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Manifesto

**Thanks goodness we are finally heading into the warmer seasons, I'm not sure about anyone else, but I have found this winter to be especially harsh and long. It is always lovely to see the fresh green shoots appear on the trees and blossoms beginning to brighten the landscape. By coincidence this newsletter contains two stories about transplantation and a second chance at life.**

It has been another busy quarter with some interesting events. I was fortunate enough to go to the annual Renal Society of Australasia in Sydney in June, it was of special interest to me as the guest speaker Dr Helen Nobel from the UK, and I completed our Renal Nurse specialist course together in London 25 years ago. Helen spoke about looking after people with kidney failure who have chosen not to receive dialysis treatment and the value of supportive and palliative care for these patients when it is needed. There is a lot of work being done in this area, to ensure the best possible support for this group.

Another interesting talk was by Kidney Specialist Prof David Johnson, who talked about Chronic Kidney disease and how it is ten times more economically viable spending health dollars on the detection and management of Chronic Kidney Disease (CKD) than on End Stage Kidney Disease, again a lot of work is being done in this area as globally it is recognised that more can be done to slow down the progression of kidney disease in many people.

More recently I attended the BEAT CKD Research Forum in Adelaide, which was a two day workshop for patients, clinicians and researchers with an interest in conducting and implementing research to improve outcomes for people with chronic kidney disease. This was a great opportunity to hear and discuss innovative methods, high-priority research projects, and to meet potential collaborators. Watch this space as we look to do some work on this here in NZ.

And still on the subject of Chronic Kidney Disease, check out the latest information brochure just added to our resource suite.

[https://www.kidneys.co.nz/resources/file/patient\\_information\\_chronic\\_kidney\\_disease-2-1.pdf](https://www.kidneys.co.nz/resources/file/patient_information_chronic_kidney_disease-2-1.pdf)

Requests for education sessions on Managing Chronic Kidney Disease in Primary Care continue to come in with sessions either booked or given in Albany, New Plymouth, Rotorua, Whanganui, Wellington Ashburton and Christchurch so far.



## World Transplant Games 2017 team, with Sara Ford, front and centre, who provided this report.

The World Transplant Games were held in Malaga Spain from June 25th to July 2nd 2017. We had a team of 12 competitors and 10 supporters go over to the games to represent New Zealand in a wide range of sports and events. A small group of us flew out a few days before the games and had a 3 day stopover in Vancouver. A great way to see an amazing city, and get to know the new members in the team that were with us. It was great to get to Malaga a couple of days before the games and catch up with old friends from other games and meet new people.



New Zealand was represented really well in all our events with us winning 9 gold 6 silver and 5 Bronze. And as a country we finished 16th on the medal table out of 52 countries which is a really great effort. We also had a young competitor this year Lisa. It was great to have a young person on our team and see her enjoying herself. The Games were a great experience from the start to the finish and I'm sure everyone had a great time.

So you're now thinking I would love to give the games a go but I'm not an athlete. If you're not an athlete just competing is an awesome experience and a great way to give sport ago. You can win a medal at events in your age group. I'm sure a lot of people think the same as me though a medal is great but to me it's a bonus. The main thing is get people talking about organ donation and for them to see how being an organ donor can help.

The next games are in Australian games on the Gold Coast from September 30th to October 6th 2018. If you would like more information on the games please feel free to contact myself on my email [saraford@clear.net.nz](mailto:saraford@clear.net.nz). Or check out our Facebook pages New Zealand Transplant Games Association, Transplant New Zealand. Or our website New Zealand Transplant Games.

