



## Spring 2021 Newsletter

### September Issue

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Welcome to our Spring Newsletter!

We hope you are all keeping well and coping with the constant changes that Covid throws our way.

We have had a busy few months here with staff changes, national events to raise awareness for kidney disease and lots of exciting research being conducted.

Warmer and longer days are on their way as we move into Spring. This is always such a lovely time of year as everything that has been hibernating over winter starts to appear.

### STAFF CHANGES

#### Jacqui Jeffrey

We are sad to say that Jacqui Jeffrey has left Kidney Health New Zealand. Jacqui has been working with us for just over three years and has been a huge asset to our fundraising team, website, and newsletter. We are sure over the years you have all got to know her through her dedicated work. Jacqui will be taking up a role with Red Cross and we wish her all the best.

and DHBs throughout the country. Becs will also be directly working with Christchurch Kidney Society to support and educate the local kidney community. Becs hopes to be a part of bridging the gap of knowledge and support around kidney health for minority ethnic groups in the South Island to produce better health outcomes for these people. You may also see Erica and Becs working together on renal projects throughout the country.



#### Becs Hayston - South Island Renal Educator

Becs has recently joined Kidney Health New Zealand in a new role as our South Island Renal Educator. Within this role she will be working closely with regional patient support groups, GP practices

Becs has 17 years renal nursing experience with a background in dialysis, patient education and support. Both her great grandmother and in more recent years her grandfather suffered from kidney disease.

Outside of nursing, Becs lives a busy life with her family of six plus their two Labradors. She enjoys

photography and more recently has dabbled with pottery. She is the company director of a small business called Ethel & Bethel Bingo Babes Ltd who provide entertainment to help local charities and communities raise money. In their downtime Becs and her family love to get outdoors including skiing, hiking, and having fun adventures.

As a family, they are planning to do more travel in the future to experience different cultures. Becs' most recent travel was to Japan in early 2020. She describes the people, culture and charm of Japan is what she hopes to experience again soon when travel becomes safe again.

These are photos Becs took of a famous 500-year-old temple tucked into a valley in Kyoto called The Silver Pavillion. Known in the native tongue as Ginkaku-ji (Gin-kaa-koo-gee) meaning "simple is beautiful". Becs visited the temple on a wet, misty winter's morning when the immaculate damp gardens were covered in moss and witnessed the sand designs being carefully crafted for the day ahead. She recalls the visit was a highlight in her travel adventures to date.



## Fundraising

### The Good Sell

We're having a fundraising campaign with a twist – and we could use your help.



Support Kidney Health New Zealand and Kidney Kids to urgently raise \$20,000 to help young people struggling with kidney disease

Kidney Health New Zealand has listed on the new charity focused trading site The Good Sell NZ <https://thegoodsell.co.nz/> the place where Kiwi's can buy, sell and donate to a good cause. List an item and choose a percentage of the proceeds to go to your chosen charity or buy an item and donate a percentage to a charity.

We encourage you to visit the site and

- donate those items you no longer use with proceeds going to KHNZ or

- visit the site and bid on the great auction items
- special auction items donated by Eugene Sanders from his "While I Still Can" event including:
  - Handcrafted Fly-Fishing Rod,
  - Steinhauser Bluetooth Headphones,
  - Black Caps Signed Shirt,
  - Pakistan Test Team Signed Practice Shirt,
  - Black Clash Bat 2021,
  - Original Oil Painting by Artist Charne Christensen



**The auction runs til 6 October 2021.**

## Running for Kidney Awareness

Jo Pearce is running 200km over the month of October to raise awareness for kidney disease. Just over a year ago Jo was diagnosed with Minimal Change Kidney Disease, and she has used running as a great coping mechanism.

We are extremely grateful that Jo is supporting us, and we wish her all the best in this venture.

If you would like to support Jo and KHNZ, she has started a Give a Little Page.

<https://givealittle.co.nz/fundraiser/helping-others-understand-my-journey-with-kidney>

## Terra Viva High Tea

*We are extremely excited to have been chosen by Terra Viva Café as their charity of choice. For every high tea or cream tea that is purchased at Terra Viva, \$1 is donated to Kidney Health New Zealand.*

*Why not make a special afternoon and head there for an afternoon cream tea with the girls, or a lovely high tea for lunch. Then afterwards go for a wander around the beautiful garden centre. This will be running until December 31st, perfect for those end of year Christmas functions coming up.*

## Renal awareness events

### National Kidney Health Awareness

Lots has happened since the last newsletter.

Erica would like to thank the Rotorua renal team for their initiative in the renal healthy lunch competition with prizes to win. The healthy eating program was aimed at lowering potassium, weight loss, improving blood results and all over good general health. The renal team offered support to their patients, menus, meal ideas etc, while in the unit. The response to this great initiative was very well received.

Another thank-you to the ADHB renal team with their initiative for a healthy cooking demonstration and blood pressure measurements in the Wesley Market on the 13th of April. This initiative was in collaboration with the renal dietitians. It was a lovely day and great response from the locals.

Other members of the renal ADHB team have been busy with screening the public in the main foyer in Auckland city hospital on the 6th of April. They screened 120 people and 17 were seen by the nephrologist that day.



ADHB renal team at the Wesley Market



### Renal healthy Lunch Competition

Start 12th April 2021 entry fee \$2:00  
For prizes.

#### Criteria:

1. No junk food / pies or fizzy drinks etc
2. Maintain a good weight
3. ACHIEVE good blood results



Suggestions for sandwich fillings eg: Egg, cheese, cheese & onion, lettuce & cheese. Peanut butter, tuna & mayo, chicken and much much more.



Chrissy Taylor and Sandy Speedy at the Wesley Market

Furthermore, we have been able to raise awareness in Kaitaia, Pacifica Festival, Tauranga (thanks to the wonderful renal team in Tauranga for their support on both days) Field Days, Masterton, Dunedin, Lower Hutt, and we have also been invited, for the first time, to the Poly X Pacifica night market.

Erica was also invited to do kidney health testing/awareness at the Maori Health Expo in Murupara. It was great working with other organizations on that day, and the response was very positive from all that attended



ADHB renal team including the Kaumatua at the kidney health awareness day

## COVID

*If you have queries regarding Covid please read the information on our website:*

<https://www.kidney.health.nz/Covid19/>



Testing at the Maori Health Expo in Murupara

**Kidney Health Newsletter** - If you'd like to hear more about the kidney community or you know someone who would benefit from getting our newsletter, you can see past newsletters and sign up here:

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

## Regional Support Groups

### Facebook Support Groups

Kidney Health New Zealand support groups are a great opportunity to connect with others around New Zealand with similar experiences. Kidney support groups are a growing need in communities around New Zealand. The peer connection between those people going through similar experiences is invaluable in feeling less isolated and more motivated and positive.

Our kidney support groups are specifically designed for patients, families and carers living with kidney related conditions. They provide a safe space to connect with others on similar journeys, experiences, and challenges.

Kidney Health Support Groups, supported by Kidney Health New Zealand bring together all members of New Zealand's kidney community.



**Our new logo encompassing all the support groups**

This includes those who are on dialysis, transplant recipients, those awaiting a transplant, or have one or more health condition that impairs kidney function. Our support groups are also for whanau, carers, and live kidney donors in New Zealand. KHNZ is working with existing support groups as well as creating new ones where there are regional gaps and specific requests for types of support within the community.

By connecting with others with similar experiences, our support groups may help you to feel more connected and less isolated on your journey. Over the next few weeks, you will be seeing more of these groups added to our website, with the links to join the relevant groups on the 'Groups' tab on our Facebook page. We are excited to share with you a new logo which encompasses our regional support groups. We are also working on special interest support groups which will also be listed on our website.

If you have questions about the support groups, please contact Leah Stewart at:

[leah.stewart@kidney.health.nz](mailto:leah.stewart@kidney.health.nz)

### **Auckland District Kidney Society Update**

We are sad to announce that Nora Van De Schrieck is retiring as the Manager of the Auckland District Kidney Society in October.

We would like to acknowledge Nora's dedication and hard work on the board of Kidney Health New Zealand and at ADKS. We will greatly miss working alongside her at ADKS and we wish her all the best. Nora will continue to serve as a volunteer at ADKS.

John Loof will be taking over as Manager on October 15th, and we are looking forward to working alongside him.

### **The Christchurch Kidney Society**

The Christchurch Kidney Society are looking forward to hosting their annual transplant gathering, 'The Kidney Function'. This is for all transplant patients, and an opportunity for you to get together and connect with others in similar positions. Leah Stewart from Kidney Health New Zealand will be this year's guest speaker. In 2017 Leah donated a kidney to a school friend and in 2020 started the Kidney Donor Whanau Facebook page.

With current Covid restriction The Christchurch Kidney Society are unable to do their usual hospital visits. However, they are still available for all patients if they need any extra support, and they are still sending out care packs for new dialysis patients, transplant recipients and donors.

They have recently launched a new website, [www.christchurchkidneysociety.co.nz](http://www.christchurchkidneysociety.co.nz) and encourage you to visit the website if you would like to purchase a renal-friendly cookbook or to hire the mobile dialysis van.

### **Kidney Kids NZ**

Kidney Kids are excited to introduce Ben Fonua who has joined the team as their Family Support Youth Navigator.

Ben has worked professionally in education and has volunteered in youth organisations for over ten years. His experience and his recent MBA degree will enhance his role as a youth navigator.

With our current lockdown restrictions Auckland clinics have been affected. Outpatient clinics at Starship remain open for any patients requiring face to face care. Only one support person is allowed to accompany the patient for these appointments. Anyone coming to clinics will be called prior to ensure they are not showing any symptoms of Covid or had any exposure.

All dialysis patients are still being seen during Auckland's level 4 lockdown, but transplant patients have been switched to zoom clinics. Face to face outreach clinics will resume mid – to late October.

Please do not be put off by Covid if you need any help. If you have any medical concerns, they encourage you to reach out.

### **Brett Butterworth**

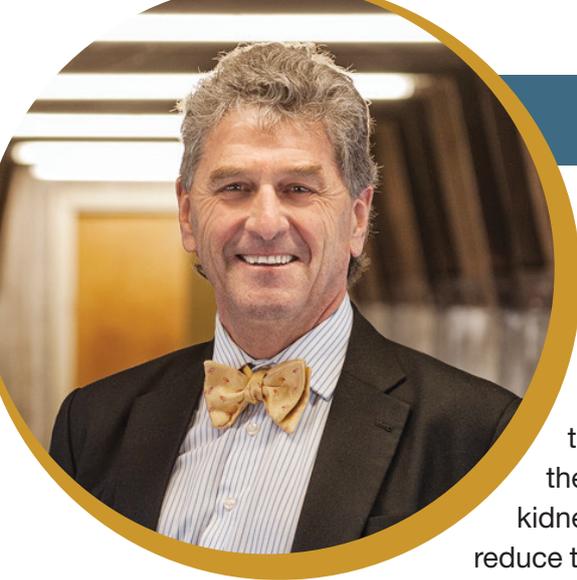
We are extremely sad to advise you that Brett has recently passed away. Brett was well known and highly respected throughout the New Zealand kidney community.

As a kidney patient he took up leadership positions at Auckland District Kidney Society as their Chairman and as a Consumer Representative on National Renal Advisory Board.

He has led many projects and initiatives as a patient representative. This included developments of new guidelines for all DHBs. Most recently he was working on a succession plan for patients' representatives on the NRAB. It is hugely unfortunate that he will not be able to see the outcome of his dedicated work.

Brett was hugely enthusiastic and professional in all he did and was highly acknowledged by both clinicians and patients.

He will be sorely missed by all in the kidney community. Our condolences go out to his whole family.



## CURRENT RESEARCH UPDATE

The Kidney in Health and Disease Research theme based with the University of Otago continues to be very active with a wide range of kidney related research both clinical and translational projects on-going. At present we have a number of clinical trials underway, some are larger multinational studies investigating newer agents to help slow the progression of chronic kidney disease: these include **ALIGN** – investigating the role of Altrasentin in people with IgA nephropathy. This agent blocks the endothelin (a potent constrictor of arterioles) receptors especially in the kidneys. By improving blood flow within the kidneys it is hoped that this will reduce the damage and hence progression of IgA nephropathy. We are involved in **ACHIEVE** – investigating the role of spironolactone to reduce the risk of heart disease in individuals on dialysis. We are also involved in a phase 2 trial of a new agent that has novel actions to improve kidney function in both diabetic and non-diabetic kidney disease.

We are also involved in trials being coordinated via the Australasian Kidney trial network. These include **PHOSPHATE** – investigating the role of phosphate binders for people on dialysis – does controlling phosphate really make a difference?

**TEACH-PD** – examining how best to train people on peritoneal dialysis.

We also have a number of investigator – initiated studies underway. The first is looking at how allopurinol – medication used to lower uric acid in order to prevent gout – is removed by peritoneal dialysis. We are looking for participants to help with this study so if anyone is interested, please contact us, we may be able to undertake the simple study in your region.

We are also very interested in cramp. We realise this is a major symptom that many individuals on dialysis suffer from, but we really know very little about cramp and how to treat it. In the first instance we have developed a very reproducible way to induce cramp in one of the muscles that control the big toe – it is relatively painless (unlike the usual cramp people get in their calf muscles). We are now using this technique to find out what increases the likelihood of getting cramp and how we can reduce this. We are doing this first in normal volunteers. Once we have a better understanding of this, we then plan to investigate cramp in individuals on dialysis to see if we can significantly reduce this from occurring.

At a laboratory level, we have two main projects investigating chronic kidney disease. The first is an on-going project looking at how lithium (an important medication used to control mood disorders) can produce long term chronic kidney disease, a small but recognised consequence of treatment and how the damage appears to be modified using amiloride – an older diuretic drug which is now very little used. The other model is a genetically induced model of hypertension where we have been investigating the close interactions between the kidneys and the heart with hypertension causing a cardio renal syndrome (damage to both) and how the actions of spironolactone may improve this providing a strong link between lab-based studies and the clinical study – **ACHIEVE** described above.

Also, we continue to hold research meetings 3 times a year. This meeting is open to the community and we have participation from members of the Otago & Southland Kidney Support Groups, as well KHNZ, frequently attending. We also offer a zoom link to anyone else who may be interested in attending by remote. We will make sure these meetings are advertised via KHNZ. The next meeting is scheduled for the end of November.

## Polycystic Kidney Disease COLLECTIVE

4th September was Polycystic Kidney Disease awareness day aiming to bring more awareness to Polycystic Kidney Disease.

Kidney Health New Zealand and researchers at the University of Otago are creating a collective partnership to increase awareness of Polycystic Kidney Disease in Aotearoa, New Zealand.

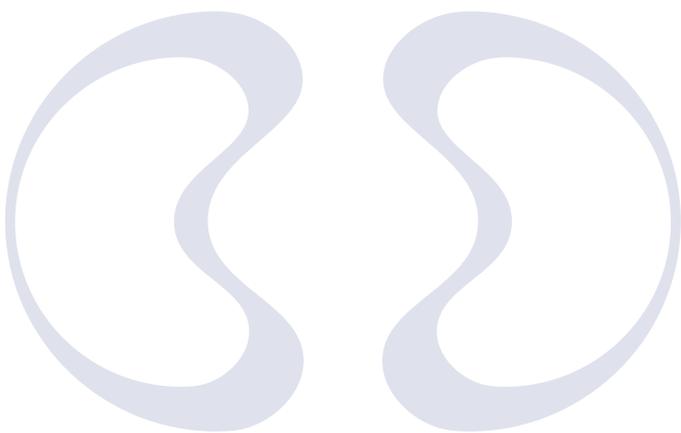
We are exploring a network for patients and families to connect and increase opportunities for patients and whanau to work with Polycystic Kidney Disease researchers, clinicians, and advocates.

The collective aims to improve wellbeing living with Polycystic Kidney Disease through patient connections, research, and education.

There will be more information coming but if you have any questions, please feel free to get in contact.

Kidney Health New Zealand: Erica Fairbank  
[erica.fairbank@kidney.health.nz](mailto:erica.fairbank@kidney.health.nz)

University of Otago: Suetonia Palmer  
[suetonia.palmer@otago.ac.nz](mailto:suetonia.palmer@otago.ac.nz)



## Kidney Health New Zealand Staff and Board Members

### Staff Members

Erica Fairbank - National Education Manager

Becs Hayston - South Island Renal Educator

Deanne Hock - Office Administrator

Anne Hindson - Fundraising Coordinator

Leah Stewart - Social Media Coordinator

Claire Christie - Newsletter Coordinator

Andy Salmon - Interim Medical Advisor

Chrissy Taylor - Contract Nurse Educator

Sandy Speedy - Contract Nurse Educator

Rose O'Hagan - Student Intern

Therese Yamit - Student Intern

Dr Terry Ryan - Kaumatua

Michael Campbell - General Manager

### Board Members

#### Auckland

John Kearns

Fale Andrew Lesa

Jo Denvir (Board Observer)

Mara Fisher

#### Wellington

Nick Polaschek (Deputy Chair)

#### Christchurch

Traci Stanbury

Christine Prince

David Shearer (Board Chair)

Thank you to the following organisations for their support:



Hamilton Library  
Palmerston North Library  
Wellington Library  
Havelock North Library  
Havelock North School  
UCOL, Masterton

St Mary's College, Wellington  
Te Kowhai School  
Pak 'n' Save Wainoni  
Eastgate Mall  
Wintec  
Foodstuffs South Island

Genesis Energy  
Stroke Foundation  
Vernon Hall Trust Fund  
REAP Centre Masterton  
WG Johnston Charitable Trust

## 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



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ph: 0800 KIDNEY (0800 543 639)

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[www.kidney.health.nz](http://www.kidney.health.nz)