



Kidney Health Month Update

March 2021 Catchup

IN THIS ISSUE

Experience Stories

A collection of stories by people with kidney disease and their families to show how it affects ordinary lives.

See our website for the latest story.

While I Still Can

1400km e-scooter challenge from Picton to Bluff to raise awareness of kidney disease and fundraise.

Free Prevention Testing

Community prevention testing is aimed at increasing early detection to prevent end stage kidney disease.

Phew, what a phenomenal month March has been. We launched Kidney Health Month to raise the profile of kidney disease in New Zealand. It was a great success. With several exciting initiatives we got into the news several times with kidney focused articles appearing on TVNZ and in Stuff.

This newsletter is just an overview of what we have been up to over the month. Many of the stories were detailed in our email newsletters throughout the month. We encourage you to register for our email newsletters through our website if you want more regular updates.

Please feel free to forward this newsletter on to people you feel it would interest or benefit so we can raise awareness of and inform on kidney issues.

You can subscribe to our newsletter by visiting www.kidney.health.nz/Newsletter

One in 10 people have kidney disease

Is it you?

Nearly half a million New Zealanders have kidney disease right now, and don't know it. Kidney disease is TOUGH but an early detection test isn't!

Kidney Health Month | March, 2021

DONATE NOW at www.kidney.health.nz/Donation

Kidney Health Month launched in March to raise awareness of kidney disease in New Zealand.

Our key message was that one in ten New Zealanders have kidney disease and most don't know it. We want people to get checked to detect the disease early - it is their best hope of having a chance to prevent end-stage kidney disease.

COVID-19 Vaccinations

Understandably there is some concern in the community over the COVID vaccine and so we will bring you updates and recommendations as they are confirmed. Any recommendations will be made in consultation with the Australia New Zealand Society of Nephrologists and the Renal Society of Australasia who are also working on producing a consensus statement on vaccination for kidney patients. This should be issued in early March.

Kidney Health New Zealand recommends all kidney patients enquire with their GP and/or nephrologist as to when and if they can receive a COVID vaccine.

Announcement of Interim Medical Advisor

Kidney Health New Zealand is pleased to announce that Dr Andy Salmon of Waitemata DHB has agreed to be Kidney Health New Zealand's interim Medical Adviser upon the retirement of Dr John Collins.

Dr John Collins retired from the role of Medical Adviser for the organisation late 2020. The board and staff of Kidney Health New Zealand and the whole kidney community wishes John well in his retirement and thanks him for his work over the last few years as Medical Adviser.

Kidney Health New Zealand is collaborating with the National Renal Advisory Board to identify the skills and process to recruit a new permanent medical adviser.

Consumer Council

Consumers of kidney health services from around New Zealand, representatives of the KHNZ board and staff of Kidney Health New Zealand will gather in Wellington for the annual Consumer Council meeting. This council guides KHNZ's thinking and direction for the following year and highlights issues that need to be addressed from around the country.

Topics to be discussed include COVID vaccination, ANZdata, NTA, KHNZ screening and testing programme, the Simpson report, ODNZ's move to the New Zealand Blood Service. From this meeting a range of strategies will be developed for Kidney Health New Zealand to action.

New Office for KHNZ Christchurch

We have moved to a new office. As we unpack boxes and set up desks the show carries on with this newsletter and the launch of Kidney Health Month.

Our new office at 6 Sir William Pickering Drive has us placed across the drive from Mobile Health who have generously offered board room facilities and the potential opportunity to partner with them in some new initiatives targeting the rural sector.

The Kidney Health website has had a makeover. Check out our new look at www.kidney.health.nz.

We will be making over more of the site as we continue to update our look.

Experience Stories

We had a great response to our request for people to share their experiences with kidney disease. All stories will be published on our website and we will continue to add more.

To read them go to:

<https://www.kidney.health.nz/Stories/>

Here is an excerpt of one to give you an idea:

Carey's Story

On the face of it, you'd think Carey Penn, Managing Director of Electrical & Automation Solutions (EAS) was a pretty normal healthy guy. He'd probably like to think even a bit fitter and active than many people his age. But in 2017 he found out he had kidney disease.

"There were no obvious signs to make me think I had any serious health problems. I was a bit tired and hadn't been feeling 100% for a while; but I put it down to putting in long hours building the business and with young kids, most parents are tired. My wife, Gemma, encouraged me to get a check-up and within days my test results were back, showing my kidney function (EGFR) was down to 21%. Which meant I was at stage 4 kidney failure.

As you can imagine this all came as a bit of a shock. Kidney Health NZ played an important role in helping me understand my illness and the journey I was now on. I fully support the work they do especially around educating everyone about the simple steps they can take to ensure their own kidney health."

Read more at:

<https://www.kidney.health.nz/Stories/Careys-Story/>

Raising the profile

One of the goals of Kidney Health Month running over March was to raise awareness of kidney disease and the impact it has. We had coverage in several news outlets. Links to several of the stories are on this page on our website:

<https://www.kidney.health.nz/News-Events/>

News Headlines:

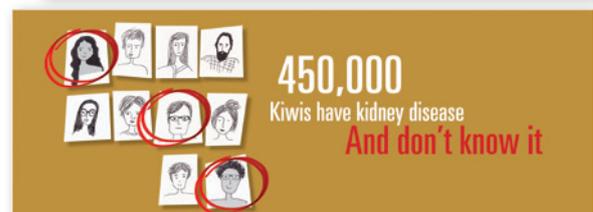
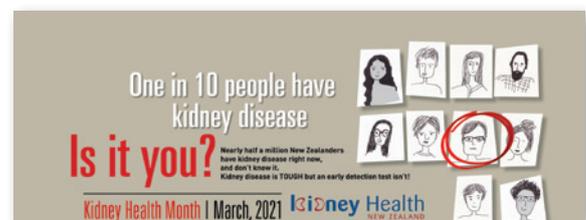
Transplant recipient giving back after kidney failure 'flipped life upside down'

and

Cricket umpire embarking on Picton to Bluff trip on an e-scooter

If you missed these articles head to our news section of our website to check them out.

In addition, we had advertising in The Dominion, The Herald and The Press to raise awareness



World Kidney Day 11 March was to raise awareness of the importance of our kidneys. Our local activities included events in hospitals and run by our local kidney support groups. We designed Kidney Health Month around this day to build on the campaign to raise awareness.

While I still can - Eugene Sanders' epic journey

1400 km's from Picton to Bluff on an off-road e-scooter was the goal for Eugene Sanders. Starting on Monday 8 March his route took him across the top of the South Island, down the West Coast and across to Bluff over 14 days. Eugene is, we understand, the first person to complete this NZ cycleway journey on an E Scooter. "While I Still Can" is a personal challenge that Eugene wanted to complete before his kidneys deteriorate further, essentially, "while he still could".

With a goal of raising awareness and \$10,000 for Kidney Health New Zealand's awareness programme left Picton. Along the way he was supported by our kidney health community, the public, and businesses to ensure he was able to raise the most money possible. The journey was covered on National news appearing on TVNZ, and in Stuff who reported on the progress and about kidney disease.



Eugene was supported by the following businesses ...

These businesses ensured that Eugene was able to complete his journey ...



Free Community Testing Programme

Early detection is key to reducing the impact of kidney disease. It gives the chance to maintain existing kidney function, which will in turn result in less people needing dialysis.

To address this issue KHNZ introduced a Roadshow programme in July 2020 which saw us provide community testing. Since that date we have visited **8 regions and provided prevention screening at 11 different locations**. Each roadshow is an opportunity to connect with the community, provide free kidney health checks and raise awareness of kidney disease.

This programme has seen us **prevention screen 544 people in the community and identify 55 people** with various stages of kidney disease that were unaware of their condition. Three people were identified as having significantly advanced kidney disease and needing specialist care immediately. These figures confirm our message of 1 in 10 people have kidney disease, and most don't know it.

Our community prevention screening programme has seen us connect with local nursing schools and student nurses to recruit them to help us with testing. This gives an opportunity for us to raise awareness amongst the nursing students of renal healthcare, kidney disease risk factors and testing. These are skills they will then take out into the workforce increasing awareness, and hopefully, early detection of kidney disease.

The roadshow has run **eight education sessions for the medical community**. These education sessions upskill healthcare professionals on the detection, management, and referral of kidney disease. They are free and widely advertised to the regions visited within the roadshow. Each of these sessions will impact on diagnosis and care of the 400,000 plus stage one to three patients.

During each of our roadshows we take the opportunity to **connect with the local DHB and renal staff**. This is providing invaluable insights into regional expertise, differences, difficulties, and systems.

March 2021, as part of Kidney Health Month, saw us include this testing with the following events:

- MP kidney disease prevention testing outside Parliament
- Attending Pacifica in Auckland
- Roadshow in Invercargill (in conjunction with finish of While I Still Can event)
- Canterbury Cricket testing profile event
- Genesis energy staff testing



Our national roadshow programme has been very successful in raising awareness of kidney disease in the community, providing education for healthcare professionals, and identifying regional issues throughout New Zealand. This programme will continue throughout 2021.

