



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

We wish you all
 a Merry Christmas
 and a
 Happy New Year

A Letter to Renal Carers

Support for renal patients and their carers, families and friends has been the first objective of the Canberra Region Kidney Support Group from the time of its incorporation. Since then, the burden on carers for renal patients has been creeping up. This is particularly concerning as the age of the population and carers increases.

As a carer, committee member of the CRKSG and now the carers' representative at RAMs (the Renal Advisory Meetings), I would like to get carers' concerns onto the agenda for RAMs, which are held almost every month. Too often carers are left feeling isolated and unsupported. My own experiences as a carer for a renal patient lead me to believe that more consideration needs to be given to the role of carers. When looking at the concerns of carers it's clear there are some common issues and sometimes carers are being taken for granted by the health system.

Medical information about renal patients is by necessity well organised. But information about their caring arrangements is generally managed fairly informally and neither the shared expectations of carers nor their individual special needs seem to have received much analysis. I hope that carers will contact me and help me become familiar with the caring community; and make up for the shortcomings of the official record. Confidentiality is a serious concern, and I will respect your privacy.

Also, I am asking carers to put forward any suggestions, brickbats or bouquets; in fact anything that affects renal carers in their efforts to care for their charges. I will take these to RAMs or further; anonymously if you wish. With your support I think it will be possible to influence the people that control renal policy in the ACT.

There are a number of avenues available to make your thoughts known to the people that control renal policy in the ACT. An email account has been set up for your use, carers@crksg.org.au. This may be accessed through the Carers section of the Contact Us page of the CRKSG website (<http://www.crksg.org.au>) or entered directly into your email client. You can also write to me at the address on the back

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page of this newsletter. Please mark the envelope Attn. Carers Rep., so that your letter goes directly to me. There are also the quarterly meetings of the Group which will commence in January 2010. You are more than welcome to come along to these meetings and discuss anything that is bothering you about renal care and facilities in the ACT. I would also be very appreciative if you brought your ideas, questions, etc., on paper or send them to me as mentioned above. If you wish to speak individually, please contact me through one (or more than one) of the methods mentioned above and I will get back to you just as soon as I possibly can.

I need to learn who are the carers in the renal community and what can be done to support them. We also need to find out what their needs might be on a more individual basis. Perhaps one size doesn't fit all! Are the expectations of the carers being met? Perhaps we are expecting our carers to soldier on without complaint!

If we are going to achieve anything for carers, you should speak to me and tell me exactly what you think is required. By communicating your concerns to me, we might just be able to achieve something.

So, phone (02 6290 1984) and leave a message, email me at the previously mentioned email address or use the CRKSG website, post a letter to the CRKSG PO Box or come to a quarterly meeting of the CRKSG. The next meeting of the Group is on Saturday 16th January 2010. For details see page 5. Be a part of making a difference for the sake of the people we care for.

Thank you

John Kelly

Organ Donor Registration

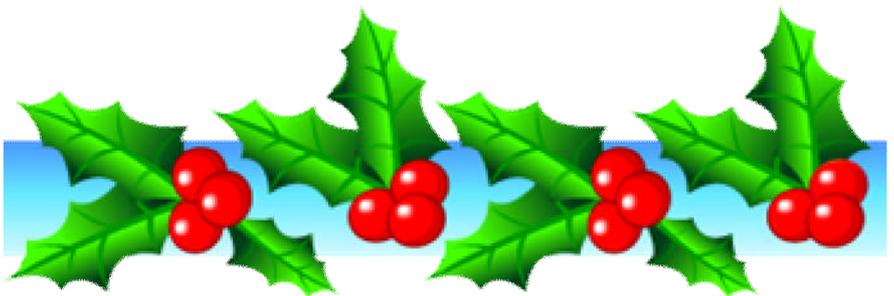
If you are viewing this newsletter online, click on the link below to register as an organ donor. Organ donor registration is completely voluntary. If you register you will receive a donor card similar to the one shown here.

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



A Thought — Carolyn Wells

I love the Christmas-tide and yet,
I notice this, each year I live;
I always like the gifts I get,
But how I love the gifts I give!



Hold a BBQ this Christmas and Win Great Prizes

Christmas is fast approaching, so what better time to get your family and friends together for a BIG RED BBQ. Its simple to take part, just register at <http://www.bigredbbq.com.au/> and you will receive your BBQ pack in the mail.

Then hold your BBQ with your family and friends and raise much needed money and awareness and help the fight against kidney disease. Big Red BBQ has a fantastic **Elite BBQ worth \$7000** on offer, so for every \$50 you raise you will receive one (1) entry into the draw.

You can download fantastic healthy BBQ recipes from the website for free. They will be updating them each week, so you can try them all.

BIG RED BBQ

Supporting Kidney Health Australia

Win a Turbo Elite BBQ

HOST A BBQ

Join the fight against kidney disease and raise awareness by hosting a BIG RED BBQ for Kidney Health Australia. Every \$50 you raise or donate earns you one entry into the draw to win a Turbo Elite BBQ worth \$7,000 from Barbeques Galore!

To qualify, hold your fundraising BBQ any time between September 1, 2009 and February 28, 2010.

Invite your friends, family or workmates around for a BIG RED BBQ. Have fun and join us in the fight against kidney disease!

