

# Donor Families Australia launch of Donor Recipient Contact Register

## Story

A consumer led movement is facilitating the connection of consenting organ and tissue donor families with recipients who have shared the same donation/ transplantation experience- a practice that is expected to lead to increased acceptance and the normalisation of organ donation and transplantation, but is actively blocked by healthcare organisations who fear that donor families or recipients will suffer disappointment or 'behave badly' if they meet.

## Significance

The view of organ donation is enhanced when the community are witness to positive relationships between bereaved families connecting with the recipients of their donation.

Silencing donor families has been normal practice across transplantation organisations where fear of relationship breakdowns has driven gatekeepers to demand anonymity from bereaved families. This lack of transparency surprises and distresses many involved in the donor- recipient equation. As consumer rights and ideas of social justice gain traction; and social media changes the way we communicate- it is timely to open a conversation that honours these relationships.

## Key Points

1. There is limited research into Donor Family– Recipient relationships
2. The conservative approach used by organ donation/ transplantation organisations in Australia is not meeting the needs of many Donor/ Recipient consumers.
3. There is limited understanding about how blocking or facilitating these relations may impact transplantation rates and well-being of all involved.
4. Previous research suggests that “Donor Families and Recipients not only desire contact, they think they have a right to meet even if the transplant professional advises against it” (p.193), quoting a respondent who stated, “If both parties are willing to meet, I just don’t see a bad outcome except not to meet at all” (p.195).

## Reference:

Lewino, D., Stocks, L., & Cole, G. (1996). Interaction of organ donor families and recipients. *Journal of Transplant Coordination*. (6); 191-195.

## Key Contact:

Interviews available from

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