



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 5

Winter 2005

Issue 2

**WEE
WEEK**

Are you 1 in 3?
Check your wee

Promoting the importance
of a regular kidney health
check for good kidney
and urinary health

Sunday 29 May –
Saturday 4 June 2005

One in three Australians is at increased risk of developing kidney disease.

The risk of kidney disease increases if you:

- have diabetes
- have high blood pressure
- are over 50 years of age
- have a family history of kidney disease
- are of Aboriginal or Torres Strait Islander descent, or
- smoke

If you have one or more of these factors you should ask your doctor for a kidney health check.

Wee Week 2005 will focus on delivering a message of early detection and prevention of kidney disease to all Australians, but in particular those in high-risk groups.

A general invitation to Canberra Activities is extended to all:

- Official launch at Parliament House on Mon 30 May 05 at 10.00 am. Attendees need to get onto the guest list for security reasons.
- Woden plaza shopping centre stand on Tue 31 May 05. Volunteers welcome, but may need to be briefed on the "theme" for this year.
- Sausage sizzle on Thu 2 Jun 05 at lunch outside main entrance to Canberra Hospital.

Renal Services begin at Moruya on ANZAC day

NSW Minister for Health announced on 22 Apr 05 that renal services will begin for the first time at Moruya District Hospital on ANZAC day.

"For the first time patients (up to eight patients in the first year – six chairs) will receive dialysis treatment in the newly established and \$310,000 renal dialysis unit at Moruya," said Mr Iemma.

Dialysis Unit Supervisor, Claire McLaren, said the Eurobodalla Renal Dialysis Unit opened on the 25th of April with Yvonne and Mervyn, the first two patients. Claire reports they were very happy to be dialysed close to home. "We have opened with two patients and can take one holiday dialysis patient as arranged through their primary dialysis unit. We eventually will have the capacity for more" said Claire.

Renal Services at Goulburn - Delayed

NSW Minister for Health announced on 21 Apr 05 that renal services would begin at Goulburn Base Hospital for the first time on 9 May, 2005. SAHS advises that it should open by the end of May.

The newly established, \$300,000 renal dialysis unit at Goulburn will operate with six chairs and will accommodate up to five patients in the first year of operation.

Both units will be managed by Fresenius Medical Care.

Renal Services at North Canberra

CRKSG are waiting for advice on North Canberra.

KHA - Consumer Participation

CEO of KHA, Anne Wilson, says the link between Consumer Participation and improvement in the health and quality of life for patients is well documented and of increasing interest to governments and health professionals. Kidney Health Australia's 'Consumer participation in Health Program' is to provide a formal structure and mechanisms for stakeholders.

The State and Territory Consumer Committees will provide support for the development of educational forums for consumers, carers and health professionals that address local issues and needs. KHA is unequivocally committed to consumer participation and is now in a position to communicate and effectively act upon the issues facing people with kidney and urinary tract disease.

Canberra: The Canberra Region Kidney Support Group has a representative on the ACT Consumer Committee and

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Hospital Parking to Cost \$5 a Day

CT 21/04/2005

Pay parking will be introduced at Canberra and Calvary Hospitals next financial year as part of a plan to ease traffic pressures and generate funds for the ailing public hospital system.

The new initiative, to be unveiled in the upcoming ACT Budget, will mean visitors to Canberra and Calvary Hospitals will pay up to \$5 a day for parking.

Health Minister Simon Corbell said yesterday workers and volunteers would be exempt from fees that would apply seven days a week during yet-to-be-finalised time periods.

The expected \$800,000 a year in revenue would initially be used to create more parking spaces, but later invested in public hospital services.

"The reason that we're doing this is twofold," Mr Corbell said.

"First of all, it will assist [ACT] Health to have some capacity to meet demands in the system, so the money will go toward health-related activities.

"Secondly, and more importantly, it will help us manage car parking at the two campuses."

Chief Minister Jon Stanhope has warned that ACT residents face tax rises or cuts to services or jobs in the Labor Government's tightest Budget to date to be delivered on May 3.

