationship that you really appreciated. List the songs they loved and play them, and cook their favourite food and eat it. During this time, you may like to write to your loved one's recipient/s or write out the story of your loved one's life for the DonateLife Book of Life. You may like to start writing poetry which can give voice to your story of loss and survival. Creative writing is known to help by re-opening a conversation cut short by sudden death. It may be a time to organise a grief buddy to make sure you have a chance to have a talk during the season.



Spiritual matters

One of the issues around coping with Christmas is the spiritual significance. Christmas may leave us with a sense of emptiness and meaninglessness.

Grief and loss may make us question everything that we believe. If we perceive our loss as untimely or unfair, it can challenge our sense of connection with our own faith or faith community. For a spiritually inclined griever, a troubling loss elicits confusion and complex emotions. Rebuilding one's spirituality is the task ahead.

Remember that DonateLife provides ongoing private and confidential counselling support in each state for all members of a donor family. You can access this at any time, even if you have never accessed or been offered this before.

Wishing you a peaceful and safe Christmas.

Diane Murphy

Family Support Co-ordinator Queensland

HERD OF HOPE: "STAMPEDING AHEAD"

They say that when God made time he made plenty of it. This would ordinarily be an asset but we just checked the count down clock to the Herd of Hope Organ and Tissue Awareness event in Sydney next year and is clearly stating: SIX MONTHS TO GO!!

There's so much excitement being created which is what we set out to achieve: to show our great nation the positive impact that donations have made throughout our country. We can only do this with your support. We invite you to take part in this once in a lifetime event.

Our aim is that on Sunday night, after the 40 head of cows have successfully crossed the

Sydney Harbour Bridge, that people sitting down to enjoy their dinner will start their conversation "Did with: vou see those cows on the bridge this morning for donation awareness?" As a result we have got them discussing tissue organ and donation and from which the topic is being brought to the attention of all, we have created a

positive example of the good that has come from giving people a second chance at life.

We are very proud to announce that the services needed are progressing well. The studies which will commence in the new year will be made available to all hospitals in Australia. This education to medical staff will be invaluable to improving the care of both donor families and transplant recipients.

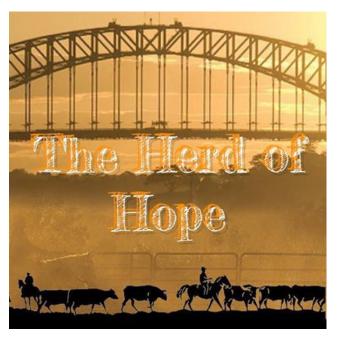
Please don't forget to join our Herd!

Visit www.herdofhope.com.au and register to take part. It will not cost anything to participate as we would like as many people to attend. Everyone from different backgrounds ages

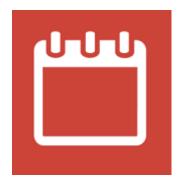
all with one thing in common-they have been touched by organ and tissue donation.

Please feel free to contact any of our board members if you require further information or would like to be involved. Check out our Facebook account, the Herd of Hope, as well as our website; they will keep you informed of our progression.

Let's bridge the gap in education together.



Upcoming Events



DFA News is d i s t r i b u t e d throughout Australia so advertising events across the nation here is a great way for everyone to know what is happening in each State or Territory and the

opportunity to join you.

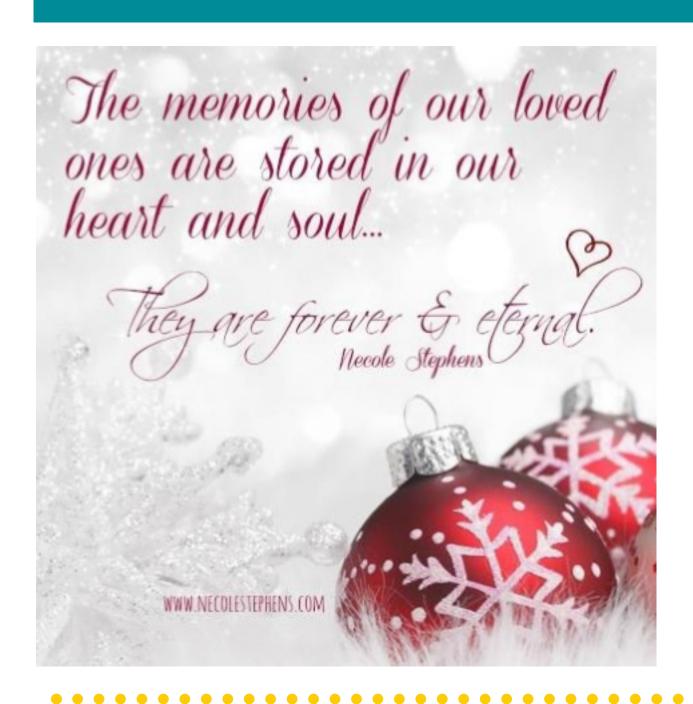
If you have a public event planned in relation to organ and tissue donation, whether you're a

Donor Family holding an event in remembrance of your loved one, a Recipient celebrating your gift or honoring your Donor, or you're involved with another organisation's event, please let us know and we can publish your event details.**

To advertise an event, contact us by our website: http://donorfamiliesaustralia.com/ contact-us

*We publish quarterly so please allow enough lead time.

