



Kidney News

Newsletter of the Canberra Region Kidney Support Group Inc.
 ABN 77 396 063 641
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The views expressed in this newsletter are not necessarily those of the CRKSG.

Volume 5

Spring 2005

Issue 3

**You are invited to the
 Twelfth
 Annual General Meeting
 of the
 Canberra Region Kidney Support
 Group
 to be held
 at the Pearce Community Centre
 on
 Sunday 25th September 2005
 at 2pm**

Afternoon Tea will be provided.

Our Annual General Meeting will be held shortly and that means a new committee will be forming. Your committee meets on the second Tuesday of each month for a couple of hours.

The committee must consist of three ordinary committee members and four office-bearers of the association. The office-bearers are the president, the vice-president, the treasurer and the secretary.

Nominations are now called for Office Bearers and ordinary members for the Executive Committee. Please contact the Secretary at crksg@yahoo.com or crksg@shout.org.au

We need your attendance and support at this meeting to ensure the continuation of the group.

NORTHSIDE SATELLITE DIALYSIS CENTRE

Dr Tony Clarkson, Acting Director, Renal Services has announced "We are happy to announce that the Northside Satellite Dialysis Centre will open for business in Oct/Nov 05.

This new Centre is a public facility, will be operated by Fresenius Company who are employing the nursing staff and supplying equipment. Fresenius will be responsible to The Canberra Hospital Renal Unit together with ACT Health for its clinical governance.

There has been some confusion as to who will be eligible for treatment at the Northside Centre. It is emphasised that both public and privately insured patients will be eligible for treatment at this Centre which will also be open to "holiday" patients and those home dialysis patients requiring respite.

If you are interested in dialysing at the Northside Satellite Dialysis Centre which will be at Calvary Hospital, could you please indicate to Anne Maguire, Clinical Nurse Consultant, CCDC Gaunt Place."

Clinical responsibility will remain with the Renal Unit at The Canberra Hospital and if investigations, procedures or administration to Hospital is required, these will be carried out at The Canberra Hospital. You will remain under the clinical supervision of your current renal doctor.

Fresenius Nephrocare, who have been contracted by ACT Health and The Canberra Hospital to operate the centre, are highly experienced and qualified in this business and this will be the 10th such Unit they have managed in Australia.

Check out the floor plan on Page 2

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Canberra Region Kidney Support Group - Kidney Week Sausage Sizzle

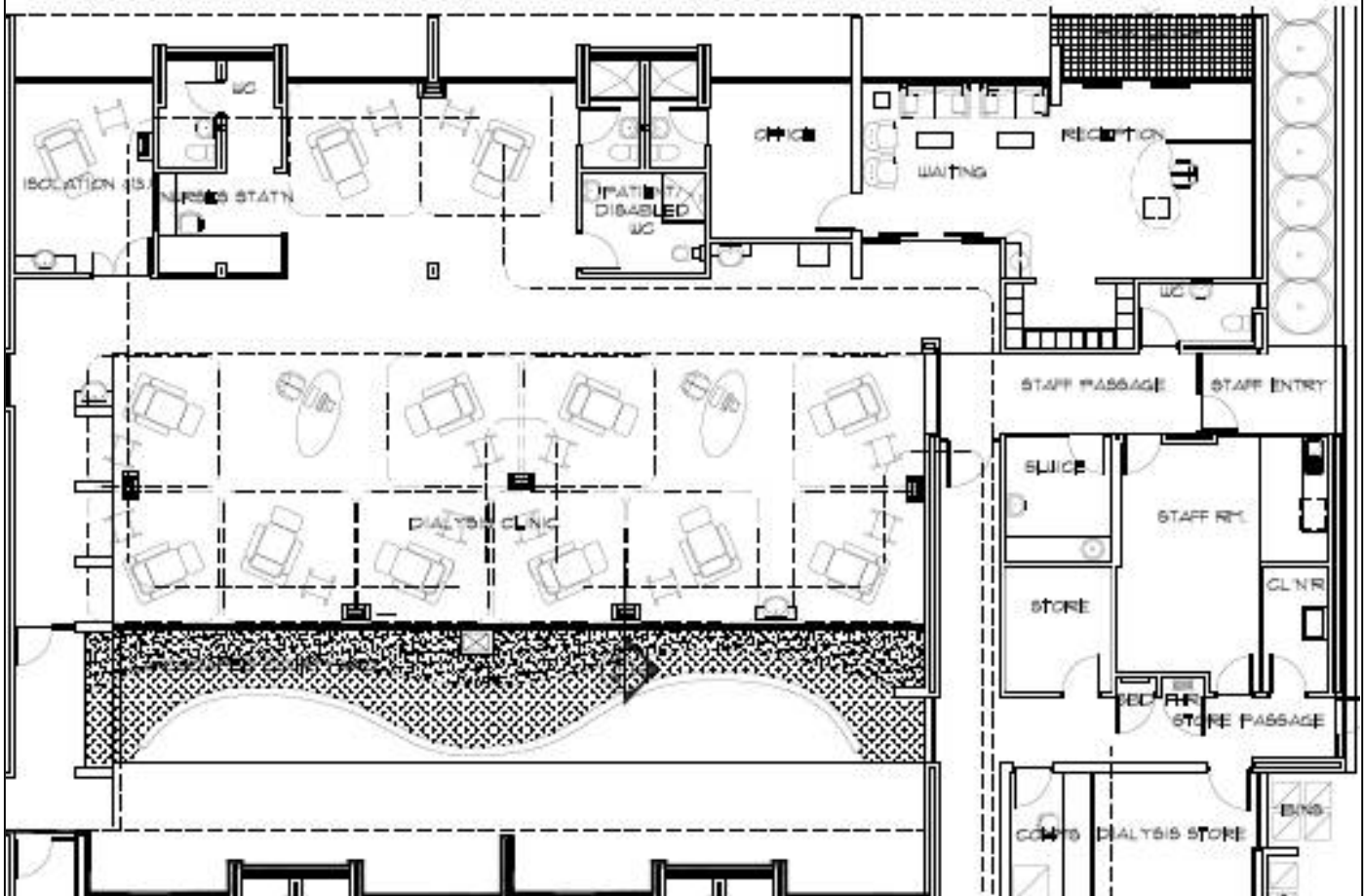


Mary and Tony Bailey, John Kelly, Vince Maguire, Nick Farley and Patrick Gordon presenting a CRKSG cap to Anne Wilson, Chief Executive Officer, Kidney Health Australia.

Special Thanks to Kennards Hire
10 Townshend Phillip, ph 6282 1515
who supplied the BBQs



and
SIMPLY FRESH FRUIT MARKET
Shop G 106 Woden Plaza Keltie St Phillip
2606 (02) 6282 9781



Floor Plan of Dialysis Centre at Calvary Hospital

OUR OWN WEB SITE

CRKSG will officially launch its own web site at the AGM.
Check it out at www.crksg.org.au



Reply from ACT Government on paid parking.

CRKSG wrote to the ACT Government on 28 April in relation to the ACT Government’s proposal to introduce paid parking at ACT public hospitals. The Minister for Health, Simon Corbell, has advised CRKSG that “a detailed study is being commissioned to guide the implementation of paid parking”. The Minister has also stated “this study will consider special arrangements which may need to be made for patients who need to attend hospital for extended or very frequent treatment. The needs of your members will be considered in detail and you will be specifically consulted in the lead up to implementation”.

CRKSG will continue to monitor the implementation of paid parking and will keep members informed.

Privately Insured Dialysis Patients

Are you a Dialysis Patient who has Private Health Insurance?

Have you been invited to dialyse as a Private Patient?

