

## **Welcome to the Spring Edition of the New Zealand Kidney Foundation for 2007.**

I had forgotten how a warm sunny day can lift ones spirits; winter seems so far away already, as the blossoms look resplendent in Hagley Park and the birds start chirping early in the morning.

Spring is synonymous with new growth and this edition of the NZKF Newsletter contains news of past events and some new initiatives, so there should be something for everyone.

I hope this edition will stimulate some discussion around the editorial and an item submitted by Barbara Wright who initially asked me the question “Why can’t someone pay for a kidney if they need one?” My initial reaction was “You can’t do that”, but after some discussion and a little debate, I felt Barbara had a point, so after a little coercion she wrote down her thoughts and has kindly agreed for me to publish these in this newsletter. Professor John Morton has provided an editorial with the hope this will stimulate some thought and debate around the subject of kidney donation. Letters and comments are more than welcome, and will be printed in the Christmas edition of this newsletter.

Since the last newsletter in June we have been busy with our new website [www.kidneys.co.nz](http://www.kidneys.co.nz) each week we are learning how we can add pictures, news items and many other functions to ensure we remain up to date. I have noticed an increase in information requests as a result of people visiting our website, so although a work in progress it is certainly receiving an increasing number of hits each month.

The NZKF Senior Renal Nurses Conference was held in Auckland this year. We were fortunate enough to have Lesley Salem, a Renal Nurse Practitioner from New South Wales, as our guest speaker. Lesley is dedicated to the health and wellbeing of Indigenous Australians, working in the area of community dialysis, as well as developing strategies for improving chronic disease management between primary and tertiary health services. Lesley was an inspirational speaker, with the nurses coming away feeling more positive about the future of renal nursing and the opportunities to make a difference for people with kidney disease. Nurses from a variety of renal units presented on a number of topics including; vascular access management, non-directed kidney donation and the impact of changing pharmaceutical subsidies on home based dialysis patients.

I recently attended a Health Expo at the Southern Cross Campus in South Auckland, it was a great opportunity to promote the NZKF in a predominantly Maori and Pacific environment where students were given the opportunity to ask questions and learn about a variety of health initiatives. I was surprised at the number of students who knew about dialysis because they had a relative on it or who had been on some form of dialysis treatment. I plan to attend further Expos to help raise awareness and prevention of kidney disease, particularly in this high risk group.

I look forward to receiving feedback on some of the issues raised in this newsletter and will publish any letters in the Christmas newsletter.

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Bev Withers is a volunteer for the Christchurch Kidney Society, but her major claim to fame is the fact she has just celebrated the 35<sup>th</sup> anniversary of her kidney transplant. Bev and another gentleman (her twin, as Bev calls him) who lives on the West Coast, both received their kidneys from the same donor on September 25<sup>th</sup> 1972. Both have gone on to live a long and fulfilling life, and continue to do so. As far as we can ascertain Bev and her “twin” are the longest surviving kidney transplant patients in the South Island.

Congratulations Bev, keep up the great work. You are a real inspiration.

## **Editorial by Professor John Morton**

In this issue a member of a kidney patient support group, reflecting on the ever increasing need for dialysis, suggests that the problem could be solved if patients in need of transplantation could simply “buy a kidney.”

The idea of remunerating living organ donors stimulated Professor Stephen Munn of the Auckland Transplant Services to review the possibility and the way in which other countries were exploring the prospect. He facilitated discussion by suggesting that there were three possible levels of financial support for donors.

Level one is the provision of support, equivalent to the unemployment benefit, to compensate donors for time lost from work and this is now provided.

The second level of support would, (in addition to level one support) provide further compensation for the discomfort and inconvenience experienced by living donors, acknowledging the potential physical and emotional risks that are involved.

Finally living organ donation could be encouraged by paying large sums to donors.

Each level of remuneration prompts distinct ethical concerns which must be debated within the community which has the ultimate responsibility to decide what the policy should be.

The poor may feel coerced if the obligation to assist their dependants compels them to donate, regardless of the consequences for themselves. Since medical advisors must ensure that people make sound autonomous decisions with due regard to all the potential adverse events it would be essential for a paid donation programme to be controlled and monitored by a responsible authority.

