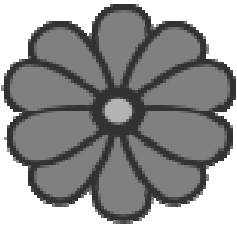


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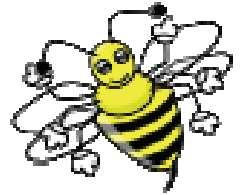
*Kidney News Of Wellington*

Wellington Region Kidney Society

November 2008



SUMMER EDITION  
REST AND RECOVER  
Especially our committee!



## Slow Survey Warning!!

Our ongoing phone survey is a bit behind schedule but is proving a very valuable exercise with members really taking time to give us their views. We can tell that even with the partial input we have gathered so far the society will be well placed to better reach it's goal of supporting the renal community. Most of the delay has been to do with producing the script and dealing with the fact that three of our committee members have had spells in hospital in the last few months. We are having a few difficulties with wrong or missing phone numbers. If you haven't heard from us by Christmas could you consider sending us your phone number by email, or leaving a message on the answerphone? If you won't be able to receive a call we have written a survey which can be posted or emailed to you.

Many people were confused as to when their membership is due and would like us to help them work it out. We've taken the latter on immediately and if this circle  is coloured your membership is overdue. We have also decided to return to a calendar year membership, with subs due in January. New subscriptions paid after the 1<sup>st</sup> October will gain the whole following years membership. We will not stop sending newsletters to members who are delaying payment to fit in with the calendar year.

Valentine BBQ replaces Christmas party this year

You are all invited to the Wellington Region Kidney Society BBQ on Saturday 14 February 2009 whether it is wet or fine. Please drop in to 290 Rintoul Street, Berhampore, Wellington on 14th February 2009 for our annual gathering. The BBQ will be operating continuously, so join us at any time between 12:30 and 4:30pm for as long as you feel like staying.



Come and meet fellow renal patients and supporters in a relaxed summer atmosphere on a (hopefully!) sun-drenched deck. This year, the Valentines Day Drop-In BBQ replaces the normal WRKS Christmas Party – so you have plenty of time to get it into your diaries. BYO drink and a contribution to the BBQ. See you there!

## Letter from the President

Isn't it fantastic that summer is here? As I am writing, it is one of those exquisite Wellington evenings – warm but not too hot, a gentle spring breeze (not a howling nor'westerly wind!). Makes you glad to be a Wellingtonian!

It has been a busy few months in the life of WRKS. Recently WRKS was one of the charities adopted by the Australian High Commission for their 2008 Melbourne Cup fundraising event. It was a terrific afternoon and WRKS benefited by just under \$1500. I would like to thank the Acting High Commissioner to New Zealand, Mr Frank Ingruber, for being such a fantastic host for the Society.

We also hosted a coffee morning at Margaret Stewart House in mid-October. It was a great opportunity to meet other renal patients and share experiences with managing our disease. I really enjoyed learning about other renal patient's experiences and I learnt a number of things about managing kidney disease that I didn't know before. Thank you to all those who organised the morning and those who shared their experiences with others.

As outlined in our last newsletter, we have started our telephone survey of WRKS members about the services we might look to develop for members and patients in the future. We haven't made as much progress in the survey as we hoped to make – in our last newsletter we anticipated that we would complete the survey over October and November, whereas we now expect that we will be able to contact everybody by the end of February 2009. I want to stress that we are committed to getting your views – it will just take longer than we originally thought.

One of the things that has become very clear over the last few months is that we are so reliant on a relatively small number of volunteers to support the work of our part-time patient liaison officer. With many of those volunteers themselves facing the health ups and downs of kidney disease, our base sometimes seems very fragile indeed. If you are able to help out in any way with the work of the Society, please phone or email any Committee member, myself or Sandra.

Finally, I would like to thank Rachel Middleton who has been acting as our patient liaison officer since September 2008, while Sandra Lallemand has been taking well-earned parental leave since the arrival of her second baby. Rachel has been doing a fantastic job, and has been instrumental in moving our October coffee morning and our member survey along. While we are delighted that Sandra will be returning to the Society in mid-December, we will be sorry to lose Rachel's energy and enthusiasm. Thank you Rachel.

I wish you all a very merry Christmas and a wonderful New Year.

