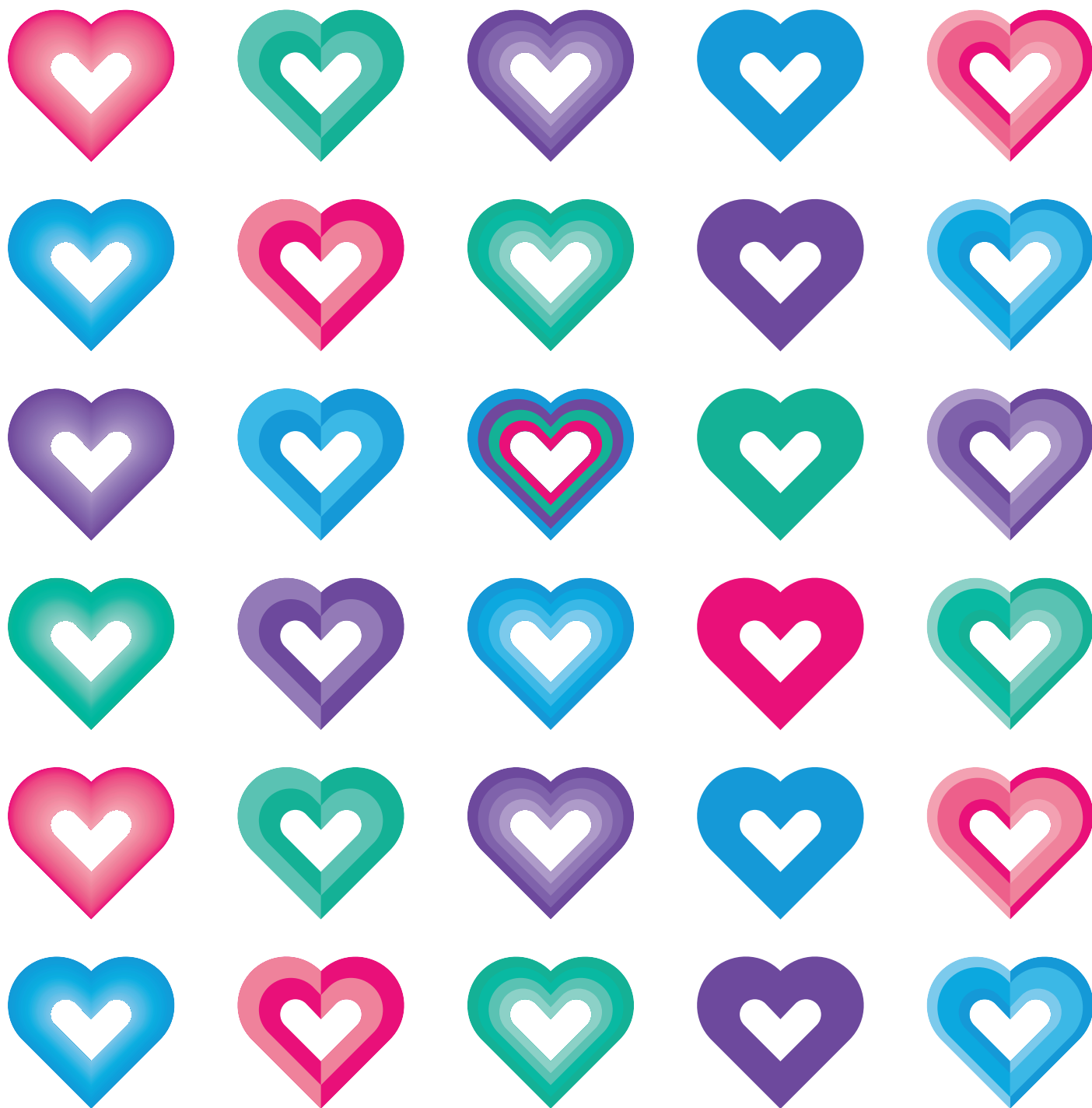


The difference we made:

Social Impact Report 2017



CHILDREN'S
HEART SURGERY
FUND

Supporting hearts for life.

Children's Heart Surgery Fund has helped achieve positive changes to the Leeds Congenital Heart Unit, resulting in improved quality of care for babies, children and adults affected by Congenital Heart Disease in Yorkshire and North Lincolnshire, and to their families' well-being. This impact report – our first ever – sets out our achievements over the last year.

Welcome



I am proud to present CHSF's first **Social Impact Report**. Doing so in our 30th Anniversary Year is particularly poignant. Our research shows that we are among the first charities in our niche sector to produce an impact report and we hope you find this an interesting and insightful read.

This report shows how far CHSF has come and represents a diverse range

of projects supported in 2017, segmented into four key areas: the Heart, the Mind, the Family, and the Future. These areas of focus demonstrate the clear, wrap-around support we offer to the LCHU, as well as the children and adults coming through the service, and the family unit.

CHSF has supported thousands of patients and families over the years, mainly through providing medical equipment. As the organisation has grown, so have the needs of the patients.

Assessing our impact brings together a whole host of information, helping us look at the bigger picture. It shows the positives, while still highlighting the areas we may wish to grow and improve.

Reading the Mitchelmore family's story, it is clear we can do more to take a holistic approach. A recent survey outlined the emotional journey the families that come through the service have undertaken. In the future, we would like to extend our service and keep supporting the whole family.

Looking to the future

Our aim is to help make the LCHU a world-class centre of excellence and we are confident we can achieve this.

As CHSF grows, we recognise we must improve the way we capture our data. This will provide even further insight into the needs of the LCHU, help us fully understand the people we support and also help us measure our impact in the future.

Sharon Milner, CEO



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**Care for
the heart**



**Care for
the mind**



**Care for
the family**



**Care for
the future**

ABBREVIATIONS

CHD - Congenital Heart Disease

LCHU - Leeds Congenital Heart Unit

LTHT - Leeds Teaching Hospitals Trust

CHSF - Children's Heart Surgery Fund

LGI - Leeds General Infirmary

PICU - Paediatric Intensive Care Unit



CHILDREN'S HEART SURGERY FUND

Who we are

Our charity was established in 1988 by Duncan Walker, then a heart surgeon at the old Killingbeck Hospital in Leeds. Due to his frustrations at the lack of funding within this specialty, Duncan felt compelled to create a charity to support the LCHU. Over its 30-year history, CHSF has awarded hundreds of grants to the unit, its patients and their families.

Our vision is to support hearts for life and our mission is to make the LCHU - now based at LGL - a world-class centre of excellence, by providing the funding and resources needed to care for a patient's Heart, Mind, Family and Future.

We have 11 trustees on our board; a combination of business people, medical staff and parents of children living with CHD. We conduct a skills review of the board every three years to ensure a variety of relevant experience. The Board meets every 10 weeks, as do our Finance and Fundraising sub-committees.

CHSF employs an enthusiastic bunch of 10 people passionate about the work the charity delivers. The overall aim of the team is to implement CHSF's work to support families and the LCHU - while adhering to our values...

Who we help

In 2017, approximately 17,680 babies, children and adults passed through the Congenital Heart Unit at LGL. They were all born with heart disease and about 40% of them face a lifetime of treatment and operations.

CHD occurs in 8-10 of every 1,000 live births and accounts for 25% of all birth defects. Although survival rates are currently over 98%, CHD remains the most common cause of death from a birth defect and is also on the increase.

In 2017, 464 of the patients treated at the Unit had open heart surgery, and around another 735 had interventional procedures - such as pacemakers, ablations, catheterisations or diagnosis:

2017	Surgical	Catheter Intervention	Catheter Diagnostic
Adult	121	192	81
Children	343	336	126
Totals	464	528	207
		1,199	

Supporting hearts for life.

Our values...

Trust

We deliver on our promises

Compassion

We pride ourselves on reliability, empathy and loyalty

Openness

We are approachable and inclusive in everything we do

Respect

We value and appreciate one another

Dedication

We always go the extra mile





Our impact in 2017

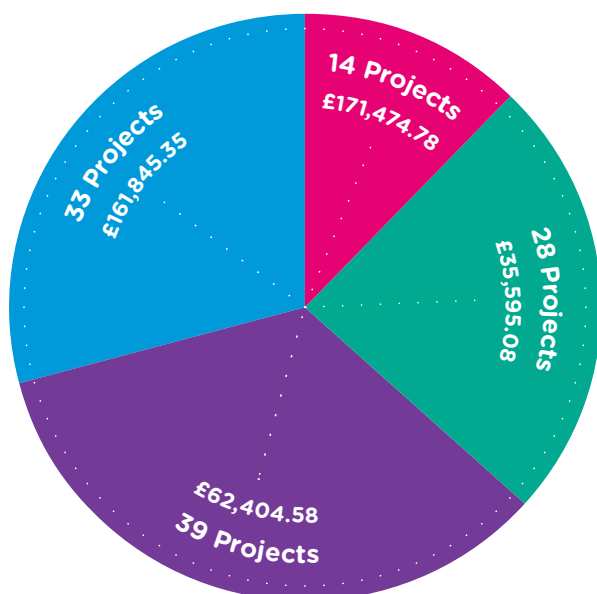
Summary

The LHT has a reputation and position as a leading UK centre for the treatment of CHD. Through our constant support over the last 30 years, we have helped maintain and enhance that reputation. We have funded state-of-the-art medical equipment, research, clinical posts and revolutionary projects. Our contributions have increased quality of patient care from womb to adulthood, allowing improved outcomes in the treatment of babies, children and adults with CHD.

Throughout our 30-year history, we have always evidenced the difference we make to the LCHU, its patients and their families. We publish case studies through various channels, including our quarterly magazine, *BraveHearts*, as well as through our website, blog, social media and the local, regional and national media. We also ask our stakeholders for feedback through questionnaires. With the constant growth of the charity, especially in the last few years, we felt it was time to publish our first Social Impact Report, making our regional charity a pioneer in measuring the difference made by local and regional organisations supporting CHD in the UK.

This report focuses on CHSF's four key areas of work; caring for **the Heart, the Mind, the Family and the Future**. We have divided our projects and activities into these four categories, although some overlap more than one area.

Children's Heart Surgery Fund's 4 Key areas - Awards in 2017



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 and 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

-  Care for the Heart
-  Care for the Mind
-  Care for the Family
-  Care for the Future

Total:
114 Projects
£431,319.79



Jessica Mitchelmore's Story



Jessica was born with a hole between the 2 lower chambers of her heart, which allowed blood to pass from the left to the right side of her heart. The oxygen-rich blood then got pumped back to her lungs instead of out to her body, causing Jessica's heart to work harder, and putting her at risk of lung disease, and other heart problems. Jessica's heart condition was detected when she was 7 months

old: she had a chest infection, and her GP heard a heart murmur. Jessica had to undergo open-heart surgery on 7th April 2017, aged 2, to correct her congenital heart disease, and allow her to have a normal life.

Jessica's mum, Jo, tells us about their experience and the impact Jessica's heart condition and surgery have had on the whole family:



Jessica was away from us in theatre for about 5 hours, after which we were able to see her in PICU. After this she was transferred to HDU (High Dependency Unit) on ward 51 and quickly back on to the main ward. The team were happy with the closure and although there was some fluid accumulation this was dealt with quickly and Jess was discharged home on 12th April, after 6 nights in hospital.

Jessica has now had her registrar check-up at which there were no concerns and has just had her consultant check-up, at which we were told that she doesn't need to be seen again for 12 months!

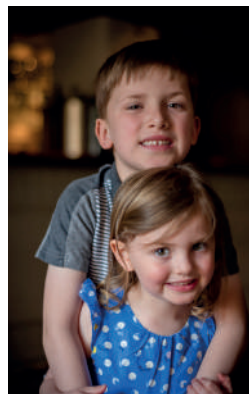
Although Jessica's heart condition is fairly simple compared to others, this has still had a massive impact on the whole family. The shock and concern at diagnosis, the never-ending worries and questions and the decision-making process have been incredibly challenging. Doing this and continuing daily life as a family, supporting Jess and our 6-year-old son Harry at the same time has been a constant challenge. We have felt like we are living our lives waiting, from one appointment to the next, from one decision to the next, from one phone call or letter to the next, and

then for a surgical date once this was agreed to be the best course of action. Waiting for the letter or call to give us a date was one of the hardest things, knowing we were on the cancellation list so everything could suddenly change if we got a call, putting everyone and everything else on hold because we just didn't know what was happening.

The stay in hospital was extremely challenging for all of us, and we are so proud of how Jessica coped with this experience, and how Harry took it all in his stride as well. For us there were lots of difficult moments, for example taking Jess to anaesthetic, waiting for "the call" to say she was ok and the surgery had gone well, crying when this call actually came, walking into PICU, sitting by her bedside through the night, supporting her as she woke and realised she was sore - all we could do was be there for her, by her side through it all. The amazing staff on ward 51 supported us all, they are truly wonderful. I will never forget being in anaesthetic, but when we walked out one of the fantastic nurses had a tissue ready to mop up the tears, and one of the fabulous play specialists had picked all our things up for us and followed us out. They know what is hard, they know when to help, and they know how to help. We can't thank them enough!



Harry has needed support as it has been so difficult



for him to understand what was happening and he was understandably worried about his sister. He has had support from the play specialists to understand this better and one of the nurses on ward 51 made him feel much more comfortable simply by explaining what she was doing when she did Jess's observations, and by involving him in this.

The practicalities of Jess being in LGI for 6 nights involved my parents and brother to care for Harry. Her surgery fell in the school holidays so he moved in with Nanny and Grandad for the week and had a great time - but we



had been liaising with school over arrangements should it be in term time.

The restrictions on what Jess has been able to do for 6 weeks following surgery have had an impact in me needing more support to get Harry to his activities etc. as I have been unable to take her with me. My husband has had to try and be locally based more often than normal and so on. When we have appointments for Jess we need friends or family to collect Harry from school, all small things but without the support of friends and family for such practical issues this experience would have been much harder.

Before surgery I thought CHSF funded a lot of the things that the NHS couldn't afford but that some may see as non-essential. I have changed that view following Jessica's surgery. The CHSF fund essential services and equipment without which the patient experience would be much less positive. Examples I can think of include:

The waiting room in outpatients - Jess loves playing there and is never distressed waiting for her appointments.

The fish tank on ward 51 - it gave Jess something she knew was on the ward and she knew she could go to see. She also loves to say hello and goodbye to the fish in outpatients.



The high chair on the ward - it sounds silly but it made a massive difference to her. When she was admitted for a non-cardiac issue she had to eat sat on our knee or in her cot, the provision of a highchair was so useful and

allowed us to achieve a little more normality for her. In addition, it was a highchair we could lift her in and out of easily, as we discovered when we got home that the one she usually used at home was impossible when unable to lift her under the arms (we were advised not to lift her under her arms for 6 weeks post-surgery).

Other equipment on ward 51 and 47 (PICU) - we were overwhelmed by how much was funded by the charity.

The reward stickers and prize trolley used by the play specialists - these made it such a different experience

for Jess and Harry - it made it fun, rewarding and they enjoyed being there. The toys used by the play therapists helped Jess loads and the play specialists are truly two very special people. We couldn't have got to where we are without them. Jess had to be sedated in November for a scan, now she just lies there with no upset at all. All thanks to the play specialists, and the preparation work and support they did with Jess and with us as a family.

The ward itself, the walls, the murals, the fact it feels less like a ward and friendlier than most.

The trolleys in HDU which the nurses use but which we could put Jess's personal things in - what a difference this makes.

CHSF Facebook pages - made us feel part of something, not as isolated.

Parent accommodation Brotherton Wing - thank you so much for allowing us both to stay in the hospital while Jess was in ICU and HDU. Although technically we are local, it still takes 30 minutes / an hour to get into Leeds and parked - we simply wouldn't have wanted to be this far away from her. What an amazing resource. The ability to have a shower and wash my hair made me feel human again after the day of her operation and staying in ICU till 4am.

Finally - **the Katie Bear, medal and certificate**. Jess loves hers, her certificate is proudly framed on her wall and she is very proud of her Katie Bear. We've even started referring to her scar as her Katie Bear scar.

Overall, what inspires us the most about CHSF is the fact we benefited so directly from equipment, accommodation, etc. We had outstanding psychological support before and during our stay in hospital and we hope that, with additional resources, the charity will soon be able to offer psychology support post-surgery for families suffering from post-traumatic stress disorder as a result of their experiences, for instance. Holistic care would also help families cope better while they are going through an extremely tough time. - Jo, Jessica's mum





**Care for
the heart**



Care for the Heart

One of the charity's main activities is to help the LCHU buy vital, innovative medical equipment that increases the quality of patient care and saves and improves lives. This funding embraces the ever-changing technologies needed to treat children and adults in this very complex field.

In 2017 we spent £171,474.78 supporting 14 projects to care for the Hearts of 17,680 patients.

Providing patients with a positive experience of care

The 320-360 patients who attend the paediatric and congenital clinics each week all have their observations, including blood pressure, taken. The charity funded new monitors that enable staff to record vital signs more quickly, improving patient comfort and overall patient experience. This is particularly important for children, who generally do not like having their blood pressure taken. The monitors also provide more accurate oxygen saturation readings and calculate Body Mass Index scores for adult congenital patients.

Detecting life-threatening conditions and saving lives

Eight families whose babies were born with a single ventricle can now constantly monitor their child's oxygen saturation from the comfort of their own home with a pulse oximeter funded by the charity. Shunt occlusion is a major cause of death in children with single ventricle and the monitor has the potential to detect some of the life-threatening shunt obstructions.

Working in collaboration with another heart charity, Tiny Tickers, we purchased 20 pulse oximetry machines, which have been placed in 10 different hospitals across the region to allow earlier detection of CHD at birth. The project is expected to show:

- Better survival rates for newborn babies battling chronic illnesses;
- Reduction on costs facing the NHS;
- Increase in NHS skills and capacity;
- Increase research into the area of CHD in babies.

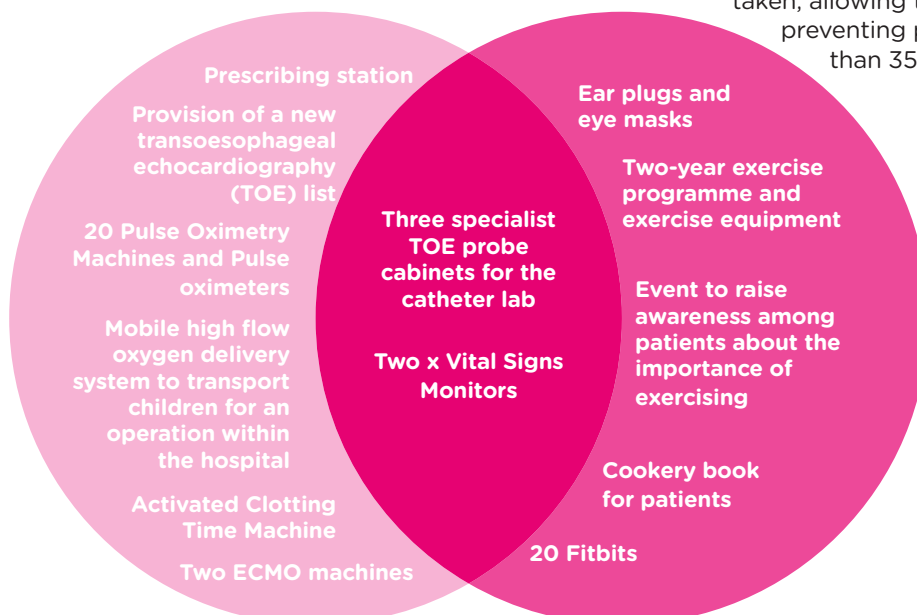


Despite advances in foetal diagnosis of CHD there are still a significant number of babies with severe problems which are not detected before delivery. We really welcome this initiative which will undoubtedly save lives.

- Dr Elspeth Brown, Lead Clinician, Yorkshire and Humber Congenital Heart Disease Network

ECMO machines are used to provide heart-lung bypass support on very sick children after an operation or complications outside of the young patient's body to help their heart and other organs recover. These machines reduce the risk of ongoing health problems and death. We bought two new ECMO machines, which have already saved nine lives.

Blood clotting during surgery can put young lives at risk and cause permanent damage to the brain and other organs. An ACT machine monitors blood clotting during heart surgery. We funded a revolutionary machine, which is quicker, more accurate, minimising the amount of blood taken, allowing to reduce doses of drugs given and preventing post-operative bleeding. No less than 350 patients use it in a year.



Children: £140,337.14

£11,300

Adults: £19,837.64



Care for the Heart

Helping the Unit become a world-class centre of excellence by improving the quality of care and developing the service.

The 716 babies and children (all conditions combined, and broken down as follows: 325 cardiac surgery, 48 cardiology and 343 non-cardiac) who were treated in PICU benefitted from better care thanks to the funding of a prescribing desk and iPads. Staff use these daily to prescribe medication accurately and access electronic resources to check drug dosages, interactions etc. Having this resource has had a positive impact on safety around medicines management since staff can be assured that all information is up to date as it is managed and updated centrally. The improved working environment has increased staff morale and allowed the service to meet standards required by NHS England.

Transoesophageal echocardiography (TOE) is a procedure to check the present condition of the heart and determine future treatment. Thanks to the refurbishment of an anaesthetic room in the catheter labs funded by the charity, the LCHU is now able to perform TOEs in a different room, which frees up the original room for other important procedures, thus reducing waiting lists and enhancing the service.

Encouraging exercising and healthy living programmes to enhance adult patients' health

By funding fitness equipment, activity trackers, staff training and informative events for patients for programmes developed by the Congenital Cardiology team, we are improving the health of 40 adults. These 2-year programmes are aimed at patients with different CHDs, and so far:

- All patients have increased their activity, which has led not only to improvement in their fitness and health, but also in their confidence;
- 20 patients born with a single ventricle have more effective circulation with the increased ability to exercise.

One patient's lifestyle has considerably improved thanks to a healthy cook book offered by the charity, and sleep on the wards has improved for around 60 patients thanks to ear plugs and eye masks, leading to a quicker and better recovery post-surgery.

A majority of respondents to our recent survey believe medical equipment is the key area the charity should concentrate on - here are a few of their comments:

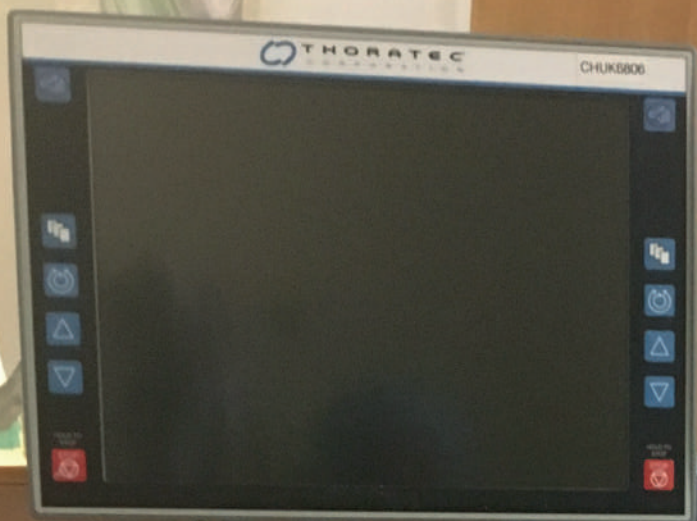


I will continue to be a supporter and think you all do a wonderful job in such difficult circumstances at a time the NHS is experiencing severe difficulties. - Parent



I am inspired by CHSF's continued support with the funding of equipment for the clinical areas that otherwise we would not be able to buy. - Clinician







**Care for
the mind**



Care for the Mind

Having to come to hospital is a daunting prospect and can cause anxiety for a lot of children. Regardless of why they are visiting, they are coming to an unfamiliar environment, unsure of who they are going to meet and what this 'doctor' is going to do to them.

These children also experience depression and anxiety at home, at school and in their day-to-day lives, when they feel different to everyone else and often have to sit out of sports and PE. As they grow up, children also become more aware of their conditions and might be worried about their future.

Studies show that anxiety has an impact on treatment and recovery, and on the children's health in the long term:



Preoperative anxiety in young children undergoing surgery is associated with a more painful postoperative recovery and a higher incidence of sleep and other problems. - American Academy of Pediatrics



In COPD patients, the presence of symptoms of anxiety and depression are common and have significant impacts that, adversely affect mortality rate, exacerbation rates, hospital length of stay, quality of life and functional status. - Journal of Thoracic Disease, Nov 2014

Although related to Chronic Obstructive Pulmonary Disease (COPD), this second study would also apply to all chronic health conditions.

Therefore, at CHSF, 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 and provide play and distraction equipment.

In 2017, we spent £35,595.08 supporting 28 different projects that benefited 10,000 babies and children.

Restful / Positive Environment - £2,706.71

- Improvement of spaces in fetal cardiology, outpatients and the ward

Play / Distraction Equipment - £17,383.31

- Storybook
- Reward stickers
- Fish Tank
- Teddy Bears and Medals
- DVD players and DVDs
- Projector lights for babies' stimulation
- Interactive movable touch screen Television
- Yorkshire Day and Christmas Parties on the ward
- Craft
- Toys and games
- Music sessions
- Video games

Patient Centred Care - £15,505

- Presents for long-term patients/birthdays
- Support for individual patients
- Four 3D Heart models
- Explanatory videos
- 30 INR Kits

Restful and positive environment

Part of CHSF's work is to ensure the children who come to hospital have the best possible experience. By making the wards and the outpatients areas welcoming and child-friendly, the charity helps reduce anxiety not only for the children, but for the whole family, including siblings.

In 2017, we supported five different projects to improve the hospital environment, including the refurbishment of the waiting area, counselling and scan rooms for Foetal Cardiology, improvements in the playroom/ waiting room in the outpatients' area of the hospital and in the parents' kitchen on the ward. This made the parents' stay in hospital easier, with a better use of the kitchen, a few steps away from their child's bedside. Providing better kitchen facilities helps these families save money by enabling them to heat meals on the ward instead of going out to eat. This also has an impact on the children's recovery, as studies show children recover quicker and better when they have their loved ones nearby to comfort and reassure them. When their safety and belonging needs are met, children's self-esteem increases, which in turn benefits their recovery.

Care for the Mind

Play and distraction equipment

There is no denying toys and entertainment in the hospital can bring sick children cheer and comfort in an unfamiliar place, and distraction from the fears they may have. Multiple studies have proven toys and entertainment can really make a difference in:

- soothing fear and anxiety;
- helping children cope with the unknown;
- helping hospital staff bond with children;
- motivating children to get better.



The management of anxiety in children leads to the best psychological and physiological response to surgery and better managing of their health. [...] Toys, by creating a positive mood in children, allow them to cope with hospital conditions. - Fatemeh Ghabeli, medical researcher

The effects are not just psychological and therapeutic: play has been proven to reduce the physical symptoms of anxiety as well. Going through a medical procedure is a venture into the unknown even for adults. For children, it is even more intimidating. Nurses and play specialists use toys and entertainment as diversion and distraction therapy, which give children the positive mindset they need to achieve healing and help with treatment and recovery.

Play and distraction equipment is CHSF's biggest expense in caring for the Mind, with 20 different projects supported in 2017, such as:

- **Katie Bear goes to hospital - a guidebook for children having heart surgery and their families**

The storybook is designed for children about to undergo open-heart surgery at the LCHU. The charity's much-loved mascot and her friends and family take the readers through everything to expect before, during and after the operation. Supported by psychologists and specialist nurses at the unit, the guidebook aids the work they are doing towards making children feel well informed and included in their care, which goes a long way to relieving some of the anxiety felt by both parent and child.



The specialist nurses have already distributed approximately 100 copies of 'Katie Bear Goes to Hospital'. Families have commented on what an excellent idea it is, and how it helps not only their sick child before coming to stay in hospital, but also the whole family. Some parents have even said their child took the book to school, and it helped teachers and other children understand too.

Ethan is about to undergo his second open-heart surgery. He had his first operation when he was a baby. Now he is five, his dad has told us how useful he finds the book in helping Ethan understand what is exactly going to happen when he comes to the ward. He recognised Katie Bear in it and is fascinated by the book. He understands a lot through the pictures alone, and asks a lot of questions. These are questions triggered by the book, that he probably would not have asked otherwise, and the answers put Ethan's mind at rest.

• Reward stickers

They encourage children to have necessary tests and treatment done, eat and drink more, etc., with the incentive of a small present from the rewards box after 6 stickers on their chart. Some children are keen to know when they will next have the chance to get a sticker! It is amazing to witness the impact of such a small and easy token on the 805 children who stayed on the paediatric ward last year.





- **Toys, games and devices for different age groups**



Last year, CHSF supported eight different projects ranging from sensory toys for babies, to game consoles and games for teenagers with limited mobility.

These games help provide a distraction and stimulation, avoid boredom and facilitate recovery. Some games also encourage children's mobility, which is instrumental in preventing post-operative complications.

The new interactive TV on the ward is proving very popular. It is a touch screen, wireless TV, so patients and families can play games, use it like a giant colouring book and draw on the screen or browse the Internet. It is a fabulous distraction and great for physiotherapy for patients who need targeted exercise. Not only does it entertain young patients and their parents, but it also encourages mobility after their operation. A fish tank, funded by the charity, has a similar impact for younger children.



The wireless TV is a fantastic piece of kit, allowing us to entertain patients, especially if they are likely to be on the ward for a while. It can help to get patients up and out of bed and moving after surgery which is key to the road to recovery. - Sarah Holroyd, Ward Sister

- **Katie Bears, certificate and medals**

We give a Katie Bear, medal and certificate to children who have had open-heart surgery to reward them for their bravery, lift their spirits and to provide them with a lifelong keepsake, which is also hugely beneficial for future visits to hospital. Parents tell us the teddy bear is an excellent way to explain to children who had surgery when they were babies all they have been through, and older children like taking their Katie Bear to nursery or school to explain their operation and heart condition

to their friends and teachers. The soft toy gives them a sense of belonging and reassures them.



The bears are a wonderful thing to be given, not only for the children, but for the parents too! I remember watching another child receiving their bear and thinking 'when Albie gets his it means he will have completed his surgery'. It was almost something to look forward to, another hospital milestone. Albie loves his bear and we have talked to him about how special Katie Bear is and why he has her. It's something I know he will treasure when he is older. - Freya Carroll, mum to three-year-old Albie



My Katie bear is amazing because she comforted me when I had my surgeries. She is nice to cuddle because she is so soft. She is special because she is the mascot for all the children like me who have poorly hearts. I will keep her forever because she is so special! - Georgia, 12 years old, heart patient

- **Parties, music and craft activities**



These activities benefit everyone, from patients and families to staff too. Their objective is to bring back normality to the ward and celebrate events the same as they are outside of the hospital environment.

For example in 2017, we funded a Christmas party and treasure hunt on the ward, which had a positive impact on everyone's morale. Music sessions and craft activities are also therapeutic for children and adults.



Care for the Mind

Patient-centred care

Children's physical and mental health improve when they are made to feel special, and when they feel involved in their own care.

- **Making patients feel special**

Gifts tailored to each individual have a positive impact on children, and we helped six children feel special in 2017:

- three birthday presents;
- one good luck present before moving to a different hospital for a long-term treatment;
- one gift as a reward for a heart patient with additional needs who was very scared about coming into hospital;
- funding for a young lady, aged 16, who was born with heart disease and needed an electric adjustable bed at home:

Ebony, 16, was born with heart disease. She has had to undergo several surgeries and procedures to correct her defects, and will need more in the future. She has a pacemaker, and also suffers from chronic pain, due to Scoliosis she developed five years ago, and for which she has had to have another major operation. As a consequence, Ebony suffers from severe depression and has hardly attended school for the past five years. More recently, she has had to have a nasogastric tube fitted to help her gain weight.



The electric adjustable bed has made a considerable difference in Ebony's life: it is very comfortable, helps relieve her back pain and she sleeps a lot better, which

is having a major impact on her health. It is also much easier for her to be fed through the tube, as she can easily adjust the bed at 45 degrees. Ebony's mum, has commented on the benefits of making Ebony feel more independent, not relying on her mum to put her in a more comfortable position, or at the right angle to use the nasogastric tube.

- **Equipment to help patients understand their conditions**

Thanks to 3D heart models and explanatory videos provided by the charity, patients and their families have a better understanding of their condition when they attend clinics. The hearts are also used by clinicians during meetings, or for training purposes.



I think that visualising where the defect is within the heart with the aid of the 3D model makes it so much easier for professionals and patients to explain and understand the effect that the defect has and possible options for treatment. - Sam Bainbridge, Congenital Cardiac Sonographer

- **INR Kits**

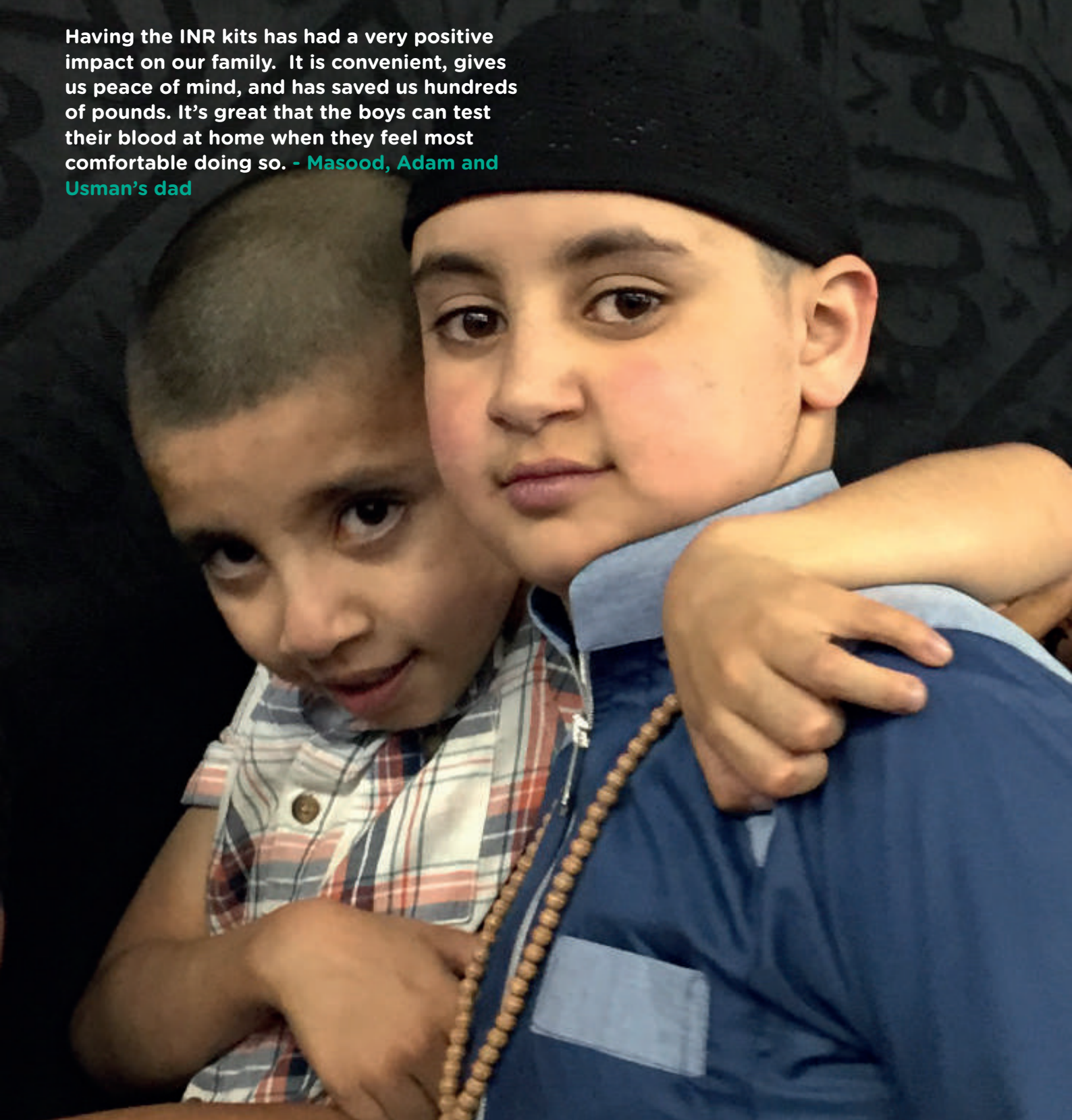
An INR self-testing kit is a vital piece of medical equipment that tests the coagulation of a patient's blood, with the aim of reducing the risk of stroke. Some children and adults need to be on anticoagulation drugs for life. This kit gives them more control over their condition as it enables them to self-test, or test with a parent's help, at home and phone in the results. Feeling in control of their own condition is psychologically beneficial to a patient. On average, the INR self-testing kit prevents children from missing twenty days of school and saves parents £200 each year. This is before any additional trips to hospital are factored in, such as for surgery and regular check-ups. The INR kit also keeps families together at home, allowing them to continue their lives as normal as possible.

These kits are not available on the NHS in the UK and never have been; they cost £299 each. They are not deemed to be a necessity as there is the option for children to come into the hospital to have their blood tested. However, the benefit of the kits is invaluable, which is why we offered them to 25 families in 2017.

Adam and Usman are two brothers from Bradford. They both have CHD and both own an INR Kit:



Having the INR kits has had a very positive impact on our family. It is convenient, gives us peace of mind, and has saved us hundreds of pounds. It's great that the boys can test their blood at home when they feel most comfortable doing so. - Masood, Adam and Usman's dad





**Care for
the family**



Care for the Family

Seeing a loved one in hospital is never easy, particularly if they are very young. We do everything we can to support families practically and financially during their child's hospital stay. We also provide an invaluable support network of thousands of fellow parents, patients and extended family members.

In 2017, we spent £62,404.58 supporting at least 483 families.

Practical and financial support

Helping families financially and practically has a considerable impact on their well-being. Living with a child with a heart condition can be emotionally very difficult at times, and especially when the child is admitted to hospital for treatment or for surgery. By alleviating financial and practical burdens, we relieve some of the pressure on the families, allowing them to concentrate on their child's needs, which in turn has an impact on the child's treatment, recovery and well-being.

Supporters commented in a survey we conducted in January 2018:



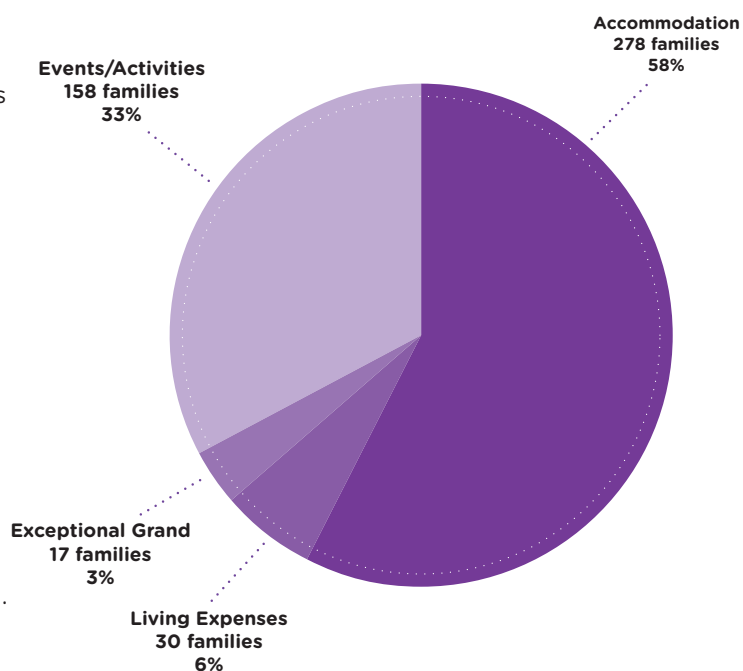
My grandson was born with transposition of the great arteries and was very well cared for and also if it wasn't for the parent accommodation and support I don't know how my daughter could have coped.

I think it's such a good idea to look after families free of charge when they're most in need.

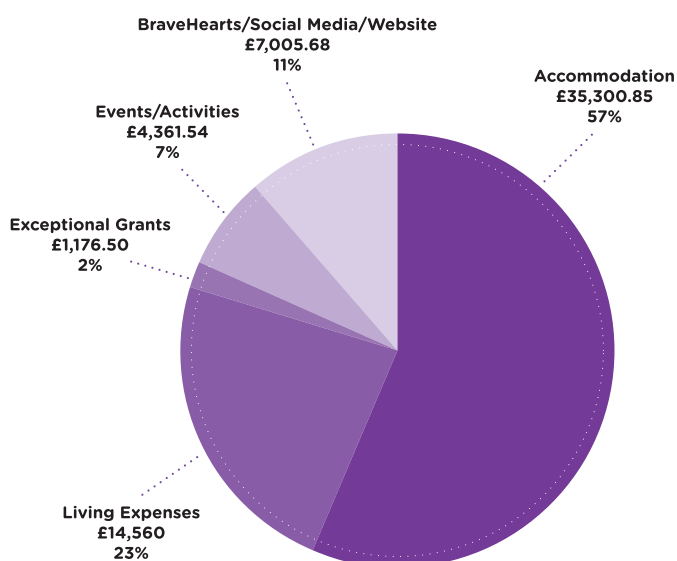
Our stay at the LGI was very comfortable.

The support the charity gives to families finding themselves in a desperate situation is inspiring.

483 families helped *



Finances = £62,404.58



*These are the families we helped directly. We know there are others who benefit from our online and printed materials and engaging with us through social media. We also know it is difficult to record all the families who stay in our accommodation due to the urgency of some situations.

Care for the Family

Practical and financial support

Accommodation

Providing somewhere to stay close to the hospital so parents can get some much-needed rest, knowing they are still close to their child.



- Seven family rooms on Brotherton Wing, Leeds General Infirmary
- Support of refurbishment and running costs of Eckersley House, a home from home close to the hospital, that supports families of sick children being treated at Leeds General Infirmary.
- Hotel room for two families

Living Expenses

Helping families meet the financial burden of travelling across Yorkshire and staying away from home while their loved one is in hospital. We donate £70 per week to families, mainly for food and travel expenses. Families who benefited in 2017 stayed in hospital between one to 18 weeks.



Exceptional Grants

- 10 supermarket vouchers for patients and families
- Three taxi fares
- Travel expenses for the family of a patient moved to a London Hospital
- Loss of salary for a self-employed dad
- Reimbursement of parking fees



Well-being

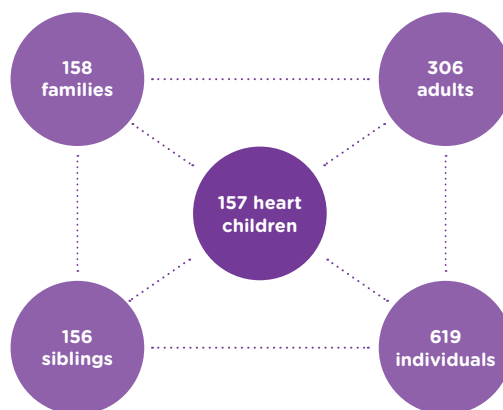
We provide exceptional grants to help families cope. Our main support is to give them a sense of belonging to a community; we aim to help them realise they are not facing CHD alone. This helps reduce stress and improve their ability to cope with their daily lives as normally as possible.

Events / Activities

In 2017, CHSF paid for cinema tickets for two families whose children stayed in hospital a long time. We also funded a gym membership for a dad. These all contributed to boost the families' morale.

The charity also organised three events aimed at getting heart children and heart families together: an Easter Hunt, a Superhero Walk and a Christmas Party. Such events allow families from the whole region to meet and exchange stories. They provide a sense of belonging and our supporters often refer to 'their heart family'. It is also a nice way for siblings to meet other siblings, and to exchange their experience of living with a poorly brother or sister. Research consistently shows that there can be adverse effects to growing up with a sibling with a chronic health condition. The brothers and sisters of children with CHD not only witness the impact of medical procedures, surgery and hospitalisation on their sibling but they also have to adapt to a number of family changes, which can impact them both directly and indirectly. A key direct change is time and the lengthy periods parents spend in hospital with their child causing the family to be separated. Events such as the Christmas Party brings all the family back together again.

Here are the number of people we helped in 2017 through our events:



Our charity events also have a positive impact on helping families deal with bereavement, which was the case for one family in 2017



- **BraveHearts, Website, Blog, Facebook Group**

Reading stories in our quarterly magazine, on our website, blog and on our Facebook Group gives families hope, particularly when they read about the achievements of older patients with the same condition as their child.

Our Facebook community group has over 5,000 members. It is a platform where parents can ask questions (e.g.: “what’s the best travel insurance?”, “What should I bring to come to the ward?”, “I’ve just found out my unborn baby has a heart condition; has anyone in the group got any experience?”, etc.), They can share their child’s inspiring milestones, and get in contact with some families from the same area.

Here are examples of comments from parents about our BraveHearts magazine:



BraveHearts is important to me because it enables my daughter to feel connected with and read about children who are going through or have gone through similar situations. It encourages her to embrace her differences, become more aware of her condition and realise she isn’t alone.

Bravehearts is important to me because we can share each other’s stories, gaining further insight into each other’s experiences and journeys. It’s also great to see celebration of successes and people coming together for all those with CHD. It’s a great source of information to our services and fundraising. I’ve found it particularly helpful in helping our family understand better. More importantly it helps patients and families feel less alone in their journey.

- **Fundraising**

Most of our supporters start fundraising for us because of their experience of the LCHU. These include:

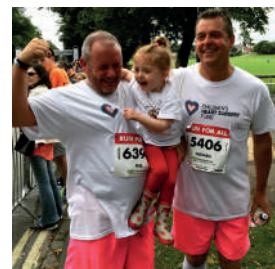
- Parents;
- Friends and families;
- Parents’ workplace.

In 2017, 112 families organised their own fundraising events, and 88 participants from family support took part in CHSF’s running/ challenges events and raised money for the charity.

Fundraising is a way for them to give back and cope with their child’s heart condition.



We enjoy fundraising as we feel it helps us give something back to a charity that has given us so much. It’s a practical way to feel like we are helping others who find themselves in a similar situation. Fundraising does act as a sort of therapy for me as I am able to get to know other families who have been through the same as us, it helps normalise such an extreme situation. I have made lots of friends through fundraising and that support is invaluable. Also, it gives us something positive to focus on. Even though we know our son is waiting for surgery we use different events and activities as something to focus our minds, the positives rather than the negatives.



We know people are inspired by the fact CHSF does not only help the sick child, but the whole family. A mum’s quote from our survey sums it all up:



They help ease the stresses of your child having heart surgery, providing accommodation, so much to the ward, tellies, beds, machines, equipment, etc. SO MUCH! That all helps our heart warriors get better. They have also given us lots of fun memories, Superhero fun day, Christmas parties, the flight with Santa. They have also inspired Isabella’s brothers to fundraise because they know and understand all that CHSF do, and by inspiring her young brothers have made them see it’s so good to ‘give back’ and ‘help people’ inspiring them to be selfless caring little boys.



If we refer to Maslow’s Hierarchy of Needs, if their basic and psychological needs are fulfilled, people can then achieve their full potential. For us, this translates by offering holistic care to families:





Care for
the future



Care for the Future

Techniques and technologies are constantly changing, so we make sure we are always aware of what is happening next in the world of CHD by funding research, clinical posts and projects. In 2017, we supported 33 projects caring for the future, at a total cost of £161,845.35.

Development of the service

- Telemedicine link between the Neonatal Unit at Bradford Royal Infirmary and the Paediatric Cardiology Department at Leeds General Infirmary.
- Probes and software for the cardiac ultrasound system to enable patients to be scanned with the latest technology.

Clinical Posts

- Year long fellowship post in Paediatric Cardiology.
- Funding of a Band 6 Youth worker to work with young people in cardiac services.
- Recruitment programme of nurses.

Professional Development

- Sponsorship of the first Leeds Congenital Heart Unit Conference
- Fees to attend conferences/training on:
 - Cardio-Thoracic Surgery
 - Paediatric Palliative Care
 - Sleep
 - Physiotherapy
 - Inherited cardiac conditions
 - Perioperative specialty
 - Paediatric Intensive Care
 - Paediatric cardiology
 - Paediatric care
 - Health & Community Care

Research

- Research post in Paediatric Cardiology
- Timing of Pulmonary Valve Replacement in Tetralogy of Fallot
- Exercise programme for patients with Fontan Circulation
- Premature babies with heart problems

Staff Morale

- Retirement parties
- Refreshments at weekly congenital cardiac multidisciplinary meeting
- Celebration of the 20th Anniversary of the Unit and of the announcement Leeds Congenital Heart Unit will remain a centre performing complex heart surgery in the UK
- Gift vouchers for staff at Christmas

In some cases, it is too soon to measure the social impact of our work in this area. However, we know we supported approximately 150 members of staff in 2017, which has had or will have an impact on the whole service, the patients and their families, and ultimately in advancing health, and saving more lives.

Development of the service

Developing the service is, in most cases, very close to caring for the heart. In 2017, we funded two specific projects that will considerably improve the work of the LCHU:

- **Probes and software for the cardiac ultrasound system to enable patients to be scanned with the latest technology:**

The probes are used to guide the intervention and to monitor the surgical outcomes so are an essential tool for the cardiologist and the congenital surgeon. In addition, having a full set of probes on all the ultrasound systems means clinicians can accommodate patients of all ages on any system which is much more efficient and provides better care. About 7,000 transthoracic scans were performed in 2017, (approx. 4,000 adults and 3,000 children) so having the correct probe to perform the study and the correct software on the ultrasound systems are key to allowing the most appropriate analysis.



Care for the Future

Development of the service

- **Telemedicine link between the Neonatal Unit at Bradford Royal Infirmary and the Paediatric Cardiology Department at the LGI:**

A new telemedicine link that will allow doctors to provide clinical healthcare from a distance is now available in Yorkshire – and is the first of its kind for the county.

Children's Heart Surgery Fund has donated £11,000 towards a telemedicine link between the Bradford Neonatal unit and Paediatric Cardiology department at Leeds General Infirmary.

The link will allow live video communication and sharing of echocardiography images between sites and is included in the 2015 NHS Congenital Heart Disease standards. The funding will provide the necessary equipment for both Leeds and Bradford. This comprises of a telecart (Bradford) and HD camera screen (Leeds).

Dr Sam Wallis, a Consultant Neonatologist and Paediatrician with expertise in cardiology is behind the project. Together with Dr Helen Jepps they provide the current inpatient and outpatient PEC service in Bradford for paediatrics and neonates. They see over 1000 patients per year including performing echocardiography, and managing new diagnoses and referrals.

Dr Wallis explained how the link works "The paediatricians in Bradford carry out echocardiograph scans of the babies in their care and the telemedicine link would enable the cardiologist in Leeds to see the scans in real time. The cardiologist would then be able to give advice about the results, make decisions about next steps and talk to the parents about the baby's condition."

The funding comes after a successful three-week pilot. During this time, the link enabled a cardiologist to allow a baby to remain in Bradford and have regular scans rather than having to be immediately transferred to Leeds.

Despite there being just 10 miles between the two hospitals, the telemedicine link removes the need for travel, thereby reducing the risk of moving some babies between sites.



Clinical posts

The charity funded two posts in 2017. Matt Guest told us about his role as Youth Work Manager:

I graduated from University in 2009 after studying for a degree in Criminology and a post-graduate diploma in youth and community work. My first role in youth work was as a detached (street based) youth worker in the North East. This involved working with a team of youth workers to go into an area and build positive relationships with young people. The aim was to engage with those young people and encourage them to become involved in positive activities, with a view to improve confidence and self-esteem and reduce a range of antisocial behaviours.

After a number of successful detached projects and some time spent working in Spennymoor Youth Centre I moved to the Anti-Bullying Service. In this role, I was responsible for delivering training on anti-bullying legislation to schools, working with victims and perpetrators of bullying and delivering mediation sessions between sets of young people and their families. After the anti-bullying service was disbanded due to cuts in government funding I took on the role of managing one of the 5 main youth centres in County Durham.

In 2014, I applied for the role of Young Person's Key Worker at the Leeds Children and Young People's Diabetes Centre. This was a brand-new role at the time and I enjoyed developing youth work in Diabetes. During this time, I set up a steering group, buddy system, peer mentoring for newly diagnosed patients, school based group work and an annual transition to high school event. Alongside these group activities I also carried a caseload for one to one referrals around various issues such as confidence and self-esteem, sexual health, home and school issues, NEET young people, resilience and independence.

In my new role as youth work manager my plan is to improve access to youth support for young people in the hospital setting. This will involve increasing opportunities for young people to engage in a wide range of fun activities in 'The Place 2 be @LTHT' which will aim to increase and improve various outcomes for those involved. There will initially be a need for a lot of role development and in the long run I want to create a youth service within the hospital which leads to young people becoming more resilient, healthier, living longer and being happier living with a long-term health condition or during their stay in hospital. I want to change the way young people view the hospital setting so that they are much more willing and able to access services.



Professional Development

Financial pressures on the NHS and time pressures on its employees can make it difficult for staff to attend conferences and training days. At CHSF, we understand the impact training has, not only on individual staff, but also on the whole team, and consequently on the development of the whole service. Training helps deliver the most up to date and research based care.

Supporting professional development in 2017 had a positive impact on:

- giving up to date research and knowledge to children, parents and fellow colleagues;
- developing strategies to maximise patients' rehabilitation in Intensive Care;
- delivering information at a very sensitive time in the care of a sick child when emotion and stress levels are high, including information about palliative care;
- helping families cope with sleep problems;
- educating and informing community midwives and health visitors about caring for babies with complex cardiac conditions;
- networking opportunities to promote the Leeds Unit and explore joint working projects with other cardiac centres nationwide.

Research

Although it is still too soon to be able to measure the impact of our contribution to research in CHD, we have spoken to clinicians undertaking different projects we funded in 2017:

Emma Beaglehole - Physiotherapist

I studied Physiotherapy at Manchester Metropolitan University and graduated in 2010. I initially started working for the NHS at Doncaster Royal Infirmary completing my junior rotations where in 2013 I began working for Leeds Teaching Hospitals within the Paediatric Physiotherapy Team. Here I worked amongst acute Respiratory care, acute Neurology, Neuromuscular, Oncology and Musculoskeletal outpatients. Currently I am working within Pain and Rheumatology services in Paediatrics where earlier this year sought the opportunity to additionally work along-side Dr Oliver in the Congenital Cardiology team.



With funding from Children's Heart Surgery Fund we are currently in the early stages of starting an exercise group for patients with a Fontan circulation. Research has

found patients with a Fontan circulation who undergo a structured exercise programme have a more effective circulation and a better ability to exercise. It seems focusing on improving muscle strength, with so called resistance muscle training, may be particularly effective. This role within Cardiology specifically appealed to me as it involves using the knowledge and skills in exercise and rehabilitation in order to assess, devise and progress towards achieving strength outcomes through the setting of goals with my patients. With thanks to the Children's Heart Surgery Fund, I am excited to see what our patients taking part in the exercise group can achieve through hard work and guidance from our team and look forward to seeing our results at the end of the two year period we have to trial the programme!

Sally Hall: Paediatric Trainee and Researcher

I am a paediatric trainee in the West Yorkshire area and have recently worked at Leeds, Airedale and Calderdale hospitals. My interest is paediatric cardiology and this is what I want my future career to be in. I worked on Ward 51 for a 6-month rotation from August 2015 to Feb 2016 and more recently have worked on PICU looking after the post op cardiac children from August 2016 to February 2017.



From this August, I am taking up a research post at Leeds university. I will be spending time in the Leeds Institute of Cardiovascular and Metabolic Medicine (LICAMM) laboratories supervised by Professor Beech. I will be looking at a newly discovered protein called piezo one, which has a role in the development of vascular disorders. I will be looking at its role in a condition where it's involvement is already known (non immune hydrops fetalis) and with this information I am hoping to begin to investigate whether it has a similar role in the development of congenital heart disease.

If I manage to obtain funding for a prolonged research period and my investigation is successful then it could lead to increased understanding about why some babies are born with congenital heart disease.

Children's Heart Surgery Fund are supporting the research post financially. I'm aware of the great work they do in bolstering the Leeds Congenital Heart Unit with equipment and facilities, but it's also important to fund research to stay one step ahead of this disease.

Staff Morale

The staff in the LCHU go above and beyond the call of duty, and we believe it is important to acknowledge the outstanding work they all do. We support staff events to encourage unity within the service.



Our additional achievements

2017 saw the second year of our two-year appeal 'Keeping the Beat', to fund a revolutionary children's heart theatre. The charity pledged £1.25 million towards the project, and the aim of the fundraising campaign is to raise a further £500,000 to provide a 'Hybrid Theatre' to the LCHU. This will enable imaging, cardiac catheterisation and surgery to come together in a way that has never been possible in Leeds before, revolutionising its cardiac surgical programme. Babies and Children who need both open heart surgery and minimally invasive procedures will be operated on by a large team of both surgeons and cardiologists. This will enable more complex and multiple procedures, which currently need to be performed in several operations, and all the services will be transferred to the Children's Wing of the hospital.

The main benefits of the new children's heart theatre will be:

- reduced need for invasive procedures;
- reduced waiting and recovery times;
- reduced incidences of post-operative complications or pain;
- reduced risk of infection;
- greater opportunities for, and access to, new research.

This will have an impact on hundreds of children per year, who will receive better care as a result.

We are pleased to report we have reached the target needed to build the hybrid theatre, and the facility will be open for business in February 2019.



Our strategic focus for the next five years

CHSF's aim for the next five years is to develop the LCHU into a world-class centre of excellence and help the Unit meet the standards required by NHS England. We will work closely with clinicians to prioritise funding, whilst still reacting to the needs of our beneficiaries. The support we offer is based on facts, and our supporters' point of view is very important to us.

We particularly want to develop holistic care, which families feel would have an important positive impact not only on their well-being when their child is in hospital, but also in their everyday life. This includes offering support to bereaved families.

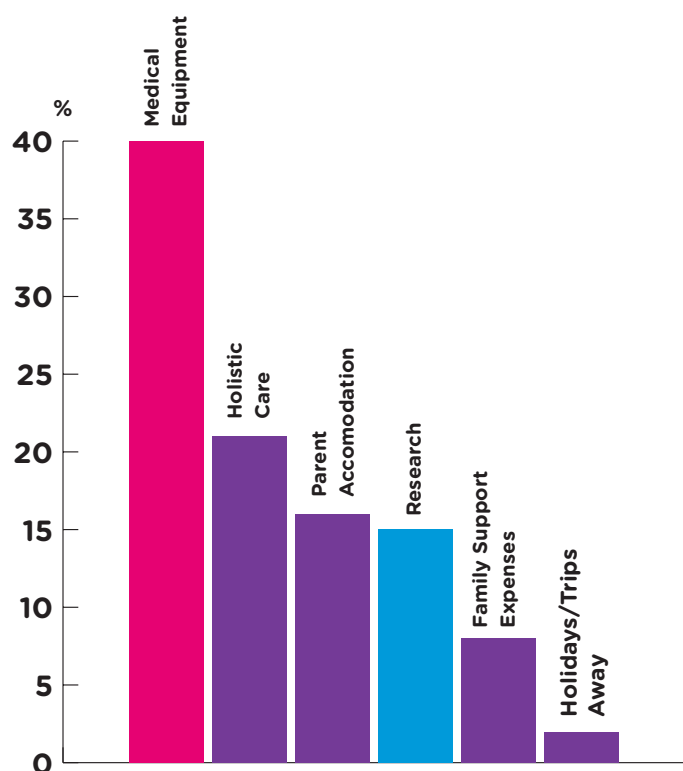
Our recent survey shows Care for the Heart (Medical Equipment) is the key area most of our supporters believe we should prioritise. Holistic Care is the second most chosen area, and more generally our objective to Care for the whole Family.

Here are a few examples about how we are planning to provide holistic support:

- 1:1 input
- Group community/education work
- Developing a range of books similar to Katie Bear goes to hospital
- Supporting siblings and close family through activities and groups, play assets and play
- Providing therapies such as parent and sibling counselling, rehabilitation and preparation for going home
- Providing bereavement support.



What do you think Children's Heart Surgery Fund should prioritise in future funding projects?



Conclusion

Our first Social Impact Report has highlighted the work we still have to do in terms of collecting data, and how, more generally, we gather and store information to measure our impact. We have already started this work by amending our application forms, which will considerably help our reporting in the future.

However, this report still makes it undeniable we are having a bigger positive impact on a larger number of patients and their families than might have been otherwise imagined – and that this is not only with regard to medical treatments, but also wider well-being measures and areas.

It is also beyond doubt that CHSF has a clear impact and benefit to the work and morale of the LCHU's wards and teams, and through them, the wider Hospital Trust. This results from the charity supporting the LTHT to manage treatment targets and retain a leading reputation for care, treatment, and medical intelligence around heart conditions.

We pride ourselves for the impact we had in 2017 in caring for the Heart, the Mind, the Family and the Future, and the projects we supported allowed us to:

- **provide patients with a positive experience of care; facilitate the detection of life-threatening conditions and saving lives;**
- **help the Unit become a world-class centre of excellence by improving the quality of care and developing the service;**
- **enhance patients' health;**

- **soothe fear and anxiety for patients and their families;**
- **offer practical and psychological help to families;**
- **develop of the service by funding clinical posts,**
- **assisting with professional development and research;**
- **boost staff morale.**

Although the nature of our work makes it difficult to give exact numbers of patients, families and staff, we can confidently say that our input has somehow made a difference to the lives of 17,680 babies, children and adults born with a heart defect in our region, to their families, and to the working conditions of at least 150 members of staff in the Leeds Congenital Heart Unit.

As we enter our 30th year, our last words go to our valued supporters. Without you, we would not have been able to fund the life-saving and life-changing projects that have benefited so many patients and their families. Thanks to you, we are able to commit to continuing to fund all kinds of projects from cutting-edge equipment to specific research - and improve lives.

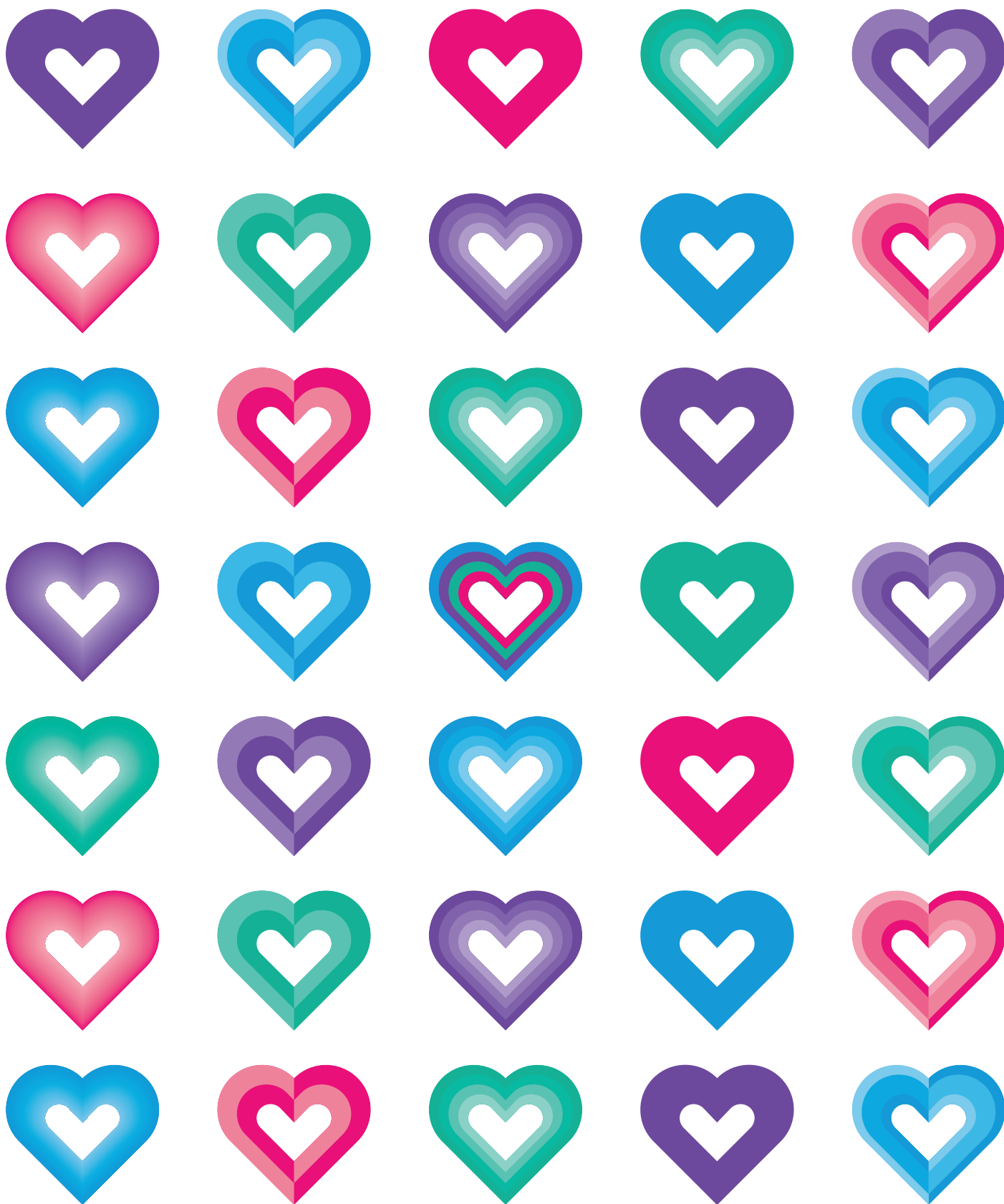
THANK YOU!



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The difference we made:
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