

## **Annual Kidney Patient Support Group Conference**

This year we decided to hold the annual conference in Hamilton, as the Waikato Region has one of the highest incidences of kidney disease in New Zealand and it was hoped we would attract some interest from the community to attend the Information morning held on the Saturday.

The Friday session, as usual, saw a representative from each support group give a brief overview of their group's activities and achievements throughout the year. I am always amazed at the dedication and hard work of these groups, nearly all run by volunteers and this year was no exception. It was also interesting to hear the different interests or projects individual groups focussed on, from more political lean, fundraising events, to others who just want to support people and their families with Kidney Disease. Some areas of interest include;

In Dunedin the local Support Group has provided the Dialysis Unit in the Hospital with Portable DVD Players and started a DVD collection for use by patients while they are on dialysis. They are very keen to lobby for better support for Live Kidney Donors and have recently developed a newsletter for its members, and to encourage membership.

Christchurch Kidney Society has had a difficult year with the loss of their much respected Chairman Graham Cox, and some changes in the committee. Despite these set backs they have managed to achieve a great deal. They now have a representative on the Chronic Conditions Review Board, so kidneys will get a good plug!

Southland Kidney Support Group were able to report on the final art work used in the advertisement placed on the back of one of their city buses, this can be viewed on our website [www.kidneys.co.nz](http://www.kidneys.co.nz). It seems to be getting noticed as when it mysteriously disappeared for a brief time people noticed, and were asking where it was.

Sue Clapperton from the Horowhenua Kapiti Kidney Society, one of the new groups this year, shared her family's story and why they decided to start up a local support group. They have monthly meetings which are always very well attended and focus on supporting those in the area with kidney disease.

Larissa from the Taranaki Kidney Support Group spoke of the increasing numbers of patients in the region, with at least 200 people on the pre dialysis list. They have a membership of 65 currently.

It was interesting to hear Tony from South Canterbury group talk about their project with the local Polytechnic (Aoraki). The Catering students have cooked some meals taken from the Renal Cook Book and served dinner to the members.

Lesley Glassey from the Ashburton Kidney Patient Society talked about the Organ Donation Forum, a combined Lions and Ashburton Support Group initiative. The Forum was held in the Ashburton College Auditorium in April this year with nearly 200 members of the general public present to hear, what can only be described as, some inspirational speakers talking about their experience as either heart or kidney transplant recipients. A couple spoke of the decision they made to donate their sons' kidneys more than 20 years ago, friends talked about their experience as a live donor and kidney recipient and a Nephrologist and Transplant Surgeon spoke of the intricacies of transplantation. Janice Langlands spoke about her role as Organ Donor Coordinator. This was followed by a question time where many questions were put to the speakers. The objective to raise awareness of Organ Donation was certainly achieved in the Mid Canterbury region with several personal stories regarding donation and transplantation appearing in the local media prior to the event.

The Wellington Regional Kidney Society is currently working on its' Strategic Plan with a workshop planned for August. They are funding for some Magazine Subscriptions for the Haemodialysis Unit for patients to use while dialysing.

Janice Langlands spoke briefly about the Memorial Services Organ Donation NZ hold annually in Auckland and bi annually in Wellington and Christchurch. This was prompted by some interest from other support groups some distance from the three main centres to hold their own service. Janice agreed to liaise with these groups to discuss further options.

### **Saturday Information Morning**

As with our annual conference we open the programme up to the general public by advertising in the renal clinics and local newspaper. This year was no exception and we were pleased to see some new faces attending.

Professor Kelvin Lynn, Medical Director for Kidney Health NZ spoke about Chronic Kidney Disease and its impact. He also spoke about the impact of diabetes on our population and the rise in numbers of those with Chronic Kidney Disease (page one of this newsletter).

Janice Langlands, Team Leader for Organ Donation NZ explained the Human Tissue Act and how this works.

Mark Hodge, Pre Dialysis Educator at Waikato Hospital spoke about his role and the choices available for those with End Stage Kidney Disease

Nicky Hagan, Charge Nurse Manager Dialysis Services, spoke about the Waikato Renal Service; it made many appreciate the short distance many only needed to travel for treatment, when we saw the vast region the Renal Service covers in the Waikato region. The establishment of Satellite Dialysis facilities in the Waikato are helping to lessen travel time.

Carol Rickard, a live kidney donor, talked passionately about her experience as a donor to her son. Carol was very positive and gave an entertaining description of her experience.

The morning concluded with lunch and farewells.

### **From the Medical Director**

I have just returned from some time overseas. Part of my time was spent representing KHNZ at the International Federation of Kidney Foundations (IFKF) conference in Mainz, Germany. The IFKF ([link to website http://www.ifkf.net/index.php](http://www.ifkf.net/index.php)) fosters international collaboration and exchange of ideas to improve the health, wellbeing and quality of life of individuals with kidney disease. There are 63 member organisations, representing 41 different countries.

The conference was attended by 80 representatives from kidney foundations and patient support groups in 19 countries, local politicians and experts from the World Health Organisation and the Centers for Disease Control and Prevention in the USA. I presented a paper summarising the activities of KHNZ over the past year ([link](#)). There is considerable interest in the work of Kidney Health New Zealand, internationally. A poster presenting our World Kidney Day activities won a prize for the outstanding poster demonstrating 'Access to Government Health Officials'

Chronic kidney disease (CKD) is now being more widely recognised as a major public health problem closely linked to diabetes and high blood pressure. 500 million people worldwide, one in ten, have some form of CKD.

Dr Gojka Roglic from the World Health Organisation (WHO), Department of Chronic Diseases and Health Promotion, presented a talk on the structure of the WHO and the emergence of non-communicable diseases as a major public health problem. Diseases such as diabetes, heart disease and kidney disease (termed non-communicable diseases) are the most important causes of death in developed countries, such as New Zealand, but are now a more common cause of death than infectious disease in many developing countries. The WHO member states, including New Zealand, have pledged to reduce deaths worldwide by 2% each year. Given that spending on non-communicable diseases is only 3.5% of the total WHO expenditure this poses a major challenge for the organisation. Any increase in funding to reduce the burden of CKD internationally must come from member states.

Dr Nilka Rios Burrows from the Centers for Disease Control and Prevention, Division of Diabetes Translation, talked about the challenges posed by the diabetes epidemic and diabetic kidney disease. Her organisation are investing in research to help identify which groups of people at risk of CKD would benefit from community based screening. The results of this work should help to guide decisions on screening programmes for CKD in New Zealand.

Paul Beerkens, the IFKF President, announced that the IFKF would put in place projects to put chronic kidney disease (CKD) on the international public health agenda by working with

major public health agencies in the USA and the European Community. These programmes align well with the goals of KHNZ nationally,

An important message from this conference was that local organisations, such as KHNZ, have an important role in role in advocating for local action on CKD and informing the Ministry of Health and Government of the international context of measures to combat CKD.

Kelvin Lynn

Medical Director



**Lake Kidney!**

## **Two True Stories proving Age and Ethnicity are no Barriers to donation.**

### **Rebecca Mason earns black belt after donating kidney**

Nine months ago Rebecca Mason was under the knife having a kidney removed to prolong her brother's life.

Now the slight 54-year-old Wellingtonian has come through a gruelling three-hour battle to earn a prestigious black belt in Seido Karate.

The 1.67 metre tall daughter of famous playwright Bruce Mason took a pummelling from male opponents far outweighing her 58kg during 40 fights.

She walked away with only a few bruises to her left arm and a treasured black belt.

But her journey to success had been even tougher after she made a gutsy decision to donate a kidney to her brother, Julian.

Her 56-year-old sibling was diagnosed with chronic kidney disease (CKD), with one kidney the size of a peanut and the other deteriorating.

"Without a transplant I was facing regular dialysis and a long queue for a suitable donor," the Matamata telecommunications expert told NZPA.

"I had no energy, had constant headaches, agonising gout and was struggling to cycle, which I'm passionate about."

"Bex and I share the same blood type and her kidney, although small, was in perfect condition.

"I didn't want to put her under any pressure to donate it to me," he said.

The decision to have such risky surgery wasn't easy for Rebecca.

"The main reason I did it was because I wanted Julian to be around for his grandchildren," she said.

As a tiny token of his thanks he gave her a special kidney-shaped gold ring, which she wore the night before their surgery.

They were operated on within an hour of each other at Auckland Hospital on June 27 last year.

Rebecca faced 2-1/2 hours of keyhole surgery that knocked her around much more than she had expected.

"I lost 5kg and there were various post-operative complications. I felt a bit ripped off when the doctor said I couldn't get back into karate for months."

But she returned to work as an executive coach within weeks and by December was doing 15 hours a week of karate training at the Thorndon dojo in Wellington.

Relaxing at her Island Bay home, she played down her sporting achievement.

"A black belt is just a white belt (beginner) who never stopped training. Getting one is not the pinnacle of the journey, it's just the start.

"Donating an organ is not a walk in the park, but I fully recovered despite my age and achieved my black belt."

The siblings say the transplant has brought them closer, and given Julian back his quality of life.

