

# Kidney Health

NEW ZEALAND

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

## Autumn 2010 edition



Miranda Walker, renal nurse takes MP Mita Rinui's blood pressure as part of a kidney health check. This year's visit to the Beehive saw us inundated with people wanting a kidney check, indicating our message is being heard even at the highest level!



Denise Beechy, from the renal unit at Middlemore Hospital testing a blood glucose level at Polyfest 2010

 **Just Water**  
*Just the best!*

Welcome to the autumn edition of our Kidney Health newsletter. I can hardly believe we are in April already; maybe the fact we managed to have our awareness week spread out over 10 days this year could be one reason for the time disappearing so quickly, we certainly had a very busy time.

### **Kidney Health Week**

As the theme for World Kidney Day 2010 was **“diabetes and kidney disease”** we decided to focus on the group most at risk, Maori and Pacific people. On Thursday 11<sup>th</sup> March – World Kidney Day, staff from Kidney Health NZ and Capital Coast DHB renal department spent the day in Cannons Creek, Porirua working with members from Porirua Health Plus PHO (Primary Health Organisation) providing screening and information about early detection and treatment of kidney disease. Included in the day were Pacific Health Services, Te Roopu Pookai Taaniwhaniwha ( a community based mental health service), Porirua Union Health Services and Maraeroa Marae Health Clinic, each service gave an overview of the services they provide within the community for Maori and Pacific people. This was a wonderful opportunity to experience how these groups work first hand – we were all impressed by the commitment of these groups to improve the health of their people. Of particular note the large proportion of people being screened who had type 2 diabetes. Plans are already under way to return to Cannons Creek at a later date. We were also joined by Alison Pask, community dietitian and Lorna Bingham, Diabetes Nurse Specialist (DNS), Capital Coast DHB, who were available for risk assessments and advice.

On Saturday 13<sup>th</sup> March we had a stand at Pasifika, an annual festival celebrating the unique cultures and identities of the Pacific nations and New Zealand. With more than 200,000 people attending the event we were kept busy taking blood pressures and giving information out to the many who came to our stand. This was another great opportunity to raise awareness in this high risk group.

On Tuesday 16<sup>th</sup> March we made our annual visit to Parliament, we had a record number of MPs and Parliamentary staff have their kidney health check, this included blood pressure and urine protein checks. This year we invited Lorna Bingham (DNS) to join us again; Lorna provided diabetes risk assessments for those present. Prior to our visit we sent packs to all MPs informing them of our impending visit. It seems word has spread about our visits as this year was our busiest yet, with people queuing to be screened. There were a significant number with blood pressures that needed further investigation.

Kidney Patient Support Group members from Wellington used the week to put posters up in trains and hand out flyers in the street informing people about the importance of healthy kidneys. In Wanganui support group members had a stand in the local mall with information about kidney disease and the importance of “getting checked” if you are at risk. In Dunedin staff from the renal unit together with members from the local support group took blood pressures and gave out information in the mall, they even made it onto local TV. Christchurch Kidney Society had information stands at the Central City Library and a manned stand together with the local diabetes society in the foyer of the hospital. Ashburton kidney support group members gave out information and took blood pressures in the town centre, once again raising awareness in the community.

**Thank you again to staff from Renal Units at Auckland, Middlemore and Wellington Hospitals for your wonderful hard work and support, we couldn't have achieved any of this without you**

## Education

Recently I spoke to nurses from a variety of areas in the health sector, including diabetes, community and practice nurses about the importance of screening for kidney disease in high risk patients. This is group we can work with to help identify kidney disease in their patient groups, in particular people with diabetes, Maori and Pacific people and those with a family history of kidney disease.



Emma Marsh (Auckland Renal unit) at Pasifika



Nurses from Wellington renal unit celebrate WKD

## The Future of Organ and Tissue Donation

The Future of Organ and Tissue Donation, an interdisciplinary seminar covering a wide range of issues to do with organ and tissue donation and transplantation in New Zealand, was held at Victoria University, Wellington recently. I was fortunate enough to attend and found it a fascinating day. It was interesting to hear from an anthropological perspective around the subjects of xenotransplantation, compensation for donors and the issue of commercialisation.

Lesley Sharp, Professor of Anthropology, Barnard College, USA, was the keynote speaker, she spoke on her current research which explores the nature of the scientific imagination specifically in reference to highly experimental efforts to develop organs of non-human origin, ranging from those culled from genetically altered simians (apes) and swine to mechanical prototypes (especially those that assist or replace the heart).

Dr Robert Webb, a Maori academic (Nga Puhī), talked about the preliminary research he is doing with Dr Rhonda Shaw, on Maori experiences of organ and tissue donation. The participants in this research often reflected upon their experiences with references to Maori specific cultural

understandings and values. This was followed by a fascinating insight into a Maori Whanau Journey into Heart Transplantation. Meri Ormsby spoke about her experience as a heart transplant patient, while one of her sisters spoke about how their whanau coped. Communication, language and culture played an integral role in the process.

Dr Ian Dittmer, Transplant Physician at Auckland City Hospital, and Clinical Director of the Department of Renal Medicine, gave an update on the Declaration of the Istanbul Custodial Group. The Transplantation Society (TTS), the governing body internationally for Transplant practitioners has become active in trying to influence the centres involved in this organ trade and traffic. In 2008 a meeting was convened in Istanbul under the auspices of TTS and WHO; this meeting included transplant physicians, surgeons, co-ordinators, anthropologists, government representatives, psychologists, and other leading advocates; subsequently the Declaration of Istanbul has been published in many leading scientific journals and clearly states the TTS position on these practices.

Ian also talked about the number of transplant centres around the world that offer foreign nationals the opportunity to have access to transplant procedures where the donors could be deemed to be outside “acceptable moral and ethical standards.” This includes executed prisoners in China, paid live donors – generally people of low economic means, or access to deceased donors where the organs should be being used for transplanting residents of that country. There is often movement of substantial amounts of money most of which rarely reaches the donor or their families.

Dr Johan Rosman, Chief Medical Officer and Renal Physician, Waitemata District Health Board, gave an overview of the current status of organ transplantation in New Zealand, comparing New Zealand to the rest of the world. He talked about the issue of organ trafficking and the risks this posed.

At the end of the day there was a panel discussion, which was brief due to time constraints, but very interesting with discussion around the issue of compensation for live donors and/or financial incentives for live organ donation – suggestions on how to increase the number of live donors included raising public awareness around the subject, with advertising campaigns, education forums a couple of ideas. Of course the issue of resources to manage increased numbers of donors, if and when this may happen, remains a further obstacle.

The area of deceased and live organ donation continues to stimulate interesting debate which is to be encouraged if we are to improve our transplantation rates.

#### **Some Facts and Figures for New Zealand 2009**

- There were 43 deceased donors
- There were 67 living donors
- There were 304 people waiting for a kidney transplant 31<sup>st</sup> Dec 2008
- There were 2099 people on dialysis 31<sup>st</sup> Dec 2008

**Since this forum I have had several calls about both deceased and living organ donation so have decided to include some information below.**

#### **How to become a donor – *(taken from the Organ Donation New Zealand website)***

The most important step when you have made a decision about becoming an organ donor is to tell your family your wishes and let them know which organs and tissues you are willing to donate. You also need to find out what other members of your family want. No-one knows when we might be faced with this decision.

In New Zealand people can register their wish to be a donor when they apply for their driver licence and subsequent renewals. This information is recorded on the driver licence with the word 'donor' and in the Land Transport New Zealand database.

However, even though this donor information is recorded on the driver licence, at the time of death the family will always be asked if they knew the wishes of their relative and their agreement to the donation of organs and tissues will be sought. If the wishes are not known, the Land Transport New Zealand information can be accessed by designated health professionals. This information can help the family to come to a decision.

It can be a little easier for families to make this decision if the wishes of their relative are known.

#### **Being a living donor**

Anybody in good health with two normal kidneys may be able to give one of their own kidneys to another person (be a kidney donor).

A potential donor should have a genuine interest in donating and a compatible blood group with the person needing the transplant (the potential recipient). The potential donor does not have to be a relative.

There are two types of living donor transplants in New Zealand;

- **Living related** – to someone who is a blood relative such as a brother, sister, cousin etc
- **Living un related** – could be a husband, wife, partner or friend.

