

Summer 2014

# lifeline



YOU  
+US

**how the  
hospital cared  
for Hugo – and  
mum Nicola too**

**help us support  
more families  
through our  
summer appeal**

**an incredible  
new research  
project into  
brain tumours**

# regular gifts

Children often stay at Weston House before or after surgery



Robyn, who has had numerous limb-lengthening operations, is just one of the patients you've helped

The hospital redevelopment will mean we can treat more children



## it's all thanks to you!

Regular gifts are crucial as they allow us to plan for the future and give us a steady income stream we can rely on. Each year, they support our four key fundraising areas: redevelopment, research, essential medical equipment, and patient and family welfare.

In the past year, regular gifts supported Phase 2B of the redevelopment – the start of the construction of the Premier Inn Clinical Building, which will complete the Mittal Children's Medical Centre.

We are the UK's largest charitable funder of medical research dedicated to paediatrics, committed to funding over £3.5 million of research every year. We also

fund the purchase of replacement or additional medical equipment. Last year, this included specialist X-ray equipment, a new ultrasound machine to assess muscle disease, and toys specially adapted to help children with their rehabilitation.

Your donations also help us care for the whole family. Last year, you helped us fund accommodation for parents to stay overnight. You also help support the ongoing annual cost of parents' accommodation, fund meals for breastfeeding mothers, contribute towards our multi-faith chaplaincy and help pay families' travel expenses. So thank you to all of you.



We are supporting vital research in neurosciences, cancer, birth defects and intensive care



This X-ray equipment helps doctors plan surgery for many children, including craniofacial patients

If you don't have a regular gift with Great Ormond Street Hospital Children's Charity, you can set one up today! Please visit [gosh.org/donate](http://gosh.org/donate) or call 020 7239 3131



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read  
online



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hello

**66** Hi, I'm Matthew, and I'm 11.

I normally read *Lifeline* but this time, I'm guest editor! When I was 18 months old, my parents were told I had a rare and life-threatening lung disease. Read their interview on page 13. I found it hard to breathe and couldn't do all the things my friends could do. I was often rushed to hospital. But then I had a heart and lung transplant. In 2012, I was in the opening ceremony of the Olympics. It was fun. This year, I'm looking forward to starting secondary

school. I've stayed at the hospital lots of times and my parents have been able to use the hospital's family accommodation nearby. Sometimes I stay there with them before or after an operation. Weston House is like a hotel. Great Ormond Street Hospital Children's Charity is a good idea – it helps pay for the accommodation. It's very important to have it.

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Matthew

**JOHN BROWN**

*Lifeline* is published by John Brown

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Great Ormond Street Hospital Children's Charity  
Registered charity no. 235825

Thank you to Matthew for guest editing *Lifeline* magazine and doing an excellent job interviewing Elizabeth Cooke.

The children's drawings in the background on this and other pages were created by our Friends members.

Print and fulfilment by: Intygra PPL Print Management

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## success story for new kidney transplants

»» Great Ormond Street Hospital (GOSH) can now transplant kidneys from donors whose blood groups were previously incompatible. New techniques that involve ‘washing’ a patient’s blood prior to transplant remove

the patient’s blood group antibodies. They include different types of ‘plasma exchange’, which allow the removal of plasma from the blood, to be replaced with new plasma – a similar procedure to haemodialysis where the blood passes

through a filter.

“Some patients may be able to receive a kidney transplant from one of their parents who was previously told they could not be a donor,” said Consultant Paediatric Nephrologist Dr Stephen Marks, who leads the kidney transplant programme at GOSH.

“There are risks involved in any transplant, but these patients can potentially go home within 10 days – the same as they would after a ‘normal’ kidney transplant.”

Although common in adults, these transplants have rarely been carried out in children in the UK. For this reason, around 40 per cent of parents have been unable to donate a kidney to their child. Four patients have now received these types of ‘incompatible’ transplants, including nine-year-old Maya (see below).

To support groundbreaking research projects like this, visit [gosh.org/donate](https://gosh.org/donate) or to find out more, visit [gosh.org/research](https://gosh.org/research)

### talking to...



**Sylwia,**  
**mum of**  
**Maya, nine**

“Maya was first admitted to Great Ormond Street Hospital (GOSH) in 2008 when a bacterial eye infection led to more serious complications with her kidneys. At four years old, she was diagnosed

with the rare condition aHUS (atypical haemolytic uraemic syndrome). This horrendous disease ravaged Maya’s little body in weeks and at one stage left her fighting for her life.

