

kidney Health

NEW ZEALAND

Prevention • Support • Research

Summer 2009.



Delegates at the Senior Renal Nurses Conference 2009

Welcome to the summer edition.

Welcome to the long awaited summer edition of the Kidney Health newsletter, there seems to have been a lot happening since the autumn edition.

A number of speaking engagements have kept me busy, travelling around the country. Any opportunity to raise awareness about kidney disease and its impact not just on the individual, but their extended family and the community, is always a very worthwhile and enjoyable part of my role. It is interesting to note that a large number of these groups are diabetes support groups or diabetes interest groups, which is very encouraging as we work to build stronger relationships with such organisations. An article written for the Dialog magazine is included in this newsletter.

We have also been given the opportunity to develop some education resources for people with kidney disease, based on the material currently available around the country and literature reviews of overseas information we hope to be able to provide an up to date information package for a variety of needs. This work is being done for the Ministry of Health and we are currently in the consultation phase of the process. We plan to have these completed and available before Christmas. The idea is for these resources to be web based enabling easy access to the information for everyone.

The 0800 free phone information line

The 0800 free phone line has become increasingly busy during the last month, with many requests from people wanting to visit New Zealand but requiring dialysis while they are here. Unfortunately this isn't always achievable with the already stretched resources in many of the country's dialysis units. There has also been an increase in the number of people requesting information about live kidney donation. This could have something to do with a couple of recent news items being screened regarding the waiting list for a kidney transplant.

Our medical director Kelvin Lynn has now taken up residence in our office, one day a week, having retired from the nephrology department at Christchurch Hospital, after 30 years service. We meet weekly to plan and discuss any current initiatives or issues.

Senior Renal Nurses Conference

On September 4 – 6th Kidney Health New Zealand held their annual senior renal nurses conference in Auckland. This always proves to be a popular event with more requests to attend than spaces available. This year was no different with the feedback being very positive. We were fortunate enough to have some excellent guest speakers as well as some very interesting presentations from the nurses themselves talking about new initiatives in their units and patient care. Nick Polasheck, Senior Renal Project Manager for the Ministry of Health spoke about the Nursing and renal service improvement in New Zealand. He

talked about the work being done by the Ministry with the national renal project. It was interesting to hear what was happening behind the scenes and reflects a more collaborative approach. Nick also talked about some of the areas being looked at; these include improved CKD management in primary care, increasing rates of renal transplantation, regional co-ordination in planning for demand and access to services and improving information for and about renal patients.

Dawn Kelly, Project Manager from the Central Regional Renal Network, spoke about the work being done in a review of renal services. The goal of this work is to ensure renal services are closely linked with community health providers; can predict and work to prevent chronic kidney disease and primary care providers are able to work with renal patients effectively. The Central Region includes Capital & Coast DHB, Hutt Valley DHB, Wairarapa DHB, Mid Central DHB, Whanganui DHB and Hawkes Bay DHB.

Judith Dee, Diabetes Nurse Specialist from Counties Manukau DHB, talked about the burden of diabetes, with the frightening prediction that the number of people with diabetes is expected to double in the next 20 years. In Kidney terms this would mean 1 new dialysis unit would be needed every year. Judith talked about the fact 50% of New Zealanders are overweight, with 20% being obese: 1 in 3 Counties Manukau children are overweight or obese. It has been proven that being overweight increases the risk of developing type 2 diabetes. Judith talked about the effect diabetes had on the kidneys and the management of kidney disease. She also highlighted the importance of developing good relationships between the renal and diabetes services to ensure optimal care for our patients.

Kidney Support Group Forums

Currently we are working on a series of kidney support group information forums, following a questionnaire sent to all support groups the feedback we received was that a “road show” type format could be a useful way in which groups can hear what Kidney Health NZ is doing, get information/education on issues specific to their own groups and to give us feedback on the issues they may have. The first was held in Wellington on October 3rd, as well as the Wellington Kidney Society, members from Palmerston North and Horowhenua Kapiti groups, also attended, with the Wellington Kidney Society organising the day, it proved to be a great success. The next one was the 14th October in Ashburton and included Christchurch Kidney Society and the South Canterbury group, this was another successful day, with a large number attending and some positive feedback. Following the success of the first two forums we will plan for further events in the New Year.

In the meantime from all of us in the office at Kidney Health New Zealand we wish you all a very merry Christmas and a healthy and happy New Year.

Below is some useful information I found on a blog site written by a respected nephrologist from the UK Professor Donal O'Donoghue, which I thought answered an often asked question well.

Q & A: Could you explain the good, medium and low eGFRs and what they mean?

Q: My transplanted kidney is now in its 15th year and as far as my blood figures show it is still doing fine. My eGFR is 42 if that is anything to go by. I am coming up to my 87th birthday. could you put in the next Kidney Life some information on the eGFR to explain to members (readers) the good, medium and low eGFRs and what they mean? Best wishes, Frank Wood

A: *Congratulations Frank, on your upcoming 87th birthday and the 15th year anniversary of your kidney transplant. Your experience of receiving a transplant in your early 70s and continuing to live a long and productive life will be a great inspiration to others with kidney disease. Thanks for your question about eGFR and what it means. eGFR stands for estimated Glomerular Filtration Rate. Glomerular Filtration Rate is now widely recognised as the best measure of kidney function. It can be estimated from the level of creatinine in the blood and since a normal GFR in a young adult is about a hundred mls per minute, the eGFR can be thought of as percentage kidney function. Talking about eGFR as percentage kidney function has been a useful way to demystify kidney disease for doctors, nurses and patients. However, eGFR isn't a perfect measure of kidney function, it has several limitations and a single figure will never tell you everything you need to know about an individual's kidney or transplant function.*

Each kidney is made up of about 1 million nephrons. The nephrons do the work of the kidney – getting rid of waste products, controlling and adjusting the blood chemistry and producing the metabolic messengers vitamin D and erythropoietin that keep our bones and blood healthy. Nephrons do this by filtering the blood through tiny specialised blood vessels called glomeruli and then fine tuning what the body needs to retain or be eliminated along the tubules which make up the rest of the nephron. Filtration of blood across these filters is therefore the first and most important stage of cleansing the blood of impurities. This is called Glomerular Filtration Rate or GFR. The GFR can be directly measured by using radioactive isotopes or by infusing certain inert chemicals into the bloodstream. This is sometimes done to very precisely measure kidney function in people offering kidneys for live donation. Such tests are not practical in routine clinical practice for day to day assessment of kidney function. Fortunately, GFR can be estimated from serum creatinine which is easily measured. Creatinine has been used to give an idea of kidney function for many years. Creatinine, used alone, is an insensitive marker of kidney function, up to 50% of kidney function can be lost before the serum creatinine concentration rises above the normal range. Estimated GFR is a better measure of kidney function than serum creatinine. Since 2006, every laboratory in the UK has calculated a standardised eGFR using a formula based on sex, ethnicity, age and serum creatinine.

Routine reporting of eGFR was one of the recommendations of the National Service Framework for Renal Services. It has allowed early identification of kidney disease in literally millions of people. Early investigation and treatment of kidney problems has become a core part of general practice.

All people with kidney disease are now entitled to a care plan designed around their individual needs to keep kidney function as good as possible for as long as possible and to reduce cardiovascular risk. We are already starting to see improvements in blood pressure control in general practice and earlier referral to the multi professional kidney team to support individuals in making decisions about transplantation and dialysis when replacement therapy is needed. The eGFR is also the way chronic kidney disease is staged and monitored over time. Staging and monitoring also requires assessment of proteinuria by measurement of the albumin creatinine ratio, or ACR, in the urine. Proteins in the urine, of which albumin is the main protein, indicate a higher risk of progressive kidney disease and of cardiovascular risk.

Thankfully, protein in the urine can be treated by certain drugs including the ACE inhibitors and ARB class of blood pressure drugs. So regular, accurate assessment of eGFR and ACR are absolutely essential for people with kidney disease. The eGFR tells GPs when specialist kidney referral is needed – when the eGFR falls below 30 mls per minute. It helps the patients, nurses and doctors in getting the timing of transplantation before dialysis right (at 15 mls per minute or below) and/or in the preparation for dialysis such as when to operate to create a fistula for haemodialysis. Looking at an individual's eGFR over time tells you if the kidney function is stable, improving or declining – it acts as a trigger for further evaluation and changes in treatment as well as providing a window on the future. But eGFR doesn't tell you everything and used alone can be misleading.

The eGFR needs to be interpreted cautiously at the extremes of age and extremes of body mass, it can be interfered with by some drugs, it is not always helpful in the acute situation and the accuracy of the equation used hasn't been proven in all ethnic minority groups and clinical situations including transplantation. It is not a perfect measure of kidney function, rather it provides a guide.