If you have a location you wish us to visit please get in contact at info@kidney.health.nz.

Rural and Remote Patients' and Carers experiences of accessing specialist kidney care

What is the impact of living further away from kidney specialist services in NZ?

Does living more rurally or remotely cost the patient and their whanau more?

Does living more rurally or remotely mean you have less access to preventative care, dialysis or transplant services?

How can we provide better kidney specialist services to people who live rurally or remotely?

Please help us find out!

Has kidney disease affected your life or the lives of someone you care for?

Do you live more than 1 hours drive or over 100km from your nearest kidney specialist centre (for specialist appointments/ dialysis/ transplant work-up or follow-up appointments?)

What we know so far: We don't really know much about the impact of kidney disease on people who live more rurally or remotely in New Zealand. Studies from other countries tell us that the further you live from your specialist renal service, the more it costs you personally and the harder it is to access all of the services available to you. We also know that the further you live from a specialist kidney service the lower your likelihood of getting a transplant.

What we want to know: We want to understand the impact of living rurally or remotely and having kidney disease or caring for someone with kidney disease and the impact this has on your life and the access to kidney specialist services.

Why do we want to know this: We want to ensure that everyone in NZ, no matter their geographic location has equal access to kidney specialist services.

We want to talk to:

- people who have kidney disease of any stage who see ANY kidney specialist service who live more than 1 hours drive or over 100km from their nearest kidney specialist service.
- carers of people who have kidney disease who live more than 1 hours drive or over 100km from their nearest kidney specialist service. We invite you to take part in research that looks at the experience and views of people with kidney disease and their carers who live rurally and remotely in New Zealand.

If you agree to take part in this study we will:

- Organise a kanohi-ki-te-kanohi (face-to-face), zoom, skype or phone interview with you (and any whanau / friends you wish to also attend) to explore your thoughts, beliefs and experiences of accessing kidney specialist services.
- We will provide a koha, (as a small appreciation of your time and sharing your story).
- We will use the information we gain from the interviews to show the impact of living rurally or remotely on accessing kidney services to try to ensure access is equal and/or policies are changed at a national level to ensure people who live rurally or remotely are not disadvantaged.

You will be interviewed by Rachael Walker who is a kidney Nurse Practitioner and researcher.

If you are interested in taking part in this research and want to know more about it, then please contact Rachael Walker on rwalker@eit.ac.nz or 027 2349205

Kidney Donor Whanau

Kidney Donor Whanau was set up in July 2020 to **connect people who have or are thinking about direct or altruistic kidney donation, transplant recipients and their whanau**. The group was established, with the support of Kidney Health New Zealand, by Leah Stewart. Leah donated a kidney to a friend a few years ago and felt that a group like this was needed to support and inform kidney donors. It is a **friendly community that you are welcomed into** to connect with others on the same path, share your experience, receive peer support, and engage your curiosity.



The group has proved popular with over 80 people signing up in the 5 months since it began. Many of them have donated to family or altruistically.

The support network gives donors the **opportunity to link up with a buddy** who may provide online, phone, or face to face connection to another kidney donor in their region, or someone considering donation. The support network is also a home for donors' stories and to feature upcoming events like Q&As with medical professionals and the opportunity to hear the journeys of donors and their recipients first-hand. The support network is backed by Kidney Health New Zealand and medical professionals.

This growing community is a invaluable way to connect our community to provide support and share information.



Leah Stewart, who set up and runs Kidney Donor Whanau.

Want to get your Kidney Health news faster?

Contact us with your email address and we will update you with all our news more regularly.

It helps us as it saves on printing costs and you get your news more regularly.

Contact deanne.hock@kidney.health.nz with your email!

Thank you to the following organisations for their support:



WG Johnston
Charitable Trust

Hamilton Library
Palmerston North Library
Wellington Library
Havelock North Library

Vernon Hall Trust Fund

Havelock North School
Te Kowhai School
St Mary's College
Wellington

Genesis Energy

Green Cross Health

WinTech
Massey University
Ucol - Masterton

Stroke Foundation

Pak'nSave Wainoni
Eastgate Mall

REAP Centre Masterton

Support Kidney Health New Zealand

Yes, I want to help in 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

ph: 0800 KIDNEY (0800 543 639)

e: info@kidney.health.nz

www.kidney.health.nz