

Kidney Health

NEW ZEALAND

Prevention • Support • Research

SUMMER 2024



IN THIS ISSUE

- Address from CEO Andrew Baker
- Our message to Minister of Health Hon. Dr Shane Reti
- Kidney Health Events & Photos -- Waitangi Day, Hakatere Marae, Paia Festival and more...
- Fundraising in the Community
- Wellington Kidney Group
- Kidney News

Welcome to the first Kidney Health NZ newsletter of 2024. We have lots to report on from the end of 2023 – as well as articles on what we've been doing since. It's been a busy start of the year for KHNZ, with testing events throughout Aotearoa New Zealand in Hawkes Bay, Palmerston North, Christchurch and Hamilton.

As well as welcoming the new year, we are also welcoming a new Government and Minister of Health Hon. Dr Shane Reti. Kidney Health NZ welcomes Dr Reti to his position – and we wish him the best in his role.

Later in the newsletter we have a feature article from the recently re-established Wellington Kidney Peer Support Group – as well as articles on the events we've attended in the past few months.

We're extremely lucky to have spoken with Shaz Dagg, an elite para-athlete, during her training

for the Kathmandu Coast-to-Coast. Shaz is an inspiration to all – and we're extremely grateful that she took time to speak to us. Shaz has selflessly been using her platform to fundraise for Kidney Kids, an organisation with a similar mission to our own.

We hope you enjoy the rest of the newsletter and if you'd like more details on an article, or if you'd like to contribute, please contact sam.faalilo@kidney.health.nz

Tēnā koe, nau mai

I hope you've managed to have a good break over the summer. It's been a long hot one in many parts of the country and this has contributed to increased fire and drought risk in a number of areas. So, I hope you're all safe and well.

We've been busy the last few months at Kidney Health NZ. We now have a full complement of staff working away to achieve our Mission to *Measurably reduce renal inequities & increase access to treatments for those with CKD.*

We employed a fabulous Fundraising Manager in December of last year, Madi Keay, who brings a wealth of knowledge and experience to this very competitive fundraising space. Madi will be working closely with the Clinical Team to understand our strategic priorities so she can seek funding from organisations who may like to partner with us.

The Clinical Team of Merryn, Becs, Erica, Carmel and Andy have been working hard to clearly define the best way to invest their time and energy, over and above the targeted screening events they currently do.

This exercise has been extremely valuable and has resulted in the creation of three significant projects which were approved by the Kidney Health New Zealand Board in February. In 2024, we hope to develop:

- 1 An 'Away from Home' dialysis programme that facilitates the exchange of patients between dialysis units, to enable them to continue to work, attend family events and remain contributing members of their communities.
- 2 A 'Primary Care Education' initiative that involves the development of resources and materials to upskill health care professionals in the community to better diagnose, manage

and support patients and their whānau with CKD in New Zealand

- 3 A 'CKD Patient Support Programme' that encourages the self-directed management of early CKD for affected individuals/whānau to help them to better understand and manage their kidney disease.

These are significant projects that will take time, money and resources to implement. We will be doing so in a staged approach. Step 1 is to seek funding to pilot these projects, and to collect valuable data to enable us to roll them out more widely. Please get in touch with me directly if you would like to get involved in supporting these valuable projects.

In addition to the above mahi, Kidney Health NZ are continuing our excellent advocacy work in the first Quarter 1 of 2024. We have arranged a visit to Parliament to test Members and their staff around World Kidney Day, and this is an excellent opportunity to highlight the issues faced by CKD patients and whānau in New Zealand.

We have a range of advocacy issues we're championing, aimed at addressing capacity constraints, improving patient wellbeing, and supporting those on their journey to organ transplantation. ☺



Letter to Minister of Health Hon. Dr Shane Reti

Ahead of Hon. Dr. Shane Reti's appointment as Minister of Health in December of last year, Kidney Health NZ prepared a briefing document for him outlining ways to deliver better health outcomes for patients with Chronic Kidney Disease.

If you're interested, we've included links and QR codes to the Introductory Letter and the full 23-page document below.



Figure 1: Link to introductory letter



Figure 2: Link to full 23-page document

kidney health NZ events

Hakaterere Marae Hauora Day, Ashburton – November 4th

Last November, nurses Erica and Sudath as well as communication coordinator Sam Faalilo travelled to Hakaterere Marae near Ashburton for another set of community testing. This was another successful event with 53 people tested. The events hosted

at Hakaterere Marae are always well-attended and are also a wonderful opportunity for us to engage with members of the community – as well as the Ashburton Kidney Society. We want to thank Liz and the entire team at Hakaterere Marae for hosting us. ∩

Wesley Community Centre, Auckland – November 25th

On November 25th, Kidney Health NZ attended the pre-Christmas Health Check event at the Wesley Community Centre in Auckland. Attended by the likes of Bowel Screening, NZ Blood, Well Woman's Trust, St Johns, Breast Screening, Smokefree Auckland and more, this was a great opportunity for members of the community to get a free health check. On the day, we were able to give 64 people kidney health checks.

Screening offered included our kidney tests, bowel screening, MMR, COVID-19 and flu vaccines, spinal checks, dental checks, cervical screening and blood type tests.

Thank you to Pacifica Connections for organising this great event. ∩



Paia Whānau Day, Palmerston North – December 9th

Last December, Manawātū Hauora asked Kidney Health NZ to be one of the health providers at the Paia Whānau Day event.

Mental Health, Rongoa practitioners, Pasifika health providers were there on the day, but KHNZ were the only people providing point of care testing for blood pressure, diabetes and kidney function. Food trucks, live bands and children's entertainment was also there – and Rotary provided free kai. In total, 40 people were tested during the day. ∩



Waitangi Day Family Fun Day, Hastings – February 6th

Kidney Health New Zealand provided free kidney health checks at the Hawkes Bay Regional Sports Park Waitangi Day event, organised by Ngāti Kahungunu Iwi Incorporated (NKII). Other Iwi-led hauora, as well as Pasifika, organisations were present on the day – these included Te Taiwhenua o Heretaunga, Health HB, Mapu Maia, and Tihei Tākitimu. 62 people had their kidney health checked at this event. 📄



Hamilton Community Testing – February 16th & 17th

Kidney Health NZ provided free kidney health checks at Central Library and Tui Pharmacy on the 16th and 17th of February respectively. These were great events with 62 people getting their kidneys checked. KHNZ want to sincerely thank the teams from Central Library – Te Koopuu Maania O Kirikiriroa and Tui Pharmacy for their hospitality. 📄



World Kidney Day – March 14th 2024

World Kidney Day is fast approaching. Kidney Health NZ is supporting renal units throughout New Zealand with resources and materials to commemorate WKD in 2024.

The theme this year is 'Kidney Health for All -

Advancing equitable access to care and optimal medication practice'.

Follow our Facebook and Instagram pages to get updates on where events will be!

Visit <https://www.worldkidneyday.org/> for more information about World Kidney Day. 📄

fundraising in the community

We want to thank Shaz Dagg and Nikita Parshotam for their contributions to our newsletter. Both individuals are doing impressive mahi, while also raising awareness of kidney disease in New Zealand.

'Limb-it-less' Shaz Dagg and the 2024 Kathmandu Coast-to-Coast

Kicking off on the 9th of February – the Kathmandu Coast-to-Coast is one of the oldest adventure races in the world, founded in 1983. If you have never heard of the Coast-to-Coast (or what it entails), I have included an excerpt from the Coast-to-Coast website at the bottom of this article which helps paint the picture.

I was able to speak to Shaz before the event and hear about the changes she's made since her first

attempt, and about her motivations in the lead up to 2024.

For Shaz's 2024 event, Coast-to-Coast organisers have approved Shaz to compete in the kayak event solo, something she was restricted from doing when competing in her first event. Since 2021, Shaz has received a specially designed socket for cycling - and a 3D-printed adaptation for her kayak. This was a groundbreaking development that marks a first in the world. Shaz has made special mention of designer Alex Huffadine and the team at Wellington Limb Centre for their amazing work at



bringing this adaption to reality.

At the time of writing this newsletter Shaz had raised over 7.7k for Kidney Kids NZ.

The following text is an excerpt from the Kathmandu Coast-to-Coast website:

“Competitors leave on foot from the black sands and lush windswept landscapes on the West Coast, running 2.2km inland to their waiting bikes. They then follow the Taramakau River to the foothills of the Southern Alps where they switch their bikes for runners and the first true test of the course.

The 30.5km run is mainly off trail, with the rocky riverbed often the only direct line up the valley. Competitors encounter multiple river crossings with frigid crystal clear water and an elevation gain of nearly 800m on their way to Goat Pass and the start of the descent.

With the very fastest athletes taking nearly 3 hours, the run is as much a test of co-ordination and strength as it is outright speed.

A short 15km ride follows before the second jewel in the course. The mighty Waimakariri River. 70kms of braids and a stunning gorge, the river section is for many both the highlight and the crux of the race. The water flows swiftly in places and mixes long calm sections with rapids up to grade 2 in size.

It takes competitors from the heart of the Southern Alps out on to the Canterbury Plains where just one final 70km ride stands between competitors and the finish on the East Coast at the New Brighton Pier amongst a vibrant beachside festival.”

– Kathmandu Coast to Coast Website

When I spoke to Shaz, she gave me a mantra that she uses



to help motivate her - and that she uses to help find strength to keep going.

“I may only have one wing, but I can still fly.”

Event Day:

After completing the 2.2km run and 50km on the bike – Shaz was just 5km away from transitioning back to running when an incident resulted in her - and her bike - somersaulting and landing with a ‘great thud’. Pushing on through immense pain, Shaz completed 18km of the mountain run before being pulled out by her medical/support team.

Shaz was brought off the run via helicopter and was discovered to have a broken collarbone and a broken humerus in her stump, appropriately named ‘stumpy’.

Kidney Health NZ wants to acknowledge this effort, especially how far she made it considering this significant break. We also want to thank her immensely for bringing attention to Kidney Kids.

We’re wishing you all the best with your recovery Shaz! A link to her page can be found on the Kidney Health NZ Facebook page.

Nikita Parshotam and the Rotorua half marathon

Kidney Health NZ is happy to support Nikita Parshotam as she prepares to attempt the Rotorua half marathon in support of Kidney Health NZ in May. Nikita is running in recognition of her father who passed away in 2021.

We wish Nikita all the best with her training! Follow the Kidney Health NZ Facebook page to get updates closer to competition time. We will have a full article about Nikita in our next newsletter.



WELLINGTON KIDNEY PEER SUPPORT & EDUCATION GROUP

Are you located in the Wellington region and looking for kidney support?

The Wellington Kidney Peer Support and Education Group are looking for members!

We're excited to advise that Wellington Kidney Peer Support & Education Group will also be hosting several workshops in the Wellington Region this year.

The first workshop was held at St Hildas Hall on Valentines Day. This workshop was attended by Carolyn Mills. Carolyn has been playing the harp as a professional musician for the

NZ Symphony Orchestra for 35 years and is the Principal Harpist.

The group was graced with an unforgettable harp performance by Carolyn. Her harp music not only captivated the hearts of the group, but also beautifully illustrated the theme of the meeting.

Special thanks to Carolyn Mills.



The next workshops will be held on the 15th of May, 14th of August and 13th of November.

If you're interested, please contact Chairperson Tracy Trubshoe-Oden at maxtra62@gmail.com – alternatively you can find them on Facebook by searching 'Wellington Kidney Whanau'.

Here's a message from Tracy:

“Hello, our Wellington Peer Support Group is currently working behind the scenes to rebrand its operational structure. We ask if you are bursting with ideas or guidance that can help us get this right then please send them through. We want to continue to seek advice from those in our neighbourhood to ensure the new support structure is as robust and effective as possible. We are currently calling strong for any new NAME ideas. And there will be many more times and issues that we will seek help from those we are here for. We want to get it right.

Please go to our Facebook page currently named Wellington Kidney Whanau to see progress as we go. Free to join anytime. Watch this space. Take care, and please know we are trying our best to make a bumpy road just that bit smoother.”
Their most recent newsletter can be found on our website at: kidney.health.nz/about-us/newsletter/

Lions Support for Renal Unit

The recovery of a Manawatū teenager from end-stage kidney failure, to become a happy and healthy donated kidney recipient, has inspired district Lions clubs to present a vital piece of equipment to Palmerston North Hospital's renal service.

Leader of the Zone 2 group of clubs Karensa Dennis said her family was in shock five years ago when 15-year-old daughter was diagnosed. Her kidneys were functioning at only 11% and the prognosis was she may only be five months away from requiring dialysis. Dennis said the team at the renal unit provided amazing support for her daughter through three years of daily peritoneal dialysis and the search for a live kidney donor. Two years ago, Karensa Dennis' daughter received a deceased donor donation.

"She is now happy and extremely healthy. She is an inspiration."

Dennis rallied several Lions clubs to fundraise for the 24-hour blood pressure monitors. The wearable units allow would-be donors to have their blood pressure checked continuously for a day, to confirm whether they are healthy enough to give a kidney to someone in need.

Nephrologists Norman Panlilio and Ankur Gupta said there was up to a five-month wait to access one of the monitors through the hospital. Having their own dedicated unit would speed up the process of identifying potential live donors.

The first of the \$6000 blood pressure machines came from the fee the city council paid the club for organising the recent Christmas Parade. ↻



Renal Resource Project - Update

After seeking feedback from the kidney community throughout New Zealand, Kidney Health New Zealand is now beginning the process of creating a suite of education resources which will be accessible and in a variety of formats.

Feedback was received from patients, whānau, and allied health and healthcare professionals working with kidney patients. Some of the common themes around the formatting of the resources include the need for more information to be translated into a wider range of languages, more graphics and less words, consideration of English as a second language for many, small amount of information at a time, in other words layers of information and consistency of wording throughout the resources i.e. kidneys instead of renal.

Consideration will be given to ensure accessibility to the resources for all, planning is underway to establish a national repository for education resources, including access for those without data and those less IT savvy. The design will include a selection of short videos clips, podcasts, booklets, flip charts, brochures and fact sheets which will contain information for those affected by kidney disease, those at increased risk, newly diagnosed, kidney replacement therapies, supportive care and information for caregivers. The information will range from what to do when the

GP tells you your kidneys aren't working properly, managing medication, treatment options through to managing fatigue, anxiety, anger and what can I as a caregiver do to support my person.

Work will be done to ensure this Information is accessible for GP's and Practice nurses to enable the information can be printed out for their patients to take away with them. Many of these resources will be useful for Primary Care and support their learning too. The KHNZ resources design will be consistent throughout with cultural considerations at the forefront, the ability to update these resources regularly will be a priority to ensure they remain current and a reliable source of information for all. Co design of these resources is critical, and we will be seeking input and feedback from patients, caregivers, healthcare teams working with kidney patients. This will be done by way of focus groups, either via Zoom or Face to Face, emails, and regular updates.

It is important your voice is heard, after all these resources are for you, and those who want to understand kidney disease and support those impacted by the disease and its treatments.

We welcome your feedback at any time, you can email Carmel at carmel@kidney.health.nz or call her on 021 460456, or 0800 543 639. ↻

Minja Ivelja celebrates fifty years with a successful transplant.

January 2nd 2024 marked 50 years since Minja received her transplant, a kidney that is still going strong to this day – making the Auckland woman likely to be one of the longest surviving kidney recipients in Australasia.



Minja, who lives on the North Shore, hadn't experienced kidney issues prior to immigrating to Melbourne from former Yugoslavia in 1969, and says nothing was diagnosed until she started bleeding during her second pregnancy, in 1971.

