


# YOUR ECHC

News from Edinburgh Children's Hospital Charity

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

Spring 2024



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**Edinburgh  
Children's  
Hospital Charity**  
More than Medicine

Scottish charity number SC020862

# welcome

from ECHC CEO,  
Roslyn Neely



**Welcome to the spring edition of *Your ECHC* – essential reading for 2024!**

We've been very busy since the last edition, and it's my pleasure to share with you, our wonderful supporters, just some of the ways that your donations have supported children and their families at the Royal Hospital for Children and Young People (RHCYP) as well as further afield.

Angus's story on pages 4 and 5 must be a highlight. We are encouraged by the life-changing impact that the laser surgery, funded by an ECHC supporter, has had for Angus and his family.

In response to the mental health crisis facing so many of Scotland's young people, we launched The Haven in Tranent in September 2023. I'm delighted to report that our service has since gone from strength to strength, with our dedicated team providing the support and assistance that so many families told us just wasn't there. Read some of the fantastic results on page 7.

We are excited to have been chosen by Edinburgh Airport as its nominated charity for the next two years. What an opportunity this affords us to show so many people from across Scotland – and around the world – the impact of our work. We're looking forward to showing all the staff at Edinburgh Airport what it means to be part of our family.

I hope you enjoy reading this edition of Your ECHC. It's just the tip of the iceberg in terms of what you are helping to achieve for so many children and their families. We are inspired by them, and by you, every day. Thank you for being part of it.

**Roslyn**





# The power of play

Nowhere is play more important for a child than in hospital. Play is familiar and reassuring. It helps children to make sense of their treatment, distracts them from scary procedures, and can be a way of communicating when words just aren't enough.

Last year, our wonderful supporters (that's you!) contributed over £50,000 to make sure that children in hospital get to play. Without you, these children wouldn't have access to the toys, games and distractions that help them through worrying and sometimes painful hospital visits.

**As the cost of living crisis continues, we need your help to support the hospital's incredible Play Team who work tirelessly every day to bring play to children in hospital, helping them to cope with what is happening to them and aid their recovery.**

**Here are two ways you can get involved and support children's recovery now:**

**1) Fund the Fun** Make a donation to our Power of Play campaign to provide toys, activities and games to the hospital Play Team.

**2) Have a Play Date** You're never too old to have fun! Just like it does for children, play at any age builds brains, reinforces relationships and relieves stress. Get your kids, colleagues, friends or family together for a Play Date.

Scan the QR code to sign up now.



**We urgently need to raise £5,000 before the end of April to help children be children, even though they're in hospital. Please scan the QR code to fund the fun by donating today.**



# A lifetime of seizures at an end

Meet Angus, an inspirational 17-year-old who is gearing up for a very different 2024 – his first year without seizures thanks to life-changing new epilepsy surgery.

Angus was diagnosed with epilepsy at four years old. The condition has affected his whole childhood, and he has had at least one seizure every week for the last 13 years.

Now, thanks to pioneering new laser technology brought to the capital via a partnership between ECHC, the Welch Trust and NHS Lothian, Angus's dream of being seizure free has finally come true.

Last October, Angus became one of the first young people in Scotland to have MRI-guided Laser Interstitial Thermal Therapy (LITT) surgery – a minimally invasive treatment which uses a laser to remove the brain tissue causing seizures.

Mum Nicki said: "Our lives have been consumed with Angus's epilepsy since he was five. He has been on lots of very heavy medication, had wires in his head, brain stimulation, so many tests and scans.



*"The build up to him having a seizure would last a few days, then after it would take another couple of days for him to recover, so I don't think he's ever had a normal day. He would say, 'I just want to get rid of my epilepsy and get on with my life.'"*

"Of course, it was nerve-racking Angus being only the second young person in Scotland to have the surgery, but we were elated that it was an option. The process was mind-blowing and recovery was so fast.



# Laser Interstitial Thermal Therapy

LITT is a new and proven, minimally invasive treatment which uses a laser to remove brain tissue that is causing seizures. Children and young people referred for laser surgery are diagnosed with refractory (medication resistant) epilepsy. They may experience severe and frequent 'drop down' seizures; up to 100 in one day.

LITT surgery treatment was previously only available at Great Ormond Street Hospital (GOSH) and in Houston, Texas. The laser equipment is now part of the Scottish National Paediatric Epilepsy Surgery Service, based at the RHCYP in Edinburgh, meaning children will come to the capital from all over Scotland to have the surgery.

The former surgery choice practiced in Edinburgh was open brain surgery, which lasted around seven hours, had a recovery time of one to three months, and resulted in an ear-to-ear scar across the top of the child's head. The LITT precision technology reduces this surgery time to around two hours, is much less invasive and has a shorter recovery time.

In appropriately selected cases, laser surgery can stop seizures entirely and cure the child's epilepsy.



Angus's scar from LITT surgery

**"You'd never know he'd had brain surgery. It's incredible this is now available in Scotland. It's going to change so many lives."**

"I can't even put into words what it means to him, and all our family, for him to be seizure free after 13 years. He's a remarkable boy who has shown so much resilience. His future is looking so bright, and we're incredibly proud and excited for him."

