

Autumn 2018

Member Matters

Young people's edition



A first-of-its-kind Sight and Sound Centre to open at GOSH
See page 11

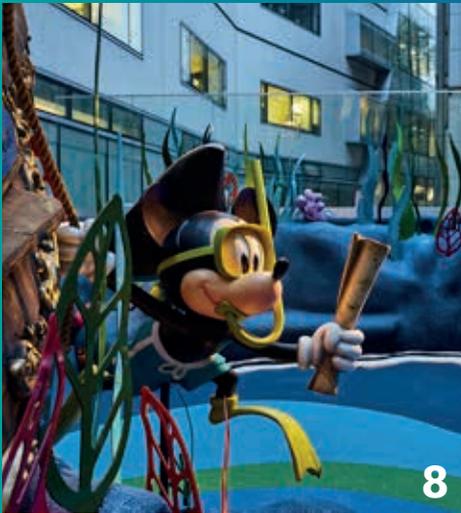


Behind the scenes

An all access pass to the hospital pharmacy

See page 6

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Welcome

Hello and welcome to another edition of *Member Matters*!

Hi everyone,

For those I haven't met, I'm Zoë and I'm one of the patient governors. I'm also the chair of the Membership Engagement Recruitment and Representation Committee. Part of my role is to look at ways that we can get more people to join the Great Ormond Street Hospital (GOSH) community and provide you, as a member, with lots of things to get involved with.

I'm looking forward to engaging with you and I hope to be able to help you get your voices heard. GOSH is very keen to hear from young people and it would be great if you could tell people about Foundation Trust membership so we can create an even bigger community!

The Young People's Forum (YPF) is a great way to get involved and you can read on page 13 about all the recent things they've done – from sitting on hospital recruitment panels to organising a careers festival. The YPF is a great way to meet new people who are all there to support each other and share experiences.

This issue of *Member Matters* is full of fantastic stories. We go behind the scenes of the hospital pharmacy on pages 6–7, looking at everything involved to make sure patients are able to take their medication. We then look at the opening of the Disney Reef on pages 8–9. I love going to see the Reef – if you're at GOSH, make sure you take a trip to The Lagoon to have a look!

On page 11 you'll learn about GOSH's new Sight and Sound Centre – a UK first! The new centre will be designed to help young people with hearing and sight loss visit the hospital for their appointments.

As well as all of the above, we'll also take a look at what some of our members have been getting up to.

Keep smiling!

Zoë



FOUNDATION TRUST NEWS

Happy birthday to the NHS!

In July, GOSH joined with the nation as the NHS celebrated turning 70. We had (lots of) cake, held parties on wards, and made wishes for the next 70 years. Did you know that GOSH is a lot older than the NHS? By 96 years!

The week of the big birthday, the Metropolitan Police, London Ambulance Service and London Fire Brigade hosted a party for paediatric patients from local hospitals, including GOSH. Patients had the chance to meet police horses and dogs and were able to see inside emergency service vehicles. There were even Stormtroopers on patrol!

We're proud to be part of the NHS at GOSH and play our role in developing treatments for the future.



GOSH staff enjoy the NHS70 Birthday Tea Dance in October

Going live with our Epic EPR

Over the 2019 Easter weekend, GOSH will launch the Epic Electronic Patient Record (EPR) system.

Not just for staff, the EPR will also include a patient portal, MyGOSH, where young people can have a window into parts of their own medical records. This will be really useful when patients are speaking to their care team.



FUTURE PROOF
ELECTRONIC PATIENT RECORDS

Paul O'Grady's Little Heroes

A very special visitor has been in the hospital over the summer, filming a six-part TV series.

His recognisable face became a familiar sight, and his laugh could be heard echoing through the corridors. The series, *Paul O'Grady's Little Heroes*, introduced a handful of the 618 children who come to GOSH every day. Over the course of the filming, the TV crew spent nearly 400 hours in the hospital and met with 24 patients and their families. Paul said: "It's been an absolute honour to film at GOSH. The children and families have been truly inspiring."



Personalising treatment for childhood arthritis

New, personalised treatments for children and young people with juvenile idiopathic arthritis could be on the horizon thanks to a new research project at GOSH called CLUSTER. Juvenile idiopathic arthritis is a condition that affects 1 in 1,000 children and leads to severe joint pain, and for some children eye inflammation (uveitis). In the project, Professor Lucy Wedderburn and other researchers at GOSH will work with scientists at nine other hospitals across the UK. Together, they will look at data from thousands of patients to work out which treatments are best for particular groups. This will lead to improved quality of life for these young people and the adults they will become.



BEHIND THE SCENES

Behind the scenes with the Pharmacy team

When we think of a pharmacy, an image of someone handing out medicines in paper packages tends to spring to mind. But there's a lot more to a pharmacy than ordering and giving out medicines.

There are 125 people in the Pharmacy team at GOSH, including pharmacists, pharmacy technicians, assistants and trainees. The team carries out a wide variety of tasks, from preparing and giving out medicines, to supporting around 250 clinical trials at any one time.

Hospital pharmacies have robots

The Pharmacy team has one very special member on hand to support them – Robbie. Robbie is the nickname for the team's 12-metre-long robot, and he looks a bit like a giant vending machine with a glass door. When you select a medicine, a robot arm whizzes up and down the shelves and uses suckers to grip the right package.

Robbie has two major advantages – he increases the accuracy of selecting the right medicine and reduces the amount of storage space needed. He's very efficient as he can store things randomly. Medicines need to be kept in alphabetical order so they're easy to find, but this isn't a good use of space. However, Robbie will find a space anywhere and remember exactly where he put it. There are some limitations though – Robbie can't store liquid medicines because the bottles come up in the chute and they might smash. It needs to be in a box and not be too heavy.



A pill that's easier to swallow

One of the major challenges for pharmacists in children's hospitals is that almost all medicines are made for adults. In general, children tend to be well, so most medicines are made for adults or the elderly, and many don't come in the right strengths for children. At the hospital, the Pharmacy team has to take medicines made for adults and change them to make them right for children.

The Pharmacy team tries to get creative to make it less unpleasant for children to take medicines. For example, when a child has to take a lot of pills every day, they try to use flavoured sprays to make the tablets taste better and easier to swallow!



A new chief in town

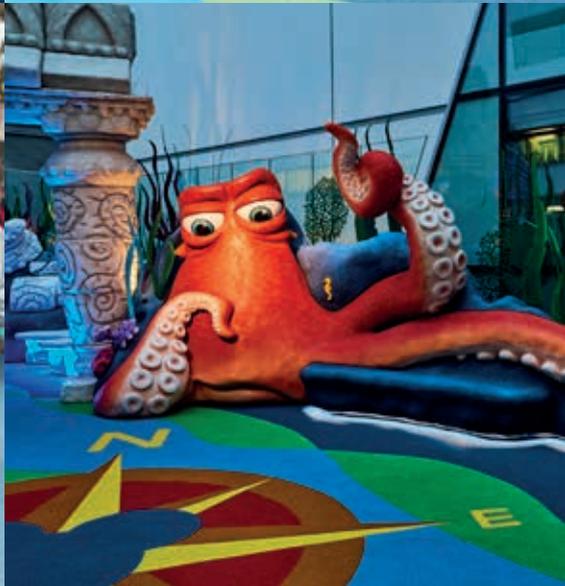
Steve Tomlin is the new Chief Pharmacist at GOSH. With more than 25 years of experience working in the field of children's medicines, he's worked across several London teaching hospitals, leading him to become the first Paediatric Consultant Pharmacist in the country.

So, while we already know we would be lost without the people handing out our paper packages, we also know that behind those packages there's a 12-metre-long robot, a lot of creativity and an extraordinary level of expertise.



Steve Tomlin

WHAT HAPPENS WHEN...



...you open a Disney Reef!

After years of designing and planning, a colourful, underwater-themed outdoor play area was opened at the hospital in June. And not just any play area – a Disney Reef!

Found at the heart of the hospital (right near The Lagoon), the Disney Reef was created by the Walt Disney team, who design Disney theme parks and stores around the world. The team also spent time with patients and the hospital's Play team to hear about what they wanted to see.

The Disney Reef has special lights, areas for reflection, as well as Disney favourites like Mickey Mouse and Goofy, Ariel from *The Little Mermaid* and Hank from *Finding Dory* – all made especially for GOSH. It's the only Disney hospital play area of its kind!

For patients who spend weeks or even months on end at the hospital, this vibrant outdoor space is great for spending time with their families.

Assistant Chief Nurse Herdip Sidhu-Bevan says: "Thank you so much to Disney for bringing the amazing Disney Reef to GOSH. This is a very special space where children can take some much-needed time away from the busy ward environment, and where they can relax outside and enjoy themselves together with their families."

Fun facts about the Disney Reef launch:

- Disney provided 500 wooden treasure chests, 30 packs of paint pens and loads of gems for patients the week before launch.
- Disney also sent over 30 packs of colouring and activity sheets for each ward.
- Special guests Mickey and Minnie visited the Disney Reef on launch day.
- We opened early to allow patients who were infectious to be the first to visit the Disney Reef.
- Did you know that Walt Disney actually visited GOSH in 1951?

The Disney Reef is open every day between 9am and 5pm.



