

Winter 2016

lifeline



Helping families be together at Christmas

Using state-of-the-art equipment to save children like Joseph

How we're investing in groundbreaking research for future generations



Meet our guest editor...



Hi! I'm Joseph, and I'm 11.

When I was two years old, I asked about the scar I had on my chest. My mum told me that the doctors at Great Ormond Street Hospital saved my life. Since then, every year I've filled my piggy bank with my pocket money and donated it to the hospital to help other children when I go back for my check-up at Christmas time.

"I was born with a heart condition where the two main blood vessels in my heart were swapped over. Dr Robert Yates and the cardiac surgeons saved my life when I was a baby - I wouldn't be here without them. Even though it's a hospital, it's a really friendly and happy place.

"In this issue of *Lifeline*, I interview Dr Yates about what it's like to operate on patients like me who have heart conditions and how important it is for children to have their family together with them at Christmas.

Joseph

Read Joseph's interview with Dr Yates on page 14.

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Read online



Lifeline online

You can read this edition of *Lifeline* on your computer or tablet. Visit gosh.org/lifeline

For Great Ormond Street Hospital Children's Charity: Giannina Walsh, Robert Butt, Jo Satchell, Lauren Necati and Mark McKenzie-Ray.

Great Ormond Street Hospital Children's Charity
Registered charity
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Thank you to Joseph for doing a great job as guest editor. Thank you to Amelia for taking part in our cover story feature. The children's drawings in this magazine were created by patients at the hospital.



INTYGRA

Front cover photography: Noel Murphy.



Thank you, regular givers!



Regular gifts from our supporters allow us to plan for the future because we know that we'll have a steady income stream day in, day out. These gifts help us to support four key fundraising areas:



1. Redevelopment projects that give children and families more space to be together at such a crucial time. You can read more about how the construction of the Premier Inn Clinical Building will provide privacy and comfort for our patients on page seven.



2. Fantastic research breakthroughs like those we're investing in as part of our exciting new research strategy. Turn to page 11 to find out more about our ambition to raise £50 million in the next five years, which will help fund research into rare and complex conditions.



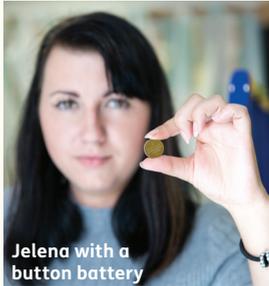
3. New equipment, such as heart monitor equipment that helps children with cardiac diseases, like Amelia, who features in our cover story on page eight.



4. Patient and family support, including Christmas parties for our patients and their siblings. These parties allow families to come together to celebrate the festive season.

Want to set up a regular gift?

If you don't already make a regular gift to us each month and would like to set one up today, please call **Supporter Services on 020 3841 3131** or visit gosh.org/donate



Jelena with a button battery

Be button battery aware this Christmas

>>> Doctors at Great Ormond Street Hospital (GOSH) have warned about the dangers of button batteries, which can be found in household items such as watches, toys and remote controls.

Alongside experts at Birmingham Children's Hospital and Sheffield Children's Hospital, GOSH specialists highlighted the risks of a battery getting stuck in a child's oesophagus (wind pipe). It can cause holes within a few hours and affect a child's ability to eat, drink, swallow or breathe.

Now, one child a month is admitted to hospital after having swallowed a button battery, compared to one child a year just five years ago.

Jelena's daughter, Valeria, accidentally swallowed a button battery and has had more than 60 operations at GOSH to help repair the damage. "In many ways, Valeria is now a normal three-year-old," says Jelena, "but she still needs a lot more operations to help her recover. I'm hoping she will start nursery this year, but it depends on her health. She's definitely ready!"

Many of the gifts we receive at Christmas contain button batteries, so please take care.



Ruby and Rosie are ready for their first day at school

First day at school

>>> Conjoined twins Ruby and Rosie had complex separation surgery at Great Ormond Street Hospital (GOSH) after they were born in July 2012. In September, they joined thousands of children going to school for the very first time.

The twins' first day at school was a huge milestone for the family and made national news, with Ruby and Rosie featuring in every major newspaper. "In the beginning, I never thought that this day would come," said Ruby and Rosie's mum, Angela. "They are such strong little girls and it's wonderful to see them go to school and lead such normal lives."

GOSH is the leading centre in Europe for the care of conjoined twins. Since 1985, more than 27 sets of conjoined twins, including Ruby and Rosie, have been cared for at the hospital.

Your feedback is important to us

>>> A massive thank you to everyone who sent us their responses to our readers' survey. Your opinions will help us to ensure we're providing all of our supporters with the information they need to know about Great Ormond Street Hospital and the charity. We'll also use your views to improve how we communicate with you.

Congratulations to Mr Tony Lawson from Crawley, who won our first prize of a three-night stay for two people at any of the 520 Small Luxury Hotels of the World™.



If you would like to give us feedback about our communications or update your contact preferences, please call our Supporter Care team on 020 3841 3131.

Roll up for the raffle

>>> We were delighted to announce Ms Butler as the winner of our spring raffle earlier this year. "I was amazed when I heard I'd won," said Ms Butler. "I never thought I'd win anything, let alone the first prize!"

