



CHILDREN'S  
**HEART SURGERY**  
FUND

# **Social Impact Report** 2020/21

*Because of You*





# CHILDREN'S HEART SURGERY FUND



## Our purpose

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



## 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 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 values of trust, compassion, openness, respect and dedication into everything we do.



Care for  
the heart



Care for  
the mind



Care for  
the family



Care for  
the future

# Welcome



## **Sharon Milner, CEO**

I am incredibly proud of this, our third Social Impact Report.

Like other charities, Children's Heart Surgery Fund (CHSF) has come through the most challenging time in our recent history. However, we adapted to the external environment, and our team used every bit of their experience and tenacity to adjust to the new normal. Whilst this has been a challenge, we have grown and learnt a lot in the process about resilience and how agile we can be.

Therefore, I hope and trust the following report illustrates how proud I am of our CHSF team, the CHSF Trustees and the NHS workforce who maintain the highest level of standards and care throughout the Leeds Congenital Heart Unit.

But most importantly, I am grateful to you, our incredible supporters and funders. You have helped patients and their families to be expertly cared for throughout this unprecedented period and to move the service forward. I hope you know how much we appreciate your committed fundraising and support and the difference you make to the lives of babies, children and adults with congenital heart disease in our region.



## **Paul Goodwin, Chair of Trustees**

The global pandemic has had a huge impact on all of us, and charities have been particularly hard hit. However, the number of children being born with congenital heart conditions did not slow down, so the work of CHSF continued in very challenging conditions.

I am consistently humbled by the way that the CHSF team and all the supporters pull together to ensure we are supporting the hearts, minds, families and futures of all our heart warriors, both young and older. This Social Impact Report shows the initiatives that we were able to support during this period. We are so grateful for your support in making this happen - thank you.

Our work continues at pace as we work with all our supporters and partners to help make a better future for all those born with congenital heart conditions.



## **Junior Frood, Youth Ambassador**

I joined CHSF as Youth Ambassador in 2018 and have been thrilled to support this truly life-saving charity with event appearances, gifts for patients, ward visits and fundraising. The thing I most enjoy is meeting heart warriors and their families, and while that has been difficult in the last 18 months, I've loved seeing how you have been getting on across social media. As soon as I'm allowed, I will be back to see you all. Thank you to all the staff both on the ward and at CHSF who have continued to work through this pandemic, you are all heroes.

I will carry on doing what I can to promote positivity, combat bullying and encourage everyone to follow their dreams in the face of adversity. Please continue to support this wonderful charity, who not only look after patients, but the entire family unit - as this report wonderfully demonstrates.



# Our Impact in 2020 and 2021

From January to December 2020, CHSF invested £219,149 in 52 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.

CHSF is delighted that our support in 2020 helped the Leeds Congenital Heart Unit to operate as a centre of excellence in the field of congenital heart disease and provide patients with optimal care and outcomes.

This report focuses on CHSF's four key areas of work; caring for the Heart, the Mind, the Family and the Future during 2020, and into the first half of 2021.



## 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 a Family  
Support Worker



## Care for the future

by funding research,  
clinical posts and projects



See page 8

10  
PROJECTS  
funding the  
HEART

21  
PROJECTS  
funding the  
MIND



See page 12

13  
PROJECTS  
funding the  
FAMILY

8  
PROJECTS  
funding  
the  
FUTURE



See page 16



See page 20

A TOTAL OF £219,149 INVESTED IN 52 PROJECTS

# BECAUSE OF YOU IN 2020

**102**  
mobile  
ECG  
devices

given to  
patients  
to check  
their heart  
rate safe  
at home



**REVOLUTIONARY  
BABY MRI COIL**

to safely scan babies  
without the need of  
general anaesthetic



high-tech  
**BABY LEO  
INCUBATOR**

for the neonatal  
intensive care unit



**42**

HOME BLOOD  
TESTING KITS



**£12,850**

given in family grants



a new, dedicated  
**SUPPORT WORKER**  
for our heart families

**£45K** donated to vital  
home-from-home  
**ECKERSLEY HOUSE**



approved funding for a  
**NEW SUPPORT BOOK FOR  
TEEN HEART WARRIORS**



**VIRTUAL  
WELLBEING  
SESSIONS**

for patients and  
their families

funded the  
**FAMOUS  
FISH TANK**  
on Ward L51  
for another  
year



**SNACKS & DRINKS**  
supplied to our awesome

**NHS**

working on the frontline  
during the **pandemic**



**2021 TRAINING FOR  
SONOGRAPHERS**



in detecting  
heart defects  
before baby  
is born



**CHILDREN'S  
HEART SURGERY  
FUND**

Help us keep supporting hearts **for life**

# Support for Adults with Congenital Heart Disease

Despite our name, Children's Heart Surgery Fund supports people of all ages with congenital heart disease, from the womb through to adulthood. Supporting adult patients is a key part of our work.

