

**WINTER 2007 EDITION**

**NEW ZEALAND**  
**KIDNEY**  
**FOUNDATION**

**CHECK OUT OUR NEW WEBSITE:**

[www.kidneys.co.nz](http://www.kidneys.co.nz)



## **Welcome to the Winter Edition of the New Zealand Kidney Foundation Newsletter 2007**

The winter has certainly arrived with vengeance this year, I actually enjoy getting rugged up to head outside, there certainly is something to be said about the changes in seasons, there is nothing nicer than being warmed up with a cup of something hot on a cold frosty morning.

Things have certainly heated up here at the Kidney Foundation, in June we held our annual Kidney Patient Support Group conference here in Christchurch, once again the open morning was well attended by members of the general public who braved the rain and cold temperatures to hear some excellent speakers, more of this later.

Our Medical Director, Dr Kelvin Lynn, has been busy putting together a discussion document of the NZKF's strategic objectives, which was also discussed at our annual conference. Kelvin will talk about this further in this newsletter.

### **The Website**

The new website is up and running. It has taken a lot of work and will continue to be a work in progress. We aim to up date it weekly and welcome any suggestions or feedback you may have. The address has changed, although the old one will still take you there for a short while. The new address is [www.kidneys.co.nz](http://www.kidneys.co.nz) I am sure you will agree, a much more user friendly address!

Eventually the kidney patient support groups will have their own page within the site they can add their news to. This will make it more accessible for those looking for support within their own areas.

### **0800 KIDNEY**

The free phone line continues to be well used with a noticeable increase in calls following news items or programmes talking about kidney disease or organ donation. Many people are often surprised they are able to donate a kidney while they are still living and want to know a little of how the process works.

I have noticed an increase in the number of calls from people who are concerned about their kidney health or who have recently been told they have a kidney problem. This could be due to an increased awareness of the 0800 line or people being more proactive, or people just wanting more information.

It is encouraging to know this service to provide support and advice to people wanting further information, is being utilised.

## **Education**

I have noticed an increasing number of requests from students and teachers wanting information about kidney disease and its treatments. This is an area the NZKF have been looking into as a way of raising awareness of kidney disease and organ donation, although our National Drink Water Week raises our profile, providing an education package for schools will go further in providing a wide range of information and education.

I recently was invited to speak at Samuel Marsden College in Wellington to Year 12 students about kidney disease and treatment. This was an ideal opportunity to find out if the information we feel it is important for the students to know actually meets the requirements of their curriculum. The feedback from the session was very positive with the teachers confirming the content met the objectives of the Health Technology paper.

### **Annual NZKF Conference for Kidney Support Groups**

This year the conference was held in Christchurch on June 15<sup>th</sup> -16<sup>th</sup>. We had 30 delegates from Kidney Patient Support Groups throughout the country; once again the standard of presentations was high with some thought provoking messages.

The first day of the conference was reserved for delegates only. A member from each support group gave a brief summary of their groups activities over the past year. It was encouraging to hear so many groups active in their communities. The Southland Kidney Support Group have raised enough money to have an advertisement printed on the back of a bus for the next three years. The group is currently trying to find the “right” graphics to promote organ donation on the bus.

The Otago Kidney Support Group was able to purchase Portable DVD players for use while patients are on dialysis in the renal unit, a very popular purchase.

Wellington Kidney Society is seeing an increase in numbers using their holiday home in Taupo which is encouraging.

Christchurch Kidney Society has funding available on application, to assist young people affected by chronic kidney disease, to meet their goals in education, music and sport.”

The afternoon was dedicated to the NZKF Strategic Goals drawn up by Dr Kelvin Lynn; these promoted some discussion and ultimately there was a general consensus the Foundation is moving in the right direction.

A panel discussion with Stewart Eadie , for the National Heart Foundation, Dr Graham McGeoch a GP representing Pegasus Health Group and Lynne Taylor, Community Liaison Officer for the Diabetes Society, helped the NZKF to better understand the role of these other organisations and where we can work together for the benefits of our many mutual patients. All three participants talked about their organisations role and where they felt the NZKF fitted within them. As many of our patients are seen in all three areas it was important we endeavour to improve communication across our services.

Saturday Morning was open to the public and we were thrilled with the turnout on what was a miserable cold wet day, I realise Christchurch people are a hardy lot.

