

Impact Report

2020-2021



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

#CHUFisForLife

chuf.org.uk



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CHUF is a registered charity in England and Wales No 1160831





Welcome



Welcome to the Children's Heart Unit Fund (CHUF) 2020-21 impact report, I wanted to begin by thanking everyone who has supported CHUF over the past year.

2020 was unpredictable for all and whilst at times it has seemed near-impossible, we've kept spirits high and smiles wide for our Heart Heroes and their families. It's thanks to YOU, our supporters, our extended CHUF family, that we have been able to adapt and continue our work across the region and nationwide.

COVID-19 had a huge impact on day-to-day life for staff and patients at the Children's Heart Unit, and our charity has been called upon to provide unprecedented levels of support to meet rising need and changing circumstances.

Throughout it all, Heart Heroes remained at the centre of everything that we do and we continued to provide innovative equipment and services that we know will make a long-term difference. By supporting CHUF you are investing in incredible care for generations to come. 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 Family.

Thank you for enabling such life-changing care.



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, by raising vital funds for equipment, facilities, aftercare, salaries and research that will make a positive difference to their hospital experiences and lives beyond treatment. Our charitable activities go far beyond providing medical equipment and personnel; CHUF provides holistic care; offering opportunities for heart children to develop their skills and mature as any healthy child normally would. All of this contributes to our Heart Heroes' ability to achieve their full potential. CHUF's reach extends to the six District General hospitals in the vast Northern region meaning that more patients can rely on CHUF funded services to support care closer to home.

Our aims



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

Our mission



To create an extended CHUF 'family' of supporters, who help people to achieve their full potential.

Our values



Authenticity: We are open, honest and caring with respect for all.

Sharing: We welcome diversity and the new outcomes inclusive collaboration brings.

Commitment: We put Heart Heroes at the centre of all we do and work towards what has the most positive impact on Heart families.



Our vision



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

Our strategic aims:

We will build **relationships** with more teams, funders, and donors so that we have a greater presence in the sector, raising more money ensuring that we can support more Heart Heroes and their families.

We will track the number of patients in each age group ensuring CHUF's support is **transformative**. We will target the support that is appropriate to each patient age group and make provisions for the holistic (non-clinical) needs of all.

We will increase **engagement** with the North East and North Cumbria Congenital Heart Disease Network, ensuring that families know how to access CHUF support when appropriate, in Newcastle and beyond.



Our impact in 2020 and 2021

The Children's Heart Unit at the Freeman Hospital is a world leading centre for excellence in cardiac care.

By providing additional support, CHUF are enabling the very best care for every Heart child from the beginning of their journey.



1 out of every **100** babies born will have a congenital heart defect, that's about **300** a year in this region alone!

This impact report focuses on our four areas of support in 2020-21:



How we support the NHS with lifesaving equipment



How we support NHS staff to deliver the highest standard of care



How we support Heart Hero families



How we support Heart Heroes

The difference we have made to Heart Heroes and their families is evidenced in:

- CHUF's internal evaluation, reports and case studies.
- Reports and feedback from clinicians, children, parents and their families. The figures we report relate to CHUF's 2020-21 financial year (April 2020 – March 2021).



There were **3658 paediatric outpatient appointments**, **1310 new patients** and **3594 review appointments**



On average **409 children** attend the Freeman Hospital Children's Heart Unit every month



245 underwent a surgical procedure in 2020-21



There were **2132 Adult congenital outpatient appointments** in 2020-21





When the world stood still, we didn't!



In March 2020 the impact of the Coronavirus (COVID-19) pandemic began affecting us all, but for children with heart conditions and their families it was an especially worrying time.

The introduction of stringent shielding measures to keep our vulnerable beneficiaries safe, had a huge impact on the services that CHUF funds, but we were determined to find new ways of working to bring smiles to Heart Heroes in the darkest times.

Thanks to your support CHUF was able to respond quickly and fully to impacts of the pandemic, here's how:

- When the communal kitchen space in Scott House could not be used CHUF was able to step in and feed families by providing meal vouchers for all inpatient visitors to enjoy a hot meal in the hospital canteen.
- CHUF supplied breakfast and snacks for the Unit to reduce the need for parents/carers to leave the ward during the day, reducing infection risk.
- CHUF funded hotel stays and transport for families that could not stay in Scott House, so they could still be there for their hospitalised Heart Heroes.
- New games and sterile toys were purchased for the High Dependency Unit as parents and children there were quarantined for their own safety. The toys, gadgets and games helped pass the time offering a much-needed distraction.
- We cared for our wonderful NHS colleagues by providing treats and surprises such as hand creams, cake deliveries and even an upgraded relaxation space, where they

could take a quiet moment to benefit their mental wellbeing.

- The CHUF-funded Clown Doctor programme continued to provide one to one support for Heart Heroes and their families on the ward. We invested in additional technology to enable video messages and real time interaction.

- In September 2020 we funded the new Clown Doctors HQ in ward 23's outdoor play area to allow in person Clown Doctor visits to resume in a safe and socially distanced way.

- We also invested in magical moments for the Heart Heroes and families on the unit, finding ways to safely celebrate holidays, birthdays and special occasions. We arranged for an ice cream van to visit the unit, a special visit from Santa's reindeers at Christmas and celebrated occasions such as Halloween and Valentine's day by providing exciting treats, such as afternoon tea, pizzas and sweetie deliveries. We focussed on providing moments for families to enjoy; an element of normality, celebrating together and bringing joy into the hospital environment.



We are incredibly proud of our response to the challenges our Heart Heroes faced in hospital over the last year and this was only possible thanks to your amazing support and donations, we thank you from the bottom of our hearts.

How we have supported the NHS with equipment

CHUF recently bought an Ultrasound system costing £54,000 for Sunderland Royal Hospital to support the unit in delivering high quality care for local families, improve timely access to investigations and reduce the need for travel to the Freeman Hospital in Newcastle – keeping care closer to home.

This CHUF-funded machine will enable a paediatric cardiac outpatient service away from any inpatient facility. The restrictions caused by the Coronavirus pandemic coupled with the rising workload of the Sunderland Royal team necessitated acquiring a second ultrasound machine that could be dedicated to outpatient paediatric cardiac activities.

A total of 72 children were scanned 346 times by the end of February 2021.

Five cases with structural CHD were diagnosed during that period. Many others were screened for cardiac murmurs and abnormalities. This enabled the clinical teams to reassure families about their child's health. Those with existing cardiac abnormalities were also seen and followed up at the cardiac clinic.



On behalf of myself, my paediatric colleagues, the children and families, we greatly appreciate the support by CHUF and those who donated towards the purchase of this equipment. I would like to extend my thanks to all those who work tirelessly at this much valued charity.

Majd Abu-Harb
Consultant neonatologist

CHUF recently supported the Congenital Echocardiography Team at the Freeman Hospital to develop the service via the purchase of a **portable 2D echocardiography machine at a cost of £38,000.**

Often within the children's clinic the current echocardiography (Echo) machines are used to capacity. This portable equipment has provided much needed additional help; allowing consultants to independently scan patients in clinic while existing machines are being used by the echocardiographers. Being a portable device, it can be moved around by registrars and echo technicians to undertake scans throughout the hospital. Furthermore, the machine can be utilised by consultants for their outreach clinic in other hospitals.



The new portable Echo machine has been used for paediatric cardiology reviews for inpatients at the RVI, along with providing essential congenital cardiology support to patients.

The Freeman Hospital is at the forefront in the UK for single ventricle/Fontan transplantation and is the first in the country to develop a surveillance pathway in the paediatric setting.

In 2020 CHUF purchased a **Fibroscan Machine** at a cost of **£30,000**. Fibroscan is performed yearly as part of Fontan surveillance. It is used to assess the liver for Fibrotic changes, this serves to track shifts specifically in the liver which could accelerate the need for cardiac/liver transplantation and/or intervention.

Before the purchase of this machine both children and adults were scanned by the gastroenterology and liver service in a Fibroscan clinic which is an adult environment. This clinic had the proper equipment but was not an appropriate setting for younger service users.

The dedicated Fibroscan machine was purchased for the congenital heart service, to further support the CHUF-funded Fontan Nurse Specialist in order to enhance the service patients receive, allowing them to be scanned in an appropriate environment. Whenever possible the scan is performed at a cardiology appointment or clustered with other investigations to reduce the number of hospital attendances patients attend yearly. Reducing the number of visits patients have to make to receive care is of course beneficial at any time, but particularly during the pandemic when unnecessary travel was advised against, meant it also helped reduce additional infection risks to vulnerable Heart Heroes.

Additionally, the scanner is portable so can be used in outreach clinics making care accessible closer to home.



Special thanks to the Merrin family who's significant fundraising enabled the purchase of the Fibroscan machine.



Thank you from the patients who will benefit from this specialist piece of equipment and thank from the team and I for your tremendous support to enable CHUF to fund the project. The Fibroscanner is the first within the cardiothoracic department which allows children to have their scan in a suitable environment and not in an adult setting as previously happened. This machine improves our ability to screen this highly complex group of patients efficiently, effectively and appropriately.



Debbie McParlin
CHUF funded Specialist
Fontan Nurse

24-hour surveillance tapes

The purchase of three additional 24-hour surveillance tapes at a cost of £4,100 has in many cases reduced or eliminated the need for multiple clinic trips after discharge, and reduced the length of stay in hospital for our Heart Heroes. The 24-hour tapes capture rhythms and records events whilst children are going about their daily activities at home without the need for hospitalisation and provides information to steer treatment. Thanks to CHUF the team at the Children's Heart Unit can now fit a tape prior to discharge thus eliminating the need to return to the hospital for monitoring.



This undoubtedly provides reassurance to our cardiac families and enables the team to be efficient allowing treatment to be expedited in a timely manner.

Debbie Lawson, Children's Cardiac nurse specialist team

Outpatient clinic support

Attending clinic can be a daunting and worrying time for our Heart Heroes, especially the little ones; meeting new doctors and nurses can be scary and unsettling. The outreach clinics which take place across our region are of great importance and we strive to ensure that the patient experience is as positive as it would be at the Children's Heart Unit at the Freeman hospital.

This is why we work with teams of specialists across the region to add value to their clinics-to make the visit more enjoyable for the Heart Hero and easier for the medical team. This year we invested in a **TV and DVD player as well as portable DVD players** for use in the North Tees and Hartlepool NHS Foundation Trust North Tees cardiac scanning room.



I cannot thank all of you enough for making this happen and I'm sure it will make a difference to patient's experience when scanning.

Dr Madhu Podalakur Consultant Paediatrician with cardiology expertise.

On behalf of the Children's Cardiac Nurse specialist team thank you for providing the funding to purchase INR home monitoring SATS machines.

These small but fantastic devices, means there is minimal disruption to families in that they do not have to attend hospital for testing of blood levels to determine the effectiveness of blood thinning medication the children take daily. As you will appreciate this undoubtedly provides relief and reassurance to our cardiac families.

Debbie Lawson Children's Cardiac Nurse specialist



The much-loved Clinic E team worked with CHUF this year to plan lots of upgrades to the paediatric cardiac outpatient clinic at Freeman Hospital, including a new TV with a DVD player as well as distraction lights. The TV and lights are now available for patients who need a little distraction during their check-ups. They've been an instant hit with our Heart Heroes, enjoying everything from Peppa Pig to Paw Patrol!

Spotlight on vCreate diaries

Whether our Heart Heroes' stay in hospital is long or short, a child's inpatient journey can be extremely stressful for families, particularly 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.

Difficulties surrounding visitation have only worsened during the Coronavirus pandemic, with disruption to scheduled care and a one-parent visitation policy in place. As a result, families are unable to spend as much time with their child in hospital which is impacting their levels of stress and increasing separation anxiety.

Recognising the challenges parents face when trying to visit their child in hospital, particularly when they are out-of-region, CHUF began investigating the use of secure asynchronous video messaging as a way of keeping families connected. In November 2020, with support and funding from CHUF, Freeman Hospital began implementing the vCreate Diaries service across the Children's Heart Unit. 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. Staff Nurse at Freeman Heart Unit's PICU, Rebecca Jack, said: **"The Diaries service has completely changed the way we do things on the unit. While we continue to update parents on their child's condition, the photos and videos we've been sharing provide parents**

with a physical glimpse into the ward and their child's wellbeing."

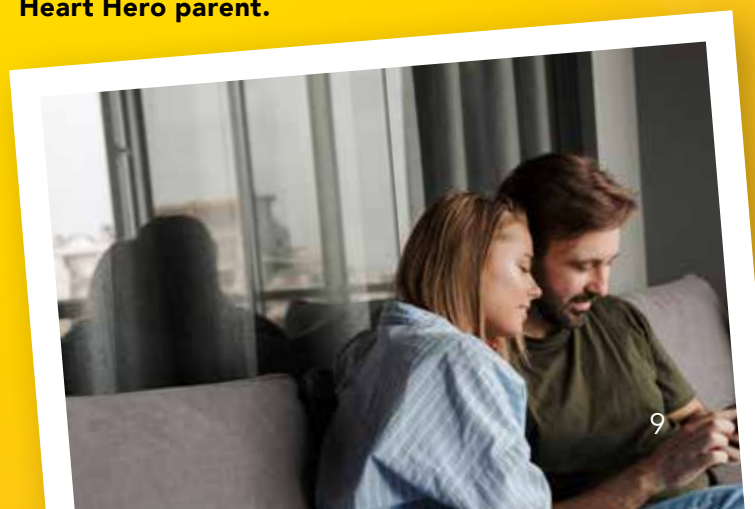
Less than a year since implementation, the impact of the service on the team, families and patients has been transformative. Instead of families missing out on key moments or special milestones the secure service allows nurses to record and save a visual diary of a child's paediatric journey that parents can download and keep forever.

"One of the greatest benefits of the service is being able to capture, save and share a child's progress on the unit with their family no matter the distance or circumstance. We have one family who live out-of-region in Scotland, hundreds of miles from the hospital, whose little boy is with us awaiting a heart transplant. His parents rotate visiting on a weekly basis, and a week's progression on the unit can be massive. Once, when his mother left hospital for the week, the patient could barely lift his head up and, by the following week, he was actively interacting and playing. It was a joy to capture this progress and share it with the family so they could experience it together."

We would like to extend our thanks to a wonderful corporate supporter Clarity Informatics who helped CHUF fund this first year of vCreate.

"This was so valuable for us when our little boy had a long stay in PICU and we couldn't be there overnight with him. Made such a difference waking up to a photo of him. Thank you for making this possible."

Heart Hero parent.



How we have supported families

PICU room décor and furniture at a cost of £3,300.

CHUF recently funded a refurbishment of the Paediatric Intensive Care Unit at the Freeman Hospital, commissioning bespoke wall murals and artwork to brighten up the space and help create an environment interesting for children.



Discretionary charitable fund



CHUF continued to provide a discretionary charitable fund which is administered by the Freeman Heart Unit staff in situations where the NHS cannot help with the little things. **The benefit of having a discretionary CHUF fund is 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 supports emergency travel and helps if people arrive in the middle of the night with nothing. The playroom is also well stocked with craft items thanks to CHUF's discretionary fund. We are always delighted to see our Heart Heroes' artwork proudly displayed.

CHUF washbags

Each family admitted to the Children's Heart Unit in an emergency situation is given a CHUF washbag. This provides basic overnight essentials. Often families who are admitted in an emergency arrive at the unit with nothing at all and CHUF is there to help in those first few hours. It costs £20 to provide a CHUF washbag.



Helping Hand



Throughout the year there are emergency situations where CHUF are able to step in and alleviate some of the financial burden for families; funding emergency taxis when a patient is transferred to another unit is just one way we have support families. We've also funded car parking costs for families who are staying with us for a significant period of time.

In 2020/21 we paid
£3,050
of car parking costs.



Bereavement support

Sadly, not all of our Heart Heroes have a happy ending. The terrible reality is that some do not recover and go home with their families. CHUF fund memory stars, bereavement bags and jewellery charms for all families who lose a child and work with the staff at the Children's Heart Unit to fund bereavement packs. CHUF also began working with Much Loved - a safe platform for families to share their memories and celebrate the life of their Heart Heroes that have been taken too soon.

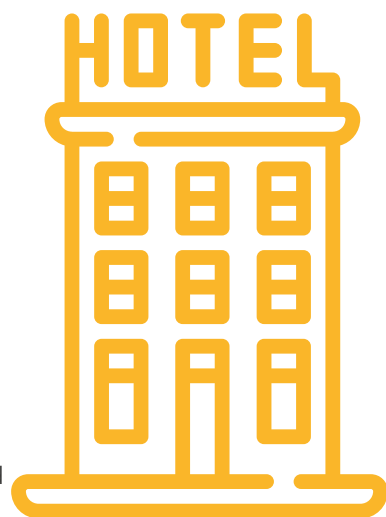
much loved



www.chuf.org.uk/donate/donate-in-memory/



CHUF are proud to have worked in partnership with The Sick Children's Trust to have funded the building of Scott House in 2015. The incredible parents' accommodation based at the Freeman Hospital, plays such an important role for Heart Families when their little ones are undergoing treatment at The Freeman Hospital. The Sick Children's Trust deal with the ongoing day-to-day work of running Scott House and we can't thank them enough for all they do to make Heart Families feel at home. CHUF are pleased to have made a donation this year of **£10,720** to support the running costs for two of the amazing rooms at Scott House. We know what a lifeline Scott House is to our Heart Hero families and what a difference this support will make to so many lives.



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 be together on Christmas Eve and over the festive period. The total cost of additional accommodation CHUF have funded in the last year has been **£3,305.95**.



2020 was a year like no other for children and families in hospital. CHUF worked hard to support each and every family adjusting to changing restrictions. In March, the communal kitchen space in Scott House could not be used due to government guidelines around Covid-19. CHUF stepped in and provided an **emergency float to feed families**.

Thanks to the support of the **National Lottery Community Fund and the P&G fund** we were able to continue to meet this newly arisen need and provided **over £14,000 of meal vouchers** for parents to have a hot meal in the hospital canteen. We also supplied breakfast and snacks for the Unit. This support has continued throughout the whole year, to ensure that Heart families are well looked after. The feedback from families has been that this support is invaluable.



"My partner and I couldn't be on the ward together at the same time due to the covid restrictions, so we were like ships passing in the night. When CHUF provided the meal vouchers for the hospital canteen, that was the one time of day we could sit down together and support each other. If we hadn't have had the meal vouchers I don't think we'd have done that- feeding ourselves didn't feel like a priority, but really it helped so much at a stressful time with our little one so poorly"

Anon



CHUF continues to support new mothers of Heart Heroes wishing to breastfeed with **breastfeeding packs. Funding 60 packs in 2020-21.**



How we have supported Heart Heroes



The last year our support of Heart Heroes, especially those in hospital, has never been more critical. The restrictions on visitors and importance of keeping children being treated in hospital safe, meant that many of the normal enjoyable activities on the Heart Unit were unable to continue. From the very beginning of the pandemic we set out to make life in hospital with reduced outside contact as easy as possible.



Magazine subscriptions
– **£100**



Additional toys for each area of the Heart Unit so that toys were not being passed around – **£2000**



Additional arts and crafts activities which could be enjoyed at the bedside working with the amazing play team to ensure that children could still enjoy arts and crafts individually – **£1300**



Unlimited wifi enabled tablets which allowed our gaming enthusiasts to enjoy uninterrupted gaming on demand as well as our Disney fans enjoying our subscription to Disney+ – **£2500** annually.

Cuski Miniboos

We continued to fund Cuski Miniboos supporting 30 more families with the adorable little cloths which can be used to absorb the parents' scent; it is then given to babies who may be incubated or are not able to be held by their loved ones so that they can still bond and feel close.



The mini boos are given to families of new admissions - mainly babies, but can be used for all children admitted to PICU. We have found that they provide a great comfort to the whole family. Being an intensive care unit, we are unable to have families staying overnight with their child, but we've had reassuring feedback that just knowing that their child has the MiniBoo to act as a comforter is a massive relief and they feel more settled in leaving their child.



Baggins Bear continued to support our Heart Heroes who underwent surgery. Baggins is there to greet our Heart Heroes as they awake from surgery and go home with them as they recover as a special momento of how brave they have been.



Celebrations



We worked hard to ensure celebrations were made extra special for our little ones who could not be at home with all of their families or other siblings. **CHUF spends approximately £5,000.00 each year to ensure that Christmas is a magical time of year 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.

In December 2020, thanks to the generosity of Rent A Reindeer, CHUF arranged for a reindeer to visit the unit and for a hot chocolate and crepes van to serve the patients, families and staff festive treats whilst they enjoyed meeting Santa's helpers in a safe and socially distanced way. In 2020, CHUF also funded

Christmas scrubs for staff to wear on Christmas Eve and Christmas Day and Christmas food vouchers and hampers for all families in hospital over the festive period to enjoy.

Other celebrations throughout the year were marked with gifts, decorations and special treats and deliveries, with **Easter** bunnies and books brightening up Easter celebrations, sweets and decorations marking **Halloween** and a **Valentines** afternoon tea to help show our love to all of the families in hospital. The celebrations for **Wear Red for CHUF** day were epic with wear red themed dress up, arts and crafts and special cake deliveries!



Adult Congenital Heart Disease patients

CHUF have been working with the team of specialist nurses at the Freeman Hospital to extend our support to **Adult Congenital Heart Disease patients**. We passionately believe in our commitment to lifelong support and have moved to implement simple but effective support of this service in the last year. With restricted visiting and the need to shield we extended our washbag support to the adult service funding **20 washbags** to be given to those who need it.

A **discretionary fund** was also established to support the team when caring for our adult Heart Heroes to help where it is most needed, whether that be with enabling out of area patients to have visitors to stay for the weekend by providing accommodation or to help mark special occasions with birthday cards and cakes. We also funded unlimited wifi on the ward to enable patients to communicate more reliably with their families by facetime or video call. Access to unlimited wifi has also helped pass the time for many of our patients who can now stream more reliably and enjoy unlimited access to the internet.





The Clown Doctors

Since 2006, CHUF has worked in partnership with TIN Arts delivering **The Clown Doctors** programme at the Freeman Hospital and close to 10,000 individuals have benefitted in that 15 years.

In March 2020 as the nationwide lockdown hit, the Clown Doctors were no longer able visit the Freeman hospital in person. CHUF and Tin Arts came together to swiftly develop a solution so that we could continue to reach out to those who needed us most. We developed a digital platform that would serve Heart Heroes wherever they were; a magical place where familiar Clown Doctor friends could continue to provide distraction, laughter and connection. We set about building a new website with a distinct identity full of new engaging content generated by the talented performing artists and play therapists we know and

love as the Clown Doctors. **The Beat Squad** is secure and tailor-made with fun videos, engaging activities and lots of ideas of things to do. CHUF made this available to Heart Heroes across the country whether in hospital or shielding at home. This new service came at an additional cost of **£10,000** to CHUF, but allows Heart Heroes to benefit from the array of content year on year.

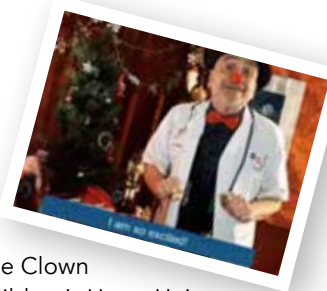


After months of reaching out virtually, in October 2020 the Clown Doctors were able to return to 'in person' delivery on Ward 23. These socially distanced visits took place using the outdoor area and playroom. Clown Doctors followed covid-secure procedures in line with advice and guidance provided by ward staff and Infection Control.

CHUF provided further funding to enable the transformation of a shed in the outdoor area into **Clown Doctors HQ** which provided a more pleasant (and weatherproof) backdrop for visits.



The 'Special Delivery' programme was established as the Virtual Clown Doctor programme, known as 'Very Special Meetings'.



The Very Special Meetings were piloted with young people, all of whom had met and engaged with the Clown Doctors during their years on the Children's Heart Unit and were now living with their condition at home and attending outpatient appointments at the Freeman.

The Special Delivery programme has been a resounding success and we are keen to continue to grow the programme.

CHUF has funded the Clown Doctor programme in 2020-21 at a cost of **£34,000**.



97 videos have been created and published online



1,908 views of videos



The Clown Doctors are such an important part of life at The Freeman. They bring smiles to faces when you really don't feel like smiling. Lovely that they are still bringing joy even in such difficult times! xxx



Natalie Holmes,
parent supporter



Introducing the...
Beat Squad

Come and join our gang on a great big adventure!



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

World leading Fontan nurse

We are honoured to have been able to fund a Fontan Nurse Specialist at the Freeman hospital. This is the first and only position of its kind in the UK. Single ventricle patients effectively have half of a functioning heart, and their complex condition means that many will require the Fontan procedure, which can hugely extend life expectancy. The Fontan system however must be carefully maintained. The Fontan nurse specialist looks after children and adults with a Fontan circulation ensuring their heart and liver function is monitored regularly. CHUF has now funded a third year of this post thanks to our supporters' incredible generosity. Because of this investment, all single

ventricle (Fontan) patients are now on a Trust approved clinical database. Meaning both adult and paediatric patients who might otherwise have been lost to follow up, have subsequently been seen in clinic or referred to a local Congenital cardiac team. Regularly sharing knowledge across the country and feeding into innovative research projects the CHUF funded Fontan nurse is a world leading position helping to improve care for single ventricle patients across the UK. A large proportion of this role is dedicated to research that could, one day, turn around life-expectancies and long-term experiences of Fontan patients.



There are three active Fontan research studies involving single ventricle patients including:



Finding genes that cause hypoplastic left heart syndrome.



Following the Fallot and Fontan population (research database).



Assessment of patterns of patient reported outcomes in adults with congenital heart disease internationally.

Specialist Nurse Team

In order to increase the capacity of the Specialist nurse team, CHUF funded the **Children's Cardiac Nurse with a special interest in Complex Discharge Planning** at the Freeman Hospital. This post is fully funded by CHUF at an annual cost of **£56,000** and is having a significant impact on discharge planning for complex patients.

Often the most vulnerable time for some of our Heart Hero babies is following discharge whilst they await further procedures. There is clear data to show that appropriate discharge planning and ongoing support for families at home is vital. The specialist discharge nurse has considerably expanded the care offered to families. The role continues to improve the service not

only through direct interaction with the patients and parents but also by developing literature available to the wider team, training other members of the department and supporting the basis for safe discharge and follow-up.

The post funded by CHUF provides incredible quality of care and allows, parents to look after their babies/ children at home with all the advantages this brings. Your ongoing support is helping us to continue to fund services like this, thank you – you are amazing!



CHUF funds a Psychology service in Cumbria and South Tees at a cost of £40,000 per year




There is robust evidence that highlights the psychological impact of living with and receiving treatment for Cardiac conditions.

This supports the importance of offering psychological care to help families manage distress and treatment-related challenges.

The role of CHUF funded psychologists:

- Direct therapy with patients and families
- Offering facilitated groups for patients
- Supporting staff to deliver high quality care

The impact of our psychology services is expansive, supporting the medical teams to continue to monitor and provide ongoing treatment. Working with the North East and North Cumbria Congenital Heart Disease Network we plan to develop the psychology service across the region in the coming years and are working with patients, parents and clinicians to ensure that the service continues to provide outstanding care closer to home.



Sarah was referred to our psychology service at 13 years old (Sarah's name has been changed to protect her identity). After receiving a heart transplant with a severe needle phobia and behavioural issues, face to face work with Sarah pre-covid focussed on needle phobia work.

The psychologist was also able to explore issues around self-esteem, and discuss the long term impacts of her transplant. At the end of the sessions with the CHUF funded psychologist Sarah was able to tolerate blood being drawn. Work continued via telephone during last summer due to covid. This work focussed initially on issues relating to self-isolation, worries about

vulnerability of her and family members. Support was also given to worries around returning to school in Autumn. There has been a reported improvement in how Sarah is tolerating procedures and no further psychology input is needed. The family very much appreciated the support given and that the service remains open for future support should it be needed.

Currently there are 36 children and young people and their families who have direct open access to the CHUF funded psychology service.

The North East and North Cumbria Congenital Heart Disease Network (NENC-CHD) covers a population of 2.9 million people in the North East and North Cumbria, and is hosted by the Newcastle upon Tyne Hospitals NHS Trust (NUTH). The network aims to provide services in line with the agreed standards of care and which operate within a Network Model encompassing the whole lifetime of care.

It works collaboratively to develop and support national, regional and network arrangements that facilitate mentorship and centre to-centre referrals. The network vision is to provide high quality, equitable care for CHD patients wherever they live within our region; provided closer to home when possible, ensuring seamless transition between fetal, paediatric and adult services and providing a holistic approach to care.



nenc-chdnetwork.nhs.uk

Working in partnership with the NENC-CHD

CHUF is working closely with the NENC-CHD network to continue to support cardiac care across the different regions, to inspire innovation and improve care. The network have established clinics in Middlesbrough, Stockton, and Carlisle to support care closer to home. A number of patient engagement forums as well as education sessions for clinicians across the network have taken place.

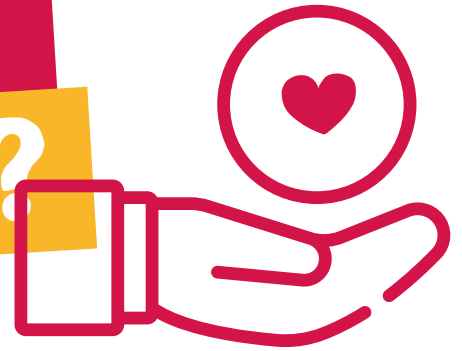
The network and CHUF team have worked closely together to continue progress throughout the pandemic and realise improvements across the network which will directly impact the care of Heart Heroes for years to come.



The Coronavirus pandemic created significant challenges for the medical teams we support. In 2020 the need arose for CHUF to support the delivery of **fetal cardiology** sessions to complement and develop current fetal cardiology services in the Northern Region. CHUF have agreed to fund additional clinics to ensure timely scanning of pregnancies in the face of COVID 19 without reducing service to new patients in the paediatric clinic. **This support is a short term top-up for the NHS costing £14,000.**



How have we fundraised?



2020/21 has been an unprecedented year for fundraising at CHUF, full of challenge and change. We are proud to share that in the face of adversity our fundraising team proved agile and worked diligently to ensure that we transformed challenges into opportunities.



The 2020 **CHUF toddle** turned virtual. With our annual in-person celebration being cancelled we worked with our supporters to encourage them to take up their own toddle at home and were thrilled to raise **£11,000** which the Sir Graham Wylie Foundation generously matched with a gift of **£10,000** effectively doubling our supporters efforts and helping to deliver twice the impact.



The annual **CHUF Christmas party** sadly could not go ahead, instead we worked in partnership with the wonderful Clown Doctors team to develop an online Christmas extravaganza, with daily advent clips of our Clown Doctors getting ready for Christmas and weekly cosy-dozy story times written and performed by the Clown Doctors themselves. We so missed seeing our Heart Heroes in person but thanks to the creativity of our partners we were able to share some Christmas magic.



The **Great North Run** was cancelled in September 2020 and therefore, **160** of our dedicated runners have had to wait another year to take part in the iconic race. Many people however got involved in a virtual 'solo' run and raised over **£4400**. We can't wait to celebrate together at the end of the race in 2021!



Despite much of our usual fundraising activity being cancelled we launched lots of new initiatives which have helped us continue to fundraise successfully and which we hope are helpful to our wonderful supporters.



The launch of our special **Tribute funds** has been a brilliant addition to our online resources. Allowing supporters to establish a virtual area in tribute to their loved one where pictures, videos and memories can be shared and also donations can be made. Over the past year we have received over **£11,000** in donations given in memory of a loved one. www.chuf.org.uk/donate/donate-in-memory/



We have also partnered with **Will for Good** to offer our supporters a platform to create their will for free. In the last year we have been extremely grateful to have received over **£68,000** of gifts left to us in a will. This incredible way of giving ensures that beyond your life you continue to enable Heart Heroes to reach their full potential. www.chuf.org.uk/donate/leave-a-gift-in-your-will/



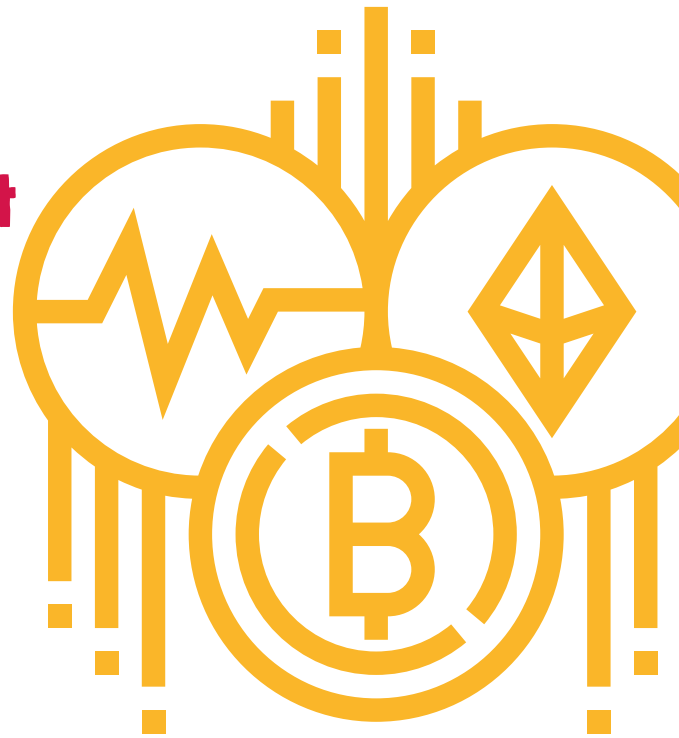
In response to the increasing need we worked with numerous **Trusts and foundations** to fund specific and immediate requests and services. Receiving over **£120,000** in awarded grants. See **page 20** for special thanks to our donors.



Our **regular giving** programme continued to grow with many more donors signing up to support CHUF, annually raising over **£8000**.



CHUF began to accept Cryptocurrency in 2020 and received a donation thought to be the largest donation to a UK charity in May 2020.



As the UK went into lockdown, we launched an appeal to raise **£15,000** in just eight weeks so we could continue our response to the Covid-19 pandemic. The appeal travelled all the way to the US, seeing two generous donors giving a combined **£38,000** in cryptocurrency.

The life-changing donation was made using the platform The Giving Block. This intermediary allows charities to accept cryptocurrency safely, making relevant checks to ensure that the charities are protected and fully compliant.

“Dan Bainbridge, one of the two generous donors, pledged over **\$10,000** to the charity. He said: **“I was a heart baby and have been personally supported by CHUF all of my life. I’ve always wanted to give back and now working in cryptocurrency I saw an opportunity to help CHUF get setup to accept cryptocurrency donations (bitcoin and ethereum) online.”**”

“Charlotte Campbell, Director of Fundraising and Operations at CHUF, said: **“The Coronavirus pandemic has been one of the biggest challenges we have ever faced. Our Heart Heroes and their families have needed CHUF more than ever, all while fundraising events came to a standstill overnight. People have given so generously and having these vital funds means we can put even more focus into supporting our Heart Families during these hard times. From the bottom of our hearts, thank you to everyone who has helped us.”**”

“Alex Wilson, Co-Founder of The Giving Block, added: **“We regularly see large donations from corporate donors through our site but it is rare to see donations of this size from individual givers. We are delighted that this money will be used to help Heart Families in the UK and look forward to continuing to work with CHUF to keep the momentum going.”**”

With special thanks to

CHUF relies upon money and support given to us by the public, from businesses and granted by trusts and foundations. We are honoured that so many continue to trust in CHUF and see value in collaborating with the charity; generously donating time, services and funding.



Sir Graham Wylie Foundation deserves a special mention. Having previously agreed to sponsor CHUF's annual toddle for the 2nd year running; they didn't hesitate to take a more flexible approach when the pandemic scuppered plans for the usual in-person event. They allowed CHUF to adapt their £10,000 in funding, to be used as a match-funding initiative for our first ever Virtual Toddle event.



Clarity Informatics, part of the Agilico Group had already chosen CHUF as their charity of the year and had originally planned staff fundraising events for

Summer 2020. In March, it became apparent that these events would no longer be able to go ahead. Without any prompting, the company reached out, asking: "how can we help?" This offer came at a time that CHUF was looking at ways to help keep families connected with each other and with medical teams. Clarity provided the first year of funding for the innovative VCreate and we couldn't be more thankful.



Long-time supporters **JT Dove** have raised in excess of £100,000 for CHUF. Despite Covid and Brexit presenting unprecedented challenges, and the team not being able to get out and fundraise as usual, JT Dove still managed to show CHUF its commitment by providing an amazing top prize for the Christmas raffle. The prize, worth £1,000 to spend at any JT Dove branch, allowed the lucky winner to renovate and create their dream home or garden. The prize also encouraged more people to get involved with CHUF's Christmas raffle, which raised £8,000! You are invaluable supporters, thank you!

Trusts and Foundations: It is fair to say that grants from Trusts and Foundations greatly buoyed CHUF services at a time when our income streams from events, 'in aid of' challenges, corporates and individuals was so massively impacted. From supporting CHUF with unrestricted funds that helped cover some of our core costs, to helping us to feed families, or supporting the creation of a new virtual Christmas advent offering, to enabling us to meet rising need for new, portable equipment, these awards, grants and donations have been life-changing. We very much hope to continue our work together! There are a few charitable trusts who have supported CHUF in the last year, that would prefer to remain anonymous; you know who you are, and we hope that our impact report reflects the incredible difference that you have helped CHUF to achieve.



Thank you...

...also to the staff 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 to all the companies that donated prizes for CHUF's Christmas Raffle, and the bakeries who got involved in raising funds for CHUF throughout Heart Month.

Last but not least, an enormous thanks to all our dedicated CHUF volunteers for your ongoing support and patience. We are so looking forward to working with you again.



Looking ahead

Like many charities, our fundraising income was hit hard in 2020 and we saw a 20% drop in income. However, despite the enormous challenges we faced we continue to be encouraged by your commitment and generosity. With your help, CHUF ended the year with a total income of over **£576,000**. Thanks to your support and the phenomenal efforts of our CHUF team, the clinical teams we support and our wonderful partner organisations it has been possible to initiate innovative and essential new projects whilst allowing us to continue life-changing support and services. This impact report features just a snapshot of what has been achieved, much of which has only been possible thanks to you. We hope you are inspired by and feel immensely proud to have played a part in this.

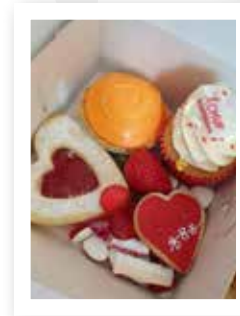
As a charity, our support has never been more needed and we have ambitious plans to grow our impact and achieve our strategic aims in the coming three years. The core CHUF values have led our actions over the last 12 months and remain at the forefront of our plans for the coming twelve months.

- **We are open, honest and caring, with respect for all.**
- **We welcome diversity and the new outcomes that inclusive collaboration brings.**
- **And we are committed to putting Heart Heroes at the centre of all we do and working towards what has the most positive impact for Heart Families.**

With your support, our vision to support pioneering services that will positively impact heart families, inspire hope and enable Heart Heroes to reach their full potential can be realised and for that we thank you from the bottom of our hearts. We couldn't do this without you! **#CHUFisForLife**



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







Impact Report

2020-2021



Charlotte Campbell
Director of Fundraising
and Operations



Alicia Clovis-Mothalib
Corporate and Trusts
Fundraising Manager



Kayleigh Edwards
Fundraising Administrator



Suzanne Smith
Finance and Grants Officer



Shannon Hands
Community and
Volunteer Fundraiser

**Inspiring hope and enabling
Heart Heroes to reach their full potential**

chuf.org.uk     **@CHUFOfficial**

CHUF is a registered charity in England and Wales No 1160831



 **info@chuf.org.uk**

 **0191 281 3166**

#CHUFisForLife



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