



Celebrating 30 years of supporting the Leeds Congenital Heart Unit. From clinical staff to patients and fundraisers - it's all Because of You.



# **Contents**

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03	Introducti	$\cap$
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- **04** CHSF Timeline
- **06** Heads of LCHU
- **07** The Teams behind the Scenes
- **08** SOS
- 10 The Heart of the Matter
- **12** A Patient Journey
- **14** Fundraising
- **15** CHSF Events
- **16** Corporate Partners
- 17 CHSF Ambassadors
- **18** #BecauseofYou Stories
- 19 Thank You

# Abbreviations used throughout:

CHSF: Children's Heart Surgery Fund

**LCHU:** Leeds Congenital Heart Unit

CHD: Congenital Heart Disease

PICU: Paediatric Intensive Care Unit

# Introduction



Sharon Milner CEO

Dear supporters,

CHSF is celebrating an amazing milestone in 2018 - 30 years of supporting hearts for life! Your donations have helped fund care and treatment for congenital heart disease patients and their families across our region for three decades and this magazine pays special tribute to those who have made it happen - it's all #BecauseofYou! When Duncan Walker set up CHSF in 1988, he couldn't have expected either the challenges which lay ahead nor the tremendous depth of support and goodwill we enjoy today from across Yorkshire. North Lincolnshire and the Humber. Together we have made huge strides in caring for those stricken with congenital heart disease - and their families. Your donations have helped develop the LCHU into a facility of both national renown and local pride.

From the early days at Killingbeck, and since I joined the charity as CEO in 2007, the CHSF and LCHU teams have grown beyond recognition. Our scope and remit has increased in line with the positive outcomes of patients – and your fundraising has been fundamental to all our achievements. Support from families has never waned, and passionate advocates have furthered our presence across Yorkshire and beyond. We couldn't do any of this without the passionate fundraising of individuals, families, schools, businesses and organisations who choose to give their time to create positive change for the good of others.

It is evident that 2013's **Save Our Surgery (SOS) campaign** has secured care for generations to come, as we now know LCHU will be a designated surgical centre. The success of SOS was thanks to the unprecedented support of so many: 600,000 signatures of local supporters to counter the proposed closure, the rallying of local politicians, enormous yet peaceful demonstrations and £240k raised in 4 months for a court case that set a legal precedent in case law history. You continued to believe in your Heart Unit despite the negativity that

was coming through the national media. Your support never waned, and for this, we salute you. Thank you to one and all!

Our more recent challenge, the **Keeping The Beat campaign** to raise £500,000 towards a new children's heart theatre, was completed within two years of its launch on May 2018. The tireless efforts of fundraisers and advocates has ensured this revolutionary and much-needed facility will open in February 2018. This amazing step forward will save lives for generations to come. Thank you.

Behind every charity sits a Trustee Board, these people are volunteers, giving their valuable time and commitment to supporting a cause in a positive and constructive way. Their role is to provide governance and support to CHSF staff. The team would like to pay tribute to both past and present members of the CHSF Board, who have made a significant contribution to the work of the Charity, over the last 30 years.

Finally, I'd like to pay tribute to ALL the staff across the LCHU (past and present) whose skill and passion in this complex specialty ensure that patients across the region get the very best care and treatment. They really are the best in their field delivering world class treatment, and we're proud to work with such inspirational teams and individuals.

CHSF has developed strong plans to make sure we optimise care for the heart, mind, family and future of congenital heart disease patients, and continue our mission of supporting hearts for life. We need your help more than ever to deliver that plan – after all, everything we can do is because of you. Here's to the next 30 years!

Yours faithfully,

Sharon Milner

# **Timeline** Children's Heart Surgery Fund

# 1988



1988

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



1989

The first big fund donation enabled a new **PICU** theatre to be built.



1997

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



2007

Sharon Milner joins as CEO



2010

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



2011

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

About Katie Bear: Rumour has it that the design for Katie Bear was drawn by a young patient called Katie, encouraged by her grandfather. Your favourite bear is available for hugs and photos at CHSF events. She's also given as a teddy to every CHD patient who has had open heart surgery at the LCHU









# Hear Segrey had Segrey

# 2012

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



### 2013

**SOS** campaign wins legal battle for LCHU to stay open.



## 2014

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



### 2014

Move to **Brotherton Wing**, opposite
Millennium Square.



## 2016

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



## 2017

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



2018

# 2018

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

**About our Logo** Like Katie Bear, our branding has also changed over the years to refresh our image and keep up with the times!











# Thank you from heads of the LCHU

We also have some clinicians on our Board, who act in an advisory capacity. This is very useful to non-clinical Trustees when assessing future projects and also ensures good governance.

We asked past and present surgeons and cardiologists why the LCHU still needs your support.

Congenital Heart Disease accounts for more than

25% of all birth defects



### Miss Carin van Doorn

Head of Congenital Cardiac Surgery

"When the Leeds Congenital Cardiac Unit started at Killingbeck Hospital in the 1980s, there was one surgeon, one cardiologist, and one anaesthetist. Nowadays, our team is 10 times this size and includes specialists in imaging (cardiac echo and MRI), intervention (keyhole catheter procedures), foetal echocardiology, electrophysiology (such as pacemakers) and intensive care specialists. Moreover, we simply could not work without our skilled nurses, cardiac liaison nurses, physios, clinical psychologists, play specialists and many more.

Over the years, CHSF and their supporters have played a crucial role in the development and sustainability of the LCHU. They have paid for vital equipment, supplied parent accommodation, supported staff education, and fought a successful campaign to keep the Unit open at a time of national reorganisation. As a congenital cardiac team, we are now building on a Centre of Excellence and want to be on the forefront of innovation and training. Thank you!"



**Dr Kate English** Adult Consultant Cardiologist

"In 1988 when CHSF was founded, the numbers of adult patients was small, but now there are actually more adult patients living with congenital heart disease than children! Recognising this in 2012, the aims of CHSF were formally changed to include the support of adult patients and their families.

Since then the CHSF has supported our work in a multitude of ways including salaries for extra support staff, research projects and further training for our trainee doctors, buying small and large pieces of equipment, and refurbishing the day room on our ward (L16) in memory of our colleague and ardent CHSF supporter George Ballard who tragically died in the summer of 2015.

The future promises to be busy and complicated as more and more people born with the most complex congenital heart disease benefit from the expertise of our paediatric team and survive into adulthood. Because of you, we can look forward to working with the CHSF team to deliver the best possible care to our patients."



# **Dr John Thomson**

Lead Cardiologist

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

We have increasingly relied on CHSF to help fund staff, both to give young doctors a "chance" in cardiology (a competitive speciality) and to help our more senior trainees along the pathway to becoming a consultant. Thanks to you and because of you, we are a large and thriving department with much to look forward to. Here's to another 30 years!"



### **Dr Kevin Watterson**

Retired surgeon and former Chair of the CHSF Board of Trustees

"I'm really proud of what CHSF has achieved over the years, it's been vital - we wouldn't have been able to achieve what we have without your support. It's a relatively small charity which punches well above its weight, and that's thanks to the team and its supporters - it's all Because of You!"

# The teams behind the scenes

# **CHSF Trustees**

Over the years we have had a variety of Trustees supporting the charity, with a diverse range of skills. We would like to pay tribute and say 'thank you' for all the years of support and dedication they have given, some longer than others.

We would like to pay a special tribute to Graham Berks. Graham has sat on the Board since its inception, we will say a fond farewell to him at the end of this year - his support and dedication has been fantastic.



**Andy Chilton** CHSF Chair, Business Co-owner, Trustee - 5 years



**Paul Goodwin** Proposition and Growth Parent representative. Trustee - 18 months



Leader for Mercer pensions.



Andv McNallv



Sharon Milner

CEO

**CHSF Staff** 

**Mark Rogerson** 



Finance Manager



Olivia Richardson



Digital Marketing Executive



**Mvriam Barker** Trusts & Foundations Manager



**Ben Andrews** Corporate Partnerships Manager



Lisa Williams Community Fundraiser



Ellie Brown Senior Corporate Partnerships Manager



**Angela Casey** Admin. & Finance Assistant



Jane McCarthy Admin. & Finance Assistant



Charlotte Anderson-Hughes Events Manager



Francis Evans Hannav Project Manager



Hanif Malik Operating Director at Penny Appeal, Board member of Yorkshire County Cricket, Trustee - 4 years

Clinical Psychologist, LCHU,



Carin Van Doorn Head of Cardiac Surgery, LCHU, Trustee - 4 years



**Graham Berks** Ex Accountant/ Entrepreneur, Trustee -30 vears



**James Oliver** Adult Cardiologist. Congenital Heart Disease, LCHU, Trustee - 4 years



Business Development Consultant, Trustee -17 years

Samantha Robinson

Head of Operations,

representative. Trustee -

NHS Digital, Parent

3 years



Simon Maule Business owner, Trustee - 18 months

# **CHSF Staff**

The CHSF executive team go above and beyond to support all aspects of our work, working closely with parents, corporate partners and many other organisations. Their commitment to the cause is unparalleled and was particularly memorable through the unexpected, campaigning years.

CHSF is wholly self-funded and has been since the very beginning. Without the support of a selfless hard-working team both past and present, we wouldn't have reached our 30th Anniversary or be as strong as we are now.



Mark Whittaker

Sara Matlev

Trustee - 7 years



Communications Specialist,

# Save Our Surgery

# Because of You: the success of the Save our Surgery campaign

In 2010, the "Safe and Sustainable" review started looking into national children's heart surgery services, following a scandal at the Bristol Royal Infirmary during the 1990s. The review aimed to determine if surgical expertise was spread too thinly over 11 surgical centres. Following consultations in 2011, it was clear the Leeds Congenital Heart Unit was earmarked for closure.

**Because of You**, the Save our Surgery (SOS) Campaign was set up by CHSF to oppose the closure and keep the Unit open.



The SOS campaign led meetings with local MPs, and attended meetings with the Joint Health Overview Scrutiny committee (JHOSC) in March 2011. There followed a demonstration against the closure at the Royal Armouries in May 2011. Over 600,000 signatures were collected in a petition and handed into Downing Street in June 2011.

**Because of You**, awareness initiatives followed, such as a stunt in September 2011 in which families from our region joined the SOS protest





outside the review's public consultation meeting in Leeds. In June 2012, the review formally recommended the downgrade of the Leeds Heart service, along with London and Leicester. Closure of surgery at LGI would have meant



**Because of You**, there was a passionate outcry against this action, with concerns that







this would lead to the deaths of children, amongst the emergency (acute) cases. In July 2012, SOS led a huge peaceful demonstration, throughout the streets of Leeds. Approximately 4,000 campaigners marched through Leeds and a local Joint Health Overview and Scrutiny Committee meeting immediately followed.

**Because of You**, the SOS campaign won an award for the best Healthcare campaign at the CIPR Pride Awards in November 2012, and on 7 March 2013, the High Court ruled that the decision to propose the closure of the unit had been unlawful.



Just 24 hours later, however, it was announced that children's heart surgery at the LGI was suspended. Medical Director Sir Bruce Keogh (the architect of Safe and Sustainable) arrived at LGI on March 28, 2013, to demand children's heart surgery should cease with immediate effect based on flawed data about mortality rates.

Doctors at the unit stated that the data used to halt operations was incomplete and inaccurate. Following complaints from local MPs, Councillors and concerned patients as well as doctors,

the unit resumed performing surgery just two weeks later.

2011 balloons were released outside LGI to reflect the number of heart procedures carried out at the Unit since 2010. The Health Secretary (Jeremy Hunt) concluded after an independent review by the Independent Reconfiguration Panel that Safe and Sustainable wasn't fit for purpose and agreed with the recent court judgement.



Because of You, numerous more SOS fundraising initiatives followed. The campaign received amazing cross-party support from MPs - over 30 battled on our behalf. LGI staff were united in the battle to stay open with patients and SOS campaigners joined through the same goal. The Veritas review, yet another independent body, concluded in 2014 that the sudden suspension of children's heart surgery at the LGI was made based on flawed and inaccurate data. A new review, welcomed by all, was created by the newly formed NHS England.

In November 2017, the LCHU was finally been given the official green light to stay open. In 2019, LGI will open a revolutionary heart theatre under criteria set by NHS England and you raised £500,000 towards this state-of-the-art facility in our Keeping the Beat campaign.

The new theatre is currently being built, it looks amazing, and the LCHU goes from strength to strength - **Because of You.** 



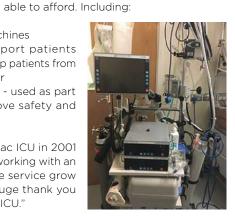




**Sharon Coulson**PICU Senior Sister

- New ECMO life-support machines
- Vapotherm Units to support patients breathing and sometimes keep patients from needing to go on a ventilator
- iPads and prescribing desks used as part of a safety initiate to improve safety and quality of care

I first started on Ward 4, cardiac ICU in 2001 and have had the privilege of working with an amazing team and witness the service grow into what we have today. A huge thank you from me and all the team on PICU."



which we wouldn't have otherwise been

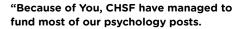




**Sara Matley** Lead Consultant Clinical Psychologist

Leeds has one of the largest CHD Psychology and Counselling teams in the country, which has been at the forefront of developing the cardiac standards in psychological care.

Thanks to your support, the team proudly celebrated the 20th anniversary of the Psychology and Counselling Service in spring 2018."



Originally, the psychology service covered just half a day a week, and I was appointed to this role in April 1998. Without your support the team would not have developed to the 7 members there are today, who are able to offer emotional and psychological support to patients and families.

Over the years, CHSF have also helped us access training courses, attend conferences, along with buying resources to use in therapeutic work.





Your donations are absol patients, their families and frame that support in term and future - areas which further explanation from s the heart o

# Please help us continue supporting hearts for life:



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



We believe that caring for the mind is just as important as caring for the body. As well as psychological support, we help create a restful, positive ward environment for patients and their families and provide play and distraction equipment throughout. We would like to do more in this area of support.







**Debbie Smith** Children's Cardiac Ward Sister

"Because of You, parent accommodation has always provided huge respite for our heart families. From the bungalow at Killingbeck in the old days to Eckersley House and the Brotherton accommodation at LGI, it has meant they don't have to travel many miles every day to support their children and gives tired parents a place to gather their energy.

The ward had a family atmosphere when I first started, and it still has to this day. Nurses can support families from diagnosis through to discharge but the only people that truly know how parents feel are other families.

CHSF provides the means for families to come together and gain support from one and other, whether that's meeting up at fundraising events or supporting each other on the CHSF Facebook page.

I would also like to pay tribute to the play specialists, Emma and Gemma - whose jobs are to support CHD children and their heart families by providing distracting and normalising play opportunities on the ward to help them all cope with what is going to happen. Facilities funded thanks to you, such as interactive TVs, arts and crafts and the resident fish tank help to keep families and their children both distracted and engaged."





# "Because of You, the whole Paediatric Cardiac Specialty, has moved on tremendously.

I have worked as a nurse on the Cardiac ICU for many years and can remember in the early days how we admitted children and adults on to the same unit after surgery.

Some of you will remember Katie's Kabin which raised money for the charity and sold hand knitted cardigans, home baking and keyrings alongside bits of rubble which we were told had been part of the Berlin Wall!



**Beverley Robinson**Clinical Educator, PICU,
HDU and Cardiology



We always wondered about the rubble...! CHSF merchandise has moved on too!

Today, I am a Clinical Educator for PICU and Cardiology so I liaise regularly with the charity to request help in the training and education of nurses.

CHSF enables staff to attend relevant conferences and just this year Leeds PICU has been represented both nationally and internationally thanks to the financial support it has offered. Thank you."

# Donate to Children's Heart Surgery Fund online at chsf.org.uk



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often overlap - but here's

ome of the clinical staff at

We do everything we can to support families practically and financially during their child's hospital stay. We award grants for travel expenses to ease the financial burden of travelling across Yorkshire to visit a child, and fund accommodation close to the hospital.



Techniques and technologies are constantly changing, so we make sure we are always aware of what's happening next in the world of CHD by funding training, and a small amount of research positions and projects.



**Scan me** and help us!

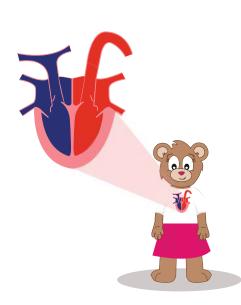
Or please call us on **0113 831 4810** 

# **A Patient Journey**



The LCHU is made up of several linking departments which help facilitate a typical patient journey - from detection to surgery, intensive care to outpatients.

Because of You, these vital services have the latest equipment and facilities, and both patients and their families have state-of-the-art care along the way from specialist nurses and psychology.



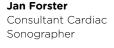












"An echocardiogram (echo) uses high frequency sound waves to assess the structure and function of the heart.

Echocardiography is perhaps the most important investigative

technique used in the routine, day-to-day management of congenital heart disease for all ages - from antenatal detection, throughout childhood to adulthood.

The technology involved in the technique has dramatically improved over the years. Nowadays the information obtained means that there is less requirement for invasive investigations such as cardiac catheterisation. We can also now obtain additional 3D echo images of your heart which can help in planning procedures on your heart.

The department has been supported by CHSF and supporters for many years providing specialist echo equipment and probes which has enabled us to have state of the art equipment and excellent diagnostic confidence. With your continued support we aim to continue to provide the best diagnostic echo images for all our patients."







Support



### Mike Fresson

Children's Cardiac Nurse Specialist

"We support the CHD patients and their families across our region from fetal diagnosis through childhood, and the adult team support through adulthood. Your donations help fund the equipment we rely on daily - for



instance, the distraction toys and stickers we use in our clinics and the INR (blood-testing) machines that patients can use at home. Because of You, we can attend meetings and conferences around the country. CHSF entirely funds the LCHU online pages - we are one of the only units to have our own dedicated website - covering fetal to adult care.

CHSF provides the resources we use to support the families - from financial support for extremely long stay patients, to the parent accommodation. You also funded the book Katie Bear Goes to Hospital, which is given to every patient due

to have open heart surgery - which has proved a huge help to families too.

With your help, we are able to provide the holistic, familycentred support we have today, and it will remain for the years to come. Thank you CHSF for all you do. and happy birthday!"





### **Dr Carol Bodlani**

Consultant Paediatric Cardiac Anaesthetist

"With your help, we have been able to acquire a number of Vapotherm units.

Vapotherm, as the unit is commonly known, is a device that helps children, most commonly very small babies, to breathe with much more ease than they would ordinarily on their own.



With the new transportable vapotherm machine, specially trained nurses are able to safely transport these children independently. Because of You, this means we can potentially fit more children in the operating theatre lists as there is often no interruption and these lists are more efficient. Thank you!"







### Tracy Massey

Deputy Clinical Perfusion Manager

"The Perfusionist shares the responsibility with the Anaesthetist for the management of the physiological and metabolic needs of the patient. When on the bypass machine the heart and lungs are stopped and the circulation is



supported by a series of pumps, an oxygenator, a reservoir, filters and tubing. All the patient parameters are monitored and controlled by the Perfusionist. Perfusionists also manage patients on extracorporeal membrane oxygenation (ECMO) on intensive care. This is a long-term

assist device for children who need extra circulatory or respiratory support.



Perfusion equipment is very expensive and the technology available to us is continually evolving. CHSF have been key in enabling us to deliver the best care to our patients by facilitating the purchase of the most up to date equipment quickly. We now have new

and additional ECMO hardware, and they have raised our profile as a profession. Because of You, our unit is fast moving towards being an international centre of excellence."





### Sara Matley

Lead Consultant Clinical Psychologist

"Nurturing psychological well-being is essential for physical health and quality of life. As a team of clinical psychologists and counsellors, we are dedicated to supporting patients and families to live enjoyable, fulfilling lives alongside their

heart condition. Thank to your donations, we offer a safe and confidential space in which difficult thoughts and feelings are shared, processed and worked through together.



The future is all about making the psychological support we can offer more accessible across the

region, so we will be working in partnership with CHSF to help us achieve this, perhaps thorough providing equipment to help us develop Skype appointments, or fund workshop days across the region. We are keen to develop the service over the next 30 years with the help of CHSF, whose support over the last 20 years has been invaluable. Thank you to everyone who contributes to CHSF!"







# Sharon Milner CEO

"The needs of the LCHU are growing and evolving rapidly - and CHSF's long-term strategy and vision to support hearts for life



depends on the continued fundraising and engagement by you, our valued supporters.

We'd love you to be part of our future, so we can continue to help patients with congenital heart disease in our region. Please pass on our message to your friends and colleagues."

To find out more, give us a call on 0113 831 4810 or visit our website at chsf.org.uk.

# **Fundraising**

We applaud all of our community fundraisers, across 30 years of fabulous fundraising.

There are so many different things you can do. From personal challenges like cycling events and running races, to coffee mornings and sponsored head shaves! Here's some great recent examples!

£7 Million

raised since 1988

£431,319.79

to fund 114 Projects in 2017





























£ 10305 13



To discuss your fundraising ideas, you can contact:

**Lisa Williams** Community Fundraiser

> T. 0113 831 4816 lisa.williams@chsf.org.uk

We'd love to hear from you.



Could you take on a 30th themed challenge for Children's Heart Surgery Fund's Anniversary Year? Whether you're walking 30km around your local park, giving up chocolate for 30 days or swimming 30 lengths at your local pool, you'll take part at your own pace and in your own time.

It's a great way to fundraise and get your own Children's Heart Surgery Fund medal too!



# **CHSF Events**

From Wear Red Day to Superhero Walk (not to mention our **Christmas Party), CHSF run** events which are always great occasions. And that's all Because of You - heart families, community supporters, businesses - you put the fun into fundraising!









Of course, our supporters take it upon themselves to raise money through cycling, running, walking, mountaineering and all sorts of external endurance events too.

Whether it's The Great North Run. Total Warrior. London Marathon. Three Peaks or White Rose Classic we really appreciate all the personal challenges you take on to help other people overcome theirs. But it's our annual Superhero Walk which allows people of all abilities and ages to take part!





**Because of You**, we organise our annual Christmas Party in the lead up to the big day each year - and this has been happening since the start of the charity in 1988. We love hosting these as they help our supporters develop networks with other families affected by CHD. We also hear it offer a focus and direction during difficult times, or when treatment is becoming more manageable.

To find out more about our Events contact or visit chsf.org.uk/events

**Charlotte Anderson-Hughes** Events & Sponsorship Manager

T. 0113 831 4817 charlotte.anderson-hughes@chsf.org.uk

We'd love to hear from you.



# **Corporate Partners**

A huge thank you at all our business partners over 30 years, including the following:





























































There's nothing we like more than really getting to know our corporate supporters – building a long-term partnership that has benefits for both of us. By selecting us as your Charity of the Year or chosen charity partner, you know that the efforts of your employees will have a great impact for the region's congenital heart patients. Why not contact us today?

For all corporate enquiries call 0113 8314810

Ellie Brown ellie.brown@chsf.org.uk Ben Andrews ben.andrews@chsf.org.uk

# **CHSF Ambassadors**



### **Dickie Bird OBE**

We're bowled over that legendary cricket umpire and commentator Dickie Bird OBE is our charity ambassador. He donated £30,000 of his own money towards our Keeping The Beat fund for a new heart theatre in 2017.

His engagement with young patients and their families during ward visits has been inspiring to see, it gives everyone a huge boost including staff. He has conducted national press interviews on our behalf, opened our new offices in Oxford Place this year and will be gracing our 30th anniversary Corporate Fundraising ball later this year.

Here's some key facts about Dickie's career:

- Born in 1933 in Barnsley
- Played for Yorkshire and Leicestershire between 1956 and 1964, scoring 3,314 runs in 94 matches
- Umpired 92 One-Day Internationals, 3 World Cup Finals and 66 Test matches

Dickie said: "I feel honoured to represent this wonderful charity, and look forward to seeing you all this year."

We're sure Dickie's generous donation, and influence in our region as ambassador, will be felt by generations to come.





### **Junior Frood**

Young dancer Junior Frood is keen to bring his experiences with bullying to his role as Youth Ambassador for CHSF.

Junior attends Leeds West Academy in Bramley and from June trains at Jelli Studios in Liverpool and is an anti-bullying campaigner, freestyle dance champion and fundraiser.

Junior says: "It hurt me so much when I heard that some children get bullied due to them having time off school or because of their scars."

"So through my anti-bullying work with the Diana Award I am going to work with the children on self-esteem issues to help them stand up to the bullies. Scars are proof that they are a survivor and a heart warrior."

"I would urge people to please donate and raise awareness of the charity as the work the charity does provides medical equipment, staff and education that saves lives."

Junior is using his own experiences of bullying to help others. He added:



"I used to get bullied because I danced and they thought boys couldn't dance - they thought it was just girls. So they used to call me names and kick and punch me and stuff. It got that bad that we had to move house."

"It's all good now because I moved schools and now I'm at high school and they all support my dancing."

Junior's talent, strength of character and communication skills make him a fabulous role model particularly for our young patients and supporters. He is already proving a big hit with charity supporters, and is inspiring patients to take up dancing and be proud of who they are.

He has raised over £300,000 for local hospices, and recently received a British Citizen Youth Award for his fundraising. We look forward to working with him more in the future.

# #BecauseofYou

Here's a selection of tributes from heart warriors and their families.









### **Albie Carroll**

Now age 3, Open heart surgery at 8 weeks

Mum Freya said: "Three years since his first open heart surgery operation and Albie has performed in his first show. Proud doesn't cover it! #BecauseofYou"



# **Laney Law-Smith**

Now age 5, Open heart surgery at 7 months

Mum Alison said: "5 years ago today since my little girl's heart surgery. We owe everything to the wonderful people at Leeds. Thank you for giving her a future. #BecauseofYou"



### Louie McAvan

Now age 2, Open heart surgery at 1 week old

Mum Kirsty said: "Today is my son's 2nd birthday. Thank you for allowing him the chance to be the happy, joyful little soul he is today. #BecauseofYou"



## **Noah Williams**

Now age 8, Open heart surgery on 1st Birthday

Mum Catherine said: "Today Noah received man of the match, and none of this would have been possible without the amazing job you did of his surgery and the endless aftercare ever since. We are so very thankful. #BecauseofYou"



# **Rachel Smith**

Born 1984, heart surgery in 1990 and 2005

Rachel said: "The staff at Leeds gave me the confidence to try for a family despite my CHD. My beautiful little boy is testament to the fantastic aftercare you have given following my heart surgeries. #BecauseofYou"



# **Stephen Hollis**

Transplant in 1990 aged 2 1/2, sadly died in 1997

Mum Sonia said: "We'll never forget this wonderful, kind, dedicated man Duncan Walker and all the staff, without whom we would not have had an extra 7 and 1/2 years with our son. Forever grateful to CHSF. #BecauseofYou"



Perhaps a family member, friend, colleague or a member of the LCHU has inspired you to get involved with CHSF?

Please tell us your story at: chsf.org.uk/becauseofyou

# **Thank You**

Since the NHS was created in 1948, the development of paediatric cardiac surgery and intervention means that the vast majority of children born with congenital heart conditions can now expect to survive to adulthood. However, these survivors are not 'cured' - their hearts will never be normal, and many of them will have ongoing issues which require lifelong medical care. However, your support enables CHSF to fund care for CHD patients of all ages - babies, children, teenagers to adults.

The sad reality is that CHD is not going away anytime soon, and treatment within this specialty is getting more complex and expensive as research leads science forwards. We are supremely confident in the amazing skills and talents within the LCHU - all heart families are in the very best hands - but we are also painfully aware of the need for more funding over the coming years to treat and support the next generation of CHD patients.

Our successes over the last 30 years have been thanks to a huge number of individuals, families, patients, supporters and groups, from Trustees to CHSF staff past and present, from local businesses to MPs. The list is endless! We also extend our thanks to all the dedicated LCHU staff we didn't have space to cover in this magazine. Please keep on supporting CHSF so we can deliver the strategy we know can best support the LCHU and its noble endeavours.

We would like to dedicate this publication to all the babies, children, teenagers and adults who have passed away, too early, as a result of CHD. They are a constant inspiration in our mission to support hearts for life.

Because of You, we have the best chance of keeping the LCHU beating for the next 30 years. Best wishes from our hearts to yours, and please keep CHSF in mind...

Thank you!

Sharon Milner CEO

Neonatal unit

PICU

**Ward Nurses** 

Play specialists

Theatre nurses

Secretarial and admin

Junior doctors

**Psychologists** 

Counsellors

Surgeons

**Anaesthetists** 

**Perfusionists** 

ODPs

**Pharmacists** 

Echocardiographers

Radiologists

Radiographers

Cath lab nurses

**Cardiac physiologists** 

**Physiotherapists** 

**Outpatient nurses** 

**Specialist nurses** 

Adult ward nurses

Managers

**Paediatric cardiologists** 

Adult cardiologists

Adult ICU staff

Obstetricians

**Obstetric anaesthetists** 

Adult cardiologists

**Pulmonary hypertension specialists** 

**CHSF** staff

**CHSF** trustees

Support staff

**Fundraisers** 

Supporters

**Families** 

Patients...

It's all because of you



# **Children's Heart Theatre**

Because of You, the new heart theatre will be ready for the first congenital heart patient in February 2019. A "hybrid theatre" allows heart surgeons and cardiologists to perform surgery at the same time, reducing treatment time for patients. This is amazing progress! Thanks to your incredible fundraising between May 2016 and May 2018 to reach the £500,000 target, the facility will care for the heart, mind, family and future of new and existing CHD patients in our region. Thank you.



# Supporting hearts for life.

