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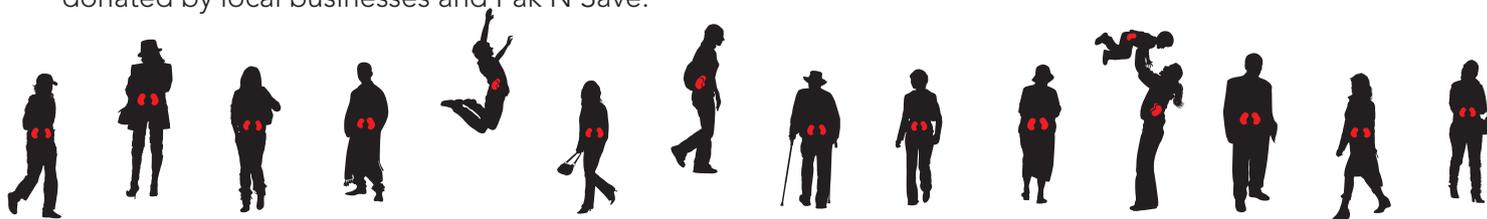
KHNZ update • From the CEO • Introducing our new fundraiser • Cycling New Zealand for kidney awareness • Research Project • From the Medical Director



Northland celebrates World Kidney Day

World Kidney Day 2018 was celebrated throughout the country, with staff, patients, family and friends getting out and “walking for kidneys” in Kawakawa, Dargaville, Whangarei, Bay of Islands and as far south as Dunedin.

The report from the Northland team follows; A fun run fundraiser went ahead on World Kidney Day Thursday March 8 with good attitudes keeping away the inclement autumn rain. Runners, walkers and sausage sizzle chefs raised nearly \$1400. Whangarei’s run/walk was attended by around 110 - 120 people and \$606 was raised. Prizes were donated from businesses (main sponsorship by Pak N Save). Thankfully the rain held off and nobody got wet at Kawakawa. Organisers report about 40 adults and kids took part, including a few in dress-up. Bay of Islands managed to raise \$215 dollars and had fun in the process. Dargaville had 40 participants and with the help of a Rapid Response barbecue, \$280 was raised. An alternative activity if the weather was not suitable was a Zumba class on site which would have been run at no cost from local Zumba tutors, so Dargaville organizers express their thanks to Dianne and Naumai for being available. A good number of spot prizes were drawn at the completion of the walk which were kindly donated by local businesses and Pak N Save.



At Auckland Hospital the renal team offered free blood pressure, blood sugar and urine screening in the main reception area, together with a photobooth which proved popular.

And further south in Dunedin the enthusiastic Otago Kidney Society team also raised awareness with their own "Walk for Kidney Health", and are already planning for next years event.



The bi-annual Home Dialysis conference was held in Auckland recently, this was a wonderful opportunity to hear about other renal services approach to home dialysis therapies. Topics included discussion around what good clinical care should look like to provide optimal clinical outcomes for that patients on home dialysis, and how to increase the uptake of home dialysis. Health literacy, including cultural and social values were other areas identified as a significant part of the education and decision-making process for people considering treatment at home. Socio-economic deprivation is creating barriers to home dialysis, this can underpin the choices patients make about their dialysis treatment, it is important that reimbursement for out of pocket expenses might increase to uptake of home dialysis. Other recommendations to ensure greater uptake of home dialysis included;

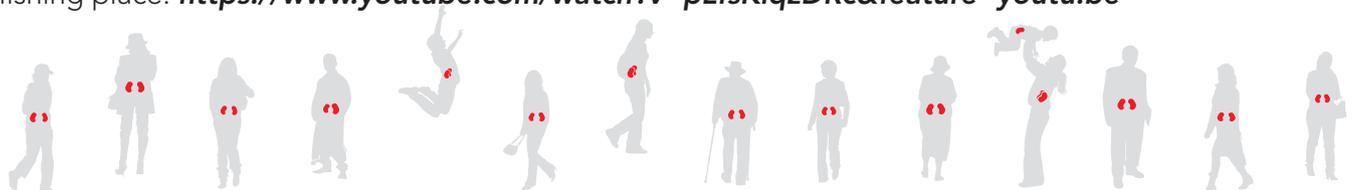
- Clinicians need to understand patient's priorities and their role in decision making
- Look at ways to support patient's confidence in home dialysis – this could include assisted care models, remote patient monitoring and community houses.
- Individualised education, ensuring home dialysis is visible to patients, this should also include opportunities to meet other patients on home dialysis.
- Enhancing the focus on treatment flexibility and potential clinical and survival outcomes of pre-dialysis education.