The Canberra Hospital is currently approaching patients with Private Health Insurance to dialyse as a Private patient. We are advised that patients would not be out of pocket as the cost would not exceed the amount paid by the Health Insurance coverage. It is understood that some funding would be returned to the Renal Unit, although no details of the percentage returned are available. CRKSG would like to hear from any member who has been approached, or other patients who have views on this issue.

Contact CRKSG at crksg@yahoo.com or crksg@shout.org.au or PO Box 5051GARRAN ACT 2605

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

KIDNEY BLOG

Kidney Health Australia (KHA) has released Australia's first kidney health consumer feedback mechanism. KIDNEY BLOG has been developed to enable people with kidney disease to share their personal views and stories. Importantly it will also provide key decision makers including members of parliament and the media with feedback from those at the front line dealing with this silent killer. Kidney Blog is an electronic facility for people to make comment on issues and post personal stories. In a busy world, where it is often difficult for individuals to be heard, KIDNEY BLOG will become a major meeting place and voice for the kidney health community.

Current Issues are:

1. Early Detection and Prevention
2. Haemodialysis
3. Donor Compensation
4. Indigenous Health
5. Organ Donation



You can also Email the government (to send your message to your Health Minister, Shadow Health Minister and Premier/Chief Minister)

Nutrition care for dialysis patients

Nutrition plays an important role in the treatment of renal disease managed with dialysis. Dietary changes are necessary to assist in the management of fluid and mineral balance as dialysis and medications are unable to replace all the functions of healthy kidneys. Nutrients are lost during dialysis and dietary advice is required to prevent protein-energy and micronutrient malnutrition. Dietary advice may also be required for other medical conditions such as diabetes.

It is recommended that every dialysis patient should receive nutritional counselling from a renal dietician at the time of commencement of maintenance dialysis therapy. Individualised advice is needed as dietary requirements vary between people. Dialysis patients of The Canberra Hospital routinely receive dietary advice from a renal dietician at the initiation of dialysis.

Nutrition counselling and interventions are required on an ongoing basis, and for dialysis patients of The Canberra Hospital this should be obtained through regular outpatient attendance at renal dialysis nutrition outpatients. Nutrition dialysis outpatient sessions are offered in the Renal Unit at The Canberra Hospital on Tuesday afternoons and Friday mornings for review of dialysis patients. Appointments are required for dietetic review and can be booked through telephoning Renal Outpatient reception on (02) 6244 2046.

CALENDAR OF EVENTS

Canberra Region Kidney Support Group Meetings

When: The Second Tuesday of each month.
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

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

**When:** 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

**Limited seating – Bookings Essential**

Contact Mikki on 62443062 or Alison on 62443353.

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Transplant Patient Education seminar

The next Transplant Patient Education seminar will be on 28th October 2005 from 1pm to 5pm
Venue unknown as yet (TCH)

Limited seating – Bookings Essential

Contact Mikki on 62443062 or Alison on 62443353.

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**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**

Wednesday 1.00-3.00  
Oct 26  
Nov 2,9,16,23,30

**Belconnen**

Monday 1.00-3.30  
Oct 10,17,24,31  
Nov 7,14

Contact: Community Health Intake 6207 9977

**Woden**

Tuesday 10.00-12.30  
Oct 11,18,25  
Nov 1,8,15  
Contact:

**Pearce**

Monday 10.00-12.30  
Oct 10,17,24,31  
Nov 7,14  
Contact:

Arthritis ACT 6288 4244

SHOUT 6290 1984

**"Living a Healthy Life with Chronic Conditions" courses**  
Participation in the "Living a Healthy Life with Chronic Conditions" courses scheduled this year has been slower than expected and some courses have been cancelled as a consequence of low numbers. Perhaps some members have not yet caught up with that the course is all about. "Living a Healthy Life with Chronic Conditions" is ideal if you have a chronic condition such as Chronic Kidney Disease (CKD) and you want to learn ways of keeping these health problems from interfering with your life. You will have the opportunity to learn with and from others, new ways of managing the impact of chronic health problems on your daily life, activities, relationships and health professional partnerships.

