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World Kidney Day - Healthy Lifestyle for Healthy Kidneys



Round the Bays Team KHNZ & Auckland renal unit



Kidney Disease and Obesity
HEALTHY LIFESTYLE FOR HEALTHY KIDNEYS
9 March 2017



Wellington renal staff at Creekfest

It's hard to believe we are heading towards winter already; it has been a busy start to the year in the KHNZ office. As you will see by the first couple of pages, there was a lot of activity around the country to raise awareness of kidney disease. The theme for World Kidney Day was "Healthy Lifestyle for Healthy Kidneys" and this struck a chord with many who came in in large numbers to support the cause.

Team Northland win the award for numbers and commitment, with the initial date for walking the Hatea Loop in Whangarei and other walks in Dargaville and Kaitia, having to be postponed due to torrential rain, but not to be deterred people came out in large numbers to participate the following week, in sunshine too. A great effort and I understand plans are already underway for next year's event. GO NORTHLAND!

Staff from the Auckland renal unit and KHNZ joined with Diabetes NZ (Auckland branch) to participate in the Round the Bays in Auckland, and the team in Wellington used the annual Creekfest to raise awareness offering free blood pressure and urine checks, in Dunedin the team took to the Mall where they offered free BP checks and advice. It's wonderful to see such dedication to raising awareness by many of the renal teams throughout the country.



Team Northland



🔗 KHNZ Consumer Council Meeting

At the beginning of March, 16 members of the Consumer Council met in Wellington to discuss the issues for kidney patients and their families throughout New Zealand. As always it was great to hear from those who have first-hand experience with renal failure, with their input we were able to identify the main issues that will be included in the manifesto which will go to Members of Parliament from all Political parties as part of election year. Max talks about this in his piece further in this newsletter. Although not all the issues could be included in the document some of the other areas discussed included;

Mental health of dialysis patients, particularly those on home dialysis, is a concern, as many feel isolated having minimal contact with the dialysis unit. Some ideas of how this can be addressed included employing health care workers to visit patients in their homes on a regular basis – monthly would be enough, even if it was just to check in for a chat. A phone call once a month could also be another option.

Earlier referral for predialysis education was seen as important, to enable time for absorbing the information given. Having renal clinic appointments early in the mornings enables patients to go to work or university etc.

The importance of advocacy and support for renal patients was highlighted, with upskilling of Primary care in CKD encouraged and needed.

🔗 Whanganui Kidney Information Forums

In February an information forum was held at Whanganui Racecourse, with around fifty people attending to hear a range of speakers, including Dr's Tom Thompson and Curtis Walker who spoke about kidney disease, other topics included nutrition in kidney disease and two patients sharing their stories about dialysis and transplantation.

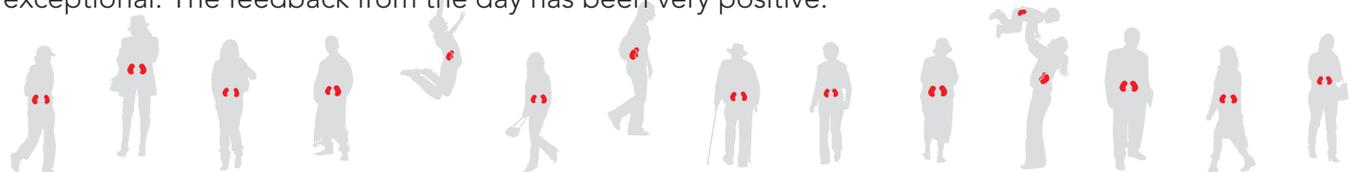


In the evening we were excited to have eighty health professionals attend the Management of Chronic Kidney Disease in Primary Care workshop. This was the first official use of the recently completed modules. The groups were split with Dr Curtis Walker, nephrologist at Mid Central Health delivering the GPs session, and Albert Robertson and myself sharing the Practice nurses session. Following these sessions an evaluation tool was used and the feedback was extremely positive, and that the modules presented were relevant to practice and would be very useful in the future.

Around 600 Chronic Kidney Disease Management in Primary Care information packs have been sent out to GP Practices, with another 700 to go, we have had a large number of orders received already for KHNZ resources, and some education sessions booked. The GP summary guides have been reviewed and printed and are currently being distributed to GPs throughout the country.

🔗 Southland Kidney Information Forum

Southland Kidney Society together with KHNZ held a very successful Kidney Information Forum in April, with around 30 people attending. Speakers included Anita Lloyd who spoke about her experience as a four times kidney transplant recipient, her positivity and energy was an inspiration. Anita was followed by a couple who had very recently lost their son in a tragic accident; they spoke about their decision to donate his organs and the impact it had on their lives and that of their family. Their bravery and willingness to share their experience in the hope this would help people and raise awareness around organ donation was exceptional. The feedback from the day has been very positive.



From the CEO



PROGRESS MADE ... BUT STILL SOME WAY TO GO

In the months prior to the 2014 General Election, Kidney Health New Zealand – with the much-valued input from a Consumer Council meeting earlier that year – compiled a pre-election Manifesto. In the weeks prior to the 2014 election that Manifesto was delivered to the then Minister of Health, and to the health spokespersons of the other political parties.

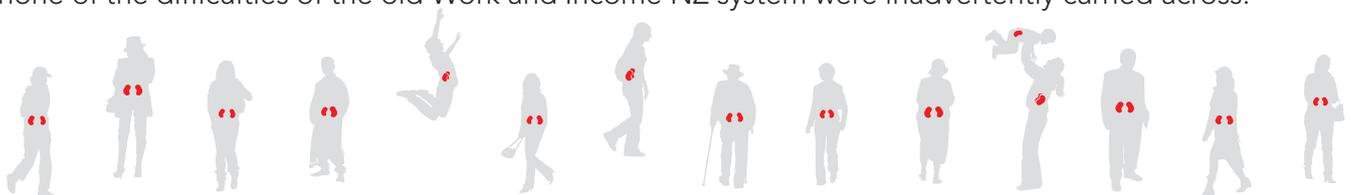
Kidney Health's Manifesto effectively offered a blueprint for better and lower cost services for renal patients in New Zealand, highlighting seven priority areas for improvement:

Addressing New Zealand's internationally low rate of deceased renal transplantation.

1. Facilitating pre-emptive live kidney transplants.
2. Increased reimbursement of lost income for live donors.
3. Reducing barriers to home dialysis.
4. Improving support for home dialysis patients.
5. Improving access to 'away from home' dialysis for haemodialysis for patients needing to travel for work or family reasons.
6. Improving General Practitioners' knowledge of how to identify and best manage Chronic Kidney Disease in the primary healthcare setting.

We are hugely encouraged to report the significant progress that has been made against a number of those priorities – due in large part to the ongoing lobbying undertaken by Kidney Health New Zealand and, it much be acknowledged, to the broad cross-party support given over the past three years to a number of vital practical and legislative initiatives. These include:

1. The initiation, by the Minister of Health, of a comprehensive review of deceased organ donation practice in New Zealand – in which Kidney Health New Zealand has been represented on both the initial expert advisory group and the subsequent sector working group. A strategy for increasing New Zealand's rate of deceased organ donation is expected to come before Cabinet in the next couple of months, and we look forward to reporting more on this once details become public.
2. Through the dedicated work of the National Renal Transplant Service, an increase in both the overall number of kidney transplants and those pre-emptively offered (i.e. patients receiving a kidney transplant before needing to go onto dialysis) has been achieved. The National Renal Transplant Service was initiated in 2014, with a target of increasing the number of live kidney transplants by 10 year on year over the following five years. It has exceeded that target in each year since.
3. The passing into legislation of the Compensation for Live Organ Donors Act late last year, providing 100% reimbursement of lost income for live organ donors – the result of unanimous cross-party political support. The Ministry of Health is currently developing guidelines and systems to enact this legislation – and, again, Kidney Health New Zealand has been invited to have input into this process. In particular, we lobbied to have some consumer input into the design of the new compensation system, to ensure that none of the difficulties of the old Work and Income NZ system were inadvertently carried across.



4. The Ministry of Health's facilitation of a consensus statement across primary, secondary and NGO renal services that prioritises early identification and intervention for the more than 400,000 New Zealanders with chronic kidney disease. Kidney Health NZ has been contracted by the Ministry of Health to develop and coordinate the delivery of training resources for GPs and other practice staff to enable better recognition of CKD. Carmel Gregan-Ford, our Education Manager and Newsletter Editor is to be commended for the many hours she has put into developing these resources over the past eighteen months or more.

