

# Impact Report 2024







The Kids Research Institute Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of the land and waters of Australia. We also acknowledge the Nyoongar Wadjuk, Yawuru, Kariyarra and Kurna Elders, their people and their land upon which the Institute is located and seek their wisdom in our work to improve the health and development of all children.

## INTRODUCTION

4 FOREWORD

## TRANSLATION

THIS RESEARCH HAS BEEN ACTIVELY TRANSLATED INTO POLICY OR PRACTICE

- 8 Critical data ensures RSV immunisation hits right targets and saves lives
- 11 Vaccine and immunisation trials pivotal in the fight against respiratory syncytial virus
- 12 Key research helps inform policy on e-cigarettes
- 14 Early learning on the move: Play Active to boost kids' energetic play nationwide
- 16 Game-changing program for kids with social and communication differences
- 18 FASD Hub a one-stop-shop for research and information for professionals and parents
- 20 Aiming high for paediatric brain tumour diagnostic testing
- 23 Partnership expands Aboriginal kids' lung health program across Western Australia
- 24 Adding up the minutes to give kids with Rett syndrome valuable physical activity

## PARADIGM SHIFT

THIS RESEARCH CHANGES THE VERY WAY WE THINK

- 28 Screen time study reveals kids missing out on language development
- 30 Wellbeing partnership building resilience after medical trauma
- 32 Research offers new hope for babies with rare leukaemia
- 34 Modelling for the health of our next generation
- 36 Rainbow roadmap a source of Indigenous pride
- 38 Memory wiping technique opens new frontiers in stem cell medicine

## COLLABORATING FOR IMPACT

THIS RESEARCH SHOWS HOW WE WORK WITH OTHERS TO MAKE A DIFFERENCE

- 42 Community and action at the heart of Journey Together project
- 44 Unravelling medical mysteries for kids with undiagnosed diseases
- 46 Beacon of hope for navigating online world
- 48 Putting malaria on the MAP
- 50 Community-led healthy skin materials on track to curb Strep A
- 52 Missing Piece study guiding new strategies to prevent rheumatic fever
- 54 Pioneering work in disease diagnosis
- 56 Clocking TikTok expertise across the Institute
- 58 Making anaesthesia safer for kids
- 60 The decades-old program helping families and kids to thrive

## IN THE PIPELINE

THIS RESEARCH IS IN THE PIPELINE TOWARDS TRANSLATION

- 64 New facility to develop crucial treatment for antibiotic-resistant superbugs
- 66 Revolutionising diabetes management for children and families
- 68 Applying the arts to wild little hearts
- 71 Learning to cope with uncertainty
- 73 Community voices to foster cultural safety
- 74 Sport Resources key to encouraging physical activity in youth living with T1D
- 76 Shopping for data to drive discoveries
- 78 Addressing climate change to safeguard the health of our children

Cover photo: Tjiego Coelho, aged 3, at Sagewood Early Learning in Success

Inside photo: Holy Rosary School Derby students Eden and Asha enjoying the 2024 Broome Festival of STEM

Our special thanks to those who have contributed to this report, including the researchers and families whose stories we have shared.





Executive Director Professor Jonathan Carapetis, AM

## FOREWORD

At The Kids Research Institute Australia our scientists are driven to make a difference to the lives of children and young people everywhere. Building on three decades of cutting-edge discoveries, we seek new preventive treatments and cures for the most baffling childhood diseases.

The Kids' purpose is to find solutions to improve the health and happiness of some of the most vulnerable members of our global community. This means we must ensure our science challenges the status quo and translates to real impact.

We do this in partnership and collaboration with research colleagues around Australia and the world, advocacy groups, policy makers, service providers, corporate and philanthropic supporters and, most importantly, the community, families and kids whose lives we seek to improve.

In our 2024 Impact Report we showcase some of the game-changing work being undertaken at The Kids.

Many of these projects have already been translated into policy and action, such as the powerful contribution The Kids has made in the global effort to develop a world-first immunisation for respiratory syncytial virus in young babies. Responsible for 3.6 million infant hospitalisations and 100,000 deaths globally each year, our work has also helped to inform an Australian-first RSV immunisation program in Western Australia.

Children with neuro-developmental delays are benefiting from a first-of-its-kind program to help parents and caregivers better understand the way their babies communicate. And Australian children diagnosed with a brain tumour now have a better chance of accessing the best treatment for their disease thanks to a trans-Tasman collaboration spearheaded by our Cancer Centre team.

Other projects are just starting their paradigm-shifting journeys. In August we opened WA's first bacteriophage manufacturing facility. This is a significant development which aims to provide patients fighting antibiotic-resistant superbugs with life-saving phage therapies.

And our ORIGINS project has launched its Data Catalogue, creating one of the country's largest data and biobanks, providing more than 16 million data points enabling world-class research discovery.

We are very proud of the work we are undertaking at The Kids and extremely thankful for the support provided by our wider community - our study participants, community reference groups, donors, funders and collaborators.

I hope you enjoy reading the stories about our impact and encourage you to find out more about our work at [thekids.org.au](https://thekids.org.au).



# TRANSLATION

THIS RESEARCH HAS  
BEEN ACTIVELY  
TRANSLATED INTO  
POLICY OR PRACTICE





# Critical data ensures RSV immunisation hits right targets and saves lives

Prevention of respiratory syncytial virus (RSV) is now a real possibility thanks to the rollout of an immunisation program backed by a decade's worth of epidemiological research led by The Kids Research Institute Australia.

A respiratory infection common in young children, RSV is responsible for 3.6 million infant hospitalisations and 100,000 deaths globally each year – prompting calls for urgent interventions to stop the virus in its tracks.

Associate Professor Hannah Moore – an epidemiologist from the Wesfarmers Centre of Vaccines and Infectious Diseases, based at The Kids – has been at the forefront of RSV research over the past decade.

With her team, she has built up a bank of crucial evidence to guide the delivery of immunisation and vaccination programs – the first of which arrived in WA this year after the State Government made the approved antibody treatment, Nirsevimab, available free to all WA babies aged under eight months, and some older children.

Associate Professor Moore's work has provided critical data to inform the \$11 million, national-first program's roll-out, identifying the best immunisation targets – and timing – to ensure maximum impact on RSV rates.

With her team, Associate Professor Moore used hundreds of thousands of WA hospital records to uncover the full extent of the RSV burden on children, families and the healthcare system. In one study published last year, they examined hospital admission patterns for 23,784 WA children aged under eight years who had been admitted to a Neonatal Intensive Care Unit (NICU) between 2002 and 2013.

*"Our results found babies born pre-term or with a chronic lung disease and admitted to a NICU had a much higher risk for acute respiratory infections, likely caused by RSV, than babies born full-term or without lung disease," Associate Professor Moore said.*

"These kinds of studies provide the clues that will help guide future RSV immunisation policies to effectively target the most at-risk groups at the best time."

In other research, the team found babies born in autumn had the highest RSV hospitalisation rates

in the first six months of life – enabling health professionals to identify, based on birth month, which children would benefit most from RSV immunisation.

Further work identified that a child's age at the time of RSV hospitalisation could help predict their later development of asthma and wheeze.

*"We found, using 252,287 WA hospital records, that children hospitalised with their first RSV infection between six to 12 months of age had the highest risk of later developing asthma, indicating that an antibody treatment could reduce the risk," Associate Professor Moore said.*

The team also explored the effect of other respiratory vaccines on RSV hospitalisations, with one study finding hospitalisation rates dropped after three doses of the pneumococcal conjugate vaccine.

Separately, they undertook a national online survey to examine community perceptions of RSV.

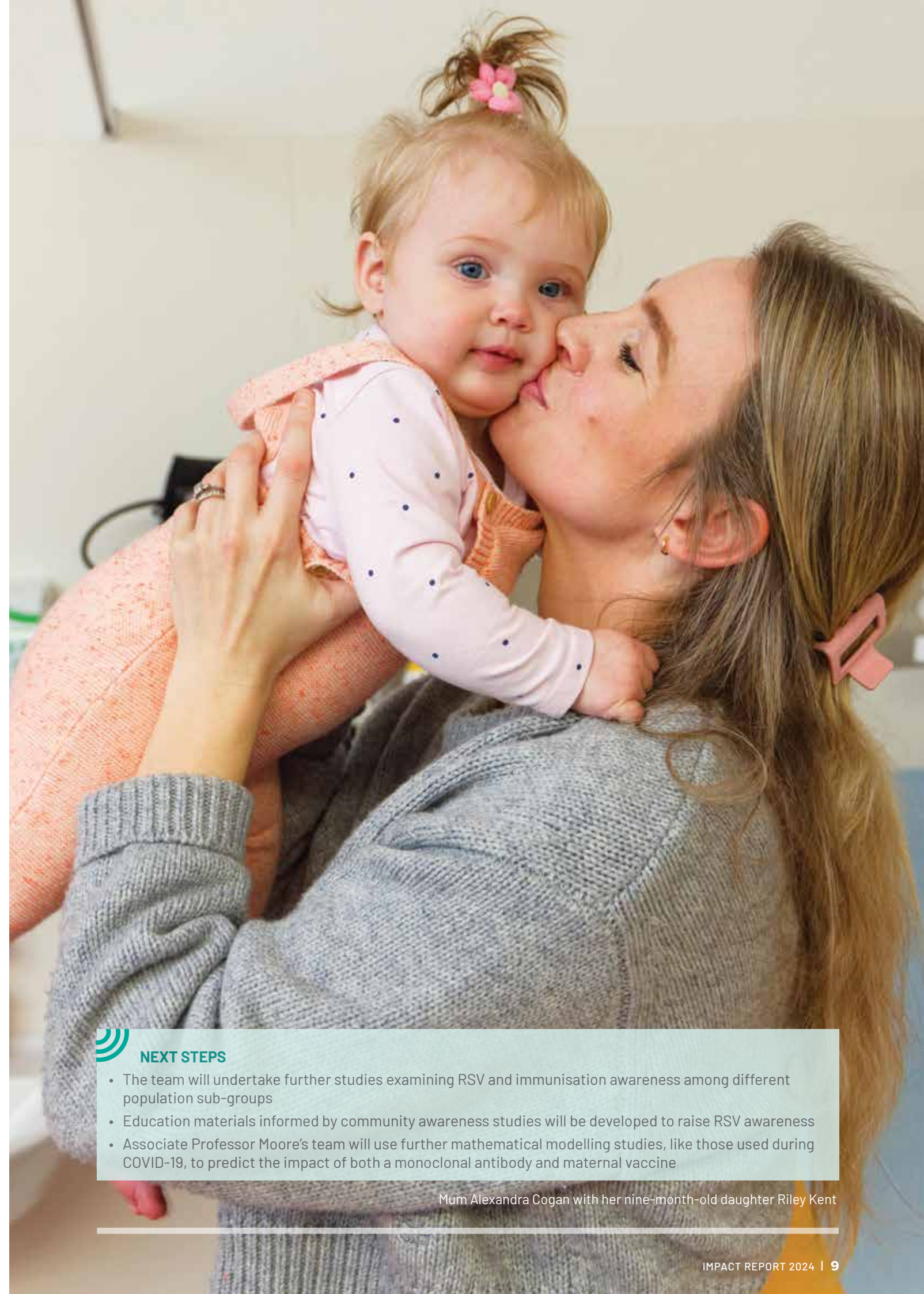
The survey found participants – especially current parents – had high RSV awareness and were open to immunisation, but found parents were less aware of virus severity and other illnesses associated with RSV, such as pneumonia and bronchitis. The results signalled there was scope for education programs targeted at planning and first-time parents.

"The community awareness study is useful to show exactly what knowledge gaps should be addressed in educational campaigns so we can ensure the RSV immunisation program has a bigger impact," Associate Professor Moore said.



The STAMP RSV Program (Surveillance-Transmission-Attitudes-Modelling and Policy) was funded by the

Stan Perron Charitable Foundation. The Infectious Diseases Epidemiology team at the Wesfarmers Centre of Vaccines and Infectious Diseases, based at The Kids Research Institute Australia, has been supported by Telethon, The Perth Children's Hospital Research Fund, Mercke Sharpe and Dohme, Sanofi-Aventis, Future Health Research and Innovation Fund through the WA Near-miss Awards program, and the Stan Perron Charitable Foundation.



## NEXT STEPS

- The team will undertake further studies examining RSV and immunisation awareness among different population sub-groups
- Education materials informed by community awareness studies will be developed to raise RSV awareness
- Associate Professor Moore's team will use further mathematical modelling studies, like those used during COVID-19, to predict the impact of both a monoclonal antibody and maternal vaccine

Mum Alexandra Cogan with her nine-month-old daughter Riley Kent





Nirsevimab can reduce RSV hospitalisations by **80% up to 180 days** post immunisation

RSV causes **100,000 deaths** globally every year

There are **3.6 million RSV hospitalisations** globally every year

RSV is the main cause of **acute respiratory infections/pneumonia** in children

Rates of RSV hospitalisation are more than double in **Aboriginal babies** than non-Aboriginal babies

RSV hospitalisations **8x greater than influenza** in children under 5

**650 – 800** RSV hospitalisations in Western Australia every year

**1 in 30** hospitalised for RSV in WA

Within NICU, risk of hospitalisation with an acute respiratory infection is **6.5 times higher** in pre-term babies and **5 times higher** in babies with chronic lung disease, than those without

**89.6%** of parents are aware of RSV, but only **64%** associated pneumonia with RSV \*from a sample

**78.7%** future parents are aware of RSV, but only **50%** associated pneumonia with RSV \*from a sample

**252,287** health records examined to determine if age at time of RSV hospitalisation could predict future asthma risk



## Vaccine and immunisation trials pivotal in the fight against potentially deadly virus

As a leading research site in Australia, the Wesfarmers Centre of Vaccines and Infectious Diseases played an instrumental role in the global effort to develop a world-first RSV immunisation for young babies.

In two game-changing clinical trials, the Centre's Vaccine Trials Group – headed by paediatrician and immunologist Professor Peter Richmond – investigated the long-acting antibody Nirsevimab in pre-term and full-term babies.

Nirsevimab was found to be 80 per cent effective at reducing RSV-related hospitalisations – a massive feat in the field of RSV prevention.

"This trial was, quite frankly, one of the most impactful results I have witnessed in the RSV prevention space," Professor Richmond said.

The trial's success led to the long-acting antibody treatment being licensed and rolled-out in Europe and North America, with Professor Richmond's influence pivotal for Nirsevimab's programs in Australia.

Findings from these trials guided the national-first \$11 million RSV immunisation program, announced by the Western Australian Government in early 2024 – a program drastically reducing RSV-related hospitalisations in the State.

Since April 2024, eligible babies and select at-risk children have been offered the antibody treatment, giving babies and children five months protection over winter – the season when RSV hits hard.

"Figures from the WA Department of Health show 80 per cent of all babies born since the program began have received Nirsevimab, and we're seeing significantly reduced RSV-related hospitalisations in young babies so far this winter," Professor Richmond said.

"Hospitalisations for babies aged under eight months are down by 30 per cent, while admissions for babies under two months are almost 50 per cent lower.

"This is a remarkable outcome – not only bringing a lot of relief for families, but also significant health care savings with decreased public health pressure on our hospitals."

As part of a two-pronged approach in the fight against RSV, the Centre's researchers have also spent many years participating in global studies to develop a maternal vaccine given in pregnancy.

Their research efforts culminated in a final study involving women from 18 different countries around the world, which uncovered that a vaccine given between 24 and 36 weeks of pregnancy was safe and effective – giving babies protection against RSV for up to 180 days after birth.

This world-first maternal RSV vaccine – almost 25 years in the making – was given the green light by the Australian Technical Advisory Group on Immunisation (ATAGI) in June 2024.

"I am extremely pleased to share that our research has translated into the successful licensing of a maternal RSV vaccine recommended for all pregnant women in Australia," Professor Richmond said.

"In the space of just months we have gone from zero protection against RSV to a maternal vaccine and immunisation program covering both pregnant mothers and young babies against this potentially deadly virus – a tremendous achievement by all involved.

"In addition, our findings suggest that we will now see a reduction in other RSV-related problems that often arise following an infection, such as ear infections and bacterial pneumonias.

"The maternal RSV vaccine and immunisations may also help decrease antibiotic use, reducing the effects of antibiotic resistance – a serious threat facing the world right now."

In the next decade, Professor Richmond hopes to see a variety of preventative immunisations and RSV vaccines licensed and available for Australian children and adults – but also the rest of the world.



## Key research helps inform policy on e-cigarettes

**Formative research undertaken by The Kids Research Institute Australia has helped inform tough new laws introduced by the Federal Government to reduce the harm caused by vapes.**

Associate Professor Alexander Larcombe, Head of Respiratory Environmental Health at the Wal-yan Respiratory Research Centre and from Curtin University's School of Population Health, has spearheaded perhaps Australia's leading program of research into the contents of e-cigarette products and the associated health impacts, the findings of which have helped to inform education campaigns, anti-vaping advocacy and policy.

Associate Professor Larcombe's research has revealed alarming findings about the presence of toxic chemicals in e-cigarettes, exposing that many products labelled as 'nicotine-free' actually contain nicotine, acting as a potential gateway to tobacco use.

"Our own research has shown that a significant portion of e-cigarette products available contain nicotine even when they are labelled as nicotine free, and every disposable vape we've tested contains nicotine at alarmingly high levels, often the equivalent of multiple packs of cigarettes," Associate Professor Larcombe said.

