



ANNUAL REPORT  
2015



Jackson lives with an inoperable brain tumour





**At Cure Kids, our vision is a  
healthy childhood for everyone:**

We are a catalyst for improving the health of children by driving the discovery of new treatments and cures through research.

Finn lives with hypoplastic right heart



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## LEADERSHIP POINT OF VIEW

In 2015 Cure Kids was proud to have committed over \$2 million to 16 new research projects in New Zealand, in addition to the ongoing support of four Cure Kids Professorial Chairs; this represents the highest level of research funding in our 44-year history.

Last year also saw the completion of an independent impact evaluation of Cure Kids-funded research. The findings illustrate our significant role as a leading funder of child-health research, demonstrating that Cure Kids' funding is continuing to deliver measurable benefits to child health for Kiwi kids.

### KEY PERSONNEL CHANGES

During the year we farewelled two valued colleagues namely, Vicki Lee (CEO) and Dellwyn Stuart (Interim CEO). Vicki's passionate leadership during her tenure contributed significantly to our position today. We wish both Vicki and Dellwyn well for the future, and are excited to build upon the strong legacies they leave.

In December we lost our inspiring Event Manager Ruthee Carnegie after a brave battle with cancer. Ruthee left us with the belief that the sun would continue to shine brightly in her memory and with the legacy of her unwavering passion for our vision.

### PROFESSORIAL CHAIRS

Professor Brian Darlow, Cure Kids Chair of Paediatric Research (University of Otago, Christchurch) was elected as an honorary member of the Neonatal Society for his significant contribution to neonatal science.

Professor Stephen Robertson, Cure Kids Chair of Paediatric Genetics (University of Otago, Dunedin), is charged with the search for genetic mutations which determine the underlying causes of many childhood diseases.

We warmly welcome our newest Chair, Professor Sally Merry, the Cure Kids Duke Family Chair in Child and Adolescent Mental Health (University of Auckland). Her reputation precedes her as a world-leading expert in the field of child and adolescent mental health.

Professor Ed Mitchell, after 15 distinguished years as the Cure Kids Chair

of Child Health Research (University of Auckland), retired from the position in December, 2015. We are very proud to have supported Professor Mitchell's world-leading research on Sudden Unexpected Death in Infancy. We sincerely thank Professor Mitchell for his ongoing commitment to child health and congratulate him on the acknowledgement of this work, from the Health Research Council, in receiving the 'Beaven Medal'.

### CONTESTABLE RESEARCH FUNDING

Each year, Cure Kids funds high-impact research projects through our granting round.

The Cure Kids Medical and Scientific Advisory Committee (MSAC), chaired by Dr Bruce Scoggins, presides over this process, making recommendations on allocation of funding.

In 2015, Cure Kids supported five projects focused on improving the detection and treatment of amblyopia; novel gene therapy, to treat Batten's disease; using sildenafil to increase the growth of vulnerable babies; a new treatment for preterm brain injuries and, finally; a quest to find new antibiotics which can help fight superbugs. I had the privilege of witnessing this granting round within my first week as CEO and felt a compelling sense of the enormous need, and opportunity, for Cure Kids to continue our critical role in funding child health research.

In 2015, partnering with Perpetual Guardian, we sought to make a difference to the health of children disproportionately affected by health conditions simply by virtue of their relative deprivation. We are grateful that with their support, we were able to resource four projects that are profiled in this report.

### FUNDRAISING PARTNERSHIPS AND EVENTS

Red Nose Day, our flagship annual appeal, raised more than \$1million and engaged over 300 businesses and at least 450 schools.

2015 was the fourth year of Cure Kids' partnership with New Zealand Rugby. The All Blacks success was among many

highlights from the year, and we are proud to stand beside New Zealand Rugby as their official charity partner.

The Kiwis Cure Batten campaign saw the successful release of the song 'Team Ball Player Thing'; now viewed over 1-million times. The campaign was a fundraiser for research into curing the currently fatal childhood condition, Batten disease.

For the 10<sup>th</sup> year running, teams of courageous Kiwis raised \$260,000 by challenging themselves to travel from Auckland to Queenstown armed only with \$10 in their pockets and a heart filled with passion.

In March, 35 teams of four tackled the Great Adventure Race in the Hunua Ranges. The teams, over 6-10 hours, put their navigation skills and endurance racing to the test, raising \$420,000 in the process.

Ticket to Hope is always a special event on the Cure Kids calendar. 14 children, living with serious health conditions, enjoyed a wonderful three-day experience in Queenstown.

### NEW STRATEGIC PLAN

In 2016, we will take an ambitious leap into our five-year strategic plan. We will lay a strong financial foundation to ensure we can say 'yes' to more research. We will explore programmes which deliver more to our partners. We will continue to cultivate a culture which nurtures our partners, donors, ambassadors, researchers and colleagues. We will continue looking for opportunities to commercialise our research outcomes, enabling even greater funds to be dedicated to improving the lives of young New Zealanders.

A sincere thank you to all of our partners, to the Cure Kids staff for their passion and commitment, and to the Directors for their wise counsel. Together, we are working towards our vision of a healthy childhood for everyone.



Frances Benge & Roy Austin  
CEO and Chairman of the Board.





MORE THAN  
**\$2 MILLION**  
INVESTED INTO  
NEW RESEARCH  
PROJECTS

TEAM BALL  
PLAYER THING  
VIEWED MORE THAN  
**ONE MILLION**  
TIMES ONLINE



ROY AUSTIN  
CHAIRMAN **CURE KIDS**

The Cure Kids team have developed an aspirational five year strategic plan towards 2020 and we welcome Frances' passionate leadership, her vision for future growth of investment in research in child health and her experience in leading successful commercial organisations.

**5** HIGH-IMPACT  
RESEARCH  
PROJECTS  
SUPPORTED  
THROUGH OUR ANNUAL  
GRANTING ROUND

RED NOSE  
DAY RAISED  
MORE THAN  
**\$1 MILLION**

**PROFESSOR SALLY MERRY**  
- CURE KIDS NEWEST AND  
FIRST CHAIR IN CHILD  
AND ADOLESCENT  
MENTAL HEALTH



FRANCES BENGÉ  
CEO **CURE KIDS**

Frances with Cure Kids ambassadors clockwise from left to right: Isabella Powell was born with cystic fibrosis; Frances Bengé, Cure Kids CEO; Elijah Amoha lives with Leukaemia; Addison Kitching lives with a heart defect; Finn Corbin lives with a heart defect; Torrance Reid lives with a heart murmur; Eva Mitchell lives with gastrointestinal failure and Emily Buick-Constable who lives with type-1 diabetes.



## WHAT WE DO AND HOW WE DO IT

At Cure Kids, our purpose is simple. Every single day, we're driven to find cures and better treatments for serious illnesses and diseases that affect thousands of children in New Zealand.

We focus on raising funds to enable high-impact medical research to find the cures our kids need.

Currently around one in 30 Kiwi kids is affected by a congenital (present from birth) malformation. While increasing advances in the medical field abound, there is still so much more to be done to address statistics such as:

- New Zealand rates of *staphylococcus* infections (affecting skin, soft tissue and the respiratory tract) are the highest in the developed world
- 40,000 hospitalisations each year for conditions associated with deprivation
- 50% of five year olds have tooth decay
- each year 100 children and young people die from inherited heart conditions.

These dramatic child health statistics highlight the increasing need for high-impact research to find new ways to treat existing conditions and cure serious illnesses. Cure Kids are the largest funder of child health research outside the government, and we are supporting the best science possible to make a difference to the health and well being of children in New Zealand.

Support from everyday New Zealanders makes this important work possible and every year

we are humbled by the generosity of Kiwis up and down the country who dig deep and donate to Cure Kids. From individuals, to community groups, small businesses, hundreds of schools and our incredible corporate partners. We are a small country, but a generous one, that cares about the health of our kids.

Since Cure Kids was established in 1971 as the Child Health Research Foundation, we have helped save and improve the lives of thousands of kids both here in New Zealand and around the world. We have invested more than \$38 million in research which has helped shape and change the way children who live with serious diseases and health conditions are diagnosed and treated.

The breadth of the work we support is wide; just some of the projects we have funded, or are currently funding, include childhood cancers, inherited heart conditions, cystic fibrosis, sudden unexpected death in infants (SUDI), stillbirth, burns, and child and adolescent mental health, among many others.

While some discoveries happen quickly, others take many years. By funding four world-class senior research positions- Professorial Chairs – in perpetuity, we enable a certainty of funding which provides some of our brightest researchers with the licence to be curious, innovative and challenging in their work, creating an environment where the breakthroughs happen.

We are proud to be a fundamental part of improving and saving the lives of New Zealand children and, with your support, we will continue to give today's and tomorrow's children the best chance of enjoying a healthy childhood.





## FUNDING THE CURE

Corporate Partner Fundraising

Public Events & Campaigns

Private Fundraising

## FINDING THE CURE

Our annual granting round selects high impact research projects from across the country

We fund long-term programmes of research supporting NZ's leading child health researchers

We partner with other research organisations on joint initiatives to make our donations go further

We hold funds historically ring fenced, to invest in specific purposes

- 9** New Project Grants
- 3** Innovation Seed Grants
- 30** Existing Project Grants

- 4** Professorial Chairs
- 2** Research Fellows
- 4** Chair Discretionary Grants
- 4** Summer Studentships

Partnership and Co-funding

- Sudden Unexpected Death in Infancy (SUDI)
- Blood Disorders

Torrance lives with a genetic heart defect



## WHERE WE FOCUS OUR SEARCH

Cure Kids is a leading funder of child health research. We concentrate on achieving results that will help find answers to many serious illnesses and conditions that impact the lives of Kiwi children and their families.

### OUR CURRENT RESEARCH FOCUSES ON THE FOLLOWING FIELDS:

#### GENETIC ANOMALIES

One in 30 children in New Zealand are born with a congenital malformation. Many will require long-term health care. Each year in New Zealand, more than 600 babies are born with a heart defect, and at least 100 young people die every year from inherited heart conditions.

#### ORAL HEALTH

Dental decay (caries) is the most common chronic childhood disease. More than 50% of New Zealand five-year-olds have dental caries which affects their eating, sleeping, school performance and behaviour, as well as impacting on general health.

#### RHEUMATIC HEART DISEASE

New Zealand has one of the highest rates of rheumatic heart disease and rheumatic fever in the world. In 2015, 98 children were hospitalised for the first time with rheumatic fever.

Rheumatic heart disease is the result of one or more bouts of rheumatic fever, which occurs when the body produces a strong immune response to a throat infection caused by strep throat, leading to scarring of the heart valves and sometimes causing premature death. Rheumatic heart disease is entirely preventable.

#### RESPIRATORY CONDITIONS

Acute respiratory illnesses in children are the leading cause of death, hospital admission and primary care use in the preschool age group. One in four Kiwi kids experiences asthma symptoms. Roughly 550,000 school days are lost to asthma each year in New Zealand.

Cystic fibrosis (CF) is the most common life-threatening genetic disorder affecting New Zealand children. Approximately one in every 3,500 babies is born with CF.

Bronchiectasis happens when the breathing tubes (called bronchi) in the lungs have been damaged and enlarged

– usually due to an infection at an early age. Bronchiectasis particularly affects vulnerable Maori and Pacific children.

Approximately one in 3,000 children in New Zealand is affected.

#### CHILDHOOD CANCER

Cancer is the leading medical cause of death in New Zealand children. Childhood acute myeloid leukaemia (AML) is a blood cancer that results in death for 40% of those diagnosed despite intensive chemotherapy and stem cell transplantation.

Chemotherapy can often have severe side effects, resulting in damage to bodily tissue unaffected by the cancer.

#### OBESITY

Obesity is an ever-increasing problem worldwide in both children and adults, ranking as the fifth leading cause of deaths globally. Obesity is a risk factor for a number of diseases including coronary heart disease, stroke, diabetes, high blood pressure, osteoarthritis and some cancers. Around a third (33%) of New Zealand children are overweight or obese. This figure rises to 51% for Pacific children and 43% for Maori children.

#### ANTENATAL AND NEONATAL INCIDENTS

Each year in New Zealand there are approximately 320 stillbirths. This number is higher than the annual road toll.

Approximately 1% of the live births in New Zealand are those with very low birth weights and contribute 50%-75% of the workload in neonatal intensive care units (NICUs). While the survival rate is high, the quality of life is often compromised.

Annually in New Zealand, approximately 780 premature infants are born before 32 weeks' gestation and survive.

Research shows that these infants are at high risk for a range of

neurodevelopmental problems, including cerebral palsy, learning difficulties, attention deficit hyperactivity disorder (ADHD), emotional problems and poor school achievement.

#### INFANT MORTALITY

Sudden unexpected death in infancy (SUDI) is still the most common cause of death after the first week of life, claiming approximately 50 babies a year. Amongst industrialised nations, New Zealand has the highest rate of death from SUDI.

#### NEUROLOGICAL CONDITIONS

Epilepsy is a common group of disorders, which significantly impact on a child's quality of life. In approximately 30% of children with epilepsy, the disorder continues into adult life.

Cerebral palsy affects approximately one in every 500 babies born in New Zealand. It consists of a group of developmental disorders of movement and posture that are caused by disturbances that occurred in the developing fetal or infant brain.

Batten disease is one of a group of inherited neurodegenerative diseases of childhood with common clinical features including blindness and seizures, culminating in premature death. About four children are born with Batten disease each year in New Zealand.

#### BOWEL CONDITIONS

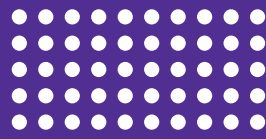
Crohn's and colitis are two forms of incurable inflammatory bowel disease (IBD). There are approximately 15,000 New Zealanders with IBD, with an estimated quarter of these cases being diagnosed in childhood. Both conditions pose serious problems, with typical symptoms being pain, diarrhoea and bleeding.

More often than not, Crohn's and colitis interfere with growth and normal development, impacting adversely upon schooling and daily activities.




**EACH  
YEAR IN  
NEW  
ZEALAND...**


**50 INFANTS**



**DIE FROM SUDI**  
(SUDDEN UNEXPECTED  
DEATH IN INFANCY)




 **33%**  
OF KIWI KIDS  
ARE OVERWEIGHT  
OR OBESE

**400**   
NEW ZEALANDERS  
LIVE WITH CYSTIC  
FIBROSIS

**780 BABIES**  
ARE BORN  
VERY  
PRETERM  
(BEFORE 32 WEEKS) 


**1 IN 4**   
CHILDREN AND  
ADOLESCENTS  
EXPERIENCE A SIGNIFICANT  
MENTAL HEALTH ISSUE

**50%**   
**OF 5 YEAR OLDS**  
HAVE DENTAL DECAY

ACUTE MYELOID  
LEUKAEMIA  
REMAINS  
LETHAL FOR   
**40% OF PATIENTS**

**320**  
BABIES ARE  
STILLBORN



**100** CHILDREN  
& YOUNG PEOPLE  
DIE FROM INHERITED  
 **HEART  
CONDITIONS**

**1 IN 30**  
CHILDREN ARE BORN  
WITH A CONGENITAL  
MALFORMATION

**450**  
CHILDREN  
WILL DEVELOP  
EPILEPSY





## 45 YEARS OF BREAKTHROUGHS

Cure Kids have been funding child health research since the 1970's, and in 2015, an independent impact evaluation was undertaken, which systematically demonstrated that all of Cure Kids' funding is delivering measurable benefits for the health of children. The findings illustrate the significant role that Cure Kids plays as a leading 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 new born 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 200 sudden unexpected deaths in infancy (cot deaths) annually in New Zealand.

### THE EVALUATION DEMONSTRATED SIGNIFICANT IMPACTS ACROSS THE FOLLOWING METRICS:

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

Cure Kids wish to thank Dr Bruce Scoggins and Dr Michelle Sullivan, who expertly led the evaluation.



## SNAPSHOT OF IMPACTS 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.
- Research showed for the first time that maternal smoking in pregnancy is a health risk for the baby resulting in significant policy changes.



### IMPACT ON INFANTS

- 200 sudden unexpected deaths in infancy (SUDI) prevented annually through the 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.



### 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, that allowed for more accurate diagnosis and better treatments for children, parents and families.
- Highlighted the importance of prenatal events and their relation to leukaemia, that enabled greater understanding by the medical profession and families.



