

Discover. Prevent. Cure

2017



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**TELETHON  
KIDS  
INSTITUTE**  
Discover. Prevent. Cure.

COVER IMAGE:  
FINLAY, WHO HAS BEEN TREATED  
FOR CANCER, WITH HIS SIBLINGS  
HARRISON AND MILLA

**KIDS** are at the   
of everything we do

Our special thanks to those who have contributed to this report: Tammy Gibbs, Elizabeth Chester, Caroline Wise, Marnie McKimmie, Stephanie Pegler, Daile Pepper, Jasmine Raisbeck, Stacey Campbell, Tamara Hunter, Jean Perkins, Ashley Schoof, Amy Sewell, Tony McDonough, and the researchers and families whose stories we have shared.



## MESSAGE FROM OUR DIRECTOR

### What is impact?

For us at Telethon Kids, it's about how we make a difference for kids and families.

It's about how our research can be used to influence policy, alter practice, and have an effect on what is known about a health or development issue. What can be done to more effectively intervene, treat, cure or even prevent?

We know that too many kids and families are facing tough battles against disease, disability and disadvantage.

Conditions like cancer, asthma, autism, mental health problems, diabetes, hearing loss and infectious diseases.

Our IMPACT Report highlights some of the research that is making a difference right now, those projects that are on their way to having a direct impact on kids and families, and research that is

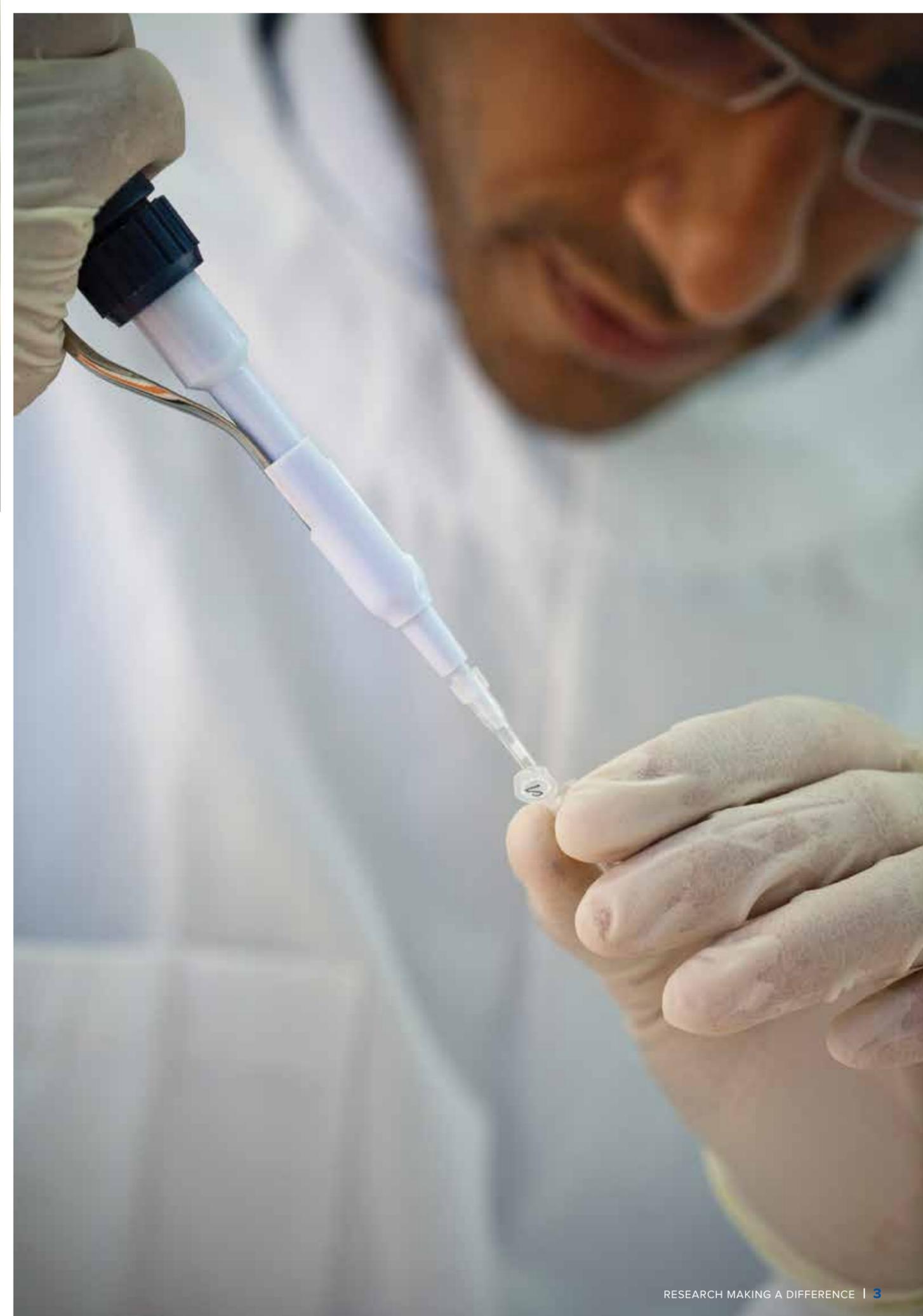
changing the way we think about these complex problems.

We also highlight some of the collaborative partnerships - with community, service providers, government, industry - that are helping us to have an impact locally, nationally and internationally.

We're having a direct impact on child health and wellbeing and that's something that makes all of us at Telethon Kids proud.

To find out more about the research that's making a difference right now, visit our website at [telethonkids.org.au](http://telethonkids.org.au)

Jonathan Carapetis  
Director



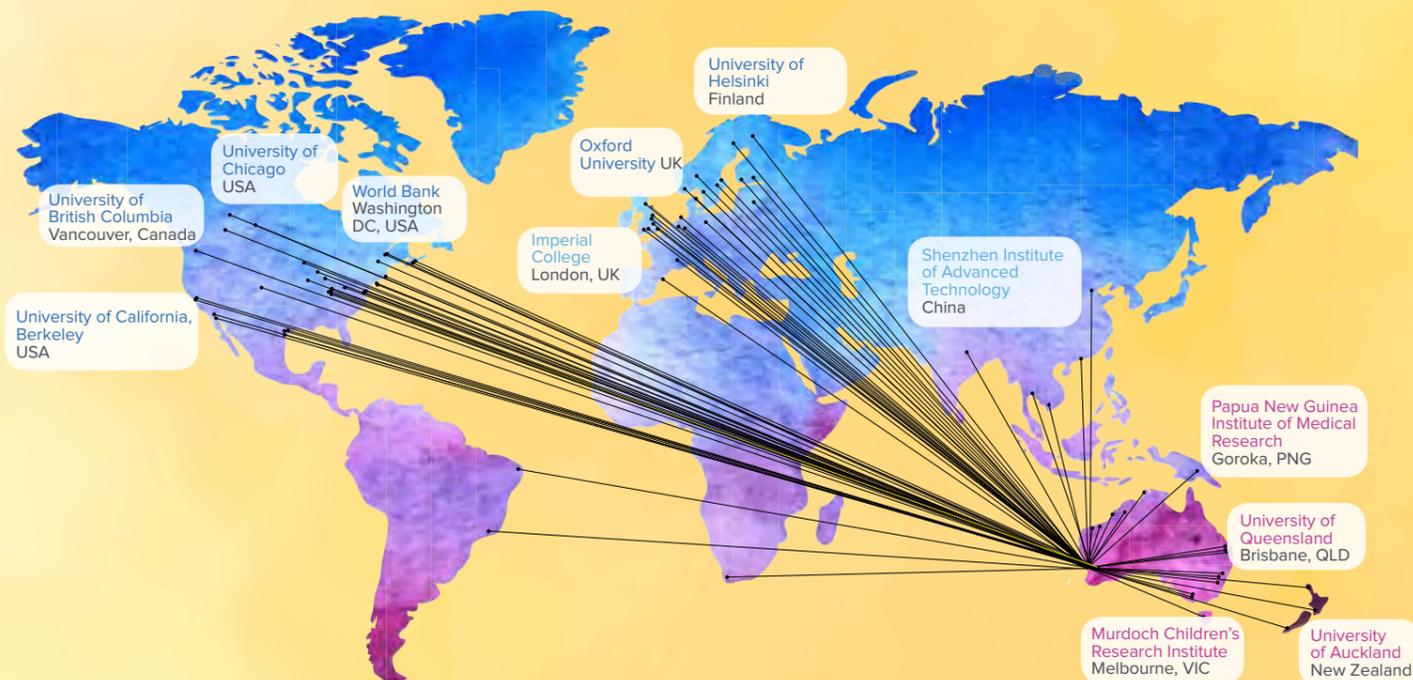


# OUR RESEARCH AT A GLANCE

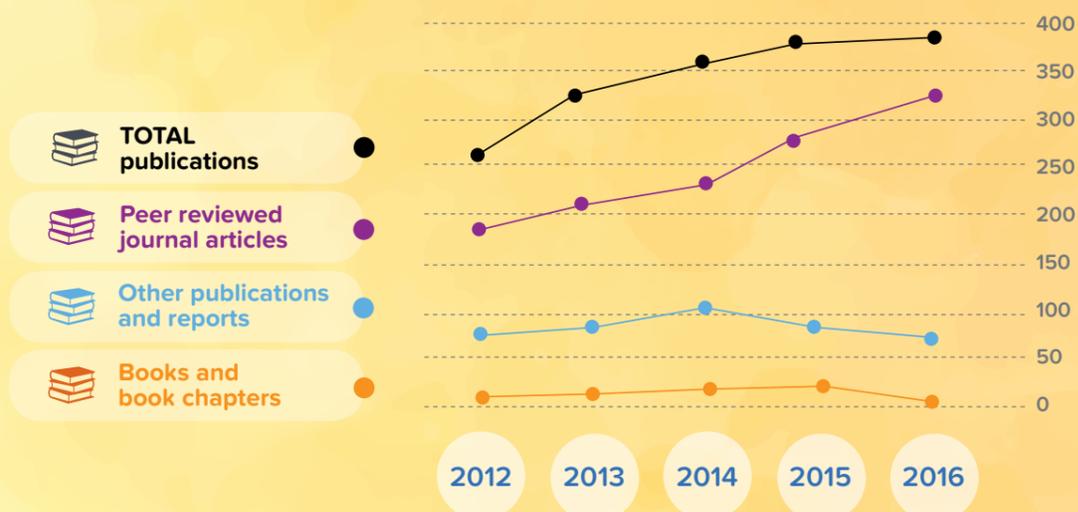
ADVANCING KNOWLEDGE

Our researchers are contributing significantly to the global bank of information on child health and wellbeing

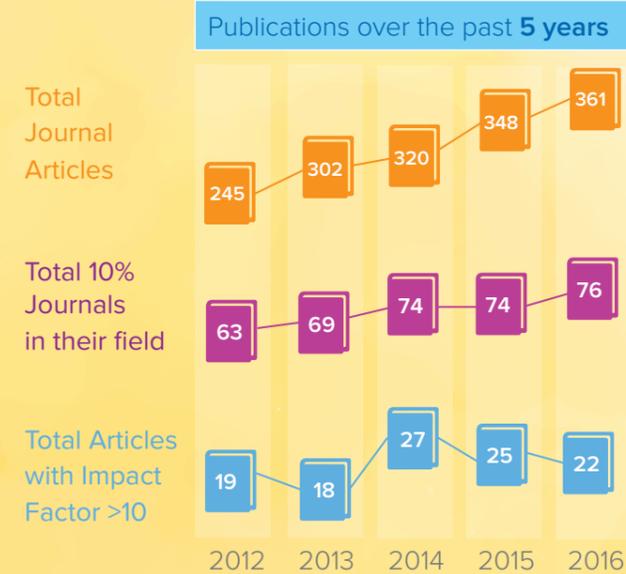
We are **ACTIVELY COLLABORATING** with colleagues and institutions around the world



Our knowledge benefits **CHILD HEALTH AND WELLBEING RESEARCHERS** worldwide

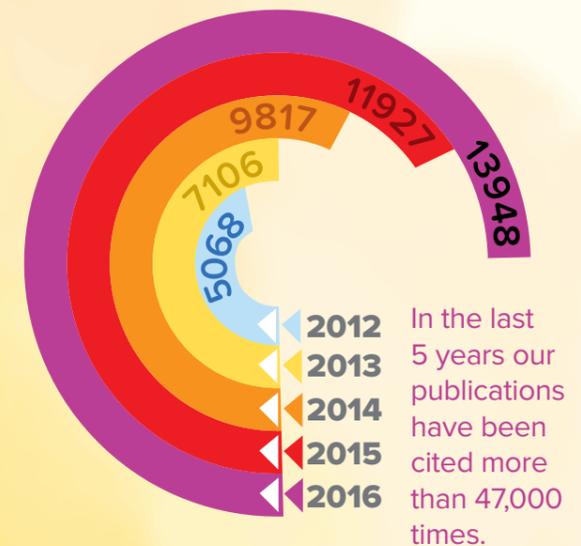


WE PUBLISH in the most **INFLUENTIAL JOURNALS** around the world



**SCIENTISTS AROUND THE WORLD** use our work on **child health and wellbeing** to advance their **knowledge and research**

Number of Citations



Citation refers to a quotation or reference in a scientific article written by other researchers around the world

Our researchers are regarded as **INTERNATIONAL LEADERS IN THEIR FIELD**



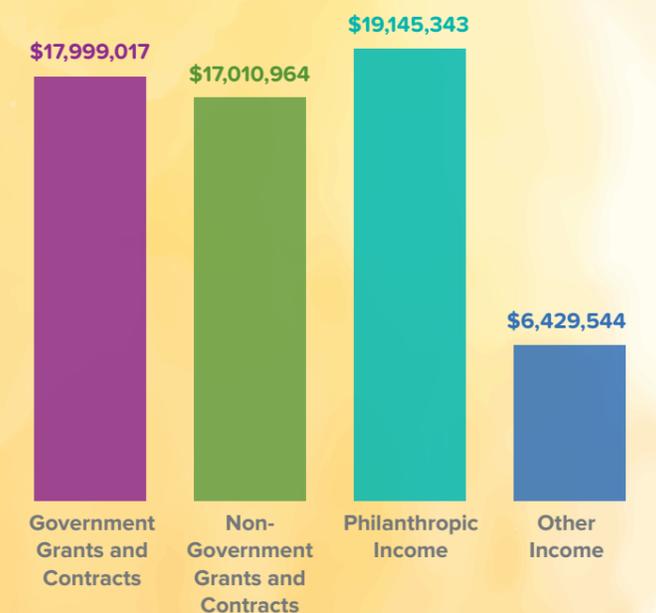
**10** of our **RESEARCHERS** have a **Scopus H-index GREATER than 40**

\*H-index of 40 is proposed to characterise outstanding scientists likely to be found only at the top universities or major research laboratories (Hirsch 2005 PNAS)

We received over

**\$60.5 million**

in funding to carry out our research in 2016



We are working with the most relevant people around the world to ensure we make a difference for kids and families

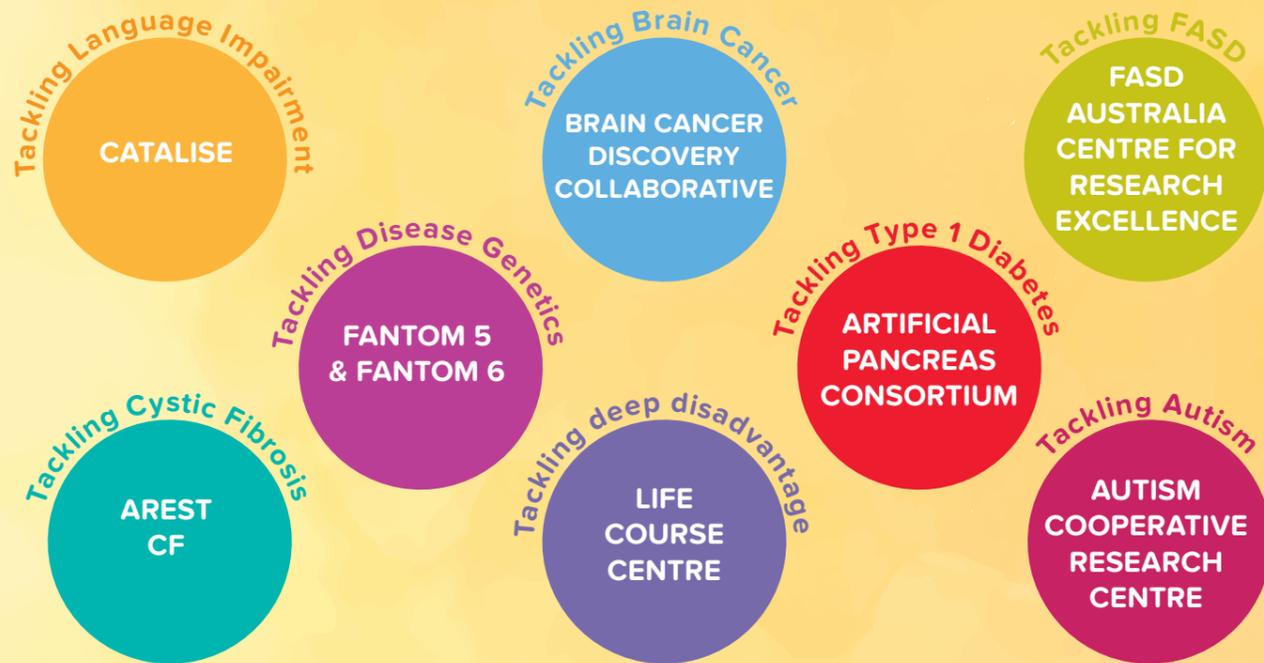
THE COMMUNITY is involved in INFORMING THE WORK that we do, ensuring it remains relevant and translatable

At Telethon Kids we have:



We join with others to tackle the biggest problems

Our RESEARCHERS were involved in more than **50** national and international research networks, including:

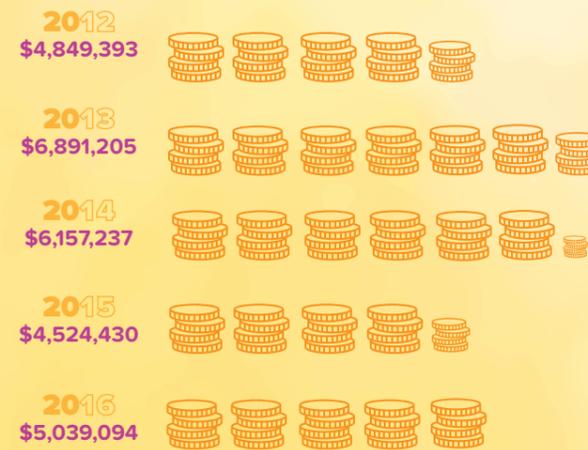


Our research has **direct commercial relevance**, which we protect to ensure that the inventions have the potential to make it to the clinic

**23** active patents



We work closely with government to ensure OUR RESEARCH is able to have an **IMPACT** on **GOVERNMENT POLICY**



We have received over **\$27 million** in government contracts between **2012-2016**

**24** reports provided to government on topics such as mental health, fetal alcohol spectrum disorder and early years

Our clinical research includes improving the diagnosis of diseases and testing new therapies and devices TO ENSURE children receive the **BEST TREATMENT** for their conditions



**UNDERSTANDING HUMAN DEVELOPMENT & DISEASE**

- Infections & Vaccines
- Ear Disease
- Language Development
- Newborn Encephalopathy
- Obesity
- Nutrition
- Hypospadias
- Asthma

**PREVENTION**

- Vaccines including:
  - Influenza
  - Hib
  - Meningococcal
  - Pneumococcal
- Allergic Disease
- Asthma

**THERAPY**

- Asthma
- Bronchiolitis
- Dermatitis
- Cystic Fibrosis
- Autism Spectrum Disorders
- Gastroenteritis
- Mental Health
- Infectious Diseases
- Allergy
- Cancer

**DEVICES**

- Diabetes
- Obesity
- Autism

**DIAGNOSIS**

- Cystic Fibrosis
- Biomarkers of Obesity
- Diabetes

We are committed to training the next generation of researchers and ensuring we build collaborative networks to support child health research in Western Australia and beyond

Students from around Australia choose to **STUDY** at the Telethon Kids Institute

 In 2016, we had **159** students

**13** Honours **17** Masters **32** MD **97** PhD

Enrolled through:

- 3** Australia National University
- 4** Charles Darwin University
- 11** Curtin University
- 5** Edith Cowan University
- 6** Murdoch University
- 4** University of Notre Dame Australia
- 2** University of Adelaide
- 1** University of Melbourne
- 1** University of Queensland
- 1** University of New South Wales
- 121** University of Western Australia

Over the past 5 years

 **61** PhD STUDENTS have successfully obtained their DOCTORATE

Our researchers are actively involved in local, national and international committees, boards, councils and advisory groups. Some of these are about **Sharing Knowledge and Expertise** to build research capacity, and others focus on **Influencing Change** to ensure research improves the lives of our children and families



People actively involved in our RESEARCH FOCUS AREAS





## PHILANTHROPY GIVES LIFE TO LIFE-CHANGING DISCOVERIES

For many years, Telethon Kids Institute has been fortunate to work alongside its philanthropists who, as individuals, families, foundations, companies or civic groups have pursued what is most highly valued in any community: the health, safety, and wellbeing of its children. It is therefore appropriate in a publication reflective of the Institute's research impact to acknowledge the crucial role of philanthropy.

We must, for example, acknowledge the long-standing commitment of Channel 7 Telethon, from whom we take our name. In the early years of the Institute, Telethon trustees clearly took note of several issues: that the research environment in Australia was underfunded when compared to government funding of research in other developed countries; that child health research in particular was under-supported; and that it was important to all Western Australians to have a first-class, independent child health research institute, one that worked with the State's universities, hospitals, community health services and policymakers for the benefit of children.

Telethon also noted that as a fully independent research entity, the Institute would not have the range of resources that universities do to ensure its research was fully funded and sustainable. Nor did the Institute have a foundation, as do hospitals and museums, established expressly for the purpose of financial assistance. With this understanding, Telethon set out to support the Institute as one of its principal beneficiaries.

Telethon's formula for support is simple. Each year, the Institute reports to Telethon on which research programs have been awarded funding by the National Health and Medical Research Council, the Australian Research Council, and other competitive funding bodies. Tallying the awards,

the Institute generally finds that the total cost of research has been underfunded by about 40 percent. Through a formal application process, the Institute then asks Telethon trustees to help offset the underfunded amount. Depending on the success of its yearly fundraising effort and the requirements of its many additional community beneficiaries, Telethon then makes an allocation to the Institute.



*No donation is without impact. This impact is felt by children, their families, and the community*

This commitment from Telethon to help the Institute meet the total cost of research is the Institute's lifeblood. Without this annual commitment, the Institute would not have made discoveries in childhood cancer, autism, cystic fibrosis, asthma, allergies, vaccines, immunology, psychosocial wellbeing, fetal alcohol spectrum disorders, rare diseases, and the list goes on. Without the support of Telethon, the Institute would not be here today.

### That's impact.

The Institute must also acknowledge BHP. In 2013, after consulting widely with

researchers, health care practitioners, parents in the community, universities, Government, and other community partners, the Institute released its five-year strategic plan. This plan called for a renewed commitment to proactively ensure that research was being translated into knowledge the community could use to benefit children, into clinical care through improved treatments or cures, and into public policy to safeguard vulnerable children while providing them with opportunities to fulfil their potential.

The strategic plan was evolutionary. The Institute would continue to do everything it had been doing, though at a higher order of magnitude with improved structures, a consolidation of focus on outcomes, better research platforms, more efficient ways of working, and with a rekindled commitment to multi-disciplinarity and collaboration with all partners. The Institute sought to become a model child health research institute on the world stage for the benefit of WA's children and beyond.

This ambition would require substantial investment over a five-year period. Fortunately, in 2014 BHP agreed to become the Institute's 'strategy enabling partner' – and the impact has been transformational.

With BHP's support, the Institute has been able to retain and recruit world-leading scientists and a top professional services



cadre; make improvements in such research platforms as bioinformatics, biostatistics, pre-clinical and clinical trials support, bioresources, and data linkage; refresh laboratory equipment; and allow researchers to spend more time on research by providing a service to help them with complex grant-writing processes.

The Institute has also been able to improve its ICT infrastructure and financial processes for managing grants, become more cost efficient, and build a stronger brand that attracts collaborative links worldwide while positioning itself more prominently within the community it serves.

BHP's vision extends beyond transforming the Institute into an ideal research environment for present and future child health research. It also incorporates an initiative to encourage bold, paradigm-shifting research by the Institute's researchers with a 'Blue Sky' program, and an initiative to make fetal alcohol spectrum disorders history in the Pilbara.

### That, too, is impact.

It would be a straightforward exercise, although running into volumes, to catalogue the impact of the Institute's other benefactors. Like the McCusker Foundation and its support of computational biology, a clinical research fellowship, and an autism project. Like the Perron Foundation, and its support of scholarships as well as of the Institute's world-first Centre for Personalised Medicine for Children. Like the Children's Leukaemia and Cancer Research Foundation, and its long-standing commitment to the Telethon Kids Cancer Centre.

Like the Minderoo Foundation, too, and its ambitions to change the life course of vulnerable children by improving their early developmental environments. Like Wesfarmers, and its support of what has become one of the world's leading centres in vaccines and infectious diseases. Like Denby Roberts, who has helped the Institute establish a necessary presence in the Kimberley for research in remote communities. Or like research fellowships provided by the Feilman Foundation, the Simon Lee Foundation, the Angela

Wright Bennett Foundation, the John Rothwell Family, and so many others.

There are many donors who make contributions to the Institute, including the Institute's own researchers and staff. Every donor at any level is essential to the whole of what the Institute undertakes daily.



In short, no donation is without impact. This impact is felt by children, their families, and the community. It is the type of impact that motivates the Institute's researchers, all of whom are passionate about their science and what it can do for the health and wellbeing of children. This is of the highest value to them, and the Institute's most remarkable privilege is to be working closely with donors in pursuit of this goal.



**"Somewhere, something incredible is waiting to be known."**

This quote by well-known astronomer Carl Sagan is just as relevant to child health and development research. Just around the corner - in the lab, clinic or office - is an amazing discovery waiting to be uncovered. It's the possibility of a 'Eureka moment' that drives many researchers to do what they do.

But breakthroughs don't happen every day, or even every year. In fact, many researchers will never experience that career-defining moment. However, just as important are the small incremental gains in research - expanding global knowledge of a disease or health issue, confirming or ruling out possible cures, treatments or interventions, adding a piece to the child health puzzle.

Right now at Telethon Kids, our researchers are working hard to discover, prevent and cure. We aren't afraid to ask the big questions or to take on the seemingly impossible, when it comes to the health of children. And we all share a restless curiosity that keeps us looking for answers to the problems facing our kids and families today. We reward and

encourage innovation and high-risk, high-return projects that push the boundaries and everything we do is grounded in solid evidence.

This IMPACT Report highlights some of the research findings that have already been translated into policy or practice, projects that are still in the pipeline and well on their way to making a difference, research that changes the way scientists think about an illness or disease, and those projects that revolve around collaboration to bring the best minds together to effect change.

Our IMPACT Report provides a snapshot of research at Telethon Kids. Find out more about how our researchers are making a difference at [telethonkids.org.au](http://telethonkids.org.au)

<p><b>TRANSLATION</b></p>	<p><b>PARADIGM SHIFT</b></p>	<p><b>IN THE PIPELINE</b></p>	<p><b>COLLABORATING FOR IMPACT</b></p>
<p>This research has been actively translated into policy or practice</p>	<p>This research changes the very way scientists think</p>	<p>This research is in the pipeline towards translation</p>	<p>And this research shows how we work with others to make a difference</p>



**TRANSLATION.**



## ROBOT BABIES INCREASE TEEN PREGNANCY RATES

They have been used in schools across Australia and the world for decades to prevent teenage pregnancy. The trouble is, research by the Telethon Kids Institute shows 'robot' babies don't reduce teen pregnancy – they increase it.

They look and act just like real babies, crying at all hours of the day and night until their needs are met.

These infant simulators or so-called 'robot' babies are given to high school students to take care of as part of an internationally developed teen pregnancy prevention program known as Virtual Infant Parenting (VIP).

Students are tasked with caring for the dolls 24/7 – ignoring them is not really an option. The dolls record how often they are rocked, fed, burped and changed. Students who neglect their dolls are marked poorly.

The theory behind the VIP Program is simple – it is believed by giving young people a taste of the exhausting real-life experience of caring for a newborn, it will discourage them from wanting to have a baby of their own.

It was a theory that made sense to many, including Associate Professor Sally Brinkman, who leads the Child Health Development and Education team at the Telethon Kids Institute. But as a researcher she was concerned there was a lack of scientific evidence to show that such a popular program, run in more than 90 countries across the world, was effective in reducing teen pregnancy.

"Teenagers are a vulnerable group and any intervention-based program targeting

them should always be backed by sound evidence, particularly when dealing with something like teen pregnancy which has potentially lifelong consequences," Associate Professor Brinkman said.



*"I think what we showed was that even the most well intentioned programs can have unexpected consequences,"*

*"And that is why research is so important. Australia has the sixth highest teen pregnancy rate out of 21 OECD countries and we shouldn't be funding programs that contribute to that problem."*

Associate Professor Sally Brinkman

"Tens of thousands of young people were doing this program every year to prevent teen pregnancy, yet there was very little research on whether it actually did what it was supposed to do."

So in 2003, as the VIP program was about to be rolled out in Western Australia, Associate Professor Brinkman saw an opportunity to scientifically evaluate the program's effectiveness. With the support of the Western Australian Metropolitan Health Services and the Education Department, Associate Professor Brinkman developed a randomised control trial to assess a version of the program, which had been adapted for the Australian context.

Nearly 3,000 Western Australian school girls aged 13-15 enrolled in the trial – the largest study of its kind ever conducted on an Infant Simulator-based program. Close to half the students were given a version of the VIP program as the intervention group, while the control group was given the standard health education curriculum.

Researchers were given permission to access the participants' de-identified medical records until they were 20 years of age to determine whether they had experienced a pregnancy.

But in 2007, just four years into what was meant to be a 10-year study, Associate Professor Brinkman noticed an alarming pattern in the preliminary data. Early results were showing that girls who undertook the VIP program were actually more likely to fall pregnant than those who did not do the program.



SARAH JOHNSON AND SVEN SILBURN FROM THE STUDY TEAM  
PHOTO COURTESY THE WEST AUSTRALIAN.

"It was quite a shock," Associate Professor Brinkman said. "We had to check the data again and again. In all honesty, I expected the program to reduce teen pregnancy, or at the very least, not have much of an impact. I didn't expect that the program was actually having the opposite effect to what was intended."

Associate Professor Brinkman immediately asked the health services and schools to pull the pin on the program in WA altogether. They simply could not continue knowing that there was a chance it put young people at greater risk of teenage pregnancy.

The research team continued to follow the girls who had already participated in the program, with their results published in *The Lancet* in 2016. The evidence showed those who did the VIP program had higher rates of pregnancy (17 per cent) compared to those who did

not (11 per cent), a small but statistically significant increase.

They also found 53.8 per cent of the pregnancies in the intervention group ended in termination, compared to 60.1 per cent in the control group, which was not statistically significant but did show the participants who had exposure to the program were more likely to trend towards going through with the pregnancy.

"I think what we showed was that even the most well intentioned programs can have unexpected consequences," Associate Professor Brinkman said. "And that is why research is so important. Australia has the sixth highest teen pregnancy rate out of 21 OECD countries and we shouldn't be funding programs that contribute to that problem."

Associate Professor Brinkman has a theory as to why the VIP program did not work as

intended. She believes a lot of the girls actually found the process rewarding, rather than a 'turn-off'.

"A lot of the girls really seemed to like looking after the dolls, even though they were keeping them up all night," Associate Professor Brinkman said. "They received a lot of attention from their friends and family while they had the dolls and it was something exciting and outside their normal routine."

"Some girls even became so attached to their dolls that they became very upset when they had to hand them back to the school or over to another student. We even needed to bring in a counsellor on some occasions to help girls deal with the separation."

Associate Professor Brinkman's results made international headlines when they were published in *The Lancet* last



year and she hopes many schools have stopped using the dolls as a teen pregnancy prevention tool. But she admits she has heard of schools still using them, despite knowing the results.

"People seem really reluctant to accept the evidence on this one, which is a bit disheartening," Associate Professor Brinkman said.

"I've seen many in the media and in online discussions suggest that the students just need to have the infant simulators for a longer period of time to truly understand the implications of having a baby, which seems odd to me.

"If a drug trial shows that the drug doesn't work, and may

indeed cause harm, people don't turn around and say 'Well they just needed to have more of the drug'. Why is it that for education programs, people have such a strong belief that they must work, despite no evidence to support them?"

Associate Professor Brinkman said these robots may be effective in other contexts such as childcare training or teaching parenting skills, but when it comes to preventing teen pregnancy, her research showed it simply does not work.

The study team included Dr Bret Hart, Prof Sven Silburn, Prof Jim Codde, Dr Judy Stratton, Dr Sarah Johnson,

Dr Murthy Mittinty, Ms Heidi Hutton and Ms Sarah Baxendale.

#### What's next?

Associate Professor Brinkman plans to continue to promote her research to an international audience to encourage schools still using the program to drop it, and to discourage others from taking it up. She is particularly worried about the uptake of the program in developing countries, where teenage mothers may not have access to support.



## MIDWIVES JOIN FIGHT AGAINST FASD

Strong support and high demand has led to the early release of an Institute-developed learning package designed to empower midwives to tackle Fetal Alcohol Spectrum Disorder by warning against and screening for alcohol use in pregnancy.

Circulated State-wide by the WA Department of Health, the modules are aimed at upskilling midwives in using the AUDIT-C alcohol risk screening tool and ensuring it is conducted three times as a routine part of pregnancy care, together with brief educational interventions.

"The reason we ask midwives to do that is, although a woman might start out with the intention of not drinking in pregnancy, this may change over the course of time," senior research fellow Dr Tracy Reibel said.



DR TRACY REIBEL

"Alcohol is a cheap, readily available drug and may be used by women if their life circumstances change or if they don't understand the implications of alcohol use in pregnancy."

"It is also really important that special occasion drinking is recorded – such as a few glasses of champagne at a wedding or birthday."

"If down the track there are concerns regarding a child's developmental delay and the question is asked 'Was there any alcohol consumption in pregnancy?', the woman may have forgotten by the time her child is three, six or 12. But if there is an AUDIT-C score in her medical records, we can either include or dismiss prenatal alcohol exposure as a possible cause."

