Overview

National Reform Agenda
Organ and tissue donation rates in Australia have been historically low. Increasing the rate of organ and tissue donation would significantly improve access to life-saving and life-transforming transplants for Australians in need and their quality of life and that of their families who care for them. The economic impact of more transplants on the health system would also be significant, particularly given the high cost of providing ongoing medical care, such as renal dialysis, compared with the cost of transplantation.

In 2008 the Council of Australian Governments endorsed the Australian Government’s National Reform Agenda to implement a World’s Best Practice Approach to Organ and Tissue Donation for Transplantation (National Reform Agenda).

The Australian Government committed ongoing funding, including $151 million over four years to 2011–12, to establish a nationally coordinated approach to organ and tissue donation processes.

The key strategic directions of the National Reform Agenda are to:

Organ and tissue donation at a glance

- One organ and tissue donor can save the lives of up to 10 people and significantly improve the lives of dozens more.
- Australia has a world-class reputation for successful transplant outcomes.
- 91% of Australians agree that organ and tissue donation has the potential to save and improve lives.
- The majority of Australians (82%) recognise that it is important for their family to know their donation wishes.
- 40% of Australians have not discussed their donation wishes with their family.
- 43% of Australians do not know, or are not sure, of the donation wishes of their loved ones.
- The most important thing that helps a family’s decision about organ donation is knowing the wishes of their loved one.
- Australia’s family consent rate is low, with less than 60% of families giving consent for organ and tissue donation to proceed.
- 1,596 people were on Australian organ transplant waiting lists at 3 June 2011.
- On average, people on the transplant list wait between six months and four years.
- In 2010–11, 328 organ donors gave 976 Australians a new chance in life.
- The number of organ donors in 2010–11 was the highest since national records began.
- Australia’s donor per million population rate lifted from 12.9 in 2009–10 to 14.6 in 2010–11 and was significantly higher than the baseline rate of 10.2. As of January 2011, Australia’s growth compares favourably with Spain’s increase of 2.4 per million people after its first full year of national reforms (1991), and the United Kingdom’s increase of 0.3 per million people for the first full year of its national reforms (2009).
- In 2010–11, 965 people donated their corneas. As a result, there were 1,513 corneal transplants.
increase the capability and capacity within the health system to maximise donation rates, and
raise community awareness and stakeholder engagement across Australia to promote organ and tissue donation.

Evidence from comparable countries demonstrates that a coordinated and comprehensive national approach, complemented by education and awareness efforts, will lead to an increase in solid organ and tissue donation and transplants.

The National Reform Agenda provides for significant investment in national initiatives to increase organ and tissue donation for transplantation in Australia and comprises nine measures, as shown in the box below.

We manage implementation of the nine measures through leadership and collaboration with the DonateLife Network comprising state and territory medical directors, DonateLife Agencies and hospital-based doctors and nurses dedicated to organ and tissue donation.

Other significant stakeholders engaged in implementation of the National Reform Agenda are: state and territory governments, eye and tissue banks, community organisations, and the broader donation and transplantation clinical sectors.

### National Reform Agenda measures

<table>
<thead>
<tr>
<th>Measure 1</th>
<th>Measure 2</th>
<th>Measure 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>A new national approach and system – a national authority and network of organ and tissue donation agencies</td>
<td>Specialist hospital staff and systems dedicated to organ donation</td>
<td>New funding for hospitals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Measure 4</th>
<th>Measure 5</th>
<th>Measure 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>National professional awareness and education</td>
<td>Coordinated ongoing community awareness and education</td>
<td>Support for donor families</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Measure 7</th>
<th>Measure 8</th>
<th>Measure 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safe, equitable and transparent national transplantation processes</td>
<td>A national eye and tissue donation and transplantation network</td>
<td>Other national initiatives, including living donation programs</td>
</tr>
</tbody>
</table>
Last year (2010) was the first full year of implementation of the Australian Government’s National Reform Agenda, a World’s Best Practice Approach to Organ and Tissue Donation for Transplantation. The collective efforts of the Authority, the DonateLife Network, community organisations and the broader sector – in partnership with the Commonwealth, state and territory governments – achieved Australia’s highest donation and transplantation outcomes since national records began.

