

No. 239 February/March/April 2024

The Kidney Society

'Helping people with kidney disease get on with life.'



**Elle's transplant: a remarkable journey
filled with challenges**

The Kidney Society “Who, what, where.”

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Facebook: <https://www.facebook.com/kidneysocietyadks>

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 to do at home.</p>	
	<p>Brian is our Community Health Educator who can help you understand kidney disease and treatments.</p>		<p>Niu our Social Worker can talk to you about “kidney disease and you”, money problems, family, housing, and many other things.</p>	 <p>Nora writes the News. Send us a story!</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>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>Deadline for the May/June/July 2024 News: Wednesday 24 April 2024. Contributions are very welcome!</p>				
<p>Contact us for information or a chat, weekdays 9 - 5, Phone: 0800 235 711, Email: contact@kidneysociety.org.nz Facebook: https://www.facebook.com/kidneysocietyadks or just come to the Kidney Society Centre, 5 Swaffield Road, Papatoetoe, Auckland.</p>				



Kia ora, Malo e lelei, Talofa lava, Kia orana, Bula and greetings to all those in the Kidney Society extended family.

A very warm welcome to the first edition of the Kidney Society News for the year and, on behalf of the team, we extend our best wishes for 2024 to all our readers.

Kidney Society always welcomes feedback from its clients and members, and we want to make it as easy as possible for you to tell us what you think are the most important issues for you and your whanau. What services and programmes you think are useful and how we can help you to live your best lives. We are doing a client survey, and it takes less than 5 minutes for you to give us your opinion. There are plenty of ways for you to participate in the survey – in the post, online or in person – whatever works for you. Please see page 22 for details and thanks for your help.

Last time I introduced our new Social Worker, Niusulu Hellesoe who started with us at the end of the 2023. The response from both our clients and health sector partners has been really positive.

If you have questions for Niusulu, feel free to contact her at the office or by email at

niusulu@kidneysociety.org.nz

Finally, this year we will be featuring stories in our magazine about people who have donated a kidney for a transplant. These incredible folk have given an amazing gift, and they deserve our recognition and appreciation. By highlighting their stories, we hope to inspire others to consider whether this option is right for them – please see page 5 for a story about Elle Yary.

Nga mihi,

Regards

John Loof, Chief Executive Officer

john@kidneysociety.org.nz

Kidney Society Events

Tokoroa, Taupo, Murupara and Turangi home visits

Monday 19 February to Thursday 22 February

Please contact Brian if you'd like to organize a visit:
027 715 3949 or email brian@kidneysociety.org.nz

Hamilton home visits

Wednesday 6 March to Friday 8 March

Brian will be visiting in your area, if you would like to see him,
please call 027 715 3949 or email brian@kidneysociety.org.nz

Tauranga home visits

Tuesday 19 March to Thursday 21 March

Brian will be visiting in your area, if you would like to see him,
please call 027 715 3949 or email brian@kidneysociety.org.nz

Gisborne home visits

Tuesday 2 April to Friday 5 April

Brian will be visiting in your area, if you would like to see him,
please call 027 715 3949 or email brian@kidneysociety.org.nz

Hawke's Bay home visits

Monday 15 to Thursday 18 April

Brian will be visiting in your area, if you would like to see him,
please call 027 715 3949 or email brian@kidneysociety.org.nz

Elle's Story: A Journey of Resilience and Gratitude



In the photos: Elle and her mother, and her brother's friend who became her donor and is now like a brother to her.

Elle (Elham) Yary, a 44-year-old woman born in Iran and living in New Zealand, has endured a remarkable journey filled with challenges, resilience, and gratitude. Elle was diagnosed with Alport Syndrome, a genetic condition affecting the kidneys.

Alport Syndrome is a very rare disease so all of the complications that come with it aren't always predicted beforehand. Elle faced unexpected complications. At 21, she became pregnant with her son. Unfortunately, following her pregnancy, her kidney function deteriorated rapidly, dropping to just 36-37%. Before this decline, Elle appeared healthy and energetic, with no signs of kidney issues.

Elle encountered additional health challenges. At 25, her vision began to deteriorate, requiring cataract surgery. By the age of 37, Elle's health took a severe downturn. Her hearing deteriorated significantly, and she experienced other unexplained health issues, including menstrual irregularities. This led to Elle having to stop her full-time work as an accountant in 2020, due to having to make so many hospital visits.

Despite her persistent efforts to seek medical attention, the doctors weren't able to find out what was going on. It wasn't until a chance encounter with a nurse who was Elle's friend, who promptly introduced her a specialist in female health who conducted a test, that Elle discovered she was five months pregnant. Due to her health struggles, she wasn't able to have her baby which led to one of the most emotional, physically, and mentally difficult times in her life. It took Elle a year to heal after this because her kidney was failing so fast but the toll this had on Elle still affects her to this day and she often thinks about the baby who'd be at school by now.

Elle's health continued to decline, nearing the point where she required dialysis. She had to leave her full-time job as an accountant to focus on her health, relying on the support of her partner and son during this challenging time.

Seeking a kidney transplant, Elle faced numerous obstacles. She wanted to bring her brother who was more than happy to be a donor to New Zealand however it was the time of COVID-19 which made everything much harder.

Elle ended up having to go to Iran to get tests done and she did so as soon as they opened the gates after the lockdown period, in July 2022. After the tests, Elle found out that her genetic condition required finding a more distant match for a kidney donor than her family. Although her family was more than willing to donate their kidney, it was disappointing that they couldn't and had to find a more distant match. It was then that one of Elle's brother's friends came forward and offered to donate his kidney and provide a lifeline to Elle. Her donor is now like a brother to her.

The whole process continued to require Elle's very resilient nature as she found out that live donor transplants weren't allowed in her home city which meant having to travel to the capital, Tehran. This incurred even more costs and time - and having to navigate the busy city of approx. 9.5 to 12 million people each day.

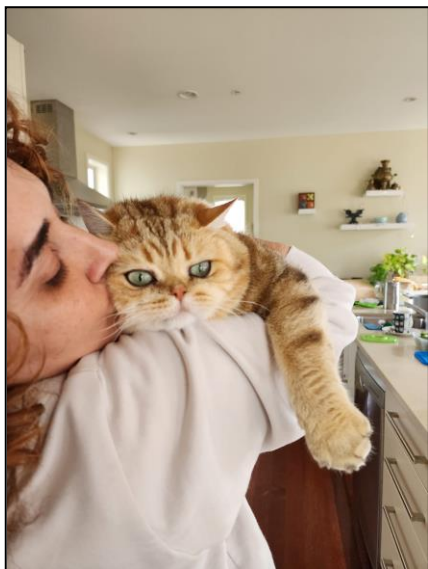
The transplant process was fraught with continued difficulties. After the first week of the kidney transplant surgery, the doctors noticed that Elle's kidney was fast failing. They had to do a biopsy and sonography, and then they realised nothing was wrong with the kidney but Elle's body was rejecting the new kidney. The medical staff put her under plasma treatment and increased the medication she was on and kept a very close eye on her.

After 29 days of recovery and treatment, her kidney function had improved, allowing her to return home to New Zealand.

Back in New Zealand, Elle faced further challenges. She experienced hair loss and changes in her appearance, her appetite increased causing a weight gain. She had to navigate the complexities of post-

transplant life. Despite the hardships, she remained determined to embrace her new reality and was pleased that her kidney function was going stable and doing well.

There've been many setbacks, including hearing loss and ongoing medical appointments but Elle has been determined to make her kidney work, especially for her son who was 21 at the time of the surgery. Her son was at university this time, away from their family, which of course made it even harder. It goes without saying that Elle's partner and son had a very difficult time while she was away in Iran.



in the photo: Elle with her cat, Leo, who she is very grateful to have had by her side during her journey. Elle says a big thank you to Leo.

Again, another testament to Elle's resilience, even though she stopped working her work as an accountant in 2020, she launched her artisan soap-making business, Elleyssoap <https://elleyssoap.com/> that same year. This proved to be very successful, Elle has received sales from around the world. She worked hard to do the research and source the best ingredients for the soap and in the last few months, Elle has restarted working as an accountant from home.

Elle remains grateful for her donor's generosity and is determined to make her kidney last the rest of her life.

"How wonderful you have to be to do this for someone. What an amazing act of kindness to give a piece of your body to someone - I cannot thank him enough."

Elle stays in touch with her donor with regular phone calls and was very pleased to hear that he and his partner recently had a healthy baby boy. She is very grateful that her donor recovery was only a few days in the hospital and then he has led a very healthy and active life post-transplant. She continues to tell him to look after himself and stay healthy.

Through the support of organisations like the Kidney Society, Elle found resources and guidance to navigate her post-transplant journey.

"I'm so thankful for the Kidney Society, it's a great thing. It's a great way to get more information especially when it comes to your exercise. Someone like Tracey coming to help me to give me exercise based on my needs is so helpful because not many personal trainers out there have this knowledge. They don't know about transplants or kidney disease."

She is determined to cherish her newfound health and live life to the fullest with her loved ones who she's eternally grateful for.

"I'm so, so blessed to have a family who were there right beside me through the whole thing and whatever I needed."

Scientists are exploring Alport Syndrome and researching more to see how they can help people with it and Elle is hoping that they can find some solutions.

Her love and taste for food is back. During the period of Elle's health declining, she lost her passion for food and things didn't taste like before so it's bringing her a lot of joy to be able to enjoy cooking and having meals with her family and friends.

Elle's journey is a testament to the resilience of the human spirit, demonstrating the transformative power of love, perseverance, and gratitude in overcoming life's greatest challenges.

"Even though my journey has been a very big rollercoaster and has come with so many challenges, I'm so grateful to have had the transplant and I think people thinking about it should do it because it can change your life for the better."

Elle has endless amounts of gratitude for her loved ones around her.

"A big thank you to all my family members from both Iran and New Zealand: my mother, brothers in Iran, my partner, son and my sister in New Zealand. You're all the reason I could do this."

Writing to your Donor's Family

<https://donor.co.nz/knowledge-centre/>



The decision to write is a *personal one*. It can be difficult to find adequate words to convey your gratitude.

Many organ and tissue recipients would like to communicate their thanks to the donor family and share a bit about themselves following transplantation.

It can be difficult to find adequate words to convey your gratitude, but it is important to remember that this correspondence will be hugely appreciated by most donor families.

Often it can be daunting to write a letter to the donor family – a card might be a better option for you.

You are encouraged to wait at least three months after the transplant before writing. This gives you time to recover and feel well.

Please remember that your transplant team and Organ Donation NZ (ODNZ) will not facilitate meetings between transplant recipients and donor family members. Confidentiality is maintained to protect the privacy of everyone involved.

A few tips for writing to the donor family

- You may wish to say thank you to the donor family and recognise the death of their family member. Talk about yourself and your family.
- It might be helpful for the donor family to hear how the transplant has changed your life. Mention any hobbies or plans you have for the future.
- Use language that is respectful and sensitive. Remember that the family are coming to terms with the death of a loved one.

- Don't include identifying information such as your name, where you live, where you work and phone numbers. All correspondence is reviewed, and nothing will be sent that contains this information.
- Simply sign the card with *from a grateful recipient* or something similar.

PLEASE NOTE:

This is only intended as a guide. If you would like further assistance, contact your Transplant Co-ordinator.

When you have finished writing

- 1. Place the letter or card in an unsealed envelope.**
- 2. On a separate piece of paper write your full name and the date of your transplant.**
- 3. Send both to your Transplant Co-ordinator.**

Your communication will be forwarded to the donor family via your transplant team and ODNZ.

The donor family may indicate they are not ready to receive your correspondence. If this is the case your letter will be held by ODNZ and forwarded when the family is ready. Your transplant team will let you know if your correspondence has not been passed on to the family.

It is also important to remember that while some donor families may choose to respond to your correspondence, some may not. Please do not take this personally. Some donor families may respond years later.

If you have any questions or concerns, please contact your Transplant Co-ordinator.

Sharing your Story

Sometimes recipients like to share their personal transplant experience. If you are speaking to the media or sharing your story with the general public, please remember not to use exact dates. The same applies if you have a presence on the internet for example a Facebook profile, blog, or other social networking sites.

There are many opportunities to share your story. If you are interested in doing so, please contact ODNZ'S Communications Advisor on (09) 360 0935 or email donornz@adhb.govt.nz.

ODNZ'S most important message is for people to talk to their families about their wishes.



A Big Welcome to Niu into the Kidney Society Team

As you may have seen in the last edition and in John's intro, we have a new team member who we're so excited to have in the team as a Social Worker. We chatted to Niu and asked her about her background, why she decided to join the Kidney Society, what her days will look like and what she's most excited about.

"I have been a social worker for 27 years. I started my social work journey in Renal Health at Auckland Hospital in the late nineties where I was a Renal Social and later took up the role as Pre-Dialysis Patient Educator."

Niu began her journey at Auckland Hospital in 2001 before going overseas. She returned in 2006 to join the Adult Social Work Team, focusing on renal care.

Transitioning to a role as Clinical Supervisor for the Renal/Oncology & Haematology team in 2008, she later ventured into the NGO sector, serving as Practice Leader for various organisations for a total of 13 years.

In 2020, amidst the COVID-19 pandemic, Niu decided to return to frontline work, joining the Mental Health and Addictions team in Managed Isolation Quarantine (MIQ). Transitioning to the



Pasifika Regional Coordination Hub in 2022 following the disestablishment of MIQ, she continued her dedication to supporting communities.

After her contract ended in September 2023, Niu took a reflective break, during which she came across the opportunity at the Kidney Society. Motivated by her passion for renal care and impressed by the organisation's expertise and professionalism, she joined as a social worker and health educator.

Niu's decision was driven by several factors, including her desire to return to the renal arena, engage directly with clients and their families, collaborate with diverse healthcare teams across regions, and contribute to the Kidney Society's impactful work. She was drawn to the organisation's responsive leadership and saw it as an exciting new challenge to be part of such a dedicated team.

"My days are always busy with a mix of phone calls, home visits, unit visits, WINZ advocacy, client registration and initial assessments, but you should always feel free to contact me by phone at the office on 09 278 1321, or FREEPHONE: 0800 235 711 or by email at

niusulu@Kidneysociety.org.nz



What is Kidney Bites?

Kidney Bites is an online patient and caregiver community creating an opportunity to meet and connect with others with a lived experience of kidney disease. It's a safe and inclusive place to ask questions, share stories, exchange ideas, learn and opportunities to be involved in research. Each month we focus on a specific topic of interest to the Kidney Bites community and are also joined by a researcher.

Who should join kidney bites?

Our team warmly encourages anyone living with kidney disease and their family members to join the Kidney Bites community, especially if you have an interest in research or being involved in research.

Meet new people and learn new skills

To learn more about engagement opportunities

To learn more about the BEAT-CKD/CRE-PACT

Share your experience with research and encourage others

Build confidence by engaging with researchers and healthcare professionals

To learn more about kidney disease and current research

Why should I join?

"I love how we know what the next topic will be about and that you have someone at the meetings to speak. You guys are doing a really great job!" - Kidney Bites attendee.

When and where can I join?

Meetings are held in the last week of each month. We encourage you to get comfy, get a drink, or a bite to eat, and join us from the comfort of your own home.



Kidney Bites will occur via Zoom and will run for one hour. Please register to receive reminder emails and invites each month.

To register and for more details please visit beatckd.org or scan the QR code. You can also email our Patient Engagement Officer, Amanda Sluiter for more information or support: amanda.sluiter@sydney.edu.au

Receiving a kidney from a deceased donor

Deciding who gets a kidney is based on two things — time on dialysis, and best match.

The deceased donor list:

Even though it is called a waiting list, a kidney is not always given to the person who has been waiting the longest. The list is like a pool of people who might be offered a kidney from a deceased donor.

Kidneys from non-directed donors are also allocated through the deceased donor list — often through the kidney exchange.

Non-directed donors are people who are alive and decide to donate one of their kidneys to someone they do not know.

How to get on the list:

Once you get to the stage when your kidneys are only just working, the team looking after you will talk to you about dialysis and transplant.

Many people who have end stage kidney disease can go on the list for a kidney transplant from a deceased donor.

However, not everyone is suitable for a kidney transplant from a deceased donor. Some people may be told that they can have a kidney transplant from a live donor but not from a deceased donor because of:

- previous transplants.
- other health conditions.
- the person's overall health.
- how their kidney disease has affected the rest of their body.
- other surgery the person may need at the time of transplant.
- lower than 80% chance of living more than 5 years after a deceased donor transplant.

How your chance of living more than 5 years is worked out:

Usually there are more than 400 people on the active waiting list. In Aotearoa New Zealand about 100 kidneys are donated each year from deceased donors. This means only people with a good chance of doing well after a transplant are able to go on the list.

Your kidney doctor and the team at your transplant centre will discuss:

- your health.
- your test results.

- how your kidney disease has affected your heart and the rest of your body.

This checks you are fit enough to have a transplant at any time. This is called your Co-morbidity Score.

Looking at all these things helps doctors to make the same decisions across Aotearoa. This means deciding who gets a kidney from a deceased donor is as fair as possible.

If you are assessed as having a lower than 80% chance and your doctor does not think that is correct, they can ask for the decision to be reviewed.

Everyone on the waiting list is reviewed every 1 to 2 years to make sure they are still well enough to stay on the list.

Your chance of getting a kidney:

- You may be lucky and get a kidney quickly. However, most people will wait for several years. Sometimes this is because of your blood group or antibodies. Some people on the waiting list may never be offered a kidney from a deceased donor.
- Deciding who gets a kidney.
- When a family offers a kidney for transplant, the New Zealand Blood Service uses the information from your monthly blood tests as well as how long people have been waiting to decide who gets offered the kidney.
- Kidneys are offered to people based on 2 things. First who has been waiting the longest time on dialysis and secondly the best match.
- There is no way of guessing the blood group of the next donor and what antibodies a person needing a transplant might have against that kidney.

Other transplant options:

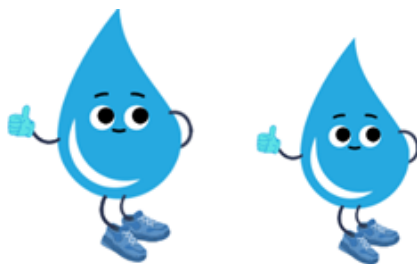
- If your health is not good enough to be on the deceased donor list, you could still be well enough for a transplant from a live donor.
- These sorts of transplants are more likely to happen, happen more quickly and you do not always need to have the same blood group.
- Talk to your family and friends about them donating a kidney to you.
- Live organ donation.

It's feeling hot, hot, hot!

By Maia Lingman and
Dayna Stockley
Kidney dietitians, Te Whatu
Ora Waitematā.

Help! I have been advised to reduce my fluid intake.

How do I manage in the hot weather?



Managing fluid allowances during hot weather can be difficult! If you have been advised to restrict your fluid here are our top tips on keeping to your daily fluid allowance in the hot weather.

Why is it important to keep to my fluid allowance?

One of the functions of healthy kidneys is to remove excess fluid from the body as urine. When your kidneys are not working properly (for some people with chronic kidney disease or for those who are on dialysis), not enough urine is made and fluid can build up in your body. This is often referred to as fluid overload, fluid retention or fluid weight gain.

Not everyone with chronic kidney disease will have to restrict fluid intake, if you have fluid overload your doctor will advise you to keep to a fluid allowance.



What are the symptoms of fluid overload?

You may notice:

- Swelling in the hands, lower legs and feet.
- Difficulty breathing and shortness of breath.
- Changes in blood pressure.
- Over time the excess fluid can weaken your heart.

Awareness is key – It all adds up!

Track how much fluid you drink over a day.
Make sure to count anything that is liquid at room temperature!

These all count as fluids! How many of these are you having?



Top Tips to help keep to your fluid allowance

- **Track your fluid intake using our fluid tracker below!**
- Try to stay cool in warm weather. Make use of fans, stay in the shade, place a flannel or ice-pack on your body.
- Reduce the sodium (salt) used in meals, including seasoning mixes. Salt makes you thirsty and acts like a sponge to hold fluid in the body.

See recipes below for ways to flavour meals without salt.

- Try not to have a drink with meals.
- Take medication with food instead of water or other beverages.
- Avoid or limit spicy foods.
- Spread fluid intake throughout the day.
- Snack on frozen grapes or cold fruits/vegetables to help quench thirst.
- Make ice cubes out of your favourite drink.
- Use smaller cups or measuring cups when drinking.
- Use mouthwash, sugar-free mints, gum, sour candy or lemon/lime wedges to quench your thirst.
- Freeze your drink bottle, this melts slowly and helps you drink slowly.

****If you are prescribed a supplement drink (such as Nepro, Renilon or Ensure) – prioritise this within your fluid allowance for the day.****

Fluid tracker

Being more aware of your drinking habits can help you to manage your fluid intake.

- Identify which situations lead to you drinking more, such as having a cup of tea when visiting a friend or when family get together.
- Know when you are actually thirsty and when you are not.

My daily fluid allowance: _____ml

Time	Type of Fluid	Amount
Example: 8am	Coffee	200ml
10am	Water	180ml

Total fluid intake over the day: _____ ml

How to flavour meals without salt



BBQ Rub

2 Tablespoons ground coriander
2 tablespoons paprika
2 teaspoons ground black pepper
1 teaspoon ground cumin
1 teaspoon dry mustard
Chilli powder to taste

Ideas:

Rub on potatoes, any meat, seafood or sprinkle on noodles or vegetables before cooking, use to flavour soup.

All-purpose Seasoning Blend

2 tablespoons garlic powder
2 tablespoons onion powder
1 tablespoon paprika
1 tablespoon parsley
1 ½ teaspoons black pepper
Chilli powder to taste

Ideas:

Use to season any food before cooking.

Savoury Seasoning

2 tablespoons crushed marjoram
2 tablespoons crushed sage
2 tablespoons crushed thyme
1 tablespoon crushed basil
¼ teaspoon celery seeds

Ideas: Use on vegetables, rice, pasta, salads or rub into tofu, meat or poultry before roasting or grilling.

Mexican Spices

2 teaspoons ground cumin
1 teaspoon paprika
1 teaspoon oregano
1 teaspoon corn flour
Chilli powder to taste

Ideas: Use to season meat for tacos, fajitas, or burritos.

By Maia Lingman and Dayna Stockley, Kidney dietitians, Te Whatu Ora Waitemata (on behalf of Auckland Regional Renal Dietitians (ARRD), January 2024



Community Dialysis Houses: A Chat With William and Tainui

We want to show people what difference our community dialysis houses make to our clients so we decided to have a chat with our clients William and Tainui so you can hear from those who use the houses themselves.



If you're thinking about dialysis at one of our community houses then hearing more about why our clients decided to start using them and continue to, may be helpful.

Our Community Dialysis House is an alternative option to dialysing at the hospital. It can be a home away from home, where you can meet others on the dialysis journey. We have 3 dialysis houses in South Auckland, all conveniently located near Middlemore Hospital.

In this video you hear about why William and Tainui use the community dialysis houses, how long they have been there, and the process of starting out.

We wanted people currently under the care of **Te Whatu Ora Counties Manukau** to know there's no complicated process or wait-list to start community dialysis at one of these houses. The Home Training team make sure that new clients are fully capable and comfortable to start their own treatment at a dialysis house.

To see our video, please scan the QR code or go to

<https://www.youtube.com/@kidneysocietyadks>

In-Vitro Compatibility of Human Blood to Pig Cells Research Progress

Report from **Fredric Dross**, recipient of last year's 'Van der Schrieck Scholarship' from the Xenotransplant conference, Oct 26-29, 2023 at San Diego.



"I take this opportunity to thank the Auckland Kidney Society for providing funding support towards travel to attend this conference.

This was a joint conference by three associations: International Pancreas & Islet Transplant Association, International Xenotransplantation Association, Cell Transplant and Regenerative Medicine.

As I mentioned in my application, I am currently Principal investigator of the research project; this will lead to Xenotransplant of kidneys in future.

This conference has given me insight on current development in this area as listed below. Challenges in Xenotransplant and developments are:

Molecular characterisation of donor pig of the first human xeno-heart transplant, donor genetic modification for xenotransplant, update on number of clinical trials internationally in xenotransplant, immunosuppression in xenotransplant controlling inflammation and coagulation, organ and tissue preservation and cryopreservation and reconditioning.

There was a session from regulatory in USA for xenotransplant by FDA team members.

The conference attendance was very beneficial to network and advance my knowledge on xenotransplant and network with specialists from similar research area in international community.

We need your thoughts to help enhance our services:

2024 client survey

At the Kidney Society, we are committed to providing you with the best support possible. To make sure we're doing all that we can to support you, we need your insights. Your feedback will guide us in understanding what's working well, where improvements are needed, and how we can enhance our range of services and resources.

Online survey

You can do the quick 5-minute survey online by scanning the QR code below or go to this link. <https://forms.gle/dG66rkf29t6DsgXg9>
We will also be sending you an email in the next few weeks with a direct link to the survey.



Request a physical copy

If you'd prefer to complete the survey in a physical copy, please email us at: contact@kidneysociety.org.nz with your address and we will send you a copy.

Community Dialysis Houses

We will be leaving physical copies of the survey at our 3 dialysis houses and would be grateful if you could please complete these and give them to Jenny.

Focus Group

For those interested, we'd like to host you at the Kidney Society office with some morning tea and have conversations about your thoughts and experiences. If you are interested, please let us know by emailing contact@kidneysociety.org.nz. Dates are not yet confirmed but it will be held in the office in April, and if we can organise transport if needed.

As a thank you for sharing your insights and helping us to enhance our services, you'll go into a draw for a Countdown voucher and a Kidney Recipes cookbook.

Exciting news on the horizon!



Photo credit: Spin Poi | spinpoi.org.nz

We're in the process of creating a **SpinPoi wellness video** just for you, and we can't wait to share it with you.

(For those not yet familiar with SpinPoi, check it out here: <https://spinpoi.com>)

We're currently designing a SpinPoi wellness video tailored specifically for our clients with Kidney Disease. As many of you probably already know, Poi is a traditional performing art deeply rooted in the culture of the Māori and Pasifika people. For those of you who may not have heard of it, a poi is a weighted ball attached to a flexible cord that is used to spin and swirl around your body.

Kate and the SpinPoi team have scientifically proven that these movements are a great way to boost both your mind and body's happiness. Poi involves the ideal blend of physical movement and mental engagement, keeping your brain and body in sync.

We will be launching the video to you (featuring some of our very own Kidney Society clients) in mid-March for **World Kidney Day** and we can't wait for you to see it and embed it into your weekly wellness practices.

Your feet are AMAZING!
But we do not really think about just how AMAZING they are until we have a foot problem.

In each foot you have 26 bones, 33 joints and 100 muscles, tendons and ligaments! That's a lot of moving parts to keep in good working order.



Unfortunately our feet are the furthest away from our heart. With all of those bones, joints etc a good circulatory systems is vital for them to stay healthy. This is often an issue for renal clients and if you also have diabetes or heart conditions this can add to the reduced blood flow and circulation to this area.

Most of the people I visit have concerns around foot health. Numbness, pins and needles, burning or electric feelings, weakness etc.

If you do have a loss of sensation in your feet then it is very important that you do daily foot checks as you can often get an injury, cut, blister etc and not even know it. If you have restricted vision then this can also make you miss little injuries or sores that can result in major health issues. If your eye site is not so good then make sure that you get family, doctors or nurses to regularly check your feet for you.

Do not let a small issue with your feet end up being a MAJOR health issue.

Below are the TOP 10 Foot Fitness Tips...

- Take a few minutes every day to check your feet. It only takes a few minutes and you can do it sitting down. If you cannot get to your feet or you need someone else to do this for you ask your GP, nurse or a family member to help.
- Walking is the best exercise for feet. But if your feet are a problem then walking is usually not as easy as it should be.

- There are a lot of seated foot exercises you can do daily to ensure improved circulation and even strength in your feet!
- Wear clean and hole free socks.
- Wear foot wear outside at all times.
- DO NOT WEAR JANDALS to do any type of distance walking or activities other than around your home. Jandals cause a lot of foot problems.
- Invest in at least one good pair of supportive shoes and do not share other peoples shoes.

Shoe Clinic in Manukau and Sylvia Park have a range of shoes for people with diabetes and osteoarthritis.

- If you have problems with your feet get your nails cut by your podiatrist or ask your diabetes nurse for assistance with this as many have foot clinics in your area that are suitable.
- If using a local pool or shared showers wear jandals or aqua shoes to prevent picking up any nasty bacterias that are left behind by others.
- If in doubt have it checked out. A small cut, blister or bumped toe can turn into something much BIGGER very quickly.

If you would like a foot exercise program for improved circulation or strength our Wellness Educator Tracey can assist you to get your feet back in step!

SHOE CLINIC have a range of shoes for people with diabetes and osteoarthritis. If you would like more information contact Tracey about a referral.

Tracey Drinkwater

Wellness Educator Kidney Society

0800 235 711, 027 378 4544 or



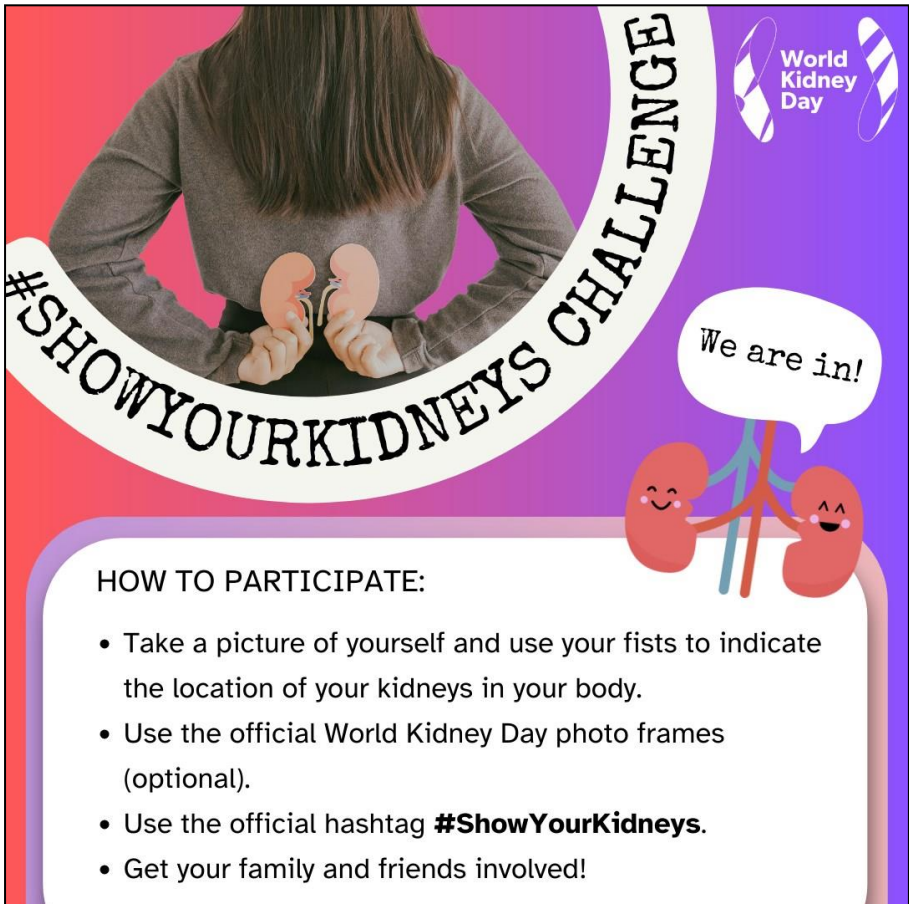
World Kidney Day (14 March 2024) is an annual day aimed at raising awareness of the importance of our kidneys. This year's theme has the goal is to raise awareness about the importance of ensuring equitable access to appropriate treatment and care for people living with kidney disease, in order to improve their

quality of life and delay the progression of the disease.

To help raise awareness about Kidney Disease in New Zealand, we're launching our new Spin Poi video so we're very excited for you to both see it and share it with as many people as you can to help extend the reach.

If you'd like to learn more about World Kidney Day and find resources to share, you can do so here:

<https://www.worldkidneyday.org>



#SHOWYOURKIDNEYS CHALLENGE

World Kidney Day

We are in!

HOW TO PARTICIPATE:

- Take a picture of yourself and use your fists to indicate the location of your kidneys in your body.
- Use the official World Kidney Day photo frames (optional).
- Use the official hashtag **#ShowYourKidneys**.
- Get your family and friends involved!

**"A society grows great when old men plant trees
whose shade they know they shall never sit in."**

-Greek Proverb



As the old saying goes 'Society grows great when people plant trees in whose shade they shall never sit'.

For many of us, the start of a new year is a time to think about the future and, for some, the question might extend to what kind of legacy we wish to leave to those who come after us? From time to time we get asked about the difference a bequest to the Kidney Society might make. The short answer is that it makes a huge difference. And not just in financial terms, it's the benefit of knowing that there are people out there who are generous enough to want to support kidney patients for many years to come.

Since our doors opened more than 40 years ago, the Kidney Society has responded to the complex needs of people with kidney disease with a mixture of care and compassion. A bequest gift from you will help us continue providing support to those in the greatest need in the years to come. You'll help ensure we can offer access to high quality information and essential support for the growing numbers of people who receive a diagnosis of chronic kidney disease.

Our vision is that one day, no New Zealanders will suffer because of kidney disease.

Until then, we're here to help, and to bring the kidney community together.

By leaving a bequest to the Society, your legacy will live on in this vision.

The decision:

The decision to leave a bequest to the Society is significant. It is very important that you speak to your loved ones and seek appropriate, objective advice. We encourage you to look after your family and friends first when finalising your Will and we are grateful for any gift you wish to leave after that. Once you have decided to proceed with completing a Will, you should see a solicitor to manage the paperwork on your behalf.

Types of gift:

The three main types of gifts you can bequest to the Kidney Society are:

- **Percentage gift:** This is a percentage of your estate and will ensure inflation doesn't erode the value of your gift over time.
- **Residual gift:** This is the remainder of your estate, or a percentage of, after loved ones are looked after and expenses deducted.
- **Pecuniary gift:** This is a specific monetary amount such as \$10,000.

Which type of bequest you choose to go with will very much depend on your personal circumstances and what suits you best.

Wording your gift:

The wording of your Will is also very important. A solicitor can help you with this, but an example of the wording required is:

*"I give and bequeath to **Auckland District Kidney Society CC24545**, the sum of \$XXX (or) XXX% of my estate (or) the residue of my estate free of all charges to be used where most needed. The official receipt of The Auckland District Kidney Society will be sufficient acknowledgement of having received this gift."*

Sandra's story

Sandra has bequeathed 5% of her estate to the Kidney Society in her Will. Sandra's husband Dave had a transplant over 20 years ago and

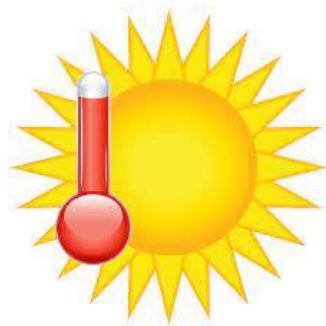
Sandra has always been grateful for the support they received from the Society right up until the time when Dave passed away.

Speaking about her legacy, Sandra says "I spoke to my family and we all felt that a gift to the Society was an appropriate thing to do so that others can get the help they need. It is deeply humbling that you are considering a gift to the Kidney Society in your Will. Your support truly makes a difference to patients in the greatest need."

Further information:

If you have any thoughts or questions on a bequest to the Kidney Society or perhaps, you'd just like to let us know you are thinking of including us in your legacy, please contact John Loof, CEO.

Email john@kidneysociety.org.nz or phone 021 663 435



Fluid Balance - When You Are Too Wet or Too Dry

The world could see another record-breaking warm year in 2024 as global temperatures are on a path to continue rising due to increase in emissions and the impact of the El Nino weather phenomenon that peaks in winter and pushes up global mean temperatures to their peak, according to leading scientists. With an extra hot summer already well underway in New Zealand, people on dialysis as well as those with transplants will need to take extra care with their fluid balance.

Here is a nice explanation of how 'fluid balance' works, from Canada's St Joseph's website:

<https://www.stjoes.ca/patients-visitors/patient-education/patient-education:-f-j/hemodialysis-fluid-balance.pdf>

In order to get the best results from Haemodialysis, it is very important to **keep the amount of fluid in your body balanced**. When fluid is balanced, you are at your ideal body weight.

Your doctor determines your ideal body weight based on:

- your blood pressure.
- how well you feel.
- clear lungs, no shortness of breath or trouble breathing.
- no swelling.
- Too wet.

What does being too wet mean?

This means you have too much fluid in your body so you are above your ideal body weight. This is called fluid overload. It is important to remember that fluid comes from what you drink and eat. Anything that is a liquid at room temperature is a fluid. Some examples are soup, yogurt and ice cream.

How would I know if I was overloaded or have too much water in my body?

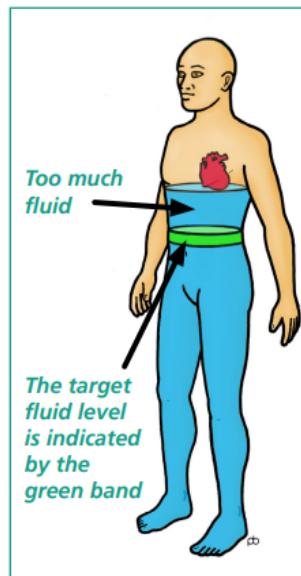
Having too much fluid in your body is described as overhydration or fluid overload.

The excess fluid causes:

- extra work for your heart
- high blood pressure
- increased risk of heart problems
- shortness of breath, especially when you lie down
- swelling of the feet, hands and/or face.

It is normal to have some build-up of fluid in the body before dialysis if you are passing little or no urine. It becomes a problem if you are still overloaded with fluid after dialysis.

Having regular dialysis makes it easier to remove this excess fluid. Reducing your salt intake and daily fluid intakes also helps.



Why is being too wet a problem?

When you have fluid overload you have an increased risk of high blood pressure and cardiovascular disease such as heart failure, heart attack and stroke. Your lungs may also be affected and cause breathing problems.

What can cause you to be too wet?

This can happen for many reasons such as:

- drinking and/or eating too much fluid.
- having too much salt in your diet.
- missing dialysis treatments.
- not able to remove target fluid during dialysis the therefore you are above ideal weight after treatment.
- taking your water pills such as Lasix or Furosemide incorrectly.
- loss of appetite for several days.
- decrease in the amount of urine you pass Fluid Balance.

How may you feel when you are too wet? You may have some or all of these symptoms:

- feel full or bloated; feet, ankles, legs, hands and/or face look or feel swollen.
- blood pressure is high.
- weight is ____ kilograms above your ideal body weight.
- short of breath and/or not able to lie flat and breathe well.
- constant cough or feel congestion in your lungs.

What do you do when you are too wet?

- If you feel any of the above symptoms of being too wet, contact your home haemodialysis nurse Call the Home Haemodialysis Unit if:
- fluid continues to build up in your feet, ankles, hands and/or face you continue to gain weight.
- the bottom number on your blood pressure is above 100 you have shortness of breath.
- you have a decrease in the amount of urine you pass.
- Contact your dialysis unit or follow their procedure and contact them for personal advice.

The Kidney Society is a well-respected charity that relies on public donations, bequests, sponsorships, and other forms of financial support from the community in order to be able to meet the needs of those with a serious kidney condition.

Heartfelt 
THANKS
TO OUR SUPPORTERS!



The Society's services are provided free of charge because we firmly believe that everyone with a kidney condition should have access to good quality support and information.

We offer our sincere thanks to the following Trusts and Foundations who have recently provided grants to help fund our client services:

- North and South Trust Ltd \$7,000
- Trust Waikato \$8,000
- St Joans Trust \$7,000
- The Frimley Foundation \$5,000
- Trillian Trust Ltd \$2,186
- D V Bryant Trust \$2,000
- Oxford Sports Trust \$1,000
- Ernest Hyam Davis and Ted and Mollie Carr Legacies \$10,000

We acknowledge, and are grateful for, the generous support received from all of the organisations listed above.

The Kidney Society welcomes public donations, and these are tax deductible. Donations can be made via the Society's website or directly into our secure bank account. Details below:

- Website address is: www.kidneysociety.org.nz
- Bank account number: 12-3032-0705009-00

Please include your details so we can send you a receipt for tax purposes.

If you would like to talk to us about a donation, sponsorship, or fundraising event, please contact John Loof on mobile: 021 663 435 or email: john@kidneysociety.org.nz

* A \$20 donation supports a client to receive this magazine for a whole year!

* A \$96 donation funds the purchase of 20 Wellness packs for clients.

* A \$240 donation funds a series of home visits to clients.