Even eating a meal before the measurement can affect the reported level. There are equations for using children but the routine laboratory based equation is not suitable for people under the age of 18 years. It's of no value in people receiving dialysis. Hence the need to look at more than one thing to get the right answers – the ABC of kidney disease is know your: A ACR – albumin creatinine ratio in the urine; B blood pressure – aim for perfect blood pressure control; C creatinine for the eGFR = percentage kidney function

The introduction of eGFR into the National Health Service has helped demystify kidney disease. It has promoted the understanding of kidney disease by doctors and nurses. I would encourage all people with kidney disease, or at risk of kidney disease, to know their eGFR and to keep track of how it is changing. Your eGFR should be discussed as part of your care planning. People with kidney disease and the healthcare professionals who care for them need to speak the same language – so you need to know your eGFR, your ACR and your blood pressure.

From our Medical Director

Kidney Health Australia CKD Summit

Melbourne 23/24 Jul 2009

“Best care for Australians with Kidney Disease – the pathway ahead”

I was invited to attend the second CKD Summit organised by our sister organisation, Kidney Health Australia. Although a lot of the meeting was devoted to local issues there was plenty of time devoted to issues relevant to New Zealand. As well as a number of very useful workshops, there were talks from a panel of outstanding international speakers and talented local kidney health consumers.

The meeting started with a session entitled **“Overviews on CKD –Strategies to Reduce CKD burden, gaps, successes, future plans.”** Professor Donal O'Donoghue from the United Kingdom reported that the NHS pays GPs if they measure and report markers of CKD such as urine protein testing and measurement of blood creatinine concentration. People in Britain can now assess their personal risk for CKD online from a website developed by the NHS. The National Institute of Clinical Excellence (NICE) has published comprehensive guidelines on the management of CKD which can be compared to the Kidney Health New Zealand guide for GPs on the management of CKD. (NICE Clinical Guide 73 can be found at www.nice.org.uk)

Professor Adeera Levin from British Columbia spoke to the meeting via a telelink. British Columbia has a similar sized population to New Zealand and about the same number of people with kidney failure. British Columbia has a very successful single funding model for the care of CKD from diagnosis to death. In New Zealand primary care funds most CKD care and renal units usually only deal with more advanced CKD and kidney failure. The BC Provincial Renal Agency, which is managed by the clinicians, holds all the funds for CKD care and is accountable to the provincial government. All patient information is held in a comprehensive province-wide renal healthcare computer system called PROMIS. Healthcare activities recorded in this system drive the payments to the providers. The National Renal Advisory Board has reviewed this system in the past and believes that a national kidney care database would improve the care of people with CKD in New Zealand.

The third international speaker was Professor Allan Collins from the United States, a former president of the National Kidney Foundation and a member of the Board of The International Federation of Kidney Foundations. He discussed the usefulness of CKD detection programmes such as those provided during Kidney Awareness Week. He pointed out that these programmes by their opportunistic nature cannot identify all the CKD in a community but they can change clinical practice. Although there are many causes of CKD he advised that focussing on people with the big two risks – diabetes and hypertension – was a cost effective approach.

An important session at the conference was a discussion of the role of national bodies, such as the Ministry of Health in our country, in the establishment and maintenance of standards of clinical care or “quality” as it is now called. New Zealand is fortunate in its involvement

since the 1970s with the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) (www.anzdata.org.au) and in having national standards of dialysis care developed by the National Renal Advisory Board. A greater challenge is the assessment of the standard of care for early CKD, particularly in those with diabetes and hypertension. The public health challenge of CKD is likely to get bigger with time. Professor Collins pointed out that it is now known that most chronic diseases increase the risk of CKD and that the Generation X population has the highest rates of obesity and diabetes. David Parker, an analyst working for the Australian Institute of Health and Welfare and a transplant recipient, estimated that the aging "baby boomers" were likely to increase the numbers with CKD by 20 to 30%. In the NHS there are now 693 quality items relevant to clinical care that are recorded in primary care and affect the income of GP practices. Payment of doctors is used to change their practice – for example, the payment for a fistula is greater than for a dialysis catheter.

Dr Stephen McDonald, a nephrologist who works at ANZDATA, talked about what happens to people with severe CKD but who are not on dialysis. These people are usually elderly and often it is unclear whether their CKD will be a problem for them during the remainder of their life. In a group of such patients followed for two years about a half died due to other diseases, a 20 percent started dialysis, 20 percent remained well with stable kidney function and 10 percent were lost to follow-up.

My "take home" messages from the conference were that CKD is likely to become even more common, the important risk factors are still diabetes and high blood pressure and the prevention message is the same for all countries.

Chronic kidney disease is common, harmful and treatable.

Professor Kelvin Lynn, Medical Director of Kidney Health New Zealand

Telephone: 0274-376-542

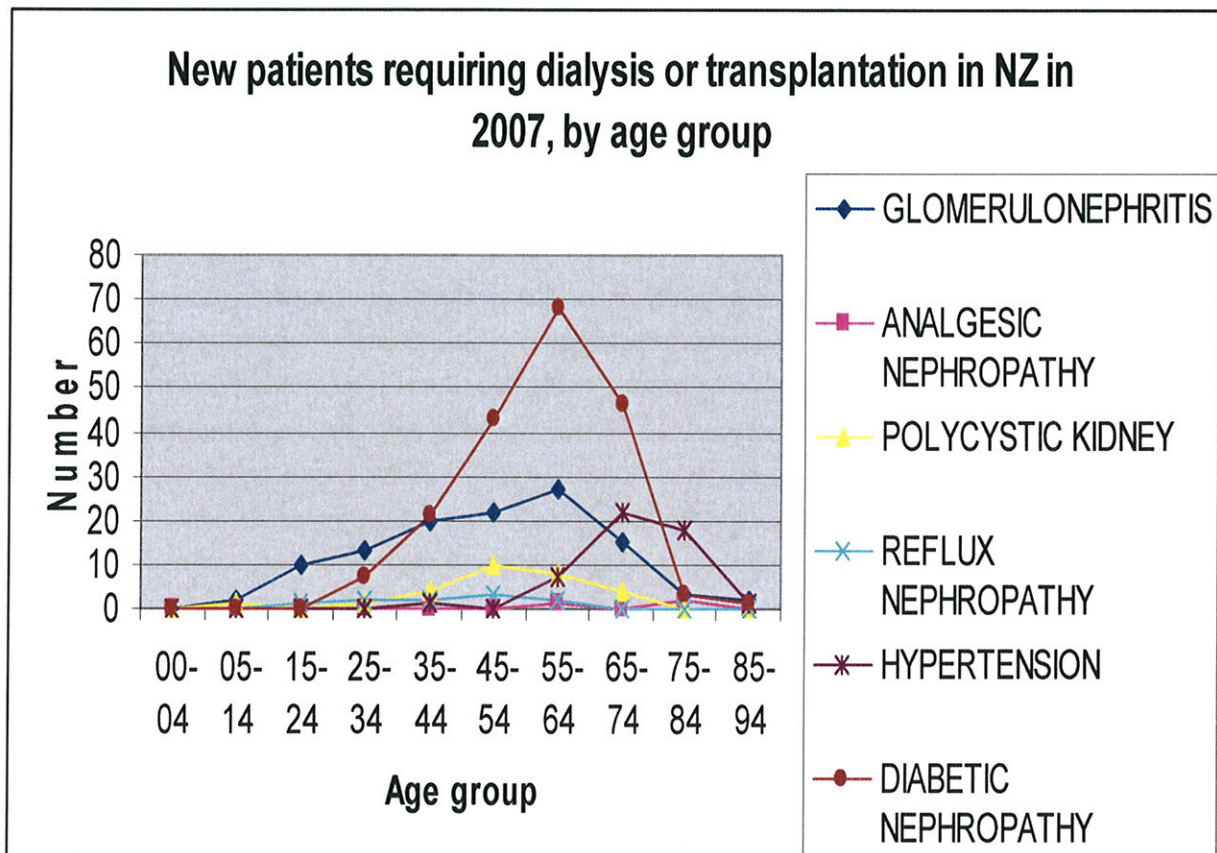
kelvin.lynn@cdhb.govt.nz www.kidneys.org.nz

Kidney Disease and Diabetes

Diabetes is the most common cause of kidney disease in New Zealand, people often have both.

Most people have two kidneys. They are located near the middle of the back, just under the ribcage. Each kidney is about the size of an adult fist. They are bean shaped and reddish brown in colour. The kidneys act as filters to clean the blood. They get rid of waste and extra fluid. They make and regulate important hormones in the body. These hormones control red blood cell production, blood pressure regulation and calcium absorption.

