cure kids

CURE KIDS ANNUAL REPORT

2018

Cure Kids ambassadors Addison and Eva

BEST FRIENDS FOREVER

EVA MITCHELL AND ADDISON KITCHING ARE "BEST FRIENDS FOREVER". THEY'RE ALSO LONG-SERVING CURE KIDS AMBASSADORS, FEATURED IN THE PHOTO ON OUR FRONT COVER, EACH WITH HEART-RENDING HEALTH CONDITIONS AND ONGOING MEDICAL CHALLENGES THAT AFFECT THEIR LIVES EVERY DAY. WHILE THEY WERE IN OUR OFFICE FOR A PHOTOSHOOT RECENTLY, WE CHATTED TO THEM ABOUT THEIR FRIENDSHIP.

Eva and Addison first met in Starship Hospital when they were both age four. They were long-term residents in a ward where children usually only stayed a week or so. Addison was being treated for a complex and life-threatening staphylococcus infection, while Eva was undergoing treatment for multiple organ issues, as well as the significant complications of an MRSA infection.

Eva and Addison are now aged 11 and seven years after their first bashful meeting, they regularly catch up to enjoy special time together.

"When I first saw Addison she was really upset and crying because they were trying to get a line* in. I'd had a lot of lines, so I knew what it was like", says Eva. "I went and told my mum 'that kid's getting a line'. Then I watched from the door."

Addison remembers seeing a little face peeking into her room, but she was too sick to say anything. Eventually Eva plucked up courage to go in and say hello, and a fast and firm friendship formed.

"We used to spend hours talking and playing games on an iPad on each other's hospital beds. We made a game up ourselves and my mum took a picture of us playing it. We took that same photo again recently, like a re-enactment", says Addison.

Not only did the girls become firm friends, their families made a special bond too. Addison's mum Kyla and Eva's mum Tiff got acquainted in the hospital tearoom. Extended family members on both sides also got to know each other.

"Parents with long stayers build a bond. The kids see each other, the parents see each other, and you have lots of things in common," says Kyla. "Eva was amazing – she gave Addison encouragement to start eating and, eventually, to get out of bed and play. She was inspirational at a really important time."

Addison lived at Starship for two months, but Eva's stay was indefinite. When Addison was discharged from hospital, Tiff and Kyla made sure the girls were able to keep their extraordinary connection.

"It was truly wonderful for Eva to have a little friend who didn't make her feel different, so it was hard on her when Addison went home," says Tiff. "She was worried about where Addison went and what had happened to her".

Eva's stay at Starship stretched out to six years in total, but Addison and her mum never stopped visiting. When Eva did eventually leave hospital, the playdates continued at each other's houses. Birthdays are always spent together too – and they recently shared their first sleepover together at Addison's house.

Tiff says "Eva and I – and her older sister Mela – have never spent a night away from each other, so the sleepover was a big step for her – and for us! But it was a real milestone, and Eva's life is all about making the milestones we never thought she would."

Another milestone both girls recently achieved was starting their first year of intermediate school. "Never in my wildest dreams did I think we would make it to this point in her life," Tiff says. "I am eternally grateful."

As a tag team of Cure Kids ambassadors, Eva and Addison are wholly committed to the important role they play. They work tirelessly writing speeches together (with a little help from their mums), and candidly talk about their stories and Cure Kids' work, often in front of hundreds of people at fundraising and awareness-raising events.

When we asked what the girls love about each other, Addison says "she's funny" and Eva said "everything". From where we're sitting, it's looking like a lifelong friendship.

Tiff: "This whole journey has given us so much, taught us kindness, compassion, understanding, to live every moment and that the greatest gift we can give is to give, be it love, time or fundraising. We are stronger, fiercer and braver than we ever would have been. When I say 'we' I mean the kids have these attributes to their personalities too. It's impacted us greatly; my heart has been smashed a thousand times, but it has received so much more joy and beautiful moments."

* An intravenous line to supply antibiotics

Best friends Eva, left, and Addison, who met in hospital when they were age four.

If you could have one wish, what would it be?

Tiff: "Can I steal three? For a cure for gastrointestinal failure, for the value of child health research to be known by everyone as it impacts us all. And for everyone to wake up every day knowing it is good to be alive and how lucky we all are to be here."

Kyla: "I am going to follow Tiff's lead and ask for an extra wish: Wish #1 – Endless funding for Cure Kids so that research can continue, especially the amazing work that Dr Siouxsie Wiles is doing into finding antibiotics to fight superbugs!

Wish #2 – For my kids to grow up happy and healthy."

ABOUT ADDISON

Addison was diagnosed with a staphylococcus infection when she was four years old. Doctors initially thought she just had a bad cold but within five days she was fighting for her life. As the infection was in her bloodstream, it affected her heart, lungs and some of her joints. She was in hospital for two months on intravenous antibiotics and had to have multiple major surgeries on her shoulders, arm and lungs to help rid the infection from her body. Although she won the battle against the infection, it permanently damaged her heart. However, despite getting a bit more tired than other kids her age and fitting in regular medical check-ups, she certainly doesn't let it stop her! Addison loves netball and is very good at hip hop dancing.

ABOUT EVA

Eva has been fighting to survive her entire life. She was born with only half a diaphragm after suffering a diaphragmatic hernia during fetal development. With a hole in her diaphragm, nothing was holding Eva's vital organs in place and they pushed up into her chest cavity, preventing her lungs from developing normally. At just six weeks of age, Eva underwent her first operation to rebuild her diaphragm and reposition her organs. After multiple surgeries, numerous bouts of pneumonia, several strokes and an ongoing challenge with a hospital-acquired MRSA bug, she has defied the odds to be alive today. Eva's stomach and bowel do not function at all, so she is fed nutrients through her blood stream via her liver. Her body is constantly developing complications that drastically put her life at risk and require immediate intervention. Eva is extremely close to her older sister Mela (who lived in hospital with her and mum Tiff) and little brother Cooper. Her favourite hobbies are singing and dancing, and she has a growing collection of beautiful baby dolls.

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HOW TO GET INVOLVED

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

DONATE

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

FUNDRAISE

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

VOLUNTEER

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

SPREAD THE WORD

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

CONNECT WITH US

facebook.com/curekidscharity
twitter.com/curekidsnz
instagram.com/curekidsnz

Phone 09 370 0222
Address Level 1, 96 New North Road, Eden Terrace 1021
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For more information on Cure Kids and child health research that you are helping support, visit **curekids.org.nz** and sign up to our newsletter.

STATE OF THE NATION

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

FAITH, HOPE AND CLARITY

Taped to the unassuming whitewashed walls of an otherwise nondescript room in a commercial building on Auckland's New North Road is a collection of colourful, small posters, emblazoned with bold, loud messages. Each poster features some large numbers. Some are very large numbers. The room is the meeting room for Cure Kids and the posters speak to diseases addressed by research projects and programmes that this organisation has supported over the years. Some of the numbers are staggering – hundreds of children with health conditions, cancers, infectious diseases. Some speak to the silent morbidities of cot death, stillbirth and rheumatic fever or suicide. What is heartening though is that Cure Kids-sponsored research supporting endeavours by Kiwi scientists is reversing the course of many of these conditions.

As Cure Kids approaches 50 years of operation, it is instructive to look back, not only at the changes in the funding and research environment over that period, but also in the rising voice of the New Zealand public, that all of our kids need the healthiest start in life possible. Cure Kids, as our nation's pre-eminent, independent child health research entity, has not just paralleled this public appetite to do better for our tamariki, it has actually driven and promoted the rallying cry that we must improve health outcomes for our children.

The ability of child health researchers to compete for research dollars with other branches of medicine can feel like an uneven contest. The broad remit of health research funders has meant that at times the voices of our most vulnerable citizens were drowned out by more strident appeals for support from other sectors. Similarly, it has taken time for the paediatric research workforce to grow and reach critical mass. Cure Kids has bent its back to both tasks and has earned respect, credibility and gratitude in equal measure for the achievements that its investments have spawned. New Zealand has much to thank Cure Kids for as an organisation that acknowledges that children require special and protected consideration to preserve their interests, and above all, their health.

For me, deciding to become a paediatrician was a no-brainer – it was the branch of medicine where one could maximise the chances of changing lives for the better, with enduring effects decades into the future. Stepping from that decision to becoming a child health researcher indicated a more slow-dawning reality in my mind – medicine did not hold all of the answers and some of the approaches to treating conditions lacked evidence and often seemed just plain blunderous. Cure Kids taps directly into the generous hearts of New Zealanders who have always held the interests of their children close. They harness and enable the talents of New Zealand researchers to find effective answers to some urgent and vexing questions. May these synergies see those colourful posters adorning Cure Kids' walls to continue to proliferate through 2019 and beyond.

MEET SOME OF OUR VERY SPECIAL AMBASSADORS

OUR AMBASSADORS ARE THE BEDROCK OF ALL THAT WE DO AT CURE KIDS. WE ARE SO GRATEFUL TO HAVE OVER 50 CHILDREN AND THEIR FAMILIES HELP TO REPRESENT CURE KIDS' MISSION AROUND NEW ZEALAND. EVERY CHILD AMBASSADOR (AND THEIR AMAZING FAMILIES) DEDICATES A GREAT DEAL OF TIME AND ENERGY HELPING US TO RAISE AWARENESS OF OUR RESEARCH MISSION – WORKING TOGETHER FOR THE HEALTHIER FUTURE OF OUR KIWI KIDS.

IZIYAH

In February 2013 at age two, Iziyah was diagnosed with a rare immune disorder called chronic granulomatous disease (CGD). This was found due to a bout of pneumonia, and he had one third of one lung removed due to an abscess.

In August 2013 Iziyah had an unrelated bone marrow transplant in the hope to cure the CGD. This was successful but in 2014, he developed symptoms of chronic graft vs host disease – a complication of the transplant– affecting mouth, gut, skin and lungs (bronchiolitis obliterans). Iziyah also has an irreversible lung condition called bronchiectasis.

On top of all the health issues, Iziyah is also losing his vision due to the original disease. This will eventually progress to blindness. He is currently blind in one eye and has a small tunnel of vision in the other eye. It is unknown as to how long this will last.

CORIN

Corin has an extremely rare genetic condition – he lacks elastin in the arteries and veins, causing them to close up. Corin is one of only 40 people around the world with this condition. Tragically, Corin's parents, Jon and Myka Copeland lost their first son, Tyler, to the same condition in 2007 – he was just three months old.

Corin, now nine years old, has managed to defy the odds. Life isn't easy though. Corin breathes through a windpipe as small as a straw. He has a stenosis of the aorta, pulmonary arteries, carotid arteries, renal arteries and his right femoral artery is completely blocked, but he has a natural bypass with his pelvic artery.

BRAYDEN

In 2009, Brayden was cooking noodles when his t-shirt caught fire from the stove element. He received burns to 45 percent of his body. He was rushed from his home in Dunedin to Middlemore Hospital where he spent three weeks in the intensive care unit until his condition stabilised.

Brayden was then transferred to the burns unit for specialist treatment before spending time in the Kidz First unit and finally to Christchurch Hospital before he returned home.

In the two years following his accident, Brayden spent more time in hospital than he did at home.

To date, he has undergone more than 20 operations and has many more ahead of him.

MILLA

At 26 weeks' gestation our brave ambassador Milla was diagnosed with a rare heart defect called truncus arteriosus. Milla's family had no history of congenital heart defects, other than a distant cousin, so this diagnosis was shocking and terrifying for her expecting parents.

Since birth, Milla has had three open heart surgeries, and will require ongoing medical management. She is bound to take this in her stride though, as she does with everything that comes her way.

Despite struggling to keep up with her friends when they run around, this year Milla tried her hand at netball and dancing and is loving being able to join in.

LUKAS

Lukas was born three weeks preterm, spending the first three and a half weeks of his life in neonatal care. Leaving neonatal care, Lukas failed a hearing test and was later diagnosed with high frequency hearing loss. Then, just before his first birthday, Lukas was diagnosed with cerebral palsy.

From the age of two, Lukas has worn foot braces to help keep him on flat feet and assist normal development of his feet. Lukas looks forward to the day when he no longer requires the braces. At five years of age, Lukas underwent a multi-level tendon operation to reduce the restriction brought about by spasticity. Lukas also undergoes regular physio and occupational therapy to improve his movement.

Not letting his disability define him though, Lukas has come along in leaps and bounds.

TED

Napier farm boy Ted is a cheeky, fun and delightful little two-year-old boy who, despite living with epilepsy and a very rare kidney condition called congenital nephrotic syndrome, has a smile that could brighten anyone's day.

Ted receives weekly renal treatments alongside a long list of daily medications and will need a kidney transplant in the years to come.

MEET SOME OF OUR VERY SPECIAL AMBASSADORS

GRACE & AMELIA

Grace and Amelia began their battle to survive in utero – they're twin-to-twin transfusion syndrome survivors, and both suffer from chronic lung disease as a result of being born prematurely at 27 weeks.

Amelia (in purple head band) requires a twice-daily steroid inhaler, while Grace has complex chronic heart disease (CHD). She has severe right ventricle dysfunction, dysplastic TV and PV, muscular VSD (which seems to be closing over time), and during her open-heart surgery, surgeons had to put a hole in her atrium to help her pulmonary valve work better. Grace is also showing signs of cerebral palsy and is currently undergoing assessment for that.

HUNTER

Sports-mad Hunter came into the Cure Kids family by winning a competition to have lunch with the All Blacks. A dream come true and also something positive for him to focus on after being diagnosed with type-1 diabetes suddenly that same year.

Having very little knowledge of type-1 diabetes, his parents hadn't picked up on the symptoms. Hunter was always thirsty, his moods changed, and he would cry at the drop of a hat, which was out of character. It was a flyer in the mail about diabetes awareness that alerted his mum Rebecca to get him checked by the doctor. From there, they went straight to hospital and Hunter was diagnosed with type-1 diabetes.

BROOKE

Brooke was born with hypothalamic hamartoma – a benign brain tumour right in the centre of her brain which causes epilepsy.

After two surgeries in Australia to remove most of the tumour, Brooke's outlook on life and the severity of her seizures changed significantly, but her treatment is still managed very carefully. While Brooke takes a full and active part in all aspects of life and school, she knows she will never drive like her friends and has to use strategies to assist her with her short-term memory issues. But Brooke is determined to have a life just like her sisters and friends and would love to have a career where she can support children also dealing with medical conditions.

KASE

Kase lives with cystic fibrosis, and was generally well until nine months of age. He had even managed to avoid hospital, apart from a bout of pneumonia at four months old. Winters over the years were a trying time for Kase, but with the help of antibiotics, he managed to get by. In late 2015 his 'cold' just didn't seem to go away.

After numerous visits to the doctor, a senior doctor in the hospital reviewed Kase's notes and he was diagnosed with cystic fibrosis. Kase has a constant medical regime to keep him healthy, including PEP (positive expiratory pressure) – morning and night with hypertonic solution and sometimes antibiotics if needed.

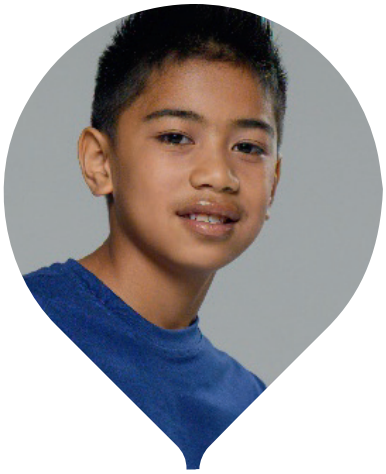
MELA

Mela is diagnosed with Moebius syndrome, a rare neurological condition that has paralysed her face and affected her eating and breathing.

In 2018, Mela underwent a very specialised surgery to give her a 'smile'. This involved taking a large muscle out of her leg and implanting it in her face. Mela will have the other side done this year.

Despite the condition having a huge impact on Mela and her family's life, they're determined to live life to the full.

"As a family, we have truly learnt what is important in life and what really matters. Life is short. Live each moment. Go on the holidays, drink the champagne. The special occasion is being here today," says Mela's Mum.



RICHIE

In July 2011 Richie was admitted to the hospital emergency department, one week after his seventh birthday. He had a persistent cough, had lost weight and become so lethargic he was short of breath even when lying flat on a bed.

It was so out of character for this out-going rugby fan who enjoyed the outdoors and playing sports with his friends. A heart scan showed that he had a severely enlarged heart due to a badly leaking valve. His mitral valve had been attacked by rheumatic fever and progressed to rheumatic heart disease, meaning he had to undergo open-heart surgery to repair the valve. He spent the next seven weeks at Starship Hospital.

Since then, Richie has required monthly penicillin injections to keep him alive.

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) CURRENT CURE KIDS-FUNDED RESEARCHERS WHO ARE BRINGING THEIR DREAMS (AND OURS) TO LIFE.

DR JOANNE CHOI

University of Otago, Dunedin

Dr Joanne Choi is a lecturer at the University of Otago Faculty of Dentistry, teaching dental technology and dental materials. Dr Choi is a recipient of a Cure Kids Innovation Seed Fund grant allowing her to develop a novel tooth-coloured shell crown to treat dental caries in children. Dental decay is the most common chronic childhood disease in New Zealand and has a greater impact on Māori and Pasifika children, as well as children from lower socioeconomic environments.

PROFESSOR ED MITCHELL

University of Auckland

Professor Ed Mitchell was a long-time Cure Kids-funded Chair at the University of Auckland. He led groundbreaking research on the risks of SUDI (cot death) in the late 1980s and early 1990s. His world-leading New Zealand Cot Death Study has been estimated to have saved more than 3000 babies in New Zealand alone and approximately 60,000 around the world.

ASSOCIATE PROFESSOR LEONIE PIHAMA

University of Waikato

Associate Professor Leonie Pihama, Director of Te Kotahi Research Institute at the University of Waikato, is leading a project concerning the place of matauranga Māori (Māori knowledge) in the development of evidence-based, cultural interventions to improve the mental health and wellbeing of young Māori.

DR NIKKI MORELAND

University of Auckland

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

PROFESSOR LYNETTE SADLEIR

University of Otago, Wellington

Professor Lynette Sadleir is a clinical researcher with expertise in epilepsy and is the Director of the Epilepsy Research Group at the University of Otago, Wellington. The Epilepsy Research Group is committed to improving the quality of life for individuals with epilepsy and their families. Their aims are to identify new and define emerging types of epilepsy, to discover the genes that cause epilepsy, and to work toward precision medicine with targeted therapies.

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

PROFESSOR FRANK BLOOMFIELD

Liggins Institute, University of Auckland

Professor Frank Bloomfield is a neonatal paediatrician and is the Director of the Liggins Institute at the University of Auckland. His research focuses on the role of nutrition in fetal and neonatal growth and development.

PROFESSOR STEVEN DAKIN

University of Auckland

Professor Steven Dakin runs New Zealand's only School of Optometry and Vision Science. His research focuses on detecting visual problems in children (particularly using new technologies such as eye-tracking) and works to understand the parts of the brain that support vision, and the mechanisms underlying vision difficulties during childhood.

"My inspiration comes from hearing stories about how our research can impact the lives of the children we work with, and the prospect of making a greater difference in the future."

ASSOCIATE PROFESSOR SIOUXSIE WILES

University of Auckland

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

"Meeting Cure Kids ambassadors like Eva and Addison has made the impact of these diseases so much more real for me now. Those amazing kids are my inspiration."

ASSOCIATE PROFESSOR BEN WHEELER

University of Otago, Dunedin

Associate Professor Ben Wheeler is a paediatric endocrinologist at the University of Otago and the Southland District Health Board. His research is inspired by his clinical practice and focuses primarily on diabetes technology and factors that impact on glucose control, as well as paediatric bone health and nutrition.

Associate Professor Wheeler's clinical work spans the lower half of the South Island and includes paediatric and adolescent diabetes, bone health, and growth problems in childhood.

He is also involved in medical education with the Otago Medical School, and supervises numerous research students.

DR ALI LEVERSHA

Auckland District Health Board

Dr Ali Leversha is a community paediatrician at Starship Hospital. Dr Leversha and her team's research focuses on inequalities, health literacy and conditions that disproportionately affect socioeconomically disadvantaged communities. The overall goal of her research is to inform practice so we have healthy children, engaged in education.

"Cure Kids funding, in partnership with the Joyce Fisher Charitable Trust, has been amazing. It has opened doors and enabled our team to undertake grassroots research that makes a difference to children's lives."

A MESSAGE FROM OUR LEADERS

Cure Kids Board Chair Joan Baker, second from left, and CEO Frances Benge with Cure Kids Patrons Sir Graham and Lady Raewyn Henry.

While each year we celebrate great advancements in the child health research space, this was an exceptional year for Cure Kids.

At the end of the 2018 financial year, Cure Kids has more than $10 million of funding committed towards over 60 health research projects in New Zealand. These projects are well underway as we enter 2019. Together we should feel proud of being part of the team that supports our world-class researchers who are leading the way with innovative, ground-breaking discoveries, solutions and support for young people affected by challenging health conditions. We are delivering the hope that every child will enjoy the opportunity for a healthy childhood.

One of the many highlights in 2018 included an unprecedented funding collaboration with the Child Cancer Foundation, to fund a New Zealand-first translational research project. Cure Kids and the Child Cancer Foundation jointly committed $1.25 million to the Precision Paediatric Cancer Project. You can read about Dr Andrew Wood's change-making research on page 21. Dr Wood's work

will enable children with difficult-to-treat and relapsed cancers to receive state-of-the-art genetic testing, opening up the possibility of more targeted treatments.

Furthermore, it warms my heart that we are supporting parents-to-be with vital information to ensure their unborn children get the best start in life. In June, we launched 'Sleep on Side; Stillbirth Prevention Campaign', a public health initiative providing vital information to pregnant women to help reduce the number of stillborn babies during late stages of pregnancy. This campaign was developed in partnership with the University of Auckland and the Ministry of Health, following new evidence that has shown if women sleep on their side from 28 weeks of pregnancy, it will save approximately 16 unborn babies a year in New Zealand, and up to 100,000 babies annually worldwide.

CURE KIDS' ONGOING COMMITMENT TO CHILD AND ADOLESCENT MENTAL HEALTH WAS REINFORCED FURTHER THIS YEAR.

Cure Kids' ongoing commitment to child and adolescent mental health was reinforced further this year with our announcement that we're now funding $2.2 million of mental health research focusing on early intervention, education and support initiatives. Mental health has a significant impact on a child's overall health and if we do not recognise problems early and intervene promptly, there can be detrimental outcomes and increased public health costs in the long term. We are delighted to be supporting Professor Sally Merry in her role as Duke Family Chair of Child and Adolescent Mental Health.

Earlier in 2018, we addressed a big issue facing our nation – New Zealand has some of the highest living standards in the world but doesn't always do well when it comes to health and wellbeing of our tamariki. Each year, 40,000 Kiwi kids under the age of 14 are hospitalised for poverty-related health conditions. New Zealand has the highest obesity rate in children among OECD countries; 12 percent of children aged two to 14 are considered obese. Adding to these harrowing statistics, respiratory illnesses are the fourth most common cause of death in New Zealand children. As you will read below, we're committed to improving the health trajectory of these young people.

Cure Kids-funded researcher Professor Cameron Grant is investigating the benefits of giving vitamin D supplements to children under two who are hospitalised with an acute lower respiratory infection.

Research is analysing data from both the Growing up in New Zealand and Growing up in Australia studies to identify potential impacts of successfully modifying different factors to reduce child obesity. Another researcher whose work we fund, Professor Boyd Swinburn, is studying four South Auckland schools to look at food and physical activity environments, the use of indigenous knowledge, and how influencers can make a difference.

Meanwhile, Dr Alison Leversha is working with lower decile schools in Counties Manukau to find better ways to treat 'school sores' (infected insect bites, cellulitis, eczema, abscesses and severe infections) in kids. Comparing topical antibiotic cream with alternatives such as basic wound care, she aims to find a solution to a common problem affecting mainly Māori and Pacific children.

With every donation, collaboration, voluntary effort and gesture of support for Cure Kids, we can continue to help talented and passionate researchers realise their dreams to make a positive impact on the health of children, not just in New Zealand, but around the world.

We could not possibly do this without your continued support, therefore we offer a very sincere thank you to all those who supported us in 2018, to the wonderful staff, Board and Medical and Scientific Committee at Cure Kids, our inspirational ambassadors and their families, and, of course, the researchers whose passion and commitment are the driving force towards our vision for a healthy childhood for our tamariki.

Nga Mihi Nui

Frances Benge
CEO, Cure Kids

Joan Baker
Chair, Cure Kids

A special note of thanks to Rod and Patricia Duke, Mark Ching and John Sargent for their remarkable support over many, many years.

We are most grateful for your continued commitment to our work.

CURE KIDS GOVERNANCE

CURE KIDS MEMBERS

BERYL ROBINSON
ROTARY IN NEW ZEALAND

TONY FORTUNE
ROTARY IN NEW ZEALAND

BRUCE RASMUSSEN
ROTARY IN NEW ZEALAND

DR TIM JELLEYMAN
PAEDIATRIC SOCIETY OF NEW ZEALAND

ASSOCIATE PROFESSOR PHILIP PATTEMORE
ROYAL AUSTRALASIAN COLLEGE OF PHYSICIANS

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

CURE KIDS BOARD

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CURE KIDS, DIRECTOR

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

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

Cure Kids Board from left, Emeritus Professor Bob Elliott; Don Jaine; Alaister Wall; Dr Bruce Scoggins; Roy Austin; Barrie Campbell; Chair Joan Baker; CEO Frances Benge.

CURE KIDS BOARD ADVISORS

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

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

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

CURE KIDS MEDICAL & SCIENTIFIC ADVISORY COMMITTEE

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

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

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

CURE KIDS VENTURES BOARD

ROY AUSTIN, CHAIR

HOWARD MOORE, DIRECTOR

FRANCES BENGE, DIRECTOR

Cure Kids is a registered charity CC25350.

RESEARCH REPORT

DR BRUCE SCOGGINS
CHAIR OF MEDICAL AND SCIENTIFIC ADVISORY COMMITTEE

Child health statistics for New Zealand have identified that a significant number of children have less than ideal health. The causes of the ill-health are familial, caused by a disease, poor nutrition or due to socio-economic status.

Children of Māori and Pacific descent have health outcomes that are significantly worse than children in European and Asian families.

If health outcomes are to be improved, evidence informed policies and health services need to be implemented. Research provides an opportunity to identify which approaches will ultimately be able to make a difference to child health.

IN 2018, CURE KIDS INVESTED

$3,684,884

IN RESEARCH

Cure Kids' assessment of child health funding opportunities, and how to prioritise them, is undertaken by our independent Medical and Scientific Advisory Committee (MSAC); a group of the country's leading child health researchers. The committee also calls on the expert views of child health specialists from around the world. This rigorous process ensures that the research we support has the highest possible chance of improving the health of children.

Cure Kids uses several funding approaches to identify research to be supported. These include:

1. ANNUAL GRANTING ROUND

A competitive process open to all child health researchers seeking to contribute to the diagnosis, prevention, treatment, and ultimately the cure, of serious health conditions and illnesses that affect our children.

2. PROFESSORIAL CHAIRS OF CHILD HEALTH RESEARCH

Cure Kids Chairs are academics who are at the top of their game, and this model allows them an element of security in their funding, enabling them to focus on their world-class research as opposed to spending time writing grant applications and chasing funding.

3. PARTNERSHIP AND STRATEGIC RESEARCH INITIATIVES

Cure Kids has a number of joint funding partnerships with other agencies and organisations funding child health. Projects supported by these partnerships are evaluated using a similar MSAC and peer review process to the Cure Kids granting round.

IMPACT ASSESSMENT

To assess the impact or payback from Cure Kids' investment in research, an evaluation was conducted in 2015 and a follow-up is currently being conducted. The updated evaluation's results will be reported publicly later in 2019.

The payback identifies all the different ways that a research study may contribute to outcomes ranging from articles in medical journals to input into an evidence informed health policy and/or health services.

Cure Kids ensures that every dollar it receives for funding of child health research is invested in excellent innovative research to enable Cure Kids to get closer to its vision of *a healthy childhood for everyone.*

"Cure Kids has become a fundamental catalyst in driving large funding initiatives in the child health research space, recognising the critical importance of collaborating with like-minded organisations with a common goal of improving child health."

FUNDING RESEARCH BREAKTHROUGHS

Cure Kids has been funding child health research since the 1970s, and in 2015, an independent impact evaluation was undertaken, which systematically demonstrated that Cure Kids' funding is delivering measurable benefits for the health of children. The findings – outlined below and next page – illustrate the significant role that Cure Kids plays as the leading charitable funder of child health research in New Zealand.

The evaluation was based on a sample of Cure Kids research grants funded from 1976 to 2010, interviewing 61 Cure Kids-supported principal investigators across 171 grants. These interviews covered 73% of all Cure Kids-funded projects over the period, 35% of fellowships and three current professorial chairs.

In addition, 78% of summer studentship recipients were tracked online Together, this information facilitated a comprehensive analysis of the Cure Kids' funding portfolio over time.

Cure Kids' impact has been wide-ranging, from understanding hormonal and metabolic factors involved in intrauterine growth restriction in unborn babies, through to developing a method for screening newborn babies for cystic fibrosis, allowing for efficient and effective treatment before irreversible damage to the lungs occurs. We are extremely proud that Cure Kids funding has also contributed to preventing approximately 3,000 sudden unexpected deaths in infancy (cot deaths) since the Cure Kids-supported 'Back to Sleep' campaign in the early 1990s.

The evaluation demonstrated significant impacts across the following metrics:

- **Knowledge production**
- **Catalysing further research**
- **Workforce development**
- **Impact on policy and practice**
- **Commercialisation**
- **International leadership**

SNAPSHOT OF IMPACT OF CURE KIDS-FUNDED RESEARCH

IMPACT ON UNBORN BABIES

- First ever case-controlled study on maternal sleep position, contributing to a 40% reduction in stillbirth rates
- Examining the impact of methadone treatment on unborn babies changed policy on methadone treatment levels in NZ and internationally
- Understanding hormonal and metabolic factors involved in intrauterine growth restriction in unborn babies

IMPACT ON CHILDREN

- Developed New Zealand's first lung function assessment tests that are now standard clinical practice
- Development of pioneering technology into understanding the genetic basis for inherited heart conditions, and subsequently, reducing sudden and unexpected cardiac death
- Discovery of genes that cause epilepsy in children, allowing for more accurate diagnosis and better treatments for children, parents and families
- Highlighted the importance of prenatal events and their relation to leukaemia, enabling greater understanding by the medical profession and families

IMPACT ON INFANTS

- 200 sudden unexpected deaths in infancy (SUDI) prevented annually through greater understanding of the risks associated with infant sleep position
- Developed a method for screening newborn babies for cystic fibrosis, allowing for earlier diagnosis and more efficient and effective treatment
- Illustrated the adverse impact car seats can have on infant breathing, leading to patenting a seat insert to improve outcomes
- Studies examining infection and chronic lung disease led to a change in clinical best practice
- Research showed for the first time that maternal smoking had an impact on a child's health in the first year of life

IMPACT ON HOSPITAL CARE

- An assessment of child admissions within adult wards which was instrumental to informing how Starship Children's Hospital was structured
- Early adoption of ground-breaking technology for viral detection and diagnosis at Auckland Hospital
- A study which resulted in the updating of the Starship clinical guidelines for hospitalisation and treatment of pneumonia and respiratory disease
- Specialised paediatric neurology service established in New Zealand for the first time as a result of a Cure Kids repatriation scholarship

IMPACT ON NEW TECHNOLOGIES

- Discovered prevention of secondary brain injury by cooling of the head. This led to the development of an innovative brain-cooling cap, the first ever practical treatment for brain injury
- Exploratory study showed a novel use of gene therapy for Batten disease may be effective in children with the condition
- Study discovered cystic fibrosis patients produce bleach in their lungs. Subsequent focus is now on developing new drugs to stop bleach formation

RECENTLY FUNDED RESEARCH PROJECTS

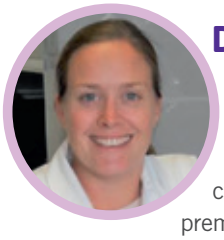
THE FOLLOWING RESEARCH PROJECTS WERE APPROVED FOR FUNDING IN THE DECEMBER 2018 GRANT ROUND.

DR CHRIS McKINLAY
University of Auckland

Are we over-diagnosing pregnant women with gestational diabetes mellitus (GDM), subjecting them to unnecessary treatment, placing an avoidable burden on an already overstretched maternity healthcare budget? Dr Chris McKinlay is investigating the use of different thresholds for GDM diagnosis with the aim to improve short and long-term outcomes for both mother and child.

DR HILARY SHEPPARD
University of Auckland

Can we use the revolutionary CRISPR gene-editing method to improve outcomes for children with the rare skin condition epidermolysis bullosa (EB)? Characterised by skin extremely sensitive to trauma and friction, EB is a devastating condition whereby the 'glue' that holds skin cells together is not present. Using new state-of-the-art advancements, Dr Hilary Sheppard is correcting the gene mutation in a patient's cells in the laboratory, growing the newly amended skin outside the body, with the aim of grafting it back on to the patient with minimal immune response.



DR JENNIFER HOLLYWOOD
University of Auckland

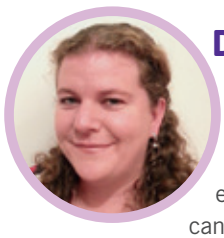
Cystinosis is a destructive disease resulting from a genetic mutation which causes grave kidney damage and potential premature death. Dr Jennifer Hollywood is investigating whether a novel combination of two existing drugs, cysteamine and everomilus, can improve outcomes in a preclinical model. This study could have wide-ranging implications for children with cystinosis as well as other disorders with similar disease patterns.

DR JOANNA BLACK
University of Auckland

Amblyopia is a common visual disorder, whereby clarity of vision is hampered in a child's eye. This can have significant impacts on reading and writing skills which can have long-lasting effects on development and is currently treated with spectacles. Dr Joanna Black has developed a novel device which sits unobtrusively on a child's glasses and can report data on whether the children are adhering to treatment; that is, wearing the glasses or not. We know that optical treatment is critical in improving vision, meaning objective data enabled by this device could help improve compliance and hence outcomes.

ASSOCIATE PROFESSOR KATIE GROOM
University of Auckland

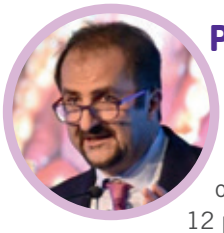
Are corticosteroids being used unnecessarily for planned or elective caesarean sections? Conventionally, this treatment is provided before preterm birth to improve lung maturation, however, there is some evidence of creep in obstetric practice that corticosteroids may be increasing risk of hypoglycaemia. Dr Katie Groom is assessing women's willingness to be part of a trial investigating the effects of later term corticosteroid treatment, with the hope of these results informing a larger trial.



DR LOUISE BICKNELL
University of Otago

It is believed there is a genetic origin to children born at the extremes of stature, either very short or very tall. These extremes can be associated with significant life-affecting conditions, especially for those at the short end of the spectrum. Dr Louise Bicknell is harnessing new technology to look for potential novel genetic causes of these extremes. Any discovery will have immediate clinical effect as it will enable genetic counselling for the child and family while helping inform them of the likelihood of risks in future offspring - as well as ending the diagnostic odyssey for children and families.

RECENTLY FUNDED RESEARCH PROJECTS



PROFESSOR MAURO FARELLA
University of Otago

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

ASSOCIATE PROFESSOR TONY WALLS
University of Otago

Bone and joint infections, usually caused by bacteria, often require hospitalisation and intravenous antibiotics. Children are prescribed an oral course of antibiotics which is notoriously unpalatable. This, combined with the regularity of dose, results in low compliance and worse outcomes. Associate Professor Tony Walls wants to improve compliance by combining the treatment cefalexin with another drug probenecid, which induces slower release of the antibiotic by the kidneys, meaning fewer doses are necessary, hopefully increasing compliance and outcomes.

PROFESSOR IAN MORISON
University of Otago

Advances in medical practice have had profound effects on survival rates for childhood cancers such as acute lymphoblastic leukaemia (ALL). However, as these children survive longer, they begin to manifest side-effects associated with the treatment. It is believed the precursor to these cancerous cells may appear before birth. Using neonatal cord samples, Professor Ian Morison and his team are investigating potential origin cells that could act as a fetal fingerprint for their rogue daughter cells in the future.

DR SARAH FORTUNE
University of Otago

Suicide rates remain stubbornly high in Aotearoa/New Zealand with children as young as 10 to 14 years dying each year. Suicidal ideation and self-harm are relatively prevalent. Those who present to hospital with self-harm are a staggering fifty times more likely to die by suicide. Dr Sarah Fortune and her team believe that better surveillance of self-harm among those under 15 years of age is important as this group provides a good proxy for risk of suicide. Dr Fortune and her team will pilot a surveillance trial at Middlemore Hospital with the hope of preventing these tragic episodes.

ASSOCIATE PROFESSOR DAVID REITH
University of Otago

Very premature babies are at high risk for many health issues including blindness associated with retinopathy of prematurity (ROP). Diagnosing ROP requires pupil-dilating medicines that allow the clinician a good view of the retina. Pupil-dilating treatments have known side-effects, and Dr David Reith believes this may be caused by inconsistencies in dosages in best-practice. Dr Reith and his team will trial lower doses of medications to see if they can give a sufficient view of the retina while having less adverse side-effects. It has a real potential to inform guidelines both here and internationally.

Want to know more about these research projects?

Please go to www.curekids.org.nz/research and enter the researcher's name in the search area for an overview of their project.

LEADING A NEW ERA OF RESEARCH COLLABORATION

CURE KIDS ACKNOWLEDGES THAT POOLING FUNDING AND RESOURCES WITH LIKE-MINDED ORGANISATIONS GREATLY AIDS THE ABILITY TO EFFECTIVELY AND SUSTAINABLY ACHIEVE GOALS FASTER. SIGNIFICANT GAINS CAN BE REALISED – PARTICULARLY IN THE HEALTH RESEARCH ARENA WHERE CONSISTENT FUNDING IS NOT GUARANTEED – AND COLLABORATION HELPS TO SPEED UP THE PACE OF INNOVATION AND INCREASE THE IMPACT OF INVESTMENT. IN 2018, CURE KIDS JOINED FORCES WITH THE CHILD CANCER FOUNDATION (CCF) AND CYSTIC FIBROSIS NEW ZEALAND (CFNZ) TO WORK ON NEW AND INNOVATIVE RESEARCH FUNDING INITIATIVES.

Cure Kids CEO Frances Benge, left, with Child Cancer Foundation CEO Robyn Kiddle and paediatric oncologist Dr Andrew Wood.

CHILD CANCER TRIAL ENABLED THROUGH COLLABORATION

With research goals aligned, Cure Kids and CCF launched the $1.2 million Paediatric Precision Cancer Project (PPCP) in April 2018.

The project, led by paediatric oncologist Dr Andrew Wood, aims to improve treatment, survival and quality of life for children with cancer who have poor prognoses. Over five years, the PPCP will offer families an advanced diagnostic test called next-generation sequencing (NGS). The five-year programme is a first for New Zealand and has been designed to ensure that the potential benefits of precision genetic testing are available to patients regardless of where they live and at no charge to the family.

This advanced capability building is paramount if New Zealand is to enjoy the benefits enabled by genome sequencing. An estimated 100-120 children will be involved in the trial with potential for more beyond the five years.

We would like to thank the Child Cancer Foundation for sharing our desire to improve outcomes for those children and families unfortunate enough to bear the burden of cancer.

COLLABORATION TO IMPROVE OUTCOMES FOR CYSTIC FIBROSIS PATIENTS

Cure Kids has been in the cystic fibrosis (CF) research space since our inception. Our co-founder Emeritus Professor Bob Elliott developed a newborn screening test for CF in the late 1970s which has contributed to improved survival and quality of life. Since then, we have enabled a number of research projects aimed at improving the treatment of children with CF, including a joint effort with CFNZ beginning in 2016 to provide targeted funding for cystic fibrosis research.

A workshop in 2018 – jointly hosted by Cure Kids and CFNZ – identified opportunities for enhanced collaboration across the cystic fibrosis community. Present at the workshop were researchers, clinicians and members of the CF community. One of the key outputs of the workshop was the need for an interconnected research, clinical and community strategy, and someone to drive it.

Dana Felbab (previously Uniservices and Roche Diagnostics NZ) has been jointly engaged by Cure Kids and CFNZ to lead this initiative. The aim is to identify research priorities for our CF community, connect the CF clinical and research communities locally and internationally, and determine how New Zealand can contribute to global research efforts.

New Zealand has a unique CF population which requires a unique solution. The ultimate goal of this collaborative initiative is to provide an accelerated path to realising health improvements for children and young people with CF in New Zealand.

We look forward to updating you with our progress.

RECENTLY COMPLETED RESEARCH PROJECTS

LOOKING AT MOTHER'S GOING-TO-SLEEP POSITION AND THE RISK OF STILLBIRTH

PRINCIPAL INVESTIGATOR

Professor Lesley McCowan
University of Auckland

Late stillbirth, defined as death of a baby in the womb after 28 weeks of pregnancy, is a tragic pregnancy complication with long-term impacts for families. It currently affects around three in every 1000 pregnant women in New Zealand and Australia annually, amounting to the loss of approximately 1000 babies each year.

IDENTIFYING THE BEST SLEEPING POSITION FOR LATE PREGNANCY

One study had reported that sleeping on the right side was a risk factor, however other studies had not found an association between late stillbirth and right-sided sleeping. Because the mother's sleep position is a factor that can be easily changed, there was an urgent need to assess the combined evidence and inform public health messages directed to pregnant women and their caregivers.

By pooling the data from five studies about maternal sleep practices and late stillbirth risk, Professor McCowan and her team created a large database for meta-analysis. The chief finding was that going to sleeping on the back from 28 weeks of pregnancy increased the risk of stillbirth by 2.6 times. The meta-analysis was also able to reassure pregnant women that it doesn't matter which side they choose to sleep on – both left and right sides appear equally safe and protective.

THE CHIEF FINDING WAS THAT GOING TO SLEEP LYING ON THE BACK FROM 28 WEEKS OF PREGNANCY INCREASED THE RISK OF STILLBIRTH BY 2.6 TIMES.

IMPLEMENTING A SAFE SLEEP CALCULATOR INTO PRIMARY CARE

PRINCIPAL INVESTIGATOR:

Emeritus Professor Edwin Mitchell
University of Auckland

In New Zealand around 50 families each year experience the tragedy of sudden unexpected death in infancy (SUDI), previously known as sudden infant death syndrome (SIDS). In the years 2007 to 2011, SUDI deaths were significantly more likely in deprived areas (decile 9 and 10). SUDI deaths were also significantly higher for Māori and Pacific babies, compared to NZ European, Asian and Indian infants.

There is compelling evidence that the majority of SUDI deaths are preventable by addressing the risk factors that contribute to a baby's vulnerability and by providing a safe sleep environment every time a baby sleeps.

GETTING A CONVERSATION ABOUT SUDI INTO THE SIX-WEEK CHECK

A Safe Sleep Calculator (SSC) was developed and adapted to integrate into the software used by primary healthcare providers. The SSC was implemented in 10 primary care practices, including three Iwi or marae-based practices. Over 1000 Safe Sleep calculations have now been completed.

Qualitative research determined that the SSC was acceptable to healthcare providers and aided the discussion of SUDI protective care at the all-important six-week infant check. This discussion had previously been rare. It was felt that the SSC could be included within a full six-week check tool and this would aid implementation in primary care. This recommendation has been taken forward and work is underway in the Northern Region to develop a full six-week check electronic tool.

QUALITATIVE RESEARCH DETERMINED THAT THE SAFE SLEEP CALCULATOR WAS ACCEPTABLE TO HEALTHCARE PROVIDERS AND AIDED THE DISCUSSION OF SUDI PROTECTIVE CARE AT THE ALL-IMPORTANT SIX-WEEK INFANT CHECK.

DEVELOPING GENE THERAPIES IN SHEEP FOR TRANSLATION TO HUMAN FORMS OF BATTEN DISEASE

PRINCIPAL INVESTIGATOR

Professor David Palmer, Lincoln University

Batten disease is a collection of inherited childhood illnesses affecting the brain. The effects of the disease can be compared to having a combination of Alzheimer's, Parkinson's, epilepsy and blindness. Affected children develop normally until they start to regress in all their developmental milestones, which can happen anywhere from 10 months to adulthood. They go blind and suffer seizures and eventually lose the ability to walk, talk and feed themselves.

Batten disease places a huge burden on family life and relationships. In addition to the stress and emotional burden, the estimated financial cost of care is between $60,000 and $100,000 per annum.

WORKING ON ADDITIONAL GENE THERAPY SOLUTIONS

Mutations in any of 13 different genes (CLN1-8 and 10-14) may cause Batten disease and presently only patients with the CLN2 form of the disease have an approved treatment.

This study aimed to refine gene therapy strategies for CLN5 and CLN6 gene mutations, with the intention of fast-tracking these strategies to human clinical trials.

Sheep are ideally suited to this translational role – they have large human-like brains and disease progression closely follows that in affected children. Gene therapy uses disabled viruses as vectors to deliver a functional gene to the tissue of interest, namely the brain and eye, in this disease.

These studies, which show that viral-mediated CLN5 or CLN6 gene therapy is safe and well tolerated, are particularly promising for children with Batten disease as the sheep physiology, neuroanatomy and size is relatively comparable.

Preliminary results from the CLN5 cohort are encouraging, however CLN6 gene therapy was not as successful. Preliminary steps towards human translation of CLN5 gene therapy is underway. Work is ongoing to optimise gene therapy for CLN6.

THESE STUDIES, WHICH SHOW THAT VIRAL-MEDIATED CLN5 OR CLN6 GENE THERAPY IS SAFE AND WELL TOLERATED, ARE PARTICULARLY PROMISING FOR CHILDREN WITH BATTEN DISEASE.

REPORTING NEONATAL, CHILDHOOD AND ADOLESCENT OUTCOMES BY GESTATIONAL AGE

PRINCIPAL INVESTIGATOR

Dr Max (Mary) Berry, University of Otago

Advances in perinatal medicine have transformed the outlook for babies born preterm and redefined the threshold for survival, even for those born at the very margins of human viability. As survival has increased, the emphasis has shifted to providing more information about the longer-term outcomes for these babies, to ensure that survival does not come at the cost of an unacceptably high burden of health problems or disabilities.

ONGOING REPORTING TO SHOW HOW PRETERM BABIES ARE DOING

Researchers report, by gestational age, the survival of all live born infants to 10 years, rates of hospitalisation to age 10, outcomes of the national Before School Check assessment at age 4, rates of special education support needs in primary school and results of national education assessment at age 16.

The 10-year survival rate increased with gestational age: 66% to >98% for those born at 23/24 and 31 weeks' gestation respectively. Hospitalisation rates, before school screening results, primary and high school achievement were shown to be inversely proportional to gestational age. However, the majority of extremely preterm children did not require special educational support and were able to sit their NCEA examinations.

Researchers concluded that high-quality survival is achievable for most infants born at periviable gestations. While some indicators are on average poorer the earlier the gestation, the results can inform parents making difficult decisions at these extremely early births of the potential issues facing their children later on in life. This research has filled a void in information, meaning clinicians and families are not making decisions based on anecdote, but rather evidence-based research.

THE MAJORITY OF EXTREMELY PRETERM CHILDREN DID NOT REQUIRE SPECIAL EDUCATIONAL SUPPORT AND WERE ABLE TO SIT THEIR NCEA EXAMINATIONS.

INVESTIGATING WHETHER DEXTROSE GEL TO PREVENT NEONATAL HYPOGLYCAEMIA HAS ADVERSE EFFECTS

PRINCIPAL INVESTIGATOR

Professor Jane Harding, University of Auckland

Up to 15% of newborn babies have low blood glucose concentrations (hypoglycaemia) in the first few days after birth, but up to 50% of infants of diabetic mothers and 66% of preterm babies develop hypoglycaemia.

This is an increasing problem, as maternal diabetes has increased from 2% in 1991 to 8% in 2010. Approximately 30% of New Zealand babies require testing for neonatal hypoglycaemia under current guidelines. Half of these will develop hypoglycaemia and 10% will require admission to newborn intensive care, incurring some $9.4 million per year in intensive care costs alone. In addition, some may experience brain damage and developmental delay, and a much larger proportion will be given formula, potentially interfering with breastfeeding.

CHECKING THE LONGER-TERM SAFETY OF DEXTROSE GEL TREATMENT

Researchers have previously shown that dextrose gel rubbed into the baby's cheek is effective for treating neonatal hypoglycaemia. A trial is underway to determine whether dextrose gel is effective in preventing hypoglycaemia and keeping babies out of intensive care. However, it's also important to find out if this treatment has any effect on children's later development.

This study assesses each child's development, vision, and growth using games and tests often used with children of this age. A summary of the results is sent to the parents.

Assessments are going well and feedback from participating families has been very positive. The follow-up rate for this study remains at 91%, which is higher than anticipated.

A TRIAL IS UNDERWAY TO DETERMINE WHETHER DEXTROSE GEL IS EFFECTIVE IN PREVENTING HYPOGLYCAEMIA AND KEEPING BABIES OUT OF INTENSIVE CARE.

RE-VASCULARISATION OF THE FEMORAL HEAD IN THE INITIAL PHASE OF PERTHES DISEASE

PRINCIPAL INVESTIGATOR

Dr David Kieser, University of Otago

Perthes disease is a childhood condition that affects 1/1200 children in the USA. The exact incidence in New Zealand is unclear, but is likely to be around 50 children per year. Perthes disease involves reduced blood supply to the head of the femur, resulting in avascular necrosis. This causes the femoral head to soften and deform. Surgery and hip construction is the main treatment option, however patients with Perthes disease still have poor outcomes and high rates of complications.

TRANSPHYSEAL STENTING TO SPEED UP REOSSIFICATION OF THE FEMORAL HEAD

The main hypothesis of this proposal is that revascularising the avascular femoral head using transphyseal stenting will accelerate reossification (rehardening) of the femoral head during the initial phase of Perthes disease.

A transphyseal stent with vascular endothelial growth factor (VEGF) was developed and tested in an animal model. Participants with VEGF-incorporated transphyseal stents experienced less avascularity and femoral head collapse. Furthermore, they experienced fewer complications of femoral neck fracture and local osteolysis.

The conclusion is that transphyseal stenting of the femoral head in the early phases of Perthes disease reduces the degree of femoral head avascularity and subsequent deformity.

Next steps include further research to validate the dose effect and confirmation of transphyseal vascular channels, then human translational research with human participants.

TRANSPHYSEAL STENTAGE OF THE FEMORAL HEAD IN THE EARLY PHASES OF PERTHES DISEASE REDUCES THE DEGREE OF FEMORAL HEAD AVASCULARITY AND SUBSEQUENT DEFORMITY IN A PRECLINICAL MODEL.

DEVELOP AND TEST ROBOTIC GAIT TRAINING FOR CHILDREN WITH CEREBRAL PALSY

PRINCIPAL INVESTIGATOR

Dr Andrew McDaid, University of Auckland

Cerebral Palsy (CP) describes a group of developmental disorders of movement and posture that are caused by disturbances within the developing fetal brain. It's the most common cause of childhood disability and is associated with over-tight muscles that can lead to permanent joint contractures, muscle weakness and poor control of limbs. This results in difficultly with many everyday tasks, one of which is walking. An ineffective gait pattern causes a child to walk slowly, fatigue quickly and can potentially confine them to powered mobility.

ROBOTIC ENGINEERING THAT HELPS CP KIDS TO WALK BETTER

This project began by enhancing the prototype of a robotic device, to make it suitable for clinical trials. Next step was designing a biomechanical modelling framework to understand subject-specific gait development. Finally, the researchers evaluated the efficacy and feasibility of the intervention with a number of case studies. The project was mainly undertaken by two Masters of Engineering (ME) students, funded by Cure Kids.

The robot control system for both gait rehabilitation and over-ground walking was tested with six human participants to validate the device performance, feasibility and accuracy of the models. Testing demonstrated that robotic over-ground gait training is feasible and could lead to more efficient rehabilitation for children with CP. The researchers hope to commence a full-scale clinical trial to demonstrate efficacy, followed by commercialisation to enable children with CP and their therapists to access the technology.

TESTING DEMONSTRATED THAT ROBOTIC OVER-GROUND GAIT TRAINING IS FEASIBLE AND COULD LEAD TO MORE EFFICIENT REHABILITATION FOR CHILDREN WITH CP.

INVESTIGATING A NEW GENE THERAPY FOR CLN6 BATTEN DISEASE

PRINCIPAL INVESTIGATOR

Associate Professor Stephanie Hughes University of Otago

Batten disease is a collection of inherited childhood illnesses affecting the brain. The effects of the disease can be compared to having a combination of Alzheimer's, Parkinson's, epilepsy and blindness. About 1 in 12,500 children worldwide are born with Batten disease, with around 4 New Zealanders affected each year. Affected children develop normally until they start to regress in all their developmental milestones, which can happen anywhere from 10 months to adulthood. They go blind and suffer seizures and eventually lose the ability to walk, talk and feed themselves. Affected children can live into their mid-20s or longer, however, depending on the mutation, and severity of their condition, premature death can occur a lot earlier.

GENE THERAPY PACKAGED INTO CONTAINERS

Gene therapy has already proved effective in animal models of Batten disease and several clinical trials in humans are showing promise. This therapy requires that each cell is individually targeted with the gene therapy, however this is difficult with the delivery systems currently in use. Professor Hughes' group is pursuing an alternative strategy that combines gene therapy with a packaging process that occurs normally in all of our cells.

Researchers aim to trick cells into packaging the gene therapy payload into small 'containers' that are transported from the gene therapy treated cells to surrounding cells. By modifying gene therapy vectors (a vector is usually a type of virus), they were able to show that this system can enhance packaging, however it is dependent on cell type and did not work in brain cells in the same way as other cell types. Now they need to learn more about how brain cells, including neurons, normally package genes into the containers.

This study requires further basic laboratory work and computer based analysis before testing can begin in animal models.

CURE KIDS IS FUNDING THIS IMPORTANT WORK

A grant from Cure Kids is enabling this gene therapy study, and supported a presentation of the work to an international conference.

RESEARCHERS AIM TO TRICK CELLS INTO PACKAGING THE GENE THERAPY PAYLOAD INTO SMALL 'CONTAINERS' THAT ARE TRANSPORTED FROM THE GENE THERAPY TREATED CELLS TO SURROUNDING CELLS.

Photo: Melt Photography

CURE KIDS PROFESSORIAL CHAIRS

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

"I see my role as to head a leading research laboratory that explores the genetic components of childhood diseases. My team's major strength is expertise in several disorders, particularly (but not exclusively) those affecting the skeleton and the brain. This expertise has expanded into areas that include cancer genetics and diseases affecting the digestive system. Connected to this work is the establishment of a national leadership role in genomics. Provision of effective genomic medicine across New Zealand is a challenge because existing infrastructure isn't configured to deliver it effectively. Additionally, we have little understanding of the genomes of indigenous New Zealanders, so we are hoping to remedy this situation.

The stability of Cure Kids funding my professorial position gives my colleagues and I space to think and rapidly test new ideas and research directions. Cure Kids understands that science works by fiddling around in your tool shed, kicking the tyres on ideas, trying things out … there is so little provision for that sort of luxury in New Zealand science, even though so often it leads to new and impactful discoveries."

"I would like to thank Cure Kids for their good faith in supporting our work on the genetics of developmental disorders in children. The close relationship between Cure Kids and the University of Otago has allowed us to contribute in a timely and prominent manner to the field once again this year."

HIGHLIGHTS OF 2018

- Securing $1.2 million Health Research Council funding over three years to explore the genetic mechanisms underpinning a specific group of disorders that have malformations of brain structure as their prime clinical manifestation. This grant will also help to cement overseas collaborations, particularly in Munich and Melbourne
- Growing expertise in computational genomics and previous investment into high-performance computing. We have substantially increased our capabilities in genome sequencing, which has enabled numerous other researchers across the University, as well as nationally, to progress their research too. This capability has also led us to the natural leaders in conversations about how to progress genomic

medicine nationally, which has evolved into our role in Genomics Aotearoa (see below)

- Continuing my leadership role in spending funds granted by MBIE to grow genomics capability nationally through a collaborative network called Genomics Aotearoa. These funds include research aiming to understand our uniquenesses nationally. It is also embedding more capability across the diagnostic and research sector by exploiting collaborations overseas
- Growing international collaborations with Munich (neurogenesis), Cincinnati and Los Angeles (skeletogenesis and bone development) and Melbourne (neurogenesis). We have published strongly this year in high profile journals, including *Cell Reports* and *Nature Medicine*
- Supporting two PhD scholars, Ben Halliday (brain development) and Annika Sjoeholm (digestive system physiology), who are in the second year of their studies.
- Recognition of my group's achievements through my election as a Fellow of the Royal Society of New Zealand, receiving the Dunedin School of Medicine Distinguished Researcher Medal, and shortlisting as *New Zealand Herald New Zealander of the Year.* These honours reflect a strong team effort.

Current research

Exploring the genetic mechanisms of disorders characterised by malformations of brain structure

Computational genomics for genome sequencing

Feeling gravity in your bones

Defining determinants of neurogenesis

WHAT IS A GENOME?

A genome is an organism's complete set of genetic instructions. Each genome contains all of the information needed to build that organism and allow it to grow and develop.

Our bodies are made up of trillions of cells (100,000,000,000,000!), each with their own complete set of instructions for making us, like a recipe book for the body. This set of instructions is known as our genome and is made up of DNA. Each cell in the body, for example, a skin cell or a liver cell, contains this same set of instructions. Within DNA is a unique chemical code that guides our growth, development and health. Genes control different characteristics such as eye colour and height.

All living things have a unique genome.

Genes make up about one to five percent of your genome. The rest of the DNA, between the genes, used to be called 'junk' DNA. It wasn't thought to be important. But we now know that DNA between genes is important for regulating the genes and the genome. For example, it can switch genes on and off at the right time. There is still much more to learn about what it all does.

Learning more about genomes can help us to identify the cause of genetic diseases.

Some rare diseases are caused by as little as a single change (variant), like a spelling mistake, in someone's DNA. Looking at the genome of a person affected by a rare disease can help find which DNA changes might be causing the problem.

In cancer, the tumour cells have developed a different genome to the healthy cells. Comparing the normal and cancer genomes may give clues about ways to treat the cancer.

For some patients, knowing more about their genome may mean that a particular treatment can be recommended.

When the genome sequences of patients with the same condition are compared, it is possible to see patterns. These patterns can be put together with health information. Once this is done we may be able to link particular patterns with whether people are likely to become ill and, if so, how severe their illness is likely to be.

Source: www.genomicsengland.co.uk

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

"The overall objective of my research activities is to advance our understanding of key aspects of the pathogenesis, detection and monitoring of inflammatory disorders of the gut – especially the inflammatory bowel diseases (IBD) and coeliac disease. The ultimate goal across all research is enhancing the management and improving the outcomes for affected children and adolescents.

My role is to lead a research team that delivers a multifaceted research plan which reflects the complexity of these conditions, including diagnosis, risk factors, and ways of improving treatment through diet and vitamin D supplementation. We aim to explore the deficits in knowledge that impact on the diagnosis and treatment of these conditions and to gain a greater understanding of why these chronic conditions are reaching epidemic proportions in certain geographic locations, including New Zealand; providing an internationally significant cohort for this research."

"Cure Kids support is helping me to elucidate key aspects of the patterns of IBD in children in New Zealand, further advance current understanding of the roles of non-invasive biomarkers in the setting of IBD and coeliac disease, and further define the impact of gut disease on children's nutrition. This is important work that could lead to better treatments and management of inflammatory disorders of the gut."

HIGHLIGHTS FROM RESEARCH PROGRESS IN 2018

- Reporting three year outcomes of NZ children diagnosed with IBD in 2015. Data collection through 2018, leading to analysis and draft by the end of 2018. Expected submission to IBD journal April 2019.
- Looking at the impact of NZ IBD guidelines in 100 children diagnosed with IBD in NZ. Dual centre data collection expected to be completed in early 2019.
- Analysing an existing tool that can be used to assess patient-specific knowledge about IBD (IBD-KID). Subsequent development of a revised tool (IBD-KID-2). Large scale validation studies commenced in Australia (four centres), Canada (three centres) and NZ (two centres).
- Further work focusing on a new tool that better enables patients to report their current symptoms (IBD-Now): manuscript accepted late 2018.
- Ongoing work across several spheres focusing on non-invasive biomarkers. Abstract submitted and accepted for presentation at Digestive Diseases

Week in May 2019. Large prospective studies (post-graduate student) that include children with IBD, others with coeliac disease and other control groups without gut disease.

- Development of laboratory-based projects that will focus on further aspects of innate defence proteins in the gut.
- Preparing for a prospective study evaluating diet patterns in children with IBD and their well siblings, along with assessment of micronutrient status in these pairs. A total of 26 of 40 case/control pairs were recruited over 2018, with expectation that further recruitment will be completed in the second or third quarter of 2019.
- Other diet-related work focused on diet-related quality of life (evaluating an adult tool in children) and projects focusing on fermentable carbohydrates in children.
- Writing two manuscripts relating to aspects of vitamin D therapy accepted for publication in 2018. A further project that involves modelling of outcome of vitamin D therapy in IBD commenced.
- Two major collaborations with colleagues in Dunedin. One is focusing on the impact of nutritional therapy in young adults. The second is a longer term evaluation of changes in the microbiota in children followed over time.

Current research

Crohns and Colitis in New Zealand children

Epidemiology and patient outcomes

Biomarkers of inflammation

Innate defence mechanisms

Diet and nutrition

Gut bacteria in gut inflammation

INFLAMMATORY BOWEL DISEASES

IBD stands for Inflammatory Bowel Disease. The two most common forms are Crohn's Disease (often just called Crohn's) and ulcerative colitis (UC).

Crohn's disease and ulcerative colitis are lifelong gastrointestinal disorders collectively known as Inflammatory Bowel Disease (IBD). The conditions are an emerging global disease, and New Zealand has one of the highest prevalence populations in the world. It is estimated that nearly 20,000 New Zealanders live with these conditions, and most are diagnosed in their formative and most productive years, between the ages of 15 and 35.

The conditions are becoming more prevalent, more severe and more complex and are being diagnosed in more and more very young patients.

Source: crohnsandcolitis.org.nz

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

"The overall aim of my research is to provide increased access to evidence-based mental health therapies for children, adolescents and their families. I have already shown the potential positive impact of using technology with the research and implementation of SPARX, a computer based delivery of therapy for depression in teenagers through a fantasy game format. Since its launch in April 2014, over 20,000 young people have accessed the site. Building on this work, my aim is to build a platform to deliver a wider range of interventions delivered on the web or mobile phone. I'm also investigating ways to improve the quality of psychological therapies delivered in person in secondary mental health services.

I have been granted a one year sabbatical for 2020. This will allow me to focus on research without distraction. My plan is to write up the many publications that will be due after completing the clinical trials this year and to set the research goals for me and the team for the next body of work."

HIGHLIGHTS FROM 2018

- Creation of a digital ecosystem that allows for identification of common mental health challenges, links to and rapid testing of digital interventions designed to support young people directly, or for parents to identify and intervene with common emotional and behavioural problems in their children. We have refined the Play Kindly app and linked this to the platform with others to follow.
- Completion of an open trial of the Kakano app, which is now being linked to the platform with the aim of carrying out a RCT (randomised controlled trial) in 2019.
- Co-designing the SUPERkids app with parents, then contracting a software development firm to build it. This will be ready for testing in 2019.
- Creation of an app for emotional wellbeing – Quest Te Whitianga. Open trial has been conducted and an RCT is scheduled for 2019.
- Creation of a chatbot, Headstrong, for older teens. A further app – Tune In – is being developed. These will be tested in online clinical trials in the latter part of 2019.
- Funding of $20.5 million for the Better Start National Science Challenge has been confirmed. The aim is to improve well-being for children by focusing on mental health, obesity and literacy. The research fellows funded by Cure Kids – Associate Professor Sarah Hetrick and Dr Karolina Stasiak – will be leading the mental health components of this work with my support. It will include the use of the digital ecosystem which we have developed for children and adolescents, their parents, schools and health clinics to become an appealing extensible interface to allow for screening, links to evidence-based interventions and monitoring of the results.

Current research

HABITS:
A National Science Challenges project

SUPERkids:
A Parenting App for Kiwi Parents

Play Kindly:
A Gamified Animated App Teaching Parenting Strategies

Kakano:
The development and evaluation of a technology-based resource for families/whanau to increase parenting capacity and improve child wellbeing (for children affected by the earthquakes in Christchurch)

Cure Kids acknowledges AccorHotels who are providing funding support for the Kakano project

Our sincere thanks to Rod and Patricia Duke for their very generous support of Professor Merry's professorial position.

"I'm indebted to Cure Kids for ongoing support that's helping develop a digital platform that I hope will become the 'go to' place for people in New Zealand wishing to support the mental health of children and young people in the short-term, and more generally health and well-being in the longer term."

cure kids
fiji islands

CURE KIDS FIJI, WITH GENEROUS SUPPORT FROM THE PUBLIC AND OUR PARTNERS, ARE WORKING TO IMPROVE THE HEALTH OF THE CHILDREN OF FIJI THROUGH RESEARCH AND EVIDENCE-BASED CHILD HEALTH PROGRAMMES. IN RECENT YEARS, WE HAVE BEEN FOCUSED ON DEVELOPING LIFE-SAVING SOLUTIONS FOR RHEUMATIC HEART DISEASE (RHD), AND OXYGEN DEFICIENCY ILLNESSES SUCH AS PNEUMONIA, TWO OF THE MOST SIGNIFICANT HEALTH CHALLENGES AFFECTING YOUNG PEOPLE IN FIJI.

CURE KIDS FIJI CHILD HEALTH PROJECTS

RHEUMATIC HEART DISEASE CONTROL AND PREVENTION PROGRAMME

In June 2014, a partnership project commenced with the aim of preventing and reducing the impact of rheumatic heart disease (RHD) in the Fiji Islands. Cure Kids is working collaboratively with the Fiji Ministry of Health and Medical Sciences (MoHMS), Auckland District Health Board, and the Centre for International Child Health at Murdoch Children's Research Institute.

The multi-million-dollar project was made possible from joint funding provided through Cure Kids' partnership with AccorHotels and MFAT's New Zealand Partnerships for International Development Fund. FIJI Water Foundation generously provided funding for echocardiography machines and the Rheumatic Fever Information System, which are critical to the delivery of the programme. We are grateful for their support, and the support of our project delivery partners.

RHD is a significant health problem in Fiji, with the Pacific region having one of the highest reported rates of RHD in the world. RHD is a leading cause of death in young people in Fiji and affects approximately one child in every classroom.

What is the project aiming to achieve?

The goal is to expand and strengthen the existing Fiji MoHMS Rheumatic Heart Disease Control and Prevention Programme by developing new models of care and prevention with the aim of reducing RHD-related morbidity and mortality. Fundamental to the Project outputs is an effective national co-ordination structure for the Fiji RHD Control Programme. Achievements to date include:

- Developing and implementing Fiji's first online patient information system for RHD. Approximately 3,000 patients across Fiji benefit from the system, allowing health professionals to monitor the treatment and care of patients as well as allowing for national-level reporting
- RHD clinical guidelines developed and more than 2000 health workers trained in providing best-practice care to patients
- More than 1000 RHD patients and their carers have participated in patient support group activities, developing a community where experiences and challenges can be shared and support provided
- Development and delivery of public awareness raising activities focused on preventing RHD and improving understanding of the condition
- Increased national patient adherence to secondary prophylaxis (preventative antibiotics to halt the progression of the disease) from 12% to 30%
- Successful pilot of innovative model for early detection of RHD cases in schools.

NO CHILD SHOULD DIE FOR LACK OF OXYGEN – THE FIJI OXYGEN PROJECT

No child, no person, should die for lack of oxygen. Severe pneumonia in children and serious newborn illnesses, for which oxygen can be a life-saving treatment, are leading causes of death in Fiji. This project addresses the pressing and challenging need in Fiji to ensure that those needing oxygen get it.

Oxygen is a vital commodity across the health service but is expensive and logistically difficult to provide. For pneumonia, the biggest killer of children worldwide, oxygen reduces death by 35% and is a 'must-have' according to WHO treatment guidelines. Improving the availability, affordability and clinical use of oxygen is a high priority for the Fiji Ministry of Health and Medical Services, with whom Cure Kids and the University of Auckland are partnering in this work.

The project meets this need through carefully tested technology, using robust oxygen concentrators and solar power systems in hospitals and health centres, to get oxygen to those who do not have it. Oxygen concentrators are small, portable machines which filter nitrogen from ambient air to supply highly pure oxygen for patients.

The project will also ensure that an improved supply of oxygen translates into better clinical outcomes through enhanced detection and case management of hypoxic illnesses.

This programme draws on successful work carried out in Africa by Associate Professor Stephen Howie, University of Auckland, and is progressing beyond initial proof-of-principle pilot work in Fiji at Nausori Health Centre and Taveuni Hospital to wider roll-out. The solutions being used in this project are highly scalable, and the ultimate goal is national coverage to ensure that no communities are left unprotected.

In 2018, our ability to upscale this work has been enabled by generous funding support from the Australian Government, AccorHotels, Armacup and ANZ.

Achievements include:

- **Installations at four health facilities: Nausori Health Centre, Taveuni Subdivisional Hospital, Savusau Subdivisional Hospital, and Nabouwalu Subdivisional Hospital**
- **More than 100 clinical and technical staff trained in detection and treatment of hypoxaemia and in maintenance of equipment**
- **2600 patients treated with oxygen**
- **Dedicated Biomedical Technician appointed by MOHMS, an important step in building capacity for this life-saving programme**

ACCORHOTELS RACE TO SURVIVE

AccorHotels have been an integral part of Cure Kids Fiji since its launch in 2006, with the biennial AccorHotels Race to Survive being the flagship fundraising event. 2018's event brought together 100 participants and crew from across the Pacific region with teams from Accor hotels in New Zealand, Australia and Fiji, and partner teams from House of Travel, Flight Centre, Rosie Holidays, JDE and DarkHorse, competing in the four-day event in November.

The event raised a record-breaking FJ$1,079,000 for Cure Kids' life-saving child health programmes in Fiji. The event has raised more than FJ$4.5 million over its 12-year history, which has been instrumental to funding the work of Cure Kids Fiji.

While Race to Survive involved gruelling challenges – from hiking and kayaking to crossing rivers on rafts, contestants also helped renovate the Nadarivatu Health Centre and met school kids being screened for RHD by the mobile screening team, gaining a profound insight into life in Fiji.

In tandem with the event, the RHD Programme team visited eight schools in the Western and Central Viti Levu divisions, screening a total of 487 children, newly identifying 12 definite and 26 probable cases of RHD. These children are now registered in the RHD programme and will benefit from the enhanced approach to RHD patient care that has occurred nationally in recent years with Cure Kids' support.

Former All Blacks Sevens captain DJ Forbes and former Sevens player Tomasi Cama Junior also took part in Race to Survive and spent time with families affected by rheumatic heart disease.

"Seeing first-hand the work Cure Kids is carrying out in Fiji and the smiling faces of local children benefiting from it was a highlight for me. Given the number of children who suffer from RHD in Fiji, it was life-changing to see the screening programme in action. Early diagnosis can make all the difference and ensure the right treatment can be started," says DJ Forbes.

AccorHotels Senior Vice President Gillian Millar says 2018's event was one of the most successful yet. "We are extremely proud of everyone who raised funds and took part and are passionate about helping Cure Kids Fiji continue their life-saving work in Fiji."

CAPTAIN COOK CRUISES FIJI PARTNERSHIP

In 2018 we were also thrilled to launch into a new partnership with Captain Cook Cruises Fiji to achieve significant health improvements for children, their families and communities throughout the country.

Amongst other efforts, Captain Cook Cruises Fiji is supporting Cure Kids Fiji by applying a $1 per room per night charge on an opt out basis to guests on MV Reef Endeavour. 100% of this donation goes directly to Cure Kids Fiji.

Cure Kids Fiji is also humbled by the ongoing support of sponsors without whom our work wouldn't be possible. A special thanks to ANZ NZ & Fiji for their ongoing support of the ANZ Fiji500, and our many other committed supporters including but by no means limited to; the New Zealand Aid Programme, the Australian Government, AccorHotels, Armacup, Fiji Water Foundation, VOMO Island Fiji, DarkHorse, Higgins, South Sea Cruises, Rosie Holidays, Pleass Beverages, UB Freight, and Star Printery.

CURE KIDS VENTURES

CURE KIDS VENTURES (CKV) IS A SEED AND EARLY STAGE INVESTMENT FUND THAT INVESTS IN THE COMMERCIALISATION OF INNOVATIONS IN PRODUCTS AND SERVICES WITH A POTENTIAL TO BENEFIT CHILD HEALTH.

CKV invests in emerging healthcare companies with products and services covering medical devices, medications, diagnostics, health information and healthcare delivery systems.

As a predominant investor in New Zealand's seed and early stage healthcare and biotech sector, CKV has established a reputation in the investment community as an informed and value-added investor. In addition to investment funds, CKV provides investee companies with healthcare industry specific expertise and access to industry networks.

2018 HIGHLIGHTS

At the end of November 2018, CKV closed the CKV Co-Fund 1 at $2 million from 12 investors/investor groups. The CKV Co-Fund 1 is a fund that enables investors who are interested in emerging healthcare companies to invest alongside CKV.

In 2018, CKV also made new investments in Avalia Immunotherapies Limited and The Clinician Limited.

THE CKV PORTFOLIO COMPANIES

ablex	**ABLEX HEALTHCARE**	Computerised rehabilitation for treating neurological conditions
AROA	**AROA BIOSURGERY**	Regenerative wound healing technology
avalia immunotherapies	**AVALIA IMMUNOTHERAPIES**	Immune therapies that support treatment and prevention of infectious diseases and cancer
breathe easy	**BREATHE EASY**	Inhaled therapy for cystic fibrosis treatment
The Clinician	**THE CLINICIAN**	Cloud-based software as a service (SAAS) health management platform for outcome measurement, patient engagement, care co-ordination and analytics
first check	**FIRST CHECK**	Mobile teledermoscopy for checking skin conditions
LCT	**LIVING CELL TECHNOLOGIES**	Cell encapsulation technology
LYPANOSYS	**LYPANOSYS**	Orally dosed botanical treatment for eczema
MicroGEM	**MICROGEM**	Instrument for DNA extraction and identification
NZeno	**NZENO**	Gene technology aimed at delivering pig kidneys to replace human kidneys that no longer function
OBJECTIVE ACUITY	**OBJECTIVE ACUITY**	Technology for the objective measurement of visual acuity applicable to very young children
PICTOR LIMITED	**PICTOR**	Diagnostic testing system – multiple tests from a drop of blood
REX BIONICS	**REX BIONICS**	Hands-free, self-supporting robotic walking device
Veriphi	**VERIPHI**	Verification device – dose and type of IV medication
UPSIDE BIOTECHNOLOGIES	**UPSIDE BIOTECHNOLOGIES**	Treating major burns by growing skin using patient's own skin cells

OBJECTIVE ACUITY

In August 2017, CKV invested in Objective Acuity, a company which was founded in July 2016 following a major breakthrough by researchers at the University of Auckland in detecting eyesight problems in very young children through revolutionary eye technology.

A camera reads tiny, involuntary movements of the eye helping optometrists and eye specialists identify vision problems which can lead to learning difficulties in young children. It is estimated one in five children have visual problems that are undetected and 80 per cent of learning happens through their eyes up to the age of 12.

Identifying vision problems in babies and toddlers has long been a difficult and often stressful process. The new technology can pick up childhood vision problems without children having to read a chart or identify pictures to get an accurate and reliable measurement.

While the initial focus is on improving outcomes in children, Objective Acuity is also looking to complement or replace traditional eye charts used in adult eye care due to the objective and automative nature of the new technology. Over an individual's lifetime, 60 to 70 percent of all people will need visual correction at one stage or another.

Researchers Dr Ben Thompson and Dr Jason Turuwhenua invented this novel visual system which detects a moving pattern and creates an involuntary eye movement called Optokinetic Nystagmus (OKN) – a reflex which allows our eyes to follow moving objects while our head stays steady, like watching telephone poles on the side of the road when travelling in a car. It has been known that OKN is an excellent measure of how well someone sees, but there was no objective measure.

With the new system, a child can sit on their parent's lap in front of a screen, watching a moving stimulus. If they can see the movement, it induces OKN, which is measured by a head and eye tracking device. Novel imaging processing algorithms extract the OKN image from the video footage of the child's eyes. The technology doesn't require language or the need to hold the child's head still. It is completely objective.

Cure Kids Ventures is excited that Objective Acuity is based in New Zealand with huge potential in the global market of optometrists and ophthalmologists, and a potential for school and pre-school screening programmes.

Professor Rod Dunbar

UPSIDE BIOTECHNOLOGIES

Upside Biotechnologies, a biotechnology company spun out from the University of Auckland, is progressing a new treatment for severe burns that is designed to improve the care and outcome of burns. The technology was invented by Professor Rod Dunbar and Dr Vaughan Feisst.

Cure Kids funded the early research of the technology by the University of Auckland. When the technology was commercialised by the University, Cure Kids Ventures was one of its first investors.

Burns are the most common paediatric injuries globally with a mortality rate of between 1.7 and 18.5 percent. All significant burns need to be treated by completely covering the wound with the patient's own skin. For larger burns, current treatment is particularly challenging as there is only a small amount of unburnt skin that can be used to cover the burn.

Upside Bio's technology enables the production of multiple large sheets of patient's own skin from a small starting skin biopsy. Several new scientific inventions are utilised. Firstly, the way the skin biopsy is initially prepared is novel and improves the number of cells available for further processing. Secondly, the cells are grown in a new type of growth medium that speeds up growth rate. Thirdly, after cell numbers have been expanded, the cells are transferred to a specially designed skin culture chamber. The chamber enables the growth of much larger skin sheets than has previously been possible. Finally, the skin itself is grown on a propriety mesh that confers superior handling characteristics.

Upside Biotechnologies has completed the research phase of its product which is named PellCel®. Plans now are for meetings with the FDA, process development and the initiation of a clinical trial towards the end of 2020.

RED NOSE DAY 2018

$900,000
TOTAL RAISED

THE FIRST RED NOSE DAY WAS HELD IN 1989. AT THE TIME IT WAS FOCUSED ON RAISING AWARENESS AND FUNDS FOR RESEARCH INTO SUDDEN UNEXPECTED DEATH IN INFANCY (SUDI). THESE DAYS RED NOSE DAY HAS A BROAD FOCUS ON RAISING MONEY FOR RESEARCH ACROSS ALL CHILD HEALTH.

"Each year we're amazed at the number of Kiwis who donate their time so selflessly to get behind this iconic appeal. Whether it's organising a community fundraiser event, hosting a school bake sale or joining in a fun run, it's heart-warming to see everyone get involved, with the health and wellbeing of children being the common thread."

Frances Benge, Cure Kids CEO

WHAT HAPPENS ON RED NOSE DAY?

- Bake sales
- Mufti days
- Community walks
- Cycling races
- Guess-how-many challenges
- Exercise-athons
- Auctions
- Daredevil challenges
- Junk sales
- Eating contests
- Fun runs
- Raffles
- Shared lunches
- Dye-your-hair-red challenges
- Treasure hunts
- School carnivals
- Discos

450 PARTICIPANTS
$25,000
RAISED

THE RED WALK

Palmerston North held the annual Red Walk, a 5km and 10km fundraising walk/run along the Manawatu River Pathway. Fundraising fun at the finish included bouncy castles, face painting, sausage sizzles, raffles and spot prizes. More than 450 participants took part, all dressed in red, and the event raised $25,000 for Cure Kids. The Red Walk was organised by Laurel Winiata, a Cure Kids ambassador parent and incredible Cure Kids supporter.

A big thank you Laurel!

$36,000
RAISED

SKYJUMP CHALLENGE

A courageous grandmother, Cure Kids ambassador Art Green, and numerous CEOs from leading companies around New Zealand, including our own CEO Frances Benge, all took the plunge off Auckland Sky Tower on Red Nose Day. Collectively they raised $36,000.

See pages 38-41 for more amazing results achieved by our partners!

$200,000
RAISED

GALA DINNER AT THE PULLMAN

A star-studded gala dinner at the Pullman Auckland was held in September, attracting more than $200,000 in donations and auction proceeds.

$17,000
RAISED

WHACKY WHEELS

Radio hosts Jono and Ben, and health and fitness icons Art and Matilda joined a whole lot of corporate contenders to race a Whacky Wheels race in Takutai Square, Britomart. Collectively they raised $17,000 for Red Nose Day.

Bike Barn smashed the competitors out of the top spot, pedalling over 200 kilometres, and PWC was the number one fundraiser – everyone's efforts were outstanding!

NEW NOSES!

This year Kiwi kids were invited to design new novelty red noses, with three winners seeing their designs sold at Briscoes and Rebel Sports stores.

RED NOSE, RED GLOWS

Nelson's Christ Church Cathedral and Palmerston North's clock tower were glowing red on Red Nose Day.

Red Walk Palmerston North organising superhero Laurel Winiata

Palmerston North's clock tower shines a (red) light!

TVNZ's The Project team show us how it's done!

Jono and Ben with Cure Kids ambassadors Hunter, Bella, Eva and Addison at Whacky Wheels

Sir Graham Henry is on point at our Gala Dinner at the beautiful Pullman

Our CEO Frances Benge jumping 1000 feet down from the top of the SkyTower – all in the name of fundraising!

Columbus Coffee plates up for Cure Kids

New novelty noses

CURE KIDS PARTNERS

WITH THANKS TO OUR GENEROUS PARTNER SUPPORTERS WHO MAKE THE LIFE-SAVING RESEARCH WE FUND POSSIBLE.

PLATINUM PARTNERS

- ACCORHOTELS
- BRISCOE GROUP
- COLLIERS INTERNATIONAL

KEY PARTNERS

- ALEXANDER JAMES
- ARMACUP
- AVIS BUDGET GROUP
- COLUMBUS COFFEE
- INGRAM MICRO
- JOHN ANDREW MAZDA
- MICHAEL HILL
- MONDIALE
- PARTNERS LIFE
- QANTAS
- ROTARY

ASSOCIATE PARTNERS

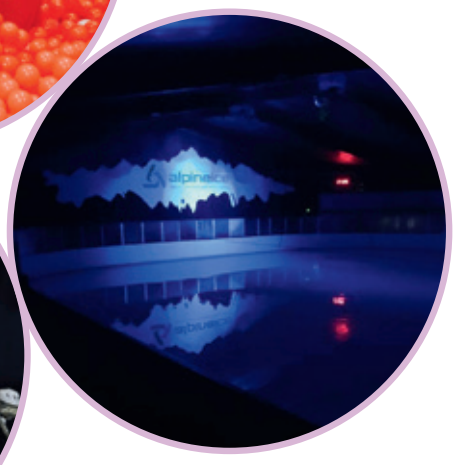
- ALL SECURE SELF STORAGE
- ALPINE ICE SPORTS CENTRE
- BIKE BARN
- BNZ
- DIAMONDS ON RICHMOND
- EVERGREEN LIFE
- FASTWAY COURIERS
- HANSEN PRODUCTS
- ISS FACILITY SERVICES
- KELLY SPORTS AND KELLY CLUB
- NEW ZEALAND FARMERS LIVESTOCK
- PIONEER
- SMITHS CITY
- SNAPPER ROCK
- STELLAR RECRUITMENT
- THE LOOP DUTY FREE

THANKS ALSO TO:

- NZME
- PUREGO PELOTON
- RUSSELL McVEAGH
- THETA
- VILLAGE KITCHEN

Qantas Ball Pit at Albany Mall on Red Nose Day as seen live on *Breakfast TV.*

Australia's super-successful SX-OPEN came to New Zealand in November and they very generously chose Cure Kids as their event charity. Alongside their financial support, ambassador Iziyah was given his dream opportunity to ride a supercross motorbike – with supercross hero Chad Reed (who posted a pic on facebook which received 49,000 likes!). The SX-OPEN will be back in New Zealand again later in the year.



Skating in the spirit of Christmas, Alpine Ice Sports Centre gave one whole day's takings to Cure Kids in December!

CURE KIDS PARTNERS

THESE PAGES SHOWCASE SOME HIGHLIGHTS OF PARTNER ACTIVITY THROUGHOUT 2018, RAISING FUNDS AND RAISING AWARENESS OF THE WORK OF CURE KIDS IN EVERY WAY IMAGINABLE!

BRISCOE GROUP

Long-standing platinum partner Briscoe Group, encompassing Briscoes, Rebel Sport and Living & Giving, raised a whopping $475,000 for Cure Kids in just 12 months through in-store fundraising initiatives. In May, 'Add What You Can' attracted $230,000 from in-store donations and from Briscoe Group initiatives such as quiz nights, fun runs, raffles and auctions. In September, the Group raised $191,600 through point of sale donations and by selling novelty red noses during the Red Nose appeal. To top off an incredible year, the '12 Days of Christmas Giving Campaign' saw stores nationwide raise over $80,000 for Cure Kids. This year Cure Kids celebrates 15 years of Briscoe Group support, and an incredible $7 million raised in total.

Team cheers at the AccorHotels Race to Survive

ACCORHOTELS

AccorHotels supported Cure Kids through an impressive number of fundraising events and also by accepting guest contributions, attracting a total of $118,000 in 2018. This was in addition to their amazing AccorHotels Race to Survive (see page 33). The 'AccorHotels Kitchen Battles Gala Dinner' saw 500 staff and guests from six hotels across Auckland raise funds towards the 'Cure Kids Fiji AccorHotels Race to Survive 2018'. Many of the individual hotels created their own events too. Novotel Auckland Ellerslie hosted a Corporate Golf Day at Akarana Golf Club, attracting 17 teams. Pullman Auckland was home to the Red Nose Gala Dinner. Sofitel Wellington dished up a degustation meal and auction night. Grand Mercure Wellington put on a superhero-themed quiz night. Grand Mercure Puka Park presented a night at the races and Mercure Queenstown Resort hosted quiz nights and in Christchurch, Novotel and Ibis raised $7,000 at a mid-winter Christmas dinner.

Competitors at the Blair Hargrave Memorial Charity Golf Day, hosted by Colliers International.

COLLIERS INTERNATIONAL

A supporter of Cure Kids since 2005, the Colliers team hosted the 2018 Colliers Latitude 45 South Lunch and charity auction during April in Queenstown. The annual long-lunch raised an impressive $75,000 for Cure Kids. Guests arrived by helicopter from Queenstown Airport to take in stunning scenery, a delicious menu of locally-sourced food and wine, then bid on premium auction items. Colliers International also hosted the Blair Hargrave Memorial Charity Golf Day in Auckland in November, attracting $32,000 in donations. Since their partnership with Cure Kids began 15 years ago, Colliers International have raised over $1.5 million!

Continued over >

QANTAS

Qantas truly soared with their large scale support for the Red Nose campaign. They developed a 'text-a-thon' and Ball Pit activation for children at Albany Mall, that was broadcast live on TVNZ's Breakfast. Qantas also sponsored two SkyJumps as well as launching a microsite and text-to-donate mechanism. The Qantas team donated return flights for eight people to Australia, spot prizes, and were proactive in championing in-house fundraising, reaching over $36,500 during September.

Cure Kids ambassadors Bella and Eva creating Red Nose cookies at Columbus Coffee.

COLUMBUS COFFEE

Thanks to the Columbus Coffee efforts during the Red Nose Appeal, Cure Kids received a whopping $35,000 donation. This phenomenal effort meant they achieved the highest year of fundraising since they became a Cure Kids partner eight years ago. Funds were donated by customers at café counters. During September, Cure Kids child ambassadors decorated Red Nose cookies at the Glen Eden store. Other stores around the country held a dinner and a bingo evening and staff at Columbus Coffee, Mitre 10 Pukekohe raised $6200 at a bingo evening.

The Ingram Micro annual golf day raised over $50,000 in 2018.

INGRAM MICRO

Ingram Micro does not do things by halves. The IT distributor generously raised $74,500 through their fundraising efforts of both staff and suppliers. Their events included an annual golf day, a baking and dress-up day, as well as payroll giving. As part of Ingram Micro's ongoing commitment to Cure Kids, the company also entered two teams in The Great Adventure Race, a challenge held in the Hunua Ranges in March 2018. To enter, Ingram Micro raised $20,000, which was a significant contribution towards their overall fundraising achievement for the year.

Cure Kids ambassador Iziyah adds weight to the winning Bike Barn team at Whacky Wheels.

BIKE BARN

The inaugural Cure Kids 'Whacky Wheels' held on Red Nose Day at Britomart, saw corporate and celebrity teams pedalling it out on stationary bikes provided by Bike Barn. Teams were comprised of Cure Kids ambassadors Art Green and Matilda Rice, Jono and Ben as well as staff from Bike Barn, Beca, PwC, BNZ, Alexander James and Columbus Coffee – all in pursuit of making the top distance within a six-hour timeframe. The event made for quite a sight as the enthusiastic cyclists dressed up

in costume for Red Nose Day! Bike Barn also raised more than $6000 in stores across the country during the Cure Kids Red Nose Day campaign.

Cure Kids guests in the 600-strong crowd at the Partners Life Raceday.

PARTNERS LIFE

In October, the second annual Partners Life Raceday for Cure Kids was held at Ellerslie Race Course. Over 250 Partners Life advisors from around New Zealand attended the event along with more than 350 guests from Cure Kids' corporate partner network. Together, they helped to raise $300,000 for vital child health research. At the same event, Michael Hill generously donated a beautiful solitaire diamond valued at $10,000 which raised $14,000 through a raffle.

The Resilient Farmer Doug Avery spoke at the Taranaki Pioneer gala dinner.

PIONEER

In Pioneer's inaugural year as a corporate partner, its teams around New Zealand were proactive in getting behind the Red Nose campaign. Pioneer Taranaki put on a successful gala dinner in Stratford raising over $60,000 for the annual appeal through ticket sales and auction items – including getting up close and personal with rugby greats and Taranaki locals Beauden, Scott, and Kane Barrett. Author of *The Resilient Farmer,* Doug Avery, (pictured) spoke at the event. In Auckland, Jason Morris, Chief Financial Officer at Pioneer joined other partners and Cure Kids CEO Frances Benge to the leap off the Sky Tower to raise funds on Red Nose Day.

Avis Budget staff got in the spirit of Red Nose Day across the country.

AVIS BUDGET GROUP

2018 marked 12 years of support from Avis Budget Group. The Christchurch branch ran its annual golf day in February, raising over $37,000 for Cure Kids. In December, Avis Budget Group arranged a toy drive, collecting 100 presents which were distributed to 40 families of Cure Kids child ambassadors in time for Christmas.

Patrick Tuipulotu and Steve Sharpe, Managing Director of Hansen Products

HANSEN PRODUCTS

Hansen Products very generously donates all of their sales profits from Fieldays New Zealand to Cure Kids. Not only this - they always go out of their way to theme their site for the kiddies attending the big Mystery Creek event – this year's was a Circus theme! Hansen co-brands their site for Cure Kids at Fieldays and covers these extensive costs themselves. Hansen Products donated a phenomenal $24,000 to Cure Kids in 2018.

TRUSTS AND FOUNDATIONS

OUR SINCERE THANKS GOES TO THE FOLLOWING TRUSTS AND FOUNDATIONS WHO HAVE SUPPORTED CURE KIDS AGAIN THIS YEAR; YOUR COMMITMENT IS VERY MUCH APPRECIATED.

TRUSTS AND FOUNDATIONS

ANZ STAFF FOUNDATION

BLUESKY COMMUNITY TRUST

BLUE WATERS COMMUNITY TRUST

CONSTELLATION COMMUNITY TRUST

DRAGON COMMUNITY TRUST

DUO TRUST

EM & MH STICHBURY CHARITABLE TRUST (PERPETUAL GUARDIAN)

FOUR WINDS FOUNDATION

GEORGE SEVICKE JONES ESTATE (PERPETUAL GUARDIAN)

THE HUGH GREEN FOUNDATION

JAMES SEARLE SAY FOUNDATION

THE JOYCE FISHER CHARITABLE TRUST

KD KIRKBY CHARITABLE TRUST (PERPETUAL GUARDIAN)

LOUISA AND PATRICK EMMETT MURPHY FOUNDATION (PUBLIC TRUST)

MILESTONE FOUNDATION

NEW ZEALAND POST

NORTH AND SOUTH TRUST

ONE FOUNDATION

PELORUS TRUST

PROCARE FOUNDATION

RODMOR CHARITABLE TRUST

THE TED & MOLLIE CARR ENDOWMENT TRUST AND ESTATE OF ERNEST HYAM DAVIS (PERPETUAL GUARDIAN)

TM HOSKING TRUST (PERPETUAL GUARDIAN)

TRINITY FOUNDATION

THE TRUSTS COMMUNITY FOUNDATION

FIJI WATER FOUNDATION

SPECIAL THANKS
TO TWO NEW FUNDERS

THE PROCARE FOUNDATION AND THE ANZ STAFF FOUNDATION

Dr Alison Leversha's research focuses on inequalities, health literacy and health conditions that disproportionately affect socioeconomically disadvantaged communities in New Zealand. We thank The Joyce Fisher Charitable Trust for their funding support of Dr Leversha's work in the Tamaki region in Auckland.

Dr Leversha hopes her long-standing research will help to inform interventions to ensure all Kiwi children are healthy, socially, emotionally, and developmentally ready to start school, and are in the best possible position to learn.

Starship Hospital community paediatrician Dr Alison Leversha and her colleagues. Their work with disadvantaged children and families in Auckland's Tamaki region has been funded by Cure Kids and The Joyce Fisher Charitable Trust.

PEOPLE OF INFLUENCE

AT CURE KIDS WE UNDERSTAND THE POWER OF SOCIAL MEDIA AND THE NEED TO HAVE INFLUENTIAL PEOPLE ON OUR SIDE, SO WE JUST LOVE IT WHEN WELL-KNOWN NEW ZEALANDERS WANT TO HELP US RAISE MONEY AND GET OUR MESSAGES OUT THERE.

There are some amazing people on our team of influencers, including radio personalities Jono and Ben, Bachelor couple Art and Matilda, current and former rugby stars Patrick Tuipulotu, Sarah Hirini (formerly Goss), DJ Forbes and Tomasi Cama, Blindspot drummer Shelton Woolright, Carolyn Keep (formerly Taylor) and *TV One* newsreader Melissa Stokes.

We thank them for all of their support they continue to give Cure Kids as volunteers and in their own time!


Melissa Stokes


Carolyn Keep


Tomasi Cama & DJ Forbes


Matilda and Art


Shelton Woolright


Jono and Ben


Sarah Hirini


Patrick Tuipulotu

COMMUNITY

NEW YORK CITY MARATHON 3 NOVEMBER 2019: TRAVEL, RUN, TRIUMPH!

SECURE YOUR SPOT!

JOIN US FOR A LIFE-CHANGING EVENT, WHILE HELPING TO FUND LIFE-CHANGING RESEARCH.

Take part in the mind-blowing New York City Marathon and be part of a team of like-minded people who are committed to achieving a major life goal while raising funds for child health research in New Zealand.

As part of the Cure Kids team, you have guaranteed entry into this highly sought-after event – no need to worry about qualifying times or ballots. In return, we ask you to fundraise a minimum of $5,000 for Cure Kids – NZ's largest funder of child health research outside the government.

ARE YOU UP FOR THE CHALLENGE?

To find out more, please phone Bekah Blair on 09 370 0222 or email bekah@curekids.org.nz

The AMAZING NYC marathon:

- ✓ Run the five boroughs of NYC
- ✓ Race with 50,000 runners from around the world
- ✓ Run the equivalent of 95.1 lengths of the Empire State Building

SPECIAL THANKS TO OUR REGULAR GIVING DONORS ACROSS NEW ZEALAND

THANK YOU FOR YOUR COMMITMENT TO CHILD HEALTH RESEARCH!

ATTENTION ALL COMMUNITY FUNDRAISERS!

WANT TO HELP FUND CHILD HEALTH RESEARCH WHILE YOU'RE TRAINING TO COMPETE IN A LOCAL EVENT?

Sign up your fundraiser for Cure Kids at www.everydayhero.com, commit to a minimum $500 fundraising goal (easy!), and we'll send you one of our snazzy training tees FREE!

CONTACT US AT:
HELLO@CUREKIDS.ORG.NZ
TO FIND OUT MORE...

Associate Business Partner Bekah Blair racing in her Cure Kids tee (in training for the NYC marathon!)

THANK YOU!

A very big thanks to all of our volunteers from around the country.

And a special mention to Georgina Astwick – you're our superhero!

"From all of us in the team at Cure Kids, thank you for your support – you're our partners in research and we appreciate it very much!"

Love Addison and Eva

HOW ARE WE DOING?

CURE KIDS FINANCIAL STATEMENTS

SUMMARISED STATEMENT OF FINANCIAL PERFORMANCE

	CONSOLIDATED	
	31.12.18	**31.12.17**
Fundraising Income	5,003,282	5,365,180
Grants Received	640,116	-
NZ Government Grant – RHD NZ Aid	700,000	700,000
Rental Income	235,806	235,186
Interest & Dividends on Investments	790,046	795,331
Unrealised Gains	728,663	5,707,996
Realised Gains/(Losses)	(53,489)	(85,405)
Other	3,458	4,753
TOTAL INCOME	**8,047,882**	12,723,041
Fundraising Expenses	(1,450,151)	(1,445,916)
Rental Expenses	(38,211)	(36,263)
Administration Expenses	(721,406)	(602,799)
Salary Expenses	(1,836,248)	(2,331,885)
Research & Development	(132,381)	(298,519)
Grants & Research Investment	(3,934,884)	(4,895,328)
NET SURPLUS/(DEFICIT)	**(65,399)**	3,112,331

SUMMARISED STATEMENT OF FINANCIAL POSITION

	CONSOLIDATED	
	31.12.18	**31.12.17**
Cash Held	2,159,890	1,540,000
Fixed Assets	81,342	95,963
Investment Property	5,500,000	5,150,000
Investment Portfolio	34,064,135	35,911,876
Other Assets	1,323,728	311,983
Total Assets	**43,129,095**	43,009,822
Grants	6,789,089	7,073,549
Other Liabilities	1,532,639	1,063,507
Total Liabilities	8,321,728	8,137,056
Total Equity including Capital Funds	**34,807,367**	34,872,766

HOW ARE WE DOING?

NOTES TO FINANCIAL STATEMENTS

In summary, the 2018 year achieved an operating surplus of $3.87 million. A commitment of $3.94 million was applied to research grants, leaving a reported deficit of $65,000 for the financial year.

Our overall expenses fell by $538,000 principally from a reduction in salary costs arising from the implementation of the Strategic Plan.

The financial position demonstrates a continuing secure financial base of $43.13 million, to be applied to fund new research initiatives, approved but undrawn research grants of $6.79 million and operational activities.

Our investment portfolio comprises listed shares, bonds and an investment in Cure Kids Ventures. The Cure Kids Ventures investment is part of a strategy to advance research opportunities that have the potential to benefit children's health.

The Strategic Plan focuses on alignment of resources to support a growth strategy in research underpinned by new funding streams. Going forward this will enable management to allocate resources to realise the greatest impact on the health of our children.

Cure Kids' ambassadors Addison, Iziyah and Eva.

Addi lives with an acute heart condition. Iziyah has a rare genetic disorder and is losing his sight. Eva has gastrointestinal failure and MRSA.

DO SOMETHING EXTRAORDINARY TODAY!

Leaving a bequest to Cure Kids – New Zealand's largest charitable child health research funder – can make a lifetime of difference for our children living with heart-breaking health conditions.

Our world-class child health researchers have made many significant life-changing and life-saving discoveries since Cure Kids was founded nearly 50 years ago, but there is still much work to be done. The pioneering research we fund is reliant on private donations and philanthropy from New Zealanders who support our mission to invest in high-impact research to transform the health of our children.

If you are interested in supporting the work of Cure Kids and would like further information, you are most welcome to arrange a confidential meeting with our Philanthropy Director, Sue Giddens, who will answer any questions you may have. Your lawyer or representative may also phone Sue in confidence to discuss details.

"It makes me so proud to be part of a team that supports medical researchers who are leading the way with innovative, ground-breaking discoveries, solutions and support for children and young people affected by challenging health conditions.

Please consider leaving a gift in your Will to help us achieve our mission."

Frances Benge, CEO, Cure Kids

If you would prefer that Sue contacts you, please complete the form below and post to:

Sue Giddens, Philanthropy Director, Cure Kids, PO Box 90 907, Victoria Street West, Auckland 1142
P 09 370 0222 E sue@curekids.org.nz

◯ **Please contact me to discuss leaving a gift in my Will to Cure Kids** ◯ **I have already made provision in my Will for Cure Kids**

TITLE Dr Mr Mrs Miss Ms Other

NAME

HOME PHONE

MOBILE

EMAIL

ADDRESS

Katie

22 JUNE 2008 – 26 MARCH 2018

In March last year, Katie, our little friend, ambassador and Cure Kids' beloved family member, died after a fierce battle with Batten disease.

Katie, our Dora-loving angel, you were courageous, beautiful and brave. You are forever our inspiration as we push forward, funding vital child health research to improve the outcomes for kids like you.

Our thoughts are with Brett, Lisa, Caleb and Amy every day.

CONNECT WITH US

facebook.com/curekidscharity

twitter.com/curekidsnz

instagram.com/curekidsnz

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

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