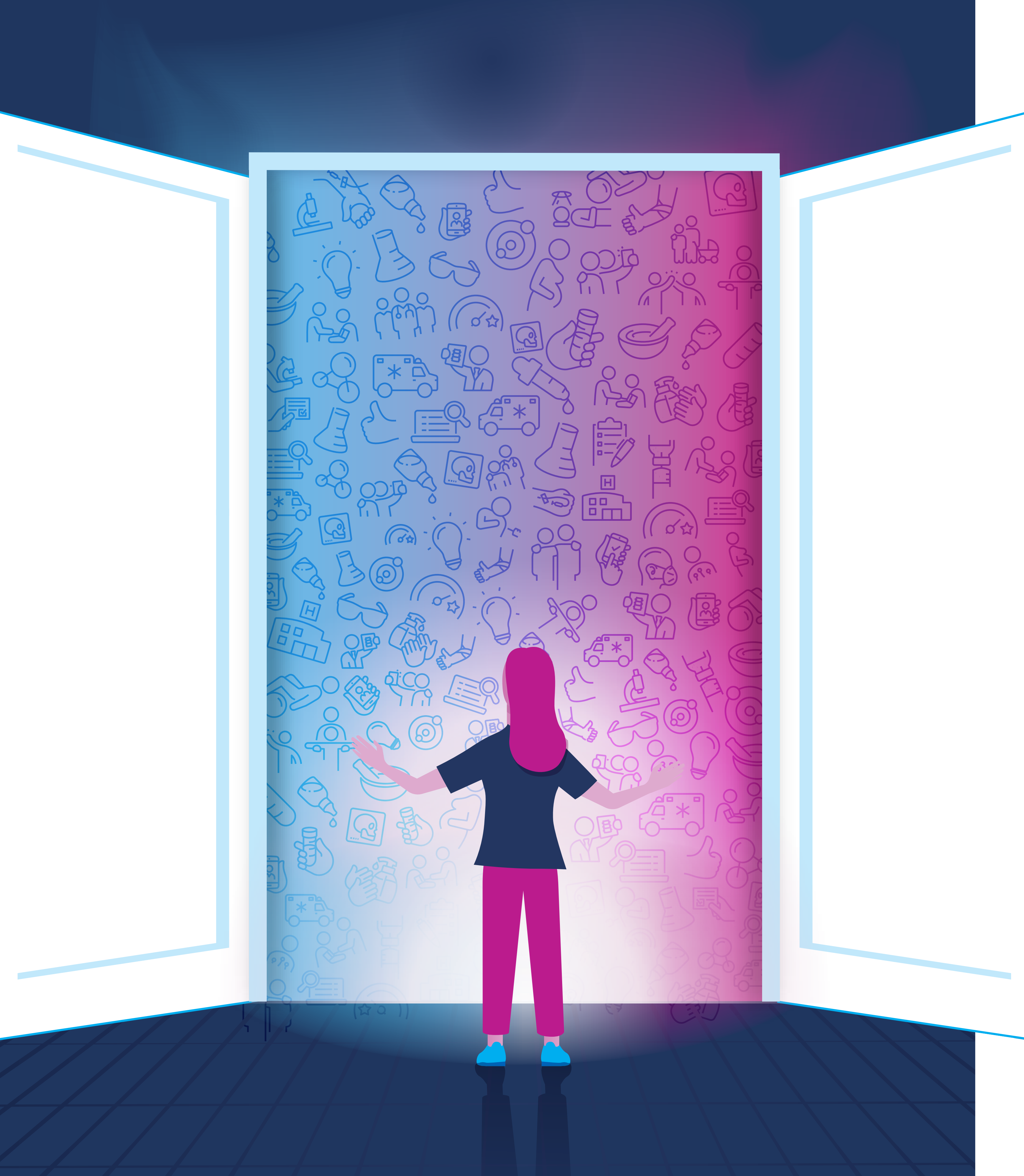


Perth
Children's
Hospital
Foundation

The gateway to more impact.

Annual Review 2024/2025

Acknowledgement of Country

Perth Children's Hospital Foundation acknowledges the traditional custodians of the land, the Whadjuk Noongar people and the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders both past and present, and pay respect to them and Aboriginal communities of today.

Contents.

Message from the Foundation.

**The Hon.
Ian Campbell**

Chairman

Carrick Robinson

Chief Executive Officer

In a world filled with challenges, the unwavering commitment of our donors and supporters is a ray of shining light – bringing hope and healing and brightening the lives of countless children and their families.

At Perth Children's Hospital Foundation (PCHF), we're privileged to be **the gateway to more impact**, helping unlock new opportunities to create greater, more meaningful change.

In the past year, we've seen the impact of our generous donors and supporters reach new levels.

World-leading rehabilitation robotics technology is coming to Perth Children's Hospital (PCH) to revolutionise the care of children having to learn, or relearn, basic functions many of us take for granted. Groundbreaking ZeroG equipment will empower and transform lives impacted by accident, injury or disability.

Kids Rehab WA at PCH is a world-leader in rehab robotics whose expertise is sought out around the globe. PCHF has been a crucial part of their journey, funding Australia's first robotic arm that's produced stunning outcomes in a generation of kids. One of those is Alexey whose sights are set on making the Australian Paralympics swimming squad; you can read about his inspirational journey in the following pages.

We're honoured to support world-leading clinical research which is helping identify and treat large numbers of WA children with a silent cardiac condition. Close to 2,000 WA kids don't know they have this inherited condition which leads to early heart disease and premature heart attacks. But with early detection and treatment these children will go on to lead full and long lives.

At PCHF, we believe all children should have this opportunity and are proud to support programs that are helping reduce health inequality and are making a real difference to the lives of Aboriginal children across our vast state. This includes the extension of the world-leading Rare Care Centre into WA's Pilbara and Northwest.

As a gateway to meaningful and lasting impact, we connect our supporters to the healing journey of sick children and their families not only in WA, but with the impact of our projects rippling outwards, to sick kids across Australia and around the world.

Children and young people have better lives and brighter futures thanks to the generosity of all our donors, partners and our dedicated and passionate staff and volunteers.

In what has been another outstanding year of opportunity and impact, we say a heartfelt thank you to everyone who has helped make what we do possible. Please enjoy reading about all the incredible ways PCHF and our supporters are bringing life-changing health care to the kids of WA and beyond.

About us.

Perth Children's Hospital Foundation proudly fuels the fight on the frontline of children's healthcare, helping sick children get well and stay well.

By working closely with those on the frontline, the Foundation has an in-depth understanding of what clinicians, researchers and families need to ensure we make a tangible impact where it counts most.

We are the specialist children's charity at Perth Children's Hospital (PCH) and Health Service and are now the 6th largest philanthropic foundation in WA. In FY 2024-25 we had another successful year, funding $6.26 million in grants, with $46.8 million committed over the next five years.

With the help of our generous donors, our efforts enable PCH and CAHS to continue to provide WA's sick children and young people with access to world-class care that comes from:

$1,677,345	The most advanced equipment and technology
$1,207,294	Innovative education and training programs
$400,104	Positive patient and family experiences
$322,840	The expertise of highly trained clinicians from Australia and around the world
$2,649,854	Ground-breaking research

Note: Preliminary figures subject to audit.

Our governance.

The Foundation recorded another strong financial result in FY 24/25, providing $6.26 million in grants to Perth Children's Hospital and the wider Health Service.

We closely monitor all costs to ensure they are controlled as much as possible without compromising the Foundations ability to deliver maximum support to children's healthcare.

Strong financial stewardship

We pride ourselves on ensuring that all funds generously donated are spent wisely to make a real and positive impact on child healthcare. To achieve this, we employ a rigorous peer review process to vet all requests for funding.

The first level of application review is by the Executive Committee of the relevant health service – Perth Children's Hospital, the Child and Adolescent Community Health Service, or the Child and Adolescent Mental Health Service. If they believe the project meets the Foundation's funding guidelines, the application is then reviewed by the Foundation Grants Sub-Committee (GSC). All research applications are also assessed by the Scientific Advisory Committee before progressing to the GSC. Finally, a request for funding over $20,000 requires the approval of the full Perth Children's Hospital Foundation Board.

In addition to establishing that each application provides a strong case outlining how it will improve health outcomes for children, the Foundation ensures that we are not being asked to fund something that the community would reasonably expect to be the responsibility of Government, such as the routine replacement of equipment. The Foundation's focus is on funding world-class expertise and training, ground-breaking research, cutting-edge equipment and technology, and positive patient experiences that the Health Service would otherwise not be able to access.

We trust that our stewardship of the funding you provide meets your highest expectations and gives you the confidence to continue your support.

Our difference.

The bravery and courage of WA's sick children inspire us every day and are at the heart of everything we do.

We've played a central role in funding advances in children's healthcare for more than a century with our origins traced back to the late 1890s, when the movement to establish a children's hospital began.

Our story is entwined with the WA's children's hospitals throughout history, first as the Children's Hospital which opened in 1909, then Princess Margaret Hospital and now, as Perth Children's Hospital.

With PCH and wider Health Service our sole beneficiary, every donation we receive goes directly towards improving the lives of sick children through world-class healthcare.

Specialist children's healthcare charity

We are the specialist children's healthcare charity at PCH. We're based on site at the hospital and have a close connection with the children's healthcare community, collaborating with PCH clinicians, researchers and families to understand the unique needs within the medical landscape. This ensures every donation is optimised to make the greatest impact.

Western Australia's spirit of generosity enables us to provide support over and above that of Government to improve and change the lives of sick children and their families.

Rigorous governance processes

We take a stringent approach to governance with strong controls over the assessment, acceptance, administration and acquittal of grants we fund. This includes a rigorous peer review process to ensure our impact is maximised.

Scientific Advisory Committee

A core part of PCHF funding is for ground-breaking research and world-class expertise which ensures kids receive the best possible preventions, cures and care in WA.

In 2024, the PCHF Scientific Advisory Committee (SAC) was established to undertake rigorous scientific reviews of research funding applications and the appointment of research fellowships and professorial chairs. In addition, the Committee provides independent advice to the PCHF Board on areas of strategic importance.

The inaugural Committee members bring significant experience and expertise from across Australia in medicine, nursing, epidemiology, physiology, psychology, physiotherapy, dietetics, clinical trials and laboratory sciences. They comprise a mix of local and interstate experts, with many internationally recognised – one member was a World Health Organisation advisor for more than 10 years.

Professor Graham Hall, a health researcher with more than 25 years' experience across healthcare, academia and the not-for-profit sector, leads the committee of 11 expert advisors.

The SAC ensures donors' contributions are invested wisely and support innovative, impactful research and expertise that improves the lives of WA kids today and into the future.

Brighter futures

Together with our supporters and our strong connections to children's healthcare, rigorous governance processes and a thorough knowledge of what's needed most to make a difference, we're creating healthier, happier futures for sick kids in WA, across Australia and around the world.

Our impact: shaping healthier futures.

Changing lives through the most advanced equipment and technology.

77

children had a more positive experience receiving the protective benefits of immunisation after the introduction of pain reducing Buzzy Bees in 41 metropolitan community health clinics

30

vulnerable babies born prematurely, with oxygen deprivation or low birth weight had safer transfers to hospital following the introduction of state-of-the-art neuroprotection equipment in emergency neonatal transport

10

delicate neonatal babies at risk of compromised airways were safely intubated in intensive care thanks to an innovative intubation video system

40

children and infants with epilepsy benefitted from the introduction of a sophisticated EEG intraoperative brain monitoring system in orthopaedic or neurosurgery

99

children with type 2 diabetes and their families have a better quality of life and improved control of diabetes after receiving a Continuous Glucose Monitoring (CGM) device, replacing the need for painful and less-accurate finger prick monitoring of insulin levels

Funding the future through groundbreaking research.