In 2010–11, 328 organ donors saved and improved the lives of 976 Australians. This was the highest rate since national records began. The increase is substantial, being a 60% increase on the calendar year baseline of 205 organ donors (the average from 2000 to 2008), and a 15% increase on the 2009–10 outcome (285 organ donors). These results indicate that the National Reform Agenda is starting to gain traction. The aim of the DonateLife Network is to achieve sustained and continued growth in donation and transplant rates in order to improve or save the lives of the 1,596 Australians (at 3 June 2011) waiting for a solid organ transplant.

In March 2011, 300 members of the DonateLife Network came from 77 hospitals across the country to participate in the second DonateLife Network Annual Forum in Sydney. Over two days, members of the network participated in discussions with peers and sector experts, including international leaders in the field. The theme was ‘Connecting people – Transforming
Lives’, focusing on our place and purpose within the Australian community and health system. Organ and tissue donation reform is a microcosm of the broader national health reform agenda and can set a new paradigm for improved performance, accountability, transparency and community engagement.

Following the annual forum, a strategic planning day was held with the Authority’s Advisory Council, state medical directors, jurisdictional representatives, agency managers and senior Authority staff. This leadership group identified six strategic priorities for the DonateLife Network for 2011–12 (see below). These priorities are critical to delivering sustainable reform and efficiency in organ and tissue donation, supporting clinical change management across the DonateLife Network, and collecting the right data to drive performance and inform change management.

### DonateLife Network strategic priorities

<table>
<thead>
<tr>
<th>Priority</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of an electronic donor record</td>
<td>The electronic donor record will support the capture of donor referral data, medical–social history and family consent, and provide a real-time system for the offer, allocation and distribution of organs and tissue.</td>
</tr>
<tr>
<td>DonateLife Hospital Performance Audit data collection enhancement</td>
<td>The enhancements to hospital performance audit and reporting will establish a national best practice framework for data analysis and will drive clinical performance accountability and improvement.</td>
</tr>
<tr>
<td>Increasing consent rates</td>
<td>Family Conversation Workshops are being developed to provide intensive training modules for clinicians on managing the donation requesting process with potential donor families.</td>
</tr>
<tr>
<td>Special audiences’ communication and engagement strategy</td>
<td>In consultation with key stakeholders, we are developing a communication engagement strategy to address potential barriers to organ and tissue donation within culturally and linguistically diverse audiences in Australia.</td>
</tr>
<tr>
<td>Integration of the Eye and Tissue Network into the broader DonateLife Network</td>
<td>The integration of the Eye and Tissue Network into the broader DonateLife Network will deliver strategies to further integrate solid organ and tissue donation processes. It will provide nationally consistent data collection processes including tissue donation, allocation, transplantation and outcome data.</td>
</tr>
<tr>
<td>Development of a performance and reporting framework</td>
<td>The development of a performance and reporting framework will provide an agreed process for collecting, reporting and disseminating data, and delivering improved access to data.</td>
</tr>
</tbody>
</table>


Leadership of the DonateLife Network was consolidated, with strengthened collaboration between the Authority, state medical directors, DonateLife Agency staff, jurisdictional representatives, the broader DonateLife Network and community stakeholders.

Our governance structure was streamlined to allow for more effective clinical and expert engagement in developing and implementing the National Reform Agenda.

The clinical content segment of the Australasian Donor Awareness Program (ADAPT) was revised and updated, and we began revising the grief and bereavement segment.

We started developing a new training module to train clinicians in managing the donation requesting process with potential donor families.

We delivered a national orientation and induction program for new DonateLife Network staff.

We rolled out Phase Two of the national advertising campaign.


We implemented a Donor Family Support (DFS) framework nationally to deliver consistent donor family support services and resources.

We focus-tested DFS resources with donor families to test their currency and usefulness, and then started revising these resources to reflect the feedback we received.

The Parliamentary Secretary for Health and Ageing launched the Transplantation Society of Australia and New Zealand (TSANZ) Organ Transplantation from Deceased Donors: Consensus Statement on Eligibility Criteria and Allocation Protocols on 1 July 2011.

