



## The DonateLife State Medical Directors' Committee

### Communiqué 28-29 October 2010

The fifth meeting of the DonateLife State Medical Directors' Committee was held on Thursday 28 and Friday 29 October 2010.

DonateLife is an Australia wide network of organ and tissue donation agencies and hospital based staff dedicated to organ and tissue donation. Under the leadership of the Organ and Tissue Authority, State Medical Directors (SMDs) in every state and territory are responsible for delivery of the national reform program in their respective jurisdictions.

The DonateLife State Medical Directors' Committee has been established by the acting Chief Executive Officer (CEO) of the Organ and Tissue Authority as a governance committee to consider and make recommendations to the Authority in respect of the strategic priorities, clinical and data governance, planning and leadership of the DonateLife Network, and the implementation at a state-based level of the World's Best Practice Approach National Reform Package on Organ and Tissue Donation for Transplantation.

The DonateLife State Medical Directors' Committee comprises the a/g CEO (Chair), the National Medical Director (NMD) and the SMDs of each State and Territory, including:

Ms Liz Cain (A/g CEO)  
Dr Gerry O'Callaghan (NMD)  
Dr Jonathan Gillis (NSW)  
Dr Imogen Mitchell (ACT)  
Dr Helen Opdam (Vic)  
Dr Phillip Sargent (Qld)  
Dr Dianne Stephens (NT)  
Dr Sally Tideman (SA)  
Dr Andrew Turner (TAS)  
Dr Kevin Yuen (WA)

The fifth meeting was attended by all but one SMD and by senior officials from the State and Territory Health Departments as well as the Commonwealth Department of Health and Ageing. The addition of officials from all health departments ensures that the efforts of the DonateLife staff reflect state and Australian government policies and processes, that legislative and funding implications are well understood by relevant departments and to promote a nationally consistent and coordinated approach to increasing organ donor rates in Australia.

#### **Progress with the National Reform Agenda**

The DonateLife SMD Committee reviewed progress against the nine Measures which comprise the Australian Government's reform agenda. The Committee focussed heavily on 10 PowerPoint Presentations which have been put together for members of the DonateLife Network to educate hospital staff. Members provided useful comments which will inform the final set of presentations ahead of distribution to the network. Members also



spent a lot of time discussing the DCD Implementation Plan and the differences in each jurisdiction.

### **Measure 1: A new national approach and system – a national Authority and network of organ and tissue donation agencies**

The intent of Measure 1 is to increase organ and tissue donation rates in Australia by establishing for the first time in Australia, a nationally coordinated approach to organ retrieval based on world's best practice models.

The Organ and Tissue Authority has been established as a new, independent authority to provide national leadership to the organ and tissue sector and to drive, implement and monitor national reform initiatives and programs. In addition, Organ and Tissue Agencies have been established in each State and Territory, headed by a State or Territory Medical Director and funded by the Authority to coordinate, oversee, lead and report to the Authority on actions taken in each state and territory under the reform program.

#### ***Annual Forum***

The Committee discussed the 2011 DonateLife Network Annual Forum noting that each jurisdiction will be asked to put forward contributions, focusing on what is working well and what could be adopted nationally with a view to presenting them to the network. The Committee noted that the Forum will be held during the last week in March 2011 in Sydney. The Committee also noted that an organising committee has been formed with Professor Jeremy Chapman chairing and will have their inaugural meeting on 3 November.

#### ***Electronic Donor Record***

The Committee noted the update on the status of the Electronic Donor Record (EDR) noting that the Advisory Council agreed at their meeting on 7 September 2010 that the DonorTRAK model will proceed. The Business Case has been documented and a budget has been constructed.

#### ***Mid-point Review***

The A/g CEO advised the Committee that the Parliamentary Secretary is keen to ensure that all elements of the reform package are operating as expected and achieving all that is possible in terms of increasing organ and tissue donation rates in Australia effectively. In this context, the Parliamentary Secretary is contemplating the potential of a mid-term 'review' of implementation progress (not of the Reform Package itself, but rather the effectiveness of implementation to date and into the future). Various options were being considered in relation to this and, noting that such a review might not proceed, options regarding timing for the review included: a sharp, short review done early next year, potentially using the Forum as a sounding board, or a review later in 2011.

The Committee discussed this proposal noting that most agreed that the review would be a positive experience to undertake. Members favoured a methodology including a short and sharp review including, for example, focussed consultation with each jurisdiction and the capacity for jurisdictions to make written submissions.

The A/g CEO reiterated that the Mid Point Review is only a concept at the moment. The decision for it to proceed will come from the Parliamentary Secretary.

