

**50** YEARS

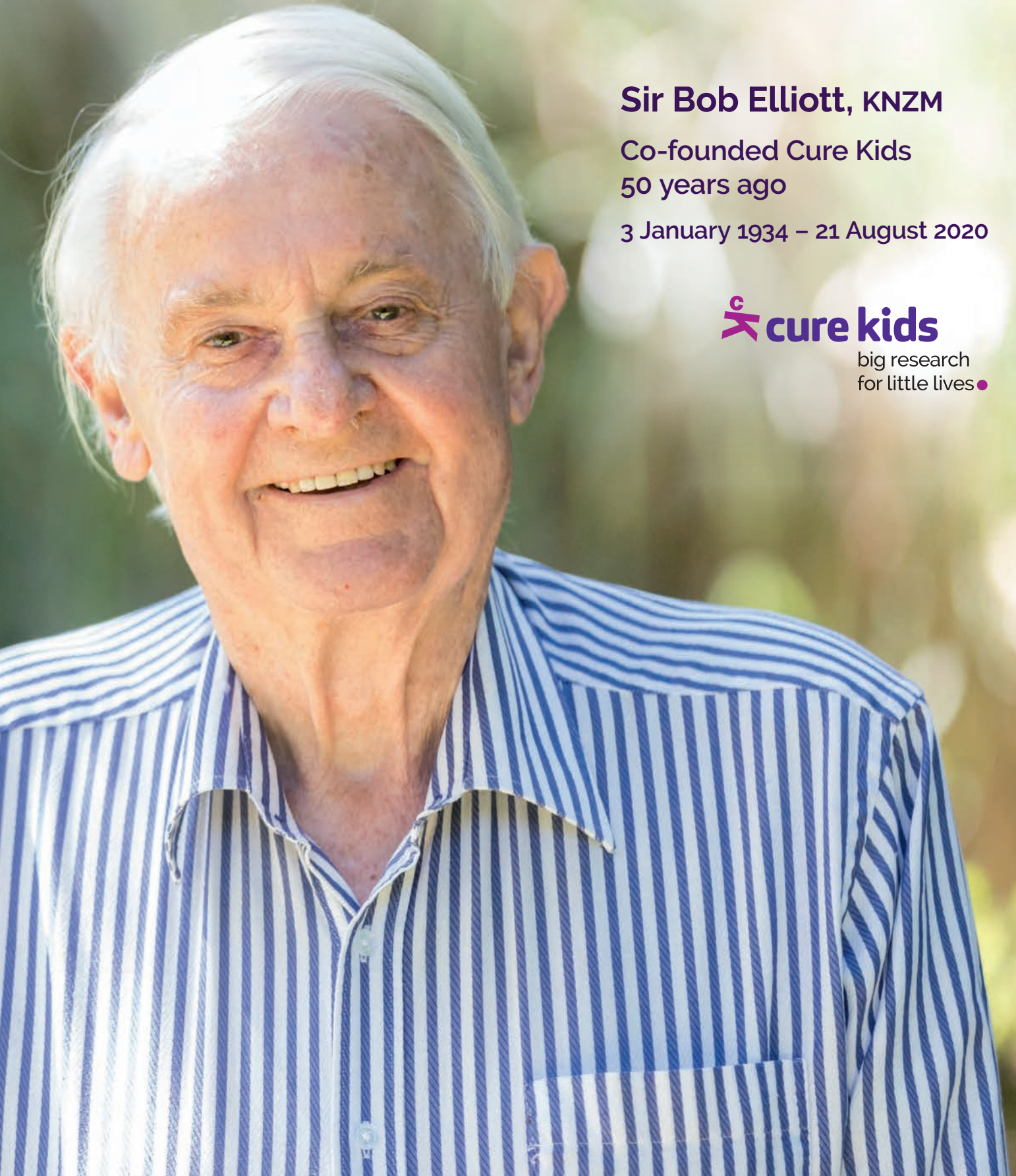
**CURE KIDS**  
**ANNUAL REPORT**  
2020

**Sir Bob Elliott, KNZM**

Co-founded Cure Kids  
50 years ago

3 January 1934 – 21 August 2020

 **cure kids**  
big research  
for little lives ●





**JUST FOR TODAY.** I will try to live through this day only and not trouble my whole life problem at once. I can do something for twelve hours. That would appeal to me if I felt that I had to keep it up for a lifetime.

**JUST FOR TODAY.** I will be happy. This assumes to be true what Abraham Lincoln said, that "most folks are as happy as they make up their minds to be."

**JUST FOR TODAY.** I will adjust myself to what is, and not try to adjust everything to my own desires. I will take my "blow" as it comes, and fit myself to it.

**JUST FOR TODAY.** I will try to strengthen my mind. I will study. I will learn something useful. I will not be a mental loafer. I will read something that requires effort, thought and concentration.

**JUST FOR TODAY.** I will exercise my soul in three ways: I will do somebody a good turn, and not get found out; if anybody knows of it, it will not count.

I will do at least two things I don't want to - just for exercise. I will not show anyone that my feelings are hurt; they may be hurt, but today I will not show it.

**JUST FOR TODAY.** I will be approachable. I will look as well as I can, dress becomingly, talk low, act cheerfully, criticize not too hit, not find fault with anything, and not try to improve or regulate anybody except myself.

**JUST FOR TODAY.** I will have a quiet half hour by myself, and relax. I will have it, but I will have it. I will save myself from too pasty hurry and indecision.

**JUST FOR TODAY.** I will have a quiet half hour all by myself, and relax. I will have it, but I will have it. I will save myself from too pasty hurry and indecision.

**JUST FOR TODAY.** I will have a quiet half hour all by myself, and relax. I will have it, but I will have it. I will save myself from too pasty hurry and indecision.

**JUST FOR TODAY.** I will be generous, especially I will not be afraid to enjoy what is beautiful, and to believe that as I give to the world, so the world will give to me.

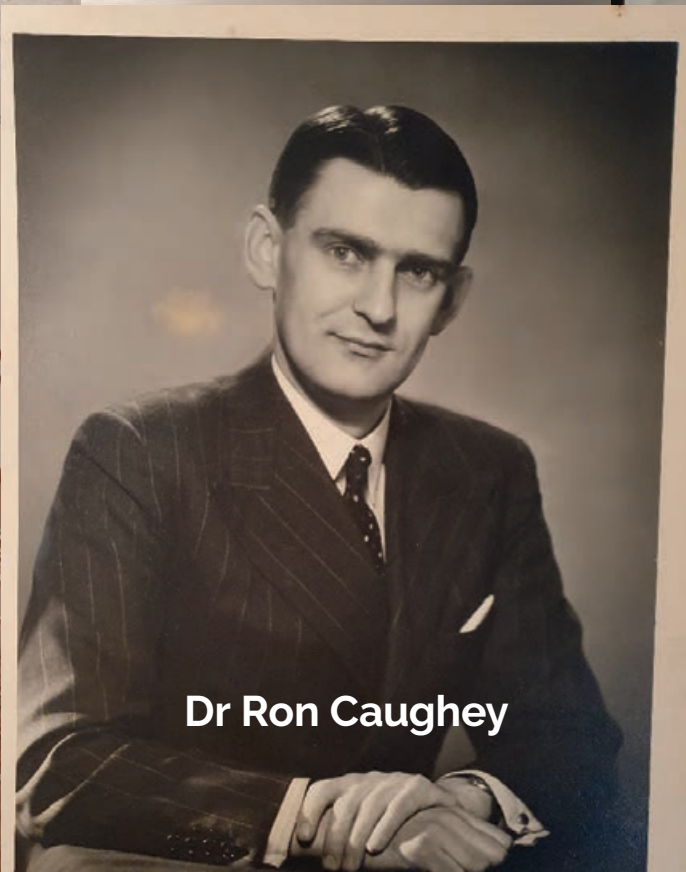
**WISDOM.**

The most likable quality they have, being our possessors is tolerance -

It is the vision that enables one to see things from another's viewpoint -

It is the generosity that compels to others the right to their own opinion and their own peculiarities -

It is the kindness that enables us to let people be happy in their own way instead of our way.



Dr Ron Caughey



**Scient Omnes Nos**

IN FIDELITATE ACQUIET CLASSE

*Alabamæ Doctorem et Presidentem Collegii Regalis Medicorum Londinensium una cum consensu Sociorum quatuor Collegii, auctoritate nostra a domo Regis et Parlamento concessa, appellasse et in Societatem nostram cooptasse doctorem et prolium virum*

RONALDUS RUDOLPHUS CAUGHEY

IN FIDELITATE ACQUIET CLASSE

*legitimosque proferre usum et fructum omnium commoditatum libertatum ac privilegiorum, quae Collegio nostro auctoritate predicta et jure concessa sunt et in futurum concedenda.*

*In cuius rei fidem et testimonium Sigillum nostrum commune praesentibus apponi fecimus. Datum Londini in Collegio nostro*

SEXTO ET VICESIMO APRILIS

Annoque Domini Millesimo nonagesimo septuagesimo tertio

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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](https://facebook.com/curekidscharity)

 [twitter.com/curekidsnz](https://twitter.com/curekidsnz)

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For more information on Cure Kids and child health research that you are helping support, visit [curekids.org.nz](https://curekids.org.nz) and sign up to our newsletter.

# SIR BOB ELLIOTT, A CHAMPION FOR WOMEN AND CHILDREN

Sir Bob Elliott was an outstanding paediatrician, researcher and advocate for children. His passing, following a period of ill health, is a sad loss, but Professor Ed Mitchell and Professor Innes Asher remember his major contributions to child health.

**Obituary: Sir Robert (Bob) Bartlett Elliott KNZM (3 January 1934 – 21 August 2020)**

Sir Bob Elliott was born in Adelaide, South Australia, educated at Adelaide High School, and studied medicine at the University of Adelaide from 1951 to 1956. After working as a house surgeon in Blenheim, New Zealand, he trained in paediatric medicine in Adelaide and Denver, Colorado. He was appointed as a senior lecturer at Adelaide in 1963, and in 1970 he moved to the new University of Auckland School of Medicine as the foundation Professor of Paediatrics.

In establishing the Department of Paediatrics, he made many notable cultural changes to improve the care and outcomes of children, which have a lasting legacy. He was critical of paediatric care in Auckland and did much to improve it, from the bricks and mortar to the workforce, especially encouraging and training future paediatricians. He was an inspirational teacher.

He wanted to see at least 50 percent of women among the paediatricians, as he knew how much women would contribute. This flew against the views held at the time by the medical establishment against increasing the proportion of women in medicine in general, and the paediatric establishment led by graduates from Otago who were mainly men.

He created a paediatric academic and clinical environment where women were encouraged. It is no accident that three of his women protégées rose to the level of professor in Auckland: the late Diana Lennon, Jane Harding and Innes Asher.

“ Sir Bob was an outstanding researcher, and the breadth of his research was truly astounding. ”

From early on, he recognised how poorly children were treated in hospital facilities, labelling the Auckland ward where children were treated for gastroenteritis a “dungeon”. He was right, of course, and the ward was quickly closed by the Hospital Board. Sir Bob remembered the Board wanting to remove him, but his employment by the University of Auckland protected him.

*Continued over >*

*Big research for little lives*



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Sir Bob had a lovely personality, being warm, insightful and informal. He was delighted by and delighted children, and had an infectious chuckle. He also had the ability to be authoritative when it mattered. His high intelligence, compassion and inventiveness led to some visionary ideas although, like all top researchers, not all his innovative ideas bore fruit.

An early one that did, was extending the heel prick test given to all newborn babies to identify cystic fibrosis at birth (Crossley 1979). This test has been adopted internationally, contributing to the increased life expectancy of children with cystic fibrosis. By treating the disease early before it causes too much lung damage, life expectancy improved dramatically from seven-10 years, now to over 40.

Fifty years ago, Sir Bob co-founded the Child Health Research Foundation – now Cure Kids – with Dr Ron Caughey and the support of Rotary. He created the position of Chair of Child Health Research, first held by David Lines and then by Sir Bob himself for 21 years (1977-99). He had the foresight to know that unless we started investing specifically in child health research, New Zealand would drop further down the OECD health rankings. Cure Kids is now the largest funder of child health research outside the government.

Sir Bob was an outstanding researcher, and the breadth of his research was truly astounding. He did the innovative work that suggested the health benefits of A2 milk, which was commercialised. He also pioneered the transplantation of insulin-producing pig cells into humans to treat type 1 diabetes (Living Cell Technologies). He continued to be active in research even as his health deteriorated. And in his last weeks, he was on national TV advocating for cheaper access to a new treatment for a child with cystic fibrosis – a children's champion to the end.

In the 1999 New Year Honours, Elliott was appointed a Companion of the New Zealand Order of Merit, for services to medical research. He was promoted to Knight Companion of the New Zealand Order of Merit in the 2020 Queen's Birthday Honours.

Without doubt, Sir Bob was New Zealand's greatest child health researcher, who led a turn for the better in the culture of paediatrics in New Zealand. He will be missed by so many. His legacy will live on with Cure Kids, paediatrics in New Zealand and our children. Our condolences go to Betsy and his family.

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*Professors Ed Mitchell and Innes Asher are from the Department of Paediatrics, Child and Youth Health within the University of Auckland School of Medicine.*



# A MESSAGE FROM OUR CEO

The year 2020 was challenging for everyone in New Zealand, although as I write this it is a wonderful feeling to know we're emerging from the cloud of COVID19. For Cure Kids, 2020 came with a poignant reminder of where we began, with the sad passing of Professor Sir Bob Elliott, who co-founded our organisation in 1971.

## A SALUTE TO SIR BOB



When I joined Cure Kids in December 2015, Sir Bob was one of the first people I had the pleasure of meeting. He was 83 at the time; an elderly gentleman with loads of energy and enthusiasm, a brain built for innovative thinking, a laugh that lit up any room and a relentless passion for child health. Sir Bob shared with me how he was motivated to establish Cure Kids (formerly the Child Health Research Foundation) because

New Zealand's child health was slipping in the OECD rankings and contributing to this was a lack of research into paediatric health in New Zealand. In his view, the only way to address these trends was to have dedicated paediatric researchers working on the big issues affecting our children's health. I was inspired by the passion he had for ensuring certainty of funding for these researchers so they could get on with the job without the concern for chasing research funding.

## LOOKING BACK TO LOOK FORWARD

As I began my role as CEO I believed that to take Cure Kids forward, I needed to understand the vision that these pioneers had for child health in New Zealand. After inspiring conversations with Sir Bob, and Dr Ron Caughey's daughter Christine, I gained a clear vision of our priorities for the future, specifically social deprivation and how it impacts children's health, particularly the health of our Māori and Pacific children. One of the burning and most urgent issues highlighted was rheumatic fever, which frequently leads to rheumatic heart disease. Our rheumatic fever and rheumatic heart disease statistics are shameful and we are proud that Cure Kids has committed \$3 million to research over three years in an endeavour to answer the questions on how we can prevent, treat and, eventually, eliminate this horrible disease of deprivation.

## THE COVID EFFECT

Sir Bob also made it clear that Cure Kids can be the voice of vulnerable children and their families. During last year's pandemic response, we stepped up to speak for immunocompromised children who face lockdown every day of their lives. We had a captive audience, literally, who listened intently to our messages. The beautiful narrative of New Zealanders pulling together to protect each other impacted Cure Kids. As the year progressed, New Zealanders' gratitude for their own health sparked an upturn of donations. These donations were often accompanied by heartfelt messages from parents who had more time than usual to count their blessings, in the form of healthy children. The pandemic taught us how fragile health is, especially for our most vulnerable children. And, with the race for a vaccine, it also highlighted to Kiwis how important scientific research is for overcoming threats to health.

“40,000 children every year are being hospitalised for completely preventable diseases and most of these can be treated in Primary Care.”

## BACKING OURSELVES

To celebrate our 50th anniversary, I am proud to say that we have established a \$10 million fund in the name of our co-founders – Professor Sir Bob Elliott and Dr Ron Caughey. Research supported by the Elliott-Caughey Fund targets illnesses that are a direct result of deprivation and is already in progress and yielding great results. For 2020, along with our usual granting round, we've pulled together \$3 million for a collaborative research effort on rheumatic fever and rheumatic heart disease. We know Sir Bob would be delighted with this initiative.

## STATE OF CHILD HEALTH IN NZ

While the government is focusing on poverty with their Wellbeing Budget, we were disappointed that it didn't include the prioritisation of child health research that we had hoped for. So to bring New Zealand's biggest children's health issues into the open, we consulted with child health experts to produce the first-ever State of Child Health report.

Big research for little lives

To shape our report, we worked with the Paediatric Society and University of Otago epidemiology services. What we discovered from this report is that skin infections, respiratory problems and poor oral/dental health are the issues which are bubbling to the top and impacting child health the most.

40,000 children every year are being hospitalised for completely preventable diseases and most of these can be treated in Primary Care. The 2020 State of Child Health Report reveals where the Government and Cure Kids, through the Elliott-Caughey Fund, could be collaborating to have the biggest impact on child health.

### SUSTAINING OUR FUNDING BASE

The COVID-19 pandemic presented big challenges on the way we operated and as a result, we swiftly transitioned from our street appeals and annual gala dinners to online and electronic platforms for fundraising. Fortunately, four years ago we moved away from higher cost event-based fundraising and while this was a poignant decision at the time, it resulted in a wise outcome for 2020. While some charities were forced to draw on their rainy-day reserves, our capital fund is ensuring the funds for the future. While we want to protect this legacy of a funding stream for research, the urgent need to help our most vulnerable is immediate. With your support and the support of our incredible devoted corporate partners, our researchers can be reassured that their incredible work can continue until our tamariki aren't facing health issues that are foreign to most resource rich countries.

“Our mission is to align Cure Kids with like-minded partners, such as The Children's Commission and the Ministry for Children and Health.”

### ONWARD AND UPWARD

Going forward, our mission is to align Cure Kids with like-minded partners, such as The Children's Commission and the Ministry for Children and Health. We aim to position

ourselves as a willing partner to help with addressing New Zealand's most urgent child health issues.

In parallel with this work at government level, we will continue to support the researchers that are so essential to our mission. They are the experts who can answer the questions which will uncover the causes, preventions and treatments for the diseases and conditions that child health is still wrestling with. A good example is Professor Stuart Dalziel at Auckland Hospital. He works right at the coal face in accident and emergency, where children are being admitted to hospital. Professor Dalziel is also involved with profound research looking at the treatment of children with asthma. Not only is Stuart and his team the ambulance at the bottom of the cliff, but also the fence at the top. Like so many of our researchers, his work is not purely academic but day by day, face to face with children who have the greatest need.

### THANK YOU FROM US

Thank you for supporting Cure Kids during one of the most unusual years in the world's history. As a country, we've all seen that human health is fragile and that medical research is the only credible way to understand and eradicate those issues which prevent our children from enjoying a healthy, bright future.

I am grateful to the Cure Kids Board, Medical Scientific Advisory Committee, our ambassador families and our researchers who are all relentless in their pursuit for child health.

Thank you to the Cure Kids team, who personally helped us 'cut the cloth to fit the purse' in 2020 ensuring we could continue to support "Big Research for Little Lives".

Ngā mihi nui,



Frances Bengé  
CEO, Cure Kids

Big research for little lives

# AN HONEST LOOK AT CHILD HEALTH AOTEAROA



Cure Kids released its first-ever State of Child Health Report in Aotearoa, New Zealand on 1 December 2020. It was an eye-opener, just as we believed it would be.

The inaugural report is inspired by a similar series of annual reports produced in the United Kingdom by the Royal College of Paediatrics and Child Health. The key priorities for the RCPCH State of Child Health in the UK are to reduce child health inequalities; prioritise public health, prevent and intervention; and build and strengthen local, cross-sector services. Our goals are similar. For New Zealand, the Cure Kids State of Child Health Report aims to:

- Demonstrate areas in which evidence-based medicine is improving child health and highlight areas where vital evidence is lacking.
- Focus on unanswered questions about health conditions, such as how to diagnose, prevent and treat diseases, and how to improve care for children.

To compile the first report, Cure Kids consulted with experts to identify three important markers of child health in New Zealand – oral health, respiratory conditions and skin infections.

The forward was written by Children’s Commissioner, Judge Andrew Becroft, who welcomes the publication of the report. “The report provides a compelling and disturbing snapshot of the health of our children, and is a clarion call to spur our policy makers and politicians into action.”

The report reveals that overall, children in New Zealand have relatively high rates of hospitalisation in these three areas, compared with similar countries, and these rates are on the increase.

“For the first time, we have a national snapshot of the most pertinent health burdens Kiwi children face today,” says our CEO Frances Bengé. “The launch of this report is a starting point for comparisons over time and helps to highlight gaps in available data, so we can build on this information in the coming years.”

“The report provides a compelling and disturbing snapshot of the health of our children, and is a clarion call to spur our policy makers and politicians into action.”

## KEY FINDINGS FROM THE REPORT

- For dental disease, data showed that less than 60% of children brush their teeth at least twice daily with fluoride toothpaste. It also shows that 40% of five-year-olds have evidence of tooth decay, with higher rates for Māori and Pasifika children. Hospitalisation for tooth decay is particularly high for children living in areas of high deprivation.

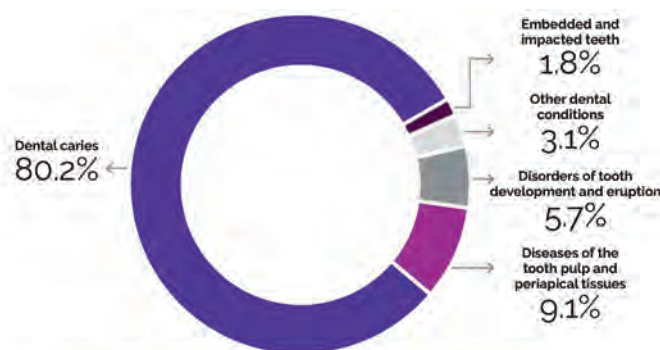
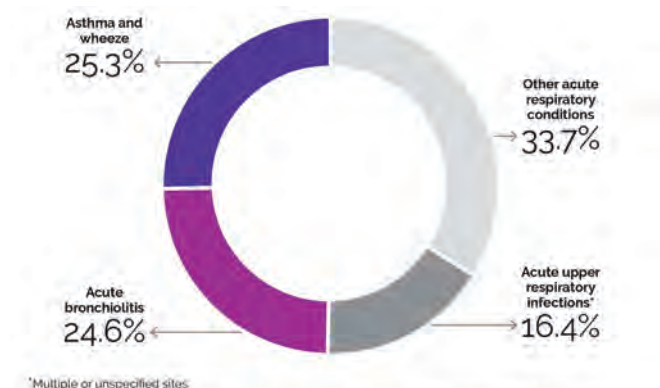


Figure 2.4: Causes of hospitalisation due to dental disease in children older than 1 year, Aotearoa NZ, 2015-19. Source: NMDS

- The report found that respiratory conditions are the leading cause of acute admissions to hospital for children, with ‘asthma and wheeze’ the most frequent diagnosis. Māori and Pasifika children, and children living in areas of high deprivation, have the highest hospitalisation rates for respiratory conditions.



\*Multiple or unspecified sites.

Figure 3.1: Causes of hospitalisations for respiratory conditions in children, Aotearoa NZ, 2015-19. Source: NMDS



- For skin infections, cellulitis, cutaneous abscesses, furuncles and carbuncles are the most likely causes of hospitalisation for children. Rates of hospitalisation for serious skin infections are highest in Pasifika, Māori, children younger than five years and children living in areas with high socioeconomic deprivation.



Figure 4.2: Causes of hospitalisation due to skin infections in children, Aotearoa NZ, 2015-19. Source: NMDS.

“The launch of this report is a starting point for comparisons over time and helps to highlight gaps in available data, so we can build on this information in the coming years.”

## RECOMMENDATIONS FROM THE REPORT

- Persistent inequalities are linked to ethnicity and income, so Cure Kids and its partnering organisations are prioritising equity in health outcomes for all New Zealand children.
- Measures that are proven to prevent disease should be urgently implemented wherever there is evidence. However, where evidence gaps remain, there is a need for investment in health research.
- Organisations that are active in funding child health research, including the Government, should collaborate. This way, more resources can pull together to improve the health of our children.
- Rates of hospitalisation for common but severe dental, respiratory and skin conditions can be reduced through

early access to primary healthcare. Ongoing culturally appropriate education for parents, children and healthcare providers is also essential.

- Investment in cost-effective preventive strategies at a national level can help to reduce risk factors tied to housing conditions; limit tooth decay due to unhealthy foods and drinks; and enable nurse-led school-based clinics, and other child-centred services, to address skin health.
- For all three health areas, hospitalisation rates are the best data currently available. However, hospitalisations are only the tip of the iceberg. Research is urgently needed to understand earlier stages of disease, when prevention may still be possible.

## THE NEXT REPORT IS UNDERWAY

During 2021, we will report on an additional health area and provide an update on progress to improve health in the first three areas. This data helps Cure Kids prioritise investments in research, and highlights the most urgent questions to improve the health of our children.

## ADVISORY GROUP FOR THE STATE OF CHILD HEALTH REPORT

### Dr Bruce Scoggins

Chair, Medical & Scientific Advisory Committee, Cure Kids

### Tara Satyanand

Research Director, Cure Kids

### Dr Nicola Austin

President, Paediatric Society of New Zealand

### Dr Mavis Duncanson

Director, NZ Child and Youth Epidemiology Service, University of Otago

### Dr Tim Jelleyman

Chief Advisor, Child and Youth, NZ Ministry of Health

### Dr Hamish McCay

Royal Australasian College of Physicians

### Glenda Oben

Research Fellow, NZ Child and Youth Epidemiology Service, University of Otago

# 50 YEARS OF BIG BREAKTHROUGHS FOR LITTLE LIVES

Throughout our 50-year history, Cure Kids is proud to have funded research projects that have resulted in significant and life-changing breakthroughs that have changed the way child health conditions are diagnosed and treated.

## Our big breakthroughs.

### Identification of risks to **reduce stillbirth by 50%**



A study on maternal sleep position partly funded by Cure Kids led to evidence which could reduce the risk of stillbirth by 50%.

*Lesley McCowan, 2017*

### Prevention of **200 sudden unexpected deaths in infancy** every year



Cure Kids funded a study of risk factors for sudden unexpected death in infancy, leading to advice on safe sleep environments which has prevented 200 deaths every year, and many more around the world.

*Professor Ed Mitchell, 1990*

### Diagnosis of cystic fibrosis at birth **increasing life expectancy by decades**



Cure Kids' founder, Sir Bob Elliott, discovered a blood test (newborn heel-prick) to diagnose cystic fibrosis (CF) at birth, enabling earlier treatment and therefore increasing the life expectancy for babies born with CF around the world.

*Sir Bob Elliott, 1976*

### Demonstration that **babies born at 23–24 weeks** can survive



Cure Kids funded a study that provided evidence that babies born prematurely at 23–24 weeks can survive and thrive.

*Dr Max Berry, 2018*

### Invention of a patented **car seat insert**



Cure Kids funded a study on babies breathing, which led to the invention of a patented car-seat insert to improve safety.

*Professor Alistair Gunn, Dr Christine McIntosh  
and Dr Shirley Tonkin, 2008*

### Generated **full-thickness human skin** in a lab



Cure Kids helped fund a study to engineer full-thickness human skin in the laboratory, using the patient's own skin cells, to enable treatment for burns or scalds.

*Professor Rod Dunbar, 2012*

### Innovative treatment for **infants with brain injury**



Cure Kids funding contributed to the development of a brain-cooling cap, to limit or reverse damage caused by brain injury in babies.

*Professor Alistair Gunn, 1987*

Big research for little lives



## IMPROVING THE HEALTH OF KIWI KIDS

Cure Kids' funding has led to a wide range of discoveries that have changed the way child health conditions are diagnosed and treated.



### PRETERM AND PERINATAL CONDITIONS

- Longitudinal study on child development proves that maternal smoking in pregnancy causes risk for babies, resulting in significant changes to advice for parents.  
*Professor David Fergusson, 1979*
- Examination of the effects of methadone treatment on unborn babies changed policy on safe levels for methadone, not only in New Zealand but around the world.  
*Professor Lianne Woodward, 2010*
- Conducted a world-first trial that showed dextrose gel massaged into the inside of a baby's cheek can be used to treat hypoglycaemia, reducing the need for admission to intensive care.  
*Professor Jane Harding, 2014*
- Study demonstrating that babies born at 23–24 weeks' gestation can survive and thrive.  
*Associate Professor Max Berry, 2018*



### CARDIOVASCULAR

- Engineering a way to develop full-thickness human skin in a laboratory for the treatment of burn injury.  
*Professor Ron Dunbar, 2012*



### INFECTIOUS DISEASES

- Studies on viruses, leading to early adoption of ground-breaking technology for detection and diagnosis at Auckland Hospital.  
*Professor Dick Bellamy, 1986*
- Development of a rapid luminescence-based test for screening fungi for antibacterial activity.  
*Dr Siouxsie Wiles, 2017*



### CARDIOVASCULAR CONDITIONS

- Establishing the Cardiac Inherited Disease Registry to identify the genetic basis for inherited heart conditions, reducing sudden and unexpected cardiac deaths in children and providing early family screening.  
*Associate Professor Jon Skinner, 2005*
- Developing a method for modelling Long QT Syndrome in beating heart cells grown from the patients' own blood cells, potentially reducing the risk of cardiac events for these children and young people.  
*Dr Annika Winbo, 2017*

Big research for little lives

# 50 YEARS OF BIG BREAKTHROUGHS FOR LITTLE LIVES



## NEUROLOGICAL DISORDERS

- Discovery of a method preventing secondary brain injury by cooling babies' heads, leading to the development of an innovative cap to protect infants.

*Professor Alistair Gunn, 1987*

- Novel use of gene therapy for children with Batten disease, a devastating neurodegenerative condition which shares symptoms with Alzheimer's disease, Parkinson's disease, and epilepsy.

*Professor David Palmer & Associate Professor Stephanie Hughes, 2003*

- Discovery of genes that cause epilepsy in children, allowing more accurate diagnoses and targeted treatments for children.

*Professor Lynette Sadleir, 2010*

- Development and testing of a robotic 'gait trainer' to assist children with cerebral palsy in over-ground walking.

*Dr Andrew McDaid, 2017*

- Managing a specialised stem cell culture facility as a result of a Cure Kids repatriation fellowship, enhancing biomedical research in New Zealand.

*Dr Adam O'Neill, 2020*



## GENETIC CONDITIONS

- Development of a method for screening newborn babies for cystic fibrosis, allowing earlier diagnosis and more efficient and effective treatment.

*Professor Bob Elliott, 1976*

- Breakthrough study to identify short 'window of opportunity' early in the life of babies with cystic fibrosis, highlighting the importance of introducing early novel treatments before irreversible lung damage occurs.

*Professor Keith Grimwood, 1998*

- Studies on genetic mutations that affect the development of the brain and skeleton, aiding diagnosis for a number of rare genetic disorders.

*Professor Stephen Robertson, 2002*

- Discovery that cystic fibrosis patients produce bleach in their lungs, enabling researchers to focus on developing new drugs to stop bleach formation.

*Professor Tony Kettle, 2002*



## INFANT MORTALITY AND STILLBIRTH

- Prevention of 200 sudden unexpected deaths in infancy (SUDI) every year in New Zealand through improved understanding of the risks associated with infant sleep position.

*Professor Ed Mitchell, 1990*

- Illustration of the adverse effects of car seats on infant breathing, leading to invention of a patented seat insert to improve safety.

*Professor Alistair Gunn, Dr Christine McIntosh & Dr Shirley Tonkin, 2008*

- First-ever case-controlled study on maternal sleep position, contributing to a 50% reduction in the risk of stillbirth rates for New Zealand babies.

*Professor Lesley McCowan, 2017*

- The implementation of a digital risk assessment tool called the Safe Sleep Calculator in Primary Care at Counties Manukau.

*Dr Christine McIntosh, 2019*



### RESPIRATORY CONDITIONS

- Development of tests to assess lung-function, which have now become standard clinical practice in New Zealand.

*Professor Innes Asher, 1982*

- Studies examining infection and chronic lung disease such as bronchiectasis, leading to changes in clinical best practice.

*Dr Jacob Twiss, 2002*

- Study showing that vitamin D supplementation during pregnancy and infancy prevents doctor visits for acute respiratory infections in early childhood. This resulted in the updating of the Starship Hospital clinical guidelines for hospitalisation and treatment of pneumonia and respiratory diseases.

*Professor Cameron Grant, 2015*



### MENTAL HEALTH CONDITIONS

- Development of a new online tool to combat depression and anxiety in young people by teaching positive skills for mental health.

*Professor Sally Merry, 2018*



### CHILDHOOD CANCERS

- Identification of the importance of prenatal events for leukaemia to improve long term health outcomes for children with hard to treat cancers.

*Professor Ian Morison, 2011*

- Co-funding the Precision Paediatric Cancer Project, an innovative clinical trial, using advanced genetic testing and drug screening.

*Dr Andy Wood, 2020*



### ORAL AND DENTAL CONDITIONS

- A study on disadvantaged children, their whānau and communities in the Tāmaki community has led to routine use of fluoride varnish by dental clinics, and additional screening checks and visits for children in the area.

*Dr Ali Leversha, 2019*



### GASTROINTESTINAL DISORDERS

- 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.

*Professor Andrew Day, 2018*



### GENERAL DISEASES AND HEALTH ISSUES

- An assessment of child admissions within adult wards, informing the design of services at Starship Children's Hospital.

*Professor Diana Lennon, 1977*

# INVESTMENT IN SUDI AND STILLBIRTH RESEARCH PAYS DIVIDENDS, YEAR AFTER YEAR

Since the 1980s, Cure Kids (previously The National Children's Research Foundation) has been putting money and influence behind the search for solutions to Sudden Unexpected Death in Infancy (SUDI), commonly known as cot death.

Four decades later, massive progress has been made to change New Zealand's SUDI statistics for the better. When the quest for SUDI solutions began, one in every 250 newborns was dying suddenly without explanation every year. Now, that rate is about one in every 1000.<sup>1</sup>

## PROFESSOR WITH A PURPOSE

Spearheading Cure Kids' quest for SUDI solutions is Emeritus Professor Ed Mitchell of The University of Auckland. After graduating from St George's Hospital Medical School in London, Professor Mitchell came to New Zealand in 1977 to work at Princess Mary Hospital for Children in Auckland, which became Starship. The hospital was barely coping with the needs of sick children in the late 1970s, let alone research.

Emeritus Professor Bob Elliott, Chair of the National Children's Research Foundation and founder of Cure Kids, persuaded Professor Mitchell into child health research. He was a research fellow even before he'd completed paediatric training.

In 1983, Professor Mitchell was asked to establish a Postneonatal Mortality Review Committee for the Auckland region. His mission was to look into New Zealand's unusually high rate of postneonatal (0 to 28 days) mortality by examining individual deaths. This work led to the New Zealand Cot Death Study.

## NEW ZEALAND COT DEATH STUDY

Conducted from 1987 to 1990, the New Zealand Cot Death Study aimed to identify preventable deaths in infants, then develop prevention strategies. From the deaths attributed to cot death, four key risk factors emerged: maternal

smoking, not breastfed, co-sleeping and baby placed to sleep in prone (tummy down) position.

A major finding of the study was that 47% of the cot death cases studied might have been prevented if babies were not placed in the prone position to sleep. This led to a nationwide 'back to sleep' public health campaign that encouraged mothers to put babies to sleep on their backs.

Following this 'back to sleep' campaign, the fall in SUDI mortality was dramatic. Within two years, the rate had halved.<sup>2</sup> In 2011, it was calculated that approximately 3000 infants had been saved simply because parents put the back to sleep advice into practice.<sup>3</sup>

## SLEEP ON THE SIDE CAMPAIGN

An adjunct to the SUDI project is the goal of reducing stillbirths in New Zealand. Each year, in New Zealand, approximately 160 babies are stillborn in the last three months of pregnancy.

Professor Lesley McCowan, Head of The University of Auckland's Department of Obstetrics and Gynaecology, and her team of New Zealand researchers have been looking at risk factors for stillbirth for a decade. The conclusion from four studies – two by Professor McCowan in New Zealand, one in Australia and one from the UK – revealed a significant increase in the risk of late stillbirth if women go to sleep lying on their back.

Emeritus Professor Ed Mitchell has also been working on the link between maternal sleep position and stillbirth. His Multi-Centre Case Control Stillbirth Study supports Professor McCowan's findings.



1 <https://www.health.govt.nz/publication/fetal-and-infant-deaths-web-tool>

2 <https://www.hqsc.govt.nz/assets/CYMRC/NEMR/SIDS-prevention-Mitchell-Blair-NZMJ-2012.pdf>

3 <http://sudinationalcoordination.co.nz/sites/default/files/2017-09/Sudden%20unexpected%20infant%20deathno%20more%20stunned%20amazement.pdf>



Special thanks to the Whatarangi family who have shared images of their whānau.

It's estimated that if all pregnant women go to sleep on their side from 28 weeks of pregnancy, there could be a 10% decrease in late stillbirth nationally. This revelation led to the 'sleep on the side' public health campaign, which is still running in NZ and the UK.

### SAFE SLEEP CALCULATOR

The safe sleep calculator is an algorithm developed by Emeritus Professor Mitchell with Associate Professor John Thompson, his Research Fellow at the time, to calculate SUDI risk and suggest specific protection needs for each baby. This has now been integrated into a web-tool called Survive and Thrive 2025, which assesses individualised SUDI protection needs and enables electronic communication and integration between community providers who support vulnerable families to lower risk.

The Safe Sleep Calculator draws on a large body of data collected by Professor Mitchell during his 30 years' involvement with SUDI research.

### WHY DOES CURE KIDS' SUDI QUEST CONTINUE?

Even though New Zealand has made great progress with SUDI, around 60 deaths still occur every year. Among the world's industrialised nations, New Zealand has the highest rate of death from SUDI.<sup>4</sup>

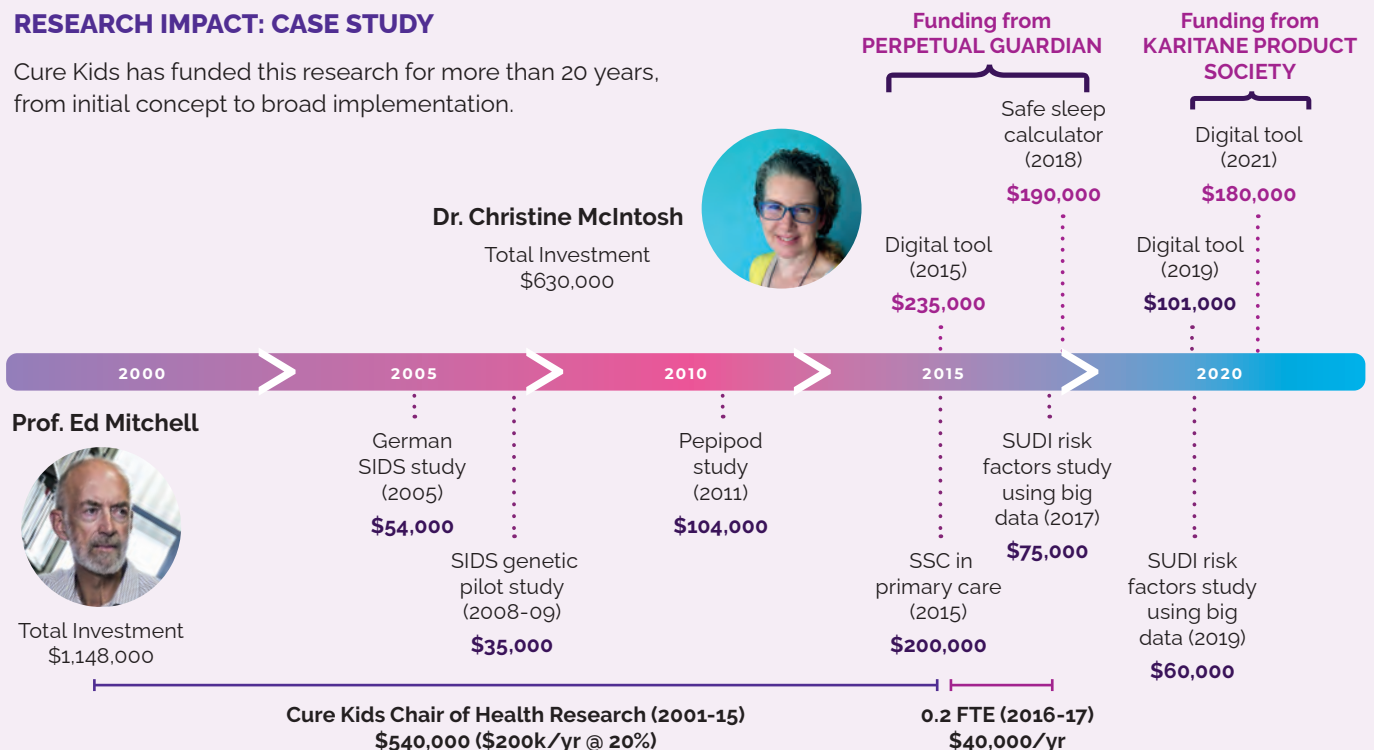
<sup>4</sup> <https://www.nzma.org.nz/journal-articles/sudi-prevention-a-review-of-maori-safe-sleep-innovations-for-infants>



Special thanks to Perpetual Guardian for helping Cure Kids support this life-saving research

### RESEARCH IMPACT: CASE STUDY

Cure Kids has funded this research for more than 20 years, from initial concept to broad implementation.



Over this period Professor Mitchell also received other funding, including \$312k in 1990 and \$1.2m in 2012 from the Health Research Council. As a result of evidence-based public health campaigns informed by this research, deaths from sudden unexpected deaths in infancy fell from 2.1 per 1000 in 2001 to 0.77 per 1000 in 2019.

Big research for little lives

# AMBASSADORS THROUGHOUT TIME

Cure Kids has enjoyed the support of many amazing ambassador families, who help us to spread awareness and raise funds. Here we take a look back at some of the ambassadors who played a big role in our history. You'll love how they've overcome the odds to get to where they are today.

## BROOKE'S ON HER WAY TO UNIVERSITY

### BROOKE



At six years old, Brooke was diagnosed with gelastic seizures – a term used to describe partial seizures with bouts of uncontrolled laughing or giggling. An MRI confirmed the cause - a hypothalamic hamartoma, a type of benign brain tumour, right in the centre of her brain.

At age nine, Brooke underwent surgery and 80% of her tumour was successfully removed. Before surgery she had been experiencing 30 to 40 seizures a day and her cognitive skills had deteriorated to preschool level. She also suffered from uncontrollable rage and precocious puberty, for which she had to have monthly hormone injections.

With removal of most of the tumour, Brooke's condition improved significantly. Sadly, at age 13, the seizures returned and she had to endure a second brain surgery in Melbourne.

## LYNETTE SADLEIR'S LIFE-CHANGING RESEARCH



In July 2018, Brooke took part in an international drug trial for CBD gel. The trial was part of neurologist Lynette Sadleir's research work. For Brooke, this gel has been extremely successful and life changing. She went from having 70 seizures per month, which lasted up to 20 minutes, to 10 seizures per month lasting only 30 seconds to a minute.

In addition to the reduction in seizures, Brooke noticed a huge reduction in tiredness. This allowed her to concentrate more at school. Her comprehension and writing greatly improved, along with her confidence. People commented on the difference they saw in Brooke in all aspects of her life.

## BROOKE'S ON A MISSION TO HELP OTHERS

Brooke is now in her second year at Massey University, where she's studying for a Bachelor of Arts degree majoring in Educational Psychology. She's flatting in Palmerston North with three friends she met last year in the university halls. Brooke is thoroughly enjoying university and living an independent life, something that seemed impossible a few years ago. She continues with her love of music, enjoys playing netball and maintains a high level of fitness. Brooke has also become more social and outgoing, as she no longer has to worry about having seizures all the time.

"Being a Cure Kids ambassador has allowed Brooke to share her story of what she has been through. She has been able to spread awareness of her condition and support her neurologist with her research. This experience has helped grow her leadership skills and confidence to where she was a prefect in her last year at school. This experience has helped shaped her goal with her studies, which is to become a Hospital Play Specialist, as she has experienced the great work they do with children and would like to help others in this way." Shona, Brooke's mum.

## SOPHIE



Sophie was born with cardio-facio-cutaneous (CFC) syndrome, a rare genetic condition that typically affects the heart, facial features and skin. She was just the 12th person in the world to be diagnosed with the condition at birth. Now 26, Sophie is so small for her age, she is often thought to be younger.

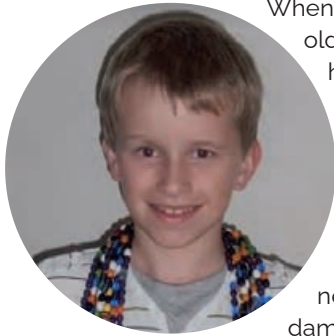
Sophie has faced a number of challenges in her life, but she hasn't let anything hold her back. Sophie was an avid participant in Cure Kids events and fundraisers over the years and looks back on her time as an ambassador fondly.

Sophie loves to cook, enjoys art and considers looking after the family dog Bear to be her main job.

*Big research for little lives*



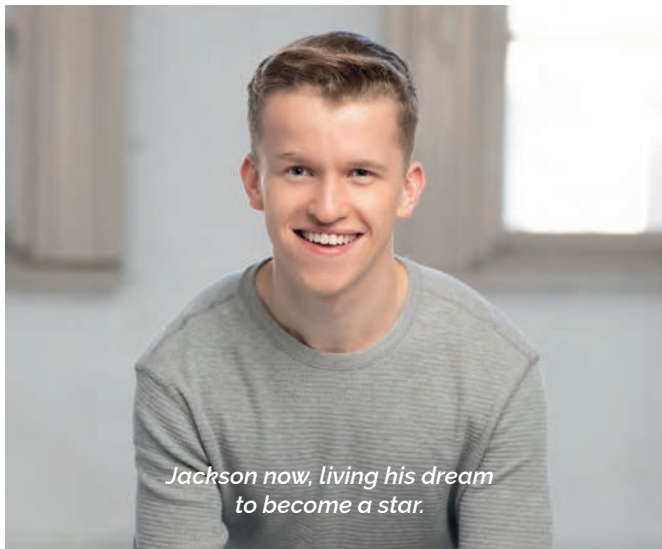
## JACKSON



When Jackson was seven years old, his family received some heart-breaking news. He had a tumour the size of a tennis ball attached to his left optic nerve and had developed hydrocephalus. This caused fluid build-up in the brain that pressed on his optic nerve, resulting in permanent damage to his eyesight.

Jackson bravely underwent two eight-hour brain surgeries to have the tumour reduced as much as possible. The second surgery involved taking off half his skull and stapling it back on afterwards. Jackson then underwent two years of intensive chemotherapy. During this time, he attended school when he could, which wasn't often – he was a very sick boy.

Jackson still has his tumour and will need regular MRIs for the rest of his life, to ensure it doesn't grow again.



*Jackson now, living his dream to become a star.*

### JACKSON'S LIVING HIS DREAM

Despite the huge setbacks Jackson faced in his early childhood, his journey has given him the confidence to know that he can do pretty much anything he puts his mind to. He's currently studying in Sydney to become a professional screen/stage actor, singer and dancer. Jackson recently completed a diploma of musical theatre, is continuing acting courses and has weekly singing lessons. He's also taken up a new job as a singing tutor.

"Being an ambassador was absolutely life changing, as it gave me so much joy. I cannot thank Cure Kids enough for all of the beautiful memories they have gifted me with. We are so lucky that Cure Kids is around, as it brings so much hope to kids fighting for their lives, just like I was. Thank you Cure Kids for everything!" Jackson

## RILEY

Riley was born three weeks early, weighing in at 2.35kg. He had to stay in neo-nates and have many heel prick tests, as well as blue light for jaundice. Following a series of tests, it was confirmed that Riley had a multi-cystic kidney. The left kidney had no functionality and four large cysts, however the right kidney was perfect. At three months, Riley was due to undergo surgery, but scans revealed his body had dissolved his bad kidney entirely. There was now no need for surgery.

Between the ages of 20 months and two years, Riley was admitted to hospital twice with a cold and breathing problems. He also experienced many episodes of respiratory illness where he wasn't admitted.



At age two Riley was diagnosed with asthma. He started on preventative flixotide and ventolin daily, plus redipred or predisone steroid. At first his asthma was induced virally, but he gained many triggers from animals, hay-fever, sudden temperature drops and dust. From 2012 to 2014, Riley was admitted to hospital seven times.

### RILEY'S LIVING LIFE TO THE FULL

Now aged 18, Riley is studying for a Bachelor of Design with Honours. He is a touch rugby referee and loves to play hockey. Riley loves living his life and is mostly free of asthma.

Riley says that being an ambassador for Cure Kids gave him some incredible experiences and opportunities. He'll never forget the tireless efforts of some of our biggest supporters, one of whom is his mum Laurel.

"My mother was by my side every hospital visit, fighting sleep to look after her baby. She even created an event in the Manawatū called 'Red Nose Family Fun Day', which was an event where you can participate in either a 5km or 10km run or walk to gather funds for Cure Kids. I am so thankful for the opportunities Cure Kids has given me over the years. I have loved every moment of it." Riley



*Riley the Youth Referee of the Year in 2020*

# MEET THE FIRST-EVER NEW ZEALANDER TO HAVE FETAL SURGERY FOR SPINA BIFIDA

Ben was diagnosed with spina bifida myelomeningocele and hydrocephalus at his mum's 20-week antenatal anatomy scan. At just 24 weeks, still unborn, he had surgery to close up his spine.

**S**pina bifida is a spinal defect that happens when the neural tube doesn't close all the way during fetal development. It's often accompanied by hydrocephalus, which involves extra fluid in and around the brain. Together, the conditions are associated with significant disability and severely shortened lifespan.

When Catherine and her husband Paul learned about their unborn child's condition, they were understandably distressed.

"You go to these scans hoping for a healthy little baby, and you get told there is something really wrong with their brain and their spine. It's an incredibly stressful time," says Catherine.

The Harpers were heartbroken but unfazed.

"We thought, 'OK, well, he has this. Does that change how much we're going to love him? No.'"

The couple dismissed the suggestion of termination, but knew they had a battle on their hands.

Children affected by spina bifida myelomeningocele and hydrocephalus have issues with

their gross motor skills and sometimes cognition, however surgery can minimise some of the damage.

Usually the surgery is performed after the baby is born, but in Ben's case pioneering surgeons at Mater Hospital in Brisbane performed the surgery in-utero at 24 weeks gestation. The Australian surgical team learned the procedure from the United States, where studies showed remarkable results.

"You double the chance of the baby walking with no assistance and you halve the chance of the baby having fluid build-up on the brain," says Dr Glenn Gardener of Mater Hospital.



After his birth, when he was just a week old, Ben had an additional surgery in New Zealand to insert a ventriculoperitoneal (VP) shunt to prevent fluid build-up in his brain. The need for a VP shunt was unexpected, because of the spinal surgery before his birth, but Ben also had a syrinx (a fluid-filled cyst) that made insertion of a shunt essential.

Today, Ben is an active four-year-old who's surpassed everyone's expectations. He can walk using a walker, even though surgeons said the likelihood was going to be low. And cognitively he's on par – even rather advanced – for his age. Ben's shunt was initially problematic, requiring several surgical corrections, however it's stable now. Catherine and her family are hoping very much that Professor Simon Malpas's remote sensor for shunt malfunction flies through its testing phase.

## MONITORING VP SHUNT FUNCTION FROM THE INSIDE

Professor Simon Malpas and his team at the University of Auckland are developing a much-needed tool for parents of children who have a VP shunt installed. It's a remote sensor that's placed alongside the drainage tube.

By detecting fluid build-up that indicates a tube blockage, this tool has the potential to reduce hospitalisations and radiation exposure from CT scans. It will also greatly relieve the anxiety of parents around the care of their children.

Within the first two years of installation, there is a 60% chance a neural tube will block. Warning symptoms of this blockage include irritability, headaches and vomiting; symptoms that are easily confused with other illnesses. Blockages that aren't quickly diagnosed and treated can lead to brain damage.

Funding from Cure Kids is allowing Professor Malpas and his team to finish testing the technology before they undertake the first human trial.



# WELCOME TO OUR NEW CHAIR OF THE BOARD FRANCESKA BANGA



We are delighted to have Franceska Banga, ONZM, as the new Chair of our Board. Franceska succeeded Roy Austin, who served on the Board for more than 23 years and stepped down as part of his retirement plan.

Franceska is a recognised CEO, Chair and Director who has held board roles on many prominent New Zealand organisations. She brings extensive governance experience, spanning finance, technology and health sectors.

CEO Frances Bengé says the appointment was a significant moment in the history of the organisation.

**"We are extremely pleased to have someone of Franceska's calibre take up the mantle. Franceska's strong professional background is playing a critical role in helping us continue to shift the dial in child health," says Bengé.**

While typically known for her financial and investment expertise, Franceska also has a strong background in health. She originally trained as an

occupational therapist where she spent much of her time working in paediatrics. Later, she was appointed as Director of Health at NZ Treasury, overseeing the Health Budget.

As the founding Chief Executive of the New Zealand Venture Investment Fund, Franceska managed \$300 million of funds under management, overseeing an investment into a portfolio of 200+ high growth New Zealand companies and catalysing over \$2 billion of public and private investment into those companies.

Franceska's governance experience includes roles as Trustee and Chair of Audit Committee of Fred Hollows Foundation NZ, Director Continuity Capital NZ, Independent of Director Constellation Capital, Chair Fab Group (Caci NZ), Independent Director Frogparking, Future Director appointee, Fisher and Paykel

Healthcare, Director and Chair of the Audit Committee of Auckland Tourism, Events and Economic Development (ATEED).

In 2016 Franceska was made an Officer of the NZ Order of Merit, for services to business and the community.

"I am honoured to have been appointed as Chair of the Cure Kids Board," says Franceska. "As the largest child health research funder outside Government, Cure Kids plays a vital role in addressing some of the big health issues affecting kiwi children, including diseases of social deprivation and child poverty.

"A key priority for Cure Kids, alongside our existing research, is to work closely with Government to address the effects of social deprivation on child health and illnesses such as rheumatic fever and rheumatic heart disease."

## THANK YOU AND FAREWELL



We would like to pay tribute to our outgoing Chair, Roy Austin, who also served as Chair of Cure Kids Fiji for 14 years, and Chair of

Cure Kids Ventures since 2011. He is an active member of Rotary, has been made a multiple Paul Harris fellow and been honoured with a Companion of the New Zealand Order of Merit for services to children's health and the community.

"I am deeply grateful to Roy for his strong vision, dedication, and passion over the years. He has made a

significant contribution to the health of our tamariki," says Bengé.

"As Chair of Cure Kids for 23 years, it has been both a unique opportunity and a privilege to have participated in the growth of children's health research in NZ and Fiji, and to share the joy of its many successes," says Roy.

"New Zealand researchers, the talented Cure Kids staff and children continue to be a major source of motivation as Cure Kids looks to the future.

"Having now retired, I wish the collective Cure Kids family every

success as they share an exciting future and build on the legacy of its history," he says.

Our long-standing Board member, Don Jaine, has also recently retired after 23 years so we extend our huge thanks and appreciation for the significant contribution that he has made to both the Board and the Management Team at Cure Kids over the years.

"Don's strengths in strategic thinking have added significant value to the strategic planning process at Cure Kids and delivered great value to the Management Team. We wish him very well in his retirement," says Bengé.

*Big research for little lives*



From left to right: Roy Austin, Franceska Banga, Dr Bruce Scroggins, Barrie Campbell, Frances Benge, Professor Stephen Robertson, Russ Hewitt

## 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 is a registered charity CC25350.

*Big research for little lives*

### CURE KIDS BOARD

**FRANCESKA BANGA** ONZM  
CHAIR, AUCKLAND

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

**FRANCES BENGE**  
CHIEF EXECUTIVE OFFICER, CURE KIDS

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

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

**ROY AUSTIN** CNZM BCom, CA.  
CONSULTANT TO NORTHINGTON PARTNERS, AUCKLAND

**RUSS HEWITT**  
SENIOR EXECUTIVE, VODAFONE

**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 Medical and Scientific Advisory Committee hard at work assessing the 2020 Contestable Granting Round applications.*

## 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

### PROFESSOR SALLY MERRY, MBChB, FRANZCP, MD.

DEPARTMENT OF PSYCHOLOGICAL MEDICINE,  
UNIVERSITY OF AUCKLAND

### PROFESSOR ANDREW DAY

MBChB (Otago), MD (Otago), FRACP, AGAF.  
HEAD OF DEPARTMENT OF PAEDIATRICS,  
UNIVERSITY OF OTAGO

### PROFESSOR ED MITCHELL

BSc, MB BS, DCH, FRACP, FRCPCH, DSc (Med), FRSNZ.  
DEPARTMENT OF PAEDIATRICS, SCHOOL OF MEDICINE,  
UNIVERSITY OF AUCKLAND

### PROFESSOR IAN MORISON, BMedSc MB CHB FRACP PhD

DEPARTMENT OF PATHOLOGY,  
UNIVERSITY OF OTAGO, DUNEDIN

**PROFESSOR BARRY TAYLOR, MBChB (OTAGO), FRACP**  
DEPARTMENT OF WOMEN'S AND CHILDREN'S HEALTH  
DEAN, DUNEDIN SCHOOL OF MEDICINE,  
UNIVERSITY OF OTAGO, DUNEDIN

### ASSOCIATE PROFESSOR JUSTIN DEAN

PhD, MScTech, BSc Tech  
DEPARTMENT OF PHYSIOLOGY, UNIVERSITY OF AUCKLAND

**PROFESSOR STUART DALZIEL, MBChB (Otago), FRACP**  
DEPARTMENT OF PAEDIATRICS, CHILD AND YOUTH HEALTH,  
SCHOOL OF MEDICINE, UNIVERSITY OF AUCKLAND

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, DIRECTOR**

**MAXINE SIMMONS, EXECUTIVE DIRECTOR**

**FRANCES BENGE, DIRECTOR**

**HOWARD MOORE, DIRECTOR**

**MATTHEW PAYTON, DIRECTOR**

### IN ATTENDANCE:

**FRANCESKA BANGA, CHAIR CURE KIDS**

**TRACEY BROWN, FINANCE MANAGER**

**CAROLINE QUAY, CHIEF INVESTMENT OFFICER**

**MICHAEL INNES, INVESTMENT ANALYST INTERN**

# CURE KIDS PROFESSORIAL CHAIRS

When Sir Bob Elliott and Dr Ron Caughey founded Cure Kids in 1971, they set up the first dedicated Chair of Child Health Research to improve the health of children in Aotearoa New Zealand. Over time, Cure Kids has established several new professorial positions. Now we fund four chairs at leading universities around the country.

Our investment in outstanding academic talent has generated significant returns. For example, the stability offered by these senior positions gives world class researchers the scope to generate significant scientific breakthroughs. Our professorial chair funding also enables significant workforce development through supporting students, employing graduates and developing associate investigators.

## PROFESSOR STEPHEN ROBERTSON CURE KIDS CHAIR OF PAEDIATRIC GENETICS AT THE UNIVERSITY OF OTAGO



Professor Robertson has been a Cure Kids chair in Dunedin since 2002. He is a clinician and geneticist specialising in genetic disorders affecting children. With his team, Professor Robertson has showed how specific genes are linked to malformations of the skeleton and brain. He has gained international acclaim for his expertise and maintains active collaborations with scientists around the world. In addition to his research, Professor Robertson sees patients throughout the South and North Islands, and teaches genetics to students in Dunedin.

Cure Kids funding supports salaries for the chair, a research technician and a summer student. We also provide a discretionary grant. Working with Professor Robertson are Dr Zandra Jenkins, Cure Kids Research Fellow; and Dr Emma Wade, Cure Kids Postdoctoral Fellow.

## DR EMMA WADE CURE KIDS POSTDOCTORAL FELLOW



Originally from Stockport in the United Kingdom, Dr Emma Wade moved to New Zealand to pursue a PhD in rare, genetic diseases with Professor Robertson at the University of Otago. Since then, she has worked as a postdoc and research fellow in the Department of Women's and Children's Health, Otago.

Dr Wade's research is focused on uncovering the genetic causes of skeletal and connective tissue diseases that affect children in New Zealand and around the world. Through her research, she discovered the role of two genes in a rare, skeletal dysplasia and revealed a novel mechanism involved in skeleton development.

Using numerous molecular tools, Dr Wade aims to not only understand which genetic changes cause disease, but also to find out more about how those genes work in pathways to ensure healthy development. She hopes to apply this knowledge to develop effective treatments for common disease and injury of the skeletal and connective tissues.

## DR ZANDRA JENKINS CURE KIDS RESEARCH FELLOW



Dr Zandra Jenkins is a research fellow with Professor Robertson's Clinical Genetics Group, Department of Women's and Children's Health at the University of Otago. Her special interest is genetic disorders of neurogenesis and skeletal development.

Dr Jenkins completed her doctorate with the AgResearch Molecular Biology Unit at the University of Otago in 1998, studying the molecular genetics of wool. Since then, she has been studying human biology and spent two years at Uppsala University in Sweden looking at protein translation with Dr Hans Johansson. Dr Jenkins continued these studies in the USA at the Children's Hospital Oakland Research Institute, where she also took up research on the regulation of iron homeostasis in patients with sickle cell anaemia and thalassemia with Professor Elizabeth Theil, a pioneer in ferritin and iron biology. After returning to New Zealand in 2003, Dr Jenkins joined Professor Stephen Robertson's group.

Using cultured human cells as model systems, Dr Jenkins studies the biological consequences of genetic changes at RNA, protein and whole cell levels. These techniques make it easier to diagnose individuals with rare disorders and plan their health management. Dr Jenkins work is also providing valuable insights into novel mechanisms of neuronal and skeletal development.

*Big research for little lives*

## PROFESSOR STUART DALZIEL CURE KIDS CHAIR OF CHILD HEALTH RESEARCH AT THE UNIVERSITY OF AUCKLAND



Professor Dalziel is a paediatrician with expertise in emergency medicine. He works as both a researcher and clinician in the Children's Emergency Department at Starship Children's Hospital. Professor Dalziel's research for the University of

Auckland Medical School takes place in the departments of surgery and paediatrics. It includes both medical emergencies, such as status epilepticus; and common childhood conditions, such as asthma and bronchiolitis. Professor Dalziel's research on respiratory conditions in children is strongly aligned to his everyday clinical practice at Starship.

Cure Kids funding supports a contribution to the chair's salary, a research fellow, and a discretionary grant.

## PROFESSOR SALLY MERRY CURE KIDS DUKE FAMILY CHAIR IN CHILD AND ADOLESCENT MENTAL HEALTH AT THE UNIVERSITY OF AUCKLAND



Professor Merry is a psychiatrist who heads the Department of Psychological Medicine at the University of Auckland. She and her team investigate the causes of mental health conditions in children and adolescents.

Professor Merry has developed innovative evidence-based strategies to treat and prevent mental health problems. Her solutions are delivered through digital platforms, such as computers and mobile phones. The professor's aim is to enable all young people with mental health problems to access practical and effective help, which will improve mental health outcomes for young people and their families.

Cure Kids funding supports salaries for the chair and a post-doctoral research fellow. It also provides a discretionary grant. Working with Professor Merry is Associate Professor Sarah Hetrick, Cure Kids Duke Research Fellow; and Dr Karolina Stasiak, Cure Kids Duke Research Fellow.

## DR SARAH HETRICK CURE KIDS DUKE RESEARCH FELLOW



Dr Hetrick is a clinical psychologist and the Associate Professor of Youth Mental Health in the Department of Psychological Medicine, University of Auckland. She is also a co-ordinating editor for the Cochrane Common Mental Disorders Group and involved in a number of systematic reviews focused on interventions for depression, self-harm and suicide prevention in young people.

Another of Dr Hetrick's roles is co-theme lead for the National Science Challenge 'Resilient Teens; A Better Start, E Tipu E Rea', which is funded by the Ministry of Business, Innovation and Employment. This programme uses digital platforms to provide easy access to interventions that support mental health and wellbeing for young people, including tools aimed at helping young people to manage suicidal ideation and self-harm. Her role includes developing guidelines to manage self-harm in school settings, and developing resources to support parents and whanau of young people who engage in self-harm. Recently, Sarah was appointed Principal Clinical Advisor for the Suicide Prevention Office.

## DR KAROLINA STASIAK CURE KIDS DUKE RESEARCH FELLOW



Dr Stasiak completed her PhD in Psychiatry working on a prototype of a digital game to teach adolescents cognitive behavioural therapy (CBT) skills to manage symptoms of depression. That project ignited her curiosity and passion for eHealth research and she has since co-developed SPARX, a gamified online self-help tool for young people, which is one of the first eTherapy tools to be ever implemented nationally.

Dr Stasiak worked with colleagues in Canterbury to introduce an online tool to support children and families post-earthquakes and has been involved in the development of using mobile phones to deliver support for depression, as well as other wellbeing apps which the team are currently implementing, in particular - Quest Te Whitianga and Headstrong. Since 2020, she has been a co-Principal Investigator of a school implementation pilot trial of HABITs (Health Advances Through Behavioural Intervention Technologies) – a digital eco-system of screening and tools for rangatahi (a project funded by the Ministry of Business, Innovation and Employment).

# CURE KIDS PROFESSORIAL CHAIRS

## PROFESSOR ANDREW DAY CURE KIDS CHAIR OF PAEDIATRIC RESEARCH AT THE UNIVERSITY OF OTAGO



Professor Day is a paediatric gastroenterologist who has been a Cure Kids chair in Christchurch since 2017. His research interests are hostpathogen interactions in the gut, chronic gastrointestinal

diseases and nutrition, especially in the context of inflammatory bowel disease (IBD). With his research team, Professor Day is investigating inflammatory stimuli, biomarkers for disease and innate immune responses.

Rates of IBD among children and adolescents in NZ are relatively high, so it's hoped Professor Day's work may lead to nutritional therapy to modulate the immune system's response, and therefore improve outcomes for children in New Zealand who live with IBD.

Cure Kids funding supports a contribution to the chair's salary and a post-doctoral research fellow. It also provides a discretionary grant. Working with Professor Day is Dr Angharad Hurley, Cure Kids Research Fellow; and Dr Teagan Edwards, Cure Kids Postdoctoral Research Fellow.

## ANGHARAD HURLEY (VERNON-ROBERTS) POST-DOCTORAL RESEARCHER



After beginning her career as a paediatric nurse, Angharad transitioned to research while working in Oxford, UK. She now has 15+ years of experience in paediatric research in the field of paediatric gastroenterology and nutrition.

Angharad recently completed her PhD on the topic of self-management for children with inflammatory bowel disease (IBD). This included the design and development of a mobile health app for children to learn self-management of their IBD. It also included development of outcome measures to assess children's self-management skills, disease specific knowledge and symptom self-reporting.

Post-doctoral work is Angharad's current focus. She is working on a multi-faceted research programme for children with IBD related to vitamin D, bone strength, telehealth management and treatment strategies.





“Our research enables us to study human heart cells and sympathetic neurons interacting (in a dish/in vitro), so that we can learn more about what triggers sudden death in families with Long QT Syndrome.”

## CURE KIDS RESEARCHER AWARDED PRESTIGIOUS INTERNATIONAL PRIZE

Congratulations to Dr Annika Winbo, who was recently awarded a prestigious, international award named the 'Heart Rhythm Society Young Investigator Award' for her research into Long QT Syndrome, an inherited heart condition.

Dr Winbo is the first New-Zealand-based researcher to win the award since it began in 1990.

A key aspect of winning was that she and her team were the first to successfully grow New Zealand patient heart cells and sympathetic nerve cells in the laboratory.

"The life-threatening arrhythmias in Long QT Syndrome typically are triggered by the sympathetic 'fight or flight' response. That means sudden death can be triggered by fear, excitement, or a simple jump into the water. Our

research enables us to study human heart cells and sympathetic neurons interacting (in a dish/in vitro), so that we can learn more about what triggers sudden death in families with Long QT Syndrome."

Special thanks to the Huge Green Foundation for helping Cure Kids fund this important work.

**Hugh Green**  
FOUNDATION

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# 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 MATARORIA LYNDON**  
UNIVERSITY OF AUCKLAND

Dr Lyndon is a public health doctor, lead clinical advisor for Māori health at Counties Manukau DHB and a senior lecturer in medical education at the University of Auckland. His research field is performance measurement of healthcare systems and his PhD is in medical education. As a Fulbright Scholar, he completed his Master of Public Health at Harvard University in 2017. Dr Lyndon is working with Moana Research to deliver the Māori arm of the Respiratory Project.

cell model from the blood of young Swedish LQTS patients. In New Zealand, these stem cells have been grown into living human heart cells with the LQTS patients' genetic makeup. They're being tested for arrhythmia susceptibility and the efficacy of potential treatments.



**DR JOANNE CHOI**  
UNIVERSITY OF OTAGO

Dr Choi is a lecturer at the University of Otago Faculty of Dentistry, where she teaches about dental technology and materials. After completing a Bachelor of Dental Technology from the University of Otago, she worked in a commercial dental laboratory for several years before returning to study towards a PhD. Her PhD research involved developing and validating a sensor system to monitor intraoral pH and temperature for long periods, to identify factors that cause dental wear. Her current research interests include dental materials and clinical oral physiology, with a focus on the development and application of new materials for dental care.



**JACINTA FA'ALILI-FIDOW**  
MOANA RESEARCH

Jacinta's passion is to ensure equity for all children. She holds a Master of Public Health, is CEO of Moana Research and is currently working on her PhD. While she's studying, Jacinta works part-time at the University of Auckland as the Pacific advisor for the Growing up in New Zealand Study. Previously, Jacinta worked for five years at the Ministry of Health and four years at the Health Research Council.



**DR JASON TURUWHENUA**  
UNIVERSITY OF AUCKLAND



**DR ANNIKA WINBO**  
UNIVERSITY OF AUCKLAND

Dr Winbo is a paediatric doctor who graduated from Umeå University in Sweden in 2009. She wrote a thesis on Long QT Syndrome (LQTS) in Sweden and in 2012 received a PhD in paediatrics, with an emphasis in cardiology. In 2013, Dr Winbo teamed up with New Zealand professor and paediatric cardiologist Jon Skinner and two years later Associate Professor Johanna Montgomery joined them. In collaboration with a US team, they've established a stem

Dr Turuwhehua is a Senior Research Fellow working for the Auckland Bioengineering Institute, and the School of Optometry and Vision Science at the University of Auckland. With a background in vision, he enjoys applying engineering techniques to solve problems and create outcomes that could have a direct benefit to clinical practice, patients and their families. Dr Turuwhehua is currently leading a cross-disciplinary research project that uses a computer-based tablet device to identify visual acuity problems in young children. This is of particular importance in detecting amblyopia, or lazy eye, for which there are no reliable objective techniques currently available

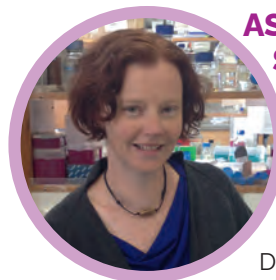
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**DR MAIRIN TAYLOR**  
UNIVERSITY OF CANTERBURY

Dr Taylor is a registered clinical psychologist and lecturer in counselling at the University of Canterbury. She and her family spent time in Japan, where she was a research scientist at a graduate university. Before this, she

worked in private practice in Christchurch with a number of NGOs, working with children, youth, adults and their whānau. Dr Taylor speaks Japanese and Te Reo Māori, and enjoys working cross-culturally with individuals from diverse backgrounds. Her research has addressed impacts of ADHD and her current project is examining a treatment programme called MindKiwi which will incorporate a Kaupapa Māori framework and then assess its effectiveness for children to ADHD in a new context.



**ASSOCIATE PROFESSOR  
STEPHANIE HUGHES**  
UNIVERSITY OF OTAGO

Associate Professor Hughes holds a PhD in biochemistry and molecular biology. She's an associate professor in the Department of Biochemistry and director of the Brain Health Research

Centre at the University of Otago. Her research area is neural development and disease. She specialises in Batten disease, a childhood brain disease that shares clinical features with Alzheimer's disease, Parkinson's disease, blindness and epilepsy. Batten disease is genetic, with at least 13 different forms caused by mutations in different genes. In her lab at the University of Otago, Associate Professor Hughes and her team study how mutations cause clinical symptoms in three disease forms. They're developing new human cell culture models and testing new drugs and gene therapy approaches for treatment.



**DR JINEY JOSE**  
UNIVERSITY OF AUCKLAND

Dr Jose holds MS and PhD degrees in organic chemistry from Texas A&M University. His research developed organic fluorescent probes and nanoparticles for cellular imaging studies. Awarded a postdoctoral

fellowship, Dr Jose focused on developing tryptamine analogues for the treatment of breast cancer. In 2012, he joined the Auckland Cancer Society Research Centre as a research fellow and is an affiliate investigator at the Maurice Wilkins Centre for Molecular Biodiscovery at the University of Auckland. He's involved in an immunotherapy project developing small molecules to treat leukaemia, and in the development and application of tumour targeting theranostic drug dye conjugates with brain penetrant properties for treating paediatric and adult brain cancers



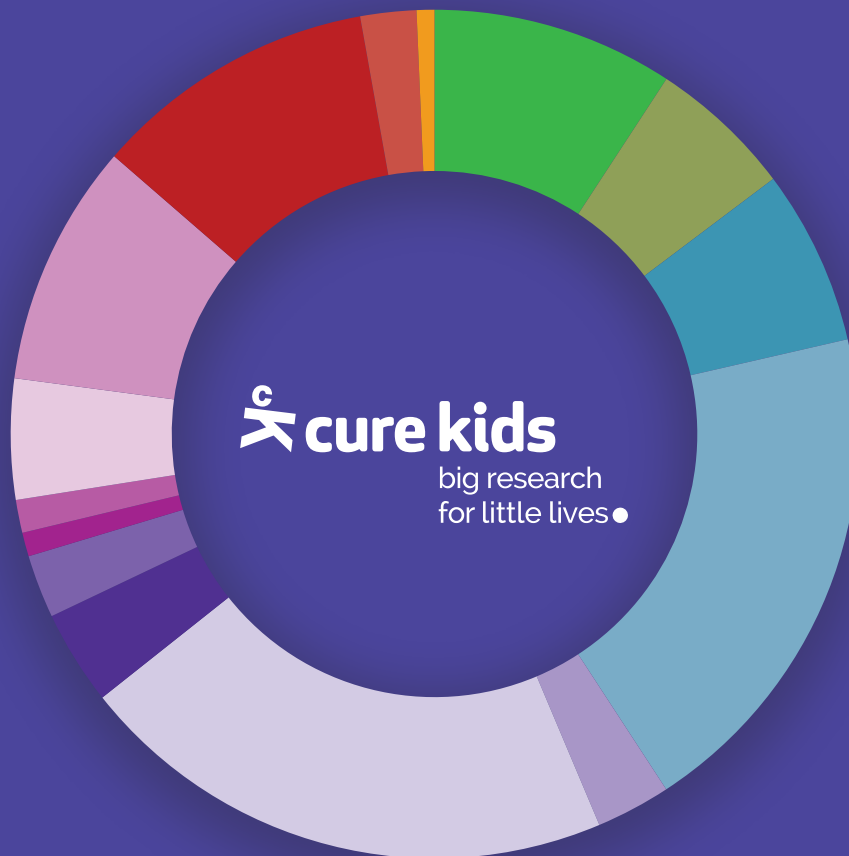
**ASSOCIATE PROFESSOR  
LOUISE BICKNELL**  
UNIVERSITY OF OTAGO

Associate Professor Bicknell undertook her PhD at the University of Otago, before heading to the University of Edinburgh to study single gene disorders of growth. In 2015, she

returned to New Zealand with a Rutherford Discovery Fellowship to establish her own research lab. Her lab focuses on rare single-gene disorders of short stature and brain growth, and how fast our cells grow and divide during critical times of organism development. Associate Professor Bicknell's longer-term goal is to investigate how additional genetic differences can influence the severity or prognosis of a condition. This will provide families with more information about what they could expect regarding their child's genetic condition.

# RESEARCH WE'RE FUNDING

Since 1971, we have invested nearly \$60 million into child health research, helping to improve diagnosis, and provide better treatment options for our most vulnerable children. Today, we are proud to be supporting over \$18 million of child health research projects across a broad range of conditions.



- Genetic conditions  
**\$1,530,970**
- Infant mortality  
**\$916,049**
- Preterm and perinatal conditions  
**\$1,109,249**
- Cancers  
**\$3,218,841**
- Disabilities  
**\$472,778**
- RF / RHD  
**\$3,436,772**
- Obesity and nutritional disorders  
**\$599,056**
- Gastrointestinal disorders  
**\$400,000**
- Oral and dental conditions  
**\$151,014**
- Cardiovascular conditions and blood disorders  
**\$208,265**
- Respiratory conditions  
**\$762,089**
- Mental health conditions  
**\$1,537,721**
- Brain and neurological disorders  
**\$1,798,135**
- Infectious diseases  
**\$354,384**
- General diseases and health issues  
**\$112,397**

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Lucca Holecliffe was diagnosed with a rare and aggressive cancer in March 2016. At the time, only nine other cases had been documented worldwide. Eight of those nine people died within nine months, while four years on, Lucca is healthy. She is one of the first children in the world with this disease to be treated with a new medicine, under Dr Andy Wood's research.

Cure Kids first funded Dr Wood's research in 2018 in partnership with Child Cancer Foundation. In 2020, Cure Kids and Child Cancer Foundation came together once again, with generous additional support from Lindsay Foundation, to boost the funding of this project.



Lucca with Dr Andy Wood



## RESEARCHING AN END TO RHEUMATIC FEVER

Rheumatic fever has been wreaking havoc with young people's lives for too long. Cure Kids has decided that enough is enough. We're putting \$3 million into research, so that we can find new ways to prevent, treat and eliminate rheumatic fever (RF), which is the precursor to rheumatic heart disease (RHD).

In New Zealand, rheumatic fever affects mostly Māori and Pasifika tamariki. It starts as 'strep throat', then becomes an autoimmune disease that causes heart, joints, brain, and skin to become inflamed and swollen. The inflammation from rheumatic fever can develop into rheumatic heart disease, which involves scarring of the heart valves. On average, rheumatic fever kills 130 New Zealanders every year.

A case in point is Matt Johnson, a former midfielder for the Blues rugby team. Matt had rheumatic fever when he was 13 and has been experiencing severe heart problems ever since. He's had three open-heart surgeries, two aortic valve replacements and, most recently, severe complications from an infected valve and dislodged stent. In November last year, Matt was in an induced coma for six days while surgeons figured out what to do. He recovered, but sadly his Super Rugby career is over. Matt is now helping to raise awareness of rheumatic fever and its long-term health impacts.

“My message is pretty simple, if you have a sore throat, go get it checked out. It could save your life,” says Matt.”



*Matt Johnson, former Blues rugby player, in hospital following a coma as a result of RHD.*

Cure Kids CEO, Frances Bengé, says rheumatic fever affects New Zealand's most vulnerable communities and is an entirely preventable childhood infection.

Rheumatic fever has been called a national shame. It's rarely seen in developed countries, but continues to be a heart-breaking problem in New Zealand. Māori children are 50 times more likely to get rheumatic fever than Pākehā children; Pasifika children are 120 times more likely to get it.

“We believe in a developed nation like New Zealand, this condition, which is preventable, simply should not exist. More research is needed for tools to help eliminate it from our country.

“We saw with COVID the difference we can make when the country comes together and realises there's an issue, so why can't we do this with rheumatic heart disease as well?” says Frances Bengé.

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The \$3 million Cure Kids has allocated to rheumatic fever and rheumatic heart disease will enable six research projects from some of New Zealand's leading researchers in the field. Each project has different, but complementary, objectives.



**Dr Nikki Moreland** is using advanced laboratory methods to identify specific biomarkers for rheumatic fever, which will enable faster and more accurate diagnosis and care.

**Dr Jacelyn Loh's** laboratory is designing a vaccine that will have broad coverage of Group A Strep, and will be tested in clinical trials for safety and efficacy against the disease.



**Dr Julie Bennett** is collaborating with researchers in Australia to trial a high-dose, longer-lasting skin implant to improve monthly penicillin injections, currently the only available method to prevent RHD.

**Dr Anneka Anderson** is piloting a patient-centred model of care to improve services for rangatahi Māori and Pasifika, by developing more appropriate ways to deliver monthly injections to prevent development of RHD.



**Dr Dianne Sika-Paotonu** is working on a novel drug development pathway, in search of different chemical forms of penicillin that might yield new options for preventing RHD.

**Associate Professor Nigel Wilson** is studying the safety and efficacy of a well-known anti-inflammatory medication, hydroxychloroquine, for preventing damage to heart valves and therefore avoiding RHD.



Our commitment to stamping out rheumatic fever, and therefore RHD, builds on the legacy of our late co-founder Professor Sir Bob Elliott who saw that children in New Zealand and the Pacific Islands were not as healthy as those in other countries, and wanted to improve the statistics.

## ABOUT RHEUMATIC FEVER

Rheumatic fever is an autoimmune disease. It happens when a child's immune system attacks other parts of the body, as well as the bacteria that cause strep throat. Typically, the heart, joints (elbows and knees), brain and skin become inflamed and swollen.

The risk of getting rheumatic fever gets higher when a child has repeated untreated strep throat infections. However, even the very first strep throat infection can lead to rheumatic fever.

While the symptoms of rheumatic fever may disappear on their own, inflammation from the attack has the potential to develop into rheumatic heart disease, where there is scarring of the heart valves.



# NEWLY FUNDED RESEARCH PROJECTS IN 2020

## ASSOCIATE PROFESSOR EILEEN LUEDERS UNIVERSITY OF AUCKLAND



Attention-deficit hyperactivity disorder (ADHD) affects about 1 in 20 New Zealand children and appears to have its roots in abnormal brain development. By analysing a set of MRI scans and participant data from other studies, Associate Professor Lueders and

her team from the University of Auckland aim to measure a possible difference in brain age between the children with ADHD and those with typical development. Apart from revealing the direction and amount of abnormal brain maturity in ADHD, the work will provide a strong basis for further studies. The resulting neurodevelopment index (scale) may also enhance existing healthcare approaches to ADHD screening, diagnosis, prognosis and treatment.

cardiac and respiratory failure. There is no readily available cure or conclusive understanding of how the symptoms occur. However, calcium ion loss has a major role in the initial degenerative phase and a leaky calcium channel in muscles can be caused by reactive oxygen species (ROS). Dr Cully and her team from the University of Otago are using a drug already in clinical trials for other diseases to target ROS-induced calcium leak in DMD. This could eventually provide a new drug-based therapeutic intervention and avoid expensive genetic alterations (currently being trialled).

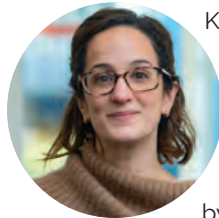
## MR RUSSELL PINE VICTORIA UNIVERSITY OF WELLINGTON



Although various treatments are available, many mental health issues among New Zealand adolescents remain untreated and often undiagnosed. Existing mental health interventions adapted into digital

formats have performed well in trials, but real-world uptake is low. A promising way to address this is through casual video games (CVGs). Angry Birds and Tetris are popular examples of CVGs. A multidisciplinary team at Victoria University developed Sparky, a CVG to support young adolescents with their mental health. Results from early studies suggested the prototype was promising and professional developers have been engaged to complete the game. Cure Kids is now funding a controlled trial evaluation of Sparky's potential therapeutic effects.

## DR FARAH LAMIABLE-OULAIDI VICTORIA UNIVERSITY OF WELLINGTON



Krabbe disease (KD) is a rare neurodegenerative disorder that typically causes infants to die in their first few years. Unfortunately, there is no treatment for KD and therapeutic strategies are limited by the brain's highly selective barrier

between circulating blood and the central nervous system. Dr Lamiable-Oulaidi and a team from Victoria University are investigating an exciting new approach. It involves a small pharmacological chaperone (PC) molecule, which can reach the central nervous system and refold misfolded enzymes. The team will use enzymatic transition state (TS) analysis to ensure the PC has exactly the right strength. This work could lead to new drug candidates for pharmaceutical development.

## DISTINGUISHED PROFESSOR MARGARET BRIMBLE UNIVERSITY OF AUCKLAND



Poor oral health is one of the most common chronic health problems in New Zealand, as outlined in the 2020 State of Child Health Report by Cure Kids. It affects nearly 40% of pre-school children, particularly children of Māori and Pacific descent. Untreated

dental decay plays a significant role in other childhood medical conditions, including asthma, middle ear infections, chronic diabetes and heart conditions. Current fluoride preventative measures don't address damage-causing plaque formation. Distinguished Professor Brimble and a team from Auckland and Otago universities are

## DR TANYA CULLY UNIVERSITY OF OTAGO



Duchenne muscular dystrophy (DMD) is caused by a mutation in the gene that encodes dystrophin, a membrane stabilising protein. This results in accelerated muscle degeneration, progressive weakness and eventual

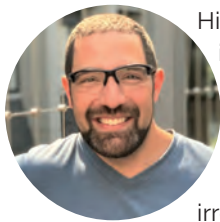
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developing a non-invasive peptoid-based therapeutic. It will re-mineralise damaged dental enamel and prevent plaque formation through direct antimicrobial activity. The aim is also to develop a fast-acting therapy, so it's suitable for children.

### DR EHSAN VAGHEFI UNIVERSITY OF AUCKLAND



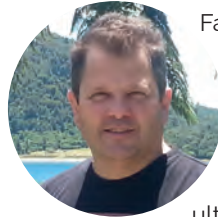
His father's loss of sight as a child inspired Dr Vaghefi to develop technologies that prevent unnecessary eyesight loss. The rapid progression of myopia (short-sightedness) in childhood can cause irreversible blindness. It's estimated that 20% of New Zealand children have myopia, which is expected to reach epidemic levels by 2050. Vision loss can be prevented if at-risk children are identified early and myopia control interventions are started. Dr Ehsan and a team from the University of Auckland, ADHB and CMDHB have developed and patented imaging technologies for accurate measurements of eye anatomy and physiology. They plan to adopt and combine these technologies in a single platform suitable for screening children.

### DR LOUISE BICKNELL UNIVERSITY OF OTAGO



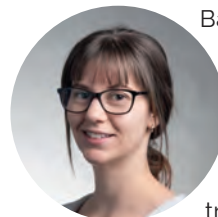
Starting with a New Zealand family, Dr Bicknell and her team at the University of Otago have discovered a new genetic disorder. Affected patients have severely reduced brain growth and other brain structural anomalies, resulting in epilepsy and severe intellectual disability. Through their international networks, they found five other patients with the same genetic alteration and clinical features. The team will use zebrafish to understand how the genetic alterations can disrupt brain development. They hope to prove this is a new disorder and confirm the diagnosis for the family. The data will be made available to the clinical genetics community. Importantly, the team will discover more about the role this new disease gene plays in brain development.

### DR MARK OLIVER UNIVERSITY OF AUCKLAND



Failure of the placenta to supply enough nutrition and oxygen can lead to foetal growth restriction (FGR) and small birth size. FGR also decreases a baby's survival chances and can affect health throughout life. Current methods - ultrasound or tummy measurement - can miss a third of FGR cases in New Zealand. A hormone in maternal blood, called C-type natriuretic peptide (CNP), may be a marker of low foetal blood oxygen and FGR. Dr Oliver and his team from the universities of Auckland and Otago are investigating whether CNP could be a useful test for FGR and low foetal oxygen. This would enable more reliable detection using an inexpensive, non-invasive test that doesn't require specialist skills.

### DR SAMANTHA MURRAY LINCOLN UNIVERSITY



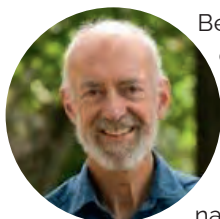
Batten disease is a group of fatal disorders that cause deafness, blindness and paralysis, often before children reach their teenage years. The average life expectancy is 8 to 20 years. There's no cure and few treatments to slow or halt its progression. Dr Murray and her team from Lincoln University recently completed trials of combined brain and eye gene therapy in CLN5-affected sheep. The promising results have led to the preparation of a new drug application to the U.S. Food and Drug Administration for human trials. Dr Murray's team will continue this work in a project timed to fit with a proposed human clinical trial run by Neurogene Inc.

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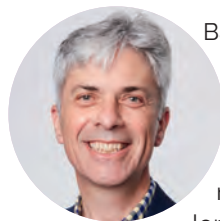
# NEWLY FUNDED RESEARCH PROJECTS IN 2020

## EMERITUS PROFESSOR ED MITCHELL UNIVERSITY OF AUCKLAND



Between 2009 and 2015, first-year deaths decreased by 29% in New Zealand. This was attributed to the Safe Sleep programme, which requires babies to have their own safe sleep space in the parental bedroom. In 2017 a national sudden unexpected death in infancy (SUDI) prevention programme, which provided wahakura or Pepi-pod safe sleep devices, was funded by the Ministry of Health. Unexpectedly, first-year mortality has since increased, especially for Māori infants. Professor Mitchell and his team are conducting a study to understand what might be causing this increase. The outcomes will be used to inform the national prevention programme and reduce SUDI mortality.

## PROFESSOR FRANK BLOOMFIELD UNIVERSITY OF AUCKLAND



Babies born at moderate-late pre-term (MLPT) gestation account for more than 80% of all pre-term births. They have excellent survival rates but are at increased risk of adverse neurodevelopmental outcomes and long-term health problems, such as cardiovascular disease, obesity and diabetes. DIAMOND is a randomised controlled trial in MLPT babies. It's investigating the role of different feeding strategies in the early days after birth until four months corrected age. Professor Bloomfield and his team are conducting a year-two follow-up of DIAMOND trial babies. Their work will determine the impact of different nutritional interventions on neurodevelopmental outcomes, as well as growth, body composition, health, behaviour and eating patterns.

## PROFESSOR CAMERON GRANT UNIVERSITY OF AUCKLAND



Pre-school wheeze is one of the most common causes of hospital admission in young children in New Zealand, Australia and worldwide. Current prevention strategies are ineffective and there's a recognised need for new approaches. OM-85 is an orally-administered bacterial lysate that stimulates immune responses for viral infection defence. Emerging evidence suggests it may prevent wheeze episodes in young children. Larger studies are required to evaluate whether it reduces wheeze-related hospital admissions in pre-schoolers. To address this critical knowledge gap, Professor Grant and a team from New Zealand and Australia are conducting a multi-centre, randomised, double-blind, placebo-controlled trial.

## PROFESSOR SIMON MALPAS UNIVERSITY OF AUCKLAND



Hydrocephalus is an abnormal build-up of fluid around the brain. It's the most common paediatric neurosurgical condition, with around 100 diagnoses in New Zealand every year. Unfortunately, the tube installed to drain the excess fluid has a 60% chance of blocking in the first two years. A CT scan is the only way to confirm the blockage and 70% of the time the symptoms - such as irritability, headaches and vomiting - turn out to be related to another issue. Professor Malpas and his team from the University of Auckland and ADHB are developing a much-needed tool that will let parents and caregivers monitor their child's brain pressure remotely and share the data with health care professionals.

# TRUSTS AND FOUNDATIONS WHO SUPPORT US

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

BLUESKY COMMUNITY TRUST

DUO TRUST

EM & MH STICHBURY TRUST

ESTATE OF ERNEST HYAM DAVIS &  
THE TED AND MOLLIE CARR ENDOWMENT TRUST

EPILEPSY FOUNDATION OF NEW ZEALAND

FIJI WATER FOUNDATION

FINDEX COMMUNITY FUND

FOUR WINDS FOUNDATION

HUGH GREEN FOUNDATION

HUGO CHARITABLE TRUST

JAMES SEARLE SAY TRUST

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LINDSAY FOUNDATION

LION FOUNDATION

LOUISA AND PATRICK EMMETT MURPHY FOUNDATION

MAS FOUNDATION

MILESTONE FOUNDATION

NORTH AND SOUTH TRUST

NZ COMMUNITY POST

PERPETUAL GUARDIAN

RODMOR CHARITABLE TRUST

TRINITY FOUNDATION

## SPECIAL MENTIONS

A big thank you to the **Epilepsy Foundation of New Zealand** for contributing \$10,000 toward Professor Lynette Sadleir's research into the discovery of the causative genes in epilepsy, with the aim of providing better treatment options to improve the quality of life and health outcomes for children living with epilepsy.

Support from ongoing funders such as the **Lion Foundation**, who donated \$24,000, provided crucial operational support to Cure Kids in 2020. Similarly, the **Rodmor Charitable Trust** gifted \$15,000 and have been supporting our work for over a decade.

*Thank you!*



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 these programmes of life-saving research.

## THE RHEUMATIC HEART DISEASE CONTROL & PREVENTION PROGRAMME

### RHEUMATIC HEART DISEASE

Rheumatic Heart Disease (RHD) is a long-term heart condition which mostly affects young people and women. It is caused by repeated infections with a bacteria known as Group A Streptococcus (e.g. 'strep throat'). If the immune system over-reacts to these infections, the resulting rheumatic fever, causes inflammation of the heart, joints, brain and skin. In the heart valves, this 'auto-immune' inflammation can result in scarring and long-term damage known as RHD.

Fiji has some of the highest rates of rheumatic fever and RHD in the world. The official documented data shows that one child in every classroom is likely to be living with the effects, whether they know it or not. Every year in Fiji, about 60 young people die due to RHD.

RHD causes long-term illness and disability. School-aged children don't usually have symptoms, and in Fiji, young people may not be diagnosed until they already have serious symptoms of the disease.

### PARTNERSHIPS

A long-term goal of the RHD Control & Prevention Programme is to embed sustainable activities in the health system to reduce the burden of RHD, which kills more young people in Fiji than any other disease.

Fiji's government has been working with experts to control this disease for many years. Cure Kids became involved in the Group A Streptococcal Project (FijiGrASP) developed by researchers from Fiji, Australia, and New Zealand. In 2014, Cure Kids was granted funding from the New Zealand Government to partner with Fiji's Ministry of Health and Medical Services (MHMS) to deliver a RHD Control & Prevention Programme, together with health experts from the Fiji National University, the University of Auckland, Auckland District Health Board, Murdoch Children's Research Institute, Telethon Kids Institute and the University of Melbourne.

This 5-year Programme delivered:

- An online patient-information system which allows healthcare professionals to track treatment and care for more than 5,000 patients with RHD;
- A team trained to detect RHD in children using hand-held scanners and echocardiography machines and link them with further care;
- Educational materials and counselling sessions to provide advice about how to live with the disease and avoid worsening symptoms;
- Public health messages to raise awareness of RHD, and encourage prevention;
- Methods to increase the number of young people sticking with regular antibiotic treatments;
- Training on the disease and its prevention and care for more than 3,000 healthcare workers;
- Collaboration with the Ministry of Health to develop best-practice clinical guidelines for RHD; and
- Initiation of support groups for more than 1,400 RHD patients and their carers.



In 2020 NZ's Ministry of Foreign Affairs & Trade committed to an additional NZ\$3 million over 3 years to build on the

*Big research for little lives*



success of the Prevention & Control programme. This new phase will support MHMS to improve access to care and expand screening and treatment programmes in schools and hospitals across Fiji, including for pregnant women and families of newly diagnosed cases. This phase will also offer peer-support for people living with RHD and public awareness programmes focused on behaviour change to encourage treatment for RHD. It will investigate some of the barriers to care for people living with the disease, along with ways to improve access.

Finally the programme includes a trial of several different methods for diagnosis of Group A Streptococcus in throat infections. Together, these activities are designed to create an effective and sustainable programme for secondary prevention of RHD in Fiji, and in doing so, both improve the quality of life for many patients, and prevent avoidable deaths.

Fiji Water Foundation also generously provided funding for an additional Vivid iq ECHO machine and training of nurses to expand early case-detection with ECHO screening beyond schools in Suva, to schools in Rewa, Lautoka, Ba and Labasa (Macuata) subdivisions.

The official partnership launch with staff from Fiji's Ministry of Health and Medical Services (MHMS), NZ Ministry of Foreign Affairs & Trade, and Cure Kids.



Front Row L-R: RHD Programme Lead Dr Jimaima Kailawadoko, His Excellency the New Zealand High Commissioner to Fiji, Mr Jonathan Curr, and Permanent Secretary for Health Dr James Fong.

## LIFE-SAVING TREATMENT WITH OXYGEN

For severe pneumonia, the biggest killer of children worldwide, oxygen can reduce the risk of death by 35%. Other respiratory conditions, such as asthma, also require treatment with oxygen, and the World Health Organization

recommends oxygen therapy for preterm and newborn babies with serious illnesses.

Although these conditions are leading causes of death in Fiji, most health facilities use oxygen cylinders, which are expensive, and can be logistically difficult to maintain, store, and use.

In partnership with Fiji's Ministry of Health and Medical Services, Cure Kids Fiji is delivering new ways to improve the availability, affordability and clinical use of oxygen to save lives.



## FIJI OXYGEN PROJECT

Since 2016, Cure Kids and Cure Kids Fiji have worked with Fiji's Ministry of Health and with Associate Professor Stephen Howie of the University of Auckland to champion the introduction of oxygen concentrators—small, portable machines which filter nitrogen out of the air to supply highly pure oxygen—in hospitals and health centres to supply life-saving oxygen to patients. The Oxygen Project team has worked to train staff at six health facilities around Fiji to use these high-tech machines, and provides ongoing monitoring, training, and support to help them to care for their local populations of more than 120,000 people.

Assoc Prof Howie is the Technical Lead for the Oxygen Project, and works with biomedical engineers and clinical staff at Fiji's Ministry of Health to ensure that the oxygen supplied actually translates into better clinical outcomes through enhanced detection and case management for patients with hypoxic illnesses. The solutions are designed to be scalable and sustainable, with the ultimate goal of national coverage to ensure that no communities are left unprotected.

*Continued over >*

*Big research for little lives*



In 2020, Cure Kids was honoured to receive a very generous grant of NZD 600,000, made possible by the combined fundraising

efforts of the Rotary Club of Remuera Inc in Auckland, New Zealand, and the Rotary Club of Suva, Fiji, with an additional commitment from Rotary International.

This funding, from Rotarians around the world, will enable eight healthcare centres to gain access to high quality medical-grade oxygen for their patients. The Rotary funding has purchased 24 oxygen concentrators and 20 oximeters, together with the equipment for monitoring and reporting. Giving pulse oximeters to specially trained nurses at ten nursing stations has already significantly extended the reach of the project, since the ten stations collectively service more than 15,000 Fijians in rural communities.

The nurses can quickly detect hypoxia and refer patients to the nearest clinic with an oxygen concentrator. Three of the sites selected to receive equipment donated by Rotary are in very remote islands with no suitable electrical supply. Rotary's funding has enabled purchase and installation of custom-designed solar-energy systems to ensure a reliable supply of oxygen for patients in severe respiratory distress.

So far the Oxygen Project has:

- **Trained more than 390 clinical and technical staff to use specialised equipment to detect and treat hypoxic illnesses;**
- **Assessed at least 1,270 patients at the new Nursing Stations enabled by the Rotary funding;**
- **Treated more than 10,500 patients with life-saving oxygen;**
- **Completed detailed assessments for the next round of installations at health facilities, which are planned in the next few months.**

### COVID-19 PANDEMIC RESPONSE EFFORT

According to the World Health Organization, approximately 19% of people who develop a COVID-19 respiratory-tract infection will have severe disease that requires hospital treatment. Oxygen therapy is an essential treatment for patients with severe COVID-19.

In June 2020, Cure Kids donated 50 new oxygen concentrators and 30 oximeters worth FJ\$126,000 to help patients in Fiji with acute respiratory infections as a result of the COVID-19 pandemic. The Ministry of Health has been

able to distribute these machines to its facilities around Fiji to enable the best possible protection for the citizens of Fiji in the event of a COVID outbreak.

This donation was made in partnership with Fiji's Ministry of Health & Medical Services, The University of Auckland, and Azimut360, and generously funded by the ANZ Fiji500 event, Armacup, and employees of FIJI Water and Neptune, through their Wonderful Giving Programme. We sincerely thank everyone who came together to make this essential, life-saving donation possible.

Cure Kids Fiji was also proud to donate the time of our Programme Lead Dr Sainimere Boladuadua to join Fiji's COVID-19 Incident Management Team (IMT) during the immediate response to the threat of pandemic. Dr Boladuadua managed introduction of a new surveillance system, which is now a central part of Fiji's outbreak response. In the longer term this online system will integrate with other essential health databases, including Cure Kids Fiji's Rheumatic Fever Information System (RFIS), and ultimately will enable Fiji to improve control of a range of infectious diseases – not only Coronavirus.

### 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. The generous support of FIJI Water Foundation has enabled Cure Kids Fiji to strengthen prevention and control of RHD by donation of a Vivid iq ECHO machine and funds for training support. This training and medical equipment will allow healthcare workers to diagnose and treat children earlier.

We were also honoured to accept a donation of FJ\$20,800 from the teams at FIJI Water and Neptune through Fiji Water Foundation's Wonderful Giving Programme. These funds directly supported the Fiji Oxygen Project to provide life-saving oxygen in health facilities around Fiji.

### ARMACUP



Armacup, New Zealand's vehicle-shipping pioneers, have been long-term supporters of Cure Kids Fiji since its launch in 2006. We are thankful for their continued support, including provision of a vehicle which has been invaluable to Cure Kids Fiji for work to improve the health of children.

*Big research for little lives*

# cure kids fiji islands

## VOMO ISLAND FIJI



VOMO Island Fiji supports Cure Kids Fiji's fundraising through guest contributions, room night donations,

accommodation prizes at fundraising events, facilitating sale of souvenir toys, and the annual 'Mt Vomo Sunrise Challenge'.

VOMO also co-hosts the annual 'Christmas Day Out' for children and adolescents living with Rheumatic Heart Disease. Vomo's ongoing support has been essential in extending the reach of our child health programmes in Fiji, and despite the challenging economic times VOMO made a generous donation of FJ\$4,500 towards the cause.

## RANADI ORGANICS



We were pleased to announce a new partnership with Ranadi Organic Plantation this year. This was launched at two health centres in Korovisilou and Nausori, thereby extending the reach of lifesaving programmes for some of the most urgent health challenges facing the children of Fiji.

The donation included the installation of equipment and training local staff to deliver respiratory care for their patients. Plans are underway for further activities to benefit the local community, the land, and the people of Fiji.

## CAPTAIN COOK CRUISES



In 2018 Captain Cook Cruises became a key corporate partner of Cure Kids Fiji, with the aim of tackling urgent child health challenges. This year, Captain Cook Cruises Fiji pledged an additional 3 years of support to Cure Kids Fiji, which will

achieve significant impact for the health of children around the Fiji Islands. Captain Cook Cruises co-hosts the annual 'Christmas Day Out' for children and young people who live with Rheumatic Heart Disease. This year, they went to Tivua Island. Cure Kids Fiji is grateful to Captain Cook Cruises Fiji for their ongoing generosity in co-hosting an event that enables children living with RHD to meet others just like them, as well as some of the amazing people who work with Cure Kids Fiji to make our RHD Control & Prevention programme possible.

## CURE KIDS FIJI WELCOMES NEW CHAIR



Cure Kids Fiji welcomed Mr Tony Whitton as Chair, succeeding Mr Roy Austin, who served as Chair for over 14 years. Cure Kids Fiji would like to thank Mr Austin for his years of service, and his leadership in delivering lifesaving, research-based health solutions to the children of Fiji.

Roy is delighted to hand the role to Mr Whitton, who was appointed to the Board of Cure Kids Fiji in 2016.

Mr Whitton is an experienced business professional, as the Managing Director of the Rosie Group of companies, comprising Rosie Holidays and Ahura Resorts (Likuliku Lagoon and Malolo Island Resort). Mr Whitton has worked in the tourism industry for over 25 years, throughout Australia and the Pacific. He is a member of the Australian Institute of Company Directors (AICD) and has served on many corporate boards, including Tourism Fiji. Mr Whitton currently serves on the board of the Reserve Bank of Fiji, and the publicly listed Fijian Holdings; he is Chair and Trustee of the International School Nadi. In 2019 Mr Whitton was awarded the Officer of the Order of Fiji by his Excellency the President of Fiji, for distinguished service of a high degree to Fiji and humanity.

Cure Kids Fiji also welcomed Mr Bobby Raniga to the Board in 2020. Mr Raniga is a lawyer by profession and has been a Director at both Fiji Islands Revenue & Customs Services and the Reserve Bank of Fiji, and a Trustee of the International School Nadi. He is currently a Director of Port Denarau Centre Management Limited and several other businesses.

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# CURE KIDS PARTNERS

We extend a huge thank you once again to all our corporate and business partners around New Zealand for the time and effort they invested in fundraising for us despite the unprecedented challenges that took place in 2020.

<b>PLATINUM PARTNERS</b>	<b>KEY PARTNERS</b>	<b>INGRAM MICRO</b>
ACCOR	ARAMEX	PARTNERS LIFE
BRISCOE GROUP	ARMACUP	QANTAS
COLLIERS INTERNATIONAL	AVIS BUDGET GROUP	RUSSELL MCVEAGH
	COLUMBUS COFFEE	ROTARY NEW ZEALAND



## BRISCOE GROUP

Since becoming a partner 17 years ago, Briscoe Group has generated more than \$8.4 million for Cure Kids, of which \$689,036.00 was raised in 2020.

“ This staggering achievement reflects the dedication Briscoe Group has for our cause. ”

<b>Red Nose Day</b>	<b>\$241,036</b>
<b>Add What You Can &amp; other campaigns</b>	<b>\$245,000</b>
<b>Cure Kids Golf Day</b>	<b>\$91,000</b>
<b>12 Days of Christmas</b>	<b>\$112,000*</b>

\* Please note that the Briscoe Group Christmas campaign information relates to funds raised in the 2020 financial year.

So to all the teams across Briscoe Group – whether you are someone who works on the front-line or behind the scenes – thank you very much. Your unwavering commitment and support is inspirational and results in a significant contribution towards funding of vital health research for our tamariki across Aotearoa.

## COLLIERS



Our much-valued partnership with Colliers began back in 2005 and over this period they have generated more than \$1 million towards Cure Kids research funding through the annual Latitude long lunch, golf days and in-house team building activities.

We are so grateful for your continued support and thank you for being our “guinea pig” for a new digital engagement tool...watch this space!

## ACCOR

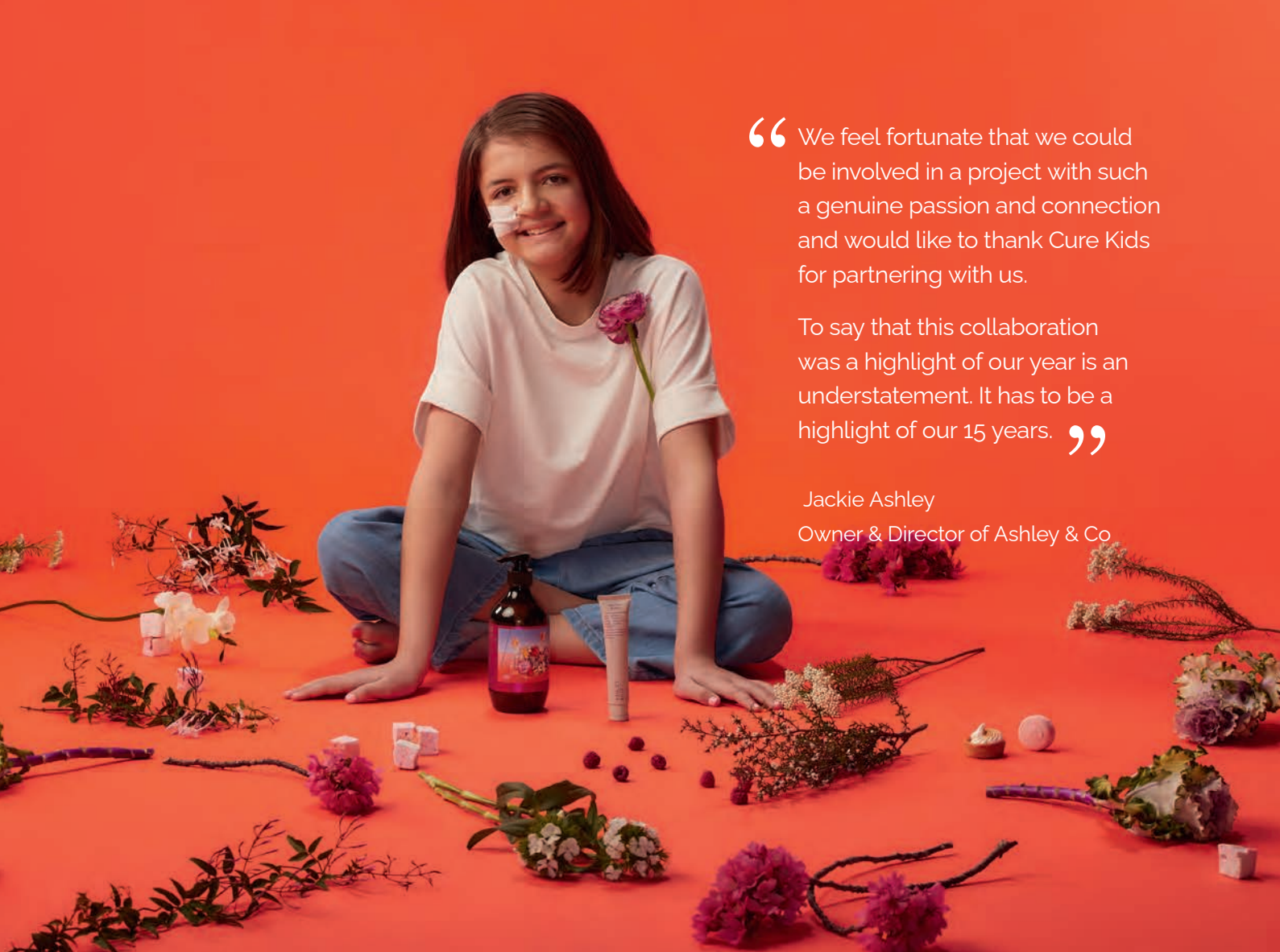


We recognise that Accor' core business is one the most significantly impacted by COVID-19. We certainly appreciate the challenging position they face at present and would like to acknowledge their contribution in helping manage the broader COVID-related circumstances.

Thank you Accor for your fundraising activities at Clearwater Golf Day and the Novotel Rotorua and for supporting our business leaders lunch in the newly-refurbished Sofitel Viaduct Harbour.

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“ We feel fortunate that we could be involved in a project with such a genuine passion and connection and would like to thank Cure Kids for partnering with us.

To say that this collaboration was a highlight of our year is an understatement. It has to be a highlight of our 15 years. ”

Jackie Ashley  
Owner & Director of Ashley & Co

## ASHLEY & CO

In the Spring we were very proud to release a unique new product collaboration with Ashley & Co and our wonderful ambassador Eva. The team at Ashley & Co developed the *Eva Edition*: A specially formulated Wonder Washup and Soothe & Zap sanitising cream, both boosted with special, healing ingredients and a beautiful scent chosen by Eva.

We were very appreciative to receive 20% of every purchase.



## PARTNERS LIFE

Our friends at Partner's Life have helped Cure Kids spread the word about some of the ground-breaking research we've funded by sponsoring a series of podcasts.



## INGRAM MICRO

The wonderful team at Ingram Micro showed their support and commitment by holding their annual golf day, taking part in our annual appeal and donating laptops to support programming in Cure Kids Fiji.

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# RED NOSE DAY 2020

Red Nose Day is Cure Kids' biggest annual appeal where incredible kiwis come together to raise money for child health research. The appeal is huge fun with businesses, schools and community groups across the country all signing up to do their bit.

## DEMONSTRATING THE IMPACT OF NEW ZEALANDERS' DONATIONS



Years of health research and significant breakthroughs were celebrated as part of Red Nose Day 2020, with the launch of the Cure Kids' Breakthroughs Report.

The report included independent evaluations of the research projects Cure Kids has funded throughout its 50-year history, demonstrating measurable benefits to the health of children.

“2020 was a tough year financially for New Zealanders, businesses and charities. We wanted to share the positive impacts of Cure Kids' funded research and let Kiwis know these breakthroughs have been made possible because of their donations,” says Frances Benge, CEO. ”

## A DIGITAL RED NOSE

**Red Nose Day went eco.**  
We ditched the old foam red noses in favour of a digital red nose.

The interactive filter was just as much fun, if not more, than the traditional red noses and was perfect for sharing on social platforms.



## A CONCERT IN YOUR LIVING ROOM

The uncertainty of COVID meant our much-anticipated annual gala dinner had to be cancelled, but Cure Kids didn't let it ruin the fun.

An exclusive invite-only concert starring Phil Madsen was hosted via zoom, with live and silent auctions running throughout the night.

**All up an outstanding \$75,000 was raised.**



## MELA MAKES THE AM SHOW



Cure Kids ambassador Mela and her grandad were featured on the AM Show. They shared Mela's journey living with the rare neurological condition, Moebius syndrome. Mela's school were there in full support, as were some of the Vantage Black Sticks Women hockey team.

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## BRISCOES DOES IT ONCE AGAIN

Red Nose Day isn't complete without the support of the superstars at Briscoe Group. The staff go above and beyond, collecting donations at check out, hosting dress up days and staff morning teas.



**\$332,037  
RAISED**

The team raised a jaw-dropping \$332,037.

## KELLY GROUP BRING THE FUN



Kelly Club and Kelly Sports were out in their schools hosting mufti days, bake sales, hot chocolates before school, raffles, bouncy castles, pancake breakfasts and many more fun events.

As a company Kelly Group NZ raised over \$12,000. Well done to everyone involved.




**\$12,000  
RAISED**

## RED NOSE FACE MASKS




**\$7,000  
RAISED**

NZ Sock Company came up with a novel way to support Red Nose Day – merino face masks – a cosy way to stay protected from COVID, and perfect for the ski slopes.

## THE PERFECT BLEND

Thanks to our good friends at Columbus Coffee, our donors were able to do good while enjoying their daily coffee. Special Red Nose Day coffee cups were created, a money-cant-buy roastery experience was donated for Cure Kids to auction off, and to top it off, their incredible staff collected donations at check out.

All up, an outstanding \$26,709 was raised.




**\$26,709  
RAISED**

## ARAMEX DELIVERS

Aramex pulled out all the stops to ensure Red Nose Day was a success. For every parcel delivered Aramex regional businesses owners donated one cent to the appeal and if they chose to increase this to two cents, the company matched it. Their CE Scott Jenyns also hand delivered some very special care packages to Cure Kids' ambassadors and offered to work a day for the franchise that had the most fun promoting the appeal.



**\$40,000  
RAISED**



They smashed their original \$10,000 goal, raising just shy of \$40,000!

## SCHOOLS GO ALL OUT

Clever little Kiwis across the country came up with fun ways to raise money, including dress up days, sports events, talent quests, teacher challenges and more.

An epic number of schools participated, raising a combined \$22,393!



**\$22,393  
RAISED**

*Big research for little lives*

# COMMUNITY FUNDRAISING



## LOCKDOWN WITH THE BEARS BOOK

Much appreciation to John and Amanda Cushen who generously devoted so much time and energy into the creation of the children's book named 'Lockdown with the Bears' and who are very generously donating all proceeds to Cure Kids.

Their touching story is all about Queenstown's Quail Rise Bears during lockdown in NZ.

## PETE'S LEGACY LIVES ON

We love updates from the Troake family who are on a mission to honour their son Pete's dying wish to complete every single golf course in New Zealand while raising funds for Cure Kids. Pete died from a rare form of bone cancer at age 17.

Jacob Troake uses Cure Kids online fundraising page to generate sponsorship money for his challenge and to allow Pete's legacy to live on.



## MEET IRON MAN RYAN

This is Ryan who has been on a mission since 2020 to complete the 2021 Taupo Iron Man while fundraising for Cure Kids along the way. Ryan says, "I'm always on the lookout for new ways to challenge myself, and this is by far the biggest challenge yet! I currently work at Recruit IT who are partnered with Cure Kids. Through this, I discovered the awesome work they carry out for kids and families across NZ."

Thanks so much Ryan.

*Big research for little lives*

## COMMUNITY FUNDRAISING

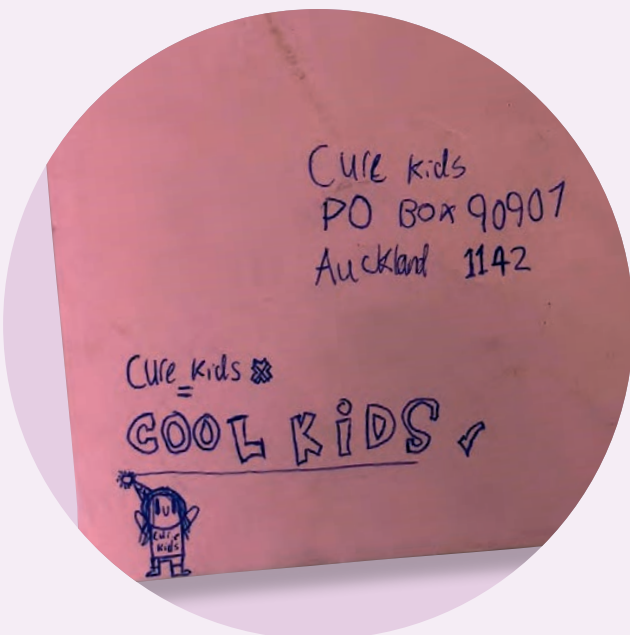


### CLEO SHAVES HER HAIR FOR CURE KIDS

On Friday 14 October, 2020 Cleo, aged 10, did something very courageous — she shaved her hair to raise money for Cure Kids. Cleo managed to secure over \$6,000 of donations within a few short weeks and is rocking her new look. The shaved hair was donated to make a wig for someone in need. Thank you, Cleo. We think you are a huge inspiration.

### KEEPING FIT IN LOCKDOWN THANKS TO BEN

Our good friend and fitness guru Ben Parore designed the #fit4curekids workout to help keep Kiwis active during lockdown. He donated the funds raised on his everyday hero fundraising page to Cure Kids which was incredibly vital at a time when many of our 2020 fundraising events had to be cancelled. Thank you so much Ben.



### THE CUTEST DONATION FROM A LITTLE KIWI

Thank you goes to Sammi for this very thoughtful donation to Cure Kids. The teams' day was made when this beautiful envelope arrived.

### ATTENTION ALL COMMUNITY FUNDRAISERS!

There are lots of ways to get involved and raise funds for Cure Kids. For more inspiration, check out our webpage.

<https://curekids.org.nz/fundraise/>

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## HOW ARE WE DOING?

## CURE KIDS FINANCIAL STATEMENTS

## SUMMARISED STATEMENT OF FINANCIAL PERFORMANCE

	CONSOLIDATED	
	31.12.20	31.12.19
Fundraising Income	2,820,016	4,466,000
Grants Received	232,499	125,000
NZ Government Grant	455,134	0
Rental Income	246,262	240,524
Interest & Dividends on Investments	670,592	795,729
Unrealised Gains	4,817,977	2,828,287
Realised Gains/(Losses)	287,921	37,958
Share of revenue and expense of an associate	166,363	0
Other	292,582	351,091
<b>TOTAL INCOME</b>	<b>9,989,346</b>	<b>8,844,589</b>
Fundraising Expenses	(494,346)	(1,110,675)
Administration Expenses	(581,150)	(671,306)
Salary Expenses	(1,645,903)	(1,841,546)
Research & Development	(273,378)	(242,053)
Grants & Research Investment	(8,795,065)	(3,267,835)
<b>NET SURPLUS/(DEFICIT)</b>	<b>(1,800,496)</b>	<b>1,711,174</b>

## SUMMARISED STATEMENT OF FINANCIAL POSITION

	CONSOLIDATED	
	31.12.20	31.12.19
Cash Held	4,060,567	3,690,857
Fixed Assets	58,536	72,107
Investment Property	5,630,000	5,630,000
Investment Portfolio	35,060,823	31,809,019
Other Assets	1,205,301	1,046,184
<b>Total Assets</b>	<b>46,015,227</b>	<b>42,248,167</b>
Grants	8,848,669	4,436,720
Other Liabilities	2,374,984	1,292,906
<b>Total Liabilities</b>	<b>11,223,653</b>	<b>5,729,626</b>
<b>Total Equity including Capital Funds</b>	<b>34,791,574</b>	<b>36,518,541</b>

Big research for little lives

HOW ARE WE DOING?

# NOTES TO FINANCIAL STATEMENTS

The 2020 financial year saw a surplus before grants and research investment expenditure of \$6.995m (2019: \$4.979m), a positive result given the impact Covid-19 had on Cure Kids' fundraising income, particularly our major gala events, corporate partner fundraising and donation income. The cancellation of events, supported by Board and management efforts to further constrain spending, saw expenses fall \$0.871m on 2019.

This surplus was applied to support research grants and chair salaries of \$8.795m (2019: \$3.267m), the largest level of funding provided in the history of Cure Kids. The deficit arising of \$1.800m was covered by reserves brought forward from prior years.

## The financial position notes at 31 December 2020:

	\$m
Cash	4.1
Property and investments (at valuation)	40.7
Other	1.2
	46.0
Less undrawn grants and liabilities	11.2
Equity	34.8

Included is \$6.7m invested through Cure Kids Ventures, the seed company investment arm. These investments are of an early-start nature, focused on children's health.



Celebrating

**50**

YEARS OF BIG RESEARCH  
FOR LITTLE LIVES

**cure kids**







Mela is a Cure Kids ambassador who lives with Moebius syndrome – a rare neurological condition that affects the muscles that control facial expression and eye movement.



# 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 50-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 and your name.)

**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

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 [twitter.com/curekidsnz](https://twitter.com/curekidsnz)

 [instagram.com/curekidsnz](https://instagram.com/curekidsnz)

For more information on Cure Kids and child health research that you are helping support, visit [curekids.org.nz](https://curekids.org.nz) and sign up to our newsletter.

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