



# 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.

**Autumn 2004**

## A letter from the Secretary

Dear Members of the Renal Community,

If you have spent any significant amount of time around level 8 of the Canberra Hospital or the Canberra Community Dialysis Centre (CCDC), you would have noticed the newsletter of the Canberra Region Kidney Support Group (CRKSG). The group has existed in various forms for many years. It has been entirely run by volunteers and has received generous donations from various individuals and organisations.

The number of people in our region affected by renal disease or its precursors has increased significantly, and it has not been possible for the small group of volunteers in the CRKSG to reach all of the renal community. This newsletter is the only means of communicating with you.

The CRKSG began in 1993 in response to the needs of Renal Patients and their Families.

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## MEDICAL UPDATE



The National Health and Medical Research Council (NHMRC) consolidates within a single national organisation the often independent functions of research funding and development of advice. One of its strengths is that it brings together and draws upon the resources of all components of the health system, including governments, medical practitioners, nurses and allied health professionals, researchers, teaching and research institutions, public and private program managers, service administrators, community health organisations, social health researchers and consumers.

A Xenotransplantation working party of the National Health and Medical Research Council (NHMRC) has released draft guidelines for public consultation. The animal-to-human trials currently being considered would be therapeutic (ie they would be intended to provide a direct benefit to the trial participants).

Xenotransplantation is the term used to cover the transplantation of cells, tissues or organs from one species to another - such as from pigs to humans.

It has become a focus for transplantation research in recent years because there are not enough human tissue or organ donors to meet demand and many patients who would benefit from a transplant wait in vain for donor organs to become available.

The procedure was initially thought unlikely to succeed but recent advances in genetic

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The objectives of the Group are:

- Provide support to the renal patients and their families and friends.
- Generate community discussion and understanding of the issues related to organ donation and transplantation.
- Be actively involved in education about renal disease and renal failure within the wider Canberra Community.
- Raise funds to assist disadvantaged patients in need of medical equipment, to purchase and acquire equipment to enhance the quality of life for dialysis patients.

The CRKSG has recently joined the SHOUT and the ACT Healthcare Consumers Association (HCCA) organisations as full members. The Self Help Organisations United Together (SHOUT) is an independent umbrella group that receives ACT government funding. Services that SHOUT provide include:

- meeting venue,
- insurance assistance,
- publicity, website and referral database,
- training and collegiate environment,
- administrative support and access to office machines, and
- desk and storage space.

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The CRKSG has recently participated in the Renal Education Program and regularly meets with representatives from Renal Unit Management.

The CRKSG NEEDS your support to continue to meet its objectives. For example, support is required to assist in the production of our newsletter or the creation of a web page on the SHOUT web site. If you can not assist with these tasks, show your support by providing an article, a recipe, or a story for the newsletter.

You are welcome to participate fully in the activities of the CRKSG, but even if you don't have the energy for that; the CRKSG is interested in your ideas, experiences and feelings. Please complete the short questionnaire below and place it in the box provided, or mail it to the Canberra Region Kidney Support Group PO Box 5051 GARRAN ACT 2605.

Alternatively, you are welcome to attend the Monthly meetings at **the Pearce Community Centre on the second Tuesday of every month commencing at 7.30 pm.**

Vince Maguire  
Secretary

Tear off and place in box provided, or Mail to:

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

What do you think are the most important things for the CRKSG to do?❖

Fund Raising	
Volunteering	
Mutual Support	
Newsletter	
Social Activities	
Public Awareness and Education	
Advocacy and Representation	
Lobbying and Political Activism	
Contribute to Research Projects	
Collaborations with AKF	

## IN THE MEDIA

Melbourne: - 18 March 2004 - Kidney Health Australia has released details of one of the world's leading Stem Cell Research Programs at Monash University this morning, at a Stem Cell Research Round Table.

Dr Tim Mathew, Medical Director of Kidney Health Australia, today said diseased kidneys show a remarkable capacity for repair, and it is a matter of understanding this process to be able to direct it.

The inherent ability of the kidney to repair suggests the presence of kidney stem cells that may be normally activated in an attempt for self-repair.

Professor Bertram and Dr Ricardo at Monash University are using experimental animal models of renal disease to identify potential stem cells present in the kidney, and others homing into the kidney from circulating bone marrow cells.

The long-term aim of these studies is to induce renal or bone marrow-derived cells to facilitate repair of a damaged kidney or to repopulate a resident kidney. Results will provide valuable insight into the role of stem cells as a new cellular-based therapy for patients with renal disease.