In New Zealand the rate of people developing kidney failure as a result of diabetes is continuing to increase at a significant rate.



Source – ANZDATA register 2008 Annual Report. (www.anzdata.org.au)

41% of new patients starting some form of renal replacement therapy in 2007 were as a result of diabetic nephropathy.

What is Diabetic Nephropathy?

Each kidney has approximately one million nephrons, the filtering unit of the kidney; with diabetes the small blood vessels (glomerulus) in the nephron of the kidney are damaged. When this occurs the kidneys are unable to perform their role

Diabetic nephropathy, if severe, can cause kidney failure.

Diabetes can affect the kidneys in other ways too, with changes to the immune system making urinary tract infections a more common problem, nerve damage to the bladder can make it more difficult to pass urine. A build up in the bladder can cause a backflow up into the kidneys causing scarring.

Kidney disease can be treated. The sooner you know you have it, the sooner you can get help to keep your kidneys working for longer.

What are the signs and symptoms of kidney damage?

The early stages of diabetic nephropathy have no symptoms. Symptoms develop in the late stages and may result in high amounts of protein being passed in the urine, with other symptoms including;

Puffiness e.g. legs and ankles

Changes in the appearance of the urine

Unintentional weight gain (fluid related)

Tiredness and trouble sleeping

Poor appetite

Pain/discomfort in the kidney region

How do you know if you have kidney disease?

The main tests are:

- Get your blood pressure checked by your doctor – high blood pressure can be caused by kidney disease or can cause kidney disease.
- Get your urine tested for protein – Leaking of protein from the kidneys is an early sign of kidney damage in diabetes. The more damage to the kidneys the more protein they leak.
- A simple test of the blood creatinine level enables overall kidney function or the estimated GFR (eGlomerular Filtration Rate) to be checked; this will tell you how much damage your kidneys have.

Early Intervention and prevention is the key.

The goal is to slow the progression of kidney damage and control related complications

The intervention of treatment with blood pressure medication has been a key step in slowing down the damage to the kidneys caused by diabetes

Angiotensin converting enzyme (ACE) inhibitors may be used, these can help reduce urine protein levels and slow the progression of diabetic nephropathy. A combination of these and angiotensin receptor blockers (ARBs) are often used. The aim is to keep blood pressure lower than 130/80.

Blood glucose levels should be closely monitored and controlled with hypoglycaemic tablets and insulin injections adjusted as needed. As kidney failure progresses less insulin is excreted, therefore smaller doses may be needed to control blood sugars.

What can you do to try and prevent diabetic nephropathy?

Aim to keep the HBA1c below 7%

Regular exercise

Avoid contrast dyes that contain iodine as these can worsen already reduced GFR

Avoid non steroidal anti-inflammatory drugs like ibuprofen and voltaren and Celebrex these may injure the weakened kidney.

Treat urinary tract infections promptly with appropriate antibiotics

Maintain a healthy weight

Take medication your doctor prescribes and check with them before taking any new medicines.

Keep all your doctor appointments.

Having chronic kidney disease doesn't mean you will need to have dialysis, your GP and healthcare team will help you stay well.



"I'm afraid the shark got your arms and legs. It's probably not a good time, but your brother's here. He needs a kidney."

Life with kidney disease – Thank you for sharing your story Esther.

Twenty years ago this month, Esther Batty from Feilding underwent lifesaving surgery, and she wants to make sure others in her situation get the same opportunity.

On June 7, 1989, Mrs Batty had a kidney transplant in England, after six months of dialysis treatment.

She traces the kidney failure that necessitated the transplant to a sore throat she suffered at Easter the previous year which developed into lupus, a chronic inflammatory disease.

Mrs Batty, originally from Palmerston North, was living with her husband and family in England when her illness was diagnosed.

"I was devastated when I first found out," she said. When the doctor told her she would eventually have to go on dialysis, "it seemed like a death sentence".

Now, she acknowledges, the prognosis was not as bad as she had thought.

Four times a day she self-administered continual ambulatory peritoneal dialysis a bag-to-bag system which performs dialysis through the natural lining of the abdominal cavity.

"It wasn't too bad. I got the chance to sit down and read a book four times a day.

"Dialysis was a huge blessing, a life-transforming thing for me. After being so ill I couldn't talk without vomiting, to have all the toxins cleared out of my bloodstream with the first dialysis was the most amazing experience. I was a different woman after that ready to get up and start living again."

Having been a nurse, Mrs Batty was aware of the importance of hygiene when carrying out the dialysis procedure.

"And it was much more gentle than [being hooked up to] a dialysis machine."

Once she began dialysis, she went on the waiting list for a transplant.

That meant being close to the hospital and ready to move immediately. It also meant six months of post-operative monitoring, and that almost put an end to Mrs Batty's chances of having an operation.

Her daughter Lynne was getting married in New Zealand in December 1989, and once the doctors found that out, they told her she would have to go off the waiting list, because she would not be around for the post-operative care.

She was given until the end of June, and if a donor kidney had not been found by then, she would have to come off the waiting list.

Mrs Batty believes God was looking after her when, early in June that year, a kidney became available.

Because she needed all the sleep she could get, the couple took the phone off the hook each night. Her husband's company provided them with a beeper to alert them if the hospital called.

At 5am, the day after the beeper was hooked up, it was activated and Mr and Mrs Batty were on their way to the hospital just five minutes away.

The surgery took about six hours, and Mrs Batty stayed in hospital for a week. Once she was discharged she had to go back every day.

She believes the availability of a transplant kidney and her recovery is nothing less than a miracle. She said family and friends did a lot of praying but there was practical support too, such as providing daily meals for the family.

Two of the couple's children were still living at home when Mrs Batty had her surgery. Daughter Sharon, who was 13, was "a marvellous help".

On Sunday, the 20th anniversary of her transplant surgery, Sharon, who now lives in Lower Hutt called her mother. "I just rang to say happy birthday to your kidney," she said.

Mrs Batty said she would be on drugs for the rest of her life, but she said she felt "remarkably well" despite what she had gone through. "[The kidney] just feels like a part of me."

Mrs Batty said she had the opportunity to go on dialysis while she waited for a donor, whereas people needing other organs, like hearts, just had to hope that an organ became available for them before it was too late.

She wants to encourage more people to state on their driver's licence that they are happy to be an organ donor, and to discuss their wishes with their family.

Under New Zealand law, family members can overrule the wishes of a dead person and prevent organ donations.

"Talk to your family and tell them what you want to do."

Mrs Batty believes her family are all potential donors. "They know what it did for me."

Did you know?

- Number of people living with a kidney transplant in New Zealand at Dec 2008 was **1351**
- Number of patients on dialysis in new Zealand at Dec 2008 was **2099**
- Number of new patients with end stage kidney disease from 1st Jan 2008 to 31st Dec 2008 was **492**
- New Zealand has one of the highest numbers of patients receiving dialysis treatment at home in the world, as at Dec 2008 there were **1085**
- The total number of patients receiving some form of renal replacement therapy in New Zealand in 2008 is **3823**
- It is estimated that more than 250,000 people in New Zealand have some form of kidney disease.
- There are currently **350** people waiting for a kidney transplant
- In 2008 there were 132 kidney transplants of which **53** were from deceased donors and **69** from living donors.
- **World Kidney Day is Thursday 11th March 2010**



Source – www.anzdata.org.au 2008 Annual Report.

BROCHURES & FACT SHEETS AVAILABLE FROM KIDNEY HEALTH NZ

Blood Pressure and Kidney Disease
Diabetes and Kidney Disease
Kidney and Urinary Tract Health for Women and Men
Organ Donation for life
Urinary Tract Infections
Kidney Donations
Reflux Nephropathy
IgA Nephropathy
Kidney Stones

Kidney Disease is a Silent Killer
Skin Cancer Fact Sheet
Car Bumper Stickers
Six Warning Signs of Kidney and Urinary Tract Disease
Need a reason to talk about the benefits of kidney donation poster
Kidney Disease in Maori and Pacific Islanders - **English**
Kidney Disease in Maori and Pacific Islanders - **Maori**
Kidney Disease in Maori and Pacific Islanders - **Samoan**
Kidney Disease in Maori and Pacific Islanders - **Tongan**

You can also visit our website:

www.kidneys.co.nz

or you can call our Information Line

'0800 KIDNEY' (0800 543 639)

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

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

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

☐ Mastercard ☐ Visa

Account number:

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Expiry Date:

Signature:

Please indicate if you would like:-

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

Name:

Address:

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Thank you for your support.

Please return this form to: 24 St Asaph Street,
Christchurch, Phone: 03 353 1240

Website: www.kidneys.co.nz, Email: info@kidneys.co.nz.