

IMPACT REPORT 2019

TELETHON
KIDS
INSTITUTE
Discover. Prevent. Cure.



KIDS are at the ❤️
of everything we do

CONTENTS

INTRODUCTION

- 4 Message from our Director
- 6 Our award-winning researchers
- 8 Our research at a glance

TRANSLATION

- 16 Smooth sailing for Drina thanks to burden-breaking technology
- 19 New focus on type 2 diabetes
- 20 Friendly Schools goes from strength to strength
- 22 Landmark folate research recognised as major public health achievement
- 24 Unique Clinikids a marriage of research and practice
- 26 New friend to improve social attention of kids with autism
- 27 National Guideline provides uniform approach to autism diagnosis
- 28 Campaign pays off as alcohol labelling gets green light
- 30 Banksia Hill Project's ripple effect
- 32 Alcohol screening tool transforming maternity practice
- 35 Atlas maps a pathway to happy, healthy childhood
- 36 New drug therapy provides hope for kids with cystic fibrosis
- 38 Game aims to alleviate depression for trans youth
- 40 Helping hand on home stretch to adulthood

PARADIGM SHIFT

- 46 Rapid response to e-cigarette findings
- 49 Let the sun shine in
- 52 Grant giving wings to a generation of Indigenous leaders
- 55 Horses helping healing
- 56 Graduation goals for community researchers
- 58 Pioneering research could be key to keeping cancer in check
- 61 WA-first technique fast tracks urgent vaccine policy
- 62 Researchers unlock key to slowing leukaemia progression in kids

COLLABORATING FOR IMPACT

- 66 Early Years Initiative off to strong start
- 68 Bobbie brings baby's brain to life
- 70 'Mama' Deb's dedication to saving children in Papua New Guinea
- 73 Warajanga Marnti Warranja – together we walk on country
- 76 FASD conference unites policy, science and lived experience
- 78 Parents helping to put FASD into perspective
- 79 Driving a vaccine revolution
- 81 Vital role for Telethon Kids
- 82 Global consortium aims to protect babies from their first week of life
- 83 Bill & Melinda Gates Foundation grant aims to prevent deadly infections in early life
- 84 People power takes tiny study to the next level
- 86 Karratha family jump at chance to join sleep study
- 88 Collaboration key to wet cough prevention
- 92 Child removal data fuels case for change

IN THE PIPELINE

- 96 Embracing the mental health of our children and young people
- 100 Busting myths around stillbirth
- 102 WA data crucial to key stillbirth finding
- 103 Helping kids get the most out of school
- 106 Energy drinks not OK for kids
- 108 Personalised analytics propel rare disease diagnoses
- 110 Ending the cycle of 'not knowing'
- 111 Big data science may help unlock simple test for asthma
- 114 Ending deadly heart disease finally within our sights
- 117 Finding answers for Tenaya: from a sore throat to open-heart surgery
- 119 Guidelines struggle to keep pace with technology
- 121 ORIGINS Project grows in leaps and bounds

Our special thanks to those who have contributed to this report: Tamara Hunter, Amy Birch, Caroline Wise, Tammy Gibbs, Elizabeth Chester, Stacey Campbell, Amanda Lewis, Alana Buckley-Carr, Kate Harford, Kerry Faulkner, Alison Batcheler, Kim Cousins, Tobias Schoep, Robert Duncan, Tony McDonough, Ross Swanborough, and the researchers and families whose stories we have shared.

MESSAGE FROM OUR DIRECTOR

 Jonathan Carapetis AM



In 2012, we committed to creating a new blueprint for a medical research institute – one that judges itself by its ability to make a difference. We wanted to ensure our research was being translated into real-life outcomes for kids, young people, families and communities. While there is still a long way to go, we have taken big strides forward in delivering on that promise.

Fast forward to 2019, and our new strategic plan has an even stronger and bolder focus on impact.

Our mission is clear: to improve the health, development and lives of children and young people through excellence in research – and importantly, the application of that knowledge.

Impact, making a measurable difference, is the first of the four strategic pillars that underpin our work.

For our research to have impact, it not only needs to be high quality and innovative, it must be useful and used.

That's why we are working closely with community, practitioners and policy makers to set research priorities. Research also needs to be translated and disseminated locally, nationally and internationally so it can lead to meaningful changes to policy and practice.

Our Impact Report shows that this is more than simply rhetoric. It highlights research that is making a difference. Some of our research is already being applied to improve real world outcomes for kids. Some is well along the impact pipeline and some research is changing the way we think about complex problems.

Collaboration and partnerships are integral to achieving our mission so we also highlight some of the special partnerships we have with the community, government, service providers and industry.

Making a difference inspires all our work at Telethon Kids and I am grateful to have committed staff who are passionate about living up to that promise, as you will see from the stories in this report.

To find out more, visit our website at telethonkids.org.au

Jonathan Carapetis AM
Director



Professor Jonathan Carapetis with Nirvana in the Discovery Centre, supported by Lotterywest

OUR AWARD-WINNING RESEARCHERS

The excellence of Telethon Kids Institute researchers has been recognised at multiple State and National awards ceremonies over the past year, including the Queen's Birthday Honours, the WA Premier's Science Awards, and the annual WA Business News 40under40 Awards.



Professor Carapetis with WA Governor Kim Beazley

Professor Jonathan Carapetis AM Member of the Order of Australia (AM)

In June 2018, Institute Director Professor Jonathan Carapetis was made a Member of the Order of Australia (AM). The award, made as part of the annual Queen's Birthday Honours, recognised his significant contribution towards paediatrics and medicine – specifically his commitment to diagnosis, treatment and prevention of rheumatic heart disease. Later that month, Professor Carapetis and Head of Aboriginal Health Research, Glenn Pearson, were finalists at the 2018 Western Australian of the Year Awards.

Dr Melissa O'Donnell Woodside Early Career Scientist of the Year

Dr Melissa O'Donnell was named Woodside Early Career Scientist of the Year at the 2018 Premier's Science Awards, in recognition of her internationally respected research on child abuse and neglect. Dr O'Donnell, co-lead of the Institute's Linked Analytics and Social Policy Team, is one of few researchers in Australia to have extensively utilised linked government data to investigate factors that increase vulnerability to child maltreatment, and outcomes for these children (see stories on her work, pages 40 and 92).



Dr Melissa O'Donnell with Minister Dave Kelly and Woodside's Tom Ridsdill-Smith

Dr Sally Brinkman NHMRC Research Excellence Award

Dr Sally Brinkman, Head of the Child Health Development and Education team and Director of the Fraser Mustard Centre in Adelaide, was honoured with an NHMRC Research Excellence Award for being the nation's top-ranked applicant in the Population Health (Level 1) category of the 2018 Career Development Fellowship scheme. The awards recognise excellence in the health and medical research sector by celebrating individual achievements, leadership and the exceptional contributions of Australian researchers to their fields of research. Dr Brinkman's research is focused on improving the health and development of young children, particularly those living in highly disadvantaged communities.



Dr Hannah Moore TEDx Speaker

Infectious diseases researcher Dr Hannah Moore had a chance to share her passion for the power of data to help fight disease, when she was chosen to speak at TEDx Perth in November. Dr Moore, who is Co-Head of Infectious Diseases Epidemiology for the Wesfarmers Centre of Vaccines and Infectious Diseases, spoke to a sold-out crowd about the unmatched power of data in providing the answers we need to keep kids out of hospital.

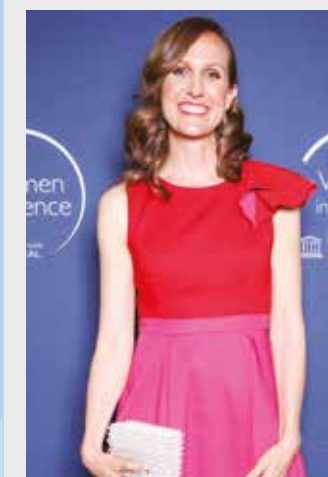


Dr Shannon Simpson 2019 Business News 40under40 Awards

Internationally recognised lung health researcher Dr Shannon Simpson was named one of WA's top professionals under the age of 40 at the 2019 Business News 40under40 Awards. Dr Simpson won the Community/Social Enterprise category in recognition of her significant findings around the long-term lung health of babies surviving preterm birth, her substantial contribution towards including the community's voice in research, and her volunteer work with young people going through the health system.

Dr Asha Bowen L'Oréal-UNESCO Women in Science Fellowship

Telethon Kids skin researcher Dr Asha Bowen was awarded a prestigious L'Oréal-UNESCO Women in Science fellowship. Her dedication to ending skin infections in Aboriginal and Torres Strait Islander children made her a clear choice as one of the most outstanding early-career female scientific researchers in Australia. She was later featured in the February issue of Vogue Australia, in a spread on talented women scientists.



Penelope Strauss AMP Tomorrow Maker

Trans Pathways researcher Penelope Strauss was named an AMP Tomorrow Maker – the first researcher from the Telethon Kids Institute to win one of the annual grants. She was one of 43 young innovators chosen to share in the \$1million Tomorrow Fund. Ms Strauss's grant will help her undertake the next phase of the ground-breaking Trans Pathways project, which found that young trans people are at high risk for suicide, anxiety and serious depression.



OUR RESEARCH AT A GLANCE 2018



The impact of research can be measured in many ways. For us at Telethon Kids, it's about how we make a difference for children, families and communities.

Here, we delve into the metrics that help define our success. This includes traditional indicators as well as the broader ways our research contributes to the global understanding of disease, influences policy and practice, builds capacity and collaboration, and has a direct effect on the lives of children.

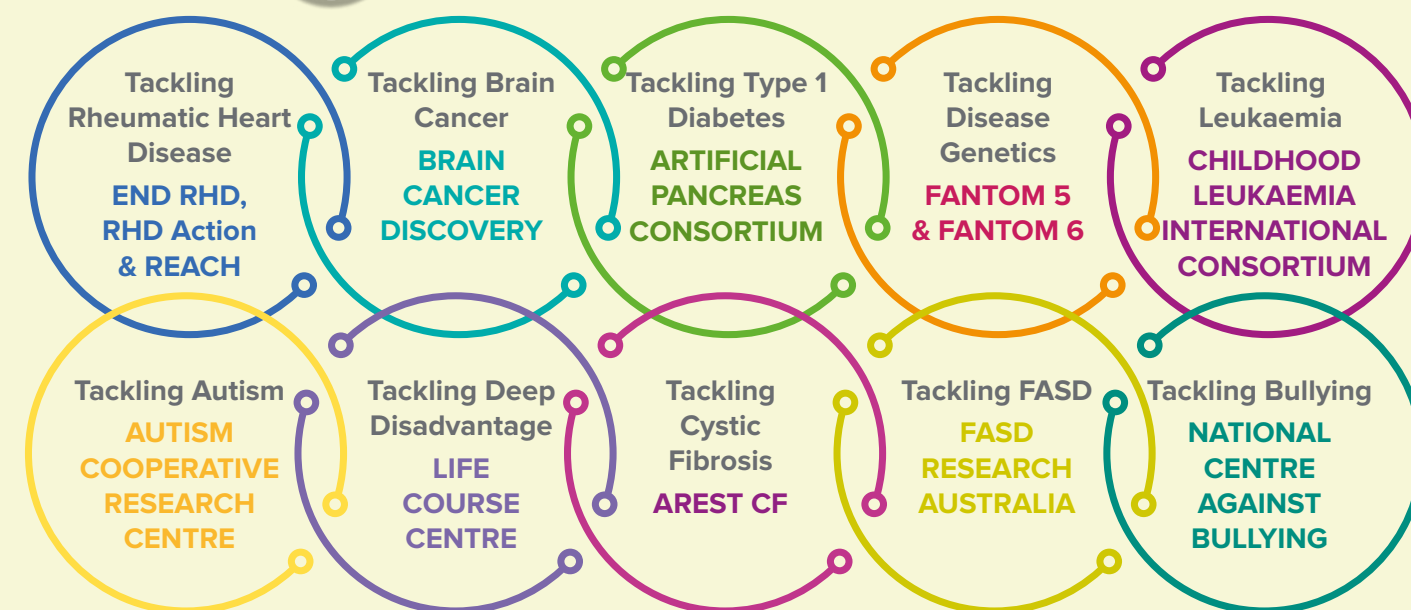
BUILD

RESEARCH CAPACITY BUILDING

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



We join with others in large national and international collaborative networks to improve the lives of children



In 2018, we had
126 students

12 Honours

4 Masters

20 MD

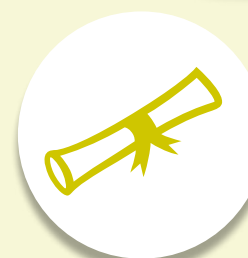
90 PhD



STUDENTS FROM AROUND AUSTRALIA AND ABROAD CHOOSE TO STUDY AT THE TELETHON KIDS INSTITUTE

Enrolled through:

Curtin University	15
Edith Cowan University	2
Murdoch University	5
The University of Western Australia	100
University of Notre Dame Australia	1
Other	3
Total	126



Over the
past 5
years

64 PhD STUDENTS

have successfully obtained their
DOCTORATE

UNDERSTAND

ADVANCING
KNOWLEDGE

Our researchers contribute significantly to the global bank of information on child health and development



We are actively collaborating with colleagues and organisations around the world in a united effort to discover more about child health and development. Some of our collaborations include:

NORTH AMERICA

- British Columbia Children's Hospital
- Children's National Health Center
- Columbia University
- Harvard University
- Institute for Health Metrics and Evaluation
- Mount Sinai School of Medicine
- McMaster University
- St Jude Children's Research Hospital
- Stanford University
- University for Systems Biology
- University of Washington
- Yale University

EUROPE

- Imperial College London
- Erasmus University
- Gustav Roussy Institute
- Karolinska Institute
- REACH
- University Children's Hospital Zurich
- University of Amsterdam
- University of Berlin
- University of Cambridge
- University of Helsinki
- University of London
- University of Oxford
- World Health Organization

ASIA

- Baranang Hindu University
- Chinese University of Hong Kong
- Hong Kong University
- International Vaccine Institute, Seoul Korea
- Papua New Guinea Institute for Medical Research
- Rett Syndrome Comprehensive Research Institute
- RIKEN

AUSTRALIA and NEW ZEALAND

- Australian National University
- Children's Cancer Institute
- Children's Hospital Westmead
- Harry Perkins Institute for Medical Research
- Menzies School of Health Research
- Murdoch Children's Research Institute
- QIMR-Berghofer Medical Research Institute
- SA Health and Medical Research Institute
- Starship Children's Hospital
- The University of Auckland
- University of Otago
- Walter and Eliza Hall Institute

SOUTH AMERICA

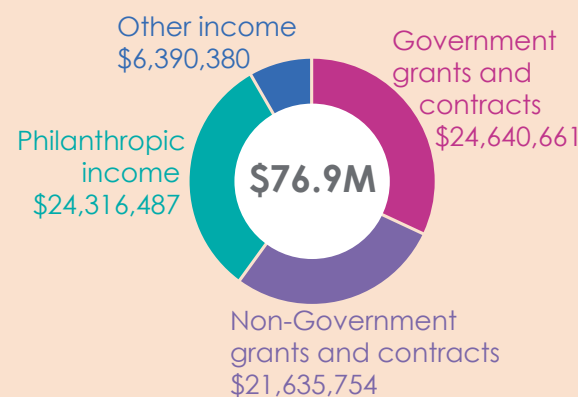
- Instituto Nacional de Cancer
- Universidade Federal do Rio Grande do Norte
- Universidade de Sao Paulo

AFRICA

- Baylor College Malawi
- Uganda Heart Institute
- University of Cape Town

Selected collaborations named

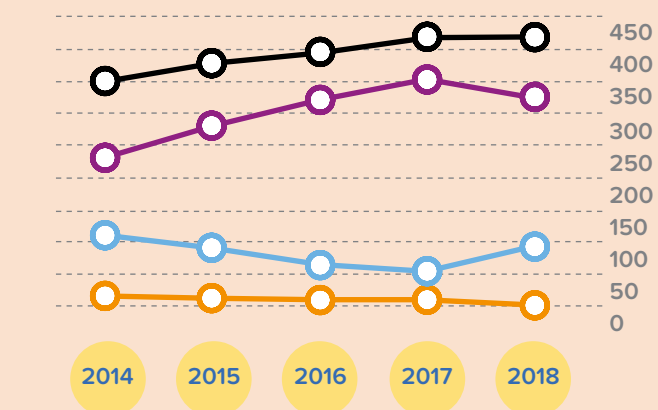
We are successful at securing a diverse mix of funding to do great research which builds knowledge on health and development



Top industry partners work with us to make a difference for children



Our knowledge benefits child health and development researchers worldwide, we share and publish our findings



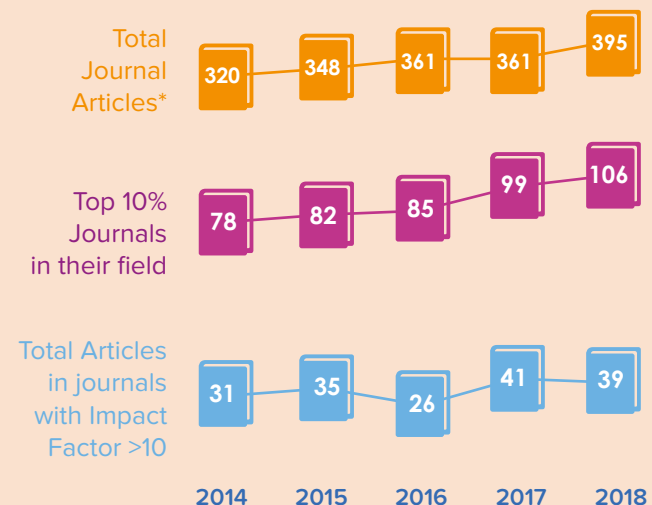
TOTAL publications **Peer-reviewed journal articles**

Other publications and reports **Books and book chapters**



WE PUBLISH in the most INFLUENTIAL JOURNALS around the world

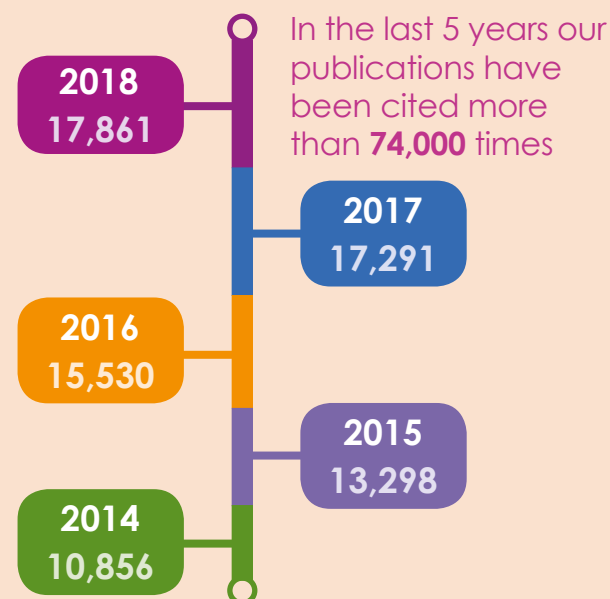
Publications over the past 5 years



*articles, letters, editorials, case reports and reviews



Scientists around the world use our work on child health and development to advance their knowledge and research



In the last 5 years our publications have been cited more than **74,000** times

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

Telethon Kids has a Normalised Citation Impact (NCI) of

2.56

which is two and a half times higher than the world average.

19.8% of Telethon Kids papers are categorized as highly cited.

NCI is a valuable and unbiased indicator of impact irrespective of age, subject focus or document type. Therefore, it allows comparisons between entities of different sizes and different subject mixes.

Source: Clarivate Analytics report for Telethon Kids Institute, Sept 2018



Our researchers are regarded as international leaders in their field



14 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)

INVOLVE

INFORMING
DECISION-MAKING

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



We work closely with government to ensure our research has an impact on government policy

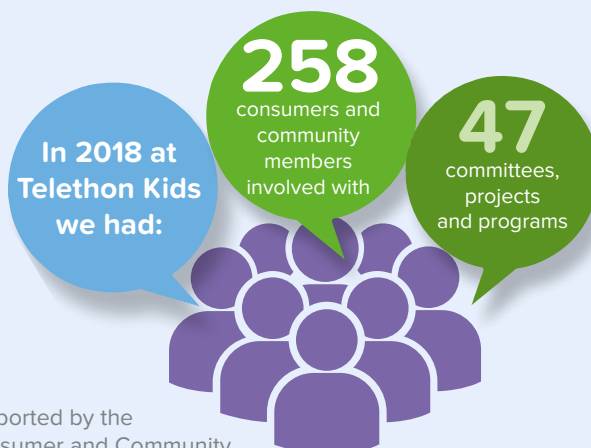
We provide commissioned reports to government on topics such as:

- > fetal alcohol spectrum disorder
- > early years development
- > bullying
- > youth health

We partner or collaborate with **38** state and federal government agencies in the areas of health, education, justice, mental health and communities

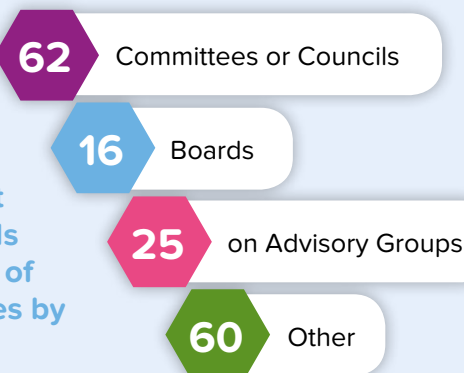


The community is involved in informing the work that we do, ensuring it remains relevant and translatable



supported by the Consumer and Community Health Research Network

Our researchers are actively involved in external decision-making groups that are working towards improving the lives of children and families by being involved in:



with influence at the state, national and international level



We are asked to provide our expertise to inform work on child health, wellbeing and development

55 TOTAL TIMES OUR EXPERTISE WAS PROVIDED

44 TOTAL TIMES OUR EXPERTISE WAS INVITED

- Independent Review of the WA Human Reproductive Technology Act 1991
- Department of Communities 10-Yr Strategy on Homelessness
- Victorian Government Transgender Policy
- Royal Commission into the Protection and Detention of Children in the NT
- Senate Select Committee inquiry on Stillbirth Research and Education
- WA Youth Health Policy

*Selected contributions named

TRANSLATE

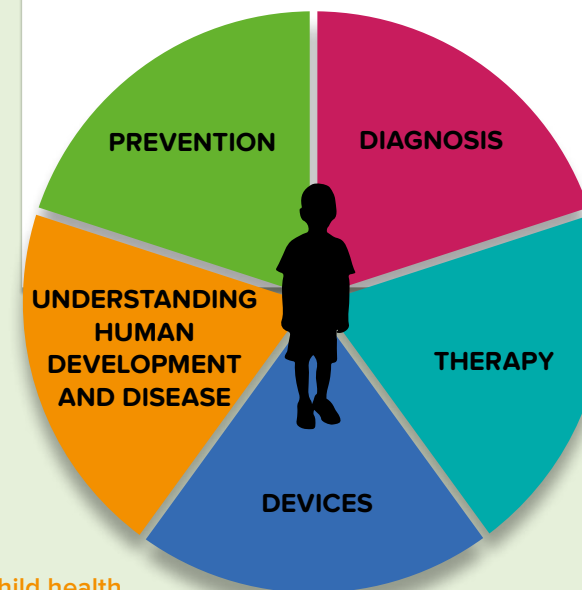
EFFECTING CHANGE

We ensure our research is translated into real-life outcomes that make a tangible difference to the lives of children, families and communities

Our clinical researchers are working to discover and trial new interventions to improve the health of children. We are actively involved in intervention studies in the following areas:

- Vaccines including influenza, Hib, meningococcal and pneumococcal
- Allergic disease
- Asthma
- Rheumatic Heart Disease
- Group A streptococcal infections
- Skin infections
- Hep B infections

- Infections & vaccines
- Ear disease
- Language development
- Newborn encephalopathy
- Obesity
- Nutrition
- Hypospadias
- Asthma
- Developmental origins of child health
- Genetic disorders
- Long-term health outcomes of young adults born preterm



- Cystic fibrosis
- Biomarkers of obesity
- Diabetes
- Skin infections
- Rheumatic Heart Disease

- Asthma
- Bronchiolitis
- Dermatitis
- Cystic Fibrosis
- Autism spectrum disorders
- Gastroenteritis
- Rett syndrome
- Skin infections
- Mental and youth health
- Infectious diseases
- Allergy
- Cancer
- Disability