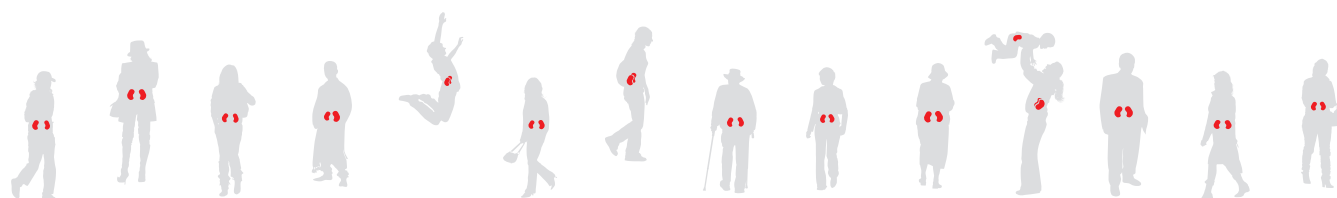
**Sara Ford – Kidney Transplant Recipient**

## The precious gift of time... thanks to organ donation.

### *The journey of my new kidney*

The saying "living life to the fullest" took on a whole new meaning from the age of twelve years when my end stage renal failure journey began.

After being diagnosed with SLE (also known as Lupus Nephritis), the battle to save my own kidneys and my life meant endless rounds of chemotherapy, heavy immunosuppression, IV steroids, hospital admissions and the care of many dedicated medical professionals such as Dr Chris Duffy, Professor Mark Brown and Professor Edmonds in the early days.



After being so unwell for most of my teenage years I was lucky enough to have a few years in remission. At this time I was able to attend the University of Waikato to pursue my dream of becoming a teacher.

During the first few years my health was stable however, shortly after my 21st birthday it declined significantly, I went into end stage renal failure and I was admitted into ICU requiring lifesaving haemodialysis. There aren't any words to accurately describe the fear of the situation, or the emotions I felt when my own kidneys died; you do experience grief and a feeling of loss.

I was in Ward 24 at Waikato Hospital for almost two years leading up to my transplant, being too sick to leave hospital with endless infections, operations, end stage renal failure, no energy, short of breath and requiring on going blood transfusions. I want to acknowledge the staff at the Waikato Home Dialysis Unit, as their training and support allowed me a six month period being on dialysis at home; especially Nicky Hagan, Tricia Casey and Mark Hodge and the many other nurses who encouraged me to get home with a machine and gain some independence.

During this time I had incredible friends and people who would bring me chocolate brownies from a café in Hamilton East called Rocket. My appetite was poor back then, needing a feeding tube. However, I could tolerate brownies!

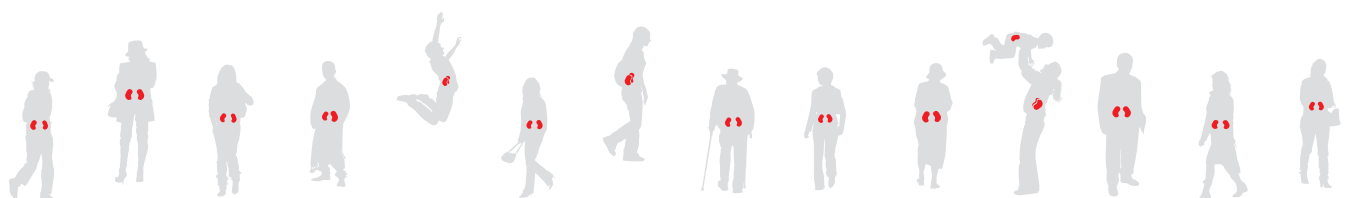
I was one of the first patients to be put on the transplant waiting list from Waikato Hospital in 2001. Dr Ian Dittmer, Dr Helen Pilmore, Prof Stephen Munn, Dr Maggie Fisher, Dr Kim Wong and Dr Peter Sizeland championed my cause and did everything to keep me alive on dialysis so I would be a successful transplant candidate. I am forever grateful to them, because in 2002 I received my kidney from a deceased donor at Auckland Hospital.