## **Measure 2: Specialist hospital staff and systems dedicated to organ donation**

The intent of Measure 2 is to increase organ and tissue donation rates in Australia by providing funding for selected public and private hospitals to employ trained, medical specialists dedicated to organ donation. Since 1 January 2009 the Authority has made available funding to each State and Territory Government, with the effect that 160 doctors and nurses in 76 key hospitals throughout Australia now work as specialist organ and tissue donation clinicians, leading improved clinical staff education and awareness to increase organ and tissue donation rates in hospitals. The State Medical Directors and their DonateLife staff in each jurisdiction work closely with these hospital based staff to implement the hospital based reforms, monitoring and guiding the performance of each hospital.

### ***Agency Managers***

The Committee discussed bringing Agency Managers in each jurisdiction together before the end of the year to discuss their role and how they reflect the national model in the funding agreements. The Committee agreed that the first meeting would be held in December 2010.

## **Measure 3: New funding for hospitals**

The intent of Measure 3 is to increase organ and tissue donation rates in Australia by providing new funding to public and private hospitals to address the additional staffing, bed and other infrastructure costs associated with organ and tissue donation. The Australian Government, through the Authority has been providing States and Territories with this additional funding, based on the activities within hospitals, since July 2009.

Discussion of this measure was held over to the next meeting.

## **Measure 4: Coordinated, Ongoing Professional Awareness and Education**

The intent of Measure 4 is to increase organ and tissue donation rates in Australia through an ongoing, nationally consistent and targeted program of recognised professional development and training, coordinated by the Authority.

### ***ADAPT***

The A/g CEO advised that the Authority's application for endorsement of the ADAPT had been considered by the Royal College of Nursing Australia (RCNA) and that RCNA has confirmed that it is pleased to endorse the workshop for the period of 27/10/2010 – 27/10/2012.

The Committee discussed a model of state and territory funding for ADAPT. Authority staff will work with each State Medical Director to determine suitable locations, costs and the number of people required to attend ADAPT courses to fit into each business model. The Authority understands that ADAPT is a very important part of the reform package.

### ***Key Education Activities***

The Committee noted progress in Measure 4 activities and agreed education activities for the remaining of the 2010/2011 financial year:

- Education Coordinators Network – national sharing and support
- Development of two family conversation training modules (current RFT)
- Training for State Medical Directors – media & Australian Public Service training
- Clinical triggers – dissemination and uptake in all jurisdictions
- Delivery of revised ADAPT and Family Conversation workshops from March 2011
- Induction as part of the DonateLife Forum in March 2011
- Donation included in schools curricula for high school students.
- Training for Organ Donor Coordinators (ODC).

### ***PowerPoint Presentations***

The National Medical Director presented 10 PowerPoint Presentations to the Committee recommending that they be used for education of hospital staff by members of the DonateLife Network with some inclusion of a transplantation element. The Committee provided feedback on each presentation.

The Committee endorsed the presentations subject to incorporation of the comments made during the meeting. These changes will be captured before being distributed to members for use. It was agreed that the slides can be adapted to individual use for presentations but learning's need to be captured. The Authority will ensure version control with a review date.

### **Measure 5: National Community Awareness and Education Program**

The intent of Measure 5 is to increase organ and tissue donation rates in Australia through an ongoing, coordinated and evidence based national community awareness and education program which will increase knowledge about organ and tissue donation and transplantation and build public confidence in Australia's new donation system. The program includes phased advertising campaign activity together with other community awareness and education initiatives.

The key aim of the National Community Awareness and Education Program is to increase Australia's low family consent rate from 58% to 75% by 30 June 2012.

### ***Feedback from the Communications Meeting***

The A/g CEO provided feedback from the Communications meeting held on 24 September 2010 including that it had been a very constructive meeting and that the integrated, collaborative network of communications officers working to the National Communications Strategy with agreed priorities was taking shape.

The A/g CEO asked State Medical Directors, as jurisdictional leaders, to guide and mentor the work of the communications officers to help build further the integrated network envisaged through the reform package. The A/g CEO acknowledged that some excellent work had been undertaken by communications officers prior to the national reforms, but that with the national reforms there was a need for change in some places to ensure that the priorities of the national reform were reflected in the day to day work of the Network. SMDs agreed to continue to provide this leadership.

### **Measure 6: Support for Donor Families**

#### ***Donor Family Support Service***

The intent of Measure 6 is that through a nationally coordinated approach deceased donor families will be provided with respectful support which is responsive to the needs of each family.

The A/g CEO passed on her congratulations to the group that came together to work on the DFS Resources. The Committee noted the update on the Donor Family Support (DFS) Meeting.

The Committee agreed to the establishment of a DFS Implementation Group and commented on the proposed Terms of Reference (ToR) for the group. The A/g CEO summarised the proposed DFS Implementation Plan by saying that the tools identified by the DFS coordinators are an excellent beginning and that the Authority, on behalf of SMDs, would agree to finesse the wording in line with SMDs' comments, with SMDs to work closely with their DFS coordinators so that each understands the changes made to the plan based on SMD feedback and are comfortable with the final plan. It was agreed that the Clinical Programs team in the Authority would amend the plan in line with SMD comments and provide a final copy to SMDS at the November meeting.

### **Measure 7: Safe, equitable and transparent national transplantation process**

Under this measure, the Authority, in collaboration with the relevant professional societies, is responsible for maintaining and auditing the implementation of approved national transplantation protocols and standards. This will ensure that the management of transplant waiting lists and the allocation of organs and tissues is effective, equitable and transparent, regardless of where the donor and recipient reside.

Prior to the Authority's establishment, the Transplant Society of Australia and New Zealand were engaged to develop nationally consistent, safe, equitable and transparent process for the management of transplantation waiting lists and the allocation of donated organs across Australia.

#### ***TSANZ***

The Committee agreed that the Authority proceed to release the Transplant Society of Australia and New Zealand (TSANZ) Consensus Statement on Eligibility Criteria and Allocation Protocols (the protocols) to the Directors General of the states and territories advising them of the result of consultations with jurisdictions and an agreed implementation date of 1 November 2010.

The Committee also noted that subject to Committee advice, the following outstanding issues will be referred to the Transplant Society of Australia and New Zealand (TSANZ) and copied to the Australasian Transplant Coordinators Association (ATCA) and the Transplant Nurses Association (TNA) for resolution:

- time between offer and acceptance of an organ has been extended from 20-30 minutes which may extend the time taken for a donation to occur;
- there needs to be a documented delisting/relisting process for urgent hearts and livers; and
- a documented process for the offer of pancreata.

The Committee agreed that the availability of NAT testing for occasional, higher-risk donors out of hours and on weekends in their jurisdictions which may extend the time taken for a donation to occur does not need to be referred to TSANZ for resolution. Members agreed that it was unknown as to how this would impact in practice, and that this requirement may not present as a real issue at all.

The first two dot points above will be sent to TSANZ and CC ATCA and TNA. The Committee agreed that the third dot point above needs to be considered in the next iteration.

The Committee agreed that, subject to the Committee's comments, the Authority will develop a paper to AHMAC detailing implementation by jurisdictions of the protocols and proposing that the National Health and Medical Research Council (NHMRC) undertake the next review of the protocols. It will be a noting paper.

### **Measure 8 – National Eye and Tissue Donation and Transplantation Network**

The intent of Measure 8 is to increase organ and tissue donation rates in Australia by introducing systems that will deliver a coordinated, accountable, national tissue transplantation service for patients across Australia.

The Committee noted the update on the progress of eye and tissue activities. SMDs agreed to raise eyes and tissues with communications officers prior to the communications meeting on 24 November so this is canvassed and progressed in that context. Members agreed that allocation and eligibility requirements for eyes and tissue should be included in the next iteration of the TSANZ protocols.

#### ***Biologicals Regulatory Framework***

The A/g CEO introduced Dr Harry Rothenfluh, Mr Glenn Smith and Dr Ian Prosser from the Therapeutic Goods Administration (TGA) who joined the meeting to talk about the Biologicals Regulatory Framework.

Following implementation of the Biologicals Framework and associated regulations on 31 May 2011 eye and tissue banks have a three year transition period to demonstrate legislative compliance in order to gain entry on the Australian Register of Therapeutic Goods (ARTG).

TGA recovers the full cost of its regulatory activities and there will therefore be regulatory costs incurred by eye and tissue banks with the implementation of the Framework. The four year funding was expected to cover development and implementation activities for one year and transition and operational costs from 2009-2013. This time frame only allows for two years of implementation costs. Additional funding has not been secured for the final year of transitional implementation or subsequent years.

It is expected that the need to demonstrate compliance with the Biologicals Framework and regulations will be beyond the capacity of many of the smaller eye and tissue banks and will place considerable resource and financial burden on the smaller eye and tissue banks.

TGA advised that in undertaking preliminary work in the development of the Framework it was difficult to quantify any cost burden on the smaller not for profit agencies. This was due to the differing levels in organisational activity and maturity.

There is a need to proactively identify a strategy that addresses the impact of the regulatory costs and any subsequent closure of eye and/or tissue banks.

The A/g CEO noted that two documents for consultation will be available in the next month or so – one on the fees and charges framework and one on the regulatory framework. There will be a period for consultation and then a pen-ultimate draft of both frameworks will be developed.

TGA advised that its website has a link that members can access to register for updates: <http://www.tga.gov.au/new/tga-update-subscribe.asp>

### ***Outcomes from CTEPC meeting***

The A/g CEO referenced the letter to her from Prof Debora Picone AM, Chair of CTEPC dated 20 October 2010 which reflected that CTEPC had agreed that the Authority “be asked to engage its State Medical Directors (and jurisdictional representatives) Committee to develop options for more effective eye and tissue retrieval, processing and storage. These options are to be considered by the Australian Health Ministers’ Conference (AHMC). The Committee noted that jurisdictions (such as Victoria) may choose to nominate another representative if different governance arrangements are in place.”

The Committee provided preliminary advice at the meeting on ongoing or planned activity in each jurisdiction to address:

- the potential impact of the Biologicals Framework;
- the structure and funding source of eye and tissue banks;
- the integration of the eye and tissue banks and activities into the DonateLife Network; and
- data collection and analysis of eye and tissue data in jurisdictions.

The Committee agreed to provide detailed plans as part of the progress reports due on 22 November 2010, noting that jurisdictions needed to form jurisdictional views about capacity of banks, likely impact of the Biologicals Framework and so on to inform the options to be developed for Health Ministers. The Committee noted that the Authority would also continue discussions with TGA on the likely impact of the Regulations in terms of driving structural efficiencies and realignment and would report back to the next meeting of SMDs and jurisdictional representatives.

### **Measure 9 - Additional national initiatives, including living donation programs**

The intent of Measure 9 is to increase organ and tissue donation rates in Australia by establishing national protocols to guide initiatives including the practice of ‘paired kidney exchange’ between living donors and recipients, and living donor liver transplantation.

The two major items in Measure 9 are the Australian Paired Kidney Exchange (AKX) Program and the Donation after Cardiac Death protocol (DCD).

The AKX Program aims to maximise the number of live donor kidney transplants that can

be performed in Australia by identifying biologically compatible donor/recipient pairs.

### ***DCD Protocol***

The National Medical Director introduced Ms Sue Huckson from the National Health and Medical Research Council (NHMRC) who discussed the approach to implementation of DCD.

The Committee provided comment on the draft DCD Implementation Plan for the DCD Protocol as developed by the Authority and agreed that it was no longer required. The Committee then proceeded to provide verbal DCD Implementation progress updates as summarised below.

### ***Tasmania***

Tasmania has had an initial conversation with the Health Minister about DCD who was supportive but wanted more information. The Tasmanian SMD will report back to the Minister after today's meeting. DCD has also been raised with the Executive at Royal Hobart Hospital and they too are supportive of the DCD program being implemented at some point. There are two possibilities for implementation:

- Victoria does the retrievals; or
- Some local urologists are trained up.

Ms Huckson commented on the importance of matching the resources with the demand or availability of organs. There is the risk that if something goes wrong, staff will remain uncomfortable with DCD. Across hospitals more broadly, staff have discomfort towards DCD. It needs to have backing at all levels. The level of comfort needs to be highly considered.

The Tasmanian SMD said Royal Hobart is the only hospital being considered for now. He anticipates getting a minimum of 5 DCD donors once it is up and running. Ms Huckson emphasised that where there is low volume, it is important to get it right from the outset.

### ***Western Australia***

WA had legislation passed last year but it was proclaimed this year. Planning for DCD implementation commenced in July this year. Each of the three major hospitals (Perth, Fremantle and Sir Charles Gairdner) have been looking at implementing the DCD Protocol. DonateLife Victoria representatives with experience in establishing a DCD program visited WA hospitals and are now adapting Victorian protocols into theirs. The hospitals are prepared as possible and are on the cusp of commencing. They are waiting for advice from the Medical Defence Association.

Ms Huckson noted the importance of harmonisation of legislation nationally. There are issues across each state in legislation i.e. the role of the coroner. The law is interpreted differently in each state rather than the law being different itself.

### ***New South Wales***

The NSW SMD noted that NSW appears to be following the implementation across the four levels of health. The Department of Health has an ethically accepted protocol and senior executive buy-in. DCD has been extended to rural and regional centres and at least three donors have come about. The Hospital Medical Directors (HMD) and Hospital Based Nurses have run education sessions which are incredibly useful and great for relationship

building. NSW has also run some DCD 'train the trainer workshops' which was very beneficial to all.

