



## **Thank You: Donors and their Families – December, 2016**

**This edition, Holly's Insight is an extract from her speech presented at the Canberra Thank You Day function.**

I am deeply honoured to represent Donor Families Australia today-an extraordinary group of people who lead by example in saving life through transplantation. My name is Dr Holly Northam I am a Senior Lecturer at the University of Canberra and a Director on the Board of Donor Families Australia (DFA) and also Share Life Australia. Today I speak on behalf of DFA.

DFA are a national independent grass roots organisation comprising families who have donated their loved ones' organs and tissues. Increasingly live donors and recipients are also reaching out to this new organisation for support and voice. Established in 2013, it is the only organisation in Australia specifically dedicated to organ and tissue donors and their families and specifically seeks to give voice to this vulnerable group of people who have often been hidden by regulatory practices.

Most importantly the organisation seeks to continue the gift of donors to save the lives of suffering people in our community. The organisation does this through its aims which are to provide care and support to all families who have donated their loved ones organs; to advocate for and give donor families a voice; to educate the community about the benefits

of donation, whilst respecting, acknowledging and supporting those touched by donation decisions.

Thanks to a grant from Donatelife, DFA are staging numerous events today across Australia to give visibility to donor families and to encourage healing relationships across the donation transplantation community.

The ACT has many, many organ and tissue donors and their families to thank- and many others who would have donated if they could have-we thank these wonderful people. Importantly we are also aware that for some, not donating has complicated their personal experience of grief- and we thank them for their wish to donate.

The high rate of donation in the ACT compared with the rest of Australia is indicative of our generous community- but evidence shows that the care and support provided to dying patients and their families in hospital by skilled doctors, nurses and the donation team is the greatest predictor of donation proceeding regardless of location. The ACT rates of donation are a tribute to our health care teams -and using international comparators can be compared with world's best. The ACT experience backs up evidence

from Spain where there is no register, but instead a focus on expert care of donors and families at end of life when offering the choice of organ donation.

The current ACT experience of low registrations compared to the rest of Australia shows that although the organ donor register is a useful tool to support organ donation decisions to be effective it must be backed up by compassionate, respectful and accountable care of donors and their families in hospital and afterwards. In reality, the donation is not a simple box to tick- the experience and consequence of making organ donation decisions can lead to significant suffering for the families involved- especially when staff are unfamiliar with what is required. The onus of responsibility must always fall to those involved to provide expert supportive care for as long as it is required- DFA help to address this need in our community.

There have been more than 7000 organ donors and an unknown number of tissue donors since 1989, but the people who agreed to donation and their courage and generosity are often invisible. Evidence that bereaved family decision-makers and the community perceive donor families as invisible and unrecognised is a barrier to donation. Thank you day helps to address this possible barrier and I thank you all for supporting this initiative.

DFA seeks to address this and other barriers to donation arguing that grieving families should not be blamed if they choose not to donate, especially if information and communication are insensitive to the patient and their family's needs. Over the coming two years we will roll out a number of strategies to ensure that donation becomes a respected and normal part of end of life care in Australia- and donors and their families are visible, heard and honoured.

The ACT Chief Minister, Mr Andrew Barr, recently promised an organ and tissue donor reflection garden here at the Arboretum- this is just one goal that we will be delighted to support in the coming year. It must be remembered that making an organ or tissue donation decision is a decision that impacts on the lives for those involved forever. Thank you to the donors and their families... Someone\* is missing

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