



Perth  
Children's  
Hospital  
**Foundation**

**Turning dreams  
into reality.**

**Annual Review 2023/2024**

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### 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.



## Message from the Foundation.



**The Hon.  
Ian Campbell**  
Chairman

**Dreams. They inspire us, they motivate us and, importantly, they give us hope of a better future.**

At Perth Children's Hospital Foundation (PCHF), we like to do more than just dream. We strive to turn dreams, no matter how big or small, into reality.

Over the past year, we've been busy bringing the dreams of some of Western Australia's most deserving to fruition. This includes those of WA's sick children and their families, clinicians and researchers, and our generous supporters who help us ensure WA's sick kids continue to receive world class health care.



**Carrick Robinson**  
Chief Executive  
Officer

When sick children and their families dreamed of being able to use the power of nature for healing, we transformed the Greenspace outside Perth Children's Hospital (PCH) into 'Waalbiirminy Waabiny Boodja', a healing nature-space to support wellbeing and aid recovery.

Influenced by the richness of Aboriginal culture, 'Waalbiirminy Waabiny Boodja' is an area where children and their families can get away from the pressures of hospital while remaining close to vital care.

When the families of children living with a life-limiting condition dreamed of a nurturing place for end-of-life and respite care, we developed WA's first Children's Hospice.

Thanks to the enormous generosity of our supporters, construction is underway on this much-needed facility named Sandcastles which translates as Boodja Mia, in traditional Noongar language.

When families of children with rare and undiagnosed diseases dreamed of having a dedicated service to help them navigate their challenges and coordinate care, we funded the world-leading Rare Care Centre, helping reduce the burden on children, parents and carers.

Many children with diabetes and their families dream of life being easier, so we've funded a range of innovative technology to achieve just this – Continuous Glucose Monitoring devices, insulin pumps and the top-of-the-range Hybrid Closed Loop (HCL) insulin pump therapy systems. These are just a few examples of how we're bringing the world's best and most advanced equipment and technology to the sick children of WA.

We're also helping PCH clinicians achieve their dreams of undertaking world-leading research to help improve patient outcomes and the lives of sick kids here and around the globe.

Of course, none of this would be possible without the unwavering support of our donors, partners, PCHF community and amazing staff and volunteers who help us turn **dreams into reality**.

To everyone, we extend our heartfelt gratitude and appreciation and hope you enjoy reading about the amazing difference your support is making to children here and around the world.



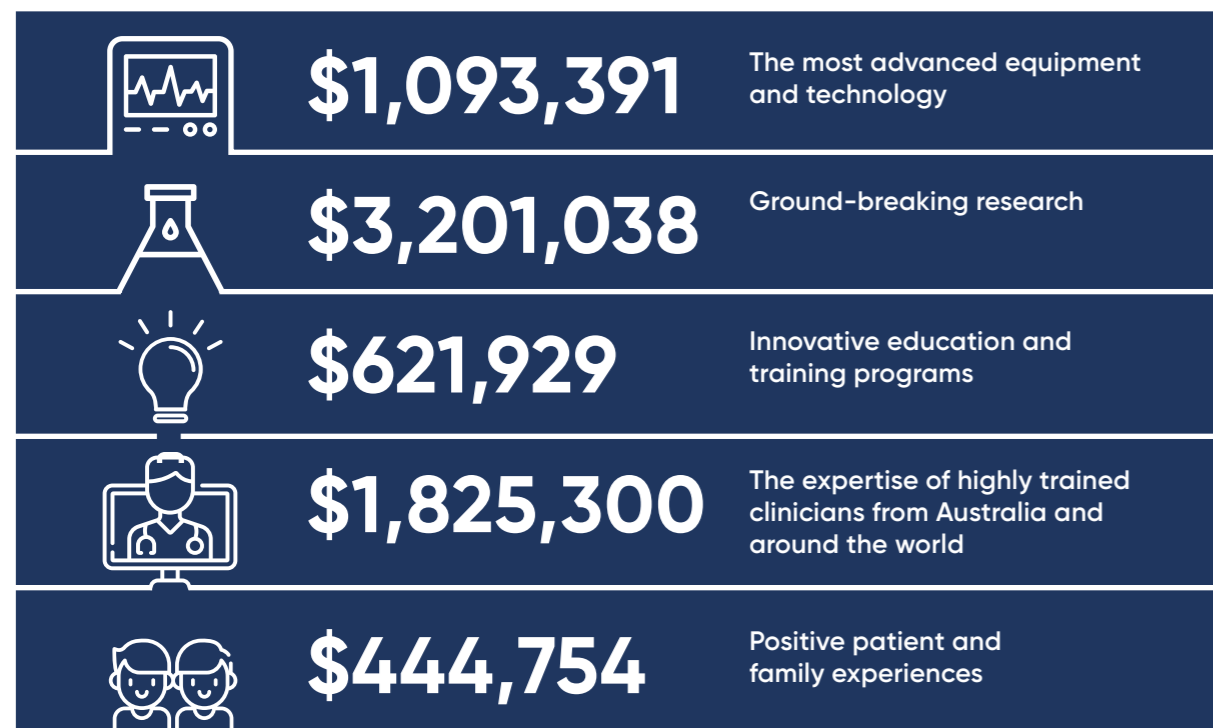
# About us.

Perth Children’s Hospital Foundation proudly fuels the fight on the frontline of children’s health care, 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 official and largest funder of PCH and the wider Child and Adolescent Health Service (CAHS) after Government and are the 5th largest philanthropic foundation in WA.

With the help of our generous partners, this 2023/2024 financial year we have provided PCH and CAHS with grant funding to the amount of \$7.19 million, giving WA’s sick children and young people access to world-class care that comes from:



Note: Preliminary figures subject to audit.

# Our governance.

In FY23/24 the Foundation recorded another strong financial result, with revenue derived from generous donors and supporters enabling us to provide \$7.19 million in grants to PCH and the wider Child and Adolescent Health Service (CAHS).

Every donation we receive makes a difference to paediatric healthcare in Western Australia and we are steadfast in our commitment to ensure that all funds we receive are spent wisely, to make a real and positive difference for children.

We are highly aware of our stewardship role - we effectively act as a conduit between donors and the "on-the-ground" impact of their generosity - and this is a role that we take extremely seriously.

We have a strict approach to corporate governance and strong controls over the assessment, acceptance, administration and acquittal of grants. This includes a rigorous peer review process which ensures that our impact is maximised.

When we receive requests for funding, those requests are submitted via a secure online platform and subject to a rigorous review by the Foundation Grants Executive Team and the Foundation Grants Sub-Committee. Finally, a request for funding over \$20,000 requires the approval of the full Perth Children’s Hospital Foundation Board.

Importantly, we need to be confident that we do not fund a project or program that the community would reasonably expect is the responsibility of Government to fund, such as the routine replacement of equipment. We are resolute in our focus on funding world-class expertise, innovative education and training programs, ground-breaking research, cutting-edge equipment and technology, and positive patient experiences. These are programs, research projects and equipment that deliver healthcare services, which are above and beyond what would otherwise be accessible to Western Australian children.

Our strong governance processes, the remarkable projects and programs being funded, and the extraordinary generosity and kindness of our supporters is propelling the transformation of children’s healthcare, resulting in improved health outcomes for children today and tomorrow.



# Kids' dreams, driving impact.

## Changing lives through the most advanced equipment and technology.



**10**

young children under the age of two years had safer brain tumour surgery thanks to EM navigation equipment



**30**

critically ill children received targeted nutritional plans aiding their recovery due to accurate energy expenditure measurement obtained using an Indirect Calorimetry Device



**74**

children with type 2 diabetes now have access to life-changing Continuous Glucose Monitoring technology to better manage their condition



**102**

children undergoing tonsillectomies wore patient-friendly wrist oximeters at home to measure their blood oxygen levels, helping improve surgical care in kids



**2,600**

children are hearing better because of specialised video reinforcement equipment, which improves hearing assessments, enabling critical interventions sooner

## Funding the future through ground breaking research.



**1,000s**

of children needing surgery in WA and around the world stand to benefit from world-leading research into a simple, portable test that could improve safety during and after an operation



**4,680**

children with burn injuries and their parents received targeted clinical interventions thanks to the Impact Study exploring the relationship between physical and psychosocial recovery after childhood burn trauma



**12**

high-risk patients received better care during their tonsillectomy thanks to the world-first SAFE-T: Tonsillectomies interdisciplinary research project



**3,000**

babies have been recruited into Early Moves, a WA-led study investigating whether a baby's early movements can predict learning difficulties later in childhood

## Funding innovative education and training programs.



**2,000**

WA children are receiving better eczema care because of the WA Eczema Project's delivery of patient and health professional education, optimising eczema care in the community



**500**

Aboriginal families have been supported in their journey at PCH by an Aboriginal Health Worker, helping to close the health gap between Aboriginal and non-Aboriginal Australians



**687**

health professionals are better prepared to respond to changes in patient conditions because of tailored immersive training, designed and facilitated by the PCHF funded state-of-the-art PCH Simulation Suite

## Funding world-class expertise closer to home.



**3,500**

WA children treated for burn injuries over the past five years received the best possible care thanks to the work of Professor Fiona Wood AO



**100s**

of children from across Australia have had innovative interventional radiology procedures as a result of the appointment of Professor Derek Roebuck, helping transform PCH into a world leader in paediatric interventional radiology



**110 - 115**

children diagnosed with cancer each year in WA receive world-leading cancer care because of Professor Nick Gottardo and his team

## Funding positive patient and family experiences.



**75**

children with diabetes were able to relax during distressing procedures by wearing Virtual Reality distraction goggles



**50**

children and young people with brain injuries and spinal and neurological conditions had their stress and anxiety levels reduced by the healing power of Music Therapy



**1,000**

approx. patients and families had their visit to hospital over Christmas brightened by festive season cheer



**6,568+**

children were entertained with activity packs while waiting for outpatient appointments, helping reduce anxiety associated with medical appointments and procedures

# Developing childhood cancer vaccines.

**We all dream of a day when there will be a cure for cancer, turning a devastating disease into a manageable, less-confronting condition. Thanks to generous donor support, we're helping world-leading cancer researchers at PCH edge closer to this long-held dream.**

We all know someone touched by cancer and while there have been incredible medical advances in recent decades in childhood cancers, the holy grail of a 100% cure rate remains elusive. While more children are surviving than ever before, they're often left with chronic, life-long problems from aggressive treatments.

The new frontier of cancer research – immunotherapy – offers new hope and could revolutionise cancer therapies, ultimately improving quality of life and survival rates in some of our sickest children.

Cancer immunotherapy uses a patient's own immune system to fight the disease. It helps the immune system detect and destroy cancer cells. But while it's revolutionised the treatment of certain adult cancers, including advanced stage melanoma and a deadly form of brain cancer, it hasn't translated yet to childhood cancers.