DCD has been very successful in NSW to date. In most cases the HMD become heavily involved as they have been well trained. However, intensivists are involved in children's hospitals as they have a good rapport with the parents. Relatives often push for donation, so doctors need to facilitate.

Now that the national protocol has come out, interested parties will get together to make sure the NSW protocols are in line. Of interest is that the NSW protocol precludes donation from donors above the age of 65 years.

There is an issue about DCD taking over Donation after Brain Death (DBD) and NSW agree that it's on the increase. It needs a lot of support. Every hospital in NSW can now facilitate it. NSW throw a lot of support at potential DCD donors. In addition, ABF has been a major incentive – hospitals are receiving the funds directly.

### ***Queensland***

The Qld SMD noted that Qld is very conservative with DCD. Qld is currently pursuing legislative changes to incorporate the National DCD Protocol. The Protocol has been included in state-wide policy. The Chief Health Officer (CHO) is very much engaged and led a pilot through the small hospitals in the State. It was a long and drawn-out process brought to a close by the national protocol. It has been able to be stepped up through the CHO, Director General and Health Minister. At the hospital level, doctors are walked through the process before signing off.

DCD Implementation will move to far North Qld (Townsville and Cairns) and then Mackay, Rockhampton and Bundaberg among others. However, there are only a small number of surgeons who are proficient in DCD at this stage. In Qld, 2 Organ Donor Coordinators are used for each DCD process. The difference with DBD is it's a much quicker process.

The A/g CEO noted that SA, NSW and QLD use KPIs on organ donation at a state level.

### ***Australian Capital Territory***

The Canberra Hospital has a DCD implementation plan similar to the national protocol. DCD is part of the enrolled nurse training in the ACT. Tasmania and NSW also have it as part of some of their university courses. Ms Huckson noted that there needs to be some caveats around the education process. If it's about raising awareness then it's a fantastic thing.

The ACT Jurisdictional Representative noted that DCD is included in part of the organ donation session provided to enrolled nurses at the Canberra Institute of Technology (CIT).

### ***South Australia***

The SA SMD noted that before 1983 all kidney retrieval was through the DCD pathway and was part of the routine process. SA has consistently maintained 8-10% of total SA donors being through DCD.

In 2006 South Australia, with the help and cooperation of Dr Greg Snell and his team from the Victorian Lung Unit, was the first state to retrieve organs from a DCD multi-organ

donor. Lungs, liver and kidneys were retrieved from that patient. SA now has had a long history of DCD, and every metropolitan hospital has experience. Two rural hospitals have potential for DCD but all resources (human and materials) would have to be flown in. The challenge is to revisit DCD activity in SA with the perspective of the National protocol and all SA teams are in the process of this currently.

The SA SMD continued by saying that they have a very structured process now. Staff have recently completed a survey to identify any issues. They have also had a recent meeting on DCD looking at two case studies then looked at the issues raised out of the survey one by one. All Hospital Medical Directors, Hospitals Based Nurses and Organ Donor Coordinators intend to revisit past practice and then look at improvements. The key thing is the pro-activity around the 'ask'.

SA has two agreements with two of the private hospitals to do a retrospective audit of all deaths. Intensivists work in both public and private systems/hospitals. The same processes used in the public hospitals are transferred into private. DBD Patients are often transferred from private hospitals to public.

Timing of the discussion is an important issue and continues to be discussed. DonateLife in SA Leadership Team meetings are very fruitful, productive forums. Intensivists (from different hospitals) listen and learn from each other and are interested in how each other do things. SA is very confident they are moving forward in the way they need to. The SA ICU bed status does allow at times patients to progress through to DBD.

### ***Victoria***

In Victoria DCD has grown up in individual hospitals. The SMD and her team need to work closely with each individual hospital due to the decentralised system. The four big hospitals (Austin, Alfred, Royal Melbourne and the Westin) have implemented DCD. The Royal Childrens Hospital, Northern, Monash, Dandenong, Maroondah, Box Hill among others are getting close to implementation. There are great resources in VIC to progress DCD implementation. Victoria supports other states with DCD and will be running a meeting on DCD shortly.

The Austin has almost half of their donors coming from DCD over the last four years. This is partly because they receive them from other hospitals and partly because they are great at identifying them. The potential for DCD to contribute 30-50% of all Victorian donors is high. Local ownership of DCD policy creation and implementation has led to doctors proactively identifying DCD donors. The challenge in VIC is working with each and every individual hospital. Once hospitals have gone through the DCD process, they are very committed to it.

### ***Northern Territory***

NT advised it has particular challenges due to its remote location.

### **Next meeting**

The Committee agreed that the next meeting will be held in Canberra on 25 November 2010 and that officials be invited to attend.