“By 2013, she was living with end-stage kidney failure. Then, thanks to a new procedure, she was

able to receive an ‘incompatible’ kidney from her father Marek.

“Since then, our lives have changed profoundly. We have become a family again and we make the most of every single day.

“Maya was given the gift of a new life and words cannot describe how grateful we are.”

”



## one great day

>>> Shopping centres up and down the country will be supporting Great Ormond Street Hospital Children's Charity over the weekend of 7-8 June in what promises to be a great day out for a fantastic cause. Family fun, entertainment and fundraising will take place across the UK.

To find out if a One Great Day event is happening near you, visit [gosh.org/onegreatday](http://gosh.org/onegreatday)



# bringing the hospital to you

>>> A new initiative is designed to take key elements of the hospital's legacy open days out on the road. The hospital open days are proving very successful but we know that some supporters are unable to attend due to mobility or distance issues. The new events can be held in sheltered accommodation and retirement homes, or at the Women's Institute, Townswomen's Guild, community or church groups. They will include talks about the origins and

development of the hospital, significant medical and research breakthroughs, memorable fundraising campaigns, current priorities and future plans.

Slide presentations and videos will illustrate the themes and there will be plenty of opportunities to ask questions.

To book a visit from our legacy team, call Richard Hick on 020 7239 3105 or email [legacy@gosh.org](mailto:legacy@gosh.org)

## a rare opportunity

>>> Works on our new Centre for Research into Rare Disease in Children are now under way. It is set to be the biggest single-site centre dedicated to research into paediatric rare disease in the world. Tragically, 75 per cent of rare diseases affect children and 30 per cent of children diagnosed with a rare disease die before their fifth birthday. With the support of philanthropic partners who wish to share this exciting vision, the new centre should open in 2018. Costing around £90 million, the dedicated facilities will help world-leading scientists and clinicians develop new and personalised ways to diagnose and treat children.



# saved from surgery

»»» David is one of four patients at Great Ormond Street Hospital (GOSH) who have been saved from surgery thanks to a new drug discovery. The patients all have hyperinsulinaemic hypoglycaemia (HH), where the body produces too much insulin, reducing blood sugar to dangerously low levels. The severest forms of HH can lead to brain damage.

David was first admitted to GOSH 10 days after he was born. Doctors tried a variety of known drug treatments such as diazoxide and octreotide, but were unable to stabilise David's blood sugar. The last option was for his pancreas to be removed – but he was then offered the drug sirolimus as an alternative after researchers identified that

this existing drug, normally used to treat kidney transplant patients, might be able to block the insulin.

"It was amazing," said mum Kristina. "Within a few weeks of being given the drug, he was much better and we were able to bring him home. David has now celebrated his first birthday."

All the patients are doing well with no significant side effects. Dr Khalid Hussain, lead author and Consultant in Endocrinology at GOSH, said: "This discovery could change the way patients are managed in the future."

Visit [gosh.org/donate](http://gosh.org/donate) and support groundbreaking research projects like this or to find out more, visit [gosh.org/research](http://gosh.org/research)

## be part of our story

»»» A new DVD, *Be Part Of Our Story*, shows how people throughout the hospital's history have pulled together to help the sickest of children.

It highlights how vital legacies have been – and always will be – in funding groundbreaking research and identifying revolutionary new treatments and cures. In the 1950s, not a single child diagnosed with leukaemia survived. Today, the majority of young leukaemia patients are in remission. Now, we are

working towards an even brighter future, where the treatments for childhood cancer are much kinder to these young patients' fragile bodies and new techniques will all but eradicate the need for invasive surgery.

To request a copy of this new DVD, talk in confidence about leaving a gift in your Will or find out about our Free Will Service call 020 7239 3105

### BE PART OF OUR STORY



Leaving a gift in your Will would help generations of children to come.



