

Volume 6, Issue 2

Summer 2006/2007

Canberra Region Kidney Support Group

Kidney News

Taking Your Kidneys on Holidays

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

Special points of interest:

- Taking your kidneys on holiday
- Getting to know your Doctors
- Fund raising for the Group.
- Dialysis Escape Line Australia (DELA)
- Renal education programmes for 2007
- Recycle your old mobile telephone

Inside this issue:

Taking Your Kid- neys on Holidays	1
Dialysing in Mos- cow	1
Extracts from Wee Whispers Newslet-	2
Dialysis Escape Line Australia	3
Getting to Know your Doctors	4
KHA Welcomes Stem Cell Research	5
Recycle your old Mobile Phones	6

Dialysis patients in Australia planning a holiday in Australia have a new updated guide to assist them access dialysis units throughout the country. Graham Herbert, a volunteer in the Perth office. was responsible for developing the Dialysis Unit Guide from his own personal experiences of searching for dialysis units during a holiday. The Dialysis Unit Guide (DUG) lists the location and contact details for most public and private Australian dialysis units

(223 units are listed in the guide). The guide may be used for a number of purposes including referrals, relocation and short-term stays. The guide is available in hard copy and online at

www.kidney.org.au The DUG provides accurate and up-to-date information in an easy-to-use format. There are tips for planning a holiday whilst on haemodialysis, as well as suggestions about medical information dialysis units may need. Note: There is also a list-



You can also take holidays overseas. (see Dialysing in Moscow.)

ing of dialysis units around Australia on a state by state basis on the CRKSG website (www.crksg.org.au).

Dialysing in Moscow from Vince Maguire

Last July my wife (Noknoy) and I spent a long weekend in Moscow, on the weekend of the soccer world cup grand final. I had to dialyse there one day (a Monday) before returning to Bangkok on the Tuesday flight. Janelle from CCDC did a good job organising the dialysis. From what I could see, the dialysis centre I went to appeared to be the only one in Moscow. It was located in an old soviet hospital, but it is run by a European company that must have a contract of some sort. The centre was huge by Australian standards. It had more that forty machines which operated 24/7 and they were planning on expanding.

Probably because of the size,

the procedures there are very systematised. You can see from the photo that all the patients have to don a set of hospital gowns before treatment. Despite this, the doctor (Valerei) and the nurse that looked after me were very attentive and friendly. Valerei had only recently visited Melbourne for a conference and had liked Australia.



Vince dialysing in Moscow

"Even though the dialysis centre was very modern and up to date, the same could not be said for the rest of the old hospital"

Dialysing in Moscow

Even though the dialysis centre was very modern and up to date, the same could not be said for the rest of the old hospital. It didn't seem to have benefitted much from the end of the cold war.

At one point a security guard was emphatically trying to stop us from getting into a lift. I misinterpreted it as petty socialist officiousness. It turns out he was trying to warn us that that it would be better to use the other lift - this lift gets stuck ! Even the good lift had a huge gap between the floor and the door where you could watch the drop to the bottom of the lift well as the lift rattled and jerked along.

For me, the trip was a bit too exhausting. A long weekend was not enough time. But we didn't have much choice. The tickets were a prize from a Thai Airlines competition. We had to use them within a limited time and that weekend was a holiday weekend in Thailand, so Noknoy could get away from work. But in the middle of the Northern summer, with about twenty hours of daylight every day and the world cup atmosphere, it was an exciting time on the streets. Maybe there is still a bit of energy being released after the end of communism

Moscow is a huge city, with lots of history, significant

monuments, museums, galleries and beautiful architecture. Not much can be said about Russian food however. Moscow has great public transport, but very little English signage. Outside of the hotel and other than doctor Valerei. I don't recall hearing anyone speaking English. Anyway, with our guidebooks, we seemed to be able to find our way around and have some fun. Moscow is a bit out of the way for most dialysis patients to go there specifically for a holiday, still it's worth considering. But be warned, it was the most expensive dialysis I've ever had to pay for. Lucky the airline tickets were free!

Some Extracts from the November 2006 edition of Wee Whispers, the Kidney Health Australia Newsletter.

National Services Guidelines For The Management Of Dialysis And Kidney Transplantation In Remote Australia The development and implementation of a National Consensus document on Standards for renal service delivery to remote areas has been determined as a critical need particularly for Aboriginal Australians and Torres Strait Islanders who make up the largest population in the these areas

The aim of the Standards is to promote comprehensive and holistic care of people requiring renal services residing in remote Australia, which will ultimately improve their health and wellbeing. A national approach to this issue will provide practical and achievable strategies, which support evidenced-based approaches to service delivery and identify gaps between what is best practice and what is currently provided. An important aspect of these standards is how they fit into and are supported by other local and national documents.