*Please make sure the event is yours and/or that you are authorised to advertise the event details.



DEFINITION OF A 'HERO'

noun, plural-roes

A person of distinguished courage or ability, admired for brave deeds and noble qualities.
 A person who, in the opinion of others, has

2. A person who, in the opinion of others, has herioc qualities or has performed a heroic act and is regarded as a model or ideal.

3. AN ORGAN AND TISSUE DONOR





THANK YOU DAY AROUND AUSTRALIA

Around the country, Sunday 20 November saw a variety of events underway to celebrate DonateLife THANK YOU DAY.

This edition, we are so pleased to present a round-up of the events in each state and territory, supported by Donor Families Australia and well attended by many Donor Families and Recipients.

CANBERRA

DFA was pleased to have the Hon. Minister Ken Wyatt and his wife amongst other dignitaries to honor our Donor Heroes and their families on Thank You Day at the Margaret Whitlam Pavilion National Arboretum where around 70 guests were in attendance.

Aunty Agnes (a Ngunnawal Elder) gave a beautiful 'Welcome to Country' and a minute silence was held as part of the formalities, along with some wonderful speeches.

Two Donor quilts were on display – one from Transplant Australia and the other, "Tree of Life," was made in Canberra and carried a leaf sewn by family members to represent donors.

















NORTHERN TERRITORY

The Northern Territory Thank You Day was held in Darwin at the picturesque Lake Alexander Reserve. The event had around fifty people in attendance and Senator Luke Gosling, MP, the Northern Territory Minister for Health, Natasha Fyles, MP and Darwin's Lord Mayor, Hon. Katrina Fong Lim, attended and spoke at the event.

Dr Sarah Jones, Acting Medical Director, DonateLife NT provided a welcome speech to all who attended and introduced Senator Luke Gosling, MP.

Donor Family personal reflections were shared by Helen Day and Ian Berry. Our two recipient guests, Chris Blackham-Davison and Victor Punguatji, who are both kidney transplant recipients, also shared their own personal reflections.

Eight people signed up on the day to be organ and tissue donors including Senator Luke Gosling, MP.

A minute silence was held before a beautiful display of butterflies were released in honour of our organ and tissue donor heroes who both transformed and saved lives.







SOUTH AUSTRALIA

The South Australian DonateLife Thank You Day event was combined with Donor Families Australia (DFA) and DonateLife (DL) South Australia. A BBQ was held following the annual Rose Planting Ceremony at the Gift of Life Garden at Bonython Park, Adelaide. This ceremony is well known and attended by many donor and recipient families.

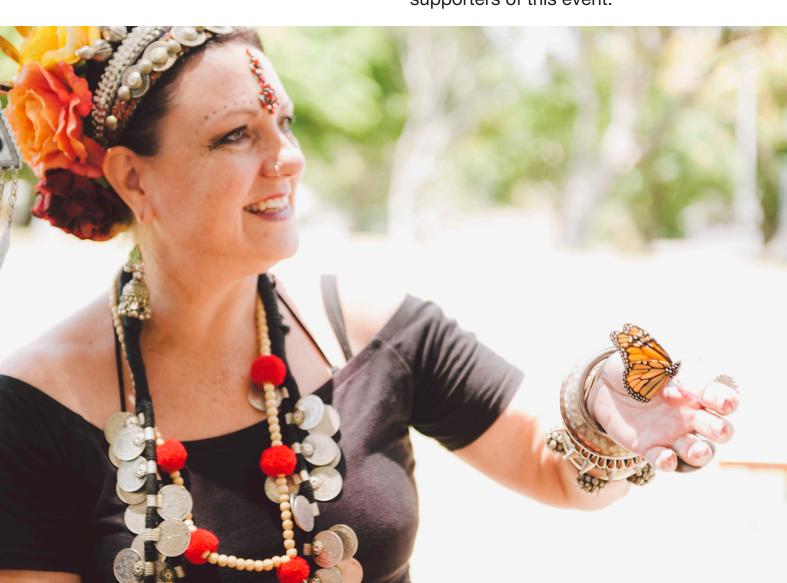
Our South Australian Committee Member, Lizzie Mazur spoke at the event sharing her journey and involvement in DFA. Lizzie's sister died whilst waiting for a transplant and then subsequently become a donor. Her speech highlighted the need to be a registered donor and she shared the joy of joining together to honour donors and their families on Thank You Day and how for a donor family, this holds great significance. Both Donor Families and Recipients spoke of their respective experiences and life changing benefits of organ and tissue donation.





QUEENSLAND

Thank You Day was celebrated at Strand Park in Townsville with a BBQ get together for Donor Families. The day was a celebration and poignant reflection on our Donor Heroes through dance, performed by a kidney recipient and her dance group. The event finished with a poem called "My Gift," backed by guitar prior to a release of butterflies by Donor Families, Recipients and the supporters of this event.





Donor Families Australia is here to:

Care

families and support 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

