



Canberra Region Kidney Support Group

Kidney News

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

With assistance from the ACT Government under the Community Support and Infrastructure Grants Program

CRISIS - Is the CRKSG going to Survive?

At the AGM of the CRKSG on Saturday 15 August 2009 there were insufficient nominations to form a new committee. The meeting resolved to put a special resolution to attendees at a meeting at a place, date and time in the near future; that the CRKSG be voluntarily wound up if a new committee cannot be formed. The current committee will continue with caretaker status, until that meeting decides the future of the Group. For the Group to continue, we need to have sufficient people come to the meeting that are prepared to serve on the committee and perhaps represent the Group in other forums, eg. RAMs.

The volunteers taking care of the Group's website and newsletter intend to keep these services going while it is possible for them to do so. The Group would then dispose of its office equipment by passing it on to another charity.

If the Group is wound up, its funds would be passed on to another organisation that would use them for the benefit of the renal community. It would be unfortunate for the Group to cease to exist and it would be a lot of work to establish a new group in the future.

Although it is a low key organisation the Group has had a beneficial influence on the lives of those affected by renal disease and has been a supporter of activism in the renal community. Whatever the future of the Group may hold, as outgoing president I would like to pay tribute to the volunteers that have kept the Group going over the past sixteen years, some of whom are no longer living. I would also like to thank the donors and supporters of the Group, whose encouragement has made much of what the Group does possible.

Finally I would encourage anyone in the renal community who has an interest in the Group to attend the meeting where its future will be decided.

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World Transplant Games 2009



The Gold Coast played host to the 2009 World Transplant games in the last week of August. Pictured is Australian athlete 'Parker' with a promotional beach ball that was prominent in the 'Donate Life Beach Walk' n'Talk' held on the first day of the games. For more details see:

www.worldtransplantgames2009.com.

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In case there is a group of members willing to form a new committee, I can inform them that the organisation is in good order. It is properly incorporated under the ACT Incorporation Act and all its annual returns to the Office of Regulatory Services are up to date. It has an Australian Business Number (ABN). It has Tax Deductible Gift Recipient Status with the Australian Taxation Office. The bank accounts have healthy balances and the Group's accounts have recently been independently certified. To receive postal mail the Group has a long established post office box at Garran Post Office, not far from the hospital. The Group receives phone answering services from SHOUT (Self Help Organisations Uniting Together) and phone messages are promptly forwarded to the Group's email. SHOUT also hosts the Group's email address and provides other email forwarding services. The Group's membership dues to SHOUT are up to date. SHOUT also provides the meeting room to the Group at Pearce Community Centre. The Group is also an up to date member of HCCA (Health Care Consumers' Association of the ACT). HCCA provides training for health consumer advocacy, assistance with lobbying, collegiate support and has a lot to do with ensuring health consumers are represented on committees managing health services and projects.

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HCCA Consumer Representative Training

Health Care Consumers Association have scheduled another training round for **new** Consumer Representatives to be held in September this year. If you, or someone you know, would like to do the training please let HCCA know as soon as possible so we can reserve your place. You can contact HCCA by email at adminofficer@hcca.org.au or give us a call on 6290 1660.

The training will be held on the North side this time at **the Kippax Uniting Church -Auditorium** (*Cnr's of Luke Street and Hardwick Crescent, Holt*). *(Please note new venue!)*

The training will be conducted over two days, Tuesday 8 September and Tuesday 15 September .

Sessions 1 and 2: Tuesday 8 September 10.00am-2.30pm

- ◆ Consumer rights – what are they?
- ◆ Why is it important to have a consumer voice in the health system
- ◆ Overview of the ACT Health System and HCCA's role.

Sessions 3 and 4: Tuesday 15 September 10.00am-12.30pm

- ◆ How to be an effective consumer representative – including how committees work, and tips on how to get your message across effectively.
- ◆ How to build your understanding of the consumer perspective: tools you can use to enhance your representative role.

