



Donor Families  
AUSTRALIA

# Donor Families Australia NEWS

Autumn 2023, Edition 30

## HIGHLIGHTS

**Upcoming AGM:  
15 November 2023**

**Fight for Donor  
Family and Recipient  
contact continues**

**South Australia  
progress**

**Concerns over  
proposed law  
restricting donor  
family story  
ownership**

## POPPY'S STORY

**My name is Janine, and I am the very proud mother of an organ donor: my daughter, Brontë Elouise Haskins, fondly known as 'Poppy'. I would like to share Brontë's story with you, as well as encourage people to consider organ and tissue donation.**

Despite being a surprise pregnancy, Brontë was very much a loved and wanted child. The decision to be a single parent was not an easy one, given I had limited family support. However, I was fortunate to have some very good friends, who would go on to establish wonderful long-standing relationships with Brontë, and they became very much her extended family.

*Share  
your  
story*

Brontë was born on the 6 July 1996, a healthy 8lb 11 ounces. For me, it was love at first sight; she brought so much joy, not just to me, but to so many others as well.

When Brontë was seven months old, I met Peter, and we married when Poppy was sixteen months old. Brontë attended our wedding in a beautiful purple dress, which matched my purple dress, and she looked gorgeous.

Brontë adored Peter, and although she never called him 'Dad' personally, she referred to him as her 'dad' when speaking to friends and colleagues.

Brontë's brother, Bailey, arrived in January 2000, and along with her stepbrothers, Jamie, and Craig (from Peter's previous marriage), our family was complete. Mind you, it did take Brontë some time accepting she had a younger brother and was not the complete centre of attention!



Throughout her childhood and teenage years, Brontë enjoyed many adventurous family holidays, in both Australia and overseas. These experiences helped to cement her compassion and understanding of the world and provided her with a deep empathy for people and animals who were less fortunate.

*Celebrating*  
**1**  
*2013-2023*



*a life that touches others goes on forever*

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Overall, Poppy was afforded a happy childhood where she was very social and outgoing, very funny, and very caring; although, she had a red hot temper and we often recall some of her amazing tantrums – we can laugh about them nowadays!

Poppy enjoyed participating in an eclectic range of activities; she was a talented horse-rider, as well as a Joey, Cub, Scout, Venturer, animal rescuer, and a great friend to many.

As a Venturer, Brontë was awarded a meritorious medal from the Chief Scout for saving a fellow Venturer from drowning.

A keen sports person, Brontë was a formidable AFL player, and I'm so glad I wasn't at the receiving end of one of her awesome tackles!

In summary, our Brontë was an outgoing, gregarious, funny, intelligent, caring, and generous person throughout her life. Poppy was also our 'wild child'.

Once Brontë gained her driver's license, our gypsy girl was often out and about, and we could no longer keep her contained at our little property in Murrumbateman.

However, sadly, like many young people, Brontë also suffered from mental health issues; it is not at all uncommon in today's society.

In the ensuing years, Brontë lead a busy and eventful life, including relocating to Melbourne for a period of time to connect with her paternal family,

particularly her younger half-sister, Jess.

Unfortunately, whilst living in Melbourne, Brontë commenced dabbling in the use of illicit substances. Our belief is that Brontë was self-medicating due to her ill mental health.

Upon her return to Canberra, Brontë was initially doing well; she was working in the hospitality industry and appeared settled. However, it was also the beginning of a troubled period where Poppy found herself involved with an outlaw motorcycle gang and being figuratively 'owned' by a gang member.

Fortunately, Brontë was able to remove herself from the tentacles of these people and settled into a kind of 'normality'. She gained employment in the hospitality industry and developed the quality and skills of a great customer service operator. We previously owned a mobile baked potato business, and it was really Poppy that kept us grounded and focused.

Brontë later gained employment as a residential youth worker for children and young people living in out-of-home care. We watched our Poppy girl thrive in this work environment up until she was assaulted by a client, with the matter being settled out of Court.



*Share  
your  
story*



Then, in March 2018, Brontë was subjected to a prolonged and horrific physical assault by a so-called 'friend' she had been staying with. This resulted in Brontë being hospitalized and ending up in ICU after an adverse reaction to the dye contrast that was administered due to being strangled.

I believe the assault was the catalyst to life becoming chaotic and unmanageable; and the people Brontë

associated with regularly took advantage of her kindness and generosity. Around this time, Brontë lapsed into substance use again.

What I would also like to impress today is that our Poppy did not wake up one day and decide she wished to become a substance user as her vocation. Like every other young person, she had dreams and aspirations she wanted to fulfil.

Following a short stint at Canberra's prison in early 2020, Brontë looked the best she had for two years; she was lucid and eating well, and we all thought there was light at the end of the tunnel.

Poppy was directed to reside with us, and she moved into the flat under our home. For the first few days she was fine, however she lapsed back into substance use. The services resourced to support Brontë unfortunately failed her (and us, as her family).

On a Tuesday in February 2020 at about 3:50 pm, I received a phone call no parent ever wishes to receive: Brontë was in ICU in an induced coma after a reported attempted suicide. Three days later, we lost our beautiful girl.

On Thursday, we were asked to attend a meeting. The meeting was chaired by Brontë's treating doctor, with Donate Life ACT staff also being present. We were told that, through extensive testing, it was evidenced that Brontë had no brain activity, followed by the question of whether we would consider organ donation on behalf of Brontë. This was something we didn't have to think twice about; we knew it was absolutely the right thing to do.

The staff from Donate Life explained the processes involved in organ donation and answered questions we had.

Saying goodbye to such a loved child is by far the worst thing I have ever experienced, and our lives have changed forever. I would not wish this on my worst enemy. Whilst our lives will never ever be the same since we lost our beautiful Brontë, we do take solace in Brontë's generous donation of her organs.