It is also possible for someone to consider **non-directed** (or altruistic) donation. Non directed donation is a term used for potential donors who intend to give a kidney to someone that they do not know. In such cases the kidney would be allocated to the best matched and low-risk person on the waiting list.

Potential donors should be over 18 years of age and in good health.

Potential donors should contact their local transplant coordinator or unit to find out whether they are compatible with the potential recipient.

The transplant coordinator can answer any questions that the potential donor has so that they can make an informed decision about having more tests. This conversation is strictly confidential and is not shared with the potential recipient.

Current research shows that kidney donation does not reduce how long you live or make you more likely to get kidney disease or other health problems later in life. *For further information go to*

<http://www.kidneys.co.nz/Patient-Information/>

## **From the Medical Director**

### ***World Kidney Day***

#### ***Diabetes, CKD and the Pacific***

The fifth World Kidney Day focused on diabetes, the commonest cause of kidney failure. This international event, marked in more than 100 countries, aimed to raise awareness about the link between diabetes and kidney disease and the need for early screening and treatment to reduce the risk of kidney disease.

The Ministry of Health estimates that there are 195,000 people with diabetes in New Zealand and there are likely to be a similar number with diabetes who unaware they have it. About 40% of people with diabetes will develop chronic kidney disease (CKD) which also increases the risk of cardiovascular disease and other complications of diabetes.

Maori and Pacific people with diabetes have an increased risk of getting chronic kidney disease. About one in three people on dialysis are Maori and one in five a Pacific person.

Early detection and treatment of CKD in people with diabetes is very important as it slows or halts the progression of patients to kidney failure. Good blood pressure and blood sugar control for people with diabetes are the best ways to reduce the risk of kidney damage. Lifestyle changes such as losing weight, exercising, stopping smoking, eating less salt and drinking less alcohol are also important.

Kidney Health New Zealand decided to work with local diabetes groups and Maori and Pacific Island health professionals to tell the story about the strong links between diabetes, ethnicity and CKD during Kidney Awareness Week.

On Wednesday 10th March Carmel Gregan-Ford spoke to Oratoa Health Unit's diabetes group in Porirua.

On Thursday 11th March, Carmel and I spent the day at the Te Akapuanga Cook Island Hall working with the Pacific Health Service Porirua, Porirua Union Community Health Services, Maraeroa Marae Health Clinic and Te Roopu Pookai Taaniwhaniwha performing kidney checks. Staff from the Wellington Hospital Renal Unit and the DHB's Diabetes Nurse Specialist assisted us. The Porirua Health Plus PHO supported the day. The energy and enthusiasm of the local people and the community health workers was very impressive.

On Saturday 13th March, Carmel, together with staff from Auckland City Hospital, carried out similar screening on 68 people at Pasifika, an event attended by over 300,000. Thirty-four percent of those screened were Pacific Islanders and eighteen percent Maori. Forty-one percent had a systolic blood pressure over 140 mmHg. A number of people were advised to see their family doctor for further assessment.

On Tuesday 16th March at our annual visit to the Beehive we were again helped by the staff from Wellington Hospital in carrying out kidney checks on the MPs and staff. All MPs receive a letter outlining the links between diabetes and kidney disease. One hundred and thirty-nine people were screened. Sixteen percent had proteinuria and 36 percent a systolic blood pressure greater than 140 mmHg.

Later that week at Polyfest in Auckland Counties Manakau DHB staff manned a stand, again just making sure we are getting our message out to those most at risk.

KHNZ's Kidney Awareness Week activities were again supported by the staff of the local renal units and patient support groups. Their help is greatly appreciated.

Kidney Health New Zealand hopes that this targeted screening of high-risk groups will raise awareness about the importance of kidney disease in our community.

***Chronic kidney disease is common, harmful and treatable.***

Professor Kelvin Lynn, Medical Director of Kidney Health New Zealand

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**From Diabetes New Zealand**

**Information for people with diabetes**

Diabetes may cause damage to your kidneys. Although you may not get any symptoms, damage can be detected at an early stage by your doctor.

Good blood pressure control and regular checks from your healthcare team are essential.

