



Canberra Region Kidney Support Group

Kidney News

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

KIDNEY HEALTH WEEK — 2015

The Minister for Health and Minister for Sport the Hon. Sussan Ley MP and Shadow Minister for Health the Hon. Catherine King MP will officially launch Kidney Health Week in the Senate Alcove at Parliament House at 10.00 am on Thursday, 28 May, 2015.

Kidney Health Week, Sunday 24 May to Saturday 30 May 2015, is designed to raise awareness of a disease that affects at least 1.7 million Australians. It is known as the ‘silent killer’ because it has no warning signs, and is related to 54 Australian deaths each day which is more than the deaths from breast cancer, prostate cancer and road deaths each day.



While there has been significant progress in the treatment of Chronic Kidney Disease (CKD) over the past five decades, sadly, the prevalence of kidney disease is rising as is the cost to the Australian people and health system.

The number of Australians receiving kidney replacement therapy (transplantation or dialysis) is growing at about 4% per year and more attention is needed to address this costly public health problem.

Early detection and appropriate treatment may slow progression of kidney disease in as many as 50 per cent of cases.

Kidney Health Australia is committed to tackling this issue by working together with all Governments and the medical community. This year's Kidney Health Week will see the release of our annual State of the Nation paper, while raising much needed awareness of the vital role kidneys play in regulating blood pressure.

Australians at high risk of kidney disease will be urged see their GP for a kidney health check and will be reminded of the vital role community pharmacy plays in promoting KidneyCheck, Australia's first self test for early signs of kidney damage.

KidneyCheck was launched by Kidney Health Australia in partnership with Siemens Australia, Amcal and Guardian Pharmacies in 2014.

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Member

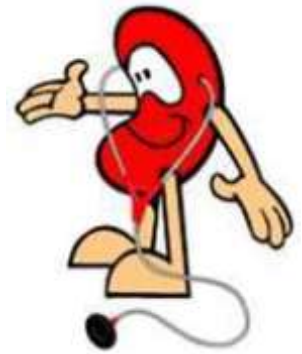


Self Help Organisations United Together

CHRONIC KIDNEY DISEASE INFORMATION SESSIONS

Kidney information sessions designed for people with renal disease and their family and friends are held at Canberra Hospital four times a year. You can talk to people who have had similar experiences and hear about the adjustments they have made in regard to work, life and leisure. The atmosphere will be relaxed and you can ask questions and join in the discussion, if you feel comfortable. Patients and families will have the opportunity to understand the changes that will affect their health and consider what choices need to be made. The program will cover:

- what your kidneys do,
- understanding your blood tests,
- treatment choices you need to make,
- how to improve your kidney function through diet, and
- insights from patients who are current haemodialysis, peritoneal dialysis and transplant patients in an informal discussion.



Should you be interested in attending one of these sessions, please contact Megan Hughes, Chronic Kidney Disease

Vale Jenny Watson — 30th April 1950 – 30th October 2014

Jenny Watson was an incredibly strong woman who spent a life of giving to others around her. But her life was not an easy one.

Having emigrated from England, the hardworking Jenny brought up **4 gorgeous children for the most part as a single 'fun mum'** – a description her children gave her.

Jenny 'overcame' cervical cancer in 1989 however shortly after moving to Queensland in 2005, Jenny's kidneys failed. This meant undergoing a 3 – 4 hour haemodialysis treatment 3 times a week for the next 4 years. While this was a very hard time in her life, Jenny remained positive and never complained.

In 2009 Jenny was offered a kidney transplant. This was an amazing gift and gave Jenny another chance at a fuller life. This also allowed Jenny to meet 3 more of her 6 grandchildren, watch one of her daughters walk down the aisle and visit England with another daughter and partner for the first time in 40 years.

Life was full ... however, there was always space in Jenny's large heart for others.

Jenny was invited to become a consumer member of the Renal Advisory Meeting (affectionately called "the RAM"). At these monthly meetings, Jenny and other consumer representatives actively work with Renal Specialists, renal nurses and allied health professionals to improve



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Vale Jenny Watson

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the 'experience' of people with kidney disease and their carers. The "RAM" continues today and provides an important avenue for patients and carer 'voices' to be heard.

Having a sense that both renal patients and their carers might benefit from having a relaxed environment where they could share, support and learn from one another, Jenny established a Monthly Morning tea. This has been running for about 4 years now and is currently held at the Hellenic Club at Woden. The Morning tea has been a great success and is a legacy to Jenny's contribution in providing a 'safe', friendly and inclusive environment for prospective, new and longstanding patients with renal failure and their families.

Jenny was also a great teacher and loved to share her knowledge, skills and lived experience to assist others. So, when approached to be a co-leader to conduct the Stanford University based course "Living a Healthy Life with Chronic Conditions," Jenny jumped at the opportunity! After a rigorous formal education, mentoring and evaluation program, Jenny co-lead three of these six week courses over a 2 year period. True to form, after each session, you would often find Jenny in deep conversation with one of the participants. There was no end to her giving!

As part of her giving spirit, Jenny also formally offered her skills and time as a volunteer at the dialysis unit at the Queanbeyan Hospital. She was the first. In spite of now needing to use a walker, every week, Jenny would take the bus to Queanbeyan Dialysis Unit where she made up the individual "run on packs" for nurses to use when connecting patients to their dialysis machines. This saved the Unit money but more importantly was something that Jenny could do sitting down, and provided her with the opportunity to talk to the patients and their families. She was 'part of the family' helping distribute morning teas and entertaining everyone with the latest news or photo of one of her beloved children or grandchildren. A memorative plaque will be placed at the Unit this year ... for "Our Dear Jenny" who is greatly missed.

Further Information

If you or someone you know would like to learn more about the supports available for people and their families with kidney failure, or are interested in sharing their knowledge, skills and experiences living with renal failure, please feel free to contact the Chronic Kidney Disease Nurse on (02) 6174 5090.

Acknowledgements

Many thanks to Jenny's family for allowing us to use some of the words from her eulogy to describe Jenny's life. Thanks also to the many clinicians who shared their lovely stories of "Our Dear Jenny".

Written by Joan C Scott and first published in the Queanbeyan Age on Friday 10 April 2015



DonateLifeWeek 2015
SUNDAY 2 AUGUST - SUNDAY 9 AUGUST

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.



KEY ANNOUNCEMENTS MADE TO TACKLE KIDNEY ISSUES

Kidney Health Australia is celebrating two significant announcements made during the same week that Australia used World Kidney Day to focus on the critical issue of Aboriginal and Torres Strait Islander Kidney Health. The announcements indicate both an ongoing commitment to support for living donors, and an increased focus on funding critical research.



At its Parliamentary Breakfast to mark World Kidney Day, supported by the Australian and New Zealand Society of Nephrology (ANZSN) and Close The Gap Campaign Steering Committee, Kidney Health Australia was encouraged to hear the issue of organ donation raised. "Noting the importance of organ donation to the kidney sector, including live organ donation, Kidney Health Australia was very pleased to hear the Assistant Minister for Health, Senator the Hon Fiona Nash, confirm the Government's ongoing commitment to supporting organ donors," said Ms Anne Wilson, CEO of Kidney Health Australia.

"Kidney Health Australia welcomes the Government's announcement that organ donation efforts will continue to be supported through key measures, including the Supporting Leave for Living Organ Donors Programme, going forward," she continued.

"This is particularly heartening to hear, as the initial trial of this important and successful scheme ends this June, and the announcement signals an ongoing commitment to continue the scheme on a more permanent basis, giving much needed certainty to future live organ donors." The announcement earlier in the week of \$10,141,300 to fund critical medical research, which will investigate ways to improve the lives of those living with chronic kidney disease, has also been applauded.

"This announcement is a big step forward in tackling the growing problem of kidney disease," said Ms Wilson, "This research will inform healthcare decisions made by clinicians, policy makers, and patients and cover the full spectrum of kidney disease, from its earliest stages through to dialysis and transplantation."

The grant, the largest ever awarded in Australia to the kidney sector by the National Health and Medical Research Council, is recognition of the increasing burden of kidney disease on Australia's health system.

"Kidney disease is truly an insidious disease that affects thousands of Australians — indeed, 56 Australians die each day from kidney related disease — so it is critical we find ways to increase early detection, improve treatment options and ultimately the quality of life of patients," said Dr Tim Mathew, Kidney Health Australia's National Medical Director. The funds will bring together leading researchers with a broad range of skills, clinical expertise and international networks to investigate high priority actions in tackling the disease, how to manage likely risks, and conduct economic evaluations of the most effective and innovative treatment options.

"What's particularly critical here is that this research draws in the 'best of the best'; previous experience in leading international trials, the Australia-New Zealand Dialysis and nt Registry, and those with strong experience in medical guideline development," said Dr Mathew.

A highlight of the new research is that it will build on, and benefit from, existing Kidney Health Australia initiatives — such as the KHA-CARI guidelines, ANZDATA, and the Australasian Kidney Trials network

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KEY ANNOUNCEMENTS MADE TO TACKLE KIDNEY ISSUES

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(AKTN) — and provide pilot funding for new research ideas and build a stronger workforce, all focused on tackling kidney disease in Australia, and abroad.

"As the national peak body that works to improve the lives of those living with kidney disease, and one that has itself provided \$30 million over the last 40 years to kidney research, we believe this research will make a big difference," said Ms Wilson, "This announcement goes a long way to addressing the previously low levels of research funding and focus that kidney disease has historically received."

