Corin lives with a rare inherited heart condition and associated difficulties.

# Big research for little lives

cure kids
big research
for little lives

# CURE KIDS ANNUAL REPORT 2019

# FROM THE FRONTLINE OF SAVING CHILDREN'S LIVES

**In October 2019, Professor Stuart Dalziel was named Cure Kids Chair in Child Health Research, selected from a large pool of stellar applicants. As a globally-connected researcher working at the frontline of paediatrics, he is strongly positioned to lead significant changes that will benefit all New Zealand children. Professor Dalziel's ultimate goal is to make sure high-quality acute paediatric care is delivered every time a child presents to a hospital emergency department in New Zealand.**

In addition to his frontline job as a paediatric emergency medicine (PEM) Physician in the Children's Emergency Department (ED) at Starship Children's Hospital, where he is the Director of Emergency Medicine Research, Stuart Dalziel is a Professor of Paediatrics and Emergency Medicine at the University of Auckland's School of Medicine. Now he is also our Chair in Child Health Research, based at The University of Auckland. Together, these four roles represent a powerful force for the advancement of children's emergency medicine.

"The appointment to the Cure Kids chair recognises that child health research in the acute space is really important. Although we like to think there's good evidence for what we do in PEM, a lot of clinical practice is extrapolated from adult evidence or doesn't have the same evidence base as with long-term interventions in paediatrics. With this new position, Cure Kids is helping to make a real difference to the future of PEM."

"Being involved with research on a global scale allows you to reflect on your practice and ask 'what are the good things that we're doing, and what can we do better?"

Professor Dalziel is a PEM pioneer in New Zealand. He completed undergraduate training at the University of Otago, then postgraduate training in paediatrics in both New Zealand and United Kingdom, culminating in a Fellowship at Great Ormond Street Hospital in London. Becoming the first New Zealand PEM specialist with a PhD has assisted his goal of inspiring and driving research related to acute paediatrics. Professor Dalziel holds leadership positions with several PEM research bodies internationally.

"Being involved with research on a global scale allows you to reflect on your practice and ask 'what are the good things that we're doing, and what can we do better?' If what you're doing appears to be going really well, there's the temptation to rest a little bit on your laurels. But if you're critically appraising what you're doing and comparing your outcomes to similar institutions around the world, you can continually aim for excellence. And that's what we want to deliver to every patient who comes through the door."

One of Professor Dalziel's shining goals for children's acute medicine is to develop the workforce throughout New Zealand.

The number one reason for admission to hospital for children in the developed world is bronchiolitis, a respiratory viral illness that commonly affects children aged under one year of age. In New Zealand, Māori and Pacific infants, and those living in the most deprived parts of our society carry the greatest burden of bronchiolitis admissions. Children arrive at the ED struggling for breath, with some needing to be admitted to the intensive care unit (ICU).

"The cornerstones of bronchiolitis management in hospital are breathing support and hydration. Our research has focused on both. With hydration, we found that a nasogastric tube is the most appropriate way to deliver fluid. It provides better nutrition, stays in more securely and requires fewer attempts at insertion, resulting in less distress for the child and family. For breathing support we've determined the place of high-flow respiratory support in management of bronchiolitis. High-flow support warms and humidifies the gases, allowing air and oxygen to be delivered at substantially higher flow rates. Prior to

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our work, its use was confined to the ICU. We showed that high-flow is safe to be used in the ED and general paediatric wards. However, the high-flow machines and attached tubes are more expensive than traditional oxygen devices. We discovered that high-flow is best used as a rescue treatment, when traditional methods of oxygen delivery haven't been enough.

"My hope is that every child who presents to an ED in Aotearoa has the same access to high-quality evidence-based care, no matter where they are, what time of the day they present, and who they see in the department."

"Another piece of research we're soon to start is about preventing children from being admitted to hospital with bronchiolitis. If we give two nebulisers of adrenaline in the ED, half an hour apart, plus two doses of steroids – once in ED and again 24 hours later – there is provisional evidence that shows we may reduce the number of hospital admissions by a third. We will confirm this in a large trial across New Zealand, Australia and Canada."

Large international studies have been the basis for a lot of Professor Dalziel's research. Recently he finished one looking at the management of status epilepticus in children, defined as seizures lasting longer than 10 minutes.

"There was no randomised controlled trial evidence looking at the medication that we had been using for 40 or 50 years. We compared this older medication with a newer one. As a result of this study, we have changed medication protocols internationally for this condition."

One of Professor Dalziel's shining goals for children's acute medicine is to develop the workforce throughout New Zealand.

"My hope is that every child who presents to an ED in Aotearoa has the same access to high-quality evidence-based care, no matter where they are, what time of the day they present, and who they see in the department."

*Hunter, Eva, Bella, Addison, Frances, Corin, Lukas, Ambassador Group Cure Kids.*

# FREQUENT FLYER

Born with a rare genetic condition that causes his arteries and veins to close as he grows, Corin Copeland has visited the emergency department of Starship Children's Hospital around 30 times. As a 'frequent flyer', he receives immediate personalised care that often makes hospitalisation unnecessary.

Now in Year 6 at school, Corin is super sporty. He loves basketball, rugby, riding his bike and being part of his local surf club. He's also crazy about parkour, a free-flowing training discipline that involves balancing, vaulting, jumping and climbing. Running parallel to Corin's active life is the daily possibility of an emergency dash to Starship ED.

"When Corin was little we had grab-and-go bags always packed. But he's in a much better place these days, so the trips aren't as frequent," says Myka, Corin's Mum.

When the Copeland family have to drop everything and head for Starship's ED, Corin's sister Kammy is usually dropped at a friend's place along the way, because an overnight stay might be required.

"At Starship they know we don't just rock up for nothing. After checking in, we go straight through to a bed or a room. With Corin, there are so many notes and there's never enough time to read through every single thing. The ED team ask 'what's going on now?' and they don't hesitate to phone other doctors in the hospital for input. We always feel included in the conversations."

Corin's dad Jon has some excellent advice for families that are experiencing a rash of ED dashes:

"Ask questions whenever you get the chance, because it helps to stop you from fretting nonstop. We learned early on to gather as much information as possible. For example, when Corin was just 2 weeks old and experiencing complete heart failure, we were told he'd have a surgery in 3 days' time. We thought he'd die before then and we were so scared. But a nurse explained that heart failure is actually a very controlled situation to be when you're in hospital. That information made all the difference."

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## HOW TO GET INVOLVED

There are endless ways you can help make a difference to the health outcomes of our children.

### DONATE

Whether you or your business give a one-off donation, or contribute on a regular basis, every little bit helps.


### FUNDRAISE

Rally your business, school or community to fundraise for child health research (see page 44).

### VOLUNTEER

We are always on the lookout for volunteers to lend a helping hand.

### SPREAD THE WORD

Follow us on social media and sign up to our monthly newsletter for the most up-to-date information about Cure Kids - and spread the word with your family and friends.

## CONNECT WITH US


facebook.com/curekidscharity

twitter.com/curekidsnz

instagram.com/curekidsnz

**Phone** 09 370 0222

**Address** Level 1, 96 New North Road, Eden Terrace 1021

**Postal** PO Box 90907, Victoria St West, Auckland 1142


For more information on Cure Kids and child health research that you are helping support, visit **curekids.org.nz** and sign up to our newsletter.

# STATE OF THE NATION

**EMERITUS PROFESSOR ED MITCHELL, ONZM**
**CURE KIDS CHAIR OF CHILD HEALTH RESEARCH (2001-2015)**
**UNIVERSITY OF AUCKLAND**

## LOOKING BACK AND LOOKING FORWARD

At the end of 2015 I "retired" from the Cure Kids Chair of Child Health Research at the University of Auckland, where I had held the position since 2001. Since that time, I have continued our research on Sudden Unexpected Death in Infancy (SUDI, previously called SIDS (sudden infant death syndrome) or cot death) and late stillbirth, albeit in a part-time capacity.

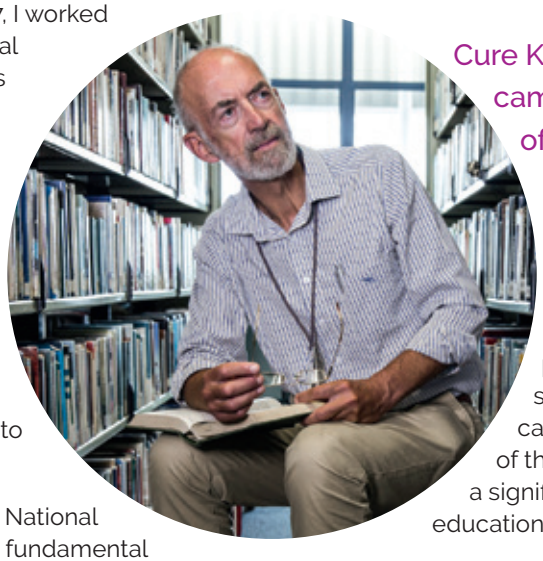
Retirement provides an opportunity to look back as well as looking forward.

When I came to New Zealand in 1977, I worked in the rundown Princess Mary Hospital for Children. As one of my colleagues at the time said, "Despite the fleas, cockroaches and rats there was a wonderful camaraderie and sense of purpose". Compared with my experience in the UK, our acute wards were full of asthma, respiratory and other infections, and rheumatic fever, which I had never seen before. Everyone was so busy dealing with sick children in front of them, there was limited time to think let alone undertake research.

The role of Cure Kids (previously The National Children's Research Foundation) was fundamental in establishing a chair of child health research. Emeritus Professor Bob Elliott was the chair from 1978 until 1999. He was my boss, mentor and friend. Even before I completed my paediatric training he appointed me as his research fellow.

In 1983 I was asked (a euphemism for being told!) to establish a Postneonatal Mortality Review Committee for the Auckland region. Postneonatal is the period from 28 days of life through to the first birthday. The rate of postneonatal mortality was very high in New Zealand compared with other comparable countries, and the thought that by examining individual deaths we would identify factors which could be changed thus preventing further deaths.

In 2 years there were 134 postneonatal deaths, of which 80 were due to cot death as we called it then. Cot death was considered to be "unpredictable, unpreventable, unexplainable tragedy". Only 10% of all the deaths were potentially preventable (e.g. road traffic crashes, other accidents, infections), thus solving our high mortality rate needed to address our very high cot death rate.



Cure Kids funded the 'Back to Sleep' campaign which reduced the rate of SUDI in NZ by half.

This led to the New Zealand Cot Death Study (1987-1990), the identification of tummy sleeping as the major risk, the prevention programme (advising parents to place baby to sleep on their backs, subsequently called 'Back to Sleep' campaign) and an immediate halving of the rate of SUDI. Cure Kids played a significant role and funder of the education programme.

Over a decade ago, research into stillbirths was where SUDI was in the 1980s. I thought we could apply the same techniques we'd used to study SUDI to this problem. In 2006, we conducted The Auckland Stillbirth Study funded by Cure Kids. This was the first time maternal sleep was studied as a risk factor for stillbirth. Ironically we found that mothers sleeping on their back doubled the risk of stillbirth. This was confirmed in subsequent studies in New Zealand and the UK, all of which were supported by Cure Kids. Cure Kids has led the education campaign ('Sleep on side when baby's inside').

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# STATE OF THE NATION

The mechanism is uncertain; it may be due to sleep disturbed breathing as I'd originally postulated, but more likely due to restriction of the maternal blood supply to the uterus and baby. Very elegant MRI studies by Professor Peter Stone have shown this convincingly. Peter has also led the physiological studies of maternal sleep and sleep position on fetal physiology. Although maternal sleep is important it accounts for only a small part of the variation in stillborn mortality. There must be other important factors which we are not seeing.

There is still much to do, and new questions to be asked. I hope new researchers ask the right questions, but only with research and funding will we know.

So what makes successful research? The key is asking the right questions. For SUDI we looked at the full range of infant care practices, which had not been done previously. The second factor is funding, and Cure Kids has played a major role as the largest funder of child health research outside the government. Finally, one needs a bit of luck. Our careful research might not have found the answer if sleep position wasn't associated with cot death. Negative findings would have been important, but obviously wouldn't have had the impact that we were privileged to witness.

So, looking forward: Our hospitals are still busy, infection remains a major problem as does rheumatic fever. But there are 'new' problems. The rise in childhood obesity bodes ill for their future health as adults, the increase in psychological problems in children (or is it being recognised more readily?), the increase in survival of children with cancer is to be lauded, but now there are concerns of second cancers and effects of radiotherapy on the brains of children. The list goes on and on and research remains the key.

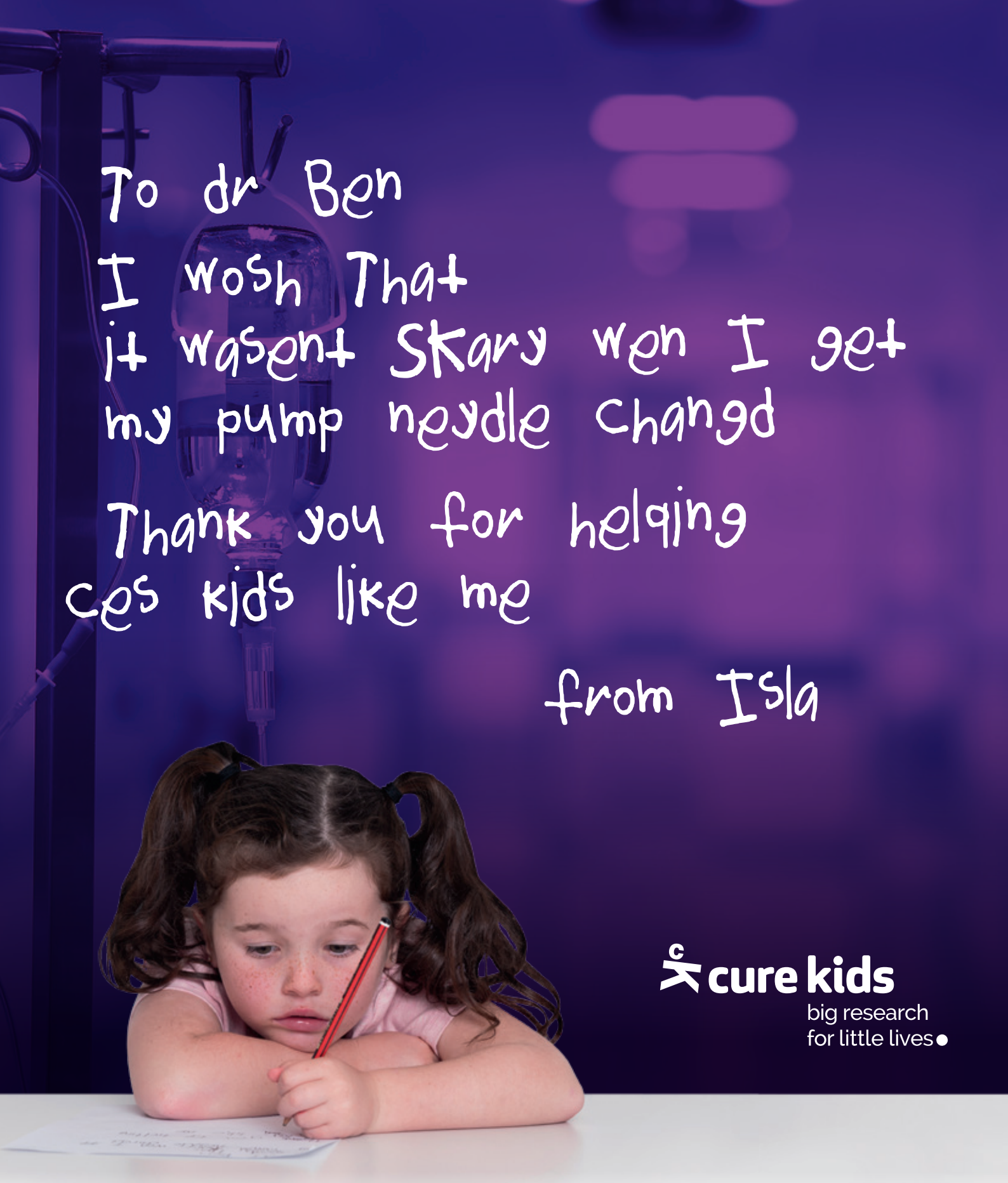
So there is still much to do, and new questions to be asked. I hope new researchers ask the right questions, but only with research and funding will we know.

I look back with a degree of pride as to what we have achieved, and I look forward to hearing of the success of those who follow. I thank Cure Kids for supporting me from the early days when I was a young research fellow, through to the chair and funding so many research projects over the years.

*1979*


*1980*

*Bob Elliott*




cure kids
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for little lives

## Isla lives with type 1 diabetes.

**Dr Ben Wheeler is a paediatric endocrinologist with an interest in type 1 diabetes, bone health and nutrition.**

Dr Wheeler works to improve compliance with type 1 diabetes treatments. Using new, less painful and less burdensome technology, he hopes to improve glucose monitoring and quality of life of those living with the condition.

# YAY FOR OUR AMBASSADORS

Three cheers for our brave ambassadors as they embrace the challenges of being a Kiwi kid, in spite of ongoing health problems.

## KEYNOTE SPEAKING FOR HUNTER

Living with type 1 diabetes hasn't stopped Hunter from embracing one of life's greatest challenges – public speaking. At a Cure Kids event in September, Hunter kept a large crowd enraptured while he recounted his health journey. He's a talented speaker who's helping us to raise money for research.

## BROOKE'S ON HER WAY TO UNIVERSITY

Living with epilepsy hasn't stopped Brooke from absolutely owning her final year at high school. Her graduation achievements include 1st equal in PE, 2nd in History, distinction in English and RE, the cup for the Outstanding Contribution to the School, NCEA level 3 with merit, and excellence endorsement in PE and RE. Brooke's next chapter begins at Massey University, where she'll be studying for a Certificate in Early Childhood Education to become a hospital play specialist.

## FINN'S RIDING HIGH

Finn was diagnosed with hypoplastic right heart before he was born and had several open heart surgeries before age three. He lives on a dairy farm with his family and loves riding motorbikes. Beyond being his family's little miracle, Finn is a motocross star. At a recent club event, he was coming second on the leader board when his heart condition made it necessary to withdraw from the competition. Finn's disappointment turned to triumph when he was awarded second place at prize giving, despite completing fewer runs than other competitors.

## EVA'S OFF TO INTERMEDIATE

Eva's bravely met challenge after challenge during her short life. She was born with only half a diaphragm and has survived multiple corrective surgeries, along with numerous bouts of pneumonia, several strokes and an ongoing fight with hospital-acquired MRSA. Starting intermediate school is her newest victory.

## MELA GETS HER SMILE

Mela lives with Moebius syndrome, an incredibly rare neurological condition that affects the muscles that control facial expression and eye movement. After 23 intricate surgeries, she can now smile. Mela took her new ability off to camp in Rotorua, along with all her classmates from year five at Campbell's Bay School. Conquering the Redwoods Treewalk and watching mud boil were just two of the camp activities that brought a smile to her face.

## BELLA'S SWEET SIXTEEN

Born with cystic fibrosis, Bella fights a never-ending battle with sticky mucus that messes with her digestive and respiratory systems. She endures 30 minutes of physio twice a day, relies on IV nutrition, swallows more than 20 pills a day and spends long periods in Starship Hospital every year. Bella's courage and strength are inspirational. Here she is with her grandfather on her 16th birthday.

## LIFE'S A STAGE FOR CHLOE

Severe respiratory issues have been a feature of Chloe's life since the day she was born. Today she lives with bronchiectasis and asthma, which require chest physiotherapy twice a day and frequent use of nebulisers. This doesn't prevent courageous Chloe from pursuing her passion for dance. Last year she took part in her first-ever dance production, winning a standing ovation for her stamina and composure.

## A SCHOLARSHIP FOR JACKSON

At age seven, Jackson's primary schooling was rudely interrupted by a brain tumour, but he didn't let that stand in the way of success. While 2 years of chemo set him back for a while, Jackson caught up with his learning double-quick and recently graduated from year 12 with Excellence Endorsed. What's more, he scored a valuable Allan William Shaw Scholarship to help pay for his tertiary education.

## A HELPFUL BEST FRIEND FOR MYKAL

Born with cerebral palsy, aka spastic dystonic quadriplegia, Mykal has no functional movement. However he does have an immense hunger for knowledge and an incredible sense of humour. And now he has a four-legged friend to improve his independence. Theo, his mobility dog, is helping Mykal to become more involved in the world, meet more people and have more fun.

## ADDISON TURNS 12

A staph infection at age four changed Addison's life forever. It affected her heart, lungs and joints. Addison was on IV antibiotics in hospital for two months and had multiple surgeries on her shoulders, arm and lungs to remove the infection from her body. Although she's now clear of staph infection, it permanently damaged her heart. Turning 12 is a major milestone for Addison, who loves netball and hip hop dancing.

# MEET SOME OF OUR RESEARCHERS

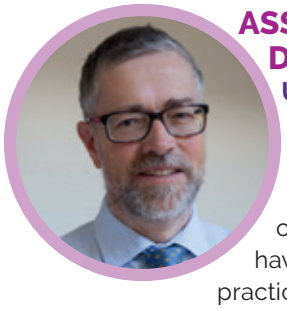
**Innovative researchers. Energetic research teams. New ideas to build on established knowledge.** Each project we fund transforms our understanding of the child health conditions affecting our children and brings us closer to breakthroughs. These pages feature (just a few) of our current researchers who are bringing their dreams (and ours) to life.

## DR NIKKI MORELAND
### UNIVERSITY OF AUCKLAND

Dr Nikki Moreland is a Senior Lecturer in immunology and runs a laboratory at the University of Auckland that focuses on rheumatic fever, an autoimmune disease that can develop after an untreated Group A Streptococcus infection (commonly known as a strep infection). Globally, Group A Streptococcus is placed in the 'top 10' infectious causes of human death. The rates of rheumatic fever in Māori and Pacific children are amongst the highest in the world, and each year between 100 to 200 children are newly diagnosed with rheumatic fever in New Zealand. Cure Kids is supporting Dr Moreland's efforts to identify new biomarkers for rheumatic fever, which could lead to the development of a much-needed diagnostic test for the condition.

## DR SARAH FORTUNE
### UNIVERSITY OF OTAGO

Dr Sarah Fortune is a Senior Lecturer in Psychological Medicine at the University of Otago. She has worked for more than 20 years as a Clinical Psychologist with children, adolescents and their families in both New Zealand and abroad. Her clinical experience spans both inpatient and outpatient settings. Dr Sarah Fortune's academic research interests include the epidemiology of self-harm and suicide, treatment interventions, preventative strategies, service provision for those experiencing suicidal distress, staff attitudes and service user experiences. Along with her team, she is piloting a surveillance trial at Middlemore Hospital reporting on self-harm among those under 15 years of age, and producing an evidence-based resource for NZ children who self-harm with the hope of preventing these tragic episodes.



## ASSOCIATE PROFESSOR DAVID REITH
### UNIVERSITY OF OTAGO

Associate Professor Reith specialises in paediatric clinical pharmacology at the University of Otago. Dr Reith and his team have found inconsistencies in best-practice for pupil-dilation dosage in premature babies. Dr Reith is leading a trial to identify whether lower doses of medication can be used to dilate the pupil of a premature baby when screening for retinopathy of prematurity (ROP), which can cause blindness. The study has a real potential to inform guidelines for pupil-dilation dosage both here and internationally.

## DR ANDY WOOD
### UNIVERSITY OF AUCKLAND

Dr Andy Wood, from the University of Auckland, is a Paediatric Haematologist-Oncologist who leads The Precision Paediatric Cancer Project (PPCP) – a clinical trial jointly funded by the Child Cancer Foundation, the Lindsay Foundation, and Cure Kids. This study is the first of its kind in New Zealand and seeks to use state-of-the-art diagnostic testing to identify the genetic mutations causing cancer in children. The research will focus on children with hard-to-treat cancer and look for specific mutations in their genes. The information will then be used to treat the child's cancer in the most targeted way possible. The aim of the project is to demonstrate that using advanced genetic testing for certain cancers can improve survival rates and quality of life for these children and their families.

## PROFESSOR LYNETTE SADLEIR
### UNIVERSITY OF OTAGO, WELLINGTON

Professor Lynette Sadleir is a Clinical Researcher with expertise in epilepsy and is the Director of the Epilepsy Research Group at the University of Otago, Wellington. The Epilepsy Research Group is committed to improving the quality of life for individuals with epilepsy and their families. Their research aims to identify new and emerging genetic epilepsy syndromes and to discover the genetic abnormalities that cause them. The identification of new epilepsy syndromes and discovery of new epilepsy genes leads to a deeper understanding of epilepsy with opportunities for diagnosis, prognosis and development of new treatments.

## ASSOCIATE PROFESSOR SIOUXSIE WILES
### UNIVERSITY OF AUCKLAND

Associate Professor Siouxsie Wiles is a Microbiologist and bioluminescence enthusiast. Head of the Bioluminescent Superbugs Lab at the University of Auckland, Dr Wiles combines her twin passions to understand infectious diseases and to search for new antibiotics. Dr Wiles is also interested in demystifying science for the general public and raising awareness of the growing threat of antibiotic-resistant superbugs.

## DR ALI LEVERSHA
### AUCKLAND DISTRICT HEALTH BOARD

Dr Ali Leversha is a Community Paediatrician at Starship Hospital. Dr Leversha's research focuses on inequalities, health literacy and conditions that disproportionately affect socioeconomically disadvantaged communities, including skin infections, rheumatic fever, hearing loss, dental decay and self-regulation. The overall goal of her research is to inform practice, so we have healthy children, engaged in education.

## PROFESSOR MAURO FARELLA
### UNIVERSITY OF OTAGO, CHRISTCHURCH

Obesity has reached epidemic proportions around the world, with New Zealand having one of the worst rates among children – 12 percent of Kiwi children aged two to 14 are considered obese. Recent research has found association between chewing patterns and body mass index (BMI). Professor Mauro Farella is investigating use of a novel, wearable device that can gather in-home data on a child's eating behaviour, such as the duration and intensity of chewing episodes. They will trial the device and, if successful, it could provide real-time feedback to try and improve children's eating behaviours and reduce obesity.

## DR CHRIS McKINLAY
### UNIVERSITY OF AUCKLAND

Dr Chris McKinlay is a Neonatologist at Middlemore Hospital in South Auckland. Dr Chris McKinlay and his team are investigating the detection thresholds for gestational diabetes to identify whether we are over-diagnosing pregnant women and subjecting them to unnecessary treatment, placing an avoidable burden on an already overstretched maternity healthcare budget. All babies are closely monitored for the first year and assessed by measuring body composition, growth, appetite, nutrition and development. The aim is to improve short and long-term outcomes for both mother and child.

> "One in four children who have the very severe epilepsies will die by 20 years of age. Trying to help these children and not being able to is what motivates me to do research. We have to find better solutions and we can't do that without research."
>
> Professor Lynette Sadleir

# A MESSAGE FROM OUR CEO

In 2019, we took a wonderful moment to celebrate the legacy and heritage of two of our Board Members. In honour of Professor Bob Elliott and Dr Ron Caughey, the co-founders of Cure Kids, we launched a 50th Anniversary Fund in their name.

In March, Cure Kids led a workshop with leading researchers from around the country with the single purpose of how to end rheumatic fever (RF) and rheumatic heart disease (RHD) in New Zealand. In December we set up a contestable granting round to fund research proposals that demonstrate high-quality, innovative research that furthers Aotearoa New Zealand's understanding, control and treatment of Rheumatic Fever (RF) and Rheumatic Heart Disease (RF/RHD).

This important initiative will be supported by the Elliott Caughey Fund. These initiatives will address child health conditions which for too long, New Zealand has said could and should be prevented. We want to galvanise our collective effort and bring together the expertise and resources from across the country that will unlock desperately needed solutions for our children and our future generations.


Forty thousand children a year are admitted to New Zealand hospitals with preventable illness, never before have we so desperately needed "Big Research for Little Lives."

In tandem to the Elliot Caughey Fund, we established a very special award to honour the enduring commitment of Mr Roy Austin to Cure Kids across more than 25 years. Roy's passion for our international significance in child health research makes this a fitting accolade.

The Roy Austin Repatriation Fellowship will support an outstanding child health researcher with an established career in medical or health research to further their work back home in New Zealand.

The Fellowship is a two-year appointment, and Fellows will be expected to continue the research aspect of their career at the highest level and establish a track record for future research leadership in their chosen field.

Every gift, partnership, and kind gesture of support for Cure Kids ensures we can support wonderful researchers.

During Red Nose Month we launched a beautiful new tagline *"Big Research for Little Lives"* a theme which so simply speaks to our mandate. As we move towards a digital future, our supporters celebrated Red Nose Day with the launch of a magically interactive story, telling the discovery fable of the Red Nose – *"Back Home to You"*. A precious and timeless resource for our future Red Nose campaigns.

On the people side of Cure Kids, we farewelled two incredible colleagues, Ryan Chandler, Research Manager and Tim Edmonds, Research Director. Both have moved on to advance their careers in the commercial and DHB sectors respectively. We thank both Tim and Ryan for the legacy they leave behind at Cure Kids and wish them well as their stars rise.

We welcomed Tara Satyanand to the role of Research Director and General Manager Cure Kids Fiji — Tara has worked on the research and development side of the Pharmaceutical Industry for the past 10 years, focusing on vaccines, antivirals and neurology products. Her knowledge and expertise will be invaluable to our mission.

In October, we were delighted to appoint Professor Stuart Dalziel to the position of Auckland University, Cure Kids Research Chair. Professor Dalziel is the Director of Emergency Medicine Research, Children's Emergency Department, Starship Children's Hospital (since 2010).

Professor Dalziel is well regarded both in the clinical and academic setting for his leadership, innovation and passion for child health and wellbeing, and is sensitive to the needs of our most vulnerable communities.

Big research for little lives

Every gift, partnership, and kind gesture of support for Cure Kids ensures that we can support wonderful researchers such as Professor Dalziel, and that we are able to realise the legacy of our founders — 40,000 children a year are admitted to New Zealand hospitals with preventable illness. N ever before have we so desperately needed *"Big Research for Little Lives."*

Thank you so much to those who supported us in 2019, to the wonderful staff, Board and Medical and Scientific Committee at Cure Kids, our inspirational ambassadors and their families, and, of course, the researchers whose passion and commitment are the driving force towards our vision of healthier children, with brighter futures.

Ngā mihi nui,

Frances Benge
CEO, Cure Kids

Roy Austin
Acting Chair, Cure Kids

Big research for little lives

# CURE KIDS GOVERNANCE

## CURE KIDS MEMBERS

**BERYL ROBINSON**
ROTARY IN NEW ZEALAND

**TONY FORTUNE**
ROTARY IN NEW ZEALAND

**BRUCE RASMUSSEN**
ROTARY IN NEW ZEALAND

**NICOLA AUSTIN**
PRESIDENT OF THE PAEDIATRIC SOCIETY

**ASSOCIATE PROFESSOR PHILIP PATTEMORE**
ROYAL AUSTRALASIAN COLLEGE OF PHYSICIANS

The five Cure Kids Members participate in constitutional and governance management aspects of Cure Kids. Three are drawn from our founding partner, Rotary New Zealand, continuing its proud association and support of Cure Kids. The fourth Member is the current President or nominee of the Paediatric Society of New Zealand, while the fifth member is a South Island-based nominee from the Board of Paediatricians of the Royal Australasian College of Physicians.

## CURE KIDS BOARD

**ROY AUSTIN** BCOM, CA, CNZM.
ACTING CHAIR, CONSULTANT TO NORTHINGTON PARTNERS, AUCKLAND

**FRANCES BENGE**
CHIEF EXECUTIVE OFFICER
CURE KIDS

**BARRIE CAMPBELL** ACA
SECRETARY/TREASURER, CURE KIDS
CONSULTANT TO BKR WALKER WAYLAND, AUCKLAND

**EMERITUS PROFESSOR BOB ELLIOTT**
MBBS, MD, FRACP, CNZM.
DIRECTOR LCT GLOBAL

**RUSS HEWITT**
SENIOR EXECUTIVE
VODAFONE

**DON JAINE** LLB, RPA.
DIRECTOR, SEQEL GROUP, AUCKLAND

**DR BRUCE SCOGGINS** BAgrSc (NZ), MAgrSc (CANT), PhD (MELBOURNE)
CONSULTANT, AUCKLAND

**ALAISTER WALL**
DEPUTY MANAGING DIRECTOR
BRISCOE GROUP LIMITED

**PROFESSOR STEPHEN ROBERTSON**
CURE KIDS CHAIR OF PAEDIATRIC GENETICS,
UNIVERSITY OF OTAGO, DUNEDIN

The Board provides governance management; administering and controlling Cure Kids. To ensure there is a breadth of experience around the Board table, the constitution requires that the Board includes at least four members with business experience, as well as a Chartered Accountant currently or formerly in public practice and the Chair or a representative of the Medical and Scientific Advisory Committee (MSAC).

## CURE KIDS BOARD ADVISORS

**PROFESSOR SALLY MERRY**
DUKE FAMILY CHAIR OF CHILD AND ADOLESCENT MENTAL HEALTH,
UNIVERSITY OF AUCKLAND

**PROFESSOR ANDREW DAY**
CURE KIDS CHAIR OF PAEDIATRIC RESEARCH, UNIVERSITY OF OTAGO, CHRISTCHURCH

The Board also has the ability to co-opt Advisory Members as non-voting Board Directors. The current Board has co-opted the Cure Kids Professorial Chairs as advisors.

## CURE KIDS MEDICAL & SCIENTIFIC ADVISORY COMMITTEE

**DR BRUCE SCOGGINS** BAgrSc (NZ), MAgrSc (CANT), PhD (MELBOURNE)
CONSULTANT, AUCKLAND

**PROFESSOR STEPHEN ROBERTSON**
BMedSci MBChB (OTAGO), FRACP, DPhil (OXFORD), FRSNZ.
DEPARTMENT OF WOMEN'S AND CHILDREN'S HEALTH,
DUNEDIN SCHOOL OF MEDICINE,
UNIVERSITY OF OTAGO, DUNEDIN

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The members of the MSAC provide the Board with research grants management advice. They draw on their considerable experience to assess applications on their ethical and scientific merit and their ability to conduct research into the diagnosis, prevention and treatment of conditions affecting children.

## CURE KIDS VENTURES BOARD

**ROY AUSTIN,** CHAIR

**HOWARD MOORE,** DIRECTOR

**FRANCES BENGE,** DIRECTOR

Cure Kids is a registered charity CC25350.

# CURE KIDS PROFESSORIAL CHAIRS

Cure Kids funds four Professorial Chairs. These are world-class senior research positions at leading universities around the country. This certainty of funding provides some of our brightest researchers with the licence to be curious, innovative and challenging in their work, creating an environment where breakthroughs can happen.

## PROFESSOR ANDREW DAY

### CURE KIDS CHAIR OF PAEDIATRIC RESEARCH, UNIVERSITY OF OTAGO, CHRISTCHURCH

Professor Day is a paediatric gastroenterologist with extensive expertise in Inflammatory Bowel Disease (IBD) in children and adolescents; New Zealand has some of the highest rates in the developed world.
His programme of research focuses on specific aspects of IBD, and is improving outcomes for young patients living with the condition.

## PROFESSOR STEPHEN ROBERTSON

### CURE KIDS CHAIR OF PAEDIATRIC GENETICS, UNIVERSITY OF OTAGO, DUNEDIN

Professor Robertson has gained international acclaim for his expertise in the field of paediatric genetic mutations, specifically those affecting the skeleton and the brain. His research involves widespread collaborations with scientists and clinicians across the globe. He was awarded the Health Research Council's Liley Medal for outstanding contributions to medical research in 2010.

## PROFESSOR SALLY MERRY

### CURE KIDS DUKE FAMILY CHAIR OF CHILD AND ADOLESCENT MENTAL HEALTH, UNIVERSITY OF AUCKLAND

Professor Merry is a child and adolescent Psychiatrist. Her work involves developing research-led treatments and prevention strategies to improve mental health outcomes for young people and their families.

Delivery through digital platforms, such as computers and mobile phones, is central to Professor Merry's work.

## PROFESSOR STUART DALZIEL

### CURE KIDS CHAIR IN CHILD HEALTH RESEARCH, UNIVERSITY OF AUCKLAND

Professor Dalziel is a Paediatrician with sub-specialty training in paediatric emergency medicine. He is the Professor of Paediatrics and Emergency Medicine at the University of Auckland, and Director of Emergency Medicine Research at Starship Children's Hospital, where he works clinically as a paediatric emergency medicine physician. His research to improve respiratory conditions in children, is strongly aligned to his everyday clinical practice at Starship Hospital.

# FUNDING RESEARCH BREAKTHROUGHS

**Cure Kids has been funding child health research since the 1970s. In 2015 and again in 2019, independent evaluations of the impact of this funding systematically demonstrated measurable benefits for the health of children. The findings – outlined below – illustrate the significant role that Cure Kids plays as the leading charitable funder of child health research in New Zealand.**

The 2015 evaluation was based on a sample of research grants funded by Cure Kids from 1976 to 2010, interviewing 61 Cure Kids-supported researchers across 171 grants. These interviews covered 73% of all projects funded by Cure Kids over this period, 35% of all fellowships, and three current professorial chairs. In addition, 78% of recipients of summer studentships were tracked online. Together, this information facilitated a comprehensive analysis of the Cure Kids' funding portfolio over time.

The follow-up evaluation in 2019 comprised interviews with 80% of researchers funded by Cure Kids during the 5-year period from 2011 to 2016. This covered 78% of all projects, and four current professorial chairs.

Cure Kids' impact has been wide-ranging, from understanding hormonal and metabolic factors involved in intrauterine growth restriction in unborn babies, through to developing a method for screening newborn babies for cystic fibrosis to enable them to be treated before their lungs are irreversibly damaged.

We are extremely proud that Cure Kids' funding has also contributed to preventing approximately 200 sudden unexpected deaths in infancy (cot deaths) every year in New Zealand.

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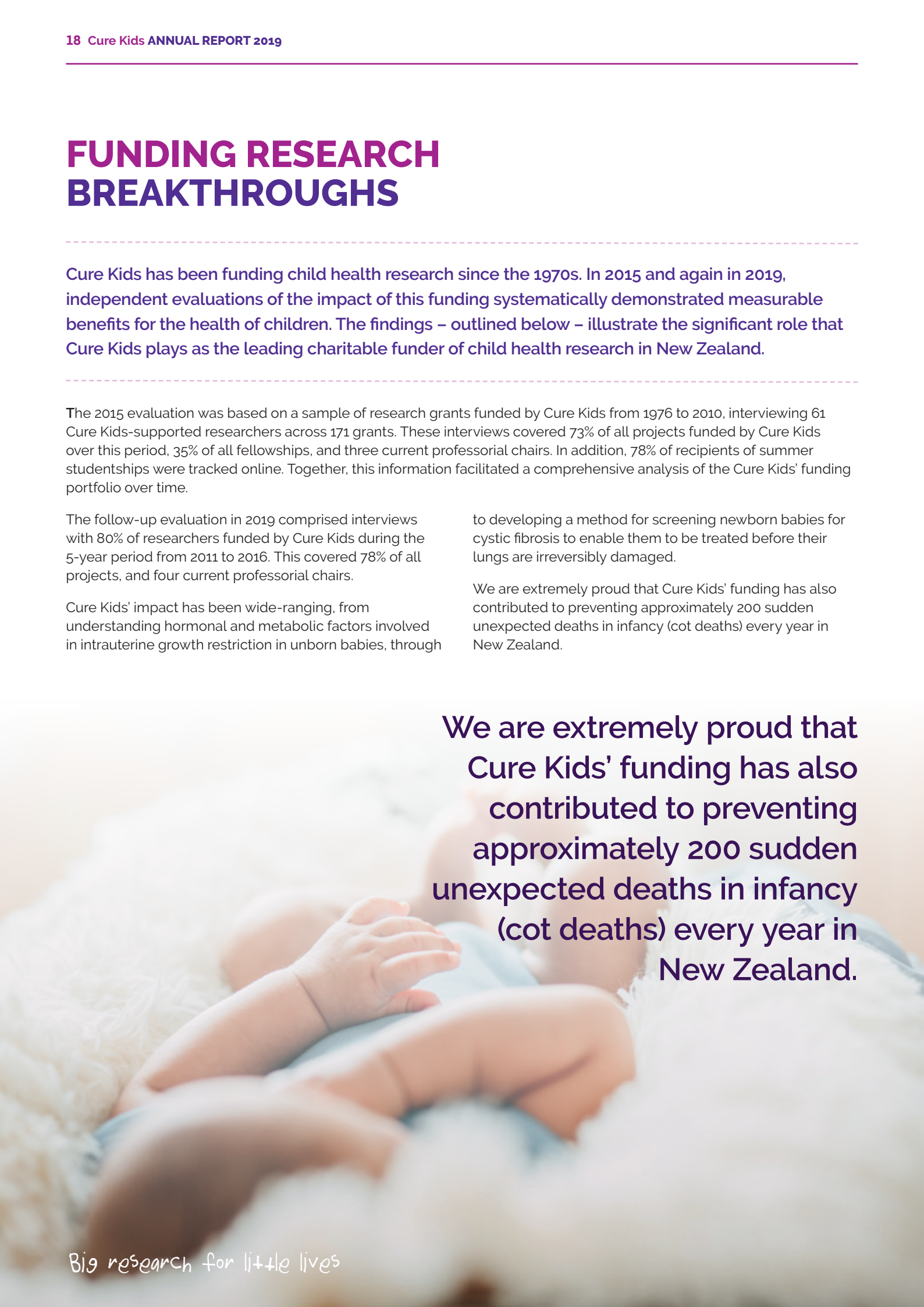


# SNAPSHOT OF IMPACT OF CURE KIDS-FUNDED RESEARCH

## IMPACT ON UNBORN BABIES

- First-ever case-controlled study on maternal sleep position, contributing to a 40% reduction in stillbirth rates for New Zealand babies.
- Examination of the effects of methadone treatment on unborn babies, changing policy on safe levels for methadone treatment not only in New Zealand but around the world.
- Research showed for the first time that maternal smoking in pregnancy is a health risk for the baby, resulting in significant policy changes.

## IMPACT ON CHILDREN

- Development of a new online tool for New Zealand youth suffering from depression and anxiety which helps by teaching positive skills for mental health.
- Creation of an app that lets children with inflammatory bowel disease (IBD) self-report the severity of their symptoms by using scales based on pictures and text.
- Discovery that group A streptococcus skin infection can also be a precursor to rheumatic heart disease.
- Development and testing of a robotic 'gait trainer' to assist children with cerebral palsy in over-ground walking.
- Development of lung-function assessment tests, that have now become standard clinical practice in New Zealand.
- Pioneering technology which explained the genetic basis for inherited heart conditions, and subsequently, reduced sudden and unexpected cardiac death in children.
- Studies examining infection and chronic lung disease which led to a change in clinical best practice.
- Discovery of genes that cause epilepsy in children, that allowed for more accurate diagnosis and targeted treatments for children.
- Identification of the importance of prenatal events for leukaemia, that enabled greater understanding of the disease by the medical profession and families.

## IMPACT ON INFANTS

- Study demonstrating that babies born at 23–24 weeks' gestation can survive and thrive.
- Prevention of 200 sudden unexpected deaths in infancy (SUDI) every year in New Zealand through the greater understanding of the risks associated with infant sleep position.
- Development of a method for screening newborn babies for cystic fibrosis, allowing for earlier diagnosis and more efficient and effective treatment.
- Illustration of the adverse effects of car seats on infant breathing, leading to invention of a patented seat insert to improve safety.
- Studies examining infection and chronic lung disease which led to a change in clinical best practice.

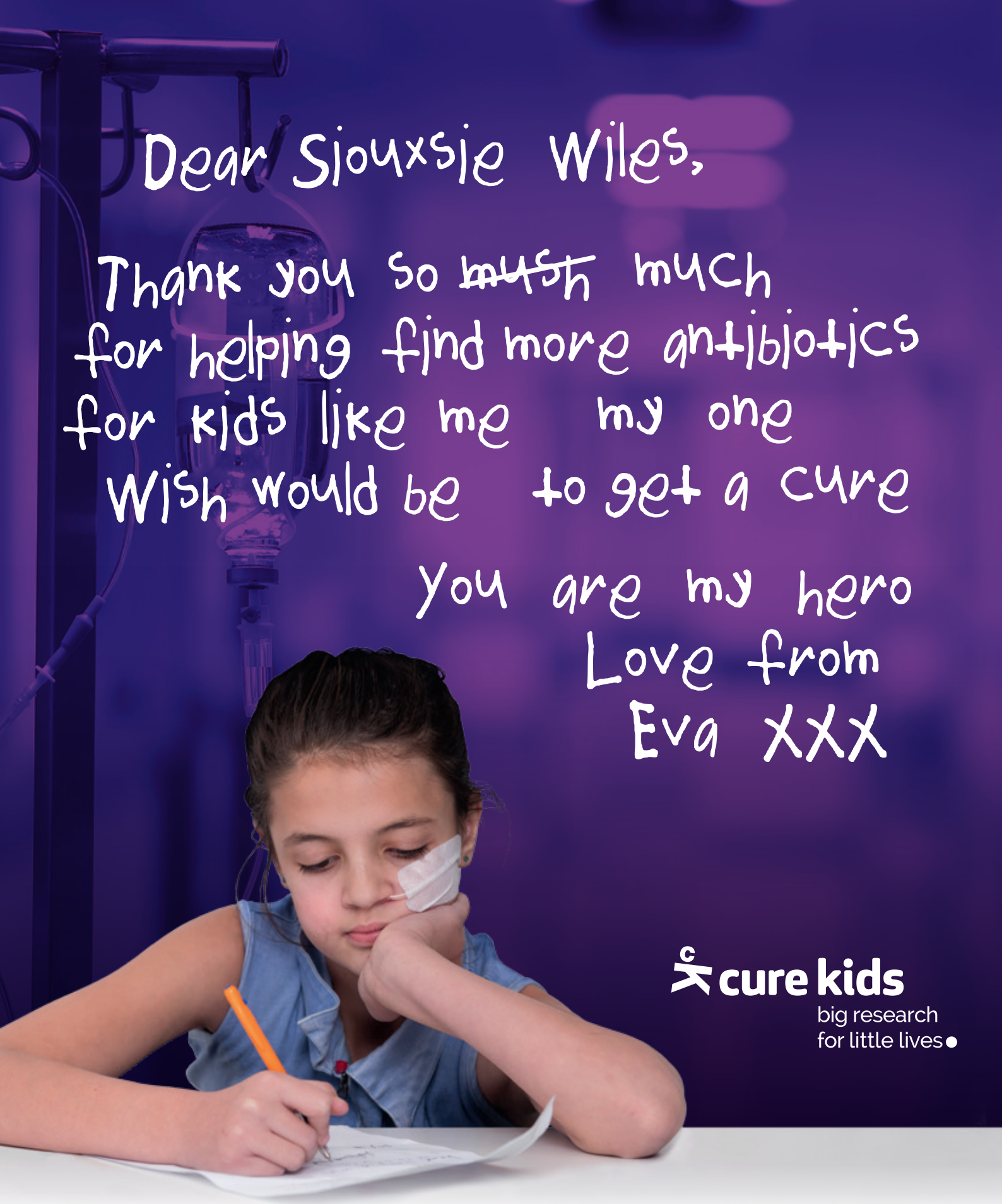
# SNAPSHOT OF IMPACT OF CURE KIDS-FUNDED RESEARCH

## IMPACT ON HOSPITAL CARE AND HEALTH PRACTICE

- A study on dental health among disadvantaged children in the Tāmaki community led to routine use of fluoride varnish by dental clinics, an additional Well Child screening check before school, and the planning of an intensive home-visiting programme.
- An assessment of child admissions within adult wards which was instrumental to informing how Starship Children's Hospital was structured.
- Early adoption of ground-breaking technology for viral detection and diagnosis at Auckland Hospital.
- A study which resulted in the updating of the Starship Hospital clinical guidelines for hospitalisation and treatment of pneumonia and respiratory diseases.
- Establishment of the first specialised paediatric neurology service in New Zealand, as a result of a Cure Kids repatriation scholarship.

## IMPACT ON NEW TECHNOLOGIES

- Engineering of a way to develop full-thickness human skin in a laboratory for the treatment of burn injury.
- Development of a method for modelling Long QT Syndrome in beating heart cells developed from patients' own blood cells, which could reduce the risk of cardiac events for these children and young people.
- Discovery of a method to prevent secondary brain injury by cooling babies' heads. This led to the development of an innovative brain-cooling cap, the first ever practical treatment for brain injury in infants.
- Novel use of gene therapy, which may be effective for children with Batten disease, a devastating neurodegenerative condition, which shares symptoms with Alzheimer's disease, Parkinson's disease, and epilepsy.
- Discovery that cystic fibrosis patients produce bleach in their lungs, enabling researchers to focus on developing new drugs to stop bleach formation.
- Identification of the importance of prenatal events for leukaemia, that enabled greater understanding of the disease by the medical profession and families.




## Eva lives with gastrointestinal failure and treatment-resistant infection MRSA.

**Dr Siouxsie Wiles is a microbiologist and bioluminescent enthusiast from The University of Auckland.**

Dr Wiles is on quest to find new antibiotics for increasingly drug-resistant infectious diseases. Bacteria have been developing new ways of resisting the attack of antibiotics. Dr Wiles is screening unique fungi found in NZ and the South Pacific for their bacteria-fighting abilities.

# RESEARCH WE'RE FUNDING

## EMERITUS PROFESSOR ED MITCHELL

### UNIVERSITY OF AUCKLAND

Every year in New Zealand, around one in every 200 pregnancies ends in stillbirth and 40 to 60 babies die suddenly in their sleep. Now researchers are using artificial intelligence and big data to reveal new insights into the causes of sudden unexpected death in infancy (SUDI). By working with Microsoft's leading data scientists, Professor Ed Mitchell and his team at the University of Auckland have shown definitively that mothers who have smoked before they were pregnant have a higher risk of SUDI. This research will enhance our understanding of the risk factors associated with stillbirth and SUDI, and help to protect at-risk babies.

## DR JACELYN LOH

### UNIVERSITY OF AUCKLAND

New Zealand has high rates of acute rheumatic fever and serious disease caused by Group A Streptococcus, which disproportionately affect Māori and Pacific children. A vaccine against these bacterial infections would greatly reduce the incidence of rheumatic fever and rheumatic heart disease. This would improve the health and wellbeing of New Zealand children, reduce health costs, and limit the spread of antibiotic resistance from over-prescription of penicillin. Dr Jacelyn Loh and her team at the University of Auckland have a promising vaccine called TeeVax under development. Their research involves finding compounds to boost the effectiveness of TeeVax.

## ASSOCIATE PROFESSOR STEPHANIE HUGHES AND DR INDRANIL BASAK

### UNIVERSITY OF OTAGO

Batten disease is a rare inherited brain disease that affects children. It is a devastating neurodegenerative condition, which shares symptoms with Alzheimer's disease, Parkinson's disease, and epilepsy. The available treatments are mainly palliative. Associate Professor Stephanie Hughes and her team at the University of Otago have successfully generated human neuron models of two forms of Batten disease in a petri dish. These models will allow their team and other researchers worldwide to compare disease mechanisms and test drug therapies.

## DR CHRISTINE MCINTOSH

### UNIVERSITY OF AUCKLAND

Every year in New Zealand between 40 and 60 babies die from sudden unexpected death in infancy (SUDI). About a quarter of these deaths are from the Counties Manukau Health (CMH) area. Dr Christine McIntosh and her team at the University of Auckland have developed the Safe Sleep Calculator, which assesses SUDI risk for infants and recommends practical changes to reduce that risk. They have demonstrated that 80% of SUDI deaths occur in the 21% of babies who have a higher risk score. In collaboration with the CMH SUDI prevention programme, Dr McIntosh has integrated the Safe Sleep Calculator into a tool called Survive and Thrive 2025, which can be used by General Practitioners, midwives, and other primary-care workers.

## ASSOCIATE PROFESSOR TRECIA WOULDES

### UNIVERSITY OF AUCKLAND

A longitudinal study of children exposed to methamphetamine before birth shows they have higher rates of adverse childhood experiences from birth to 36 months. The Infant Development, Environment and Lifestyle (IDEAL) study showed that these experiences include poverty, maternal mental illness, and problematic use of alcohol and illegal drugs. Using data from the IDEAL study, Associate Professor Wouldes and her team at the University of Auckland are investigating the impact of prenatal exposure to methamphetamine in adolescents, by assessing health, mental health and behavioural problems, with a view to developing targeted interventions.

## DR JASON TURUWHENUA

### UNIVERSITY OF AUCKLAND

Amblyopia, also known as lazy eye, is a paediatric condition that affects motor development, impairs reading, and almost doubles the lifetime risk of legal blindness. Early diagnosis and treatment significantly improve visual acuity, but measuring visual acuity is difficult with pre-school children. Dr Jason Turuwhenua and his team at the University of Auckland have developed an automated, computer-based test to objectively determine visual acuity in pre-school children. This test could reduce costs and lead to better treatments for ambylopia.

## PROFESSOR PETER STONE
### UNIVERSITY OF AUCKLAND

Late stillbirth (after 28 weeks) is a tragedy that often happens without any explanation. Professor Stone and his research group at the University of Auckland have shown that maternal supine position during sleep is a risk factor for stillbirth. Their work also looks at how the sleep positions of pregnant mothers affect unborn babies who are not growing as well as expected. Professor Stone's team is using a new technique that combines magnetic resonance imaging (MRI) scanning with a novel analysis process to measure oxygen transfer from mother to baby across the placenta, as well as oxygen levels in the baby. The long-term goal of this project is to provide a better understanding of how vulnerable unborn babies respond to stress, such as the mother lying on her back, with a view to preventing stillbirths.

## PROFESSOR RUSSELL SNELL AND DR JESSIE JACOBSEN
### UNIVERSITY OF AUCKLAND

Fragile X syndrome is the leading known cause of inherited intellectual disability and autism spectrum disorder. According to the patient-support organisation Fragile X New Zealand, more than 1000 New Zealanders are affected. Professor Russell Snell and his team at the University of Auckland are hoping to develop a model of this syndrome, which they can then use to test potential treatments. Their work has the potential to accelerate understanding of this complex genetic syndrome, and in the longer term to underpin clinical trials of targeted therapies.

## DR JINEY JOSE
### UNIVERSITY OF AUCKLAND

Between 2010 and 2014 cancer of the central nervous system made up 20% of all childhood cancers in New Zealand. Researchers have discovered promising treatments which would limit cancer growth, but delivering these agents to the brain is a challenge since the blood-brain barrier which protects the brain also blocks therapeutic agents. Dr Jiney Jose and his team at the University of Auckland are focused on tumour targeting, with small-molecule drug-dye conjugates that can penetrate the blood-brain barrier. Their work could lead to treatments for brain cancers in both children and adults.

## DR MAIRIN TAYLOR
### UNIVERSITY OF CANTERBURY

A debilitating disorder affecting 5–10% of New Zealand children, attention-deficit hyperactivity disorder (ADHD) is associated with higher rates of mood disorders, anxiety disorders, defiance disorders, risk-taking behaviours, and criminal offending. Dr Mairin Taylor and her team at the University of Canterbury are adapting an established mindfulness programme (MyMind) to treat ADHD. They will incorporate a Kaupapa Māori framework with Te Reo Māori and Tikanga principles, through ongoing consultation and partnership with mana whenua and Māori researchers and clinicians. The programme will be trialled for effectiveness in improving behaviours and psychosocial outcomes with New Zealand children.

## DR JENNIFER KNOPP
### UNIVERSITY OF CANTERBURY

Despite a decrease in New Zealand's birth-rate, premature birth and admissions to neonatal intensive care units (NICU) have actually increased, resulting in increasing demand for assisted ventilation. However, misuse of assisted ventilation can cause ventilator-induced lung injury and extend babies' stays in NICU. Dr Jennifer Knopp and her team at the University of Canterbury are conducting research to characterise patient-specific lung mechanics and gain a better understanding of how NICU babies breathe. It's hoped that their results will improve delivery of assisted ventilation, reduce risks of lung injury, and reduce reliance on assisted ventilation.

## DR ADAM O'NEILL
### UNIVERSITY OF OTAGO

For 1–3% per cent of New Zealand children, disorders in the development of their brain affect how they move, think, feel, and behave. Neurodevelopmental conditions in this category include intellectual disability, autism spectrum disorder, attention deficit hyperactivity disorder, and dyslexia. Understanding the molecular changes that lead to neurodevelopment disorders is made difficult by limited access to the tissue of relevance — the developing human brain. Dr Adam O'Neill and his team at the University of Otago are using stem-cell research to model the development of a child's brain condition from its onset to maturity. The aim is to inform detailed diagnoses for children with neurodevelopment disorders, find clues to the diverse causes that lead to these conditions, and ultimately improve management and treatment.

# A BETTER START

**A Better Start is funded by the Ministry of Business, Innovation & Employment (MBIE) as one of the 11 National Science Challenges. 'A Better Start / E Tipu e Rea' funds mission-led research designed to predict, prevent and intervene early so that children have a healthy weight, are successful learners and young people can access the tools that they need to look after their health and wellbeing.**

**Cure Kids partnered with the programme in 2017 to co-fund a joint contestable funding round and ten projects were funded, from a total funding pool of $2.8m.**

Here's an update on eight of the ten completed research projects funded by the joint partnership initiative with Cure Kids:

## DR YVONNE ANDERSON
### UNIVERSITY OF AUCKLAND

***Whānau Pakari: understanding barriers to engagement, participation and retention in obesity intervention for children and adolescents.***

Whānau Pakari is a multi-disciplinary intervention programme for children and adolescents with weight issues. This research is increasingly focused on working collaboratively to improve provision of healthcare services for Māori, and working to address health inequity. Interviews have confirmed that engagement with healthcare services is affected by location and traveling distance, nature and timing of work, socioeconomic circumstances, and transport access. Dr Anderson and her team also found that wider system and societal factors have an impact on engagement with healthcare services, such as societal norms and attitudes towards body-weight, and the impact of past experiences of weight stigma. This research has informed development and delivery of other programmes to promote healthy lifestyles. .

## GAYL HUMPHREY
### UNIVERSITY OF AUCKLAND

***See how they grow: Developing and trialling an interactive Child Growth Chart for New Zealand children***

Dr Humphrey has created an interactive smartphone application (app) for New Zealand families, to measure the growth of their children aged 0-24 months, and to facilitate better health literacy among parents, while encouraging greater engagement around monitoring their children's eating, activity, sleeping, and related behaviours. Testing showed that the app was easy to use and had a positive impact on the health and wellbeing of children in the trial. Engaging with parents and care-givers early in their parenting journey, when their child is younger than 6-months of age, presents an ideal opportunity to support and develop their depth and breadth of knowledge around growth and monitoring. The app is well-positioned to provide further research to understand the impact of mobile health tools on reducing childhood obesity.

## PROFESSOR BOYD SWINBURN
### UNIVERSITY OF AUCKLAND

***Obesity Prevention Using Systems Science in school children and adolescents (OPUSS-schools)***

Four Papakura schools tested a series of systems-related approaches to food and physical activity. The first task involved working with school students to create systems maps of the influences on food and dietary intake, and in particular those variables in the school food environment. Results show that there are several places where systems thinking can be included in the New Zealand school curriculum. The second task was to test a Māori approach to health (Atua Matua) within their local school environments. Several approaches were tested, and some worked well enough to be applied at scale. The third task was to test a low-cost monitoring system. This was successfully tested in three schools, demonstrating the feasibility of an opt-out method of parental consent to increase response rate. The systems maps, interventions, and monitoring systems developed by vanguard schools to enhance their food and physical activity environments had overall positive impacts on physical health, especially healthy weight, oral health, and mental health and wellbeing.

## DR NIGEL HARRIS
### AUCKLAND UNIVERSITY OF TECHNOLOGY

***High intensity interval training and mental health in adolescents***

Dr Harris is leading a programme of research that will assess the effectiveness of High-Intensity Interval Training (HIIT) to improve mental health in schools, compared with their existing Physical Education (PE) programmes. The HIIT programme has produced significant improvements in fitness outcomes, such as greater



strength, greater self-perceived fitness, and greater movement competency than normal PE lessons. However, in terms of the surveys used to determine mental health, there was no effect. Qualitatively, the teachers also reported a greater sense of self-esteem, accomplishment and self-efficacy amongst their students, and improved class dynamics. This is supported by the fact that many of the schools voluntarily chose to maintain the HIIT programme, which will continue to be monitored by the team for ongoing research and development.

## DR JOANNA TING WAI CHU
### UNIVERSITY OF AUCKLAND

***MyTeen – Increasing competence and mental health literacy: A mobile-based intervention to support parents of teenagers***

Dr Chu has developed an SMS-based mobile intervention aimed at promoting confidence and mental health literacy for parents of adolescents. User testing revealed that fathers share similar parenting concerns as mothers, but are less likely to access support or feel supported. Testing also confirmed that a significant proportion (17%) of parents have teenagers who have experienced mental health issues in the past year, but very few have sought professional services. This study addressed the need to provide parents with the tools and knowledge to be able to respond with competence and confidence, and to promote positive well-being in their children. Participants who received the text message programme reported feeling more competent as parents, less stressed, and having better communication with their adolescent. This boost held at the three-month mark, two months after they'd received their last text message.

## DR LEONIE PIHAMA
### UNIVERSITY OF WAIKATO

***Te Taonga o Taku Ngākau: Ancestral Knowledge as a Framework for Wellbeing for Tamariki Māori***

Traditional Māori approaches of child-rearing hinge on collective responsibility, rather than individual endeavour. However, isolation caused by urbanisation over the past few decades has led to a collapse of the collective approach. Dr Pihama and her team focused on the development of evidence-based, cultural interventions to improve the mental health and wellbeing of young Māori. Results show that Kaupapa Māori approaches and practices provide whānau, hapu and iwi with clearly defined tikanga, reo and matauranga Māori to inform the wellbeing and connectedness of tamariki and mokopuna within their cultural genealogical framework. Dr Pihama's research shows that to improve outcomes for tamariki Māori, it is critical to incorporate traditional approaches to Māori health.

## PROFESSOR JOHN EVERATT
### UNIVERSITY OF CANTERBURY

***Facilitating emotional well-being and positive behaviours in children with literacy learning difficulties***

Reading difficulties contribute to poor achievement at school and restricted job opportunities in the future. Professor Everatt is investigating the extent to which culturally responsive and research-informed interventions can improve literacy in young readers, and in turn, increase self-esteem and resilience. Results show the interventions produced gains in vocabulary development, morphological awareness, reading, and spelling, and reading comprehension. Children in the study also demonstrated improvements in self-concept, self-efficacy, resilience and negative behaviours.

## PROFESSOR CAMERON GRANT
### UNIVERSITY OF AUCKLAND

***Growing Up in Australia and New Zealand: Translational modelling to inform an evidence-based childhood obesity intervention agenda***

Professor Grant conducted a series of statistical modelling exercises to assess important aspects of obesity among New Zealand pre-schoolers. His aim was to identify high-impact, readily modifiable risk factors for childhood obesity with a view to informing future research and interventions. Results reveal that food insecurity, screen time, junk food, and reduced sleep duration in early life (up to age 2 years) are statistically associated with increased odds of obesity and/or being overweight at age 4 ½ years. This research suggests that future efforts to design interventions for obesity in children should focus on these exposures and begin in the first 1,000 days.

# TRUSTS AND FOUNDATIONS WHO SUPPORT US

We are enormously grateful for ongoing financial support from these trusts and foundations.

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## SPECIAL MENTIONS

The Paediatric Precision Cancer Project received a $250,000 cash injection from the **LINDSAY FOUNDATION**. Led by Dr Andy Wood, this project uses whole-genome sequencing as a targeted therapy approach for children with hard-to-treat cancers.

A huge thanks to the **HUGO CHARITABLE TRUST** for committing $155,000 to supporting Dr Sarah Fortune's research into child and adolescent self-harm surveillance and suicide prevention.

For many years, the **ESTATE OF ERNEST HYAM DAVIS & THE TED AND MOLLIE CARR ENDOWMENT FUND** have supported research into finding causative genes in childhood epilepsy. This funding has led to better treatment paths and will ultimately lead to improved long-term outcomes for children with epilepsy.

# cure kids fiji islands

**Cure Kids Fiji is working to improve the health of the children of Fiji, with generous support from people and organisations who are inspired by the impact we can make with research and evidence-based medicine. Cure Kids Fiji focuses on rheumatic heart disease and severe respiratory illnesses such as pneumonia. We are actively expanding both of these programmes of life-saving research.**

## CONTROL AND PREVENTION OF RHEUMATIC HEART DISEASE

### RHEUMATIC HEART DISEASE

Recurring bouts of rheumatic fever (RF), and the immune system's response, cause rheumatic heart disease (RHD), and can eventually lead to heart failure and stroke. Rheumatic fever mainly affects children aged between 5 and 15 years. The disease is a leading cause of premature deaths, and creates a huge burden for public health systems.

Rates of RHD are higher in the Pacific Islands than in most other parts of the world. In Fiji, approximately one child in every classroom is affected by RHD. The age-standardised death rates in Fiji are more than twice the global average, and the risk of death for people with RHD is eight times greater than for other people. In young Fijians, RHD is the most common cause of death from illness or disease.

### PARTNERSHIPS

In June 2014, Cure Kids teamed up with researchers in the Fiji GrASP (Group A Strep Project), the Centre for International Child Health at Murdoch Children's Research Institute in Melbourne, Australia, and the Auckland District Health Board in New Zealand, to support Fiji's Ministry of Health and Medical Services (MoHMS) in its efforts to prevent and control RHD.

The multi-million-dollar programme was made possible by joint funding from NZ's Ministry of Foreign Affairs and Trade (MFAT) and AccorHotels. FIJI Water Foundation also generously provided funding for echocardiography machines and an information management system to track cases of rheumatic fever. We are grateful for the support of these partners, and for the highly skilled Fiji-based team who deliver the programme.


### PREVENTION AND CONTROL

RHD control and prevention is a national priority for Fiji, and the Fijian government launched a major control and prevention strategy in 2005. Evidence from New Zealand shows that early diagnosis of RF and mild RHD, with an effective secondary prevention programme to prevent fever from recurring, can reduce mortality and morbidity.

The aim of Cure Kids Fiji's RHD Prevention and Control Programme is to develop and adapt models of care and prevention, and coordinate existing activities to ensure sustainable national disease management. This includes secondary prophylaxis with antibiotics to halt the progression of the disease.

Achievements to-date include:

- **Development and implementation of a new online patient-information system, which allows healthcare professionals to monitor and report on treatment and care for more than 4,400 patients with RHD;**
- **Roll-out of a programme based on the information system to detect RHD cases early and promote preventative treatment;**
- **Implementation of innovative models for early detection of RHD using echocardiography machines, including school-based screening;**
- **Development and delivery of messages designed to raise public awareness of RHD, and encourage evidence-based measures to prevent and control disease;**
- **Improvement of rates of adherence to preventative treatment – from 12% to 39%;**

*Continued over* >

- **Development of clinical guidelines for RHD;**
- **Training of more than 2,600 health workers in providing best-practice care to patients;**
- **Initiation of support groups, enabling more than 1,000 RHD patients and their carers to participate in activities, and share their experiences and challenges; and**
- **Integration of RF/RHD services and activities into the Fijian Government's budget and health services.**

The long-term outcomes include a reduction of health inequities and significant progress towards universal access to care.

The research carried out by the Fiji GrASP researchers from 2005 to 2011 and the MFAT-funded Fiji Islands RHD Control and Prevention Programme from 2015–2019, have set a strong platform for further interventions through establishing relationships, rapport and trust with the Fiji Government and communities across Fiji. The long-term outcomes include a reduction of health inequities and significant progress towards universal access to care. Raising the standard of care for RHD will in turn reduce maternal morbidity and mortality, disease severity at diagnosis, the incidence of RF, and the prevalence of RHD.

## LIFE-SAVING TREATMENT WITH OXYGEN

No child, no person, should die for lack of oxygen. For severe pneumonia, which is the biggest killer of children worldwide, oxygen can reduce the risk of death by 35%. Other severe respiratory conditions, such as asthma, also require treatment with oxygen, and the World Health Organization recommends oxygen therapy for preterm babies and newborn babies with serious illnesses.

Although these conditions are leading causes of death in Fiji, oxygen is expensive and can be logistically difficult to provide. Cure Kids Fiji's Oxygen Project has been designed to addresses the challenge of improving the availability, affordability, and clinical use of oxygen in Fiji.

### OXYGEN PROJECT

Since 2016, Cure Kids has partnered with Fiji's Ministry of Health and Medical Services to pilot broader use of oxygen concentrators in hospitals and health centres to supply oxygen to those who need it. Oxygen concentrators are small, portable machines which filter nitrogen from ambient air to supply highly pure oxygen for patients.

This project builds on evidence generated by Associate Professor Stephen Howie, of the University of Auckland, who has led the work to pilot use of oxygen concentrators, and to ensure that an improved supply of oxygen translates into better clinical outcomes through enhanced detection and case management of hypoxic illnesses. The solutions are designed to be scaleable and sustainable, with the ultimate goal of national coverage, to ensure that no communities are left unprotected.

Achievements include:

- **Installations at six health facilities around Fiji: Subdivisional Hospitals at Taveuni, Savusau, and Nabouwalu, and Health Centres at Lekutu, Nausori, and Wainunu;**
- **Training of more than 140 clinical and technical staff — to use specialised equipment to detect and treat hypoxic illnesses;**
- **Treatment of more than 6,100 patients with life-saving oxygen;**
- **Appointed of a dedicated Biomedical Technician by the Fiji MoHMS, to ensure that machines can run reliably and efficiently and ensure long-term sustainability of the Programme.**

Over time, this work has been enabled by generous funding support from the Australian Government, AccorHotels, Armacup, ANZ Bank, and the Fiji Water Foundation.

## PARTNER SUPPORT

Cure Kids Fiji is humbled by the committed and passionate support of our sponsors and donors, without whom our work would not be possible. We would also like to extend a special thanks to the many individuals and organisations who participate in and support our events to help us reduce costs and maximise fundraising. This includes the MFAT NZ Aid Programme, the University of Auckland, the Australian Government, AccorHotels, Armacup, Fiji Water Foundation, VOMO Island Fiji, DarkHorse, Higgins, Rosie Holidays, Pleass Beverages, UB Freight, and Star Printery.

### FIJI WATER FOUNDATION Wonderful Giving Programme

Cure Kids Fiji is proud to be a long-time partner of FIJI Water Foundation, one of Fiji's largest philanthropic organisations. FIJI Water Foundation has a range of priorities which include improving access to healthcare services for underprivileged communities. The generous support of FIJI Water Foundation has enabled Cure Kids to extend its RHD programme, including the Rheumatic Fever Information System, a live database of young people and adolescents living with RHD, and echocardiography equipment critical to the detection of new cases.

In 2019, we were humbled to be nominated as charity of choice by staff and management of FIJI Water, and its sister company, Neptune. Cure Kids Fiji received a cheque for FJ$21,700 from the Wonderful Giving programme, which will be used to support the Fiji Oxygen Project.

### ANZ FIJI & NEW ZEALAND The ANZ Fiji500

Every year for the last 3 years a team of riders, with the support of ANZ, has set off on a 500 km road-bike ride around Fiji's main island to raise funds for Cure Kids' Fiji Oxygen Project. Since its inception, this event and the continuous support of ANZ has enabled over FJ$314,000 in fundraising and has made an incredible impact on expanding the oxygen project throughout Fiji.

### ARMACUP

Armacup, New Zealand's vehicle-shipping pioneers, are a long-term supporter and have been an integral part of Cure Kids Fiji since its launch in 2006. Armacup generously donates USD$6 for every vehicle shipped to the Fiji Islands, among many other activities, and this year we are thankful to receive close to FJ$91,000 from Armacup which will be invaluable in accelerating Cure Kids Fiji's work in the child health space.

### CAPTAIN COOK CRUISES

Only a year and a half into the partnership, Captain Cook Cruises Fiji has successfully raised over FJ$23,000 for Cure Kids Fiji's child health initiatives, through guest-giving initiatives, 100% of which goes directly to Cure Kids Fiji. We're grateful to the team and their guests for their commitment to making a real difference in the lives of our children.

### VOMO ISLAND FIJI

VOMO Island Fiji supports Cure Kids Fiji's fundraising through guest contributions, room night donations, accommodation prizes at Cure Kids Fiji fundraising events, facilitating sale of the Cure Kids Fiji souvenir toys, and the annual 'Mt Vomo Sunrise Challenge'. VOMO also hosts the annual Christmas event 'Christmas @ VOMO' for children and adolescences living with Rheumatic Heart Disease and their guardians. VOMO's ongoing support has been key to extending the reach of our child health programmes in Fiji, and in 2019 alone raised upwards of $17,000 towards the cause.

# CURE KIDS PARTNERS

Thanks to our corporate and business partners for supporting child health research through fundraising events, in-store collections and event sponsorship.

### PLATINUM PARTNERS

ACCORHOTELS

BRISCOE GROUP

COLLIERS INTERNATIONAL

### KEY PARTNERS

ARMACUP

AVIS BUDGET GROUP

COLUMBUS COFFEE

INGRAM MICRO

JOHN ANDREW MAZDA

LANDMARK HOMES

PARTNERS LIFE

QANTAS

ROTARY IN NEW ZEALAND

## BRISCOE GROUP

The Briscoe Group – Briscoes, Rebel Sport, Living & Giving – have raised an epic $7.5 million for Cure Kids over 16 years. During 2019, the Briscoe Group gathered a total of $743,000 by supporting five key events:

- **$150,000 for our April Superbugs campaign, a quest to find new antibiotics to fight superbugs**
- **$166,000 from their midwinter *Add What You Can* retail appeal**
- **$175,000 for our spring Red Nose Day appeal**
- **$140,000 for the Cure Kids Golf Day**
- **$112,000 for the 12 Days of Christmas Giving**

Our heartfelt thanks to the incredible front-line staff at Briscoes who continue to be some of our biggest advocates.

## COLLIERS

Colliers has been a Cure Kids partner since 2005, so far contributing more than $1.2 million towards Cure Kids research funding. Their staff, suppliers and customers are encouraged to engage with every fundraising opportunity, from golf days to corporate lunches and movie nights. For 2019, a highlight was Colliers' Annual Long Lunch, which raised $70,000.


## ACCOR

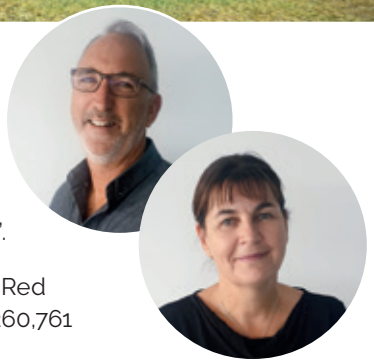
Accor made an outstanding contribution to our research funds in 2019, reaching a grand total of $228,211. They created and ran five amazing fundraising events – *Kitchen Battles* at Novotel and Ibis hotels in Auckland, *Send in the Clowns* quiz night at Grand Mercure in Wellington, Novotel Queenstown Quiz Night, *A Night at the Prom,* held at Novotel Tainui and Ibis Tainui in Hamilton, and *Arabian Nights* at Rotorua Novotel.

*Cure Kids' ambassador Corin and his Dad Jon at the Landmark framing celebration. Jon was employed by Landmark North Shore/Rodney and was the Project Manager for the build.*

LANDMARK
HOMES

## BUILDING HOPE PROJECT

We are forever grateful for the generosity of Landmark Homes' North Shore/Rodney franchisees Paul and Debbie Brett. They built a five bedroom, 3 bathroom, 283m2 home at 37 Kano Way in Hobsonville, then sold it by auction and donated all profits to Cure Kids.



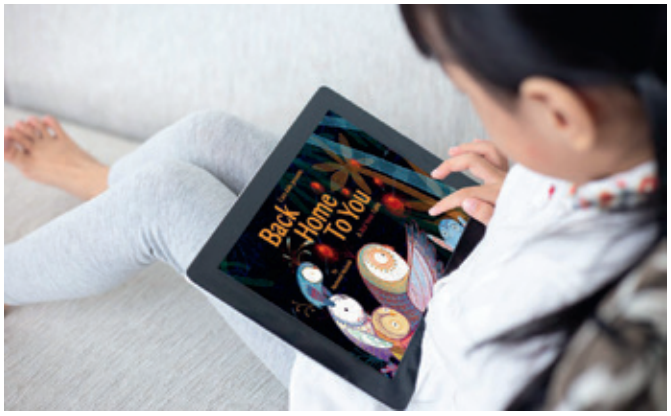
More than 50 businesses from around New Zealand came on board and donated materials, labour or both to the build. The result was 'the house that love built'.

The house was auctioned on Red Nose Day, raising a total of $260,761 for Cure Kids.

# RED NOSE DAY 2019

$1,122,000
TOTAL RAISED

Red Nose Day is Cure Kids' most famous tradition. It's our biggest annual fundraiser and a chance to shine a light on research for children's health. It's also huge fun! We're constantly amazed by the Red Nose Day fundraising ideas our supporters come up with.




## LAUNCH OF OUR STORYBOOK APP

"For Red Nose Day 2019, we created a magical storybook app that allows New Zealanders to help Cure Kids raise funds, while enjoying a precious moment with their tamariki."

Frances Benge, Cure Kids CEO

A special highlight for 2019's Red Nose Day appeal was the launch of our storybook app, titled *Back Home to You.* Written and illustrated by Raymond McGrath, it's a story of exploration and imagination, where a red nose is more than something you wear, it's a beacon of hope. Proceeds are ongoing, as more people download the app.

## IN-STORE FUNDRAISING

Cure Kids partners never cease to amaze us with their tireless support of Red Nose Day. Briscoes and Rebel Sport staff up and down the country went all out, dressing in red, donning wigs, and asking customers to add a donation to their purchase. Columbus Coffee rolled out the red and, in Warkworth, Mitre 10 MEGA put a red nose on Kong. They were just some of hundreds of Kiwi businesses that got in behind Red Nose Day.

## GALA DINNER

$320,000
RAISED

The annual Cure Kids Red Nose Gala Dinner, held on Friday 13th September at the Pullman Hotel, was attended by 425 people.

Proudly sponsored by Partners Life, the event raised an outstanding $320,000! Melissa Stokes was our MC, Sir John Key gave a keynote address, and Hollie Smith put her golden voice to work.

## RED NOSE FAMILY FUN DAY

Well done to Cure Kids' ambassador super-Mum Laurel and her team for making their Red Nose Family Fun Day in Palmerston North such an outstanding success. Laurel has planned and managed the event in its entirety for many years.

*Photo credit: Imagen Photography*

## RED NOSE DAY IN SCHOOLS

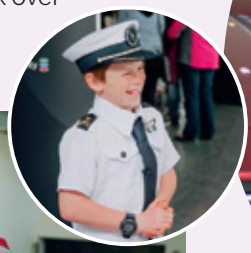
Parnell District School is a long-standing supporter of Cure Kids and every year their student committee plans an incredible day of fundraising. This year Professor CK arrived to cheer them on. Professor CK also visited Marina View School, where close to $2000 was raised for Cure Kids.

## RED NOSED MAZDAS!

John Andrew Mazda donated $100 to Cure Kids for every red Mazda sold during September.

## THANKS QANTAS!

In the lead-up to Red Nose day, a group of Cure Kids ambassadors dressed up as pilots and took over check-in desks at Qantas. They collected donations and lots of smiles!



# OUR INFLUENCERS

We're so lucky to have some famous people helping us out. Here are some of the influencers who've been sending publicity our way recently.

## PROFESSOR CK

Cure Kids now has a larger-than-life mascot who's helping us to raise both awareness and funds. Professor CK, shown here with Addison, was created with help from the Rush family. She's a passionate advocate for children's health and helped out enormously with the latest Red Nose Appeal.

## CAROLYN TAYLOR

Former children's TV presenter and media personality Carolyn Taylor danced up a storm for Cure Kids on Dancing with the Stars NZ. Coached by her professional dancing partner Johnny Williams, she raised $40,197.24 towards Cure Kids research funding.

## MELISSA STOKES

Television news presenter Melissa Stokes helped us out by MCing our gala dinner. Her witty banter helped the evening to raise $321,605 for research funding. Melissa offered her services as an influencer out of the blue; it was a call our CEO was very happy to get.

## ALEX NANKIVELL

Midfield back for the Chiefs, Alex has a very personal reason for becoming an ambassador for Cure Kids. His eldest brother William died from neuroblastoma, a form of child cancer that affects about 11 Kiwi kids every year.

## ART & MATILDA

New parents Art Green and Matilda Rice welcomed their first child last year, and they still find time to help us out at fundraising events.

## SHELTON WOOLRIGHT

While Shelton's music and photography career is currently based in London, he's often in New Zealand and loves to help us out however he can.

## JONO PRYOR

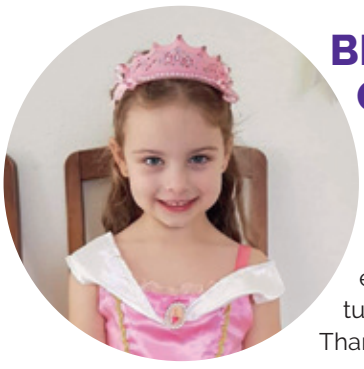
Radio host and TV personality Jono Pryor lends us his humour and good nature to help promote fundraisers, like Red Nose Day.

# COMMUNITY FUNDRAISING

## NYC MARATHON

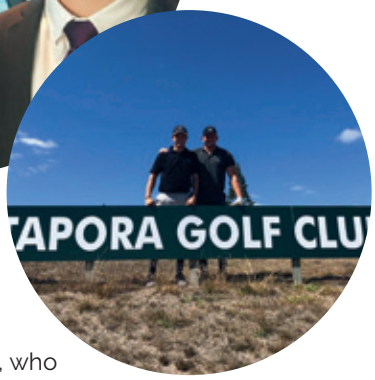

**$137,602**
**RAISED**

Running the New York City Marathon for Cure Kids has really taken off! In 2019, 16 runners completed the marathon on our behalf, earning $137,602 for child health research. One of our runners, Ben Parore, made international headlines when he pushed the handcycle of a partially-paralysed contestant to the finish line.



## BIRTHDAY GIFTING

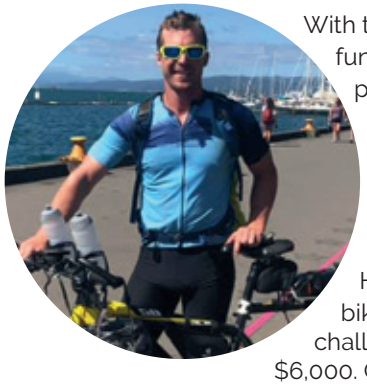
Asking friends and family to donate to Cure Kids in lieu of gifts is an incredibly selfless deed, especially when you are turning 5 years old! Thanks Delta.




## PUTTING WITH PURPOSE

In memory of his brother Pete, who died from a rare form of bone cancer at age 17, Jacob Troake and his family continue to raise money for Cure Kids by playing at every single one of New Zealand's golf courses. Jacob uses a Cure Kids online fundraising page to gather sponsorship money for his challenge.

## AOTEAROA BIKE CHALLENGE



With the dual-purpose of fundraising for Cure Kids and promoting the sustainability benefits of electric bikes, Callum Spence cycled from Auckland to Wellington as part of the Aotearoa Bike Challenge. He converted a mountain bike into an e-bike for this challenge and raised nearly $6,000. Callum was inspired by a little girl called Esme, who's battling cancer.

**ATTENTION ALL COMMUNITY FUNDRAISERS! WANT TO HELP FUND CHILD HEALTH RESEARCH WHILE YOU'RE TRAINING TO COMPETE IN A LOCAL EVENT?**

**https://curekids.org.nz/fundraise/**

## HOW ARE WE DOING?
# CURE KIDS FINANCIAL STATEMENTS

### SUMMARISED STATEMENT OF FINANCIAL PERFORMANCE

| | CONSOLIDATED | |
|---|---|---|
| | **31.12.19** | **31.12.18** |
| Fundraising Income | 4,466,000 | 5,003,282 |
| Grants Received | 125,000 | 640,116 |
| NZ Government Grant | 0 | 700,000 |
| Rental Income | 240,524 | 235,806 |
| Interest & Dividends on Investments | 795,729 | 790,046 |
| Unrealised Gains | 2,828,287 | 728,663 |
| Realised Gains/(Losses) | 37,958 | (53,489) |
| Other | 351,091 | 3,458 |
| TOTAL INCOME | **8,844,589** | **8,047,882** |
| Fundraising Expenses | (1,110,675) | (1,450,151) |
| Administration Expenses | (671,306) | (759,617) |
| Salary Expenses | (1,841,546) | (1,836,248) |
| Research & Development | (242,053) | (132,381) |
| Grants & Research Investment | (3,267,835) | (3,934,884) |
| NET SURPLUS/(DEFICIT) | **1,711,174** | **(65,399)** |

### SUMMARISED STATEMENT OF FINANCIAL POSITION

| | CONSOLIDATED | |
|---|---|---|
| | **31.12.19** | **31.12.18** |
| Cash Held | 3,690,857 | 2,159,890 |
| Fixed Assets | 72,107 | 81,342 |
| Investment Property | 5,630,000 | 5,500,000 |
| Investment Portfolio | 31,809,019 | 34,064,135 |
| Other Assets | 1,046,184 | 1,323,728 |
| Total Assets | **42,248,167** | **43,129,095** |
| Grants | 4,436,720 | 6,789,089 |
| Other Liabilities | 1,292,906 | 1,532,639 |
| Total Liabilities | 5,729,626 | 8,321,728 |
| Total Equity including Capital Funds | **36,518,541** | **34,807,367** |

HOW ARE WE DOING?

# NOTES TO FINANCIAL STATEMENTS

The 2019 financial year noted an operating surplus of $4.98 million, from which $3.26 million was applied to research grants and chair salaries. The balance of $1.72 million being held in reserves.

Expenses continue to be a focus of management, and this year reduced by 7.5%.

The financial position notes at 31st December 2019:

| | $m |
|---|---|
| Cash | 3.7 |
| Property & investments (at valuation) | 37.4 |
| Other | 1.1 |
| | 42.2 |
| Less undrawn grants and liabilities | 5.7 |
| Equity | $36.5 |

Included is some $5 million invested through Cure Kids Ventures, the seed co. investment arm. These investments are of an early-start nature, focused on children's health.

*Iziyah has a rare genetic disorder and is losing his sight.*

# Big research for little lives

## You can have a significant long-term impact on the health of our children.

**Thanks to the support of our wonderful and loyal regular giving community, Cure Kids has been able to support many brilliant researchers throughout our 49-year history.**

These researchers work tirelessly to find answers to the health challenges that stop our children having the childhood they deserve. Asthma, cancer, heart problems, sudden unexpected death in infancy, mental health – these are just a few areas of research we fund.

Cure Kids funding has led to many significant life-changing and life-saving discoveries, but there is still a lot to be done. The research we fund is reliant on private donations and philanthropy from New Zealanders who support our vision of healthier children, with brighter futures.

**Please consider joining our regular giving community.**
**Together, we can have a significant long-term impact on the health of our children.**

**YES, I would like to become a regular giver to help improve, save, and extend the lives of children living with serious health conditions.**

☐ $20/month ☐ $50/month ☐ $100/month ☐ $200/month ☐ Other: _____

Set up your donation online at **https://curekids.org.nz/ways-to-donate/regular-giving/**

Or, pay by: **Credit card** ☐ Visa | ☐ Mastercard

Name on card: _____

Card Number: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ Exp date: ☐☐ / ☐☐

Signature: _____

☐ **Bank transfer**

Please send a direct deposit into Cure Kids' account. Our bank details are:
**Cure Kids, ASB North Harbour Commercial branch, 12-3107-0023265-00** (please use the reference Regular Giving).

☐ **Set up by phone**: Call us on **09 370 0222**

Please complete your details:

FIRST NAME _____ ADDRESS: _____

SECOND NAME: _____

EMAIL: _____

PHONE: _____ SIGNATURE: _____

## CONNECT WITH US

facebook.com/curekidscharity

twitter.com/curekidsnz

instagram.com/curekidsnz

For more information on Cure Kids and child health research that you are helping support, visit **curekids.org.nz** and sign up to our newsletter.

cure kids
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