The ACT Government must boost revenue or cut spending to keep the Budget in surplus in the wake of a slowing national economy and end to Canberra's property boom.

Escalating health costs are one of the key pressures on the bottom line.

The ACT Government is expected to spend \$628.9million on health this financial year, compared with \$386.3million on public schooling, \$90.8million on policing and \$118million on housing.

Mr Corbell said parking was particularly constrained at Calvary Hospital.

The plan was to create an extra 100 spaces - up from 716 - at the Bruce campus surrounded by Canberra Nature Park and Haydon Road. Mr Corbell said people were parking at Canberra Hospital to avoid fees in nearby Woden, which was limiting spaces for legitimate hospital visitors.

The Government would commit \$70,000 for a traffic study at Canberra Hospital, which had almost 2100 parking spaces.

Possible sites would be identified for a new multi-storey car park and alternative locations for the helipad, at present on top of the car park near the maternity section, closer to the emergency department.

Seriously ill patients who were transported to Canberra Hospital in the helicopter were currently wheeled on trolleys through maternity to reach casualty.

Mr Corbell expected a community backlash over the paid parking decision.

"Oh look, whenever you bring in pay parking it's not popular.

"But it's important in terms of managing demand and freeing up parking spaces for genuine visitors rather than for people who are parking there to avoid pay parking elsewhere, especially in Woden, and it also assists us in funding additional parking spaces at Calvary."

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Pay parking was introduced in Belconnen and Tuggeranong last year to bring the suburban centres in line with other areas, including Civic, Dickson, Woden, Manuka and Kingston.

Letter to Mr Jon Stanhope

I write to you on behalf of the members of the Canberra Region Kidney Support Group. The aim of the group is to assist its members to cope better with the effects of renal failure and its treatments.

The Canberra Times reported on 21 Apr 05 that the upcoming ACT Budget will introduce pay parking at Canberra and Calvary Hospitals next financial year at a cost of \$5 a Day. The CT have quoted Health Minister Simon Corbell as saying workers and volunteers would be exempt from fees that would apply seven days a week during yet-to-be-finalised time periods.

I would like to remind you that not only is there no Government program to help in the prevention, early detection, and appropriate management of chronic kidney failure; there appears to be no understanding of the treatment for kidney failure. Haemodialysis patients spend up to five hours on a dialysis machine and additional time before dialysis preparing for their treatment and after dialysis preparing for their safe departure. This treatment is carried out on the 8th floor of TCH and at the Canberra Community Dialysis Centre (CCDC) on Gaunt Place. Unless dialysis patients are exempt from the pay parking arrangements, they may be subject to a cost of \$15 a week for their life saving treatment.

As Gaunt Place does not have a sealed car park and parking is haphazard at best, I would like an assurance that your Pay parking decision will not apply to Gaunt Place.

CRKSG

National Chronic Kidney Disease (CKD) Strategy Workshop Outcomes – Feb 05

KHA convened a stakeholder workshop on 4 Feb 05 in Sydney to discuss the development of the National Chronic Kidney Disease (CKD) Strategy. The aim of the Strategy is to develop chronic disease management strategies and programs to facilitate comprehensive and holistic best care for patients across the continuum of progressive kidney failure. Participants were tasked with considering the key outcomes and measures of success of a National CKD Strategy by 2010. The Workshop Summary Report has been released. The key outcomes and measures of success included:

- patients will have a greater access to their preferred dialysis options. This will be achieved by:
 - increased opportunities for patient choice,
 - education to enable GPs to better manage patient expectations,
 - increased patient self management and promotion of the 'expert patient' concept,

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KHA - Consumer Participation Continued

we are looking for other patients or carers to join the Committee. If you cannot participate on the Committee, you can raise issues that affect the kidney community by contacting KHA at consumer@kidney.org.au or by phone 1800 682 531. Alternatively, you can contact your local representative through SHOUT on 6290 1984, E Mail crksg@yahoo.com or by post to PO Box 5051 GARRAN ACT 2605.

