



CHILDREN'S  
HEART SURGERY  
FUND

## Social Impact Report 2019/20

*Because of You*



# Welcome



## Sharon Milner, CEO

I am delighted and proud of what our supporters have helped us achieve in aid of the Leeds Congenital Heart Unit, since 1988. This Social Impact Report shows the diversity of projects your fundraising and donations helped us deliver in 2019, a year in which we pushed into our third decade of dedicated support for patients with congenital heart disease and their families.

The state-of-the-art hybrid children's heart theatre funded through CHSF's Keeping The Beat campaign has truly revolutionised the Unit. Hundreds of young patients have benefited thanks to the ground-breaking equipment provided by our fundraisers and supporters. There are tremendously life-affirming case studies to read in this report - including the Ambient Experience Interventional Suite which successfully reduces patient anxiety before surgery.

CHSF continues to support the Unit directly with equipment ranging from entertainment aids like iPads and TVs to bespoke life-support machines and training simulators for staff working in the Paediatric Intensive Care Unit. Both young and older patients with congenital heart disease continue to benefit from the INR blood-testing kits and home ECG devices you have funded. The feedback from families who took part in our Family Camp, used our new holistic care services and stayed in the parent accommodation could not be any more positive.

All that remains is for me to wish you well - stay safe and please enjoy this report knowing you continue to make a huge difference to the NHS staff, heart patients and their families who need it now more than ever. Thank you.



## Paul Goodwin, Chair of Trustees

Being a parent of a child born with congenital heart disease gives a very special perspective on the impact that CHSF can make to patients and their families. It has been a privilege to serve as a Trustee since 2017 and Chair since January 2020.

COVID-19 has impacted all charities, and CHSF is certainly not immune. Fundraising activities have been cancelled or radically changed, and CHSF has needed to adapt to this environment. The help needed by patients, families and NHS has not slowed down. It is in these unprecedented times that we need your support more than ever.

Monitoring our impact remains critical to ensuring we grow and continue to meet the needs of the Leeds Congenital Heart Unit as it plans for its exciting future. Reading the inspiring feedback from clinicians, patients and supporters shows how we are making a huge difference to so many lives across our region.

Thank you, and please continue your support for patients of all ages with congenital heart disease and their families. As you read this report you can see the impact you are having.



## Hanif Malik OBE, Ambassador

As a former Trustee of five years with CHSF, I have witnessed at first hand the incredible life enhancing work carried out by the charity. I am privileged to remain involved with an organisation that makes such a huge difference to the lives of not only the children but their families.

I've been fortunate in working for and alongside charities for the past 25 years and I can honestly state that CHSF is amongst the very best. Let's continue to give it the support it deserves from across all our communities.



# CHILDREN'S HEART SURGERY FUND

## How we make a difference



### Our charity...

Children's Heart Surgery Fund (CHSF) was established in 1988 to support the Leeds Congenital Heart Unit. Over the past 32 years we have spent more than seven million pounds supporting the Unit, the 17,000+ babies, children and adults from Yorkshire, the Humber and North Lincolnshire treated each year, and their families.



### Our cause...

Congenital heart disease (CHD) is a heart condition or defect that develops in the womb before a baby is born. CHD is one of the most common types of birth defects, affecting up to 8 in every 1,000 babies born in the UK. While for the majority of babies their conditions are minor, some are more serious, and they do not survive. However, thanks to advances in early diagnosis and treatment, around 8 out of 10 babies will grow up to become adults.



### Our vision and mission...

Our vision is to support hearts for life. Our mission is to support the Leeds Congenital Heart Unit in becoming 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...

Our values are Trust - we deliver on our promises; Compassion - we pride ourselves on reliability, empathy and loyalty; Openness - we are approachable and inclusive in everything we do; Respect - we value and appreciate one another, and Dedication - we always go the extra mile.

**We know that caring for people with congenital heart disease  
involves more than treating just the heart itself.**

**This is why we are here for the**

**heart, mind, family and future.**



**Care for  
the heart**

by providing revolutionary  
medical equipment



**Care for  
the mind**

by creating a positive and restful  
environment on the wards and funding  
play distraction equipment



**Care for  
the family**

by contributing towards living  
expenses, offering parental  
accommodation and giving  
exceptional grants



**Care for  
the future**

by funding research,  
clinical posts and projects



# Our impact in 2019 and 2020

From January to December 2019, CHSF, with the support of generous funders and fundraisers, invested £287,797 in 63 different projects and initiatives.

These benefited the 17,130 patients, and their families, from across Yorkshire, the Humber and North Lincolnshire who passed through the Leeds Congenital Heart Unit during the year.

Our continued support is ensuring that the Leeds

Congenital Heart Unit continues to operate as a centre of excellence. It is pushing the boundaries of what is achievable in the field of congenital heart disease and providing patients with the best possible 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 2019, and into the first half of 2020.



See page 8



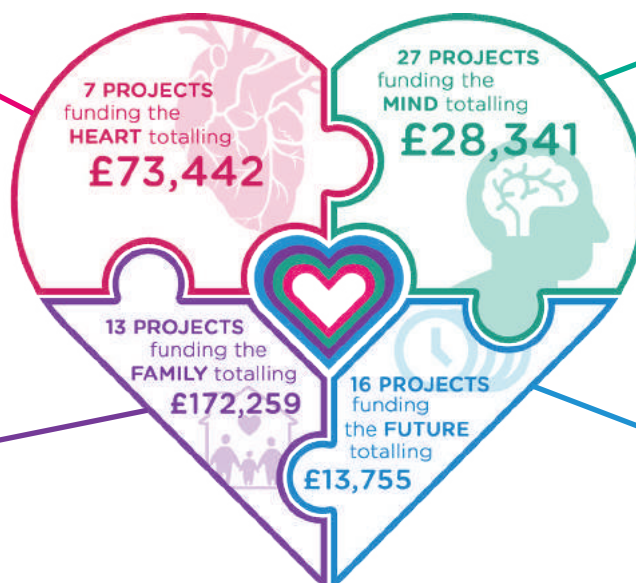
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A TOTAL OF **£287,797** INVESTED IN **63** PROJECTS

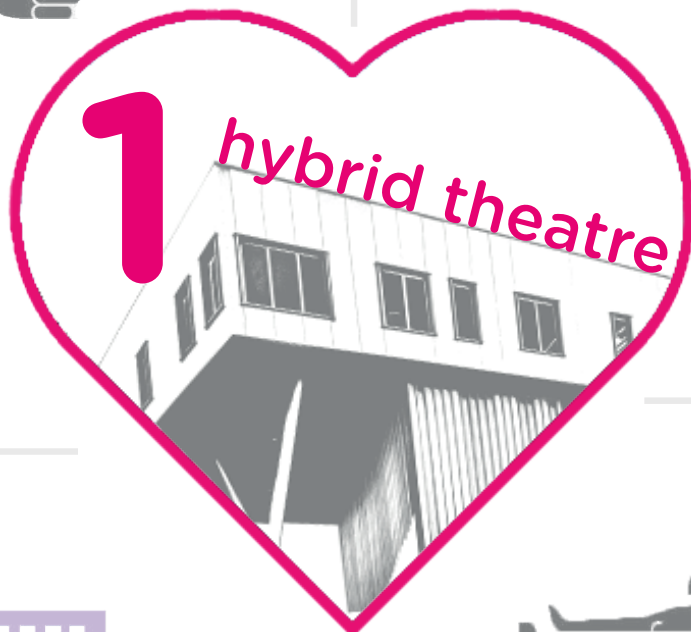
**60** KARDIA HOME  
ECG DEVICES



**60** HOME  
BLOOD  
TESTING  
KITS



CONDITION  
**6** VIDEO  
ANIMATIONS



**£30k**

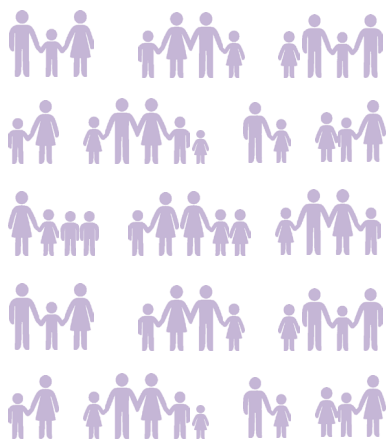
Eckersley House  
FAMILY ACCOMMODATION



ACTIVITY  
CAMP FOR

**14** local  
heart  
families

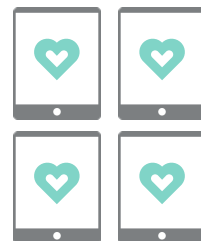
in partnership with  
OVER THE WALL  
family camps



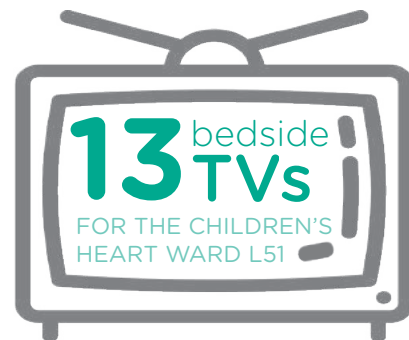
**£18,298**  
FAMILY  
GRANTS

**321** Katie Bear  
TEDDIES &  
MEDALS

given to babies and  
children who had  
**OPEN HEART  
SURGERY**



**4** iPads  
for PICU



**1** CONGENITAL CARDIAC  
RESEARCH NURSE



Some of the ways that  
**CHSF** supported the  
**HEART, MIND, FAMILY**  
and **FUTURE** in 2019.

# One Year On: The New Children's Heart Theatre

In 2018 and 2019, CHSF awarded £1,877,187 to fully kit out a state-of-the-art hybrid children's heart theatre at Leeds Children's Hospital.

**"It's made a fabulous difference to what we are able to do for our patients. It really is the most incredible facility. I think it's really helped us take our care for children with heart disease to the next level. We are very grateful to the Children's Heart Surgery Fund and everyone who funded it for what they have done for us over the last year with this project."**

Dr John Thomson, Consultant Paediatric Cardiologist

Since 23 May 2019, 464 babies and children aged up to 16 years have undergone procedures in the theatre.

The first year in the theatre has been a great success. It has transformed the way clinicians and surgeons work together and improved the experience for the young patients.

**"The theatre has revolutionised management of congenital cardiac patients. It allows interventional cardiology to complement cardiac surgery to give the best outcomes. Not only does it allow for joint procedures to be done safely, but it also reduces the need for multiple general anaesthetics in high risk procedures."**

Mr Osama Jaber, Consultant Congenital Cardiothoracic Surgeon, Lead Clinician for Congenital Cardiac Surgery

**"The hybrid theatre has had a massive impact on how we work. With cardiac surgeons and interventional cardiologists now working side by side we can deliver much better and safer treatments to our patients."**

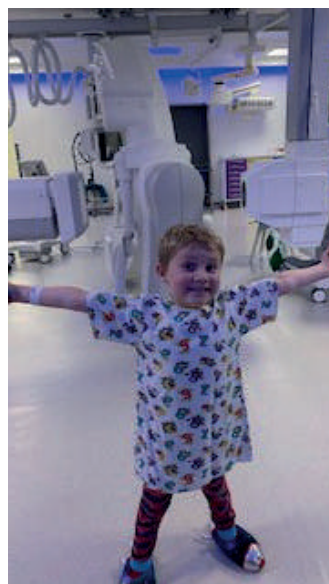
Miss Carin van Doorn, Consultant Congenital Cardiac Surgeon

**"I think people need to know how important it is that this amazing theatre saved two incredibly poorly hearts and gave them a second lease of life."**

Leanne Watts, mother of Harley and Joey

**"Proximity of the theatre to the cardiology ward has improved patient experience as it is a quicker journey. Being closer to the MRI scanner has facilitated us to perform general MRI scans in high risk cardiac children with the added safety net of having proximity to our cardiologists and surgeons."**

Dr Carol Bodlani, Cardiac Anaesthetist



**"George has been able to have the best possible care and life chances using the expertise of the team at Leeds and the amazing surgeries and procedures which can now be carried out in this state-of-the-art operating theatre."**

Jane Hinkins, mother of George





# George Hinkins' Story

George, age six, was one of the young patients with a complex heart condition treated in the hybrid children's heart theatre in 2019 and in 2020. He had his third open heart surgery in June 2020.

George's mother, Jane Hinkins says:

**"The amazing care and support we have had as a family since finding out during our 20-week pregnancy scan in 2013 that our baby had a very complex heart condition, Ebstein's Anomaly, has been so important.**

**The condition would require a number of major open-heart surgeries in the future and George living life with only half a working heart.**

**It was very worrying and unexpected news to receive, however we have had absolute faith and confidence in the expertise and dedication of the team at the Leeds Congenital Heart Unit throughout our entire journey with George.**

**Thanks to them George had his first open heart surgery (a Blalock-Taussig shunt at 36 hours old). He then had his Glenn surgery at 10 months old and in June had his tricuspid valve cone repair.**

**He went into surgery chatting away to everyone. He is an 'old pro' with it being his third open heart surgery and three stays on the ward last year for Cath lab surgery. We are all so proud of him.**

**We were so grateful to CHSF for providing us again with a family room in the Brotherton Wing. This allowed us to wait whilst George was in surgery and for my husband to stay in overnight whilst George was in Intensive Care and the High Dependency Unit.**

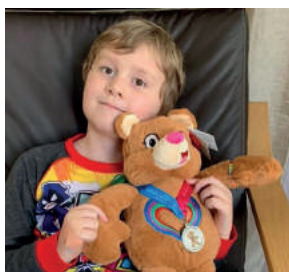
**George's sister Poppy made 'Happy Beads' and bags of sweets as thank you gifts. She gave them to the brilliant team at CHSF, the wonderful nurses, Mr Jaber who did such an amazing job with George's complicated eight-hour surgery and Dr Michael, who has been George's lovely and brilliant consultant since he was born.**

**Since George has recovered from his major surgery in June with improved oxygen levels, he has had so many 'firsts'. He has managed to play football with his friends, played for 30 minutes in the South Bay at Scarborough, and can walk round most of Harewood House now.**

**As parents we have always had 100% confidence in the cardiac team from the moment George was born with**

**his very complex and severe single ventricle cardiac condition. Several surgeries later we continue to be so grateful that our child has, and will always have in the future, access to the best team and equipment.**

**A huge thank you from George for everything everyone has done for him as a child to help him have the best possible chance of living a fun-filled life with his serious heart condition. As a family we are so very grateful to everyone who supports the invaluable work of CHSF which supports children like George and people like us."**





**Care for  
the heart**





# Care for the Heart

We fund vital, innovative equipment. This helps the Leeds Congenital Heart Unit save and improve lives, as well as keep up with the ever-changing technologies needed to treat children and adults in this very complex field.

Our support for the heart included:

## Bespoke heart-lung machine

A bespoke heart-lung machine is making a big difference to the treatment of young heart patients.

The purpose of a heart-lung machine is to temporarily take over the function of the heart and lungs during heart surgery while the heart is stopped. It maintains the circulation and the oxygen content of the patient's body until the surgery is complete.

Heart-lung machines are traditionally heavy and bulky. Andrew Nichols, Clinical Perfusion Manager, developed specifications for a bespoke heart-lung machine which allows it to be tailored to the needs of the young patients with complex heart conditions.

Patients can stay on this portable bypass machine for much longer periods of time than a traditional heart-lung machine. It is easily transported around the hospital and takes up minimal space in a busy surgical theatre.

Andrew Nichols says:

**"The equipment has a small footprint and is portable, enabling us to transport the patient and the machine together to the intensive care unit. It also has unique features designed to make it less invasive to the patient and enables it to be used for a longer duration. This is making a huge difference to the way we are able to treat young heart patients from across Yorkshire during heart surgery."**

The bespoke heart-lung machine is used interchangeably between the hybrid children's heart theatre and the Paediatric Intensive Care Unit. High-risk patients can be kept on the same machine when being transferred, freeing up the other heart-lung machines for other patients.

Andrew Nichols says:

**"We have been using the bespoke heart-lung machine during larger paediatric heart operations. These are typically complex surgeries involving the aorta and have involved deep hypothermia. The benefit of this is that we can get used to working with the special pump whilst still having the familiar set up in theatre."**



**7 PROJECTS SUPPORTED • £73,442 INVESTED**  
**17,130 BABIES, CHILDREN AND ADULTS BENEFITED**

# Care for the Heart

## Kardia Devices

We provided 60 new Kardia mobile ECG (heart tracing) devices for patients who experience heart palpitations. These devices enable patients to use their mobile phone to measure their heart rate, wherever they are.

The patient initially downloads an app to their mobile phone. They then pick up their phone when they wish to measure their symptoms and hold their fingers to the device for thirty seconds. This allows them to record a medical-grade ECG result. Data is then fed back to their cardiologist at the Leeds Congenital Heart Unit, who can then judge whether their heart rate is normal or if it needs further investigation.

The advantage of using this device is that it allows patients to record their ECG at a time when they are experiencing the symptoms, rather than hoping they happen when wearing a hospital heart monitor for a limited time period.

Recording this kind of heart information and diagnosing any problems early can have long-term benefits to the patient's health and potentially save their life. Issuing patients with this device is also a more efficient approach to monitoring their hearts, removing the need for a hospital stay and more costly devices.

James Oliver, Consultant Adult Congenital Cardiologist, says:

**"We've found the mobile devices to be of great value. They have been instrumental in diagnosing important heart rhythm abnormalities in some patients and in others they provide reassurance that symptoms such as palpitations are of no concern."**



## Pedestal Mounted Contrast Injector



A Pedestal Mounted Contrast Injector is a crucial piece of medical technology used by clinicians to assist them in a type of x-ray called angiography. This piece of equipment injects an x-ray dye directly into the blood to check blood vessels.

Katrina Kimberley, Radiographer Team Leader, says:

**"We are hugely grateful to Children's Heart Surgery Fund and have been using this Contrast Injector since the hybrid theatre opened."**

The x-ray dye is too thick to be injected into the chambers of the heart by hand, and blood vessels do not show up clearly on a normal x-ray. The dye highlights the blood vessels when they are looked at using the x-ray machine, allowing doctors to spot any potential problems.

Without this equipment, anomalies within young patients might remain undetected for longer making treatment more difficult in future. A huge thank you."





# Parallel Simulator

A Parallel Simulator is used to train medical staff in how to operate a lifesaving ECMO heart-lung bypass machine. ECMO acts as an artificial heart and lung for patients, keeping them alive for extended periods of time on the Paediatric Intensive Care Unit (PICU) after heart surgery.

Andrew Nichols, Clinical Perfusion Manager, says:

**“ECMO is only used in a small number of hospitals around the UK. Currently in Leeds we are only able to offer ECMO to patients who require this support following cardiac surgery. We are seeing an increased need for its use as a primary therapy in acute heart and lung failure.**

**Our ambition is to be recognised as a national paediatric ECMO centre. The benefits are that more children from our local area and beyond can receive lifesaving treatment at the Leeds General Infirmary, rather than having to travel to another centre at the sickest time of their lives.**

**Successful ECMO programmes not only offer excellent patient outcomes, but also provide hospitals with significant additional funding.”**

In order that more patients can be treated using ECMO life-support, and more young lives saved, CHSF funded a Parallel Simulator. This has enabled Andrew Nichols and his team of perfusionists to train 12 Paediatric Intensive Care nurses to be proficient in delivering the ECMO support.

The Parallel Simulator attaches to the ECMO heart-lung bypass machine and allows the trainee to predict, react to and respond to various simulated training exercises. It is programmed with a variety of medical emergency scenarios, such as when the pressure in the pipes increases or if bubbles appear in the pipes while a patient is on the bypass machine.

The Parallel Simulator is proving to be an essential training resource. It is used by the team on a monthly basis to test their skills and ensure they are proficient in dealing with all possible emergency situations.

Andrew Nichols says:

**“The Parallel Simulator has been instrumental in moving our programme forward and ensures the training of our ECMO nurses is as modern and as interactive as possible.”**

Santosh Sundararajan, PICU Consultant, says:

**“The Parallel Simulator is helping us to train ECMO nurses and PICU medical staff to work as team in managing real life based ECMO emergencies. We are incredibly thankful for this vital teaching equipment. This equipment is being used in monthly team training and will further help us to improve survival for children needing ECMO support.”**

Andrew Nichols plans to develop the service by creating an independent training programme for the entire multidisciplinary team in PICU on site in Leeds General Infirmary.







**Care for  
the mind**



# Care for the Mind



We believe that caring for the mind is just as important as caring for the body. We help create a restful and positive experience on the ward for patients and their families with a variety of toys, games, crafts and other equipment. This can help to speed recovery and provide distractions for the whole family.

Our support for the mind included:

## Distractions for patients



We gave PICU four iPads to provide entertainment for young patients while they recover following heart surgery. The iPads will also be used as distractions for patients during medical procedures.

**“Thank you very much to everyone who has donated to CHSF as it has allowed the children on the PICU to have access to four brand new iPads and covers. This will give some of the sickest children in the hospital the opportunity to listen to music and watch programmes, which we have not been able to offer before. It is greatly appreciated by all the staff, children and families.”**

Leanne Williams, Acting Family Care Sister



The children’s cardiac ward now has 13 brand new bedside TVs for patients. These are a welcome distraction and a way to relax for children recovering from or awaiting surgery.

**“The new TVs are great because they have given us lots of positive distraction. It’s nice that Ava can be distracted from things like being fasted, or waiting to go down to theatre, by watching her favourite TV programmes. It’s great for us parents too, as the days can be long here, so we can use them too when the little ones are resting.”**

Laura Fletcher

## INR kits

CHSF provided 60 INR kits so patients can test their blood for clotting at home, with the aim of reducing the risk of a stroke.

All the patient has to do is a finger prick blood test, transfer it to an INR kit with a measuring strip and either phone the hospital or transfer the results via an app on their mobile phones. The test takes less than a minute and the results are instant.

INR kits gives these patients more control over their conditions and removes the need to make regular visits to the hospital for blood tests and miss lessons at school.

**“We have had a tricky time in getting Evelyn’s meds right and having the kit at home has been fabulous. I could not imagine weekly trips to hospital and the battle we would have.**

**Evelyn had such a fear of the daily blood tests in hospital and had a difficult time interacting with the nurses so getting her to do the test was a battle, but with the Home kit she is so much more relaxed. She even holds out her finger now and helps us turning it on and off and reading her INR level.”**

Anna Hunter



**27 PROJECTS SUPPORTED • £28,341 INVESTED  
17,130 BABIES, CHILDREN AND ADULTS BENEFITED**

# Ambient Experience Interventional Suite

Going into a medical theatre for a procedure can be very stressful for young heart patients, and their parents who accompany them.

The Ambient Experience Interventional Suite in the hybrid children's heart theatre is designed to promote feelings of calm and relaxation when patients undergo a clinical or surgical procedure. The multi-sensory environment, consisting of soft lighting, sounds and projections, allows each baby, child and teenager to experience images, colours and music designed to reduce their anxiety.

The response to the Ambient Experience over the past year has been overwhelmingly positive from patients, parents and clinicians.

Clinicians are noting that anxiety and distress in patients (and parents) has reduced and they appear and report feeling more relaxed. They have commented that patients who had undergone procedures prior to the installation of the hybrid children's heart theatre are now calmer when they return for further procedures and experience the Ambient Experience for the first time.

Parents have reported that the lights and screen have a calming effect on them and their children. One parent stated that although the theatre was busy with lots of medical staff, the atmosphere felt relaxed which took away her feelings of stress.

**"The lab itself with its attractive monitors and distraction aids has made a massive difference to the way we comfort the children during the anxious time of induction of anaesthesia."**

Dr Carol Bodlani, Cardiac Anaesthetist



Many of the children request 'room themes' – choosing lighting, music and images to distract them. Their involvement in the process is helpful in keeping them calm and relaxed before their treatment. It enables

young patients to have some control during a stressful and unfamiliar experience and engage with and build trust with the medical team.

Two young patients reported back:

**"It was better than the previous lab. It was a more relaxing environment and the big screen showing the underwater film was a nice distraction."**

**"Before I had my procedure, I went to the Ed Sheeran concert and missed 90% of the concert because I had one of my episodes. Dr Hares was aware of this and played Ed Sheeran as I waited. This made me feel happy."**

As the Ambient Experience is reducing stress and anxiety in patients, we anticipate that these patients will feel less anxious and more positive about procedures in the theatre in the future.

Sharon Milner, CEO, Children's Heart Surgery Fund says:

**"In a short space of time we were hearing the positive difference the distraction equipment was making towards patient anxiety, upon entering the theatre and leaving. The Ambient Experience is, and will no doubt continue to be, a positive addition to children living with congenital heart disease, for many years to come."**







In 2019, Joey Watts had two procedures in the hybrid children's heart theatre. His brother Harley had a procedure in early 2020.



During Joey's first procedure he watched fish on the big screen. During the second procedure Joey chose what he wanted to watch - which were images of dinosaurs. His mother, Leanne, says that the distraction provided by the Ambient Experience made him feel calmer and helped him to develop relationships with the clinical staff.

Leanne says that she thinks that the Ambient Experience has definitely played a part in Joey feeling less anxious about further treatments, saying his attitude is one of "not being bothered - I can do this".

Harley, who had his procedure in January 2020, says the Ambient Experience made him less anxious and as he was too busy looking at the TV screens to notice what was going on around him, he didn't feel scared. Leanne says that she believes the distractions of the screens and music made a huge difference to his experience as well.

Both boys are doing really well. They are able to do limited exercise and are keeping busy fishing and training with a local football team.

Filipa Ferreira, Congenital Cardiac Intervention Nurse Specialist, says:

**"I think the Ambient Experience is amazing!!"**

**The equipment is really good, and we can connect Bluetooth and put music on for the teenagers when they ask for a special playlist, and that helps them feel less stressed.**

**For small babies, the big screen with cartoons helps them as they focus on the screen and not everything around them, such as the equipment and medical staff wearing masks. This helps to reduce anxiety and upset in the babies and provides a positive experience for them and their parents.**

**The Ambient Experience has a positive impact on our workflow. As the experience is more relaxing and less stressful for patients, they are calmer and so go to sleep quicker, which improves our workflow.**

**I think the Ambient Experience is good for everyone - staff, parents and patients. I would like to thank Children's Heart Surgery Fund and everyone who supported it so much for your help providing this equipment."**





**Care for  
the family**



## Care for the Family



Throughout our 32-year history we have been a constant source of practical and financial support for families. This allows them to focus on their sick child during their treatment in hospital, when they need them most.

In 2019 we supported 461 families by:

- providing travel, living expenses and exceptional grants for families living at a distance from the hospital and those experiencing financial challenges.
- funding family rooms on Brotherton Wing and financially supporting Eckersley House so parents could rest while remaining close to their child.
- bringing families together to enjoy themselves at events and parties, such as the Superhero Walk and the CHSF Christmas Party.

In addition, we allowed more than 5,000 family members to share their experiences and concerns in the positive and supportive environment of our private Facebook group.

In April 2019, mum Kailey told us:

**“Kacie was admitted to Leeds Children’s Hospital and diagnosed with dilated cardiomyopathy in August 2008 when she was ten days old. She’d suffered an idiopathic myocardial infarction. In other words, a heart attack, at nine days old.**

**It was the worst thing we’ve ever gone through as a family, we were young parents – only 20 at the time, and without the support of not only our family and friends but also the staff I don’t know where we would’ve been!**

**We stayed in the parent’s accommodation funded by CHSF, which was an absolute godsend and meant we never had to be away from her. We were able to stay at the hospital every single night and to be honest we would have been lost without these facilities.**

**Kacie is now 10 years old and leads a normal life, always full of energy. She’s completely free of medication and her heart still looks perfect. She’s on 3-yearly check-ups now as she’s doing so well! That’s all thanks to CHSF and their supporters.**

**We still don’t know how or why Kacie went through what she did, but we do know we couldn’t have got through it without the amazing support we had from Children’s Heart Surgery Fund and the hospital. She’s our little miracle.”**

We are always looking for new ways to support families. In 2019, as we planned, we started to introduce elements of holistic care designed to promote wellbeing.

In October 2019 we delivered, in partnership with Over the Wall, a weekend residential Family Camp (see pages 18 and 19). In 2020, we introduced welcome packs of toiletries and refreshments for families arriving on the ward, and online self-care sessions, including movement and relaxation techniques.

We are continuing to expand this programme of holistic care. This will be delivered by the new role of Family Support Worker, who will be joining CHSF in autumn 2020.



**461  
families**

directly benefited  
from our services



accommodation  
**291 families**



event & activities  
**114 families**



living expenses  
**46 families**



exceptional grants  
**10 families**

**13 PROJECTS SUPPORTED • £ 172,259 INVESTED**



# Family Camp

Our first Family Camp for families with children with congenital heart disease took place at South Dearne in Conisbrough in South Yorkshire from Friday 4 to Sunday 6 October 2019. It was delivered in partnership with Over the Wall, a UK charity that supports children and young people facing serious health challenges.

This weekend residential camp gave families the opportunity to spend quality time together in positive shared experiences, with the aim of strengthening their bonds and increasing their wellbeing and resilience.

Fifty-five parents, children with congenital heart disease and their siblings took part in a variety of activities during the weekend, supported by volunteers and staff from Over the Wall. These included craft activities, board games, archery, obstacle courses and abseiling.

The outdoor activities encouraged each family to work together as a team and take on new challenges. Young heart patients (and their siblings) were able to progress at their own pace and choose their own level of challenge.

We received very positive feedback from parents. They reported back how much they valued this precious time doing things together as a family, having fun and sharing their experiences with other families.

Parents commented:

**“We enjoyed doing activities we wouldn’t normally do. Even our six-year-old did abseiling! We gained lots of precious memories and new skills.”**

**“We had an amazing time at family camp this weekend. Met some new friends, had lots of fun, brilliant family bonding time with amazing staff and volunteers. Thank you so much.”**

**“The thing that I loved most about this weekend is that all of us could get involved with all the activities that were offered. This meant that we didn’t have to separate and got to experience everything together creating those precious family memories.”**

Young heart patients, some of whom are classed as being in the ‘high risk’ category, were able to safely take part in activities such as abseiling and archery. This allowed them to achieve more than they would previously have thought possible.

Parents reported:

**“This weekend he completed so many physical challenges and stepped completely out of his comfort zone. I have never seen him smile so much and be so proud of himself.”**

**“She is so happy and can’t wait to tell everyone about what she had done over the whole weekend. For her to absolutely smash it at abseiling and do it five times amazed us.”**

Following the success of this residential weekend, and interest from many families in attending again, we plan to deliver a further Family Camp in partnership with Over the Wall in 2021.





# The Turner Family

Jade Turner and her family attended our first Family Camp.

**“When we go on a holiday and they ask for parents to come up to the front to volunteer, I am the mum that quickly hides away!**

**Going to the Over the Wall family camp, I soon realised that this camp was going to be my idea of a worst nightmare. Singing, dancing, abseiling...!**

**Inside I was dreading it, but my partner and the kids were so looking forward to it. So, I put on a brave face and tried to show that I was excited!**

**When we arrived, we were greeted by such lovely volunteers and staff. They gave us t-shirts to wear and free water bottles and that’s when we met our volunteers for the weekend...**

**Each family is assigned either one or two volunteers to help your family in any way possible over the weekend. From carrying your water bottles, to playing games with the kids or even making you a cup of tea... I was beginning to come around to this camp!**

**I realised how important these ladies were to our family. When it’s lunch time and you’ve got three kids to sort out and suddenly, you’ve got someone helping you – it’s unreal!**

**On the first night of the camp the children were allowed to dress the parents up and paint our faces –**

**no rules! Our kids were in their element! I was cringing on the inside, but the laughter and smiles were worth it!**

**One of my children is extremely quiet and he doesn’t like social situations. Yet, he became very close to some girls who were staying at the camp with us. He was doing things out of his comfort zone and not wanting mum or dad there!**

**Our son Bobby has just turned four and has hypoplastic right heart syndrome. Before we went on the camp, we were worried he wouldn’t be able to do all of the activities that his brothers could. But he did it all, apart from the abseiling! If it was too cold outside there was a room full of games we could take him to but this wasn’t often as he wanted to join in.**

**Each mealtime or group meeting means dancing! The mum who normally hides away was joining in! Sometimes we get so wrapped up in the taking care and organising that we forget about the joining in and letting our hair down.**

**The Over the Wall family camp makes sure you do just that. No one is left holding the bags or waiting with one of the children. You have volunteers by your side making sure you enjoy your family.**

**We go on plenty of holidays but the Over the Wall camp was the first time we actually felt like a family with nothing holding us back. You really don’t need to worry about anything – apart from brushing up on your dancing skills!”**





Care for  
the future





# Care for the Future



As techniques and technologies are constantly changing, we make sure we are always aware of what's happening next in the world of congenital heart disease by funding research, staff development and clinical posts and projects. This investment helps to improve lives and patient care, now and in the future.

Our support for the future included:

## Cardiac MRI Research

CHSF funded a toy MRI scanner to use in a cardiac MRI research study which allows young patients to prepare for an MRI scan through play (see page 22).

Dr Malenka Bissell, Clinical Lecturer in Paediatric Cardiology, is keen that taking part in cardiac MRI research is a positive experience for the young patients. As part of the study they are able to play with the toy MRI scanner, watch a DVD or access Netflix in the scanner, and wear doctors' scrubs instead of hospital gowns. This allows them to feel more relaxed and confident.

Feedback from parents has been positive, with one commenting: **"I must say that my daughter, aged 6, was very anxious and upset about her upcoming medical MRI. We thought that helping with this research might also be beneficial to her and help to remove the fear and anxiety she was feeling about the MRI scan. It absolutely did and she is actually looking forward to returning for her medical one. Hearing her say she enjoyed her visit and it be such a positive experience for her is wonderful to hear."**

As the MRI scan will be a more pleasant experience, it increases the likelihood that young patients will feel comfortable having both clinical and research MRI scans without the need for general anaesthetics in future.

This will allow Dr Bissell to undertake increased research into paediatric congenital heart disease, an under-researched field, using cardiac imaging (MRI).

Dr Bissell says: **"I am very grateful to CHSF and their supporters who are helping to ensure that research is taking place that will improve care for young patients with congenital heart disease. This will also help us achieve our ambition to make Leeds a world-wide centre of excellence for both treatment and research in this field."**

## Professional Development



During 2019, we made a significant investment in the professional development of a wide range of staff in the Leeds Congenital Heart Unit. This is allowing them to increase their knowledge and expertise which is benefiting patients and improving the service.

Amy Allen, Senior Sister and three other members of the Paediatric Critical Care Team attended the Paediatric Cardiac Intensive Care Society conference. Amy says:

**"The event was attended by individuals who work in intensive care units across the globe and we found their stories and updates really interesting. Two of the nursing staff presented a poster about a catheterisation project and a number of paediatric intensive care units have requested their information. Thank you again for allowing us this opportunity to represent the Unit and the charity at such a thought-provoking event."**

Marie Wray, Children's Cardiac Nurse Specialist, attended the Single Ventricle Conference. Marie says:

**"This was something I was particularly interested in attending as it discussed the whole life span of this group of patients. I generally meet families when a diagnosis of single ventricle anatomy has been made during pregnancy so it is really useful to have as much information as possible about what life is like with these kind of complex heart conditions when counselling these families before their babies are born."**

# Toy MRI Scanner Research

In 2019, CHSF funded a model toy Siemens MRI scanner along with toy figures, a toy hospital and ambulance as part of a research MRI scan study at the Advanced Imaging Centre in Leeds General Infirmary.

This model toy allows young patients to learn about the experience of having an MRI scan through play. It gives them time to explore and ask questions about what is going to happen to them during their visit. This is designed to reduce anxiety and allow them to feel prepared for their actual scan.

James, aged six, who has Tetralogy of Fallot, was one of the young participants. James and his mum hoped that taking part in the study might mean his next clinical MRI scan could be done while he was awake and eliminate the need for James to have a general anaesthetic.

Ruth Foley, MRI research nurse, says:

**“James had brought his favourite teddies with him to accompany him onto the scanner so our first job was to scan them first to make sure they didn’t have any metal in them... we think they enjoyed their scan too!**

**James was so prepared after spending time playing that when he saw the real MRI scanner his shouts of “WOW! That’s so cool” made everyone smile! Dr Malenka got him ready for his scan and James said he felt like a space man going into space.**

**Our participants are able to watch a film or series whilst on the scanner. James had already decided he was watching the film ‘Minions’ and loved that only he could hear it with his special earphones. His mum, Claire was able to sit with him during the scan and James could see her through the mirror we use.**

**Once James and his teddies were ready, we started the scan and what a superstar James was! We were all very proud of James and when his MRI scan was finished his first question was “can I go play with the toys again?”**

James and his mum left feeling more confident that when James has to have a clinical MRI scan that he will be able to tolerate it being awake.

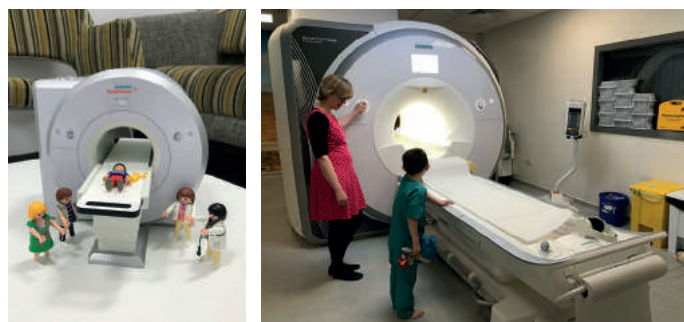
Claire Noonan, James’s mum, says:

**“When we were offered the chance for James to trial an MRI while awake, we were more than happy to take part.**

**Anything that reduces the number of times James has to be put to sleep for procedures and surgery means the world to us, as we all know it doesn’t get any easier when we see them go off to sleep and kiss them goodbye.**

**James loved the whole MRI awake experience. The playing beforehand, watching the movie, me getting to be with him throughout...**

**Everyone at the LGI has been amazing where James’ care is concerned, we cannot thank you all enough!”**







## Looking ahead

I am writing these words in very challenging times for us all due to the impact of the COVID-19 pandemic, but thrilled to see this, our third Social Impact Report and the difference the charity made in 2019. And as the “1 in 100” statistic of new-borns with congenital heart disease continues to bring poorly new-born babies to the Unit, our positive mission and vision outlined in this report will carry on making the best use of your much-valued fundraising support.

Like most other organisations, CHSF has experienced huge changes as the pandemic has brought significant challenges to how the charity would typically operate. Our usual ways of fundraising, particularly within the community and CHSF events, have been massively disrupted.

Following the successful models of the Virtual 10k and Superhero Walk from 2020, we will continue virtual events in the immediate future, and we trust your support will be undiminished into 2021. We thank you in advance for this.

We have had to cut costs and will be moving offices in the near future – which will see us move closer to the Children’s Hospital. This is not only to save money but is reflecting the huge shift towards home-based working. More details on this to follow.

Whilst we were on the verge of significant growth within the CHSF team before lockdown, we have had to pause our plans for the time being, which will give us time

to reset. That said, we are still pressing ahead with the delivery of additional support for families. This means we will have a dedicated person starting with us shortly, who will focus on the needs of our beneficiaries.

We have adapted to work in a different way, as no doubt you have, and digital marketing has become very much a focal point. The investment in a new database last year had led to cultural changes within CHSF, meaning we can give supporters much more targeted updates in the future and use our data more strategically.

Please join us at [chsf.org.uk/stay-updated](https://chsf.org.uk/stay-updated) to ensure we have your latest marketing preferences. Your fundraising and donations will continue to fund the most important projects within the Leeds Congenital Heart Unit and carry on the delivery of the expanded programme of services for families introduced in 2019. We would love to keep you informed of all our progress!

## Thank you...

for supporting Children’s Heart Surgery Fund, as we continue our aim to support the Leeds Congenital Heart Unit becoming a world-class centre of excellence. I must pay tribute to the ceaseless work of the NHS staff at the very centre of our specialty who save lives on a daily basis, but without you, and your generous support, we simply would not survive.

**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  
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