Michael Papesch

**President WRKS**



## Your Taupo Holiday Home has had a make over!

If you haven't used the WRKS dialysis home for a while you might be pleasantly surprised as in the last year the three bedroom house has had new carpet and a lovely new lounge suite which were both purchased and installed with the support of the Lakeland Lions Club of Taupo. You can also look forward to a new queen sized bed, purchased with donated Barter Card points. The dialysis room has a near new king single from a friend of the society. We are also very grateful to Craig Smith and Vicky StClair who have replaced the stove.



The WRKS holiday house in Taupo has a GAMBRO haemo dialysis unit and dialysis users can make priority bookings. Anyone can use the house, helping us to pay the bills, and there are special rates for members of WRKS, NZKH, and sister societies. It is lovely and warm in the winter so consider having a break outside the busy summer period. For more information or reservations, contact:

Alan and Margaret Griffith at 04 9049884 or [amgriffith@clear.net.nz](mailto:amgriffith@clear.net.nz)

## An Introduction From the



## Kidney Patients Network

*WRKS' vision is to help renal patients to achieve the best quality of life, as close to a normal life as possible. There are many ways for this to occur, and many channels through which it can happen. We are delighted to include the following introduction from the Kidney Patient Network (KPN). WRKS and KPN will be working together to ensure that we complement each other in supporting kidney patients and their families.*

“KPN has recently formed as a support group and resource for patients. As kidney patients ourselves, we listen to patient's needs and help to meet those needs. Our goal is to provide finances and resources to those who have been diagnosed with kidney failure and those on dialysis for costs that are not already covered by the New Zealand health care system. We have “**Get Togethers**” the last Friday of the month (except December) 1.30pm @ the Steak House, Cobham Court, Porirua, outside the dialysis unit. Get togethers are open to anyone with kidney failure or a transplant. Please call Lana Schmidt 977 9194 to confirm the meeting or learn more about KPN.

Our current fundraiser is the **KIDNEY WALK** Saturday 14 February to Saturday 21 February. A Journey of Hope for Kidney Patients. Tana Fatu will be walking from Porirua, Wellington to Palmerston North and back. He will be walking 400K over 7 days to raise funds for kidney patient's needs. We have many generous sponsors including Michael Jones, a former All Black who will be available for interviews and autographs at the end of the walk. He is also doing an interview on the Good Morning Show in February to promote the Walk. On the 21<sup>st</sup> of February we will be celebrating with free blood pressure checks from the Whitereia nursing students, free Just Water and lots of other giveaways, food, music, and more. Come & join us for a fun day!”

For information about future “Get Together's”, events and how the Network can help you, contact Army Onosai, Chairman, 238 4123 or Text: 021 121 9609

Email: [army-lee@hotmail.com](mailto:army-lee@hotmail.com)

Check out our website: <http://kidneypatientnetwork.wellington.net.nz>

## **WRKS DONATES NEW TELEVISION FOR DIALYSIS TRAINING ROOM**

In September this year the Society donated a new 21 inch television for the haemodialysis training room at Margaret Stewart House. The previous television had broken down some months earlier and had not been replaced as Capital and Coast DHB do not supply televisions. Having some entertainment can be an invaluable support for haemo patients, be they in training or using dialysis on an on-going basis. The television was purchased using the proceeds of bequests to the Society from the families of Ken McLeod and Terry O'Sullivan. We were sorry to hear of their passing, but pleased to have been able to use their bequest to the direct benefit of new haemodialysis patients.

CCDHB have tentatively approached the Society to purchase TVs for the new haemodialysis unit in the new Wellington Hospital. We are awaiting further details of what the DHB requires before considering their request further. We have been asking you your views on this as part of our survey and so far most people are in favour.

## **BRILLIANT!!**

The Wellington Region Kidney Society and the Wellington Zoo were selected to be the two charities of the Australian High Commission's annual 2008 Melbourne Cup fundraising party. Invited guests, some decked out in full racing day attire, came to the commission on Tuesday 4 November 2008. At the gala, attendees paid a minimum \$5 donation at the door, and the High Commission staff ran a range of sweepstakes on the race, in addition to charity auctions on donated goods.

This year the High Commission raised just under \$3,000, which will be split evenly between the WRKS and the Wellington Zoo. The WRKS benefited by just under \$1,500 from the event. The proceeds were handed over to Brendon Veale of the Wellington Zoo and Michael Papesch, President of the WRKS, by Mr Paul Irons of the High Commission at a ceremony the following week.