More Patients Head for Home Dialysis

Kidney Health Australia – Victoria - 31 March 2005

More kidney patients on dialysis will head for home for their treatment in the future for improved patient outcomes and as government tries to stem the cost explosion of kidney disease in Victoria, a meeting of senior medical specialists from metropolitan and regional Victoria was told today. "Home dialysis can significantly improve rehabilitation and length of survival," said Associate Professor John Agar, Director of Nephrology Barwon Health. "Also it currently costs government an average of \$60,000 a year for just one patient to dialyse and a move to home dialysis cuts this by a third, down to \$40, 000," he said.

While home haemodialysis in Victoria only accounts for 7.7% (national 10%) of the dialysis pool it brings many advantages including:

- The ability to perform dialysis at a time that suits the family and not the dialysis unit;
- Flexibility to dialyse more frequently and for longer hours and to use the nocturnal approach if preferred;
- No time and cost in transport;
- No requirement for remotely resident families to move;
- Associated with higher rehabilitation and longer survival.

The falling popularity of home haemodialysis in Australia (with its population located often at large distance from major health centres and with the many advantages it brings) is concerning and could be due to:

- Stress and exhaustion of families expected to be present and share responsibility for dialysis;
- Absence of support to enable access of helper to Carer's scheme;
- Cost of installation and extra power and water usage;
- Shortage of machines and training facilities.

Associate Professor Agar said there was an urgent need for a pilot program to be conducted to establish the cost benefits of home dialysis and how it can be made more user friendly - possibly through some financial incentives.

Kidney Health Australia Chief Executive Anne Wilson said, Kidney Health Australia takes the position that the principles underpinning any home haemodialysis program should include:

- Home haemodialysis should be offered to all suitable patients;
- There should be ready access to a training program;
- Financial and accommodation support should be available for patient and family during training if forced to live away from home;
- The performance of dialysis in the home should be cost neutral to the patient and family; and
- Adequate and automatic remuneration should be available for the dialysis helper to compensate for the time spent.

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National CKD Strategy

Workshop Outcomes – Continued

- shift to non hospital dialysis, with the cost savings used to provide increased support and care,
- provision of outreach services by hospital staff,
- increased use of nurse practitioner roles,
- subsidies for patients,
- increased support for remote patients.
- Awareness of CKD will be increased at all levels:
 - CKD will be recognised as a national priority area,
 - CKD will be well integrated with other national priority areas,
 - The language and focus of public discourse will shift from *renal* to *kidney*,
 - An increased number of patients (increase by 20%) will know they are at risk or have early CKD.
- Strategies will be in place to build the medical and allied health workforce.
- Patients will have access and equity in transplantation
- A co-ordinated and systematic primary care approach to CKD prevention and early detection will be embedded in general practice, including:
 - Increased capacity for regular health checks for indigenous people,
 - Increased patient awareness of risk factors and risk reducing behaviour.
- The sector will have the capacity to monitor and evaluate outcomes and build a national dataset.
- The rate of organ donation will increase:
 - The number of live donors will double,
 - The number of deceased donors will increase to at least 20 per million.

The full report is available from KHA web site under Health & Medical or

<http://www.kidney.org.au/?section=2&subsection=443> .

Canberra has a representative on the National CKD Strategy Risk Reduction and Prevention Working Group. If you would like to participate or comment of the National Chronic Kidney Disease (CKD) Strategy, contact CRKSG through SHOUT on 6290 1984, E Mail crksg@yahoo.com or by post to PO Box 5051 GARRAN ACT 2605.

Renal Resource Centre Brochures

The Renal Resource Centre has produced the following brochures, which are available at the Centre, for purchase, or for download from www.renalresource.com.

