

Autumn 2017

Member Matters



A movement for dystonia

Pioneering research has
life changing impact.
Read Katie's story on page 8



GOSH needs you!

Get involved and nominate
yourself for the 2018 Members'
Council elections.

Page 6



**Run together this Christmas
and help transform young lives.**

SUNDAY 3 DECEMBER, Clapham Common
gosh.org/londonsantadash



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Introduction

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



Since I joined Great Ormond Street Hospital (GOSH) in April 2016, I've seen a lot of work happening across the Trust that is preparing us for a future where we can provide even better care for the children we treat for many years to come.

One of the biggest infrastructure investments currently underway is the brand new wing of the Mittal Children's Medical Centre, the Premier Inn Clinical Building, which will offer state-of-the-art facilities across seven new wards. Our first clinical services are getting ready to start moving into their new home in November and I am sure the next edition of Member Matters will give you a glimpse inside the new wing at GOSH.

Another major investment at GOSH is the development of our new Electronic

Patient Record System (EPR) and Research and Innovation Platform. This programme will significantly transform how we deliver care and meet the increasing needs and expectations of our patients and of our staff.

Due to launch in 2019, the EPR is also being designed to improve the experience of patients and their families through a patient portal where they can access their own clinical details.

I hope you enjoy this edition of Member Matters and reading about what's been happening lately at GOSH.

Loretta Seamer
Chief Finance Officer

Cannabis-derived drug reduces epilepsy seizures

Research at Great Ormond Street Hospital (GOSH) has shown that cannabidiol – derived from cannabis but with the psychoactive elements removed – reduces seizures in children with a form of drug-resistant epilepsy, known as Dravet syndrome.

In the trial, involving 120 children, the average number of seizures was reduced by 40 per cent. Professor Helen Cross, Consultant in Paediatric Neurology at GOSH, says: "This drug could make a considerable difference to children who are living with Dravet syndrome and currently enduring debilitating seizures."



Professor Helen Cross led research that could reduce seizures in thousands of people living with epilepsy.

100,000 genomes

GOSH has exceeded targets by recruiting our thousandth family into the 100,000 Genomes Project.

This pioneering research aims to sequence 100,000 genomes from around 70,000 people to help doctors better understand, and ultimately treat, rare and inherited diseases and various cancers.

GOSH patient Freddie, aged nine, got involved in the project after being diagnosed with Cryopyrin-Associated Periodic Syndromes – an auto-inflammatory condition. His mum Angela says: "Taking part in the project has really helped Freddie. He feels like he is doing something to help others."



GOSH patient Freddie, aged nine, participated in the 100,000 Genomes Project



Meet the new Chairman

We are delighted to welcome Sir Michael Rake as our new Trust Chairman. Starting in November, he brings to GOSH a wealth of successful leadership experience in business and service industries such as KPMG, EasyJet, BT and the Confederation of British Industry (CBI). He is also a Senior Business Adviser at the Chamber of Commerce and Chatham House, and Vice President of the Royal National Institute of Blind People (RNIB).

"I am honoured to be given this opportunity to serve such a well-loved organisation which makes a dramatic difference to the lives of children with rare diseases in the UK and elsewhere. It will be a great privilege to work with leading clinicians and researchers who deliver world-class care and pioneering research in collaboration with key partners," says Sir Michael Rake.

One day at GOSH

A fascinating short film that shows 24 hours at GOSH has been launched as part of a campaign called One Day at GOSH.

The campaign, launched in March, highlights the life-saving activities that are carried out at the hospital every single day, and explains the need for charitable support.

In just 48 hours, it reached more than one million people on Facebook!

Watch the video at gosh.org/one-day-gosh.

Digital connections

Earlier this year we reached a key milestone in our Electronic Patient Record (EPR) Programme as interim Chairman, Mary McLeod, signed contracts with providers Epic and Aridhia. The signing of the contract marks the beginning of an exciting partnership with both providers. EPR Programme Parent Representative and Foundation Trust member Fleur Hambury told us how excited she was to "see the hospital moving forward with technology", and what a difference it would make to have everything in one place, including online appointment booking. The EPR team is building a focus group of patients, parents and families.

To get involved, email EPR@gosh.nhs.uk.

FUTURE PROOF

ELECTRONIC
PATIENT RECORDS



MEMBERS' COUNCIL ELECTIONS

Step up your involvement at GOSH – run for the Members' Council elections

The 2018 Great Ormond Street Hospital (GOSH) Members' Council elections will soon call for nominations in the patient and carer, public and staff constituencies. Nominations for the 22 seats open on Tuesday 14 November 2017.

Why does GOSH have a Members' Council?

It's our duty as a Foundation Trust and as a membership organisation, but GOSH is also committed to listening to patients, parents and carers, and staff.



What do councillors do?

Councillors bind the hospital to its members and play a vital role in future direction. They also do the following:

- Hold the Non-Executive Directors to account for the performance of the Board.
- Represent the interests and views of members.
- Advise the Trust on strategy and priorities, to make sure that we are tackling the issues that are important to patients and families.

Who can nominate themselves for election?

GOSH Foundation Trust members aged 16 years or over can nominate themselves, but there are exceptions.

Find out more at gosh.nhs.uk/ftelections.

Membership	Constituency	No. of seats
Public	North London and surrounding areas	4
	South London and surrounding areas	1
	Rest of England and Wales	2
Patient and parent and carer	Patients from outside London	2
	Patients from London	2
	Parents and carers from outside London	3
	Parents and carers from London	3
Staff	Members of staff who hold a permanent contract or a fixed-term contract of 12 months or more	5

Simon Hawtrey-Woore, a public councillor for North London and surrounding areas, shares his experience.



Why did you want to be on the Members' Council?

I have a 12-year-old daughter with disabilities and strongly believe in the effectiveness of shared responsibility for her healthcare. GOSH really values and respects the 'lay' voice and it's a privilege to be able to provide that perspective when I can.

What commitment is required?

It all depends on you and how involved you can and want to be. The basic commitment is to attend a minimum of five Members' Council meetings a year (meetings are two-and-a-half hours long) and the Annual General Meeting. Councillors serve a three-year term.

What's involved?

Being both the voice of my constituency and hearing members' views is a big part of my role. We also encourage transparency and make sure the Non-Executive Directors hold the Board to account and any issues are effectively and timely addressed.

I've been involved in quite a few different areas, including observing Trust Board meetings – a key experience! I've also sat on the Learning Disability Steering Group and am passionate about the Learning Disability team – supporting them by sharing my own experiences.

What training and support has GOSH given you?

New councillors attend an Induction Training Day and then complete mandatory online training. There are also training seminars at Members' Council meetings. I've had support from across GOSH – I only had to ask.

What skills and knowledge have you gained?

Public sector governance and experiencing how committee meetings are effectively chaired and consensus created.

What's your biggest achievement?

There are two standouts: helping to bring learning disability to the forefront of thinking at GOSH, and recruiting members while in The Lagoon or at the Race for the Kids events.

What would you say to others thinking of becoming a councillor?

If you are passionate about improving child healthcare, prepared to speak up and can commit to GOSH, then give it a go!

If you're interested in nominating, be sure to attend the Members' Council elections information session on Thursday 9 November, 5-6.30pm in the Charles West Boardroom. Go to gosh.nhs.uk/ftelections for the Members' Council role description, a step-by-step guide to nominating and voting.

Contact us
foundation@gosh.nhs.uk
020 7405 9200 ext 5668

14 November 2017 – NOMINATIONS OPEN

12 December 2017 – NOMINATIONS CLOSE

8 January 2018 – VOTING OPENS

31 January 2018 – VOTING CLOSES

1 February 2018 – RESULTS ANNOUNCED

Remember to
VOTE!

Even if you decide not to stand for election

PIONEERING RESEARCH

A movement for dystonia

Research at Great Ormond Street Hospital (GOSH) has helped pinpoint the specific gene causing Katie's condition and identify a promising new treatment.

When Katie was two years old, her parents noticed that she was unsteady on her feet.

"She started falling over," recalls her mum, Sarah. "Her hearing, balance and walking were checked, but it was all dismissed because doctors felt she just had a narrow walking gait."

Katie's movement became less and less controlled and she was referred to GOSH for further tests. The family met with Paediatric Neurologist Dr Manju Kurian, who diagnosed her with dystonia – a condition where incorrect signals from the brain cause uncontrollable and sometimes painful muscle spasms.

Although the condition had been identified, investigations continued to determine what specific type of dystonia Katie had and how best to treat it. Over many years, Dr Kurian and her colleagues began spotting that some dystonia patients experienced similar symptoms such as toe curling. Slowly this group of patients grew to include more than 20 young people. With a group of this size, the team was able to start analysing the patients' DNA to look for the underlying cause of the condition.



Katie and her mum Sarah are hopeful for the future after seeing the effects of deep brain stimulation treatment.

They found that some children in the group had lost the same part of chromosome 19. By focusing on this particular section of chromosome 19, Dr Kurian's team pinpointed the KMT2B gene as the cause of Katie's dystonia.



"To learn we weren't alone and that other people were going through similar experiences was a hallelujah moment. It also helped because Dr Kurian could assure us that of these people, a few had undergone deep brain stimulation, and we were told the prognosis looked good."

Deep brain stimulation is a treatment where small wires are placed in the part of the brain that controls movement. The wires stimulate the movement centre of the brain via a power pack implanted in the patient's chest, similar to a pacemaker.

"No one knows exactly why stimulation of that site in the brain works," confirms Dr Kurian. "But it does seem to help treat the symptoms of dystonia."

While it is still too early to tell what the effect will be on Katie, she and Sarah have noticed developments following her deep brain stimulation procedure.

"I can walk a bit more," says Katie. "Mum thinks that I'm sitting up and laying straighter."

Having already seen the effects of deep brain stimulation treatment, Sarah and Katie are hopeful for the future.

Prestigious award for GOSH researcher Dr Manju Kurian



Dr Manju Kurian, Paediatric Neurologist at GOSH and the UCL Great Ormond Street Institute of Child Health, was recently awarded with a prestigious L'Oréal UNESCO fellowship recognising promising female scientists. Dr Kurian has worked at GOSH since 2011, where she spends part of her time in clinics seeing patients with movement disorders, and part of her time in the lab searching for the genetic causes and possible new treatments for these conditions. "To have your achievements recognised with this award really means a lot," says Dr Kurian.



Mannequin challenge

Hidden away on the fourth floor of Great Ormond Street Hospital (GOSH), the Clinical Simulation Centre (CSC) team are revolutionising the way we think about learning and development.

The CSC provides an immersive clinical environment for technology-based education. By recreating different crises using realistic patient mannequins that can mimic the physiology of diseases, they test participants' responses to stress, things going wrong, and all aspects of clinical care in a carefully designed environment.

"We simulate patients and scenarios in the CSC. Teams from across the hospital – and the world – can run through procedures and certain scenarios," says Dr Richard Paget, Medical Lead at CSC. "For example, we can practise diagnosing a condition or dealing with an emergency on functional mannequins."

A typical simulation

Two rooms are carefully staged to be as realistic as possible – a ward room and an intensive treatment unit. The rooms replicate real life, with backdrops, equipment, monitors, medicine and a mix of people.



Participants are given a backstory for each of the patient mannequins. Simulations last 20–40 minutes and participants are observed from a control room.

The mannequins are operated remotely – their limbs can be moved and their breathing and other physical signs are controlled. If, for example, the scenario was looking at warning signs of a critically ill child, certain physiological features can be added to the mannequin. They can be given a swollen tummy, their heart rate changed or their face colour altered to replicate different symptoms.

Participants use the cues – the monitoring equipment, the backstory and the mannequin's symptoms – to determine what the issue is.

After the simulation, participants talk about how they felt, how they responded and what they learned.

"Understanding how people felt is important. We're trying to understand their emotional response to feeling stressed, anxious, happy or exhausted – whatever the emotion might be," says Elizabeth



The CSC recreates different crises using realistic patient mannequins.

Akers, Non-Medical Lead for Clinical Simulation at the CSC. "We attempt to guide learners towards self-discovery of the likely solution, rather than providing it to them. Doing it in this way will more likely have an impact on a participant's behaviour and on future performance."

Future aspirations

Many of the courses at the CSC are designed for the unique challenges faced in paediatric medicine. Most large hospitals have a simulation centre with core courses, but at GOSH, the CSC runs specialist programmes for areas like anaesthesia and critical illness.