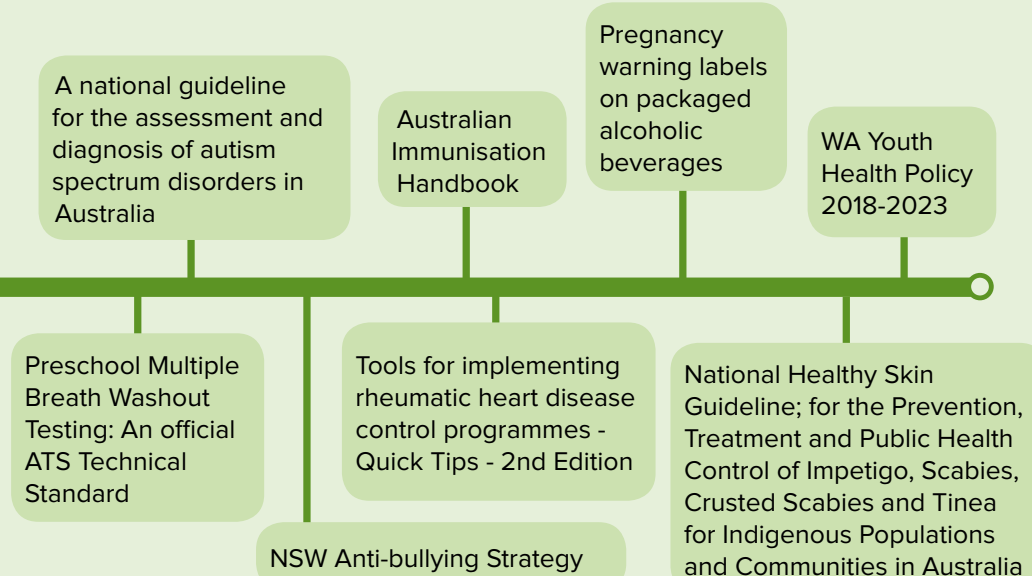
- Diabetes
- Obesity
- Autism



Our research drives real-world changes through contributions to guidelines, policy and practice

In 2018, we contributed to*:

*Selected contributions named



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

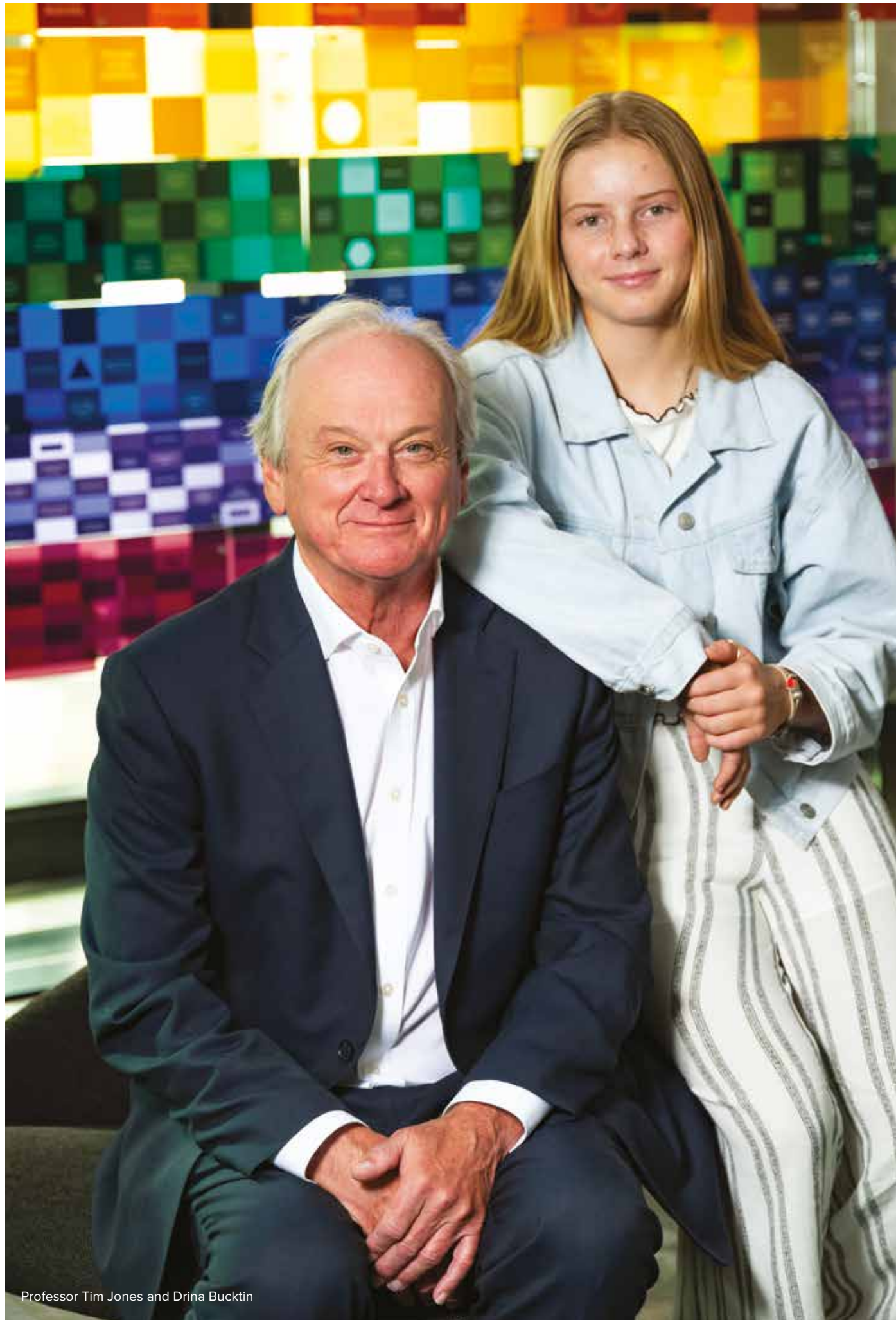
12 active patents



TRANSLATION

TRANSLATION

*This research has been actively
translated into policy or practice*

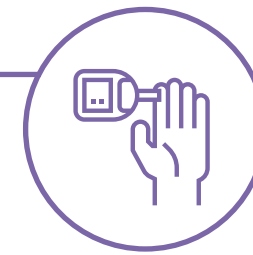


Professor Tim Jones and Drina Bucktin

SMOOTH SAILING FOR DRINA THANKS TO BURDEN-BREAKING TECHNOLOGY

Soon-to-be teenager Drina Bucktin loves hanging out with her friends and making the most of her new-found independence. This freedom hasn't always been a given, however. Drina has type 1 diabetes, a chronic disease which means every mouthful of food — or exercise, sleeping, stress or puberty — can affect her blood glucose levels.

Thankfully, recent diabetes technology is helping the 12-year-old keep on top of her condition and be independent, while significantly easing the disease burden on her family.



The study, published in the prestigious *Diabetes Care* journal, found the technology reduced parents' stress and anxiety and improved their sleep and family functioning.

A few years ago, Drina's family took part in the Children's Diabetes Centre's 'CGM and Everyday Diabetes Care' trial – a study which explored the effect of continuous glucose monitoring (CGM) with remote monitoring on psychosocial outcomes in parents of children with type 1.

The system works by transmitting blood glucose readings every five minutes via Bluetooth to a mobile phone or smartwatch. It can also share readings with other devices and send push notification alerts of highs (hyperglycaemia) and lows (hypoglycaemia).

"Life is a lot less stressful on everyone and I have a lot more freedom since using the CGM with remote monitoring – I love it," Drina said.

Drina's mum, Heidi, said the technology had been life-changing for the family.

"Since I can share the management of her blood glucose levels (BGL) with the school nurse and coaches, it (CGM) has allowed me to pursue my professional career as I'm not hanging around the school or constantly on the phone providing advice or ready to drop everything to attend to Drina," Heidi said.



Drina Bucktin

"It's been great for my sanity, my own professional development and contribution to the family income."

Heidi said Drina had taken on more of her own disease management knowing she had support from those around her, while her 'nagging' mum could monitor from a distance.

The technology had particularly made an impact on Drina's competitive sailing, which included representing Australia in a competition in New Zealand recently.

"We can monitor Drina's BGL during a race without the fear of her crashing dangerously low, and without dosing her with sugar to make sure she doesn't go low," Heidi said.

"We can also share the Dexcom (CGM with remote monitoring) with her coach so we don't have to be on the water every time she trains or races.

"We actually get a small part of our life and sanity back while Drina gets to join in with the other kids without mum or dad hanging around all the time."

- Drina's mum Heidi

Children's Diabetes Centre Co-Director Professor Tim Jones said this was the first CGM study to assess psychosocial outcomes as a primary outcome.

"Parents of a child with type 1 diabetes live in constant fear that they will put their child to bed at night, but they won't wake up in the morning because their blood glucose levels have dropped to dangerously low levels overnight," Professor Jones said.

"Some diabetes technologies have the potential to make life more stressful so we wanted to find out if this technology might improve glucose levels and improve quality of life.

"This study has demonstrated unequivocally that the use of CGM with remote monitoring can improve the quality of life of families living with type 1 diabetes — parents sleep better, family stress is reduced, and anxiety is reduced."

- Professor Tim Jones

Professor Jones said it was important to note that at the time of the study, CGM was not publicly funded in Australia and usage was low (CGM became fully subsidised for children in April 2017).

"While many families who participated in the study could not have afforded to pay for it (approximately \$5,000 annually), almost all of the participants decided to continue once the funding came through — this is telling," he said.

"Before this subsidy, only 5 per cent of our patients used CGM but this has risen to 70 per cent.

"We're putting our patients on CGM from diagnosis now — we are about improving outcomes and reducing the disease burden and this technology is doing that."

Professor Jones said results from this study were influencing CGM usage globally.

"We are a world-recognised centre for this type of research so what happens here will be published and disseminated internationally and it will add to the evidence for CGM use," he said.

He also predicted the technology would take over from finger pricking — something families have until now had to perform on children six to eight times a day.

This study was performed at the Children's Diabetes Centre, a JDRF/National Health and Medical Research Council-funded Centre of Research Excellence based at the Telethon Kids Institute.

NEW FOCUS ON TYPE 2 DIABETES

Researchers at the Children's Diabetes Centre at the Telethon Kids Institute have begun researching type 2 diabetes to tackle the rising incidence of the disease among young people in Australia.

Type 2 diabetes (T2D) is a serious and costly disease with chronic complications including accelerated development of heart, kidney and eye complications, as well as limb amputations.

In the past, the disease was usually only diagnosed in people as they got older but now, younger people, including children, are getting it.

Our researchers have reported the incidence of T2D in children and adolescents in Western Australia and found Aboriginal and Torres Strait Islander children and adolescents aged under 18 years have a more than 20 times greater risk of being diagnosed with T2D compared to those of non-Indigenous descent.

Centre researcher Dr Aveni Haynes is currently working alongside investigators in northern Australia to try and establish the number of Aboriginal and Torres Strait Islander children, teenagers and young adults (less than 25 years) with T2D living across Northern Australia (WA's Kimberley region, Northern Territory and Far North Queensland).

"By working out how many young people there are with T2D, this can be used to plan how to prevent more young people getting T2D in the future and how to provide health services to those who already have it; and to reduce their chances of getting other diabetes-related diseases and complications."

- Professor Liz Davis



Professor Liz Davis, Co-Director of the Children's Diabetes Centre and head of type 2 diabetes research, said the role of food insecurity — the state of being without reliable access to a sufficient quantity of affordable, nutritious food — in childhood, was another key research area as it had been shown to play a major role in the development of chronic diseases in kids, including obesity and T2D.

"Previous research has shown that up to one in five Australian children experience food insecurity," she said.

"In one of our research projects, we are seeking to determine the prevalence of food insecurity in WA's communities, and how it links to dietary quality, quality of life, degree of over-eating, and obesity.

"The primary outcome of this project will help to inform clinicians across WA of the barriers faced by children and families who struggle with food insecurity and help them devise individualised treatment plans around weight management, both to prevent T2D and manage the disease."



Professor Liz Davis

WHAT'S NEXT

- "We still need to learn who benefits the most from this technology, how we can make it acceptable so we have 100 per cent uptake and how we can get the data to be more easily interpretable for families so they can manage it themselves." — Professor Tim Jones

FRIENDLY SCHOOLS GOES FROM STRENGTH TO STRENGTH

What began as a small formative research project 20 years ago has grown into a universal bullying prevention and social skills development program which has helped countless Australian children and their families. Now the Friendly Schools project is evolving to meet new challenges.



Friendly Schools, led by Professor Donna Cross and the Telethon Kids Health Promotion and Education Research (HPER) Team, was first developed in 1999 after research revealed a clear need to help and support children who are bullied, as well as their families and teachers.

Focused on understanding bullying, developing and evaluating school strategies to reduce all forms of bullying, and informing national and international policy and practice, the program is now spread across 14 large empirical trials.

In 2005, significant interest from schools led to resources developed by the program being commercialised and disseminated, with training and support, to schools Australia-wide. It's estimated more than 3,000 Australian schools have used the resources to improve their school policies and practices and the wellbeing of their students.

The resources have also been taken up by schools in the United States, Singapore and New Zealand, with Scandinavia, Canada and the United Kingdom investigating whether it would transfer to their schools as well.

In their 20th year of Friendly Schools's research, the research team are focusing on the needs of sub-populations of more vulnerable children and young people. The increasing prevalence of digital technology use by children is also shaping ongoing research efforts.

Professor Cross said that as digital technology had evolved, so too had Friendly Schools.

"We're increasingly working to meet the needs of schools and parents in managing children's safer use of digital technology, in ways that improve their development and learning opportunities, and reduce harmful outcomes, including cyber bullying," Professor Cross said.

"With children using digital technology from increasingly younger ages, urgent action is required to promote positive digital behaviours and to reduce potential risks of harm."

Professor Cross said that despite growing research investigating children's use of technology and the internet, and the consequences of this increased engagement, little research had been conducted with parents to determine their needs or effective ways of enabling them to guide their children's digital behaviour.

"Likewise, many school staff lack the confidence and skills to teach and foster safer digital technology use by their students, and schools have indicated they need support in this regard," she said.

However, she said if previous results were anything to go by, the Friendly Schools research would continue to make a positive difference in the lives of children and their families for many years to come.

"With children using digital technology from increasingly younger ages, urgent action is required to promote positive digital behaviours and to reduce potential risks of harm."

- Professor Donna Cross



School students across Australia are benefiting from Professor Donna Cross's Friendly Schools project

"When this project began in 1999, we never envisaged that our work would have the impact it has had on school policy and practice and children's social development not only across Australia, but internationally."

- Professor Donna Cross

"This is due to the important work being conducted by the Friendly Schools staff here at Telethon Kids, without whose passion, skills and willingness to build a better life for children, many of these results would not have been achieved."

A review of 80 international studies indicated that

15% of young people experienced cyber bullying



More than **one quarter of students aged 8 to 14**

reported **being bullied** every few weeks or more often, while **9%** reported **bullying others** every few weeks or more



Modecki, K.L et al (2014)

WHAT'S NEXT

- This pipeline of research is continuing, led by The University of Western Australia and Telethon Kids, with the aim of further developing and testing interventions to improve social and emotional learning practice in schools.
- Next steps will include the development of an app to deliver cyber safety advice and coaching to parents.

LANDMARK FOLATE RESEARCH RECOGNISED AS MAJOR PUBLIC HEALTH ACHIEVEMENT

The Public Health Association of Australia has rated mandatory folate fortification – which led to a dramatic decline in neural tube defects – as one of the top 10 public health achievements of the past two decades.



The move, announced in November 2018, honoured the paradigm-shifting work of Professors Carol Bower and Fiona Stanley, who in 1989 made a landmark discovery about the vital role of maternal dietary folate in early pregnancy in reducing the risk of neural tube defects such as spina bifida.

Not content to establish the science – and determined to see that the whole WA population could have access to adequate dietary supplementation – they followed their research up with decades of dedicated campaigning and advocacy.

Their efforts paid off, leading initially to a health promotion campaign around the importance of folate. It's estimated that about 4,000 Australian children have been saved from debilitating and deadly birth defects since health promotion efforts began in 1993.

When data collection showed health promotion wasn't having the same impact in Aboriginal populations as in the wider Australian population, however, the researchers continued to push for changes in government policy to address the health needs of all prospective mothers and their babies in the community.

Partly in response to their continued advocacy, in 2009 Food Standards Australia New Zealand introduced national mandatory fortification of wheat flour for breadmaking. This change had a swift impact, resulting in a significant

14.4 per cent national decline in neural tube defects (NTD) such as spina bifida from 2011 to 2016, regardless of a mother's culture, age, education or choice of hospital system.

"This drop in neural tube defects is seen across the country and is 'spot on' with our modelling for the level of fortification that has been introduced – so it is working as expected," Professor Bower said.

Importantly, she said fortification reduced neural tube defects in the Aboriginal population by 68 per cent, with rates dropping from 2.43 cases per 1,000 births between 2007 and 2009, to 0.82 cases per 1,000 births between 2011 and 2016 – similar to that of the non-Aboriginal population.

"That gap has now been closed between Aboriginal and non-Aboriginal rates of neural tube defects."

- Professor Carol Bower

"In the Aboriginal population, health promotion to take folic acid supplements before and in early pregnancy had no effect. However, with mandatory fortification, the rate of neural tube defects has fallen to that of the general population," Professor Bower said.

"That gap has now been closed between Aboriginal and non-Aboriginal rates of neural tube defects.

"One of the reasons for fortifying was that you reach everybody regardless of pregnancy planning, and it's equitable because everybody gets additional folate if they eat fortified products."



Professor Carol Bower with some of the original health promotion material developed to promote folate intake.

DATA KEY TO POLICY WIN

A key tool in the push to achieve mandatory folate fortification came in the form of data provided by the Western Australian Register of Developmental Anomalies (WARDA) – originally established by Professors Carol Bower and Fiona Stanley as the WA Congenital Malformations Registry in 1980.

The first of its kind in Australia, the Registry was eventually merged with the WA Cerebral Palsy Register to become WARDA, with the State Government making it compulsory to report developmental anomalies.

WARDA – now seen as a national exemplar and one of the most complete registers of developmental anomalies in existence – provided vital, high-quality data demonstrating that rates of NTD remained high in the Aboriginal population despite

health promotion campaigns for voluntary maternal folic acid supplement use.

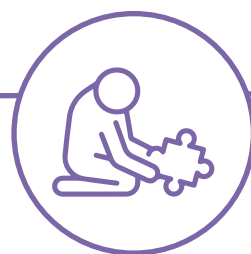
The register continues to enable the ongoing monitoring of the impact of mandatory fortification, as well as providing data for other kinds of research and serving as an important source of information for policymakers and health service providers.

"It was established as a general birth defects register but the very first research project that we did with the data being collected was a study of NTD and folate," Professor Bower said.

"It has since been an important source of information for many, many other projects, such as our work in the area of FASD, which includes efforts to extend the age at which FASD can be notified to the register from six to 15 years of age."

UNIQUE CLINIKIDS A MARRIAGE OF RESEARCH AND PRACTICE

Autism now accounts for 47 per cent of children on the National Disability Insurance Scheme, making it a key health priority for Australia. A unique new model developed by the Telethon Kids autism research team marries cutting-edge research with clinical practice to offer families innovative, evidence-based interventions designed to help kids reach their full potential.



Launched in January this year and located at Telethon Kids' former home on Roberts Road, Subiaco, CliniKids is a warm and modern clinic for children with developmental delays and/or autism spectrum disorders.

The model is an Australian first, not only providing families with diagnostic and clinical psychology, occupational and speech therapy services, but also giving them an important opportunity to be part of novel research.



CliniKids General Manager Gemma Upson said the new service aimed to address the enormous gap between research findings in the field and their translation into clinical practice. One research paper has put the lag between research and practice at 12 years; another a staggering 17 years.

"That's massive in a child's life," Ms Upson said.

"Research is obviously conducted in a very controlled environment and sometimes that can't be easily translated into the messy real world we live in."

"The CliniKids model has the ability to innately feed clinical expertise into our research and vice versa, so that we can trial interventions in a real-life setting and also evaluate the financial implications."

"Having interventions that are evidence based is very important but if the cost is prohibitive to families and service providers, it may not be widely accepted."

The clinic is going to bridge that gap – trial the research in a real-life clinical setting, communicate that to the providers, and help educate the community."

- Gemma Upson

An estimated 2 per cent of Australian children have an autism diagnosis, and extensive research has shown that commencing therapy



in early childhood will reduce their level of disability. Early intervention could be the difference, for example, between a child developing speech or remaining non-verbal.

The Institute's autism research, led by Professor Andrew Whitehouse, is regarded as world-leading – however, Ms Upson said advances had been limited by the absence of a centre like CliniKids, dedicated to new diagnosis and intervention methods in young children.

"It's early days yet and we are busy building our programs and data collection systems, however feedback from families so far has been very positive," Ms Upson said.

Families felt reassured that services were provided in a judgement-free atmosphere, and in a modern, purpose-built clinic where everyone was treated with compassion.

"Our families have the confidence too, that our interventions are backed by a skilled research team which uses highly evidence-based interventions," she said.



CliniKids is supported by many donors including the Angela Wright Bennett Foundation, Rowley Foundation and the Australian Government.



NEW FRIEND TO IMPROVE SOCIAL ATTENTION OF KIDS WITH AUTISM

Children with Autism Spectrum Disorder sometimes find it difficult to look at faces or understand what others may be thinking or feeling. But an attention-training game developed by researchers at the Telethon Kids Institute is helping to improve social skill development in school-aged kids with autism.

Researchers, led by Dr Gail Alvares, designed and evaluated an app-based game that rewarded children for selecting pictures of faces and ignoring pictures of objects, like trains or clocks. Using a machine called an eye-tracker, children were measured on how they looked at faces and objects before and after playing the game.

After playing the game for 15 minutes, children more frequently looked at pictures of faces first rather than objects, and this was compared to a group of children who played a similar version of the game without being rewarded for selecting faces.

Although the research is still ongoing, Dr Alvares said the results suggested this kind of training early in a child's life may have the potential to improve their social behaviours in later years.

"We believe that difficulties in social development for kids with autism may

be due to difficulties in visual attention that develop very early, within the first few years of life," she said.

"The results from this research may indicate that games could be used to help aspects of social skill development for children on the autism spectrum, such as understanding faces."



Dr Gail Alvares



NATIONAL GUIDELINE PROVIDES UNIFORM APPROACH TO AUTISM DIAGNOSIS

One of the most important policy changes ever implemented in the area of autism research and practice came to fruition in October 2018, when the Autism CRC released *A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia*.

Telethon Kids Autism Research Team Head Professor Andrew Whitehouse – who is also Chief Research Officer of the Autism CRC – and Telethon Kids autism researcher Dr Kiah Evans led the development of the Guideline, sitting on the executive committee responsible for the document.

Dr Evans said the Guideline brought disparate state and territory assessment and diagnostic practices together into a coherent, streamlined benchmark practice, with the aim of providing consistency for people on the autism spectrum nationally.

"Since being launched in October the Guideline has already been downloaded more than 9,500 times



– both by people in Australia and overseas – and is being used by major diagnostic services providers around Australia," Dr Evans said.

In addition, an interdepartmental working committee is meeting at a Federal level to discuss wider implementation of the Guideline, and two new research projects have kicked off, examining clinicians' uptake of the Guideline and its implementation in a rural setting.



Professor Andrew Whitehouse and Dr Kiah Evans

To download the Guideline, go to <https://www.autismcrc.com.au/knowledge-centre/resource/national-guideline>. Once you've registered your details, you'll receive a link via email.

CAMPAIGN PAYS OFF AS ALCOHOL LABELLING GETS GREEN LIGHT

Following strong evidence and lobbying by Telethon Kids Institute researchers, along with others including the Western Australian Government, labels to warn women about the risks of drinking during pregnancy are to become mandatory on all alcohol sold in Australia and New Zealand within two years.



Leading Fetal Alcohol Spectrum Disorder (FASD) researcher Professor Carol Bower, who was instrumental in presenting evidence to support the decision, said mandatory labelling was part of multiple actions required to reduce birth defects caused by prenatal alcohol use.

"This is one important step in a suite of health promotion and public health approaches because this is a product that actually causes birth defects," she said. "Women ought to be given that information and there is no more immediate place than on the product."

In early 2018, the Food Regulation Standards Committee invited Professor Bower to make a submission as a public health stakeholder to the targeted consultation regarding policy options for pregnancy warning labels on packaged alcoholic beverages.

Professor Bower, along with Dr Roslyn Giglia and Dr Martyn Symons, made the submission on behalf of the Institute and the FASD Research Australia Centre of Research Excellence, of which Professor Bower is Director. Their review found a five-year trial of voluntary labelling since 2011 had been unsuccessful, with testing revealing that labels were hard to read and had unclear messages that could be easily misinterpreted to mean it was okay to consume alcohol during pregnancy.

In October 2018, health ministers around Australia, with strong support from WA Health

Minister Roger Cook, agreed to introduce mandatory labelling at a meeting of the Australian and New Zealand Ministerial Forum on Food Regulation.

Food Standards Australia and New Zealand (FSANZ) are now developing consistent labels and standardised messages, with consumer testing and input from the researchers, industry and public health organisations. These are expected to be ready by the end of 2019.

"This is a major win for clarity – every alcohol product will have the same message on the bottle and packaging, with specifications to the size, colour and wording so there will be consistency," Professor Bower said.

"This is a major win for clarity – every alcohol product will have the same message on the bottle and packaging, with specifications to the size, colour and wording so there will be consistency."

- Professor Carol Bower

Following a 'wash-in' period of 12 months to allow time for existing alcohol product to leave the shelves and industry to work to get the new labels on, it is expected that all alcohol will carry the new labelling by 2020.

"Once in place, the mandatory labelling needs to be evaluated to determine if women are seeing the labels and clearly understanding why not drinking alcohol in pregnancy is the safest option," Professor Bower said.

"We are concerned to ensure there is good evidence supporting what the message is and then to find out how well it has been seen and taken note of."



Professor Carol Bower

BANKSIA HILL PROJECT'S RIPPLE EFFECT

Eighteen months on from the publication of its findings in *BMJ Open*, the game-changing Banksia Hill Project is continuing to reshape the way authorities manage and support vulnerable young people within the justice system.



