

Newsletter

Alya's Story Organ Donation Week 2021



Crawford 25th

One of our 'Homes from Home' is celebrating 25 years of helping families

Our Impact

How many families we've helped this year, average stay, and more

Welcome



Welcome to the Autumn/Winter edition of our newsletter. Please come on in and get cosy, there are a number of exciting things that we want to share with you.

Despite the challenges of the last year, we are so pleased that we have managed to support 1,521 families – you will find the stories of some of them in this newsletter, alongside our impact statistics on page eight.

We're taking part in Organ Donation Week, which runs from 20-26 September, and we are raising awareness of how we support families, like Alya's on page five, in our transplant flats.

Last, but certainly not least, we're celebrating the 25th birthday of Crawford House, one of our 'Homes from Home' in Newcastle. It has helped 12,181 families since it opened and the Ralph family, on page 11, stayed very recently.

Connect with us on social



[thesickchildrenstrust](#)



[thesickchildrenstrust](#)



[TheSCT](#)

Grayson-Ripley Family Story

I broke down in tears on the chair when they told me my baby, Luna, had a heart condition. I was so lucky my partner, Liam, was there by my side because it is just not something you can hear on your own at your 20 week scan.

Luna had very little chance of making it to birth because her heart wasn't working properly. The condition she was diagnosed with, hypoplastic left heart syndrome (HLHS), meant her heart would be underdeveloped and not pump blood around her body effectively. She would need at least three heart surgeries to help her heart to work properly and we would face spending a lot of time away from our home in Hull.

Despite everything we were prepared for, Luna was born weighing an incredible 7lbs and she looked healthy. We spent just hours with her before she was taken down for her first heart surgery. It was her most critical surgery and it went well.

Since that operation, Luna has been recovering in hospital and we have been staying at Eckersley House. It's a 'Home from Home' run by The Sick Children's Trust and it has been extremely useful because it meant we have not been far away from Luna. If we need to be there, we can. The kindness shown to us by giving us a place to stay has really helped us while our baby has been in hospital.

Amy Grayson, Luna Ripley's Mum



You are warmly invited to look around
The Sick Children's Trust

Enter our prize
draw to win
£250!

Online
**AUCTION
HOUSE**
2021

filled wall-to-wall with
fantastic prizes

3-17 October 2021

We are delighted to reopen the doors of our virtual house; our Auction House. Feast your eyes on the wonderful prizes on offer, place your bids and help raise vital funds.

Please bid generously and help keep families with a seriously ill child in hospital from around the UK together in one of our 'Homes from Home'.

Charity Reg No: 284416

Register for our online auction at
sickchildrenstrustauctionhouse.org



**The Sick
Children's
Trust**

We're here, so families can be together

Natania Goes Back To School

It was the scariest moment of my life when Natania was taken to surgery at GOSH. I had no idea what was wrong with her, just that she had pressure on her brain that needed to be relieved. I was sitting in the parents' room, with people who were going through their own situation, just hoping she would be ok. This was when a nurse told me I had a room at The Sick Children's Trust's 'Home from Home' Guilford Street House.

I felt so fortunate to be given a place to stay so that I could be with my daughter throughout her surgery and her recovery. It turned out that she had a haemorrhage that was causing the pressure on her brain.

I really appreciated having my own space where I could process everything privately. The 'Home from Home' isn't just a place where you can sleep, it's a place where you can speak to people, get support and advice.

Natania can't wait to get back to school and is looking forward to returning to her classes and seeing



her friends. She has found her recovery quite frustrating at times, but she knows how lucky she is to not have any long-lasting side effects. She has come so far and I am very proud of her.

**Evarine Ssebugwawo,
Natania's Mum**

**Do you have a
story you could
share with us?**

[sickchildrenstrust.org/
shareyourstory](http://sickchildrenstrust.org/shareyourstory)

Organ Donation Week 2021: Alya's Story

Organ Donation Week 2021 is 20-26 September and we are sharing the story of brave Alya, who has had not one but two heart valve transplants. Her family stayed with us in Eckersley House while Alya had these critical operations.

Our six-year-old daughter Alya loves to dance. Every Saturday night, she is there dressed up in front of the television ready to dance her socks off to Strictly Come Dancing. It never fails to make me smile and fills me with so much love.

Alya turns seven years old in February and in this short time has had three major heart surgeries due to a heart defect called truncus arteriosus, which meant her heart didn't work properly and made it difficult for her to breathe.

Alya's second heart surgery was to transplant a donor heart valve. This time was really traumatic as she was in intensive care for over a week and over the course of our stay was in and out of surgery three times. We stayed at Eckersley House until she was discharged and every night



Adam and I alternated between sleeping next to Alya and sleeping at Eckersley House. The hospital is noisy so after a night in Eckersley House we felt much more rested.

