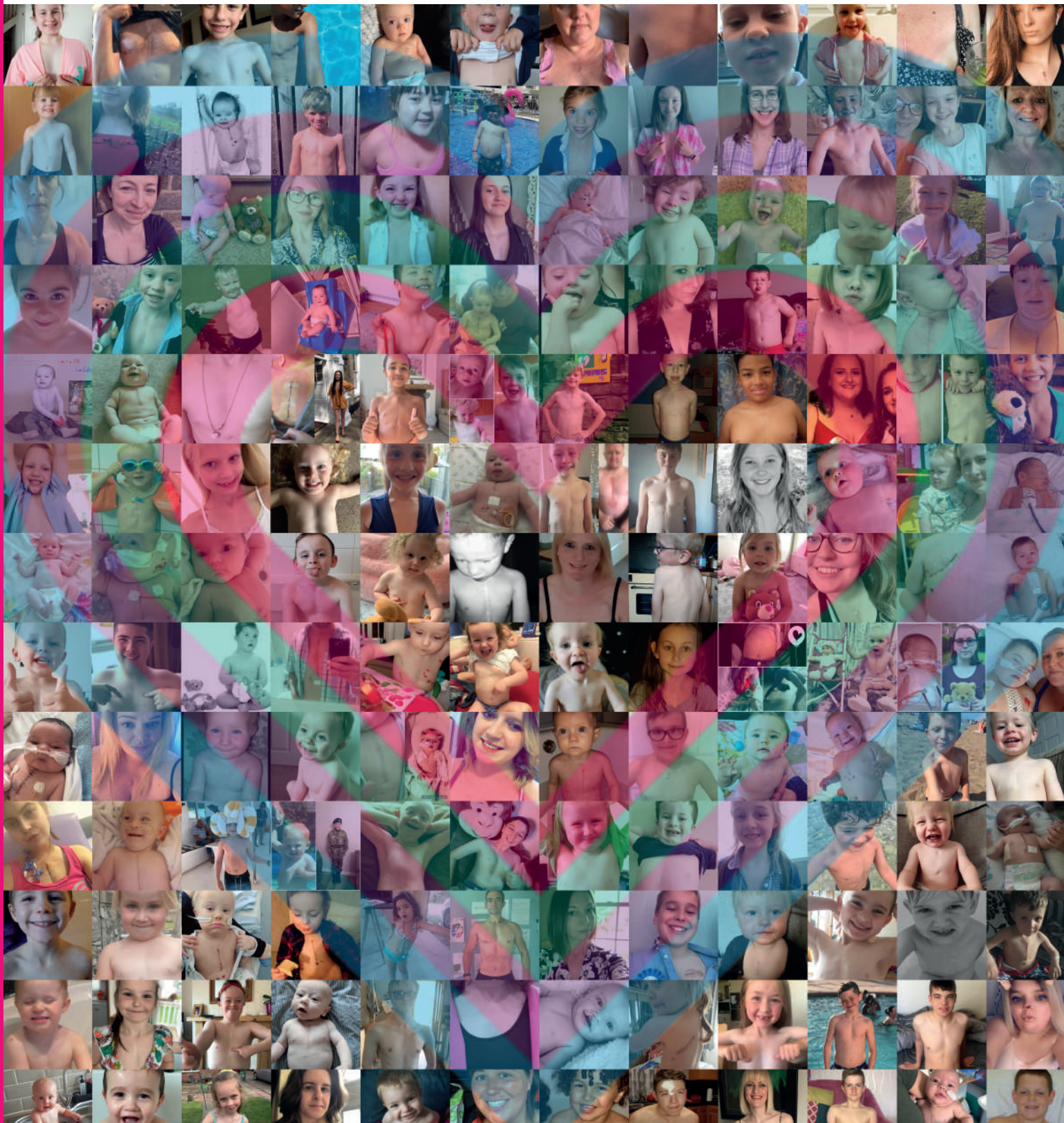




CHILDREN'S
HEART SURGERY
FUND

Social Impact Report 2018 and 2019

Because of You



Welcome



Sharon Milner, CEO

We are incredibly proud of the impact we have made through our charitable projects and the recent rapid development of our organisation. But we are conscious there is so much more for us to do. We have ambitious plans to continue our growth and have developed a new three year strategy so we can deliver a more significant impact.

Last year we recognised the need to improve our systems, including our data collection, as we recognise how important it is to have all our information in one place, using one system. This is vital in managing our growth and is enabling us to work in a more streamlined and collaborative way.

The hugely successful Keeping the Beat appeal has supported a revolutionary new hybrid children's heart theatre. This specialist cardiac surgical facility will help Leeds to remain at the forefront of paediatric cardiac care and ensure that the Leeds Congenital Heart Unit will continue to provide excellent care to babies and children for generations to come.

We hope you will find this an interesting and insightful read, and we want to take the opportunity to thank all our supporters for their contributions and continued support - without you we simply wouldn't exist.



Andy Chilton, Chair of Trustees

I have been a Trustee and Chairperson of this amazing charity for over five years, which has been a most rewarding experience. I'm so proud to be a part of CHSF and even prouder of what it achieves.

With greater demands on the NHS and therefore the charity, our strategy is to ensure we can meet the growing needs of the Leeds Congenital Heart Unit as effectively as we possibly can.

Monitoring our impact is critical to ensuring we continue to grow, and I'm delighted to see this report expresses our achievements in 2018/19. Reading the inspiring feedback from clinicians, patients and supporters shows how we are making a huge difference to so many lives.

Please continue your incredible support for patients of all ages with congenital heart disease and their families. You are literally saving lives and making those affected healthier and happier. Thank you.



Dickie Bird OBE, Ambassador

I can't think of a better use of my money than helping babies and children in my home county who need heart surgery to survive. Every time I visit the heart ward, I'm humbled to meet youngsters and their families facing the huge battles ahead with smiles on their faces. Their incredible bravery underlines why everyone should get behind this tremendous cause.



CHILDREN'S HEART SURGERY FUND



Our charity...

was established in 1988 to support Leeds Congenital Heart Unit. Over its 30-year history, Children's Heart Surgery Fund (CHSF) has awarded more than seven million pounds in hundreds of grants to the Unit, its patients and their families.



Our cause...

is congenital heart disease (CHD) – the most common form of birth defect in humans. CHD affects 1 in 100 babies worldwide, with about 12 affected babies born each day in the UK. It is on the increase and more than 40% of patients face a lifetime of treatment as their condition is incurable.



Our vision...

is to support hearts for life. Everything we do is designed to support more than 22,500 babies, children and adults with congenital heart disease across Yorkshire and North Lincolnshire.



Our values...

are Trust, Compassion, Openness, Respect and Dedication.



Our mission...

is to make the Leeds Congenital Heart Unit a world-class centre of excellence by providing the funding and resources needed to care for a patient's **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

#BecauseofYou

30 Years of Children's Heart Surgery Fund

In 2018, Children's Heart Surgery Fund celebrated 30 years of supporting the Leeds Congenital Heart Unit (LCHU). From clinical staff to patients and fundraisers – it's all **Because of You**.

1988



1988

CHSF started by surgeon Duncan Walker at Killingbeck Hospital, Leeds with the motto "Each Child a Childhood".



1989

The first big fund donation enables a new **Paediatric Intensive Care Unit** theatre to be built.



1997

Killingbeck site closes (charity moves to Brotherton Wing Old People's Home).



2007

Sharon Milner joins as CEO.



2010

CHSF begins pledging money to "home from home" Eckersley House to help the parents of CHD patients stay on site. Because of You, that amount is now nearly £400k.



2011

Save Our Surgery (SOS) Ltd is set up to fight the closure of LCHU.



2012

CHSF launches BraveHearts magazine, and a special edition follows to promote the fight to "Save Our Surgery".



2013

SOS campaign wins legal battle for LCHU to stay open.



2014

Wear Red Day launches as an annual event – it was created by a parent supporter to raise money for the SOS court case.



2014

Charity moves to **Brotherton Wing**, opposite Millennium Square.



2016

Keeping the Beat campaign launches, and reaches £500,000 target two years later Because of You!



2017

LCHU gets the official green light to stay open from NHS England! Also, Katie Bear Goes to Hospital, an interactive book for young CHD patients launches.

2018



2018

CHSF celebrates 30-year anniversary with ambassador Dickie Bird OBE and moves to 3 Oxford Place, Leeds.

2019



Following the successful Keeping the Beat appeal, the new state-of-the art **hybrid children's heart theatre** is opened by HRH The Countess of Wessex.



Our impact in 2018 and 2019

The Leeds Congenital Heart Unit has a deserved reputation as one of the foremost centres for the treatment of congenital heart disease in the UK.

With the equipment, research, clinical posts and revolutionary projects CHSF funds, we are enabling the Leeds Congenital Heart Unit to improve care and outcomes for patients, and develop into a world-class centre of excellence.

This report focuses on CHSF's four key areas of work; caring for the **heart**, the **mind**, the **family** and the **future** during 2018 and 2019.

The difference we have made to the Leeds Congenital Heart Unit, its patients and their families since 2018 has been evidenced through:

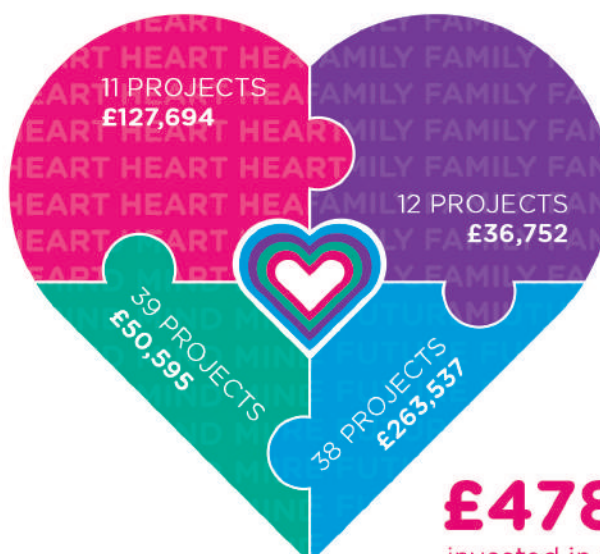
- CHSF's internal evaluation, reports and case studies.
- Reports and feedback from clinicians, children, parents and their families.

The figures we report relate to CHSF's 2018 financial year (January - December 2018). Figures for 2019 will feature in the 2019 and 2020 Social Impact Report.

congenital heart disease in our region



LEEDS CONGENITAL
HEART UNIT treated
22,588
babies, children
and adults in 2018
697 418
INTERVENTIONAL
PROCEDURES SURGERIES



a total of
£478,578
invested in 100 projects

Keeping the Beat: A New Children's Heart Theatre

We awarded a total of £1,877,187 towards a state-of-the-art children's heart theatre at Leeds Children's Hospital, which opened in March 2019. Because of your support, this included £500,000 raised through the Keeping the Beat appeal.

This cardiac hybrid theatre allows cardiac surgeons and cardiologists to perform surgery at the same time. This means the skills of both specialists can be employed together, reducing treatment time for patients.

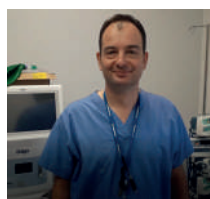
Miss Carin van Doorn, Head of Congenital Cardiac Surgery said:

"The new hybrid operating theatre allows surgeons and catheter specialists to work together during operations, which is particularly beneficial for complex and for high risk patients."

HRH The Countess of Wessex officially opened the theatre on 26 March 2019.

The first operations took place on 23 May 2019. The following day, Cardiac Anaesthetist Dr Carol Bodlani reported that:

"The staff absolutely love it and the children and their parents are all saying 'wow' when they go in to the theatre and are all so much more relaxed and happy".



An interview with Dr John Thomson, Lead Clinician for Congenital Cardiology:

What has the hybrid theatre enabled you to achieve that you couldn't before?

"We're now adjacent to all our other colleagues doing the technical and difficult work in children's heart surgery and catheter treatment, so we're next to the surgical teams. We are very close to the intensive care unit. We've already done a number of cases directly with our surgical colleagues where we've been able to bring our catheter skills and their surgical skills together – the hybrid cases.

We've treated a number of children, including the smallest child we've ever treated at 1.7 kilos who had a hybrid procedure. It's been really good to be together, and in a very specific environment designed for what we need to do.





Does the new hybrid theatre improve efficiency?

We're able to treat patients better. The equipment is already providing us with better images and allowing us to perform better treatments, as well as working with other groups of professionals to achieve the best possible outcomes.

Has it resulted in less invasive procedures, as predicted?

Yes it has. We're now able to do more procedures without necessarily having to open up patients' chests to get to the heart. We can do that in different ways. We've moved to treating smaller children with keyhole techniques using this equipment. These patients really are out of hospital quicker and that's a very important thing for us and for our patients.

Undoubtedly, the less invasive we are with treatment, i.e. you don't do a large open incision, then patients do recover quicker and get less post-operative pain.

The exposure to radiation is significantly less with this equipment because it's new and state of the art. The X-ray equipment like everything improves massively over time. Our previous catheter lab was over 10 years old and the X-ray doses were very much higher than they are now in this new lab. That's really important for growing people that are having treatments because you want to minimise exposure. So that makes a big difference.

And undoubtedly, we can do more complex procedures and certainly we have available to use more arrows in our quiver for treating patients with heart problems. We're able to choose different treatments that are available to us because of this equipment.

In what ways does the hybrid theatre help Leeds advance congenital care?

This is a very technical area of medicine. To be at the forefront and do anything that's new or better, requires a huge amount of high-end equipment and we've got that now.

We are able to treat more difficult patients and we are able to treat smaller patients, just as we hoped we would do at the beginning. I think that's really helping. It's helping the patients, but it's also helping us describe and improve some of these treatments that are used elsewhere in the country and the world as well.

What would you say to CHSF supporters who contributed to Keeping The Beat?

I'd like to say a really big thank you to all the supporters of Children's Heart Surgery Fund and the Heart Unit here in Leeds. The work and the fundraising you've done has really made a massive difference - this is a fantastic facility. And without the charity, and the work that you do to fund CHSF, we really couldn't make the difference that we are doing to patients with congenital heart disease."





**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.

“The truth is that the NHS struggles to fund the equipment to provide the care that the families of Yorkshire rightly expect and that is where CHSF has repeatedly and unfailingly stepped in. From equipment to perform keyhole procedures safely to machines to “print” 3D hearts so we can understand and treat them better – they have supported us year on year.”

- Dr John Thompson, Lead Clinician for Congenital Cardiology



Our support for the heart included:

3D Heart Printer

A 3D heart printer is providing valuable information in the treatment of patients, particularly those in complex cases. A model of a patient's heart can be created which helps clinicians to improve their understanding of the patient's anatomy and make decisions about the surgical approach.

The lead clinicians working with the printer have found it has surpassed their expectations and are genuinely excited by the opportunities it will bring for patients.

There was much interest around the first model that was generated. Dr Hamish Walker, Consultant at the Leeds Congenital Heart Unit said;

“Our first full model was received extremely well by the team and even those familiar with 3D models were surprised by how good the representation was. This particular model has also been used to impress visiting clinicians and potential future members of the team!”

Transportable Vapotherm Unit



Vapotherm is a device that helps children, particularly very small babies, to breathe more easily than they would ordinarily on their own. A new transportable Vapotherm Unit has given the team the ability to move babies who are dependent on these machines from the ward to other areas of the hospital for their procedures.

Cardiac Anaesthetist Dr Carol Bodlani said:

“This will benefit not only children with heart disease but also other children who are dependent on Vapotherm machines, to be transported around the hospital safely. Children will be able to stay in their familiar surroundings in the ward after most procedures. Having equipment like this improves theatre efficiency and can mean we offer operations to more children.”

**11 PROJECTS SUPPORTED • £127,694 INVESTED
22,588 BABIES, CHILDREN AND ADULTS BENEFITED**

Care for the Heart

Two Vein Viewer Flex machines

A Vein Viewer Flex uses infrared to show a patient's veins beneath the skin. This helps make the experience of blood tests or cannulas more positive for children and adults with heart conditions and reduces their anxiety.

The two Vein Viewer Flex machines funded by CHSF are improving the experiences of many heart patients and their families.

"The Vein Viewer has been a big help to us and our patients. Taking blood samples can be a difficult experience for some children, but the Vein Viewer helps to make the process quicker and easier. It also helps to distract the children who might otherwise be anxious. They love the neon green lights."

Sammy Slater, Phlebotomist, Karen Heany, Phlebotomist Team Leader and Fiona Ashworth, Phlebotomist.



25 Kardia mobile devices

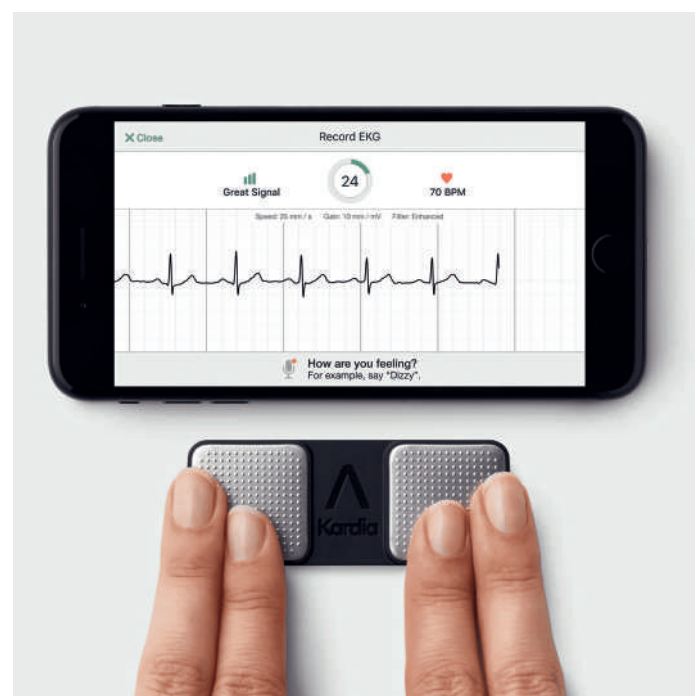
We have funded 25 new Kardia mobile devices. These devices attach to a patient's mobile phone and record an ECG (heart tracing). This is then sent to their cardiologist who can assess the reading to make a diagnosis and recommendations.

This has strong psychological benefits to the patient, who can feel in control of their own health and work in partnership with their cardiologist.

"I had a teenage boy who presented with troublesome episodes of palpitations, but he would only have symptoms every couple of weeks. So, despite us trying to catch his symptoms on a heart monitor this was never possible as we only had the option to fit him with a 24 hour, 48 hour or 7 day monitor."

We spent two years trying to diagnose his palpitations without success – until we managed to get an Alivecor Kardia device. The family attached this to their mobile phone, took it home and 4 months later we caught an episode of his palpitations. We were able to confirm his symptoms were being caused by an abnormally fast heart rate (Supraventricular Tachycardia or SVT). He has now undergone a procedure which should stop him having any further episodes of palpitations."

- Dr Claire Davidson, Consultant Paediatrician





Case Study: 3D Heart Printer

A female patient with congenital heart disease was the first patient to benefit from the 3D heart printer.

She had a known problem with the drainage of her right lung, caused by her heart defect. There were severe concerns about the feasibility of a surgical procedure – that it would be too risky and not effective – so she had not been operated on.

She was selected to have 3D heart models printed. The models produced allowed the surgical team examining them to have a better anatomical understanding of the defect. This has opened up new possibilities for the patient that were not there before.

The models gave the surgeons the confidence that the operation could take place and the defect corrected, thus improving the patient's long-term prognosis and quality of life.

The patient has now been approved for surgery, which will take place in autumn 2019.

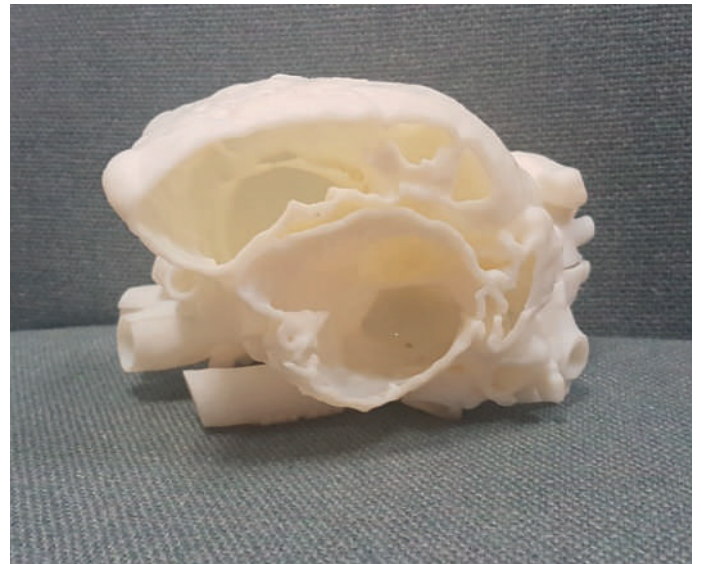
Dr Vitor Ramos, Consultant at the Leeds Congenital Heart Unit, said of the case:

“I think this is an excellent case to highlight how 3D printing can have a massive impact in the management of patients with congenital heart disease, especially patients that were denied interventions or surgeries due to being considered too risky or just inoperable.”

There are four other patients with similar conditions which result in abnormal drainage of the right lung. All have previously been assessed as too high risk for surgery but are now being considered for interventional procedures, conditional on the findings of their 3D heart models. For these models the team will be experimenting with colour printing and producing colour heart models.

Patients with complex cases will continue to benefit from this new 3D heart printer. The aim is to produce one heart model, which takes 6-8 hours of preparation, each week.

As well as helping the surgical teams, 3D heart models will be useful tools to help explain procedures to patients and enable them to understand more about their own heart conditions.





**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, positive ward environment for patients and their families. We provide play equipment in the playroom, with games consoles, DVDs, toys and craft resources, as well as our resident goldfish.

“The whole experience was quite emotional but had it not been for Children’s Heart Surgery Fund providing accommodation for us to stay in at the hospital and personal touches for Finley, such as little toys, sticker reward charts, blankets and so on, it could have been a traumatic time.” - Rachel Clayton

Our support for the mind included:

Katie Bears

We gave Katie Bears, medals and certificates to the 314 babies and children who had undergone heart surgery at the Leeds Congenital Heart Unit. We have found that having their own Katie Bear really makes a difference to children following a major and traumatic operation, soothing fear and anxiety and speeding recovery.



Music



Professional musicians from Brightside Music provided interactive music-making sessions for patients and families on the Children’s Cardiac Surgery Ward, Paediatric Intensive Care Unit and at Outpatients. They sang and played music to enhance the atmosphere

and offered patients and families the opportunity to get involved using a box of percussion instruments.

Their gift of music was a welcome distraction from hospital routines and procedures. It provided opportunities for creativity and self-expression and created positive experiences for patients and families.

“A little boy’s mother had to leave and he was distraught, crying and screaming. By chance the ladies from Brightside came in and started playing music. The boy stopped and listened. It was so lovely to see how he was distracted and was able to calm himself.”

- Mike Fresson, Children’s Cardiac Nurse Specialist

Visits to the Wards



As well as providing play equipment, we arrange for visitors to the wards to meet children and their families.

Zulfi Karim, the Deputy Lieutenant of West Yorkshire joined staff, patients with congenital heart disease and their families on the Children’s Cardiac Surgery Ward to help celebrate Eid on 5 June 2019.

Ward staff helped decorate the Ward with the patients and arranged Eid-themed games and activities including a star-filled piñata.

“I was thrilled to meet these inspirational young people and their families who are facing difficult challenges with courage and smiles on their faces.” - Zulfi Karim

**39 PROJECTS SUPPORTED • £50,595 INVESTED
22,588 BABIES, CHILDREN AND ADULTS BENEFITED**

Ronnie Cassels' Story

"We'll never forget the staff that helped us during that stressful and trying time."

We had just begun packing up to head home from Flamingo Land when Ronnie fell ill. I told Michelle (my wife) to phone an ambulance, while I performed CPR and asked Ryan (my eldest son) to go to reception and get first aiders with a defibrillator.

We lost count how many times the first aiders and then paramedics administered the defib. All that Michelle could say was "it's been too long." After this they managed to get Ronnie down the stairs, where they had to stop and start CPR again and get Ronnie good enough to go in the helicopter.

Thinking back, we were so very, very lucky that it happened where it did, as everything that helped save Ronnie was available. If it had been an hour later it could have been a lot worse, as we would have been driving back to our home in Scotland.

The consultants, doctors and nurses at Leeds were superb and very professional and kept us up to speed with what was happening with Ronnie. One that sticks in my mind is Mr Jaber, who sat us down and went through all the pros and cons of all the medical procedures being carried out.

We're all so grateful and indebted to the people who helped Ronnie get back to where he is just now. In 2019, Ronnie received runner-up for young sportsman of the year - sponsored by Disability Scotland."

- Steve Cassels, Father





Tracy Massey, Deputy Clinical Perfusion Manager said:

“Ronnie was put on ECMO (life support) as he had a very unstable rhythm and was unable to maintain his own cardiac output. The ECMO supports the circulation by having an external pump that can pump the blood if the heart is not capable. It provides a period of rest for the heart which gives it time to recover. This was an unusual situation in Leeds as we are not an ECMO referral centre so when we do put patients on ECMO they are usually post-surgery.

When Ronnie arrived, he was very seriously ill and it was unclear what had caused his arrest. Having the ECMO available allowed further investigations and a diagnosis to be made whilst his circulation was supported.

ECMO experience and understanding has increased significantly over recent years and it is being used successfully in a wider range of situations. Ronnie was one of these unusual patients.

We are very pleased to have been given funding by CHSF for the upgrade of our ECMO consoles and trolleys to the 2nd generation model. This means we have the latest equipment available to us to treat more children in the future.”



Congenital Cardiac Surgeon Mr Osama Jaber told us:

“Having this equipment available to support Ronnie’s heart not only allowed time for further investigations and a diagnosis to be made but also allowed a period of stability of his circulation for his weakened heart to recover. Without this technology, it is doubtful that he and other children with heart and/or lung failure would survive.”

Ronnie’s story demonstrates that equipment provided by CHSF supports the mind as well as the heart. The ECMO life-support machine stabilised Ronnie’s heart and kept him alive. During this respite, medical staff had the opportunity to undertake further analysis of Ronnie’s condition and the time to keep his family informed and supported during a period of extreme stress.





**Care for
the family**



Care for the Family



We support families practically and financially during their child's hospital stay so they can focus on supporting their child at what can be a stressful and upsetting time.

We award grants for travel and living expenses to ease the financial burden of traveling across Yorkshire and North Lincolnshire to visit a child. We also fund accommodation close to and within the hospital so that parents can rest while still remaining close to their sick child.

We offer an invaluable support network of thousands of fellow parents, patients and extended family members on our Facebook community group.

“CHSF has supported Tom on so many levels. We’ve spent many nights in accommodation supported by the charity. At every stage, equipment that has literally kept him alive was donated or funded by CHSF.”

- Steve and Jayne Hook

“We’ve stayed in accommodation, Alfie has played on the ward with toys provided by CHSF, and he has an INR home testing kit funded by the Charity.”

- Emma Brook

“When all of our attention needed to be focussed on Matilda, CHSF looked after everything else that allowed us to do this - thank you!”

- Sean Skippen

Our support for families comprised:

- Accommodation in seven family rooms on Brotherton Wing and support towards Eckersley House close to the hospital.
- A Superhero Walk and a Christmas Party – two events that brought heart children and families together to bond and share experiences.
- Food and travel expenses for families who had to travel across the region and stay away from home.
- Exceptional grants to help families cope that ranged from supermarket vouchers to theatre tickets.



507
families
directly benefited
from our services



accommodation
274 families



event & activities
175 families

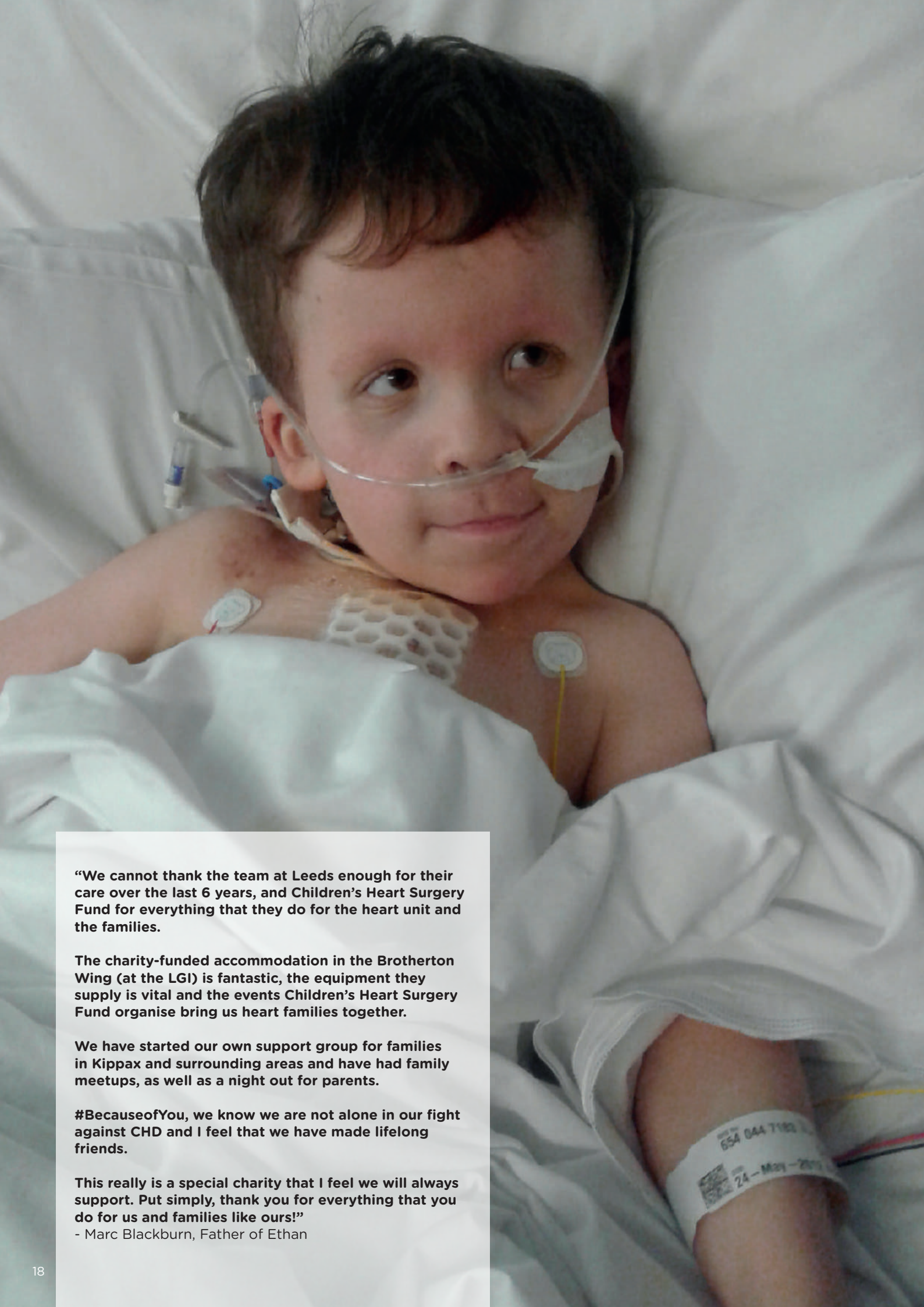


living expenses
30 families



exceptional grants
28 families

12 PROJECTS SUPPORTED • £36,752 INVESTED



"We cannot thank the team at Leeds enough for their care over the last 6 years, and Children's Heart Surgery Fund for everything that they do for the heart unit and the families.

The charity-funded accommodation in the Brotherton Wing (at the LGI) is fantastic, the equipment they supply is vital and the events Children's Heart Surgery Fund organise bring us heart families together.

We have started our own support group for families in Kippax and surrounding areas and have had family meetups, as well as a night out for parents.

#BecauseofYou, we know we are not alone in our fight against CHD and I feel that we have made lifelong friends.

This really is a special charity that I feel we will always support. Put simply, thank you for everything that you do for us and families like ours!"

- Marc Blackburn, Father of Ethan



Community Fundraising

“Just remember the reason you’re doing the fundraising; the smiles on these babies faces. Fundraising for CHSF not only saves the lives of these children but makes the process of it all substantially easier for parents at such a stressful time.”

- Steph Matu and Karen Jackson

In 2018, 119 families and their friends and colleagues across Yorkshire and North Lincolnshire fundraised for CHSF following the treatment of their children at the Leeds Congenital Heart Unit.

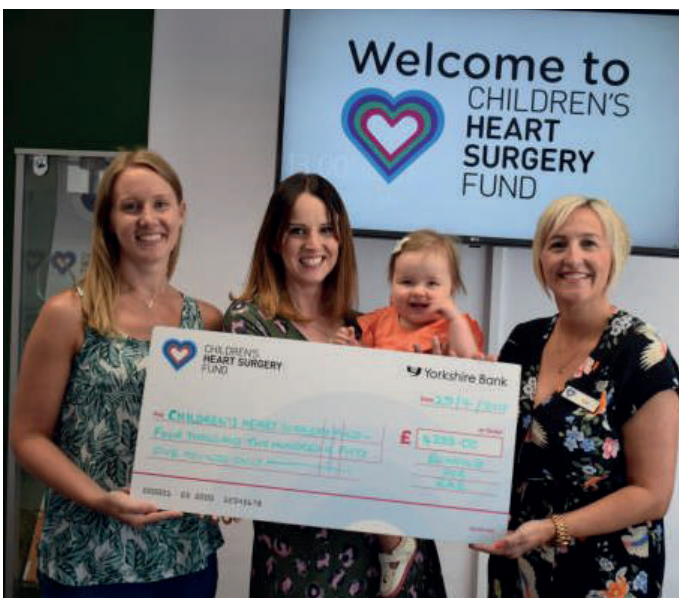
During the year they walked, baked, cycled, danced, skydived, played instruments, took photographs, held balls, dinners and parties, played football, raffled prizes, climbed mountains, drank coffee, celebrated birthdays, made crafts, cut their hair, packed supermarket bags and gave up chocolate to “give something back”.

“Thanks to the work of Children’s Heart Surgery Fund and the money raised by the charity we have had amazing support before, during and after Rae’s surgery. It was such a difficult time in all our lives and CHSF made this process a lot easier for us.

All of our hospital visits have been made better by CHSF. From toys in the waiting room for clinic appointments, to life-saving equipment and a place for parents to stay on the ward. Without the work that this charity does we would not have received this amazing support, right on our doorstep.

I wanted to raise money for this amazing charity so that they can continue to do their amazing work and help families like mine in the future.”

- Gina Vanni-Buckley





Care for
the future



Care for the Future



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, clinical posts and projects – and campaigning on the subject.

Thanks to our supporters, we have been able to approve millions of pounds of funding for all kinds of projects. From funding cutting-edge

equipment (such as in the new cardiac hybrid theatre featured on pages 6 and 7) to specific research projects, we are always looking to improve lives.

“I look at my past experiences as an opportunity to help and make a difference - this is my way of giving something back.”

- Tom Wilkinson, Patient, Fontan Exercise Programme

Our support for the future included:

Clinical Posts

In August 2018 Dr Helen Parry, one of five Adult Congenital Heart Disease Trainees in the UK, took up her new Clinical Fellow's post in Advanced Congenital Echocardiography (ultrasound scan of the heart).



Helen's aim is to improve the accuracy of the ultrasound assessment. This could help to avoid unnecessary tests and procedures and identify patients who would most benefit from intervention. This would contribute to the future development of the service at Leeds General Infirmary.

Helen said:

“I am excited about my research and imaging fellowship, I think it will be valuable in the progression of echocardiography in congenital heart disease here in Leeds. I am immensely grateful for the support from CHSF in making this possible.”

Professional Development

Emma Beaglehole, Specialist Physiotherapist within the Congenital Cardiology team, applied for funding to attend and present at a physiotherapy conference in Southampton. This gave her the opportunity to network and meet with her peers from around the country. She was able to share her knowledge and valuable experience of working within cardiology physiotherapy at the Leeds Congenital Heart Unit.

CHSF previously funded Emma's position at Leeds General Infirmary and she was fundamental to the Fontan Exercise Programme (page 22).



Care for the Future

Research

Over the past two years, CHSF funded an exercise programme for adults with a Fontan circulation, chiefly funding a physiotherapist one day a week to run the programme.

Some of the most complex forms of congenital heart disease are treated by surgically creating a Fontan circulation, in which blood does not go through the heart in order to get to the lungs. This means that blood flows to the lungs passively rather than being actively pumped. As a result, Fontan patients have significantly limited ability to exercise.

Existing research indicates that Fontan patients who take part in regular exercise have a greater capacity for physical exertion and a more efficient circulation. If they can maintain regular exercise there are likely to be major benefits to their health over time.

The exercise programme over the last two years has proven to support this research by producing clinically relevant outcomes benefiting patients physically and mentally. Feedback has been overwhelmingly positive and clinically meaningful improvements have been seen in exercise ability and quality of life.

Patients have reported:

"I feel much healthier and stronger in general. I find it very enjoyable and rewarding also and do think it's improved my overall well-being as well."

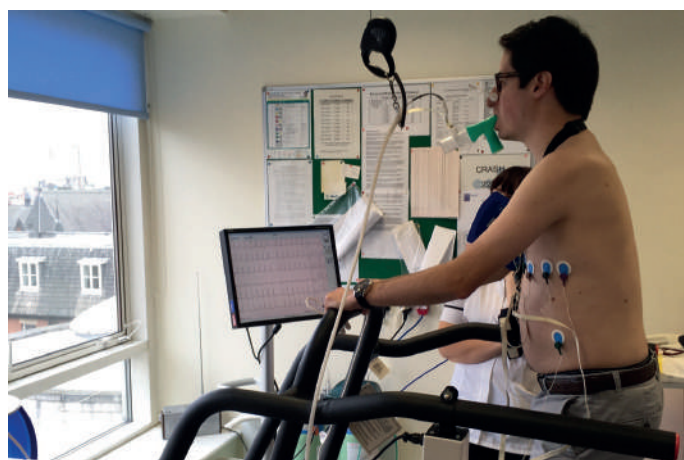
"I am constantly getting stronger and can see the improvement on a monthly basis as I push myself harder and increase the workload and rate."

All patients who successfully completed the full 12 months of physiotherapy intervention, demonstrated clinically significant improvements:

- Exercise tolerance as measured by an incremental step test improved by 138%
- Upper and lower limb muscle strength improved by 53%
- Exercise capacity in a cardiopulmonary exercise improved by 34%

Patient, Tom Wilkinson, who was treated at the Leeds Congenital Heart Unit in 1989, took part in the Fontan Exercise Programme. He said:

"Building knowledge for the future is hugely important. Those of us with heart conditions are in the unique position of being able to help develop more understanding of this complex organ."



The plan now is to take this service forward and use the benefits of what has been learnt and incorporate these into the service. This will include:

- Inviting patients who didn't take part in the research study to become involved.
- Running an annual education event.
- Reviewing assessment tools from the study.
- Creating individual programmes for patients.

"We are eternally grateful for the support of Children's Heart Surgery Fund which has enabled us to initiate this project so that we are now able to review the service and plan the future for our patients with a complex condition."

- Sarah Hibbert, Specialist Physiotherapist in Adult and Children's Congenital Cardiology



Looking ahead

It's an exciting time for Children's Heart Surgery Fund. A new decade will bring an ambitious new approach to extending our support for families.

We believe it is vital we make a difference to the 'whole' family by providing the wrap-around care from the minute the patient and family step into the Hospital, to when they leave, and beyond.

We will start to develop our holistic offer in 2020, providing a holistic care programme for families. This will include welcome packs, holiday camps and complementary therapies.

We believe it is essential we give support to the heart patient, the parents and family members. We feel this will build their resilience and enable them to cope with the often long 'emotional' journey ahead of them.

We have strengthened our internal processes by changing our supporter database and upgrading our website. Now we are keen to utilise these systems to enhance and diversify our income streams. This will ensure we are sustainable for the future.

We aim to develop and improve our Digital Marketing strategy and are hoping to see a significant improvement in communication internally and externally. We plan to seek out new supporters, as well as to retain our excellent, committed supporters.

By streamlining and segmenting our data, we are hoping to give people what they want, not what we think they want.

We are excited and committed to enhancing all the four critical areas for Children's Heart Surgery Fund - the **heart**, the **mind**, the **family** and the **future**.

Thank you...

for supporting Children's Heart Surgery Fund, as we continue our aim to ensure the Leeds Congenital Heart Unit becomes a world-class centre of excellence. Without the generous donations of so many, we simply would not be able to make the considerable difference we make to health care and our families.

Sharon Milner CEO



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