A personal highlight of the conference was the session "*Home Haemodialysis and the art of caravan maintenance - Getting home haemo out of the house*", given by Australian DJ Rob Smith and Dr Pascal Kopperschmidt a production specialist at Fresenius Medical Care, these two men gave an honest and humorous account of their travels and experiences around the world whilst managing their dialysis requirements.

Rob is a passionate advocate for nocturnal home dialysis and believes in constantly pushing the boundaries of renal treatment to live life to the fullest – and indeed he does.

Pascal and Rob developed their friendship through a mutual interest in being able to travel without the restrictions that dialysis can bring. With Pascals technical know how and Robs can do anything attitude it was a match made for a very successful friendship, and consequently they managed to modify a caravan, complete with portable dialysis machine capable of being used pretty much anywhere that has a water supply. Both shared photos of their adventures throughout Europe and there are plans for many more adventures. They truly were inspirational.

A great clip to watch is Robs first adventure with his "portable" haemodialysis machine out to his beloved fishing place. <https://www.youtube.com/watch?v=pLfsKlqzDRc&feature=youtu.be>



From the CEO



Kia ora tatou

In our last newsletter, I commented that the work that KHNZ undertakes is only limited by the income we receive. I also mentioned that KHNZ was about to embark on a major strategic planning exercise, involving our staff, Board and our Consumer Council.

This newsletter updates you on both of these exciting opportunities – and how KHNZ is using each to inform the other. We welcome Jacqui Jeffrey into her role as KHNZ's first ever Fundraising Coordinator. And we explore some of the emerging strategic priorities that we will be seeking financial support to undertake.

Kidney Health New Zealand is fortunate to have a strong financial base. Around a third of the income we need each year to fund our advocacy, education and patient support work comes from the income generated from our investment portfolio – comprising bequests and other large donations received over the years. But only a third. The other two thirds of our work has to be funded either from donations or by 'dipping into' those investments. And that is only sufficient to sustain our existing work – it provides no opportunity to broaden the support we could potentially be offering.

With that in mind – and through the fundraising strategy approved by the Board late last year – KHNZ hopes to increase the income we receive (from trust and grant applications, individual donations, bequests and corporate sponsorship) over the next three years and beyond. There is so much more we could be doing to support kidney patients and their families, local kidney support groups and societies. There is also so much more we could be doing to raise awareness of chronic kidney disease – a disease that affects one in ten New Zealanders, yet currently goes undiagnosed for 90% of those 400,000 New Zealanders living with early stage CKD. Elsewhere in this newsletter I write about some of the concerns raised for NZ kidney patients from analysis of the latest ANZDATA statistics – the Australia-NZ data set that records how NZ kidney services are performing against a range of indicators – and Kidney Health NZ's advocacy for the including some patient-reported indicators alongside the clinical ones we traditionally rely upon.

Enjoy your Autumn read!

Ka kite

Max

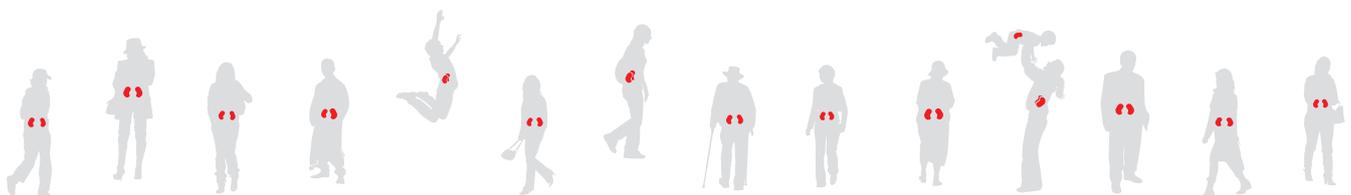
Introducing Jacqui, KHNZ Fundraiser

A big welcome to Jacqui who has joined the KHNZ team as our fundraiser. I've asked Jacqui a few questions, so you can get to know her.

So where were you prior to joining KHNZ?

Prior to joining Kidney Health New Zealand, I worked for Youthline Central South Island as their funding coordinator. I also run events and coordinate a small farmer's market in Kaiapoi.

I have run both large and small community events and continue to do a couple of family events throughout the year. I love to create events where families and communities can come together to have fun and spend quality time together.



