

Newsletter

Parents' Perspectives: **Claudia and Ben's Story**



Mother's Day

Louise shared what life was like in hospital through her diary

Virtual Fundraising

We celebrate the virtual fundraising success of our supporters

Welcome



Welcome to the Spring/Summer 2021 edition of our newsletter.

The Sick Children's Trust continues to be inspired by the creative fundraising ideas from our supporters, which you'll find throughout this newsletter. We know that with all the rules and regulations fundraising hasn't been easy. We extend a huge thank you to you all.

The families who we support in our 'Homes from Home' have an experience that many can't imagine – having a seriously ill child in hospital. For Mother's Day, Louise shared her diary with us to show what this was like for her and the difference that we made. You can find this on page ten.

As always, we are working to keep families together while keeping them and our staff safe. We hope you enjoy reading the stories of some of these families. If you have stayed with us and would like to share your story, please visit thesickchildrenstrust.org/share-your-story

Connect with us on social



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My Tips For Hospital Stays

Millie and her daughter, Georgia, are used to spending time in hospital as Georgia was born prematurely and has two lifelong health conditions which has led to multiple hospital admissions. Millie is sharing her top tips for hospital stays:

1 Exercise

Adam and I walked a lot when we were in hospital, even just to go outside the hospital to get a coffee. At home I always take Georgia for a walk when I can. I also miss the gym, so I take on challenges like a 30 day squat challenge, as they only take a few minutes a day to do.

2 Social media

When it's not possible to see people, stay connected with social media. We have daily video calls with family and it's great for Georgia to get familiar with voices and faces - even if she does now think people live in my phone!

3 Take time out

Whether it's just to have a bath or watch your favourite tv programme. This was important for us and staying at Stevenson House meant we could have some time out from the hospital to recharge and reset.

4 Enjoy your comforts

Your favourite chocolate bar, bubble bath or glass of wine should all be enjoyed.

By Millie Quickenden

Meet the Moore-Atkinson Family

“ Knowing we could be on the ward in seconds if anything was to happen was a lifesaver.”

Chelsea Moore, Ada's Mum

At just 24 hours old, Ada underwent surgery to disconnect her windpipe from her oesophagus and reconnect her oesophagus to her stomach. She was in theatre for six and a half hours. It was the longest time of our lives.

Once Ada was woken up and off the ventilator, we had another major setback as one of her lungs collapsed. The doctors said it could take anything from weeks to months for it to heal naturally.

We were worried, scared and devastated.

Initially we thought we'd be able to go home every day as we live locally in Sheffield. After seeing Ada, how fragile she was and how her condition could change so quickly during her post-op recovery, we just couldn't leave her.

Having Magnolia House there, knowing we could be on the ward in seconds if anything was to happen, was a lifesaver. Not only that, but we could make sure we were looking after ourselves and get some sleep so we were ready to tackle each day.

It's still a long way to recovery but Ada is the happiest, cheekiest nine-month-old you could meet. She is an amazing little girl and a true warrior.



Can You Help Us?

2020 was a challenging year for so many and sadly, The Sick Children's Trust saw a significant drop in income due to cancelled events and the uncertainty that COVID-19 brought with it.

While we were able to keep our ten 'Homes from Home' open to support families, to do this safely we had to close around 50% of our bedrooms and all of our communal areas.

This year, we will continue to work closely with our hospital partners as well as continue to adapt and navigate new regulations.

We know that 2021 is going to be equally challenging, and we predict a shortfall in income but our focus is to ensure we are able to get our 'Homes from Home' back to full capacity and supporting all the families who need us.

We are extremely grateful to everyone who continues to support us, we couldn't help families like the ones in this newsletter without you.

If you would like to help us to support more families please donate today.



The Virtual Racers Club

Racing Towards Their Fundraising Target

In January the Virtual Racers Club held a two and a half hour virtual race to raise money for us because we supported one of their members while his son received treatment at Great Ormond Street Hospital. The club raised a fantastic £1,000 from the event. We spoke to them to find out more.

Where did the inspiration come from to turn your gaming into raising money?

It started off as a suggestion to the event administrator to utilise the efforts the drivers go through doing a long race for some good. He immediately agreed and went about organising the event.

Why did you want to fundraise for The Sick Children's Trust?

Matt Sykes first brought The Sick Children's Trust to our attention shortly after he joined our community, regularly racing in the charity's colours.



Most of us are fathers, so we could empathise with Matt's story and it was a very quick decision that we would use our first ever charity race to show support for this great cause.

How many people took part?

15 drivers and our commentator.

How did you fundraise?

Drivers paid an entry fee, but many of them donated more than the requested amount. Through word of mouth, family members, friends and colleagues donated before, during and after the event.

Have you ever done virtual fundraising before?

No, but it was a resounding success and we will look at doing more in the future.

