



# Kidney News

Newsletter of the Canberra Region Kidney Support Group Inc.  
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The views expressed in this newsletter are not necessarily those of the CRKSG.

Volume 4

Summer 2004

Issue 4

## News from the Acting Director of the Canberra Renal Unit

Dear All,

First of all, my sincerest apologies for missing the Canberra Region Kidney Support Group meeting (Patients' Forum – see opposite page) held early in October, but a number of circumstances saw me distracted enough to miss the event completely. I heard all went well with much interest from the many participants. Myself and the rest of the Renal Unit are strongly supportive of the need for a robust and energetic patient support group in the region, as this will lift the profile of renal disease and help to advocate for and shape renal services in the region.

The contracts for the new dialysis facilities in Goulburn, Moruya and north-side Canberra are continuing to be developed with the hope that patients will be dialysing in them sometime early in the New Year. It now appears that Southern Area Health Service (soon to become Greater Southern AHS with the merger of SAHS and Greater Murray AHS) will use Statewide Renal Services (based at Royal Prince Alfred Hospital in Sydney) as the provider of medical supervision for the Units at Goulburn and Moruya. The exact nature of this support and how it intersects with The Canberra Hospital Renal Unit is still being sorted out and I will update the CRKSG when things are clearer.

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## The Patients' Forum – Did You Miss It?

On Sunday 10 October 2004, the CRKSG invited all Canberra patients, their Family, Friends and/or Carers to attend a forum, on a range of issues common to renal patients. The aim was to find out what progress has been made and where we are at with kidney failure. There were over 50 attendees who enjoyed a sausage sizzle and drink supplied by the CRKSG. Vince our Secretary and Ray Hemsworth did an excellent job on the sausages. There was a quiet hum of conversation as we got to know each other and compare our situations.



Thanks to Lindsay Warren (pictured) from the Canberra Community Dialysis Centre (CCDC) who spoke on Nocturnal Dialysis. Thanks also to Kennards, who supplied the BBQ equipment.

We are planning on having another Social gathering in the New Year for both new and old members, so become a member today.



*Merry  
Christmas  
From the  
Canberra  
Region Kidney  
Support Group.*

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## Living a Healthy Life with Chronic Conditions

My being a member of the Canberra Region Kidney Support Group, having a chronic condition, experience in running small groups, and having a genuine interest in self management of chronic conditions' enabled me to participate in the recent 'Self Management of Chronic Conditions Peer Leaders' Training Workshop'. This course is designed to train members to co-lead 'Living a Healthy Life with Chronic Conditions' Courses, a six week education program, 2 ½ hours per week, designed to assist people with chronic conditions to develop ways of taking a more active part in their self care. Stanford University in California originally developed the course.

### What is a Chronic Condition?

Health problems are normally either 'acute' or 'chronic'. Acute health problems usually have a single cause and a rapid beginning. Once diagnosed and treated, people will return to a normal life. With 'acute' conditions, the patient follows the Health Providers directions or orders. Chronic health problems have multiple causes varying over time and gradual beginnings. Diagnosis is often uncertain and unlike acute conditions, where full recovery is expected; chronic conditions may lead to persistent loss of physical conditioning and treatment does not cure the illness. With 'chronic' conditions, the patient and Health Providers roles change to a partnership.

While there are many different chronic conditions, such as Diabetes, Arthritis and Renal Failure, the problems that people experience are often the same. Most people with chronic conditions suffer fatigue and loss of energy. Some experience pain while others have trouble breathing. Sleeping problems are common and some people experience depression. The course covers topics such as:

- Manage your symptoms,
- Communication skills,
- Working more effectively with your health team,
- Pain management,
- Fatigue, energy conservation, and relaxation skills, and
- Dealing with negative emotions.

The course has been extensively researched and results have shown:

- Improved health due to an enhanced understanding of the symptoms caused by your chronic condition,
- Improved well-being and quality of life,
- Improved self-confidence,
- Enhanced ability to cope with pain, and
- Daily tasks are made easier.

This course provides those attending with a tool box of strategies to use. The principles of adopting healthy lifestyles, managing the physical, emotional and social impact of your condition, and how to achieve better communication with health care providers. The best strategy for me was the Communicating with your Doctor session. It always seems that there is never enough time during a doctor's appointment. I now feel confident that using a few items from my tool box (the strategies learnt on course) that I can communicate with my doctors better.

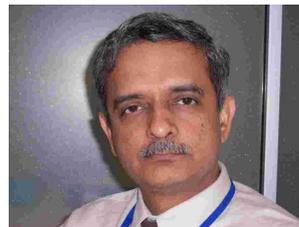
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I believe that patients need to play an active part in decisions about their health care in partnership with their health team. This course teaches skills to enable patients to be more active in the management of their disease. There are probably other courses that would also assist patients - I am not saying it is the one and only course. The six week, 2 ½ hours per week, **Living a Healthy Life with Chronic Conditions'** Courses is available in the ACT. The article is submitted to 'spread the word' and advise others about participating in the program.

To end this article I would like to quote the President of SHOUT:

"Finally, as people living with a chronic condition we need to manage our conditions and to minimise their impact on our lives and not let them control us. Chronic conditions are something we did not want or plan for on our life's journey but our ability to adapt and accept what we can't change will enable us to lead a productive and healthy life regardless."

For more information about the course - contact Susan Sullivan at Arthritis ACT on 62884244, Monday to Friday 9.30 to 2.30pm or E-Mail [ss\\_arthritisact@bigblue.net.au](mailto:ss_arthritisact@bigblue.net.au).



### Know your Doctors

*This issue is the third in a series of articles on the Renal Doctors at Canberra Hospital.*

**Dr Balaji Hiremagalur**

Dr Balaji Hiremagalur Renal Specialist at the Canberra Hospital was born in Bangalore, South India. Bangalore is considered to be the silicone valley of Asia. Balaji trained in Nephrology at the Christian Medical College And Hospital, Vellore, India. The Christian Medical College And Hospital at Vellore is a premier institute of Nephrology in India. The department has to its credit the first successful transplant in India. Over the years, the department has collaborated with leading Nephrology centres in Australia. After completing the Nephrology training in 1988, he practiced as a consultant in Nephrology, at a tertiary private hospital in Bangalore. In January 1998 Balaji, his wife Aruna and children migrated to Australia to start a new life in the middle of the Australia continent, yes in Alice Springs. I asked the good doctor why Alice Springs and he advised me that his Nephrology Professor from India who was working in Alice had enticed him to migrate and practice in Alice Springs. After a few years in Alice Springs, Balaji moved to Queen Elizabeth Hospital in Adelaide to undertake his Fellowship. He completed his advanced training at Princess Alexandra Hospital, Brisbane and was awarded his fellowship (FRACP) before commencing as a Renal Specialist at The Canberra Hospital in 2003. Balaji values the opportunity of educating his children in multicultural Australia and plans to apply for Citizenship next year, when he is eligible. Balaji is completing Diploma in Bio Statistics this year and will be enrolling in to Masters program next year. The studies will assist in planning and analysing research in nephology and to practice evidence-based medicine. Balaji's away from work interests include Classical Indian music and gardening.

## Dialysis Unit Guide - SA

Unit Name: Renal Unit North Terrace  
Suburb / Town: ADELAIDE Ph: 08 8222 5203

Unit Name: Flinders Renal Unit  
Suburb / Town: BEDFORD PARK Ph: 08 8204 5211

Unit Name: Berri Home Dialysis Centre  
Suburb / Town: BERRI Ph: 08 8580 2464

Unit Name: Ceduna Dialysis Unit  
Suburb / Town: CEDUNA Ph: 08 8625 2404

Unit Name: Lyell McEwin Satellite Dialysis  
Suburb / Town: ELIZABETH VALE Ph: 08 8282 0306