Over the next couple of years, Alya did really well. We were in hospital only for short stays to change her

“It was an exhausting ten days so being able to go to Eckersley House to have a shower, sit in a private room and have a cup of tea in bed helped us to restore ourselves.”

feeding tube and for MRIs. By the time she reached four years old though, it was discovered that the donor valve that Alya had received was leaking and needed replacing.

Again, we were supported by The Sick Children's Trust. It was an exhausting ten days so being able to go to Eckersley House to have a shower, sit in a private room and have a cup of tea in bed helped us to restore ourselves and enjoy some down time – even if that was just 20 minutes as it helped us to sort our own thoughts out.

Alya knows about her heart and the special valve she has and deals with everything very well. We talk about any of her worries and answer any questions to reassure her. Alya will need more heart surgery because she will grow out of the valve she currently has, but knowing there is a place to stay that is close to her side so she doesn't have to go through this alone is a huge comfort.

Clare Waites, Alya's Mum



Did you know?

In the last year, we have supported over 50 families with a child on the transplant list.

Four Ways Scott House's Transplant Flat Helps Families

Hello, my name is Linsey and I'm the House Manager at Scott House, where we have a transplant flat.

This flat is primarily used for families who have a child that has had a heart transplant, but we do support all kinds of transplants here. Typically, families will move in a week before they are due to be discharged and we act as a supportive stepping-stone between the hospital ward and home.

There is a long list of ways that this flat helps families, but for Organ Donation Week I'm sharing just four of them:



- 1 If there are any issues, major or minor, a nurse or doctor can be at the flat within minutes, bringing comfort to the family.
- 2 The family can learn to live together as a unit again, sometimes siblings have been apart for months while waiting for a transplant. Prior to the pandemic siblings could stay in our 'Homes from Home' and we are working closely with hospitals to make this possible again as soon as we can.
- 3 Parents can learn to administer medication in a safe, secure setting close to the hospital.
- 4 Families can have support from The Sick Children's Trust staff as they get used to their new normal.

Linsey Brough, House Manager at Scott House

Holly's Story Crawford House 25th

Our 'Home from Home' Crawford House in Newcastle turned 25 in September and over the years has helped 12,181 families. Recently, Crawford House supported Sadie Ralph while her 16-year-old daughter Holly recovered from surgery.

"After a round of chemotherapy in our local hospital in Nottingham, the doctors decided that the best course of action for my daughter Holly would be to remove the tumor altogether. This was an intense, specialist operation and we were told that Newcastle Royal Infirmary would be the best place for Holly to have this procedure.

Holly's surgery was a mammoth 11 hours. She had all of her knee removed, except her kneecap, and rebuilt with metal. Essentially, she now has a bionic leg.

The operation was very successful, but it did mean two nights in intensive care which meant I couldn't stay there overnight and I needed somewhere that was close by.



A kind nurse on the ward put me in touch with Crawford House, a 'Home from Home' run by The Sick Children's Trust. Andrew, the House Manager, came to pick me up from the ward to show me around the 'Home from Home'. It's a truly lovely house with all the amenities that make a house a home. I could do some much-needed washing and have a comfortable place to rest.

I only needed to stay for two nights and it was such a relief. I can imagine that for families who need this service for weeks, or months, it is an incredible weight off their shoulders to know that they have somewhere to stay, free of charge, that they can cook their own food in, or have some space to relax and watch some TV."

Sadie Ralph, Holly's Mum

★ Super Supporters ★

Our wonderful supporters help us to keep thousands of families together every year, just minutes from their sick child's hospital bedside.

Here are some of our Super Supporters from the last six months.

★ Chaz Truman

We supported Chaz and Katie in Acorn House back in 2020. Once restrictions eased in April Chaz decided to do a skydive and raised an incredible £4,510.



★ Natalie Engstrom

Natalie stayed with us 13 years ago and recently shaved her hair off to raise £1,567 for our 'Homes from Home' – thank you Natalie.



★ The Hope Family

The Hope family organised a wonderful golf day to and raised £5,025 for us after we supported Will and Laura in Crawford House. Thank you.



★ Ray Lydiard

Ray did a wing walk and raised a fantastic £2,191 for us. We supported Ray's family three years ago when his son was diagnosed with a rare cancer.



★ Elaine Russell

Elaine's fundraising efforts have generated over £1,000 and will go a long way to keeping families with a seriously ill child in hospital together. Thank you.



★ Honey Gray and Deborah Ewing

Honey, 10, and her mum Deborah walked 155 miles throughout August - the equivalent distance from their home in Lowick to Leeds Children's Hospital. They raised a fantastic £1,096.



