



Donor Families Australia INC

Submission

**Senate Committee for Community Affairs Inquiry:
Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of
Information) Bill 2023 (Cth)**

Board of Donor Families Australia

<https://www.donorfamiliesaustralia.org/>



Contents

Preface	Page 4
Acknowledgement	Page 4
Philippa's story	Page 5
Background	Page 6
Problem	Page 7
Recommendations and Conclusion	Page 10
Appendix (1) Chronology of significant events (Prior to 2020)	Page 12
Appendix (2) Chronology of significant events (2020-)	Page 17
Advice by Lavan 23 June 2023	Attachment (1)
Advice by Lavan 30 April 2021	Attachment (2)

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Preface

Thank you for the opportunity to provide a submission to the Senate Committee Inquiry into the proposed legislation.

Please note:

- DFA were not provided Terms of Reference for this inquiry.
- DFA only discovered this legislation was being presented to the House of Representatives a week before it was passed.
DFA had received no notification or consultation to enable us to provide advice regarding this legislation.
- DFA have received only a four-business day extension to enable a submission.
- DFA have not had the opportunity to engage widely and consult with our 1000 plus membership when drawing together the evidence, we may have inadvertently missed voices and views, for which we apologise.
- DFA provides evidence that the proposed amendment and its development and passage provides further evidence of a continuing lack of consumer collaboration and consultation in delivery of the national organ donation program.

The evidence we present represents the 10 years of experience gained as our volunteer organisation has worked tirelessly without government funding to provide support, care and information to donor families and others touched by organ and tissue donation decisions. DFA are passionate in our desire for the practice and representation of organ and tissue donation to be done well in Australia. DFA seek to maximize our declining consent rates. DFA believe this can be done by providing excellence in care and support before, during and after the event for donors and decision makers. DFA believe Australia can lead the world in donation for transplantation. DFA wish to collaborate with national and jurisdictional institutions and healthcare providers to co-create practices and care that limits fear, offers compassion and makes it easy for people to agree to deceased donation. DFA believe organ and tissue donation should be a part of normal end-of-life care in Australia.

We commend the Government for their willingness to progress review and harmonization of the Human Tissue Act/ Transplantation and Anatomy Acts, but if amendments are to be made to the Act/s, it is essential that these amendments are appropriate, transparent, acceptable to the community, sensible and importantly, create trust and do no harm.

The purpose of this submission from Donor Families Australia is to share our concerns regarding the unintended consequences to donor families and our support community if this proposed amendment is passed in its current form. Importantly, we also foresee unintended consequences that could negatively impact potential recipients and reduce Australia's already poor consent rate and organ and tissue donation rate.

Acknowledgement

DFA acknowledge and pay respects to all deceased and living organ and tissue donors, their families and communities who support them. DFA also acknowledge and pay respects to the people who receive or need the gift of organ and tissue donation. DFA offer our love and support to all these communities, connected in such a unique and powerful way, these shared experiences are our gift to humanity.



Philippa's Story

Many in our community are unaware of the process of organ and tissue donation until faced with what is often an unexpected crisis and the impending - or already revealed, death of their loved one. In this vignette, Executive Board member and Secretary of Donor Families Australia Inc., Philippa Delahoy, uses parliamentary privilege to share the name of her husband, and her reflection of donating her husbands' organs. The sharing of stories requires revisiting grief but may also help with the hope that the information will benefit others – a hope that may provide healing. We thank Philippa for her generosity in helping others understand.

A donor family experience with the process of organ and tissue donation

My husband Scott was a fit, healthy 44-year-old when he contracted swine flu. He was admitted to ICU with double pneumonia and placed in a drug-induced coma to be intubated and placed on ECMO (a machine that oxygenates the blood, externally). Tragically, 13 days later, Scott suffered a massive brain haemorrhage that was incompatible with life; this occurred at **approx. 11am**.

I want to share what happened next to the Senate Inquiry so that you can understand the lived experience of consenting to donation and perhaps understand a little of why the donor family community is so important to those who have shared this experience. Organ donation isn't as simple as signing up to a register, there is so much more to this process and so many steps along that way that are too overwhelming for families to continue with consent.

Around 6pm, two donation co-ordinators arrived at ICU to begin the consent process. The consent process consists of many forms to be completed.

Around 8pm, the two co-ordinators and I started to complete the forms. The forms require consent to be given for every organ and tissue type. I recall at one point being asked whether Scott's thigh bones could be donated and for a split second I thought, but how will he walk...such was the level of disconnect between my still healthy-looking husband and the fact that he was brain dead. I was also asked if he had any sexually transmitted diseases, obviously this wasn't a concern, nevertheless it was confronting; can you imagine the same question being asked of a parent consenting for their teenager? In between these process meetings, I held a bedside vigil with Scott as family and friends came to say goodbye and to sit with me in my grief. During one of these times, the donor co-ordinators came into the room to ask if they could measure Scott to estimate the size of his organs for potential recipients. After I agreed, they proceeded to take out a tape measure and record his measurements; all the time that Scott was still looking fit and healthy.

Finally, **around 3am** the following day, I was told that recipients had been matched and that the donation and transplant teams were in place. Unfortunately, the team decided to wheel Scott away while I was in the bathroom and I had to run down the corridor to keep up with Scott's bed.

