



Donor Families Australia
STRATEGIC PLAN 2016 - 2020
National Strategic Planning Meeting
Quest Apartments, Mascot, Sydney: 22-23 October 2016

It is with great pride that I introduce the report¹ covering our inaugural Strategic Planning weekend of October 2016 in Sydney. The weekend brought together the Committee of Donor Families Australia for their first face-to-face meeting. After almost four years of Skype meetings it was nice to be able to put a face to the voice; it was like meeting an old friend for the first time. This group of people, representing all states and territories, had generously given up their weekend and free time normally spent with family and friends, to tackle the important issues concerning Donor Families.

Bruce McDowell, Chairman

Our Vision

Care, Support, Advocate & Educate

Donor Families Australia seeks to continue the gift of donors to save the lives of suffering people in our community and to care for those who have donated. The organisation does this through its aims which are to:

- Provide care and support to families who have donated their loved one's organs and /or tissues
- Advocate and give donor families a voice, and
- Educate the community about the benefits of donation, whilst respecting, acknowledging and supporting those touched by donation decisions.

*Living Donors are also acknowledged as key stakeholders

Strategic Plan 2016 - 2020

Authentic and credible representation of donors and their families

- Continue to provide support, voice and advocacy for donor families
- Gain full support and ensure donor family representation throughout all Organ and Tissue Authority activities, policies and outcomes

Maintain independence

- Make representations to the Minister and Commonwealth Department of Health regarding our new committee makeup

Attain financial independence

- Become a Registered Charity Organisation
- Pursue funding applications and sponsorships

How will we achieve this?

Communication and Engagement:

We will continue to develop and grow engagement with our Members and key stakeholders.

Specifically:

- Member personal contact – acknowledge anniversaries and important dates; provide personal support.
- Newsletter – issues to become more interactive: invite *Letters to the Editor*; provide more real stories about real people including sensitive areas such as death of recipients.
- Leverage and grow Facebook community

Advocacy:

We will advocate for community respect and reciprocity for Donor Families, and organisational acknowledgement and accountability, specifically towards:

- Donation decisions and the related consumer experience
- Sensitive use of appropriate language
- Formal evidence of the donation outcome (eg: death certificates)
- Public recognition of benefit of the donation (eg: correspondence regarding outcomes, 'Thank

¹ This document is an excerpt of the full Strategic Planning Weekend report.

- Website – undertake wholesale review, refresh and expand content, continue to keep content up to date, and ensure our messaging is consistent and aligned with our core values
- Facebook:
 - Develop and refresh content on our official Facebook page
 - Continue support of Kevin Green’s Donor-Recipient Facebook group
- Be an independent voice for complaints
- Develop volunteering education and support
- Develop Position Statements (eg: Opt-in / Opt-out process for organ donation).
- Educate patients, families, healthcare professionals, community, governance and regulatory stakeholders.
- You Day,’ memorials, media voice)
- A transparent, credible and accountable feedback and complaints process.
- Addressing the Donor–Recipient desire to meet in an ethically and legally approved, and psychosocially supported manner by challenging policy makers
- Addressing perceived deficiencies in national Donor Family–Recipient letter exchange by challenging key stakeholders.

Priority Actions:

ACTION 1: Develop a Donor Family Charter of Rights that advises families what they should expect regarding communication and the appropriate use of language.

ACTION 2: Offer support and advice to the Organ and Tissue Authority, media outlets and other organisations regarding media representation of organ and tissue donation to donors and their families,

ACTION 3: Bring issues relating to the use of insensitive language to the attention of the Organ and Tissue Authority and other collaborators. Seek an urgent collaborative review of Donor Family and Recipient communication by the Organ and Tissue Authority, offering to work in consultation to ensure the expectations and needs of donor families are properly addressed in written communications and offering advice on appropriate terminology to enable respectful and compassionate communication that meets community expectations.

ACTION 4: Offer a collaborative approach to the Organ and Tissue Authority towards structuring and implementing a transparent national communication process on donation outcomes for all families and health care professionals involved in organ and tissue donation.

ACTION 5: Develop a collaborative, transparent and accountable national legislative, policy and practice strategy to support and address the relational needs of organ and tissue donor families and recipients by seeking an urgent review by the Organ and Tissue Authority on barriers and enablers of meetings between these consumers.

ACTION 6: Collaborate with the Organ and Tissue Authority to enable informed consent regarding death and the organ and tissue donation process and ensure this information is freely available to the community.

ACTION 7: Seek to embed trained donor family volunteers as family support guides.

ACTION 8: Advise standards for appropriate hospital environments and accommodation for families to be with dying and deceased loved ones.

ACTION 9: Maintain a “watching brief” over the DonateLife logo review (per assurance by the Acting CEO following the EY recommendation). This issue will be included in ongoing discussions with key leaders.

ACTION 10: Progress efforts to attain charitable institution status to enable Donor Families Australia to receive tax deductible donations. Pursue funding applications with the Packer Foundation and a range of other funding organisations and possible sponsors.

Reveal our vision to others and support them to make our vision real!