training is critical
Innovative equipment allows doctors and nurses to prepare for emergencies
page 10

music matters
Find out about our new music programme
page 8

Edinburgh Children’s Hospital Charity
child first, patient second

staying in touch
why communication is key
page 6

Scottish charity number SC020862
Dear Reader,

In this issue of Edinburgh Children’s Hospital Charity’s *Friends* magazine, we’re highlighting the importance of staying in touch. Time spent in hospital, away from family and friends, has the potential to be an isolating experience both for children and young people and their parents/carers who are taken away from day-to-day normality. ECHC understands that this is exactly when the support of loved ones is most needed and it’s the reason we’re funding the technology to make this easier (read more on page 6).

We also want to stay in touch with you, our supporters. On page 15 you can learn about the new rules affecting charities. This will ensure you only hear from us if you want to. If you would like to keep hearing about what we’re up to — including projects like our new music Programme and innovative training for hospital staff, then please stay in touch!

With best wishes from

the ECHC team

You can also visit our website at echcharity.org
find us on facebook.com/echcharity
and follow us on Twitter @echcharity

First Floor,
1 Wester Shawfair,
Danderhall, Dalkeith,
EH22 1FD
0131 668 4949
hello@echcharity.org

for up-to-date news follow us on @echcharity

---

*our aim*

*“We believe nothing should get in the way of being a child.*

*we exist to transform the experiences of children and young people in hospital so they can be a child first and a patient second.”*
ECHC had a chance to raise awareness of our work with MSPs in early January 2018, when we were selected to have an exhibition at the Scottish Parliament. The aim of our exhibition stand was to explain that while people mostly associate us with working in Edinburgh at the Royal Hospital for Sick Children, we are in fact heavily involved in projects supporting children from all across Scotland including the area of children’s mental health.

Our Chief Executive Roslyn Neely met First Minister Nicola Sturgeon who said: “Edinburgh Children’s Hospital Charity does some incredible work supporting children and families in the east of Scotland as well as raising funds for equipment and services. I was honoured to have the opportunity to meet Roslyn and hear first-hand about their work. I’m sure ECHC will go from strength to strength over the next year.”

Roslyn said: “It is incredible to have the backing of the First Minister. We really appreciate the support we receive from all politicians which allows us to reach people who may not be aware of our work.”

After meeting us at the Scottish Parliament, many MSPs have pledged to visit our projects in future and some even took on our challenge to take part in a competitive game of ‘Operation!’

We are very grateful for all the support we received and appreciate the boost we have been given by the First Minister.

Since November 2016 ECHC have received fantastic support from one of our corporate partners, Canon Medical Research Europe Ltd. After a hugely successful first year which saw over £4,000 raised, staff voted to continue their partnership with ECHC into 2018. Things have already kicked-off in style with one employee running the West Highland Way, raising over £1,400 in the process. With many more exciting fundraising and awareness raising events on the horizon we’re sure that this year is going to be even bigger and better!

If you would like to find out about the ways in which your company can become a partner of Edinburgh Children’s Hospital Charity, please get in touch! Email hello@echcharity.org or call 0131 668 4949 to talk to one of our corporate fundraisers.

Children and families at the hospital recently received a visit from the 12th century historical reenactment society Historia Normannis, who provided something a little out of the ordinary when they descended on the hospital in full period costume. Members of the reenactment group, including Lord John, two noble ladies and three knights shared fascinating stories of everyday life in Norman times including how they dyed their clothes, cooked their meals and defended themselves from rivals.
staying in touch

The staff within Edinburgh Children’s Hospital are amazing and make stays as fun filled and good as they can be under her circumstances. During long hospital stays it’s so important to have contact with the outside world. It really helps to keep your spirits up.

Aud, Kira’s mum

Kira (14) has spent the past three and a half years in and out of hospital being treated for a form of cancer called neuroblastoma. For some of that time she was kept in isolation to protect her weakened immune system. Kira’s mum, Aud, told us what it’s like “We most miss sleeping in our own beds and our home comforts; we miss being free to walk outdoors and to exist within society; we miss ‘normality’; we miss family and friends; school; being able to go the supermarket - everything that other people can take for granted.”

Everyday life may be turned upside-down, but families like Kira’s take strength from staying connected. Aud explains “The staff within Edinburgh Children’s Hospital are amazing and make stays as fun filled and good as they can be for Kira under her circumstances. During long hospital stays it’s so important to have contact with the outside world. It really helps to keep your spirits up.”

With this in mind, ECHC have funded the hospital WiFi system KidsNet for the past eight years, which provides free, safe internet access for children and family members helping to make the experience of being in hospital more positive and less of an interruption to ‘normal’ life.

However, we want to make it easier than ever to stay in touch. The system in the current hospital presents limits to connectivity which can be a source of frustration, particularly for older children. In advance of the move to the new children’s hospital opening, ECHC is funding enhancements to the ‘bedside environment’ for inpatients that will provide entertainment, distraction and connectivity to the outside world; giving young patients a practical way to control their immediate environment when in hospital. This will take the form of a tablet, TV and a controlled lighting system for each bed.

Ginkgo are the agency in charge of delivering the enhancements funded by ECHC, in the new hospital. They plan to work with staff and young patients on the content of the new system, which will benefit from an enhanced WiFi connection throughout the hospital and enable the use of FaceTime and Skype for staying in touch, as well as streaming TV and films. Games, bedtime stories and educational materials to help understand medical treatments and after-effects could be available. There could also be activities information to keep children and young people connected throughout the hospital, including those run by ECHC’s own Arts Programme.

We rely solely on donations to fund projects that will transform the experience of being in hospital for children and young people.
We have recently launched a new Music Programme which aims to help those in hospital regain a sense of control by providing an outlet for expression and creativity – and importantly, by letting children lead the way.

Many children and young people in hospital are particularly vulnerable because they lack control over what is happening to them and their environment. It is this lack of control that makes the positive effect of music in hospital particularly important.

Alongside our partnership with the Scottish Chamber Orchestra, which has been running for several years, ECHC have launched a new initiative with Edinburgh-based community music group Tinderbox Collective. Their aim is to ‘ignite a spark’ in young people and provide exciting opportunities to those who need them most.

Jed Milroy, musician and General Manager of Tinderbox Collective, explains “Tinderbox takes the idea of an orchestra and expands it in every direction possible to include as many people, as many instruments and as many ways of making sounds as we can - so that it is as exciting and innovative as possible.” Musicians from Tinderbox have been working in the Child and Adolescent Mental Health Service since last year, engaging young people in drumming, songwriting and DJ-ing workshops. The project has now expanded to include regular sessions at the Royal Hospital for Sick Children.

Tinderbox is comprised of respected local artists and gigging musicians; Mike Kearney will visit all the wards throughout the hospital while Hailey Beavis will be running regular sessions working with patients in the oncology and neurology departments who tend to be longer term.

Catriona, our Arts Programme Coordinator, explains why long term patients are a particular focus for the project: “We spoke to one young boy whose interest in music had been sparked at school and led to him playing the cello – we want to make sure that children who are in hospital for a long time don’t miss out on that initial inspiration to learn an instrument or continue accessing music.”

The benefits of playing music are wide-ranging, Jed explains: “We believe that playing music together lets people express themselves emotionally – it also involves working together as a team, making friends, developing confidence and letting people see that they have creative ideas - because everybody’s creative, everybody’s musical, that’s something we believe because we know it to be true!”

The Scottish Chamber Orchestra also deliver dynamic workshops for children on the wards – this year, the workshops were based on the children’s book The Chimpanzees of Happytown and composer Paul Rissman’s music set to the story. Joanna from SCO said “it was wonderful to have the children joining in with the songs and playing along on their own percussion instruments. We hope it created a really positive and fun atmosphere for the children and allowed them to experience and engage with live music.”