### 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.



# CURE KIDS PROFESSORIAL CHAIRS

## PROFESSOR BRIAN DARLOW

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

### 2015 RESEARCH HIGHLIGHTS:

- Elected to Honorary Membership of the Neonatal Society (UK) in recognition of notable contributions to neonatal science
- Invited to deliver the RACP Montgomery Spencer Oration at the Paediatric Society of New Zealand Annual Meeting in recognition of contributions to paediatrics
- Acceptance of three abstracts relating to the NZ Very Low Birth Weight (VLBW) Study at the Paediatric Academic Societies' Meeting to be held in Baltimore in May, 2016

Professor Brian Darlow is a clinical neonatologist, trained in both the UK and New Zealand, with a brief spell in Papua New Guinea. The subspecialty of neonatology is concerned with the medical care of newborn infants, especially those that for whatever reason require admission to a neonatal intensive care unit (NICU).

Prof Darlow has been the Cure Kids Chair at the University of Otago, Christchurch, since 2007. His research portfolio is notable, with perhaps the most well-documented being The New Zealand Very Low Birthweight (VLBW) Study. Prof Darlow is the lead investigator on this longitudinal cohort tasked with tracking health and development outcomes of children born premature or very low birthweight (<1500 grams) in New Zealand in 1986.

A dataset of this size, 300 survivors, combined with the length of time over which they've been tracked, provides a treasure trove of data for analysis of

a variety of adverse outcomes likely associated with prematurity or VLBW.

### THE NEW ZEALAND VLBW ADULT FOLLOW-UP

The origins of the VLBW pertained to retinopathy of prematurity (ROP). ROP is characterised by the underdevelopment of a preterm baby's eyes, where the abnormal growth of blood vessels in the retina can result in vision loss.

ROP is one of a number of adverse outcomes that can precipitated by prematurity. Advances in medical practice has meant that, where previously very small or very early babies would not have survived, they now do; and we must now countenance the health problems and higher rates of disability and developmental problems which many of those born VLBW experience throughout life and into adulthood.

Prof Darlow and his team are currently revisiting those babies who were born very premature in 1986, as well as age-matched, yet born at term, healthy controls for comparison. The study participants were followed up at 7-8 years, 23-24 years, and finally, now, at 29-30 years.

Cure Kids funding supports the Project Manager, Julia Martin, who has the often difficult task of reconnecting with these families in order to conduct comprehensive assessments on the health and mental status, functional outcome and quality of life in young adulthood. At this point, 180 participants and 82 controls have made their way to Christchurch for two days of testing. An average of three participants are tested a week, and the team plan to have clinical assessments completed by June 2016.

Last year, a Cure Kids-supported Summer Studentship recipient, Georgia Moody, undertook a project interviewing a parent of 40 of the babies from the cohort, including 30 controls, to assess their views on their son/daughter's health and social functioning. Georgia's hard work was awarded with the Best Young Investigator Award when she presented at the Perinatal Society of New Zealand's ASM earlier this year.

Cure Kids funding has also enabled cranial magnetic resonance imaging (cranial

MRIs) to be undertaken on all participants born earlier than 28 weeks, as well as a random sample of the rest of the cohort, and finally, a random sample of 50 controls. This imaging is now completed with results still to come.

The scans include a battery of tests, examining white matter development and brain growth and tissue distribution.

Also undertaken were numerous respiratory function tests. An interesting finding from these was that adult survivors of VLBW showed more evidence of airway obstruction than controls.

The results will ultimately inform the policies and care concerning very preterm survivors as well as future newborn care.

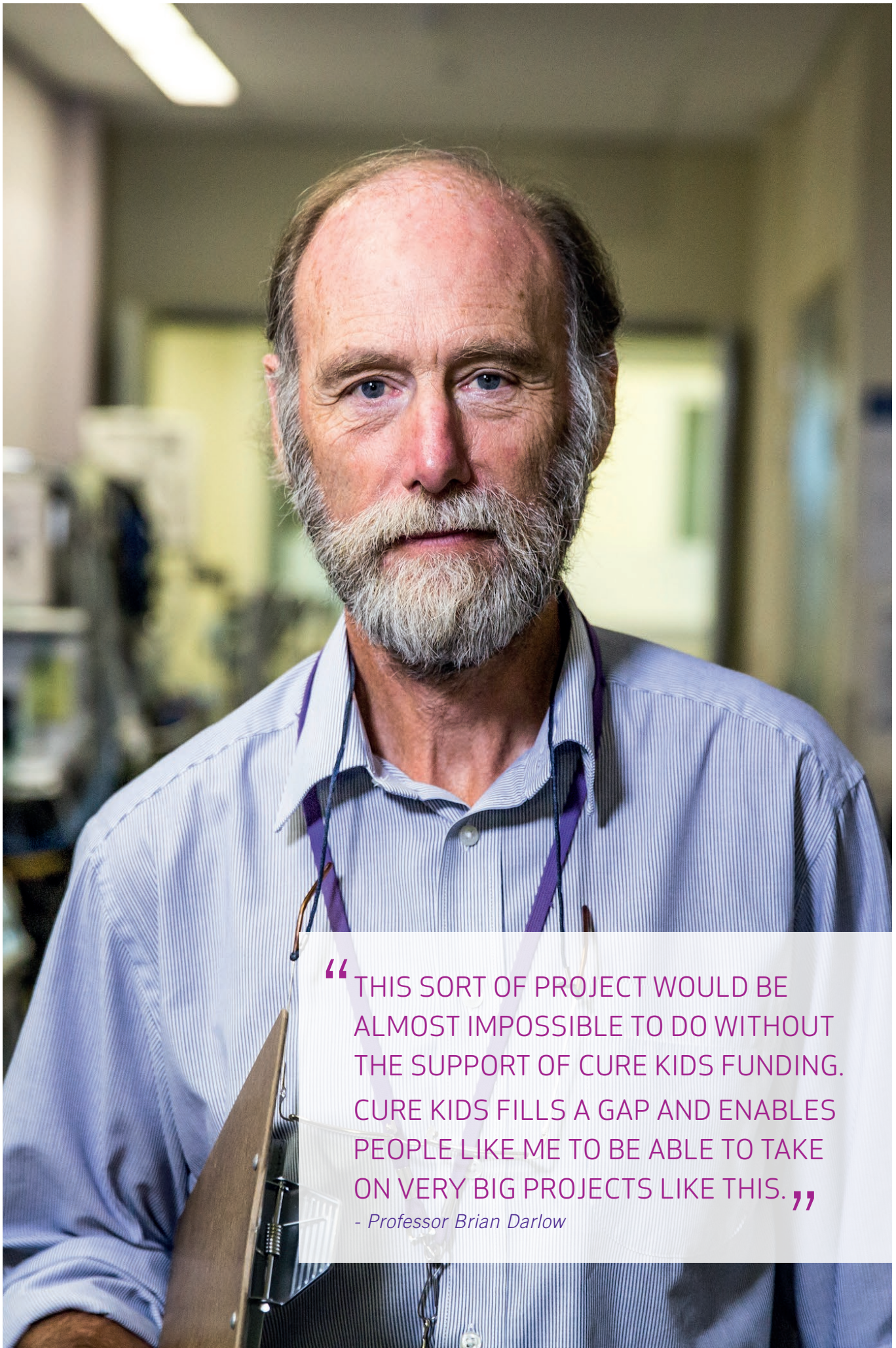
### THE BOOST-NZ STUDY

Prof Darlow is also the lead researcher on the BOOST-NZ study, a randomised controlled trial which is investigating what level of oxygen is safe in augmenting breathing in very preterm infants. The study is funded by the Health Research Council, with part of Prof Darlow's time supported by Cure Kids.

The trend has been to treat babies with lower levels of oxygen to prevent problems such as retinopathy of prematurity, however, when the hospital outcomes of four similar trials happening in Australia, Canada, the UK and the US are combined with NZ data, what emerges is that lower oxygen levels are associated with increased infant mortality.

From here, a meta-analysis of all 5000 infants in these five studies ought to more clearly elucidate any problems associated with different levels of oxygen. Whilst also being a co-author on the Australian arm, Prof Darlow is a member of the writing group for the pre-planned meta-analysis of the five studies. This group will meet in December 2015, to rapidly progress the combined analysis of the studies, which should lead to great improvements in outcome of preterm infants requiring oxygen.





“ THIS SORT OF PROJECT WOULD BE ALMOST IMPOSSIBLE TO DO WITHOUT THE SUPPORT OF CURE KIDS FUNDING. CURE KIDS FILLS A GAP AND ENABLES PEOPLE LIKE ME TO BE ABLE TO TAKE ON VERY BIG PROJECTS LIKE THIS. ”

- Professor Brian Darlow



## PROFESSOR ED MITCHELL

CURE KIDS CHAIR OF CHILD HEALTH RESEARCH, THE UNIVERSITY OF AUCKLAND

### HIGHLIGHTS:

- Awarded Health Research Council Beavan Medal for his ground-breaking research into sudden unexpected death in infants
- Finalist in the Auckland District Health Board's Health Excellence Awards for the smart inhaler
- Invited to give the Kaarene Fitzgerald public lecture in Melbourne

Professor Mitchell, a paediatrician and child health epidemiologist, has held the position of Cure Kids Chair of Child Health Research at the University of Auckland for 15 years.

His work is both specialised and varied. As an epidemiologist, he is concerned with the study of populations, which includes the identification of risk factors that may be correlated with, or even causative of, certain conditions or adverse outcomes.

Prof Mitchell has dedicated much of this research to Sudden Unexpected Death in Infancy (SUDI/COT DEATH). He has toiled away over the decades investigating what factors, both modifiable and not, could be identified as contributing to tragic events such as SUDI or stillbirth, or that may predispose children to chronic conditions at an increasing rate such as that of obesity, which is teetering on endemic in New Zealand.

Included here is an overview of the work Prof Mitchell continues to do in various areas of child health.

### SUDI (SUDDEN UNEXPECTED DEATH IN INFANCY)

A pioneering study undertaken by Prof Mitchell in the late '80s elucidated ground-breaking data on the risk factors attendant with cot death. Sleep position, namely prone or side sleep, was shown to be associated with a marked increase

in risk of cot death. These findings were the impetus for the Ministry of Health and Cure Kids-funded prevention programme ('Back to Sleep Campaign').

25 years later, cot death statistics have plummeted from a peak of around 260 in the mid-1980s, to approximately 50 each year today. This is generally attributed to the implementation of a number of practices and awareness campaigns around the numerous risk factors associated.

Prof Mitchell and his team are now using the wealth of data they've gathered over the years to create a 'SUDI Risk Calculator'. The calculator's purpose is to determine risk profiles for vulnerable families based on the numerous and complex ways within which the risk factors interact. These include sleep position, bed-sharing, breastfeeding and maternal smoking.

Cure Kids support has facilitated the building of the technology, and is now enabling the device to be tested and evaluated in primary care practices in New Zealand. Prof Mitchell is confident that if all appropriate and modifiable risk factors are known, and acted on, the number of babies' lives lost to SUDI could be reduced to single figures.

### STILLBIRTH

Prof Mitchell has various projects investigating the risk factors associated with having a stillbirth. Following on from The Auckland Stillbirth Study (TASS), concluding in 2011, a larger nationwide study, The Multi-centre Case-control Stillbirth Study, was initiated to confirm or refute the findings. The findings from TASS highlighted several risk factors associated with an increase in stillbirth, with ostensibly the most profound being, an increase in stillbirths when mothers did not sleep on their left-hand-side. As of October 2015, 164 mothers who have experienced a stillbirth have been interviewed for the multicentre study.

In the UK, Cure Kids are supporting a larger study, again, that will build on Prof Mitchell's projects as well as similar projects undertaken in Australia. It is necessary that they explore these findings in more depth before launching a public health campaign to reduce stillbirth.

This study is ongoing.

Prof Mitchell and his team are also carrying out research exploring the link between maternal sleep and sleep position, and maternal and fetal physiology as potential risk factors for adverse fetal outcomes.

In addition to these studies, the team are investigating the theory that greater accuracy in fetal movement monitoring, achieved through a new piece of technology that distinguishes a mother's movements from that of her baby, could act as an important marker for identifying increased risk of stillbirth and perinatal outcomes.

### ADDITIONAL PROJECTS

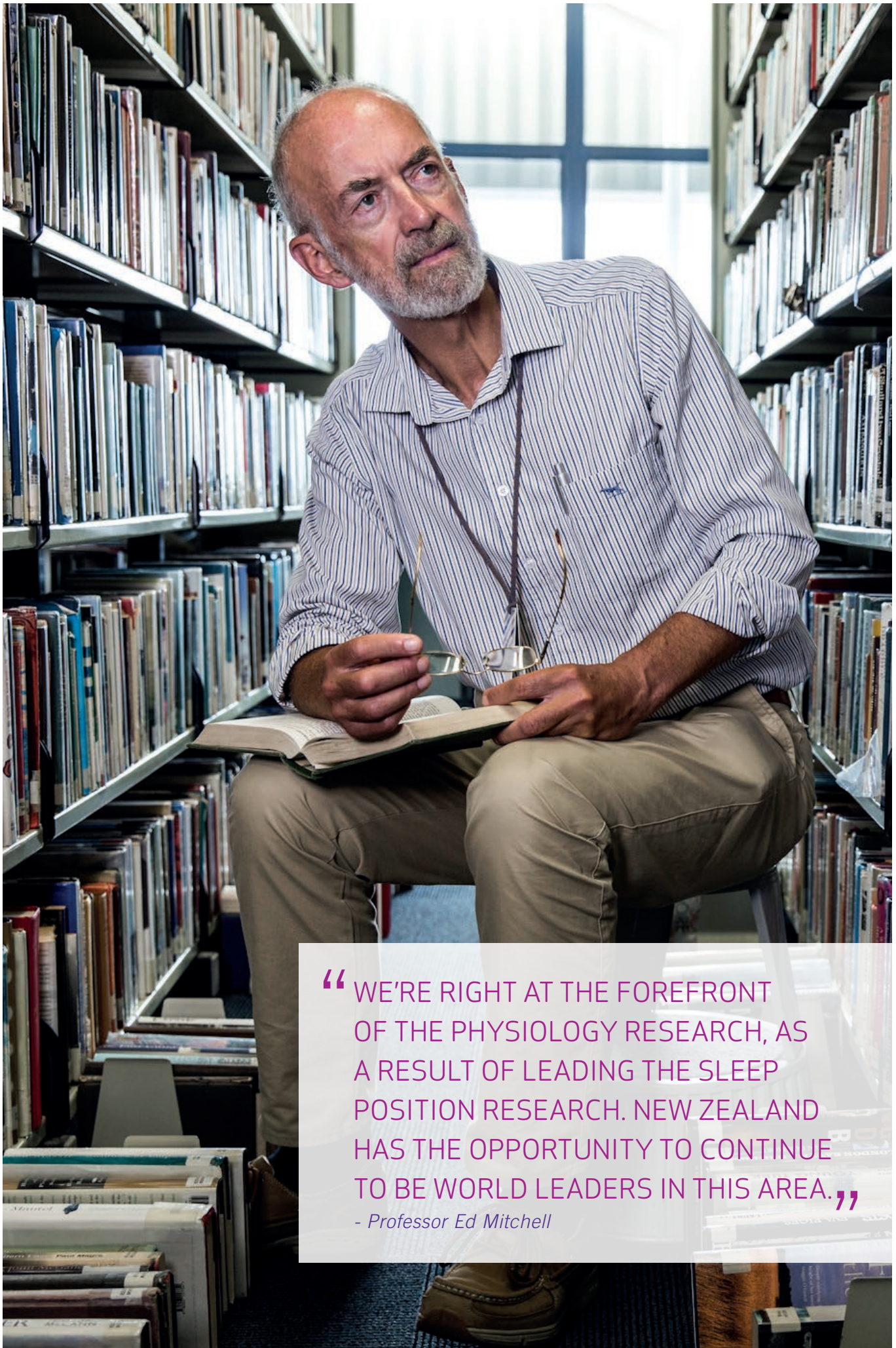
Additionally, the team are involved with investigating whether a regime of probiotics given to pregnant mothers and their infants, until two-years-of-age, has had an effect on the composition of the child's gut microbiota – the trillions of microorganisms living in our intestinal tract – and whether this varies in those who do, and don't, develop eczema.

Prof Mitchell and his team are furthering their analysis of probiotics in pregnancy, however, in this study they are testing the hypothesis that probiotics given to mothers late in their pregnancy and early in the infant's life are associated with a reduced risk of cognitive, behavioural and mood problems. Recent findings point to a relationship between the gut microbiota and healthy brain function through their ability to activate neural pathways and affect learning and anxiety.

After 15 distinguished years as the Cure Kids Chair of Child Health Research at the University of Auckland, Professor Ed Mitchell retired from the position in December 2015.

Cure Kids is honoured to have supported Professor Mitchell's international leadership on Sudden Infant Death Syndrome (SIDS) and his major contributions in other fields, including asthma, childhood obesity, child health and development, Maori and Pacific health, intrauterine growth restriction, and most recently stillbirth. We look forward to celebrating his achievements and career highlights further during 2016.





“ WE’RE RIGHT AT THE FOREFRONT OF THE PHYSIOLOGY RESEARCH, AS A RESULT OF LEADING THE SLEEP POSITION RESEARCH. NEW ZEALAND HAS THE OPPORTUNITY TO CONTINUE TO BE WORLD LEADERS IN THIS AREA. ”

- Professor Ed Mitchell



## PROFESSOR STEPHEN ROBERTSON

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

### HIGHLIGHTS:

- Description of a new genetic regulator of bone development in humans
- Submission of full proposal to the Health Research Council (HRC) Project Funding Round

As a paediatric geneticist, Professor Stephen Robertson is charged with investigating the incredibly complex nature of the human genome; searching for genetic misspellings – mutations – that could determine the underlying causes of childhood diseases. Prof Robertson's lab, located at the Dunedin School of Medicine, is world-leading, and has a reputation for its specialisation in mutated genes that cause malformations in the skeleton and brain.

The term geneticist evokes a certain image of a scientist in a lab tinkering with all likes of compounds and implements. And while Prof Robertson does much lab work, the picture is worthy of far greater marvel, including glowing zebrafish and microscopes that are mind-bogglingly powerful.

Prof Robertson's job is not however restricted to the lab. Like any good scientist, he understands the importance of imparting knowledge and expertise on to young students to support and encourage individuals to choose a career path dedicated to researching paediatric conditions with a genetic basis, hence why he delivers high-quality and clinically-relevant lectures to senior students majoring in genetics.

Lastly, Prof Robertson is at the other end of the 'lab to bedside' spectrum. He is a practising clinical geneticist. There are one in thirty children born with a congenital malformation in New Zealand, and Prof Robertson does his part at the research end, as well as the clinical end to improve outcomes for these children.

### WHAT CURE KIDS FUNDING MEANS TO PROFESSOR ROBERTSON'S WORK

Professor Robertson says he feels "immensely lucky" to have secure, long-term funding from Cure Kids. It means he and his genetics team can:

**Explore new ideas** – Cure Kids funding means Professor Robertson can 'dip his toe in the water' with new ideas.

**Move faster** – secure funding means being able to respond quickly to new ideas.

**Be broad** – it gives his team the opportunity to extend into new areas that new findings relate to and to adopt a wider perspective in their field of endeavour.

**Follow ideas over time** – many of the world's most exciting discoveries have been slow evolving. Professor Robertson says long-term backing can lead to 'spectacular' dividends.

### LOOKING AT HOW BONES HEAL UNDER STRESS

How do we improve the healing process for children with weakened or fractured bones? By studying rare bone disorders, Professor Robertson's team has discovered functions in genes that make bones solid and strong as well as the identity of genetic switches, which are activated to convert stem cells into growth mode. Over the past year this work has progressed to using mice models.

### DISCOVERY OF NEW DISEASE GENES

Using new and enabling genetic sequencing technology, the genetics team has located new genes that play roles in human skeletal and brain development, and as with previous studies, hold promise in understanding and intervening in other disease states in these organ systems.

### OPTIMISING WOUND HEALING AND CLOSURE AFTER TRAUMA, BURNS AND SURGERY

Professor Robertson and team have discovered that a new disease gene that plays a role in bone development is also active in wound healing. The team is pursuing promising insights into this

observation with the aim of potential therapeutic options for wound healing.

### BILIARY ATRESIA

Each year in New Zealand seven children are born with extra hepatic biliary atresia (BA), a disease in which the bile ducts that connect the liver to the intestines are blocked or missing. Resulting from this, bile backs up in the liver and spills into the bloodstream, causing infants to become jaundiced, and eventually liver failure. It is the most common condition resulting in liver transplantation in children.

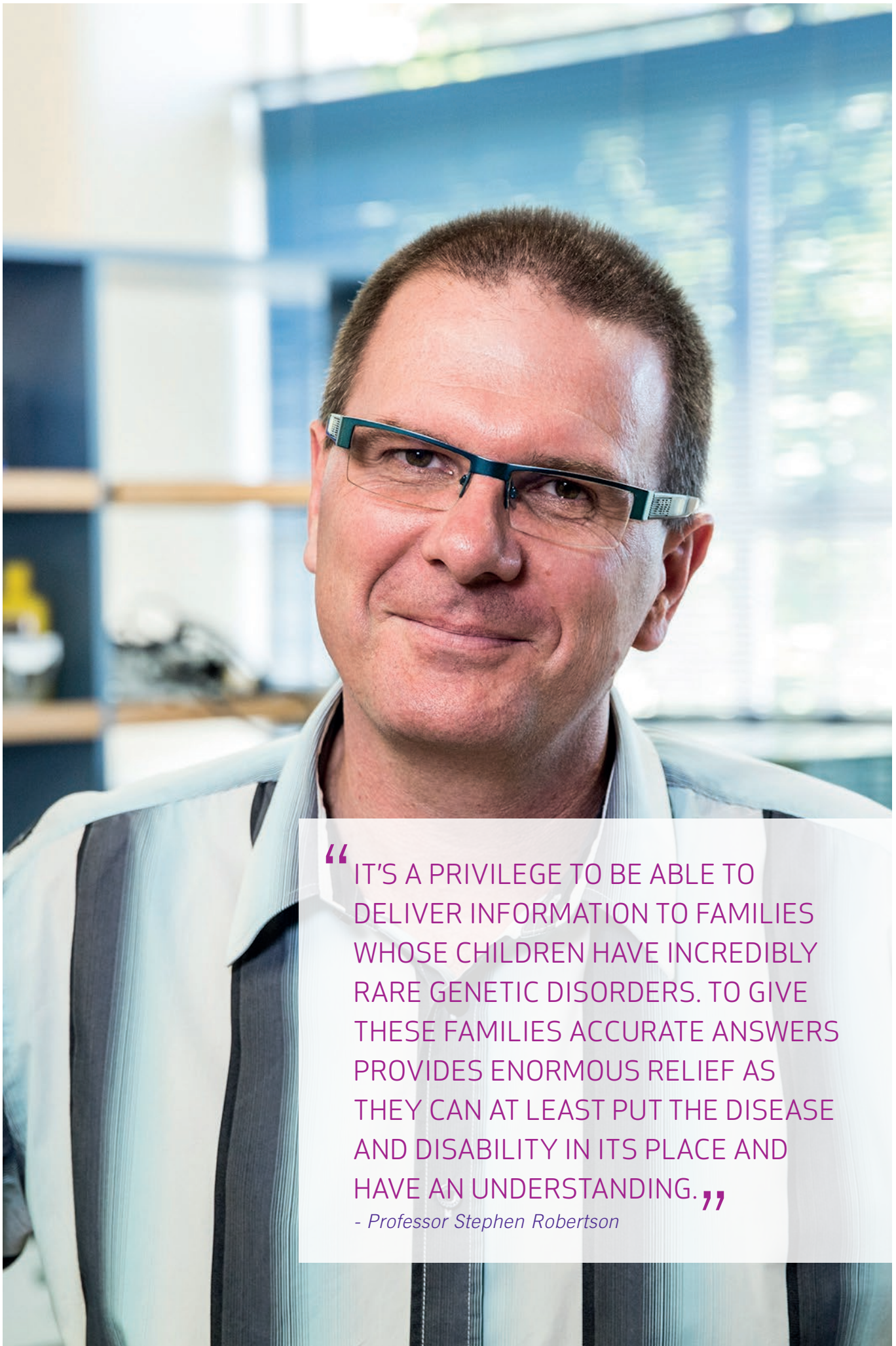
Infants with the condition will undergo major surgery to restore normal bile flow in the first weeks of their life, and many go on to require a transplant or they will die.

So little is known about this condition – is it environment? Is it genetic? Or is it a combination between the two? Because its origins are so poorly understood, predicting which infants will have it is difficult.

PhD student, Sophia Cameron Christie is exploring possible precipitating events, and is doing so by studying an iwi which has rate of BA 50 times higher than the average Maori population (in which the condition is already over-represented). Besides the circumstances – 13 cases in this family in 25 years – this concentration of BA provides strong evidence to support the supposition that there is a genetic dimension to the disease. The fact that it has only presented recently, despite a shared ancestry dating back over 150 years, also suggests environmental factors could be involved.

Ms Cameron Christie aims to find the genetic factors that confers susceptibility to this disorder in this iwi which in turn could lead to the development of strategies to identify susceptible infants and also the environmental factors involved, leading to interventions to mitigate or eradicate these predisposing factors.

As of writing, the team have found a small number of regions in the DNA which appear to be prime candidates for the mutation which underlies this condition in the iwi. Further genomic sequencing is required to shed light on these findings.



“ IT’S A PRIVILEGE TO BE ABLE TO DELIVER INFORMATION TO FAMILIES WHOSE CHILDREN HAVE INCREDIBLY RARE GENETIC DISORDERS. TO GIVE THESE FAMILIES ACCURATE ANSWERS PROVIDES ENORMOUS RELIEF AS THEY CAN AT LEAST PUT THE DISEASE AND DISABILITY IN ITS PLACE AND HAVE AN UNDERSTANDING. ”

- Professor Stephen Robertson



## PROFESSOR SALLY MERRY

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

### HIGHLIGHTS:

- SPARX was highly recommended at the New Zealand Innovators Awards in the Innovation in Health and Science category
- Attendance at a conference of leaders in the field of mental health in Vancouver; subsequently leading to an invitation to be a keynote speaker at the 5th Annual e-Mental health conference
- Funding for Better Start Challenge confirmed

Professor Sally Merry is a child and adolescent psychiatrist. She established the Werry Centre for Child and Adolescent Mental Health, based in the Department of Psychological Medicine at the University of Auckland, while also acting as the Centre's Director.

Professor Merry became Cure Kids' fourth Professorial Chair in 2015, through the generosity of the Duke Family Trust with further research funding provided by the Hugh Green Foundation.

At least one in four Kiwi children and adolescents will experience a significant mental health issue. These psychological, emotional and behavioural conditions impact on the child's day-to-day life.

The aim of the Cure Kids Duke Family Chair in CAMHS (Child and Adolescent Mental Health Service) is to investigate insights into the causes of mental health conditions and develop research-led treatments and prevention strategies with the aim of improving outcomes for young people and their families.

Professor Merry's reputation precedes her as a world-leading expert in the field of child and adolescent mental health, with a specific focus on e-therapies.

Recognising the growing use of smart technology amongst children and adolescents, Prof Merry and her team seek to harness this potential by developing engaging and immersive therapies that can be utilised in the homes of children and families living with a mental health issue.

In 2015, Professor Sally Merry and her team have been progressing the following projects:

#### SPARX

SPARX is a cognitive behavioural online therapy intervention for adolescents with depression, which became one of the world's first nationally-implemented mental health interventions for young people. The programme uses a fantasy game format to achieve the same ends as a counsellor or psychologist would when delivering 'talking therapy', known as cognitive behaviour therapy (CBT). Put simply, CBT, looks at the links between people's self-perception, the way they behave, and how they feel.

#### HABITS

'HABITS' (Healthy Behaviour Information Technologies) will be funded by Ministry Business Industry Environment, with supporting funding from Cure Kids as part of the recently launched 'Better Start' National Science Challenge. HABITS is a project targeted to adolescents in which a digital platform of self-help tools will be developed to help young people manage common mental health problems and be more resilient.

#### THE TrACY STUDY

MATCH (Modular Approach to Therapy for Children) is an evidence-based therapy designed in the United States by Professor John Weisz (Harvard University) and colleagues. It provides a flexible set of

treatment modules with which to address the most common childhood mental health problems, namely anxiety, depression, trauma-related symptoms and disruptive behaviour, as well as co-morbidity between these conditions.

The TrACY study is an exciting international research collaboration involving researchers from the Werry Centre, Harvard University and Le Va, as well as clinicians from five DHBs: Northland, Waitemata, Waikato, Counties Manakau (including Vaka Toa) and Capital and Coast (including Te Whare Marie and Health Pasifika). The efficacy of MATCH within a New Zealand context is being evaluated to see whether it may be a worthwhile therapy for CAMHS to adopt. The team have recruited their target of 200 participants, data analysis and publication of results is planned for 2016.

#### FUTURE RESEARCH

While still in its nascent stages, Professor Merry is further developing her programme of research centred on the potential for technology to create positive change for children.

An opportunity exists to extend the accessibility of support for proven good parenting practice by developing and testing a programme of 'digital interventions' to improve mental health in very young children of Aotearoa. This will be achieved by supporting parents to improve their parenting practices, to better understand their children's needs, to manage common childhood emotional, behavioural and developmental problems and to know when to seek further help. Intervening at this early stage has been shown to more than repay the cost of intervention in terms of better long-term outcomes for the children, and using technology to increase the reach of these effective interventions is likely to be even more cost-effective.



“CURE KIDS FUNDING HAS ALLOWED US TO BE AMBITIOUS AND TO “THINK BIG” AS WE TRY TO TACKLE THE IMPORTANT ISSUE OF MENTAL HEALTH FOR OUR YOUNG PEOPLE. ONGOING SECURE FUNDING HAS ALLOWED US TO FOCUS ON HOW WE MIGHT USE TECHNOLOGY TO SUPPORT YOUNG PEOPLE TO BE RESILIENT, AND TO SUPPORT PARENTS TO RAISE RESILIENT CHILDREN.”

- Professor Sally Merry



## GRANTING ROUND 2015

Each year, Cure Kids funds high-impact research projects through our granting round. The Cure Kids Medical and Scientific Advisory Committee (MSAC), consisting of many of the country's leading child health professors, preside over the process of making recommendations for funding. In 2015, Cure Kids supported five projects, all with the aim of improving the health of New Zealand children.

### DETECTING CHILDHOOD AMBLYOPIA ('LAZY-EYE') USING A TABLET COMPUTER

**PROFESSOR STEVEN DAKIN**  
SCHOOL OF OPTOMETRY  
AND VISION SCIENCE,  
THE UNIVERSITY OF AUCKLAND  
(\$100,000 - 2 YEARS)



Amblyopia is a visual condition where a difference in a child's eyes causes the brain to 'ignore' one eye, which eventually leads to very poor vision in that eye. An estimated 20,000 children live with this condition in New Zealand, which can greatly reduce their quality of life. Conventional treatment consists of occlusion therapy which involves patching the good eye to 'train' the lesser functioning eye to see again.

As one could imagine, children are not always amenable to this treatment, due to the stigma associated with an eye patch. For treatment to have the best chance of success, amblyopia needs to be accurately diagnosed as early as possible. Current methods of detecting the condition are flawed, with false positive rates approaching 40%, meaning thousands of children and families are diagnosed each year whom of which don't actually have the condition. Besides the public health costs associated with such errors, it can also be emotionally draining on the families, with research showing that misdiagnosis can engender mistrust in health systems resulting in impacts on future compliance with health recommendations.

Prof Steven Dakin and his team have created a series of novel, cost effective, tablet-based screening methods that promise to dramatically reduce the false positive rate. This project will compare the tablet-based screening with conventional methods in a sample of children both with, and without, amblyopia. Prof Dakin's tests keep children engaged, mitigating the chance of a child being failed due to lack of concentration.

Conventional methods, such as chart/letter lists, measure only visual acuity (estimating the smallest letter a child can read), which fails to capture the complexity of the condition.

In contrast, Prof Dakin runs a battery of tests that give a far more complete picture of a child's vision, and a far more accurate diagnosis. His group's results will inform best-practice that they hope will help refine national screening programmes such as the current B4 School check.

Early and accurate diagnosis greatly improves the prognosis for these children, improving their chances of having a future unhampered by visual impairment.