## talking to...

**Claudia,  
mum of  
Jesse, 14**

“ Jesse has been a Great Ormond Street Hospital (GOSH) patient since he was a baby. In 2007, he had a bone marrow transplant for myelodysplasia, a blood disorder that meant his bone marrow wasn't working. The transplant saved his life and we will always

be grateful to GOSH for giving our precious son a future. I wanted to give something back so I became a Foundation Trust (FT) member and am now an elected councillor representing parents and carers outside London. I have found it immensely interesting and rewarding. I really am able to help shape GOSH's future, ensuring that the parents' voice

is heard. FT elections are due at the end of the year so join now! Membership is free and joining takes minutes. You can choose your level of involvement and benefit from NHS staff offers. ”

To become an FT member, visit the charity desk in the Lagoon restaurant, go online at [gosh.nhs.uk/foundation](http://gosh.nhs.uk/foundation) or call 020 7239 3131

“ This summer, we're looking forward to... going to the beach...

**Ronni, five**

...and going to Ireland!

**Fredi, seven ”**

## Puffin and Woodpecker greet children

“““ Two new wards have just opened at the hospital. The first, Puffin Ward, is a new and improved version of our same-day admission unit Dinosaur Ward. Its 16 cubicles allow confidentiality and give children somewhere private to rest before they go to theatre. There's also a play

area and parents' room.

The second is our new post-anaesthetic care unit, Woodpecker Ward, which replaces the Island Day Unit.

Children who have had a general anaesthetic can be reunited with their parents on Woodpecker Ward to recover there before going home.

## appeal ticks the box

“““ Thank you to all the responders to our Gift Aid appeal. Over 3,000 supporters ticked the Gift Aid box, meaning we will be able to raise an extra £96,000 for sick children.

Your support could be worth a lot more than you think



# can we show you?



## welcome to the hospital

**The redevelopment of the hospital's main entrance and reception aims to put patients and families at ease as soon as they arrive**

Our main entrance has just reopened, having been redesigned to make a brighter and friendlier space. Coloured glass panels above the doors of the main entrance create an inviting and exciting first impression of the hospital, helping to ease patients'

### Workstations allow staff to deal with multiple requests

fears of visiting hospital. The main entrance canopy will also include a beautiful sculpture by glass artist

Chris Wood. The inspiring artwork recognises and celebrates organ donation and transplantation.

Two sets of automatic doors have been installed to help reduce cold breezes in the reception area.

A key feature inside the building is the new reception counter, designed in the shape of a boat as part of a nautical theme. Workstations on

the reception desk have been planned for flexibility, allowing staff to deal with multiple requests,

reducing waiting times and congestion. There are also designated waiting areas, a quiet zone and interactive entertainment for children and young people.

Patients, families and staff members were all involved in selecting the reception's furniture by visiting exhibitions last year to try out seating, which has been chosen to create a comfortable and relaxing environment.

Kiosks housing a 3D interactive wayfinding system help visitors make their way around the hospital corridors.

The temporary entrance that visitors had been using since the beginning of last year is now closed for the second phase of the refurbishment. An alternative entrance through the Frontage Building that will allow easier access to the outpatients clinic, will open in the autumn.

It will provide an additional waiting area as well as outpatient facilities and potential retail space.

The boat-shaped reception counter (above) and relaxed seating (below) of the newly opened main entrance





# work in progress

**Completing the Mittal Children's Medical Centre will enable us to treat an anticipated increase in demand**

Construction work on the second of two buildings that make up the Mittal Children's Medical Centre is under way.

The first part of the centre, the Morgan Stanley Clinical Building, opened in 2012. The next stage will see the hospital's old Cardiac Wing replaced by a state-of-the-art Premier Inn Clinical Building.

The Mittal Children's

moving the Cardiac Wing's wards and offices to other locations on the hospital campus. Careful planning has made the transition to alternative areas as seamless as possible for both patients and staff. Preparations for the Premier Inn Clinical Building have begun, with preliminary building works, such as essential drainage systems, installed.

Coming to hospital can

**Coming to hospital can be stressful and traumatic**

Medical Centre is named in recognition of the generous support of Aditya and Megha Mittal and family. With the completion of the centre and its amazing new facilities, the hospital will be able to treat an anticipated increase in demand of up to 20 per cent more patients. Preparing the site for the works has involved



**An artist's impression of the Mittal Children's Medical Centre once the Premier Inn Clinical Building is completed**



**“ This summer, I'm looking forward to... swimming outdoors Kimberly, nine ”**

be a stressful and traumatic experience for children and their families. Children need space to play and eat with other patients while parents need to be able to stay comfortably by their child's bedside.

When finished, in 2017, the centre will have world-class facilities that embrace the latest technologies, making real differences to the patients we treat.

**We still urgently need to raise £30 million to finish this phase of our ambitious redevelopment programme. Please visit [gosh.org/donate](http://gosh.org/donate) or call 020 7239 3131 and make a donation today. Find out more at [gosh.org/redevelopment](http://gosh.org/redevelopment)**



# care that never ends

**The support the Family Liaison team gave Nicola when Hugo was in hospital, including a room nearby, meant the world to her**

"I found out something was wrong at my 12-week scan," says Nicola. Baby Hugo had exomphalos – an abdominal wall defect where some of the organs are inside the umbilical cord, forming a bubble outside the baby's tummy. In Hugo's case it was his liver and part of his bowel, so he would need surgery soon after birth.

"From that point on,

we were whisked into a whirlwind of appointments. There's a risk of rupture – we were told that three out of four babies make it..."

When Nicola was about 30 weeks pregnant, she was invited to visit Great Ormond Street Hospital (GOSH) to help prepare herself for where Hugo would be in intensive care.

"I have to say it was the

most terrifying thing ever – you know that if you're walking into the place you've only seen on TV there must be something very wrong with your child. But the Family Liaison Sister Esther and the Neonatal Intensive Care Unit (NICU) nurses were brilliant. They explained

**"Hugo was put straight on life support"**

what the equipment was and what to expect."

On 9 December, 2010, Nicola had a planned caesarean at University College Hospital. "Hugo didn't thrive so he was put straight on life support and taken off to GOSH nearby."

He had his first operation the following day – his stomach was opened so a silo bag could be stitched to his skin to hold the organs on the outside of his body. "It looked like a Christmas pudding," says Nicola, "but it helped keep the organs sterile and was used to push the organs down. It puts pressure on the lungs so it has to be done gradually."

"Hugo had ups and downs including infections and feeding issues, but by the time he had the last operation – his sixth – he was doing really well."

Hugo was in NICU for three-and-a-half weeks. During that time, Nicola





Hugo's parents hold him for the first time at two-and-a-half weeks old

stayed at the charity-funded family accommodation in GOSH's Italian building: "It was absolutely amazing. It slowly dawns on you that you've been given a room for every night you're at the hospital. I had a double bed, wardrobe, TV, bathroom

## "It's really important in so many ways"

and use of a kitchen. It's really important in so many ways. My husband Billy could spend weekends there



Hugo in the Neonatal Intensive Care Unit

to have some normality at what was a very lonely and hard time. I had a phone so I could call NICU

when I wanted. I'd wake up at three in the morning, wonder how Hugo was and phone them. Or if he was having a difficult time, they would call me. I could be dressed, out of the door and at the hospital in 10 minutes. It meant the world to me. The charity also provided food vouchers while I was breastfeeding."

Once Hugo was out of NICU, Nicola had a bed in his room on the ward so she could sleep next to him.

"I really don't know how I would have coped. I felt like I was a patient as much as Hugo sometimes. Some days are so long – the minutes are like hours. You think it will never end. On one day, I just couldn't stop crying but Esther was there with me all day. They do so much to encourage you."

At nine-and-a-half weeks, Hugo could go

home. "It was terrifying but you're still not on your own. You can call the ward any time of day or night and get their advice. I often did."

In February this year, after a further three operations, Nicola was told Hugo wouldn't need any more surgery for the foreseeable future: "I cried all weekend – I felt a million different emotions," says Nicola.

"I'm still in touch with two of the NICU nurses. They feel like part of our family. Even now, I can phone Squirrel Ward if I'm

## "They do so much to encourage you"

worried. It's like the care never ends. You come away realising these things cost money, so I've become a charity ambassador – to raise money for research for children like Hugo and for the hospital to help parents like me when they feel desperate. I love going to events to explain why we need to keep redeveloping the hospital. For some children, it's where they might spend all or their last days. Where would you want your child to be?"

To donate to our summer appeal towards the family accommodation and welfare services, please call 020 7239 3131 or visit [gosh.org/donate](http://gosh.org/donate)

# support for parents

"Hi, I'm Matthew, your *Lifeline* guest editor for the summer issue. Today I'm going to ask Elizabeth from the Family Accommodation team a few questions."

## Where is the hospital's accommodation?

We've got Weston House on Great Ormond Street and the Italian building on Queen Square. There's the mums' unit inside the hospital and then some accommodation in Powis Place. All the accommodation is within a five-minute walk from the hospital.