Why did you decide to come to KHNZ?

I was looking for a new challenge and the opportunity to work for a National organisation that has the potential to positively impact the lives of so many people really appealed to me. This organisation has achieved so much, and I hope that I can help us to achieve even more.

Tell us a little about yourself? Do you have a family, have you always lived in Canterbury?

I grew up in Nelson in a big family, being the youngest of five kids, and left there to come to Christchurch for University. This is where I met my husband and have stayed ever since. I am a parent of three children Tessa, Kaylee and Zander. We live in Kaiapoi and have the benefits of living in a small town while still being close to Christchurch and everything that has to offer.

What do you like to do in your spare time (if you have any!)?

When I do get some time, I upcycle glass jars into colourful fairy houses I would like to create a magical fairy garden one day.

Where is your favourite place to holiday?

When I get to go away for holidays I love to go camping in Wanaka. It is gorgeous there and so peaceful, it is a great place to relax. If I can't go to Wanaka, I head to Nelson to spend time with family there.

🌀 Helen's Biking Tour of Aotearoa for Kidney Health New Zealand



Helen started her journey on February 24th she not only raised funds for Kidney Health New Zealand, she raised awareness of kidney disease as she travelled through the country, we can't thank you enough Helen for your passion and dedication to the cause, not to mention cycling 3000kms to do it.

Below is a little snippet of her journey taken from her wonderful blog:

<https://www.facebook.com/Helens-Tour-Aotearoa-Blog-and-follow-me-on-the-map-1999345947009365/>

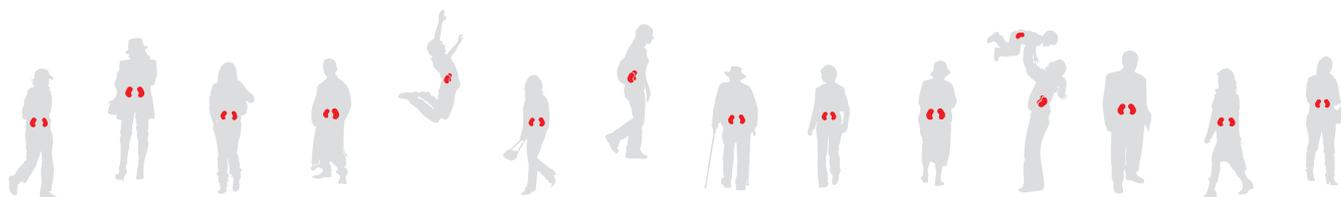
It started on 21 September 2016. A coffee catch-up with a friend. Nek minnit - I'd signed up to bike the length of New Zealand, 3000 km from Cape Reinga to Bluff.

I am dedicating the journey to my parents - my Mum, Jane, who lives in the Hutt Valley and my Dad, Alex, who passed away from kidney disease just over 2 years ago.

Kidney disease doesn't get much profile but it's something to know about. Many people may be at risk of it and you can lose 90% of your kidney function before you get any symptoms. Knowing your risk and getting a simple health check early on can make all the difference.

I've decided this two wheeled hikoi is like having a love affair with our country. It's definitely not all about the destination ... very much about the small places and people you meet on the way. The days are long, but they are rich.

The Kaipara Estuary really is magnificent. Kidneys and estuaries have a lot in common...both filter and clean-up liquids. Estuaries filter sediment and nutrients coming down from the catchments and kidneys keep your blood in tip top condition. Both pretty cool.



As I approach Wellington (home for me) my mind turns to friends and family... and my charity mission too...

When the filters in your kidneys get damaged your body fills up with excess waste and water. Some people get transplants which changes their lives. I've had two lovely men in my life with damaged kidneys. My uncle Ken went into hospital almost every day for blood dialysis over many years. It was very tiring for him. My Dad was able to do peritoneal dialysis at home 4 times a day. This is where you have a tube that drains out fluids that have built up in the cavity around your organs ...and then swap it for a fresh lot. I'd never heard of that. These treatments became part of their routines, but they had incredible support. I am grateful for this and so want to raise both funds and awareness for Kidney Health NZ to support other kiwis.

Today's short day means we won't make the 30-day event cutoff (even with the extra 2 days allocated for the Whanganui stranding). A little disappointing but for the most part our aim has been to stay healthy, see the country, meet people and have fun. Hoping to be 1 day over (4 days left to Bluff?!) I'll still be very proud of that!