Kelvin Lynn began the morning with his presentation –Putting Kidney Disease in Context. This was a very interesting presentation, and certainly bought home the impact kidney disease has in this country. I have included some of the statistics Kelvin presented late in this newsletter. Kelvin talked about Chronic Kidney Disease (CKD) as a collective term for all manifestations and stages of kidney disease, with the key identifier giving an estimate of overall kidney function called the eGFR. He talked about the best way for a doctor to pick up CKD with three simple tests.

1. Measure your blood pressure.
2. Check your urine for protein
3. A blood test to measure the blood creatinine level (this enables eGFR to be calculated).

Kelvin highlighted the estimated cost of treating kidney failure vs the cost of transplantation, he also talked about what we know works when treating Chronic Kidney Disease and some new ways of dealing with it.



### **Saturday's Information Morning**

Madeleine Price a renal dietician at Christchurch Hospital spoke about the importance of nutrition in kidney disease; she highlighted the importance of maintaining a healthy diet while trying to adhere to the “renal diet”. She also mentioned the importance of maintaining a healthy body weight in an effort to minimise complications.



Michael Papesch spoke about his experience as a kidney transplant recipient and his wife Paula Martin spoke of her experience as a kidney donor. Michael and Paula both spoke openly and honestly about their experiences. I have included Michael's presentation in this edition and will put Paula's presentation in the next edition. Michael described briefly his time on Peritoneal Dialysis and some of the ups and downs he experienced during that time,

**Bobbie, Nora & Tafale (NZKF Council) with Rachael (Auckland) and Glen (Tauranga)**

his experience as a kidney transplant recipient was wonderful to listen to particularly with his sense of humour and honesty. Paula described watching Michael's health deteriorate with his decline to end stage renal failure and then onto dialysis. She talked about the trips to hospital and her decision to donate a kidney to Michael, the tests and investigations she endured prior to being told the surgery could go ahead and some of the frustrations she felt. Paula too was honest: like Michael her sense of humour shone through and must have been a great help both pre and post the transplant. They both provided some very useful information and a thought provoking presentation which received very positive feedback.

Sarah Armstrong the Kidney Transplant Coordinator at Christchurch Hospital spoke about her role and gave an insight into the process involved for somebody wanting to go the transplant waiting list and for somebody wanting to donate a kidney. It was interesting to hear her talk about the number of altruistic kidney donors the service has had so far and the process they go through too.

Janice Langlands from Organ Donation New Zealand (ODNZ) spoke about her role as an Organ Donor Coordinator and the role of ODNZ. With the Organ Donation Bill currently being heard at the select committee Janice was able to discuss some of the barriers to organ donation and how ODNZ is planning to address these. She also talked about the positive feedback she receives from the donor families when they receive a letter of thanks from the recipients of their family member's organs, this often helps the donors family to feel the decision they made to donate their loved ones organs was the right one.

The conference closed with a light lunch and the chance for people to talk to the speakers more informally. We hope to run more of these information mornings in the future.

### **From the Medical Director's Office**

## **New Strategic Goals for the Foundation debated at the 2007 New Zealand Kidney Foundation Patient Support Group Annual Conference in Christchurch**

The Foundation was established in 1979 to increase the rates of kidney transplantation and to raise funds for research into the understanding, prevention and cure of kidney diseases. Much of the focus of the Foundation's activities has been on supporting people with kidney failure. Little attention has been paid to early detection of kidney disease in the community because of concerns about the effectiveness of such measures.

### ***In 2007 the Foundation faces new challenges:***

The International Society of Nephrology and the International Federation of Kidney Foundations have characterized chronic kidney disease as "common, harmful and treatable". To respond to this challenge we need to do things differently in the future.

We need a single body representing the needs of all kidney patients to the public, Government, the Ministry of Health and DHBs so that our message comes through loud and clear. The Government is currently focusing on the management of chronic diseases; diabetes, cancer and heart disease in particular. Kidney disease on its own is not seen as a priority. But many people with kidney disease now have other chronic diseases such as diabetes and heart disease: thus the Foundation has the opportunity to work with other groups such as Diabetes Societies and the National Heart Foundation to obtain government support.

In spite of our best efforts the rates of deceased donor transplantation have fallen and currently there is a community debate as to whether legislation and regulation by government will reverse this trend. The Foundation has a role to play in this debate.

Diabetes, now the commonest cause of kidney failure, affects 4 % of the population and is a public health epidemic. Effective treatment of blood pressure and diabetes reduces the incidence of kidney disease and slows its progression when present. Early detection and treatment, particularly of hypertension and diabetes, is more cost effective than dialysis or transplantation and has significant advantages for affected individuals and the health system. We still do not have well developed systems in the community for picking up high risk individuals with early kidney disease who would benefit from intensive treatment. Even when we have effective treatments there are still many barriers to their successful implementation.

