



CHILDREN'S  
**HEART  
SURGERY  
FUND**

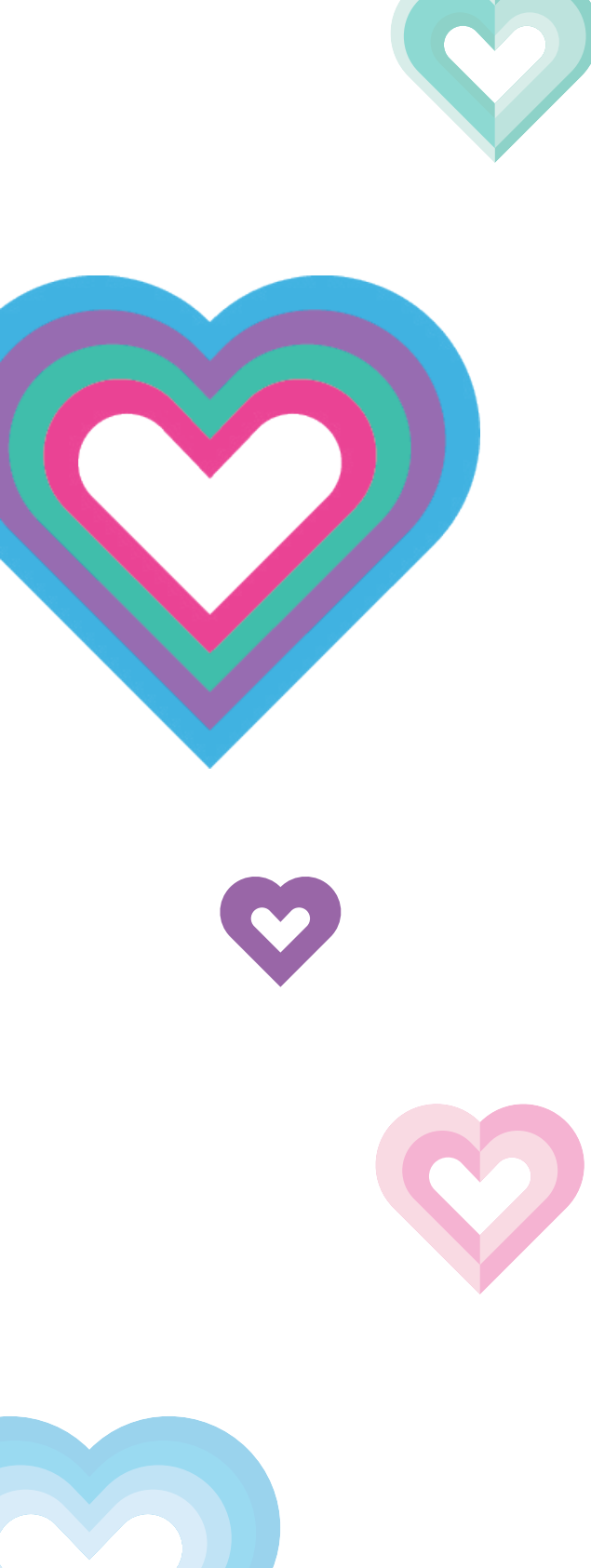


**IMPACT**

**REPORT**

2022/23





**On the cover:** Faryal with Katie Bear  
We met heart hero Faryal while she was staying on the children's heart ward in September 2022 after open heart surgery.

Figures for 2022



**Congenital heart disease (CHD)** occurs in **1 in 125 babies** and is the **most common birth defect globally**

Leeds Congenital Heart Unit is there for a population of **5.6 million**

The LCHU is the Cardiac Specialist Surgical Centre for the whole of Yorkshire, Humberside, North East Lincolnshire and North Derbyshire.

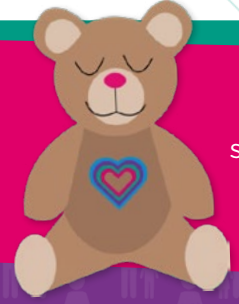


and every year...

CHSF SUPPORTS OVER **23K** CHD patients, heart families and NHS staff across our region

approx **350** patients have open heart surgery at the Leeds Congenital Heart Unit

approx **700** babies, children & adults have INTERVENTIONAL PROCEDURES such as pacemakers catheters and stents



Every child who has open heart surgery at Leeds receives a teddy called **Katie Bear**, a **medal** and a **certificate** from CHSF

More than **408** families received bespoke **emotional, financial, and practical** support from our **Family Support Workers** in 2022 & 2023

Because of the life-saving work at LCHU **90%+** of CHD patients reach adulthood

# Welcome to CHSF's 2022/23 Impact Report!

I'm heart mum Caley Flynn and this is baby Alec who was born 11 weeks premature at our local hospital in Sheffield in August 2022.

His diagnosis of a serious heart condition saw Alec transferred to Leeds, more than an hour away from our home.

Coarctation of the aorta is a serious heart condition and he had heart surgery at 7 weeks old.

CHSF were incredible for us, giving vouchers for food, providing toiletry bags and even offering to pay the cost of our fuel when travelling.

We were a long way from home, but thanks to the parent accommodation, which is also funded by CHSF, we didn't have to worry about where we were going to stay or how we were going to pay for it. We could just focus on putting all our efforts into being there for our baby, which was all we wanted to do.

Now one year on, and 13 months old - Alec is an amazing little boy. So loving, funny and a little monkey all at the same time. We wouldn't have it any other way.

What CHSF do to help patients with heart conditions, and families like ours, is vitally important. We would have been lost without it. I hope that's the message you get from reading this report.

Please continue to get behind this amazing charity. You can make an incredible difference to so many people's lives.

Best wishes,

**Caley x**

(P.S See page 16 for how the CHSF Family Support Team helped us in particular!)



Read about more of our amazing heart heroes and their families on our website: [chsf.org.uk/blog](https://chsf.org.uk/blog)







**Kieran Brady**  
Chair of Trustees

# A word from our Chair...

Hi I'm Kieran, Chair of Trustees for CHSF - thank you for supporting this wonderful charity. My role as Chair is to ensure the Board sets a clear vision, ethos and strategic direction for the charity, and to work closely with the CEO and CHSF team.

A good friend of mine told me their experiences of CHSF and the LCHU after their son was diagnosed with congenital heart disease, so I reached out to see how I could help. I became a Trustee on witnessing the tremendous work CHSF are able to do because of your donations, and I can think of no better cause than one which nurtures little lives at their most vulnerable.

I have been active in fundraising for CHSF myself, for instance walking the Yorkshire Three Peaks, dressing up as an elf during the CHSF children's Christmas party - and no one can forget the time I painted myself blue to do my best Genie impression for a fundraiser at work!

I hope the projects and families featured in this impact report inspire you to get involved with CHSF, if you don't do so already.

