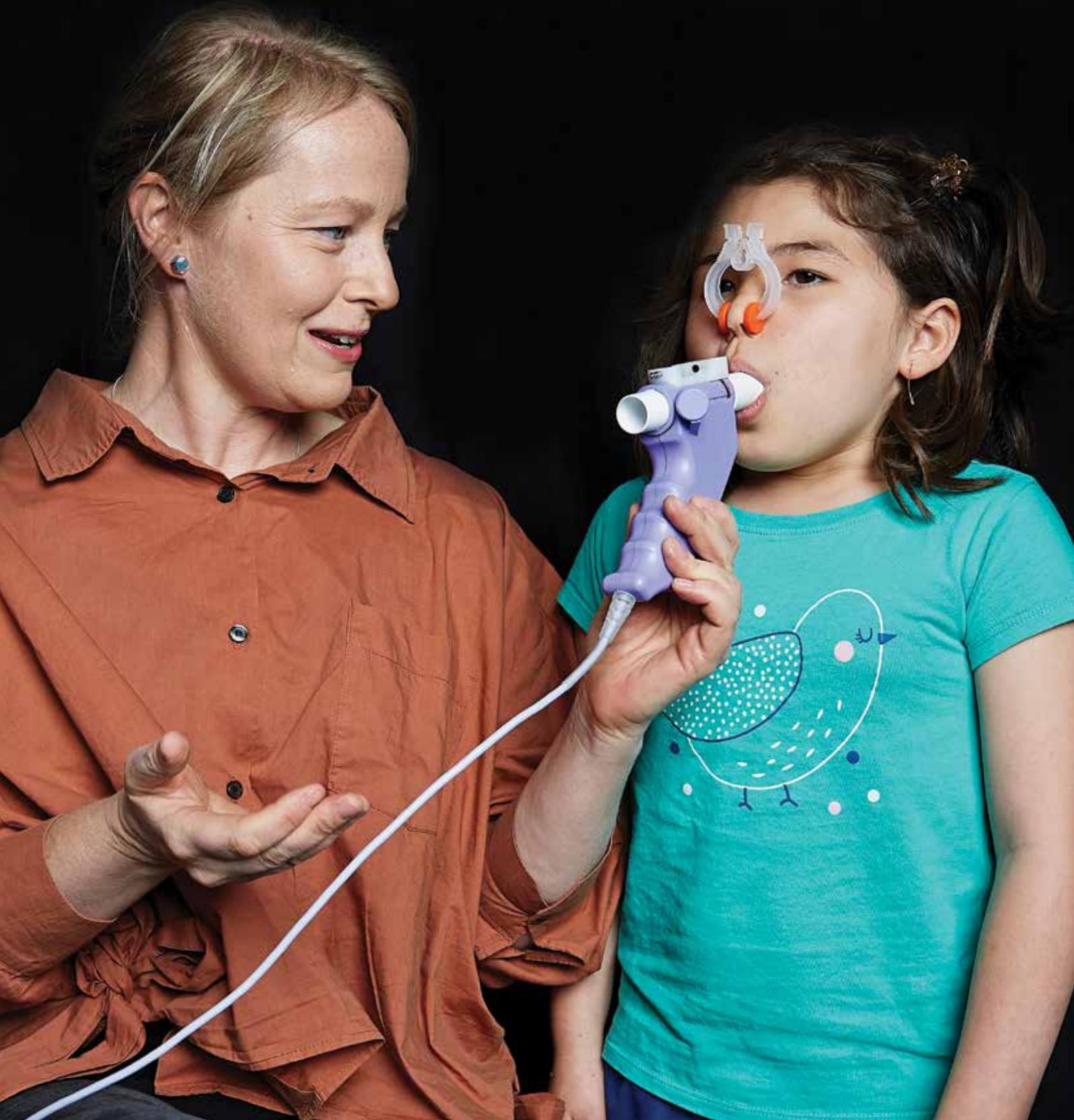




2021 IMPACT REPORT



TELETHON KIDS INSTITUTE

30 YEARS

OF HELPING KIDS BE KIDS

In 2020, we celebrated 30 years of making a difference.

And we did this with those who matter most — the kids whose lives we've changed through the research we do.

We told some of their stories and, in doing so, captured a small snapshot of the abundance of work we're doing, and remain committed to pursuing at Telethon Kids.

You can read their stories and get to know these amazing kids at telethonkids30.org.au. They'll change your life like they've changed ours.

They are the reason we keep asking and answering the difficult questions; we want to help kids here, and around the world, be just that — kids.



Ari (right), with his brother Ashton, is a whiz at Lego, X-box, cuddling and smiling. Read Ari's story at telethonkids30.org.au

Telethon Kids Institute 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.

Cover: Dr Shannon Simpson with Mia

2021 IMPACT REPORT

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

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MESSAGE FROM OUR DIRECTOR

Jonathan Carapetis AM



2020 was a year like no other. It was a year we witnessed a global pandemic stop the world in its tracks and a year where health – our own health and the health of our families and community – became a focus world-over. The COVID-19 pandemic taught the world something that we've always known – there is nothing more important for a strong, cohesive and thriving community, than our health.

It has been a global race for researchers and health experts all over the world, working together to find solutions to this deadly pandemic. And with some of the world-leading infectious disease experts right here at Telethon Kids Institute, our team has played, and continues to play, a vital role in this effort.

But we didn't let this detract from the important research we continue to do at the Institute, across an extensive spectrum of child health issues. Because day by day, month by month, year by year, our work must improve the health, development and lives of children and young people.

2020 also marked our 30th birthday at Telethon Kids Institute and we chose to celebrate this milestone with those who matter most – the kids whose lives we've changed through the research we do.

Research that has impact – that makes a difference to children, young people, families and communities – is the very reason we exist.

It's what drives our passionate and dedicated researchers to keep doing what they are doing.

And it's what brings community, researchers, practitioners, policymakers and funders around a shared vision of happy healthy kids.

In a year like no other, I am proud to present our seventh Impact Report. In this report, you will find many examples of how our researchers, and those with whom we collaborate, are affecting lives for the better. Some of the research featured is being put into practice in clinic and community while other research is in its impact infancy. Importantly, everything we do at Telethon Kids Institute is focused on impact – delivering an outcome that will change lives around the world.

We thank everyone who walks this path with us – our study participants, donors and funders, collaborators – as without you, we couldn't do what we do: asking and answering the difficult questions so we can help kids be kids.

To find out more about our research, I invite you to visit our website at telethonkids.org.au

A handwritten signature in blue ink that reads 'Jonathan Carapetis'.

Professor Jonathan Carapetis AM
Executive Director

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OUR AWARD- WINNING RESEARCHERS

The excellence of Telethon Kids Institute researchers has been recognised at multiple State and National awards ceremonies over the past year, including the Australian of the Year Awards, the Eureka Prizes, the Premier's Science Awards, the Tall Poppy Awards, and the annual Business News 40under40 Awards.



Professor Helen Milroy

Winner – Western Australia's 2021 Australian of the Year; co-winner – 2020 Australian Mental Health Prize

In November 2020 Professor Helen Milroy – a pioneering mental health champion and co-director of Embrace – was twice honoured when she was named WA's 2021 Australian of the Year and co-winner of the 2020 Australian Mental Health Prize within days of one another. Professor Milroy, a descendant of the Palyku people of the Pilbara region, was recognised for her ongoing contribution to improving health and mental health outcomes in Australia, particularly for Aboriginal people, children and young people. Professor Milroy holds multiple prestigious roles nationally and in WA. As well as being an Honorary Research Fellow at Telethon Kids, she is Stan Perron Chair of Child and Adolescent Psychiatry at the Child and Adolescent Health Service and The University of Western Australia (funded by Perth Children's Hospital Foundation).



Associate Professor Asha Bowen

Winner – 2020 Australian Museum Eureka Prizes

In November 2020 paediatric infectious disease expert and clinician-scientist Asha Bowen was named Emerging Leader in Science at the Australian Museum Eureka Prizes. Associate Professor Bowen, whose work is driven by a passion to reduce the heavy burden of skin sores for Aboriginal children living in remote areas of Australia, was recognised for her outstanding leadership qualities and patient care expertise when driving new skin health research. Associate Professor Bowen is Head of Skin Health at the Wesfarmers Centre of Vaccines and Infectious Diseases and an infectious disease paediatrician at Perth Children's Hospital. She heads a number of research projects – including the SToP Trial – in partnership with Aboriginal co-investigators, organisations, health workers and communities.



Associate Professor Chris Blyth

Finalist – 2020 Australian Museum Eureka Prizes

In September 2020 Associate Professor Chris Blyth – Co-Director of the Wesfarmers Centre of Vaccines and Infectious Diseases, based at Telethon Kids – was part of a group of Australian researchers named as a team finalist for the Australian Infectious Diseases Research Centre Eureka Prize for Infectious Diseases Research. The Australian Paediatric Influenza Immunisation Research Group built upon a decade of research to successfully advocate for the flu vaccine to be included on the National Immunisation Program for young children for the first time in Australia's history. The decision contributed to a dramatic increase in the number of children vaccinated against flu – from just 80,000 in 2017 to an estimated 1 million in 2020. The collaboration included the Wesfarmers Centre, WA Department of Health, UWA, the National Centre for Immunisation Research and Surveillance, and several others.



Associate Professor Hayley Christian

Winner – AIPS WA Tall Poppy Science Awards

In September 2020 Telethon Kids Institute and University of Western Australia physical activity researcher Hayley Christian took out the top prize at the Australian Institute of Policy and Science's WA Young Tall Poppy Science Awards, in recognition of her research focused on promoting more active childhoods. Associate Professor Christian was named WA Young Tall Poppy Scientist of the Year for her work investigating how interventions focused on the child, family, and social and built environments can improve children's physical activity, health and development. The Tall Poppy Science Awards are held on a state-by-state basis to celebrate researchers across science, engineering and mathematics and honour up-and-coming scientists who combine world-class research with a passionate commitment to communicating science.



Dr Chris Brennan-Jones

Winner – 2020 WA Premier's Science Awards; Winner – Business News 40under40 Awards

In September 2020 clinician-researcher Dr Chris Brennan-Jones, whose work focuses on improving outcomes for Aboriginal children suffering debilitating ear infections, was named Woodside Early Career Scientist of the Year at the 2020 Western Australian Premier's Science Awards. The honour came just two weeks after he won the Woodside STEM Award for Excellence in Science at the annual Business News 40under40 Awards. Both prizes recognised Dr Brennan-Jones' work in collaborating with Aboriginal community members to develop the Djaalinj Waakinj Ear Portal Program, which has changed clinical practice and slashed waiting times from two years to just 10 days. Dr Brennan-Jones is Head of Ear Health at the Wesfarmers Centre of Vaccines and Infectious Diseases and an audiologist at Perth Children's Hospital.



Dr Penelope Strauss

Finalist – 2020 WA Premier's Science Awards

In August 2020 youth mental health researcher Penelope Strauss was named a finalist in the ExxonMobil Student Scientist of the Year category of the WA Premier's Science Awards when she was a PhD candidate. Now a Research Fellow in Youth Suicide Prevention within the Youth Mental Health team at Telethon Kids, Dr Strauss's research is focused on suicide prevention in LGBTQA+ young people. As part of her research she led the ground-breaking Trans Pathways Study – the largest study ever conducted into the mental health of trans young people in Australia.



Dr Jess Buck

Science & Technology Australia Superstar of STEM

In December 2020 Telethon Kids Cancer Centre researcher, Kamilaroi woman and Forrest Fellow Dr Jessica Buck was named one of Australia's official Superstars of STEM for 2021-22. Sixty women working in science, technology, engineering and mathematics (STEM) disciplines across Australia are selected every two years to take part in the program, run by Science & Technology Australia to increase the public visibility of women in STEM and create role models for young women and girls. Dr Buck, a post-doctoral research associate with the Cancer Centre and UWA, was the first Aboriginal Australian woman to graduate from Oxford University with a PhD. Through her research she is working to find more effective and less damaging treatments for children's brain cancer.



Professor Elizabeth Davis

Recipient – Diabetes Australia Outstanding Achievement Award

In November 2020 Professor Elizabeth Davis, Co-Director of the Children's Diabetes Centre and Head of Endocrinology and Diabetes at PCH was one of three diabetes leaders to receive the Outstanding Achievement Award from Diabetes Australia. The Awards were announced on 2020 World Diabetes Day to recognise people who have demonstrated outstanding service and support for people with diabetes. The award recognises Professor Davis' internationally renowned research program in paediatric diabetes and obesity and her major role in developing and improving services and support for kids and families affected by diabetes across WA, Australia and internationally.

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Helping WA families navigate a global pandemic



It's hard to measure how much the COVID-19 pandemic changed our world. As the virus began to spread in early 2020, talk of a vaccine seemed like a pipe dream, but now Australia's vaccination roll-out is in full swing – a light at the end of a long, dark tunnel. Here's how the Telethon Kids Institute's advocacy, leadership and innovation is helping our community make sense of the shift to a new normal.

Our leadership – a seat at the table

As global vaccine developments started to ramp up, Telethon Kids Institute experts were closely influencing historic public health policy decisions. Associate Professor Chris Blyth is chair of the **Australian Technical Group on Immunisation (ATAGI)** – the group of independent scientists directly advising the Federal Government on the vaccination program. Our Director, Professor Jonathan Carapetis, is a member of the **National COVID-19 Health and Research Advisory Committee (NCHRAC)** and in 2020 chaired a sub-group of the Committee focusing on asymptomatic infections. Dr Asha Bowen is the Paediatric and Child Health Division representative on the **Royal Australasian College of Physicians COVID-19 Expert Reference Group**.



Associate Professor Chris Blyth



Professor Jonathan Carapetis



Dr Asha Bowen

Our advocacy – keeping the community informed

Throughout the pandemic, Telethon Kids Institute became a trusted source of independent information for families in Western Australia. In the media, our respected team of infectious disease experts was taking questions not only from journalists, but often directly from the public. Our youth mental health team shared tips for families with children who were anxious about the ongoing uncertainty. As the vaccine roll-out continues, Telethon Kids Institute is working with WA's many multicultural groups to spread the message to the state's Culturally and Linguistically Diverse (CALD) communities through a series of grass-roots public forums.

Our innovation – helping in the global research fight

The pandemic has brought the importance of cutting-edge medical research into sharp focus. At the Telethon Kids Institute, we are proud to be partnering in major global projects looking for new ways to tackle the virus. Professor Steve Stick and Professor Tobias Kollmann are examining the **use of Interferon** – a naturally occurring protein known to boost the immune system – to reduce the infectiousness of COVID-19 to slow its spread. The trial, known as CONCORD-19, is taking place in Chile as the country battles a surge in case numbers. Recruitment for CONCORD has finished, with 341 families recruited. The trial was made possible thanks to a \$2.6 million contribution from BHP Australia, with drug supplies kindly donated by Biogen. Results are expected later this year. The BRACE trial, supported by Minderoo Foundation, looking at whether an existing vaccine for tuberculosis can protect frontline health workers from COVID-19, has reached its final stage of data collection. Staff from hospitals across Perth were part of this global trial, with the Telethon Kids research group effectively becoming the 'control' group thanks to WA's very low rate of infections.

DETECT schools study

Telethon Kids Institute researchers worked with the State Government to **swab 13,988 students and staff at schools across the state to determine if there was any asymptomatic spread of COVID-19**. Children from Years 4-12 were given a less invasive but highly accurate swab over the course of 2020, with no cases of COVID-19 detected. These results in the early days of the pandemic helped parents, students and teachers return to the classroom with more confidence.

Understanding vaccine hesitancy

Telethon Kids Institute researchers led by Associate Professor Chris Blyth teamed up with The University of Western Australia for the '**Coronavax**' study – a survey to gauge community attitudes to the COVID-19 vaccine. The aim of the study is to work out why some people are more reluctant than others to roll up their sleeves, what their concerns are, and how public health advocacy can convince them to trust the science. Part of the research involves intensive monitoring of social media trends and how misinformation is spread online. The team is also partnering with the Commonwealth and State Government to inform more effective communication strategies.

Rethinking youth mental health service delivery

When the first lockdown hit in March 2020, WA's mental health service providers were forced to innovate quickly, switching many of their services to a telehealth model. Telethon Kids Institute researchers have evaluated that transition, finding the flexibility of telehealth was a big bonus for some young people. The '**Mind the Distance**' report found both face-to-face and telehealth options for mental health appointments should remain available after the pandemic is over.

Developing our understanding of the virus

The **Infectious Diseases Epidemiology Team** is involved in an international study comparing Influenza A to COVID-19. The study is focused on the southern hemisphere and is seeking to understand the natural history of both viruses, the spectrum of disease, risk factors for severe illness, and immune responses to the infections. The research team is following all children hospitalised with COVID-19 and Influenza A in Australia to try to understand which children get sick and what their illness is like. This will help develop understanding to better combat both viruses in the future.

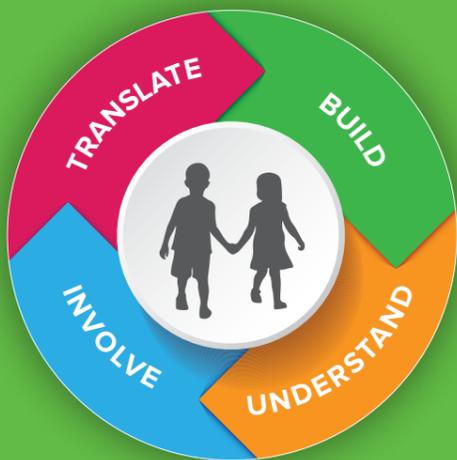
SPOTLIGHT PROJECTS

Mapping the spread

Dr Nick Golding from the **Geospatial Health and Development Team** is using advanced computer modelling to predict where and how a potential outbreak could spread. The team will provide the data in realtime to the State and Federal Health Departments – an important weapon in their arsenal to combat new outbreaks. Part of this study includes tracking how WA responded to regulations like mask wearing during the short lockdowns in early 2021 and monitoring the vaccine roll-out to determine which areas might still be vulnerable to COVID-19.

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OUR RESEARCH AT A GLANCE 2020



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

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



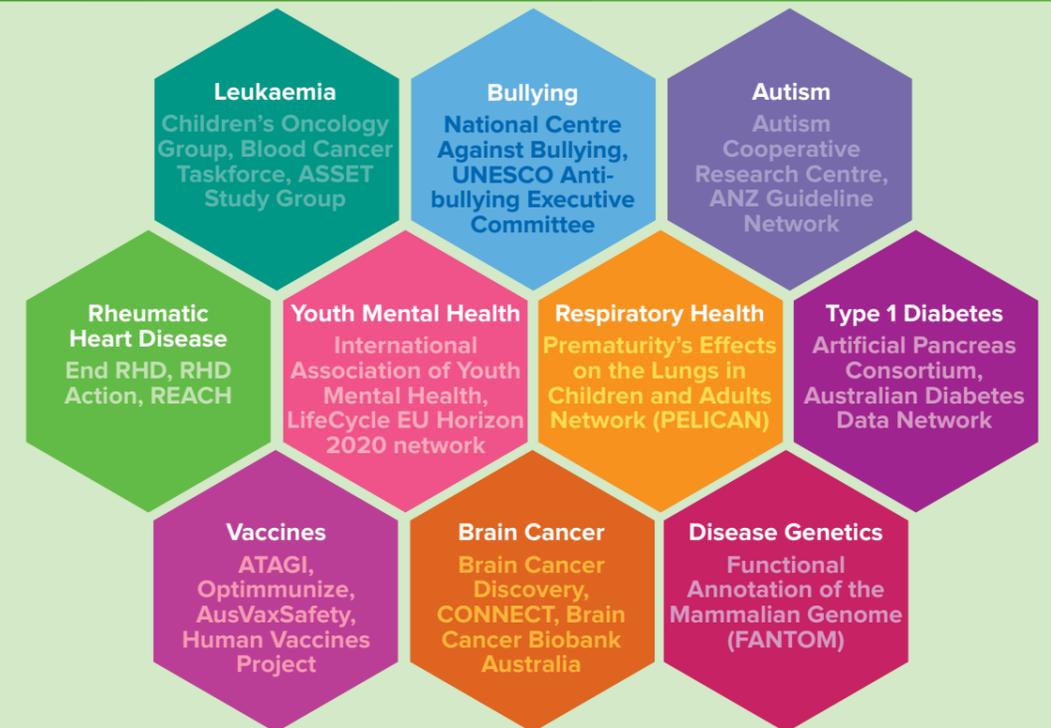
BUILD

RESEARCH CAPACITY BUILDING

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



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



We're helping to build the capacity of the medical research sector in WA by sharing our state-of-the-art facilities, equipment, technology and expertise

Researchers from **15** external organisations use our equipment and access our technical expertise including in **radiotherapy, microscopy, imaging, molecular biology** and **flow cytometry** for a range of projects in cancer, respiratory health, immunology, drug development, regenerative medicine and epigenomics.

In 2020, we had 179 students

24 Honours

19 Masters

9 MD

127 PhD



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

Enrolled through:

Curtin University	29
Edith Cowan University	5
Murdoch University	6
The University of Western Australia	129
University of Notre Dame Australia	2
Other	8
Total	179



Over the past 5 years

67 PhD STUDENTS

have successfully obtained their DOCTORATE

UNDERSTAND

ADVANCING KNOWLEDGE

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



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

NORTH AMERICA

- British Columbia Children's Hospital
- Harvard Medical School
- Institute for Systems Biology
- McMaster University
- Purdue University
- St Jude Children's Hospital
- Stanford University
- University of British Columbia
- University of California
- University of Toronto
- University of Washington
- World Bank
- Yale University

AFRICA

- Bandim Health Project
- Kintampo Health Research Centre
- Uganda Heart Institute
- University of Cape Town

SOUTH AMERICA

- Instituto Nacional de Cancer
- University of São Paulo
- Universidade Federal do Rio Grande do Norte

EUROPE

- Erasmus University Medical Centre
- Imperial College London
- Institute for Child Health
- Oxford
- Reach
- Swansea University
- University of Barcelona
- University of Cambridge
- University Children's Hospital Zurich
- University College London
- University of Manchester
- World Health Organization

ASIA

- Banaras Hindu University
- Education University of Hong Kong
- Hong Kong University
- Hunan Chest Hospital
- International Vaccine Institute
- Kyushu University
- Papua New Guinea Institute of Medical Research
- RIKEN
- Shenzhen Children's Hospital
- Waseda University

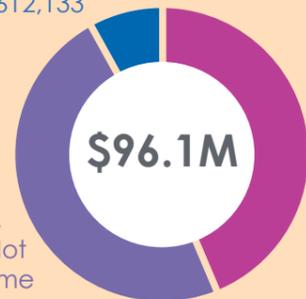
OCEANIA

- Autism New Zealand
- Colonial War Memorial Hospital Fiji
- Cure Kids Fiji
- Harry Perkins Institute of Medical Research
- Menzies School of Health Research
- Murdoch Children's Research Institute
- QIMR, Respiratory & Immunology
- South Australian Medical and Health Research Institute
- Starship Children's Hospital
- The Children's Hospital at Westmead
- University of Auckland
- University of Otago
- Walter and Eliza Hall Institute



We secure a diverse mix of funding to do great research which builds knowledge on health and development

Other income
\$7,612,133



Public income - grants and contracts
\$42,893,071

Philanthropic, Private and Not for Profit income
\$45,666,144

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



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



Source: Clarivate



We publish in the most influential journals around the world

Publications over the past 5 years



Source: Clarivate
*includes articles, letters, editorials and reviews



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



19% of Telethon Kids papers are in the top 10% of citations

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

Source: Clarivate Analytics



Our researchers are regarded as international leaders in their field

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

40



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

INVOLVE

INFORMING DECISION-MAKING

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



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

In 2020, we provided commissioned reports to government on topics such as:

- education
- early child development
- junk food advertising

We partner or collaborate with **63** state and federal government agencies in the areas of health, education, justice, mental health and communities



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

In 2020 at Telethon Kids we had:



We also had strong involvement and engagement with Aboriginal Elders and community members working across many projects and as key representatives on steering groups and committees

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



with influence at the state, national and international level



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

National Preventive Health Strategy	WA State Housing Strategy 2020-2030
Food Standards Australia New Zealand, pregnancy warning labels on alcohol	National Mental Health Commission Research Strategy
NSW Student Behaviour Strategy	WA Suicide Prevention Action Plan
Ministerial Roundtable on COVID-19 Recovery: Mental Health, Alcohol & Other Drugs	Food Standards Australia New Zealand, caffeine products

*Selected contributions named

TRANSLATE

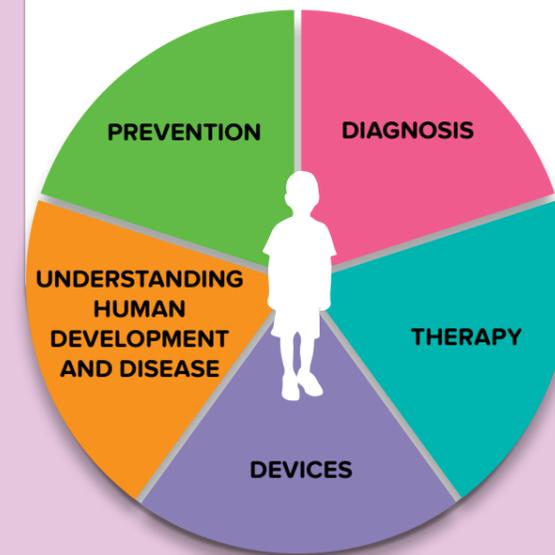
EFFECTIVE CHANGE

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

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

- Asthma
- Developmental Origins of Child Health
- Ear Disease
- Genetic Disorders
- Infections & Vaccines
- Language Development
- Long-term health outcomes of young adults born preterm
- Nutrition
- Obesity
- Respiratory Disorders

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



- Biomarkers of Obesity
- Diabetes
- Early detection of lung disease associated with Cystic Fibrosis
- Skin Infections
- Rheumatic Heart Disease (RHD)

- Allergy
- Asthma
- Autism Spectrum Disorders
- Bronchiolitis
- Cancer
- Cystic Fibrosis treatment
- Disability
- Equine Assisted Learning in Aboriginal Youth
- Gastroenteritis
- Infectious Diseases
- Mental and Youth Health
- Neonatal health
- Perioperative medicine
- Rett Syndrome
- Skin Infections

- Autism
- Diabetes
- Obesity

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

In 2020, we contributed to*:

- Interventions for children on the autism spectrum: A synthesis of research evidence
- Development of Clinical Guidelines (Extreme Prematurity, Neonatal Sepsis, and Bronchiolitis) for the Neonatal Emergency Transport Service, WA
- Community Navigators – a review of existing models to inform Early Years Initiative actions
- Technical standards for respiratory oscillometry



We've translated our research into tools and products that can be used in the community and by researchers, including*:

*Selected examples named



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

22 active patents

TRANSLATION

THIS RESEARCH HAS BEEN
ACTIVELY TRANSLATED INTO
POLICY OR PRACTICE



Victor is an amazing artist with a wonderful imagination. Read Victor's story at telethonkids30.org.au

NEW POLICY HELPS KIDS HUFF AND PUFF THEIR WAY TO STRONGER, HEALTHIER BODIES AND BRAINS



Childcare centres have flocked to take up a new evidence-based policy which will help ensure young children get more of the physical activity they need to be healthy and developmentally on track.



Young children need at least three hours of physical activity a day to be healthy and developing well – but only a third of Australian children aged 2–5 years are getting the recommended dose.

Now, researchers led by Associate Professor Hayley Christian are working with childcare centres to help children establish good physical activity habits early in life – leveraging years of research to come up with a comprehensive physical activity policy which will show them how.

“Physical activity is essential for children’s health and development and is a really important behaviour to establish early on in life, but few young children are getting the daily physical activity they need,” Associate Professor Christian said.

“We know that kids need at least three hours of physical activity per day, preferably more, to be healthy and developing well.

“This should include lots of short, sharp bursts of energetic play throughout the day – physical activity that makes them huff and puff – as well as light intensity active play and lots of different types of explorative, imaginative active play.”

Associate Professor Christian said that even though childcare centres were required to meet national quality standards around physical activity, many early childhood educators weren’t sure of the recommendations, let alone how to ensure they are met.

“We saw a real need for evidence-based guidance, training and support and that’s what we’ve sought to address in developing the Play Active program,” she said.

Developed by Telethon Kids researchers in collaboration with 10 partners across government, not-for-profit, the private sector and academic institutions, Play Active was launched in December 2020.

“Since then we’ve had more than 200 expressions of interest from child care services and we now have 80 centres on board for an evaluation, or pragmatic trial of the policy,” Associate Professor Christian said.

“It’s been an incredible response to the program launch. We actually had to draw the line because we’ve only got so much capacity and resources to run the evaluation.”

Centres who signed up have been randomly allocated to receive the Play Active program immediately or continue with their current practices and be waitlisted to receive the program later this year.

Those who receive the program immediately will be assessed and supported to modify and then implement the policy with their staff and parents. Once they’ve adapted the policy for their own needs – and it’s been signed off by the



Associate Professor Hayley Christian (third from right) and the team behind the Play Active program

Play Active research team to ensure it retains key recommendations – they get access to training and a resource guide.

Centres will have three months to implement the policy before being reassessed.

“It’s not a big period to take on a new policy and then try and implement it – policies sometimes take years to be implemented and have a meaningful impact – but we hypothesise that within those three months we’ll see some positive changes, at least in educators’ practices around promoting physical activity in the centre,” Associate Professor Christian said.

She said the pragmatic trial approach – combined with work being done by two PhD students to look at how centres in regional and remote areas may differ in their needs – enabled childcare centres and researchers to see the policy in action and identify where it might need to be tweaked.

“One size doesn’t fit all. What may suit a Perth centre may not suit a service in, say, Bunbury, Kalgoorlie or a remote area,” Associate Professor Christian said.

“This evaluation is going to help with understanding the key ingredients we need to keep the same, and what needs to be adapted to allow Play Active to be expanded to other parts of WA, and potentially other states, as well as to other types of early childhood education and care providers, like family day cares or out of school care services.

“It’s only the first step. Ultimately, we’d like Play Active to be used by multiple early childhood education and care providers nationally. We know it’s doable with the support of our current and future partners.”

▶ **The Australian 24-hour Movement Guidelines for the Early Years** state **young children should have three or more hours of physical activity per day, including energetic play** – but only a third of Australian children aged 2-5 years are achieving the recommended daily dose of physical activity

▶ **The Play Active Program** gives childcare centres **clear guidance on how to support young children to meet physical activity guidelines**, with the policy setting out how much physical activity, sedentary time and screen time children should have while at childcare

▶ **Managers and educators receive training, professional development and resources to help implement the policy**, including a practical guide with tips and advice to help children be as active as possible throughout the day

Play Active is a joint initiative between the Telethon Kids Institute, The University of Western Australia, Queensland University of Technology, University of Southern Denmark, Goodstart Early Learning, Minderoo Foundation-CoLab, Collaborate for Kids, Nature Play Australia, Cancer Council WA, Australian Childcare Alliance, WA Department of Local Government, Sport and Cultural Industries and WA Department of Health. The Australian National Health and Medical Research Council provided funding.

DJAALINJ WAAKINJ LEADS TO BETTER HEARING – AND HAPPIER KIDS



Debilitating yet preventable middle ear infections in Australian children disproportionately affect certain groups, including young Aboriginal children. Left untreated, these infections can lead to permanent hearing loss and affect language, education and quality of life – but waiting times for treatment can be brutal, with many kids having to wait up to two years to be seen. Now, an innovative Telethon Kids program is helping to slash waiting times so children can have their ear problems checked within days.

Among childhood's universal milestones are first words – what was it and when was it said? While many families may argue over whether it was 'mama' or 'dada', for parents of children with middle ear infections and hearing loss, these questions can be met with sadness.

It's a story that's easily recognisable for Nikki Naylor, Jahkye's mum.

"I had two children with no ear issues so when bub had his newborn hearing screening, I wasn't expecting any problems," Nikki said.

"It turns out he had glue ear, which was the start of ongoing issues."

At 14 months, Jahkye had his first lot of grommets.

“Before surgery he was not able to say 'Mum' due to his hearing loss – his talking and hearing was not that of a 14-month-old,” Nikki said. “Not long after his first surgery, I heard him say that three letter word – 'Mum'. I can't even explain what that felt like for me. He kept getting better because he could finally hear.”

Middle ear infections in Australia are common among children, but they disproportionately affect certain groups. A Telethon Kids study found that young Aboriginal children are at increased risk of developing middle ear infections compared to non-Aboriginal children.

Dr Chris Brennan-Jones, Head of Ear Health at the Wesfarmers Centre of Vaccines and Infectious Diseases, based at Telethon Kids Institute, said the results clearly demonstrated the urgent need to prioritise early testing and treatment for Aboriginal children suffering otitis media (OM).

"Some children spend over two years on waiting lists for treatment of ear infections. That's too long

for children who are in crucial stages of language, behavioural and educational development," Dr Brennan-Jones said.

"Working with the local Aboriginal community, the Djaalinj Waakinj (listening and talking) Ear Portal Program was established to address this gap. It ensures access to early diagnosis and intervention – within days instead of years – by reducing unnecessary travel and waiting times."

The Cockburn-based project is a telehealth-driven clinical research program which uses technology to remotely diagnose and prioritise treatment of children with otitis media to prevent hearing loss. More than 150 children are currently enrolled in the South Metropolitan project, but a generous donation from globally-recognised ship-building firm Austal – matched by a private benefactor – will enable the program to significantly increase the number of children seen each year.



Dad Stephen Harris, Mum Nikki Naylor, Stephen Jnr, 4, Ataliyah, 8, and Jahkye, 3



Natasha Morrison checks Jahkye's ears



MAKING A DIFFERENCE TO KIDS' HEARING ALL OVER THE WORLD

Globally, there are an estimated 31 million episodes of chronic suppurative otitis media (CSOM) every year, with 22 per cent of cases affecting children under five years of age. Prevalence varies widely between countries, but the condition disproportionately affects people experiencing socio-economic disadvantage.

Many people who are affected by CSOM do not have good access to specialised ear care – a significant problem that attracted the attention of Cochrane ENT, a global independent network of researchers, professionals, patients, carers and others which produces systematic reviews of healthcare treatments around the world.

In a bid to address the issue, Cochrane ENT prioritised the production of systematic reviews on non-surgical treatments for CSOM – a call that was met by Dr Chris Brennan-Jones, who led an international collaborative group to complete a total of seven reviews.

In a rare honour, these reviews were released as a 'Special Collection' to mark World Hearing Day 2021. Funded by the NHMRC, the reviews were profiled by the World Health Organization (WHO) and resulted in Telethon Kids being admitted as a full member of the WHO World Hearing Forum in 2019. The team's research was also cited in the WHO World Hearing Report 2021, informing the approach to prevention and treatment of otitis media globally.



650,000
Australian children
are affected by
otitis media (OM)
every year, with **Aboriginal children** experiencing some of the highest rates in the world



In November 2020
Telethon Kids researchers
published findings
revealing close to
40 per cent
of Aboriginal babies
begin to **develop middle ear infections between two and four months of age**



By **6-8 months** this
increased to more than 50 per cent
of kids – clearly
demonstrating the need
for early testing and
treatment

Just like Telethon Kids, Austal – also based in the Cockburn area – is committed to helping the communities where we live and work.

“By supporting the Djaalinj Waakinj Ear Portal Program, Austal will make a real impact for local families and help ensure no child in the local community starts school with preventable or treatable hearing loss,” said Val Swift, Aboriginal Cultural Governance Advisor at Wesfarmers Centre of Vaccines and Infectious Diseases.

Hearing loss caused by untreated OM is a lifelong burden, with the impact on lost wellbeing (due to unemployment, impacts on mental health and quality of life) estimated to cost \$17.4 billion per annum in Australia.

“There is an assumption that living in metropolitan Perth means you can access medical services without restrictions. But that isn't the case for many Aboriginal families,” Ms Swift said.

“By working with the community to design and deliver the program, we're ensuring the cultural security of the program so families feel safe and comfortable to participate,” said Natasha Morrison, Aboriginal Research Assistant with the Djaalinj Waakinj program. “We're making this a service they can access without restrictions.”

Telethon Kids researchers collaborated with ear health researchers from across Australia to update the *Otitis media guidelines for Australian Aboriginal and Torres Strait Islander children*, with results from Djaalinj Waakinj informing the update.

Together, the 2020 OM guidelines and a new smartphone app called OMapp improve access to the most up-to-date, critically appraised evidence on best practice in OM and hearing loss prevention and management for Aboriginal and Torres Strait Islander children across all Australian settings.

Developed by members of the Centre of Research Excellence in Ear and Hearing Health of Aboriginal and Torres Strait Islander Children, including Telethon Kids researchers, OMapp enables free fast access to the guidelines, plus images, animations, and multiple Aboriginal and Torres Strait Islander language audio translations to aid communication with families.

The Djaalinj Waakinj (listening and talking in Noongar language) Ear Portal Program was co-designed and governed by an Aboriginal Community Advisory Group in partnership with:

- Telethon Kids Institute
- Perth Children's Hospital
- Cockburn Integrated Health and the WA Country Health Service
- Moordijit Koort
- Babbingur Mia
- Boodjari Yorgas
- CAHS Community Health

It has not only dramatically increased access to service and reduced the cost of treatment for families, but has increased family satisfaction with ear health care through the provision of culturally appropriate care.

WHAT'S NEXT

- ▶ Investigate extending the Djaalinj Waakinj program across the Perth metropolitan area to take in areas beyond Cockburn and Armadale – initially to Rockingham and Midland – where the program would have the greatest impact
- ▶ In partnership with the Aboriginal Community Advisory Group, develop new approaches that will improve prevention and treatment of otitis media in the community

CLOSING THE GAP: HITTING 'RESET' ON HOW WE MEASURE EARLY DEVELOPMENT IN ABORIGINAL KIDS



In 2020, the National Closing the Gap partnership made improving early development of Aboriginal and Torres Strait Islander children one of its top priorities. Australia will measure progress in this area using the AEDC – a program developed and supported by Telethon Kids Institute researchers since 2003.

Emphasising the importance of strong foundations for health, wellbeing and opportunity, the Australian Early Development Census (AEDC) program has been monitoring how our children are developing for more than a decade.

The AEDC arose out of work done in the early 2000s, when Telethon Kids Institute researchers adapted the Canadian Early Development Instrument (EDI) for use in Australia. As part of the development process, and to ensure it was culturally inclusive and appropriate, Professor Sally Brinkman and team adapted the instrument for Aboriginal children – changes which resulted in improvements for all children.

In 2009 the resulting Australian Early Development Index (AEDI, later renamed AEDC) was adopted by the Australian Government and the census program was rolled out nationally – making Australia the first country in the world to collect national data on the developmental health of all children starting school.

Held every three years, each census since then has collected information for more than 95 per cent of children in their first year of full-time school, including Aboriginal and Torres Strait Islander children. When teachers complete the checklist for Aboriginal and Torres Strait Islander children in their class they do so in consultation with cultural consultants.

“Consultants bring unique cultural knowledge and are well placed to support teachers with Instrument completion, because of their personal understanding of Aboriginal and Torres Strait Islander children’s ways of learning and behaving,” Professor Brinkman said.

Professor Brinkman – who is Co-Director of the Fraser Mustard Centre and was central to developing the AEDC – said each census takes a holistic view of a child’s early development, providing a well-established measure that tells

us how well children have been supported in all aspects of their health, wellbeing and learning.

AEDC indicators focus on the importance of children developing well in all five domains: Physical health and wellbeing; Social Competence; Emotional Maturity; Language and Cognitive Development; and Communications Skills and General Knowledge.

“The indicators used in the AEDC are very sensitive to policy change and community action – you could call them the ‘canary in the coal mine’,” Professor Brinkman said.

“These areas are an early indicator of later health and educational outcomes throughout school and later life”.

Professor Brinkman said the recent inclusion of the AEDC as a measure in the national Closing the Gap strategy targets demonstrated a commitment to improving conditions for Aboriginal and Torres Strait Islander children and their families.

In 2020 – driven by Aboriginal and Torres Strait Islander leaders and their communities – the targets were reset, with the AEDC included in the 17 new targets to help measure children’s early development. The new focus takes a strengths-based approach to tracking progress, switching the perspective from ‘developmentally vulnerable’ to ‘developmentally on track’.

The goal is ambitious: to increase the number of Aboriginal and Torres Strait Islander children assessed as being developmentally ‘on track’ to 55 per cent by 2031. The most recent measure in 2018 showed 35 per cent were on track, which has improved slightly since 2009.

“With this new target of ‘on track’ specifically for Aboriginal children I would hope to see, over the next few years, more of a focus on trying to identify those communities that are doing well – and identifying the community strengths, support systems and cultural knowledge that is contributing to better outcomes for children,” Professor Brinkman said.

She said her involvement in developing the AEDC was one of her proudest career achievements, and seeing the potential it had to help achieve real change for Aboriginal and Torres Strait Islander children through Closing the Gap was extremely gratifying.

“The AEDC is used in so many different policy frameworks and outcome indicators, from local government to State and Federal governments – so many different policies use the AEDC as a target measure,” Professor Brinkman said.

“Seeing it integrated into all of these things is nice but at the same time, it still requires action to change the results.”



CLOSING THE GAP

- ▶ Six Closing the Gap targets were created in 2008 in response to a call to achieve **equality for Aboriginal and Torres Strait Islander people in health and life expectancy within a generation**, with a seventh target focused on early childhood added in 2015
- ▶ Ahead of four of the seven targets expiring in 2018, the **Coalition of Australian Governments (COAG)** agreed to **refresh the Closing the Gap framework in partnership with Aboriginal and Torres Strait Islander people**
- ▶ The targets were reset in 2020, with a new focus on a **community-led, strengths-based strategy**
- ▶ The 17 new Closing the Gap targets are a shared commitment to **empower Aboriginal and Torres Strait Islander people to live healthy and prosperous lives**

AEDC



- ▶ The AEDC is a **nationwide data collection of early childhood development at the time children commence their first year of full-time school**
- ▶ Providing evidence to support **health, education and community policy and planning**, it highlights what is **working well** and **what needs to be improved** or done to **support children and families**
- ▶ First run in 2009, the **AEDC is held every three years**. The 2021 AEDC data collection commenced in Term 2 of this year, and will be the **fifth collection**
- ▶ Initially known as the Australian Early Childhood Index (AEDI), the **program was renamed the Australian Early Development Census (AEDC)** in 2014



FACING THE FUTURE: GIVING KIDS IN TUVALU A BETTER START AS THEIR COUNTRY SINKS INTO THE SEA



Children in the tiny Pacific nation of Tuvalu face a unique threat that should be a wake-up call to other countries across the world. By the time they are adults, their country will no longer exist – the nine sandy atolls that make up Tuvalu will be swallowed by rapidly rising sea levels as a result of climate change. Telethon Kids Institute researchers have helped identify the key health and developmental challenges facing the country's children, with the hope of paving the way for an easier transition when they must inevitably leave their island home behind.

Tuvalu – the world's fourth smallest nation – is classified as a 'threatened state' as the ocean that surrounds it continues to consume it.

The series of thin islands in the vast Pacific Ocean are home to a population of 11,000 people with a rich culture and history, but isolation and lack of resources means child development has fallen well below the benchmark.

Professor Sally Brinkman and her team were asked by the Tuvalu Government and the World Bank to examine the status of child development across the nine islands of the country. They used the early Human Capability Index (eHCI), an easy-to-use survey instrument developed by Professor Brinkman and then adapted to local culture and context.

In 2015, the Tuvaluan eHCI was used to assess every single three- to five-year-old child across Tuvalu – no easy feat given the islands can only be navigated by boat, with some islands harder to reach than others.

Despite the access challenges, Professor Brinkman estimates around 90 per cent – or just under 600 kids – were assessed.

The results were confronting.

Children in Tuvalu showed high rates of 'stunting' – meaning they are smaller than expected for their age. The condition has a strong link to poor cognitive development.

Professor Brinkman said poor nutrition was likely to blame, with the sandy islands wholly unsuited to growing fresh nutrient rich food and climate change making agriculture almost impossible.

“It's not just the lack of variation in the diet or the lack of fresh food, in some cases there's just not enough food and that's stunting the growth of these kids,” she said.

“Worms are also endemic in Tuvalu as well as diarrhoea because there are lots of issues with sanitation. There is nowhere for the waste to go other than into the sea, and of course children spend a lot of time in the water. So, there are a lot of factors contributing to poor physical growth.”

The team found this poor growth also translated to other areas of child development. The results were delivered directly to the country's Prime Minister, who took immediate action – allocating International Development Assistance funds from the World Bank.

“Generally, countries choose to spend that money on roads or electricity and infrastructure,” Professor Brinkman said. “Very rarely does it go to so-called human capital, but on the basis of these results, Tuvalu decided they wanted that money to go into early childhood development initiatives.”

Tuvalu's future is written. The rising sea levels cannot be reversed, so it is a matter of 'when' not 'if' the islands sink into the Pacific Ocean.

But Professor Brinkman said the future of its people – those children – is far from set in stone.

“The kids in Tuvalu are the future,” she said.

“How do you maintain your culture and your sovereignty when your country is going to disappear? What does that look like? These are the questions the next generation will have to answer.

“But if they can enhance the health, development and early education of their kids so that they're better able to read and solve problems, then at least they're better equipped to navigate the world beyond Tuvalu.”

EVALUATING EARLY CHILDHOOD EDUCATION IN THE VILLAGES OF NORTHERN LAOS

Northern Laos is a challenging place to run an education system. The mountainous region is made up of dozens of different ethnic groups, speaking more than 100 different languages and dialects. Access is difficult and during the monsoon season remote areas can be completely inaccessible.

The Government of the Lao People's Democratic Republic (PDR) is committed to improving access to quality education. To help with this the World Bank financed a project to improve the country's early childhood education system and promote the development of children living in disadvantaged villages.

Professor Sally Brinkman and her team conducted an impact evaluation to understand the benefits of delivering different models of early childhood education across almost 400 villages throughout the poorest regions of Northern Lao PDR.

The focus was on comparing two main types of early education: community-based playgroup sessions for children aged 3 and 4, run by a local caregiver in a purpose-built hut; and a more formal pre-school setting which welcomed 3- and 4-year-olds into existing 5-year-old preschool classes, run by a trained teacher.

Evaluation results showed improved access to early childhood education, resulting in a dramatic increase in attendance. Before the project, fewer than 25 per cent of children had attended early education – a figure which increased to 80 per cent as a result of the project.

Both types of early education were found to have benefits for the children's early development, however it was the sessions run by the community, outside of the formal education system, which showed greater improvements in a range of different areas.



"Since the project started, we've seen policy shifts within the government to try and bring early education underneath the Education Act," Professor Brinkman said.

The Government of Lao PDR has now made further investment into both playgroup and formal preschool early education programs to ensure their sustainability in future.

"It's really important that the Laos government continues to support early childhood education for these villages," Professor Brinkman said.



▷ The tool is a measure of **where a child can be placed on a developmental spectrum** – it can determine whether a child is thriving or doing poorly on different aspects of development

▷ **The early Human Capability Index (eHCI)** is an easy-to-use survey tool developed by Professor Brinkman that can be completed by parents/caregivers, childcare workers, teachers, allied health and other health or early childhood practitioners

▷ **At least 12 countries are now using the eHCI to measure early childhood development**, adapted to their own language and culture. They include Brazil, China, Indonesia, Lao PDR, Tajikistan, India, Bulgaria, Tonga, Kiribati, Peru, Samoa and Tuvalu



Professor Sally Brinkman

Professor Sally Brinkman is Head, International Child Development at Telethon Kids Institute and Co-Director of The Fraser Mustard Centre, based in Adelaide.

The Centre, a research collaboration between the Telethon Kids Institute and the South Australian Department for Education, was created to bring together leading Australian child researchers and innovative government policymakers and planners to improve research translation.

TEACHING EDUCATORS TO SEE NEURODISABILITY THROUGH KIDS' EYES



A workforce training intervention developed to help justice staff better understand and work with young people affected by neurodisability is set to expand to the education sector.

In 2018 findings from the ground-breaking Banksia Hill Project revealed that 89 per cent of young people in detention who were assessed as part of the project had at least one form of severe neurodevelopmental impairment.

The study – the first in Australia to assess and diagnose young people in a youth custodial facility for Fetal Alcohol Spectrum Disorder (FASD) – saw a multi-disciplinary team of clinicians and researchers assess more than 100 young people aged 10–17 who at the time were detained at WA's Banksia Hill Detention Centre.

The project identified FASD in 36 per cent of those assessed but, even more concerningly, found high levels of neurodisability more broadly. Almost every single young person the team examined had some form of previously undiagnosed severe neurodevelopmental impairment.



Dr Hayley Passmore

The findings raised wider questions about missed opportunities for intervention which could have prevented the young people from becoming involved in the justice system in the first place, but also highlighted the need for better support for those who did find themselves there.

As part of the project then PhD student Hayley Passmore worked with Banksia Hill staff to develop Reframe Training, a training program designed

to help frontline workers better understand and provide more effective support to young people with FASD and other forms of neurodisability.

Dr Passmore has since delivered the program to more than 350 frontline justice staff from across WA, with evaluation showing it has changed the way they recognise and respond to young people with disability; and has presented it to youth detention staff, lawyers, social workers and other frontline staff in the Northern Territory at the invitation of the NT Government.

Now, Dr Passmore is partnering with the WA State Government to revise and expand the resources for use in schools.

"We're in the process of developing an entire Reframe package specifically for educators, but because we're talking about thousands of staff across the state, it will be delivered via the Department's online training platform rather than face-to-face," Dr Passmore said.

“The training won't be FASD-specific but neurodisability more generally – focusing on behaviour that educators and teachers might be seeing in their day-to-day engagement with young people and providing strategies to support those behaviours.”

Designed in consultation with Department staff and allied health professionals, including a paediatrician, neuropsychologist, speech and language therapist and occupational therapist, the package will focus on generalised strategies that can benefit all children, but particularly those with underlying neurodevelopmental issues.

"We're saying to staff, we know many of the children you are educating will not have a formal diagnosis, and because of that, we want to provide you with some tools to use that aren't harmful to young people that don't have a diagnosis but will hopefully support you regardless of what an individual's specific needs are," Dr Passmore said.



Central to the package will be a series of short films shot in classroom settings, developed in consultation with the Department and designed to help teachers put themselves in the shoes of a child with neurodisability.

"The films provide an immersive experience, drawing people into the story in a way that can often stay with them longer than just a generic training module," Dr Passmore said. "It's all about empathy, drawing the viewer into the narrative from the perspective of that young person."

She said the ultimate goal was to get teachers encountering certain behaviours to stop and think about what might really be going on with a child and whether they may need to modify the way they work with that child.

“The tag line is **Recognise. Reframe. Respond.** So recognise what might be going on for this young person, reframe the associated behaviour, and then respond appropriately,” she said.

