



Canberra Region Kidney Support Group

Kidney News

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

Amazing Race Winner Tyler Atkins Promotes Kidney Disease Research

Amazing Race winner Tyler Atkins has signed up to receive phone services from charity telco provider, KHA Comms, that directs all its profits to Kidney Health Australia.

After winning the first series of *The Amazing Race Australia*, Tyler and team-mate Nathan Joliffe took a surfing holiday in Bali to keep the outcome a secret before the final episode.

Tyler, who has a kidney related disease himself, described the service which has just over 1000 users as a “tremendous innovation” that will enable him to help other kidney sufferers while talking on his phone.

Tyler described the service that provides home and mobile services as a fantastic way for all Australians to make a contribution to an important cause.

“That’s what being a real Australian is all about—standing up for our mates,” Tyler said. “We have too many people, including young people, dying of kidney disease. We have to do something about this silent killer”.

All profits from KHA Comms go directly to the charity. Competitive rates mean people are able to save money while supporting health research and easing the burden on those with the disease at the same time, according to Kidney Health Australia.

CEO of Kidney Health Australia Anne Wilson said: “There are 10,000 people in Australia on dialysis and that means they spend up to 6 hours a day three or four times a week hooked up to a machine. Through providing dialysis patients a discounted phone service we are helping to reduce their costs while keeping in contact with their family and friends.”

KHA Comms now has more than 1000 customers, with this number increasing daily.

Derek Finch from KHA Comms said “Initially our current supporters joined seeing KHA Comms as another way to offer help. After they realised they were saving money, the word started to spread and we are now signing up customers with no previous links to Kidney Health Australia which is great.”

In this issue:

Amazing Race Winner Tyler Atkins Promotes Kidney Disease Research	1
Recent Graduations from the ANU	2
Calendar of Events	3
Discuss Organ Donation with Your Family	3
Beef Hot Pot	4
From the KHA August 2011 Newsletter	5
Eurobodalla Renal Support Group	5

Recent Graduations from the ANU

Two members of the renal community were surprised to meet each other at the graduation ceremony held at ANU on Friday 15 July. Robert Little received a Bachelor of Laws degree and Vince Maguire received a Diploma in Asian Studies.

Robert, (pictured right) was born in 1973 with obstructive reflux nephropathy (posterior urethral valves).

He first started Continuous Ambulatory Peritoneal Dialysis (CAPD) at age 12 – at the time the youngest in the ACT – and had his first living related donor transplant from his mother in 1987 aged 14.

In 1996 he commenced haemodialysis and then received a living related donor transplant from his father in 2002.

Robert currently works for the Department of House of Representatives Committee Office. Robert is the Chair of the DonateLife Principal Advisory Committee and the Transplant Consumer Representative on the Renal Advisory Meeting (RAM).

Proving that kidney failure need not hold you back Robert has Degrees in Arts (Honours in Political Science), Asian Studies and Law from the Australian National University. He also has Graduate Diplomas in Applied Finance and Investment and Financial Planning from the Securities Institute of Australia.

Since his transplant in 2002 he has travelled extensively in United States and Europe.

Vince, (pictured right) retired on medical grounds from the Australian Public Service in 2004 (I'll have to check this) after 21 years of service. He was diagnosed with renal disease whilst a university student in 1980. After graduating in Science he joined the public service in 1983, where he was retrained in Computer Science. He commenced dialysis for the first time in 1987, continued to work full time and received his first transplant in 1990.

His first transplant lasted seven and a half years. During this time he was able to study German after work and received a ZDaF (Zertifikat Deutsch als Fremdsprache) from the Goethe Institut. He travelled briefly in Germany.

He recommenced dialysis in 1997 and had to reduce his working hours, then eventually retired in 2004. He received a transplant from a DCD donor in 2008 after a wait of more than ten years.

In retirement, his fiancé helped him to travel on many occasions to her native country, Thailand, where he dialysed at a number of Thai hospitals over a number of years. He studied Thai at ANU and was eligible for his Diploma in Asian studies in 2009, but didn't attend a graduation ceremony until July 2011, the same month that his fiancé - now his wife of many years - came to stay permanently in Australia and was able to attend the ceremony.

Vince has had a close association with the Canberra Region Kidney Support Group over many years and has helped produce many editions of this newsletter. He represented Northside dialysis patients at Renal Advisory Meetings at times in the past when he was still a dialysis patient.



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

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

Discuss Organ Donation with Your Family

As part of the new national reform of organ and tissue donation, the family of every potential donor will be asked to give their consent to donation if the situation arises. The request will be made only by trained health professionals.