Improving access to services and providing better support to the primary health care area to improve chronic and end stage disease management are seen and should be seen as important aspects of a renal service. Many States and Territories including national bodies have developed or are developing strategies that incorporate the principles that support this approach. The Standards are an opportunity to build and standardise renal service provision and availability across Australia. The Standards were

and availability across Australia. The Standards were developed through a process of broad consultation with a wide and varied group including service providers, renal clinicians, consumers and the Aboriginal community controlled health sector and as such are endorsed and supported by Kidney Health Australia. The standards can be viewed on the Kidney Health Australia website www.kidney.org.au.



Show Your Support with Kidney Health Australia Christmas Cards

Purchasing Christmas cards from Kidney Health Australia is a fabulous way to show your support and help raise our profile.

Kidney Health Australia receives no funding from government to support its work promoting kidney and urinary tract health. You can help us by purchasing Christmas cards. This year we have seven different cards, which you can view on our web site at www.kidney.org.au or contact our Christmas card hotline for a brochure and to place orders: (08) 8334 7555 or email <u>christmascards@kidney.org.au</u>



Sample Kidney Health Australia Christmas Card

Calendar of Events

Canberra Region Kidney Support Group Meetings

- When: The Second Tuesday of each month. 13th February, 12th March, 10th April, 14th May, 11th June
- Where: The Pearce Community Centre Building 1, Collett Place Pearce ACT 2607

When: 7.30 pm

Help

The CRKSG needs members to: Lobby or participate as Patient Representatives, contribute to the newsletter, and act as patient support . The CRKSG can provide the infrastructure that can support anyone with bright ideas that further the aims of the group. We are desperately in need of people with ideas!

Happenings

If you have some happenings or would like to congratulate someone, let us know. Contact the CRKSG at <u>crksg@shout.org.au</u>, by post at PO Box 5051, GARRAN ACT 2605 or via the <u>Contact Us</u> page of the CRKSG website.

Dialysis Escape Line Australia (DELA)

The NSW branch of DELA has been launched and is coordinated by Jacqui Devlin. Jacqui says DELA gives both pre and current dialysis patients the opportunity to get away from their everyday surrounds. DELA arranges the setup of temporary dialysis units in remote locations with the support of a medical team of five. DELA also organises day excursions. For further information on DELA, please contact Jacqui Devlin on 0419 496 387, (02) 9977 0297 or

dela_nsw@chariot.net.au. DELA is colocated in the Sydney and Adelaide Kidney Health Australia Offices. "The CRKSG needs members to: Lobby or participate as Patient Representatives"



Dr. Giles Walters

Getting to Know your Doctors — Dr Giles Walters

Continuing the introduction of Renal Doctors at Canberra Hospital.

[CRKSG] What is your date and place of birth? [Dr. Walters] December 1965, Plymouth, UK.

[CRKSG]Where did you study, including residency? [Dr. Walters] I studied at Queens' college, Cambridge, UK followed by 3 years at Edinburgh University. I worked in hospitals around Edinburgh for the next 4 years, including Kirkcaldy, the City Hospital, the Western General Hospital, the Re-

Fund Raising

A large vote of thanks must go to Intencity Belconnen for their efforts to raise a significant sum of money which was given to the CRKSG on 23 November 2006. They will be presented with a Certificate of Appreciation to include on their 'wall of certificates'. A facsimile of the Certificate is shown below.

Intencity is an interactive game machine centre in the Westfield Shopping Centre, Benjamin Way, Belconnen. Intencity was established on 1995, featuring interactive games, competitions and merchandise. There are now 16 centres across Australia located in cinema and shopping complexes. Intencity Belconnen may be contacted by telephone on (02) 6251 7271, email: <u>inten-</u> city_belconnen@villagenal Unit at Edinburgh Royal Infirmary, St Johns Hospital Livingston and the Falkirk and District Royal Infirmary.

[CRKSG]What hospitals have you worked at? [Dr. Walters] After working around Edinburgh, I moved to work in Leicester, UK. During that time, I did 4 years research in the Centre for Kidney Research in the Children's Hospital at Westmead in Sydney.

[CRKSG]What made you decide to move to Australia? [Dr. Walters] A Great job opportunity, my wife loves the weather and I think it is the right place for us.