I am now fifteen and a half years into my kidney transplant journey, living each and every day with gratitude and heart-warming love for my gift and I certainly have my appetite back! My family and I celebrate my transplant anniversary every year, it is bitter sweet. I think about my daughter, my husband, my donor and the borrowed time I have been so generously given from my donor, their gift of life that has given me time to see my daughter grow into a teenager, to travel the world, to create a beautiful home and to fulfil my passion for teaching. I have also been back to Waikato University to complete a Post Graduate Diploma in Education as well as further studies in teaching and learning as a mature student.

I am under the wonderful care of Middlemore Hospital Renal Transplant Team and have been for the past thirteen years. I know how lucky I am to have them all. I attend regular transplant clinic appointments, have regular blood tests to monitor my kidney function and for the rest of my life will remain heavily immunosuppressed to stop my transplant from rejecting.

As a transplant recipient I am focused on making my life count, being compliant and honouring my donor and those who have changed my life and the lives of so many individuals fortunate enough to receive transplants. Life is truly precious. Surround yourself with those who make you happy.

My second chance has meant I have married the most incredible, handsome, loving man who is by my side through all the ups and downs of my health journey. Never giving up, always encouraging me to battle on along the way when life throws its curve balls. The other very important person is our daughter. Without my donated kidney I wouldn't have been around to experience the absolute delight of loving a





child and being such a proud Mum. I am so blessed. My goal is to live long enough to see her grow up, attend her college graduation, and attend her wedding at the very least!

I have also fulfilled my passion of teaching, working with incredible students and staff. To say this is rewarding is an understatement, teaching children has given me purpose and the sincerity of the profession never ceases to amaze me. I am continuously inspired to reflect on my own practice as a teacher, without my transplant this wouldn't have been possible.

My family and I attend the annual Service of Thanksgiving every year in recognition of those who have given the gift of life to others. It's a very emotional service, my daughter and I light a candle every year to acknowledge and remember the gift, but also the loss my donor family reflects on the day their loved one passed away.

Living would not have been possible without the selfless act of organ donation. Through organ donation we celebrate new life and new beginnings. It's a joyful thing to live, however without the gift of life, the many health professionals, transplant coordinators and others involved at such a fragile time, for those living with a transplant or awaiting a transplant, the path back to health would be much more difficult, if not impossible.

Thank you for taking the time to read my transplant story. I have just turned forty; this was a profound moment for me, a time to reflect back on my transplant journey, through all the highs and lows. I can honestly say I will never waste a single moment of my life. My kidney transplant isn't a cure for end stage renal failure or Lupus however it is the best form of treatment currently available. Living is such a privilege; organ donation has given me time that I continue to make the most of celebrating life with my loved ones. Thanks to my new kidney I have ticked off a few things on my bucket list which I am so grateful for.

Nobody knows what the future will bring, however without organ donation; I wouldn't be here to share my story.

**Anna Maharaj**

## From the CEO

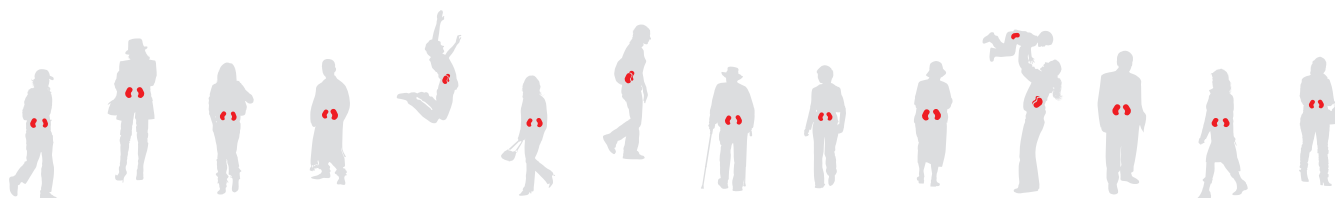


As I write this, I've just arrived in Christchurch after driving up from Dunedin. Weather was atrocious – Winter's reminder that it hasn't quite finished with us yet. But there were plenty of signs of Spring to counter that. The greening of recently sown paddocks; and lambs aplenty grazing in others. It was wonderful to see how Spring could still emerge, despite everything Winter was still trying to throw it. A little like life really – and a metaphor that I am sure many of you will be able to identify with.

The seasons change – and sometimes it seems to take an inordinately long time. Like cheese. Remember the two old blokes in the Mainland ad? It is true. "Good

*things take time."*

I wrote in our last newsletter of the pre-election 'manifesto' that Kidney Health New Zealand had again prepared – a recognition of the gains made for kidney health in New Zealand over the past three years – but equally a challenge to all political parties to do more for kidney patients and their families. I want to acknowledge the health spokespeople from Labour, New Zealand First and the Greens who took the time to meet with our Board chairman Dave Henderson and I to discuss our manifesto. And Health Select Committee chairman and National MP Simon O'Connor – who, while not holding direct portfolio responsibility for Health, had nevertheless been sufficiently impressed with KHNZ's lobbying of the Health Select Committee to want to hear what other priorities we wanted to pursue. And finally, in late August, our Medical Advisor Dr Colin Hutchison and I were invited to meet with the Health Minister, the Hon Dr Jonathan Coleman himself.



In that meeting we raised three issues – the two we had identified in the manifesto (which you can view on our website: [www.kidneys.co.nz](http://www.kidneys.co.nz)), and a further, more pressing issue that had arisen since the manifest was drafted back in June. We reiterated our concern that the national Deceased Organ Donation Strategy launched by the Minister in late July would only succeed if it was appropriately funded and had, in its implementation, as strong a level of renal sector input as had been committed during its development. To date, the funding committed has been minimal, and any wider renal sector input non-existent. And that, we believe, is unacceptable – and risks undermining the increase in deceased organ donation that the Strategy is intended (and has the potential) to deliver.

Secondly, we raised the need for greater consistency in the delivery of renal services across New Zealand. There will always be some regional variation. Demographic and geographical differences mean renal units have to prioritise their services differently, given the particular challenges that they face. But the fact remains that every kidney patient in New Zealand should be entitled to the same level and quality of service regardless of those differences; regardless of where they live.

To that end, KHNZ has entered into conversations with both the National Renal Advisory Board and the Ministry of Health to ensure that appropriate renal performance indicators are incorporated into the Long-Term Conditions Strategy that the Ministry is currently developing. The indicators proposed are patient-focused and span the full spectrum of chronic kidney disease, from early identification and treatment, through to ensuring best practice in end stage kidney disease.



Thirdly, as you will know, the Government passed legislation in late 2016 providing full compensation for lost income for live organ donors. A twelve month transitional period was established, during which any live organ donor would initially receive the existing WINZ sickness benefit for up to twelve weeks post-surgery, but be able to claim full compensation retrospectively once the Ministry of Health had established the necessary reimbursement processes. Recently KHNZ learnt that some of the information being provided by the Ministry of Health to transplant coordinators for the transitional assistance arrangement was at best misleading, at worst incorrect. Since raising this issue with the Minister of Health, we have had the opportunity to speak with Ministry staff, who have agreed to both re-drafting the information provided to transplant coordinators and potential donors and, more importantly, contacting every person who donates a live organ during this transitional period to ensure that they receive the full reimbursement they are entitled to.

In the midst of all of this, KHNZ has reluctantly decided to end its long-standing tele-fundraising contract. While tele-fundraising has brought in a significant amount of income over nearly ten years to support our work, the net amount received had been progressively declining. Nor was tele-fundraising part of any deliberate fundraising strategy. As a not-for-profit organisation that receives minimal government funding, and whose work is therefore largely dependent upon past and current donations, the KHNZ Board has agreed to fund the development of a comprehensive fundraising strategy. In reality, our work in supporting kidney patients and their families, providing education and political advocacy, and raising public awareness of kidney disease is only limited by our income. Our hope is that by taking a more intentional approach to fundraising and grant applications, we will be able to do even more to support you and those for whom you care. In the meantime, your ongoing support – financial and otherwise – is very much appreciated.