WHAT'S NEXT

- ▶ Dr Passmore and her team are in ongoing discussions with other sectors to provide resources contextualised for their own workforces, including police and disability workers
- ▶ The team has been funded by the Kimberley Brain and Mind Foundation to partner with WA Police and several Aboriginal-led organisations to trial and evaluate Reframe workshops with Kimberley-based police

THE ONE-STOP APP HELPING TO KEEP KIDS SAFE ONLINE



A free new app developed by Telethon Kids and Bankwest has drawn on more than 15 years of cyber-safety research to give parents a one-stop-shop that helps them confidently navigate their child's online behaviour.

Parents, carers and educators have enthusiastically embraced an innovative tool in the battle to keep kids safe online following the launch of Beacon – an Australia-first, evidence-based cyber safety app.

Beacon, which is free to download, gives parents access to individually tailored, trustworthy information to help navigate their child's online behaviour.

The app, developed as part of a three-year partnership with Bankwest and launched in September last year, pairs more than 15 years of cyber behaviour research at Telethon Kids with Bankwest's cyber security expertise.

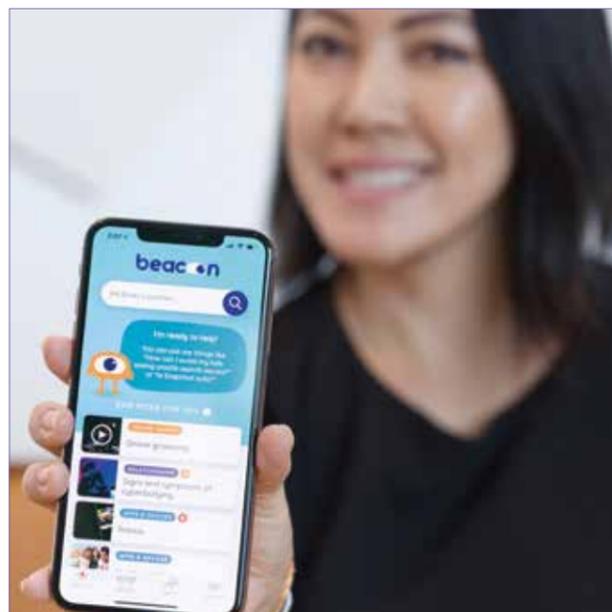
Parents receive personalised content from a comprehensive library of strategies and tips for addressing challenging issues such as screen time, gaming and cyberbullying.

The collaboration was prompted by Bankwest research that revealed high levels of concern from parents for their children's online safety, along with confusion over where to get help and advice.

Professor Donna Cross, Telethon Kids Program Head of Development and Education, said the partnership with Bankwest had allowed for extraordinary outcomes, while continued collaboration with national and international partners meant the app could remain fresh and keep up with the constantly evolving online landscape.

“Through ongoing collaborations, we have been able to create and maintain a tailored and dynamic translation platform with regularly updated content to support parents through difficult decisions in an ever-changing online world,” Professor Cross said.

The app was developed via a multi-phase process conducted over 12 months in collaboration with parents and a range of partner organisations, including the Fathering Project and the Office of



Bec Nguyen

the eSafety Commissioner, to ensure it met the needs of the target audience – parents and carers of children aged up to 18 years. In the six months since Beacon's launch in late 2020, the app has been downloaded more than 13,000 times.

Digital project manager Bec Nguyen said that in addition to making valuable contributions to the development and content process, partner organisations had contributed significantly to promotion and dissemination of the app.

“More than 50 local, state and national organisations – including government, national cyber safety educators, the technology industry, nationally recognised support services and not-for-profit community organisations – are supporting the dissemination of Beacon Australia-wide,” Ms Nguyen said.

“Ongoing collaborations with these partners ensure that we are all playing our part to keep Australian children and young people safe online, by getting Beacon into the hands – and onto the phones – of all parents and carers.”

APP PROVIDES A BEACON TO ALL-AT-SEA PARENTS

As a parent of two children who regularly use electronic devices for school and leisure purposes – including a laptop, phone and game console – Perth dad Rory Murray is all too aware of how hard it can be to stay across the kinds of things they may be encountering online.

“As kids are growing older they're using new apps all the time,” Rory said. “They hear about different apps from their friends or new apps that have been released and as a parent you just can't keep up with that.”

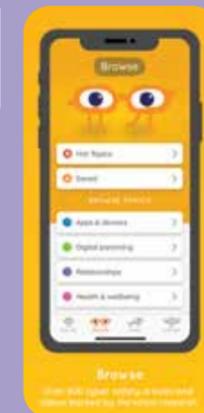
Downloading the Beacon app, however, has prepared him with the information he needs to have really helpful conversations about cyber-safety with his 11-year-old son and 13-year-old daughter – something he said his kids appreciated because it showed he cared about them. He especially liked the family agreement feature, which enables families to discuss and reach a consensus around screen use and online content.

“That allows us to periodically go and have these conversations with each child and go through a number of different elements around cyber safety,” he said. “It reminds us of all the different categories of information and the different issues we need to talk about to make sure they're all covered, to have the conversation from an informed perspective.”

Rory said he also appreciated the broad range of topics available.

“By having an app like Beacon you can just have a quick browse, then go and do some research and then you can keep up to date really easily with what they're doing and what's involved.”

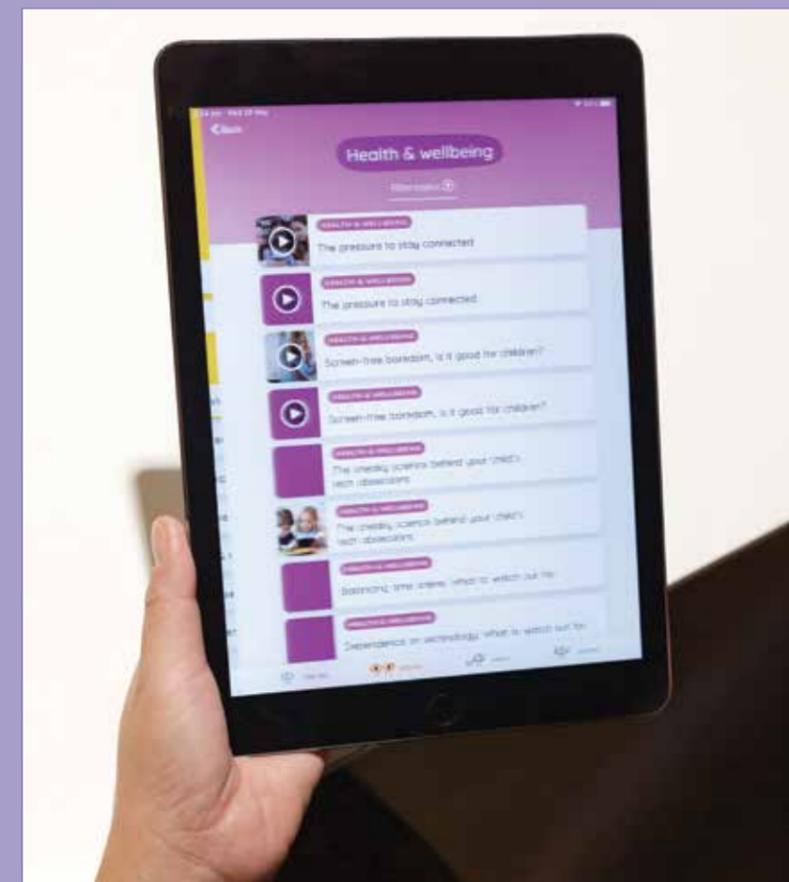
“A lot of it is not so much about looking for an answer to a question, but having all that information at your fingertips,” he said.



DID YOU KNOW?

▶ **Telethon Kids researchers** have conducted more than **30 projects investigating young people's online behaviours since 2007**, supported by more than **\$5 million in funding**

Since its launch the Beacon app – developed with Reach Health Promotion Innovations – has been named a **finalist in the 2021 WA Incite Awards (Best Social Impact)** and **Ms Nguyen has been named a 2021 Finalist for Women in Tech Awards (Product category)** for her role in the app's development



Beacon is funded through a partnership with **Bankwest through Channel Seven's Telethon.**



ACCENTUATING THE POSITIVE TO SUPPORT STUDENT BEHAVIOUR



One third of Australia’s children will be better supported at school, thanks to a Telethon Kids Institute evidence review of what works best to support student behaviour needs.

New South Wales schools will focus more on prevention, early intervention and promotion of student wellbeing, under a recently released student behaviour strategy informed by Telethon Kids Institute research and recommendations.



Professor Donna Cross

Researchers led by Professor Donna Cross, Program Head of Development and Education at Telethon Kids, undertook an evidence review in collaboration with the NSW Department of Education and other stakeholders.

Released in 2019, the report – *Strengthening school and system*

capacity to implement effective interventions to support student behaviour and wellbeing in NSW public schools – provided the local context and evidence base needed to strengthen the NSW education system’s approach to student behaviour and support for schools and teachers.

The *New South Wales Education Student Behaviour Strategy*, released in March this year and currently being rolled out across the state, is based on local and international best practice and focuses on early intervention, increased support, and professional development – all aimed at assisting teachers’ classroom management and student behaviour needs.

Senior research fellow Dr Natasha Pearce said the report which originally informed the strategy had helped the NSW Department of Education to take a proactive systems approach rather than reactive approaches to poor behaviour, and to

focus on embedding positive behaviour influences within relationships, the curriculum, and the wider school process.

“Our report used three sources of evidence and identified common themes across all three to develop a plan for good practice and implementation support,” Dr Pearce said.

“The results have provided the evidence to strengthen the capacity of the system and schools to implement effective interventions and support student behaviour and wellbeing across the continuum of care.”

Dr Pearce said that to ensure the report reflected local context, researchers mapped the current capacity of New South Wales’s student behaviour support system and gathered evidence from NSW educators to identify approaches that were working well and opportunities for improvement.

“By taking the research and evidence-based practice and putting it into a New South Wales context, we have been able to impact a large-scale policy implementation plan that is highly context-relevant,” she said.

In line with the recommendations, the state’s new behaviour strategy moves beyond management and discipline only, to include a wellbeing and prevention approach – giving schools easier access to allied health and professional behaviour support services.

Professor Cross said the collaborative nature of the report – which saw researchers work in partnership with the NSW Department of Education (Learning and Wellbeing Directorate), the Centre for Evidence and Implementation, and NSW school staff and stakeholders – allowed for more impactful recommendations.

“Combining years of research with evidence-based practice by our team and others from around the world allowed us to impact policy and practice in a meaningful and sustainable way,” Professor Cross said.

She said the resulting strategy was innovative and would deliver a new system of learning and wellbeing to students and teachers.

“It will put early intervention and an expert workforce at the forefront of student behaviour initiatives within the New South Wales education system.”



Dr Natasha Pearce

WHAT’S NEXT

- ▶ The Student Behaviour Strategy is being phased in, with consultation continuing on a suite of new policies and procedures, due to be released in Term 3, 2021

CLINIKIDS PUTS THE 'EVIDENCE' IN EVIDENCE-BASED PRACTICE



Autism researchers at Telethon Kids have led the most comprehensive review of the evidence for autism intervention ever compiled, empowering families to make informed decisions on how best to support their child.

In 15 years of working in the autism field, CliniKids Director and Angela Wright Bennett Professor of Autism Research at Telethon Kids Andrew Whitehouse is yet to meet a child on the autism spectrum who isn't, in their own way, amazing.

It's why he feels so strongly that any intervention designed for kids with autism should be carefully thought through and – crucially – backed by high quality evidence.

"Autism interventions should be about identifying the strengths that every child brings to the world and minimising their barriers in life, so the world can see just how amazing we know they are," Professor Whitehouse said.

“The problem for parents has been that there are so many interventions out there for kids on the autism spectrum that navigating their way to high quality interventions has been practically insurmountable.”

That struggle to choose the most effective therapies is now set to become much easier thanks to a landmark report led by Professor Whitehouse which has shed new light on the evidence base underpinning autism interventions.



Professor Andrew Whitehouse

Interventions for children on the autism spectrum: A synthesis of research evidence was commissioned by the National Disability Insurance Agency (NDIA) and produced by networks provided by the Autism CRC, the world's first national, cooperative research effort focused on autism.

The comprehensive report, which involved 58 systematic reviews drawing on data from nearly 1,800 unique studies, was undertaken over four months during last year's long COVID-19 lockdown.

Professor Whitehouse, Research Strategy Director at Autism CRC, said prior to the report there was no clear demarcation between evidence-based and non-evidence-based autism interventions in Australia – making the task of choosing interventions overwhelming for families.

“It is critically important that families have an authoritative document that provides a clear summary of what interventions are supported by evidence,” Professor Whitehouse said.

“This report will empower families to make informed decisions around intervention.”

But it will not just be families who benefit from the report, with Professor Whitehouse saying it was also written with clinicians and policymakers in mind.

“There are many audiences for a document like this,” he said. “Families who are making intervention decisions for their children are a key audience, but the document also provides evidence-based information for clinicians who are searching for answers in this area.”

“More broadly, the report provides key information for policymakers who are charged with devising evidence-informed policies to support the broader autism community.”



Professor Whitehouse said an interesting finding to emerge from the report was that the quantity of intervention was not linked to more positive outcomes for the child.

“There are a lot of assumptions we hold in the autism field,” he said. “One is that the more intervention your child receives, the more positive the outcomes are going to be. Our report identified that there is no obvious link between the amount of intervention received and the size of the effect of that intervention. Certainly, the amount of intervention a child receives is important, but it is by no means the only factor.”

Professor Whitehouse said the NDIA was currently using the report to improve National Disability Insurance Scheme (NDIS) operational procedures.

The next step would be to develop an autism guideline based on the report's evidence.

“A guideline has scientific evidence as its foundation, which is then shaped by clinical experience and wisdom, along with family preferences and contextual factors,” he said.

“But the foundation is scientific evidence, and that is what this report provides. Now we have this base, the autism field is poised to develop a guideline that provides clinical recommendations that guide national practice. This would immeasurably improve how we provide clinical services to children on the autism spectrum in Australia. This report was the first step, but not the last step.”



Maps showing the autism intervention report has had around 8,000 downloads in more than 100 countries since it was published in late 2020.

WHAT'S NEXT

- ▶ Use the report as the foundation for the development of an early intervention autism guideline and recommendations
- ▶ Create a transparent framework through which autism practices and standards are regulated in Australia



The report was commissioned and funded by the **National Disability Insurance Agency**

Professor Andrew Whitehouse is supported by **Angela Wright Bennett Foundation**

RIVER IS A 'DIFFERENT KID' SINCE STARTING AT CLINIKIDS



Twins Rose and River with mum Tiffany

Five-year-old River was diagnosed on the autism spectrum when he was aged 4.

Prior to diagnosis, mum Tiffany Little said she knew River was developing a bit differently to his twin sister Rose however, because Rose had hit all her milestones early, she had given him a bit of leeway.

"River was always a little dreamier than Rose," she said.

"He used to cry and scream a lot, flail his arms around — we couldn't leave the house.

"His behaviours became more noticeable when he started bush school. He wouldn't join in and would have a high-pitched scream if he didn't want to do something. He was always on his own. That's when I decided to get him assessed for autism."

Tiffany said the family was living in Margaret River at the time of River's diagnosis but moved to Perth soon after to ensure he had access to the best autism interventions available.

“I had heard of CliniKids and wanted River to go there because the therapies were science based and they had new therapies unavailable elsewhere,” she said.

"I also knew how much research went into the therapies and this gave me confidence in knowing

River was getting the best science-backed interventions available.

"I wanted to take him to the best because the foundations for the rest of his life are built in these critical early years."

Tiffany said River was a 'totally different child' since starting at CliniKids a little over a year ago.

He had improved his social skills, was talking more, could start conversations and knew more appropriate ways of expressing his emotions.

"At kindy, River wouldn't or couldn't play with other kids – he simply didn't like to interact with others," she said.

"Through treatment, he has learnt to play with someone other than myself or Rose and he's also learnt to allow for flexibility in play. He's also learnt so much from Rose."

Tiffany said River's transition to pre-primary had gone well and he had made friends.

"He loves his friends, and they love him, and their conversations are so cute," she said.

Tiffany said the family also participated in research at CliniKids.

"We will continue to take part in research, not only for River and our family's benefit, but to help other children on the autism spectrum," she said.

DID YOU KNOW?

- ▶ **Autism Spectrum Disorder (ASD)** is a complex neurodevelopmental disorder that affects the way a person interacts and communicates, as well as the way they learn and behave
- ▶ **A third of all participants** in the NDIS have an **autism diagnosis**
- ▶ **CliniKids is the first stand-alone clinical service offered by Telethon Kids.** It integrates cutting-edge research with a clinical service, providing families with access to individually tailored, holistic supports and the best evidence-based therapies
- ▶ **The autism intervention report** has been downloaded approximately **8,000 times** by people in more than **100 countries** since it was released late 2020





MESS + FUN = FUTURE STEM STARS



What do strawberries, slime and sliced bread all have in common? They're all being used as tools to educate and inspire the next generation of researchers as part of the increasingly popular Telethon Kids Discovery Centre Schools & Outreach Program.

Brought to life by former teacher and now Telethon Kids Schools Coordinator Sistha Halim, the Discovery Centre Schools & Outreach Program blends messy, hands-on experiments with real-life science to educate and inspire the next generation of budding scientists.

The program helps the Institute connect with the younger community in a fun, educational and unique setting, reaching kids via school excursions, incursions, and school holiday workshops which simulate fundamental Telethon Kids research in areas such as lung health, diabetes, and genetics.

During the school term, a typical excursion sees primary school classes from all over Perth visit the Institute for a two-hour session. Students don a lab coat, engage in an exciting, hands-on experiment, and see a state-of-the-art working laboratory – all while being guided by some of Telethon Kids' best and brightest minds.

"What makes our excursions so unique is the fact the sessions are delivered by actual Telethon Kids researchers," Miss Halim said.

"We also offer school incursions, which are just as special, with our researchers hosting demonstrations and sharing an insight into life as a



Telethon Kids Schools Coordinator Sistha Halim

researcher in classrooms right across the Perth metropolitan area."

The learning doesn't stop at the end of the school term, with a school holiday program packed with 1.5 hour workshops on a range of topics – from poo and gut health to blood typing and DNA sequences – kicking in during the breaks for children aged from 5 to 14.

"The school holiday workshops are designed so that children can continue to learn about the areas they enjoy and observe how the STEM subjects they do in school are then translated into real life-saving medical research," Miss Halim said.

It's not just schoolchildren who find the program fun, with Telethon Kids researchers like PhD student Denby Evans getting just as much out of it as the kids.

Ms Evans regularly volunteers in the program to help build awareness of opportunities in science for the younger generation.

"Great scientists start out as curious children," Ms Evans said. "The little girl with endless questions might one-day cure cancer, or the boy with the big imagination could invent life-saving technology."

"When we engage these children, we aren't just playing games and sharing simple facts. We are sparking curiosity, delivering inspiration, and most importantly, empowering the next generation of scientists."

Discovery Centre Manager Cristin Taylor said the program was an integral part of the Telethon Kids Institute's commitment to the community and had achieved phenomenal reach in its first year of operation.

"In 2020 alone more than 1,500 kids from 23 schools came through our school program, with hundreds more engaged through our school holiday workshops," Mrs Taylor said.

"By introducing students to our researchers and facilities we hope to inspire the next generation and – one day – even welcome some of them back to the Institute as real-life researchers."

WHAT'S NEXT

- ▶ Continue to grow the programs offered, giving more researchers the opportunity to get involved and more schools the chance to visit



The Discovery Centre was made possible thanks to a **\$1.5 million grant from Lotterywest.**



ATLAS REVEALS STATE OF CHILD HEALTH



An interactive Child Development Atlas created by Telethon Kids researchers is giving policymakers, planners and services easy access to important data about the health and wellbeing of WA families – helping them to better understand and plan for their communities' needs.



Scott Sims and Dr Rebecca Glauert

Having a sense of place is a fundamental ingredient for human wellbeing and helping us to feel we belong. But it's also critical for anyone who wants to tackle the 'wicked' health and social problems that stop kids and families from thriving and place a strain on government and other services.

For nearly a decade Dr Rebecca Glauert and her team dreamed about creating an atlas that pulled together and visualised available data on child health and development in a way that could help researchers, planners, policymakers and other organisations make better decisions about where to locate services and how to help children and families.

“This idea came about more than 10 years ago when I went to Canada and saw some exciting mapping work they had there,” Associate Professor Glauert said.

“We had been working closely with government partners for over 10 years, utilising their data to undertake research aimed at improving the health and wellbeing of children. Since we were already working with all these data, we thought let's just make it available for everyone to improve policy and decision making that can help children and families more effectively.”

After trying for years to get funding, Associate Professor Glauert and team were eventually able to get work on the WA Child Development Atlas under way with the support of The Ian Potter Foundation and Minderoo, through CoLab – Collaborate for Kids.

Launched this year after three years of collaboration, negotiation and development, the Atlas already has more than 500 subscribers across the State, from government agencies and local government authorities to schools, community organisations and parenting groups.

Those who've explored the WA Child Development Atlas have raved about its value as a free community resource that will help them better identify priority areas, target services and plan strategically. The team is also fielding a constant stream of requests from others interested in learning about how they may be able to use the Atlas.

Researcher Scott Sims said the tool was generating particular interest among local governments, which are now required to produce community health profiles to aid their public health planning.

“Normally every single one of them would have to collect data from government agencies – now they can just go to the Atlas and get a view of their local government area,” Mr Sims said.

“We've already created community profile infographics – data snapshots – for quite a lot of communities.”

Jay Weatherill, CEO of Minderoo Foundation's Thrive by Five initiative, said the Child Development Atlas was key to improving developmental outcomes for children.

“It will assist communities develop and implement local plans which are critical to improving outcomes for children and young people,” Mr Weatherill said.

“I also believe it will be instrumental in getting government and non-government agencies to work through communities to implement cross-agency plans to improve outcomes for kids.

“Currently in many communities we have lots of services but little planning.”

Mr Charles Goode AC, Chairman of The Ian Potter Foundation, said the Child Development Atlas was the first resource of its kind in Australia dedicated to children's development.

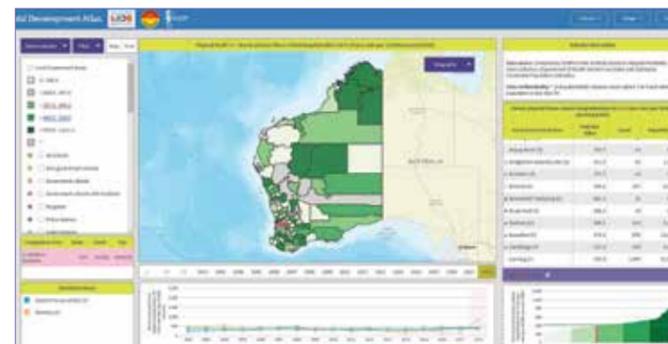
“We see strong potential in scaling this invaluable resource nationally,” Mr Goode said.

The team plans to do just that, recently receiving a grant to partner with more than 20 groups across the country to create an Australian National Child Health and Development Atlas.

The team recently received a grant to partner with more than 20 groups across the country to create an Australian National Child Health and Development Atlas.

“People are doing different things across the country in terms of visualisation of data on children and young people and geographically mapping it,” Associate Professor Glauert said.

“We want to bring the best bits of everything everyone's doing together into one spot and create the best resource we can. It won't be



WHAT'S NEXT

- ▶ To meet demand for snapshot community profiles, the researchers are seeking funding to create a reporting function that automatically generates local community profiles for download
- ▶ The team is also proposing community implementation work by partnering with several communities in WA to develop community-based social and community plans using the Atlas

exactly the same as the Child Development Atlas but will serve a similar purpose.”

She said the Atlas had been a labour of love but it was gratifying to see it being taken up so enthusiastically.

“It's so exciting to see this tool we've dreamed about for so long being used in exactly the way we hoped.

“We're so grateful for all the partners who have patiently supported us through this long process – it was nice to see that they understood and supported our vision.”

Associate Professor Glauert's team has since joined the School of Population and Global Health at The University of Western Australia but will continue to lead the WA Child Development Atlas and develop the national project in collaboration with Professor Donna Cross and the Development and Education team at Telethon Kids.

Find out more at childdevelopmentatlas.com.au

DID YOU KNOW?

- ▶ The WA Child Development Atlas is an **interactive map** which visualises deidentified **population-level data from multiple data sets collected by government and other agencies**
- ▶ The Atlas contains **five different geographical boundary types**, including WA's local government areas
- ▶ **Users can view community wellbeing profiles across a range of indicators**, choosing which communities to include – making the comparison of profiles for different areas quick and easy
- ▶ The Atlas draws on longitudinal data sources going back to 1990, allowing users to **identify changes and trends over time**
- ▶ The **data target children and young people aged 0–24** and include indicators of child and youth development including **birth weight, preterm birth, chronic diseases, mental health, and hospitalisations**
- ▶ The team wants to ensure existing data are maintained and kept up to date, but also to extend the data drawn on. The researchers are in discussions to **add maternal child health nurse data from the Purple Book all WA parents receive when a child is born**, and envisage that in the future the Atlas could include **data associated with pollution and climate change**
- ▶ To make the Atlas more appropriate and relevant for Aboriginal communities, the team is seeking approval for the **inclusion of data by Aboriginality**

DOGS AND KIDS: GOOD FOR THE HEAD, HEART AND HEALTH



It was the right story at the right time: six months into COVID-19, as the world was reeling from the relentless blows of a ballooning pandemic, along came a warm, fuzzy tale about kids and dogs that hit everyone in the feels.



Arlo Pradera (6) and his dog Comet, who are taking part in the PAWS study. © West Australian Newspapers Limited

Media across the world lapped up research led by Associate Professor Hayley Christian which found that having a family dog – and regularly playing with it and taking it for walks – could boost young children’s physical and emotional health.

High-reach outlets from the BBC, CNN, Fox, The Times of India and Xinhua to the New York Times, Washington Post, Daily Mail, Modern Dog Magazine and This Dog’s Life carried various takes on the research, with many seizing on the idea that children are more likely to be kinder and less likely to have emotional problems if there’s a dog in the family.

The results focused on the benefits for preschool-aged children and followed earlier research by

Associate Professor Christian and team that having a dog had a range of benefits for school-aged children, and that dog ownership has benefits for stress and mental health in adults.

The study found children aged 2–5 years from dog-owning households had increased pro-social behaviours like sharing and cooperating and were less likely to have conduct or peer problems, compared to children without a dog.

Associate Professor Christian said the beneficial impacts for young children had a lot to do with how often children played with or walked their family dog, but even the researchers were surprised by the strength of the results.



“While we expected that dog ownership would provide some benefits for young children’s wellbeing, we were surprised the mere presence of a family dog was associated with many positive behaviours and emotions,” Associate Professor Christian said.

“Also, the increased time children spend with their dog whilst playing with it or going on family dog walks may be one of the key mechanisms through which dog ownership facilitates young children’s social-emotional wellbeing.”

Associate Professor Christian said the positive response from around the world showed the timing was right – with a pandemic in the background, people were ripe for good news – but also reflected the strength of the study, which involved more than 1,600 families, and the fact there had previously been little research about the impact of dog ownership on such a young age group.

“The way the research was picked up by the international community was just incredible – it was such a good opportunity to shine a light on the great research coming out of our Institute here in Perth,” she said.

Associate Professor Christian cautioned that while research was increasingly showing the child health and developmental benefits of dog ownership – a choice many had made during the pandemic – it involved a significant responsibility and commitment that shouldn’t be rushed into.

WHAT’S NEXT

- ▶ The positive results have led to further international funding, with the team now piloting a community-based intervention as part of the PAWS study. The intervention uses personalised text message prompts – along with a dog pedometer and diary for kids to fill in – to encourage parents to get their kids out and about with the family dog
- ▶ “What we’re trying to do is find simple but important strategies that can improve child and family health and wellbeing,” Associate Professor Christian said. “We are already seeing that this light-touch approach is having a positive impact. It’s the kind of thing which could be easily scaled up to the wider community and be a very cost-effective way to increase physical activity and improve child development outcomes.”

- ▶ Associate Professor Christian’s paper on **preschool-aged children and dogs** featured in more than **500 media articles** and made it into the top 5 per cent of the almost 18 million research outputs ever tracked by Altmetric (which measures the online impact of journal articles)
- ▶ The paper – which **used a Dogs and Physical Activity tool** developed by Associate Professor Christian to **help measure the child health and development impact of dog ownership** – surveyed 1,646 WA parents
- ▶ It found **children from dog-owning households were 30-40 per cent less likely to have conduct or peer problems**, had **23 per cent fewer total difficulties**, and were **34 per cent more likely to have pro-social behaviours than children without a family dog**
- ▶ **Family dog-walking at least once a week and active play with the family dog three or more times a week** increased the likelihood of preschoolers’ pro-social behaviour by up to 74 per cent
- ▶ The findings emerged from the Play Spaces and Environments for Children’s Physical Activity (**PLAYCE**) project, a **three-year Healthway-funded study** (2015–2018) which investigated **early childhood education and care, home, and neighbourhood influences on preschoolers’ physical activity**



This research was funded by Healthway and the Human-Animal Bond Research Institute (HABRI).

Associate Professor Christian has previously been supported by a National Health and Medical Research Council Early Career Fellowship and has received two consecutive National Heart Foundation Future Leader Fellowships.

She is also a Chief Investigator on the Australian Research Council Centre of Excellence for Children and Families across the Life Course, which is a \$32 million investment to deliver transformative research and translation to break the cycle of deep and persistent disadvantage and improve outcomes for all Australians.

PANDEMIC PIVOT KEEPS VITAL SKIN PROGRAM ALIVE



The unique circumstances that upended 2020 for so many brought both challenge and opportunity for members of the SToP (See, Treat, Prevent skin sores and scabies) Trial team working with remote Aboriginal communities across the Kimberley.

Faced with a global pandemic, the prospect of COVID-19 spreading to remote communities, and the reality of the high chronic disease burden experienced by remote living Aboriginal people in the Kimberley region, Aboriginal leaders recommended all non-essential visiting services to remote communities, including Telethon Kids research, cease.

The decision could have brought vital research occurring across the Kimberley to a halt, but building on already established relationships, the SToP Trial team instead pivoted – using virtual technology to continue priority health promotion activities and engage with partners they were no longer able to visit in person.

“The SToP Trial team has been working with nine communities throughout the Kimberley region for the past three years, identifying children with skin infections and referring them to the clinic for treatment, as well as working with local services to enhance skin health practice and prevention,” said Associate Professor Asha Bowen, Head of Skin Health at the Wesfarmers Centre of Vaccines and Infectious Diseases, based at Telethon Kids Institute.

“This is a really great partnership between scientists, health services and the community. We’re finding better ways to work and sharing knowledge so we can all work together towards improving skin health.”



This art piece by Bardi artist Luke Riches titled “Gathering Circles” represents the 9 Aboriginal communities that work with the Telethon Kids Institute Skin Team on the SToP Trial. The circles vary in colour and composition, just as the communities hold their own unique identities. The backdrop of pindan orange and coastal blues convey the land and sea setting that makes the Kimberley so beautiful. The dot painted trails show a connection between the communities, of both foot trails and song lines that unite the people.

There has traditionally been a large gap between the discovery of public health knowledge and its application in practice. With skin infections in remote Aboriginal children among the highest in the world, turning research into a community health message quickly is a high priority.

Skin infections are common, and not always prioritised for treatment. They cause itching, discomfort, disturbed sleep and school absence. If untreated, skin infections can lead to sepsis, kidney disease and rheumatic heart disease.

For these reasons, according to Wesfarmers Centre PhD student Tracy McRae, early intervention – and even better, prevention of skin infections altogether – is the most powerful weapon in tackling these possible long-term effects.

“Our skin plays a vital role in keeping us healthy, so the information gained from the SToP Trial will contribute to the ultimate goal of reducing the number of children and families affected by preventable diseases caused by skin infections,” Mrs McRae said.

“By working in partnership with communities, Kimberley Aboriginal Medical Services, WA Country Health Service (WACHS) – Kimberley, and Nirrumbuk Environmental Health and Services, we’re able to translate research into practice quickly.

“We’re turning our research into community health messages and practices, and training people in the community to prevent, identify and treat skin infections.

“We know that translating research into targeted prevention messages and empowering communities to take a lead role are the key ingredients to create change.”

HIP HOP 2 STOP VIDEO

It didn't take long for shyness to make way for excitement when a group of children from Dampier Peninsula communities got together last year to make a fun hip hop video with a serious message.

Produced by Broome-based Goolarri Media and led by Aboriginal community members working in partnership with the SToP team, the Hip Hop 2 SToP video focuses on important environmental health messages to keep skin strong and healthy.

Thanks to the COVID-19 pandemic, project consultation, planning, lyric writing and educational workshops all occurred online via Microsoft Teams – a first-time experience for the community and researchers alike.

Children from Ardyaloon (One Arm Point), Beagle Bay, Djarindjin and Lombadina worked with Broome Hip Hop artist Jacob Hamaguchi to come up with the lyrics, which remind viewers to ‘take a shower so you smell like a flower’. The chorus encourages kids to ‘keep their liyan strong’, which means spirit and connection to community.

While co-designing all happened virtually, the SToP trial team received permission to travel to the communities in October 2020 to film the video on country over five days as part of a Woombooriny Amboon Angarriya Partnership Initiative (WAAPI) youth empowerment camp, designed to build the capacity of our future leaders.

Hip Hop 2 SToP was launched in December 2020 and has since been viewed more than 1,400 times on YouTube.



“We are so lucky to work in partnership with Aboriginal health service providers and community members throughout the Kimberley, and filming the video was a great way to celebrate the vital work we are achieving together to reduce the burden of skin infections,” said SToP Trial lead, Associate Professor Asha Bowen.

The National Healthy Skin Guideline – development of which was led by Associate Professor Bowen – is now the gold standard for **the treatment, prevention and public health control of skin infections in Aboriginal and Torres Strait Islander populations across Australia.**

Launched in 2018, the **guideline was developed in collaboration with leading researchers and clinicians in the skin health field** to help healthcare providers easily **diagnose, treat and prevent skin infections. It has since been viewed more than 7,600 times, with more than 2,600 downloads.**

Extra resources co-designed with communities were launched last year to **complement the guideline.** The suite of resources associated with the project has since been implemented by Queensland Health and has been adopted and implemented as the **healthy skin training package throughout regional WA.**

A 50% REDUCTION IN SKIN SORES IN THE KIMBERLEY WILL PREVENT, PER YEAR

21 Aboriginal babies from being hospitalised with skin sores

10 Aboriginal children from developing Acute Rheumatic Fever

1 death from Rheumatic Heart Disease

WHAT'S NEXT

- ▶ The SToP Trial is now halfway through, with expected completion in 2023
- ▶ With little community transmission of COVID-19, the team will continue visiting and working in communities in 2021 and 2022, although virtual technology will play an ongoing role in the trial
- ▶ The team will continue to ensure ongoing engagement with, and building the capacity of, local Aboriginal community members to ensure real-world impact and sustainability of healthy skin activities beyond the life of the trial

PARADIGM SHIFT

THIS RESEARCH CHANGES
THE VERY WAY WE THINK



Nina is a beautiful, gentle soul
who takes everything in her stride.
Read Nina's story at
telethonkids30.org.au

PRECISION HEALTH ACCELERATOR TAKES SOME OF THE GUESSWORK OUT OF RESEARCH



Running any research project is a feat of logistical gymnastics – and often, you don't know what can go wrong until it happens. The aim of the Precision Health Accelerator at Telethon Kids is simple: to streamline scientific research every step of the way, using system biology approaches, cutting-edge technologies, and analysis pipelines.

The brainchild of Professor Tobias Kollmann*, the Accelerator seeks to fast-track scientific research. It's a unique hybrid model – combining research with a service platform and providing end-to-end solutions for projects. The team's work ranges from helping to design the study to sample collection and data analysis – all while offering bespoke project management and logistics.

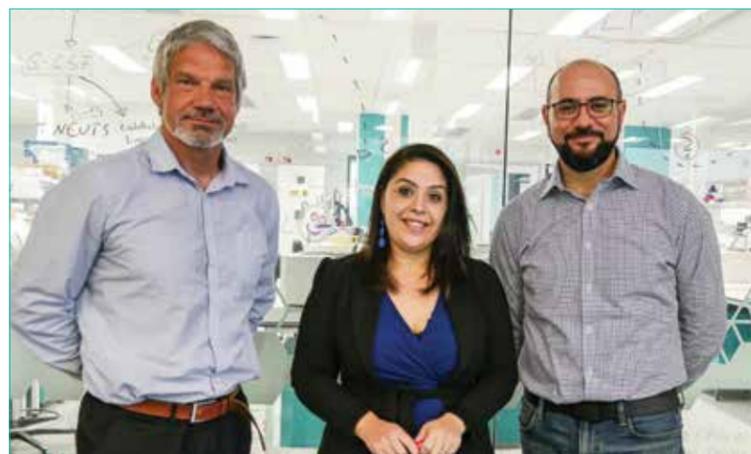
Program Manager Dr Rym Ben Othman said the Accelerator team aimed to collaborate with other researchers to identify opportunities to implement studies optimally – anticipating potential problems or roadblocks before the work begins.

"We optimise the protocols for the study and inform on the best practices from the clinical to lab processes – everything from governance to ethics and clinical data capture, to make sure the project follows all the guidelines," she said.

“Things as simple as using the wrong type of needle to take blood samples can mean those samples aren't suitable for some specific downstream analysis, so it's really useful for projects to have the right procedures in place from day one.

"On the lab side, we make sure the protocols are written in a way that is suitable for the study and the information is recorded in the same way."

The Accelerator is supporting a range of projects, both inside and outside Telethon Kids Institute. They range from immune profiling to help identify biomarkers for Rheumatic Heart Disease, led by Professor Jonathan Carapetis, to investigating whether frontline health workers can be protected from COVID by an already established vaccine – part of the BRACE project, led by Professor Tobias Kollmann and Northern Star Professor of Children's Respiratory Health Stephen Stick.



Professor Tobias Kollmann, Dr Rym Ben Othman and Dr Rad Aniba

Crucially, the Accelerator program offers a cutting-edge multi-omic approach to sample analysis, meaning several layers of molecules are examined together to give a 360-degree view of the information that underlies a particular disease.

Dr Ben Othman said the Accelerator operated like a 'concierge service', putting researchers in touch with the best providers and helping to set up new collaborations with experts in the field to carry out complex data analysis.

"We test and develop new protocols and we collaborate with other researchers to help them access those new technologies, and to do advanced analysis for systems biology, using different 'omic' platforms – whether that's RNA sequencing or DNA sequencing or other techniques," she said.

"We aim to combine lab technologies with advanced analysis pipelines to help researchers accelerate their projects."

*Professor Kollmann is co-funded by the Perth Children's Hospital Foundation. His research is generously supported by the McCusker Charitable Foundation, Stan Perron Charitable Foundation and Channel 7's Telethon.

UNLOCKING THE MYSTERIES OF THE IMMUNE SYSTEM TO TACKLE CHILDHOOD CANCER



The Telethon Kids Cancer Centre is at the cutting edge of developing new, safer ways of treating children with cancer using their own immune systems. Led by Professor Terrance Johns, the Centre has become the first in Australia to work on developing new immunotherapy treatments for paediatric cancers – and the research is so promising it is now underpinning a significant amount of the Centre's work.



For decades, surgery, radiation therapy and chemotherapy have been the main weapons in the fight against childhood cancer. But while they can be efficient at killing cancer cells, toxic radiation therapy and chemotherapy treatments take their toll on little bodies – often leading to lifelong impairments or even secondary cancers that could ultimately take the child's life.

Now a new contender is in the ring to fight childhood cancer: immunotherapy. Its potential is so exciting, it has driven a conscious shift in focus for the Telethon Kids Cancer Centre. From sarcoma and leukaemia to adolescent melanoma and brain cancer – almost every research group is working to find new treatments that harness the immune system to fight cancer.

“It's really exciting to think that this centre-wide focus could lead to the next major breakthrough in immunotherapy,” Professor Johns said.

Immunotherapy, which involves 'supercharging' the body's own immune cells to fight the cancer, has been used to successfully treat some adult cancers but has had less success in children, especially in solid tumours.

"I think one of the main reasons why we simply don't know enough about children's immune systems in the context of cancer," Professor Johns said.

"We don't know how the immune system interacts with cancer in children and how that may be different to adults – and most of the current immunotherapy treatments have been developed in adults."

For Dr Bree Foley, Senior Research Officer in the Telethon Kids Cancer Immunotherapy Team, unlocking the mysteries of the immune system is all in a day's work.

"Cancer is really clever and it finds many ways to evade the immune system – it hijacks the normal processes," Dr Foley said.

"What we're trying to do is basically get the immune system to start doing its job again. How can we boost it? What kind of weapons or extra ammunition can we give to the immune cells to really kick-start them and basically get them to do their job?"

The answers might be nearer than you expect.

Continued over....



Dr Joost Lesterhuis

Dr Joost Lesterhuis and his colleagues in the Sarcoma Translational Research Team are working on an immunotherapy gel that could be applied directly to the tumour during surgery.

“The key thing about sarcoma is surgery is always the first treatment, which means that we have access to the cancer itself,” Dr Lesterhuis said.

“So we’re developing a gel that the surgeon can apply during surgery and then close the wound and the patient goes home.

“Then over the course of days or weeks, the gel releases this immunotherapy into the wound area and activates an immune response. The immune cells can then mop up any remaining cancer cells.”

A type of immunotherapy known as cellular therapy has already seen some success in treating children with leukaemia. It involves genetically engineering the patient's own immune cells in the lab to specifically target the cancer and growing them to an army of millions, before putting them back into the patient to travel around their body and fight the cancer cells.

Dr Bree Foley and the Centre's Cancer Immunotherapy Team are working to fast-track this process by using healthy adult donor cells instead.

“We’re trying to make what we call ‘off the shelf’ cellular therapy where we take cells from healthy people, supercharge them in the lab and then give them to a cancer patient so the patient doesn't need to wait for their therapy, the therapy is all ready to go,” she said.

“It’s definitely the next big hope in cellular therapy because it can be taken from healthy people and given to patients.”



Dr Bree Foley

Finding safer treatments for children with cancer is what drives Dr Raelene Endersby, Co-head of the Brain Tumour Research Team.



Dr Raelene Endersby

“Children with brain cancer have a reasonable chance of being cured of their disease, but one of the problems we have with survivors of childhood brain cancer is that they suffer from a lifetime of negative side effects that are a direct consequence of the treatments we give them,” Dr Endersby said.

“Treatments like radiation therapy and chemotherapy are very damaging to the normal cells in the brain that are left behind once the tumour has been eradicated.

“So we need to find more treatments that are safer and less toxic for children.”

For Professor Terrance Johns, driving a whole-of-centre focus on immunotherapy is a challenge he knew he needed to take on.

“We are genuinely at the cutting edge here and it’s one of the reasons we chose this area because we felt there was a deficit of people working in this space,” Professor Johns said.

“There’s certainly no one in Australia working on immunotherapy in children and while there are individual groups working in this area overseas, there is not a comprehensive cancer centre with an underpinning focus on immunotherapy in children.”

Cancer is still the leading cause of death by disease for Australian children. For our dedicated team of researchers, the stakes couldn't be higher.



Professor Terrance Johns



The vital work of the Telethon Kids Cancer Centre is made possible by the generous support of **Australian Lions Childhood Cancer Research Foundation, Children’s Leukaemia and Cancer Research Foundation, Channel 7 Telethon Trust, Stan Perron Charitable Foundation, Sock it to Sarcoma, Simon Lee Foundation, The Kids Cancer Project, The Pirate Ship Foundation, Perpetual, Brady Foundation, My Room Children’s Cancer Charity, Cure Brain Cancer Foundation, BrainChild, Cancer Council WA, Cancer Council NSW, NHMRC, Cancer Australia, WA Department of Health**

WHAT’S NEXT

- ▶ Continued development of the immunotherapy gel for treatment of sarcoma
- ▶ Working on ‘off the shelf’ immunotherapy from healthy donor blood
- ▶ Exploring ways to use immunotherapy to treat brain cancer patients

STANDING UP TO A CRUEL DISEASE



Boys diagnosed with the extremely rare muscle-wasting disease Duchenne Muscular Dystrophy are often using a wheelchair by their early teens. After research by the Telethon Kids Institute proved the value of standing wheelchairs, there is now a framework in place to help families apply to access the costly equipment under the NDIS.

Klair Bayley knew her son Logan would eventually need a wheelchair. Diagnosed with Duchenne at the age of five, Logan's muscle strength reduced dramatically as he went through primary school.

"He didn't want to use a mobility scooter in high school because he thought people would think he was less mature. He wanted to feel safe in a big environment with bigger kids," Klair said.

Motorised wheelchairs with a standing function – allowing the user to stand fully upright while being supported – had just become a reality. But they were extremely expensive, and not funded by the government.

That's when Klair joined forces with Telethon Kids Institute's Co-Head of Child Disability, Associate Professor Jenny Downs. In 2012, they received a small philanthropic grant to pay for standing wheelchairs for 14 boys. They were determined to not just help those boys, but to carry out rigorous research that could help every boy with this cruel disease access a standing wheelchair.

The results were life-changing.

 "It's not really a device for standing, it's a device for living," Associate Professor Downs said.

While the rarity of Duchenne meant the study was relatively small, it found that giving the boys the option to stand up was associated with significant physical and mental health benefits.

Using a standing wheelchair allowed the boys to do some things more independently. They could speak eye-to-eye with their friends, reach items around the home, and crucially, take themselves to the toilet.



Logan Bayley



Associate Professor Jenny Downs

"They're teenage boys and the standing wheelchair meant that they could toilet themselves more independently – giving them more privacy and capacity to do things by their own schedule," Associate Professor Downs said.

"If they can manage more independently by themselves, that's brilliant."

Now 19, Logan Bayley still uses the chair to stand – and his mum credits the equipment with helping to keep her son more mobile than he otherwise might have been.

"It's a complete gamechanger," Klair said. "It felt empowering that we were in some way giving back what Duchenne was taking away."

The boys involved in the study maintained their joint position in standing because they were moving more – but the biggest benefit was to their mental health.

"Both the parent- and child-reported evaluations of mental health indicated the boys were in a much healthier place mentally after they received the standing chair," Associate Professor Downs said.

 "There's some evidence that when a boy with Duchenne loses the ability to walk and a wheelchair becomes a necessity, there is a decline in his mental health. But here we were seeing the boys go in the opposite direction."

"Using these wheelchairs was promising to the boys' quality of life because there was opportunity for more independence."

The findings of this research had a further impact – providing the trigger for the development of a 'consensus statement', developed by local and international experts, which is now used by therapists when they make a case to have a boy's standing wheelchair funded by the NDIS.

"The NDIS have not turned anybody down since we published that research, because the occupational therapists and physios can actually use the evidence base for their recommendation to purchase these expensive pieces of equipment," Klair said.

"It's being used in healthcare systems all around the world. That's something we're really proud of – to see this having an impact for kids and young adults everywhere."

WHAT'S NEXT

-  More research to understand the value of the chairs as the boys grow older and their muscles become weaker, particularly for functioning in activities of daily living and respiratory health



We gratefully acknowledge the funding of **Save Our Sons Duchenne Foundation** for this work

PUTTING MALARIA ON THE MAP



A global network of researchers led by Kerry M Stokes Chair of Child Health, Professor Pete Gething, is working to help support informed decision-making for malaria control at international, regional and national scales. Together, they are helping countries most affected by deadly malaria use their limited resources for maximum impact.

For just over a decade, between 2005 and 2017, global progress against malaria was improving year-on-year. Around 2018, for complex reasons, the gains stopped coming and – in some places – cases even started to increase again.

In response to this faltering progress, in late 2019 the World Health Organization (WHO) launched an initiative called High Burden to High Impact — a multi-faceted approach focused on the ten countries in Africa (plus India, with its own special set of circumstances) that collectively contribute around 85 per cent of the world's malaria deaths and disease.



Professor Pete Gething

International malaria expert Professor Pete Gething and his team were already generating maps of malaria risk on a global scale for the Malaria Atlas Project (MAP), on behalf of international policymakers like WHO and the Bill & Melinda Gates Foundation. The new WHO focus meant a pivot

to also cater to a different set of stakeholders: individual countries who need support for their day-to-day, month-to-month operational decisions.

That pivot has translated into sophisticated modelling highly tailored to the needs of each country. Using this modelling, Professor Gething and his MAP team are producing cutting edge statistics along with incredibly detailed and bespoke characterisations of what a country's — and sometimes even a province's — malaria problem really looks like.

The resulting risk maps – much more detailed than any the MAP team produce on a global level – are co-developed with governments to help them

implement the measures most suited to their country's circumstances.

Professor Gething said reducing transmission and saving as many lives as possible was a balancing act of finite budget and resources, so it was vital that countries had information pertinent to their own conditions in order to make the best decisions on intervention tools. Potential measures include bed nets for people to sleep underneath, spraying houses and other buildings with insecticide to reduce mosquitoes, and providing access to healthcare so people can go to a clinic to get anti-malarial medication.

"We're building relationships with these countries; working closely with them to understand what they need, what data they have," Professor Gething said.

"We can drill down to create one-kilometre radius maps that are dynamic through time so we can see the changing passage of malaria through the year. We then map out where they currently have interventions, for example, what fraction of people are sleeping under a bed net in a one-kilometre pixel, so they can look at the data and see where the obvious gaps are.

"This points to how to better target scarce resources to get maximum impact."

The team gathers data from three main sources: survey results from door-knocking with detailed questionnaires in selected villages; administrative data from medical clinics, including the number of diagnosed cases and distribution of interventions; and environmental covariates such as temperature, rainfall, and vegetation density, that go into the model and help predict malaria.

Professor Gething said more data meant more answers for exactly where to allocate budget and resources – right down to individual provinces.

"While these interventions aren't rolled out in a reactive, responsive way, they do help the next several years of planning with a purpose for aiming to manage malaria better in the future," he said

THE COVID CONUNDRUM

COVID-19 has proven its role as a disruptor reaching all corners of the world. With this in mind, WHO and the Bill & Melinda Gates Foundation asked Professor Pete Gething and the MAP team to create a model analysing how differing levels of pandemic-related disruption could affect malaria control in Africa. The results were worrying, revealing that COVID could set control efforts back decades.

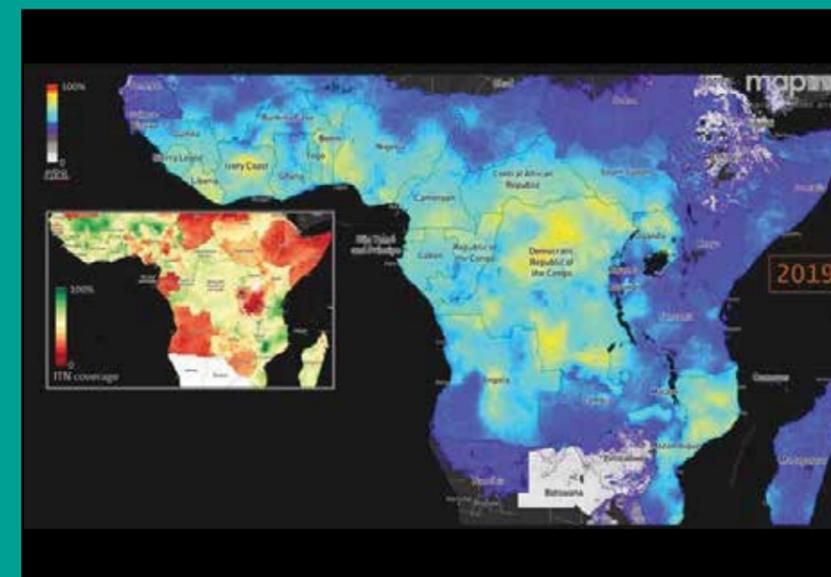
Professor Gething said the team explored what would happen if different interventions (bed nets, spraying with insecticide, and medication) were reduced by certain fractions, and what that would look like in terms of deaths and disease.

"We ran analyses for the whole continent...and the outcome was that there was potential to go back 20 years if people were to stop giving these interventions," Professor Gething said.

"We would very quickly have a malaria problem on our hands that is much bigger than COVID-19.

"WHO took those results and launched a massive advocacy campaign for African governments, saying no matter how they do it, they've got to keep rolling out these interventions. The implications, otherwise, are incredibly serious. There would be a massive spike in mortality.

"On the basis of that, they were able to reverse that decision in nearly all countries. Bed nets and sprays were barely disrupted, and our work directly contributed to that," he said.



The Malaria Atlas Project used sophisticated Big Data analytics to create detailed maps showing malaria risk that countries use to target resources. This one estimates the percentage of children infected with malaria in 2019 along with (inset) the percentage currently using an insecticide-treated net to protect them from mosquitoes at night.

DID YOU KNOW?

- ▶ In 2019 nearly **half the world's population** was at risk of malaria
- ▶ There were **229 million malaria cases globally** in 2019, with **409,000 malaria-related deaths**
- ▶ **Children under 5 years** of age are the **most vulnerable group affected by malaria**; in 2019, they accounted for about two thirds of all malaria deaths worldwide

- ▶ **The WHO African Region shoulders more than 90% of the overall disease burden.** The region has reduced its malaria death toll by 44% since 2000, but progress has slowed in recent years

WHAT'S NEXT

- ▶ The MAP team members consider their work with each African country they are involved with a partnership. Their aim is to foster local African researchers, build capacity and empower locally driven research so that in 5–10 years this important work can be truly owned by each country
- ▶ Working with other Institute researchers, the team plans to apply geospatial modelling techniques across WA child health challenges – with aims including improving equal access to mental health services; potentially creating a 'Food Atlas' measuring and monitoring food access across the state, for replication nationally; and examining how the built environment can be modified to improve children's physical activity, eating habits and weight status



Professor Pete Gething's role as the Kerry M Stokes Chair of Child Health is a partnership between **Curtin University, Telethon Kids Institute** and the **Channel 7 Telethon Trust**

WHAT'S IN A NAME?



Mum Laura, Charlotte and brother Josh



For thousands of WA children living with undiagnosed diseases, it's hope. The computational biology team, a founding group of the new precision health program at Telethon Kids, is relentlessly pursuing technologies that can give more children the name they seek – a diagnosis – in research that is at the frontier of this field.

Charlotte brings her family so much joy.

And while Perth mum Laura West has an abundance of love for her daughter, she also has so many unanswered questions.

"People say, 'What's wrong with her' and I actually have nothing to say when people ask the question. Doctors scratch their heads and say this shouldn't be happening," Laura said.

With Charlotte having already been through 60 surgeries and countless tests and procedures, nobody knows what treatments might be most effective or, sadly, how long she will be with her family.

Imagine Optus Stadium seated at capacity with 63,000 children. That's approximately the number of children, just like Charlotte, living with a rare disease in Western Australia, yet more than 70 per cent of children suffering from a rare disease remain undiagnosed.

This enormous number translates into an equally heavy burden of suffering and uncertainty across our community.

It takes an average of five to seven years for a child with a rare disease to get a diagnosis – a journey that can be substantially longer in the most challenging cases. A diagnosis provides clarity – a powerful breakthrough that can connect these children with critical therapies or even, one day, a cure. Additionally, it provides a valuable connection to other children and families around the world who are suffering from the same condition, reducing feelings of isolation.

Research can get us there.

Telethon Kids Institute is discovering and delivering new solutions to end the diagnostic odyssey, along with new insights and pathways that, importantly, bridge diagnosis with care.

The genomics revolution means we can now detect tiny variations in DNA, which are uniquely different in every individual and which may be the cause of symptoms.

Our Institute is the catalyst for a collaboration of specialised teams of clinical geneticists, mathematicians, computer and laboratory scientists finding answers for each child.



Dr Timo Lassmann



Professor Gareth Baynam

Rare diseases expert Gareth Baynam and computational biologist Feilman Fellow Timo Lassmann head up the Institute's pioneering team of disease detectives. They have seen many patients, most of them children, who suffer with severe conditions and who have spent years without answers – something Professor Baynam says has become a global child health issue.

“We focus on children with the most perplexing and challenging medical mysteries in WA,” Professor Baynam said.

The team gathers medical information about a child, shares it with specialists the world over, and searches global genetic population databases to look for similar disease symptoms.

Complementing this is world-first technology developed by Dr Lassmann and his team. Together, they created a computer algorithm that searches individuals' genes for the specific variation causing the disease.

WHAT'S NEXT

- ▶ Dr Lassmann is developing original algorithms to pinpoint the likely cause of disease faster. Simultaneously, our lab researchers are developing new assays to more rapidly validate the function of hundreds of variants in parallel. Taken together, the research aims to end the diagnostic odyssey for families in WA

In addition to his work at Telethon Kids, Dr Lassmann is helping to ramp up global progress on rare diseases. In recognition of his considerable expertise, he was recently asked by the International Rare Diseases Research Consortium (IRDRC) to join a newly formed taskforce focused on integrating new technologies for the diagnosis of such diseases

Charlotte's story was shared by her mum, Laura, at the **2020 Telethon Ball Gift of Giving auction** and a very generous ballroom of donors rallied behind her story, **raising more than \$1 million dollars to support Telethon Kids research into decoding undiagnosed diseases.** Through cutting edge genetics research, we are now in a position to address some of the most challenging medical mysteries faster, so that families like Charlotte's get the answers they need.



Developing innovative algorithms is challenging research work and can take the team years. Once developed, however, the algorithm can be applied within mere hours. Thanks to this work, the team now can diagnose around 60 per cent of cases – ten per cent more than when it started.

"Through the use of artificial intelligence and machine learning techniques, we bring in data that tells us how genes are expressed in our body," Dr Lassmann said.

"We integrate this information with the clinical descriptions of what's wrong with the child to find the needle in the haystack – the one mutation in 100,000 that may cause the disease."

Diagnosis means more than an answer. It also means a reduction or end to costly and invasive tests, and opens up access to treatments, therapies, medication, and disability funding.

"There is so much urgency and responsibility to be able to do this better at an even greater scale," Professor Baynam said.

Laura has seen first-hand some of the research in action with Charlotte.

"She went from complete immobility to being able to walk," Laura said. "This research may be able to give us closure ... ideas about what our future might look like."



Rare and undiagnosed diseases research is supported by the McCusker Charitable Foundation and the Telethon Ball Gift of Giving donors

THE IMMORTAL LEGACY OF JETTE FORD



The Institute farewelled one of its most treasured employees this year, as Telethon Kids Cancer Centre research officer Jette Ford closed the door on a quietly stellar 37-year career which has helped to change the face of cancer research in WA and around the world.



Humble to a fault, Jette Ford wouldn't tell you herself that – together with Telethon Kids founding researcher and Honorary Emeritus Fellow, Professor Ursula Kees – she pioneered paediatric cancer research in Western Australia.

She also wouldn't tell you she's one of the few people in the world who can reliably coax immortality out of cancer cells taken directly from patients – an exceptionally difficult task but one she's mastered 116 times.

The significance of this feat and what it means for cancer research here and overseas cannot be overstated.

"She has probably cultured more cancer cell lines than anyone else in the world," said Brain Tumour Research Co-Head Dr Nick Gottardo, who trained in lab work and cell culture under Ms Ford as a PhD student.

Although notoriously difficult to establish, cancer cell lines are essential tools in the ongoing global effort to better understand and find new, gentler therapies to beat cancer.

"These unique models enable us to do a great deal of scientific work, including drug testing and screening to try and identify new treatments for, in our case, children with cancer," explained Co-Head of Leukaemia Translational Research, Dr Rishi Kotecha.

"Without them, we wouldn't have been able to do a fraction of the research we've undertaken at Telethon Kids.

"But Jette hasn't just produced these cell lines for our use here – we've sent them all over the world,

to other parts of Australia, to the UK, America, Europe, parts of Asia – where other researchers are also using these resources to try to improve outcomes for children with cancer.

“Her work is not just renowned locally, it's renowned nationally and internationally, so she's had a really important role in cancer research over the last 30 years or so.”

Exactly how Ms Ford managed to repeatedly harness the immortality of cancer cell lines outside the body – including from tiny samples of incredibly rare cancers that few others have been able to tame – remains a source of awe to her colleagues.

"She's a magician when it comes to growing up cell lines," according to Cancer Centre colleague Joyce Oommen, who now cares for the extensive biobank of patient samples and cell lines Ms Ford established.

"Somehow she just knows what a happy cell looks like versus an unhappy cell."



Professor Kees attributed Ms Ford's skill to her unique patience and rare work ethic.

"It requires patience and insight to read these cells and she did it on a daily basis – often in her own time – and especially when they were in the critical stage," she said. "Her dedication and success rate are second to none."

Ms Ford herself credits her success to her lifelong motto: "Always be good at what you're doing. Work hard, do it to your best ability and you'll always have a job."

Having witnessed the birth of the Telethon Kids Cancer Centre and broader Institute, helped

pioneer paediatric cancer research in WA, and mentored countless students and clinicians-turned-researchers, including Drs Gottardo and Kotecha, Ms Ford retired this year as Telethon Kids' second longest-serving employee.

"Like so many other students and researchers Jette took me under her wing and taught me everything she knew," Dr Kotecha said. "I owe a large part of my success today to her mentorship.

"She leaves an amazing legacy, not just in terms of the cell lines and tissue samples she leaves us with, which will enable us to continue advancing science for years to come, but her personal legacy."

HUMBLE BEGINNINGS PRODUCE WONDERFUL RESULTS

Within months of starting at the new cancer research unit Jette Ford had established her first cell line.

Since then, as part of the Telethon Kids Cancer Centre which emerged from the fledgling unit, she has nurtured 116 cell lines out of 1,000 patient samples, overseen the arrival and management of a growing array of cutting-edge technologies – including Western Australia's first liquid nitrogen tank – and built and cared for the Institute's extensive biobank of paediatric cancer samples. Lab records reveal her handwriting on at least 9,000 samples – some going back to 1984.

Throughout it all, the research undertaken by Ms Ford and Professor Ursula Kees, focused predominantly on childhood leukaemia but also encompassing other paediatric cancers, was generously supported by the Children's Leukaemia and Cancer Research Foundation (CLCRF) – which has raised millions of dollars to support this and other work within the centre over the years.

Longstanding CLCRF chairman Geoff Cattach was there when both Professor Kees and Ms Ford started. As the father of a 7-year-old boy with leukaemia, he was desperate for a cure and, with the Foundation, eager to support the new research focus.

Mr Cattach's son Brent was just the third child in WA to successfully receive a bone marrow transplant as part of the then-revolutionary program begun by visionary PMH oncologist Dr Michael Willoughby in 1984. Professor Kees and Ms Ford were also involved, carrying out vital lab work as part of the program.

Brent, now 43, survived but has experienced long-term health issues as a result of the harsh leukaemia treatment typical of the day.

Mr Cattach said he was proud, through the CLCRF, to have had a key hand in supporting research which has helped to make leukaemia treatment gentler and more effective over recent decades.

"They've got children's leukaemia to a stage now where it's almost curable – not quite, but close to it," Mr Cattach said.

“If you could get to a stage where they could have a needle and prevent it, that would be even more amazing. In the meantime, the next best thing is knowing they can virtually cure it – and without the horrific problems attached to it that we had back in our day.”

He said Ms Ford's work had helped to shine a light on WA's scientific strength.

"Once they started sending her cell lines overseas for people to do their research on, they couldn't get hold of them quick enough – it was terrific publicity for WA as well."

Mr Cattach has been CLCRF chair for 39 years now and – despite helping to care for both Brent and another son, Stewart, who survived two brain tumours – plans to continue fundraising efforts to support leukaemia research at Telethon Kids for a while yet.

"It's been a labour of love and a long, hard road, but it's been a wonderful result," he said.

COLLABORATING FOR IMPACT

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



Aroha is an old soul, perceptive and funny. Read Aroha's story at telethonkids30.org.au



Professor Jonathan Carapetis with the RHD Endgame Strategy

RHD ENDGAME TANTALISINGLY CLOSE



Professor Jonathan Carapetis has made eliminating rheumatic heart disease his life's work, and nearly 30 years into the task he's never been more confident the end is in sight. But his optimism relies on government funding and facilitating a series of vital strategies identified in a recently released blueprint – designed to wipe out the disease within a decade.

It's a disease many people have never even heard of – and for good reason, since for most Australians it was eliminated almost half a century ago – but for thousands of Aboriginal and Torres Strait Islander people, rheumatic heart disease (RHD) is still very much a reality.

Caused by Strep A bacteria, RHD starts with a sore throat or a skin sore. Without appropriate treatment, these problems can spark an abnormal immune reaction in the heart, leading to life-threatening damage to the heart valves. Many children who end up with RHD require open heart surgery and lifelong medical treatment. Others – their cases picked up too late – simply die.

All that could change thanks to a comprehensive strategy released late last year following years of intense collaboration between researchers, Aboriginal and Torres Strait Islander leaders, communities and people with lived experience of RHD and its precursor, acute rheumatic fever (ARF).

Compiled over five years by the END RHD Centre for Research Excellence, an Australia-wide collaboration based at the Telethon Kids Institute since 2015, the RHD Endgame Strategy lays out a blueprint that would allow the Federal Government to meet its commitment to eliminate RHD in Australia by 2031.

The Strategy, endorsed by 26 leading health and research organisations and launched in September 2020, reviews current and potential strategies to fight ARF and RHD and identifies five Priority Action Areas which, collectively, have the greatest potential to achieve elimination.

Chief among them is the requirement that action must be led by Aboriginal and Torres Strait Islander people, with community-based programs focused on healthy environments, early prevention, and care and support for those who already have RHD.

Telethon Kids Institute Director Professor Jonathan Carapetis – one of the world's leading experts on RHD and senior author of the Endgame Strategy – said the Strategy marked the first time a comprehensive evidence base had been developed showing how RHD could be eliminated.



"I'm more hopeful than I've ever been about the prospect of tackling RHD in Australia – this Strategy gives us the recipe to do exactly that," Professor Carapetis said. "But it will only happen if the practical strategies outlined are supported by government, with a catalytic investment to back them up."

He said RHD was a disease usually only seen in developing countries, yet Aboriginal and Torres Strait Islander people had some of the highest rates in the world, with more than 5,000 living with RHD or ARF.

"Without implementation of the Endgame Strategy, this number will more than double in the next decade," Professor Carapetis said. "At least another 8,000 Aboriginal and Torres Strait Islander children will develop ARF or RHD by 2031 if we simply stick with business as usual."

"Of these people, 650 will likely die and 1,300 will need open heart surgery."



"With the Endgame Strategy we literally have in our hands the prescription to prevent the next generation of Aboriginal and Torres Strait Islander children and their families from bearing the physical and emotional scars of RHD."

"Australia has an obligation to act."

Since its launch the Endgame Strategy has informed updates of RHD Action Plans in Queensland and the Northern Territory; and the National Aboriginal Community Controlled Health Organisation (NACCHO) is hoping to host a national implementation unit for the Strategy.

In February 2019 the Federal Government announced it was committing \$35 million to develop a vaccine to prevent RHD and other life-threatening conditions caused by Strep A – work Telethon Kids is heavily involved with as a key partner in the Australian Strep A Vaccine Initiative (ASAVI). Global philanthropic organisation, Open

Philanthropy, has also contributed US\$5.3 million to fund the Strep A vaccine clinical trial.

Following the Endgame Strategy's release, the 2021/22 Federal Budget included \$12.1 million for continued support of RHD control programs, with another \$12.8 million to be invested tackling RHD over the coming four years.

But lead author of the Endgame Strategy and END RHD Head of Strategy, Dr Rosemary Wyber,

said that while this re-funding of existing strategies would help, continuation funding alone would not change the trajectory of RHD in Australia.

"The RHD Endgame Strategy makes it clear that a transformative shift to Aboriginal and Torres Strait Islander leadership and substantive ongoing investment to address the structural, social and environmental determinants of health are also needed," Dr Wyber said.

WHAT'S NEXT

- ▶ The Endgame Strategy is helping to guide discussions on the development of a WA RHD Action plan
- ▶ The END RHD coalition, including all the major peak bodies for Aboriginal Community Controlled Health Organisations in jurisdictions where RHD is a significant problem, is championing the implementation of the Endgame Strategy

DID YOU KNOW?

- ▶ The **Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE)** was established in 2014 to address the **urgent need for a comprehensive, evidence-based plan to eliminate RHD across Australia**
- ▶ The **NHMRC-funded CRE** brought together **leading experts from 16 institutions across Australia**, including Telethon Kids Institute, with expertise in areas including infectious diseases, epidemiology, ethnography, disease modelling, and economic analysis
- ▶ In addition to a series of research studies, some of which are ongoing, the **END RHD CRE synthesised the collective experience of communities, clinicians, Aboriginal Community Controlled Health Organisations, and government and non-government organisations**, pairing it with **25 years of research to produce the RHD Endgame Strategy**
- ▶ The **Strategy was launched** by **Federal Health Minister Greg Hunt and NACCHO CEO Pat Turner AM, together with Professor Carapetis**, in September 2020
- ▶ It was **produced in collaboration** with **Aboriginal and Torres Strait Islander communities and leadership, including NACCHO**
- ▶ The **Strategy lays out five key priority areas** for **immediate attention**, with a strong emphasis on Aboriginal and Torres Strait Islander-led approaches
- ▶ **Implementation** could **prevent an estimated 8,000 new cases and 650 deaths by 2031**
- ▶ Having **delivered on its primary goal of producing the Strategy**, the END RHD CRE wrapped up in March this year

STRATEGY A CHANCE TO END THE CYCLE OF SADNESS

For Pat Turner, CEO of the National Aboriginal Community Controlled Health Organisation (NACCHO) and co-chair of END RHD, the Endgame Strategy offers an opportunity to not only end a cycle of infection, disease and tremendous sadness caused by RHD, but tackle wider issues leading to a gap in outcomes for Aboriginal and Torres Strait Islander people.



Pat Turner

She said those working in the busy Aboriginal and Torres Strait Island primary healthcare sector rarely chose to focus on a single disease.

"There is too much to be done – we can't afford to have our favourite diseases," Ms Turner told the Strategy launch last September. "But rheumatic heart disease sticks out. It's the greatest cause of cardiovascular inequality for our people in this country. Non-indigenous people literally don't get it. Ninety-eight per cent of people who get RHD are our people.

"We get it because of overcrowded housing, because despite our best efforts, showers don't work, taps don't run, and clothes don't get washed. We get it because our clinics are overrun with demand and sometimes skin sores and sore throats go untreated. We get it because the diagnosis is missed and sometimes it is too late for treatment.

"All that needs to change."

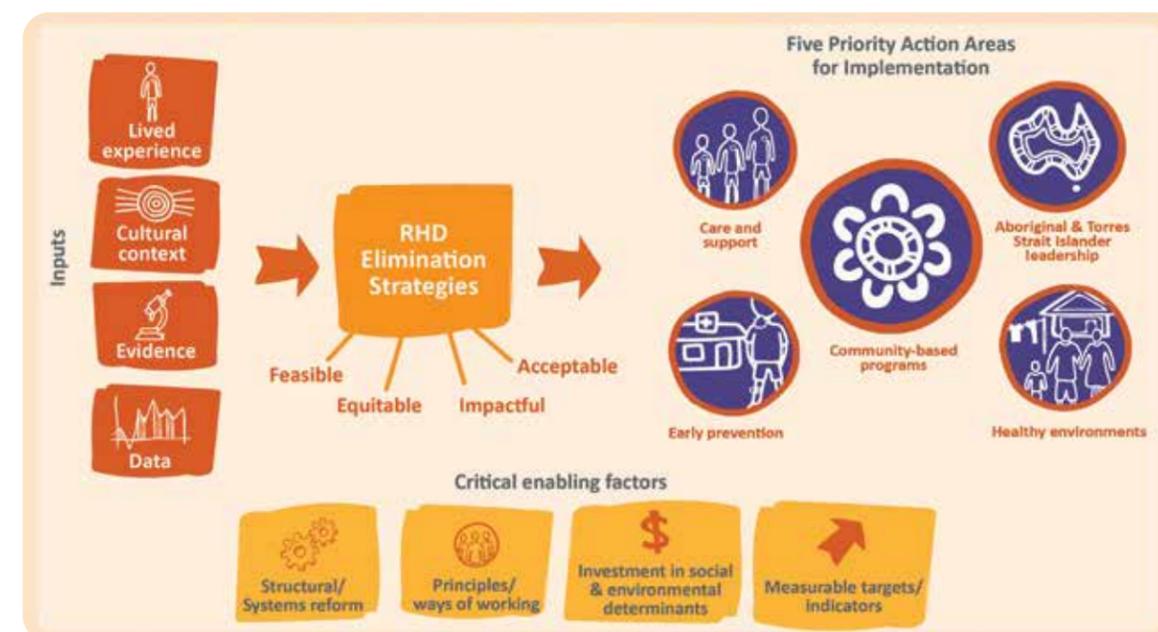
Ms Turner said NACCHO had prioritised RHD because it exemplified the gaps in prevention in the health system and in outcomes – and because tackling RHD would address so many other health outcomes with similar risk factors.

"The only possible solution is a comprehensive, Indigenous-led, primary healthcare-based strategy of both prevention and treatment," Ms Turner said.

"This work is transformative, not just because we can save lives and prevent human suffering with rheumatic heart disease – that is important – but also because a comprehensive community-led approach to primary care and environmental health will help address so much more – ear disease, eye disease, childhood lung infections. RHD is just the start of this new way of working.

"We are delighted to have the Endgame Strategy behind us, to give us the technical foundation for all the work ahead. The next steps to put this into practice are a collective responsibility.

"I really believe that today we are stepping into the beginning of the end of RHD and I cannot tell you how much that means for our people."





THE CHANGE-MAKERS: HOW A GROUP OF ABORIGINAL ELDERS IS FIGHTING FOR HOUSING EQUITY



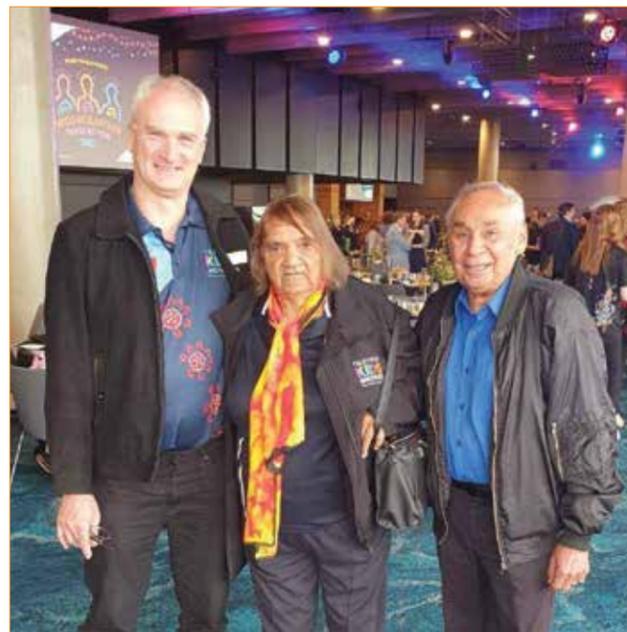
A child can't thrive if they don't have a roof over their head. Housing shortages, high rates of Aboriginal homelessness and housing insecurity are having a real impact on the health and wellbeing of families and their kids. A group of respected Aboriginal Elders is trying to turn the tide – working with Telethon Kids Institute to demand change.

Aboriginal Elder Albert McNamara has seen a lot of change in his 77 years, but plenty of things have stayed the same. His mother – a Yamaji woman from Wiluna – was taken from her own mother at just three months of age. This injustice, and many others he has witnessed in his lifetime, have driven him to fight for change – to give the next generation of Aboriginal children better opportunities than he had as a child.

"Years ago, Aboriginal people weren't even recognised as citizens in their own country, but now we're starting to get a voice and make things happen," Uncle Albert said.

"But we're still battling to be heard about how we want to look after and bring up our kids."

Alongside seven other Aboriginal Elders, Uncle Albert has taken up that battle. Since its inception in 2016 he's been an Elder/Co-researcher on the Ngulluk Koolunga Ngulluk Koort /Our Children Our Heart project, which brings the Elders together to



Dr Brad Farrant with Aunty Muriel Bowie and Uncle Albert McNamara

offer leadership, co-design, and advocacy on key areas of Aboriginal health.

The project seeks to bring together the Perth (Boorloo) Aboriginal community(s), service providers and policymakers to develop culturally appropriate strategies to improve the lives of Aboriginal children.

A key area of focus for the Ngulluk Koolunga Ngulluk Koort Elders is housing and homelessness. Dr Brad Farrant, leader of the project team, said secure housing was the foundation for kids to live happy, healthy lives.

"It's very hard to have good early childhood development when you don't have a house," Dr Farrant said.

"This has a flow-on impact on other areas of the child's life – their health, education and general wellbeing. So, it's really important that the fundamental needs of children and families are addressed because everything is inter-related."

The Elders have been tackling this issue head-on by engaging directly with politicians and policymakers, as well as housing service providers like Shelter WA, to not just advocate for more resources and support, but push for culturally safe practices in agencies that operate in the Aboriginal housing sector.

They have also worked hand-in-hand with Noongar Mia Mia, an Aboriginal-controlled housing organisation, to develop a Housing Standards Code of Conduct for inclusion in Residential Tenancy Agreements.

"This has not only helped the tenants but it's been a big help to Noongar Mia Mia," Dr Farrant said.

"There's no doubt the Elders have had a significant impact on the housing and homelessness space in WA."

Uncle Albert says there is still plenty of work for the Elders group to do, and with WA's housing squeeze ramping up yet again, big challenges lie ahead.

"If you want to make change, you've got to work together and then we can make things happen," he said.

WHAT'S NEXT

- The Ngulluk Koolunga Ngulluk Koort Elders will continue to advocate for better outcomes for Aboriginal children in the key priority areas they have identified.



Aunty Oriel Green OAM

In June 2021 **Noongar Elder Aunty Oriel Green OAM**, was recognised in the **Queen's Birthday Honours List** for her service to WA's Aboriginal community. Aunty Oriel is a key member of the Ngulluk Koolunga Ngulluk Koort Elders group and Telethon Kids Institute is proud to work alongside her to secure a better future for all Aboriginal children.

POOLING KNOWLEDGE: ORIGINS SPURS GLOBAL NETWORK



Researchers leading WA's landmark ORIGINS Project – a collaboration between Telethon Kids Institute and Joondalup Health Campus – have spearheaded a global network that will see them join forces with similar interventional cohort studies across the world to maximise data collection and learnings for all.

Now in its fourth year, The ORIGINS Project has more than 5,500 families involved in the study and is making steady progress in its bid to better understand how to optimise the early environment – providing crucial insights expected to boost the health and quality of life of the next generation.

ORIGINS researchers will follow 10,000 families over a decade, undertaking repeated observational measures, collecting biological samples and testing interventions from pregnancy through to early childhood.

Across Australia and around the world, other researchers are similarly following local populations – each running interventional cohort studies that explore different research themes over time.

Now, eager to learn from these similar studies and harmonise data collection in a way that benefits everyone, ORIGINS has established the Interventional Cohort Network so the different groups can share what they have learned.

ORIGINS Senior Program Manager Jackie Davis, who facilitates the network, said building on existing relationships just made sense.

“Establishing the Interventional Cohort Network is allowing us to learn from other similar cohorts that are each unique in what they are collecting but have a similar structure,” Ms Davis said.

The network – which evolved from the work of ORIGINS Co-Director Professor Susan Prescott, who works with multiple international organisations – currently consists of four projects: ORIGINS, GenV in Victoria, BestSTART SWS in New South Wales, and Born in Bradford (BiB) in the United Kingdom.

Despite plans for an inaugural meeting in Amsterdam being thwarted by COVID-19, the group has held virtual meetings and has already prioritised what they hope to achieve in collaboration.



ORIGINS Senior Program Manager, Jackie Davis

Ms Davis said the group had begun by comparing their methodologies – aspects that were working well and others that were challenging – and discussing potential future collaborations, with a particular focus on embedding interventions for disadvantaged populations within cohorts.

The network is also looking at key measures they can collect across the different cohorts which can then be analysed for comparison, establishing similarities and differences; and discussing multi-site interventions and how they can be adapted to the needs of each community.

“An overarching key focus of the network is to discuss how to best translate the research that is coming out of the studies to ensure it is valuable and relevant,” Ms Davis said.

“The biggest challenge for interventional cohorts is in the methodology of proving cause and effect. When you're actually intervening with the cohort by having them involved in the study, it is difficult to identify the exact influence on health outcomes. We are testing things in the real world with real-life impacts and influential factors, and these factors vary enormously globally.”

Ms Davis said it was a different way of looking at research.

“We're all in agreement within the network that, while our studies are not purely observational,



Born in Bradford UK team

ultimately the kids benefit regardless of the research outcomes and findings and that is what we are all hoping to achieve,” she said.

Ms Davis said the collaborative nature of the network – including the way it harmonised data collection and provided a valuable resource of long-term data on the health and wellbeing of families – opened the way for the different cohort studies to identify and answer new health challenges.

“Cohort studies of young families provide the ability to track whole communities and identify common concerns in health and other social determinants, such as psychosocial, financial and educational,” she said.

“Importantly, this ability to monitor in realtime can indicate critical opportunities and ways to intervene to prevent future health problems in subsequent generations.”

Ms Davis said that although ORIGINS was a community project, its ultimate goal was to address the rising global burden of non-communicable diseases.

“Collaboration nationally and internationally will enable harmonisation of multiple data collections and testing of interventions in different population groups,” she said.

WHAT'S NEXT

- ▶ The Network meets quarterly and hopes to eventually gather in person
- ▶ A key goal over the next 12 months is to introduce a new nested sub-project into several sites, using the same variables applied to each cohort. The projects will then match data collection and compare outcomes within the differing populations
- ▶ The group is also planning to develop a manuscript outlining their work, findings and comparative data

FROM UK TO WA – THE IMPACT OF COVID

ORIGINS researchers have reached across the world to compare the experiences of families dealing with COVID-19 in a hard-hit area of the United Kingdom to those of Perth families, who have remained relatively unscathed.

A collaborative paper being developed between The ORIGINS Project and the Born in Bradford study in the United Kingdom demonstrates what can be achieved when large cohort studies pool their knowledge.

The two projects examined the similarities and differences experienced by families in their very different cohorts as a result of the initial COVID-19 lockdown last year.

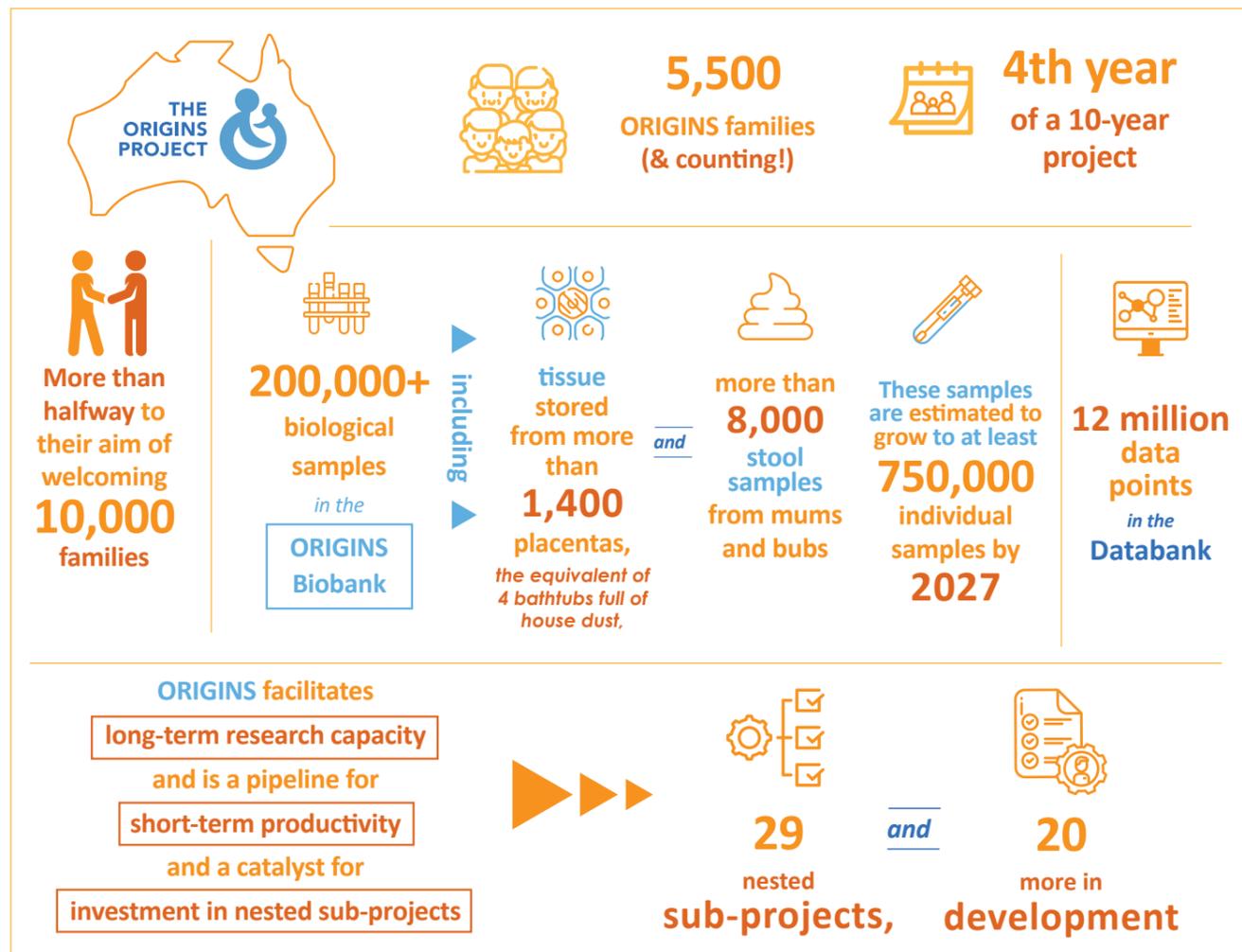
"Bradford is a particularly disadvantaged area of the UK which has been hit very hard by the pandemic," lead author and ORIGINS Research Fellow, Dr Lisa Gibson said.

"The population has experienced extended lockdown and high numbers of cases of infection. By comparison, the ORIGINS cohort in Perth, WA has been relatively untouched by COVID and has been fortunate to have low case numbers."

In a yet-to-be published paper which has been submitted to an international journal, researchers from the two studies focused not on virus contraction, but the impact of lockdown on families' day-to-day lives and functioning, such as financial pressures, their mental health, and feelings of isolation and anxiety.

"Both of these studies are looking to understand people's experiences of living through this pandemic in two very different environments," Dr Gibson said. "There are notable differences but many similarities in the initial impacts of a global pandemic."

Further collaborative research between the ORIGINS and Born in Bradford cohorts is now under way to examine attitudes and perceptions around COVID-19 vaccination, as well as the intention to vaccinate among parents and children.



ORIGINS DECISION LEADS TO LIFE-CHANGING DISCOVERY

The ORIGINS Project is not only changing long-term outcomes for future generations but is providing critical information for families in the short-term, through real-time feedback.

Elizabeth Roberts never fully understood what led to the death of her first child, Tiana, just 15 days after the little girl's birth in Malaysia.

So when she heard about The ORIGINS Project at an antenatal appointment while pregnant with her second child, she jumped at the chance to sign up.

"The nurse explained all the extra assessments and testing we would receive in my baby's first five years if we joined the study, and we knew that would be really important to us this time around," Elizabeth said.

It turned out to be a good decision for the whole family: at son Tate's one-year ORIGINS assessment – part of standard ORIGINS protocol – the ORIGINS paediatrician noticed he had multiple birthmarks and low-set ears.

Blood and skin prick tests revealed Tate had DiGeorge Syndrome, a genetic condition caused when a small part of chromosome 22 is missing, which can lead to congenital heart problems, developmental delay and trouble learning.

"When I heard the symptoms and diagnosis, I realised it may have been me that had unknowingly passed on the DiGeorge gene to Tate," Dad Mark said. "I had struggled a bit with

learning and development issues myself and had also had to have my ears fixed as a child. Back then we didn't realise it had a name."

Elizabeth said if the family hadn't been part of ORIGINS, they would never have known any of this until Tate presented with chronic heart issues or other health conditions much later in life.

Now aged 18 months, Tate has been diagnosed with a heart condition requiring surgery and with under-developed leg muscles, affecting his ability to walk. He is now seeing multiple specialists – valuable expertise Elizabeth said she wouldn't have had access to otherwise – and, along with Mark, is undergoing genetic testing.

"The ORIGINS doctor explained Tate's condition to us and organised all the specialists from cardiology, dermatology, physiotherapy and audiology," Elizabeth said.

"We can now offer Tate some early intervention that will make a huge difference with his development and management of his syndrome."

ORIGINS Co-Director Professor Desiree Silva said stories like the Roberts' were what ORIGINS was all about.

Although the project's overall aim was to collect and analyse samples and data to inform the causes of chronic conditions, the real-time feedback provided to families through free regular assessments and sample collections often provided families with the opportunity to intervene early in conditions that otherwise might not have been identified until much later in life.

"The impact of the family journey during our longitudinal study is changing outcomes for people," Professor Silva said.

"These diagnoses that are being made along the way are also being tracked. If there is an abundance of certain findings, this can impact on the development of more specific studies and translation into clinical practice change – encouraging testing for certain conditions to become standard for child health nurses or GPs."



Elizabeth, Mark and Tate Roberts
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The ORIGINS Project is generously funded by the **Paul Ramsay Foundation** and the **Commonwealth Government of Australia** through the **Channel 7 Telethon Trust**.

RAPID-FIRE RESEARCH THE LATEST WEAPON IN WAR ON JUNK FOOD ADS



A new rapid research funding model is translating into quick results, with findings informing a public health campaign that could banish much of the unhealthy but influential advertising kids see on the way to and from school.



Dr Gina Trapp

By mid-2019 population health researcher Gina Trapp had spent more than a year pursuing on and off a project she knew could have a big impact on kids' health – if only she could get it funded.

Keen to understand how many junk food ads kids were exposed to on their way to and from school – and how this translated into their eating habits and overall health – she had been sending prac

students out to comb the streets near schools and take photos of whatever outdoor advertising they came across.

Initial results were shocking – showing kids were being bombarded with junk food ads on buses, trains and static signs within metres of schools – but a lack of funding and staff meant progress was slow.

Enter Cancer Council WA, which had been discussing with Institute leadership ways the two organisations could partner on research to propel quick, easy advocacy wins on shared policy priorities – particularly around childhood obesity.

Among other goals, both organisations were keen to see junk food advertising removed from government-owned property, including public transport and billboards.

Cancer Council WA Obesity Prevention Manager Ainslie Sartori said the organisation approached Healthway about joining forces with the Institute to fund a new advocacy approach.

“The idea was to invest in very quick research, turn it around really fast and use it to advocate for the particular policy change we were seeking from government,” Mrs Sartori said.

Healthway was supportive of the idea and the Rapid Obesity Policy Translation (ROPT) program was born.

With Dr Trapp already chipping away at exactly the kind of research needed, Cancer Council WA commissioned her to formally audit the amount and type of outdoor advertising children were exposed to on the way to and from school.

“It was perfect timing because I'd already been doing this research, but on a shoestring,” Dr Trapp said. “We had this data collection half underway already, but it was heavily reliant on the availability of students.”

Now with the resources she needed, Dr Trapp was able to rapidly scale the project up and fund biostatistical analysis – achieving in just eight months what it would have taken her more than two years to do on her own.

One of the more startling findings of the audit, which logged more than 5,500 outdoor ads, was the sheer number of junk food ads on State-owned assets.

“It was shocking to see the amount of junk food advertising on government-owned assets like buses, bus shelters, billboards, and also freestanding signs along the roadside, which local governments have control over,” Dr Trapp said.

“Eighty per cent of food ads on bus shelters were for junk food and alcohol.”

Together with complementary studies from Curtin and Deakin universities – also backed by the ROPT program – Dr Trapp's findings underpinned a joint statement by Telethon Kids, Cancer Council WA and other trusted health agencies calling on the WA Government to ban junk food and alcohol advertising on State-owned assets.

“We wouldn't have been able to do that without Gina's research – it gave us the evidence of what was happening in WA in terms of advertising around schools and on billboards and public transport,” Mrs Sartori said.

At a pre-election forum a couple of months later, Health Minister Roger Cook promised to launch a taskforce to look at implementing such a ban if the government was re-elected.

While the taskforce has not yet materialised, in February this year the City of Mandurah – having been sent the research while considering its own approach to junk food advertising – ratified a policy to prohibit unhealthy food, alcohol and tobacco/smoking advertising on street signs, bench seats, banner poles, bins, billboards and bus shelters on City-managed lands and road reserves.

“The City of Mandurah's decision is a positive step forward and it would be great to see other local governments following suit, but there's only so much local governments can do and we'd really like to see the State Government take the lead on this,” Mrs Sartori said.

WHAT'S NEXT

- ▶ In June this year the State Government announced a further \$2.1 million via Healthway to fund Cancer Council WA and Telethon Kids to conduct public health activities over the next three years
- ▶ Dr Trapp will lead a project assessing the before and after impact of a fast-food outlet being built across the road from a Perth high school

RAPID RESULTS REVEAL JUNK AD OVERLOAD

Dr Trapp and a team of researchers mapped the advertising environment within a 500m radius of 64 randomly selected public and private primary, K-12 and secondary schools across Perth, covering high and low socioeconomic areas.

Working in pairs, research assistants trawled the streets by foot and took a geotagged photo of every outdoor ad they found. They recorded as much information as possible about each ad, including type (billboard, bus shelter, freestanding); whether it was advertising food or non-food; healthy or unhealthy food; and proximity to schools and food businesses.

The researchers identified 5,636 outdoor ads, with 30 per cent of those (1,708) devoted to food. Of those food ads, 74 per cent were for unhealthy foods – and one in three of those unhealthy food ads was for alcohol.

“Only 8 per cent of the food ads featured any kind of healthy food item,” Dr Trapp said.

Schools in lower socioeconomic areas had a higher proportion of total food ads, unhealthy food ads and alcohol ads.

The team also recreated bus, train and walking routes to 24 schools to calculate how many junk food ads kids might typically see on their way to and from school.

“If kids took the train to school, it worked out to be on average 37 junk food ads they were exposed to per one-way trip, compared to 2.4 healthy food ads,” Dr Trapp said. “The top three foods advertised were sugar-sweetened beverages, fast foods, and alcohol.”

“If you assume the amount and proportion of junk food ads stay constant, on average, Perth school children would be exposed to just under 15,000 junk food ads on their journey to and from school over the course of a year, compared to only 960 healthy food ads.”



“It was less for catching the bus and less for walking to school but it was still really high – and when you compare the number of ads for a healthy food product versus an unhealthy food product, it’s outrageous.”

Dr Trapp said it was well established that junk food advertising was linked to kids’ food preferences, the types of food they pestered parents to let them eat, and their dietary intake and weight status, however, much of the research on children’s exposure to junk food advertising so far had focused on television advertising.

“Very little research has quantified what’s going on in our outdoor spaces, and what’s interesting is that compared to TV advertising, with outdoor advertising you can’t switch it off – it’s always ‘on’ compared to other mediums of advertising,” she said.

WE SHOULD ALL STAND BEHIND THIS IMPORTANT MESSAGE



CEOs of leading health agencies launched a joint statement calling on the WA Government to ban junk-food ads on State-owned assets.

‘HEARTBREAKING’ FAST-FOOD DECISION COULD HELP CHANGE PLANNING LAWS

Cancer Council WA (through funding from Healthway in partnership with Telethon Kids) have funded the first stage of another Rapid Obesity Policy Translation project being led by Dr Gina Trapp – one that will allow her to analyse the food-buying habits of children from a northern suburbs high school before and after a major fast-food outlet is built directly across the road.

Approved despite the objections of public health advocates and school leadership, the outlet – which will be visible from classrooms – will be built this year.

“It’s heartbreaking, really,” Mrs Sartori said. “This school is trying so hard to keep their kids healthy and has worked to build up a really healthy canteen, and suddenly they’re going to have this fast-food outlet right across the road. But at the moment, planning legislation doesn’t allow this kind of public health impact to be taken into consideration.”

Mrs Sartori said results from Dr Trapp’s project would inform efforts to change the legislation.

“If we are going to argue this kind of community impact, we need to provide a lot of evidence,” she said. “Gina’s research is going to be absolutely crucial going forward because we’ll be able to show what happens before and after an outlet like this goes in.”



“That sort of evidence is vital but it’s so rare to get it – that’s where this Rapid Obesity Translation Policy program really comes into its own.”

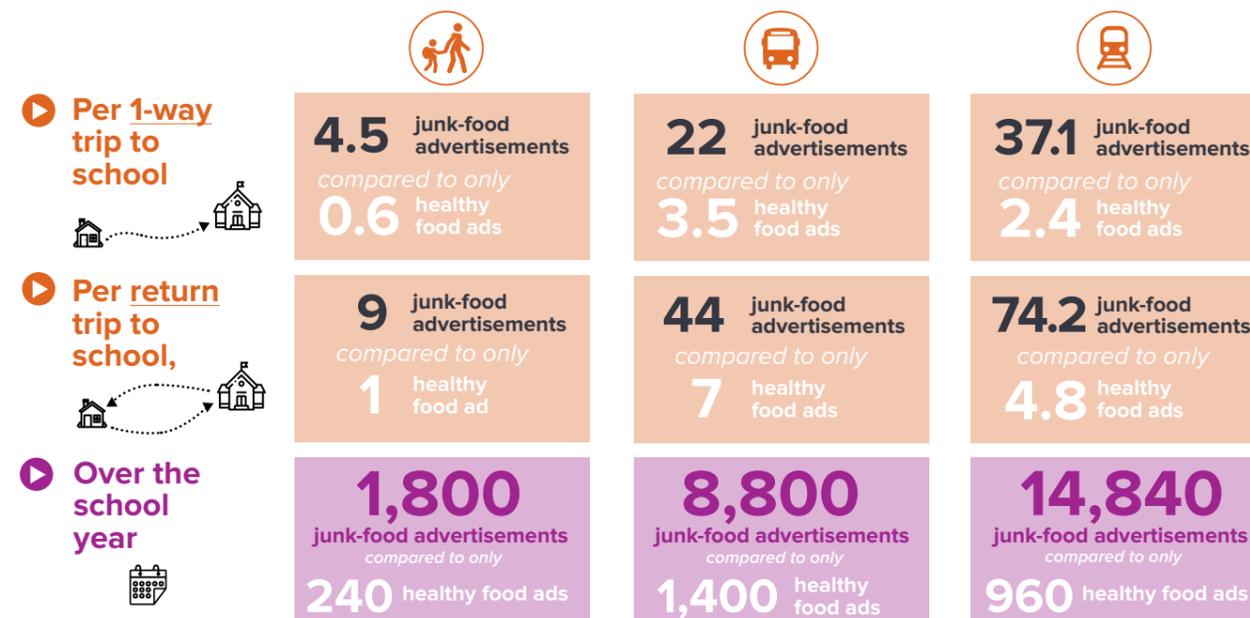
The project’s funding was originally earmarked for another study but was quickly diverted once the outlet was approved and Cancer Council WA realised how urgently Dr Trapp needed to move in order to get important comparative data before construction.

“We know it takes about five months for one of these outlets to get built, so to be able to just channel some funding to Gina straight away to conduct this research was perfect timing,” Mrs Sartori said.

Dr Trapp said such a project would have been impossible through normal funding mechanisms.

“It can take up to a year to write the grant, be assessed, and receive the money if you’re successful,” Dr Trapp said. “By then the outlet has been built and the boat has sailed.”

JUNK-FOOD ADVERTISING ON THE WAY TO SCHOOL:



HOW THE PANDEMIC HAS SHAPED THE MENTAL HEALTH OF OUR KIDS



Telethon Kids Institute researchers went into 79 WA primary and secondary schools in 2020. They were looking for asymptomatic COVID-19 cases and also the impact COVID-19 was having on the mental health of children, their teachers and parents. They found increased levels of emotional distress among students and families.

As COVID-19 shut down the world almost overnight in early 2020, there were a lot of unknowns. Telethon Kids Institute was asked by the State Government to conduct non-invasive swabbing of WA schoolchildren to make sure there were no asymptomatic cases of the virus lurking in the community, and to look at the mental health of students, teachers and parents.

In total, 13,988 swabs were collected by the DETECT schools program, finding no cases of the virus in our schools.

At the same time, the Institute conducted wellbeing surveys in 79 WA schools. The first cycle of surveys in June/July 2020 involved 24,003 primary and secondary students, 1,202 school staff and 3,463 parents. A second cycle of surveys was undertaken in October 2020 with 18,008 students, 862 staff and 2291 parents.

Just over half of the students surveyed reported that COVID-19 had little or no negative impact on their lives, while 65 per cent said they felt 'confident' about their future.

Of most concern, an emotional distress scale in the study revealed that the rate of emotional distress among secondary school students (38%) has nearly tripled since the last benchmark survey in 2014 (14%). It's not known how much of this is attributable to COVID-19. The rise aligns with a significant increase in demand on mental health services during that six-year period and is in keeping with increased rates of emotional distress amongst young people also seen in other states. Most parents responded that they felt equipped and supported to manage their child's learning at home but were short of time. Communication between schools, teachers and parents was rated

highly. Despite clear challenges, most staff reported feeling supported professionally and physically safe in the school environment.

Forty-five per cent of school staff felt the pandemic had impacted negatively on their students in June/July of 2020, dropping to 37 per cent by October.

Telethon Kids Institute epidemiologist and the Kerry M Stokes Chair of Child Health at Telethon Kids and Curtin University, Professor Pete Gething, said the results could point to a level of 'background emotional distress' that had been flying under the radar since the 2014 survey.

“It is quite possible there is an underlying increase in emotional distress and mental health problems among students that has been bubbling away for some time before the pandemic hit,” Professor Gething said.

“It may well be exacerbated by the pandemic, but we cannot say for sure whether the pandemic has caused this distress.

“Other indicators show there has been an overall increase in youth mental health problems in recent years, so these findings really pose a bigger challenge for the community to determine the real extent of emotional distress among our children.”

▶ DETECT was led by Professor Peter Gething, Professor Donna Cross, and Associate Professor Asha Bowen

▶ The Telethon Kids Institute has a number of resources available to help families and schools support the mental health of young people. See embrace.telethonkids.org.au

FINDING THE RIGHT RECIPE FOR YOUTH MENTAL HEALTH



What are the 'active ingredients' needed for good mental health in children and young people around the world? In early 2021, Telethon Kids Institute researcher Dr Amy Finlay-Jones led a global team in trying to answer that question to help better prioritise mental health spending.

For some young people, it's the environment around them. For others, it's having strong relationships with friends and peers. And for most, it's a combination of different factors – a unique recipe that helps them maintain good mental health.

In late 2020, the UK-based charity Wellcome Trust set out to identify which factors had the biggest impact on a child's mental health, with the aim of targeting the organisation's philanthropic and research spending.



Dr Amy Finlay-Jones

Telethon Kids Institute youth mental health researcher Dr Amy Finlay-Jones led one of two teams tasked with conducting research all over the world to distil ten common 'active ingredients' that contribute to youth mental health.

The research put the spotlight on six very different countries: Australia, India, Kenya, Pakistan, South Africa and the United Kingdom, with a focus on young people with additional challenges such as those from migrant or refugee backgrounds, chronic illness or disability, and LGBTQIA+ young people.

Dr Finlay-Jones said young people in the research countries had plenty in common but were all different – often in surprising ways.

“Some of the things that we thought would be universally accessible turned out to not be universal at all,” she said.

“We thought things like 'being in nature' might be universal because it's accessible, it's something everyone can do that's good for their mental health.

“But then when we went to Pakistan, the young people were saying 'No that's no good for us, I'm not allowed outside my house without my parent and if I do go out alone it's dangerous,'

so that was very important for us to recognise.”

Dr Finlay-Jones' team, alongside colleagues from the University of Liverpool, the Human Development Research Foundation in Pakistan and other major research institutes, interviewed more than 120 young people across the research countries.

Areas identified as 'active ingredients' included housing, social relationships, parenting and family, and perspective shifting – being able to actively change your way of thinking.

But the number one ingredient identified by young people in all six countries was 'a sense of purpose'.

“This was important for people in all the countries we researched in, but it was important for different reasons,” Dr Finlay-Jones said.

“In Australia, young people were saying 'we don't have a sense of purpose' and it was almost like their sense of purpose was too loosely defined.

“But in other countries, young people said that their purpose in life was determined the moment they were born, and their entire life was mapped out – their purpose was dictated by family, culture and social class.”

WHAT'S NEXT

▶ The findings will now be used to pinpoint the key areas of youth mental health that need research and investment, with the hope of identifying best bets for better outcomes for young people around the world



Dr Amy Finlay-Jones is the **Starlight Fellow** and **Julie Bishop Award** recipient

LEVERAGING GLOBAL LUNG HEALTH EXPERTISE TO HELP PRETERM BUBS



In a global collaboration championed and led by award-winning preterm lung health researcher, Dr Shannon Simpson, the world's leading preterm scientists and doctors have joined forces to help give babies born very prematurely the best possible life.



Dr Shannon Simpson

For more than a decade, internationally recognised preterm respiratory researcher Dr Shannon Simpson – Head of the Children's Lung Health team at the Wal-yan Respiratory Research Centre – has dedicated her career to understanding the impact of preterm birth on lung health.

About **15 million babies** are born before **37 weeks' gestation every year** (about **11 per cent** of global births), with rates of preterm birth increasing worldwide. **More than two million** of these babies are **born very preterm** (less than **32 weeks' gestation**) and are at increased risk of chronic lung disease through life.

"We know from research that babies who survive the neonatal period often have significant respiratory complications throughout life," Dr Simpson said.

"Our work has shown that about half of children born preterm continue to have breathing problems in their primary school years. Most have abnormalities if we image the chest and over a third will have lung function outside the normal range.

"Really recent evidence from our team shows that the lung function of children born very preterm is moving even further away from normal during the primary school years – and this worries us."

Last year, keen to maximise global efforts to help such children, Dr Simpson established (and now co-chairs) an international consortium of clinicians, researchers and consumers interested in understanding and improving long-term lung

health outcomes for those born preterm. Known as PELICAN (Prematurity's Effect on the Lungs in Children and Adults Network), the consortium is the European Respiratory Society's fourth paediatric Clinical Research Collaboration.

"Bringing together preterm lung health research and expertise from across the globe will enable us to better treat and support children born prematurely, to give these kids and their families a better quality of life," Dr Simpson said.

"I'm really excited to lead this initiative, which will help preterm kids right here in WA and internationally."

Dr Simpson said that as part of its work PELICAN would establish a harmonised global data repository which pulled together all existing lung health data from cohorts of survivors of preterm birth.

"Our main aim is to understand the impact surviving preterm birth has on the lungs and the natural history of lung disease throughout life, and to determine which neonatal and lifetime exposures contribute to the progression of lung disease in those born prematurely," she said.

"We hope this work will ultimately lead to better treatments and inform clinical practice and long-term management for those born very prematurely."

COMMUNITY CONNECTION

Perth mother-of-four and Tiny Sparks WA co-founder Amber Bates is on the PELICAN Scientific Steering Committee with Dr Shannon Simpson. Ms Bates is a member of the Telethon Kids CONNECT program and has been a long-term community advisor on preterm research at the Institute.

"As a mother of a child who was born prematurely, it gives me both comfort and hope to know that the world's best preterm respiratory researchers and doctors are working together to improve the outlook for our children," Ms Bates said.

Dr Simpson said it was vital to have community members and those with lived experiences such as Ms Bates involved in research and projects such as PELICAN.

"We're doing this research for those kids born preterm and their families. We couldn't do the work we do without their support and input," she said.

"This project is not just a collaboration with scientists and doctors across the globe, it's also about involving consumers in the direction of research."



Dr Shannon Simpson and Amber Bates

DID YOU KNOW?

- ▶ PELICAN is an international collaboration between researchers, doctors and consumers
- ▶ The consortium is co-chaired by Dr Shannon Simpson with Dr Jenny Hallberg, of Sweden's Karolinska Institutet
- ▶ The 3-year project aims to combine current preterm lung health data to develop lifelong lung health trajectories for those surviving preterm birth and enable future scientists and doctors to take research and clinical practice in this area to the next level

- ▶ Dr Simpson is a Wal-yan Respiratory Research Centre Team Leader. The Centre is a powerhouse partnership between Telethon Kids Institute, Perth Children's Hospital Foundation and Perth Children's Hospital

IN THE PIPELINE

THIS RESEARCH IS IN THE PIPELINE
TOWARDS TRANSLATION



Adam has a big love for books and Zach has a big love for his big brother. Read their story at telethonkids30.org.au

RSV: THE HIDDEN VIRUS



Despite respiratory syncytial virus (RSV) being the leading cause of hospitalisations in the first year of life, there is currently no routine preventative option for otherwise healthy babies. Telethon Kids Institute researchers are working to change that.

A serious respiratory infection, RSV is a leading cause of morbidity and mortality in children globally, causing 3.2 million hospitalisations every year – including 1,000 Western Australian children. Treatment often sees babies hooked up to oxygen and feeding tubes, meaning that for families of hospitalised babies, RSV can be terrifying.

“With no drug to treat the virus, the need for prevention therapies including vaccines is urgent. The World Health Organization agrees, recognising the development of an RSV vaccine as a global priority.”

Telethon Kids researchers have responded to the call, with four clinical trials targeting RSV under way at the Institute, including one which is on track to create the first comprehensive model of the burden of RSV strains.

Others under way include two phase three trials testing maternal vaccines – where mums receive

the vaccine rather than the baby – and a phase three trial of an RSV antibody treatment in babies.

Professor Peter Richmond, Head of the Vaccine Trials Group at the Wesfarmers Centre of Vaccines and Infectious Diseases, said the studies followed two successful international trials involving Telethon Kids researchers – published in the New England Journal in 2020 – that provided the proof of principle for these approaches.

“By having the vaccine during pregnancy, mums are protected from RSV and those antibodies are passed to their babies in utero, protecting the baby for their first few months while those antibodies persist and while babies are most at risk for severe RSV infection,” Professor Richmond said.

“These clinical trials bring us closer to a vaccine that will protect millions of babies annually, providing significant public health benefit in Australia and beyond.”

In parallel with global clinical trials, the Wesfarmers Centre is improving our understanding of RSV and its impact through epidemiological studies, modelling and genomic identification.

“To help design the right prevention program for RSV, we need to have better information about the true infection rate in young babies and in particular, those at highest risk, such as those born pre-term, as well as the long-term impacts of RSV infection,” said Dr Hannah Moore, who is Co-Head of the Infectious Diseases Epidemiology team.

“We are well on the way to be able to predict the likely impact of future prevention measures using

dynamic transmission models which will enable us to advise on the best future vaccine policy.”

Dr Moore's study is part of a broader research picture that is providing contemporary data on the preventable RSV burden in at-risk groups, understanding the changes over time with genetic variations of RSV strains in Australia, and examining long-term impacts of RSV infection.

“The net result of all this work will be to provide information that will be critical to inform and implement effective prevention policy for Australia and importantly, is relevant for children and their families in WA,” Professor Richmond said.

WHAT'S NEXT

- ▶ Telethon Kids researchers will continue to participate in the international clinical trial, Melody, to determine whether a long-term antibody will prevent RSV-confirmed lower respiratory tract infections
- ▶ International collaborative studies will track and monitor seasonal RSV fluctuations across the globe



Dr Hannah Moore, Dr Mejbah Bhuiyan and Professor Peter Richmond

2020 SAW RSV RATES ROLLERCOASTER – SCIENTISTS ARE STILL WORKING OUT WHY

Winter typically brings a surge in respiratory viral infections, but the 2020 Australian winter was very different. Public health measures in place to control the spread of COVID-19 saw a major shift in the typical seasonal pattern of other respiratory viruses.

Following an abnormal winter that saw a significant drop in rates of RSV (98 per cent fewer winter cases in Western Australian children than a typical season), the 2020 summer saw unexpectedly large numbers of children presenting to paediatric hospitals around Australia. In all, hospitals experienced a more than 600 per cent increase in admissions for respiratory infections – mainly from RSV.

“The speed and magnitude of this increase was greater than the usual winter peak of RSV. Weekly

detections in December 2020 were 2.5 times higher than the normal winter weekly peak,” Dr Hannah Moore said.

Studies seeking to understand exactly why we've seen such a significant rise in RSV cases are ongoing and involve Telethon Kids researchers, national and international collaborators.

“Further research will help us learn potential ways to reduce the spread of infection when it is circulating in the community and minimise the number of kids experiencing severe, life-threatening illnesses,” Dr Moore said.

“Anomalies in infectious disease behaviour like the recent summer surge show how unpredictable transmission dynamics can be and how important robust data are.”

DECODING RSV

- ▶ **Viruses, including RSV, are constantly changing.** These genetic variations occur over time and can lead to the emergence of new variants that may have different characteristics and long-term impacts
- ▶ The RSV genome encodes instructions organised into sections, called genes, to build the virus. Scientists use a process called **genomic sequencing** to **decode the genes and learn more about the virus.** Genomic sequencing allows scientists to identify RSV and monitor how it changes over time into new variants, understand how these changes affect the characteristics of the virus, and use this information to better understand how it might impact health
- ▶ **Telethon Kids Institute research is creating the first comprehensive burden of strains model to identify which RSV strains are the most important to characterise and track in terms of health.** Our research is also contributing WA strains to an international study that will look at the global variation in RSV strains and how these might impact on the effectiveness of vaccines and antibody treatments

BABY GEORGE JOINS THE RSV FIGHT



With a toddler at day care, a newborn at home and an RSV season around the corner, enrolling in a Telethon Kids RSV study was a no brainer for Perth Mum Jessica Fitzpatrick.

Having already taken part in Telethon Kids research with her older child, Austin, Jessica was keen to contribute further.

"When I was pregnant with Austin, I was part of a Telethon Kids study that tested whether vaccinated women pass on their antibodies. That meant I was protected in pregnancy and Austin was protected over his first winter," Jessica said.

Her second baby, George, is now helping researchers find answers to RSV.

"Our friends' son was hospitalised twice with RSV when he was a baby so we know the effect it can have – we'll do what we can to protect George from that," Jessica said.

“As someone who works in a medical field, I understand the benefits of early vaccination. It's a win-win situation – we're protecting George and playing a part in helping other newborn babies avoid serious illnesses in the future.”

The study George is enrolled in will determine whether a monoclonal antibody treatment specific for RSV, given as a single injection, will protect babies for five months over the winter season. Already shown to protect preterm babies, it is now being evaluated in babies born at term.

Jessica and George Fitzpatrick

AMBITIOUS FLU PROGRAM AIMS TO PROTECT KIDS FOR LIFE



A bold research program – funded by generous donors who dug deep at the 2019 Telethon Lexus Ball – is working to give young children lifelong protection against potentially deadly influenza.

In 2016, just 10 per cent of Australian children aged six months to four years were vaccinated against the flu. Two years later, this worryingly low vaccination rate would see tragic consequences, with the flu seasons of both 2018 and 2019 marked by a surge in childhood flu-linked deaths and severe complications nationwide.

It was a disaster that could have been prevented, had vaccination rates been higher.

Associate Professor Chris Blyth, Co-Director of the Wesfarmers Centre of Vaccines and Infectious Diseases, based at Telethon Kids Institute, said low vaccination rates placed those in the community who were most susceptible to flu complications – including children – at the highest risk of infection.

“The devastating reality for doctors is there is only so much we can do to save the life of a child after life-threatening complications from influenza – like severe pneumonia and inflammation of the heart, brain, or muscle tissues – have taken over,” Associate Professor Blyth said.

“Our best bet is to prevent influenza from happening in the first place, and this can only be achieved by finding a safe and effective way to provide long-term protection early in life.”

The Telethon community dug deep in the wake of those two terrible seasons, donating more than \$2 million to the Telethon Kids Institute at the 2019 Lexus Ball after hearing the heart-rending story of two-year-old Lucy DeLuis, who died in July 2019 just five days after being diagnosed with influenza.

Thanks to this generous support, Telethon Kids scientists have been able to ramp up a bold influenza research program, starting with the FluBub Study. Expected to deliver crucial information needed to tailor vaccines, policies and programs to ensure the safety of our children, the study also will pave the way for a greater ambition – to develop a single flu injection that would give children lifelong protection against all strains of the disease.



Associate Professor Chris Blyth

“The FluBub Study is investigating giving flu vaccine at two months of age instead of the current six months as per the National Immunisation Program (NIP), allowing us to establish how immunological protection is generated and test the potential advantages of early-life vaccination,” Associate Professor Blyth said.

“From there, we will apply cutting-edge systems vaccinology approaches that will provide us with the key to truly unlock the secrets of flu immunity and inform future vaccine development.”

“Telethon means we can accelerate truly world-first projects like this.”

It is hoped results from the FluBub Study, along with providing an in-depth understanding of flu epidemiology and disease, will spark further changes to the NIP.

In 2020, thanks to the work of a consortium of influenza researchers across the country including Associate Professor Blyth, universal influenza vaccination for children aged six months to four years was included on the NIP for the first time in Australia's history. As the pilot state for a funded immunisation program, Telethon Kids' Western

Australian data played a vital role in the decision.

The life-saving significance of this public health measure – which is set to more than halve the number of children in this age group hospitalised by severe influenza – was recognised when the consortium was named a finalist in the 2020 Eureka Prizes.

Since then, Telethon Kids researchers have used an Institute-built mathematical model to estimate the number of Western Australians affected by flu each year under different childhood vaccination schedules. The model, which demonstrated the cost-effectiveness of the current WA preschool and primary school influenza vaccine program, led to policy changes expected to save the WA Department of Health millions of dollars in a typical influenza season.

Thanks to these and other policy updates – and the research behind it – WA now leads the country, with some of the highest childhood flu vaccination rates of any state. Since 2019, approximately half of all WA children aged six months to four years have been vaccinated against flu – significantly reducing their risk of becoming unwell with the virus.

“Increased vaccination rates show that policy changes make an impact, giving families confidence to vaccinate their children. It’s important that – as a community – we don’t lose sight of the importance of vaccinating against influenza,” Associate Professor Blyth said.

WHAT’S NEXT

- ▶ FluBub will continue recruiting to sites across Western Australia and South Australia
- ▶ Associate Professor Blyth and team will assess the cost-effectiveness of different vaccination strategies in typical, mild and severe influenza seasons
- ▶ COVID-19 surveillance will continue as we learn about coronavirus infection in children

DID YOU KNOW?

Every year Telethon Kids researchers contribute to national and international health surveillance networks which help monitor the global impact of infectious diseases like and guide public health policy.

Associate Professor Chris Blyth contributes to both Paediatric Active Enhanced Disease Surveillance (PAEDS) and FLuCAN (Influenza Complications Alert Network).

FLuCAN is national sentinel surveillance program which collects real-time data on patients hospitalised with flu, to assess flu severity and vaccine effectiveness.

PAEDS, which operates in children’s hospitals across Australia, including Perth Children’s Hospital, collects data on children unwell enough to come to hospital due to a range of infectious diseases. Focused particularly on vaccine-preventable diseases, PAEDS uses the data to identify and monitor conditions of public health importance in children, including polio-like illnesses, influenza, pertussis, and meningococcal disease.

Associate Professor Blyth said the information gathered enabled the Australian Government to understand – and declare to the World Health Organization (WHO) – its status in relation to various infectious diseases.

“It’s because of PAEDS that, for example, Australia is able to declare to WHO that it remains polio-free,” Associate Professor Blyth said. “Using this and data from other groups around the world, WHO is then able to get a better picture of the global impact of a range of problematic diseases.

“The data we collect also helps researchers to understand what factors put children at risk of developing certain diseases and to monitor vaccine effectiveness and safety.”

In 2020, COVID-19 was added to the list of conditions monitored by PAEDS, with FLuCAN also expanding its normal approach to influenza to collect enhanced clinical data on COVID-19.

“Together, this information was used to help understand the incidence and severity of children requiring hospitalisation for coronavirus,” Associate Professor Blyth said.

IN LUCY’S NAME

This ground-breaking research was made possible thanks to attendees at the 2019 Telethon Lexus Ball, who supported the Institute’s influenza research program after being inspired by the DeLuis family.

The DeLuis’ two-year-old daughter Lucy sadly lost her life in 2019 – just five days after being diagnosed with influenza – and her family is now

dedicated to supporting research that will develop more effective weapons against the disease.

“This research is a critical step to ensure children like Lucy have greater protection against influenza, and will ultimately provide us with the knowledge and capability to design stronger, longer-lasting vaccines,” Associate Professor Blyth said.



Associate Professor Chris Blyth with Ollie DeLuis

HELPING PARENTS OF TRANS YOUNG PEOPLE TRAVEL AN UNKNOWN ROAD



Families and young people who are trans or gender diverse are working with Telethon Kids Institute researchers to come up with resources that will provide better support to parents as they navigate their child's gender identity journey.

In 2017 the landmark Trans Pathways report made headlines across the country when it revealed the pressures trans young people are under – prompting a rethink about the support they receive.

With the focus largely on findings that trans young people were at high risk for suicide, self-harm, anxiety and depression, less attention was paid to another important outcome of the survey: its inclusion of the experiences of parents of trans young people.

In addition to seeking the views of 859 trans young people aged 14–25, Telethon Kids researchers surveyed 194 parents and guardians – and found many were crying out for help.

The report found trans young people had much better mental health outcomes if they had parental support, however many of the parents surveyed revealed they struggled to process their child's gender identity due to a woeful lack of support and resources.



Helen Morgan and Dr Yael Perry

“Overwhelmingly parents told us they simply lacked information on what it means to be trans, which made it difficult for them to help their child,” report authors Associate Professor Ashleigh Lin and Dr Penelope Strauss wrote.

“The dissemination of more information and the destigmatisation of trans young people is therefore vital.”

Now, researchers from Embrace @ Telethon Kids are working with families to fill that gap, developing resources from the ground up to give parents more support as they navigate their child's gender identity journey.

Supported by a Healthway grant and led by Dr Yael Perry and research assistant Helen Morgan, the Transforming Families project has consulted dozens of parents and young people to better understand what parents need, to inform the development of tools and resources parents wish they'd had access to earlier.

Top of parents' wish list is an online hub which acts as a one-stop-shop for reliable, tailored information, avenues of support, stories of others' lived experience, and useful tools like templates for letters which help parents communicate with schools, health professionals, and other community organisations as their child's needs change.

Dr Perry said parents – even when they wanted to be supportive – often experienced a complex set of emotions and challenges while trying to help their child. This included the mental burden of having to become an advocate and educator around others, including extended family.

“It can be exhausting trying to find reliable information, including spending hours online where they often encounter misinformation and transphobic content, while also trying to advocate for their child and look after their child's – and their own – mental health and wellbeing,” Dr Perry said.

“A lot of it is about the world in which their children are growing up, fears for the future, will they have a relationship, will they be able to hold down a successful job, will they be able to walk down the street without being attacked.”

Ms Morgan said many of these concerns could be alleviated when parents were well supported with high quality information and access to others with similar experiences.

“What they are asking for is a place where they can easily retrieve evidence-based information so they actually know what gender diversity is all about and can make informed choices,” she said.

“They also want support: access to good quality healthcare providers that are competent in the area; and peer support – particularly with parents of other trans young people, which can be a really powerful facilitator for acceptance.

“Thirdly they're asking for practical information and support on transition, so things like scripts, templates and information on where to buy appropriate clothing or how to inform their school about their child's intentions to socially transition.”

Ms Morgan said that while people often focused on the negatives and challenges of parenting a trans young person, many parents found there were positive aspects and that they had the capacity to become powerful agents of change.

- ▷ **Trans Pathways** was **Australia's largest survey** ever conducted into the **mental health of trans young people** and the first to include the perspectives of parents of trans young people
- ▷ Researchers surveyed **859 young people** and **194 parents and guardians of a trans young person aged 25 or younger**
- ▷ As well as providing a snapshot of the current mental health of Australian trans young people, the survey aimed to **identify the support needs of trans young people and of their parents and guardians**
- ▷ **Parents** reported they needed more **information and awareness of trans issues** to adequately support their trans and gender diverse children
- ▷ The report has generated a raft of new research focused on **identifying and meeting the needs of both parents and young people**



“We see parents who go on to use the resources they've accessed to upskill and increase acceptance in others,” she said. “They create mini-revolutions in their own right.”

The next step of the Transforming Families project will see the researchers and parents work together to co-design an online hub featuring evidence-based tools and resources, which will then be evaluated.

“The ultimate aim is to help parents and children better understand and communicate with one another – in turn improving the mental health of both the young people and parents and improving family functioning and wellbeing more broadly,” Ms Morgan said.

WHAT'S NEXT

- ▷ Embrace @ Telethon Kids plans to undertake another national Trans Pathways-style survey later this year, this time focused on the mental health of parents of trans young people



The Transforming Families project is generously supported by **Healthway**

Dr Yael Perry is supported by the **Giorgetta Charity Fund**



NO MORE 'FLYING BLIND': SUPPORTING PARENTS OF TRANS AND GENDER DIVERSE KIDS

Perth Mum Jane* considers herself pretty progressive, educated and open-minded, but it still came as a shock when – after several months of anxiety, school refusal and self-harm – her 11-year-old child came out as trans.

Jane cried for two months straight and has spent the two years since then effectively flying blind, trying to manage her own mental health and wellbeing while at the same time doing everything she can to understand the options and get Mark* the support he needs.

"Some of it was about the fact that I thought I would be better at this," Jane said.

"Firstly I thought 'How did I not know?' I mean, I'm with this kid all the time but I didn't pick this up in any way, shape or form so I thought I was stupid and a failure.

"A huge part of it was also being scared for his safety and how hard this was going to be for him – how was he going to make it in the uncaring society we live in?"

“I also thought 'I'm so tolerant and accepting of everything but this is gutting me and I don't understand why'. It threw me for a six and I did a lot of grieving – I still haven't quite got to the accepting place.”

Jane said there remained a huge void in information focused on helping parents navigate their child's gender identity journey.

Beyond an SBS Insight episode which shared the experiences of trans young people and their families – information she found hugely helpful – the first resource she came across that was specifically targeted at parents was a pilot parenting group being run at the Gender Diversity Service at Perth Children's Hospital, as part of the GENTLE study. GENTLE is a collaboration between Telethon Kids and the Gender Diversity Service.

Like the Transforming Families project, the therapeutic group is being explored as an option in response to Trans Pathways findings that parents of trans and gender diverse young people desperately need more support.

Telethon Kids research assistant Helen Morgan, who is undertaking a doctoral degree in clinical psychology and who co-facilitates the parenting group, said the pilot program aimed to find out

more about what parents needed, and to give them peer support and good information.

"It's about making sure they get the time and space they need but also providing them with evidence-based information and therapeutic approaches and practical resources for support," Ms Morgan said.

“It's four sessions, eight hours in total, and the feedback from parents – as we expected – has been 'We want more'.”

Preliminary findings indicate overall improvements in aspects such as parental stress and acceptance of, and confidence in, supporting their child's gender identity. The majority of parents strongly agreed the program satisfied their needs, would help other parents, and they would recommend it to other parents of gender diverse young people.