Unit Name: Renal Unit Women's & Children's  
Hospital  
Suburb / Town: NORTH ADELAIDE Ph: 08 8204 7343

Unit Name: Payneham Dialysis Centre  
Suburb / Town: PAYNEHAM Ph: 1300 734 834

Unit Name: Port Augusta Renal Dialysis Unit  
Suburb / Town: PORT AUGUSTA Ph: 08 8648 5746

Unit Name: Port Lincoln Home  
Suburb / Town: PORT LINCOLN Ph: 08 8683 2065

Unit Name: Wayville Satellite Dialysis Centre  
Suburb / Town: WAYVILLE Ph: 08 8373 1050

Unit Name: North Adelaide Satellite Centre  
Suburb / Town: NORTH ADELAIDE Ph: 08 8267 5018

Unit Name: Noarlunga Satellite Dialysis Centre  
Suburb / Town: NOARLUNGA Centre Ph: 08 8384 9449

Unit Name: Hartley Dialysis Centre  
Suburb / Town: BRIGHTON Ph: 08 8296 8992

Unit Name: Modbury Dialysis Clinic  
Suburb / Town: MODBURY Ph: 08 8396 6155

Unit Name: Maintenance Dialysis Ward 3A  
Suburb / Town: WOODVILLE Ph: 08 8222 6349

### Source:

The latest information is available on the Kidney Health Australia Web site

### Member Recommended Dialysis Units.

The Mater Hospital is 1.6 kms north of Sydney Harbour Bridge and is able to offer haemodialysis to privately insured patients. Contact: Helen Thomson, Cohen Renal Unit, Mater Hospital, Rocklands Road, North Sydney, NSW 2060. Ph: 02 9929 6979. Fax: 02 9954 7469. E Mail: Helen Thomson [HThomson@matersydney.com.au].

## CALENDAR OF EVENTS

### CANBERRA REGION KIDNEY SUPPORT GROUP MEETINGS

When: The Second Tuesday of each month, except January  
Where: The Pearce Community Centre  
Building 1, Collett Place  
Pearce ACT 2607  
When: 7.30 pm

### Renal Education Program: "Living With Kidney Failure - 2005"

When: February 18<sup>th</sup> and 25<sup>th</sup>  
May 20<sup>th</sup> and 27<sup>th</sup>  
August 19<sup>th</sup> and 26<sup>th</sup>  
November 18<sup>th</sup> and 25<sup>th</sup>  
Where: Canberra Community Dialysis Centre  
(CCDC) Gaunt Place Garran  
When: 1.30 pm

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*FREE CRKSG Membership  
APPLY NOW!*

Don't miss a copy of the newsletter  
Become a Member TODAY

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### Correction

In the last issue we incorrectly listed the ACT Health Services - Independent Living Centres address. The correct address is 24 Parkinson Street Weston ACT phone 1300 885 886 or (02) 6205 1900. Email: [ILCACT@act.gov.au](mailto:ILCACT@act.gov.au). The Independent Living Centre (ILC) is an information resource centre that provides an equipment display of hundreds of items that people are able to try and compare. An equipment database of 6000 items, plus information on a range of organisations and services, complements the display.

You can browse the equipment at the centre (except continence management equipment for which an appointment is necessary) and information displays between 12 noon and 2.00pm Monday to Friday. No appointment is required during this time and limited assistance is available.

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CRKSG Monthly meetings of the Canberra Region Kidney Support Group Inc are held at the Pearce Community Centre, Building 1, Collett Place, Pearce on second Tuesday of each Month (except Jan) commencing at 7.30pm.

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Coming soon  
CRKSG Web Site

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## IN THE MEDIA

### **Kidney donations that don't kill with kindness**

By Jacqueline Maley the Sydney Morning Herald. October 29, 2004

When Trevor Karsten received a kidney from his wife, Robyn, he gave her a pair of pearl earrings.

Such a transaction may be acceptable, even expected, in a marriage, but under the ethics of organ transplantation it is strictly forbidden.

The ethical issues confronted by living kidney donors, as well as the health problems, emotional fall-out and technical details of transplantation, were addressed in a booklet launched yesterday by the NSW Health Minister, Morris Iemma.

*Kidney Donation by Live Donors* is a set of guidelines, drawn up by transplant clinicians, allowing non-directed, "anonymous" live kidney donation to occur for the first time.

This means a person can elect to give a kidney to a stranger, for no reason other than altruism. Two successful kidney transplants from living anonymous donors took place in South Australia earlier this year, and doctors in NSW have received expressions of interest.

"We don't expect it to be large numbers [but] for those people who are genuinely interested in donating and who are stable, there are safe guidelines within which it can happen," said Dr Josette Eris, one of the authors of the guidelines and the chairman of the NSW Transplant Advisory Committee.

As the road toll in NSW declines, so does the number of kidneys from deceased donors. There are currently 758 patients in NSW and the ACT receiving dialysis as they wait for a kidney, but only 84 kidneys were donated from deceased donors in 2003.

The good news is live donations are on the rise. Dr Eris, who is also the head of the Renal Transplant Unit at Royal Prince Alfred Hospital, said the proportion of live kidney transplants at the hospital has increased from about 15 per cent a decade ago to about 55 per cent now.

Doctors stress the guidelines are not an attempt to spook for kidneys. Even when anonymous donors come forward, they are thoroughly screened, both psychologically and physically.

They will not receive pearls for their troubles, only some pain and scarring. But, as Robyn Karsten, a mother of three says: "With a transplant, as with childbirth, at the end there is new life."

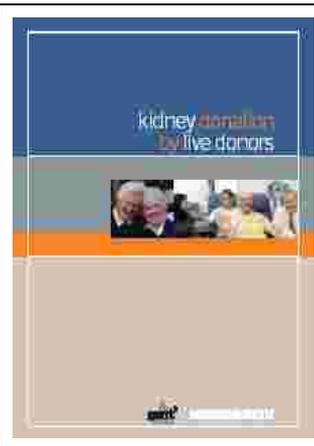
Check out the Renal Resource Centre web site [www.renalresource.com](http://www.renalresource.com) under News - Kidney Donation by Live Donors for full details of the NSW Department of Health booklet, titled 'Kidney Donation by Live Donors'

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from NSW Department of Health.

Live kidney donation is a gift. A gift by choice and not by chance. It is a gift of a normal functioning kidney from one living human being to another.

This guide provides information about the process of live kidney donation to people who are thinking about becoming kidney donors.



File link:

[http://www.health.nsw.gov.au/pubs/2004/pdf/kidney\\_donation.pdf](http://www.health.nsw.gov.au/pubs/2004/pdf/kidney_donation.pdf)

Pages 40; File size: 277Kb; Type: Guideline

Date of Publication: 01 October 2004

SHPN: 040163 ISBN: 0734737092

## **CRKSG – Your Consumer Representative**

The Health Care Consumers' Association (HCCA) provides a voice for consumers on local health issues. It does this by:

- Working with health services to achieve services that are responsive, respectful, accessible and affordable to all.
- Encouraging direct consumer involvement in health decision making.
- Lobbying and advocating on behalf of ACT health consumers.

HCCA has a well established consumer representatives program which includes a forum of representatives and related support activities, information seminars and training. The Canberra Region Kidney Support Group is represented at the HCC as a consumer representative.

The CRKSG has also been requested to attend the National Workshop as the ACT representative from the Kidney Health Australia (KHA) Consumer Advocacy Group.

If you are skilled or interested in lobbying and advocating on behalf of consumers, the CRKSG are looking for your assistance. Contact Vince Maguire or Patrick Gordon today, or attend the next monthly meeting. The Monthly meetings of the Canberra Region Kidney Support Group Inc are held at the Pearce Community Centre, Building 1, Collett Place, Pearce on second Tuesday of each Month (except Jan) commencing at 7.30pm.

The CRKSG needs your help to provide articles for the next newsletter. Contact the CRKSG at [crksg@yahoo.com](mailto:crksg@yahoo.com) or PO Box 5051, GARRAN ACT 2605 or leave your article at the CCDC.

## On Holidays – A Pacific Cruise

I joined the **Dialysis Escape Line Australia Inc** in March 2004 but was too late to apply for the 2004 Pacific Island Dialysis Cruise which was booked out. However, I received a call one day from Nancy (**Dialysis Escape Line Australia Inc** founder) who said that there had been a late cancellation and asked if I was still interested in a Dialysis Cruise. I sure was. When I told my wife, she asked what ports we would visit. I didn't know – did it really matter, we needed a holiday.

After being on dialysis for six years and having spent some time in hospital earlier in the year, my wife and I were looking forward to a holiday. The idea of a holiday without having to rely on finding out if a hospital would take you as a 'holiday patient' was a bonus.

After a few letters and faxes asking questions of Nancy, we managed to sort out all the paperwork and took off to Sydney the day before departure. I was not about to have any Airline problems spoil my Cruise. Julie, my Renal Nurse arranged for me to dialyse in Sydney on the morning of the Cruise departure. After dialysis, I returned to the motel, picked up my wife and luggage and headed for the Sydney Wharf.

There was a long wait to check in and board the Pacific Sky, but the anticipation of a 7 day, 8 night cruise of the Pacific was enough to remind you why you were waiting. Once we checked in and the luggage was delivered to the cabin, we made our way to check out the dialysis rooms and to meet the Doctor and Nurses. This meeting introduced us to Dr Tony Clarkson (a Renal Physician recently retired after 40 years), three Nurses (Sue Owen from Payneham SA, Samantha Tan from Sydney and John Lancaster from Tasmania) and Manuel Lopes the Fresenius Technician; who would look after the dialysis needs of 12 dialysis patients.

We departed Sydney Harbour around 5 pm Thursday 21 Oct under a partly cloudy sky. At dinner the first night, the 21 people who made up the dialysis cruise party were seated over four tables. Introductions were exchanged and we dined on a five course meal. The meal was great, however I 'picked' at my meal as my stomach had a little trouble with the rocking of the ship.

On the first day at sea (Friday), my appetite returned, as the sea was calm, and I had a feast at breakfast. It was then time to check the Ships' facilities. I had a massage to make sure that I was in 'holiday' mode and we checked out the different activities. The Ship produces a 4 page guide each day that tells passengers what is on. You can do as little or as much as you want. If you want to find a seat and read a book you can. If you want to participate in activities you can start with a early morning walk at 8am, a fitness program at 9am, maybe table tennis, cards, quilling, beer quots, trivia quiz, square dancing, Bingo, play the pokies or gaming tables at the Casino, or visit one of the four lounges or bars and even a cinema. There is also a Hair and Beauty Salon and shops to visit. The first of our party commenced

dialysis.

The Captain's Welcome Cocktail Party was held on Saturday night followed by the Celebrity Show featuring Brett Annabel. I dialysed Saturday afternoon for the first time. Whilst I dialysed, my wife watched 'Perfect Match' where single people were matched up and won prizes. She said it was very entertaining.

Next morning we arrived in Noumea, New Caledonia. At the port of Noumea, you could select what you wanted to do (at an additional cost). We went on a guided tour of the Island. Other options included Bays and Beaches by Horse drawn carriage, motor trike, helicopter scenic flight, Jet Ski and many more. You can also do your own thing as Nancy, Sue, Sam and John did by visiting a five star resort on the Island to take advantage of their pool, or more correctly the pool and pool side bar. The temperature was 27 degrees and very humid, and I took advantage of being able to drink more than usual. It was either fortunate or unfortunate that shops were closed on the Sunday depending on how you looked at it. My MasterCard survived the day. That night was 'Fright Night' and a very entertaining presentation by the Pacific Sky Entertainers plus participation by passengers.

