

Kidney Health

NEW ZEALAND

Prevention • Support • Research

SUMMER 2024



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Welcome to the KHNZ Summer 2024 Newsletter! In this final newsletter for the year, we'll look back on some of the highlights from the past months, as well as share some updates from the team at Kidney Health NZ.

With over 1,300 people tested at 25 early detection events throughout the country, it has been a huge year for public screening. Since the last newsletter we've been in the community throughout Auckland, Levin, Hamilton and Wellington, attending some awesome community, Marae and Pasifika health day events.

Lastly, we have some interesting research going on in New Zealand as well as an update on the PHOSPHATE trial that has recently finished up.

Those with Polycystic Kidney Disease (PKD) and those who were involved with the PHOSPHATE Trial (**P**ragmatic randomised trial of **H**igh **O**r **S**tandard **PH**osph~~A~~**T**e **T**argets in **E**nd-stage kidney disease) can find that information near the end of this newsletter.

If you'd like more details about any of the articles in this newsletter, or if you'd like to contribute in the future, please contact –

sam.faalilo@kidney.health.nz 📧

CEO ADDRESS

Tēnā koutou katoa,

As we approach the end of the year, I want to take a moment to reflect on the progress we've made at Kidney Health New Zealand (KHNZ) and share some exciting updates with you all.

Our mission to support New Zealanders living with chronic kidney disease (CKD) continues to gain momentum, thanks to the dedication of our team, the strength of our partnerships, and the generosity of our supporters.

This year, we've worked tirelessly to improve awareness of CKD, with a strong focus on addressing the unique challenges faced by Māori and Pacific communities, who are at significantly higher risk of developing kidney disease than the general population. By providing educational resources and advocating for better access to care, we aim to empower individuals and communities to take proactive steps in managing their kidney health.

I'm also proud to highlight our efforts to drive innovation in kidney health, including the development and launch of Kiri, our innovative digital assistant designed to support individuals to better manage their kidney health. Since her introduction, Kiri has proven to be an invaluable tool, offering tailored advice and resources based on specific questions asked by users. Her presence (available on our website) has been especially impactful in bridging gaps in access to care for those in rural areas and communities disproportionately affected by CKD.




This year, our advocacy work has also taken centre stage. Through our National Travel Assistance (NTA) advocacy, we have been able to highlight the challenges faced by patients who need to travel for life-saving treatments like dialysis and

transplantation workups. Many of these individuals bear significant financial and logistical burdens. By participating in a working group representing 34 patient support organisations, we have been able to effectively communicate these challenges to senior MPs within Government and Opposition, as well as decision-makers within Te Whatu Ora.

From exploring new technology solutions such as Kiri to simplifying healthcare access, KHNZ is determined to make kidney care more equitable and accessible. These initiatives are part of our broader commitment not only to support patients but also to challenge the systemic barriers that make kidney disease an under-recognised and underfunded long-term chronic health condition.

Looking ahead, we have ambitious plans to secure sustainable funding to further expand our reach and impact. We understand that this work is urgent and necessary, and we're excited about the opportunities to build stronger connections with the public, our healthcare partners, and policymakers.

Finally, I would like to acknowledge and thank the Board Members who have moved on from KHNZ this year. Mara Fisher, our Deputy Chair, Christine Prince, and Jo Denvir have each contributed enormously to our work. Their invaluable guidance, expertise, and passion for improving kidney health have left a lasting legacy that will continue to benefit New Zealanders for years to come. We wish them all the very best in their future endeavours.

Thank you for being part of this journey. Together, we can create a future where every New Zealander has access to the resources and care they need to live well with - or prevent - kidney disease. 

**Ngā mihi nui,
Andrew Baker
Chief Executive Officer
Kidney Health New Zealand**

STAFF PROFILES

Kidney Health NZ is excited to welcome several new staff to the team in 2024. Here's a brief introduction to some of the talented individuals joining us!

MADI KEAY - OPERATIONS MANAGER

Madi brings an interdisciplinary background in economics, indigenous studies, and sustainable development, complemented by Master's research exploring the community benefits of involving young people in post-disaster volunteering.

