

WINTER 2022 Newsletter

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STABICRAFT

We are incredibly grateful to Paul Adams and Barbara Sutton at Stabicraft who have very generously donated a 1550 Fisher boat and trailer package that was auctioned on Trade Me a few weeks ago. The whole package was listed with a \$1 reserve and the final bid was a whopping \$60,100! All proceeds will go towards Kidney Health New Zealand's mahi with kidney donation and transplant projects.



Paul is the co-founder of Stabicraft and wanted to give back to the renal community, as he knows the journey all too well, being a patient himself. Last year Paul received a life-saving kidney transplant, donated by his fiancé, Barbara.

Paul and Barbara teamed up with a wonderful group of supporting businesses to help build the boat. Gene Denton, from Whitiangler, a fishing charter company in Whitianga, very generously donated either a free fishing charter, or a free lesson on how to get the most out of the 1550 Fisher boat.

Thank you so much to all the companies who supported this incredible build:

- Sheetmetal Craft
- Hutchwilco Boat show
- Stabicraft Southern
- Northchill
- Creation Signs
- Arc Alloy
- Whitiangler
- Royans
- Yamaha
- DMW Trailers
- Ultralon
- Wakefield Metals
- Navico
- Sea-Thru
- Howard Andersons

KIDNEY HEALTH MONTH

March was Kidney Health Month, with World Kidney Day on March 10th. This year Kidney Health New Zealand focused on kidney donation and asking people if they have “Had the Conversation?” This was aimed at increasing awareness around kidney donation and if families knew about their loved one’s thoughts and wishes. KHNZ focused on the different types of donations available as well.

This year was a little different due to the impacts of Covid. Normally renal units around the country celebrate World Kidney Day by holding blood pressure checks or by having information stands around the hospital, but unfortunately that was not appropriate this year. Staff and patient safety was the priority.

Kidney Health New Zealand still pushed ahead with as many testing opportunities as possible. We started the month off by having a very successful day of free kidney testing at Te Papa. KHNZ nurses, Erica and Becs, secured a great spot right at the door and braved the chilly Wellington winds. The turnout was fantastic. One of the best things about our free kidney testing events is the people who come and visit, and the lovely stories told. Erica and Becs often hear wonderful stories from family members who have already donated or are thinking of donating.

Erica had a busy month with free kidney testing in Masterton, and various locations around Auckland. In total there were five days of testing.

KHNZ is planning to do some free kidney health checks in Christchurch and around the country in the next few months, so keep an eye out on social media for the dates.

Thank you so much to everyone who supported Kidney Health New Zealand over Kidney Health Month. We hope that everyone will continue to discuss kidney donation and what their wishes are as this will change someone’s life.



Te Papa Testing

Parliament Testing

This year Kidney Health New Zealand’s annual MP testing on the steps of Parliament was held on May 5th. Unfortunately, due to unforeseen circumstances we were unable to do our testing during March which was Kidney Health Month.

Thankfully the weather was in our favour, and we set up outside Parliament for the day. We had an extremely busy day with non-stop testing which was fantastic. Erica and Becs were both doing testing and tested over 80 people in four hours which shows just how quick and easy it is to get your kidney tested.

Testing at Parliament is a really important day for us, we are able to show what we do, how quick and easy it is, but also, we have the chance to talk to MP’s about how important our work is.



Parliament Testing



Kaumataua Talk

At the end of May, Kidney Health New Zealand’s National Education Manager Erica was invited to speak to Kaumatua at the Maraeroa Marae Health clinic in Waitangiura in Wellington.

This was part of our kidney health month schedule, but unfortunately it was pushed back to May due to Covid.

Erica was invited to talk about Kidney Health New Zealand and our mahi. She also discussed kidney health and how to keep your kidneys happy and healthy. Sixteen kaumatua attended and they all really enjoyed the presentation and Erica had some great korero with them.

Hornby High School

Hornby High School got involved with Kidney Health Month this year too. We were hoping to do free kidney health checks for all the teachers but unfortunately that was not possible due to Covid. However, they still carried on and raised awareness throughout the whole month.

The Year 7/8 Junior Leaders made a kahoot quiz for classes to play, organised daily facts in the notices and put-up informative posters about kidneys around the school. Kahoot is a fun quiz that classes from throughout the world can access and play.



Hornby High School

NEWS BITES

YouTube Exercise Channel for CKD Patients

The Auckland District Kidney Society are about to launch a YouTube wellness and exercise channel. Hosted by Tracey Drinkwater, the Wellness Educator at Auckland District Kidney Society.

