

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

What is the Canberra Region Kidney Support Group?

The Canberra Region Kidney Support Group Inc (CRKSG) is an incorporated association within the laws of the Australian Capital Territory. It is an income-tax exempt charitable institution, as a patient self-help group, providing support among persons with or affected by renal conditions.

The CRKSG began in 1993 in response to the needs of Renal Patients and their Families. The objectives of the Group are:

- ◆ Provide support to the renal patients and their families and friends.
- ◆ Generate community discussion and understanding of the issues related to organ donation and transplantation.
- ◆ Be actively involved in education about renal disease and renal failure within the wider Canberra Community.
- ◆ Raise funds to assist disadvantaged patients in need of medical equipment, to purchase and acquire equipment to enhance the quality of life for dialysis patients.

Membership is open to:

- ◆ Patients (haemodialysis, peritoneal and transplant), their families and friends,
- ◆ Health professionals, and
- ◆ Health related support agencies or organisations.

Funds:

Our Association is a registered charity and has no paid staff. We are therefore reliant on volunteers, donations and fund raising to continue our services. All donations \$2.00 and over are tax deductible.

Activities

The activities of the CRKSG include:

- ◆ **Newsletter**
To keep members informed about renal issues of interest and to give you

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an open line for comment. Just go to the Newsletters link on the Group's website to view newsletters from the past year or two.

◆ **Fund Raising**

Fund raising enables us to provide assistance to those with difficulties in meeting costs resulting from their treatment. This is arranged in conjunction with the Renal Unit Social Worker.

◆ **Patient Information**

Various resources, including holiday dialysis facilities, and access to a variety of booklets and information.

◆ **Advocacy**

CRKSG has advised the ACT Health Council and is affiliated with the Health Care Consumers Association of the ACT (HCCA) and Self Help Organisations United Together (SHOUT) ACT.

Access to Community Programs

Members have access to ACT Community programs such as:

- ◆ Living a Healthy Life with Chronic Conditions, and
- ◆ Consumer Representative training.

Contacting the Group

The Group may be contacted in a number of different ways. We can be contacted via post, email or telephone. Contact us by:

post:

CRKSG
PO Box 5051
GARRAN ACT 2605,

email:

crksg@shout.org.au, or

leaving a telephone message:

Self Help Organisations United Together (SHOUT) Office during business hours (9:00am - 5:00pm) Eastern Australian Time:

International - 61 2 6290 1984;
Domestic - 02 6290 1984.

Messages left by telephone will result in some delay in responding. The messages are collected from the SHOUT office at irregular intervals.

Should you wish to contact the Group seeking assistance, you should do this via the Renal Unit Social Worker .

Kidney Kids Camps

Kidney Kids Camp is a five-day camp run especially for young people aged between 7 and 17 years, who are affected by kidney disease. The camps cater for approximately 50 to 60 youngsters and are supervised by a similar number of carers.

Camps are conducted in Queensland, South Australia, Victoria and Tasmania. The camps rotate between these states on an 18 month basis.

National Kidney Kids Camp 2009

The National Kidney Kids Camp is on again in 2009 and the wait is not too long. This year Kidney Kids Camp is in Queensland! If you wish to attend, be sure to keep 14 — 18 April free so you can come along and join in all the fun. The camp will be held at Tallebudgera, North Palm Beach.

To obtain application forms or more information - contact Susan.Bruveris@kidney.org.au or phone Kidney Health Australia on 03 9674 4300.



Kidney Health Australia Tees Off Against Hypertension

5 February 2009 — Kidney Health Australia today said hypertension, found in 85% of Australians with failed kidneys, is a major contributor to Chronic Kidney Disease which kills 40 people a day.

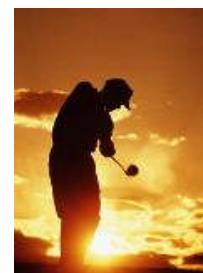
Hypertension can cause damage to the blood vessels and filters in the kidney, making removal of waste from the body difficult.

Kidney Health Australia will launch a national awareness campaign to **OUT** hypertension today at the Kidney Health Australia annual golf day being held at the Kingston Heath Golf Course in Melbourne to **stress the importance of sport, lifestyle, exercise and taking time out to relax to combat hypertension.**

Anne Wilson CEO of Kidney Health Australia said whilst there is no known cure for most causes of Kidney disease, once detected early it can often be managed and treated so people can delay kidney failure and not be forced onto dialysis.

"Our modern lifestyle and pressure of work has placed time constraints on many people to relax, have time out for exercise and also consider the impact of fast food diets which adds obesity issues to the prevention and treatment of kidney disease."

