



Canberra Region Kidney Support Group

Kidney News

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

Privacy Policy

Your privacy is very important to the Support Group. This statement outlines to you the type of information gathered, how the information is used and how it is shared. The practices of the Group in collecting information comply with the [Privacy Act 1988](#), as amended.

Collection of Personal Information.

No personal information is collected by visiting our website.

You may visit the site without revealing any personal information.

The only way the CRKSG can collect any of your personal information is if you supply that information. If you contact the Group via

the contact page on the website, we collect only that information you provide.

The minimum we collect is your name, email address and any information you provide in the body of the message. If you contact the Group via the membership application form we will only collect that information which you provide.

Personal information will not be released to a third party unless we have a legal

requirement to do so or we cannot progress a matter which you have raised with the Group without providing some or all of the information held.

Under normal circumstances we only use your personal information to contact you by letter, email or to send you a copy of the Group's newsletter.

Access to Your Personal Information.

We will respond as quickly as possible to any request from you to provide access to your personal information. If there are any inaccuracies in the detail we hold, we will make every endeavour to correct this immediately it is brought to our atten-

tion.

Relationships with Other Organisations.

The Group's website contains links to a number of other sites. The CRKSG is not responsible for the privacy policies or the content of those sites.

The foregoing detail is also available at the Group's Website at — <http://www.crksg.org.au/privacy.php>.



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Hairdresser gives client a kidney

By Clare Weaver — December 31, 2006

For most people, a trip to the hairdresser means getting a new style and blow-dry. But Bernadette Keegan's life changed forever when the woman who has cut her hair for eight years offered to give her a kidney as well.

The Sydney mother-of-two, who endures daily dialysis because of a genetic kidney disease, was facing a wait of up to 10 years for a compatible donor organ.

Her hairdresser, Jennie Maley, who runs a salon in Richmond in Sydney's north-west, was so moved by Ms Keegan's plight that she volunteered to help.

Against the odds, her blood and tissue tests proved she was a perfect match.

Now the two - who until recently had a normal business-client relationship rather than a friendship - are preparing for a transplant at Westmead Hospital, on January 31.

Ms Keegan, 47, a psychologist, described the events as "absolutely amazing". She told *The Sunday Telegraph*: "You don't really expect to go to the hairdresser and get a kidney. I didn't say anything when she first offered because I was so shocked."

Ms Maley, 53, first considered donating a kidney after Ms Keegan joked she had a "hot date" at Nepean Hospital's renal unit after having her hair blow-waved.

"I went home, had dinner and enjoyed my partner's company - but I couldn't stop thinking about Bernie," she said. "So I got my blood tested and I asked Bernie if she might consider me. It took 24 hours for the offer to sink in, but her daughter told me she cried the whole way home."

Ms Maley said her partner, Denis Johnston, and children Kristie, 28, and son Camm Sorrenson, 26, were backing her decision.

"At first my partner said I will support you but I don't understand why you are doing this. Then I got him to meet Bernie so he could understand - my family are all supporting me, it's great."

The two women have grown close through the experience. "Bernie is as private as I am outgoing - we are almost the opposite," Ms Maley said. "She didn't even tell me about her illness, I heard through friends," she

added.

Having a kidney removed is a gruelling operation with a two-month recovery period. "People ask if I am scared but I am not sick and it's only two months out of my life," Ms Maley said.

"My surgery is being done by Howard Lau, who treated Kerry Packer, so I feel I am in good hands."

The pair want to boost awareness of organ donorship, as Australia has one of the lowest rates in the world.

"What people need to realise is just being a donor on your driver's licence is not enough - you need to register with Medicare or your wishes can be over-ruled," Ms Maley said.

Ms Keegan is looking forward to being well enough to travel overseas and spend time with her children, Lauren, 10, and Daniel, 14.

"It will be nice to go out and not have to worry about getting home for dialysis," Ms Keegan added.

She discovered she had polycystic kidney disease - which causes kidney failure - at the age of 15 but her health only started deteriorating eight years ago. She began dialysis to clean her blood in 2003.

Despite fatigue, she goes to work and undergoes treatment at night. Dr Tim Mathews, medical director of Kidney Health Australia, described the situation as "unusual".

"There are some 1500 people waiting for a kidney transplant, with an average wait of four years," he said.

He said Kidney Health Australia would like to encourage more people to consider kidney donation. About 40 per cent of kidneys come from live donors and between 97 and 98 per cent of those are relatives of the recipient.

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CRKSG Projects

Over the last few months the Group has financed a number of projects. We have purchased a dishwasher for the Kidney Health rooms in the Canberra Community Dialysis Centre (CCDC), a microwave oven for the Renal Unit in The Canberra Hospital and plumbing in a disadvantaged kidney patient's home to allow home dialysis.

The microwave will bear a memorial plaque to Patrick Gordon who passed away recently (See elsewhere in this newsletter).

Calendar of Events

Support Group Meetings.

When: The Second Tuesday of each month.
13th February, 12th March, 10th April,
8th May and 12th June.

Where: The Pearce Community Centre
Building 1, Collett Place
Pearce ACT 2607.

When: 7:30 pm.

Membership

In the first half of January 2007 we sent a letter to everyone on our membership list asking for confirmation of name, address, email and phone details. The letter also asked you to advise if you were no longer interested in receiving communications from the Group. Of over 70 letters sent, we have received only just over 30 responses. If you have not responded, could you please do so as soon as possible. The only cost of responding is your time. A stamped self-addressed envelope was included with the letter to facilitate your response.

We need to know if we are sending the newsletter, etc. to the correct addresses and indeed we also need to know if you are no longer interested in receiving correspondence from the Group.

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!

You do NOT need to be suffering a kidney related illness to participate!

If we cannot get people to help, the Group is in danger of folding.

Obituary — Patrick Gordon

We advise readers that Patrick passed away in The Canberra Hospital on the morning of 16th January 2007.

Patrick was a driving force in the Group and will be sadly missed by his colleagues and friends.

Patrick's funeral service was held in the Chapel at Norwood Park Crematorium in Mitchell on Monday 22nd January 2007.

No Warning Signs

12th February 2007

About 2 million Australians may be affected by early-stage kidney disease and not even know it, Kidney Health Australia said today as it released details of No Warning Signs, a community awareness program to combat the silent killer in Australia.

Anne Wilson CEO of Kidney Health Australia said, “The No Warning Signs campaign to be officially launched on March 8th World Kidney Day is a major call to action for Federal and State Governments to put Chronic Kidney Disease on the National Agenda”.

Ms Wilson said that at this stage despite overwhelming evidence of the tsunami of kidney disease heading towards Australia’s health budget, there is no nationally coordinated preventative communication program in place by any level of government.

“On average, six new patients are accepted onto the Australian dialysis program each day. The cost of treating a patient with dialysis is \$72,000 per annum and the number of patients on dialysis is increasing at 6% per annum”.

“Research shows over 25% of all patients coming to dialysis and transplantation do not see a kidney specialist until less than 90 days before dialysis starts, which is a clear indication of the need for a national awareness campaign in understanding and recognizing the early causes of kidney disease”.

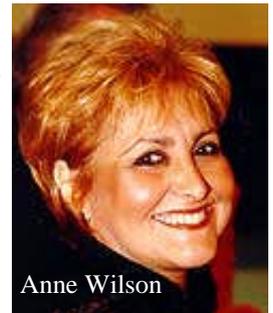
“People would soon know if they were missing half the money in the bank, half of the use of an arm or had been short served by a half a meal in a restaurant, but in the case of kidney disease most people do not know they have a problem until their kidney function is well over half gone.”

Dr Tim Mathew, Medical Director of Kidney Health Australia said, “Many people do not understand the main job of their kidneys is to remove toxins and excess water from our blood. Our kidneys are roughly the size of two fists and are located deep in our abdomen, beneath our ribcage”.

“Every day our kidneys filter an average of 200 litres of blood – a quantity that would fill 20 buckets!

“Besides this impressive, daily feat, kidneys also help to control our blood pressure, to produce red blood cells and to keep our bones healthy.”

“Kidneys gradually lose their ability to function making it a “silent” disease as it often goes unnoticed because it may not be “felt”, Dr Mathew said.



Anne Wilson

Facts About Organ Donation

Organ Donor Awareness Week, 18th—24th February 2007

The Australian Organ Donor Registry is a clear way to tell your family that you want to save lives. **The drivers licence is not enough!**

Even if you can't donate blood, you can still save lives by donating organs. Improving Australian organ and tissue donation rates is a National imperative. The ACT ranks highly compared to other States and Territories in donation rates.

Australian rates for donation are very low compared to the rest of the world, and yet our transplantation techniques and survival rates are amongst the worlds best.

There is an epidemic of kidney failure in Australia and the economic burden of kidney disease will significantly increase for Australia over the next few years. Increasing transplantation rates will provide enormous cost savings.

Currently the ACT has approximately 70 individuals waiting for organ transplantation **to save their lives.** You are 10

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times more likely to need a transplant than to ever be in a situation at death where you can become a donor.

Every 2 and a half days someone dies waiting for a transplant in Australia. **There are approximately 1800 people in Australia at the moment waiting for organs to save their lives.**

Organ Donation rarely occurs unless brain death has occurred and this is less than 1 in every 100 deaths. Brain death is different to coma. When someone is brain dead their brain is no longer functioning at all. There is no blood going to their brain, and there is no oxygen going to their brain, the cells have all died and they cannot recover. No one who was found to be brain dead has ever recovered.

Australia has very low donation rates because people don't talk about Organ Donation, and don't tell their families their wishes. Please talk to your family and friends about your wishes regarding donation and encourage discussion. Encourage them to respect your wishes about donation.

Family consent is requested at the time of potential donation and families will often say NO to donation if they do not know your wishes.

Most of the worlds religions support Organ Donation.