Wow what an adventure! Funny thing with setting goals. I put my name down 18 months ago... just keep moving forward and it unfolds in front of you from that day on.

30 days + 2 (extra for Whanganui stranding) + 1 (just because). Reached Stirling Point yesterday at 6pm... surreal to be there! Steve and Amanda (and Marley) were there to cheer me in. Thank you so much! I feel great - as fit as a fiddle. I've had a ball.



Research Project



Merryn Jones - RN, PG Dip NS
Living Kidney Donor Coordinator
Haemodialysis Nurse Renal Service

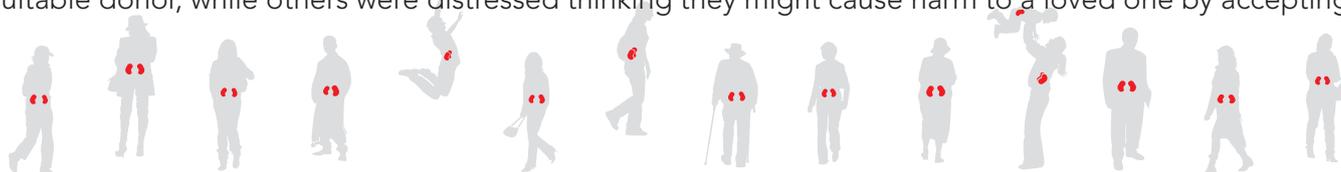
Merryn recently completed her thesis. Below are some of the findings from her research which she presented at the Renal Society of Australasia in Sydney supported by Kidney Health New Zealand.

The decision-making of patients with ESRD as they seek to recruit living kidney donors or wait for offers of a kidney donation

This is the first study in NZ where the sole focus was to examine the decision-making of patients with ESRD as they seek to recruit living kidney donors or wait for offers of a kidney donation. All of the patients in this study either stated that it was hard to ask family or friends for a kidney donation, or described difficulty with asking, many stating that 'it's hard to ask'. In an age where LKD is encouraged as the gold standard for renal replacement therapy, it is important to identify barriers to transplant in order for health services to attempt to address those barriers. For many patients, being expected to recruit kidney donors is a barrier in itself. Almost half of the participants in this study had never asked anyone to donate due to concerns for the health and wellbeing of the loved ones, or limited potential donors available in their social networks, or due to poor communication skills, health literacy, or self-efficacy.

Some patients are lucky enough to receive offers when they are diagnosed with renal disease, and sometimes those offers will result in a transplant. However, many of the renal patients in this study had relatives who were well intentioned, but were ineligible to donate due to chronic health conditions. Many of the Māori participants in this study were from large families, but because co-morbidities are a prevalent finding in Māori health, just as they are in other indigenous cultures, they struggled to identify suitable donors.

Support was a key theme identified by many participants, with almost all desiring more support in order to be able to approach potential donors. Some participants were distressed at not being able to find a suitable donor, while others were distressed thinking they might cause harm to a loved one by accepting



a kidney. This suggests that counselling, cultural or spiritual support should be available to recipients. In addition, patients felt that having accurate information about the transplant process *before* they approach potential donors was paramount, in order to be prepared to answer questions as they approached others to ask for a kidney. Findings from this research therefore indicate that psychosocial support could be routinely offered to all recipients, ideally before the patient has approached any potential donor, addressing concerns such as self-efficacy, reciprocity, and relationship management, as well as providing skilled counselling for depression or negative quality of life, or distress that may arise as the result of being diagnosed with a chronic, life-limiting disease. Development of a screening tool to assess specific recipient needs is recommended, and further NZ-centred research is required to determine how such a tool can be developed to best serve NZs unique cultural and ethnic profile.

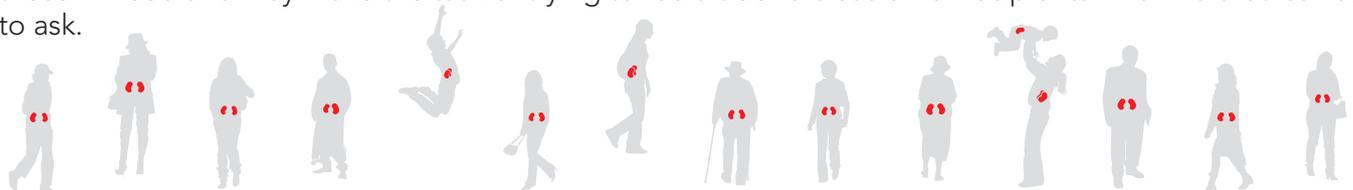
Māori patients in this study stressed that there was a need to involve whanau in decision-making when it comes to treatment options, and this is congruent with other NZ research (Durie, 1985; Walker et al., 2017). More research into streamlining care pathways for Māori may support more Māori to choose transplant options. Māori face significant disparities in LKD transplant with low likelihood of receiving pre-emptive kidney transplantation (Walker et al., 2017). Further investigation examining whether this is because the recipient has not approached whanau regarding transplant, or whether there is a challenge in conversion rates from starting donor workup through to successful transplant might give an indication of challenges many Maori face in recruiting suitable donors.

