Children's Hospital Foundation

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How your support in 2020/21

worked wonders for sick kids

Hayley, photographed with her mum Peta, was diagnosed with stage 4 liver cancer. Hayley is palliative, but is considered stable with ongoing six monthly check-ups.

Vision and Mission

Our vision is for every sick child to have the best possible health care, with access to world-class research and clinical treatment in a healing environment.

Our mission is to help save children's lives and work wonders for sick kids and their families.

On behalf of Queensland's sick kids and their families, thank you for your support. You are truly working wonders.

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Aboriginal and Torres Strait Islander readers are advised that this publication contains images of deceased persons.

Born with multiple joint deformities, five-year-old Patrick has undergone ongoing plaster casting of his torso and legs and faced multiple surgeries since birth.

In 2021, his upper body torso plaster was removed and replaced with halo gravity traction. This was a big moment for Patrick as he could experience a bath and go swimming for the first time since he was six-months-old.

The family temporarily relocated to Brisbane last year from the Northern Territory to aid Patrick's treatment at the Queensland Children's Hospital.

"We are so grateful for the Foundation's services and resources provided to our young child and family during years of hospital stays. They have greatly enhanced the quality and experiences we have had being away from our interstate home." Patrick Snr, Patrick's dad.



Thank you

A heartfelt thank you to all of our dedicated and generous supporters who have continued to support us over the past year, when times have been tougher than ever. Whether you have made a single donation, a regular monthly gift, hosted or attended a fundraising event, taken part in a challenge, left a gift for Queensland kids in your Will, donated gifts-in-kind, supported us through a corporate partnership, volunteered your skills or time, or simply spread the word about the work we are doing, thank you.

No matter how big or small, every little thing you do works wonders for sick kids, enabling us to invest in life-saving research, purchase state-of-the-art medical equipment to support Queensland Children's Hospital's expert staff, and to deliver support and entertainment services to patients and their families.

Thank you to Professor Ian Frazer AO, who has again this year chaired and guided our Research Advisory Committee. Through this committee, we ensure donor funds are directed to the highest quality paediatric research in the areas of greatest need.

To the team at Children's Health Queensland, you have done an incredible job of treating and supporting Queensland's sickest kids and their families during a busy and difficult year, at risk to your personal health. Our gratitude for the work you do for Queensland's kids and their families cannot be overstated.

Karen Prentis

Board Chair

Your support in numbers

We simply could not do what we do without the incredible generosity of the community and our partners. Every dollar donated is helping us invest in the futures of sick kids.

Over\$1.18 millioninvested

into the Children's Brain Cancer Centre, thanks to The Lott, the Federal Government and many generous individuals

1,043 people

pounded the pavement in our second annual 42k Your Way fundraising event

\$17 million in donations

received from our valued corporate partners, donors and the wider community



\$11.1 million raised

during the 2020 Nine Telethon

▲ **1 excavator** auctioned off

by Pickles Industrial for medical research



\$\$ \$26,000 raised

for brain cancer research at Hero Day for Slater a collaborative event hosted by Slater's family and his school, Musgrave Hill State School



Your impact in numbers

Because of you, we were able to invest \$12.9 million into our patient and family services, equipment and clinical support and research.

Over 200 Indigenous welcome packs

handed out to Aboriginal and Torres Strait Islander families to support them through their hospital journey



supported through the Children's Health Queensland Bereavement Coordinator role, funded in partnership with Scarlett May Foundation



provided by our Steggles Cuddle Carers

△ 85 researchers

received funding grants to improve health outcomes for sick kids

i 363 patients and siblings

took part in Juiced TV - some more than once



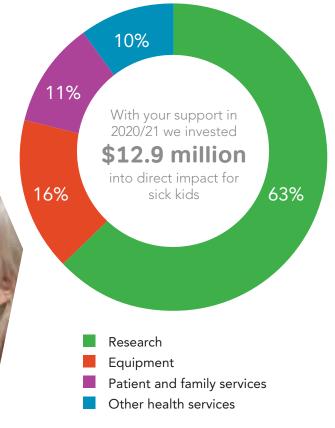
* 143 sick kids and their families

attended the inaugural Kids Ball at Queensland Cricketer's Club as part of the 2020 Nine Telethon

1 state-of-the-art digital PET-CT scanner

purchased for the Queensland Children's Hospital, in partnership with the Queensland Government and the generous Gift in Will of Geoffrey Carrick

What we are investing in together



We also make multi-year investments into children's health. This includes our larger research programs, such as:

\$5 million

for the Children's Brain Cancer Centre

\$5 million

for the Woolworths Centre for Childhood Nutrition Research

\$2.5 million

for the Queensland Cystic Fibrosis Research Program

Tommy, Esther and Rosie were all born with albinism, and Esther was diagnosed with cancer at four-years-old. Esther collected Bravery Beads, and the family were supported during their long stays at Queensland Children's Hospital.

How we leverage your support

The Foundation puts collaboration at the heart of everything we do. To achieve positive health outcomes for sick kids and demonstrably reduce the burden of disease on Australian children, we have continued to develop and grow key research and clinical collaborations. These collaborations between Queensland's top medical minds allow us to ensure every dollar donated has the greatest impact possible.