With a focus on promoting equity through effective resource allocation, Madi has worked across various sectors to address systemic barriers and enhance outcomes for underserved communities. Their experience includes developing impactful strategies to maximise community benefit, aligning resources with diverse needs,



and fostering inclusive engagement.

Currently pursuing a Master of Child and Family Psychology, Madi's research examines how proactive initiatives can strengthen community resilience and well-being, reflecting a commitment to sustainable, equity-focused solutions.

This expertise informs Madi's work at Kidney Health New Zealand, where she strives to improve health outcomes by advocating for education, accessibility, and equitable care for people affected by kidney disease.

Madi has also worked with The Charity Collective, Student Volunteer Army and the Tourette's Association, among others. [D](#)

DR ANDREW (ANDY) MGNALLY - MEDICAL ADVISOR

Andy was born and raised on a farm near Kakanui, just south of Oamaru, North Otago. After secondary school at Waitaki Boys' High School, he undertook his medical degree at Otago University, enjoying his student days in Dunedin and Christchurch.

Postgraduate junior doctor and physician training took place in Christchurch, Melbourne, Auckland, Dunedin, and Leeds (UK). He has been a Consultant Renal and General Physician at Hawke's Bay Hospital since 2015.

Andy's focuses in the workplace are providing holistic, compassionate, evidence-based, and individualised care for his patients. He values communication and teamwork in the healthcare environment. It is a privilege getting to "know" patients, their whānau, and the local/national community, through work.

Kidney medicine meets Andy's workplace goals and values. He finds it interesting as kidney disorders impact



the whole body, offering a broad scope of clinical presentations and practice. The nuances of dialysis and transplant patient care challenge Andy's physician skills on a daily basis.

Andy is extremely grateful for the opportunity to be part of the KHNZ team, joining as Medical Advisor back in July. He looks forward to contributing to the legacy of supporting, educating, and advocating for individual Kiwis, families, communities, and healthcare providers, who experience kidney disease. An important goal of Andy's at KHNZ is to further enhance patient and health professional awareness of Chronic Kidney Disease (CKD), and that early screening for, and detection of, individuals/whānau/communities at risk of CKD is essential. There are a number of CKD management/treatment recommendations that, if introduced early, can significantly improve patients' prognoses and quality of life.

Andy loves living in the sunny Hawke's Bay with his family. In his downtime, he enjoys swimming, running, cooking, listening to music, and connecting with people. [D](#)

SINI TAUNAHOLO-ROPETI - CONTRACT RENAL EDUCATOR

Sini Taunaholo-Ropeti joined the Kidney Health NZ team in October as the Contract Renal Educator. Of proud Tongan descent, Sini has a background in Public Health with a focus on preventive care. Holding a Bachelor's Degree in Health and Social Development, Sini is also a part of the Bowel Screening team at Te Whatu Ora | Health New Zealand, Te Toka Tumai Auckland.

Sini's commitment to kidney health is deeply rooted in



personal experiences. Her husband, of Samoan descent, was diagnosed with PKD (polycystic kidney disease) and has been on dialysis since November 2023 while awaiting a transplant. Additionally, two of their five children are also affected by this condition. These challenges have ignited a profound passion within Sini to raise awareness about kidney health, advocate for early detection, and empower whānau to prioritize their health.

Sini is dedicated to fostering understanding and support within our communities as we navigate the journey toward better kidney health together. [D](#)

kidney health NZ events

Matariki Event – Wellington

On the 27th of June Kidney Health NZ were invited to be part of the Te Rangi Hauora o Pāremata Matariki Celebration 2024, an enterprise that was organised by Hon. Peeni Henare along with the Parliamentary Services Health and Safety team.

KHNZ provided BP and blood glucose checks - along with education.

A huge benefit of this event was the opportunity to push the messages about the rising prevalence of kidney disease with politicians. Some extremely meaningful conversations were had with Hon. Peeni Henare, and also Hon. Jenny Salesa.

This was an opportunity for CEO Andrew Baker and National Clinical Manager Merryn Jones to highlight to politicians the challenges facing those living with CKD and their whānau, but also the challenges that are present in the health system.