### A NOVEL GENE THERAPY STRATEGY FOR BATTEN DISEASE

**DR STEPHANIE HUGHES**  
DEPARTMENT OF  
BIOCHEMISTRY  
THE UNIVERSITY OF OTAGO  
(\$100,000 - 1.5 YEARS)



Batten disease is an inherited neurodegenerative childhood disorder. Although quite rare, its impact is always devastating. The progression of symptoms includes, losing the ability to walk, talk and feed, invariably leading to premature death.

No effective treatments exist, however, promising gene-therapy research funded by Cure Kids has proven curative in a form of the disease (CLN5) in a sheep model with naturally occurring Batten disease.

The disorder is characterised by a defective enzyme that usually assists in the recycling of waste from cells; or, in some forms of the disease, a defective membrane protein. The missing enzyme means there is an accumulation of cellular debris that can't be broken down.

Dr Stephanie Hughes will undertake gene-therapy in mice, which proved effective in CLN5 sheep, with naturally occurring CLN6 Batten disease. The therapy will be tested both pre and post onset of the disease. The latter being useful, as, often children are diagnosed well after onset of the disease, and hence it is vital that there is a treatment to reverse the symptoms post onset.

CONTINUED . . .

Disease symptoms manifest in mice in a very similar way as to those in humans, with mice having the additional benefit of having rapid disease progression, meaning the work can proceed at a rapid rate.

The mice will be closely monitored with behavioural tests beginning at two months of age and continuing on a monthly basis. The tests are devised to assess many of the manifestations of Batten's disease such as blindness, anxiety, motor function, and seizure analysis.

The results of this study, and the previous sheep model study in CLN5, have the potential to lead to human trials among children living with Batten disease, finally giving them and their families hope of an effective treatment. There also exist possible spill over benefits for other lysosomal storage diseases that affect thousands of children all over the world.



## GRANTING ROUND 2015

### STRIDER NZAUS: A RANDOMISED PLACEBO CONTROLLED TRIAL OF SILDENAFIL THERAPY IN DISMAL PROGNOSIS EARLY ONSET INTRAUTERINE GROWTH RESTRICTION



#### DR KATIE GROOM

DEPARTMENT OF OBSTETRICS AND GYNAECOLOGY, THE UNIVERSITY OF AUCKLAND (\$70,873 - 1.5 YEARS)

Intrauterine growth restriction (IUGR) is a term used to characterise poor growth of a baby in a mother's womb. It affects approximately 10% of all pregnancies, some of which require very early delivery (less than 32 weeks' gestation).

We know that very preterm birth, in addition to growth restriction, can subject babies to numerous short and long-term adverse health outcomes, including cerebral palsy and hypertension. Tragically, it can also be a contributing cause to stillbirth. IUGR is characterised by placental insufficiency, more specifically, a lack of oxygen and nutrients reach the baby through the placenta.

The only available treatment is for an obstetrician to plan an early birth. As these adverse health outcomes associated with very early birth are numerous, it is imperative that treatments are found to improve growth and wellbeing in the womb enabling better health for these babies.

Dr Katie Groom is the lead investigator on the multicentre STRIDER NZAus Trial, funded by the Health Research Council. This randomised placebo controlled trial is testing whether sildenafil is an effective treatment to improve the wellbeing of very growth restricted babies still in the womb. Sildenafil has the potential to dilate blood vessels within the mother's pelvis and so improve blood supply and oxygen delivery to the baby.

Cure Kids funding will support a Clinical Trial Manager to oversee the completion of recruitment as well as supporting the planning of an essential longer-term follow up of recruited mothers and their children. The primary outcome of this study is fetal growth velocity. The trial is part of larger international collaboration which will be able to assess the effect of sildenafil on health and wellbeing of off-spring through to early childhood.

Cure Kids funding is critical to realise the potential effect of sildenafil as a treatment for fetal growth restriction.

### PROMOTING OLIGODENDROCYTE PROGENITOR CELL MATURATION AS A TREATMENT FOR PRETERM BRAIN INJURY



#### DR JUSTIN DEAN

THE DEPARTMENT OF PHYSIOLOGY, THE UNIVERSITY OF AUCKLAND (\$100,000 - 3 YEARS)

Approximately 500 babies are born very prematurely each year in New Zealand. While the rate of survival of these babies has greatly increased due to advances in perinatal care, the fact is, they are at high risk of developing long-term problems, including neurological disorders.

For example, of the 500 babies born very prematurely, up to 15% will develop cerebral palsy, while as many as 50% may develop problems with learning and memory in later life. Clinical evidence suggests that reduced blood flow to the brain at the time of birth can cause damage to the white matter regions of the brain.

The white matter contains the fibres (axons) that connect different parts of the brain together. These fibres are coated with myelin, which allows signals to travel rapidly in the brain, much like the insulation on electrical wire. New studies suggest that the cells that make myelin, termed oligodendrocytes, do not mature correctly in preterm brain injury, meaning they fail to produce myelin.

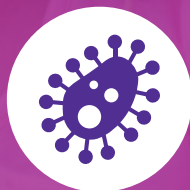
Dr Justin Dean has previously undertaken work that strongly suggests that a chemical in the brain termed PH20 is released following injury, which causes oligodendrocytes to stop maturing and producing myelin.

In this study, using a preclinical animal model, Dr Dean and his team will use a unique PH20 inhibitor to determine whether blocking PH20 activity after white matter injury will promote oligodendrocyte development and myelination, and thus restore brain function.

This work will greatly improve the understanding of the mechanisms of preterm brain injury, and may provide new treatment strategies targeted towards promoting normal brain development and maturation after injury.

## NEW DRUGS FOR RESISTANT SUPERBUGS

**DR SIOUXSIE WILES**  
MOLECULAR MEDICINE &  
PATHOLOGY, THE UNIVERSITY  
OF AUCKLAND  
(\$100,000 – 2 YEARS)



Since the serendipitous discovery of penicillin in the late 1920s (from the fungus *Penicillium*) by Alexander Fleming, antibiotics have been a bulwark against invading diseases and infection in patients undergoing routine surgery or chemotherapy.

We are now in an era where antibiotics are becoming increasingly ineffective against rapidly evolving superbugs. Some experts predict that, in as soon as ten years' time, we will have run out of effective antibiotics. Dr Siouxsie Wiles says, 'key to managing this crisis is the discovery of new antibiotics'.

Of specific concern to the New Zealand population is the bug *Staphylococcus aureus* (SA), as New Zealand has the highest rates in the developed world. Skin and soft tissue infections related to SA result in 700 children under five admitted to hospital each year, with thousands more treated in primary care.

Most antibiotics in clinical use are from soil microbes, and it is because of this that Dr Wiles plans to mine a bank of just under a thousand different species of fungi, native to NZ and the Pacific, held by the International Collection of Microorganisms from Plants (ICMP).

They will use a specially cultivated form of bacteria in the lab that has been engineered to glow when alive. This enables them to easily determine whether the bacteria is alive, as, if there is no light, which is a proxy for life, the bacteria are dead.

This facilitates the rapid assessment of numerous different flora and fungi. A previous one-year research grant from Cure Kids enabled this work to get underway, where they have already begun screening the ICMP for antibacterial activity against SA; so far, of the 121 fungal species tested, 19 have been identified as having the ability to kill SA.

This grant allows them to continue to screen the diverse range of fungi, and then supports the further analysis of those that have proven effective in killing SA.

The importance of the antibiotic ineffectiveness should not be taken lightly. If alternatives to the ever-weakening antibiotics aren't found, medicine will be set back a number of years.

The sheer number of children admitted to hospital for this one bug is reason enough to consider this work a public health priority and necessity.



## INNOVATION SEED FUND 2015

2015 saw the Cure Kids Innovation Seed Fund (ISF) being run for its second year, after a resounding success in its pilot stage the year prior. The ISF supports the early stage investigation of innovative research ideas which successfully demonstrate the potential to improve the understanding, diagnosis, therapy, and prevention of paediatric conditions. Once again the quality of applications was exceptional with Cure Kids committing to funding three projects.

### NOVEL CREAMS TO TREAT ANTIBIOTIC-RESISTANT STAPHYLOCOCCAL INFECTIONS

#### DR SIOUXSIE WILES (\$49,130 – 12 MONTHS)

Infectious microbes are responsible for as many as 1 in 4 hospital admissions in New Zealand. This burden disproportionately falls on Maori and Pacific children, while at the same time, costs DHBs \$15m each year. Additional to this, the capacity of medical personnel is stretched, meaning less resources to treat other conditions.

Of particular importance is the superbug *staphylococcus aureus* (SA), endemic in New Zealand with rates at over 400 per population. From 2007 – 2010, 163 children were classified as having an invasive disease (including musculoskeletal, respiratory and central nervous system) as a result of SA, 12% of which were infected with a strain completely resistant to antibiotic treatment. The first-line treatment for SA skin and soft tissue infections is the topical (applied directly to the skin) cream fusidic acid. Increases in infections, and the over-prescription of fusidic acid has resulted in resistant strains of SA which could lead to completely untreatable superbugs.

While the quest for new antibiotics continues, short-term solutions are necessary to extend the useful life of antibiotics, by formulating them so that SA is resensitised to their attack. A recent discovery by Dr Wiles and her team

has found that in the presence of iron, vitamin C is able to kill clinical isolates of SA. Furthermore, it was found that vitamin C was able to resensitise 13/21 clinical isolates to oxacillin, to which they'd previously been resistant. Vitamin C creams are presently used for anti-aging purposes.

The overarching objective of this project will be to repurpose these current topical creams using vitamin C and ferrous iron, with the end goal of these reformulations killing superbugs. The implications of this work if successful are great. Hundreds of children are admitted to hospital each year with skin or soft tissue infections, and increasingly ineffective treatments are likely to see this incidence increase, without a concomitant increase in treatment options. New topical creams for treatment will mean we will once again have a first line defence against these infections, greatly improving the quality of children's lives.

### PERSONALISED MECHANICAL VENTILATION IN NEONATAL INTENSIVE CARE.

#### PROFESSOR GEOFFREY CHASE (\$8,800 – 12 MONTHS)

Over 500 babies each year require mechanical ventilation (MV) to support their breathing in a New Zealand NICU due to disease, surgery or prematurity of birth. Achieving appropriate flows of oxygen for each baby is difficult, as each baby responds differently to ventilation.

Either too much or too little flow can have serious adverse effects on the babies, and hence, a more accurate, patient-specific MV method is of critical importance.

The problems associated with NICU MV has led Prof Geoff Chase and Dr Jennifer Dickson to undertake an observational trial in partnership with Dr Bronwyn Dixon at Christchurch Women's Hospital that will gather data from current and retrospective patients to obtain a greater understanding of patient-specific respiratory mechanics.

The research will determine whether computer models of lung mechanics can be used to measure lung properties specific to the baby, accurately enough to guide their care, using only ventilator data without any invasive interruption of a patient's care. The number of infants affected by inadequate methods of mechanical ventilation highlight why research of this nature is critical. This seed funding will enable the research team to collect airway pressure and flow data from the ventilator during normal care of infants. Initially, data will be collected on 20 patients over a period of six months.

The data will inform the creation of a neonatal-specific lung mechanics model for NICU patients. The results will also inform the design of a randomised clinical trial, the gold standard of medical research, which could provide the robust proof needed to develop the work into a new standard of care. This research could offer great potential for the hundreds of babies requiring MV in NICU every year, along with tens of thousands affected worldwide.



## HUMAN GALL BLADDER EPITHELIUM TREATMENT OF HAEMOPHILIA

### PROF BOB ELLIOTT

FAC8 LTD

(\$50,000 – 8 MONTHS)

Haemophilia A (HA) is an inherited blood clotting disorder, which mostly affects boys due to its mode of inheritance. Blood-clotting is the body's response to the breaking of a blood vessel. It helps prevent excessive bleeding by way of platelets – types of blood cells in your blood – migrating to the area of injury and subsequently gathering to form a barrier to lessen the bleeding.

The responsible protein is known as Factor VIII, which is either defective or completely absent in HA patients. Previous research funded by Cure Kids looked at the possibility of using pig liver cells, in pill form, to treat haemophilia. Practicality issues emerged, as the cells appeared to disrupt the wall of the capsule. An alternative method is the use of porcine gall bladder cells, however, this too proved not entirely effective.

We arrive at another method again; one being investigated in this project. This entails the use of human gall bladder cells that are removed from gall stones. The first step of the project is to investigate whether human gall bladder cells behave similarly to porcine cells; namely, that they can produce sufficient amounts of Factor VIII, and if so, when encapsulated, the pills are able to release the protein effectively.

Current treatments have a number of stumbling blocks. Nearly a quarter treated have developed inhibitors that render treatment ineffective. Likely the most effective treatment is liver transplantation, however, a compelling case for transplantation, above issues with haemophilia, is needed to justify a life-long course of immune suppression which accompanies the transplant. Ultimately, if human gall bladder epithelial cells can prove to produce sufficient levels of Factor VIII, as well as react well to encapsulation, then the outcome could be as good as a liver transplant with the added benefit of being far more accessible with no need for immune suppression.

Isabella lives with cystic fibrosis. Emeritus Professor Bob Elliott (University of Auckland) was one of the founding members of Cure Kids in 1971. Prof Elliott is world-renowned for his research in a number of child health fields, including cystic fibrosis, where, from 1976 to 1979, he was instrumental in developing the test for cystic fibrosis screening of all NZ newborns; helping extend life expectancy.



## CURE KIDS RESEARCH GRANT SUMMARY

# NEW RESEARCH GRANTS AWARDED IN 2015

In 2015, Cure Kids supported 16 projects all with the aim of improving the health of New Zealand children.

### GRANTING ROUND

#### Detecting amblyopia more accurately using tablet-based technology

This project builds on a seed grant received last year, and it seeks to improve the accuracy of out-of-date card/chart based tests that are notorious for over-diagnosing.

#### A novel gene therapy for Batten disease

Gene therapy that has proved successful in preclinical trials for one form of Batten disease will now be tested in another form with the hope that if successful, the method can move forward to clinical trials.

#### A randomised controlled trial (RCT) using sildenafil aiming to improve the outcomes of babies with slowed growth in the womb

Intrauterine growth restriction (IUGR) can result in severe health complications and currently has no treatment. This study will seek to improve the growth of these vulnerable infants.

#### Promoting Oligodendrocyte Progenitor Cell Maturation as a Treatment for Preterm Brain Injury

Can stimulating the maturation of brain cells which produce myelin – a fatty insulation that ensures effective transfer of information in the brain – reverse brain injury in preterm babies?

#### A quest to find new antibiotics to fight superbugs

This project, stemming from a seed grant last year, is investigating New Zealand microorganisms from plants as to their ability to kill the bug *staphylococcus aureus*.

### INNOVATION SEED FUND

#### Novel treatments for antibiotic-resistant Staphylococcal skin infections

In the presence of ferrous iron, vitamin C-based antibiotic creams can be resensitised to kill the superbug *staphylococcus aureus* (SA). This project will repurpose anti-aging creams to kill SA.

#### Personalising mechanical ventilation in neonatal intensive care units (NICU)

An observational trial in current and retrospective NICU patients undergoing mechanical ventilation to augment breathing, with the data used to inform patient-specific respiratory mechanics.

#### Human gall bladder epithelium treatment of haemophilia

Can encapsulated human gall bladder cells produce sufficient amounts of the blood clotting protein, Factor VIII, to protect the body against excessive bleeding?

### HEALTH CONDITIONS ASSOCIATED WITH DEPRIVATION

#### Vitamin D used to prevent hospital readmissions with acute lower respiratory infections (ALRIs)

A randomised controlled trial to determine whether vitamin D supplementation in children for 12 months can reduce the number of hospital readmission for ALRIs compared to the control group.

#### Working together with children, whanau and their communities to improve health, development and school readiness among vulnerable children and families in the Tamaki community

Can provision of health, developmental and educational assessments help ensure all children in the Tamaki area are healthy, socially, emotionally and developmentally when starting school?

#### Randomised controlled trial (RCT) comparing three different treatments for mild to moderate impetigo in children

Can hydrogen peroxide cream be at least as effective as the increasingly antibiotic-resistant conventional treatment, fusidic acid? Also included is a comparison to simple wound care as a control.

#### Implementing a SUDI Safe Sleep Calculator into Primary Care to identify and address risk in infants more vulnerable to SUDI

Can an assessment of families vulnerable to SUDI which calculates the interaction between a number of risk factors be used in primary care to increase awareness and reduce the incidence of SUDI?

