‘Big improvements but a long way to go’

The launch of the *Increasing Organ Donation in NSW: Government Plan 2012* in August last year has provided the platform for a focussed effort in NSW to improve organ and tissue donation rates. In 2013 NSW continues to see a sustained increase in organ and tissue donation and transplantation rates. At the end of July 2013 there were 70 donors which is an increase of 56 per cent year to date compared with 2012. The number of organs transplanted was 207, an increase of 47 per cent for same time last year and consent rates have increased from 55 per cent in 2012 to 61 per cent at June 2013. Our eye and tissue banks have also seen demonstrated improvements over the past twelve months and an increase in donation rates. The femoral head program is currently 22 per cent above this time last year and the corneal transplantation waiting list has been reduced by 48 percent.

While all these improvements are encouraging there is still a long way to go.

NSW continues to roll out the national education program for donor family conversations. A range of training programs have been implemented as part of the larger professional education program for clinicians. These have included:

- General ADAPT workshops with 241 participants;
- Medical ADAPT workshops with 77 participants;
- Core Family Donation Conversation seminars with 70 participants;
- Practical Family Donation Conversation workshops with 83 participants.

In addition NSW continues to provide simulation training follow up for staff who are conducting donor family conversations. To date, 35 clinicians have attended designated requestor simulation training.

The Communication with Families regarding Organ and Tissue Donation in Intensive Care (COMFORT) study, previously known as the ‘Designated Requestor trial’, now has eight NSW hospitals participating. Patient enrolment has commenced in six hospitals and as at July 2013, there were 14 donor families enrolled. The study is expected to extend over the next two to three years.

NSW has developed a Cultural and Linguistic Diversity (CALD) Implementation Strategy to support the National Engagement Strategy for those communities. This strategy aims to promote organ and tissue donation in CALD communities and staff have been actively attending a range of events to promote the important message.

Dr Robert Herkes  
State Medical Director

From left: Lions NSW Brian Rope and Jean-Claude Legrand, Hospital Scientist, Dr Meidong Zhu, Laboratory Manager Raj Devasahayam and Phil Bower, Chairman of Lions Save Sight and Public Health Care Foundation.
Two Sydney councils have thrown their support behind the DonateLife message. At opposite ends of the city, south-west Sydney’s Liverpool Council and Waverley Council, home of Bondi Beach, both took proactive steps to highlight the importance of organ donation awareness with their constituents.

Commencing in August, Liverpool Council now presents a talk on organ donation at monthly citizenship ceremonies.

“Around 80 individuals become citizens each month in the Liverpool region, so this is a really significant initiative,” said Ellie McCann, Strategic Project Manager at the NSW Organ and Tissue Donation Service.

The talks are currently being conducted by the Mayor of Liverpool, Cr Ned Mannoun, who has a personal commitment to organ donation. The Mayor’s two-year-old son, Solomon, was born with kidney failure.

“What we’re waiting for now is when he gets to 10 kilos, then I can donate my kidney,” Cr Mannoun recently told the Seven Network’s Sunrise program. “He’s the gift – I wouldn’t have it any other way.”

Solomon is currently 8.5 kilos and receives nine hours of dialysis each night. The Mayor and his wife are keenly awaiting sufficient weight gain to allow the transplant. “Then hopefully he’ll have a normal life like any other little kid,” Cr Mannoun said.

Waverley Mayor, Cr Sally Betts, also understands the importance of making constituents aware of the Australian Organ Donation Register and included a link beside her regular column on Council’s website, to encourage constituents to sign up.

“I encourage everyone to sit down and have a general chat with your family about what your wishes are in relation to these issues,” Mayor Betts said. “It’s really important to have these conversations early on as it can reduce some of the worry about these matters for your family at a time of grief.”

Mayor Betts recently spent an afternoon with local kidney recipient, four-year-old Poppy Ivison. Poppy was born with renal failure and spent the first three years of her life in hospital and on dialysis — now she is a fun-loving four-year-old after receiving a life-saving kidney transplant.

“Poppy is a beautiful little girl and the changes in her life highlight the importance of making a decision and talking to your family about donation. She now has a wonderful future,” Mayor Betts said.
The complexities of managing paediatric organ donation with a family from a non-English speaking background was amongst a host of presentations given at the second NSW OTDS Annual Forum, themed ‘The foundations of the Future’.

Delegates from across the state gathered in Sydney on September 3, to hear a day-long program of outstanding presentations covering topics from paediatric donation, to rural considerations for organ donation, and from advances in corneal storage to managing complex patient privacy issues.

Sessions focused on past achievements, current projects, research and the future direction of the NSW OTDS, showcasing many projects that involved health professionals and the wider community.

Mr Terry Clout, Chief Executive of the NSW OTDS and of the South Eastern Sydney Local Health District, opened the forum, which was attended by Ms Yael Cass, Chief Executive of the Australian Organ and Tissue Authority and its National Medical Director, Dr Jonathan Gillis.

Dr Robert Herkes, State Medical Director of the NSW OTDS, presented on the service’s four-year history, its future direction and the efforts and contributions of all his team across NSW.

Ms Mary Campbell, Donation Specialist Nurse from the North Coast Local Health District, presented the strategies implemented to support the increase in rural donations in the North Coast of NSW. She outlined the difficulties experienced by rural teams in facilitating donation and supporting families, particularly in the indigenous community.

Dr Con Petsoglou, Deputy Director of the Lions NSW Eye Bank, spoke of the advances in corneal transplantation surgery. Delegates said this was an inspiring presentation which highlighted the development in solutions and technology that has supported the ability to restore eyesight in 750 people in 2012-2013.

The development and organisation of the forum is attributed to a small working group lead by Mrs Jeanette Lacey, Donation Specialist Nurse John Hunter Hospital. Jeanette volunteered to chair the organising committee and together with 11 other colleagues, created an innovative program. The efforts of each person on the organising committee was acknowledged and applauded by Dr Herkes, on behalf of the NSW executive.
NSW Highway Patrol’s helping hand

NSW Health and NSW Police are celebrating over a year of success with a program that ensures the safe and efficient transfer of medical teams and organs for transplantation.

Since January last year, NSW Police and NSW Health have operated the NSW Emergency Medical Transfer – Standard Operating Procedures, developed collaboratively between the Highway Patrol and the NSW Organ and Tissue Donation Service.

Time is critical when it comes to transporting life-saving organs for donation, so NSW Health has sought assistance from the Highway Patrol on many occasions. These officers are highly experienced, skilled and trained and having this level of support for medical teams has greatly assisted in saving many lives.

The Highway Patrol’s role in this community service is formally recognised and supported within NSW Police, with all requests across NSW now managed from Sydney by the Rescue Control Officer, creating a more efficient and streamlined process.

The topic of organ donation and transplantation is now part of the Highway Patrol officer’s orientation and training too, with around 50 officers attending the recent training session in July.

Remembering donors in the Hunter

The Annual Organ and Tissue Donation Remembrance and Thanksgiving Service will be conducted at the Hunter Wetlands Centre on Sunday, 28 October 2013.

“We’ll celebrate that sense of renewal in the wetlands,” Hunter New England Health Donation Specialist Nurse, Jeanette Lacey said.

“We will also reflect on the sense of freedom there. With organ donation, our recipients are freed of dialysis, of oxygen machines, and it’s a profound gift that we will honour on the day.”

The very first service of thanksgiving for the Hunter’s organ and tissue donation service was held in 1992 at Christ Church Cathedral. Organisers say this years’ service is shaping as the biggest attendance on record.

For the past five years, John Hunter Hospital has been the highest organ donating hospital in NSW and in recent times has concentrated its efforts on increasing opportunities for Hunter residents to become tissue donors.

“This year, we’ve had a marked increase in tissue donations. Hunter people are generous at a time of great sadness, and for that we are very grateful,” Mrs Lacey said.

Key members of the John Hunter Organ and Tissue Donation Service will attend, and the service will feature the uplifting voices of community singers, Sing, Sing, Sing.

“We aim to raise spirits and show respect. We have chosen a beautiful place, which resonates our themes of rejuvenation and freedom,” Mrs Lacey said.
Teenagers become street smart

Around 17,000 students from 138 high schools attended this year’s streetsmart event – aimed at reducing severe injury and death in road accidents - held at Sydney’s Olympic Park in August.

The program is open to students in Years 10 to 12 in all NSW and ACT schools, and gives them information and strategies in an attempt to reduce the shocking statistics on youth injury and fatalities.

In 2010, there were 53,863 road traffic crashes involving 18 to 25 year olds. Of these, 73 had fatalities and 14,915 resulted in injuries. Westmead Hospital’s Trauma Service, which has run this three-day event for the last seven years, is committed to decreasing these numbers.

Organisers say the event’s content and structure is set up to treat young people as adults allowing them the freedom to choose from a range of interactive exhibits.

NSW Organ and Tissue Donation Service staff assist in the planning of this event and conduct an interactive stand which provides students with information about organ and tissue donation.

This is a great opportunity that generates open discussion on difficult and sensitive subjects with young people that also encourages decision making on the DonateLife message: Discover, Decide, Discuss.

One of the largest agricultural shows in the world, the Commonwealth Bank AgQuip Field Days, took place in August – and DonateLife was there to meet the crowds.

Over 100,000 visitors attend this annual event, held in the small NSW town of Gunnedah, providing an outstanding opportunity for raising community awareness of organ and tissue donation.

Stall organiser and Donation Specialist Nurse, Emily Daley, said the three-metre square stall despatched 1920 organ donation registration pamphlets – and 43 people signed-up on the spot.

“The stand-out issue evident during the three days was that the majority of people were not aware that the RTA registry had been discontinued and that they now need to register on the Australian Organ Donor Registry,” Emily said. “We can easily say that at least 90 per cent of the visitors that we spoke with didn’t know this. Although we were amazed by this observation it also meant that we had an attention-grabbing sentence to attract people over to the stall.”

Visitors repeatedly voiced support for the "opt-out" system, Emily said, along with disappointment when learning that senior next of kin can refuse donation on behalf of a registered willing donor.

“These points prompted great conversations between ourselves and the visitors, and hopefully their families and friends back in the community,” she said.

The stall attracted a wide range of people – from young children to enthusiastic teenagers through to the elderly. Organisers say they plan to contact the Australian Organ Donor Registry in approximately six months, to complete a retrospective audit of the amount of new registrations in the surrounding areas, to gauge the effectiveness of their presence at the event.

“We had quite a few recipients themselves and also families of donors approach our stand to tell their story,” Emily said. “There were many and varying opinions within the crowd, however overall a very supportive outlook for Australia’s organ and tissue donation service.”
Parliamentary Secretary visits Nepean Hospital

The former Parliamentary Secretary for Health and Ageing, Shayne Neumann, met a kidney recipient whose life has been changed by the successful transplant surgery, along with a donor and the many health professionals who help facilitate organ retrieval and transplants at Nepean Hospital, on a recent visit to Sydney’s west.

Mr Neumann met Michael Cahalane, 49, and his partner Julie Edwards, of Colyton, and heard about their participation in the Paired Kidney Exchange Program. Ms Edwards, 53, offered her kidney to her partner but was unsuitable due to their differing blood types.

As a result, through the program, they ‘swapped’ kidneys with a woman donor whose blood type was suitable – and Ms Edwards’s kidney went to another needy recipient.

“We swapped with someone in Brisbane – so Julie actually helped two people, and the other person helped two people,” said Mr Cahalane, who had spent two and a half years receiving nine hours of dialysis every day.

The former Parliamentary Secretary was joined by former local Federal Member for Lindsay, David Bradbury, who also spent time with Mr Cahalane and Ms Edwards, hearing about the life-changing surgery.

Mr Bradbury encouraged all local families to consider and discuss their wishes relating to organ and tissue donation.

“While it is important to register to be an organ and tissue donor, families will still be asked to give consent. It is preferable that families understand the wishes of their loved ones before they are put in the position where they have to make that decision,” Mr Bradbury said.

Mr Neumann took the opportunity while visiting Nepean to outline the Federal Government support for living donors.

“The Federal Labor Government initiated support for living donors, through their employers, with up to six weeks paid leave up to the national minimum wage rate,” Mr Neumann said. “This will help to reduce any financial stress that the surgery and recovery may put on them, their families and their employers.”

Mr Bradbury and Mr Neumann enjoyed a viewing of the work created as part of the Groundswell Project, which promotes organ and tissue donation within the community through film.

“The Groundswell Project is doing a tremendous job of creating healthier community attitudes about ageing, illness, dying, death and bereavement,” Mr Bradbury said.

“This group has been able to stage the FilmLife Festival thanks to Federal Government funding. I encourage them and other groups in the region to consider ways they can promote organ and tissue donation within their communities and organisations.”

Taking the message to the Indian community

Over 60 members of the Indian community, including many from the Telugu community, attended a successful organ donation seminar in August.

Expert speakers included Liverpool Hospital’s Dr Sundaram Rachakonda, Dr. Deepak Bhonagiri and Associate Professor Anders Aneman, along with Professor Richard Allen, from the Royal Prince Alfred Hospital, Dr Priya Nair from St Vincents Hospital and Ms Ellie McCann, from NSW DonateLife.

Guest community speakers shared their inspirational personal journeys, from being on the waiting list to becoming a transplant recipient, and spoke of how their lives changed.

The seminar covered all aspects of organ and tissue donation and transplantation, as well as providing a deep insight into Hinduism in the context of organ donation.
Aboriginal collaboration to promote organ and tissue donation

A national Aboriginal pamphlet has launched ongoing engagement with Aboriginal communities in Northern NSW, to enable culturally respectful conversations about organ donation.

This initiative is a collaboration between the Donation Specialist Nurse, Mary Campbell, Aboriginal health workers, the local Aboriginal community and various state and national organisations.

The project won the collaborative team category of the Northern NSW Local Health District quality awards and has been submitted as part of NSW Health Innovation Awards as well.

2014 Australian Transplant Games

The announcement that the 2014 Australian Transplant Games will be held in Melbourne was made by Chris Thomas, Transplant Australia CEO, at the Transplant Australia Miracle Dinner recently.

NSW State Medical Director, Dr Robert Herkes, attended this evening along with members of the NSW DonateLife team, celebrating the miracle of life with NSW Transplant Australia.

With a ‘Christmas in July’ theme, the Miracle Dinner was proudly supported by Dooley’s Catholic club, which for the fourth year in a row not only hosted the event but handed over a cheque for $12,000 to support the Australian transplant athletes attending this year’s International Transplant Games in Durban.

The event focused on giving thanks to the donors and donor families for making such a difference to people’s lives through transplant surgery. Guests met recipients who had only just received transplants while others had received them up to 35 years ago.

The evening also raised funds with raffles and an auction, to support the 36 recipients attending this year’s Transplant Games.

Organ and Tissue Donation Service

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