

“During our 12-year journey, CHSF have been by our side the whole time. We can never repay them for how they have supported us and other families.”
Natalie Varley, Heart Mum

Our vision

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.

Our purpose

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

Our mission

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.

Our values

We embed our core values of trust, compassion, openness, respect and dedication into all aspects of our work. We believe these values guide our behaviour, decisions and ultimately our actions.



Welcome



Sharon Milner, CEO

Welcome to this, our fourth annual Social Impact Report, and my last as CEO of CHSF.

2021 proved to be another highly challenging year, but with your amazing support and inspiration, the CHSF team were able to deliver for our beneficiaries. As you will read, our charity mission to support the Heart, Mind, Family and Future of congenital heart patients in our region has continued at pace.

We are particularly proud of the inroads we have made in our Family Support work. The wraparound care your donations and grants provide is needed more than ever as people struggle with the cost-of-living crisis, at such a critical time in their child's life.

Developing a service like this during COVID times was a difficult process to navigate. However, the feedback we have received is hugely gratifying. We now have an extra member of the family support team and we are working together to cover more areas, including some support for the adult service.

The hospital is now opening up and both heart parents and siblings can now visit their poorly child, sister or brother which is a game-changer for the wellbeing of the family unit. It is clear the Leeds Congenital Heart Unit is able to function better through these turbulent times because of your help and support.

We can't thank you enough for everything you do to support our vital cause.

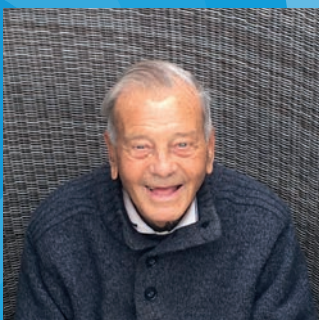


Paul Goodwin, Chair of Trustees

As we transition to a 'new norm' of living with COVID, I am delighted that CHSF has continued to thrive and support its pillars of heart, mind, family and future. This report again highlights the breadth and depth of the support for our heart warriors, none of which would have been possible without you, our supporters. Thank you.

As we move forward, we enter a period of change, with a new team under new executive leadership, uncertain economic and political conditions, and of course, a new Leeds Children's Hospital on the horizon. Our focus though, remains the same. We will help the Leeds Congenital Heart Unit be a world-class centre of excellence with a thriving regional support structure, supporting the clinical teams, the patients and their families.

Thank you again for your continued support.



Dickie Bird OBE, Ambassador

Since 2017 I have been proud to be the Ambassador for this fantastic cause. I will never forget my visits to the Heart Unit. It means more to me than anything when parents of poorly little babies thank me for the donations I've made. I can't think of anything better to do with my money than put it towards care for local heart families when they need it most. The Heart Unit saves lives from all over Yorkshire every single day, and CHSF have helped them do this for well over 30 years. Please continue to support this wonderful charity.

Our Impact in 2021 and 2022

From January to December 2021, CHSF invested £643,363 in 68 different projects and initiatives. This benefited the 17,000 patients, and their families, from across Yorkshire, the Humber and North Lincolnshire cared for by the Leeds Congenital Heart Unit.

In 2021, we increased our support to the Leeds Congenital Heart Unit, spending significantly more on beneficiaries than in previous years.

We also increased our support for families during the year, providing more financial support and exceptional grants to families in need.

This report focuses on CHSF's four key areas of work; caring for the Heart, the Mind, the Family and the Future during **2021**, and into the first half of **2022**.

You will see on pages 6 and 7 some of the projects CHSF supported **#BecauseOfYou**.



Care for the heart

by providing revolutionary medical equipment



Care for the mind

by creating a positive experience for patients and their families in hospital with equipment, distractions and support



Care for the family

by providing family grants, accommodation, wellbeing sessions and assistance from Family Support Workers



Care for the future

by funding research, clinical posts and projects



See page 8

11
PROJECTS
funding the
HEART

27
PROJECTS
funding the
MIND



See page 12



See page 16

19
PROJECTS
funding the
FAMILY

11
PROJECTS
funding
the
FUTURE



See page 20

A TOTAL OF £643,363 INVESTED IN 68 PROJECTS

Leah's Story

Leah's mum, Rebecca, tells us about their journey with congenital heart disease so far and how Leah and her family have been helped by CHSF...

Heart warrior Leah was born with a heart defect, but her congenital heart disease went undetected until she attended a GP appointment for a cough four years later.



“We found out Leah had a sinus venosus ASD in September 2020 when she was 4 years old. She was born with it, but it was a huge shock because we never knew about it until she had a GP appointment for an unrelated cough.

When they listened to Leah's heart, they heard a murmur and referred her for a heart scan. This confirmed the ASD.

After further appointments for various scans and discussions we got a surgery date for April 2021. The time around the date was surreal but we tried to make it as positive as we could.

With Leah being five years old by the time of surgery she was asking lots of questions and was really scared. Children's Heart Surgery Fund helped so much with the 'Katie Bear Goes to Hospital' book and the Play Therapists were able to help Leah see it all from a child's point of view.



We were told of the 'Leeds Congenital Hearts' website and the children's cardiac specialist nurses who have helped us every step of the way. They are always at the end of the phone or email.



Leah went into hospital the day before her operation for her pre-operation tests to be done. She was so brave having her canula put in for her blood test. The staff working that day really helped us get through it.

The next day was Leah's surgery day. Leah was in theatre for around six hours. When we got the call to say she was out of theatre later that evening her surgeon was happy to say it had been a success. I visited her in intensive care and despite all the tubes and machines she looked ethereal. We couldn't believe it.

Leah thankfully started to recover quicker than we ever expected. She had tough days to come after surgery, but she did amazingly and thrived. She moved through high dependency and back onto Ward L51, where she got her Katie Bear (who she adores!).

Leah's had her first check-ups now and we're happy she's doing really well. She's back at school and is so happy to have spent some time in the sunshine, playing on the beach and seeing her family and friends.

The support of Children's Heart Surgery Fund has helped so much from gifts for Leah, to chats and cuppas with me. We'll be forever grateful to the nurses, the surgeons, doctors, housekeepers, Children's Heart Surgery Fund... and all the people who helped us.”



Read about a book CHSF has funded for older children and teenagers on page 15.

BECAUSE OF YOU IN 2021

CHSF funds projects in four key areas



rewards for children after an MRI scan



SENSORY EQUIPMENT

for heart ward

NEONATAL RESOURCE FILE



attendance at certified course



heart ward **FISH TANK**



games for ward L51



BABY FRIENDLY BREASTFEEDING initiative



Folder for ward DVD's



4 iPads for PICU



48 HOME BLOOD TESTING KITS



patient education video

MRI-SAFE ECG SYSTEM



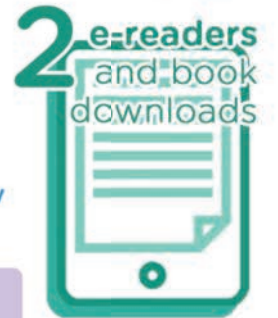
to monitor babies during scans



ADULT CHD RESOURCE FILE



International fellowship in Fetal and Neonatal Cardiology at University of Alberta



2 e-readers and book downloads

4 regional cardiac nurse specialists

to care for patients and families at hospitals in Bradford, Calderdale, Sheffield and Grimsby/Scunthorpe.



LEEDS CONGENITAL HEARTS

ACHD and Congenital Cardiac nurse specialist **CONTACT CARDS**



Hospital **DIRECTION CARDS**

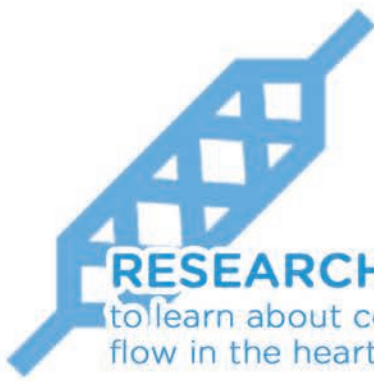


REFRESHMENTS for weekly cardiology team meetings

2 ADVANCED LIFE SUPPORT QUALIFICATIONS



DEVELOPMENTAL TOYS FOR WARD 51



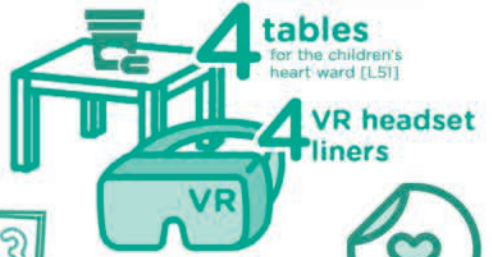
RESEARCH STENT

to learn about complex blood flow in the heart and lungs



2 microwaves for the heart ward parents room and staff room

cardiac feeding magnets



4 tables for the children's heart ward [L51]

4 VR headset liners

2 ECG MACHINES



for hospitals in Grimsby & Scunthorpe

158 KARDIA DEVICES



allowing patients to check their heart rate at home using their smartphone



CHILDREN'S BOOKS for ward L51

WELCOME PACKS

of essentials for families arriving on the ward



STICKERS for the ward

GIFTS

for birthdays and special events on the ward



DECORATIVE LIGHTS

for the children's heart ward



INFUSION-PUMP SPACE STATION

to give babies life-saving meds via a drip during MRI scans



APPLE MACBOOK AIR

to show Fetal Cardiology presentations for training



Dräger Babytherm INCUBATOR

for neonatal cardiac babies



12 pairs of HEADPHONES for HDU



FAMILY SUPPORT WORKER for heart families



FRIDGE/FREEZER

to store milk for mums who are breastfeeding on the unit



FRIDGE FREEZER for parent room on Ward L51



65 BLOOD PRESSURE MONITORS for adult patients



BUSINESS-CARDS for children's cardiac specialist nurses



PAINTS AND CRAFTS for the ward L51 playroom



TRAVEL COSTS FOR 4-NURSES to attend a conference in London



to support vital home-from-home ECKERSLEY HOUSE



support for the scientific network meeting of CONGENITAL CARDIAC ANAESTHETISTS





**Care for
the heart**



Care for the Heart

We fund vital equipment that helps to save and improve the lives of people with congenital heart disease.

Our support for the heart included:

Pro11 Headsets

In the hybrid cardiac catheter lab/surgical theatre, communication during any procedure is vital to ensure the highest level of care. CHSF is delighted to have provided eight Pro11 headsets that are helping to improve communication between team members and increase efficiency and patient safety.

The communication system within the theatre is based on a tannoy-style system operated from the control room. A speaker relays a live feed from the theatre to the control room, while a microphone is used for the team in the control room to communicate with the theatre team. However, it only allows one-way communication at any time.