There are now more adults with congenital heart disease than children. As survival through childhood improves, the number of adults with congenital heart disease will continue to grow, as will CHSF's support for them.

James Oliver, Adult Congenital Cardiologist says:

**"CHSF provides amazing support for adults with congenital heart disease. The charity has helped to fund staff posts, such as psychologists and youth workers and supported one of our consultants, Dr Helen Parry, in her first year as a consultant. CHSF provides funds for medical equipment so patients can test their blood or heart rhythms at home. They have paid for us to produce videos that explain various different congenital heart conditions, funded an upgrade to the day area on the adult surgical ward and provided vouchers for Costa Coffee in the hospital so patients can have a little treat during their stay. The list goes on..."**

Our support for adults included:

- Handheld fans for patients with breathing difficulties.
- Home testing and monitoring equipment – blood pressure monitors, INR kits to test blood for clotting and mobile ECG kits for monitoring heart rhythms.
- Tesco vouchers for patients who were not allowed visitors due to COVID-19 so they could buy provisions when discharged from the ward.
- A Fingertip Pulse Oximeter to check patients' blood oxygen levels during walking tests in consultations.
- A Clinical Psychologist role which enabled the Psychology and Counselling Service to increase resources and introduce a surgical follow-up clinic for adult patients.



**"The fan helps me when I feel really short of breath due to my heart condition, as it allows me to take deeper breaths. It is quite a powerful little fan, and I am grateful to have been given one."**

Tom, patient



**"Eight months ago, I found myself in a stressful situation and found that I became symptomatic with my cardiac problems again. I reached out to the cardiac nurses at Leeds General Infirmary and was issued a 'Kardia device' - a small ECG monitor that connects to my mobile phone.**

**Not only has it offered reassurance it has helped me realise my symptoms**

**were often a side effect of poor self-care. Having the device has genuinely made a huge difference to my wellbeing, both physical and mental, from reassurances it had offered. Many, many thanks for making these devices available. Keep up the amazing work!"**

Jill, patient



**"In 2010 I had an Aortic Root Replacement which has left me with a metallic valve and the need to take Warfarin and have regular INR checks.**

**Initially I had to attend various community INR clinics which meant taking time off work and over time having to take additional holidays. This is the second INR home testing kit that you have kindly supplied me with, and it has been a massive benefit.**

**I can take my INR whenever needed and phone in the results without the need to attend community clinics. Through this lockdown this kit will be of great help."**

Daniel, patient

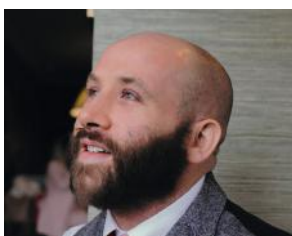




# Leigh's Story

**"If you asked me what my best feature is, I would tell you it's my scars"**

After being born with a heart defect and battling paralysis, inspirational heart hero Leigh reflected in May 2020 on his journey with congenital heart disease as he looked forward to fatherhood, and walked 50 miles to raise money for CHSF.



**"On the 6th September 1985 I was born in Harrogate Hospital. Me and my mum went back to the maternity unit, and it was there that she realised something wasn't quite right. The midwife came to review my mum's concerns and I was taken away. I was having difficulty feeding and my lips were a shade of midnight blue.**

In that five minutes, my parents' world was turned upside down. The doctors and midwives told my parents that I needed to go to Leeds for further investigation. 'Your son may have a heart problem'. The main cardiac unit back then was at Killingbeck Hospital.

My dad accompanied me to Killingbeck for further investigations. There must have been something going on because the lady in the picture published in the Yorkshire Post was the late Baroness Trumpington. My mum was still in a daze and patiently waited for any news in Harrogate Hospital. There were no mobile phones or internet back then - it was a pay box phone to keep in touch with one another.

One investigation after another and finally they came up with a diagnosis. I had a TGA (Transposition of the Great Arteries). My parents were given a run down that without an operation I wouldn't survive past two.

Fast forward to when I was 18 months old, I'd have minor surgery and medication to get me to the right weight for the surgeons to carry out my major surgery. I was just starting to crawl and stand - I mention this because I was about to start that learning journey all over again. Whilst having my major operation I had a blood clot that burst and paralysed my left side - the medical term is 'left hemi paralysis'.

The surgery was a success, and I was soon reunited with my parents, and they took me home. I was to have regular check-ups (annually) and liaise with physiotherapy to try and get me walking and crawling. Throughout my school days I had speech and language support and physio support. I was regularly put into casts to try and get my foot at 90 degrees and help stretch the tendons.

Skip to the present day and I look back at what I have achieved:

1. I live my life to the fullest
2. I love my family and friends
3. I've been with my partner for 14 years
4. I am becoming a dad in July
5. I went to high school
6. I went to university
7. I got a degree in children's nursing (2010)
8. My first proper job is at Royal Derby Hospital on the Neonatal Intensive Care Unit (NICU)
9. I became a mentor and qualified in speciality (neonatal nurse)
10. I worked at Pinderfields NICU
11. I now work in an amazing place called Martin House
12. I learnt to drive a manual car (even with a dodgy leg!)

The list can go on and on, but that's not the point. Just because I have a heart condition and a 'left hemi' shouldn't stop me from reaching my goals in life, in fact it aided me to do more things. It added fuel to the fire.

My life so far has been an interesting one and I am sure I am not done with it yet! If you asked me what my best feature is, I would tell you it's my scars. My scars have been with me since I was 18 months old. I've grown up with them and they've grown up with me.



They tell my story, a piece of history, a tattoo that will forever be with me. They do not define me, but I define them. They are a piece of me, and I would be lost without them."



Leigh as a baby at Killingbeck Hospital, being visited by Baroness Trumpington. Photo credit: Yorkshire Post



**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:

## Headlight Camera

During a procedure, surgeons are the only members of the theatre team that are able to see the structures deep in the heart. The heart can belong to a new-born baby and be the size of a walnut.

CHSF bought a Headlight Camera that allows the whole team caring for the patient at the time of the operation to gain a better understanding of the procedure from the surgeon's viewpoint.

The Headlight Camera is worn on the head of the operating surgeon. It is unobtrusive and allows the surgeon to focus on their work. It is operated on an iPad Pro and streamed on Wi-Fi, allowing images to be displayed on a TV screen live in the theatre. These can be recorded for later review and used for training.

The Headlight Camera is helping to improve understanding of abnormalities of the heart, operating techniques, team working and quality of care for patients with increasingly complex heart conditions.

Giuseppe Pelella, Consultant Congenital Cardiac Surgeon says:

**"I would like to thank the Children's Heart Surgery Fund for the Headlight Camera, iPad and TV screen that was donated to our Unit."**

**"This camera is making such a difference to me and my team. It is a great tool that is helping the Cardiac team to follow the procedures in theatre and to learn more about complex cardiac surgical repairs. This will help us to improve the quality of care we can give to our patients."**

Members of the theatre team fed back how beneficial the Headlight Camera is for their work.

**"It helps us to see more of the intricate anatomy. For a surgeon it is really, really important."**

**"It has allowed us to observe the operations a lot better. It is very useful when we have students and visitors. We are not disturbing the surgeons. We can stand off to the side and explain to them what is going on."**

**"It helps us a lot in our daily job to see more of the cardiac anatomy and the complexity of the cases we are dealing with."**



# Care for the Heart

## Blood Pressure Monitors

CHSF funded 15 blood pressure monitors for adult patients to test their blood pressure at home.

Some patients needed to monitor their blood pressure as part of surveillance following repairs to their heart or changes in their medication. Some patients needed them for frequent blood pressure monitoring as they were pregnant.

Allowing a patient to check their blood pressure at different times of the day to get an average provided a better picture of the patient's blood pressure. It eliminated the need for patients to come to hospital for 24-hour tests and empowered patients to take on the responsibility of monitoring their own blood pressure. It allowed the medical team to prescribe appropriate medication and monitor the effects of interventions.

Due to COVID-19, some appointments could be set up via telephone. If the patient could provide up-to-date blood pressure readings over the phone, then the patient would not need to attend clinic in the hospital. This reduced the need for patients to travel and the risk of them contracting the virus.

Hannah Swift, Adult Congenital Nurse Specialist says:



**“Our patients have really benefitted from the home blood pressure machines when they have had their medication altered in clinic. It has allowed them to easily monitor the effects of this at home, and then get in touch with us to resolve any issues or concerns. Patients with specific heart conditions where blood pressure control is vital, have said how they feel reassured with regular blood pressure monitoring.”**

**Our doctors have also found in the past that patients' blood pressure in clinic is raised due to anxiety, so having it taken in their own environment provides a better representation of their true blood pressure.”**

## Radiofrequency Puncture Generator



CHSF funded a Baylis Radiofrequency Puncture Generator, a new and state-of-the-art radiofrequency machine. This allows clinicians to perform controlled tissue punctures on patients' hearts during procedures using radiofrequency energy, with minimal surrounding damage.

For example, it can be used during a procedure on a baby whose pulmonary valve is closed meaning the baby's blood doesn't carry enough oxygen, so their skin has a blueish

tone. The machine will be used to make a small hole at the valve which will allow the blood to start moving in the correct direction to the lungs, rectifying this defect and improving outcomes for the baby.

Filipa Ferreira, Congenital Cardiac Intervention Nurse Specialist says:

**“A huge thank you to CHSF supporters for helping to fund this life-saving radiofrequency machine which is now installed in the hybrid children's heart theatre and has updated an older model which was fifteen years old. This machine is used in acute situations, which can happen every day, and is having a positive impact on the treatment of patients.”**

Dr Jamie Bentham, Consultant Paediatric Cardiologist says:

**“This Radiofrequency Puncture Generator is a great asset to the Leeds Congenital Heart Unit. We use it during keyhole surgery to make a 0.3mm hole in a baby's blocked heart valve allowing us to then cross the valve and open it with a balloon. It complements the state-of-the-art equipment we currently use in patient treatment and helps to make a significant difference to the quality of care and outcomes we can provide for young patients with serious heart defects.”**



## Baby Leo Incubator

CHSF funded a Dräger Babyleo® TN500 IncuWarmer incubator for the Neonatal Intensive Care Unit (NICU) at Leeds Children's Hospital.

NICU cares for around 1,600 premature and sick babies each year from Yorkshire, the Humber and North Lincolnshire. Around 150 of these babies have significant heart conditions. These babies stay on NICU until they have gained enough weight to have the best chance for successful heart surgery.

**“Our time on NICU was a crucial period to get us to Alfie’s heart surgery and I’m blessed every day for all they did for us.”**

Lisa, parent

The team at NICU was delighted to receive the Dräger Babyleo® TN500 IncuWarmer incubator, which is the latest in neonatal technology, having been identified as being the best facility for treating critically ill babies.

It has many benefits, including the following:

- It works as an incubator when closed and a warmer when open. The heating system is designed to keep the temperature stable, so heat loss and overheating are avoided. It replaces two pieces of equipment that previously did the same job, resulting in important space saving on a busy ward.
- It is designed for easier access to the patient for both staff and families. The hood opens using one finger. The hand ports through which medical staff and parents can touch the baby are larger than traditional incubators. It has a variable height adjustment so it can be moved up and down benefitting staff and family members.

Catherine Livingstone, Neonatal Cardiac Senior Sister and ‘Beaters’ team leader says:

**“The new Babyleo® allows us to provide a quiet, warm and calm environment which allows the babies to put all their energies into growing rather than into keeping warm. This will improve their long-term outcomes and reduce the duration of their stays.**

**This incubator is very adaptable as it has many modifications for the tiny premature baby, or a bigger cardiac baby requiring full intensive care, or a surgical baby recovering after theatre.**

**Parents have expressed that it is lovely that the incubator can be lowered to a point where they are at chair level with parents, improving bonding and wellbeing. The quiet anti-click features on the door opening and lid means parents are more forthcoming in caring for their baby as they feel they are not disturbing them.”**

Dr Lawrence Miall, Consultant in Neonatal Medicine says:

**“The Dräger Babyleo® hybrid incubator is the most up-to-date incubator on the market and allows small newborn babies with congenital heart disease to be nursed and treated in the best thermal environment.**

**The incubator can be adapted to be open or closed and provides overhead heat when the lid is open for procedures, scans and treatment. It also allows us to personalise the baby’s environment with the baby’s name and a choice of coloured lighting.**

**For some of the smallest babies with congenital heart disease, especially those born prematurely, the hybrid incubator offers the best developmental care environment in their critical early weeks.**

**Thank you to Children’s Heart Surgery Fund’s generous funders for this fantastic equipment.”**







**Care for  
the mind**



# Care for the Mind



We provide equipment, distractions and support that helps patients and their families to have a positive experience in hospital.

Our support for the mind included:

## Distractions for patients



CHSF provided the Play Specialists on the children's cardiac ward with distractions that included:

- Craft supplies which encourage a sense of normality for children. They enable the Play Specialists to use art as a therapeutic medium through which patients can channel frustration they may feel while on the ward or undertake a mindful activity.
- Virtual Reality headsets and games to use with consoles for patients over the age of 12 years. Some games allow the older patients to experience a virtual reality gaming experience and encourage mobilisation, which is an essential part of their recovery.
- Mobiles, teething toys and rattles which help to support the ongoing development of the youngest patients and ensure some normality in their early years.

**"We are very grateful to CHSF for the extra items to support our patients, families and staff in what was an extraordinary year. We will continue to do our best with the resources we get #becauseofyou. Many thanks!"**

Emma Marshall and Gemma Jackson, Ward L51 Play Specialists

## Katie Bears

After open heart surgery all our young heart warriors received a Katie Bear teddy, a certificate and a medal from CHSF. These become treasured keepsakes for many patients and are positive milestones that form part of a patient's journey with congenital heart disease.



**"I just wanted to say thank you so much for Roxy's bear, certificate and medal. Her face lit up when I placed it in her crib. Thank you again, they're something she will cherish forever."**

Rebecca, parent

## Support for families and staff during the COVID-19 pandemic



COVID-19 put enormous pressure on the NHS, as well as on families whose child was receiving treatment during the pandemic. With cafes closed, food shops often not fully stocked, and only one parent allowed on the ward with their

child, we did all we could to support families and staff during this stressful time.

- We provided parents who were unable to leave the ward for supplies with packs of tinned food, snacks, toiletries and drinks, in addition to our usual support with accommodation and financial grants.
- We hosted a virtual Christmas party and a virtual 'Shake, Rattle and Boogie' session and provided children with activity resources, such as colouring and treasure hunts, when they couldn't attend school.
- We supplied staff in the Leeds Congenital Heart Unit with cold drinks, coffees, coffee vouchers and packs of food, refreshments and hand creams.
- We created digital online resources, support and advice on mental wellbeing for parents and promoted coronavirus advice and support from the Heart Unit and the Psychology and Counselling Service.

Lisa Beaumont, Therapeutic and Specialised Play Manager said:



**"We are hugely grateful for the continued donations of refreshments, snacks, food and lots of wellbeing packages. This has been invaluable in supporting our children, their parents and our staff. Our journey would have been a lot longer and harder without all this wonderful support."**

# Bella's Story



Some children with congenital heart disease will be on blood-thinning drugs for the rest of their lives after surgery. On average, they need to come into hospital to have their blood tested every one or two weeks, sometimes more often.

CHSF supplies the Leeds Congenital Heart Unit with INR kits so patients can test their

blood for clotting at home, removing the disruption for the whole family of coming to hospital for regular testing.

The need for these kits during the COVID-19 pandemic has been even greater as they reduce the risk of children and their parents contracting the virus by regularly attending hospital appointments.

Bella's story, told by her mother Rebecca in 2020, demonstrates that these INR kits can be life changing for children and their families.

**"Isabella is six in December. She has Hypoplastic Right Heart Syndrome which means she has no right ventricle. She has spent many nights in hospitals due to heart procedures. From open heart surgeries to cardiac catheter procedures and MRI scans. All the heart surgeries Bella has had are life prolonging surgeries.**

**Before she was born, we were made aware that she would need three stages of heart surgery. She had her final stage in July this year and the difference in her is amazing. I never realised just how much she had deteriorated before this surgery until she recovered, and she could run up a flight of stairs. Before the surgery I would have to carry her up the stairs.**

**Bella has had many blood tests and each one has been traumatic for her. The older she is, the harder blood tests are. The last few blood tests were horrendous and emotionally draining for both her and me.**

**I can't even begin to tell you how grateful I am that Bella and I are able to do her INR test together at home. She loves that she has some level of control of the machine, picking the finger we can use and the plaster. She's proud of herself and how brave she is. We make it a fun experience because she needs to do it so regularly and it will be something she'll need to do for the rest of her life.**

**Bella started Year 1 in September and on her first day of school we needed to do a blood test. The INR machine**

**meant that we were able to do the test and she could get on with the first day back at school after six months off, due to the pandemic and her big heart surgery!**

**If we didn't have the INR home testing kit, having to go into hospital all the time would be an absolute nightmare! It would be traumatic for Bella and also a hospital is one of the last places we want to be at the moment with the pandemic.**

**The convenience of this machine for so many reasons is a godsend, and we are so grateful to Children's Heart Surgery Fund for taking away the trauma of regular blood tests for Bella."**







# Support for the Congenital Cardiology Psychology and Counselling Service



The Congenital Cardiology Psychology and Counselling Service provides support and resources for patients of all ages with congenital heart disease under the care of the Leeds Teaching Hospitals Congenital Cardiac Consultants, and their families. They may need help dealing with their heart condition or find life challenging at this time.



**“Seeing your child go through something so serious as open-heart surgery, it really has a negative impact on your mind.”**  
Laura, parent

CHSF part-funded a Clinical Psychologist post and attendance at a maternal health care conference. This has helped the Psychology and Counselling Service to increase their support for patients and their families,

improving wellbeing and mental health.

## Clinical Psychologist

The Clinical Psychologist post has increased the resources and support available to both children and adult surgical patients.

This post has also made it possible for the Service to introduce a new surgical follow-up clinic for adult patients, to coincide with their six-week post-surgical check. This helps them to screen adult patients coming through surgery for potential signs of trauma and provide the appropriate treatment responses.

It is expected that the introduction of this post will further benefit the team as they look to develop the support available to patients across the network in Yorkshire, the Humber and North Lincolnshire, which may include visiting peripheral clinic sites to increase the accessibility of the service.

**“I would like to thank CHSF for its on-going interest, support and investment in the Congenital Cardiac Psychology and Counselling team.”**

Dr Sara Matley, Consultant Clinical Psychologist

## Maternal Mental Health Conference



CHSF funded Sandie Allison, Counsellor, to attend a Maternal Mental Health Conference. The focus of the conference was on improving early identification and treatment of mothers who present with perinatal mental health problems.

The conference gave Sandie the opportunity

to learn about the support services and resources provided by a diverse range of health and social care professionals working with parents with young children and expectant mothers.

Sandie says:

**“I can identify those patients who are likely to be at increased risk of experiencing stress, anxiety and/or depression after receiving a fetal diagnosis of CHD. It is important to identify those patients whose psychological health and wellbeing are adversely affected early, and to be able to offer psychological intervention. The patients who are responsive to psychological therapy are more likely to develop positive coping strategies throughout their pregnancy, up to the birth and after. The longer-term benefits of early psychological intervention are that parents can cope better when adjusting to, and/or facing multiple surgeries over the years.”**

As a result of Sandie attending the conference, the Psychology and Counselling Service has expanded their support for mothers and parents at Fetal Cardiology clinics.

Sandie has developed closer working relationships with colleagues in the Fetal Cardiology and Fetal Medicine teams to promote the preventative model of psychological care and the positive impact of early intervention.



**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.



We supported families with living expenses, exceptional grants and accommodation at and near the hospital while their child was receiving treatment, a virtual Christmas party, welcome packs of toiletries and refreshments on arrival at the ward, and online self-care sessions.

**“It was only during our stay at Leeds Hospital that we realised how much Children’s Heart Surgery Fund did. Accommodation, specialist medical equipment, toys, games and even a fish tank (which Mylo loved so much we had to buy him one!) supplied by the charity. We cannot thank CHSF enough for everything they do.”**  
Rick, parent



Alayna was born with multiple life-threatening heart conditions and had her first operation at just eight months - the Glenn Shunt. This procedure improves the flow of blood to the lungs in complex conditions where only one ventricle is working properly.

Although it was a success, the doctors knew she would need a more complicated surgery when she was older.

At four years old, Alayna had the Fontan procedure, which was a much more invasive open heart surgery.

For Alayna’s mum, Sameeda, CHSF’s support was a lifeline.

**“CHSF have been amazing - they provided accommodation while Alayna was being treated in Paediatric Intensive Care and the High Dependency Unit. My room was within the hospital building which was a relief as I could go to Alayna at any time.**

**We can’t thank CHSF and the Leeds Congenital Heart Unit enough for everything they do. Please donate if you can, to help future children like Alayna.”**

We teamed up with Hälsa Wellbeing to offer our heart families self-care and relaxation sessions, which was a new initiative for us. We had originally planned to provide face-to-face sessions but due to the COVID-19 pandemic, we adapted and provided these sessions online.

Sessions ranged from self-massage and yoga to talking therapies and how to deal with stress. Virtually everyone who took part fed back that their wellbeing had improved as a result. People said they were better able to respond to changing circumstances, they felt less lonely and had more social contact.

Comments included:

**“I really enjoyed it and found out loads about stress response, feelings and ways to help ourselves and our families. It was a really considered approach to the kind of stuff we know but lose sight of when stressed out.”**

**“After the relaxation and self-care class, this is definitely something I will be making time to do again! I know I’m stressed due to isolating with a toddler, but I didn’t realise just how tense and stiff I actually was. I finished the class feeling very relaxed and light! I feel I am almost sane again!!”**





# Family Support Worker

CHSF has introduced the new role of Family Support Worker to provide practical and emotional support to families, as well as managing and implementing a new programme of wellbeing care.

CHSF decided to create this role following a survey of parents who requested holistic care and a dedicated person to support families' emotional and practical needs while their child undergoes treatment in hospital.

One parent stated:

**"The staff on the ward are really busy and although they are great at caring for the whole family, they also have a lot of work to be getting on with. Any extra support for families would be amazing, such as someone to talk to when we find it particularly difficult, without being worried this person has something we think is more important to do."**



In October 2020, Sarah Cherry joined CHSF as our first Family Support Worker to help our congenital heart families in Leeds Children's Hospital and to offer flexible support to families after discharge.

## An interview with Sarah Cherry, CHSF's Family Support Worker



### What is a Family Support Worker?

A Family Support Worker takes a holistic approach to meet the needs of the whole family, especially in times of difficulty such as when a child is in hospital. I offer emotional and practical support to ease stress by providing care tailored to the needs of each family.

### How do families connect with you?

Mostly it comes from the Congenital Cardiac Nurse Specialists when they go out to clinics. They will often give me details of families so I can give them a call before they come in for treatment. I can start to build relationships with parents from the very beginning.

I am also seeing a lot of families coming back so they will give me a ring to let me know they are coming in for surgery. Parents know if they are worrying about anything they can call me before they come in.



### What is a typical day like for you?

It would be hard to describe this as no two days are ever the same and that is why I love my role so much.

I visit the ward two to three days each week, this includes the children's cardiac ward, the neonatal ward and the paediatric intensive care unit. I hand out Welcome Packs and visit families to introduce myself and offer support.

I have links to services to signpost families for extra support and advice when needed. I want to build a network of support that families can access beyond their child's hospital stay.

I manage the financial assistance package which includes funds to cover travel costs and Tesco vouchers for food and essential items. I support benefit applications and can offer advice around things like housing and finances.

I can also just be present for families, take them for a hot drink and have a chat about anything and everything to offer a few minutes of escapism.

The nursing teams are amazing, and they highlight families to me. I can go to them for advice and support, and they are always on hand to help me. I think we complement each other as together we can create the wrap around care for families they need.

### How have families responded to your role?



It's a mixture. Some families are fine and don't need support. It's amazing how they adapt. Others really want my support and say how just having a familiar face when they are so isolated is a comfort to them.

I have had really nice responses from returning parents whose children have been treated on the ward before I started.

I spoke to a mum who helped me shape what we include in the Welcome Packs. When her child was 'blue lighted' to the hospital at the beginning of the pandemic she had a really difficult time as she arrived with nothing, and shops weren't open, and she didn't know Leeds. She said that someone coming in with a Welcome Pack with toiletries and sachets of coffee and tea would have been so heart-warming.

### What would you like to introduce into the support for families going forward?



I have met many challenges due to the restrictions we all face due to COVID-19. This is something I am hoping to overcome once we begin to ease into our new normal. I've chatted to parents who have had an online session with me and would like to meet in person for a catch up. People want face-to-face contact now.

I want to provide events and activities outside the hospital for families to help build relationships and promote positive interaction for children. I want to be able to do some fun sessions with children and some fun family days.

Creating a time out within the hospital is also a priority, offering a space for parents to spend a short time having a hot drink talking to other parents and having a chance to relax and recharge is something I feel strongly about.

---

Parents and nurses have provided extremely positive feedback about Sarah's support for families.

**"Sarah Cherry is our support worker and has been absolutely amazing. Always there when we needed her."**  
Parent

Emma Duffy, Congenital Cardiac Nurse Specialist says:

**"Your input for parents is invaluable. We are so grateful that you are in post and the work you do for our cardiac patients and their families has been amazing. You provide support for our most vulnerable parents, in a way that our team is unable to, as we simply don't have the time. I know many parents are very grateful, including the single parent of a child undergoing cardiac surgery. You sat with her whilst her baby was in surgery and supported her when she had no one else."**

**The very sad death of a child recently and the organisation of flying her back to her home country with her parents, I believe would have been very difficult/not possible had it not been for you. This is life changing for these parents and we have been able to make the best out of a very sad and difficult circumstance.**

**The examples of the great work you have done since you have been in post are endless. I don't know what we did without you!"**



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:

## Sonographer Resources



CHSF funded the printing of training resource reference cards for obstetric sonographers, developed by the fetal cardiology team in Leeds. Each obstetric department and each obstetric

sonographer in the network of hospitals across Yorkshire, the Humber and North Lincolnshire has received the pocket reference guide.

This resource is supporting sonographers to detect more cardiac defects during the routine 20-week ultrasound scan. This enables planning of appropriate delivery and treatment plans and allows parents to obtain the support they need to prepare them for the future.

Jan Forster, Consultant Congenital Sonographer says:

**“A big THANK YOU for your support of our fetal cardiology resource training cards. The cards detail the normal views to obtain during the anomaly scan and support the online training delivered over the last year, supported by the Yorkshire and Humber Congenital Heart Disease Network.”**

## Staff Development

CHSF part-funded the final year of a Masters degree in health and community care at Leeds Beckett University for Sharon Coulson, Senior Sister, Paediatric Intensive Care Unit (PICU).

Sharon says:



**“As part of the course, I wrote a paper which was submitted to a professional nursing journal and was published, which I am really proud of. This involved work around medication safety on the unit and how staff are managed after a medication incident.**

**The process which I designed in collaboration with our clinical educator at the time has been embraced by other teams across the children’s hospital. On PICU it has improved both patient safety and staff satisfaction.**

**By completing the course, it has enabled me to improve my knowledge and equip me with the expertise to contribute more effectively to developments in practice and improve the experience of patients and families on the unit.”**

CHSF funded Children’s Cardiac Nurse Specialist, Marie Wray, to attend a neonatal palliative and end-of-life care conference designed to improve support given to families following an antenatal diagnosis or admission to the neonatal unit.

Marie says:

**“Our antenatal and neonatal service is increasing in numbers every year and we want to continue to improve the services we offer to our families. By attending this conference, kindly funded by CHSF, it allowed me to network with other teams and share good practices to ensure the Nurse Specialist Team and I are offering these vulnerable babies the best possible care.”**

CHSF funded Sarah Gardner, who started in a new role of Adult Congenital Heart Disease Nurse Specialist in 2020, to attend the Advanced Symposium on Congenital Heart Disease in the Adult.