A world-leading childhood cancer project involving PCH's Professor Nick Gottardo aims to understand why immunotherapy has had little success in treating children with cancer.

"It could be completely game-changing, if you find the reason why they don't respond and adapt that so that they do, you are bringing in a new therapy that will hopefully be much more effective than current treatments but equally less damaging, because it's using a system the body already has," said Professor Gottardo, Head of Department of Paediatric Oncology and Haematology, PCH.

Professor Gottardo is collaborating with researchers from the University of Western Australia (UWA) who have successfully developed immunotherapy vaccines for

abnormalities known as 'dark matter' uncovered in adult cancers. The vaccines effectively allow the immune system to 'see' tumours for the first time and go on the attack.

The same sophisticated systems will be adapted to children's cancer to uncover dark matter specific to children and missed in other mapping studies. Research will focus on two of the most common childhood cancers: acute leukaemias and brain tumours.

## Cancer vaccines

Unlike infectious diseases vaccines which help prevent illness, cancer vaccines are designed to treat existing disease. They are well tolerated and less toxic and take advantage of the natural ability of cells to distinguish between what's normal and abnormal.

Cancer vaccines which focus on cell mutation help the immune system recognise patient-specific cancer mutations, called neoantigens (dark matter), and destroy them. The vaccines target mutated tumour cells and spare normal healthy cells resulting in limited toxicity.

In childhood cancer, research of this nature is extremely limited as most immunotherapy research focuses on adult cancers and the required technology is only available in a few laboratories worldwide, including here in Western Australia.

Researchers aim to discover more hidden neoantigens than ever before, uncover the strength and type of immune response by immune cells and which immune responses are associated with prolonged survival/lack of relapse.



"It could lead to practice-changing paradigms for kids not just in WA but all over the world."

Professor Nick Gottardo, Head of Department of Paediatric Oncology and Haematology, PCH

"We need to find more specific treatments, that attack the cancer but not a child's normal body," Professor Gottardo said.

"If we can identify the 'dark matter' in children's cancer, we can then develop immunotherapies designed to harness a child's immune system to seek out the cancer cells and destroy them."

Both Professor Gottardo and UWA collaborator, Professor Bruce Robinson AM, are international leaders in cancer research and their approach to identify additional, hidden neoantigens is highly innovative and has not yet been achieved elsewhere.

Research findings will guide the development of future immunotherapy cancer vaccines, which Professor Gottardo is confident are five to ten years away. Importantly, this project could also inform therapeutic synergies with other novel treatments currently under development.

Given the lack of studies in this field and the huge potential of immune-based therapies, this project could have a significant impact, leading to entirely new personalised therapeutic approaches with lower toxicity. There's the potential to generate long term tumour control, prevent late relapse and improve survival rates and quality of life in some of our sickest children.

With immunotherapy, the dream of finding a cure for cancer is now realistic according to Professor Gottardo and Perth Children's Hospital Foundation is proud to be playing a role in the quest to turn this into reality.

"I think, speaking for all paediatric oncologists, our dream is for 100% cure, we know that's a very high bar and we've taken decades to get to 85%, but we have a lot of toxicity," Professor Gottardo said.

"The last 15% is not going to come through doing more of the same because we have pushed the limits of intensity of treatment and we cannot give these kids anymore. It's going to come from using our understanding of how cancers develop, what the abnormalities are and finding the weaknesses in the different cancers and exploiting those, that is precision medicine, that is how we're going to cure those who are incurable and lead to less side effects."

WORLD-CLASS EXPERTISE

# Top medical minds transforming young lives.

## Meet our world-class medical experts who are driving medical advancements at PCH.

Thanks to the generous support of West Australians, we have funded, and continue to fund some of the world's best medical experts and clinicians, so that WA kids have the best possible care right here at home.

### Raising the profile of mental health

The Stan Perron Chair of Child Psychiatry is helping provide better mental health support for those in need. Professor Helen Milroy AM provides significant local, state and national leadership on children's mental health, as well as cultural safety for Indigenous families.

"What the professorial chair allows me to do, which is different to a clinical position, is to focus much more broadly on systems, research, evidence to change and improve what we do, to get the better outcomes for children and young people facing mental health challenges," said Professor Milroy.

### Childhood and Adolescent Dissociation Project

An area of research that Professor Milroy is focusing on is the impact of trauma on mental health. The Dissociation Project is in a data collection phase of a three-year study, which will be the first in Australia to routinely screen for dissociation in a health setting and develop measures to improve clinical outcomes and quality of life.

"The difficulty with trauma, is that it can take many different forms in children. Children can look okay but not be okay. So the impacts might not be noticed until later down the track," said Professor Milroy.

"One of the things that happens in order for a young child to cope with overwhelming trauma is to dissociate, which is where they leave their mind and body and they become

a little bit disconnected. That gives you a coping mechanism to get through the trauma. However, it can lead to developing illnesses such as eating disorders, psychosis, depression, anxiety or self-harm behaviours.

"The Dissociation Project is considering what this looks like in children, do we understand it and do we know how to intervene. What we've been finding out is that we need better evidence and trials to be able to design an intervention to trial."

### Mental wellbeing of burns patients

A key ongoing collaboration with Professor Fiona Wood AO at the Stan Perron Centre of Excellence for Childhood Burns has been to address the mental wellbeing of children with burns.

Historically, burn treatment has focused on physical healing but more recently research has shown burns lead to poor psychological health.

"Children who have a serious burn are much more likely to have mental health outcomes, but they may not realise this for several years," said Professor Milroy.

"We have wonderful hospitals that focus on the physical health recovery, but they don't focus on the mental health recovery.

"We designed a psychosocial recovery brief intervention for children to try and enhance their coping and resilience following a burn. This has provided a better recovery process for their emotions earlier in the piece, instead

"We all want to see happy, healthy children and families. We want to see children thrive."

Professor Helen Milroy AM

of waiting until they are perhaps further distressed down the track.

"And we've had a really good result. Children who participated enjoyed the program and it's had a positive impact on them. It benefits not just the psychosocial recovery of the burn, but it also enhances their capacity to cope with life."

### Cultural Safety Review

Professor Milroy continues to support Aboriginal mental health workers in their clinical work, providing strategic direction and leadership. Last year her team undertook a cultural safety review of the whole child and adolescent mental health system, which identified some training needs. They have since developed a more comprehensive training package and an Aboriginal case study.

### Excellence in radiological services

PCH has one of the best radiology departments in the world, with the largest and most experienced paediatric interventional radiology (IR) department in the southern hemisphere. Four of the nine paediatric IR consultants in Australia and New Zealand currently work at PCH.

Professor Derek Roebuck is a global expert in paediatric interventional radiology and – thanks to the Foundation – he's been the Simon Lee Foundation Chair of Paediatric Radiology at PCH now for five years.

"During my time at PCH we've introduced a 24-hour IR on call service that gets used for emergencies. We have a really good training centre now, with four fellowship roles for doctors progressing towards a consultancy position in paediatric radiology. And we've expanded the number of treatments we offer," said Professor Roebuck.

"I don't think any of that would have happened if we didn't have the time built into the job, thanks to the Foundation."

The IR department has become the "go-to" centre in Australia for the interventional management of renovascular disease.

"When I worked in London, I helped start up the biggest team treating renovascular disease for young patients. We would get referrals from all over Europe and the Middle East. After being part of this team, I decided to bring this experience with me to Perth, and we now also have a good relationship with Adelaide, where they refer their children to come here for treatment."

The department is committed to keeping up with developments in radiology and expanding the range of treatments available for kids with rare conditions. Some of the new procedures implemented at PCH include endovascular aortic recanalisation, cryotherapy and tumour embolisation. The team has also developed new ultrasound services such as elastography and contrast enhanced ultrasound.

"We recently had a young patient with a tumour in their kidney which was removed, but it recurred in their liver. We used a technique called cryoablation, which is a freezing technique where a needle is inserted into a tumour and you freeze the tumour to destroy it.

"Cryoablation is something the Foundation supported not long after I arrived, and we've been using it to treat mostly benign tumours and malformations that need freezing.

"Our most recent patient was the first time we used this procedure at PCH to treat a malignant disease, so that was definitely a step forward for us."



"We want to be the best in the world, and it's inspiring to work with people who are highly ambitious to get the best results for the kids."

Professor Derek Roebuck



MAJOR PROJECTS

# Natural healing through nature.



“When you’re having a really tough time, when anyone is getting a little bit emotional, you go outside into nature and it’s instant relief.”

Di, Luca’s mum



## Dreams of a place where patients and families could relax and escape the stress of medical care have transformed a patch of grass near PCH into an award-winning nature-space.

The much anticipated \$4 million nature-space Waalbiirninny Waabiny Boodja, meaning ‘to heal, to play, on Country’, was officially unveiled in February 2024. Developed, in consultation with Noongar cultural advisors, the space was inspired by the healing energy of Country, incorporating traditional and contemporary cultural themes into its design.

“In this nature space, we wanted to have the different symbols of the major animals and plants that bring forth the healing, from out of the leaves, and through the different flowers that are blooming over the different seasonal times,” said Barry McGuire, cultural advisor.

“And then to highlight a few animals that are used for healing like the frog, the strength of it gave us our spiritual strength through our dreams, and the crow, and the white cockatoo, which is the symbol of our skin system, our kinship systems,” said Barry.

Four distinct zones with accessible play equipment have been created that can be used as:

- A nature-space providing a sense of fun and normality away from the clinical hospital environment
- A rest and relaxation space
- A natural learning precinct offering educational opportunities on native flora, fauna and Noongar culture
- An entertainment space for performers and outdoor events

Noongar themes and storylines are at the heart of Waalbiirninny Waabiny Boodja, which includes a discovery path called Koodjal Noorn (two snakes), shelter pods honouring the six Noongar seasons, a cubby referencing Noongar mia-mias, an interactive play space incorporating animal sculptures and a climbing net depicting the web of the trapdoor spider, a unique Noongar story connected to Kings Park.

The nature-space also showcases a diverse range of plants native to the Kings Park area including banksia, eucalyptus, native shrubs, mallees and flowering plants.

“There is strong evidence that nature is a powerful healer in kids and adults alike, helping to improve wellbeing and assisting in boosting recovery rates, so it’s brilliant that WA patients and families now have a purpose-built space where they can be together outside of clinical settings, whilst still remaining close to care,” said PCHF Chairman Hon. Ian Campbell.

### A place to escape and relax

In 2022, Luca was diagnosed with high risk neuroblastoma – a form of cancer which grows in the body’s nerve cells and is most common in kids under five years. He endured a difficult 16 months of treatment, where most of that time was spent in hospital. Luca’s mum, Di said they spent many days and weeks at a time in the oncology ward.

