



# bear facts newsletter

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Official Newsletter of **Perth Children's Hospital Foundation**

## *Funding innovative equipment for Kids Rehab WA*

In 2014, Perth Children's Hospital Foundation funded Australia's first Paediatric Robotic Arm used by the Kids Rehab WA team's occupational therapists located at Perth Children's Hospital. This is now assisting children and young people with a range of mobility issues to improve upper arm movement, strength and control. In 2017 a second robotic arm was funded, allowing the rehabilitation team to help hundreds of children to achieve results which have exceeded expectations.

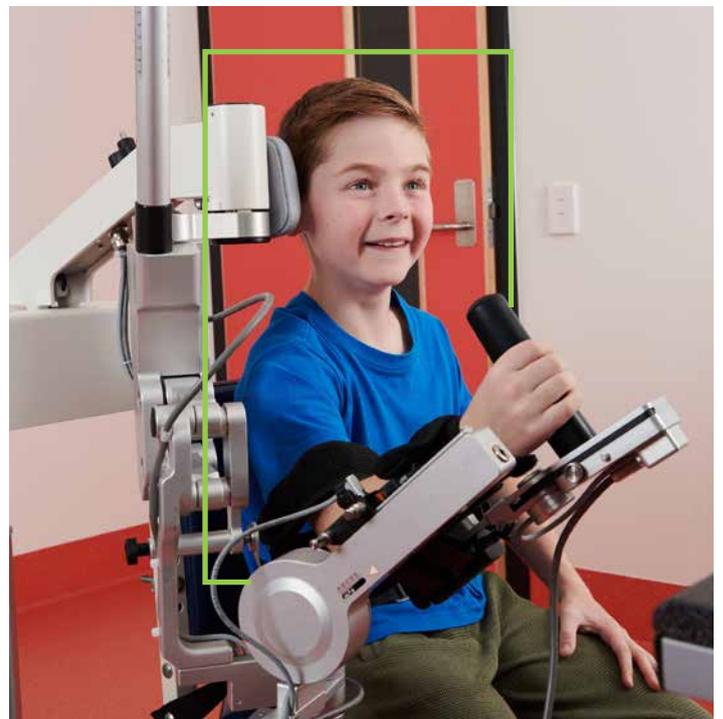
To help meet their demands, the Foundation has purchased a YouGrabber system which complements the Robotic Arm. While the Robotic Arm works on upper limb mobility and strengthening, the YouGrabber focuses on fine motor control and development of the hands and fingers as well as reaction time, visual attention and concentration.

To keep children motivated, the devices use computer games that can be tailored to suit the level of recovery they have reached. Immediate performance feedback helps therapists to monitor and analyse the child's progress and therapists can then decrease the level of physical support the patient gets from the device as they improve their strength and mobility.

Senior Occupational Therapist, Jenny Colegate, says the equipment has been a game changer for patients and therapists alike.

"The Foundation allowed us to lead the way in this field as we were the first hospital in Australia to install this ground breaking equipment. The children are so motivated by the robotic devices and really want to play the games that are part of their therapy again and again. It is incredibly rewarding for the children, their families and all of us who work in the therapy team."

"If you want to see real change, you need engagement from the child and you want to always challenge them,"



remarks Dr Jane Valentine, Head of Kids Rehab WA at Perth Children's Hospital.

"Thanks to the Foundation and its donors, we have Australian first robots that facilitate this. They also recently approved funding for the purchase of the next stage of robotic arm, enabling kids that are further along in their recovery to access a harder level of rehabilitation. This is very exciting, as it means that these kids will see an even better outcome from their treatment."

"Technology is ever changing and improving, so we are extremely thankful to the Foundation for funding that means our patients have access to the very best cutting edge equipment."

Dr Jane Valentine

# CEO message

Welcome to our latest Bear Facts Newsletter.

Kids Rehab WA at Perth Children's Hospital, supports thousands of children and teens a year following a catastrophic brain or spinal injury or chronic conditions such as cerebral palsy that limit physical movement.

Thanks to the support we receive from our many donors, extensive research is now underway in WA to diagnose infants with cerebral palsy as early as possible. Early intervention minimises developmental delays and improves function and mobility increasing the quality of life of these children.

We are also proud to be funding ongoing research into technology that helps children and teenagers with cerebral palsy to walk better, helping them to participate more fully in their schools and wider communities. However, more work is still required to continue funding research into new treatments and investment in innovative equipment and technologies.

The Foundation has also been able to fund five Australian first robotic devices allowing the Kids Rehab WA team at Perth Children's Hospital to maximise early recovery and ongoing functional gain for children with spinal cord or acquired brain injuries, cerebral palsy or weakened upper limb strength. Therapists are consistently seeing results above and beyond international standards.

Thank you for your ongoing support and helping us improve the quality of life for children facing the challenges of daily life.

Carrick Robinson  
CEO  
Perth Children's Hospital Foundation

## A step in the right direction

### Every 15 hours, an Australian child is born with Cerebral Palsy.

Thanks to the generosity of Perth Children's Hospital Foundation donors, research is underway to find new and innovative ways to provide treatment to children and adolescents with cerebral palsy.

Cerebral Palsy is a movement disorder that affects people in different ways and can impact body movement, muscle control and coordination, muscle tone, reflex, posture and balance. Although cerebral palsy is a life-long condition, some of these symptoms of cerebral palsy can improve over time.



Over the past four years, physiotherapist Dayna Pool and her research team have conducted and published numerous studies to establish the effect of electrical impulse devices to improve children's ability to lift their toes, rather than using a rigid brace. The original 'Walk Aide Device' was highly successful in improving walking ability, strength and balance in a group of 32 children and teenagers.

"More recently, I've been exploring new technology that has been released. It doesn't replace the Walk Aide but for some patients it's better. This new device is more slim line and much cheaper. The simplicity of this technology means that trials will now be more streamlined and hopefully, wait lists will be reduced. The devices will be available to more children with cerebral palsy and acquired brain and spinal cord injuries and more children both nationally and internationally will be able to consider the use of this treatment." explained Dayna.

William, 17, was born with spastic hemiplegia cerebral palsy, affecting his right side. Weak leg muscles made it difficult for him to control how he moved his foot, causing him to sometimes catch it on the ground. It caused frequent tripping which greatly impacted his confidence and ability to keep up with his peers.

"The first time Will tried on the device, he didn't really like the sensation of the electrodes, but he soon got used to it and now doesn't even notice them," commented William's mum, Anne.

His walking has improved so much. He wasn't able to put his heel on the ground at all, but with the new technology, his heel nearly touches the ground and he walks with a swagger! This project has been life-changing for Will. We are so thankful to the Foundation and their donors for funding it."



# Early Intervention in Cerebral Palsy

Fortunately, there are interventions that can help reduce the impact of CP on the body and improve quality of life. These include physiotherapy and occupational therapy, surgery, medication, speech pathology and educational support. It is widely recognised that early intervention substantially improves the quality of life for children with disability.



Thanks to Perth Children's Hospital Foundation funding, the Kids Rehab WA team at Perth Children's Hospital have established the Early Intensive Intervention Program (EIIP) for children who are identified as at risk for CP.

Previously, diagnosis of CP was generally made between 18-24 months of age but advances in medicine and technology now mean that these children can be diagnosed as early as three months of age. This means that the rehabilitation team can better tailor their treatments to minimise developmental delays, improve function and mobility and encourage independent movement, without the use of walkers or wheelchairs.

Further research, also made possible through Foundation

funding, is now underway to identify possible cognitive impairment in children with CP within the first 1000 days of life – the most critical time for the cognitive development of a child. Early intervention at this stage is likely to have a greater, positive lifelong effect for children, allowing them to ultimately live their healthiest and happiest lives.

Born prematurely at 27 weeks, Ruby was diagnosed with CP at three months old. Ruby has attended intensive therapy at the hospital to improve her mobility and regularly visits hospital for treatment ranging from physiotherapy, six monthly botox injections and hip surveillance.

"It's very hard to balance therapy, medical appointments and leisure.

We try and get Ruby to do as much therapy as possible; sometimes we even manage 75 hours in three weeks!!! But we have to also make time and encourage her to enjoy her childhood," said Naila, Ruby's mother.

She has been to the United States for orthopaedic surgery and has completed over 250 hours of therapy. Ruby is very focused and can now walk independently for short periods as well as being able to safely get herself to the floor from a standing position.

Ruby is a very social, energetic girl and doesn't let anything hold her back. Dreaming of being an astronaut, ballerina, doctor, teacher and most recently, an acrobat, Ruby is determined to achieve whatever she sets her mind on.



# Your support is making a big difference...

Thanks to the generosity of your support, over the last 12 months Perth Children's Hospital Foundation was able to provide over **\$6.6 million** in grants to give kids a chance to live their healthiest and happiest lives.

	<b>Research</b> Enabling staff to discover new and improved ways of preventing and treating childhood disease.	<b>\$1,545,781</b>
	<b>Expertise</b> Attracting, training and supporting world class clinicians, medical researchers, allied health support staff and nurses who care for thousands of children and their families each year.	<b>\$3,356,085</b>
	<b>Family assistance</b> Supporting families through the Regional Assistance Program which helps to cover accommodation costs for families who live outside the Perth metropolitan area while their child is in hospital.	<b>\$138,675</b>
	<b>Medical equipment</b> Ensuring the hospital staff have access to the most technologically advanced medical equipment so they can provide the best possible care to children.	<b>\$1,191,869</b>
	<b>Funding for fun</b> Making a hospital stay a better experience for children and their families through a range of activities from our Artist in Residence and Music Therapy programs to our Fun on Four recreational area.	<b>\$394,286*</b>

\* plus corporate sponsorships and volunteering

We were also able to commit an additional **\$28.43 million** in funding to longer term projects and initiatives at Perth Children's Hospital over the next five years.

## Thinking of future generations

Through Frank's very generous bequest, the funding of the position of Professor Britta Regli-von Ungern-Sternberg, affectionately known as Professor Britta, was secured for five years.

This funding from Frank's bequest has allowed Professor Britta to continue to treat patients, teach the next generation of medical specialists, and lead clinical research projects which will benefit generations to come.

After taking care of family and friends, by choosing to leave a bequest in your Will to Perth Children's Hospital Foundation, you will be comforted to know

that this gift will be used to transform the health care of WA's sick children and young people so they can live their healthiest and happiest lives. Also, by advising us of this intention, we'll invite you to join our Kids at Heart group of like-minded supporters.

"Our very good friend of many years, Frank, left the bulk of his estate to the Foundation and we know that he would be looking down in approval knowing that his decision is helping children now and into the future."

Reg Byers and Blair Doncon,  
Executors and friends.



**For more information on how to leave a bequest in your Will as well as what appropriate wording to use, please call Tony Hagan, Manager – Donor Care on 64565530.**