The investment in Bluetooth Pro11 headsets allows effective two-way and hands-free communication between all team members. This is vital during the electrophysiology cases and high-risk interventions to ensure the best possible outcome for patients.

The Pro11 headset system also integrates with external broadcast and audio-visual streaming facilities. This can enable the theatre team to take part in real-time remote broadcasts and seminars, and broadcast live cases to peers.

Stephen Kimberley, Cardiac Physiologist says:

“These wireless headsets enhance communication every single day between all team members working in the hybrid theatre.

We use them for all kinds of procedures including diagnostic, interventional and electrophysiology cases. A huge thank you to CHSF and their supporters for making the job safer and more efficient with these brilliant headsets.”

Dr Dom Hares, Consultant in Congenital Cardiology says:

“It is no exaggeration to say that they have revolutionised the communication in the lab during cases, which improves patient safety and team dynamics. We could not work without them! Thanks for all the ongoing support!”

Feeding Magnets

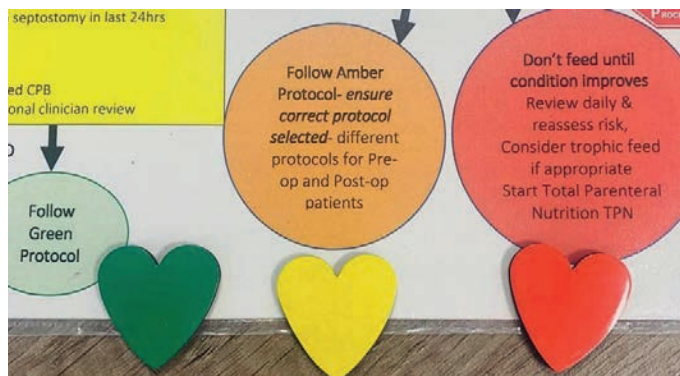
All infants are placed on a coloured feeding protocol pre-surgery and post-surgery. This allows staff and parents to identify how infants should be fed and what they can eat, depending on their clinical condition.

CHSF is helping staff to identify quickly and easily which protocol the infants are on through an investment in green, yellow and red magnets. This is helping to ensure hospital stays are not extended due to feeding issues and it is improving patient safety.

Alix Dunlop-Jones, Chief Dietician says:

“They are being used to identify which feeding protocol babies are following, guided by how they are feeling and what cardiac condition they have.

They are an easy and bright way for nursing staff and dietitians to know the current feeding status of a patient, keeping babies safe and full of that all-important nutrition. Thank you CHSF and all your supporters!”





Care for the Heart

Baby MRI Incubator

CHSF funded a state-of-the-art Baby MRI Incubator for the Leeds Congenital Heart Unit. It consists of an MRI coil to take high quality images of babies' hearts and a closed incubator.

The Baby MRI Incubator enables clinicians to perform MRI scans on babies with complex heart defects without the need for general anaesthetics, which can put babies' lives at risk.

It also provides an alternative to CT scans. CT scans use radiation, provide only limited information about the heart and vessel structure and reveal nothing about blood flow and heart function.

The detailed images provided by the MRI scans will feed into tailored treatment plans. As a result, outcomes for patients will improve and the death rate in babies with congenital heart disease will reduce.

While Baby MRI Incubators are widely used for brain scans, this state-of-the-art Incubator is the first in Europe to take images of babies' hearts.



Dr Malenka Bissell, Clinical Lecturer in Paediatric Cardiology at the University of Leeds and at Leeds Children's Hospital received the MRI coil in 2020. She then started to optimise the quality of the images this camera could produce and undertook initial research with babies with mild heart conditions. See CHSF's 2020/21 Social Impact Report for more detail.

When the closed incubator arrived in January 2021, Dr Bissell tested it with the MRI coil to ensure they worked together as expected.

"I need to do a little bit more testing, but it is essentially fully functional. The warming option and the suspension for the uneven floors and lift doors are amazing and it is a fully COVID secure environment for the baby."

After a feed on the ward, the sleeping baby is settled into the Baby MRI Incubator wearing headphones and transported directly into the MRI scanner. It creates a cosy wrap and offers additional noise protection. A general anaesthetic is not needed to keep the baby still as the baby stays asleep in the Incubator, allowing detailed and advanced images of the heart to be taken.



Dr Bissell continued to undertake research scans in 2021 with babies with mild heart conditions using the Incubator. These 3D flow MRI scans show a three-dimensional image of the heart in one scan, while 8-10

images are needed with standard 2D scanning to achieve the same level of detail.

Dr Bissell has found that the new 3D flow MRI scans are just as accurate as the 2D scans but much faster. This research has been published in the 'Journal for Magnetic Resonance Imaging'.

These scans have revealed new information such as how much blood was flowing into each lung of new-born babies. Previously, this type of information was only available for older babies aged from 3-6 months, who had MRI scans under general anaesthetic.

Between June 2020 and November 2021, Dr Bissell and her team scanned a total of 22 babies. Dr Bissell is pleased with achieving this outcome in spite of restrictions presented by COVID-19.



At the start of the 2021 academic year, a paediatric doctor in training and a radiographer joined the research team. They started scanning sicker babies with complex heart defects following the arrival of an infusion pump space station, funded by CHSF. This allows infusion pumps which continuously supply babies with life-saving fluids to be taken into the MRI scanner.



A new MRI safe ECG monitoring system, also funded by CHSF, allows the babies to be monitored during transportation and MRI scans. This system uses a flat ultrasound probe, rather than ECG stickers which can irritate new-born skin.

Dr Bissell has reported that great progress is being made in formalising the use of the Baby MRI Incubator and integrating it into clinical practice. The number of patients being scanned has now returned to pre-COVID-19 levels, and the number of requests for clinical scans is increasing, so a greater number of scans are taking place.

The detailed information provided by these scans is enabling clinicians and surgeons to better predict what they will need to do during procedures and surgeries. They can plan effectively and be fully prepared for what they will find. This is allowing them to shorten these procedures and surgeries.

Dr Bissell is expanding her work with advanced 3D flow MRI scans to include older babies and children, who are too big for the Incubator. She is now able to achieve very useful results with a short 15-minute research 3D flow MRI scan, using headphones and a video as distraction, without the need of a general anaesthetic.

Looking forward, Dr Bissell plans to integrate and formalise these 'rapid awake' scans for all high-risk patients into clinical practice with the intention of creating a dedicated MRI list of patients in a year's time. This will then allow expansion of 'rapid awake' scans for other babies not formally on the 'high risk pathway'.

Dr Bissell is continuing her research which includes predicting the narrowing of the main body artery (aorta) both before and after babies are born.

Dr Malenka Bissell says:

"I am very grateful to CHSF and their funders for the Baby MRI Incubator. It will make a big difference to the treatment and outcomes for babies categorised as high-risk, allowing new research into paediatric congenital heart disease and strengthening the reputation of the Leeds Congenital Heart Unit as a centre of excellence."

River-Phoenix MRI Research Scan

River-Phoenix had an MRI research scan in the Baby MRI Incubator in July 2022 when he was three months old (see photo on the left).

River-Phoenix has hypoplastic left heart syndrome. The left side of the heart doesn't develop completely and is too small meaning not enough oxygenated blood gets through to the body.

Mum, Eleasha, talks about River-Phoenix's experience:

"The MRI scan at first was a little nerve-racking, but the staff were so lovely and reassuring it made it a lot easier to let him go ahead. The nurses were so good at answering all the questions we had to ask and easing our worries or concerns. They made sure we were 100% comfortable with the procedure.

It took River a little bit to get settled into the Incubator but once he was in and the little headphones were on, he was fine. The staff swaddled him because he loves to be cuddled tight.

River sleeps really, really well anyway so I knew he wouldn't be much trouble having the MRI scan done. He slept almost all the way through and only got a little fed up and cried towards the end.

It was nice to get the chance to sit down at the end of the scan, see the pictures and discuss anything we wanted to ask. If he gets asked to have another scan in the future, I will give consent again.



I can't believe how well River is doing. It's so surreal looking at him knowing what he went through. I honestly didn't think I'd be sat here with him today. The staff and nurses in the hospital deserve medals!

He's such a smiley, happy little baby, so content, so strong and just amazes me every day. He's only three months old and has already been through so much. I was told at his check-up last week that even though River is one of the high-risk patients, he's one of the ones they are least concerned about. That is just amazing to hear. They have no worries with him and since being home he's just thrived and come on loads!"



**Care for
the mind**



Care for the Mind



We provide equipment, toys, crafts and other distractions on the cardiac wards and in outpatients to support patients and their families to have a positive experience in hospital.

Our support for the mind included:

Bags of Lego



Around 100-150 children aged 6-12 have an MRI scan each year. Staff and psychologists are keen that they have a positive first experience, as most will have regular MRI

scans throughout their lives. CHSF has provided small bags of Lego as treats for these children after their first MRI scan, irrespective of how it went. Small toys last longer than sweets and all children can enjoy them. The toys have been positively received by both patients and parents.

“I want to say a big thank you to the supporters for these gifts. We scan a lot of children and some have learning difficulties or special needs. The gifts give them something to look forward to and they feel rewarded for being so brave. Their little faces just light up when we hand them their little gifts. Thank you so much.”

Lisa Lewis, Cardiac/Congenital Radiographer



Developmental toys

CHSF provided small toys that young babies can hold in their hands to assist with their development and toys that allow them to spend time on their tummies. These toys help these babies who have had surgery in their first few weeks of life to develop their skills and reach developmental milestones.



“These toys are invaluable for our high-risk babies to be able to develop their skills, particularly starting to spend time on their tummies which helps them to develop head control and prepares them for rolling and

crawling. It is positive for the baby and their parents/ carers, ensuring bonding and happy times during a very stressful experience.”

Sarah Hibbert, Clinical Service Manager, Paediatric Physiotherapy

Sensory toys

Many young babies and children can be in hospital for long periods of time. Some patients have complex needs or life-changing prognoses, and some will need end-of-life care.

CHSF has provided sensory lights and toys which can be used as stimuli to enhance their growth and development. This equipment can help children to build nerve connections in their brains and support the development of language and motor skills. It can create a calm and soothing environment for patients and their families in difficult circumstances.

“The sensory toys can be lights, balls or different textures and help to stimulate children of any age. It ensures that even though they are on critical care, these children still get that chance to enjoy play and express who they are. It’s just spectacular to see the difference stimulation with the use of sensory equipment can make to a child. Thank you.”

Megan Holmes, PICU Play Leader

High Dependency Unit headphones

CHSF replaced broken headphones that parents wear on the High Dependency Unit during ward rounds. These headphones are used to block out conversations between medical staff and other patients and families.

“Thanks to CHSF supporters we have received 12 new pairs of headphones for heart parents to wear during the HDU ward rounds. Wearing headphones helps ensure patient confidentiality while allowing parents to stay at their child’s bedside.”

Niamh Hoggard, Nurse, Ward 51





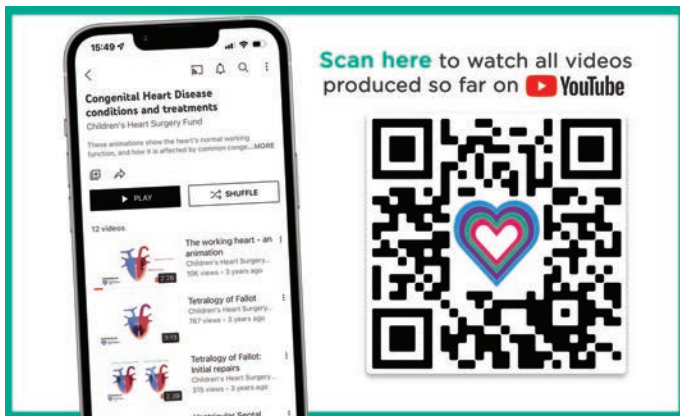
Patient Cardiac Education Videos

While there are various videos available on the internet that explain congenital cardiac conditions, the explanations are often not very clear and are usually confined to covering the basic condition rather than the treatment and long-term consequences.

Since 2018, CHSF has funded twelve videos about congenital heart defects that explain simply and clearly the conditions, treatments, and long-term implications.

In 2021, a video about the Ross Procedure was produced which explains the use of this procedure for the treatment of congenital aortic valve disease. It provides an alternative for standard valve replacement for some patients, removing the need to take blood thinning Warfarin medication. In children, the new aortic valve can grow as the child grows.

The twelve videos are available to clinical staff, to patients and families on the Leeds Congenital Hearts website and are hosted on CHSF's YouTube channel.



These videos have a variety of benefits:

- Patients and families can have many questions and concerns about their condition and treatment. The videos are useful to explain what will happen and can help to relieve stress and anxiety.
- Medical conditions can be difficult to understand so animated videos with attention-grabbing visuals and clear explanations can help to simplify complicated conditions.
- Access to the information in these videos can enable patients and families to ask questions of their clinician or surgeon with some understanding and confidence. This can help them to feel more in control of their, or their child's, condition and treatment.

James Oliver, Lead Clinician for Congenital Cardiology, says:

“Myself and a number of colleagues use the videos regularly and have found patients to be very receptive to them. In many cases they have developed a significantly greater level of understanding of their condition.”

We have received positive feedback from families about the videos which have been viewed 49,332 times so far.

“Brilliant as always, can show my daughter as she gets older why she is a little heart warrior with her pulmonary stenosis and regurgitation of her blood.”

“These videos are absolutely brilliant and so informative. I was able to show Aria, mine and her heart conditions and she enjoyed watching the videos. Thank you so much CHSF.”

“The pulmonary stenosis and pulmonary valve replacement ones explains Ethan’s condition perfectly!! These are brilliant.”

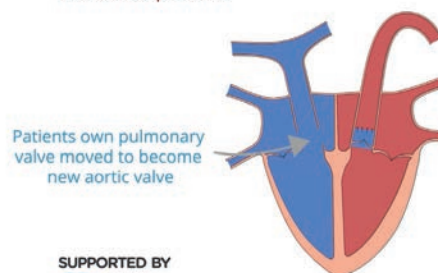
“The pulmonary stenosis one helped us loads in showing others Ava’s heart condition!! THANK YOU CHSF.”

“Really good videos to explain Coarctation of the Aorta. Would love to see my daughter’s other - Aortic Stenosis in the future!”

“Thank you for this video. It was really informative. My Father has atrial septal defect (ASD) and an open-heart surgery is scheduled in July this year.”

CHSF is keen to produce further videos to inform and educate patients and families about other congenital cardiac conditions.

The Ross Operation



SUPPORTED BY
CHILDREN'S
HEART SURGERY
FUND

LEEDS CONGENITAL
HEARTS



My Heart Surgery Support Pack



In 2017 CHSF funded “Katie Bear Goes to Hospital”, a book designed to support young children coming to Leeds Children’s Hospital for heart surgery. This book helped Leah, featured on page 5 of this report, to feel less anxious about the experience.

In 2021 CHSF was delighted to fund “My Heart Surgery Support Pack”, a new guide designed specifically to support young people aged 13-18 in preparation for their heart surgeries.

Devised by the team of psychologists in the Leeds Congenital Heart Unit, the guide features former teenage heart surgery patients sharing their tips, stories and experiences. These include what to pack, how to keep on top of school work and how to not get bored on the ward.



Dr Rachel Avison, Senior Clinical Psychologist at the Heart Unit, says:

“We’d had some really good feedback to “Katie Bear Goes to Hospital”, and a few parents were requesting something for older children. But we didn’t want to write it as a hospital team.

We felt the experts were the young people who have been through it and had heart surgery before. So we handed it over to them. An open day was held at the Heart Unit for former teenage patients where they brainstormed ideas for tips and advice for those facing similar heart surgery journeys.

What makes it complicated for teenagers and young adults is they are in a really significant stage of their lives. There’s lots of change, lots of adjustments - applying for school, university applications, trying to “fit in”. The thought of coming away from that life and having maybe two weeks in hospital and then six more weeks recovering can be really life-changing for lots of young people.

