

Spring 2016

# Member Matters



## 3D printing

**Making a difficult procedure easier to carry out in children**



Behind the scenes with the Portering team

See page six



# 5k family fun run

Sunday 15 May 2016 | Queen Elizabeth Olympic Park

[raceforthekids.co.uk](http://raceforthekids.co.uk)



**SIGN UP  
TODAY**

# Contents

	<b>4</b> Foundation Trust news		<b>6</b> Behind the scenes with hospital Porter Hayden
<b>8</b> 3D printing makes difficult procedure easier		<b>10</b> 100,000 Genomes Project – first diagnoses	
<b>13</b> Members' Council in the community			
<b>14</b> How you can get involved			
			<b>16</b> Key dates for your diary

## Introduction

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



I'm Simon Hawtrey-Woore and I am a Public Councillor on the Members' Council, representing members from North London. As a parent of a 10-year-old with disabilities who comes to Great Ormond Street Hospital (GOSH), I already had a connection to the hospital, and I was inspired to step up my involvement by becoming a councillor and helping to improve patient and parent engagement.

Although we want our membership community to grow, it's important that we also engage with you effectively. Please do drop by and see us at any of our 'meet a councillor' sessions. These run from 12 to 1pm in The Lagoon restaurant before every

Members' Council meeting. You can see the dates at the back of this newsletter. We're here to listen to your views and act as a link between you and the Trust.

Read on to hear about exciting new developments for GOSH – such as 3D printing – and go behind the scenes with one of the hospital's porters. You will also see lots of ways to get involved in the hospital.

I would like to thank you for continuing to support GOSH and hope you enjoy reading this edition of *Member Matters*.



## Morgan Stanley Garden to feature at RHS Chelsea Flower Show

“One of the most significant and poignant gardens of my career” is how plantsman and designer Chris Beardshaw has described the Morgan Stanley Garden for Great Ormond Street Hospital (GOSH), which will feature at the RHS Chelsea Flower Show on 24–28 May 2016.

The enclosed, courtyard-style garden has been designed by Chris to work as a show garden and as a permanent garden scheme. It will provide a private and reflective space for parents and families of the children undergoing care at GOSH and will appear at RHS Chelsea Flower Show prior to being completed at the hospital in summer 2016.

An artist's impression of the Morgan Stanley Garden

## Give to GOSH appeal

Over the festive period and into the New Year, Great Ormond Street Hospital Children's Charity was the partner for *The Independent*, *Evening Standard*, *i* and London Live's Give to GOSH appeal.

Ending on 14 February 2016 – the hospital's birthday – funds raised by the appeal will help support research programmes for children with rare diseases, the creation of a new unit for children with heart failure, the Louis Dundas Centre for Children's Palliative Care, and patient and family support programmes at the hospital.

Visit [gosh.org/givetogoshappeal](http://gosh.org/givetogoshappeal) to see the coverage and exciting video content.



## Care Quality Commission report rates GOSH as 'good'

**In April and May 2015, the Trust was visited by the Care Quality Commission (CQC). The CQC are the independent healthcare regulator for England. They look at hospital services to make sure they are meeting standards of quality and safety**

We are very pleased to have been rated as 'good' overall, with the report highlighting many areas of outstanding practice.

Full reports for the inspection have been published on the CQC website.

*"We are particularly pleased that the inspection team identified the 'caring' element of our services as 'outstanding' across the board."*

Peter Steer,  
GOSH Chief Executive

*"The children and young people we met were extremely positive about the treatment they received."*

Professor Sir Mike Richards,  
CQC Chief Inspector of Hospitals

While the report is good, there are always areas we need to improve. We know that our record keeping and administration processes have not been as good as our clinical care. Work is now well underway to ensure our processes for managing data correctly are as robust as possible going forward. The CQC's Chief Inspector of Hospitals said: "Although we found many examples of compassionate care, the Trust has recently identified a large backlog of patients waiting too long for surgery. I know that the Trust has introduced initiatives to tackle this. I am confident that the Trust will give this the priority it deserves."

# BEHIND THE SCENES



Behind the scenes with hospital Porter **Hayden Peters**

**Hayden Peters** has been working at Great Ormond Street Hospital (GOSH) since February 2015 after being in the construction industry

## Daily duties

"The role of a porter is really diverse. One day I could be doing lots of patient transfers. Another day I could be running around transporting beds and cots. It keeps me on my toes.

"We have a number of different tasks: we collect blood products and deliver them to wards, we transfer patients across the hospital, we ensure the corridors are clean and pristine, and we make sure we're on top of health and safety. We're like the veins of the hospital – we deliver everything and keep GOSH moving and running.

"The nurses in particular are always happy with us – if they request something, we're usually able to help within 10 minutes or so. I'm a general porter, but there are also theatre porters and kitchen porters to look after those areas, so we cover all bases.

"If it's really busy, you hardly get a moment to sit down. You finish a job and the next job will come in straight after, so the day flies by!"

## Rewarding work

"I like my role because I get to help everybody and everyone's a team player. I've met some great people. They'll always point me in the right direction for a job and they've made me become a better porter for it.

"To be part of the team that cares for the children here is something I am very proud of. I never had this same pride working on building sites. The porters are a small but very close-knit team. It is genuinely a pleasure to work here.

"The best thing is keeping everyone smiling, busting jokes and making the children laugh. Some of the parents are really kind so you have a chat with them and a giggle in the lift. It brightens my day and makes it go quickly.

"When I'm happy and I'm having a really good day at work, I tend to sing and dance along the corridors!"

## Did you know?

There are 28 porters at the hospital, operating 24 hours a day, 365 days a year.

## Talking to Mark Davis, Head of Portering

"Every single patient that is treated at GOSH has some input from my teams. When a patient arrives they lie in a bed delivered by us. The forms completed by the medical staff were delivered by us using pens transported

by us. The food families and staff eat was delivered by us in its raw state and then redelivered by us once prepared. The oxygen that patients breathe is supplied via masks that we delivered. All of this is usually done

without any patient or family ever seeing us. The things we are best known for, such as moving patients or collecting specimens, make up only a tiny percentage of what we do."

# GOSH in the 21st century

Katie with her mum and dad

## 3D printing makes difficult procedure easier to carry out in children

An exact replica model of a trachea (windpipe), created using a 3D printer, has been used at Great Ormond Street Hospital (GOSH) to trial a complex procedure with incredible accuracy prior to a patient going under anaesthetic.

Using the model, teams at the hospital can select the equipment that is best matched to individual patients in both size and shape before they undergo surgery, which reduces the time patients spend in the operating room.

3D printing has shown a lot of potential in medicine. It can create models that help doctors to explain to patients what is happening inside them and how surgical procedures can treat medical problems. But a team of clinicians and researchers at GOSH have shown that it could also make complex surgical procedures even safer for children.

### Personalised models

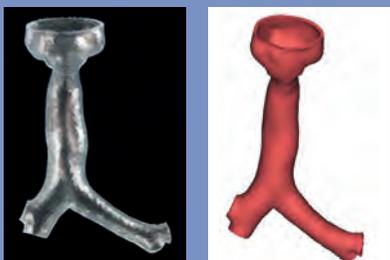
Following successful use in a number of cardiac conditions, the team demonstrated that a simple CT scan of a patient's chest can be used to create anatomically accurate 3D tracheal models. Consequently, surgeons and anaesthetists are able to trial procedures before operating on a patient. The models are completely personalised to patients and can be created in a matter of hours.

The technique was trialled in six-year-old Katie, a patient at GOSH with a lung condition that requires repeat 'lung-washing' treatments in order to

clear dangerous build-ups of material. The procedure involves ventilating one lung while the other is washed out. Although this process is relatively straightforward to perform in adults, the tubes used to ventilate and wash out the lungs are large and sometimes difficult to use in children. Therefore, multiple tubes have to be positioned with great precision and as quickly as possible in order for it to be safe in children whose lung capacity is severely reduced.

### Less risk

After producing a CT scan of Katie's lungs, the team used a 3D printer to create a 'made to measure' tube that was an exact replica of her trachea in terms of its shape and size. This allowed the anaesthetic team to match up the most appropriately sized tubes and practice their insertion into the airways before she had surgery. As a result, the actual surgical procedure was quicker, more efficient, and with less risks for Katie.



3D printer and computer models



### Tailor-made

"Each time a child comes in to have their procedure, they will have grown and so require different equipment to be used for their treatment. A model that is tailor-made to the child each time they have treatment means that the right sized tubes can be identified prior to surgery, and a child can potentially be under anaesthetic for a shorter period of time."

Colin Wallis  
GOSH Respiratory Consultant Physician



# PIONEERING RESEARCH

The first children to receive a genetic diagnosis through the 100,000 Genomes Project have been given their results at Great Ormond Street Hospital (GOSH)

## First diagnosis in groundbreaking DNA project

The genetic results come from the first wave of families who were recruited as part of the pilot phase of the project. These patients came from across the UK, some travelling long distances in order to take part in the rare genetic disease aspect of the pilot, which was led by GOSH.

As well as removing a large amount of uncertainty for the families, the results stand to have a major impact on many areas of their lives, including future treatment options, social support and family planning.

The main 100,000 Genomes Project, launched in December 2014, set out to analyse the DNA of 100,000 NHS patients and their families using a process called whole genome sequencing. The findings are helping researchers and clinicians better understand, and ultimately treat, rare and inherited diseases and common cancers. The

programme is now well established across the country.

GOSH is part of the North Thames Genomic Medical Centre (NTGMC), which is recruiting more than 100 families a month for the project. The NTGMC is co-ordinated by GOSH in collaboration with partners University College London Hospital NHS Foundation Trust, the Royal Free London NHS Foundation Trust, Barts Health NHS Trust, Moorfields Eye Hospital NHS Foundation Trust and London North West Healthcare.

Professor Lyn Chitty, a clinician at GOSH and clinical lead for the NTGMC, says: "It's really exciting to see the results coming through and the difference this can make for families. It increases confidence in the project and shows that the application of genomics can live up to the promise of changing the way we diagnose and treat patients in the future."



## Georgia's story

For the first few years of her life, doctors couldn't work out exactly what was wrong with Georgia. She had problems with her eyes, kidneys and speech. After lots of tests, they explained that Georgia's problems were likely to be in her genes, but that they didn't know what her genetic condition was.

Mum Amanda says: "It's very hard living with an undiagnosed child. Basic hopes for health, growth and development are all uncertain and we don't even know if she will have a normal life expectancy."

When the family heard about the 100,000 Genomes

Project, which takes the most in-depth look at a person's DNA to date, they were keen to sign up. They came to GOSH, and Georgia, her mum and her dad all gave samples of their blood to be scanned for information.

### Phone call

It was almost a year before they received a phone call from GOSH geneticist Maria Bitner-Glindzic, who explained that they had found a gene in Georgia that was likely to be the cause of her problems.

The diagnosis is going to change many things for the family. Her mum and dad

now know that they didn't pass the gene problem to Georgia and so can have more children knowing it's unlikely that they would have the same condition. They also hope to connect with the other families that have children with the same gene change.

Georgia is now four and they are hoping that over time they will find out more about her condition and her prognosis. Amanda says: "Medicine is not yet at the stage to offer treatment for Georgia's condition, but we have come so far in her lifetime already – who knows what the future holds?"

# MEMBERS' COUNCIL ACHIEVEMENTS

Our Members' Council bring a wealth of professional and life experience to their roles. Committed to adding real value to decision-making, councillors are engaged in a wide range of activities. These vary from sitting on committees and focus groups to attending training and development sessions outside the Trust

The focus for all councillor engagement is to ensure that the voices of patients and parents and carers remain at the heart of the organisation. This enables representatives to fulfil their duties in holding the Trust to account on behalf of you, their members.

We look at how two of our councillors have been participating in engagement activities and how they have kept up to date with key issues.

## Mariam Ali



The Trust is halfway through an ambitious four-phase redevelopment programme to rebuild two-thirds of the hospital site over a 20-year period. Our link councillor for this project is Mariam Ali (Parent and Carers from London Councillor). Mariam contributed at workshops on design aspiration and reviewed the design brief structure. She relayed to the team how the buildings and interior impact on the experience of patients and their families. Mariam experienced way-finding herself through a tour of another hospital and arranged a trip for redevelopment teams to her place of work to offer them another perspective on design and construction.

Contact Simon or Mariam at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk)

Read more about our redevelopment plans online at [gosh.nhs.uk/about-us/redevelopment](http://gosh.nhs.uk/about-us/redevelopment)

Members' Council representatives sit on the Trust's Patient and Family Engagement and Experience Committee. Listening to parents' feedback on facilities and working in collaboration with the Redevelopment Team, the committee provided recommendations for the replacement of 48 overnight stay beds for parents in the Morgan Stanley Clinical Building.

## Simon Hawtrey-Woore



In attendance at a seminar for business governors, Simon Hawtrey-Woore (Public Councillor for North London and surrounding areas) looked at the importance of foundation trusts having high-quality data for delivering their strategies and managing their operational and financial risks. Simon raised queries about the key challenges facing trusts. He would also like to connect more with other trust governors to share best practice around data quality and governance and the impact this has on trust services.

# MEMBERS' COUNCIL IN THE COMMUNITY

In February 2016, Great Ormond Street Hospital (GOSH) celebrated its fourth year as a foundation trust. Membership has steadily grown to more than 9,000 people – a collective voice of patients, their parents and carers, staff and members of the public

Engagement with the hospital and local communities is just as important as recruitment. Our aim is to continue increasing opportunities for your representatives on the Members' Council to reach out and enable members to share their views.

GOSH is situated in Bloomsbury, which is home to a diverse ethnic and multicultural community. In October 2015, we held our first

membership and engagement stall at the Bloomsbury Festival Family Day. It was a fantastic opportunity to meet and recruit a wide variety of members and raise awareness about GOSH services alongside the work of Great Ormond Street Hospital Children's Charity. Current and former patients spoke to the Members' Council about their experiences, and they met students and local residents.



*"Signposting people to our volunteer services and speaking to young people about careers in the NHS was a highlight for me. We are looking forward to connecting more with our members by being part of the 2016 Bloomsbury Festival."*

Deirdre Leyden, Membership and Governance Manager

## London Santa Dash

On Sunday 6 December, membership was on the move again, joining more than 1,700 fun runners for the inaugural Great Ormond Street Hospital Children's Charity London Santa Dash on Clapham Common.

Representatives from the Members' Council held a stall and engaged with the sea of Santas, many of whom were patients and parents. Foundation Trust members and councillors will team up once more with the charity on Sunday 15 May for the RBC Race for the Kids. This year, for the first time, the event will be in the Queen Elizabeth Olympic Park – come and say hello and meet your Members' Council!



# Get involved

As a hospital for children, it is important that children and young people are able to participate in the planning and development of our services. Patient and public involvement at Great Ormond Street Hospital (GOSH) is an ongoing and two-way dialogue



## Patient-Led Assessments of the Care Environment (PLACE) inspectors

Patient-Led Assessments of the Care Environment (PLACE) inspections occur once a year throughout every hospital in England.

At GOSH the assessments see patients, parents or carers come to the hospital as part of teams to assess how the environment supports the privacy and dignity of our patients, food, cleanliness and general building

maintenance. It focuses entirely on the care environment and does not cover clinical care provision or how well staff are doing their job.

We are looking to recruit assessors for the 2016 PLACE inspections. Are you a patient, parent or carer who might be interested in helping us? To find out more and get involved, please email [tamryn.rickson@gosh.nhs.uk](mailto:tamryn.rickson@gosh.nhs.uk)

## Patient Experience team volunteers

The Trust has a Patient Experience team who co-ordinate various surveys and focus groups taking place across the Trust.

Our dedicated group of volunteers helps us by being out and about in the hospital, engaging with our patients and their families to ask for their feedback. They offer support to anyone who may need help in completing surveys. They are an asset to our team.

As we are increasing engagement with our families, we would like to recruit more volunteers.

If you are already a GOSH volunteer and would like to join this project, please email [emma.james@gosh.nhs.uk](mailto:emma.james@gosh.nhs.uk)

If you would like to register to become a volunteer to help out on this project, please visit [gosh.nhs.uk/volunteer](http://gosh.nhs.uk/volunteer)

## RBC Race for the Kids

Our 5k family fun run is back and bigger than ever! The event is taking place on Sunday 15 May in a brand-new location – London's iconic Queen Elizabeth Olympic Park. Join thousands of people as they follow in the footsteps of sporting legends from the London 2012 Olympic and Paralympic games and raise vital funds for GOSH. Find out more at [raceforthekids.co.uk](http://raceforthekids.co.uk)



Main photo: © James Murray

# Key dates for your diary

## Members' Council and Trust Board meetings

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

For further information and to book your place, please contact us at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk)

## Members' Council meetings 2016

All meetings run 4 – 6.30pm

Wednesday 27 April  
Wednesday 29 June  
Wednesday 28 Sep

## Trust Board meetings 2016

Please visit [gosh.nhs.uk/trustboardmeetings](http://gosh.nhs.uk/trustboardmeetings) for further details on times for the Trust Board meetings.

Members are welcome to attend the public session.

Friday 1 April  
Friday 20 May  
Wednesday 20 July  
Wednesday 28 Sep

## Annual General Meeting and Annual Members' Meeting

Thursday 15 Sep 2016

Lecture Theatre  
Weston House  
63-67 Great Ormond Street  
London WC1N 3HZ

5.30 – 7pm

For further information, please contact us at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk)



## RBC Race for the Kids

Sunday 15 May 2016

Our 5k family fun run is back and bigger than ever! The event is taking place in a brand-new location – London's iconic Queen Elizabeth Olympic Park.

RBC Race for the Kids is open to everyone, and you can make your way around the course however you like. Visit [raceforthekids.co.uk](http://raceforthekids.co.uk) to sign up.

[foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk) [gosh.nhs.uk/foundation](http://gosh.nhs.uk/foundation)

Follow us on Twitter [@GreatOrmondSt](https://twitter.com/GreatOrmondSt), Facebook [facebook.com/GreatOrmondSt](https://facebook.com/GreatOrmondSt) and Instagram [greatormondst](https://instagram.com/greatormondst)

The Trust has recently moved to a specialist database provider to store and maintain its membership records. We want to continue to keep you up to date with Trust news and events and are always looking at ways to reduce printing, so if you would like to receive this magazine electronically or can update us with new contact details, please do so by emailing [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk)