



FEATURED STORY:

# "WE MADE IT!"



Meet Kylan:

"We couldn't have got here without everyone in CHI at Crumlin, so we're forever grateful."

Kylan aged 6-months-old ▶



Wonderful little Kylan was delivered via emergency c-section due to Intrauterine Growth Restriction (IUGR) at 27 weeks, 4 days gestation.

He weighed just 650g, but is here today thanks to the extraordinary circle of care in CHI at Crumlin, of which you – our *Whatever It Takes* community – are a vital part. His parents know all too well the incredible impact of your support and are delighted to share their journey with you... **continued on page 2**

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## A MESSAGE FROM OUR CHIEF EXECUTIVE

A chara,

I hope that you and your loved ones are keeping safe and in good health. During these uncertain times, you have been constant in your support. Though we have all been keeping our distance, we've felt your presence, standing by our side to help sick children and their families when they most need it. **Thank you.** I hope the stories in this newsletter will leave you in no doubt of the important role you play in the life of every child that passes through the doors of CHI at Crumlin. You are part of a caring community whose kindness continues to spread joy, and provide compassionate loving care to Ireland's sick children. 2020 was a year like no other, but because of amazing support like yours, last year Children's Health Foundation committed €6m to paediatric research and €1.6m to purchase vital medical equipment. As an important part of the circle of care that surrounds every sick child, you also helped support care programmes for the little patients in hospital, their parents and their families, including the much-needed refurbishment of Nazareth Ward in CHI at Crumlin – which you can read more about on page 6.

Thank you for supporting the patients, parents and staff in CHI at Crumlin – it means the world to them and to us.

In 2021 we will embark on a new strategy – Transforming Care for Sick Children – to achieve ambitious growth for the coming years. We have high aspirations – driven by sick children and their needs. Our promise to these brave children and their families is one of commitment – we want to continue to provide world-class facilities, research, and compassionate, loving care for every sick child in Ireland. If you'd like to see a copy of our new strategy, please visit our website here [www.childrenshealth.ie/news](http://www.childrenshealth.ie/news)

We hope you will continue with us on this journey and that together, we can keep giving every sick child the very best chance.

Thank you so much for making a real difference in the lives of our little patients, every day.

Warmest wishes,

*Denise Fitzgerald*

Denise Fitzgerald

Chief Executive, Children's Health Foundation



## FEATURED STORY

# "WE MADE IT!"

*Kylan was delivered via emergency c-section due to Intrauterine Growth Restriction (IUGR) at 27 weeks, 4 days gestation. "He weighed just 650g, less than a bag of sugar," says Kylan's mam Sarah, "the first few weeks are a blur to me, but I will never forget how small and frail he was, seeing every vein in his body as his skin was so thin, his rib cage, and his whole hand covering only my baby fingernail."*

Kylan spent over 14 weeks in maternity hospitals in Dublin, before being transferred to CHI at Crumlin for specialist tests. Being born three months premature, Kylan's lungs hadn't had the chance to fully develop, and he continued to have problems breathing. Sarah says, "We'd just never got to a place where we could safely bring him home, so it was decided that the next step was to transfer him to Crumlin. As scary as it felt at the time, looking back, we were blessed to be able to get to Crumlin as soon as we did."



▲ Kylan and Mam, Sarah celebrating 'World Prematurity Day', Kylan's babygrow is hanging above them – it's the one marked number 5.





▲ Kylan and Mam, Sarah.

Although COVID-19 had an impact and meant that Sarah and Kylan's Dad, Dylan, couldn't both visit him at the same time, they were able to appreciate the little milestones more. Sarah fondly remembers the first time they could look at Kylan without masks on! Sarah describes Nazareth Ward as being almost like home and even given the hard times,

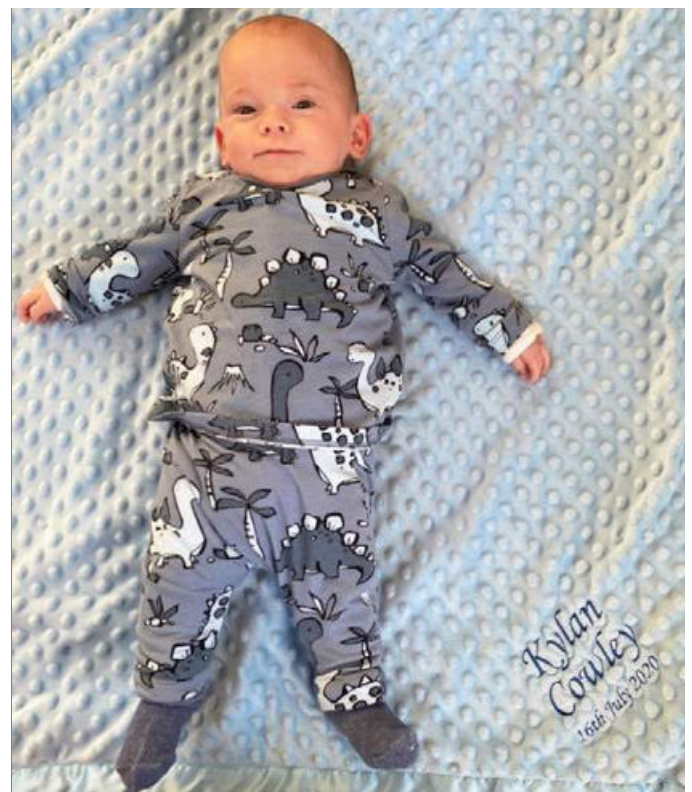
remembers the whole journey as a positive experience, *"Once we were at Crumlin, I was able to do so much more myself, dress him, change him – and I remember thinking it was a really nice feeling to have our own space."*

Kylan's underdeveloped lungs meant that he had trouble breathing, *"he has apnea of prematurity, so sometimes his brain forgets to signal his lungs to breathe. He also refluxes his milk, which can block his airway and cause trouble breathing. He would turn blue and stop breathing at least 3-4 times a day. It was terrifying."* Thanks to the incredible care teams in CHI at Crumlin and the kind support of people like you, Kylan was given the world-class care and treatment that he needed and the days turned into weeks before this happened again.

Sarah remembers, *"After only a few days in CHI at Crumlin he was started on medication. I think it was nearly two weeks later before he had another episode, it was such a milestone, I was like – he's not turning blue anymore! This is amazing!"* Your support is saving lives and means that families like Kylan's can celebrate milestones together, and that babies like Kylan can heal and come home.

**1 in 10 babies are born prematurely**, and Kylan was on Naz Ward on **World Prematurity Day**, in November last year. Sarah remembers, *"One of the nurses asked me to bring in one of Kylan's babygrows and on the ward they had hung up 10 babygrows and one of them was Kylan's, it was very special."* You may remember that thanks to your kind support, Nazareth Ward was refurbished last year (see update on page 6), and little Kylan was staying in the ward during this time. Sarah remembers being delighted when a new chair to sleep in arrived. **You have provided comfort and care to families like Kylan's in some of their toughest times.**

Kylan's family are so grateful that supporters like you continue to do whatever it takes for sick children, just like Kylan. Sarah says, *"before I became a Mam, I never actually really understood the impact that fundraising has on the hospital and the difference that the support makes to the lives of these children and their families. **These sick babies need the world to help them.**" YOU are their world, YOU are making a difference to the lives of all the little patients and their families in CHI at Crumlin, and Sarah could see this first-hand.*



▲ Kylan at 6 months old.

Despite the challenges he's faced, Sarah says that Kylan is, *"a really, really happy baby. Now he's rolling over, he's smiling, it's just amazing."* Kylan is still receiving oxygen support at night-time to help his lungs and to keep him stable. He will also need further check-ups and some ongoing care because he was born so prematurely, but Sarah and Dylan are just delighted to have Kylan home. Sarah says, *"There is still a lot going on and he does still need a lot of attention still, but we're just lucky that he's come this far and he's done so well. He's learning so much and getting stronger every day. **We couldn't have got here without everyone at CHI at Crumlin, so we're forever grateful.**"*





# Remember Saoirse?

Your support has made an extraordinary difference to the lives of young patients like Saoirse, a brave and remarkable young lady.



▲ Saoirse on The Late Late Toy Show!

Saoirse was only seven-years-old when she was diagnosed with Osteosarcoma, a rare bone cancer. She immediately started receiving chemotherapy and treatment in CHI at Crumlin, but because of where the tumour was situated in her tibia, there was no other option but to remove her leg. During the COVID-19 pandemic, the Galway family have been travelling up and down to Crumlin frequently, and call it their second home.

Despite their world being turned upside down, you may remember that Saoirse and her family organised **Saoirse's Summerfest Fundraiser** last August, to give back to all the charities that had supported them on their journey. The fundraiser was an incredible success and raised over €25,000, to be split between the chosen charities including Children's Health Foundation Crumlin. Saoirse's mam Roseanna says, "We had no experience of support like this before, and just couldn't believe the services that were there to help families. It was amazing. We felt that it was right to give back so that other families could benefit from funds raised and receive the same support and care that our family was so lucky to receive."