Pope John Paul II stated:

"It is the decision to offer without reward, a part of one's body for the health and wellbeing of another person. We rejoice that medicine, in its service of life, has found in organ and tissue transplantation, a new way of serving the human family."

Fast Facts

As at 31 December 2005, 16% (1365) of the 8528 people receiving dialysis were on the transplant waiting list.

The majority of the people on the waiting list are aged less than 55 years and 81% are waiting for their first transplant.

The average waiting time for a transplant is about 4 years but waits of up to 7 years are not uncommon.

On average one Australian each week dies while waiting for a transplant.

The survival rate following a transplant is high - 96% of recipients are alive at 1 year, and 87% are alive at 5 years.

Compared to international figures Australia has a low deceased organ donation rate of 10 donors per million population in 2005.

Live kidney donations represent approximately 39% of all kidney transplants (246 live donor transplants performed in 2005).

1 Jan 2005 - 31 Dec 2005 - 623 transplant operations (decrease of 4% from 2004, 649 transplant operations).

2005 - 1407 on kidney transplant waiting list, 377 kidney transplant operations performed (from deceased donors), 246 kidney transplant operations performed (from live donors).

World Kidney Day – 8 March 2007

Following is a media release from Kidney Health Australia for World Kidney Day.

The cost of treating kidney disease in Australia is rising by \$50 million a year and will jump from \$700 million in 2006 to \$900 million in 2010, according to the first ever report on The Economic Impact of Kidney Disease in Australia released today.

Commissioned by Kidney Health Australia and carried out by the George Institute of International Health [<http://www.thegeorgeinstitute.org/>], the report being released this morning outlines major holes in the current health policies and highlights ways the government can save hundreds of millions of dollars in the next decade through new initiatives.

Anne Wilson C E O of Kidney Health Australia said, “The detailed and comprehensive report identifies clearly that the Federal Government can save hundreds of millions of dollars in the future by extending home dialysis and transplantation.”

The key findings of the report are:

- Over the last 25 years, while the Australian population has grown less than 40%, the number of Australians being treated with dialysis or a kidney transplant has grown more than 400%.
- In 2010, the number of Australians commencing renal replacement therapy (RRT) will increase between 19% and 47% above the current incidence of RRT.
- This equates to an additional 850 patients commencing RRT each year.
- In 2010, the number of Indigenous Australians commencing RRT will increase between 19% and 84% above the current incidence of RRT.
- Conservative estimates indicate that the total health sector cost for providing RRT services to 2010 will be between \$4.26 and \$4.52 billion.
- Approximately 60,000 life years (and 30,000 quality-adjusted life years) would be gained by providing RRT for all cases of end-stage kidney disease (ESKD)
- Increasing the number of kidney transplants by 10% to 50% would save \$5.8 million to \$25.9 million
- Increasing the rate of home haemodialysis to an optimal level would produce a saving of \$88.2 million
- Increasing the rate of PD to an optimal level would produce a saving of \$135.4 million.

Ms Wilson said, “despite the significant burden of disease there is no national strategic plan addressing Chronic Kidney Disease (CKD) issues and planning for the projected growth in incidence and prevalence of CKD”.

“There are also no systematic national programs (government or non-government) in place addressing ways of bridging the gaps that exist in the delivery of the advances in clinical care that have occurred in the last decade.”

International Water Day

Media Release 22 March 2007.

Drink Water, Nature's Health Drink.

With over two million Australians showing some sign of kidney disease, Kidney Health Australia has chosen International Water Day to call on people to drink water, nature's health drink.

Anne Wilson C.E.O of Kidney Health Australia said, "the organisation would also be encouraging all companies to print out fact sheets from the Kidney Health Australia website for the workplace water cooler, to get the kidney health message out to millions of Australians".

"Water is nature's health drink and the linking of kidney health awareness with drinking water is a perfect way for getting our vital message out to the broader community."

On average, five new patients are accepted onto the Australian dialysis program each day, the cost of treating a patient with dialysis is \$72,000 per annum and the number of patients on dialysis is increasing at 6% per annum.

Research shows over 25% of all patients coming to dialysis and transplantation do not see a kidney specialist until less than 90 days before dialysis starts, which is a clear indication of the need for a national awareness campaign on understanding and recognising the early causes of kidney disease.

Ms Wilson said research has shown that many people do not understand the main job of their kidneys is to remove toxins and excess water from our blood.

"Every day our kidneys filter an average of 200 litres of blood – a quantity that would fill 20 buckets!"

"Besides this impressive, daily feat, kidneys also help to control our blood pressure, to produce red blood cells and to keep our bones healthy."

Kidneys gradually lose their ability to function making it a "silent" disease as it often goes unnoticed because it may not be "felt", Ms Wilson said.

About Kidney Health Australia.

Kidney Health Australia is a national organisation committed to reducing the burden of kidney disease through funding and stimulating innovative research; providing education and support; promoting access to high quality healthcare, and increasing public awareness and commitment to advancing kidney health and organ donation.

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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.