In the operating theatre, I sat with Scott holding his hand as his life support was switched off. I was horrified to see the colour drain from his face as his heart slowed and eventually stopped. This took a torturous 5 minutes and I wanted to shout that the Medical team had made a mistake, how could he have survived 2 minutes, 3 minutes, 4 minutes without life support? Eventually, his heart stopped beating, I kissed his now blue lips for the last time and left the operating theatre into the arms of my parents. I'm often asked why I sat with Scott when his life support was switched off and my simple answer is that I didn't want him to leave this earth alone.

Senators, if for a second, you can imagine that instead of Scott, this is your loved one, wouldn't you want to meet, commune, share stories and support people who had been through the same experience? Please find it in your hearts to stop this amendment and put donor families at the centre of organ and tissue donation where we belong.



Background

This legislation is being rushed through the parliament in direct response to legal advice received by DFA in July 2021. DFA brought this advice to the attention of the Commonwealth and OTA. DFA deeply regret that to date, we have been actively excluded, omitted, or silenced from consultation and engagement by the OTA and Commonwealth regarding this proposed amendment to legislation and other matters pertaining to organ and tissue donation practice. Since learning of the proposed 2023 amendment that is now under review, DFA sought further legal advice¹ that confirmed that the legislation would provide more power to the OTA and its agencies and continue to silence and threaten bereaved families of donors, and recipients. This directly impacts DFA and the support that is provided to Australia's donor families and the positive work of educating, role modelling donation and garnering support for organ and tissue donation in Australia.

DFA sought legal advice in 2021² regarding the application of legislation that pertains to organ and tissue donation in Western Australia (WA). This followed an extended history of people who had donated their loved ones' organs and/or tissue experiencing threats, intimidation, bullying and paternalism from Organ and Tissue Authority personnel and some DonateLife Agency and hospital staff. These misuses of power have been experienced most frequently in the context of bereaved people who expect to have the freedom of speech to use their deceased loved ones' names in sharing with others that their relative donated organ/s and/or tissue³.

The legal advice made clear that DFA, OTA and many bereaved organ and tissue donor family members across Australia along with their friends and communities were breaching WA legislation- and potentially other state and territory legislation. This risk has implications for organisations named after organ and tissue donors such as *Zaidee Foundation*, *Hookes Foundation*; and for political leaders such as Prime Ministers- especially Prime Minister Rudd, who spoke about many donors by name and engaged with many donor families at the launch of the OTA. Other examples include the use of donor's names by Health Ministers federally and at a jurisdictional level, and at services of remembrance hosted by DonateLife Agencies.

To be explicit, wherever people share stories that include the names of donors they are at risk of being penalized depending on their jurisdiction. This legislation extends to individuals sharing to friends, families and in all the places they work and play that their loved one was a donor; in conversations between bereaved people following a death, donor families comforting each other over a cup of tea, the media reporting on a story from a family and DonateLife Agencies across Australia are breaching or potentially breaching the legislation. Each state and territory have different Human Tissue Acts/ Transplant and Anatomy Acts, the varied legislation regarding donation has added to the confusion.

In July 2021 DFA met urgently to consider the implications of the legal advice on the ongoing work of the organisation, recognising DFA were (and continue) to break the law, as do all the other people and organisations listed and many more. The DFA Committee agreed that as a matter of urgency DFA were responsible to alert key people and organisations

¹ Advice by Lavan 23 June 2023 (Advice regarding the proposed amendments to the Australian Organ and Tissue Donation and Transplantation Authority Act 2008 (Cth) (OTDA) and the implications for Donor Families Australia (DFA) and families of deceased donors and recipients).

² Advice by Lavan 30 April 2021 (a letter of advice with respect to legislation surrounding the ability of organ donor families (next of kin of minor/adult deceased donors) to disclose or give to any other person any information or document whereby the identity of "a person" may become publicly known regarding the Human Tissue and Transplant Act 1982 (WA), (Appendix 1)

³ DFA chronology of significant events (Appendix 1 & 2)



responsible under the legislation⁴. We agreed we should seek to collaborate to resolve the issue; request a national moratorium on prosecution for all involved and then advocate that states, territories and the Commonwealth act with urgency to harmonise and humanize the legislation to meet community human rights expectations to enable the freedom of speech for all bereaved organ and tissue donor families in Australia. We approached Dr Anne Webster (MP) instigator of the 'Parliamentary Friends of Organ Donation' for guidance and help⁵.

Following this correspondence there ensued many efforts to connect with the Federal Attorney General, the Health Minister/s, the OTA and Commonwealth/ Jurisdictional agencies to enable DFA to collaborate as healthcare consumers⁶ to support legislation at a Federal and State/ Territory level that would meet contemporary expectations and enable those most impacted by the decision to donate, freedom of speech and association. A chronology of the major events in the history of DFA, and the correspondence we have engaged in regarding this, and other practices and policies related to the experience of DFA is listed in **Attachment (2)**.

Problem

We have sought clarification from the Minister's office and have had a meeting with an official from the Department of Health. On both occasions we were informed that this amendment only applies to the activities of DonateLife and the OTA, however our independent legal advice contradicts these reassurances. DFA understand that this amendment does not provide any relief for families of donors to speak freely. Instead, it provides additional powers to the Organ Donation Authority and its Agencies. **At no stage in the effort to have this legislation amended has there been any consideration of the needs of families touched by donation decisions, instead, just efforts to protect and give additional power to the OTA and its agencies.**

The entire process of developing this amendment has been rushed, without appropriate consultation and does not meet the standard expected for good governance. These actions and the implausible denial of impact to Donor Families has increased confusion and despair within the donation community. Many have lost trust, and believe that it is impossible to have credible, authentic consumer voices heard in this sector of healthcare practice, policy, and legislation.

DFA have been advised that as an independent organisation that it will not be able to publish or disseminate information that hadn't already been published by the OTA or a DonateLife agency (secondary publication). The implications of this advice for DFA and all families of deceased donors and recipients is very distressing.

1. Most Donor Families will continue to be prohibited to say their loved one (by name) was a donor.
2. Families who are involved in events as mentioned in the proposed amendment lose their right to the material they have contributed to, handing all intellectual rights for the information they have shared to the OTA/ or Agency. There is no mention of a withdrawal of association if they later regret this decision or the ability to put a subsequent stop by the OTA and its agencies in using that material.

This issue is of significant concern to the wider community with a 2022 petition garnering huge support for legislative change to enable families to have this freedom to control their loved one's information including saying their name in

⁴ Email (6 July 2021) regarding DFA consultation and draft letter to Dr Webster (MP)

⁵ Letter to Dr Anne Webster, MP, Member for Mallee (Appendix 3)

⁶ <https://www.safetyandquality.gov.au/our-work/partnering-consumers/australian-charter-healthcare-rights>



relation to donation.⁷ In having said ‘yes’ to donation, families have, unbeknown to them, handed over control of their loved one’s information to the government without knowledge, consent or understanding.

The use and management of Donor information has remained a contentious and troubling issue for Donor Families for many years. There is great confusion in the donor and recipient community about what families are allowed to say and do, with many examples over time of redacted letters, lost letters, callous and hurtful approaches, and statements by senior administrators to families in hospitals that they cannot talk to the media or anyone else about the donation and a general paternalistic approach of control, silencing and removal of grieving families’ freedoms of speech and association.

In the current and proposed legislation, by law, families are not permitted to let each other know, or their families or neighbor’s or communities speak of their loved one’s donation and share their name as having been an organ or tissue donor. Whilst at the same time there is no preparation by authorities of potential donors and their families that freedoms of speech will be impacted when they consent on the Australian Organ Donor Register if at the time of death their families authorise donation of their loved one’s organs or tissues.

1. This amendment seeks to restrict the use of our loved one’s name and information/ story to four activities **for the purposes of the OTA and DonateLife only**. As clearly stated in the explanatory notes of the amendment, this provision does not allow donor families to tell our loved one’s stories for activities beyond the remit of the OTA and DonateLife.
2. Donor Families Australia is a not-for-profit organisation that is independent of the OTA and DonateLife and as such we have our own activities where storytelling is an important element of our support activities; activities that are not listed within the remit of the OTA and DonateLife.
3. If the amendment continues in its current form, we fear that Donor Families Australia will no longer be able to provide support to our 1000+ strong membership.
4. We fear that our social media sites, our website, our newsletter, our anniversary emails to donor families that are so meaningful to them, our marquee event ‘Donor Heroes Night’ and our consumer lead, co-created conference will be found to contravene the amendment. Clearly this is against the Charter of Health Care Rights, freedoms of speech and is also deeply unethical.
5. If Donor Families Australia cannot provide these services and face to face and online places of refuge, love and care, who will provide the support, comfort and community to donor families? Many families receive limited support from the funded programs associated with the OTA,/ DonateLife agencies but this is insufficient for many families and individual’s needs. There is clear evidence that shared support between people who have had similar experiences provides long term positive outcomes. As a caring society, we can point to many support organisations of consumers with similar experiences; it is critically important to donation to provide positive independent support in the community for donor families. To be able to support one another, after losing precious family members in often sudden and tragic events helps in the healing process of finding a path through grief. It is a sad omission that Donor Family support in collaboration with Donor Families has not been listed as one of the approved activities of the OTA and its agencies clear that the Authority or a Donate Life Agency does not have support as one of its activities as it is not specifically listed in the amendment to the legislation.

⁷ ‘Let organ/tissue donor families “say their loved ones’ name’ Started July 2022.



6. At a time of unbearable pain and despair, donor families thought of others and consented to donation, now Donor Families ask for nothing in return other than the common respect and agency afforded others.

7. 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.

8. It is through storytelling as a community that donor families grieve and heal, that our loved ones live on and that their life-changing gift can be celebrated and become something that all aspire to do following their death. In the United States there are parades to remember donors and their families, a National Donor Memorial, and a National donation Medal. None of this is possible if the donor family is unable to say the name of their loved one in relation to organ donation. It is not surprising our donation rates are so low. **It should be noted that the US donation rates reached their highest levels ever in 2022- despite the impact of Covid-19.**

Finally, this amendment will further adversely impact a specific cohort of our donor families, those that live in the Australian Capital Territory (ACT). In a progressive and transformative move, Donor families in the ACT are currently able to share their loved ones' donation with the Registrar of Births, Deaths and Marriages so that the organ and tissue donation can be acknowledged on the death certificate; an act that costs nothing and yet leaves a permanent legacy of organ donation. The proposed amendment in its current form will outlaw 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 and is not within the remit of the OTA and DonateLife as it is a supporting Donor Families activity.