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The CRKSG needs members to:

- Lobby or participate as Patient Representatives,
- Contribute to the newsletter, and
- Act as patient support officer.

The CRKSG can provide the infrastructure that can support anyone with bright ideas that further the aims of the group.

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**Canberra Dialysis Caravan**

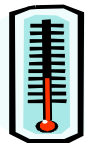
Angela and Chris Lount and the CRKSG have commenced raising funds to buy a caravan and make the necessary modifications to equip it with a dialysis machine.

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.



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Happenings



Weddings

Congratulations to Julie and Jason Voutos on their recent nuptials

Farewells:

Farewell to Mary Brammall who is retiring. A special thank you from the Home training patients.

Congratulations:

Congratulations to Renal Specialist Belaji Hiremagalur. Balaji, his wife Aruna and children migrated to Australia in January 1998, and recently became Australian Citizens..

If you have some happenings or would like to congratulate someone, lets us know. Contact the CRKSG at crksg@yahoo.com or or crksg@shout.org.au or PO Box 5051GARRAN ACT 2605

MY LONG OVERSEAS HOLIDAY -- KYLIE WALFORD

It was early on a mid-September morning in 2004 when my mum (Cheryl), dad (Terry, or Terence as Mum prefers to call him) and I set off for Canberra Airport to begin our ten week holiday, and dialysis tour, of Europe and Japan. We were visiting nine cities and I was dialysing in eight of them.

It was a long and exciting but tiring trip and I have a long story to tell. First, some background information. Our dialysis planning had started six months earlier in March when we decided that it would be so much easier if we could somehow just book all the necessary dialysis sessions without going through a long drawn out process. We had heard of a dialysis booking agency listed on the internet which would do that. It was a service offered by Fresenius, the dialysis machine makers.

The ladies at the agency were very pleasant when contacted either through the internet or by telephone but, for some reason, over a period of more than six months were unable to confirm bookings, or were changing details of confirmed arrangements, even after we had left Australia. To be fair, we did change our itinerary about six weeks before we left as we decided to shorten the trip from twelve to ten weeks. We were forced to change it again shortly before we left because we had no confirmations at all for two cities in Spain. It appears that the problem was that the agency had little control over bookings with the individual units making all the decisions.

As you would appreciate, my dialysis had to take priority over bookings for travel and accommodation in our travels around Europe and Japan. The booking agency even informed us that they had previously booked dialysis sessions for a client who then booked travel and accommodation, only to then have the dialysis cancelled. We were determined to avoid such a disaster.

Eventually the penny dropped that the only way we were going to achieve a satisfactory dialysis regime was to book it ourselves at each individual city. In the end, we used only one dialysis centre booked by the booking agency and that was in Venice. It turned out to be one of my favourite places for my dialysis.

Our approach to finding a good dialysis centre was to go into Google on the net and enter something like "Holiday dialysis in London (or Paris, or Florence etc)". Sometimes it was very easy to find the right place as in London and Amsterdam. On other occasions it was more difficult but it wasn't impossible. We eventually found out that Gambro have a centre available to visitors in Barcelona. The internet site globaldialysis.com was a reasonably good source of information although details were scarce. All we were really looking for was the names of units and their contact details.

Our trip to Europe was via Tokyo. All our air travel was with Japan Air Lines and they looked after us wonderfully. We had made them aware that I was a dialysis patient and they made it their business to check that I was OK both before and during flights. They refrigerated my perishable medicines and made sure we were allocated the most comfortable seats available. Unfortunately, our own international carrier does not go to such trouble, as we have

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subsequently discovered in respect of our next trip to Hong Kong.

In our planning we discovered that triple rooms in hotels are no cheaper than short stay apartments. The minimum stay for apartments generally is three days. When we arrived in London we had to deal with being allocated a substandard apartment but mum, being the assertive person she sometimes has to be, stuck to her guns and we were shifted to a clean, modern apartment on top of Paddington Rail Station. As we were to be in London for 16 days our comfort there was going to be most important.

Our search for a dialysis unit in London very quickly led us to The London Clinic. The London Clinic is situated in Harley Street which is, as you may know, the famous street of medical specialists in London. The Clinic is a hospital but is cleverly disguised not to look like a hospital. We walked past it twice before we realised that it was where we were meant to be going. It is much like every other building in the street, ie four stories and looking like an apartment building of considerable size.

The Clinic is an exclusive establishment catering mostly for wealthy clients, many of whom were of Arab origin. The dialysis unit was an afterthought at the hospital after it was realized that they had patients who went into kidney failure and would need dialysis treatment. It is small with only four beds but very well staffed with most competent nurses and a variety of machines as per your choice. I saw my nominated specialist on only one occasion in seven dialysis sessions and that was as he walked past me. Dialysing in London was certainly not a culture shock after experiencing dialysis in Australia, which is what you would expect.

The London Clinic was like everything else you buy in London – it was not a cheap dialysis. Depending on the clerk at the counter I had to pay amounts for my seven dialyses ranging from GBP250 to GBP315, ie A\$640 to A\$790. I could never figure out why there were these differences. We just lived with it. Paying by card was OK.

The London Clinic was the only place that wanted a compulsory blood test before you dialysed. Their main concern was with Hepatitis B. Hepatitis C is not a concern to them. The blood test cost GBP95 – definitely not cheap. Although The London Clinic was by far the most expensive dialysis I had on our trip, the quality of service matched the price.

A couple of tips if you are going to London for the first time. Because of cost we ate only once at a restaurant in London. The main reason for this was that we lived near two food outlets (both on Paddington Station) – Sainsburys and Marks & Spencer. At both stores we were able to purchase fresh (not frozen) meals on special at about three pounds 50p. These meals were of very high quality and always on special as they have a brief shelf life.

This is an extract taken from Kylie's 'My Long Overseas Holiday'. Check out her full story on the CRKSG web site at www.crksg.org.au as Kylie visits Paris, Venice, Rome, Florence, Milan, Barcelona, Amsterdam, and Tokyo.

14 Ways You Can Help Fellow Patients Who Have Chronic Kidney Disease

About 13,700 Australians are currently kept alive by Kidney Replacement Therapy that requires either ongoing dialysis treatments or a kidney transplant to sustain life. Many patients who have End-Stage Renal Failure are apprehensive or even frightened about the prospect of living the rest of their life with a chronic disease. The good news is that the therapies used to treat Chronic Kidney Disease (CKD) have improved dramatically, and many patients live long, productive, and extremely rewarding lives.

A knowledgeable patient (knowledgeable about both CKD and the life-saving treatments that they are receiving) is able to actively participate in the decisions that affect their own care, which often leads to more independence and a happier and healthier quality of life.

The challenge that faces many patients is how to find educational information that is developed by patients for patients. Canberra has a "Living With Kidney Failure" program in which experienced patients share their knowledge and experience with new patients. Such programs can help to decrease the fears and anxieties that most new patients experience, while also providing them with knowledge from the most valuable perspective—a fellow patient!

In addition to helping fellow patients adjust to CKD, patients can also educate lawmakers, the media, and the public about dialysis and kidney transplantation. The best way for others to learn about CKD is from us—the patients who are affected! You can help shape how others view CKD, and potentially have a positive influence on the individuals who make decisions about the care that patients receive. The following are 14 ways your efforts can help fellow patients who have chronic kidney disease:

(1) Educate Lawmakers

State and national legislative bills can have a profound effect on the quality of care that is provided for patients on dialysis, thereby positively (or negatively) affecting their quality of life. Like the general public, many lawmakers at the local, state and national levels know little about the dialysis process. A knowledgeable patient can be very influential in helping these elected officials learn about CKD and the impact that their votes have on the care and quality of life experienced by patients with CKD.