#### What's next?

Modifying the learning package for use in the Northern Territory and advocacy to make the package available in other jurisdictions.

#### What is AUDIT-C?

AUDIT-C is a three question alcohol risk screening tool suitable for use with pregnant women. Each question is scored relevant to the answer given, leading to a total score. The total score indicates whether a woman's alcohol use risk profile is low, medium, or high.

It is recommended the AUDIT-C tool is used three times during pregnancy to identify any changes in a woman's use of alcohol. Importantly, AUDIT-C is a means of starting a conversation with a woman about the impact of alcohol on baby's development.

## DAMAGE FROM ALCOHOL

- ▶ **Fetal Alcohol Spectrum Disorder (FASD)** includes neurodevelopmental and/or physiological damage from a child's exposure to alcohol during pregnancy. Disabilities are lifelong and may not be seen at birth.
- ▶ May result in **delayed development, social, behavioural and learning problems**. These can lead to **poor school performance, unemployment, substance abuse, mental health problems and early engagement with the justice system**.
- ▶ **The placenta cannot keep harmful substances such as alcohol away from the fetus**. The National Health and Medical Research Council of Australia advises women who are planning a pregnancy, are pregnant or breastfeeding that **'no alcohol is the safest choice'**.



## NEW NATIONAL TOOL TO HELP IMPROVE FASD DIAGNOSIS

Expected to shine a light on hidden harm from alcohol use during pregnancy, Australia's first national Fetal Alcohol Spectrum Disorder diagnostic tool has been developed by the Institute in partnership with the University of Sydney.

Commissioned by the Commonwealth Department of Health, the new Fetal Alcohol Spectrum Disorder (FASD) diagnostic tool will now be used and relied on by health professionals across the country.

The tool is the result of seven years of hard work – surveying clinicians, researchers, parents, carers and community and advocacy groups, conducting extensive literature reviews and analysing every FASD diagnostic tool in use around the globe.

It provides clear and straightforward comprehensive directions on how to test for and diagnose brain damage due to exposure to alcohol before birth – including when there are no obvious related physical abnormalities.

Lead researcher Professor Carol Bower, of the Institute's Alcohol and Pregnancy & FASD Research team, says the new diagnostic instrument, guide and accompanying online training modules will provide the foundation to improve rates of diagnoses of FASD in Australia.

And by ensuring earlier and accurate diagnosis, it will enable earlier intervention and

management, resulting in better tailoring of services, better outcomes and improved quality of life.

"Harmonised with Canada's new FASD guideline, the Australian diagnostic instrument and guide will provide the evidence base for prevention, diagnosis, management and advocacy for improved services and supports," she said.

"It will give clinicians the confidence to consider a diagnosis of FASD, the knowledge to make the diagnosis, and the information they need to manage or refer an individual and family and also to take steps to prevent FASD."

Professor Bower said previous research had indicated that what had been picked up in Australia in recent years was barely the 'tip of the iceberg' of the damage done when alcohol crosses the placenta and harms the unborn child.

"I think because clinicians have not always been thinking about FASD as a potential diagnosis, cases have been missed," she said.

"These are the kids who would have had quite serious problems

from prenatal alcohol exposure and might have been diagnosed with intellectual disability, ADHD, autism or learning disabilities. Sometimes they were just thought to be really naughty kids."

The new Australian diagnostic instrument and guide is now being disseminated to paediatricians, medical professional colleges, State and Commonwealth health departments, parent and carer support and advocacy groups and the Australian Medical Association.

At the request of consumers, included in the guide is a consent form and support information for before and after diagnosis. The diagnostic teams are encouraged to prepare a report that lists the individual's strengths and difficulties and contains a management plan that builds on those strengths.

"Parents have told us that it was such a relief to finally get a FASD diagnosis because then they knew that it was not that he or she won't do what they ask, it's that he or she can't," she said. "And that can often reframe how a child is managed."



PROFESSOR CAROL BOWER

### What's next?

Evaluate the dissemination and effectiveness of the instrument and guide and use of the training modules. The Commonwealth Department of Health has just called for grants to provide FASD diagnostic services and models of care in Australia, utilising the Australian FASD diagnostic instrument.

## DIAGNOSING FASD IN AUSTRALIA?

The new Australian FASD diagnostic instrument has adopted the concept that Fetal Alcohol Spectrum Disorder be used as a diagnostic term. For a diagnosis of FASD, an individual must have prenatal alcohol exposure and severe neurodevelopmental impairment in at least three of ten specified domains of central nervous system structure or function.

## DAMAGE FROM ALCOHOL

Fetal Alcohol Spectrum Disorder (FASD) is brain damage from an unborn child's exposure to alcohol during pregnancy. The disabilities are lifelong and may not be seen at birth.

FASD results in delayed development, social, behavioural and learning problems. These can lead to poor school performance, unemployment, substance abuse, mental health problems and early engagement with the justice system.

The placenta cannot keep harmful substances such as alcohol away from the fetus.

The National Health and Medical Research Council of Australia advises that for women who are planning a pregnancy, pregnant or breastfeeding 'no alcohol is the safest choice'.



## VACCINE SURVEILLANCE BRINGS SAFETY REASSURANCE

In 2010, a large number of children experienced febrile convulsions after receiving the FluVax influenza vaccination and many parents began to question its safety.

While the FluVax vaccine was quickly recalled for use in children, these concerns played a major role in the significant drop in children receiving their annual influenza vaccine.

Throughout 2008-2009, almost half of Perth's children received the FluVax vaccine as recommended by the Department of Health, yet by 2010-2014, vaccination numbers had dropped to less than 10 per cent.

To restore confidence throughout the community, a national initiative called AusVaxSafety was developed by researchers, clinicians and public health officials to monitor vaccine safety in Australia.

According to Dr Chris Blyth, Honorary Research Fellow at the Telethon Kids Institute, the research program was initially guided by surveys conducted in WA general practice and immunisation clinics in 2010.

These surveys asked parents whether their child developed any side effects in the three days following their influenza vaccination.

"The surveys were progressively implemented nationwide, utilising a tool developed in WA general practice by Dr Alan Leeb and Ian Peters called SmartVax to send SMS messages directly to parents' smart phones," Dr Blyth said.

"AusVaxSafety checks with parents to see if there have been

any adverse reactions to the vaccine. This approach ensures that side effects can be readily identified and safety signals rapidly flagged.

"The data is analysed weekly by Telethon Kids Institute researchers and fed back both to public health officials and the community."

Between 4 April 2016 and 4 September 2016, the families of 3,745 Australian children receiving the flu vaccine completed the surveys. The results showed that 9.3 per cent of participants experienced side effects from the vaccine, but the vast majority were mild and lasted 1-2 days, such as a sore arm or fever.

Only 1.1 per cent attended their GP or Emergency Department, and this data was used to show that the influenza vaccine was safe for use in young children. Surveys are being sent to children and adults in 2017 in all states and territories.

"AusVaxSafety has demonstrated to parents that we are committed to ensuring the safety of the vaccines recommended for children in Australia. The surveillance system has now broadened to include the

Pertussis (whooping cough) and Zoster vaccines, and gives parents the confidence to protect their family from life-threatening illnesses," Dr Blyth said.



MEMBERS OF THE TELETHON KIDS AUSVAXSAFETY TEAM CHRIS BLYTH, PARVEEN FATHIMA, PETER JACOBY AND TOM SNELLING

### What's next?

Following initial programs with childhood vaccines and shingles vaccine in the elderly, AusVaxSafety is now moving to monitor all vaccines in all ages. With 110 sentinel surveillance sites in all states and territories and funding from the Commonwealth Government, AusVaxSafety is uniquely placed to become the whole-of-life vaccine safety surveillance program in Australia.



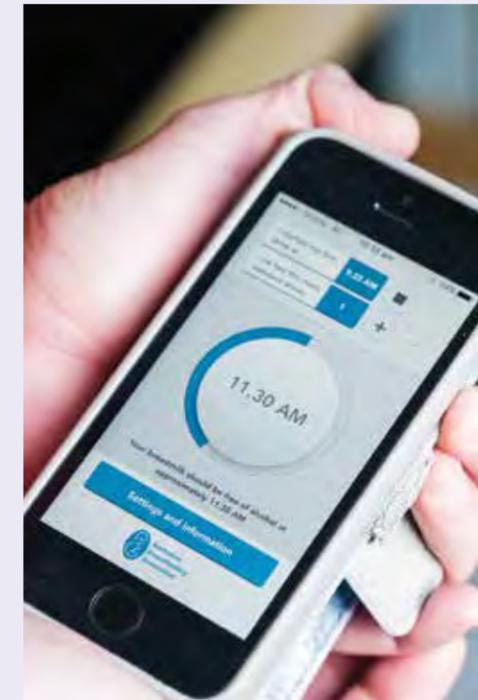
## MOTHERS LEARNING TO FEEDSAFE

A new phone app developed by Telethon Kids Institute researcher Dr Roslyn Giglia is helping mothers change the way they approach alcohol and breastfeeding.

Committed to ensuring the latest research gets into the hands of those who need it most, Dr Roslyn Giglia reworked her findings on alcohol usage, protecting breastfeeding and keeping babies safe into an easy-to-use free phone app that has changed the habits of mothers in Australia and New Zealand.

Developed in partnership with the Australian Breastfeeding Association and Reach Health Promotion Innovations, and supported by funding from Healthway, the Feedsafe app helps to determine when breastmilk is alcohol-free and limits interference with let-down and milk supply.

Released in 2014, its popularity exceeded all expectations and it was the second most downloaded free health and fitness app in Australia for three days.



See [www.feedsafe.net](http://www.feedsafe.net) for more information.

### What's next?

Finalising a survey of 240 health practitioners to determine if they are using NHMRC guidelines to advise breastfeeding mothers on harm minimisation.

The app has now been downloaded around 100,000 times and has an average use of 928 times per day.

While NHMRC guidelines advise that not drinking alcohol when breastfeeding is the safest option, the app uses further guideline advice – based on Dr Giglia's research – to assist those women who do choose to drink occasionally to do so in the safest way possible.

"I wanted to provide a harm minimisation message," she said. "So that if you are going to drink – and some mothers are, as that is the culture we live in – here is a really safe way that protects your breastfeeding and your baby."



DR ROSLYN GIGLIA



## PROGRAM AIMS TO STOP SKIN INFECTIONS IN THEIR TRACKS

Four Kimberley communities will put to the test a new three-pronged approach to identify, treat and prevent skin infections, such as skin sores and scabies.

An innovative program set to run for about two and a half years aims to halve the number of children affected by skin infections – a major cause of health problems in remote Aboriginal communities.

The SToP program (See, Treat and Prevent) is a partnership between Telethon Kids Institute, Western Australia Country Health Service-Kimberley and Kimberley Aboriginal Medical Services.

The ‘see, treat and prevent’ approach will put resources in place to help diagnose skin infections; assess the effectiveness of new treatments identified in clinical trials; and boost prevention through health promotion and environmental health activities driven by each community.

Paediatric infectious diseases specialist Dr Asha Bowen, from the Institute’s Wesfarmers Centre of Vaccines and Infectious



DR ASHA BOWEN

Diseases, said it was vital to educate health-care workers, parents and the community to identify the problem so that more children could be properly diagnosed. One study had revealed that many children presenting to hospital were not picked up as having skin infections – missing a golden opportunity to treat them to avoid later complications. Skin infections can lead to life-threatening conditions such as kidney disease, rheumatic heart disease, bone infections and blood poisoning.

Dr Bowen said the program would also incorporate the latest treatment from two recently published trials.

“These showed that treatment with a short course of oral antibiotics is just as effective for school sores as the standard treatment, which is a painful injection of penicillin,” she said.

“The other study showed that ivermectin, a tablet, was more effective for treatment of scabies than the traditional approach of applying an oily, topical cream all over the body. Testing whether these approaches work in the Kimberley to reduce the overall burden of skin infections by 50 per cent will be an important extension of these big trials.”

The availability of alternative treatments is an important step after an earlier study in the Pilbara revealed many children were reluctant to attend clinics because of the penicillin injections.

One study had revealed that many children presenting to hospital were not picked up as having skin infections – missing a golden opportunity to treat them to avoid later complications.

About 40 per cent of all Aboriginal children in remote areas are affected by skin sores at any one time – the highest prevalence in the world. Scabies is also endemic in some communities, with up to one-third of children affected.

“Our current skin infection research aims to address the burden through implementing the latest evidence-based treatment regimens, whilst building the environmental health, training and health promotion components that are critical to effective management of skin infections,” Dr Bowen said.

In a project aimed at educating people about the importance of healthy skin spearheaded by indigenous health worker Marika Hayden, children from the Njaki Njaki community in Merredin have created a hip-hop music video called Gotta Keep It Strong.



WORKSHOPS IN MERREDIN

“There were about 40 Aboriginal children and their families in a community hall learning about skin infections and then writing the lyrics of the songs,” Dr Bowen said. “During this time, a few of the kids realised they had a skin infection and called me over to check it out. One even needed to go to hospital to get treatment. It was great to see them translating what they were learning directly into seeking help for their own skin problems. “The key message in Gotta Keep It Strong is that the skin is important for health, identity, culture and family.”

The video will also hopefully tackle the perception that

because so many children get skin infections so frequently, everyone thinks it is normal.

The Telethon Kids Institute is also involved in developing national guidelines for the clinical care and control of skin infections.

“These will mean that we have a consistent approach to treatment of skin infections whether you are a patient in Broome in WA, Alice Springs, NT, or Moree in NSW,” Dr Bowen said.

Other studies are investigating the burden of skin infections in hospitalised children and working to understand the concurrent burden of Group A streptococcus-related skin

and throat infections, with the aim of determining the best strategy for primary prevention of acute rheumatic fever.



## SKIN SORES & SCABIES

- ▶ **Impetigo**, also known as school sores or skin sores, is a highly contagious type of skin infection caused by the *Staphylococcus* or *Streptococcus* bacteria. More common in the hotter months, the infection is easily spread and is characterised by inflamed blisters that pop, weep and form crusts.
- ▶ **Scabies** is a skin infestation caused by mites which burrow into the skin to lay their eggs. It leads to red bumps or blisters on the skin that are very itchy. If scratched, it can allow a strain of *Streptococcus* or *Staphylococcus* bacterium to cause infection.

### What's next?

- ▶ Continue to reduce the burden. “Even if we successfully halve the current burden, we will still have one in five kids affected by skin infections at any one time. That is still unacceptably high. The Kimberley goal is less than 5 per cent.”
- ▶ Use the resources and lessons from the SToP program across the north of Australia to reduce the burden in other areas through the Hot North partnership.
- ▶ Monitor the risk of antibiotic resistance to inform the next phase of research, such as whether a new form of treatment will be needed.



## DECADES OF BULLYING RESEARCH PAYS OFF

**D**edicated to making all students feel safe at school, Professor Donna Cross and her team at the Telethon Kids Institute have challenged and overturned damaging attitudes that saw bullying tolerated as a normal part of childhood and allowed the significant harm to go unnoticed.

Drawing on evidence gained in 11 trials involving 30,000 students, the Health Promotion and Education Research team developed and made available worldwide a valuable whole-school approach to bullying prevention that is now recognised internationally as a comprehensive, evidence-based framework that can reduce bullying behaviour.

In doing so, they have triggered changes in schools around the globe, aided in the rewriting of policies from the classroom level to the heads of government, and led researchers in the field.

Their search for a better way forward began 20 years ago, prompting the team to design, trial and continue fine tuning its Friendly Schools Plus program – the first effective anti-bullying initiative for schools developed through extensive research with Australian children and adolescents.

Shown to work in both primary and high schools and requiring the co-operation of parents, teachers and students, Friendly Schools Plus provides proven strategies not only for those being bullied or cyberbullied, but for bystanders and the students who are doing the bullying as well.

With a central goal of bringing the entire school community together in order to create and maintain a friendly and safe

school culture, the initiative is based on extensive research carried out by Professor Cross and her Telethon Kids research team, the Child Health Promotion Research Centre at Edith Cowan University, and Curtin University.

The program resource package, which is regularly updated to include the latest findings and is designed to align with both the Australian Curriculum and the National Safe Schools Framework, is being used across Australia as well as in Singapore, USA, New Zealand and the UK.

Professor Cross and her team work closely with Hawker Brown Education on the production and distribution of the resource package as a means of ensuring high quality translation of their research work and to provide a vehicle to shift attitudes around the tolerance of bullying.

“Our Friendly Schools Plus program has been used in 3000 Australian schools,” Professor Cross said, “and key elements of it, and the whole-school approach that we promote, are being used by most schools in Australia.”

“It was our research that contributed to the Federal Government developing the National Safe Schools Framework, which is the policy document that guides school responses to providing a safe and healthy environment for children.

“We have also been given the great privilege and opportunity to talk to almost every education system and sector in the country to support their policy advice; and we constantly have individual schools asking us to

*“For me the ‘lightbulb moment’ was the realisation that young people often did not have a literacy around how to deal with bullying. It was just ‘Suck it up and get on with it.’”*  
Professor Donna Cross

The program provides a ‘Map the Gap’ audit tool to identify school strengths and needs and ensures students are surveyed for their input. Its strategies aim to enhance social skills and conflict resolution skills; boost resilience and empathy; increase understanding and awareness of bullying; improve communication about bullying; foster adaptive responses to bullying; encourage peer and adult support for students who are bullied; and promote peer and adult discouragement of bullying behaviour.



**Bullying** is now regarded as a **health problem** and not just a disciplinary problem. Increasing evidence shows both offline bullying (e.g. hitting, teasing) and cyberbullying have lasting effects on young people (those who bully, those who are bullied and bystanders), including damage to self-esteem, academic results and mental health. **Approximately 1 in 4 students in Years 4-9 is bullied every few weeks or more often.**

PROFESSOR DONNA CROSS WITH EWAN AND LOUIS

read and update their policies and provide advice on their wellbeing practices based on our study findings."

Professor Cross said addressing bullying effectively in schools had been shown to be complex, taking consistent commitment and effort by school staff to promote positive social behaviour, prevent bullying and protect students.

That was why the Friendly Schools Plus program needed to be so comprehensive – schools had to 'bite it off seriously' to make a difference, she said.

She warned that 'cherry-picking' the program would not get results, which was why her team continued to work so hard to maintain the integrity of Friendly Schools Plus.

"In translating our findings, we determined, along with other bullying prevention researchers, that small 'doses' of an

intervention can make things worse," Professor Cross said.

"Some research even suggests that if schools only help a few of the students who are being bullied – but don't effectively stop the bullying behaviour of the perpetrators – their efforts can increase the intensity of the bullying on those who are still being victimised.

"It's a bit like taking medicine: you need to take the right medicine and in the right dose to get the right effect. If you under-deliver the right dose, then it is likely the program will not be effective, and may even lead to negative outcomes.

"But this work also requires a change in thinking about bullying. We still have much to do to help people to see that bullying is also a health problem, not just a behavioural problem; and that the child who is doing the bullying doesn't just need consequences, he or she also

needs understanding and help to learn how to change their behaviour, because they are also on a trajectory that could lead to poor future outcomes. They may be more likely to be involved in domestic violence, criminal activity or a broken marriage because of the nature of how that behaviour has evolved."

In the late 1990s, when she was busy researching student attitudes to smoking, road safety, nutrition and physical activity, it was feedback from schools that drove Professor Cross to focus efforts on investigating bullying.

"The schools we were working with back then strongly encouraged us to address the perceived negative peer pressure and bullying that was driving these other poor health behaviours," she said.

"For me the 'lightbulb moment' was the realisation that young people often did not have a

literacy around how to deal with bullying. It was just 'Suck it up and get on with it'.

"Consequently in 1999 we led a comprehensive and systematic review. And we identified for the first time what were the best evidence-based practices known to help schools reduce bullying. We compiled a set of best practice principles, organised within a health promoting schools model, and validated these with all the leading experts around the world.

"We were then fortunate to receive funding to use these practices in a large longitudinal trial targeting 10-year-olds, which is the age group that experiences the most bullying."

The Friendly Schools Project was evaluated by following 2000 students, their teachers and parents across Years 4-6 from 2000 to 2002, and was found to be effective in reducing self-reported bullying victimisation.

"We had an effect but we thought we could do better," said Professor Cross. "So we led other studies involving a wider range of age groups and more actively engaged with parents by helping them to understand ways they could support their children if they were being targeted, were bystanders or were being perpetrators.

"In total, we have completed 11 large trials and many other formative studies and when we have significant research findings for policy or practice we use our vehicle – the Friendly Schools Plus program resource package – to carry those updated messages to parents, schools and young people directly."

Professor Cross said that while these social and emotional learning activities and anti-

bullying strategies were now very much in demand, when starting out the research team had constantly come up against the attitude that bullying did not hurt children and helped toughen them up and prepare them for life.

"So our message at first was a hard sell – the message that bullying causes a lot of immediate harm to the target, the perpetrator and the bystanders.

"Also we needed to help the community realise that there is significant long term harm, including biological changes. Severe social difficulties can impact on our stress response and even alter gene expression in some individuals, which can contribute to long term physical and mental health problems.

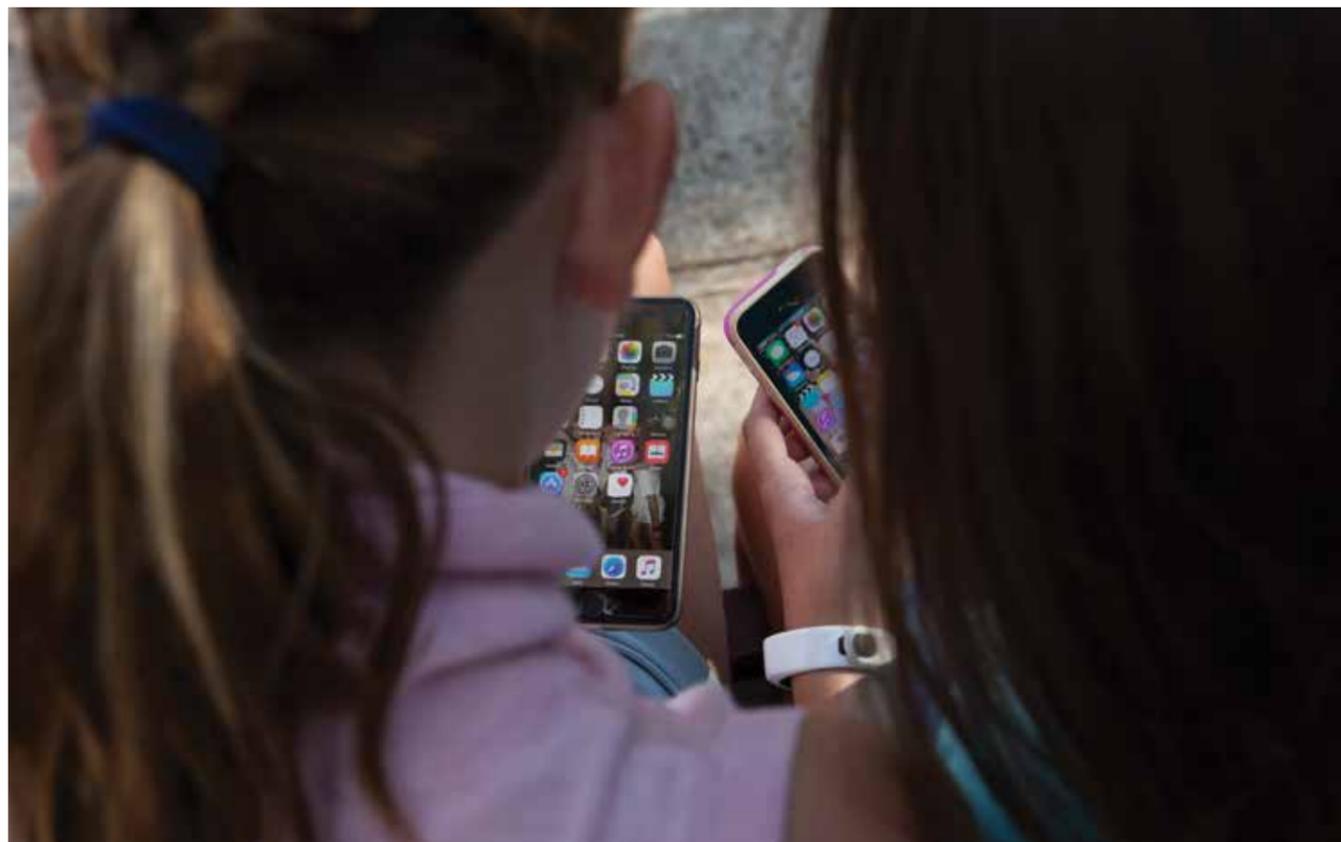
"Then with the rise in cyberbullying, parents and other adults could often directly see for themselves the nature of bullying sent online through words, images and videos, and I think this insight made the potential effects of bullying on young people seem much more real."

While great progress has been made, our researchers know there is still much work to be done.

"It's heartbreaking that I still regularly receive messages from parents telling me about the difficulties they are having helping their children who are experiencing bullying at school, and who do not feel sufficiently skilled to address bullying," said Professor Cross.

## What's next?

- Updating Friendly Schools Plus following three new studies - addressing anxiety and bullying; perpetrators and ways to change their behaviour; harm minimisation strategies for image sharing on social media (including the new Image Up app which delays uploading for a few seconds to allow age-relevant safety reminder messages).
- A new study looking at real time online behaviours to better understand and target interventions to support, children, parents and teachers.





## DATA REVEALS IMPORTANT CLUES ABOUT CHILD ABUSE AND NEGLECT

Researchers working on the Developmental Pathways Project being undertaken by Telethon Kids' Linked Analytics and Social Policy Team are determined to find out what makes families vulnerable to child abuse and neglect, and do something about it.

As a trained psychologist working with struggling families, Dr Melissa O'Donnell saw first-hand the urgent need to deal with child abuse and neglect as a public health issue: to find avenues for prevention, early support and intervention that refocused efforts on keeping children safe and providing much-needed assistance prior to abuse and neglect.

The insight she gained at the coalface fuelled her determination to step up, join the Telethon Kids Institute's Linked Analytics and Social Policy research team, and play a key part in pinpointing the primary factors that made families vulnerable to child abuse and neglect. Such knowledge would then aid services in designing and targeting effective strategies and programs.

"I felt there was a real need to look at what contributed to risk," Dr O'Donnell said. "And if I could help identify that and support policy and programs that really did prevent child abuse before it occurred, or intervened early to support those families, then it would create a better system for the families themselves."

After working for ten years to analyse 20 years of de-identified linked data from the WA Department for Child Protection and Family Support and the WA Department of Health relating to 524,534 children, she has done just that.



*"Often these families are the hardest to research as they are reluctant to discuss child protection issues, substance use or mental health issues. So by using the linked de-identified data, we have been able to investigate and determine issues relating to risk while still protecting the privacy of families."*

Dr Melissa O'Donnell

Her team's research findings, based on the longitudinal population data, have provided evidence highlighting the most pressing areas where services need to work to support families prior to abuse and neglect.

Dr O'Donnell found that children with disabilities are three times more likely to be maltreated compared to other children, but that risk varies by type of disability.

And regardless of the cause, the disability types most strongly associated with maltreatment often co-occurred with a number of other risk factors,

such as parents who are young or who have been hospitalised for mental health issues, and living in more disadvantaged neighbourhoods.

"These families already face additional stressors and have fewer resources to access services for their children's special needs," said Dr O'Donnell, a University of WA Fellow.

The findings have been used by the WA Department for Child Protection and Family Support to redesign services and formulate its recently released Building Safe and Strong Families: Earlier intervention and family support strategy. Aimed at diverting families from entering the child protection system, this strategy widens the Department's primary focus of assessment and substantiation.

"We have also used them to do more training with child protection workers and we fed the information back into the Royal Commission investigating children with a disability who were abused," said Dr O'Donnell.

"And as a result of our research, we successfully lobbied to get changes made so that the National Child Protection Framework has now taken a public health approach to child abuse."

With the project funded by the National Health and Medical Research Council and the Australian Research Council, the

linked de-identified records that Dr O'Donnell's team examined included Birth Registrations, the Midwives Notification System, Mental Health Register, Hospital Morbidity Database, Mortality Database, WA Register of Developmental Anomalies, the Intellectual Disability Exploring Answers database and the Department of Child Protection and Family Support data.

"So we were able to look at parental mental health and the factors associated, children with disability and their risk, and substance use in families – such as mothers with a child born with neonatal withdrawal syndrome," Dr O'Donnell said.

"Often these families are the hardest to research as they are reluctant to discuss child protection issues, substance use or mental health issues. So by using the linked de-identified

data, we have been able to investigate and determine issues relating to risk while still protecting the privacy of families."

Dr O'Donnell says the findings have placed further emphasis on the need to take a whole-of-government approach, as well as the need to ensure that parents facing challenges and adversity have the appropriate services and support structures in place to enable their children to achieve their full potential and ensure their wellbeing.

"It's about all government agencies supporting families," she said. "And I think Treasury has become much more aware of the need to invest funds early on, because there has been a large rise in the number of children and families being investigated."

### What's next?

Investigate the reasons for the recent rise in newborn and infant removal from families. Evidence found will be used to improve support and safety plans for high-risk families and to ensure support services are meeting the families' needs.



DR MELISSA O'DONNELL

## COST OF REMOVING A CHILD FROM ITS FAMILY

### Child

*Distress of separation from family, being in multiple placements and having limited support once they leave care.*

### Family

*Trauma of child removal, for Aboriginal families exacerbates inter-generational trauma from a history of the Stolen Generation.*



## STUDENT WELLBEING JUST AS IMPORTANT AS ACADEMIC SUCCESS

A team of researchers passionate about the social and emotional wellbeing of children have been refining a survey questionnaire that allows schools to better support their students in this important area.

Telethon Kids Institute Senior Research Fellow Tess Gregory and Head of Child Health Development and Education Sally Brinkman feel strongly that whilst schools have long played a major role in building the wellbeing of students, the outcome data available to school systems focus too much on the academic achievement of children, at the expense of supporting students in other areas of life.

Based in South Australia at the Fraser Mustard Centre, the pair have worked with the education department to rollout a population level 'census' to nearly every public school. This has enabled them to measure the wellbeing of children so that the system responsible for educating them can also better support their wellbeing.

The survey of wellbeing and student engagement looks at happiness, optimism, life satisfaction, perseverance, emotion regulation, sadness, worries, connectedness to adults and peers, engagement, academic self-concept and bullying.

It provides invaluable information to the South Australian Department for Education and Child Development and its schools to put in place policies and programs targeting the particular needs of their student population.

"We are really excited to see the systematic measurement of student wellbeing within the whole education system," Dr Gregory said.

"While some schools measure these things, until it becomes a systematic collection where education systems can look at this data alongside their attendance and academic achievement data, student wellbeing is not going to be elevated to the same level of importance as literacy and numeracy."

It seems teachers and parents are realising the benefits of better knowing how their children are feeling, with an impressive 90 per cent of all South Australian government schools now volunteering to take part in the annual survey. Each school then receives a report on their students' results, and the department is able to use internal data linkage systems to explore the association between child development, student wellbeing and engagement, academic achievement, and school attendance.

For instance, early research showed a student's ability to persevere was essential for later academic achievement. The department is now exploring programs to develop perseverance in students to see if helping children in that area would have an impact down the track.

"In a lot of places schools look at how individual students are going," Dr Gregory said. "The thing that is different about this collection is that it focuses on the wellbeing of the whole class and school rather than the



individual. It's designed to take a population health approach to thinking about wellbeing, social and emotional skills."

Dr Gregory and Dr Brinkman are now focused on improving how the survey is working from a psychometric perspective so that it can better differentiate between children.

"We need to ensure that the policy decisions made based on this data are not impacted by any problems with the different scales or how the instrument is working," Dr Gregory said.

She said the close collaboration between the Department and Telethon Kids Institute through the Fraser Mustard Centre was essential to the success of this work. The strong engagement by the department ensured the data was not left sitting on a shelf somewhere. Instead, the results were being used to benefit students across the State. Other states were also looking at getting involved.

"As academics, we could never have done research quite like this independently, and the department would not have had access to experts to do the underlying psychometric work that we have done," Dr Gregory said of the department's policymakers.

"By working together we have ended up with a much better instrument that's much more rigorous, as well as very high engagement by schools and students."

### What's next?

When children start school the Australian Early Development Census measures their social, emotional and physical health, along with their language and communication skills. The researchers are preparing to look at how school readiness relate to social and emotional wellbeing in the middle school years.

Is wellbeing determined early and therefore intervention needs to happen sooner? Or are the intervening years important and students need more support later?

### SCHOOLS GET ONBOARD

*In 2014, less than three in 10 eligible government schools opted to take part in the student wellbeing survey. By 2015, 60 per cent took part, and 90 per cent in 2016. In 2016, 43,000 students in the middle years from 500 schools took part.*



DR TESS GREGORY WORKING WITH A STUDENT



## NEW POLICY PROVIDES MUCH-NEEDED FOCUS ON OVERLOOKED YOUTH

The need for a West Australian Youth Health Policy has been evident for years. Now, with the Telethon Kids Institute helping to drive the project, it is finally about to come to fruition.

Young people have, until recently, largely been forgotten in the West Australian health system.

“For many years young people, and I mean that group of people who are no longer children but not yet adults, have been a group left without any real voice in the health service,” the Institute’s Associate Professor Donald Payne said.

“There has been no real focus on developing health services for this group or for developing training programs for people working in this area. As a result this is a group who have fallen behind in terms of health outcomes and improvements.”

Over the past two years the Institute has played a key role in working with the Department of Health and the WA Child and Youth Health Network to

get a final version of the West Australian Youth Health Policy up and running, with the hope that it will be ready by the end of this year.

Associate Professor Payne, Head of the Youth Health and Wellbeing Team, said the policy was the product of an ongoing collaboration with many agencies and organisations and would have practical benefits for youth.

A number of clinicians and researchers from the Institute had contributed advice, data, and provided access to young people with experience of navigating the health system. A big effort had been made to try to ensure that young people were involved in developing the policy.

“Until now, this hasn’t been an area that has been recognised as being particularly important,” A/Professor Payne said. “Therefore there has been no real focus, no one within the Health Department who has been responsible for ensuring that young people receive the services they need, that they are able to access these services and that health outcomes for young people improve.

“If we have a specific policy, and within it there are things that become mandatory for health services to provide, then that will increase the visibility of this group and inevitably lead to better outcomes.”