The two-year study, which was the first in Australia to assess and diagnose young people in a youth custodial setting for Fetal Alcohol Spectrum Disorder (FASD), revealed that more than one third of young people assessed by the team had FASD – the highest known prevalence in a justice setting worldwide.

The team, led by Professor Carol Bower, also found 89 per cent of the young people examined had at least one form of severe neurodevelopmental impairment – providing evidence that youth with neurodisability are grossly over-represented in youth detention in WA.

The results are still rippling through government departments, police, custodial authorities, and the Children's Court, and have led not only to changes in policy and practice, but increased community understanding of FASD and widespread interest in Australia and overseas

"The delivery of training resources, pioneered by Hayley Passmore, to more than 100 Banksia Hill custodial staff means they are now better equipped to be able to recognise and work effectively with young people with neurodevelopmental impairment," Professor Bower said.

"Here in WA the findings, and the continuing advocacy and analysis by team members, have changed the way the justice workforce engages with these young people."

- Professor Carol Bower

"We're also seeing moves to improve the way police and the Children's Court interact with young people with a communication disorder or a different language who come into the justice system – another important finding."

The training resources developed, delivered and evaluated by Ms Passmore were a key outcome of the Banksia Hill Project, and are now in hot demand.

The Department of Justice has commissioned further paid training sessions for staff including newly recruited youth custodial officers and community youth justice officers, and other sectors, including police, child protection and education, are also keen to receive the training. In addition, Ms Passmore has received requests to access the resources from researchers, service providers and agencies worldwide.

"These requests are increasing rapidly given the global interest in FASD and justice-involved youth. I'm now seeking funding to evaluate the effectiveness of the training with other workforces, and to develop a 'train the trainer' model to ensure the training remains sustainable."

- Hayley Passmore

The Children's Court is also changing the way it responds to young people coming before it, thanks to the study's findings. Judicial officers have relied on assessment reports prepared by the team to better understand mitigating factors for sentencing; and there's growing recognition of the language and other barriers faced by many young people as they try to navigate the justice system.

Follow-on research led by Banksia Hill Project team member and speech pathologist Natalie Kippin revealed significant levels of language difficulty among young detainees, with almost half meeting the criteria for language disorder. Much of that language disorder was associated with FASD.

The research also found considerable language diversity, with less than a third of the young people assessed speaking Standard Australian English as a first language.

Ms Kippin said these communication barriers meant many young people were going through highly verbal legal and rehabilitation processes at a significant disadvantage.

The findings have led to interest in the provision of intermediaries to help respond to language and communication needs when young people are engaging with police and the courts.



Hayley Passmore and Natalie Kippin

WHAT'S NEXT

- Professor Bower and team are now advocating for **further collaborations with government, community and service providers to better respond to the needs of young people in the justice system**. This includes strengthening health and neurodevelopmental assessments, evaluating rehabilitation programs, training the justice workforce, and reducing the over-representation of Aboriginal people in custody.
- Ms Passmore and members from the Telethon Kids leadership team are meeting with the heads of seven WA State Government departments, to discuss a cross-government approach to upskilling frontline professionals in the justice, police, health, education and child protection sectors, to better manage neurodevelopmental impairments.
- The team will host a **WA Youth Justice and Health Forum** in November, to discuss the intersection between the justice, health and education sectors and collate priorities from community, service providers, researchers and government.



Members of the Banksia Hill Project team

ALCOHOL SCREENING TOOL TRANSFORMING MATERNITY PRACTICE

A screening tool to help midwives and other health professionals contribute to the prevention of Fetal Alcohol Spectrum Disorder (FASD) is changing maternity practice across WA public hospitals and expanding knowledge about the risks of drinking alcohol in pregnancy.



Alcohol risk screening and preventive education are now being embedded into routine maternity care after the validated AUDIT-C (Alcohol Use Disorders Identification Test – Consumption) and associated Learning Guide were rolled out across WA Health.

The AUDIT-C project, funded by the WA Department of Health and led by Associate Professor Tracy Reibel during her time as a senior research fellow at the Institute, comprises three questions that score a woman's alcohol intake in pregnancy, with the total score indicating either low, medium or high risk for both herself and for her baby.

Midwives had reported in a previous study that they were concerned about their capacity to effectively ask women about their alcohol use in pregnancy, thus hampering their ability to provide advice and support. The Learning Guide was then developed to improve knowledge, understanding and effective use of the AUDIT-C screening tool.

Midwives who participated in an evaluation of the Learning Guide indicated it provided them with the skills to confidently and routinely use AUDIT-C in a non-judgemental way with all pregnant women, and offer brief interventions as required. A companion survey of pregnant women showed that routine questions about alcohol use were positively accepted, prompting them to ask more about the impact of alcohol on their baby's development.

In July 2018, it became mandatory to record alcohol risk into the WA Health Midwives Notification Form completed for every birth in Western Australia. To help with the change, WA Health provided open access to the AUDIT-C Learning Guide to all health professionals likely to care for pregnant women, including nurses, general practitioners, obstetricians and Aboriginal health workers.

"By asking women about alcohol, health professionals can then advise why the Australian guidelines recommend they should not drink alcohol during pregnancy," Associate Professor Reibel said.

"We know women want to be told why we are recommending that they don't drink. By advising them based on the best evidence, referred to in the Learning Guide, we hope to reduce the rates of women drinking in pregnancy and therefore bring down the rates of FASD."

- Associate Professor Tracy Reibel

"We know women want to be told why we are recommending that they don't drink. By advising them based on the best evidence, referred to in the Learning Guide, we hope to reduce the rates of women drinking in pregnancy and therefore bring down the rates of FASD."

Associate Professor Reibel said making alcohol risk screening standard for all pregnant women removed the risk that women may feel stigmatised and singled out in being asked about their alcohol use.

Pregnancy medical records incorporating this information also provided valuable information for retrospective reference, in future cases where a child's developmental problems were being investigated.



Behind the scenes of filming for new resources aimed at helping GPs use the AUDIT-C screening tool.

"If a child comes in at age seven with developmental issues, for example, doctors will be able to refer to records to establish if AUDIT-C was applied and then assess any history of alcohol use for its relevance in diagnosis," Associate Professor Reibel said.

Heather Jones, senior manager of FASD projects at the FASD Research Australia Centre for Research Excellence (FASD CRE), said another key outcome of the AUDIT-C project was a move to add information gathered as part of alcohol risk screening to state and national data bases.

"Thanks to successful advocacy by FASD CRE co-directors, Professors Carol Bower and Elizabeth Elliott, along with others, to establish national mandatory reporting of alcohol use in pregnancy in each state and territory, data collected via the Midwives Notification Form will now contribute to the WA Health Perinatal Data Base and Australian Institute of Health and Welfare's National Perinatal Data Collection," Ms Jones said.

"This not only adds strength to ongoing advocacy work, but enables researchers and policymakers to monitor the success of interventions and campaigns."

Although already available to all health professionals, the resources in the AUDIT-C Learning Guide are now being specifically updated for general practitioners. This project, funded by the Western Australian Primary Health Alliance, will produce three short videos adapting the message to prompt doctors to ask, assess and advise women using AUDIT-C.

"It's three routine questions doctors can ask during their consultations with women to promote a healthy pregnancy, that we hope will become part of their normal interaction with all pregnant woman," Ms Jones said.

She said such conversations could be challenging but needed to be embraced, both by midwives and medical practitioners, for the best outcomes for both mothers and their babies.

"It's about not scaring them but advising them that the best way forward now they know they are pregnant is to try and stop drinking, and the reasons why."

- Heather Jones

"With women who have high alcohol use it becomes quite a careful conversation – they need to be cognisant about why they might be drinking," Ms Jones said.

"Alcohol might be being used to self-medicate for a whole range of reasons related to mental health issues or domestic violence. If they want to stop drinking but can't, they can be referred on to appropriate services for help."

She said women who were assessed as low or medium risk commonly raised concerns about damage from drinking and binge episodes before realising they were pregnant, sometimes even asking if they should consider abortion.

"It's about not scaring them but advising them that the best way forward now they know they are pregnant is to try and stop drinking, and the reasons why."

Ms Jones said broader use of AUDIT-C and its resources would also improve understanding of FASD among health professionals, including those who were trained overseas and less aware of the Australian drinking culture.

WHAT'S NEXT

- 2019 - AUDIT-C Learning package and resources available for use by general practitioners.
- 2019 - Evaluation of the use of the AUDIT-C and Learning guide by midwives across WA maternity services.

What is it?

- The AUDIT- C (Alcohol Use Disorders Identification Test – Consumption) is a validated, three-item, pregnancy-specific standardised method for assessing how much and how often a pregnant woman is drinking alcohol.

Work to date

- 2014/15 - Alcohol and Pregnancy and FASD: Midwives' Knowledge, Attitudes and Practice project, led by Dr Jan Payne, funded by Healthway.
- 2016/17 – The Midwives and Women AUDIT-C Intervention project, led by Associate Professor Tracy Reibel, funded by WA Department of Health.



About FASD

Fetal Alcohol Spectrum Disorder (FASD) is characterised by severe neurodevelopmental impairment resulting from an unborn child's exposure to alcohol during pregnancy. The effects of prenatal alcohol exposure are lifelong and may not be seen at birth. Problems include brain damage leading to delayed development, social, behavioural and learning problems. These can lead to secondary outcomes such as poor school performance, unemployment, substance abuse, mental health problems and early engagement with the justice system. FASD can be found in all parts of our society and impacts the individual, their family and the whole community.



What are the recommendations for alcohol in pregnancy?

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, who are pregnant, or who are breastfeeding, that 'no alcohol is the safest option'.



ATLAS MAPS A PATHWAY TO HAPPY, HEALTHY CHILDHOOD

Collaboration is at the heart of everything CoLab does – after all, it's the grounding of its name.

It's no wonder, then, that the Child Development Atlas is proving popular even before its official launch – because it brings together government services with community, practitioners and researchers. And it's doing so to build a brighter future for Western Australian children.

Initially conceived by the Telethon Kids Institute's Developmental Pathways and Social Policy team and supported by CoLab to bring it to fruition, the Child Development Atlas is an online, interactive tool that maps data on indicators of learning, wellbeing, social, and developmental outcomes for children and families.

Piloted with a select group of stakeholders including policymakers, practitioners, researchers and community members, the Atlas uses government data to map indicators of child development that can help provide insights into the associations between neighbourhood-level factors and children's outcomes.

Developmental Pathways and Social Policy co-head Dr Rebecca Glauert said the Child Development Atlas, which has recently finished the testing phase, had been piloted by representatives from state and local government, research institutes, community services and consumers.

"We've included a broad range of indicators in the Atlas, selected to reflect what is important to governments, service providers, and researchers, as well as the broader community," Dr Glauert said.

"While most of these are health- and social-related, with some early education indicators, we'll be continually refining this list to increase the range of information available in the Atlas."

CoLab Co-Director of policy, Mr David Ansell, said the ground-breaking platform would allow communities to better tailor programs and services to improve the wellbeing of children.

"The pilot of the Child Development Atlas has been warmly received by service providers," Mr Ansell said. "They believe it will make a real difference to their ability to support families as they navigate the challenges of early childhood."



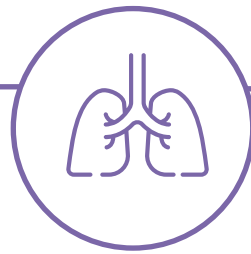
Dr Rebecca Glauert



The Child Development Atlas has been developed in partnership with Western Australian Government agencies with funding assistance provided by the Minderoo Foundation and Ian Potter Foundation.

NEW DRUG THERAPY PROVIDES HOPE FOR KIDS WITH CYSTIC FIBROSIS

The family of two girls with cystic fibrosis are hopeful after Telethon Kids Institute spin-off company, Respiration, received \$20 million in funding to develop a promising new therapy.



Christine Donaldson remembers vividly the moment her third child, Isobel, was diagnosed with cystic fibrosis (CF).

Isobel, born three weeks early, had been failing to gain weight and after a series of tests, doctors told Christine and husband Gerard that she had CF, a genetic condition that causes persistent lung infections and progressive lung damage.

"I was devastated," Christine said. "When you're pregnant with your child, you have this idea of how great their life will be, and when you're given this CF diagnosis, there's such an incredible grieving process that their life might be hard, or their life might be limited."

Two years after Isobel was born, the Donaldsons welcomed their fourth child and second daughter, Ruby. Soon after, they received the devastating news that Ruby also had CF.

"In the early days it was me coming to term with the diagnoses emotionally because the girls were relatively healthy," Christine said.

CF causes the lungs to produce abnormally thick and sticky mucus, trapping bacteria and leading to recurrent infections which can cause permanent damage and result in lung failure.

Since birth, Isobel and Ruby have received constant medical treatment and physiotherapy to keep their lungs healthy, but antibiotic resistance means they are desperately in need of new treatments to fight off constant infections.

"We know that if infections are left untreated there is the possibility of permanent lung damage," Christine said.

"You're always wondering what's going on under the skin. They look so healthy on the outside. Any cough I hear them do, in the back of my head, I'm wondering where that's going and what damage it's causing."

Now, a new therapy being developed by Telethon Kids spin-off company Respiration could provide new hope for kids like Isobel and Ruby.

"You're always wondering what's going on under the skin. They look so healthy on the outside. Any cough I hear them do, in the back of my head, I'm wondering where that's going and what damage it's causing."
- Christine Donaldson

The treatment – a chemical added to an inhaled antibiotic therapy – is the brainchild of leading Australian pulmonary specialist, and Respiration Founder and Director, Dr Barry Clements.

"Persistent lung infections and the inevitable decline in lung function remain urgent unmet needs in cystic fibrosis," Dr Clements said.

"In my 35 years treating cystic fibrosis, I've become increasingly frustrated with the limited effectiveness of antibiotics in treating lung infections.

"With no new antibiotics on the horizon, I found this chemical that weakened the defences of resistant bacteria in the laboratory.

"I took this chemical and combined it with an antibiotic (tobramycin) and found it increased the killing power of the antibiotic on these resistant germs, but also improved the patient's overall lung function."



The Donaldson family at the Respiration launch

Now, thanks to a \$20 million investment from the Medical Research Commercialisation Fund's Biomedical Translation Fund (MRCF BTF), and \$4 million from the US Cystic Fibrosis Foundation, Respiration will take the therapy into larger clinical studies, in the hope it will one day soon be available to patients.

Dr Clements said the ultimate aim was to reduce infections, reduce hospitalisations, and improve the quality of life and life expectancy in these patients.

Although further testing and statutory approval are required, if the results continue to be positive the formulation could be ready for clinical use in as little as four years.

"At that stage, there will be opportunities to further explore the potential of this formulation for use against other micro-organisms (including fungus and TB), with different antibiotics, and for treating other diseases such as non-CF bronchiectasis," Dr Clements said.

Christine was thrilled at the news, saying the prospect of increased lung function was fantastic.

"That's going to give our girls longevity and hopefully keep them out of hospital so they can just enjoy being kids," she said.

WHAT'S NEXT

- The formulation will undergo further clinical trials over the next 12-24 months to establish safety and stability sufficient to obtain regulatory approval for clinical use in humans.
- Pending that approval, the definitive multi-centre Phase 3 efficacy study will be performed and if the results prove positive, the formulation will then be ready for use in the clinic.



Telethon Kids Clinical Trials Coordinator Sam Grogan (L), with sisters Ruby and Isobel, who have CF, and paediatrician Dr Barry Clements

GAME AIMS TO ALLEVIATE DEPRESSION FOR TRANS YOUTH

A digital game adapted by Telethon Kids Institute researchers is set to deliver engaging, accessible help to prevent depression for trans and gender diverse young people.



With disproportionately high rates of mental health problems in this group of young people and cost, stigma and privacy concerns affecting their access to appropriate services, youth mental health researcher Dr Yael Perry and her team have developed a digital solution to help overcome the barriers.

"Digital health interventions are widely accessible, delivered with high fidelity, private, low cost and can be widely disseminated," Dr Perry said.

"For this particular population, there is very little that has been done around mental health, so we are keen to fill that void."

In a Healthway-funded project, the team consulted trans and gender diverse young people aged 11 to 18 years to seek their feedback about the use of online health interventions and the established digital game, SPARX, to help prevent depression.

SPARX, a therapeutic game designed by University of Auckland researchers, has been evaluated as equivalent to face-to-face therapy in treating depression in young people aged 11 to 19. It has also been widely and successfully adapted for use by same sex-attracted young people and for different cultural groups.

Using a fantasy game format, users – represented by a personal avatar – progress through seven levels, each level presenting different scenarios and targeting different cognitive behavioural skills. At the end of each level users have the opportunity to reflect on the new skills they have learned and to relate

it back to real-life difficulties they have experienced.

"The aim of the game is to restore balance in this fantasy world that has been overrun by 'GNATS' (gloomy negative automatic thoughts)," Dr Perry said.

"As this is an evidence-based intervention, we are starting from a pretty good point from which to adapt and enhance the game to make it much more acceptable for this population, which means they are more likely to use it."

"A lot of young people are not able to come out to family, friends or health professionals so this is a way they can access some assistance without feeling like they need to be 'outed' along the way."
- Dr Yael Perry

The young people consulted about the game suggested tweaks including non-binary avatars, and changes to language and some scenarios to more closely reflect themselves and their experiences.

"We have increased the customisation so people really feel the avatar is reflecting them and changed some of the language to incorporate gender neutral pronouns," Dr Perry said.

"They want trans-specific scenarios but not exclusively – like all young people, many general scenarios apply to them."

"We've changed one scenario to depict them being misgendered by a parent or friend using the wrong pronoun. It teaches them ways to provide feedback about how it makes them feel when the wrong pronoun is used and doing that in an assertive rather than aggressive way."

"The game uses the same format and cognitive behavioural principles, just changing the context."

Currently with developers to implement the changes and adapt it for delivery on a mobile device, the game is expected to be ready soon for a pilot study to test its acceptability with a small group of trans and gender diverse young people. A notebook attached to the game provides guidance and links to a newly developed resource with advice about dealing with gender dysphoria, which was requested by consultation groups.

Dr Perry said if licensed for national use in the future, the game could be accessed online by all trans and gender diverse young people, or by referral through services such as headspace or community-based queer spaces.

WHAT'S NEXT

- Pilot study in WA with 10-12 young people to test acceptability and feasibility.
- Seeking funding for a national mobile trial with 150-200 young people, to test effectiveness of the intervention on a large scale. If successful, this would help secure an Australian licence for the game, allowing it to be offered to all trans and gender diverse young people.

"It could be accessed privately – a lot of young people are not able to come out to family, friends or health professionals, so this is a way they can access some assistance without feeling like they need to be 'outed' along the way," Dr Perry said.



Dr Yael Perry is supported by The Giorgetta Charity Fund.

Mental health of trans and gender diverse young people

- Almost **one in two** have **attempted suicide**
- **Three in every four** have **experienced depression or anxiety**
- **60 per cent** felt **isolated from health and medical services**
- **42 per cent** reported service providers **did not understand or respect their gender diversity**

Source: Trans Pathways report, Telethon Kids Institute, 2017



Dr Yael Perry and Dr Ashleigh Lin

HELPING HAND ON HOME STRETCH TO ADULthood

Telethon Kids Institute data linkage research confirming young people who have experienced out-of-home care face serious disadvantage has bolstered a national push to extend formal support to the age of 21, and prompted a trial of the concept in WA which could lead to permanent policy change.



Telethon Kids Institute researcher Dr Melissa O'Donnell is only too familiar with the problems that can befall some of the most vulnerable people in our society.

Named Woodside Early Career Scientist of the Year at the 2018 Premier's Science Awards for her internationally recognised work in the area of child abuse and neglect, she has spent more than 10 years investigating the factors behind child maltreatment and what happens to those who experience it.

Now, her research into outcomes for children taken into the child protection system is helping to challenge a long-standing policy – replicated in every state of Australia – which has traditionally seen young people turned out of care and largely left to fend for themselves the moment they turn 18.

Early last year, a data linkage study undertaken by Dr O'Donnell, Fernando Lima and Dr Miriam Maclean – from the Institute's Developmental Pathways and Social Policy team – demonstrated that young people who have been in care fared much worse in terms of their mental health, education, health, and interaction with the juvenile justice system than those of a similar socioeconomic status in the general population.

The results lent strength to Home Stretch, a national campaign which has urged all states to change legislation to support young people in care until the age of 21 so as to help them transition properly into adulthood; and were immediately requested by the WA Office of the Auditor General as evidence assisting its inquiry into young people leaving care.

By October last year, WA Child Protection Minister Simone McGurk had announced that

the Department of Communities would support a pilot program of extended care, to be rolled out in coming months.

Dr O'Donnell, who is on Home Stretch's WA committee, was part of the multi-agency expert group charged with developing the pilot program. She is advising the evaluation component of the pilot and, pending any modifications, hopes to see the program implemented for all young people transitioning from care within 12 months.

"This is really exciting for us," Dr O'Donnell said. "We've really been pushing as part of the Home Stretch campaign that we need to increase the leaving care age to 21 years.

"The outcomes for these young people are particularly bad and we needed to look at how we can provide transition support for them to ensure they are not just cut off at 18 years of age.

"At 18, many young people are still at high school, so it causes particular challenges when told on their 18th birthday that their care has finished, and they need to find their own accommodation and be independent."
- Dr Melissa O'Donnell

"For these young people who have had significant trauma in their lives, it is really tricky to navigate independence."

The pilot program will support young people to stay in a current foster care arrangement that



Dr Melissa O'Donnell

they like until aged 21, or to transition in and out of care as they feel able.

Alternatively, a transition support worker will help them find accommodation and guide their education and work options until they are 21.

"They have suffered so much trauma in their lives, we are hoping to give them a better chance for better educational, work and mental health outcomes."
- Dr Melissa O'Donnell

"Our research has shown that many of those young people will have mental health issues, so we need to ensure they have a mental health plan in place to support their mental health needs."

Advocacy for change has continued nationally, with Victoria also announcing a trial extending the foster care leaving age, and South Australia agreeing in principle.

"We are definitely trying to put pressure on the other states now to match what has been done in Victoria and Western Australia in terms of extending the leaving care age and to do their own pilots," Dr O'Donnell said.

The Home Stretch campaign



<http://thehomestretch.org.au>

A national advocacy campaign by a group of concerned organisations seeking for all state and territory governments to give young people in out-of-home care systems the option to remain in care until the age of 21, to provide them with more support for a better start in life.

"We are hoping a lot of the work we are doing looking at the transition support being offered will provide information and evidence for other places that want to implement pilots as well."

WHAT'S NEXT

- In a related project called **Navigating through life**, Dr O'Donnell's team will again join up with the WA Department of Communities to track the outcomes of young people leaving care from age 16 through to the age of 23, by using linked data, interviews and surveys every six months.

OUR PROJECT IN DETAIL

The Telethon Kids Institute, through the Developmental Pathways and Social Policy team, was commissioned and funded by the Department for Child Protection and Family Support to investigate outcomes for children who had left out-of-home care, up until 23 years of age. The project used linked data from government agencies, including the WA Departments of Health, Education, Corrective Services, and Communities. Service contacts and outcomes, such as educational attainment, were compared with a similar group of WA children who had contact with the Department for Child Protection and Family Support but had not been in care, and a control group of similar children who had no contact with the Department.



Our data and the Auditor General's **2018-19 Young People Leaving Care** report highlighted poor outcomes for young people leaving foster care at 18 including:



THROWN IN THE DEEP END, JESSICA GOES IT ALONE



Jessica's young life has been touched by domestic violence, sexual assault, addiction and hospital psychiatric admissions. At 14, home became a series of short-stay foster homes, groups homes, respite care and hostels. Now aged 18, she is living independently, juggling study and part-time work to meet rent and pay the bills.

It's been tough. That she has graduated from Year 12 and come this far, she attributes to the support of a good case worker who helped her through the turbulent years following her removal into care.

However, at 18 she finds she has been cut off from that important guidance and source of advice about eligible supports and allowances.

"At 18 many young people still need a lot of guidance and don't have family to go to," Jessica said. "If they've had a case manager for a long time and have built that respect and bond with them and their support is gone – it can be like repeating what happened in your home life."

"You sort of get thrown in the deep end and have to learn for yourself. It can be lonely and if you don't know how to budget, things are not going to go so well."

She said extending care to 21 years, as proposed, would provide ideal backup while young people found their feet, allowing them to step back support as and when they felt ready.

"The new program will be really beneficial," she said.

"At 18 many young people still need a lot of guidance and don't have family to go to."

- Jessica

Now at TAFE studying community services and youth work, Jessica hopes to start a degree in law, criminology and justice next year and has also applied for entry to the Police Academy. She's motivated to effect change.

"It took a lot for me to get to where I am now," she said. "I just want to see other people able to change their lives around and get on the right pathway. They will then be able to help others who have been in their situation."

"With domestic violence, sexual assault – the world at the moment is influencing the younger generation and soon it is not going to be a pretty country."

"It took a lot for me to get to where I am now. I just want to see other people able to change their lives around and get on the right pathway. They will then be able to help others who have been in their situation."

- Jessica

"Only a very small percentage of young people succeed in life after being in care. If we put more support in place and make sure everything is running smoothly, that percentage will go up so much. Then, rather than having young people going to prison, suiciding or getting themselves all wrapped up in 'stuff', they will actually get a qualification and do good things."