With the increasing use of social media sites, such as Facebook, some patients and their families in this study were turning to such sites in an attempt to recruit donors. Potential areas for development might include development of sample social media templates sharing the patient's story and providing information about how to make contact with the patient's donor coordinator. These could be developed in a variety of languages and be able to be customised according to the patient's needs.

Revisiting the transplant conversation regularly throughout the patient journey is important, as attitudes towards transplant and circumstances can change. Ensuring transplant eligibility is included on clinical letters to the patients and their GP helps to consolidate the transplant option. Educating GPs about the benefits of transplant and early referral to renal services, as well as up-skilling clinicians working in smaller referring centres, helps ensure clinicians have current/best practice information. Gordon's (2011) study demonstrated that transplant professionals' opinions and attitudes influenced the uptake of living kidney donations. She found that positive opinions lead to positive results, while Martin (2013b) stated that talking about transplant generally results in higher transplant numbers. These statements do not solely relate to patients and their families, but highlight the need for positive media stories about organ donation, and also the need for health professionals to communicate similar positive messages. Conversations regarding positive outcomes for patients between transplanting centres, renal service staff, general practitioners and community health workers are also important, as a positive culture between health professionals leads to congruent messages being relayed to the patient.

Campaigns that raise awareness of the need for organs, or that encourage people to talk with their families about their wishes to donate in the event of death, are important for keeping the donation topic alive. There is generally a poor understanding of the circumstances whereby organs can be procured in the event of death in NZ, and more work needs to be done to educate the public. Internationally, the use of Intensive Care champions in organ donation has seen a rise in the rates of deceased organ donation, and greater support for this initiative could be provided to each hospital in NZ.

Lastly, some patients may never pursue, or be successful in, recruiting live donors. Until artificial kidneys can be grown in a petri dish or 3D printed, there will continue to be a need for deceased kidney donations. Where organ transplant conversations are promoted, the rates of transplantation have been seen to increase (Australian Government Organ & Tissue Authority, 2016). Talking about transplant and keeping the media focus on positive stories, helps both living and deceased donation rates as families discuss their viewpoints on organ donation research that evaluates the effectiveness of media or public education campaigns would be useful. Increasing public understanding about how donation benefits recipient's lives may lead donors to feel more comfortable with donation as an acceptable way to help those in need and may make the task of trying to recruit donors easier for recipients who find that it's hard to ask.



Emerging Strategic Priorities: Addressing Disparities in Renal Care

Max Reid, Chief Executive Officer

When the Kidney Health New Zealand Board recently spent a day together – as the first step in developing the organisation’s next Strategic Plan – they considered a number of key documents. These included notes from the recent Consumer Council meeting held in Wellington in March, the results of the Consumer Survey undertaken by KHNZ in 2016-17, and the findings of the most recent New Zealand Nephrology Annual Data Report, published last year.

Drawing upon clinical and demographic data from the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, as well as information provided by New Zealand’s National Renal Transplant Service, this latest report raises several concerns – primarily around the need for more timely, equitable and nationally consistent treatment available to dialysis patients. These include:

- Low permanent vascular access rates for haemodialysis patients
- Disparities in renal replacement therapy treatment rates among Māori and Pacific patients and younger patients, and
- Variability of access to Home Dialysis and support for those who are dialysing at home.

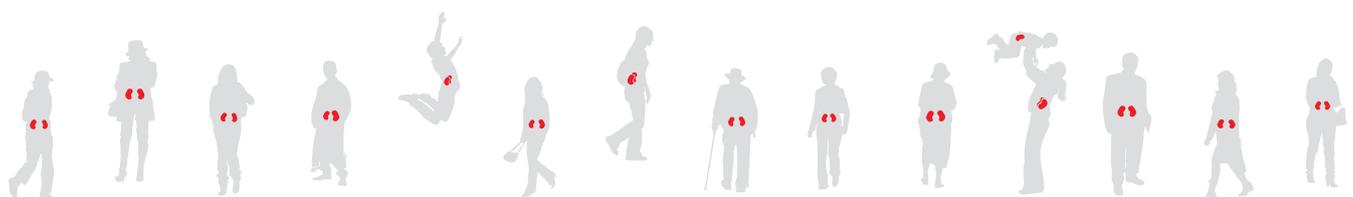
Similar concerns have been raised by KHNZ’s own Consumer Council in recent years – and it is likely that KHNZ’s emerging Strategic Plan will give significant priority to addressing these. Indeed, analysis of the latest NZ statistics from ANZDATA (still to be publicly released as this newsletter goes to print) sadly show that little progress has been made in these areas over the past year.

While the number of New Zealanders commencing haemodialysis continues to rise, the proportion of patients dialysing at home continues to fall – with home haemodialysis rates remaining below 20%. And, as we hear at each Consumer Council meeting, the support available to home dialysis patients varies markedly across the country – with those living in rural communities or furthest from their renal team being most disadvantaged.

Those variations are even more marked for Māori and Pacific renal patients, who continue to be doubly disadvantaged. Not only are Māori and Pacific far more likely to have end stage kidney disease, they continue to be more than 25 times less likely to receive a pre-emptive transplant than their European counterparts.

Some of these disparities reflect ethnic differences; others – particularly in terms of access to appropriate renal replacement therapies and support are driven by geography and demographics. KHNZ, however, supports the strongly held view of our Consumer Council, that there should be a minimum standard of care and support available to renal patients wherever they live in NZ – and that, currently, is clearly not the case.

As important as analysis of the NZ clinical and demographic information gleaned from ANZDATA is (in terms of its potential to drive improvements in renal care), alongside this is a growing trend internationally to also develop patient-reported measures of care. The UK Renal Registry, for example – their equivalent of Australasia’s ANZDATA Registry – has developed a series of *patient*-reported experience measures. Coordinated by Kidney Care UK, their PREM project utilised renal units from across England and Wales to survey more than 11,000 renal patients – including those on dialysis, transplant recipients, and those at the pre-dialysis stage. Patients were able to rate their experience across a wide range of aspects of care –



everything from access to and responsiveness of the renal team, and how involved they felt in decisions about their care, right down to issues around transport and how painful they found the experience of in-centre needling.

The Australia-New Zealand Society of Nephrologists (ANZSN) is currently exploring the development of a similar tool for Australasia, and KHNZ is planning to discuss this initiative with the Ministry of Health to see if such patient-reported experience measures could be included in the Long-Term Conditions Strategy that the Ministry is in the process of developing.

From our Medical Advisor - Dr Colin Hutchison



Kidney checks and Finger Pricks.

This year Kidney Health NZ (KHNZ) had the awesome opportunity to partner with Hawke's Bay Renal Unit to provide free "Kidney Checks" at the Napier "Harbour to Hills" Half Ironman event. While an extreme endurance sporting event which saw participants swim 2km, cycle 95km and run 21km may not seem the most obvious time to do a "health check", it is a great time to catch the friends and families of the competitors who had up to 9 hours of cheering to do.

Napier turned on the best of its Hawke's Bay weather for us as we offered people free blood pressure checks and a urine "dip-stick" to check for protein (an early marker of kidney disease). Mike Bond, the race director, and his team did an amazing job of raising the profile of our team who had the opportunity to be based directly opposite the finish line. Through the course of the day we had lots of spectators, a few passer-by's and some competitors come in for a Kidney Check. Everyone was given a report card to let them know whether their blood pressure was high or low and if their urine had protein in it or not. If concerns were raised they were asked to book into see their GP to have a follow-up.

Looking to the future we are hoping to take the kidney checks we offer at community events to the next level by providing a finger prick blood test which will allow people to know immediately if their kidneys' percentage function is normal. This trio of blood pressure, urine protein test and kidney function (on the blood test) gives a full picture of whether someone's kidneys are working well or not.

These community events are a really great opportunity for the KHNZ team to raise the profile of Kidney Health across New Zealand and help people realise that a kidney check can be as easy as 1, 2, 3. In addition to the people we get to meet on the day we hope that there is then a ripple effect as these individuals go out and encourage others in the community to think about their kidneys too.

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.