### NEW DISCRETIONARY GRANTS

#### Monitoring fetal movement to reduce the number of stillborn babies

The use of a complex software programme isolating a mother's movement from that of the fetus, to determine if this could be a predictor of increased risk of stillbirth.

#### Can probiotics provided to mothers improve the health of their children?

Gaining a greater understanding of the effects of probiotics on the function and composition of organisms in the gut of children, and the role this plays in presence of eczema.

#### Effect of early probiotics on childhood cognition and behaviour

Will children whom of which were given probiotics as infants (as were their mothers in pregnancy) have reduced risk of cognitive, behavioural and mood problems at 11 years-of-age?

#### Simulating child cancer models to gain a greater understanding of the mechanisms involved for more effective treatments

To develop and characterise models of a mutated gene responsible for Acute Myeloid Leukaemia (AML) with the aim of improving treatment and survival.

## CURE KIDS RESEARCH GRANT SUMMARY

## OPEN GRANTS AWARDED IN PREVIOUS YEARS

## OPEN GRANTS

## Optimising babies' weight through nutritional intervention in obese mothers

A sustainable nutritional intervention in overweight mothers to reduce the cycle of obesity and its adverse effects on children.

## Innovative therapies for Batten disease and childhood epilepsy

Can the use of cannabis-derivatives reduce the distressing symptoms associated with Batten disease and other childhood epilepsies?

## Early detection of bacteria in the lungs using a non-invasive breath test?

Laboratory analysis of mucus build up in the cystic fibrosis lung to determine an effective breath testing diagnostic of harmful bacteria.

## Using robots to increase the mobility of children with cerebral palsy

The use of robotic therapy to aid children with cerebral palsy to develop more effective gait patterns enabling them to walk faster, for longer periods of time, and with a more 'natural' style.

## Can a novel intervention improve quality of life for children with sleep problems?

Testing the efficacy of a mandibular advancement splint in children who suffer from sleep-disordered breathing, in order to prevent further health issues developing in the future.

## Are babies treated with dextrose gel, a measure for reducing low blood sugar in babies, symptom-free at two years of age?

A study of children at two years of age assessing whether there are any adverse effects eventuating from the dextrose gel used to treat their hypoglycaemia at birth.

## A high-oxygen solution to pneumonia deaths in Pacific children

A pilot project in Tonga to test and refine a 24/7 portable oxygen system, with limited or absence of power, in reducing pneumonia-related child mortality.

The search for new drugs to fight drug-resistant *staphylococcal* skin infections

The search for, and assessment of, resilient antibiotics for effective treatment of skin infections through the screening of a unique collection of native New Zealand fungi.

## Improving the eyesight of children using a tablet computer

Exploration of different methods to improve the diagnostic screening of amblyopia ("lazy eye") to facilitate early treatment to prevent an enduring impact on vision.

## Transform a tooth with a 'transformer tooth': a novel approach for child oral health

A randomised control trial assessing the effectiveness of placing a stainless steel crown over decayed primary molar teeth in children to improve dental hygiene.

## Ventilator gas flows and bronchopulmonary disease in preterm babies: a randomised controlled trial

A trial into the effects of low ventilator flows compared with standard flows, to attempt to reduce lung injury in extremely preterm babies, thereby improving long-term health.

## A computer model to adjust the insulin dose in preterm babies with high blood sugar levels

A computer programme that helps to keep blood sugar levels in a safe range for preterm babies treated with insulin, to help avoid brain damage after preterm birth.

## PROVIDE: a randomised controlled trial of increased protein intake in extremely low birth weight babies (ELBW) in the first week of life to improve neurodevelopmental outcome

A randomised control trial into protein intake in ELBW babies, to determine whether an additional one gram per day of protein will improve neurodevelopmental outcome.

## The effects of vitamin D supplementation during pregnancy and infancy on dental health in early childhood

The two and half year follow up into the effects of vitamin D supplementation during pregnancy and infancy on tooth decay in socioeconomically deprived children.

## Bronchiectasis Exacerbation Study (BEST)

A study to determine whether antibiotics are necessary to treat bronchiectasis when chest physiotherapy may be effective with viral infections and which is the most effective antibiotic to use.

## Children of SCOPE: the influence of foetal and maternal adiposity on obesity at five-years-old

A research project to identify determinants of obesity and insulin resistance in children at five years of age, with particular emphasis on factors operating during pregnancy.

## Cot death prevention brochure

Funding of a brochure, radio campaign and television commercial on cot death prevention.

## Crohn's and Colitis in New Zealand children

Evaluating new ways to detect bowel inflammation through non-invasive testing.

## Early prediction of brain damage after acute brain injury in children

This study will establish whether 'silent' seizures are common with children's acute brain injuries and probably worsen the brain damage as they do with adults.

## Engineering full thickness human skin for the treatment of burn injury

This project will test new methods of engineering large areas of full-thickness skin for 'three dimensional' grafts for burns patients.

## Inherited heart conditions – National Screening Programme

This study aims to reduce sudden death in the young through increased detection and management of inherited heart diseases via the development of a national registry and by developing genetic tests for clinicians and coroners.

## International study of growth and development

A study on the prevalence of obesity in children living in different centres worldwide to be able to make comparisons within and between countries and obtain baseline measures for assessment of future trends.

## Longitudinal evaluation of the neurological development of preterm infants

A research project to understand the effects of early brain abnormalities on children's longer-term brain development and function using MRI methods.

## Multi-centre case control stillbirth study

Extending an Auckland study that found a link between sleep position and prolonged sleep in the late stage of pregnancy and stillbirths.

## Oral dextrose gel to prevent low blood sugar levels in new-born babies

A study to trial the effectiveness of dextrose gel as a prevention rather than a treatment of hypoglycaemia and its consequences in at-risk babies.

## The New Zealand VLBW adult follow up - MRI scanning and other support

To either substantiate or refute the hypothesis that VLBW (very low birth weight) results in lower levels of education attainment and tertiary participation, emotional problems and poor social functioning as well as increased rates of cardiovascular, pulmonary, renal and visual abnormalities.



## CHILD HEALTH CONDITIONS ASSOCIATED WITH DEPRIVATION

RESEARCH SHOWS THAT IN RECENT DECADES, CHILD HEALTH INEQUALITIES HAVE INCREASED IN NEW ZEALAND, FOR REASONS THAT ARE INTIMATELY RELATED TO DEPRIVATION. FOR 0 – 14 YEAR OLDS, THERE WERE, ON AVERAGE, 40,000 HOSPITALISATION ANNUALLY FROM MEDICAL CONDITIONS WITH A SOCIAL GRADIENT; CONDITIONS THAT INCREASE IN NUMBER AND SEVERITY THE LOWER DOWN THE SOCIOECONOMIC LADDER FAMILIES ARE.

Last year, in partnership with Perpetual Guardian, Cure Kids piloted a new programme of research funding which invited the New Zealand child health research community to propose ideas to tackle health conditions related to children living in relatively deprived circumstances. Profiled here are the four interventional research projects funded through the initiatives:

### **DOES VITAMIN SUPPLEMENTATION PREVENT HOSPITAL READMISSION WITH ACUTE RESPIRATORY INFECTIONS? A RANDOMISED CONTROLLED TRIAL**

#### **ASSOCIATE PROFESSOR CAMERON GRANT**

DEPARTMENT OF PAEDIATRICS, THE UNIVERSITY OF AUCKLAND  
(\$200,000 – 3 YEARS)

Ten per cent of children under two-years-of-age in NZ will be hospitalised with an acute respiratory infection with 80 per cent of these being lower respiratory tract infections (ALRI); one quarter of which will be re-admitted in the future as a result of recurrent ALRI.

The risk of being hospitalised is 4 to 5 times greater for children living in the most versus the least deprived 20 per cent of households, with similarly stark disparities among ethnicities. Dr Cameron Grant, a paediatrician at Starship Children's Hospital, will carry out a trial intervention to prevent readmission from ALRIs through vitamin D supplementation.

The intervention is building on similar research carried out overseas, however, before widespread adoption of any clinical

practice, it is paramount that it be tested in the relevant population. Moreover, 50 per cent of New Zealand newborns are vitamin D deficient, providing an added justification for intervention.

The trial will enrol 600 children under two-years-of-age, and will take place over a period of 18 months. Half of the children will take vitamin D supplements for 12 months, while the other half will be administered a placebo. Data will be collected throughout the study through interviews and medical records. Results of the study will inform Starship Clinical Guidelines, which are used by clinicians throughout New Zealand in the care of children admitted to hospital.

### **COLLECTIVE IMPACT: WORKING TOGETHER WITH CHILDREN, WHANAU AND THEIR COMMUNITIES TO IMPROVE HEALTH, DEVELOPMENT AND SCHOOL READINESS AMONG VULNERABLE CHILDREN AND FAMILIES IN THE TAMAKI COMMUNITY**

#### **DR ALISON LEVERSHA, COMMUNITY PAEDIATRICIAN, COMMUNITY CHILD HEALTH AND DISABILITY SERVICES, STARSHIP CHILDREN'S HEALTH (\$92,422 – 2 YEARS)**

Good education predicts good health, and disparities in health and in educational achievement are closely linked. Māori and Pacific children and youth are disproportionately represented in both adverse health and educational achievement statistics. Recent work in the Starship school health clinics in low decile

schools in the Tamaki area, has identified health and developmental concerns for many of the children.

Educational professionals report poor health as a key reason only 80% of children attend a kindy, kohunga or language nest prior to starting school, compared to 97% nationally. School principals also cite poor health as a contributing factor to poor school attendance and difficulties engaging with learning. In view of the concerns that poor health is having a significant negative impact on whether a child is developmentally ready to start school as well as how well they do whilst at school, Starship Community Paediatrician Dr Alison Leversha is collaborating with the Ministry of Education, local principals, the Manaikalani Education Trust and the Tamaki Regeneration Company on a new initiative.

This collaboration, funded by Cure Kids, will provide health, developmental and educational assessments for all 400 five year old children starting school in the Tamaki community during 2016. The Starship team will also work with a local NGO which supports vulnerable families to identify and attend suitable early childhood care and education centres (ECECs).

Health will now play a role in the early engagement process thus reducing the adverse effects of poor health on educational attendance and achievement. The goal is to ensure all children in the Tamaki area are healthy, socially, emotionally and developmentally ready to start school, and are in the best possible position to learn. This collaboration and intervention will have implications for national roll-out of educational and health interventions targeting vulnerable children and families.



EVERY YEAR, **OVER 40,000 CHILDREN ARE HOSPITALISED WITH CONDITIONS WITH A SOCIAL GRADIENT**; CONDITIONS THAT INCREASE IN NUMBER OR SEVERITY THE LOWER DOWN THE SOCIOECONOMIC LADDER FAMILIES ARE.



## CHILDREN GROWING UP IN RELATIVE DEPRIVATION, COMPARED TO THOSE IN MORE ADVANTAGED ENVIRONMENTS, ARE...

**4-5 TIMES**

MORE LIKELY TO DIE FROM SUDDEN UNEXPECTED DEATH IN INFANCY (SUDI)

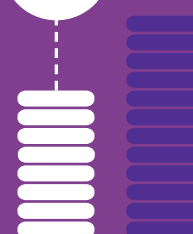
**4-5 TIMES**



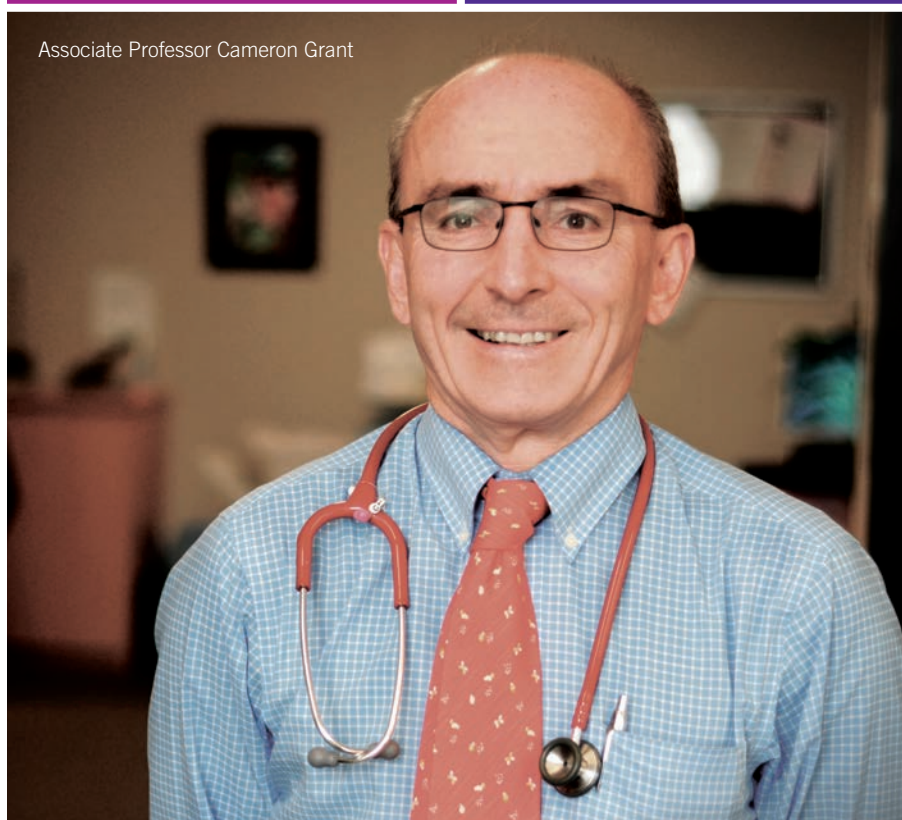
MORE LIKELY TO BE HOSPITALISED FOR AN ACUTE LOWER RESPIRATORY INFECTION (ALRI), SUCH AS PNEUMONIA

**40%**

GREATER RISK OF DYING



Associate Professor Cameron Grant



**OVER \$690K**  
TO SUPPORT  
4 PROJECTS



CONTINUED...

# CHILD HEALTH CONDITIONS ASSOCIATED WITH DEPRIVATION

## COMPARING THE OLD WITH THE NEW: RANDOMISED CONTROLLED TRIAL OF THREE DIFFERENT TREATMENTS FOR MILD TO MODERATE IMPETIGO IN CHILDREN

**DR ALISON LEVERSHA, COMMUNITY PAEDIATRICIAN, COMMUNITY CHILD HEALTH AND DISABILITY SERVICES, STARSHIP CHILDREN'S HEALTH (\$200,000 - 2 YEARS)**

Serious skin infections have been among the top three reasons for admission to Starship and KidzFirst hospitals over the last 15 years. The effects are disproportionately borne by Pacific and Maori children, who are 4-5 times, and 2-3 times, more likely respectively to be admitted with serious skin infections than European children.

Skin infections are among the most common health issues affecting children in low decile schools, with increasing concern of the impact on school attendance and subsequent educational problems. The most common skin infection in schools is impetigo or 'school sores', affecting close to a third of children in schools in socioeconomically disadvantaged communities.

Currently, impetigo is treated with fusidic acid – an antibiotic cream applied to the surface of the skin. However, bacterial resistance to this medication is now approaching 30 percent causing concern about its ongoing use contributing to

further antibiotic resistance. It is therefore necessary that alternative treatment options be examined.

Dr Leversha, from Auckland's Starship Children's Hospital, will undertake an intervention which will recruit 480 children, aged 5-13, who present with school sores at school-based health clinics. Dr Leversha will compare fusidic acid with an alternative treatment, hydrogen peroxide cream, applied to the skin infection, while also assessing these against simple wound care to help further illustrate potential benefits.

If successful, the results of the study will inform evidence-based skin infection guidelines locally, nationally and internationally.

## IMPLEMENTING A SUDI SAFE SLEEP CALCULATOR INTO PRIMARY CARE TO IDENTIFY AND ADDRESS RISK IN INFANTS MORE VULNERABLE TO SUDI

**PROFESSOR ED MITCHELL, CURE KIDS CHAIR OF CHILD HEALTH RESEARCH, THE UNIVERSITY OF AUCKLAND (\$200,000 - 2 YEARS)**

A pioneering study into sudden unexpected death infancy (SUDI), by Prof Ed Mitchell, in the late 1980s, achieved great success, saving an estimated 3,000 babies in the time since it was implemented. However, we still lose

around 50 babies to SUDI each year.

Families from disadvantaged backgrounds are nearly six times more likely to lose a child from SUDI. Maori and Pacific families are also dramatically overrepresented in the figures.

The vast majority of SUDI deaths are preventable by disseminating knowledge about the interplay between various risk factors associated with SUDI. With over 30 years in this field, Prof Mitchell has collated a large body of research, which he has used to develop a SUDI Safe Sleep Calculator (SSC).

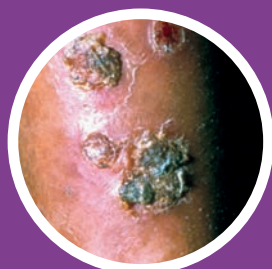
The SSC can give an individual risk rating based on a number of these risk factors that primary care teams can then support the family to address.

For the SSC to be effective, we need to know if primary care providers are willing to adopt it in practice, and if so, whether or not the knowledge imparted will be retained, and implemented, by at-risk families.

Pilot data from primary care providers and families, on the usage of the SSC, will be used to further refine it before a more comprehensive trial in 200 at-risk families.

The families chosen (determined by an initial SSC assessment) will be followed up to assess whether or not there has been a change in the risk factors they addressed with their primary care providers.

The SUDI Safe Sleep Calculator is already capable of being integrated into current primary care computer systems, and once the initial pilot intervention is complete, rapid roll-out of it to the majority of primary health care providers will be possible.



**PACIFIC CHILDREN ARE 4 to 5 times...**

**MAORI CHILDREN ARE 2 to 3 times...**

**MORE LIKELY TO BE ADMITTED WITH SERIOUS SKIN INFECTIONS THAN EUROPEAN CHILDREN.**

## KIWIS CURE BATTEN

Through the love of our national game and the power of music, Cure Kids set a mighty goal this year to inspire the All Blacks, unite Kiwis and create a world free of Batten disease.

Kiwis Cure Batten is a rallying cry for all Kiwis to join Cure Kids in a global movement to help raise funds to find a cure for children living with Batten disease.

Batten disease is an inherited collection of brain diseases that robs apparently healthy children of the ability to walk, talk and feed, and eventually leads to death. Symptoms can be likened to a combination of epilepsy, Parkinson's, Alzheimer's and blindness.

At present, there are no effective forms of treatment for the devastating disease – it always results in premature death.

In 2012 Cure Kids funded pre-clinical research which has proven to be curative

for a form of Batten disease. We are now working with the research teams to progress this work to the point where human trials could commence.

The findings of this New Zealand-led research are significant for the international research community, as well as families and children worldwide living with Batten disease, providing genuine hope.

Through the #KiwisCureBatten campaign, Cure Kids partnered with the All Blacks and released a collaborative song called 'Team Ball Player Thing', with the aim to raise as much money as possible to tackle the disease.

The song, produced by Brooke Howard Smith, Jesse Griffin and Joel Little has been viewed more than one million times online.

With witty lyrics written by Kiwi kids, a host of talented Kiwi musicians including Lorde, Brooke Fraser, Dave Dobbyn, Gin Wigmore, Kimbra, and many more performed the song in an incredibly moving way.

Thank you to the 150 inspiring people who brought this project to life, we are overwhelmed with the many good sorts who are all working together to ultimately achieve the same goal, to find a cure for Batten disease.

**#1**   
**ON iTUNES**  
 WITHIN 90 MINUTES  
 OF RELEASE



**21,000**  
 HITS  
 TO THE  
 WEBSITE 

DONATIONS  
 RAISED  
**\$250,000**

MORE THAN  
**ONE MILLION**  
 VIDEO  
 VIEWS 



## HOW ARE WE DOING?

**CURE KIDS FINANCIAL PERFORMANCE**

## SUMMARISED STATEMENT OF FINANCIAL PERFORMANCE

	CONSOLIDATED	
	31.12.15	31.12.14
Fundraising Income	3,783,171	3,766,163
NZ Government Grant - RHD NZ Aid	-	1,029,574
Rental Income	232,175	230,503
Interest & Dividends on Investments	831,427	887,038
Unrealised Gains	5,550,359	262,627
Realised Gains/(Losses)	83,095	(111,289)
Other	4,728	34,833
<b>TOTAL INCOME</b>	<b>10,484,955</b>	6,099,449
Fundraising Expenses	(1,272,315)	(1,476,307)
Rental Expenses	(35,075)	(32,446)
Administration Expenses	(507,168)	(777,973)
Salary Expenses	(2,184,408)	(2,049,682)
Research & Development	(974,913)	(719,242)
RHD NZ Aid Grant	-	(846,955)
Grants & Research Investment	(2,471,875)	(2,028,025)
<b>NET SURPLUS/(DEFICIT)</b>	<b>3,039,201</b>	(1,831,181)

## SUMMARISED STATEMENT OF FINANCIAL POSITION

	CONSOLIDATED	
	31.12.15	31.12.14
Cash Held	460,151	378,357
Fixed Assets	119,365	160,600
Investment Property	4,550,000	4,300,000
Investment Portfolio	33,564,682	30,391,211
Other Assets	281,228	813,454
<b>Total Assets</b>	<b>38,975,426</b>	36,043,622
Grants	4,083,494	3,384,056
Other Liabilities	1,060,545	1,867,381
<b>Total Liabilities</b>	<b>5,144,039</b>	5,251,437
<b>Total Equity including Capital Funds</b>	<b>33,831,387</b>	30,792,185

HOW ARE WE DOING?

# NOTES TO FINANCIAL STATEMENTS

The Cure Kids 2015 financial statements have been prepared under New Zealand GAAP accounting standards. Accounts for the 2016 year will be prepared under PBE IPSAS. Chartered Accountants Walker Wayland in conjunction with EY (previously Ernst and Young) continue to provide financial expertise, audit and governance over the Cure Kids financial reporting.

2015 net fundraising income after expenses, was in line with the 2014 net income while the net surplus was driven largely from unrealised gains in the investment portfolio.

Of significance to the financial performance review, while fundraising direct expenses for 2015 were budgeted at 30.2%, an actual performance of 27.6% was achieved contributing to a consistent downward trend since 2013. A key driver in the five year strategic plan is to advance the reduction of expense ratios by implementing strategies which generate higher return on investments through regular giving programs and reducing reliance on variable sources of income. In light of this, funds have been allocated to the resources required to deliver on our goals in the medium to long term strategic planning period.

The administration expenses included in the statement of performance includes fundraising, research and general expenses and accommodates trademark and intellectual property costs.

In the investment portfolio Cure Kids realised income on funds invested excluding the A2 portfolio of 3.23% and a total return on income and gains, excluding A2 of 9.4%. Cure Kids has continued to sell down holdings in A2 to facilitate its investment diversification strategy. Judicious management of this investment portfolio has resulted in the accumulation of \$33 million in capital funds, highlighted in the annual accounts provided.

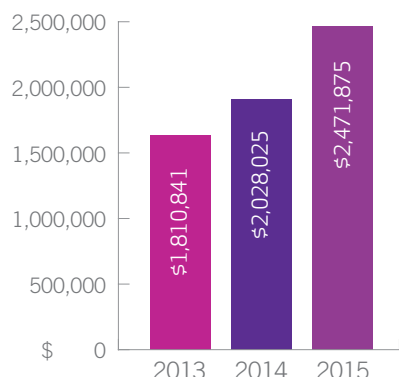
The majority of these funds are ring fenced for specified commitments which allow Cure Kids to:

- Provide funding in perpetuity for our Cure Kids Chair of Child Health Research at the University of Auckland
- Support defined programmes of research where funds have been raised or endowed for that specific purpose, including SUDI and blood disorders
- Maintain and grow our programme of research funding in addition to our Research Chairs in line with our strategic objectives.

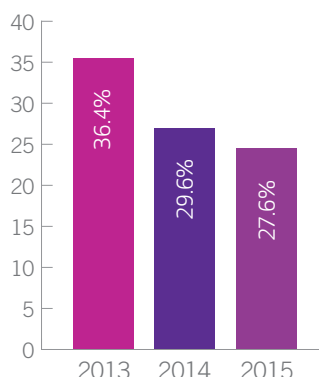
The commercial property in Remuera continues to deliver a net return of 4.33%.

Cure Kids continues to maintain a secure financial position appropriate to carrying out its objectives in supporting the research chairs and granting focused on research, delivering material advancements to childhood health outcomes.

TOTAL INVESTED IN NEW RESEARCH PROJECTS { \$ }



PERCENTAGE OF EXPENSES AGAINST INCOME { % }



TOTAL DOLLARS INVESTED IN RESEARCH TO DATE MORE THAN **\$38.8 MILLION**



## AUGUST 21 2015 RED NOSE DAY

Kiwis from Bluff to Cape Reinga got REDiculous for Red Nose Day in August, raising more than \$1 million for Cure Kids. Thousands of kids from more than 450 schools and pre-schools took part in Red Nose Day this year, raising money through school mufti days, bake sales, fun runs and colouring competitions to help cure kids. We also had an incredible response from businesses across New Zealand with more than 300 businesses coming on board to fundraise.

New to Red Nose Day this year was the 'Red Beard Challenge', led by well known Kiwis, including Steven Luatua, Art Green and Brendon Pongia. The celebrities and other Kiwi good sorts dyed their beards a REDiculous bright shade of red for the cause and shaved them off on national TV during TVNZ's Breakfast programme, raising more than \$60,000.

"I was fortunate enough to spend time with some Cure Kids ambassadors earlier in the year. They're such great kids, and that's why I'm honoured to be involved," said Luatua.

One business that got particularly REDiculous this year was Mike Greer Homes, who donated \$100,000 from the sale of a house, situated in Millwater, north of Auckland, to Cure Kids.

Another highlight was the first ever Red Nose Day Family Fun Day which was held in Palmerston North and was organised by one of our inspirational ambassador mums, Laurel Winiata, raising more than \$10,000.

On the evening of the iconic Red Nose Day itself, which fell on Friday the 21st

of August, a finale party was held with the generous support of Accor Hotel Group.

The night included a celebration of the amazing fundraising efforts of our partners, schools and businesses, as well as hilarious skits from comedians Urzila Carlson, Tim Batt and Joseph Moore, and our MC's, Brooke Howard Smith and Jessie Griffin.

The night was topped off with an auction that raised a further \$6,000 for child health research. Thanks again to everyone that supported Red Nose Day 2015.





**450 SCHOOLS**  
AND PRE-SCHOOLS  
ON BOARD TO  
FUNDRAISE



**300**  
NZ BUSINESSES  
FUNDRAISED



**9,697**  
LIKES, COMMENTS  
AND SHARES ON  
RED NOSE DAY POSTS  
ON FACEBOOK

**60,000**  
RED NOSES  
DISTRIBUTED  
AROUND NZ



**13,886**

VISITS TO THE  
RED NOSE DAY  
WEBSITE



BRISCOE  
GROUP RAISED  
A RECORD  
**\$450,000**



**15 GUYS**  
GREW BEARDS  
AND DYED THEM  
BRIGHT RED

**250,000**

RED NOSE DAY  
COLUMBUS  
COFFEE CUPS WERE  
USED THROUGHOUT  
THE COUNTRY IN AUGUST





SEPTEMBER 30TH - OCTOBER 4TH 2015

## \$10 QUEENSTOWN CHALLENGE

For the 10<sup>th</sup> year in a row, teams of courageous Kiwis took up the challenge of travelling from Auckland to Queenstown armed only with \$10 in their pockets and a heap of passion.

This year saw 30 teams of two arrive at the Novotel in Auckland sporting an eclectic array of costumes and a truck load of enthusiasm. Setting off with Queenstown in their sights, the teams made their way south managing to fit in BMX riding in Taupo, boot camp at the Waiouru Military Camp, kayaking in Kaikoura, Segway riding in Hagley Park in Christchurch, pottery painting in Temuka and wine tasting in Gibbston Valley all the while raising funds for Cure Kids along the way.

An overnight ferry ride across the Cook Strait and a 5am rock climbing session were among the challenges accepted in good spirits by all involved.

It was incredible watching the 60 competitors unleash their inner superhero not only on their physical journey to Queenstown, but also in their quest and commitment to raising the minimum required entrance fee of \$7,000 before the race even began.

The overall winners were Eva's Angels and the Spirit of the Race Award was given to the Ohana Breathers. Best Dressed went to the Bud Jaks, while Team Korbs took out the title of Fundraising Champions.

It was very special for us to have Team Korbs on board this year who took the challenge on in memory of their late son, and inspiring Cure Kids ambassador,

Korbin who lived with congenital heart disease. They set an impressive goal of raising \$18,000 for Cure Kids; \$1,000 for every amazing year that Korbin was with us.

The teams raised a total of \$277,070. An incredible \$259,585 of this went to Cure Kids and \$17,485 to the Queenstown Trustees to distribute to local charities. Cure Kids is immensely grateful to all the competitors, sponsors, volunteers, donors and partners who got behind this event and made it such a success in 2015.

A TOTAL OF **\$277,070** WAS RAISED BY THE TEAMS







**30 TEAMS  
OF TWO**



**\$259,585**  
OF THE TOTAL RAISED  
WENT TO CURE KIDS

**\$17,485**  
TO THE QUEENSTOWN  
TRUSTEES  
TO DISTRIBUTE TO  
LOCAL CHARITIES





## MARCH 27TH 2015 GREAT ADVENTURE RACE

In March, 35 teams of four undertook the gruelling challenge of competing in the Cure Kids Great Adventure Race held in the spectacular Hunua Ranges.

The teams put their navigation skills to the test and ran, hiked, mountain biked and even traversed waterways for Cure Kids, raising an amazing \$421,000!

Team MC Hammer from Meredith Connell took out first place in an impressive time of seven hours and seven minutes. The 'Best Dressed' award went to team Pullman of Steel from the Pullman, Auckland.

"Winning was really fantastic, but at the end of the day, it wasn't about coming first. The most memorable part of the event for me was closing in on the finish line and seeing the Cure Kids ambassadors cheering us on.

That was enormously powerful for me and summed up what the event was all about," said Michael Walker from winning team, MC Hammer.

A huge thanks to all of the competitors and supporters who made this event possible. All teams certainly did our Cure Kids ambassadors proud, a few of whom formed part of the welcoming committee as teams finished the race. Thank you to Accor who showed their overwhelming support in numbers this year, entering a whopping eight teams in the race!





MARCH 27TH 2015

## TICKET TO HOPE

Ticket to Hope is always one of the most special events on the Cure Kids Calendar and the 13th annual event was no exception. A group of 14 children living with serious illnesses or health conditions and a parent/caregiver were treated to a magical, action-packed three-day experience in Queenstown in June.

Skyline lugging, splashing around in the Alpine Aqualand pools, helicopter rides, a golf cart tour and afternoon tea at The Hills, exhilarating AJ Hackett zip lining and even bungees for the brave parents as well as KJet jet boating were just some of the activities that had the kids (and the adults that accompanied them) smiling from ear to ear!

Celebrities Art Green, Steven Luatua, Brooke Howard-Smith and Shelton

Woolright joined us for the weekend and were a fantastic addition to the event. Leading the charge on all things fun these celebrities gave up their time to help make the kids and parents feel like VIPs for the entire weekend.

This year's event was made possible by the generosity of a number of people and organisations including, members of the New Zealand Venture Capital Association, Queenstown businesses, - many of

whom donated their services to the event - including McDonalds (Frankton), Patagonia Chocolates, Cup and Cake (Queenstown) and of course, our partners.

A special thanks to the Mercure Resort Queenstown and all the AccorHotels staff that volunteered their time to ensure the event was a huge success.







Emily lives with type-1 diabetes



# CURE KIDS AMBASSADORS

Cure Kids are blessed to call more than 40 courageous kids from all over New Zealand our treasured ambassadors.

These children live with a range of serious, and in some cases, life threatening health conditions. Many have had to fight since the moment they arrived in the world and all remind us every day of why the work that we fund at Cure Kids is vital and makes a tangible difference to the lives of children like themselves.

At Cure Kids, we are a bit like one big family all working towards one common goal – a healthy childhood for all. Our incredible ambassadors are an essential part of that family and they help make incredible things happen at Cure Kids.

Together with their families they share their stories and are generous with their

time for our events and campaigns, because they too want to be part of finding cures and better treatments for kids just like themselves. Their courage is the inspiration for our action.