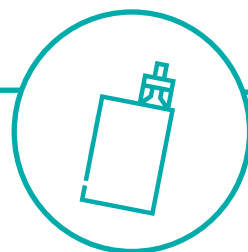
PARADIGM
SHIFT

PARADIGM
SHIFT

*This research changes
the very way we think*

RAPID RESPONSE TO E-CIGARETTE FINDINGS

Telethon Kids Institute-led research revealing that six out of 10 'nicotine-free' e-cigarette liquids contained nicotine and other potentially harmful chemicals received extensive media coverage and produced a rapid response from the Federal Government.



Just a day after the findings were published in a research letter to the Medical Journal of Australia in January, the Therapeutic Goods Administration (TGA) issued a media release warning consumers about the potential risks of purchasing electronic cigarette liquids.

The release quoted the research's findings that undisclosed and potentially harmful ingredients had been found in e-cigarette liquids being sold in Australia – including nicotine and an acutely toxic chemical typically found in pesticides and disinfectants.

It is illegal in Australia to sell e-liquids containing nicotine, which is classed as a Schedule 7 Dangerous Poison under the Poisons Standard (with specific exemptions such as some nicotine replacement therapies and tobacco for smoking).

A team led by Associate Professor Alexander Larcombe, Head of Respiratory and Environmental Health at Telethon Kids and part of the School of Public Health at Curtin University, bought 10 e-liquids on-line and over the counter from Australian suppliers and had an independent commercial laboratory test them.

All 10 had been labelled 'nicotine-free'. Six samples were found to have trace levels or low doses of nicotine in them, while all 10 were found to contain 2-chlorophenol – a chemical used in insecticides, herbicides and disinfectants and which is known to irritate human airways and skin.

The analyses also revealed by-products of animal or human bodily functions, suggesting the manufacturing process had been contaminated by mammalian blood, urine or faeces.

Dr Larcombe said the findings suggested consumers were purchasing e-liquids without really knowing what was in them, highlighting the lack of regulation around the labelling and manufacture of e-cigarette products in Australia.

"We went into this not knowing what we would find and many of the findings were a bit surprising."

- Dr Alexander Larcombe

"What they did show is that there's no way people can tell what's in these products based on what the label says. We wanted to raise awareness, to get people thinking about it more so they can make more informed



decisions about what they're consuming," Dr Larcombe said.

"There's a lot of uncertainty out there – people think they know what they're breathing in or that it's completely benign and is just water vapour. Maybe a few of those people now realise that it's not."

Although based on a small sample, the research revealed similar findings to an early NSW-based study, and received national and international media coverage – highlighting the intense interest in a subject which continues to divide consumers, policymakers and health groups.

The TGA response noted that the evidence for e-cigarettes as an option to quit smoking remained mixed, and that there were concerns that significant use of nicotine-containing e-cigarettes by adolescents could be a gateway to longer-term cigarette smoking.

"At this time, no electronic cigarettes have been approved in Australia as a therapeutic good for smoking cessation. Since the TGA does not regulate these products, their quality and safety is not known," the statement said.

In a position echoed in a viewpoint article he was recently invited to write for *The Lancet*

Respiratory Medicine, Dr Larcombe said there was a clear need for more research to establish the true impacts of e-cigarettes – particularly on pregnant women, babies and children who may be exposed to the aerosol produced by the devices. Apart from the impacts of 'vaping', there had also been instances of young children dying from drinking e-liquids.

"There is this perception that e-cigarettes are safe to use during pregnancy, and it's completely unsubstantiated and almost certainly untrue because women and their unborn babies are still getting exposed to nicotine and other potentially harmful chemicals,"

- Dr Alexander Larcombe

We know that nicotine can cross the placental barrier, and we know that nicotine impacts brain development and affects the behaviour, memory and learning of a child, as well as lung growth and development.

"So, if a pregnant woman is thinking of switching to e-cigarettes instead of smoking, which the literature shows a lot of women are, the outcomes might be just as bad. We just don't know.

"We really don't know the answers to a lot of the questions that people are asking about e-cigarettes. What is needed now is a lot more research."

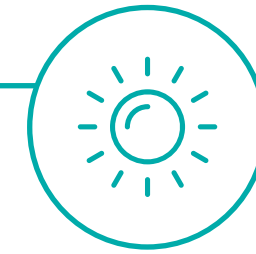
Dr Larcombe's research has been supported by funding from the Australian Competition and Consumer Commission, Health Department of Western Australia and the National Health and Medical Research Council. The research published in the MJA was a collaboration between Telethon Kids, Curtin University and The University of Western Australia.

WHAT'S NEXT

- Dr Larcombe and his team are analysing the results from further e-cigarette research, including some investigating the relative impact on mouse lung function of e-cigarettes compared to regular cigarette smoking, versus giving up altogether; and other tests investigating the impact of e-cigarette smoking on pregnant mice and their offspring.
- Dr Larcombe is part of a Thoracic Society of Australia and New Zealand working party which is currently working on a position statement on e-cigarettes.

LET THE SUN SHINE IN

For decades Australians have been told to minimise sun exposure to prevent skin cancer, however researchers at Telethon Kids Institute have challenged that message, based on multi-pronged research that shows some sun exposure may hold important health benefits.



Head of the Institute's Inflammation Team, Professor Prue Hart, said the results from three significant research streams at the Institute have made it increasingly apparent that some exposure to direct sunlight is important for good health – and not just because it produces vitamin D.

In what she described as the 'next big wave of knowledge,' Professor Hart said research led by herself, Dr Shelley Gorman and Dr Debbie Palmer pointed to multiple beneficial molecules being created on the skin by exposure to direct sunlight.

"Our combined work stretches across autoimmune, metabolic disease and skin allergies, and carries the common thread that there are some beneficial effects of sunlight, not all of it vitamin D-related," Professor Hart said. "There are other important mediators that need to be considered and researched.

"Based on this, we think Australian authorities may have been too strict with the 'sun safe' messages, and as a result people aren't getting enough exposure because of the fear of skin cancer."

The most recent work in the field is from the Childhood Allergy and Immunology Research Team, led by Dr Palmer which, for the first time, demonstrated an association between greater direct UV light exposure for babies in the first three months of life, and lower incidence of eczema.

Intended as a study to gauge the benefits of vitamin D supplementation in warding off eczema in babies born to allergy-prone families, the research found instead that

vitamin D supplementation, given in the form of drops to babies from birth to six months of age, was no match for direct sunlight.

The research, which studied 195 infants, found higher rates of eczema in babies who had less UV light via sun exposure in the first three months of life than babies who had greater sunlight exposure.

"...we think Australian authorities may have been too strict with the 'sun safe' messages, and as a result people aren't getting enough exposure because of the fear of skin cancer."

- Professor Prue Hart

"Our findings indicate that sunlight exposure appears to be more beneficial than vitamin D supplementation as an allergy prevention strategy early in life," Dr Palmer said.

"This suggests vitamin D supplementation alone isn't the answer, and that there are other elements at play that can only be obtained from direct UV exposure."

She concluded that further research was needed to explore the bioactive molecules involved. More investigation was also needed to understand and recommend safe levels of sun exposure so policymakers could develop healthy guidelines.

Professor Hart said Dr Palmer's finding that it was sunlight, rather than vitamin D supplementation, which produced positive results had been a surprise.

"It was very much unexpected but it's really reinforcing this idea that the beneficial effect of some sun is so multi-pronged," Professor Hart said. "Yes, some people may get skin cancers but there are all these other benefits and there are now three different areas of research showing this benefit.



Professor Prue Hart and Dr Shelley Gorman

"Debbie's research provides yet another piece of strong evidence supporting the need for the good parts of sun exposure, and reinforces that you can't fight this message that sun is good for you by simply telling people to take vitamin D out of a bottle."

Building on 20 years spent investigating the impact of ultraviolet radiation on health, Professor Hart has recently finished human trials delivering narrow band ultraviolet B treatment to a group of people with early signs of multiple sclerosis (MS).

She found the therapy, previously used for the treatment of the skin condition psoriasis, delayed MS in high-risk patients. Trials of vitamin D supplements trials had not shown the same reduction in the progression of the disease.

Also close to human trial stage is work by Dr Shelley Gorman, who in 2014 released research showing low dose UV light given to mice on a high-fat diet found reduced signs of type 2 diabetes. Those results prompted her to investigate the molecule nitric oxide. She found that blocking release of nitric oxide from skin after UV exposure prevented many of its beneficial effects.

"We are now trying to find out how that happens and what pathways are involved," Dr Gorman said.

"One thing we are really interested in is if UV light changes the way adipose tissue works. Brown adipose tissue is responsible for making heat – when babies get cold, brown fat creates heat to keep them warm.

"In the past 10 years it has become a really exciting area of research because it was previously thought to be just a baby thing and didn't apply to adults, however some adults do have little deposits, especially in neck areas which are exposed to sun.

"We have this hypothesis that exposure of skin to sun may send a message to underlying tissues like brown adipose to produce heat, and now we are doing animal studies to see if that is the case."

Dr Gorman said the researchers were currently making great strides towards gathering the research that policymakers needed to develop

specific sun exposure guidelines, particularly for people at risk of autoimmune disease, metabolic disease and type 2 diabetes, and pregnant women and babies.

"Australia should be the capital of where this research is undertaken; we're a country that gets more sun than anywhere else and it's really about finding where that balance is in the message we give people about safe sun exposure."

- Professor Prue Hart

"We do need to work with the people who develop health policy, like the Cancer Council, and they need evidence," Dr Gorman said.

Professor Hart said the results of the combined research showed there was a need for much more money to be invested in the area.

"Australia should be the capital of where this research is undertaken; we're a country that gets more sun than anywhere else and it's really about finding where that balance is in the message we give people about safe sun exposure," she said.

"You should never get sunburnt, but a lot of the messages now are about how much sun you need to get vitamin D, when there are all these other molecules to consider – so it may turn out you need a bit more sun or a bit less sun."



Dr Debbie Palmer

SUNNY OUTLOOK FOR ALLERGY-PRONE BUB

There's a history of asthma and eczema on both Emma Snelgar and her husband's side of the family, so it's not surprising that she chose for her son Felix to be part of Dr Debbie Palmer's research into sunlight exposure, vitamin D and eczema.

Like her husband, Emma's first son Ollie, now aged five, suffered the painful skin allergy, with an additional egg allergy, when he was a baby. Emma said Ollie's eczema was particularly bad around his mouth, and eventually became infected due to constant picking and licking.

She tried everything before resorting to steroid treatment, which finally beat it.

When second son Felix was born, Emma wanted to do all she could to prevent him from suffering that same discomfort, so jumped at the chance to participate in research which may provide answers.

She signed him up for Dr Palmer's study, the findings of which were published in the *Journal of Allergy and Clinical Immunology* in 2018. Felix was one of 195 children to take

part, with 97 receiving vitamin D supplements and 98 a placebo.

Felix was also one of a number of participants across both groups to wear a UV dosimeter clip, designed to gauge his exposure to sunlight. Emma said this mostly occurred during the safer, low UV periods of the day – either early in the morning or late in the afternoon.

Test results showed both Felix's UV exposure rating and vitamin D levels were 'quite high'; and he was among the babies found less likely to be diagnosed with eczema than those who had had less sun exposure.

Emma, who works as a nurse for the Childhood Allergy and Immunology Research Group, encouraged anyone who could participate in studies of these types to help.

"The research is gradually uncovering things that do help to manage and prevent these allergies, and participants have the added benefit of having the immediate support of experts if they need it."

- Emma Snelgar

"For Ollie, his allergies weren't life threatening but for other children they can be, so anything we can do to stop that happening to a child, if we can, we should do it," Emma said.

Dr Palmer said although the results were promising, much work is still needed to be done to determine safe levels of sun exposure.

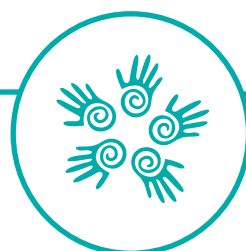
"There's a lot more work that needs to be done before we can translate this into a solid community message, but definitely from an allergy point of view, it's opening up a really important area of research," she said.



Emma Snelgar with her sons Felix and Ollie, who took part in the study. Photo courtesy The West Australian

GIVING WINGS TO A GENERATION OF INDIGENOUS LEADERS

In 2005, the Telethon Kids Institute won a National Health & Medical Research Council Indigenous Capacity Building Grant that drew together a team of 10 dedicated investigators – all Aboriginal researchers working to improve the health of people in their communities. Since completing the grant in 2009, many have emerged as national leaders in their fields.



The grant, *Not Just Scholars but Leaders: Learning Circles in Indigenous Health Research*, was the first of its kind aimed at developing a critical mass of Indigenous researchers who could undertake high quality research into health priorities determined by Indigenous people.

The five-year project – developed and led by Associate Professor Deborah Lehmann – saw Indigenous researchers linked up with centres of excellence in research in Australia and internationally, to pursue research across a spectrum of issues including mental health, self-esteem, gender, substance abuse, bullying, juvenile justice, primary health care, and human rights.

Professor Juli Coffin, who recently returned to Telethon Kids, was one of the 10 original Capacity Building Grant investigators. The only one living in regional Australia at the time, she said the opportunity it had offered her had been nothing short of amazing.

"It was the mentoring and support I got; people always said I had a different way of looking at things and held some innovative ideas, but I never really got to put them into practice," Professor Coffin said.

"So for me, that was one of the first times I could see a need and answer it in a way I knew the community would respond to, without being told how I had to do it."

Glenn Pearson, Head of the Institute's Aboriginal Health Research Focus Area – who was invited into the group to undertake his own doctoral project – said for many of the investigators, the grant and the work it

facilitated had been their introduction into the scientific world, providing a safe place to explore their fields.

"It brought us into a space to do our research helped by senior researchers like Deb Lehmann who were the arms around us, put there to both hold us and put the right pressure on us," Mr Pearson said.

"They supported us when we came together and when we went back into our research worlds, and that has formed the foundation for all our work since."

Associate Professor Lehmann mentored the original group from its inception, helping the participants achieve their goals and become independent researchers.

She said it had been a mammoth task – managing a big team of investigators spread across institutions around the country, organising meetings and workshops, and overseeing the diverse needs of each member of the group. However, her prediction at the time – that many were poised for great careers – was spot-on.

She was delighted many had done so 'fantastically well', applauding them as leaders in Aboriginal health research and for being committed to translating that research into practice.

"Leading that grant was the hardest thing I've done," she said. "I value the knowledge and friendship of all the investigators and am delighted that it progressed; it was just a question of mentoring and helping them."



Professor Juli Coffin and Glenn Pearson

"I'm pleased we supported them; the outcome has been really good and they really should be the people working here and telling us how to do Aboriginal health research."

In addition to their research, those who took part in the grant hosted a National Roundtable on Research on Racism towards Indigenous Australians, which led to a united Declaration and a submission to the Human Rights and Equal Opportunity Commission.

The grant produced five completed PhDs, with most who took part now regarded as leaders in their respective fields of research. Many

have retained links to Telethon Kids – including Professor Coffin who, although based in the Kimberley region, recently re-joined the Institute after holding distinguished positions including Head of Campus and Executive Director, Notre Dame Broome.

"Living in the Kimberley has its challenges when it comes to professional connectivity, but with the right space to think and create in a culturally responsive way, I hope to see Aboriginal ways of working in the research space as the norm instead of the exception," Professor Coffin said.

NHMRC Indigenous Capacity Building Grant

Where are they now ?

Professor Juli Coffin

Now Ellison Professor of Aboriginal Research at Telethon Kids, Juli leads the cutting-edge Equine-Assisted Learning Program and is highly regarded for her innovative research methods.

Associate Professor Ted Wilkes AO

Ted was the Director of the Derbarl Yerrigan Aboriginal Health Service in Perth for 16 years and is a former Associate Professor at Telethon Kids. He is also a former co-team leader of the Aboriginal Australian Research Program at Curtin University's National Drug Research Institute. In 2014 he was made an Officer of the Order of Australia for distinguished service to the Indigenous community in areas of public health and welfare, among other achievements.

Professor Cheryl Kickett-Tucker

Cheryl is a leading researcher in the School of Education at Curtin University, focusing on Aboriginal education and wellbeing. She is founder of the Pindi Pindi Pty Ltd Centre for Research Excellence in Aboriginal Wellbeing and was named WA Local Hero 2019 as part of the Australian of the Year Awards.

Associate Professor Michael Wright

A Research Fellow in the School of Occupational Therapy, Social Work and Speech Pathology at Curtin University, Michael is currently lead investigator on the Looking Forward, Moving Forward Project; funded by the NHMRC until 2021. He was lead investigator on the Looking Forward Project (2011 – 2015) that developed the Minditj Kaart-Moorditj Kaart Framework. Co-designed by Nyoongar Elders and service providers, it is a culturally-safe system change intervention that has been implemented in mental health and drug and alcohol services in the Perth area.

Professor Ngiaire Brown

One of the first Aboriginal doctors in Australia, Ngiaire is a founding member and was Foundation CEO of the Australian Indigenous Doctors' Association, and is a founding member of the Pacific Region Indigenous Doctors' Congress. In 2015 she established not-for-profit organisation Ngaoara, focused on Aboriginal child and adolescent wellbeing. She is currently a Commissioner with the National Mental Health Commission.

Professor Dawn Bessarab

Formerly of Curtin University, Dawn is Director of the Centre for Aboriginal Medical and Dental Health at UWA. A social worker with extensive experience in Aboriginal child protection, community and family violence, she is chief investigator on several NHMRC grants and is highly regarded for her expertise.

Associate Professor Dan McAullay

A registered nurse and former Aboriginal health researcher at Telethon Kids focused on maternal, infant and child health, Dan is currently Director of the Centre for Improving Health Services for Aboriginal and Torres Strait Islander Children and Families (ISAC), based at UWA.

Dr Janet Hammill AM

Janet, whose research focuses on FASD and other alcohol and substance abuse-related harm, now leads the Collaboration for Alcohol Related Developmental Disorders within the Perinatal Research Group at the University of Queensland Centre for Clinical Research. In 2008, Janet was made a Member of the Order of Australia (AM) for service to the community through health services for Indigenous women and children, and research into the effects of FASD.

Dr Jocelyn Jones

Jocelyn is an Aboriginal epidemiologist and Senior Research Fellow at The University of Western Australia, specialising in qualitative and data linkage methods. She completed her PhD in 2018.

Professor Helen Milroy

Helen, a child and adolescent psychiatrist, left the grant project partway through but went on to hold significant national roles including as a Commissioner with the Royal Commission into the Institutional Responses to Child Sexual Abuse and a Commissioner with the National Mental Health Commission. Currently a UWA Professor, she was recently appointed the Australian Football League's first Indigenous Commissioner.

HORSES HELPING HEALING

While her initial work at the Telethon Kids Institute was around bullying, Professor Juli Coffin's most recent research focuses on the healing power of horses – also known as equine-assisted learning.

"You or I could be the best psychologist in the world but we can't get the same result someone interacting with a 600kg horse can get," Professor Coffin said.

Equine-assisted learning is an innovative form of experiential learning, based on the idea that horses can help people to express themselves more openly and honestly. Participants are guided to interact with horses in different ways, enabling them to develop new insights and skills that will help them relate better in relationships and cope with life's challenges.

Professor Coffin first ran the equine-assisted learning program as Nguudu Barndimanmanha (horses making good) in Geraldton, on Yamaji country in WA's Mid West. A staggering 370 young Aboriginal people went through the pilot program – the youngest just six years old.

Some took part to develop leadership skills, and others to help overcome behavioural issues that often resulted in school suspension and relationship issues.

"The biggest focus is around healing and trauma," Professor Coffin said. "The leadership component is really important, though, because we didn't want the program stigmatised in the community as being for people who were mentally unwell."



Professor Juli Coffin

She said if there was trauma at home, some kids found it difficult to express that or even know if it was normal – often resulting in behavioural issues. Teachers and caregivers could mistake this for attention-seeking, and children were often misdiagnosed and medicated to manage their behaviour.

"What we do is not about unpacking the issues," Professor Coffin said. "It's a resourcing program about providing our most vulnerable young people with the tools around healthy relationships and self."

"The one thing it does do effectively, that's hard to do in a classroom, is self-regulate emotions like anger, sadness, fear and happiness. It starts to set up much better patterns around the types of issues Aboriginal youth are having in their learning environment."

"My thinking is I'm sure there's a better way than setting up another cycle of drug addiction – it's an alternative way to provide calmness and regulate emotions."

WHAT'S NEXT

- The program has moved to Yawuru country in the Kimberley, where it is known as Yawardani Jan-ga (horses doing healing).
- Professor Coffin is training nine practitioners to help deliver equine-assisted learning, in collaboration with the Equine Institute of Australia.



Juli Coffin is supported by Mineral Resources and the Ellison Family, while the Aboriginal research area is supported by the Packer Foundation and Telethon.

GRADUATION GOALS FOR COMMUNITY RESEARCHERS

Five Fitzroy Crossing women have been awarded nationally-recognised qualifications after working with the Telethon Kids Institute's Alcohol and Pregnancy & FASD Research Team, thanks to funding from 100 Women.

The women completed their Certificate II in Community Services at Northern Regional TAFE last year while working with Telethon Kids researchers to carry out the Alert Program® Study.

Project coordinator Bree Wagner said the relationship had created valuable outcomes for both Telethon Kids and the wider Aboriginal communities where the women live.

"We call them our two-way partners," Ms Wagner said. "The research would be almost impossible to do without their support."

"They helped us form and maintain positive relationships with community members, ensuring we're working in a culturally appropriate way and following cultural protocols."

The women learnt a wide range of skills, including health and safety, working with a diverse range of people, communication skills, preparing a resume, and first aid.

Ms Wagner said the women had been integral in providing cultural support and translation services, as well as helping parents involved in the Alert study fill out questionnaires. They had also helped with student testing in Fitzroy Valley schools, and were involved in sharing feedback with the families.

Ms Wagner said the TAFE certificate the women had earned would enable



them to build further on the skills and experience they had acquired.

"The skills these women gained have allowed them to branch into roles within the community space, giving them the experience to find the job they want," Ms Wagner said.

"It's given them the confidence to have a greater voice in their community and set a positive example for their children."

Since graduating in August 2018, several of the women have secured employment.

One works as a family support worker through the local women's resource centre, another has joined the Remote School Attendance Strategy team, and

a third woman has recently secured employment as a mental health worker.

Asked why they chose to pursue the certificate, all five women said they wanted to help people by strengthening the health of children in their communities, so they could get an education and grow up to get a good job.

Results of the project will be available later this year.



The Alert Program® Study was funded by a National Health and Medical Research Council Project Grant and 100 Women.

PIONEERING RESEARCH COULD BE KEY TO KEEPING CANCER IN CHECK

Cancer research is being reimagined after a collaboration between the Telethon Kids Institute, the Peter Doherty Institute for Infection and Immunity, and international researchers unlocked game-changing new knowledge about how the immune system puts melanomas to sleep.



The team behind the pioneering research – led at Telethon Kids by Dr Jason Waithman, Head of the Cancer Immunotherapy Group – believe the breakthrough has the potential to effectively cure cancer, by rendering cancer cells permanently dormant.

The researchers set out to investigate the role of a particular immune cell – tissue-resident T (T_{RM}) – in controlling the growth of melanoma tumours.

“Our initial research found that T_{RM} cells can make cancer cells dormant, or put them to sleep, through a process called cancer immune-surveillance,” Dr Waithman said.

Using a mouse model developed by Dr Waithman, a team of researchers – led by Thomas Gebhardt at the Peter Doherty Institute at the University of Melbourne – was able to track both the T_{RM} and cancer cells and observe them in action.

This allowed them to not only analyse up-close the relationship between the immune system and cancer, but to capture stunning real-time video of T_{RM} cells keeping melanoma cells in check.

Various colours used to clearly identify the different cells, along with firefly genes that helped to light the cancer cells up, made these tiny tumours visible to the researchers.

“This meant we could track immunity in this setting in exquisite detail,” Dr Waithman said.

“We’ve known for a long time that this suppression process could happen, but found it very difficult to study in the past.”

Dr Waithman said the research and associated model represented a major step forwards in the control of cancer.

“There are three stages of cancer control, referred to as the ‘three Es’,” he said. “Cancer can be eliminated, the cancer cells can escape and cause tumours, or a state of equilibrium can be reached. These can all be mediated by the immune system.”

This last stage — reaching equilibrium — is driving the next part of the research.

“We’ve discovered that T_{RM} cells act like security guards, surrounding the tumour and preventing it from escaping,” Dr Waithman said.

“Through the research we watched this unique cell population surveying the cancer and keeping it asleep. When we depleted that specific cell type, the tumours would then re-emerge.”

- Dr Jason Waithman

“Now we want to know how tumour cells escape and if there’s a way of preventing this from happening. By looking more closely at how equilibrium is maintained, we can develop new strategies that make this process occur more frequently.”



Dr Jason Waithman

Dr Waithman said the researchers hoped the findings would lead to treatments to potentially convert aggressive cancers into a chronic, manageable condition.

“This really has the potential to put cancer to sleep forever, essentially providing a cure.”

- Dr Jason Waithman

The initial research, *Tissue-resident memory CD8 T cells promote melanoma-immune equilibrium in skin*, was published in *Nature*.

WHAT'S NEXT

- With further funding, Dr Waithman and the team hope to look more closely at whether T_{RM} cells can fully eradicate cancer cells, or if they just suppress them.
- They also want to determine if these cells are the targets of current immune-based cancer therapies – knowledge which could lead to novel therapeutic targets for cancer, or specific therapies for different types of patients.