The Queensland community should be proud of their commitment to funding these research solutions to unlock answers for our community's sickest kids. Progress is made in partnership with the Federal and State governments, Children's Health Queensland, corporate partners, individuals, Universities, Medical Research Institutes and domestic and international Trusts and Foundations.

One of our most significant current collaborations includes the Children's Brain Cancer Centre, where we have been able to double our initial investment commitment from \$5 million to \$10 million over five years with your support. We also collaborate with a variety stakeholders to invest into state-of-theart medical equipment, and support global studies in care for young people with childhood cancers through the Queensland Children's Tumour Bank. We are proud to fund a globally recognised cystic fibrosis research program, and our comprehensive collaboration with Woolworths are just a few examples of our multi-partner collaborations.

These collaborations allow us to leverage your donations many times over to achieve the best possible outcomes for kids.

It is also thanks to our corporate partners that we are able to leverage your donations to their maximum benefit, evidenced by our Tax Appeal, when The Lott matched donations for the first \$500,000 raised during the month of June.

For every dollar we have raised in FY20/21, almost \$13 has subsequently been invested into research projects, medical equipment and family and patient support services by our collaborating partners.

Eden was diagnosed with severe congenital protein C deficiency when she was just nine days old – an extremely rare genetic disorder that causes her blood to clot for no reason. It is a lifelong condition, and the only known case in Australia.

"The team at the Children's Hospital Foundation are the most kind and compassionate group of people. They help make a daunting time a little easier and I'd like to thank them all from the bottom of my heart for everything they have done to support us." Nicole, Eden's mum.

Your impact



GOAL: Improve children's health by funding research and improvements to clinical care that lead to faster diagnoses, better treatments and ultimately cures for some of the most devastating childhood illnesses and injuries.

\$8.2 million went into funding research

during FY2021.

We are proud to fund world-class paediatric research through a variety of annual grant rounds, overseen by our expert Research Advisory Committee chaired by Professor Ian Frazer AO. This committee ensures our commitment to accountability and transparency when awarding funds to researchers and projects.

Following initial seed funding from the Foundation, four Queensland paediatric researchers were able to leverage this funding to garner interest and further funding of \$13.1 million from large national and international funding agencies, including the National Health and Medical Research Council, the Medical Research Future Fund and the US Department of Defense.

Photo

Some of the Children's Brain Cancer Centre research team at the University of Queensland TRI Lab, co-directed by Professor Brandon Wainwright (middle).



Changing outcomes for kids and young people with brain cancer

Despite advances in other types of childhood cancer, survival rates for brain cancer have made little progress over the past 30 years.

A team of four directors – Professor Brandon Wainwright, Dr Tim Hassall, Professor Bryan Day and Professor Greig de Zubicaray – guide the centre, which involves collaborators from QIMR Berghofer Medical Research Institute, Queensland University of Technology – Institute of Health and Biomedical Innovation, The University of Queensland's Institute of Molecular Bioscience, The Diamantina Institute and Queensland Brain Institute, and the clinical infrastructure and specialists of Children's Health Queensland Hospital and Health Service.

This year, the Children's Brain Cancer Centre (CBCC) saw the implementation of the liquid biopsy program, which has developed a liquid biopsy approach to monitor the response of brain tumours to treatment and the emergence of resistance at the genomic level, led by CBCC Codirector Professor Brandon Wainwright.

CBCC researchers discovered the spinal fluid collected in routine lumbar punctures can be used to create a 'genomic fingerprint' of a child's cancer. The 'fingerprint' can then be used to create individually tailored treatments. Those same fluid samples also tell when a child's tumour starts to change, which means the treatment plan can respond in real time. Thanks to your support and the support of our corporate partner The Lott, this revolutionary approach to genetically tailored treatments could become standard for kids in Australia by 2023. Just this year, the Children's Hospital Foundation lost one of our treasured CBCC ambassadors, Slater, at six-years-old. Slater has been an ambassador for the Centre since its inception, and his bravery, resilience and cheeky personality will live on through the research being conducted there. Slater and his mother, Bianca, have made an immeasurable contribution to our cause and towards the fight against paediatric brain cancer. We cannot overstate our gratitude to them both. Slater is very sorely missed and leaves a significant legacy in enabling vital research into children's brain cancers.



Photo Slater, with his mum, Bianca.

"Inever even knew brain cancer is the most common cause of death to kids out of any disease."

Ava's story

After months of visiting the Emergency Department with worrying symptoms, doctors ordered a full MRI of three-year-old Ava's brain and spine. The MRI revealed that Ava had a brain tumour the size of an orange wrapped around her brain stem.

Ava was put under a general anaesthetic to have a full brain and spine MRI, and her mum, Amanda, recalls the moment she woke up.

"We were escorted back to the ward where about four medical staff were waiting. I was asked if I wanted to have the conversation in front of Ava, and my whole world crumbled in that moment."

Ava was diagnosed with a high-grade aggressive ependymoma brain tumour. Ava underwent a major operation after her diagnosis with Queensland Children's Hospital surgeons removing most of her tumour. Her recovery involved learning to walk, talk and eat all over again.

Her surgery was followed by seven rounds of chemotherapy, but her tumour continued to grow despite the treatment. She underwent further surgery and radiation, sadly to no avail. Her tumour still continued to grow.

In another attempt to control the cancer spread, Ava underwent another seven-hour surgery. However, the tumour was unable to be fully removed as it is too close to vital vessels and nerves. If surgeons had removed it entirely, she would have had a stroke or died. This means that Ava's tumour is now deemed inoperable. "I was looking for some kind of reason that she was diagnosed with this disease, but there wasn't one. It was just something that happens to more kids than I ever knew. I never even knew brain cancer is the most common cause of death to kids out of any disease." Amanda recalls.

"Looking back on the time of her diagnosis now seems like such a daze. The Children's Hospital Foundation were a godsend. The volunteers were helping us with the basics like navigating the hospital or providing me comfort as I escorted Ava into theatre not knowing if she would come out alive or changed forever. Ava's favourite thing before surgery was a visit from Dexter or Nanook, the therapy dogs. How wonderful that was at a very dark time for all of us."

"Kids are the future of our world and if this disease is impacting them so badly, at such a young age, shouldn't we be doing everything we can to find a cure? All I know is I would do anything to save my daughter and the other kids I have met throughout this journey and spare all the families the pain and suffering we are experiencing."



Giving regional Indigenous Australian kids care closer to home

Remote Indigenous Australian children have a higher incidence rate of bronchiolitis than non-Indigenous Australians.



Nasal high flow therapy provides support for children with respiratory conditions and can avoid an escalation of care during hospitalisation. While the safety of nasal high flow therapy has been studied in metropolitan and regional hospitals, there has until now been limited data on safe use in remote settings.

With your support and the support of our corporate partner The Lott, we have invested in a study, led by Sally West (James Cook University's Centre for Rural and Remote Health) in Cooktown, Weipa and Thursday Island, implementing nasal high flow therapy in remote areas with the same scientific scrutiny as previous settings.

This will allow infants with bronchiolitis presenting to remote emergency health-care settings access to high flow care. These same children would previously have been disadvantaged by the non-provision of nasal high flow care and required to be transported to a tertiary facility in a metropolitan area. Subsequently, this will also lessen the incidence rate of these retrievals which can have a resounding impact on Indigenous patients and their families being treated far from their communities and Country. This project is in partnership with Torres and Cape Hospital and Health Service.



Photo Sally West

Healthy lives for all Aussie kids through better food and nutrition

Our \$5 million investment into the Woolworths Centre for Childhood Nutrition Research in partnership with long-standing partner Woolworths, aims to provide evidence-based research to develop new knowledge and interventions to enable Queensland children to live healthier lives. Poor diet impacts children's physical, mental and social health. Thanks to Woolworths funding and the support of the Queensland community, this Centre is building a world-class research program investigating the biological, clinical, social and public health factors related to improving childhood nutrition. The Centre focuses on all children but pays particular attention to those living with disadvantage who tend to suffer disproportionately from health and nutrition-related issues.

The Centre brings together researchers in public health nutrition, immunology, and gastroenterology to develop new knowledge in partnership with the broader community. The research program is currently working to understand the impact of diet on the role of bacteria that live in the gut, and their impact on brain development, allergies and mental health. Through working with families, communities, and schools, the research is improving food literacy and the feeding of children, especially for those doing it tough.

The Centre is guided under the Directorship of Professor Danielle Gallegos from Queensland University of Technology.



Burns research to have international impact

Thanks to your support, Queensland Children's Hospital Burns and Trauma Researcher and Griffith University Senior Research Fellow, Bronwyn Griffin, was awarded a Mary McConnel Career Boost grant of \$50,000 for her research focussed on decreasing the incidence, severity and burden of trauma and burns.

Thanks to this early funding, Dr Griffin has gone on to receive an additional \$2 million funding from the US Department of Defense (DoD) to implement her evidence-based research on burns first-aid in the pre-hospital field of care in the US.

"Thanks to the Children's Hospital Foundation supporters, for helping make possible some of the critical foundational work to help boost the level of our globally recognised research that has led to this exciting outcome," Dr Griffin said.

"Implementation of adequate burns firstaid means that children will have better outcomes in their burn care journey such as faster healing time, less risk of skin grafting, meaning a less likelihood of long-term scars and a lifetime of painful surgical treatments."

The quality of Dr Griffin's work has allowed her to partner with world class paediatric clinician researchers in the US, who will be critical allies in translating the evidence into guidelines and implementation into practice.

Her Mary McConnel Career Boost grant assisted Dr Griffin by investing in specialised research expertise to optimise the outcomes of her research, and allowed her to evaluate, publish and present the effectiveness of cool running water for 20 minutes in paediatric burns, boosting her national and international research profile.

As part of Dr Griffin's grant, she was also offered invaluable mentorship from Sharon Mickan – a highly respected Australian researcher and Professor of Healthcare Innovations at Bond University. "Without my Mary McConnel grant and mentorship, this additional funding boost simply would not have been possible, and I am looking forward to meeting up with Sharon to celebrate this success together."

The DoD is a globally competitive research funding body, with the value of the grant providing immeasurable hope for sick kids across the globe who experience burns injuries.

Thanks to your support, another four outstanding Queensland women were awarded almost \$200,000 to help work wonders in the field of paediatric research in FY20/21. The Mary McConnel grant program, which first launched on International Women's Day in 2018, aims to support women researchers to increase delivery and dissemination of research, thereby boosting the researcher's track record and competitiveness for future funding. The recipients all received \$50,000 funding to overcome barriers to career progression and receive one-on-one mentoring support from a leading research professional.

We are sincerely grateful to the Federal Government for their ongoing commitment and support of female researchers through this program.

Six-year-old Charlie is one of the hundreds of children treated for burns at the Queensland Children's Hospital each year. He sustained primarily full thickness burns to 38 percent of his body after accidentally pulling a deep fryer off the kitchen bench in 2015.

Charlie underwent 11 operations and will need ongoing treatments for many years to come to manage his scarring as he grows. Grace was diagnosed with leukaemia in August 2018 after her parents noticed she was lethargic and had recurrent temperatures. After a few weeks of testing with no answers, her parents made the decision to take her to Queensland Children's Hospital as her condition was worsening. It was here that she was diagnosed with acute lymphoblastic leukaemia.

During two years of treatment, she underwent lumbar punctures, bone marrow aspirations, and intravenous chemotherapy, as well as daily oral chemotherapy at home. As a result of her treatment, she developed severe neuropathy and stopped walking for a period of time. With hard work and the assistance of the physiotherapy department, she started to walk again after a few months. Happily, her leukaemia has been in remission since this time.

Her treatment was officially completed in November 2020, but she will receive ongoing blood tests and follow up appointments over many years to monitor for possible cancer recurrence, or lasting effects of her treatment. When kids like Grace feel sick, scared and exhausted from their cancer treatments, it is your support that has helped them by funding integral research like Professor Radford's.

Alleviating the effects of chemotherapy in children with leukaemia

Sixty kids in Queensland are diagnosed with leukaemia every year.

Treatment is intensive and is associated with extended hospital stays and chronic side effects. You are helping researchers understand why some leukaemia cells survive chemotherapy and helping them to find ways to make those cells weaker, as well as understanding why chemotherapy can harm healthy cells too.

Associate Professor Kristen Radford's team is looking to alleviate the negative effects that chemotherapy has on children with leukaemia through her latest research project.

Her team of researchers have discovered a factor called E-selectin that gives leukaemia cells a helping hand to survive chemotherapy and are working to find the best way to block it. Blocking E-selectin has also been proven to alleviate sideeffects for patients. This research could lessen chemotherapy side-effects in children, enabling them to get better and go home sooner.



Equipment

GOAL: Improve children's health by funding critical, life-saving equipment right across Queensland and northern New South Wales, allowing doctors to achieve better outcomes for sick and injured kids.

\$3.3 million

funded hospital equipment and non-clinical services, of which **\$427,330** supported vital equipment for 20 regional hospitals during FY20/21.





Digital PET-CT funded for Queensland Children's Hospital in Australian-first

Together with the Queensland Government, we co-funded a state-of-the-art \$5 million digital Positron Emission Tomography – Computed Tomography (PET-CT) scanner at the Queensland Children's Hospital - a first for an Australian paediatric hospital.

The digital PET-CT scanner provides high quality images of how tissues and organs are functioning, and is commonly used to diagnose cancers, neurological and endocrinological conditions, and inflammatory and infectious diseases.

Thanks to the provision of this dedicated digital PET-CT equipment, Queensland Children's Hospital patients will no longer be required to travel to the Royal Brisbane and Women's Hospital to receive vital scans during their difficult health journeys. To receive these scans, a child has to be transported by ambulance, if they are well enough to travel, to Herston and back to South Brisbane. Having this scanner on-site at the Queensland Children's Hospital will make this process much less distressing while saving money and time spent travelling across Brisbane. This will greatly improve the experience for both the patients, as well as the clinicians caring for them.

This new digital technology will have an impact on hundreds of Queensland's sickest kids for many years to come, through the ability to achieve earlier diagnoses. Through delivering faster scan times, there is potential for reduced radiation exposure for young patients going through treatment. Faster scan times also means a shorter procedure, reducing the risks associated with long periods under anaesthetic.

The service has been operational in Queensland Children's Hospital since November 2021. This funding was only made possible through the generosity of the late Geoffrey Carrick, who kindly left us a substantial gift in his will to ensure sick Queensland kids have the best chance of living full and healthy lives. We are delighted that the room housing the scanner is complete with distraction artwork reflecting Geoffrey's property in Far North Queensland as a calming environment for the thousands of children this will benefit.



Three-year-old Liam from Ballina was diagnosed with leukaemia on Mother's Day 2021. His family were advised they'd be staying in Brisbane for treatment at Queensland Children's Hospital for six months, despite having only packed to stay for one week.

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Children's

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SIEMENS

Liam finished his leukaemia treatment in November 2021, and while he will need to return to hospital for regular check-ups and tests, his family returned home for Christmas to reunite with their family.

The new digital PET-CT scanner will provide easier and faster scans for paediatric oncology patients, just like Liam.

"I have some big scars on me, but I'm proud of them. They're a constant reminder of what I have been through, and the amazing people who have helped me."

