### **Kidney Kids NZ**

SPRING NEWSLETTER ISSUE 7



#### Report on the 29<sup>th</sup> Annual General Meeting of Kidney Kids NZ

Our AGM was held at our new office on the 8th August. The Chairman, Mark Roberts, reported a successful 2019 year and highlighted two major initiatives, the release of the profile booklet "Who We Are" during the year and the launch of the sponsored paediatric nephrology scholarship in conjunction with Starship Foundation, starting early in 2020.

Chief Executive, Keith Mackenzie, reported on the strong financial situation our organisation is in after a year of good fundraising but warned of the effects of Covid-19 on the 2020 year results where a deficit is expected. Fundraising events have been cancelled or postponed and corporate funding has been compromised by the economy.

Our 2019 camps were extremely successful, but the 2020 camps have been cancelled. However, planning for the 2021 camps is underway.



Our family support team have increased their contact with our families and our numbers are increasing year on year. Our team attend the regional clinics run by the Starship nephrologists and met many new families and were able to provide support.

The Kidney Kids NZ Board was strengthened by the election of four new Board members: Adelle McBeth, an ex-kidney kid and businessperson, Siobhan Richards, a kidney kid mum and businessperson. Erica Fairbank, a renal nurse representing Kidney Health New Zealand, and Steve Barden, family man and businessperson. We also thank the existing Board members for their continued service, Mark Roberts (Chairman), Clint Alcock, Kelly Finnigan, and Sally Velvin. Special thanks go to our Founder, Elaine Simons, for her continued support as Secretary.

Keith Mackenzie

**Chief Executive and Board Member** 

# **Kidney News**

#### **Kidney News**

Kia ora Everyone, spring is on its way and we hope that our families have kept well over the winter months and are staying that way. Please continue to follow the Ministry of Health Guidelines as this certainly has been a challenging year to date.

#### **Update from Family Support**

We would like to welcome 22 families so far this year to Kidney Kids NZ.

Here are a couple of gorgeous photos on the right of two of our new kidney kids.

National travel is still not possible due to the uncertainty of the COVID 19 virus.

We plan to get back to normal and do our regional trips in the North and to the South Island once we are advised it is safe to travel. It is imperative that we all do our best to keep safe and well.

#### **Clinics**

We hope that clinic visits will resume either later this year or in the New Year.
Renal clinic dates will be advised as per usual.



Welcome Selena and Charlie and their families.



### **Lockdown Transplant Story**

#### Riays's Story

Riays Asiata was 9 months old, playing happily on the floor when Mum Nga noticed a distention around her abdominal area. She pointed it out to her husband, who couldn't see the distention, but told his wife to take Riays to the GP if she was worried.

The next afternoon, the Asiata family headed to the doctor. They chatted away about the cold Riays had come down with before having a look at the distention on her stomach. The doctor undid Riays's nappy to check her urine. To Nga's horror, she saw that Riays's urine was almost black — she recalls thinking at the time it was the colour of Coca-Cola.

An ambulance was called for Riays immediately and she and her family were taken to Lower Hutt Hospital, where her long journey began. Hospital staff found tumours on both of her kidneys, and little Riays was to spend the next five and a half years being treated with dialysis.

#### **Kidney Donors**

Kidney Kids thank our incredible donors who have given new life to our kidney kids. You are selfless, loving and super human beings.

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

Click on this link

In 2020, as New Zealand went into a nationwide lockdown, Nga received the call she had been waiting for – a kidney was available for Riays and the transplant could take place. While the rest of the country stayed home, Riays and Nga travelled to Auckland, where they were to spend the next six weeks.

While Nga felt lonely and isolated experiencing a kidney transplant for her daughter in lockdown, she is the first to say how well it all worked out. According to her, it went better than she thought possible. There was minimal foot traffic in the hospital, meaning less chance of infection. The planes were almost empty, they were secluded in a hotel for recovery, and while it was hard not having the support from family, Nga says it was for the best to keep Riays safe.

Riays hasn't made it back to school yet – the winter bugs, the risk of COVID-19 and a case of chicken pox at her school has kept her home. In Term 4, she will go back for lessons with a teacher aide in the library, where she won't be exposed to a full classroom environment. While her GP has cleared Riays to go back to school, Nga says as a parent she hasn't felt comfortable sending her back just yet. And a mother's intuition is nothing to be scoffed at – it's what saved Riays from her kidney disease in the first place.

### Kidney Donor Whānau

#### CALLING ALL NEW ZEALAND DONORS!

Kidney donor Leah Stewart and Kidney
Health New Zealand have launched a formal
support group for kidney donors and those
considering donation in New Zealand. The
group is called Kidney Donor Whānau. The
idea came out of a shared interest in
re-launching donor support in NZ, and
creating a safe space that is actively
monitored by an organisation and clinicians.

#### **ABOUT KIDNEY DONOR WHANAU:**

kdow is a place for New Zealand's kidney donors to find connections. We welcome living kidney donors in New Zealand, individuals considering direct or altruistic kidney donation, transplant recipients, kidney



Above photo of Leah with her recipient Denisha

patients and their whānau. This is a friendly community that you are welcomed into to connect with others on the same path, share your experience, receive peer support and engage your curiosity.

To join KDW, members need to sign up via the form on KHNZ's website and then join our closed Facebook group.

#### See links below:

https://www.kidney.health.nz/Patient-Support/

Kidney-Donor-Whanau/Kidney-Donor-Whanau-Sign-up-Form/

#### Closed Facebook group:

https://www.facebook.com/groups/kidneydonorwhanau/

If you wish to contact Leah directly about the project, you can do so via email to:

kidneydonorwhanau@gmail.com

Information sourced from The Christchurch Kidney Society (Inc.) Renal Messenger Newsletter Winter 2020

## Congratulations

#### Formal photos

The photo on the right is of Brianna Gregg looking gorgeous in her formal gown with her very proud Dad Patrick.





We spotted this beautiful formal photo of Maddie Collins, another one of our kidney kids and her partner.

It is wonderful to hear of our kidney kids achievements. Please let us know if you have something to share.

Please email: rsherman@kidneykids.org.nz

#### **Congratulations Chelsey**

Well done to kidney kid Chelsey Batchelor.

Chelsey achieved outstanding in the advanced course Emerging Stylist. She continues her job at Servilles Newmarket as a fulltime colourist. She's done so well as she's completed a total of three courses and achieved outstanding for all of them.



# Keeping safe

#### How to stay safe

As we all know COVID 19 does not discriminate and once again we are at level 2 or 3 of lockdown. Please everyone take care and follow the instructions provided by the Ministry of Health and if you haven't got the COVID 19 tracker please keep a detailed record of where you have been and who you were with.

- Keep your Distance
- Track your whereabouts
- Wash your Hands
- Wear a Mask
- Keep Safe and well



#### Be prepared

The Ministry of Health website is updated regularly. Follow the governments advice. They recommend that you have a supply of face masks accessible at home for every member of your family. Click on link for more information

#### **Mental Health**

Mental health issues related to lockdown and the pandemic are especially hard for people with depression and anxiety. The wonderful NZ charity MIND have a 24 hours helpline: 1737 (even if you are just feeling out of sorts).

Keep in touch with friends and loved ones.

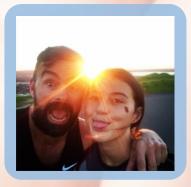


During lockdown we ran a donation campaign with a competition. Kidney Kids was delighted to be able to give away 3 JBL Pop portable speakers and a lego duplo set to 3 lucky winners of the competition.

Congratulations to the Thompson, Taylor and MacDonald Families. Thanks to JBL & Lego for the prizes.



### 333x3 Challenge Please support Michael Coley



My name is Michael Coley I live in Grey Lynn Auckland with my 17 year old daughter Ruby and 2 year old Golden Retriever Kubo.

Supported....after recovering from Kidney Cancer myself in 2013 and subsequently watching my amazing Mum battle with an unrelated Kidney Illness and going through dialysis, I thought it was really important to try and find a way to help @kidneykidsnz in any way I could to support NZ children suffering with Kidney illness. It was tough going through Kidney illness as an adult and think it must be incredibly tough for children and their families to have to deal with this.

Motivated....Back in mid 2015 I started a fundraising effort 333x3 and took on running up and down my favourite place to run, Maungawhau Mt Eden - 999 times in 333 days (3 times a day for 333 days!). Every time I went up Maungawhau I put \$3.00 in my fundraising account.

The journey took a little longer than expected due to some unforeseen injury/illness breaks but eventually got through 1000 plus laps - that's over 2000km!

I was joined by an amazing friend Steve Lowe who also ran lots of laps keeping me company

**Rewarded**....Due to our very generous families, friends and a wide group of the community donating as we went, that effort collectively raised over \$20,000 for Kidney Kids.

**Committed**....Five Years on I'm celebrating that effort and trying to raise some more profile and money for Kidney Kids New Zealand. It's a very challenging time on the planet for all of us, but especially for the immunocompromised in our

communities. Charities that support the people suffering ongoing health issues rely on significant donations from the public to survive and at this time, more than ever, we need to stand by them. In July 2020 I ran a commemorative 33 days worth of laps on Maungawhau for a total of 99 laps and donated \$5.00 per lap to celebrate #333x3fiveyearson.



Also did a mini duathlon one day of riding and running laps to add a bit of extra cash, \$600 odd in July - clearly a drop in the ocean, so time to get serious!

I'm now taking a selection of the iPhone photographs of the amazing Maungawhau and views of Auckland I took on my 333x3 journey 5 years ago, framing them up and auctioning them off to raise some more for @Kidneykidsnz You can own your piece of the effort to have on your wall at home by bidding on the 333x3 auction - There are 33 small, 3 medium and 3 large framed photographic prints to try and win at the auction!

All the funds raised from the sale of these prints will go to Kidney Kids NZ to help with the amazing work they do with the Kidney Kids families.

You can visit my Instagram @michaelcoley\_nz to have a look at the progress and get all the detail on the Auction and then share with as many people as possible please! #333x3fiveyearson #mountainsaremadetoclimb

Click here to see
Michael's work



## Administration

#### Camp KeeWee

This year until further notice our camps are sadly on hold. We are following Ministry of Health guidelines and want to keep our kidney kids safe and well. However we are planning for Camp KeeWee next year. Hopefully this will be late March 2021. We will keep our families updated when we have more information.

#### **KanTabs**

Please note we do not collect KanTabs at the Kidney Kids Office.

Please contact your local Lions Club.

South Island – David Clearwater Mbl: 027 480 0967

Beavertown Blenheim Lions – Tricia Dawson Tel: 03 577 9127

Auckland and North Island drop off points:

Hill Crest Lions (North Shore) – Lynda Tel: 09 444 6915 Mbl: 021 866 963

Orewa Lions - Laurie Tel: 09 426 3122

Warkworth Kowhai Lady Lions – Lois Tel: 09 425 8482

Thames Lions - Peter Spooner Tel: 07 889 7069

Lower North Island - Terry Hemmingsen Mbl: 027 480 5834

Titahi Bay Lions - John Linschoten Mbl: 027 451 1806

We have recently had lots of enquiries. It is only wine bottle tops with the plastic bit removed and can tabs off coke, lemonade cans etc which are accepted. Please also note that another option is that some people take their collection to a metal man themselves and deposit any funds directly into Kidney Kids account via our website.

#### Kidney Kids NZ Charity Golf Day 2020

We are holding our first fundraiser event of the year on September 11th at Akarana Golf Course in Mount Roskill and are looking forward to this charity golf day.

This tournament is open to all.

Entries close 20th August if you wish to register so please get in touch asap. Please call 021 224 9114 or email admin@kidneykids.org.nz This also applies if you wish to donate a prize. Thank you for your support.

#### Thank You

To all of our KanTab collectors and Lions for partaking in this initiative and for supporting us at Kidney Kids.

## Administration cont'd

#### **Office Hours**

Business hours are Monday to Friday 8:30am until 5:00pm Kidney Kids NZ Tel: 0800 215 437

#### We have moved offices

Our new address is:

Kidney Kids NZ
Suite 4/37 Wilkinson Road
Ellerslie
Auckland 1060

We are located upstairs and there is no lift access. If you plan to visit us please call ahead as we work between home and the office. Thanks - The Kidney Kids Team

#### **Contact Details**

If any of your contact details change, please let the team at Kidney Kids know. We send our newsletters 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 phone Kidney Kids freephone 0800 215 437* 

Please note with regards to any changes or cancellations to events outside of Kidney Kids ie tickets to ten pin bowling, you will need to get in touch with the organiser depending on lockdown and COVID 19.

#### We all need a little support

Supporting Kidney Kids NZ in whatever way you can is always appreciated. Your support helps us to support our families nationwide. If you would like to donate to Kidney Kids you can go to our

website and click on the 'Donate' button...

http://www.kidneykids.org.nz/

#### **Special Thanks**

A special mention to John Linschoten Treasurer of the Lions Club of Titahi Bay for coordinating the KanTab Programme in this region.

Kidney Kids NZ are very grateful for all of your hard work and support.





# Acknowledgements

Kidney Kids NZ has many companies, charities, trust 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:















