

Summer 2013

# lifeline



YOU  
+US

**why baby Ava  
was rushed into  
surgery minutes  
after birth**

**the conjoined  
twins who  
have turned 10  
thanks to the  
hospital**

**state-of-the-art  
facilities you're  
helping to provide**

# Host a Peter Pan party

Make your child's birthday that little bit more special...

Download our party pack today, filled with everything you need to host a fun party, and make a difference to the sick children at Great Ormond Street Hospital.

[www.gosh.org/peterpanparty](http://www.gosh.org/peterpanparty)

## inside

- 04 Our top news stories
- 08 How the hospital saved Charlie when he had months to live
- 09 Why raising funds for a new surgery centre is vital
- 10 Read why mum Kelly was shocked when she saw her baby's first scan
- 12 Guest editors Zainab and Jannat interview a top surgeon
- 14 The incredible operation that helped Chantelle to eat again
- 16 Amazing research projects that your donations are making possible
- 18 Thanks to all of you for fundraising – here's a selection of your brilliant initiatives
- 22 Events for you to take part in



hello



“ We're Jannat (left) and Zainab. We're your guest editors.

**Jannat:** When we were five or six, our parents showed us pictures and videos of us as babies joined together. I didn't know if it was true as it looked weird!

**Zainab:** I was surprised at first as I never thought that could happen. Now, when we meet new people, first they ask if Jannat is my sister. Then they ask if we are twins – and then they ask who is older. They are normally shocked to find out, but they get used to it. I'd like to be a doctor!

**Jannat:** And I want to be a lawyer – when our class has debates, our team wins! Our mum tells you more about our separation operation on page 13. We also interview surgeon Joe Curry who has performed operations like ours.

**Zainab:** We ask him about the new surgery centre that the charity needs to raise funds for. We hope you can help. ”

Jannat and Zainab

photography – cover/above: David Harrison

JOHN BROWN

Lifeline is published by John Brown

For John Brown: Sarah Kovandzich, Jilly Slattery, Andy Cowan, Georgia Harrison, Christine Cavaleros, Joanna Mead, Simon Gandy [www.johnbrownmedia.com](http://www.johnbrownmedia.com)

For Great Ormond Street Hospital Children's Charity: Robert Butt [www.gosh.org/lifeline](http://www.gosh.org/lifeline) [blog.gosh.org](http://blog.gosh.org)

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

Thank you to our guest editors of *Lifeline*, Zainab and Jannat, who did an excellent job of interviewing Mr Joe Curry.

The drawings in the background on this and other pages of *Lifeline* were created by Alice (5) and Belle (5).

Print and fulfilment by: Intygra PPL Print Management

intygra ppl



read online



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

40 Bernard Street London WC1N 1LE [www.gosh.org](http://www.gosh.org)

Tel: 020 7239 3000 Fax: 020 7837 5062 Supporter Services: 020 7239 3131 [supporter.care@gosh.org](mailto:supporter.care@gosh.org)

# new gene discovery

»» The genetic cause of a rare condition that causes large moles to grow on the skin and brain before birth has been identified in a study led by Great Ormond Street Hospital and the UCL Institute of Child Health.



Poppy, six, at the hospital with mum Kirsty



Dr Veronica Kinsler

Researchers have found that the condition, multiple congenital melanocytic naevi (CMN), is caused by a mutation in a gene called NRAS. There is currently no treatment for CMN, which can lead to neurological

problems such as fits, and increases skin cancer risk.

Poppy, whose main birthmark is on her head, is one of many children who are closely monitored.

Mum Kirsty said: "When Poppy was younger, we hardly went out. We still put lots of sun cream on her as well as a sun hat and

protective suit." Paediatric Dermatologist Dr Veronica Kinsler, lead author of the study, said: "This is a big breakthrough. We can now develop tests to differentiate between people carrying the gene and those who don't – and finally start to look for new ways to treat it."



# appealing news



»» Thank you to everyone who sent in a stocking at the end of last year with a message of support for patients who were in Great Ormond Street Hospital over Christmas. They gave the hospital a festive atmosphere and were heart-warming to read.