Monday 25 October. I had lost track of what day of the week it was, but we anchored off Mystery Island, an uninhabited sandy islet all but surrounded by coral reefs. Tenders took us ashore.



It takes only a couple of minutes to walk to the other side of the island and about 45 minutes to walk all the way around. There is ample shade on the sandy beach, but the tropical sun is strong and you must use sunscreen. That night, on board, was Island Night where you can wear your Island gear and dance the night away under the stars.

Tuesday 26 October. I thought that Mystery Island was good, but the Isle of Pines was pure bliss. Apart from the obvious, swimming or snorkelling, sun bathing and relaxing, the Isle of Pines was a picturesque island. I have never seen sand so white and fine it was like powder. The water was cool and refreshing and the colour was so blue it was paradise. However, I returned to the ship early so that I could dialyse. Whilst the ship is anchored at a port, dialysis is only done during the afternoon so that all patients can make the most of the ports. That night after our normal five course meal we were entertained by a 'Shake Rattle and Roll' show which capped off the day.

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Wednesday - Another Luxurious day at sea! The days' Bingo jackpot was at \$2,500.00, there was an Ice Carving demonstration, Marriage Match (a game to see how well Married couples know each other) and the show in the Show lounge was an Australian theme titled 'G'Day G'Day'.

Thursday (last full day) I dialysed in the morning. In the afternoon, was 'Battle of the Sexes' an activity to find out who is superior – the boys or the girls. The Bingo jackpot of \$3000.00 was won – not by me. After dinner, a Passenger Talent show unearthed some talented passengers.

The last day, we packed and said good bye. Until the next cruise.

Cruise fares (depending on Cabin type and number of nights – anywhere between \$2,000 and \$5,000 adult twin occupancy in cabin per person, see [www.pacificsky.com](http://www.pacificsky.com)).  
 Dialysis Levy \$500.00 (this patient levy and *Dialysis Escape Line* raffles and sponsorship contribute towards the additional rooms required for dialysis).  
 Dialysis Treatment at approximately \$270.00 per treatment.  
 Most private Health Funds cover this cost.



**Nancy (at the back) Sam, Sue and John**

**Dialysis Escape Line Australia Inc Membership** DELA Membership 04/05: \$20.00, pay by Cheque or Credit Card.

Name: \_\_\_\_\_ Address \_\_\_\_\_ Phone: \_\_\_\_\_  
 Haemo  Peritoneal  Recipient  Supported

Card type: Visa / MasterCard / Bankcard Name on Card: \_\_\_\_\_ Card Number: \_\_\_\_\_ Expiry Date: \_\_\_\_\_  
 Send to: Dialysis Escape Line Australia Inc PO Box 324 Stepney SA 5069



**Renal Replacement Therapies**  
 ..... getting better all the time

The Renal Resource Centre NSW presented a one day conference for NSW and ACT renal patients in

Sydney on 23 Oct 04. The conference covered:

- New Trends in Dialysis;
  - Preventing Complications in Cardiovascular and Renal Bone disease;
  - Making the Most of Life;
  - Transplantation Update, including the future directions in Transplantation; and
  - Stem Cell Research.
- A 2 disc DVD pack or a 2 tape VHS set of the Conference is available Complete the order form below.

**Order your own copy of today's Renal Replacement Therapies Conferenc**

**Please fill in this order form and send to:**  
 Effective Productions & Editing, 24 Hampshire Avenue, West Pymble, NSW. 2073

Name & Postal address: \_\_\_\_\_

2 disc DVD pack @ \$25.00 incl. gst - Quantity		Total cost	\$
2 tape VHS set @ \$25.00 incl. gst - Quantity		Total cost	\$

Please make out cheques and postal orders to Effective Productions & Editing P/L

Enquiries to Richard Jeffery: 0412 232 080 / (02) 9499 4400 / [effective01@optusnet.com.au](mailto:effective01@optusnet.com.au)  
 The video production costs have been covered by the generosity of Amgen Nephrology  
 The above costs reflect only duplication and postage