FAMOUS FACES IN THE HOSPITAL

Many famous faces have been spotted meeting patients around GOSH. Here are just a few...



James McAvoy, Gnomeo and Juliet with Brandon and his little brother Frankie on Elephant Ward.



GOSH Charity Children's Champion Tess Daly with four-year-old GOSH patient Elliot, who received a heart transplant at GOSH in 2016.



England cricket stars Sam and Tom Curran with Yuvan on Fox Ward.



Tour de France trophy winner Geraint Thomas MBE visited patients and staff on Koala Ward.

GOSH

IN THE
21stCENTURY



Introducing... a new centre for sight and sound

Each year, more than 8,000 children and young people visit GOSH for sight and hearing loss conditions.

The Great Ormond Street Hospital Sight and Sound Centre will be a UK first.

Many patients and their families are looking forward to the opening of the new centre, like nine-year-old Josh. Josh visits GOSH with his mum, Wendy, for treatment for his rare condition, Norrie disease, which affects his sight and hearing.

“Josh finds the current waiting room areas a bit noisy and chaotic,” explains Wendy. “We take our own braille playing cards and games.”



What will be in the Sight and Sound Centre?

- State-of-the-art booths for hearing tests, as well as an eye-imaging suite.
- A garden with plants to see, touch and smell.
- Special artwork, thanks to GOSH Arts.



The garden is designed for children and their families to engage with nature. There will be bird-feeding stations, nesting spheres and insect houses.



The Sight and Sound Centre will be specially designed with patients like Josh in mind.

Building work will begin on the centre towards the end of this year, with the opening expected in 2020.

For more information, visit [gosh.nhs.uk/news/new-sight-and-sound-centre](https://www.gosh.nhs.uk/news/new-sight-and-sound-centre) or contact SightandSound@gosh.nhs.uk.

MEMBERS' ACHIEVEMENTS

Diana Award

Foundation Trust and YPF member Ezara-Mai won a prestigious Diana Award for her work in raising awareness of rare diseases and collecting an amazing £11,000 for GOSH Charity. GOSH staff told the Diana Award panel that Ezara-Mai is always helpful, polite and considerate of others.



(Gareth) Southgate tribute

Archie and his brother were travelling home from a YPF meeting in the summer when they decided to pop a photo of England Manager Gareth Southgate on the sign at Southgate station. TFL then temporarily renamed the station 'Gareth Southgate'. You can read more about the story at bbc.co.uk/news/uk-england-london-44844999.



British Transplant Games

In August, two GOSH teams, GOSH Renal and GOSH Hearts and Lungs, attended the British Transplant Games in Birmingham. GOSH had 12 competitors this year, with over 90 supporters including brothers, sisters, nans and grandads. The children took part in a variety of events including athletics, badminton, table tennis, tenpin bowling and football, to name just a few.

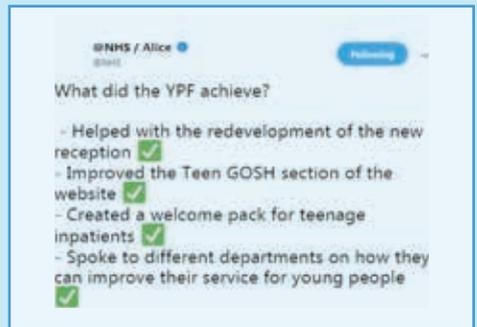


Archie and Demi

YPF members Archie and Demi were invited to speak to members of the House of Lords to share their views on health and wellbeing in early adolescence. Archie and Demi were supported by the Royal College of Paediatrics and Child Health and were able to give examples of what they felt would help support people at this age.

Twitter takeover

GOSH Governor and NHS Youth Forum member Alice took control of the @NHS Twitter handle for a week during July. Alice spoke about her rare condition and her multiple GOSH appointments and treatments over 12 years. Alice also spoke about her time as a YPF member and spread the word about some of the YPF's achievements.



YOUNG PEOPLE'S FORUM UPDATE



Not your average GOSH recruitment panel

Foundation Trust and YPF members held their own stakeholder panels in July, as the hospital was hiring a non-executive director to sit on the Trust Board. The three young panel members were keen to take part and test the five candidates on their approach to teamwork, communication, problem-solving, facilitation and leadership skills.

"It was an invaluable experience being on the stakeholder panel – representing the YPF and the voice of young people." – Sandra, panel member.

BIG Meet Up



After GOSH YPF hosted the first ever BIG Meet Up last year, Derbyshire Children's Hospital and Nottingham Children's Hospital will take the baton on Saturday 10 November. The BIG Meet Up brings together all of the hospital youth forums across the country.

Follow [@NHSCYPMeetUp](#) for updates or email amy.sutton@gosh.nhs.uk.

YPF update

In August, GOSH held its first ever Careers Festival, exclusively for GOSH patients aged 14–18. Teens met with people from a range of companies like Morgan Stanley, Premier Inn & Restaurants and McCann Enterprise. There were also workshops and tips on how to have the perfect interview, how to build confidence, and how to 'sell' yourself in the world of work.

GOSH patient Grace, says: "There are lots of different ways to get to where you want to go, and even if there's a bump in the road, you can get around it."

The Careers Festival will be back in February 2019!



Are you ready to take over GOSH?

Ever wondered what it's like to be a pharmacist at GOSH or what our medical director does?

Takeover Challenge is a fun and exciting week that will see GOSH open its doors for children and young people to 'take over' professional roles in the hospital.

Whether you want to find out how things work or who's in charge, or you just want to experience working in a hospital – this event is for you!

Takeover Challenge: **19–23 November**

Contact amy.sutton@gosh.nhs.uk to find out more.



MY STORY



14-year-old TJ from Northamptonshire

TJ has Lennox-Gastaut syndrome, a very rare form of epilepsy that causes up to 100 seizures a day. After taking part in a clinical trial of cannabidiol, a medicine taken from cannabis, his seizures have stopped completely.

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/council-of-governors.



TJ with brother Casey (left)

A diagnosis of epilepsy

When he was three years old, TJ developed pneumonia. The sudden change in his body temperature caused by pneumonia triggered TJ to have a serious seizure called a 'febrile convulsion'.

Several years later, his mum Janet received a phone call from his school to say that TJ had suddenly fallen to the floor. Later that year, he was diagnosed with epilepsy, which doctors thought might have been triggered by scarring on his brain due to the severe seizure when he was younger. TJ's seizures became more frequent – sometimes up to 100 a day – and could range from mild fits or more serious drop attacks, where he would fall to the floor, sometimes injuring himself.

TJ was eventually referred to GOSH, where specialist doctors tried to pinpoint the cause of the seizures using telemetry monitoring, a test that records brainwaves over time.

At the end of 2013, TJ was diagnosed with a severe form of epilepsy called Lennox-Gastaut syndrome. At the same time, GOSH researcher Professor Helen Cross was about to start a new clinical trial looking at whether cannabis-based medicines could help reduce seizures in children with complex forms of epilepsy.

The clinical trial

Within two years, TJ was accepted on to a cannabidiol trial at the National Institute for Health Research GOSH Clinical Research Facility. His parent's Janet and Kevin were nervous about putting their son on a research trial with cannabidiol, a substance taken from the cannabis plant, but were reassured when Professor Cross explained that the cannabidiol medicine did not contain the chemical responsible for marijuana's psychological effects. Janet says: "We were desperate to help TJ. We knew we had no real alternative."

While TJ was on the trial, the family had to carry a medical card with them to explain that the cannabidiol was part of TJ's treatment for his epilepsy.

Seizure free for 18 months

For three months, TJ took cannabidiol every day and the seizures slowly became less frequent. Janet says: "It wasn't easy, but we were given advice on the dosages and we supported TJ with the medications he needed." The seizures eventually stopped, and he has now been seizure free for 18 months.

TJ was one of 225 patients on the clinical trial, which took place at hospitals across the US and Europe, including GOSH. At the end of the trial, the average number of drop attacks for patients was reduced by around 40%, compared to only 17% in patients given a dummy drug.

TJ's communication has also improved. He enjoys telling jokes and mimicking his parents and friends. Janet explains: "We're so thrilled to have our son back. Before, we would fear leaving the house because he might have another seizure and there was just no way of knowing. We're now looking forward to days out together as a family of four, something we really haven't been able to do before."

Find out more about pioneering research at GOSH at [gosh.nhs.uk/research-and-innovation](https://www.gosh.nhs.uk/research-and-innovation).

KEY DATES FOR YOUR DIARY

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

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

Council of Governors meeting

Wednesday 7 November 2018
Starts at 4:30pm

Trust Board meeting

Wednesday 5 December 2018

Members are welcome to attend the public session of each Board meeting. Exact timings will be given nearer the date. Please visit: gosh.nhs.uk/trustboardmeetings.

Santa Dash

Sunday 9 December 2018
Clapham Common, London

Fancy a festive 5km or 10km fun run to raise money for GOSH?

Sign up now at gosh.org/londonsantadash

Patient Christmas parties

Thursday 13 December 2018

Friday 14 December 2018

Held at the Royal National Hotel, Bloomsbury.

Join us to celebrate the festive season with our last patient parties of 2018.

YPF meeting

Saturday 15 December 2018
10am-4pm

Want to attend? Email: ypf.member@gosh.nhs.uk or find out more at: gosh.nhs.uk/young-peoples-forum

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