Our charity is needed more than ever in these challenging times.

Best wishes,

*Kieran*



# About us



## VISION

(where we want to be)

We support hearts for life. We work to ensure that people born with congenital heart disease, a heart condition that develops in the womb, have the best health outcomes and quality of life, throughout their lives.



## PURPOSE

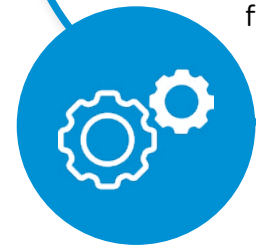
(what we do)

We support babies, children and adults living with congenital heart disease across Yorkshire, the Humber, North Lincs & North Derbyshire treated at the Leeds Congenital Heart Unit, and their families.

## MISSION

(why we exist)

We support the Leeds Congenital Heart Unit as a world-class centre of excellence by providing the funding and resources needed to care for a patient's heart, mind, family and future.



## VALUES

(how we do what we do)

We embed our core values of trust, compassion, openness, respect and dedication into all aspects of our work.

**TRUST** We deliver on our promises

**COMPASSION** We pride ourselves on reliability, empathy and loyalty

**OPENNESS** We are approachable and inclusive in everything we do

**RESPECT** We value and appreciate one another

**DEDICATION** We always go the extra mile

Funded projects that



Page 8-9

Funded projects that



Page 12-13

Funded projects that



Page 16-17

Funded projects that



Page 20-21





## REGIONAL NURSE SPECIALISTS

Ensuring the best possible care close to home.

### Heart mum Tiffany said:

“Oscar was diagnosed with a heart condition at my 20-week scan, and had two open heart surgeries as a baby in 2013.

“When he was born, we stayed in the lovely hospital accommodation both within Brotherton Wing and Eckersley House. This was a massive help for us as a young family especially just after giving birth and not being very well myself.

“In 2021, Oscar was urgently listed for a heart transplant in Newcastle and he stayed as an inpatient on the children’s cardiac ward in the Leeds Congenital Heart Unit for 16 months on an IV Support for his heart.

“In this time, CHSF helped us financially and mentally with treats for both us and Oscar, and fun things to do.

“They also helped with accommodation and travel costs throughout the stay, which was always a big help as Oscar wanted us close and we also wanted to be a walk away if anything was to happen.

“Oscar remembers the children’s cardiac ward as actually a really, happy place with ups and downs. He remembers the amazing ‘pub night’ CHSF’s Family Support Worker Sarah Cherry did for him, meeting a pony, being the first to write to Santa, the big bag of presents on Christmas day, the eggs at Easter and many other things.

“But mostly he remembers we were always there when things went wrong in the night or through the day, and that’s because we could always be so close to him.

“Oscar had his transplant in November 2022 and back home in Bradford by December which is when we met our local Cardiac Nurse Specialist Araminta - who came and helped with dressing changes for his line and any other issues. This was a great for us as Oscar struggles with new people. So having the same person looking after him really helped.

“Oscar is now 10 years old, doing well and living at home.”



### Bradford-based nurse Araminta Stafford said:

“In the last 15 months since specialising as a Cardiac Nurse Specialist, I have been able to offer more local support alongside the great support patients get from

the team in Leeds and in Oscar’s case, the Transplant team at Newcastle.

“Oscar was discharged home from The Great North Children’s Hospital in Newcastle in December 22 following his life-changing heart transplant in November 22 and I have been able to support the family and provide care closer to the home.

“I have visited Oscar at home to provide central line\* cares on several occasions...

**\*WHAT IS A CENTRAL LINE?** A central line is a tube that doctors place in a large vein to give fluids, blood, or medications quickly.



**Cat Brown**  
Lead Nurse  
YHCHD Network

“The Local Paediatric Cardiology Nurse Specialists based at Grimsby & Scunthorpe, Sheffield, Bradford and Calderdale & Huddersfield have been a great success and the feedback has been excellent.

They have become an extension of the Leeds team and their hard work is valued greatly. By them being based closer to the patients’ homes they can provide seamless care between services and locations. This has improved the experience for patients and their families.

Thank you to CHSF supporters for making these roles possible.”

**These four regional nurses were brand new for 2022 and in total have supported nearly 3,000 patients across the areas they served.**

This life-changing, local care makes a huge difference to families of young patients living with congenital heart disease and has only been possible because of you.

...and have been able to develop a rapport with both Oscar and his mum.

“This helps to reduce anxiety about different unfamiliar nurses visiting and saves the family an additional trip to the hospital for line cares in between their numerous other hospital appointments - both at Newcastle and LGI. It can also shorten their hospital visit by having me visiting at home to undertake suitable elements of his care.

“I have been a point of contact for Oscar’s school and have been involved in trying to support a reintroduction into the formal education system and they are able to call me should they need any cardiac specific questions answering.

“Oscar’s family are able to contact me for any queries they might have, and I am able to promptly action any issues and liaise with other professionals as and when required. I have also successfully signposted or referred Oscar to other local professionals for specific support.”



We want to ensure that all patients and families have the best CHD care as close to home as possible. You can help us to keep making this a reality.



or visit [www.chsf.org.uk/donate](http://www.chsf.org.uk/donate) to make a donation. Thank you.





### MRI Infusion Pumps

Dr Malenka Bissell, Clinical Lecturer of Paediatric Cardiology at the University of Leeds and consultant at Leeds Children's Hospital said:

"These two new pumps enhance the safe delivery of medication during MRI (Magnetic Resonance Imaging) scans on babies with CHD.

"Having two additional dedicated neonatal pumps means we can create a neonatal-specific drug library with pre-programmed dosage and safety limits for the most important neonatal medications.

"This greatly increases medication administration safety."

With special thanks to



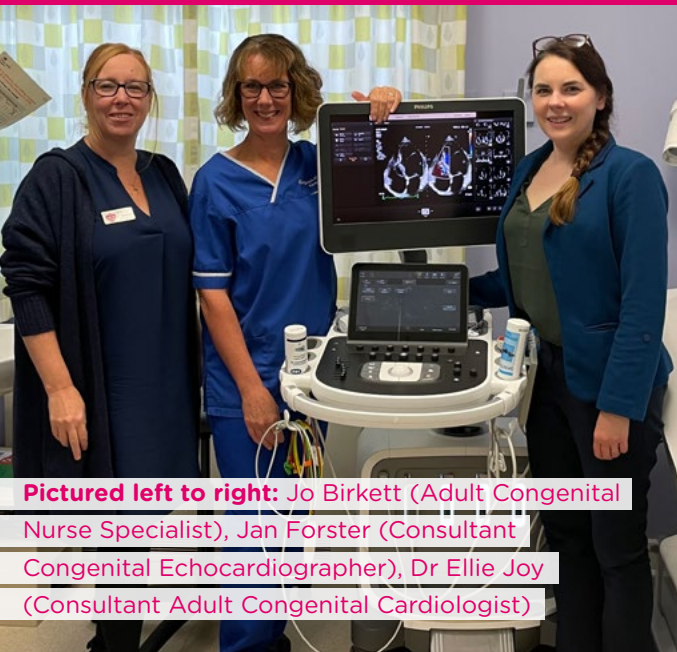
### ECHO machine and couch for Wharfedale Hospital

Jan Forster, Consultant Congenital Clinical Scientist said:

"Thanks for your incredible support in allowing us to purchase a new echo machine and bed so that patients with CHD can be seen at Wharfedale Hospital in Otley.