Following a request from the National Paediatric Epilepsy Surgery Service to ECHC, we identified the Welch Trust as the ideal partner to bring the LITT technology to Scotland.

Victoria Welch, Trustee of The Welch Trust and a former paediatric nurse, said, "We are so happy to hear about Angus's successful

procedure and so proud that the LITT technology we helped bring to the hospital is already changing lives. This is a heart-warming piece of news and is also an important milestone in the Welch Trust's commitment to advancing medical care for very sick or terminally ill children."



**We are currently fundraising to enable more young people like Angus to benefit from laser surgery in the future. We need to raise £70,000 over the next five years towards the running costs of the LITT equipment. If you can help to support our work, please get in touch on [hello@echcharity.org](mailto:hello@echcharity.org)**



## Edinburgh Airport's new charity partner has landed

**(Spoiler: It's us!)**

We are delighted to announce that we are flying high as **Edinburgh Airport's** new Charity of the Year for 2024 and 2025!

More than 60 different charities and organisations put themselves forward to be the airport's next partner, so we're over the moon to have been chosen. We are enormously grateful to our incredible supporters who championed us, and to all of the airport staff who voted for us.

Children come to the hospital from across Scotland. Just like the airport, we are local to Edinburgh, but we serve a nation.

With Edinburgh Airport as our partner, we hope to reach every child who needs our support, and make a huge impact on so many young lives. Together, the sky's the limit!

Gordon Robertson, Edinburgh Airport's Chief Communications and Sustainability Officer, said: "The work ECHC does to impact the lives of young people and their families when they need it most is truly inspiring, and it's a charity we are proud to partner with for the next two years."

**If you're heading off on holiday soon, keep your eyes peeled for our donation boxes and signage featuring some superstar children who were instrumental in us winning the airport's support. Be sure to drop us some spare change (any currency much appreciated) if you can!**

find us on  /echcharity



## The Haven goes from strength to strength

The Haven, our children's mental health service based at The Fraser Centre in Tranent, launched in September last year in response to the growing mental health crisis facing children and young people.

Our team is here to listen, to support and to help families through the challenges that having a child who struggles with their mental health can bring.

At this early stage, 52% of visitors reported improved mental health during or following their session. One young person who was finding it difficult to attend school, is now going back. A mum who had not found the right support to cope with her child for 13 years, felt able to come through our doors for help. As families told us:

*"It's the first time in a long time I've felt some relief."*

*"When I came in I felt stressed, now I feel normal."*

The Haven is succeeding and we are changing lives for the better. But we need to do more. It is ECHC's ambition for every child who needs a Haven to have one in their local community. With your help, this is possible. Look out for our Big Give Appeal coming this May to find out how you can support this much needed service.

## What would you do with £25,000?

Spend it? Save it? Whatever you would choose to do, join Your Lottery today, and you could be in with a chance of winning – every week. It costs just **£1 per entry** – there's never been a better time to have a flutter!

There's a 1 in 63 chance of winning with Your Lottery, so sign up today, and be proud, as you are making a real difference to seriously ill children. **Use the QR below or call 0370 050 9240, and you could be our next winner!**



## Make a Will Month

Could you make a lasting gift to help support children who need to use the hospital in future? 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 2024. If you would like to be a Future Funder and have a lasting impact for seriously ill children, please email [hello@echcharity.org](mailto:hello@echcharity.org)

## Spotlight on...

# Emma, ECHC Youth Worker

Meet Emma – our bubbly and brilliant youth worker. Emma is here to support young people through their hospital journey – whether it's chatting about their favourite hobbies, playing multiple games of Uno or simply offering a listening ear on a tough day. She can often be found on the wards, in our trademark red t-shirt and accompanied by her trusty bag of board games!

Emma says, "What I love the most about being an ECHC Youth Worker is that the type of support I provide varies depending on the young person I meet, so every day is so different.

"Sometimes, it's just about providing some distraction, so doing an activity that takes them away from the fact they're in hospital. I often meet young people and all they really need in that moment is for someone to talk and laugh with them while playing a game, or someone they can vent to on the hard days.

"I love finding out what young people are passionate about. I met a young person recently who loved kickboxing and it was obvious they could have chatted about it for hours and hours. It's amazing to see how enthusiastic they get.

"When I was young, I benefitted a lot from youth work, so I know first-hand how much of a difference it can make.



Emma,  
ECHC Youth Worker

**"It meant so much to me just knowing that I had that safe person who I could go to for support. I want to be that person for other young people."**

"Young people in hospital, especially those with long term conditions who spend a lot of time here, can miss out on the experience of just being a young person. They don't always get the opportunity to be themselves as their health condition takes priority. I want to give them that little bit of space to find out who they are."

