



## **World View Ripples – December 2013**

**I would like to briefly reflect on the International Organ Donation Congress recently held in Sydney. International conferences are exciting because they allow one to see similar problems through different eyes and provide transparency, debate and new ideas for 'curly questions'.**

Donatelife (Australia) was a major sponsor and delegates came from around the world. A focus of the donor and their family was seen in a presentation from the Chinese who showed a video of a donor family who had offered to donate their infants' organs, which deeply touched the delegates. The scientific program looked at strategies to improve transplantation outcomes as well as technical aspects of the donation process. Approaches to increase the organ donation rate through increasing consent to donation were presented and included strategies to educate school students, health care professionals and changes to public policies.

A number of papers specifically looked at the care of donor families including one from Korea which found that donor families often suffered depression and would benefit from follow-up support. A South Australian paper looked at time delays in the organ donation process, finding that donation sometimes took up to 24 hours to arrange which had consequences for the family of the donor. An interesting debate looked at the role of Registers in recording organ donation decisions. At the conclusion a vote was held and delegates were asked to vote for or against the use of Registers based on information presented in the debate. The 'for' case won. I was disappointed in the quality of the arguments, believing them to be simplistic because they did not explore the ethical complexity of this area or the

implications for the families and those caring for the deceased.

An important discussion led by a US delegate proposed that Register information should be used to direct donation decisions. Known as 'first person consent,' it presumes that if a registration is documented by an individual, the family will not be asked for their agreement to donate; but rather, the discussion will inform the family that their relative wanted to donate and steps to enact that decision were being undertaken. This is a strategy used in some US states.

I briefly presented my research findings which identified the central importance of trust for bereaved families considering organ donation on behalf of their loved one. I identified that hope flourishes for families who trust those caring for their relative. I discussed that some families use deep hope, a hope that stretches beyond the death, even when faced with death and the question of donation. This tended to occur when families were empowered, knowing their loved one was well cared for. This finding supported evidence that few families over-ride loved ones' wishes to donate if they receive compassionate care and respect. It is of interest that almost 6 million Australians have registered on the Australian Organ Donor Register, a significant indicator of community trust in organ donation processes. As a health care professional and a witness to the

generosity of our community who hope to help save and improve lives through donation, I believe there is an obligation to ensure that the care provided at death is worthy of this trust.

Christmas has deep meanings, but for me, I will always honour the first donor family I was privileged to work with. They taught me the meaning of unconditional giving when they permitted me to care for their loved one at Christmas. Like so many other families, I found their courage and generosity remarkable, they believed donation was 'the right thing to do'. My warmest wishes for deep peace, joy and hope to them, and to all.

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