From all the team at Cure Kids, thank you.





## 2015 RECIPIENT EVENT HIGHLIGHTS

Cure Kids are proud to partner with organisations and individuals across New Zealand as the recipient charity for some amazing events. Here are some 2015 highlights.

### WHEELS FOR CURE KIDS - JANUARY

Champion freestyle motocross rider, Levi Sherwood, along with Nitro Circus star Jed Mildon and Event Organiser Luke Price raised over \$8,000 at the first ever "Wheels For Cure Kids" event in Tauranga in January 2015; it was a spectacular day which saw over 2000 people attend.



### PORTS OF AUCKLAND GOLF DAY - MARCH

Associate Partner, Ports of Auckland, ran their annual golf day for Cure Kids and raised their highest amount ever at more than \$55,000 which brings their fundraising total to just under \$227,000 in the eight years since the partnership started.

### GODZONE BUILDING RESILIENCE DINNER - FEBRUARY

2015 was the first year that Cure Kids became the official charity partner of the one of the worlds toughest adventure races, GODZone. Big thanks in particular to New Zealand Rugby Players Association CEO, Rob Nichol, for pulling together a Cure Kids team who went on to raise an amazing \$35,000.



### DUCK RACE FEBRUARY

The 2015 Rotary Dunedin Race was the 6th edition of the annual event, and raised an impressive \$5,000 for Cure Kids.



### INGRAM MICRO GOLF DAY - FEBRUARY

Ingram Micro's inaugural Cure Kids Golf Day was held at North Shore Golf Club in sparkling summer conditions, and even hotter golf was on display. A brilliant day was had by all, and over \$35,000 was raised for Cure Kids.



**TOUGH GUY AND GAL  
& TOUGH GUY AND GAL  
JUNIOR, JUNE - OCTOBER**

This series of fun, off-road running races around New Zealand raised over \$39,000 for Cure Kids.

**THE BABY SHOW  
WELLINGTON - MAY**

Cure Kids was nestled in the Activities Area of the Wellington Baby Show all weekend. We had great fun with our face painters and jungle portrait board!



**SILENI ESTATE CHARITY  
DINNER AND AUCTION,  
NAPIER - SEPTEMBER**

A fun evening of introducing Cure Kids to the Hawkes Bay and sharing ambassador stories of resilience. Attended by just under 200 people it raised more than \$45,000.



**VSL WORLD  
VINTAGE  
RUGBY CARNIVAL - NOVEMBER**

More than 500 rugby players from around the world enjoyed a week long World Vintage Rugby tournament organised by VSL Events in Queenstown and generously helped raise just under \$19,000 for Cure Kids.



**KONRAD HURRELL  
BEARD SHAVE  
JUNE**

Kiwi league star Konrad Hurrell grew an impressive beard and shaved it off raising \$3,000 for Cure Kids.



**ROTARY DEVONPORT FINE  
HOMES TOUR OCTOBER**

Devonport Rotary, with the generous support of Bayleys Real Estate, Devonport and local businesses, raised \$10,000 for Cure Kids during their second annual Fine Homes Tour of Devonport. Ten of Devonport's finest homes opened their doors and gardens for visitors to peruse and enjoy in the spring sunshine.



## 2015 NZ RUGBY

2015 saw the fourth year of the partnership between New Zealand Rugby and Cure Kids, and what a year it was! Another global success was just one of the many highlights from a memorable year, and we are so proud to stand beside New Zealand Rugby as their official charity partner.

We kicked off the year with an All Blacks and Cure Kids ambassador video shoot at Eden Park in Auckland. All Blacks Kieran Reid, Beauden Barrett and Luke Romano helped us record a poignant video called “When I Grow Up” which illustrates the stark contrast of the hopes and dreams of our beloved All Blacks with the hopes and dreams of Cure Kids ambassadors that live with serious health conditions. Partnerships such as this one enable research to help children’s dreams come true. The powerful piece will be used as an ongoing fundraising tool through a number of channels.

Further Cure Kids ambassadors’ highlights from the year included attending Captain’s Runs, All Black Test matches and the Wellington Sevens tournament. Together, with New Zealand Rugby, we are delighted to be able to provide these opportunities for ambassadors like four year old Torrance. Torrance lives with a heart defect but doesn’t let that slow him down – he’s rugby mad and last year was able to meet one of his heroes, All Black, Sonny Bill Williams, and attended his first ever live Test-match.

Another very special ambassador event was meeting the Black Ferns at ‘Jump’ trampoline park in Auckland. This was a fun way for our women’s team to engage with some of the brave kids that live with serious illnesses and health conditions and for the ambassadors to enjoy an afternoon of fun with this inspiring group of sports women.

One of the biggest milestones of the year was the release of “Team Ball Player Thing” – our All Blacks supporter song. See page 29 for more detail on this amazing campaign.

Raising money to fund research is a key component of the partnership between New Zealand Rugby and Cure Kids, and we are fortunate to auction off memorabilia and experiences at fundraising events and collect outside the All Blacks Test matches. When it comes to finding a cure every dollar counts, and the support of New Zealand Rugby with our fundraising efforts is invaluable.

And last, but certainly not least, All Blacks can get REDiculous too! A group of All Blacks helped promote our Red Nose Day campaign theme of getting ‘REDiculous’ to help raise funds during Red Nose Day, 2015.

Steven Luatua also led the charge on the Red Beard Challenge that gained momentum with a number of high profile New Zealanders raising more than \$60,000.

We are very grateful to extend our partnership with New Zealand Rugby into 2016 and look forward to working with all our national teams to raise funds and awareness for Cure Kids and ensure that our research and results impact child health in every community in New Zealand.









## PLATINUM PARTNERS



“At AccorHotels we are passionate about giving back to our local communities and through the key partnership we have with Cure Kids, our hotels are able to support a number of initiatives helping to fund cures for life-threatening children’s illnesses”. *Chris Sedgwick, AccorHotels Senior Vice President of Operations - New Zealand, Fiji and French Polynesia.*

The AccorHotels and Cure Kids partnership goes back more than 10 years and during that time the group has raised over \$4 million. This has primarily been achieved through the hard work and dedication of the staff who participate and run numerous fundraising activities and events throughout the year, as well as donations received from guests staying in their hotels.

In 2015, staff from AccorHotels took part in many Cure Kids events including, the Great Adventure Race, the \$10 Challenge, Ticket to Hope and Red Nose Day - which saw staff from around the country dress up in red attire and participate in local street collecting. In 2016, the group will again run its biennial event, the AccorHotels Fiji Race to Survive for Cure Kids. It will be the 10th anniversary of the event which started in 2006 and has led to the development of the Rheumatic Heart Disease Control and Prevention Programme in Fiji.



“2015 was another cracker year for Briscoe Group supporting Cure Kids. We recorded our best year yet for fundraising revenue and we saw even more new fundraising events and campaigns being self-driven out of our stores. Through our commitment to fundraising for Cure Kids we are continually improving staff engagement and the overall team culture. Our staff are honoured to be part of the Cure Kids family and it shows when we run campaigns like Red Nose Day, Add What You Can and the new Christmas Giving campaign launched by our Riccarton

team. Our customers and suppliers are also on board and helped us reach those magical milestones that allowed us to surpass \$700,000 of fundraising in 2015. Together, our team, customers and suppliers will continue to fundraise as much as possible for Cure Kids to ensure we play a major role in improving child health research.” *Alaister Wall, Deputy Managing Director*

Briscoe Group has been a cornerstone Key Partner for Cure Kids for more than ten years and 2015 was yet another incredible year for the partnership; not only did Briscoe Group break yet another fundraising record, but this time the cause was a little closer to home. Cure Kids has embarked on a mission to fund Batten disease research and through this process discovered that a Briscoe Group staff member is Mum to two children with Batten disease. Batten disease is rare, inherited neurodegenerative disease that robs an apparently healthy child of the ability walk, talk and feed, and eventually ends their lives before they reach adulthood. Briscoe Group staff used this as motivation to raise even more funds for Cure Kids so that we can inch closer to a cure for this currently fatal disease. More than \$100,000 of the funds raised by Briscoe Group went directly to Batten disease research.

Cure Kids is extremely grateful for the phenomenal support of Briscoe Group staff, suppliers and customers who both fundraise as well as raise awareness for Cure Kids and the vital research we fund.



Colliers International continued our proud and very important tradition in 2015 of involvement with, and raising money for, Cure Kids.

Over and above our usual fundraising activities, the highlight was our Real Estate Management (REM) division’s fantastic participation in Cure Kids \$10 Queenstown Challenge. REM entered three very enthusiastic teams - raising over \$20,000 between them.

As well as this, the shopping centre teams at Centre City in New Plymouth, The Hub in Christchurch and Bethlehem Town Centre raised over \$5,000 from Christmas gift wrapping and Santa photos. Shopping centres throughout the country also promoted and raised funds for Red Nose Day. It’s great to see Colliers’ staff continue their whole-hearted support towards the work carried out by Cure Kids. *Bruce Gallie – Chief Operating Officer*

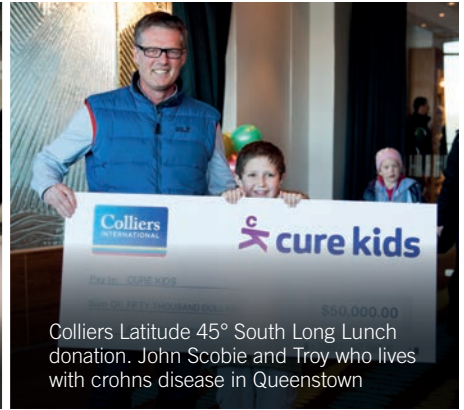
Colliers has been a Key Partner since 2005. They continue to raise the bar in terms of engaging their staff, suppliers and customers. From golf days to corporate lunches, street collecting, movie nights and everything in between – Colliers International know how to have fun raising funds! Special thanks to the Queenstown team that raised \$50,000 for Cure Kids at the annual Latitude 45 Degrees South Lunch.



Avis Budget Auckland Golf Day



Jorja, who lives with burns getting #Rediculous with BNZ



Colliers Latitude 45° South Long Lunch donation. John Scobie and Troy who lives with crohns disease in Queenstown



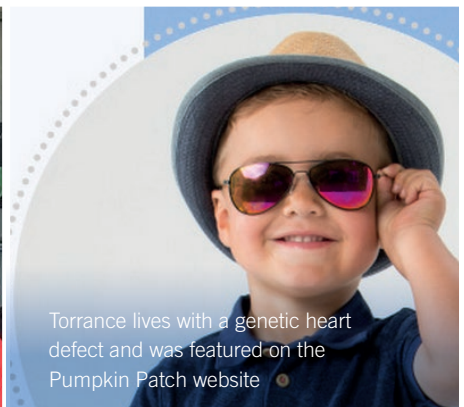
Finn lives with hypoplastic right heart



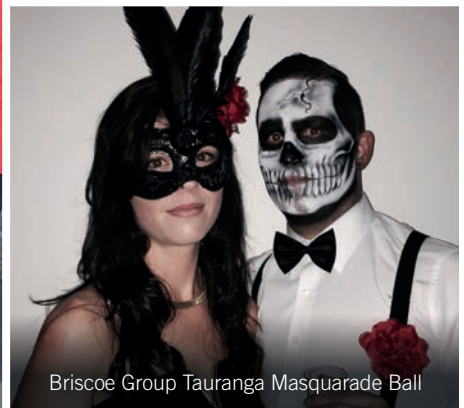
Jackson who lives with an inoperable brain tumour with the Mike Greer Homes House Build crew



AccorHotels – Novotel Christchurch Quiz Night and Skydive with Art and Matilda from The Bachelor NZ



Torrance lives with a genetic heart defect and was featured on the Pumpkin Patch website



Briscoe Group Tauranga Masquarade Ball



## KEY PARTNERS



“Having supported Cure Kids since 2003 we are proud to continue to assist them in their efforts of making a life-saving difference to Kiwi kids. We remain committed to Cure Kids and their work.” *Mark Ching, Managing Director*

Since 2003, Armacup has supported Cure Kids as a Key Partner, exemplifying the commitment and passion required from a loyal supporter. Owner and Managing Director of Armacup, Mark Ching, was personally responsible for introducing Cure Kids to the Mitchell family in 2011. Eva Mitchell, who lives with gastrointestinal failure, is now a Cure Kids ambassador and Tiff, Eva’s mother, has been an amazing supporter of Cure Kids ever since, speaking at numerous events and organising many fundraisers.



Avis, Budget and Apex have had a fantastic year working with Cure Kids! We loved the launch of #KiwisCureBatten with NZ musicians creating ‘Team Ball Player Thing’, and our staff had a blast with Red Nose Day – really getting creative to

find ways of raising funds whilst having fun at their local branches. We love working with the broader Cure Kids team and partners and are always looking for new and innovative ways to push the message and raise money for such a great cause.” *Kathryn O’Neil, Managing Director*

Since 2006, Avis Budget Group has proudly supported Cure Kids, and in 2012 they officially became a Key Partner.

Avis Budget Group once again held their staff road-show in the main centres and presented a fantastic Cure Kids-Avis Budget Group partnership update to their employees. Fundraising initiatives included a nationwide Red Nose Day campaign, and two excellent golf days in Auckland and Christchurch for Avis Budget Group clients and suppliers.



“At the Bank of New Zealand, we’re proud of the contribution we’ve made over the past six years to support Cure Kids and the incredible work they do to improve the lives of thousands of New Zealand kids who live with serious health conditions. The research they fund and hard work is something that should inspire us all.” *Anthony Healy – CEO*

BNZ has had a strong relationship with Cure Kids since 2008. After several years of enjoying a very successful and engaging relationship we were thrilled to officially sign BNZ on as a Key Partner in 2014. As part of this relationship, BNZ has been a proud advocate of Red Nose Day in its stores nationwide. In 2015, BNZ teams took part in the Great Adventure Race and the \$10 Queenstown Challenge, and continued to demonstrate the investment that Cure Kids makes towards the future health of New Zealand children.



“Our association with Cure Kids, although still in its infancy has already been a rewarding one. We were introduced to Cure Kids by our West Auckland Service Manager, Jason McLeod. His step daughter, Eva Mitchell is a Cure Kids ambassador so we got involved with Red Nose Day last year and the relationship has blossomed since. When given the opportunity to support Cure Kids with four vehicles to help them continue the amazing work that they do, we jumped at the chance. Curing kids - who doesn’t want to play a part in that?” *Julian Stone, John Andrew Mazda Dealer Principal*

Cure Kids are extremely grateful to have begun our newest key partnership in October 2015 with John Andrew Mazda.

As suppliers of four vehicles to drive the momentum of Cure Kids, John Andrew Mazda are also participants of Red Nose Day, and support Cure Kids through numerous fundraising events and ambassador functions.



“The entire team at Mike Greer Homes are honoured to have had the opportunity to support Cure Kids, and the work they do. To have had the impact on the lives of so many children and families in the way that Cure Kids have, is an amazing achievement, and Mike Greer Homes is truly proud of its association.” *Mike Greer, Owner*

Mike Greer Homes began its partnership with Cure Kids in 2015 when they became a Key Partner. They established a fantastic foundation year for the partnership by building a house in Auckland, auctioning it off, and donating \$100,000 of the proceeds to Cure Kids.

Mike Greer Homes believes there is no better way for them to give back, than to build a house along with support from suppliers, and raise funds to support Cure Kids.



“New Zealand Rugby and the All Blacks highly value our relationship with Cure Kids’ – from celebrating a song to rally the country behind the All Blacks at the Rugby World Cup, to connecting our people with the Ambassadors, families and staff that make up Cure Kids – our partnership is strong. We are proud to stand behind a cause that provides hope and support to so many, and we look forward to another year working alongside Cure Kids.” *Steve Tew, CEO*

New Zealand Rugby have partnered with Cure Kids since 2012. We are extremely grateful for all of the wonderful opportunities that this partnership has provided. Among other milestones New Zealand Rugby played a major role in establishing the Cure Kids Chair of Child and Adolescent Mental Health, provided the biggest names in international rugby to help promote our fundraising campaigns and worked closely with Cure Kids to help fund research that is significantly impacting the lives of children both here and around the world. Please see page 42 for more detail on our partnership.



*Through its extensive chain of branches throughout the country, Oil Imports gave extremely generously throughout 2015 – its first year as a Key Partner of Cure Kids.*

A great turnout of Oil Imports staff also attended our inaugural Key Partner Roadshow as they came up with many ideas about how they plan to engage with Cure Kids in years to come. We are extremely pleased to have a family-owned, New Zealand business on board as a member of our partner family.

## PUMPKIN PATCH

“Pumpkin Patch have been associated with Cure Kids since 2006. They are our charity of choice and we are very proud of our ongoing association. We are pleased to support both Red Nose Day and Add a Dollar campaigns in our stores. It was great to help facilitate Cure Kids’ launch into Australia last year and I must say our Australian staff really embraced this new initiative, as did our customers.

We have also been lucky enough for staff members to attend Ticket to Hope and participate in the Tough Guy and Tough Gal challenge which saw many of our team at head office getting muddy for charity and having many laughs throughout the day. Dressing Cure Kids Ambassadors for photoshoots is also a privilege we have enjoyed as a company.”

*Luke Bunt, Managing Director*

2015 saw Pumpkin Patch achieve Cure Kids’ first highly successful trans-Tasman fundraising campaign. In 2016, Pumpkin Patch’s main fundraising for Cure Kids will include the Add a Dollar campaign through Australasia and of course Red Nose Day in New Zealand.



“Rotary is proud of its 45 years of ongoing partnership involvement with Cure Kids (formerly called the Child Health Research Foundation which was founded by Rotary in New Zealand in 1971). You can proactively support Cure Kids’ research initiatives to find cures for children’s life-threatening illnesses, and have fun at Cure Kids’ fundraising events.” *Beryl Robinson, Cure Kids Member representing Rotary*

*in New Zealand since 2006, and Past Governor of Rotary International District 9920 Inc.*

In 2015, Rotary and Rotaract raised more than \$42,000 for Cure Kids. 58 Rotary clubs throughout New Zealand raised over \$20,000 for Red Nose Day. Other highlights were the Rotary Club of Devonport donated \$10,000 from their Fine Homes Tour, and the Rotary Club of Dunedin South again held their annual Duck Race that contributed \$5,000. Other Rotary family involvement included the Rotaract Club of Botany Manukau’s “The Life Sabers” team of Margaret Lu and Brendan Vercoelen who raised \$7,200 and enjoyed the \$10 Queenstown Challenge.



“In 2015 it was again a privilege to be a Cure Kids partner. As part of our social responsibility programme we look for a charity with a national reach & one that allows our staff and customers to make a contribution to a fantastic and worthy cause.

The goal of making a life-saving difference for Kiwi kids through medical research is not a short-term goal but a long-term vision that will benefit generations. Mico has been proud to be associated with that vision and goal, standing alongside Cure Kids as a Key Partner.” *Bryn Harrison, General Manager*

Mico became a Key Partner of Cure Kids in 2005 and has supported Cure Kids through fundraising activities with staff, customers and suppliers across their branches nationwide.



# FIJI

## FIJI ISLANDS RHEUMATIC HEART DISEASE CONTROL AND PREVENTION PROJECT

In June 2014, a four-year 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, 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 as a result of joint funding provided through Cure Kids' partnership with Accor Hotels and MFAT's New Zealand Partnerships for International Development Fund. FIJI Water Foundation generously provided funding for echocardiography machines which are critical to the delivery of the project. We are grateful for their support, and the support of our project delivery partners.

### 2015 HIGHLIGHTS:

- The programme is formally launched by the Minister for Health and Medical Services, the Hon. Mr Jone Usamate
- National acute rheumatic fever (ARF) and RHD training package for nurses developed with 343 nurses trained in the ARF and RHD diagnosis and management
- 133 village health workers trained in sore throat and ARF awareness
- RHD Mobile Clinic launched and in use for general awareness and conducting RHD patient echocardiograms
- 90 RHD patients and family members participate in support group activities
- Complete RHD patient audit conducted and updated onto national information system

### What is rheumatic heart disease and how big is the health problem in Fiji?

RHD is a serious heart condition that occurs following an attack of ARF which can occur after a strong immune response to a throat infection caused by a Group A Streptococcus ('strep throat' infection). If appropriate antibiotic treatment is not administered, inflammation of the heart can cause scarring of the heart valves resulting in significant morbidity and possible death. In Fiji it is common for children to present to clinical services

late – already with symptomatic RHD – which means they are often too late for adequate treatment. RHD is a significant health problem in Fiji, with the Pacific region having one of the highest reported RHD incidences in the world. Echocardiography-confirmed RHD prevalence in Fijian children, aged 5-14 years, is 35.4 per 1,000 which equates to approximately one child in every classroom living with RHD. In Fiji, at least 60 deaths a year are attributed to RHD.

### What is the project aiming to accomplish?

The goal is to expand and strengthen the existing Fiji Rheumatic Heart Disease Control Programme to include developing new models of ARF/RHD care and prevention with the aim of reducing RHD related morbidity and mortality. Fundamental to Project outputs is an effective national co-ordination structure for the Fiji RHD Control Programme (Fiji MOH). Increasing capacity at this level will provide a governance model that can continue beyond the life of the Project.

### Output 1: Register-based secondary prevention programme operational including quality improvement processes

- Scoping and implementation of national web-based register system
- Develop a national co-ordination model and provide training
- Explore system level barriers to improve patient adherence and implement interventions/new models based on findings
- Develop and deliver a Data Management plan to include:
  - Data quality monitoring
  - Case ascertainment
  - Scoping integration into national clinical and public health information system

### Output 2: Best practice guidelines for clinical care for ARF/RHD implemented and monitored against benchmarks

- Patient and health care worker focus to identify current deficiencies and barriers to improved care
- Evaluation of health care system barriers to delivery of effective clinical care
- Establishment of benchmarks and best practice monitoring

### Output 3: Model for early detection of ARF/RHD cases developed and implemented nationally

- Determine system level implications of national echocardiographic screening programme, to inform the development of national case-detection programme
- Follow-up and evaluation of the people already screened via echo ultrasound in Fiji with a focus on clinical outcomes and experiences
- Determine efficacy of school-based, nurse-led echo screening
- Workforce development and training (competency development and maintenance) for sonographers, doctors, and nurses and other health professionals in the use of echo
- Implementation of a national case-detection programme

### Output 4: Primary prevention guidelines developed and implemented including health promotion

- Development and implementation of primary prevention guidelines for health care professionals
- Baseline evaluation of public awareness of ARF/RHD
- Development and implementation of a health promotion strategy







# TRUSTS, FOUNDATIONS AND BEQUESTS

WE ARE GRATEFUL FOR THE GENEROUS SUPPORT PROVIDED BY THE FOLLOWING TRUSTS AND FOUNDATIONS FOR 2015

- THE HUGH GREEN FOUNDATION  
-----
- DRAGON COMMUNITY TRUST LTD  
-----
- PELORUS TRUST  
-----
- TRUSTS COMMUNITY FOUNDATION  
-----
- DUKE FAMILY TRUST  
-----
- ENDEAVOUR COMMUNITY FOUNDATION  
-----
- FOUR WINDS FOUNDATION  
-----
- MT WELLINGTON FOUNDATION  
-----
- INFINITY FOUNDATION  
-----
- WHANGANUI FOUNDATION  
-----
- THE TRINITY FOUNDATION LTD  
-----
- TAIWANESE BUSINESS ASSOCIATION  
-----
- JAMES SEARLE SAY FOUNDATION  
-----
- DUO TRUST  
-----

## PERPETUAL GUARDIAN

- THE ALICE AND STAN FLAVELL TRUST  
-----
- THE TED AND MOLLIE CARR ENDOWMENT FUND  
-----
- T.M. HOSKING CHARITABLE TRUST  
-----
- KD KIRKBY CHARITABLE TRUST  
-----
- EM & MH STICHBURY CHARITABLE TRUST  
-----
- GEORGE SEVICKE JONES ESTATE  
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## HIGHLIGHTS

Cure Kids are fortunate every year to be the recipients of overwhelming support from a number of different trusts and foundations.

We would like to highlight just a few of the significant grants we received.

For the second year in a row, the Ted and Mollie Carr Endowment Fund has generously supported research into finding causative genes in childhood epilepsy. In 2015, a grant from the trust has enabled the employment of a research assistant to predominantly recruit and investigate individuals and families living with epilepsy in Auckland.

The Auckland recruitment is on the back of Associate Professor Lynette Sadleir's work studying children and families in Wellington with epilepsy. The success she and her team have had in identifying and diagnosing specific types of epilepsy has led to better treatment paths and ultimately will lead to improved long-term outcomes.

The T.M. Hosking Trust has, for the second time in three years, provided Cure Kids with funding to support the investigation of families who have lost a loved one to an inherited heart condition. The testing can provide families with a cause of death, as well as the risk associated with other family members, which can be incredibly assuring for these families.

We would also like to express our deepest gratitude to three Perpetual Guardian Trusts who helped bring about a new initiative finding interventions into child health conditions associated with deprivation. The support of Perpetual Guardian allowed four interventions to be funded which are profiled in this annual report (page 26).



**THANK YOU**  
TO OUR GENEROUS DONORS

CURE KIDS VENTURES

# INVESTMENT UPDATE / OVERVIEW



MAXINE SIMMONS,  
CEO CURE KIDS VENTURES

Cure Kids Ventures (CKV) is an \$8 million seed investment fund. CKV invests alongside the New Zealand Government’s Venture Investment Fund (NZVIF) as an approved partner in its Seed Co-Investment Programme. The investment mandate is to invest in new or early establishment phase healthcare businesses that have products or services with potential to improve child health. Investing since 2008, CKV now has a portfolio of 13 investee companies at different stages of development.

PORTFOLIO PERFORMANCE IN 2015

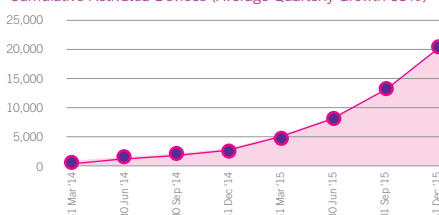
A maturing portfolio of companies with a (yet to be realised) gain of 27%.

HIGHLIGHTING AN EXPANSION STAGE CKV PORTFOLIO COMPANY; ADHERIUM

A company name change from Nexus6 to Adherium during the year and 2015 proved to be an especially big year for this portfolio company. Adherium designs and manufactures medical device solutions for monitoring and improving adherence to prescribed medication. Founded by CEO, Garth Sutherland in 2001, the business signed a major global supply and development agreement with multinational pharmaceutical company AstraZeneca in July 2015. This was the first agreement of its type, linking a digital health technology with a major respiratory medication on a commercial scale.

A successful listing on the Australian Stock Exchange followed in late August with A\$35m in additional capital raised to provide the business with funds to rapidly scale. A significant milestone for this Auckland based company which is growing rapidly as illustrated by the number of Smartinhaler™ devices now being activated.

THE EXPANDING REACH OF THE SMARTINHALER™ PLATFORM  
Cumulative Activated Devices (Average Quarterly Growth 59%)



THE CKV PORTFOLIO NOW INCLUDES THE FOLLOWING COMPANIES:

ADHERIUM (previously Nexus6)	Smart inhaler monitoring for better control of asthma
AROA BIOSURGERY (previously Mesynthes)	Regenerative wound healing technology
BREATHE EASY	Inhaled therapy for Cystic Fibrosis
IM-ABLE	Computerised rehabilitation for neurological conditions
LIVING CELL TECHNOLOGIES	Cell encapsulation technology
NUTRA-P INVESTMENTS	Orally dosed botanical treatment for eczema
PHOTONZ	Production of omega-3 by fermentation of algae
PICTOR	Diagnostic testing system - multiple tests from a drop of blood
PODSCAPE HOLDINGS	Cyber-safe confidence re-affirming games for children
REX BIONICS	Hands-free, self-supporting robotic walking device
SYFT TECHNOLOGIES	Instrument for measuring volatile chemicals
VERIPHI (previously Klein Medical)	Verification device - dose & type of IV medication being administered
ZYGEN	Instrument for DNA extraction and identification



# CURE KIDS GOVERNANCE

## CURE KIDS MEMBERS

**BERYL ROBINSON**  
ROTARY IN NEW ZEALAND

**TONY FORTUNE**  
ROTARY IN NEW ZEALAND

**CHARLES WILSON**  
ROTARY IN NEW ZEALAND

**DR DAVID NEWMAN**  
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 in New Zealand, continuing its proud association and support of Cure Kids. The fourth Member is the current President or nominee of the Paediatric Society of New Zealand, while the fifth member is a South Island-based nominee from the Board of Paediatricians of the Royal Australasian College of Physicians.

## CURE KIDS BOARD

**ROY AUSTIN**  
BCom, CA. CHAIRMAN, CURE KIDS CONSULTANT TO NORTHINGTON PARTNERS, AUCKLAND

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

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

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

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

**GEOFF FLETCHER**  
COMPANY DIRECTOR, FORMER MANAGING DIRECTOR OF BMW GROUP NEW ZEALAND

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

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.

## CURE KIDS BOARD ADVISORS

**PROFESSOR STEPHEN ROBERTSON**  
CURE KIDS CHAIR OF PAEDIATRIC GENETICS

**PROFESSOR ED MITCHELL**  
CURE KIDS CHAIR OF CHILD HEALTH RESEARCH

**PROFESSOR BRIAN DARLOW**  
CURE KIDS CHAIR OF PAEDIATRIC RESEARCH

**PROFESSOR SALLY MERRY**  
CURE KIDS DUKE FAMILY CHAIR OF CHILD AND ADOLESCENT MENTAL HEALTH

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

## CURE KIDS MEDICAL & SCIENTIFIC ADVISORY COMMITTEE

**DR BRUCE SCOGGINS (CHAIR)**  
MAgrSc (Cant), PhD (MELBOURNE) CONSULTANT, AUCKLAND

**PROFESSOR BRIAN DARLOW**  
MA, MB, BChur, MD (CAMBRIDGE), FRCP, FRACP, FRCPCH, CHRISTCHURCH SCHOOL OF MEDICINE AND HEALTH SCIENCES. UNIVERSITY OF OTAGO, CHRISTCHURCH

**PROFESSOR BOB ELLIOTT**  
MBBS MD FRACP CNZM. LCT GLOBAL. AUCKLAND

**PROFESSOR ALISTAIR GUNN**  
MBChB, FRACP, PhD FRSNZ. DEPARTMENT OF PHYSIOLOGY, UNIVERSITY OF AUCKLAND

**PROFESSOR ED MITCHELL**  
BSc, MB BS, DCH, FRACP, FRCPCH, DSc (MED), FRSNZ. DEPARTMENT OF PAEDIATRICS, SCHOOL OF MEDICINE, UNIVERSITY OF AUCKLAND

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

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

**PROFESSOR SALLY MERRY**  
MBChB, FRANZCP, MD. DEPARTMENT OF PSYCHOLOGICAL MEDICINE, UNIVERSITY OF AUCKLAND

The members of the Medical & Scientific Advisory Committee (M&SAC) provide the Board with research grants management advice. They draw on their considerable experience to assess applications on their ethical and scientific merit and to conduct research into the diagnosis, prevention and treatment of conditions affecting children.

Special thanks to Doctor Bruce Scoggins, Chair of the annual meeting of M&SAC granting round.

Cure Kids is a registered charity CC25350.

# ASSOCIATE PARTNERS

**alexander james**



**COLUMBUS**  
COFFEE



## EVENT AND SUPPORT PARTNERS:

AJ HACKET - BUNGY, AJ PARK, BDO, CADBURY, CUP AND CAKE, DOUGLAS PHARMACEUTICALS, EVENT DYNAMICS, EY, FONTERRA, GIBBSTON VALLEY WINERY, IMAGETEXT, JB WERE, KJET QUEENSTOWN, LIBBY AND BEN, MARS, MICROSOFT, NEW BALANCE, NZ SKI, OVERLAND, OVER THE TOP, PROVOKE, RADIATION, RICOH, RUSSELL MCVEAGH SKYLINE, THETA, THE HILLS, TOLL, WALKER WAYLAND







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Victoria St West  
Auckland 1142

Cure Kids is a registered charity CC25350

 [curekids.org.nz](http://curekids.org.nz)

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

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

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



Torrance lives with aortic stenosis, Isabella lives with cystic fibrosis,  
Finn lives with hypoplastic right heart and Addison lives with a heart defect.