

# Care FOR Kids



*your  
impact*



AUTUMN 2022

You're working wonders for kids like Ava

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## A message from Olivia

As we settle into a New Year after all the challenges the past few years have brought the world, I am humbled to bring you our latest Care for Kids newsletter.

This newsletter showcases the amazing world-class care you're bringing to children and young people. Your donations allow us to support the whole family, because when a child gets sick or injured, their whole family are impacted.

Parents and caregivers may have to relocate, take time away from work, give up work entirely, or be separated from their other children whilst they care for their sick or injured child.

It is thanks to your incredible support that we can offer many services that help the whole family through an incredibly difficult, and sometimes very long, hospital and health journey.

This includes ensuring Aboriginal and Torres Strait Islander kids have access to world-class care closer to home, meaning they don't have to travel too far from their communities. It includes incredibly



important bereavement support, when a family is facing the unimaginable loss of a child. It includes year round financial and emotional support, to make a difficult time for families, that little bit easier.

None of it would be possible without you.

I hope that when you read this report, you take a moment to reflect on the incredible impact you're having on sick and injured kids and their families every day.

Thank you.

*Olivia Jary*

**Olivia Jary**

Chief Marketing and Fundraising Officer  
Children's Hospital Foundation

### Photo

*Olivia, with Liam, who has down syndrome and was diagnosed with leukaemia.*



## Ava

You might remember little Ava, whose story we featured in an appeal letter last year. We are delighted to say that Ava is continuing to defy the odds of paediatric brain cancer and is inspiring everyone around her with 'her warrior princess attitude'.

Ava is now five and a half years old and completed 12 months of chemotherapy at the end of October 2021. While it is a relief for Ava and her family to no longer be undergoing treatment, her mum, Amanda, says they're currently living in limbo.

"We've been advised that we just watch and wait now. Many people would be excited to be off treatment, however it is a scary time for us. Even though treatment is hard, at least we know that we are actively fighting the beast," Amanda said.

"Now, every twelve weeks, we wait for a scan and just pray that her remaining tumour doesn't grow."

Ava spent her most recent Christmas holidays doing all the things she loves most – plenty of arts and crafts, baking for

Santa, swimming, playing Lego, PlayStation, and most importantly, spending cherished time with her family.

In a huge milestone, Ava started primary school in February, having celebrated her last day of kindy in December.

"She loves to tell everyone that her biggest achievement from kindergarten was getting all the way across the monkey bars. Her teacher told me that she had been persevering every day, so determined to make it all the way. That's my girl, I thought. She never gives up," Amanda said.

"Ava's next scan is a big one for us as it is the first one where she is more than three months off treatment."

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**"No matter the results, we will all put on our superhero capes and follow Ava's lead - be strong, carry on, and live life to the full every single day."**

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### **Photo**

*Ava, who has completed treatment for paediatric brain cancer.*

## Supporting all families, always.

Thanks to you, we are able to provide compassionate and culturally sensitive support for families who have suffered the devastation of the death of their child.

You have helped fund a dedicated Bereavement Coordinator for Children's Health Queensland's Bereavement Service, in partnership with Scarlett May Foundation. This role enabled the expansion of the Queensland Children's Hospital's palliative care service to offer bereavement support for all families connected with Children's Health Queensland who experience the death of a child.

We're also proud to have been funding the Children's Health Queensland Remembrance Ceremony for more than 10 years. The Ceremony provides the opportunity for children to be remembered in a shared experience with others who have also lived through the death of a child. Clinicians, families and friends also have the chance to connect with one another, making the transition between hospital life and normal life less abrupt and disruptive.

Our generous supporters have also helped to fund Queensland Children's Hospital's Welfare Service, allowing families the chance to access Final Farewell funds to support funeral payments if they're experiencing financial hardship in the most tragic of circumstances.

Losing a child is something no family should ever have to face, however that is sadly the reality for some families. We're so grateful for your generosity in helping to fund some of Children's Health Queensland's incredibly important bereavement programs, which has seen the expansion of bereavement support to all families cared for by the health service.

Another incredibly special program you allow us to provide is memory-making. Finding ways to remember a child has proven to help parents,



carers and families cope with their emotions and better adapt while they are grieving. Your support provides memory books and support boxes to these families.

This support helps mothers like Jenni, who lost her three-year-old George to sepsis.

"His body tried so hard to fight the infection, but after having a stroke, losing circulation to his left leg then losing blood flow to the right side of his brain, his body couldn't fight any longer. He was taken off life support and passed away in my arms on 26 September 2019. Our beautiful ray of sunshine was gone," Jenni said.

"The Bereavement Coordinator reached out to me, and gave me the time, space, a listening ear and platform to express the sadness I was feeling after our huge loss. It was because of this experience that I knew I wanted to help others who were experiencing the same feelings of losing a child. Those early days are so incredibly hard and having the option to reach out to others who understand those feelings and can listen, offer some comfort and support during those first months is so important. Helping others cope with their new grief at a devastating time after the loss of their child is invaluable."

Jenni will be bravely sharing her story as part of this year's Nine Telethon (see page 6 for more information).

### **Photo**

*George, who passed away from sepsis on 26 September 2019.*

# Harrison helped by insulin infusion pumps

In early July 2021, 10-month-old Harrison was rushed to his local hospital after becoming severely ill. Hospital staff quickly identified that Harrison was suffering from DKA (diabetic ketoacidosis) and he was immediately airlifted from his hometown of Dalby to Queensland Children's Hospital.

Harrison made a full recovery after spending several days in the Paediatric Intensive Care Unit receiving insulin and other fluids to stabilise the ketoacidosis. He was subsequently diagnosed with Type 1 Diabetes.

However, life for Harrison and his family has changed forever. With support from the Queensland Children's Hospital Endocrinology Department, Harrison and his family have received guidance, education and resources on how to manage the ongoing care and daily treatment of T1D. For a young child like Harrison, it is incredibly difficult to manage diabetes using insulin pens, because the smallest deliverable amount of insulin from a pen is too much insulin for a child of his age. The benefit of the insulin infusion pump, particularly for young children like Harrison, is the ability to administer very small doses of insulin.



*Harrison with his insulin infusion pump.*



Given Harrison's diagnosis at such a young age and the impact on the family's day-to-day life, Harrison's mum, Dimity, has been unable to return to work as planned. This has placed immense financial pressure on the family to manage the costs of Harrison's diagnosis and ongoing treatment.

An extremely generous supporter (just like yourself!) donated to support the purchase of Tandem T-slim insulin pumps, which have been integral to Harrison's treatment and quality of life.

Harrison's mum, Dimity, says the pump has allowed them time to focus on Harrison and their family.

"Thank you for making this pump possible. It has allowed us to take the time and focus on our 'new normal', and getting Harrison's Type 1 Diabetes under control," Dimity said.

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**"Thank you from the bottom of our hearts for helping our family and all the other families who came before us and who will come after us."**

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If you'd like to have a discussion regarding purchasing a specific piece of equipment or facilitating certain research, please contact our Supporter Care team on **1300 742 554**.



## Get ready for Nine Telethon

We are delighted that the Nine Telethon, in support of the Children's Hospital Foundation, will be held on Saturday 23 April, 2022, after last year's COVID-related postponement.

For close to a decade, the Nine Telethon has called on big-hearted people like you to make a massive difference for sick kids and their families.

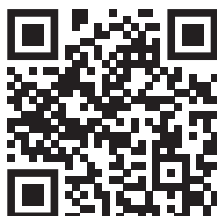
Despite the global pandemic, the 2020 Telethon was an enormous success, and we hope to build on that again to raise even more funds to support sick and injured kids.

Save the date and get ready to join us for a night packed with entertainment, music from Missy Higgins and Eskimo Joe, and some extraordinary kids with inspirational stories.

You can tune in and donate on the night, or get involved in lots of other ways, including buying a ticket to the Telethon Concert, hosting your very own Telethon Party, posting about Telethon on your social media or fundraising in your local community!

All money raised from the Nine Telethon will help support sick kids by funding life-saving medical research, cutting-edge medical equipment and patient and family support programs.

To find out how you can get involved, follow us on Facebook or visit [9telethon.com.au](http://9telethon.com.au)



## Look at what's happening in your community!

There are plenty of ways to get your community involved in supporting sick kids and their families at the Queensland Children's Hospital.

### Telethon Parties

are a fantastic way to celebrate Nine Telethon! It's time to get your creative thinking caps on and take part in the only televised fundraising event in Queensland!



### Moreton Bay Multi-Sport Festival

is on in May and participants will now have the chance to fundraise for sick kids. Keep an eye out on our socials for when registrations begin!



### Think outside the box

and create your own fundraiser just because you can! Get in touch with our Community Partnerships team for your very own Community Fundraising Toolkit to get your creative thinking flowing!



### Community Partnerships Team

 [fundraise@childrens.org.au](mailto:fundraise@childrens.org.au)

 07 3606 6100



## Giving regional Indigenous Australian kids care closer to home

Remote Indigenous Australian children have a higher incidence rate of bronchiolitis – an inflammatory infection of the respiratory tract – 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, until now there has been limited data on safe use in remote settings.