In the medical community donated organs are considered a “gift of life” rather than a commodity to be bought and sold but sometimes the community is ahead of the doctors in such matters.

The New Zealand Kidney Foundation welcomes Barbara Wright’s stimulus to this debate and will be interested in the outcome. Iran, which has had an organ purchasing scheme for years has no waiting list for dialysis and transplantation, but there are conflicting views about its soundness from the ethical perspective. From an ethical and economic perspective this observer supports the necessity for debate and second level remuneration for organ donors.

### WHY ARE WE WAITING...../

I have been asked recently for feedback on the future plans of several of the different health providers in our region.

What I have noticed is that these documents all project increasing numbers of patients requiring dialysis in the next decade. This is going to put huge pressure on already strained renal resources. Early intervention, introduction of more dialysis “satellite” centres, increased awareness of donor transplantation and home dialysis are seen as some of the keys to cope with future demand.

BUT.....I am thinking, the answer could be much simpler than that....why not let kidney patients who require a transplant simply **buy** a kidney!

Everyone gasps in horror at this suggestion...“think of all the ethical problems”, but really, what are they?

Kidney patients requiring transplantation are lucky in that 99% of the population is equipped with two kidneys – one more than they need. Therefore, there should be plenty of kidneys around for those people who desperately need one to save their life. But it’s not as easy as that – who wants to give up a kidney, for nothing in return, to someone they have never seen or heard of?

Why not make the purchase of a kidney legal? Why not put a price on a kidney – say \$20,000. Let an organization, such as the Kidney Foundation act as a broker for the kidneys, ensuring no more can be charged and that the process is legal, anonymous and above board and that the donor and kidney are in A1 condition.

If I go to the shop for something I need, I don’t expect to get it for free-why should I wait on a list expecting that someone should give me something for nothing? If a live donor was prepared to sell me, through the kidney broker, one of their kidneys, they would end up with \$20,000.00. This might be enough to also give **them** a kick start in life – maybe a deposit on a house, an overseas holiday, a new venture. Win win for both of us. Some people would argue that is unethical for people to sell kidneys, but, really, we are already **begging** them to give them to us through all sorts of donor awareness campaigns.

There would always be a place for the donation of kidneys as we have now and I’m sure that those awesome kind of people who currently donate organs would carry on giving us the gift of life.

But the cold, hard fact is that there are simply not enough of these type of people around – in fact statistics show that the number of donors is decreasing.

There could be an argument put forward that only the wealthy could afford to buy a kidney – perhaps so – but surely if 2/3rds of people could scrape together the money to buy one, that only leaves 1/3<sup>rd</sup> of people on the waiting list left to have the scarce number of donated organs. Again a win win situation. But, if the price of a kidney was set at \$20,000, most people would be able to raise this amount in New Zealand – whether it be from family, friends, community groups etc. Perhaps the government could introduce interest free loans for people who had to purchase an organ for life – surely as needy as a student loan. Maybe some of the recipients who had to raise a loan to purchase

a kidney could then work to raise the money to pay the loan back. The government could perhaps allow them to earn this extra income without it being included in their gross annual amount, thereby affecting their benefit etc.

With kidney purchases placed on a legal footing, doctors and surgeons would not be faced with ethical issues regarding surgery. In fact, they would be helping their patients towards a better life.

Transplantation provides the best solution to kidney problems but the current donor system simply cannot provide enough. Although some people are fortunate enough to receive a transplant, often it comes too late to provide the best possible benefits as the patient has begun to deteriorate after years on dialysis. If that same patient could have access to a live kidney early on, it could be a much improved outcome.

It seems such a logical thing that a renal patient should be able to simply buy a kidney from someone who wants to sell one. If I wanted to buy a kidney I would pay the broker \$20,000 to hold the money in trust for me until someone sold them a kidney that was the right match. In fact, taking it one step further, perhaps the broker could advertise for a kidney with the same blood group as me?

The health system would end up with big cost savings also – not just from savings on actual dialysis procedures but with all the other things that go wrong with the renal patient.