You may also remember that Saoirse was on the Late Late Toy Show last November, with her mam Roseanna. This was a special experience where Saoirse shared her story, which had begun exactly a year before. The night was a milestone for the family and Roseanna remembers, "Saoirse was so excited to be on the Toy Show, she was on a high afterwards. We stayed in a hotel on the night of it, and she loved this."

*She also loved coming home to Galway, as people recognised her from the Toy Show. It was a big moment."*

Thanks to the extraordinary circle of care in CHI at Crumlin and the kindness and support of people like you, Saoirse is now doing really well. Roseanna says, "Saoirse is doing great, she did very well in her last review in CHI at Crumlin. She is working hard with rehab and physio and is nearly walking unaided." These special milestones would not be possible without the wrap-around care in CHI at Crumlin – of which you are a vital part. Thank you for being there for families like Saoirse's.

Although COVID-19 restrictions have meant that she can't get out and about, Roseanna says that "Saoirse is very happy and full of energy. She spent midterm learning to ride her bicycle again and has been absolutely flying it since!" Saoirse finished chemotherapy last September and her family know all too well the impact of your support. Thank you for making a difference for children like Saoirse.



▲ Saoirse and her mam Roseanna in CHI at Crumlin



▲ An incredibly proud moment for Saoirse's mam Roseanna appearing on The Late Late Toy Show.



## Research Spotlight: Dr Brona Murphy

# Developing Personalised Treatment for Children with Brain Tumours



▲ Dr Brona Murphy

Your support is changing lives, helping to facilitate research into the cause, prevention and cure of childhood illness in Ireland. Ground-breaking research led by Dr Brona Murphy is currently underway at the National Children's Research Centre (NCRC), thanks to the support of Dalata Hotel Group and the kindness of people like you that make research like this possible.

Every year in Ireland, approximately forty-five children are diagnosed with a brain tumour. Brain tumours are the most common cancer among those aged 0-14, and of these, around 10 are medulloblastoma (MB). This is an extremely fast-growing cancer that requires aggressive treatment including a combination of surgery, radiotherapy, and/or chemotherapy.

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## Every year in Ireland, approximately forty-five children are diagnosed with a brain tumour.

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While this approach to treatment gives the child the best possible chance of survival, it also kills healthy cells alongside the cancer cells, and means that children can experience severe side effects and a cost in quality of life.

*"These children can experience developmental delays, poor mobility, delayed speech, poorer cognition, and tend not to do as well as their peers in school,"* says Dr Murphy,

*"so I wanted to see if I could make better outcomes for the paediatric population."*

Dr Murphy and her team aim to develop a model that will predict how each individual patient will respond to both currently available and new treatment options, so that the most effective and least harmful therapy can be given.

This will lead to a more personalised approach to treating children with MB, so that the dose and severity of therapy is reduced where possible, leading to better outcomes and an improved quality of life.

Dr Murphy and her team are hopeful that the outcomes of their research will have a profound and life-changing impact on the lives of children diagnosed with MB and their families throughout Ireland and beyond.

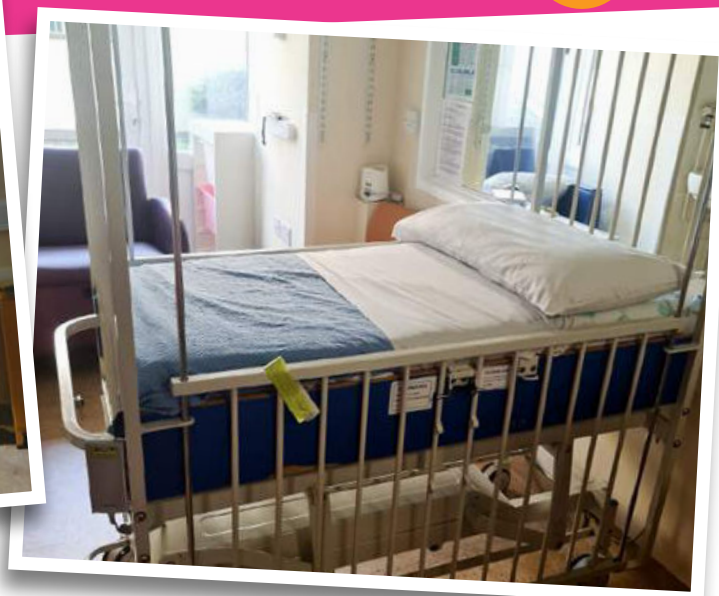
**As Dr Murphy says, *"Without your support none of this research would be possible. Like many of the studies being conducted in Children's Health Ireland, it is allowing the researcher freedom to really understand childhood diseases, for the benefit not just of the children in Ireland, but children all over the world...and you are also creating and training a workforce that is dedicated to paediatric research for the future as well."***

Thank you for giving every sick child the very best chance, today, tomorrow and into the future.



