

Issue 2, Autumn 2012

Brave Hearts

Children's Heart Surgery Fund



**SPECIAL
ISSUE**



**Help us fight to
Save Our Surgery**



BraveHearts

SOS campaign special issue

4 S&S explained:
Who, what, where,
when and why
guide to review

5 Latest news:
Politicians unit to
attack decision
to stop surgery

6 Fighting on:
The reasons why
LGI must keep
heart surgery



14 SOS story:
How 600,000
people backed
our campaign

18 One voice:
Leeds march
unites 3,000
campaigners

**22 Business
as usual:**
CHSF's vital
work goes on

The next regular issue of BraveHearts will be out soon.
To subscribe call 0113 392 5907 or email ch.sf@leedsth.nhs.uk

• Cover stars: Ruby Brice, her big brother Harry and her twin Daisy (left to right). Photo by Real Image Photography. Read more about Ruby's story on pages 12-13
• BraveHearts is produced on behalf of the CHSF by The Big News Company

Get in touch

Phone
0113 392 5907

Email
ch.sf@leedsth.nhs.uk

Web
www.chsf.org.uk

Facebook
Join our group page



Ten month old Lucy Hagyard, who had a tetralogy of fallot repair when she was aged six months



By CHSF Director
Sharon Cheng

Proud to keep on fighting for all our children

WELCOME to this special issue of BraveHearts magazine, all about our campaign to Save Our Surgery.

Trustees and employees of the Children's Heart Surgery Fund were deeply disappointed by the decision not to choose Leeds as one of the units to carry on doing children's heart surgery and, quite frankly, were completely baffled by this quite ludicrous decision.

But we're more confident than ever that common sense will win the day and we are campaigning very hard.

This special issue will tell you the latest news; go through the logic why Leeds should keep surgery; update you on our campaign; and introduce you to some of the heart heroes who are the reason we are continuing to fight.

We've launched a Fighting Fund to raise money to make sure we can do everything possible to keep surgery in the Yorkshire, Humber and North Lincolnshire region.

The details of how to donate are on this page – if you can give, that would be fantastic. Money is already coming in from our amazing supporters – an incredible £40,000 in the first few weeks of the Fighting Fund.

Dozens of fundraising events are being organised – from cake sales to dress down days in offices across the region.

In the meantime, it's business as usual on the heart wards and also in the CHSF office. The next issue of BraveHearts will be out soon and will focus, as usual, on the vital projects we've paid for, our fabulous fundraisers and our incredible families.

HELP US SAVE OUR SURGERY

and we are getting professional advice about a possible legal challenge as well.

We are asking our supporters to give generously to help fund this work, to spread the word to their friends and workmates, and to run fundraising events to help.

Whether or not you can donate or raise £1, £100 or £1,000, your efforts will help. And, if we don't need to spend all the Fighting Fund on the campaign, we'll put it straight into our usual vital work funding equipment and resources on the heart wards.

Here's how you can donate to the Fighting Fund – your help is much needed, and much appreciated, thank you.



For ways to donate/fundraise please
contact the fundraising office on
the following numbers

0113 392 5742

0113 392 5907

www.saveoursurgery.net



Heart patient Amelie Brown

The Safe and Sustainable review has lasted years, cost millions and led to protests by hundreds of thousands of people. And yet few argue against its basic principles. So what is the review all about?

FEWER, LARGER, SAFER



Families from our region joined the CHSF Save Our Surgery protest outside the review's public consultation meeting in Leeds last year

How it all began

There was a scandal at the Bristol Royal Infirmary during the 1990s. A public inquiry said 30-35 children who had surgery at that unit between 1991 and 1995 died unnecessarily because of sub-standard care.

The inquiry made lots of recommendations about improving standards. It took a long time for the NHS and politicians to agree to change things, but the last Labour Government set up the Safe and Sustainable review into children's heart surgery in England.

What the review wants to do

The review wants to introduce more than 150 new standards, and the main idea is to have fewer, but larger, surgical centres.

Every centre would have at least four surgeons, who would each do 100-125 operations a year. This means each unit would do 400-500 operations a year.

The idea is that, by doing this number of operations, each surgeon will become expert in many types of heart defect, and there will be better cover for holidays and emergencies.

The review believes this would mean better

outcomes for patients because the units would be safer and more sustainable.

Non-surgical work would be done in local clinics as part of regional networks.

How they chose the units

The review had to ask the public what they thought so, last year, they held a public consultation.

They suggested four options for which units should still do surgery, and asked the public what they thought about those options. Leeds was only in one option. Because of what the public said, the review ended up looking at 12 options instead of the original four.

The review's decision

On July 4 this year, the review's decision-making team (made up of NHS managers with advice from three medical experts) chose which units would still do surgery.

They scored each option, and Option B came first, with Option G second. The only difference between these two options was that Option G had Leeds instead of Newcastle – all the other units were the same in both options.

What the head of the review says

The chairman of the decision-making team has spoken out in defence of the review.

Sir Neil McKay, said: "The decision followed a three year comprehensive review which included engaging with families and clinicians, listening to people's views and testing possible configurations.

"The case for change has never been stronger and the NHS remains committed to implementing service improvements for children with heart disease."

What happens now

There have been challenges to the decision from the units that will have to stop doing surgery (Leeds, Leicester and London's Royal Brompton).

The new Health Secretary, Jeremy Hunt, has been asked to look at the review's decision and he has the power to say it's okay, or to make them reconsider. There may be legal challenges as well.

While that is going on, the review team are starting to get ready to make the changes, which they say will happen in 2014.

The case for change has never been stronger and the NHS remains committed to implementing service improvements for children with heart disease

Sir Neil McKay
Chair of the JCPCT

All of us at CHSF would like to say huge thanks to the thousands of people who back our Save Our Surgery campaign. Your support is vital.

