



Canberra Region Kidney Support Group

Kidney News

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

Improved Donation Rates to have Far Reaching Effects on Those Waiting for Transplantation

Transplant Australia, the national community voice for organ and tissue donation and transplantation, on Friday, September 23 welcomed a government report which finds that Australia has further potential to almost double its rate of donation.

This is on top of a significant increase in donation over the past two years as the result of the implementation of a National Reform Package including the establishment of the Organ and Tissue Authority.

The Mid-Point Review Report of the Organ and Tissue Donation Reform Package found that future donation rates of 23-25 donors per million head of population were 'potentially achievable'.

In 2010 Australia achieved 309 donors which equated to a rate of 13.8 donors per million. This resulted in the lives of 931 Australians being saved. This is up from an average of 205 donors each year between 2000 and 2008 before the program was implemented.

Transplant Australia Chairman, Dr Alan Amodeo, said the implications of a rate of 25 donors per million would have far reaching effects on the lives of many terminally-ill Australians.

"Transplant Australia encourages the Authority, the DonateLife network and all health care professionals working in organ and tissue donation and transplantation to embrace this report as a springboard for future performance," Dr Amodeo said.

A rate of 23 to 25 donors per million would translate into an increase from 309 donors (2010) to more than 500 donors per year resulting in more than 1,600 organs. This could potentially see:

- The rate of patients dying while waiting for a transplant dropping dramatically as more organs would be available meaning waiting times would be substantially reduced
- The number of Australians transplanted from deceased donors every year reaching beyond 1,600 patients
- A significant reduction in the transplant waiting list (currently 1,575 patients) while the criteria for acceptance on to the list could be expanded resulting in many more patients on dialysis receiving a transplant

Transplant Australia supports the findings in the report that although the Authority has been given a solid pass mark in its first two years of operation, much more can still be achieved.

"We have said all along that hospital cultures are very difficult to change and it is evident from this report that further work needs to be done to ensure that hospitals in every state and territory embrace the reform package," Dr Amodeo said.

"We would also like to see the further development of professional training and education for clinical staff."

(Continued on page 4)

In this issue:

Improved Donation Rates to have Far Reaching Effects on Those Waiting for Transplantation	1
CRKSG Purchases New TV for Renal Outpatients Waiting Room	2
Calendar of Events	3
Walk with Rebecca	3
RAM	3
Honey and Ginger Crisps	4
From the KHA September 2011 Newsletter	5
Eurobodalla Renal Support Group	5

CRKSG Purchases New TV for Renal Outpatients Waiting Room

Some months ago the television set in the Renal Outpatients waiting room of The Canberra Hospital gave up the ghost. The Group was approached by the Renal Unit Social Worker with a view to the Group donating a television set for installation in place of the old set. The Group agreed.

A new set has been purchased. It is a 24" flat panel, full high definition LCD set. The TV has been installed and is in use.

A plaque has been attached to the set. Pictured below, the plaque and the Group's President attaching said plaque to the television.



The plaque attached to the television set.



Chad Tissavirasingham, President of the CRKSG, affixing the plaque to the donated television set

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>

Alternatively register by calling: 1800 777 203.



At the height of a political corruption trial, the prosecuting attorney attacked a witness. "Isn't it true," he bel-lowed, "that you accepted five thousand dollars to compromise this case?" The witness stared out the window, as though he hadn't heard the question. "Isn't it true that you accepted five thousand dollars to compromise his case?" the lawyer repeated. The witness still did not respond. Finally, the judge leaned over and said, "Sir, please answer the question." "Oh," the startled witness replied, "I thought he was talking to you."

Calendar of Events

Quarterly Meetings

Meetings for the Group are held at the Pearce Community Centre, Building 1, Collett Place, Pearce on the dates indicated below. Meeting times will be 2:00pm on each occasion.

Meeting dates for the remainder of 2011 are as follows:

10th December 2011

All welcome

WALK WITH REBECCA

Rebecca Baker, a 21-year old from Mount Gambier has walked from Mount Gambier to Darwin to raise awareness and funds for Kidney Health Australia.

Rebecca was born with bladder exstrophy and had almost 40 operations to combat continuous kidney infections before the age of 14. She is using the walk to raise awareness about kidney health issues.

“Walking from Mount Gambier to Darwin will be one of the biggest challenges in my life, but I am doing it to raise awareness and much needed funds for Kidney Health Australia. Kidney disease and kidney related illnesses contribute to the death of more people than breast cancer, road accidents and suicide,” Rebecca said.

Timothy Mathew, Medical Director of Kidney Health Australia “Early kidney disease causes no symptoms and is often undetected and unrecognised in the Australian population.”

Dr Mathew said that, if detected early, in many cases kidney disease could be treated and well managed.

Donations to Rebecca’s cause can be made at www.everydayhero.com.au/rebecca_baker

Renal Advisory Meeting (RAM)

From the minutes of the September RAM.

A database for transplant follow up is presently being finalised. The new database is designed to assist in generating annual reports for renal physicians and provide better clarification in relation to outcomes. Work is currently progressing on updating the details of over 200 transplant patients.

Education of renal patients is a priority. Tailored education for specific groups, including patients and their carers will be developed.

There are also steps being put into place to provide long-term dialysis outside a hospital setting in a safe and efficient manner. The objective of this is to encourage 90% of patients to utilise services outside the hospital setting. We already have one example with the self-care unit at Weston which is due to commence operation in October.

Other items on the agenda to be considered and developed are:

- Identify a primary point of contact for each dialysis patient to whom questions and requests for assistance will be directed;
- Create a separate education stream for carers; and
- Create a network of existing patients and carers who would be prepared to have new patients and carers referred to them.

Honey and Ginger Crisps

INGREDIENTS - Makes 48 cookies

- ½ cup honey
- ½ cup salt reduced margarine
- ½ cup sugar
- 1 egg
- 2 cups flour
- 2 tsp baking soda
- 1 tsp ginger
- 1 tsp cinnamon
- ½ tsp ground cloves (optional)

NUTRITION

Nutrient	Per serve
Energy (kJ)	501
Protein (g)	2
Fat - Total (g)	4
Carbohydrate - Total (g)	19
Sodium (mg)	82
Potassium (mg)	26
Phosphorus (mg)	19

Thanks to Kidney Health Australia for supplying this recipe.

METHOD

1. Preheat oven to 190°C
2. Cream honey, margarine, sugar and egg.
3. Sift remaining ingredients together; add to margarine mixture.
4. Chill for one hour.
5. Make level tablespoons of dough into balls; flatten slightly with fork.
6. Place 5 cm apart on a greased baking tray.
7. Bake for 10 to 12 mins.
8. Cool on wire rack.

Recipes from a CD entitled, Healthy Eating with the Renal Recipe Bank. Produced by Janssen-Cilag for the Government of South Australia.

Disclaimer: Always consider your individual circumstances when using this resource. The information contained herein is of general nature and is not intended to replace the advice of an Accredited Dietician or Renal Physician. Please consult an Accredited Dietician for individual dietary advice.

(Continued from page 1)

cian groups and we are pleased this has been identified in the report and that the Authority has made it a key strategic priority for this year.”

Transplant Australia will continue to monitor the success of the reform package and in particular the availability of transplantation services, including operating theatres, staff resources and retrieval services, in teaching hospitals as more organs become available.

“Transplant Australia is pleased that the reform package has had bipartisan support at both Commonwealth and State levels and it is crucial that enough resources are in place across the sector to ensure as many Australians as possible have access to life-saving surgery,” Dr Amodeo concluded.

From the KHA September 2011 Newsletter

LIVING KIDNEY DONOR REIMBURSEMENT SCHEME

Kidney transplantation is the most effective treatment for end-stage kidney disease for those people who are suitable. Compared with dialysis, transplantation is associated with improved life expectancy, superior quality of life, and reduced health care costs.

At the beginning of August 2011, 1136 Australians were on the transplant waiting list which represents approximately 11% of the people on dialysis. The average waiting time for a kidney transplant in Australia is 4 years, but waits of up to 7 years are not uncommon.

In 2010, there were 310 deceased donors in Australia (13.8 donors per million population (pmp)), compared with 259 (12.1 donors pmp) in 2008 and 202 (9.8 donors pmp) in 2006. However the number of deceased organ donors will never meet the demand for kidney transplants, and it's for this reason, there is a need to increase the rates of living donors.

While most medical expenses related to living donation are covered by the public health system, live donors do not receive any reimbursement for travel expenses or lost income which can be from 2-6 weeks worth of work.

Kidney Health Australia is supportive of a reimbursement scheme which would reimburse live donors for reasonable and verifiable expenses incurred in the act of live kidney donation. Such a scheme would be carefully regulated in a way that avoided any potential abuse and would ensure the altruism remained the sole focus of live kidney donation. Government-funded live donor reimbursement schemes already exist in many countries including Canada, France, New Zealand and the United States.

Eurobodalla Renal Support Group

Eurobodalla Renal Support Group & Organ Donor Awareness team after training for the Sydney to The Gong bike ride in November.



Flying the Flag for Donate Life on the NSW South Coast.

“Have you spoken with your family about Organ Donation?”

Today is a great day- OK

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.