The number of people on dialysis in New Zealand is predicted to increase by 4-6 % annually. In spite of evidence of the benefits of increase frequency and duration of haemodialysis and home dialysis there are major barriers to implementing these therapies. In spite of a desire to increase community based dialysis nearly half of all patients are on hospital dialysis.

Over the past year the Executive Committee have been reviewing the goals of the Foundation. The results of this work have been endorsed by the Council. The 2007 New Zealand Kidney Foundation Patient Support Group Annual Conference was an ideal forum for debating these goals with consumers and their supporters.

***The New Zealand Kidney Foundation's goals in 2007 are:***

1. To establish the New Zealand Kidney Foundation as THE credible, nationwide voice regarding kidney disease in the community.
2. To collaborate with patient support groups and the National Renal Advisory Board in the development of the Foundations policies.
3. To advocate for the recognition of kidney disease as a major chronic disease for New Zealanders, particularly Maori and Pacific Island peoples, that has significant social and economic impact.
4. To work with primary care practitioners, other non-government organisations and the Ministry of Health, for the inclusion of markers of kidney disease as part of chronic disease assessment in primary care.
5. To promote transplantation as the most effective and cost-efficient treatment for end-stage kidney failure to the public, Ministry of Health, Government and other key stakeholders and to reduce barriers to living kidney transplantation.
6. To advocate for equitable access to all forms of dialysis therapy and recognition of the special needs of people on dialysis.
7. Funding of research to address issues important for the prevention and treatment of kidney disease in New Zealand identified by, and in keeping with, the goals of the Foundation.

The Foundation would appreciate feedback from readers on these new goals.

**From Michael Papesch**

Paula and I are here to talk to you today about our experiences as a kidney donor, in Paula's case, and the kidney recipient, in my case.

This is the story of the Kidney Kids – as my mother-in-law likes to call us.

The story of the Kidney Kids starts with my kidney disease.

In June 1996 I didn't know the first thing about kidney disease. For a couple of months I had been feeling really tired, and was finding it harder and harder to keep up with my circuit class at the gym. In January 1996 I had been at the front of the class, by June I was lagging far behind. I couldn't explain the change. My shins and ankles were swelling up – to the point that if I pressed firmly on my shinbone, I could make an indentation into the skin of half an inch or so.

I thought it was stress. A year earlier I had started a new management job and I was struggling with it. I was working long hours and my last performance assessment hadn't been too good. My then wife was nagging me about overworking. Being stubborn the last thing I wanted to do was to confirm that I had been working too hard – and so I didn't see a doctor for several months.

Well, my doctor didn't think it was stress at all. He looked at me incredulously when I suggested it to him. Instead he did a simple dip stick test in a small urine sample. Before I knew it I was off to the Renal Unit in Wellington Hospital.

At this stage I had no idea what was going on. There were lots of questions. What have I got? How could this happen to me? How could I have kidney disease- I was young – about 34 years old – and pretty healthy. Wasn't I?

A week later I had the biopsy. By that time I was so fluid overloaded that the pressure on my internal organs was killing me. I couldn't lie down. I had to sleep sitting up. I spent hours sitting in a hot bath because that took the pressure off. On the day of my biopsy my then wife had to rush me to hospital at two in the morning because the pain was too much to bear.

When the biopsy results came back I found that I had *membranous glomerulonephritis*. I had no idea what this meant. The doctors at Wellington Hospital seemed pretty excited – it seems they don't get too many *membranous* cases in Wellington. I had novelty value. I had endless visits at my hospital bed from the trainee doctors and registrars – being asked the same questions over and over again. It seemed like I was today's case study – a training video, but a real live one.

A few months later I discovered that Jonah Lomu had the same thing that I had. This helped a lot – if only because I could say to people "I've got the same thing as Jonah Lomu". At that point everybody would nod knowingly and wouldn't ask too many more questions that I didn't know how to answer. But it was handy for another reason – as it transpired whatever happened to Jonah seemed to happen to me some 12-18 months later. Watching Jonah was like watching a forecast of what was about to happen to me.

This was the start of my rollercoaster experience with kidney disease. Various treatments were tried – and each worked for a time. First cab off the rank was a six month cocktail of chemotherapy and steroids. I remember a couple of things about this regime. First was the impact of the steroids – they make you hyperactive. I remember getting up one Saturday morning – about 5am – and completely re-arranging the kitchen cupboards by the time my then wife struggled out of bed. Steroids also make you ravenously hungry. Another evening I recall opening the fridge door, and eating the fridge, starting at the top and working all the way down to the bottom. The second thing I remember about this regime is that it worked.

It worked for about 3 years. And then it stopped. So we tried it again. But it didn't work that time, it never even took hold. So we tried another drug, - Cyclosporin. And this worked. I was also told it would help my ever growing bald spot, but it didn't. I guess you can't have it all.

Cyclosporin worked for about 2½ years. In June 2004 I remember getting a really bad dose of the flu. Two weeks later my swollen ankles were back in business.

After that it was a countdown to dialysis. The countdown lasted about a year, and was by far the worst part of the experience. I was literally waiting to become sufficiently ill to receive dialysis. That year consisted of constant headaches, bouts of vomiting and diarrhea, excruciating body cramps, extreme tiredness and fluid overload.

When it came, dialysis was such a relief. I had been worried about it. I had elected to do peritoneal dialysis because of the flexibility that it would give me to travel. But in the countdown all I could see before me was an endless stream of bags and tubes. In fact, once I started I couldn't recall ever having felt so good.

Peritoneal dialysis was like changing the oil on your car. It's a bit fiddly and time consuming, but if you were careful it was straightforward. It was strangely easy to break your life into 4 to 6 hour segments between treatments, provided you planned ahead. I was lucky that I had an office job and a sympathetic employer with a well furnished sick bay – and people who were prepared to come and visit me at lunchtimes as I did my oil change.

Dialysis is a mixed blessing however. Yes, it keeps you alive. But it is a very imperfect solution. I hope I wasn't on dialysis long enough to face the worse side-effects – lower life expectancy because of the co-morbidities. But it does have more immediate setbacks.

- For example, I did have the odd rush into hospital because my potassium levels were too high – with the risk of interfering with my heart function
- I was often fluid overloaded – with the risk of very high blood pressure
- But on a number of occasions I was dehydrated. One day I collapsed through dehydration outside my office, having to be rescued by the Green MP Sue Kedgley who called for the ambulance
- I experienced the unintended weight gain as your body absorbs calories from the glucose rich dialysis fluid. In a year I put on about 8 kilos even though I was sticking pretty close to a Weight Watchers diet.
- And worst of all, I suffered a bout of peritonitis – an internal infection that is a risk with the dialysis process. This was the most excruciating pain I can ever recall. And by the time I made it to the A&E department my blood pressure had plummeted to 60 over 30. Despite these setbacks, at least dialysis keeps you alive. It's amazing what you will put up with when the alternative is a slow death. The other key factor in making dialysis bearable

Was the potential end in sight – at that stage Paula was being worked up to be a donor.

On the whole the transplant went smoothly. It hurt like hell for the first two days – this was an issue about getting the dosage of the pain relief right. I had a minor rejection episode in the second week. What gave me a lot of comfort is that the renal specialists seem to know a lot about managing rejection - a lot more than they knew about the cause and progression of the initial nephrotic syndrome. Aside from the anxiety that the rejection caused, I felt great from about the third day of the transplant.

And I still do. Transplantation has been a new lease of life, a sense of wellness that I haven't had for over 10 years. I know that one day it will end, and we'll be back to square one, but I'm going to enjoy every moment of it between now and then.

Looking back on my experience over the past ten years, there are five reflections that I want to share with you today.



**Michael tells his story**

First, New Zealand's health system is top class when there is something really wrong with you. It's very easy to moan about the health system – in part because our expectations, and because the stakes are so high. But in my experience the people at the coal face of the health system are professional and responsive while making the inevitable and tough rationing decisions that are inherent in all health systems.

Second, communication is an important issue. Paula and I are reasonably intelligent people. But even so the health system is determined to tell you the minimum that it thinks that you need to know. When my chemotherapy/steroid cocktail failed the second time in 2001, I had no idea that there was another option in the wings. Rather, I had spent the last three months of this regime thinking that this was "it", not even sure what "it" was.

A few years later we found that the dialysis co-ordinator at Wellington Hospital – Helen Hoffman – was someone who was able and willing to spend the time to take you through what you didn't know. She was invaluable in helping us navigate the system and clarify the confusing and uncoordinated messages from the various points of contact. Is there a role for patient advocates – or patient navigators – in the health system? Is this is the potential value-add for regional Kidney Societies?

Third, many of the kidney publications and websites really lack the sense of what it is you're dealing with. There is an awful lot of "jolly-hockey sticks" material out there. Sometimes the material made it seem as if kidney disease and dialysis are lifestyle choices.

I had a number of discussions with the medical specialists about the choice of dialysis versus transplantation. In all of them the doctors mentioned that transplants were a better long term option, but this seemed to refer to the cost or inconvenience of dialysis and the side effects of it. Otherwise there was a picture that you could stay on dialysis "forever". What wasn't really clear is that people on dialysis have significant health complications and much worse life expectancy than transplant patients. I've seen figures subsequently that transplant recipients live, on average, for 17 years. The average life expectancy for dialysis patients is just over 5 years.

We clearly want to provide a supportive and reassuring environment for people with kidney disease who are facing quite a distressing situation. But I wonder sometimes if we over-sanitise it. I also wonder if this matters for attracting live or cadaveric kidney donors.

Fourth, I'd like to touch on the issue of kidney donation. It's clear that the current strategy for kidney donation is not working. As much as the next person, I would like to think that altruistic cadaveric or live donations could provide a solid and reliable foundation for kidney donation in New Zealand. But it's not. In 2006 there were 25 deceased donors, and 47 living kidney donors. This compares to 433 people waiting for a kidney.

In NZ much of the public debate has been about increasing the rate of cadaveric donations. From what I've heard, the focus has been on registers, informed consent, and tensions with families of the recently deceased. Yet, in NZ as well as internationally, it is live donors that are becoming increasingly more important.

The question I haven't really heard in this discussion is: "what would it take to improve the rate of live kidney donation?" I wonder what the answer would be if we didn't rely on family donors, or the strength of family relationships, to provide many of our donors. I wonder what the friends – not the family but the friends - of the 433 people on the waiting list would answer. But surely their answers would be the strongest guide to where transplant policy should go.

It was certainly striking that, in my case, it was the immediate family that came forward to see if they could donate a kidney. If we are to increase the rate of donations, will we need to look wider than the immediate family? If so, what would it take to persuade them to come forward?

We should prepare for answers that we might not like.

We could certainly do more to let people know what the real chances of being a donor are. Many people thought it was a sheer statistical fluke that Paula and I were a match. They were astonished to find that the chances for any one person being a donor for someone else is somewhat larger than zero.

We also need to be a lot sharper in our communications about the real health and life expectancy consequences of kidney disease. I find the figures of comparative life expectancy of transplants versus dialysis quite stark, but they are absent from the public discussion. As a result there is no sense of urgency in the debate.

We should also be prepared to accept that altruism is not enough. If what it takes to increase the rate of kidney donation is to pay someone for it, so be it. I'd rather have that than have people die on the waiting list. And I'd much rather have a legal payment for kidneys than the illegal and dangerous black markets that are appearing around the world today.

Fifth, and finally, through my kidney disease, I have found out a lot about the inner strength of the human being. I have learnt about that irrepressible drive and will to live. I have also learnt that kidney disease doesn't need to get you down. On dialysis, I was able to work full time, to travel overseas for short holidays, and to enjoy our holiday home in the Marlborough Sounds. It couldn't have happened without the support from a whole range of people – such as Baxters Healthcare delivering bags of fluid here, there and everywhere. But if you wanted to make it work, it could.

Life is truly what you make it.

**A Special Thank You to Michael and Paula for their generosity and support of the New Zealand Kidney Foundation. Paula's story will be in our September Newsletter.**

**Some Statistics of Interest.**

**As at December 2005 in New Zealand there were**

- **1,855 people on dialysis**
- **1,220 alive with a kidney transplant**
- **436 new dialysis patients (41% of those as a result of diabetes)**
- **4-6% annual increase in patients needing dialysis**
- **93 kidney transplants (50% from living donors)**
- **1,100 people with marginal kidney function**
- **At Feb 07 there were 531 people on the waiting list for an organ, of these 507 were waiting for a kidney.**

*I am always looking for items of interest and/or feedback from our newsletter, if you would like to contribute in any way you can contact [carmel@kidneys.co.nz](mailto:carmel@kidneys.co.nz) or phone me on 0800 543 639.*

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

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

Enclosed is a cheque payable to the New Zealand Kidney Foundation, 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 the New Zealand Kidney Foundation in my Will.
- Information about kidney donation/transplants.
- More information on general kidney health.
- To become a member of the New Zealand Kidney Foundation

Name:.....

Address:.....

.....

***Thank you for your support.***  
Please return this form to: PO Box 139, CHRISTCHURCH  
Phone: 03 353 1242 or email: [info@kidneys.co.nz](mailto:info@kidneys.co.nz)