

# WHO WE ARE



# FOREWORD

The Starship Paediatric Kidney Service has the privilege of providing medical care to children and adolescents throughout New Zealand. We are proud of the level of medical care that we provide. However, we recognize that living with kidney disease involves so much more than medications, lab tests, and procedures that we prescribe. What we don't provide answers to are the real life, day to day matters that seem to be turned upside down when a child has a chronic kidney disease. This is where an amazing organisation steps up and takes action - Kidney Kids!

As you will see in this brochure, Kidney Kids provides a vital connection for kids and their whānau, wherever they might be in the country, to ensure that they don't feel like they are on their own figuring out the ever-changing world of living with chronic kidney disease. This includes providing camps for the kids to interact with one another, providing emergency support to get to clinics when life is becoming too stretched, or connecting whānau who have much in common, just to name a few.

We are grateful for the extra support that we get at Starship from Kidney Kids, whether through the funding of research projects, special equipment, or our first Kidney Kids/Starship Foundation Fellowship - a programme geared to provide training for paediatricians who want to become more skilled in caring for kids with kidney disease so that there is a better network of physicians who are familiar with treating kidney problems throughout the country. We are particularly excited about the new Youth Navigator position and look forward to improving care and support for adolescents and young adults as they move to adult services, in collaboration with Kidney Kids.

I can say without reservation that Kidney Kids is a vital part of providing support to kidney kids throughout New Zealand and that we look forward to working together to improve the health of kidney kids and their whānau in the years to come.



**Dr Robin Erickson | Lead Clinician**  
**Department of Paediatric Nephrology**  
**STARSHIP CHILDREN'S HOSPITAL**

*Kidney Kids NZ is a non-profit organisation established in 1990 to support children and their families and whānau with kidney disease and/or urinary tract disorders nationwide.*

**Kidney Kids NZ is a registered charity that supports families throughout New Zealand.**

**Kidney Kids NZ is a non-for-profit organisation that is dependent on grants and donations.**

**We provide families with resources, information, events, personal development, hospital visits, home visits and any other assistance required.**

# WHAT IS KIDNEY KIDS

Starship Children's Health is the main hospital for children with chronic kidney disease. This can mean lengthy periods away from home for the child and their parent/caregiver. During this time away, Kidney Kids aims to help alleviate the stress by offering emotional and practical support to families while their child receives specialised medical treatment.

Once referred, Kidney Kids provide continued support to the whānau, with advocacy and hospital or home visits. Kidney Kids also provide educational support for children who fall behind at school as a result of having kidney disease. We also organise special events each year, the highlight on our calendar being our camps.

Kidney Kids currently supports approximately 400 families nationwide.



I have been Chief Executive of Kidney Kids for more than nine years and have served on the Board for eleven years.

With 40 years' experience in the commercial sector, my focus is on ensuring Kidney Kids is a sustainable organisation, so we can continue to support the growing number of Kiwi children with various forms of kidney and urinary tract conditions.

Kidney Kids is a not-for-profit organisation founded in 1990. It is a nationwide organisation, passionate about providing support to children, young people, and their families experiencing the difficulties of kidney disease. Although our team is based in Auckland, we travel nation-wide to meet with our kidney kids and their families.

As a small charity with just five staff, Kidney Kids relies on the generosity of the public through donations, as well as grants from community organisations and the support of corporate partners.

**Keith Mackenzie**  
**Chief Executive**



I started Kidney Kids in 1990 as a parent support group.

My oldest daughter Jennifer was diagnosed with chronic renal failure at birth and my second child Rebecca was diagnosed with the same condition. One of the things I found frustrating was the lack of information and support for families who have a child with a kidney condition or abnormality of the urinary tract.

When my youngest was four years old I decided I needed to take action to ensure other families wouldn't have to deal with a lack of support and information when they find out their child has a chronic kidney condition.

In 2006 I was honoured to be awarded a Queen's Service Medal for what I have achieved for Kidney Kids. I'm still actively involved as the Secretary for the organisation.

**Elaine Simons QSM**  
**Founder & Secretary**

*Our mission is to support kidney kids and their families/whānau throughout New Zealand on their journey with kidney disease.*

# STRATEGIC GOALS



To ensure that those children who experience kidney disease have the best lives possible, and that they are not disadvantaged as they progress through education and into employment as young adults.



To make Kidney Kids more sustainable by improving our funding strategies, with increased corporate involvement through project partnerships.



To partner with Starship Foundation to provide funding for a nephrology fellowship to ensure the ongoing training of pediatric care physicians at Starship Child Health.



To support the development and implementation of Renal Reality: a patient database management system for Starship, to improve patient care throughout the country.



To develop and run a Transition Programme to help young adults to transfer from paediatric care to adult services and achieve the best possible outcome for every young adult.

*Kia Ora*

*Our kidneys have a vital role in keeping us healthy. They are an amazing organ filtering waste and water from our blood 24/7, helping to keep our blood pressure in check, our bones strong, and making red blood cells.*

*Kidney disease can start at the beginning of life and abnormalities can be detected before birth, in early childhood, or a little later. Kidney or urinary tract disorders can be mild and require medical treatment for a short time, but with End Stage Kidney Failure their kidneys no longer function. Therefore, dialysis treatment or a kidney transplant is necessary.*

*Kidney disease is a life changing condition and impacts heavily on the family/whānau. To the outside world kidney kids may not look sick but the strength and determination displayed by both our kids and their whānau is inspirational.*

*At Kidney Kids we share information and offer educational, practical, and emotional support, and work closely with other support agencies to help provide the correct services for our whānau.*

*The team at Kidney Kids are privileged to walk alongside our brave tamariki with kidney disease as they make their way forward in life.*

*“He aha te mea nui o te ao  
He tangata, he tangata, he tangata”*

*“What is the most important thing in the world?  
It is the people, it is the people, it is the people”*

**Rachel Barrett**  
**NATIONAL MANAGER SUPPORT SERVICES**



# HONOUR

In March 2019, Honour (then aged 5) was suddenly diagnosed with End Stage Kidney Failure. In October 2019 she had a transplant with a kidney donated by her Mum. On 14 October 2020, the family celebrated one year since Honour's kidney transplant, and they wanted to reflect with gratitude on the gift of life and time that transplants bring to families like theirs. Not just to recipients and their families, but the life it brings to the community as we all join together in bringing LOVE into a difficult situation. Honour's family held a competition for people to have a go at guessing how many kidney (jelly) beans were in the jar. Those who entered made a donation to Kidney Kids.

# 400+

## KIDNEY KID FAMILIES NATIONWIDE

# 316





NORTH ISLAND



### KIDS AGES

0 - 5 .....	49
6 - 10 .....	82
11 - 15 .....	122
16 - 21 .....	158

### KIDS ETHNICITY

 NZ European .....	278
 Maori .....	76
 Pacific Islands .....	26
 Other .....	31



# 95

SOUTH ISLAND

PUBLIC DONATIONS

47%

COMMUNITY GRANTS

39%

CORPORATE

8%

GOVERNMENT

4%

OTHER

2%

# FUNDING

*Where our funding  
comes from*

Figures as at March 2021

# EVENTS

## CAMPS

Both Camp KeeWee (8-14 years) and Camp Yak (15 upwards) serve similar purposes - to give the opportunity for our kids to connect with each other. Friendships made at camps are significant and these relationships serve as strong pillars of support as a young person continues their journey with kidney disease. We see the fun, activities, and fellowship provided through camps as a vehicle to deliver life-long support to each kidney kid.

With the worldwide pandemic, we have adapted and created Virtual Camps to accommodate our kidney kids and siblings. These have been a great success.

## REGIONAL FAMILY EVENTS

Starship nephrologists travel to the regions for approximately 20 paediatric renal clinics per year. Kidney Kids staff attend these clinics as well as providing early support for new families at the onset of their kidney journey. We hold get togethers when visiting the regions for our kidney kid families.

## REGIONAL CHRISTMAS PARTIES

We hold Christmas Parties in the main regions. These events are full of festive fun and Christmas goodies! They are also a perfect opportunity for new families to meet up with other parents and kidney kids, and make their own connections.





*Our mission is to support kidney kids and their families/whānau throughout New Zealand on their journey with kidney disease.*

# OUR TEAM



## RACHEL BARRETT

### **National Manager Support Services**

Nursing was a passion since childhood and the earlier years I worked in surgery and oncology, in the UK and NZ. While raising my family, I worked for Mercy Hospital, providing private nursing care for patients in their home environment, with family. I then began supporting renal clients and whanau in the community and this led me to Kidney Kids, where I have been for eight years. The experiences gained, nursing, supporting, and caring for people is indeed a privilege! Powerfully memorable, and humbling! To all our incredible kidney kids, young adults, and whanau nationwide, 'Kia kaha.'



## BEN FONUA

### **Family Support Youth Navigator**

I have worked professionally in education and volunteered in youth organisations for over ten years. My experiences and recent MBA degree will enhance my role as a youth navigator for Kidney Kids. Children with kidney disease are faced with a myriad of challenges. As the youth navigator, I will endeavour to mentor, counsel, and support every child and their family as they transition into adulthood. Achieving autonomous self-management of their healthcare is our main objective. We will fulfill this with assessments and implementing relevant resources to meet each kidney kid's needs.



## RACHEL SHERMAN

### Family Support Coordinator

Having previously worked for a Sydney based charity The Living Kidney Donor Program and in Aged Care, I'm thrilled to have joined a great team of hard-working and dedicated people at Kidney Kids, supporting families and children with kidney disorders. I have been with Kidney Kids now for over two years and was lucky enough when I first started to have visited Camp KeeWee 2019, one of our annual camps where I met some of our families and got to see first-hand the joy of our kidney kids at camp laughing, smiling, chatting and having a wonderful time experiencing new activities and meeting new friends.



## KELLIE GAUDIN

### Fundraising & Office Administrator

I've worked across a number of industries over the course of my career but my role at Kidney Kids and the not-for-profit sector has been the most fulfilling. I work in a Fundraising and Administration role where I manage the Grant and Foundation applications as well as looking after accounts and administration. I love working with our team and supporting our kidney kids and their families on their journey with kidney disease.

# KATHERINE PATON

## Ambassador

I'm Katherine, I'm 27, and I have end stage renal failure caused by a genetic mutation. I was diagnosed in 2008 and I was on peritoneal dialysis for seven months before I received a transplant from my mum. I was lucky enough to have my mum's kidney for six wonderful years. It allowed me to continue living a normal life. I travelled to France in 2010 and took part in the World Winter Transplant Games. In 2012 I travelled to France and Bulgaria to compete and train in rhythmic gymnastics, and early in 2014 I travelled to America to compete in two rhythmic competitions. I was able to finish high school, get my vet nursing degree and start a full-time job. I also attended several Kidney Kids camps. These camps were very special to me. I made many great friends and overcame lots of challenges. I'm still in contact with many of my kidney kid friends.

Sadly, in December 2014 I was told my kidney was failing and in June 2015 it was removed. I went back onto haemodialysis for five months then back onto peritoneal dialysis. I never let that stop me. In 2016 I went back to gymnastics. In 2017 I represented New Zealand in Level 10 at the Australian Nationals and in 2018 I got to travel to Europe (Belarus, Russia, Bulgaria) to compete in two World Cups and a World Championships. All while on dialysis - I just took my supplies and my boxes were all shipped to my destination.

My journey has been tough at times. I have good days when I feel great and bad days when I have to stay home all day. I think of the things I can control like what I eat and drink and my attitude. I do the best I can.

I'm proud to be an Ambassador for Kidney Kids and happy to give back to this great organisation to support the kids.







# WALTER NEILANDS

## Ambassador

Walter Neilands is a Kiwi TV personality, best known for hosting TV3 children's programme Sticky TV and starring on several other TV shows including the 2019 season of Dancing with the Stars, where he wowed the nation (and judges) by back flipping off the judges table!

Walter is proud to be a Kidney Kids ambassador and loves getting involved in our fundraising activities and events. Walter is leading the Water in Schools project, encouraging all children to drink water instead of sugar-based drinks.

Walter loves hanging out with our kidney kids and their families, supporting them on their journey. With his infectious energy and huge grin, Walter inspires our kids to be the best they can despite the challenges along the way.

# JONAH LOMU

**RIP Jonah Lomu 1975 - 2015**

Jonah Lomu was an inspiration to many, but none more so than our kidney kids who were on the same journey as Jonah with kidney disease. Jonah was our Patron for over ten years and spent many hours at our camps and events offering support to our kids. His inspirational words are still very much remembered at Kidney Kids.



# IMELEINA

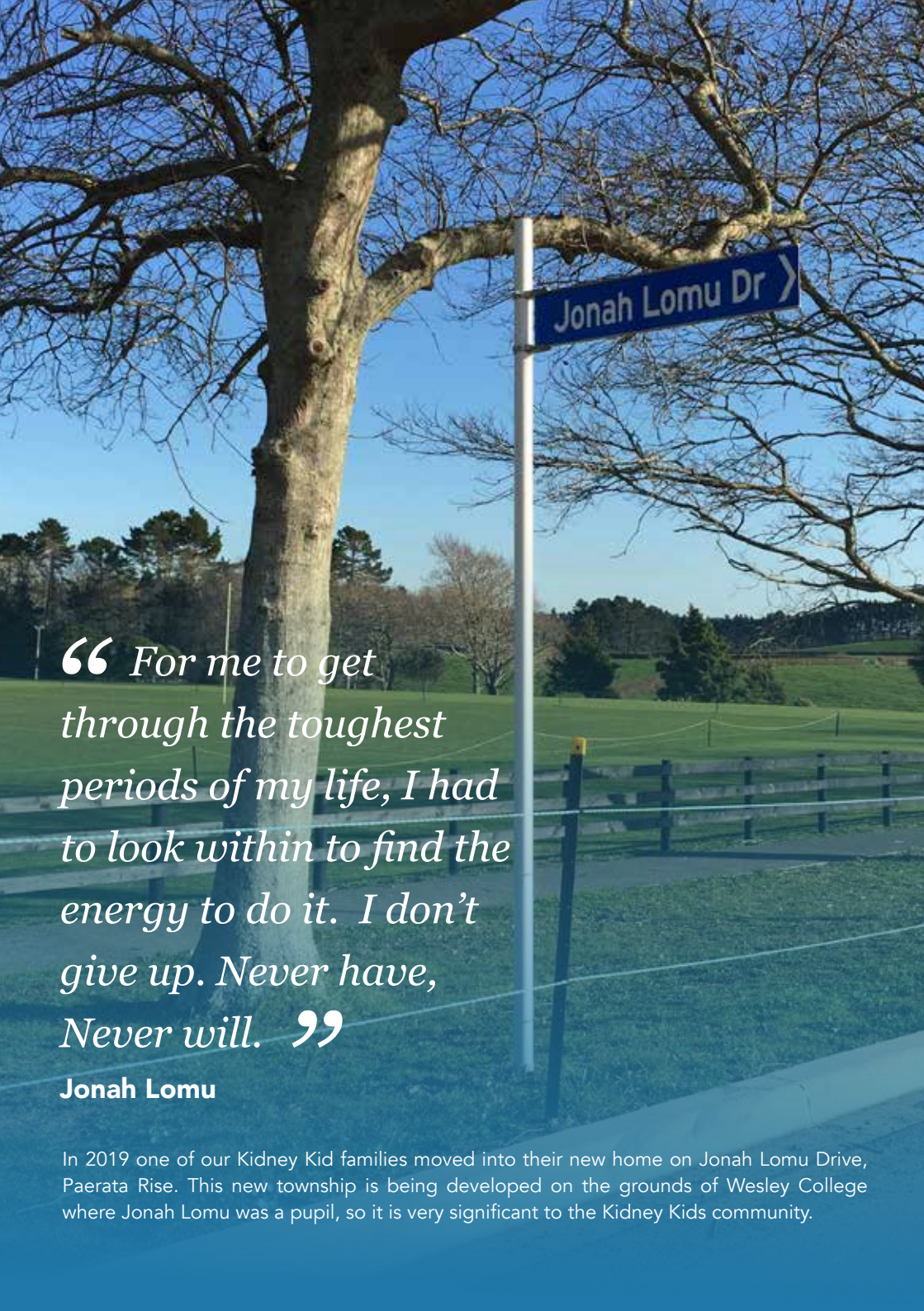
In 2012 at the age of three Imeleina Ale (now 12 years old) was diagnosed with Nephrotic Syndrome, a serious kidney condition. For seven years she battled through peritoneal dialysis and haemodialysis plus numerous surgeries. Imeleina had haemodialysis treatment at Starship Hospital four days a week, four and a half hours each treatment. Imeleina's life changed again when she received a kidney transplant on the 4th July 2019.

Imeleina 12 now is thriving post-transplant. "Imeleina loves going to school five days a week and spending time with her Tongan Dad, family and siblings. She has lots of new friends and can't wait to travel overseas". Says proud Mum Tumua.

*Imeleina (10) enjoying the water slide at Camp KeeWee*







*“ For me to get through the toughest periods of my life, I had to look within to find the energy to do it. I don’t give up. Never have, Never will. ”*

**Jonah Lomu**

In 2019 one of our Kidney Kid families moved into their new home on Jonah Lomu Drive, Paerata Rise. This new township is being developed on the grounds of Wesley College where Jonah Lomu was a pupil, so it is very significant to the Kidney Kids community.



# Kidney Kids NZ

Learn more about Kidney Kids,  
see our great work, and find a link to donate...

[www.kidneykids.org.nz](http://www.kidneykids.org.nz)  @kidneykidsNZ

