

Canberra Region Kidney Support Group

Kidney News

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

Australia's First Kidney Early Detection Program Starts at Roxby Downs Market Stall

13 November 2007 — A market stall in the centre of the South Australian mining town Roxby Downs will provide the grass roots start of one of Australia's most important primary health care programs.

Kidney Health Australia with the support of the Federal Government and BHP Billiton will launch "Kidney Evaluation for You" KEY an early detection program which will evaluate kidney function, cardiovascular health and diabetes in high risk individuals,

Dr Tim Mathew, Medical Director of Kidney Health Australia said until now a primary health care program for chronic kidney disease (CKD) detection has not existed.

"Australia is urgently in need of a KEY program as approximately 1 in 3 Australian adults are at risk of developing CKD, which is the 7th most common cause of death exceeding diabetes, respiratory disease and suicide.

"CKD is often referred to as the "silent killer" as 80 - 90% of kidney function can be lost before an individual experiences any symptoms. Yet the level of awareness of CKD amongst the general public and health professionals is low and many risk factors of CKD are modifiable.

Dr Mathew said, "The KEY program is a pilot program focused on detecting silent kidney disease in those at high risk with the aim of reducing the chance that they would progress to kidney failure or premature heart attack. The program goes public for the first time at the Market Stall on Saturday morning."

KEY - CKD Early Detection Project Manager Olivia Corso who will man the stall with Dr Mathew on Saturday morning said The KEY project will begin screening participants at BHP Billiton at Olympic Dam on 4th - 8th February 2008. All BHP Billiton employees and their family are invited to participate if you have one or more of the following risk factors:

- Anyone aged over 50 years (>35 years if of Aboriginal or Torres Strait Islander descent)
- Anyone with diabetes

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- Anyone with high blood pressure (on or not on treatment)
- Anyone with a first degree relative (mother, father, brother or sister) with kidney disease.

Dr Mathew and Ms Corso will arrive in Roxby Downs today holding a workshop with local GPs and meeting with BHP Billiton Medical Team, Roxby Downs Health Service, Andamooka Community Health Service and Woomera Hospital.

The KEY pilot program will also take place in Townsville, finishing in Perth during World Kidney Day on 13th February 2008.

Ms Corso said people interested in finding out more about the KEY program and how to take part in the free pilot study to check the health of their kidneys should visit the Kidney Health Australia market stall at Roxby Downs between 8.30am and 12.30 pm on Saturday morning.

Kidney Health Australia www.kidney.org.au

Kidney Health Info Line 1800 682 531 TTY - 1800 005 881

FAST FACTS ON CKD IN AUSTRALIA

Chronic Kidney Disease (CKD) is a significant and growing public health problem, responsible for substantial burden of illness and premature mortality. In Australia, it is a fact that:

- 1 in 3 adults are at increased risk of developing CKD
- A person can lose most of their kidney function before experiencing any symptoms
- 1 in 7 adults have at least one clinical sign of existing CKD
- Approximately 2 million Australians may be affected by early-stage kidney disease and don't know it
- Over 40 Australians die of kidney failure each day
- 11.3% of all deaths in Australia are due to, or associated with, kidney failure
- Deaths from kidney failure have doubled in the past 20 years
- Every day, 6 Australians commence expensive dialysis or transplantation to stay alive
- Most people with CKD will die from cardiovascular causes before requiring dialysis or transplantation
- Aboriginal and Torres Strait Islanders experience excessive death and disability due to CKD
- The dialysis-dependent population has risen by an average of 8% per year over the past decade, and is being fuelled by the ageing population, and Type 2 diabetes epidemic
- There is consistent evidence that with proper medications and management, the number of people with kidney failure can be significantly reduced. However, early stages of kidney disease often go unrecognised, and the knowledge of what can be done to help patients is often not applied.

Read more facts and statistics on CKD in Australia - [Kidney and Urinary Fast Facts](#).

Calendar of Events

Support Group Meetings.

When: Quarterly on second Tuesday of each month.
13th November 2007, 12th February 2008, 13th May 2008 and 12th August 2008.

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

When: 7:30 pm.

All welcome

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 will not have the means to assist those in need, or at worst, is in danger of folding. We have been pleading for a response with little success.



Wishing You All
a Very Merry Christmas
and a
Happy and Prosperous
New Year

The Centre for Health Record Linkage

The Centre for Health Record Linkage (CHeReL) has contacted the Group asking for our assistance in providing information about CHeReL to our readers. The following is provided for your information and for you to take action if you so desire.

At this stage the Group has no policy on providing information to CHeReL and will NOT be providing any personal data from our membership list. If you wish to participate we would suggest you contact CHeReL as outlined below.

Below is a text provided by CHeReL for your information:

Quote

The Centre for Health Record Linkage (CHeReL) was established to support health research, and planning and evaluation of health services in NSW and the ACT. It is a collaboration of the Cancer Institute NSW, the NSW Department of Health, the Sax Institute, the NSW Clinical Excellence Commission, the University of Sydney, the University of Newcastle, the University of New South Wales and ACT Health. The Cancer Institute NSW is the host organisation for the CHeReL.

Information about our health and health care is recorded throughout our lives as we come in contact with the health system. Much of this information is kept in databases by hospitals, health departments and other organisations that provide health care.

The CHeReL provides a service to link health-related databases for research that is for the public benefit. All services provided by the CHeReL have the approval of a human research ethics committee and the database owners, and all personal information that is provided to the CHeReL is kept highly secure and confidential. While the CHeReL holds personal information, such as name and address, it does not store health information, which stays in the original database. A system of numbered keys enables database owners to provide unnamed linked health information to researchers.

Personal information that is held by the CHeReL is used only in accordance with privacy laws, and in accordance with any conditions placed on the use of personal information by the database owners and human research ethics committees.

For further information about the CHeReL please visit our website at www.cherel.org.au, email us on cherel@cancerinstitute.org.au or contact us by telephone on (02) 8374 3515.

Unquote

CHeReL also provided a flyer, a copy of which can be seen via the Home page of the Group's website at www.crksg.org.au.

Give the Gift of Life for Christmas

10 December 2007 — 53% of all organ transplants are kidney-related. The average wait for a kidney transplant in Australia is about four years, with waits of up to seven years not uncommon. One person a week is dying whilst waiting for transplant, according to Kidney Health Australia.

Kidney Health Australia today has urged the Australian community to use the lead up the Christmas, to register as an organ donor and 'give the gift of life'.

Anne Wilson, Chief Executive Officer of Kidney Health Australia, said, "The number of new kidney failure patients commencing dialysis or transplant in 2006 was 2378 representing an increase of 8% from the 2210 people entering these programs in 2005. The number for 2006 was the highest ever recorded."

"This is increasing pressure to lift organ donation rates with kidney transplants making up around 53% of all solid organ transplants in Australia in 2006."

Dr Tim Mathew, Medical Director of Kidney Health Australia, said that kidney transplantation is successful in over 90% of

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cases and Australia has one of the best success rates of kidney transplant survival in the world.

"Sustained funding is needed at a federal and state level to support organ donation in hospitals which are working hard under the current collaborative program to increase the level of transplantation".

"Patients on dialysis and their families are under great pressure waiting for the telephone call which could spell a new chance at life through a kidney transplant."

Kidney Health Australia Launches Patients Poll

13 November 2007 — Kidney Health Australia has commenced an online poll asking patients over 50 or those having diabetes or high blood pressure if they have had their kidneys checked by their local GP in the past twelve months.

Dr Tim Mathew, Medical Director of Kidney Health Australia said, "there are often no symptoms in the early stages of many kidney conditions with patients losing most of their kidney function before they are aware of the problem which overnight will have a dramatic impact on their own life and that of their family.

"The aim of the poll is to alert people in high risk groups to the need for ongoing and clear communication with local GPs over potential Kidney Disease.

Dr Mathew said, giving a written record of your major, past medical and surgical events to the doctor on your first visit is an excellent idea.

"Knowing about your family's medical history is also helpful. If you have a chronic illness, consider keeping a record of your contact with health professionals in an exercise book."

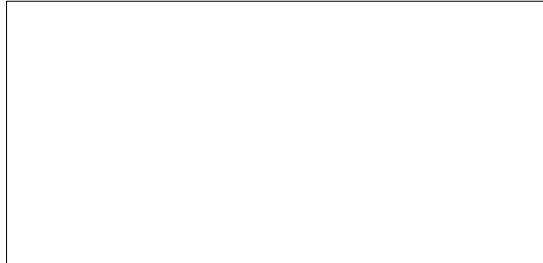
Dr Mathew said that good communication is important and asking questions can make your visit to your GP more useful. Writing down questions and making notes about answers can be helpful when reviewing information after your visit to the doctor. Some of the questions which may help could include:

- Can you describe my condition in simple language?
- How will this condition affect me in the future?
- How serious is this condition?
- Will I need regular check ups?
- What sort of tests will be needed?
- What sort of treatment will be needed?
- Why do I need this test, treatment, surgery or procedure?
- When will I need to start treatment?

The survey is on the home page of Kidney Health Australia at www.kidney.org.

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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.