

Summer 2016

# lifeline



YOU  
+US

**How play  
helped Myla  
to prepare for  
life-saving  
surgery**

**How a new garden  
at the hospital will  
help patients  
and families**

**Groundbreaking  
discovery to prevent  
spina bifida**



## Meet our guest editor...



## Hi! I'm Myla, and I'm 10.

I first came to Great Ormond Street Hospital (GOSH) when I was eight years old because I had puffy legs and eyes.

"The doctors found out that I had problems with my kidneys and I had to have them removed. I was put on dialysis until April last year when my mum donated one of her kidneys and I had a kidney transplant. In September, I was well enough to go back to school.

"When I was at GOSH, I made really good friends with my play specialist, Lynsey. She helped me understand my condition and prepare me for surgery. In this issue of *Lifeline*, you'll find an interview I did with Lynsey, where she talks about the difference the Play team makes. They can only help patients like me thanks to funding from Great Ormond Street Hospital Children's Charity.

Myla

Read Myla's interview with Lynsey 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/summer](http://gosh.org/summer)



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  
no. 1160024.

Thank you to Myla for doing a great job as guest editor and for taking part in our cover story feature.

The children's drawings in this magazine were created by patients at the hospital.



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, like



the new state-of-the-art surgery centre, which will allow the hospital to treat more seriously ill patients. Staff, patients and families will also benefit from a new garden being moved to GOSH over the summer after appearing at the RHS Chelsea Flower Show. You can read more on page seven.

### 2. Fantastic research breakthroughs, which



include gene therapy and other pioneering developments from the hospital's research partner, the UCL Institute of Child Health. On page 11, you can read more about how the hospital's arts programme, GO Create!, brought research to life in an exhibition.

### 3. New equipment, such as cutting-edge



microscopes to help neurosurgeons perform delicate and life-saving surgery, which we could only fund thanks to your generous donations that went above and beyond your regular gifts.

### 4. Patient and family support, including play



specialists who provide vital support to our patients to help them cope with being in hospital. You can find out more about their work in the cover story on page eight and the guest editor interview on page 14.

**Thank you to all of our donors who support us with a regular gift.**

## 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](http://gosh.org/donate)

## A royal celebration



»»» We joined thousands of people up and down the country in June to celebrate the 90th birthday of Queen Elizabeth II. Her Majesty has been a royal patron of Great Ormond Street Hospital (GOSH) since 1965.

Her Majesty's birthday was marked with a weekend of celebrations, which culminated in the world's largest ever street party – The Patron's Lunch – on The Mall on Sunday 12 June.

Thanks to the hospital's relationship with her Majesty, we were invited to host our very own table at the lunch. We had some very special guests, including GOSH patient Amy and her family, and volunteer Sheila, who has volunteered for us for 28 years. They enjoyed a picnic lunch while being entertained by street performers and circus acts.



The Queen visits GOSH in 1952

To celebrate Her Majesty's birthday, we held our very own indoor street party for patients at GOSH in the hospital's restaurant, The Lagoon, and welcomed schools, communities and fundraisers all over the UK to join in by raising money for the hospital in their own ways.

You can find out more information about our celebrations for the Queen's 90th birthday at [gosh.org/queenat90](http://gosh.org/queenat90)

## Tell us how we're doing

»»» Did you notice the survey that came with this issue of Lifeline magazine? We'd like to make sure that we're providing you with all of the information you need to know about Great Ormond Street Hospital and Great Ormond Street Hospital Children's Charity. We also want to find out if you feel properly informed about how the money you donate has made an impact at the hospital.

Once we have received your completed survey, you'll be entered into a prize draw to win one of five incredible prizes. The first prize is a city break for two people at any of the 520 Small Luxury Hotels of the World™ properties worldwide. Other prizes include an iCandy MiPeach toy pushchair for children and Elemis skincare his and hers kits worth £68\*!

\*Terms and conditions apply, visit [gosh.org/survey](http://gosh.org/survey)



Please spare a few minutes of your time to complete our survey if you can. Thank you!

## Where are they now?

In summer 2009, Great Ormond Street Hospital (GOSH) patient Oscar was the guest editor for *Lifeline*, where he interviewed Dr Paul Veys, Director of the Bone Marrow Transplant Unit. Now age 16, Oscar looks back on his time at GOSH and tells us what he's been up to.

»»» "I've been coming to GOSH since 2002 for treatment for leukaemia, including two bone marrow transplants.

"I don't remember much about my first stay, as I was so young. However, I contracted a second leukaemia when I was six years old and I spent the best part of 18 months at GOSH. All the doctors, nurses and physiotherapists were really friendly and the play specialists kept me busy.