We also received just over 100,000 donations, totalling £1.68m, which is a truly phenomenal response and our best Christmas ever in terms of

fundraising. This funding is vital to the work of the hospital and will be used to buy the latest medical equipment, pay for family support services, contribute towards the ongoing redevelopment, and support a number of groundbreaking research projects in coming years.

All of this will ultimately help the many thousands of patients we treat get better and get home.

Thank you again.

# into the future

»» Jan Filochowski, who became Chief Executive Officer of Great Ormond Street Hospital last year, has outlined his observations on the hospital since taking up his role. He said:

"For me, the hospital is a place that's bursting with life and people and that's a very big change from what I saw from the outside."

Setting out the way forward, he said:

"The hospital's mission is to provide world-class paediatric care, research and education. My role is to provide sureness of direction to support this.

"This includes decisions on investment in services, infrastructure and people – all of these elements need to come together to provide a clear strategy and vision for the future.

"Our biggest challenge is to evolve and develop in

**"We need to be able to look into the future and see how services are likely to develop"**

order to remain the premier children's hospital in the UK.

"We need to be able to look into the future and see how services are likely to develop and then prepare ourselves to deliver care appropriately."



Chief Executive Officer Jan Filochowski

# listening lessons

»» A number of the hospital's Foundation Trust patient, parent and carer members have been getting involved in a training programme for some 160 junior doctors. The sessions are designed to give trainees skills in attentive listening to patient and carer experience, especially if care has not gone well.

'Creating a conversation, not sides' is part of the thinking, with the participating doctors reflecting on what they hear from patients, what they feel in response, and how that may in turn

improve their own communication style and clinical practice.

Dr Soubhik Pal, who is leading the project on behalf of UCL Partners, said: "Giving patients time to tell their stories can provide doctors with much food for thought at this crucial time in their training. We are very grateful to the patients and carers who have come forward to help us."

To become a Foundation Trust member and take part in key projects, visit [gosh.nhs.uk/foundation](http://gosh.nhs.uk/foundation)

# a Royal tour

»» HRH The Prince of Wales paid a special visit to Great Ormond Street Hospital earlier this year, meeting staff, patients, parents and supporters on cancer wards Lion and Elephant, and on neurosciences ward Koala.

On Lion Ward, six-year-old patient Joseph wore a crown he had made specially for the occasion and chatted to The Prince about his Airfix kit.

“He told me he used to get glue all over his fingers when he was a little boy, and I said that I never did!” Joseph remembered.

The Prince visited the Complementary Therapy programme, where a nurse therapist provides patients



Katie and mum Emma with The Prince of Wales

on the cancer wards with massages. It is funded by charitable support.

On Koala, The Prince sat with eight-year-old epilepsy patient Katie. “He was kind and friendly,” she said.

He also met Neurology

Consultant Professor Helen Cross – the Prince of Wales’s Chair of Childhood Epilepsy. The Prince supported the charity in fundraising for the post, which was created 10 years ago.

# breakthrough for babies

»» A study funded by Great Ormond Street Hospital Children’s Charity has investigated a new way to treat babies suffering with necrotising enterocolitis (NEC), where severe inflammation destroys tissues in the gut. NEC is the most common gastrointestinal surgical emergency in newborn babies, with mortality rates around 15 to 30 per cent in the UK. In the study, amniotic fluid stem (AFS) cells were harvested from

animal specimens. NEC-affected animal samples injected with the AFS cells showed significantly higher survival rates a week after being treated, compared to control groups. Inspection of their intestines showed the inflammation to be significantly reduced – with fewer dead cells, greater self-renewal of the gut tissue and better overall intestinal function.

Honorary Consultant Dr Paolo De Coppi, UCL Institute of Child Health, who led the study, said: “Stem cells are well known to have anti-inflammatory effects, but this is the first time we have shown that AFS cells can repair damage



Dr Paolo De Coppi

in the intestines.” The research paves the way for a new form of cell therapy to reverse inflammation damage in babies’ intestines.

Find out about more pioneering research online at [gosh.org/brtl](http://gosh.org/brtl)

# win a luxury hamper!

»» Did you notice the readers’ survey that came with this *Lifeline* magazine? Your views are valuable to us as we rely on your feedback to make sure we are providing you with all the information you need to know about the hospital and the charity. By returning the survey, you could win a luxury Harrods hamper worth £175!



Please spare a few minutes of your time to complete the survey. Thank you!

“ My favourite things to bake and eat are... flapjacks! Amina, 10 ”

# study takes Xtreme measures

»» Former patient Jack, nine, is one of 12 children who recently took part in an Xtreme Everest expedition to help researchers better understand how to treat children in intensive care who have low oxygen in their blood.

The group trekked from Lukla to Namche Bazaar in Nepal, where they underwent rigorous tests at an altitude of 3,500 metres.

They were also assessed before setting off, to gather baseline data on

their normal physiology.

“The testing we are doing is a world first,” said Dr Mark Peters, Intensive Care Consultant at the hospital who led the expedition. “At high altitude, we can isolate the effect of low oxygen on otherwise healthy children.

“We want to determine the physiology of kids who do well at low oxygen levels to then apply that knowledge to treat patients in intensive care.”

Patient Jack said: “I’m really glad that I’m helping other children get better.”



Jack with dad Lee

Read more online at [gosh.nhs.uk/news](http://gosh.nhs.uk/news)



# the only chance to save Charlie

With just months to live, a new operation at Great Ormond Street Hospital changed everything

Charlie, now four years old

When Charlie was born in 2008 in Coventry's Walsgrave Hospital, he wasn't breathing properly.

He was moved to Leicester Hospital where he spent the next few weeks of his life in intensive care. He was stabilised and given a tracheostomy (where a

his hair and developing a rash all over his body.

Charlie was transferred to a hospital in Newcastle where doctors confirmed he had a life-threatening immune disorder. He had no thymus organ and was unable to produce T cells.

"Basically he didn't have an immune system," says mum Rachel.

The family was told that Charlie probably had six to 12 months to live. He was moved back to Walsgrave where he stayed in isolation.

"It was a really frightening

time," says Rachel. "Charlie had no real quality of life.

"There was a centre in the US that had carried out some thymus transplants but Charlie was too poorly to fly and the treatment was horrendously expensive."

Then in spring 2009 the family heard about groundbreaking research that Dr Graham Davies was doing at Great Ormond Street Hospital. Early in 2010, Dr Davies contacted the family to tell them a transplant

## "Charlie finally has the chance for a normal life"

programme had started there and that Charlie could have an operation that June.

"Everything went well," says Rachel. "Small incisions were made in his thighs and 'slivers' of donor thymus were placed into his legs.

"He will always have some symptoms of his condition, like reduced hearing, but he has done brilliantly. In January 2011 he started nursery. I was overwhelmed taking him - I never thought that day would come! We are so grateful. Finally, Charlie and our family have the chance for a normal life without constant fear of infection."

To find out about more patients who have benefited from our groundbreaking research visit [gosh.org/brtl](http://gosh.org/brtl)

# surgery centre update

A better environment can make all the difference to our patients and their parents or carers

Caring for patients in state-of-the-art facilities that support our skilled experts is the aim of our new surgery centre planned for Level 6 of the Mittal Children's Medical Centre.

The centre will treat babies, children and young people who have been referred to the hospital because of their complex

## "More privacy, space and comfort"

needs and who cannot be treated elsewhere. Surgery may be anything from an urgent operation for a baby born with a defect, to planned surgery for a child needing a limb lengthened. The new facilities will



An artist's impression of the planned high dependency bay, where parents can stay at their child's bedside

bring together 48 surgical beds that are currently spread across the hospital.

In the new centre, there will be more privacy, space and comfort than is currently possible in some areas of the hospital that are too cramped for parents to sleep by their child.

There will be a four-bed high-dependency bay for patients who need round-the-clock care, with recliner chairs for parents or carers. Single bedrooms will be en suite with a parent area, sofa bed and Patient Bedside Entertainment and Education system. Other facilities planned include a treatment room, an assisted bathroom for children with disabilities, and a special sensory room for children who have a sensory deficit such as blindness or cerebral palsy. An adolescent

dining and recreation room will also be provided for children aged 11 and over.

Play Specialist Jane Aston says: "Research shows that adolescents need their own space so here they can get away from the 'children's ward', share their experiences and have an area where friends can

## "Friends can visit them, maintaining vital connections"

visit them - maintaining vital connections with their normal lives."

Please help us make all this possible by responding to our appeal.