This toxic setting is the context of Australian organ and tissue donation today. Several states are undertaking inquiries as to why donation rates are so low, and one must only assume that the continuing silencing of Donor Families and withholding of community and professional education about organ and tissue donation is impacting Australia's donation rates. There have been many reviews into organ donation in Australia, and the problems mentioned in this submission have been raised previously, and yet there remains an extraordinary inertia and complacency regarding the impact of this critical problem for those in need of transplant. In a 2015 Review into organ donation and transplantation program instigated by Assistant Minister of Health, Fiona Nash ⁸ it was recommended that DFA recommendations be considered regarding harmonization and humanizing of legislation and processes to enable credible critical review of practice to support improvements, with a comment that it was impossible to find the complaints process.

Evidence that points to failures in providing appropriate care and support for donor families, include the time taken to facilitate organ donation extending from the time death is confirmed until retrieval surgery (time spent for families and hospital staff caring for a deceased person in an Intensive Care Unit. The data demonstrates these times have extended from an average of 22.7 hours in 2018 to 28.5 hours in 2022 in Australia ⁹ Of note, in 2008 (prior the OTA) the median time was 15.3 hours ¹⁰

⁸ Review of organ donation and transplantation program

<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22media/pressrel/3858024%22>

⁹ Time from brain death to donation, Australia (2018-2022) https://www.anzdata.org.au/wp-content/uploads/2023/05/s03_pathway_2022_ar_2023_v1.3_20230523.pdf

¹⁰ Time from brain death to aortic cross clamp 2003-2008 (2008) <https://www.anzdata.org.au/wp-content/uploads/2009/01/2009Pages37-55.pdf>



Recommendations and Conclusion

DFA is not satisfied with the current proposed amendment. It is confusing and does not meet community expectations or standards. We seek an inquiry into the way the legislative change has been developed; we demand appropriate widespread community consultation with Donor Families and others impacted by existing legislation relating to organ and tissue donation to bring them in-line with the 21st Century and expectations of transparency, freedom of speech and association and humanity.

The amendment to the Human Tissue Act in the ACT was developed with authentic community consultation with Donor Families Australia and we thank Tara Cheyne MLA for her ongoing support of donor families throughout Australia and for her willingness to assist other States and Territories with changing their legislation relating to organ and tissue donation.

DFA has presented compelling reasons to challenge the amendment and all existing nation legislation pertaining to organ donation. Our position is supported by the attached legal advice. We recommend that the Committee reference the recent changes to the legislation pertaining to organ donation in the ACT. There they acknowledge the rights of the families of deceased organ and tissue donors, and recipients the right to ownership /control of information by families of deceased loved ones and freedom of speech.

Before legislation had even passed the Lower House, for the sake of credibility, transparency and trust, there should have been a proper and respectful consultation period with those that the legislation has been designed for. We urge the Committee to consider, how would each one of you respond and feel if you were told following the organ donation of a loved one (that is a complex process that lacks community transparency/ education) that you were not allowed use the name of your loved one in relation to organ and tissue donation. This is the reality for many Donor Families of Australia.

Please accept our concerns and recommendations and we trust that with your support and review of the amendment, new wording will provide clarity to Donor Families and a revised amendment will harmonise the legislation across the country without harming the rights and well-being of donor families. No other bereaved families are so restrained in their human rights.

DFA believe 'Enough is enough!' The Australian public would be understandably distressed to know that bereaved people across Australia are silenced and treated in this way. In signing the Australian Organ Donor Registration form, we are certain many would be horrified to realise they would be waiving the rights of their family members to talk about them after their death as being a donor. In addition to this submission, we will also be presenting a complaint to the Australian Human Rights Commission.



Appendices

APPENDIX 1 Chronology of significant events (Part 1)

Date	Event	Comment	Evidence
15/12/2012	Opening of the Donor Awareness Fountain in Geraldton WA by Donor Family Australia (DFA)	Honouring our Donor Heroes, Creating Awareness for Organ and Tissue Donation.	<i>Donor Awareness Fountain Geraldton WA</i>
15/1/2013	Certificate of Incorporation	Organisation becomes Inc.	RegistrationNo.A10166 Incorporated in WA
20/1/2013	Committee meets for its first meeting	Joining of Donor Families right around the country.	Available upon request.
9/4/2013	Panel Media Sydney Town Hall Sydney	Prior to ABC's 4 Corners programmed being aired. DFA was part of the panel for the Media Conference with Sharelife Australia. DFA message was that Donors are heroes.	Available upon request.
10/5/2013	First DFA Newsletter	Connecting Donor Families. Newsletters are produced ongoing to keep Donor Families and the wider community up to date with issues that impact them. These newsletters provide support to help families in their grief and honour their Donor Hero loved one.	https://www.donorfamiliesaustralia.org/files/ugd/8a154b_8a858ecdc8a44343837b8f991acd445a.pdf
30/9/2014	Donor Family Dinner	Grouping Donor Families together for peer support.	The Honey Bar Clarendon St South Melbourne
03/10/2014	Commenced sending Anniversary emails to Donor Families	Supporting families on the anniversary of their loved ones passing. These emails are sent to all members on their loved ones anniversary.	Available upon request.
1/07/2015	Ernst and Young Review	DFA executives and Members attended the various sessions held across Australia to provide a voice for Donor Families and their loved ones.	Available upon request.