There will be videos on safe and suitable exercises for people with chronic kidney conditions, safe for all levels including people on dialysis treatments and post-transplant.



The first series has videos on exercises for postural improvement, circulation, strength, and a few short chair-based exercise sessions with clients who are currently having dialysis treatment and who have had transplants, with lots more videos to come.

Keep your eye out for more information or contact:

The Auckland District Kidney Society
on 0800 235 711 or kidneysociety@adks.co.nz
for more information.



Kidney Kids Virtual Camp

This year due to Covid, Kidney Kids held their annual camps a little differently. They held their first ever virtual camp on April 8th and 9th. There were over 100 children who participated from 5-15 years old. It was a fantastic online event and so good to see so many families joining in.

Kidney Kids and their siblings were invited to virtual camp in their living rooms, backyards or wherever the children decided to camp overnight. Everyone connected to a live zoom link so campers could tune in. There was also a special virtual camp Facebook page set up for campers to communicate and share photos with each other during the camp. Campers also received a map of New Zealand showing them where all their fellow Kidney Kids were based around the country.

The camp involved hat decorating, a movie night, pancake making, rhythmic gymnastics and lots of fun in-between.

A big thank you to Walter who was the camp MC and Georgie who joined from Starship. Another big thank you to Ophelia, Olivia, and Vikki Lee from Goode PR who very

generously helped and contributed towards this camp and sourced goodies for the camp kits which were sent to each family.

Young Adults Kidney Kids (YAK) Virtual Camp Evening

YAK Evening Kidney Kids Camp has always remained the hallmark of services for kidney kids and their families. The COVID pandemic has intensified the isolation and stress of children and their whānau. The support team was determined not to let the pandemic stop our kids from enjoying camp, so Kidney Kids decided to host a Virtual Camp for 2022.

Ben Fonua, the Youth Navigator, hosted this year's Young Adults Kidney Kids (YAK) and their siblings. The age group ranged from 16 to 21 years old. Their online-savvy campers made the most of it. They participated in varied fun activities that could be shared through a screen.

The YAK campers were engaged in zoom meeting activities with Ben. These activities included cooking sausage sizzle, smores, campfire sing-alongs, and movie night - replacing the in-person activities of a summer camp. The virtual campers found out that online camping experience is still possible.

The Kidney Kids support team created a private virtual camp Facebook page for all campers to share their cooking results, camping grounds, and experiences. This platform was utilized for announcements, sharing photos, and making new friends. Campers also received a map of NZ displaying the different locations where their fellow kidney kids lived.

One of the attendees shared why he enjoys the annual camp. "I liked virtual camp because I got to still see my old friends and make new friends. I don't think about my medical problems while I'm at camp."

A huge thank you to everyone who was involved in making this a great camp. While everyone hopes to return to in-

person camps, all agreed that the effort put into this year's camp created an unforgettable time.

Governor General

Dame Cindy Kiro took up the appointment of Governor General of New Zealand in October 2021. She replaced Dame Patsy Reddy who was also patron of Kidney Health New Zealand. Dame Cindy has kindly agreed to continue as patron of Kidney Health New Zealand.

2022 Government Budget

Kidney Health New Zealand is delighted that the Government has seen fit to invest \$11 million into the National Strategy: Increasing Deceased Organ Donation and Transplantation. KHNZ has lobbied Government for a number of years culminating in the publication of the KHNZ-funded NZIER report "Transforming lives and saving money". The report demonstrated that by raising the number of transplants, New Zealand could alleviate some of the inequity in transplantation outcomes, add years to lives and save the health system money. Effectively a kidney transplant is cheaper than dialysis by some hundreds of thousands of dollars.

Health New Zealand and the Māori Health Authority

Kidney Health New Zealand is pleased to see the appointment of Dr Curtis Walker, a nephrologist from Mid-Central DHB to the board of Health New Zealand and Fiona Pimm, (recently appointed) board Chair of the New Zealand Blood and Organ Service to the Māori Health Authority. We know they will be great advocates for the kidney community.

On the back of the launch of the NZIER report, KHNZ presented the report to Health New Zealand and the Māori Health Authority. From that KHNZ was able to engage with the interim Health New Zealand team and was invited to present a proposal to be included in the Health Plan. KHNZ understands that this engagement will continue through the year as the plan is further refined.

Consumer Council

Kidney Health New Zealand organised a meeting of its Consumer Council on 30 April 2022 by Zoom. It was attended by consumers from throughout the country as well as members of the kidney support groups.



The theme was to answer the question how could Kidney Health New Zealand contribute to reducing inequities in health?

Each support group attending gave an update on what was happening in their region. Support groups from the South Island reported that as there is no dermatologist at CDHB and Southern, this is causing issues for transplant patients. Support groups also noted that they are experiencing issues due to low engagement from patients.

Merryn Jones, a transplant nurse from Hawkes Bay presented on how to engage with Māori patients and Denise Beechey, a transplant nurse from Counties Manukau presented how they developed the Live Donor Kidney Aotearoa programme in Counties and how it increased the numbers of Māori and Pasifika live transplants. The intention is to take what was discussed and use it to update Kidney Health New Zealand's strategic plan.

KHNZ understand that an appointment has been made to fill the dermatology vacancy at CDHB.

STAFF CHANGES

We are sad to announce that we have some staff changes at Kidney Health New Zealand.

Anne Hindson - Fundraising Coordinator

Anne Hindson made a significant contribution to Kidney Health New Zealand, she hit the ground running and was a key member of the team as we went all out to promote KHNZ in our March kidney appeal month a few years ago, despite covid this promotional and funding activity has continued with some great coverage this year. Anne has continued to build relationships and work with those affected by kidney disease. She worked hard to get sponsorship during a very challenging time, one of these projects was with Stabicraft. The auction of one of their boats led to a significant donation which will help with transplants in the future. On behalf of the Kidney Health New Zealand board, I want to thank Anne for her contribution.

- Christine Prince

Michael Campbell - General Manager

After three years of admirable service to Kidney Health New Zealand we are sad to announce that Michael Campbell, General Manager finished on 17 June 2022.

Michael's enthusiastic service has helped KHNZ expand its reach throughout New Zealand. He spearheaded our external engagement via roadshows, online kidney patient and donor groups and ably led the organisation during Covid.

The Board expresses its appreciation to Michael for his services. This enthusiasm and leadership will be deeply missed. We wish him every success with his future endeavours on behalf of the kidney community.

As everyone in the renal community appreciates it has been a challenging time but also an exciting one with the move to Health NZ and the creation of Māori Health; over the coming months KHNZ will be engaging with stakeholders and the rest of the renal family to ensure we are best placed with the right resources to support those affected by kidney disease.

This will help support the recruitment process which we will commence in July.

From June 17th, please direct all KHNZ business enquiries to Traci Stanbury, Acting General Manager KHNZ, board member, traci.stanbury@kidney.health.nz

- David Shearer - Board Chair

Michael Campbell and Erica Fairbank

It is with great sadness, as staff of Kidney Health New Zealand we farewell Michael as our General Manager, and see Erica our National Education Manager reduce her hours; both to chase new endeavours. Michael and Erica have paved the journey for Kidney Health New Zealand over the past three years and we couldn't be prouder of them.

Thanks to them, our free kidney health checks have become well known throughout the country, making a difference to the lives of many people in the early detection of kidney disease. We have gained incredible contacts within Parliament and the Ministry of Health to assist with lobbying for improved outcomes for Tangata Whenua and the wider kidney community. Michael and Erica have built many important relationships within our education and medical sectors assisting with spreading the word about kidney disease.

A very exciting recent event was celebrating the Health Budget announcement with new funding totaling \$11 million to support “Increased Deceased Organ Donation and Transplantation: A National Strategy” in Aotearoa. Michael was heavily involved with this achievement which is a huge win for all New Zealanders who face the need for new organs.

Although Erica is reducing her hours significantly, we are excited to still have her onboard on Fridays continuing some of the projects she has initiated. The Browns Bay Project is one she will continue to work on, providing renal education and support for high-risk patient groups.

We have thoroughly enjoyed working alongside you both, Michael and Erica. We look forward to keeping in touch and continuing the great work you have initiated for our kidney community in Aotearoa. Wishing you both all the very best for your exciting new adventures. You will be missed.

- KHNZ Staff members

RESEARCH OPPORTUNITIES

M-FIT Trial

What is the M-FIT trial?

Expression of interest to be a member of the Consumer Advisory Board.

Fatigue is a common symptom and a high priority for people receiving dialysis and may be linked to reduced quality of life. Regular exercise may help with fatigue, but it is unknown what type of exercise is best for improving levels of fatigue in people receiving dialysis.

The M-FIT trial aims to find out if different types of exercise programs help improve fatigue levels in individuals on dialysis. The trial will include up to 400 patients across 16 hospitals in Australia and New Zealand.

This clinical trial will compare 3 different exercise programs: walking, resistance exercise, or a combination of aerobic (cardio) and resistance exercise against a control (stretching). The programs will be delivered through a mobile application on their personal smart device. Participants will be randomly assigned to one of the four groups. Participants will be asked to exercise 3 times a week at a level assessed to be safe for them for 12 weeks, and complete exercise testing,

surveys about their fatigue, how they feel and regular check-up sessions with an exercise professional. The researchers will look at which group of patients improved their ratings of fatigue level and whether their exercise capacity improved.

The Australasian Kidney Trials Network is coordinating the trial which has been co-designed by people who are receiving dialysis treatment.

Why do we need a consumer advisory board?

The researchers want to make sure that the trial is designed in a way that is meaningful to people on dialysis and focuses on outcomes that are important to them. The Consumer Advisory Board will help ensure the trial documents that are provided to patients are clear and useful, including when the trial results are shared with the kidney care community. Consumer engagement in research is expected by the National Health and Medical Research Council.

What time commitment is involved?

A one hour meeting every 2-3 months, via Zoom and a half-day reviewing trial documents and mobile application. **Join meetings until December 2026.**

Reimbursement for reasonable travel costs and time will be in accordance with Health Consumers NSW recommendations.

Who are we looking for?

- 8-10 people from Australia and New Zealand, including:
- At least one caregiver of a patient who fits the trial eligibility criteria
- We will aim for at least 70% of the members to fit the trial eligibility criteria:
- Kidney failure, receiving dialysis (>3 months of haemodialysis or peritoneal dialysis)
- Age over 18 years
- Able to read and write English
- Access to a smart device with internet access
- Not receiving a kidney transplant in the next 12 months
- To avoid a conflict of interest, Consumer Advisory Board members cannot be participants in the trial.

When does it start?

The trial is expecting to recruit its first participants by approximately June 2022. The consumer group is starting soon but still keen to receive expression of interests.

Will members be acknowledged for their input?

With permission, members will be acknowledged on the AKTN website and other trial documents.

How do I become involved?

If you are interested, please contact:

Tze Goh, Renal Physician

Auckland City Hospital, GohT@adhb.govt.nz

Peritoneal Dialysis

If you are currently on peritoneal dialysis (PD) and have before or currently exercise while on PD, you are invited by the University of South Australia to take part in a research opportunity.



This short survey asks if you have experienced any side effects or negative health incidents related to exercise or everyday activity, while receiving PD. It is completely anonymous and should take only 10 - 15 mins to complete.

Link to survey:

<https://research.unisa.edu.au/redcap/surveys/>

SUPPORT

We know how isolating it can be on dialysis or as a renal patient so over the last year we have been setting up Facebook support groups. Once they are all set up these will cover all areas of New Zealand and we will also have pages for certain kidney issues. These pages are run by other patients who understand what living with chronic kidney disease is like. Our pages are easy to find by going onto Facebook and searching the page you would like to join.

Our current Facebook support group pages are:

- Aotearoa Kidney Whānau
- Kidney Donor Whānau
- PKD Collective NZ
- Wellington Kidney Whānau
- Otago Kidney Whānau



Kidney Health New Zealand Staff and Board Members

Staff Members

Becs Hayston - South Island Renal Educator

Deanne Hock - Office Administrator

Claire Christie - Communications & Grants Coordinator

Leah Stewart - Social Media Coordinator

Andy Salmon - Medical Advisor

Chrissy Taylor - Contract Nurse Educator

Sandy Speedy - Contract Nurse Educator

Dr Terry Ryan - Kaumatua

Traci Stanbury - Acting General Manager

Board Members

Auckland

John Kearns

Mara Fisher

Jo Denvir

Fale Andrew Lesa

Christchurch

David Shearer (Board Chair)

Christine Prince

Traci Stanbury

Receiving your Newsletter

If you would like to change the way you receive your newsletter, please let us know by emailing

claire.christie@kidney.health.nz

We will then add you onto our email database which will have the newsletter emailed directly to you.

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
- Eastgate Mall
- Wintec
- Genesis Energy
- Stroke Foundation
- REAP Centre Masterton

Support Kidney Health New Zealand

Yes, I want to join the fight against kidney disease and support Kidney Health New Zealand

I/we would like to donate: \$100 \$50 \$30 Other: _____

Payment type: Mastercard Visa

Card number:

Card expiry date: / / Name on card: _____

- I would like: A Receipt for my donation Information about Gifting to Kidney Health New Zealand in my will
- Information about Kidney Donations/Transplants To become a member of Kidney Health New Zealand

Name: _____

Address: _____

Please return this form to Kidney Health New Zealand, PO Box 20072, Bishopdale, Christchurch.
Or direct deposit to ANZ Account - Kidney Health New Zealand - 06 0501 0280602 00



Prevention • Support • Research

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e: info@kidney.health.nz

www.kidney.health.nz