Wear Red Day is back – all you need to know inside

Meet the LGI's new head of surgery

How you can help young heart heroes like Oliver
Celebrating the brave kids and amazing staff

Three patients from the heart unit have scooped prestigious Yorkshire Children of Courage awards. Libby Carstairs, Isabella Cook and Joe Barry each took home a prize at the star-studded bash in Leeds to recognise children’s achievements across the medical and charity sectors. Paralympian double gold medallist Hannah Cockroft MBE was on hand to honour the winners and nominees while the night was hosted by BBC TV presenter Steph McGovern and Britain’s Got Talent star Jack Carroll, himself a former winner at the event.

The last few months have brought lots of positive news for the heart unit at the Leeds General Infirmary, its staff, patients and all here at the CHSF.

After working under the threat of closure during the national Safe and Sustainable review of surgery, the success of our Save Our Surgery campaign means a second review that promises to be more open and transparent. You can read this recognised.

We’ve been busy spending the money raised by our generous supporters and can bring you news of some fantastic projects. For example, we’ve taken our spending to more than £335,000 with another £35,000 grant. And we’ve agreed to fund a two-year post to develop research and innovation for the unit – more on that in future issues of BraveHearts.

We’re very excited about the return of Wear Red Day, and hope hundreds of schools and businesses across the Yorkshire, Humber and North Lincs region will join our annual fundraising day. Find out more on pages 10-11. It’s only with your support that we can fund more vital work and, as always, we thank you from the bottom of our hearts. Enjoy your new issue of BraveHearts!
Goole Mayor leads town’s fundraising

GOOLE Mayor Stephen Harrison has helped raise £4,500 for CHSF after choosing us as one of his charities of the year.

As well as raising so much money through a variety of events, Cllr Harrison was a major supporter of the Save Our Surgery campaign to keep surgery at the Leeds General Infirmary.

Little Libby bowls over cricketers

HEART hero Libby Cotton inspired a charity cricket match that netted over £3,500 for CHSF and the Calderdale bravery award scheme.

The four-year-old’s dad Wayne organised the 20/20 match between Bradshaw Cricket Club’s Sunday team and local residents, and arranged raffles and a sporting memorabilia auction.

Libby, who recently had a mitral valve repair, is pictured with a framed photo produced with nails and thread by one supporter and donated to the CHSF.

Oliver’s Army marches to £10k raised

FUNDRAISERS Darren and Susan Vaines have raised another £5,000 for CHSF — bringing their total for 2013 to more than £10,000.

After choosing the Yorkshire Three Peaks in June, they recently hosted a sportsman’s ball for their charity Oliver’s Army — set up in celebration of their son Oliver (this issue’s cover star) — which raised money for CHSF. One hundred and fifty guests attended the ball at the New WheatSheaf in Castleford.

One year old Oliver has had surgery for tetralogy of fallot and will need further operations.

NHS starts second national review bid

THE new national review of children’s heart surgery by NHS England has started — and is aiming to decide a plan for the future by June 2014.

The original Safe and Sustainable review, which had decided that the Leeds General Infirmary would stop performing surgery, was suspended by Health Secretary Jeremy Hunt in June.

That move, which was welcomed by CHSF, followed our Save Our Surgery campaign, SOS Limited’s victory in a High Court judicial review, and an report by the Independent Reconfiguration Panel that criticised the review.

The new review is looking again at all aspects of surgery across the country, and has promised to include services for adults with CHD — something the CHSF campaigned for.

CHSF Director, Sharon Cheng, said: “We hope that the new review will be more open and transparent than the original process. We’ll work constructively with the review team to help achieve the best outcome for patients, and will make sure our concerns from the first time around are taken on board.”

NHS England are publishing a fortnightly blog about the review’s progress, which can be found on www.nhsengland.co.uk, and CHSF will post links and updates on our Facebook community group.
Children's Heart Surgery Fund

Ward toy donation and fun run kick-start charity partnership

Give A Gift runners give CHSF their all

Could you volunteer and help heart kids?

Ward toy donation and fun run kick-start charity partnership

DOZENS of children, their families and even Katie Bear took to the paths of Roundhay Park in Leeds to support CHSF in the Give A Gift 5k Fun Run.

The event, which looks set to have raised around £7,500, was the latest in a series of activities being organised by Give A Gift, a partnership of organisations from the Muslim community. The group launched its fundraising efforts during Ramadhan, when they collected and donated hundreds of toys to the heart unit. Other events are planned, including a fashion show. Hanif Malik, CEO at Hamara, said: “We were overwhelmed by the response to the toys appeal and the Give A Gift 5k was another wonderful opportunity for members of the community to come out and show their support for the fantastic work carried out by the children’s heart unit.”

CHSF director Sharon Cheng said: “We are extremely grateful to Give A Gift, a wonderful organisation that has already planned, including a fashion show. We were overwhelmed by the response to the toys appeal and the Give A Gift 5k was another wonderful opportunity for members of the community to come out and show their support for the fantastic work carried out by the children’s heart unit.”

The Give A Gift runners, and our very own Katie Bear, line up before the start of the event in Roundhay Park.

Hilton staff go to the ends of the Earth

EMPLOYEES at the Hilton in Leeds city centre got on their bikes to take in an ‘around the world in a day’ challenge to raise funds for CHSF and Martin House Children’s Hospice.

The challenge is hosted by Hilton hotels across Europe for a range of good causes, and those taking part are encouraged to run, walk, bike and swim to reach a combined total of enough miles to lap the Earth twice! CHSF and Martin House are the Leeds city centre Hilton’s charities of the year for 2013, and staff have taken on a number of fundraising challenges – including the Yorkshire Three Peaks.

Could you volunteer and help heart kids?

Your charity needs you! We’re searching for a team of volunteers who can help raise awareness and funds for CHSF.

CHSF’s community fundraiser Claire Priestwood is working on some new and exciting volunteer opportunities and would like to hear from anyone who is interested in registering for any of the roles.

Claire said: “Volunteers are at the heart of every charity and every day we see the passion and enthusiasm our supporters have for the cause.

“Increasing the volunteers we have will enable us to raise more funds and awareness of the charity and the work of the heart ward and from level of time and commitment need and location.

“Many of the roles are flexible to fit around your other commitments, and are a brilliant way to get involved with your community and to give something back, and we’ll love you to be a part of it.”

The current volunteering opportunities include street and office-based project coordinators, fundraising car drives and office-based project coordinators. If you think you have a few hours to spare and would like to know more, please contact Claire on 0113 392 5093.

Collecting tins at the ready for Katie’s padiatric intensive care unit.

We are looking for individuals who have some time to offer making a real difference in their local area. We have many roles on offer varying from collecting cans to office projects, we’ve got something for all...
Here are just some of the projects we’ve funded in recent months. Some are expensive, some are cheap. All help to make a big difference...

- Buying a hand-held mini doppler machine to be used on Ward L47
- Buying wall art for the new anaesthetic room, theatre and catheter recovery rooms
- Paying for the furniture in the parents waiting area on Ward L47
- Spending nearly £60,000 on an echo machine for the fetal cardiology department
- Allocating funding for two years for a new consultant to develop a research and innovation portfolio
- Getting a broadband contract for Ward L12 so patients can get on the internet
- Buying a birthday present for a long-term patient on Ward L12
- Buying portable DVD players and DVDs for the outpatient department
- Refurbishing the breastfeeding room on Ward L12
- Buying two new microwaves for the parents’ kitchen in the Stables
- Getting new reward stickers for various wards and clinics

Thank you!

Funding for new LGI unit website

The heart unit will get a brand new website, thanks to funding from the CHSF.

The new site, which will be aimed at patients and parents, will replace the current site at www.childrensheartunit.org.

It is being developed and will be launched next spring. Once live, it will be packed with information, videos, photos and links to help support patients and families.

We've bought this chest trolley for Ward L47. It's used for emergencies and holds equipment that opens chests in a hurry – potentially helping to save lives

One of four new sets of waterproof scales we've funded for Ward L47, which help make sure urinary catheters can be removed at the earliest opportunity to improve the patient’s comfort, and reduce the risk of infection. They were funded by Darren and Rebecca Perella

Eckersley House gets £35k boost

CHSF has awarded another £35,000 towards the annual running costs of Eckersley House, the flagship parent accommodation at the Leeds General Infirmary.

That means that – thanks to your generous support – since 2010 we’ve been able to grant more than £335,000 to The Sick Children’s Trust, the charity that runs the house. That figure includes £250,000 to help build the house, which has now helped hundreds of heart families by giving them a place to stay while their child is a patient on the unit.

CHSF’s Claire Priestwood said: “We are delighted that we can continue our partnership with Eckersley House, and carry on giving families some very practical support at a really difficult time.

“Eckersley House is a great facility and supporting it is absolutely core to CHSF’s work.”

ChSF's Claire with Eckersley House fundraiser Laura Loverton

Docking kit helps PICU patients

VITAL equipment bought by CHSF for the new children’s intensive care unit at the LGI is now in place.

Thanks to your donations, we spent nearly £25,000 on 11 syringe pump docking stations for Ward L47.

After surgery, structured control of medication is needed and some patients will need up to 12 pumps

Funds raised at Oliver’s Army ball (see page five) will benefit from.

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Making this kit a vital part of safe treatment.

Debbie Smith, PICU’s senior sister, said: “I would like to thank people who donate money and time. The docking stations have made a big difference to the unit and time efficiency, which will impact greatly on patients. Thank you from the PICU team.”

CHA’s memory ball raises £2k towards online overhaul

Alexa’s memory ball raises £2,000 towards online overhaul

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It's a welcome LGI return for surgeon Carin

Welcome back to Leeds – can you tell us about your memories of the unit when you worked here before?

I did part of my training in Leeds at the old Killingbeck hospital and at the LGI and then I was a consultant here for nearly three years, it was my first consultant job, working with Kevin [Watterson]. I started as a consultant in 1999 and was here for about three years.

What made of the Leeds service since you've been back?

When I came to look around I found there had been a lot of good changes.

I was working in Denmark at that stage but actually quite wanted to come back to the NHS – so it was a very positive choice to come back here. I think that the way Leeds is now set up – that you've got both the adults and children's services at the same location and a brand new children's hospital – is very good.

Also, there are fabulous staff – the whole congenital team is fantastic.

The national Safe and Sustainable review has caused uncertainty about the future of surgery in Leeds and led to the CHSF's Save Our Surgery campaign. What's your message to parents still worried about the future?

I have a lot of respect for the way the campaign was fought.

There is obviously still a certain amount of uncertainty in the whole of the UK about the whole Safe and Sustainable process, but I think that Leeds has all the building blocks in place to be a fantastic player in that and there is a very large special population here that deserves a local service.

New Head of Congenital Cardiac Surgery, Carin van Doorn, trained in Leeds at both the LGI and Killingbeck.

CHSF plays a major role. There are a number of very important family needs that can not be fulfilled by the NHS – that is where charities play a very, very important role.

Parents often tell us they are amazed at how surgeons manage to do such a difficult and emotional job. How do you see your role within the cardiac team?

As a surgeon you need to detach yourself emotionally – you have to be very focused. Once you are in the operating room you put your emotion to one side.

You are just there to do a very good job and to work together with your team – as isolated people we can't do that.

Everyone plays a different role in that team - the nursing staff are much better equipped and much better trained to give more attention to the different needs of a child and of the family as a unit.

My main concern is to make sure that the heart as a pump functions well. I will give them the necessary updates and will treat them with a lot of respect, but there are lots of needs of that family that in my role I can not meet.

The real challenge is to get a group of people together that complement each other and make sure that all the family's needs are identified.

It's so very important that you are able to act on those and, I have to say, I think it's a very good unit here.
"We were totally petrified but knew Ruby without this operation"

Mum Natalie tells how baby Ruby's routine newborn check changed their lives...

"We didn't find out anything was wrong with Ruby until she was three days old. She was a very sleepy baby and didn't feed well at all. During a routine baby check the doctor told us she could detect a heart murmur but, as Ruby was born six weeks early this was common and we thought it would probably heal on its own. But when the midwife checked Ruby's oxygen saturations and found out it was only 37%, she was rushed to the neonatal ward at St James's Hospital and put on a ventilator.

We were devastated – we couldn't believe our newborn baby girl had been so seriously ill and we just didn't know. An ECG and heart ultrasound scan and be confirmed the awful news that Ruby had a rare life threatening heart defect and without surgery she would die.

Ruby was transferred to the heart unit at the LGI and, at that point, our lives changed forever. We didn't know if Ruby would survive. She had her first heart operation at four weeks old. A BT shunt was fitted – a temporary measure as she was too small for her full repair. We were able to take her home when she was six weeks old. We knew the repair would follow but Ruby needed to be a certain size before that could be attempted and she struggled to gain weight.

We visited cardiac outpatients every three months and after about a year Ruby was showing signs she needed her next operation as she became blue and breathless and wasn't meeting her milestones.

I received the phone call I was dreading on the December 19, 2010 to say Ruby was now at the top of the surgery list and a bed was ready for her and she needed to go into hospital in two days time. There was then a mad rush to see family as we had to cancel all our Christmas celebrations.

Ruby underwent nine hours of open heart surgery on December 21. The surgeon was very honest with us and said he had no pre-surgery plan for Ruby as her defect was so complex he was going to decide what he could do once he could see her heart. We were petrified but knew that without this surgery she would die anyway.

Handing her over to the surgery team was probably the hardest thing we have ever had to do but we knew she was in the best hands and without this operation... well, it doesn't bear thinking about.

After the longest day of our lives, we got the call to say she was out of theatre and recovering in intensive care and seeing her again was such a relief. She was so pink and looked so well.

Ruby recovered well and was off her ventilator and breathing by herself after just 14 hours, and was back up on the ward two days post-op.

We took Ruby home six days after her surgery and she has come on in leaps and bounds. She has now caught up with all the other children in her milestones and gained the weight she needed very quickly. The difference in her was amazing.

Today Ruby is a lively, busy chatterbox who does not let her condition stand in the way of leading a normal life. She attends mainstream school, is excelling in her learning, loves being around other kids and has made lots of friends.

She knows her limits and knows when to have time out to rest and she has coped so well with what life has thrown at her so far.

It was a massive shock to be told how poorly Ruby was and what would face us for the rest of her life. We struggled at first to accept her condition as we didn't know what the future would hold, but Ruby soldiered on and was such a happy baby. We knew we had to stay strong for her.

With the support of our family, friends and all the staff at the unit we made it through the other side. I underwent counselling through the hospital in the run up to Ruby's second operation – this helped me a great deal and I know that service is available to us if we ever need it again.

My advice to any other parents going through this is to stay strong and accept all the advice and help that is available to you as it can help so much.

We went through some very tough dark days but we had to be positive and put our daughter's life in the hands of the doctors and surgeons. Without them Ruby would not be here today.

We have had many cardiac outpatients appointments, and I’m nervous every time we go. We know that she will need more surgery within the next couple of years but we’re not fazed. She is in the right hands. She has done amazingly well and we are so proud of her."

Katie's casefile
Name: Ruby Varley
Age: 4
From: Leeds
Mum & dad: Natalie and Alex
Brother: Ethan, 4mths
CHD CV: Tetralogy of Fallots, pulmonary atresia with ventricular septal defect and overriding aorta

HOW YOU CAN HELP
TO FUNDRAISE...
• Call 0113 392 5742
• Download our fundraiser registration form at www.chsf.org.uk
• Ask for a copy of our fundraising guide, packed full of tips and an A-Z of ideas – from abseiling to zumbathons!

TO DONATE...
• Call 0113 392 5742
• Donate at www.chsf.org.uk
• Send a cheque made payable to "Children's Heart Surgery Fund" to CHSF, Room 001, Ground Floor, Old Nurses Home, Leeds General Infirmary, Leeds, LS1 3EX

Visit us @ www.chsf.org.uk

Visit us @ www.chsf.org.uk

Today Ruby is a lively chatterbox who does not let her condition stand in the way of leading a normal life. We know she will need more surgery, but we’re not fazed. She’s in the right hands.
I am a person first... not a heart condition'

Star Jemma tells us how living with congenital heart defects hasn’t stopped her achieving sporting success

When Jemma Greenwood was born with a number of severe and complex heart conditions, doctors didn’t expect her to live beyond her first birthday. Thirty-three years and multiple procedures later, Jemma is a national equestrian champion. Despite not seeing herself as a role model, all of us at CHSF think she is an inspiration and were keen to hear more about her riding achievements.

What does your heart condition mean for your general health in the future?

My condition is degenerative and I don’t know how it will affect me in the future, but I don’t think about that – I just take each day as it comes and try to stay as healthy and active as possible.

How has having a heart condition affected you?

I have a self-limiting condition and most exercising activities are beyond my capability but I have always had a go to test my limitations. Practically, I have to plan to enable me to get around. I also need plenty of layers to keep warm as well as having trouble over the years getting footwear to fit comfortably due to problems with circulation. Also I cannot go on medium or long haul flights so holidays are limited.

Tell us a bit more about your horse riding achievements...

I have ridden since I was 3 years old – riding got me out in the fresh air, is good exercise and very therapeutic. Five years ago, I started doing dressage competitions through Riding for Disabled at the Middleton Park Equestrian Centre in Leeds. Since then I have been to the National RDA Championships every year, culminating this year in winning the competition at my grade. Over the last two years I have competed in a few para equestrian competitions, leading to me representing the northern region twice at the para equestrian home international. I also participated this year in the talent development and finished 5th overall in the senior competition.

What would you say to youngsters growing up with a heart condition?

Don’t let your life be limited or defined by a heart condition. Try to find something that interests you and use it as motivation to help you achieve. That way your health and wellbeing will improve and you will earn the respect of others.

I am a person first... My parents always treated me like any other child and didn’t prevent me from doing what everyone else could do. I am the same in every way except for the condition.

Practically, I have to try – dry slope skiing, pogo stick, bouncey castles, funfair rides, zip wires and outdoor pursuits. They gave me a normal childhood.

Tell us a bit more about your horse riding achievements...

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I am a person first... My parents always treated me like any other child and didn’t prevent me from doing what everyone else could do.
Thirty brave supporters proved their feet could handle the heat to raise money for CHSF by taking part in our fire walk at Stockeld Park. Together, they raised around £8,000 as they completed the challenge of conquering the burning hot coals...

Katie's Club

It's Good To Be Different
(By Amy Ball, aged 15)

I don’t want to be different,
I just want to be the same,
Don’t want people to judge me,
When they only know my name.

I am strong inside,
But they don’t know,
They don’t know what I’ve been through,
They only know what I show.

People use the word ‘normal’,
I’m not normal at all,
What is normal,
Is it short or tall?

I want to be like all my friends,
Or maybe them like me,
I want to be like anyone,
Like anyone but me.

Truth is if we were all the same,
Life just might not be,
I am a different person deep inside,
Just want people to see what I see.

I wish there were people who understood,
But nobody’s like me,
I’m unique in my special way,
That’s how I’m meant to be.

God made me this way,
And that’s how I’ll live,
It may not always be easy,
But God knows how strong I am.

Sometimes living with CHD is hard,
But it won’t beat me,
I am stronger,
No matter what it thinks.

I know that I’m different,
But that’s a good thing,
It would suck if we were all the same,
I love being me! (Including my CHD)

Email your photos and work to info@chsf.org.uk or post them to Katie’s Club, Children’s Heart Surgery Fund, Room 001, Old Nurses Home, Leeds General Infirmary, LS1 3EX. The winning poem or drawing will get a £10 gift voucher!
Visit us @ www.chsf.org.uk

Dress for success... Wear Red Day is back!

LAST year, hundreds of schools and businesses across the region supported Save Our Surgery Ltd’s fight to retain children’s heart surgery at the LGI by taking part in Wear Red Day – raising more than £40,000. Next year, CHSF will be adopting Wear Red Day to raise funds for our usual charitable activities...

WEAR red this February and help CHSF to make a difference in the lives of young heart patients.

Schools, organisations and businesses across Yorkshire, Humberside and North Lincolnshire are encouraged to support CHSF and register to take part in Wear Red Day 2 on Friday, February 7, 2014.

We ask those taking part to make a small donation to wear red clothes to school or their place of work and raise much needed funds for CHSF.

The first Wear Red Day was held by Save Our Surgery Ltd as part of their effort to campaign against plans to end surgery at the Leeds General Infirmary. This time around, Wear Red Day 2 will raise money for CHSF, with funds being spent on vital projects such as equipment for the heart unit and family support services – the type of projects you read about in this magazine. And we want to make Wear Red Day 2 bigger and better than the first event, with more schools and businesses taking part.

Katie Bear will be out and about across the region on the day, so if you want to organise a Wear Red Day event and want Katie to attend, let us know. So, why not ask your child’s school, or your boss, if they will take part?

All they’ll need to do to register their school or business to be involved in Wear Red Day 2 is to log onto www.chsf.org.uk/wearred and fill in the simple form.

So, get those red clothes ready. And remember – the redder, the better!

What you need to know
- Wear Red Day will take place on Friday, February 7
- Schools and businesses across Yorkshire, Humberside and North Lincs are encouraged to take part, with pupils and employees making a donation to wear red clothes
- You can register your school or workplace at www.chsf.org.uk, or contact us via events@chsf.org.uk or 0113 392 5742 to find out more information

Joybelles Singers
Leeds Cathedral, Sun Dec 8, 2.30pm
Tickets: £5.00 adults; £3.50 children/concessions; under-2s free. Tickets from 0113 392 3987 or events@chsf.org.uk

Christmas Carol Concert
Featuring performances by:

Lindley Choir

Heart to Heart Valentine Ball
Charity Ball
Saturday 8th February 2014
7.30pm – 1am
The Royal York Hotel
Station Rd, YO24 1AA

Information and bookings
07951 187701 / 0113 3923987
heartball@hotmail.co.uk
www.chsf.org.uk/valentine-ball

In aid of the Children’s Heart Surgery Fund
Reg. Charity No 1148359 – Reg. Company No 812979
OUR SUPPORTERS WALK OVER HOT COALS FOR OUR HEART HEROES. WHAT WILL YOU DO?

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