A total of 26 people had BP and blood glucose testing at Te Rangi Hauora o Pāremata Matariki Celebration 2024. One person at this event was urged to seek urgent care from their GP, which was arranged. 📞



EFKS Grey Lynn – Auckland

On Saturday 14th September, Kidney Health NZ provided testing and health education to the Samoan community who attend the EKFS Church in Grey Lynn, Auckland. This was at the invitation of The Cause Collective who work predominantly with the Pasifika community.

Those tested at this event were predominantly older and, as we tested, several told us that they had

someone in their family who had chronic kidney disease or were on dialysis.

A total of 31 people were screened at this event. Of that group, 26% were found to have CKD and were referred to their GP for follow up.

Many thanks to EFKS Grey Lynn for hosting us, as well as The Cause Collective for the invitation. 📞



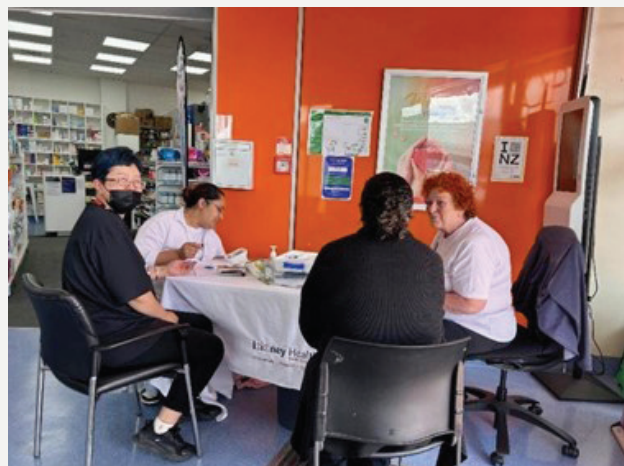
Tui Pharmacy & K'aute Pasifika Health Clinic

On Friday October 8th, Kidney Health NZ delivered health education and kidney disease testing to the Hamilton West community at Tui Pharmacy.

During this clinic outreach, KHNZ also had the opportunity to visit K'aute Pasifika Health Clinic and meet their dedicated team.

K'aute Pasifika offers a range of services, including diabetes management, urgent care, health screenings, holistic care, medication, and vaccinations.

During the event, 24 individuals were tested, of whom, 3 were identified with low kidney function and subsequently referred to their GPs for further evaluation and follow-up. ↻



Samoa Methodist Church – Otara

On Saturday 26th October, Kidney Health NZ provided testing and health education to the community who attend the Samoan Methodist Church in Otara, Auckland. This was at the invitation of Total Healthcare.

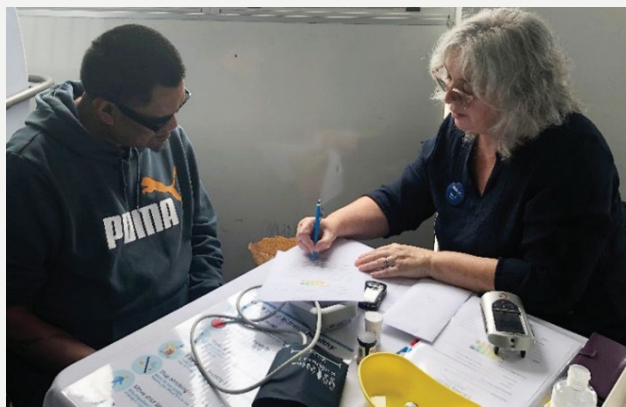
A total of 18 people were screened at this event. Five people at this event were found to have low kidney function and were referred to their GP for follow up.



Thanks to Total Healthcare for the invitation and Samoan Methodist for having us. ↻

Kererū Marae – Levin

On Saturday 16th November, supported by supported by Community Grant funding, Kidney Health NZ provided testing and health education at the second annual hauora day at Kererū Marae in Koputoroa, north of Levin. This marae services Ngāti Ngārongo and Ngāti Takihiku whānau of the Manawatū and Horowhenua districts.



A total of 26 people were tested at this event, with 9 people being referred for follow up.