“From experience, I know that a nature space right on the doorstep of the hospital is something that many oncology families and others going through treatment will really appreciate,” said Di.

“Nature is a huge part of our lifestyle because I just feel like it’s very healing in many ways. And when you’re stuck inside a room for such a long time, just popping outside for some fresh air and having this space which is relaxing, a space to sit with shade and look at the trees is very beneficial for everyone.”

From sick children and their families looking for somewhere to relax and rejuvenate, to healthcare staff wanting to unwind from the pressures of the hospital environment, this healing nature-space was made possible thanks to funding from PCHF and founding partner Rio Tinto.



# A home away from home.

Construction on WA's first children's hospice is underway. The aptly named Sandcastles is expected to open in late 2025, realising a long-held dream to provide specialised respite and end-of-life care for children and their families.

Families of the 2,000 WA children living with a life-limiting condition face unimaginable heartache every day, not knowing if it will be their last with their precious child.

A diagnosis can lead to a journey spanning weeks, months or even years. This comes with an ongoing emotional, economic and psychological impact on families, placing incredible stress on them and their wellbeing. Having somewhere to escape, connect and create special memories, while still receiving hospital quality care, is something families have only been able to dream of, until now.

Sandcastles pays homage to the therapeutic healing properties of the sun, sea, sand and ocean breeze. Naming of the hospice was developed by our Noongar cultural advisors, with Sandcastles directly translating to Boodja Mia in traditional Noongar language.

Sandcastles will be a self-contained, homelike seven-bed facility, with three family suites, built close to the beach and nature near Swanbourne Beach. Inspired by the natural surrounds of the area, the design includes a kitchen, dining and living space, playrooms, a physical treatment area inclusive of a hydrotherapy pool, clinical spaces, outdoor living and a play space.

Upon completion, it will become a sanctuary for children with life-limiting conditions and their families. A place where they feel relief from the stress and exhaustion of their daily reality and create lasting memories away from a clinical setting.

The hospice will provide:

- A place for whole families to be together in their greatest time of need, away from the clinical setting of hospital. They will enjoy precious time together, create special memories and connect with other families going through similar challenges
- Care for children who have a life limiting diagnosis with little prospect of being well and who require 24/7 care. The hospice will assume care of these children for a period of time allowing their families much needed respite
- End-of-life care for children with the safety net of clinical care in the comfort of a highly respectful and supported environment
- Support for the families of children with a life-limiting condition
- State-wide bereavement service for families following the death of a child



**"Sandcastles will touch the lives of countless sick WA kids and their families, with services to help improve their quality of life as they continue to persevere through life-limiting conditions."**

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



## Fleur's story.

Fleur was a spirited 12-year-old, who had her whole life ahead of her until one day she collapsed and was in serious pain. Her family rushed her to hospital and soon discovered she had an aggressive type of brain cancer. After multiple emergency brain surgeries at PCH, Fleur barely survived. She had severe brain damage, paralysis of the right side of her body and was facing a long road to recovery. As Fleur's mum Miranda explains, she defied all odds, "Three days became three weeks, three weeks became three months and she worked herself up to a healthy child again."

Unfortunately, Fleur's cancer spread and stopped responding to treatment, and she sadly passed away in August 2022. She was one of the original children to feature in the hospice educational video on the importance of allied health services, for kids with life-limiting conditions.

Her family said she was looking forward to the opening, but they know she will be there in spirit.

"Fleur loved the beach, this was one of her happy places. We went quite often to see the beach, making sandcastles. So the name (of the hospice) is amazing for us. To see that it's being built close to the beach was a dream for her. And it's finally happening," Fleur's mum Miranda said.



In loving memory of Fleur

"If you have a place like this and you can do that with your family all together, it's amazing. It's a dream come true for a lot of families in difficult situations. We are really thankful from the bottom of our heart, even though our daughter couldn't make it, a lot of other people will benefit from this."

"Not every family has the facilities or the accommodation to actually do the final days and the final weeks at home," Fleur's dad Michael said.

"It needs to be enjoyable, comfortable. It needs to be surrounded by friends and family, which is hard to get into a hospital. And a hospice is a much better place to accommodate it."

INNOVATIVE EQUIPMENT AND TECHNOLOGY

# Breaking barriers for kids with disabilities.



## The Kids Rehab WA program is empowering the lives of kids with disabilities through the help of life-changing equipment and technology.

With public health and disability funds being allocated primarily to basic and essential needs, children with lifelong neurodisabilities often face funding shortfalls for necessary equipment and services. This hinders their ability to participate fully in daily activities and enjoy typical childhood experiences. That's where our Kids Rehab WA fund comes in.

Based at PCH, Kids Rehab WA helps ease the struggle for around 1,600 WA children with acquired and congenital spinal cord injuries each year. They support these children by providing specialised equipment, technology and therapy to those who would otherwise go without due to financial and social barriers. With our contribution, the program offers early intervention, cerebral palsy mobility, intensive rehabilitation, spinal and acquired brain injury rehabilitation.

## Olivia's Dream.

No parent ever wants to see their child struggle and Olivia's mum, Bianca, knows all too well what that feels like.

Olivia sustained an Acquired Brain Injury (ABI) following the removal of a brain tumour when she was just eight years old. Prior to her tumour, Olivia was very active, taking part in dance and sports, but her ABI has affected her balance and movement.

Olivia had to undergo intensive rehabilitation. It meant learning how to swallow, speak and move again. A program was tailored specifically to meet her changing needs, which included ongoing physiotherapy, education, occupational therapy and speech therapy.

Through sheer determination, Olivia transitioned from a wheelchair to a walker and quad sticks, and can now walk unaided for a short period, although her balance is still compromised.

In 2021, Olivia was introduced to the sport of FrameRunning, an inclusive recreation and rehabilitation activity for people with conditions affecting mobility or balance.

Thanks to a FrameRunner funded by PCHF, Olivia is pursuing her Olympic dream to one day compete in the Paralympics.

A FrameRunner is essentially a three-wheeled 'running bike' with a saddle, which allows users to easily propel themselves forward using one or both feet.

The FrameRunner has had such a positive impact on Olivia, her mum Bianca explains.

"It was very difficult for Olivia following the removal of the tumour because she struggled with not being as active as she once was," Bianca said.

"It was amazing watching Olivia in the FrameRunner for the first time. She has a very competitive streak and it's difficult to find an all-ability activity like FrameRunning, so it's been really fantastic.

"Olivia's goal is to one day take part in the Paralympics – she would absolutely love to race and win a medal."

PCHF is proud to have funded some of the first FrameRunners in WA for Kids Rehab, as it allows kids affected by mobility and balance issues to exercise, have fun and enjoy a sense of freedom.



"Working with hospital clinicians to provide specialist equipment like the FrameRunner, and access to innovative programs is a game changer, giving children and teenagers with disabilities and chronic illness the freedom to achieve better health outcomes through physical activities," PCHF CEO Carrick Robinson said.

Thanks to continued PCHF funding, Kids Rehab WA is helping kids with disabilities move forward, build a stronger future and fulfill their dreams.

### The 6 F's

The international framework for childhood disability focuses on maximising six key areas of a child's life: Function, Family, Fitness, Fun, Friends and Future to achieve meaningful outcomes for children with disabilities. It is this ethos that is at the heart of Kids Rehab WA.



# Transforming care through the world's best technology.

In a world of ever-evolving technology, the unwavering support of our community has turned our dream for WA's sick children to have access to the world's best and latest equipment and technology into reality. This means WA's sickest children continue to receive the best care possible close to home.

## Life-changing diabetes tech

### CGMs - Type 2 Diabetes

Managing diabetes can be stressful and time-consuming for kids and their families.

Continuous Glucose Monitoring (CGM) devices make life easier and improve health outcomes by providing automatic glucose readings, making painful fingerprick testing a thing of the past.

While the technology is fully funded by the Australian Government for children with Type 1 Diabetes (T1D) – the most common type of diabetes in children – those with Type 2 Diabetes (T2D) are excluded from the program.

We're making this life-changing technology available to PCH's T2D patients, so that families who need it most can best manage their child's diabetes, regardless of their financial situation.

"These children have a very complex disease with high risk of future complications, and I believe continued access to this technology will sustain the improved outcomes, lead to further improvements for other kids and significantly reduce the burden of disease," said Nurse Practitioner Mark Shah.

Previously not seen in children, T2D is increasing in kids around the globe and is caused by the body being resistant to the insulin it produces.

### Donated pump program - Type 1 Diabetes

This high impact program helps kids with T1D live safer, more normal lives.

Insulin pumps provide better blood glucose control than manual insulin injections, resulting in fewer episodes of life-threatening highs and lows in glucose levels.

Despite this, almost 50% of WA kids with T1D don't use an insulin pump to manage their condition. For some families, it's because they can't afford the life-changing technology.

Our donated pump program provides access to children who otherwise would miss out on this best-practice therapy.

"Our team is very grateful for the Perth Children's Hospital Foundation support which allows equity of access to all WA families living with T1D, and allows them a choice in their treatment," said Professor Elizabeth Davis, Head of Department, Diabetes and Endocrinology, PCH.

### Automated therapy systems - Type 1 Diabetes

Hybrid Closed Loop (HCL) insulin pump therapy systems are the gold standard in diabetes therapy, effectively acting as an artificial pancreas to deliver the right amount of insulin to the body as needed.

The system includes a CGM and a pump to automate blood glucose control - increasing insulin delivery if glucose levels are high, suspending insulin if glucose levels are low.

This program offers HCL pump therapy to children with T1D under the age of seven and who otherwise could not afford it.



Starting children on HCL therapy soon after a diagnosis is expected to lead to significantly more children meeting the recommended blood glucose targets and more positive patient outcomes.

"These new technologies dramatically improve diabetes care and the lives of children with diabetes and their families," said Professor Tim Jones, Consultant Endocrinology.

"Making them available to all young children will make a major difference to their futures."

Large studies consistently show that HCL therapy improves glucose levels and quality of life for patients.





### Tailored nutrition

The Paediatric Critical Care Unit (PCCU) at PCH is one of the first in Australia and New Zealand to use the highly specialised technology of an Indirect Calorimetric device (IC) to accurately measure energy requirements of critically ill children.

Energy expenditure is highly variable among very sick kids and during various phases of illness. The IC provides personalised, accurate nutrition which aids faster healing and recovery, and reduces the risk of complications such as malnutrition or pressure sores. So far, it's been used on a range of children including those with severe burns, traumatic brain injuries, obesity, oncology diagnoses, severe cardiac conditions, cystic fibrosis and many more.

When two-year-old Hailey was admitted to the PCCU with severe burns, her weight quickly began dropping. The IC device was used to precisely measure her energy needs so that PCH dietitians could create a highly tailored nutrition plan, assisting her recovery.

"The IC allowed us to regularly and accurately adapt Hailey's feeding plan based on ever-changing circumstances," said PCH Senior Dietitian, Tamara Farrell.

"Having the ability to accurately determine nutritional requirements and maintain Hailey's weight and nutritional status throughout her lengthy admission meant she was better prepared for the rehabilitation journey ahead."

### Echocardiography machine

When doctors want to quickly determine how well a child's heart is functioning, or if there's a cardiac problem to treat, echocardiography provides the answers.

The technology uses ultrasound to create high quality images of heart structures and blood flows for diagnosis of heart problems and can also help with the insertion of specialised drips such as central and arterial lines.

A state-of-the-art echocardiography machine funded by the Foundation will improve the care of gravely ill children in PCH's PCCU.

WA's most vulnerable sick children will benefit from earlier diagnosis and treatment, reducing the time they spend in the PCCU and potentially save lives.

"The equipment will provide, immediate, state-of-the-art diagnosis of cardiac lesions and dysfunction facilitating rapid, often life-saving management," said Dr Simon Erickson, Head of Department, Paediatric Critical Care Unit, PCH.

"It's crucial that we are able to offer this to the sickest children in intensive care who are at high risk of cardiac abnormalities and require rapid diagnosis and treatment."



# Accelerating life-changing early detection of cerebral palsy.

**Learning that your child has been diagnosed with cerebral palsy (CP) can be an overwhelming and distressing time. For families, it brings uncertainty and worry about what the future holds for their child, as they try to understand the diagnosis. Early detection can make a huge difference to the lives of children with CP.**

Cerebral palsy is a physical disability caused by damage to the developing brain before, during or after birth. Intervention can start very early, with potentially better outcomes if an infant is diagnosed as at risk of CP.

Thanks to a world leading PCH service, babies can now be diagnosed as early as three months of age and referred for further support and intervention if required. Until recently, this program was limited mostly to babies born in metropolitan Perth. PCHF funding provided to CAHS is enabling a state-wide CP network, known as Accelerate WA, to provide early screening services for vulnerable babies in regional and remote areas.

Starting with a pilot program in the Kimberley region, the PCH Kids Rehab WA Early Intervention Team has been facilitating training and support to local health professionals on the early detection and assessment of CP. This has included training on screening and intervention planning for Cerebral Vision Impairment (CVI) – a condition which affects up to 70% of children with CP.

Senior Occupational Therapist, WA Country Health Service Kimberley, Sascha Wood, has been involved in the pilot program in the Kimberley and says it's important families have access to early diagnosis.

"There's so much evidence that early intervention is critical in helping babies thrive and identifying their needs, so families can access the support they need, whether it's in the Kimberley or Perth," said Sascha.

"Having face to face sessions in the Kimberley in a familiar environment, especially with vulnerable families is so valuable. It's quite comforting to know they have their local team here to support them."

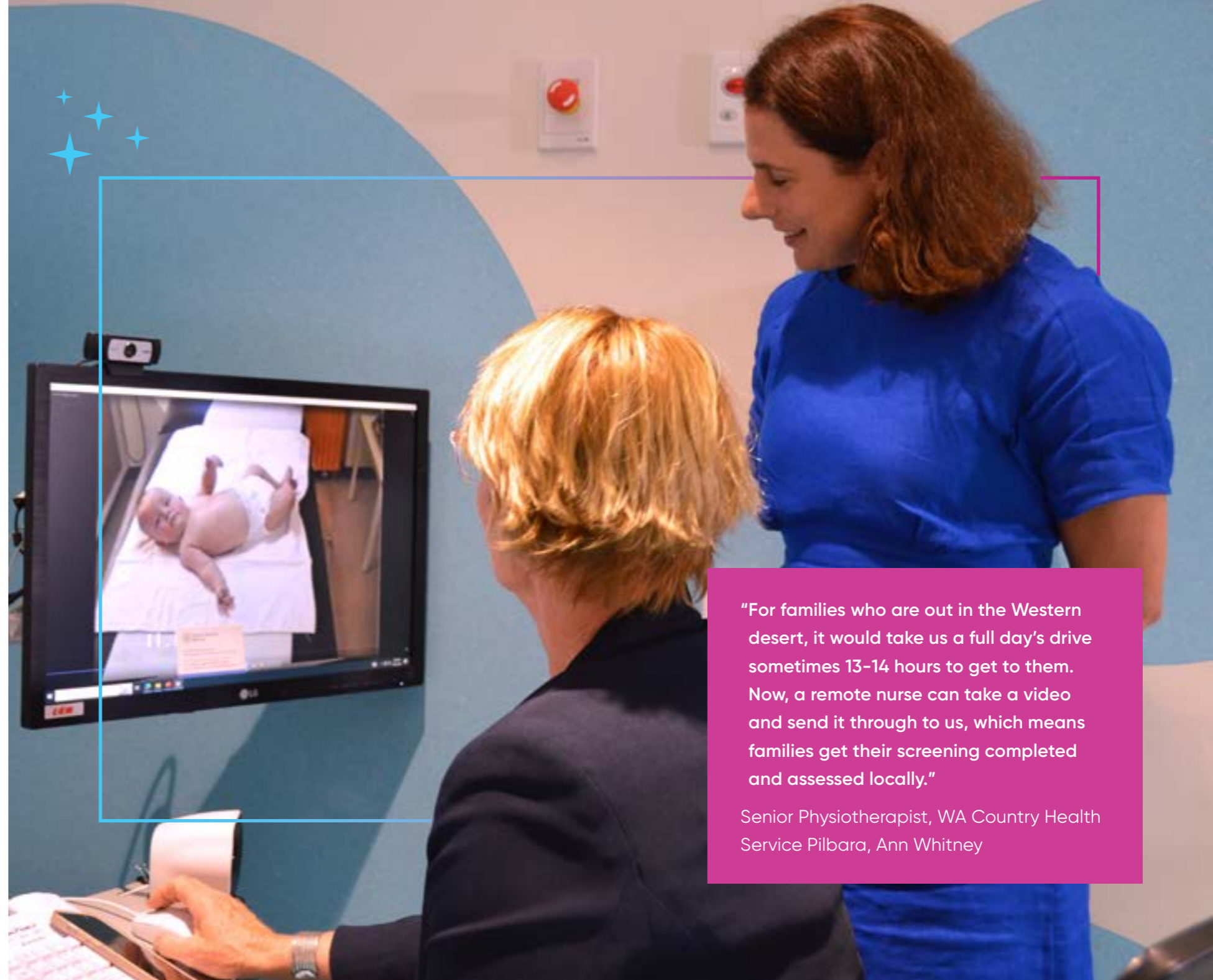
The initial success of the program has seen the Accelerate WA program extend to the Pilbara. Senior Physiotherapist, WA Country Health Service Pilbara, Ann Whitney, has been trained in the General Movements Assessment (GMA), which is used to identify absent or abnormal general movements and can be highly predictive of CP.

General movements are assessed with the infant lying awake on their back while they are calm and alert. The baby is videoed and assigned an optimality score. Currently, videos are sent to the team in Broome, who assess the baby and provide the Pilbara team with the score.

"The optimality score gives us more information about a child – for example whether the left arm is adhering to less movement than the right arm. We can really target what we're looking for and what we're intervening with for that child," said Ann.

"We know it takes so long to get that next step happening, which in the context of a baby's life, a couple of months is a really long time. So it's comforting for families to be able to stay in the region and have their screening done and assessed locally."

Later in 2024, Ann will attend advanced GMA training, along with two local physiotherapists



**"For families who are out in the Western desert, it would take us a full day's drive sometimes 13-14 hours to get to them. Now, a remote nurse can take a video and send it through to us, which means families get their screening completed and assessed locally."**

Senior Physiotherapist, WA Country Health Service Pilbara, Ann Whitney

who will complete their basic GMA training. When they return, they hope to fully establish the program in the Pilbara.

With better access to CP screening for babies born in the Kimberley, we're helping reduce the severity of disability and improve the quality of life for some of our most vulnerable children.

Cerebral meaning 'of the brain' and palsy referring to 'a lack of muscle control' affects body movement, muscle control, coordination and tone, reflex, posture and balance. Children with CP may also have visual, learning, hearing, speech, epilepsy and intellectual impairments. It is the most common cause of physical disability in Australian children.

# Enhancing care for our smallest patients.

The journey of parenthood is an emotional rollercoaster, but for those who welcome their babies into the world earlier than expected, the ride is even more intense.

From their very first breaths, premature babies face health challenges. But, thanks to PCHF funding, new initiatives and technology are helping give our most fragile infants the strongest start in life.

## Connecting with a baby's brain hundreds of kilometres away

For every 1,000 live births, up to three babies can develop abnormal brain function ranging from mild to severe due to lack of oxygen. Hypoxic-ischaemic encephalopathy, or HIE as it is known, is diagnosed soon after birth and can result in life-long consequences, including disabilities such as cerebral palsy.

To improve long-term survival and reduce the incidence and severity of disability, babies diagnosed with moderate or severe HIE, immediately receive cooling therapy to reduce a newborn's body temperature to 33.5 to 34.5 degrees Celsius.

For families living in remote WA communities, getting a timely diagnosis hasn't been that easy, until now. Thanks to innovative technology adopted by the Newborn Emergency Transport Service (NETS WA), distance is no longer an issue. New portable brain wave equipment transmits brain wave data in real-time via an internet uplink, allowing medical staff up to 1,800km away to provide time critical assessments and diagnosis.

"A baby with a brain injury that is not cooled is at a significantly increased risk of movement and learning disabilities," said Associate Professor Jonathan Davis, Medical Director for NETS WA.

"This equipment provides medical staff with vital information about a newborn's brain health in a much shorter timeframe. It also

means we can detect and treat seizures more quickly and effectively during the journey."

## Making neurosurgery safer, more accurate

New electromagnetic (EM) technology is providing real-time guidance for Neurosurgeons during delicate procedures on children aged two years and under.

The navigation software is being used for a variety of critical procedures such as endoscopic brain surgery, excision of brain tumours, shunt placement and the treatment of brain abscesses and epilepsy.

Dr Snigdha Saha, a Neurosurgeon at PCH said the software utilises best practice face-mapping technology. "This not only makes surgery more accurate, but it also helps to prevent complications and reduces the risk of repeat surgery."

"Having access to this technology is critical, as the margin for error during cranial neurosurgical procedures is very small," said Dr Saha.

One of the first times the software was used at PCH was during a successful operation on a toddler with hydrocephalus – a condition caused by a build-up of cerebrospinal fluid in the brain.

"Usually fluid produced in the brain serves to cushion both the brain and spinal cord and is then absorbed back into the body. If it isn't absorbed and begins to build up, it can become life-threatening," said Dr Saha.

By inserting a shunt (small tube) into the brain during surgery, built-up fluid can be moved to a different part of the body, relieving pressure on the brain.



The first newborn to undergo brain wave recording flew from Kalgoorlie to PCH. During the 600km journey, a Perth-based neonatology expert could review the baby's brain waves in real time.

## Saving premature babies from life-long disability

Advances in treatments have led to dramatic improvements in survival rates of premature babies here and around the globe. But many of these babies go home with a lifelong disability such as developmental delay and severe hearing or visual loss.

A world-first, international study led by PCH called PROTECT is investigating if a safe, anti-inflammatory medication used to improve blood circulation problems in adults could help our most vulnerable babies.

Pentoxifylline (PX) has been shown in animal models to work very effectively in reducing inflammation of bloodstream infections and bowel inflammation, common issues in preterm infants. If PX is shown to improve survival and/or major disability in extremely preterm babies, it will be rapidly translated into routine practice. This could have a significant impact on patient care and be potentially life-changing for our most fragile babies and their families.

## Setting a new standard for sleep studies

Ground-breaking research known as the Chin up study is being carried out to see if sleep studies can be performed for vulnerable babies within the neonatal intensive care unit (NICU). Normally these babies are transferred to a sleep laboratory at PCH, which could invite clinical risk (especially babies in their first 100 days), but as the Chin up study is showing, this may no longer be necessary.

"Sleep studies are important investigations while managing babies with upper airway obstruction. However, the study is often delayed due to the complex needs of the babies and is disruptive for babies and parents," Consultant Neonatologist and lead researcher Dr Dimple Goel said.

"Conducting the sleep study within the NICU will help us diagnose a condition faster with greater safety and accuracy to improve outcomes for the baby," Dr Goel said.

The Chin up study brings together experts from Neonatology, Respiratory, Genetics, Plastic surgery, Speech pathology and Ear, Nose and Throat specialities at PCH.

It's the advanced medical technologies like these that are giving our tiniest warriors a fighting chance at a healthy future.



# Better lives for kids with burns.

**For Ruby and her family, it had seemed like just another normal day. Four-year-old Ruby had been to kindy and her six-week-old little sister was providing mum and dad with many of those adorable newborn moments.**

That evening, within seconds, everything changed.

Wanting to help her mum with dinner, Ruby grabbed a bowl of piping hot vegetables from the microwave. It was the first time she'd ever gone near the appliance and the contents spilled into the air, scalding Ruby from her chin down to her abdomen and along her right arm.

After applying first aid at home, Ruby was rushed to hospital for specialist care for what turned out to be third degree burns, the most serious type of burn injury. Over the next 19 days Ruby bravely endured many agonising procedures, even the daily bath was excruciatingly painful.

"It was horrendous, the skin becomes very sensitive with a burn and seeing your child in that much pain, you literally can't do anything about it but stand there and tell her it's going to be okay," said mum Asha.

With infection risk heightened by her injury during her initial hospital stay, Ruby couldn't have visits from anyone other than her mum and dad while undergoing treatment that included spray on skin and surgery for skin grafts.

When she was well enough to go home, Ruby was wrapped in bandages. Most of the activities that four-year-olds love were put on hold for several months. There was no kindy and no sport, and Ruby had to wear a compression garment for 23 ½ hours of the day to help her skin heal.

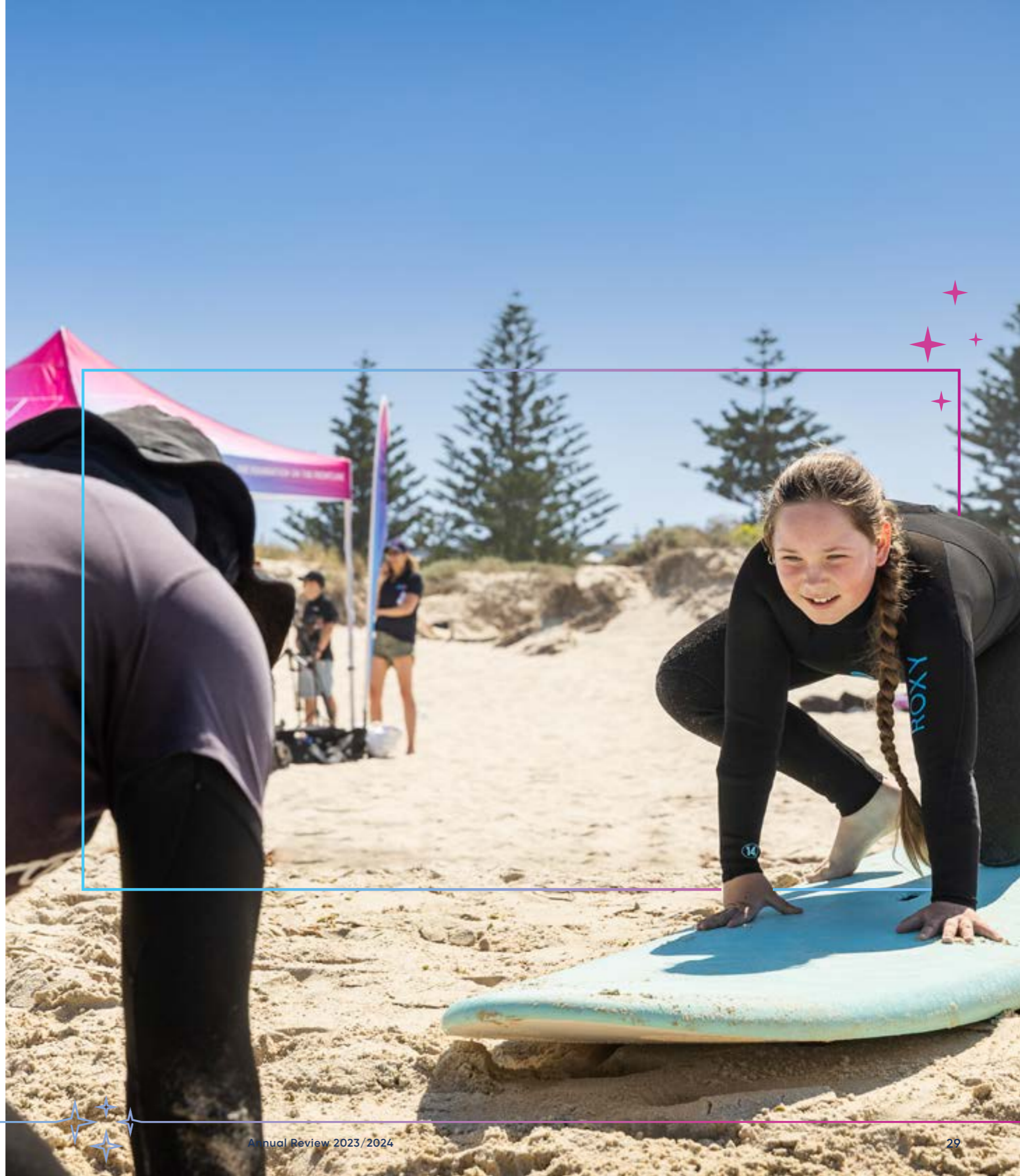
Leaving hospital is not the end of the journey for burns patients. Over the following years, they require multiple trips back to hospital for ongoing management. Ruby has had up to 30 or so surgeries in the six years since her injury, many for laser therapy to improve scarring.

Now 11 years old, Ruby is enjoying school, playing basketball and hanging out with her friends. A unique surfing intervention, part of the Australian-first Move to Improve program run by PCH, and a trampolining program offered by the PCH burns unit have assisted Ruby's recovery.

"She loved both programs and they have not only strengthened her body but given her the confidence and belief in her body that she can do those normal things we all take for granted," said Asha.

While daily life has taken on a new rhythm for Ruby's family, the journey isn't over. There could be more surgery when Ruby turns 16 and due to the injury, Ruby no longer has sweat glands from the tops of her shoulders to her mid chest so is at risk of overheating. Her metabolism also now works differently to other children her age.

"Some of the treatment Ruby had at the burns unit never existed years ago, so while we can't stop the trauma, we can make it better through medical advances and ongoing investment in medical technology and research, to help improve outcomes and make it a little bit easier for them to get on with life," Asha said.





## Leading the way with burns care

Over the past five years, world-leading burns specialist, Professor Fiona Wood AO, and her team at the Stan Perron Centre of Excellence for Childhood Burns have made significant medical advances that are helping transform burns care for children like Ruby.

Burns are one of the most devastating childhood injuries, often leaving kids with lifelong issues, both physical and mental. For example, burns patients face an elevated risk of cancer, mental health and heart issues.

The burns unit at PCH is one of the few centres in the world striving to improve outcomes from childhood burn injuries and enhance lifelong recovery.

"We are proud of what has been achieved in the last five years to ensure research translates into clinical excellence, and education and prevention initiatives underpin all we do to support patients, their parents and caregivers, providing holistic care for anyone who suffers a burn injury," said Professor Fiona Wood, AO.

Centre highlights include:

**Physical outcome measures** – clinicians now know that Grip Strength is a quick and easy measure of physical function following a burn injury, this is especially true for young girls as burn injury impedes strength development.

**Quality of life measures** – a range of outcome measures have been tested giving clinicians a better understanding of when burn-specific quality of life measures are appropriate to use, helping improve mental and social well-being after a burn injury. Support for parents and caregivers has improved as a result of research into parental stress.

**Acute care dressings research** – a study is underway exploring the use of negative pressure devices to improve healing and outcomes. Researchers are investigating the routine use of negative pressure wound therapy. This not only improves wound healing, but improves graft uptake in those requiring acute care surgery and reduces the number of painful dressing changes patients require.

**Research Biobank** – this has grown into the largest biobank of childhood burns in the world, providing a rich resource for researchers here and globally.

**Impact study** – twelve months of psychosocial data has been collected from parents and children with new burn injuries, providing significant insight into the mental wellbeing of burn patients in the longer term.

**Exercise studies** – a range of exercise choices to help with burn recovery are being developed and include trampolining and surfing.

**Biomarker study** – burn blister fluid samples have shown high levels of proteins are associated with cellular damage/repair in the first 24 hours after a burn, whereas after this point more proteins are associated with antimicrobial/bacterial defence. Higher levels persisted in blister fluid for more than seven days which may indicate that the removal of burn blisters up to two days post burn is optimal to prevent prolonged inflammation.

**Vitamin D research** – blood samples analysed for vitamin D content found 76% of burns patients had levels below normal. Reconstructive surgery patients up to seven years postburn, had consistently low levels of vitamin D across all seasons, in contrast to other burns patients.

**Digital innovation** – one innovation that safely captures clinical photography will help improve burn outcomes. For example, it would allow an Emergency doctor at Broome Hospital to send a photo of a burn wound directly to the on-call doctor at the PCH burns team for immediate assessment. The best treatment for the child could be decided in real time whilst maintaining data safely. In the case of burns, early intervention is the key to improving clinical, functional and scar management practices and outcomes.

"We thank and value the Perth Children's Hospital Foundation who are important collaborative partners in supporting all the work we do to help kids who experience these devastating injuries," Professor Wood said.



## Tender care for the rare.

The world's first Clinical Centre of Expertise for Undiagnosed and Rare Diseases (Rare Care Centre) is transforming the way children and families living with rare diseases receive care. By enhancing the quality of life for those with rare and undiagnosed conditions, it enables these children to thrive and flourish in the best way possible.

Rare diseases are complex and progressive conditions that affect less than 1 in 2,000 people. Children suspected of having a rare disease may exhibit symptoms, but on average, it can take up to five years for them to be diagnosed with a rare disease. Receiving a diagnosis like this puts immense strain on children and their families. They face years and sometimes decades of obstacles, navigating through endless healthcare and treatment, and sadly there is often no cure.

Launched in 2022, the Rare Care Centre provides early identification of children with potential rare diseases and pathways for earlier and more accurate diagnosis, along with access to research and clinical trials. It's the first time families have been able to receive dedicated support and coordination of care, helping identify unmet needs and connecting them to resources available to them.

Two years in and the Centre has supported 176 children and families and the number of referrals continues to grow. The feedback from families has been overwhelmingly positive, which has resulted in much-improved healthcare experiences. This includes:

- Receiving more relevant and timely information, practical and emotional support
- Reduced feelings of isolation
- Improved mental health and wellbeing resulting in a decrease in stress
- Increased access to the National Disability Insurance Scheme (NDIS) and welfare services

The Centre's clinical service continues to expand and has established a global reputation as a world leading centre in rare diseases, through national and international recognition.

Over  
**63,000** children  
**6 in 10** deaths

in Western Australia, live with a rare or undiagnosed disease. That's more than the capacity of Perth's largest sporting stadium.

in children are due to rare diseases with the mortality rate 13 times higher than common diseases.

**"Although they are called "rare", collectively the impact of rare diseases is massive. This is an area of such severe and large unmet need, rare and undiagnosed diseases are like a hidden, global epidemic."**

Professor Gareth Baynam, Medical Director, Rare Care Centre

## Cameron's Story.

When Cameron was born at 38 weeks, he was put on life support and flown to Melbourne to have open heart surgery at just 11 days old. This followed a series of other surgeries including eye and kidney surgery.

Before turning one, Cameron was diagnosed with Kabuki syndrome – a rare congenital disorder which occurs in around one in 32,000 births. Some of the common features include distinctive facial features, skeletal (bone) abnormalities and neurological (brain) abnormalities and various health problems.

Cameron has had a developmental delay with numerous health conditions including food aversions, immune deficiency, mild hearing loss, sensory processing disorder, hypotonia (poor muscle tone), dental issues, autistic and obsessive-compulsive traits, microcephaly (a birth defect which results in a smaller than expected head) and micronathia (undersized jaw).

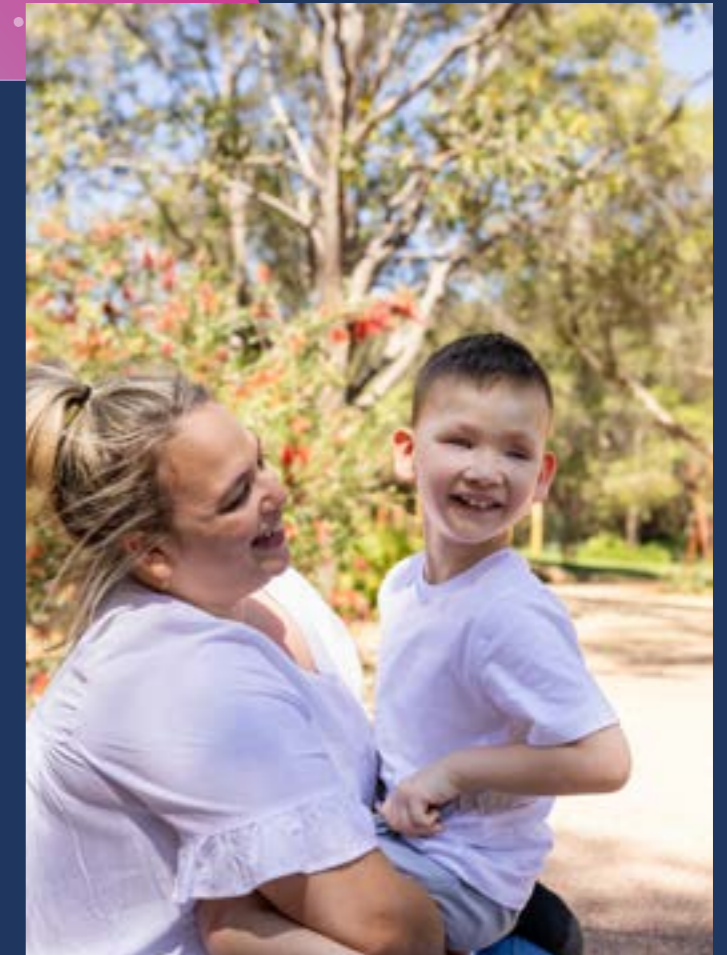
Now at the age of eight, Cameron's surgeries are behind him. Cameron's Mum Sarah says he's a very loud, happy, caring and playful boy who loves doing what most boys his age love to do – sing, play on his tablet and watch fast cars doing burnouts.

As he's getting older, Cameron is learning to cope with behavioural, social and emotional challenges. His ongoing treatment includes visits to his paediatrician and sleep, dental, immunology, ophthalmologist and renal clinics. He also has regular clinical sessions with his therapy team which include speech, physiotherapy and occupational therapy.

Sarah says she's grateful for the support they've received from the Rare Care Centre.

"Without Cameron's therapist and medical team, I couldn't raise Cameron the way I have. The support and guidance from all of them has helped me shape Cameron. I didn't know the first thing about raising a child with a disability and complex needs," said Sarah.

The Centre has also helped Sarah explain Cameron's condition through a social story and supported her with accessing welfare services and entitlements such as the NDIS.



"Things would become very difficult to navigate (without the support of the Rare Care Centre) and the medical system is very chaotic. I'm very grateful for the guidance, support and to have someone to talk to," said Sarah.

For families like Cameron's, the Rare Care Centre is a lifesaver, giving hope to children and easing the stress of caring for a child with a rare disease.

# Fostering the next generation.



**“Fostering WA-based translational research has immediate benefits for vulnerable WA children as it ensures that our research is targeted at the most important issues with the largest burden in WA, such as asthma”**

Dr David Hancock, Advanced Trainee, Respiratory Medicine

## Today’s early and midcareer researchers are the scientists of tomorrow who will make the breakthrough discoveries which improve children’s health.

The newly appointed Stan Perron Charitable Foundation Early Career Research (ECR) Award helps up-and-coming researchers at PCH follow their dreams of making a real impact on the future of children’s health and medicine.

The inaugural recipient, Dr Mary Abraham, a paediatric endocrinologist, is undertaking a two-part, 18-month project aiming to optimise the management of hypoglycaemia (low blood glucose levels) in kids with Type 1 diabetes (T1D).

Dr David Hancock, an advanced trainee in respiratory medicine, is investigating the genetic factors that predict respiratory disease in the first year of life – a potential game-changer that could unlock early detection and treatment for those carrying the highest burden of disease in our community.

### Dr Mary Abraham – diabetes

T1D is the most common form of diabetes in children and is a life-long condition in which the pancreas produces little or no insulin. More than 100 WA children and teens are diagnosed every year, with more than 1,100 currently using the PCH diabetes service.

Without insulin, glucose levels fluctuate between dangerous highs and lows. Hypoglycaemia or low glucose levels are known as ‘hypo’ or ‘low’ and can occur as often as once every couple of days. Regular hypo episodes affect quality of life, and a severe low can result in coma or convulsions.

In the past, the incidence of severe ‘hypo’ amongst children was much higher so families and healthcare professional were cautious around managing hypo episodes. But management of T1D has improved significantly in recent years largely due

to improved insulin delivery systems and continuous glucose monitoring devices, along with better education on diet and exercise.

With improvements in diabetes management, the current hypoglycaemia treatment is likely to lead to overtreatment and be counterproductive with high glucose levels. This research is exploring the most appropriate glucose level at which to commence ‘hypo’ treatment safely.

It will also provide evidence-based knowledge to inform international guidelines.

“There are no other studies reviewing the most appropriate glucose level at which hypo treatment should be initiated,” said Dr Abraham, Paediatric Endocrinologist, PCH.

Our aim is to review ‘hypo’ management with the intention of making it less intrusive and more friendly, yet insuring safety from severe hypo, for those living with T1D.

A survey of families will help researchers understand how they manage T1D in daily life and their experiences of treating hypo episodes, as well as opinions of current guidelines. This data will inform part two, a randomised cross-over trial of 65 participants, aiming to determine if it is safe and effective to lower the cut-off for hypo treatment without worsening diabetes management.

“The project has potential global reach and the acceptance of lower glucose thresholds before initiating management of hypoglycaemia will allow these children to have less disruption in their lives,” said Dr Abraham.

### Dr David Hancock – recurrent wheezing

Wheezing illnesses including asthma are extremely common, yet doctors struggle to accurately diagnose children with these conditions until it is too late. By identifying new mechanisms of asthma that can be used to make an early diagnosis at birth, Dr Hancock hopes to unlock new opportunities for early intervention before the onset of disease, transforming current clinical practice.

Very little progress has been made in asthma in young children in decades. As a result, 40-50% of WA children with wheezing disorders have suboptimal control of their symptoms leading to unnecessary burdens of disease.

Previous research has identified abnormalities in the respiratory cells lining the airway (the epithelium), which contribute to the development of repeated viral infections, recurrent wheezing and asthma. These abnormalities have been called the ‘vulnerable epithelium’. Researchers have shown that the ‘vulnerable epithelium’ can be used to identify high-risk children after they have presented to hospital with wheezing.

The aim of this new research is to show that childhood respiratory disease can be predicted at birth through the genetic features in a newborn’s respiratory cells. This would provide the first-ever opportunity for early intervention before the onset of disease, a paradigm shift in clinical practice.

Dr Hancock’s project is the first step in the development of novel diagnostic tests to unlock early detection and intervention for children with the highest burden of disease in our community.

“By understanding the genes that lead to the development of recurrent wheezing, we hope to unlock new ways to identify and manage children before they are burdened with poorly controlled disease,” said Dr Hancock.

This project aims to unlock new opportunities for a preventative approach to recurrent wheezing/asthma, changing the path of disease and reducing the burden of suffering of children and their families.

Understanding the differences between children who do and who do not go on to develop recurrent wheezing or frequent viral infections in the first year of life will transform clinical practice, allowing conditions to be treated before they become chronic. Early detection will allow for personalised management plans and provide increased clarity around a child’s future.

For the WA health system, early intervention will reduce the incidence of poorly controlled disease, flowing through to a reduction in healthcare costs. Early biology of asthma will also provide the information needed to work towards a cure, rather than the current focus of symptom relief.



GROUND-BREAKING RESEARCH

# Supporting grieving families.

**PCH is leading Australian-first research into outreach services for families of children who have died unexpectedly in intensive care.**

The FOOTPRINTS program provides acutely bereaved families with a service tailored to their needs that isn't currently available. Researchers will assess the level of grief and distress felt by vulnerable families and whether the service can reduce the impact of traumatic grief and improve outcomes.

"We have an established palliative care service at PCH that looks after families that have children with chronic long-term illnesses, but for the families of children who pass away from sudden illnesses or injuries, they don't have that support," said Head of PCH's Paediatric Intensive Care Unit (PICU) and research lead Dr Simon Erickson.

"It's an unbearable thing for families to deal with. We see it in the intensive care unit with families who have the worst time of their lives. It's a sudden shock and sudden loss that can happen so quickly.

"Our ability to support these families is constantly improving, but there is still a gap in service for families who lose their children suddenly in our paediatric intensive care unit. With the FOOTPRINTS program, we hope to change this and to find a way to support these vulnerable families."

Catherine is a mum who has lived through it all and is providing lived experience for the FOOTPRINTS program to help guide the research. In 2015, at just four weeks old, Catherine lost her son Riley to whooping cough.

"Riley was too young to be vaccinated and he spent five days in hospital. It really wasn't until day four that we realised there was a chance he could die," said Catherine.

"It was very, very sudden to us. Very shocking. You've got so much grief and trauma, but you've also got this shock that you're dealing

with. Riley's death was covered in the media the next day as well, so that was another layer of trauma and processing that we needed to do."

Overall, Catherine says they've coped reasonably well. "We were fortunate enough to have good support from clinicians and a good support network. I've networked a lot with other families who faced loss and grief, and everyone responds so differently. Many families don't have the support we have. And that's why I'd love to see more evidence-based support for families facing this shock and grief.

"When I found out about the FOOTPRINTS study I thought this is amazing. It needs to happen, but it's such a sensitive area, so we need to make sure we have good consumer involvement and community engagement in this area of research, to make sure that it's meaningful and appropriate."

Catherine said if there had been a service like FOOTPRINTS available to them at the time of Riley's passing, it would have helped them through their grief journey.

"Undoubtedly this service would have made our experience easier, not just for myself but for my husband, our extended family and other children. Any extra layers of support at a time when you are at your most vulnerable is a bonus."

Catherine has transformed the unexpected loss of her son Riley into a powerful force for good, setting up the Immunisation Foundation of Australia in his memory. Through her advocacy work, Catherine was also recognised as the 2016 Young Australian of the Year.



Nursing Research Fellow, Arielle Jolly, says this area is under researched, but the FOOTPRINTS research team believe it's important for families to have an enduring connection to clinical staff who were present or involved in the time of death.

"We anticipate the service will be run by a PICU liaison nurse and a social worker, someone who can form that connection between the acute time of death and the ongoing support that will be offered," said Arielle.

They also want families to have an understanding of what happened in the PICU, in a way that is best for families during their grieving process.

"The limited evidence that is there, suggests that families don't often have a good understanding of all the life-saving measures that happened," said Arielle.

Catherine adds, "To have someone to help answer some of those questions, helps you get on that pathway of grief. You can't grieve properly if you don't understand what's happened."

"Having worked in intensive care and seen what it's like for families, and then to feel that sense that we let them go home with nothing, I really look forward to being able to transform that into seeing we don't let families go home with nothing. We actually support them in their grief journey, having been there for them at their most terrible moment in their lives," said Arielle.





GROUND-BREAKING RESEARCH

## Leading the way in research excellence.

### We're supporting innovative research to make a positive difference in the health and wellbeing of WA children.

At the forefront of ground-breaking medical advancements, our world-class research teams are transforming the future of healthcare for kids in WA. This vital work which is helping to transform sick children's lives would not be possible without the generosity of our donors.

#### Revolutionary Asthma Diagnosis Test

Wheezing, shortness of breath, and coughing are telltale signs of asthma, which hospitalises more Australian children aged 0-4 years than any other age group.

Frequent wheezing is extremely common in pre-school aged children, affecting tens of

thousands of young WA kids. However, there is currently no effective way to diagnose asthma from other conditions that cause recurrent wheeze. In this age group, 70% will outgrow their wheeze. So for them, asthma treatment may not be useful, it may even be harmful.

Conventional treatment is steroid-based medication, which has a wide range of side effects including growth impairment resulting in reduced adult height.

In an Australian first, researchers at PCH are collaborating with Edith Cowan University to develop a non-invasive urine test that will accurately diagnose asthma in preschool aged children. It will enable earlier asthma diagnosis and safer and more appropriate treatment for wheezing children.

"Many children suffer from asthma-like illness in the preschool period. It is often impossible for doctors to know which of these children will benefit from asthma treatment," said Professor Andre Schultz, Respiratory Physician, PCH and Project Lead.

"A diagnostic test will help doctors prescribe treatment to children who will benefit, and spare children who will not from unnecessary exposure to potentially harmful drugs."

#### Saving young hearts

A world-leading study has kicked off that aims to identify and treat large numbers of children at risk of early heart disease from an inherited condition, which goes largely undetected in the community.

Familial hypercholesterolaemia (FH) is the most common and serious cause of inherited high cholesterol. If undetected and untreated, it leads to premature coronary artery disease and a significant risk of premature death.

In WA, an estimated 10,000 people – including 2,000 children under 16 years of age – have FH, but most are unaware, putting them at risk.

Individuals with FH who are diagnosed and treated from a young age can expect to have a normal life expectancy, emphasising the importance of early detection.

"Our dream for FH is that every child and adult has the opportunity to be diagnosed. Because once they're diagnosed, the actual management is quite straightforward. You can really change the natural history of heart disease in families with FH by protecting all individuals," said Dr Andrew Martin, who is leading the research.

**Approximately one in 250 children will be born with very high levels of low-density lipoprotein (LDL) or 'bad' cholesterol, putting them at a significantly higher risk of sudden death in adult life.**

The study aims to identify at least 25% of all children with FH in WA within three years. A Nurse Practitioner-led model integrated with General Practice will be used to identify an estimated 500 children aged 16 years and under.

#### Early Moves

An Australian-first study investigating whether a baby's early movements can predict learning difficulties later in childhood has reached a major milestone.

Led by Professor Jane Valentine, Co-Head, Kids Rehab Research WA at PCH and Professor Catherine Elliott, Curtin University School of Allied Health and Director of Research at Telethon Kids Institute, Early Moves has recruited 3,000 babies into the ground-breaking program.

Early Moves aims to understand the link between very young babies' movement patterns, called 'general movements' and later development. These general movements are over 90% accurate in detecting motor problems in babies such as cerebral palsy, but they may also predict other developmental disorders including cognitive impairment and autism spectrum disorder.

"We know that the first 1,000 days of life is a critical time of neuroplasticity in a baby's brain. Identifying delays at this early stage allows the opportunity for intervention at a time when a baby is most able to benefit," said Professor Elliott.

Early Moves is following the WA infants and tracking their development in the first two years of life in one of the biggest and longest-running studies of its kind.

As part of the study, parents capture their baby's early movements via a secure app, where specialist clinicians will review and conduct formal assessments (including early screening for cerebral palsy risk) to identify movement abnormalities.

At the age of two, parents will receive another assessment that will look at their child's cognitive, language and motor development.

"We are so pleased to have been able to achieve this milestone and offer this opportunity to West Australian families. We now have a rich data set from which to answer this very important research question, relating to early identification of cognitive development," said Professor Valentine.

# Funding the future.

**Fellowships at PCH are developing the next generation of medical professionals, ensuring we maintain the highest quality care for sick children in WA.**

Funded by the Foundation, our fellowship programs are leading the way in cultivating future leaders in medicine through clinical practice and research opportunities. The programs are integral to attracting and retaining local doctors and top-tier professionals from interstate and overseas. They are also driving ongoing advancements in paediatric healthcare in WA.

## Paediatric Radiology Fellowship

PCH's Medical Imaging Department has grown into one of the world's best. It is highly commended by the accrediting body and promoted as the benchmark in quality to other Australian and New Zealand children's hospitals.

The program is strengthening PCH's position as a leader in the field, recruiting the next generation of radiology leaders as well as contributing to global expertise. Prior to the program, radiologists had no choice but to travel interstate and overseas to continue their education and train as Consultants.

The fellowship's reputation is now attracting interest from around the world, including the UK and USA. The newest fellow to join PCH hails from Bustamante Hospital in Jamaica. Coming from a region where healthcare is not as well-resourced as Australia, the fellow will be the Caribbean's first Consultant Interventional Radiologist once he completes his tenure.

His predecessor, Dr Jonathan Erikson, has completed his 12 month fellowship and now has the knowledge base and skills to effectively run and manage a paediatric radiology department. During his fellowship he also completed a number of research projects, two of which have been published (MRI findings on morning glory disc anomaly and the use of multiple projections of umbilical venous catheter placement in neonates) and a further three that have been submitted for publication.

## Oncology Fellowship

2023 Paediatric Oncology fellow, Dr Sarah Trinder sits on the Australia and New Zealand Children's Oncology Group (ANZCHOG) Leukaemia and Lymphoma subgroup (LLG), who meet quarterly to discuss clinical trials by way of fostering collaboration.

In the past year she has continued her involvement in a number of projects that have since gained momentum including:

- A successful grant application for a study to identify immune targets for childhood cancer patients that may lead to less toxic therapy options
- COCO-KIDS pilot trial, which is now in recruitment phase and will assess whether coconut oil mouthwash can be used to prevent oral mucositis in childhood cancer patients
- Zero Childhood Cancer Project (led by Sydney Children's Hospital). Sarah was successful in securing the Zero Precision Medicine Fellow Sydney Children's Hospital for 2024. During this fellowship she will broaden her experience in Molecular Oncology

Taking over from Dr Sarah is Dr Matthew Paladino, who will coordinate patient samples and curate the sample data from PCH for the Zero program.

## Simulation Suite Fellowship

Now in its third year, the Simulation Fellowship aims to improve the quality and safety of care for sick children in WA through simulation education.

The fellow has successfully designed and facilitated immersive scenarios to meet the learning needs of different multidisciplinary teams, including medical and nursing staff in general paediatrics, paediatric intensive care, emergency medicine and post anaesthetic care.



The simulation suite is a state-of-the-art suite that reflects global best practice. In 2023, 687 health care professionals attended a simulation session or course run by PCH, which across the board has received an overwhelmingly positive response.

The fellow was instrumental in reviewing the existing library of paediatric simulation scenarios with the simulation team. They identified 16 key scenarios, which have now been improved and refined.

In addition, the fellow, together with simulation nurse educators, developed a new two-hour education session for new psychiatry registrars. The psychiatry registrars are often adult trainees with limited paediatric medical experience, however they may be required to act as a first responder in a medical emergency. The session has been designed to increase their understanding of hospital emergency procedures and escalation processes, as well as improve their confidence in delivering basic hospital paediatric life support as first responders.

## Clinical Research Education Fellowship

Research plays a crucial role in transforming paediatric healthcare. The Clinical Research Education Fellowship – the first of its kind in Australia – integrates research into clinical

practice to deliver world-leading paediatric healthcare in WA. It aims to instil a culture of research amongst healthcare personnel so that evidence based medicine is applied on a daily basis.

In 2023, the fellow was a member of the organising committee for the 2023 Child Health Symposium and developed four new workshops based on interest from researchers:

- Setting up Clinical Trials
- Manuscript Writing
- Oral Presentation of Research Skills
- Navigating Research Ethics and Governance in WA

Their active involvement in delivering seminars and workshops significantly enhanced the fellow's oral presentation skills.

The fellowship's success has expanded the reach of its resources beyond the Child and Adolescent Health Service, including healthcare personnel from all WA Health Service Providers, WA Country Health Service, Universities and Research Institutes.

# Healing holistically through positive patient experiences.



**Hospitals can be scary and upsetting places, but by funding positive patient experiences we're helping reduce anxiety and the challenges of visits, improving the health and well-being of kids and their families.**

Through the generosity of our donors, our dream of improving the hospital experience has become a reality for many sick kids and their families.

## Music Therapy becomes permanent

Over the past 10 years, the healing power of music has played a key role in speeding up the recovery of hundreds of children undergoing neurology and spinal rehabilitation at PCH.

When Archie was diagnosed with a rare brain tumour and had surgery at 11 years of age, he went from being an active, soccer-loving tween to being bedbound at PCH for months on end, unable to walk or talk. Archie was scared and frightened, and anxious about what lay ahead.

Music had always been a big part of his young life, so when music therapy was introduced during rehabilitation, it became central to his healing.

"All you want is to hear your child's voice again and with music therapy he started finding words when we hadn't heard him speak for two months," said mum Fay who,

along with Archie's whole family, was involved in music therapy sessions that often included the playing and singing of music favourites such as Vance Joy's hit Riptide.

Music therapy is much more than just the playing of nice songs. This evidence-based therapy offers a holistic approach to recovery, leading to physical, functional and social and emotional improvements.

"It makes me feel very relaxed and calm, it controls my emotions and is very helpful," said Archie, who wrote his own song as part of the therapy, which he continues to receive as an outpatient after leaving hospital.

Exposure to music has the potential to induce brain plasticity, the ability to change the structure and function of the brain. This makes it a powerful tool for patient rehabilitation, assisting with a variety of upper and lower limb physical skills and improving cognition, behaviour and communication, including speech and language, and social and mental wellbeing.

PCH Music Therapist, Karen Twyford, says it works because music is something we can all relate to.

"It's familiar and connects us with people and can make us feel happy, calm, excited or motivated," Karen said.

"We can shape the different musical elements like pitch, tempo or dynamics depending on how we want the brain to respond."

Professor Jane Valentine says music therapy is a powerful and important tool in the Kids Rehab WA clinical program.

"It really does help drive the recovery program for the child and the family, in that very difficult period of early recovery, and then later on when the children are able to interact and learn," Professor Valentine said.

"Music therapy offers a vibrant and challenging way to learn, which we know integrates neuroplasticity and speeds up the recovery program."

Music therapists work alongside clinicians to develop therapeutic programs tailored to the patient's condition and musical interests. Depending on the stage of recovery, this may consist of patients simply listening to music played or sung by the therapist. In later stages, children can interact and learn through playing various instruments, music games, song writing and analysis.

For parents and families, music therapy offers a way to interact and engage with their child and also cope with the difficulty of having a sick child in hospital.

Perth Children's Hospital Foundation has supported music therapy for children with brain injuries and spinal and neurological conditions since 2013. Since 2019 alone, more than 200 infants, children and young people and their families have experienced music therapy's mind and body benefits.

PCHF CEO Carrick Robinson said: "We're incredibly proud to have helped so many children on their road to recovery through this evidence-based therapy and are grateful to the numerous supporters of the Foundation who have helped make his happen over the past 10 years."

Recognising the remarkable impact of the Foundation-funded program, the government's Child and Adolescent Health Service (CAHS) has taken over ongoing funding at PCH. The powerful healing benefits of music therapy will now be available permanently for children with brain injuries, spinal and neurological conditions.

Music therapy services are also available for infants/children and adolescents referred to PCH Oncology and Haematology.

## Taking the sting out of procedures

Having a needle is one of the most distressing and painful experience kids go through and some are left so traumatised, that their on-going healthcare can be compromised as they become too frightened to even enter hospital.

For doctors on the giving end, it can be stressful and heartbreaking to watch a child suffer.

To the rescue come Buzzy Bees, small vibrating devices with ice-pack wings that help dull the body's ability to feel pain through the combination of vibration and cold temperatures. These colourful devices engage children so that they remain calm and relaxed, allowing procedures to run smoothly.

Buzzy Bees can support children through any painful procedure such as IV line insertions, immunisations and the insertion of Continuous Glucose Monitoring devices for diabetes.

"Painful experiences in hospital as a child can have lifelong consequences," said Dr Andrew Martin, Head of Department and Consultant, General Paediatrics PCH.

"Most PCH patients will need an IVC inserted and many will endure multiple attempts. With the right equipment we can do this better."

## Keeping Kids in No Distress (KKIND)

Nobody wants to see a child in distress while visiting hospital.

KKIND is a PCH service helping kids cope with the trauma, anxiety and distress caused by illness, injury or hospitalisation.

Foundation funding of a KKIND Occupational Therapist and resources are helping bring comfort to sick kids and their families. Funding has supported the implementation of resources for families to support their child and the upskilling of clinical staff to improve patient experiences.

For burns patient, Ruby, the service helped make hospital visits less traumatic.

"She'd have massive anxiety before we would go near the hospital on surgery days, but when KKIND was brought in they helped manage Ruby's fears," said her mum, Asha.



THANK YOU  
**Our amazing community.**



**"As Vietnamese war refugees, we feel a moral obligation to give back to the Australian community who helped us during our time of need.**

Angie Nguyen,  
 Vietnamese Generous Hearts WA Inc.



**Every year our incredible community pulls out all the stops to fundraise for WA's sick kids. We couldn't do what we do without your efforts and say thank you to everyone who has supported us over the past year.**

One of the most touching and generous fundraisers was by Vietnamese Generous Hearts WA Inc.

This group of compassionate former Vietnamese refugees raised an incredible \$505,231 for PCHF's diabetes program, providing much-needed equipment and technology to help WA kids with diabetes live safer, more normal lives.

The community fundraising organisation is led by Angie Nguyen and Yen Ly who were inspired to give back to the country that gave them a safe, new life after fleeing

Vietnam with little more than the clothes on their back in the 70s.

Now a self-employed finance consultant, Angie left Vietnam in 1979 at the age of 15. With nothing but a small aluminium tin of candied lemon slices and an army water bottle, Angie and her sister set out in search of freedom. Leaving Vietnam in the dark of the night, Angie feared being captured and imprisoned, so the sisters could not even say goodbye to their closest family and friends.

"After the fall of South Vietnam, a lot of people risked their lives for freedom," Angie said.

"Many died at sea, but some of us were fortunate enough to be rescued and resettled in countries such as Australia, America, and Europe.

The sisters arrived in Australia with nothing. They had no money and couldn't speak English.

"The Australian people and Government opened their arms and hearts to welcome us which gave us the opportunity to thrive and to give our children a better future.

"We really connected with raising funds for PCHF because children are the future of this state. With diabetes there is no cure, and it can be a hard condition to control. Anything we can do to make it easier on the kids and parents would be incredible."

PCHF CEO Carrick Robinson said: "Managing diabetes can be painful, time consuming, and highly stressful for children and their families.

"New technologies such as Continuous Glucose Monitoring (CGM) devices, insulin pumps, and Hybrid Closed Loop (HCL) insulin pump therapy systems are proving to be a game-changer, but these can be expensive, and for many families are out of reach.

"Thanks to the incredible generosity of Perth's Vietnamese community, we are able to provide new technology free-of-charge so that WA families who need it most can best manage their child's diabetes, regardless of their financial circumstance."





# Thank you.

Over the past year, an amazing \$7.19 million has been donated to PCH to help WA's sick kids get well and stay well. Thank you to all of our donors.

## Principal Partners

BIG W  
Euroz Hartleys Foundation  
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## Major Corporate Partners

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## Major Community Events and Supporters

Driven Project  
Euroz Hartleys Port to Pub - Ceinwen Roberts  
General Transport Equipment  
Hakim's Promise to Help Sick Kids - Hakim Mousavi  
HBF Run for a Reason  
Lions Club - District 201 W2  
Lions Club of Dunsborough  
Little Folk Inc  
Livestock & Rural Transport Association of WA  
Market West Annual Cherry Auction  
North Perth Bowling Club  
PCH Tennis Classic  
PCHF Gift Stall - Janet and John Reynolds  
PCHF Gift Stall - Nancy Chiam  
Perth Firefighters Calendar  
Putt4Dough Annual Golf Day - WAITTA  
Rock Paper Scissors  
Snowflake Ball - Kind Hearted Australia  
St Hilda's Year 9 Lapathon  
Vault Fitness Charity Spin - Todd Duffridge and John Kirchner  
Vietnamese Generous Hearts WA Inc  
Zweck Fashion Gala - Klara Forrest

## Bequests and Enduring Trusts

Estate of Alexander John Ewart  
Estate of Desmond Palmer Phillips  
Estate of Elizabeth Bowie  
Estate of Eric Edward Southwell  
Estate of Margaret Rose Batty  
Estate of Neville Frederick Powell  
Estate of Terrence John Richardson  
Estate of the Late Ruth Lawrence  
Estate of Yvonne Gibbs  
June Yule Endowment  
Trust of Elizabeth Ann Bothwell  
Trust of Patrick Connolly



# Thank you.

## Sandcastles - WA's Children's Hospice

Andrew and Cate McKenzie  
Australian Government -  
Department of Health and  
Aged Care  
Barton Family Foundation  
Cancer Council WA (via a generous  
bequest from the late John Street)  
Hassell Studio  
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Tony Fini Foundation

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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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