22/11/2015	First DonateLife National Thank You Day	DFA initiated with the Minister of Organ and Tissue Donation Fiona Nash MP public acknowledgement across the Australian community of the generosity of organ and tissue donors and their families, and the impact of their decisions on the broader community .	DFA Chairman went to Canberra to contribute to the discussions of the National Thank You Day. Launch attended my Minister Wyatt. Available upon request.
1/01/2016	OTA leaflets distribution to local community	Geraldton MLA, Ian Blaney, made a commitment to make 2016 the year to promote Organ and Tissue Donation after discussions with DFA Chairman	OTA leaflets were placed in every letter leaving Mr Blaney's office, providing constituents with facts on organ and tissue donation, and the process for registering as a donor. He encouraged other politicians to follow his lead. <i>Hon MLA Ian Blaney with DFA Chairman at announcement.</i>
01/01/2016	Newsletter reaches a circulation of over 6,000.	Community has embraced the Newsletter	Available upon request.
01/05/2016	DFA attends Launch of Ernst and Young Review in court yard of Parliament House	Chairman of DFA stands beside Minister of Organ and Tissue Donation representing Donor Families	<i>Fiona Nash MP at Launch of EY Review</i>
15/11/2016	ACNC Charity status	DFA became a Not for Profit Charity as registered with the ACNC	
26/7/2016	National Donor Family Dinner	Melbourne	Available upon request.
18/10/2016	DFA National Strategic Planning Weekend workshops , Sydney. Special guest OTA CEO Felicity McNeill	Two days of face to face around the conference table formulating DFAs Strategic Plan. Report Available upon request.	<i>DFA Executive Committee with CEO of OTA at Strategic Planning Weekend.</i>



20/11/2016	DFA organises Thank You Day events around the nation.	DFA held picnics in states and territories. All were well attended by the community.	Available upon request.
17/3/2017	Attended Community Consultative Forum Melbourne on the topic of Consenting adults meeting.	DFA representation on the importance of consenting adult donor and recipients being able to meet.	Available upon request.
16/9/2017	National Donor Family Dinner	Melbourne	Available upon request.
9/3/2018	DFA committee members attend meeting with OTA CEO Lucinda Barry on the topic of letter writing.	Meeting held in room at the Sydney airport. DFA provided recommendations and proposed changes that needed to be made to the process to address problems of lost and missing letters between donor families and recipients. Also, to address issue of misuse of letters, heavily redacted and misuse of authority in managing personal information	Available upon request.
7/12/2018	Contribute to the 2 nd Ernst and Young Review	DFA consultation presents Donor Families points of view for the review.	Available upon request.
10/12/2018	National Donor Family Dinner	Melbourne	Available upon request.
26/1/2019	DFA Executive Committee member Dr Holly Northam receives OAM for work done in Organ and Tissue Donation.	DFA was very proud of its inaugural committee member in being awarded the OAM for services rendered.	<i>Dr Holly Northam received OAM for her contributions to Organ and Tissue Donation.</i>
28/1/2019	DFA is an inaugural member of the OTA's Community Engagement Group	DFA joins other pro-donation groups and individuals to help contribute the community's perspective on Organ and Tissue Donation.	Available upon request.



2/3/2019	National Donor Family Dinner	Newcastle	<i>Donor Family Dinner Newcastle NSW</i>
23/5/2019	ACNC Deductible Gift Recipient status	DFA becomes an ACNC DGR	
4-5/10/2019	DFA Conference over 2 days at the University of Canberra ACT	The Conference brought together a wide range of community representation with a wide range of views. Was highly successful.	<i>DFA Conference Canberra</i>
19/2/2020	Tara Cheyne MP ACT introduces Acknowledgement of Donation on the Death Certificate in the ACT.	As a result of Tara's presence at our conference she was able to present to the ACT Parliament a new way of creating a legacy and helping donation awareness.	Available upon request.
26/2/2020	DFA committee members attend launch of Commonwealth Parliamentary Friends of Organ and Tissue Donation.	The Chairman addressed the gathering on the good work that was being done by the ACT Parliament on Acknowledgement of donation on the death certificate. This was a conference initiative.	Available upon request.
23/4/2020	Launch of Ernst and Young review	In it is Recommendation 26 provides that: States and territories establish a nationally uniform process for arrangements for donor families and recipients over the age of 18 to be identified to each other based on the principle of mutual informed consent	Available upon request.



18/5/2020	Inaugural Donor Heroes Night.	Community is invited to leave their porch light on in honour of our Donor Heroes. This is now a annual event. With the most recent having over 200,000. Very successful event not only honouring our Donor Heroes but raising awareness in the community.	<i>Inaugural Turn on your Porch Light for a Donor Hero</i>
9/9/2020	Kurri Mongrels Bike Association ride for Donor Families.	This bicycle club rode through the countryside to promote Organ and Tissue Donation and raise much needed funds for DFA to do the work they do.	<i>Bike ride raising awareness of Organ and Tissue Donation and raising funds for DFA .</i>
25/9/2020	DFA works with the OTA on the letter writing policy.	Donate Life NSW is found to have 69 unsent letters in its office. Donor Families mail has not been on sent to their respective recipients. During the process the OTA lets DFA know that it is against the law for Donor Families to include the first name of their loved on in a letter.	Available upon request.

N.B. Chronology of Significant Events Part 2 follows on from this document.

