

Spring 2018

Member Matters

Young people's edition



A Royal Visit

The Duchess of Cambridge visits GOSH for a grand opening.

See page 8



**We go behind the
scenes with GOSH Arts**

See page 6

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Welcome

Hello and welcome to the Spring edition of *Member Matters*!

I'm Zoe and I have recently been elected as a patient Governor as part of the new Council of Governors. I stood for election as I really hope to represent the voice of the young people in the hospital whilst drawing on my experiences of the hospital and my recent transition to adult care. Being a patient at GOSH inspired me to study medical engineering and I'm hoping to use lots of the things I learn to help to develop the hospital.

I am also a member of the Young Person's Forum (YPF) and being a part of the YPF has given me a huge insight into the hospital and the way it cares for its patients. I never appreciated how many components there was to all my care. Working with the other YPF members has also given me new ways to cope with my complex health condition (read more on page 14), and it's really good to hear other people's views and experiences.

There are so many opportunities to get involved from volunteering to joining the YPF to fundraising. I would also say to everyone - don't be afraid speak up for what you believe in to help your own care and the hospital.

This edition is packed full of cool features. On pages 6 and 7 we go behind the scenes with GOSH Arts to meet the team that works hard to make the hospital a colourful and interesting place to visit and stay. On pages 8 and 9 you can see what happened when HRH the Duchess of Cambridge came to GOSH to open the new Premier Inn Clinical Building, and on pages 14 and 15 you can read my own story – about what brought me to GOSH and what I am doing now!

I hope you enjoy this edition!

Zoe



FOUNDATION TRUST NEWS

Fulfilling Our Potential – Our new plan for GOSH

In October, Great Ormond Street Hospital (GOSH) held its first Open House Week, where we talked about our plan for the hospital – to fulfil the potential of every child and family who comes to GOSH. We spent time talking to patients, families and staff about how the hospital should change to work even better, and how we make sure we are reaching our potential every day!



GOSH construction reaches new heights

In December, GOSH celebrated our new research building, the Zayed Centre for Research into Rare Disease in Children (ZCR), reaching its highest point with a special ceremony.

The building, which is a partnership between GOSH, UCL Great Ormond Street Institute of Child Health and GOSH Children's Charity, will be finished in 2018, and will

have brand new laboratories dedicated to finding new medicines and treatments for many different illnesses, as well as a new outpatients clinic.

Introducing...

GOSH has had some new leaders join us in the past six months.



Sir Michael Rake joined us in November, as our new **Trust Chairman**. He comes with lots of leadership experience from large businesses like easyjet and BT, as well as from charities. He is also the Vice President of the Royal National Institute of Blind People (RNIB).



Our new **Chief Nurse, Alison Robertson**, started at GOSH in April. Alison completed her nurse training at GOSH from 1983 to 1987 and held her first staff nurse post on the Neurosurgical unit. She is highly experienced and has held the position of Chief Nurse at several different teaching hospitals.



Matthew Shaw joined us in March and is GOSH's new **Medical Director**, which means he will have direct responsibility for the hospital's doctors. Matthew is a spinal surgeon with years of experience.



EPR preparing for lift off!

"The Electronic Patient Record (EPR) programme is preparing for lift off and we are all getting excited as the countdown to go live begins. The teams are working really hard in the clinical system design stage at the moment. The patient portal steering group is focusing on how the EPR can help you and your family to better communicate with your care teams at GOSH, so you feel more in control. There's lots to look forward to when the new patient portal lands in spring 2019!"

— Faiza, EPR Patient Representative and Chair of the Young People's Forum (YPF)

FUTURE PROOF

ELECTRONIC
PATIENT RECORDS



BEHIND THE SCENES

Behind the scenes with GOSH Arts

GOSH Arts is the Great Ormond Street Hospital arts programme. GOSH Arts offers exciting opportunities for patients, families and staff to get involved in lots of different artistic and cultural activities, as well as commissioning artworks that help us make the hospital an environment that welcomes patients and families and inspires creativity.

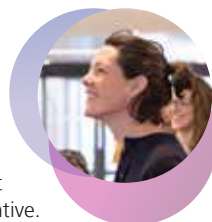
Almost every day, GOSH Arts runs sessions for patients and families which cross all art forms, including theatre, visual arts, dance and music. Last year alone, the team worked with almost 60 artists and organisations ranging from the Wigmore Hall to the V&A museum, from Turner Prize winners to cutting-edge digital artists.

The GOSH Arts team is Susie Hall and Vivienne Reiss, Heads of Arts, and Helena Copsey and Caroline Moore, Arts Managers. Find out more on Twitter [@GOSH_Arts](#).



Susie Hall, Head of Arts

"We get to work on all sorts of projects that an arts team wouldn't normally get to be involved in, such as an app to alleviate anxiety during blood tests, or a project engaging young people in the future design of the hospital."



**Caroline Moore,
Arts Manager**

"There isn't really a 'normal' day at GOSH Arts! I love that my role is so diverse and creative. The constantly changing and evolving environment means we have to be really flexible to the needs of patients and staff, so no day is ever the same!"

Super
GOSH



Helena Copsey, Arts Manager on how she came to work at GOSH

"I work with artists to develop new artworks for the hospital, and make sure we involve patients, families and staff in the process. Last year I helped select over 50 original artworks to display in parent and staff rooms in the new Premier Inn Clinical Building (PICB), making spaces feel more comfortable and homely."



This year the GOSH Arts team has unveiled many exciting artworks in the newly opened PICB, that inspire the imagination and make the hospital feel more welcoming and family friendly. Below are just a few examples...

Throwing Shapes

The playroom walls and windows have been transformed with fun colourful shapes by artist Joceline Howe. Joceline's work encourages play and she has also made a series of large plastic shapes that patients can play with.

Windows

A set of two virtual windows bring views of the outside world to the bedside. The remarkably realistic windows display living landscape which change periodically to reveal new outdoor scenes.

Super GOSH

Graphic artist Rob Lowe, also known as Supermundane, worked with young people and Play staff to develop designs for two teen social rooms. The patterns created by young people during the sessions were used by Rob to develop the final artwork and can be spotted in the final design.

Nature Trail

Inside the Mittal Children's Medical Centre, you may spot a jumping rabbit in the grass, or a deer darting between the trees in our newly extended Nature Trail, an interactive artwork that now spans the full length of the corridor. The animals are created by over 100 LED panels hidden beneath the woodland wallpaper. Motion sensors detect individuals as they move along the corridor, triggering the animals to accompany you along your journey.



Throwing shapes



WHAT HAPPENS WHEN...

HRH enjoys craft time with Renae, age 10.

You open a new clinical building

HRH, The Duchess of Cambridge visited patients, families and hospital staff at Great Ormond Street Hospital (GOSH) in January to officially open the Mittal Children's Medical Centre, home to the new Premier Inn Clinical Building.

In the heart of a central London hospital, you might not expect to find a vast turquoise lake framed by snow-capped mountains. You may not expect to lock eyes with a pink chameleon as you walk down the corridor. But GOSH is no ordinary hospital. From a menagerie of ward mascots to fully equipped playrooms for all ages, the Mittal Children's Medical Centre was designed to be more than just a clinical space.

Oriel, age 14, receives a royal visit from HRH the Duchess of Cambridge.



A royal visit

Her Royal Highness spent time with cardiac patients, some of whom have spent months in hospital on pioneering heart devices, which help them to stay alive whilst they wait for a heart transplant. GOSH is just one of two centres in the UK to offer this treatment.

The Duchess also met children with rare and complex medical conditions who were taking part in an art activity. She joined them as they drew what they liked most about their bedrooms and the new facilities. The activity, which took place in one of the hospital's playrooms, was facilitated by GOSH Arts, the hospital's arts programme.

Great Ormond Street Hospital patient Oriel Gray, 14 from Brecon and her mum Fiona Gray, 49 also had a special visit from The Duchess. Oriel is in hospital recovering from surgery to reconstruct her ear. Oriel said of the meeting "She was really friendly and very beautiful. I told her that the hospital feels like a second home because my mum can stay with me and I have my own bathroom. As a teenager that's really important. The new ward is amazing and all the nurses and doctors make you feel welcome. After my surgery yesterday, it was great to take my mind off everything. She said I must be very brave"

GOSH's first clinical building sleepover

First-hand insight into the experience of children and families who stay at GOSH will help us when we design and build new buildings in the future. That's why a team of 10 staff members from the hospital, and GOSH Charity volunteered to stay overnight on Leopard Ward, before patients and families moved in. The sleepover volunteers recorded their experiences, from the comfort of the beds and sheets, to toilet flushes and noise levels. Many were pleasantly surprised by the size and comfort of the patient beds, while everyone was impressed by the spaciousness of Leopard Ward and the bright animal artwork.

The volunteers' experiences and feedback are now being reviewed, and preliminary recommendations drawn up. The sleepover comments – good and bad – will be applied to future projects, helping GOSH to continue delivering a better hospital experience for everyone.

Explore the new centre with an immersive virtual reality video! For the best experience, we suggest watching it on the YouTube app, which you can download to your mobile device. Visit gosh.org/experience-great-ormond-street-hospital-virtual-reality.



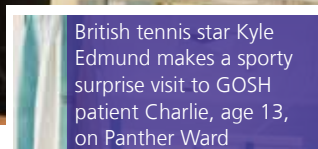
The Duchess of Cambridge with a team of GOSH nurses.

FAMOUS FACES IN THE HOSPITAL

Many famous faces have been spotted meeting patients and staff around Great Ormond Street Hospital (GOSH) wards. Here are just a few...



Nicole Scherzinger makes a Christmas wish with Stefan, age 10



British tennis star Kyle Edmund makes a sporty surprise visit to GOSH patient Charlie, age 13, on Panther Ward



Shirley Ballas brings her Strictly sparkle to George, age 9, on Koala Ward

Steve Blackshaw and Helen Glover enjoy lots of festive fun with Joseph and Sophie at GOSH's Christmas Party 2017



Esmee, age 6, celebrates Christmas cheer with Mr Poppy at GOSH's Christmas Party 2017



Nikki's story

Nikki was diagnosed with AVM when she was six years old. Now 13, Nikki has had more than 330 appointments and procedures at GOSH.

Nikki's condition has never held her back. A keen beauty and baking vlogger, she has nearly 300,000 subscribers on YouTube and is a reporter for children's channel CBBC. Earlier this year she even interviewed the Prime Minister for CBBC.

As part of Professor Kinsler's research, the cause of Nikki's AVM was discovered and she started taking a new medication six months ago.

Nikki says: "I was excited to take part in the study as I thought being able to take a drug to control or shrink my AVM would be a lot less painful than having regular operations. As I've only been on the drug for just over six months, it's not enough time to tell, but the first scans have been positive and show no further growth."

To watch Nikki's videos, search for Nikki Lilly on YouTube.



Behind the research

Researchers at Great Ormond Street Hospital (GOSH) and the UCL Great Ormond Street Institute of Child Health (ICH) have discovered that drugs normally used to treat cancer could reduce the facial swellings of thousands of children born with a life-threatening blood vessel condition.

In arteriovenous malformation (AVM), abnormal blood vessels can lead to swellings on the face, serious bleeding and stroke. In the new research, scientists pinpointed what causes these faulty blood vessels and identified an existing drug – currently used to treat skin cancer – that could repair the blood vessels. When it was tested in the lab the drug reduced the size of the swellings and increased blood flow by 75%.

The lead researcher, Professor Veronica Kinsler, Consultant Paediatric Dermatologist at GOSH and ICH, said, "This is a huge leap forward and the most exciting part is that there are already approved drugs available to use."

MEMBERS' ACHIEVEMENTS

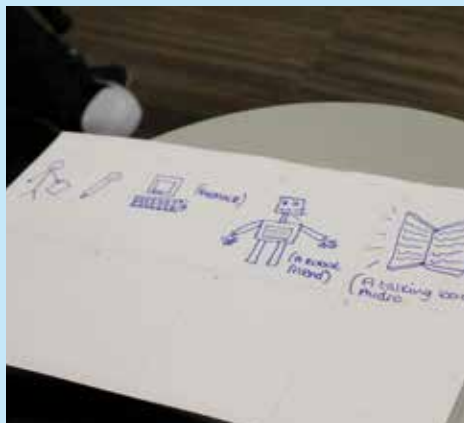
YPF have their say

Our Young People's Forum (YPF) is a group of current and ex-patients, aged 10 to 25, who meet to give their opinions and make suggestions on a range of topics and issues.

They use their own experiences to guide and support the hospital, particularly on projects that will have a direct impact on patients. In the last two years, membership has grown rapidly, and we now have over 70 members.

YPF members have been very busy, as they have been involved in everything from looking at the hospital's brand, and giving feedback about our catering and how we can make the food at GOSH more delicious and healthy, to advising on new building work, from taking part in a Virtual Reality Focus group to help educate medical staff on how patients and families respond to bad news, to giving their opinions of GOSH's new Electronic Patient Record system (EPR).

Our Young People's Forum members come to GOSH from all over the country. Joining the YPF offers the opportunity to meet other people who have been patients at GOSH and is a fantastic way to get involved and have your say. Find out more by emailing us at ypf.member@gosh.nhs.uk.



Salad Bar is now open

The YPF have been campaigning for a Salad Bar and more fruit and vegetables in the hospital canteen, The Lagoon, so they were pleased to see that the Salad Bar has now opened and is proving very popular with patients.

The restaurant has also added a pizza, and chicken bar to the menu so salad has been a great alternative to chips!



YOUNG PEOPLE'S FORUM UPDATE



Big Youth Forum Meet Up

In October, young people from across the country joined members of the Great Ormond Street Hospital (GOSH) Young People's Forum (YPF) for the first ever Big Youth Forum Meet Up. Organised by young people for young people, the event brought together more than 80 people to discuss the big issues surrounding health and hospital care.

Comedian and ex-GOSH patient Alex Brooker kicked off the morning with a Q & A session. Attendees then spent the day sharing their thoughts on the rights of children and young people in healthcare, practical issues around spending time in hospital and the importance of emotional wellbeing. They also had opportunities to take part in workshops on a range of topics, including first aid, CPR training and public speaking skills.



Takeover Challenge

For a week last November, 26 children and young people took over adult jobs in both the hospital and Great Ormond Street Hospital Children's Charity as part of the Children's Commissioner's Takeover Challenge. The annual challenge puts young people into decision-making positions, allowing them to learn about different roles in the workplace and to gain confidence and valuable life skills. It also gives staff and organisations the opportunity to benefit from a fresh perspective.

Hannah's experience with the GOSH Immunology team "Takeover let me see a new side of GOSH. I am a sibling of a patient at GOSH, so I only see my brother on the wards, accompany him to appointments or hear about the tests that he has gone through. This time I experienced it from a work perspective, working with teams trying to help resolve problems. I saw GOSH from the side of giving help to others behind the scenes - it was truly inspirational."



MY STORY

Zoe's story

Zoe was in a skiing accident at the age of 13, and as a result spent her teens in and out of hospital. She's now joined the Council of Governors to use her voice to benefit patients.

If you'd like to tell us your story, please contact the editor at foundation@gosh.nhs.uk

To learn more about the Council of Governors visit gosh.nhs.uk/about-us/foundation-trust/members-council.



"When I was 13 I went on a school trip to France. I had a bad accident while skiing, which led to an ongoing knee injury. Before my accident I was part of a lot of sports teams and the accident had a huge impact on me as I had to stop what I loved.

"I was referred to Great Ormond Street Hospital's (GOSH) Pain Control Service, which helps children and young people with chronic pain. Chronic pain is when someone has continuous or recurrent pain for at least three months or more.

"The Pain Control Service helped me come to terms with my injury and accept there wasn't going to be a 'magic fix'. I had a lot of physio and spoke to a psychologist to help me manage my pain on a day-to-day basis. We also came up with ways I could replace sport – like playing the piano. I paced myself, and am now able to do water sports, and even teach people how to sail and windsurf.

"I was also referred to GOSH's Rheumatology team for more investigations into the source of my pain. GOSH is a much nicer environment than other hospitals that I have been to. All the doctors and nurses were really caring and made sure they kept me updated on what was happening – not just my mum! They also never gave up. There were many times my case was called a 'mystery' but they kept investigating and trying to find ways to help me.

"I was discharged from GOSH in 2017. My transition to adult services wasn't easy, and I'm passionate about improving this for future patients. Going to adult services was made more difficult when I moved out of home to study medical engineering at Cardiff University. Uni is hard because you have to manage things that other students have to do such as cooking, washing and work, but also your own complex medical condition.

"Last year I joined the GOSH Young People's Forum (YPF). The YPF is making a positive impact on patients and the hospital community. Joining gave me the confidence to stand for election, and in January this year I was delighted to be elected to join the Council of Governors. I'll be representing the views of patients.

"The Council of Governors helps make sure the hospital is running well, and we represent the views of patients, parents and staff. As I'm hoping to work as a medical engineer in a hospital setting one day, I hope it will also give me a chance to learn more about how hospitals work.

"As a governor, I'm hoping to improve patient experience for teenagers at GOSH. For me this means improving communication between the different services as well as improving the way that care for both physical and mental health conditions can be integrated. I hope to be the voice for all patients and encourage other young people to have the confidence to speak up!"

KEY DATES FOR YOUR DIARY

All meetings are open to our Foundation Trust members and the public.

Council of Governors meeting

Tuesday 24 July 2018,
3–5.30pm

Trust Board meetings

Wednesday 23 May 2018

Wednesday 25 July 2018

Thursday 27 September

Thursday 8 November

Wednesday 5 December

Please visit gosh.nhs.uk/trustboardmeetings to confirm meeting dates and times.

Annual General Meeting

Tuesday 2 October 2018,
5–7pm

For further information and to book your place on any of the above meetings, please contact us at foundation@gosh.nhs.uk.

Patient summer party

Tuesday 12 June 2018

The Lagoon restaurant

Join us for our summer party, which is sure to be filled with fun, colour and sunshine – whatever the weather!

Patient Eid party

Monday 18 June 2018

The Lagoon restaurant

Come and celebrate Eid with us in The Lagoon with lots of activities, from a henna artist to a funky photobooth, as well as entertainment including a dance act, not to mention a hot middle-eastern buffet and a candy floss and popcorn stand.

Membership on the move!

As a Foundation Trust, it's important that we engage with our local communities and with young people in particular. We like to go out to schools and speak to students about GOSH and ways you can get involved. If you'd like us to visit your school and help us grow the membership voice, please do get in touch! Contact Membership and Governance, at foundation@gosh.nhs.uk.

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