



Canberra Region Kidney Support Group

Kidney News

The views expressed in this newsletter are not necessarily those of the CRKSG

The Impact of Kidney Disease and What Government Should Do About It! World Kidney Day 11 March 2010

The National Consumer Council of Kidney Health Australia will release its special report titled *'The Impact of Kidney Disease and what Government should be doing about it'*. The full report may be downloaded from the link below. If reading this online you need only click the link below to obtain a copy.

<http://www.kidney.org.au/LinkClick.aspx?fileticket=oQTbr%2fYhZ3c%3d&tabid=606&mid=1613>

The release of the report highlights one of the failings of the national health system that is going to balloon into an even bigger problem because of the ageing of Australia's population. It is hoped that the Federal Government initiative to reform Australia's health system - announced on 3 March 2010 - will help to address this problem.

David Parker, Chairman of the National Consumer Council said the report will provide a unique insight for Members of Parliament into the patient's view of how patients, families and carers are treated by the current system and the areas needing urgent reform.

Anne Wilson CEO and Managing Director of Kidney Health Australia said the report by the National Consumer Council highlighted many issues which needed to be addressed and Kidney Health Australia strongly supported the call for reform.

Seven immediate interventions urgently needed across all states and territories include:

1. Adequate dialysis capacity that enables patients to:

- Access and choose from a full range of treatment options in their own region.
- Access respite and holiday dialysis in other regions and interstate to facilitate contact with family and friends.

2. A patient transport and accommodation scheme to ensure patients who need to re-currently travel to receive dialysis treatment are adequately reimbursed.

3. A scheme which meets out-of-pocket expenses incurred by patients choosing to undertake dialysis treatments in their own homes.

4. A reimbursement scheme for people donating a kidney to a loved one. This scheme

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Melbourne Grand Prix Link to World Kidney Day in Australia

The sixteen year old grandson of Australia's most famous racing car legend Sir Jack Brabham, three times world Formula One Champion, will officially launch World Kidney Day in Australia on 11 March 2010 in Melbourne.

Matthew Brabham, (pictured right) with his father Geoff Brabham, a Le Mans and Bathurst 1000 winner, will join Kidney Health Australia on the steps of the Victorian Parliament to make a noise about kidney disease and launch the 2010 campaign message “*Protect Your Kidneys Control Diabetes*” with the roar of his Formula Ford.



Type 2 Diabetes is the primary diagnosis causing kidney disease in 20-40% of people starting treatment for end stage renal disease worldwide. In Australia, the number of new Type 2 Diabetes patients starting dialysis increased 5-fold between 1993 and 2007.



Matthew Brabham driving his Formula Ford.

Matthew who will race in the Melbourne Grand Prix on 25 March 2010, will also become a Young Ambassador for Kidney Health Australia. Matthew will help spread awareness about Chronic Kidney Disease by displaying a small symbolic Kidney Health Australia Red K on his car in honour of his grandfather Sir Jack Brabham who is on dialysis.

Sir Jack and Lady Margaret Brabham (pictured right) are the Patrons of Kidney Health Australia.

You can read more about their grandson Matthew at www.matthewbrabham.com.



Organ Donor Registration

If you are viewing this newsletter on-line, click on the link below to register as an organ donor. Organ donor registration is completely voluntary. If you register you will receive a donor card similar to the one shown here.

<https://www2.medicareaustralia.gov.au/pext/registerAodr/Pages/DonorRegistration.jsp>



Yothu Yindi Singer's Sidney Myer award to Help with his Music and Dialysis Treatment

Indigenous musician Mandawuy Yunupingu is among winners of the nation's most lucrative performing arts prizes.

He joins stage actress Julie Forsyth, the Footscray Community Arts Centre and the Black Arm Band in sharing more than \$120,000 in the Sidney Myer Arts Awards.

Yunupingu has had international success as lead singer of the band Yothu Yindi, while also setting up a foundation to strengthen Yolngu culture.

He says he was "blown away" when told he would be getting the award at a ceremony in Adelaide.

"I'm just overwhelmed and excited to have been chosen to get this award," he said.

Yunupingu says the money will go towards furthering his musical career, and to continue his dialysis treatment until he can get a kidney transplant.

"I'd think that it'll open up avenues and... keep me on track with treatment in my kidney situation," he said.

The above item © ABC 2010. The original item may be found on the internet at:

<http://www.abc.net.au/news/stories/2010/03/05/2838103.htm?section=justin>.

Calendar of Events

In an endeavour to encourage more renal community participation, meetings for 2010 will be held on Saturdays at 2:00pm at the Pearce Community Centre, Building 1, Collett Place, Pearce on the dates indicated. Each meeting should only take around 15 or 20 minutes unless there is something of significance to discuss, so come along and put in your two cents worth and perhaps have a tea or coffee along with a biscuit and discuss any concerns you might have.

You never know, you might have some good ideas about what the Group should be doing! Don't forget this Group was set up to support the renal community and we need to know what needs to be done to provide that support.

Meeting dates for 2010 are as follows:

- 16th January 2010,
- 17th April 2010,
- 14th August 2010, and
- 11th December 2010.

The meeting on 14th August will most likely be the AGM. This will be confirmed or an alternative date will be advised in due course.

All welcome

(Continued from page 1)

should reimburse all reasonable and verifiable expenses incurred by the donor, including loss of income and out-of-pocket expenses, and preserve leave entitlements.

The National Consumer Council calls on Government to reduce the future burden of kidney disease in the community and on individuals by:

- 1. Recognising chronic kidney disease as a major chronic disease** of the 21st century and one that multiplies the morbidity and cost of cardiovascular disease and diabetes.
- 2. Developing a national program to increase awareness and early detection** of chronic kidney disease through increased professional education and the introduction of specific programs in primary care aimed at monitoring, improved management and better outcomes in early chronic kidney disease.
- 3. Funding and resourcing** the development and delivery of high quality information and education services in chronic kidney disease, patient support programs and the training in and promotion of these services in the community.

Dr Tim Mathew, Medical Director of Kidney Health Australia said chronic kidney disease is a difficult disease to promote to the community as it is basically invisible and does not cause pain. A person can lose up to 90% of their kidney function before experiencing any symptoms.

Hence it is known as the **SILENT KILLER** and in many cases has been treated as a silent issue in the political arena when compared with other chronic diseases.

The special report points out to Members of Parliament over 1 million hospital bed days or 4% of all bed days in 2006-07, were occupied by people with a principal diagnosis of Chronic Kidney Disease and this demand is expected to double within a decade unless a new approach is taken.

Anyone who is suffering from Chronic Kidney Disease and needs help should call the Kidney Health Australia Help Line on 1800 4 543 639.

The National Consumer Council of Kidney Health Australia Special Report and video comment from its Chairman David Parker can be obtained from the official International World Kidney Day website.



<http://www.worldkidneyday.org/video/david-parker-chair-australian>

David Parker (pictured left) started on dialysis in 2005 and received a transplant in 2008. David is involved with seven different boards and advisory committees nationally and in the ACT working on organ donation, renal service delivery and public health and consumer advocacy. His interview covers dialysis from a patient's perspective and the need for Government to act in relation to the ageing population.

Kidney Health Week — 2010

23rd May to 29th May inclusive.

A Sunday Conversation

by Vince Maguire

On Sunday 14th March, a broad spectrum of people with different connections to the delivery of renal services collected at the Federal Golf Course clubhouse for a ‘conversation’ on the question of “How Can We Make the Dialysis Experience Better?” In February, most patients and carers should have received a letter from John Scott, the home dialysis representative on RAMs, asking for suggestions for the ‘conversation’; and an invitation to attend.

The attendees met in the ‘Scott Room’, the name was a co-incidence – John isn’t a famous golfer, which was decorated for wedding receptions. Along with gum leaves and pine cones sitting on the prayer-mat in the centre of a circle of orange chairs, the decor left some of the attendees wondering what to expect, especially after the facilitator summoned their attention by ringing a pair of tiny cymbals, then started talking about bumble bees and butterflies.

By the end of the day, the scepticism had disappeared. The remaining attendees had an overwhelmingly positive impression of the process they had participated in during the day. At the start of the process, everyone had the opportunity to put forward written questions around the theme of the dialysis experience. Related questions were consolidated. The questions formed the basis of about eighteen discussions (referred to as conversations). Six ‘conversations’ were held at one time and attendees were free to enter or leave any ‘conversation’ at any time.

Despite the occasional chaos of people coming and going, the ‘conversations’ seemed to give even the most hesitant attendees a chance to get their concerns and suggestions onto the record. At the end of the day the remaining attendees tried to prioritise the importance of each ‘conversation’, by rating each ‘conversation’s’ written summary with coloured stickers.

Even though the ‘conversations’ were about different issues, there seemed to be common themes re-appearing in the written summaries. The attendees mainly agreed that the system deals with day to day medical needs quite well, although occasional mistakes inevitably do happen, but other needs of patients and carers are not being met. The need for emotional support during the transition to regular dialysis was one such theme.

Another was the need for patients to have greater control over their own circumstances. “Don’t let dialysis control you, better to have control over dialysis.” With better information and understanding of their situation, patients feel empowered to make their own decisions and feel able to make choices about their treatment and fitting dialysis into their life. There are many aspects to making this possible: better communication and explanations from the clinicians, dependable patient transport, a reliable dialysis schedule and a non-stressful dialysis environment for example.

Carers have been taken for granted by the system and are largely unsupported. The ‘conversation’ around carers drew the attention of many of the attendees, as did the ‘conversation’ about the role of general practitioners in the delivery of renal services.

We, the attendees, all hope that this ‘open space conversation’ investigating “How Can We Make the Dialysis Experience Better?” has been a useful contribution to the further development of the renal service and we hope we adequately represented those who were unable to come along. The convenors will be drawing on their own experiences of the day and the written summaries of the ‘conversations’ and will no doubt be consulting further with the renal community about what actions should be taken. Let’s all look forward to what is already a pretty good service getting even better.

If Undelivered Please Return To:

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Garran ACT 2605

Phone: 02 6290 1984
E-mail: crksg@shout.org.au
Web: http://www.crksg.org.au



MEMBERSHIP APPLICATION/RENEWAL

Canberra Region Kidney Support Group Inc
PO Box 5051 GARRAN ACT 2605.
ABN: 77 396 063 641

Last Name: **First Name:**

Address:.....

Email:

Phone No:

I would like to make a voluntary donation to CRKSG for the amount of: \$..... Membership is free. All donations \$2 or more are tax deductible. Cheque/Money Order payable to CRKSG Inc. Please accept this application for membership of the Canberra Region Kidney Support Group Inc.

Signature: **Date:**.....

Post Form to:

The Treasurer
Canberra Region Kidney Support Group Inc
PO Box 5051
GARRAN ACT 2605.

NOTE: This form may also be used to notify a change of address/contact details.