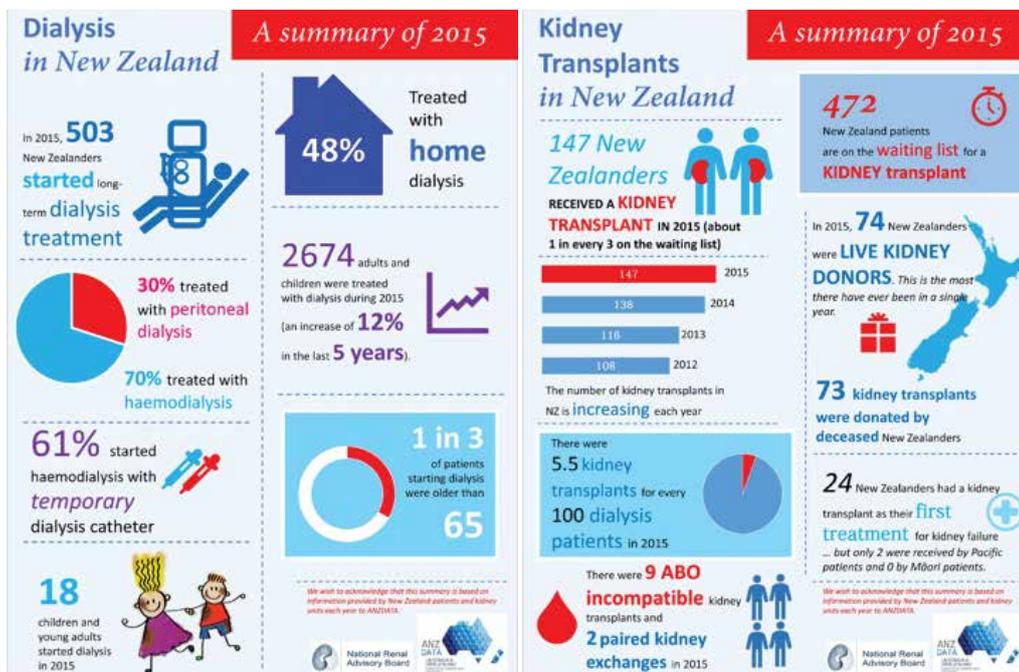
Without question, there is much to be celebrated in the progress that has been made over the past three years. There is, however, much more still to be done.

To that end, Kidney Health New Zealand – again, with input from kidney patients throughout the country – is currently in the process of drafting a further Kidney Health election Manifesto. This will highlight and prioritise the work that is still to be done to ensure that the growing number of kidney patients in New Zealand receive world class medical care and support. Priorities for this year's pre-election Manifesto include:

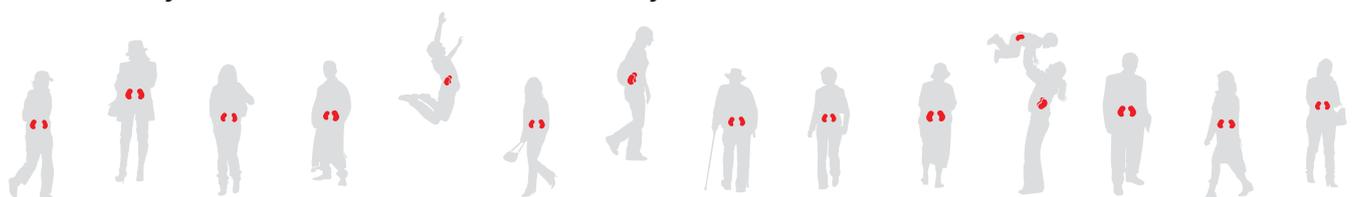
1. Ensuring the forthcoming Deceased Organ Donation Strategy is adopted by Cabinet and, more importantly, adequately funded
2. Ensuring nationally consistent dialysis services across New Zealand – including
 - a. equity of access to 'out of district' dialysis for patients needing to travel,
 - b. equitable access to social work and other community-based support for patients dialysing at home, and
 - c. ensuring that patients on home dialysis face no additional costs than were they to be dialysing in-centre.

Max Reid

What's happening with Kidney Diseases in New Zealand



This summary is based on information received by ANZDATA from renal units in NZ



3 Use of Non-Steroidal (NSAIDs) medication for pain in Chronic Kidney Disease

Many people assume that over-the-counter medications are harmless. This is definitely not true, and many pain medicines (also known as analgesics) that can be purchased without a prescription can be harmful to people with kidney disease. The tablets and capsules used to control pain are the most obvious ones. But many other common products—including cough, cold, and allergy preparations—often contain an analgesic. Also, topical creams and gels used for ailments such as joint pain often contain an analgesic. Even though you apply these creams and gels to your skin, some of the analgesic can be absorbed into your bloodstream, so these preparations should not be used unless they are recommended by your kidney team.

There are some pain medicines that should not be taken by people with kidney disease. This includes people who have reduced kidney function, who are on dialysis, or who have had a kidney transplant. Always check with your kidney specialist before you start taking pain medicine. You should also check with your kidney team when you receive a prescription for pain medication from a doctor other than your kidney specialist, or when you are thinking about taking an over-the-counter medication.

Deciding which pain medicine is best depends on a variety of factors, such as why you need to take it, which other medications you take, and whether you have a disease or condition in addition to kidney failure. Again—avoid all pain medicines until you have checked with your kidney team. Some pain medicines are definitely more harmful than others. People with kidney disease should generally avoid nonsteroidal anti-inflammatory drugs (NSAIDs), a group of over-the-counter pain relievers, unless they are prescribed and carefully monitored by a kidney specialist.

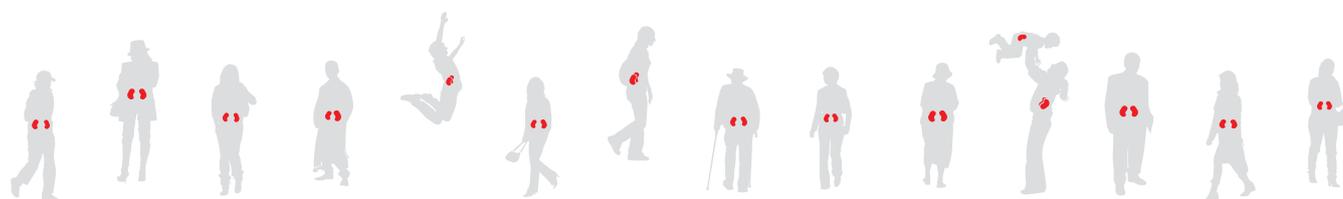
People with type 2 diabetes should avoid NSAIDs where possible. Reduced kidney function and albuminuria (protein in the urine) are both risk factors in people with diabetes. Preservation of kidney function to prevent the development of chronic kidney disease (CKD) and to reduce cardiovascular risk is an essential part of the management of patients with type 2 diabetes. NSAID kidney damage can be made worse when NSAIDs are used at the same time as some blood pressure medication such as ACE inhibitors or ARBs as these medicines impair the regulation of blood flow leaving the kidney. Kidney function can be damaged even further if a patient is also taking a diuretic. The combined potential effect of these three medicines has been referred to as the “triple whammy”. This combination of drugs can result in high potassium levels, Acute Kidney Injury and cardiac failure.

What is Acute Kidney Injury (AKI)?

Kidneys can either be injured over a long time, we call this chronic, or a short time we call this acute. A short time normally refers to days or weeks. Acute kidney injury is a common complication of other illnesses such as excessive diarrhoea and vomiting, particularly when people have other health conditions. When acute kidney injury is identified early it is often fully reversible.

This combination of medicines should be prescribed with caution, particularly in people with CKD or diabetes. If patients become acutely unwell it may be necessary to discontinue or reduce the dose of these medicines. In patients with reduced kidney function who are taking NSAIDs, or in patients at increased risk of kidney toxicity, a blood test to check serum creatinine and potassium should be done after one to two weeks of treatment and then monitored regularly.

Even if your kidney function is good, long-term use with high doses of these pain medicines may harm the kidneys. Kidney damage happens because high doses of the drugs have a harmful effect on kidney tissue and structures. These drugs can also reduce the blood flow to the kidney. If you are older, your kidneys may have a stronger reaction to these medicines and you may need a smaller dose.



Kidney disease from pain medicines is often preventable. You can change your risk by how you take medicines. Even with normal kidney function, you should use pain medicines:

- Exactly as prescribed or as on the label
- At the lowest dose possible
- For the shortest period of time.

Important points

Talking with your doctor about pain medicines can also make a difference:

- If you have kidney disease, ask your doctor before taking a pain medicine, particularly NSAIDs and higher dose aspirin.
- If you have high blood pressure or heart disease, make sure you only take NSAIDs under your doctor's supervision. This is especially important if you take diuretic medications or are over 65 years of age.
- Make sure your doctor knows about all medicines you are taking, even over-the-counter medicines.
- You should tell your health care team how often you use these drugs and how many of pills you take.
- Follow the instructions on the label.
- Throw away any unused pain medicines after the expiration date.

References:

<https://www.uptodate.com/contents/nonsteroidal-antiinflammatory-drugs-nsaids-beyond-the-basics>

<http://www.bpac.org.nz/BPJ/2013/October/docs/BPJ55-pages8-19.pdf>



From the Medical Director – Dr Colin Hutchison

Adult polycystic disease (APKD) is a hereditary form of kidney disease which is autosomal dominant, meaning that the children of an affected individual have a 50% chance of developing the condition. It is the most common genetic cause of end stage kidney disease (ESKD) and accounts for about 10% of all patients on dialysis.

Here in New Zealand there are hundreds of families where many members have developed kidney failure requiring dialysis support or transplantation. As the name suggests APKD is a condition where “cysts” grow within the patients kidneys. These cysts in themselves are not dangerous, as they are just small fluid filled sacs. But unfortunately over time hundreds of these cysts can grow in each kidney and get larger with time. As a result the room within the kidney for “healthy” cells gets less and less as time goes by.

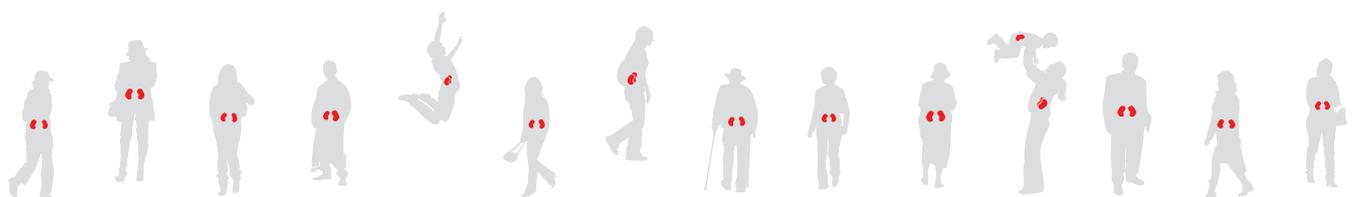
Adult polycystic kidney disease is typically present from early adult life but some patients will never know they have it until they have a scan of their kidneys. As the cysts grow patients gradually lose kidney function and many go on to need kidney support by their 40-60s. However, some people will have the cysts but never develop kidney failure as their cysts grow very slowly.

All patients with APKD should be seen by their local Kidney team and family members should be offered screening to identify APKD early in adult life to provide the best care possible.

To date there is no specific treatment for APKD in New Zealand.

Tolvaptan is a new treatment for APKD. Tolvaptan is a selective, competitive vasopressin receptor 2 antagonist initially it was developed and used to treat low sodium levels (hyponatraemia).

Essentially it helps the kidneys excrete water without losing sodium.



In patients with APKD Tolvaptan works by slowing the growth of the abnormal cysts within the kidneys and therefore reduces the rate of the progression of kidney disease. Unfortunately it does not stop it all together but potentially could delay the development of kidney failure and dialysis requirements. Recently the European Medicines Association, the Scottish Medicines Consortium, and NICE in England have all approved Tolvaptan for the treatment of early APKD to prevent progressive kidney disease. As an organization, here at Kidney Health New Zealand, we seek to ensure that all New Zealanders have access to world class kidney care. We have therefore already started to lobby PHARMAC and the Ministry of Health to ensure that Tolvaptan is reviewed in a timely manner. We see Tolvaptan as important drug for patients with APKD to have access to in New Zealand.

☺ Rongoā Māori

I recently had the privilege to join the renal team from Auckland City Hospital to a workshop on Rongoā Māori.

Rongoā is an important aspect of health care to many Māori people despite their concurrent use of western medicine. It represents the passing on of culture and history. Traditional treatment may be sought for a variety of reasons including illness that is atypical or not responding to conventional treatment, mental illness and chronic “lifestyle” conditions such as type II diabetes.

Treatment includes plant remedies from native flora (Rongoā rākau), massage (mirimiri) and prayer (karakia). Illness is treated by addressing aspects of health including spiritual, psychological, emotional, cultural, social, environmental, family and physical health.

