

Attention: Senate Standing Committee on Community Affairs

Dear Senate Standing Committee,

I am writing to you in response to the proposed amendment to the Australian Organ and Tissue Donation and Transplantation Authority Act 2008, specifically relating to “*Disclosure of Information Section 58A(3) of the Bill 2023*” which states:

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:

(a)the publication, dissemination or disclosure is for the **purposes of any of the following activities of the Authority or a DonateLife Agency:**

(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

(b)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*).

On the 18th May 1993, I sadly became a Donor Dad to my 10 year old son Ben, who passed away following failed corrective surgery. With my wife and I having agreed to organ donation, we were required to sign an authorization document for the release of Ben’s body for the purpose of retrieving his organs. At the time there was no mention of any restrictions that would apply to Ben’s information at the time of signing the document. Several months later when I wished to send a letter to Ben’s recipients, I was informed that the letter could not contain any personal details of our family or Ben that would breach our confidentiality, which I thought was strange as I considered as a family, we legally had control of our own personal information. That aside, letters were sent and received only using first names in all instances.

When the Organ and Tissue Authority was formed in 2008, I became aware that even first names were blocked, which resulted in letters being altered or returned to the Donor Families for correction. I was informed that some had even been rewritten without the Donor Family being advised.

It recently came to light that in fact OTA were breaching the Human Tissue Act themselves, while continuing to censor Donor Family letters of correspondence to their recipients. I now understand that to allow OTA to continue their current practice, the amendment to the Human Tissue Act has been secretly put forward without involving Donor Families, nor Donor Families Australia who had raised the issue in the first place. The Act will require all families to gain authorisation from OTA/DonateLife if they wish to divulge personal information about their Donor Hero loved one for whatever reason.

OTA/DonateLife has become very authoritarian with little or no compassion for Donor Families and I feel only sees us as a supply chain.

I have been a very active participant in promoting organ/tissue donation and transplantation over the past 30 years, having worked with ACCORD, the Red Cross, Australians Donate, ShareLife Australia, and for the last 10 years with Donor Families Australia. During this time, I have published a story in the Readers Digest in Oct 1995 called Ben's Gift. That was followed later by the ABC's Australian Story also titled Ben's Gift. Further activities involved public speaking at high schools, and media involvement when called to help publicise Organ Donation Week involving Ch9's Today and Ch7's 11am News in addition to Sixty Minutes. Other activities involved two World Transplant Games and several National Transplant Games, a presentation to the Transplant Nurses Association, training sessions to Transplant Coordinators, and upwards of 40 presentations to Rotary, Lions and Probus groups. All in the spirit of promoting organ/tissue donation.

I am now however becoming extremely despondent with OTA/DonateLife's approach to organ donation and what I truly believed was a philanthropic cause.

With this proposed change I believe that I will be restricted in my current endeavours and those Donor Families within NT, SA and WA under their State and Territory Human Tissue Act, which enables those not complying to be liable for prosecution resulting in fines or even jail.

I am therefore very concerned under these changes that I will be in conflict as a Donor Parent with the Human Tissue Act, and possible prosecution if I were to continue my Donor Family support and promotional work involving;

- The Donor Families Australia (DFA) website servicing and supporting 990 plus members,
- The DFA Facebook Page with 2,970 followers,
- The DFA Members: DFA Group with 210 members,
- The National Donor Heroes Night with this 4th Year producing an involvement of over 208,000 actions involving; Facebook, Instagram, Twitter and YouTube,
- Rotary, Loins and Probus Clubs presentations promoting organ and tissue donation, and
- Various media outlets that are interested in promoting organ donation unless I gain previous approval from OTA/DonateLife.

I now wonder where my freedom of speech has gone, and the freedom to be able to divulge my own son's information. Where is OTA's support, transparency and compassion in the support of all Donor Families including those within DFA. One also wonders whether OTA will advise future Donors and their family members, what censorship applies to them at the time their family member signs up onto the National Donor Register.

I have no problems with change and improvement involving the Human Tissue Act as the ACT Government has already implemented. However, it must involve those directly impacted by such

changes which does not involve only a few selected representatives currently working within OTA's subcommittees.

Yours Truly,
Graham Harrison.