"I would like to congratulate Professor Jonathan Craig, from the Children's Hospital at Westmead and the University of Sydney, in securing this grant," continued Ms Wilson, "In addition to this work, he is a Director on Kidney Health Australia's Board, where he remains a tireless advocate for patients with kidney disease, and their families."

"Professor Craig has brought together leading kidney researchers Professor David Johnson, Professor Jeremy Chapman, Associate Professor Stephen McDonald, and Associate Professor Carmel Hawley, to participate in this project."

The project is unique in that it will be able to span the entire research translation pathway — from Australia's world-class platforms in registries (ANZDATA), systematic reviews (Cochrane), trials (AKTN), as well as guidelines and implementation (KHA-CARI) — to maximise health outcomes. "Kidney Health Australia would like to thank all of the Members of Parliament, the ANZSN, the Close The Gap Campaign Steering Committee, for their ongoing support and focus on these critical issues." Kidney Health Australia is a national health care charity with a vision 'to save and improve the lives of Australians affected by kidney disease'. As the national peak body, Kidney Health Australia promotes good kidney health through delivery of programs in education, advocacy, research and support.



Beef Steaks with Spanish Onion Sauce

INGREDIENTS - Serves 4

- 4 small potatoes, mashed
- 2 tsp salt reduced margarine
- 4 pieces of steak 2-3cm thick
- 1 Tbsp salt reduced margarine
- 1 medium Spanish onion, cut into wedges
- 2 Tbsp sherry
- 1 tsp fresh thyme, chopped
- 1 MAGGI Brown Onion Gravy Mix
- boiling water
- freshly ground black pepper
- 1 tsp balsamic vinegar (optional)
- 4 medium zucchinis, steamed



METHOD

1. Heat 2 tsp salt reduced margarine in a heavy-based frying pan. Add the steaks.
2. Cook over a moderately high heat for about 2-3 minutes per side for medium-rare steaks.
3. Remove from the pan and keep warm.
4. Add 1 Tbs salt reduced margarine to the pan.
5. Add the spanish onion and cook, stirring occasionally, for 4-5 minutes.
6. Add the sherry and thyme.
7. Cook for a further 1 minute.
8. Place the gravy mix in a measuring jug. Make up to 1 cup with boiling water, whisk until smooth, then add to the pan.
9. Bring to the boil, stirring constantly, then simmer over a low heat for 2 minutes.
10. Season with black pepper and stir in the balsamic vinegar if desired. Spoon the sauce over the steaks.
11. Serve with mashed potato and steamed zucchini

NUTRITION

Nutrient	Per serve
Energy (kJ)	1820
Protein (g)	46
Fat - Total (g)	19
Carbohydrate - Total (g)	18
Sodium (mg)	330
Potassium (mg)	1080
Phosphorus (mg)	426

Thanks to Nestle Australia for supplying this recipe.

TIP: Fillet, sirloin, scotch fillet or rump steaks are all suitable.

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.

Calendar of Events

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

Proposed meeting dates for 2015 are as follows:

- 13 June, (large meeting room)
- 12 September, (AGM?) (small meeting room) and
- 5 December. (small meeting room)

All welcome

RAM Morning Teas at Hellenic Club, 10:30 to 12:00 —

Thursday 14th May,
Wednesday 17th June,
Thursday 16th July,
Wednesday 12th August,
Thursday 17th September,
Wednesday 14th October,
Thursday 12th November, and
Wednesday 16th December

Eurobodalla Renal Support Group

The Eurobodalla Renal Support Group & Organ Donor Awareness.

Present — A Community Awareness Event.

“Find Out Friday

When- Most Fridays

Venue- Bridge Plaza. Batemans Bay.

Time- 9.30am to 5.00pm

We urge all Australians to take the time to register as Australian Organ and Tissue Donor's.

Are You Registered?

Australian Organ Donor Registration forms available.

And then

Make sure you “Have The Chat That Save's Lives” because your family & love ones must agree with your decision if they are ever asked before your organ & tissue decision will proceed.

On Display Donate Life “The Book of Life”

Chat with Brad Rossiter — Dual Organ Transplant recipient – Kidney & Pancreas and Double Leg Amputee.

For more information visit — Donate Life. www.donatelife.gov.au and Kidney Health Australia. www.kidney.org.au

“We look forward to seeing you there”.

Brad & Lorae Rossiter.

M- 0458534470

Co-Chairs & Founders.

Organ Transplant Recipient- Kidney & Pancreas.

2012 Eurobodalla Shire citizen of the Year.



Brad and Lorae at the Hawk Cup



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 address shown at the top of this page.

NOTE: This form may also be used to notify a change of address/contact details.



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>