"We have limited space to perform the specialist echocardiograms at LGI, to assess patients of all ages with congenital heart disease and a growing population of patients.

"This new service allows a visiting team from Leeds to provide specialist care in a timely fashion, in an accessible and convenient location. The purchase of the echocardiogram allows us to diagnose and monitor heart conditions as part of the consultation."



**Pictured left to right:** Jo Birkett (Adult Congenital Nurse Specialist), Jan Forster (Consultant Congenital Echocardiographer), Dr Ellie Joy (Consultant Adult Congenital Cardiologist)



### Oxygen Saturation Probes

Sarah Gardner Adult CHD Nurse Specialist said:

"A big thank you to CHSF supporters for funding these oxygen saturation probes which ACHD fellow John is modelling!

"They are being provided to adult patients requiring regular monitoring at home, either because of their heart condition or as part of their recovery process.

"The equipment provides the patient and LCHU team with important data to assess their progress away from the hospital."



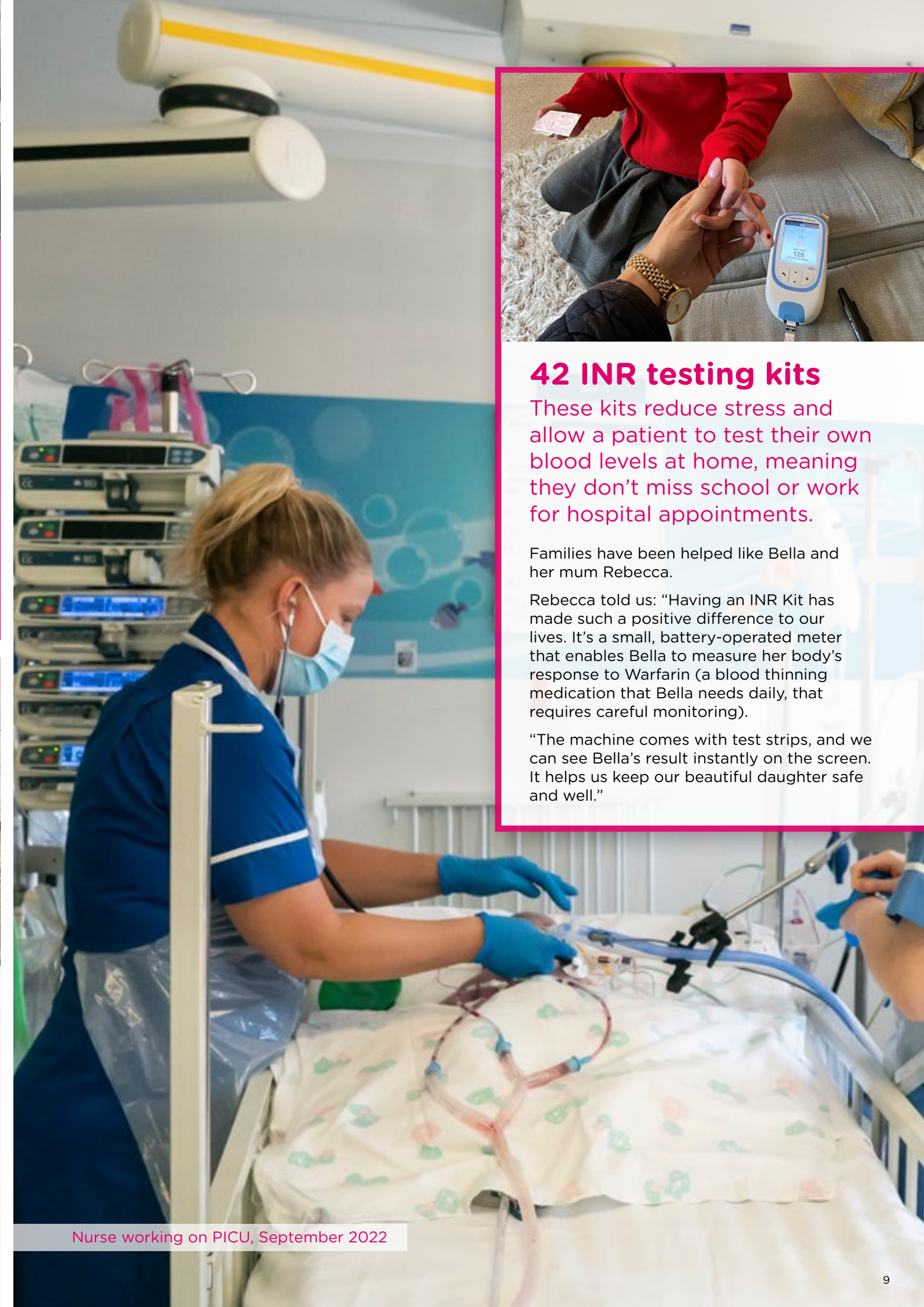
### Draeger Babytherm

Dr Lawrence Miall, Consultant Neonatologist said:

"The Draeger Babytherm platform has been a great asset to the NICU and has been in daily use since it was provided.

"It is used for nursing babies with surgical and cardiac problems who do not need to be in a full incubator. It is also used for procedures such as inserting central lines and lumbar punctures, keeping the baby as warm and comfortable as possible. It also allows easy access to the babies when they have cardiac ultrasound scans.

"This equipment has really benefitted some of the sickest babies on the neonatal intensive care unit and we are very grateful to CHSF for their generous support"



Nurse working on PICU, September 2022



### 42 INR testing kits

These kits reduce stress and allow a patient to test their own blood levels at home, meaning they don't miss school or work for hospital appointments.

Families have been helped like Bella and her mum Rebecca.

Rebecca told us: "Having an INR Kit has made such a positive difference to our lives. It's a small, battery-operated meter that enables Bella to measure her body's response to Warfarin (a blood thinning medication that Bella needs daily, that requires careful monitoring).

"The machine comes with test strips, and we can see Bella's result instantly on the screen. It helps us keep our beautiful daughter safe and well."



*“You can’t change the fact your child has CHD. What you can do is teach them it doesn’t need to limit how they can enjoy life.”*

**Colin Clewes is an adult CHD patient** and sits on the board of CHSF Trustees. Colin told us a bit more about his story and how he has been supported by the Charity...

**When did you find out you had congenital heart disease?** “My condition was diagnosed when I was just 11 days old. I suddenly became extremely ill and had to be rushed by my parents to hospital. Luckily for me, a nurse who had just undertaken a placement with the cardiac surgery team at the hospital in Louisville USA recognised my symptoms and before my parents could blink I was in theatre having the first of my aortic repairs.

“Since that day, over 41 years ago, I have undergone two more open heart surgeries. Both at Leeds, back in the day when everything was at Killingbeck Hospital.”

**What would you say to parents who have children with congenital heart disease? Should they worry about what their children can achieve?** “Simply don’t worry. Sounds strange but you can’t change the fact your child has congenital heart disease. What you can do is teach them it doesn’t need to limit how they can enjoy life.

“What is achievement? It’s different to all of us, it’s just a question of perspective. 41 years ago, the impossible in medical terms for congenital heart patients was far different to what it is today. So tomorrow’s impossible will be far different again.

“So please, please don’t limit what you think your child can achieve – as you’re the one then who is limiting them. Give them strength, believe for them, and they will surprise you without a doubt at just what they can achieve in a fulfilling life.”

**How would you sum up CHSF?** “The team achieve far more than they realise and have always been there for the Leeds Congenital Heart Unit (LCHU) when needed. Yorkshire and its CHD patients are lucky to have a charity like CHSF attached to the LCHU.”



# LANDING MONITOR

for the perfusion team during ECMO

**Andy Nichols**, Clinical Perfusion Manager at the Leeds Congenital Heart Unit said:

“The Landing Monitor has been a really useful addition to our ECMO program. The clarity of the display gives quick, concise reassurance of the patient’s status.

“Having real time measurements and calculations available has helped to guide any interventions the ECMO circuit requires.

“The majority of our ECMO runs using the Landing Monitor have been for cardiac support. Many of these have been as a primary therapy with no surgical intervention, which is a sign of how the service is evolving.”

## WHAT IS ECMO?

**ECMO (Extra Corporeal Membrane Oxygenation)** is utilised on the sickest patients who are suffering from either cardiac and/or respiratory failure and can no longer support themselves physiologically.

ECMO artificially pumps oxygenated blood around the patient’s circulation, preserving life until the patient is either bridged to recovery or to an alternative therapy.

The duration of support can range from a few days to a few weeks, with machine and patient working together.

## Colin received a Kardia machine funded by Children’s Heart Surgery Fund.

Colin said: “I had been suffering with atrial fibrillation attacks for a while and one of the consultants suggested they arrange a Kardia mobile device to record my episodes during my daily life so they could help consider a better treatment plan. I didn’t think too much of it and a week later it arrived in the post.

“What surprised me is it came and the note said it had been funded by CHSF. Even though I know of the great work the Charity does, I didn’t know they helped adult patients as well. It came as a complete surprise at just how much the charity goes to help everyone in their journey with congenital heart defects.

“The use of the Kardia device is simple. Hold your fingers to the points on the small device that fits to the back of your smart phone and a medically-approved electrocardiogram (ECG) is taken.

“My use of this device allowed my consultant to suggest a cardioversion (a medical procedure that uses quick, low-energy shocks to restore a regular heart rhythm) and long-term treatment plan. It provided peace of mind and helped with a better understanding of my episodes of atrial fibrillation.”

Scan to hear more about this life-saving piece of kit, funded because of you!



...or search ‘CHSF Landing Monitor’ on YouTube



**LANDING MONITOR PERFORMANCE IN NUMBERS, SINCE IT WAS INSTALLED**  
 12 PATIENTS | YOUNGEST PATIENT: 5 MONTHS | OLDEST PATIENT: 15 YEARS  
 TOTAL USAGE: 1720 HRS | LONGEST PERIOD OF USE: 263 HRS (11 DAYS)  
 SHORTEST PERIOD OF USE: 75 HRS (3 DAYS)



Among the medical equipment funded in 2022 were **120 ‘Kardia’ mobile ECG devices** which allow adults and children with congenital heart disease to monitor their heart rate by themselves at home using their mobile phone.

The results are emailed to the hospital directly - eliminating disruption to school and work.

The latest study in Leeds showed this equipment enabled over half of patients who were reporting palpitations to be subsequently diagnosed by using the Kardia machine from home.





Isabel lives with CHD, Autism and Sensory Processing Disorder

## Isabel's Play Therapy

**Isabel is 10 and lives in Creswell, North Derbyshire. She had open heart surgery at Leeds when she was 3 months old. She also has a diagnosis of wAutism and Sensory Processing Disorder and treating both conditions together comes with extra challenges.**

Mum Natalie told us how the play team and CHSF-funded sensory toys helped with a recent hospital visit:

“When Isabel was in for her MRI in December 2022 the play specialists went above and beyond in making sure Isabel was comfortable and settled on the ward. They had previously met Isabel for her sedated echo three years earlier. They made Isabel's bed all sensory for her.

“This included lights that could be changed and sensory toys that helped relax Isabel for her time in hospital. We often distract Isabel with our iPhones or bubbles or strawberries. When she is having a scan, she's ok until she feels the jelly and then it is a struggle to get Isabel to lay still and cooperate.

“We will tell Isabel she's going to the hospital the night before appointments so she's aware of the change in routine. Isabel is always happy to take her clothes off for her scans due to clothes being a sensory issue for her.

“We would like to thank Children's Heart Surgery Fund for everything they do in supporting the Leeds Congenital Heart Unit. Your support has been amazing over the last eight years. Especially for providing us with accommodation. We live 50 miles from Leeds, so this was one thing we didn't have to worry about!”



Isabel in hospital, 2022



### New CHD animation

Thanks to you, we have a new CHD animation video, **Transposition of the Great Arteries (TGA)**. These videos are a valuable resource for patients and families to understand congenital heart conditions and their treatments. Since its release in June 2022, the TGA video has been viewed over 7,850 times. The most-watched video in the playlist, Coarctation of the Aorta, has over 22,000 views!



Scan to watch all videos on YouTube



### Activity Sheets for Peripheral Clinics

CHSF's Digital Marketing Manager Olivia created activity sheets for young patients across our regional clinics, and your donations funded these to be printed along with boxes of pencils.

Children's Cardiac Nurse Specialist Christine Helm said: “The activity sheets provide a much needed distraction for children attending outpatient appointments. Appointments can sometimes involve a lot of waiting and periods where the doctors are talking to parents, so they help keep youngsters entertained through their appointment.”

### iPad mini for Chesterfield

Heather Durward, Associate Specialist in Paediatrics at Chesterfield Royal Hospital said:

“A huge thank you to CHSF supporters - the iPad Mini is already being used to entertain younger children with cartoons and videos while they are being scanned or having ECGs.

“This distraction equipment allows us to obtain better and more detailed images as the child is more relaxed and settled.”



### Refurb of L51 Playroom

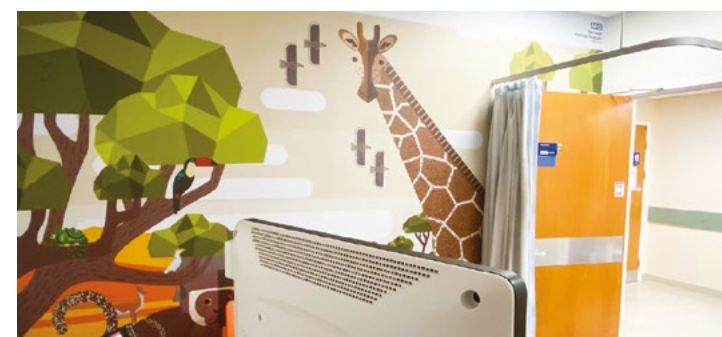
Play Specialist Anna Grisdale said: “As the playroom space is so small making the most of the floor space is vital to allow easy access for patients and their families to move around and take part in activities.

“The renovation raised storage to head height to free up the floor space, plus added foldable mats to keep the room functional for all ages and lidded storage to protect our resources. This has reduced the amount of time needed to clean and we can therefore focus on patient experience and wellbeing.

“The improved space has created a much-improved environment away from the bed spaces for socialisation and therapeutic play.”

Emma Marshall Play Specialist and Team Leader added: “The new layout and design allows the play team to move equipment for a baby play session on the floor, to an art activity on the foldable table or to a desk for our teenage patients to sit at for activities. Enabling a multi-purpose approach has increased the possibilities of play and activities to all ages of inpatients.”

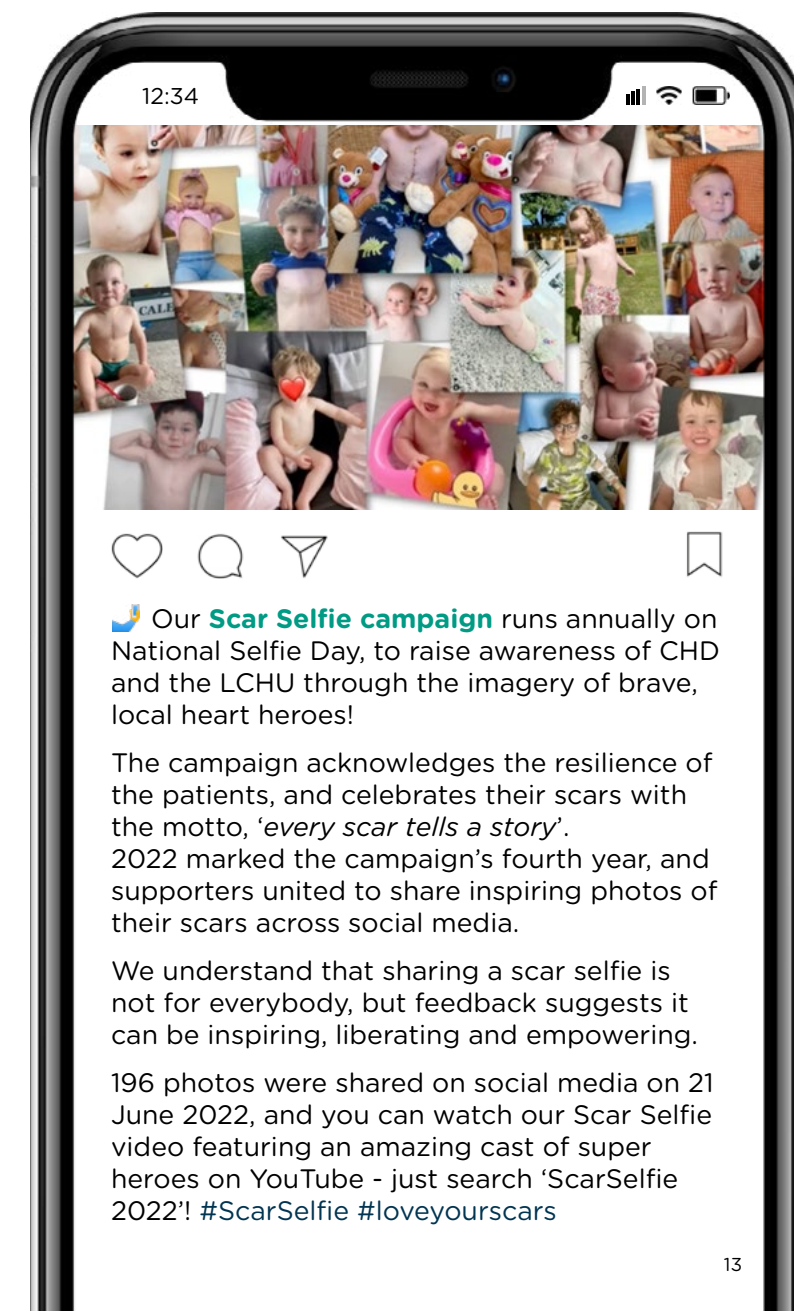
**Thank you to Priority Space for funding the playroom refurb**



### ECHO room redecoration and sensory toys

Sophie Bancroft, Cardiac Sonographer said: “Thank you so much. This project has made the three echo rooms much more inviting and distracting for all our patients, particularly young children and adults with learning difficulties who attend our department for echocardiography.

“CHSF have enabled us to purchase more distraction toys and decorate one of the walls in each of our echo rooms. The scanning environment is now much calmer and relaxing resulting in more efficient, higher quality echos. Wait times for our patients in busy clinics have been reduced and patient experience has been improved.”



Our **Scar Selfie campaign** runs annually on National Selfie Day, to raise awareness of CHD and the LCHU through the imagery of brave, local heart heroes!

The campaign acknowledges the resilience of the patients, and celebrates their scars with the motto, ‘every scar tells a story’. 2022 marked the campaign's fourth year, and supporters united to share inspiring photos of their scars across social media.

We understand that sharing a scar selfie is not for everybody, but feedback suggests it can be inspiring, liberating and empowering.

196 photos were shared on social media on 21 June 2022, and you can watch our Scar Selfie video featuring an amazing cast of super heroes on YouTube - just search ‘ScarSelfie 2022!’ #ScarSelfie #loveyourscars





## The need for the Breastfeeding Project

Previous to funding from Children’s Heart Surgery Fund, there was a shortage of staff at the Leeds Congenital Heart Unit (LCHU) who were knowledgeable about breastfeeding, as well as a lack of equipment for mothers to express breast milk while their child was being treated.

Mothers were having to share limited equipment, and queue for one specific room on the ward.

To add further pressure, in trying to keep their breast milk supply going, mothers would need to walk over from local accommodation to the ward overnight to express milk. There was no portable pump or suitable storage space to allow them to express milk overnight where they were staying.



### Project funded by Morrisons Foundation

**David Scott, Morrisons Foundation Trustee said:** “I’m delighted that we’ve been able to support CHSF’s phenomenal work. The new facilities will make a huge difference for many years to come and I’m so proud that the Morrisons Foundation, together with CHSF has helped to make this happen.”



Thanks to the generosity of the Morrisons Foundation, a range of breastfeeding equipment including a **portable privacy screen** was bought for the LCHU in 2022.



Mothers can express while with their baby and have less worry about needing to share pumps while on the ward. A selection of **mobile breast pumps**, along with appropriate **cold storage facilities**, mean mothers now no longer need to walk across to the hospital in the middle of the night as they can express breast milk in local accommodation provided for them by CHSF.

# Breastfeeding project at LCHU



ONEGLOBAL

CHSF also developed a booklet to give advice and support for breastfeeding mothers who are establishing a milk supply for their babies.

The book was translated into multiple languages, for mothers where English might not be their first language. Thank you to corporate supporters OneGlobal for translating the books.

You can read the booklet online at: [bit.ly/chsf-breastfeeding](https://bit.ly/chsf-breastfeeding)



## Charlie’s story

**Charlotte’s son Charlie was diagnosed with hypoplastic left heart syndrome and had to have open heart surgery when he was just five days old. Charlotte told us:**

“I had never expressed with any of my other children but was supported so well by the nurses – initially on the post-natal ward and then through PICU.

“I was given access to an expressing machine whilst in hospital and was also loaned an electric pump to bring home which was just absolutely amazing.

“Alix the dietician was amazing throughout and still is now! She not only talked out my expressing worries but she was able to talk through Charlie’s needs in a way we understood, helping us make the best choices and supporting me when I made the choice to stop expressing and move to formula at the right time for Charlie.

“We still see Alix regularly where she keeps an eye on Charlie’s weight and supports us with our tube-feeding journey.”

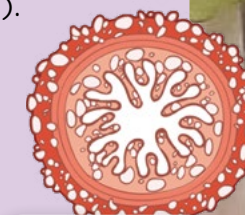
### Preventing **Necrotising Enterocolitis (NEC)**

Being fed with breast milk is particularly important for babies who are premature and/or have certain cardiac conditions due to their increased risk of developing a potentially severe infection called Necrotising Enterocolitis (NEC).

With NEC the tissue in the bowel (small and large intestines) becomes inflamed. The infection can vary from being mild to severe, but giving mother’s breast milk is known to help prevent a baby from developing it.



Healthy small intestine



Inflamed NEC small intestine





# Care for the Family

I'm Sarah and I head-up the CHSF Family Support Service. I joined the charity in October 2020, and am here to support families with whatever they need during their child's hospital stay and beyond. This is a tailored service and we aim to meet the needs of each individual family.

In July 2022, I was joined by a new Family Support Worker, Shelly Aston, and together we offered a range of practical, emotional, financial and sign-posting support for our families throughout the year.



**Sarah Cherry**  
Family Support Supervisor

## SUPPORT FOR FAMILIES IN 2022 & 2023 INCLUDED:

- 578 families stayed in CHSF-funded family accommodation
- 400 welcome packs delivered to families on the ward
- 136 emergency packs handed out
- 752 meal vouchers for the hospital canteen given
- 54 'Welcome to the World' new baby packs for neonates
- 6 'Cardiac Cafe' events, across the region
- 8 transition packs given to young people
- 102 external referrals completed for financial support
- 408 individual families received specific tailored support
- 2 sensory events for cardiac patients with additional needs
- 1 Fontan day for cardiac kids transitioning to high school
- 524 Tesco supermarket vouchers given
- 354 travel grants awarded
- 136 days of free parking to support a long-term inpatient



**Mum, Caley Flynn said:** "We were visited by Sarah from CHSF very early on from Alec being admitted onto a ward in Leeds.

"She made us feel at ease from the start by sorting us with free accommodation onsite so that we didn't have to travel home each night. This was until there was room for us at Eckersley House - a 2 min walk from the Ward Alec was staying on.

"Sarah sorted a range of things for us, to help us settle into our new temporary life. These included:

- **One-off payment** from CHSF to help with immediate costs of not being at home.
- **Tesco vouchers** for the first two weeks
- **Toiletry bag**, which was very useful as during a stressful time the simplest of things are easily forgotten.
- A **parking permit** that allowed us to keep the car close by for if we needed to use it.
- **Fuel costs** when we needed to nip home.



Sarah visiting Alec, Caley and Adam in Sept 2022

"We stayed on the heart ward for a week before Alec's surgery, which lasted 3 hours. Then we had the call from his surgeon explaining that it had been a success and we could go to see him in the Paediatric Intensive Care Unit (PICU).

"Sarah took time from her day to come down to PICU to check in on us all and see how Alec was recovering. That made us feel like we weren't on our own in this difficult time."

**Chantelle**  
Online

TODAY

Sarah especially was amazing, she was a pleasure to chat to and really felt like more of a friend rather than someone just working at the hospital. She made me feel that little less lonely when it came to being on the ward and even kindly took me for a cup of tea to help clear my head space. I will never forget such generosity, and I will forever be in debt for everyone's support so far in my journey at Leeds.

**Lea**  
Online

TODAY

Me and my partner stayed at the hospital for over 100 days. We relied on Children's Heart Surgery Fund to help us with accommodation as we live 1 hour and 30 minutes away. Our baby had a very rare heart condition and it was very touch and go with her. It gave us peace of mind knowing that we were just a short walk away just in case anything happened.

Sarah and the CHSF team were there from day 1, always asking if we needed anything and always went above and beyond to help us.

When our Daughter passed away on July 26th the CHSF team said we didn't need to leave the accommodation so we could spend time with our Daughter in the Chapel of Rest and actually have time with her, and not be rushed home. They were always very reassuring. I couldn't thank Sarah and team enough for everything they have done.



"Hello, I'm Shelly. Here are just a few examples of what a day can involve working in the Family Support team at Children's Heart Surgery Fund."

## EVERYDAY ESSENTIALS

"Today I continued to support one of our long-term inpatient families whose baby has unfortunately been in hospital with us for the last few months.

"The family are currently staying in our hospital accommodation and finding it increasingly difficult to fund everyday items whilst being away from home. I delivered them some essential toiletries to save them having to buy these and some washing tabs so that they could wash their clothes

"CHSF has been fortunate enough to receive these kinds of items via donations from local businesses and organisations. It is a real privilege to be able to pass on these items to our families in need."

## HELP FOR LONGER STAYS

"Today I also spoke to a family who were very worried about getting into debt because of all of the additional expenses of food and drink whilst their child is an inpatient.

"They only had one income coming in as mum couldn't currently work because of being here for her child, and she only gets paid for the hours she works because of the kind of job she does.

"I was able to help them with a travel grant to pay dad's expenses so that he could get across to see them both but still return to work the next day. I was also able to give them a shopping voucher for food and essentials and some canteen vouchers to make sure mum kept eating enough.

"One of our parents was really upset because their baby's condition has turned out to be more serious than they first thought, so I took them for a coffee to talk things through and see what we could do to help. I will make sure I spend time with them every day whilst they are

going through this difficult time and we will be there for them however we can to see them through all the emotional ups and downs.

"Before we offered financial support and free accommodation, we had people sleeping in their cars because they couldn't afford a hotel room and parents going without food so that they could afford to be there for their child.

"When parents are going through such a difficult emotional time we really don't want them to get into debt or go without, so we keep in touch daily with all our families to make sure they are coping financially and we step in if not.

"We work closely with the nurses and admin staff on the ward and they always tell us if there are families that need us who we haven't seen yet. We help with solving practical problems as well as helping financially and emotionally."

Find out more at [www.chsf.org.uk/family-support](http://www.chsf.org.uk/family-support)



CHSF put on events for our heart community throughout the year which provide opportunities for CHD patients in our region to have fun and meet other heart heroes and families.

We know that great friendships and bonds are formed when heart families get together, and it's a chance for children and parents who have gone through similar experiences to support each other whilst having a good time.



**"It was great getting to meet other parents and talking about your children with someone actually understanding you."**

In 2022, CHSF launched a series of social events for heart parents and adult patients around the region, hosted by our amazing Family Support Workers and including special guests from across the Leeds Congenital Heart Unit.

These 'Cardiac Cafe' sessions included a sandwich lunch and hot drinks, and were a safe space for everyone to relax and get to know each other.

Thank you to everyone who joined us at Cardiac Cafe's in:

- Bradford
- Leeds
- Hull
- Scunthorpe
- Wakefield
- York

**Family Support Supervisor, Sarah** said: "Today we held one of our Cardiac Café events in Wakefield and I had some lovely conversations with families local to the area. These events are a great opportunity to capture the parents' and patients' voice, to enhance the service we provide and support the work we do.

"I spoke to a young adult patient. We discussed the transition process from the children's service to adult's and the things she may have found useful during her experience. I also spoke to a parent about a future topic for CHSF events, where we could hold a café specifically centred around children with additional needs. We had a wonderful morning eating delicious pastries, meeting new people and connecting."



## Festive fun for families.

300 patients and their family members attended our Christmas Party last year. Everyone was entertained by Boomchikkaboom, our youth ambassador Junior Frood, mascot Katie Bear, our fantastic volunteer elves and of course, Father Christmas.

Due to the pandemic, 2022 was the first Christmas event we'd been able to host in two years and it was so great to be able to see so many smiling faces. It was so popular that we actually hosted two parties back-to-back to keep up with demand.

A huge thanks to everyone who made the parties a success, including the big man himself...SANTA!

Huge thanks to our friends at Irwin Mitchell, Priority Space and Morley Glass for making Christmas Parties possible in 2022 and 2023 as well as a donation in the name of Bonnie Kemp, in memory of Jean Ruth Coleman.



## Fang-tastic family fun.

In 2022, thanks to your donations we were able to welcome around 200 patients and family members to our Halloween party - a huge thank you to Asda for sponsoring the event and for Corporate Partners Hilton Leeds City for hosting us.

We had such a FANG-tastic time with our heart warriors and families at 'Hocus Pocus at the Hilton' Halloween Party! The party was such a success we were able to repeat the event in 2023 and made it even bigger!

"Brilliant job by you all. My grandchildren loved it. This time last year was a different story. But thanks to all you brilliant people, a happy family now. Much love and gratitude, a very grateful Grandma xx"

"We had a fa-boo-lous time, thanks so much."

"We had an brilliant time, was so much fun!!! Thank you."



Mia on PICU, Sep 2022 being looked after by Senior Sister Rachel Boyes



Mia now, with her Mummy, Daddy, twin sister and Katie Bear

**Mia was born with Tetralogy of Fallot. She had a narrow valve leading up to the lungs from the heart, a hole in her heart and her oxygenated blood and deoxygenated blood was mixing.**

Dad, Tom, also has congenital heart disease. He was born with two holes in his heart and a leaky valve. He needed two open heart surgeries - one at 6 years old, and another aged 21.

Tom says: "During Mia's treatment, CHSF helped us with travel costs and accommodation at the hospital. They also helped us with money as I couldn't go to work for eight weeks. The team supported me if I needed it at any point.

"Mia has had her surgery now and is doing amazing. Thank you so much for everyone who helped her."



# Care for the future

## Paediatric Critical Care Annual Conference

Clinical educator and Band 6 Sister Angela Crowther said: "Many thanks to CHSF supporters for offering myself and the team the opportunity to attend the Paediatric Critical Care Societies Annual Conference in Leicester."

"Myself and four other nurses, along with two junior medics, attended the two day conference allowing us the opportunity to showcase some of the ongoing education work in the Leeds Paediatric Intensive Care Unit and learn from our colleagues in other centres."



## Palliative Care Training for nurses

The Yorkshire & Humber Congenital Heart Disease Operational Delivery Network put on an educational event in November 2022 focusing on palliative care in babies and children with CHD.

Lead Nurse Cat Brown said: "The event was great, with over 90 delegates from across the Yorkshire & Humber region. It was our first face-to-face event since the pandemic so the funding from Children's Heart Surgery Fund meant we were able to hold it at a venue with excellent amenities."

"The event evaluated well with feedback such as 'more of this please!' and 'excellent session on a topic I wasn't familiar with.'"



## International Fellowship in Canada

CHSF collaborated with Leeds Hospitals Charity in 2022, to offer financial support for Leila Rittey's international fellowship in International Fetal and Neonatal Cardiology in Edmonton, Canada.

Leila says: "I am now back working in Leeds and this extensive training has allowed me to be able to cover compassionate leave taken by one of the Fetal Cardiology Consultants to ensure that the Fetal Cardiology clinics aren't reduced and patients waiting for longer than they should be seen. I am also able to teach the sonographers and other consultants what I have learnt whilst away to enable that the whole Fetal Cardiology Department are benefitting from the world class training that this funding allowed me to obtain."



## European Paediatric Cardiology Conference

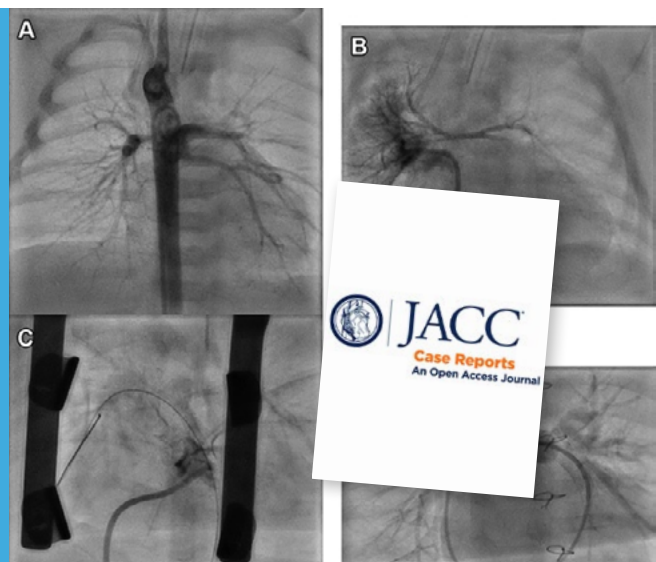
Dr Malenka Bissell and dietitian Alix Rhodes were able to attend and present at the annual AEPC (Association of European Paediatric Cardiology) in Geneva. Showcasing research internationally underlines the Leeds Congenital Heart Unit's status as a world-class centre of excellence.

## International Cardiac Journal case report

Thank you for funding the open access fee for a report paper which Dr Jamie Bentham worked on, published in a renowned international cardiac journal (JACC Case Reports). The paper is called 'Alternative Hybrid Approach to Promote Native Pulmonary Artery Growth in Pulmonary Atresia'.

Dr Bentham said: "JACC journal has a high impact factor and therefore publishing an article there brings an important contribution to the speciality. It will also have a positive impact for the whole department."

You can read the paper Dr Bentham published on JACC Case Reports at: [bit.ly/chsf-jaccjournal](https://bit.ly/chsf-jaccjournal)



# You can help to Fund our Future

**Choose to leave a gift in your Will to CHSF and we promise to develop and grow the work we do for babies, children, teenagers and adults affected by congenital heart disease in our region for generations to come.**

Legacy donations are absolutely crucial to the welfare of patients and their families, and to ensure our vital cause has a future. They provide things like life-saving medical equipment - in and out of hospital, and fund essential projects for family support.

## Write a Will for free

We have two free Will writing services available, and by using this service, you are under no obligation to leave a gift in your Will to CHSF.

We are proud to be partnered with both **The Goodwill Partnership** and **Octopus Legacy**, to allow anyone 18+ to easily write or update a simple Will for free. This can be done online, over the phone or a home visit service if you prefer.

Found out more and get started at [www.chsf.org.uk/free-wills](https://www.chsf.org.uk/free-wills)



Scan the QR below or visit [www.chsf.org.uk/legacy](https://www.chsf.org.uk/legacy) to find out more about leaving a legacy gift to CHSF.





# 10 ways you could help

## 1 Make a personal donation

Every penny that is raised for CHSF goes towards supporting our region's heart warriors and their families. As a publicly-funded charity, it's your incredible donations that keep the charity going.

Visit [chsf.org.uk/donate](https://chsf.org.uk/donate) to make a life-saving donation.



## 2 Put on an event in your community

Do you have a great idea for an event in your neighbourhood, but not sure where to start?

We have a fundraising pack full of ideas to start raising vital donations for CHSF.

Download now at: [chsf.org.uk/fundraising-pack](https://chsf.org.uk/fundraising-pack)



## 3 Take part in a CHSF Event

We always have a wide range of fun and exciting activities to help CHSF raise funds to support hearts for life.

Choose from challenge events like our Skydive and Firewalk, long-distance cycling and running races and even year-round challenges you can do in your own time at home, in the garden or in local area.

For more details on a CHSF event or if you have any questions, queries or suggestions, please do not hesitate to contact us at [events@chsf.org.uk](mailto:events@chsf.org.uk). Visit [chsf.org.uk/events](https://chsf.org.uk/events) to check out our latest events you can sign up to!

## 4 Make it your business to support CHSF

By selecting CHSF as your business or workplace's chosen charity partner, you know that the efforts of your company and employees will have a great impact on our region's young heart patients and their families.

There are big benefits to businesses - more engaged employees as well as great PR in the community and among customers too.

Our team would be delighted to talk to you about how your business can get involved. **Drop us an email at [corporate@chsf.org.uk](mailto:corporate@chsf.org.uk)**



## 5 Help us reach out to Trusts, Foundations and other Grant Giving organisations

We are so grateful for the support we receive from charitable trusts, foundations, and grant givers. Gifts from these organisations can make some of the biggest CHSF-funded projects happen.

We'd love to hear from you if you work for one of these bodies, or can refer us to a grant-maker.

Please get in touch with our Head of Philanthropy at [nicola.graves@chsf.org.uk](mailto:nicola.graves@chsf.org.uk)

## 6 Give the gift of time

We are regularly looking for committed volunteers who can use their time and skills to help the charity. Volunteering with CHSF can provide a chance to develop and learn new skills, meet new people and give something back.

If you'd like to be kept up to date with volunteering opportunities that are available, please email the team at [info@chsf.org.uk](mailto:info@chsf.org.uk)



## 7 Play our Lottery

It's your chance to win £100 with CHSF every week of the year!

Because our lottery is smaller than most, there are more chances of being the lucky winner.

Join today at [chsf.org.uk/lottery](https://chsf.org.uk/lottery)



## 8 Spread the word

Our social media channels are growing all the time. It's a great way to spread awareness of our cause and help generate support for our charity. Not involved already? Follow us on:

-  [/childrensheartssurgeryfund](https://www.facebook.com/childrensheartssurgeryfund)
-  [@childrensheartssurgeryfund](https://twitter.com/childrensheartssurgeryfund)
-  [@CHSurgeryFund](https://www.instagram.com/CHSurgeryFund)
-  ['Children's Heart Surgery Fund'](https://www.linkedin.com/company/ChildrensHeartSurgeryFund)
-  [@ChildrensHeartSurgeryFund](https://www.tiktok.com/@ChildrensHeartSurgeryFund)
-  [@chsurgeryfund](https://www.youtube.com/@chsurgeryfund)

## 9 Set up a regular direct debit gift

By giving a regular donation to CHSF, you enable us to plan for the future while saving lives today.

It's really easy to do, and a little each month can add up to a huge life-saving difference.

Visit [bit.ly/chsf-dd](https://bit.ly/chsf-dd) or scan the QR code below



## 10 Join our mailing list

Be among the first to know the latest CHSF news! We send a monthly newsletter called BraveHearts. You can sign up to marketing by email, post or phone on our website. Just go to: [chsf.org.uk/stay-updated](https://chsf.org.uk/stay-updated)





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