We knew the more prepared the young person is for heart surgery, the better they cope with it. So we wanted to help with that preparation. We’re hoping the teens that contributed feel really proud that they’ve shared their stories and are helping many other people coming into hospital.”

Cait Gregory, who had her second open heart surgery at age 15, was one of the contributors.

She was born with Tetralogy of Fallot, a defect which affects normal blood flow around the heart. Cait had her first surgery at 14 months old.



Despite initial hopes that she would be in her late teens or early twenties before needing further surgery, doctors were forced to bring this forward due to a leaking heart valve. Cait said as soon as she heard she needed more surgery, her “anxiety shot up”.

She took part in the open day before her surgery, helping to provide the viewpoint of someone gearing up to their hospital stay. Having heard the advice first-hand from those who had been through it helped hugely in her preparation for surgery.

“It was a lifesaver. I got to talk to people about it and hear bits of what was going in the book from the people themselves. And reading the book since, there’s a lot more that I didn’t know that would have been really helpful.

Being physically well is obviously important but so is being mentally well and making sure that you’re in the right head space.

I would hope that people who are in my situation going into surgery would feel a lot easier about the whole situation and know that there are other people that have been through it or are going through it. The book is really helpful and just shows that everyone is feeling the same way.”



**Care for
the family**



Care for the Family



We are a constant source of practical and financial support for families so they can focus on their sick child during their hospital treatment.

In 2021, Sarah Cherry, CHSF's Family Support Worker helped 150 families whose child was hospitalised, with 116 of these families receiving specific and tailored support.

The programme of support Sarah provided and managed included parent accommodation

in and near to the hospital, financial grants, an online activity camp for families, online wellbeing sessions and activities, welcome packs of essentials on arrival at hospital, and referrals to external services.



One highlight was the upgrading and refurbishing of the parent accommodation in Leeds General Infirmary where 220 families stayed during the year.

CHSF has seven rooms on Brotherton Wing, specifically for the use of parents while their child is undergoing and recovering from heart surgery. The accommodation is vital for parents, giving them the comfort and reassurance of being a few minutes away from their child. They have access to a communal kitchen, a laundry room and a lounge.

Although most of the bedrooms were fit for purpose, they did not provide parents with a positive place to relax and recharge. By updating and upgrading the rooms, we were able to create a warm and inviting environment that meets parents' physical needs and takes into consideration their emotional wellbeing.



Work was done to make the rooms less clinical and more spacious. The sinks in each of the bedrooms were removed. The bathrooms were upgraded, bedrooms were painted, and new blinds and beds were provided.

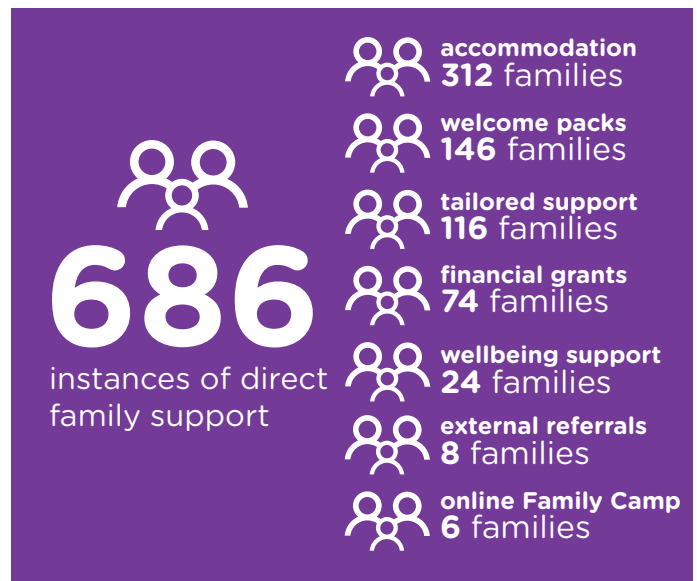
Sarah Cherry, Family Support Worker says:

“Supporting the refurbishment of our parent accommodation was such an exciting opportunity and the wellbeing of parents was at the forefront of our

minds throughout this makeover journey from start to finish. Parents now have a positive place to relax and recharge, a space that is calm and non-clinical, and most importantly somewhere which offers comfort close to their child during their hospital stay. This project was truly invaluable.”

Josie, parent says:

“We got a key for our own accommodation whilst our daughter was in hospital, the room was amazing with a shower and a bath which was lovely after five days in hospital. An hour-long bath whilst my partner was with my daughter was very much needed. The accommodation we received made sure that me and my partner could stay with our daughter anytime we wanted and ensured that if there were any problems during the night, we could get there within 10 minutes rather than an hour.”





Children's Heart Surgery Fund

Private Group · 5.3K members

CHSF's private community group on Facebook is a peer-support forum for heart families to network with others who have had shared experiences.

The group consists of patients with congenital heart disease, parents and family members who find it an enormously supportive service. Many networks and friendships have been formed as a result of this private group. We are very proud to witness how our heart families help each other.

Set up in 2010, the group currently has over 5,300 members. Members have to answer a few basic questions to join, to ensure it is the right group for them. Just like any other forum, the CHSF marketing team monitor posts to make sure essential etiquette is followed.

The main benefits for members are that it can provide reassurance, companionship and basic information which doesn't need medical input. The group is not a medical resource and does not provide medical advice. If we see a question which is medical, we refer members to the relevant hospital teams.

Families and patients also give fantastic feedback in response to questions we put to them, such as their thoughts on events we run and types of support we provide. We also use the group as a bulletin board to share our news and keep them up to date with our work.