**"I was feeling pretty down and in a lot of pain and wasn't feeling myself today after my spinal operation. Then Emma walked in really happy and cheery and asked if I wanted to play Uno. That one small thing made me feel so much better! Thank you for making my day!"**

Young person after a youth work session





# Nora's hospital journey

Nora was a happy toddler until everything changed very suddenly. One day at nursery, just before her second birthday, Nora's heart began beating very fast and she became lethargic. She was rushed to the children's hospital.

Marie, Nora's mum, tells us: "Our world collapsed. In the next few hours, she had three cardiac arrests. Nora's heart was incredibly poorly and they didn't know if they could save her.

"The only thing that could help was a life support machine called ECMO which was in Glasgow but transferring her was very risky.

"She was on ECMO for a week, unconscious and intubated. It was terrifying, but every hour was a victory. We found out she had also suffered a stroke. When she woke up 12 days later, she could only move her right side.

**"Back in Edinburgh, she had to relearn everything – eating, talking, walking and using her left arm and hand. The progress she made each week was spectacular! We couldn't be prouder."**

"The intensive care, Borthwick ward, Physio and Occupational Therapy teams were so great and really helped her to be a toddler again.

"ECHC was by our side every step of the way. Once she was allowed out of the ward, we just loved going to the Hub to play almost every day, chat with the team and take part in the many activities offered like Therapets or sessions with the zoo.

"We know that ECHC's involvement with Nora helped her recovery, supported her to cope with what had happened, and saved us as family. Nora's future is looking so bright now – we are so grateful to the hospital and ECHC teams."





### Pumpkins a plenty

If you can't get to a pumpkin patch, we'll bring a pumpkin patch to you! Thanks to the incredible generosity of Kilduff Farm in East Lothian, we had 450 pumpkins to fill our very own Hub Patch for Halloween, allowing families who would miss out on pumpkin picking due to being in hospital to create lasting and positive memories.



### Does he ever rest?

Phenomenal fundraiser Dave – who doubles as Duloch Spiderman – and dad Kevin took on the mammoth challenge of conquering Mount Everest Base Camp. Dave and Kevin climbed 17,600ft, trekking for 11 days and battling altitude sickness. Dave began fundraising for ECHC during lockdown and has now raised over £23,000 for children in hospital.



### Hair today, gone tomorrow!

Pierre Schoeman, Scotland rugby international and Edinburgh Rugby prop forward, braved the shave and let us buzz off his luscious locks, raising an amazing £10,050 for children facing a hospital stay. Thank you so much for your sheer determination (okay, we'll stop now) and generosity, Pierre!



### Singing sensations

Well the weather outside was frightful, but our choirs were so delightful! An enormous thank you to everyone who sang, shook buckets and jingled bells on The Dome steps over Christmas, raising a phenomenal £9,500. Here's to Christmas 2024 where we'd love to raise even more!

Without wonderful supporters like this, we couldn't be there for children when they need us most. Have an idea for a fundraiser? Get in touch: [hello@echcharity.org](mailto:hello@echcharity.org)  
If you're already fundraising let us know and you could be featured here!

find us on  [echcharity](https://www.facebook.com/echcharity)

# Challenge Yourself!

## 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 [echcharity.org/events](https://echcharity.org/events) or scan the QR code.



- **April 7th**  
Kilomathon Scotland 📍 Edinburgh
- **April 13th**  
Tandem Skydive 📍 Glenrothes (Limited spaces left!)
- **April 25th**  
Ultimate Sports Quiz, Brewhemia 📍 Edinburgh (Tables selling fast!)
- **April 28th**  
Kiltwalk 📍 Glasgow
- **May 25th**  
Edinburgh Marathon Festival 📍 Edinburgh
- **June 14th**  
ECHC Get Together, Prestonfield House 📍 Edinburgh
- **August 18th**  
Scottish Half Marathon and 10k 📍 Edinburgh
- **September 15th**  
Kiltwalk 📍 Edinburgh
- **September 22nd**  
Women's and Men's 10k 📍 Edinburgh
- **October 5th**  
Tandem Skydive 📍 Glenrothes
- **October**  
Gamechangers: Gaming Marathon 📍 Virtual
- **November 2nd**  
Supernova 5k 📍 Forth Road Bridge

Spaces available for the team relay, 10k, 5k & junior races



April 13<sup>th</sup>  
Skydive



May 25<sup>th</sup> – Edinburgh  
Marathon Festival



September 15<sup>th</sup>  
Kiltwalk, Edinburgh

# 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 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	<input type="text"/>
Full name	<input type="text"/>
Address	<input type="text"/>
	<input type="text"/>
Postcode	<input type="text"/>
Email	<input type="text"/>
Phone No	<input type="text"/>

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 RETURN YOUR DONATION FORM TO:

**Freepost Plus RTYB-TEXG-SZGG**  
**Edinburgh Children's Hospital Charity**  
**1 Wester Shawfair, Danderhall, Dalkeith EH22 1FD**

You can also donate by scanning the QR code, visiting [www.echcharity.org/donate](http://www.echcharity.org/donate) or calling **0131 668 4949**



**Edinburgh Children's Hospital Charity**



## 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.

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