- Alport's Syndrome
- Diabetes and Your Kidneys
- Glomerulonephritis
- Heart Health & Kidney Disease
- IgA Nephropathy
- Low Protein Diets
- Nephrotic Syndrome in Children
- So You Have Kidney Disease
- From Me To You - So Your Relative Needs a Kidney?
- Understanding and Preventing
- Renal Bone Disease
- Urinary Reflux
- Rehabilitation & Exercise for Renal Patients

CALENDAR OF EVENTS

**Canberra Region Kidney Support Group
Kidney Week Sausage Sizzle**

The CRKSG is planning a Sausage Sizzle in the Hospital grounds during Kidney Week on Thursday 2 June 2005. Anyone interested in assisting, please contact CRKSG at crksg@yahoo.com or PO Box 5051 GARRAN ACT 2605 or leave a message at SHOUT 6290 1984.

The BBQs are provided by Kennards Hire – 10 Townshend Phillip, ph 6282 1515. Support those that support us



Canberra Region Kidney Support Group Meetings

When: The Second Tuesday of each month.
14th Jun 05, 12th Jul 05, Annual General meeting on 9th Aug 05, 13th Sep 05, 11th Oct 05, 8th Nov 05, and 13th Dec 05.

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: May 20th and 27th
August 19th and 26th
November 18th and 25th

Where: Canberra Community Dialysis Centre (CCDC) Gaunt Place Garran

When: 1.30 pm

Limited seating – Bookings Essential
Contact Mikki on 62443062 or Alison on 62443353.

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

Living a Healthy Life with Chronic Conditions Course

The “Living a Healthy Life with Chronic Conditions” Course is a six week education program, two and half hours per week, designed to assist people with chronic conditions to develop ways of taking a more active part in their self care. *The Course is free to participants.*

Tuggeranong Friday 10.00-12.30 Aug 19,26 Sep 2,9,16,23	Belconnen Monday 10.00-12.30 May 2,9,16,23,30 Jun 6
Wednesday 1.00-3.00 Oct 26 Nov 2,9,16,23,30	Monday 1.00-3.30 Oct 10,17,24,31 Nov 7,14

Contact: Community Health Intake 6207 9977

Woden Thursday 10.00-12.30 Jul 28 Aug 4,18,25 Sep 1,8	Tuesday 10.00-12.30 Oct 11,18,25 Nov 1,8,15
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Contact: Arthritis ACT 6288 4244

Pearce Monday 10.00-12.30 May 2,9,16,23,30 Jun 6	Monday 10.00-12.30 Oct 10,17,24,31 Nov 7,14
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Contact: SHOUT 6290 1984

Consumer scholarships to attend the 3rd Australasian Conference on Safety and Quality in Health Care

The Australian Council for Safety and Quality in Health Care invites consumers to participate in the 3rd Australasian Conference on Safety and Quality in Health Care in Adelaide from 11-13 July 2005. The Council is offering a limited number of consumer scholarships to cover the costs of travel, registration and accommodation.

Consumers who have an interest in issues related to the safety and quality of health care and who are prepared to take the knowledge gained from the conference back to their local communities and health services are invited to apply for these scholarships.

Information about the scholarships and application forms can be found in the Events section of the Councils website: <http://www.safetyandquality.org> by phoning (02) 6289 4244 or from The Office of the Safety and Quality Council MDP 46, GPO Box 9848, Canberra ACT 2601.

Details of the conference can be seen at the Conference website: <http://www.sapmea.asn.au/conventions/aaqhc2005/index.html>

Member's Dinner at the National Press Club



Members and guests of the Canberra Region Kidney Support Group dined at the National Press Club in March. Vince Maguire, Mrs Helen Clarkson and Dr Tony Clarkson, Mark Kerr, Tahlei O'Dea, Nick Farley, and Lisa Cuthbertson.

A Haemodialysis Prayer

By Norah Pacey address unknown

Lord, Omnipotent and wise
Bless me as I dialyse.

Reach out your all-embracing arms
Help me silence my alarms.

Keep the heparin running free
Steady the conductivity.

The venous pressure as you know,
Is sometimes high and sometimes low.

Arterial needle's sucking now
You'll know the answer, show me how.

Protect me Lord, I ask of you
From clotted lines and blood leaks too.

And something else I crave to mention,
Deliver me from hypotension.

