

# YOUR ECHC

News from Edinburgh Children's Hospital Charity

[echcharity.org](http://echcharity.org)

Spring 2023

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The little boy who has spent 259 nights of his short life in hospital



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**Edinburgh Children's Hospital Charity**  
child first, patient second.



Scottish charity number SC020862

# welcome

from ECHC CEO,  
Roslyn Neely



**Welcome to the spring edition of *your ECHC*. I hope you enjoy reading about some of the inspiring support we can deliver for children and families because you have helped us to do so.**

I'd like to start by thanking you. Thank you for the unwavering and loyal support that you've shown over a challenging period.

A global COVID pandemic and a move to the brand-new Royal Hospital for Children and Young People (RHCYP) have challenged the best of us. But you, our wonderful supporters, have been there for us throughout – and for that we salute you.

Without you, we could not have continued to fund an enormous range of creative adventures, activities and performances which distract, reassure and entertain children in hospital.

Without you, we could not have continued to fund ground-breaking research and advanced medical equipment to help our NHS colleagues tackle the most complex illnesses.

Without you, we would not be able to transform bedsides into art galleries, waiting areas into discos and courtyards into concerts – all to ensure children are less afraid, less worried and feel more comforted throughout their hospital journey.

The reality is that every day young lives are held on a knife edge as children, families and NHS staff fight devastating and complex illnesses. Every day, families do their best to put on a brave face. And every day we are there to support them.

We couldn't do this without you. So please enjoy reading about how your support continues to make life better for thousands of children, young people and families each year.

Thank you!

Roslyn



# Hector the Hero

Little Hector was born at 23 weeks, weighing just 655grams (1.6lbs). Doctors said he may only live for a day or two and his parents were told to say their goodbyes.

But Hector the Hero defied the odds and celebrated his first birthday last November.

He has hydrocephalus due to a bleed on his brain, chronic lung disease, a feeding tube and centralised sleep apnoea – a sleep disorder where breathing rapidly stops and re-starts.

Mum Marie Clare said: "Hector spent 161 days in the Simpsons Neonatal Unit, then a further 98 days at the RHCYP, during which time he had 15 operations.

**"For the first two months of Hector's life, we were just focusing on making it to breakfast, then lunch, then dinner – praying he would survive.**

"The care and love we have been shown by everyone at the RHCYP has been outstanding. The doctors, nurses, domestics, physios and

ECHC team have all been such a huge part of his journey. It's thanks to everyone there that Hector is here with us.

"Hector loved it when people from the charity would visit to dance, sing and do creative play and massage with him. One of the first times we saw him laugh was during an ECHC show, which was really special.

"When he was born, we decided that even if we only had one day, 11 days or 111 days with him, we would make sure they were the very best days. It certainly hasn't been easy, but it has been the best year of our lives because Hector's here."



**It's only through donations from supporters like you that we can be there for families like Hector's.**

**If you can, please consider helping today at [echcharity.org/donate](https://echcharity.org/donate)**

for up-to-date news follow us on [@echcharity](https://twitter.com/echcharity)



# All Aboard the Clubfoot Train!



Babies born with clubfoot face a five-year treatment journey which begins shortly after birth and involves multiple hospital visits, stretching, casting and sometimes surgery. It can be a long, challenging and painful process.

The orthopaedic and physiotherapy teams asked ECHC to help create a keepsake for children with clubfoot; to keep them on the right track with rehabilitation and stop them running out of steam. Together we came up with the idea of a wooden train, based on building blocks so that it's fun to play with too!

Zoe (pictured), age 7, was one of the first children to receive her completed train. Mum Anna said:

**"Clubfoot hasn't stopped Zoe. She does gymnastics, ballet, swimming, and loves running around with her friends. In fact, we often forget that she has clubfoot! She's an inspiration to us."**

"Zoe was very excited to contribute to ECHC's clubfoot train project. We think this is a lovely idea to help children on their clubfoot journey. It recognises progress and commitment to the treatment plan and gives children something they can really look forward to each time they attend hospital."



# Transforming A&E at Livingston's St John's Hospital



When a child is injured or unwell, the possibility of a long wait in an unfamiliar place can make the whole experience scarier.

Working alongside Staunch designers, and thanks to supporter donations, we transformed the paediatric area of St John's Emergency Department into a colourful, calming and child-friendly environment.

Local children and young people were actively involved in the makeover. When asked what they liked most about their West Lothian landscape, the unanimous answer was the green hills, trees and birds – all of which have been incorporated into the awesome new artwork.

## Complementary Therapy

Going through medical treatment, or supporting a child through treatment, can be a very worrying time. Thanks to supporters like you, complementary therapy sessions are now available to children and families using the hospital, offering relaxation and relief.

Our Complementary Therapist Susie offers massage therapies, personalised aroma nasal inhalers, and a listening ear – all of which help to reduce anxiety and pain, improve sleep and increase wellbeing. As one parent said, "After my massage I felt refreshed and ready to face the challenges ahead."



## Make a Will Month

This March is Make a Will Month, and we've teamed up with Jones Whyte Solicitors to offer a free will writing service to all ECHC supporters throughout 2023. If you would like more information please email [hello@echcharity.org](mailto:hello@echcharity.org)

**These projects would not be possible without your support. To make a donation, visit [www.echcharity.org/donate](http://www.echcharity.org/donate)**



# To Infinity and Beyond...

## Space Academy

When a child has an illness that they could pass on to someone else, or when they need to be protected from infection, they may be placed in clinical isolation. This can mean staying in their hospital room for days, weeks or even months at a time, unable to play outside or to enjoy visits from friends and relatives.

Children in isolation often feel confused, scared, sad and lonely. We wanted to find a way to help them feel a little better, so asked ourselves, 'Who goes through a similarly isolating experience?' And we all agreed on astronauts!

With the backing of Tim Peake himself, we designed and launched Space Academy – a 21-day programme of activities, based on the real-life experiences of an astronaut.

Young patients become the captain of their hospital journey from blast off to touch down. Using the Space Academy app, they complete daily missions to entertain, distract and gain a sense of control at a time when they have very little.

Katie, aged 9, was one of the first to embark on the cosmic quest. Her dad said:

*"Space Academy has kept Katie's brain engaged in something other than her treatment; she has really enjoyed the combination of arts, crafts and science experiments."*

Our heartfelt thanks to Tim Peake for supporting our out of this world project and to Barclays for their very generous funding.

**We rely solely on donations to fund projects like Space Academy which make time spent in hospital that little bit better for children and their families. If you feel inspired to help, visit [echcharity.org/donate](https://echcharity.org/donate)**

find us on  /echcharity

# Upcoming Events

We have something for everyone! Sign up today to help seriously ill children in hospital. To find out more about any of the below and to get involved, visit [www.echcharity.org/events](http://www.echcharity.org/events)

- **April 1<sup>st</sup>**  
Tandem Skydive 📍 Glenrothes
- **April 9<sup>th</sup>**  
Kilomathon Scotland 📍 Edinburgh
- **April 23<sup>rd</sup>**  
2023 TCS London Marathon
- **April 30<sup>th</sup>**  
Kiltwalk 📍 Glasgow
- **May 27<sup>th</sup>**  
Edinburgh Marathon Festival
- **June 3<sup>rd</sup>**  
Tough Mudder 📍 Drumlanrig Castle
- **June 9<sup>th</sup>**  
ECHC Get Together 📍 Edinburgh
- **July 1<sup>st</sup>**  
Tour de Little France 🚲 Virtual
- **September 17<sup>th</sup>**  
Kiltwalk 📍 Edinburgh
- **September 24<sup>th</sup>**  
Scottish Half Marathon & 10k, 📍 Edinburgh
- **September 30<sup>th</sup>**  
Tandem Skydive 📍 Glenrothes
- **October 6<sup>th</sup>**  
Save Point Gaming Marathon 🚲 Virtual
- **October 22<sup>nd</sup>**  
Women's and Men's 10k 📍 Edinburgh
- **December**  
All Wrapped Up 📍 Edinburgh



April 1<sup>st</sup>  
Skydive



May 27<sup>th</sup>  
Edinburgh Marathon



July 1<sup>st</sup> — Tour  
de Little France



October 22<sup>nd</sup>  
Scottish 10k

# Please donate today!

## Yes, I'll help **today** with a gift of...

- ☐ **£15** could pay for a child to understand, through play, the technology their surgeons use and help take away the fear of medical procedures.
- ☐ **£44** could help provide a listening ear for a worried parent, a chance to talk through their emotions with someone who understands.
- ☐ **£120** could provide escape and distraction through magic for eight children, whose stay in hospital could be painful and scary.
- ☐ **Other** £

For security reasons please use the freepost envelope enclosed and do not send cash through the post

☐ Cheque made payable to Edinburgh Children's Hospital Charity

☐ Card

Card No:

Expiry:  /  CVC:

Signature

Date

## MY DETAILS:

Title

Full name

Address

Postcode

Postcode

Email

Phone No

You don't have to leave your email address or phone number, but if you do, we'll use these to keep you updated on our news, appeals and how you can get involved. You can opt out at any time by emailing [hello@echcharity.org](mailto:hello@echcharity.org) or calling **0131 668 4949**. We promise to keep your details safe and never sell them or swap them with anyone. Our privacy policy has been updated for fundraising purposes. The updated policy can be viewed at [echcharity.org/privacy-policy](http://echcharity.org/privacy-policy) or you can contact us for more information.

## PLEASE FOLD AND SEND YOUR DONATION FORM IN THE SELF ADDRESSED FREEPPOST ENVELOPE:

Edinburgh Children's Hospital Charity

First Floor, 1 Wester Shawfair, Danderhall, Dalkeith, EH22 1FD



**Edinburgh  
Children's  
Hospital Charity**  
child first, patient second.

You can also donate online at  
[www.echcharity.org/donate](http://www.echcharity.org/donate)  
or call **0131 668 4949**

## Yes, I'll help long term by giving **regularly**

I want to give £

Every (please tick)

Month

Quarter

Year

on the (please tick)

1st

15th

25th

**Instruction to your bank or building society to pay  
by Direct Debit** Edinburgh Children's Hospital Charity  
Direct Debit Originator Number 801897



Account Name

Bank / Building Society Account No

Sort Code

Name of Bank / Building Society Branch

Bank Address

Postcode

## Instruction to your bank or building society

Please pay Edinburgh Children's Hospital Charity Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with Edinburgh Children's Hospital Charity and, if so, details will be passed electronically to my bank / building society.

Signature

Date

## BOOST YOUR DONATION BY 25P FOR EVERY £1 YOU DONATE THROUGH GIFT AID.

*giftaid it*

Gift Aid is reclaimed by Edinburgh Children's Hospital Charity from the tax you pay for the current tax year. In order to claim Gift Aid on your donation you must tick the box below.

I am a UK taxpayer and would like ECHC to reclaim the tax on donations I have made in the last four years and for all future gifts of money that I make to be Gift Aid donations. I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year then it is my responsibility to pay the difference. ☐

No I am not a UK tax payer. ☐

Please email [hello@echcharity.org](mailto:hello@echcharity.org) if you wish to cancel this declaration.

## THE DIRECT DEBIT GUARANTEE

- This Guarantee is offered by all banks and building societies that accept instructions to pay Direct Debits.
- If there are any changes to the amount, date or frequency of your Direct Debit Edinburgh Children's Hospital Charity will notify you 10 working days in advance of your account being debited or as otherwise agreed. If you request Edinburgh Children's Hospital Charity to collect a payment, confirmation of the amount and date will be given to you at the time of the request.
- If an error is made in the payment of your Direct Debit, by Edinburgh Children's Hospital Charity or your bank or building society, you are entitled to a full and immediate refund of the amount paid from your bank or building society. If you receive a refund you are not entitled to, you must pay it back when Edinburgh Children's Hospital Charity asks you to.
- You can cancel a Direct Debit at any time by simply contacting your bank or building society. Written confirmation may be required. Please also notify us.

Scottish Charity Number: SC020862