

KIDNEY COMMUNITY *Issue 8*

From the Health Services Manager - WA



Last month Kidney Health Australia's 43rd birthday was celebrated on 9 August, the date the organisation was first registered in 1968. After a simple post on Facebook highlighting the day, over 100 Facebook family members sent us Happy Birthday greetings. Our Facebook profile can be found via the name – Kidney Health Australia – and its family now includes 921 'friends' with this group growing daily.

Just as our Facebook friend numbers are getting bigger, our Kidney Community continues to grow! We're delighted to welcome all our new readers and in this issue we will highlight some of the fabulous work happening in Western Australia. We've also got some great pictures from our special friends who participated in the annual Kidney Kar Rally and our consumer story this month comes from Wayne in Victoria. Remember, this newsletter is for You ... so we'd love to hear your story too!

Cheers Jenny Duggan

The theme for the 2011 BIGRED BBQ is "Target 10,000". Kidney Health Australia is aiming to get 10,000 registrations for the BIG RED BBQ this year to help us reach our goal of touching Australian households with our message about kidney disease. You can register at www.bigredbbq.com.au and it costs just \$10 and for that you will receive:



- A Healthy BBQ Recipe Cook Book
- Free "Our Card" discount card
- Entry into the draw for our major competition and a BBQ pack

With Summer fast approaching, this is the ideal time to have a BBQ with family and friends so why not do it for a cause? Even if you can't hold a BBQ, you can still support us by registering for \$10 to receive our great offers above.

For any questions regarding our BIG RED BBQ campaign, please contact Joshua Donchi on 03 9674 4310 or email bigredbbq@kidney.org.au

TeleConnect Peer Support Program

TeleConnect provides support to people living with kidney disease, kidney donors and recipients, their carers and family members by connecting them with trained Peer Support Volunteers who have similar experiences, through a national telephone and/or email peer support service. If you are interested in becoming involved in this program please contact Matty Hempstalk at matty.hempstalk@kidney.org.au

Medical Matters with Dr Marie Ludlow... *Living Kidney Donor Expense Reimbursement Program*



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, 1,136 Australians were on the transplant waiting list. This 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 recent years the rate of organ donations from deceased donors has increased.

In 2010 there were 310 deceased donors in Australia (13.8 donors per million population (pmp)), compared with 247 (11.3 donors pmp) in 2009 and 259 (12.1 donors pmp) in 2008. However, the number of deceased organ donors will never meet the demand for kidney transplants. Therefore, there is a need to increase the rates of kidney transplantation by increasing the number of living donors.

Single kidney donation is the most frequent living donor procedure as most people can live a normal, healthy life with only one kidney. Last year, 292 Australians donated a kidney to a loved one. However, the rate of live donations decreased 18% in the past two years. The reason for this is unknown but it is possible financial considerations are having an impact. Studies overseas have found 45% of living donors experience some financial hardship and 24% of potential living donors chose not to donate because of anticipated financial hardship.

While most medical expenses related to living donation are covered by the public health system, living donors do not receive any reimbursement for travel expenses or lost income while they recover. It may take anywhere from 2 to 6 weeks before a donor can return to full duties, whether it be paid employment or responsibilities in the home.

Kidney Health Australia believes the Government should introduce a living kidney donor expense reimbursement program to reduce the financial burden on donors. Government-funded living donor reimbursement schemes already exist in many countries, including Canada, France, New Zealand, United Kingdom and the United States. Implementing such a reimbursement scheme in Australia would mean better support for patients and families of living donors.

An increase in living kidney donation contributes to better outcomes and quality of life for people living with kidney disease as well as reducing the burden on the health system with fewer people requiring dialysis. If you would like to be involved in advocating to Government on this issue please contact Kate Johnson on 03 9674 4316 or kate.johnson@kidney.org.au

2011 Kidney Kar Rally

This year's Kidney Kar Rally has been another huge success, with a few adventures and lots of laughs. Competitors started in Wagga Wagga and travelled up through NSW to Port Macquarie where everyone enjoyed a great lay day to rest and recuperate and then headed back down finishing in Cowra.



Congratulations to **Kar 11 "The Blues Brothers"** on winning this year's rally. The Kidney Kar Rally raises much needed funds for Kidney Health Australia's Kidney Kids Programs.

This year the top 3 highest fundraisers were:

1. **Kar 68 – Artline Kitchens**
2. **Kar 8 – Bathurst Surf Lifesaving Club**
3. **Kar 46 – Team Iddy**

A big thank you to all the officials and supporters of each car who helped make this year's rally the biggest yet. Together, the cars raised over \$510,000.