Sarah says:



**“CHSF kindly funded the fees for me to attend this conference so I could advance my knowledge on the subject of congenital heart disease in the adult, as there is so much to learn.**

**Each day there were specialist guest speakers who explained and discussed each condition, in addition to highlighting studies and future advances in congenital heart disease.**

**This course enabled me to get a good background and broaden my understanding as a basis to build upon in practice. This now means I can care for and advise our patients confidently and safely.”**

# MRI Coil for Paediatric Heart Scans



CHSF funded a Noras Variety 16-channel multipurpose coil. This is used by Dr Malenka Bissell, Clinical Lecturer of Paediatric Cardiology at the University of Leeds and Consultant at Leeds Children's Hospital, and her

colleagues to take the highest quality images during paediatric MRI heart scans.

## MRI coil



The MRI coil will be used to take high quality images of babies with complex heart defects in MRI scans in a closed incubator. This set-up of coil and closed incubator - the Baby MRI Incubator - will be revolutionary in the

treatment of babies with complex heart defects.

It will enable clinicians to undertake MRI scans of these babies' hearts without the need for general anaesthetics, which can cause cardiac arrests and deaths. Some babies with complex heart defects have not been able to have MRI scans which provide the most detailed information about their condition for this reason.

As well as taking standard images of the heart, the MRI coil produces advanced images that allow clinicians to see how the blood moves through the arteries (known as 4D flow MRI). They can see how narrow a vessel is and how much blood flows through it.

Images from the MRI coil provide very detailed information which clinicians need to treat these high-risk babies, reduce mortality in this group and improve their health outcomes, and enable pioneering research studies.

Malenka says:

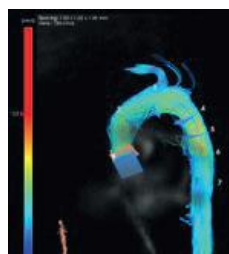
**"I am delighted to receive this MRI coil. This specialist camera is taking consistently good quality and accurate images during MRI scans. These images are giving us new and detailed information which will improve outcomes for these high-risk babies."**

## Optimising image quality

Once Malenka received the MRI coil, she started to optimise the quality of the images this camera could produce by taking scans of 16 babies with mild heart conditions, despite the challenges of COVID-19. The MRI coil produced clear pictures of babies as young as one day old and as small as 2.5kg.

Parents of babies who took part in these research MRI scans commented how stress-free the experience was, and how valuable they found the extra information from the scans. For example, clinicians were able to estimate the likelihood of the baby needing heart surgery in the next few days following the scan.

## Presentations



Malenka presented the research scans in a case study at two large virtual international meetings - EuroCMR 2021, the European cardiac MRI conference and AEPC 2021, the European paediatric cardiology conference.

The initial results have also been submitted to the national congenital cardiac anaesthetic network meeting for presentation, hosted in Leeds.

## Research Study

Malenka is currently preparing the first research study for publication showing that neonatal scans in the Baby MRI Incubator can give accurate results when measuring blood flow.

Malenka demonstrates in this study that the advanced 4D flow MRI imaging is much faster in measuring blood flow in all the vessels around the heart at the same time, but just as accurate as measuring flow the traditional way in each vessel separately.

As the full assessment can be completed in under ten minutes, clinicians will be better able to predict problems, such as which babies will have too much or too little blood flowing into the lungs, at an earlier stage.

Following the optimisation of the images and Malenka's initial research, she is looking forward to using the MRI coil in the closed incubator to take MRI scans of babies with the most complex heart defects for the first time. We look forward to reporting on this in our next Social Impact Report.





# Looking Ahead

I am delighted to say we have continued to deliver to our beneficiaries through a time when life was unpredictable and uncertain, making our support even more meaningful. And we will continue to deliver life-saving care for patients with congenital heart disease and positive, life-changing support for their families.

Our Family Services work has been a real success. To help and support the families during their most stressful time has been extremely important to us, and the feedback has been extraordinary. My team, the CHSF Trustees and I are very proud of this holistic family support, and we hope to expand on this direct support to our families, in the future.

Looking further ahead, the Leeds Teaching Hospitals NHS Trust 'Hospitals of the Future' project aims to deliver plans for two new state-of-the-art hospital buildings, including a dedicated Children's Hospital, by 2025. CHSF will make sure the Leeds Congenital Heart Unit is given everything it needs, both now and in the future, to maintain its status as a world-class centre of excellence.

We hope you enjoyed reading this report and feel inspired by what you have learnt. We still have a long way to go, but can look positively to the future, knowing we can adapt when we are really up against it.

## Thank you...

for supporting CHSF during what has been an unprecedented year for us all. We are so grateful to everyone who raised funds, made grants and donations, gave gifts-in-kind and remembered us in your 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. We want you to know that our mission to support hearts for life will continue. We 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 made donations, grants and raised funds.

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

*Because of You*



CHILDREN'S  
**HEART SURGERY**  
FUND



Registered with  
FUNDRAISING  
REGULATOR

0113 831 4810 | [info@chsf.org.uk](mailto:info@chsf.org.uk)

[www.chsf.org.uk](http://www.chsf.org.uk) Registered Charity no: 1148359