37

children with post-tonsillectomy haemorrhage were safely treated in a world-first pilot study with the drug TXA delivered via nebuliser, avoiding urgent intravenous treatment or surgery and providing clinicians an opportunity to safely change future clinical care globally

42

children with cancer enrolled in early phase clinical trials and received groundbreaking treatment that otherwise would not have been available to them

28

babies in neonatal intensive care participated in sleep studies conducted at the bedside, resulting in earlier diagnosis and discharge home

25

babies with CVI, a leading cause of vision loss in children, were recruited into a study and received comprehensive visual, sensory, fine and gross motorskills and general development assessments

200

children were enrolled in a study predicting adverse respiratory events in children undergoing general anaesthesia

Supporting innovative education and training programs.

20

neonatology doctors expanded their expertise in safe intubation following training in the cutting edge CMAC Difficult Intubation Video System for newborns in ICU at risk of airway compromise

40

registrars, senior registrars and nursing staff are better equipped to treat lung collapse after being trained in chest drain insertion using an innovative model that is now used in regular teaching for fellows, nursing staff and registrars

20

PCH staff attended simulated learning presentations on the latest evidence-based practice for working with children who have severe difficulty eating and drinking and are at risk of aspiration and/or choking

50

junior PCH emergency doctors, 10 medical students, 10 nursing staff and 20 Midland Hospital doctors improved their skills in ear and nose foreign body removal following simulation-based training using anatomically accurate 3D printed models

Investing in world-class expertise closer to home.

3,500

children and families benefitted from the Stan Perron Centre of Excellence for Childhood Burns with world-renowned burns specialist, Professor Fiona Wood AO at the helm

400

children and families have been accepted into PCH's world-leading Rare Care Centre, guided by Professor Gareth Baynam, for life-changing care and support as they navigate the complex needs of living with a rare disease

1,000

children and families benefitted from advanced interventional radiology procedures improving outcomes in complex conditions under Professor Derek Roebuck's guidance

Funding positive patient and family experiences.

145

patients watched a video aimed at reducing distress in patients undergoing a medical imaging procedure used to assess swallow safety in those at risk of food/fluid entering their airways - another 8975 people watched the video online

90+

children with disabilities had the opportunity to participate in reading, vision development and mobility activities and play, improving their skills and life enjoyment thanks to communication and play items

75

diabetes patients attending CGM device workshops used Virtual Reality Smileyscopes to reduce their anxiety and relax during sessions on the insertion of CGMs and diabetes management

35,416

play packs were distributed to children aged 3-10 years to ease anxiety and promote emotional regulation while waiting for hospital appointments

INNOVATIVE EQUIPMENT AND TECHNOLOGY

The rise of rehab robotics.

> "ZeroG allows them to start their rehab and do it quite intensely from very early on in their journey because it gives them a lot of support and enables them to work safely at their limits."
>
> Rae Robinson,
> Intensive Rehabilitation Coordinator, Kids Rehab WA

Robots are increasingly improving our everyday lives helping with everything from vacuuming our floors to medical interventions.

Rehabilitation robots are one of the most important new therapeutic devices to improve recovery and long-term outcomes for children having to learn, or relearn, basic physical functions after illness, injury or due to disability.

Kids Rehab WA, PCH's paediatric rehabilitation service, has been a world leader in rehab robotics since integrating robots into clinical care in 2015. PCHF has been a crucial part of the journey since the early days.

"Having the support of donors and Perth Children's Hospital Foundation with our robotics program means our staff are sought out around the world to present their knowledge," said Rae Robinson, Intensive Rehabilitation Coordinator, Kids Rehab WA.

An upper limb robotic device funded by the Foundation 10 years ago was an Australian first and revolutionised rehab for children with neurological conditions caused by brain and spinal cord injuries, cerebral palsy and brain cancer.

The technology produced stunning results, helping a generation of children regain movement in their shoulders, arms and elbows, changing their lives for the better.

The device is still in use today, but with technology rapidly evolving, a more advanced robotic arm funded by PCHF will take upper limb rehabilitation to the next level. The technology complements other robotic devices used in Kids Rehab programs and allows children to benefit from intensive early stimulation of the nervous system to maximise recovery.

"The new technology enables us to help WA children at an earlier stage of rehabilitation, which offers the greatest chance of functional recovery," said Jenny Colegate, Senior Occupational Therapist, PCH.

"New features enable supported movement against gravity for a much broader range of arm movement and fine motor movement development for finger control – all of which can help with self-care such as getting dressed, managing shoelaces and using a knife and fork."

In another Australian-first, Kids Rehab is introducing a game-changing advanced dynamic bodyweight support system, the ZeroG 3D, thanks to PCHF and our generous supporters.

PCH is the first children's hospital in Australia to empower and transform young lives with this revolutionary piece of equipment. While wearing a harness connected to the ZeroG 3D robot mounted on a ceiling track, children are able to move through space safely in all directions and have fun while practicing functional skills like walking, balancing, sitting, squatting and lunging – they can even practise kicking balls and roller skating or bike riding! All without the fear of falling, thanks to an inbuilt fall protection mechanism.

"If I was describing it to a child, I'd probably describe it as being magic," Ms Robinson said.

"ZeroG allows them to start their rehab and do it quite intensely from very early on in their journey because it gives them a lot of support and enables them to work safely at their limits.

"Having this means we can offer world-class technology and innovation for every child that needs it, here in Perth."

PCHF is proud to have supported Kids Rehab WA in their journey to becoming a world-leader in children's rehabilitation robotics.

"We're extremely grateful for our supporters who have created such meaningful impact turning Kids Rehab into a world leader and helping WA children flourish and thrive so they can live their best lives possible," said PCHF CEO, Carrick Robinson.

Going for Paralympic gold

Six days a week, Alexey's alarm goes off at 4.30am. In the early morning darkness, while many are still asleep, Alexey makes his way to his local swimming centre to train for two hours and to chase his dream of joining the Australian Paralympic squad.

Alexey's story is one of remarkable courage, resilience and fierce determination to overcome incredible health challenges.

He was born healthy but his parents soon knew something was not right. At four weeks of age, Alexey was diagnosed with a stroke which caused bleeding in his brain.

Despite undergoing two surgeries, Alexey failed to develop like other babies. He didn't move much and his distraught parents knew something was wrong with the left side of his body. By 17 months of age, Alexey was having hundreds of seizures every day and would often drop to the floor and become unresponsive.

The only cure was to undergo more frightening surgery to remove half of his brain. Alexey was only the second person in WA to undergo a complex hemispherectomy to remove the damaged right hemisphere of his brain.

"The difference after the surgery was ginormous because the seizures stopped almost immediately," said Alexey's mum, Anna.

"I think it was day two or three after the surgery when he said two words together – a child who had not spoken anything in years!"

Alexey began to thrive but it took three years of intensive rehab for him to learn how to walk, talk and move his left arm. He was the first child in Australia to use the state-of-the-art robotic arm, funded by the Foundation, to strengthen his muscles and regain the use of his left arm.

"Alexey has gained a lot of movement in the left side of his body, not only his arm, with the support of the robotic equipment. From a child's perspective it was fun and enjoyable because it was basically playing a computer game while strengthening his muscles."

For Alexey, the robotic technology set him on the path to sporting glory. Regaining the use of his left arm meant he could take part in hydrotherapy and learn how to swim. He discovered a love for swimming and progressed from rehab to competitive swimming.

At 16 years old, Alexey's dedication and passion is truly inspiring. Every training session covers up to four kilometres and when he's not in the pool, he's building strength at the gym. He's a swimming club captain, volunteers helping junior swimmers and is studying to become a technical official for swimming competitions.

Alexey competes nationally and in recent years has won multiple state para championships. He holds five Australian swimming records for his age and his future looks bright as he sets his sights on making the Australian Paralympic team.

"I love swimming because I can move freely in the water and it's just my own little world," Alexey explained.

While his left arm will never function as well as his right and he lives with cerebral palsy and vision loss, Alexey has embraced a life filled with happiness and joy.

His mum Anna adds, "Lots of people fundraise and donate for a cure but sometimes we can't fix things and we need to learn to live with it. Rehabilitation is often overlooked.

"There are children and families who have fought so hard to survive and they may not be cured but they need all the help they can get to live their best lives.

"Most families would not have the opportunity to travel to Europe or the United States to get the most advanced technology for rehabilitation, and the fact our children have access to that level of robotic equipment and therapy is a great blessing and would have been impossible without the help of the Foundation."

EDUCATION AND TRAINING

Fellowship opens doors to advanced radiology for kids.

Dr Jheuvan Leslie is currently completing an Interventional Radiology Fellowship at PCH, made possible through funding from Perth Children's Hospital Foundation.

Dr Leslie made the journey from Kingston, Jamaica, where he worked at Bustamante Hospital for Children, the largest paediatric hospital in the English-speaking Caribbean.

An early interest in pharmacology stemmed from a desire to discover new treatments from plants. But inspired by his family GP, Dr Leslie soon set his sights on medicine. He has long held a passion for computer science and during medical school this led him to explore the possibilities of medical imaging and radiology.

After graduating, Dr Leslie began practising in Jamaica, and by his third year, discovered his love for paediatrics.

"Kids tend to bounce back quickly, which makes working with them especially rewarding," he said.

In 2024, Dr Leslie was selected for the PCH fellowship, an opportunity he describes as transformative. "I'm incredibly grateful to PCHF for this opportunity," he said. "Back home, interventional radiology is more focused on adult care, so many doctors aren't as comfortable managing paediatric cases."

During his fellowship, Dr Leslie has learned techniques rarely available in Jamaica, including using advanced radiology to treat lymphatic and venous conditions in children. One of the most rewarding procedures he's performed is sclerotherapy – injecting a chemical to shrink fluid-filled pockets and ease swelling in areas like the stomach, limbs or face.

One of the most challenging aspects of his work has been the delicate task of placing catheters (tiny tubes used to move things in and out of the body) into small arteries, which requires hours of skill, patience and planning.

Dr Leslie is actively involved in projects advancing the field of paediatric

interventional radiology. Together with Dr Craig Gibson, Head of Medical Imaging at PCH, and Professor Derek Roebuck, he's working on the publication of a new sclerotherapy technique. He's also contributing to a systematic review of hepatic artery embolisation – a procedure using tiny tools to block blood vessels in the liver, to stop uncontrolled bleeding.

"Some of the procedures we perform are groundbreaking," Dr Leslie said. "The research is still relatively new, so being among the first in the country to treat children with innovative techniques like Bleomycin Electrosclerotherapy – using both medication and electric current to treat dysfunctional veins, is significant. It's especially exciting given some lymphatic malformations don't respond to traditional treatments. This new technique offers a safe, effective alternative, giving hope to patients who thought they had no other options."

When Dr Leslie completes his fellowship, he plans to return to Jamaica and implement the skills he's gained, with his first goal being to set up a comprehensive Vascular Access service.

Mason's journey of hope

When baby Mason was born, his mum Shenae never imagined his first months would be spent fighting just to feed and grow.

Born at Joondalup Health Campus, everything seemed normal until Mason began vomiting after every feed. Within hours, he was losing weight rapidly, dropping from 2.9kg to 2.5kg in just two days. An X-ray revealed he had tracheoesophageal fistula (TOF), a rare and serious condition where the oesophagus isn't properly connected to the stomach.

With food unable to reach his stomach and at risk of entering his lungs, Mason needed urgent surgery. He was rushed to PCH by the Newborn Emergency Transport Service (NETS WA) and underwent emergency surgery the same day.

While the procedure successfully connected his oesophagus, it revealed another challenge. Mason's oesophagus was extremely narrow, too small even for a feeding tube. He required round-the-clock suction and couldn't swallow his own saliva.

At just three and a half weeks old, Mason began a series of delicate oesophageal dilations – tiny balloon procedures to gently widen his oesophagus. Interventional Radiology Fellow Dr Jheuvan Leslie, has performed most of Mason's 15 dilations to date, helping him learn to swallow and feed.

Mason spent seven weeks in the Neonatal Intensive Care Unit (NICU) and more than two months at PCH, with more hospital stays expected as his treatment continues.

From being fed just 0.5mL of milk at a time via 'dummy dips', Mason is now happily drinking full bottles. At more than seven months old, he's thriving and even enjoying small amounts of solid food, including purees and mashes, as well as sipping from a cup.

"Dr Leslie was fantastic," said Shenae. "He always checked on Mason after each procedure. We felt confident he was in the best hands."

GROUND-BREAKING RESEARCH

Getting to the heart of 'silent' cardiac condition.

Every week, three WA babies are born with Familial Hypercholesterolaemia (FH), the most common and serious cause of inherited high cholesterol.

These seemingly healthy newborns display no signs of an invisible condition which is passed down through the generations and, if left untreated, significantly raises the risk of premature heart disease and early heart attack.

High levels of low-density lipoprotein (LDL) – also known as bad cholesterol – build up over the years, with the accumulated damage leading to a 20-fold increase in the risk of premature heart disease.

If treated from a young age, children with FH can expect to have a normal life expectancy and the opportunity to live long and full lives. But 95% of people with FH, including close to an estimated 2,000 WA children, are unaware they're walking around with a condition that has them on the path to early heart disease.

World-leading PCHF-funded clinical research aiming to identify and treat large numbers of children with FH has led to a significant increase in detection rates. Over the past year, 140 WA children have been identified through a Nurse Practitioner-led model of diagnosis and care integrated with General Practice.

First degree relatives have a 50% chance of also having FH and, where someone with FH has been identified, cascade screening of first and second-degree relatives is picking up other family members who are unaware they have the condition.

About FH:

- **By age 50, 50% of men and 20% of women with undetected FH will suffer fatal or non-fatal heart attacks**
- **Up to 95% of children don't know they have FH**
- **One in 250 Australians have FH – 10,000 in WA**

"The benefits are that you identify other family members with FH, brothers and sisters, aunts and uncles and cousins, who can then also be offered treatment to prevent future heart disease," said PCH Consultant Dr Andrew Martin, who is leading the research.

"For children it's changing their life trajectory from someone who before detection had a very high risk of suffering premature heart disease, to now being able to completely prevent it."

Clinical care of children identified with FH is delivered at PCH by recent WA Nursing Excellence Award winner and Nurse Practitioner, Jemma Weidinger. Children with cholesterol levels above the target range are given advice and education on healthy lifestyle choices and started on low dose, well-tolerated statins once they reach eight to 10 years of age.

Preliminary research data is showing the cholesterol-lowering therapy is working and is effective at bringing cholesterol down to safe levels where kids with FH are no different to other, healthy children.

Until now, detection of what is a treatable condition has been so poor that this unique project is expected to have significant and life-changing results.

"For individuals there is personal protection, in that they won't go on to suffer from

premature heart disease, while at a population level, the number of young adults with FH ending up in a coronary care unit with premature heart disease will reduce within a generation," Dr Martin added.

Western Australia is leading the effort in FH research and this groundbreaking project aims to diagnose and treat 500 WA kids, adding an extra 20 to 30 years to their lifespan on average.

However, others remain undetected in the community and researchers are now advocating with the Commonwealth Government for the introduction of a universal screening program of all children between the ages of one and four – an initiative PCHF funding has paved the way for.

"The benefits and value of this PCHF funding are enormous. It's allowed us to lay the foundations for wider population screening for FH, as well as ensure that WA children will be able to benefit from two international clinical trials for non-statin cholesterol lowering treatments.

"It's giving children and families an opportunity to dramatically reduce their risk of future heart disease which, for generations of their family prior to diagnosis of FH, was tragically marred by heart attacks in early adult life, early mortality and sudden death."

Now, thanks to this research, FH is being reframed as an easily detected and treatable paediatric disorder rather than a devastating adult illness. Children diagnosed with FH will go on to have normal lifespans and the opportunity to enjoy long and rich lives.

On track for a healthy life

Burke is just like any regular 11-year-old. He's mad keen on sports and being active, and if there's a ball around, you'll find him playing with it.

You would never know Burke has such a serious condition that could reduce his lifespan by up to 20 years.

Burke found out he has Familial Hypercholesterolaemia (FH) after several family members were diagnosed – his grandfather, great-aunt and his mum Jacqui.

"With FH, it's like a silent condition, there's no visible or physical reminders that you have it so it's really hard to remember it's something that's going on internally because there's no sign of it on the outside," said Jacqui.

Burke's family had always suspected there were heart issues running in the family. His great-grandmother had a major coronary event at 46 and her brother died when he was just 42 years old. Burke's grandfather always had high cholesterol despite being meticulous with his health and fitness.

"When we got the phone call to confirm that Burke had FH, I was obviously devastated and when I passed on the information to Burke his first reaction was to burst into tears saying, 'I don't want to die'," Jacqui added.

But by learning more about the condition, Burke now knows that with early detection and treatment he has every opportunity to lead a full and normal life.

"He doesn't have the calcium buildup; he doesn't have elevated cholesterol yet. So, at the point where there starts to be a spike that can be treated and it can be managed his entire life.

"The research is key, because there's so many people walking around at the moment that are ticking time bombs that don't know they could have major coronary heart disease at a young age and finding out early means you can implement treatment regimes and give our kids the ability and opportunity to live full lives," Jacqui said.

CENTRE OF EXPERTISE

Giving new hope for rare care in remote regions.

Rare and undiagnosed diseases (RUDs) are the biggest cause of death in children in high income countries like Australia.

In fact, six in 10 deaths in children are due to rare disease, and children with a rare disease are 13 times more likely to die than those with more common conditions. In Western Australia alone, around 63,000 children are living with a rare or undiagnosed condition – that's about one in every 12 kids.

These conditions are often serious, lifelong and affect every part of a child's and family's life. The care these children need is complex and involves many different doctors, specialists and services. Trying to manage it all can be incredibly overwhelming for families.

Since 2022, the Rare Care Centre at Perth Children's Hospital has been a game-changer for families across WA, offering a new way to connect services and better support children with rare diseases. By bringing different experts and services together, the Centre helps families feel more supported and less alone in navigating their child's complex care needs.

Now, the Centre is turning its focus to children and families in the Pilbara. An estimated 1,712 children in the Pilbara and 3,000 children in the entire Northwest of WA have a RUD. Living remotely presents many challenges such as limited access to specialist care, fewer local services and long travel times.

To help change this, the creation of a new Pilbara Hub is underway. The hub will offer more direct care, better coordination and flexible support, combining face-to-face visits with virtual appointments, so families don't have to travel far for help.

Medical Director at the Rare Care Centre, Professor Gareth Baynam, says the new

hub is about helping those who need it most and building on the existing long-term relationships in the Pilbara.

“We’ve been running healthcare innovations in the Pilbara for a decade now. Everything from 3D facial analysis to new models of care, to providing clinical whole genome sequencing and Aboriginal language translations,” said Professor Baynam.

“We want the service and the quality of life, for children and families living with a rare disease in remote regions, to be at least as good as the kids in the city.

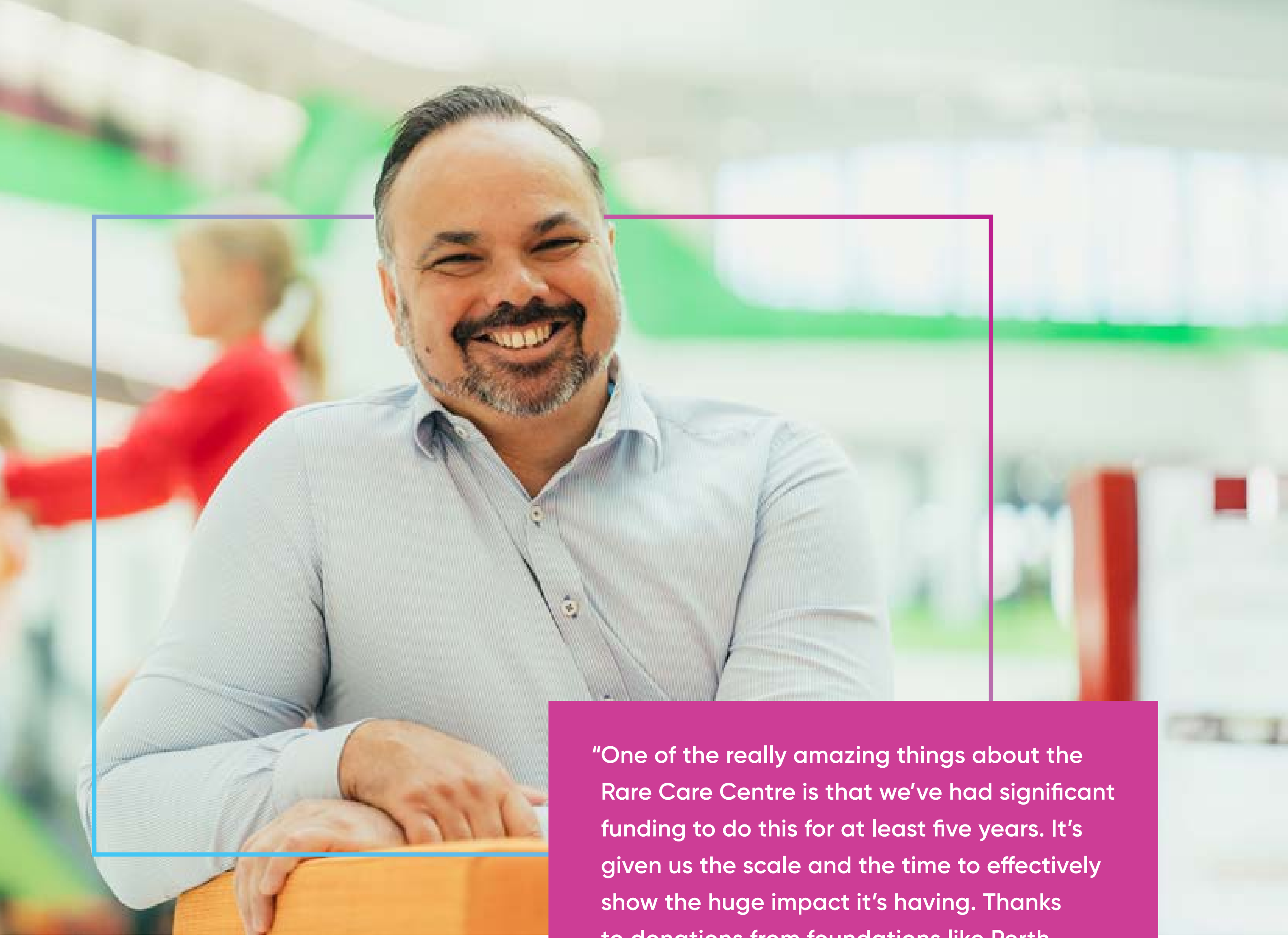
“The Rare Care Pilbara Hub is an opportunity to not only close the care gap between rural and remote regions and the city, but also to leapfrog past it and to create new innovations that will benefit every child, everywhere, living with a rare and undiagnosed disease.

