

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

I'm , a very proud Daughter of an Organ donor. My Mum, Maree became a Hero by giving three people a second chance at life on 5 May 2013 after suffering from a catastrophic aneurysm at the age of 52 years. I was 34 at the time, my two Brothers 29 and 25.

I'm writing to object to *The Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023*, specifically the proposed new insertion of 58A (3) (starting page 9, line 31), shown (whole 58A shown in full) below:-

- 17 **58A Publication, dissemination or disclosure of patient**
18 **information—DonateLife Agencies, grant recipients and**
19 **authorised family members**
- 20 *Scope*
- 21 (1) This section applies if:
- 22 (a) an organ or tissue donation and transplantation has occurred;
- 23 and
- 24 (b) the organ or tissue donor or recipient has died.
- 25 *Publication, dissemination or disclosure by a DonateLife Agency*
26 *or grant recipient*
- 27 (2) Either of the following:
- 28 (a) a DonateLife Agency;
- 29 (b) a person who is a party to an agreement that:
- 30 (i) is in force; and

- (ii) provides for the making of one or more grants under paragraph 11(1)(g) to the person;
- may publish, disseminate or disclose information that is likely to enable the identification of the deceased organ or tissue donor or the deceased organ or tissue recipient (as the case requires) if:
- (c) the publication, dissemination or disclosure is for the purposes of any of the following activities:
- (i) an educational activity that is relevant to an organ or tissue donation and transplantation matter;
 - (ii) a commemorative activity that is an organ or tissue donation and transplantation matter;
 - (iii) a promotional activity that is relevant to an organ or tissue donation and transplantation matter;
 - (iv) a community awareness activity that is relevant to an organ or tissue donation and transplantation matter; and
- (d) the publication, dissemination or disclosure is made with the consent of an authorised family member of the deceased organ or tissue donor or recipient; and
- (e) the publication, dissemination or disclosure is made:
- (i) using a service to which paragraph 51(v) of the Constitution applies; or
 - (ii) using an electronic service (within the meaning of the *Online Safety Act 2021*); or
 - (iii) in a Territory; or
 - (iv) in a Commonwealth place (within the meaning of the *Commonwealth Places (Application of Laws) Act 1970*); or
 - (v) by a constitutional corporation.

Publication, dissemination or disclosure by an authorised family member

- (3) An authorised family member of the deceased organ or tissue donor or recipient may publish, disseminate or disclose information that is likely to enable the identification of the deceased organ or tissue donor or the deceased organ or tissue recipient (as the case requires) if:

- 1 (a) the publication, dissemination or disclosure is for the
2 purposes of any of the following activities of the Authority or
3 a DonateLife Agency:
4 (i) an educational activity that is relevant to an organ or
5 tissue donation and transplantation matter;
6 (ii) a commemorative activity that is an organ or tissue
7 donation and transplantation matter;
8 (iii) a promotional activity that is relevant to an organ or
9 tissue donation and transplantation matter;
10 (iv) a community awareness activity that is relevant to an
11 organ or tissue donation and transplantation matter; and
12 (b) the publication, dissemination or disclosure is made:
13 (i) using a service to which paragraph 51(v) of the
14 Constitution applies; or
15 (ii) using an electronic service (within the meaning of the
16 *Online Safety Act 2021*); or
17 (iii) in a Territory; or
18 (iv) in a Commonwealth place (within the meaning of the
19 *Commonwealth Places (Application of Laws) Act 1970*).
- 20 (4) Subsections (2) and (3) have effect despite anything in a law of a
21 State or Territory.

22 *Secondary publication, dissemination or disclosure*

- 23 (5) If information has been the subject of a publication, dissemination
24 or disclosure under subsection (2) or (3), a person may publish,
25 disseminate or disclose that information if:
26 (a) the publication, dissemination or disclosure is for the
27 purposes of reporting on any of the following activities:
28 (i) an educational activity that is relevant to an organ or
29 tissue donation and transplantation matter;
30 (ii) a commemorative activity that is an organ or tissue
31 donation and transplantation matter;
32 (iii) a promotional activity that is relevant to an organ or
33 tissue donation and transplantation matter;
34 (iv) a community awareness activity that is relevant to an
35 organ or tissue donation and transplantation matter; and

- 1 (i) using a service to which paragraph 51(v) of the
2 Constitution applies; or
 - 3 (ii) using an electronic service (within the meaning of the
4 *Online Safety Act 2021*); or
 - 5 (iii) in a Territory; or
 - 6 (iv) in a Commonwealth place (within the meaning of the
7 *Commonwealth Places (Application of Laws) Act 1970*).
- 8 (6) Subsection (5) has effect despite anything in a law of a State or
9 Territory.

I strongly object to this clause being inserted into the Act as this will directly affect me in my freedom of speech. To understand my objection, you must understand my Mum's story and my family's story.

As previously stated, my Mum suffered a catastrophic aneurysm on Friday, 3 May 2013 at 9:30pm as she was getting ready for her nursing night shift. By the time my brothers and I arrived at our local hospital, it had been established that she had in fact suffered an aneurysm. We were told that specialist Doctors from our closest major hospital ((North Queensland) were on their way via rescue helicopter. The Doctors arrived, tested and assessed Mum and decided that even though chances were slim, they would airlift her to the major Hospital where she could receive further assessment and treatment by their Neurosurgeon but advised that there was minimal chance of a good outcome. Mum was airlifted around 1:30am in the morning. We followed her up in our car which was a three-and-a-half-hour drive north from our hometown. When we were thirty minutes from arriving in the larger centre, I received a call from the Neurosurgeon advising that after further scans and tests, it was determined that brain death was imminent for Mum. Upon arrival at the Hospital, we were placed in a waiting room for an hour before we could see Mum. During that long, torturous wait, I broached organ donation with my two Brothers. Mum had discussed her wish to be an organ donor with me on a few occasions throughout her life. My Brothers and I chose to honour her wish. When we finally were allowed to see Mum, we notified her ICU nurse that Mum wanted to be an organ donor and to please let whoever know so that her wish could be granted.

From there, we spoke to a DonatLife member based at the hospital and started the paperwork process. In the meantime, we had to wait for full brain death to be established by Mum's Doctors. Mum was officially pronounced brain dead at approximately 3pm the afternoon of Saturday, 4 May 2013. We were in shock, devastated, overwhelmed, tired, so extremely tired as we had been awake for over 31 hours and I can't explain the gut-wrenching sadness. As a family, we chose to drive back home to the support of our family and friends and we left Mum at the hospital alone at 5pm that day. Mum's organ retrieval took place around 1am Sunday, 5 May 2013. Three very significant dates for our family 3 May, 4 May and 5 May 2013.

If you have lost someone your love, you know that time waits for no one. Life just continues on. On Sunday, 5 May the DonatLife team member let us know that Mum's organ retrieval went well and she was able to donate her lungs, liver and a kidney. We later learned that all three organ recipients were doing well after their transplant and we were so happy because it felt like even though we had lost our Mum, someone else got to have a second chance with their loved one. In my darkest days after Mum's death, that was like a shining light at the end of a very dark tunnel.

Living rurally, I found it very difficult to gain support, I just wanted to speak to another donor family who would understand what I was going through. I was desperate for support, I was struggling. I didn't want to speak to the DonateLife counsellor – she had absolutely no idea on what I was going through and I found talking to her only left me frustrated. I was not only dealing with the sudden death of my Mum, but also the extra emotions of Mum's organ donation. It's very complex and I didn't get the support I needed or wanted from DonateLife.

I found and still find solace in a private group of donor families and recipients on social media. This is where I receive the support I need, this is where I find understanding, this is where we can support each other – not DonateLife. What do DonateLife do for donor families post donation of their loved one's organs? They do nothing! It's like the OTA and DonateLife get what the need from a family (organs and/or tissue) and then leave them behind in their despair and grief. A major part of my involvement in this private social media group is that I can proudly say my Mum's full name and talk about her dates. The 3rd of May 2013 when she had her aneurysm, the 4th of May 2013 when she was declared brain dead and the 5th of May when she became a donor Hero and gave the Gift of Life.

From my understanding, the amendment proposed in *The Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023* will legally stop me from being allowed to provide details of my Mum's donation including her name, date of death, date of donation though any way I choose except though events as dictated by the Organ and Tissue Authority and DonateLife. This is unfair and unjust and I object. I should have every right to disclose whatever I wish about my Mum's death and donation.

I plead with you to walk a mile in donor families' shoes and consider the consequences of approving this amendment.

Regards