



Impact Report

2022-2023

You are supporting pioneering services that positively impacts heart families, inspires hope and enables Heart Heroes to reach their full potential.

#CHUFisForLife

chuf.org.uk     @CHUFOfficial

CHUF is a registered charity in England and Wales charity no: 1160831



Chuf.

For hearts, for families, for life

Welcome

Welcome to Chuf's 2022-23 impact report, I wanted to begin by thanking everyone who has supported our charity over the years and welcome our new supporters to the Chuf family. Our impact report is an opportunity to summarise key achievements of the last year, celebrate and share the amazing impact Chuf are having on the lives of Heart Heroes, their families and the teams who care for them. 2022-23 was an exciting twelve months at Chuf with a brand refresh focussed on highlighting our lifelong support of Heart Heroes and significant growth in charitable giving.

In the last year we've continued to step in to support the NHS, providing top up support quickly and targeted at the time of need. Our unwavering commitment has enabled us to grow our fundraising activity, allowing us to invest in new services and research whilst continuing to ensure that Heart Heroes have access to the very latest equipment, technology and expertise.

I hope that you enjoy reading our impact report and that it conveys just how valued and important your support is to our charity and to every Heart Hero and family that benefits.

Thank you for enabling life-changing care.
For hearts. For families. For life.



Charlotte Campbell
Director of Fundraising
and Operations

Our charity

Chuf supports children and families who receive treatment at the Children's Heart Unit based at the Freeman Hospital and six district general hospitals in the North, by raising vital funds for equipment, facilities, aftercare, specialist staffing and research beyond NHS capacity. Our charitable activities go far beyond providing medical equipment and personnel; Chuf provides holistic care; offering opportunities for heart children to create magical memories and develop their skills to achieve their potential.



Our aims

To provide top-up support over and above NHS capacity to assist heart children and their families from the moment they need specialist care. Our Trustees and fundraising team work closely with medical staff, Heart Heroes and families to ensure that Chuf's support is targeted to where it is most needed.



Our vision

To support pioneering services that will positively impact heart families, inspire hope and enable Heart Heroes to reach their full potential.



Our values



✓ **Always there:** Sometimes situations are hard but facing things head on together and always being there for each other, helps everyone cope even in the hardest times. We are on this journey with you; whatever happens we are 'always there'.

✓ **Commit to doing the right thing:** At Chuf we always go above and beyond to get the best outcome— by going the extra mile to get the best result for as many individuals and families as possible.



✓ **Champion the little things:** Not everything in life needs to be big and flashy to make a difference. At Chuf we champion the little acts that make a big difference to someone's day. We are not about big gestures for the sake of it. We understand that people might not remember exactly what we did but they'll remember how we made them feel.



✓ **A place for everyone:** Chuf offers a place for anyone affected by a child with a heart condition. Whether they're now a teenager or grown-up, or if they're a parent, fundraiser or medical professional. Everyone is part of the Chuf family, for life.



The difference we made in 2022-23



Chuf supported the NHS with **16 new projects** for the benefit of Heart Heroes receiving treatment across the North East and Cumbria.



We gave over **£200,000** to support projects that the NHS simply could not afford.



We raised over **£640,000** thanks to our amazing supporters.



We enabled **152** families to have access to vCreate whilst on the unit allowing them to receive real time updates via pictures and videos of their Heart Heroes when they are unable to be there.



We enabled **22** families to attend the British Transplant games.



1820 videos and pictures were shared to bring comfort to families of Heart Heroes in hospital thanks to Chuf's support.



We gave approximately **4200** food vouchers to families staying in hospital to help alleviate the financial burden of living in Hospital.



We covered over **£2000** of parking costs for our Heart Hero families.



We funded over **£2300** worth of arts and crafts activities to support our budding artists staying on the Childrens Heart Unit.



we continued to support the salaries of specialist nursing posts and members of the multidisciplinary team across the unit where the NHS were unable to, ensuring that the very best in innovative care was available for our Heart Heroes.



The Clown Doctors met with **1247** of our incredible Heart Heroes, in clinic, on the Heart Unit and virtually!

Evidence tells us that the single most important factor to a child's developmental outcomes and a parent's sense of well-being is the parent/ baby bond. How can we support parents to nurture that physical bond when their child is so sick?

Working with the specialist physiotherapy team at the Freeman Hospital, Chuf began to fund a pioneering research and development project in 2022.

Thanks to innovative and world class medical and surgical interventions at the Children's Heart Unit, many children with congenital heart disease are now surviving more complex heart defects. However, the implication on their development and quality of life, is also beginning to come to light.

Paediatric cardio physiotherapist Rachel McConnell, having had some experience working within the SCBU environment, began to recognise similarities between these children and babies on Cardiac PICU. There has been fantastic evidence-based work within the SCBU environment over the last 15 years which has led to an increased understanding of the pre-term infant and how early prolonged hospitalisation can influence their development and quality of life for the rest of their lives. This has led to evidence-based programmes designed to assist Health Professionals to care for vulnerable babies and optimise their developmental outcomes

whilst supporting parents to be involved as parents and nurture their babies no matter how sick they are, which is an important factor for the wellbeing of all children and their families. This is challenging for very sick post-op babies. The very babies who are most at risk of developmental compromise. Working to support the specialist physiotherapy team, Chuf are funding research and development to establish a clear pathway for supporting Heart parents to touch, hold and nurture their babies in these situations.

Currently there are no other children's cardiac centres in the UK implementing a programme to support parents of sick, post-operative babies in this way. It is hoped that through Chuf funding, the team at the Freeman Hospital will be able to implement change not only within the Childrens Heart Unit, but across paediatric cardiac care nationally.



The key areas of focus are:

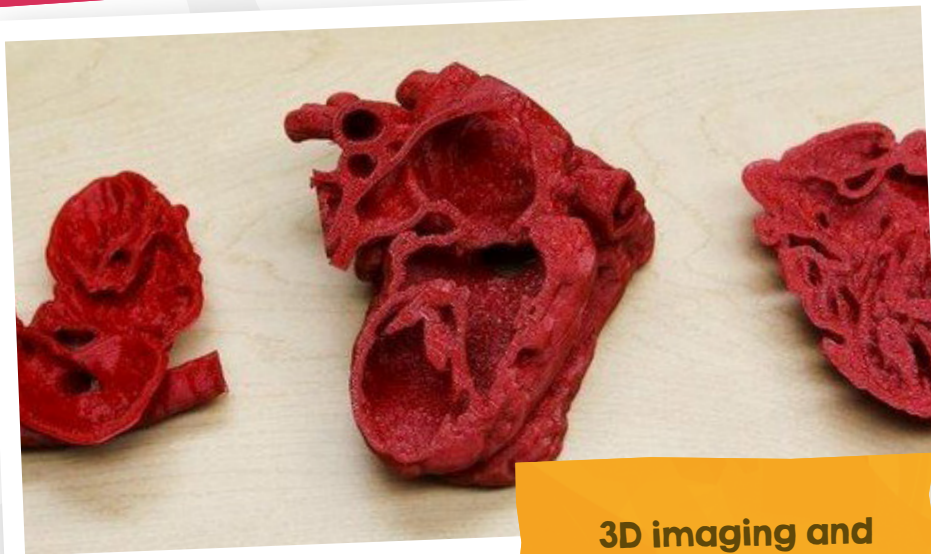
Promote skin to skin care: working with the multidisciplinary team to create a policy to enable it to be used safely within Cardiac paediatric intensive care unit.

Establish a Developmental Care Team involving the wider multidisciplinary team, with parents and baby at the centre of developmental assessments and goals.

Seek feedback from parents. We know from experience and informal parental feedback how valuable parents find support given during developmental care, particularly regarding touching their sick baby and providing opportunities for skin-to-skin care.

When she was born, I only saw her for a few minutes and then she was taken to another hospital, whilst I had to stay where I was. I did not see her again until the next evening. I had the chance to do skin-to-skin care with her 2 days later. At this moment, I felt like she was mine. It was the first time I had properly smelt her and felt her warmth.

How we have supported the NHS with equipment



**3D imaging and workstation
£88,000**

The software and the virtual models created have helped our discussions in the surgical meetings to plan some complex surgical procedures. They have also been exceptionally helpful for patient education.

DR. KAITAV ADHVARYU, CONSULTANT PAEDIATRIC CARDIOLOGIST.

Working in partnership, Chuf and The Newcastle Hospitals' charity have joint funded innovative 3D imaging and an additional workstation for the benefit of congenital heart disease patients. Children and adults with congenital heart disease significantly benefit from detailed heart imaging to enable the clinical team to make more informed decisions about patient management. This specialised software will provide access to tools for creating cardiovascular 3D printed models. These models are useful for patient education and are also used in surgical planning for complex surgeries.

Supporting vulnerable and complex paediatric clinics

The specialist nursing team run a home monitoring programme for very vulnerable and complex children which requires baby weighing scales, saturation monitors and INR home testing kits to be sent home with the family on discharge. By closely monitoring Heart Heroes at home the nursing team can advise and support Heart parents to spot any changes quickly. During the year, ten additional Sats monitors were purchased to support the safe discharge of patients home with their families at a cost of £5,500, alongside an additional 10 INR home testing kits at a cost of £3723.

“ These small, but fantastic, devices mean there is minimal disruption to families. It allows the family to manage the effectiveness of blood thinning medication whilst at home, avoiding frequent hospital visits. This undoubtedly provides relief and reassurance to our cardiac families.

CHILDREN'S CARDIAC NURSE SPECIALISTS FREEMAN HOSPITAL



Accuvein

The Accuvein has been trialled in Clinic E and on Ward 23 and was found to make identifying suitable veins for cannulation and venepuncture more accurate. It also provided distraction for patients during the procedure.

The Accuvein was funded by Chuf at a cost of £4465.00 and has significantly decreased the time spent taking vital blood samples, which in turn has decreased the distress for both the child and their loved ones.

An additional Accuvein has been purchased for the Heart Unit with help from some funds donated by one of our wonderful corporate supporters SMS Manufacturing Ltd.

ECG devices for home monitoring

Chuf have funded four personal portable electrocardiograms for patients attending clinics in Sunderland with infrequent palpitations.

This can be a worrying symptom for families and can be due to an underlying problem with the electrical rhythm of the heart. The best way to diagnose it, is to have an ECG performed at the time of the symptoms if the rhythm of the heart is normal, it can be reassuring for families. If it is abnormal, the ECG aids diagnosis so that they can receive appropriate treatment.

The handy portable machines are loaned to families for a 3 month period to capture episodes of palpitations and to aid diagnosis.

How we have supported families



Feeding families fund

Throughout the pandemic Chuf worked hard to support every single family facing the most difficult time of their lives. As a result of everchanging restrictions we introduced subsidies for meals from the hospital canteen for parents. Three years on, following consultation with staff and parents Chuf continued our feeding families support for longterm families and we have been overwhelmed by the feedback received.



The food was a godsend really. It just made things a bit easier. With so many things to worry about at that time, it just removed another worry from us and gave that peace of mind. It was massive for us, and a sign of how important Chuf is and how much help they give, and we really felt that.

Sam Harrison

This past year we have spent over £25,000 feeding our families, providing meal vouchers, discretionary hardship supermarket vouchers, special treats such as pizza nights and organising coffee, crepe and ice cream vans to visit the ward; providing a much-needed lift for patients and their families as well as the staff team.

Celebrations



We continue to work hard to ensure festivities and milestones are extra special for our little ones who cannot be at home to celebrate with all of their family. Chuf spends over £6,000 each year to ensure that Christmas is a magical time for our Heart Heroes. Every Heart Hero attending a clinic appointment at the Freeman Hospital during December receives a soft toy. Treats like this make such a difference to the children who are often worried about attending their check-ups.

Chuf also funds Build-A-Bear's complete with outfits for babies and children spending Christmas Eve on the ward; providing comfort for our Heart Heroes over the festive period. This year we also funded hampers for parents which included festive treats to enjoy together as a family.



Families celebrating Eid on the ward received gift boxes of goodies, special treats and deliveries.

Emergency accommodation and respite family breaks



At Chuf we stepped in to not only provide hotel accommodation for families who have been unable to stay in Scott House, but also to provide respite accommodation for families who have more than one child.

At Christmas, Chuf provided hotel accommodation for our families who had a little one in hospital and other children at home to ensure that families could all be together on Christmas Eve and over the festive period. The total cost of additional accommodation this last year has been **£4,160.**

Transplant games

The 2022 transplant games took place in Coventry with 22 families taking part in the celebrations. The games provide an amazing opportunity for Heart Heroes and their families to meet others who have been on a transplant journey and work towards raising awareness of organ donation. Chuf funds the Freeman Children's team to attend and compete in the transplant games covering all costs including accommodation, travel and entry to the games. We are so incredibly proud of our transplant families and love celebrating their achievements!

Fantastic! Thank you to Chuf for all of your support, we had such a magical, amazing, inspirational weekend. Heart Hero family

Every year Chuf sets aside £21,000 to ensure that families who wish to attend the transplant games with the Freeman children's team can do so. It costs approximately £1000 per family to cover all costs and as part of our lifelong commitment to Herat Heroes it is our privilege to continue to fund Heart families' participation in the games.

Bereavement support

Sadly, the terrible reality is that not all of our Heart Heroes recover and go home with their families. At Chuf we are there throughout the good times and also the unthinkable hard times.



We show up and provide support to families throughout their whole journey. We fund memory stars, bereavement bags, jewellery charms and work with the staff at the Children's Heart Unit to fund bereavement packs at a cost of over **£2,500** per year.



Discretionary charitable fund



Chuf provides a discretionary charitable fund which is administered by the Freeman Heart Unit staff and exists to support the little things that the NHS cannot help with. This means that staff on the ward can be spontaneous with treats for Heart Heroes, parents and staff.

They can organise movie nights or purchase new toys when needed. The fund also allows them to be responsive to unforeseen situations and supports things like emergency travel or support for people arriving in the middle of the night with nothing. The playroom is also well stocked with craft items paid for from Chuf's discretionary fund. We are always delighted to see our Heart Heroes' artwork proudly displayed.



How we have supported Heart Heroes



Since 2006, Chuf has worked in partnership with TIN Arts delivering The Clown Doctor programme at the Freeman Hospital and over the years thousands of individuals have benefitted.

Chuf continued to fund the Clown Doctor programmes in 2022- 23 at a cost of £45,000.

The Clown Doctors remain one of the most important services we fund and embody our value that there is a place for everyone. The ability of the play therapists to connect with Heart Heroes of all ages is second to none and their input into the recovery of our patients is invaluable.

The amazing Clown Doctors met 1247 times with our Heart Heroes with 393 individual children benefiting from their bespoke care.

The work of the Clown Doctors is not restricted to within the walls of the Heart Unit and our programme of Very Special Meetings designed to continue the relationship with the Clown Doctors after discharge saw over 30 meetings take place across the year.

In March 2022, as hospital COVID protocols changed, the Clown Doctors started to venture out of the playroom to see children on the ward again. They commented that they were able to spend time with teens who wouldn't necessarily have come down to the playroom, and staff were happy to see them back on the ward. In May visits started to take place in clinic again. On 10th May the Clown Doctors told us: We ventured down to clinic and it's great to be back in after two years. We saw lots of different ages. What is wonderful about clinic is we get to touch base with children we have seen growing up. One mum

commented **"it leaves a lasting positive impression on them which is a really positive memory of the hospital"**. Clinic have been overjoyed to see us all **"come up smiling and chatting, very lovely"**.

The difference the Clown Doctors make is tangible and immeasurable.

"Mum said that he totally loves bubbles now, since the time when he was upset and the Clown Doctors first distracted him using bubbles. They've been a comfort and joy to him ever since."

"Today we spent time getting to know a young teen. Sometimes our job is to listen. For some young people having a conversation on lots of different topics is as important as say engaging with a magic trick. We try to pitch the visits at the right level for each individual to meet their needs. We met a boy who told us all about his love and interest in cooking, his Chinese heritage and culture. It was a very gentle insight into his life."

"Sarah's mum was asking her today how happy it made her feel to see the Clown Doctors online and when they walk past on the corridor. Sarah said "really happy" with a huge beaming grin. Mum also said that her partner had commented yesterday about how people don't realise the impact that we have, and that Dr Cherrywolf could make millions as a YouTube star!"

"One baby's dad we played with in the corridor was thrilled because she focused on a thumb light moving and he said, 'that's the first time I've seen her focus.'"

Music stars

Little Music Stars sessions were introduced to aid children's social, emotional and physical development whilst they spend time on the ward. Just because they're unable to participate in the groups and activities that they normally might outside of hospital, doesn't mean that families can't learn, play and enjoy the sensory benefits that music therapy can bring.

Chuf funded these weekly music sessions on the Children's Heart Unit at a cost of £2940 per year.

Sophie Patton, Play Nurse Specialist, explains why these sessions are so important:

It brings a sense of 'normality' to their long days whilst in hospital. Music stars helps with their continuing development, for example speech, fine and gross motor skills and social interaction. It's a great stimulation for the children, and is emotionally uplifting for the whole ward. It's nice to be able to get the children and parents together once a week from all areas of the heart unit.



Tonies

Tonie boxes are musical story boxes endorsed by the National Literacy Trust as a way to boost children's speech and reading levels by offering hours of entertaining stories and songs that can be played and enjoyed with or without a grown-up present. Chuf spent **£724.77** on new tonie boxes and brand new story characters. These boxes include a self-record function, meaning that a parent can record themselves reading their little one's favourite bedtime story and the child can listen to the soothing sound of their parent's voices at the touch of a button, even when they can't be together all the time.



Cuski miniboos

Chuf have been funding Cuski miniboos for our Heart Hero families since 2018. These small cloth comforters are used to help with the very important bonding process between parents and their baby when Mums and Dads can't hold their little ones after birth.

Smell is the first sense a baby develops and scientists believe that a baby's ability to smell their parent is one of the most important steps in learning to recognise them. A handy pack of two comforters means that Mum or Dad can always have one with them and one with baby so little one never has to be without their familiar, comforting scent.

Chuf has spent £745.20 on Cuski miniboos in 2022-23 to provide this vital connection between parent and baby.



vCreate software and Ipad

In 2020 we began funding the subscription to vCreate software for the Children's Heart Unit at the Freeman Hospital and it has since become a vital part of the service. Whether long or short, a child's inpatient journey can be extremely stressful for families, particularly if and when they are unable to be together at the unit. For many parents, who must juggle work commitments, other children and potentially travel long distances to the hospital, it can be challenging to visit every day.

Recognising the challenges parents face when trying to visit their child in hospital, particularly

when they are out-of-region, Chuf continue to invest in the use of this secure asynchronous video messaging as a way of keeping families connected. The secure system allows paediatric professionals to record and upload short video-clips and photos of the children on approved devices which are then shared directly with parents. The system has been used by over **152** families across the unit with over **1820** pictures and videos recorded. **Chuf funded V Create for a third year at a cost of £4,200.**



Baggins Bear

Children who undergo heart surgery are given a Baggins Bear to celebrate their bravery and act as a memento of their journey. Baggins arrives at their bedside during recovery and has a book which can be translated into any language to help engage with all families. It's a lovely keepsake for the children to take home with them. Chuf spent **£4,710** on new Baggins Bears in 2022 which will make surgery day a little less scary for over **450** children.



Clinic E

Chuf refreshed Clinic E's waiting area by purchasing a new TV and games for children visiting the Freeman for their outpatient appointments.



How we have supported the staff who care for our Heart Heroes

The Children's Heart Unit staff are amazing, providing care and support to our Heart Heroes day in and day out. As well as supporting additional training costs and materials not available through the NHS, Chuf supports little things that can boost a tough day. We help stock the wellbeing room and provide seasonal treats, wellbeing cards and special Christmas scrubs. We provided vouchers for staff to spend at the Chuf shop for 'lifting each other up day' which was a hit!



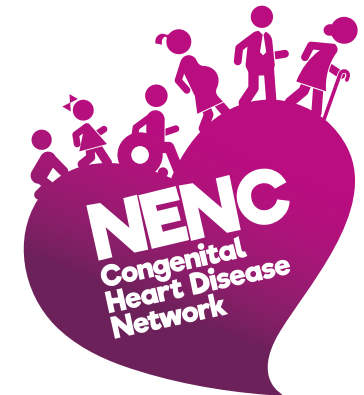
Helping children (and adults) play on the unit.

As well as funding the build of the invaluable play facilities at the Children's Heart Unit at Freeman Hospital, Chuf was instrumental in establishing the incredible play nursing team. We continue to support their development and vital work by funding materials they can use to keep little hands busy. Over the last year we have funded over £2,300 worth of arts and crafts materials, new toys and rewards. Because our care is lifelong, we ensure that our adult Heart Heroes also benefit from entertainment during what can be long and lonely stays. Chuf also funded x5 new Ipad for PICU and x4 for adult congenital heart patients at a cost of £4566.73 and continued to pay for superfast wi-fi and subscriptions to Netflix and Disney+ for all of our Heart heroes to enjoy.



Network support

Chuf works closely with the North East and North Cumbria Congenital Heart Disease Network to support cardiac care across the region, inspire innovation and improve care. In 2022-23 we supported the team with their patient engagement focus groups, which have given patients the opportunity to have their say about the things that work well, and what they feel they might need from services in the future.



With special thanks to

Chuf is fortunate to receive grants from trusts and foundations, as well as support, donations and volunteers from a wide range of business friends from the North East and much further afield, we are thankful for your ongoing support and fundraising endeavours that help us to deliver unparalleled care for Heart Heroes. 2022-23 saw companies taking on physical events such as the Tough Mudder, Dragon boat racing and hill hikes as well as participating in office challenges including bake offs and wearing red for Chuf. Every golf day, charity night, like and share makes a difference.



JT Dove – are our long-term business friends whose multiyear and ongoing support sees hundreds of staff members, suppliers and clients all getting involved in a range of fundraising activity throughout the year. JT Dove once again blew us away with their dedication; organising golf days, race nights, raffles, a Casino night and coming out in force to scale the National 3 Peaks to raise an amazing **£25,000**. This takes their overall total fundraising for Chuf to over £200,000 An incredible legacy for MD Steve Robinson who took well earned retirement after the cheque presentation saying “fundraising for Chuf has been one of the proudest parts of working for this incredible company. I know that I’ve handed the reins over to an incredibly capable team and will still be supporting the JT Dove family from afar!”



Transcendit once again sponsored the Chuf running vests for the Great North Run at a cost of £3,000,



Victors Restaurant Newcastle let their customers decide who their chosen Charity would be, Chuf supporters came out in force and we were delighted to benefit from their special launch events charity nights, their diners helped to raise an excellent £3050 to help Chuf feed families on the ward.



M&C Roofing held a row-a-thon which raised an awesome £3426 in 12 hours.



BT Newcastle Delivery Hub had their fundraising plans scuppered during the pandemic, but they came back with a vengeance in 2022 holding bake sales, an office triathlon and donning their finest 80’s gear in a charity night that raised over £3,000. The pictures really made us smile!



Hart Door Systems and Collingwood insurance both chose Chuf as their first ever charity of the year partnership raising over £1,000 and £2,500 respectively.



Orion Contract Services Ltd has selected Chuf as their chosen charity and kicked things off by kindly supporting the costs of Build-a-bears for children spending Christmas on the unit at a cost of £1,000, they have pledged their support to even bigger plans for 2023/24.



Following Heart Dad Craig Woods’ experience on the ward, his company SMS Manufacturing Solutions Ltd donated £3000 towards the cost of a new Accuvein for ward 23



Not content with making a generous £5,000 donation, Smyths Toys Superstore Metrocentre helped Chuf to make Christmas bright by providing £500 worth of toys for our Christmas Party!



WL Distillery, Dreamworld Cakes and Cake Stories all got involved with 2023’s Heart Month commercial partnerships. They released tasty ‘Heart Month Special’ treats and pledged to donate a percentage of the sales to our charity. You have been a joy to work with and we can’t thank you enough for helping to raise the profile of our charity throughout February.



In October 2022 Hay and Kilner staff voted to make Chuf their charity of the Year and began their fundraising with Christmas jumper days, a big staff quiz, Wear Red for Chuf Day to name just a few.



The Provincial Grand Lodge Durham, together with the Dunelm Lodge Masons provided a grant to help pay for gifts from Santa at the 2022 Chuf Christmas Party.

With special thanks to



Chuf continued to work with our charity chums the Sir Graham Wylie Foundation to deliver another wonderful Toddle for Heart Families and friends. Their £10,000 grant helped to bring ALL the fun of the fair. We're so grateful for this annual support that makes the toddle possible!

BEYONDLY

Beyondly made an incredible grant of £17,000 towards our Clown Doctor Programme, we are proud to be one of the first of your chosen charities!



D'Oyly Carte Trust and Hadrian Trust provided grants totalling £6,000 towards our Clown Doctor Programme. Huge thanks to you both for supporting empowerment and smiles for Heart Heroes for the second year in a row!

THE



Both the Shears Foundation and Barbour Foundation stepped in to support the development of skin to skin care pathways for families on the Heart Unit with their combined grants totalling £20,500 towards the cost of our Specialist Cardiac Neonatal Physiotherapist. Thank you for trusting

Chuf to forge the way in this area, supporting an innovative post that will provide benefit for Heart Heroes far into the future!



The Richard Henry Holmes Masonic Benevolent Fund kindly offered a grant of £5000 towards Chuf's bereavement support and feeding families programmes. These services are little things, that make a big difference!



Crowne Plaza Newcastle once again took on the major costs of Chuf's Christmas party. Their gift in kind support saves Chuf around £3,000 each year. Thank you Crowne Plaza for helping Chuf bring Christmas sparkle to our Heart Families each year!



Newcastle Building Society once again continued to lend a hand by getting staff, volunteers and their communities involved in our events.

Thank you to everyone that nominated Chuf to receive donations from their company's charity or community funds, or who fundraised independently and asked your employer to match fund.

A big thank you also to all the companies that donated prizes for Chuf's Christmas Raffle; we couldn't do it without you, and to the companies who got involved in raising funds for Chuf throughout Heart Month. Whilst there's too many to name, a special thank you should go to EVERY

individual supporter that liked and shared our social media posts, got families, workplaces and schools involved in our awareness campaigns, participated in the Great North Run, took on bike-rides, held garden parties or thought about us when collecting in-memory of a loved one. We see you, we thank you.

Last but not least, an enormous debt of gratitude is owed to all our dedicated Chuf volunteers for their ongoing support, you are our superheroes!

Transplantation Research



Chuf is proud to lead the way by supporting innovative research that could one day change the future of our Heart Heroes' care and life-chances for the better. In 2022 Chuf provided a grant of £40,000 to explore a project around the Hypothermic Oxygenated Perfusion (HOP) of Human Hearts.

The research came about, because the demand for healthy, usable donor hearts vastly outweighs the supply. Even when a heart becomes available for transplant, the traditional method of storage for transport, within a cold box, (called Static Cold Storage or SCS) is limited to 4 hours. This time pressure makes the coordination of donation and implantation very difficult. Moreover, for patients with congenital heart disease who have undergone multiple heart operations in the past, it is very challenging for surgeons to safely remove their hearts and prepare for donor heart implantation in such a short time period. In this time, the heart is very susceptible to damage from lack of a blood supply between removal from the donor and placement in the recipient. This gap between the demand and supply is even worse in the paediatric cohort.

You may already know that Chuf previously invested in the innovative Transmedics Organ Care System (OCS) a warm heart perfusion device, which keeps blood pumping around a donated heart and increases the amount of time for transportation. It also allows surgeons the chance to run tests and make adjustments to the heart allowing them to save hearts that would be unviable under the old cold box system, making them viable, and increasing the number of donated hearts that actually make it to a patient awaiting their gift of life. Sadly, this

equipment, whilst an undoubted game changer for adult hearts, cannot be used on hearts from donors with body weight under 50kgs. In other words, until now babies and children have not been able to rely upon the benefits of a perfused heart.

Professor John Dark approached Chuf with some hope. A new machine, the XVIVO perfusion box had been created in Sweden by Professor Stig Steen's team, with clinical trials proving its efficiency over OCS, including a reduction of damage to the cells in hearts caused by cold storage in transportation. Even more encouragingly, the XVIVO perfusion box had the ability facilitate and perfuse smaller hearts from donors weighing over 20kgs. From 2017 to 2021, 28 DCD donors with a body weight between 20 and 50kg donated their abdominal organs, but not hearts, due to the lack of suitable heart perfusion device (data from the NHSBT database). If these 28 donor hearts were accepted for paediatric recipients, the paediatric transplant activity would be increased by 19.3% over the same time period.

Additional research was needed to unearth more conclusive data on the equipment, and on patient outcomes when using the machine on hearts donated after circulatory death (which currently accounts for 40% of all donated

hearts). But there were not the necessary funds within the NHS to take on this pioneering research.

Supported by the results abroad and encouraged by the additional proposed multi-centre clinical trials due to take place in Europe, North America and Australia, Chuf could appreciate the potentially lifesaving, game-changing impact of this research into the future. It was hoped that this study, would greatly improve knowledge about ischaemic insult (cell damage) to human hearts, but also that it might provide the scientific explanation underlying this novel preservation strategy which could change the odds and success of heart transplants in the future.

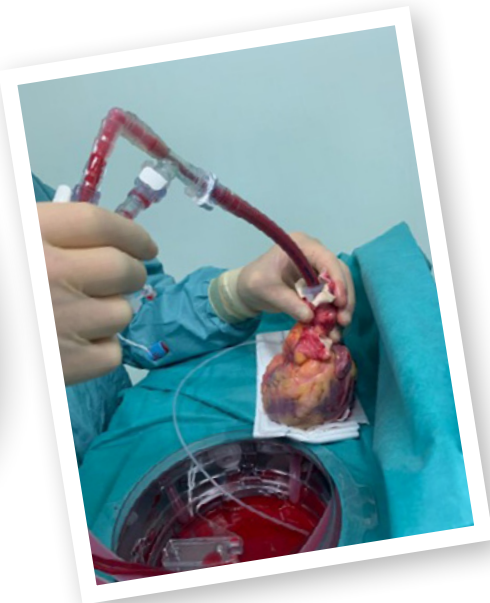
We are excited to report that the findings of the research demonstrated that the XVIVO machine could more safely preserve human DCD hearts, meaning that a much better preserved heart can reach the recipients. It is hoped that this research and it's findings can pave the way for the initiation of a DCD transplant programme

with the paediatric transplant team at the Freeman Hospital utilising hearts from donors with body weight of 20-50kg.

This could open the door to a 20% increase in hearts suitable for paediatric heart transplant. This will bring hope and better chances for our younger Heart Heroes awaiting transplant. We look forward with anticipation to seeing the progress of both adult and child heart transplantation pathways and hope that you, our Chuf supporters can see the incredible value that this project has brought to the field.

This research plays a great part in keeping the Northeast at the cutting edge of life changing cardiac care, enhancing further still the reputation of the Children's Heart Unit as a world leading specialist centre. It would not have been possible without the funds that you raise for Chuf. Your support enabled us to be a part of this incredible step forward in knowledge, for that, the words 'thank you', don't seem to be enough!

This could open the door to a **20% increase** in hearts suitable for paediatric heart transplant.



Looking ahead

2023-24 will see us celebrating 40 years of being there for Heart Heroes and their families, bringing exciting new challenges to engage our supporters, and a new logo that reflects how we've grown over the last 40 years.

We look ahead to providing more life-changing care and support for the future and will be continuing to work closely with teams across the region to improve care beyond the hospital walls of the Freeman Hospital.

We will of course continue to invest money raised by our supporters in innovation and direct care, and bring a taboo shifting campaign that all of our Heart Heroes and supporters can get involved in. **#MyScarIsMySuperpower.**

Thank you once again to every Chuf supporter, you really are enabling life changing care.

#CHUFisforlife.

For Hearts. For Families. For Life.



Ivan Hollingsworth
Chair of the Board of Trustees
(Heart Hero parent)



Impact Report

2022-2023



Charlotte Campbell
Director of Fundraising
and Operations



Alicia Clovis-Mothalib
Corporate and Trusts
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Finance and Grants Officer



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Volunteer Fundraiser

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