

# Kidney Health

## NEW ZEALAND

Prevention • Support • Research

AUTUMN 2024



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**Welcome to the 2024 Autumn newsletter from Kidney Health NZ!**  
**With World Kidney Day and National Kidney Month now in the “rear view”, KHNZ are eager to report on all the impressive work that the kidney community have been doing throughout Aotearoa NZ in the past few months.**  
**World Kidney Day (WKD) is one of the most important events on the kidney calendar and we’re extremely grateful to all those who contributed this year.**

We’re sad to announce the departure of Dr Andy Salmon, our Medical Advisor, who has been with the organization for several years.

Andy’s commitment, tenacity, and meticulous attention to detail, especially in identifying and addressing the challenges faced by the kidney whānau in New Zealand, has been extraordinary. He will be sadly missed.

Subsequently, we’re pleased to announce that Dr Andrew McNally from Hawkes Bay Regional Hospital will be stepping into this role. We welcome Dr McNally to the role and will feature an article about him in our next newsletter. 🍷



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www.kidney.health.nz



## World Kidney 2024 (WKD) – Thursday 14th March

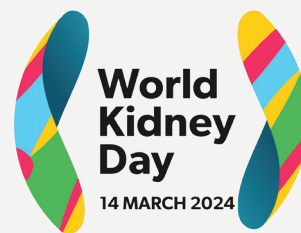
World Kidney Day 2024 was a huge success this year with events held in Dunedin, Christchurch, Palmerston North, New Plymouth, the Bay of Plenty and Auckland.

WKD is a great opportunity for the kidney community to get out and spread awareness of kidney disease throughout NZ.

Although not as well-known as some of the other organs, the kidneys play a vital role in keeping our bodies healthy by filtering blood and removing wastes and excess fluid.

The theme this year? 'Kidney Health for All – Advancing equitable access to care and optimal medication practice'

Below is a series of short reports from the WKD events that KHNZ were involved in. 📄



### Auckland City Hospital

An amazing WKD event was held by ADHB at Auckland City Hospital. We'd like to express our thanks to kaumātua Patrick for blessing this event – and the team at ADHB for running such a well-run WKD event. 📄



### Tauranga Hospital

The Bay of Plenty Renal Patient Council hosted a meet & greet in the Hospital Lobby and offered kidney related information and resources. Many thanks to the BOP Renal Patient Council for their commitment to WKD 2024. 📄



### Taranaki Hospital & Centre City Pop-Up

KHNZ were happy to support the Taranaki Renal Team with resources for their WKD pop-up. With five hours of testing offered, the team from Taranaki were able to complete over one hundred blood pressure and blood glucose checks. 📄



## Palmerston North Hospital

Thanks to the MidCentral DHB team who hosted a WKD event in the Palmerston North Hospital Lobby. Over forty people received blood pressure checks and the Donor Coordinator for that area was also available to speak to those interested in kidney donation. 🇾



## Christchurch Hospital

The team at Christchurch Hospital hosted a kidney awareness campaign in the Christchurch Outpatients Lobby, offering kidney related resources and blood pressure checks. Thanks to the Christchurch team for their participation on WKD. 🇾



## Dunedin Hospital & the Warehouse South Dunedin

The Otago Kidney Society provided information and advice about kidney disease at South Dunedin Warehouse. Nurse Lein supported the society and conducted blood pressure checks on the day.



Kidney Health NZ want to say 'ka pai' to all the renal units, societies, hospitals, individuals and peer support groups for their participation on WKD – and their contributions to this newsletter.

If you want to stay in the loop for World Kidney Day

2025 then join us at Kidney Health NZ on Facebook and Instagram.

Similarly, if you'd like to connect with one of the groups featured, please message us on Facebook, or call us. 🇾

## Online access to CKD information, resources and support

At Kidney Health New Zealand (KHNZ), we are excited to introduce an innovative new tool designed to simplify your search for kidney health information, resources, and support. Meet Kiri, your go-to virtual assistant.

Kiri uses our extensive library of health resources to provide real-time answers to your questions. You can easily access Kiri on our website by visiting [www.kidney.health.nz/kiri/](http://www.kidney.health.nz/kiri/)

To use Kiri, simply type in your question, and she will respond in clear, understandable language. For example, you might ask, "What does an eGFR of 30 mean?" or "Should I monitor my salt intake if I have Stage 3 kidney disease?" Kiri is also multilingual, capable of communicating in Māori, Samoan, Tongan, and several other languages.