Isaac's Story

Isaac has always been very active. He's part of a football team and is always riding his bike to the park to meet his friends. Everything was as it should be but in November Isaac wasn't feeling well. Over the weekend, he was vomiting every evening before bedtime, then it became constant throughout the day.

Something was clearly very wrong.

Several scans showed there was an issue with Isaac's heart. His left chamber wasn't pumping and his whole body was suffering. He was put on heart medication straight away. The next day we were told that we needed to be put in touch with the heart transplant team at either Great Ormond Street Hospital or Newcastle's Freeman Hospital. David and I were completely shocked. It was so unexpected and happened so quickly.

We were transferred to Newcastle and Isaac was put on the heart transplant list, but in the meantime he needed to be fitted with a ventricular assist device (VAD) which is an electric powered heart pump that works with the heart to improve blood flow. The operation



took four hours, but it felt like nine.

We have no family or friends in Newcastle, which is around three hours away from our home. Scott House is so convenient and we feel at home there. It is just a short walk from Isaac's side. When Isaac started to come round from his operation, David would go over at 4am to sit with him. When Isaac had an unsettled night, we could just walk out the door and be there.

We hope the VAD will be a bridge to recovery and Isaac's heart will do well with its support. He will remain on the heart transplant list and time will tell what the future holds.

Emma Sidaway, Isaac's Mum

Become a Super Supporter

You may have not considered virtual fundraising before, but we are here to help you every step of the way with whatever you choose to do.

For the sporty...



Do a virtual sponsored walk



Stream a challenge with your family

For the social...



Have a birthday fundraiser on Facebook



Host a virtual quiz night

Please head to sickchildrenstrust.org/fundraise/run-your-own to register your activity and one of our friendly team will be in touch.



Super Supporter Kate

Kate ran a virtual half marathon and tracked her progress on her phone, raising £1,284.46

"The most wonderful part was about 11 miles in - I ran past a family in the park and noticed the dad has nudged his young daughter and pointed out my The Sick Children's Trust top- she had a matching hoodie on and was so excited."

A Note From Jack

We supported Jack's parents while he received hospital treatment for Non-Hodgkin's lymphoma, which is a form of blood cancer. With coronavirus restrictions, only one parent could stay with Jack on the ward but Eckersley House meant his parents could easily swap with one another, giving them one less thing to worry about and reassuring Jack that his family was always close by.

"I didn't want to go into hospital and was scared about what would happen to me, but once I was there and we knew what the treatment would be, I felt better.

Leeds hospital is very big when you first see it. I saw quite a lot of it going for my scans. The nurses and doctors were very nice and friendly. I enjoyed playing on the PlayStation and doing different activities on the ward, which helped pass the time during my treatment.

It was good to see my mum when I'd been in a few nights with my dad, and my dad when my mum had stayed with me because only one could be on the ward at once.

I'd just like to say thank you for providing somewhere for my mum and dad to stay whilst I was in hospital as we live far away. It would have been really hard for them, driving backwards and forwards. We're very thankful."

Jack Carr, 13 years old



Life in Hospital: Louise's Diary



For Louise, becoming pregnant with Eliana was a dream come true. At one of her scans though, she and husband Richard found out that Eliana had several complications. From the day Eliana was born until now, hospital has been a huge part of their family life.

For Mother's Day, Louise shared her hospital diary with us.

Day 63: 21 Week Scan

The sonographer was ages doing the scan and I got the feeling that something wasn't right. After an hour we were taken into the 'sad room', the one with butterflies on the wall and little boxes of tissues everywhere.

We knew we'd been sent in there for bad news.

Her colleague came in who was a heart specialist and things became a bit clearer. Eliana has some quite serious heart defects, we were shown a sketch to explain what might be going on.

From now we will be under Leeds Children's Hospital, where Eliana will have a specialist looking after her. We need to go there tomorrow so they can do a heart scan.

“Until then, I just need to do whatever I can do to keep her strong.”



Day 64: Our First Day at Leeds

I don't have enough words to praise the team at Leeds. For something so daunting they have made this feel like it isn't the end of the world and there is some hope. And that's all we wanted was some hope.

Eliana's condition has been explained properly to us, her heart is more complex than the country's leading specialists have seen in a while. Her prognosis is not what we had hoped.

We heard a little bit about a place called Eckersley House in passing, someone mentioned it was run by a charity that housed families with children in Leeds. I'm not quite sure why we would need it right now?

Anyway, the plan is for me to be induced at 39 weeks and until then I just need to do whatever I can do to keep her strong.



To read Louise's full diary, please visit
sickchildrenstrust.org/louisesdiary

Super Supporters

Our wonderful supporters help us to keep 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.

Jenny Williams

Jenny walked 101km for us from 23 November to Christmas Eve after her granddaughter spent 101 nights in hospital and we supported her family. Thank you Jenny for battling the cold weather and raising £650 for us.



Joe Taphouse

Joe braved the shave for us in January, saying goodbye to his beard and raising an excellent £1,250 in the process – thank you Joe.

Emily Murphy

Emily created a 'Community Mask Tree' in Guildford, where she hung her handmade masks and asked people to donate to her JustGiving page if they took one. She has raised £504! Thank you Emily.



Mamta Mistry

Over Christmas Mamta dropped off a wonderful collection of gifts to Eckersley House because we supported her when her daughter was in hospital 12 years ago. This makes a huge difference to families over the festive period, thank you Mamta.

Julie Sihota

Julie raised an incredible £6,040 by shaving off her hair in December and we think she looks fabulous! Thank you Julie.



Stephen Sinclair

Stephen became a regular giver last year after we supported his family in Eckersley House for two months because of his daughter Ava's liver condition. Thank you Stephen for your regular gift, helping us to plan for our future.

Parents' Perspectives: Claudia and Ben's Story

Baby Hugo did not have the easiest entry into the world. At the end of a long labour, Hugo wasn't breathing and required emergency hospital treatment to make sure he didn't get brain damage from the lack of oxygen to his brain. His parents, Claudia and Ben, stayed with us in Chestnut House in Cambridge during his treatment.

Claudia:

"I couldn't wait for that first cuddle with my son, but as they lay him on my chest he was still and not breathing. Sirens, buzzers and medical staff filled the room."

"Hugo had to be transferred to Cambridge to undergo a cooling treatment, which involves reducing his temperature by a few degrees before warming him back up over the course of a few days."

"I was worried I wouldn't see him before he left but I could say hello. I put on a brave face as he left with Ben, but my heart was breaking on the inside."

"When I arrived at The Rosie Hospital, Ben was already in a room in Chestnut House, run by The Sick Children's Trust."



"We were walking into the unknown and the staff at Chestnut House made us feel so calm and reassured at such an uncertain time in our lives. We found it invaluable that there was always someone there if we needed to talk. I was also suffering quite badly following the birth so to know that I could just go straight downstairs to Chestnut House to lie down was a huge relief."

“**The Sick Children’s Trust made a horrific situation that much easier.**”

Ben:

“It was horrific. We never expected this to happen, we’d researched every eventuality but never thought of this. I was asked to cut the cord, we were elated and so emotional. When the buzzer went off, those feelings disappeared and were replaced with confusion and fear. It felt chaotic and we had no idea what was going on.”

“I went to The Rosie Hospital in Cambridge with Hugo, but by the time I got there I hadn’t slept for two days and was in such a daze.”

“After Hugo was settled into NICU, I met someone from The

Sick Children’s Trust who took me to Chestnut House. They gave me keys and told me that Chestnut House was a place that both Claudia and I could stay while Hugo got better.”

“The Sick Children’s Trust made a terrible situation that much easier. Without it we would have to drive from Colchester to Cambridge every day, which wasn’t really an option because we couldn’t face leaving Hugo, or we would’ve had to ask our family and friends to help raise around £1,000 to pay for a hotel nearby and food.”

Since leaving hospital in December 2019, Hugo has been doing well and enjoying the company of both his parents who have worked from home during the coronavirus pandemic.

Hugo has just celebrated his first birthday.



Saraswati Puja 2021 Online Celebration

Lockdown has meant that many cultural events have had to be reimagined, using creativity to take them online so that they can still be celebrated. The Scottish Association of Bengali Arts and Sanskritik Heritage (SABASH) ran their annual Saraswati Puja online this year and raised £413 for us.

How do you normally celebrate Saraswari Puja in person?

We in SABASH celebrate it through several cultural events involving dance and music. It is a festival of mirth for children and youngsters, for whom Saraswati Puja is a “no study” day. This event is predominantly for the kids, by the kids and therefore youngsters take active part in this event.

How did you change the celebration to make it work online?

In the wake of the COVID-19 pandemic, we had to pivot and move all our events online. We planned this event meticulously



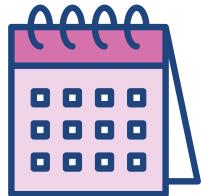
to provide kids and youngsters the opportunity to showcase their talent and delight our stay at home audience from the safety of their homes. All participants rehearsed and practiced at home and finally it was all brought together through an online event by SABASH media/digital team.

How did you run your virtual event?

This was run as an online event with people performing live from their respective homes and pre-recorded videos of different cultural activities involving dance, play and music being played online. The event was telecast live on our YouTube and Facebook channel.

Dates for Your Diary

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



Great North Run - 12 September 2021

Take part in the world's largest half marathon and raise money to keep families with a seriously ill child in hospital together.

Royal Parks Half Marathon – 10 October 2021

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.

Online Auction House - 3-17 October 2021

Save the date for this year's Online Auction House! Filled wall-to-wall with fantastic auction items, feast your eyes on the wonderful prizes on offer and decide what you'd like to claim for your own.



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.

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Registered Charity Number: 284416

 **The Sick Children's Trust**

We're here, so families can be together



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