NOVEL MODEL LEADS TO LIGHTBULB MOMENT

The ground-breaking research demonstrating how the immune systems keeps melanoma in check was made possible thanks to a novel cancer transplant model developed by Dr Waithman.

"A transplantable model is ideal as it gives us full flexibility to modify the cancer cells prior to transplantation," Dr Waithman said.

"That meant we could include multiple tags on the cancer cells, making them express different fluorescent colours and glow like a firefly. This in turn allowed us to track the cancer progression and observe the disease in action."

Dr Waithman said the researchers took a clinically relevant strategy by targeting the outermost skin layers where melanoma naturally occurs. This involved light abrasion of skin, followed by epicutaneous application of melanoma cells.

Using his model they were able to observe outcomes reflecting distinct disease stages seen in patients, including progressively

growing tumours, spontaneous metastatic spread, stably controlled small tumours, and tiny dormant melanoma lesions which persisted long-term.

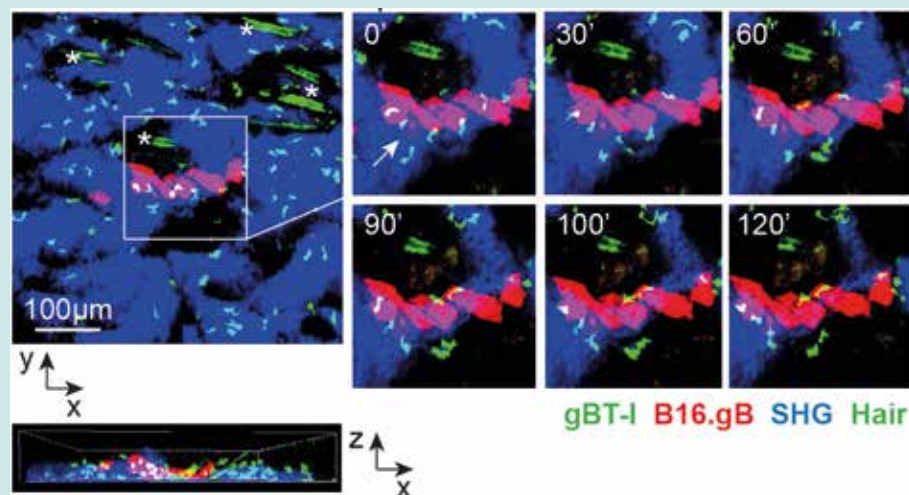
"Interestingly, we saw tumour outgrowth sometimes occurring many months after inoculation – suggesting these tumours lay dormant," Dr Waithman said.

"This was a lightbulb moment that prompted us to then ask challenging questions about how the tumours were able to remain dormant – a process caused by immune-mediated equilibrium.

"This led us to identify the T_{RM} cells – leading to the exciting research which has just been published in *Nature*."



Jason's research has been supported by BHP, Cancer Council Western Australia and the Brady Cancer Support Foundation.



Dynamic imaging of T_{RM} cells (green) keeping cancer cells (red) in dormancy. Note auto fluorescent hair (green, asterisks).

WA-FIRST TECHNIQUE FAST TRACKS URGENT VACCINE POLICY

Analysing samples is a vital part of research, providing the answers needed to move forward with innovative new treatments and life-saving vaccines. But this process is often very time-consuming, taking many months to complete, and the long wait for information can have devastating consequences.



This is especially true for children in Papua New Guinea, where pneumonia is a major killer for kids. Pneumonia is responsible for one million deaths globally each year, but Papua New Guinea has the highest rate – 23 per cent of children don't make it to their fifth birthday.

With new vaccine policies urgently required to save the lives of children, researchers from the Telethon Kids Institute worked closely with the Papua New Guinea Institute of Medical Research (PNG IMR) to collect samples and find a way to analyse them as soon as possible.

Thanks to funding from the Wesfarmers Centre of Vaccines and Infectious Diseases, researchers established a new technique that dramatically reduces analysis time. Instead of just 24 samples a day, researchers can now analyse 96 every 90 minutes.

"With this new method we could get through 2,400 samples within a week, where as previously this would have taken us more than six months," said Dr Lea-Ann Kirkham, Co-Head of the Wesfarmers Centre's Bacterial Respiratory Infectious Disease Group.

"We were able to get answers much faster, identifying which vaccines worked best at preventing pneumonia and informing new vaccine policies at the time they are urgently needed."

Telethon Kids is the only place in Western Australia currently using this fast-track technique, which involves extracting DNA to quickly identify the number of specific bacteria present to identify how well different vaccines are working.

"The most exciting thing about this new method is that we now have a platform that can be used across all microbiology studies and on a much greater scale, including areas such as ear infections, rheumatic heart disease and skin infections," Dr Kirkham said.

"It opens the door for the Wesfarmers Centre of Vaccines and Infectious Diseases to be a key player in a diverse range of international collaborations – the opportunities are endless."

WHAT'S NEXT

- Researchers from Telethon Kids are currently using the new fast-track technique to assist clinicians at King Edward Memorial Hospital in their studies to prevent skin infections in premature babies.
- This method will also play a vital role in a \$35 million grant developing a world-first group A streptococcus vaccine.



This research is supported by Wesfarmers Limited.

RESEARCHERS UNLOCK KEY TO SLOWING LEUKAEMIA PROGRESSION IN KIDS

When three-year-old Flo Parker injured her hip on a camping trip five years ago, her parents Marny and Daniel thought it would be nothing more than a common childhood injury. But when she reverted to crawling due to the pain she was in, they knew something was seriously wrong.



Scans later revealed the unimaginable: their daughter had a rare form of leukaemia growing in her bone marrow. After years of harsh chemotherapy Flo is now in remission, but the treatment that saved her may have life-long lasting effects.

"In the long term, bone density is a possible issue we may be looking at," Marny said. "My understanding is that she could be looking at the early onset of osteoporosis, in her early 30s."

Now, in findings which offer hope to kids like Flo, Telethon Kids Institute researchers have discovered a drug that can not only prevent bone density loss, but has the potential to slow leukaemia progression. The world-first discovery has prompted a change in thinking around the best way to target treatment.

Telethon Kids Cancer Centre researcher Dr Laurence Cheung, who led the team which made the discovery, said the findings, although pre-clinical, were promising and suggested that targeting the microenvironment around leukaemia cells could not only help fight leukaemia, but simultaneously provide relief for one of its most common and painful side-effects – bone loss.

"Acute lymphoblastic leukaemia is the most common cancer among children and remains a common cause of cancer-related death before 20 years of age," Dr Cheung said.

"When we created a pre-clinical model replicating this leukaemia sub-type, we witnessed substantial bone loss during development of the cancer. We wanted to discover what was causing the bone loss, which the existing literature suggests is experienced by more than a third of children diagnosed with acute lymphoblastic leukaemia.

"We managed to identify a signal produced by the leukaemia cells which instructed cells in the surrounding microenvironment to eat away at the bone. Then we thought, what if we stop these cells from eating the bone away – will this have an impact on the development of leukaemia?"

- Dr Laurence Cheung

"We managed to identify a signal produced by the leukaemia cells which instructed cells in the surrounding microenvironment to eat away at the bone. Then we thought, what if we stop these cells from eating the bone away – will this have an impact on the development of leukaemia?"

The researchers used a commercially available drug called zoledronic acid – already known to be safe for children and used to treat brittle bones – to target the bone-eating cells in the microenvironment around the leukaemia cells.

"Importantly, we found that this not only compensated for leukaemia-dependent bone fragility, but also reduced leukaemia progression," Dr Cheung said.

He said the discovery that cells surrounding the leukaemia cells could contribute to failure or success showed how important it was to look at the whole picture. Although similar thinking had previously been applied to cancer in adults, the finding offered an exciting new treatment angle for children.



Flo Parker with mum Marny, Dr Laurence Cheung and Dr Rishi Kotecha

"To date, the main strategy for cancer therapy in children has focused on targeting malignant cells with chemotherapy, which is toxic for leukaemia cells but also toxic to the patient," Dr Cheung said.

"This new research could provide us with a powerful adjuvant therapy. It won't replace chemotherapy, but we propose that using chemotherapy and treating the microenvironment at the same time will have more benefit than just chemotherapy on its own.

"Although there's quite a way to go yet, it's exciting to think about the potential dual benefit this offers, and the paradigm shift it represents for children's leukaemia."

This research was carried out in collaboration with Curtin University, The University of Western Australia, the Harry Perkins Institute of Medical Research, St. Jude Children's Research Hospital, USA, and Perth Children's Hospital.

WHAT'S NEXT

- The researchers plan to expand the study, using similar treatment on other sub-types of the same kind of leukaemia to see if a similar impact can be achieved; and to ensure that zoledronic acid is compatible with conventional chemotherapy agents.



This research was supported by the Children's Leukaemia and Cancer Research Foundation and Cancer Council Western Australia.



COLLABORATING FOR IMPACT COLLABORATING FOR IMPACT

*This research shows how we work
with others to make a difference*

EARLY YEARS INITIATIVE OFF TO STRONG START

A 10-year agreement forged between the State Government, Minderoo Foundation and Telethon Kids Institute is well underway, with the first of four locations announced by Community Services Minister Simone McGurk at the end of 2018.



CoLab – Collaborate for Kids – is a joint initiative of the Minderoo Foundation and Telethon Kids, focused on giving every Australian child the best foundation in life.

The Early Years Initiative, announced in March 2018, sees the two organisations join forces with the State Government in a \$49.3 million unprecedented partnership, working to empower and support communities to assess the needs of their children and families in identifying what works best in their individual environment.

Over a decade, the initiative will try, test and deliver evidence-informed, community-led approaches to child development in four communities.

The initiative will work within four communities – metropolitan, regional, remote and ultra-remote – with the Central Great Southern shires of Katanning, Broomehill-Tambellup, Kojonup and Gnowangerup selected as the first community to take part.

With more than 50 language groups calling Katanning home, the region is the most ethnically diverse in Western Australia, with numerous cultural and religious backgrounds.

Engagement has already begun in the Central Great Southern, with other locations due to be announced later this year. The partnership has drawn together an impressive board, led by former Children's Court magistrate Dr Sue Gordon and former UnitingCare West chief executive Sue Ash, who are co-chairs.

"Research tells us the first four years of a child's life are critical in creating the platform for their future success," Dr Gordon said.

"The enthusiasm of the Central Great Southern shires to be involved in this unprecedented initiative demonstrates the strong desire for this kind of commitment to change for children.

"The Early Years Initiative will work with communities like those in the Central Great



Minderoo's Nicola Forrest and CoLab Director Professor Donna Cross

Southern to discover the best approaches to improving the health, learning and development of our children. Our goal is to achieve real and lasting progress and then apply our learnings across the board for the benefit of the whole state."

Minderoo's Mrs Nicola Forrest said Minderoo's greatest successes have come from collaboration.

"One cause I'm particularly proud of is the Early Years Initiative, a ten-year partnership between the State Government, Telethon Kids Institute and Minderoo," Mrs Forrest said. "Because of the Initiative's structure, it's able to have incredible impact across communities and really support and empower families and children.

"That kind of collaboration is the key to our philanthropy. We live by the motto 'If you want to go fast, go alone. But if you want to go a long way, you have to go together'".

WHAT'S NEXT

- The remaining three communities are due to be announced by the State Government by the end of the year.
- Engagement in the Central Great Southern community is continuing to establish a framework for the Early Years Initiative.



CoLab - Collaborate for Kids - is a partnership between Minderoo Foundation and Telethon Kids Institute.



Children at the Katanning Library

BOBBIE BRINGS BABY'S BRAIN TO LIFE

A lovable blue creature by the name of Bobbie has won the hearts and minds of Western Australians and is helping to build a stronger understanding of early childhood development.

Bobbie was the central character in the **Bright Tomorrows Start Today** campaign, seen across television, social media, newspapers and shopping centre billboards for seven weeks from October to December 2018.

The campaign was created by CoLab – Collaborate for Kids – a joint partnership between Telethon Kids and the Minderoo Foundation focused on giving every Australian child the best foundation in life.

Bright Tomorrows Start Today uses communications science to address current thinking patterns in Australia to explore key concepts of early childhood development and learning.

The first phase of the campaign aimed to lift public recognition of the significance of the early years, and the importance of interacting from birth to build young brains.

Working with the creative team at 303 MullenLowe and Siamese, Bobbie was created as a representation of a baby's brain, showing how it responds to meaningful moments.

Bobbie's name was chosen from hundreds of suggestions made by children during the Telethon weekend.

Evaluation has since shown the campaign's key messages were widely understood by the West Australian public. It scored significantly above the benchmark for similar campaigns when compared for novelty, affective impact and relevance.

Of those who remembered seeing the campaign, more than 90 per cent recalled the TV commercial, demonstrating its significant visual impact.

The results pointed to a significant shift in understanding that children begin to learn from birth. There was also a shift in acknowledging that the first two years of life have a long-term effect on brain development.



WHAT'S NEXT

- The next phase of the campaign is now in development, with Bobbie being used to transform the way early childhood is understood across Australia.



Channel 7's Monika Kos, Professor Donna Cross and Nicola Forrest with Bobbie.



Nicola and Andrew Forrest with Bobbie.



CoLab - Collaborate for Kids - is a partnership between Minderoo Foundation and Telethon Kids Institute.

'MAMA' DEB'S DEDICATION TO SAVING CHILDREN IN PAPUA NEW GUINEA

Children living in Papua New Guinea have good reason to call Clinical Associate Professor Deborah Lehmann 'Mama Deb' – her dedication to preventing pneumonia can be credited with saving the lives of many thousands of babies.



Professor Lehmann with past Huli staff of the PNG Institute of Medical Research

The highly-respected researcher spent 17 years living in Papua New Guinea (PNG), following her passion to reduce the burden of childhood infectious diseases. Now, an award named in her honour will allow others to follow in her footsteps.

Funded by the Wesfarmers Centre of Vaccines and Infectious Diseases, the annual Deborah Lehmann Research Award will provide training and development for early career researchers and students in the Western Pacific Region, ensuring her groundwork can be built upon for many years to come.

Professor Lehmann's research in the region began in the Southern Highlands of PNG in August 1981, after she accepted a position as Director of the Tari Research Unit (TRU).

"I remember walking into the TRU's office – a two-room hut where I met the village reporters, some wearing their traditional Huli wigs and loin cloths," Professor Lehmann said. "There weren't any computers at that point and I was perplexed by the working hours being precisely 7:45 to 4:06, especially when no one had watches!

"I signed up for two years and ended up staying for 17 – I met my partner Michael Alpers at the Papua New Guinea Institute of Medical Research (PNG IMR) in Goroka and have continued to work closely with the Institute for over 37 years now – more than half my life."

- Professor Deborah Lehmann

Professor Lehmann's work has been primarily focused on the prevention of pneumonia – the major killer of young children in PNG and other third world countries.

After becoming Director of Pneumonia Research at PNG IMR, she spent a



number of years investigating which pneumococcal vaccines could provide the best possible protection for babies, and the optimum time to provide them.

"Even now, infant mortality caused by pneumonia is 10 times higher in PNG than in Australia, and back then it was far worse," Professor Lehmann said.

"We really needed to try and address this dire situation in any way we could, whether it be through vaccination, nutrition or appropriate diagnosis and treatment.

"We also documented that even if you lived one hours' distance from a hospital, a child's risk of dying from pneumonia was much higher, so access to health care was vital."

Although Professor Lehmann made significant research strides while in PNG, things were not always plain sailing, and she has many quirky memories of the years she spent there.

"During my time in Tari, all of our data had to be transported by road to another town for data entry into a mini computer that took up the space of a whole room," she said.

"Miraculously no data were lost on the way, however some data from a maternal nutrition study were in a suitcase stolen from my house – and were later seen decorating a Huli's wig!" Professor Lehmann said.

"One day we were working in our office and a big tree was being cut down outside – someone tried to provide some advice but was told 'Don't tell us what to do, we know how to cut down trees'. The next minute the tree came crashing down on our roof – luckily no one was injured."

- Professor Deborah Lehmann



After nearly two decades in PNG, Professor Lehmann moved to Australia in 1998 and joined Telethon Kids, where she has used the skills and research expertise she acquired in PNG to establish programs in acute respiratory infections, otitis media (middle ear infections), and Aboriginal health.

She has led ground-breaking work including the Swimming Pool Study, which established the health benefits of introducing swimming pools into remote Western Australian Aboriginal communities; and the Kalgoorlie Otitis Media Research Project.

Professor Lehmann continues to collaborate with researchers at PNG IMR and in Australia on significant ongoing research projects, and has encouraged others at Telethon Kids – many of whom she has mentored – to collaborate on projects in the region, including Dr Peter Richmond, Dr Christopher Blyth, Dr Lea-Ann Kirkham, Dr Anita van den Biggelaar, and Dr Ingrid Laing.

Renowned as a generous and compassionate mentor devoted to training and nurturing the next generation, Professor Lehmann has had a profound impact on the careers of countless younger researchers, including 10 Aboriginal researchers whom she mentored as part of an NHMRC Indigenous Capacity Building Grant (see story on page 52).

Combined with her considerable research achievements, that contribution as a mentor means Professor Lehmann's influence will be felt at the Institute – and most importantly by children and their families – long after her impending retirement.



Professor Deborah Lehmann with inaugural recipient Celestine Aho

DEBORAH LEHMANN RESEARCH AWARD



The impact of Professor Lehmann's work in PNG over the past 30 years is impossible to measure, according to Dr Tom Snelling, Director of the Wesfarmers Centre of Vaccines and Infectious Diseases.

"We know pneumonia is responsible for more than one million childhood deaths around the world each year, so Professor Lehmann's work preventing pneumonia ensures many thousands of kids make it through their vulnerable early years," Dr Snelling said.

"We are very proud to announce the Deborah Lehmann Research Award in recognition of Professor Lehmann's dedicated research in PNG, and we look forward to seeing young researchers continuing her legacy by providing better prevention and treatment solutions for children in this region."

The inaugural recipient of the \$30,000 annual award, Celestine Aho, was formally announced in March 2019. Ms Aho will investigate the true burden of otitis media and the cause of these infections among children living in the Eastern Highlands of PNG.

Ms Aho's passion for research around otitis media stems from her little brother's hearing loss and learning difficulties after recurring ear infections as a baby, and she is now determined to highlight the importance of ear health.

"My family knew little about the effects of otitis media on hearing as it was considered a normal part of growing up, and we didn't have education around ear health issues or awareness of audiology support services," Ms Aho said.

"As part of my research, I hope to bring emphasis on the awareness of otitis media in the community and in primary health care."

WARAJANGA MARNTI WARRANJA – TOGETHER WE WALK ON COUNTRY

A \$5 million commitment from BHP has allowed Telethon Kids researchers and Aboriginal communities to join hand-in-hand in a bid to make Fetal Alcohol Spectrum Disorder history in the Pilbara.



Local leader and CEO of Wirraka Maya Health Service, June Councillor, has spent years working to highlight suspected high rates of Fetal Alcohol Spectrum Disorder (FASD) among Aboriginal children and youth in some Pilbara communities. In response, and at the request of BHP, in 2014 the Telethon Kids Institute with Wirraka Maya established a FASD research program in Port Hedland, Yandeyarra and Warralong.

The Warajanga Marnti Warranja – Together We Walk on Country program was based on successful strategies employed in the Kimberley and elsewhere in the world, but adapted for the Port Hedland context.

The program, including its name, was carefully developed after close consultation with the local Community Reference Group and the Hedland FASD Network, representing more than 30 health, education and justice services.

"Naming the program was actually a really important contribution," one FASD Network member said.

"Alcohol is a sensitive topic. If you just called it Hedland FASD or something like that, people might be embarrassed and reluctant to engage. The name, and the use of the Nyangumarta language, reflects the collaborative nature of the program."



The Pilbara FASD team: (from left) Michelle Gray, Sangita Daniel, Adrian Clinch, Glenn Pearson, David Tucker, Elaine Clifton, Kaashifah Bruce, Roz Walker, James Fitzpatrick.

Glenn Pearson, Head of the Aboriginal Health Research Focus Area at Telethon Kids, said the \$5 million commitment from BHP had enabled the Institute to develop a foundation to work with Aboriginal families and children in the Pilbara both on research and other issues around FASD, including prevention.

"The Institute has developed relationships with community that involve much more than just scheduling research," Mr Pearson said. "It's really important that these communities can set the conditions on which they are involved in research that affects them."

"It's also provided the opportunity to build local capacity and provide research training and career development for Aboriginal people to work in their own communities."

- Glenn Pearson

Community researcher Margaret 'Sissy' Ramirez said she had learnt the importance of having good data to help Aboriginal people to tell their stories.

"It's a really important way for people to understand your message," she said.

Fellow community researcher Elaine Clifton said she saw Telethon Kids as the face of FASD in the Pilbara, and working with researchers had taught her to be curious about why a particular behaviour was happening.

"Through research and education people are listening and yarning about it," she said. "As long as we walk together, we know we are supported."

Since embarking on the program the research team has collected more than 1,000 surveys to ascertain community awareness of FASD; trialled a school-based therapy program that reached more than 100 primary school children; and conducted FASD diagnostic clinics to increase the number of local children receiving a FASD diagnosis.

As a result, the team has helped make FASD a front-of-mind issue for Pilbara health and medical services, schools, and non-government organisations – leading to increased diagnoses of children with FASD, the development of a clinical referral mechanism, and research into potential therapeutic interventions.

"Our work, including strong engagement with the Port Hedland community and local capacity building of Aboriginal co-researchers, has proven successful in maintaining levels of awareness about the risks of drinking during pregnancy at around 94 per cent," Mr Pearson said.

An additional \$5.4 million worth of funding has also been secured to translate FASD prevention research in other sites.

Chief investigator on the program, Dr James Fitzpatrick, said BHP's commitment – together with the leadership of Aboriginal community members and organisations – had created a clear path forward to making FASD history in the Pilbara.

"Through 'walking together', the community as a whole is focused and mobilised in tackling FASD and giving their children the best start to life. This is the power of translational research. FASD is preventable and we all want every child to have the best possible start in life."

- Dr James Fitzpatrick

Mr Pearson said the Institute was extremely grateful to BHP for its partnership and funding, which would help to set Pilbara children at risk of FASD on a more positive trajectory.

"This program will increase the opportunity for children not even born yet to have a quality of life consistent with other children," Mr Pearson said.

"It's imperative that we continue to work together to create a brighter future for all children and a community that understands, welcomes and supports them."



The Pilbara FASD Project was supported by BHP.



Launching the project in the Pilbara in 2016

WHAT'S NEXT

- The team aims to continue working with Pilbara communities and progress towards a broader program that works with families.
- Over the coming years, they hope to increase community involvement and leadership in the research by employing local management staff; increasing the number and capacity of community researchers and local champions; continuing to expand the role and involvement of the community reference group; and exploring ways to support increased community policy advocacy.
- The team plans to focus efforts on influencing policy to more deliberately identify opportunities and strategies to advocate for change at the community, local, state and national government levels.



FASD CONFERENCE UNITES POLICY, SCIENCE AND LIVED EXPERIENCE

Held every two years, the Australasian FASD Conference is a significant and unifying event for those in the Fetal Alcohol Spectrum Disorder sector. The latest conference, held in Perth last November, saw researchers, professionals and families sharing insights and galvanising momentum for future collective action.



Hosted by the multi-site FASD Research Australia Centre for Research Excellence (CRE), which has its Perth node at the Telethon Kids Institute, the 2nd Australasian FASD Conference 2018 was attended by more than 350 delegates, including international researchers, health, justice and education sector professionals, and families and carers of people with FASD.

The event opened with Federal Health Minister Greg Hunt and Indigenous Health Minister Ken Wyatt announcing a \$7.2 million 10-year action plan which will drive continuing efforts to reduce the impact of FASD on individuals, families and communities.

Co-Director of the CRE and leader of its Perth arm, Professor Carol Bower, welcomed the new action plan, saying the funding would help continue the national progress made in addressing FASD – progress which could only be made by giving all stakeholders a voice.

She said a key aim of the CRE was to involve consumers, parents and carers of people with FASD in guiding its work.

"The conference firmly embedded the perspectives of consumers, parents and carers in guiding future research and policy priorities, building on previous community reference group consultations," Professor Bower said.

"The highlight for me was seeing how much people enjoyed seeing everybody involved with FASD getting together to think about how we progress the research."

"The highlight for me was seeing how much people enjoyed seeing everybody involved with FASD getting together to think about how we progress the research."

- Professor Carol Bower

"We don't often get to meet each other face-to-face, and we enjoyed the confluence of clinicians, carers and researchers, policy and practice people."

The conference also firmed connections between clinicians and researchers around Australia and with international researchers, opening opportunities for strengthened collaboration. One included a Memorandum of Understanding with Canadian FASD researchers to work together on prevention, diagnosis and management of FASD.

Professor Bower said the conference helped researchers to refine the focus of future research beyond the current CRE.

"There is a lot to do in FASD, but it is clear that FASD is just part of a bigger picture of neurodevelopment in childhood – for example, we have a project looking at trans-diagnostic approaches to early development," she said.

"Often before you can make a definitive diagnosis such as FASD, autism or ADHD, there are hints that progress might not be going right at

that stage. That's an important development of our FASD work and other research at the Telethon Kids Institute."

