

Care FOR Kids

*your
impact*




Children's
Hospital
Foundation

SPRING 2021

You're working wonders for kids like Grace

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A message from Rosie

This year has really shown us what we can achieve together for sick kids. I was amazed by the response to our appeal to raise funds for kids and families fighting brain cancer.

You're helping world-class researchers on their quest to improve survival and survivorship in children and young people with brain cancer. On behalf of all kids with paediatric brain cancer, thank you.

It's always wonderful to see patients return home and continue in life, often after enduring an incredibly difficult journey. Six-year-old Grace was in a tough battle with leukaemia for over two years, so I'm excited to share an update on her journey with you.

Thanks to your support, we are proud to have introduced a Play Ability loan library to assist patients who are unable to use the mainstream toys and entertainment options. Working in consultation with families, we now provide an inclusive range of toys and entertainment suitable for a variety of learning and sensory needs.



Your incredible support continues to fund essential new equipment like the Optos ultra-widefield retinal imaging device. Using this device provides essential information for the diagnosis and management of eye disease, in children aged 6 months to 18 years.

I hope you enjoy reading this report and seeing the impact you have on sick and injured kids every day.

Thank you for working wonders for sick kids.

A handwritten signature in black ink that reads "Rosie Simpson".

Rosie Simpson

Chief Executive Officer
Children's Hospital Foundation

Great news from Grace

You may recognise six-year-old Grace from our 2020 Christmas Appeal.

Grace is a fighter and was in and out of hospital for over two years following a leukaemia diagnosis in 2018. It was a tough journey, and she had to overcome many hurdles including learning to walk again, not once but twice following complications from her gruelling treatment.

Grace finally finished treatment in November 2020 and got to ring the bell to signify her brave fight and mark the end of her treatment. This gave her and her family the best Christmas gift ever, as it meant she was able to go home and spend Christmas with her family.



Grace continues to do well and gets stronger every day, and in January this year she was extremely excited to start Prep.

Philippa, Grace's mum told us "It was so nice to be at home together for Christmas and for Grace to have finished her treatment. We had a lovely family catch up on Christmas Day and Grace loved being with her cousins. She started Prep this year and absolutely loves going to school. She has made lots of new friends and is excited to see what each day brings."

Grace will have ongoing blood tests and follow-up appointments for the next 10 years to ensure she stays well.

Your continued support will help more sick kids like Grace get better quicker and go home sooner to be with their families.

Photos

Above Grace with her sister, Hannah, enjoying the Book Bunker service at the hospital.

Left Grace during her hospital stay with her mum, Philippa.

Zayden's Toy Box - guaranteeing play for all sick kids

With your support, we have been improving the hospital experience for sick kids and their families for more than 30 years, helping them to cope during an emotional and at times uncertain journey.

Sick kids and their siblings have a wide variety of medical and support needs and this is no different when it comes to one of the most important things - play!

Many children with complex conditions are unable to access mainstream toys and games while in hospital, but with your support, we have created a Play Ability loans library. This provides much needed entertainment and distraction for children with varying abilities and needs including children with vision impairment, varying mobility or cognitive abilities and sensory needs.

This has made a huge difference in the lives of many families, but it was particularly special for four-year-old Zayden.

Zayden was diagnosed at two years old with an extremely rare condition GABRB2 Genetic Mutation, so rare that Zayden was one of only 15 children in the world known to have it.

Due to his condition, Zayden lived with multiple disabilities including visual impairment and complete immobility. He also had a significant global developmental delay and was unable to communicate using words, with his family relying on expressions to interpret his wants and needs.

As a regular visitor to Queensland Children's Hospital and Kidzone, Zayden and his older brother Rylan would often use the Play Ability toys. The family were asked to share their feedback on the existing toys and what further resources they felt would be helpful to improve inclusivity within Kidzone and throughout our services. Adele, Zayden's mum provided invaluable feedback and suggestions, playing a crucial role in the service development.



Sadly, in May this year, brave little Zayden passed away. He and his family played such a huge part in establishing and developing the Play Ability service that we wanted to recognise their contribution.

In memory of Zayden, the Play Ability library has been renamed Zayden's Toy Box.

Adele said, "The introduction of the Play Ability loans made a huge difference in Zayden's life, so thank you to everyone who supported it.

Zayden was born with a rare life-limiting condition. He was also born with a superpower; without ever speaking a word he brought so much joy to everyone around him. Zayden's smile isn't around to light up the world anymore and the pain of that is so very devastating but knowing that he will continue to spread joy to others through Zayden's Toy Box brings us incredible happiness and comfort. Like a small part of him is still here, still spreading his super infectious smile.

The Queensland Children's Hospital was a second home for Zayden, within those walls we learned that pain and joy could co-exist. We hope that Zayden's Toy Box can also help other families feel joy in painful times."

Photo

Zayden, enjoying one of the playability sensory toys.

Tuning into what kids need!

Eight-year-old Seanna has such a bubbly personality you would never know the struggles she has faced and the tough medical journey she has been on.

Seanna had a severe anaphylactic reaction when she was just 11 weeks old and after that nothing was ever the same. 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 from the Foundation and in particular the Music Therapy service.

Research shows that music helps build, or rebuild, important neurological pathways that help sick kids regain control of their language, speech, movement, and coordination. It also works wonders in easing a child's anxiety, reducing their pain during procedures and ultimately, helping to make hospital a less daunting place.

Photos

Seanna - feeling calm and enjoying Music Therapy during one of her treatments.



"Before music therapy Seanna would get very distressed during medical procedures and it was so upsetting for her, and us to see. Once the music therapist arrived, she would talk to Seanna and build up a rapport, so she was calm and at ease. They would play instruments, sing songs, and interact over music which would distract Seanna from what was happening. Not only did this make the situation easier and calmer it gave Seanna some positive memories to associate with being in hospital" said Crystal.

Thanks to your support, we've funded one of Australia's largest music therapy programs at Queensland Children's Hospital for over 25 years, to ensure sick Queensland kids receive the best care.



Intravenous passport to improve experience of sick kids

The development of an intravenous (IV) "Passport" for children with complex health conditions is revolutionising the management of IV devices in Queensland.

Adjunct Professor Amanda Ullman from Menzies Health Institute Queensland and Children's Health Queensland was supported by funding from the Children's Hospital Foundation to lead the team in the development of the Passport.

"One of the first procedures that children undergo when they are unwell is the insertion of an IV device, invasive hollow tubes that allow administration of medications and fluids into the bloodstream. For children with complex and chronic health conditions, such as cancer or cystic fibrosis, these IV devices can remain in place for years." Dr Ullman said.

"Parents and primary caregivers are the central figures in managing these long-term health conditions, including their child's IV. They have asked us for consistent resources to plan their child's IV needs, now and in the future."

To help navigate this, a team of clinicians, researchers, and app developers (Griffith University's App Factory) have partnered with parents and children to create an IV Passport. Within the app, families can document current, historical, and future IVs, as well as a link to accurate resources for problem-solving common issues they may face at home or in hospital.

The IV Passport is now being tested by children and families at the Queensland Children's Hospital, and will soon be available across Android and iOS devices.

Associate Professor Craig McBride, a paediatric surgeon at the Queensland Children's Hospital, has been a key partner in the development of the IV Passport.

"Some children have dozens of complex IVs before they reach school age. Providing a resource so both families and clinicians can accurately plan, document, and manage these vascular access devices across multiple sites and throughout the child's life has to be better for safety, as well as satisfaction." Dr McBride said.

"It shifts the balance of power and means families can be more engaged in vascular access decisions for their child."

The Foundation was incredibly proud to fund research that will have a resounding impact on so many sick kids and their families.

We are committed to helping child health researchers, just like Dr Ullman, discover new and improved ways to significantly improve children's health outcomes.

This project, and the resulting IV Passport, is a tangible example of how research outcomes can change the hospital experience for sick and injured children right across the state, helping them to get better and go home sooner.



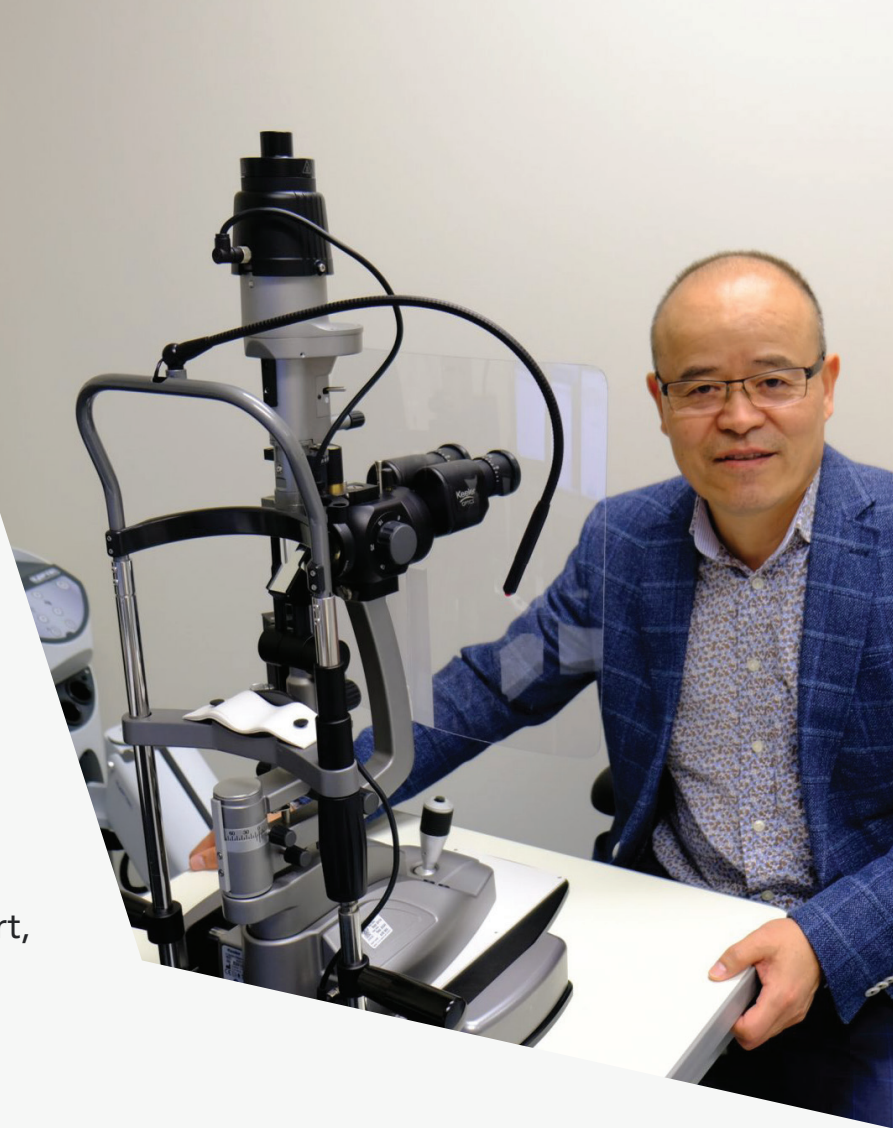
Photos
Prof Amanda Ullman

Sights set on improving eye care

Thanks to your incredible support, children aged six months to 18 years are benefitting from the Optos ultra-widefield retinal imaging device now available at Queensland Children's Hospital.

This device provides essential information for the diagnosis and management of eye disease and takes a photo of the entire retina with a single shot.

This captures retinal images that were not possible with the previous retinal camera. As well as reducing the risk of missing eye disease, and therefore preventing vision loss, this device has provided improved training opportunities for ophthalmology registrars and fellows.



Dr Shuan Dai, Queensland Children's Hospital Director of Ophthalmology said

“We are incredibly grateful for all your support which enables us to deliver the best eye care for children and their families, in Queensland and beyond. In the last year over 6,500 children have had retinal imaging which has helped immensely to diagnose and monitor their eye conditions.”

Photos

Above Dr Shuan Dai, Director of Ophthalmology at Queensland Children's Hospital.

Left Ultra-widefield retinal imaging device



Bruce's lasting legacy

Bruce has experienced firsthand the essential work of the Children's Hospital Foundation and has committed to working wonders for sick kids long into the future by leaving a gift to the Foundation in his Will.

Bruce's life story is one of extraordinary resilience and courage, after he left an abusive family situation when he was only 12 years old, seeking solace with an uncle who lived close by. He spent a day shovelling coal to rustle up some money to purchase a train ticket and hopped on the first train to Sydney.

He arrived at Kings Cross early one morning, with no plans for accommodation or food, and found himself homeless. After a few weeks, a family noticed that he was without any family or a home, and took him in.

"I will be forever grateful to this family, as they saved me from a dangerous, unknowing and distressing time where I was often hungry and sad," Bruce said.

When Bruce married at 21, he had already served in the Vietnam War, and gained an apprenticeship, having learnt the value of money at such a young age. After speaking with a friend, he decided to invest in the stock market, purchasing shares in a company which is today

known as Rio Tinto. Bruce purchased the shares for 20 cents each. Bruce went on to buy a large cattle property in New South Wales and settled down to live a happy life with his wife and son. When his wife passed in 2017, he sold the property and moved to Queensland, where his son and grandchildren reside.

Despite the years of hardship that Bruce endured during his youth, he feels that his life has been rich and varied and counts his blessings to have had a healthy family with a son, daughter-in-law and two beautiful grandchildren.

He has decided to leave a gift in his Will to the Children's Hospital Foundation as he now wishes to give back to society which has been so good to him.

We are sincerely grateful to Bruce for his commitment to work wonders for sick kids now, and into the future.

To find out more information on how to leave a gift in your Will, contact our Community Relationship Manager, Diane Baartz.

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