This event was a valuable networking opportunity for KHNZ to work with the Kererū Marae community as well as local hauora providers in Manawatū and Horowhenua. ↻



kidney health NZ events

Kawerau Testing

On the last weekend of November. Kidney Health NZ, supported by supported by Community Grant funding Mataatua funding, partnered with Whānau Ora Māori Community Health Services to deliver free kidney health checks in Kawerau.



The event was coordinated by Guy Moniker, Whānau Ora's health services coordinator, and aligned with White Ribbon Day, an initiative aimed at raising awareness about domestic violence and promoting a culture of respect and non-violence.

The day was highly successful, with a steady turnout of people engaging in meaningful conversations about their lifestyle choices and the impact these have on their overall health.

A total of 24 people were tested at this event with 3 people being referred for follow-up with low kidney function.

Kidney Health New Zealand team members provided valuable education and guidance, emphasizing the importance of early detection and prevention of kidney-related conditions.

Kidney Health NZ is extremely grateful to everyone who attended one of our events this year as well as all the organisations that have graciously hosted us throughout the country in 2024.

As Kidney Health NZ looks forward to 2025, we encourage anyone who would welcome a screening event in their community to make a submission using the link below. While we can't guarantee we can get to your area, all submissions will be considered. ↷

<https://forms.gle/8uxyHlteP7vqxSw96>



fundraising in the community

In this final newsletter of the year, we want to thank and acknowledge the hard work that Alister Belamy has put into his training for the 2025 Rotorua Half Marathon raising awareness of kidney disease.

Allister Belamy, known as allisterruns0to21 on Instagram, has been diligently training for this event since June 2024. Inspired by his mum, Allister has made huge strides during the year as he gets himself ready for his first ever marathon in 2025.

The first event in Allister's journey came with the Taupo 5km on August 3rd. Going out on the day to run a personal best of 32.53, Allister, in his own words, "went out and left it all on the track".

Recovering from a sickness the week before, Allister was stoked to come away with a personal best.

Allister just recently smashed the Kapiti 10km - and is on track to participate in the 2025 Rotorua Half Marathon in May. Would you like to support Allister? Follow him on **Instagram at @alisterruns0to21** ↷



Wellington Hospital Renal Ward 500th Kidney Recipient


Wellington Hospital's Renal Ward recently reached a milestone — performing its 500th kidney transplant since the new regional hospital opened in 2009.

Jazmin Torrance, a Lower Hutt resident, was the recipient of the 500th transplant. After struggling with kidney disease and dialysis for five years, Jazmin noticed significant improvements just days after her surgery: "I feel massively different—eating well, sleeping better, and my energy levels have really improved. It's been life changing."

She credits the renal team for their exceptional care: "They treat you like a real person and have supported me every step of the way."

Clinical Nurse Specialist, Claire Beckett says the impact of kidney transplants is what motivates her work: "It's inspiring to see patients achieve dreams they couldn't while on dialysis—whether that's



starting a family or traveling the world. That hope is what keeps me going." 

KHNZ Medical Advisor Dr Andy McNally calls for at-risk patients to check eligibility for new shingles vaccine

Hawke's Bay Nephrologist Dr Andy McNally is welcoming the expansion of a publicly funded vaccine programme to help protect thousands of at-risk Kiwis from the shingles virus.

Up to 15,000 Kiwis will benefit over the next two years from widened access to the varicella zoster virus vaccine (Shingrex).

From July 1 2024, access to the vaccine was widened to include immunocompromised people aged 18 or older who are pre and post a solid organ transplant, haematopoietic stem cell transplant or cellular therapy, patients with blood cancer, those living with poorly controlled HIV infection, and those receiving disease-modifying anti-rheumatic drugs (DMARDs) for specific conditions (polymyalgia rheumatica, systemic lupus erythematosus, rheumatoid arthritis).

People with primary immunodeficiency, and stage 4 or 5 chronic kidney disease, including patients on dialysis, have also been deemed eligible.

Dr Andrew McNally said shingles was a disease that caused a blistering rash and shock-like pain.

"Now that we have got this vaccine, people may not have to go through it at all, or have a minimised shingles experience."


He said shingles affected an area on the body called a dermatome, "an area of skin supplied by a nerve".

"Herpes zoster and shingles can be a devastating disease, particularly for those more vulnerable members of the community," McNally said.