While Kiri is an excellent starting point for answering your kidney health questions, she is not a substitute for the expertise provided by our team of dedicated nurses, or the personalised care provided by your doctor. Nonetheless, Kiri serves as a valuable resource for preliminary information and guidance.

We are committed to continually enhancing Kiri's capabilities and welcome your feedback as we refine this tool to better serve your needs.

Explore Kiri today and take the first step towards better kidney health with KHNZ.





# kidney health NZ events

## Pasifika Festival



On Saturday 9th March and Sunday 10th during National Kidney Month, four renal nurses working for Kidney Health NZ attended the Pasifika Festival 2024 at Western Springs in Auckland.


A total of 151 people were tested over the two days – a number we're extremely proud of.

This event was a great opportunity to network with other health care providers, such as the gout team who were in the tent next to us. We referred those we tested to each other's tents. The Heart Foundation also came and chatted with us, and sent some people to us, and we to them.

Eleven Pacific nations are represented over the weekend, showcasing traditional and contemporary music and dance, and Island foods and crafts from Samoa, Niue, Tonga, Cook Is, Tokelau, Tuvalu, Kiribati, Fiji, Tahiti, Hawaii, and Aotearoa.

Many people don't have easy access to seeing their health practitioners; networking with Māori and



Pasifika health providers means the KHNZ team are more likely to be invited to provide support at cultural events such as Pasifika, church and community health events and Marae-based oranga and hauora events. 



## West Hamilton Events

On March 25th KHNZ conducted a regional outreach initiative, hosting a series of events in Murupara, at Ruatahuna Hauora Centre and Kohunga Reo.

A total of 21 people were tested at these events. 📈



## Parliament Testing

On March 26th, KHNZ was privileged to provide kidney health checks at New Zealand Parliament.

Conducting testing at parliament provides KHNZ with a fantastic opportunity to advocate for change directly at the source. It's also an opportunity to educate about what chronic kidney disease (CKD) is, and how it is affecting New Zealanders.

In New Zealand 1 in 10 people will be affected by kidney disease – and because symptoms can be hidden for some time, early detection screening is key to prolonging healthy kidneys.

This was an amazing opportunity for us and we want to sincerely thank all those who were involved – and those stopped in for a test.

This was a fantastic way to wrap up National Kidney Month. 📈



## Cook Island Pa Metua Expo in Otago

On April 30th nurse Sandy attended the Cook Island Pa Metua Expo. Chatting to people about how to look after their kidneys and doing blood pressures, this was a lovely event.

Many people we spoke to did have hypertension and diabetes combined and they were aware of the targets they were trying to achieve with blood pressure and blood sugar readings, which was encouraging.

Thanks to the organisers for such a nice event. 📈





# kidney health NZ events

## Taranaki education and screening

On May 7th, KHNZ provided education to two groups at the offices of Pinnacle PHO in New Plymouth.

Matire Ropiha-Stewart, Lead Diabetes Community Coordinator for Diabetes NZ in Taranaki arranged for the Taranaki Diabetes Support Group to come to hear



KHNZ's National Clinical Manager Merryn talk about how diabetes can lead to chronic kidney disease (CKD) if not well managed. They were then offered free kidney health checks following the talk.

In the afternoon, Matire had organised kaimahi / clinicians from three GP practices and the PHO to attend a longer presentation about chronic kidney disease management in primary care. There were twelve clinicians in attendance, including three long term conditions nurse specialists, diabetes CNS, pharmacists, dieticians, and kaitautoko.

On May 8th, two further sessions for consumers were arranged – this time in South Taranaki. Education and testing was offered at Stratford and Te Hāwera on CKD and diabetes. A large group of 41 people from Stratford, Eltham and Ōpūnake attended the first session. This included the Diabetes, Heart and Stroke group from Ōpūnake who travelled together from the western side of the Maunga in 4 cars.

These events were a wonderful opportunity for KHNZ to work collaboratively with Diabetes NZ to deliver CKD education to not only diabetic patients, but also health practitioners in the wider Taranaki region. 🍷



## fundraising in the community

### Nikita and the Rotorua half marathon

Selflessly running in recognition of her father who passed away in 2021, Nikita has now completed her first half marathon!

Kidney Health NZ were happy to support Nikita with a couple of KHNZ T-shirts, as well as sharing her Givealittle page on our social media platforms.

On race day, Nikita finished the half marathon in two hours and three minutes – an amazing achievement.

Nikita raised an outstanding \$3,120 for Kidney Health NZ. Thankyou Nikita for your amazing effort!

And congratulations on running an awesome half-marathon! 🍷



NIKITA PARSHOTAM

#3658)

FINISHED

GUN TIME: 02:11:42

PLACE	FEMALE	16-34
505 OF 994	175 OF 500	93 OF 233

NET TIME: 02:03:27



## Rocco and his mullet

During April, Kidney Health NZ received donations with the message, "Go Rocco!! #Operation Mullet". But before we could find out more details ourselves, KHNZ were contacted by the Hunter family.

We found out that there was a young bloke named Rocco who'd been growing his mullet for three and a half years, and at some stage recently, a decision had been made that it was time for it to go. Rocco not only wanted to cut it off, but he also wanted to do so in a way that could raise money for charity.

Communications Coordinator Sam Faalilo was able to video chat with Rocco and his dad, to find out a bit more about their story.

Asking Rocco about his motivations, we came to

learn about the amazing sacrifice Rocco's dad had recently made.

In December 2023, Rocco's Dad donated his kidney to his brother, Rocco's uncle, which in Rocco's own words was "so cool".

Out on the family boat near the Poor Knights Islands, and surrounded by family, Rocco's mullet was ceremoniously cut off.

Kidney Health NZ want to express our sincere gratitude for choosing our organisation to donate to – Thanks Rocco! We hope you're enjoying your new school!

Rocco raised over \$5,000 for KHNZ – a monumental effort! 🍷



## Waikato DHB – Kai and Cuppa Group

Kidney Health NZ want to thank the Waikato DHB 'Kai and Cuppa Group' for their donation during National Kidney Month in March.

The Waikato DHB 'Kai and Cuppa Group' pick a different organisation each month to donate to - and KHNZ are thankful to have been their March recipient. 🍷





## One Day Renal Transplant Workup

A new one-day renal transplant work-up programme (ODRTW) being led by Health New Zealand Bay of Plenty | Te Whatu Ora Hauora a Toi has started paying dividends, with a recent programme participant receiving their kidney after being assessed through the new process. .



At the time 49-year-old Glenn McLean received a kidney transplant, he was doing dialysis for five hours or more every second day.

Two years ago, Glenn was recovering from a heart attack. He'd been in a coma for four weeks and his kidneys were failing. Several different appointments are required to determine suitability for a kidney transplant, and these can often take months and even years to complete.

Glenn's wife wanted to see if she was a suitable donor, but completing the necessary appointments and tests to determine if her kidneys were a match would take around a year.

In June 2022, the renal service at Hauora a Toi Bay of Plenty, introduced a new streamlined process, after recognising that the current transplant workup was taking too long. The new process allows patients to complete the majority of their assessments all on the same day.

The new process meant Glenn's assessment for kidney transplant suitability was completed much quicker than expected and he was able to be put on the transplant list sooner. Glenn received a new kidney in January this year. The surgery was conducted in Auckland.

Glenn is grateful for his new lease on life. "If the opportunity for a new kidney happens, then go for it. You then have to look after it well, as someone gave you that second chance," he said.

The one-day renal transplant workup programme has reduced the time for patients to be listed for a transplant, removed some of the costs and burdens, improved access, and reduced inequity for patients and their whānau.

"It's great to see the number of patients listed for transplant grow significantly because of the programme – doing most of the investigations in one day has dramatically reduced the time taken," said Dr. Scott Crawford, Nephrologist at Health New Zealand Bay of Plenty.

"From 11 listed for transplant in 2022, we now have 26 listed which is fantastic. One of our Eastern Bay patients on dialysis took only 132 days from referral to listing," he added.

As for the future, Glenn is looking forward to getting out and about and eating some decent food. "When you are on dialysis you have limited food options, so I'm looking forward to a nice meal and a holiday in Fiji with family," he said.

There are around 200 kidney transplant operations performed each year in New Zealand, while chronic kidney disease affects around 210,000 people. [D](#)



## Australia New Zealand Kidney Exchange programme (ANZKX)

A successful kidney transplant means not requiring dialysis, which is life altering for patients and their whānau. For most people it means a longer and improved quality of life. It gives freedom to travel and freedom in what to eat and drink. It can also mean improved fertility and many people have successful pregnancies after a transplant.