APPENDIX 2 Chronology of significant events (Part 2, Dec 2020 to date)

Date	By whom	Reference	Relevant points to highlight
14/12/20	OTA CEO	Letter page 1 and 5	<p>DFA (Donor Families Australia) consults with the Organ and Tissue Authority (OTA) in relation to letter writing between Donor Families (DF) and Recipients. OTA CEO writes to DFA as to why families cannot include the first name of their deceased loved one in their letter to the Recipient.</p> <ul style="list-style-type: none"> • CEO states all jurisdictions prohibit health professionals from disclosing identifying information. • CEO does not want health professionals to be exposed to fines and penalties. • CEO points out that only the donor can give consent for health professionals to pass on information. • CEO confirms that DFs do not have control or ownership of their loved one's information as they do of their loved one's organs and tissues.
30/4/21	Lavan Legal Services	DFA seeks legal opinion in relation to OTA CEOs letter (Appendix 1) of the 14/12/20.	<p>The Chairman of DFA approached Lavan legal services in Perth WA for legal advice on disclosure of information within the Human Tissue and Transplant Act 1982 (WA).</p> <ul style="list-style-type: none"> • Lavan states that only the deceased donor can give consent for their information to become publicly known. • The state government organ and tissue transplantation process currently acts outside of the law in WA. • The state government is currently acting unethically in not letting families know that they are unable to talk about their loved ones donation publicly. • The state government is currently acting unethically by knowingly contravening its legislation. • "From a legal perspective, there are no requirements in the HTTA that donors and/or their families/next of kin must be informed of their rights after consenting to organ donation. Consent can only be given if medical advice (not legal advice) has been given. From an ethical perspective, this is certainly an issue which we can understand could be close to the heart of many donor families".
21/5/21	Meeting with WA local Labor Member Geoff Baker	Follow up email of thanks 22/5/21.	<ul style="list-style-type: none"> • First presentation of Lavan's advice to the state government. • Asked for the legislation to be amended to allow for the next of kin to be given the authority to give consent for their loved ones information to be made publicly known.
22/5/21	DFA	Copy of WA legislation with example of possible amendment.	<p>Included with Geoff Baker's email how the legislation looks today and how it could be amended to give next of kin the authority to make their loved one's information publicly known.</p>



Date	By whom	Reference	Relevant points to highlight
11/6/21	CW Dept of Health	First reference to DFA's legal advice by Comm	Acknowledgement from the Cth Dept of Health that DFA has legal advice as to disclosure of information
22/9/21	Notes taken by DFA for DFA	Notes taken of meeting with DFA, CW Dept of Health and OTA	<ul style="list-style-type: none"> • Three organisations discussed Lavan's legal advice. • CW Dept Health advised DFA would be consulted along the way of any progress made re amending legislation. • OTA confirmed that SA and the NT have the same legislation as WA and acknowledged that it was a problem. • DFA had written to a Federal politician including Lavan's advice. DFA was told this letter was referred onto the Attorney General of Aus. • DFA referred to the Charter of Health clients. In it is mentioned that health consumers have a right to be treated within the law. • Cwth Dept of Health suggested that we need to work with all states and territories to have a uniformed approached. DFA said this does not help DFs who wish to act within the law now. • DFA mentioned that the OTA in the CEO's letter showed a duty of care for its health workers but who is showing a duty of care for Donor Families?
4/10/21	DFA	Notes taken from meeting with Geoff Baker MP	<ul style="list-style-type: none"> • MP's approach was to play down Lavan's advice and kept saying DFA was overreacting. The Member was ok with DFs and government departments to continue breaking the law. • He made it clear that he was not going to take this any further.
3/11/21	North Metropolitan Health Service WA	Cancellation of Remembrance Service	<ul style="list-style-type: none"> • Letter explaining cancellation of WA Service of Remembrance. • The reason for cancellation – Due to unforeseen circumstances. Have not let the public know why the service has been cancelled. • Have advertised a Memorial Service in Bunbury because it is a PRIVATE EVENT.
8/11/21	OTA Update to the Community Engagement Committee	Page 2	<ul style="list-style-type: none"> • Acknowledgement of meeting with DFA and Com Dept of Health regarding legal advice from Lavan. • OTA said there are concerns about the implications this has for donor families who publicly share that their family member became a donor to help raise community awareness about donation or to commemorate their loved ones in remembrance services. • The OTA says it will keep everyone up to date with any developments.



Date	By whom	Reference	Relevant points to highlight
			<ul style="list-style-type: none"> • OTA will not share any new DF stories on website until advised otherwise.
15/12/21	National Health and Medical Research Council (NHMRC)		<ul style="list-style-type: none"> • DFA contacted the NHMRC so as to confirm whether ethical standards are being breached by government departments. • Advising DFA that ethical standards for organ and tissue donation will be reviewed at the end of 2022.
23/1/22	DFA to Minister of Health SA Mr Wade		<ul style="list-style-type: none"> • DFA lets the Minister know that Lavan’s legal advice is applicable to SA as legislations are identical.
8/3/22	Minister Wade’s response via Health Dept SA CEO Dr C McGowan		<ul style="list-style-type: none"> • Dr McGowan advises DFA that Donate Life SA is not a state government dept. He quotes the Australian Organ and Tissue Donation and Transplantation Authority Act 2008 (Cth) as if to say Donate Life SA responds to this legislation. • To the question of whether the SA health personnel should be telling the deceased donors next of kin that they could be fined up to \$20 000 if they make their loved ones donation story public Dr McGowan says there is no legal requirement for them to do so. Unfortunately, Dr McGowan seems to be only ruled by the legal requirements and not ethical standards and the need for an informed consent from the family.
14/3/22	WA Minister for Health to DFA		<ul style="list-style-type: none"> • Assurance of legal transfer of deceased donor information away from the hospital environment to other government depts. (DFA is not convinced that hospitals are legally making the deceased donor’s information available to other government departments as no one has given consent for this information to be passed on.) • “Donate Life WA will in future include information about the prohibition on public disclosure during its work with donor families until such times that the legislation is amended”. (To DFA’s knowledge Donate Life WA has never done this nor does it have any intention of doing so.) • “It has not been routine practice for Donate Life WA to inform families of the specific requirements of Section 34 of the WA HTTA as there is no legal requirement upon DLWA to provide this advice”. There is not mention of ethics by the Minister. The Minister is of the belief that legislation is the only standard within health. Interestingly this is also the understanding of the CEO of the SA Health Department as per appendix 12.



