

Committee Secretary
Senate Standing Committee On Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

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

25/06/2023

My name is Bruce Dagleish, the father of a donor and the great uncle of another donor, both boys donated their lungs and both kidneys to help 6 people who struggled with health issues. Our families are still grieving at the loss of our boys, January 2019 for my son and November 2019 for my great nephew but get solace in the knowledge that our boys have helped 6 people and they live on in our hearts by helping those people.

We get great support from other donor families and recipients in groups on social media where they share their feelings and journeys through the loss of our loved ones and donation of their organs and recipients telling of their joy of a renewed life while coping with the knowledge that a family lost someone in order for them to get the gift of life. We also support other donor families and recipients by sharing what we have done to cope with the loss of our loved ones and sharing information on our contact with the recipients through DonateLife. Some donor families have been able to be in contact with recipients which is something our family would like to do in the future and this would be impossible if we aren't able to use the social media groups as we do currently. We believe that contact between the 2 parties should be allowable if both parties wish this to happen and **only** if both parties agree to it.

While current legislation does not allow DonateLife to pass on information donor or recipient families and they don't, we believe that in the future this should be amended to allow for the transfer of information if both parties agree to it. We are of the belief this can help donor families through the grieving process and can also help recipients with coping with the knowledge that someone has died to get their transplant. Being in contact directly may help both parties to live their lives more fully knowing the donor family or recipient know who they are and how they are going, instead of getting anonymous letters or cards passed through a government agency that invades the privacy of the sender by reading all correspondence to ensure no personal information is included within the correspondence. While this is currently the rules for correspondence, it doesn't stop making it feel like you are a second-class citizen having to send it through a screening process.

Lastly, I have no idea who the people are who decide on these rules and regulations but I am pretty sure none of them have been through the donation or recipient process and

actually know how it feels to lose a loved one then go through the process of donation (lots of paperwork) before the actual harvest of the organs for transplant can begin or for a recipient to be so ill that only an organ transplant can save their life but someone has to die for this to happen. Walk in our shoes for a while then think about how these changes will probably affect the majority of organ donation families before you stop us having our freedom of speech and dictate what where and when we can talk about our families.

Bruce Dalglish