"Every one we have looked at also contains other chemicals and substances known to cause respiratory issues or lung damage when inhaled.

"The nicotine in e-cigarettes is particularly concerning from the perspective of young people as we know that its use impacts the developing brain, leading to a range of health and developmental issues.

"Unfortunately, recent research has shown that young vapers are also about three times more likely to take up cigarette smoking, a well-established health hazard."

**On 1 January this year, the Federal Government outlawed the importation of all disposable vapes and it is also moving to stop the manufacture, supply, advertising and commercial possession of non-therapeutic and disposable single-use vapes.**

Recognising that research alone is insufficient, Associate Professor Larcombe actively shares his findings and works diligently to influence public perception and policy.

Establishing himself as a credible, reliable, and respectful source of information, he engages with policy makers and regularly participates in media interviews and public events, to educate the public about the dangers of vaping.

**Associate Professor Larcombe's advocacy work throughout the year has included:**

- Member of the Minderoo Foundation "uncloud.org" Campaign Reference Group
- Scientific advisor and campaign launch speaker for the Cancer Council WA "Clear the Air" campaign
- Member of the Australian Council on Smoking and Health (ACOSH)
- Member of the National E-Cigarette Monitoring and Evidence Consortium (NEMEC)
- Author of the highly read *The Conversation* article What's in vapes? Toxins, heavy metals, maybe radioactive polonium
- Podcast interviewee on the Distance is No Obstacle Podcast produced by Rural Health West, on the topic vaping and e-cigarettes
- Expert interviewee for multiple radio, television, newspaper and magazine stories

**The combined impact of Associate Professor Larcombe's research and advocacy work has helped to shape public perception of e-cigarettes and reinforce the critical message that these products are far from harmless.**

This concerted effort has played a pivotal role in informing and supporting the implementation of robust policies to safeguard the health of the Australian youth.



This research is funded by the Wal-yan Respiratory Research Centre - a powerhouse partnership between Telethon Kids Institute, Perth Children's Hospital and Perth Children's Hospital Foundation.



### NEXT STEPS

- Associate Professor Larcombe's current research aims to build upon studies examining the toxicity of e-liquids
- A limitation of our previous work is that it investigated the chemistry of the e-liquid, which is not completely representative of the aerosol the "vaper" inhales. This has been seized upon by vaping proponents as a way to discredit existing research work
- Through existing collaborations, our current research is investigating the inhalable aerosols produced by e-cigarettes available to Australians to the level of rigour demanded by regulatory bodies. The research will focus on "puff-bar" type devices which are extremely popular with adolescents
- Work will include comprehensively assessing the "vape" produced by these devices in terms of its physico-chemistry (e.g., nicotine, flavourings, metals, particulate matter), and relating these outcomes directly to the resultant health risks, via known chemical exposure guidelines

Associate Professor Alexander Larcombe





## Early learning on the move: Play Active to boost kids' energetic play nationwide

More than 80,000 Australian children are expected to benefit from a trial being rolled out to 700 childcare centres across the country that aims to boost declining physical activity levels.

In the early years, play contributes significantly to kids' cognitive, social, physical and emotional development, yet most Australian children don't do enough energetic play for their health and development.

Australia is currently sitting at a D- for children's activity – a statistic that hasn't changed since 2015.

Research from The Kids Research Institute Australia's Child Physical Activity, Health and Development team, led by Professor Hayley Christian AM, has identified that only one in ten Australian kids aged three to five are getting the recommended amount of daily energetic play.

"The Australian 24-Hour Movement Guidelines for the Early Years state children aged three to five years should be getting three or more hours of physical activity per day, including 60 minutes of energetic play," Professor Christian said.

"But our research has found that while most children get enough physical activity, they are missing out on the 'huff and puff' they do in short bursts that is essential for their health and development."

Professor Christian said early childhood education and care (ECEC) services play an important role in encouraging young children to be physically active, healthy and developing well.

"Given young children spend a lot of time in childcare, there is a huge opportunity here to increase their physical activity and energetic play levels, and this is where the Play Active program comes in," she said.

Backed by 10 years of research and co-created with the ECEC sector, Play Active is the only program of its kind in Australia that provides evidence-informed guidelines on the amount of physical activity, sedentary time and screen time children should have while attending early childhood education and care.

"We've modelled the physical activity program on our partner Cancer Council's successful SunSmart program for childcare centres.

*"Play Active provides a service-tailored physical activity policy, free professional development, resources and support on how ECEC services can build more opportunities for energetic play into the day."*

*"This will help early learning services meet and exceed National Quality Standards around physical activity and aligns to the Early Years Learning Framework."*

The Child Physical Activity, Health and Development team has worked with multi-sector partner organisations including leading research institutes, universities, ECEC services and agencies, government and not-for-profit organisations to adapt Play Active for scalable delivery across Australia.

The program is being rolled out nationally with support from the Federal Government's Medical Research Future Fund (MRFF), and additional support from the WA Government's health promotion agency, Healthway, to ensure equitable access to Play Active among priority populations throughout WA.

"Play Active is a real-world program supported by research and evaluation. Evidence from this trial will inform an Australia-wide delivery model," Professor Christian said.

"Nutrition, sleep and sun protection policies are required in national ECEC regulations but there is no guidance around how much physical activity, sedentary and screen time children should have while in care. Play Active fills this gap."

"We are also hopeful that Play Active will lead to positive change in addressing active play-based learning in the early years long term."



### NEXT STEPS

- Expanding Play Active across Australia to reach more than 700 ECEC services and 80,000 children over the next four years
- Evaluating how well Play Active is implemented across different states and territories, and the longer-term effectiveness of the program for increasing young children's physical activity
- Identifying future delivery partners beyond the life of the existing grant funding for long term sustainability of the program



Play Active will support thousands of children attending early childhood education and care services across Australia to move more, every day so that all young Australian children can have an active and healthy start to life.

Goodstart Early Learning Banksia Grove Educator Sydney Behrends with (left to right) Willaim Alimu, 3, Ariyan Gadani, 3, and Findlay Stewart, 4, at the national launch of the Play Active Program



**Play Active's funding partners:** Australian Medical Research Future Fund, Western Australian Health Promotion Foundation (Healthway), Heart Foundation and the Australian Centre of Excellence for Children and Families across the Life Course (Life Course Centre). Play Active has also been supported by a The Kids Research Institute Illuminate Award, funded by the Gubgub Wallace Family.

**Play Active's sector partners:** Early Childhood Australia, Australian Childcare Alliance WA, Australian Childcare Alliance QLD, Australian Childcare Alliance SA, Goodstart Early Learning, YMCA WA, Sonas Early Learning, Sagewood Early Learning.

**Play Active's supporting partners:** Cancer Council Western Australia, Nature Play WA, Play Australia, Play Matters Collective, WA Department of Local Government, Sport and Cultural Industries, Health & Wellbeing Queensland.

**Play Active's research partners:** The Kids Research Institute Australia (lead organisation), The University of Western Australia, University of Queensland, University of South Australia, University of Sydney, University of Southern Denmark (Denmark), University of Victoria (Canada).



## Game-changing program for kids with social and communication differences

A world-first program for babies with differences in their social and communication skills is aiming to help parents and caregivers better understand the different ways their child communicates.

Launched in Western Australia earlier this year, The Kids Research Institute Australia's Inklings program is for babies aged 6-18 months who are showing differences in their social interaction and communication development.

Backed by more than a decade of rigorous research, Inklings uses short videos of a caregiver interacting with their baby to help them better understand the different ways their baby communicates. With guidance from a trained practitioner, caregivers learn strategies to build on their own strengths as a responsive communications partner for their baby.

Helping to launch the pilot program, Minister for the NDIS and Government Services Bill Shorten said Inklings aimed to literally change lives. "It's about as close to a miracle as you can get, because what

we see is that if you can help them early enough, you can give them a different trajectory in life," Mr Shorten said.

*"The program puts Australia at the head of the world in redefining early childhood supports. What we have learned from Inklings has the potential to change the way we help our littlest Australians who have delays."*

The 10-session Inklings program is delivered fortnightly over six months, either in-clinic or via telehealth.

The Inklings program builds on landmark research conducted by The Kids Research Institute Australia, University of Manchester, La Trobe University and CAHS, which found improvements in parent-child interactions and children's language skills.

Professor Andre Whitehouse, the Angela Wright Bennett Professor of Autism Research, welcomed the Federal and State Governments' support of Inklings.



Lara Macchiaverni with mum Patricia



NDIS Minister Bill Shorten with Vicki Rosewall and Brooklyn, two-and-a-half



Inklings is funded in Western Australia by the National Disability Insurance Agency as part of a partnership between NDIA, The Kids Research Institute Australia, Child and Adolescent Health Service (CAHS) and WA Country Health Service (WACHS).

## Mother's inkling about Lara

Perth mother of two Patricia Macchiaverni first had an inkling that her daughter, Lara, was developing differently in her first few months of life.

"If you ask any mum what you want for your kid, the universal answer would be happiness," Ms Macchiaverni said.

"For me, I couldn't tell if Lara was happy or not, she wasn't smiling. I felt like I was failing as a mum because I couldn't give her the basic things that she needed."

Ms Macchiaverni sought advice as Lara approached seven months of age, but was told to 'wait and see' - a common response to concerns around social and communication skills.

"I could see I was literally losing Lara, I couldn't interact with her anymore, and there was nothing I could do."

Determined to find an answer, she began to look for other possibilities to improve Lara's social and communication skills, which was how she learned about Inklings.

"I love the program. I honestly wasn't expecting this program would change things so much. It fully transformed the way we interact with Lara, even now that she's two-years-old."

"The fact that we have the video, and we can see ourselves in this third person perspective made a huge impact, it showed me that there were so many opportunities for her to communicate that I was missing."

When Ms Macchiaverni started to incorporate the practices she learnt at Inklings, she felt it became a chain of positive improvement - Lara's interest to communicate increased because her caregivers were responding in a way she understood. As a result, her communication improved significantly.

"She was communicating in her own unique way. Not in the way I was expecting, but Inklings helped me understand exactly what her own little interactions were."



## FASD Hub a one-stop-shop for research and information for professionals and parents

A website providing the latest research and resources on Fetal Alcohol Spectrum Disorder (FASD) is helping parents, educators, health professionals and policy makers navigate the complexities of the neurodevelopmental impairment condition.

The FASD Hub is a one-stop-shop to improve access to the evidence base for FASD in Australia and houses the most comprehensive and credible resources, tools, videos and stories to build awareness of FASD. It also hosts a directory of services and clinics offering FASD assessment and diagnosis across Australia

Born out of a national action plan to increase awareness and prevent prenatal exposure to alcohol, the FASD Hub website was launched in 2017 by a collaboration led by The Kids Research Institute Australia and the University of Sydney in partnership with the Menzies School of Health Research, the National Organisation for Fetal Alcohol Spectrum Disorder, and the Australian and New Zealand FASD Clinical Network.

Leading paediatrician and FASD Hub Advisory Group Chair, Professor Elizabeth Elliott AM, said the creation of the FASD Hub had been critical.

*“Before it was established, there was no single destination for credible, evidence-based resources about FASD for clinicians, researchers, and policy makers,” Professor Elliott said.*

“Many resources were available only in hard copy, were from overseas, and were limited to certain jurisdictions – meaning different people

had access to different information. The FASD Hub set out to change this – and to showcase Australian data for the local context.”

FASD is the leading preventable non-genetic developmental disability in Australia and can occur when a person is exposed to alcohol before birth. People with FASD can experience difficulties with physical activities, language, memory, learning and behaviour. About one in five people with FASD have distinctive facial features and others have a range of birth defects. People with FASD have their own individual strengths and interests, but all experience a degree of difficulty in everyday activities and will need additional support to thrive.

In Australia, FASD is underdiagnosed and often misdiagnosed.

The FASD Hub Australia was launched by the FASD Research Australia Centre of Research Excellence under the leadership of The Kids Research Institute Australia Emeritus Professor Carol Bower AC and The University of Sydney Professor Elizabeth Elliott AM.



Professor Elizabeth Elliott AM and Emeritus Professor Carol Bower AC

### NEXT STEPS

An evaluation of the FASD Hub Australia website has found that 92% of visitors were likely or very likely to recommend the FASD Hub to colleagues, acting as central resource which hosts:

- 104 Australian resources around FASD, alcohol and pregnancy
- 399 Australian publications
- 102 FASD-informed services and clinicians
- eLearning modules which have been completed by nearly 2,000 health professionals to date

[fasdhub.org.au](https://fasdhub.org.au)



## Aiming high for paediatric brain tumour diagnostic testing

Australian children diagnosed with a brain tumour now have a better chance of accessing the best treatment for their disease thanks to a trans-Tasman collaboration spearheaded by The Kids Research Institute Australia cancer researcher Professor Nick Gottardo.

The Kids and Perth Children's Hospital were among 11 organisations across Australia and New Zealand participating in a clinical study to validate a new diagnostic test for children with brain cancer to better understand the genomic and cellular characteristics of brain tumours.

Known as the AIM BRAIN Project, the study was initiated in Australia by Professor Gottardo who foresaw the opportunity to more accurately diagnose paediatric brain cancers in Australia, based on advances in tumour profiling developed in Germany that helps to decode the individual characteristics of each child's disease.

There are more than 120 different types of brain cancers and each of those have multiple sub-types. Understanding the genetic and cellular make up of each cancer is critical to determining how best to treat the disease and optimise survival outcomes.

"Australian and New Zealand clinicians and researchers were relying on the goodwill of our German colleagues and collaborators to do this for us," Professor Gottardo said. "We were sending tissue samples of brain cancers to Germany to help us obtain more accurate information about their disease and guide how best to treat our patients here."

Professor Gottardo – who is Co-Head of Brain Tumour Research at The Kids and Head of the Paediatric and Adolescent Oncology/Haematology Department at Perth Children's Hospital – led an Australian and New Zealand collaboration of cancer researchers to raise funds to bring in this technology to improve diagnostic accuracy for childhood brain tumours.

Under the AIM BRAIN Project, tumours from 269 child cancer patients were tested and benchmarked against the German 'gold standard' diagnostic testing, with 99 per cent concordance.

*"Traditional methods of diagnosing a brain tumour tell us only half the story," Professor Gottardo said. "Treating brain cancer is very different for every patient depending upon their age, the type of cancer and the stage of the cancer."*

"With this diagnostic technology we can actually understand the different characteristics of each tumour and formulate a more appropriate treatment plan."

Importantly, the team have worked together to get this new test officially accredited in Australia and work is separately underway to have it covered by Medicare so it is accessible to all Australian families.



The AIM BRAIN Project was funded by the Federal Government through Cancer Australia, the Robert Connor Dawes Foundation and Carrie's Beanies for Brain Cancer. The study was run under the Australian and New Zealand Children's Haematology Group (ANZCHOG).



### At a glance

- Brain cancer kills more children in Australia than any other cancer
- Every year about 120 kids are diagnosed with brain cancer
- Children with the worst survival rate – 55 per cent – are aged five years or younger
- Glioma and medulloblastoma are the two most common types of brain cancer
- In general, children diagnosed with a malignant brain tumour will have a better outlook than adults
- Because a child's nervous system is developing, some kids have physical, behavioural or learning difficulties as a result of the tumour and/or the treatment



Professor Nick Gottardo





## Partnership expands Aboriginal kids' lung health program across Western Australia

A program aimed at raising awareness of the dangers of a chronic wet cough in Aboriginal children has been extended to 14 remote and regional towns in Western Australia - thanks to a partnership between The Kids Research Institute Australia and Cystic Fibrosis WA.

CFWA's Education and Outreach Lead Michelle Buck and her team have been connecting with health professionals, educators, and community members to deliver the program, now in its third year, to share culturally secure materials such as flip charts, posters, banners, flyers, stickers, badges, videos, and training materials.

A wet cough experienced by a child for more than four weeks can be a sign of underlying infection known as protracted bacterial bronchitis (PBB). If left untreated, this can lead to permanent, life-shortening lung damage known as bronchiectasis.

"At CFWA, we are passionate about applying our knowledge and skills to help build better lung health across WA. We are excited about expanding our capabilities to provide valuable services to people with other respiratory conditions beyond cystic fibrosis," Mrs Buck said.

Recent research undertaken by respiratory clinician researchers Professor André Schultz and Dr Pam Laird - from the Wal-yan Respiratory Research Centre and Perth Children's Hospital - identified PBB in 10 per cent of Aboriginal preschool children in communities in the West Kimberley region of Western Australia.



Michele Buck with four-year-old Graham Smith

"In 2022 we expanded our funding and services to enable this by delivering a pilot community-based chronic wet cough education program in regional WA.

"It's been extremely valuable to be able to draw on the work that The Kids' BREATH team has done in partnership with Aboriginal communities, and to use the range of resources developed as part of the team's research so far to deliver this important health message.

"Our long-term goal is to empower a network of local navigators to ensure ongoing awareness of chronic wet cough in the community, and through this partnership we have begun to make solid tracks."

The Kids' BREATH (Building Respiratory Equity for Aboriginal and Torres Strait Islander Health) team has partnered with Aboriginal medical services, Aboriginal families, and clinicians in communities in the Kimberley region of WA, Derbarl Yerrigan, Wiluna, Northern Territory and Queensland to co-design and implement chronic wet cough information campaigns which are culturally meaningful and sustainable within these communities.

The aim of the campaigns is to raise awareness and develop solutions for timely detection, accurate diagnosis, and optimal management of chronic wet cough in Aboriginal children - with the ultimate aim to improve the lung health of Aboriginal kids.

Alongside this research, Cystic Fibrosis WA (CFWA) is continuing its work to deliver this important health message to many regional and remote communities throughout Western Australia, using resources developed by The Kids and Aboriginal communities, made possible with funding from Telethon and other supporters.

**NEXT STEPS**

- CFWA received further funding from Channel 7 Telethon Trust and other supporters in 2024 to enable this important work to continue
- The BREATH team will evaluate the wet cough health promotion campaigns delivered in the Kimberley region of WA, Derbarl Yerrigan, Wiluna, Northern Territory and Queensland. If the campaigns prove to be successful, it is hoped that the campaign together with the implementation approach can serve as a guide for raising awareness and improving management of chronic wet cough in Aboriginal children right across Australia

Since the beginning of CFWA's community based chronic wet cough education program, the team has:

- visited **24** regional towns
- met with **154** health professionals
- yarned with more than **62** community groups
- trained **21** people to become chronic wet cough community champions,
- and
- delivered **311** resource packs to both community and events.



The Wal-yan Respiratory Research Centre is a powerhouse partnership between The Kids Research Institute Australia, Perth Children's Hospital Foundation and Perth Children's Hospital.

Five-year-old Janelle Dick



## Adding up the minutes to give kids with Rett syndrome valuable physical activity

Leana Eikelboom was two and half years old when she was diagnosed with Rett syndrome. Now 31, her lived experience – and that of her Mum, Jane – has helped shape a new resource that’s helping people with Rett syndrome lead more physically active lives.

Affecting approximately 400 people in Australia, Rett syndrome is a rare neurological disorder that occurs almost exclusively in girls and affects mobility and development, impacting everything from walking and talking to eating and breathing.

Physical activity is vital to help kids with Rett syndrome maintain good health but research led by Professor Jenny Downs, Head of Child Disability at The Kids Research Institute Australia, has shown many with Rett syndrome participate in limited physical activity and live sedentary lives.

*“For many families with a child with Rett syndrome, their days are already incredibly busy with caring responsibilities, so getting time for physical activity can be a challenge,” Professor Downs said.*

*“Our previous research showed that for many people with Rett syndrome, they are sitting or lying down for up to 83 per cent of their day.”*

Prompted by these findings – part of a 12-year pipeline of research aimed at better understanding physical activity in Rett syndrome – Professor Downs, her team and international colleagues have worked with families including Jane and Leana to develop ActiveRett, an online resource designed to help families, carers, therapists, and teachers support people with Rett syndrome to live more physically active lives.

ActiveRett is geared around using everyday routines to increase physical activity – in particular, focusing on the amount of time spent standing or walking. It is used by families, carers, therapists and schools.

**“The idea behind ActiveRett is using daily activities around the home, school or community to**

**achieve an extra 10 to 20 minutes of physical activity each day – anything from walking around the shops, standing to brush teeth, or doing chores around the house like setting the dinner table,” Professor Downs said.**

*“It’s called Uptime – opportunities for standing and walking rather than sitting and lying. It would be phenomenal if all girls in the world with Rett syndrome were ‘up’ for an extra 20 minutes a day. All those minutes add up and there would be an important population health effect.”*

Jane Eikelboom was one of six parents from around Australia who co-designed ActiveRett.

*“We worked with Jenny and Dr Michelle Stahlhut (a physiotherapist from Denmark) to bring our ideas to the table – the sort of activities that worked for us as a family in getting our daughters to be more active,” Ms Eikelboom said.*

*“As a parent, you want to do everything for your child, and you often feel like you have to do as much as you can to give your child the best life.*

*“The great thing about ActiveRett is it’s about everyday activities. It’s reassuring for parents that you don’t have to do big things – you don’t have to enrol in something or do things after school, it’s the normal everyday things that can make a difference.*

*“You just need to be aware of what you’re doing and incorporate movement. Anything around the house can become a movement activity.*

*“I don’t think anything like this exists, it’s a great resource backed by research and families’ experiences.”*



Leana with her parents, Jane and Hank Eikelboom, and The Kids researcher Professor Jenny Downs

**Rett syndrome** is rare, occurring in approximately **1 in 9,000** live female births

It is a **genetic disorder with serious consequences for the development of motor functioning and cognitive skills. Diagnosis comes as a major shock** to parents of girls who were born without any signs of the condition but then lose development skills over time

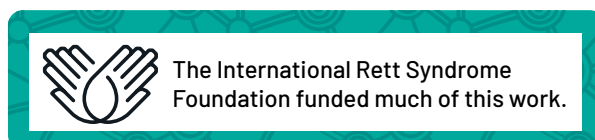
Around **400** people in Australia live with Rett syndrome

Those with **Rett syndrome** can experience **poor growth, seizures, spinal curvature, altered breathing patterns, low bone density, and gastrointestinal and sleeping problems**

**Since 2011** the Rett syndrome research team has undertaken **multiple trials here and overseas** looking at **barriers and facilitators of physical activity in kids with Rett syndrome**

They’ve **co-designed and evaluated a range of interventions and resources to support both families and health professionals**, including guidelines for managing scoliosis and gastro-intestinal issues; the Nourish parent resource on gastrostomy; and outcome measures for trials, including a gross motor scale, hand function scale and QI disability

Around **half of children with Rett syndrome** will learn to walk; around **one third** will continue to walk independently



The ActiveRett resource is available at: <https://rett.telethonkids.org.au/resources/activerett/>





# PARADIGM SHIFT

THIS RESEARCH CHANGES  
THE VERY WAY WE THINK





## Screen time study reveals kids missing out on language development

Toddlers exposed to screen time at home are hearing fewer words and making fewer vocalisations, findings from the first longitudinal study to measure the relationship between family screen use and children's language development have shown.

The research, led by The Kids Research Institute Australia Senior Research Officer Dr Mary Brushe, found that for every minute of screen time, young children engaged in fewer back-and-forth interactions with their parents.

The study – part of Dr Brushe's PhD with the University of Adelaide – followed 220 Australian families over a two-and-half-year period, using a Fitbit-like device to measure the amount of electronic noise and parent-child talk surrounding children aged between 12 and 36 months. This included noise generated by screens used in the child's presence, whether the screen was being viewed by the child or parent.

Dr Brushe's study found that three-year-olds exposed to just under three hours of screen time per day – the average for this age group – could be missing out on more than 1,100 adult words, more than 840 vocalisations and 194 conversational turns per day.

Worn at home by children for 16-hour periods at multiple points in time (when the children were aged 12, 18, 24, 30 and 36 months), the device used LENA speech recognition technology to reveal the number of adult words, child vocalisations and parent-child interactions that occurred during the recorded period.

In all, researchers coded more than 7,000 hours of audio to calculate the amount of screen time children were exposed to as opposed to other electronic noises.

*"We wanted to understand how much screen time children were exposed to during the early years and whether that interfered with the amount of language these kids heard and spoke in their home," Dr Brushe said.*

"We know the amount of talk and interaction is critical for children's early language development –



Callum and Lauren Walley with two-year-old daughter Elizabeth

this study highlights that screen time may be getting in the way of that."

The findings – published in the *Journal of the American Medical Association (JAMA) Pediatrics* – showed the more screen time children were exposed to, the less parent-child interaction they experienced during the critical early years.

"Our findings support the notion of 'technoference' as a real issue for Australian families, whereby young children's exposure to screen time is interfering with opportunities to talk and interact in their home environment," Dr Brushe said.

"The results were most profound when children reached three years of age. Just one minute of screen time was associated with seven fewer adult words, five fewer child vocalisations and one less back-and-forth interaction."

Dr Brushe said the findings suggest children whose families follow current World Health Organization screen time guidelines – one hour a day for children aged 36 months – could be missing out on up to 397 adult words, 294 vocalisations, and 68 conversational turns every day.

"We know, however – both from our own data and from international estimates – that children on average are exceeding these guidelines," she said.

**"Based on the actual average daily screen time for children in this study at 36 months – 172 minutes, or just under three hours – they could in fact be missing out on up to 1,139 adult words, 843 vocalisations and 194 conversational turns per day.**

"What's also interesting is that the study did not necessarily capture parental use of mobile phones in the presence of their children. The devices only picked up noise associated with screen time – for example TV shows, videos or games.

"If anything, we have probably underestimated how much screen usage – and associated 'technoference' – is going on around children because we haven't been able to capture parents' screen-related

activities like reading emails, texting, or quietly scrolling through websites or social media."



### Tips for parents

- Opt for interactive co-viewing as a way to reduce the burden of screen time
- Encourage children and families to engage in conversation when the screen is on
- Sing along with theme songs, repeat phrases or questions from the screen to encourage interaction
- Use the content of a show to start a conversation after the screen has been turned off



The study, *Screen time and parent-child talk when children are aged 12 to 36 months*, was a collaboration with the University of Adelaide, the University of Oxford, and the Menzies Health Institute at Griffith University.



## Wellbeing partnership building resilience after medical trauma

Helping children build resilience and cope with the trauma associated with medical emergencies and chronic health conditions is the focus of a promising pilot program being undertaken by The Kids Research Institute Australia.

The intervention program initially helped young people who had suffered burns, with childhood trauma researchers from The Kids' Embrace team providing mental health support early in patients' hospital presentation and treatment.

The success of the Wellbeing Project has now seen it extended to support children and young people living with type 1 diabetes (T1D).

It aims to create bespoke community-led and trauma-informed programs that improve the wellbeing of children and families, after promising results from the pilot program for children who have experienced burns.

Childhood trauma senior researcher Dr Alix Woolard said many kids facing medical trauma were getting to a crisis point before they received mental health support.

*"We're hoping this can be a good early screen and indicator before they get to that point," Dr Woolard said. "We know that kids who experience medical trauma do not typically receive mental health support. We have shown that this program works in an acute setting with the burns project, and we expect it will translate to this chronic setting."*

"All of the issues we found in the burns project, like being triggered by hospital settings, the change in life circumstances, life being different to how you pictured, or having to recount your story and bring up distressing emotions, these are all issues in T1D as well. We think the Wellbeing Project can improve mental health outcomes for kids and families facing many conditions."

So far, the transfer of the Wellbeing Project to children with T1D has involved community conversations to gain insight from young people and families affected by T1D into what research they believe needs to be done in the field.


"It's been a really strong introduction to this new group because the Diabetes Centre is so embedded within the community," Dr Woolard said.

"This gives us fantastic exposure to ensure our research is as translatable as possible and that we're doing what this community wants to see done."

Focus groups will now revise the Wellbeing Project to tailor it to children and families impacted by T1D.



Millie Fraser with mum Bethanie

 **NEXT STEPS**

- Further consultation with families to ensure the intervention fits their specific needs
- Recruitment of families to be part of the intervention
- Expansion of the burns trial after the successful pilot study

 **Embrace is supported by its principal partner, Rio Tinto.**

## Coping strategies help Millie get through burns trauma

**When Millie Fraser required surgery after spilling boiling hot two-minute noodles on her leg, the then eight-year-old found the experience very traumatic.**

Her mother, Bethanie Fraser, said her daughter lived with autism and was upset by the experience, which also included the need for spray-on skin. "But she did really well, and it healed really well," Mrs Fraser said.

While attending a follow-up appointment Mrs Fraser and Millie, now aged 10, were approached to participate in the Wellbeing Project's burns study.

PhD student Elmie Janse Van Rensburg, a research assistant on the burns project, helped Millie with her emotional regulation, giving her strategies to help her better understand her feelings.

"In the first session, Millie didn't talk and she made me sit with her, as it was done via Zoom, but as we got further into it, she looked forward to our appointments and she really enjoyed what Elmie was talking through with her," Mrs Fraser said.

"We were going through the autism diagnosis as well, so it was really good timing, talking about big feelings and emotional regulation at the same time.

*"She's able to verbalise her feelings a little better after talking it through, and the reasons behind her feelings a bit more."*



## Research offers new hope for babies with rare leukaemia

A pilot clinical study has found an immunotherapy drug can dramatically increase survival rates for babies with a rare form of leukaemia, paving the way for a major international clinical trial.

The phase two study – led by The Kids Research Institute Australia and Perth Children’s Hospital’s Associate Professor Rishi Kotecha – tested the safety and effectiveness of a drug called blinatumomab for the treatment of acute lymphoblastic leukaemia (ALL) in infants diagnosed under 12 months of age.

The results, published in the prestigious *New England Medical Journal*, showed it was safe and feasible to administer blinatumomab to babies with ALL and, remarkably, also identified a strong signal for efficacy, with over 30 per cent improvement in disease-free survival at two years from diagnosis – from 49.4 per cent to 81.6 per cent.

Associate Professor Kotecha, co-head of The Kids Leukaemia Translational Research team and consultant in clinical haematology and oncology at PCH, said the small-scale pilot study involving 30 babies from around the world had significant global implications for the disease.

“Infant ALL constitutes a subgroup of childhood leukaemia which has really poor survival rates, significantly lower than many of the other forms of blood cancers we see in children,” he said.

“The most distressing thing is seeing a newborn baby with this disease; for parents it’s the worst scenario you can imagine.

“The pilot study has shown a massive early improvement to survival, and it really shows that this strategy can have a real impact on the way we treat babies with ALL worldwide.”

Associate Professor Kotecha said there had been very few improvements in survival rates for babies with ALL over the past 20



Associate Professor Rishi Kotecha

years, so new trial was an exciting step forward.

“Blinatumomab is an immunotherapy drug that links the immune system to destroy the leukaemia cells.

“What’s exciting is that it doesn’t have the toxic side effects we see from chemotherapy, which is known to kill healthy cells as well as cancer cells. This is what causes the horrendous side effects we associate with chemotherapy, and when we’re treating very young babies it’s particularly distressing.

“The immunotherapy allows babies the chance to recover in between chemotherapy cycles, while still attacking the cancer cells.”

In the pilot trial, babies were still given conventional chemotherapy in addition to blinatumomab, but in the upcoming Interfant-21 trial, one of the chemotherapy treatment blocks will be completely replaced by the immunotherapy drug.

### NEXT STEPS

Findings from the pilot trial will now be expanded to test the drug in a larger cohort of babies in the upcoming global Interfant-21 trial, involving all 10 of the tertiary paediatric cancer centres in Australia and New Zealand, including Perth Children’s Hospital



The Interfant-21 trial has been funded by the Medical Research Future Fund and the Kids’ Cancer Project.



## Modelling for the health of our next generation

Nearly 170 years ago a British doctor applied geospatial mapping to identify the source of a cholera outbreak in central London. Using a street map to plot the location of the homes of the sick, Dr John Snow was able to pinpoint a 'ground zero' for the outbreak – a contaminated water pump.

The handle for the pump was removed and the epidemic stopped.

Today, The Kids Research Institute Australia is harnessing immense data sources that enable us to apply the same method to address serious public health concerns in Western Australia and across the world.

Professor Peter Gething, the Kerry M Stokes Chair in Child Health at The Kids and Curtin University, and Dr Ewan Cameron, from the Geospatial Health and Development Team and Curtin University, have been leading this work to understand exactly where public health issues are concentrated to help find the solution to these health challenges.

*"In WA, of our 620,000 children and young people, one in ten have asthma, three in ten are considered obese, 2,600 have type 1 diabetes and 20 per cent have a developmental delay when they start school, Professor Gething said.*

"We also know suicide is the leading cause of death in children, and in the past decade self-harm hospitalisation of young girls aged 14 years and younger has trebled. For girls aged between 15 and 19 years it has doubled.

"Imagine if we can use geospatial mapping to understand exactly where these serious public health issues are concentrated and use research, policy and practice to stem the tide of poor health in the most vulnerable members of our community."

Professor Gething and Dr Cameron's team have built *Virtual WA* – a digital replica of the State. Using neighbourhood spatial modelling with data including

population characteristics, demographics, connections to public transport, schools, GP clinics, hospitals and workplaces, they have built a comprehensive map of our community.

Dr Cameron said the team was then able to use the information to ask real-world questions: where do children with asthma live and what is the role of air quality? Do areas with high suicide rates have easy access to mental health services? Can kids more easily walk to school and would this help combat rising child obesity?

"The information will help to inform policy and research to address these challenges to the health of our kids," he said.

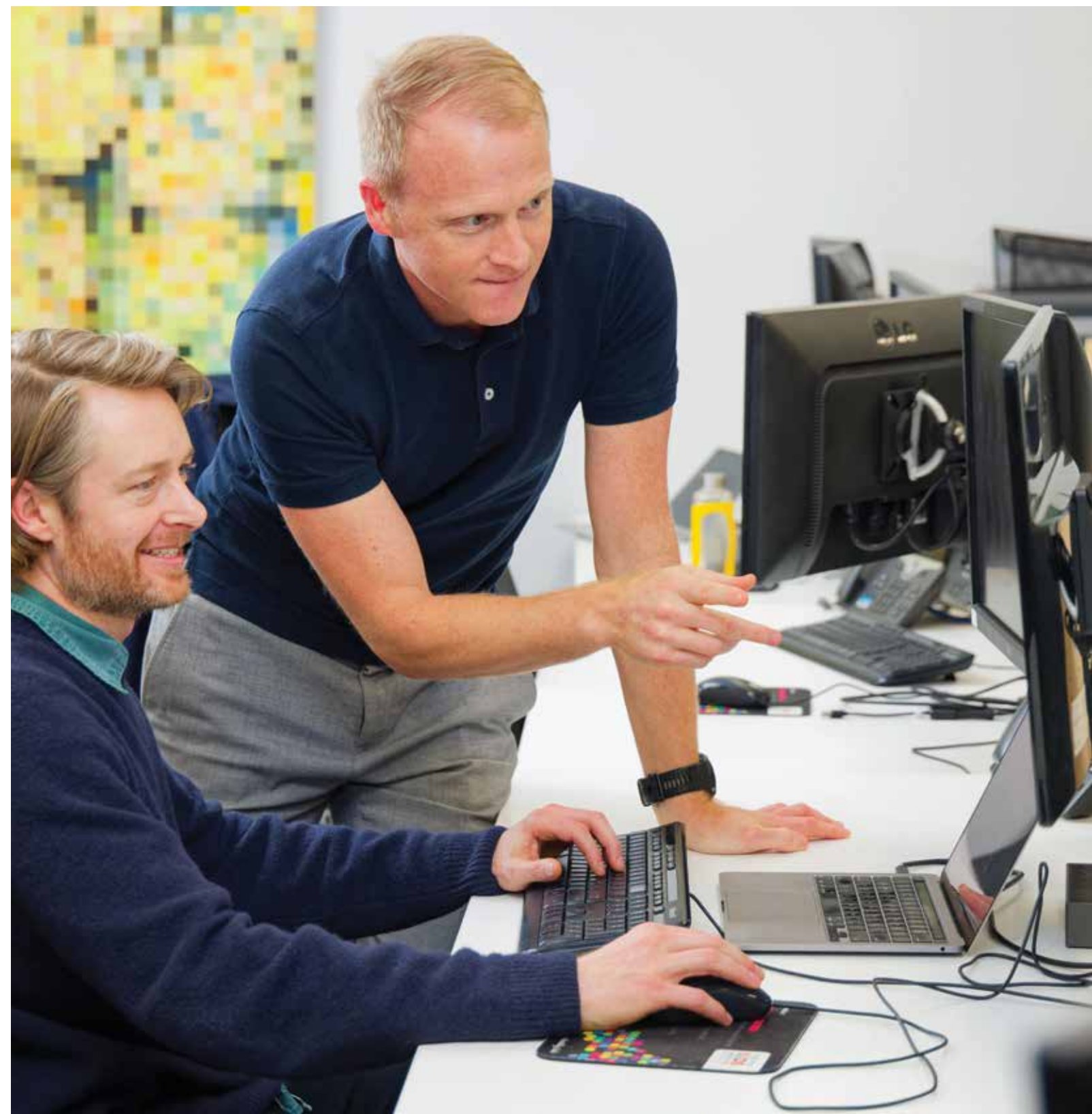
Professor Gething said much of the work now being undertaken built on game-changing research developed by the team over the past 18 years that focused on one of the world's deadliest diseases: malaria.

"We have used geospatial modelling to map the prevalence of malaria in some of the world's poorest countries, and developed the world's largest database of malaria prevalence, incidence, mortality and interventions across Africa.

*"By building a huge toolbox of new analytical approaches, we've been successful in bringing these complex data together and answering the questions that policy makers needed to answer.*

"Globally, we are in the midst of a data revolution – with the volume and complexity of data being generated growing exponentially – and data on population health and wellbeing is no exception.

"Viewing these data sets through a geographical lense – and harnessing the power of asking 'where?' – we have an unprecedented opportunity to use data and analytics to deliver the insights we need for improved policy and practice – to ensure a bright future for happy, healthy kids."



Dr Ewan Cameron and Professor Peter Gething





The Walkern Katidjin team - A/Prof Yael Perry, Shakara Liddelow-Hunt, James Hill, Lily Hayward (seated)



This project was supported by the National Health and Medical Research Council, with additional funding from Embrace @ The Kids. Support was provided by Wungening Aboriginal Corporation, Yorgum Healing Services, First People's Rainbow Mob WA, SHQ, Elizabeth Morgan House, ACON, Nunkuwarrin Yunti, Aboriginal Medical Services Alliance of the Northern Territory and Thorne Harbour Health.

Walkern Katatdjin's research team comprises staff from Kulbardi Aboriginal Centre, Murdoch University; The University of Western Australia and Kurongkurl Katitjin, Edith Cowan University. Their work is overseen by a Governance Committee and guided by a Youth Advisory Group.

## Rainbow roadmap a source of Indigenous pride

**Alarming statistics laying bare the social emotional wellbeing and mental health challenges facing Aboriginal and Torres Strait Islander LGBTQA+ youth are driving a multi-partner program to provide them with greater support.**

A first-of-its-kind national survey of 619 participants released in 2023 found that nearly half of respondents had attempted suicide in their lifetime, 19 per cent had attempted suicide in the past year and more than 90 per cent reported having high or very high levels of psychological distress.

Participants also reported having low feelings of connection to their spirit and ancestors, to Culture, and to an Aboriginal and Torres Strait Islander LGBTQA+ community.

More promisingly, survey participants reported high levels of connection to family and kinship networks, generally good physical health, and feelings of belonging to distinct Aboriginal and LGBTQA+ communities.

The survey was part of the Walkern Katadjin national research project based The Kids Research Institute Australia to identify the needs of Aboriginal and Torres Strait Islander LGBTQA+ young people aged 14 – 15 years.

**The three-part project has comprised yarning groups and in-depth interviews with youth around Western Australia as well as the national survey.**

Lead author of the report on the survey results, Shakara Liddelow-Hunt, said the community had been talking for a very long time about concerns regarding young queer mob dying by suicide, having a hard time, being discriminated against, struggling to connect and having a place in community.

*"We finally got this report out that confirmed they were right and now we have some evidence about young people's strengths and needs that we can work with to take the next steps to fix this," Mx Liddelow-Hunt said.*

"We're part of this broader movement, which has momentum from a lot of communities and organisations."

Since the report's release, Walkern Katatdjin team members have shared findings with services, clinical networks and policy networks. Findings have also been presented at conferences including the International Meeting on Indigenous Child Health in Oklahoma and the Society for Mental Health Research in Perth, WA, which received the Best Consumer-Led Research award.

They were also published in *Rainbow Realities*, a federal government-commissioned report to inform the LGBTQA+ Health and Wellbeing Action Plan.

Now, a roadmap is being developed after a workshop held in late 2023 with the project's Youth Advisory Group, Governance Committee, Elders and service representatives.

*"It's been so important for us to work with community every step of the way, so this was an opportunity to come together to decide the action that needs to follow our survey findings," Mx Liddelow-Hunt said.*

Governance Committee member and social worker Tahlia Blow said one of her key takeaways from the Walkern Katatdjin project was seeing the resilience of young LGBTQA+ mob who participated.

"I look at some of what has come out and I admire so many of these young people who have given their time and thoughts to this project," she said.



### NEXT STEPS

- Development of training package for Aboriginal Community-Controlled Organisations to help them better support Aboriginal and Torres Strait Islander LGBTQA+ young people
- Lobbying for Aboriginal representation on the federal government's LGBTI+ Action Plan
- Completing co-design of an intergenerational yarning intervention to improve SEWB and mental health of Aboriginal and Torres Strait Islander LGBTQA+ young people



## Memory wiping technique opens new frontiers in stem cell medicine

In 2006, when a Japanese scientist building on the earlier work of a British biologist discovered a way to reprogram adult cells into other cell types – making them ‘pluripotent’ – the scientific world was entranced.

Here, at last, was an alternative to the ethical dilemma posed by the use of embryonic stem cells to tackle disease – a discovery that would go on to earn Sir John B. Gurdon and Shinya Yamanaka the Nobel Prize in Physiology or Medicine.

Previously, the prevailing dogma had been that mature cells were what they were: they could not be manipulated to return them to an immature stem cell ripe for repurposing.

Yamanaka’s find opened the door to using a patient’s own cells to regrow, repair or replace damaged or diseased cells, organs or tissues – reducing the risk the new cells would be rejected by the patient’s immune system.

There were challenges, however, that have to date limited science’s ability to make the most of this exciting discovery.

Induced pluripotent stem cells – aka iPS, or ‘blank slate’ cells – turned out to have long epigenetic memories, with an unpredictable habit of being influenced by the cells they once were.

The tendency of a skin cell reprogrammed into an iPS cell and then into, say, a pancreatic cell to suddenly start behaving like the skin cell it once was makes it an unreliable saviour when attempting to repair a pancreas.

It’s a problem an Australian team co-led by The Kids Research Institute Australia’s Dr Sam Buckberry may just have solved.

In a paper published last year in the journal *Nature*, Dr Buckberry and colleagues from the

Harry Perkins Institute for Medical Research, The University of Western Australia, Monash University and the University of Adelaide revealed they had developed a method to wipe the memory of iPS cells.

“Using adult stem cells in stem cell therapies holds enormous promise, but the fact they retain a partial memory of the cell type they used to be limits their therapeutic potential,” Dr Buckberry said.

*“We have found a way to erase a cell’s memory of the kind of cell it used to be, to make iPS cells function more like embryonic stem cells.”*

The team achieved the feat after studying the way the epigenetic coding of sperm and egg cells is essentially erased during the early development of an embryo.

“This reset allows the early embryo cells to start fresh and become any cell type as the embryo grows and develops,” Dr Buckberry said.

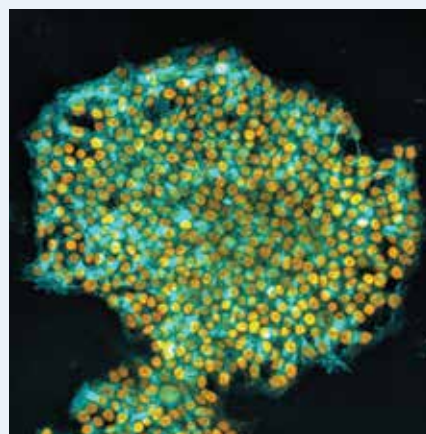
“By introducing a step during the reprogramming process that briefly mimics this reset process, we made iPS cells that are more like embryonic stem cells than conventional iPS cells.”

Although there are many hurdles to cross before the discovery can be translated into regenerative therapies, this ability to effectively make iPS cells forget their past identities considerably enhances their medical potential.

“It opens up so many more avenues for what you can do with patient-derived stem cells, and possibly will make them clinically safer,” Dr Buckberry said.

“It makes them more likely to transform into any desired cell type – for example, new insulin-producing cells for someone with diabetes, or neuronal cells for someone with Parkinson’s – but without the ethical challenges of using stem cells sourced from embryos.”

Dr Buckberry said that in building on the foundational discoveries of pioneers like Gurdon and Yamanaka, the team was standing on the



Human iPS cells Photo: Jia Tan, Polo Lab

## What is epigenetic memory?

Our DNA carries sequences of instructions known as genes. When various factors influence gene activity (turning them on or off) without changing the DNA sequence itself, this is known as epigenetics – literally meaning ‘above genetics’.

A cell’s epigenome is a collective term to describe all the epigenetic modifications in a cell. Each of our cells contains the same DNA, but the epigenome controls which genes are turned on or off, which determines whether it becomes a heart cell, a kidney cell, a liver cell, or any other cell type.

Think of the DNA as a cookbook and the epigenome as a set of bookmarks: the bookmarks don’t alter the recipes, but they direct which ones are used. Similarly, epigenetic marks guide cells to interpret the genetic code without changing it.

When we reprogram a mature cell into an iPS cell, we want to erase all its ‘bookmarks’. However, this doesn’t always work completely. When some bookmarks remain, this ‘epigenetic memory’ can influence the behaviour of the iPS cells, making them behave more like the cell they used to be than the type of cell we want them to become – potentially affecting the function of the cells once they’re created.

shoulders of giants to accelerate regenerative medicine and open new frontiers for clinical-grade stem cell therapies.

“Translation is where the impact is but before you can get there you have to build up a foundation of fundamental knowledge, and that can take decades,” he said.

“This work demonstrates the immense power of that kind of basic but fundamental science.”



### NEXT STEPS

Dr Buckberry is the co-inventor on a patent that has now been licensed to iCamuno Biotherapeutics, a pioneering biotechnology firm specialising in iPS cell technologies



Dr Sam Buckberry



Dr Buckberry, a genome biologist and bioinformatician, spearheaded this work with co-lead authors Dr Xiadong Liu, Dr Daniel Poppe, and Jia Tan. The project was co-led within Professor Ryan Lister’s lab at Harry Perkins Institute of Medical Research, and Professor Jose M. Polo’s lab at Monash University and the University of Adelaide; and included researchers from Westlake University, Queen Mary University of London, Mater Research Institute, University of Queensland, Queensland Brain Institute, South Australian Health & Medical Research Institute, Duke-NUS Medical School and CSIRO. Dr Buckberry, who has received funding from the NHMRC and WA Department of Health, is Head of Epigenetics within the Indigenous Genomics program at The Kids. He is also affiliated with the Australian National University and is on the executive committee of the Australasian Genomics Technology association.





# COLLABORATING FOR IMPACT

THIS RESEARCH SHOWS HOW WE WORK  
WITH OTHERS TO MAKE A DIFFERENCE



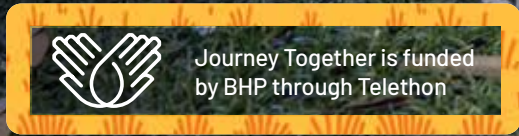
# Community and action at the heart of Journey Together project

A unique initiative is combining research, action and advocacy to deliver evidence-based improvements to the health and wellbeing of Aboriginal families in Perth and Western Australia's north west.

Journey Together is a ground-breaking partnership between communities, researchers and service providers to develop a deep understanding of what is needed, and what works, to grow strong, healthy kids, and co-design new solutions.

Journey Together co-lead and The Kids Research Institute Australia Director of First Nations Strategy and Leadership, Associate Professor Glenn Pearson, said three priority projects were already delivering on the initiative's key undertaking to respond to immediate local needs, with each developed in response to urgent community-identified priorities.

*"We said at the outset that we wouldn't wait until the end of the project to start acting on what we learn," Associate Professor Pearson said. "The communities and services we are partnering with have identified key priorities, and by embedding research into these priorities we are having impact and evolving as we go." The initiative is in its fifth year of operation.*



Four-year-old Neveah Charles



## Kumaparniku Wraparound Services Port Hedland

Imagine trying to get your car fixed when it breaks down and discovering that you have to take it to a different garage to fix each part: one for the brakes, one to replace the windscreen, one to change the tyres – and each of them are in different locations and don't share information.

That has been the challenge for Aboriginal families in Port Hedland trying to access support services for homelessness, health, education and family relationships.

The Journey Together Initiative collaborated with the Julyardi Aboriginal Corporation to help at-risk families with young children find the support they need and empower them to have confidence in seeking help.

Since its commencement the project has worked intensively with 16 families, enabling them to access services on more than 4,000 occasions.

*"As result of this work, these families feel more supported, children's health needs are taken care of and they are safer, and children are attending playgroup and school," Associate Professor Glenn Pearson said.*



## Integrated Paediatric Care model Perth

Indigenous children in Perth with complex health needs are receiving fast-tracked support under a new model that has reduced red tape and is delivering more timely paediatric services.

With a 90 per cent attendance rate by the 200 children taking part in the collaboration with Derbal Yerrigan – Perth's biggest Aboriginal community-controlled

health service – critical diagnoses and interventions are being made earlier in the children's lives.

Associate Professor Pearson said the initiative provided a paediatric coordinator who supported and engaged families and helped them understand the complicated requirements of the health and social service system.

*"As a result children and families are receiving support more quickly, it is more effective and better tailored to their needs, it's culturally safe and coordinated with their school, and paediatricians' time is better used so they can see more children," he said.*

## Perinatal Care and Early Childhood Development East Pilbara



With limited access to maternity care, women in the East Pilbara are forced to travel 600km to Port Hedland or 1,300km to Perth to give birth.

Now, a partnership with Puntukurnu Aboriginal Medical Service is helping to give newborns in remote communities the best start in life by supporting expectant mothers before and after they give birth, at a time when they are often long distances from their family and support structure.

The program uses culturally secure and evidence-based midwifery care and educates parents on caring for their children.

## NEXT STEPS

To understand what works for overcoming complex intergenerational poverty and trauma, and to see change, Journey Together intends to continue working with families and collecting data for at least a generation – 20 years – after which participating children may have become parents themselves



## Unravelling medical mysteries for kids with undiagnosed diseases

**Three hundred and fifty million people live with an undiagnosed disease worldwide and three quarters of them are children.**

Having an undiagnosed disease leaves many questions unanswered for families – what treatment is available, will medication help, how can the disease be managed, is it hereditary, what does the future hold?

To have a diagnosis is to have an answer – it solves the riddle for that child and family – but determining the diagnosis is like finding a needle in a haystack.

Genome sequencing – determining the entirety of a person’s DNA sequence – can provide answers for around 40 per cent of children and adults with an undiagnosed disease. For the 60 per cent who do not receive a diagnosis, new ways and collaborations are needed to find a diagnosis to open up treatment options and potentially find cures for these people.

It is the hope of a diagnosis that sparked the idea for the world’s first Undiagnosed Hackathon, bringing together 95 participants from 28 countries and six continents at the Karolinska University Hospital in Sweden. Through an international melding of multi-disciplinary minds, the aim was to uncover previously undiagnosed diseases for 11 children and two adults from around the world.

The invited clinicians, geneticists, bioinformaticians, molecular biologists, scientists,

data developers and AI specialists would work together for 48 hours sifting through extensive volumes of data, analysing genetic profiles, and talking with families and their clinicians.