Savings in the dialysis area could be put to use for other areas of the hospital.

I think the health system and the government should be looking seriously at this issue, instead of their future planning simply providing for more and more dialysis patients.

Certainly, there will be huge problems to work through to make sure the system is legal and viable – such as availability of surgeons, theatres etc. etc. but it seems to me that there is nothing that really is a total obstacle. Some people may not agree with the idea of purchased kidneys and that would be fine, they would still be able to wait on the list but at least the opportunity would be there for those who do. The idea of purchasing of a kidney would also need to be introduced sympathetically, alongside reinforcement of the current donor system, so these types of donors were not lost. However, in particular, with the cadaver donations, these people are normally giving several organs anyway. Assistance to the people receiving these organs would still not be available through other means.

There is, of course the risk of a purchased organ rejecting but modern methods of transplantation have seen this risk diminish. I guess it would be like anything in life where one takes a risk in order to reap rewards. Occasionally there is failure but the chance of success is far greater. People who purchased a kidney would go into the transaction aware of this risk.

We have simply come to accept that it is wrong to buy an organ, and only third world countries would do this, but if managed properly, this could be the key to improving future renal services for both patients and providers. In a country the size of New Zealand this should be achievable.

**These are the thoughts of Barbara Wright, we welcome your thoughts and comments, and thank Barbara for sharing this article.**

## From the Medical Director's Desk.

### Kidney Health Australia stages International Chronic Kidney Disease Summit

Globally there is an increasing awareness of the significance of chronic kidney disease (CKD) as a major public health problem closely linked to diabetes and cardiovascular disease. Our trans Tasman cousins in Kidney Health Australia have been very active in raising public awareness about CKD in their country. Kidney Health Australia (together with the Australian and New Zealand Society of Nephrology) organised an International Chronic Kidney Disease Summit on CKD in Sydney in July 2007. I was invited to attend as an observer. Representatives from both State and Federal health management in Australia were invited and there was extensive media interest.

In recognition that we can all learn from the experience of others, the organisers invited some important guests from overseas. They were:

Professor Allan Collins, Chair of the United States Renal Data System (USRDS), President of the US National Kidney Foundation and well known contributor to public health issues in CKD.

Dr Desmond Williams, Senior Public Health advisor for the US Centre for Disease Control (CDC) whose is in charge of managing the Kidney Disease Initiative.

Mr John Davis, CEO of the National Kidney Foundation responsible for the Kidney Early Evaluation Program (KEEP) for CKD in the USA.

Professor John Feehally, Chair of the Joint Specialty Committee for Renal Medicine, and member of the Renal Advisory Group in the United Kingdom was heard through an interesting pre-recorded a presentation.

A number of well known Australian nephrologists spoke and the meeting was facilitated by Mr George Negus (previously with *60 Minutes* and the *Today Show* in Australia)

The meeting addressed the burden of disease from early CKD and end stage kidney failure, and Australian indigenous issues. The challenges to early detection and evaluation of CKD and to governmental responses were also discussed.

The conclusions from the summit are particularly relevant to the New Zealand Kidney Foundation in its quest to raise awareness about CKD.

- The barriers to success in raising awareness of CKD are the same in New Zealand as they are in Australia, the United States and the United Kingdom.
- Foundations such as ours need to move away from a predominantly expert hospital doctor focus on dialysis and transplantation to become more involved in the community with primary health workers. This approach facilitates a *person*, rather than an *organ specific*, health message and allows collaboration with other groups, such as the National Heart Foundation and Diabetes New Zealand.
- It is vitally important that we know how many New Zealanders have CKD and we need a national surveillance system for chronic disease, including CKD.

## **Experiences of a kidney donor – Speech to NZ Kidney Foundation Conference 16 June 2007**

### **Introduction**

I've been asked to speak about my experiences as a kidney donor. I'm the other half of the "kidney kids" as my Mum likes to call us. Michael and I are very happy to help promote the cause of live kidney donation. Live donation doesn't seem to get talked about too much in the organ donation debates here at the moment but I think is really a critical part of the picture of dealing with increasing levels of kidney disease both here and internationally.