## IN THE MEDIA 2

The Associated Press March 03, 2004  
NEW YORK - Playwright Neil Simon has received a kidney transplant courtesy of his friend and longtime press representative. Simon and Bill Evans were recovering at a New York hospital after the surgery Tuesday, Simon's wife, Elaine Simon, told the New York Times for Wednesday editions. "Everything is excellent," she told the newspaper. Neil Simon, 76, has suffered kidney problems for several years. Before the operation, he had been receiving dialysis treatment three times a week. Evans, 53, has served as a publicist on many of Simon's plays, including "The Dinner Party," "45 Seconds From Broadway" and "The Goodbye Girl." He took several tests to ensure his kidney would be accepted by Simon's body. Simon told the Times shortly before the operation that he and Evans had been friends for 25 years. "It's wonderful of him to do this," Simon said.

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manipulation of animals and the mechanisms of transplant rejection have made xenotransplantation appear more feasible.

The Xenotransplantation Working Party undertook public meetings in all capital cities during February 2004 as part of its second round of public consultation on xenotransplantation. All issues and concerns raised at these public meetings were noted and will be considered by the Working Party over the coming months.

This information and for further information on Xenotransplantation, log on to:

[www.nhmrc.gov.au](http://www.nhmrc.gov.au)

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*FREE CRKSG Membership*

*APPLY NOW!*

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Don't miss a copy of the newsletter

Become a Member TODAY

## CALENDAR OF EVENTS

### CANBERRA REGION KIDNEY SUPPORT GROUP MEETINGS – DATES FOR 2004

WHEN: 13 APR, 11 MAY, 8 JUN, 13 JUL, 10 AUG, 7 SEP, 12 OCT, 9 NOV, AND 14 DEC.

PLACE: PEARCE CENTRE, TIME: 7.30PM

### TRANSPLANT EDUCATION SEMINARS

WHEN: 30<sup>TH</sup> APR 04 , PLACE: CANBERRA HOSPITAL, TIME: 1PM  
LIMITED SEATING – CONTACT MIKKI ON 62443062 OR ALISON ON 62443353

WHEN: 29<sup>TH</sup> OCT 04 , PLACE: CANBERRA HOSPITAL, TIME: 1PM  
LIMITED SEATING – CONTACT MIKKI ON 62443062 OR ALISON ON 62443353

### RENAL EDUCATION PROGRAM - LIVING WITH KIDNEY FAILURE – DATES FOR 2004

WHEN: 20<sup>TH</sup> & 27<sup>TH</sup> MAY; 19<sup>TH</sup> & 26<sup>TH</sup> AUG; AND 18<sup>TH</sup> & 25<sup>TH</sup> NOV  
PLACE: CCDC, TIME: 1.30

### KIDNEY AWARENESS WEEK (30/05-05/06)

Kidney Health Australia.



## DIET - Protein

Various waste products can build up in your blood. Each kind can have different effects on your health. Kidney patients can also suffer from a lack of nutrients. This article discusses PROTEIN.

Protein is an essential nutrient that enables the body to build muscles. It is needed for the repair and maintenance of body tissue and reduces the risk of developing infections or becoming unwell. Correct protein intake is necessary. Too much protein can cause high blood levels of the waste products from protein digestion. Low levels of protein can lead to fluid retention and to a reduction of the body's ability to fight off infections. The breakdown products of proteins are:

- Urea - chiefly from protein provided by foods and
- Creatinine - produced from normal muscle 'turnover'.

The amount of protein you should eat depends on individual needs and may change over time. The need for a change in diet is largely based on your blood results and is only advised once these results become raised above the norm. You should not alter your diet without advice from your doctor or a Renal Dietitian.

My experience. At first it all seemed very difficult trying to abide by the restrictions placed on what I could and could not eat. However after a number of visits with the Dietitian and the use of reminders, I increased my protein intake. I found that I had to remember to have high quality proteins whenever possible. I'd have an egg with my toast for breakfast, or maybe some baked beans. I changed to having chicken

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sandwiches for lunch. I paid attention to making sure that the protein intake was from high quality proteins that contain all the amino acids that are essential to build, maintain, and repair our bodies.

A reminder may be as simple as:

### Meat and meat alternatives

- Meat
  - Poultry
  - Fish
  - Eggs
- ✓ Choose lean meats,
  - ✓ Trim fat from meat and remove skin from poultry before cooking
  - ✓ Use minimal fat or oil to cook meat, poultry and fish and use monounsaturated or polyunsaturated oils.
  - ✓ Use low fat cooking methods such as stir fry, grilling, poaching, baking in foil.
  - ✗ Eat processed meats such as luncheon meat, salami and sausages only occasionally as these are high in fat.

