



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

## ACT Quality in Healthcare Awards – 2009

The ACT Quality in Healthcare Awards were established in 2002 to recognize leadership and innovation in patient safety and quality of care. They were also established to publicly honour innovations that improve the delivery of care and safety within the ACT health care system.

The categories where awards were judged were, safety, access and efficiency, innovative models of care, consumer participation and system support.

The Renal Advisory Meetings (RAMs) was a winner in the 2009 ACT Quality in Healthcare Awards in the category, Consumer Participation.

Research has shown the benefits of patient/consumer involvement in health policy and decision making. In 2003 ACT Health published its own consumer feedback standards and in 2004, a policy of systematic management of consumer feedback was introduced for all of ACT Health. In December 2005 the Canberra Region Support Group and the Renal Service recognised a need to develop a renal advisory group. RAMs was established in response to this need and to the above policy. A number of activist staff and consumers had established forums for consumer involvement before this. The introduction of the policy provided the impetus for the establishment of a formal and truly representative forum, with well defined terms of reference and scope of influence.

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The aim of the group was to provide a vehicle for interchange of information between the consumers of renal services and renal staff. The group aimed to:

- understand the needs of all stakeholders in the renal service,
- develop a partnership between healthcare providers and consumers to identify and prioritise initiatives that may improve care and well being
- provide a forum to allow open communication which can result in problem resolution in an informal setting, and
- improve the services provided by ensuring that they are driven and focused on improving outcomes.

RAMs is now approaching four years of age and is firmly established. The inaugural meeting of RAMs was in April 2006. From this and subsequent meetings, the terms of reference, structure and the selection process for consumer representation and other membership was developed.

Membership is sought from a number of areas, including, renal physician (Chair), clients from each of the renal service areas in the ACT, a carer, Kidney Health Australia, Greater Southern Health Service, Renal Dietetics, Renal Social work and Clinical Nurse Consultant from each renal service area.

*(Continued on page 2)*

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The present carer representative is also a committee member of the CRKSG.

RAMs has been instrumental in the development of a strong connection between consumers and the service. Some outcomes of RAMs include:

Implementation of the Renal Resource Room at the Canberra Community Dialysis Centre in Gaunt Place, Garran.

Active contribution to Renal Service Planning Days.

Consumer representation and participation in the Renal Service Presentation to the 2009 Accreditation Surveyors.

Streamlined transport arrangements for patients from NSW attending the Canberra Hospital Renal Service.

The list of outcomes above is just a sample of the achievements of RAMs. The group can claim ownership of a much longer list than that shown above.

## 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**

## Organ Donor Registration

If you are viewing this newsletter on-line, 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/DonorRegistration.jsp>



## How We can Make the Dialysis Experience Better

### Expression of Interest

#### What is this letter about?

I write to invite you to join with us in a conversation about "How We can Make the Dialysis Experience Better".

The conversation will be held on a Sunday, 14 March 2010. The venue will be the Federal Golf Course in Red Hill, Canberra. The conversation will begin at 9:00AM and conclude at 4:00PM to allow for all issues and ideas raised in conversation by the participants to be heard.

There is no cost to you to attend this conversation.

#### Who organised this conversation?

The conversation has been organised by current kidney patients and carers. Your hosts are the patient and carer members of the Renal Services Advisory group. These consumer representatives will be your hosts for the conversation at the Federal Golf course.

#### Who supports this conversation?

The conversation has the support of Renal Services at the Canberra Hospital, ACT Health and the ACT Division of General Practice.

#### Who is invited?

This invitation is extended to:

- all current dialysis patients
- former dialysis patients who have had transplants
- partners and/or carers of dialysis patients
- clinicians involved in the management of renal disease. The clinicians include Nurses, Renal Specialists, GP's, Dieticians and Social Workers.
- administrative staff who are directly involved with dialysis and transplant patients

#### Why are we having this conversation?

We would like to hear from you about the issues that concern you and the ideas you have for improving the dialysis experience.

The issues and ideas discussed will be the ones that you want to talk about.

The people who attend will decide which issues and ideas the group as a whole would like to see progressed as a priority to improve the dialysis experience.

#### What will happen with the issues and ideas discussed?

The consumer representatives will take the issues and ideas you raise to the Renal Advisory Meeting forum.

The Renal Advisory group is where patients and carers meet with Renal Services on behalf of all patients and carers.

We will work on the priorities you identify as our priorities.

Our aim is to improve the care and wellbeing of individuals with kidney disease.

#### What do you want from me?

We are really keen to have you at this conversation. If you would be interested in attending we would like to hear from you.

We will be providing a light lunch as well as morning and afternoon teas. We would appreciate you telling us of any specific dietary needs.

#### How do you respond?

You can let us know of your interest in two ways.

You could fill in the form on the next page and place it in an envelope. When you are finished please hand the sealed envelope to your renal nurse. The nurse will ensure that it is delivered directly to me.

If you can't attend on the day but have an issue that you would like us to know about please complete the form describing the issue and return it as above.

We are keen to hear from you.

#### What happens next?

The consumer representatives will use the information you provide to complete arrangements for our conversation on the 14th of March, 2010.

#### What if I change my mind?

We are asking only for an expression of your interest to attend. We understand that things may change. We will be in touch with you closer to the time to confirm your attendance.

On behalf of all patients and carers on the Renal Advisory group I hope you can attend. We very much look forward to hearing from you.

Regards  
John Scott  
Home Dialysis Representative

## HOW WE CAN MAKE THE DIALYSIS EXPERIENCE BETTER

Invitation to join in a conversation

Sunday, 14 March 2010

### RESPONSE FORM

My name is.....

I will attend      YES/NO

I will be accompanied by .....

Dietary requirements.....

Issue(s) I would like to see addressed:

If you are indicating that you will attend, we recommend you include some additional contact details on this form to facilitate contacting you again about the meeting should the need arise.

## Renal Health Services Plan 2009 – 2014

A draft Renal Health Services Plan has been developed to meet the increasing demand for renal services. ACT Health has asked for feedback on the plan. We recommend that you obtain a copy and provide any comment you might have. Please provide all comments by COB Monday 29 March 2010 to either the postal or email addresses listed on the ACT Health website.

The purpose of the plan is to provide strategic directions for service development to meet this increasing demand for renal services, for the period 2009 to 2014 with a longer term, ten year vision. The plan is in draft format and is available for perusal and can be accessed via the ACT Health website at <http://health.act.gov.au/c/health?a=da&did=10010771&pid=1265605058>.

If you don't have access to the internet you can obtain a copy of the Plan by post from Health Planning, GPO Box 825, Canberra ACT 2601 or by email from [healthplanning@act.gov.au](mailto:healthplanning@act.gov.au). No telephone number is provided on the Health website for this purpose, although we suspect a copy could be obtained by calling the hospital on their regular telephone number (02 6244 2222) and asking for a copy.

ACT Health has asked for feedback on the plan. We recommend that you obtain a copy and provide any comment you might have. Please provide all comments by COB Monday 29 March 2010 by either the postal or email addresses listed above.

The document consists of 45 pages and is too large to include in this newsletter.

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## Hospital Transplant Funding Supported by Kidney Health Australia and International Transplantation Society

**A \$17 million three year program to cover the costs of transplants in Australian Hospitals has been supported by Kidney Health Australia and the International Transplantation Society.**

Anne Wilson, CEO and Managing Director of Kidney Health Australia and Dr Jeremy Chapman, President of the International Transplantation Society, in a joint statement said the program, set up under the Federal Government's Organ and Tissue Authority to improve Australia's level of organ donation, which is among the lowest in the world, is a positive step for the hundreds of Australians waiting for an organ transplant.

**Ms Wilson said, 63% of all organ transplants are kidney-related with an average wait of four years, waits of seven years not uncommon. One person a week on average dies whilst waiting for a kidney transplant.**

**Dr Chapman said the funding from the program was urgently needed to ensure that already stretched resources of 'Intensive Care Units' to treat critically injured people were not diverted to maintain a potential deceased organ donor whilst families made decision on organ donation.**

"By providing the \$17 million of funds the Government is providing hospitals with the ability to look after living patients who are critically ill, and in life threatening situations, whilst still looking after the needs of potential deceased organ donors and their families. Australia is at the leading edge of ensuring ethical care of deceased organ donors and this program further improves the process," Dr Chapman said.

Dr Tim Mathew, Medical Director of Kidney Health Australia, said that kidney transplantation is successful in 92% of cases and Australia has one of the best success rates of kidney transplant survival in the world.



The number of kidney transplants in Australia from deceased donors in 2009 was 446 - the second highest total in the last 20 years and the new initiative could lift this level and give many more people a second chance at life. The number of people waiting on the kidney transplant list at February 1st 2010 was 1291.

**A special church service will be held in Perth on 21st February — to reflect and give thanks for those special people who have given others a second chance of life through the donation of organs and tissues for transplantation.**

Kidney Health Australia said the 3.00pm service at Wesley Church, to celebrate and recognise organ donors who have given the gift of life, highlights the outstanding success of transplantation in Australia.

## H1N1 Influenza Vaccination Program

We have been requested to pass on the following information.



**Health Protection Service**  
Howard Florey Centenary House, 25 Mulvey Street, Holder ACT 2611  
Locked Bag 5, Weston Creek ACT 2611  
Phone: (02) 6205 1700 Fax: (02) 6205 1705  
Website: [www.health.act.gov.au](http://www.health.act.gov.au)  
ABN: 82 049 056 234

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Dear Community Service Organisation

I am writing to inform you about the H1N1 influenza vaccination program, as your organisation may have contact with certain people at a higher risk of catching influenza and/or developing serious complications if they do catch the disease.

The program provides free H1N1 influenza vaccine for everyone aged six months and over, providing protection against the H1N1 influenza virus.

Those at higher risk include:


- o those with chronic medical conditions including respiratory conditions, renal disease, metabolic diseases, cancer, neurological diseases, diabetes mellitus, cardiac disease and those with immuno-suppression.
- o children in special schools
- o Aboriginal and Torres Strait Islander people
- o pregnant women
- o individuals with moderate to severe obesity
- o health care workers, and
- o parents and guardians of children aged 0 to 6 months (because they are too young to be vaccinated).

I am asking that you pass this information to any members of your organisation that may benefit from being vaccinated.

I have attached two letters from the Chief Health Officer, Dr Charles Guest. The letter addressed to *Dear Health Professional* is for your information. The letter addressed to *parents and guardians* may be given to parents and guardians of children that attend your organisation.

If you require any further information on the H1N1 influenza vaccination program please do not hesitate to contact me on 6205 0860.

Yours Sincerely



Sandra Burgess  
Acting Immunisation Coordinator  
Health Protection Service  
ACT Health  
6205 0860  
5 February 2010

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**Chief Health Officer**  
Level 2, 11 Moore Street, Canberra City ACT 2601  
GPO Box 825 Canberra ACT 2601  
Phone: (02) 6205 0881 Fax (02) 6205 1884  
Website: [www.health.act.gov.au](http://www.health.act.gov.au)  
ABN: 62 049 056 234

Dear Parent/Guardian

**Reminder - H1N1 Influenza Vaccination Program**

I am writing to remind you about H1N1 influenza vaccination. This vaccine is available for all people aged six months and over and I would like to encourage everyone to have the vaccine prior to the 2010 influenza season which is expected to start earlier than previous years.

The most effective way to protect your children and yourself from H1N1 influenza is immunisation. Children are effective transmitters of the H1N1 virus, partly because of the nature of their close interactions at childcare, preschool and school.

In 2009, one in five people reported in Australia as having laboratory confirmed H1N1 influenza were children under 10 years of age. One thousand children under 10 were hospitalised, comprising 24% of all hospitalisations for H1N1 influenza in Australia. Importantly, three quarters of all children hospitalised with H1N1 influenza had no known underlying illnesses or medical conditions that made them more vulnerable to this disease.

The H1N1 influenza strain has been the predominant influenza in circulation in the ACT and other parts of Australia since June last year. It is currently the circulating strain in the northern hemisphere and it is possible that there may be a resurgence of the virus after the school holidays with overseas travellers returning to Australia. It is expected that H1N1 pandemic influenza will remain the predominant circulating strain both overseas and in Australia during 2010.

Any person wanting protection should receive the vaccine now, particularly those in priority groups who are more susceptible to complications, or are more at risk of catching the disease. The priority groups include those with chronic medical conditions aged six months and over, children in special schools, Aboriginal and Torres Strait Islander people aged six months and over, pregnant women, individuals with moderate to severe obesity, health care workers and parents and guardians of children aged 0 to 6 months (because these children are too young to be vaccinated).

The vaccine can be obtained from General Practitioners (GPs) and special community clinics. Whilst the vaccine is free your GP may charge a consultation fee. There is no fee to attend a community clinic and this can be arranged by phoning 6207 9977. Children who are 6 months or older, but who have not yet had their 10<sup>th</sup> birthday, require two doses at least four weeks apart to be fully protected.

Further information can be found on the ACT Health web site [www.health.act.gov.au](http://www.health.act.gov.au) under the Influenza Pandemic (H1N1) 2009 link. For further information on the Parvax® H1N1 vaccination program contact the Health Protection Service on 6205 2300.

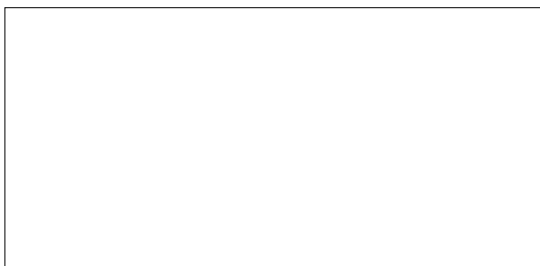
Yours sincerely

Dr Charles Guest  
Chief Health Officer

2 February 2010

**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.