★ Jacqui Hussey

Jacqui stayed with us at Eckersley House 10 years ago. She has always remembered us and earlier this year gave a fantastic donation of hand knitted blankets, teddies, food and toiletries. She also brought in £127.90 from a collection box. Thank you.



Get To Know A Friend of The Sick Children's Trust

Friends of The Sick Children's Trust have one very important thing in common – ensuring that we can keep families with a seriously ill child in hospital together by giving a regular monthly donation. We have been speaking to some of our Friends to find out a little more about them.

Could you tell me a little bit about yourself?

Our names are Andy and Jacqui, we're married and we live in the countryside in Devon, where we are enjoying our retirement. Before that we lived in the hustle and bustle of London.



become a Friend of The Sick Children's Trust.

How did you first hear about The Sick Children's Trust?

Back in 2012 we noticed an advertisement for a carol concert in All Hallows-By-The-Tower, hosted by The Sick Children's Trust. We decided to go along.

What made you decide to give a regular donation?

The concert was fantastic. The most touching thing was hearing a testimony from a family. They spoke about how staying in a 'Home from Home' meant that they could focus on their sick child. It was after this we decided to

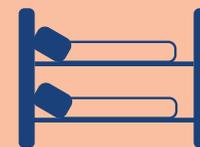
How does your donation make a difference to families?

You really are making a difference to families during some of the most difficult times of their lives, bringing some comfort to them by supporting their stay in a 'Home from Home'.

Not only that, but our regular donation helps The Sick Children's Trust plan for their future so that they can keep families together. It's a great thing to be part of.

Our Year in Numbers - 2020/21

We've helped **1,521** families with **21,888** nights of accommodation in our ten 'Homes from Home'.



Families stayed on average for **14 nights** and we saved families **90 minutes each way** of travel time.

99% of families say that staying in our 'Home from Home' helped them to cope and they would recommend us to another family in their situation.



Considering the challenges of COVID-19, where we had to close around **50%** of our bedrooms and all communal areas, this is a huge achievement. It wouldn't have been possible without the efforts from dedicated supporters and staff, so a huge **thank you** to you all.

Meet Josh

Josh's son, Charlie, underwent major brain surgery at just eight months old. During this time Josh and his wife, Courtni, stayed in Crawford House. Josh recently took part in the Great North Run to raise money for us.

The situation would have been tough in normal circumstances, however happening during a global pandemic made it all the more difficult. As a result of COVID-19 restrictions only one of us could be at Charlie's side before and after the operation, which meant the other would have needed to go home.

Fortunately for us though, the Great North Children's Hospital, based in Newcastle's Royal Victoria Infirmary, were able to contact Crawford House and arrange a room for us to stay, meaning neither of us had to go home. We could also both spend time with our son, and alternate throughout the day and night to be by his side.

I'd say I'm a typical man and generally hold my emotions close to my chest, it's never easy to show how you're truly feeling. For me, Crawford House gave us the space and privacy needed to deal with our emotions.

It's impossible to explain just how much of an emotional rollercoaster it is when your child is unwell and needs to be in hospital. Everything can seem fine one minute, and then the next it's not.

I've wanted to do the Great North Run for a long time, but only for a charity which I've had experience of and believe in. The support that The Sick Children's Trust gave me and my wife last November was incredible – it gave us a home closer to our son. I want to do something to say thank you for being there for us, and all the other families, through such a traumatic time.

Josh Yorke, Charlie's Dad



Events Calendar

Here are some of our upcoming events that we'd love you to get involved with. For more information please go to sickchildrenstrust.org/events



3 October - Virgin Money London Marathon

#TeamSCT will be cheering our runners along in the London Marathon – and if you want to run for us in 2022 please register your interest on our website.

3-17 October - Online Auction House

Browse our fantastic lots, place your bids and help raise vital funds to give families with a seriously ill child in hospital a warm and comfortable place to stay in one of our 'Homes from Home'

10 October - Royal Parks Half Marathon

Royal Parks Half Marathon is an iconic run through the scenic parks of London. During this 13.1 mile race you will be cheered on by our encouraging supporters!

1 January - Squat for The Sick Children's Trust

Start the new year off with a 31 day squat challenge and help us to raise money that will keep families together.



Please help us keep our vital
'Homes from Home' open by
giving a regular monthly gift

£5 will help to pay for the cleaning of our
'Homes from Home' ensuring a safe
environment for families.



£10 will help us provide pillows, duvets
and sheets so parents can have a
comfortable night sleep.



£15 will go towards paying for our 'Homes
from Home' front line staff, so they can
support families when they need it most.



Any amount that you can give will be truly appreciated
and will go a long way to supporting us to keep our
'Homes from Home' open.

The Sick Children's Trust
4th Floor
28-30 Worship Street
London EC2A 2AH

sickchildrenstrust.org

Registered Charity Number: 284416



We're here, so families can be together