### Milk and milk products

- Milk
  - Cheese
  - Yoghurt
  - Custard
  - Ice Cream
- ✓ To reduce fat intake, choose the reduced fat or low fat varieties of milk, cheese, yoghurt, custard and ice cream.

Low quality proteins lack one or more of the amino acids that are essential to our bodies. It is necessary to include these in the diet also:

- Bread
- Breakfast cereals
- Pasta
- Rice
- Legumes
- Nuts
- Potato

The various renal cookbooks available are well worth buying as they stretch the possibilities of the diet. If you have a recipe, please send it in so others may enjoy.

**This article has been produced by "Patients Helping Patients".**

**Remember** - individual patients have individual dietary requirements. What you need will depend on the stage of your kidney failure, your blood tests, and the kind of dialysis you may be having. Further information can be obtained from your dietitian regarding any of these dietary aspects. The dietitian can work with you to design an individual eating plan that will meet your dietary requirements.

Contact: Your Dietitian or Community Health Intake on 6207 9977.

### IN THE MEDIA 3

Damien Carrick ABC Radio 9 March 2004.

When Victorian cricket coach, David Hookes, met an untimely death back in January, he was not a registered donor, but he had made it clear to his family that he wanted to be one, and so after he was declared clinically brain-dead, his family allowed his organs and tissue to be used.

Inspired by Hookes' decision, Prime Minister John Howard says he'll become an organ donor. And recently, the David Hookes Foundation was created to promote organ donation. Now the Foundation has a big job ahead of it, because Australia's rate of organ donation is low. Last year the rate was 9.4 donors per million, compared with 22 in the USA and 34 in Spain. And even among registered donors, the rate of donation isn't high. That's because at the point of death, about half of the families of registered donors object to their organs and tissues being used, and at present doctors respect those objections, and donations don't proceed.

To bump up the rate of organ donation, last week Federal Health Minister, Tony Abbott announced plans to encourage the States to remove the rights of families to automatically over-rule the wishes of a deceased family member who is a registered organ donor. At present, each State and Territory has a Human Tissue Act, which covers organ donations.

Full transcript is available @ [www.abc.net.au/rn/](http://www.abc.net.au/rn/) Navigate to "Select a Program" and select "The Law Report".

### IN THE MEDIA 4

**The David Hookes Foundation has been established to inspire more Australians to register as organ donors** 7 March, 2004

Organ Donor Week ran from Sunday, February 22. A record number of Australians have registered to become organ donors in the two weeks, since the launch of the David Hookes Foundation and the start of Organ Donor Week. The national Organ Donor Register normally receives around 2000 calls a month.

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Since February 22, there have been 12,800 calls and another 7,200 online registrations, including 4,945 during Organ Donor Week. That is up from 931 registrations during Organ Donor Week last year.

Currently some 1800 Australians are awaiting transplants.

Every year, one in six people who could be saved by organ donation dies because a matching organ does not become available.

At the end of January of this year, 26870 people in the ACT had registered their intention on organ donation on the Australian Organ Donor Register.

See <http://www.davidhookesfoundation.com/>

For full details.

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*The CRKSG needs your help to provide articles for the next newsletter*

*Contact the CRKSG at  
[crksq@yahoo.com](mailto:crksq@yahoo.com)*

*or*

*PO Box 5051*

*GARRAN ACT 2605*

*or*

*leave your article at the CCDC.*

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### HEALTH CONSUMER REPRESENTATION

The Canberra Hospital Clinical Health Improvement Program (CHIP) is running a project on central line management.

Haemodialysis patients may be familiar with vascular catheters and other types of central lines used before their fistula or loop is ready to use. Central lines are widely used for other purposes. The Project is studying aspects such as insertion and removal, infection rates, comparative usefulness of different types, and patients' experiences.

Vince Maguire is the Patient Representative on the project. Vince is interested in hearing from Haemodialysis patients on their experiences or opinions of management of central lines. Vince is at the CCDC on Mon/Wed/Fri evenings, you can contact him there or through the CRKSG.



**MEMBERSHIP APPLICATION  
OR  
MEMBERSHIP RENEWAL  
FOR FY 04/05**

**Last Name:** ..... **First Name:**.....**Phone No:**.....

**Address:**.....

Please accept this application for membership to the Canberra Region Kidney Support Group Inc  
ABN: 77 396 063 641

**Signature:**.....

**Date:**.....

Post Application to:

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

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