Today I'm going to talk to you a bit about my experiences as a donor and then pose some questions about what might be done to increase the number of transplants from live donors. This is just my experience and no doubt others would have a different story to tell.

### **Getting the news and making the decision**

I first met Michael in early 2002. He told me quite soon after we met about his kidney condition, which I have to confess didn't really register with me at all. I knew he took a whole lot of pills and that every three months he went off to see Alastair MacDonald at the renal clinic and got some news about his protein loss and creatinine levels – whatever they were. He was basically very healthy but had a medical condition that was well under control.

After about two years, as Michael has said, things started to change. I remember when Alastair broke the news to us that Michael was on the way to dialysis. He couldn't say how far away that might be – maybe five years or as little as two. Neither of us knew what dialysis really involved but we knew things were bad. I remember Alastair saying to us that this is one of those life-changing moments but there was definitely a sense of disbelief about the whole thing. Five years didn't seem that far away and two seemed like no time at all. Alastair also started talking about transplants and the possibility of a pre-emptive one, which seemed like a distinct possibility given the kind of timeframes we were looking at.

We were given a bunch of pamphlets about kidney failure, dialysis and transplants and went away to absorb the news. There wasn't really a decision for me to make at this stage – it just seems like something you do. Michael's sister and nieces were also willing to be considered so we thought we had a reasonably good pool of people to draw from.

### **Match making**

The first thing was the blood match. I'm O negative, the universal blood type, so am compatible with everyone. None of Michael's immediate family were the right blood type (he's O positive so has to receive from another O) so pretty soon it was narrowed down to me.

I think we had the tissue match done in about April 2005. It just involved blood being taken from both of us and sent away to Auckland for some kind of test that took about 6 weeks to do. We couldn't imagine what might be going on with our blood over such a long period.

At our next appointment with Alastair in May, he had the requisite slip of yellow paper with the results and somberly announced that the cross-match was...negative. Michael and I both looked at each other. For me, there was a small sense of relief that I was off the hook but my overwhelming emotion was disappointment. Now what were we going to do? However, Alastair carried on talking about the next steps towards a transplant and we had to interrupt and clarify what was going on – it turns out “negative” means you are a match ie it’s negative for a rejection, and positive means you’re not. Phew! So on we went.

### **Being tested**

The next thing for me was a whole lot of tests to see if I was healthy enough to be a donor, including whether I had two kidneys to start with (not everyone does). There was a whole heap of tests: blood and urine tests, ECG, chest x-rays, appointment with a psychologist, renal ultrasound, MRI. Most of these were pretty routine and kind of interesting – I’ve never really had anything wrong with me so found being in the hospital system a new experience.

However, these tests were spaced out over a period of about 12 months and it became very frustrating that things couldn’t go faster. The backdrop to all this was that Michael’s kidneys didn’t last anything like two years and he became very ill, very quickly. I seem to remember a period of constant migraines, vomiting, tiredness, cramps, emergency trips to hospital for one thing or another. After about six months of this, he was on dialysis.

That was a whole other shock to both our systems. They say that when one person in a couple is on dialysis, it’s like they both are and that’s pretty much how I found it in terms of the restrictions on our lives and the endless worry. Having said that, we managed pretty well, I think. Michael kept on working full time, we managed to have occasional trips away thanks to Baxter’s wonderful delivery service, and we retained a certain grim sense of humour about it all. But it was clear that the need for a transplant had become a whole lot more urgent and having a partner with a chronic and life-threatening illness is one of those things in life that’s up there on the stressful life events scale. So all in all, it was not an easy time.

My testing regime continued and all seemed pretty routine. It seemed to be assumed that the transplant would be going ahead, to the extent that Michael wasn’t even on the cadaveric waiting list. We found it hard to get any kind of steer on when it might happen, though and found that difficult.

After about 10 months of testing, when we were just about at the end of it all (or so I thought), one of the tests came back with some inconclusive results so I had to have two more tests that hadn’t originally been scheduled – a renal arteriogram and a renal scan. Plus I also ended up with an unexpected visit to an endocrinologist and some more tests from him. All of this happened within a few weeks so thankfully I didn’t have to wait too much longer.

