

# WHO WE ARE



# FOREWORD

The care of children with chronic kidney disease involves many facets of the healthcare system, including support from non-governmental organisations to reduce the impact chronic illness may have on their families. Unlike many other chronic illnesses such as cancer and heart disease, kidney diseases are often silent and of insidious onset. The affected children and their families are frequently unprepared for major upheavals which can place huge strain on families, parents and other children. Some of these families and children will require transfer to Starship Hospital for long periods of time. Families' financial resources may become strained. Kidney Kids have been able to assist with emergency resources for many of these families, whilst their children are receiving treatment in Starship. Kidney Kids' help in these difficult circumstances has been invaluable.

For many years, Kidney Kids have organised annual camps for children with kidney disease. This allows children to develop friendships with other children with similar health needs, and to know that they are not alone with their illness. First and foremost, these camps encourage outdoor pursuits that can be undertaken by all. The camps have also been a means of networking for parents of children with chronic kidney disease.

Kidney Kids and its supporters have also raised funds to purchase much needed equipment for children with chronic kidney conditions. Finally, Kidney Kids have also supported clinical research in children's kidney diseases which has benefited children with chronic kidney disorders throughout the world.

Kidney Kids has and will continue to play a pivotal role in the welfare of children and their families with chronic kidney diseases.

**William Wong | Clinical Head**  
**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 over 400 families nationwide.



I have been Chief Executive of Kidney Kids for more than six years and have served on the Board for eight 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 four 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 children's hospital.



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



## 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”*

*Imeleina enjoying the water slide  
at Camp KeeWee*

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

### **Imeleina Ale**

*In 2012 at the age of three Imeleina (now ten years old) was diagnosed with Nephrotic Syndrome, a serious kidney disorder. For the past seven years she has battled through both peritoneal dialysis and haemodialysis plus numerous surgeries. Imeleina has been having haemodialysis treatment at Starship Hospital four days a week, four and a half hours each treatment. She is a bright and outgoing girl who loves to perform with dance and song. You may recognise her as the face on our collection boxes around the country. Imeleina received a kidney transplant on the 4th July 2019 and is doing very well and is now looking forward to going back to New Lynn Primary School later in the year as a well kidney kid.*

400  
FAMILIES



423  
KIDNEY KIDS



335  
NORTH ISLAND

88  
SOUTH ISLAND

### KIDS AGES

|         |     |
|---------|-----|
| 0 - 5   | 45  |
| 6 - 10  | 83  |
| 11 - 15 | 133 |
| 16 - 21 | 162 |

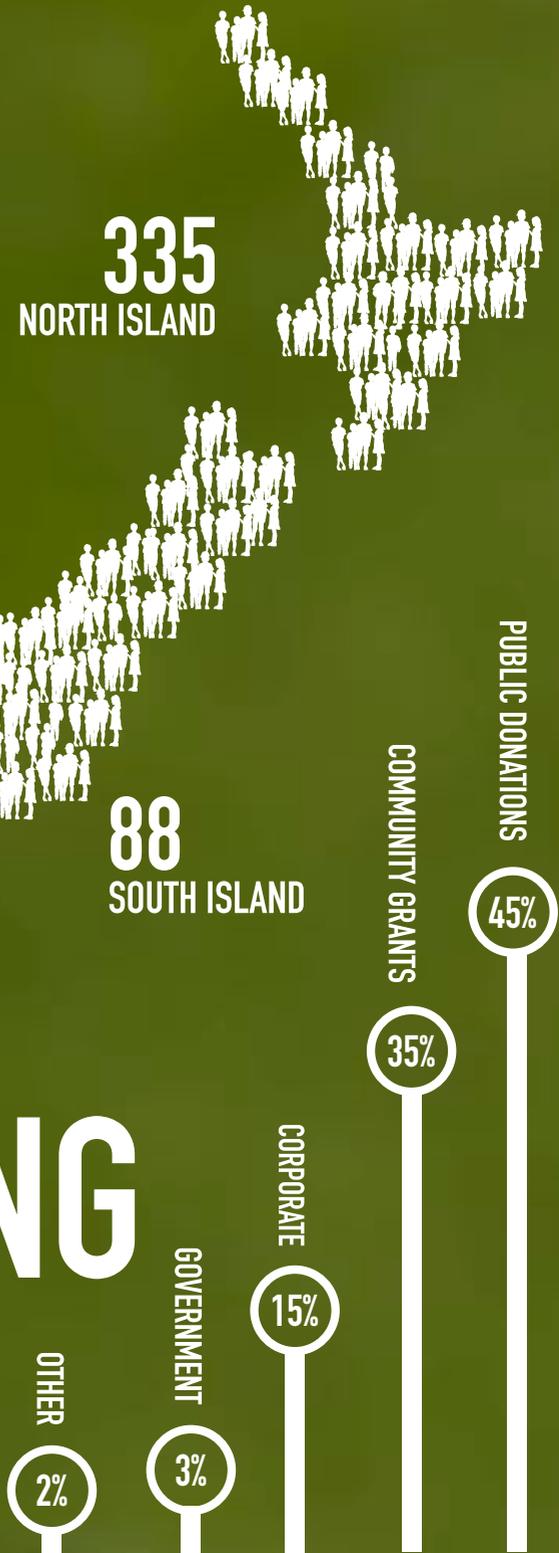
### KIDS ETHNICITY



# FUNDING

*Where our funding comes from*

Figures as at 18 July 2019



# EVENTS

## CAMPS

Both Camp KeeWee (8-15 years) and Camp Yak (16-21 years) 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.

## REGIONAL FAMILY EVENTS

We play fun and crazy games, share a meal, and meet families when we visit the regions and hold our family events. The events are a great opportunity for our families to relax and have some light-hearted fun, and an opportunity to share with others.

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 aim to arrange a family get together after each of these clinics whenever possible.

## REGIONAL CHRISTMAS PARTIES

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 over mince pies and ice cream. Christmas wouldn't be Christmas without the wide-eyed faces of the younger kids waiting patiently for the arrival of Santa, who never forgets our kidney kids and their siblings.



*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

I have had the privilege of spending much of my career in the medical field working as an oncology nurse in the U.K., before returning to New Zealand with my family. I worked at Mercy Hospital in the surgical field as well as managing their Home Healthcare Service. More recently, I have been involved with the care and support of renal patients, spending time in the hospital and visiting patients at home. This experience led me to Kidney Kids in 2013 and my current role supporting kidney kids and their families. Kia Kaha to all our kidney kids and their whānau.



## DALE VAN DEN BERG

### Family Support Worker

My passion for working with people led me to studying social work at MIT where I gained an insight into New Zealand's unique cultural landscape and gained valuable experience working with people from a diverse range of backgrounds. When I first joined Kidney Kids, the medical field was completely new to me, but thanks to the leadership and support of my team I am now confident that this is exactly where I need to be. I'm so grateful to our kidney kids and their families, who allow me to work alongside them.



## 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 was lucky enough to have visited Camp Keewee 2019, one of our annual camps, where I met some of our families and experienced first-hand the joy of our kidney kids who were laughing, smiling, chatting and having a wonderful time meeting friends and experiencing new activities.



## 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 25, 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.

*“ 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**

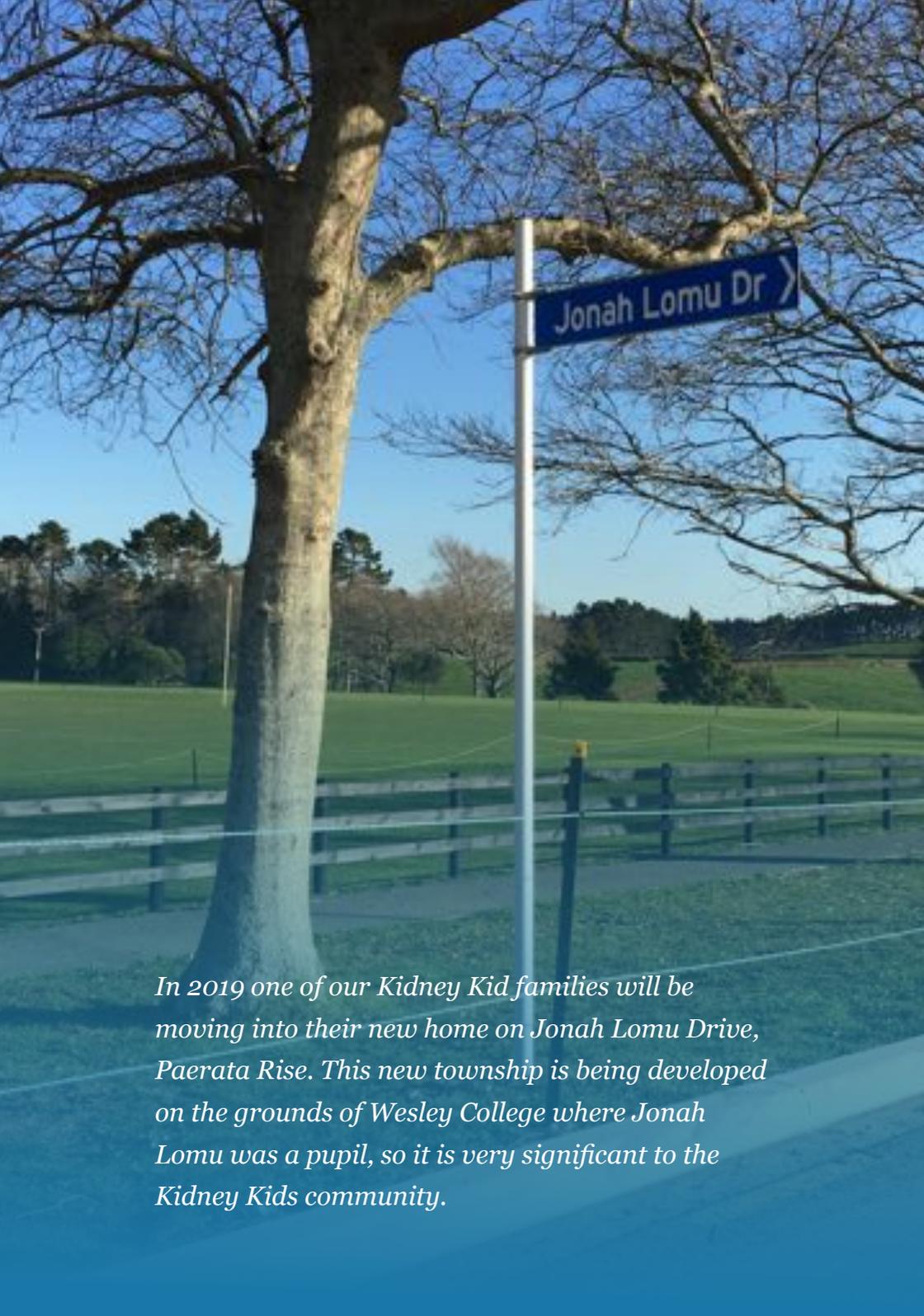
# JOELI VIDIRI

**Ambassador**

We are privileged to have former All Black and Fijian rugby union football player Joeli Vidiri as an ambassador for Kidney Kids.

Joeli battled kidney disease for a decade and was on haemodialysis for several years before receiving a kidney transplant in 2015. After receiving his transplant, Joeli pioneered the Sports for Health programme in Fiji to educate children on the importance of leading an active and healthy lifestyle.

Joeli is a well-respected member of the community, especially to the kidney kids who love seeing him at social events - a recent highlight of which was Christmas where Joeli dressed up as Santa.



*In 2019 one of our Kidney Kid families will be moving 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

