

## Senate Inquiry

Thank you for the opportunity to speak up about the proposed Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023

It is a shame this is the first time anyone has had the opportunity to make comment on this Bill. I am a Donor Family member, my daughter passed away and became a Tissue Donor. It was only, via other people letting me know, that I even have had a chance to make comment now on something that directly impacts myself and my family. It would seem the government was keen to rush this through. The question has to be asked why wasn't it consulted on?

On the face of it, it will create confusion, uncertainty, fear and mistrust. Who wants to be part of something that is to be so heavily regulated by both State and Federal Governments. 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.

Donor Families and their loved ones deserve better from governments. They deserve respect not this sort of mistreatment in their grief.

Here in WA, where my wife and I are based, we can't go to another Donor Families house with other invited Donor Families present to have a cup of tea without contravening WA legislation. Because in WA Donor Families don't have the authority to make their loved ones information publicly known. This was made even more clear when I received a letter from the Health Minister of WA saying I won't be prosecuted as long as my conversation was around awareness and education. In my example of having a cup of tea my conversation was to be neither, it is to be supportive. This activity is not mentioned in the letter from the Minister thus making our meeting of Donor Families amongst other activities subject to prosecution.

This situation is disgusting and not helped by this proposed Commonwealth legislation where it is made very clear that supporting Donor Families is not an activity of the Organ and Tissue Authority and Donate Life. The legislation mentions educational, commemorative, promotional and community awareness as its activities. It is more note worthy by what it has left out than what it has included.

How can we trust the government with our loved one's information if they aren't transparent. The government did not consult with our only Donor Family organisation DFA.

The only solution here is for – DONOR FAMILIES OF DECEASED DONORS NEED TO OWN THEIR LOVED ONES INFORMATION UNCONDITIONALLY.

Thank you for the chance to express my feelings around this proposed legislation.

Bruce McDowell