He said the previous vaccine was a live one that came with the risk of other complications, whereas the new vaccine was non-live.

"In Hawke's Bay we have over 100 patients who have had a kidney transplant and this vaccine was previously not accessible to these patients."

He said patients would get two vaccines two to six months apart and that wait times would not be an issue.

"Shingles can reoccur, so the idea of the vaccine is to minimise it coming back the first time and perhaps subsequent times — some patients have it reactivate more than once." 

Taranaki Base Hospital adapts kidney dialysis machine to treat farmer's condition

Mark Walsh has had kidney issues most of his life - and has travelled out of the region for specialist dialysis treatment sometimes twice a week - but not anymore.

The father of two, who also runs an adventure tourism business, first became aware he had kidney disease as a 13-year-old. At 16 he had his first transplant, but the new organ lasted only about a year and a half.

Now in his mid-30s, he has since had a second transplant.



"Two years ago, in 2022, that's when I had my second transplant from my dad, but it hasn't quite gone as well as they'd hoped. They had hoped the disease would go into remission, so it's not in remission but it's not attacking the kidney as hard as it did the first time," he said.

Walsh had an auto-immune disease which complicated his condition. Up until now that had meant travelling for treatment.

"I was driving from Ōpunake up to New Plymouth here, then catching a flight from New Plymouth up to Auckland, catching a taxi up to the hospital there and then doing my plasma apheresis."

"It's usually three-and-a-half hours and then I'd have to wait around for usually the 4.30pm flight back to New Plymouth and drive home again, so I wasn't getting home until 7-7.30pm."

If there was no machine available at Auckland, he would have an even more arduous trip to Hamilton.

"So, I'd drive up there at 3.30 or 4 o'clock in the morning and then get on the machine there at about 8.30 in the morning and then do that for three or four hours and then you sort of have a break and go and get something to eat afterwards.


"I'd usually drive home for about an hour or so and stop off and have a break and sometimes have a little sleep for an hour and then carry on home again."

But now Taranaki Base Hospital has adapted an acute kidney dialysis machine so it can be used to treat Walsh's condition by performing the plasma apheresis he requires to prolong the life of his new kidney.

ICU clinical nurse manager Ian Perry, one of the staff behind the new service, said there was a serious side to the new service.

"We did this because we saw his plight of having to sometimes fly to Auckland twice a week and then with the flights if he couldn't fly then he missed out on the treatment."

"And we know the health service is a lot about equality and equitably and we thought it only fair if we had the capacity and we had the machinery that with the right training and equipment we could provide the service locally."

The new service would be available to other patients as and when they presented themselves, Taranaki Base Hospital said. 

The IMPEDE-PKD Trial



The IMPEDE-PKD trial is a clinical study looking at whether metformin (a medication) can protect kidney function for people with polycystic kidney disease (PKD).

The study is being done around the world and will include 80 people in New Zealand.

People with PKD and who have kidney function (eGFR) between 38 and 90 ml/min and also who have large kidney size or a decrease in kidney function over the last year (of 5%) or 3% a year over each of the last 5 years may be able to take part. The research team can let you know. If you take part in the study, you will be asked to take either metformin or a sugar pill (inactive tablet) for 2 years and your kidney function will be regularly measured.

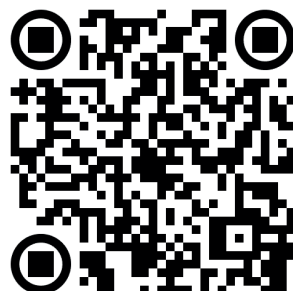
Currently there is only one treatment for PKD that may prevent new cysts called tolvaptan - the IMPEDE-PKD trial is looking for new treatments that can help. Metformin is already widely used to treat diabetes and other conditions.

This study is being rolled out across Aotearoa New Zealand in stages.

Want to be involved? Check for recruitment updates at

<https://kidneytrials.com/impede-pkd/> **OR**

email Rachel on impede-pkd.nz@otago.ac.nz



PHOSPHATE Study – New Zealand Trial Ends

Pragmatic randomised trial of **High Or Standard PHosphAte Targets in End-stage kidney disease**

To all the participants, whānau and Te Whatu Ora kidney services teams (nurses, dietitians, specialists) – thank you so much for your support of the PHOSPHATE trial since 2019!! Your time, mahi and willingness to be involved is greatly appreciated.

