03

COLLABORATING WITH OUR KEY STAKEHOLDERS

Australian Organ and Tissue Donation and Transplantation Authority
The Royal Hobart Hospital Clinical Team promoting “What are you waiting for?” During DonateLife Week 2016

Competitors of the Lorne Pier to Pub swim show off their support for organ and tissue donation

DonateLife stall at the Alice Springs Show – Nurse Nicole and Warren chatting about organ donation

Showing support during DonateLife Week

Local Sunshine Coast businesses get behind Jersey Day
DONATELIFE NETWORK

Increasing organ and tissue donation for transplantation in Australia is a shared responsibility. We work in collaboration with state and territory governments, the broader donation and transplant clinical sectors, eye and tissue banks, and community organisations to implement a nationally coordinated leading practice approach to organ and tissue donation.

The OTA manages the implementation of the national program through leadership of, and collaboration with, members of the DonateLife Network (DLN). The network comprises State/Territory Medical Directors, DonateLife Agencies (one in each state and territory), and hospital-based doctors and nurses who specialise in organ and tissue donation.

State and territory governments employ DLN staff through funding agreements with the OTA. The roles and responsibilities are consistent with the model and approach of the national reform program in the public hospital sector (and, where mutually agreed, in the private hospital sector).

Donation specialists in the DonateLife Network are responsible for:

» managing the organ and tissue donation process as part of end-of-life care

» supporting donor families to make informed and enduring decisions about the opportunity for donation

» supporting professional clinical education in managing the donation process

» participating in clinical practice review and audit.

At 30 June 2017 the DLN comprised 248 OTA-funded staff (147.98 full-time equivalents). These fractionated roles were occupied by 172 doctors and nurses specialising in organ and tissue donation in 89 hospitals across Australia, and 76 staff in eight DonateLife Agencies across Australia.

Figure 17 shows the contribution of each jurisdiction to the national reform program in 2016 within the context of population size and funding provided by the Australian Government.

A summary of 2016–17 highlights and achievements for each jurisdiction is provided in this section.
The Commonwealth Government provides funding in selected public and private hospitals, with the greatest potential for organ and tissue donation, to employ trained, clinical specialists dedicated to organ donation.

The 2008 funding model for state and territory funding agreements was based on population and a rurality factor. Since that date, the Budget allocation has been indexed by the Budget Wage Cost Index.
During the year we forged a key partnership between the NSW Organ and Tissue Donation Service (OTDS) and the Wellington Aboriginal Corporation Health Service. The aim of this partnership was to drive awareness activities, develop networks and increase understanding in Aboriginal communities of the importance of organ and tissue donation for transplantation.

**Life Giving Stories wins an Australian Multicultural Marketing Award**

Life Giving Stories was an innovative, artistic social marketing and multimedia campaign that addressed the importance of organ and tissue donation within multicultural groups. It was the outcome of a strategic partnership between the NSW OTDS and the NSW Multicultural Health Communication Service. The campaign involved the production of a unique and inspiring storytelling stage event which brought together donor families and transplant recipients to recount their personal stories.
DELIVERING OUR SERVICE

DonateLife VIC successfully expanded the hospital-based Donation Specialist Nursing Coordinator model to include the six health services with the greatest organ and tissue donation potential. This process involved recruitment, education and mentoring of additional Donation Specialist Nursing Coordinators, providing not only optimal coverage for donation activity but also embedding expert staff within hospitals to help influence culture and practice.

A FOCUS ON EDUCATION

During the year we appointed two Clinical Development Coordinators to further develop the training of new staff members and help upskill donation specialist staff. The Clinical Development Coordinators coordinated well-attended network meetings on consent, collaborative requesting and self-care, as well as a session on innovations in donation and transplantation.

COMMUNITY INITIATIVES

Community and media activities continued to grow, with more volunteers engaged and a greater push on registration messaging. The yearly growth rate in new registrations almost doubled between 2015 and 2016, with almost 40,000 new Victorian registrations on the Australian Organ Donor Register.
Strategic planning results in improved outcomes

Implementation of the strategic plan to improve organ donation in Queensland, developed collaboratively between DonateLife QLD and the Queensland Department of Health, led to a significant increase in donor numbers. In 2016 there were 106 donors in QLD, a 47% improvement on 2015, when there were 72 donors.

Improving organ donation practice

The Best practice processes to optimise organ donation for transplantation guideline was introduced into DonateLife hospitals in Queensland during the year. This guideline incorporates a trained requester model and criteria for the routine referral of potential donors to the DonateLife Agency. Key performance indicators and targets were developed to monitor the actions being undertaken in relation to the strategic plan and the guideline.

Recognising the State Manager’s contribution

Tina Coco was awarded an Order of Australia (AO) in the General Division in this year’s Australia Day Honours. This was for ‘distinguished service to community health as a leader of, and advocate for, organ and tissue donation and transplantation coordination organisations at the state, national and international level’.
Bereavement follow-up

During the year we established a bereavement follow-up service in intensive care units. This has enabled DonateLife SA staff to better understand what factors have supported distressed families during their loved one’s final hospitalisation. The quality of care around end of life is recognised to have an impact on the donation decision.

Increasing donation opportunities

Developing pathways for rural hospitals and embedding specialist staff in emergency departments and paediatric intensive care units has enabled organ and tissue donation to be offered at more locations in South Australia. Identifying donation opportunities outside of metropolitan ICUs is an essential part of increasing donation rates.

Increasing donation conversation workshop attendance

The majority of SA intensive care specialists have now attended the core Family Donation Conversation workshop and our goal is to have 80% trained by 2018. Completion of the course by relevant staff is central to ensuring families make an informed decision about donation.
Service expanded

During the year the DonateLife WA Donor Family Support Coordinator participated in Advanced Care Planning workshops conducted by Palliative Care WA in metropolitan and regional centres of the state. This complements the work being undertaken by DonateLife WA to embed consideration of organ and tissue donation as a routine part of end-of-life care.

New hospital increases donations

St John of God Midland Public and Private Hospital opened in November 2015 as Perth’s newest hospital. The DonateLife WA team met with various stakeholders and conducted education sessions throughout the hospital. To date there have been three organ donors and two tissue donors at the hospital, which is a testament to the engagement between the hospital’s team and the team at DonateLife WA.

Education and collaboration

Two perioperative workshops on organ and tissue donation were successfully conducted in 2016–17 at the St John of God Midland Hospital and the Sir Charles Gairdner Hospital. The evaluations indicated that the professional needs of the participants were met.
An independent organ and tissue donation service

In 2016 DonateLife TAS began the delivery of organ and tissue donation services as an independent jurisdiction. This was a significant achievement following the 2009 implementation of the national reform program in Tasmania. The success of this transition to independence was due to the dedicated work of DonateLife TAS staff and their commitment to developing the clinical skills and capability to provide the full range of organ and tissue donation services.

Improving organ donation practice

Preparing for the transition to independent provision of donation services gave us the opportunity to review and establish clinical structures and processes to support ongoing improvement in donation practice. This has ensured organ donation services are an integrated and embedded part of end-of-life care in Tasmanian hospitals.

Developing new relationships

To complement the transition to independent provision of donation services, there has been a focus on developing relationships with the transplantation sector to strengthen and support the safety and quality of donation practice in Tasmania.
**Community education**

Education and awareness-raising continued to be a priority for DonateLife NT this year. We participated in the NT Show Circuit, held displays at conferences, and undertook promotional activities through a variety of media and forums. DonateLife NT was a major sponsor of the Top End Gran Fondo, a high-profile local cycling event with over 500 participants.

**Indigenous education**

DonateLife NT began its Indigenous education program this year with a presentation to the Top End Health Aboriginal Cultural Advisory Group. We also presented to Danila Dilba Aboriginal Health Service, attended the men’s health promotion night at the Titjikala community, and visited Bathurst Island with a local Indigenous kidney recipient, to undertake education activities. The participation of local Indigenous transplant recipients in our Indigenous education activities has been a key to our success in this area.

**Donor family and recipient support**

In November 2016 a Thank You Day event was held at Lake Alexander in Darwin. Many local donor families attended, as did a number of prominent local dignitaries. To further commemorate donors and their families, Service of Remembrance ceremonies were held at the George Brown Darwin Botanic Gardens and the Alice Springs Olive Pink Garden.
A workshop for theatre staff

During the year DonateLife ACT developed a workshop that provides operating theatre staff with an overview of the donation process up to, and including, organ retrieval. The workshop, consisting of four two-hour sessions, was first run in October 2016, and then again in June 2017. The feedback has been overwhelmingly positive. We would like to acknowledge DonateLife VIC for sharing their theatre workshop information and also Dr Deb Verran for assisting with the first workshops.

Increasing multicultural donation awareness

DonateLife ACT has been working to strengthen the ACT’s multicultural donation awareness through a number of initiatives. We presented at the Australian Sangha Association’s (Buddhist Monks) National Conference in February 2017 and held a stall the Canberra Multicultural Festival. We also attended the Reconciliation Action Plan Expo at the Aboriginal and Torres Strait Islander Cultural Centre in May 2017. This event was attended by over 150 local community members who gained knowledge about organ and tissue donation.

Expanding the tissue donation service

We have been working towards the expansion of our eye and tissue donation service in 2017–18, with plans to include musculoskeletal tissue donation. This will be undertaken with the assistance of the NSW Bone Bank, Australian Biotechnologies, Queensland Tissue Banks, and the Donor Tissue Bank of Victoria. Key DonateLife ACT staff will undertake ‘train the trainer’ education to prepare for the implementation of musculoskeletal tissue donation, as well as to support ongoing training needs as the service expands over time.
COMMUNITY STAKEHOLDERS

Increasing the number of people who donate their organs and tissues is a challenge for the whole Australian community. The community, health care workers and clinicians involved in end-of-life care must recognise that without donation there can be no transplantation. Unless individuals and their families consent to donation, and clinicians act to facilitate donation at every possible opportunity, transplant rates cannot improve.

We work to engage and collaborate with all of our community stakeholders to build our capacity and capability to optimise every donation opportunity to save and transform lives through transplantation. The OTA and our key stakeholders are working to increase consent rates by encouraging all families to discover, decide and discuss (see Figure 19).

Over 2016–17 we engaged with our community stakeholders through a number of activities under the national community awareness and education program. These activities included:

» DonateLife Week
» DonateLife Thank You Day
» Community Awareness Grants
» school education resources
» media and public relations
» community education and outreach
» social media
» printed and online public information.

In partnership with our stakeholders, we also facilitated a number of events and forums to promote organ and tissue donation in the community sector. Input from our community stakeholders remains a vital element of how we work in this critical sector.

A list of our community stakeholders is included in Appendix 1.

DONATELIFE WEEK 2016

DonateLife Week is Australia’s annual national awareness week to promote organ and tissue donation. It is led by the OTA, in partnership with DonateLife Agencies in every state and territory, and with participation from the broader organ and tissue donation and transplantation sector and other key stakeholders. The theme for DonateLife Week 2016 was, ‘What are you waiting for? Join the Australian Organ Donor Register online today to save lives – donatelife.gov.au.’

FIGURE 18: Encouraging consent to donation
The campaign achieved a 61% increase in new registrations in July 2016 and a 78% increase in August 2016 compared to the previous year, with a total of 41,785 Australians joining the Australian Organ Donor Register (AODR) during the campaign period.

The campaign was supported by a suite of printed, video and online materials. This included the ‘Faces of DonateLife Week’ which featured Australians waiting for a transplant, organ and tissue transplant recipients, living donors, and families of deceased organ and tissue donors, as well as ordinary Australians who had joined the AODR.

The #endthewait social media campaign was a key component of DonateLife Week 2016. This campaign highlighted that while Australians wait for things every day, there are some people waiting for a transplant that will one day transform their lives.

DONATELIFE THANK YOU DAY 2016

DonateLife Thank You Day is a national day to honour all living and deceased organ and tissue donors and their families, and to acknowledge their generosity, which saves and transforms the lives of others. Held for the first time in 2015, Thank You Day 2016 retained the focus on inviting the broader Australian community to join in thanking those who generously agree to organ and tissue donation. This was achieved through targeted media coverage and social media engagement supported by community events.

DonateLife Thank You Day 2016 was supported and promoted through the DonateLife Network, professional peak bodies, and community partners.

As part of the campaign, we produced a video featuring transplant recipients, living donors and donor families. In addition, Australians were invited to create and share on social media a ‘thank you’ message to all living and deceased organ and tissue donors, and their families, for their generosity which saves and transforms the lives of others.
DONATELIFE FORUM

The 2017 DonateLife Forum was held on 11 May at the Brisbane Convention and Exhibition Centre, with a theme of ‘Where to from here?’ The forum attracted over 300 delegates from the organ and tissue donation and transplantation sectors, the intensive care community, community organisations, donor family members, transplant recipients and OTA staff. The event enabled these delegates to come together to share experiences and ideas on how to better implement and further embed the national reform program into clinical and community practice.

Invitations to participate in the forum were extended to community members this year for the first time. The previously named DonateLife Network Forum was renamed the DonateLife Forum to reflect this more inclusive approach and the forum program included presentations relevant to both the clinical and community sectors.

The positive collaboration demonstrated on the day was impressive. It provided a platform for our future efforts to consolidate and build on our significant past achievements, and to drive the reform program forward.

COMMUNITY CONSULTATIVE FORUM

A Community Consultative Forum on contact between donor families and transplant recipients was held on 17 March 2017. It provided an opportunity for sharing and open discussion about different Australian stakeholder experiences, perspectives and insights into the complex issue of direct contact between donor families and recipients. It was also an opportunity to improve knowledge of this issue, and promote awareness and understanding of the diversity of public opinions among different stakeholder groups.

Participants at the forum included donor families, transplant recipients, peak bodies, governments and the DonateLife Network. The forum provided an opportunity for all participants to share their different perspectives and views on identity disclosure, communication, and contact between families and recipients.

Dr Helen Opdam (National Medical Director), Dr Dale Gardiner (United Kingdom Deputy National Clinical Lead for Organ Donation), and Dr Sarah Jones (NT State Medical Director) at the DonateLife forum