Among them was Precision Health Program Head Timo Lassmann, Honorary Research Fellow Professor Gareth Baynam, and Dr Tudor Groza from Perth Children’s Hospital.

With the patients at the core of the hackathon, experts were split into five teams and tasked with the challenge of solving individual cases. The intense, time-bound collaboration fuelled accelerated problem-solving, allowed innovation to thrive and sparked cross-pollination of ideas and creative solutions that would not have been possible otherwise.

Across the two days, the expert teams were able to analyse 10 of the 13 patients, with four receiving a diagnosis, another four given possible diagnoses that would need more analysis, and two whose cases remained unsolved.

Associate Professor Lassmann said the hackathon success was a testament to the power of open science and collaboration with international colleagues.

*“It was fantastic to be part of a patient-driven effort to provide a diagnosis to children suffering from an undiagnosed condition. The power of open science, sharing of data unencumbered by institutional and other policies will have long-lasting impacts well beyond the event itself,” Associate Professor Lassmann said.*

Professor Baynam, who is also Medical Director of the Rare Care Centre, said it was incredible to help solve medical mysteries for children, and in doing so create new ways to help thousands more.



Associate Professor Timo Lassmann

*“The Undiagnosed Hackathon is global kindness in action,” Professor Baynam said.*

*“Together, expert scientists from around the world gathered to generate new solutions and new partnerships to help some of the most vulnerable children on our planet. The answers produced will bring so many children out of the dark clouds of uncertainty.”*

Upon returning home to Perth, our researchers continued to volunteer their time and expertise to work on resolving the remaining cases.

“For children and families, a diagnosis provides a prognosis,” Associate Professor Lassmann said. “It helps them know what to expect and gives them ideas about what the future holds. A diagnosis gives them answers.”

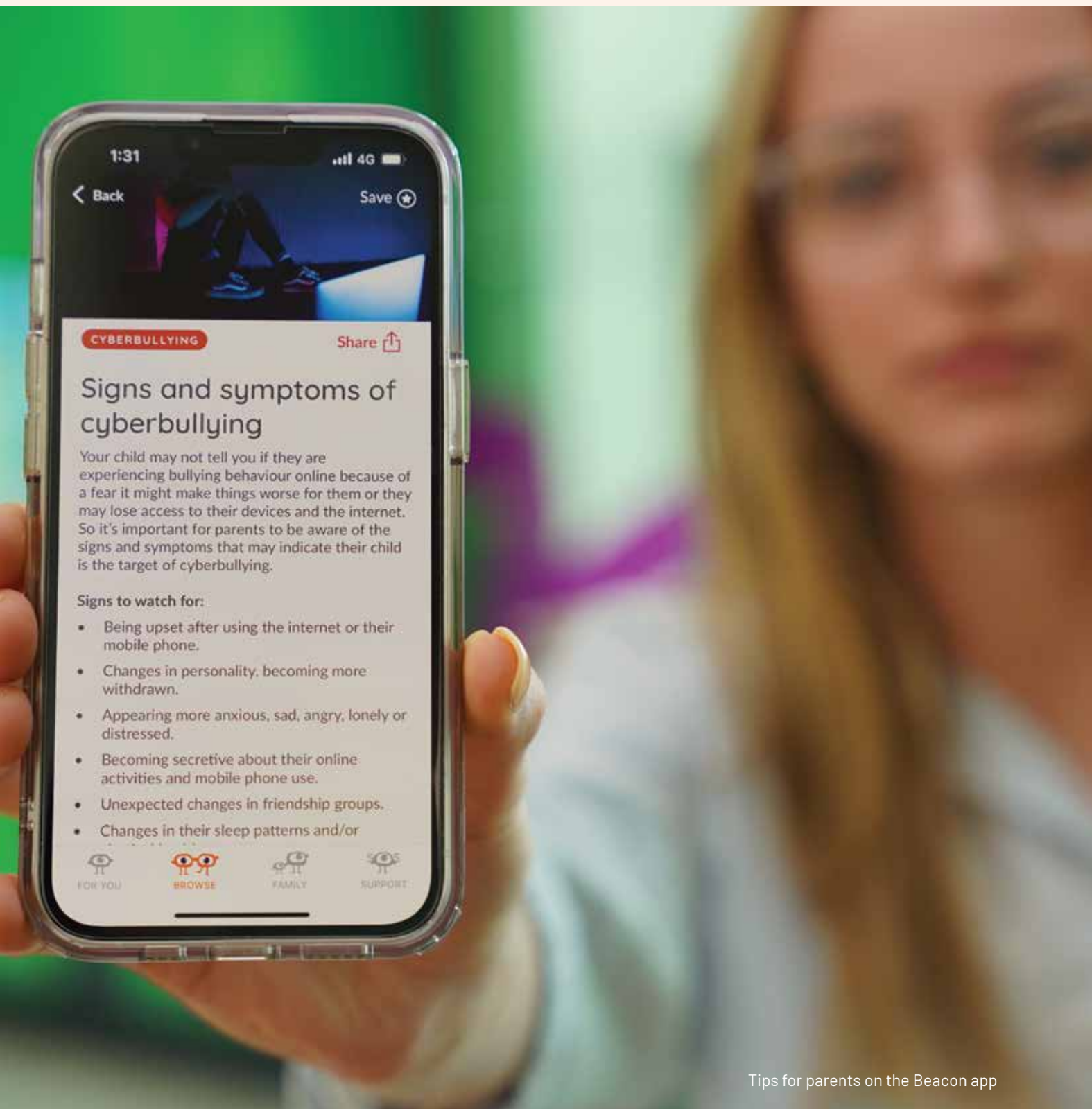


Google Open Source Peer Bonus

In 2023, Associate Professor Timo Lassmann received Google’s Open Source Peer Award for his work on Kalign, an algorithm he developed 23 years ago as a first-year PhD student. Kalign, now freely accessible to scientists everywhere, has since helped build a breakthrough artificial intelligence method used to accurately predict the shape of thousands of proteins.

\* The Undiagnosed Hackathon was organised by the Wilhelm Foundation, Karolinska Institutet, Karolinska University Hospital and software company Phenotips.





Tips for parents on the Beacon app

## Beacon of hope for navigating online world

In a world where TikTok dances and Minecraft adventures take centre stage, kids are spending more time online than ever before. While they're busy unleashing their creativity, making new friends, and exploring digital environments, parents are left wondering: how do we keep them safe in this ever-changing landscape?

It's a question that inspired a partnership between the Telethon Kids Institute and anti-bullying organisation Dolly's Dream – to get Beacon, the free cyber safety app, into the hands of parents and carers across the nation.

Co-designed with input from parents, carers, and cyber safety experts including the Office of the eSafety Commissioner, Beacon provides families with trustworthy, practical resources to help them confidently navigate their children's technology use and reduce associated harms.

Families receive content tailored to their needs – including articles, videos, and alerts – from a comprehensive library of strategies and tips to help address challenging issues such as screen time, gaming, and cyberbullying. The content is regularly updated in response to changing Australian societal and online trends.

Program Head of Population Health at The Kids Research Institute Australia, Professor Francis Mitrou, said the collective expertise of both Dolly's Dream and The Kids had enabled Beacon to continue to support all families with cyber safety advice to help keep kids and families safe.

"With a shared commitment, we've empowered families from all walks of life to tackle online risks with greater confidence and resilience. This joint

effort has enabled Beacon to evolve into a more comprehensive and reliable resource, equipped to address the diverse challenges faced by families in today's digital age," Professor Mitrou said.

*"Partnering with Dolly's Dream, we will increase our reach into rural and regional communities across Australia, ensuring wider access to essential cyber safety resources."*

Founders of Dolly's Dream Kate and Tick Everett said they wanted an app to further support parents and carers in navigating their way around the online world to help their children.

"Through our partnership, we hope Beacon will provide the support and information to families and communities that we wish we had," they said.

The Beacon app is free and available now for download for iOS and Android.

### About Dolly's Dream

Dolly's Dream was created by Kate and Tick Everett following the shattering loss of their 14-year-old daughter, Dolly, to suicide, after ongoing bullying. Kate and Tick's goal is to prevent other families walking this road. They want to change the culture of bullying by addressing the impact of bullying, anxiety, depression, and youth suicide, through education and direct support to young people and families. Dolly's Dream is proudly brought to you by the Alannah & Madeline Foundation.



This work was supported by Bankwest and Dolly's Dream.



## Putting malaria on the MAP

The Kids Research Institute Australia is at the forefront of a global effort to track and prevent malaria – one of the world’s leading causes of disease and child deaths, particularly in developing countries.

Funding from the Bill & Melinda Gates Foundation has facilitated a move by The Kids Malaria Atlas Project (MAP) to a new Africa-based node at the Ifakara Health Institute in Dar es Salaam, Tanzania, to help create greater global impact.

Housing the world’s largest malaria database, MAP uses cutting-edge geospatial modelling and analytics to map and monitor malaria globally, tracking the impact of control interventions, policies and programs.

The move will help strengthen analytical capacity in affected countries, address inequalities in global health funding, decision making and leadership, and empower the next generation of African spatial modelling researchers for sustainable impact.

Led by MAP Senior Research Fellow Dr Susan Rumisha (originally from Tanzania), the Dar es Salaam Node operates in close alignment with the Perth Node, which is led by Kerry M Stokes Chair in Child Health at Curtin University and The Kids, Professor Peter Gething.

Professor Gething said the establishment of both MAP Nodes would help drive world-leading research aimed at achieving the best outcomes for malaria control and elimination in Africa and globally.

*“Bringing the MAP team to Africa is allowing us to significantly boost research in the region as well as strengthen research capacity in a continent where malaria is endemic,” Professor Gething said.*

Sub-Saharan Africa (SSA) carries the heaviest toll of the global malaria burden, with 95 per cent of malaria cases and deaths occurring in this region.

MAP team member and Dar Node technical lead Dr Punam Amratia (originally from Kenya) has joined Dr Rumisha in relocating to Dar es Salaam from Perth to establish the node, build the local research team, and drive research, including provision of enhanced technical support to malaria programs in the region.

Dr Rumisha said the MAP African-based Node would benefit the continent through its research and innovation in geospatial analytics for malaria, generating robust evidence to guide malaria decisions and assess impact.

*“Working closely with national malaria programs in the region is allowing us to integrate local knowledge, expertise and context into our methodologies and analyses, in turn allowing us to tailor our approach to suit countries’ priorities and demands,” Dr Rumisha said.*

The latest tranche of funding – which builds upon many years of funding support from the Foundation – will help MAP generate the annual geospatial malaria modelling and analytics that describe the global landscape of malaria transmission, infection, morbidity, mortality, and intervention coverage.

### NEXT STEPS

- Other areas of focus will include research to better understand the drivers of malaria trends in Africa, including the recent slow-down in progress against the disease; work on evaluating future threats, including growing drug and insecticide resistance and climate change; and analysis of strategies to improve the efficiency and impact of current and future malaria control tools
- The Dar es Salaam Node team is growing, strengthening in capacity, and has continued supporting the malaria programs in generating robust evidence for malaria
- The MAP team is working to establish strategies for strengthening skills and developing modelling capacities including delivering training programs, developing curriculums for geospatial analysis, and mentorship programs analysis
- Mechanisms to recognise African leadership in modelling are under way, with dedicated efforts to respond to the gender inequalities in modelling



This research is supported by the Bill & Melinda Gates Foundation.



Dr Susan Rumisha (left) and Dr Punam Amratia (right) moved to Tanzania to further establish the East Africa Node of the Malaria Atlas Project



## Community-led healthy skin materials on track to curb Strep A

Healthy skin is a vital factor in the fight against life-threatening conditions like sepsis, heart disease and kidney disease, all of which can be caused by the bacteria Strep A.

With skin a key entry point for the dangerous bacteria, researchers from The Kids Research Institute Australia's Healthy Skin and ARF Prevention team have developed a large program of work focused on investigating healthy skin strategies to control Strep A and Staph aureus.

At the centre of the program is the SToP Trial, a large clinical trial in Western Australia's Kimberley region, which aims to decrease skin infections in Aboriginal children by 50 per cent. Since commencing in 2019, the project has produced paradigm-shifting research, informed therapeutic guidelines for healthcare workers, and delivered a suite of health promotion tools.

These have included eight healthy skin books, a HipHop2 SToP music video and, most recently, an updated version of the National Healthy Skin Guideline first launched in 2018.

The Telethon-funded second edition of the guideline, developed by a multi-disciplinary group including Aboriginal clinicians, has built on the first edition to include more skin conditions experienced over a wider geographical area.

Clinical Professor Asha Bowen said the guideline had evolved significantly since the first edition, with updates informed by newer research findings generated by the SToP Trial.

"The second edition includes diagnosis and treatment of scabies, skin sores, tinea, eczema and headlice, which can contribute to Strep A bacteria becoming invasive when skin is scratched, as well as a new chapter on the culturally-informed health promotion resources," Professor Bowen said.



Children's story book *Kaal Tackles Eczema*, co-authored by Aboriginal community members and the Healthy Skin team, was launched in February this year

*"Given the success of the first guideline - viewed online more than 10,000 times - we're expecting the second edition, with its updates and expanded focus, to make a significant impact."*

Results from the SToP Trial have also informed Koolungar Moorditj Healthy Skin, a first-of-its kind project that aims to understand more about the health needs of urban-living Aboriginal children. The results of this study informed the development of several community-driven health promotion resources.

Led by Aboriginal Elders and community members, the Koolungar Moorditj Healthy Skin Team have co-developed resources including a children's story book and strength-based music video called *Moorditj Skin means Moorditj Health*.

Featuring local talent and produced by a Supply Nation-Certified organisation, the music video was created to support healthy skin practices in a fun, engaging and catchy way.

Children's story book *Kaal Tackles Eczema* was co-authored with an Aboriginal community advisory group to fill a gap in health promotion resources focused on eczema.

The book - funded by Telethon and the WA Future Health Innovation Research Fund and launched in February this year - supports children and families to identify eczema early, enabling preventive measures that can both relieve discomfort and avoid potentially invasive bacterial infections.



The Healthy Skin and ARF Prevention team has been supported by the Wesfarmers Centre of Vaccines and Infectious Diseases, Ian Potter Foundation, WA Future Health Innovation Research Fund, NHMRC, Medical Research Future Fund, Perpetual, Perth Children's Hospital Foundation, WA Health, RACP, L'Oreal, Healthway, The Kids Research Institute Australia, and the Channel 7 Telethon Trust.

### NEXT STEPS

- The Healthy Skin and ARF Prevention Team is working on making tinea treatment Terbinafine more palatable by formulating a chewable, chocolate-flavoured base
- A Healthy Skin app, intended to help families identify skin infections and provide easy access to all Healthy Skin team resources, will be launched this year
- The team has received further funding to develop more co-authored healthy skin books and find better treatment for scabies and head lice





## Missing Piece study guiding new strategies to prevent rheumatic fever

A Kimberley study seeking to better understand Strep A in remote settings is helping to guide new approaches to prevent acute rheumatic fever (ARF) – an auto-immune response that typically begins with a sore throat and causes high fever, tiredness and swollen joints.

More common in remote areas, where it affects Aboriginal children and families, recurrent episodes of ARF can scar the heart – leading to devastating consequences like open heart surgery, heart failure and stroke.

With growing evidence suggesting ARF can also result from skin sores caused by Strep A bacteria, the Missing Piece study – led by Clinical Professor Asha Bowen from The Kids Research Institute Australia – has monitored both sore throats and skin sores among 5–15-year-olds in the Kimberley to investigate the link between Strep A skin sores and ARF in remote Aboriginal communities.

Professor Bowen said that with high rates of ARF and rheumatic heart disease (RHD) in the Kimberley, the work was essential to guide diagnostic and treatment guidelines and inform the most effective prevention strategies for ARF.

Beginning with a small pilot study in 2017, the study was expanded in 2019 to a wider prospective school-based surveillance program in two Kimberley towns that has since informed national health guidelines. Community relationships were guided by The Kids' Kulunga Aboriginal Unit and strong collaboration with the Broome Regional Aboriginal Medical Service and the Derby Aboriginal Health Service.

The school-based study measured the burden of Strep A using a mix of clinical assessment methods and tools developed and tested by the Missing Piece team, including a game-changing molecular point-of-care test for Strep A.

Among other outcomes, results from the follow-up study have since informed updates to the third edition of the Australian Guidelines for management of ARF and RHD, used throughout Australia.

*"This is the first time in two decades that an accurate understanding of the concurrent burden of Strep A impetigo (skin sores) and sore throats has been determined, which has policy and guideline impacts for ending RHD in Australia," Professor Bowen said.*

As well as impacting national guidelines, the study has led to increased engagement with health clinics and schools in Broome and Derby, including delivery

of health promotion resources; and the team has secured vital new funding to enable further research.

In a new project co-designed with Aboriginal people and in partnership with Aboriginal medical services across remote Australia, the team will use a Medical Research Future Fund (MRFF) grant secured together with the Kirby Institute to upscale Strep A point-of-care-tests that can detect Strep A bacteria in under 30 minutes – drastically reducing what was previously a five-to-seven day wait for results.

*"The Missing Piece study has provided opportunities to now roll out an evaluation study of new point-of-care tests for Strep A sore throats at 30 clinics across Northern Australia," Professor Bowen said.*

"It is hoped this will follow the impact of molecular point-of-care tests for COVID, flu, RSV and sexually transmitted infections and eventually become the standard of care at remote clinics across Australia. This new test is an important addition to clinical care to prevent ARF in Aboriginal Children."