Dr Tim Mathew, Medical Director of Kidney Health Australia said people can prevent hypertension - related kidney damage by keeping blood pressure below 130/80, having your blood pressure checked on a



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regular basis, eating a healthy diet and taking the medication your doctor prescribes.

"For patients who have hypertension and kidney disease, the most important treatment is to control blood pressure with drugs to lower blood pressure and protect the kidneys from further damage."

The cost of treating kidney disease in Australia is rising by \$50 million a year and will jump from \$700 million in 2006 to \$900 million in 2010 - *The Economic Impact of Kidney Disease in Australia*; report was undertaken by the George Institute of International Health three years ago.

Eurobodalla Renal Support Group and Organ Donor Awareness

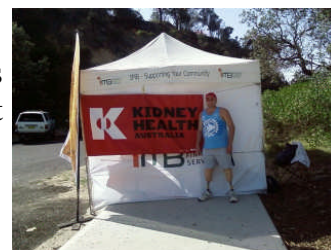
The Eurobodalla Renal Support Group and Organ Donor Awareness was established by Brad Rositer. Brad is a 45 year old living in Batemans Bay on the NSW south coast. He is married to Lorae and they have a son who will be 20 this year.

Brad was a type one diabetic and suffered with the affliction for a long time. He is legally blind and was on dialysis for 7 years and has had both legs amputated.

Brad said, "On 11th May 2007 I received the greatest gift from another Australian that any person can ever receive and that was a kidney and pancreas transplant. So no more dialysis and no more diabetes and I have a completely new life and all is going fantastic".

He also says with his experience and knowledge of what life can deal, he has now established the Eurobodalla Renal Support Group & Organ Donor Awareness.

The Group was invited to attend the Australian Surf Boat Rowers' Championships at Broulee over the first weekend of February. Brad, Lorae and son along with Pat and Sharon Siciliano and daughter took up the invitation and maintained a stall for the duration of the championships. During the championships they handed out more than 1000 organ donor registration forms.



Broulee Stall

The Group found that a rather large percentage of people they spoke to were unaware of the Organ Donor Register. The greatest misunderstanding was of the current laws between States and Territories – a major point was driver's licence versus organ donor register.

The next meeting of the Group is on Thursday 26th February at the Batemans Bay Bowling Club, commencing at 11:30am. Stay for lunch after the meeting!

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>

The printed version of this newsletter contains an organ donor registration form.



Calendar of Events

Support Group Meetings.

When: Quarterly on first Tuesday of each month.

4th November 2008, 3rd February 2009, 5th May 2009 and 4th August 2009.

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

When: 7:30 pm.

All welcome

Eurobodalla Renal Support Group and Donor Awareness

Next meeting: Thursday 26th February at the Batemans Bay Bowling Club, commencing at 11:30am. Stay for lunch after the meeting!

Organ Donor Awareness Week 2009

In the ACT, Organ Donor Awareness Week (AODAW) for this year will be held from 22nd February to 3 March.

This year the theme is Talk, Tell & Transform Lives. Australians will be encouraged to talk to their families and make their wishes clear with respect to organ and tissue donation. This discussion with family is very important so that they completely understand your wishes in the event of your death. It should be understood that one donor can save up to 10 lives.

Australian Organ Donor Awareness Week is the largest public awareness campaign in Australia associated with organ and tissue donation.

The aim of Australian Organ Donor Awareness Week is to raise donation rates in Australia. It is hoped this will be achieved by focusing on the pressing need for organ and tissue donation, by encouraging families to discuss their wishes, by highlighting the very high success rate of organ transplantation in Australia and promoting the registration with the Australian Organ Donor Register. A blank Donor Registration form is included in this newsletter.

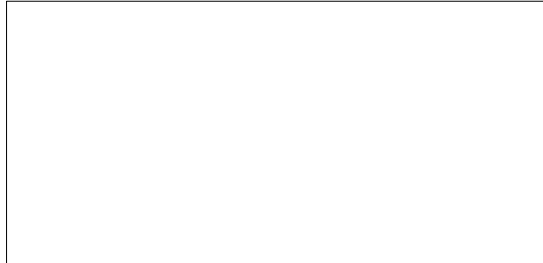
The main community event in the ACT is the Terry Connolly ORGANised Walk. This year the walk will be on Wednesday 25 February at 6.45am from Regatta Point. It's a pleasant walk around central basin of Lake Burley Griffin followed by a free breakfast. The walk is named in honour of Justice Terry Connolly who was a tissue donor. A link to a brochure relating to the walk may be found on the CRKSG website home page (<http://www.crksg.org.au>).

There will also be Other events including a media launch and the presentation of the Chief Minister's Awards for Organ Donation Awareness.

Further details of AODAW activities may be found on the Gift of Life website (<http://www.giftoflife.asn.au>).

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.