Thank you to everyone who has taken part in our spring and autumn raffles this year. They help us to raise money so that we can enable Great Ormond Street Hospital to continue providing world-class care to seriously ill patients from around the world.

There are two raffles every year, with a top prize of £5,000. Each raffle ticket costs just £1.

We're so grateful for your support. The winner for our exciting autumn raffle will be announced this December. Good luck to all those who are taking part!

To find out more about our 2017 raffles and enter, please call Supporter Services on 020 3841 3131 or visit raffleentry.org.uk/gosh

Our thanks to you

>>> We want to thank everyone who donated to our Play appeal over the summer. Your incredible generosity helped us to raise more than £212,000, which will fund play specialists at Great Ormond Street Hospital (GOSH). Play specialists help patients to understand their condition and the life-saving treatments they urgently need by using games, role play and other play techniques tailored to children and their illnesses.

Thanks to you, we can support more patients like Myla, whose play specialist, Lynsey, helped her to overcome a fear of needles and prepare for her kidney transplant. We wouldn't be able to provide this vital care without your kindness. Thank you.



If you would like to find out more about our appeals or update your contact details, please call Supporter Services on 020 3841 3131 or email supporter.care@gosh.org

Guest editor catch-up

Adam Reynolds was the guest editor of the winter 2008 issue of *Lifeline*. Now 22 years old, he tells us about his memories of Christmas at Great Ormond Street Hospital (GOSH) where he was treated for brittle bone disease, and being an ambassador for the hospital and charity.

“I came to GOSH when I was seven years old. I used to stay on an old ward – Dickens Ward – in the hospital’s Southwood Building. It was very dark, with little segregation from other patients. It made me concerned about going to hospital.

“Later, I moved to the newer Kingfisher Ward, which was part of the redevelopment at the time – the experience was second to none! It had a very bright and welcoming feel, and was more private – I never had to share the ward with more than three patients. It made an incredible difference to my visits.”

Being guest editor

“Interviewing Lee Houghton from the hospital’s Redevelopment team for *Lifeline* was a unique experience. I fondly remember asking him if they were going to be blowing anything up! I have to admit I was a little disappointed there were no scheduled explosions.

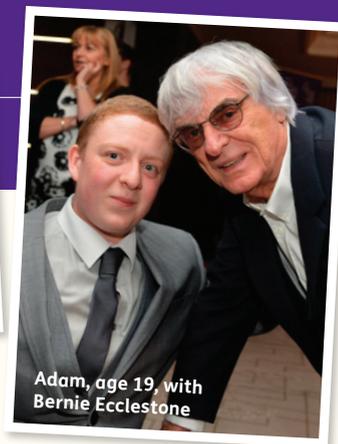
“I believe that as GOSH continues to expand and improve its facilities, its already incredible levels of service can only continue to improve.”

Christmas at GOSH

“I went to one of the patient Christmas parties, which are funded by Great Ormond Street Hospital Children’s Charity. It was absolutely incredible. My mum and both my sisters were invited too, which made for a memorable day out for the whole family. A real highlight for me was meeting Sir Paul McCartney!



Adam, age 15, with Sir Paul McCartney



Adam, age 19, with Bernie Ecclestone

Volunteering

“I’ve volunteered with the charity since I was 12, and I’ve had so many incredible opportunities. As an ambassador, I get on stage in a room full of people and inspire them to donate as much money as possible. During the interlude of singer Mark Knopfler’s world tour, I spoke in front of 12,000 at the Royal Albert Hall. Public speaking has given me skills – like self-confidence and charisma – that are helping me mature at a fast pace in my job at an IT distribution company.

“I think the best thing to remember around this time of year is just how incredibly lucky we are. There will be children celebrating Christmas at GOSH, and incredible staff who give their all to support their patients, who won’t get to spend any time at home at all this Christmas Day.”

Adam’s story

Adam has osteogenesis imperfecta, or brittle bone disease, which means that all the bones in his body can break easily. When he was seven years old, Adam was referred to GOSH for surgery on his broken bones and stayed under the hospital’s care until he transitioned to adult services at the age of 18.

In addition to his regular check-ups, Adam returned to GOSH every three months to receive pamidronate treatment to help strengthen his bones. The daily calcium and vitamin D supplements he took at home increased the levels of those vitamins in his blood, and he had infusions at the hospital to extract the additional minerals from his bloodstream so his bones could absorb them.

For more information on becoming a volunteer ambassador, visit gosh.org/volunteer

Building the hospital of the future

There's nothing more reassuring for our seriously ill patients than having their parent right beside them, especially at Christmas. Our major redevelopment of Great Ormond Street Hospital (GOSH) will make this a reality for many more families for generations to come.

Many of the hospital's inpatient wards are housed in a building that has been around since the 1930s. They are too cramped for parents and children to stay together and are quickly becoming unsuitable for treating seriously ill children.

Right now, we're busy constructing the Premier Inn Clinical Building. Since the building's Topping Out ceremony in September last year, the construction team have fitted floors and put up doors and walls to create the space that children will need to be treated for a variety of serious conditions. They have also knocked through the walls on each floor that connect the

"I can't wait for my bigger, better room on the new ward."

Ava, age seven, who is a patient at GOSH

Premier Inn Clinical Building to the Morgan Stanley Clinical Building to create the Mittal Children's Medical Centre.