“It will become a template for how we transform rural and remote health more broadly in the state and globally, because there is no such centre elsewhere in the world.”

The project is currently being co-designed with local communities and the first families are expected to access the service in early 2026.

Rare care on the global stage

Through global partnerships and a collaborative approach, the Rare Care Centre is advancing rare disease research, care and advocacy worldwide, ensuring no child is left behind. At the heart of this work is a strong focus on raising awareness, building knowledge and strengthening the



capacity of healthcare professionals and sectors, to better support those living with rare conditions.

> "One of the really amazing things about the Rare Care Centre is that we've had significant funding to do this for at least five years. It's given us the scale and the time to effectively show the huge impact it's having. Thanks to donations from foundations like Perth Children's Hospital Foundation, we've been funded for success rather than failure, and I'm looking forward to the next 10, 20, 30 years!"
>
> Professor Gareth Baynam, Rare Care Centre Medical Director

Global Nursing Network for Rare Diseases

The Centre has created a Global Nursing Network for Rare Diseases in partnership with Curtin Singapore and SingHealth Duke-NUS Genomic Medicine Centre. The Network was developed to connect and increase collaboration and leadership among nurses across the globe caring for people living with a rare or undiagnosed disease. It has experienced significant growth with over 600 members across 60 countries.

European Rare Diseases Research Alliance

The Centre is the Australian lead in the European Rare Diseases Research Alliance, a $630 million seven-year project that brings together over 170 organisations from 37 countries, with the shared goal of advancing rare disease research.

Lancet Commission on Rare Diseases

The Lancet Commission on Rare Diseases is a revolutionary initiative, aimed at developing fair and informed recommendations to improve the lives of people with rare diseases. Named by one of the world's most respected medical journals, the Commission brings together a multidisciplinary team of experts to develop equitable, evidence-based policy recommendations that can drive systemic change in healthcare systems worldwide. Professor Baynam is on the Steering Committee and is one of 27 Commissioners, who are contributing to global policy discussions to help shape the future of rare disease care worldwide.

Savannah's stride forward

At just eight years old, Savannah has already faced a long and uncertain road to diagnosis.

She's one of only a small number of people in Australia and among just a handful globally, living with TRAPPC9 – a rare genetic disorder that impacts both cognitive and motor development.

"There's only one person in WA with Savannah's condition, and just three kids in all of Australia. It's rare, and that can make it really hard to find the support Savannah needs," said mum, Trinh.

Since October 2024, Savannah has been supported by the Rare Care Centre, where a dedicated team of specialists experienced in rare conditions provides her with the tailored care she requires. It's not just the medical expertise that matters, it's the sense of belonging and understanding that has truly made a difference for Savannah and her family.

"We just want to make sure Savannah, and others like her, have a voice and a place in the world. People with rare conditions don't want to be seen as different, they just want to be part of the community."

Mitchell's miracle journey

Mitchell's fight for life began the day he was born. Born prematurely, Mitchell spent the first two weeks of his life in PCH's Neonatal Intensive Care Unit (NICU).

He was diagnosed with Pallister-Killian Syndrome – a rare genetic disorder affecting fewer than 500 people worldwide. Mitchell wasn't expected to live past the age of five, but now, at six, he continues to defy the odds.

Coordinating Mitchell's care has become a full-time responsibility for his family. He also lives with type 1 diabetes and epilepsy, adding layers of complexity to his care. Seizures, developmental delays and physical challenges are part of his daily life. He requires numerous surgeries, all which carry extra risk due to his condition.

"Rare Care has been an essential resource and prime point of contact to help us coordinate the multiple different healthcare teams that need to be engaged when Mitchell undergoes a surgery or procedure," said mum Jaya.

"Being a carer for a child with a rare or undiagnosed disease, there's not a lot of support. It can often feel like you're on your own, and that's why dedicated initiatives like the Rare Care Centre are so vital for families like ours."

IMPROVING HEALTH EQUALITY

Closing the health gap.

Our vision is for all children to live healthy and happy lives and we're proud to support innovative programs that help reduce health inequality and improve the lives of Aboriginal children across Western Australia.

Aboriginal children are some of our most vulnerable children and continue to have poorer health than non-Aboriginal children. They're over-represented in a range of health issues, experiencing more chronic ear and respiratory issues, type 2 diabetes, acute rheumatic fever leading to rheumatic heart disease and negative impacts of repeated hospitalisations for injuries and preventable conditions.

With the help of our generous donors and supporters, we're striving to close the health gap between Aboriginal and non-Aboriginal children.

"We're committed to improving the health outcomes for this high-risk group of WA children and are proud to support programs that are helping reduce inequality," said PCHF CEO, Carrick Robinson.

"Our support extends from unique hospital projects through to community-based care and programs to help Aboriginal children live their healthiest and happiest lives."

Social and cultural factors play a big role in determining the health and wellbeing of Aboriginal children. PCHF projects are providing a better understanding of the challenges and fears around accessing health care services and the gaps in the delivery of culturally safe care.

Early intervention can make a significant difference and not just with health. Lower immunisation rates are linked to a lack of access to adequate housing and long-term healthcare follow-up.

"To close the gap in health outcomes requires all health services to create culturally safe and welcoming spaces in clinics and services, train non-Aboriginal staff to be more culturally safe when delivering clinical care and the employment of more Aboriginal staff across a range of roles," said Mel Robinson, Director of Aboriginal Health at PCH.

"PCHF is helping reduce inequity by prioritisation of programs that are able to translate outcomes across the health service and allow the delivery of culturally safe care."

Improving immunisation rates

A reluctance amongst Aboriginal families to cause pain and distress in their children means many Aboriginal children are missing out on the protective benefits of immunisation.

However, an innovative Buzzy Bee device, funded by PCHF, has been introduced into community health clinics across metropolitan Perth to reduce fear and improve vaccination rates, which are lower in Aboriginal children.

Andrea Padley, a clinical nurse with the Child and Adolescent Health Service Aboriginal Health team said the devices are making immunisations more comfortable for kids.

"Having innovative tools like Buzzy Bees that help reduce the pain of injections has been really helpful. By placing it on the arm, between the injection site and the brain, it helps to block nerve signals, so the child hopefully doesn't feel the needle as much," Andrea explained.

Gnaala Karla Booja, Wilman Country man, Kyle, said his daughter Kyla's recent immunisation with the assistance of a Buzzy Bee will help protect not only Kyla but Elders in his community, many of whom are immunocompromised.

"Getting your jabs can be a traumatic experience. The Buzzy Bee is more of a soothing and approachable way of delivering the immunisations," Kyle said.

Emerging health priorities

While many Aboriginal families have strong cultural, spiritual and organisational practices, others have experienced intergenerational trauma which affects optimal neurodevelopment – social, cognitive and emotional functioning – of their children.

Koorliny Moort – meaning 'walking with families' – is a hospital program that was established in 2012 to bridge the gap in paediatric health services for Aboriginal children. Significant demand in the years following its opening saw long waitlists for neurodevelopment services.

Research conducted in 2016 revealed the success of the Koorliny Moort service – it reduced visits to the emergency department, hospitalisations, non-attendance of appointments and the length of hospital stays.

Today, the Koorliny Moort program manages approximately 1,000 children with a wide range of medical conditions in the clinic program at PCH and outreach sites.

With children's health continuing to evolve, a new PCHF-funded research project aims to identify the current health priorities for Aboriginal children and families referred to Koorliny Moort, and which delivery model best suits their health needs. It's the first project in Australia to be co-designed with Aboriginal and Torres Strait Islander stakeholders and addresses three of the four priority reforms of the National Agreement of Closing the Gap to overcome inequality.

Researchers want to understand what's important to Aboriginal children and families in their clinical care, so that programs can be designed to address health needs in a meaningful and culturally safe way.

This will enable families to feel empowered to address their health and wellbeing needs. Children and young people will enjoy improved quality of life with expected improvements in school attendance, reduced juvenile justice contact, improved mental health, improved access and support for disability services and inclusion in the community.

Transforming care

The Foundation is also supporting the unique role of an Aboriginal Health Research Facilitator, helping non-Aboriginal researchers engage and work better with Aboriginal children, young people and families to transform care.

Research plays a crucial role in advancing healthcare but is often led by non-Aboriginal clinical experts.

The Aboriginal Health Research Facilitator is creating more culturally safe pathways and ensuring strong engagement with the Aboriginal community and Elders to identify research priorities and ultimately improve care.

"PCHF projects are helping to reduce health inequity and close the gap by allowing the health services provided by PCH to ensure that access is equitable and culturally safe for all children from diverse backgrounds," Mel Robinson said.

WORLD-CLASS EXPERTISE

A lifeline for the littlest patients.

Driven by compassion and clinical excellence, Associate Professor Jonathan Davis has dedicated his career to improving outcomes for the tiniest and most vulnerable patients – newborns in critical need of emergency care.

As the Medical Director of the Newborn Emergency Transport Service (NETS WA), Associate Professor Davis is leading groundbreaking research projects and pioneering innovations in infant transport care with life-changing impact.

WA's geography spans 2.6 million square kilometres – roughly the size of Western Europe! It is the largest transport area operated by a single team anywhere in the world. The NETS WA team often travels up to 2,300km from Kununurra to Perth to transport infants in need of urgent medical care. An infant could be spending the best part of two days in transit, so ensuring the safest and best possible care becomes even more critical when faced with such distances.

A close relationship with PCHF is helping drive innovations for these littlest WA patients forward.

Backed by funding from the Foundation, Associate Professor Davis has been embedding his research projects into the clinical care NETS WA provides, which is paving the way for breakthroughs in infant transport care.

Hot Wheels and Cool Cot trial

During NETS WA transfers, a preterm baby or an extremely low birth weight baby needs to be kept warm at 36.5 – 37.5 degrees, while HIE babies (infants who are oxygen deprived at birth), need to be kept cold at 33 – 34 degrees. Therapeutic temperature control is essential to protect their delicate brains and reduce the risk of brain damage or long-term disability.

A game-changing two year study is being carried out by NETS WA to determine whether a bespoke portable neuroprotection cot, equipped with an intelligent temperature regulation system, can accurately control a baby's temperature during transport over current conventional methods.

The thermal regulation device, which is attached to the neuroprotection cot can measure and adjust the core temperature of a baby to ensure they are kept at the optimal temperature (warm or cold) during transport.

Until now, no studies have compared this technology to current temperature control methods in the neonatal transport environment. NETS WA is the first in Australia to be using this equipment.

"Worldwide, there have been very few randomised control trials in the transport environment because it's difficult to do. It's difficult to talk to parents when they're in stressful situations, and trying to record the data is challenging," said Associate Professor Davis.

"We are the first team in Australia, possibly the first team in the world with this device – to be able to move babies without anything being disconnected. This means the babies don't lose the therapeutic input that the machine provides from the moment they leave and return to the bedside.

"It's invaluable in our WA environment, because we move babies further than anybody else. We're very pleased with the trial to date and to be providing one of the first opportunities for babies to be safely transported from anywhere in the state using this technology."

> **"It all started with the cots and the idea of ensuring we can deliver the best possible care wherever we go – to the farthest corner to the sickest baby."**
>
> Associate Professor Jonathan Davis, Medical Director, NETS WA

Portable brain wave technology

It's been two years since NETS WA first began using portable brain wave equipment, and it's making an incredible difference in the care they provide. Professor Davis and his team were the first in the world to report the use of this equipment during neonatal transport.