Although on a cocktail of anti-rejection drugs for the rest of his life, he's cycling 100km a week and flying his two-seater glider.

"With her kidney inside me, people are asking whether I've started doing karate kicks or sitting down to pee," he said.

"It's all good, I can never thank her enough. The hospitals are constantly getting bad press but the Auckland renal unit and its staff are fantastic."

## **Living Donation from a Maori Perspective**

Kidney donor defies beliefs

Jun 16, 2008 8:44 PM (taken from TVNZ website)

An Auckland woman has defied Maori beliefs to save a friend's life, giving a kidney to a gravely ill Australian man.

And Tamela Brownrigg hopes her decision will make other Maori to consider being living donors.

Aussie Roger Garraway is now part of Brownrigg's whanau because he has one of her kidneys - an issue of great sensitivity to Maori.

"Many people in our community may find this quite confronting and quite challenging but I hope this might touch just one person," Brownrigg says.

Garraway says there aren't enough thanks on the planet for "somebody who does this for you".

Garraway and his family travelled from Australia for an emotional celebration of Brownrigg's life saving generosity.

Brownrigg's brother Peter Mihaere says the donor and recipient have shared a special bond and have come together as one.

The connection came through Brownrigg's 20 year friendship with Garraway's partner - a bond that meant breaking with cultural tradition.

"It's ok, you can survive and you can be ok afterwards," Brownrigg says.

Garraway is also keen to promote the cause through a Maori tattoo he is planning for the back of his hand.

"It's people all over the world who need to think outside their comfort zones to do these things," says Garraway.

A growing number of Maori and Pacific Island people are in need of new organs.

### **Statistics for Maori and Pacific people**

As at April 1st 2008 there were 559 people waiting for a kidney transplant in New Zealand. The incidence of kidney failure among Maori and Pacific people is substantially higher than among non indigenous people, this together with lower rates of transplantation, leads to higher rates of prevalent dialysis patients: The statistics for these are as follows;

#### **As at Dec 31st 2006 Number of Maori New Patients 163**

Number of Maori on Dialysis	678
Number of Maori with a Transplant	110
Number of Maori Transplanted in 06	10
Deaths from Kidney Disease	123

#### **As at Dec 31st 2006 Number of Pacific New Patients 71**

Number of Pacific on Dialysis	363
Number of Pacific with a Transplant	77
Number of Pacific Transplanted	7
Deaths from Kidney Disease	54



## **News from Kidney Health New Zealand.**

The office continues to keep busy as we continue to slowly rebrand our resources and raise our profile. A letter for KHNZ was sent to all MPs informing them of the success of World Kidney Day and to remind them about our work. The date for next years World Kidney Day is 12<sup>th</sup> March, so planning is now underway to ensure this event is even bigger than before. Chronic Kidney Disease continues to be the main focus for this event with early intervention and detection just two of the key messages we want to promote.

The 0800 free phone line has been extra busy recently, with several news stories relating to kidney donation prompting people to seek further information regarding live donation, there have been a number of requests for information via our website too.

We are excited to finally have our Chronic Kidney Disease Management Guide in General Practice hot off the printing press, planning is now underway as to how we can launch this to achieve maximum coverage. The aim is for all GPs in New Zealand to receive one before the end of the year.

The review of the constitution has finally been completed and our Strategic Plan is beginning to take shape with the completion date not too far away.

Planning is underway for our annual Senior Renal Nurses Conference being held in September. Also we have been asked to assist South Canterbury Kidney Patient Support Group with an Organ Donation Forum, similar to the very successful campaign run in Ashburton. The Lions group has also agreed to take an active role in this event. The Education Manager of KHNZ is hoping to speak to 15 – 16 year old students in South Canterbury prior to the event regarding Organ Donation.



**P r e v e n t i o n • S u p p o r t • R e s e a r c h**

Yes, I want to help in the fight against kidney disease and support  
Kidney Health New Zealand

\$100    \$50    \$20    \$10   or Other  
\$.....

- Enclosed is a cheque payable to the Kidney Health NZ, or please charge:-  
 Mastercard                       Visa

Account number:

Expiry Date: .....                      Signature: .....

**Please indicate if you would like:-**

- A receipt for your donation  
 Information about making a gift to Kidney Health NZ in my Will.  
 Information about kidney donation/transplants.  
 More information on general kidney health.  
 To become a member of Kidney Health NZ

Name:  
.....

Address:  
.....

***Thank you for your support.***

Please return this form to: 24 St Asaph Street,

Christchurch, Phone: 03 353 1240

Website: [www.kidneys.co.nz](http://www.kidneys.co.nz), Email: info@kidneys.co.nz.

