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**KIDNEY
HEALTH
AUSTRALIA**

Patron-in-Chief
Her Excellency Ms Quentin Bryce, AC
Governor-General of the Commonwealth of Australia

Patrons
Sir Jack Brabham, AO, OBE
Lady Margaret Brabham

22 November 2012

Attention:
Mr Ben Brungs
Office of the Chief Health Officer
NSW Ministry of Health
Locked Mail Bag 961
North Sydney NSW 2059
bbrun@doh.health.nsw.gov.au

Kidney Health Australia – Response to Consultation Request regarding:

- **Deceased Organ and Tissue Donation – Consent and Other Procedural Requirements;**
- **Practice Guidelines for when doctors accede to a family's objection to donation; and**
- **Designated Officers – Procedures and Guidelines**

Kidney Health Australia welcomes the opportunity to comment on the *Deceased Organ and Tissue Donation – Consent and Other Procedural Requirements*, the *Practice Guidelines for when doctors accede to a family's objection to donation*, and *Designated Officers – Procedures and Guidelines*.

Kidney Health Australia is the peak body representing those affected by kidney disease, and as such brings a considered health consumer and patient perspective to the ongoing discussion and reform to the organ donation agenda. In addition, Kidney Health Australia has sought comment on the provided documents from a number of medical practitioners and nephrologists. However, Kidney Health Australia would like to advocate that due to the technical nature of these documents and their intended use within the medical community that comment should also be formally sought by the NSW Ministry of Health from the *Australian and New Zealand Society of Nephrology* (ANZSN) and the *Renal Society of Australasia* (RSA) as the two relevant medical professional bodies.

The State of Kidney Disease in Australia

These changes are particularly important for those suffering from kidney disease - a disease burden which is growing and can therefore be expected to add an additional strain to the health system, including the organ donor waiting list. For example, it is estimated that approximately 1.7 million Australians over the age of 25 years have at least one clinical sign of existing CKD¹. CKD may further deteriorate into end-stage

¹ White SL, Polkinghorne KR, Atkins RC, Chadban SJ. Comparison of the prevalence and mortality risk of CKD in Australia using the CKD Epidemiology Collaboration (CKD-EPI) and Modification of Diet in Renal Disease (MDRD) Study



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kidney disease (ESKD), when renal replacement therapy (RRT) in the form of dialysis or transplantation, is then required to stay alive.

Without kidney function death will occur in a matter of days. At the end of 2010 a total of 10,590 Australians were on dialysis, and according to the Australian Institute of Health and Welfare this figure is expected to increase 80 per cent by 2020. Currently, 1,068 people are waiting for a kidney transplant in Australia², representing a shocking 70% of all 1,537 people waiting for a transplant³.

The cost of treating CKD is equally daunting. Economic modelling commissioned by Kidney Health Australia conservatively estimates that the cumulative cost of treating all current and new cases of ESKD from 2009 to 2020 Australia wide to be between \$11.3 billion and \$12.3 billion⁴. Clearly increasing the number of available donors, and therefore reducing the high costs associated with ongoing dialysis should be pursued.

Kidney Health Australia Comment

In light of the above considerable challenges, the changes to the NSW Organ Donation policy to decommission the NSW Roads and Maritime Services (RMS) Organ Donor Register are welcomed by Kidney Health Australia. In addition, the broader activities encompassed by the *'Increasing Organ Donation in NSW: Government Plan 2012'*, designed to remove barriers and increase the awareness in an effort to double NSW organ donation rates, are encouraging.

Kidney Health Australia's overarching view is that provided the changes outlined in the attached documents are designed with the primary goal of aligning New South Wales with the Federal and other State and Territory arrangements, they represent positive developments. Indeed, the move to 'switch-off' the RMS register was one which Kidney Health Australia has supported for a number of years. Such harmonisation will remove existing barriers (such as the two tier system) and allow for the possibility of increased donation rates.

In this context the attached documents appear to take into consideration the key issues relating to the new arrangements and importantly, offer guidance to those engaged in the process. They appropriately outline the key issues regarding consent and outline the way in which an approach will be made to the family of the deceased. From a consumer perspective, the way in which the engagement with the family of the deceased is carried out appears to be accommodating and sensitive - critical in improving the understanding and ultimately, the outcomes in such difficult circumstances. In particular, Kidney Health

GFR estimating equations: The AusDiab (Australian Diabetes, Obesity and Lifestyle) Study. *Am J Kidney Diseases* 2010;55(4):660-70.

² www.anzdata.org.au

³ <http://www.anzdata.org.au/anzod/v1/waitinglist2012.html>

⁴ Cass A et al. The Economic Impact of End Stage Kidney Disease in Australia: projects to 2020. Published 2010. Available at: <http://www.kidney.org.au/LinkClick.aspx?fileticket=vave4WFH73U%3d&tabid=635&mid=1837>



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Australia welcomes the clauses that outline the need for detailed documentation, including recording the reasons for differing points of view of the family.

Conclusion

Kidney Health Australia appreciates the opportunity to comment on the continued rollout of the *'Increasing Organ Donation in NSW: Government Plan 2012'* and the associated policy and procedures. Furthermore, Kidney Health Australia would welcome further opportunities to engage on future developments, including around the planned communication and education activities – an area where as the peak body representing health consumers Kidney Health Australia could further assist.

Yours Sincerely,

Anne Wilson
MD/Chief Executive Officer
Kidney Health Australia

Dr Timothy Mathew AM
Medical Director
Kidney Health Australia