Visit [gosh.org/lifeline](http://gosh.org/lifeline) or call 020 7239 3131 and make a donation towards the new surgery centre

An assisted bathroom will cater for children with disabilities





# straight to surgery

Like most mums expecting a second child, Kelly felt more relaxed than she had with her first baby – until her three-month scan...

Kelly had had no problems with the birth of her son A-J, now seven. So pregnant again, when it was time for the first scan, Kelly wasn't worried. But then it showed that her baby's abdominal wall hadn't formed properly

so the intestines were on the outside of the baby's body – a condition known as gastroschisis. Kelly says: "It was such a shock. I was actually born with it myself but it isn't hereditary." In 1986, Kelly's condition

had only been discovered at birth. She was rushed to Great Ormond Street Hospital where she spent 12 weeks. It had been the first case of its kind to be seen at the hospital.

It was arranged that Kelly would have her baby at UCH, around the corner

**"I had to go in to be induced that day"**

from Great Ormond Street Hospital, so that her baby could be transferred straight after birth. She also met surgeon Joe Curry who talked her through the procedure. It was explained that as the intestines were in contact with the amniotic fluid in the womb, they could become damaged so she needed regular scans.

"I knew I would have the baby early," says Kelly. "But at 35 weeks, they said her bowels had dilated so they wanted to deliver her even sooner – I had to go in to be

**"It was hard to see but I was just glad she was okay"**

induced that day."

On 22 November last year, baby Ava was born by normal delivery, weighing less than 4lb. Dad Daniel was at the birth: "It was hard to see but I was just glad she was okay."

The intestines were now

exposed to the air so an operation needed to happen within hours.

While Kelly waited to be discharged, Daniel went ahead to Great Ormond Street Hospital where Joe Curry's team started the delicate process of putting Ava's intestines back inside her abdomen. But Ava's case was complicated so this couldn't be done all at once.

"They could only push part of it back at first, then they put the rest in a silo bag to protect it and she was taken to the Neonatal Intensive Care Unit," says Kelly. Day by day, doctors eased more of the intestines back – a process aided by suspending them above Ava's body so that gravity helped them into place.

"It's incredible how they

**"I still look at her and think, I don't know how they did it!"**

did it," says Daniel.

During this time, Ava had an unexpected visitor – Ed Kiely, who performed Kelly's operation in 1986. Kelly says: "My mum and dad were



Kelly and Daniel with four-month-old Ava

photography: David Harrison

Kelly. But then there was a setback – a nurse found blood in Ava's stools.

"It really made me panic," says Kelly. Ava had caught necrotising enterocolitis (NEC), which can cause the contents of the intestine to leak. Luckily after a week of antibiotics and being 'nil by mouth', she was fine. Finally after seven weeks at Great Ormond Street Hospital and two more at her local hospital Ava could go home.

"I was scared but we were over the moon," says Kelly. "Now she's doing really well and hopefully she'll be able to lead a normal life. I still look at her and think, I don't know how they did it."

able to meet him too!"

After a week, Ava was ready to be closed up. The next challenge was feeding – she needed a special type of milk, which at first made her sick. After two weeks, she was well enough to move to Squirrel Ward. "The care was amazing," says



Like mother like daughter: mum Kelly as a baby (right) and baby Ava (above)



To donate to the surgery centre to help more children like Ava, call 020 7239 3131 or visit [gosh.org/donate](http://gosh.org/donate) or text GOSH05 and the amount you wish to donate (eg GOSH05 £10) to 70070

# back to theatre

"Hi, we're guest editors Zainab and Jannat. We're interviewing Neonatal and Paediatric Surgeon Joe Curry about why the hospital needs a new surgery centre."

## What sort of operations will take place in the centre?

It's going to encompass a range of surgeries including orthopaedic, ear, nose and throat, plastic surgery, craniofacial and some patients from my specialty - general surgery. My main focus is the upper part of the intestine - operations similar to the one we did for Chantelle (see pages 14-15).

## Why does the hospital need a new surgery centre?

It will make the patient journey so much easier from the minute they arrive to the minute they leave. Transportation between rooms and the operating theatre, and areas such as X-ray and intensive care, will be much easier as corridors are wider and the lifts bigger. The rooms on the wards are fantastic in terms of space - children can have their comforts around them and parents with them 24/7.

## What sort of amazing equipment will there be?

Some of the older facilities we have date back to the 1930s and 40s. They were appropriate for the time, but they are not appropriate for today. The practice of surgery is advancing rapidly, and so is the technology associated with it. The theatres will have all the modern equipment that supports modern surgery - particularly keyhole surgery, which is another area of expertise of mine.

## How many staff are involved in an operation?

As well as the operating theatre staff, there are the people in the laboratory who prepare blood tests and blood for transfusions, for instance. Then there are the people in the X-ray department. Probably 40 to 50 people are involved in planning an operation like yours! But you might only see a small number of those.

## How has operating on patients changed?

Something we have significantly advanced in the last 10 years has been keyhole surgery. When you can have surgery through tiny little openings in your tummy, it means you get better quicker, you have less pain as you are recovering and you have less scarring on your tummy - so people aren't so aware that you've had surgery. We are now also looking at procedures we can do on babies even before they are born.

Zainab (left) and Jannat interview Joe Curry in one of the new operating theatres that opened last year in the Morgan Stanley Clinical Building

photography: David Harrison



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



watch it online

## Is there anything else you'd like to say?

Just how grateful we are as doctors and other health professionals for the facilities that the work of Great Ormond Street Hospital Children's Charity and its supporters provides. Without that equipment and without that ability to work in this environment, we would not be able to provide the treatments we can provide. We remain very, very grateful.

## What's the best thing about your job?

That's the other side - being able to tell parents and children that the operation has worked so they can look forward to a normal life.

Please help us complete the new surgery centre. To find out more, call fundraising on 020 7239 3131 or visit [gosh.org/lifeline](http://gosh.org/lifeline)



talking to...

## Nipa, mum of Zainab and Jannat, age 10

I found out I was having twins when I went for my first scan. At first I was happy, but then they said they couldn't see if they were separate so I was crying. I was referred to Great Ormond Street Hospital and told that as it was just a liver they were sharing, the operation was not as risky as if they had other major organs connected. Obviously there were risks, but they gave me confidence that there was nothing to worry about. When the twins were born, the doctors had to wait for the liver to grow, so the operation took place six weeks later. They already knew from my scans that Jannat had a hole in her heart and would also need an operation for that, but at a later date. But after the separation, she was having trouble breathing and wasn't able to suck a bottle. She got weaker and weaker so she had the operation just four days after the separation. We stayed in hospital for three months. They had excellent care - it could not have been better. The staff were so friendly and our questions were always answered. When I could finally take them home, everyone was overjoyed. Although they might not always show it now, they are really close.



# through the keyhole

**When Chantelle developed a major problem with her oesophagus, only an amazing operation using keyhole surgery could help**

One day in April 2011, when Chantelle was three-and-a-half, she was happily playing in the garden with her family. Then, the next

day, she woke up sick. "At first I just thought it was heatstroke and I told her dad off for not keeping her hat on," says

mum Maria. "But a week later she was still ill."

Chantelle was rushed to the local hospital with dehydration where she was kept on a drip for two weeks and eventually fitted with a naso-gastric (NG) tube so she could be fed a liquid diet.

Chantelle went home with the tube fitted, but her mum and dad struggled to get the tube down, so it was back to hospital again.

Local doctors couldn't get to the bottom of Chantelle's illness, and this was one of

**"There was no other choice but to operate"**

the hardest things for Maria: "I couldn't find anywhere to get any information about it."

In September 2011, Chantelle was finally referred to Great Ormond Street Hospital. Maria says:

"It was supposed to be straight in, straight out, but when they put a scope down, that all changed.

They showed us a picture of what I can only describe as blood blisters on the inside of Chantelle's oesophagus."

Doctors hadn't even been able to get a neonatal camera past the obstruction to see how long it was.

"We now know that the



Chantelle at home with mum Maria

Chantelle had an operation in which the oesophagus was removed from up near the collarbone down to the stomach. The stomach was

**"She has no idea what she went through!"**

then stretched up like a tube to reach the collarbone, moving the stomach compartment up into Chantelle's chest. The whole procedure was all done by keyhole surgery.

"It baffles you when they tell you they're going to do that!" says Maria.

After the 10-hour operation, Chantelle's parents spoke to Paediatric

Surgeon Joe Curry. "He had a big smile on his face, so we knew it was OK," Maria says. "Joe's seen us laugh, cry and shout! No matter what's gone on, he's always stayed calm."

Although Chantelle's oesophagus was examined in the lab after being removed, the cause of her condition remains unknown. Joe Curry says:

"This kind of thing is seen if a child has swallowed something such as drain cleaner – we saw that a lot before safety lids were mandatory – but there's no history of that for Chantelle. It seemed to happen naturally and we don't know why."

Two years after her first problems, Chantelle is now running around the garden playing with her sister Lilly-Rose.

"Chantelle is still quite pale but she has come a long way," says Maria. "Most of the time, she can

eat whatever she wants.

"She has no idea what she went through – she just knows she's got her scars and thinks she's got a new belly!"



Recovering in hospital in 2012

**"Joe's seen us laugh, cry and shout! No matter what's gone on, he's always stayed calm"**

damage was all the way down the bottom third," says Maria. The hospital made several attempts to widen Chantelle's foodpipe, including an oesophageal dilatation, in which a balloon is passed into the oesophagus and inflated to try and widen it. She also had a stent put in – a metal mesh cage that is gradually expanded.

"They got her to about 10mm which they were happy with," says Maria, "but as soon as they took that out it closed up again.

"There was no other choice but to operate."

And so, in June 2012,

Big brother Joshua with his arms around Chantelle and little sister Lilly-Rose



To help more children like Chantelle, call 020 7239 3131 or visit [gosh.org/donate](http://gosh.org/donate)

# research update

In the past year, kind donations left in supporters' Wills have totalled over £10 million, helping us to fund our redevelopment work, provide support and accommodation for families, and purchase specialist equipment. Our focus is to fund research to enable us to find new treatments and cures, such as these two projects.



## Research into regenerative medicine

Dr Paolo De Coppi (see page 7) is leading clinically focused research into regenerative medicine. This groundbreaking field of science aims to engineer rejection-free organs and healthy tissues for transplant, built up using a child's own cells.

The science has already been used by the hospital to transplant a replacement trachea (windpipe), which saved the life of Ciaran (left), who had been born with a fatal narrowing of his windpipe. The trachea

was grown from his own stem cells. Now, the team hopes to build more complex organs such as the gullet and bladder.

## Research into gene therapy

Gene therapy involves modifying patients' DNA in a lab and reintroducing it to provide a cure for what have until recently been untreatable and often fatal conditions. It has already been successfully used to treat children who have a severe immune disorder – including Jack (right). Now our research team wants to deliver trials of



gene therapy for other conditions, such as severe forms of inherited skin disease, metabolic diseases, HIV and cancer.

read more online



For more information about current research projects taking place at Great Ormond Street Hospital, visit [gosh.org/brtl](http://gosh.org/brtl)

To find out more about how a legacy can help, visit [gosh.org/legacies](http://gosh.org/legacies)

All legacies left to Great Ormond Street Hospital make a huge difference to the work we do. Here are some examples of individual bequests from donors and the research projects that our supporters helped make possible in the last year.



**£2,000** towards the Kiss it Better appeal

Cancer is the biggest cause of childhood mortality in the UK outside of accidental death. These funds help the hospital to collaborate in national and international clinical trials that will help us pioneer new therapies. These will mean fewer deaths and improved treatments for children with related chronic health conditions.



**£558.75** towards tetralogy of Fallot research

This project has enabled the hospital to contact past patients who were operated on as babies for the heart defect tetralogy of Fallot. Patients sometimes need a follow-up operation later in life so, by assessing their long-term health, doctors can gain vital information that will help them carry out heart operations on the next generation.



**£2,000** towards understanding cancer

Through this research, scientists are hoping to understand more about the relationship between how tumours in children grow, and the natural ability of a child's body to reject the cancer. Examining the various mechanisms that control this balance is fundamental in the development of new treatment approaches.



**£150,000** towards research for blind children

This project is aiming to pioneer retinal transplants that will improve or restore sight to blind children whose photoreceptors have died or are not functioning. Currently there are no clinical treatments for this condition. Scientists hope to develop methods to isolate pure populations of photoreceptors suitable for transplantation.



**£25,000** towards childhood leukaemia research

About 80% of children suffering from paediatric leukaemia are now living for more than five years after their treatment – but intensive chemotherapy drugs are used, which have significant associated toxicities. These can cause lifelong medical conditions. This project aims to identify clinical drugs that have minimal side effects.



Carmel, co-founder of Kiss it Better, with daughter and cancer patient Jojo

...everyone who has donated, spread the word, baked a cake, run a marathon, 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...



Carol with her son Matthew

at Matthew's school, which involved all the children dressing up in Peter Pan outfits (and being part of a Guinness World Record!).

"I have helped with bucket collections, sold pin badges and run the London Marathon. My husband cycled from London to Paris and is arranging another charity bike ride soon.

"Matthew and I take part in the RBC 5k Race for the Kids every year and he has even written a poem about the hospital that was sung by Kings College Choir. I enjoyed accepting a cheque

## charity ambassador Carol's endless energy for fundraising

Carol Thompson has been actively supporting Great Ormond Street Hospital Children's Charity for 10 years.

"The world-class skills of the hospital's doctors and nurses, and the wonderful technology, helped save my son Matthew's life when he

needed surgery at only four months old, after he was born with a rare heart and lung condition. He still attends the hospital two to three times a year.

"I have organised a range of fundraising events including 'Peter Pan days'



from Willmott Dixon on behalf of the charity and have made speeches at fundraising events. It is a pleasure to help raise money every year as our way of saying 'thank you'."

Please join our network of volunteers who can act as ambassadors for the charity in their local community by organising fundraising activities and helping engage people with the work of the hospital and charity.

Get involved! Visit [gosh.org/become-an-ambassador](http://gosh.org/become-an-ambassador) or call us on 020 7239 3131



## it's curtain up again

Thanks to your support, the Theatres for Theatres campaign has been a huge success. Now it's back for Act II...

Following the initial successful campaign to fund state-of-the-art operating theatres, Theatres for Theatres will now help us fund more operating theatres in our new clinical building, due

to open in 2017.

Whether you want to hold a special theatre performance, organise a collection or something else, we'll support you with everything you need to get started. Please join us for Theatres for Theatres Act II.

To find out more, please visit [gosh.org/theatresfortheatres](http://gosh.org/theatresfortheatres) or call 020 7239 3015

## fundraise for us this summer

Here are five fantastic fundraising ideas that are perfect for the summer months.

1. Get friends and family over for a garden party or barbecue.
2. Collect money through a fancy dress or dress-down day at work.
3. Sell strawberries and cream to colleagues during Wimbledon.
4. Hold a Big Kids Sports Day – challenge your friends or colleagues to a tug of war or space hopper race in the park.
5. Sign up for a sponsored run, swim, cycle or skydive. See page 22 or check out [gosh.org/challenges](http://gosh.org/challenges) to find out more.



more ideas online!

For more top tips, ideas and materials visit [gosh.org/fundraising](http://gosh.org/fundraising) or email [fundraising@gosh.org](mailto:fundraising@gosh.org)

“ My favourite things to bake and eat are... chocolate brownies! Isobel, 13 ”



“ My favourite things to bake and eat are... cookies! Reuben, two ”



# grab a bucket!



Great Ormond Street Hospital Children's Charity's bucket collectors

*This October, we will be holding our second Donations Make a Difference week.*

We're asking supporters to hold a bucket collection in their local community with friends, family and colleagues to help raise £50,000. Money raised will help fund a recovery bay for operating theatres in the new surgery centre.

For more top tips, ideas and materials visit [gosh.org/makeadifference](http://gosh.org/makeadifference) or call us on 020 7239 3131

“ My favourite thing to bake and eat is... coconut cake **Jude, seven** ”



# reap rewards from recycling

*We've teamed up with The Recycling Factory to recycle unwanted mobile phones, ink cartridges and gadgets to raise vital funds for Great Ormond Street Hospital Children's Charity.*

Recycling couldn't be easier, and there is no cost to you or your company. All materials, including recycling envelopes, postage and collections are completely free. So please ask your company to get involved.



For freepost envelopes, collection boxes or if you have queries, contact The Recycling Factory on 0800 091 0696, email [gosh@trf-uk.com](mailto:gosh@trf-uk.com) or visit [therecyclingfactory.com/gosh](http://therecyclingfactory.com/gosh)

# 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.

If you would like to find out more about doing the same, visit [gosh.org/payrollgiving](http://gosh.org/payrollgiving)

# giving in memory



Tess

**Tess and twin brother Toby were born in London in 1981.**

Tess was the second born. A prolapsed cord and a bleed during birth caused her to get hydrocephalus.

Tess was operated on at Great Ormond Street Hospital when she was nine weeks old, but the hydrocephalus left her with some brain damage that meant she was hemiplegic, with a weak left side.

She lived to be 31, when she died in tragic circumstances, but had drafted a Will

18 months earlier, stating:

“After tax, any debts and all expenses have been taken care of, I leave all of my money (if any) to be divided equally between my favourite charities: Great Ormond Street Hospital and Help For Heroes.”

Tess's parents asked friends and family to make donations rather than bring flowers to her funeral, knowing that Tess had always thought that she owed her life to the skill of the surgeons at the hospital.

This has raised a total of £4,265.37 from 69 donations, with £2,810.37 of this raised for the hospital. We are sincerely grateful to Tess and her family.

To make a donation in memory of a loved one, visit [gosh.org/inmemory](http://gosh.org/inmemory) or call 020 7239 3002

# more thanks to

- › Charlie Pitcher for rowing solo across the Atlantic
- › Karen and Jim Smith for raising £57,000 towards their Brighter Future Fund in memory of son Harry
- › City of London School for Boys for making us their charity of the year and raising a staggering £64,000
- › The 1,100 schools and organisations that raised over £80,000 for the Christmas Poster Appeal

For more on these stories and other ways to donate, visit [gosh.org/getbettergifts](http://gosh.org/getbettergifts)

# talking to...



**Anthony, who had heart failure**

“ After I got back from a school trip, I collapsed and was rushed to Great Ormond Street Hospital. I had pneumonia and three other infections which led to heart failure. From having an 11 per cent chance to live, being resuscitated over 12 times and having to learn how to walk again, who would have thought

I would be running the RBC Race for the Kids? But I did it! I even convinced one of my consultants who was part of the team that saved my life to run it with me! There is not a word to express the feeling that went through my body as I ran, but I tell you this now – you will catch me running every year! ”

To find out about challenge events visit [gosh.org/challenges](http://gosh.org/challenges)

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

→ Hospital Open Days  
→ 19 Sep and 7 Oct 2013

Supporters interested in leaving a gift in their Will to the hospital can visit us to see first hand how legacies make a difference to our patients. Register your interest at [legacy@gosh.org](mailto:legacy@gosh.org) or call 020 7239 3131

→ Free Will Month  
→ October 2013

Have your Will updated or written for free throughout October. Go to [legacy@gosh.org](mailto:legacy@gosh.org) or call 020 7239 3131 for more information

→ Santa Run  
→ December 2013

Join over 3,000 Santas for a 10k race around Greenwich Park. Visit [gosh.org/santarun](http://gosh.org/santarun)

sign up online

→ Cycle India  
→ 8-17 Feb 2014

Hop in the saddle for our brand-new 10-day cycling adventure in India. Visit: [gosh.org/cycleindia](http://gosh.org/cycleindia)



Go online to find out about some other exciting challenge events



Visit: [gosh.org/getinvolved](http://gosh.org/getinvolved)  
Call: 020 7239 3131  
Email: [supporter.care@gosh.org](mailto:supporter.care@gosh.org)



## Have you seen our breakthrough guides?



Our guides give a unique insight into our pioneering research developments through time.

If you would like to request a copy of one of these guides, please contact our Supporter Services team on 020 7239 3131, email [supporter.care@gosh.org](mailto:supporter.care@gosh.org) or write to Supporter Services, Great Ormond Street Hospital Children's Charity, 40 Bernard Street, London WC1N 1LE.

Great Ormond Street Hospital Charity

# Bake it Better

for Great Ormond Street Hospital Children's Charity

Your cakes make the difference

We are asking people up and down the country to dust off their cake tins and get baking like crazy, to help the thousands of children that we look after each year.

Visit [www.gosh.org/bakeitbetter](http://www.gosh.org/bakeitbetter) to find out how you can get involved

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





[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://www.twitter.com/GreatOrmondSt)