I felt really comforted that all the specialists were being so cautious and so thorough – it was pretty clear they weren’t going to let me do something that would turn out to be dangerous for me. However, it was also very stressful at the time for both of us as for a few weeks it looked like the whole thing might be in doubt and we’d spent nearly a year on this process, and I kind of had to go through the whole decision-making stage all over again.

Finally we got the go ahead and were then told we could be booked in for the next month (June). We decided we needed a bit more time to adjust and opted for August instead. Having this kind of flexibility was definitely an advantage for us both.

### **Preparing for the operation**

We had a couple of months to warn people at work, including for me finishing up a very big project that I was leading. I arranged for my Mum to come and stay with me for a week or so after I got home; the neighbour was organized to feed the cats; many people made offers of casseroles, and I stockpiled lots of trashy books. We also arranged to go on holiday to Queenstown and see the Southern Alps in snow (somewhere I'd never been) – thanks again, Baxter's. And about 10 days before the operation, Michael decided to propose. So we had plenty to distract us in the leadup to the big day.

There was a real sense of unreality about it all. It was only other people's reactions that suggested it was a really big deal. I don't think it really hit me till about the day before.

Michael went in to hospital 24 hours early. He got to have his own room in the renal ward (not as luxurious as it sounds) while I would be on the general surgical ward. This was one of my big worries. I really wanted to be sure that someone would come and tell me how he was doing – I didn't want to be relying on family to convey news – and I wanted to be sure that I'd be able to see him. I was assured that this would all be taken care of.

### **The operation**

I had to be there at 7am on the day. Mum took me in and I had time to go in and see Michael before heading off to surgery. I think I was first on the list that day so didn't have to wait around too long. Just as well. I was very nervous by then but the staff were really good and put me at my ease. I don't remember anything after them giving me something to take the edge off my nerves, until I woke up again about five hours later.

### **Recovery**

I woke up feeling really, really sick. The morphine had disagreed badly with me and I felt nauseous and in lots of pain. I can't remember too much about the first 24 hours. I know I felt pretty knocked around and very tired so I slept a lot. They say it's always harder on the donor but I had expected that would be something to do with the pain – I hadn't counted on feeling just so incredibly sick and I was also pretty disappointed that the morphine disagreed with me. I'd been looking forward to that little self-administered pump.

I also desperately wanted to know if the transplant had been successful. Andrew Kennedy-Smith, my surgeon, came by and said all was well and various members of the renal team popped in to give me updates on Michael's progress.

Although I'd been really bothered about not being near him, I think it was probably a good thing for the first night. We were both in a lot of pain and wouldn't have been much good for supporting each other initially. I remember Michael's sister coming to see me on that first night and telling me how much pain he was in. I was in no mood to have any sympathy for him and just wanted to know if the kidney was working. After that though, I would have liked to have been nearer to him. It was hard being apart and getting down to see him was not as straightforward as it might have been.

The kidney did work though. They said it was functioning even before he was off the operating table and everyone who came to visit me said how amazing his colour was. It truly seemed miraculous to me and I knew that everything we'd been through was all worth while.

I was in hospital for about four days and then went home. Michael came home about two days later but was immediately readmitted because of a mild rejection episode. More stress and anxiety – we weren't out of the woods yet.

Meanwhile, I was still feeling terrible and had had to have several trips to my GP to try and do something about the nausea and other discomfort I had. Nothing seemed to work so I eventually resorted to travel ginger calm tablets which thankfully relieved the nausea.

When Michael came home, he was like a different person – better colour, eyes all sparkly and full of energy from the steroids. The upside of this was that he had plenty of energy to start planning the wedding although I was less enthusiastic about it at that time.

We both went back to work after about a month. In retrospect, that was too soon for me. My job was very stressful and even though my boss was very understanding, I found I had no resilience to deal with any of it. I think that the stress of the last year, with Michael on dialysis and the anticipation of the transplant, finally caught up with me, and after about 2 weeks my doctor ordered me home for some more rest. None of the doctors I talked to during this time seemed at all surprised by this turn of events but I wondered if I might have been able to have been better prepared for the emotional impact it would have on me so I could have planned better.

I'm sure everyone reacts differently but I suspect there's something about being the partner of someone who is really sick, on top of being a kidney donor and having what is, after all, a pretty major and unnecessary operation. As Andrew said to me, "with Michael we took a sick person and made him better. With you, we took a well person and gave them an operation they didn't need. It's no wonder he recovered faster than you."

After about 4-6 months, I think I came right. I also stopped worrying about how long the kidney might last for and as a result became much less anxious. There was no one moment of a great sense of relief. It just gradually got better and of course, life without dialysis is just fantastic. I don't think I'm a saint despite what everyone says– just very, very lucky to have been able to do something for someone I love that has improved both our lives so much.

## **Conclusion**

I said at the beginning that I thought getting the numbers of live donations up is a really critical part of addressing the demand for kidney transplants. This isn't just about making life better for those individuals and families who are directly affected. Kidney disease places a huge burden on our health system (as it does internationally) and keeping people on dialysis is expensive – I think about \$65- \$70,000 a year for Michael. Getting more people off dialysis has got to make sense and live donations are going to be one of the key ways for that to happen.

I don't want to say anything that would put anyone off being a donor but I also think we need to get real about what it's like and take some steps to making the whole thing a more attractive proposition for donors.

We have friends and people in our wider families who've said they'd now consider it should this kidney fail but I'm not sure we could ask this of them given the time and cost involved.

Things that could make it a better package for donors might include:

- **Support before and after, including more intensive follow up**

- Info about what to expect, including emotional impacts

- Better connection with donors' GPs especially since they'll be the ones doing most of the follow up support

- Being able to talk to people who have been through it themselves – and get honest information – lots of the information available is a bit short on specifics and also paints such a rosy picture that it just doesn't seem real

- **Timeliness of work-ups**

- 1 year is too long. You have to put life on hold to a certain extent and it might all come to nothing. It's both stressful but also must make it hard for some people to commit

- **Donors shouldn't be out of pocket as a result**

- I was very lucky to have enough sick leave accumulated to cover my time off, and an understanding employer. Many people wouldn't be in this situation and being a donor could cause real financial hardship. If I'd had to rely on the financial support available to donors, I literally wouldn't have been able to pay my mortgage.
  - I also experienced costs from all the follow up visits I needed to my GP to deal with the after-effects. It doesn't seem reasonable that I should have to personally cover those costs.

I think also more information and greater awareness are important – hence us agreeing to talk publicly about our experiences. I know a lot more now than I did a couple of years ago and I suspect I had the same misperceptions or slightly confused notions about kidney failure, dialysis and transplants that many people seem to have.

Dialysis is not a lifestyle choice, and people die if they don't get transplants – it might not be immediately but both quality of life and life expectancy are reduced and there are significant social and economic impacts both for individuals and their families but more widely as well.

We also need to normalize live donation. Lots of people seem to think me and Michael being a match is some kind of miracle, and that the whole thing is somehow "special" or "romantic". I've also had questions about whether Michael has taken on any of my characteristics after the transplant, or even whether any of my memories might have been transferred to him. I wonder if more people would consider donation if there wasn't all this mythology attached to it.

There's no doubt in my mind that I've absolutely done the right thing and I would encourage people to look at being a donor as an option. A few months of discomfort are completely outweighed by Michael's increased life expectancy and our vastly improved quality of life. Plus I think I've done something for the greater good by freeing up a kidney from a deceased donor for someone else and saving the health system a fair chunk of money. I feel very, very fortunate that we've had this opportunity to improve Michael's health so much and improve both our lives. I hope that by talking about our experiences we can stimulate some more debate and discussion about the issue of live donation and encourage even more people to consider it.



Paula Martin.

**From Palmerston North Kidney Support Group:**

JVL Prestige Limited have kindly agreed to help the group by providing free advertising on two of their large LCD screens based in Fitzherbert Ave, a very busy road leading to Massey University Campus. The Group is wanting to promote organ donation, both living and deceased donors, so is looking for a catchy slogan to have showing on the screens. Any suggestions please contact Barbara Wright C/o PN Kidney Support Group on (06) 357 0594.