Asha's story

Asha began treatment for Ewing sarcoma – a rare type of bone and soft tissue cancer – on her 16th birthday.

As a teenage girl, Asha underwent ovarian stimulation and had some of her eggs collected and frozen in the weeks before her first round of chemotherapy to protect her fertility – a journey very few kids her age could imagine.

Amid the frequent hospital admissions and doctors' appointments that she went through over the course of her ongoing cancer journey, Asha managed to remain clear-headed and a pillar of strength.

"I've always just thought that the doctors are going to do everything they can to get me better, and never let the thoughts of what cancer can result in slip into my mind," Asha said.

In March 2020, Asha became the first cancer patient in the world to undergo a revolutionary and lifesaving operation using an implant to encourage her own tibia (where her cancer was growing) to regenerate. Performed by doctors at Queensland Children's Hospital in a nine-hour operation, the aim of the surgery is that Asha's own bone will regenerate enough to replace the implant as it slowly dissolves inside the body.

"I have some big scars on me, but I'm proud of them. They're a constant reminder of what I have been through, and the amazing people who have helped me."

As part of her journey, Asha would regularly require scans which would require travel to and from the Royal Brisbane and Women's Hospital (RBWH).



Asha is now 18 and is thrilled to know that the digital PET-CT equipment to allow kids going through a similar journey to hers will have more comfortable and convenient care at Queensland Children's Hospital. She speaks of her trips to RBWH for scans below.

"My first trip to the RBWH for a routine PET-CT scan at 15-years-old was a long and tiring event. As a Queensland Children's Hospital patient, I was accustomed to the vibrant colours and uplifting atmosphere that the hospital provides. I was not familiar with the area in RBWH, the staff, or having adult patients around me. Initially this came as quite a culture shock. I have had many MRIs in the children's hospital. All of these were very calm experiences, and the nurses, radiographers, and doctors were familiar to me, made me feel very safe and comfortable and I was allowed to have my mum present for every test.

A PET-CT scan is the longest type of scan I have had to have. There is a lot of different aspects creating pressure for the patient. For example, before each scan I feel a sense of anxiety for the results, the fear of recurrence of disease is present and the pressure to be very still during the scan while already uncomfortable from previous treatment is tough.

It was so scary for me at 15, so I can only imagine what is it like for the younger patients who must travel all the way there and be still for so long. By the end of the scan, almost the whole day has passed, leaving me so tired. Being alone in the dark room for an hour while the dye is distributed and then alone in the machine while the images are taken can be very nerve-wracking and emotionally draining.

Travelling to and from different hospitals in ambulances is arduous and exhausting on top of very long days of treatment, and it's always nicer undergoing tests and treatment when you're in a familiar environment with staff that you know and trust. This equipment is going to make a huge difference, and impact so many kids for the better."

3D Photo Lab equipment

With your support and thanks to the Queensland Government's Commemorative Grant Round, the Children's Hospital Foundation funded three-dimensional (3D) craniofacial camera equipment which is assisting surgeons at the Queensland Children's Hospital to produce better surgical outcomes for kids with abnormalities to the bones in their head or face.

Each year, this equipment plays a key role at the hospital in the treatment of around 150 children with craniofacial disorders, such as cleft lip and palate (gap in the roof of the mouth or lip), microtia (ear deformity), craniosynostosis (fusion of the skull bones), or facial trauma. \$137,500 was invested into this piece of equipment and allows surgeons to accurately pre-plan surgical procedures using detailed and realistic images to help improve surgical outcomes. The noninvasive system produces consistent high-quality 3D images within seconds, without the use of any radiation.

The speed, safety rating and quality of the images makes the equipment ideal for use in a paediatric setting and eliminates the need for a CT scan which subjects children to more radiation.

The 3D Photo Lab equipment is integral in surgeries to correct common facial abnormalities including cleft lip and palate. Cleft lip and palate affect about one in every 800 children born in Australia. Around 100 children receive surgery for the condition at the Queensland Children's Hospital every year.

MacKenzie's story

10-year-old MacKenzie was born in 2011 with a condition called microtia and atresia. She had a tiny left ear, and after failing two routine hearing tests, she was referred to specialists at just 16 weeks of age. These specialists revealed to her parents, Lana and Alex, that MacKenzie had no ear canal.

Microtia means "small ear" and occurs in about one in every 10,000 children. Microtia means that the external ear is incomplete or underdeveloped. Microtia can range from a slightly smaller ear to complete absence of the ear. It may affect only one ear (unilateral), like MacKenzie, or it can affect both ears (bilateral). Atresia is absence or underdevelopment of the ear canal and also commonly affects the tiny hearing bones in the middle ear. MacKenzie underwent a CT scan at around three years of age which allowed doctors to assess the structure of her middle ear. She underwent surgeries and was fitted with hearing aids to assist her quality of life until she was old enough to have reconstructive surgery.

In 2019, Queensland Children's Hospital Plastic and Reconstructive Surgeon and Chief of Surgery, Dr Stuart Bade, discussed options for a reconstruction of then eight-year-old MacKenzie's ear. This would entail him building a new ear from rib cartilage using the 3D photography suite to create a comprehensive surgical plan. Using photos taken of MacKenzie before the operation, Dr Bade used data from that image to create a mirror image of her ear before printing a 3D copy of the image. He then was able to have this 3D model in front of him as he worked during the procedure, ensuring he was carving the cartilage as accurately as possible.

The 11-hour surgery successfully took place in August 2020, and MacKenzie now has a brandnew ear which has provided her with a new confidence to take on life. She loves music, singing and drama and has a dream to become the next Taylor Swift. Or, she'd love to become a doctor like Dr Bade and help people just like he helped her.





Helping children with brain injuries

Thanks to you, we are proud to fund a high density (HD) electroencephalography (EEG) machine at the Children's Centre for Health Research. This piece of equipment is central to a research study monitoring brain waves in children affected by stroke and brain injury, led by Children's Health Queensland's Dr Michaela Waak, and University of Queensland's Professor Karen Barlow.

The machine will help determine the best rehabilitation and management strategies for their long-term recovery, while offering insight into children with a variety of brain injuries just like Rowan. It is a more child-friendly option to an MRI, particularly for those suffering from brain injury. MRIs can often be a triggering experience for these children, who often require an anaesthetic.

The EEG machine process allows paediatric patients to have a more pleasant experience and enables the patient to be awake, giving clinicians a more comprehensive understanding of their brain patterns. This provides researchers with more detailed information about the progress of a patient's recovery.

Rowan's story

After years of practice, eight-year-old Rowan fulfilled his dream of racing in a motocross event in November 2020. What began as one of the family's most memorable days quickly became their worst, when the then seven-year-old was thrown 15m through trees during practice.

He was intubated and ventilated at the scene of the accident, and quickly transferred to Queensland Children's Hospital, where he underwent emergency surgery - a right decompressive craniectomy, which is a brain surgery that removes a portion of the skull to stop a brain bleed and allow for swelling. He was then placed into an induced coma.

Doctors were unsure whether Rowan would survive or wake up from the coma and, if he did, whether he would walk or talk again. He endured a long battle to regain some of his physical strength, including multiple brain and skull surgeries. He had a stroke within the occipital lobe of his brain during his time in intensive care due to the pressure in his skull, which caused him to lose his eyesight.

He has also had multiple CT and MRI scans, further brain surgeries to clean an infection and fit a surface drain, and then to put in an External Ventricular Drain (EVD) and another to re-insert the skull plate.

Rowan is due to have another surgery later this year to fit a titanium skull plate to replace his damaged skull bone.

He currently wears a helmet to protect his skull and uses a cane to walk due to his full blindness.

Rowan's progress continues to amaze everyone who works with him as he reaches goals and milestones regularly. Rowan's long-term goal is to become an Australian Paralympian. His parents cite him as always happy and positive, often saying "fingers crossed I get my eyesight back", and always with a big smile on his face.

The HD EEG machine that you made possible allows kids like Rowan to have a more pleasant treatment experience, allowing him to be awake and giving clinicians a more comprehensive understanding of his brain patterns while his recovery progresses.

Patient and Family Support

GOAL: Support patients and their families when they are in hospital by providing a range of programs and activities that complement and enhance clinical care and provide distraction and entertainment for children and their families.

\$1.4 million

was funded into patient and family services at Queensland Children's Hospital and Children's Health Queensland facilities state-wide. Archie was diagnosed with Acute Lymphoblastic Leukaemia (ALL) in June 2020. He is now in the maintenance phase of his chemotherapy, which will take him through to the end of his treatment in August 2022. Archie has been collecting Bravery Beads during his treatment, and is a frequent visitor to Kidzone.

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SC ONCOLOGY DAY UNIT

Staff

Despite another year impacted by COVID-19, our Patient and Family Services team - based at Queensland Children's Hospital, worked tirelessly to ensure families were as supported as necessary during the waves of lockdowns across the state.

We provided families with precious memories on special occasions like Christmas, Easter, Mother's Day, Father's Day and Riverfire to name a few. To make Christmas as special as possible at Queensland Children's Hospital and in facilities state-wide, we organised COVID-safe activities such as Paediatric Intensive Care Unit baby photos, Christmas lunch for families at Somerville House, 12 Days of Christmas Craft including a letter writing activity with a virtual response from Santa, Christmas Day gifts and a visit from Santa. There were more than 140,000 positive interactions with patients and their families over the 12 month period, including:

Volunteer services

Approximately 200 volunteers

who committed 3,882 hours of support and provided over 76,713 positive interactions with patients and their families



Memory making



♀ 1,650 kidsparticipated

in a special date activations

₩ 799presents

for birthdays and difficult days provided to children in hospital

Entertainment

□ 5,641 toys and games

loaned to inpatients including digital distraction devices and Zayden's Toy Box toys





Rearly 10,000 check-ins

into Kidzone, our dedicated playroom on Level 6 in the Queensland Children's Hospital

35,143 craft packs

were provided to inpatient units and outpatient clinics



Support

Over 7,500 free meals

provided to families in the Queensland Children's Hospital in partnership with the Scarlett May Foundation

ි **12,338** families

were supported while their child was undergoing surgery



ad hoc requests and letter mail outs supported by our admin volunteers



29,638 families

were assisted by our Woolworths Wayfinders



received a ward orientation from our Family Liaison Team

354 families

supported by our Ellen Barron Family Centre volunteers



"We learnt within the walls of the hospital that pain and joy can co-exist, and we hope that Zayden's Toy Box can help other families feel joy in painful times."

> ZAYDEN'S -TOYBOX ***** European

Zayden's legacy: play for all

A Queensland Children's Hospital patient and Children's Hospital Foundation ambassador left a legacy for other sick kids, thanks to an inclusive play program we founded thanks to your generous support.

Four-year-old Zayden was born with a lifelimiting ailment called GABRB2 genetic mutation – a condition known to affect only 15 children internationally. He sadly passed away in May 2021 and Zayden's Toy Box has been named in his honour – a loans library of switch adapted and sensory toys for children with vision impairment, varying mobility or cognitive abilities and sensory needs.

His condition left him with multiple disabilities including visual impairment and complete immobility. He also had a significant global developmental delay meaning he was unable to communicate using words, speaking to his family using his smile and flicking open his eyes to say yes.

As regular visitors to Queensland Children's Hospital, Zayden and his older brother Rylan would often use toys provided by our Patient and Family Support team. The family were asked to share their feedback on the existing toys and what further resources they felt would be helpful to improve inclusivity throughout our services.

Through this, Zayden and his family, including his mum Adele and brother Rylan, were instrumental in our considerable further development of the 'playability' loans library, with Adele providing invaluable feedback and suggestions. Adele says the loans library being renamed in Zayden's honour allowed his legacy to live on at his second home – Queensland Children's Hospital.

"Zayden wasn't only born with his condition, but also with a superpower – he could bring so much joy to those around him without even speaking a word," Adele said.

"It's devastating that Zayden's smile is no longer around to light up the world anymore but knowing he will continue to spread joy through Zayden's Toy Box brings us incredible happiness and comfort – as though a small part of him is still here, spreading his infectious smile.

"We learnt within the walls of the hospital that pain and joy can co-exist, and we hope that Zayden's Toy Box can help other families feel joy in painful times."



The inclusivity that Zayden's Toy Box allows is imperative to the continuation of our support for patients and families. We became aware very soon after we paused our services in Queensland Children's Hospital due to COVID-19 that some of our existing toys and games loans were not inclusive enough for kids of all abilities. Thanks to the generosity of supporters like you, we are now able to provide this much needed entertainment and distraction to benefit children of all abilities.

Throughout the development process, the Children's Health Queensland Occupational Therapy team also recommended types of switch adapted and sensory toys that would be most beneficial for patients to loan between physio sessions to help hit key treatment milestones, while also being, simply put, a lot of fun.

Music Therapy

Thanks to your support, we've funded one of Australia's largest Music Therapy programs at Queensland Children's Hospital for more than 25 years, to ensure sick Queensland kids receive the best care possible.

Your support directly enables us to fund six registered Music Therapists at the hospital, who are all professionally trained in the use of music to achieve therapeutic change for children. They are skilled in using and modifying the various elements of music (through voice, instrumental play, recorded music, and music technology) to support targeted treatment plan goals, with high levels of knowledge in childhood development and counselling techniques.

Music is something most children and young people relate to, using it naturally and instinctively. Music Therapy assists in helping children cope with pain and procedures, participate in rehabilitation or self-regulate. It offers opportunities for development, selfexpression and connection, drawing on children's strengths to build their self-esteem to manage the challenges that come with treatment in hospital. As a patient's recovery progresses, music therapy can be combined with other allied health services, including occupational therapy, speech pathology, and physiotherapy, ensuring more complex treatment goals can be reached.

Last year, the Music Therapy team worked wonders for 391 patients at Queensland Children's Hospital providing over 1,882 occasions of service.

Seanna's story

Eight-year-old Seanna's bubbly personality would never give away the struggles and tough times she has faced during her medical journey.



When she was just 11-weeks-old, Seanna had a severe anaphylactic reaction, and nothing has been the same since. Never knowing what if, or when something might cause an anaphylactic reaction has been terrifying for Seanna's parents, Crystal and Ernest. Safe foods can quickly turn unsafe without notice, reactions can present themselves in several different ways and the family have made more trips to the Emergency Department than they care to remember.

What they do remember is the support they have received because of you and in particular the music therapy service.

"Before Music Therapy, Seanna would get very distressed during medical procedures and it was so distressing for all of us. Once the Therapist arrived, she spoke to Seanna and built up a rapport, so she felt calm and at ease. They would then play instruments, sing, and interact over music which would distract Seanna from her treatment. Not only did this make the situation easier, but it also gave Seanna some positive memories to associate with the hospital," Crystal said.



A new oncology waiting room

Thanks to funding from our corporate supporters Woolworths, BIG W, New Farm Deli, and Tour de Cure, a well-known area of the Queensland Children's Hospital has recently undergone a refit to foster a more positive hospital experience for sick kids and their families.







The refurbishment of the oncology day unit's waiting room has provided patients, families and visitors with a multipurpose area to not only wait, but to learn and play in a comfortable, private and welcoming space. When families who are undergoing treatment for cancer come in for outpatient appoinments, this can often involve a lot of waiting. This newly refurbished area includes several construction changes, including two purpose built lounging areas where patients and families can find privacy, lie down and enjoy entertainment.

Complete with a state-of-the-art interactive digital play wall and 10 new artworks by senior local and Indigenous artists (chosen by the Children's Health Queensland Arts in Health Program), the pieces emphasise landscape, home, and the connection to nature and Country. Research shows that a beautiful environment, including interesting and diverse artwork, enhances the experience of patients and families as they wait for treatment.

This new waiting area allows families to feel calmer while they wait for what can often be a daunting appointment, treatment cycle or while they anxiously wait for important results. These additions have helped make the new space a place of respite and comfort for current and future patients of the 5c oncology ward and will also further improve the quality of care given to oncology patients due to the practicality and improvement of the space. Taleigha-Rose was diagnosed with leukaemia in 2020 when she was 14 years old. Her treatment is ongoing and has included chemotherapy, lumbar punctures, bone marrow aspirations, central line insertions and skin biopsies, but throughout it all Taleigha-Rose has stayed positive and determined to get through it.

Throughout her cancer journey she has been supported by the Children's Hospital Foundation. Enjoying the Bravery Beads program, Kidzone, emergency supplies, craft packs, digital loans, and much more. All of these have all been invaluable in helping her get through the tough times.

Taleigha-Rose is looking forward to being able to return home and see her dad and brother every day, and she hopes to be able to return to playing netball once her treatment has finished.

our support in 2020/21 worked wonders for sick kids

Evie's story in her parents' words

After being diagnosed with cystic fibrosis at four weeks of age, Evie has been required to be in and out of hospital for prolonged periods of time, away from her family and friends at our home in Chinchilla. Luckily, she now has Children's Hospital Foundation as her family when we are in Brisbane.

We first met the Foundation in 2019, when Evie's health deteriorated very quickly, and she was admitted into the paediatric intensive care unit at Queensland Children's Hospital.

We soon met Erin – one of the Foundation funded Music Therapists – who sang to Evie to help comfort her. I will never forget she sang to Evie 'Coming Round the Mountain', to which this day we often listen to. It was from there that Evie built a strong bond with Erin and relied on the wider Music Therapy team and Foundation team, along with all of the volunteers, to help get her through the many, many procedures that were to follow.

Isolation is something that most people are just getting used to with the recent pandemic, however for Evie, it's been such a big part of her life since she was diagnosed. She is often left isolated in hospital, unable to attend a lot of the activities due to the risk of exposing her to other infections. It is only thanks to donations that are given to the Children's Hospital Foundation that Evie, and other kids just like her, are able to enjoy these same activities in the safety of their rooms.

Everything the Foundation does helps families like ours get through the toughest times that you have ever faced, when you are unsure if you can make it through. And then the Foundation team arrive in their green shirts, and as a parent, a wave of relief washes over you – a sense of comfort, of support.

Evie was recently asked to be a 42k Your Way ambassador for the annual fundraising appeal, and to be the local Chinchilla face for the Woolworths Easter appeal. She absolutely loved helping raise funds for a charity so close to her heart, and dove in head-first. She was able to bring awareness of the charity to our Chinchilla community and her friends of what it's like being so far away from home, and her family, friends and living with a lifelimiting illness.



Mahalia has a rare disorder characterised by abnormalities of the 22nd chromosome, which has led to many health complications. Despite the incredible amount little Mahalia has been through, she remains happy, loving and upbeat.

Get in touch

Despite the extraordinarily challenging times we all find ourselves living through, because of you, the Foundation will continue to go above and beyond to make sure our sickest kids are put first.

We will adapt to the ever-changing environment to continue to support the incredible work of Children's Health Queensland within the walls of the Queensland Children's Hospital and beyond. Your support is more important than ever, because we can't do what we do without you. There are so many ways you can help us make a difference to the inspiring children and their families right across the state.

To make a donation or chat to a member of our friendly staff, please call **1300 742 554**

To find out more about the amazing work you have achieved, please scan the QR code below or visit **childrens.org.au**



Because of you...

Our sincere thanks go to the individuals and organisations who have so generously supported the Children's Hospital Foundation in 2020/21, including those who chose to give anonymously. Every single donation will work wonders for sick kids.

We could not do what we do without our incredible team of volunteers who always show up with a smile and a shoulder of support. Your gift of time makes all the difference. On behalf of the inspiring children, their families and all of us, thank you.

Lilly-Grace has a syndrome which affects her spine development, causing her legs to be 'frog shaped' and unable to straighten. As a result, she has no bowel or bladder control, and her lung capacity is only at 50 per cent. She's also undergone open heart surgery. You might recognise her from her frequent stints on Juiced TV - the show made by kids in hospital for kids in hospital.



Thank you!

Bubbly and vivacious Matilda was diagnosed with leukaemia in late 2017, just after her sixth birthday. After over two years of treatment, Matilda is now in remission and has recently marked the significant milestone of being more than two years cancer-free.

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Our Scholastic Book Bunker volunteers.

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From left to right Rosie, Diane, Gayl and Fay.

Children's Hospital Foundation

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