Date	By whom	Reference	Relevant points to highlight
16/4/22	DFA to Minister Health WA Donor Families	Participation at the World Transplant Games (WTG)	<ul style="list-style-type: none"> • The WTG will be conducted under WA law and as such those organising and sponsoring (WA and Federal Gov) will be knowingly contravening WA legislation. • DFA recommends the amendment of WA legislation to coincide with the Games. • DFA provides the Federal Tissue Act clause 58 as its example of how the WA legislation should read. The Federal Act allows for the OTA CEO to seek consent from the partner of the deceased to make their information publicly known.
27/6/22	DFA	Notes from Minister Sanderson's WA Officer Phone Call.	<ul style="list-style-type: none"> • Discredited Lavan – Not in the top 5 legal firms in Perth. Health Minister would never use Lavan for Health legal advice. • Said Lavan's advice to let families know that they cannot talk about their loved one's donation without breaking the law would be "ludicrous". • Told me that laws are broken every day. • DFA said DFs not owning deceased loved one's donation information is violation of their human rights. Shows a lack of respect on the part of the government. • Told WA government does not want to amend law as it would allow consenting adults, DFs and Recipients to meet. Clear the government would rather knowingly contravene legislation than let consenting adults meet.
7/7/22	WA Health Minister to Mr McDowell	Response to World Transplant Games Contravening Legislation	<ul style="list-style-type: none"> • "I appreciate your valid concern that risk of prosecution may prevent donor families from speaking about their deceased relatives donation". • "Individuals won't be prosecuted for the disclosure of personal information where consent has been provided by the next of kin". Therefore Donate Life WA won't be prosecuted for presenting a Donor Family at its remembrance service. This confirms that Donate Life WA is knowingly contravening legislation at its remembrance services. • This letter is meant to provide reassurance to the next of kin that they will not be prosecuted. For myself and my wife this letter comes as a shock. It confirms I am committing an unlawful act every time I speak about my daughter's gift. My wife and I were not told this at the time of giving consent for retrieval.
20/7/22	DFA	DFA Media Release	<ul style="list-style-type: none"> • "Donor Families seek law change in WA to celebrate the lifesaving gifts of loved ones".



Date	By whom	Reference	Relevant points to highlight
			<ul style="list-style-type: none"> • Media release circulated amongst WA media for media conference at Lake Monger in Perth. • Media represented by Channel 9, ABC, Channel 7, various radio channels and the West Australian. • DFA did a live radio interview and featured in a live segment on Channel 9 news. • Curtin University picked up the story for its radio.
26/7/22	DFA	Change.org Petition	<ul style="list-style-type: none"> • “Our daughter is a donor hero, yet we have no legal right to say her name when sharing her donation story”. • Shared photo of Karen and Bruce with their daughter’s photo turned around demonstrating the restrictions of the current law by not being able to make the loved one publicly known. • 17 639 have signed DFA’s petition.
6/9/22	ACT Health Minister Rachel Stephen-Smith MLA	Amendment to the Tissue Act in the ACT	<ul style="list-style-type: none"> • “The ACT Government considers the need to address the identified legal concerns, too important to postpone and has chosen to move ahead now”. • “I will be moving a Government Amendment to the Bill to further amend the Act to allow the sharing of donor information with the consent of family. The amendments I will move avoid the existing narrow terms to ensure relevant family members are able to consent to the disclosure”. • The Minister confirms that without this amendment donor stories at remembrance services cannot be shared. • “As you may be aware, the disclosure of information section of the Act currently makes it an offence for DonatLife ACT staff to share information about donors where there is a risk that the identity of a donor may become publicly known”.
9/9/22	DFA to ACT Health Minister Stephen-Smith		DFA appreciates the progress made by the ACT in leading the country in reform within organ and tissue donation
28/9/22	WA Attorney General Mr John Quigley MLA		<ul style="list-style-type: none"> • “It would not be appropriate for the Registrar, Births, Deaths and Marriages to knowingly contravene legislation by including a deceased’s donor status on a document that may be made publicly available”. • The Attorney General states it is not appropriate for his government department to knowingly contravene legislation, but for some reason it is ok for other government departments to knowingly contravene legislation. • The Attorney General is acknowledging Lavan’s legal advice.



Date	By whom	Reference	Relevant points to highlight
2/11/22	Proposed Amendment to the Birth, Death and Marriage Registration	Tissue Donation Statement Amendment Bill 2022	<ul style="list-style-type: none"> • Nicola Centofanti MLC introduces a Bill for An Act to amend the above mentioned Act. • Nicola Centofanti MLC is hoping to introduce Acknowledgement of Donation on the Death Certificate in SA.
24/11/22		Amended Legislation in the ACT for Disclosure of Information	<ul style="list-style-type: none"> • ACT amendment to Transplantation and Anatomy Act 1978 – Section 49 (4) (c) (iv) • With the consent of - if the relevant person is a deceased person to whom subsection (1) (a) applies—the relevant person’s next of kin or legal personal representative; • Is passed in the ACT Parliament 24/11/22. • In the ACT Donor Families are finally respected.
24/11/22		Hansard ACT for the amended legislation.	<ul style="list-style-type: none"> • “The changes will allow for DonateLife ACT, with consent, to share stories of individuals and their loved ones at its organ donor remembrance ceremonies such as the annual DonateLife ACT Service of Remembrance and Thanksgiving. The changes will also allow for DonateLife ACT, with consent, to help raise awareness of organ donation through other activities where stories of individuals and their loved ones are shared”. • Consistency with Human Rights – “The amendment acknowledges that everyone has the right to recognition as a person before the law, is equal before the law and is entitled to the equal protection of the law without discrimination. By increasing the exemptions to the restrictions on the disclosure of information in section 49 (4) (c) of the TA Act, living adults, children, legally incompetent people and deceased donors are all recognised as being equal before the law and they and their families are afforded the same rights to disclose information. Prior to the proposed amendment, only living donors and adult transplant recipients were able to consent for their stories to be shared. This discriminates against the families of children, legally incompetent and deceased donors, as they are not provided with the same rights to share their loved ones’ stories”.
22/12/22	Chief Minister NT Natasha Fyles		<ul style="list-style-type: none"> • “I am supportive of donor families being able to commemorate their loved one’s donation. The Northern Territory is currently examining legislative options that would allow families to speak publicly about loved ones who have



Date	By whom	Reference	Relevant points to highlight
			<p>generously donated their organs. In addition, options to allow government employees to share donor stories, with the consent of families, is also being considered”.</p>
22/12/22	Nick Steele Qld Hlth on behalf of Yvette D’Ath MP Minister of Health		<ul style="list-style-type: none"> • In his letter Mr Steele confirms Qld’s opinion that Donor Families making their loved ones information publicly known at Donate Life Qld Remembrance Services is not prohibited by Qld’s Act. • Qld’s Act is the same as the ACT. The ACT has already put in place legislation to specifically allow Donor Families speaking at Donate Life ACT Remembrance Services as prior to the amendment it was unlawful to. • Enquiries to Mr Steele’s referred officer confirmed that the OTA had told Qld Health that it was ok for Donor Families to speak at their Remembrance Service in direct conflict to the ACT experience. • The referred officer agreed that Donor Families in Qld do not own their loved one’s information as the family is not authorised to give consent to the hospital staff to pass the donors information on. • The referred officer agreed there were potential ethical issues with Donor Families making their loved ones publicly known at a Qld health function.
5/1/23	WA Health Minister Sanderson		<ul style="list-style-type: none"> • “Hon Stephen Pratt spoke recently in the Legislative Council of attending Donatelife WA Service of Remembrance last month, and he acknowledged the moving speech made that day by a donor family member regarding her child s generous gift”. Minister’s letter confirms Mr Pratt’s MP appearance at the Donate Life Remembrance Service where Donate Life WA knowingly contravened legislation. • Minister reaffirms that DFs will not be prosecuted for knowingly contravening legislation. This is little comfit to families who have no idea that they are breaking the law as DFs were not given all the information they needed to make an informed consent.
20/1/23	Premier of Tasmania		<p>“The Tasmanian Human Tissue Act 1985 currently prevents the disclosure of information of donors, even with appropriate consent of the next of kin, to donor families or recipients, which would allow for families and other persons to celebrate the significant contribution of donors and organ donation more generally”.</p>



Date	By whom	Reference	Relevant points to highlight
20/1/23	National Health Medical Research Council (NHMRC) – Director Ethics and Integrity		<ul style="list-style-type: none"> • “Legislation and ethics guidelines are related, but independent of one another. All NHMRC ethics guidelines require adherence to relevant laws and ethics guidelines may either extend the requirements in legislation (by providing more detail about what is required) or may defer to legislation, where relevant”. • “Ethical standards are critical in the practice of organ and tissue donation and transplantation and in the development of related policy and clinical guidelines”.
29/1/23	DFA to Nicola Centofanti MLC SA		<ul style="list-style-type: none"> • This letter points out to the MP the similarities between WA and SA laws in relation to disclosure of information and references letters from the CEO of Health in SA and the Attorney General of WA. • DFA supports the MP in her endeavours to introduce amended legislation to allow acknowledgment of donation on the death certificate. • It pointed out, that from the WA experience their tissue Act would need to be changed to reflect the ACT amendment before the acknowledgement could be passed.
14/3/23	Hon SA Health Minister Picton	Response to DFA letter	<ul style="list-style-type: none"> • Minister acknowledgement that SA Human Tissue Act does not allow for Next of Kin to publicly disclose information about the deceased donor. • Minister is waiting for a Federal review. • Minister has written with pen he is willing to take action if review is too far away.
<p>N.B. All references cited can be provided on request.</p>			