With the same goals in mind, the team at the Institute has also brought together people from many different disciplines and agencies to form the Youth Health and Wellbeing Alliance, with support from the WA Commissioner for Children and Young People.

The alliance involves government departments such as Education and Corrective Services, along with the Department of Health, non-government organisations,

universities, patient organisations, consumers and more.

“There’s a whole group of children and young people growing up with chronic illnesses and there’s a major gap in appropriate provision of services for these young people as they transition to adult care,” Associate Professor Payne said.

“Adult health services are yet to recognise the scale of the issue. While a few services – such as those caring for young people with cystic fibrosis, diabetes and congenital heart disease – have developed specific transition services, many adult services are not set up to accept young adults into their care.

appropriate community-based health services for young people, introducing monitoring and evaluation of health outcomes for this group, and investigating whether services meet young people’s needs.

A/Professor Payne also hopes to promote a broader focus on ensuring there is a recognition that adolescence and young adulthood is a time when health behaviours develop and that these can have a major effect on health in later life.

“There is a huge gain to be made from recognising and investing in the health of young people before it gets too late,” he said. “This will have major benefits for the whole healthcare system.”

### What’s next?

The team plans to look at improving the opportunities for young people to find out about the services that are available and how to access them, including working with the Youth Advisory Council of WA to explore the possibilities provided by apps and web-based technology.

*The majority of adult health services are yet to acknowledge the specific needs of young people. This will be a major focus of the policy.*  
Associate Professor Donald Payne

“In fact, the majority of adult health services are yet to acknowledge the specific needs of young people. This will be a major focus of the policy.”

Other goals include providing and promoting access to





STEPHANIE TREND, LILIAN CHA AND PROFESSOR PRUE HART



## MENINGOCOCCAL RESEARCH PAVES WAY FOR VACCINE USE

A series of Telethon Kids Institute studies looking at safety and persistence of protective antibody responses for Meningococcal ACWY vaccines in children has led the way for its use in Australia after a significant rise of W strain infections.

The vaccine was used to treat a Kalgoorlie community after a Meningococcal W disease outbreak in November 2016, and has now been recommended for adolescent programs across four Australian states.

In 2017, it will be provided to WA teenagers aged 15-19 as part of a three-year vaccination program.

According to Professor Peter Richmond, Head of the Vaccine Trials Group which sits in the Wesfarmers Centre of Vaccines and Infectious Diseases, the study

results have been available to help inform government policy at a critical time, allowing young people to be protected from Meningococcal W when they are most at risk.

Professor Richmond's team has also worked on a series of Meningococcal B vaccine studies in teenagers and young adults that have contributed to the vaccines being licensed in Australia and overseas.

### What's next?

A meningococcal B vaccine is being rolled out to teenagers in South Australia to examine the impact of immunising large community groups against the disease.



## UV AND VITAMIN D

Researchers at the Telethon Kids Institute are continuing to hone in on the effects of Ultraviolet radiation and vitamin D on the immune system.

Professor Prue Hart, head of the Inflammation Laboratory, said vitamin D was only one of many molecules produced by our skin after UV or sunlight exposure.

"It is naive to think that we have evolved with only one of these molecules being important in maintaining our good health," Professor Hart said.

"The literature is full of reported associations of low vitamin D levels in individuals with a particular type of ill-health condition, and incorrect

conclusions that vitamin D was causal. Intervention trials are giving equivocal, disappointing outcomes."

Professor Hart said researchers were taking a step back and testing the effects of the stimulus for vitamin D production, ie UV exposure.

There had been promising signs in a trial of narrowband UV-B phototherapy for people with early multiple sclerosis, called Clinically Isolated Syndrome, with

preliminary data suggesting a delay in their progression to MS.

Another study at Telethon Kids is looking into links between UV exposure and vitamin D levels on the development of type 2 diabetes, with Dr Shelley Gorman, head of the Cardiometabolic Sunhealth team, investigating the effects of UV and vitamin D on the development of metabolic syndrome and obesity.

### What's next?

"We are planning a replication trial of narrowband UVB phototherapy to delay progression to MS in Edinburgh, Scotland - a city in which background UV radiation exposure is low."

*"The literature is full of reported associations of low vitamin D levels in individuals with a particular type of ill-health condition, and incorrect conclusions that vitamin D was causal."*  
**Professor Prue Hart**





PARADIGM  
**SHIFT.**



## ELDERS INSIGHT LEADS TO SPINE-TINGLING BREAKTHROUGH

**D**r Michael Wright clearly remembers the crucial 'aha' moment he experienced while working closely with distressed Nyoongar families to identify what was limiting their engagement with mainstream services, despite a spate of mental health crises.

Answering his questions on how to fix 'the broken system', the Nyoongar Elders from Armadale to Bentley provided an invaluable insight into the root of the problem.

"Those mainstream services don't have a relationship with us because they don't know who we are," they told him.

"They see us as being one homogeneous group – Aboriginal and Torres Strait Islander – but we are more than that. It's all about our country, our kin and our family. They just don't understand Nyoongar culture."

"And that was it," Dr Wright said. "That was what it was all about."

"If we couldn't improve that interface between Aboriginal people and the system itself, then we were not going to go anywhere."

"So we decided we needed to work with these public and non-government mental health and drug and alcohol services – that had too often operated on a basis of one-size-fits-all – and ensure Nyoongar Elders were able to tell the story that is unique to them."

"And that is when the breakthrough came and we began forming relationships."

Aimed at reducing alienation and ensuring mental health and drug and alcohol mainstream services adapt to accommodate the Nyoongar perspective, the

Looking Forward project continues to be guided by Elders and is based upon the four ethical principles that provide the foundations for working with Nyoongar people: securing trust, creating relationships, sustaining commitment and working in partnerships.



*"Once the Elders and the senior management were working together – having that relationship – the CEOs realised very quickly how smart the Elders are."*

Dr Michael Wright

The Elders, Dr Wright said, had the wisdom to insist from the very start that in recognition of their status as 'Budiya' (Nyoongar word for boss) in their community that they should talk directly to the senior management of the local mental health and drug and alcohol service providers.

"That was the minimum standard they set," he said.

"So we started these monthly conversations with 18 Nyoongar Elders and the services' CEOs and that is what we have been doing for three years. And it has been transformational."

"Once the Elders and the senior management were working together – having that relationship – the CEOs realised very quickly how smart the Elders are."

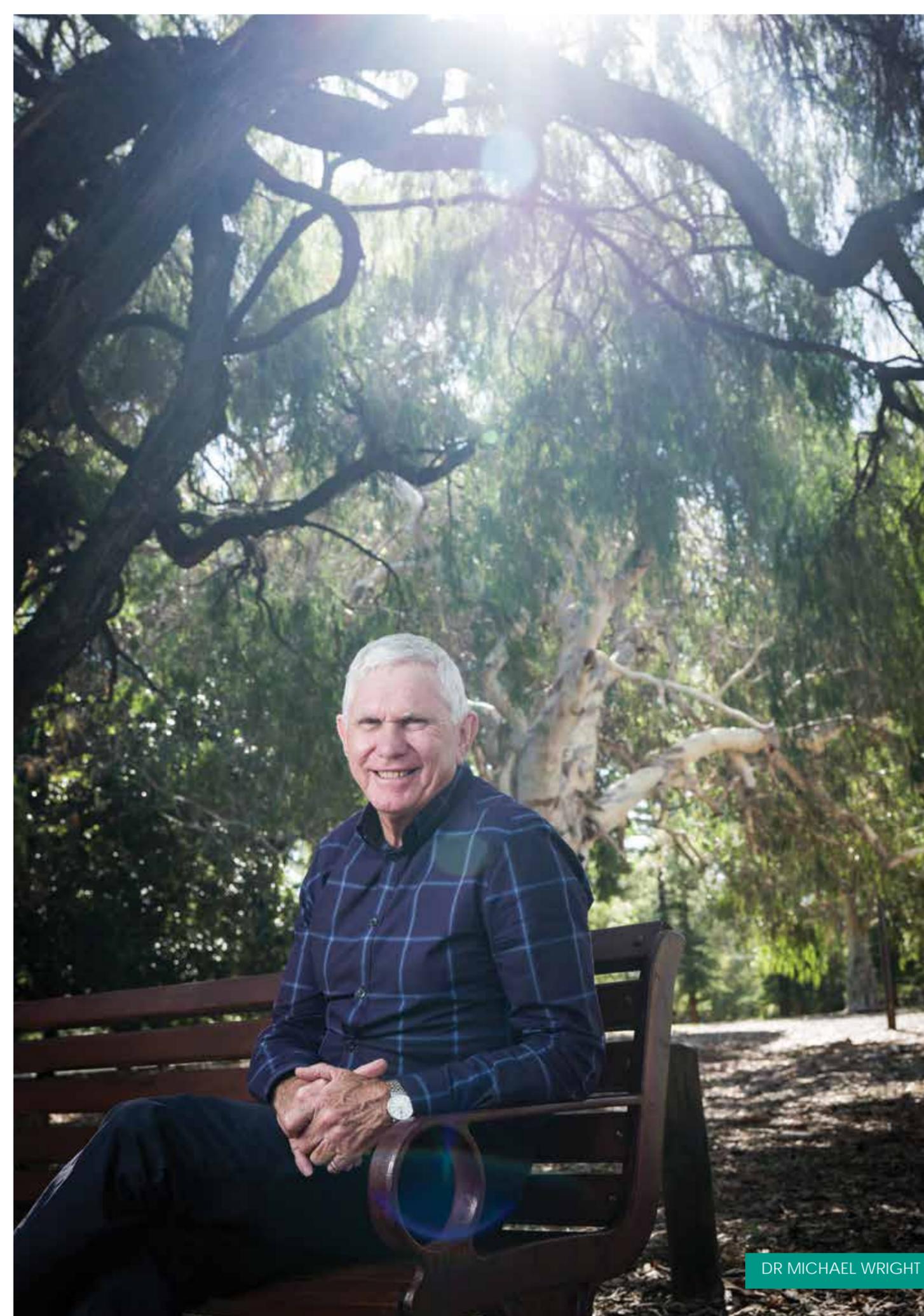
"That's the sort of thing that gets to my heart and gets me all tingly up the back of the neck. And I think it is the first time that something like this has been done at this level in Australia."

Since the initial community consultation process undertaken in 2011 and 2012, the Looking Forward project has successfully overhauled the way mental health services and drug and alcohol support services respond to the needs of Nyoongar families living in the area from Armadale to Bentley.

As a result, some mental health providers that previously had no Aboriginal clients and no Aboriginal staff now had in excess of 100 Nyoongar clients using their services, according to Dr Wright.

Looking Forward has involved a unique collaboration between the Institute, the Elders, The University of Western Australia and Curtin University, with funding from the WA Mental Health Commission, Lotterywest and Ruah Community Services.

A further \$2.5 million has now been provided by the NHMRC and service providers to use what has been learned to develop a transferable, culturally secure systems change framework.



DR MICHAEL WRIGHT

Funding partners include the WA Network of Alcohol and other Drug Agencies, WA Association for Mental Health, WA Council of Social Services, Hope Community Services, MercyCare, Palmerston Association, Richmond Wellbeing and St John of God Healthcare Midland.

"Would I have thought five years ago that we would be where we are now? You hope so, but I really have been just blown away," Dr Wright said.

To start the project off, the Looking Forward team, in conjunction with Nyoongar Elders, held a number of events and activities to assist the 10 service providers to develop an understanding of and respect for, Nyoongar culture and its centrality to mental health and wellbeing. Activities included damper and bush medicine making, storytelling, community days and walks on country.



*"That's the sort of thing that gets to my heart and gets me all tingly up the back of the neck. And I think it is the first time that something like this has been done at this level in Australia."*

Dr Michael Wright

These helped prepare services to work "more openly and authentically" with Nyoongar Elders, Dr Wright said, as they sought to reflect on and reconfigure their own service structures and delivery processes to better meet the concerns of Nyoongar families.

From late 2013, the project team facilitated regular meetings with Nyoongar Elders and service providers to shape a way forward for systems change.

During this time, the team collected data that would identify and describe the conditions necessary for "respectful and authentic engagement".

After some data analysis, an engagement process titled Debakarn Koorliny Wangkiny (Steady Walking and Talking) was developed and trialled.

"So we have built the foundations for change and also the platform for measuring how this change is happening," Dr Wright said. "How it is impacting on both service delivery and the organisation and how it has increased the service's footprint into the Aboriginal community.

"And this model is transferable.

What we have done here, you can replicate somewhere else with local Elders, as long as you apply the key principles of the work."

A Chief Investigator at the Centre for Research Excellence in Aboriginal Health and Wellbeing, Dr Wright is a Yuat Nyoongar man from the Moora and New Norcia area of WA, north of Perth. He has worked as a hospital-based social worker and a mental health service manager, and holds a Fellowship position at the Curtin University National Drug Research Institute.

"This project actually grew out of my PhD on Aboriginal people living with serious mental illness," he said.

"I was looking at care-giving practices to see if they were different for Aboriginal people and non-Aboriginal people. And every time I interviewed families back then, we would invariably get around to the experience of Aboriginal people in the public system with mental health services, and some of their stories were just outrageous.

"No one was taking into consideration the cultural

## LOOKING FORWARD GREAT GAINS

- **Usage rates have increased.** Mental health provider Richmond Wellbeing started off with no Aboriginal clients and no Aboriginal staff and **three years later had 100 Nyoongar clients and 14 staff.**
- **Aboriginal Elders were made patrons of the 2016 WA Mental Health Conference.**

aspects of why that person was there and the healing role of the extended family. It was as though once the medical model kicked into gear, everything else faded in relevance."

Much has now changed.

"Now the Elders are guiding service providers, they are engaged in a full multi-sensory experience, on a spiritual journey of transformation," Dr Wright said.

"And they are being introduced to many concepts that, for most, are totally unfamiliar to their worldview.

"For some it has been very challenging, but they are finding the experience enthralling, exciting and rewarding."

### What's Next ?

- Measure the new reach of the mainstream mental health and drug and alcohol services into the Nyoongar community.
- Provide a mechanism for State-wide change by co-designing a culturally secure systems change framework, shaped by this relationship-based approach. Around \$2.5 million has been provided by the NHMRC and service providers to support this research.

## NEED FOR CHANGE

- **An historic mistrust of the public system was contributing to low usage rates and Nyoongar clients with mental illness or drug and alcohol issues presenting much later. They were sicker, had a longer recovery period and there were often compliance issues. Some had suffered significant trauma from being part of the Stolen Generation.**



PHOTOS: SERVICES STAFF ENGAGING WITH NYOONGAR ELDERS ON COUNTRY



# RESEARCHERS UNLOCK POTENTIAL NEW CANCER WEAPON

In an exciting breakthrough for cancer treatment, a new weapon to enable the immune system to combat the disease may have been unlocked.

Research by the Cancer Immunology team at Telethon Kids has revealed that some interferons – naturally occurring compounds that help coordinate the body's defence against infection – have the capacity to make cancer go to sleep.

Dr Jason Waithman, said the more researchers could understand how the immune system works, the more they could harness it to combat complex diseases.

"Our immunology research is looking to harness the body's natural defences to fight cancer and this is now being accepted by clinical oncologists as one of the standard pillars of treatment for people with certain cancers," Dr Waithman said.

Getting the immune system to recognise cancer cells is key to improving and developing effective therapies.

Dr Waithman said the team's findings would change the way people thought about interferons. Although research into these chemical messengers has been underway for more than 60 years, nobody has closely looked at the 13 alpha subtypes to see if they do different things.

"We asked a very simple question: why does the body produce so many and are some more effective than others against cancer?" he said.

The outcome was that certain interferons did stop the growth of cancer cells. They could convert an aggressive cancer such as

melanoma – one of the most common cancers in Australian adolescents – into a chronic, manageable condition.



*"In my mind, this research has produced some of the most exciting results we've seen in the laboratory."*

Dr Jason Waithman

"We haven't figured out how this is working yet," Dr Waithman said. "That is the next phase. Once we figure out how the immune system puts the cancer to sleep, why don't we just engineer it with this weapon? Why not use existing cellular technology that's already clinically approved and let's arm them up with new weapons to put the cancer to sleep?"

"In my mind, this research has produced some of the most exciting results we've seen in the laboratory."

Dr Waithman's team is also working on a cancer vaccine in partnership with a biotech company, with personalised treatment tailored to an individual's cancer.

"We now have the power to look into everyone's cancer and identify on a personal level what sort of mutations they have in that cancer," he said. "My job is to make a vaccine that gets the

body to recognise that mutation so that your body can then hunt down the cancer and destroy it."

He said a new cellular therapy was also coming to WA.

"It's a living drug where you can take cells from an individual with cancer and engineer them in the lab to be able to recognise the cancer. This is mainly in leukaemia and lymphoma patients. You can basically train them up to recognise their own cancer and make a huge army and put them back in."

## What's next?

▶ "The next phase (with chemical messengers) is to find the human equivalents of these, as studies to date have been done in mice. We want to find the human equivalent to drive it down the clinical pathway."

▶ "The other thing we want to do is understand how this is occurring. Can we even bypass these compounds and figure out how the immune system can make the cancer go to sleep. When we understand how it works, can we induce it more often?"

## WHAT IS IMMUNOTHERAPY

**Immunotherapy** harnesses the body's immune system to target and kill cancer cells. It shows immense potential to improve cancer treatment, adding another option to chemotherapy, radiotherapy and surgery.