### NEXT STEPS

- Translation of study findings into storybooks co-designed with school communities
- A two-year implementation trial of molecular Strep A point-of-care tests is expected to commence in 2024 to explore integrating them in rural and remote clinics through the First Nations Point of Care Testing Network
- A National Health and Medical Research Council (NHMRC) Ideas grant will enable the exploration of new ways to understand natural immunity to Strep A to prevent infections and subsequent diseases



The team's work has been supported by END RHD Centre of Research Excellence, WA Child Research Fund (WACRF), WA DoH (Merit Award), Wesfarmer's Centre for Vaccines and Infectious Diseases, a National Health and Medical Research Council 'Ideas Grant' and a 'HOT NORTH CRE Fellowship'. Ongoing work by investigators Dr Janessa Pickering, Bernadette Wong and Professor Bowen is supported respectively by the Stan Perron Charitable Foundation, a UWA PhD scholarship, and an NHMRC Investigator Award.



## Pioneering work in disease diagnosis

The Kids Research Institute Australia is playing a key role within a global team of experts whose work is transforming efforts to tackle a potentially deadly disease that disproportionately affects Aboriginal and Torres Strait Islander children in remote Australia.

Left untreated, repeat episodes of acute rheumatic fever (ARF) – a multiorgan inflammatory disorder that results from the body’s autoimmune response to Group A Streptococcus (Strep A) infections – can progress to rheumatic heart disease (RHD), heart failure, and premature death.

Despite its dangerous nature, ARF is notoriously difficult to diagnose thanks to its similarities to other common childhood illnesses.

Now, a global team of experts including researchers from The Kids have joined forces to pioneer a transformative shift in diagnostics, reshaping how we perceive and diagnose ARF and RHD.

**The Acute Rheumatic Fever Diagnosis Collaborative (ARC) Network represents experts in bacterial pathogenesis, immunology, genetics, systems biology, bioinformatics and epidemiology, as well as clinicians working to identify and validate biomarkers for ARF.**

Discoveries made by the network – including ongoing work towards a highly sensitive diagnostic test that can provide fast-tracked results – are expected to enhance epidemiological surveillance, inform vaccine safety and trials, and drive innovations in ARF prevention and treatment strategies.

In Western Australia, contributions to the global scientific effort are being led by Dr Timothy Barnett, Professor Samuel Lundin and The Kids Director, Professor Jonathan Carapetis. They are supported

by Clinical Professor Asha Bowen and Dr Chris Gorman from The Kids, who are leading the ARF diagnostic core and Biobank respectively, along with several additional members of their teams.

Dr Barnett, head of the Strep A Pathogenesis and Diagnostics team at the Wesfarmers Centre of Vaccines and Infectious Diseases based at The Kids, said the network had become a pivotal tool in leveraging expertise and furthering current biomarker research.

“The ARC Network provides the scientific and clinical expertise, resources and clinical networks that are needed to understand the underlying biology of ARF and enable development of an ARF diagnostic test,” Dr Barnett said.

*“Through this incredible network of global experts working collaboratively, we are getting closer to creating an ARF diagnostic tool and making the dream of rapid, accurate and sensitive ARF diagnosis a reality.”*

The ARC Network is made up of members from Cincinnati Children’s Hospital Medical Center, The Federal University of Minas Gerais, State Children’s Hospital, Menzies School of Health, Charles Darwin University, Tidzewe Center, Baylor College of Medicine, Texas Children’s Hospital, The Children’s Hospital and Institute of Child Health Lahore, Children’s National Medical Centre, The Uganda Heart Institute, Biotome Inc, The University of Western Australia, The Kids Research Institute Australia and Perth Children’s Hospital.

### NEXT STEPS

The ARC Network will build on recent discoveries from several international research groups, including recent discoveries made by Dr Barnett’s and Professor Carapetis’ teams at The Kids, to develop a diagnostic test for ARF

Right: Dr Timothy Barnett





## Clocking TikTok expertise across the Institute

Early career researchers across The Kids Research Institute Australia have come together in a serendipitous project that is laying the groundwork for a more informed discussion of the impact of social media on kids and young people.

What started as an investigation into how energy drinks are marketed towards young people turned into a multi-team collaboration after Institute researchers realised there was no standardised way to conduct content analysis on TikTok.

TikTok – used mostly by children and young people – is the fastest growing social media channel across the Asia-Pacific region, including Australia. But the popular platform is marked by a lack of clear research on how it is used and the impact it has on its young users.

Researchers from the Brain and Behaviour, Chronic and Severe Diseases and Early Environment research areas set out to change that, working together to come up with a more effective way to analyse engagement on TikTok.

“We’d wanted to do TikTok research for ages, so while we were looking into energy drink advertising, we thought it was a perfect opportunity to collaborate and come up with a best-practice approach for analysis on the app,” chief investigator Dr Karen Lombardi said.

“TikTok united the team, and while we looked at different angles, fundamentally we were all working together.”

Project Coordinator and PhD candidate Joelle Mandzufas said it had quickly become apparent that while many young people were using TikTok as a source of information, it was difficult to determine what they were seeing and how they were reacting to it.

*“We also thought that eventually the platform might be a great way to reach our audience with credible evidence-based information,” Ms Mandzufas said.*

*Supported by an internal Research Focus Area Collaboration grant of \$50,000, a group of 19 mostly early career researchers (ECRs), spread across 12 teams, joined forces to publish a protocol that could be used to ensure content analysis across the app followed the same approach.*

With the protocol paper published, the group split their efforts across mental health, parenting and physical health streams.

“I think the great buy-in from research groups across the Institute was primarily because we had a ready-made project which had already been piloted, and a clear research plan led by ECRs that would not be a significant time-burden and would work best with collaboration,” Ms Mandzufas said.

So far, papers have been published on the use by young people in the LGBTQIA+ community of TikTok as a means of building community; a harmful viral drinking trend by young TikTok users in the United States; and dieting behaviours found on the app.

Learnings from the work so far are already being disseminated via workshops and presentations to public health practitioners and researchers interstate and overseas.

### NEXT STEPS

- Six more papers are expected to be published by the end of the year, with content analysis of TikTok videos focused on subjects including autism and ADHD, ear health, skin health and parenting tips
- The team is partnering with the University of Otago (NZ), which will base a student assessment on the protocol
- The team will develop a checklist identifying common elements across popular TikTok videos, for future health promotion
- The team plans to undertake a qualitative study exploring how people engage with mental health content on TikTok

Team members (clockwise from back left) Melinda Edmunds, Rigel Paciente, Nicole Wickens, Eliza Kouznetsova, Joelle Mandzufas, Dr Karen Lombardi, Dr Alix Woolard



## Making anaesthesia safer for kids

Every year in Australia, one in 20 children has surgery.

When kids are having surgery, the most common problem that can occur during anaesthesia is a respiratory adverse event.

Therefore, lung function is of extreme importance and being able to continuously study lung function during surgery helps doctors improve patient care.

In a world-first, the Perioperative Medicine team at The Kids Research Institute Australia - headed by Perth Children's Hospital and The University of Western Australia paediatric anaesthetist Professor Britta Regli-von Ungern-Sternberg - has designed and tested a novel piece of equipment which allows researchers to continuously study lung mechanics during anaesthesia and surgery.

The equipment is the result of an international collaboration with biomedical engineers at the Laboratory of Respiration Technologies at Politecnico di Milano in Milan, Italy. Designed, built and bench-tested in Milan, the novel equipment was flown to WA accompanied by a biomedical engineer, who worked with the research team to integrate it into the theatres at Perth Children's Hospital.



The equipment uses the continuous Forced Oscillation Technique (FOT) to monitor lung function by sending sound waves into the lungs and measuring how they bounce back. This tells researchers more about the child's lung function, for example if there

is any narrowing of the airways.

While FOT machines are used regularly in awake patients, this is the first continuous FOT equipment to be used in paediatric anaesthesia, which can be used during spontaneous and mechanical ventilation.

Professor Regli-von Ungern-Sternberg said the team had successfully tested the equipment in two trials in children having surgery at Perth Children's Hospital but it needed to be adapted for use in very small children, such as newborns and small babies.

"To extend the use of this equipment to neonates and infants, we needed to develop new dead space connectors," Professor Regli-von Ungern-Sternberg explained.

"Dead space is the space where we move air during ventilation which is not taking part in actual gas exchange, and we need to keep this as small as possible.

"Therefore, all connectors must be as tiny as possible."

After consulting with the Italian engineers and with anaesthetists, the team paired up with ADARSH Australia, a WA-owned and operated fabricator of component parts to design new dead space connectors.

*"We worked with ADARSH, undertaking several rounds of Computer Assisted Designing (CAD) and 3D printing to custom-make a T-connector that eliminates the need for several connector pieces, thereby significantly reducing the size and therefore the dead-space," Professor Regli-von Ungern-Sternberg said.*

The next stage involves testing the new dead space prototype for newborns by using artificial lungs, before taking the equipment into theatre.



Emily Bell

## Best practice for 'difficult' airways

Babies under 12 months of age can have what is known as 'difficult' airways. When babies are small, their airways are also small and, therefore, can be tricky when it comes to anaesthesia.

Professor Britta Regli-von Ungern-Sternberg - head of the Perioperative Medicine team at The Kids Research Institute Australia, Consultant Paediatric Anaesthetist at Perth Children's Hospital, and Chair of Paediatric Anaesthesia at The University of Western Australia - explains how the physiology of these small babies plays a part.

"Small babies have a very small oxygen reserve, meaning that if ventilation is interrupted, their oxygen levels drop very fast," Professor Regli-von Ungern-Sternberg said.

"At the same time, their oxygen consumption is very high, making them extremely prone to hypoxemia, a low level of oxygen in the blood.

"This makes airway management extremely important when these small babies are having surgery."

Professor Regli-von Ungern-Sternberg was one of 23 leading paediatric anaesthesia airway management experts from around the world who developed guidelines on airway management in babies under one year of age.

These include the American Society of Anesthesiologists guidelines, the European Society of Anaesthesiology and Intensive Care/British Journal of Anaesthesia guidelines and the translation of the European guidelines into German.

Professor Regli-von Ungern-Sternberg said the guidelines improved patient care in general and were particularly important for emergency situations.

*"In those situations where people need to act fast and teams need to work closely together, we all need to be on the same page," Professor Regli-von Ungern-Sternberg explained.*

"The neonatal guidelines summarise best practice and give clear evidence on how to best work in a difficult scenario - they have changed routine clinical practice around the world.

"An individual anaesthetist - unless working in a highly specialised tertiary centre - will not be confronted with a difficult neonatal airway that often, so guidance is very important to ensure best care."

The guidelines provide evidence-based recommendations to assist clinicians around the world to provide the best medical care and ensure patient safety. The new guidelines were published in September 2023 and have been implemented around the world.



Professor Britta Regli-von Ungern-Sternberg



## The decades-old program helping families and kids to thrive

It's a brave move to upend your entire family to seek a fresh start – or safety – in a new country: even braver when the country you're moving to has a completely different language, structure and cultural outlook.

For the children of migrant and refugee families, it can be especially tough – not only trying to fit into a completely new environment but, as the fastest learners in the family, often speaking for older relatives who struggle to navigate everyday tasks and to understand local rules, regulations and ways of doing things.

Coupled with the challenges of getting kids into schools, parents into jobs and keeping a roof over everyone's heads, it can be a highly vulnerable time for families – especially those who have come from conflict zones or have had little previous access to education.

For decades, the Federal Government has sought to ease the transition by providing an immersive settlement program that not only helps new migrants and humanitarian entrants improve their English skills, but supports them to acclimatise socially, tackle daily activities, and navigate health, education, social security and other government and service systems.

The Adult English Migrant Program (AMEP) was originally established in 1948 to help thousands of refugees displaced by World War II develop English skills and settle into Australian society.

In the decades since, the AMEP has directly helped more than two million migrants and humanitarian entrants, in turn delivering a range of positive impacts for their children and families.

Until recently there's been no way to measure the extent of that impact, but now an exhaustive



evaluation led by a team from The Kids Research Institute Australia has used the power of data linkage to show just how valuable the program is.

Last year, a team of researchers led by Professor Francis Mitrou and Dr Ha Nguyen completed the AMEP Impact Evaluation Project – the most comprehensive study of AMEP participation undertaken in the \$300 million per year program's 76-year history.

Working closely with the Department of Home Affairs, the team spent four years building a profile of those using the AMEP, analysing its effectiveness, and evaluating its economic and societal impact beyond simply improving migrants' English. Across five research papers, they examined outcomes including language, employment and income.

The research found AMEP participation improved clients' English proficiency, especially when they studied for longer periods, and was associated with improved labour force participation, higher income levels, and reduced reliance on income support. But Professor Mitrou said that while understanding these kinds of outcomes had been an important objective, they were only part of a much bigger impact story.

*"When we consider people from non-English-speaking backgrounds – particularly humanitarian refugees or people who may have had very little access to education and who arrive in Australia with nothing – the AMEP is a game-changer in terms of how we set those families up for success in Australia," he said.*

*"It's a powerful tool that helps lift disadvantaged migrant families out of poverty and isolation. That in turn has powerful consequences for their children's wellbeing, education and ability to thrive and lead the happy, healthy lives we want for all Australian kids."*

## More than just words, AMEP embeds families in the Australian way of life

While the AMEP's key aim is to improve migrants' English, communication and digital skills to help them into employment or further studies, there is also a strong focus on social skills and community connection.

"We want them to be able to feed their families and pay their rent and to get them off the social system as much as possible, but it's also about building up their social skills and confidence," said Rania Soliman, who leads AMEP delivery across North Metropolitan TAFE's sites.

"When people arrive in Australia they have no clue about how things work or the social aspects of our society, so we build those topics into the program as well."

This could be as basic as water safety: with some migrant families never having seen beaches or pools before, it's vital to teach them how to keep themselves and their children safe.

"Schooling is another aspect – they don't know a lot about how the Australian schooling system works so

we support them in that," Ms Soliman said. "We also make them aware of community-based things such as sports they can do for the kids and themselves."

With women making up 65 per cent of AMEP participants, a key ingredient in the program's success has been on-site, free childcare.

PJ O'Keefe, who manages the AMEP portfolio for South Metropolitan TAFE, said onsite creches had made the AMEP vastly more accessible for female clients, many of whom were juggling significant family and cultural responsibilities.

*"Being able to bring their kids with them opens up their opportunity to participate," he said. "If we didn't have this, so many people would be locked out of learning and development and the ability to participate socially and economically in Australian life."*

"That learning doesn't just benefit them as individuals – they're developing skills that benefit the family group and their community."



Photos: Department of Home Affairs

### DID YOU KNOW?

- The AMEP, delivered at around 300 sites across the country, is Australia's longest running settlement program, celebrating its 75th anniversary in 2023
- The program helps tens of thousands of migrants and humanitarian entrants every year, with about 403,000 enrolled in the period examined by the evaluation project (2003-2019)
- The top 10 countries of birth for AMEP participants during the evaluation period were China, Iraq, Vietnam, Afghanistan, India, Myanmar, Thailand, Iran, South Korea and Sudan
- 65% of participants were women
- 97% of all clients were aged between 18 and 65 years
- On average, each client received 332 tuition hours with AMEP, with those on humanitarian visas typically requiring more support (an average of 414 tuition hours)
- 90% of clients spent three years or less in the program



The AMEP Impact Evaluation Project was undertaken by researchers from The Kids Research Institute Australia and The University of Western Australia with input from the Australian Government's Department of Home Affairs, and was co-funded by the Australian Government in partnership with the Australian Research Council Centre of Excellence for Children and Families over the Life Course (ARC Life Course Centre).





# IN THE PIPELINE

THIS RESEARCH IS  
IN THE PIPELINE  
TOWARDS  
TRANSLATION







## New facility to develop crucial treatment for antibiotic-resistant superbugs

Western Australia's first bacteriophage manufacturing facility has been opened in a significant development that brings patients battling antibiotic-resistant infections a step closer to life-saving phage therapy.

Bacteriophages, or 'phages', are 'friendly' viruses naturally present in the environment, including waterways and soil, which selectively target and eliminate antibiotic-resistant bacteria – offering a potential alternative to traditional treatment therapies.

In phage therapy, patients are treated using specific phages matched to their bacterial infection from a phage library generated by the research team. Once identified as suitable matches, the phages undergo rigorous purifying and sterilising processes to ensure their safe use in humans.

Phage therapy is not new: it was employed until a century ago but fell out of use when antibiotics gained prominence. However, the lack of new antibiotics since 1987 has heightened the urgency for alternative treatments to combat antimicrobial resistance (AMR) – recognised by the World Health Organization as one of the world's most pressing health concerns, with more than 10 million annual deaths projected within the next 25 years if nothing is done.

Given this escalating global concern, phage therapy research is gaining momentum as a promising complement or substitute for traditional antibiotics.

The Phage WA manufacturing facility – spearheaded by a team at the Wal-yan Respiratory Research Centre – represents a crucial step toward making phage therapy a clinical reality for Western Australians facing antibiotic-resistant bacterial infections.

Associate Professor Anthony Kicic, Scientific Lead of Phage WA and a researcher at the Wal-yan Centre – a powerhouse partnership between The

Kids Research Institute Australia, Perth Children's Hospital Foundation, and Perth Children's Hospital – and the Curtin School of Population Health, said the manufacturing facility's opening was the next key step in bringing patients closer to faster and more effective phage treatments.