Donna Kerridge, a rongoā practitioner shared her wealth of knowledge and experience with the group. We learned about the plants used and Donna shared stories of healing by touch, massage and plant remedies. The Ministry of Health currently funds 19 providers across the country to deliver rongoā services. These services include mirimiri (massage), karakia (pastoral support) and whitiwhiti kōrero (cultural support). This does not include the use of rongoā rākau, the main element of rongoā healing. All Ministry funded rongoā providers are required to adhere to the rongoā standards, Tikanga-ā-Rongoā.

Dr Glenis Mark PhD, talked about the research she has completed with the aim of fostering collaboration between Rongoā Māori and Medical treatment. I think we all left the day with a better understanding and respect of Rongoā and I look forward to learning more in the future.

☺ World Transplant Games – Malaga 2017

The World Transplant Games is a celebration that demonstrates the success of the transplant operations and the possibility that the people receiving a transplant have a fully healthy life. This event aims to significantly improve understanding and acceptance of organ donation. This year it is being held in Malaga, Spain 25th June – 2nd July 2017.

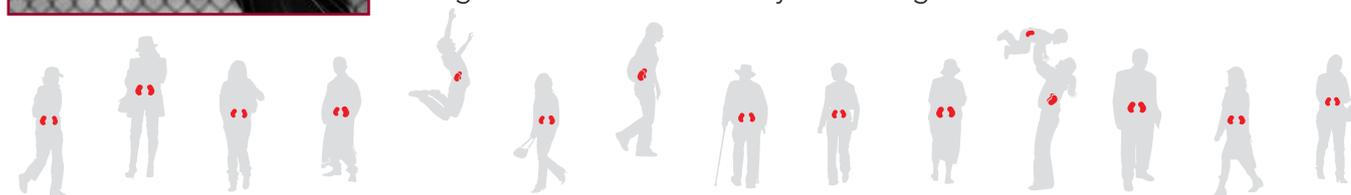
Matthew Field is the one of the Ambassadors for the Games and just happens to be a Kiwi!



MATTHEW FIELD – MANAWATU, NEW ZEALAND

Age 29 | Kidney Recipient

Growing up sport was everything to Matthew, he always dreamed of competing at high level, and played Football and Cricket at a regional level for Manawatu, first XV Rugby at high school and premier grade Rugby league for Victoria University of Wellington. *continued overleaf...*



When his kidneys failed at the age of 22, his dreams were shattered. Dialysis twelve hours a night every night left him with no energy or confidence to play sport. He didn't miss the higher level of sport but the freedom and social aspects of being involved in a team, club, and sports community. Post-transplant, with a renewed boost of confidence, he slowly began to set new goals. "It is important not to underestimate the implications of being confident enough to be involved in sports and physical activity during and after a serious illness. This makes programs like Fit for Life and the Transplant Games all the more special as they get people involved nomatter their level of skill, experience, fitness, or social status. " Matthew was unsure how much he could push his body post-transplant. He had many questions with limited definite information available to him.

His journey post-transplant began when he saw an advertisement for the World Transplant Games during a clinic visit. It appealed to him because it seemed a reachable goal that would give him the chance to meet similar people. He was also granted a role to coach a girls 1st XI Football team, who showed him how fun and enjoyable being part of a team and competition is.

Today he focuses on living well, looking after his transplant and inspiring others by competing in the Australian and World Transplant Games. He trains for athletics two-three times a day with sprint trainings, gym work, and recovery sessions. He plays social basketball and football once a week and work in an active job thirty-six hours a week looking after racehorses. "I truly believe there is a place in sport and fitness for everyone.

Being involved makes you feel so much better physically, emotionally and of course brings people together socially."

*If you would like to learn more <http://wtgmalaga2017.com/>
Good luck to the New Zealand Team!*



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

I/we would like to donate: \$100 \$50 \$30 Other: _____

Payment type: Cheque (made payable to Kidney Health NZ) Mastercard Visa

Card number:

Card expiry date: / / Name on card: _____

I would like: A receipt for my donation Information about gifting to Kidney Health in my will

Information about kidney donation/transplants To become a member of Kidney Health NZ

Name: _____

Address: _____

Please return this form to Kidney Health New Zealand, PO Box 20072, Bishopdale, Christchurch.