Dr Jason Waithman's research is supported by Cancer Council WA, Perpetual Trustees, BHP, Cancer Australia & Cure Cancer Australia, Brady Cancer Support Foundation and the Department of Industry, Innovation and Science.



IN THE  
**PIPELINE.**



## DRUG FIND COULD REPRESENT BIG WIN FOR OUR LITTLE PATIENTS

**D**r Rishi Kotecha knows too well the devastation of a leukaemia diagnosis in a child. While treating children with the disease as a consultant at Princess Margaret Hospital, he is also leading a team of researchers in the race to find a drug that will increase survival rates for infants.

"Our aim is to always take research from the bedside to the bench and back to the bedside again."

With this one statement, Dr Rishi Kotecha outlines the sense of urgency felt by a doctor who works as both a paediatric oncologist and a scientist searching for the cure.

Leukaemia is rare in babies who are less than one year of age. Perhaps one or two infants are diagnosed in Western Australia each year. Sadly, only 40 per cent of these young patients survive.

"Chemotherapy is very, very hard on a child, especially the babies," Dr Kotecha said.

"Babies spend a lot of time in hospital because they suffer from a lot of toxicities occurring as a side effect of the chemotherapy. The families and their infant are trapped in hospital and that's really difficult."

"It's really hard on their little bodies – a lot of them go to intensive care with complications and many do unfortunately pass away. It's extremely tricky to manage."

Older children with leukaemia have a better prognosis, with a survival rate of up to 95 percent. It is this gap Dr Kotecha is working hard to close in the laboratory at the Telethon Kids Institute, where he leads the research team alongside the Head of Leukaemia and Cancer Genetics, Professor Ursula Kees.

Looking forward, Dr Kotecha is excited about the research his team plans to conduct.

"It is the high-risk subgroups of leukaemia which have such poor outcomes that we are currently investigating," he said.



*"Chemotherapy is very, very hard on a child, especially the babies."*

**Dr Rishi Kotecha**

"That will be my focus going into the future. Being a clinician, the emphasis will be looking at translational work that will help improve outcomes for our patients."

It's a thrilling time for the Leukaemia and Cancer Genetics Team, who published a paper earlier this year detailing their breakthrough discovery of a drug called Romidepsin, which works well in combination with traditional chemotherapy in laboratory models for infants with acute lymphoblastic leukaemia.

The research that led to this discovery had its genesis in the diagnosis of twin newborns many years ago, while Dr Kotecha was working on the ward.

"They were such little babies and I felt so sad at the time. I really wanted to help," he said.

He began looking at the twins' genetic features in the laboratory as the basis for his PhD, adding samples from other infants as more were diagnosed.

Dr Kotecha and his team produced models representing the disease in humans, which he was then able to use to test a variety of drugs. He found several classes of drugs that seemed to work.

The Telethon Kids Institute Leukaemia Team are now testing the drugs identified by Dr Kotecha in mice.

"To validate our findings, we are now testing the drugs in mice that have the leukaemia," Dr Kotecha said. "We look to see whether the new drug improves survival compared to no drug. When we find a drug linked to a good outcome, we then have to do combination testing to ensure that it is compatible with normal chemotherapy, because in the clinic we are going to be giving the new drugs in combination with standard chemotherapy."

The team has just realised one of the drugs is working particularly well in the animal models in combination with chemotherapy.

The animal trials should be finished by the end of 2017, and from there the team hopes to move their findings to clinical trials.

Although such trials can take up to 10 years to finish, Dr Kotecha is hopeful his discovery will be available long before then.

DR RISHI KOTECHA WITH JACKSON



## CHEEKY JACKSON HEADS HOME AFTER 7.5 MONTH NIGHTMARE

“Should I call my husband? Does he need to come?”

Michelle Pianta knew deep down something was very wrong with her seven-and-a-half month old son Jackson as she waited at Bunbury Hospital for his blood test results.

The answer was yes and it wasn't long before Michelle and Marc Pianta began living their worst nightmare.

“The paediatrician said just by looking at him he didn't need to see the results, ‘I'm almost certain that he's got leukaemia’ he said,” Mrs Pianta recounted.

The couple drove their sick son to Princess Margaret Hospital and did not leave for seven-and-a-half months – the same length of time Jackson had been alive before his diagnosis of infant acute lymphoblastic leukaemia.

“What people don't realise is that when you are diagnosed with acute lymphoblastic leukaemia under 12 months of age, the survival rate drops dramatically,” Mr Pianta said.

Jackson began a regime of intense chemotherapy, but did not lose his cheeky nature.

“He's standing in his cot shaking the sides, having chemo at the same time,” Mr Pianta said.

“It's insane the amount chemo that he has had and it hasn't even phased him.”

Although Jackson coped with the intense treatment, it was not always easy. At one point

the little boy suffered multiple bacterial infections, badly scaring his parents.

Under the care of Dr Kotecha, Jackson has recently been given the OK to go home, although he will still be taking oral chemotherapy once a day. His parents are excited to do normal family things like giving him a proper bath, which they haven't been able to do since he became ill.

The couple, who allowed the Telethon Kids Institute team to use samples taken from their son for research, said the work Dr Kotecha was doing was amazing.

“It's invaluable, the research that they do,” Mr Pianta said. “All of the previous patients that have consented to it have added to the research, to get where they are today. There is still a long way to go, but without that research Jackson's treatment wouldn't be available, and he wouldn't be here with us now.”

The couple has been warned that the disease could recur.

“It's still scary – the doctors have told us the whole way along he's got great results following his bone marrow tests, but unfortunately with this disease, because it is so aggressive, there are still no guarantees,” Mrs Pianta said. “It could come back at any time. And if he relapses the disease is more aggressive and harder to treat.”

“What people don't realise is that when you are diagnosed with acute lymphoblastic leukaemia under 12 months of age, the survival rate drops dramatically.”

Marc Pianta, Jackson's Dad



THE PIANTA FAMILY

“The reason we think we might get quicker results is that we are testing drugs that are already approved for use in patients,” he said. “They are not completely new drugs that have just been developed by pharmaceutical companies. They have already been approved for use in adults and older children.”

“We are purposely picking FDA-approved drugs, which will accelerate translation into clinical trials.”

### What's next?

We hope to get the survival rate for babies with acute lymphoblastic leukaemia up to 70 per cent – more comparable to older children with high risk leukaemia – by doing collaborative research within international clinical trials groups.

For now, though, they are grateful their son can come home and spend some special time with his big sister.

“I think it will feel a bit strange. We have literally lived in the hospital, in one of the rooms, for the past seven-and-a-half months,” Mrs Pianta said.



The Children's Leukaemia and Cancer Research Foundation has been a long-time supporter of our cancer research.



## NATIONAL GUIDELINES BRING NEW ORDER TO AUTISM DIAGNOSIS

Clinicians across Australia are looking forward to the release of the country's first national guidelines for the diagnosis of autism, to be released in September. Professor Andrew Whitehouse is leading the team developing the guidelines.

The way health professionals diagnose autism differs widely depending on where in Australia they practice.

This postcode lottery can mean delays in diagnosis, misdiagnosis or inequity in access to intervention services for children and their families, adding to the stress parents encounter as they try to navigate a complicated system to ensure their child receives the help they need.

This is set to change in September, however, when a new set of guidelines for the diagnosis of the neurodevelopmental disorder is released at the Asia Pacific Autism Conference in Sydney – ensuring health professionals across the country adhere to world's best practice.

Professor Andrew Whitehouse, head of the Autism Research Team at the Telethon Kids Institute, is chairing the project, which was commissioned by the National Disability Insurance Agency and Autism Cooperative Research Centre.

"We have a situation where the process for diagnosing autism is completely different between suburbs, between states, and that doesn't help anyone," Professor Whitehouse said.

"It means confusion for families and inequity in terms of access to services. And it provides governments with a huge quandary about how to plan for future service provision if they don't have a proper idea of

the numbers of children being diagnosed."

Autism is diagnosed based on behaviour, but the assessment of those behaviours currently differs depending on which clinician a family sees.

The most recent statistics show 200,000 Australian families were directly affected by Autism Spectrum Conditions, with 1 in 160 individuals receiving a diagnosis.

Professor Whitehouse said inconsistent diagnosis standards were likely a contributing factor in the huge growth in the number of children being diagnosed, which had doubled every three years since 2006. New data was expected to show 230,000 have autism.

"The National Disability Insurance Scheme offers an exciting opportunity to standardise the process, and ensure a fairer system for families needing help," Professor Whitehouse said.

He said clinicians across the country agreed the guidelines were long overdue. Autism was the most prominent neurodevelopmental condition that did not yet have consistent diagnostic guidelines.

"At the moment the diagnostic process is not very streamlined," he said.

"There are often long waiting lists, and it's often an expensive process, both financially and emotionally, to go through.

"These guidelines hope to streamline this process to ensure every child receives the same diagnostic protocols, and that families can be sure of the diagnostic outcomes."

The comprehensive guidelines will outline who is qualified to diagnose autism, what assessments they should use, and where children should be observed.

"This is about upskilling the national workforce in the diagnosis of autism, which will give families more confidence going forward," Dr Whitehouse said.

### What's next?

The next step will be to inform all Australian clinicians about these guidelines, and ensure that health professionals have adequate resources to provide the best practice diagnostic process.

## WHAT ARE AUTISM SPECTRUM CONDITIONS?

A group of **complex neurobiological disorders that typically last throughout a person's lifetime. Characterised by varying degrees of impairment in communication and social skills and by repetitive behaviours.**

"These guidelines hope to streamline this process to ensure every child receives the same diagnostic protocols, and that families can be sure of the diagnostic outcomes."

Professor Andrew Whitehouse

PROFESSOR ANDREW WHITEHOUSE



# LIMITING LONG TERM LUNG DAMAGE IN PRETERM BABIES

**W**ith premature babies facing lung problems well into childhood, researchers with the Children's Lung Health group are working to identify ways to improve the long-term impact.

A Telethon Kids Institute study into the respiratory consequences of preterm birth has shown that babies born very early are at significant risk of lung disease, with structural abnormalities, poor lung function and respiratory issues by the time they reach upper primary school.

The study tested the lung function of 221 children aged between nine and 11 years – 163 who had been delivered at less than 32 weeks gestation, and the rest born at full term.

The results showed the preterm children had significant levels of respiratory disease, with 92 per cent having structural abnormalities in their lungs and about half reporting recent breathing difficulties, including wheeze and shortness of breath when exercising.

The study also found that the earlier the baby was born, the worse their test scores, with lung

function improving for every additional week of gestation. Those who required a lot of oxygen after birth also tended to have worse lung function as school children.

Telethon Kids researcher Dr Shannon Simpson, of the Children's Lung Health group, said the information would help determine better ways to treat premature newborns and nurture their lung growth over time.

"The collaborative program of research is multi-faceted – understanding the impact of preterm birth over the life course, exploring the underlying mechanisms of the lung disease that impacts on children born preterm, designing and conducting interventions to improve lung disease, and translating these findings into clinical practice," Dr Simpson said.

The lungs are one of the last organs to develop fully so are

commonly affected when a baby is born prematurely. Researchers are keen to know more about the long-term impact on the lung development of such babies.

"We have found that children born very preterm have ongoing lung disease throughout childhood that appears to be getting worse," Dr Simpson said.

"Understanding the mechanisms of why lung function is declining also guides us to potential new therapies.

"Long-term follow-up is of increasing importance, with growing concerns that survivors of preterm birth – particularly those with bronchopulmonary dysplasia (BPD) – will go on to develop premature COPD (chronic obstructive pulmonary disease) in adult life; a hypothesis that is strengthened by the high prevalence of emphysema and obstructive lung disease in young adult survivors of old BPD.



*"We have found that children born very preterm have ongoing lung disease throughout childhood that appears to be getting worse,"*

Dr Shannon Simpson

Just over 8 per cent of WA babies are born prematurely, mostly between 32 and 37 weeks. Those born before 32 weeks are most at risk of ongoing lung problems.

A premature baby may need ventilation, where a machine does the work of breathing, or continuous positive airway pressure (CPAP) where the baby does the breathing with some extra air pressure to keep the lungs open between breaths.

"Our research also suggests that this ongoing lung disease may be related to persistent inflammation in the airways after preterm birth. There are no current treatments or best practice guidelines for treatment of a child presenting to a doctor with ongoing breathing problems after preterm birth."

### What's next?

- ▶ Continued monitoring of the study group: "This longitudinal cohort are now adolescents and we would like to study them again to see how their lungs are going now."
- ▶ A proposed trial of inhaled corticosteroids: "ICS is an anti-inflammatory agent that is used in some other lung diseases, such as asthma. If the ongoing lung disease is inflammatory in nature, then it is possible that this medication may stop the progression of disease."
- ▶ Working on the inflammatory mechanisms.
- ▶ Understanding if the airway epithelium is playing a role in ongoing lung disease.



**Bronchopulmonary dysplasia is the most significant chronic lung complication of premature birth. It causes the lungs to grow abnormally or be inflamed and means the child can have asthma-like symptoms throughout his or her life.**

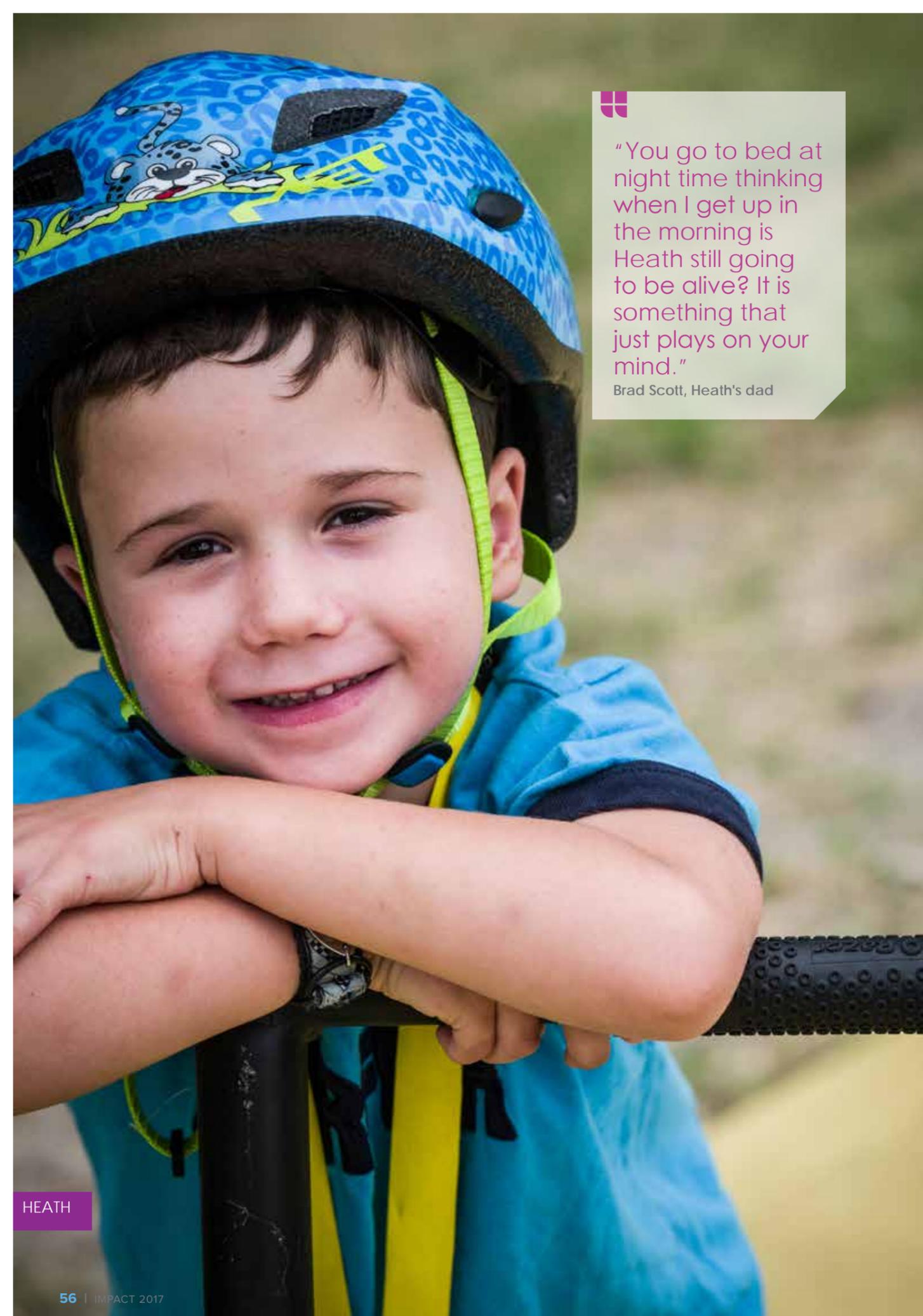
**If a premature baby is lacking surfactant, a protective substance crucial to aiding the breathing process, artificial surfactant may be given.**



Jan and David Lord have been supporting the preemie babies research of Dr Shannon Simpson.



DR SHANNON SIMPSON



“You go to bed at night time thinking when I get up in the morning is Heath still going to be alive? It is something that just plays on your mind.”  
Brad Scott, Heath's dad



## HIGH HOPES FOR PREVENTING LOWS

Researchers led by the team at the Children's Diabetes Centre at Telethon Kids have taken a key step along the way to a fully automated closed-loop insulin delivery system.

Experiencing a 'hypo' is one of the main worries for people living with type 1 diabetes – if left untreated, very low blood glucose levels can cause a seizure or coma.

The team at the Children's Diabetes Centre, working with five hospitals across Australia, has conducted the first in-home trial of an insulin pump designed to predict and prevent hypoglycaemia – another step on the way to a fully automated closed-loop insulin delivery system.

The Predictive Low Glucose Management study involved 154 participants aged 8-20 years who were on insulin pump therapy.

Used in conjunction with sensors, the pump incorporates continuous glucose sensor data into an algorithm and has a suspend-before-low function which cuts off the basal insulin delivery when a hypo is predicted. This potentially can reduce the duration and frequency of hypoglycaemic episodes.

Dr Mary Abraham, of Princess Margaret Hospital, said hypos were disruptive to both the child and their family.

“The fear of hypoglycaemia may lead to restriction and avoidance of activities, exercise, school camps and sleepovers,” Dr Abraham said. “Parents resort to overnight testing to prevent overnight hypos, impacting on their sleep and affecting their daily functioning.

“Prior to this randomised controlled home trial, we had conducted in-clinic studies to establish the effectiveness of the system in preventing hypoglycaemia and found that the system reduced the need for treatment of hypoglycaemia with exercise, excess insulin bolus and increased overnight basal.”

Symptoms of low blood glucose levels include shaking, dizziness, drowsiness, confusion, headaches and irritability and can be caused by mismatch between insulin, food and activity.

The system will be of particular benefit to those with impaired awareness of these lows.

“These children are at increased risk of severe hypoglycaemia as they are not able to perceive hypo symptoms and take adequate treatment,” Dr Abraham said.

“Hypoglycaemia avoidance is known to restore awareness and the use of this system by preventing hypos will therefore be possibly beneficial in improving awareness.”

Fifteen-year-old Sophie Lumby, who was diagnosed with type 1 diabetes at the age of four, was one of the trial participants.

“I thought it would be interesting to trial a new pump and see what effect it would have on managing my diabetes and what it would be like to have the suspend-before-low function on a pump and if it would actually work to prevent lows,” Sophie said.

“In school, I find it really difficult to do tests when I am low as

*In WA, about 120 children are diagnosed with type 1 diabetes every year.*

*An insulin pump is a small portable device that is attached to the body to deliver insulin. Basal refers to the amount of insulin delivered continuously to mimic regular insulin production by a pancreas. Bolus is an extra dose of insulin given to cover carbohydrate intake or to bring high blood glucose levels back into normal range.*

*People with type 1 diabetes aim to keep their blood glucose levels as close to normal as possible and avoid episodes of hypoglycaemia (low blood sugar) that can lead to loss of consciousness, coma and occasionally death, and hyperglycaemia (high blood sugar), which increases the risk of long-term health complications.*



MARY ABRAHAM, TIM JONES, CHARLES CZANK, LIZ DAVIS, JENNIFER NICHOLAS

my mind doesn't think straight and I can't seem to recall all the necessary information I need. Before tests I get very stressed managing my sugar levels as I am always worried that I will go low and that it will affect my marks.

"The suspend-before-low function definitely did help me in avoiding hypos – it didn't completely eliminate all hypos yet it did make it a lot easier to manage what my blood glucose level was doing. It also helped my parents and I sleep through the night a little easier knowing that the pump would suspend me before going low, which should prevent anything drastically bad from happening.

"I hope that trials like this will help people better manage their diabetes and give more people a chance to go on to the pump as it is a real life saver."

Dr Abraham said the biggest challenge was ensuring the person wore and used the sensor effectively.

"For the system to work effectively, one needs to wear the sensor continuously and calibrate it regularly," she

said. "The sensor is another attachment to the body just like the insulin pump and the challenge is to maintain its continuous use, especially when the child and/or parent is troubled by mechanical and technical sensor issues."

**What's next?**

"We have commenced our trial on the next-generation technology, the closed-loop system, which is an automated insulin delivery system which adjusts the basal insulin delivery according to the sensor glucose levels. The patient has to bolus for his meals and hence the system is referred to as hybrid closed-loop system. This will potentially further improve the time in target range."



This research is supported by the Juvenile Diabetes Research Foundation.



## THE HIDDEN BURDEN OF DIABETES

When Jodie and Brad Scott welcomed their fourth child Heath into the world, they were prepared for the many sleepless nights that come with caring for a newborn.

What they did not expect, was that five years later they would still be waking up three times a night to check on their son.

"You go to bed at night time thinking when I get up in the morning is Heath still going to be alive? It is something that just plays on your mind," Brad said.

Heath was diagnosed with type 1 diabetes when he was three years old after he lost a dramatic amount of weight in a short period of time.

Since then, his parents have had to give their son round the clock care in order to keep his blood glucose levels within a healthy range.

If they fall too low, Heath could fall into a diabetic coma.

"We test him before he has dinner, we test him again at 10pm, quite often I'm up a 1am testing him, at times it's another 4am test," Brad said.

"If you think back to the times you've had a newborn baby and you're up every two hours doing a feed - the impacts it has on your body. A baby



BRAD, HEATH AND JODIE SCOTT

grows out of that, a diabetic doesn't."

Along with the late night checks, Jodie and Brad have to count the carbohydrates Heath eats at every meal and then use a mathematical formula to determine how much insulin he needs to be injected with.

"The idea of deliberately hurting your child because you need to keep them alive, it's a hard thing to process and it's a hard thing to come to terms with," said Jodie.

"Every time I did them, it hurt him and it's not why I'm here."

The often sleep deprived parents also live in fear they will get the dosage of insulin wrong.

"It is a life threatening disease, you're actually treating your child with basically something that can kill them. You get the dose too high you could actually kill your child," said Brad.

They also worry about the long term health effects of diabetes.

As he ages, Heath is at greater risk of developing complications such as eye disease, heart disease and stroke.

"One of the hardest things for me to hear recently, was Heath saying 'I can't wait until I get bigger and I grow up because then I will be like the boys and I won't have diabetes'," said Jodie.

"Having to explain to a child that this is their life, makes it really hard."

Both Jodie and Brad hope research will not only provide better treatment options for their son, but also one day a cure.

"Anything that helps in any way, either from knowing how it occurred, to why it occurred, and if we can stop that in future generations, that would be fantastic, to not have kids being diagnosed with this anymore," said Jodie.

"We deal with what we deal with now but I'd love him to have the chance to have a normal childhood, just be a kid," said Brad.



COLLABORATING  
**FOR IMPACT.**



# TELETHON KIDS KIMBERLEY: RESEARCHERS AND COMMUNITIES WORKING TOGETHER

In 2016, with enabling donations from Denby Roberts, Stan Perron, Wesfarmers and Centurion, the Institute established a permanent presence in the Kimberley. Our aim was to be closer to the children, families and services we work with, and to have Kimberley communities come to see us as a committed, familiar and trustworthy partner. Only in this way could we work closely on the child health issues they felt were most critical. We call our presence there **Telethon Kids Kimberley**.

Based in Broome, Telethon Kids Kimberley provides a launching site for cutting-edge, place-based research across Western Australia's north.

Our presence in the Kimberley also provides the opportunity to deliver on our commitment to build capacity, and in particular create research career opportunities and pathways for Aboriginal people to work in their own communities.

John Jacky, a local Aboriginal man based in Broome and coordinating Telethon Kids Kimberley, says our researchers have the opportunity to work closely with communities, families and Aboriginal Community Controlled Health Organisations.

"We want to ensure that research is appropriate, respectful and culturally-responsive and leads to better health policy, services and support that engages and responds to the needs of local Aboriginal children and families," says John.

"This is something that has previously been difficult to do with the 'fly-in, fly-out' nature of past research."

But what sort of research is necessary? After all, the people of the Kimberley are proud, have a strong sense of identity and

culture, and many families are thriving.

However, a complex interplay of socio-economic factors, disempowerment and the legacy of colonisation and government policies has meant there are a number of families who are struggling. This is reflected in significantly poorer health outcomes for Kimberley Aboriginal children throughout childhood and into adulthood.



*"We know that by working in close partnership with communities we have every opportunity to make a difference in the lives of all children."*

John Jacky

For example, 44 per cent of Aboriginal children in the Kimberley were rated as developmentally vulnerable in the 2015 Australian Early Childhood Census, as compared to the State average of 23 per cent.

Aboriginal children in the Kimberley suffer higher rates of

ear, skin and lung infections and the serious lifelong conditions that can result from these infections such as kidney disease, rheumatic heart disease, permanent hearing loss and premature death. And the rates of Aboriginal youth suicide and self harm in the Kimberley are more than seven times the national average.

John says developing meaningful community-led strategies that empower families and services to respond to such issues requires strong partnerships between communities, health services, researchers, government agencies and non-government organisations.

"We understand that and that is why we're here," says John.

"Happily, Telethon Kids is not going it alone in the Kimberley."

Since setting up in Broome, we have developed an important collaboration with the Kimberley Aboriginal Medical Services and its members, including the Broome Regional Aboriginal Medical Service, Derby Aboriginal Health Service, Ord Valley Aboriginal Health Service, Yuri Yungi Aboriginal Health Service in Halls Creek, and the Nirrumbuk Environmental Health and Services.

"We have agreed that all parties in this collaborative agreement will help will finalise a process for introducing and co-designing research to be conducted together in the future," says John.

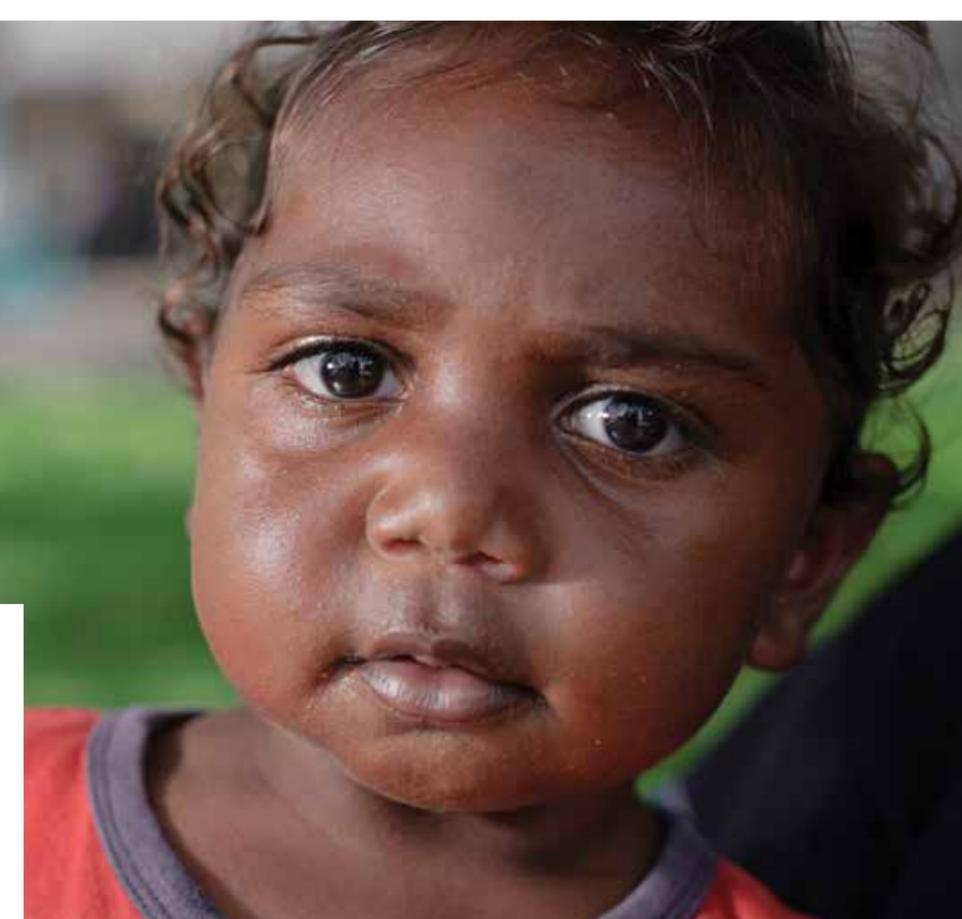
"We believe the promise of good health and education should exist for all children, and are especially concerned about the vulnerable children and families in the Kimberley.

"We know that by working in close partnership with communities we have every opportunity to make a difference in the lives of all children.

"We will be able to bring about real changes on the ground. And this is ground we now share."



Telethon Kids Kimberley is supported by Denby Roberts, Stan Perron, Wesfarmers and Centurion.



## What's next?

The Kimberley communities have been supportive of our presence. They have also been responsive. Through the first ever Kimberley Aboriginal Child and Family Health Research forum co-hosted with the Kimberley Aboriginal Medical Services last year, attendees shared with us what research we could do together that would be most meaningful to them going forward.

- How do we build resilience in our young people in order to reduce self-harm and suicide?
- What can we do for our children now that will prevent chronic diseases in their later years?

- What are the best strategies for preventing infectious diseases?
- Are there ways health services can increase their effectiveness and improve service delivery?
- How do we develop culturally-informed parenting skills programs that support families and adequately prepare young children for school?

Our researchers will be working on these significant research questions in the coming years.



BREE WAGNER AND SUE CHERELE



## GETTING KIDS INTO GEAR FOR LEARNING

Researchers from the Telethon Kids Institute are relying upon the local knowledge of Aboriginal women from the remote Fitzroy Valley region to run a school program designed to help children, including those with FASD, adjust their levels of alertness and attention in the classroom.

Have you ever thought about why you reach for that cup of tea before going into a meeting?

Rather than simply enjoying the taste or needing the caffeine hit, it could be that bringing the cup to your mouth and taking a sip is helping you become more alert or getting into 'just the right gear' for listening.

It is this philosophy that underpins the Alert Program® Study which is led by Dr James Fitzpatrick, Head of the Alcohol, Pregnancy and Fetal Alcohol Spectrum Disorders Research Group.

Study coordinator Bree Wagner said the program taught children their bodies functioned like a car engine and how to adjust their levels of alertness, or 'change gears'.

"Like a car you can be in high gear, which is when you are feeling hyped up or agitated, or low gear where you might be feeling lethargic, droopy, tired or flat," Ms Wagner said.

"The goal is to get kids' engines into just the right gear for learning in the classroom where they are alert, attentive and focused.

"The program is really flexible so you can adapt the way you teach it or describe the concepts to suit the particular setting that you are working in."

Ms Wagner and her team at the Institute worked with the program developers, local occupational therapists and teachers to modify

it to suit a school setting so it could be taught as a series of lessons. They are currently in the process of implementing the Alert Program® in nine remote schools across the Fitzroy Valley in the Kimberley region of Western Australia.

"We hope that it makes a difference to the kids' skills, so they can engage with learning, and therefore improve their educational outcomes for the future," Ms Wagner said. "And carry those skills over to their post-school lives because they're skills we all use every day.

While all children attending primary school in the Fitzroy Valley will receive the program, the study will also investigate if the program is also a potential intervention option for children with FASD.

"Kids with FASD often have greater problems with attention, their memory and problem-solving skills," Ms Wagner said. "Using different sensory strategies like having something in your hand to fidget with, or chewing and working your muscles can be regulating."

Adults automatically used sensory strategies like having a cup of tea - a tool for the mouth - or fidgeting with their pens - a tool for their hands - to self-regulate.

"As adults no one thinks twice about doing these things," Ms Wagner said.

"But in the classroom, kids will often need to get some movement, and they're not going to just hold on to the chair and do something subtle, they might get up and run around. That's really distracting to other kids and the teacher could think that's bad behaviour."

A group of Aboriginal women from the Fitzroy region have been employed as community researchers on the project.

"The community researchers have been integral to fostering relationships between researchers and community

*"The goal is to get kids' engines into just the right gear for learning in the classroom where they are alert, attentive and focused."*  
Bree Wagner

"We are building capacity in teachers and support staff, such as Aboriginal education officers and education assistants, to deliver a curriculum version of the Alert Program®. Then we are measuring the outcomes for the children before, after and at follow-up."

members, providing cultural guidance and language support and working in a two-way partnership to run the project," Ms Wagner said.

Muludja Community woman Sue Cherele is lead community researcher on the project. She has already seen the difference the program can make, not only in the classroom, but in the home as well.

"We did a workshop with parents so they could understand why kids were playing up and getting in trouble as well," Ms Cherele said. "We have seen a difference from the teachers and the parents getting to better understand their children. A better connection with their children. So when the kids go back home they understand what the kids are talking about, like whether their engine is high or low."

Ms Cherele said people in her community lived close to each other, and improvements in relationships and behaviour had been noticeable.

"In my community everything is much better now," she said. "The kids know what to do when they are feeling bored, or feeling high or low."

"The kids know you aren't always just right. They learn you have to be in high gear if you are going to the football, you have to be in high gear to cheer for your team. But not in the classroom."

Ms Wagner said the community researchers, from four Aboriginal language groups, were equally as important to the success of the project as Institute staff.

"Without their support and their guidance, the project would not be able to be what it is," she said.

"We are able to share our knowledge around research, the project and the science, but we rely heavily on our community researchers to provide their knowledge and expertise around language, around cultural protocols, how to build relationships with communities, and introducing us to families."

For now, teachers in these communities are learning how to recognise when children are in high and low gear and strategies to help them switch – like doing chair push-ups or wriggling on a cushion.

The program could turn traditional teaching methods in schools upside down.

"Teachers need to be in tune with the kids to know what strategies will work for different kids and offer them more class-



appropriate strategies than perhaps the kids will choose themselves," Ms Wagner said.

Rather than seeing a child that cannot sit still as naughty, it's about realising they might need a less disruptive method for switching gears.

#### What's next?

Analysis of the findings in 2018 will allow the team to prepare guidelines for the use of the Alert Program® with children who have impairments in self-regulation and executive functioning in similar settings.



100 Women is supporting the empowerment of Aboriginal community researchers on this project through training and development opportunities.

## WHAT IS FASD

**Fetal alcohol spectrum disorder (FASD) is caused by prenatal alcohol exposure and can result in lifelong physical, behavioural and neurocognitive abnormalities.**

*FASD can affect a person's memory, thinking, learning, focus, attention behaviour and emotional control.*

**Disabilities associated with FASD significantly impact on quality of life and social and economic participation.**





# NOVEL CoLab SEEKS TO NARROW THE EARLY CHILDHOOD GAP

A new partnership between Telethon Kids and the Minderoo Foundation is trying to change the ways Government and communities address deep disadvantage and neglect.

There's little question that existing service systems and policy settings in Australia have failed to make the change needed to improve the developmental status of our most disadvantaged children, with the gap continuing to widen between the most advantaged and least advantaged.

It's a gap that a new partnership between the Telethon Kids Institute and Minderoo Foundation, known as CoLab – Collaborate for Kids, is determined to address.

As CoLab Director Professor Donna Cross describes it, the partnership brings together the best minds around the world and Australia to combine what we know about the importance of the first 1000 days of life.

Professor Cross said the funding provided by Minderoo had created a unique opportunity for Telethon Kids to accelerate the implementation of practical and relevant early childhood research throughout Australia for those who need it most.

"We want to help deliver an early childhood system that is developed collaboratively, informed by evidence and driven by leadership with long-term thinking," Professor Cross said.

"Our mission is really novel – trying to mobilise and bring policymakers on board with researchers and practitioners.

"This is a new role for researchers where we work alongside

policymakers rather than conduct studies from the outside.

"It is clear we need to work with government in a different way because improving the futures of our children requires non-traditional partners working together over a sustained period of time."



*"It is clear we need to work with government in a different way because improving the futures of our children requires non-traditional partners working together over a sustained period of time."*

Professor Donna Cross

As its name suggests, collaboration is at the core of how CoLab will work.

In 2016, the CoLab team consulted extensively with stakeholders and undertook research to develop a strategic plan to guide its work for the next five years.

A scoping study was undertaken to collate all Telethon Kids research activities conducted over the past five years for children from pre-birth to eight years of age. Findings indicated

that while a significant amount of research was being conducted or planned, several critical gaps existed for economically disadvantaged families and their children – offering potential opportunities for CoLab.

A number of consultation processes were also undertaken, including a Strategy Summit involving more than 70 participants from the social services, early childhood, education, research, government and philanthropic sectors, as well as stakeholder meetings and a Delphi survey.

CoLab is also collaborating at a global level, evidenced by a series of events in March featuring one of the world's leading child development experts, Dr Jack Shonkoff from the Center on the Developing Child at Harvard University.

Dr Shonkoff met state government ministers, shadow ministers and heads of government agencies who work with families, and presented to more than 800 early childhood policymakers and practitioners.

As part of the recent announcement by the Minderoo Foundation of additional funding, CoLab has commenced partnering with innovative and leading research centres around the world including the Harvard Center on the Developing Child.

"These partnerships will enable us to take what we're learning to scale and allow us to pursue a bipartisan cross-government



long term commitment to turn around the sorts of difficulties that nearly one in five children could potentially experience in Australia," Professor Cross said.

### What's next?

- Develop projects and tools to help policymakers, practitioners and communities, such as the Child Development Atlas. Funded by The Ian Potter Foundation with support from the Minderoo Foundation, the Atlas will bring data sources together to produce geo-spatial maps to help service providers and community members improve how services are delivered in their communities.
- Coordinate economic research to support policymakers and practitioners determine the long-term benefits and costs of early year's services in Australia. This economic analysis will be based on a 'whole child approach'

looking at the long-term benefits to children's health, education and social wellbeing.

- Translate knowledge into tools and products to address issues such as the impact of poverty on the developing child, and why the early years matter.
- Develop a declaration which outlines the empirical evidence showing the need to support very young children and their families, especially those facing adversity; and highlight a call to action, based on this evidence.
- Harness the knowledge and skills of experts from across Australia to develop a guide on how to deliver place-based approaches.
- Develop long-term collaborative relationships with leading early childhood research groups such as the Harvard Center for the Developing Child.



CoLab was made possible by Minderoo's founding commitment of AU\$1m annually. Minderoo recently announced an additional \$75 million investment in early childhood development, which provides an opportunity to expand the work CoLab is already doing and pursue unprecedented new partnerships, such as the one with the Harvard Center.

Nicola Forrest explains:

"Minderoo's investment in CoLab represents our belief that the translation of evidence to practitioners, policymakers and families is just as, if not more important, than the generation of new knowledge itself. Evidence without translation is a lost opportunity.

"By ensuring every child starts their education with the social, emotional and physical skills to learn, we will build a stronger, connected and more vibrant Australian community."



KIDS AT PLAYGROUP IN TONGA  
PHOTO: WORLD BANK/CONOR ASHLEIGH



## PLAYGROUP PROGRAM TRANSFORMS EARLY LEARNING IN TONGA

In Australia, community playgroups are seen as the 'soft touch', with a focus on more structured learning popular. But a research project in Tonga is finding the benefits can last a lifetime.

Associate Professor Sally Brinkman is encountering a major problem with her community playgroup study in the Pacific island nation of Tonga – they have proved too popular. Although half of the nation's communities have new playgroups set up for the study, many of the parents of children currently not allocated places are travelling to nearby communities to allow their children to take part.

"In research terms we call that contamination, but in the real world it's great that everybody likes them and they're taking advantage of them," Associate Professor Brinkman said.

Although the government of Tonga has recently enshrined in legislation their intention to deliver preschool to all children living on the nation's 54 islands, the cost of doing so has been prohibitive.

That is where the Global Practice for Education's funding to undertake projects across the Pacific – the Pacific Early Age Readiness and Learning Program (PEARL), managed by the World Bank – has filled the gap.

The PEARL program in Tonga provides a range of services, including public awareness campaigns, the delivery of community playgroups to support child development and school readiness, and teacher training to support early reading. In addition, technical assistance has been provided to support monitoring and evaluation of

child development and early reading skills.

Associate Professor Brinkman, Head of Child Development and Education at the Telethon Kids Institute, is a world leader in measuring development across populations, having developed Australia's national census of early child development, the Australian Early Development Census.



*"Being able to support lower-to-middle income countries in a culturally appropriate way has been very satisfying,"*

*Professor Sally Brinkman*

Her work ensured Australia was the first country in the world to conduct a whole-of-country census of child development in all five-year-olds. The census captures all aspects of development including social and emotional skills, communication skills, physical health and language and cognitive development in five-year-olds.

In conjunction with local community members in Tonga, Associate Professor Brinkman has

now created a new measure of child development: the Early Human Capability Index. The index is not only reliable but also culturally appropriate and locally owned. Now Tonga is the second country in the world to benefit from knowing more about the needs of all their nation's children, with all children aged three to five included in the census.

"Being able to support lower-to-middle income countries in a culturally appropriate way has been very satisfying," Associate Professor Brinkman said.

In an Early Childhood Development in Tonga report, former Tonga Education and Training Minister Ana Maui Taufe'ulungaki said Tonga had been concerned it was not making satisfactory progress in its educational performance, and that it lacked reliable data on which to assess its performance.

Tonga hoped the PEARL program would benefit all children, Dr Taufe'ulungaki said.

Following the census in 2014 Associate Professor Brinkman, along with the World Bank and the South Australian Playgroups Association, has been leading the delivery of community playgroups throughout the nation; and later this year will conduct a second national survey to determine the impact.

"My research theory, that we are starting to try and test, is even though community playgroups



## COMMUNITY PLAYGROUPS IN TONGA

Local community members were trained to be able to deliver the playgroups.

"School readiness is the foundation for educational success, and this program is helping raise awareness of the importance of child development," Associate Professor Brinkman said.

"The data we collect will allow policymakers to better provide the help that children and families need."

### What's next?

A second census of early development will be undertaken in August this year, with the results to be ready by the end of 2017.

Associate Professor Brinkman and her team worked with the Playgroups South Australia to create resources that would suit the Tongan communities.

They used local products to ensure sustainability, for instance coconuts, sand, sticks and stones for sensory play activities. New community playgroup leaders received training from Playgroups SA, and a starter pack containing activity lists, blocks and toys.

"We are trying to enhance the community's understanding of how to use local products to teach the basics of early maths and literacy, social and emotional development," Associate Professor Brinkman said.



"You don't need much money to do that, but you do need an understanding of child development and an awareness of how to use everyday moments to enhance a child's learning and interest in learning. For that knowledge we relied on Playgroups SA."

## CHANGING CHILDREN'S LIVES THROUGH LEARNING

An early cost benefit analysis has revealed that **Tongan children attending the community playgroups will earn 17 to 22 per cent more as working adults.**

Professor Brinkman said the figure reflected the children's enhanced cognitive development through early learning, which impacted on their school readiness and led to doing better in school assessments as they got older.

Previous studies had determined the difference this would make to future earnings.

are seen as the 'soft touch', they're the only early learning environment where you have the parents involved as well," Associate Professor Brinkman said.

"By providing these activities and doing them with parents participating, it means you are teaching the parents as well as enhancing child development. You are increasing 'dose', to use medical terminology.

"You might go to two sessions a week, but because you have been taught how to make playdough, or do learning activities, it means you can do them at home. You are increasing a whole lot of parenting skills and confidence, and therefore child development. Whereas you don't get that if you are sending your child to day care or similar."

The implementation of community playgroups has

relied on a collaborative effort between the World Bank and numerous organisations, including the nation's government, churches, parents and community volunteers, Playgroups South Australia, and the Telethon Kids Institute.

Associate Professor Brinkman said community leaders had taken ownership of the playgroups, which began rolling out in 2014. Churches were raising funds to help support them, and volunteers from local communities were enhancing the delivery of them – for example building new huts to house them.

Community playgroups were the answer for Tonga, which needed early learning services that were universally available across 54 islands; were relatively cheap; and could benefit from the strong community spirit that exists across Tonga.



KIDS AT PLAYGROUP IN TONGA  
PHOTOS: WORLD BANK/CONOR ASHLEIGH



## PARTNERING TO END RHEUMATIC HEART DISEASE

Researchers from the Telethon Kids Institute are teaming up with leading health organisations from around Australia, sharing expertise and knowledge to end rheumatic heart disease (RHD) in this country.

Although it is generally considered to be a disease of developing nations, RHD persists in Australia's Aboriginal communities at some of the highest rates in the world, affecting one in 43 Aboriginal people living in remote and rural areas.

The damage to the body caused by RHD is deadly – resulting in heart failure and other complications including stroke – but adhering to the prevention regimen of a penicillin injection every 28 days for a minimum of

10 years can prove very difficult.

Telethon Kids Institute Director Jonathan Carapetis leads the national Centre for Research Excellence to End RHD (the END RHD CRE), which is focusing on a series of evidence-based interventions to prevent and treat the infections that lead to acute rheumatic fever and RHD.

These recommendations will form a National Endgame Strategy that will be put forward to the Australian Government in 2020. The team is also working



*Young Aboriginal Australians in the Northern Territory are up to 122 times more likely to have rheumatic heart disease than their non-Aboriginal counterparts.*

on multiple strategies for the longer term, including more effective treatment options via long-acting penicillin, and developing a vaccine against the bacterial cause of the infection, *Group A streptococcus*.

In support of the Endgame Strategy, Telethon Kids is spearheading an alliance of organisations who will act as the critical link between the research of the END RHD CRE and the health workers, families and community groups that will work together to end RHD in Australia.

Called the END RHD Coalition, the founding members of the partnership include the Australian Medical Association, Australian Heart Foundation, National Aboriginal Community Controlled Health Organisation (NACCHO), Menzies School of Health Research, Aboriginal Medical Services Alliance Northern Territory (AMSANT) and the END RHD CRE based at Telethon Kids Institute.

"The new Coalition aims to mobilise the organisations and individuals who will need to work together to inform as well as implement the National Endgame Strategy," Professor Carapetis said.

"This will complement our research agenda to ensure that the Endgame Strategy is practical, acceptable and appropriate to communities, clinicians and government, and that we are ready to hit the ground running when the strategy is finalised.

"But of course we are not waiting until 2020. We know a lot about what needs to be done right now, so the Coalition will also raise awareness of the importance of RHD, and



the resources and strategies required to make a difference.

"By working together, we can bring the burden of RHD for Aboriginal Australians down to the same level as non-Aboriginal Australians – ending the disparity of the disease once and for all," Professor Carapetis concluded.

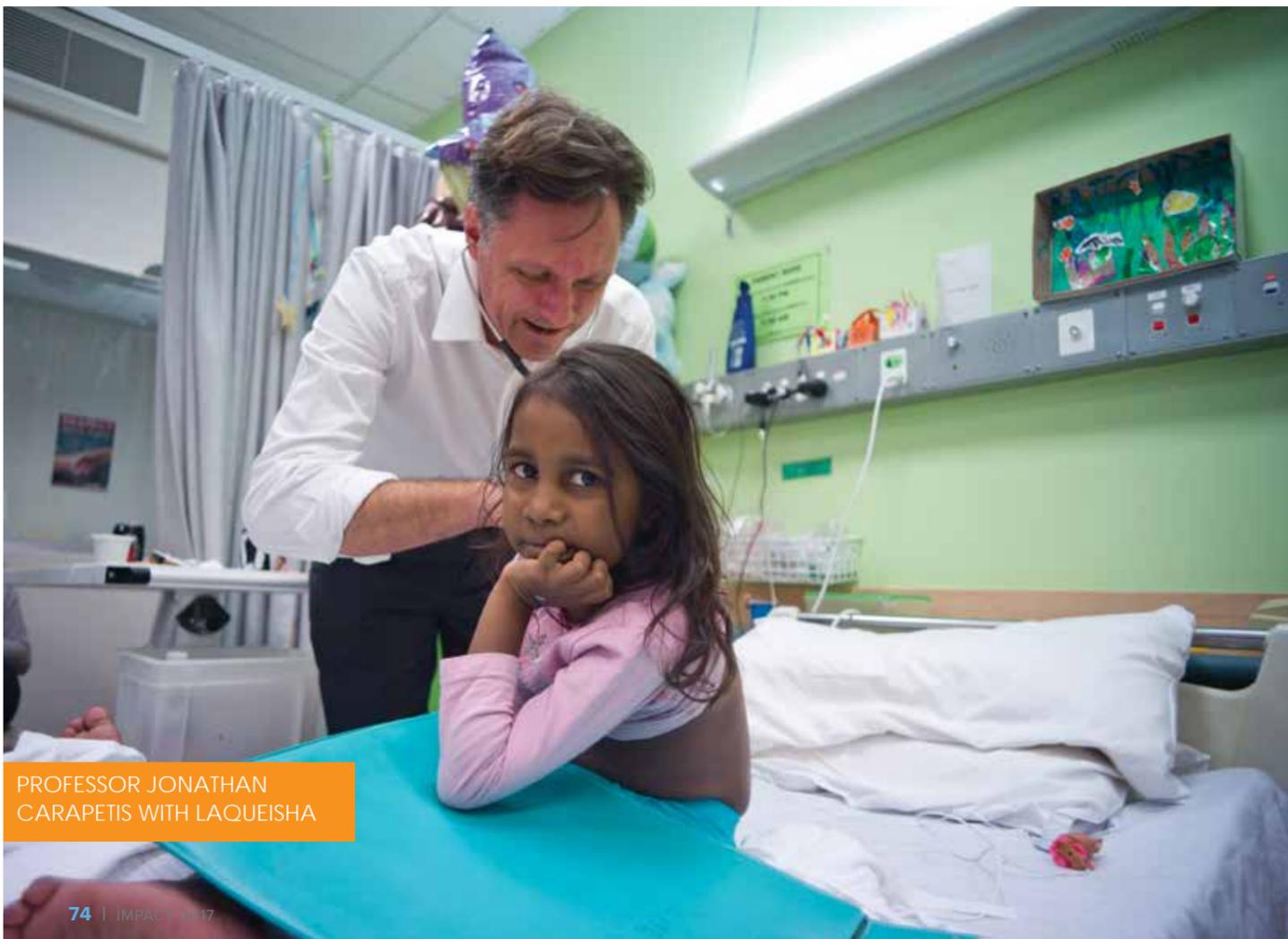
### What's Next?

A broad range of peak representative bodies, including Aboriginal health providers, cardiac societies and community organisations, will be approached to join the Coalition and provide their input & support for the 2020 National Endgame Strategy.



*The Wesfarmers Centre of Vaccines & Infectious Diseases at the Telethon Kids Institute was established in 2014 thanks to a \$5 million foundation grant from Wesfarmers Limited.*

*The Centre aims to prevent and improve the treatment of infectious diseases in children and adolescents, with reducing the high rates of rheumatic heart disease, lung, and ear infections in Aboriginal children a key area of focus.*



PROFESSOR JONATHAN CARAPETIS WITH LAQUEISHA

**KIDS** are at the ♥  
of everything we do

For further information about donating to the Telethon Kids Institute, subscribing to our mailing list or joining us for a tour of our facilities please contact us on:

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