The technology has enabled NETS WA to assess an infant faster and provide assurance they are getting the right treatment at the right time.

"When we do physical examinations, we can often misinterpret things, but this 'window to the brain' gives us additional electrographic brainwave information to help us determine if a baby has had an injury and whether they need a certain course of treatment.

"If they don't need any treatment, it means they won't be kept away from their mother longer than they need to. They can carry on with feeding, bonding and attachment – all the important things that newborns thrive on."

Thanks to funding from PCHF, the equipment is now serving as a gateway to more impact. Professor Davis has been collaborating with colleagues at the University of Helsinki, using their innovative machine learning technology to recognise and compare patterns in the brain wave data NETS WA has collected, to further advance the care they provide.

Reducing trauma of newborn medical transfers

Separation can influence how babies cope with stress and recovery, yet there has been limited research into the effects of parent-infant separation during intensive medical care and transport, or how to reduce the impact of these experiences.

The NETS WA team, led by Associate Professor Davis is partnering with clinical psychologists (Jeneva Ohan and Michael English) from the Healing Kids, Healing Families team at The Kids Research Institute Australia, on an Australian-first project. Funded by PCHF, the research will explore how NETS WA can provide trauma-informed, compassionate care that eases stress for families and helps babies recover and thrive.

"We know that attachment is important for babies and for mothers. It has an impact on breastfeeding and how health develops in the future. This research will help us to understand how we can better support parents and enhance infant recovery during NETS WA transfers."

George – the real-life manikin

The golden hour is the first hour after birth, a crucial window where the right care can make a big difference to a preterm baby's survival and long-term health. Simulating what to do during this time helps healthcare providers keep babies at a healthy temperature. This is vital, as being too hot or too cold can increase the risk of serious complications.

The NETS WA outreach education team led by Dr Alex Wilson (Consultant neonatologist) and Associate Professor Davis has developed the training course NeoSTARs for GPs, midwives, nurses, paediatricians and other healthcare providers on how to deliver the best care while they wait for NETS WA to arrive. Late in 2024, they introduced George the manikin in their golden hour simulation, thanks to funding from the Foundation.

George the manikin is a realistic representation of a preterm 29-week infant – everything from his weight, lung volume and facial features. This lifelike representation enhances user immersion and fosters a more productive learning environment.

"George allows us to create a richer learning environment by providing real lifelike engagement. The manikin delivers that feeling of, this is a real child."

This year, five courses will run in Port Hedland, Geraldton and at Perth Children's Hospital.

> "The geography of WA has made us think about innovative ways to look after these babies. And that innovation means we're leading the world in this area."

Associate Professor Jonathan Davis,
Medical Director, NETS WA

MAJOR PROJECTS

Laying the foundations for WA's first children's hospice.

Exciting progress is underway at Sandcastles (Boodja Mia), Western Australia's first dedicated children's hospice.

A long-held vision is beginning to take shape as construction progresses on WA's first children's hospice. West to West Group is responsible for the construction of Sandcastles, which will see the Swanbourne site transformed into a 'home away from home' for some of WA's sickest kids.

The first two concrete slabs have been poured, forming the foundations of the basement and ground floor. In total, 110 truckloads of concrete were needed to complete the pour of the ground floor, which took place in two phases.

This significant milestone paves the way for the next phase of construction – erecting the walls and columns of what will become the heart of the hospice. Once complete, this main care floor will include an arrival lounge, seven single guest bedrooms, three family suites, a hydrotherapy pool, clinical spaces, a bereavement suite, kitchen, dining and living areas and dedicated play spaces.

By the end of the 2024-25 financial year, the construction team had completed:

- Building the formwork needed to pour the ground floor concrete
- Laying concrete blocks to start forming the basement walls
- Pouring concrete to create the walls for the lifts and stairwells
- Preparation works for future installation of services including electricity, communications and gas.

Sandcastles is funded by PCHF thanks to generous contributions from the Stan Perron Charitable Foundation, Cancer Council WA via a generous bequest from the late John Street, Minderoo Foundation, Lotterywest, the Federal Government and the WA community.

Sandcastles will bring new hope and comfort for children with life-limiting conditions and their families. It is anticipated to open in 2026.

"It's a proud moment in Western Australia's history as we officially begin construction on the state's first-ever children's hospice. Sandcastles will touch the lives of countless sick WA kids and their families and we are eternally grateful to our generous donors and supporters, including the Western Australian public."

Hon. Ian Campbell, Chairman
Perth Children's Hospital
Foundation

"We're delighted that Sandcastles is another step closer to becoming a reality for the children and families going through unimaginable challenges. Sandcastles will become a sanctuary of compassion and care where families can create precious memories together and connect with others on similar journeys – all while receiving exceptional hospital-quality care."

Carrick Robinson, CEO
Perth Children's Hospital
Foundation

INNOVATIVE EDUCATION AND TRAINING

Connecting regional babies with early CP diagnosis.

Finding out early if a child has cerebral palsy (CP) is life-changing and ensures a brighter future for children and their families.

Early diagnosis of CP opens the door to early intervention which can reduce the severity of disability and greatly improve quality of life for children and their parents. When support is delayed, health and functional outcomes for children worsen and stress and poor mental health and wellbeing increases in parents.

Thanks to a world-leading PCH early intervention service at Kids Rehab WA, babies can be diagnosed as early as three months of age with CP or at high-risk of CP, the most common childhood physical disability.

But in WA's regional and remote areas, many children are not diagnosed until they're closer to two years of age. This is considered too late to take advantage of neuroplasticity, the critical window of time when a baby's brain is at its most adaptable and can learn new skills.

Accelerate WA success

Accelerate WA, a PCHF-funded pilot program expanding the PCH early intervention service into the Kimberly region has had great success at reducing the age of CP diagnosis.

Local clinicians have been trained in early assessment and detection of CP including the General Movements Assessment (GMA), which identifies absent or abnormal movements highly predictive of CP. General movements are assessed from three-minute videos taken of babies lying awake on their back.

Thanks to the program, the average age of diagnosis has reduced from 19 months to under five months, well within the timeframe for life-changing, early intervention.

Fast-tracked referral and intervention pathways are now offering babies in these regions the best start in life.

"When we see them early we're not only treating their motor problems, we're also identifying and treating vision problems, learning problems, feeding problems and speech problems," said Professor Jane Valentine, Paediatric Rehabilitation Consultant, Kids Rehab WA.

"We're intervening for all these issues of concern and improving outcomes in all of them."

Previously, these children wouldn't have been referred for support until they were two to four years old, too late for effective intervention. By that age, children often require management of the complications of CP and face dramatically different life journeys with poorer health and quality of life.

With early diagnosis and intervention, children and families have better quality of life through reduced disability and improved parental mental health.

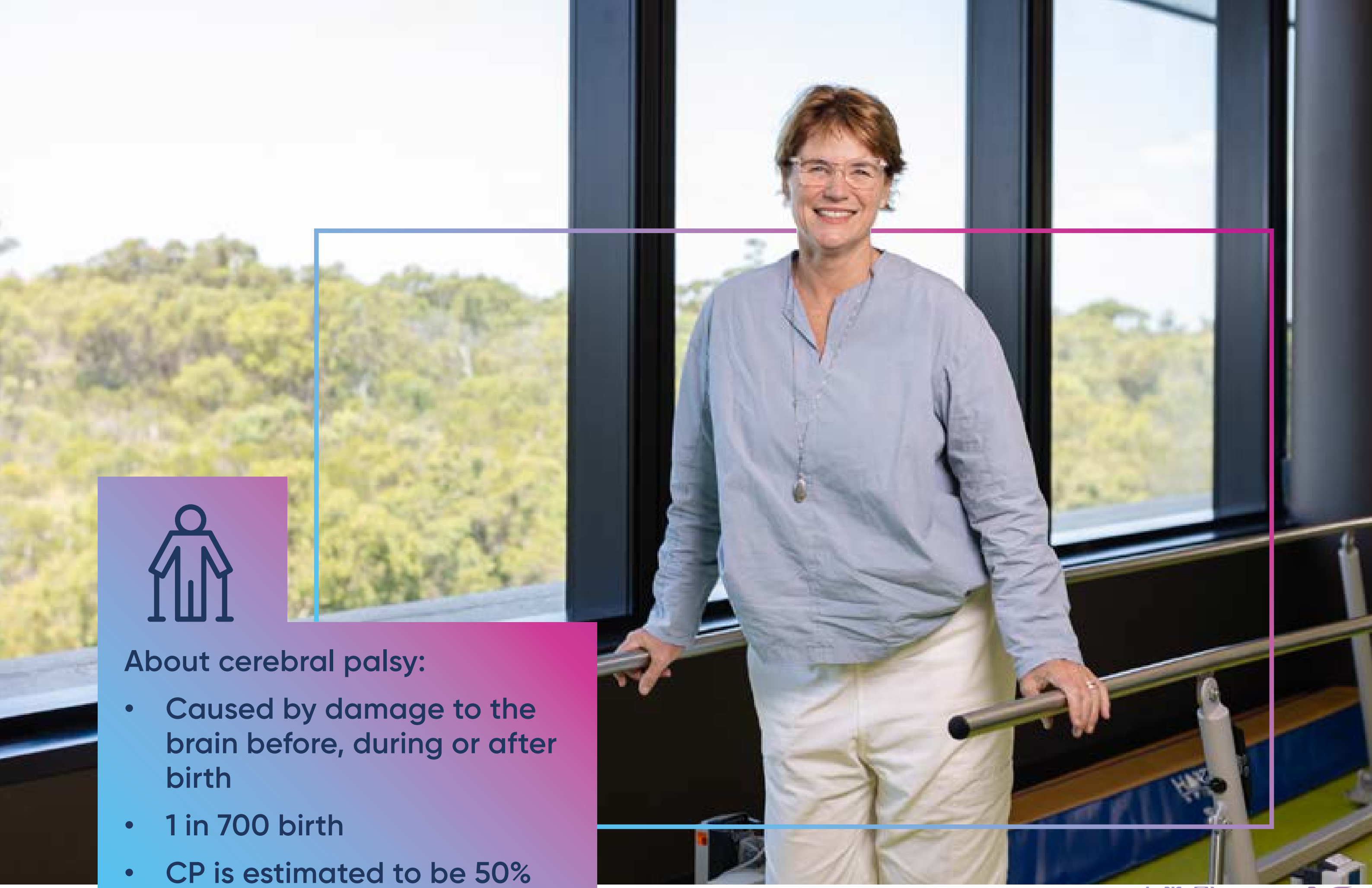
"It's been really empowering for parents to have the support of a local team who knows what their child needs and can help them become better informed for what will be a lifetime of interacting with the health system.

"Equally empowering is if we can eliminate a parent's anxiety and concern by monitoring a baby and ruling out CP in a child who was considered high risk at birth."

Statewide access with CONNECT-CP

After the success of the Accelerate pilot program, PCHF is proud to continue working with Kids Rehab WA to tackle the urgent need for early CP detection and intervention across the state.

Many vulnerable children in other WA regions are missing out on crucial interventions that



About cerebral palsy:

- **Caused by damage to the brain before, during or after birth**
- **1 in 700 birth**
- **CP is estimated to be 50% higher in Aboriginal children**
- **60-70% of children with CP have vision impairment known as CVI**

could transform their lives and give them the best possible start in life.

In an exciting development, further statewide rollout of the program, now known as CONNECT-CP, is being proposed to address this critical need.