And please Lord, let me end this day
Weighing just what I ought to weigh.

And in return I'll promise thee
The perfect patient I will be.

Lifeline Canberra Health and Well-being Seminar "The Possibilities", 15 June 2005

Lifeline Canberra is hosting a seminar focussing on health and well-being in June 2005. This will be a locally organised seminar that appeals to a multi-disciplinary audience. We believe that our community can benefit from the challenges, concepts, ideas and forward thinking of our presenters. We know that our seminar will be of intense interest to people from across the spectrum of our community. The seminar will be of particular interest to community sector organisations, educators, health workers, cultural and educational organisations, Aboriginal and Torres Strait Islander Associations and organisations, community leaders and many others. The seminar will be held at the National Convention Centre in Canberra on 15 June 2005 and it is estimated that approximately 250 -300 delegates will attend.

"The Possibilities" Seminar will provide delegates with the opportunity to hear international, national and local speakers on the topics of health and well-being.

Keynote speaker Kakkib li'Dithia Warrawee'a (pronounced Gagga da deer) is an internationally renowned Indigenous Australian, an Aboriginal Spiritual Philosopher, Doctor of Traditional Medicine, Keeper of the Law, Songman and Elder. He is an author and a brilliant and erudite speaker. He will be speaking to "The Possibilities" for Australia from an Indigenous and philosophical overview.

Invited speaker Mr Hugh Mackay will give social commentary on "The Possibilities" for our community. Challenges and changes, implications, baby boomers and their impact on service delivery, employment, culture and societal expectations. Hugh is a psychologist, social researcher and author. He has written ten books, including four best sellers in the field of social psychology and four novels. To find out more about our Health and Well-being "The Possibilities Seminar, contact Pamela Neame at the Seminar Secretariat on 02 6251 0675.

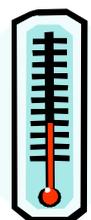
Canberra Dialysis Caravan

Angela and Chris Lount and the CRKSG have commenced raising funds to buy a caravan and make the necessary modifications to equip it with a dialysis machine.

The aim is to have a dialysis caravan available for all self care patients so that they are able to get away for an affordable holiday, without having to book into a hospital or travel back home for dialysis.

Target is: \$18,000
Funds currently raised: \$4,687

Anyone able to donate can contact Angela on 6253 9615 or the Canberra Region Kidney Support Group.



The Importance of Consumer Participation

Kidney Health Australia is implementing a structure that systematically elicits consumer feedback and involvement at a State and Territory and National level. This process has been developed to ensure that all Kidney Health Australia programs logically involve consumer feedback and to remind us of the needs and the desires of the community in which we serve.

KHA have established consumer committees in some states and we have found their input and assistance to be invaluable. Some of the issues that they have assisted us with are:

- Understanding expectations.
- Identification of the gaps and priority issues particularly in relation to accessing renal units and facilities.
- Issues surrounding treatment costs.
- Personal and social health situations.
- Development of social support systems.
- Transplantation.
- Insurance.
- Discrimination.
- Transport issues.

KHA are in the process of expanding their committee structure and are seeking nominations for participants who would like to join the Canberra consumer participation groups.

KHA have found that these groups need to meet face to face every second month, with additional contact between meetings to follow up issues as they arise.

The criteria for selection to be a member of Kidney Health Australia's Consumer Participation Committee are:

- ✓ Passion
- ✓ Commitment
- ✓ The ability to articulate and understand the issues that affect people living with kidney and urinary tract disease
- ✓ Willingness to feed back views and give opinions
- ✓ Sometimes be willing to communicate thoughts publicly and politically.

If you are interested in assisting KHA and are willing and able to provide KHA with active advice, or if you know someone who you think would be a valuable participant, please contact Janine Bevan, at Kidney Health Australia on 0400 120 141 or email janine.bevan@kidney.org.au.