At that time, Minja – who barely spoke English, and relied on her husband to translate – learnt her kidneys weren't working properly. One had failed, and the other was operating at a very minimal level, daughter Sandra Ivelja says.

Then, after a couple of years on dialysis, Minja's pager went off: they had a kidney.

She'd never had an operation, didn't quite understand, was scared and questioning whether she would live or die. Despite this on January 2nd, 1974, Minja received a new kidney.

That "beautiful gift" five decades ago enabled Minja to live a full life, she says.

Each May, the family attend the annual Transplant Thanksgiving Service at Holy Trinity Cathedral, where Minja and her daughter joke she's regarded as almost a celebrity.

"She's such an inspiration... they go, 'oh my god, this woman had a kidney for 50 years. My kidney can last,'" Sandra said.

"That's what gives me pleasure," Minja said, "when you tell people it's been 50 years, and it's still going".

Clinical lead for Organ Donation New Zealand, Dr Joanne Ritchie, said Minja's story is "just amazing."

"Having a transplanted organ for 50 years, it's absolutely life-changing, and life-saving," she said.


People live much longer after a kidney transplant than they do on dialysis, and being on dialysis means it can be "really hard" to work, travel, or have a family, Ritchie said.

Ritchie said when organ donation is raised with a whānau, in a situation where it may be possible, it's much easier for people to make a decision when they know what their loved one wanted.

She encouraged everyone to have a conversation with those close to them about their wishes.

Ritchie also wanted to convey her thanks to those who give such life-changing gifts, and "how grateful we are to people who donate in some of the worst situations possible."

Minja hopes that her experience inspires others to talk about organ donation and realise the significance it can have.

"We are born like dust; we go like dust. If you don't need it anymore, give it to somebody who does need it." 

Kidney Research UK teams up with Diabetes UK and the Juvenile Diabetes Research Foundation

Just like New Zealand, diabetes is the leading cause of kidney disease in the UK, so Diabetes UK, JDRF UK and Kidney Research UK have joined forces to identify the research gaps and care needs in the field.

Diabetes can damage the blood vessels in the kidneys and impair their function, leading to the development and progression of kidney disease. Up to 50% of people living with diabetes in the can experience kidney disease, with one in five people with diabetes needing treatment for it during their lifetime. Diabetes is also a leading cause of end-stage kidney disease, with almost one in three people who need dialysis or a kidney transplant having diabetes.

The three organisations will draft an article together, summarising the outcomes of their recent workshop. It will be shared at the Diabetes UK Professional

Conference 2024, to help bring in more investment and get researchers working on this issue sooner.

This partnership is the first step towards a new narrative where it is hoped that fewer people with diabetes will experience kidney damage, and those who do can access less invasive treatments that make a real difference to the progression of kidney disease. Kidney Research UK, Diabetes UK and JDRF are raising the voices of people living with diabetes and its complications, accelerating focused research fuelled by collaboration, and championing coordinated care pathways, which could transform the quality of life of people with diabetes and kidney disease.

This entire article can be found on the [kidneyresearchuk.org website](https://www.kidneyresearchuk.org).

Kidney Stories & Experiences

Have you donated a kidney? Received a kidney? Or been on a 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

Our 0800 543 639 support line is open Mon – Fri

9am – 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 – glen@oks.nz

Australia

Kidney Health Australia

careteam@kidney.org.au – 1800 454 363



Thank you to the following organisations for their support!

- Green Cross Health
- The Kingdom Foundation, proudly managed by Perpetual Guardian
- 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
- Pak N Save Wainoni
- DP Boocock Family Trust
- Wintec
- Genesis Energy
- Stroke Foundation
- REAP Centre Masterton
- Stabicraft



Receiving your newsletter If you would like to change the way you receive your newsletter, please let us know by emailing sam.faalilo@kidney.health.nz

We can add you on to our email database which will have the newsletter emailed directly to you.