At WRKS we are extremely grateful to the Acting High Commissioner, Mr Frank Ingruber, who hosted the event, and to all of the staff at the High Commission for so enthusiastically running the sweepstakes and other fundraising activities at the gala. Special mention should be made of Mr Paul Irons and Mr Ian Franca who brilliantly co-ordinated our involvement in the gala, and made sure everything went smoothly for us on the day.



Photo shows Paul Irons (right) presenting Michael Papesch with the donation

## **The Gap between Organ Supply and Demand**

*The following is a summary of an article in the Economist magazine of 11 October 2008, about the pressures faced world-wide in meeting the demand for transplantable organs, including the world-wide shortage of kidneys available for transplant. This article raises some uncomfortable issues, but issues that need to be an on-going focus of the whole renal community in New Zealand. WRKS does not necessarily endorse some of the policies reported in the Economist article, but we have reported them because they raise a number of issues and options that readers may be interested in.*

### **The size of the supply-demand gap**

Last year more than 7,000 Americans died while awaiting an organ transplant – almost double the number of American soldiers killed in Iraq since 2003. The World Health Organisation has found that, worldwide, only one in ten people in need of a new kidney manage to get one. The worldwide problem has been exacerbated by a fall on road toll deaths in rich countries (such as NZ) which (along with strokes and heart attacks) have historically been the main source of transplant organs.

There are currently about 100,000 Americans on waiting lists for a range of organs, with 4,400 being added every month. Presently just under 2,500 transplants of all types are carried out each month in America. In Britain more than 7,600 are waiting for various organs, up 50% on a decade ago.

The supply-demand gap has created some unwanted and undesirable consequences. Organ-harvesting scandals now rage in India, where the sale of organs used to be legal but is now banned. One doctor has been accused of luring Indian labourers into his clinic with job offers, but who were then offered up to US\$2,000 to part with a kidney. Some who refused are said to have had a kidney removed anyway after being drugged. South African clinics recruited donors from Brazil, Israel and Romania with offers of US\$5,000 to US\$20,000, with the recipients paying up to US\$120,000 for a “transplant holiday”. Another key destination for transplant tourists has been China, where organs were taken from executed prisoners (China now says that it has largely stopped this practice). A New York body-snatching ring is currently being prosecuted for stealing body parts from corpses from funeral homes, possibly with the collusion from the funeral home and biomedical firms.

### **Variations in Donation Rates**

Britain’s cadaveric kidney donation rate (at 13 donations per annum per 1,000,000 of population) is a third of Spain’s (34.3 donations per 1,000,000). British studies indicate that a large driver of this gap is the objections raised by family members of patients who are announced brain-dead. Such sensitivities explain why a number of countries – including Britain – have an “opt-in” system of donation, where those willing to be donors must sign up. Another approach is an “opt-out” system, where everyone is assumed to be a donor unless they have specifically registered an objection. (In most “opt-out” systems, the approval of the next of kin is also required). European countries with an opt-out system have comparatively high rates of cadaveric donations – of over 20 per million – which is one reason why Britain is considering such a system as well.

But an opt-out system is no panacea – Greece has an opt-out system with a very low donor rate of 5.8 per million of population; whereas the United States has a donor rate of 26.6 per million with an opt-in system.

Spain has managed to more than double the rate of cadaveric donations over the last 20 years. Part of the success seems to be in how Spain's media covers transplants – to allay public fears – as well as the way that transplant teams are organised in hospitals. A recent British study found that copying Spanish transplant teams' methods could boost UK donation rates by 50%, which would be enough to cover the UK's needs. But as high as Spain's cadaveric donation rates are, there are waiting lists in Spain, and Spain is increasingly looking to live donations to help manage its renal transplant waiting lists. Living donor rates across countries can vary as much as cadaveric rates – with some countries as low as zero, to more than 20 per million per annum in others.