The aim of this study is to find out whether it is better to give more medicines to lower the phosphate blood level compared to less medicines to allow a higher phosphate

level in the blood stream. The PHOSPHATE trial is coming to an end in Aotearoa New Zealand but is ongoing internationally.

Unfortunately, this means that results are unlikely to be available prior to 2028-2030. The trial is going incredibly well with over 2,500 participants currently recruited worldwide from the UK, Canada, Australia, Israel, Thailand and Brazil.

If you have any questions, please contact Suetonia and Rachel at phosphate.nz@otago.ac.nz

THE PHOSPHATE Trial

PHOSPHATE TREATMENT for DIALYSIS PATIENTS

ADVANCED KIDNEY DISEASE... is sometimes treated with a TRANSPLANT BUT more often with DIALYSIS

DIALYSIS CAUSES PHOSPHATE to build up in ARTERIES

I HATE taking these

The treatment for PHOSPHATE BUILD UP is...

UP TO 12 LARGE CHALKY TABLETS PER DAY with meals

I REMOVE THE PHOSPHATE from FOOD & REDUCE BUILD-UP

SO... THE SCIENTIFIC COMMUNITY We NEED to EVALUATE this TREATMENT to MAKE SURE it'S WORKING

THE GLOBAL COMMUNITY

UK, THAILAND, CANADA, AUSTRALIA, NEW ZEALAND, BRAZIL

3600 PATIENTS

8 KIDNEY CENTRES

150 PARTICIPANTS

We started in NEW ZEALAND IN 2019

JOINED TOGETHER TO CONDUCT A CLINICAL TRIAL

CELEBRATING OUR PROGRESS 2024 NZ TRIAL ENDS

RESULTS AVAILABLE ONCE THE TRIAL ENDS 2028

INTERNATIONAL TRIAL ENDS 2028

INTERNATIONAL TRIAL ENDS 2028

TO: the PARTICIPANTS RESEARCH TEAMS, NURSES, DIETICIANS, SPECIALISTS & WHĀNAU

THANK YOU ALL

FROM KIDNEYS everywhere!

ACKNOWLEDGEMENTS

Kidney Health NZ would like to recognise the passing of two well-known figures in the kidney community, Dr William Wong and Laurie Williams.

Dr William Wong was a paediatric nephrologist based at Starship Children's Hospital and passed on Monday 9th September 2024 surrounded by family. Dr Wong was well-known for his humour, as well as

his ability to show true empathy for the families he worked with.

Laurie Williams was a healthcare professional who worked in the renal space at ADHB. Known by many in the Auckland medical community, Laurie was much respected. ∑

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 Monday to Friday - 8.30am – 5pm
The Kidney Health New Zealand 0800 number and info@kidney.health.nz email service
not be attended from 23rd December - 13th January

Nationwide

Kidney Health NZ support line

info@kidney.health.nz – 0800 543 639

Kidney Kids

office@kidneykids.org.nz – 0800 215 437

Virtual

Facebook Support Group – **Aotearoa Kidney Whānau**

Facebook Support Group – **PKD Collective NZ**

Facebook Support Group – **Kidney Donor Whānau**

Facebook Support Group – **Wellington Kidney Support Society**

Facebook Support Group – **Otago Kidney Whānau**

North Island

The Kidney Society (previously ADKS)

kidneysociety@adks.co.nz – 0800 235 711

Wellington Kidney Support Society

Mattytoole@gmail.com

North Island continued...

Taranaki Kidney Support Group

margarethshome@xtra.co.nz

Bay of Plenty Support Group

Kaywyn.McKenzie@bopdhb.govt.nz

Whanganui Support Group

gbullock@xtra.co.nz

South Island

Christchurch Kidney Society

03 341 0906

Ashburton Kidney Society

ashburtonkidneysociety@gmail.com

Otago Kidney Society

info@oks.nz

Australia

Kidney Health Australia

careteam@kidney.org.au – 1800 454 363

Thank you to the following organisation 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