*"Our team at the Wal-yan Centre has spent the past five years creating a large library of phage viruses and matching them with the various strains of bacteria that cause serious infections, to find the best treatment to destroy them and clear infection," Associate Professor Kicic said.*

"Last year, nationwide ethics approval for compassionate use of phages was granted, offering new hope to patients suffering from chronic, recurrent infections that no longer respond to antibiotic treatment.

"We were also successful in securing WA and federal government funding to initiate a manufacturing facility and a translational trial program for patients with antibiotic-resistant lung infections."

The opening of the cutting-edge facility means the team can now develop safe phage treatments for critically ill patients right here in WA.

"While small-scale phage facilities exist in Sydney and Melbourne, they will not be able to meet national demands, including WA patients, within practical timelines," Associate Professor Kicic said.

"The establishment of a WA facility is a monumental step toward delivering faster phage treatments to patients in need not only here but also around Australia and overseas."

### **DID YOU KNOW?**

- Phage therapy holds remarkable potential for treating antibiotic-resistant lung infections caused by pseudomonas and other prevalent bacterial infections like Golden Staph, skin and ear infections. It can also be a valuable tool in surgical settings where antibiotics are becoming less effective due to bacterial resistance
- Phage therapies have a proven track record of success, curing infections and saving lives in Australia and around the world



Phage WA has been made possible through funding from the Federal Government, the Western Australian Government, Conquer Cystic Fibrosis, Cystic Fibrosis WA, Perpetual's Impact Philanthropy Program, the Rothwell Family Foundation, the Stan Perron Charitable Foundation, and Therapeutic Innovation Australia.

Attending the Phage WA launch, WA Medical Research Minister Stephen Dawson, Executive Director of The Kids Professor Jonathan Carapetis, Scientific Lead Phage WA at The Kids, Associate Professor Anthony Kicic, and Taryn Barrett, mother to nine-year-old Connor Barrett, who has cystic fibrosis and is at higher risk of developing antibiotic resistance



## Revolutionising diabetes management for children and families

Imagine living with a condition that requires you to make approximately 180 health-related decisions every day for the rest of your life.

This is the reality for children living with type 1 diabetes (T1D) – an autoimmune condition that destroys the ability of the pancreas to produce insulin, without which the body cannot utilise glucose, a simple sugar that comes from the food we eat and is needed for energy.

One of the thousands of Australian children living with T1D is 11-year-old Meela Goldsworthy, who was diagnosed at the age of four. Like all children with T1D, Meela needs regular injections or a pump for insulin and her glucose levels need to be closely monitored to maintain them within a safe range. Every day Meela and her family must carefully manage her diabetes to reduce her risk of both short- and long-term complications.

Living with T1D is exhausting and unrelenting and can be life-threatening. But a groundbreaking new project, led by Professor Tim Jones and Helen Clapin at the Rio Tinto Children's Diabetes Centre at The Kids Research Institute Australia, is providing hope for families like the Goldsworthys.

DiabHQ is an innovative new platform that integrates diabetes data from a range of different sources so it can be used more effectively to accelerate research and translation, improve clinical care, and help patients and families with self-management.

With the DiabHQ data layer complete, the next focus is a Patient Portal that will provide patients and families with a one-stop shop for their diabetes needs.

Meela's mum Lisa Goldsworthy, who has been involved in the project since its inception, is excited about DiabHQ and its potential to relieve the fatigue, stress and frustration associated with T1D, allowing children and their families more time to live a normal life.

*"DiabHQ will allow us to connect with clinicians and researchers and to share the needs of our community," she said.*

*"The Patient Portal will allow us to do almost everything we need in one place – we'll be able to access resources and support, track Meela's progress, and view upcoming appointments and events.*

*"Easing the burden for children living with T1D and their families will improve mental health, physical health and quality of life."*

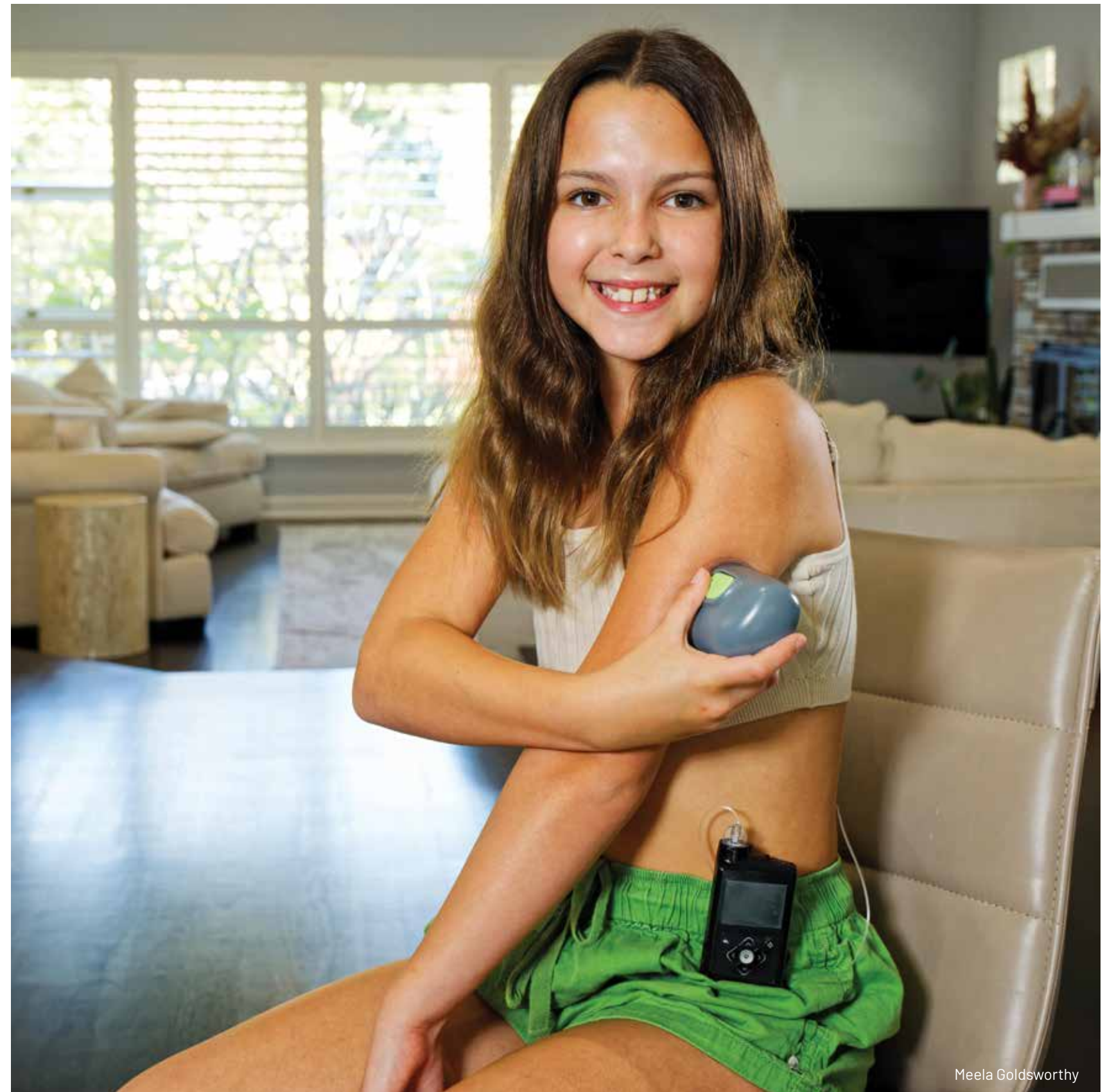
### NEXT STEPS

- The Patient Portal is on track for implementation at Perth Children's Hospital by early 2025
- DiabHQ is being designed so that it can be scaled to other diabetes centres across Australia in the future



The DiabHQ project has received funding from the Stan Perron Charitable Foundation and is supported by the Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence.

**Collaborating institutions:** The Kids Research Institute Australia and the Child and Adolescent Health Service.



Meela Goldsworthy



## Applying the arts to wild little hearts

When author Maurice Sendak first sketched out the story of a rambunctious little boy sent to his room without supper, there's no way he could have known his rollercoaster tale of childhood imagination would still be speaking to the hearts of wild young things more than six decades on.

Published in 1963, *Where the Wild Things Are's* enduring ability to give safe expression to the turbulent emotions of childhood made it a natural choice when Spare Parts Puppet Theatre came to adopt a framework – developed by The Kids Research Institute Australia – that seeks to maximise the capacity of the arts to enhance children's social and emotional wellbeing.

Using the book as the centrepiece for the first of Spare Parts' 2024 Puppet Playtime sessions, a performer brought the story to life before leading toddlers and caregivers through activities – including story stones and puppet making – designed to provide a healthy outlet for their wild emotions.

The session was inspired by *Expressing Emotions* – one of a range of critical wellbeing factors identified by the Social and Emotional Wellbeing through the Arts (SEW-Arts) project led by the Institute over the past three years, in close partnership with Healthway and Edith Cowan University.

"We've always known the arts can have a positive effect on mental health and wellbeing but how that relationship works has never really been understood," The Kids Senior Research Fellow and SEW-Arts lead Leanne Fried said.

**"The SEW-Arts framework, developed in consultation with psychologists and young people aged 12–17, identifies wellbeing factors the arts can tap into and provides evidence-backed resources and guidance to help arts organisations intentionally target those factors when working with children and young people," Ms Fried said.**

Since developing the framework Ms Fried, fellow researcher Sarah Falconer and their team have

worked with 33 visual arts, drama, dance, music, circus and other arts organisations throughout WA to adapt their programs, with Healthway providing additional funding to organisations willing to adopt and build on the framework.

"Arts organisations have contributed significantly to development of the framework and are helping us adapt it to diverse populations," Ms Fried said.

The SEW-Arts team has also helped train teaching artists and arts administrators in how to implement the framework and has developed training modules that can be delivered independently, as well as tools to help organisations evaluate their progress and impact.

**"The framework has provided a language for arts organisations to talk about SEW and identifies important key messages to convey to young people," Ms Fried said.**

"The goal is to have organisations that work with children and young people really focused on promoting SEW in addition to their main core practice. There is no reason why the framework can't be applied to other organisations beyond the arts."

### NEXT STEPS

- A recent funding increase and extension will allow the SEW-Arts team to expand the number of organisations they work with, including more regional and some local government arts organisations
- They will also use the funding to develop professional learning for teaching artists working in schools, and to help arts organisations embed the framework in an ongoing way
- The team is working closely with its Aboriginal Reference Group to ensure the framework is suitable for Aboriginal people to use



The SEW-Arts project and associated resources have been developed by The Kids Research Institute Australia with funding

from Healthway, in partnership with Edith Cowan University and with advisory support from The West Australian Ballet, the WA Youth Theatre Company and the Art Gallery of Western Australia (AgWA)



Eli Roy and his mum Courtney take part in a Puppet Playtime session at Spare Parts Puppet Theatre. Photo: Spare Puppets Theatre

## Taking SEW-Arts to the next level

**Spare Parts Puppet Theatre is so far the only arts organisation focused on the early years to adopt the SEW-Arts framework, with staff adapting its wellbeing factors and key messages to be developmentally appropriate for their younger audience.**

The *Expressing Emotions* wellbeing factor, for example, was adapted into *Expressing and Naming Emotions* for the *Where the Wild Things Are* session, with caregivers also given a take-home resource.

**"The caregiver resource told the parents something that blew my mind when I first heard it, and that is 'toddlers experience peaks and troughs with their hormone levels that are way more intense than pubescent teenagers experience'," Spare Parts Learning and Engagement Officer Naomi Corteen said.**

**"The mood swings, the emotions seeming to come out of nowhere suddenly make so much more sense. So we offered ways to address sensory needs that will help your child regulate those emotional peaks and troughs – that in turn makes expressing emotions easier."**

Spare Parts' initiative in adding value to the framework led Healthway to offer them a larger grant which will help them turn the SEW factors – originally tailored to older children – into a new framework specifically targeted at the early years.

"It's turning into a whole new program, which is very exciting," Ms Corteen said.

She said that although Spare Parts had always existed to promote wellbeing, the SEW-Arts framework had provided valuable structure and background material informed by psychologists.

"The other exciting thing about the framework is it can be used as a tool to convince people of the importance of the arts and to hopefully to lobby for change when it comes to how they're valued in schools, educational and other settings."



## Jake takes competition in his stride

Ten-year-old Jake Saunders has gone from a child who struggled to cope with sports carnivals to one who now competes at State level in Little Athletics, thanks to learning strategies that have helped him cope with his anxiety.

Mum Caroline Saunders said Jake, who was diagnosed with autism at two-and-half years of age, had been an anxious toddler but between therapy and knowing his triggers, she had thought they had a handle on it.

Despite this, Mrs Saunders decided to join the CUES-Junior study because she had a policy of always saying 'yes' to opportunities for parental learning and upskilling.



Jake Saunders

"It was only after the initial chat with Gail Alvares (lead of the CUES-Junior trial) that we discovered Jake was a lot more anxious than we thought," Mrs Saunders said.

Prior to CUES, one situation which would trigger Jake was school sports carnivals.

"Jake always had trouble with winning or losing and big crowds and would physically shake or have a meltdown after a race," Mrs Saunders said.

"He always put a lot of pressure on himself, and he would worry about his heart beating too fast. Through CUES, we developed a strategy to help him cope with these situations by playing short games like UNO and Snap so he would get used to winning or losing.

"He also learnt breathing techniques – three deep breaths – to ground himself."

Mrs Saunders said the program had helped Jake learn how to manage his anxiety and he now understood how his body responded physically to adrenaline. He had also learnt good sportsmanship skills and was far more resilient – all of which combined had allowed him to pursue his passion for running, with a more confident Jake recently making the State Little Athletics championships in the 400m and 800m events.

"Jake says he feels free when he's running – he's found something he truly loves to do and has thrown himself into it," Mrs Saunders said.

"He often comes second and now instead of getting upset, he displays great sportsmanship by shaking hands with the other competitors and saying, 'good job'."

More than half of all autistic people have a mental health condition

Four out of every five autistic individuals may experience an anxiety disorder in their lifetime

One third of participating children were clinically improved at the end of the eight-week program

Two months post-program, 59 per cent reported a clinical improvement



The CUES-Junior trial was funded by the WA Department of Health and Channel 7 Telethon Trust through the WA Child Research Fund, and PhD funding through The University of Western Australia.

**Collaborating institutions:** The Kids Research Institute Australia, The University of Western Australia, Newcastle University upon Tyne, Stanford University, and WA Child and Adolescent Health Service.

## Learning to cope with uncertainty

A small group program to help parents tackle anxiety in young children diagnosed with autism has found significant improvements in both children's anxiety and parental mental health and wellbeing.

Researchers from The Kids Research Institute Australia recently trialled the Coping with Uncertainty in Everyday Situations (CUES-Junior) program to see whether it could be delivered to families of young children diagnosed with autism, and if it was effective in managing anxiety around uncertainty (or fear of the unknown).

Lead researcher Dr Gail Alvares, Senior Research Fellow at The Kids' CliniKids, said the CUES program had a significant effect on reducing the impact of uncertainty anxiety on both children and families compared to the study's control group.

Dr Alvares said a third of the children were rated by independent assessors as clinically improved at the end of the eight-week program – a figure which climbed to 59 per cent two months later.



Dr Gail Alvares

"Parents also rated improvements in children's anxiety around uncertainty, and improvements in their own parental anxiety and stress," she said.

"The program aims to support children's capacity for coping with worries around uncertainty and change."

Dr Alvares said anxiety disorders (for example, separation anxiety or social anxiety) could present in early childhood and be more complex in autistic individuals.

"Autistic children are more likely to experience anxiety concerns, which can have a large impact on them and the families who support them. However, there are not many effective programs available, especially for younger children, so we looked at ways to support these children and their families before anxiety became a significant issue."

The CUES-Junior study recruited parents or primary caregivers of 64 children aged four to seven years and on the autism spectrum. In addition to attending the group program, which was facilitated by psychologists, participants completed questionnaires and interviews before and after the program.

During the program, parents learnt about uncertainty and its relationship to anxiety, plus were given individualised tools and strategies to manage uncertainty at home and other everyday situations such as school and shopping.

Uncertainty situations common to the families included teacher changes, birthday parties, playing with other children at playgrounds, and unpredictable sensory experiences in public toilets (for example, hand dryers).

Deep breathing, trampoline time, relaxation, role playing, and social stories were some strategies families tried out to support their child's ability to cope.

Dr Alvares said the group environment also gave parents the opportunity to meet people in similar situations.

"If you have a child who has difficulty around uncertainty, the functional impact is high and it can be very isolating as it's easier to avoid social situations than attend," she said.

"This group not only tackled strategies to help parents manage children's uncertainty but also provided them with an opportunity to build a community."

### NEXT STEPS

- Researchers are developing a digital group program to benefit more families of autistic children, especially families who live in regional or remote areas. The program is being co-designed with parents
- This research demonstrated that providing an early parental program in small groups may benefit children's anxiety around the unknown, however further research is needed to see whether these effects last in the longer term





## Community voices to foster cultural safety

Life imitates art in a new project that seeks to entrench cultural safety for young Aboriginal and Torres Strait Islander people into WA's mental health system.

When the Embrace @ The Kids childhood trauma research group began the Cultural Safety Project, Noongar artist Valerie Ah Chee was commissioned to create a visual representation of what the project hopes to achieve.

