

## Janelle Colquhoun

24 June 2023

Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 – Parliament of Australia

Dear Senate Inquiry Committee

I am an organ transplant recipient (kidney and pancreas) and am extremely grateful to the anonymous amazing donor family who agreed to gift organs and tissue from their family member, at one of the worst times in their lives. This year in July it will be 15 years of life extra I've had due to this amazing gift.

I am writing to the Senate Inquiry committee as I am horrified by the proposed legislation to take away the right for donor families, and families of deceased recipients, to speak publically about their loved ones. This proposed legislation makes it illegal in all states and territories for the donor family to talk (or post on social media etc) the name of their loved one, or any other information about them. Already WA, SA and NT have legislation which makes it illegal for the donor family to speak publically about their loved one. This of course is outrageous and wrong - and would-be donor families are not currently (in these 3 states) being warned before they make the decision to donate their loved ones organs or tissues. (we already have terrible rates of donation in this country, so how much worse is it going to get if this legislation passes?)

this would mean, the next time a young footballer dies tragically of a head injury, the family will not be allowed to give the news that their terrible loss has nonetheless meant that he has gone on to help others.

Until now the Organ and Tissue authorities have been run by each state and territory, this new legislation will make it a federal agency, and stop us in Queensland, as well as already in WA, SA and NT, from holding the beautiful Thanks-giving Services each year, where donor families and recipients come together to hear stories from both sides and have recipients say thank-you to the donor families. It is a beautiful ceremony.

Also, will the many facebook and other online groups which offer support to donor families and recipients be forced to close down if this legislation goes ahead? Would Donor Heroes Night, which is celebrated each 18 May to remember those people who have donated, would this also be illegal? It even is proposed in this legislation, that when a recipient dies, their family is also not allowed to publically say they were the recipient of an organ or tissue donation. I can guarantee my family will be breaking the law and talking out about the many years of extra life I was gifted because of my organ transplant.

Pleas, I don't know why the Organ and Tissue Authority and Donate Life want to stop donor families and families of deceased recipients from speaking publically about their loved one, and why they would want to decrease the number of people who agree to organ and tissue donation. I know each year on the anniversary of my transplant, I post all over social media, and get tons of people saying they

have now signed up to organ and tissue donation and had the talk with their family, because they realise what a difference it can make to a person's life.

Regards,

Janelle Colquhoun