We completed a report on options for more effective eye and tissue product retrieval, processing and storage, for consideration in 2011–12.

The Australian Paired Kidney Exchange Program got under way and the first match run occurred in October 2010. A total of 15 kidney transplants have successfully been achieved over 2010–11 as a result of this program.

Implementation of the national Donation after Cardiac Death Protocol was rolled out in the second half of 2010, resulting in an expansion of the potential organ donation pool and contributing to the increase in donation rates.

Highlights for 2010–11
The 2010–11 year was one of consolidation. Here are some of the significant highlights:
Improved capacity in the health sector

Business Management Plans were implemented across each state and territory, with progress reports submitted to the Authority each quarter.

A dedicated data and audit officer was appointed in each jurisdiction to support the DonateLife Hospital Performance Audit. These officers were appointed to ensure consistent audit processes, provide supervision, support and training, coordinate and run case review meetings, provide feedback to hospital staff, and meet regularly to review the audit process.

Increased community awareness

In 2010–11 the DonateLife communication campaign achieved and sustained increased levels of family discussion about donation wishes, knowledge of family members’ donation wishes, and awareness of the role of family consent. Extended use of the campaign – ‘DonateLife. Discuss it today. OK?’ continued to prompt Australians to discuss their donation wishes with family members, because in Australia family consent is always sought before donation can proceed.

In May 2011 the second phase of the campaign – ‘DonateLife. Know their wishes, OK?’ – was launched to encourage Australians to ask about and know the donation wishes of family members so that they are prepared, should the situation arise, to confirm the wishes of the deceased.

The DonateLife campaign is a key component of the National Community Awareness and Education program and was supported by community-based activities conducted by the DonateLife Network, community organisations and other key stakeholders during 2010–11.
In 2010–11 the Australian Organ Donor Awareness Week was renamed DonateLife Week following consultation with the sector to reflect the new nationally consistent approach to community education and awareness. DonateLife Week activities were supported by the DonateLife Book of Life and by national campaign advertising activity.

The DonateLife brand, as the national brand for organ and tissue donation, was increasingly used across the sector to provide a unifying symbol for building community awareness and support for organ and tissue donation.

The year ahead

The Authority is now well positioned to focus on our six strategic priorities for 2011–12. The foundations of the National Reform Agenda are now settled and our work will focus on supporting and delivering clinical practice reform across the DonateLife Network.

Acknowledgments

I would like to acknowledge the contribution of Ms Elizabeth Cain, who was the Authority’s acting CEO for the period March 2010 to February 2011 and was integral to achieving many of the outcomes mentioned above. The Authority would not have progressed to where it is now without her leadership and dedication to implementing the National Reform Agenda.

I would also like to thank Dr Gerry O’Callaghan, the inaugural National Medical Director, for his expert advice and unfailing commitment to progressing the National Reform Agenda, with particular focus on developing the national clinical network. As a well-respected voice in the donation and transplantation sectors, and with experience of the National Organ Donation Collaborative (2006–08), Dr O’Callaghan was well placed to embrace this lead role in the Authority.

Dr O’Callaghan leaves us at the end of this reporting period but will maintain his involvement in the sector through his position as a member of the Advisory Council.

I would like to acknowledge the continued leadership of the Advisory Council’s Chairman, Mr Sam Chisholm, and the 12 members who provide me with ongoing advice on matters of relevance to organ and tissue donation and transplantation.

I would also like to thank the state medical directors from all eight jurisdictions who have provided leadership and guidance to the DonateLife Network.

Our stakeholders, including the Department of Health and Ageing, led by the Secretary, Ms Jane Halton PSM; state and territory governments; and our 50 charter signatories also deserve acknowledgment. All have been integral to setting the strong foundations and solid progress achieved in 2010–11.

Finally, I thank the Authority staff whose ongoing commitment, persistence and versatility have contributed to our many accomplishments.

I am pleased to present the Authority’s 2010–11 Annual Report.
National Medical Director’s report

In its first full year of operation, the DonateLife Network has seen a continuation of increased donation rates for both organ and tissue, which are described in detail elsewhere in this report. From my perspective, it is important to take this opportunity to recognise the increased depth and diversity of skills and expertise within the network, and particularly in hospitals in remote and regional Australia.