For more details, to register and to find everything you need to host your own BIG RED BBQ, visit www.bigredbbq.com.au or call **1800 4 KIDNEY** (1800 4 543 639)

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organic fire brand*

KIDNEY HEALTH AUSTRALIA

Vic Permit No. 09/2724

Kidney Health Australia — ACT Consumer Council

The ACT Government is being asked to consider financial support to home dialysis patients to help defray the costs of water and electricity being used by these patients. This is on the basis that each person doing home haemodialysis is saving the ACT Health Budget some considerable amount of money, but those people are incurring quite hefty water and electricity bills in the process. It is now known from experience in Australia and overseas that home nocturnal dialysis provides better health outcomes for renal patients, so as many people as possible should be encouraged to dialyse at home.

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Old kidneys for old folks

Some weeks ago the Fairfax press published a piece from the Health Editor, Julie Robotham headed “Old kidneys for old folk in transplant plan”.

The following is a précis of that item. The “old kidneys” are organs transplant doctors reject. They are considered too old or too unhealthy to give another person a better go at life.

The suggestion now is they may be harvested after death from those in their 60s or 70s for implantation into the elderly suffering from renal failure. The article suggests this may unleash an ethical storm.

“People have been hesitant to recommend the approach in case it’s seen to be discriminatory” in denying people access to the healthiest organs because of their age, said Peter Macdonald, president-elect of the Transplantation Society of Australia and New Zealand.

Transplants were usually carried out in the expectation the graft would last 13 to 15 years, Professor Macdonald said.

“But an older person may be very happy with a transplant that has a good chance of giving them five to 10 years of good quality life.”

A Federal Government paper has suggested that the medical quality of organs available for transplantation will fall as more kidneys are received from older donors. It also says that consideration will be given to whether these should be allocated in another way. This “other way” could apply to possibly the worst 10% of kidneys.

Those older than 70 are not accepted for transplants from deceased donors. Those in their late 60s rarely reach the top of the donor waiting list. This group comprises 1300 of the 10,000 Australians on dialysis.

Last year there were 459 kidney recipients in Australia from deceased donors.

Jonathan Ehrlich, a renal physician at Prince of Wales Hospital, said: “Rather than talking about the life of the kidney per se, you’ve got to think about what sort of function it would provide for an individual. It may still be beneficial for older people because their outlook on dialysis isn’t good . . . anything that’s going to improve in general the supply of organs has to be a good thing.”

Dr Ehrlich said doctors had absolute discretion to accept or refuse any kidneys that became available to their patients, so covert age discrimination was already possible.

“What a doctor bases that decision on, it’s almost impossible to say,” he said.

Tim Mathew, medical director of the advocacy group Kidney Health Australia, said the community should debate the question, which pitted “utility versus equity”. Extracting the maximum functioning time from a donated kidney – which favoured younger, healthier recipients – had to be balanced against fair access to medical treatment for everyone.

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The ACT and federal governments are also being asked to provide support for people who wish to become live kidney donors. Currently 43% of all kidney transplants are from live donors, so if governments removed some of the burdensome costs of live donation, more people might be willing and able to become a live donor.

The allocation protocols for transplantation are currently being reassessed to ensure they continue to be well structured and soundly based. An important matter for renal patients is that the allocation system for kidneys is seen to be sound and fairly based.

Calendar of Events

In an endeavour to encourage more renal community participation, meetings for 2010 will be held on Saturdays at 2:00pm at the Pearce Community Centre, Building 1, Collett Place, Pearce on the dates indicated. Each meeting should only take around 15 or 20 minutes unless there is something of significance to discuss, so come along and put in your two cents worth and perhaps have a tea or coffee along with a biscuit and discuss any concerns you might have.

You never know, you might have some good ideas about what the Group should be doing! Don't forget this Group was set up to support the renal community and we need to know what needs to be done to provide that support.

Meeting dates for 2010 are as follows:

16th January 2010,
17th April 2010,
14th August 2010, and
11th December 2010.

The meeting on 14th August will most likely be the AGM. This will be confirmed or an alternative date will be advised in due course.

All welcome

Dialysis Escape Line Australia Cruises and Tours

Dialysis Escape Line Australia (DELA) organises tours and cruises for dialysis patients.

There are usually one or two cruises each year and one tour to Port Douglas staying at the Sheraton Mirage resort. The next Port Douglas tour is being arranged for the end of April 2010.

There is a cruise to New Zealand next February which is fully booked. There is a further cruise being organised for October 2010. Advertising for this cruise is proposed to commence in the last half of January next year.

To participate in any DELA hosted tour or cruise you need to be a member. Membership can be arranged through the DELA website at <http://www.dialysisescapeline.org/> if you have access to the internet or failing that through their mailing address at PO Box 324, Stepney SA 5069. Requests for information may also be made by email to dele@chariot.net.au. If you wish to speak to DELA they may be contacted on 08 8227 0181.

If as a dialysis patient you are interested in travel, it pays to be a member of DELA because membership puts you on a priority mailing list for all tour and cruise brochures.

You might also have a yen to travel a little further afield, if so, Dialysis Abroad might interest you. Dialysis Abroad organises tours to places such as Bali, Japan, Italy and can be contacted by email at info@dialysisabroad.com.au, by telephone at 0433 285 556 and they can be found on the web at www.dialysisabroad.com.au.



If Undelivered Please Return To:

CRKSG
PO Box 5051
Garran ACT 2605

Phone: 02 6290 1984
E-mail: crksg@shout.org.au
Web: http://www.crksg.org.au



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.