

IN THIS ISSUE

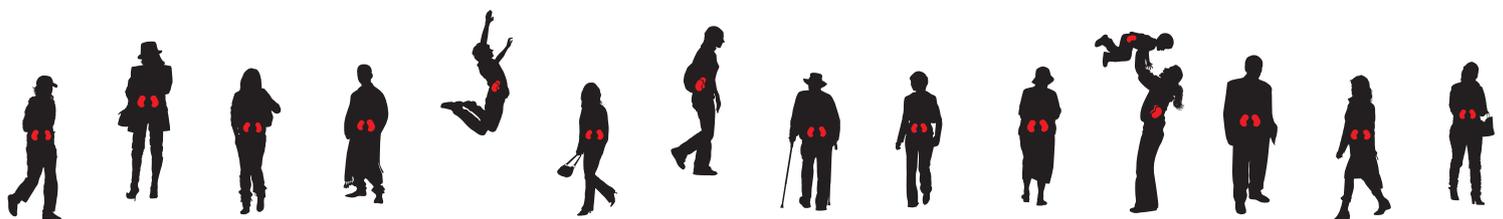
Acknowledging our Muslim community • Introducing the KHNZ staff • CEO update • World Kidney Day review • Don't let the flu get you • Dialysis poems • Fundraisers update • Kidney statistics

**Kia Hora te marino
Kia whakapapa pounamu te moana
Hei huarahi ma tatou i te rangi nei
Aroha atu, aroha mai
Tātou i a tatou katoa
Hui e! Tāi ki e!**

**May peace be widespread
May the sea be like greenstone
A pathway for us all this day
Let us show respect for each other
For one another
Bind us together!**



I couldn't write this newsletter without acknowledging the tragic events in my hometown, it has shaken our country to the core, to see the headline "Terrorist attack in Christchurch leaves 50 dead" is not something I'd ever thought I would have to see, but sadly it has not been the case. Our thoughts and deepest sympathy go out to the Muslim community, You are Us. The front page of the newsletters Te Reo/English translation was taken from a message I saw among the floral tributes that had been placed outside the Botanical gardens, and thought it was a good reminder for us all.



Following a request from our readers let me introduce the staff at KHNZ

Carmel Gregan-Ford Acting Chief Executive Officer National Education Manager, RGON, BHSc

Carmel has a wealth of knowledge in the area of Kidney nursing as well as education and assistance. From Renal Nursing in London in 1988, and Charge Nurse in the Kidney Transplant Unit, London in 1992, Carmel moved on to a position as Public Health Nurse in Timaru. Her experience in Renal Education extends from Clinical Nurse Educator and Clinical Nurse Consultant for Auckland Healthcare and Baxter Healthcare respectively, to Consultant for the Strategic Renal Services Review and Pre Dialysis Educator with Auckland DHB. Carmel's most recent previous position as Kidney/Pancreas Transplant Coordinator with the Auckland District Health Board leaves her well equipped to take on the challenge as National Education Manager for Kidney Health NZ.



As National Education Manager, Carmel has the responsibility of overseeing the 0800-KIDNEY Information Line, assisting the set up of new patient support groups across New Zealand, providing education to various groups as they may require, and ensuring Kidney Health New Zealand's resources are kept up-to-date.

Carmel lives in Christchurch with her husband and three children, and is enjoying working with the Kidney Health team.

Dr John Collins Medical Advisor

John Collins is a nephrologist in Auckland. He graduated from Otago University with an MBChB in 1974, and subsequently trained in Wellington, commencing Renal Training in 1979. He undertook a three year renal research fellowship at the University of Southern California in Los Angeles from 1981-1984. He returned to New Zealand to take up an appointment at Auckland Hospital where he continues to practice. He is an Honorary Associate Professor of Medicine at the University of Auckland. He also provides private nephrology consultations at Mercy Specialist Group in Epsom, Auckland.



He has had a very long-standing interest in Chronic Kidney Disease and Dialysis and has published many papers in these areas. He has a strong commitment to early diagnosis of kidney disease and implementation of strategies to control disease as much as possible at an early stage. He is a keen supporter of kidney education and screening of at-risk populations to identify silent kidney disease. He would like to see improved outcomes for Maori and Pacific people who are the highest risk groups with kidney disease.

Deanne Hock Office Administrator

Deanne joined Kidney Health NZ in October 2006 as part time Office Administrator, working 3 mornings a week.

Previously Deanne worked for Perpetual Trust. Returning to work after being home with her young family. Deanne is enjoying the variety of work with Kidney Health and is an asset to the team.

She lives with her husband and two boys in Christchurch.



Jacqui Jeffrey Fundraising Coordinator

Jacqui joined KHNZ in March 2018 as part time fundraising coordinator. Prior to joining Kidney Health New Zealand, Jacqui worked for Youthline Central South Island as their funding coordinator. Jacqui also runs events, and coordinates a small farmer's market in the town she lives in. Jacqui has run both large and small community events and continues to do a couple of family events throughout the year. "I was looking for a new challenge and the opportunity to work for a National organisation that has the potential to positively impact the lives of so many people really appealed to me. This organisation has achieved so much, and I hope that I can help us to achieve even more." Jacqui lives in a town on the outskirts of Christchurch with her husband and three children.

From the acting CEO/National Education Manager – Carmel Gregan-Ford

It has been another busy couple of months with the Consumer Council held in late March, as always this was an opportunity to hear from the group about the issues, they see are a priority for renal patients. Professor Suetonia Palmer and Dr Rachael Walker were invited and spoke to the group as part of their project they are working on "identifying patient priorities in research". This provided a great opportunity to discuss consumer engagement in research and treatment. Board member Dave Shearer talked to the draft Strategic Plan and the group identified areas under each heading that they felt needed to be addressed. This will help form the direction of KHNZ, it is hoped the final plan will be available on our website by June this year.



I attended the Federation of Primary Health Alliance meeting where the Director General of Health Dr Ashley Bloomfield spoke about the need to ensure we have a strong and equitable public health and disability system that works for all. We all know that there are opportunities to improve the structure, sustainability and achieve equity of health outcomes, especially for Maori. He talked about the work currently being done in the Ministry of Health outlining the areas the Health Minister sees as a priority going forward, these include Wellness and Mental Health and Addiction. He felt primary care had a big part to play in these areas.

KHNZ was pleased to see the Minister of Health's announcement that the NZ Blood Service will take over management of the deceased organ donation service in New Zealand.

The Minister in his press release enumerated a number of functions the new service will undertake:

- improve public awareness;
- provide advice and information to support donation conversations;
- improve registration systems;
- ensure effective clinical governance;
- work with the sector to coordinate processes.

In our interactions with the Minister we have indicated the need for the new service to be properly funded to undertake this suite of functions, so we look forward to watching the progress, and supporting the process where we can.

I was fortunate enough to attend the International Society of Nephrology World Congress in Melbourne recently. As the World Congress only ever comes to this side of the world every 20 years or so, it was a wonderful opportunity and I was very excited to meet some of my nephrology idols! There were around 3000 delegates, although with the number of sessions and size of the Exhibition Centre it was never overwhelming. One of the many highlights was the Film night awards. The concept was to showcase films that reflect patient experiences or provide education for patients on renal topics, such as commencing dialysis. six short films (about 6 minutes each) had been shortlisted from Hungary, Malaysia, Australia, Kosovo, Germany and Brazil. These were very powerful and can be seen with this link <https://isnwc2019.org/program/film-award>

An exciting announcement was made on the final day of the congress when the research from the CREDENCE trial presented by the George Institute of Global Health showed the new drug treatment, Canagliflozin, which could reduce kidney failure in patients with diabetes and kidney disease.

The new treatment for people with diabetes and kidney disease reduced kidney failure by a third according to the trial, it also showed heart failure was reduced by over 30% and major cardiovascular events were reduced by about 20%.

This is a significant medical breakthrough as people with diabetes and kidney disease are at very high risk of kidney failure, heart attack, stroke and death. The fact there is now an effective way to reduce the risk is exciting, although not yet funded in New Zealand it is hoped it won't be too long before it will be. Watch this space.

Our social media accounts have been working overtime over the past month. I attended a session at the WCN on how to use Twitter, this has helped and enabled me to engage with other Twitter users on the latest nephrology updates. Our Facebook Page has over 900 followers, and growing, a big increase in the last couple of months. The Crocketts video stories were a big hit. I hope to get more stories on video to share in the future.

The Point of Care testing machine has arrived and been calibrated ready for use. There has been a lot of interest in this and I think it will be a real game changer for our screening program and hopefully potential funders. The machine is small and very portable it only requires a small amount of blood and gives both the Creatinine and eGFR results within 30 seconds.



World Kidney Day 2019

World Kidney Day was celebrated around the country in a variety of ways. In the mighty Waikato the renal team, along with very special guests, were on standby giving free blood pressure tests and promoting the importance of our [#kidneys](#) at [#waikatohospital](#).

In Nelson Linda and her team took the opportunity to just get together over a cuppa and cake and korero.

In Northland, Kaitaia, Kerikeri and Whangarei renal teams organised fun run walk events to raise awareness and promote a healthy lifestyle, its wonderful to see such great support and participation. The photos show the numbers that turned out for a great event, the numbers increase every year. Great work.

Auckland and Waitemata renal services took the opportunity to offer free kidney health checks in their respective communities.

In the deep south the Otago Kidney Society organised a "walk for kidneys".



Flu can be deadly for people with kidney failure – get immunised

Influenza-linked illness is associated with more than 1,000 deaths from kidney failure each year in the United States, according to a recent study¹.

One of the study's authors, Dr David Gilbertson, says flu immunisation should be a key strategy in protecting patients with kidney failure.

In New Zealand, if you have a kidney condition you are eligible for a free flu shot from your doctor or nurse. Immunisation is especially important for all people of any age with chronic conditions such as kidney conditions, people 65 years and over, pregnant women and young children as they are at a higher risk of complications when they get flu.

Free flu shots are available for eligible adults and children six months and older from April to December 31 each year. However, now is the best time to get your annual flu shot so you're protected before flu season strikes.

The two funded flu vaccines this year will contain four inactivated virus strains, specially formulated for the New Zealand 2019 season.

Flu can be anywhere, so you can easily catch it. Even if your kidney condition is well managed, being fit and healthy will not always protect you from flu.

Immunisation is the best protection against influenza. Even if you still catch the flu after immunisation, your symptoms are less likely to be severe. What's more having a flu shot every year can keep people 65 and over healthy and active for longer.

Influenza is not the same as a cold. It is a more serious disease that can also make other existing conditions, such as kidney disease, worse.

Get immunised to stop the spread of flu around your community. Even if you don't feel sick, you could still be infected with the virus and pass it on to others.

Please note, flu immunisation from your practice nurse or doctor is free for people with kidney conditions. If, however, you have a consultation or check-up with your doctor at the same time, a consultation fee may apply. The influenza vaccine is a prescription medicine. Talk to your doctor, nurse or pharmacist about the benefits and possible risks. And, if you're between 65 and 80 years old, ask if you're also eligible for free shingles immunisation. Check out www.fightflu.co.nz to find out whether you qualify for free flu immunisation or call 0800 IMMUNE 0800 466 863.

¹ The article, entitled "Excess Deaths Attributable to Influenza-Like Illness in the End-Stage Renal Disease Population," appears online at <http://jasn.asnjournals.org/> doi: 10.1681/ASN.2018060581.

Anthony shares his story and some of his poems

Life with kidney failure becomes uncertain. Will end-stage of the disease with no renal function occur? Is the wait and tenuous future of a kidney transplant a good option? Shall I do haemo- or peritoneal dialysis? And if the former shall I train for home dialysis, and pursue the follow-up instruction for nocturnal? Accompanying the time of getting to grips with these searching decisions one has to deal with a range of unpleasant symptoms attendant upon declining health. While a measure of harmony may be restored once dialysis is underway, being dependent on a machine means life cannot be lived entirely as formerly. Moreover, dialysis though lifesaving does not replace the intricate fine tuning and hormonal influence of the kidneys which operate 24/7.

For many the internet's social media make available the thoughts, trials and triumphs of thousands in similar situations. It is a valuable resource for all warriors getting to grips with the changed existence kidney disease has presented to them. Composed during my first two years of home haemodialysis and shared online these poems express the trials, fun and hope all dialysis warriors face. If they bring some humour to you and your loved ones I shall be happy; but even more so if they inspire you to reanimate your creative side (of whatever nature) and to share your inspiration online or anywhere for the enjoyment of us all.

IN PRAISE OF HAEMODIALYSIS

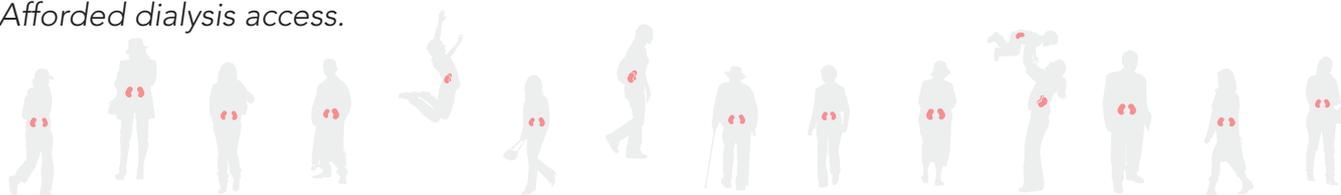
*Circulating through a machine
My blood is rendered quite clean.
Life's prospects had paled
Since both kidneys failed
But now a fair future is seen!*

FRESENIUS 4008B

*For a machine that lengthens my days
I have nothing but heartfelt praise.
My health well restored
I'm now rarely bored
And pursue my old pastimes and ways.*

CREATION OF THE FISTULA

*Feeling ill - in a mess I confess,
Surgery delivered success!
With almost no pain
A joined artery and vein
Afforded dialysis access.*



Thank you for your support on World Kidney Day

Kidney Health New Zealand wants to thank all the people out there who supported World Kidney Day this year. I hope your celebrations went well. If you fundraised for Kidney Health New Zealand, we appreciate your support. Please check out our website for bank account details to get the funds to us. World Kidney Day is a great way to raise awareness of kidney disease and to take the opportunity to acknowledge individual kidney health journeys.

Thank you again for taking the opportunity to celebrate World Kidney Day. We look forward to doing something bigger and better in 2020.

<https://www.kidneys.co.nz/Donation/>

What your donations achieved!

KHNZ has had a busy couple of months thanks to the donations we have received. Carmel, our Education Manager was able in April to attend the International Society of Nephrology (ISN) Conference World Congress of Nephrology in Melbourne. This conference was a great way to keep up to date with the latest advances in kidney treatment, and to connect with other kidney health professionals in Melbourne.

The National Consumer Council, which is made up of patients and their supporters from around the country was able to meet in Wellington in March. This council is a way of hearing about the issues facing kidney patients around the country. The National Consumer Council allows KHNZ to set a direction and priorities for the next year, which means we can be sure we are addressing the real-life problems people affected by kidney disease face.

Your donation also helped to keep our 0800-line open. This line is free to anyone seeking information or advice on kidney health. Managed by an experienced renal nurse we provide advice and support for callers 7 days a week.

Keeping connected with health professional and patients alike is a strong focus of KHNZ. Your donations mean that we can continue to represent patients, provide advice, support and education on kidney health. Thank you.

Want to Help?

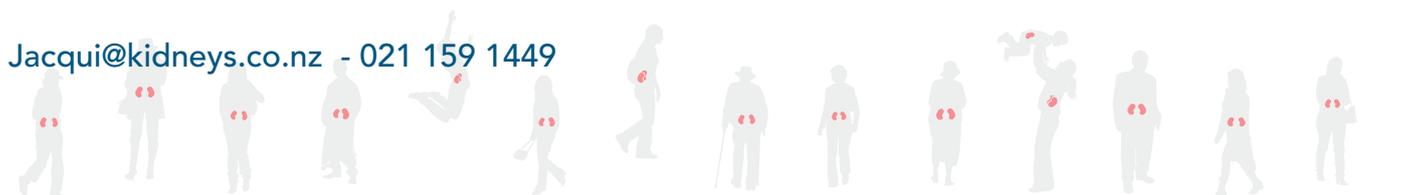
Interested in supporting Kidney Health New Zealand? Get in touch, whether it is raising awareness, fundraising or donating, we would love to hear from you.

Choose to share your challenge event.

Are you taking on a challenge? A marathon, bike race or something else? Share your challenge with us to create a fundraiser for Kidney Health New Zealand. Your efforts can raise awareness of kidney health and help us with much needed funds. Show your support through creating a Give a Little page or wearing one of our t-shirts. Simple actions can have a big impact.

Get in touch with Kidney Health New Zealand if you are interested in sharing your challenge event.

Jacqui@kidneys.co.nz - 021 159 1449



Key Statistics from 2017 Data

615 Patients started treatment for end stage kidney disease

4658 Patients being treated for kidney failure in New Zealand at end of 2017

187 Kidney transplants (40 per million)

65-74 Age group with the highest risk of starting treatment (and increasing)

849 The number of Pacific patients per million starting treatment
(12 fold higher than European patients)

14 ABO incompatible transplants

445 Patients active on the kidney transplant waiting list

2768 Number of people living on dialysis

436 Patients doing home haemodialysis



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: Cheque (made payable to Kidney Health NZ) Mastercard Visa

Card number:

Card expiry date: / / Name on card: _____

I would like: A receipt for my donation Information about gifting to Kidney Health in my will

Information about kidney donation/transplants To become a member of Kidney Health NZ

Name: _____

Address: _____

Please return this form to Kidney Health New Zealand, PO Box 20072, Bishopdale, Christchurch.