Once it officially opens in 2017, the state-of-the-art centre will include a new surgery centre, a high-specification respiratory ward and a high-dependency area where the most unwell children can be carefully helped back to health. There's vital space for parents and carers to stay, as well as more room for children to eat and play.

Play Specialist Lizzie Penn knows how important it is for families to have a



The new building will comprise **SEVEN floors**, each focusing on a different clinical speciality



There will be **NINE playrooms** designed for children or teenagers to enjoy

77

There will be **77 inpatient bedrooms** with their own en-suite bathrooms and space for one parent to stay

comfortable space to be together. "The big, bright bedrooms will really help families by providing privacy at a time when they need it most," she says.

Thank you so much to all of our supporters for your outstanding contribution to this vital new building, which will help us ensure that there are first-class facilities to match the world-class care the hospital provides. Your donations are helping us to build a brighter future, brick by brick.

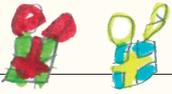


Ava is looking forward to having a bigger room on the ward

We urgently need to raise £20 million to finish the next phase of our ambitious redevelopment programme. Find out more at gosh.org/why-we-need-your-help/redevelopment

The best Christmas present ever





When baby Amelia was undergoing heart surgery, having somewhere comfortable to stay close by made a frightening Christmas that bit easier for her family.

On Christmas Day 2009, Jacey and her husband Phil received the best present ever. Their daughter Amelia opened her eyes for the first time since her heart surgery.

Born just four months earlier, Amelia had struggled to gain weight and was referred to a feeding specialist. The weekend before Christmas, while her parents were changing her nappy, Amelia suddenly stopped breathing.

“Amelia started gasping for breath. Her eyes rolled back, she went white and then she just stopped breathing,” says Jacey, who gave her mouth-to-mouth resuscitation while Phil called an ambulance. “I’d never performed first aid before, but I remembered someone describing how to resuscitate a baby. It was terrifying. But, fortunately, I did it right and she started breathing again.”

The ambulance arrived and rushed the family to the Royal London Hospital where Amelia was stabilised before being moved to Great Ormond Street Hospital (GOSH).

“It was so frightening,” says Jacey. “But all the staff at GOSH were really compassionate. They had so much time for us, which was amazing really when their job is so busy. To seem so calm and always say, ‘Don’t worry, we can talk to you’, means so much.”

“All the staff at GOSH were really compassionate. They had so much time for us...”

Amelia was diagnosed with complete atrioventricular septal defect, a congenital heart disease that causes holes to form between the left and right sides of the heart. The condition had meant Amelia’s heart was beating so fast, it was burning all the calories she was eating – the equivalent of running a marathon every day.



Amelia, following her surgery

“It was amazing to be so close to the hospital and was one less thing for us to have to think about.”

“Dr Troy Dominguez explained Amelia’s condition, but everything was a bit of a blur,” says Jacey. “Amelia was lying in intensive care, and all of our attention was on her.”

A few days after being admitted, Amelia had an operation to patch the two holes in her heart. “They told us they had to stop Amelia’s heart for 45 minutes while they repaired the holes. She was in surgery for two hours and we went for lunch, waiting for the call. Thankfully, when it came, it was good news.”

Jacey and Phil were able to stay in GOSH accommodation and be with Amelia the whole time. “We had our own self-contained flat with a bathroom,” says Jacey. “It was amazing to be so close to the hospital and it was one less thing for us to have to think about. Someone else had organised everything and you could just go there and sleep.”

**We’ve been receiving
Christmas messages to the
hospital for our patients for
over 16 years**





Amelia and her family are excited to spend Christmas together

Amelia’s week-long recovery meant the family were at GOSH over Christmas. “It was surprisingly Christmassy on the ward,” says Jacey. “Everyone there did so much to take our minds off the fact we were in hospital with our daughter at Christmas. When Amelia was in the Paediatric Intensive Care Unit, they put a Father Christmas bed sheet on her bed, which we loved.

“There were Christmas decorations around the hospital, which made it feel really Christmassy. We weren’t expecting that at all. We went and had Christmas lunch in The Lagoon, the hospital’s restaurant, which was really tasty.

“It’s wonderful that people are generous enough to think of children like Amelia who are poorly at Christmas. But it is also lovely for the parents to know someone is thinking of your family.”

Amelia was discharged on New Year’s Eve and the family drove home past all the fireworks in central London. “Everyone was celebrating New Year’s Eve and we were celebrating having our little girl home,” says Jacey.

“Once Amelia was better, we had a fake Christmas in January with crackers and everything. We had pigs in blankets and the

“It’s wonderful that people are generous enough to think of children like Amelia who are poorly at Christmas.”



rest of the trimmings. It was a lovely way to celebrate having Amelia home.”

Amelia gained lots of weight straight away. “She started to thrive and do really, really well,” says Jacey. “It’s all fine and now she’s full of beans.”

Amelia attends cardiac clinic every 18 months, and consultants are happy with her progress. She is now a happy, healthy seven-year-old who loves to dance and wants to be a dancer on *Strictly Come Dancing*. She can’t wait for Christmas!

Make a donation this Christmas
 You could help fund accommodation at GOSH so mums and dads can stay close to their children. Please call Supporter Services on **020 3841 3131** or visit **gosh.org/christmas-together**



An urgent need to improve child health

For many children with complex and rare diseases, research is their only hope. That's why we are investing £50 million to unlock vital breakthroughs that will help more children.

When Demi was born, our family could not have been happier," says her mum, Tracy. "She was a happy and healthy baby girl."

But when Demi was 18 months old, Tracy became concerned. Demi frequently bumped and fell into doorframes and walls. As she grew, Demi developed hearing loss and visual impairment. She also lost the use of her arms.

After many tests, the family were referred to Great Ormond Street Hospital (GOSH). Paediatric Neurologist Professor Francesco Muntoni and his team discovered that a faulty gene was causing the breakdown of Demi's muscle and nerve tissue. They started to give her a simple targeted treatment as part of a clinical trial.

"Following the treatment, Demi could sit and stand independently for the first time in years," says Tracy. "Research has helped Demi

significantly. We will be eternally grateful to GOSH for everything they've done for us."

Children like Demi are at the heart of everything we do. Many of the seriously ill children that come to GOSH have rare and complex conditions that are life-limiting or life-threatening. That's why we've launched a new strategy that will see us investing £50 million into research over the next five years.

Seventy-five per cent of rare diseases affect children, but sadly, paediatric research to tackle these kinds of conditions is significantly underfunded. There's a misunderstanding that children are just small adults, but they require treatments that are tailored to their health problems. So with our new strategy, we want to invest in supporting research into personalised medicine for seriously ill children to create a step change.

We have six priority areas: cancer, immune system disorders, birth defects, muscle wasting disorders, hormone and cell function disorders, and heart conditions. The research takes a 'bench to bedside approach', which means we focus on turning research from the laboratory into personalised treatments for children.

Thanks to your generous support, we're able to fund pioneering research that leads to life-saving treatments, keeping more families like Demi's together at Christmas.

For more on our research strategy, visit gosh.org/research



Talking to...

Dr Stephen Holgate, Chair of Great Ormond Street Hospital Children's Charity's Research Strategy Advisory Board

“Research is all about trying to gain insight into why diseases begin and progress in childhood, and their impact on families. It's essential if we're going to unravel the complexities of some of the diseases that are confronting us. The pinnacle of the strategy is putting the children and the families at the heart of it all.”

How does it all add up? 

World-class support

Thanks to you, 2015/16 was another record-breaking year of fundraising for Great Ormond Street Hospital Children's Charity. We raised just under £94 million, which is an increase of 15.7 per cent on last year.

There are so many ways our amazing supporters raised money. From the 1,732 Santa lookalikes who joined in our London Santa Dash, raising £177,000, to the runners who achieved a massive £1 million milestone through our 5k family fun run RBC Race for Kids. Other big successes included our Valentine's appeal, which raised more than £500,000 for a new specialist microscope and other surgical instruments.

It was an exceptional year for people leaving us generous gifts in their Wills, with £17.8 million left by supporters to help meet the hospital's needs. We've also seen a rise in the number of people who make regular gifts to the charity, which is fantastic.

One of the ways we spent our income last year included £2.2 million on parent and staff accommodation. This vital part of our hospital means parents with children in intensive care can stay nearby. We also spent £5 million to fund 150 pieces of life-saving equipment.

The remaining £39.6 million from the income that was raised will be held in our reserves and used to support our ongoing committed projects, such as the redevelopment of the hospital, including the Mittal Children's Medical Centre.

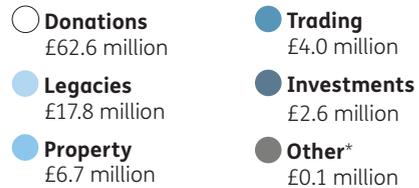
We simply can't help the hospital without your support – thank you so very much.

To find out more, download a copy of our annual report from gosh.org/about-us

How the income was raised



Total:
£93.8
million



*Other includes grants, auctions, tickets and sponsorship.

Total income raised year by year





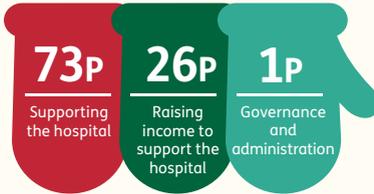
How does it all add up?