A workshop held the day before the conference saw lawyers, police, child protection staff and consumers join researchers to hear valuable insights which will help guide management of people with FASD in the justice system. Those insights were made possible thanks to ground-breaking work carried out by Professor Bower and her team at Telethon

Kids, which revealed that more than a third of young people in the Banksia Hill Youth Detention Centre had FASD, and nine in 10 had severe neurodevelopmental impairment.

"In our Banksia Hill study 36 per cent of young people had FASD, but we also found that 89 per cent had at least one severe developmental impairment, so in justice we believe we should be focusing generally on neurodevelopment, not just on FASD," Professor Bower said.

She said those who had attended the workshop had been highly engaged.

"We had a really good group of people and a lot of energy that we hope we can build on to guide management and how justice services are structured," Professor Bower said.

WHAT'S NEXT

- It is anticipated that with wider marketing, including internationally, the CRE will attract even greater interest in the FASD2020 conference to be held in Sydney, offering further opportunities for partnerships and collaborations for all stakeholders.



See Banksia Hill Project story, page 30.



Panel discussion at the 2nd Australasian FASD Conference

PARENTS HELPING TO PUT FASD INTO PERSPECTIVE

For Neil Reynolds, foster dad to siblings aged seven and 10 years, who both have FASD, the 2nd Australasian FASD Conference was full of opportunities that only reinforced his positive outlook.

Well researched and with seven years' experience parenting children with the condition, he and his wife know that a consistent, appropriate approach helps each child to maximise their achievements.

"That's the message we tried to convey through the conference: that there is hope for these kids," said Neil.

"There's a big difference that can be made – you get massive rewards from them and they can achieve amazing things. You just need guidance and support because they are not like anybody else in the community. You've just got to do it a little bit differently and if you stick at it, you get great rewards," he said.

Testament to this approach, Neil's foster daughter is now completing Year 5, is able to read and enjoys school. She is a 'gun' at computer games and has become highly engaged in maths study, since it has been delivered via an iPad.

"She is certainly achieving far greater than the expectation was at the beginning of her schooling," he said.

"Socially she is well-liked and accepted, and she is positive about the learning process, even though not achieving as highly as the

other kids."

Neil's seven-year-old foster son, who is more seriously affected, is now satisfactorily managing Year 2, following years of consistent, therapeutic, 'good old-fashioned' parenting.

"The reality with these kids is you get out what you put in and if you put in a whole lot, you get a whole lot back."

- Neil Reynolds

"But unlike a mainstream child where it just happens, with these kids you've got to just keep pushing and encouraging until you get what you want," he said.

The conference enabled Neil to share his positive message with other parents, dispelling what he says is general negativity about the outlook for these kids. Added to that, listening to the successes researchers and clinicians were having was highly affirming for all.

"It's great for parents to be able to sit down and hear of clinicians having success with some of their clients and some of the projects they have put in place," he said.

"There are researchers finding things out about dealing with behaviours and it's good they can pass this on to the parents, so they can put it into place.

"It's also good to speak to people who have done those things and had some success – the effort in consistently following these guidelines is certainly worthwhile."

Neil said parents and carers felt valued in being able to share their insights and perspectives with researchers and clinicians.

"There are so many different aspects of FASD," he said.

"It was a fantastic opportunity. Often you have clinicians together, researchers together or parents and carers together, but it is rare you get them all in the one place – and so many of them, with so much passion and knowledge about the subject."



Neil Reynolds

DRIVING A VACCINE REVOLUTION

Imagine a future where a child could be vaccinated against a virus at birth, and that treatment was not only highly effective in almost all babies, but was also the only vaccination necessary for that disease for the child's entire life. The Telethon Kids Institute is now part of an ambitious, yet achievable, global bid to produce such one-shot vaccines.



According to the Telethon Kids Institute's newest senior researcher, Professor Tobias Kollmann, one-shot vaccines are within reach – if only the amount of funding needed for the research could be made available.

"We know what we have to do, and we know how to do it: the only thing keeping us from realising this dream is securing the necessary funding," Professor Kollmann said.

A world leader in infectious diseases research, Professor Kollmann recently relocated to Perth from Canada – bringing his research team with him – to spearhead the Institute's role as the first international hub of the Human Vaccines Project.

Modelled on the successful Human Genome Project – which revolutionised biomedical research after bringing together leaders in their field to sequence the human genome

– the Human Vaccines Project draws together top researchers from around the world to collaborate on comprehensively sequencing the human immune system, and determining the rules for long-lived protective immunity across globally diverse populations.

Professor Kollmann said the project aimed to attract \$1-2 billion in funding over 10 years to decipher how vaccines work. That knowledge would be the start of a 'vaccine revolution' and be translated into the next generation of vaccines, targeting difficult infectious diseases like TB, HIV and malaria, and even vaccines for non-communicable diseases like cancer.

"It's a very, very, ambitious goal given it's even more complex than the Human Genome Project, but when successful will transform the future of human health."

- Professor Tobias Kollmann

"It's a very, very, ambitious goal given it's even more complex than the Human Genome Project, but when successful will transform the future of human health," Professor Kollmann said.

"The human genome consists of about 20,000 genes. Analysing the human immune system is a million times more complicated than that – yet we have the tools to do it! The human health benefits would be monumental."

Telethon Kids Institute Director, Professor Jonathan Carapetis, said the Institute's goal of improving kids' health would be significantly boosted thanks to its role as a partner in this ground-breaking international initiative.

"This is an example of some of the best research organisations in the world coming together and inviting us to come on board

ABOUT THE HUMAN VACCINES PROJECT

The Human Vaccines Project is a bold public-private initiative that aims to decode the human immune system to make the next leap forward in human health. By cracking the code to human health, the Project will enable the creation of next-generation vaccines, diagnostics, and therapies across diseases. To learn more, visit www.humanvaccinesproject.org and follow @HumanVacProject on Twitter.



Professor Tobias Kollmann

to lead a particular component of the work," Professor Carapetis said.

"It makes the most of our expertise in understanding the immune system and engaging populations at highest risk of disease, like in Papua New Guinea and Aboriginal kids in Australia, which is instrumental in making sure we can understand how all kids can most benefit from vaccines."

Professor Kollmann said vaccination had been one of the most successful medical interventions to date. However, scientists still didn't know exactly how vaccines worked and why they worked for some people and not others. Flu vaccinations for example, only worked as desired in up to half the population.

"It's an odd thing to say because we know they work, but we don't understand how they work," he said.

"That's a difficult message to package, especially at a time when in Australia and other countries, infectious diseases haven't been

at the forefront and more and more people are becoming vaccine-hesitant, or even anti-vaccination.

"Then we have measles outbreaks all over the world because of increased resistance to vaccinations in children in particular – so the downside is immediately palpable and we know this is a dangerous dynamic."



The Perth hub of the Human Vaccines Project and the recruitment of Professor Tobias Kollmann and his laboratory team from Canada has been made possible by the Perth Children's Hospital Foundation, Telethon, Stan Perron Charitable Foundation and McCusker Charitable Foundation.

VITAL ROLE FOR TELETHON KIDS

Telethon Kids is one of several academic partners in the Human Vaccines Project, with others including the Vanderbilt University Medical Center, University of California San Diego, The Scripps Research Institute, J. Craig Venter Institute and La Jolla Institute for Allergy and Immunology.

Professor Kollmann said that as a regional hub for the project – the only partner outside of North America and the only one with a paediatric research focus – the Institute would make an invaluable contribution to the project's mission of 'decoding the human immune system to transform human health.'

"This will not only make a significant contribution to the development of vaccines and immunotherapies against infectious diseases, but also potentially cancers," he said.

Professor Kollmann's new lab at Telethon Kids builds on existing relationships with Perth-based collaborators and consolidates their expertise in conducting large-scale observational cohort studies in high-risk populations.

The group will utilise cutting-edge technologies, coupled with ground-breaking bioinformatic approaches, to help determine how and why an individual's immune system responds the way it does when challenged.

"This understanding will underpin our uncovering of the key mechanisms crucial to the infant response to vaccine or infection," Professor Kollmann said.

"Given that millions of infants die each year from infection or lack of vaccination, the importance of this work cannot be overstated."

- Professor Tobias Kollmann

He said the initiative would bring Telethon Kids and Western Australia to the forefront of impactful and prominent international medical research efforts.

The lab's relocation to Perth also adds to the growing momentum around systems and computational biology, currently being fostered at Telethon Kids and elsewhere in WA.



Clinical Research Manager Jennifer Kent and Christina Davies with her baby Cate at the launch of the Human Vaccines Project hub in Perth

GLOBAL CONSORTIUM AIMS TO PROTECT BABIES FROM THEIR FIRST WEEK OF LIFE

Babies are most vulnerable to life-threatening diseases such as pneumococcal and whooping cough in their first few weeks of life, yet current vaccines can't be given until two months of age.

Every year more than one million babies around the world don't live long enough to be immunised against these deadly diseases, so researchers from the Wesfarmers Centre of Vaccines and Infectious Diseases have teamed up with a consortium which aims to optimise current or develop new vaccines to provide immediate protection from birth.

Funded by a National Institutes of Health (NIH) US\$15 million grant, the Expanded Program on Immunization Consortium (EPIC) Study is led by some of the world's leading infectious disease experts, including Professor Tobias Kollmann, who recently moved to the Telethon Kids Institute from the University of British Columbia, and Professor Ofer Levy, of the Boston Children's Hospital and Harvard Medical School.

Professor Peter Richmond, Head of the Vaccine Trials Group at the Wesfarmers Centre, said EPIC arose out of a desire to understand more about how newborn babies' immune systems develop, and how they respond to vaccinations.

"The first stage of the study involved pioneering a technique which gives unprecedented insight into the dramatic changes occurring in a baby's body in the first week of life – all using less than a quarter

of a teaspoon of blood," Professor Richmond said.

"In the past we haven't had the tools to look in depth at the immune response in very early life, because the necessary testing required

large volumes of blood which can't be taken when babies are that small.

"Researchers now have access to vital information that can be used to optimise the design of vaccines and allow babies to be vaccinated a lot earlier, with the added benefit of longer-lasting immunity."

This major NIH research grant was secured thanks to initial pilot data funded by the Wesfarmers Centre. Led by Professor Richmond, Senior Research Fellow Dr Anita van den Biggelaar, and Professor William

Pomat, Director of the Papua New Guinea Institute of Medical Research, this involved obtaining samples and investigating vaccine responses in 30 newborns born in PNG.

The Wesfarmers Centre's involvement in the EPIC Study also paved the way for Professor Kollmann's move to Telethon Kids from Canada and opened doors to further collaboration opportunities involving the ground-breaking Human Vaccines Project.



This research is supported by Wesfarmers Limited.

"Researchers now have access to vital information that can be used to optimise the design of vaccines and allow babies to be vaccinated a lot earlier, with the added benefit of longer-lasting immunity."

- Professor Peter Richmond



BILL & MELINDA GATES FOUNDATION GRANT AIMS TO PREVENT DEADLY INFECTIONS IN EARLY LIFE

Newborn babies and their fragile immune systems struggle to fight off nasty infections such as septicæmia, pneumonia and gastroenteritis – all common causes of infant mortality in many countries around the world.

Now, in an exciting first for the Telethon Kids Institute, the Wesfarmers Centre of Vaccines and Infectious Diseases has been awarded a Bill & Melinda Gates Foundation grant as part of its mission to ensure more children and young people survive and thrive.

The US\$500,000 grant follows an earlier grant from the Immunising Pregnant Women and Infants Network (IMPRINT). The funding will enable a team

of researchers including Dr Anita van den Biggelaar, Senior Research Fellow at the Wesfarmers Centre, to investigate whether giving newborn babies probiotics daily over their first seven days can boost immunity and improve gut health – significantly reducing the risk of life-threatening infections.

"Thanks to the support of the Gates Foundation, researchers from the Wesfarmers Centre are currently conducting the pilot study in Papua New Guinea in collaboration with the PNG Institute of Medical Research," Dr van den Biggelaar said.

"The newborns involved are receiving a first dose

of probiotics within the first three days, followed by six additional doses throughout their first 10 days of life.

"The results from the pilot study will give us interesting insight into how probiotics can help with healthy colonisation of the gastrointestinal tract and program healthy development of the immune system."

Dr van den Biggelaar said the team hoped the data they obtained would lead to a large multi-site study in PNG involving thousands of babies, aimed at demonstrating the protective effect of probiotics in preventing major infections such as sepsis and pneumonia.

Project collaborators include Professors Peter Richmond and Tobias Kollmann (Telethon Kids), Dr Tobias Strunk (UWA), Professor William Pomat and Dr Rebecca Ford (PNG IMR), and Dr Andrew Greenhill (Federation University Australia).

"The results from the pilot study will give us interesting insight into how probiotics can help with healthy colonisation of the gastrointestinal tract and program healthy development of the immune system."

- Dr Anita van den Biggelaar



Dr Anita van den Biggelaar

PEOPLE POWER TAKES TINY STUDY TO THE NEXT LEVEL

Passionate community engagement and promising results have seen a small neuromuscular disorder study begun as a Masters project blossom into a five-year, National Health and Medical Research Council-backed program of research, with international collaboration.

One of the biggest problems facing young people with neuromuscular disorders is the risk of breathing problems caused by muscle weakness during sleep.



The resulting hypoventilation – breathing at an abnormally slow rate, leading to increased carbon dioxide in the blood – can eventually lead to lung failure, the most common cause of death in people with neuromuscular disease. It's a problem Telethon Kids Institute researcher and Perth Children's Hospital respiratory paediatrician Dr Adelaide Withers would dearly love to solve.

In 2016, thanks in large part to a scholarship from Muscular Dystrophy WA, she began a Masters project aimed at better understanding, predicting, and ultimately preventing hypoventilation.

Her pilot study, *Clinical Predictors of Respiratory Failure in Paediatric Neuromuscular Disorders*, is working with 37 children and young people from across WA who have neuromuscular disorders, including Duchenne muscular dystrophy and Spinal Muscular Atrophy, to identify early markers of hypoventilation.

"If we can identify the onset of hypoventilation earlier, we know that there's effective treatment," Dr Withers said. "It's very well shown that using non-invasive ventilation improves not only quality of life but reduces morbidity and mortality and prolongs kids' lives."



"I figure if I can pick this up earlier and treat it as early as possible I know I'm going to be improving the quality and the length of the life of my patients, which is all I want to do. That's why I come to work every day."

- Dr Adelaide Withers

Designed as a 12-month project involving overnight sleep studies, lung and motor function tests, and quality of life questionnaires, results so far from the pilot study – helped by a high level of engagement from participant families – have been so good they've spawned two bigger projects amounting to a five-year program of research into respiratory outcomes for neuromuscular disease.

The first, funded by the Duchenne Parent Project in the Netherlands and led by Telethon Kids Head of Children's Lung Health, Professor Graham Hall, is a two-year study monitoring respiratory outcomes in boys with Duchenne muscular dystrophy.

Together with the initial results from Dr Withers' pilot, the protocols from that study have in turn provided the basis for a five-year, \$1.6 million National Health and Medical Research Council grant. This will broaden the scope of Dr Withers' original study and adds a US cohort into the mix, thanks to a collaboration with Stanford University and the Lucile Packard Children's Hospital in Palo Alto.

Professor Hall said the overlapping projects were a great example of how working closely and openly with consumers and community members could take a piece of research to the next level.

"Initially we thought we'd have to scale back the project because the burden would be too high," Professor Hall said. "But the neuromuscular community said, 'We recognise this will be hard yakka but if this means we'll never have to do this again and that we'll get better treatment, please go ahead.'"



Professor Graham Hall and Dr Adelaide Withers



"Since then the project has only continued to grow, with the neuromuscular community reference group heavily involved at every stage and helping to shape our protocols and research questions in significant ways."

- Professor Graham Hall

Dr Withers said this had included a novel shift to in-home sleep studies, in response to participant concerns about the disruption of having to spend the night in hospital.

"We're very conscious of minimising the burden for these families, as they've often already got such a high burden because their children are often severely disabled," she said.

"So, when they told us that they hate having to come in to do sleep studies, we decided to try home sleep studies instead. Part of the NHMRC project will involve comparing home and in-lab sleep studies, which will be a lot more pleasant for the patients – and we probably wouldn't have looked at that if

it hadn't been for the community reference group.

"They've been incredibly committed to this research and really important in helping us steer the direction of what we do."

WHAT'S NEXT

- Dr Withers is continuing to recruit for her pilot study, and hopes to transition most of the participants over to the longer term NHMRC study.



This research is supported by Muscular Dystrophy WA and the Duchenne Parent Project in the Netherlands.

KARRATHA FAMILY JUMP AT CHANCE TO JOIN SLEEP STUDY



Mackenzie Crane and family

Mackenzie Crane was 10 months old when her parents, Jodie and Scott, were given the life-changing news that their daughter would never walk.

The Karratha family had noticed that beyond learning to sit up at around five months, Mackenzie didn't appear to be progressing. When a physiotherapist noted the by then eight-month-old had low muscle tone, they took her to the local paediatrician.

"The paediatrician looked at her and did a few things and then looked at me and said 'Right, I need you to get on a plane to PMH,'" Jodie said. "I think the whole world went 'boom'."

"We ended up in Perth, where they ran some tests. Eventually they told us 'Your daughter will never walk'."

Mackenzie was diagnosed with Spinal Muscular Atrophy Type 2, a genetic muscular disorder which affects the nerve cells that control voluntary muscles. It was a working diagnosis only, though, as doctors were for years unable to identify the specific genetic fault causing her muscle weakness.

Late last year, Genetic Services of Western Australia finally identified an incredibly rare mutation on Mackenzie's MORC2 gene. Jodie was told Mackenzie was one of only four reported cases in the world with that mutation.

"It turns out the mutation Mackenzie has is so rare it doesn't even have a name," Jodie said. "It doesn't change anything though – the symptoms are pretty much the same." Following Mackenzie's initial diagnosis, the family initially experienced shock and grief.

"This was followed by a steep learning curve and then adjustment to our new situation," Jodie said. "We tried to stay positive and focused on what Mackenzie could do rather than what she couldn't."

As a result, Mackenzie, now 13, has been able to enjoy experiences including overseas travel, concerts and shows, community and social involvement, and has attended the local primary and high schools with the help of education assistants.

In late 2017, the Cranes noticed Mackenzie wasn't waking up as refreshed as usual, and was experiencing headaches and low energy. A sleep study revealed multiple episodes of obstructive sleep apnoea.

Mackenzie's paediatric respiratory specialist, Dr Adelaide Withers, suggested the family join the *Clinical Predictors of Respiratory Failure in Paediatric Neuromuscular Disorders* study.

The Cranes – eager to understand more about Mackenzie's condition and to help with research which may benefit other families – jumped at the chance to be involved. Although the research has not changed Mackenzie's treatment, the family is pleased to be contributing to the search for answers.

"The more we know about neuromuscular disease and respiratory health, the better. The deterioration of breathing is a key concern for children like Mackenzie, so hopefully this study will help further identify risk factors and possible future treatments."

- Jodie Crane

Jodie said participation in the study hadn't been onerous, with the appointments tying in neatly with Mackenzie's regular trips to Perth for respiratory and other checks, including routine sleep studies.

"We've had a few lung function/ breathing tests over the past six months that are not invasive or time-consuming, and the staff are always lovely and accommodating," she said.

"The research may or may not benefit Mackenzie at this point but down the track it will certainly benefit other people. It's just good to be involved in it, and to have someone keeping an eye on her."



Researchers from Stanford University, who are collaborating on the neuromuscular disorder study, visited the Institute in May.

COLLABORATION KEY TO WET COUGH PREVENTION



Paediatric lung health researcher Pam Laird has decades of clinical experience but says her experience working towards improved early diagnosis of chronic wet cough and lung disease in Kimberley Aboriginal children has changed her world view – particularly around the importance of grass roots community collaboration.

Prevalence of chronic lung disease in Aboriginal children is conservatively estimated at 1.5 per cent. A wet cough, which is caused by mucus in the airways, often indicates low grade bacterial infection if the cough is present for more than four weeks. Such an infection can lead to permanent lung damage.

“Chronic wet cough can lead to really serious health issues, but it’s often curable – if we find it and manage it early,” Ms Laird said.

“What we were finding during our visits to the Kimberley is children in Aboriginal communities

were often presenting to doctors far too late, when they’d had their wet cough for a long time and already had lung damage, which could have been prevented if they’d been treated earlier.”

She said culturally appropriate early management was key, but to achieve that, researchers had to work in partnership with communities.

“As researchers, we can’t go into these communities with a paternalistic Western model of medicine and think we can fix the problem.”

- Pam Laird

“You’ve got to establish relationships with the community first and find out what their understanding is, what they need and what is

already working well. Then, together we can find solutions to providing health care in a way that’s culturally meaningful and sustainable.”

With the help of staff at Telethon Kids Kimberley, Ms Laird and Telethon Kids paediatric lung health researcher Dr André Schultz worked with 40 families as well as local health service providers – including the Kimberley Aboriginal Medical Services (KAMS), Broome Regional Aboriginal Medical Service (BRAMS), and WA Country Health Service – to come up with a strategy to raise awareness and improve recognition and management of chronic wet cough and lung disease.

They took a two-pronged approach, speaking at length with families to gauge what they understood about wet cough and lung health; and interviewing health practitioners to find out what they knew about these problems and what they saw as the barriers to managing affected children.

“We found that wet cough in children is normalised, both within the medical profession and families,” Ms Laird said.

“Knowledge about chronic wet cough in children is not widespread in the medical profession, since it was only formally recognised in 2006 that chronic wet cough in the absence of other signs or symptoms could represent serious disease.

“Health practitioners haven’t really had it on their radar as a public health issue before now, so haven’t been screening for it, and families haven’t known that a chronic wet cough could be such a big issue.”

“Families told us they’d never ever received any information like this before. They said ‘If you’d told us, we would have gone and got help for the kids’.”

- Pam Laird

Using this information, the researchers shaped a comprehensive implementation strategy which they tested for effectiveness in the Kimberley. The strategy centred around a health information campaign enlisting West Coast Eagles rookie and Balgo boy, Francis Watson, as a cultural ambassador to feature in radio, television, social media and print advertisements as well as community appearances and talks. The team also produced a culturally relevant flip chart about lung health and a short animation featured on YouTube.

The materials and advertisements, along with workshops and training sessions for local health practitioners, were pushed out during



From left: Community researcher David Ougham, Pam Laird, physiotherapist and co-researcher Annie Scanlon, André Schultz, John Jacky (Telethon Kids Kimberley), and community researcher Craig Sampi, at Djarindjin in the Dampier Peninsular





Dr André Schultz and Pam Laird

a three-month campaign late 2018, targeted at Aboriginal communities and health services around the Broome area.

"It was an amazing community effort on a shoestring budget, but the results have been really positive," Ms Laird said.

Although the team is still measuring the outcomes, anecdotally doctors are already reporting an increase in the number of children presenting and being treated, and families are telling Ms Laird stories of children who had been unwell for years, receiving treatment and experiencing vastly improved health.

"It's so much bigger than the research," Ms Laird said. "It's all the knock-on effects. Little lungs are being made healthy as we go – if we find children with lung sickness, we are able to tell families to present to their local clinic for help. And because we're doing the project in collaboration with the local medical clinics,

they have the skills to manage the children. Families are also getting valuable information about healthy lungs and what warning signs to look out for in the future.

"The benefits have been amazing. Families are empowered with health information so they can advocate for their children's lung health, medical practitioners are being trained in early management of lung disease, local Aboriginal people are being trained in research skills, and we as Telethon Kids researchers are learning directly from local Aboriginal people about how to do things the local way.

"It's a game changer for us and I have come to see that the only way forward is walking and learning together."

- Pam Laird

"It's really reiterated that the medicine is only going to get you so far: if you don't have trust and relationships with families, you are never going to get anywhere in the long term."

WHAT'S NEXT

- Results of a world first-study measuring prevalence of chronic wet cough and protracted bacterial bronchitis (bacterial infection of the mucus in the lower airways or lungs) in four Kimberley Aboriginal communities will soon be published. Preliminary results suggest prevalence of chronic wet cough could be greater than 10 per cent in the Kimberley.
- The researchers will complete their formal evaluation of the wet cough campaign and its impact on practitioners and communities.
- The team plans to develop the state's first teaching models for medical staff to provide culturally appropriate management of chronic lung disease in Aboriginal children.

LEADERS BACK WET COUGH PROJECT

In 2014, Kiarna Collard was diagnosed with bronchiectasis, the chronic lung disease that can develop if wet cough is untreated.

Managing the disease is traumatic for the now nine-year-old, who must spend long periods – up to a month at a time – hospitalised in Perth more than 2,000 kilometres away from her family in Djarindjin, a community of 300 people about 170 kilometres north of Broome, on the Dampier Peninsula.

She must also manage the disease in between hospital visits, relieving her symptoms with a nebuliser, a portal under her arm for medication, and chest physiotherapy two to three times a day.

Mother Belinda Sampi, a Community Navigator in Djarindjin, said the trips to hospital were tough for her young daughter, who not only missed her family, including her five brothers, when she was away, but suffered educationally from missing so much school.

Given this personal experience with chronic lung disease, Mrs Sampi was only too happy to back the Telethon Kids Institute's wet cough program in the Kimberley.

She first learned of the program from Telethon Kids senior researcher and wet cough program lead Dr André Schultz, whom she met through Kiarna's attendance at regular respiratory clinics he ran in Broome.

Keen to educate others in Djarindjin, Mrs Sampi helped the team launch the wet cough project in the community. She continues to spread the message through friends and family, and has urged the local school to educate students and parents about the need to treat wet cough early.

"I said from the start, I'd like to help to educate people around illnesses like wet cough because I deal with it around my little one and I'd hate to see someone go through the same situation as we are," Mrs Sampi said.

"It could be a lifetime condition for Kiarna and has a big impact on her. The message is that it's important to get to it when kids are young, so it doesn't impact later in life.

"When children have a cough, some parents here still think it's just a normal cold, so it's a matter of educating parents that if kids have that cough for more than four weeks, it's damaging their lungs.

"Personally, I think it's very important to get the message across because I wasn't aware when my little one was diagnosed, so I did more research about what it does and what we can do to help.

"It's good to see this type of education in our community."



Kiarna Collard with mother Belinda Sampi

Wet cough is caused by mucus in the airway. A wet cough in a child for more than four weeks could indicate infection in the lungs. Left untreated, over time this can lead to permanent, life-shortening lung damage, including the condition bronchiectasis.

Conservative estimates based on research in central Australia suggest the prevalence of chronic lung disease in Aboriginal people is 1.5 per cent, however recent studies suggest this may be much higher.

CHILD REMOVAL DATA FUELS CASE FOR CHANGE

Telethon Kids Institute research which revealed Aboriginal children are 10 times more likely than non-Aboriginal children to be placed in out-of-home care has focused attention on child protection practices, and is feeding a push to improve support for Western Australian families at risk of losing their children.



The work, led by award-winning child abuse and neglect researcher Dr Melissa O'Donnell, confirmed what members of the Aboriginal community had long suspected: that Aboriginal children, including babies, are now more likely than ever to be removed from their families.

The findings prompted the research team, including Telethon Kids Patron Professor Fiona Stanley and leading Aboriginal researcher Dr Rhonda Marriott, of Murdoch University, to call for urgent action to prevent further intergenerational trauma.

Their plea attracted widespread media attention and was followed by a slew of requests from those working with affected families, who were keen to use the research findings as part of efforts to improve child protection practices.

"What people were telling us was the numbers seemed to be rising, but they didn't have the data to prove it," Dr O'Donnell said.

"This research has acknowledged that yes, this is happening, and has opened the way to ask questions about what the government is going to do to address this and reduce the number of removals, and how can we find some solutions."

Since the paper's publication in the journal *Child Abuse & Neglect* in February, the researchers have been asked to meet with

the State Child Protection Minister to discuss the findings, and Dr O'Donnell has been invited to discuss the results at a meeting in the UK in September, which will focus on international rates of infant removal.

The researchers have also agreed to hold focus groups for various support services, agencies and lawyers, and the findings have been used as part of a legal symposium discussing the lack of legal representation for families facing the removal of children via court order.

"The fact that many families don't have legal representation and are therefore unable to contest allegations when orders are sought in the Children's Court, for example, is a real indictment on the system," Dr O'Donnell said.

"It's especially concerning given the growing number of 'until 18' orders that are now being sought for babies removed at birth, meaning those families can never get their child back."

Dr O'Donnell said the issues surrounding child protection were complex, but the strong response to the research showed there was a growing appetite for change.

"Ever since we released the paper everyone wants to talk to us – it's just taken on a life of its own," she said.

"There's more and more concern about how our child protection processes support children who are removed as well as how well we support those families to address the underlying issues that may be putting children at risk."
- Dr Melissa O'Donnell



Dr Melissa O'Donnell

"It feels like there's a lot of momentum, partly as a result of the Coroner's report into the suicides of 13 young people in the Kimberley, many of whom were involved with child protection.

"There's more and more concern about how our child protection processes support children who are removed, as well as how well we support those families to address the underlying issues that may be putting children at risk."

Dr O'Donnell said the evidence base that might illuminate these and related issues, including the child protection processes that may disadvantage families from seeking natural justice, was currently inadequate. However, her upcoming research, including a review of the Children's Court's case files for infant removals, and a potential review of national child protection data around removals, aimed to remedy this.

"What we're trying to do is highlight the systemic issues that are resulting in this rise in babies being taken from their families. Hopefully we can bring all that information together to then start pushing further for the changes that need to happen."

This work was funded by the Australian Research Council and undertaken with the cooperation of the Western Australian Government Departments of Health, Communities, Education, and Justice.

WHAT'S NEXT

- Dr O'Donnell will undertake a review of the WA Children's Court case files for cases involving infant removal to identify issues of concern.
- She has requested access to the National Child Protection Minimum Dataset to find out more about how the various states manage child protection orders, as well as how often children are reunited with their families.

The researchers reviewed child protection data from the Australian Institute of Health and Welfare (AIHW) from 2012-2016 along with linked data from Western Australian government departments. The resulting study, published in the journal *Child Abuse & Neglect*, found:

➤ The number of Aboriginal children in out-of-home care increased 21 per cent from 2012 to 2017, while the number of Aboriginal infants – those under the age of one year – in out-of-home care increased 17 per cent between 2013 and 2016.

➤ Nationally, 56.6 per 1,000 Aboriginal children were in out-of-home care in 2016, compared to 46.6 per 1,000 in 2012. By contrast, 5.8 per 1,000 non-Aboriginal children were in out-of-home care in 2016, up only slightly from the 2012 rate of 5.4 per 1,000.

➤ Similarly, the number of Aboriginal infants in care rose from 24.8 to 29.1 per 1,000 between 2013-14 – when the AIHW began collating data about children in out-of-home care under the age of one year – and 2016. Over the same period, the rates for non-Aboriginal infants rose from 2.6 to 3 per 1,000.

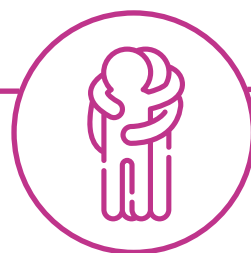


IN THE PIPELINE IN THE PIPELINE

*This research is in the
pipeline towards translation*

EMBRACING THE MENTAL HEALTH OF OUR CHILDREN AND YOUNG PEOPLE

Embrace – a new research collaboration based at Telethon Kids – will bring a new focus to understanding and improving the mental health of children and young people.



Fiona's son Sam was just 17 when he took his own life.

"When I realised Sam was gone, everything stopped. It was like my world had ended," Fiona said. "Never in a million years did I think this would happen. He was always so happy."

"I look back and I look for signs in his eyes or some sign that he was sad, but I can't see it. Sam wasn't bullied, he wasn't on drugs, he hadn't split up with his girlfriend. It's so confusing because you don't understand."

Sadly, Sam's story is not an isolated one. Suicide is the leading cause of death in 15-24 year olds in Western Australia, accounting for one in three deaths in young people.

Now a new collaboration based at Telethon Kids – called Embrace – will become the first research centre in the state devoted to the mental health of children and young people aged 0-25.

Led by some of Australia's top mental health researchers, Embrace will find new ways to help



Dr Ashleigh Lin and Fiona Bailey



Photographs of Fiona's son, Sam

kids at the lowest times in their lives – when they're experiencing trauma, depression, anxiety, or thoughts of suicide or self-harm.

Co-lead, Associate Professor Ashleigh Lin, said Embrace would bring together clinicians, service providers and government stakeholders to tackle the issue of mental health with a collaborative, holistic approach.

It would also seek to prevent crisis before it starts, by giving kids and communities the tools they need to better cope with challenges they face, including bullying, unsafe cyber behaviours, and stressful experiences. "Embrace will work towards deeply understanding the experiences and needs of

children and young people by listening to their voices and evaluating innovative ways of helping them," Dr Lin said.

"We'll then promote these solutions to mental health service providers and policymakers to create real and effective change."

Dr Lin said mental health was a complex issue that was still not fully understood.

"That's why research is so important," she said. "It's how we come to understand where problems originate, create new ways of helping vulnerable kids, prove which therapies work best, make sure kids get the right support, and discover how best they thrive in their families, schools and communities."

"Embrace will work at deeply understanding the experiences and needs of children and young people by listening to their voices and evaluating innovative ways of helping them."

- Dr Ashleigh Lin



It was essential, she said, to find new ways to prevent and treat mental health issues in order to keep children and young people on the right trajectory, so they could develop into happy and productive adults.

"Embrace will find answers to our most pressing mental health problems, and will push boundaries to not only create a more effective mental health system, but make a genuine difference for those vulnerable to suicide, self-harm, trauma, depression and anxiety."



Embrace has been supported by the Gift of Giving donors at the 2018 Lexus Ball for Telethon.



Professor Helen Milroy and Associate Professor Ashleigh Lin

How is Embrace unique?

- **Embrace** is WA's first and only research centre devoted to the mental health of children and young people aged 0-25 years. The team aims to develop early intervention strategies in childhood to prevent mental health crises later in life
- **Embrace** values the diversity of our community and seeks individualised solutions to help every young person and their families, especially those most vulnerable
- **Embrace** is driven by the needs of young people and families in WA
- **Embrace** is deeply connected in the WA community. Based at Telethon Kids, its research will involve young people directly and be conducted in partnership with local mental health service providers, schools, community groups, and government departments, to address the needs of our WA community and put everything we learn into action to help WA kids now

Our Values

Embrace
operates according
to the following values:

Health Equity

**Cultivating positive mental
health and wellbeing**

A holistic approach

Sustainable

Empowerment

The #SupportEmbrace Campaign – Embrace Ambassadors Maggie Dent and Nic Naitanui led a campaign to rally the community behind Embrace, raising both awareness and donations for mental health research. The campaign encourages people to post a photo of their younger self on social media to show today's young people that you know what it feels like to go through tough times.

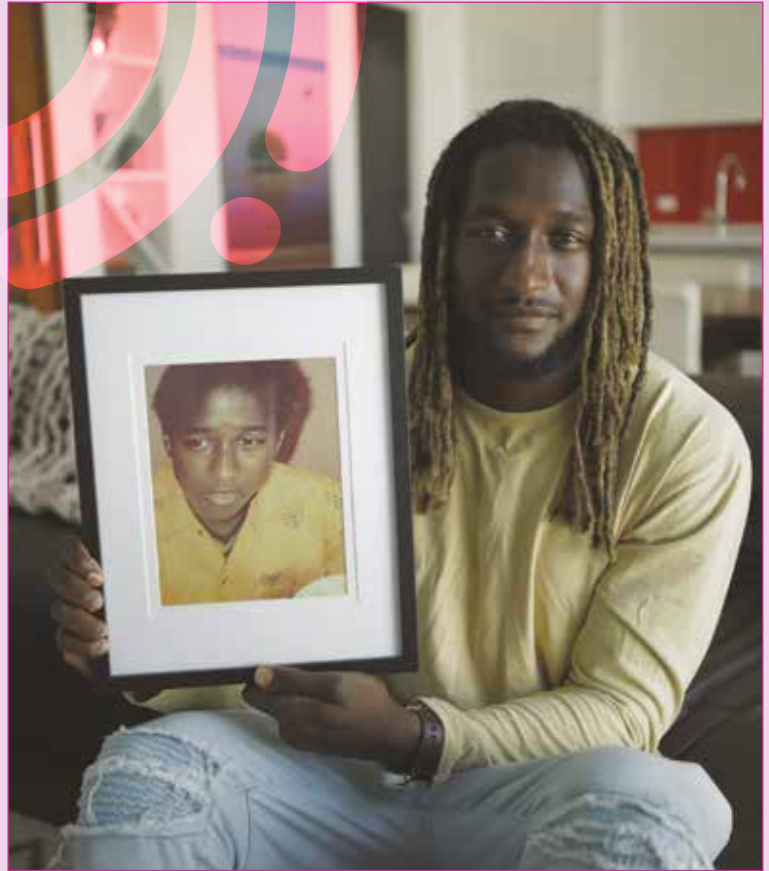


"Every single young person is struggling and vulnerable around the things that knock them down. We really have to look at: what are the things that genuinely support our teens? How do we support them in school journeys? How do we support them at a community level? How do we support them in families? I really believe today's world is giving our young people on that adolescent journey more challenges on so many levels and we need to work out how do we create the safe base around them, so they can come out the other end."

- Parenting author and Embrace ambassador **Maggie Dent**

"We need to prioritise mental health. The longer we take, the more lives are lost and that's the reality of it. We need to fight as soon as we can and get as much help into it as we can. Let's all rally behind the Embrace team to help give kids a brighter future."

-AFL player and Embrace ambassador **Nic Naitanui**



For more information, visit embrace.telethonkids.org.au

BUSTING MYTHS AROUND STILLBIRTH



Telethon Kids Institute researchers believe a public education campaign, like the one around Sudden Infant Death Syndrome (SIDS), would help to reduce the number of babies who are stillborn.

Research shows that deaths from SIDS in Australia dropped from 500 in 1989 to 113 cases in 2015, following the 'reduce the risks campaign' linking babies' face-down sleep position to increased risk of SIDS.

Telethon Kids Institute researcher Carrington Shepherd said that nationally, six babies were stillborn each day and, like SIDS, some of those deaths were preventable. There was a 'tragic over-representation' of Aboriginal people in those figures.

"But there's a real sense of fatalism that stillbirth is unavoidable, that it's not preventable – and that's not true," Dr Shepherd said.

"However, we don't fully understand which deaths are avoidable and which aren't, and this really hampers our work in this space."



Dr Carrington Shepherd

Dr Shepherd has teamed with the Institute's Dr Brad Farrant to lead further research on the topic. Dr Farrant and his wife Jaime are parents to daughter Kaya, who died unexpectedly during labour in 2011.

"It's still a very stigmatised space. The public understanding around stillbirth is quite low, with a lot of myths."
- Dr Brad Farrant

Dr Farrant said he believed Kaya's death – from a combination of infection and intrauterine growth restriction – was among those that were preventable.

"It's still a very stigmatised space," Dr Farrant said. "The public understanding around stillbirth is quite low, with a lot of myths."

"There's much work to be done in public health education to create an environment where we are able to have adult conversations around what we need to do to reduce stillbirth."

The Farrants gave evidence to the Australian Senate Select Committee on Stillbirth Research and Education in December 2018, and Dr Farrant said the time was now right, in the wake of that inquiry, to ramp up research.

Accordingly, he and Dr Shepherd are developing a small team of researchers at Telethon Kids and nurturing broader collaborations with the University of South Australia and the stillbirth charity Still Aware. Together they have formed the Stillbirth Parents, Educators, Awareness advocates and Researchers (SPEAR) collaboration.

Dr Shepherd said improving available data was a crucial first step in helping researchers.

"At the moment we are all coming from different angles; we have data boffins, clinical researchers, and scientists all working separately with their part of the picture, but if we could combine that we'd get a clearer picture of what needs to be done," he said.

"Then, we'd like to have that information linked to other administrative data and available to third party researchers like us."



Brad, Jaime and Djuna

"The data needs to be better. Placental dysfunction is one of the biggest risk factors for stillbirth, yet we don't systematically collect data about it. We'd like to see more information collected through autopsy processes and we'd like to see that happen systematically."

- Dr Carrington Shepherd

Dr Farrant said a big focus would be having a national conversation about stillbirth the way the community had previously had around SIDS.

"The parallels with SIDS are instructive," he said. "One of the key factors in the SIDS campaign was raising public awareness around sleeping position, and maternal sleeping position has been identified as a factor in stillbirth – so there are strong parallels."

"The SIDS campaign was very effective in not just raising awareness and dispelling myths but in getting people's interest."

"We need to do what we can to get people talking about stillbirth – this could be one of the most important things we do in terms of prevention."

WHAT'S NEXT

- A national public education campaign.
- A nationally co-ordinated approach to data collection.
- Ramping up examination of placental dysfunction as one of the big risks in stillbirth.

Putting parents at the fore

It was a conversation between Telethon Kids Institute researcher Brad Farrant and University of South Australia PhD student Danielle Pollock, at the International Stillbirth Alliance Conference in Scotland last year, that gave rise to the group

SPEAR: Stillbirth Parents, Educators, Awareness advocates and Researchers.

The pair joined up with Telethon Kids researcher Dr Carrington Shepherd, Claire Foord, founder of charity Still Aware, and Associate Professor Jane Warland, of the School of Nursing and Midwifery at the University of South Australia, to form the group, which aims to ensure that the voices of bereaved parents are heard in stillbirth policy, research and ultimately practice.

Dr Farrant, Danielle Pollock, Claire Foord and Jane Warland have all personally experienced stillbirth in their lives, with their experiences as bereaved parents a key driver as they seek to change the conversation around stillbirth.

Dr Farrant said that for him, the most important function of the group – which was still in its early days – was public education.

"Not long ago, it was thought the best thing for bereaved parents was to have the baby taken away and never spoken of again," he said.

"Thankfully, through a concerted advocacy and education campaign this is no longer the case. Unfortunately there is still a lot of stigma and lack of understanding about stillbirth, and this is why public education is such a vital component of stillbirth prevention."

"Conversations need to happen to educate the public, and it's important that the voices of bereaved parents are 'front and centre' of those conversations."

WA DATA CRUCIAL TO KEY STILLBIRTH FINDING

A 1970s initiative dreamt up by former Telethon Kids Director Professor Fiona Stanley, which saw midwives begin collecting key data about all births in Western Australia, has been crucial to new findings about stillbirth and pregnancy published in the prestigious international journal *Lancet*.

Head of Child Disability at Telethon Kids, Associate Professor Helen Leonard, is part of a West Australian perinatal epidemiology group, some of whose members collaborated with researchers in Finland and Norway for the world's first large-scale study into the link between stillbirth and subsequent pregnancy.

The study involved 14,452 births, including 3,521 from Western Australia. The Australian data was collected from 1980-2015 through the Western Australian Midwives Notification System, under which midwives began recording information about mothers' pregnancies and births from 1975 onwards.

"Now that data collection is absolutely routine, that information has been sentinel to a lot of studies including this one," Associate Professor Leonard said.

She said while women were generally advised by their doctors that it was best to wait at least two years before conceiving again after a live birth (sooner after a miscarriage), guidelines on the appropriate interpregnancy interval following a stillbirth were vague.



Associate Professor Helen Leonard

The new research showed there was no evidence to support the notion that waiting was beneficial, allowing doctors to provide clearer advice and providing reassurance for women who intentionally or unexpectedly became pregnant again soon after experiencing stillbirth.

"I was surprised that such a high percentage of women did conceive relatively soon after, and I was very happy about the fact that conceiving relatively soon had no worse impact on the outcome of the next pregnancy, so it's a really good news story," Associate Professor Leonard said.

She said a letter from a mother, who was looking to conceive again after a stillbirth and had read the research, summed up the significance of the findings.

"Women in my situation usually never get any answers as to why they lost their pregnancy, and it seems like such a murky and difficult area that nobody wants to touch," the letter read.

"Now that data collection is absolutely routine, that information has been sentinel to a lot of studies including this one."

- Associate Professor Helen Leonard

"So, there is little to no research or information for us women who want to make an informed decision about how to proceed with our lives and our fertility.

"This gives me hope that proceeding with a future pregnancy when I feel ready will be safe (regarding concerns on inter pregnancy interval) and will help to ease my anxiety moving forward."

concerns on inter pregnancy interval) and will help to ease my anxiety moving forward."

HELPING KIDS GET THE MOST OUT OF SCHOOL

In 2014 Professor Steve Zubrick was one of nine chief investigators who were awarded nearly \$28 million in funding to create the Australian Research Council Centre of Excellence for Children and Families Over the Life Course, of which he is Deputy Director. Five years on, Telethon Kids-led studies emerging from the collaborative research centre – set up to investigate and prevent the transmission of deep and persistent disadvantage across generations – are leading to better outcomes for kids and their families.

Professor Zubrick and Dr Kirsten Hancock are among several Telethon Kids researchers working through the Life Course Centre to tackle intergenerational disadvantage and identify ways all kids can get a better start to life.



Dr Hancock's work has focused predominantly on what helps and hinders children to do their best at school, including family background factors and the way these can affect what children have in their 'backpacks' when they arrive at the school gate.

"My work has particularly targeted student absenteeism, including the different reasons students miss school and the impact of those reasons on NAPLAN outcomes," Dr Hancock said.

In one of her most recent studies, Dr Hancock led a team, including Professor Zubrick, that collated data on entire cohorts of Western Australian children to show how different types of absences related to NAPLAN outcomes. Surprisingly, they found in-term holidays have little impact on NAPLAN scores. Rather, it's unexplained absences schools need to worry about.

Professor Zubrick said the results showed it wasn't just the number of days missed that caused students to fall behind, but the type of absences.

"Unexplained absences account for about one third of all absences in the study population and were associated with the largest academic gaps," he said.

"Vacations during the school term were generally not associated with student achievement, but we found that children



Professor Steve Zubrick and Dr Kirsten Hancock

with unexplained absences had a greater risk of falling behind."

Dr Hancock said the group most affected by absences was high-achieving students, whereas the estimated effects of absence on achievement were considerably lower for low-achieving students – raising questions about what students were missing out on when they were away from school.

"It's an important discovery that high-achieving students are the ones most affected by absences, and this includes legitimate absences, like illness," Dr Hancock said.

"Attendance policies often focus on disadvantaged students, and these findings show that attending school is important for all students. But we also need to know why low-achieving students are not falling further behind when they're absent."

Dr Hancock said the next step was translating the research findings into practical solutions for schools and students.

"Although findings are still being disseminated, this research has led to us working with student support services to look at ways schools can encourage better attendance and reduce unexplained absences," Dr Hancock said.

"It's an important discovery that high-achieving students are the ones most affected by absences, and this includes legitimate absences, like illness."

- Dr Kirsten Hancock

In other outcomes, the Life Course Centre's 2018 annual report showed the relative rate of poverty has remained stubbornly unchanged in recent years, hovering at around 10 per cent of Australians living below the poverty line.

Professor Zubrick said about 700,000 Australians lived in entrenched disadvantage (defined as poverty for four or more years), with the Centre's research showing that generally, as children experienced more disadvantages, they found it much harder to catch up to their more advantaged peers.

Amongst other research, Telethon Kids researchers working through the Centre have examined how combinations of different types of disadvantages contribute to the way children develop language skills over time.

"Our studies have been important for government departments, including those in Western Australia, because of the information they provide on the proportion of families experiencing different types of challenges, and where different policy supports are needed."

- Professor Steve Zubrick



Life Course Centre staff and students from the Universities of Western Australia, Queensland, Melbourne, and Sydney met for a research retreat at The Vines in Perth, in May.

WHAT'S NEXT

- Dr Hancock will discuss absence patterns in professional development workshops for school principals. The workshops will help principals work with their own school data, pinpoint problem areas, and generate strategies appropriate for their school.
- Along with CoLab, the Life Course Centre team is working with several government departments to find better ways of designing services for young children and their families.



- The Life Course Centre is a national research centre which aims to tackle the problem of **deep and persistent disadvantage within families and across generations**, and to **translate research findings into practical solutions**.
- **Established in 2014**, the Centre is a multi-site collaboration between **The University of Western Australia and universities in Queensland, Melbourne and Sydney**, along with **seven corporate partners and three state governments**.
- It has **collaborative links** with national and international partners, including research institutions in **North America, Europe, and Asia**.



Dr Kirsten Hancock

ENERGY DRINKS NOT OK FOR KIDS

In the largest study of its type in Australia, Telethon Kids Institute researchers have found more than half of young people who consumed energy drinks suffered negative health effects – leading the Institute to call for a ban on sales of the products to children under the age of 18.



The Amped Up study, led by public health researcher Dr Gina Trapp, surveyed 3,688 Western Australian high school students about their energy drink use.

Preliminary findings showed more than 50 per cent of those surveyed had tried an energy drink, with 55.4 per cent of that group reporting they had experienced adverse outcomes – some serious enough to require medical assistance.

According to the survey, 24.6 per cent had experienced heart palpitations, 24.5 per cent had had trouble sleeping or insomnia, 24.3 per cent had headaches, and 24 per cent had upset stomachs.

The findings were included in a Telethon Kids submission to the State Government's Select Committee on Personal Choice and Community Safety in October 2018.

"We are advocating for a ban on the sale of energy drinks to children under 18 years of age due to negative impacts they can have on health," Dr Trapp said.

"Children and parents are largely unaware of these health risks, despite packaging stating the drinks are not recommended for consumption for children.

"They provide a potent source of caffeine and can contain high levels of sugar, sodium and herbal stimulants."

Dr Trapp said the growth in popularity of these drinks was concerning, with annual sales in Australia increasing more than 600 per cent between 2001 and 2012.

Other peak health bodies, such as the Australian Dental Association and Australian Obesity Policy Coalition, support a ban.

Existing research shows energy drinks have been connected to cardiovascular and neurological issues such as seizures, psychosis and cardiac arrest.

There is also evidence linking energy drink consumption in children and young people to substance use and a range of behavioural problems.

Dr Trapp said young people who had tried energy drinks reported confusion surrounding their ingredients and appropriate serving sizes.

"Although labels are legally required to carry warnings and other information, they're not easily seen or understood," she said.

Serving sizes were also a problem, with 320mg per litre the maximum amount of caffeine permitted — unless the product was called a 'dietary supplement'.

"Labels must also state the maximum recommended daily amount is 500ml per day, however energy drinks are available in sizes larger than this," Dr Trapp said.

Data from the Australian Poisons Information Centre shows a five-fold increase in calls regarding energy drinks, with the most common symptoms palpitations, agitation, dizziness and gastro-intestinal upset, and at least 128 people requiring hospitalisation.

