

Kidney Health

NEW ZEALAND

Prevention • Support • Research

Spring 2011

I'd like to say it feels as though this year has flown, but I would be lying as it seems a lot has happened in 2011, but as planning for next year is already well underway it seems to suddenly be speeding along towards 2012 rather quickly now.



Kidney Health Week 4th – 10th March 2012 including World Kidney Day Thursday 8th March

Plans are underway for our awareness week next year. The theme for World Kidney Day is **Transplantation**. We have decided to use this opportunity to focus on the benefits of transplantation.

A pack containing printed tee shirts, with the word Thank you, in 8 different languages, together with cards, with the same design, will be given to transplant recipients, along with a packet of freesia bulbs (generously donated by **Oderings**). The idea is for the recipients to plant the bulbs in their community on March 8th, it could be their local community centre, school, library etc. The local media will be contacted so they can attend the planting, take a photos and talk about why you are giving something back to the community.

We are hoping to have lots of stories from recipients talking about their experiences and some donors who are happy to share their stories too. Experience tells us the media like these types of stories, so we are hoping to get better publicity this year which will be an opportunity to raise awareness about kidney disease in a roundabout way.

We will be promoting all organ transplants as we are working with Organ Donation New Zealand (ODNZ), although KHNZ will be having a particular focus on kidneys of course. We are going to organise at least one function to recognise live donors, this will be at Government House in Wellington. We are also hoping to have similar functions in Auckland and Christchurch, although these have yet to be confirmed, as they depend on the local Mayors availability.

If you know of anyone who would be happy to tell their story please let us know. An article by Kelvin Lynn on the subject of transplantation features further in this issue.

Kidney Information Forums

These continue to be well attended; I recently spent time in Wanganui where I spoke to a group of kidney patients and medical staff. In New Plymouth, Kelvin and I spoke at the kidney information forum, to about 50 people, there were a great variety of speakers and the feedback was very positive. It was a good opportunity to meet the two new nephrologists to Taranaki; Dr Alastair Williams, one of the new kidney specialists, spoke about the plans for the care of kidney patients in the region, which were greeted enthusiastically. I know the local support group were pleased to meet people who were keen to become members.

At the end of October we participated in another kidney information forum for the Wellington Regional Kidney Society, held in Porirua, there was a great turnout here too. We were welcomed by a cultural group of music students from St Michaels School, who were fantastic and full of enthusiasm. The theme for the day was transplantation, the Kidney Transplant coordinators from Wellington spoke about the process of being a kidney donor and for the process for a recipient. A wonderful woman spoke about her experience of being a non directed (altruistic) kidney donor, she talked about her recovery from the operation and the thrill she



has knowing the person who received her kidney is doing well. She was an inspirational speaker.

Clare Beckett and Sheryl Sparkes , Transplant Coordinators speaking at the Kidney Information Forum in Porirua

We look forward to holding more of these information forums in 2012

0800 information line and website

These continue to keep me busy, answering questions and providing information on a wide range of kidney related issues. Needless to say the recent focus regarding Jonah Lomu has certainly meant an

increase in calls and requests for information around kidney donation. It will be interesting to know how many of those calls go on to be live kidney donor. The fact that awareness is raised about kidney disease can only be a positive thing.

New Office

We have finally moved into our new offices, and I must admit they are quite an improvement on our previous one, although I think anything would be! Our new address is Level One, 230 Antigua Street, Christchurch 8011.

A Marathon Effort

Congratulations to Craig Whitaker, aka One Kidney, who managed to pass 2307 runners after starting last and completing the Auckland marathon recently. Craig was raising money, and awareness for Kidney Health New Zealand. A mighty effort. He was sponsored by **The Shoe Clinic** for every person he passed during the marathon. Craig shares his story below.



Most children remember their first holiday, trip to the beach or birthday party, but my very first memory of my childhood is not a happy one...

My name is Craig and I remember at the age of 3 ½ years, sitting in a cold stainless steel bath at Auckland Hospital, in pain with tubes and monitors everywhere. I was scared and upset. I had endured a 9 hour operation to remove my kidney, which had become the surgeon's mission to save it as he felt he was able to. This is because I was born with an undiagnosed urinary tract defect and this went undiagnosed for 3 years and resulted in my left kidney becoming diseased.

Unfortunately luck was not on my side after this surgery as I developed an allergy to the sutures used to close the wound, resulting in an open wound for an extended period of time and then an ugly scar after it finally healed.

However, my second memory is a happier one. After two weeks of being bedridden, the doctors removed my drains and at last I was 'free!' I ran down the corridor as fast as my legs could take me... and would have continued to run if it wasn't for my specialist who caught me in the act!

If we then skip forward 9 years to a routine check-up, an elevated blood pressure was detected and after 12 further months of tests and a kidney function test late in 1990, my specialist concluded that my problematic kidney was again losing function and would have to be removed.

In January of 1991, I had a second operation and this time the kidney was removed, with the added bonus of the removal of most of the ugly scar tissue which was the result of my first operation.

Why Running:

Well as you now know I developed a desire to run at a very early age. I loved to run and I can remember always looking forward to athletics days at school and loved it when it was cross country time. My parents entered my brothers and I in athletics competitions from a young age and I did pretty well especially in the longer distance events.

Over time other things became important (like school work), but my passion for running was reignited in my late 20's, where I started competing in triathlons (from sprint to half ironman distance events). My slender frame meant that running quickly became my strength again across the three disciplines and more recently, I have taken on the challenge of the marathon!

A fantastic effort, Thank you Craig.

From the Medical Director – Kelvin Lynn

Transplantation – ongoing challenges for patients and the health system

Support for kidney transplantation has been a core activity for Kidney Health New Zealand since its establishment in 1979. For most people with kidney failure a transplant is the best treatment providing superior survival and quality of life to dialysis treatment and being cheaper in the long run. Sadly, many New Zealanders that could benefit from a kidney transplant are missing out because of the lack of donors. There are two types of kidney transplant: a transplant from a living donor or from a person who has died suddenly – usually called a deceased donor. At any time there are about 350 people waiting for a deceased donor kidney and the average waiting time is between three and five years.

Organ Donation New Zealand (www.donor.co.nz) reports that in 2010 there were 41 deceased organ donors or 8.7 donors per million population and 50 kidney transplants from these donors. The world leader for organ donation is Spain with 32 donors per million population. New Zealand organ donor rates are low compared to other countries with similar health systems. We do better with living kidney donation with 60 live donor kidney transplants in 2010.

Since kidney transplantation started in New Zealand in 1965 there have been significant advances in preventing and treating rejection. Now a person receiving a deceased donor kidney can expect to have a 95% chance that it will be working at one year and then for many more years. On average a live donor kidney transplant should work for 15 to 20 years.

The co-ordination of deceased organ donation is managed by Organ Donation New Zealand based in Auckland. Kidney transplants are carried out at Auckland, Wellington and Christchurch Hospitals. Live donor transplants are co-ordinated by transplant co-ordinators at these centres. More information on donation can be found at www.donor.co.nz or www.kidneys.co.nz.

There are significant barriers for potential live kidney donors. Just finding out about who can be a donor and what the benefits of transplantation are can be a challenge. Good sources of information are the transplant coordinators at the three transplant units on Kidney Health New Zealand's website. The process of assessing potential donors is lengthy – too lengthy according to many who have been through the process. Work is being done at transplant units to reduce the delays in getting special tests done and in freeing up more operating theatre time for transplants.

For some people with kidney failure new transplant technologies offer new options. Kidneys can be transplanted from some live donors with an incompatible blood group after the recipient has had special treatment to remove rejecting antibodies from their circulation. A paired kidney exchange programme is being developed and the first pair of exchanges has already been carried out. More information is available at www.kidneys.co.nz/Organ-Donation--Transplantation/Live-Kidney-Donation/Paired-Kidney-Exchange/

How might we increase our organ donation rate?

Would an organ donor register as some countries have be a help? KHNZ believes that this would be an expensive and inefficient process unlikely to make a big difference.

Would more discussion in families and communities about the benefits of organ donation help to increase donor rates from some groups in our community who traditionally have low donor rates?

Should we have a system where everyone is considered to be a potential organ donor unless they indicate otherwise – an “opt-out” system?

Should we consider increasing the financial assistance to reimburse the expenses of live donors or even provide a “reward” for these donors?

The theme for World Kidney Day on March 2012 will be *Donate - Kidneys for Life – Receive*. KHNZ will be working with Organ Donation New Zealand on a number of activities devoted to increasing awareness of the benefits of organ donation and stimulating community discussion.

SOLID – An exciting new dialysis study!!!

SOLID is an acronym which stands for “**S**odium Lowering In **D**ialysis”.

SOLID is a scientific dialysis study which will begin in late 2011 in New Zealand. Patients on home haemodialysis in Counties Manukau, Auckland, Waitemata, Capital and Coast and Canterbury DHBs will be eligible to participate in the study and we would like to have as many patients as possible participate!

The trial is endorsed by the Health Research Council of New Zealand and the Australasian Kidney Trials Network.

The study will be co-ordinated from Counties Manukau and nephrologists from all over the country will also be involved.

We will begin approaching patients to invite them to enrol in the study around February next year.

What is the study about?

The study is based upon the knowledge that where salt (sodium) goes in our bodies, water goes too. A lesson which we all know from the dieticians!

In dialysis patients this is very important as really the only way for water to leave the body is on dialysis. Therefore, if a dialysis patient has too much salt and hence water in their body, they may not be able to get rid of it. It will cause high blood pressure and damage their heart and blood vessels.

We think that if we can reduce the amount of salt in dialysis patients' bodies, then we can improve the quality and quantity of dialysis patients' lives.

So how do we reduce salt?

The way that we are going to reduce salt in the body is to reduce the amount of salt in the dialysate which home haemodialysis patients use. The idea is that with less salt in the dialysis fluid, the patient will end up with less salt in their body at the end of dialysis.

After a year of having dialysis with less salt in the dialysate we hope to show that the trial patients' blood pressures, blood vessels and hearts will be in better shape than they were at the start of the trial.

What is involved for the patients?

The study is what we call a controlled trial. Half of the patients in the study will receive the low salt dialysate for a year and the other half will continue on their usual dialysate.

Everybody in the study will have an MRI scan of their heart at the beginning of the year and everyone will have an MRI scan of their heart at the end of the year.

The scans will be reviewed by a prominent New Zealand's cardiologist (heart specialist) called Dr Ruvin Gabriel. He will be looking to see if we've improved the hearts of the people on the low salt dialysate over the course of the year.

We will also be measuring some other things like blood pressure every 3 months during the study to see if they improve with the low salt dialysate.

We believe that all the patients in the trial will benefit from the close attention that they will receive during the study and that the information that we get from doing this study will help to improve the health of all dialysis patients in New Zealand.

At Counties Manukau, we've already performed a smaller pilot version of this study and showed that low salt dialysate is safe and causes no additional symptoms.

How will information from the trial help dialysis patients in the future?

We are really excited about this study, as we think that it has the potential to show that a simple and cost free alteration to the amount of salt in dialysate can ultimately save lives.

Want more information?

The doctors involved are;

Counties Manukau	Dr Mark Marshall, Dr Chris Hood and Dr Jo Dunlop
Waitemata	Dr. Janak de Zoysa
Auckland	Dr. Imad Haloob
Wellington	Dr. Grant Pigeon
Christchurch	Dr. David Macgregor

If you are interested in participating in the trial or would like to know more about it then please feel free to email Dr. Jo Dunlop on Joanna.dunlop@middlemore.co.nz or speak to your dialysis nurse or SMO.

We remember:

Allan Livingston

Allan was a stalwart of the Nelson/Marlborough Kidney Patient Support group, he helped set up the group and worked hard, along with his wife Faye, to provide support and information for people with kidney failure in the region. He will be missed by us all. Our thoughts are with his family. R I P Allan

The staff at Kidney Health New Zealand would like to wish you all a Happy Christmas and a Safe and Healthy New Year. Thank you for your continued support, particularly during such a difficult year. We look forward to the earth settling down in 2012.



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

\$100 \$50 \$20 \$10 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
- More information on general kidney health.
- Information about kidney donation/transplants.
- To become a member of Kidney Health NZ
- Information about making a gift to Kidney Health NZ in my Will

Name:.....

Address:.....

.....

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Thank you for your support.

Please return this form to: Kidney Health New Zealand, Level 1, 230 Antigua Street, Christchurch 8011



Don't forget to check us out on Facebook, head to our website and click on the icon and you're there