

# Birth of a new era



Research reimaged at The Kids



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Cover image: Professor Jane Pillow with preterm baby Dan Alistair Amado, who is part of a study led by The Kids investigating whether an inexpensive set of eye masks and ear plugs could hold the key to better outcomes for babies born too soon

This page: Co-Head of Brain Tumour Research, Associate Professor Raelene Endersby (left), with Senior Research Fellow Dr Jess Buck

# Solving the biggest challenges to the health and happiness of kids everywhere

The Kids Research Institute Australia’s purpose is to find solutions to improve the health and happiness of children and young people everywhere.

We work hard to address the challenges that are specific to kids and our job is not done while there remain opportunities to improve young lives.

For more than three decades, the Institute has been at the forefront of cutting-edge science that has led to new discoveries, preventative treatments and advances in cures for some of the most baffling childhood diseases.

Throughout this time, Telethon and the Western Australian community have been constant supporters of our work and mission.

Since our beginnings as the first child health-focused research organisation in Western Australia to the world-class institute we are today, Telethon has been by our side.

That will not change. Our new name reflects the fact that The Kids, as we will be known, and Telethon, are independent entities, linked by a shared aim to improve the lives of children.

The Kids is part of a national and global research ecosystem. The significance and breadth of the research we do to deliver better outcomes for kids stretches well beyond our state border.

Throughout its history, The Kids has been at the forefront of some of the most significant advances in child health.

Our researchers confirmed the importance of folate during pregnancy to prevent neural tube defects in newborns and they have unlocked the key to slowing the progress of childhood leukaemia. They have developed national guidelines to assess autism and provided crucial evidence to guide immunisation programs for the potentially deadly respiratory syncytial virus.

Our new name and brand align with the launch of our 10-year strategy - ‘Research Reimagined’ - which sets out a comprehensive plan for even greater impact in the years ahead.

This is not something we can, or want, to do alone. Working alongside community and partners is a key driver of our strategy.

Over the next decade and beyond, we will focus our research on solving priority problems facing kids’ health, across the globe. This includes work on a vaccine for Strep A, one of the world’s deadliest pathogens, developing kids’ cancer treatments that are more effective and less toxic, and bringing together international leaders in the field of neuro-disability to identify high-risk children in their first months of life to receive early, evidence-based support.

Critically, we will continue to have an overarching commitment to address the health and wellbeing of Aboriginal children and families, informed by, and in genuine partnership with, First Nations communities and leaders.

To reflect this commitment, The Kids’ new branding encompasses an Indigenous theme of family, country and culture.

Our new brand continues to place kids at the forefront of everything we stand for. That is what drives all of us at The Kids.



**Professor Jonathan Carapetis AM**  
Executive Director

**Naomi Flutter**  
Chair

# OUR HISTORY

**JUNE - The WA Research Institute for Child Health** is officially opened. Fiona Stanley is the inaugural Director of the Institute



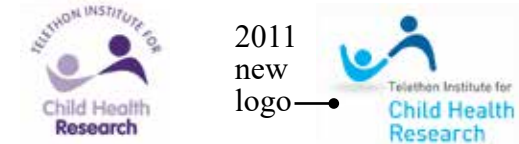
1980s

- Princess Margaret Hospital and The University of Western Australia executives meet to discuss the need for a **child health research unit**.

1990

- Working party formed, chaired by Lou Landau, to consider establishment of an **independent research institute**.

- Paediatrician Lou Landau and epidemiologist Fiona Stanley** envision a multidisciplinary institute for scientists, researchers and clinicians to investigate the causes, prevention and management of childhood diseases and disability.



2011 new logo

1994

**MARCH - The Institute changes its name to the Institute for Child Health Research**

1995

**JUNE - The Institute changes its name to Telethon Institute for Child Health Research** in recognition of the ongoing support from Western Australians through Channel 7's Telethon

1997

**JULY - The Institute raised \$11.2 million dollars, matched by both State and Federal Governments to build a new home at 100 Roberts Road, Subiaco**



2000

**SEPTEMBER - Governor-General, His Excellency Sir William Deane** officially opens the **Roberts Road building**



2011

**JULY - Plans announced to build a state-of-the-art research facility for the Institute within the new children's hospital on the QEII Medical Centre site**



**JULY - Jonathan Carapetis** is appointed the Institute's new Executive Director



2012

**DECEMBER - Fiona Stanley** retires

2014

**FEBRUARY - The Institute changes its name to Telethon Kids Institute**



2018

**SEPTEMBER - The Institute moves to its new home at the new Perth Children's Hospital**



2023

WA Governor Chris Dawson and Mrs Darrilyn Dawson become Patrons of the Institute

2024

**AUGUST - The Institute changes its name to The Kids Research Institute Australia, to be known as The Kids**



**NOVEMBER - Telethon Kids Institute** together with **Telethon Speech and Hearing** and **Telethon**, announce that by mutual agreement, both organisations will stop using **Telethon** in their name. This reflects the growing reach and number of beneficiaries of Telethon



## Premier's foreword

For more than three decades Western Australians have been justifiably proud of the ground-breaking research undertaken by the Telethon Kids Institute.

Since 1990 it has grown exponentially in impact and stature. The Institute's research findings have helped kids not just here in WA, but across Australia and globally, and its reputation as a leader in the sector has attracted some of the brightest minds in the field to live and work in our State.

The list of new discoveries and treatments is impressive. From helping kids with respiratory conditions to breathe easier to saving the lives of some of our sickest children who have battled cancer, and reducing neural tube defects in babies with their world-leading work on the importance of folate, Telethon Kids has truly led the way.

Perhaps most compellingly, since its inception Telethon Kids has been committed to working in partnership with communities to address the ongoing disparity in outcomes for Aboriginal children compared with other Australian children.

My Government recognises and supports the role that cutting-edge research has in improving the lives of West Australians. Just recently the Institute's research on the respiratory syncytial virus (RSV) – the leading cause of infant hospitalisation in the country – helped inform our decision to introduce the Australia-first \$11 million immunisation program for babies to protect against the disease.

We are excited to see what comes next for the Institute as it launches an ambitious impact-focused strategy and a new brand – The Kids Research Institute Australia.

I have every confidence The Kids will continue to make Western Australians proud of the home-grown research making a difference to the lives of kids everywhere.

We both applaud and embrace The Kids' 10-year Strategic Plan to Reimagine Research to pursue new breakthroughs and deliver innovative solutions to the biggest challenges to the health and happiness of kids.

My Government is fully committed to supporting medical research in this State as a means to ensure improved health for Western Australians, and as a critical pillar of our diversified economy. In 2020 we established the Future Health Research and Innovation Fund to ensure WA has the capability and expertise to capitalise on health and medical research innovation opportunities.

Nearly \$250 million has been allocated over the next four years to support health and medical research and innovation in our State.

On behalf of all Western Australians, I congratulate and celebrate The Kids Research Institute Australia as it embarks on this next phase to achieve its vision of happy, healthy kids.

**Hon Roger Cook MLA**  
Premier, Western Australia

# Telethon tees off a lasting legacy for child health research in WA

It all began over a game of golf.

While walking the fairways nearly six decades ago, two men - Sir James Cruthers, the then Managing Director of Channel 7, and Jim Clarkson, CEO of Princess Margaret Hospital for Children (PMH) - discussed the concept of a 'telethon' to raise money from the community for research at PMH.

The following year, in 1968, Telethon was established by Sir James and his colleague Brian Treasure.

From humble beginnings Telethon has gone on to raise more than half a billion dollars for medical research into childhood diseases, as well as equipment, critical services and opportunities for WA children.

More than a fundraiser, generations of West Australians have grown up with Telethon and each year it unites the community through an unwavering spirit of generosity.

Channel 7 Telethon Trust Chair Richard Goyder AO said the Institute continued to be one of the biggest beneficiaries of the Telethon Trust and received funding for a range of its research work and projects.

"Channel 7 Telethon's fundraising results, thanks to the generosity of Western Australians, has enabled Telethon to support quality research at the Institute for more than 30 years as part of our commitment to improving the health and wellbeing of sick and vulnerable WA children," Mr Goyder said.

"Telethon looks forward to seeing the research work continue with a focus on making breakthroughs on childhood diseases and delivering outcomes for the WA community."

Professor Fiona Stanley AC, Patron of both The Kids Research Institute Australia and Telethon, said the funds raised in those early years helped build many child health research careers.



Channel Seven's Basil Zempilas and The Kids Executive Director Professor Jonathan Carapetis at Telethon in 2018



The Kids researchers Associate Professor Francis Mitrou and Professor Asha Bowen and The Kids Head of Kulunga Cheryl Bridge with Fat Cat

"Telethon originally supported my research into cerebral palsy and neural tube defects," Professor Stanley said. "Telethon was supporting many of the outstanding researchers working in child health in WA in the 1970's and 80's and helped us to build a critical mass of scientific talent that attracted others to the State."

When the Institute was formed in 1990 – bringing all of these researchers and more under one roof – Telethon continued to support research projects as well as running costs and infrastructure.

Professor Stanley said Telethon has played a critical role in supporting innovative research which has made a difference to the children of WA and beyond.

"Telethon's support over the course of more than 30 years has led directly to ground-breaking research into childhood cancer, funded research which has led to new therapies for ear infections – a major cause of childhood hearing loss - and funded pivotal trials contributing to the licensing of more than 10 childhood vaccines."

Telethon now supports 136 children's charities, beneficiaries and community organisations.

While together they have agreed that it's time for the Institute's name to change to reflect the growing scale and scope of both organisations, the relationship remains strong and focussed on the future.

# OUR IMPACT

In its simplest form, science is about asking questions and finding answers. But it's what we do with those answers that truly make a difference. At The Kids Research Institute Australia, we want our research to have impact so we can change the lives of children and young people for the better.

DISCOVER • PREVENT • CURE

## CHILDHOOD SARCOMA



World-first immunotherapy gel applied inside wound after removal of solid tumours showing promising results in reducing recurrences



## HEALTHY SKIN

Developed national healthy skin guidelines to guide diagnosis and treatment of skin sores, scabies and fungal infections



## DEVELOPMENTAL DELAYS

Game-changing early intervention program for children showing neuro-development delays



## INFANT LEUKAEMIA

Survival improvements of 50-80% using new immunotherapy in combination with standard-of-care chemotherapies



## EAR INFECTIONS

Nasal therapy to prevent childhood ear infections – which are the major cause of childhood hearing loss



## CYSTIC FIBROSIS

Led paradigm-changing discoveries that lung changes can be detected early in CF, changing life trajectories with early interventions



## RHEUMATIC FEVER

Developing a diagnostic test for RF instead of current diagnosis based on clinical features

## RSV



Took part in two game-changing trials investigating a world-first RSV immunisation for babies.

Our epidemiological research helped identify best immunisation targets for Australian-first immunisation program for babies



## VACCINES

Conducted pivotal trials that contributed to the licencing of more than 10 childhood vaccines



## STREP A VACCINE

Leading the world in developing a platform to accelerate vaccines for Strep A



## PLAY ACTIVE

Evidence-based program of physical activity for childcare centres launched nationally



## EARLY YEARS CENSUS

Led the development and adoption of first national census of early childhood development



## RHEUMATIC HEART DISEASE

Developed a blueprint for eliminating RHD in Australia



## CEREBRAL PALSY

Developed the first cerebral palsy register in Australia



## CHILDHOOD BRAIN CANCER

Led trans-Tasman clinical study to validate a new diagnostic test for kids with brain cancer to better understand genomic characteristics of tumours



## SUICIDE CLUSTERS

Spatial epidemiology used to identify suicide clusters



## CYBERBULLYING

Developed Beacon – a cyber safety app for parents



## AUTISM

Key role in the development of national guidelines to assess and diagnose Autism Spectrum Disorder in Australia



## CHILD DISABILITY

Broke the mould for how quality of life is measured in intellectual disability



## RARE AND UNDIAGNOSED DISEASES

Pioneering genomic interrogation tool integrated into a national initiative, aiming to elevate diagnostic rates for rare diseases to over 70%



## TYPE 1 DIABETES

First in Australia to introduce insulin pump therapy to children with diabetes. Now at the international forefront of trials of an artificial pancreas



## PERIOPERATIVE CARE

Developed chewable tablets giving children sensation of a full stomach to reduce stress of fasting before surgery



## MALARIA

Using cutting-edge geospatial modelling to track and monitor malaria to inform control interventions, policies and programs



## FETAL ALCOHOL SPECTRUM DISORDER

Developed and implemented a diagnostic tool for fetal alcohol spectrum disorder in Australia



## FOLATE

Helped discover that folic acid in a mother's diet before and during pregnancy helps prevent neural tube defects



## RESPIRATORY DISEASE

Demonstrated the important role of safe sun exposure and Vitamin D during pregnancy for the development of a baby's lungs, brain and bones



## VAPES

Found the majority of e-cigarettes contained known lung toxins and potential carcinogens



## SUPERBUGS

Opened WA's first phage manufacturing facility which could see patients battling antibiotic-resistant superbugs have access to life-changing therapies



## SCREENTIME

World-leading study found toddlers exposed to screentime at home are hearing fewer words and making fewer vocalisations



## VIRTUAL WA

Developed a digital replica of the State to inform public health policy on matters including asthma, obesity and suicide



Professor Melissa Penny and Professor Pete Gething

# World-leading global health researchers call Perth home

## They are leaders in their fields.

A year ago Professor Melissa Penny was based at the University of Basel in Switzerland where her team used complex mathematical modelling to identify what vaccines, medical interventions and treatments are needed, and where, to save lives against diseases such as malaria. Governments, global health organisations, funders, and pharmaceutical giants are guided by her work.

Until 2019, Professor Pete Gething was at the University of Oxford in England leading a geospatial intelligence and epidemiology project working with the World Health Organization to stamp out malaria in Africa. The preventable disease killed more than 600,000 people in 2022, with children aged under five years accounting for three quarters of those deaths.

Now, the pair and their families call Perth home after they relocated their life's work to The Kids Research Institute Australia.

"The breadth and diversity of research being undertaken at The Kids, the professional support services offered to research teams and the Institute's commitment to embedding community into every aspect of its work is world-leading," Professor Gething said.

According to Professor Penny, who is the inaugural Fiona Stanley Chair of Child Health Research at The Kids and The University of Western Australia, The Kids Research Institute Australia is the envy of the world.

“The way the Institute is working to close the health equity gap between Aboriginal and non-Aboriginal kids and integrating that across every part of research is very powerful,” she said.

"Many organisations have not even touched on five per cent of the work that The Kids is doing in this space."

The Kids Executive Director Professor Jonathan Carapetis said the Institute had built its reputation on conducting research in genuine partnership with kids, community and families at its heart.

"That sets us apart from others in the sector," Professor Carapetis said. "Working directly with people with lived experience and providing researchers with professional service support ensures the research we undertake is not only meaningful but embraced by our stakeholders."

At The Kids, Professor Penny heads the Intervention and Infectious Disease Modelling Team. Their work focuses on using mathematical models which ask 'if we use a new drug or vaccine, how many lives will it save and how will it impact the transmission of disease?'

"We use this research to inform pharmaceutical companies, drug developers, funders and governments about where to focus and to support policy making within the global health community and at a World Health Organization level."

Professor Gething is the Kerry M Stokes AC Chair in Child Health and Professor in Epidemiology at Curtin University and The Kids and the Program Head for Child Health Analytics.

With the pandemic impacting soon after he moved to Perth, he quickly mobilised his team to work on data modelling to inform National Cabinet and the State Government on their COVID-19 response.

They are now applying data analytics to Western Australian public health concerns. "We have an amazing opportunity to use our techniques to address health challenges such as infectious diseases, asthma, childhood obesity, developmental delays and mental health and understanding where we need to target vulnerable populations," Professor Gething said.

"Modelling is an incredibly powerful way of asking 'what if' and answering questions regarding what would happen if we acted in one way or another. It's very empowering for decision makers."

Professor Penny said the innovative modelling and data analytics tools developed for infectious diseases and global health were incredibly powerful, driving health improvements across populations in WA and worldwide.

"The Kids is leading the way in applying these cutting-edge approaches," she said.

# Aboriginal health a priority at The Kids

The disparity in health outcomes for Aboriginal children compared with other Australian kids drives every medical scientist at The Kids Research Institute Australia.

“It is simply not good enough that in 2024 the death rate for Aboriginal children aged zero to four years-old is more than two times the rate of non-Indigenous infants,” The Kids Director of First Nations Strategy and Leadership, Associate Professor Glenn Pearson said.

“This statistic is carried through at almost every age and stage of First Nations people’s lives. At The Kids we are working extremely hard to reverse this trend.”

From preventing sore throats and skin sores caused by streptococcal A to the most cutting-edge advances in genomic medicine, the health and wellbeing of Aboriginal children and families is embedded across all research areas.

Critically, The Kids engages with Aboriginal communities at every step of the research journey.

Considered the gold-standard in connecting community before, during and after research projects are undertaken, Aboriginal community engagement is led by The Kids Kulunga team.

“We provide support, advice and community navigation for all researchers to ensure that their project responds to community needs and meets standards for Aboriginal health research,” Head of Kulunga Cheryl Bridge said. “We work really closely with Aboriginal communities to build their awareness and understanding about the research so they feel comfortable participating with the important work being carried out.”

The non-negotiable community-led approach can be seen in action in Perth where community co-designed research is working alongside advocacy and action, and through The Kids Journey Together Initiative in WA’s north-west.

The BHP-funded groundbreaking partnership between communities, researchers and local services is designed to develop a deep understanding of what’s needed, and what works, to grow strong healthy kids.

In Newman and Western Desert communities, the Puntukurnu Aboriginal Medical Service has been working to address problems impeding women’s pregnancy journey and a safe and healthy start to life for their babies. The project team is implementing a system of perinatal care and early childhood development support through family support workers, midwives, child health nurses and general practitioners.

The Julyardi Aboriginal Corporation in Port Hedland is providing wraparound support for disadvantaged Aboriginal families needing help navigating employment, housing, health and family support services. The aim of the project is for at-risk families with one or more children under five years to achieve the goals they have identified as important for their family and increase empowerment, self-efficacy and family safety.

And in Perth, Derbarl Yerrigan Health Service has developed a paediatric service unit to provide Aboriginal children with timely and equitable access to specialist paediatric care in a culturally safe and trusted environment.

“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 that we’re partnering with have identified key priorities and by embedding research into these projects we can have impact and evolve as we go.”

To understand what works for overcoming complex intergenerational poverty and trauma, and also to see change, Journey Together is intended to continue working with families and collecting data for at least 20 years, when the young children in the participating families become parents themselves.

Findings from the WA Aboriginal Child Health Survey, the largest cohort study of its kind when it started 25-years ago, will be revisited as part of the Journey Together initiative.

“This will give us significant insights into whether much has changed since the study was done,” Associate Professor Pearson said. “It will allow us to go back to the community and connect the dots because, fundamentally, this is their story.”



Connecting with communities and families is a non-negotiable part of The Kids research in Aboriginal health. From top to bottom, Isla Bernard, 8, Albie Morgan-Tory, 8, Shanara Bedford, 10, Te-Aranga Morgan, 6, and Ripeka Morgan, 5.

# Improving life trajectory for kids with developmental 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 communication partner for their baby.

Launching 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.”

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.

"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."

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 the Child and Adolescent Health Service, which found improvements in parent-child interactions and children's language skills.

Professor Andrew Whitehouse, the Angela Wright Bennett Professor of Autism Research at The Kids, said the key to the program was it was carried out by caregivers, who were the most important people in their baby's life.

To find out more about Inklings visit [inklings.org.au](http://inklings.org.au)



Patricia Macchiaverni with her daughter, Lara

# Globally unique study helps premature babies learn the rhythm of life

**An international study led by The Kids Research Institute Australia is using an inexpensive set of eye masks and ear plugs to teach babies born too soon how to tell night from day – a simple skill which could have lifelong implications for their health and development.**

Led by Professor Jane Pillow, the CIRCA DIEM study aims to kickstart premature babies' circadian rhythms – internal body clocks which govern everything from our sleep and body temperature to our appetite, metabolism, mental health, immune system, and ability to think.

"Circadian rhythms are vital for growth and development and typically develop in the latter stages of pregnancy, shortly before birth," Professor Pillow said. "Preterm babies are born before that intrinsic rhythm has developed, when they're still reliant on their mother's circadian signals – then suddenly those signals aren't there anymore.

"Many of these babies, some born as early as 24 weeks, go on to be cared for in noisy hospital environments with constant lighting for months – and we know from recent studies that in this environment they don't develop a circadian rhythm before they go home.

"That's a concern, given disrupted circadian rhythms are associated with a range of health issues including increased infections, cardiovascular disease, obesity, metabolic syndrome, motor problems, behavioural issues, neuropsychiatric conditions, and cancer."

The CIRCA DIEM trial started in 2019 at the Child and Adolescent Health Service (CAHS) Neonatal Intensive Care Unit (NICU) based at King Edward Memorial Hospital (KEMH), expanding to multiple NICUs across Australia and New Zealand in 2021 to become the largest and most comprehensive study of its kind in the world.

**CIRCA DIEM** involves researchers from **The Kids and hospitals around Australia and New Zealand**, with King Edward Memorial Hospital and Fiona Stanley Hospital the main recruiting sites in WA



Preterm baby Dan Alistair Amado, born at 30 weeks, is part of the CIRCA DIEM study

Five hundred and forty-five of a planned 954 babies have been enrolled, with the CAHS NICU at KEMH the lead enrolment site. Additional sites are expected to come on board in Canada and Sweden.

Half the participating babies are fitted with eye masks and ear plugs every night while in hospital, then exposed to more light during the day so their brains clearly register the difference, while the other half receive routine care. Regular follow-ups throughout early childhood will help the research team determine how the intervention impacts on the children's health and development over time.

“Premature babies are at increased risk of just about everything, especially infections,” Professor Pillow said.

Jamyka Amado, mother of little Dan Alistair Amado – born at KEMH this month at just 30 weeks – said having her son arrive so early had been scary, leaving her worried for his future development.

"The hospital is noisy, with lots of beeps and lights, but when we have seen him with the mask and ear plugs he has been sound asleep and very comfortable."

Globally, more than **14 million babies** are born preterm – before 37 weeks



– every year

**22,053 preterm babies** (8.2% of all births) were born in Australia in 2022, including 3,083 (9.5%) in **Western Australia**







Angus Hollington

# Team WA leading the mission to see kids with cancer survive and thrive

Game-changing research and treatment breakthroughs in childhood cancer will be made possible thanks to one of WA's biggest ever philanthropic gifts.

The Stan Perron Charitable Foundation will contribute \$135.5 million over the next decade to a multi-partner collaboration led by The Kids Research Institute Australia and Perth Children's Hospital (PCH), which aims to improve outcomes for kids with cancer through the discovery of more effective and less toxic treatments.

The Perth Children's Hospital Foundation will also make a multi-million dollar contribution over the next five years and The University of Western Australia will add up to \$9 million to help improve the lives of kids impacted by cancer in WA and across the globe.

Cutting-edge laboratory and clinical research has been shown to improve short, medium, and long-term patient outcomes through seamless integration between researchers and clinicians.

Importantly, it can immediately translate into improved treatment, survival and whole-of-life outcomes for patients. While this is already happening at The Kids and PCH, the initiative will give the work a longer-term future, underpinned by sustained funding instead of short-term, project-based grants.

Professor Nick Gottardo, Head and co-lead of The Kids Cancer Centre Brain Tumour Research Programme, said in the past 70 years only 50 new drugs had been approved to treat paediatric cancers, whereas for adults 60 cancer drugs are approved every year.

"Current treatments for kids' cancer cause severe and often lifelong side effects including problems with emotions, reproduction, growth, development, hormones, learning, memory problems, heart, lung, digestive system, hearing, vision and most strikingly, can cause secondary cancers," Professor Gottardo said.

The experience of Angus Hollington, 21, shows exactly why we need to do more for kids with cancer. He spent nearly half his life as a childhood cancer patient, surviving two separate bouts of cancer: first, Ewing's Sarcoma, an aggressive cancer of the bone and tissue diagnosed when he was 11; and then at 16, Acute Myeloid Leukaemia caused by the chemotherapy used to successfully treat his Ewing's.

By the end of that second round, he was an amputee – the leg that had been saved at such a heavy cost during his first bout of cancer finally succumbing to a nasty infection.

"Realistically for me I was kind of happy they got rid of it," he says now. "For six years it caused pretty much every problem I had. So yeah, while I don't have a leg, I survived two cancers – I'll take that."

Professor Gottardo said the funding would give WA researchers the chance to build on the world-leading work already being undertaken.

"It will advance our pre-clinical discovery pipeline to significantly improve outcomes for kids yet to be diagnosed with cancer, to discover more effective and less toxic treatments that will be adopted worldwide and to improve the lives of kids impacted by cancer globally. Our vision is for all kids with cancer to survive and thrive."

Chair of the Stan Perron Charitable Foundation, Elizabeth Perron, said the intent and objectives of the WA Comprehensive Kids Cancer Centre aligned perfectly with the intent of the Foundation established by her father.

"The Foundation's guiding principles for giving expressly target any activity that improves the health and well-being of children in Western Australia," Ms Perron said.

Key local partners also include the Harry Perkins Institute of Medical Research, Sir Charles Gairdner Hospital, Linear Clinical Research, and the Cancer Council of Western Australia.

1,240 Australian children and teens will be diagnosed with cancer this year



Most current standard treatments of paediatric cancer were approved more than 30 years ago



Cancer is the leading cause of death by disease for Australian children



There are more than 12 major types of paediatric cancers and more than 100 sub-types



In 2024, 143 children and adolescents (0-19 years) will die from cancer in Australia



# Clinical trials a game-changer for potentially deadly winter virus

**When identical twins Henry and Archie Cooper turn two next month it will be an extra special celebration – it’s a milestone their parents worried they wouldn’t reach after a close call with respiratory syncytial virus (RSV) at just seven weeks of age.**

The respiratory infection, responsible for 3.6 million hospitalisations and 100,000 deaths globally each year, left the two tiny newborns hooked up to machines and struggling to breathe.

The Woodlands family’s ordeal in October 2022 began when mum of four, Alice Hug, noticed the twins were congested and having trouble feeding.

“Henry started sucking in his chest to breathe, so we rushed him straight to Perth Children’s Hospital. They put him on high-flow oxygen and inserted a feeding tube, and I slept in a chair holding him upright for four nights,” Ms Hug said.

“I was breast-feeding the twins, so Archie boarded at the hospital at the same time and was also experiencing RSV symptoms. We took the babies home when Henry was discharged, but just eight hours later Archie’s condition took a turn for the worst and we had to go back for a second, four-night admission.

“Archie ended up being hardest hit by the virus,” Ms Hug said. “He wa in such a bad way that he was almost transferred to the intensive care unit – that’s when I really started to panic. The whole experience was absolutely devastating – it was awful watching my brand-new babies relying on machines .to breathe.” Ms Hug said.

Professor Peter Richmond, Head of the Vaccine Trials Group at the Wesfarmers Centre of Vaccines and Infectious Diseases, based at The Kids Research Institute Australia, Head of Paediatrics at The University of Western Australia and Head of Immunology at Perth Children’s Hospital, treats the 650–800 Western Australian babies and young children admitted to hospital with RSV each winter.


“With no vaccine available to prevent this deadly virus, Professor Richmond and his team have spent the past 25 years collaborating on the global effort to develop a world-first RSV immunisation for young babies.


Their dedication finally paid off in 2022, when two game-changing clinical trials investigating a long-acting antibody treatment for babies proved to be safe and effective at providing newborns with vital protection against RSV in their first 180 days of life.


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

“The findings led to the WA Government introducing Australia’s first ever RSV immunisation program in April this year, and we are already seeing hospitalisation rates for babies aged under eight months down by 30 per cent, and admissions for newborns like Henry and Archie 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.”

 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



Alice Hug with her identical twin sons Henry and Archie Cooper



Associate Professor Timo Lassmann

# Transforming child health with cutting-edge artificial intelligence

## Associate Professor Timo Lassmann is a data detective.

The computational biologist from The Kids Research Institute Australia uses his expertise in deciphering data to help researchers find answers to complex child health questions.

He has developed an innovative artificial intelligence (AI) algorithm that not only analyses vast amounts of health and biological data, but also predicts health outcomes accurately with an explanation of how it reaches those conclusions, crucial for medical decision-making.

“Traditional AI models – often referred to as ‘black boxes’ – deliver results without revealing the underlying reasoning,” explains Associate Professor Lassmann.

“Our algorithm takes this a step further by creating ‘white box’ programs, which not only provide accurate predictions but also make the decision-making process transparent and understandable.

“This allows researchers to trust and verify the AI’s recommendations so they can be confident in further investigation of the AI’s results.”

Professor Lassmann spent five years creating the AI model, resulting in computer code equivalent to a 4,000-page book.

**This AI capability is needed now more than ever as today’s technology – which can generate the complete genetic code for a human within hours for less than a thousand dollars – has resulted in an explosion of data with billions of pieces of health information about a single person.**

Rather than drowning in data, Associate Professor Lassmann is harnessing the power of AI to look for patterns within the data and pinpoint the biological markers for further investigation.

The AI model can be applied to a broad range of childhood diseases and has already helped in the search for a diagnostic test for rheumatic fever (RF).

Professor Jonathan Carapetis, The Kids Executive Director and an infectious diseases specialist, says no blood test currently exists to diagnose rheumatic fever.

“Doctors rely on clinical features and lab tests to diagnose RF and this can be inaccurate and result in patients not getting treated when they need it,” explains Professor Carapetis.

“Our team has been looking at kids with and without RF, plus those who may have other diseases that could be confused with RF, like flu or malaria, to see if we can identify the combination of proteins that separate those with RF from those who don’t. This gives us promising leads for the development of a diagnostic test.

“A manual analysis of data by some of our collaborators identified 20 possible proteins worth exploring. When Associate Professor Lassmann ran the data through his AI model, it identified lots of different combinations of proteins as well as telling us how closely they matched to RF,” says Professor Carapetis.

Associate Professor Lassmann’s AI work is helping to crack the complex codes that underlie many childhood diseases, paving the way for personalised treatments and interventions.

“Our AI tools help us decode the vast and complex information within our genes, and we believe this will lead to more effective and personalised healthcare solutions,” Associate Professor Lassmann explains.

“Through the power of AI, we can dive deeper into the data so we can understand and utilise it in new ways.

“In many cases, we’re looking for a needle in a haystack, and the AI technology is helping us find those unique biological markers – the ‘needles’ – which are hidden in the massive amount of data.

“Those ‘needles’ could hold the key to finding a new treatment or intervention that could change a child’s life.”

# Boosting cultural safety in mental healthcare for Aboriginal kids

**Displaying the Aboriginal flag or artwork and having Aboriginal staff would help alleviate fears of young Indigenous people regarding clinical healthcare services, a cultural safety project has found.**

The project identified that concerns regarding entrenched racism and biases and historical fears about the Stolen Generation were preventing Aboriginal young people from accessing mental health support services.

Preliminary thematic analysis also found that feelings of shame and stigma had created barriers to accessibility in these settings.

The project investigating the cultural safety of mental health services for Aboriginal and Torres Strait Islander youth has been undertaken by The Kids Research Institute Australia's Embrace team.

Young people taking part in the study – led by Palyku woman and Embrace Co-Director, Professor Helen Milroy AM – said cultural safety meant providing a sense of belonging, a sense of connection and a sense of trust.



Professor Helen Milroy AM

“There are some simple ways that we can address this immediately – things like having an Aboriginal staff presence in your workforce, and adding visual cues like artwork and the Aboriginal flag,” Professor Milroy said.

“But there is no quick fix here – fostering a relationship over time requires attentive listening and connecting over the young person's interests, such as sport or music. There should also be an expectation for non-Indigenous staff in mental healthcare settings to have an awareness of culture and to consult with their Aboriginal staff.”

Researchers including Lisa Kickett and Thomas Betts worked with Aboriginal communities, young people, and carers of young people with mental healthcare needs to make services more culturally safe.

Young people recognised the importance of nurturing the relationship with a mental healthcare professional to overcome obstacles such as distrust of clinical spaces. Aboriginal mental healthcare staff also suggested cultural safety needed to be better entrenched into their workplaces.

Other early recommendations to emerge include the embedding of cultural factors like kinship and Country into assessments, greater flexibility around engagement in locations young people are more comfortable, such as community centres, sports clubs and creative facilities, and recognition of the value of dadiri, or 'deep listening'.

In the second stages of the research project, due to wrap up by the end of the year, young people and families who have been through mental health services in Western Australia will be consulted further about their experiences.

**The project is receiving support from from the Child and Adolescent Mental Health Service, Derbarl Yerrigan Health Service, Yorgum Healing Services, The Kids Kulunga Aboriginal Unit and Langford Aboriginal Association.**

# The queen of common-sense backs The Kids Research Institute Australia

**Her words of wisdom have helped shape the lives of young ones for more than two decades.**

Now the legacy of beloved parenting author and educator Maggie Dent is set to live on well beyond her lifetime, thanks to a special relationship with The Kids Research Institute Australia.

For Ms Dent, her commitment is deeply personal.

The relationship began in 2003 with the release of Ms Dent's self-published book, *Saving Our Children from Our Chaotic World*. A portion of the book's profits was donated to The Kids, marking the start of a significant philanthropic bond.

Since that time Ms Dent has become a proud member of the Fiona Stanley Circle, a special group of supporters that are including a gift in their Will to The Kids – ensuring their support extends beyond their lifetimes.

Inspired by her admiration for The Kids Patron Professor Fiona Stanley AC, whose pioneering work sparked her own passion for empowering parents, Ms Dent's involvement is a testament to her dedication to improving the lives of children.

“I have an enormous passion for children who are vulnerable and struggling,” Ms Dent said.

“The more I learn about the incredible work coming out of this Institute, the more convinced I am that my support here is well placed.”

Ms Dent's connection with The Kids' mental health researchers has been particularly influential. She has consistently drawn on mental health research conducted and recommended by the team to inform and enrich her work.

Associate Professor Yael Perry, Program Head of Mental Health & Youth, along with the Embrace @ The



Maggie Dent

Kids team – Western Australia's pioneering research collaboration focused on the mental health of infants, children, and young people aged 0-25 – lent their expertise to Ms Dent for her latest book, *Help Me Help My Teen: Supporting Our Teens Through Tough Times*.

“I am so grateful that when I am researching a book, I know I can always reach out to The Kids to get current, well-researched knowledge that validates what really matters in raising happy, healthy kids,” Ms Dent said.

As Ms Dent's legacy continues to support parents and inspire us all, her enduring partnership with The Kids ensures that her passion and commitment to happy, healthy kids is making a difference.

## We think of the fingers, we think of the toes

We think of the eyes, we think of the nose

We think of the laughter, we think of the tears

We think of the tummies, we think of the ears

We think of the breathing, we think of the air

We think of equity, we think "What is fair?"

We think of the mind, we think of the brain

We think of the suffering, we think of the pain

We think of immunity, we think of the cure

We think of the newborns, we think premature

We think of the therapies, we think of the genes

We think of the future, we think of the teens

We think of the progress, we think of the scope

We think of the parents, we think of the hope.

We think of the kids. Every little detail.

Anything that might harm them

and everything that could help.

That thinking leaves the lab and changes the world.

It becomes treatments, medicines, policies and

programs for happier, healthier kids everywhere.

## Think of the kids

**The**  
**KIDS**  
RESEARCH INSTITUTE  
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