With thanks and regards

**Max Reid**



**Prevention • Support • Research**

## A great initiative



### **Healthcare in 15 minutes at home**

Sitting on her deck with a cup of tea may seem an unlikely place for Pamela Sharp to have an appointment with her renal specialist, Dr Kannaiyan Rabindranath, but often that's exactly where she can be found.

Pamela received a kidney transplant in 2016 and needs ongoing follow up appointments as she recovers. That used to mean a regular three-hour return trip between Rotorua and Hamilton, as well as waiting time in the renal clinic at Waikato Hospital.

That was until Pamela signed up to SmartHealth, Waikato District Health Board's online healthcare service, and started having online appointments with Dr Rabindranath from home.

SmartHealth includes HealthTap, a free online platform and mobile app that allows patients to access a range of health services via smart phone, tablet device or computer. Now Pamela can easily fit her appointments into her day. Her travel time has reduced, but her care has stayed the same.

*"It's a brilliant service," Pamela says. "Instead of having to travel in to the hospital I can have an appointment from home in 10-15 minutes. I'm still talking one-to-one with Dr Rabindranath, I can ask questions, get answers and we can make a plan for my care."*

Pamela's blood pressure monitor is connected to her iPhone, which sends readings through to Dr Rabindranath via HealthTap, so he has all the information he needs before each appointment.

*"It's all very straightforward, very simple," says Pamela. "My partner thinks it's great too, because he doesn't have to drive me to Hamilton every time. One appointment used to take two of us out for the day."*

*"It's especially useful in winter, when it's cold and raining. Not having to come out in bad weather, especially if I'm not very well, is brilliant."*

But when the weather is good, Pamela can continue meeting with Dr Rabindranath from her deck, in a fraction of the time she used to spend in the car.

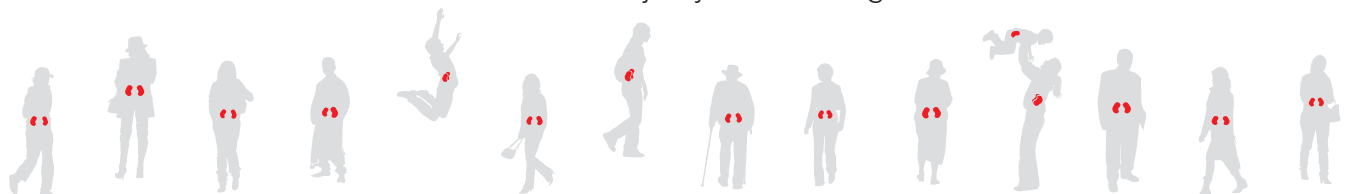
## From the Kidney Health New Zealand 2017 Manifesto

By the time you receive this we may or may not have a new Government, as part of our role advocating for people and their families with kidney disease, KHNZ sent it's 2017 manifesto to all major political parties in the lead up to the election, it remains to be seen what the outcomes will be, needless to say we will continue to raise these issues and others at every opportunity no matter which party is in power. Below is sample of some of the issues raised. To read the entire manifesto visit our website.

### **Ensuring timely, equitable and nationally consistent delivery of dialysis treatment**

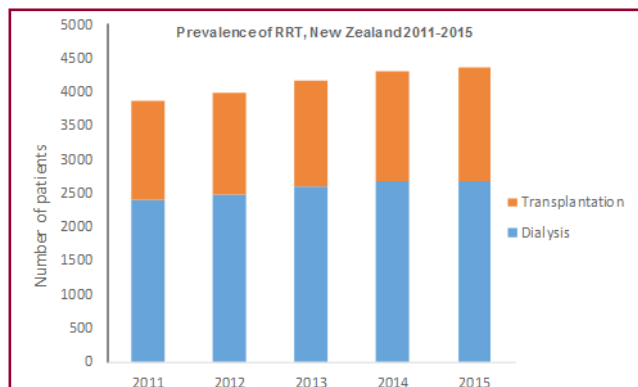
*What is the issue?*

Renal replacement therapy (RRT) is treatment to replace kidney function when a patient reaches end-stage kidney disease and includes either dialysis or a kidney transplant. In 2015 (the latest data available)<sup>1</sup> over 500 adults and children started RRT – the majority commencing



dialysis. Overall, nearly 2,700 New Zealanders were being treated with dialysis by the end of that year – continuing the year on year increase that the graph overleaf highlights.

While the rate of starting dialysis or kidney transplant treatment for European New Zealanders seems to be trending downwards, the equivalent rate for Māori and Pacific patients is substantially higher; nor is it decreasing. Overall, 156 patients starting dialysis treatment in 2015 were Māori (30% of all patients) and 104 (20%) were of Pacific ethnicity. Inequities in the incidence of end-stage kidney disease based on ethnicity have persisted over time.<sup>2</sup>



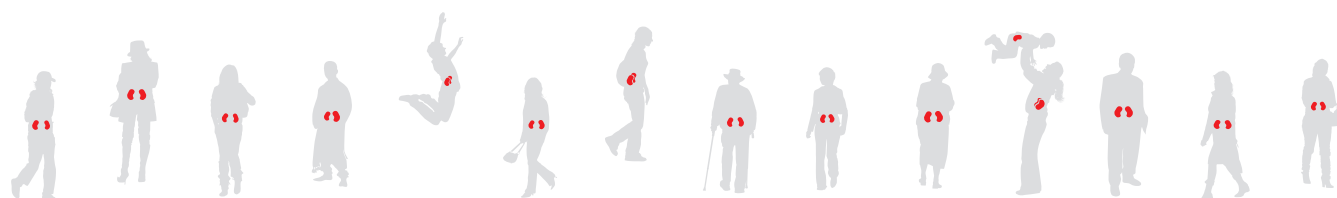
Nearly half (47%) of all patients starting renal replacement therapy in 2015 had kidney disease caused by diabetes. This rate was substantially higher than the comparable rate in Australia (37%) and is indicative of the complexity of end-stage kidney disease care in New Zealand and the consequences of diabetes on the health of New Zealanders. Over half of all patients (54%) treated with dialysis have diabetes, and this rate has increased from 45% in 2006. As is well-recognised, the prevalence of diabetes amongst those of Māori and Pacific ethnicity is considerably higher than that of the general population, further compounding this inequality.

The 2015 New Zealand Nephrology Annual Data Report (already cited) draws upon clinical and demographic data from the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, as well as information provided by the National Renal Transplant Service. A number of areas for further investigation and action are identified in the report, adding further weight to KHNZ's own concern to see more timely, equitable and nationally consistent treatment available to dialysis patients. These include:

- Low permanent vascular access rates for haemodialysis patients
- Disparities in RRT treatment rates among Māori and Pacific patients and younger patients
- Issues of access to Home Dialysis

### Permanent vascular access:

Over 60% of patients commencing haemodialysis started treatment with a temporary dialysis catheter. This is a sign of a system failure to engage the patient in timely planning for dialysis. Starting dialysis on this "temporary" access is associated with worse patient outcomes (higher risk of procedures, serious infections, and hospitalisation). Additionally it creates a barrier to earlier transition from in-centre dialysis to home dialysis – representing a saving of some \$25,000 per new dialysis patient per annum. Currently none of New Zealand's renal units achieved the national standard of 50% of patients commencing haemodialysis with permanent vascular access. KHNZ suggests that, given the clear patient and economic benefits of prioritising permanent vascular access, much greater emphasis – and, where necessary, funding – needs to be directed towards improving the levels and consistency of pre-dialysis training, and to ensuring surgical waiting lists have the capacity to prioritise vascular access procedures.





## Disparities in Renal Replacement Therapy treatment rates across age and ethnicity:

While the number of NZ European patients commencing dialysis has remained relatively stable, the number of Māori and Pacific patients receiving dialysis continues to increase.

Similarly, there is persistent inequity in access to transplantation based on both ethnicity and age. In 2015, no Māori patients and only 2 Pacific patients received pre-emptive kidney transplantation compared with 21 New Zealand European patients. In the last 5 years since 2011, 3 Māori patients had pre-emptive transplantation compared with 82 New Zealand European patients – a 27-fold difference. Only one child (aged below 15 years) received a pre-emptive transplant in 2015.

**24** New Zealanders had a kidney transplant as their **first treatment** for kidney failure ... *but only 2 were received by Pacific patients and 0 by Māori patients.*



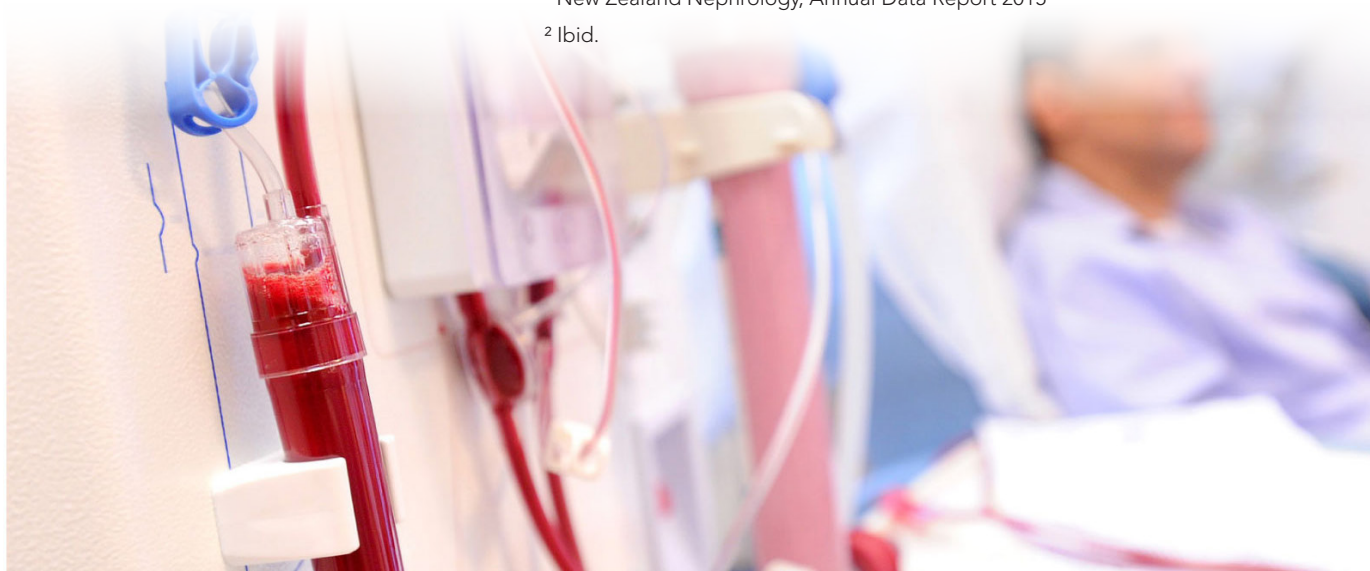
**61%** started haemodialysis with **temporary dialysis catheter**



Children and young adults also have the highest rate of starting dialysis care after late referral – a figure that has remained static at 25-30% of children starting dialysis. This compares with an overall late referral rate of 8.5% of patients. Late referral reduces the opportunities for patients to start dialysis care with permanent vascular access, with their preferred dialysis modality, or a kidney transplant as first treatment for kidney failure.

<sup>1</sup> New Zealand Nephrology, Annual Data Report 2015

<sup>2</sup> Ibid.



## 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.

**Kidney Health**  
NEW ZEALAND

ph: 0800 KIDNEY (0800 543 639) e: [info@kidneys.co.nz](mailto:info@kidneys.co.nz)  
[www.kidneys.co.nz](http://www.kidneys.co.nz)