An initial focus group, which led to the state-wide survey, found adolescents consumed energy drinks to conform with peers and to stay awake and play video games, complete assignments or play sport.

Full findings from the study will be published later this year.



Dr Gina Trapp



Popular energy drink brands include

Red Bull, Monster, Mother, Rockstar and V

Half the young people surveyed had tried an energy drink, with **23.4 per cent** consuming them **monthly**, **19.2 per cent** consuming them **weekly** and **2 per cent** consuming them **every day**

The average age of **first consuming an energy drink** was **10**

55.4% of young people who had consumed an energy drink said they experienced at least **one adverse reaction**

WHAT'S NEXT

- The research team is hoping to secure funding to run a parent-based intervention program, educating parents and caregivers on the dangers of energy drink consumption by children.
- The team will also be pushing for changes to labelling, making warning labels and ingredients clearer and easier to see.

PERSONALISED ANALYTICS PROPEL RARE DISEASE DIAGNOSES

Telethon Kids Institute researchers are at the forefront of rapid improvements in the diagnosis of rare diseases, with the Institute's Genetics and Rare Disease program using powerful new tools to decipher conditions that until now have defied understanding.



Just six years ago, researchers – including rare diseases expert Professor Gareth Baynam and computational scientist Timo Lassmann – were far less confident about diagnosing with certainty a child presenting with a complex array of severe and unusual symptoms.

But within a very short period, those odds have dramatically risen.

"If you'd come to me in 2013 and asked, what are the chances of a child with a combination of severe and unusual characteristics having a confirmed diagnosis, I'd have said nine per cent.

In 15 months it went to 30 per cent – tripling.

"Then we created the Undiagnosed Disease Program and took the diagnostic rate from 30 per cent to 55 per cent – all in a few years."

- Professor Gareth Baynam

Professor Baynam, Clinical Geneticist and an Honorary Research Fellow at Telethon Kids, said rapid improvements in the diagnosis of rare diseases were set to continue globally, with the Institute at the forefront of that wave.

Professor Baynam works with the Institute's Genetic and Rare Diseases Program – a critical part of the Undiagnosed Disease Program, which brings together a multidisciplinary team of clinicians and a team of computational scientists led by Dr Lassmann, who are pursuing a unique approach that treats every patient as an individual.

Dr Lassmann said that instead of treating each child as a 'blank canvas', the researchers undertook a targeted analysis of each patient's information, using medical indicators the clinical team had identified.

"The main activity here is phenotyping: very accurate descriptions of what's wrong with the child," Dr Lassmann said.

"We use that information as a starting point to look for disease genes that we know to be associated with those phenotypes. We then apply large genomics data and build predictor models that interrogate that patient's genome in a way that's guided by the phenotype.

"The difference, on the computation side, is that other approaches treat all the patients the same, using one machine-learning method to find disease-causing variants. What we do is build machine-learning algorithms for each patient.

"I call this 'personalised analytics'. It's a new thing we do – build an entire analysis pipeline around what's wrong with that particular child – and it seems to be better than treating everyone the same."

- Dr Timo Lassmann

"As we go forward we want to merge this as much as possible, to make use of all the information we have, whether it's genomics, transcriptomics or something a clinician noticed."

Recently, Professor Baynam and Dr Lassmann collaborated with international colleagues to write a commentary published in the journal *Cell*, discussing technological advances in the field that will help in the future.



Dr Timo Lassmann and team

Both said it was an important article, shining a light on rare disease diagnosis in a high impact way to help galvanise researchers worldwide around a common mission.

The article's authors, including Professor Baynam and Dr Lassmann, are part of an international taskforce formed to help advance diagnosis for children with unsolved medical mystery conditions. The taskforce is part of the International Rare Diseases Research Consortium – a global collaborative founded in 2011 which aims, by 2027, to create the means to diagnose all people living with a rare disease within one year of coming to medical attention.

"The goal is deliberately ambitious, but so too have been previous targets – and they have been exceeded ahead of time," Professor Baynam said.



This research is supported by the Feilman Foundation and McCusker Charitable Foundation.

WHAT'S NEXT

- Incorporating 3D facial analysis approaches together with **CliniFace** – combining the faces and voices of children and families to unlock answers for children with rare disorders and improve their health.
- Increasing health equity and cultural safety through partnering with the voice (language) of Aboriginal children and families, via the UNESCO-endorsed **Life Languages Initiative** – part of the United Nations Year of Indigenous Languages.

ENDING THE CYCLE OF 'NOT KNOWING'



There are 63,000 children living with a rare disease in Western Australia alone.

While previously many would have gone undiagnosed, rapid progress in rare disease diagnosis in recent years means more than half can now look forward to knowing what the condition is that's made them ill or limited their abilities.

Professor Gareth Baynam said phenotype-informed genomic sequencing, for example, had delivered a diagnosis for dozens of children in WA – including some who were amongst only a handful of people in the world with their condition.

"These diagnoses have altered medical and surgical treatment and given insights into the potential to develop new therapies, drugs or treatments," Professor Baynam said.

"It also gives us clarity to investigate further things like metabolomics; from a simple wee sample, for example, we can look for clues about how the body is metabolising things and what that means for potential new medicines to help."

Perhaps most importantly, however, the 'not knowing' had ended for many children and their families.

"Imagine going through life circulating around the health system with multiple health issues and you don't have a clue what's causing it or a name for it. How do you speak to the school about that or to doctors or family and friends?"

- Professor Gareth Baynam

"You feel incredibly isolated, but once you know the answer and connect to people with the same experience, you have a community and a shared experience and clarity for the future."

"That removal of isolation is the most powerful thing we do. People often feel a need to know what caused this and to connect with others in same situation."

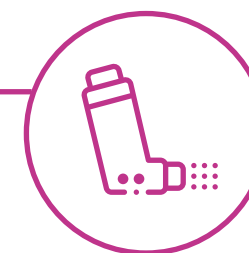
- Professor Gareth Baynam



Professor Gareth Baynam

BIG DATA SCIENCE MAY HELP UNLOCK SIMPLE TEST FOR ASTHMA

Paediatric respiratory physician and Telethon Kids researcher André Schultz has had to wait more than a decade to test out a simple idea which – if promising early results are any guide – could revolutionise the way asthma is diagnosed. The answer could lie in the study of metabolites – the unique chemical fingerprints left behind by cellular processes in the body.



When Dr Schultz first heard about the science of metabolomics 11 years ago, he was intrigued by the potential it held for unlocking the mechanisms behind asthma.

Despite being the most common long-term medical condition in Australian children, asthma remains poorly understood. It's often preceded by a recurrent wheeze in babies and small children – but not all children with wheeze go on to develop asthma.

There are currently no clinically viable methods to accurately diagnose asthma before six years of age, leaving doctors unable to predict which children will stop wheezing naturally and which will go on to have chronic issues. As a result, many children are treated with asthma medication as a precaution, even if they may not need it; while others who would benefit from treatment miss out.

"There's a real need to provide clarity as early as possible in a child's life," Dr Schultz said.



Dr André Schultz

"If we could predict whether or not a recurrent wheezer really has asthma, we could avoid unnecessarily exposing children to medications which can have side effects, and ensure we capture those who really do need this treatment."

After hearing about metabolomics in 2008, Dr Schultz wondered whether high-powered analysis of the metabolites in children's urine might deliver that predictability, by identifying tell-tale metabolomic signatures indicative of underlying disease.

"The idea was that, through a simple, non-invasive urine test, perhaps we could understand and predict asthma much earlier in a child's life," Dr Schultz said.

"I've been wanting to test this theory since I first heard about metabolomics, but we just didn't have the expertise in Perth at the time and I

didn't have the scientific track record to get the funding to do anything.

"Also, network biology, or the science of analysing big data – which you need to be able to process the thousands of metabolites from each patient – hasn't been possible until fairly recently."

"The idea was that, through a simple, non-invasive urine test, perhaps we could understand and predict asthma much earlier in a child's life."

- Dr André Schultz

Last year Dr Schultz and a team including research assistant Sherlynn Ang began recruiting pre-school and school-aged children with and without asthma to the Metabolomic Asthma Profile (MAP) study. They've signed up more than 200 families, who have responded so enthusiastically that the team now hope to be able to follow the children long-term.

"The thing with asthma is it often comes and goes," Dr Schultz said. "Those with pre-school age asthma may not have school-aged asthma, and may have adolescent age asthma – or they might not."

"People go in and out of these groups as they get older but we have no way of figuring that out yet. We hope the MAP study will give us answers and help us predict what their trajectory might be over the lifetime."

Early results from a pilot study in 2018 revealed what appeared to be clear differences between school-aged children who were healthy or had different patterns of asthma and wheeze.

"We were surprised how great those results looked. For me to see a difference between healthy school-aged children, and healthy school-aged children who previously had asthma or wheeze but now don't, for example, is amazing."

- Dr André Schultz

He said part of the reason for the study's success so far was that it wasn't especially onerous on participants, and families understood the importance of what the team was trying to accomplish.

"When I designed this study I was dead keen on getting three samples at different time intervals, and I knew we weren't going to get those if we went in there and made it painful or difficult for families," Dr Schultz said. "So, because I have little kids of my own, it's a really kind, non-invasive study. "We're taking some wee, doing some lung function testing, and the worst thing we do is once-off skin prick testing.

"As a result, we've had excellent retention rates and really good follow-up, and we're embarking on a long-term retention and engagement strategy.

"I think families, like doctors, can understand the challenge of trying to predict, diagnose and treat asthma properly in young children. They really get it. They want to see how it turns out and we are keen to tell them."

The MAP study is funded by the Telethon-Perth Children's Hospital Research Fund, established by the WA Department of Health and Channel 7 Telethon Trust, and is a collaboration between the Telethon Kids Institute, Perth Children's Hospital, Murdoch University and Edith Cowan University.



Sherlynn Ang

WHAT'S NEXT

- The team expects to send further samples for metabolomic analysis over the next few months. If the results are as positive as those from the pilot study, they hope to secure funding from the National Health and Medical Research Council to take the study long-term.
- The metabolomic approach using urine samples has proven so participant-friendly that the team hopes to extend the model into other areas of respiratory research. Ultimately, Dr Schultz hopes the results will lead to the development of simple, non-invasive dipsticks that can help diagnose different kinds of lung health problems.

ENDING DEADLY HEART DISEASE FINALLY WITHIN OUR SIGHTS

It's been a huge year for those working to eliminate rheumatic heart disease (RHD), with breakthroughs including \$35 million in funding to develop a Strep A vaccine, a bipartisan commitment to tackle the disease, and a national roadmap for action combining to mean we've never been better placed to end RHD, once and for all.



Rheumatic heart disease (RHD) is a preventable disease that should no longer exist in a country as wealthy as Australia. Yet it does, affecting Aboriginal and Torres Strait Islander children at some of the highest rates in the world.

Starting from a Strep A infection of the skin or throat, when left untreated RHD can be fatal. Even with careful management – usually monthly antibiotic injections for at least ten years – it is still life-shortening. In fact, in Western Australia's Kimberley region, the average age of death from those living with the disease is just 41 years old.

But with a commitment from both major political parties, a global mandate from the World Health Assembly to prioritise ending the disease globally, the beginnings of a national RHD Roadmap, and a Strep A vaccine in the works, Telethon Kids Director and leading RHD researcher Professor Jonathan Carapetis believes the idea of ending the disease is finally starting to become a reality.

"In my 25 years working on RHD, I have never felt more confident that the end is in sight for this disease, which for too long has been a national shame for Australia," Professor Carapetis said.

Driving the momentum is END RHD, an alliance of peak bodies of which Telethon Kids is a founding member and Professor Carapetis is Co-Chair.

"What's exciting about END RHD is that it's the first time that the research, advocacy, and Aboriginal Community Controlled Health sectors

have come together with one voice to say: RHD needs to end, and this is how," Professor Carapetis said.

"We know what is needed to end RHD in Australia: guaranteed Aboriginal leadership; targets to track progress; an RHD roadmap to bring together all relevant government departments and stakeholders; funding for community-led activities; and investment in research. This past year, END RHD has seen huge progress towards achieving these goals."

In late 2018, END RHD was commissioned to write a draft RHD Roadmap by the Commonwealth Department of Health. Tabled at the Council of Australian Governments (COAG) Health Council meeting in March this year, it has now been progressed to the Australian Health Ministers' Advisory Council (AHMAC), to be reported back to the COAG Health Council in November.

In February 2019, further progress towards achieving the priority asks was made when \$35 million in federal funding was awarded to Telethon Kids to lead a national consortium to develop a Strep A vaccine – a development Professor Carapetis described as an absolute game-changer in the fight to end RHD.

"Not only will a Strep A vaccine help us end RHD, it has the potential to save over half a million lives globally by preventing other Strep A-related diseases as well," he said.

"As part of the Global Strep A Vaccine Consortium we have been working collaboratively with organisations across the



From left: Associate Professor Asha Bowen, Mr Glenn Pearson, the Hon Ken Wyatt AM, MP, Miss Tenaya Bell, Ms Vicki O'Donnell, Ms Pat Turner AM, Professor Jonathan Carapetis AM, Professor Andrew Steer

world towards developing a safe, globally effective and affordable Strep A vaccine – and this funding will continue to position Australia as a leader in this space."

"Not only will a Strep A vaccine help us end RHD, it has the potential to save over half a million lives globally by preventing other Strep A-related diseases as well."

- Professor Carapetis

With the release of the RHD Endgame Strategy – bringing together more than five years of collaborative, community-driven research from the End Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE) – due at the end of this year as well, Professor Carapetis said there would be no unanswered questions about what is needed to eliminate RHD in Australia.

"We have the foundations to eliminate this disease: Aboriginal leadership, growing political will, and world-class research. With all of this on our side, there is absolutely no reason why we can't consign this disease to the history books once and for all."

- Professor Carapetis

WHAT'S NEXT

RHD Endgame Report: Due for release in late 2019, this critical synthesis of evidence and policy analysis will provide a comprehensive, fully-costed guide to ending RHD in Australia by 2031.

RHD Roadmap: Currently being reviewed by the Australian Health Ministers' Advisory Council (AHMAC), the RHD Roadmap outlines the top-level priorities of work needed to eliminate RHD. It will be reported back to the COAG Health Council in November.

Strep A Vaccine: Together with key partners such as Murdoch Children's Research Institute, work will begin to accelerate an existing Strep A vaccine candidate into a clinical trial within five years.



The Bupa Foundation supports the END RHD Communities Project – a community-led, research-backed approach to tackling rheumatic heart disease in remote Aboriginal Communities – which is a critical piece of work informing the development of the RHD Endgame Strategy.



Timeline

A year in review

- May 2018** An Australian-sponsored World Health Assembly resolution is passed, calling for global action to tackle rheumatic heart disease. Representatives from END RHD attend the historic event in Geneva.
- June 2018** Representatives from the END RHD CRE attend a World Health Organisation consultation meeting in London discussing global efforts to develop a Strep A vaccine.
- October 2018** Telethon Kids is awarded \$950,000 by the Federal Government to work in conjunction with the Kimberley Aboriginal Medical Service (KAMS) and Nirrumbuk Environmental & Health Services to establish a new END RHD Community in Western Australia.
- November 2018** END RHD co-hosts a parliamentary breakfast with the Snow Foundation, where the Hon Ken Wyatt MP, Minister for Indigenous Health, and the Hon Warren Snowdon MP, Shadow Assistant Minister for Indigenous Health, commit to making efforts to end rheumatic heart disease a priority.
- December 2018** The END RHD CRE publishes The Cost of Inaction on Rheumatic Heart Disease, which predicts more than 10,000 Aboriginal and Torres Strait Islander children will develop RHD or ARF by 2031 unless urgent action is taken.
- February 2019** The Hon Greg Hunt MP, Minister for Health, and The Hon Ken Wyatt MP, Minister for Indigenous Health, award Telethon Kids Institute \$35 million to lead a national consortium to develop a Strep A vaccine.
- March 2019** At the Council of Australian Governments Health Council Meeting, ministers commit to ending RHD and refer the RHD Roadmap to the Australian Health Minister's Advisory Council (AHMAC) for review, to be reported back to the COAG Health Council in November 2019.
- May 2019** The Wellcome Trust funds the Global Strep A Vaccine Consortium to mobilise and coordinate global collaborative efforts to develop a Strep A vaccine.

What is RHD?

Rheumatic heart disease (RHD) starts with a Strep A infection of the throat or skin. When left untreated, the infection can lead to acute rheumatic fever (ARF), which causes sore joints, rash, fevers, and heart inflammation. While the other symptoms of ARF go away, the heart damage remains – and this is known as rheumatic heart disease.

WHO HAS IT?

In late 2018, the END RHD CRE released The Cost of Inaction on Rheumatic Heart Disease which found:

- There were more than **4,500 Aboriginal or Torres Strait Islander** people in Australia living with RHD or its precursor, acute rheumatic fever.

Without urgent action, it was predicted **more than 10,000** Aboriginal and Torres Strait Islander people would develop the disease or its precursor, acute rheumatic fever, by 2031. Of these people:

1,370
will need
heart surgery

563
with RHD
will die

\$317 million
will be spent on
medical care

FINDING ANSWERS FOR TENAYA: FROM A SORE THROAT TO OPEN-HEART SURGERY

When Katrina Walley took her seven-year-old daughter Tenaya to the local emergency department for the fourth time within a month, she was determined she wouldn't be leaving without answers.

Tenaya had been complaining of a sore throat, stomach pains, and breathlessness. At night-time, she found it hard to lie down flat to sleep – a sign of heart failure.

"I knew something wasn't right," Katrina said. "We got to the hospital around 8 or 9pm. At this point, her oxygen levels started dropping, so she was put on oxygen."

By 11pm, they were being flown from their home in rural Western Australia to Perth Children's Hospital via the Royal Flying Doctor Service. On arrival Tenaya was rushed to the intensive care unit (ICU) and put on a life-support machine, where she would remain for the next two weeks.

"I will never forget any of that – seeing my baby in the ICU."

- Katrina Walley

Katrina was told Tenaya's heart was failing as a result of rheumatic heart disease (RHD), and that the little girl urgently needed surgery to have one of her heart valves repaired.

"I was in shock at first. I just went and sat in one of the rooms by myself," Katrina said.

Tenaya was in hospital for a month before she was strong enough to have the surgery. She hated being away from her school, friends, and family, and was scared about having to have surgery.

"By the second month, she started to cry every time she saw a nurse," Katrina said. "[On the day of the surgery] she was crying when they put the oxygen tubes in, but when she was asleep, I felt better that she was resting and that something was going to get done."

The surgery to repair Tenaya's heart valve went well and after two months in hospital, she was finally discharged. However, just a few days later, she had to be rushed back into surgery to drain excess blood pooling around her heart.

Two months on from two rounds of open-heart surgery, and Tenaya and her family are in the process of relocating permanently to Perth so she can be closer to specialist medical care. Every month, Tenaya must have a penicillin injection to prevent her condition getting worse, and Katrina says Tenaya is struggling to understand that she will need to have them until she is at least 21.

"She doesn't like having them, but she'll go to get them done – but then she starts crying," she said. "After the injection she is always in pain for two days."

In February this year, Tenaya and her family attended a press conference where the Hon Ken Wyatt AM, MP awarded \$35 million in funding to Telethon Kids to lead the development of a Strep A vaccine that would prevent children developing RHD. The announcement made national news, and Tenaya was the star.

"She was a bit excited, watching and telling everybody," Katrina said. "Teachers at the local school said that her cousins were saying 'we saw Tenaya on the news, she's famous now!'"



Although a vaccine won't help kids like Tenaya who are already living with rheumatic heart disease, Katrina said it was special to be part of an announcement for something that has the potential to stop kids in the future developing the disease.

"It was good knowing there is something that will make it easier to stop it," she said. "Research is really important so kids like Tenaya and their parents won't have to go through this."

GUIDELINES STRUGGLE TO KEEP PACE WITH TECHNOLOGY

An ORIGINS study aims to find out more about family screen habits to help provide clearer, more realistic advice about how to make the most of rapidly evolving technology, while avoiding the drawbacks.

Today's parents are the first generation to raise children who have access to mobile screen technologies like smartphones and tablets almost as soon as they are born – and many are struggling as they try to figure out how to manage this brave new world.



"Parents are confused around management of digital technology, with education policy calling for increased use of technology to support learning, and public health policy calling for no screens for very young children and very limited use by slightly older young children," Professor Silva said.

Australian guidelines recommend digital media use should be avoided by children under the age of two years and limited to less than 60 minutes per day for children aged two to five years, yet the evidence suggests children not only start engaging with screens at much younger ages than this, but dramatically exceed the suggested limits.

Recent data revealed the majority of young Australian children spend an estimated 22 hours a week on screens, compared to just six hours a week playing outside.

ORIGINS Project co-director Professor Desiree Silva said the early use of digital technology was resulting in less free play, unsupervised viewing, sleep disruption, addictive behaviours, obesity, speech and language delay, and difficulties around social interaction and self-regulation.

"The recommendations haven't kept up with wide and easy use of mobile touchscreen devices, and are based around more traditional technology like television and desktop computers."

- Professor Desiree Silva

Professor Silva said it was important to understand more about family use and views about mobile technology devices, including their impact on bonding and parenting from infancy – knowledge which could then be used to inform more robust guidelines.

"It is also important to understand what mobile technology is replacing, which I suspect is our connectedness to nature," she said.

An ORIGINS sub-study being carried out by Curtin University's Professor Leon Straker and Dr Juliana Zabatiero, in collaboration with Professor Silva, will interview parents about their family screen habits, along with what they think about the use of mobile touchscreen devices by young children.

A small number of parents signed up to a bigger ORIGINS study looking at the impacts of technology use on early development will be asked how many and what kind of screen devices they have in their homes, what a



Professor Desiree Silva



Mother Jamee Brien and her children Cooper, Chelsea and Mackenzie, are taking part in ORIGINS research about children's use of technology. Photo courtesy The West Australian.

typical week of screen device use looks like for them and their family, why they use them, and how they manage that use.

"Within the larger study we're looking at screen time and impacts on things like behaviour, emotional, motor, language and cognitive development," Professor Silva said.

"This smaller study will involve interviews with parents that allow us to dig more deeply into how families use electronic devices, particularly mobile screen technology. It will go into much more detail.

"The information we gather from these interviews will inform public policy, future research, and the development of realistic, co-designed interventions aimed at helping parents to better guide their young children's use of screen technology."

- Professor Desiree Silva

About ORIGINS

The ORIGINS Project is a **\$26 million, 10-year collaboration** between the **Telethon Kids Institute and Joondalup Health Campus** which aims to recruit **10,000 pregnant women and their families** to collect information on how a child's early environment and parents' health and genetics influence the risk of a wide range of disease and chronic conditions.



ORIGINS is supported by the Paul Ramsay Foundation and the Federal Government through Channel 7 Perth's Telethon.

ORIGINS PROJECT GROWS IN LEAPS AND BOUNDS

It's been a big two years for the collaborative ORIGINS Project, a longitudinal birth cohort study which launched in 2017 with plans to recruit and follow the progress of 10,000 Perth babies and families over a decade.



The largest study of its kind in Australia, ORIGINS is a partnership between Telethon Kids and the Joondalup Health Campus, aimed at reducing the rising epidemic of non-communicable diseases by providing a healthy start to life. ORIGINS researchers are collecting detailed information about babies and their families to understand more about how the early environment influences the risk of diseases

like asthma, allergies, diabetes and obesity.

So far almost 2,000 families have been recruited, and more than 1,500 ORIGINS babies have been born. Of those, almost 500 have attended their one-year clinic appointments.

Unique among other birth cohort studies, ORIGINS currently has 600 fathers participating in the research. The project has ensured active community involvement, holding dozens of events bringing study participants and community members together with paediatricians and health nurses to monitor and discuss childhood health.



Milestones so far include:

- More than **250 local, national and international researchers, clinicians and consumers** involved
- **15 sub-projects** have been launched off the main project, looking at multiple aspects of child and family health and development
- **12 active ORIGINS Research Interest Groups** have been launched, to facilitate collaboration, provide expertise, develop nested sub-projects, and support students
- More than **3,000,000 data points** collected from participant samples and questionnaires
- Wide media coverage – more than **30 media items with an audience reach more than two million people**
- **ORIGINS Forum** held in August 2018 attracted more than 160 attendees, generating collaborative ideas for future ORIGINS Project research and sub-projects
- **Annual family fun day** attracted almost **200 attendees**
- **Researchers** have presented at more than **30 conferences and community events**
- **10 research papers have been published** from the data and knowledge obtained from the project
- A book chapter called 'The ORIGINS Project' was published in the international book **Pre-emptive Medicine: Public Health Aspects of Developmental Origins of Health and Disease**
- Co-Director **Prof Susan Prescott** won the **Independent Book Publishers 2018 Gold Medal** in the health category for her book **Secret Life**. She was also a finalist in Forward Review's Indie Book of the Year.

For more information on ORIGINS visit originsproject.telethonkids.org.au



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:

T | 08 6319 1000

E | contact@telethonkids.org.au

W | telethonkids.org.au



Northern Entrance, Perth Children's Hospital,
15 Hospital Avenue, Nedlands WA 6009
PO Box 855, West Perth WA 6872
T | 08 6319 1000
E | contact@telethonkids.org.au
W | telethonkids.org.au

PRINCIPAL PARTNER



STRATEGIC PARTNER