At Kidney Health Australia opportunities also exist for individual people to provide us with feedback at several levels: in treatment and care, consultation, service delivery development, policy development, planning and evaluation, education and training. We are also interested to hear from people who are keen to read high level policy documents, and provide us with written feedback from a consumer's perspective. This voluntary role would be best suited to someone who has a good understanding of health, and who may be in a situation where they have some spare time to read information and send their comments back to staff at Kidney Health Australia. If you are interested in assisting us or in this manner, please call Janine Bevan, at Kidney Health Australia on 0400 120 141 or email janine.bevan@kidney.org.au

IN THE MEDIA - NICK'S STORY

The Canberra Times Sat 26 Mar 05.

Police delivered a message at Easter a decade ago that gave 40-year-old Nick Farley a second chance at life and he has grabbed it with gusto.

Mr Farley said he was diagnosed with IgA Nephropathy – a kidney disorder caused by deposits inside the organ's filters – in 1993 and developed end stage renal failure in 1994.

He was on dialysis and waiting for a kidney transplant when he decided to take a holiday to East Gippsland over Easter in 1995.

It turned out the Department of Defence employee was virtually uncontactable because the borrowed mobile did not work and the holiday flat had no phone connection.

Mr Farley and his friends kicked around a football on Easter Monday before deciding to head out in a boat to Metung pub for lunch.

They opted for a bottle of champagne before taking the trip and Senior Constables Keith Blackhurst and Tony Parfrey pulled up in a paddy wagon 10 minutes later.

"They asked if a Nick Farley was here. By this stage I felt heart palpitations and in the back of my mind, I was sensing or at least hoping for a miracle," he said.

"I was asked how long I intended to stay on holiday. I thought I'd play along with this and I said 'as long as I could unless I had a better offer'. He told me that the Royal Melbourne hospital had a kidney for me and they wanted me there as soon as soon as possible."

They had four hours to get to the hospital so the officers loaded Mr Farley into their paddy wagon and drove him to Bairnsdale airstrip for the flight in the air ambulance. The operation was a success and he left hospital a week later.

"This life changing event and the very fact that I am still here to talk about it would not have happened without a very special person's consent to organ donation during the most difficult circumstances", he said.

"Perhaps the most emotional and treasured moment of this journey so far [was] having written a thank you letter to my donor's family for the first time in January, I recently received a beautiful reply from my donor mother."

The gift had given Mr Farley the opportunity to promote organ donation and to be part, for the first time, of the Australian team for the World Transplant Games in Canada in July.

Editor's Note: Nick is a member of the Canberra Region Kidney Support Group and recently manned an Information Booth during Organ Donor Awareness Week at one of the main shopping centres here in Canberra.

AUSTRALIA DAY HONOURS LIST 2005

Congratulations to Miss Nancy Elizabeth Douglas-Irving Medal of the Order of Australia (OAM) recipient for 2005. Citation: For service to the community as the founder and administrator of Dialysis Escape Line Australia, a (South Australia) support group for people with kidney disease.

Prospective Fit out at CCDC

When the CCDC (Canberra Community Dialysis Centre) was opened around ten years ago, the number of patients using the centre was much less than the number today. Originally the centre was used predominantly by self care patients that couldn't dialyse at home for some reason, and by patients training for home dialysis. The nursing duties developed around this situation and the ratio of nurses to patients didn't need to be high. The number of nurses on duty at CCDC originally was small relative to the number today. The facilities for the nurses at CCDC were adequate for such a small complement of nurses. The current nursing staff at CCDC have made representations to the hospital management that the facilities for nurses at CCDC and the nursing duties be brought into line with reality. What does this mean for the clients at CCDC? It means that there will be some changes to the layout of CCDC to give the nursing staff a private tea room of a suitable size. It may also mean that the tea rounds will in future be performed by the hospital's food services staff. Clients at CCDC are entitled to have any concerns that they have about these changes given consideration by the hospital management. The CCDC CNC (clinical nursing co-ordinator) Lindsay Warren could be approached directly. Any clients that do not want to deal with the matter directly with Lindsay can have their concerns represented by Vince Maguire from the CRKSG (Canberra Region Kidney Support Group). Vince will ensure confidentiality. Although the exact fit out has not been planned, it is likely that the additional space for the nurses will come at the expense of loss of space in the waiting area used by patients and their carers, and the loss of the space currently used in the pre-dialysis information sessions

Kidneys for sale a death risk

Clara Pirani, Medical reporter - The Australian
7 Mar 05

Australians suffering kidney disease are so desperate for transplants they are travelling overseas and paying up to \$100,000 to buy a kidney.

