

Canberra Region Kidney Support Group

Kidney News

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

New report confirms dialysis patient transport woes: Kidney Health Australia

New research conducted by Kidney Health Australia, published in the current issue of *Renal Society of Australasia (RSA) Journal*, highlights that patients living with kidney disease often suffer from inadequate transport support.

The 'Challenges in methods and availability of transport for dialysis patients' report surveyed Australian renal units around the nation, with staff at the coal-firming that the transport system for dialysis treatment is inconsistent, has variations in availability and leaves many patients significantly out of pocket.

The journal article highlighted that dialysis patients are often slugged with high parking fees at hospitals, and those relying on transport support can struggle to obtain assistance to return home after dialysis treatment. The situation is often exacerbated if their treatments are outside regular business hours or fall on weekends.

Kidney Health Australia CEO and Managing Director, Anne Wilson, said that addressing transport issues will go a long way to benefiting kidney consumers, their families and the health system.

"Transport is a factor that affects patient treatment choices and quality of life. Dialysis is a necessary and lifesaving treatment, and we know that transport is one of the biggest burdens on both renal units, and patients," said Ms Wilson.

"Dialysis patients are unique as they require ongoing treatment three times a week, every week. For those too unwell or unable to drive themselves, a strong and reliable transport system is critical to maintaining their life saving treatment."

"The report identified that half of all patients seeking assisted transport have difficulty getting to, or from treatment. For those who are able to drive, they face high parking fees – especially in the large cities – of up to \$15 per treatment. For some-

(Continued on page 3)

In this issue:

New report confirms 1 dialysis patient transport woes: Kidney Health Australia

New Exercise Program Helping Dialysis Patients

2

Chronic Conditions Seminar Series:Trannsport Options for Ageing and Disability

Mini Pavlovas with Mixed Fruit and Toasted Coconut

Calendar of Events 5

Eurobodalla Renal 5 Support Group

Member



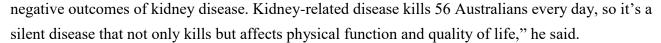
From the KHA December 2015 Newsletter

New Exercise Program Helping Dialysis Patients

Deakin University and Western Health Melbourne researchers have launched an Australian-first exercise program to help fight the debilitating physical side-effects often experienced by people undergoing dialysis treatment. In partnership with Kidney Health Australia, resistance bands and exercise guides are being sent to every one of Australia's 300 dialysis treatment units at more than 100 Australian hospitals.

Deakin and Western Health Professor Paul Bennett said despite almost 12,000 Australians receiving dialysis treatment, the importance of exercise was often overlooked. "The combination of chronic kidney disease and sitting on dialysis – for four to five hours, three times a week – causes people to deteriorate physically at an alarming rate," Professor Bennett said.

"Exercise has been shown to improve physical function, quality of life, muscle condition and the dialysis treatment in patients, as well as decreasing depression, cardiovascular risk and a range of other



Further information and resources will be found on the Kidney Health website soon at kidney.org.au.

For detailed information regarding packs please contact Professor Paul Bennett at p.bennett@deakin.edu.au.



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.





CHRONIC CONDITIONS SEMINAR SERIES

GETTING AROUND: TRANSPORT OPTIONS FOR AGEING AND DISABILITY

PRESENTERS:

- Robert Altamore & Craig Wallace, People With Disabilities ACT
- Tom Valentine, Team Leader, Flexible Bus Service
- Jane Thompson, Policy Manager, COTA (Council on the Ageing) **ACT**
- Fergus Nelson, Chief Executive Officer, Just Better Care



Thursday 18 February, 2016 7:00 - 8:30 pm at SHOUT Building 1, Pearce Community Centre, Collett Place, Pearce



FREE TO ATTEND, NO RSVP REQUIRED

These seminars are aimed at anyone who has a chronic condition, however, if you are a carer or other interested party you are more than welcome to attend.

You are invited to a forum about transport options for older people, people with a disability or chronic conditions, hosted by People With Disabilities ACT. A panel will outline some of the transport programs, assistance and services available for people with disability and others who need assistance.

The Chronic Conditions Seminar Series is organised by the following not for profit organisations: Arthritis ACT (incorporating Osteoporosis ACT), ACT ME/Chronic Fatigue Syndrome Society, RSI & Overuse Injury Association of the ACT, Epilepsy ACT, MS Australia (ACT office), Pain Support ACT, People with Disabilities ACT, Mental Health Foundation ACT & Diabetes ACT.

For more information contact the SHOUT office on (02) 6290 1984

Dialysis patient transport woes

(Continued from page 1)

one on dialysis, this may add up to almost \$2,300 a year," she added.

