

The **Kidney** Society **news**

No. 232 July/August 2022

The Kidney Society

(Auckland based), covering the Northland, Auckland, Waikato, Bay of Plenty, Lakes, Tairāwhiti & Hawke's Bay regions

'Helping people with kidney disease get on with life'



The Kidney Society YouTube Wellness Channel is **HERE!!!!**

The Kidney Society News is proudly supported by our printers




Kidney Society “who, what, where”

P O Box 97026 Manukau City, Auckland 2241

Phone 09 278 1321, or FREEPHONE 0800 235 711

e-mail: kidneysociety@adks.co.nz website www.kidneysociety.co.nz

Kidney Society Centre, Auckland: 5 Swaffield Road, Papatoetoe, Auckland 2025. Office hours: generally, 9 - 5 Monday to Friday, Answerphone a/hrs

<p>Contributions to the Kidney Society News are always welcome. Why not write us a story or send us a photo!</p>		<p>John our Chief Executive Officer is responsible for managing the Society overall. John leads the staff as they go about supporting Kidney Society clients.</p>	
	<p>Gina our Office Manager is in charge of running the office, the community houses, raffles, events organising and general administration.</p>		<p>Tracey our Wellness Educator can help you keep mobile and feel good “the gentle” or “the active” way. She can find you a gym or give you exercises for at home.</p>
	<p>Brian our Community Health Educator can help you understand kidney failure and treatments and how these things affect you and your family.</p>		<p>Maria our Office Assistant works with Gina to keep everything in the office ticking over, leaflets printed, the News mailed out and more.</p>
	<p>Jenny keeps an eye on things at the dialysis houses, shows new people how things work and helps them settle in.</p>		<p>Nora just writes the News. She likes getting people’s stories because she knows how much our readers appreciate those. Send her your story for the next News!</p>

**Deadline for September/October News:
Wednesday 10 August. Contributions very welcome!**

**Contact us for information or a chat, weekdays 9-5,
phone 0800 235 711, email kidneysociety@adks.co.nz
or just come to the Kidney Society Centre, 5 Swaffield Road, Papatoetoe, Auckland**

0800 235 711



Kia ora, Mālō e lelei, Talofa
lava, Kia orana, Bula and
warm winter greetings to you all

Exciting things have been happening at the Kidney Society. Firstly, after many months of restrictions, our Client Services team of Brian and Tracey are now able to visit clients at home. We know how much of a challenge this Covid time has been for all of you, especially given that the Society has only been able to provide support by phone, email and on-line. Now that things have changed, our team are looking forward to getting out and about in the community and reconnecting with you.

The second exciting thing is that we have launched a YouTube wellness and exercise channel hosted by Tracey Drinkwater who many of you will know is the Society's Wellness Educator. Look for further details later in the magazine or contact the office on 0800 235 711 or kidneysociety@adks.co.nz for more information.

Finally, this is your magazine, and we are dedicated to making it the best it can be.



On the next page is our annual reader survey.

We would welcome your feedback on what you would like to see in the magazine in the future.

We love producing and distributing the magazine, but it is expensive. We would like to see as many of our members as possible to switch to receiving the on-line edition of the magazine. If this sounds like you, then please let us know by contacting the office.

All members who switch from the paper copy to the digital copy in the next month will go into the draw for a \$100 prize pack from Radiant Health.

Thanks for your help!

**Ngā mihi, Regards,
John Loof, Chief Executive Officer**

Please participate in our Annual Reader Survey



One of our goals is to provide you with the best possible magazine, that's why we want to know what you think of the Kidney Society News and how we can improve it. We've got some questions and we would love to hear from you.

Please remember to include your contact details because all survey responses go in the draw to win a prize pack from 'Radiant Health'

You can get back to us in several convenient ways:

- call the office on 0800 235 711
- by email to kidneysociety@adks.co.nz
- by mail to P O Box 97026, Manukau City, Auckland 2241

Question 1: The Kidney Society News is published six times per year. **Is this about right or would you like to see more issues or fewer issues?**

Question 2: **What things would you like to see less or more of in the magazine?**

Here are some possible topics to start you thinking:

- Health tips
- Exercise information
- Lifestyle stories
- Recipes
- Inspiring client stories
- Medical information
- Puzzles
- Financial/extra assistance
- Travel/holiday options
- A question and answer and shared ideas page

Question 3: Would you like to receive your Kidney Society News on-line? There are many benefits to reducing the number of copies that are printed and posted, we believe we could save over \$4000 per year if 10% of our readers moved to receiving a digital copy!

Question 4: Would a section where we answer reader's questions be useful?

Question 5. Is there anything else you'd like to tell us about the magazine?



Kidney Society YouTube Wellness Channel is HERE!!!!

Finally, after many delays The Kidney Society's Wellness Programme YouTube channel is online and ready. With a HUGE thanks to the Kidney Society team, Dr Voss for the funding and some of our wonderful clients for being part of the filming.

We know how challenging it is to find suitable online exercise information for our clients.

The channel has been developed for our clients so we can reach and support as many of you as possible, no matter where you are or what is happening.

We have started with some basic exercises and information to support people with CKD to improve and maintain their general wellness with safe and suitable exercises.

The first series of videos covers:

- How to improve your posture
- Exercise and ideas to improve your circulation in your hands and feet.
- Basic lower and upper body strength exercise to help with your mobility.
- 3 short chair-based exercise programmes to help you get started.

Many of you have been supported already by the wellness programme and have been sent a wellness pack with our foot roller, balls and bands which you can use alongside the videos to assist you with your programme.



Our goal is to add more content to the channel over time, with more to come such as balance exercises, Zumba style sessions, walking programmes and more

exercise ideas and tips to help you manage your condition and live well.

We would love your feedback on what YOU would like to see on the channel too.