That same hope is a key theme of *Dabakan Kooliny* ('Go slowly' / 'Walk slowly'), after the artwork was unveiled to support the project's plans for 2024.

A central layer features a sturdy and nurturing tree providing safety and connection for children sitting among its branches. These children are supported by layers of family, community, and culture, which work as safety nets as they embark on their holistic journey towards social and emotional wellbeing.

"Often programs are imposed from the outside, and they are adapted for Aboriginal people, rather than culturally derived," Embrace Co-Director, and Palyku woman, Professor Helen Milroy said.

"When working from a cultural perspective, it is important to start with a cultural conceptual understanding first, which often comes in the form of art and story. This helps us to build a more comprehensive model to examine and build across our research which can then be delineated down into the elements that need to change within services. It also allows our research to embed elements of cultural safety right from the beginning.

*"Indigenous artwork in particular is all about storytelling, and Valerie's artwork shows children as part of an ecological framework where they are connecting back with nature, they are connecting with community and there's a harmony to their relationships. It is a story that instils hope, which is what we want this research to do."*

The two-year project, funded by a Federal Government Medical Research Future Fund grant, is led by Aboriginal researchers and comprises an Aboriginal and non-Aboriginal team, who work closely with Aboriginal service providers and Aboriginal and Torres Strait Islander leaders in social and emotional wellbeing and mental health and suicide prevention.

The project aims to identify the requirements of cultural safety for Aboriginal and Torres Strait Islander young people and their families, with the expectation that its findings will transform the existing mental health system for Aboriginal and Torres Strait Islander youth and reduce the mental health burden placed on this group.



## Sport resources key to encouraging physical activity in youth living with type 1 diabetes

Sports coaches across Australia can now access WA-designed sport resources, which aim to help coaches better understand type 1 diabetes (T1D) and encourage children living with the condition to stay in sport.

We know exercise is important for good physical and mental health in all people, but there are additional benefits for people living with T1D including optimising blood glucose levels - leading to fewer health complications later in life.

Despite this knowledge, currently kids with T1D tend to be less active than their peers.

Research has found one of the main barriers to participating in exercise and sport has been a lack of knowledge and awareness of the condition by their coaches. Many coaches also reported they lacked the confidence and understanding to provide adequate support for young people living with T1D.

Type 1 diabetes is the most common chronic condition in children, affecting more than 1,100 children in Western Australia. The condition is lifelong, with no cure, and these children face increased risk of cardiovascular complications that can shorten their life expectancy.

Researchers at the Rio Tinto Children's Diabetes Centre, a JDRF Global Centre of Excellence based at The Kids Research Institute Australia, have teamed up with young people living with T1D, their parents, and coaches to develop the first-of-their-kind T1D sports resources, Take PART (Physical Activity Resources for Type 1), to provide the information coaches need to safely include kids with T1D in community sport teams.

Co-director of the Rio Tinto Children's Diabetes Centre, Professor Liz Davis, said people living with

T1D could participate in all forms of physical activity, but it could sometimes be more challenging.

"We want to encourage young people living with T1D to feel more confident to participate in sport and physical activity to help them live a healthier life," Professor Davis said.

*"The resources equip coaches to better understand the condition and help support and encourage young people playing sport."*

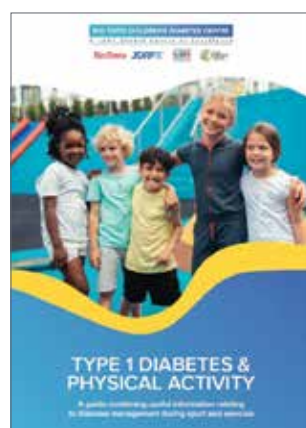
"We hope these resources help young people living with T1D and their parents feel more confident during community sport and encourage participation in a variety of different activities."

Thirteen-year-old Madeleine Pontifex, who was diagnosed with T1D at the age of seven, got involved in co-designing the resources because she believed if more coaches had information on T1D management, then more children would feel comfortable playing sport.

"For kids living with T1D wanting to get into sport, having these resources means that coaches will understand, and they won't have to worry on their own," Madeleine said.

### The resources include:

- A physical activity booklet providing an in-depth overview of T1D
- A 'My Diabetes' individualised document for players to personalise about their diabetes and support they may require
- A pocket wallet guide designed to be a small, handy resource that can be kept in a coach's pocket or coaching bag
- An A4 Fact Sheet, providing an overview of key information to be aware of, and
- A poster designed to be hung in a club room or foyer providing an overview of key information.



The Take PART resources have been funded by Diabetes Australia Research Program (DARP) 2023 Grant Round Y23G-TEOS, and supported by JDRF and Rio Tinto through the Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence.



Madeleine Pontifex

### NEXT STEPS

- Researchers from The Kids Research Institute Australia will continue to work with the Department of Local Government, Sport and Cultural Industries for dissemination of the resources to WA's 90+ state sport organisations
- Resources will be made available through the PCH Diabetes Clinics, JDRF Australia and participating sports organisations across Australia
- The resources will be reviewed and updated to respond to feedback, new evidence from research and community preferences



## Shopping for data to drive discoveries

What if researchers could shop for different data to help uncover how, when and why chronic conditions such as asthma, obesity, allergies and poor mental health develop?

Data is transforming the landscape of research and innovation, and ORIGINS based at The Kids Research Institute Australia (The Kids) and Joondalup Health Campus is turning this concept into a reality.

ORIGINS is a longitudinal study of more than 20,000 individuals including mothers, partners and children. Collecting data and biological samples to create one of Australia's largest data and biobanks, the research platform follows the progress of pregnant women and their families from early childhood and across the lifecycle.

This extensive biobank of more than 400,000 biological samples and the databank platform, with more than 16 million data points, enables world-class research discovery.

The Data Catalogue, launched by ORIGINS in 2023, is a set of data visualisations hosted by Power BI, which provides a snapshot of all the data and bio-samples held in the ORIGINS platform.

The ORIGINS Data Catalogue is made up of five sections, which allow a user to enter the platform and identify exactly what they would like to view. It features tools such as a measurement library, biobank overview, subproject breakdown and advanced search capabilities – permitting researchers to see what data and bio samples they have collected to date across all time points.

ORIGINS Data Manager Sarah Whalan, who led the project, said the catalogue was built in record time, alongside ORIGINS' external consultancy group, Data Divers, to provide unparalleled access to the data sets to help accelerate outcomes.

"We had a huge influx of researchers who were requesting different points of data, and we were finding the process was very manual and a few silos were beginning to form," Dr Whalan said.



"The Data Catalogue provides a critical first step in understanding the available data and bio samples, allowing researchers to navigate the data with precision, ensuring that research is backed by reliable information.

*"This accessibility not only accelerates the pace of discoveries but also enhances collaboration across fields."*

Associate Professor Paula Hooper, adjunct research associate at The University of Western Australia, said the system had become a vital tool when establishing new research projects.

"The platform is great when it comes to identifying the depth of data, the different variables and subprojects running, and to compare data across different categories. It really means we can get full visibility as to what is there."



ORIGINS is funded by the Paul Ramsay Foundation and the Commonwealth Government of Australia through the Channel 7 Telethon Trust, and the Stan Perron Charitable Foundation.

Members of the ORIGINS team





## Addressing climate change to safeguard the health of our children

Researchers from The Kids Research Institute Australia who are working to better understand the serious threat climate change poses to children's health have led a study revealing the dramatically heightened risk of preterm births as the world gets hotter.

A comprehensive review led by researchers from the Wal-yan Respiratory Research Centre, The University of Western Australia (UWA) and Flinders University found a 60 per cent increase in the average risk of preterm birth due to exposure to extreme temperatures driven by climate change.

The alarming finding was one of a range of significant relationships between climate change and child health identified by the team, with respiratory diseases, mortality and morbidity found to also be significantly influenced, albeit not as dramatically as preterm birth.

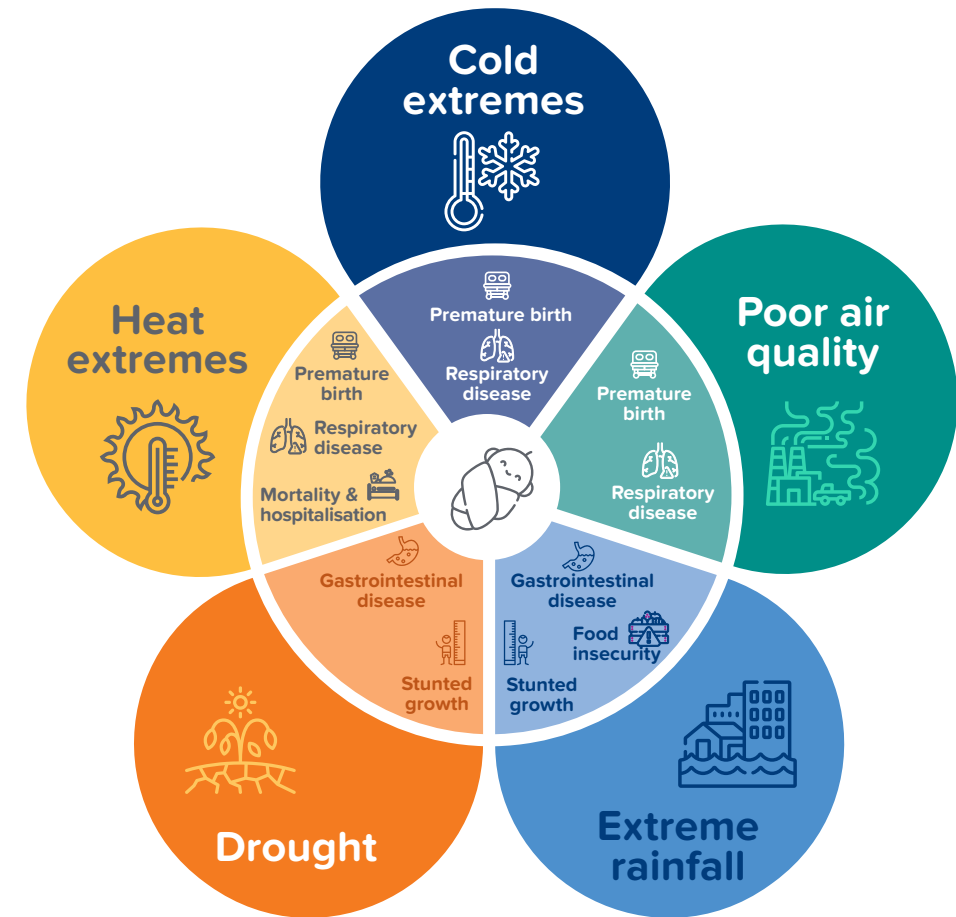
It wasn't all bad news, with the team also uncovering key protective factors against climate-related child health threats, including economic stability and strength, access to quality healthcare, adequate infrastructure, and food security.

The findings were the result of a systematic review and meta-analysis undertaken by the team to unravel the intricate relationship between climate change and health of children globally. While the impact of climate change on human health has been explored in multiple studies, few to date have focused on the health effects faced by children.

Lead author Dr Lewis Weeda, from the Wal-yan Centre and UWA, said being able to quantify the magnitude of impact on child health outcomes was paramount for effective planning and mitigation strategies.

"Our findings underscore the urgency of addressing climate change to safeguard the health of current and future generations," Dr Weeda said.

He said while the team had identified protective



factors to minimise impacts on child health, these were all susceptible to local geographical, climate and socio-economic conditions – highlighting the need for targeted interventions tailored to specific communities.

"The identified protective factors serve as a foundation for designing interventions that not only mitigate the health risks posed by climate change but also enhance the overall resilience of communities," he said.

Insights gleaned from the review are now actively shaping several projects within the Wal-yan Respiratory Research Centre – a powerhouse partnership between The Kids Research Institute Australia, Perth Children's Hospital and Perth Children's Hospital Foundation.

Geospatial studies are under way across Australia, with a specific focus on Western Australian children and in particular Aboriginal children, to identify realistic solutions and mediating factors.

Factors being explored include public education of the health risks caused by climate change, promotion of personal behaviours to reduce environmental exposures, reviews of health-service planning and

allocation of resources to cope with the increases in climate-related hospital presentations, and upgrades in public housing to protect children from climate threats.

These initiatives aim to offer tangible, community-specific strategies to mitigate the adverse impacts of climate change on children's health.

Dr Weeda said that without proactive measures, the social, financial, and health costs would escalate, leaving our children at increasingly higher risk.

"As we face the future, the imperative is clear: take action now to protect the health of the most vulnerable among us."



Dr Weeda's paper titled *How climate change degrades child health: A systematic review and meta-analysis* was published in *The Science of the Total Environment* and was supported by Population Matters. Dr Weeda received funding from The University of Western Australia 'Scholarly Plus' scholarship in support of his research.



Dr Lewis Weeda



# THANK YOU

We thank all our generous supporters - all of the individuals, corporates, trusts and foundations - who help deliver and drive our research impact so we can continue to make a difference for children, young people, families and communities. We simply could not do it without you.

Our longstanding partner, Telethon, continues to achieve remarkable levels of community engagement and support, and we are humbled to be one of their many beneficiaries. We are grateful for the enormous support they and all our supporters have given us over the years.

Read more about the philanthropy that supports our work in our Annual Report: [thekids.org.au](http://thekids.org.au)

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

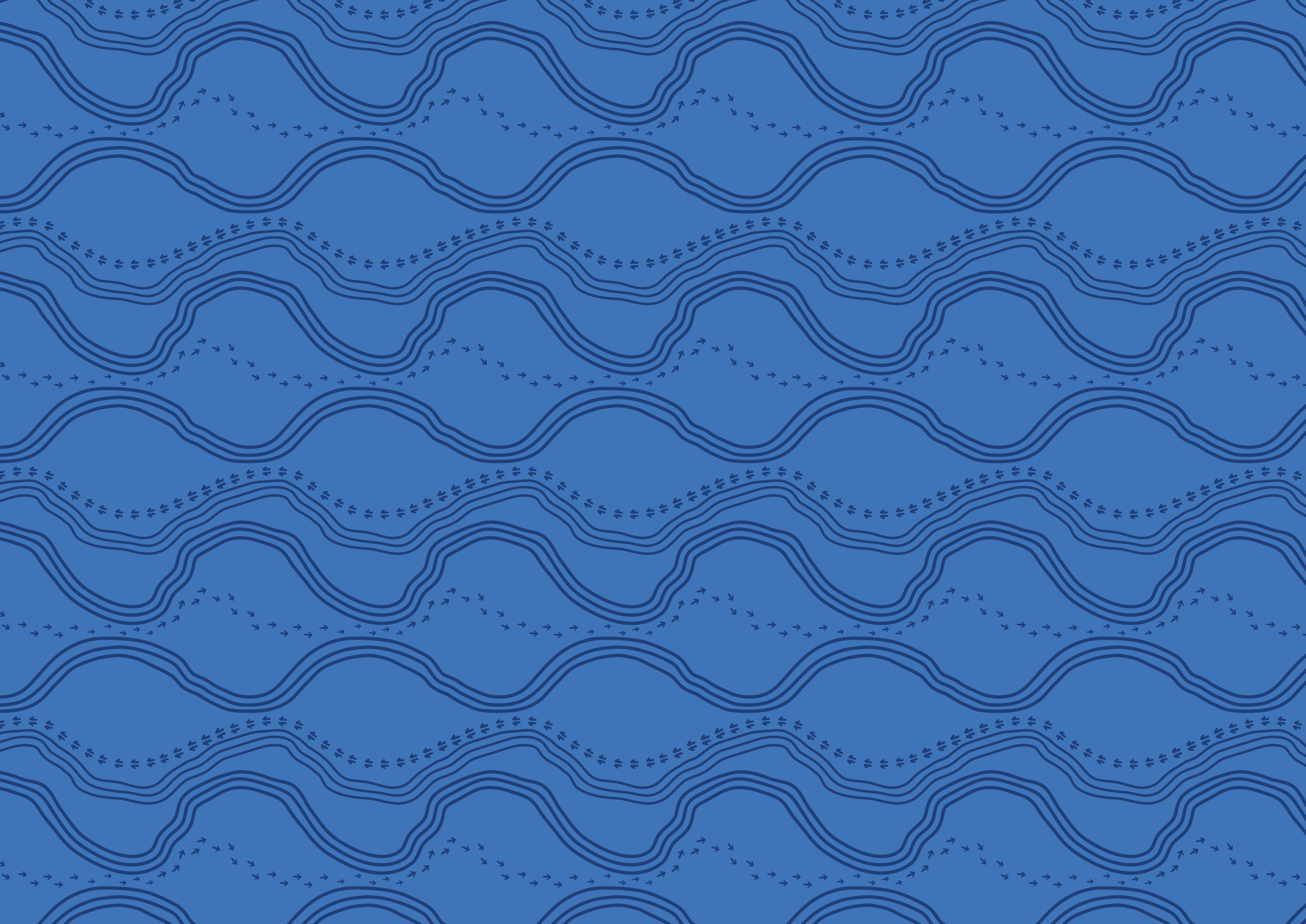
T | 08 6319 1000

E | [contact@thekids.org.au](mailto:contact@thekids.org.au)

W | [thekids.org.au](http://thekids.org.au)











Northern Entrance, Perth Children's Hospital,  
15 Hospital Avenue, Nedlands WA 6009  
PO Box 855, West Perth Western Australia 6872  
T | 08 6319 1000  
E | [contact@thekids.org.au](mailto:contact@thekids.org.au)  
W | [thekids.org.au](http://thekids.org.au)