One example of the ways heart families help each other is the following post from heart mum Mia Heffernan which reached over a thousand people on the group and had 95 comments of support...

Facebook
x

Mia Heffernan

14 March · 🌐

⋮

Hello everyone, my son Axel is due to have open heart surgery tomorrow, my head is all over the place. Im happy but i am so unbelievably scared. Is there any advice anyone could offer me and my sons dad on what to expect? They said that there will be tubes and wires etc coming out of his body, i am expecting it but mentally im finding it all hard to process, it was hard enough seeing him in picu before his surgery.

Picture of my brave boy 🙏💙



👍❤️👍 103
95 comments

Chloe Slade

What a beautiful boy. Good luck tomorrow baby Axel! You're in the absolute best hands. They truly are angels, the surgeons there. You can do this mama, I know right now it feels like you can't but you will find the strength and get through this. Sending you massive hugs, from a mumma who was there not so long ago. Please message if you need to xxxxx

Like Reply ❤️

Lisa Marie Oiseaux

Just know that they will do the absolute best for him and he's in the very best hands!! Try and keep distracted during the operation and try not to worry if it goes over the time you expect. Huge hugs! From another heart mummy xx

Like Reply ❤️

Darren Vaines

Make sure you also look after yourselves, it's important to be there with him when needed, it's a dreadful feeling but he's going to be fixed and well and happy, it goes without saying the staff are just amazing 🙏

Like Reply ❤️

Others sent pictures of their own heart warriors to give hope and inspiration to Mia and her family...

Facebook x

103 95 comments

Danny Moore
If there is anything I can pass on it would be just be there for each other tomorrow and try and do something positive. We had a walk into the registry office and registered the birth on our daughters heart day. Then just slept waiting for that call. Stay strong they are the best people sending lots of hugs and strength to you ❤️. Here she is 5 years old on Wednesday x you or your partner ever need a chat my inbox is always open x



Like Reply

Dan Jerwood
Here's our little heart warrior now at 7! Has the same cheeky smile as your lad. The team at Leeds are amazing and he'll be just fine! Another post said leave the hospital, get some fresh air and something to eat - exactly what we did!!



Like Reply

Kirstie-Jay Dean-Miller
This was my little girl the night she came from theatre...and this is her now ❤️



Like Reply


Mia Heffernan
Kirstie-Jay Dean-Miller seeing them pictures is such a huge relief, your little girl is a gorgeous little warrior 🥰❤️

An update on Axel...

Facebook x

Mia Heffernan
22 June at 17:31 · 🌐

3 months ago today we was told for the 4th time Axel was going down to surgery! 4th time lucky after months & months of hospital stay's he finally had it! From only being able to feed via a tube to now eating everything in his sight & can't forget he's just started crawling too! All thanks to the amazing surgeons & nurses at LGI



58

“Me and my family were incredibly grateful for the support from CHSF’s Facebook community. We didn’t know what to expect during open heart surgery, and to receive both words and pictures of comfort was really reassuring.”

Mia, Heart Mum

Speaking to other parents of children with heart conditions can be a lifeline.



To join CHSF's private group on Facebook scan this QR code or visit bit.ly/chsf-group



**Care for
the future**



Care for the Future

We fund training, research, staff development, clinical posts and projects to help improve patient care and outcomes, now and in the future.

Our support for the future included:

Congenital Cardiac Anaesthesia Network Meeting



On 7 October 2021, CHSF helped to sponsor a virtual Congenital Cardiac Anaesthesia Network Meeting for UK members of the Congenital Cardiac Anaesthetists Network and their internationally based peers.

In the spirit of working collaboratively and strengthening relationships, participants presented new advances in the field of congenital cardiology, shared ideas, and discussed and debated challenging cases.

“An excellent presentation. It is great to encourage all the cardiac centres to make a similar progress in the ultrafast extubation.” Delegate

Dr Wendy Lim, Paediatric Cardiac Anaesthetist says:

“Our meeting was a great success. It was an ideal opportunity for us to showcase the phenomenal work done here at Leeds, work which I think that the other centres don’t really know about.”

I would like to thank CHSF for their generous sponsorship. This provided us with many opportunities to share and collaborate on developments in the field of congenital heart disease. It has given us access to some projects that we would like to implement here in Leeds to improve the hospital journey for our CHD patients.”

Advanced Life Support Training Courses



CHSF funded three members of staff to take part in Advanced Life Support (ALS) courses. An ALS course teaches essential skills, including delivery of CPR, recognition and management of the deteriorating patient, and working in a team during emergency situations. It helps the participants to be effective and confident in stressful, complex and high-risk environments.

Theatre Practitioner, Georgina Gilchrist-Roberts (pictured) says:

“It was a challenging but very rewarding experience and I’ll hopefully be able to apply this to my role as an Operating Department Practitioner in Cardiac theatres at Leeds General Infirmary in the future.”

Rachael Bell, Specialist Operating Department Practitioner says:

“Thank you so much for your support which allowed me to attend the two-day Advanced Life Support course. This intensive course has provided me with some absolutely invaluable skills and knowledge which I now apply every day to my work within the operating theatre environment.”

Since applying for this course I have also started a new training role to become an Anaesthetic Associate. This is an exciting, advanced role which will see me being more directly responsible for patient care during surgical procedures. I have started this new post feeling much more equipped to take care of my patients with the reassurance and confidence to know what to do in those difficult, life-threatening situations.”

Adult Congenital Heart Disease Resource File

CHSF funded an adult congenital heart disease resource file so up-to-date information about different heart conditions is available to staff in the network of hospitals across Yorkshire, the Humber and North Lincolnshire.



Hannah Swift, Adult Congenital Heart Disease Specialist Nurse, says:

“Following CHSF’s support for paediatric and neonatal resource files, which were very well received by staff, I am delighted the charity has supported the production of an adult resource file.”

This is a helpful reference document for cardiology nurses and other staff members that is allowing them to increase their knowledge of heart defects so they feel more confident in caring for adult patients. Thank you.”



Care for the Future

Tiny Tickers Sonography Training



CHSF is supporting Tiny Tickers, a charity which helps to improve the detection, care and treatment of babies with serious heart conditions.

Funded by CHSF, Tiny Tickers is providing fetal cardiac sonography training at key hospitals in Yorkshire and

North Lincolnshire to detect congenital heart disease in the youngest of patients. They started at Airedale General Hospital in October 2021 and have continued to deliver further training sessions in 2022.

The training covers the most up-to-date NHS recommendations on what sonographers should look for when examining the heart as part of the 20-week scan.



This specialist fetal cardiac training enhances the confidence and skills sonographers need to detect heart defects during pregnancy scans.

Our two charities worked together on a similar project in 2016 resulting in training for 226 sonographers. A comparable result is expected this time.

Anne Rhodes, Head of Training, Tiny Tickers says:

“It is an absolute pleasure to be able to work together again with Children’s Heart Surgery Fund to provide our sonographer training across Yorkshire. Our training is always very well received and recent studies have shown that the antenatal detection rate of CHD has increased due to regional training programmes such as this.”

Sharon Milner, CEO, CHSF says:

“We must pay tribute to CHSF’s incredible supporters for helping us fund yet more life-saving training through Tiny Tickers for sonographers in our region. Thanks to public donations, this training will make a huge difference to future children with congenital heart disease and their families.”

Apple MacBook Air



Dr Shuba Barwick was provided with an Apple MacBook Air to use as a tool in fetal cardiology, the study of the unborn heart. It is being used in Dr Barwick’s teaching practice with paediatric cardiologists

in training, obstetricians and obstetric sonographers in the Yorkshire and Humber region and also nationally and internationally.

Sonographers need regular training in order to improve detection rates of abnormalities in unborn babies, which they refer to fetal cardiologists for their opinions.

The aim is to identify as many babies as possible that have congenital heart disease before they are born rather than after delivery. The Apple MacBook Air is playing a vital part in helping to improve these detection rates. It has the highest quality of imaging and can be used to store fetal echocardiograms, which are ultrasound images of the heart.

Early diagnosis of congenital heart disease helps in planning the appropriate place for the delivery of the baby. It benefits the wellbeing of the family to have the antenatal diagnosis, providing them with options to manage the pregnancy. It improves outcomes for the baby before and after cardiac surgery.

Dr Shuba Barwick, Consultant in Fetal and Paediatric Cardiology says:

“A big thanks to CHSF supporters for helping to fund the MacBook Air. The laptop is great at dealing with the high-quality images I need to help teach the sonography department. It’s also being used to help teach future Fetal Cardiologists and Obstetricians so we can maintain the expertise in the department and around the region.”



Goodbye and Looking Ahead



After 16 years as CEO of CHSF, I have decided now is the time to move on from a charity I care so deeply about, however, I am extremely proud of our achievements over the years. These include the Save Our Surgery campaign, and the much-needed revolutionary hybrid children's heart theatre you supported through our Keeping the Beat appeal.

I have been incredibly lucky to have worked with some fantastic people. Thank you to the CHSF team for how invested they have been in their roles - it's been a pleasure to work with such dedicated and talented people. Thank you also to the Trustees I have worked with over the years, for their commitment as volunteers to share their invaluable experience with the CHSF team.

I am delighted to be able to hand over to Leeds-born Heidi Watson who has a broad breadth of experience in the charity sector and is very excited to be able to continue to work in healthcare, having come from the charity, Shine. Shine was formed in 1966, initially to help families and individuals affected by spina bifida and hydrocephalus and today boasts a community of 75,000 individuals, families, friends, and professionals.

Heidi is taking over CHSF at a great time. Of course, there is still so much more to do - funding the ongoing training needs of staff at the Leeds Congenital Heart Unit, and looking at future technology, research and innovation within the specialty of congenital heart disease. We would be nothing without the incredible team of medical specialists within the Heart Unit, which is now lauded as a world-class centre of excellence.

It has been an absolute privilege to support your children and families at such a crucial time. I will never forget incredible supporters like you who help turn CHSF's charity vision to support hearts for life into reality. Your kindness, selflessness and passion has meant so much to so many.

Thank you...

for supporting Children's Heart Surgery Fund during what has continued to be unprecedented times for us all. We are so grateful to everyone who has raised funds, awarded grants, made donations, given gifts-in-kind and remembered us in their wills.

As long as babies are born with heart disease in our region then patients and their families need a dedicated charity to support them on their heart journey. CHSF will continue to deliver amazing life-saving projects with your help, and #becauseofyou.

Sharon Milner, CEO





Thank You!

We would like to thank everyone who has made donations, awarded grants, raised funds, given gifts-in-kind and remembered us in their wills

As a totally self-funded charity we can only do what we do

Because of You



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