There are many ways that you can help to educate your elected officials. Letters and e-mails that provide lawmakers with an overview of important issues that affect patients with CKD—and you in particular—can be very influential. In-person meetings are also very effective. One good way to meet elected officials face-to-face is to attend Town Hall meetings, which are often held locally to allow constituents the opportunity to talk with their elected officials. You can also call the local office of your elected officials and arrange an appointment to discuss important issues that affect the lives and health of kidney patients who are constituents in that lawmaker's district. Remember—lawmakers are elected officials who represent you, and they need to know what issues you feel are important! Contact information for your State Minister for Health, Shadow Minister for Health and Premiere/Chief Minister is available at

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<http://www.kidney.org.au/blog/>

(2) Educate the Media

Patients and family members can act as "local CKD media representatives" to make sure the local media provides information to the public about dialysis and kidney transplantation. The following are some tips on how to educate the media:

- * Use a variety of methods to get the word out about dialysis and transplantation (TV, radio, print).
- * Let your passion and concern about improving the lives of kidney patients guide you.
- * Obtain a current media directory from the library or Internet.
- * Make phone calls to discover the names of health, feature, city or assignment editors of local newspapers and journals.
- * After getting a reporter on the phone, introduce yourself and explain that your objective is to make sure the public understands dialysis and kidney transplantation.
- * Ask the person if he/she has time to talk or if you should call back later (set a date and time).
- * Let the person know you are aware of his/her time limitations. Ask how you can help get a story written and printed.
- * Let reporters and assignment editors know that CKD is a major health epidemic in Australia.

Become a Kidney Health Australia (KHA) Speaker Representative.

(3) Educate the Public

It is important for the general public to know about the risks of kidney disease, including the importance of detecting diabetes and high blood pressure (the two major causes of kidney disease) early, and how to keep these conditions under control. There are many ways that you can get involved in helping to educate the public about kidney disease. Many public service organizations welcome guest speakers (like you!) that provide education about important public health issues such as CKD. You can also write letters to the editor of your local newspaper, particularly if you are responding to an article, film, or television show that mentioned kidney disease. In the letter you can either confirm or correct the information that was presented, relate your own experiences about CKD, and provide advice for others (especially those who are at high risk for CKD). Remember that you are writing about yourself—patients are the best role models for letting others know about CKD.

(4) Get Involved in Professional Organizations so the Voice of Patients with Kidney Disease is Heard

Kidney Health Australia needs your support as evidence to be a true representative body when we seek support to both Government and to funding partners. Please visit their web site at www.kidney.org.au.

(5) Organize "Meet and Greet" Coffee Meetings or a Support Group A restaurant/coffee shop is often an ideal place to organize "meet and greet" coffee or patient support group meetings. Other "free" places where you could hold a meeting include a patient's home or a local community center. These informal gatherings can be especially valuable for new patients, who are eager to hear useful tips on everything from caring for a vascular access to diet and exercise.

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(6) Attend and Participate in Educational Meetings For Patients

Some professional groups partner with patients to organize patient-focused educational meetings. These meetings typically offer an opportunity for patients, family members, and other interested individuals to come together for a full day, share a meal, and hear expert speakers on a variety of topics. Patients are often welcomed as speakers who can share their firsthand experiences with dialysis and transplantation.

(7) Realize that “One Friend Can Make a Difference”

Sometimes just being a friend to one or two fellow patients and sharing with them what you know about dialysis and/or kidney transplantation is enough to make them feel more comfortable about becoming a patient with CKD. New patients in particular often benefit just by knowing that they are not alone and that others share their same worries and concerns. Take the initiative and introduce yourself to a new “patient friend”. Remember—“One friend can make a difference.”