Supporters gathered at the LGI to await the JCPCT decision on July 4. Campaigners have been given fresh hope by the scrutiny committee



Decision with Hunt as MPs attack plan

Health Secretary could tell review chiefs to think again after Leeds plea

THE CHSF's Save Our Surgery campaign has been given fresh hope in the wake of the decision to stop surgery in Leeds after a regional health watchdog referred the NHS's decision to the Government.

Yorkshire's joint health overview and scrutiny committee – the regional watchdog made up of 15 local councils – voted to ask new Health Secretary Jeremy Hunt to review the decision.

The watchdog voted unanimously to refer the decision after hearing evidence from the CHSF, parents, doctors, politicians and Leeds Teaching Hospitals NHS Trust.

The committee spent three hours quizzing the man chairing the decision-making panel, Sir Neil McKay, and also heard from Leslie Hamilton, the Newcastle surgeon who was a key advisor to the review panel. Sir Neil told the committee:

"Uncertainty is the enemy of progress. We want to get on with an implementation plan at the earliest opportunity."

But John Illingworth, chair of the committee, said it would begin to collate information "immediately" in support of its submission to the Health Secretary, who now has the power to overturn the decision. He said: "The committee is not satisfied there is going to be any improvement for the people of Yorkshire."

After the meeting, committee member and Bradford Councillor Adrian Naylor said: "To move the service from a population centre of 14 million in Yorkshire and Humber to one of 2.8 million in Newcastle is confusing."

The Government has indicated that Mr Hunt will seek advice from the Independent Reconfiguration Panel before giving his verdict.

What will happen now

- Health Secretary Jeremy Hunt has to decide on the plans
- He'll rule whether the decision stands, or if he wants the NHS to reconsider
- The CHSF is taking legal advice about other possible ways to fight the decision
- While we wait, it's business as usual at the unit and the CHSF

What the MPs say

I am very concerned about the sites that have been chosen

Ed Miliband
Labour Leader
Doncaster North

I've never understood how they could come to a decision not to have a centre in Yorkshire

Ed Balls
Morley & Outwood

The decision flies in the face of patient choice

Stuart Andrew
Pudsey

The decision clearly fails all four tests for redesigning health services

Jason McCartney
Colne Valley

Collecting over half a million signatures is extraordinary – that must make everyone sit up and take notice

Greg Mulholland
Leeds North West

The CHSF backs the introduction of new clinical standards, but the decision to stop surgery in Leeds doesn't make sense

We want the best for our kids... this isn't it

THE Children's Heart Surgery Fund will keep fighting for our Save Our Surgery campaign because we feel children in the North will get a better service if the LGI carries on operating.

We accept the argument for change. We agree that dozens of new standards should be implemented across the service. We understand the rationale for fewer, larger surgical units.

But the CHSF believes patients in Yorkshire, Humber and North Lincolnshire will get a poorer service than they currently receive, if the decision of the Joint Committee of Primary Care Trusts (JCPCT) is upheld.

The overwhelming response from the public, parents, patients, politicians, NHS staff and businesses from around our region – and beyond – has shown that hundreds of thousands of people share our view.

We haven't got space to detail all our concerns about the review, but here are the CHSF's main campaign arguments...

Patient choice is being ignored

Patient choice is enshrined in the NHS constitution, but we feel that has been ignored.

Our campaign, and an independent survey by PriceWaterhouseCooper (PwC) shows, if Leeds no longer performs surgery, the vast majority of families from our region would not choose to travel to Newcastle for surgery.

Instead, the survey showed their preference would be Liverpool, Birmingham or London.

The PwC survey said: "There was more reluctance amongst members of the public to consider travelling to Newcastle as a centre.

"If the preference of the parents and the public were factored into assumptions of patient flows, they may have implications for projected levels of activity at – in particular – the Newcastle centre."

The survey questioned families from



Four-year-old Samuel Kelly with big sister Mary-Jane. Samuel's already had two life-saving surgeries at Leeds in the space of nine months

Doncaster, Leeds, Sheffield and Wakefield postcode areas – who the JCPCT all assumed would travel to Newcastle. However, just small number from Sheffield said they would choose Newcastle, while not a single family questioned from Leeds, Wakefield or Doncaster said they would choose Newcastle.

If the JCPCT had used these figures – from the independent report they set up – Newcastle could not have been chosen as a surgical centre because it could not hit the review's target of performing 400-500 operations each year.

But the JCPCT assumed 25% of families from those postcodes would choose Newcastle. Using that figure, Newcastle would reach an estimated 403 operations per year – a fraction

above the 400 they need. The CHSF believes these figures are wildly optimistic and go against all evidence.

Doctors won't refer patients to Newcastle

The JCPCT accepted evidence that parents should be "properly managed" to make sure enough patients have surgery in Newcastle.

They said patients' choice of where to have surgery would be influenced by the doctors who referred them, with the assumption that these doctors would send patients to Newcastle.

However, they did this without asking those doctors where they would refer to if Leeds wasn't performing surgery – and many clinicians in the Leeds network are saying they would not refer patients to Newcastle. The



Around 10,000 children pass through the LGI's heart unit each year. Here are just a few of those who have had, or will need to have, heart surgery

How you can help...

WE'RE asking our supporters to help the campaign by:

- Donating to our Fighting Fund via our website, www.chsf.org.uk, by text message or by post. See page 3 for full details
- Writing to – or meeting with – your local MP. Most MPs in our region have been supportive of our campaign, but need further evidence and family stories about how the changes may affect their constituents in order to take to the decision-makers. You can find the contact details for your MP via www.parliament.co.uk
- Writing directly to the new Health Secretary, Jeremy Hunt. He's now reviewing the decision and you have the opportunity to let him know your thoughts. You can write to him at the Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS or via the contact form on the department's website, www.dh.gov.uk

CHSF thinks it's bizarre to make massive assumptions rather than fully researching what will happen. Like patient choice, this casts doubts on Newcastle's ability to be sustainable.

Public opinion should count for more

Our petition had more than 600,000 signatures and was one of the largest petitions ever handed into the UK Government.

But it was only counted as a single response to the public consultation. This was despite 22,000 text messages – which the JCPCT was told couldn't be traced – being counted as 22,000 separate responses.

The CHSF believe this goes against the evidence of the recent report of the Children and Young People's Health Outcomes Forum,

which says: "Where health outcomes are better, it is because children, young people and their families are involved in decisions about their care... their voices need to be heard and responded to consistently."

Going from best co-location to worst

Patients in our region already have the best possible co-location of children's services – everything our patients need is under one roof at the LGI. This is by design, not accident.

The service moved from Killingbeck hospital years ago precisely because it was a standalone heart unit. Now, with the Leeds Children's Hospital sited in the LGI, everything is on tap. In Newcastle, the heart unit is based in the Freeman Hospital

and most other children's services, and the maternity unit, are based at the Royal Victoria.

Having gold standard co-location was a recommendation of the official inquiry into the Bristol heart babies scandal – the starting point for what became this review.

The British Congenital Cardiac Association (BCCA) agrees. Talking about the review, they said: "It is important that the centres designated to provide paediatric cardiac surgery must be equipped to deal with all of the needs of increasingly complex patients.

"For these services at each centre to remain sustainable in the long term, co-location of key clinical services on one site is essential."

The Paediatric Intensive Care Society has

Continued on next page

Co-location of key clinical services on one site is essential

British Congenital Cardiac Association



Katie Bear's mascot friends have supported the Save Our Surgery campaign, pictured here with charity director Sharon Cheng

Continued from last page

said it "would dismiss any suggestion that a service located on another hospital within the same city can be regarded as being equivalent to a service located on the same hospital site".

But the JCPCT agreed a watered-down definition of co-location to accept the Newcastle model of two hospitals in the same city.

Also, in Leeds – again, unlike Newcastle – maternity services are on the same site as the heart unit, so mothers with high-risk pregnancies don't find their babies taken to a different hospital to get treatment.

The CHSF believes co-location is a clear example of how patients from our region will get a worse service in the future than they do now, should Leeds stop performing surgery. Our region moved away from a standalone unit years ago – this is a backwards step.

Put the doctors where the patients are

The CHSF believes logical healthcare planning would be to put the doctors where the patients are – not to move the patients to the doctors.

The unit in Leeds serves 5.5 million – double that of Newcastle. The population of Yorkshire and Humber is expected to grow at a higher rate than the national average and at twice the rate of the North East.

The BCCA said: "Where possible, the location of units providing paediatric cardiac surgery should reflect the distribution of the population to minimise disruption and strain on families."

Again, the JCPCT ignored the BCCA's advice, and basic healthcare planning principles. The CHSF believes it makes no sense to move clinicians and surgery away from such a major population centre.

Chosen option has more negative health impacts

The review team did a health impact assessment – an independent report that looks at the effect on vulnerable sections of society.

The option they chose had more negative impacts than the option that included Leeds instead of Newcastle. The JCPCT heard this evidence, but still chose the Newcastle option.

The JCPCT heard one impact of stopping surgery in Leeds would be a very detrimental effect on children's intensive care services for non-heart patients, because the heart and non-heart intensive care wards can share beds and staff when they need to because they are next to each other.

In Newcastle, the impact would be slight

because the two intensive care wards are in different hospitals.

Not enough weighting was given to access

The JCPCT made their decision by scoring each of the options for which units should be designated. Option B got the highest score and Option G came second – the only difference between the two was that Option G contained Leeds instead of Newcastle.

The scores were based on an arbitrary system that saw 'travel and access' weighted at less than half the points given to 'quality'.

The CHSF believes this arbitrary scoring – that wasn't based on the public consultation – ignores the fact that, for the parents of sick children, being able to be with their kids is a massive contribution to the quality of the service they receive.

Parents tell us it is difficult enough to manage to be with their children in hospital without forcing them to travel much further.

And, as some doctors have given evidence to say, in a small number of emergency cases, quick access to the surgical centre can be vital.

Not a clinically-led decision

The then Health Minister, Simon Burns, told the CHSF at a meeting last year that this would be a clinically-led decision, a point that Government ministers have said over and over again – but there wasn't a single clinician on the decision-making panel.

The panel did hear from three influential clinical advisors, one of which was a heart surgeon at Newcastle.

Adult review is pre-judged

A review into adult congenital heart surgery is just getting started, but the CHSF believes it has been pre-judged by the children's review.

The same surgeons operate on children and adults so, if children's heart surgery is ended in Leeds and the surgeons move elsewhere, it is very likely adult surgery will have to stop.

The JCPCT said they didn't have the power to change adult services, but admitted the children's review will have a big impact on the adult review. The CHSF believes this means the adult service is being changed without proper consultation with patients.

Adult patients lose out

The adult service in Leeds is gold standard. It is the second largest interventional centre and the fourth largest adult surgical centre. Newcastle has no dedicated adult congenital

Louise Payne explains why co-location of services is so important to her daughter Zoe 'We see no sense in being sent to Newcastle, Zoe's care would suffer'



Zoe, six, from North Lincs, with brother Reuben. She's a "determined, exasperating, and courageous little girl"



I'm thinking about future babies born with multiple problems, just like my Zoe

"ZOE was born following a planned delivery at the LGI after her heart defects and DiGeorge syndrome were diagnosed late in my pregnancy.

She had a massive VSD, small ASD and an interrupted aortic arch, and other non-heart problems that needed immediate investigation and treatment.

She had heart surgery when she was eight days old, and her prognosis was bleak for a while. She currently has supra-aortic stenosis and a bicuspid aortic valve.

Even before Zoe's surgery, we needed maternity, neonatal, immunology, kidney, cardiac and other services. Afterwards, she needed treatment by

a neurologist, endocrinologist and other specialists. She even started orthopaedic treatment for bilateral talipes while in the cardiac unit – her heart surgeon even signed her casts.

Since then, Zoe has had bowel surgery, more orthopaedic treatment and two ENT operations – and she'll need more non-cardiac surgery.

She has learning, communication, mobility and complex behavioural difficulties. She can't cope with long car trips, and public transport is impossible.

We can't read the facts and believe stopping surgery in Leeds would not result in a worse outcome for families from our region. We see absolutely no

sense at all in being sent to Newcastle – the distance alone would be a massive problem for future cardiac surgery and would split our family and put us under massive financial strain.

More importantly, Zoe's care would be split across yet another hospital. Newcastle is further away than Birmingham and Liverpool, and provides fewer children's services.

But these problems pale into insignificance when I think about a future baby born with multiple medical problems just like Zoe, in congestive heart failure, being sent to Newcastle and away from their mother.

We must keep surgery in Leeds."

consultants, whereas Leeds has four who fulfil the BCCA criteria. Liverpool has no adult service – it is based in Manchester with a single surgeon travelling from Liverpool.

Referring doctors at Leeds have said they are unlikely to refer to Newcastle or Manchester if Leeds isn't designated.

The alternative is Birmingham, which will need to increase its surgical capacity from 60 cases to more than 200 cases per year if they take on patients from our region and also from the Leicester unit.

The CHSF believes adult patients are being left facing a worse model of care than they have now, and thinks it makes sense to look at the adult and children's reviews together.

Decision goes against the Government's tests for reconfiguration

Health Secretary Jeremy Hunt, who will now decide whether to uphold an appeal against the JCPCT's decision (see page 5), should be guided by four tests for any reconfiguration of NHS services set out by this Government.

Former Health Secretary, Andrew Lansley, said the clinical benefits must be clear; the changes must have the support of clinicians; the views of the public must be considered; and the changes must support patient choice.

The CHSF believes this decision fails all four of those tests. The charity hopes Mr Hunt sees the common sense and clinical logic why Leeds should keep its children's heart surgery. ■

The location of surgery units should reflect population distribution

British Congenital Cardiac Association

The CHSF says...



Our campaign is not just local people fighting for a local hospital – the whole of the North stands to lose out under the review's plans

Lose Leeds... and the whole North loses out

THE Trustees of the Children's Heart Surgery Fund welcome any attempt to improve the standard of care for children born with congenital heart defects. Our charity exists to do just that.

We support many of the basic principles of the Safe and Sustainable review. We accept the idea of fewer, larger surgical units, and applaud the introduction of a raft of new standards.

However, we are dismayed by the decision regarding which units should continue to perform surgery, and deeply concerned about the process followed to

make those decisions. Because of that, we can not support the findings of the review and will continue to campaign to keep surgery at the Leeds General Infirmary. We are convinced this would be the best outcome for patients across Yorkshire, Humber, North Lincolnshire and, indeed, the whole of the North of England.

Our campaign is not about localism. Our duty as a charity is to promote the best interests of the patients of our region, and it is our strongly-held belief that keeping surgery in Leeds is the best option for them. Our supporters could not have

spoken more decisively – our petition received more than 600,000 signatures calling for Leeds to retain surgery.

The Safe and Sustainable review promised to deliver better care for children across the country. Expert, independent evidence given to the review's decision-makers proved stopping surgery in Leeds will simply not deliver on that promise for the children of the North of England.

It is not acceptable that a review that starts out aiming to improve something results in it getting worse. We will do everything possible to change this decision.

Expert, independent evidence given to the review's decision-makers proved that stopping surgery in Leeds will not deliver the promise of better care for the children of the North

'Not being there for Seb's surgery broke my heart'

While new mum Cathy Baines was recovering at the LGI, her baby was fighting for his life in a different hospital...

THE Leeds General Infirmary has both maternity services and the children's heart unit, which means that some mums whose babies may need treatment soon after birth can have a caesarean section in the same hospital as the heart unit. In Newcastle, the maternity unit is in a different hospital to the heart unit so, if the plans to stop surgery in Leeds go ahead, this would no longer be possible for those treated in Newcastle instead of Leeds. Cathy Baines has experienced being in a different hospital while her baby had surgery – Seb was treated in Killingbeck before the heart unit moved to the LGI in the 1990s so all services could be under one roof.

"SEB was born at the LGI by caesarean section sixteen years ago. He stopped breathing at 19 hours old, but an amazing nurse called Andy revived him.

He was rushed to Killingbeck for emergency corrective surgery (he had severe coarctation of the aorta) – while I was stuck at the LGI.

I received a telephone call from Killingbeck to tell me he'd had his operation – wow, that was a very tough day that I'll never forget.

The LGI arranged a taxi for me to be able to visit Seb for one hour each day – this went on for the first week before they discharged me and arranged for a nurse to visit me at Killingbeck, where I was allowed to stay with Seb.

I know what it's like to be apart from your baby when he's being operated on at another hospital and during his recovery – it's heartbreaking.

I cannot believe that they are wanting to go back to this ridiculous type of care.

It is very lonely and stressful. While at Killingbeck we would at times have to wait until a doctor came from the LGI to give us information on Seb, which was very frustrating and time consuming.

The advantage of having everything under

I just cannot believe they are wanting to go back to this ridiculous type of care



Above, Seb with proud mum Cathy, who says: "Seb doesn't feel sorry for himself – he's very positive and focused on his future – he knows exactly what he wants and works hard to achieve his goals". Left, being treated at Killingbeck 16 years ago

one roof is to save time, and a greater chance to save more lives.

To have to travel further for surgery (which I believe will put lives at risk when it's an emergency situation) at greater expense for families is wrong.

I'm a single parent and I also have a nine year old daughter, Mia. I worry about Mia and what would happen to her if Seb was admitted to a hospital further away.

Who would look after her? How would she get to see Seb? How would she cope worrying about Seb when I wasn't with her? I work

part-time around Seb and Mia, we are on benefits and don't have a car, so we are in the low income category that will definitely struggle financially and emotionally if we had to travel to Newcastle when Seb has his next surgery.

He'll need a valve replacement and surgery to remove a membrane that is growing underneath his valve. His coarctation of the aorta is monitored as this may need further surgery.

Having separate hospitals simply does not work. I was told Seb was dying when he was rushed to Killingbeck as an emergency. What if he hadn't got there in time? Thankfully, he did."

CHSF Trustee Jon Arnold on the Save Our Surgery fight



Jon's daughter Zoe, now aged five, before the surgery that saved her life at three weeks old

Put the kids back at heart of the review

THE more I hear about the Safe and Sustainable review, the more depressed I get. This review started with the best intentions – it was the once-in-a-generation chance to make big changes to children's heart surgery that would improve care for years to come.

But, instead of improving standards, this review has taken a decision that I believe would leave children in this region with a worse service than they currently receive. They chose Option B over Option G – the only difference being Option B had Newcastle; Option G had Leeds. Option B is clearly worse for the children in our region.

Worse co-location of key services; worse access to the surgical unit; worse negative impacts for vulnerable groups; worse impact on children's intensive care beds; a greater number of families disrupted at greater financial and emotional cost.

Those are all indisputable facts from the evidence the decision-makers heard but, strangely, none of that held any sway.

Nor did the biggest whammy of all – evidence that shows Newcastle won't get to 400 operations per year, the minimum needed and whole point of the review.

The review team has repeatedly failed to explain why, if Leeds has to stop doing

surgery, they assumed our families will travel to Newcastle – the only standalone heart unit and the one which will have the worst co-location of services in the country. For most, either Liverpool or Birmingham (or both) are closer, quicker, easier and cheaper to get to.



Why should our patients go back to a model of care we discarded 14 years ago?

local unit. It's not. It's about protecting our children and those who will follow them – across the whole of the North.

Somewhere along the way, the patients have stopped being at the centre of the plans. It's time to put those children back at the heart of this review.

'If we were forced to travel, family life would stop. I'd be heartbroken'

Sally Boocock explains why losing the co-located services of Leeds would be a disaster for daughter Ruby and family

"MY little girl Ruby suffers from a genetic abnormality called DiGeorge syndrome, which is a deletion of a chromosome, and that has given her multiple medical conditions.

She's three years old, has a twin sister called Daisy and a big brother, Henry, who is five.

Ruby's prognosis is poor. Her major defect is her heart – she has tetralogy of fallot with severe pulmonary atresia with a large VSD.

Ruby had open heart surgery last February, when she was two, and is now on Kevin Watterson's waiting list for more surgery.

She'll need more operations throughout her childhood to improve her quality of life and extend her life expectancy.

But her problems don't end with her heart. She has mesenchymal liver haematoma – a rapidly growing tumour stuck to her liver.

She's on the waiting list for open liver surgery.

She also suffers from vesicourethral reflux and right-sided hydronephrosis, which are kidney problems.

Ruby has other more mild conditions such as chronic leg pains, flattening of the plantar arch, developmental delays, recurring infections because of weakened immunity, chronic fatigue, shortness of breath, low oxygen saturation levels, dysphagia and eye problems.

She's a remarkable little girl, considering what she has to contend with every day. She is so resilient and very brave.

Even when she's in hospital, she barely cries or complains – it's like she knows she has to be strong.

Having a child who is sick is a full time job. I won't lie, it puts a great strain on life.

It's always there on your mind. One minute everything can be okay, and the next your whole world is tumbling around you.

We have a slightly different outlook on life now – we do anything and everything

If anything happened to Ruby, her dad wouldn't get there in time to say bye



Ruby and twin Daisy. Ruby had the first of a number of heart operations when she was two



Ruby needs a children's hospital. I've worked in the NHS for years – I know gold standard care when I see it

we possibly can together. It changes you as a person – you take nothing for granted. Life is so precious, embrace it while you have the chance.

Ruby is cared for by specialist medical teams who are all co-located at our brilliant children's hospital within the Leeds General Infirmary.

GOLD STANDARD CARE

These teams also come and see us at our local hospital in the joint clinics, and I think this is an excellent model of care.

Because they are all co-located, the liaison between different specialists is excellent, very quick and very organised.

When Ruby had her heart surgery she had access to all the other specialists involved in her care. Had something happened in relation to her other conditions, help would have been on hand straight away – something which is

extremely important. Ruby needs a children's hospital. Living only an hour from the hospital, family life was able to carry on with only a little disruption.

The service that Ruby receives at Leeds is consistently excellent, the staff are wonderful, the care is outstanding. I have worked in the NHS for 14 years, so I know gold standard care when I see it – and Leeds is it.

If children's heart surgery in Leeds stopped and we were forced to travel to units further away our family life would also stop.

The travelling time would be unacceptable and the cost of having to travel further would put even more strain on us financially.

Ruby would be separated from her siblings, including twin Daisy, and her dad. It would be heartbreaking. If anything was to happen to Ruby in an emergency, her Dad and siblings would not get there in time to say goodbye."



From the streets of Yorkshire right to the Houses of Parliament

How the region's public and politicians have answered our SOS to keep surgery in Leeds

THE Save Our Surgery campaign has thrust the CHSF into the public limelight like never before. Trustee Jon Arnold describes how the campaign grew...

THE campaign got underway back in late 2010, when it was clear that the review could threaten the future of children's heart surgery at the Leeds General Infirmary.

The charity had been closely involved with the process even before that point – for example, I'd attended Sir Ian Kennedy's team's visit to the LGI to assess the unit.

The first priority of the campaign was to raise awareness of the review – not only among parents, but also the wider public and the region's politicians.

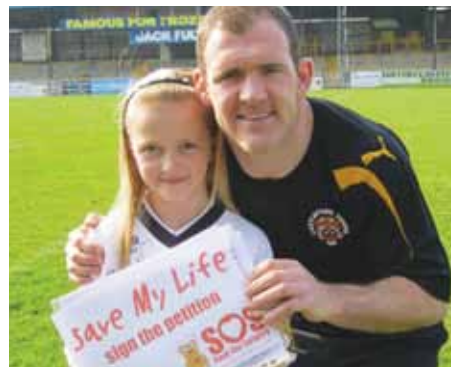
An on-line petition was started by Kerry Singleton (mum of patient Sienna), and we quickly realised we need to create a paper petition to reach the masses.

We appealed to families in our regional clinics – visiting 17 areas for public meetings where we explained the complexity of the review to families and the public.

As families became fully engaged, the media interest started to grow.

A group of parents and charity representatives travelled to London to meet with some of Yorkshire and Humber's MPs. That first meeting in the House of Commons was chaired by Stuart Andrew MP, who continues to be one of the campaign's most dedicated supporters.

I remember sitting in a committee room in the House of Commons listening to mum Lois Brown tell the MPs her daughter Amelie's incredible story. I was blinking away the tears



Ebony Bastow with Castleford Tigers captain Danny Orr. The Tigers were one of many clubs who let us collect signatures at matches

and I'm pretty sure many of the MPs were as well. It was a powerful, personal story and, combined with the logical and factual arguments we also presented, meant every MP in the room committed themselves to the campaign there and then.

Much of the early focus was on collecting signatures for the petition. CHSF chairman and heart surgeon Kevin Watterson set us the target of getting half a million signatures. Frankly, I thought that would be impossible!

My first night collecting signatures was at Kinsley dog track. When every single punter we approached signed up, that's when I thought we might just reach our target.

Over the next few months, our amazing supporters gathered hundreds of thousands of signatures, simply by dedicating time to talk to the public about what was going on.

Our supporters were phenomenal, and

the response from the public was incredible. Ultimately, we got over 600,000 signatures, and I was honoured when my daughter Zoe knocked on the door of No.10 to hand in the petition on behalf of everyone.

We held a demo outside the consultation meeting and, as the campaign grew, so did the media coverage. Suddenly our supporters found themselves on TV, in the papers and on the radio. Everyone did an incredible job.

Towards the end of last year, we met with the then Health Minister, Simon Burns, to brief him on our concerns. Because of the public support for our campaign, MPs and ministers were taking notice, and the issue has been debated in both the House of Commons and the Lords a number of times.

Since the decision, we've been back to Parliament and now most of the region's 54 MPs are actively supporting us. Labour leader Ed Miliband has written of a "major flaw" in the plans and parents have recently met with Deputy Prime Minister and Lib Dem Leader Nick Clegg to talk to him about the campaign.

Hopefully, the politicians will be able to exert the influence to overturn the decision – but, quite simply, we wouldn't have got as many of them on board if it hadn't been for that petition.

So, to the CHSF staff who have worked tirelessly during the campaign, and to our supporters who stood outside supermarkets, sports grounds, festivals, train stations and the like – and to everyone who put pen to paper on that petition – my fellow trustees and I thank you.

We wouldn't have a chance of keeping surgery at the LGI without you."



Massive petition put Save Our Surgery campaign on the map

HUNDREDS of CHSF supporters hit the streets of the region to collect signatures for the Save Our Surgery petition last year.

Thanks to their efforts, the petition stood at an incredible 500,000 signatures when it was handed in to No.10, and then rose to over 600,000.

That huge figure made it one of the biggest petitions ever handed into a UK government on any issue, and so many people coming together with one voice to say "save our surgery" was incredibly powerful. It was enough to secure an important debate on the review in Parliament.

Come rain or shine, our supporters collected signatures at supermarkets, shops, sports grounds, stations, businesses and events around the region, and thousands more flooded in on-line.



All of us at CHSF would like to say huge thanks to the everyone who collected signatures and signed the petition. It was an amazing team effort!



We wouldn't have had a chance of keeping surgery at the LGI if it hadn't been for that amazing petition

Jon Arnold, CHSF Trustee

We were in the House of Commons listening to Lois Brown tell her daughter Amelie's incredible story. I was blinking away the tears and I'm sure many of the MPs were as well



Our poignant broken heart was a powerful message as we kept the campaign in the media in the run-up to decision day (far left). Lois Brown, mum of heart patient Amelie, and the Cononley Singers from Skipton recorded a special version of Elton John and Kiki Dee's classic Don't Go Breaking My Heart to show their support (left).

Winning mass support



MIA'S RALLYING CALL TO SAVE HEART UNIT

Leeds heart unit 'must stay open'



MPS BACK FIGHT TO SAVE A KIDS' HEART SURGERY UNIT



LISTEN TO US



ACROSS TV, radio, newspapers, Facebook and Twitter, campaign supporters have worked tirelessly to publicise our cause.

Hundreds of articles and interviews have been published or aired, and thousands of posts and Tweets across the social media have helped spread the latest campaign news.

CHSF trustee Jon Arnold said: "The coverage our supporters generated in the early days of the petition gave the campaign its momentum."

"Without our supporters keeping the campaign in the public eye it wouldn't have been as successful as it has been so far. We owe a huge debt of gratitude to everyone who has contributed."

CHSF takes the fight to Downing Street

ONE of the highlights of the campaign so far was the trip to Downing Street to hand in the Save Our Surgery petition.

Heart patients Isabella Cook, Zoe Arnold and Kim Botham knocked on the door of No.10, accompanied by charity officials, ward staff and many Yorkshire and Humber MPs and Peers.

When the famous door opened, they handed over more than 500,000 signatures in support of keeping surgery in Leeds (the number grew to more than 600,000 – one of the biggest petitions ever handed in to the UK Government

and easily the biggest for a regional issue). Leeds North West MP Greg Mulholland said: Collecting over half a million signatures is quite extraordinary and that must make everyone sit up and take notice."

The charity has continued to work with the region's MPs – over 30 of them have pledged their support to our campaign and are now lobbying new Health Secretary Jeremy Hunt to step in.

MPs from all major parties have supported us, and we expect another debate in the Commons in the autumn.



Heart patient Zoe Arnold displayed the campaign's 'we shall not be moved' attitude at No.10!



Is your MP supporting the campaign? Write to them with your views. Find their details at www.parliament.co.uk

Heart patients Isabella Cook, Zoe Arnold and Kim Botham hand in our petition at No.10 alongside charity officials, ward staff and many of the region's MPs. Isabella, Zoe and Kim are also shown below, posing for the media outside the Houses of Parliament (pictured left to right).



Kevin Watterson, Sharon Cheng and Jon Arnold from the CHSF gave evidence to the region's MPs following the July 4 decision to stop surgery

Just three weeks after the bitter disappointment of the review's decision, 3,000 CHSF



Nurses from the LGI showed their pride in the service and many said they were moved by the show of support from parents and patients. Some of the biggest cheers of the day were when Senior Sister Heather Wardle spoke, right. Afterwards she said: "It is not about us but about the children as the services are for them. We want to show the parents we support them."



supporters gathered in Leeds to prove that the fight isn't over — it's only just beginning



CHSF supporters turned out in Leeds in their masses on a glorious summer's day to show their support for the Save Our Surgery campaign

United we stand, and together we march...

THOUSANDS of CHSF supporters from around the county joined together in Leeds in a show of unity that sent a single clear message to the review chiefs just a few weeks after they had ruled that surgery in Leeds should be stopped.

That message rang out loud and clear as nurses, doctors and politicians from all three main parties marched with a 3,000-strong crowd through the city – we shall not be moved.

The tears from three weeks earlier, when Leeds wasn't one of the units chosen to continue children's heart surgery, turned to cheers as speaker after speaker denounced the decision and vowed to continue our campaign.

Perhaps the loudest cheers of the day were reserved for the nursing staff, who held aloft banners proclaiming their pride in their

service and warning that more than 450 years of combined cardiac nursing experience would be lost if the decision isn't overturned.

Ward sister Heather Wardle told the crowds in Millennium Square: "We've been ignored once. Let's hope this message is one that gets across." Demonstrators were joined by politicians of all main parties, including shadow chancellor Ed Balls, MP for Morley and Outwood, who told the Yorkshire Evening Post: "I have looked at the analysis and I've never understood how they could come to the decision not to have a centre in Yorkshire."

Stuart Andrew, Conservative MP for Pudsey, told the rally: "This turnout... shows how strongly people feel about this issue. Parents won't travel to Newcastle – they

Continued on next page

How could they decide not to have a centre in Yorkshire?

Ed Balls MP



• Unless stated, all demo photos are courtesy of Real Image Photography (www.realimage.lavoracms.com)

Continued from last page

will go to Liverpool or Birmingham instead and Newcastle won't reach the required 400 operations a year. How are families expected to go to Newcastle three times a day? It's simply not possible and it's simply not fair."

Greg Mulholland, Liberal Democrat MP for Leeds North West, told the crowds: "This was a bad decision and we won't stand for it. We will fight and fight until it is overturned."

Hilary Benn, Labour MP for Leeds Central, where the LCI is located, received huge cheers as he said: "We won't rest until the unit is reprieved and goes on doing what it has been doing for so long – providing the best quality service to the people of Leeds and of the region."

After the speeches, the demonstrators took to the streets to march through the city centre. As onlookers cheered and buses and cars beeped their horns in support, the chant "we shall not be moved" rang out from the marchers.

At the front of the procession, a flag showing the huge area of the country served by the unit was carried by patients Kim Botham and Joe Barry. Joe, aged 16, then led a string of patients



Alan Scott Photography



Courtesy of Gaynor Bearder



The charity's supporters were joined by politicians, including Stuart Andrew (far left, middle) and Hilary Benn (far left, bottom), and a host of mascots from regional sports clubs and charities, while dozens of media outlets covered the demonstration



We won't rest until this unit is reprieved and goes on providing the best quality service

Hilary Benn MP

Young heart patient Joe Barry gave a stirring speech to the crowds (above), followed by a number of mums who pointed out that big increases to their journey times meant they would choose closer units over Newcastle if Leeds does stop surgery (left, bottom). One of those speakers, Sally Boocock (right), ended the rally with a vow to keep fighting, which led to huge cheers ringing out across Millennium Square



and parents who told the rally why they wanted to keep the service in Yorkshire.

Heart mum Sally Boocock whipped up a frenzy of support when she declared: "We may have lost the first battle, but we have not lost the war. We will keep fighting."

CHSF Trustee Dr Sara Matley said: "It was an incredible day. The decision on July 4th wasn't unexpected, but it was massively disappointing. But the rally in Leeds showed that you can't keep the people of this region down for long."

"Heart parents and patients know how to fight, and we clearly showed the decision-makers that we will continue to make our logical arguments why Leeds should have been designated. We hope the powerful message from the demo will be further evidence to the Health Secretary that he now needs to review this flawed decision." ■



Despite the campaign, it's been business as usual for the CHSF...

THE Children's Heart Surgery Fund is a registered charity based at the Leeds General Infirmary.

We fund vital equipment, resources, research and training to advance the treatment of children and young adults with congenital heart defects.

We provide a support service for the children and their families by kitting out family rooms and playrooms on the wards and contributing to the hospital's parent accommodation.

We fund key staff posts, and provide travel and other grants to families in the time of need.

Our aim is to ensure these children have the best possible chance of survival. Our hope is to give 'each child a childhood'.

Katie Bear is our wonderful mascot. Katie was born at the LGI and had heart surgery when she was a young bear.

She is doing well now and gets to as many events as she can!



From dancing shoes to walking boots... £23k raised in nine days thanks to Joel

HEART hero Joel Bearder inspired an incredible fundraising effort when family and friends raised £23,000 in just nine days.

First, Joel's mum Gaynor teamed up with pal Vicki Green to host a ball. Then, the next weekend, Vicki's husband Chris led a team of CHSF supporters on a 25 mile Huddersfield to Leeds walk.

Gaynor and Vicki's ball raised a whopping £14,500 – with some of the money being spent on a state of the art 3D unit that will be used as a distraction and play therapy tool on the heart ward.

The intrepid hikers raised more than £8,500,



Allan Scott and Paul Barker give the 3D kit a thumbs up

and plucked up a last show of energy to celebrate when Chris revealed the total at the end of the walk.

Joel, now five, was born with critical aortic stenosis. You can read his story in issue one of BraveHearts, available at www.chsf.org.uk.



Vicki Green (left) and Gaynor Bearder (right) at the ball, and the exhausted walkers celebrate reaching Millennium Square



New £45k ECMO kit will help to save lives

THE CHSF is delighted to have been able to fund a new ECMO system for the heart unit at the LGI.

This vital piece of kit, which cost £45,000, will help save the lives of some of the sickest youngsters who have open heart surgery at the unit.

The state of the art system is used to help children who struggle to come off the bypass machinery after surgery.

In the last issue of Bravehearts magazine, we asked for your help to fund the purchase of this system, and

Stephen Hansbro from the clinical perfusion department at the LGI explained how the machine will be of benefit.

He said: "There are a small number of neonatal and paediatric cardiac patients who... following heart surgery, fail to wean from bypass. The aim [of the ECMO machine] is to rest the child's heart, so it is not under any stress, allowing it time to recover."

Trustee Dr Sara Matley said: "We would like to thank everyone who

contributed to the appeal to help fund this system.

"This is the latest in a long line of major purchases we've been able to make recently that ensure staff and patients at the unit have access to the best possible technology to help their treatment.

"It's a great feeling to be able to turn the money raised by our generous supporters into such a concrete and valuable project that will benefit many children for years to come."

Pounding the streets

Not quite Team GB, but Team CHSF bring home the medals at the Leeds Run For All

TEAM GB and Paralympics GB may have been getting all the sporting headlines this summer, but we think Team CHSF deserve our congratulations for a sterling effort in the Jane Tomlinson Run For All 10k race in Leeds.

Around a dozen runners and walkers took part in the annual event to raise money for the CHSF, and each was rewarded with a Run For All medal as they made it over the finishing line on the Headrow (in varying states of exhaustion).

Our gold medal winner was definitely Allan Scott – dad of heart patient Cameron – who completed the course in an impressive time of 42 minutes and 39 seconds, which saw him home in 124th place out of



Some of the CHSF runners getting ready to take on the Leeds 10k course

the 5,500 runners. Others completed the course at a more leisurely pace, which was understandable given the race took place on one of the few glorious days of this summer. The

CHSF's Angela Casey said: "Mass participation events like this are key to our fundraising and, between them, our runners raised thousands of pounds."



The team celebrate reaching the LGI four hours after leaving Hull. Unfortunately the rain hit on the way home!

Fab five get on their bikes for Bradley

FIVE intrepid fundraisers pedalled their way from Hull to Leeds – and back – to raise more than £2,000 for the CHSF.

Chris Fenton, David Serjeant, Chris Young, Martin Savage and Mike Roberts completed the 120 mile ride in under nine hours, raising £2,218. The team, which was supported by Cliff

Pratt Cycles, was inspired by Chris' son Bradley Fenton – who was diagnosed with hypoplasia of the aorta and coarctation of the aorta when he was 11 days old, and had open heart surgery the next day. Chris said: "This charity was of great support when Bradley was poorly with his heart and, therefore, is very close to mine."



KATIE'S NEWS ROUND

A BIG thank you to everyone who has taken part in fundraising events over the past few months – here are just a few examples of the great efforts of our amazing supporters...

• ERKAN and Lisa Can raised a fantastic £2,650 by running the Leeds half marathon and Leeds 10k, and holding a raffle and stall in Otley market.

• RICHARD Pickles and friends completed a coast-to-coast cycle ride, raising more than £1,000.

• THE Sam Tandy Smile a Mile Walk – held in memory of Sam, who sadly passed away in 2008 – raised almost £2,000. More than 20 walkers embraced the 'anything goes' fancy dress theme to join Sam's mum and dad Janice and Adrian on the walk.

• CASSIE Symms is planning another Zumbathon after her first event raised nearly £500. Zumbathon II will be on November 29 at Carlton Park Hotel in Rotherham. Contact the office for info.

Thank you for reading this special edition of Bravehearts magazine. Our next issue will be out soon.

Brave Hearts

Children's Heart Surgery Fund



Next issue out soon.

To subscribe call

0113 392 5907



We'll carry on fighting to keep surgery at the LGL because we believe it offers the best service for the children of the North of England. Including Lyall. A heartfelt thank you for your support.

Visit www.chsf.org.uk/donate or call 0113 392 5742