[CRKSG]Have you any specialised kidney interests? [Dr. Walters] the immunology of glomerulonephritis, specifically identifying which cells are damaging the kidney in these conditions and attempting to identify potential therapeutic agents in this area.

[CRKSG]Finally, please let us know about your family. [Dr. Walters] My wife, Sherna, and I have four children, Isaac aged 4, Lydia aged 3 and Coomi aged 20 months and Lois aged 6 months.

<u>leisure.com</u> or via their website, http:// www.intencity.com.au/.

Their hours of operation are:

Sunday – Thursday 10:00am – 10:00pm



Friday & Saturday
10:00am – 11:00pm.

	Certificate of Appreciation
	This certificate is awarded to
	Intencity Belconned
	in recognition of their fund-raising efforts in support of the
CAREFRAN RECICION	Canberra Region Kidney Support Group
*	Signature Date
TONEY BURYOUT CROPP	Signature Date

"A large vote of thanks must go to Intencity Belconnen"

Kidney Health Australia Welcomes Stem Cell Research Bill

7th December 2006: Kidney Health Australia today welcomed the passing of the stem cell research bill in Federal Parliament saying if it was successful it could help cope with the epidemic of Kidney disease which was confronting Australia.

The organisation had backed the development of the Private Members Bill by former Health Minister Senator Kaye Patterson to put the issue on the Parliamentary agenda.

Anne Wilson CEO of Kidney Health Australia said, "The organisation was already funding valuable stem cell research which was aimed at providing people with the opportunity to repair their own kidneys". "This is a long path to success but we need to be exploring every avenue possible to try and create a system which allows for kidney repair and offers an alternative to dialysis which people have to endure to stay alive when in end stage kidney failure."

"Kidney Disease, the silent killer, causes or contributes to at least 9.5% of all deaths in Australia".

"Apart from the cost to the community the amount of human suffering is tragic and one only has to visit a dialysis unit to view the human cost of kidney disease in Australia," Ms Wilson said. "Kidney Disease, the silent killer, causes or contributes to at least 9.5% of all deaths in Australia"

Kidney Health Australia On-line Bulletin

20th December 2006

FAITH (Family Accommodation Initiative – Transplant Housing) was launched in September. Providing quality accommodation facilities for rural living donor families for the period of their transplant, this exciting initiative is an Australian first and was nominated for a WA Premier's Award. We look forward to commencing the national rollout of this initiative over the coming year.

National Chronic Kidney Disease Strategy

This year saw the completion of the inaugural National Chronic Kidney Disease Strategy. This piece of work represents the views of the kidney community and provides the overriding framework for programs and services to reduce the incidence of chronic kidney disease in Australia.

Kidney Kids Capers

Kidney Kids Capers were held around Australia throughout 2006. In Adelaide, Sydney and Perth, children were able to take part in a fun-packed three-day activity program, commencing with a family fun day. In Sydney the activities included Taronga Zoo, Darling Harbour and Penrith Panthers World of Entertainment.

Melbourne held a Kidney Kids Capers day for the first time in December, hosting over 90 participants, including 'kidney kids' and their families at Scienceworks. Participants travelled by ferry from Southbank and were treated to an exclusive show in the Planetarium, as well as a visit from Santa after the lunch.

Feedback from all the events has been extremely positive, with many looking forward to next year's events already.

New offices

Our WA team moved to a brand new facility in Subiaco, which was fitted out with a generous grant from LottteryWest. Canberra Region Kidney Support Group

PO Box 5051 Garran ACT 2605

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



We're on the Web www.crksg.org.au

Recycle Your Old Mobile Phones for Kidney Health Australia and Help Clean Up Our Environment

Kidney Health Australia has joined with Aussie Recycling Program to raise much-needed funds to fight kidney disease. All you have to do is collect unwanted mobile phones that would otherwise be thrown in the bin. For every mobile phone that we collect, the Aussie Recycling Program will donate \$3 to Kidney Health Australia.

If you have any unwanted phones or can help us to collect as many mobile phones as possible, please contact KHA at the email address below for further information. Your employers can also support us by registering with the Kidney Health Australia Mobile Phone Recycling Program and pledging their unwanted mobile phones.

KHA will provide reply-paid satchels that hold up to five mobile phones. Small recycling bins and satchel holders are also available for corporate supporters. Every mobile phone collected will help so please don't dump your old phones, donate them for Kidney Health Australia instead. For further information or request a reply-paid satchel, please email <u>susan.sayer@kidney.org.au</u> or telephone (03) 9674 4302.

