

Spring 2018

# Member Matters



## A Royal Visit

HRH, The Duchess of Cambridge helps open the Mittal Children's Medical Centre.

See page 10



**Meet some of  
our new governors**

See pages 6–7



**GREAT  
ORMOND  
STREET  
HOSPITAL  
CHARITY**

**Bake it  
BETTER**

# **GET YOUR BAKE ON**

**21-27 MAY 2018**

**James**, age four, was treated for neuroblastoma, a rare childhood cancer.

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the lives of seriously ill children.**

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## Introduction

### Welcome to *Member Matters*, the magazine for Foundation Trust members

I'm extremely passionate about Great Ormond Street Hospital (GOSH), its history and its future, so I feel privileged to play my part to support the organisation in going from strength to strength. GOSH has huge potential, not least because of the way our work here inspires others and resonates globally. Even during the short time I've been in post I've been really struck by the commitment demonstrated by our passionate staff, our membership, the public, donors and even members of the Royal Family.

Like all Trust hospitals we face challenges in the current environment and my role as chairman is to support and hold our executive team to account, work with our Council of Governors and develop and maintain relationships with key members of the political landscape in which we operate. Having witnessed

first-hand the devastating impact of paediatric rare disease, I understand all too well the importance of advancing the diagnosis and treatment of these conditions and for me, overseeing the development of the care, education and research potential of this special place is very important.

I'd like to take this opportunity to welcome our newly elected Council of Governors. Thank you for putting yourself forward. You will play a crucial role in shaping our diverse agenda and helping to give our patients a voice.

I hope you enjoy this edition of *Member Matters* and reading about some of the fantastic things that have been happening lately at GOSH.

**Sir Michael Rake**  
Chairman

# FOUNDATION TRUST NEWS

## ***Fulfilling Our Potential*** – Our new strategy

In October, Great Ormond Street Hospital (GOSH) held its inaugural Open House Week, where we launched our refreshed strategy, *Fulfilling Our Potential*, and encouraged staff to think about how we fulfil the potential of every child and family that comes to the hospital. The new strategy is based on what patients and families, our staff and membership felt we should change. It was an interactive week of workshops, events and conversations – ensuring that *Fulfilling Our Potential* is not just a document, but a philosophy we live and breathe in the hospital every day.



## **An Epic Electronic Patient Record system**

The Electronic Patient Record (EPR) system will go live in spring 2019. The programme is currently in the clinical system design phase, the process in which all of the clinical content required for the EPR to go live is developed. A working group of nursing and medical experts have started to input into initial designs to ensure the system supports a broad range of clinicians, and patient and parent representatives are working on the patient portal element of the EPR. This is a really exciting time for Great Ormond Street Hospital (GOSH), as the EPR Programme continues to enable the biggest clinical transformation the organisation has ever seen.

**FUTURE PROOF**  
ELECTRONIC  
PATIENT RECORDS



## Our new Medical Director and Chief Nurse



GOSH has recently welcomed two new senior members of staff. The Trust's new **Medical Director, Matthew Shaw**, joined us in March. Matthew is a highly experienced clinical leader. He is a practicing orthopaedic surgeon and has been Clinical Director of the spinal unit at the Royal National Orthopaedic Hospital for the last seven years.



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 a number of different teaching hospitals, delivering corporate direction to the quality, safety and experience agenda.



## GOSH construction reaches new heights

In December, GOSH marked a crucial milestone in the construction of the Zayed Centre for Research into Rare Disease in Children, as a topping out ceremony was held to mark the moment when the building reached its highest point.

The Zayed Centre for Research, which is a partnership between GOSH, UCL Great Ormond Street Institute of Child Health and Great Ormond Street Hospital Children's Charity, is due for completion at the end of 2018. It will be the first purpose-built centre of its kind in the world and will support translational research that focuses on taking discoveries from the lab bench to patients' bedsides. Work has now begun on the interior of the centre, which will house state-of-the-art laboratories and highly specialised facilities for the development of new gene and stem cell therapies, genomics and regenerative medicine, as well as an outpatient clinic.

# GET INVOLVED



## Introducing our new Council of Governors

In January 2018, our membership, elected 27 peers to join the Council of Governors (previously known as the Members' Council). These individuals were elected to represent the views of patients, parents and carers, members of the public, GOSH staff and local stakeholders.

A big part of these individuals' role is to hold the Non-Executive Directors to account for the performance of the Trust Board, to help tackle issues that are important to patients and families and to ensure the interests of members and the public are represented.

Here, we caught up with three of our new Governors, representing public, patient and staff constituencies.

### **Zoe Bacon, Patient Governor**

"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 the hospital.

"It has been a really good experience. So far we have only had introduction sessions where I have met the other governors and learnt about some of the things that they want to achieve as well as what opportunities we will have in the role. I am really excited for the first meeting at the end of this month!"

## Our new Council of Governors



### **Simon Yu Tan, Public Governor**

"Having worked in early years development at the Department for Education and served several school boards, I have a deep understanding of the wellbeing of children. I joined the Council of Governors because I'm extremely passionate about children's health and wellbeing. My experience as a counsellor means I have a natural ability to engage with patients and understand people's opinions.

"I have sat on many committees in the NHS and worked extremely hard to ensure patients' needs are fully met. Both my work and personal experience will enhance the Council of Governors and I'll be looking to bring lots of passion, energy and determination to represent the complex needs of patients and ensure children can benefit from the best possible care in this Trust."



### **Paul Gough, GOSH Service Manager, Staff Governor**

"I work as a Service Manager in the Charles West Division, which means I have responsibility for the day-to-day management and planning for a group of departments. My departments are Genetics and Haemophilia. I have worked at GOSH for six years and wanted to get more involved in the governance of the organisation, so nominated to join the Council of Governors.

"What we do at GOSH is really important – it can be easy to lose that in the day-to-day, but we make a big difference to a lot of people's lives. As a staff governor, I want to do my part in trying to ensure that the decisions we make at a strategic level are properly scrutinised, so that we can do as much good as possible with the resources available."

# PIONEERING RESEARCH

## Cancer drugs could transform the lives of children with serious facial disfigurements

Drugs normally used to treat cancer could reduce the facial disfigurements of thousands of children born with life-threatening blood vessel defects, according to pioneering research by Great Ormond Street Hospital (GOSH) and the UCL Great Ormond Street Institute of Child Health (ICH).

In arteriovenous malformation (AVM), abnormal blood vessels lead to painful facial disfigurements, life-threatening bleeding and complications like stroke. Until now, effective treatment options have been severely limited.

Following DNA testing, researchers have been able to pinpoint the group of genes responsible for causing blood vessel defects and, for the first time, have identified drugs that could treat the condition.

The groundbreaking study, which involved testing the DNA of over 150 children with blood vessel defects, revealed that several patients had faults in the group of genes responsible for the correct formation of blood vessels. The researchers found



that there is an existing drug that can repair these blood vessel defects and is already widely used to treat skin cancer. When it was tested in the lab as a potential new treatment for AVM, the drug reduced the size of the blood vessel swellings and increased blood flow by 75%.

Lead researcher Professor Veronica Kinsler, Consultant Paediatric Dermatologist at GOSH and Principal Investigator at ICH says: "This is a potentially life-saving discovery. Understanding that these birthmarks are caused by faulty genes is a huge leap forward, and the most exciting part is that there are already approved drugs available to use as part of clinical trials. We've seen some very encouraging results in the lab and are hopeful that clinical trials in children will help those suffering with AVM."



## Nikki's story

Nikki was diagnosed with AVM when she was six years old. Now 13, Nikki has had more than 330 appointments and undergone dozens of 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. Her parents George and Tanya set up The Butterfly AVM Charity to support families affected by the condition. The charity has so far raised more than £250,000 and provided a grant to help fund this study.

As part of Professor Kinsler's research, Nikki was found to have a fault in several important blood vessel forming genes. In the six months since Nikki began taking medication, there has been no growth in her AVM. However, it's too early to say whether the treatment has been effective.

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."



Earlier this year Nikki interviewed the Prime Minister for CBBC.



# GOSH

IN THE  
21st CENTURY



HRH enjoys craft time with Renae, age 10.

## Premier Inn Clinical Building – the official opening

HRH, The Duchess of Cambridge visited patients, families and 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. Her visit is a fantastic endorsement of the building's importance and the event marks a significant milestone in the history of the hospital.



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



The Duchess of Cambridge with a team of GOSH nurses.

### **The completion of the Mittal Children's Medical Centre has taken eight years and is transforming our ability to help more seriously ill children fulfil their potential.**

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. The two interlinking buildings are full of features – large and small – designed to make the hospital an easier place to be for young people and their families.

#### **A royal visit**

After walking through the hospital, Her Royal Highness visited some of the wards in the Premier Inn Clinical Building (PICB), and spent time with cardiac patients, some of whom have spent months in hospital on pioneering heart devices that help them to stay alive while they wait for a heart transplant. The Duchess also met children with rare and complex medical conditions who were taking part in an art activity.

## **How do you prepare a clinical building?**

Preparing a new clinical building for the arrival of patients, their families and medical teams is no easy task. Once construction is finished, the building is handed over to an expert team, tasked with bringing the spaces to life and ensuring they're ready to welcome patients and families. In charge of that team is Sara Spearpoint, Head of Operational Commissioning and Space Management.

"Every area of the clinical building has precise requirements – everything from the layout of ward beds, to the air circulation in the isolation rooms and operating theatres. My team's role is to manage all this vital behind-the-scenes work and equip the building, making sure everything will work, that it's fit for purpose and, most importantly, safe for patients."

## **GOSH's first clinical building sleeperover**

First-hand insight into the experience of children and families who stay at GOSH has the potential to change the way we develop and equip buildings in the future. That's why a team of 10 staff members from Sara's team, the hospital, and GOSH Charity, volunteered to stay overnight on Leopard Ward, before patients and families moved in. The sleeperover 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 sleeperover observations – 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](https://gosh.org/experience-great-ormond-street-hospital-virtual-reality).**

# MEMBERS' ACHIEVEMENTS

## 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

"The Takeover Challenge 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."



Hannah worked with the Immunology team as part of the Takeover Challenge.



## 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 for the first ever Big Youth Forum Meet Up. Organised by young people for young people, the event brought together more than 80 attendees 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. Participants 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.

## Growing the Young People's Forum

Our Young People's Forum (YPF) is a group of current and ex-patients, aged 10 to 25, who meet to voice 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 – anything from the new Electronic Patient Record system to catering. In the last two years, membership has grown rapidly, and we now have over 70 members. But we're always looking to recruit more!

## Encourage your young person to get involved!

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](mailto:ypf.member@gosh.nhs.uk).



# COUNCIL ACHIEVEMENTS

## Saying farewell to our councillors

Our new Council of Governors were elected in January (meet some of them on page 6), so we'd like to say a fond farewell to the 24 wonderful councillors who have represented GOSH patients, parents and carers, staff, the public and local stakeholders over the past election term. Below, a few share what the experience has meant to them.



**Gillian Smith,**  
councillor representing  
public members in  
south London and  
surrounding area

"It's been a privilege to serve the public constituency of South London, Surrey, Kent and Sussex. I have enjoyed meeting many members at events, who have shared their experiences and views of what makes GOSH great and how it could be even better. I have represented your views and anonymised stories in meetings. You may not personally know the impact you make, but it makes a real difference to have your engagement. Thank you."



**Muhammad Miah,**  
appointed councillor  
representing The  
Children's Hospital  
School at GOSH  
and UCH

"Over the six years it's been a unique experience, with GOSH going through big changes like redevelopment. We were able to provide our contribution on many things such as the canteen food, way finding and even potential designs for the frontage building. I leave with a sure outlook that everyone involved thoroughly cares about GOSH wanting the best for the hospital and everyone with in it."



**Carley Bowman,**  
councillor representing  
parents and carers  
from outside London

"Listening to what parents and patients have to say and using their stories to help change GOSH for the better is the thing I'm most proud of. I've learned a lot too – particularly how challenging it is to run a hospital like GOSH and how dedicated and driven the staff are. I've enjoyed the insight being a councillor has given me and I will support the hospital in any way I can in the future."



**George Howell,**  
councillor representing  
patients from outside  
London

"A highlight for me was helping to create, and subsequently chair the Young People's Forum. Over the last few years, it has been great to see it grow and become a powerful voice for young people at GOSH. Through the Members' Council I was extremely fortunate to meet the surgeon who saved my life – this moment was incredibly special."



# BEHIND THE SCENES



## Behind the scenes with GOSH Arts

GOSH Arts is the arts programme at Great Ormond Street Hospital (GOSH). Our participatory programme and art commissions inspire creativity, create welcoming environments, and offer meaningful and exciting cultural opportunities across a variety of art forms for patients, families and staff.

Last year alone, we worked with almost 60 artists and organisations ranging from the Wigmore Hall to the V&A, and from Turner Prize winners to cutting-edge digital artists.

Art in healthcare is increasingly recognised as contributing to the health and wellbeing of patients, families and staff. Almost every day, GOSH Arts runs participatory sessions for patients and families which cross all art forms, including theatre, visual arts, dance and music.

**We caught up with some of the people who work behind the scenes at GOSH Arts to find out what makes them tick.**

### Head of Arts Susie Hall on what she likes about working at GOSH:

"I've always believed that the arts for children and families can, and should be, of the highest quality, so being in an institution that also prioritises the needs of the child is hugely important to me. I am constantly inspired by the heritage and values of the hospital. How families and staff feel about this institution, how it develops and what it stands for, are all such rich sources of ideas for the arts programme.

"It's also really exciting to have such interesting and varied colleagues. 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."



## Arts Manager Caroline Moore on a normal day at GOSH Arts:

"There isn't really a 'normal' day at GOSH Arts! For instance, I recently visited the Southbank Centre to see if a show for ages 7+ would be appropriate for families in the hospital. Halfway through the performance, I found myself holding a stranger's hand and chanting 'pollination for the nation' with 40 other members of the audience. The next day, I was in an arts group meeting for a new clinical building, listening to ideas from three world-class artists for a potential commission. And after that, I went to a rehearsal with 30 other members of the GOSH Staff and Parent Choir."

"I love that my role is so diverse and creative. The constantly changing and evolving environment means we have to be really flexible and very responsive to the needs of patients and staff, so no day is ever the same!"



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

"I've always been passionate about the positive impact art and artists can have on our lives, and I believe that everyone should have the chance to engage with art in a meaningful way. Previously, I worked for the brilliant charity *Paintings in Hospitals*, managing loans of artworks in healthcare organisations across the UK. My role at GOSH involves working closely with artists to develop new artworks for the hospital, ensuring they are integrated into our new buildings and that we involve patients, families and staff in the design process."

"My favourite projects so far have been working with Studio Weave to develop the Lullaby Factory, adding a unique xylophone bench to the Harmony Garden, and helping staff to select over 50 original artworks to display in parent and staff rooms throughout the Premier Inn Clinical Building, making spaces feel more comfortable and homely."

The GOSH Arts team is Susie Hall and Vivienne Reiss, Heads of Arts, and Helena Copsey and Caroline Moore, Arts Managers.

To find out more about GOSH Arts and how to get involved, visit [gosh.nhs.uk/parents-and-visitors/go-create](https://gosh.nhs.uk/parents-and-visitors/go-create) or email [GOSHArts@gosh.nhs.uk](mailto:GOSHArts@gosh.nhs.uk).

Follow us on Twitter and Instagram @GOSH\_Arts.



# 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](http://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](mailto: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.

## F1 British Grand Prix

**Saturday 7 and  
Sunday 8 July 2018**

This year GOSH is the official charity for the 2018 Formula 1 British Grand Prix. We are looking for volunteers to represent Great Ormond Street Hospital Charity at Silverstone on Saturday 7 or Sunday 8 July 2018, by bucket collecting around the circuit. To apply to volunteer, or for more information contact [f1challenge@gosh.org](mailto:f1challenge@gosh.org).

## 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 child's school and help us grow the membership voice, please do get in touch! Contact Membership and Governance at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk).

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To help save the hospital money, you can subscribe to receive *Member Matters* by email. Simply register your contact details at [gosh.nhs.uk/membermatters](http://gosh.nhs.uk/membermatters).

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or on Facebook  
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