Paediatric mannequin technology, which is still relatively new, is at the heart of CSC training. Dr Paget explains: "We're working with a 3D-scanning company to build mannequins that can open and close their eyes, which is a compelling

cue for intensive care scenarios. We're looking at making latex tissue and skin, and building on our work to develop mannequins for surgery – we want to be able to open their chest in a cardiac emergency scenario and have mannequins specially designed for keyhole surgery. There's nothing currently on the market for keyhole surgery so this is an exciting area for us to work in."



MEMBERS' ACHIEVEMENTS

Young people descend on GOSH

The Young People's Forum (YPF) has been involved in planning the first ever national YPF meet-up with hospital youth forums across the country – creating the agenda, inviting speakers and even helping to decide on branding. The event took place on Saturday 14 October, where young people from across the UK joined us at GOSH. Look out for photos on social media under the hash tag #nhscypmeetup



The YPF helped decide on branding for the national YPF meet up.

Teen Cafe



Young people can often feel lonely in hospital, missing school and friends. So, to help them see that they are not alone, Faiza Yasin, from our YPF, has started the Teen Cafe.

The cafe is open every Wednesday from 6.30–7.30pm in The Lagoon. It is an opportunity to enjoy time away from the ward and socialise with other teenagers.

Rated by you

Once a year, patients and parents come in to Great Ormond Street Hospital (GOSH) with fresh eyes and rate everything from the cleanliness of floors to how tasty the jelly is. These inspections are known as Patient Led Assessments of the Care Environment (PLACE).

This year, the inspection team of 11 assessors was joined by one Healthwatch representative, one independent assessor and two Foundation Trust and YPF members, Sophie and Costa.



"It was great to see behind the scenes. Going from being a patient to helping the staff was a great moment for me," says Costa.

Results show that 90–95 per cent of areas scored very highly. Most wards scored 'very confident' when it came to first and last impressions of patient care. No ward scored below 'confident'. Food tasting went really well. And there were lots of positive comments about the cleanliness and appearance of wards and communal areas.

It was incredibly pleasing to get feedback on how welcoming, friendly, professional and proud of GOSH all the staff are.

Costa was on the PLACE assessment team.

COUNCILLORS' ACHIEVEMENTS



Councillors participate in hospital walkabouts.

Councillors join hospital walkabouts

Great Ormond Street Hospital (GOSH) councillors Carley Bowman, Sophie Talib and Rebecca Miller carried out unannounced inspections on Bumblebee and Eagle Wards in July.

The councillors used the Department of Health's 15 Steps toolkit – assessing quality of care under four categories: welcoming, safe, caring and involving, and well organised and calm.

The group were particularly impressed with the techniques used on Eagle Ward to help younger patients understand procedures and treatments with play therapy.

Carley says: "The walkabouts are a great opportunity to offer a parent's perspective on the hospital – often picking up on those little things that make the difference between a really good or a really bad experience. Staff are always willing to listen and are very proactive about making positive changes."

Designs for the future

GOSH has embarked on an ambitious redevelopment programme which aims to rebuild two-thirds of the GOSH site over the next 20 years. The upgrade work is crucial to maintain and advance our position as one of the world's leading centres for paediatric care and research.

Councillors represent hospital at donor presentation

GOSH councillors Teskeen Gilani and Sophie Talib represented the hospital recently to receive a £50,000 donation to Great Ormond Street Hospital Children's Charity. GOSH supporter and Foundation Trust member Mr Banerjee and his family attended the hospital in August to present their generous donation.



Some of the world's best architects took part in a competition to design a new clinical building, with construction due to start in late 2019. A group of councillors formed an evaluation panel to assess the designs.

Councillor Fran Stewart, representing parents from London, says: "It was satisfying to see requirements for the whole family were considered – differentiating between the needs of younger patients, teenage patients and their siblings. It was also reassuring that attention was paid to the overall capital cost and ongoing costs."



A group of councillors formed an evaluation panel to assess redevelopment designs.

BEHIND THE SCENES



Volunteering at GOSH

Dressed in bright yellow shirts, with warm and welcoming smiles, more than 1,000 volunteers working in over 100 different roles support Great Ormond Street Hospital (GOSH) patients, families and visitors.

Jamie Wilcox, Head of Volunteer Services, explains how volunteers support GOSH.

"Some volunteers work directly with patients, such as supporting play workers. Some baby buddy, which includes feeding and holding babies and supporting patients and families. Others have non-bedside roles, like GOSH guides, administration and pharmacy support.

