

Care for Kids



Impact Report

March 2019 Edition

How you've helped work wonders for sick kids

Great news for children with cystic fibrosis

New rehabilitation equipment for Henry

Jude's future gift will work wonders



Henry,
3 years,
ENT
(ear, nose,
throat)

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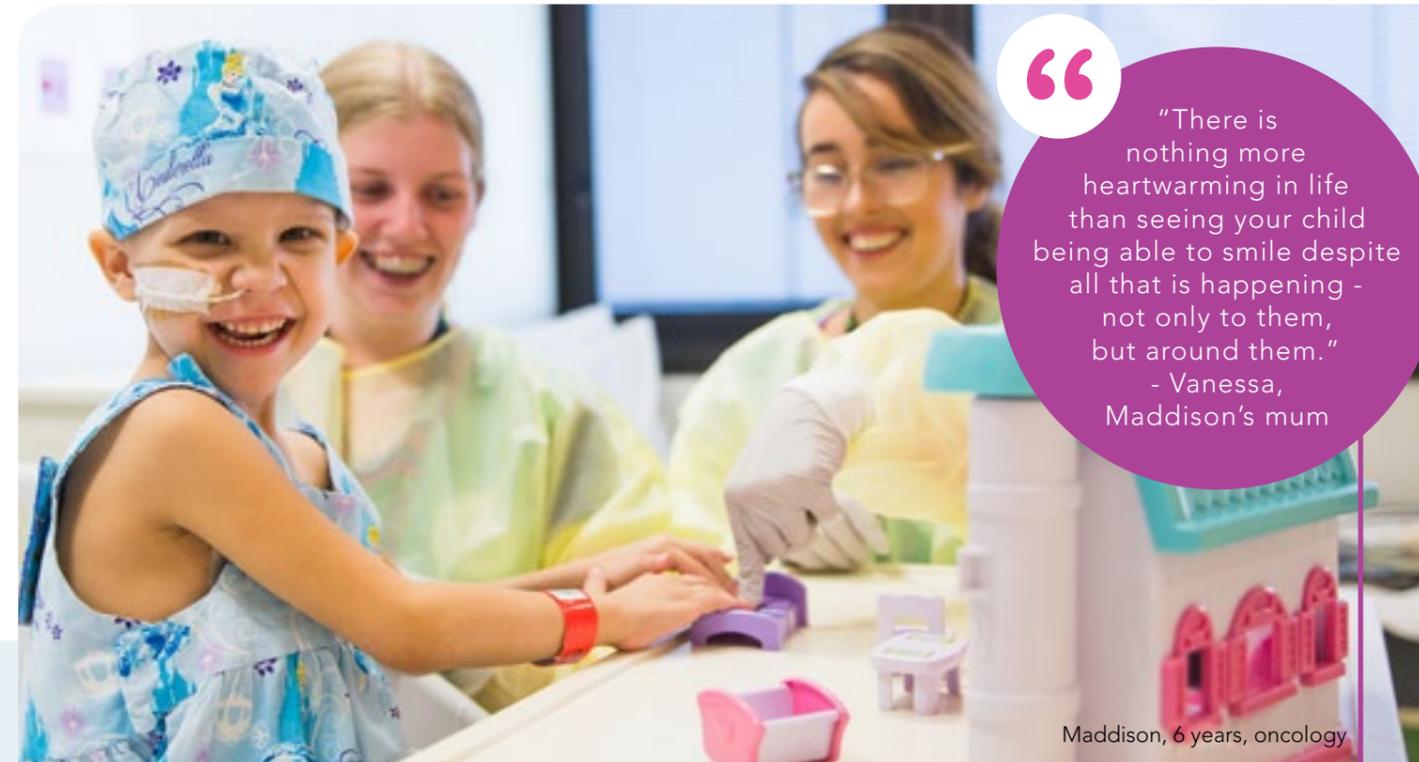
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Maddison, 6 years, oncology

“There is nothing more heartwarming in life than seeing your child being able to smile despite all that is happening - not only to them, but around them.”
- Vanessa, Maddison's mum

“

Your support truly works wonders for sick kids



Reflecting on the stories of brave kids in the Care for Kids Impact Report, I'm overwhelmed by your generosity that makes such a difference to sick and injured children and their families.

I'm proud to share these incredible stories so you can see the lives you've changed - like Henry, who after 210 days in hospital is at home and improving every day. Henry loves being outdoors watching the birds and playing with animals, and now he's able to move around in a specialised wheelchair funded through your generous support.

Read the incredible news of how children living with

cystic fibrosis will have greater access to life-changing medication. Meet the researchers who are exploring new and improved ways to help sick kids get better. These good news stories are possible because of your commitment to funding vital medical research and equipment. Thank you so much!

Your support is truly working wonders for sick kids and their families. Maddison's mum, Vanessa, shares the difference you've made to their family: "There is nothing more heartwarming in life than seeing your child being able to smile despite all that is happening - not only to them, but around them."

You help to make these special moments for children in hospital.

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. I'm so grateful that you share our vision.

Together we're working wonders for sick kids and their families.

Thank you!

Warm regards,

Rosie Simpson
Chief Executive Officer

How you've worked wonders

Maddison is able to smile because of your generous donations - making the long journey of battling cancer much easier for Maddison and her family.

Vanessa first took her daughter to hospital in July 2017 when she was having trouble bearing weight on her left leg. Maddison was transferred to the Children's Hospital - more than 350km away from her home and her family - and doctors delivered the devastating news that there was a large cancerous lump in Maddison's pelvis. This tiny little four-year-old had the fight of her life ahead of her.

Maddison - with her trademark colourful outfits and beaming smile - bravely battled through 14 rounds of chemotherapy and 28 doses of radiation before finishing her treatment in July 2018 - a year after being diagnosed

with Rhabdomyosarcoma, a rare form of cancer made up of cells that normally develop into skeletal muscles.

Maddison missed Pre-Prep and most of Prep as she endured surgeries, chemotherapy and high-intensity radiation to shrink the cancer that affected her ability to walk and devastatingly, her ability to dance. Maddison's treatment spanning more than a year - has shrunk her tumour from about the size of a grapefruit to the size of a grain of rice.

The activities offered by the Children's Hospital Foundation - made possible because of your generous donations - worked wonders for Maddison when she was missing out on time with her friends and family.

The entertainment services you provide help sick kids to regain some of the fun of being a child.

Maddison says her favourite things about hospital are when volunteers bring board games and toys; music therapists pop in to play and sing; and when she stocks up on reading from the Book Bunker. She also loves attending fun events with her brother Andrew.

"There is nothing more heartwarming in life than seeing your child being able to smile despite all that is happening - not only to them, but around them. Or, knowing that the friends your child has made along the way are there because of the play equipment purchased through the amazing fundraising work of the Children's Hospital Foundation."

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Great news for children with cystic fibrosis

Hundreds of Australian children living with cystic fibrosis now have greater access to a life-changing medication. This is thanks to an international collaboration in clinical trials, supported by Children's Health Queensland's respiratory physician Professor Claire Wainwright, whose Research Fellowship was funded by the Children's Hospital Foundation.

From 1 October 2018, Orkambi® became available on the Pharmaceutical Benefits Scheme (PBS).

Cystic fibrosis is a life-long genetic condition that causes the body to produce abnormal amounts of thick, sticky mucous within the lungs, airways and digestive system. This leads to impairment of the digestive functions of the pancreas and traps bacteria in the

lungs resulting in recurrent infections, and irreversible damage. There is currently no cure.

Clinical trials have shown that Orkambi® can slow the rate of decline in lung function and reduce the number of infections in patients with cystic fibrosis, who have two copies of the F508del mutation, the most common form of this condition in Australia. With

the support of the Children's Hospital Foundation, Professor Wainwright and her team continue to undertake research into new therapeutic approaches to improve the health outcomes of children with cystic fibrosis.

"It's very exciting that children with cystic fibrosis - who carry two copies of the F508del CTFR mutation in Australia will now have access to Orkambi®. This medicine can reduce the frequency of chesty episodes, and reduce the need for hospital admission.

It also slows down the deterioration in the function of the lungs that is seen

in people with cystic fibrosis over time, which is a great opportunity to see improved outcomes for children with cystic fibrosis," Professor Claire Wainwright said.

It is predicted that around 200 children with cystic fibrosis in Queensland, and approximately the same number of adults, will now have access to this potentially life-changing medicine.

Each year around 80 babies with cystic fibrosis are born in Australia, about half have two copies of the F508del mutation.