(8) Encourage Organ Donation

There are more than 7,468 people are receiving life saving dialysis. On average they wait four years for a kidney transplant and one will die weekly in this wait. The need to educate the public on the importance of organ donation and its benefits is greater than ever, and you can be a role model and educator to friends, family, lawmakers, the media, and the public.

(9) Participate in Fund Raising

Help raise funds for special educational programs and services that improve the quality of life for patients with kidney disease. Many patients are unable to participate in activities that are costly (be sensitive to the fact that the definition of costly varies for everyone). It is always preferable for patient-oriented meetings to be free-of-charge for patients. However, meetings can be costly and funding is typically required. Often times local businesses, renal care companies, philanthropic organizations, or individuals are willing to provide donations for worthy educational programs. Be creative with fund raising and try to remove money as a barrier to patient education and participation.

(10) Determine if a Clinical Trial is Right for You

A clinical trial is a research study that is used to test new therapies. A clinical trial can be the safest and fastest way to discover treatments that will improve the health of patients with CKD—now and in the future. A typical medical center is often participating in several clinical trials, and some of these trials will involve patients with CKD. Your health care team will be able to tell you about any clinical trials at your facility. However, before you agree to become involved in a clinical trial, understand what the trial is trying to accomplish, the potential benefits of the new therapy, and the potential side effects—make sure that the clinical trial is right for you!

(11) Become an Author

Many kidney-related trade journals and Internet sites (e.g., www.kidney.org.au) are willing and even eager to print articles that are written by patients. Kidney-oriented publications are especially receptive to articles that contain helpful tips that will help improve the quality of life of other

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patients. The Canberra Region Kidney Support Group (CRKSG welcomes articles to be published on its new web site)

(12) Become a Speaker

Sharing your story and point of view can have a dramatic effect on how others view CKD, and many organizations welcome hearing a presentation given by a patient. If you have limited (or no) experience speaking to a group, it is normal to feel a bit anxious. However, you can overcome anxiety and learn how to be a more effective speaker by joining an organization such as Kidney Health Australia (www.kidney.org.au), where you can receive great tips and practice public speaking in a friendly non-threatening environment.

(13) Remember to Always Vote

We see our elected leaders on television, read about them in the newspapers, and occasionally encounter them in person. Most of the time our elected officials are doing the talking: They tell us about themselves, their plans, their policies, and their problems. Election season turns things around. Now it's our turn to speak, and our leaders need to listen. They know that to get our votes they need to understand and respond to our interests and concerns. Make sure that your voice is heard at the ballot box!

(14) Take Care of Yourself

Becoming involved in your own care and improving your own health often inspires others to do the same. Learn all you can about kidney disease and be an active participant in your day-to-day health decisions. Long-term patients know—knowledge is power.

Remember that although we are individuals who happen to have a chronic disease, our lives are not defined by that disease.

Adapted for Australia, from The Kidney Advocacy Network (weKAN), an offshoot of the Renal Support Network (RSN) www.RenalNetwork.org based in the United States.

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.
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**Mobile Phones use In Case of Emergencies**

Telstra have commenced sending messages to more than seven million customers advising them to store ‘ICE’ in their mobile phones. The idea originated in Britain and has attracted international interest.

Mobile phone users are urged to store the contact details of a friend or relative in their handset under the acronym ICE – for use in Case of Emergencies.

Ideally your ICE contact should know your basic medical information, such as blood type and allergies, and be able to help emergency services make decisions if needed. You could also store your blood type under your ICE entry.

The ICE number would allow police and rescue workers to quickly alert family members if someone was involved in a serious accident.



**MEMBERSHIP APPLICATION  
OR  
MEMBERSHIP RENEWAL  
FOR FY 05/06**

Post Application to:  
Canberra Region Kidney Support Group Inc  
ABN: 77 396 063 641  
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

**Signature:**.....

**Date:**.....

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

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| POSTAGE |
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