Increased donation rates have resulted in more transplants being available in Australia than ever before. This increase in donation and transplantation is cause to congratulate the individuals responsible and acknowledge their hard work throughout 2010–11.

Whenever donation and transplantation occur we must also reflect on the generosity of donor families who have made this possible. I have frequently encountered very strong and consistent feedback from families and friends of organ and tissue donors that knowing the wishes of loved ones during life is of paramount importance. This provides families with a much-needed sense of validation in their contribution to end-of-life decision-making and gives DonateLife staff a great sense of legitimacy as they support families. It has been gratifying to know and hear that our national advertising campaign has had such a strong resonance with donor families and clinical staff.

DonateLife Network staff were also welcomed at thanksgiving ceremonies across the country. It is a humbling and inspirational experience to meet donor families and their friends and hear their stories of both the experience and of the loved ones whose lives these ceremonies celebrate.

This year has seen increasing collaboration and cooperation of hospital teams to support each other in the implementation of the National Reform Agenda. DonateLife staff from the Alfred Hospital in Melbourne travelled to Western Australia to provide support for the implementation of
Donation after Cardiac Death in that state following legislative changes. Hospital medical directors, organ donor coordinators and hospital senior nurses travelled to other parts of the country to observe successful clinical practices and learn new skills. Clinical staff from the Royal Darwin Hospital were welcomed at the Queensland Eye Bank where they learned corneal retrieval techniques to support corneal donation and transplantation in the Northern Territory for the first time. It is very exciting to experience the evolution of the DonateLife Network.

Part of this evolutionary process has been ongoing research activity. One of the many projects was the Predict Study coordinated by DonateLife staff at the John Hunter Hospital, Newcastle. The aim of the study was to validate an Australian-based tool that is ethically and medically acceptable to be used by intensive care clinicians in intensive care units in order to predict the time to death after withdrawal of life-sustaining treatments. The results will be available in 2011–12. The expected outcome of the trial is to provide intensive care clinicians with a tool to support decision-making and help to predict, with an acceptable degree of certainty, which patients will require prolonged palliative care planning and which will only survive for a short period. It is also expected that the tool will help clinicians identify suitable candidates for Donation after Cardiac Death. Many others in the network produced excellent scientific work during 2010–11 and presented or published their achievements both in Australia and overseas.

Tools for implementing the National Reform Agenda

The 2010–11 year saw important work done to develop and disseminate tools to support the implementation of the National Reform Agenda and influence clinical practice. These tools included:

1. The National Donation after Cardiac Death Protocol

Supported by an implementation framework and a plain language consumer guide, this protocol was transferred to the Authority by the National Health and Medical Research Council (NHMRC) in July 2010 and subsequently implemented across jurisdictions during 2010–11.

2. Revised ADAPT program

The long-standing ADAPT course provided to intensive care nurses and physicians as a component of their postgraduate training underwent content revision as part of a collaborative process with the Australian New Zealand Intensive Care Society (ANZICS), the College of Intensive Care Medicine of Australia and New Zealand, and the Australian College of Critical Care Nurses. The revised content reflects the new national framework, increased demand, and recent scientific developments (including the third edition of the ANZICS Statement on Brain Death and Organ Donation edition 3.1). It also prepares the course for new and varied forms of delivery.
3. DonateLife Hospital Performance Audit
The DonateLife Audit is used to measure and report on actual and potential organ donation activity and to identify missed opportunities for organ donation. The audit process (which includes case review meetings) raises staff awareness about donation activity and helps determine how to overcome local barriers to organ donation. In 2010 the Authority captured the first full year of nationally consistent audit data. Analysis of this data enabled the Authority to target and prioritise interventions to address those hospitals that are underperforming and have potential for increased donation activity. It also allowed the Authority to identify leading hospitals in donation activity with the possibility of learning from these organisations.

In the future, the DonateLife Audit will facilitate the direct comparison of similar institutions and help informed decision-making on staffing levels in hospitals based on donation activity.