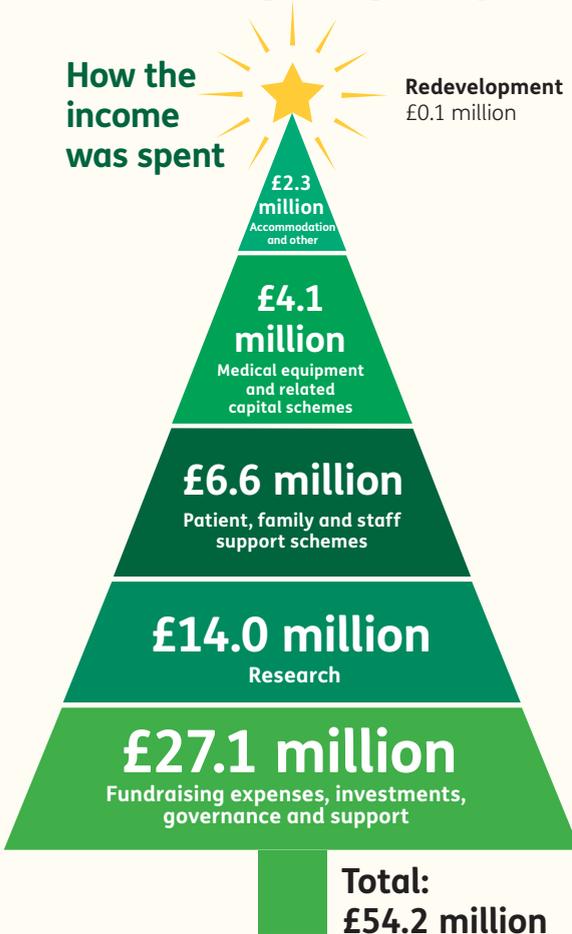
What we need to raise next

2019/20	£100 million
2018/19	£100 million
2017/18	£100 million
2016/17	£100 million

Where your £1 goes



How the income was spent



Talking to...



Tim Johnson, Chief Executive, Great Ormond Street Hospital Children's Charity

“Thank you so much for everything you’ve done over the past year. Every child that’s baked a cake, every family that’s run together, every supporter that has helped us with a regular gift or direct debit – every moment dedicated to GOSH helps make an extraordinary difference to the lives of our patients and their families. Thanks to the tireless commitment of our supporters, volunteers and staff, GOSH remains a world-class children’s hospital.

“But I know you’ll agree that we have to do more. Together, we can rise to the challenges ahead, such as beating our 2016/17 fundraising target of £100 million to support the hospital.

“Our future research goals focus on delivering personalised medicine for children with rare and complex conditions. This year, we’ll start putting our five-year research strategy into action. You can read more about it on page 11.

“In 2016/17, we want to continue funding our redevelopment programme, as well as £2 million of new medical equipment, and £5 million of projects that will help the hospital care for the child and the family, not just the patient.

“We need your support now more than ever. Thank you for everything you do to help keep families together. Have a lovely festive season and a very happy New Year to you all.”

Children and staff at the hospital love to hear from you. Please write a message of goodwill on the Christmas stocking we sent you and send it in. Thank you.



Heart to heart

Joseph with his consultant, Dr Robert Yates

“Hi, my name is Joseph and I’m the guest editor for *Lifeline*. I come to Great Ormond Street Hospital (GOSH) around Christmas every year for a check-up with my consultant, Dr Robert Yates. I’m interviewing him about the equipment he uses and what he likes about Christmas at the hospital.”

Q What does your job involve?

I’m a children’s heart doctor. I perform keyhole operations to treat patients with heart conditions and I talk to families a lot about their child’s condition.

Q What do you like most about your job?

Something unexpected happens almost every day, so it keeps me on my toes. I’m always learning new things because no two children with heart problems are the same, so I can’t ever be complacent. It’s lovely to be able to help children and help parents realise there are things we can do to give them a good quality of life.

Q What do you do in an operation?

There are two major types of operations. Open heart surgery often involves operating

on hearts that have holes in them or pipes the wrong way around. We use a bypass machine, which does the work of the heart and lungs while we’re operating. The second kind is keyhole surgery, where we use a technique called catheterisation to take a fine tube and push it into the artery at the top of the leg, up the vein and into the heart. We can do things like close small holes and open narrow valves and arteries.

Q What is an echocardiogram machine and how do you use it?

It’s like a camera attached to a computer, and it uses sound waves to make pictures of the heart, which are transmitted to a computer. We’re able to get information on the heart without having to perform surgery.



Q Why do you need a new echocardiogram machine and how much do they cost?

The echocardiogram machines do lots of work, around 20,000 echoes a year at GOSH, and just like a smartphone they need upgrading to get better pictures and more accurate information quickly. The upgrades enable us to look at the heart in more sophisticated ways so we can do operations we might not have been able to do. Each machine costs about £75,000.

“I’m always learning new things because no two children with heart problems are the same.”

Q What’s your favourite thing about Christmas at GOSH?

All the staff try to make it a fun time. We dress up and there are lots of special events like parties, which make it really special at Christmas. It’s also really lovely to see all the decorations go up.

Q How do you think the hospital helps families staying at GOSH over Christmas?

One of the most important ways that we help families is by providing accommodation, so they can stay near their children, feel at home and be comfortable. Although we try hard to provide accommodation, there’s never enough room, so we’re always looking for more.

Q Is there anything you’d like to say to supporters who donate over Christmas?

A huge, huge, huge thank you. That includes individuals like you, but also the people who provide their time by volunteering at GOSH. We can’t thank them enough.



The thing I like most at Christmas is... wrapping presents for my friends and family.
Maddison, age six

Talking to...



Joseph and his mum, Ruth, present a cheque at GOSH

Ruth, Joseph’s mum

“ Joseph was born with transposition of the great arteries, which means that the two main arteries in his heart – the pulmonary and the aortic – were swapped over. Without surgery, he would have died.

“Dr Yates was there before Joseph was born – he did a scan when I was pregnant with Joseph. We knew there was something wrong, but the surgeons couldn’t do anything until he was born. He had open heart surgery at two weeks old.

“It was a terrible time for us, but GOSH was amazing and supported us. We stayed in parent accommodation, funded by

Great Ormond Street Hospital Children’s Charity. I had a buzzer, so if anything happened, they could alert us straight away.

“We come back every year to see Dr Yates. It’s nice for Joseph to see the same doctor who knew him even before he was born, and for Dr Yates to see Joseph progressing every year.

“Joseph has donated money to Great Ormond Street Hospital Children’s Charity all through his life. GOSH is really important to him and I’m so proud of him.



True story

The need for research

Seven-year-old Josh has spent his life visiting Great Ormond Street Hospital (GOSH) after he was diagnosed with a rare condition that caused him to be blind from birth.



Josh with his mum, Wendy

We're investing **£50 million** of research into rare and complex childhood diseases over five years.



to affect your child because not much is known about the condition. It was a very worrying time – all we wanted to do was celebrate the birth of our son and introduce him to his older sister, Chloe.”

Three months later, Josh was referred to Dr Alison Salt at GOSH’s Neurodevelopmental Assessment Service. “Dr Salt referred us to other departments in the hospital – audiology, ophthalmology, rheumatology and genetics,” explains Wendy. “They’ve all been really

“The hospital has been a lifeline for us. They’ve taken us on board as a family.”

interested in learning about Norrie disease. The departments have worked together to share experiences and understanding of the disease, and that is a huge step for such a tiny community.”

Now age seven, Josh regularly visits the hospital accompanied by his 10-year-old sister, Chloe. “The hospital has been a lifeline for us,” says Wendy. “They’ve taken us on board as a family. The staff are very sensitive, especially if Chloe is with us. Having a blind brother has been the most enormous learning curve for her, but she’s adjusted very well. I quite often catch her explaining to Josh what’s going on around him. She’s very good at filling him in on the social cues that he misses. She’s fiercely protective of him but doesn’t cut him any slack!”

For the past seven years, the family have been supported by teams from across the hospital. GOSH even hosted the first multidisciplinary brainstorm meeting for Norrie disease in the world. “I was lucky enough to attend, and it was so uplifting to hear all these amazing minds working together to look at possible research routes,” says Wendy.

I knew from day one there was something different with Josh,” says mum, Wendy. “His eyes weren’t working properly.”

In the weeks following her little boy’s birth, Wendy took Josh to A&E to find out what the problem was. When he was two weeks old, Josh was diagnosed with bilateral retinal detachments – he was blind. “This was followed by his diagnosis of Norrie disease at Guy’s and St Thomas’ Hospital at the age of four weeks,” says Wendy.

“Josh’s diagnosis was completely unexpected.”

Around 20 people in the UK are known to have Norrie disease, and 800 people worldwide. It causes boys to be born blind or to go blind shortly after birth. It can also cause hearing loss, autism and cognitive impairment.

“Josh’s diagnosis was completely unexpected and we didn’t know what to do or where to go,” says Wendy. “When you’re dealing with a rare genetic disease, you don’t know how it’s going



Josh likes to play on his trapeze and trampoline

Helping to set up that meeting was Professor Maria Bitner-Glindzicz, an Honorary Consultant at GOSH and Professor of Clinical and Molecular

“Helping other children who have Norrie disease, like Josh, is 100 per cent dependent on research.”

Genetics at the hospital’s research partner the UCL Great Ormond Street Institute of Child Health.

“Professor Bitner-Glindzicz has been incredible for us as a family and also for the Norrie community,” says Wendy. “She has been the driving force behind us setting up a Norrie disease foundation in the UK. Our aim is to strengthen and support the Norrie community and to get further research going. Helping other children who have Norrie disease, like Josh, is 100 per cent dependent on research.”

Around 70 per cent of what we learn is through sight, so Josh has had to overcome many challenges. But he has a supportive team inside the hospital and outside at his school, including a qualified teacher who helps the

visually impaired and a mobility instructor who teaches him how to use the cane.

“Josh has learned to read and write through braille, which means he can keep up with his peers in the classroom,” says Wendy. “Josh’s hearing has begun to change and we’ve talked to him about the use of hearing aids if needed. He’s going to have to confront a lot of new barriers, but Josh has an incredible spirit and sense of humour, which we are very thankful for.”

Josh’s care will continue at GOSH over the next few years. He recently came back to the hospital for a balance test using a chair that was made to look like a space rocket. “The staff told Josh he would be going into space for half an hour. He had great fun being whizzed around!”

“My hopes for Josh are that he’ll continue to thrive and achieve whatever he wants, that he’ll find his own way in the world with the confidence and the determination that he has. I hope that he’ll be proud of who he is.”

To find out more about research at GOSH, please visit gosh.nhs.uk/research-and-innovation



Fantastic fundraisers

A BIG THANK YOU to 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 a few highlights, plus some upcoming fundraising events and ideas.

Back to school

>>> Gabriella has been a patient at Great Ormond Street Hospital (GOSH) since she was diagnosed with a rare condition called juvenile dermatomyositis (JDM) in October 2015. After being treated at GOSH, Gabriella returned to school where she has been raising awareness of her condition.

In the autumn last year, Gabriella's arms and legs started aching and a butterfly-shaped rash appeared on her face. It took just one hour at GOSH for her to be diagnosed with JDM, a condition that attacks the body's immune system, causing weakness and discomfort in the muscles and skin rashes.

Following months of treatment at GOSH, where, at one point, Gabriella had to use a wheelchair to get around, she started secondary school earlier this year. "The desire to get back to her friends and lead a 'normal' life has been a massive part of Gabriella's recovery," says her mum, Lyn. "Without the research at GOSH, Gabriella would not be on the correct medication and going through this rite of passage with her friends.

"When Gabriella was lying in her hospital bed but beginning to get better, all that kept her going was mentally planning a JDM awareness assembly for her school and a sponsored fun run."

With the support of her school, Gabriella raised a fantastic £1,647.92. "I wanted to fundraise at school so that people knew more about my condition," says Gabriella. "I also wanted to raise as much money as possible for



"I wanted to fundraise at school so that people knew more about my condition."

GOSH so that more children could have the opportunity to have their lives saved."

In September, Gabriella was part of Great Ormond Street Hospital Children's Charity's #BacktoSchool campaign, where supporters were asked to donate to help get more children back to school. That same month, Gabriella won the Herts Advertiser 'Young Achiever of the Year' award for all her hard work. "She was incredible," says Lyn. "She gave two utterly amazing speeches, where she not only continued to raise awareness of JDM but also congratulated the other finalists. It was a very proud moment."



The thing I like most at Christmas is... Christmas music! Monroe, age two

If you would like to fundraise at your local school, please visit gosh.org/fundraise-for-us and download your free schools fundraising kit.



I owe GOSH everything

Trevor explains how his experience of being a patient at Great Ormond Street Hospital (GOSH) has inspired him to leave a legacy.

>>> “Quite simply, without this great hospital, I wouldn’t be here.

“I was born in December 1965 at approximately 7.30am and was admitted to GOSH around midnight that same day with tracheoesophageal fistula, a rare condition where I had problems with the connections between my food pipe, wind pipe and stomach.

“My nan, God bless her, thought I would never see Christmas. However, she didn’t reckon on the skill and dedication of the nursing and surgical teams, and a certain Professor Andrew Wilkinson. He and the wonderful team at GOSH came through and saved the day.

“I had more treatment at the hospital following my surgeries. I was running a very high temperature, which led to the doctor discovering an abscess in my lung. After an X-ray confirmed those suspicions, I had emergency surgery to save my life.

“I remained an outpatient at the hospital until I was eight years old. Everyone from Professor Wilkinson to the nurses on the ward did everything in their power to provide me with the best care possible. My mum calls the professor a ‘miracle worker’! She was amazed he could perform delicate surgery on such a small baby when he was ‘a large man with big hands’. “The nurses always took time to play with the children and make our stay as least stressful as possible. They were always available to answer questions, and they were cheerful, polite and courteous.

“The hospital was always well decorated at Christmas. There was a Scottish piper who toured the wards and a Batman and Robin act visited in their Batmobile. All the staff played their part in helping the children celebrate, and



Left: Trevor as a baby.

Below: Trevor with his mum.



“Quite simply, without this great hospital, I wouldn’t be here.”

my mum recalls that Professor Wilkinson took the time to wheel me around the ward to look at everything that was going on.

“I cannot express in words my gratitude to the staff of this wonderful hospital – I literally owe them everything. Every sick child deserves the level of care I was fortunate enough to have received.”

If you’d like to find out more about leaving a gift in your Will, or for details of our free Will service, please contact Judy Anderson at legacy@gosh.org or call on 020 3841 3205.

If you would like to make a donation in memory of someone dear to you, please contact our Tribute team on 020 3841 3002.

Pushing forward

When Bradley's 10-week-old granddaughter, Eve, sadly passed away, he was inspired to fundraise for Great Ormond Street Hospital (GOSH) thanks to the world-class care she received.

Eve was only a day old when she was diagnosed with a serious abdominal tumour. Following weeks of treatment at GOSH, including chemotherapy and surgery, Eve passed away when she was just over 10 weeks old.

Touched by the care the family received while Eve was at GOSH, both Bradley and his brother Warren decided to support the charity through their family business, iCandy. "The astonishing care came from every shining star that we encountered, be they nurses, social workers or other medical staff," says Bradley.

"The only way we can truly reflect our gratitude is to go forward shouting from the rooftops about the inspirational work that is carried out at the hospital."

As joint CEO of iCandy, Bradley chose for his company to raise £100,000 for an enclosed isolation recovery bay at the hospital. They have pledged a donation from the sale of two of their award-winning Peach pushchairs

– in primrose and honeycomb colours – as well as the company's first toy product, the MiPeach, to Great Ormond Street Hospital Children's Charity. You may have noticed that the toy was also donated to the charity as a prize for our most recent summer survey. The winner of the prize was Mrs Eadon from Essex, who kindly donated the pushchair to the hospital to be used by the children in the playrooms.

"My family and the family business are so happy to be working closely with the charity in order to not only raise vital funds for them but also to promote awareness of the incredible work that is undertaken," says Bradley.

To support iCandy's partnership with the charity to fund an enclosed isolation recovery bay at the hospital, please visit [justgiving.com/company/iCandy](https://www.justgiving.com/company/iCandy)



Running for George

Lucy explains why she wants to give back to the hospital that saved the life of her son, George.

>>> When Lucy was pregnant, she was told that her son, George, had been diagnosed with tetralogy of Fallot, a condition that affects the structure of the heart. George underwent life-saving open heart surgery at Great Ormond Street Hospital (GOSH).

While George was recovering in intensive care, Lucy was inspired to fundraise for Great Ormond Street Hospital Children's Charity. She decided to sign up to the London Santa Dash on Sunday 4 December with her family, including little George, who she'll be carrying around the course. They'll all be wearing Santa suits, even George!

"I know that the charity helps make the hospital a little less frightening and traumatic for children and parents, as well as provide better medical treatments," says Lucy. "We'll be forever grateful to GOSH for what they've done for George so far and the treatment he'll need going forward."

"All we can do is try and help raise vital funds so that they can continue to be an amazing hospital, offering first-class treatment to more children and families."

There are only a few places left for the London Santa Dash, so sign up now at [londonsantadash.co.uk](https://www.londonsantadash.co.uk) or find out more by emailing londonsantadash@gosh.org



Get involved

Here are just a few of our exciting fundraising events that you can get involved with.



Christmas Carol Concert 13 December 2016

Join us for a truly magical evening for all the family at our 17th annual Christmas Carol Concert, which is taking place at St Paul's Church, Knightsbridge, followed by a sparkling Champagne and canapé reception at The Berkeley. For more information and to buy tickets, please call **020 3841 3272** or email carol.concert@gosh.org

Bad Hair Day 10 February 2017

Wear a wacky wig or style up something silly to fundraise for Great Ormond Street Hospital Children's Charity. To find out more and register for your free fundraising kit, please call **020 3841 3036** or visit gosh.org/badhairday



London 2 Brighton Challenge 27-28 May 2017

Take part in our trek from Richmond Park to Brighton sea front with a choice of 30km, 44km, 56km or 100km routes through the British countryside. Visit gosh.org/london2brighton to sign up.



RBC Race for the Kids 2017 Summer 2017

Our annual 5k family fun run is back for 2017. Everyone is welcome to participate, and you can sprint, stroll or even scoot your way to the finish line! Register your interest at raceforthekids.co.uk and we'll be in touch when registration opens.

Legacy Open Days 20 June 2017, 2-4.30pm 29 June 2017, 2-4.30pm 12 July 2017, 2-4.30pm

We hold regular open days for our supporters who have included us in their Wills or are thinking of doing so. They are small, informal events where you and a guest have the opportunity to take a guided tour of Great Ormond Street Hospital and hear about its history and exciting research developments taking place. It's our chance to show you first-hand how legacy gifts make a huge difference to our patients, families and staff. For more information or to book your place, call **020 3841 3205** or email judy.anderson@gosh.org

Find out about more exciting challenge events online

Visit gosh.org/challenges
Call **020 3841 3164**
Email challenges@gosh.org

COME TO NEVERLAND AGAIN WITH PETER PAN AND WENDY

And support Great Ormond Street Hospital
Children's Charity this festive season.

Thanks to J M Barrie's amazing gift to Great Ormond Street Hospital in 1929, every performance of Peter Pan benefits the hospital, so enjoy a great family night out and support us when you go and see one of the many shows opening this season.



21 October - 29 January
Peter Pan Goes Wrong (Mischief Productions)
Apollo Theatre, London
apollotheatrelondon.co.uk/peter-pan-goes-wrong

16 November - 28 January
Peter Pan, an adaptation by Sally Cookson
National Theatre, London
nationaltheatre.org.uk

2 December - 1 January
Peter Pan
Northcott Theatre, Exeter, Devon
exeternorthcott.co.uk/calendar/peter-pan

2 December - 8 January
Peter Pan (pantomime)
The Plaza, Stockport, Cheshire
stockportplaza.co.uk/whats-on/peter-pan

2 December - 1 January
Peter Pan (pantomime)
The Hawth, Crawley, West Sussex
parkwoodtheatres.co.uk/The-Hawth

9 December - 2 January
Peter Pan (pantomime)
The Octagon, Yeovil, Somerset
octagon-theatre.co.uk/whats-on/childrens/peter-pan

10 December - 2 January
Peter Pan (pantomime)
Victoria Theatre, Halifax, West Yorkshire
imaginetheatre.co.uk/pantomimes/2016-peter-pan-halifax

December 16 - 31 December
Peter Pan
Chichester Festival Theatre, Chichester, West Sussex
cft.org.uk/whats-on/event/peter-pan

There's still time to visit our online shop for a fabulous range of great value gifts and essentials.
www.gosh.org/shop

Happy shopping!

Christmas cards



Amelia's Snowmen **£4.50**
Other designs from **£4.25**

Exclusive to GOSH



Bernard Bear **£10**
Child and adult hoodies from **£20**
Being @ GOSH bag **£7.50**

NEW!

GOSH Elf **£6.50**

Gifts for the family



Memory Books **£7.99**
Create Your Own Solar System **£9.99**
Scented candles from **£4.00**

100 per cent of the profits from all of your Christmas purchases go to the hospital, so this year, by choosing to buy your cards and gifts from our shop, you are **helping to make GOSH more extraordinary every day.**