Brontë was declared 'life extinct' the next day, however her organs were kept alive until they were retrieved by an amazing team of medical staff the day after that. The surgical team were flown in from Sydney and the surgery was performed.

Whilst we were devastated, we also knew that our Poppy would have liked to keep giving.

Recently, I was fortunate enough to meet up with one of Poppy's recipients; she received one of Brontë's kidneys and her pancreas. From being a Type 1 diabetic and undertaking dialysis every



second day, Brontë's recipient is now living a full and healthy life; she is no longer insulin dependent or undertaking dialysis.

The experience of meeting Brontë's recipient was amazing; there were tears, laughter, and a heartfelt connection. It was interesting that she asked me if Brontë liked peanut butter and scotch finger biscuits – yes, she did! The recipient said she now craves both peanut butter and scotch finger biscuits.

In summary, it is heartwarming to know that Brontë lives on in others.



At the hospital, consenting to organ donation made sense, and as a family we continue to feel that the biggest gift a person can give is the gift of life. To us, it was such a simple decision.

However, since then, I have learnt that the Organ and Tissue Authority (OTA) have submitted a Bill which essentially means that they 'own' Brontë's story and can do whatever they would like to do with it. This is something I do not understand.

Brontë has been the subject of magazine articles and a Compass (SBS) episode, where we had to consent to the content being viewed by anyone who could access it (nationally and internationally). We did not receive this option from the OTA and were not aware that they could take Poppy's story to do with what they wanted. So disappointing. If we had have known that at the time, I probably would not have consented to providing a speech at the Remembrance Day earlier this year.

Further, the Bill has clearly dissuaded many donor families to consider their consent to donate their loved one's (or their own) organs. This is evident from comments made on social media sites which provide a therapeutic and supportive (by choice) platform for both donor families and recipients. Personally, I would also have rethought these

implications if the Bill was implemented before we lost Brontë.

It also seems that the Bill will be influential in shutting down therapeutic social media sites by not helping donor families around the nation legally talk about their loved ones. If this eventuates, it will be damaging for families of organ donation and donor recipients.

Whilst donor families have made such difficult decisions to donate the organs of their loved ones. I can only wonder what the future will provide with these damning amendments when the Bill is implemented. Very, very sad.



# CHAIRMAN'S MESSAGE

Welcome to all our new members, our existing membership and others within the community with an interest in organ and tissue donation. It may have only been a few months since our last edition, but the work done in that timeframe on behalf of Donor Families has probably outdone any period in our ten year history.



I would personally like to thank and congratulate the Donor Families Australia Committee for their efforts over this period. I'm sure as you read on you will understand the enormity of the task we took on and appreciate the position taken on Donor Families' behalves.

First and always most important in our Newsletter is our Donor Hero story of Brontë. Mum, Janine, has provided us with a beautiful story of her life. Brontë achieved much and affected many in her too short life. Thank you to Janine and others who have contributed to this Newsletter. If any Donor Families wish to tell their loved one's story in future editions of our Newsletter, please email us at: [admin@donorfamiliesaustralia.org](mailto:admin@donorfamiliesaustralia.org).

Now more than ever in our ten year history, it is very clear that there is a lack of will amongst the public sector and some politicians to ever assist consenting Donor Family adults and consenting Recipient adults to meet. Donor Families Australia has taken it upon itself to implement such a process. Read how you can be part of this very important development and how you could be assisted to meet your consenting Donor Family or consenting Recipient. The more people that register, the more effective the registry becomes.

SA Committee member, Jackie Robson, has reported on her very important meeting with state government department heads. Donor Families Australia welcomes SA public sectors in consulting with Donor Families.

We have again featured the wonderful work done by Nagle Catholic College in Geraldton WA. Its students have been hard at work improving the garden area around the Donor Awareness Fountain honouring our Donor Heroes. If you are a Donor Family member from the Midwest area of WA or know of a Donor Family in this area and want your loved one to be honoured on the Fountain wall, please make contact with us.

It's AGM time of the year. Donor Families Australia will be holding our AGM on Wednesday 15 November 2023. Anyone interested in joining the



committee will need to ensure their membership is up to date. Nomination details and forms will be forwarded to all members.

On 10 August 2023, the Federal Upper House passed the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 around disclosure of information. It was not until late May 2023, via notification from a Donor Families Australia member, that we even became aware of this Bill's existence. It was clear to Donor Families Australia that the Organ and Tissue Authority (OTA) and Federal Health Department were endeavouring to have this Bill passed without Donor Families being aware of it.

Please read included articles from Paul Cross and Donor Families Australia's letter to the Joint Committee on Human Rights Australian Parliament House. These articles help to form a better understanding of what has been passed, and will be implemented in February 2024.

Major concerns or elements of this Bill are:

- Lack of consultation. Not one Donor Family was consulted despite the Bill being *about* Donor Families.
- The speed at which this Bill proceeded through Parliament with the intent of no one knowing about its existence is a very concerning development especially if there is to be any trust between those implementing policy on organ and tissue donation and the community.
- We now have in place two levels of government legislating on what Donor Families can say and do.
- It now confirms that Donor Families do not own and control their loved ones information, with the one exception, the ACT.
- "It removes the prohibition for Donate Life and the OTA to share family stories", as provided from the Minister of Organ and Tissue Donation,

Ged Kearney's office. Once the family has consented for their loved one's story to be passed onto Donate Life and the OTA, and this is published, shared or presented (remembrance service) the family no longer controls that story i.e. Donate Life, the OTA, the media and or any other community member can freely access that story and republish without any knowledge or consent from the family. (DFA will be insisting that families be given a consent form to sign letting them know what it means to pass on their loved one's story to Donate Life or the OTA).

- If families have already had their loved ones stories published or disseminated by Donate Life and the OTA and are not willing to have their story passed on by them via "secondary publication" as referred to in the legislation, they have until February 2024 to have their loved one's story rescinded.
- If families pass on their loved one's story, it must meet four activities as laid out by the legislation. How do Donor Families know if the story fits the activity criteria as laid out in the legislation? Will there be activity monitors to ensure families are obeying the legislation? Why should Donor Families have to relinquish their freedom of speech when discussing their loved one's donation?
- This legislation overrides states and territories. In so doing it ensures that the public sector workforce no longer contravenes their respective legislations as they have been doing for decades. However it does not ensure that Donor Families no longer contravene their respective legislations. An example of this is in WA, SA and the NT where it still is unlawful for Donor Families to meet and share their stories by way of supporting each other. Why wasn't the legislation amended to consider the impact on Donor Families and their freedom of speech? What message is being delivered to the community when governments are protecting their own staff but not the families of Donor Heroes?
- If Donor Families don't want to be caught up in the Federal Governments bill, they can simply not consent to pass on their deceased loved ones story to Donate Life or the OTA or if they have already done so have the story rescinded.

Donor Families Australia feels that the new Bill is a case of total over the top legislation increasing the anxiety and grief to a group that has already experienced enough. We would like to think that the

public sector and the government should be making every endeavour for the donation process to be as simple and as kind on those personally impacted, but on 10 August 2023, it achieved the opposite.

During our lobbying to the Federal Parliament to make changes to the Bill, Donor Families Australia would like to thank, firstly the (pro bono) legal advice provided by Lavan on what the new Federal law means to Donor Families. This meant that Donor Families Australia was able to talk about the Bill from a legal perspective with a better understanding on how it would impact our members.

Donor Families Australia had great backup from the legal minds of Felicity McNeil and Paul Cross. Both were able to guide us as to our next moves as we travelled through uncharted waters. Their ability to strategically manoeuvre the days' transactions assisted the Donor Families Australia committee to continue on regardless of what was put in front of us.

Special mention goes to committee members Dr Holly Northam and Philippa Delahoy. Both virtually put aside their day jobs for four weeks as we all went on this roller coaster ride of talking and writing to anyone that would listen.

As committee members made contact with politicians and their staff, there were those that stood out and were prepared to go that bit extra for organ and tissue donation. Special thanks to Senator Linda Reynolds MLA who gave a wonderful speech during the passing of the bill through the Upper House (view online at: <https://www.youtube.com/watch?v=IMCpaqxPx78&t=157s&authuser=1>).

To quote the Senator: *"I am almost speechless to think in this day and age, we would prevent consenting donor families and consenting recipient families from meeting and sharing where they are consenting to do so"*.

Senator Perin Davey MLA also presented the case against the Bill. To quote the Senator: *"This legislation is designed to restrict the human right of freedom of speech... when donor families say yes to donation, unbeknown to them they have handed over to the government their loved one's information"*. (view online at: <https://www.youtube.com/watch?v=3Th6zOWgvwl>).

Senator David Pocock and his staff helped with seeking assurances from the Attorney General Hon Mark Dreyfus KC MP for the Australian Law Reform Commission to prioritize the national harmonisation and humanisation of the National Human Tissue Acts. Thanks also to the offices of Senator Lidia

Thorpe, Senator Jackie Lambie and Senator Jordon Steele-John.

This edition of our newsletter has focused predominately on the legislation to ensure our members are kept fully informed on the issues that directly affect them. Thank you to our membership for entrusting us to work on your behalf.

**Bruce McDowell**

Chairman

Pictured: Scenes from Geraldton WA where Nagle Catholic College students have been hard at work improving the garden area around the Donor Awareness Fountain honouring our Donor Heroes.



# INSIGHT TO DONOR FAMILY EXPERIENCES

**In August, as the South Australian representative of Donor Families Australia, I was invited to a meeting with a number of government officials.**

In attendance were the Family Support Co-ordinator from DonateLife, Director for Blood, Organ and Tissue Programmes (Department for Health and Wellbeing), Executive Director from Public Health Planning and Response, (Department for Health and Wellbeing) and Registrar, Births, Deaths and Marriages (Attorney-General's Department).

The meeting was very positive and participants were genuinely wanting to hear from Donor Families Australia on topics that concerned donor families. This was the first time that Donor Families Australia had been invited to a meeting with department officials and I encouraged with those in attendance the need to consult with donor families on topics that affect them and topics that they have lived and experienced.

There were three main topics that I discussed. Following are some of the main discussion points.

1. The Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023.
2. Death Certificate acknowledgement.
3. Consensual meetings between donor families and recipients.

## **The Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023**

This Bill has already passed, albeit as an interim bill. According to the Bill's explanatory memorandum, its purpose is to "broaden the disclosure of information provisions" in the enabling legislation for the Australian Organ and Tissue Donation and Transplantation Authority (OTA).

However, Donor Families Australia believes (and we have had legal advice) it will have the opposite effect.

The change effectively requires me to hand over my experience and that of my loved one to the OTA and/or Donate Life SA if I don't want to be prosecuted for speaking about my husband. And once Donate Life have vetted my loved one's story to comply with the new legislation's four activities myself and my family are confined to that version or, again, risk prosecution. My husband, a healthy 61

year old died extremely suddenly and myself and my children made the decision to donate Pete's organs during a time of extreme grief and shock. That is *our* story and we should be able to share *our* loved one's story in any format, whenever and to whoever we want to. It helps everyone to be able to share their grief.



There is a need to make SA legislation donor family friendly and in so doing encourage the community to become donors. As per the clause of the SA Tissue Act, donor families are not permitted to speak about their deceased loved ones in relation to organ and tissue donation as that would make the deceased donor publicly known, placing the donor family in fear of penalties and or fines up to \$20,000. Donor families should not have the additional burden of having to worry about what they say or do in relation to their loved one's donation. Legislation should be that under no circumstances can families be prosecuted, and families should own and control their deceased loved one's information. Families should have the authority to give consent for their loved one's information to be published and disseminated unconditionally.

Families should not be legislated by two levels of government which has now occurred because of this bill. Each state and territory maintain laws that guide and restrict the sharing of information about organ and tissue donors. This bill overrides these restrictions. This legislation needs to be redone so that all states and territories are affected equally.

## **Death Certificate Acknowledgement**

You may know about the very important legislation that passed in the ACT Legislative Assembly last year with tri-partisan support. This legislation gives organ and tissue donor families the option to have their loved one's donation recognised on their death certificate regardless of whether it was given while they were alive or following their death, and to receive a letter of acknowledgement from the chief minister —an Australian first. Requests for a letter from the Chief Minister, or for changes to the death register, would only be able to be made by the family, with the provision of verifying information. There are a number of existing avenues for recognition of organ donation, including an acknowledgement letter from DonateLife, the Gift of Life Walk and

the annual Services of Remembrance. However apart from these there are no other formal, tangible avenues for families to see the significance of the donation acknowledged. Being able to have the donation placed on death certificates would mean a great deal to all the families who have gone through such a difficult decision, as would a formal acknowledgment by the chief minister.

By going down this path, it allows the family to make the request at any time. Importantly, by being optional, up to the family, and not time limited, it gives the family control and agency in deciding how and when they wish to have their loved one's donation recognised. But the proposed amendment bill in its current form and the SA Tissue Act will not allow the sharing of the organ and tissue donation information about the individual donor with the Registrar, as this is not one of the four activities sanctioned by the OTA and DonateLife.

### **Consensual meetings between donor families and recipients**

We know many Donor Families and Recipients want consensual meeting. From our experience this has provided a great amount of support to both parties (i.e: the recipients and the donor family) as they take on the challenge of their grief and recovery. In this day and age, it is incredible that consenting adults cannot meet.

I thanked everyone for initiating the meeting and I informed them I was more than willing to attend future meetings on behalf of Donor Families Australia. It shows us that at least some government agencies especially here in South Australia recognise how important it is that donor families are listened to and that Donor Families Australia can be a conduit between donor families and the state.

**Jackie Robson**

SA Member Representative



# AGM

## **ANNUAL GENERAL MEETING**

**Time/** 8 pm AEST

**Date/** Wednesday 15 November 2023

**Venue/** Via Zoom (link provided to all members)

**To Attend/** Email: [admin@donorfamiliesaustralia.com](mailto:admin@donorfamiliesaustralia.com)

# PROPOSED LAW TELLS FAMILIES TO DO IT OUR WAY OR RISK PROSECUTION

**The Senate is considering new laws that have raised serious alarm amongst families who have each contributed significantly to patients and the health system.**

A Senate committee will report on the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 next week. The report will coincide with DonateLife Week.

According to the Bill's explanatory memorandum, its purpose is to "broaden the disclosure of information provisions" in the enabling legislation for the Australian Organ and Tissue Donation and Transplantation Authority (OTA)

likely to enable the identification of the deceased donor or recipient if it is for the purposes of either the OTA's or a DonateLife Agency's educational, commemorative, promotional or community activities that are relevant to an organ or tissue donation and transplantation matter."

It adds, "This provision does not allow for the publication, dissemination or disclosure of information for activities beyond the remit of OTA and DonateLife."

In its submission to the inquiry, the Department of Health and Aged Care (department) said, "The Bill seeks to broaden the disclosure of information provisions in the OTA Act to allow DonateLife agencies, grant recipients and 'authorised family members' to publish, disseminate or disclose



However, donor families believe it will have the opposite effect. They argue that the Bill includes a provision that practically restricts them from talking about their experience other than via official campaigns run by the OTA, DonateLife or a related entity.

The provision relates to the publication, dissemination or disclosure by an authorised family member.

The explanatory memorandum says, "This item stipulates that an authorised family member of a deceased organ or tissue donor or recipient may publish, disseminate or disclose information that is

information about deceased donors/recipients for the purposes of the OTA'S community awareness, promotional, educational or commemorative activities, without breaching law of a state or territory."

It added, "It does not create any new restrictions on disclosures."

Yet that view is not shared by donor families. They say the change effectively requires them to hand over their experience and that of the donor to the federal government and align their activities to those of the OTA or DonateLife.

Bruce McDowell's daughter passed away and became a tissue donor. In his submission to the inquiry, Mr McDowell says, "Donor Families should be able to freely tell the stories of our loved ones within our community, without the approval of the OTA or a DonateLife agency and without connection to the OTA and DonateLife activities. When I said yes to organ and tissue donation I did not expect to lose control of my loved ones information."

Philippa Delahoy is the secretary of Donor Families Australia. In her submission to the inquiry, she says, "My husband, Scott, became an organ and tissue donor on 21st January 2011; a remarkable legacy that tells you everything you need to know about this beautiful, generous, optimistic, community-minded Australian."

"When I consented to the donation of Scott's organs and tissue, I did not consent to handing over ownership of Scott's donation story to DonateLife or the OTA.

"In retrospect, I have serious doubts about whether I would have consented to the donation, if I had known that the Government would attempt to introduce such draconian measures restricting my freedom to share Scott's story," says Ms Delahoy.

The government's failure to consult them on the change has compounded donor families' anger.

The department acknowledged this absence of consultation in its submission to the inquiry. It

said it consulted with the OTA, the Department of the Prime Minister and Cabinet, and the Attorney General's Department.

The department disputes the donor families' interpretation of the changes. Yet it does acknowledge that protections are conditional on donor families aligning their activities with OTA or DonateLife.

Each state and territory maintain laws that guide and restrict the sharing of information about organ and tissue donors. The Bill being considered by the Senate overrides these restrictions but only where donor families provide their consent to OTA or DonateLife and their separate activities align with those of these agencies.

The Bill does not protect donor families from action by the jurisdictions where they do not provide consent or align their activities.

The department's submission to the inquiry confirms this exclusion. It says, "Where a family chooses to consent to the OTA or a DonateLife agency using information about their loved one for community awareness, educational, promotional or commemorative activities, that family will continue to be able to engage in other communications about their loved one. Where those communications align with the purposes of the OTA Act, it will operate to remove any risk of those activities being inconsistent with relevant state and territory laws."

# COALITION CALLS FOR INQUIRY EXTENSION IN SENATE COMMITTEE REPORT



## **The Coalition has urged a Senate committee to extend its inquiry into changes to organ and tissue arrangements that have raised alarm amongst donor families.**

The Senate Community Affairs Legislation Committee has published its report on the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023.

According to the Bill's explanatory memorandum, its purpose is to "broaden the disclosure of information provisions" in the enabling legislation for the Australian Organ and Tissue Donation and Transplantation Authority (OTA)

However, donor families used their submissions to the inquiry to argue that the Bill includes a provision that practically restricts them from talking about their experience other than via official campaigns run by the OTA, DonateLife or a related entity.

Their concern has been compounded by the lack of consultation on the Bill.

The Bill protects families from prosecution under state and territory laws restricting communication about deceased donors but only where they consent to share their story through OTA or a DonateLife agency. Their own activities must also align with those of the government agencies to be protected from prosecution.

The Senate committee, chaired by Labor's Marielle Smith, has acknowledged the concerns of donor families in its report but recommended that it be supported.

The committee accepted reassurances from the OTA that Bill "will not affect the ownership of information relating to deceased donors and recipient, and that the bill does not impose any restrictions on how family members conduct community awareness, promotional, educational or commemorative activities or engage in any other communications about their loved one."

The health department also described the changes as "interim" to address immediate issues pending a broader review of state and territory laws "to properly resolve the disclosure of information issue as well as the other identified inconsistencies."

In its additional comments to the report, Coalition senators said, "The Coalition supports the intention of this Bill however it has concerns over the failure of the Labor Government to properly consult and communicate these changes."

"While this Bill does a lot to expand the list of authorised family members and permits the Organ and Tissue Authority, DonateLife agencies, grant recipients and authorised family members to publish, disseminate or disclose information about deceased donors for the purposes of the OTA's community awareness, educational or

*Thank you*



*for your legal advice and support*

commemorative activities, it doesn't address concerns regarding the rights of donors, donor recipients and their families," they said, adding, "While the committee received a guarantee from the department that this amendment won't impact the rights of organ donor families and recipients, more work must be done to clarify their concerns, or else this legislation will risk sending organ donation backwards."

The Coalition said the committee "must seek an extension from the Senate for this inquiry, so that donor families can have the opportunity to properly engage with the legislative process for a Bill that directly impacts them, and so that this committee can explore other ways in which this Bill can be improved upon."

"Lavan was delighted to be able to provide some pro bono assistance to Donor Families Australia on an issue that is understandably of high importance to the members of Donor Families Australia and their families. It is pleasing to see that some progress is being made to change this anomalous situation. It is fair to say that we were more than surprised that the law placed the restrictions that it does on responsible publication of donor stories. The reaction from those whom Donor Families Australia has lobbied suggests that our surprise was shared by those whom Donor Families Australia lobbied.

For those not familiar with Lavan, we are a full service law firm, based in Perth, but with access to a network to provide legal services Australia wide.

As part of our commitment to the community, we have a very active focus in the area of pro bono, as well as other areas of appropriate community and social issues. We believe that the role of a law firm extends to playing an active and responsible role in our community. Our assistance to Donor Families Australia was an expression of that commitment.

We wish Donor Families Australia well in its the ongoing steps fully to correct this legal anomaly and stand ready to assist."

***Iain Freeman***

Lavan

# DONOR FAMILY-RECIPIENT FIRST PERSON CONTACT: NOW IS THE TIME!

**The Federally led Organ and Tissue Authority have made it very clear that it has no intention of ever allowing consenting Donor Families and consenting Recipient to meet. Their DonateLife offices around the country have gone to great lengths to ensure this will not happen.**

As a result of this backward approach to organ and tissue donation Donor Families Australia has put in place its own contact registry. If you wish to meet with your opposite, please read on and follow the steps put in place by Donor Families Australia.

From the inception of organ donation and transplantation worldwide, those in the medical and psychology arena have made the decision that such contact would be detrimental to both Donor Families and their Recipient, as well as having a negative impact on the organ donation and transplantation system that may well reduce organ/tissue donation rates across the community.

However, Donor Families Australia has been very conscious of the increasing interest being expressed by Donor Families and Recipients and their families to have a formal process that will enable consenting parties to meet in person. Along with this interest has been a number of meetings arranged by the Donor Families and Recipients. The response to these meetings has been very positive.

This trend has been gathering momentum in countries around the world and has been trialled within Australia for a period of a few years during the early 2000's within Transplant Australia resulting in 13 successful meetings. During 2016/17, there were two forums, both held in Melbourne, discussing the topic of First Person Donor/Recipient contact by consenting parties. Donor Families Australia members attended both meeting and were encouraged to note that the



consensus was near to 100% in agreement that those in attendance supported donor-recipients meeting providing that both parties have consented. This view was also shared by the ethicist leading the discussions Ms Dominique Martin. Further support has been given from the most recent Ernst and Young review on organ and tissue donation stating at Recommendation 26 That consenting donor families and consenting recipients should be assisted to meet.

However, the bureaucratic wheels turn slowly and for OTA/DonateLife to be involved would require the Federal and State amendments to their respective legislation. During the years that followed it has become clear that the OTA which has been established to both serve Donor Families and Recipients, has no intention of proceeding in this matter.

In frustration, Donor Families Australia established its own a Donor/Recipient Contact Registry where Donor Families Australia membership involving its Donor Families and associate Recipient members could freely register their own person details and give their consent to be able to contact directly with each other. A detailed protocol was developed and scrutinised by Dr Holly Northam OAM, (PhD, RN, RM, M CritCareNurs) Associate Professor in Nursing at the University of Canberra (UC) who has achieved a Churchill Fellow (2006) in organ donation ethics.

In February 2017, DFA went live with its Donor/Recipient Contact Registry (accessible at the Donor Families Australia website—[donorfamiliesaustralia.org/contact-register](https://donorfamiliesaustralia.org/contact-register)) which provides the three steps to register. The shortcomings of our Donor/Recipient Registry is that it only becomes more effective as more Donor Families and Recipients register their information. The accuracy of the Registry is also strengthened by the depth of information provided, including copies of correspondence between parties.

During the past six months, the OTA/DonateLife has succeeded in forcing changes through the Federal Parliament concerning the Federal Tissue Act, Disclosure of Information Clause 58A, once again without any consultation with the parties involved – the donor families and recipients. Following the passing of the amendment Bill, Liberal MP Ms Linda Reynolds stated in Parliament that if both parties consent to make contact, then it should be legally made possible for those that are seeking emotional closure.

If both the Adoption and IVF legislation, as part of history, can be changed to accommodate contact between parties, why is Organ/Tissue Donation and Transplantation so different?

The powers that be are often asked why this draconian legislation remains in place. They always

respond by bringing up the fear factor—that donor families are potential extortionists and stalkers.

What is the reality? Contact brings closure to both parties. For donor families, they seek confirmation that their loved one's gift has given some relief or even extended the life of a recipient who would otherwise face imminent death. For recipients, they seek to know the back story of the donor that has made such a change to their lifestyle and the family that supported their loved one's wishes to donate.

Our feeling is that the bureaucrats may be watching too much American TV or movies, and when asked for proof, none is forthcoming.

The simple fact is that when a meeting of donor families and recipients and their families is either televised or publicised in the press, it is always an uplifting story which is good for the organ donation rate overall.

Let's all raise our voices to change this injustice and allow consenting donor families and their recipients to have first person contact.

**Graham Harrison**

DFA NSW Representative

Dear friend of David Ridoutt and family who was son, Ben's, kidney recipient until his passing

*C'mon South Australia!*

Congratulations to the Hon Nicola Centofanti MLC for putting forward a Bill in the South Australian parliament to acknowledge donation on death certificates.

On 29 September 2023, the Bill was passed in the SA Upper House. It now needs to be passed in the Lower House. Here's a chance to see how much the SA Labor Party dominated Lower House wants to fix the declining consent rates in its State. What better way to tell the community just how important donating one's organs and tissues are to those in need and how highly we regard those that do.

If you live in SA, and want to have this Bill passed, please let your local state MP know what it would mean to have this acknowledgement on the death certificate if you so choose. Here's a chance for SA to be the first state in the nation to do so—behind only the ACT!

*\*see next page for Media Release*

# MEDIA RELEASE



## **Hon Nicola Centofanti MLC**

Leader of the Opposition in the Legislative Council

Friday 29 September 2023

### **Honouring those who gave the gift of life**

Families are now closer to having their loved one's organ and tissue donation recognised in the death register and on the donor's death certificate after legislation introduced by Leader of the Opposition in the Legislative Council, Nicola Centofanti, passed the Upper House.

Under the Births, Deaths and Marriages Registration (Tissue Donation Statements) Amendment Bill 2022 it would be a free, opt-in process for families with no time limit – which means those whose loved one was an organ or tissue donor before the change comes into effect would have these acknowledgement options available to them.

Dr Centofanti said this could provide an opportunity for a simple yet meaningful way to pay tribute to those willing to give others a second chance at life.

"The decision to donate is an incredible gift, with organ and tissue donations transforming and saving many lives across the country each year and I believe it's important families have a formal option to have their loved one's gift recognised," Dr Centofanti said.

"While the remarkable act of organ donation will be forever remembered by families, having this acknowledgement in official records creates a lasting tribute to these selfless South Australians.

"I know it won't be for everyone, but for some, it will mean a great deal to have official recognition of their loved one's donation. It will help ensure the memory of the generosity of their loved one - in life and in death - is recognised and their actions live on.

"The passing of this bill marks a significant step forward in acknowledging those who generously gave the gift of life."

In 2020, the ACT became the first jurisdiction in Australia to provide the opportunity for a donor's next of kin to apply to have the statement "The deceased gave a gift of life, generously donating organs/tissue" added to the death register and the donor's death certificate.

If you want to be a donor, make sure you tell your family and friends. Registering is easy, please visit [www.donatelife.gov.au/register-donor-today](http://www.donatelife.gov.au/register-donor-today)

Media Contact: Ben Harvy 0430 306 424



Donor Families Australia celebrating our 10<sup>th</sup> anniversary



28 July 2023

**Parliamentary Joint Committee on Human Rights**

**Australian Parliament House**

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Dear Committee members

## **REQUEST FOR COMMITTEE REVIEW OF ORGAN AND TISSUE AUTHORITY LEGISLATION IN LIGHT OF COMMUNITY AFFAIRS LEGISLATION COMMITTEE REPORT**

Donor Families Australia (DFA) is writing to you in your role as members of the Parliamentary Joint Committee on Human Rights to ask you to review the *Australian Organ and Tissue Donation and Transplantation Authority Amendment (Information Disclosure) Bill 2023* in light of the Community Affairs Legislation Committee's report into the legislation. We are asking for your support for this Legislation be subject to further parliamentary scrutiny prior to passage by the Senate as recommended by some members of the Community Affairs committee (para 1.19 refers).

Members of DFA have already spoken to Senator O'Sullivan and the Member for North Sydney, Ms Kylea Tink MP, but are formally approaching your committee for support on our request for greater consultation and discussion on the proposed changes contained in this Bill.

### **WHO ARE DONOR FAMILIES AUSTRALIA?**

[Donor Families Australia](#) (DFA) was established in 2013 and is the only organisation that represents Donor Families nationally. Our 1000 strong membership comprises of families who have donated their loved ones' organs and tissue. We advocate and give donor families a voice. We educate the wider community about the benefits of organ and tissue donation, whilst emphasising the very important role of donor families in this process. As such, only we can speak from lived experience of how this Bill will directly affect our membership and donation and consent rates in the future.

### **WHY ARE WE SEEKING COMMITTEE'S SUPPORT FOR FURTHER CONSIDERATION OF THIS BILL?**

DFA notes that in the report of the Community Affairs legislation Committee released on 26 July 2023, your committee made no comments on this Bill (para 1.36 refers).

We are asking you to reconsider this in light of the ongoing restrictions that are placed on donor families and transplant recipients in sharing their lived experience and owning their own stories, both under federal and state and territory laws. ***This Bill does not go far enough in protecting the human***

***rights of organ donors and recipients in both owning and sharing their information with the community.***

When someone dies suddenly because of cancer, suicide, aneurism, flu, cardiac arrest, diabetes there is no contemplation by the government at any level to preclude a family from talking openly about their loved one and their experience. No limitation on them sharing their story to help others, raise money for others or just how they choose to grieve and remember their loved one.

But if in the course of their sudden and tragic death, a loved one becomes an organ and tissue donor, federal, state and territory laws place restrictions on a family's right to talk about and share their loved one's experience, their experience of donating the gift of life.

This Bill goes some way to try and address this issue at the federal level for the purposes of the work of the Organ and Tissue Authority (OTA) and Donate Life agencies. However, it is neither clear that it will not inadvertently restrict the use of information by families, and most importantly has not taken the opportunity to address this issue at the state and territory level where extreme restrictions will continue to be in place. This view is not just that of DFA, with the Community Affairs Legislation Committee noting that their finding that the Bill would not affect the ownership of information was 'on balance' only (para 2.47). If the Committee could only come to this conclusion, the concerns of the Community who are not legal experts can be readily understood and need to be further discussed.

***This Bill was introduced to Parliament on 2 June without any prior notice to the community.*** The Department of Health and Aged Care (DOHAC) confirmed in their written submission [<https://www.aph.gov.au/DocumentStore.ashx?id=1796e53a-6372-4dde-a087-3a7861ebf71b&subId=744879>] they consulted with the Departments of the Prime Minister and Cabinet and Attorney General's, and with first nations people on the definition of a 'family member' but at no time did they consult with the community – donor families or recipients.

Given this Bill makes changes to individual and family use and ownership of their private family information (recipients or donors), this in itself is grounds for concern about denying the community the opportunity to contribute to the development of laws that have a significant impact on their day-to-day life. This has been a repeated area of concern identified by multiple Parliamentarians in both houses [<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=ld%3A%22chamber%2Fhansard%2F26702%2F0036%22>].

More importantly, if they had, organisations such as ***DFA would have recommended legislative drafting similar to the ACT which ensures that there is no doubt in who owns the personal information of a lost loved one.*** If they had DFA would have highlighted the continuing travesty that is the state and federal human tissue acts that can make it a prosecutable offence for some families to come together and discuss their loved ones and their organ and tissue donation.

In response to our raising of concerns, the OTA on 21 July confirmed that "[e]ach jurisdiction has its own Human Tissue Act (HTA), and these have varying limitations around the disclosure of information that may identify an organ and/or tissue donor and/or transplant recipient. While these provisions all have the same intent...there are differences about who is prohibited from disclosing information... [t]he provisions in [NT], [SA] and [WA] go further by prohibiting all persons from disclosing information, including the family members of donors". They further confirmed this Bill will not address this issue.

In response to our submission the DOHAC provided responses to questions without notice from the Committee and advised the Bill was now an 'interim measure' and they 'will continue to work with jurisdictions to progress this work' (para 2.41). ***Whilst a commitment to resolving the human right discrimination within the HTAs in each state and territory are welcomed, in a subsequent meeting***

**with the Department, DFA was advised this is not a priority.** The formal minutes of the meeting failed to even include the discussion of this issue.

Further, the lack of any discussion of this by the Minister in her speech or inclusion in the Explanatory Memorandum reaffirms our concerns that without specific riders in the passage of this Bill, **this advice is nothing more than a tick and flick exercise to pass the Bill and the DOHAC and the Government must be held to a timetable for delivery of unified HTA laws in Australia through the Health Ministers' Council.**

Secondly, the **DOHAC must advise what they mean by this now being an 'interim' measure.** What further changes to the OTA legislation are proposed, and when? And will families and the broader community be excluded again from a discussion on laws that affect their human rights, their ownership of their own personal information and that of their loved ones?

The Community Affairs Legislation Committee did not hold any hearings on this Bill. The **Coalition Senators have acknowledged the considerable lack of consultation with the community on this Bill and the rushed nature of the process. They have asked that the Bill be given further scrutiny,** and that the community be properly consulted by the Community Affairs Committee before recommending this Bill for passage.

**We are asking the Joint Committee on Human Rights to:**

- 1. Support this request by also reviewing the proposed changes to this Bill, at the federal level.**
- 2. Seek clarity on when and how the human rights of families being infringed by state HTA laws will be addressed as part of the national health ministers council priorities and confirm that our human rights under this legislation will be fully protected.**
- 3. Give the community time a chance to speak to the parliament, and the parliament the opportunity to directly question why we weren't consulted in the first place, and ensure the intentions of this Bill and the future reforms needed across Australia are clear, appropriate and do not infringe the human rights of organ and tissue donors and recipients.**

DFA are strong supporters of organ and tissue donation and are keen to ensure that any opportunity to improve both the ownership of personal information is protected and empowers families to speak freely and supportively of donation. If the Government is taking the opportunity to 'quickly fix' something, we ask that they do it properly, fulsomely and with full consultation with the community to ensure that in giving the gift of life, families are not being asked to also give way their right to their loved one's story.

Noting that this Bill may be introduced for passage as early as next week, we seek your urgent assistance on this matter.

We can be contacted through any members of our executive committee:

- Bruce McDowell (Chairman, Mobile: 0427 645 262)
- Associate Professor Holly Northam OAM (Board member, [holly.northam@canberra.edu.au](mailto:holly.northam@canberra.edu.au))
- Philippa Delahoy (Secretary, [philippa.delahoy@gmail.com](mailto:philippa.delahoy@gmail.com))

Yours faithfully,



Bruce McDowell, Chair of 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



**Care**

Provide care and support to families who have donated their loved one's organs and /or tissues

**Support**

**Advocate**

Advocate and give donor families a voice

**Educate**

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

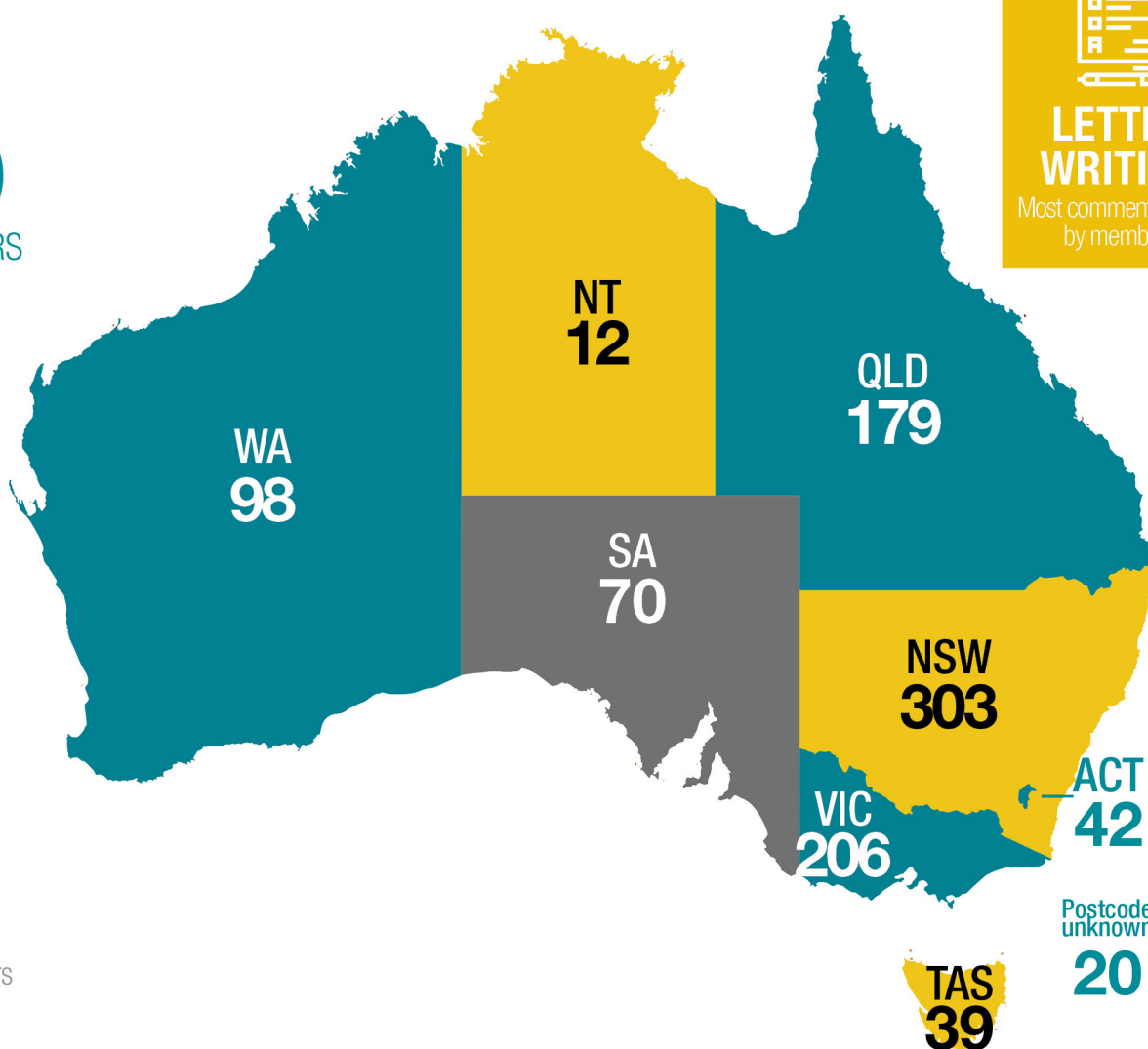
*...in 2022*

**969**  
TOTAL MEMBERS



**LETTER WRITING**

Most commented topic by members



**2,973**  
Facebook  
Donor Families  
Australia followers

To find out more and to become a member please visit our website at [donorfamiliesaustralia.org](https://donorfamiliesaustralia.org)