A study published in today's Medical Journal of Australia reveals patients who pay for a kidney – a practice outlawed in Australia – are more likely to die or have complications than those who wait for one locally.

Some reports claim that up to 90 per cent of transplanted kidneys in China are retrieved from executed prisoners.

Researchers studied patients at four renal units in NSW and identified 16 Australians who had travelled overseas for kidney transplants between 1990 and 2004. Five have subsequently died from hepatitis, bacterial infection or other complications.

"The chances of dying from having a transplant overseas are markedly increased," said Bruce Pussell, professor of medicine at the Prince of Wales Hospital in Sydney.

China, India, Iraq, Lebanon, The Philippines and South American countries and are the most common destinations. However, patients rarely know who the organ came from, and donors are often not screened for infectious diseases.

"There are reports of people coming back with HIV and Hepatitis," Dr Pussell said.

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"Within our group we've had two people come back with Hepatitis B who subsequently died within 12 months of returning."

The study reviewed only patients who returned to Australia after a transplant, which means that deaths and complications overseas may never be reported.

About 2000 Australians are on the waiting list for kidney transplants, yet only about 520 are performed each year.

The thought of spending years attached to a dialysis machine while waiting for a kidney transplant was enough to prompt Kelvin – who asked that his surname be withheld – to take drastic action.

In constant pain and unable to work, the 39-year-old Sydney businessman paid \$100,000 for a kidney transplant in China from an unknown donor last October.

"The waiting list here was just so long, and dialysis was intolerable because it takes seven hours, every second day," he told The Australian.

"I couldn't work, I couldn't travel and I felt sick and tired all the time."

Kelvin's doctors warned him about the dangers, but he took the risk. The international sale of human organs is a shadowy business, often run by middle-men who sell diseased or incompatible organs to desperate patients.

Kelvin was lucky on two counts. He was wealthy enough to pay for reliable doctors, and he had well-connected relatives who worked in a reputable hospital in China.

"I would never have done it if I had to use the middle-men. That's very, very dangerous," he said. "I flew over there to look at the hospital and talked to the doctors and patients and that made me feel more comfortable."

The operation cost \$50,000 and he spent a further \$50,000 on medication, flights and accommodation.



'Energy for Life' Support Program

If you're taking Aranesp, then has your Renal Doctor or Nurse told you about the Energy for Life support program?

This program has been developed by Amgen Australia to support patients with chronic kidney disease by providing information to help them feel confident about living with and managing their condition. The Energy for Life support program offers newsletters, diet tips and recipes, a journal for patients to keep track of how they're feeling, and advice on topics such as stress management, depression, managing fatigue and exercise. Patients will receive a patient pack containing a range of materials, such as books and videos, designed to help them understand more about chronic kidney disease and make living with it a little easier.

Enrolment forms are available from your renal team and when complete can be forwarded by reply-paid envelope. Once enrolled, patients will automatically be registered for the Energy for Life support program. The program is supported by Amgen Australia and does not cost patients anything.



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

Post Application to:
Canberra Region Kidney Support Group Inc
PO Box 5051 GARRAN ACT 2605.

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

Address:.....**E Mail:**.....

I would like to make a voluntary donation to CRKSG for the amount of: \$..... Membership is free.
All Donations over \$2 are tax deductible. Cheque/Money Order payable to CRKSG Inc
Please accept this application for membership to the Canberra Region Kidney Support Group Inc
ABN: 77 396 063 641

Signature:.....

Date:.....

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

POSTAGE

Sausage Sizzle Lunch 2 June
Hospital main Entrance