Iran has the highest living donor rate in the world – 23 per million. It is the only country that has sanctioned monetary compensation for organs. Iran allowed payments for unrelated living donors in 1988- and by 1999 it had eliminated its kidney transplant waiting list, a feat no other country has achieved. In Iran, a patient seeking a kidney must first seek a suitable donor within the family; if that fails, s/he must wait up to six months for a deceased donor. They then apply to the national renal transplantation association for a kidney from a living donor volunteer. Donors are offered two forms of compensation. First, they are given a fixed US\$1,200 fee plus free health insurance for a year. Second, the donor gets a lump sum from the recipient, or (if the recipient is too poor) a monetary gift from a designated charity of up to US\$4,500.

In every other country, such arrangements are illegal. The World Health Organisation (WHO) has reinforced the concept of a world-wide ban in the latest draft of its "Guiding Principles" for transplants which are currently being updated. The WHO's view is that the legal sale of organs is likely to exploit the poorest and weakest groups in society, would undermine altruistic donations, and may also lead to human trafficking.

The pressure on waiting lists has led other countries to explore other options. Israel has passed a law to allow donors to be paid fixed compensation of US\$5,100 for loss of earnings for live donors. A number of doctors in western countries advocate for such payments, to cover at least donor's costs, on account of the savings of health expenditure, and the benefits for the length and quality of patient lives.

**Notes on the NZ situation:**

- *In 2006 NZ's cadaveric donation rate was about 10.1 per 1,000,000 of population (although Organ Donation NZ puts the donor rate in 2006 at 6.0 per 1,000,000), and the live donation rate was about 12.2 per 1,000,000*
- *NZ law prohibits the payment for organs.*
- *Live kidney donors can receive limited compensation for loss of earnings – donors are able to apply for the sickness benefit of NZ\$184/week for a single person over the age of 25 from Work and Income for the period of up to 12 weeks. Kidney Health NZ has lobbied Government Ministers for better financial support to cover the actual loss of earnings for live kidney donors.*

## WRKS COMMITTEE MEMBERS 2008

<b>Michael Papesch (President)</b>	<b>389 5953</b>
<b>Ted Fecteau (Treasurer)</b>	<b>934 6330</b>
<b>Dave Henderson</b>	<b>972 7708</b>
<b>Mike Logan</b>	<b>388 8381</b>
<b>Arthur Sanford</b>	<b>479 0630</b>
<b>Rob Cameron (Membership)</b>	<b>586 3640</b>
<b>Alan &amp; Margaret Griffith (Taupo bookings)</b>	<b>904 9884</b>
<b>Sandra Lallemand (Patient Liaison Officer)</b>	<b>382 9693</b>

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*Our thanks  
go to....*

*Jeff Orr  
of Copy Express in Petone,  
who kindly sponsors our  
newsletters,*



*the Community Organisation Grants  
Scheme (COGS) which is run by the  
Department of Internal Affairs,*

*and NZ Post, which supplies us with postage-  
paid envelopes.*

Perhaps the best way to stay informed about what your society is up to is to **GET INVOLVED!** You can join the WRKS for \$10 a year (or \$15 for family membership).

**YES** I would like to join WRKS and I enclose a cheque as follows

<input type="checkbox"/>	Individual Membership (\$10.00)	<input type="text" value="\$"/>	Name	<input type="text"/>
<input type="checkbox"/>	Family Membership (\$15.00)	<input type="text" value="\$"/>	Address	<input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/>	Donation (Much appreciated)	<input type="text" value="\$"/>		
<input type="checkbox"/>	Total enclosed with this form	<input type="text" value="\$"/>		
Receipt required?		<input type="checkbox"/> Yes	<input type="checkbox"/> No	Phone
				<input type="text" value="Area Code ( )"/>

Please make cheques payable to Wellington Region Kidney Society Inc.

Donations of \$5 or more qualify as a tax deduction

Please tick your main association with kidney issues.

<input type="checkbox"/> Hospital dialysis	<input type="checkbox"/> Home haemo-dialysis	<input type="checkbox"/> CAPD	<input type="checkbox"/> Outpatient
<input type="checkbox"/> Transplant	<input type="checkbox"/> Transplant Donor	<input type="checkbox"/> Supporter	

THANK YOU FOR YOUR SUPPORT

Please send to the Membership Secretary, Wellington Region Kidney Society, PO Box 7302, Wellington 6242.

## COMMITTEE MEETINGS

A reminder that these are held on the 4th Tuesday of every month. They take place at 5.30pm in the Seminar Room at the Renal Ward in Wellington Hospital, and anyone is welcome to join us.

## CONTACT DETAILS FOR THE WRKS



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