



Canberra Region Kidney Support Group

Kidney News

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

AMBASSADORS PROMOTE THE GIFT OF LIFE

23rd February 2011

Four prominent Australians were today appointed by the Parliamentary Secretary for Health and Ageing, Catherine King as DonateLife Ambassadors.

Ms King announced that well-known Australians Amanda Keller, Denise Drysdale, Derryn Hinch and Tania Major would help to promote organ and tissue donation as part of the Australian Government’s DonateLife campaign.

Ms King said the DonateLife Ambassadors would play an important role in helping to normalise discussion about organ and tissue donation.

The four ambassadors join the Governor-General of the Commonwealth of Australia, Her Excellency Ms Quentin Bryce AC, who was announced as the inaugural DonateLife Ambassador at the national launch of DonateLife Week.

Ms King said that although the majority of Australians support organ and tissue donation, 40 per cent don’t know their loved one’s views and many do not know how to start a conversation on the subject.

“That is why DonateLife Week is about talking about it today, any day,” Ms King said.

“I sincerely thank our DonateLife Ambassadors for championing the cause and encouraging Australians to start talking about the life-saving and life-changing gift of organ and tissue donation.”

Research conducted by the Organ and Tissue Authority found that young people aged 18 to 29, and older Australians were less likely to have discussed their donation wishes with family members. Men of all ages were less likely than women to have had a discussion with family members about their donation wishes.

DonateLife Week (20-27 February) is part of the Australian Government’s \$151 million national reform of organ and tissue donation, which includes a national community awareness and education program. It promotes the message that ‘Any day is a good day to talk about organ and tissue donation, especially this week because it’s DonateLife Week’.

Find out more about the DonateLife Ambassadors at www.donatelife.gov.au.

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Kidney Census Reveals Patients Need to Know more About Dialysis

18th March 2011

Results from a recent survey conducted by Kidney Health Australia have shown that patients facing dialysis need a greater understanding of the choices available to them.

Kidney Health Australia conducted the census *The Consumer Perspectives on Dialysis: First National Census* to investigate the experiences, perceptions and preferences of people currently undertaking dialysis in Australia. It also aimed to better understand what the barriers may be for undertaking dialysis in the home.

CEO of Kidney Health Australia Anne Wilson said the survey had provided an important insight into what patients knew about their treatment options and how they felt about the process.

She said it revealed patients needed to be made more fully aware of the variety of treatments available and how these different treatments might suit their needs. Ms Wilson said home dialysis for example had shown to be more beneficial for a patient's health and was more cost effective to the health system.

"Hospital dialysis costs the Australian health care system \$79,072 per patient per year compared to \$49,137 for home haemodialysis. Travelling for treatment is also costly for individuals in terms of time and money and at home treatment can be conducted on a more regular basis or even overnight, but of course there are also ongoing costs associated with home treatment."

Ms Wilson said however the survey revealed that many dialysis patients had not even been informed about the option of home dialysis by their renal specialist, while many of the respondents said medical staff had not sufficiently educated them regarding the type of dialysis treatment they were on.

"The results also showed that once patients have become established in their particular form of dialysis, they are less likely to switch modes of treatment, so patients need to be educated and alerted early on in their treatment process about the option of home dialysis and other treatment options," she said.

Ms Wilson said home dialysis however would not suit everyone and would not be able to be managed by every household and patient. "Many people find the social interaction and connection with other people they receive while undertaking dialysis at a public hospital or satellite centre helps them tremendously. What's vitally important is that patients are made to understand the choices they have and how that will impact on their lives."

The Consumer Perspectives on Dialysis: First National Census was undertaken with financial assistance from Amgen, Queensland Health, the Sydney Maxwell Welland Estate (with the support of Equity Trustees), and The Eirene Lucas Foundation.

The full report can be viewed at www.kidney.org.au.

KEY FINDINGS

- Many patients were not given a choice regarding the kind of dialysis they were about to begin, and were also not informed by specialists or renal nurses why they did not have such a choice.
 - ◊ 49% of respondents noted that they were not given a choice regarding the type of dialysis they would receive, and of this percentage, 41% of respondents were not informed as to why they did not have a choice.

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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.



Calendar of Events

Quarterly Meetings

Please note we have previously listed a meeting for 12th March and 11th June. These meetings will no longer take place. Revised dates are shown below.

Meeting dates for the remainder of 2011 are as follows:

16th April 2011,

13th August 2011, and

10th December 2011

Please note, the meeting on 13th August will probably be the AGM. All welcome

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OUR NEW DONATELIFE AMBASSADORS ON THE GIFT OF GIVING

Amanda Keller – Television and radio presenter

I am proud to put my hand up as a DonateLife Ambassador. My family has been touched directly by organ donation. My nephew, who is now a strapping 20-year-old, had only a few months to live as a toddler. He needed a new liver, and to our eternal gratitude, another family going through the worst moment of their lives chose to donate one from their loved one. How do you say 'thank you'? Well one way I can say thanks is to encourage others to have the 'donation conversation' with their families so more people like my nephew get another crack at life.

Derryn Hinch – Journalist and broadcaster

Nothing I say can match the comments made this week by Sonja Brennan. She lost her 18-year-old son Mitchell after a road accident. In her grief a mother made a decision that meant in death her son would save lives as an organ donor. People, like me, who are on the waiting list, can never repay such selfless, life-saving, generosity. All we can say to people like the Brennan Family is 'thank you for such a precious gift. The gift of life'.

Tania Major – Indigenous advocate and 2007 Young Australian of the Year

Your choice now can save a life. I want to encourage every Australian to consider that a simple choice today can make a significant difference to someone else's life in the future. You never know who might need a transplant maybe even you or one of your friends and family.

Denise Drysdale – Television presenter

I am proud to be a DonateLife Ambassador. I have been a registered organ and tissue donor since the 1980s, and have carried the card in my wallet. I've also made sure my family know what my donation decision is. When my mother passed away four years ago, at age 84, I consented for all of her organs and tissue to be donated. They were able to use her corneas to give other people the gift of sight. The decision was easy because I believed so strongly in the good that could be achieved through donation and because I knew it was something she wanted. Just knowing that when you die, you can help somebody to live is a truly amazing thing.

Deville Sausages & Creamy Garlic Mash

INGREDIENTS — Serves 4

- **CREAMY GARLIC MASH** - 2 ½ cups water
- 400 g potatoes
- 30 g butter (salt reduced)
- ½ cup milk
- ½ tsp MAGGI Garlic Stock Powder
- parsley (optional), chopped **DEVILLED SAUSAGES**
- 1 packet MAGGI COOK IN THE POT Devilled Sausages Recipe Mix
- 1 Tbsp oil
- 8 sausages
- 1 onion, sliced
- 1 small apple, sliced
- 1 ½ cups water
- 2 Tbsp tomato sauce



METHOD

1. Prepare the mashed potatoes by bringing the water (do not add salt to the water) to the boil in a saucepan. Add potatoes, bring back to boil and cook 10-15 minutes or until just tender. Drain.
2. While the potatoes are cooking, prepare the Devilled Sausages. Heat oil in pan, brown sausages; drain oil. Add onion and apple to pan; cook 2 minutes.
3. Combine MAGGI Devilled Sausages Recipe Mix, water and tomato sauce. Add to pan; bring to the boil, stirring. Reduce the heat and simmer, uncovered, 10-15 minutes or until sausages are cooked. Stir occasionally.
4. Mash the drained potatoes with a fork or vegetable masher until free from lumps. Beat in the butter and sufficient milk to make a soft consistency. Beat in the MAGGI Garlic Stock Powder and parsley, if used, and continue to beat until the potatoes are smooth and fluffy.
5. Serve with Devilled Sausages.

Tip: Floury potatoes mash well. Look for Desiree, Nadine or Red Rascal varieties.

NUTRITION	
Nutrient	Per serve
Energy (kJ)	2213
Protein (g)	27
Fat—Total (g)	33
Carbohydrate - Total (g)	33
Sodium (mg)	1530
Potassium (mg)	945
Phosphorus (mg)	370

Thanks to Nestle Australia for supplying this recipe.

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.

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- ◇ 48% of respondents noted that they did not have a choice in the location of their dialysis. Of this percentage, 53% were not informed why they did not have a choice. The proportion of patients who reported a choice in dialysis location was lowest in New South Wales (46%) and highest in South Australia (62%).
- Three months or more is considered sufficient time to begin educating patients about their forthcoming dialysis treatment.
 - ◇ 64% of patients were not receiving educational information three months or more prior to their first treatment.
 - ◇ 34% received information less than two weeks before starting dialysis.
- The most commonly reported sources of information about dialysis were nephrologists (80%), specialist renal nurses (36%), education days at Renal Units (33%) and general practitioners (23%).
- Only 13% of patients not currently dialysing at home were prepared to do so. However, 25% were prepared to do so if there was a paid carer, 34% if there was paid nursing support and 31% if expenses were reimbursed.
- The proportion of patients willing to dialyse at home varied between States and Territories:
 - ◇ SA 13%
 - ◇ VIC 16%
 - ◇ ACT 22%
 - ◇ NSW 25%
 - ◇ WA 26%
 - ◇ QLD 28%
 - ◇ TAS 30%
- The proportion of patients who had seen a psychologist was lower for patients who dialysed at a satellite centre or at a private hospital, but was equivalent for respondents who dialysed at home or at a public hospital. Patients who had seen different types of psychological support varied considerably:
 - ◇ 23% Psychologist
 - ◇ 60% Social Worker
 - ◇ 90% Dietician

Eurobodalla Renal Support Group & Organ Donor Awareness Community Awareness & Education Discussion Day's-

The Eurobodalla Group holds many Community Awareness days throughout the year.

Venue — Bridge Plaza Batemans Bay NSW 2536

Time — From 9.30am to 5.30pm

Every one is welcome to come along and have a chat regarding Kidney Health, Organ Donation and Transplantation.

Information available from Kidney Health Australia & Donate Life.

Australian Organ Donor Registration forms available.

Chat with a Dual Organ Transplant Recipient- Kidney & Pancreas

Remember- Every Day is a Good Day to Talk About It!

For further details contact the Eurobodalla Group by email at — ersg.oda2536@hotmail.com

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.