Even if you have registered your wish to be a donor, your family will still be asked to give consent. However, families that do not know the wishes of their loved ones are less likely to give their consent.

Current statistics show that a third of Australian adults had not informed their family of their wishes. A quarter had never discussed organ and tissue donation with anyone close to them. Around half of Australian families could not recall having been told

the wishes of their family members.

Some of the reasons people give for not discussing donation are:

It's not my family's business

Yes it is. Your family will be asked to give consent for you to become a donor when you die.

I'll think about it. Later.

Most people who become donors die suddenly and unexpectedly.

I don't have time. I'm too busy.

It does not take long to register your wishes on the Australian Organ Donor Register and to have a discussion with your family.

My family won't understand.

Organ and tissue donation is a sensitive subject. The decision to become a donor is a personal and important one. To make the right decision for yourself, you need to have the facts so that your decision is informed. Your family might also need time to discover the facts and make their own decisions. Discuss organ donation with them. It is important that members of your family know each others' wishes.

For more information on discussing organ donation with your family, visit the [DonateLife](#) website. You may register for organ donation by accessing the organ donor website using the link or calling the telephone number on Page 2 of this newsletter.

The foregoing is an excerpt from the DonateLife "Discuss Organ Donation" fact sheet.

Beef Hot Pot

INGREDIENTS - Serves 8

- 1 tablespoon polyunsaturated oil
- 2 onions, chopped
- 1.5 kg lean diced casserole beef
- 1 teaspoon crushed garlic
- 2 tablespoons grated lemon zest
- 6 carrots, sliced diagonally
- 2 x 400g cans tomatoes
- ½ cup beef stock (Masset salt-reduced)
- 2-3 tablespoons corn flour (approx.)
- Freshly cracked pepper
- 2 tablespoons chopped parsley
- 4 cups cooked rice



METHOD

1. Heat a little oil in a deep-sided pan on high and fry onions until browned. Remove and put aside.
2. Heat a little more oil on high. Brown beef in small batches, removing each batch before adding the next.
3. Return beef and onion to pan.
4. Add garlic, lemon zest, carrots, tomatoes (with their juice) and stock. Stir to combine.
5. Reduce heat to low, cover and simmer (cooking gently at a level where tiny bubbles rise to the surface) until fork tender, about 2 hours. Stir occasionally.
6. When ready to serve, check consistency and seasonings. If required, thicken with cornflour blended with a little water. Season to taste with some freshly cracked pepper.

NUTRITION

Nutrient	Per serve
Energy (kJ)	1836
Protein (g)	56
Fat - Total (g)	8
Carbohydrate - Total (g)	32
Sodium (mg)	280
Potassium (mg)	1010
Phosphorus (mg)	519

Recipe supplied by Meat & Livestock Australia

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.

From the KHA August 2011 Newsletter

RESTLESS LEGS SYNDROME

Restless Legs Syndrome (RLS) is a condition that causes uncomfortable and unpleasant sensations in the legs causing the urge to move or kick your legs. It occurs in up to 50% of people on dialysis or in the months before dialysis starts but often disappears over time. It was considered to be a form of inflammation in the nerves of the legs but is now believed to be due to a chemical disturbance in the brain related to toxins retained in kidney failure.

The symptoms can be distressing and cause loss of sleep. People with RLS get an uncomfortable feeling in their lower legs that is more marked at rest and gets worse as the day progresses. The feeling goes away when the legs are moved purposefully.

RLS is more common in people with diabetes and anaemia, and can sometimes be corrected with iron supplements even if there is no evidence of iron deficiency. There is no special test to diagnose RLS but sometimes sleep studies are helpful in excluding other conditions. The initial treatment should not involve special medications. All people with RLS should be treated with iron replacement therapy. Other approaches described as helpful include:

- Regular mental activities such as crosswords and Sudoku
- Avoidance of aggravating factors such as caffeine, alcohol and nicotine
- Massage
- Warm baths
- Exercise

For more information regarding RLS, please visit www.rlsorg.au or download the "[For Patients](#)" guide on the Kidney Health Australia [website](#), and, of course, speak with your doctor.

Eurobodalla Renal Support Group

All Welcome, , , ,

"Get Together Lunch"

When- **Sunday 28th August 2011.**

Next anticipated- **11th December 2011.**

Venue- **Club Catalina Sports & Leisure
Princess Highway, Batemans Bay**

Time- **12.00 noon**

Come along & meet like minded people for a friendly, easy chat.

For full details contact

Brad & Lorae Rossiter

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Note- Lunch at Regular Club Prices

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.