UPDATE:

# Upgrading Naz Ward



**Thank you! You are helping to provide comfort and care to some of CHI at Crumlin's tiniest patients.**

**Children's Health Foundation Crumlin has been funding the redevelopment of Nazareth Ward – the oldest baby ward in the Hospital, and fondly called Naz Ward by many.**

First built in the 1950s, Nazareth Ward's rooms were not equipped to accommodate today's machines or monitors, and parents slept on the floor. Even with the year that was 2020, this much-needed refurbishment has progressed safely and has made an incredible difference to the comfort and care of the sick babies and their families in CHI at Crumlin.

We are delighted to update that at this stage, seventeen patient rooms and the treatment room have been upgraded. Six of these rooms include a small extension, which while small, is an important addition to the room, as it gives parents enough space to fully extend the new chair beds without disturbing the cot that their baby is in.

Kylan's mam Sarah remembers being delighted when a new chair to sleep in arrived for their room – you can read more about Kylan's journey on pages 2-3.

The lighting in the rooms has also been replaced with dual level low power lighting. In the past, parents

tended not to switch on the ceiling lights during the night, for fear of disturbing their sleeping baby. Task lighting and additional sockets have now been installed beside the chair beds, to provide softer light and easy access to charge devices such as mobile phones or laptops – allowing parents to more easily keep in touch with family, friends and work, in this difficult time away from home.

The treatment room was also upgraded to modern standards, with modern lighting and easy-clean surfaces installed. New shelving systems were installed in the store rooms and the staff changing/shower was also upgraded.

*"It's amazing to see the difference in the rooms of Naz Ward. Those nights of trying to snatch a few hours sleep while sitting up, or sleeping in what was a very cramped space on the floor, are gone. I know that this upgrade will make all the difference to the families who stay there and will provide them with much-needed comfort in a difficult time."*

– Catherine, mam of David who was a patient on Naz Ward.



# Thank you for CONTINUING TO do whatever it takes FOR SICK CHILDREN!

We have been overwhelmed by the kind-hearted spirit, creativity and energy of all our supporters making a difference in their communities, all over Ireland. In a year of uncertainty, thank you for going the extra mile and for continuing to find new and exciting ways to support the sick children in CHI at Crumlin.



In July last year, Dessie and Betty Flynn held a beautiful outdoor garden party to celebrate their 50th Wedding Anniversary. In lieu of presents, they very generously asked their family and close friends to make a donation to Children's Health Foundation Crumlin and raised an incredible €3,106!

Dessie and Betty's son, Desmond, was a patient of St. John's Ward in the '80s and thanks to the amazing staff in CHI at Crumlin, Desmond made a great recovery. The Flynn family have continued to show their appreciation and support over the years, and in past Christmases have held many fundraisers through Wren Boys Humming on St. Stephen's night, to raise funds for St John's Ward. Their ongoing support has made a very real difference to the lives of the children and their families in CHI at Crumlin. Thank you Flynn Family!

If you'd like find out more about fundraising for Children's Health Foundation Crumlin, you can reach us at [communities@childrenshealth.ie](mailto:communities@childrenshealth.ie) today.



## 10KM A DAY FOR A YEAR!

Joe Hammel is raising funds for Children's Health Foundation Crumlin by running 10km a day, for a whole year. *"It is tough but the support that I have received to date provides me with much needed confidence boosts to keep going."*

In June 2019, Joe's 7-year-old son, Joseph, was diagnosed with having a large inflammatory tumour between his heart and lung.

*"In the 12 hours after admission to CHI at Crumlin, Joseph's health rapidly deteriorated and Joseph needed two blood transfusions in the next 36 hours. He underwent surgery for a biopsy on the tumour within a number of days of admission. Then in December 2019, Joseph underwent his second surgery to remove the tumour on his lung."*

*Joseph was fully aware of everything and the fantastic medical team kept him informed of everything throughout this journey. Joseph's bravery was remarkable.*

*From the first day we arrived in CHI at Crumlin on 18 June 2019, through the months of chemo, surgeries and rehabilitation, we can never repay the hospital and staff for everything they did for us."*

Joe has been running 10km each day since July 1st 2020, and has so far run over 2,000km. Thanks to the generosity and support of family, friends, and neighbours who see him running by, he has raised over €30,000 to support the little patients and their families in CHI at Crumlin!

*"We will forever be grateful and never forget the exceptional care provided to our son Joseph by CHI at Crumlin. Our son's recovery is down to the truly amazing talent and care provided by the medical teams in Crumlin, and we want to see this amazing work continue to benefit current and future sick children"*



**Check out Joe's fundraising page here [www.justgiving.com/fundraising/joehammel](http://www.justgiving.com/fundraising/joehammel).**

**You can be like Joe and make a big difference for the little patients in CHI at Crumlin!**

**Join us and show your support by taking part in Kilometres4kids this year. To find out more, visit [www.cmrf.org](http://www.cmrf.org) and see how you can translate your kilometres into vital funds for sick children in CHI at Crumlin.**





**FOR BEING PART  
OF OUR AMAZING  
COMMUNITY  
OF SUPPORTERS!**

2020 was a year like no other, but your ongoing support and kindness made all the difference to the sick children and their families in CHI at Crumlin.

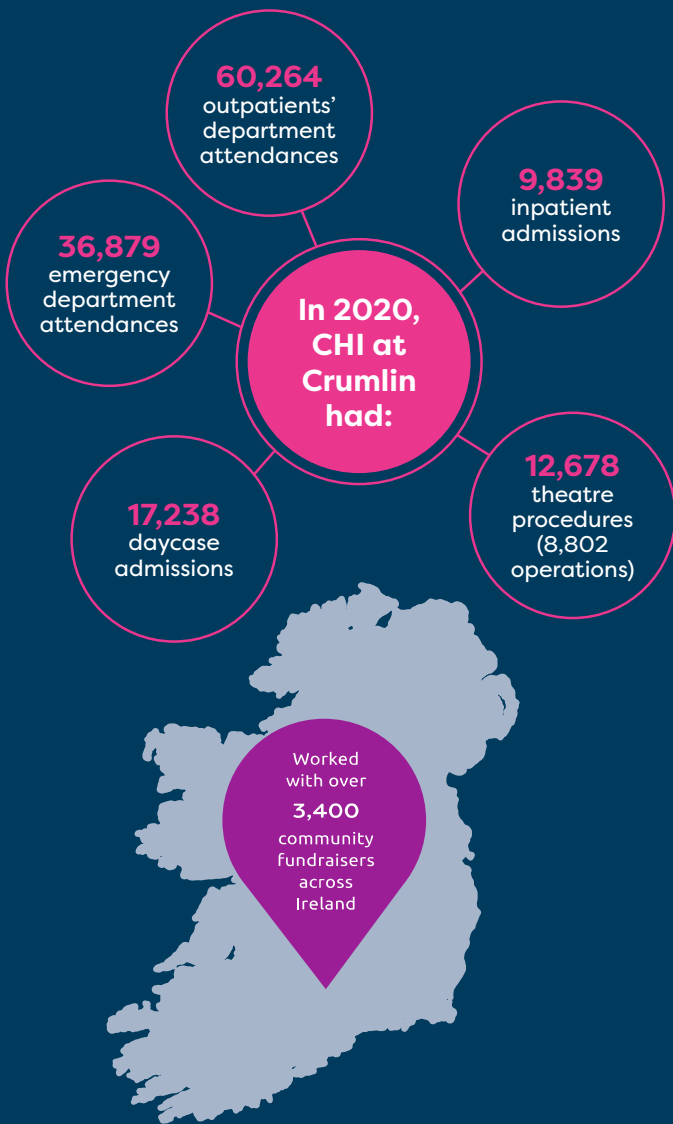
Even in these unexpected times, thousands of sick children continued to visit CHI at Crumlin and were able to receive the care that they needed. We are so grateful for all the individual donations, bequests, fundraising events and many creative ways that amazing people like you find, to support these little patients when they need it most.



Children like Hayley and Shaye...



You are part of an amazing community of care, supporting children's health in Ireland by giving every sick child the very best chance. And we have achieved so much together...



Your phenomenal support in 2020 has helped make a real difference for sick children in CHI at Crumlin in so many ways during this challenging time, as the hospital faced the new challenge of COVID-19 while continuing to provide urgent and ongoing care to patients and their families:

