

Kidney Kids NZ

Spring NEWSLETTER 2023



Kidney News

Kia ora to our kidney kids whanau and supporters. Spring is finally in the air.

AGM

Our AGM was held on 22nd July. We would like to sincerely thank Erica Fairbank, Heidi Watson & Clint Alcock who have stepped down from their position as board members 2023 for their support and contribution to Kidney Kids NZ. We appreciate your time and energy. We welcome our new board Jean Koh a Nephrologist from Starship hospital and Sarah Manson a parent from Christchurch.

Update from Family Support

Welcome to our new families who have joined our Kidney Kids whanau in the past few months. There have been 9 new families in recent weeks. We look forward to getting to know you better and supporting you through your journey. You should have received welcome packs from us. *Remember the Support Team are here to support you* support@kidneykids.org.nz or call 0800 215 437 Rachel, Rachel, Ben & Carmel.

Photo above taken of kidney kid Nikau with his welcome pack goodies. Thanks to Nikaus Mum for sending us this great picture. We love receiving photos of our kidney kids and hearing news of what our families are up to.



Clinic Updates & Thank you Dr Wong!

Clinic Updates

Kidney Kids are working closely with Starship to make sure we can all support our kidney kids and their whanau as best we can. The team have had a couple of very beneficial meetings with Starship this past quarter.

If you have a clinic appointment and you need some support, please let Rachel Barrett know, email rachel@kidneykids.org.nz

Regional clinics are booked through to the end of the year. Thank you to the reception and nursing staff who make us so welcome at the paediatric clinics, where we catch up with our Kidney Kid families and welcome new families too.

Upcoming Clinics

9th October Taranaki

10th October Hutt

11th October Palmerston North

17th October Tauranga

8th & 9th November Wellington

10th November Napier

24th November Gisborne

24th November Hamilton

30th November 1st December Christchurch

7th December Invercargill

8th December Dunedin

A Thank You to Dr William Wong

Dr William Wong, after many many years of providing first class medical service to children all over New Zealand is hanging up his stethoscope and retiring from his passionate position at Starship Hospital. Dr Wong an enormous thanks from us all at Kidney Kids NZ. You have been a huge part of the renal journey for so many throughout NZ and therefore leaving very large shoes to fill. We will not forget you, our kindest and best wishes always. Thank you from Kidney Kids NZ.

CAMP KeeWee & CAMP YAK 2024

Camp will be held 12-14th April next year. More details to follow.

ANZSN Conference

ANZSN Annual Scientific Meeting Consumer Day

Keith, Carmel, Sarah Manson (Board Member), and (Rachel Barrett online), attended this years Consumer Day held in Christchurch.

The consumer workshop began with each attendee giving a brief introduction on where they were from and the reason they were there. The attendees from all around the country ranged from people currently on dialysis, those with a kidney transplant, support people and caregivers, kidney donors and allied health workers including two health professionals.

The common theme during this session was the need for better collaboration/communication between the various kidney organisations including patient support groups, NGO's and the medical teams.

The speakers included Te Tahu Hauora – The Health Quality and Safety Commission who talked about the importance of including consumers and whanau in the decision-making process for health care and how that process might be improved. Consumer involvement in research and patient partnership was highlighted and the importance of this to assist in setting priorities for future activities, and to be consumer led.

Other speakers included a dietician who gave a very good overview of the nutrition requirements for someone in the different stages of kidney disease. The dermatologist presented on being sun smart and the skin cancer risk for patients who are immunosuppressed and reminded the audience of New Zealand's increased risk of skin cancers due to state of the ozone layer.

The takeaway message from this was to Slip Slop Slap whenever going outside in the daytime.

Kidney Kid Friendships

One of our kidney kid Mums Melissa put up this gorgeous Facebook post which we thought would be lovely to share. A beautiful friendship formed at Camp KeeWee held in March this year of two little girls (kidney kids), who met and bonded, both living in different cities.

“Earlier this year my daughter Imogene was extremely lucky to attend Kidney Kids Camp (where she had a ball of a time!). Yesterday I had to attend a conference in Wellington for work, so we took the opportunity for Imogene to catch up with Hannah. The girls had a fabulous time together!!

Thanks [Kidney Kids NZ](#) for providing the opportunity to develop new friendships”



Limb-it-less Shaz Dagg

Kia Ora, I'm Shaz Dagg, a New Zealand para-athlete. A few years ago, I lost my arm in a farming accident but have not let that stop me from living my life to the fullest.

In 2024 I will be conquering New Zealand's Coast to Coast as a solo, female amputee. This is no small feat given the race involves 243km of kayaking, biking and running. I am so lucky to have such a supportive team helping me to develop special equipment so that I can complete this race solo.

Not only will I be completing this notoriously difficult race, I am also using this as an opportunity to raise funds for a charity very close to my heart – Kidney Kids NZ. I recently discovered I only have one kidney, so this charity is very important to me. Kidney Kids provides vital support to children in Aotearoa living with kidney disease. You can read more about Kidney Kids here <https://kidneykids.org.nz/>

So please get behind me and help support the amazing work of Kidney Kids. Every little bit helps, and all donations will be gratefully accepted. With my training already well underway, your support will help keep the morale up as we knuckle down with the rigorous training.

Don't forget to follow my journey via my Facebook and Instagram pages, as I will be posting regular updates as I prepare for the big event!

Instagram: @paratriathlete_shazdagg Facebook: @limb-it-less Shaz Dagg

To support and donate to Shaz's cause and to Kidney Kids, please [click here](#) on her Givealittle page.

Womans Day recently posted a fantastic article on Shaz Limb-it-less Shaz "I chose to cut the bugger off!" to read this article please [click here](#)

18th November - First solo attempt as an amputee to kayak length of Lake Taupo

Shaz is also doing the first solo attempt as an amputee to kayak the length of Lake Taupo on November 18th. She will be starting at 5:30am from Tokaanu Boat ramp and kayaking to Taupo Yacht Club. Approximately 42 kilometres. Kidney Kid families in the region this is an amazing effort, please come and cheer Shaz on. We will be sending an email out regarding this.

Kidney Kids think Shaz is ABSOLUTELY AMAZING and would like to say a huge THANK YOU Shaz for what you are doing for us!. Everyone please get behind Shaz and support her. More to follow in coming months.



Prune Belly Syndrome

Prune Belly Syndrome (also known as Eagle-Barret syndrome or triad syndrome) is a rare congenital condition that affects the development of abdominal muscles, the urinary tract (subsequently affecting kidneys) and in males, undescended testicles. The name “Prune Belly” comes from the lack of abdominal muscles and so the tummy skin looks wrinkly like a prune. 50% of people born with Prune Belly Syndrome won’t live past 2 years old and 74% of survivors will need a kidney transplant at some stage in their lives. Many babies are born already in kidney failure. Commonly, UTI’s and kidney reflux cause further damage to already “dodgy” kidneys. People with PBS will need multiple surgeries at different stages depending on the severity of their condition.

There’s just a handful of people in New Zealand with this condition and my son James is one of them. He’s just 20 months old. He’s already been through a lot and has got a long journey ahead of him, but he’s our little miracle and defied the odds. There’s just 2 of us families (that I’m aware of) that are part of Kidney Kids, and that speaks to the rarity of the syndrome and the severity of kidney problems associated with it. We found out when I was just 13 weeks pregnant that he had a severely enlarged bladder due to a blockage somewhere and subsequently that there was damage to his ureters and his kidneys, so he’s been a Kidney Kid his whole life! One of James’ kidneys is multi-cystic and the other one is currently doing all of the work. Our nephrologist has said it’s likely he’ll need a new kidney in around 10 years but you never know with kidneys!

It can be a pretty lonely time when someone you love has a difficult diagnosis and/or a rare disorder. In fact, when dealing with any sort of medical situation it can be really hard when people don’t understand what it’s like. We face an added difficulty with James and Prune Belly Syndrome that most doctors we encounter have never seen a case! There’s a USA based Facebook group which has been immensely helpful with support and through that group I learnt about the Prune Belly Syndrome Network. They hold a conference every few years where people gather from all over the USA (and sometimes from all over the world) to listen to lectures from medical professionals and network with other people and families affected by Prune Belly Syndrome.

I was able to head over the states for this conference in July. My trip was partly funded by the Lottery Minister’s Discretionary Fund, their generosity paid for flights and accommodation and I wouldn’t have been able to go without their support. I left my kids, my son (my Kidney Kid) and my daughter who is 4 years old, at home with my husband and ventured solo on a once in a lifetime trip to Columbus, Ohio. I joined around 100 others for the conference and it was an amazing experience. I was the first person to have come from New Zealand to the conference, and for the first time ever I met people with the same condition as my son. I met someone who was 47 and has had 3 kidney transplants.

If you’re interested in learning more about Prune Belly Syndrome then there’s a great podcast telling more information about the condition <https://www.pediacast.org/prune-belly-syndrome-pediacast-534/> . If you know someone with this rare disorder then reach out because you are not alone! The Prune Belly Syndrome Network in the USA has a pretty good Facebook group and website. Or if you email Kidney Kids, I’m sure they’ll pass on my information. *Thanks so much to Heather for sharing this article with our families.*



Well done Abby Carter!

Abby Carter one of our young adult kidney kids from Nelson, has a passion for speedway, - and here she is at Greymouth Speedway!. Read on for her inspiring story. We are super proud of you Abby!.

“Every young girl's dream is to own a pony and this was certainly mine, until I started to go to speedway to watch my older brother race. The pony dream went on the back burner and was replaced by the racing bug. Although you can start speedway racing at 12 years old, my doctors weren't supportive of my involvement in such a high risk sport and it wasn't until I got the go ahead from my specialist when I was 17, that I purchased my first race car, a Production Saloon, and my dream of racing became a reality.

Now in my third season of racing I have been fortunate to have been awarded the Most Improved Production Saloon Nelson driver every season, but the highlight of my career so far, happened at my favourite track Greenstone Park Speedway in Greymouth.

The King of the Coast race meeting is the highlight of the speedway racing calendar in Greymouth. I raced in a field of 16 drivers, many who are very experienced. I had a great day and finished third overall, my first time on the podium at my favourite track.

Along with the King of the Coast awards and trophies, they also have a Queen of the Coast award. This is given to the highest female points scorer for the whole day from all of the classes racing. To my surprise I was awarded the Queen of the Coast trophy for 2023, a huge honour and a great way to finish by speedway season.

Super proud to be a Kidney Kid and proud to be following my dreams!”



We would like to acknowledge and thank Stephen Roberts, Shakey Finger Photography for his awesome photos of Abby and permission to share in this newsletter.

[Click here](#) for Facebook link to Shakey Finger Photography

Thanks too Abby, you are AMAZING!

Starship Dietitians - Salt

How to reduce salt (sodium) intake for children and teenagers with renal disease

We recommend low salt diets for a few reasons. Too much salt can contribute to high blood pressure. It also makes you want to drink more and can cause fluid retention (holding excess water inside the body).

Fresh foods are preferable to packaged or takeaway foods. Homemade meals using fresh vegetables, rice, pasta and either vegetarian proteins or fresh meat/fish/chicken contain much less salt than ready-made or takeaway meals.

To reduce the salt in home cooking, use herbs and spices (not in a premade blend), garlic, ginger, onion and lemon juice or vinegar to add flavour. Use only a small amount of salt in cooking and remove the salt shaker from the table. A lower salt diet is better for everyone's health, so it is great if parents and caregivers can lead by example and avoid adding salt at the table too.

Foods that contain high levels of salt include: chips, crisps, salted nuts and many types of crackers. Processed meats such as hot dogs, sausages, ham, salami, luncheon, bacon and corned beef are high in salt because it is used as a preservative in these foods. Sauces and condiments, such as soy sauce, fish sauce, Worcester sauce, marmite/vegemite and stock powder contain a lot of salt. Two minute-noodles, canned soup and packet meals are also high salt foods. Cheese is salty and should be eaten in moderation.

Label reading is recommended to help you choose lower salt products. On nutrition information panel's salt is referred to as sodium. You can also use food labels to compare the sodium content of similar products to help you choose the lower sodium version e.g. crackers, corn chips. ***The example below shows that the flavoured corn chips contain significantly more sodium than the natural corn chips.***

How much sodium per 100 g is too much?

General guide:

Low sodium	Medium sodium	High sodium
Less than 120 mg sodium per 100 g	120 – 600 mg sodium per 100 g	More than 600 mg sodium per 100 g
Good choice	Okay But aim for lower sodium options where possible	Limit

Supreme cheese corn chips

Serving/pack: 10 Serving size: 27g

Nutrient	Per Serving	Per 100g
Energy	580kJ	2150kJ
Protein	2.1g	7.9g
Fat, total	7g	26g
Carbohydrate	17.7g	60g
Sodium	167mg	609mg
Potassium	68mg	250mg

Natural corn chips

Serving/pack: 10 Serving size: 30g

Nutrient	Per Serving	Per 100g
Energy	596kJ	1990kJ
Protein	1.7g	5.7g
Fat, total	6.8g	22.5g
Carbohydrate	18g	60.1g
Sodium	1mg	5mg
Potassium	43mg	142mg

Low Salt Baked Nachos

This recipe uses individual spices rather than a packet mix and 'Natural Corn Chips' to reduce the salt it contains.

It can be made with canned beans to be vegetarian and budget friendly.

Ingredients

Cooking spray (or oil)
300 g natural corn chips
2 tsp olive oil (or other oil)
1 small onion diced
2 cloves garlic minced
1 tsp chilli powder
1 tsp oregano
1 tsp smoked paprika
1 tsp cumin
1 tsp ground coriander
2 cans mixed/pinto/kidney/black beans
OR 1 can pinto beans and 200g lean beef mince
1 cup frozen corn kernels
1 carrot grated
1 capsicum diced
½ cup grated cheese

Instructions

- Preheat the oven to 220°C. Lightly spray a baking tray with cooking spray (or grease with oil)
Place corn chips in a single layer on the prepared baking tray. Set aside.
- Heat olive oil in a large non-stick frying pan over medium high heat until shimmering. Add onion, garlic and mince if using. Cook, breaking up mince with a wooden spoon as it cooks, until beef browns and no pink spots remain, about 3-5 minutes.
 - Add capsicum and carrot, cook until soft, about two minutes. Drain excess fat if needed.
 - Stir in the herbs and spices, the beans and corn. Cook until fragrant or mixture has thickened.
Top corn chips with the bean mix. Sprinkle over grated cheese.
 - Bake until the cheese melts and nachos are heated through, about 7-8 minutes.
Remove from the oven and serve with toppings as desired/per dietary advice.

Topping suggestions:

Sour cream, avocado, sliced black olives, jalapenos, chopped coriander, shredded iceberg lettuce, diced tomato.

Recipe adapted from: [Healthy \(-ish\) Sheet Pan Nachos - Cook Fast, Eat Well \(cookfasteatwell.com\)](https://cookfasteatwell.com)



Some inspiration

Next to Nothing in the Fridge!

Can't think of what to make for dinner and you only have three or four ingredients in the fridge?

Google the ingredients you have, and several recipes will be there to make a meal. Give it a try. A great challenge for the kids with school holidays coming up.

Calling all Kidney Kids Whanau, do you want to win something?

We would like to acknowledge our Kidney Kids Good Sorts. It can be individual or the whole family. There will be a winner each month so if you have something wonderful to share please let us know.

Kidney kid Louisa Thomsen as Moana

Louisa was cast as Moana in Moana Junior for her recent school production and as her Mum said "she absolutely smashed it for her 2 nights. All those notes hit, a novel of lines nailed not to mention the confidence in which she performed. Even a standing ovation."

Louisa the Kidney Kids Team think you are inspirational. What an amazing effort. Well done!

Thinking of Donating a Kidney?

If you are thinking about donating a kidney, the NZ governments Ministry of Health Website has useful information

[Click on this link](#)



A Call to Arms...

VACCINES ARE SAFE FOR KIDS WITH KIDNEY DISEASE!



Vaccines can help prevent:

Chickenpox

can lead to
pneumonia

Whooping Cough

can cause breathing
failure in babies

Polio

can cause paralysis

Measles

can cause brain injury

COVID

can cause pneumonia

Each of these can be
especially dangerous for
children with kidney
disease.



Talk to your doctor
today about vaccines for
your child!



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Admin

Stay Safe & Healthy

It is still very important for your health and the health of others when you are in a crowd to wear a mask and wash hands frequently. Ministry of Health website [Click Here](#)



Mental Health Awareness Week—18-24 September

Although we are unable to provide this service, there are professional services available in the community. You may find these links helpful or contact your GP and Renal Team.

Helpline 24 hours phone counselling service can be reached by calling or texting: **1737** <https://mentalhealth.org.nz/our-campaigns/mental-health-awareness-week> [click here](#)

“What’s your best discovery?” asked the Mole. “That I’m enough as I am” said the boy.

Contact Details

Please let us know if your contact details change as soon as you move. We send our newsletter out quarterly by email. If we have your email address you should be receiving these. Please email changes to Rachel Sherman rsherman@kidneykids.org.nz or **freephone Kidney Kids 0800 215 437**.

Kidney Kid Families

If you have information on a kidney condition you think would be beneficial to share with others, or some news you wish to share please email rsherman@kidneykids.org.nz and we can include this in our next newsletter.

Tickets to events

It is your responsibility to check directly with the organisation hosting the event. Events can be cancelled or postponed. Kidney Kids take no responsibility for any events organised outside our organisation.

Reminder please check your emails

Please read and open your emails from us at Kidney Kids. Some emails may contain information about upcoming tickets to events. Unfortunately some families have missed out in these as they have not opened the email. Also remember to check your junk email file on a regular basis and to delete spam.

How to support our kidney kids and their families nationwide—click on this [link](#) to make a donation—Thank You!

Acknowledgements

Kidney Kids NZ has many companies, charities, trusts and other organisations who support us throughout the year. This support enables us to continue to provide the much-needed support services to our Kidney Kids families nation-wide. We would like to take this opportunity to give thanks, to the following:



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