Kids Rehab at PCH will act as the central hub of CONNECT-CP with ongoing support and connection offered across two other metropolitan sites – King Edward Memorial Hospital and Fiona Stanley Hospital – and three priority regional sites.

International clinical researcher, Dr Nofar Ben Itzhak, will lead the statewide rollout that will see local workforces across the regions scaled up to deliver best practice, culturally appropriate early assessments and referrals. Dr Ben Itzhak specialises in the area of Paediatric Neuropsychological Rehabilitation, most recently working as primary researcher and project coordinator of a large-scale, multi-centred randomised controlled clinical trial in Belgium.

A key component of the program is advanced digital tools enabling remote video assessments, giving children access to early intervention regardless of where they live in WA. These tools will allow the secure collection, monitoring and sharing of early assessments and outcomes, leading to better patient outcomes.

"For example, if a clinician in Kalgoorlie is unsure about a baby of concern, a video could be uploaded to the system for support from the early intervention team at PCH who can assess the child and guide the on-the-ground team," Professor Valentine explained.

Kids Rehab WA is leading the way nationally by establishing the biggest CP early intervention referral service in the country.

"These projects have direct impact to the child, direct impact to the family and direct impact to the clinician and we couldn't do this without PCHF.

"The Foundation enables us to establish evidence-based clinical practice and transform it into ongoing, sustainable clinical care which can then be taken over and funded by Government."

Accelerating vital early CP therapy

As a young baby, Henry had seemed the picture of health. For the first four months, there were no obvious signs of any health issue for his Broome-based family to be concerned about.

When his mum, an experienced Occupational Therapist, noticed he wasn't using one of his arms and couldn't sit properly to start solid foods she began to worry.

"My mind went to the worst case, it could have been worse things than CP when they start showing neuro signs," said Henry's mum Marnie.

"We were also concerned because the services up here aren't specialised and it crossed our minds that we might need to move to Perth, but we've been really impressed with the support we've received locally and the help via telehealth has been a huge relief."

Recognising the benefits of early detection and intervention for children like Henry, local Accelerate-trained clinicians at Broome hospital quickly swung into action conducting assessments and referring Henry to the Early Intervention clinic at PCH.

Interventional therapy began soon after with a large portion delivered via telehealth, allowing the family to stay in Broome close to family and other support networks. Collaborating with the PCH team ensured Broome-based clinicians were able to implement best practice clinical care that's helped Henry make incredible progress.

"It's opened up his world really quickly. In the space of a few months of therapy he was using his right arm a lot, he's standing now and moving towards walking, he can engage with his friends and play with his brother," said Marnie.

"I'm not trained in this area so without the support provided we wouldn't have been doing the right stuff to get as many gains as we've got."

Those gains are being felt not just by Henry but his parents too.

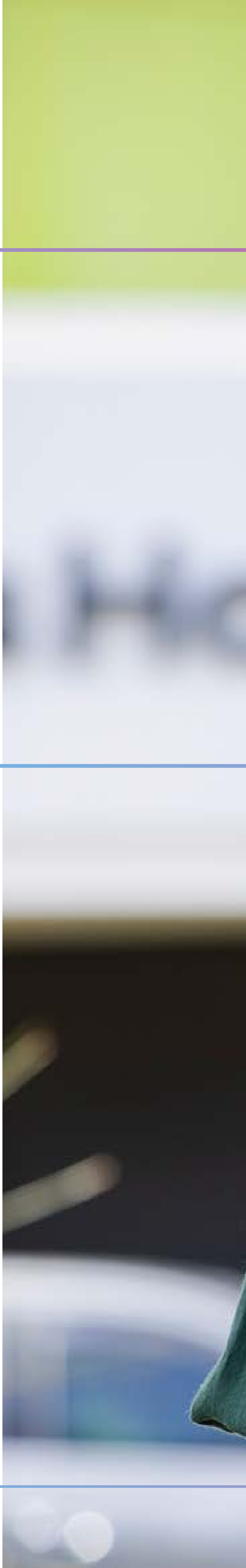
"It's made us feel empowered that there is something we can do rather than get stuck in the impairments, it's made us feel much more hopeful."

Now 17 months old, Henry is a happy and easy-going toddler who enjoys being around others and anything with wheels including his tricycle and his brother's scooter. The impact of his vital early therapy will be felt for many years to come.

"Early intervention services are basically setting up a kid for the rest of their life to have a more fulfilling life. The difference in all areas will be immeasurable and for families the hope that it gives is massive," Marnie said.

> "Early intervention services are basically setting up a kid for the rest of their life to have a more fulfilling life. The difference in all areas will be immeasurable and for families the hope that it gives is massive."
>
> Marnie, Henry's mum

PhD Pathway: Advancing research from the frontline.



We're proud to support the Child and Adolescent Health Service PhD Pathway – an innovative program helping doctors, nurses and other clinical professionals pursue a PhD while continuing to care for patients.

The PhD Pathway is creating new opportunities for clinicians to undertake research that transforms children's health outcomes. With protected time to pursue their PhD, clinicians can stay connected to the frontline while making new discoveries – bridging the gap between their academic pursuits and everyday patient care.

Breaking barriers in diabetes care

Dr Kate Lomax is on a mission to make diabetes care more accessible for every child.

A paediatric endocrinologist at PCH, Dr Lomax began her PhD journey in 2024 through the PhD Pathway program. Her research focuses on ensuring all families - regardless of financial circumstances - can access life-changing diabetes technology. She believes early adoption of the right technology can empower children to better manage their condition and lead to healthier futures.

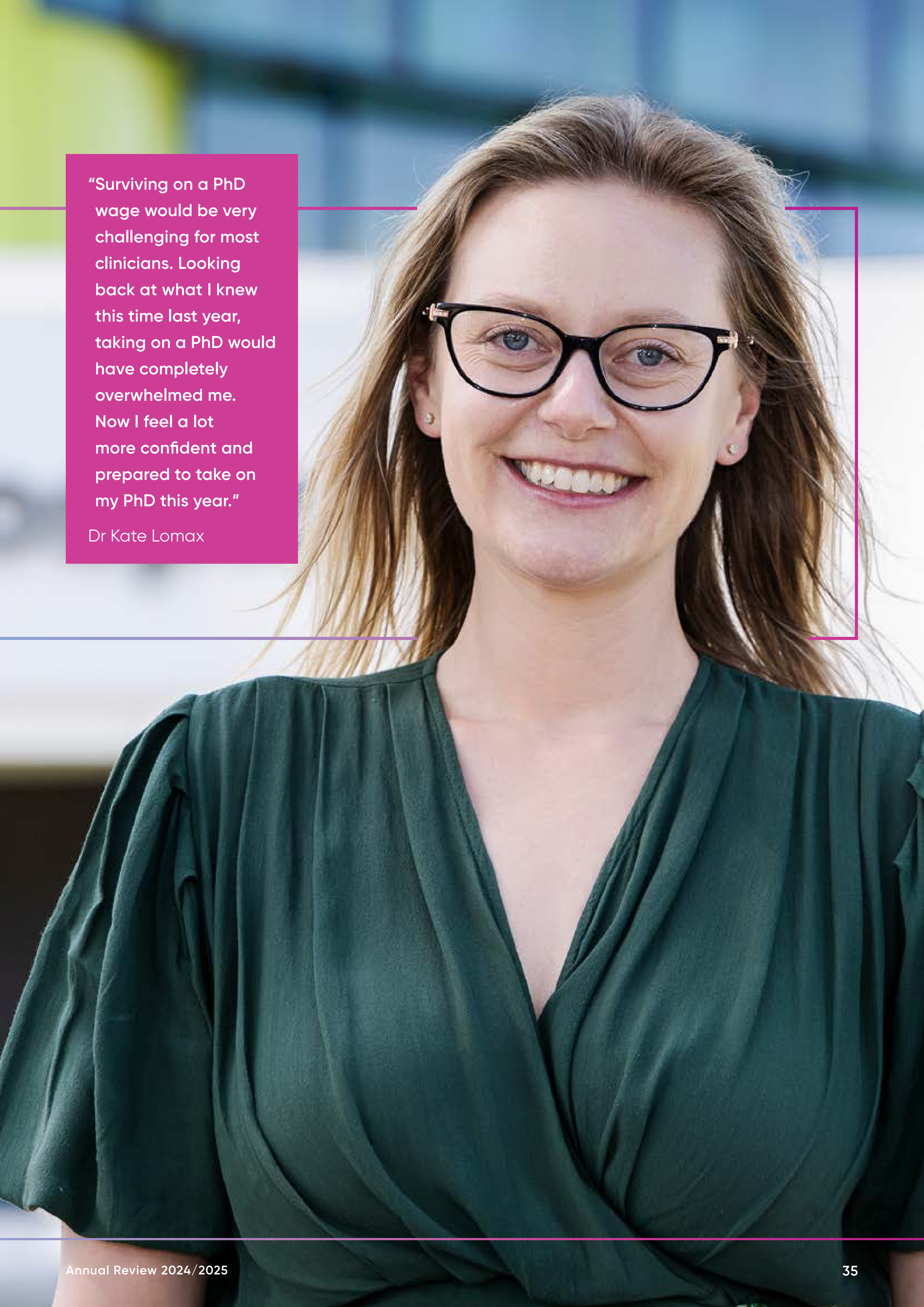
In her first year, Dr Lomax has balanced her clinical role with developing essential research skills, from writing ethics proposals to project recruitment and learning about data management. It's a steep learning curve, but one she says has been made possible thanks to the protected time and support built into the program.

Dr Lomax credits her progress to the guidance of experienced mentors and supervisors, including Prof. Liz Davis, Head of Endocrinology and Diabetes at PCH, and Dr Craig Taplin, Clinical Lead of Diabetes at PCH. Their mentorship has helped her grow both as a clinician and a researcher.

"I love working in paediatric diabetes, because it's such a fantastic opportunity to work with kids and families to form good habits early on, as well as to be early adopters of some really innovative tech," she said.

Moving into her second year in the program, she now feels more confident in navigating the research process as she begins work on her PhD.

"Surviving on a PhD wage would be very challenging for most clinicians," she said. "Looking back at what I knew this time last year, taking on a PhD would have completely overwhelmed me. Now I feel a lot more confident and prepared to take on my PhD this year."



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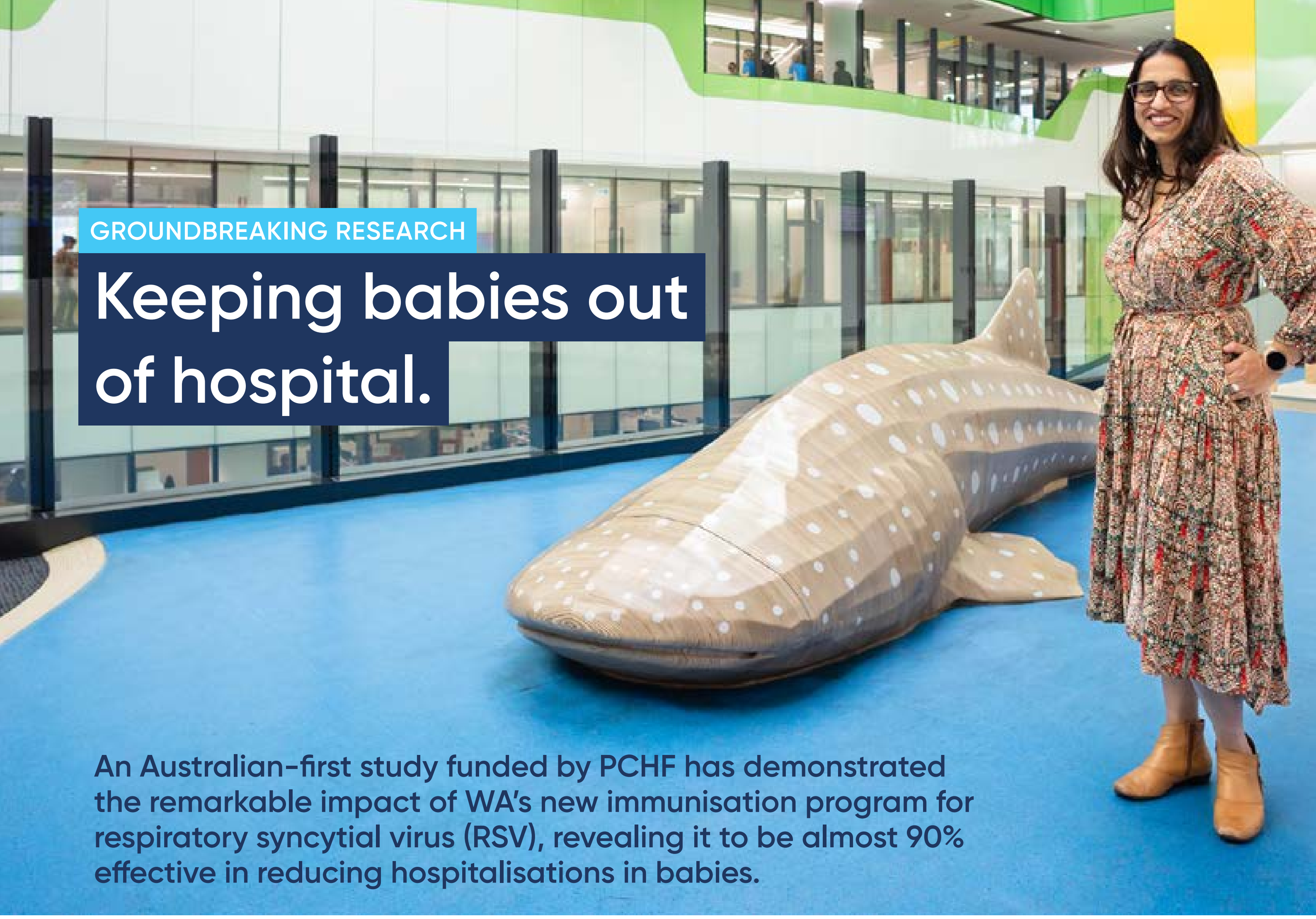
Dr Kate Lomax



GROUNDBREAKING RESEARCH

Keeping babies out of hospital.

An Australian-first study funded by PCHF has demonstrated the remarkable impact of WA's new immunisation program for respiratory syncytial virus (RSV), revealing it to be almost 90% effective in reducing hospitalisations in babies.

RSV is a life-threatening virus that affects the airways and lungs, sending 3.6 million children to hospital worldwide each year. It is especially dangerous for vulnerable young babies at high risk of potentially deadly complications such as severe bronchiolitis and pneumonia.

The REVIVE study investigated RSV-related hospital admissions following the introduction of WA's immunisation program providing babies with nirsevimab.

Published in the Journal of Infection, the study shows that more than 500 WA families avoided hospital stays last winter, thanks to the immunisation program led by WA Health. The WA Department of Health led the way as the first Australian state to offer the free RSV immunisation program for all babies born throughout the winter season.

REVIVE study lead, Dr Ushma Wadia, said Western Australian researchers have had a long-term commitment to providing protection against RSV.

"Last year, the WA Department of Health led the way as the first Australian state to offer the free RSV immunisation program for all babies born throughout the winter season and this was extremely successful," Dr Wadia said.

More than 24,000 doses of nirsevimab were distributed throughout April to September last year, providing coverage to 85 per cent of newborns and 66 per cent of a 'catch-up' cohort of babies in the lead-up to their first winter season.

"Our team worked alongside WA Health to evaluate hospitalisation rates at Perth Children's Hospital, Fiona Stanley Hospital and Joondalup Health Campus, and allowed us to become the first place in the southern hemisphere to successfully demonstrate the major impact of RSV immunisation in young babies."

The study also investigated the effect immunisation had on the severity of RSV cases, with nirsevimab recipients 60 per cent less likely to require oxygen or assistance with their breathing if admitted with RSV.

PCHF CEO Carrick Robinson said the results of the groundbreaking study were extremely promising.

"With a dramatic reduction in hospital admissions for RSV, WA is setting the standard in protecting our youngest and most vulnerable. Not only does this ease the pressure on our hospitals and emergency departments, but it also ensures families are spared the stress and strain of hospital stays.

“Funding innovative initiatives like this have the potential to make a real difference in the lives of children and their families, as well as reducing the burden on the healthcare system, not only in WA but across Australia for years to come.”

The success of WA’s nirsevimab program also contributed to the rollout of a national, $174.5 million RSV immunisation program now underway for all pregnant women and newborn babies which hopes to keep 10,000 Australian babies out of hospital.

For Professor Chris Blyth, Head of the Wesfarmers Centre of Vaccines and Infectious Diseases and PCH physician, it is the global significance of this work that is hugely significant.

The REVIVE study was made possible thanks to researchers at the Wesfarmers Centre of Vaccine and Infectious Diseases, based at The Kids Research Institute Australia.

Going forward, the team will look to expand the research to investigate the effectiveness of RSV immunisation in Aboriginal children, with results used to advocate for ongoing funding for this vulnerable cohort.

Protecting young lives

Childhood immunisations help keep our kids healthy and the PCHF-funded RSV research is assisting with the take-up of this important new immunisation program.

Results of the REVIVE research gave Charlotte the confidence that her twin babies Finn and Ember would be protected when she took them home.

“They both spent nearly a month at PCH when they were born. Finn in particular took a while to manage his breathing himself,” Charlotte said.

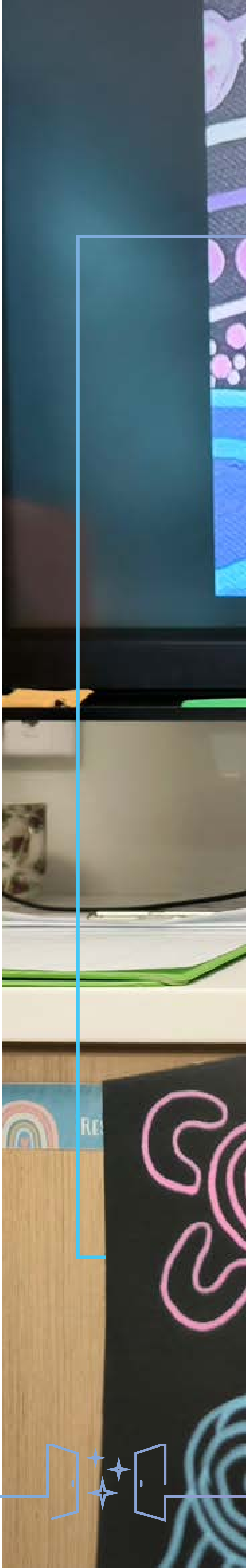
Finn and Ember were offered RSV immunisation before being discharged. With the twins about to celebrate their first birthday, Charlotte said the study’s results were “amazing”.

“The immunisation research is really important and I’m really grateful that we got it (the RSV immunisations),” she said.

“Hopefully, it’s something that will continue to be available and accessible for everyone.”

Painting paths of positivity.

The Perth Children's Hospital Foundation funded Arts program returned in 2024, creating little moments of magic in the everyday for patients and families during their hospital stays.



For many children and their families, hospital stays can be overwhelming. The unfamiliar environment, coupled with pain, discomfort and long stretches away from home, can lead to distress and feelings of isolation. For those who spend extended periods in hospital or return frequently, it can feel like life is on pause, with days spent in wards or clinics. And for children from regional or remote communities, they may find the entire experience culturally unfamiliar and traumatic. These emotional challenges don't just affect the patient; siblings and other family members can also feel the strain.

The PCH Arts program continues to make a positive impact by bringing creative and interactive experiences to children and families, helping to support their social and emotional wellbeing during their time at PCH.

Engaging in creative activities has been shown to ease stress and anxiety, offer comfort and even support quicker recovery during hospital stays. Art therapy can play a powerful role in boosting emotional strength, enhancing self-esteem and awareness, and supporting both cognitive and sensory development.

Executive Director at the Child and Adolescent Health Service (CAHS), Ali Devellerez said it's a fabulous program that caters for all ages from four up to 16 years – including siblings, mums and dads.

"It really engages children and their families and makes their stay at PCH a more positive and unique experience. The reinvigorated program is a well-rounded innovative program with a cultural emphasis on it. One of the artists we have engaged in the program is an Aboriginal artist, and he's doing some incredible work connecting with families here," said Ali.

"We also have an international puppetry troupe who are working across languages other than English including French, Italian and Spanish. So there's opportunities for families of non-English speaking backgrounds to also engage with the arts," said Curator and Art Program Coordinator for PCH, Helen Mathie.

"Puppet artists bring a unique opportunity to communicate with both non-English speaking and non-verbal children. Many autistic children that come here can comfortably interact with a puppet without needing to speak. The children might have come to hospital feeling anxious or uptight. Hospitals are a noisy environment, so being able to de-escalate those feelings in such a friendly way through puppetry is wonderful. Families are just so grateful that their children are able to participate in something so positive."

The Mandala art program, which is delivered for children staying on the mental health ward has also been very successful.

"The artists set up in the courtyard outside in a calming environment. So, not only are they having the art connection, but they are also outside in nature, in the fresh air, all of those things that are really great for a person's mental health," said Ali.

"Art is a safe place for everyone to have busy hands and let their minds relax. The correlation between good arts and good mental health is well documented now, and we're seeing more of it being integrated into clinical environments," said Helen.

While medical treatment focuses on healing the body, the PCH Art program works in parallel, offering vital social and emotional support that helps children process their experiences.

"It has a great effect in terms of just reducing the stress of the family while in hospital. If they can have a less stressful experience, then that obviously leads to better health outcomes for the child while they're here," said Ali.

"Sometimes children can be in a lot of pain and discomfort. So it's a positive distraction. I like to think it even helps them develop some little coping strategies that they can take away into their lives when they're at home, particularly if they're living with a longer term condition."

Having the Arts program back in place is leading to new possibilities in creating positive patient experiences at PCH.

"It truly brings the hospital to life. It allows us to really embrace our values and deliver great care and positive experiences for families that are often, facing a lot of adversity," said Ali.

"Noongar artist Kevin Bynder makes it so welcoming and comfortable for our regional and remote families, as a lot of them know him. So for them, to turn up and see a familiar face makes a huge difference. He spends a lot of time working in the Arts program, but importantly, talking to the families and helping us create a meaningful connection to the family and the area that they've come from.

"Without funding from the Foundation we just wouldn't be able to run this program. It has such a direct impact on a child's experience and making them feel comfortable while at PCH."

Finding joy in puppetry

After a traumatic accident involving a dishwasher and a steak knife, 10-year-old Landen discovered a surprising talent during his recovery at Perth Children's Hospital.

While making a toastie at home in Mandurah, Landen fell backwards into an open dishwasher, where a knife became lodged in his back. Doctors said that just a millimetre difference and he could have been paralysed. Thanks to the skills of PCH's neurosurgery and orthopaedic teams, the knife was safely removed with no lasting damage.

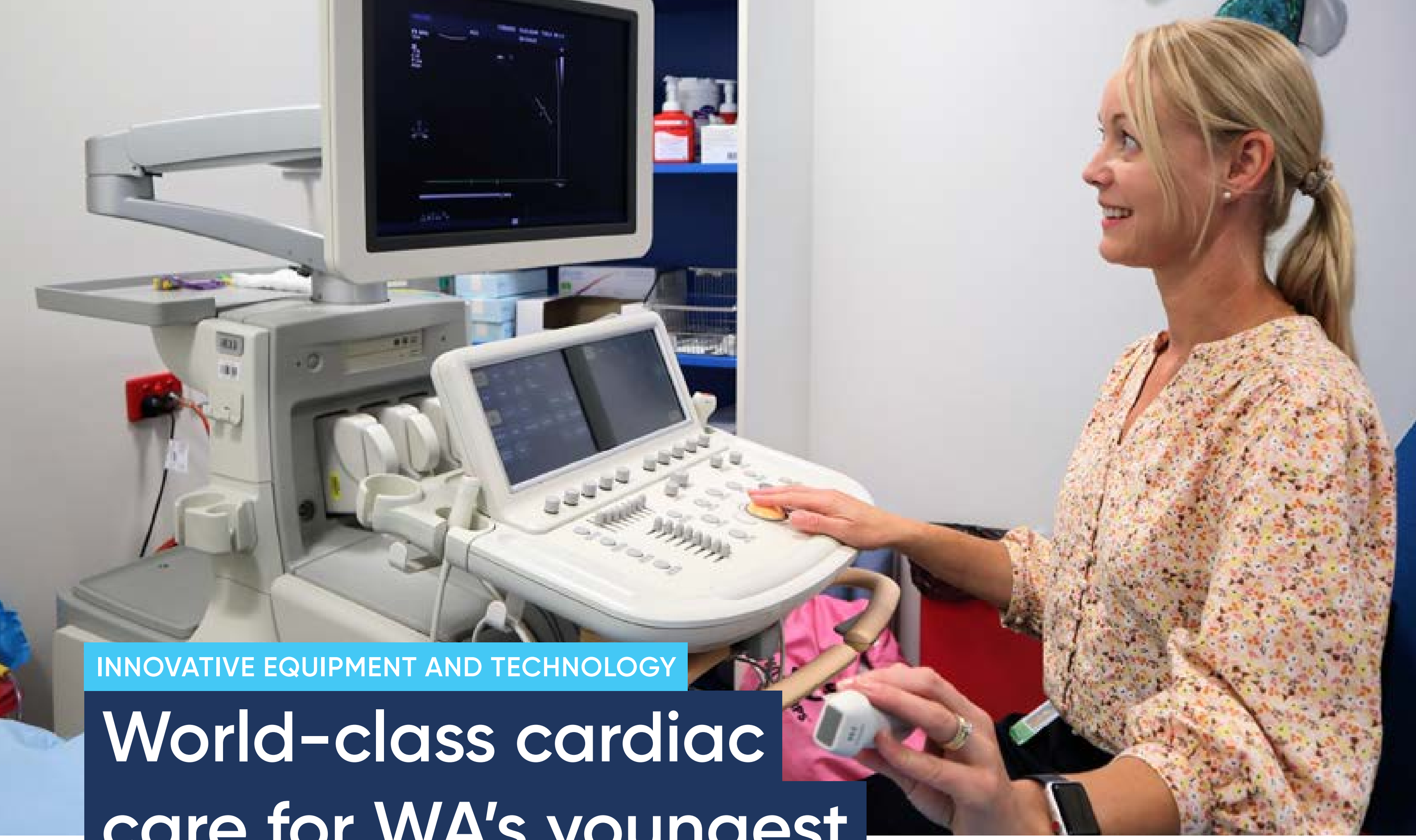
During his stay, Landen took part in a workshop with the Di Filippo School of Puppetry, where he uncovered a passion for marionette puppetry. Now back at school, he's proudly showing off his 'battle wound' and a new creative spark.

Landen's mum, Emma, praised the care he received and shares a reminder to all families to never stack knives facing up in the dishwasher.

"Stacking the dishwasher is something so mundane that most people don't think twice about it, but it goes to show how even the smallest actions can have a huge impact," she said.

"Despite being such a traumatic event for our family, everyone at PCH was lovely. It really was the best outcome we could have hoped for.

"The overall experience we had throughout Landen's hospital stay turned a traumatic experience into something positive."



INNOVATIVE EQUIPMENT AND TECHNOLOGY

World-class cardiac care for WA's youngest patients.

Thanks to the incredible generosity of our community, we're delivering even greater impact through advanced cardiology equipment right here in WA.

With access to some of the most sophisticated technology available, children with serious heart conditions are receiving world-class care without leaving the state.

Saving young hearts with Automatic External Defibrillators

Children living with serious heart rhythm disorders face a constant risk of sudden cardiac arrest. To stay safe, they require constant access to an Automatic External Defibrillator (AED), so that life-saving help can be given immediately if their heart goes into a life-threatening abnormal rhythm.

Adults with the same condition can have a defibrillator implanted, giving them peace of mind and freedom from carrying equipment. But for young children, their small size means this option isn't yet possible.

"An out of hospital cardiac arrest carries a significant risk of death or permanent neurological damage. There is very good data to show that children who suffer an out of hospital cardiac arrest and receive appropriate CPR early, before professional help arrives, have a better chance at surviving without permanent consequences," explains Paediatric Cardiologist, Dr Stephen Shipton.

"AEDs not only deliver a controlled shock to an individual experiencing a cardiac arrest due to a lethal heart rhythm, but they also instruct the first responder (often not a medical professional), on how to provide effective CPR in real time, to help optimise the patient's chances to return to normal rhythm and circulation."

AEDs for infants

Standard AEDs are not suitable for small infants, as their high-energy shocks, which are designed for adult bodies, can cause serious harm to young children. In an emergency, infants with life-threatening heart conditions need a device that can safely deliver a much lower energy dose.

Thanks to the purchase of advanced Mindray AEDs, specially designed for paediatric use, infants with a life-threatening abnormal heart rhythm, can receive the right level of care.

Point of care monitors

Children with certain heart conditions are at higher risk of developing blood clots than those with normal healthy hearts. To prevent blood clots, they are prescribed medication like Warfarin. While effective, the medication needs to be carefully monitored through regular blood tests to ensure it is working safely. Traditionally, this means visiting a pathology centre every two weeks or even more often, to have a blood test taken.

This can be stressful and disruptive, especially for children who may need to constantly miss school and parents who have to take time off work. Point of Care (POC) monitors offer a much more convenient solution. These small, easy-to-use devices allow blood tests to be done at home with a simple finger prick. Results are immediate, and with proper training, families can manage the testing themselves.

Through PCHF's generous donations, children with heart conditions that require regular blood tests can now stay on track of their own treatment with access to a POC monitor.

Portable ultrasound devices

Thanks to funding from the Foundation, advanced portable ultrasound machines are now being used in regional clinics across WA. These handheld devices will make it easier to check children's heart health more closely. It also means better screening for children in remote communities, where conditions like rheumatic heart disease often go undiagnosed until serious damage has occurred.

With better equipment and support for regional staff, children can get the care they need sooner, leading to better outcomes and healthier futures.

By supporting families with lifesaving tools like AEDs and home testing monitors, and investing in cutting-edge ultrasound equipment, PCHF is making a lasting difference in the lives of WA kids with heart conditions.

Noah's story

Noah knows all too well what a lifesaver it is to have an AED with him. He's been living with Long QT Syndrome, a genetic condition causing rapid, chaotic heartbeats that can potentially result in 'fainting' and life-threatening seizures, especially during times of physical activity or stress.

When he was 10, Noah had a critical incident while swimming at a friend's house. With access to a community defibrillator (AED), Noah's heart was shocked to correct its rhythm and keep him alive. An ambulance took him to hospital, where he had two further cardiac arrests and thankfully pulled through.

Following his scare, Noah received two personal AEDs thanks to PCHF – one for school, and one to keep with him wherever he goes.

Now 17, Noah is thriving. He has returned to the footy field, won a sports award and hopes to soon start an apprenticeship. While he still attends PCH for check-ups, thankfully Noah hasn't needed to use the AEDs, but they've constantly been by his side, providing his family with peace of mind.

"Having the AEDs takes away some of that stress and worry about Noah's heart condition. We're forever grateful to PCHF for providing Noah with the defibrillators," said Noah's mum, Fiona.

OUR COMMUNITY

Our heartfelt thanks.

We're truly appreciative of our amazing community which each year goes above and beyond to raise funds for the sick kids of WA. This dedication and support makes our mission possible and we're deeply grateful for everyone who has contributed over the past year.

Among the most heartwarming fundraising efforts were a first-time, solo swim in the iconic Euroz Hartleys Port to Pub and a team of family and friends in the HBF Run for a Reason – all inspired by the courageous journey of Sonny, who was diagnosed with Stage 4 kidney cancer just before his second birthday.

Sonny underwent an eight-hour operation to remove the tumour and half of his kidney, followed by intense chemotherapy and radiotherapy. Weekly treatment is expected to finish by August, with ongoing scans and check-ups for years to come.

Sonny's bravery was front and centre of mind as Janelle – one of four teams who swam for PCHF – made her first solo attempt at the 19.7km crossing to Rottnest in the Port to Pub. She even swam with a picture of Sonny

in her wetsuit, drawing on his story when the challenge got tough.

Although the two had never met personally, Janelle was moved by Sonny's journey after his family connected with her on social media in the lead up to the event. The family got behind Janelle, sharing her story and helping her raise $13,000 for PCHF which will fund world-class childhood cancer initiatives at PCH.

Sonny's family didn't stop there with fundraising. They were then inspired to raise money for PCHF in the HBF Run for a Reason, mobilising a team of family and friends who walked and jogged 3km together as Team Sonny the Superstar.

Due to his compromised immune system while receiving treatment Sonny couldn't attend the run, but his parents, Lauren and Daniel, along with siblings, grandparents and extended family and friends crossed the finish line to give kids like Sonny a fighting chance.

Setting out with a goal of raising $15,000, the team smashed their target raising almost $30,000 for children's cancer programs.

We're deeply grateful for these extraordinary efforts and the unwavering support from everyone in our PCHF community over the past year. A heartfelt thank you; your passion, kindness and compassion is making a real and lasting difference to the lives of WA's sickest children.

Thank you.

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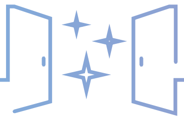

Over the past year, an amazing $6.26 million has been donated to PCH to help WA's sick kids get well and stay well. Thank you to all of our donors.

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City of Perth
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HBF Run for a Reason
Henry Watkins
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PCHF Community Stall – Janet
Reynolds, John Reynolds and Nancy Chiam
PCHF Gift Shop
Perth Firefighter Calendar Committee
Putt4Dough Annual Golf Day – WAITTA
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Silicon Valley Community Foundation
South32
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West to West
Zweck Fashion Gala – Klara Forrest

Bequests and Enduring Trusts

Bendix Family Charitable Endowment – Perpetual Foundation
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In Memory of Pat and Les Valentine
Jack Family Charitable Trust
June Yule Endowment – Perpetual Foundation
Swift Family Bequest – Perpetual Foundation
Trust of Patrick Connolly

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Andrew and Cate McKenzie

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Euroz Hartleys Foundation

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McAuliffe Family

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McIlroy Family

McShane Family

Motteram Family

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Neve Family

Oliver-Dawe Family

Pitts Family

Pointon Family

Potts Family

Polidano Family

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Waller Family

Weston Family

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Thank you for your generous support.
It really is making a difference to the lives
of sick kids in WA and across the world.

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