Jane said that even though many of the other parents had older children who were at different points in their gender identity journeys, she would happily take part in the group again.

"There was no one there who exactly matched our stage and circumstances so it wasn't a perfect fit, but it was close," she said.

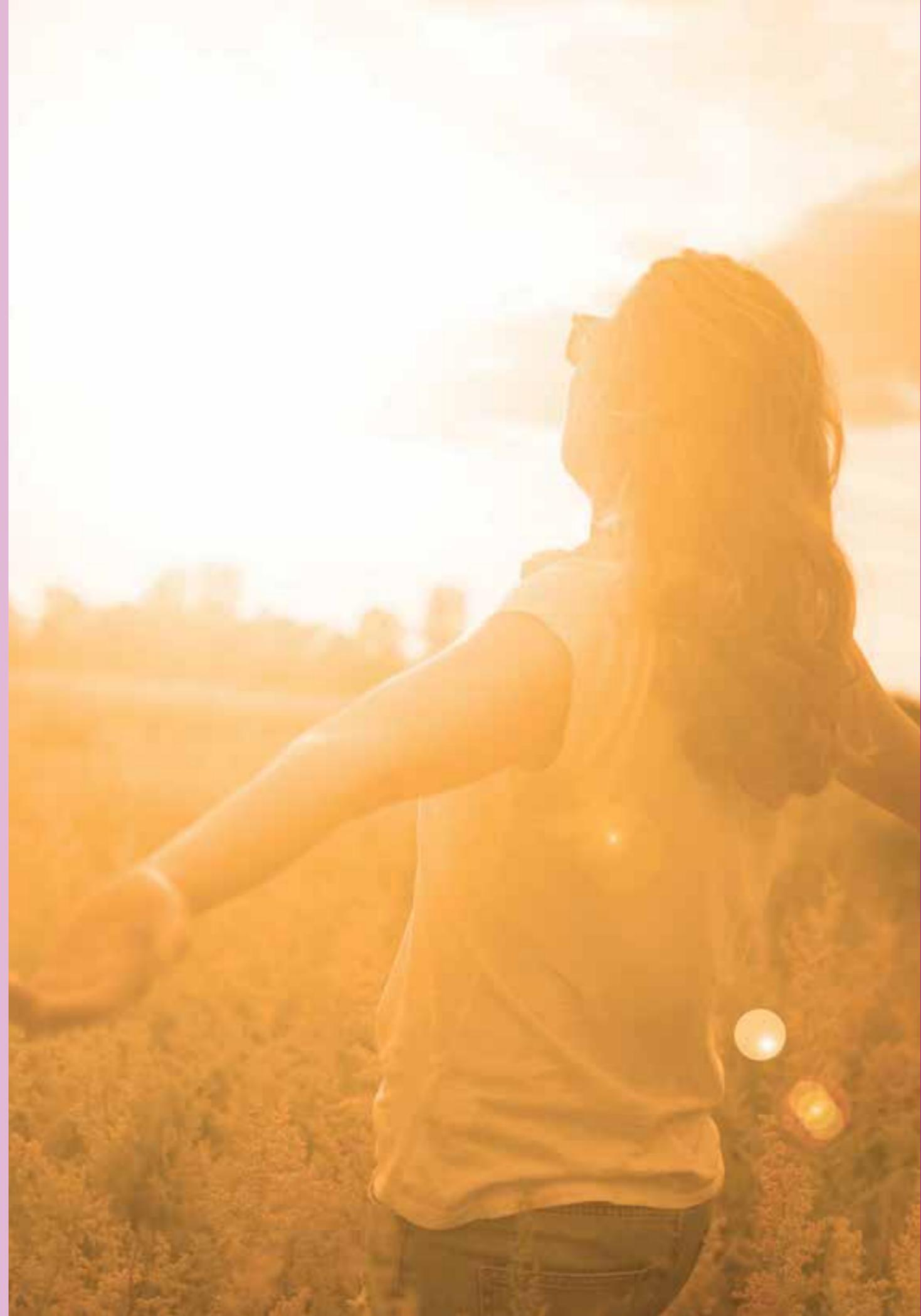
"It was the first thing that had said 'Parents, the adult section of this process, this is for you – come and tell us what's missing and what we need to do'.

"At the end of the day I loved it – I loved the sharing and listening, getting the practical help, and knowing we were helping to find gaps in service for people like me. I need tangible assistance right now so I really want to see the program take off for my own sake – but even if it's too late for me it's good to know that other people won't feel like they're flapping in the wind."

*Names changed to protect privacy

WHAT'S NEXT

- ▶ GENTLE and the Gender Diversity Service are currently running a second parenting group and will evaluate the results to explore the feasibility of turning the initiative into an ongoing program that can be used by gender diversity clinics across Australia



PHAGE THERAPY A CF 'GAME CHANGER'



Parents of children with cystic fibrosis live in constant fear their children may contract life-threatening, difficult-to-treat lung infections – but cutting-edge work being undertaken by Wal-yan Respiratory Research Centre researchers is offering new hope.

The word 'pseudomonas' lives, rent-free, in the back of Perth mum Lisa Hopkins' mind pretty much 24/7.

Lisa's 9-year-old daughter Emma lives with cystic fibrosis (CF) and the prospect of her contracting pseudomonas – a harmful bacteria that causes serious lung infections in children with CF and can cause irreversible lung damage – is one of Lisa's most persistent fears.

Just as scary is the idea that the medications families like the Hopkins rely on so heavily to keep their children healthy may one day not work.

"We're always worried about Emma's risk of developing an infection – particularly with stagnant water at the park, swimming pool, weekends away camping, in the school yard – it's constant," Lisa said.

"She's been on antibiotics since she was six weeks old and fortunately has only been admitted for IV treatments a couple of times, but we are scared about antibiotic resistance.

"It's a constant fear every time she becomes unwell. As a parent I don't know how many antibiotics the doctors have up their sleeves to treat these infections and whether they'll work."

But knowing there is cutting-edge research on a new treatment – happening right here in Perth – gives Lisa hope.

The work taking place in the Telethon Kids lab is bacteriophage therapy (more commonly known as phage therapy), which involves turning predatory phage viruses against bacteria like pseudomonas. Already showing great success in the lab, the treatment could improve the quality and length of life for children, including Emma, who live with CF.

"It's great to see people like Associate Professor Anthony Kicic using their passion to help people like Emma," Lisa said.

"If you're being told current treatments aren't working, you feel like you're at a loss. But phage therapy will literally be a lifesaver for so many people with CF and their families. It's such a game changer. It gives us hope and reduces our stress levels – it is reassuring to know the researchers are working hard to develop another weapon in the tool belt."

The Hopkins family consider themselves lucky that Emma is healthy and has not, at this stage, developed pseudomonas. However, in most cases, colonisation with this bacterium is inevitable.

For some children it can sadly develop in the first few months of life.

Treating pseudomonas is multi-faceted and includes at least two weeks in hospital for IV antibiotics, as well as lung physiotherapy.

To reduce the treatment burden, the aim is to administer phage therapy in a similar way to an asthma puffer.

"It would be life-changing to have medication that is less taxing on Emma's body," Lisa said.

"The medications we make them go through are not pleasant – you feel so bad. You're telling them 'I'm sorry, but you have to do this'. You want to stop the pain, but they have to go through it to stop the infection.

"With IV antibiotics, we run the risk of damaging her veins and there is also a high risk of wound

infection – so a puffer treatment would be so much less risk and less invasive.

"With the amount of trauma kids with CF experience, not to mention time away from school and friends, to have something that doesn't require long stints in hospital would be incredible."

Lisa said the family were big supporters of the research being conducted at the Wal-yan Respiratory Research Centre, with Emma involved in several CF research projects and clinical trials, including AREST CF.

"We try and be a part of any clinical trial that we reasonably can be. We explain to Emma that we are helping be part of the process to find a cure, just as the people before her helped develop enzymes."



Emma doing lung function testing as part of her involvement in a clinical trial for CF



- ▷ **Pseudomonas is a form of bacteria that causes common lung infections to which children with CF are particularly vulnerable.** Treatment often requires weeks in hospital with IV antibiotics and respiratory physiotherapy
- ▷ Dubbed '**superhero viruses**', phage are like microscopic armies, which have the ability to **multiply to destroy harmful bacteria including pseudomonas**
- ▷ Researchers have identified **thousands of bacteriophage (phage) viruses effective at killing lung-damaging bacteria.** Of those, at least **500** are effective at **destroying pseudomonas alone**
- ▷ Antibiotic-resistant bacteria (**superbugs**) have been recognised by governments and industry as a serious and growing issue – **phage could be an alternative CF treatment to antibiotics**
- ▷ The team are working on a **map of how to translate this research into clinical practice** – one of the first in western medicine



Associate Professor Anthony Kicic

COULD PERTH LAKES HOLD THE KEY TO FIGHTING ANTIBIOTIC-RESISTANT SUPERBUGS?

Bacteriophage therapy emerged after Perth researchers discovered a naturally occurring virus living in the city's lakes and rivers that could potentially fight antibiotic-resistant superbugs.

Called bacteriophage or, more commonly, phage, the virus works by preying on and killing host bacteria – a trait of particular interest to researchers anxious to find new weapons against antibiotic superbugs such as pseudomonas.

Increasingly recognised as a global health issue, superbugs are a major threat for children with cystic fibrosis (CF), who are prone to chronic airway infections caused by such bacteria. Treatment for these damaging lung infections typically involves extended antibiotic use, which can cause extreme side effects including nausea, poor gut health – and antibiotic resistance. Accordingly, there is an urgent need for alternative treatments that are more effective and gentler on kids.

Wal-yan Respiratory Research Centre researcher and Head of Airway Epithelial Research at Telethon Kids, Rothwell Family Fellow Associate

Professor Anthony Kicic, first had the idea of hunting in Perth lakes for bacteriophage as a potential answer in late 2019.

"The remarkable thing about bacteriophage viruses - which I have nicknamed superhero viruses - is the way they are able to kill harmful bacteria," Associate Professor Kicic said.

"We knew from results in eastern European countries there was real potential to harness this ability and use it to develop phage therapy for children with lung infection. Stagnant wet areas where there is abundant bird life provided the ideal environment to collect the bacteriophage we needed to explore this."

Starting with an ice-cream bucket on the end of a long pole, Associate Professor Kicic went trawling in ponds and lakes around metropolitan

Perth, bringing the samples back to his lab to be filtered, cleaned and purified. From there, he and his fellow Wal-yan Centre researchers extracted the bacteriophage – enabling them in turn to develop and successfully test phage therapy.

The team has since been able to demonstrate the effectiveness of phage therapy against a range of harmful bacteria affecting children with CF, including pseudomonas.



"Phage has this incredible ability to recreate itself inside the bacteria and multiply – effectively creating a microscopic army against the bacteria, destroying the lung infection," Associate Professor Kicic said.

The team is now building a phage library – manually collecting further samples from Perth's waterways to extract bacteriophage that can be screened for use against specific bacteria, and partnering with the Subiaco Wastewater Treatment Facility to source even more samples.

"We've spent the past year adding to this library and then using it to play matchmaker, screening thousands of phage viruses against individual bacteria strains taken from the lungs of WA kids to find the perfect match," Associate Professor Kicic said.

"Once correctly identified, we are seeing a 100 per cent success rate with killing that particular bacterium."

WHAT'S NEXT

- ▶ The researchers are working to finish the phage library and working towards clinical use
- ▶ A phage therapy taskforce has been established between researchers, clinicians, WA Health Department, PathWest and CF consumers to make this treatment possible. The taskforce's main aim is to streamline the pipeline so phage therapy may be used on compassionate grounds within the next 12 months – likely in young adults who are no longer responding to antibiotics
- ▶ In the future, the aim is for this treatment to be made available for younger children with CF as an alternative to antibiotics to treat their early infections, rather than waiting for the bacteria to become antibiotic-resistant



RESPIRATORY RESEARCH CENTRE

Healthy lungs for every child, for life

A Powerhouse Partnership



Associate Professor Anthony Kicic is a researcher with the Wal-yan Respiratory Research Centre, which is a powerhouse partnership between Telethon Kids Institute, Perth Children's Hospital Foundation and Perth Children's Hospital.

The Wal-yan Centre, which launched last year, is a global epicentre for paediatric respiratory research, informing clinical practice and driving a new research agenda for childhood lung health.

Building on 30 years of experience, where WA's respiratory researchers have been recognised as among the best in the world, the Centre brings together clinicians, scientists, and community members from across the globe with a united goal – to prevent childhood respiratory illness and ensure that all children have healthy lungs for life.

The English translation of our Noongar name of place is **Place of Healthy Lungs**. **Wal-yan** means **lungs** and **Warlang-up** means **healthy place**. The Centre sits on Noongar land, and we respectfully acknowledge the traditional owners. We also acknowledge Walter Jnr McGuire and Elder May McGuire for the Noongar name of place with English translation.



The Wal-yan Centre is supported by several organisations, including **Northern Star Resources, Rio Tinto, BHP Australia, Stan Perron Charitable Foundation, as well as Channel 7 Telethon, Mineral Resources, Cystic Fibrosis Australia and Cystic Fibrosis Western Australia**

Associate Professor Kicic is the **Rothwell Family Fellow**

THE SIX-MINUTE TESTS THAT COULD SAVE LIVES



It takes about five minutes to boil water and brew a pot of tea. Thanks to research, in that time we can now get an answer that could save a child's life.

Children at risk of potentially life-threatening Strep A infections no longer need to wait up to five days for their results, after Telethon Kids researchers successfully piloted rapid tests that can give patients an answer in just six minutes.

In a study conducted by the Skin Team in the remote Kimberley region of Western Australia, researchers led by Associate Professor Asha Bowen demonstrated that rapid, molecular point-of-care tests (POCT) can be used in remote settings to accurately detect the presence of Strep A bacterium on the spot.



Dr Dylan Barth collecting a dried blood sample while Slade completes the SToP Trial jigsaw puzzle

Found in the throat and on the skin, Strep A is often responsible for sore throats and painful skin infections, which – if left untreated – can lead to irreversible and potentially deadly heart and kidney damage.

Associate Professor Bowen, who is Head of Skin Health at the Wesfarmers Centre of Vaccines and Infectious Diseases, said using this cutting-edge technology could prevent serious illness and save many lives.

"This could revolutionise detection and then treatment of Strep A infections in remote Aboriginal communities," Associate Professor Bowen said.

"In the time it would usually take to get the standard tests processed and results returned to these remote regions, treatment may be missed and the infection potentially spread to others.

"With our study we've been able to have the children tested at in-school clinics and the results generated within minutes and then referred on to their GP, who can set them on the right course of treatment."

Associate Professor Bowen said the study was part of a wider research project aimed at finding the 'missing piece' about how Strep A skin sores and sore throats contribute to rheumatic fever. It is hoped POCTs will detect Strep A faster and ultimately prevent kids from developing Acute Rheumatic Fever (ARF) or the more severe condition Rheumatic Heart Disease (RHD).

"Aboriginal Australians living remotely have some of the highest rates of rheumatic heart disease in the world, and these areas also face major issues around antimicrobial resistance, so improved testing will make a big difference in advising appropriate medical treatment going forward," Associate Professor Bowen said.



Associate Professor Asha Bowen



"If we want to achieve the Endgame Strategy of eliminating RHD by 2031*, then we have to find ways to intervene early – this could be a big part of the answer."

Associate Professor Bowen said the rapid tests had the potential to do more than just improve rates of Strep A infections – they could also help to strengthen relationships between health care providers and Aboriginal families.

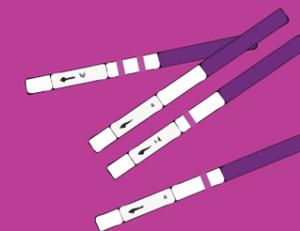
"We found the nurses who work for the local Aboriginal Medical Service, and do regular school visits with our team, are really excited about getting an immediate result and then being able to connect with families and encourage them to get treatment," she said.

"The schoolchildren were really engaged, watching the machine generate their results in realtime.

"Already this is a really strong partnership which has allowed us to pair field research with an innovative technology trial that could be a real breakthrough in preventing rheumatic fever in kids."



Slade with his blood sample



▶ The on-the-spot tests for Strep A infection reduce wait time by five days – allowing treatment to be started earlier and reducing potential spread to other children



▶ Telethon Kids piloted the technology in 2019 and found it to be helpful. The team has since built it into the ongoing study to learn more about the next steps needed before it can be routinely implemented



▶ The team hopes the tests will eventually become part of standard care in remote Australian clinics



▶ If left untreated, Strep A infection can lead to ARF or, worse, the chronic condition RHD



▶ More than **5,000** Aboriginal and Torres Strait Islander people are currently living with ARF or RHD

* See the Endgame Strategy story on page 64

STAYING ACTIVE WITH TYPE 1 DIABETES



A ground-breaking new app developed by Telethon Kids researchers may soon make exercising safer for young people with type 1 diabetes.

Regular exercise can add years to the lives of young people living with type 1 diabetes (T1D), but it can also play havoc with their blood glucose levels.

Consequently – and despite physical activity being critical to managing their diabetes – people with diabetes are often reluctant to exercise.

“Regular physical activity is recommended for people with type 1 diabetes because the health benefits of an active lifestyle play an important role in their treatment,” according to Dr Vinutha Shetty, who is head of exercise research at the Children’s Diabetes Centre at the Telethon Kids Institute.

“It not only improves their cardiovascular and bone health, but also reduces their insulin requirements and improves blood lipid profiles,” Dr Shetty said. “Exercise also has considerable psychological and psychosocial benefits, such as improved quality of life and wellbeing.

“But exercise is also a challenge for people living with type 1 diabetes because the blood glucose response to exercise is unpredictable, increasing the risk of hypoglycaemia (low blood glucose levels).”

Dr Shetty, also an endocrinologist at Perth Children’s Hospital, said this fear of having a ‘hypo’ was the biggest barrier to young people with diabetes exercising – and the catalyst for Dr Shetty and the exercise research team to co-design a new smartphone app alongside young people with T1D to help them exercise safely.

Called acT1ve, the app contains exercise guidelines and tailored advice specifically for young people living with T1D – the first of its kind to do so.

“From our focus groups, young people told us that exercising safely was one of the biggest challenges they faced in managing diabetes and that’s where the idea of developing an exercise app specifically for them came from,” Dr Shetty said.

“acT1ve asks the user questions about the activity they are going to do, and based on this detailed information, it gives advice on when and what to eat, when to have insulin and how much insulin to have and when to check blood glucose levels. The advice is based on international exercise guidelines.”

The app was initially tested by a small group of young people with T1D to gauge their thoughts, with promising results.

“The young people found acT1ve very useful, informative, extremely functional and there was high user satisfaction,” Dr Shetty said.

“Users considered the app as a security blanket or like having a personal trainer all the time, allowing them to exercise and manage their diabetes with confidence.”

Dr Shetty and her team are midway through the clinical trial of acT1ve – a necessary step before

the app can hopefully be approved for general use.

“Once the efficacy and safety of this app for diabetes self-management around exercise is established, we will identify pathways for regulatory approvals and development strategies to implement the app in the clinical setting,” Dr Shetty said.

“The whole point of developing the app is to get people who are reluctant to exercise to start exercising and build confidence and we hope that by preventing low blood glucose levels, acT1ve will encourage them to be physically active more frequently and gain the many benefits of exercise.”

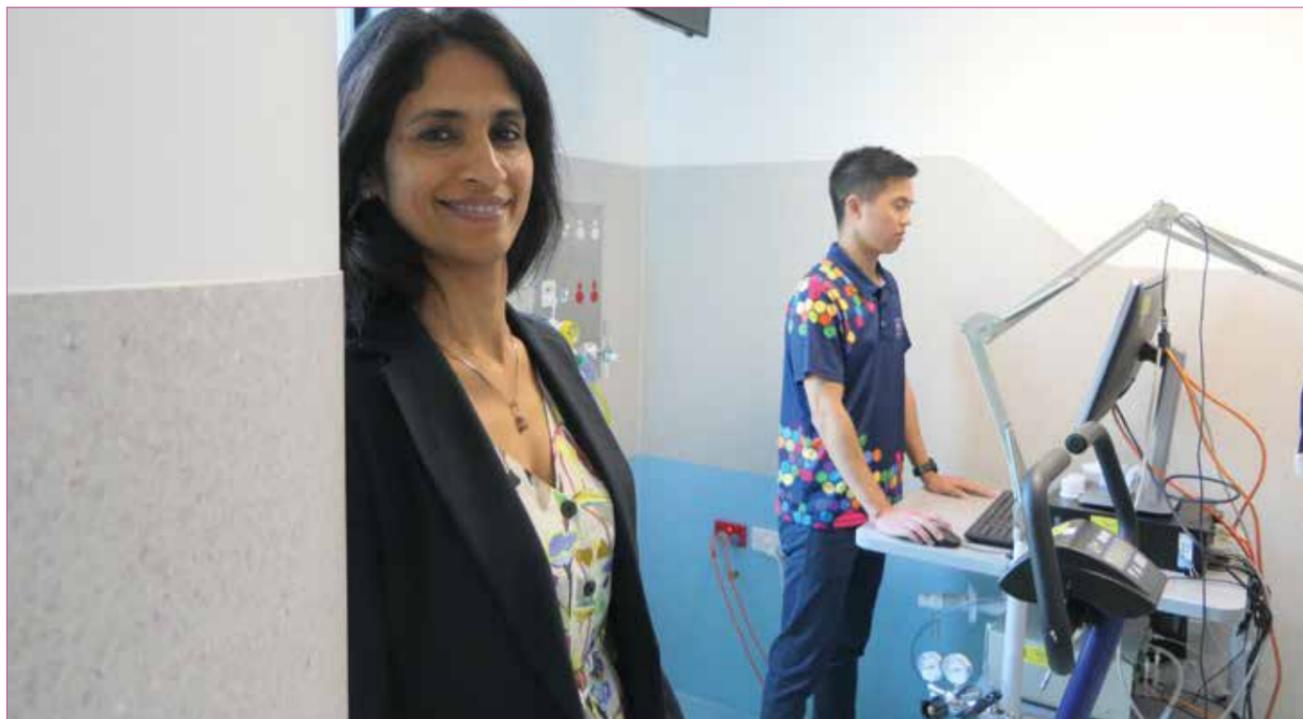


JDRC and the Channel 7 Telethon Trust helped to fund the app



WHAT’S NEXT

- ▶ Work with Commercialisation and Partnerships teams at Telethon Kids Institute and the WA Health Department to establish relationships with the Therapeutic Goods Administration, patent lawyers and commercialisation experts
- ▶ Identify potential industry partner to partner with in commercialising the app
- ▶ Promote and facilitate a range of events including community information evenings, panels with policymakers, and workshops to engage relevant stakeholders to ensure app availability in clinical practice



Dr Vinutha Shetty with Wayne Soon Photo courtesy Diabetes WA

Type 1 diabetes is a chronic autoimmune disease that results from the immune system attacking the insulin-producing cells of the pancreas

Currently, **type 1 diabetes cannot be prevented** but it can be managed by administering insulin, monitoring glucose levels, having a healthy, balanced diet and getting regular physical activity

In WA, about **160 children are diagnosed with diabetes every year**, and the number is increasing



DON'T STOP HER NOW – GINA'S HAVING A BALL

Thirteen-year-old Gina Latimer loves nothing more than being active, but living with type 1 diabetes (T1D) means exercising could cause her blood glucose levels to go low.

Despite the risk of having a hypo (low blood glucose levels), Gina said she refused to let T1D stop her from exercising.

"I have experienced a hypo after sports," she said.

"For me it just feels like a regular low so I know there is nothing to be worried about.

"If I go low, I just have some glucose tablets and some carbs to bring my blood glucose levels up. It's normal to have a low after sport."

The avid young sportswoman, who was diagnosed with T1D in 2016, currently swims six times a week for two hours per session. Before swimming became her focus, she played soccer, basketball, and badminton, and also rode horses (she won two bronze medals at the Long Course Junior State Championship in March and two silver medals at the Short Course State Championship last year).

Gina recently tested the Children's Diabetes Centre's acTive app and enjoyed using it, saying she always liked to learn something new.

"The app did help me since it tells you what to eat before exercising," she said.

"I felt more educated because the app gives you an idea about what you are doing before exercising – it made me feel more confident than I already am.

“Diabetes will not stop you from doing anything so just keep a positive attitude. Exercising is probably my favourite thing to do and I will not let anything, especially diabetes, stop me.”

What is a hypo?	A condition that occurs when a person's blood glucose levels falls to less than 4mmol/L
What causes it?	Too much insulin , delaying or missing a meal, not eating enough carbohydrate, increased activity, gastroenteritis
Mild hypo symptoms?	Hunger, shaking, palpitations, pale skins, sweating

- acTive provides:**
- ▷ **Personalised insulin dose and carbohydrate advice for exercise** lasting up to **60 minutes** based on the user's input on the type, intensity and duration of physical activity they are about to complete, duration since the last insulin bolus, and their current blood glucose levels
 - ▷ Information on **hypoglycaemia treatment, pre and post-exercise insulin and carbohydrate advice**
 - ▷ **Educational food guide** that highlights the importance of low and high glycaemic index (GI) foods in the context of exercise management



Gina Latimer
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Miles and Isla are twins - Isla is fascinated by tiny creatures while Miles love sport. Read their story at telethonkids30.org.au



Ditza, with her son Jeremiah, chose to become a medical doctor after years participating in research. Read Ditza's story at telethonkids30.org.au



Marlee loves music, horse riding and her blue heeler Dixie. Read Marlee's story at telethonkids30.org.au



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

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