Thanks to your support, 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 infants would previously have been disadvantaged by the non-provision of nasal high flow care and required to be

transported, while ill, to a tertiary facility in a metropolitan area, often very far from home.

Access to this treatment means all Australian children can have greater access to excellent care. It also minimises the negative impact travelling far away from their communities can have on Indigenous patients and their families.

This project is in partnership with Torres and Cape Hospital and Health Service.

### Photos

*Above* Weipa nurses post education session

*Bottom* Cooktown education session with Dr Donna Franklin, Sally's research partner



# Yes!

I'd like to work wonders  
for sick and injured kids.



First name \_\_\_\_\_

Last name \_\_\_\_\_

Address \_\_\_\_\_

Suburb \_\_\_\_\_

State \_\_\_\_\_ Postcode \_\_\_\_\_

Contact no \_\_\_\_\_

Email \_\_\_\_\_

## Please accept my gift of:

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☐ Please tick if you'd like to make this a monthly  
gift and become a monthly giver.

## Please find my payment details:

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Card Number

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Name(s) on card

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Expiry

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Signature(s)

\_\_\_\_\_

See our privacy policy overleaf

☐ Please tick if you'd like your receipt supplied by email

Email address \_\_\_\_\_

## Other ways you can donate:

☐ Cheque (payable to Children's Hospital Foundation)

☐ Money Order (payable to Children's Hospital Foundation)

OR

Donate Online via  
**childrens.org.au**



 **PayPal**  
now accepted online

# 1300 742 554



Chloe, who was diagnosed with leukaemia, having a great time at Kidzone funded by supporters like you.

## Leave a Gift in your Will

No matter how large or small, every gift left to the Children's Hospital Foundation makes a difference to the lives of sick kids and their families.

Leaving a gift in your Will helps to work wonders now and long into the future.

☐ Please tick if you'd like a member of the Foundation to contact you and send this form back in the pre-paid envelope provided.

Full name: \_\_\_\_\_

Contact number: \_\_\_\_\_

OR email address: \_\_\_\_\_

Alternatively, you can contact us at **1300 742 554** or email **giftsinwill@childrens.org.au**



**All donations over \$2 are tax deductible.** Australia Post prohibits the postage of bank notes and coins as per the prohibited goods guide, part D3.2

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☐ Please tick here if you do NOT want to receive communications from other charitable organisations.

Please phone 1300 742 554 if you do NOT want to receive future communications from the Children's Hospital Foundation.

# Jonathan the brave

Two-year-old Jonathan had a rocky start to life, after being diagnosed with Hypoplastic Left Heart Syndrome (HLHS) within 24-hours of being born. HLHS is a condition whereby the left side of Jonathan's heart was born too small to function effectively and was unable to pump his blood around his tiny body.

To alleviate his condition, Jonathan underwent two open heart surgeries – the first of which was performed when he was only seven days old.

"Before he was taken away, we held him for what could have been the last time. It was not the beginning to his life that we had imagined," Jonathan's mum, Jess, remembers. "His chest remained open for three days post op to allow his swelling to go down, and I will never forget that sight."

Jonathan has since undergone two further open-heart surgeries, and his treatment is ongoing. He will require cardio appointments every few months to monitor his progress, and he will need another surgery in a few years.

His family cite the support they received from the Foundation as invaluable during one of the most difficult periods for the family.

"Music Therapy was integral during our time in the hospital and helped both our children see hospital as a less daunting place. When we needed a bit of time outside with our daughter, the Steggles Cuddle Carers were wonderful at providing comfort to Jonathan. We feel so grateful that there are so many ways the Foundation brings fun and laughter to the kids (and their parents!) when they need it most."

Due to the support that Jonathan received during his hospital journey, his family decided to donate a monthly gift to the Foundation.

"We became regular givers because we know firsthand that our little contribution means a lot. We wanted to give back because of the



support we had been given while Jonathan was in hospital. It would have been so much tougher without their support," Jess said.

"We want to ensure that this continues for not just Jonathan, but for all the other kids in hospital too. When our son requires his next surgery, we're going to need even more support and distraction than ever as he is older now. Knowing that he will have the best support and a range of distractions when he goes in for his next open-heart surgery is the only thing that makes it tolerable."

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**As a monthly giver, you can make a direct and ongoing impact to the lives of sick kids and their families, just like Jonathan's.**

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Your continued support is not just saving lives, it's giving back lifetimes. Every child's life you help to save by funding medical research, world-class care and integral support programs is a child who gets to return home to their everyday life, and to celebrate special milestones they may not have seen without it.

**For more information or to become a monthly giver:**

 [childrens.org.au/monthlygiving](https://childrens.org.au/monthlygiving)

 1300 742 554