- "Having parking provided or reserved for dialysis appointments would go a long way in reducing patient out of pocket costs, and a coordinated approach in establishing databases of transport services to identify access issues would be a good first step.
- "Sadly, almost half of those surveyed during the research indicated a lack of subsidised transport for rural patients as a key concern.
- "We often forget that treatment for end stage kidney disease is not just dialysis," said Ms Wilson, "It's a routine, a minimum of three return trips a week, every single week. Every extra hurdle, every extra cost takes its toll – we need to think about the patient's journey, and work smarter to support them."

The full journal article is now available online. For further information on Kidney Health Australia's advocacy work regarding patient transport issues, visit kidney.org.au.



Mini Pavlovas with Mixed Fruit and Toasted Coconut

INGREDIENTS - Serves 8

- 4, 1cm thickslices Bethonga Gold pineapple, cut into chunks
- ½ Mini Me® yellow seedless watermelon and/or Mini Me® red seedless watermelon, cut into chunks
- ½ Bethonga Jazz rockmelon (green) and/or Bethonga Harmony rockmelon (salmon), cut into chunks
- 4 egg white
- 220g (1 cup) caster sugar
- 1 tsp vanilla essence
- 2 tsp cornflour
- 1 tsp white vinegar
- 1 passionfruit
- 300ml whipping cream
- 30g (1/3 cup) desiccated coconut



METHOD

- 1. Line 2 baking sheets with baking paper and draw 8 10cm circles on them. Turn paper over. Preheat oven to 150°C (300°F/Gas 2).
- 2. Put egg white in a clean, grease-free bowl and whisk using electric beaters until soft peaks form.
- 3. Gradually add sugar, a tablespoon at a time, whisking well after each addition to ensure sugar dissolves, until mixture is thick and glossy. Fold in the vanilla essence, cornflour and vinegar.
- 4. Spoon mixture onto circles, flattening them slightly. Reduce oven heat to 140°C (275°F/Gas 1). Bake for 1 hour. Turn oven off. Leave for a further 1 hour with door ajar.
- 5. Meanwhile, scoop pulp from passionfruit and push through a sieve to remove seeds.
- Whip cream until soft peaks form, then fold in passionfruit juice. Chill until needed.
- 7. Heat a dry frying pan over medium-high heat. Add coconut and cook, shaking pan constantly until coconut is golden. Remove from pan immediately.
- 8. Top each meringue with cream and fruit and scatter with toasted coconut. Use within 30 minutes.

NUTRITION		
Nutrient	Per serve	
Energy (kJ)	829	
Protein (g)	3	
Fat - Total (g)	6	
Carbohydrate - Total (g)	37	
Sodium (mg)	35	
Potassium (mg)	137	
Phosphorus (mg)	23	

Thanks to Perfection Fresh 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.

Calendar of Events

Meetings for the Group are held on Saturdays at 2:00pm. Venue and dates for 2016 to be advised.

All welcome

Proposed meeting dates for 2016 are as follows:

TBA

RAM Morning Teas at Hellenic Club, 10:30 to 12:00 — Thursday 18th February, Wednesday 16ty March, Thursday 14th April, Wednesday 18th May, Thursday 16th June, Wednesday 13th July, Thursday 18th August, Wednesday 14th September, Thursday 13th October,

Wednesday 16th November, and Thursday 15th December.

Eurobodalla Renal Support Group

The Eurobodalla Renal Support Group & Organ Donor Awareness are thrilled to bits to bring you-

"Find Out Friday"

When- Most Fridays!

Where- The Bridge Plaza Batemans Bay

Time- 9.30am to 5.00pm

Donate Life *The Book of Life* on display.

Visit <u>www.kidney.org.au</u> and <u>www.donatelife.gov.au</u> for kidney health & organ donor information.

Talk with Brad Rossiter kidney & pancreas organ transplant recipient, double leg amputee & legally blind.

Organ Donor Registration forms available.

Register today & "Make sure you have the chat that saves lives"

Contact Brad Rossiter for more details or to arrange an informative & educational Guest Speaking engagement.

Best Regards,

Brad Rossiter

m. 0458534470

Inspirational Guest Speaker Kidney & Pancreas Organ Transplant Recipient Double Leg Amputee. Legally Blind. Citizen of the Year 2012 Eurobodalla Shire. Batemans Bay Local & Community Advocate





Brad & Lorae



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 am All donations \$2 or more are tax deductible. Cheque/Money Ord this application for membership of the Canberra Region Kidney	ler payable to CRKSG Inc. Please accept
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.



Canberra Region Kidney Support Group

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