4. Donor Family Support Service
This is a nationally consistent program of support that provides donor families with respectful support that is responsive to the needs of each family. The national Donor Family Support (DFS) Service Framework outlines the support offered to donor families in Australia.

A DFS coordinator position has been funded in each jurisdiction to implement DFS consistently and to provide ongoing support for donor families.

The donor family support resources were focus-tested in early 2011 to ensure they met the need of families. The resources will be revised in line with the findings of the focus testing and revised resources will be available in late 2011.

5. Family Consent Workshop
Work has begun on the development of this advanced skills workshop to provide comprehensive training for clinicians on sensitive communication with families.

This is an exciting and crucial tool for influencing the outcome of family discussion to advocate for donation as an outcome and simultaneously support donor families in the decision-making process.

In February 2011 we lost a valued colleague and friend, Janette Hall from South Australia. Janette was the hospital senior nurse at the Lyell McKewin Hospital in Adelaide and a tireless advocate for her professional goals as well as a devoted mother and wife. Janette became an organ and tissue donor, and it was a great honour to be able to acknowledge her contribution with the Janette Hall Professional Training and Development Scholarship. The scholarship was announced at the DonateLife Network Annual Forum in March 2011, where her colleagues and friends from DonateLife South Australia read the reflections of her husband, Dr Simon Hall.

There have been many highlights in a very busy year, with the continued focus on saving and improving the lives of Australians through increasing organ and tissue donation and transplantation. This year saw the launch of the TSANZ Organ Transplantation from Deceased Donors: Consensus Statement on Eligibility Criteria and Allocation Protocols, the implementation of the Australian Paired Kidney Exchange Program, and the beginning of the process for national integration of the eye and tissue banks into the broader DonateLife Network.
International collaboration

In February 2011 I had the privilege of visiting the Gift of Life Donor Program in Philadelphia where I learned a great deal from the extremely hospitable team led by CEO, Mr Howard Nathan, who subsequently participated in the second DonateLife Network Annual Forum. This organ procurement organisation has a donation rate of 39.2 donors per million population, as well as an active tissue retrieval program. We have much to learn from such an experienced and high-performing program. We are fortunate they have agreed to partner with us in the development of our Family Conversation Workshop and training materials later in 2011. The Gift of Life Institute has an international reputation for excellence in training organ and tissue donation professionals.

As part of this trip I was invited to speak at a consensus workshop hosted by the Canadian Blood Authority in partnership with the Canadian Critical Care Society on the role of physicians in organ donation.

Acknowledgments

My greatest pleasure of the last year has been the task of introducing our new CEO, Ms Yael Cass, to the DonateLife Network and clinical communities of intensive care, transplantation and other partners. It has been rewarding to observe the warm reception she has received and the strength of leadership she has demonstrated engaging with clinical colleagues.

After two years as inaugural National Medical Director, I decided to step down from my position effective from 1 July 2011. It has been an absolute privilege to have been part of this program and to have had the opportunity to work with such a passionate and expert group both within the DonateLife Network and at the Authority in Canberra. I look forward to resuming my role as a member of the Advisory Council in 2011–12.
Taylor’s gift

Taylor was just 15 months old when she became a donor. Her gifts have saved the lives of two baby boys who now not only have the gift of life, but also the gift of time and a chance to grow up with their loving families.

Taylor was a very independent, outgoing and lively child. Every day was an adventure and another excuse to laugh, smile and play. She had total confidence that she was the centre of her family and greatly adored by everyone around her, but was also a great sharer. When she died it seemed a very important and logical choice for us as her parents to decide to offer her organs for donation. We know with total certainty that she would have wanted to share anything she could with others and would be very proud of what she has been able to contribute after she left us.

We will probably never know Taylor’s recipients nor get the chance to meet them or tell them about Taylor, but this doesn’t diminish the importance of the gifts she gave or the rightness of the decision to authorise her donation.

Being a donor is more than the gift the donor gives – it’s also about the community you join when you are a donor family, the joy you get from knowing someone else is healthy because of her, and the knowledge of how very proud she would be of the special gift she gave to these complete strangers, with not a thought of receiving anything in return. It’s a great comfort to know that a little piece of our angel lives on in the precious children of other families.

Lea and Peter