All you need to do to find our YouTube channel is use the link below or, once in YouTube, search 'Kidney Society'.

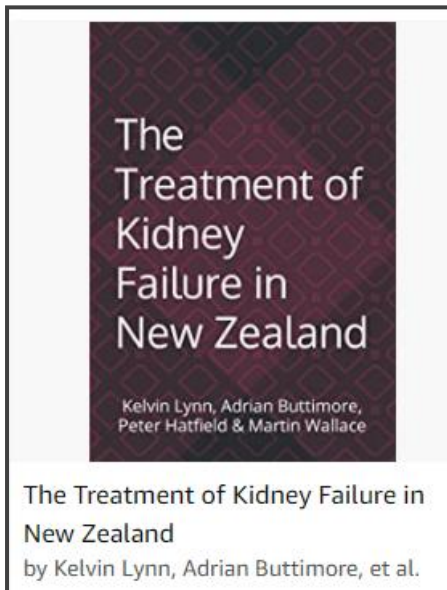
<https://youtube.com/channel/UC1uP59-O1pCnuS97IY91Grg>

REMEMBER to CLICK SUBSCRIBE & LIKE!!

Tracey Drinkwater, Wellness Educator

027 378 4544, freephone 0800 2345 711 or email tracey@adks.co.nz

Highly recommended – an interesting and surprising read!



This book tells the history of the treatment of people with kidney disease in New Zealand, beginning in the early 1950s.

The first PD treatment was carried out in 1954, and the first successful kidney transplant also in 1954. Haemodialysis as a 'long term' treatment started in 1959.

Dialysis then, although in principle the same treatment as it is today, was a huge challenge compared to dialysis as we know it today... when it can still be a challenge nevertheless.

The book includes experiences of living a life with kidney disease as recounted from patient interviews. These stories are a testament to the bravery and determination of these individuals. The stories are illustrated with many anecdotes and historical photographs.

Copies of the book are only available by ordering online from

Amazon Australia for NZ\$18.19 including delivery.

Go to **Amazon Australia** (not Amazon US - their delivery charge is much higher) and search for 'the treatment of kidney failure in New Zealand'.

<https://www.amazon.com.au/Treatment-Kidney-Failure-New-Zealand>

Use this payment method

Please select a payment method to continue.

Order Summary

Items:	\$15.69
Delivery:	\$2.50
<hr/>	
Order Total:	\$18.19
Order Totals include GST. See details.	

A perfect match



Reprinted with kind permission from the editor of **eastlife** magazine, April 4, 2022

It's been exactly a year since Peter Young's wife Pauline gave one of her kidneys to him.

Pauline Young says she doesn't want to be made a hero for giving one of her organs to her husband Peter Young whose kidneys were steadily failing over the last few years. Her husband of 50 years had

reached a dangerously low point with only three percent of his kidney functioning.

The Howick Local Board member for Botany had only two options. He could either go in for dialysis twice a week for the rest of his life or opt for a kidney transplant. The latter option involved either a kidney donation by a loved one, getting a very expensive kidney transplant overseas or being on the waitlist for a cadaver kidney which could be years of stressful waiting, considering his age.

Funnily, it was a heated argument that sealed the deal at the most unexpected moment.

"We were both on the edge and arguing about something," says the 75-year-old board member describing the moment when his wife surprised him with her decision of donating her kidney to him.

"The stress levels were high and then suddenly in the midst of the argument she said, 'I'll give you my kidney' as we were driving to see the renal doctor. I couldn't believe it, so I asked her if she was sure she wanted to do it.

"She said she was certain and even told the doctor about it. After which we were sent to a psychologist to check if she was emotionally and psychologically fit to donate her kidney to me," he says about the comprehensive screening process they had to go through to see if her kidney was the right fit for him.

"There were scans, x-rays, blood tests to find out if we were the right match. It's a long process."

In the month of March which is devoted to Kidney Health, Peter says that 40 years of being a vegetarian and being a volunteer at the Buddhist Temple worked well in his wife's favour.

She was considered fit to make the donation.

When a 71-year-old Pauline confided to her close friends about going through the transplant surgery, her friends were genuinely worried for her.

They tried to gently caution her saying she was putting her own health at risk to save her husband. There is always a risk involved in any surgery.

Donating a kidney to a loved one is scary idea. So many factors come into play. Being a Buddhist at heart, Pauline didn't want to make a big deal of it.

"I just did it for selfish reasons," she says, making light of it. "I gave you my kidney so that I don't have to drive you twice a week to the

hospital for dialysis and then wait till you finish. This way I can go to the Buddhist temple and continue with my service,” she told her husband.

Exactly one year after the kidney transplant and health scare, Peter says that due to good post-operative care and being treated by very skilled and good-hearted doctors, he is out of the woods. He feels young again!

The major surgery didn't stop founder of the Botany and Flat Bush Ethic Association from continuing his community work two month after the surgery.

Talking about their recovery he says the very next day after the kidney transplant, his wife walked up to his hospital bed to find out how he was doing.

“She is a strong woman,” he says full of admiration. “Pauline does not want any thank you. She is like a lot of Buddhist monks who donate their kidney without even wanting to find out who they donated it to.

“They don't want any acknowledgement for it,” he says of the altruistic gesture which is considered highly rewarding.

“Even our renal doctor said that more people need to be aware that a person can easily function with one kidney if it is a healthy one.”

Peter attributes his recovery to the fact that he kept healthy with plenty of exercise and acupuncture treatment prior to the major surgery. He is also grateful to New Zealand's health system that allowed him to have a free kidney transplant under very good care. “We have a very good health system, and I am so thankful for that,” he says.

The couple recently celebrated their 51st wedding anniversary and Pauline's birthday with flowers and cake.

It was also a celebration of the fact that they had both survived a major surgery with Pauline giving Peter a gift of life as a true act of love. But of course, she won't hear of it!



EASTLIFE IS A FREE ONLINE MAGAZINE!!

Go to <https://eastlife.co.nz/> to register for a free onlinesubscription to EastLife Magazine! A very good read!

Kidney Fitness NZ Hits the Road

Have you ever wanted to pack your bags jump in the car and drive away with no fixed plan?

Hi I am Cameron, a long term kidney patient who has had 2 transplants and multiple hours of dialysis, with my kidney not doing so well now. You may also wonder where the kidney fitness came from? Just before my last transplant in January 2020 I really started to get into my fitness and spent many hours working with Tracey Drinkwater and the team around what I do. I had big dreams that after my transplant I was going to become a personal trainer and see how I could help other people in my situation

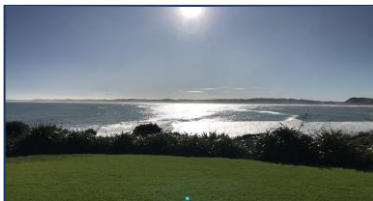
I often ponder the above question and think how cool that would be to just pack up and go, I spent 2 weeks living in my car in Wellington at the protest and this even more made me want to do this so a few months back I made the decision to follow this dream. I started selling everything and looking for the right Van to make this happen.

The road hasn't been easy with so many things not going to plan, and some hard lessons learned. I'm now just weeks away from leaving Auckland for hopefully 2 or so years on the road.

What do I want to do and what do I want to see, well I'm not 100% sure, I'm going where the wind takes me fishing, walking and find any option to meet new people and share knowledge with them.

If you would like to follow my journey or get in contact with me, I would be happy to touch base with you and maybe even have me visit, you can check out my blog on Facebook called Kidney Fitness NZ Hits The Road or email me kidneyfitnessnz@gmail.com.

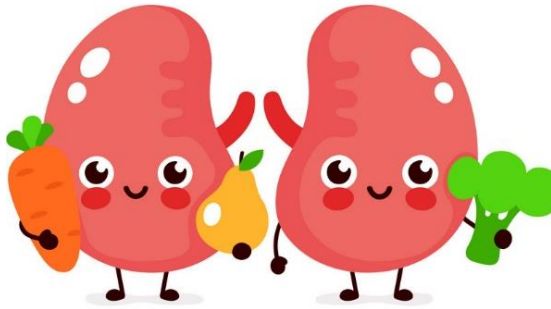
Below, Manu Bay in Raglan, a lovely spot I love to visit and just a taste of what I will see and my New Home I will be living in.



Cameron

Kidney friendly recipes

Many people with chronic kidney disease



may be encouraged to follow diets such as a low sodium (salt) diet to help improve their health. Sometimes it can be hard to come up with new ideas for what to cook. Australian Dietitian Dr Kelly Lambert and dietitian students Celine Kanos and Ellen Jackson have

recently published a cookbook full of low sodium, low potassium, low phosphate and low protein recipes for main meals, light meals, and snacks. Each recipe specifies what type of diet it is suitable for and includes a breakdown of nutrition information.

Please note these recipes are great for anyone but are low protein and so those on dialysis should increase the protein (meat, nuts, dairy or plant-based protein equivalent e.g. legumes, tofu, beans) portion of their meals.

You don't need to restrict your potassium or phosphate intake unless you've been advised to by your kidney dietitian. If you aren't sure what diet, you should be following check with your dietitian.

We have included a couple of our favourite recipes below!

The cookbooks are available to download free online from:

<https://kidney.org.au/your-kidneys/living-with-kidney-disease/health-and-wellbeing/recipes-and-meals>

Chicken and Veggie Patties with side salad Serves 4

Ingredients:

Patties

300g chicken mince
¼ cup zucchini, grated
¼ cup carrot, grated
½ cup rolled oats
100g sweet potato, mashed

The information contained in this article is designed to provide helpful information to most people. It may not be applicable to all readers as individual dietary requirements differ.

Side salad

4 cups iceberg lettuce
1 cucumber
2 spring onions
12 cherry tomatoes



Instructions

Combine all patty ingredients in a bowl and mix well
Shape into patties
Heat a frying pan over medium heat with a drizzle of olive oil and cook patties for 3-5 minutes a side or until cooked through
Chop lettuce, cucumber and spring onions and mix all salad ingredients together.
Serve patties with salad on side.

Salt free seasoning mix -

Ingredients

1 tablespoon garlic powder; 1 tablespoon onion powder
1 tablespoon of dry mustard; 1 tablespoon of paprika
1 teaspoon of thyme
1 teaspoon of basil
1 teaspoon of cayenne
½ teaspoon of pepper

Instructions

Combine all ingredients together and mix well
Sprinkle over meats or any cooking

Simple seafood marinade

Ingredients

¼ cup olive oil
Rind of 1 lemon
2 tablespoon of lemon juice
2 garlic cloves, minced
¼ teaspoon black pepper
2 tablespoon chopped parsley



Instructions

Combine all ingredients and spread over fish before cooking.

Amelia Thomsen, Auckland City Hospital (on behalf of Auckland Regional Renal Dietitians (ARRD))

ADKS BOARD UPDATE

A vacancy exists on the Kidney Society Board. The Society is looking for new board members who are willing to help grow the organisation and its services. Previous governance experience and knowledge of community health services is desirable but not essential. Strong community connections and the ability to influence are seen as being important. This is a wonderful opportunity for someone wanting to make a difference in the community healthcare space. We particularly encourage applications from Women, Tangata Whenua, Pasifika, younger members of the community, Individuals with a disability. Please direct all enquiries to Board Chair, Tony Miller via email – Tony.Miller@carters.co.nz

Positive Pathways Manukau City....



We at the Auckland Business Chamber are reaching out to people who may have compromised health and are needing help in securing either part time or full-time employment.

Positive Pathways Programme

We are based at Manukau out in South Auckland and have a team dedicated to the Positive Pathways Programme:

- 16 week employment preparation programme
- Regular intakes throughout the year with a new intake every six weeks
- The programme is funded by MSD for clients who are in receipt of a benefit **OR** have proof of medical certificate

- Starts with a letter of referral from MSD through people's client manager
- Once we receive the letter of referral, we arrange an interview here at our offices at 33 Lambie Drive in Manukau.
- First week of training is Monday to Friday 8.45 am to 2.00 pm
- Second week and weeks thereafter, 2 full days a week (with job search coach)
- In first week of training:
 - Build confidence
 - Create a new industry standard CV
- Interview practice and strategy Job search strategy
- Second week of training
- Work with job search coach
- Book extra trainings such as First Aid Cert, Security Licence, Forklift Licence, Word/Excel day course, etc
- Book Dress for Success (for interview and work clothes)
- Arrange driver licence training
- Meet our Business Development Managers and put CV out to employers for interviews
- Driver Licence Training
- Our Drive team run programmes to help take clients to the next stage of their driving licence. The Manager, Robyn-Lee, is happy to get a 'spinner' for the steering wheel to assist clients who are practiced drivers to sit their driver's licence.
- Learners Licence Training
We run in-house training across three days for learner licence training and testing.
- Restricted and Full Licence
For clients who know how to drive and are ready to get their restricted or full licence, we have seven dedicated driving instructors. An instructor will take the client out for an assessment drive to see whether they are competent enough to drive and are very close to getting their licence. We will provide them with two additional sessions with the instructor, who will take them out on the testing route and give them tips to prepare them for their test. A car is supplied for the client.
Should you have any queries please feel free to contact Sue on 0800 709 907.

Positive Pathways Programme

Supporting you back into work



Confidence
and skills



Jobs, Jobs,
Jobs...

Friendship
and
Mentoring



Drivers
Licence



This is for you:

- If you are in receipt of a benefit AND have a health condition, injury or disability, and
- are motivated to work full or part time, and
- are open to advice and guidance

We'll help you:

- promote yourself to employers
- understand your strengths and skills
- to find a great job and mentor

Find out more:

Talk to your Case Manager or call **0800 709 907**.

CONTACT:
hcid@chamber.co.nz

LOCATION:
33 Lambie Drive, Supa Centa, Manukau City
Ph: 0800 709 907

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Better Evidence And
Translation for Calciphylaxis

Consumer and Community Advisory Committee Expression of Interest for Membership

What is BEAT-Calci?

Better Evidence And Translation for Calciphylaxis (BEAT-Calci) is the name of a clinical trial that aims to find the best treatments for a condition called calciphylaxis.

Calciphylaxis is a rare disease, involving painful skin wounds, that occurs in some people with end-stage kidney disease.

Currently available treatments have not been fully studied yet, so doctors caring for patients with calciphylaxis are unsure what the most effective treatments are and so do not know how best to care for patients.

The trial uses a new design that tests multiple treatments at once and does not stop until we have an answer to the question. This makes discovering the best treatment quicker and more reliable. Patients that participate in BEAT-Calci will receive treatment over a period of 26 weeks, with initial treatments including drugs or new dialysis technology. The researchers will look at whether participants receiving treatment have an improved calciphylaxis outcome, which will be measured by an assessment of the skin wound.

Why do we need a Consumer and Community Advisory Committee?

The BEAT-Calci team understand that research needs to be performed in collaboration with consumers. The researchers want to ensure that the trial is designed in an appropriate way, with a focus on what matters most to consumers with kidney disease and their community. The BEAT-Calci Consumer and Community Advisory Committee (CCAC) will facilitate links with the kidney community and will work with the BEAT-Calci research team to make sure the study information and its results are communicated appropriately to consumers and the wider community.

Who are we looking for?

BEAT-Calci needs 4-6 people who want to contribute to research and:

- Have direct experience and an active interest in kidney disease
- Have an interest in being involved in planning research and communicating evidence

What does it involve?

- A one hour meeting every 4-6 months, via teleconference.
- Contributing to tasks in between meetings, such as reviewing participant and community facing documentation.
- Contribution for a minimum of 12-month period.

When does it all start?

The CCAC is established but is looking for additional members.

Will members be acknowledged for their input?

With permission, members will have their contribution acknowledged on the BEAT-Calci website and other trial documents.

How do I become involved?

To express interest, please contact:

BEAT-Calci.study@sydney.edu.au

telling us a little bit about your experience, and interests relevant to the research.



Thirty Years...

A Journey I would like to share with you

It was quite late, almost 10pm, I would usually be in bed by now for an early start at 6am in the morning at the airport where I worked. I was a little on edge because my routine was disrupted somewhat and if I was up too late there was a chance I may oversleep my alarm and be late for work. It had never happened yet but there was always a first time.

The phone rang and I answered it.

"Hello, Paul speaking?"

"Paul Christian Sommer?"

"Yes"

"This is the Renal Department at Auckland Hospital. We have a kidney that is a good match for you, can you come into ward 7 and the surgeons can do the operation tomorrow morning. Oh, and please do not eat or drink anything before you arrive tonight."

"I ahh ... Oh but they said it would be five years"

"Yes, well we have one for you now"

"Now? but I wasn't expecting ... you mean, now, tonight?"

"Yes"

"Oh, I don't know, I can't think. I will have to ring you back"

"Well, we will give you fifteen minutes if you don't ring by then we will give it to another person"

I hung up (The old fashioned phones that you placed back on its recharging base)....

"Who was that?" Sharon my wife asked, perplexed with a late-night call and my replies that she overheard.

"It was the hospital; they have a kidney for me. But the doctors said it would be five years!"

"Oh, that is marvellous dear. When do we go?"

"I said I had to think about it"

"Oh no you don't, you must take this now! This is it – ring them right back".

By this stage I was not in a state of being able to think coherently for myself and for the next few hours would rely heavily on other people's input. I rang back and told them I would be there soon. I then rang work, the late shift. This night was an early finish as there were no aircraft departures or arrivals after 10pm and I just happened to catch the team leader before she put the lights out.

"Hi, Paul, here, I won't be able to make it to work tomorrow or maybe for the next two months. Can you let the morning shift know?"

"Yes, I will but why will you be away so long?"

"I am going into hospital to have a kidney transplant. I will have to let Admin know when I can come back"



"Oh, that is wonderful. I will leave a message for the morning shift and get them to advise Admin as well, good luck!"

I did not drive to the hospital that night, my wife did. I remember thinking on the way – 'will I come out again, perhaps I will die!' I tried to tell Sharon what things needed to be done at home, but she simply dismissed it all. A very capable woman she simply gave me encouragement and told me not to worry about anything.



It is all a blur from here. They must have admitted me, poked and prodded and did all manner of tests. Found me a bed and in the morning, I awoke for more tests. Sometime in the morning, I did not have to wait long as you often do, I was wheeled into a prep room. Then I remember the theatre itself and many people in scrubs and masks, chatting and those without masks smiling at me. Someone asked me my name and another behind my head as I lay on the slab said I want you to count to twenty, so I did – one, two, three ...

The next thing I remember was waking in a sleepy stupor with a young nurse sitting beside my bed. There was a bright light shining.

"Wh ... where am I? Is this heaven? Are you an angel?" Smiling she answered *"No you are in Auckland hospital. You have had a transplant operation and it was very good. You are alive and well"*

"Oh, that's good" I said as the room and other earthly items came into focus.

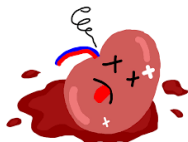


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I don't recall anything after that until I think it must have been the next day as I had slept a lot. Sharon came to visit, and I found out the operation had taken six hours! And I had slept blissfully through it all.

Over the next day or days, I can't remember exactly as I was in a drugged state, I don't remember any pain, they kept checking and testing and consulting. Apparently, the new kidney did not 'kick start' straight away and I suppose they did all manner of medical procedures to get it going. But I was happy, I was alive.

Yet the kidney was still asleep.



"We are going to give you a strong drug over several doses, eleven in all. The first one will be

very strong and then they will gradually reduce in intensity. You will have some discomfort, and this will stop any rejection that your body is making of the new graft and get your kidney working. When it does you will know straight away as you will feel a change in your body”.

With this announcement that I took in my stride albeit lying down in a drugged stupor, I was about to experience something so horrific that I would never take this drug again or wish it on anyone. If the medical staff had simply told me that I may hallucinate this could have alleviated 90 per cent of my trauma. The nurses all knew what it did but for some reason did not or were not allowed to warn me.



I have great admiration and respect for what the surgical staff did for me and the medical staff and doctors that attended to my recovery. However, I believe they grossly let me down by not giving me this simple warning. If they, had I could have laid back and enjoyed the ride!

I was going to bore you with the details of what transpired but I think not, other than to say for the next several days under the influence of this powerful drug I hallucinated. In fact, I was quite a star medically wise. All the doctors came to view what this drug was doing to me. The nurses were happy that at last the doctors would see what effect it had on patients first hand rather than try to convince them themselves. An experience I don't wish to repeat or wish on anyone.



As traumatic and dramatic as it was, it worked. I remember the moment my kidney kicked in and I felt a warm glow flow through my body. I knew it was my kidney because parts of me that had laid dormant now suddenly came intensely alive again. It was a wonderful feeling.

As I recovered from this experience still somewhat drugged up, I remember my wife telling me that Muldoon had died. At the same time the Barcelona Olympic Games were on and in my drugged state when I was well enough, I would walk to the TV lounge wheeling my drip stand with me. I can still remember the distinctive “Bar-ce-lona” theme tune and watch the TV screen that was dazzling with stars so much so I could only watch a short time (the effect of the drugs).

My wife was a champion. To this day there are probably things I did that she has never told me. Yet she was there and stayed beside me and saw to my every need. Through it all I never felt any surgical pain until I was home and off the drip.

In the end I was actually in hospital only about ten days altogether. Yet it seemed like a lifetime and by way of an incredible medical journey I was given a new life.

That was thirty years ago, July 1992.

At the time the government of the day had decreed that patient had to pay part of their treatment and surgery costs. I cannot now remember how much it was. Never before or since has the New Zealand public had to pay for medical treatment in the public hospitals. Yet I had that privilege. **I must be one of the few who have had to pay for their Kidney Transplant in a “free” public hospital.**



I did go back to work after six weeks, too short, I would come home exhausted. I should have stayed home another two weeks.

Coming through the drama of the first few days and weeks of my transplant I never looked back. From then on, I led a normal life as I had done before dialysis. In fact, I was only on CAPD dialysis one year to the week of my transplant. Since then, apart from the regular hospital checks blood tests and negotiating my drug regime with doctors I got on with life and it did not impact on my future plans in any way.



I worked, I travelled and over the past thirty years my kidney and related health issues remained stable. Over those years I was supported by the good people at ADKS and also volunteered my time and support and actually worked with the team for a few years after I left my airport job. Since then, I have seen and done many wonderful things.

Through the expert work of various medical staff, I was given a new life where in times past I would have simply died. For this I am most grateful. At all times I was encouraged and never depressed or fearful because of my strong faith in God and He has certainly given me a miracle of a new life.

That is where I am today. I am much older, and the body is slower yet my mind is still keen and health wise I am as good as I have ever been. I am retired now and spend my time writing and touring New Zealand in my motorhome. I have finished one book and am nearly finished a second which I would like to publish internationally.

We are all different. I have had a relatively easy ride compared to many who have other medical complications. Many are unable to have a transplant while others wait for that phone call. I would say to anyone who has misgivings about having a transplant that it really is a no brainer. Dialysis will keep you alive, but a transplant will give you a whole new life again. Thanks for listening to my story.



Paul Sommer
Kidney Transplant 30 Years July 1992 – 2022

Fundraising 12 April – 13 June 2022

Member donations	\$1,215
IM donations	\$ 400
TOTAL	\$1,615

Since the last News we received the following grants:

- NZ Lotteries - \$60,000 for operating expenses
- ANZ Staff Foundation- \$20,000 for salaries
- Esme and Tom Tomblason Charitable Trust - \$4,000 for operating expenses

In Memoriam:

Donations were received in memory of Christine Ransom. These gifts, like all donations and gifts made in someone's memory are used with care towards our services for people with kidney conditions.

If you would like to support the printing and mail-out of the News to our over 3,000 readers with a targeted one-off or regular donation, please contact Gina, 0800 235711 or email gina@adks.co.nz – or simply make a donation via our website or directly into our Bank account, ASB Bank 12 3032 0705009 00. It would be a great help!



Self-Care is for Everyone (Really!)

When did self-care become something that was only for a certain type of person? Self-care is a necessity to enjoy as often as you want, it's not a luxury. Let's shed some light on the truth about self-care.

You read that right. You are allowed to have as many moments of self-care as you want throughout the day. For some, it's indulgent. For others, it's simple pleasures. The definition of self-care is: "the practice of taking action to preserve or improve one's health." But when we think of self-care, we often think of indulgent shopping, brunches, or spa days. While there isn't one best way to practice self-care and those things can be a lot of fun, those activities aren't always realistic.

The intention of self-care is to address which areas of your life may need more attention than others. Are you taking care of your health? What about your physical, social, and emotional health?

So, reflect on your day and think about what you do to preserve or improve your health. What do you do for yourself when you're running on fumes or need a quick pick-me-up? There are many activities that can be considered as self-care that don't require anything more than yourself and a little bit of time. Here are some of the *fit* team's favourite ways to incorporate quick and easy self-care into your routine:

- Change up your night-time routine to make time for some music or a relaxing bath.
- Video call a friend or family member.
- Make your bed in the morning.
- Take a leisurely walk with no destination.

Does that seem like something too simple or something you already do? Maybe you want something a little more special. We understand the need for something that makes a long day less stressful. When you reframe the self-care concept, it's important to try different things during the week so you can find a routine that fits your schedule and recharges you at the same time. A few of our favourite "mid-level" self-care activities are:

- Try a new yoga flow or meditation technique.
- Use a new product in the bath or shower (or try a homemade facial mask!).
- Write in a gratitude journal in the morning or before bed

- Read or listen to a book or some music for an hour.
- Remember, there's no one-size-fits-all approach when it comes to self-care. It has to change and evolve with you, and that's the best part of it. Your self-care needs are as unique as you are and will change as your situations change. No matter your situation, you deserve to have at least one moment of peace in your day. You wouldn't let your friend run themselves down, so why would you run yourself down? How are you finding the time to take care of yourself?

<https://fit.sanfordhealth.org/blog/self-care-is-for-everyone>

Looking after your fistula or graft with a fistula cover - for sale from the Kidney Society:

There are various reasons why people like to cover their fistula, especially if it is 'well used' and getting rather big. Some people don't like how it looks; others want to make sure they don't damage their fistula. It is only light protection for your fistula, but it helps avoid scratches and can help remind you it is there!



Option 1: buy from the Kidney Society:

Fistula Cover, lower arm, black only. Length 18 cm or 21 cm, longer or shorter by request.

Special price for Kidney Society registered haemodialysis patients only: \$5 each or 2 for \$10

Phone the Kidney Society on 0800 235 711 for information or to order send cash with your name and address to Kidney Society, P O Box 97026,

Manukau City, Auckland 2241, or call in at the Centre, 5 Swaffield Road, Papatoetoe, Auckland.

**If you are ordering over the phone you can pay by either credit card, or directly into our Bank account, ASB Bank 12 3032 0705009 00
SORRY: BANKS NO LONGER ACCEPT CHEQUES....**

Option 2: Make your own Fistula Cover

The easiest way to make a **seamless fistula cover** is to buy a suitably sized pair of leggings or tights or similar.

After trying many different kinds, we now prefer **Clio Furry Leggings** available from The Warehouse at between \$15 and \$20 each. They have just the right amount of stretch – not too loose, not too tight. They are nice and soft on the skin with a 'furry' lining. We get four fistula covers out of one pair.









The fabric does not fray much but it's best to make a simple single fold seam using a **three-step stitch** as shown below (also called 'bra stitch'). This way the fabric stays nice and flat and retains its stretch.

Using the existing bottom hem of the leggings for two of the covers, you only need to hem the remaining 6 edges. By making your own, you can adjust the length to suit your fistula. Settings marked on machine are like this:



Option 3: order online!

https://www.etsy.com/nz/market/fistula_cover


 <p>PICC line cover glucose sensor fistula subcut... Ad by PICCLiNDesign ★★★★★ (272) NZ\$13.42</p>	 <p>Picc line cover: freestyle libre, glucose monitor, d... Ad by PICCOCOVERuk ★★★★★ (690) NZ\$20.65</p>	 <p>Picc line cover: freestyle libre, glucose monitor, d... Ad by PICCOCOVERuk ★★★★★ (690) NZ\$13.42</p>	 <p>PICC line cover glucose sensor fistula subcut... Ad by PICCLiNDesign ★★★★★ (272) NZ\$13.42</p>
 <p>Picc line cover: freestyle libre, diabetes, chemo, f... PICCOCOVERuk ★★★★★ (690) NZ\$20.65 Bestseller</p>	 <p>Free Style Libre: PICC Line Covers Cancer Chem... ClevelandCathy ★★★★★ (762) NZ\$15.47 Bestseller</p>	 <p>PICC line cover glucose sensor fistula subcut... PICCLiNDesign ★★★★★ (272) NZ\$13.42</p>	 <p>More colours Picc line cover: freestyle libre, glucose monitor, d... PICCOCOVERuk ★★★★★ (690) NZ\$18.58</p>

You can also find longer; plain fistula covers on Amazon:
<https://www.amazon.com/gardening-sleeves/s?k=gardening+sleeves>

RESULTS
Price and other details may vary based on product size and color.

<p>Sponsored</p> <p>Cut Resistant Sleeves - Protective Arm Sleeves for Gardening Yardwork (1 Pair) ★★★★☆ ~ 339 \$14.95 Save 5% with coupon (some sizes/colors) Ships to New Zealand Small Business</p>	<p>Best Seller</p> <p>Sponsored</p> <p>UV Sun Protection Compression Arm Sleeves - Tattoo Cover Up - Cooling Athletic Sports Sleeve for Football, Golf & Volleyball ★★★★☆ ~ 19,595 \$21.95 Ships to New Zealand</p>	<p>Sponsored</p> <p>GOUODO Arm Sleeves for Men & Women UV Sun Protection Arm Sleeves Compression Sleeves for Baseball, Volleyball ★★★★☆ ~ 1,909 \$12.99 Save 10% with coupon (some sizes/colors) Ships to New Zealand</p>	<p>Best Seller</p> <p>Sponsored</p> <p>Kevlar-Sleeves Arm Protection Sleeves with Thumb Hole, [18" Inch Long, 9"-14" Wide] Safety Arm Guide Cut, Heat Resistant Protective... ★★★★☆ ~ 3,743 \$19.99 Ships to New Zealand</p>
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Restless Leg Syndrome and Chronic Kidney Disease

 With thanks to Davida.com, an invaluable source of information for people with kidney disease!
<https://www.davita.com/education/kidney-disease/symptoms/restless-leg-syndrome-and-chronic-kidney-disease>



Restless leg syndrome (RLS) can disturb your sleep.

If you Have [chronic kidney disease \(CKD\)](#), it can also disrupt your [dialysis](#) time. The uncomfortable and sometimes intense feelings in your legs can make sitting still for your dialysis treatment unpleasant. You may want to cut your session short because the

feelings in your legs are unbearable. Sometimes patients are unaware that the sensation in their legs is a medical condition and can be treated.

What is RLS?

RLS is a condition where you feel an uncomfortable sensation in your legs and are compelled to move them. It occurs when you are trying to relax or fall asleep. You may get RLS when you have been sitting or lying down for an extended period of time, such as when you're on dialysis or sitting in a car or plane. The uncomfortable sensations vary from person to person. Some people report an itchy feeling, while others report a crawling or "creepy" sensation. RLS can also be painful; the sensations can feel like burning, aching, or pricking.

Moving your legs gets rid of these uncomfortable feelings. You may find yourself walking or pacing, jiggling your legs and feet or tossing and turning in bed to stop the RLS. The symptoms of RLS are more pronounced at night, particularly at bedtime. This urge to move your legs disrupts your sleep patterns. You may have difficulty falling or staying asleep, which can lead to insomnia. During the day, you may feel fatigued and irritated.

What causes RLS?

RLS generally affects older people. However, there are some health conditions that are associated with RLS. They include the following:

- Nerve damage from diabetes
- CKD
- Perhaps iron deficiency or lack of erythropoietin

Diabetes can contribute to RLS. Diabetes can damage tiny blood vessels and nerves. Often, people with diabetes are told to carefully examine their feet for any outward signs of damage because they may not be able to feel a wound or injury due to nerve damage.

In the past it was thought that iron deficiency or lack of erythropoietin (epo) could be a cause of RLS. A common complication of CKD is low iron levels or anaemia. Healthy kidneys produce erythropoietin, a hormone that helps make red blood cells. When the kidneys are damaged, they make little or no erythropoietin. With low iron levels and fewer red blood cells being produced, anaemia can develop in the early stages of kidney disease and get worse as the renal disease progresses. Nearly all

patients in end stage renal disease (the point where dialysis becomes necessary) have anaemia.

Depending on the cause of your anaemia (low epo levels, low iron levels or a combination of both), your doctor will prescribe medication or supplements. In addition to treating anaemia, it has been shown in animal studies that epo stabilizes and/or prevents nerve damage for those with diabetes. Although the direct cause of RLS isn't certain, it is believed that treatment with epo and iron supplements still help treat RLS.

More recently studies have shown that RLS may be associated with low levels of parathyroid hormone (PTH). Because people with kidney disease are at risk for bone disease, their doctors will monitor their PTH level to make sure it isn't too high. In patients suffering from RLS a common trait was that they had low PTH levels. Another common factor in those who reported having RLS was the number of neurologic and psychiatric drugs that were administered. Although it's difficult to know if either these drugs or low PTH cause RLS, these findings are reasons for doctors to avoid over suppression of PTH and to carefully consider the prescribing of neuropsychiatric medicines.

How is RLS treated?

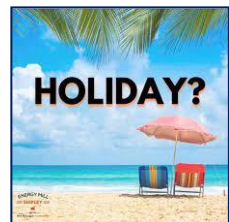
Restless leg syndrome can be treated by your doctor with epo; iron supplements; altering PTH treatment; changing certain anti-depressants, cold and cough medications or anti-seizure drugs that may be causing or enhancing RLS or may prescribe drugs such as clonazepam or benzodiazepines to alleviate symptoms.

Your doctor may also suggest self-administered home therapies to help you get a better night's sleep. These might include:

- Massage
- Warm baths
- Warm/cool compresses
- Relaxation techniques
- Changes to your sleep environment
- Exercise

Holidays plans anyone?

If you are hoping for and thinking about a holiday this summer, and need to dialyze, go to Holiday



Dialysis Information on the Kidney Health Website www.kidneys.co.nz. Here is an extract:

Below is a brief summary of dialysis facilities in NZ. If you would like to try and book holiday haemodialysis – now that we can again..., please refer to the Kidney Health NZ website www.kidneys.co.nz for contact details.

Some if not all the dialysis units will still be dealing with COVID amongst their patients – so it may not be possible to book a spot. However, here is a list of the holiday and hospital options:

Mobile Dialysis Units:

Waikato: Freedom Dialysis Project - Camper Van

- Christchurch Mobile Dialysis Unit

Hospital Dialysis Units – South Island

- Nelson Dialysis Unit
- Dialysis South Invercargill satellite dialysis unit
- Christchurch Hospital
- Dunedin Hospital

hospital Dialysis Units – North Island

- | | |
|---|--|
| <ul style="list-style-type: none">• Kaitaia Dialysis Unit• Kawakawa Dialysis Unit• Whangarei Dialysis unit• Waitemata Renal Units – 3 units• Auckland City Hospital - City Site• Auckland City - Greenlane Site,• Middlemore Hospital• Renal Care Centre Mangere | <ul style="list-style-type: none">• Waikato Hospital• Rotorua Hospital• Tauranga Dialysis Unit• Whakatane Dialysis Unit• Palmerston North Hospital• Gisborne Satellite Dialysis Unit• Hawkes Bay Hospital• Taranaki Dialysis Unit• Wellington Hospital |
|---|--|

Has your address or phone number changed?

Has your address or phone number changed? We have no way of knowing unless you tell us. Please remember to let us know BEFORE you move, or as soon as you have a new phone number.

The Kidney Society NEWS is FREE for Auckland/Northland/Waikato/Bay of Plenty/Lakes, Tairāwhiti/Gisborne and Hawke's Bay people who are pre-dialysis, on dialysis, supportive care or who have a transplant.

Others, including supporters, are welcome to subscribe to the Kidney Society News for \$20 per year (6 issues).

For changes to our mailing list, to have your name taken off the list or added to it, or to subscribe, please fill in the form below and send to: FREEPOST 1875, Kidney Society, P O Box 97026, Manukau City, Auckland 2241. You can also phone 09 278 1321 or 0800 235 711, or email kidneysociety@adks.co.nz

Name

Phoneemail

Address

.....
Please do the following: (tick box)

add my name to your mailing list (**free for Auckland/Northland/Waikato/Bay of Plenty/Lakes, Tairāwhiti/Gisborne and Hawke's Bay people who are pre-dialysis, on dialysis or supportive care, or have a kidney transplant**).

I have kidney disease

please change my contact details as per above

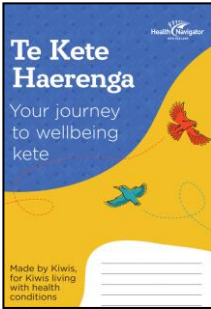
please take my name off your mailing list

I am **a supporter**, or **a person with kidney disease not living in one of the regions above**. I would like to receive the magazine, please sign me up as a **paying News subscriber**, \$20 enclosed.

OPTIONAL: please sign me up as a **Kidney Society Financial Member**, \$20 annual subscription enclosed, or pay to our bank:

123032 0705009 00, remember to add your name and 'subs'.

Use of your name, address, and any other information about you is exclusive to the Society and its staff for use in the provision of our services to you



Te Kete Haerenga - Your Journey to Wellbeing Kete



Te Kete Haerenga – an online self-management toolkit – will give power back to you in your journey to wellbeing and hauora. Designed for and with people living with long-term health conditions (LTCs), the kete can be used to describe what's important to you and your whānau, what you wish to achieve in your life and how others can best support you in that journey.



Te Kete Haerenga is a beautifully designed tool to assist with moving away from prescriptive models of health towards shared decision

making and patient/provider partnerships. It will support you to explore who you are as a person and how your LTC affects your quality of life. But, also, it will support you to have those conversations with care providers. By using Te Kete Haerenga, you can identify together what things you can manage now and what you can do over the longer term.

Te Kete Haerenga – Your Journey to Wellbeing is a self-management toolkit that can help you make changes to your health and wellbeing. This toolkit replaces the resource known as Take Charge.

Nearly everyone can improve some aspects of their health and wellbeing with the right knowledge, support, and skills, which this toolkit can help you learn. Come on a journey to hauora, **whatever that looks like for you!**

Te Kete Haerenga – my action plan

Information about how to make an action plan plus an action plan template.

Te Kete Haerenga – what to do when I'm unwell

An acute plan (emergency plan) for when you become unwell.

Te Kete Haerenga – thinking about change



To all our known supporters and those who want to remain anonymous

Some of you – individuals, businesses and community organisations - support the Kidney Society without even telling us. Every year we receive numerous gifts in kind and cash to help us deliver our services, manage our properties and keep our costs down.

A BIG THANK YOU TO ALL OUR SPONSORS AND SUPPORTERS!

They all support the Society with products and services when we need them, and Pressprint makes it possible for us to bring you

THE KIDNEY SOCIETY NEWS IN COLOUR .