Next year's rally will be our most adventurous yet with cars starting in Mandurah, just south of Perth, travelling across the Nullarbor and finishing in Bendigo.



To enquire how to participate or support the rally, please contact Joshua Donchi on 03 9674 4310 or email Joshua.Donchi@kidney.org.au



Quotes of the Month

"Live like there is no tomorrow! Constantly move forward and appreciate the motivation for your existence! It has cause! It has meaning! It has reason! Never give up and never look back! Choose to make a meaningful difference in your life and the life of others. Do it every day and DO IT BIG" - *Unknown Author*

"How your day goes is all about your perception and positivity. If you have it in mind that nothing can stop you, it simply won't...just believe and follow through with this mindset."

- *Unknown Author*

Victorian Consumer Profile Wayne McGlone



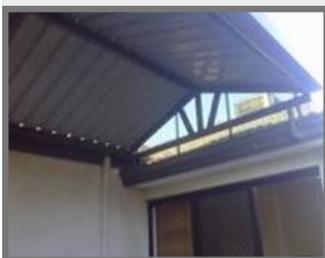
Hi, my name is Wayne McGlone. I have polycystic kidneys; it is a hereditary disease that was passed on to me and my sister from my father. Dad had kidney failure in the 70s and ended up with a transplant that worked for 20 years. It's funny, dad had six brothers and the disease is nowhere else to be found in the family. Because of what I observed with my dad's illness when I was a boy I was terrified of dialysis and of kidney failure. The 70s were early days in renal treatment. When my father found out that I had polycystic kidneys he was very upset but we discussed it and both agreed that it was better to have lived than never to have lived at all. Anyway around three and half years ago I was told that I needed to go onto haemodialysis as my kidney function was down to less than 5%. At first I was sent to various dialysis centres until a spot became available for home haemo training. I was appreciative of this as I thought it was going to be difficult to continue to hold onto my job going to dialysis centres three days of the week.

I work full time, have four children various ages from 8 to 24 years and enjoy playing guitar and blues harp in a cover band and a contemporary Christian band. Doing home dialysis has meant that I haven't had to sacrifice my work or the things that I love to do. My wife Deborah has been terrific support assisting me along the way. Last year my family and I went to Queensland for a two week vacation. During this time I did dialysis at a local private hospital. I have met some very inspirational people, patients, Kidney Health staff, nurses and doctors on my journey living with chronic renal disease. There is a community of people working together to meet the challenges. Treatment has certainly come a long way since the 70s. I'm sure that researchers will one day find a cure for polycystic kidneys which will help future generations of my family. About two months ago my sister had a successful kidney transplant. In my family we are all very happy for her and so grateful to the donor family. My family having had two transplants really know how wonderful and special the gift of organ transplantation is. I'm also on the list. So cheers to you all, to life and living!

DATA ... Who Are We?

The Dialysis and Transplant Association of Victoria (DATA) is a charity run by volunteers, who all have Renal Disease, and is based in Blackburn, Melbourne. DATA was started in the 1970s as a support group. Over the years DATA has grown and is now well known throughout the Victorian renal community. Not only does DATA run two holiday houses (as discussed in a previous *Kidney Community Newsletter*) but also offers a bi-monthly magazine called *Shoestring*, which promotes activities, tells stories from DATA members and provides interesting information from the renal medical side, along with recipes. DATA activities include a summer BBQ at DATA headquarters, Christmas in July, the DATA Annual General Meeting, and the DATA Christmas BBQ (which this year is being held at the Melbourne Zoo). DATA also has a scholarship program for children with kidney disease or children of people suffering kidney disease who are members of DATA. Applicants who have completed Year 7 to 11 can apply and must submit 12 months of their school reports together with a written essay on their chosen career. Up to three scholarships are awarded annually at the AGM. Membership for DATA is only \$10 a year. For more information: www.datavic.org





FAITH Housing in Morley WA obtains funding from PEACH

In February 2011, Waroona WA residents Ted and Margaret Russell moved into one of the Kidney Health FAITH houses that are available for country and interstate patients who are having kidney transplants. Ted was very

fortunate that his loving wife Margaret was compatible and the transplant was carried out on 23rd February 2011.

