

# Kidney Health

NEW ZEALAND

Prevention • Support • Research

SPRING 2023



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**In our Spring Newsletter we cover the ANZSN Conference that was held in Christchurch, as well as share some pictures from events we've attended in the last couple months.**

The ANZSN Consumer Day was a massive project undertaken by Kidney Health. Nephrologists and renal specialists from all over New Zealand and Australia came together for just under a week – to hear about kidney related research and other medical presentations.

We want to congratulate Prof Rob Walker from the Dunedin School of Medicine on being awarded the prestigious College Medal by the Royal Australasian College of Physicians, for his significant international contribution to understanding and managing kidney disease. Congratulations Professor Walker.

We would also like to congratulate Drew Henderson and Leanne Te Karu who have been appointed as co-chairs of the Renal National Clinical Network. We are sure that Drew and Leanne will help to bring the voice of all

New Zealanders affected by kidney disease to the Network.

As this will be the last newsletter for the year the team at Kidney Health NZ want to wish everyone a safe, happy, and healthy Christmas and New Year.

We look forward to connecting with you all again in the New year. We've been working hard in the background to prioritise our activities and efforts for 2024 and are excited about sharing our plans with you as they evolve. 



## Australia and New Zealand Society of Nephrologists (ANZSN) Conference

Consumer Day – On September 3rd, Kidney Health NZ held New Zealand’s largest renal consumer meeting at the 2023 ANZSN Consumer Day. Hosted at the Te Pae Christchurch Convention Centre, this was an opportunity for kidney consumers and renal organisations to come together and network – as well as to share ideas for collaboration.

Thanks to all those who attended. This was an amazing opportunity to have all the renal communities of Aotearoa together for an afternoon of networking and sharing. We hope you found it informative, as well as found some opportunities to network and work with some of the other societies and consumers in the renal community. 🌟



## ANZSN Consumer Workshop for Clinicians

On Monday 4th September, the day after the Consumer Day, KHNZ Project Manager Traci Stanbury chaired a Consumer Workshop for Clinicians to complement the Consumer Day.

41 delegates attended the 90-minute Consumer Workshop - with NZ clinical representatives from Canterbury, Bay of Plenty, Otago, Waitemata and Auckland Renal Units all in attendance.



**If you'd like more information on any of these presentations, please contact [sam.faalilo@kidney.health.nz](mailto:sam.faalilo@kidney.health.nz)**

## Kidney Health NZ want to extend a warm thanks to the following organisations, and people for their support:

### LJ and Anne from the Health Quality Safety Commission

LJ and Anne from the Health Quality Safety Commission spoke to us about the '*Code of Expectations for health entities' engagement with consumers and whānau*' that was passed in the Pae Ora (Healthy Futures) Act 2022.

This new code, launched by the Minister of Health on August 25th, 2022, sets the expectations for how health entities are to work with consumers.

This was an interesting and insightful presentation that provoked some great conversations during the Q&A session. We look forward to seeing how this new code of expectations has an impact on consumer engagement with health entities.

The code of expectations can be found on the Te Tāhū Hauora Health Quality & Safety Commission website, or at the link below.

<https://tinyurl.com/yfk76ana>

### Bay of Plenty (BOP) – Renal Patient Council

Rick Rapana and Kaywyn Mackenzie spoke about the successful formation of the BOP Renal Patient Council, and why it needed to be formed. One highlight of their report was their acknowledgment that clinicians in the BOP were working collaboratively with members of the council, something that was proving very beneficial.

If you would like more information, please contact Rick (Council Chair) or Kaywyn (Group Facilitator) at [boprenalgroup@gmail.com](mailto:boprenalgroup@gmail.com)

### Beat-CKD: Consumer Impact and Involvement in Research

Anastasia Hughes and Jasmin Mazis from the BEAT-CKD (The Better Evidence and Translation – Chronic Kidney Disease) team came and spoke to consumers about research being conducted by ANZDATA.

This research is currently under ethics review - and will be available on our website once approved.

### Renal Nutrition – why food matters

Te Whatu Ora Waitaha Canterbury Renal Dietitian Hilary Dumbleton gave an amazing presentation on food – and its relation to those with CKD.

#### Some key parts of information are.

- Diabetes and High Blood Pressure (HBP) are the most common causes of Chronic Kidney Disease (CKD)
- Eating too much salt forces the kidney to work harder than they must – this can increase BP.
- Type 2 Diabetes is the most common form – for many, a healthy lifestyle can prevent this.
- Food and drink choices can slow down the progression of CKD.

For more information, please contact [sam.faalilo@kidney.health.nz](mailto:sam.faalilo@kidney.health.nz)

### Exercise for Wellness – How to use exercise to manage CKD

Tracey Drinkwater from The Kidney Society (Auckland), gave an excellent demonstration of some of the exercises she encourages those with CKD to be doing, or to be incorporating into their daily lives.

The Kidney Society operates a wellness YouTube channel that has some kidney friendly workout and wellness tips. This is a great resource for anyone dealing with CKD.

Interested? Search 'The Kidney Society' on YouTube.

### Slip, Slop, Slap, App: Skin cancer prevention

Dr Anne Collins, an Otago plastic surgeon with a passion for post-transplant skin care, visited the ANZSN Consumer Day to inform kidney consumers about a self-assessment skin care app that she is developing.

Dr Collins described the app as a self-assessment imaging service, where users could document lesions on their skin – and have the photos analysed by a skin care professional.

She hopes her app will be available in early 2024.

# in the community

## Hauora Day in Counties Manukau

On Saturday the 26th of August, nurses Erica and Sandy attended the Hauora Day at Universal Church in Manukau. This was an amazing event that was opened with a beautiful church service that "really set the scene."

Hosted by Bowel Screening Counties Manukau, this was an extremely well organised and well attended event with over 45 people receiving kidney health checks.

Thanks to the Bowel Screening and Universal Church Group for their support during the day – we hope to see you again next time. 🍷



## Kidney Health CEO Andrew Baker – Visit to The Kidney Society

We want to extend a warm thank you to John Loof and the team from The Kidney Society who hosted our CEO Andrew Baker in September.



Joining Andrew was his counterpart Chris Forbes from Kidney Health

Australia - and Breonny Robson, General Manager Clinical and Research for Kidney Health Australia.

It was an excellent opportunity to get together and view one of the dialysis houses that successfully operated by The Kidney Society

In the photo is Andrew Baker, Breonny Robson and John Loof outside one of the community dialysis houses in South Auckland. 🍷

## Church Visits

### EFKS Panmure, Samoan Methodist Grey Lynn and Samoan Methodist Onehunga

During October, Kidney Health NZ nurses Erica, Sudath, Sandy and Chrissy attended two Health Day Events hosted by Samoan churches in the Grey Lynn and Panmure areas.

Alongside our kidney health checks, there were opportunities for breast, bowel, cervical, blood pressure, diabetes, and liver screening.

Also in attendance was the Heart and Stroke Foundations, Spinal Check NZ, Allergy NZ and Smokefree NZ. This was a great event - with great turnout from providers and consumers.



We want to thank EFKS Panmure and Samoan Methodist for their effort in making these events a reality – and we also want to thank the over 50 people who came and received one of our kidney health checks. 🙏

## Spring Hui – Active Canterbury

On Friday 13th of October, communications coordinator Sam Faalilo and Manager of Christchurch Kidney Society Jo Houghton attended a spring hui, aimed at bringing together gyms and fitness programme providers with health coaches, navigators, and organisations with unique health requirements.

A well-attended event, this was a great forum for organisations to greater understand who is offering catered fitness programmes in the local area.

While a lot of the programmes were focused for the elderly – it was acknowledged that some could be utilised by those suffering from unique conditions, given the programme recommended is suitable to



their current fitness and health requirements - similar to the Green Prescription.

Keep an eye on our Facebook – and our website for an update. 🙏

## Kidney Health NZ Resources We need your help!

KHNZ has a project underway to update and create education/information resources for consumers, whānau and medical professionals. It is important to us that these resources meet the needs of everyone.

We welcome any suggestions, think of this as an opportunity to put a “wish list” together.

Tell us what you think is the best way to deliver these resources e.g., videos, podcasts, brochures, fact sheets etc.

We are happy to have a chat with you – if you would prefer.

Please don't hesitate to contact us if you have any questions.

**Please send all suggestions/ideas, to:**

**E: [carmel@kidney.health.nz](mailto:carmel@kidney.health.nz)**

**M: 021 460 456**



## Streamlined kidney transplant workup programme – Bay of Plenty

A one-day kidney transplant workup programme, allowing patients with CKD to complete numerous tests on the same day, has significantly sped up the process for prospective recipients.

As most of us who are involved in the kidney space will know, the workup process to get listed on the national renal transplant wait list can take months – or in some cases, even years.

In most areas of New Zealand, people need to make multiple visits to hospital to attend specialist investigations. The financial cost for patients and their whānau is significant, with many ‘hidden costs’. The impact of time, loss of work, and the costs of travel, parking, and accommodation over a period of months and often, years was substantial. This long process magnified inequities in access for Māori and those living rurally/remotely.

The programme, which is a cross-departmental effort between Te Whatu Ora – Health New Zealand, Hauora a Toi Bay of Plenty’s Renal service, the Māori health service Te Pare o Toi, and the various planned care services which provide the investigation, has the primary aim of reducing barriers to achieving a listing on the kidney transplant waitlist, and to reduce inequities of access for patients with chronic kidney disease to transplant – It does this by streamlining and shortening the time taken to complete the normal renal transplant workup investigations.

In June, Dr Crawford presented the one-day renal transplant workup programme (ODRTW) nationally to the Te Whatu Ora and Te Aka Whai Ora Clinical Quality Assurance Committee. Dr Crawford said the committee was very supportive of exploring the potential of introducing this programme to other renal centres as a new ‘model of care’. They recognised its impact on reducing inequities which exist for patients who may

benefit from kidney transplants, particularly those who are regional, rural and remote.

“One of the many challenges for renal transplants is the ability to get patients through the workup process in a timely manner and listed on the national renal transplant wait list,” explains Hauora a Toi Bay of Plenty Nephrologist Dr Scott Crawford.

“The renal service at Bay of Plenty recognised this burden and the enormous benefits if many of the specialist investigations could be prioritised for patients on a single day. These investigations may involve cardiology, dental, clinical physiology, radiology, and bloods and urine workups.

“Our Renal Scheduler coordinates with all the Planned Care departments and scheduling teams to line up the required investigations on a given day. She can provide clear instructions outlining all of the appointments and ensure that there is a common single point of communication for the patient. The patient-centred programme has also improved collaboration between planned care schedulers themselves, who feel a bigger part of the whole process.”

The programme has reduced the time to transplant listing, removed some of the costs and burdens, improved access, and reduced inequity for patients and their whānau.

Māori health service Te Pare o Toi has wrapped support around for patients, involving assistance with parking, transport, food, and a place to rest, refresh and re-energise.

So far, 42% of the patients taking part in the single day renal transplant workup have been Māori. Patient feedback has been positive; “great and easy to navigate”, “so much easier – all good”, “one day makes it better”, and “absolutely makes sense!” 

## Taranaki Doubles Dialysis Chairs

The new \$3 million Ōhane Dialysis Unit at Tauranga Hospital has doubled the number of dialysis chairs previously available – going from seven to 14.

Operationally, that means the Ōhane Dialysis Unit can care for up to 56 patients a week when fully operational. This also means that the unit can dialyse more people closer to their home – so there’s less travelling and financial burden for them.

The unit, which took about nine months to build, was given a ceremonial blessing on Friday the 8th of

September before opening its doors to patients on Monday 11th.

Te Whatu Ora Hauora a Toi Clinical Nurse Manager – Renal, Katie Johanson, said it represented a step forward in renal care for the Bay of Plenty.

“Our goal is to make the new unit as accessible, welcoming and patient-centred as possible. It’s a huge burden on a patient’s life to go on dialysis three times a week, and we want to make that as positive an experience as possible,” Johanson said.

"We've also got a goal with the new building to help patients become more independent.

"There's more space, so we'll have more time with them, and they'll have their own kitchenette area, so they can make it more homely and more welcoming for their whānau.

"All the patients are really looking forward to moving

in. It'll be lovely to be in surroundings which are more modern and comfortable.

"It'll be nice for the nurses and doctors here as well. They are amazing, they always try to work things out for us, and we discuss our care with them. They're very compassionate people." 🔄

## Child in the United Kingdom, first to receive a special type of kidney transplant that does not require her to take long-term drugs.

Eight-year-old Aditi Shankar has become the first child in the UK to receive a special type of kidney transplant that does not require her to take long-term drugs to stop rejection of the organ.

Doctors at Great Ormond Street Hospital say the breakthrough was made possible by reprogramming her immune system before giving her the new kidney.

To do that, they used bone-marrow stem cells from the donor – Aditi's mother. It means Aditi's body accepts the new organ as her own. Within weeks of the transplant, Aditi was taken off immunosuppression, removing the risk of long-term side-effects from these powerful drugs, which usually have to be taken daily to prevent organ rejection.

She is now back at school, with both her immune system and transplanted kidney working normally.

Aditi has an extremely rare inherited condition, Schimke's immuno-osseous dysplasia (SIOD), which weakened her immune system and meant her kidneys were failing.

Specialists at Great Ormond Street Hospital spoke with international colleagues about the special transplant approach, which has been used in other children with SIOD.

First, a bone-marrow transplant using stem cells from her mother, Divya, rebuilt Aditi's immune system.

Six months later, she had a kidney transplant – again donated by her mother – and her immune system accepted the organ.

Divya Shankar, Aditi's mother said: "I was so happy to give her blood cells and a kidney. I just feel so proud."

Prof Stephen Marks, children's kidney specialist at GOSH, says Aditi's treatment appears to have been a success.

"She is the first patient in the UK who has had a kidney transplant to not require immunosuppressive medication after the surgery," he says.

"A month after the transplant, we were able to take her off all of her immunosuppression, which means she doesn't get the side-effects of the drugs.

"It really is great to see that she is an active eight-year-old girl, back to school, able to have an excellent quality of life."

Prof Marks will be presenting details of the case to the European Society for Paediatric Nephrology conference in October.

An editorial detailing the findings is also due to be published in the journal Paediatric Transplantation.

Despite the operations success, it is expected that the procedure is unlikely to be widely used, as the double transplant carries increased risks to the patient.

Kidney Research UK chair of trustees Prof Jeremy Hughes said: "Like any new treatment, it is not without risk and in this case as stem-cell transplantation means the patient must also undergo chemotherapy and radiotherapy.

"However, for a patient to receive a transplant and not require a lifetime of immunosuppressant medication is a significant breakthrough and whilst at this time the process is limited in scope, it does open the door for further future development that could have the potential to overcome one of the major challenges in transplantation care." 🔄

## Research Opportunities

### University of Otago – Decision Making About Haemodialysis Vascular Access – Patient & whānau values, perspectives, and experiences.

The University of Otago are still wanting to talk to adult patients (aged 18 years or older) who have had a fistula, graft or line for haemodialysis, and can talk to us for about an hour in English.

Patients can bring a whānau member or carer if they would like to. We can also organise a Māori or Pasifika support person to be present during the interview.

This research study aims to understand what is important to patients about the fistula, graft or line they use for haemodialysis, and what is important when patients decide which one to use. Understanding this will help us design research that is useful to patients.

You will receive a \$50 petrol or grocery voucher in appreciation of your time and knowledge sharing.

**If you are interested in this research, please visit our website at <https://www.kidney.health.nz/research/> to find all the details.**

# Kidney Support

Headed into the Christmas and New Year season can be a high stress environment for many – we thought this would be a great opportunity to share what support is available throughout Aotearoa New Zealand.

Our 0800 543 639 Support Line will be **closed** from the 23rd December to the 8th January.

## Nationwide

### Kidney Health NZ Support Line

– info@kidney.health.nz – 0800 543 639

### Kidney Kids

– office@kidneykids.org.nz – 0800 215 437

## North Island

### The Kidney Society

– kidneysociety@adks.co.nz – 0800 235 711

### Taranaki Kidney Support Group

– margarethome@xtra.co.nz

### Whanganui Support Group

– gbullock@xtra.co.nz

### Palmerston North Kidney Support Group

panburton31@gmail.com

### Wellington Peer Support Group

– Mattytoole@gmail.com

## Facebook Pages

- Kidney Health NZ
- Kidney Society ADKS
- Christchurch Kidney Society
- Kidney Kids NZ

## South Island

### Christchurch Kidney Society

– christchurch.kidney.society@gmail.com

– 03 341 0906

### Ashburton Kidney Society

– lizcarrick64@gmail.com

Otago Kidney Society – glen@oks.nz

### Southland Kidney Society

– karennoobs@yahoo.com

## Australia

### Kidney Health Australia

– careteam@kidney.org.au – 1800 454 363



## Facebook Support Groups

– Search these names to find them.

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

## 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

In an effort to reduce our carbon footprint, we ask that anyone who would prefer to receive their newsletter digitally please notify us.



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

- Green Cross Health
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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
- Pak N Save Wainoni
- DP Boocock Family Trust
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- Stroke Foundation
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