## Who can stay in the accommodation?

In Weston House, the patient stays with the parent – as you did after your transplant. The other accommodation is for parents only. It's mostly used by parents of children on the intensive care wards.

## How many families stay there during the year?

About 1,200 parents use the accommodation each month and stay for anything from a few days to many months.

## Why is it good for families to stay there?

Families come from various parts of England, Scotland, Wales, Ireland and even as far away as Malta... so it's good that they can stay near the hospital. All parents of intensive care patients, no matter where they live, are guaranteed accommodation.

## What services are provided?

In Weston House, all the rooms are en suite. It's like a hotel – you've stayed there, so you know. And on each floor, there's a fully functional kitchen.

## How many staff are there and what jobs do they do?

There's the manager, Erin, then Eloise who does the bookings for Weston House. I do the bookings for the rest. We have three housekeepers, maintenance staff and many cleaners.

## Will accommodation staff know what's happening at the hospital?

We have a computer system to check which wards the children are on. We also speak to the family liaison sisters daily on the phone and to parents. The nurses let us know where a child is likely to be at a particular time – if they are going for tests or surgery, for example.







[gosh.org/lifeline](http://gosh.org/lifeline)

watch it  
online

### How much does it cost to run the accommodation?

At Weston House, there are 117 beds. It works out at approximately £3,000 per bed each year so that's approximately £350,000 a year – just for Weston House. The other accommodation obviously has to be paid for as well! Maintenance is a big problem as the rooms are used a lot.

### Do families have to pay for the accommodation?

No – and a large proportion of the cost of funding the accommodation that we are able to provide each year comes from the charity's generous supporters. We can't thank them enough.

**To make a donation towards the family accommodation and welfare services as part of our summer appeal, please call 020 7239 3131 or visit [gosh.org/donate](http://gosh.org/donate)**



talking to...

**Christian,** **66** **W**hen dad of **Matthew, 11** 18 months old, he collapsed on my lap. He wasn't getting enough oxygen and his heart was five times larger than it should have been. He was diagnosed with severe primary pulmonary hypertension and transferred to Great Ormond Street Hospital (GOSH) where he spent the next six-and-a-half weeks. His mum Sharon and I were able to stay in the hospital's accommodation, so we could get back to the ward quickly if something was wrong. She was also five months pregnant and had tests nearby at University College Hospital. The condition can be genetic (luckily it wasn't). It was an emotional time.

"Matthew has had more than 30 operations, including a heart and lung transplant when he was four-and-a-half. He often stays with us in the hospital accommodation the night before an appointment. It takes away a lot of the pressure.

"Without GOSH, we wouldn't have our son. We're forever indebted to the skill, care and treatment it has given him – and being able to stay in the hospital accommodation has been a godsend."

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# the calming powers of Koala

**When Rudy was diagnosed with a brain tumour, the staff on neurosciences ward, Koala, were there to care for the whole family**

When Rudy was five, he started being sick for no apparent reason.

Everything pointed to a stomach problem but Rudy remained unwell despite medication. Then, dad Sam showed a paediatrician a video of Rudy walking in an unbalanced way. Sam says:

“We were instructed to go to A&E. Rudy had a brain scan that showed he had a sizeable tumour. It was a big shock I didn’t see coming.”

They were then sent to Great Ormond Street Hospital’s neurosciences ward, Koala. “We met the most reassuring and calm

team of staff,” says Sam.

Rudy had an operation the next day to release the pressure in his brain and doctors took a biopsy.

“Waiting for the results felt like a lifetime,” says Sam, “but we were able to go home. Rudy’s laughter and appetite returned.”

Rudy was found to have a

**“It felt like their job was to look after me as much as Rudy”**

rare kind of tumour, called pilocytic astrocytoma, that was rapidly growing on top of his spinal cord.

After a difficult operation to remove it, more surgery was needed to remove a large blood clot as well as air that entered his brain during the first operation.

“One week later, we had our first good day with no headache, temperature or vomiting – Rudy was on the up at last!” says Sam. “The future looks good – we were recently told we don’t need to go back for six months.”

“From the nurses who looked after Rudy as if he was their own to the cleaner Syed who helped me change Rudy’s sheets, to volunteers who played with him so I had time to talk to the consultants, and our surgeon popping in on his weekend off, everybody worked together to make Rudy better. And it felt like their job was to look after me as much as Rudy.”



# new chance of a cancer cure

**An innovative research project could help brain tumour patients fight their own disease**

Every week in the UK, 30 children are diagnosed with cancer and although survival rates have improved dramatically in recent years, we are still not able to cure every child. In children, the most common type of solid tumour occurs in the brain.

Survival rates vary dramatically. More than three out of 10 brain tumours in children (30 per cent) are types known as gliomas. More than 87 per cent of children with low grade gliomas will live for more than five years after surgery. But for higher grade gliomas, the outlook for babies younger than a year is poor. Now, Dr John

**“The project has reached an exciting time”**

Anderson, Professor of Experimental Paediatric Oncology and Honorary Consultant Oncologist at Great Ormond Street Hospital and its research partner UCL Institute of Child Health, is focused on finding new treatments. His research project involves a



sample of a child's immune cells being extracted and then exposed to fragments of the glioma removed from the patient. Once primed to recognise the glioma, the immune cells are re-injected into the child, where researchers hope they will help the body fight the remaining cancer cells.

If successful, it will be the first time children with high grade glioma have had a chance of a cure.

“The project has reached an exciting time with the launch of a clinical trial,” says Professor Anderson, who hopes to have the first phase results early next year.

The trial aims to see how possible it is to make and give vaccines to children that stimulate their immune system to attack the cancer.



To support GOSH research and find out more, visit [gosh.org/research](https://gosh.org/research)



# it's a family affair

**£1,456**  
per day

*pays for the family accommodation that allows children and their families to stay together near the hospital.*

They can stay overnight where the child has an early outpatient appointment the following day, or for longer periods where a patient has a substantial recovery period ahead or ongoing complex needs, while families learn skills from hospital staff.

**£95**  
per day

*provides a support worker who gives emotional and practical support to children and families affected by cancer.*

Great Ormond Street Hospital is a national centre of excellence for cancer treatment in children. The Psychosocial team sees approximately 200 newly diagnosed patients each year.



**“Children are so brave and always manage to put a smile on my face”**

**Gurpreet Kalyan**  
*Oncology Psychosocial Liaison Worker*

**£60**  
per day

*provides food vouchers for all breastfeeding mothers staying at Great Ormond Street Hospital.*

Some babies are too premature or too sick to breastfeed but their mums can still produce breast milk, which is extremely important and nutritious for these babies. Breastfeeding and expressing milk is also

a really positive thing for mums to be able to do for their sick babies. Being close to their babies and making sure they have regular nutritious meals is hugely important to sustaining a mum's breast milk supply.

**“Mums can still produce breast milk, which is extremely important”**

**£637**  
per day

*pays for the 24-hour multi-faith chaplaincy services that help families cope with the spiritual and emotional impact of a patient's illness or death.*

The chaplains arrange support meetings such as coffee mornings, as well as baptisms and other faith rituals, funerals and memorial services.

Donations to the *Lifeline* appeal will help fund our vital patient and family support services. Here are just some of the areas we fund.

**£30**  
per day

*pays for the cost of calls received by the Child Death Helpline from anyone affected by the death of a child.*

Delivered jointly by Great Ormond Street Hospital and the Alder Hey Children's Hospital, the freephone helpline is manned by bereaved parent volunteers, who are given specialist accredited training. An interpreting service is also available.



**“Seeing my colleagues’ compassion inform their professionalism makes me feel privileged”**

Jamie Johnstone  
Bereavement Service  
Support Worker

read  
more  
online



For more information about our patient and family support services, including accommodation and counselling, visit [gosh.org/patientandfamily](http://gosh.org/patientandfamily)  
Or, to make a donation to our summer appeal visit [gosh.org/donate](http://gosh.org/donate) or call supporter services on 020 7239 3131

**why we  
need  
your help**



**40%**

of patients we treat  
are under four  
years of age



**54%**

of patients we  
treat come from  
outside London

Our accommodation



**95-100%**

of our five  
accommodation  
facilities are occupied  
at any one time. We  
provide:

- 236 parent bed spaces on wards
- 117 beds in the patient hotel Weston House
- 8 self-contained flats
- 6 care-by-parents flats
- 2 isolation flats

...everyone who has donated, spread the word, baked a cake, run a race, or done anything in aid of Great Ormond Street Hospital Children's Charity. We can't include all of you, but here are some of the highlights, plus some upcoming fundraising events and ideas...