In Aotearoa, around 50 percent of kidney transplants come from deceased donors and the rest are from live donors, usually a friend or family member who is willing to donate one of theirs.

live donors still functioning five years post-transplant compared with 80 percent for transplants from deceased donors.

A paired kidney exchange can happen when a live donor (Donor #1), who is willing to donate to a spouse, friend or relative (Recipient #1), is unable to donate because they have an incompatible blood or tissue type. ANZKX will help find compatible donors amongst other registered pairs (such as Donor #2 and Recipient #2), enabling two compatible living donor transplants to occur.



While ANZKX transplants predominantly happen in Auckland – Wellington and Christchurch Hospitals are also involved. As part of building the trans-Tasman collaboration a team of kidney and transplant specialists recently visited the team at Wellington Regional Hospital.

Surgeries don't always happen in the same hospital, and kidneys are often put into chilly bins and flown around the country, and also to and from Australia.

However, approximately 30 percent of potential donors who wish to donate a kidney to a relative or friend are unable to do so due to incompatible blood group or tissue matches. In comes the Australia New Zealand Kidney Exchange programme (ANZKX).

The ANZKX program, run by the Royal Melbourne Hospital, is a collaborative trans-Tasman living donor kidney transplant programme, involving centres in both Australia and Aotearoa. The primary goal of the program is to increase the number of living donor kidney transplants by identifying matches for incompatible donor-recipient pairs, so friends and family who want to donate a kidney to a loved one but aren't a good medical match, can be paired with others in the same situation.


The program aims to help more people with kidney failure get transplants instead of staying on dialysis. Transplants are the best and most cost effective treatment for kidney failure so the ANZKX programme has the potential to improve outcomes for patients and their whānau while reducing health service costs.

Long-term results from living donor kidney transplants are excellent, with 88 percent of transplants from

Capital and Coast have been actively involved in the Australia New Zealand Kidney Exchange programme since its conception and have exchanged kidneys with Auckland and Christchurch. Some of these exchanges have been part of trans-Tasman chains.

During 2023, six Wellington regional recipients received a transplant via the kidney exchange, three transplants were performed in Wellington and three in Auckland; four donation procedures were done in Auckland and three in Wellington. 2023 was the programmes most successful year yet with 25 donors in Aotearoa and 55 in Australia.

More and more altruistic donors are also signing up to the programme; these donations can set off transplant chains, with one in Australia expected to reach 20! Aotearoa has put a lot of energy and focus into increasing the number of living donors, so much so that the number is nearly twice as high as Australia's.

We are thrilled to be part of this team and part of the exchange and look forward to growing the relationships with our national colleagues and the trans-Tasman team. 

## **KHNZ CEO Andrew Baker comments on Dialysis Capacity in recent Radio New Zealand media report**

A three-year-old Canterbury girl who is on home dialysis had four dialysis machines fail in one week – and there is no backup option in the South Island.

Her mother Emily Cromie said regularly failing equipment made a difficult job “horrendous” at times, and she wanted change for other rural families.

Harper Cromie, from Glenroy near Darfield, led a relatively normal life by day as a bubbly, sassy girl who made friends with everyone, Emily said.

But at night she slept hooked up to a dialysis machine because of a rare and very aggressive form of kidney disease.

Like many preschoolers, she was a wriggly sleeper so often knocked cords and set off the machine’s alarms.

It was exhausting for Emily and Nic, who are farmers, but caring for Harper was made much harder due to the machines regularly breaking down, and replacement machines could only be sent from Auckland, Emily said.

“They should be condemned, the lot of them. They fault constantly. It is disgusting that they are even in service if they are this unreliable,” she said.

Looking after Harper was a stressful, round-the-clock job, especially for Emily.

“I’m the one that has to technically hurt her. Injections, putting her nasogastric tube down into her stomach. It’s horrible, I hate it, it makes me cry every time,” Emily said.

“Harper doesn’t know. She looks at me and says, ‘I’m sorry, I’m sorry’, like I’m punishing her for something she has done wrong, which is not the case. It’s just so hard.”

As they dealt with all that, Emily and Nic often felt they were on their own when it came to the health system.

The doctors and nurses who looked after Harper when she went to hospital were wonderful, but much of her care was at home, made harder because they lived rurally, Emily said.

There were no back up machines like the ones Harper used in any South Island hospital if things went wrong.

Kilos of medical supplies also had to be sent down from Auckland but were often delayed or waylaid.


Emily looked at funding a machine herself but it was too hard, she said.

However, the family has had some good news.

Harper is due to get a kidney transplant in July.

Emily, though, wanted to fight for others.

“I am aware of the ridiculous financial cuts and everything for our already failing health system but I am so determined to make sure that no parent ever has to go what we have had to.”

Christchurch Hospital paediatric specialist James Hector-Taylor said delivering dialysis to rural patients was a challenge. 





The units were sensitive to movement which could affect how they worked and so there were always two machines delivered to patients under five, he said.

Each child has a local paediatrician, but Starship Hospital in Auckland ran the child dialysis programme for the whole country, because it was the only place with suitably trained specialist doctors and nurses, he said.

"Starship has explored having spare machines closer to patients, but they often sit unused while still requiring maintenance, and therefore are still likely to malfunction," Hector-Taylor said.

"The current approach of delivering machines and supplies directly to families continues to be the most effective way of delivering paediatric dialysis treatment."


Families could always perform dialysis manually in an emergency, he said.

However, Emily said that was very intensive and hard to do when sleep deprived, when mistakes could cause complications.

Kidney Health NZ chief executive Andrew Baker said he was not surprised to hear of the challenges the family faced – many other rural patients had a tough time too.

Some travelled four hours, three times a week to get their dialysis, he said.

He wanted community dialysis hubs created in more places to make it easier.

"We need more dialysis units, we need more chairs – so we need the infrastructure, we need more equipment, we need investment put into the funding of staff, and we need to attract those staff by paying them well," he said. 

## WE'VE CHANGED HOW WE ACCEPT PAYMENTS

Over the past few months, KHNZ have been making the transition from PayPal to Stripe.

We have now made the full transition to Stripe, with all digital donations now going through the Stripe service.

Our direct deposit details haven't changed, and direct donations can still be made to our bank account.

If you have any issues with donations or using Stripe, please contact **sam.faalilo@kidney.health.nz** for assistance.

## Kidney Stories & Experiences

Have you donated a kidney? Received a kidney? Or been on dialysis? We want to hear your story! 'Transplant Stories from around the Motu' is a project aimed at raising awareness of live donation, kidney transplantation and the experience of being on dialysis.

Launched during National Kidney month in 2023, we hope this library of experiences can help alleviate the fears of kidney failure – and help to encourage more donations.

If you'd like to check this library out, visit **<https://www.kidney.health.nz/information-and-resources/stories/>**.

We're looking for people from all ages and all walks of life to contribute to this library, so if you'd like to share your experience with us – please get in touch at **sam.faalilo@kidney.health.nz**.

# Kidney Support in New Zealand

Our 0800 543 639 support line is open Mon – Fri  
8.30am – 5pm

## Nationwide

### Kidney Health NZ Support Line

info@kidney.health.nz – 0800 543 639

### Facebook Support Group

Aotearoa Kidney Whānau

### Facebook Support Group

– PKD Collective NZ

### Facebook Support Group

– Kidney Donor Whānau

### Facebook Support Group

– Wellington Kidney Whānau

### Facebook Support Group

– Otago Kidney Whānau

### Kidney Kids

office@kidneykids.org.nz – 0800 215 437

## North Island

### The Kidney Society (previously ADKS)

kidneysociety@adks.co.nz – 0800 235 711

### Wellington Kidney Peer Support Group

maxtra62@gmail.com

## South Island

### Christchurch Kidney Society – 03 341 0906

### Ashburton Kidney Society

lizcarrick64@gmail.com

### Otago Kidney Society

info@oks.nz

## Australia

### Kidney Health Australia

careteam@kidney.org.au – 1800 454 363



## Thank you to the following organisations for their support!

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- WG Johnston Charitable Trust
- R O Dixey Trust
- Massey University
- Vernon Hall Trust Fund
- Havelock North School
- Te Kowhai School
- Hamilton Library
- Palmerston North Library
- Wellington Library
- Havelock North Library
- St Mary's College, Wellington
- UCOL Masterton
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- DP Boocock Family Trust
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- Stroke Foundation
- REAP Centre Masterton
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