Refreshments and a light lunch will be provided at each session.

Looking forward to hearing from you soon.

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Most of the renal community served by the Canberra Hospital are familiar with the CRKSG from its newsletter. Those with internet skills may even have ventured into the CRKSG website and might even be receiving newsletters by email. However many people are not aware of the less visible activities of the CRKSG, both past and present.

Active members of CRKSG have always been a reliable source of assistants to Kidney Health Australia and the organ donor co-ordinators, particularly during Kidney Health week and Organ Donor Awareness week. CRKSG members have contributed to the planning and evaluation of Kidney Health week in a number of years and have been members of the Kidney Health Australia consumer representatives' group in the ACT. When the renal education sessions are run at the hospital, CRKSG has often been called upon to make a small contribution to these events. On a few occasions the Group has hosted information sessions itself.

CRKSG has been an early and active promoter of a forum for representatives of patients and their carers to meet with senior personnel of the hospital's renal service. This forum is formally known as Renal Advisory Meeting and more commonly known as RAMs. RAMs is well established now, but there has been a long history of various committees that preceded RAMs under different directors of renal services. CRKSG has always tried to keep momentum behind the idea of patient representation, often during difficult times in the hospital administration. RAMs has achieved a lot for patient welfare since its inception (see the article on RAMs below).

Through its association with the Health Care Consumers' Association of the ACT (HCCA), CRKSG members have been invited to sit on various hospital steering committees that oversee projects connected in some way with improving renal services. The 'Respecting Patient's Choices' committee valued members' input on the matter of the accommodation of organ donation into 'Advanced Directives' (where patients may direct that they are not to be given treatment under certain circumstances). Anyone who has used a vascular catheter to dialyse has benefited from the contribution CRKSG made to the Central Lines improvement project several years ago.

CRKSG also made a small contribution to the drafting of the latest ACT Renal Services Plan. From time to time CRKSG has provided some assistance with the design of surveys, either for ACT Health or Kidney Health Australia.

In the past the CRKSG provided a lot of assistance to home dialysis patients. An indirect effect of members' activism has been to make the home dialysis service more comprehensive. Although there were various schemes at territory, state and federal level to assist patients at home, often the home dialysis patient used to fall into the cracks and had to bear the cost of telephone, electrical and plumbing modifications, dialysis furniture, scales, thermometer, sphygmomanometer, etc. Now much of these are provided as part of a comprehensive system for home dialysis, but originally the CRKSG raised money and helped disadvantaged home patients meet these costs.

In conjunction with the renal social workers the group has provided other assistance to disadvantaged patients. In many cases this has been very simply full (sometimes it was only part, usually 50%) payment or re-imburement of some costs (substantiated by a receipt or invoice) incurred in them getting treatment. By using the social worker as an intermediary, the assisted patient can retain anonymity if they so desire. Some of the more interesting cases the social worker brought to us included a patient on the transplant waiting list whose home telephone had been cut off (before the mobile phone era). The Group subsidised the rental of a 'receive calls only' line until the patient received a transplant. Another case was a home dialysis patient in the country that had everything he needed to dialyse at home and keep running his small property – except a pump to bring enough water to his house. CRKSG contributed to the cost of buying and installing the pump.

Organ Donor Registration

If you are viewing this newsletter on-line, click on the following link to register as an organ donor. Organ donor registration is completely voluntary. If you register you will receive a donor card similar to the one to the right.

<https://www2.medicareaustralia.gov.au/pext/registerAodr/Pages/DonorRegistration.jsp>



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The group has had a quiet time lately. As Canberra has grown, groups with more specific aims, such as Gift of Life, Transplant Australia and Kidney Health Australia's consumer representatives group have become established in the ACT. This is a good thing, even though it has meant the CRKSG has less involvement in some areas. The Group still has much potential and there will always be a need for an organisation that is focussed on local issues and devotes its resources specifically toward the welfare of local patients.

Irrespective of what happens to the Group, the PO box will continue until March 2010, the website will probably continue until July 2011 as the URL, ie. www.crksg.org.au, is paid up until then. Should the Group be wound up, there may well be some changes to the information displayed on the site.

There probably should be no further donations to the Group until it is determined exactly what is going to happen in the future. Donations will be received but donors should be aware that the funds will be transferred to another charity serving the renal community in the event of the Group dissolving.

Patients Get A Voice in First National Survey on Dialysis Delivery

24 August 2009 — Kidney Health Australia today announced it has launched the first stage of a national survey of all kidney dialysis patients to examine barriers and issues affecting the clinical pathway they have experienced in their battle with kidney failure.

Over two hundred kidney patients in Tasmania will be the first to receive the survey this week.

Anne Wilson CEO of Kidney Health Australia said, the projections of numbers needing Kidney Dialysis in Australia over the next 10 years and the current Federal Government's drive to make the health system more efficient will ultimately force the current Rudd Government to review the delivery of dialysis in Australia.

"A nationally coordinated CKD policy on prevention, detection and management is urgently needed to treat more patients with the funds available."

Ms Wilson said "this will be the first national census of people on dialysis where the patients and their families will have a voice and it's designed to inform Kidney Health Australia of appropriate strategic directions in the provision of dialysis in Australia and to assist in providing informed advice to all levels of government".

At the end of 2007, 9,642 people in Australia were receiving dialysis treatment.

Dr Tim Mathew, Medical Director of Kidney Health Australia said, "Dialysis for Chronic Kidney Disease is the most frequent reason for hospitalization".

"In 2007-08, regular dialysis for CKD was recorded as the principal diagnosis in 989,000 (almost 1 million) separations 12.6% of all hospitalization in that year".

"This survey will allow us to better understand dialysis patient's perceptions, experiences and preferences of type of dialysis treatments and settings".

How much does Kidney Failure cost the Australian health system? The best available evidence we have on cost per person per year on dialysis is:

- ◆ hospital Haemodialysis - \$82,764,
- ◆ satellite Haemodialysis - \$48,631,
- ◆ home Haemodialysis - \$44,739,
- ◆ peritoneal dialysis (CAPD) - \$56,828,

The cost of dialysis in 2006 was estimated to be \$646.6 million. On 2005 figures the cumulative cost of dialysis from 2004 to 2010 is expected to be \$4.5 billion.

Calendar of Events

There will be an Extraordinary General Meeting of the Group on a date to be advised. We expect the meeting to be held early-mid October 2009. The meeting is being called to determine the future of the Group. If there is sufficient interest, to elect a new committee. If not, perhaps to dissolve the Group.

All welcome

Renal Advisory Meeting (RAMs) — What is it and what does it do?

R.A.M. was formed some 3-4 years ago to discuss matters of concern among Renal Patients.

Rams consists of the following specialist representatives:

- ◆ 1 Renal Doctor (Chair),
- ◆ 2 Renal Nurses,
- ◆ 1 Renal Dietician, and
- ◆ 1 Social Worker.

The meeting also consists consumer representatives from the following areas:

- ◆ Acute Dialysis,
- ◆ Satellite Dialysis,
- ◆ Northside Dialysis,
- ◆ Peritoneal Dialysis,
- ◆ Home Dialysis,
- ◆ Transplantation, and
- ◆ Carers.

The CRKSG, among others, covers many of the consumer representative positions and advocates for all of them.

Some of the matters discussed and acted upon include, waiting times, permit parking for dialysis patients, nocturnal dialysis, renal ambulance transportation, patient medication management template,

A newsletter, RAM Page, is also produced and distributed to patients.

Chronic Disease Self Management

Having trouble adjusting to life with a long term medical condition? You might even be a carer, partner or friend. Free guidance from trained facilitators is available two and a half hours each week over a six week course. Call SHOUT on 62901984 to ask about 'Living a Healthy Life with Long Term Conditions' or see <http://www.shout.org.au/images/stories/brochure09.pdf>.

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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.