"Volunteers sign up for a range of reasons. Some volunteers are ex-patients and parents who enjoy giving something back, others wish to gain skills or support their career progression. Some use it as an opportunity to stay social and active, and many simply want to make a difference.

"Last year, our volunteers contributed 222,000 hours of their time to GOSH. This is equivalent to around £2.1 million in donated time."

JUDITH Play volunteer



Volunteering is not Judith's first experience of GOSH. In 2005, her daughter, then aged 12, was diagnosed with Ehlers-Danlos syndrome – a condition that affects connective tissue. "For the next five years, there were intensive physio programmes, outpatient appointments and amazing care at GOSH," explains Judith.

Starting out as a GOSH guide and then volunteering in the Activity Centre, Judith became a play volunteer on Eagle Ward in 2014. "That's where you'll find me every Tuesday from 10am–3pm," says Judith.

"This gives me a unique role to get to know the children – their regular dialysis means we meet every week. It's a wonderful gift to build relationships over time – many from pre- to post-kidney transplant.

"I am deeply aware that whatever I give, I also receive; be it fun, empathy, care, or trust. There's hardly been a Tuesday when I've left without at some point having truly laughed.

"As a volunteer, I have found new friends, new skills, a renewed sense of pride and purpose and a deep affection for all who are part of the

JASON Weekend Club Volunteer



Jason started volunteering at GOSH in October 2014. "At the time, I had taken up a new teaching post. I love working in a school, but it is very easy to get bogged down in performance data and the paperwork. I wanted something that made me really grounded about what I do during the week, while also reminding me of the bigger picture," explains Jason.

"For two Saturdays or Sundays each month, I am a Weekend Club Volunteer."

At Weekend Club, volunteers play alongside patients and their siblings. Hosted in the Activity Centre or on the wards, activities include board games, arts and crafts, Mario Kart, talent shows, face painting and dressing-up.

MALCOLM GOSH Guide Team Leader



All volunteers start at GOSH as a guide.

"Guides help people when they come to the hospital," explains Malcolm. "We guide visiting friends and relatives, taking them to departments, wards and clinics. We direct visitors to meetings and take deliveries to theatres, wards and departments.

"I feel that I get more out of volunteering than I give. Each time I volunteer I come away with an inner warmth, knowing I've helped in a small way. By guiding I help with the smooth running of the hospital, which in turn helps frontline staff give the best possible care to children."

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

Members' Council meetings

Wednesday 29 November 2017

All meetings are from 4–6.30pm

Trust Board meetings

Wednesday 29 November 2017

Members are welcome to attend the public session. Please visit gosh.nhs.uk/trustboardmeetings to confirm dates and times for the Trust Board meetings.

For further information or to contact your councillor, please email us at foundation@gosh.nhs.uk

Halloween party

Tuesday 31 October 2017

The Lagoon restaurant
Boo! Patients are invited to have a spook-tacular time at our Halloween patient party.

Christmas party

Tuesday 12 December 2017

Wednesday 13 December 2017

Royal National Hotel,
Bloomsbury

Join us to celebrate the festive season with our last patient party of 2017.

YPF meetings

Saturday 16 December 2017

Sunday 28 January 2018

Saturday 24 March 2018

The Young People's Forum (YPF) is open to any patients, ex-patients, or siblings of patients aged 11–25 years. Meeting times, dates and locations will be confirmed closer to the date. Contact ypf.member@gosh.nhs.uk for more information.

Santa Dash

Sunday 3 December

Clapham Common

Our festive fun run is back for 2017!

Join us on Clapham Common for London Santa Dash. Everyone is welcome to dash, jog, scoot or stroll the festive 5k or 10k route in a free Santa suit.

Register at:
gosh.org/get-involved/fundraising-events/london-santa-dash

2017/2018 Members' Council elections

On 14 November 2017, nominations for our 2017/2018 Members' Council elections will open. We're calling for Foundation Trust members aged 16 and over to put themselves forward for nomination in the patient, parent and carer, public and staff constituencies. There are 22 roles open for election. Interested in nominating? Attend the Members' Council elections information session on Thursday 9 November, 5–6.30pm in the Charles West Boardroom or see pages 6 and 7 for more information.

Membership Engagement Services Ltd

33 Clarendon Road
London N8 0NW

Email foundation@gosh.nhs.uk or visit our website gosh.nhs.uk/foundation

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