## proud to be an ambassador

*Zoe wanted to give back for the hospital's help and support.*

"Noah was born in 2008 with congenital heart disease. He had his first operation at two hours old. He spent six months, on and off, in the Cardiac Intensive Care Unit at Great Ormond Street Hospital (GOSH) and

underwent three open heart surgeries. Throughout that time we lived at GOSH in the parents' accommodation with Noah's twin sister and we spent every day at Noah's side. It was a brutally stressful period that our entire family endured.

"Noah is now nearly six and currently thriving. We

return to GOSH every six months as outpatients and consult with them on what we as parents can do to assist his recovery and development. I wanted to give back for everything they have done, and continue to do, for Noah and for the support they give us as a family.

"As a charity ambassador, I raise money personally through organising nearly-new sales, raffles, cake stalls and collection boxes, as well as encouraging local fundraising. I really enjoy attending events to spread the word about the amazing work of GOSH, to thank other people for their contributions and to hear the inspirational stories of people I meet."



For more on being a charity ambassador see [gosh.org/ambassador](http://gosh.org/ambassador) or call the community fundraising team on 020 7239 3066



**“This summer, I’m looking forward to... being back on my bike Libby, 13”**



## make every payday count

>>> Thank you to all our supporters who donate to Great Ormond Street Hospital Children's Charity through their salary each month. Payroll Giving is a simple, tax-efficient way to donate.

To find out more about doing the same, visit [gosh.org/payrollgiving](http://gosh.org/payrollgiving)



## stockings filled with funds

>>> A great big thank you to everyone who sent in a stocking last Christmas for the staff and patients.

We decorated the hospital with thousands of stockings over the festive period. We also raised an incredible £1.68 million from your donations to the appeal. The funds are essential for Great Ormond Street Hospital – they will help us achieve our



annual target of raising over £50 million each year and enable us to treat thousands of desperately sick children.



## explore Iceland for GOSH

*The Gastroenterology team at Great Ormond Street Hospital (GOSH) is seeking 30 trekkers to make an amazing seven-day trek in July through the beautiful wilderness of Iceland.*

The department is one of the largest in the country, treating thousands of children who have complex and life-limiting conditions.

Dr Neil Shah, along with other members of the Gastroenterology team, have organised this event to help raise funds. The beautiful trek across ice and lava fields, past volcanoes

and waterfalls and through streams and mountain passes is a challenging, once-in-a-lifetime experience in the land of the midnight sun.

By signing up to this trek, you will be joining the hospital team to raise awareness and much-needed funds for the charity.



To sign up for the Iceland Fire and Ice Trek now or to find out more, visit [gosh.org/iceland](http://gosh.org/iceland) or call 020 7239 3164 or email [challenges@gosh.org](mailto:challenges@gosh.org)



Bill (below, right) and twin brother Lenny get ready for Bake it Better

## grab the flour and get raising!

*This year, Bill is able to host his own bake sale for Bake it Better, thanks to the hospital.*

Bill and twin brother Lenny, now 10, were born seven weeks early at University College Hospital (UCH). Bill was found to have a rare condition known as VACTERL syndrome (vertebral anomalies, anal atresia, cardiovascular anomalies, tracheo-

oesophageal fistula, renal anomalies and limb defects). As a result, he faced serious problems with his bowel, bladder and digestive tract.

His parents were told he needed to be transferred to Great Ormond Street Hospital (GOSH) immediately – and had a 50 per cent chance of survival. Bill's windpipe and oesophagus were joined, so

his first operation was to pull his oesophagus down and sew it back together.

After a further four operations, including the removal of his bowel and gall bladder, Bill was discharged. Since then, he has had 13 operations, recently returning for a bladder reconstruction, which has made him much more independent.

"Bill still likes going to GOSH for outpatient appointments," said mum Fran. "It is testament to the amazing care he has received from the doctors, nurses and invaluable play specialists that his traumatic experience is remembered almost fondly."

Join Bill in hosting a Bake it Better bake sale at home, school, work or at your local community group. Help us raise £125,000 for the new clinical building at GOSH.

To register your interest in hosting a bake sale during Bake it Better week (Monday 13 to Sunday 19 October) and to receive a FREE bake kit, visit [gosh.org/bakeitbetter](http://gosh.org/bakeitbetter)

## equipment appeals provide new machines

»» Thank you for supporting our February Valentine's and Bone Scanner appeals. We had an amazing response to both. We have been able to purchase a 3D echocardiogram machine, which is used to provide high-resolution images of 12,000



patients' hearts, valves and major blood vessels each year, and a new DEXA bone scanner machine, used to treat patients with conditions such as arthritis, cystic fibrosis and cancer by monitoring bone density. Thank you for your enormous generosity.