"When I was in isolation after my bone marrow transplants, Vicky – the play specialist – came to spend time with me every day. She brought me lots of games to play and other things to do. That enabled Mum or Dad to go out to get lunch, as they weren't allowed to eat in my room."

### Being guest editor

"It was really lovely to see Paul and have a chance to catch up. When you spend so long in hospital, the staff become almost like family.

"There is constant research into more advanced ways of treating leukaemia and other diseases. We bumped into Paul at my last clinic visit and he was telling us about the ways that they are using bone marrow transplants to treat all sorts of other diseases."

### Today

"I still have clinic visits every six months, but when I turn 18, I'll transition to adult care at University College London Hospitals.

"I'm currently at catering college, where I'm about to finish my Level 2 Professional Cookery Course. I'm also a young leader at



Oscar, age nine, as guest editor in 2009



Oscar, age 16, on holiday in France, 2016

Cubs and Beavers and I work in the kitchen at a local café on Saturdays. I meet up with friends at the weekend and we usually go skating."

### The importance of donations

"The ongoing research at GOSH is so valuable. Play specialists, who are funded by the charity, can improve how patients and families feel on a daily basis, which is just as important.

"It all helps towards the healing process."

### Oscar's story

Oscar first came to GOSH when he was three years old. He was diagnosed with acute lymphoblastic leukaemia (ALL), an aggressive form of cancer that could only be cured by a bone marrow transplant.

Oscar underwent two bone marrow transplants at GOSH. Unfortunately, following the second transplant, he contracted graft-versus-host disease, where the new donor cells began to fight his body. Given just a 10 per cent chance to live, Oscar became the first child in Britain to receive a new type of stem cell treatment.

The treatment worked, and in 2007, Oscar was able to go home, returning to school in 2008.



### **Professor David Goldblatt, Consultant Paediatric Immunologist and Director of Clinical Research and Development**

**“** I grew up in South Africa, and trained in Cape Town. I aspired to come to Great Ormond Street Hospital (GOSH), the place that I considered to be the best for paediatrics in the English-speaking world.

“My responsibility is to oversee the strategic direction of the clinical research that makes a difference for our patients. Our new state-of-the-art research facility, the Zayed Centre for Research into Rare Disease in Children, due to open in 2018, will be the first of its kind in the world. It will give us the opportunity to bring together hundreds of clinicians and researchers under one roof to drive forward new treatments and cures for children with rare diseases.

“The work taking place at GOSH, its research partner the UCL Institute of Child Health and later the Zayed Centre for Research will lay the foundations for a revolution called ‘personalised medicine’. This means treatments are developed and customised according to a single patient’s needs. Within the next 10–20 years, we could be offering personalised treatments to all our individual patients.

“The charity is absolutely fundamental to all of this – without the support of their generous donors, we wouldn’t have our incredible facilities, the researchers and other members of staff we need to make this future a reality.”

Find out more about research at GOSH and the hospital’s pioneering breakthroughs in medicine at [gosh.org/breakthroughs](http://gosh.org/breakthroughs)

Talking to...



Professor David Goldblatt

### **Your vital support**

“We’d like to say a big thank you to everyone who supported our surgical microscope appeal. Your generous donations helped us to raise more than £530,000, which funded a brand-new, cutting-edge microscope. This vital piece of equipment will allow the Neurosurgery team at Great Ormond Street Hospital to operate with greater accuracy so that our patients have a better chance of recovery.

The new equipment also means that neurosurgeons will be able to perform up to 1,000 additional life-saving procedures each year, helping more patients like our previous Lifeline Guest Editor Sophie, whose family say a huge “thank you” for your kind support.

As well as the microscope, the fantastic response to this appeal has enabled us to also buy additional surgical instruments for our new operating theatre. None of this would have been possible without your support. **Thank you.**



Sophie and her neurosurgeon, Mr Kristian Aquilina

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](mailto:supporter.care@gosh.org)



## The space to reflect

This summer, families will be able to enjoy a garden right in the heart of Great Ormond Street Hospital (GOSH).

**D**esigned by award-winning plantsman and *Gardeners’ World* presenter Chris Beardshaw, the Morgan Stanley Garden for GOSH will provide families with a much-needed secluded and reflective space for years to come.

**“This unique opportunity has allowed us to explore the creation of a quiet, contemplative garden.”**

At the moment, the closest green space for families is at one of London’s parks, but many don’t want to leave GOSH or their child’s side. The garden will improve their experience by providing a place where they can collect their thoughts or have difficult conversations away from the wards.

“You can imagine the pressures on parents whose children are spending time at the hospital,” says Chris. “This unique opportunity



Chris Beardshaw

has allowed us to explore the creation of a quiet, contemplative garden in contrast with the buildings and daily workings of the hospital.

“As the garden is intended as a place of peace and quiet, a cool, calm, green, leafy design spangled with woodland flowers is the ideal solution.”

The idea for the garden grew from the long-standing relationship between Morgan Stanley and GOSH, and is the latest in a series of projects on which the two institutions have worked together.

The garden debuted at the RHS Chelsea Flower Show – where it won a gold medal – and was rebuilt at the hospital with help from the BBC’s *DIY SOS* team. With 30 trees, topiary and hedging, 1,000 plants and 30 tonnes of soil, the garden sits on a hospital rooftop, providing a beautiful idyll for families to admire and enjoy.

“We’re extremely grateful for this amazing garden,” says Medical Director Dr Vin Diwakar. “It will make a real difference for families of children in our care.”

To find out more about the Morgan Stanley Garden at the RHS Chelsea Flower Show, visit [morganstanley.com/chelseaflowershow](http://morganstanley.com/chelseaflowershow)





# Play is a serious business

The support that Myla and her mum Michaela received from Play Specialist Lynsey Steele was more than just a game: it was absolutely vital in understanding Myla's condition and helping them cope with being at Great Ormond Street Hospital (GOSH).



**M**yla has a very positive relationship with GOSH, and that's because of Lynsey," says Michaela, who has been coming to the hospital with Myla since December 2013. In that time, they've both developed close relationships with Play Specialist Lynsey, who works on Eagle Ward – the hospital's ward for patients with kidney problems.

**"I knew that Lynsey's title was 'Play Specialist'... but she did so much more than play."**

"Myla was rushed to GOSH after blood tests at her local hospital revealed she needed specialist care," says Michaela. "The doctors took two biopsies in the first 48 hours."

Doctors at the hospital revealed that Myla had acute nephritis, a condition that affects the kidneys' ability to process fluid and proteins. Her only treatment options were dialysis and a transplant.

"Coming to GOSH was a big shock," says Michaela. "I didn't realise what was happening at the time, but Myla was going through a lot of trauma, and she was in a lot of pain. She couldn't understand what was happening, and neither did I, so I couldn't really explain it to her."

"Then, Lynsey stepped in."

Lynsey is one of 34 full-time members of the Play team. Funded by Great Ormond Street



Myla with Play Specialist Lynsey



## Eagle Ward

Nephrology and renal transplants

**Eagle Ward has two playrooms, one for younger children and an adolescent room, so children can spend time with young people their own age.**

Hospital Children's Charity, it's her job to help seriously ill children at the hospital come to terms with their illness through play.

"I knew that Lynsey's title was 'Play Specialist', and I thought, 'Okay, she's come here to play'. But she did so much more than that. She took Myla through each stage of her illness and they started documenting it together in a journal."

**"I can't imagine having gone through this experience without Lynsey."**



"They would pretend to do injections, cannulas and blood tests on teddy bears so that Myla began to understand what was happening to her. They discussed the implications of her kidney failure and what would happen once she began dialysis."

But it wasn't just Myla that Lynsey was helping to cope with her condition. Play specialists provide support for the whole family, which was incredibly important to Michaela: "Lynsey explained things and could tell me how Myla was dealing with her condition and experience at GOSH. I was riddled with emotion and fear, whereas Lynsey had a different perspective, which she used to reassure me."

Play specialists like Lynsey help children to overcome their fears and anxieties about their time in hospital and any upcoming treatments.





Myla and Lynsey practise pretend injections on teddies

# £29,523

could cover the cost of one member of the hospital's Play team for a whole year.

## "Myla's relationship with Lynsey has stayed strong."



There is a risk that if anything comes as a shock to a patient, their treatment will be jeopardised. This could mean that their recovery time is affected or their surgery is cancelled.

Some children are too young or find it too difficult to communicate how much pain or discomfort they're in, so play specialists use other approaches: "Myla and Lynsey drew a rating scale of one to 10 so that Myla could express what level of pain she had. It's such a simple idea that I wouldn't have come up with," says Michaela.

Myla stayed on Eagle Ward for three months before going home to continue her dialysis treatment. However, 13 months later, complications meant that she had to return to hospital. "Myla needed a kidney transplant, and I came up as a match," says Michaela. "So in April 2015, I donated one of my kidneys."

After Myla underwent her transplant, she and Michaela were offered charity-funded accommodation nearby. "It was difficult for me to get around and Myla had daily blood tests to ensure that everything was functioning okay. To be just across the road and not worry about transport – it was perfect."

As Myla came to the end of her stay as an inpatient, Lynsey helped prepare her to manage her condition outside of the hospital. "Lynsey built a routine around Myla's medication, so she

knew what to take and when. Myla doesn't like the taste of some of her medicine, so Lynsey recommended soft drinks to mix it with to make it taste better."

Although Myla was able to go home during the summer, unfortunately, she couldn't go out much. "Myla was very unwell, and experienced a lot of vomiting as her medication was adjusted. It wasn't very fun at all. But hopefully, this summer will be different!"

In September 2015, Myla was well enough to return to school. She still visits the hospital for regular check-ups as an outpatient. "Myla enjoys coming to GOSH, and her relationship with Lynsey has stayed strong. We pop up and see her when we can, and Myla still has friends on the Ward who are having dialysis.

"I can't imagine having gone through this experience without Lynsey. That kind of support was crucial."

## Donate now!

If you would like to make a donation to fund play specialists at GOSH, please call **Supporter Services** on **020 3841 3131** or visit **[gosh.org/summer](http://gosh.org/summer)**

# Putting art under the microscope



Earlier this year, Great Ormond Street Hospital's (GOSH) arts programme, GO Create!, unveiled a new exhibition that explored how children interpret medical information.

Artist in Residence Sofie Leyton spent almost a year working with clinicians, researchers, patients and their families to create *Under the Microscope*. The exhibition focused on the complexities of heart disease in young people and the pioneering work to develop gene therapy to help treat children with rare diseases.

Sofie ran workshops and observed patients in clinic to learn about the language young people use to describe heart disease. She then translated her findings into colourful, embossed images of hearts that stood out from printed words used to talk about the anatomy and diseases of the heart.

The exhibition was placed in the corridor that links GOSH with its research partner, the UCL Institute of Child Health. "There's a very intimate relationship here between the hospital and the Institute," said Professor David Goldblatt, Director of Clinical Research and Development at GOSH. "Rather nicely, Sofie's



In Isolation, exhibited in the roof garden of the Octav Botnar Wing

exhibition was placed in the corridor that is really the artery between the two."

Visitors could also listen to stories recorded by patients and families. In another installation, guests could listen to a patient's experience of gene therapy, a pioneering technique that edits genes to treat or prevent disease.

Attending the exhibition, Dr Peter Steer, Chief Executive at GOSH, said: "There is increasing evidence to show that art makes a huge difference in healthcare – not just to the environment, but to patients' wellbeing and, ultimately, to helping them get better faster."



Winter Garden, exhibited in the corridor that links GOSH with the ICH



You can find out more about our gene therapy appeal to help fund gene therapy treatments by visiting **[gosh.org/genet](http://gosh.org/genet)**



# Record-breaking appeal

We joined forces with *The Independent*, *Evening Standard*, *i* and London Live for the record-breaking Give to GOSH appeal. Thanks to our generous supporters, we raised more than £3.5 million for the patients, families and staff at Great Ormond Street Hospital (GOSH).

**T**he appeal ran from late November 2015 to 14 February 2016 (the hospital's 164th birthday) and was the most successful seasonal appeal in the history of the newspaper.

The funds will go towards the Louis Dundas Centre for Children's Palliative Care and the creation of a specialist unit for children with heart failure. Approximately £1 million will be spent on life-saving research programmes to find new cures and treatments for rare diseases.

The kind supporters of our appeal have also helped to fund patient and family support, including 10 members of the Play team last year. However, play services at the hospital are an ongoing need, and our funding covers not just members of staff, but toys, equipment and weekend cover. As the team is funded 100 per cent by the charity, the crucial support they provide would not exist without donations.


Thank you to everyone who kindly donated to the Give to GOSH appeal. We could not have reached this extraordinary total without you.



To find out more about our play specialists and why we urgently need to raise more funds, please visit [gosh.org/summer](http://gosh.org/summer)

How the money raised will be spent

**RESEARCH PROJECTS** Approximately  
**£1 MILLION**

**MORE THAN 1,000** nights in family accommodation will be provided. 

**MORE THAN 100** families coming to GOSH and in financial need will receive food vouchers.

**Money raised will help fund** the new **14-bed unit** for children with heart failure, and a high-dependency bay.

**Money raised will help fund** the **Chaplaincy and Spiritual Care team**.

**Money raised will fully fund** the current priority needs of the **Louis Dundas Centre for Children's Palliative Care**.

 **Money raised will fund 10 members of the Play team.**



England footballer Jack Wilshere with GOSH patient Chloe, age seven

**8,500** 

**GENEROUS SUPPORTERS**  
DONATED TO THE APPEAL.

**35** **250**  
**CELEBRITIES** **STORIES**  
SUPPORTED THE APPEAL WERE PUBLISHED IN  
NEWSPAPERS, ONLINE  
AND ON LONDON LIVE

Talking to...



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

**“** People across the country pulled out all the stops to support the Give to GOSH appeal. Together, they helped us to raise more than £3.5 million – a phenomenal total that surpassed all of our expectations. “All the donations will help to give seriously ill children the best chance for life. We are all eternally grateful. **”**



Nigel Howard Evening Standard

Thank you

**“** There are times when ‘thank you’ doesn’t seem enough... Your donations have ensured that GOSH will remain a beacon of light and hope for families in their darkest hour. **”**

– Candace Livingstone, mum of GOSH patient Elliott who featured in the appeal

**“** I am astounded... The response has been humbling... I cannot tell you what it means to witness how people want to be part of what we are trying to do for the children here at the hospital. **”**

– Martin Elliott, Professor of Cardiothoracic Surgery at GOSH



# The power of play



Watch a video showing how play helps children at GOSH understand their conditions at [gosh.org/summer](https://gosh.org/summer)

“Hi, my name’s Myla and I’m the guest editor for *Lifeline*. I’m interviewing Lynsey Steele, who was my play specialist when I stayed on Eagle Ward at Great Ormond Street Hospital (GOSH), about what she does and how she helps patients.”

## Q What does your job involve?

I’m a play specialist on Eagle Ward, where we see patients with kidney problems. When children come to the Ward, we play in the play room or I visit them in their rooms if they’re unable to leave. We also talk about the operations they’re having and I help them to cope with procedures, from cannulas and blood tests to dialysis.

## Q How does your job help patients like me?

For some children, coming to GOSH might be the first time they’ve ever been to hospital, so it can be a scary or worrying time. I help them have fun by playing with them,

In the past six months, the Play team interacted with 23,339 children – that’s nearly 130 every day!

and then I’ll use play techniques to explain any procedures they might be having, for example injecting Play-Doh using toy needles. Techniques like these help children understand more about their treatment and become less scared.

## Q What games do you play with the patients?

We have lots of different board games – Monopoly is my favourite! Some children like playing on computer consoles, and we take part in arts and crafts and baking. We also like to celebrate patients’ birthdays and Christmas on the Ward.

## Q How do you help prepare patients for surgery?

If younger children are coming in for a kidney transplant, I use their favourite cuddly toy character and we’ll take all of the tubes involved

in a surgery – for example, a neck line – and stick them on the character so that the patient feels more comfortable around that equipment.

For older children, we draw pictures to show the placement of the tubes and the new kidney, so that they understand what’s going to happen in surgery.

## Q How do you help mums and dads?

Mums and dads can have a bit of a well-earned break while their child is playing, and it helps them to see that their child is enjoying themselves. We also involve patients’ siblings so that they can play while understanding more about their brother or sister’s treatment.

“Play gives patients a positive experience of being at GOSH.”



## Q What difference does it make to have play specialists?

We help children to understand their conditions and cope with being in hospital. For example, they might be scared of needles or of having blood tests, but by playing with the equipment, including syringes, plasters and gauze, we help them be more comfortable about what they’re going through.

Play gives patients a positive experience of being at GOSH. When children go home after their procedure, they’re much happier.

## Q Is there anything you’d like to say to charity supporters who donate?

I’d like to say a huge thank you for all of their donations and support. It’s because of them that the charity can fund the play specialists and play workers at GOSH.

We need to raise money to continue funding play services at the hospital. Please visit [gosh.org/summer](https://gosh.org/summer) to make a donation.



## Michaela, Myla’s mum

“Myla has a very strong and close relationship with Lynsey. When she was an inpatient on Eagle Ward, Myla always responded to Lynsey.

“Lynsey made sure that Myla didn’t miss out on anything, even her education! She helped her make friends on the Ward, which, at the same time, taught Myla about dialysis. Seeing other patients like her on dialysis helped Myla come to terms with needing a machine to support her until she was able to have a transplant. And although she didn’t celebrate a birthday while being in hospital, she was always involved in other children’s parties.

“When Lynsey’s around, Myla doesn’t need me to be there – she feels very safe and secure – so it’s reassuring to have that support in the hospital environment.”

”

Find out more about Myla and Michaela’s story on **page eight**.

My favourite toys to play with in summer are... my Ben 10 games! **Abdal, age eight**





After Anne-Marie's first daughter Yasmine was born with spina bifida, she decided to take part in a pioneering research study at Great Ormond Street Hospital's (GOSH) research partner.

# Changing lives through research



**D**uring Anne-Marie's first pregnancy, a routine scan revealed that her daughter, Yasmine, would be born with spina bifida, a condition where the spinal cord does not form properly.

This news came as a big shock for Anne-Marie and her family: "We were told about Yasmine's condition when I was about 22 weeks pregnant," says Anne-Marie. "I had done lots of baby research, as all expectant mums do. Whenever I came across spina bifida, I kind of ignored it because I was taking folic acid, so it wasn't an issue to really think about. When they did tell us, it was completely unexpected."

In the earliest weeks of pregnancy, a layer of cells on the back of the embryo curls up like a sheet of paper and closes to form the neural tube. This tube matures into the baby's brain and spinal cord. If a fault occurs during this process, it can cause a neural tube defect.

Since the 1990s, the Department of Health has recommended that women take folic acid supplements before and during the early weeks

## "It was completely unexpected."

of pregnancy to prevent neural tube defects. However, some women who take folic acid still go on to carry babies who have a neural tube defect.

With support from their family, Anne-Marie and her husband, Matt, decided to continue with the pregnancy. "My heart goes out to anybody who has to make that decision," says Anne-Marie. "In our situation, we were supported by our family and they have been amazing. Yazzy is part of it and all she has done is to enhance our family."

Yasmine was born on Valentine's Day 2008. "There was such elation and jubilation that she had arrived and we just knew she'd be fine," says Anne-Marie. "She had to have an operation that same day. She had what was essentially a hole quite low down on her back with a blister over it. The doctors at St Georges Hospital took her straight down to the neonatal unit and we saw her about an hour later."



Yasmine

The family heard about a study being led by Andrew Copp, Professor of Developmental Neurobiology and Head of the Newlife Birth Defects Research Centre at the UCL Institute of Child Health, GOSH's research partner.

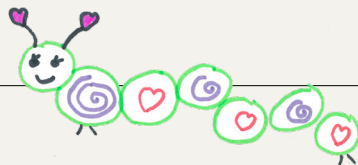
Professor Copp has made it his life's work to understand what causes the faults in the development of the neural tube, and investigate how simple vitamins can be used to prevent the faults from occurring.

## "We don't let Yasmine's condition get in the way."

Following decades of study and tests, Professor Copp launched a pilot study on women who were at high risk of having children with neural tube defects. "I was eligible for the study and decided to enrol," says Anne-Marie. "I was placed in the randomised group and given a bottle with higher dose folic acid and another bottle that had either inositol or a placebo. Because inositol is a vitamin, I felt comfortable taking it while pregnant. I would have had more







## "Yasmine is the light of our lives."

reservations had it been an unknown drug of some sort."

Some time later, Anne-Marie and Matt received some more happy news: they had become pregnant with their second daughter Zara while on the study.

Professor Copp and his team closely monitored Anne-Marie throughout her pregnancy. When Zara was born in 2010, she arrived healthy and without a neural tube defect.

Following the end of the study earlier this year, Professor Copp and his team announced their groundbreaking discovery. In a group of high-risk women, taking vitamin B8 (also known as inositol) alongside folic acid before and during pregnancy could be more effective at preventing neural tube defects than using just folic acid alone.

Yasmine now attends mainstream school and uses a wheelchair. She has regular physiotherapy sessions and will need more operations when she's older. "Yasmine is confident, outgoing, eloquent, fun – the light of our lives," says Anne-Marie. "We don't let her condition get in the way. She went to a birthday party earlier in the year with a climbing wall, and she went up it! She loves swimming and we have lots of sporting facilities on our doorstep."

"My aspirations are the same for both my daughters. I want them to work hard, to be independent, to go to university and study and get good jobs, and get married and have children if they want to. I just want them to have happy and fulfilled lives."

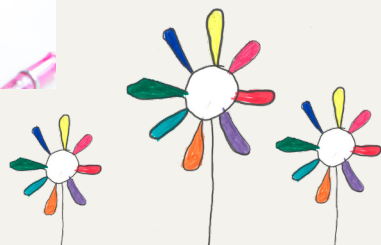
To find out more about research at GOSH, please visit [gosh.nhs.uk/research-and-innovation](http://gosh.nhs.uk/research-and-innovation)



Yasmine with sister, Zara



**My favourite toy to play with in summer is... my scooter!**  
**Josh, age four**



# 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.



## A home from home

**Vikki is mum to Abbie and Sonny, who are both patients at Great Ormond Street Hospital (GOSH). Vikki's family have set up their own TeamGOSH Fund to help raise money for charity-funded accommodation at the hospital.**

>>> Vikki's daughter Abbie has been coming to GOSH since 1999 for treatment for her rare condition, craniosynostosis, which prevented one side of her head from forming properly in the womb.

"During the first five years of her life, Abbie had extensive surgeries on her skull to try and reshape the curvature in her face and head," says Vikki. "She underwent major eye surgery to correct her vision, which had also been affected."

Just before Christmas 2015, Abbie had reconstructive surgery on her nose area. Sadly, shortly after Abbie was discharged, Vikki's youngest son, six-year-old Sonny, was admitted to GOSH. "It was only a week before Christmas" says Vikki. "If it hadn't been for the accommodation provided by the hospital, my family would have been torn apart."

Sonny was discharged earlier this year, but still returns to GOSH for ongoing treatment, as does his sister Abbie.

Vikki wanted to do something in recognition of the care her son and daughter continue to receive at the hospital. She set up a TeamGOSH Fund named after Abbie and Sonny, which allows family and friends to unite their fundraising into one joint Fund.

The first event that Vikki took part in was the charity's annual 5k family fun run, RBC Race for the Kids, where she raised more than £1,000: "I got into running only four years ago, and now I regularly run, cycle, climb and swim just about anywhere. I'm happy to support the hospital in any way I can."

"We want to raise £12,000 towards family accommodation. So far, I've collectively raised £4,280 from a number of events, including my first ultra marathon – the North Burn 100 – and a 20-mile obstacle race. I've also been to New Zealand to run six of the nine great walks – all in aid of Great Ormond Street Hospital Children's Charity."

"Abbie has organised and performed at a school concert, raising nearly £4,000, and our local football club also held a charity race night in Sonny's honour, raising an impressive £800!"

"All of our fundraising can never repay the hospital for what they've done for our family. It really is just our way of giving something back."

To find out more about Sonny and Abbie's TeamGOSH Fund or to donate, please visit [justgiving.com/teams/SonnyandAbbieArthurGOSHFund](http://justgiving.com/teams/SonnyandAbbieArthurGOSHFund)





# A long-lasting legacy

Alan Sanson tells us how the memories of coming to Great Ormond Street Hospital (GOSH) to visit his younger brother Edward in the 1960s inspired his family to leave a legacy.

“Edward was born in June 1960 with transposition of the great arteries. Among many things this meant his lips, toes, fingers and cheeks were blue. Within weeks, he had his first life-saving procedure at GOSH.

“Five years later, doctors in Canada developed a pioneering operation for his particular defect. Edward was in GOSH over Christmas 1965 on ward 1A, which was hand-decorated with Winnie the Pooh. He was one of the first children to receive the treatment, so no one knew how long of a life it would give him.

“I remember looking through a porthole window and seeing Edward in his room after his major op. He was pink – no longer blue – and laying on the bed with his bunny sitting on the pillow.

“I also remember the big wooden revolving doors into the hospital, and the wooden rocking horse in the restaurant. I used to drop a bouncy ball down the stairwell from five floors up and

get it to bounce all the way down.

“If there was anything Edward wanted to do, he would do it. He had his own business designing and hand-making bespoke wooden furniture. He married and had a lovely daughter.

“Edward died of a cardiac arrest on 6 August 1990 when he was 30 years old. He had the most fulfilled life, fuelled by his innate determination and happy approach to living.

“Now, whenever we receive newsletters from the charity, the passion of the hospital staff flows out. But there is always more research to be done to help so many poorly children and their families. We recently decided to increase the proportion of our estate that we’re leaving to the charity in our Wills.

“Thank you, Edward, Dad, Mum, and all the doctors and nurses for giving us all an amazing, privileged life.”

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](mailto:legacy@gosh.org) or 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.



Alan, right, with his brother, Edward



# Talking to Tanya Mitchell

**Deputy Director and Head of Supporter Relations**

“I’ve been at Great Ormond Street Hospital Children’s Charity for 10 years now. It has been the most incredible and humbling experience, made even more so by the generosity of our supporters.

“We need to raise around £100 million every year to support the extraordinary work that Great Ormond Street Hospital (GOSH) undertakes. While the NHS does an incredible job to fund the hospital’s day-to-day running

**“Our supporters have helped our fundraising go above and beyond what we thought possible.”**

costs, our supporters enable us to go the extra mile to support the children, families and staff. With their help, we’re able to fund pioneering research such as gene therapy, state-of-the-art equipment, and the hospital’s rebuilding and refurbishment.

“Fundraising also allows us to fund children, family and staff welfare, including accommodation for mums and dads to be close to their child when it matters most, and play specialists to help children understand their conditions and cope with being in hospital.

“Over the years, our supporters have helped our fundraising go above and beyond what we thought possible. One of our appeals funded a specialist X-ray machine – a DEXA bone scanner – to help patients like Joel, who was born with femoral hypoplasia, a condition that gave him a curved spine, short thighs and club feet.

“Joel required frequent X-rays, which impacted on his long-term health. But thanks to our generous donors, we were able to raise



more than £471,000 for the new scanner, which is less detrimental to the health of Joel and others like him.

“More recently, as part of our Christmas stocking appeal, our supporters helped us to raise almost £1.4 million. But, more importantly, the appeal allowed supporters to send in stockings containing messages of support. Stanley – who has a rare genetic condition – featured in our Christmas 2015 edition of *Lifeline*. He and his family loved reading the messages, which we also displayed around the hospital by featuring them on plasma screens and the patients’ bedside entertainment system.

“I’ve been blessed to work with the children, families and staff at the hospital to discover where funds are most needed to create the biggest impact. Part of that great experience is gaining the support from our incredibly generous, kind and compassionate supporters, who really do care as much as I do about the hospital.

“Thank you to everyone who has donated to us over the years. You put the ‘great’ into ‘Great Ormond Street Hospital’. We simply couldn’t do this without you.”

To find out and why we urgently need to raise money to fund more play specialists, please visit [gosh.org/summer](https://gosh.org/summer)

## Get involved

There are lots of fundraising events you can get involved with throughout the year. Here are just a few!



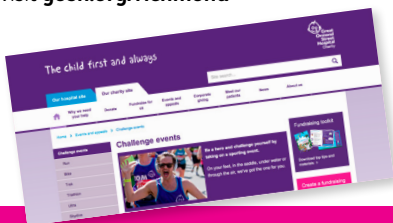
### London to Brighton bike ride 11 September 2016

Leave the city behind and head for the coast on this 54-mile cycling challenge. Visit [gosh.org/londontobrighton](http://gosh.org/londontobrighton) for further details.



### Richmond Running Festival 18 September 2016

Take on a challenge and run the scenic route with this 10km route, which starts and ends in beautiful Kew Gardens. Reach the finish line and you'll enjoy a glass of prosecco! For more information, visit [gosh.org/richmond](http://gosh.org/richmond)



**Find out about more exciting challenge events online**

Visit: [gosh.org/challenges](http://gosh.org/challenges)  
Call: 020 3841 3164  
Email: [challenges@gosh.org](mailto:challenges@gosh.org)

### Legacy Open Days

22 September 2016, 2-4.30pm  
6 October 2016, 2-4.30pm  
17 October, 2-4.30pm

We hold regular open days for our supporters who have included us in their Wills or are considering doing so. They are small, informal events where you have the opportunity to take a guided tour of Great Ormond Street Hospital and hear about its history and current exciting research developments. 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](mailto:judy.anderson@gosh.org)



### Bake it Better 17-23 October 2016

We knead you to hold a bake sale and raise some dough for the patients at Great Ormond Street Hospital.

To register your interest, visit [bakeitbetter.org](http://bakeitbetter.org) or contact the Bake it Better team on 020 3841 3036 or email [bakeitbetter@gosh.org](mailto:bakeitbetter@gosh.org)



### Kilimanjaro trek 9-19 February 2017

Step up to the challenge and climb the world's highest free-standing mountain with this once-in-a-lifetime adventure. To see further details, visit [gosh.org/kilimanjaro](http://gosh.org/kilimanjaro)

## Have you picked up your Sparks card?



**Become a Sparks club member, and every time you shop at Marks & Spencer, they'll donate 1p to us.**

Just select Great Ormond Street Hospital Children's Charity when you register your card online.

With more than £100,000 raised for us so far, every penny really does count.



## Hop for GOSH!

Only £15!



**The classic space hopper has been given a purple makeover for Great Ormond Street Hospital Children's Charity!**

Designed by our charity partner TOBAR Group Trading Ltd, the special edition toy is available at every Hawkin's Bazaar store and in our GOSH shop [gosh.org/shop](http://gosh.org/shop)

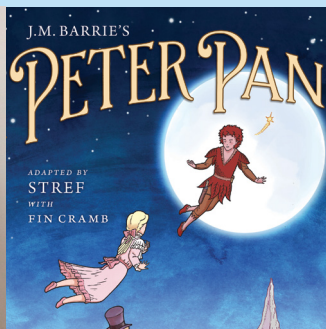


We receive 10 per cent of proceeds from every purchase.





# Shop at **GOSH** this summer!



Shop for **GOSH** this summer!

We have a fabulous range of handpicked gift ideas for you online at **[gosh.org/shop](https://gosh.org/shop)**

By buying gifts from our online shop, you'll be helping seriously ill children and their families at Great Ormond Street Hospital **to get better and get home.**

**100 per cent of the profits** from all of your purchases go to the hospital.

## Happy shopping!

