



Donor Families Australia  
admin@donorfamiliesaustralia.org

## URGENT

The Hon Ged Kearney MP  
Assistant Minister for Health and Aged Care  
Via email

30<sup>th</sup> May 2024

Dear Minister Kearney,

**Urgent response required: Re failure to engage with Donor Families Australia in the consultation process in reviewing the draft *The NHMRC supported by the OTA Ethical guidelines for cell, tissue and organ donation and transplantation*.**

Thank you for your previous correspondence regarding a failure of your government and institutions to recognise or engage our peak health consumer group in consultation. You may recall in August of 2023, you rang me regarding the Amendment to the Federal Tissue Act. **You assured me that Donor Families represented by Donor Families Australia as key stakeholders, would be consulted in the future** where its membership is directly affected.

Donor Families Australia- the peak national consumer body that represents the voices of over a thousand people who have altruistically donated relatives' organs and tissues, finds itself omitted from government consultations again. On this occasion it is with regard to the review of the *Ethical guidelines for cell, tissue and organ donation and transplantation*. The NHMRC have provided us one week to consult with our extensive membership and respond regarding the draft guidelines.

DFA stayed in touch with the NHMRC for over 3 ½ years to ensure that we would be included in supporting the work of the NHMRC to ensure appropriate representation of Donors and Donor Families. Below is a timeline of events and dishonoured promises.

- **12 December 2021**, following the request of the DFA committee, I wrote to the NHMRC seeking DFA involvement in consultation and requesting information regarding the progress of the guideline review.
  - **15th December 2021** Jillian Barr, Director, Ethics and Integrity, NHMRC replied, "we will add you to our list of stakeholders to be informed about the consultation".
  - Subsequent regular email correspondence continued to ensure DFA consultation.
  - **20<sup>th</sup> January 2023**, "We will certainly ensure that Donor Families Australia receives the documents and look forward to your feedback on them" (Jillian Barr, Director, Ethics and Integrity, NHMRC).
-

- **28<sup>th</sup> May 2024** (Two days ago). Hannah Hawkins (Acting Director, Ethics and Integrity NHMRC), stated the guidelines “recently underwent public consultation and the feedback from the consultation is being reviewed by the Australian Health Ethics Committee (AHEC) on 6th June 2024. Regrettably, it seems that the DFA was not included on the stakeholder list”.
- Continuing.... *“We apologise for this oversight and would like to offer you the opportunity to review and respond to the material before the AHEC meeting....We propose that you provide your feedback by 4 June and we will ensure that AHEC is made aware of your response”*.

**This email was received in response** to my most recent prompt regarding opportunities to consult on guidelines sent **22<sup>nd</sup> May 2024**.

Ironically the guidelines refer to respecting Donor Families. Tragically the continuing disrespect and callous omission of Donor Families represented by Donor Families Australia by the various government departments who are accountable to you and the community has been appalling. In this current low trust environment, it is even more important to respect and listen to Donor Families who wish to ensure the experience of donation is one that enables and supports donation consent. Partnering with consumers of the experience of donation can help your organisations understand the human experience and its impact on decision making by the potential donor (through Registration) and the Donor Family.

One week’s notice is not tenable to enable the authentic and sensitive consultation and feedback required to meet the professional and public expectations that are positioned within the guidelines. It is unethical to omit Donor Families represented by Donor Families Australia from consultation. We require a 2-month period to enable appropriate communication, consultation, and collation of feedback with our extensive membership. We expect you to ensure that this is offered to DFA by COB Friday 29<sup>th</sup> May, 2024 to enable the work of authentic consultation to begin.

We look forward to your early response.

Kind regards



Bruce McDowell  
Chairman