When Margaret and Ted came out of Sir Charles Gairdner Hospital, they moved into the FAITH three bedroom house in Thorpe Street, Morley whilst they recovered and attended the Renal Clinic for regular check ups. During the Russell's staying, they found that the current lounges were extremely uncomfortable. Soon after the operation, they contacted friends and had two recliner rockers dropped off on a loan arrangement. Both houses had ideal outdoor courtyard areas but because they were not covered, and with the weather being extremely hot in March 2011, they could not avail themselves to sit outside as there was a high risk of getting sunburnt. Because the television in the house, being some years old, struggled with the conversion over to digital reception, they elected to purchase a new television for this house as a donation to Kidney Health Australia in appreciation for the use of the house and facilities.

Ted made contact with Jenny Duggan and suggested that if Kidney Health Australia were interested in obtaining some funds to upgrade the facilities, he would assist with an application to People Employed by Alcoa Charity Help (PEACH). Ted is a long serving employee of Alcoa World Alumina at the Pinjarra Refinery and, as many other employees, a contributor to the PEACH fund. An application was designed to obtain funds to cover the installation of gable roof patios over the courtyard areas of the two houses (enabling protection from the elements) and to purchase two leather recliner rocker lounge suites and one 81 cm full HD LCD TV (with built in DVD). The application was successful and funding was approved to the value of \$12,000. In mid July, the patio refurbishment was completed and the lounges and TV/DVD were purchased and installed.

Many thanks to the PEACH committee for supporting this worthwhile application as numerous country and interstate patients staying at the FAITH houses will benefit. Also many thanks to Ted and Margaret for their generous donations and also for facilitating the grant. Ted and Jenny have received positive feedback from recipients from the country who have been fortunate to utilise the new comfortable additions to the FAITH houses.

THE WA BIG RED WALK

SUNDAY 16TH OCTOBER

VARIETY PAVILION—SAW AVENUE—KINGS PARK,
PERTH

A Letter from Lulu...

Representing the Renal Support Group of South West WA



As the local peritoneal dialysis

nurse, I became increasingly aware of the lack of support available for kidney disease sufferers in the South West. Sufferers are isolated at home, some self-administering dialysis. After numerous requests from patients as to how others manage to lead normal lives, Ron and Ray hurried me along to launch the first meeting in January.

It was discussed and decided that the emphasis would be on getting to know each other with regular get-togethers in Busselton or Bunbury. Events would be social, self-funded, voluntary and would not involve fundraising. A newsletter is posted to 90 known renal disease sufferers every couple of months and the existence of the group is spreading.

Christmas in July was organised by Maurice and held in a room generously provided by St John of Gods Hospital. Santa visited, food was donated by those attending, and each person received a gift. We did a sing along, told stories of kidney disease and had a laugh. The group is attracting pre-dialysis clients, PD, HD, transplant recipients, as well as donor families, giving the group plenty to discuss.

The aim is to encourage everyone with kidney disease and their family to be involved, take on a small task or help someone else. The group is self sufficient in its support of each other in an attempt to improve understanding of renal disease. If you have renal disease and live in the South West of WA please join us, we want to hear your story. I can be contacted on 0417182811.

Regards, Lulu Paxton

State	Upcoming Events	Date
National	ANZSN 47th Annual Scientific meeting Adelaide conference centre.	Sept 19th - 21st
WA	Renal support Group of SW WA meeting contact Lulu 0417182811	Sept 25th 10am - 12pm
WA	Big Red Walk contact Colin 08 9381 9311	Oct 16th
NSW	Eurobodalla Renal Support & Organ Donor Awareness, Bridge Plaza Batemans Bay contact Brad 0458 534 470	Sept 2,9,16,23,30
QLD	Brisbane KHA support Group Meeting, Norman Park Bowls Club contact Matty 0404 177 748	Sept 7th 10am
VIC	Kidney Kids Capers	Sept 24th & 25th
SA	Kidney Kids Capers	Oct 8th & 9th

Recipe of the Month: Savoury Corn Fritters

Ingredients (Serves 6) :

1 cup self raising flour
1 egg
1/2 cup corn kernels
1/2 cup cream style corn
2tbsp red capsicum, finely chopped
oil for frying

Nutritional Info Per Serve

Energy	748kj
Protein	4 grams
Fat	8 grams
Carbohydrate	23 grams
Sodium	280mg
Potassium	95mg
Phosphate	202mg



Method:

- Mix flour, egg, corn and capsicum
- Heat oil in pan
- Drop in tablespoons of batter forming six fritters
- Fry each side over medium heat for 2-3 minutes until lightly browned
- Garnish with red capsicum