Ashlin, 13 years, cystic fibrosis

Professor Claire Wainwright

New rehabilitation equipment for Henry

Henry, 3 years, ENT with mum and dad



Through generous supporters like you, the Children's Hospital Foundation was able to purchase four new types of rehabilitation equipment for our young patients, like Henry.

Henry was sick with a chest infection at the age of three and eventually, he lost his ability to move and speak. He was placed on life support and was transported from the Rockhampton Hospital to the Children's Hospital.

After two and half months Henry was diagnosed with interior horn cell damage associated with the enterovirus. He lost normal function of his muscles and was not strong enough to breathe by himself. Henry

now has to be on a ventilator. Henry uses the Zippie IRIS wheelchair which you helped to fund. It enables him to move easily and is fitted to suit his physical needs. In addition to the Zippie IRIS wheelchair, the Children's Hospital Foundation has funded rehabilitation equipment including the Flamingo Shower Seat, the Ki Mobility Express Focus CR

Tilt in Space Wheelchair, and the JAY3 back Posterior Deep Lateral Backrest.

The rehabilitation equipment is available to inpatients with a newly acquired disability or who need rehabilitation after surgery. It is also available on loan for patients who are discharged home and are waiting for their permanent equipment.

This investment has allowed the Queensland Paediatric Rehabilitation Service to better assist patients aged 1 to 16 years with a wider range and severity of disabilities and living requirements. It means better rehabilitation care and shorter stays in hospital.



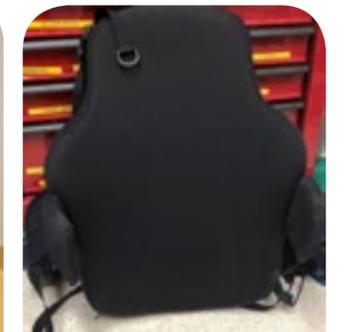
Zippie IRIS wheelchair



Ki Mobility Express



Flamingo Shower Seat



Jay3 back Posterior Deep Lateral Backrest

Supporting amazing researchers

Dr Severine Navarro



The Children's Hospital Foundation has provided financial and mentoring support through the Mary McConnel Career Boost Program for Women in Paediatric Research. This year, we're delighted to share with you the nine female researchers you've helped us support.

Dr Helen Petsky aims to improve the diagnosis, management and monitoring of paediatric respiratory illnesses.

Dr Leanne Sakzewski aims to develop new approaches to rehabilitation for children with cerebral palsy, which is the most common childhood physical disability in Australia.

Dr Natalie Bradford will conduct research to support children, adolescents and families with cancer or palliative care needs.

Associate Professor Amanda Ullman aims to prevent complications that can occur with the insertion and management of vascular access devices.

Dr Zephania Tyack aims to improve the physical and psychological impacts of childhood burns and other skin conditions.

Dr Suzanne Parker aims to design antibiotic dosing regimens for treating infants and children with severe infection.

Dr Severine Navarro is investigating the safety and effectiveness of the "AIP-2" protein, which protects patients against inflammatory conditions including coeliac disease and asthma.

Dr Debbie Long aims to improve neurodevelopmental outcomes in infants undergoing cardiac surgery.

Dr Emma Hamilton-Williams aims to develop and test new immunotherapy approaches for the treatment and prevention of type 1 diabetes.

Jude's future gift will work wonders

By including the Children's Hospital Foundation in your Will, no matter how big or small, your generosity can help many children for years to come.

The Children's Hospital Foundation helps sick and injured kids by funding life-saving medical research, investing in vital new equipment, and providing support and entertainment for children and their families.

research that achieves faster diagnoses, better treatments and ultimately cures for some of the most devastating childhood illnesses and injuries.

Sadly, Jude knows all too well the devastation of losing a child, and the importance of funding medical research.

Jude's baby son, Mark, had a very rare condition. That is why Jude is so passionate about funding medical research and has pledged to leave a gift in her Will which will support life-saving medical research.

"I don't think any money is ever wasted on research," says Jude.

"If research can help just one little baby, it's worth it. It can't prevent what happened to my son, but it may prevent other children and parents going through the same experience."

"If everybody left something, it would make a huge difference. It's thinking of the future and how it can help children – maybe even your grandchildren or great grandchildren. It is a legacy that you will be proud of."

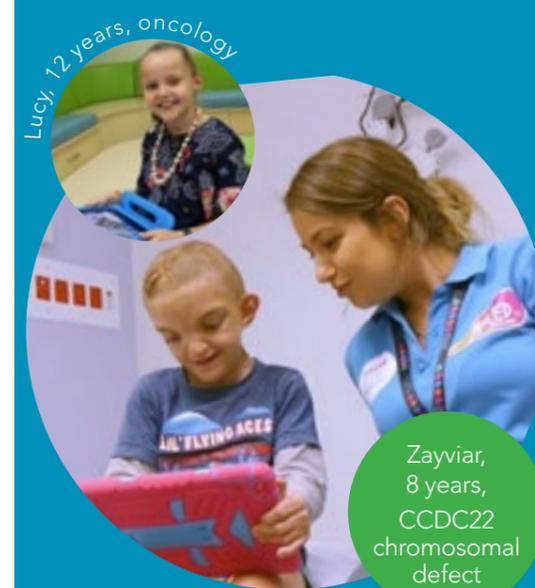
To find out more about leaving a gift in your Will to help work wonders for sick kids, please email giftsinwills@childrens.org.au or contact our Community Relationship Manager, Diane Baartz, on 07 3606 6138.



Jude

We are committed to making a difference in the fight against childhood illness and injury so every child can grow up as happy and healthy as possible.

By choosing to leave a gift in your Will, you can help fund life-saving medical



Lucy, 12 years, oncology

Zayviar, 8 years, CCDC22 chromosomal defect

Juiced Box

The power of television

Do you remember the launch of Juiced TV in 2015, that was funded by generous supporters?

Juiced TV is a weekly program made by the kids in hospital for the kids in hospital. It has touched the lives of thousands of patients and their families and it is just another way we work wonders by providing support and entertainment to sick children and their families in hospital.

Powered by this success, Juiced TV has recently introduced 'Juiced Box' which allows patients in regional hospitals throughout Queensland to access Juiced TV. They'll be able to watch multiple episodes, have their say about program content and eventually film their very own segments.

Juiced TV is looking at expanding their service into every major paediatric hospital, connecting patients and families throughout the country.

This service improves the hospital journey for our patients and their families allowing kids to interact with each other. It gives patients and their siblings the chance to star in their own TV show, supporting their healing and wellbeing in the process.

Thank you for bringing joy to our sick kids.

Volunteer Story

Little things make a big difference

Did you know you're helping us to provide little things that can make a big difference to a child's experience in hospital? Simple things like Play-Doh, colouring pencils, books and games.

There is a lot of waiting involved for children receiving outpatient oncology treatment. We're helping to make it easier for them, with volunteers and resources to keep them entertained.

Dylan,
3 years,
oncology

Dylan and Anna love using these resources and interacting with the volunteers. Anna asks her mum every time if her favourite volunteer Sheila will be there and looks forward to her appointments.

Dylan's mum Nicole says that "No matter how many toys and

books I bring, the waiting is especially difficult for my two-year-old son Dylan, especially when he is feeling unwell or he is fasting for a general anaesthetic. Every time I see the volunteers in the waiting room, I breathe a sigh of relief, while Dylan is excited to see the volunteers' friendly faces with their new toys."

Outpatient play



Help work wonders for sick kids

Please accept my gift of \$

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Phone Email

PLEASE DEBIT MY: Visa Mastercard Amex Diners

Card Number: / /

Name(s) on card: Expiry: /

Signature:

OR CHEQUE / MONEY ORDER (payable to Children's Hospital Foundation) All donations over \$2 are tax deductible

- I/We would consider leaving a gift in my/our Will to Children's Hospital Foundation. Please send me/us more information.
- I am/We are intending to leave a gift in my/our Will to Children's Hospital Foundation. Please send me/us information about your free Will writing service
- I/We have already left a gift in my/our Will to Children's Hospital Foundation.

Please return this form in the enclosed envelope, or:

Mail: PO Box 8009 Woolloongabba QLD 4102

Phone: 1300 742 554

Visit: www.childrens.org.au

Please tick here if you would like your receipt supplied via email.

Thank you for working wonders for sick kids

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Please tick here if you do NOT want to receive communications from other charitable organisations.
Please phone 1300 724 554 if you do NOT want to receive future communications from the Children's Hospital Foundation.