## pop to the shop

»»» A fantastic new pop-up shop has been created in the Lagoon restaurant while the old shop in the hospital's reception area is temporarily closed for the redevelopment programme. In response to your comments in our retail survey last year, we aim continually to improve our product range and service. We now have a very special new range of products that includes tea towels, aprons, mugs and bags, designed exclusively for Great Ormond Street Hospital Children's Charity. We asked you to tell us one word that summed up the hospital for you and based on your amazing responses, our friends at Busy Being helped us create this new inspirational range.

Visit our pop-up shop in the hospital, shop online at [gosh.org/shop](http://gosh.org/shop) or call 0844 858 9324. All profit (100 per cent) from sales goes to support the hospital



## dad has 70th birthday gift for charity

*Lucy tells how her father Stanley Tse celebrated his birthday by helping children and families at the hospital.*

"Stanley Tse is Chairman of the SeeWoo Group and was, until recently, President of the London Chinatown Chinese Association. As a high-profile figure in the Chinese community, his 70th birthday was never going to be a small affair!

"He had already told me he didn't want any presents so we thought it would be an ideal opportunity to ask friends and family to donate to a charity of his choice. Stanley is a keen supporter of many different charities and this was the perfect way to give him a really memorable birthday

present – the satisfaction of helping sick children.

"His grandson – my son Charlie – has been under the care of Great Ormond Street Hospital since birth so I was very keen for us to support this special hospital. We raised £11,070. The life-saving treatments and first-class care of the hospital are truly inspiring."

**Make your birthday, wedding, anniversary or another occasion extra special by asking for donations to Great Ormond Street Hospital Children's Charity in place of gifts. For details call 020 7239 3002 or visit [gosh.org/get-better-gifts](http://gosh.org/get-better-gifts)**



# want to join in?

We organise a wide range of activities, services and fundraising events all year round. Here are a few:

→ **Great North Run**  
→ **7 September 2014**

Be our Angel of the North in the nation's biggest and best half marathon. Visit [gosh.org/gnr](http://gosh.org/gnr)

→ **Halloween Moonriders**  
→ **31 October 2014**

Join us on a spooky spin in the city – it's guaranteed to get you shaking in your saddle! Visit [gosh.org/moonriders](http://gosh.org/moonriders)

→ **Santa Run**  
→ **December 2014**

Join over 3,000 Santas for this exciting 5k and 10k run around Victoria Park in London. Visit [gosh.org/santarun](http://gosh.org/santarun)



sign up  
online



→ **Kilimanjaro Trek**  
→ **12–22 February 2015**

Step up to the challenge and climb one of the most impressive and well-known mountains in the world. Visit [gosh.org/Kilimanjaro](http://gosh.org/Kilimanjaro)

Go online  
and find  
out about  
our exciting  
challenge  
events



Visit: [gosh.org/challenges](http://gosh.org/challenges)  
Call: 020 7239 3164  
Email: [challenges@gosh.org](mailto:challenges@gosh.org)

## Would you like to be part of our story?

A gift in your Will, no matter if it's large or small, will help children benefit from our pioneering work in ways our predecessors could never have imagined. Our new DVD, *Be Part Of Our Story*, tells you more.



To request a copy, or talk in confidence about leaving a gift in your Will, or to find out about our Free Will Service, call Richard Hick on 020 7239 3105 or email [legacy@gosh.org](mailto:legacy@gosh.org)

[Our hospital](#)[Our charity](#)[Patients & Parents](#)[Research](#)

## Want to read more?

Visit the lifeline blog for more news and stories from the hospital and charity

[blog.gosh.org](http://blog.gosh.org)



[Facebook.com/GreatOrmondSt](https://www.facebook.com/GreatOrmondSt)



[Twitter.com/GreatOrmondSt](https://twitter.com/GreatOrmondSt)





Bill had 13 operations before his 10th birthday. Now he's holding a bake sale.

Help children like Bill and raise some dough with a bake sale.

**Bake it Better week**  
13–19 October 2014

Register your interest and get your free Bake It Better fundraising pack  
[www.bakeitbetter.org](http://www.bakeitbetter.org)

**Bake it Better**