You can help yourself by:

- Managing your diabetes – take your medication, make healthy food choices, maintain a healthy weight, keep active and monitor your blood glucose level.
- Having your blood pressure checked regularly.
- Not smoking

**New Zealand Diabetes Facts:**

- 195,000 New Zealanders have diagnosed diabetes; of those:
  - 180,000 have type 2 diabetes
  - 15,000 have type 1 diabetes
- Diabetes affects more than 340,000 families
- 19 people are diagnosed with diabetes each day
- 800,000 overweight or obese people are at risk of developing type 2 diabetes

For further information please contact Chris Baty, President, Diabetes New Zealand, 021-933-929

**New Patient Education Resources**

Last year we were given the opportunity by the Ministry of Health to develop web based renal information resources. The aim was to provide better information resources for renal patients and their families living with renal failure.

The development of these resources was designed to enhance the current resources available where possible, not necessarily replace local resources that may be customised for their patient group, but to provide best practice resources for renal patients and professionals who need them.



We undertook a stock take of renal patient information resources currently being used in New Zealand Units, some Australian Units, and kidney patient support groups. With this information we determined priority topics to be covered and put together seven draft documents, a representative reference group was formed to review the draft documents. Members of this group included, renal patients, pre dialysis nurses, a transplant coordinator, dieticians, Maori and Pacific representatives, nephrologists, a social worker, transplant patient, palliative care professional and representatives from kidney patient support groups.

The draft documents were sent to all members in the group prior to meeting in Wellington where constructive discussion about each information resource took place. Changes were made to the documents following this meeting, and sent to the group for approval before they were sent to the graphic artist to work his magic in the presentation and graphic area. Pictures and video footage were inserted into some of the resources before the final drafts were put on the Ministry of Health website for those on the reference group to view before final changes were made.

The seven web based renal information resources are;

- Kidneys and Kidney Disease
- Chronic Kidney Disease and Diabetes
- Nutrition in Chronic Kidney Disease
- Treatment Options for Kidney Failure
- Having a Kidney Transplant
- Being a Kidney Donor
- Conservative Management

These resources will now be available on a variety of websites, including the Ministry of Health, Kidney Health New Zealand, Auckland District Kidney Society, Wellington Kidney Society and District Health Board websites as requested. Check out the new resources at:

<http://www.kidneys.co.nz/Patient-Information/>

We look forward to any feedback you might have and hope you find these new resources useful. Plans are already underway for further resources to be developed in the near future, so watch this space.....

Celebrating World Kidney Day around the country.



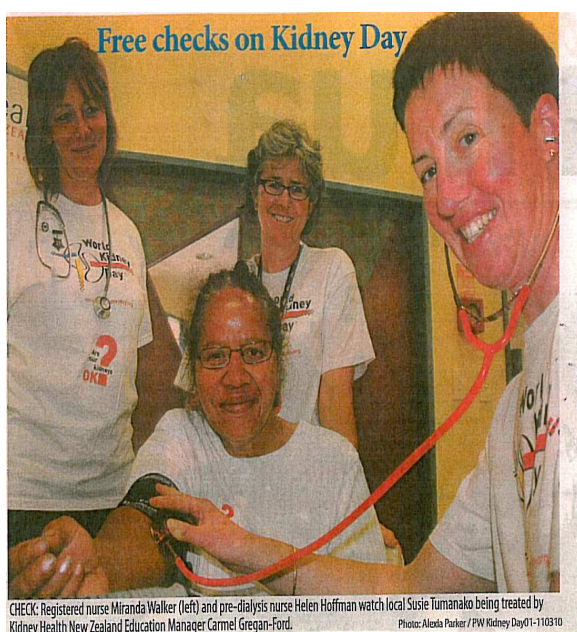


Wanganui Support Group

Porirua/Cannons Creek



Polyfest – South Auckland



CHECK! Registered nurse Miranda Walker (left) and pre-dialysis nurse Helen Hoffman watch local Susie Tumanako being treated by Kidney Health New Zealand Education Manager Carmel Gregan-Ford. Photos: Alexandra Parker / PIN Kidney Day01-110310



Christchurch Kidney Society display.