We are very grateful for the generous donations which have enabled us to fund our new Music Programme. We require ongoing funding to continue running this, as well as our overall Arts Programme. If you feel inspired to help provide children and young people with a more positive experience of hospital through music, you can donate to us by visiting echcharity.org/donate or by calling 0131 668 4949.
advantages of using lifelike dummies and replica life support machines that simulate the output of a critically ill patient. “Simulation training has become an integral part of our Critical Care practice. Over the last nine years that we have had the ‘SimBaby’ we have run scenario training for hundreds (maybe even thousands) of nurses and doctors in critical care, theatres and emergency departments.” ECHC have funded equipment for this training since 2008, which also benefits hospitals across Scotland. As Jon explains:

“Managing acute emergencies in critically ill children requires more than traditional lectures and textbook work – these have been fantastic training tools.”

Edinburgh’s Royal Hospital for Sick Children is one of the first major hospitals to adopt the highly innovative approach of in-situ simulation training, as it’s known, but the evidence shows that it is having a really positive impact on outcomes for patients. A study compared the picture ‘before’ and ‘after’ the introduction of regular in-situ training; after three years of weekly simulation training for staff to practice dealing with a deteriorating patient, the results showed that fewer children needed to be admitted to intensive care, and those who were admitted recovered more quickly and there were fewer deaths overall.

Dr Ulf Theilen, Paediatric Intensive Care Consultant who lead the study, said “We are delighted to see the regular team training having such a good effect for patients and their families. It shows the benefits from bringing different groups, making the team perform even better when it really matters.”

As a charity, ECHC want to support staff to provide the best possible care for children and young people so that they have a better chance of recovery and their families can return to normal life more quickly. Providing grants for training and research is an important part of what we do and the improvements made in treating critically ill children (thanks to this ECHC funded equipment) just goes to show how much of a difference it can make.

The answer: simulate scenarios that are as close as they can be to the real thing - in which all the staff who would need to respond in a genuine emergency are able to practice performing under pressure, making decisions, communicating and delivering complex critical treatments effectively. To make this kind of training possible, ECHC have funded specialist equipment in the form of life-size dummies or ‘Sims’. These mimic the responses of a deteriorating child or baby and allow critical care teams to hone their skills so they are prepared when someone’s son, daughter or grandchild requires an actual emergency response.

Dr Jon McCormack, Consultant in Paediatric Anaesthesia and Critical Care highlights the.
If you have a great idea to raise funds no matter how big or small, we would love to hear from you and support you with advice and a free fundraising pack with everything you need. Just email hello@echcharity.org or phone the community fundraising team on 0131 668 4949.

This year, Phil Crane is set to undertake a grueling trek from Amsterdam to Istanbul covering more than 2,500 miles to raise money for ECHC. Phil, who embarks on the arduous expedition on his 69th birthday, is planning to walk through eight countries in just seven months to follow in the footsteps of famous author Sir Patrick Leigh Fermor who inspired the walk. Phil has spent a lot of time in the hospital over the years as his daughter suffers from a chronic kidney problem, diagnosed when she was five.

“Being able to fulfil this dream as well as raising money for ECHC is incredible. From my own experiences of the hospital and the charity with my kids and grandchildren I know just how fantastic the service is they provide. I’m self-funding the entire trip so every penny raised goes to the charity. I have already managed to raise more than £2,000 but I would love for the total to be around £2,500 once I have completed the taxing trek.”

We are always amazed by people who do incredible challenges to raise funds for us. We have a packed calendar of events throughout 2018 – there’s something for just about everyone! To find out more about any of the events listed below, visit echcharity.org/events or email hello@echcharity.org.

### April
- **22nd**: Virgin Money London Marathon 2018, London
- **26th**: Sports Quiz, Edinburgh

### May
- **26th - 27th**: Edinburgh Marathon Festival

### June
- **15th**: Golf Day, Edinburgh
- **16th - 17th**: Tough Mudder Scotland, Drumlanrig Castle

### July
- **1st**: Forth Bridge Abseil, South Queensferry
- **29th**: Big Fun Run, Edinburgh

### September
- **1st**: Highland Fling Bridge Swing, Pitlochry
- **9th**: Great North Run, Newcastle
- **9th**: Pedal for Scotland, Glasgow to Edinburgh
- **16th**: Kiltwalk, Edinburgh
- **23rd**: Scottish Half Marathon & 10K, Edinburgh
- **28th - 29th**: The Girly Get Together, Edinburgh

### October
- **6th - 7th**: Tandem Skydive, Glenrothes

### November
- **9th, 10th & 11th**: The Kelpies Supernova 5K!

Charity places available! This fantastic 5K route is a great opportunity to immerse yourself in a light journey around the iconic 30-metre-high horse-head sculptures, the Kelpies. Why not make your entry count and apply for one of our charity places? Run for ECHC and you will also receive your own unique fundraising pack which includes a t-shirt, online fundraising page and personalised sponsor forms.

### December
- **13th**: All Wrapped Up For Christmas, Edinburgh

### Your Fundraising

We are always amazed by people who do incredible challenges to raise funds for us.
In May 2018, the rules governing how we can use your personal information are changing. The changes mean that organisations and companies including Edinburgh Children's Hospital Charity will no longer be able to contact you without you giving your express permission. Read our Q&A below to find out what this means.

**How will the changes affect me?**

We won’t be able to update you, our supporter, on the wonderful work you help us to do or tell you how you can continue to support us unless you give your express permission for us to contact you.

**How will the changes affect ECHC?**

We need to raise £2.2 million this year to transform the experiences of children and young people in hospital and other local healthcare settings. Without your support, it might not be possible to fund some of the services or projects we currently provide.

Our full privacy statement can be viewed online [echcharity.org/privacy](http://echcharity.org/privacy). If you would prefer a hard copy please let us know.

---

**What do I need to do?**

To give your permission for us to contact you in the future, we need you to let us know your contact preferences. Are you happy for us to contact you via post, email, phone or SMS? Let us know online at [echcharity.org/privacy](http://echcharity.org/privacy), by contacting us on 0131 668 4949 or by emailing hello@echcharity.org.

**What if I do nothing?**

If we don’t receive your contact preferences by 25 May 2018, we will have one opportunity to contact you after which you will no longer hear from us unless you get in touch directly.

---

**You can donate online at echcharity.org/donate or fill out the form below**

I WOULD LIKE TO GIVE £  

**YOUR DETAILS:**

Title:  
First name:  
Surname:  
Address:  
City:  
County:  
Postcode:  
Tel No.:  
Email:  

**PAYMENT METHOD**

- [ ] Cheque (made payable to Edinburgh Children’s Hospital Charity)  
- [ ] Card  
- [ ] Charity Voucher/Card  

**Card No.:**  
**Expiry Date:**  
**Security Code:**  

- [ ] I am interested in making a regular donation  
- [ ] I do not require an acknowledgement  
- [ ] I would like an acknowledgement by email  

---

**Add Gift Aid to your donation**

Please treat as Gift Aid donations all qualifying past, present and future donations to Edinburgh Children’s Hospital Charity. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

Please return this form to: Edinburgh Children’s Hospital Charity  
First Floor, 1 Wester Shawfair, Danderhall, Dalkeith, EH22 1FD  
Tel 0131 668 4949
New rules are coming that mean you’ll need to ‘opt in’ if you want to receive our magazine, mailings or email updates.

Visit echcharity.org/privacy to find out how you can opt in to hear from us in future.

You can also call us on 0131 668 4949 or email hello@echcharity.org for more information.