

Autumn 2018

# Member Matters



**A first-of-its-kind Sight and Sound Centre to open at GOSH**  
See page 10



## Behind the scenes

An all access pass to the hospital pharmacy

See page 14

# LONDON SANTA DASH



Take part in our festive 5k or 10k and help seriously ill children at Great Ormond Street Hospital.

**SUNDAY 9 DECEMBER, CLAPHAM COMMON**

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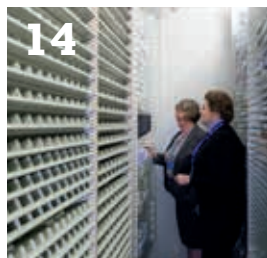
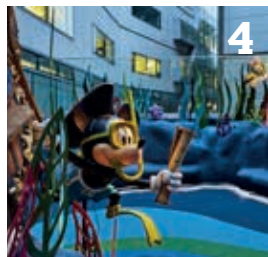
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## Introduction

**Welcome to the autumn 2018 edition of *Members Matters*.**

My name is Nigel Mills and I've recently celebrated 10 years at Great Ormond Street Hospital (GOSH), which is something of a surprise as I originally came here on a one-year contract!

After working in adolescent health as a clinical nurse specialist for eight years, I'm currently leading a project to improve transition for young people and their families at GOSH. It's amazing to see first-hand how the hospital has transformed and grown over the last decade, and I'm so pleased to have recently been appointed as a staff governor on the Council of Governors.

In this edition of *Member Matters*, you'll find features on some of the incredible work that goes on behind the

scenes at the hospital, how the Trust is planning for the future, and also a look at council and member achievements over the last few months.

As someone who is passionate about all things related to adolescent care, I'm delighted that this issue includes a look at pioneering research into the use of cannabidiol, and how a trial at GOSH has helped 14-year-old TJ become seizure free. Have a read on pages 8–9.

I hope you enjoy this edition of *Member Matters*. It really showcases how the Trust is at the forefront of innovation and is working hard on ways to improve children and young people's care and experiences.

***Nigel Mills, staff governor***



# FOUNDATION TRUST NEWS

## GOSH opens the Disney Reef

The Disney Reef, a colourful, underwater-themed outdoor play area, opened in June to patients, families and staff. The Reef, positioned at the heart of the hospital, was designed by Walt Disney Imagineers in collaboration with the hospital's Play team and patients. For those who spend weeks or even months on end at the hospital, the Disney Reef is a vital outdoor space where they can enjoy time with siblings and family. It's open every day between 9am and 5pm.



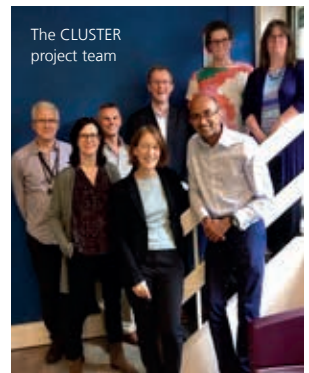
**FUTURE PROOF**  
MULTIMEDIA  
PATIENT RECORDS

## Going live with our Epic EPR

Over the 2019 Easter weekend, the Trust is going live with the Epic Electronic Patient Record (EPR) system. The EPR will allow staff rapid access to all patient information in one place. The EPR isn't just for staff though. There's now a patient portal, MyGOSH, where patients can have a window into appropriate parts of their own medical records and improve communications with their care team and the hospital.

## Personalising treatment for childhood arthritis

GOSH researchers have been awarded £5 million to develop new, targeted treatments for children and young people with juvenile idiopathic arthritis, a condition that affects 1 in 1,000 children and causes inflammation of the joints and severe pain, and in some children eye inflammation (uveitis). Co-led by Professor Lucy Wedderburn at GOSH, the CLUSTER project will bring together 10 centres across the UK to analyse data from thousands of patients. This large-scale approach will help identify which treatments work best for particular patient groups, leading to more personalised care for children and young people with this serious condition.





GOSH staff enjoy the NHS70 Birthday Tea Dance in October



## Happy birthday to the NHS!

In July, GOSH celebrated with the nation as the NHS turned 70. This landmark encouraged us all at GOSH to reflect on the role the NHS plays in our lives. Teams across the hospital held parties, sharing their thanks to the NHS and their wishes for the next 70 years. We're proud to be part of the NHS at GOSH and play our role in developing pioneering treatments for the future.



## Dr Peter Steer to leave GOSH

GOSH Chief Executive Dr Peter Steer announced he will leave the Trust at the end of the year to take up the position of Chief Executive at Mater Group in Brisbane, Australia. Dr Steer joined GOSH in January 2015 and since that time, the organisation has made numerous research breakthroughs, as well as expanded and improved its facilities by opening the Mittal Children's Medical Centre. Dr Steer leaves the Trust in a strong financial position, having delivered a surplus in 2017/18. Peter says: "It has been a privilege to have worked with the exceptional staff at GOSH. Their research and clinical expertise are world-leading and they work tirelessly and compassionately to serve young patients and their families with the most complex and rare health needs." Work will now be undertaken to appoint Dr Steer's successor.

## Our new Membership Relationship Manager

Jess Haddrell is GOSH's new Membership Relationship Manager. Her role is focused on recruitment, membership communications and engagement opportunities – as part of delivering the Trust's Membership Strategy. Jess has a background in patient and public involvement and health behaviour research. She joins GOSH from University College London Hospital where she was interim Membership Manager. Say hello at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk).

# GET INVOLVED

## @GreatOrmondSt Twitter profile - now live!

The hospital has launched a new Twitter profile, which will feature more hospital-focused content, join in with national health campaigns, and share the incredible stories of our patients, families and staff!

Join the conversation and help create some noise by tweeting **@GreatOrmondSt** and sharing what you think makes GOSH so special. We'll be looking out for tweets and sharing a few with our followers.



You can still follow all of GOSH Charity's fabulous fundraising **@GOSHCharity**



**@GreatOrmondSt**



**@GOSHCharity**

# Be involved in our Membership Strategy and help us recruit!

You may not be aware, but we have a Membership Strategy that guides us on membership recruitment, communications and engagement of members. Some of the ideas within the strategy are:

## Recruit

- We will identify the most effective means of recruiting the groups that will make our membership more reflective of national demographics. Of course, we would love to get more young people involved!
- Our ideas for 2018-2021 include:
  - Child-friendly communications in easy-to-read formats, for parents to read to their children (up to 10 years).
  - Membership materials when a patient turns 10, to encourage our younger patients to join the membership.

## Communicate

We will hold seminars on projects and developments happening across the Trust, to share information and provide an opportunity for members to give feedback and influence decisions that are made about the hospital's services.

## Engage

We will ensure that feedback channels are clear and easy to use. All Trust members, regardless of geographic location and age, will be able to engage with the Trust's activities.

## Get in touch

If you would like to provide us with advice or guidance on any innovative ways we can engage with our membership, please get in touch at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk).

We want to recruit as many members as possible, so please encourage your friends and family to become Trust members at [gosh.nhs.uk/join](http://gosh.nhs.uk/join).

# PIONEERING RESEARCH

## Cannabis-derived drug cuts seizures for children with epilepsy

A drug derived from cannabis has reduced the number of seizures in children with two severe forms of epilepsy – Dravet syndrome and Lennox-Gastaut syndrome.

“These types of epilepsy are difficult to treat as they are resistant to the majority of drugs currently available,” says Professor Helen Cross, Consultant in Paediatric Neurology at GOSH, who led the UK arm of the two international clinical trials.

In the first research trial, 120 children with Dravet syndrome from across Europe and the USA received cannabidiol twice a day. Dravet syndrome affects just one in every 40,000 children in the UK and causes frequent seizures as well as behavioural and developmental problems. After 14 weeks of cannabidiol treatment, the number of seizures dropped by 40% on average and seizures stopped completely for 5% of patients.

In a second study, which was also carried out at the National Institute for Health Research GOSH Clinical Research Facility, cannabidiol reduced the

number of drop attacks in children with Lennox-Gastaut syndrome. Drop attacks, a type of seizure characteristic of children with this condition, cause the child to drop suddenly to the floor and can result in serious injuries. At the end of the trial, the average number of drop attacks reduced by around 40%, compared to only 17% in patients given a dummy drug.

The drug used in this study is a carefully-formulated medicine which contains virtually none of the psychoactive ingredient. Although cannabis oils are available to purchase, these have not been produced to the same high standard and it's not known how effective or safe they are.

Evidence from both these trials is now being considered by regulators in Europe to determine whether the drug can be offered to patients. The US regulators have already approved the medication.

Professor Cross said: “Cannabidiol could make a considerable difference to children who currently endure frequent and debilitating seizures.”



## TJ's story

In 2009, when TJ was 5, he suddenly fell to the floor with a seizure while he was at school. Later that year, TJ was diagnosed with epilepsy, which was thought to be caused by a severe and prolonged convulsion he had when he contracted pneumonia aged 3. TJ's seizures became more frequent, ranging from 5–100 each day. He was referred to GOSH where he was diagnosed with Lennox-Gastaut syndrome and accepted onto the cannabidiol trial with Professor Cross.

Initially, TJ's parent's Janet and Kevin were apprehensive about putting their son on a trial of a drug derived from cannabis, but they were reassured that this drug had had the psychoactive ingredient removed. Janet says: "We were desperate to help TJ. We knew we had no real alternative."

After three months of cannabidiol treatment, the seizures slowly became less frequent and eventually stopped completely. TJ has now been seizure free for 18 months.

"We're so thrilled to have our son back," says Janet. "Before, we would fear leaving the house because he might have another seizure. We're now looking forward to days out together as a family of four."

TJ's communication has also improved drastically. He enjoys telling jokes and mimicking his parents and friends. Janet says: "We're so proud of TJ and everything he has overcome. Not once has he ever moaned or complained."

*Top right: TJ in policeman's uniform*

*Bottom right: TJ with brother Casey (left)*



Find out more about pioneering research at GOSH and how you can get involved: [gosh.nhs.uk/research-and-innovation](https://gosh.nhs.uk/research-and-innovation).

# GOSH IN THE 21st CENTURY



## Introducing... a new centre for sight and sound

Opening in 2020, the Great Ormond Street Hospital Sight and Sound Centre will be the UK's first dedicated medical facility tailored specifically for children with sight and hearing loss.

With more than 8,000 patients and 25,000 patient visits each year, children and young people with sight and hearing loss represent the largest outpatient group at GOSH.

Our exciting new project, supported by Premier Inn & Restaurants, will bring hospital staff from multiple disciplines together in one place – with specialist facilities for outpatients being seen by Audiology, Cochlear Implant and Ophthalmology teams, as well as related specialties including Ear Nose and Throat, and Speech and Language Therapy.

### Designed with the patient at the centre

Many patients and their families are looking forward to the opening of the new bespoke centre, including nine-year-old Josh, who visits GOSH 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 mum, Wendy. "We take our own braille playing cards and games."

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

The centre aims to provide a tailored environment for children with sight and hearing loss, including some unique sensory experiences for its young visitors. Finding their way to clinics can often be difficult and overwhelming for patients in the current facilities. Lots of signage, bright corridors and the waiting area layout can make it hard to communicate by lip reading or sign language, and noise levels can also make verbal communication difficult.



GOSH patient Josh and his mum Wendy

# Artist Impressions



*As part of the building's plans, a garden includes plants chosen specially for children and their families to see, smell and touch. The garden is designed to offer quiet green spaces for patients, families and staff, as well as providing areas to engage with nature, like bird-feeding stations, nesting spheres and insect houses.*



*Children with sight and hearing loss, and their families, were involved in the design briefing of the Sight and Sound Centre, helping to create a welcoming, homely environment that is fully accessible and easy to navigate.*



The Italian Hospital, where Sight and Sound be based.

## How is it being funded?

GOSH Charity has committed to cover the entire £25 million cost of the Sight and Sound Centre. Fundraising has already begun too, with an incredible £10 million pledge from Premier Inn & Restaurants.

*For more information, visit:*

***[gosh.nhs.uk/news/new-sight-and-sound-centre](https://gosh.nhs.uk/news/new-sight-and-sound-centre)***  
***or contact [SightandSound@gosh.nhs.uk](mailto:SightandSound@gosh.nhs.uk).***

## What will be in the Sight and Sound Centre?

- State-of-the-art soundproofed booths for hearing tests, an eye-imaging suite, a dispensing opticians and other testing facilities.
- A garden with plants designed with senses in mind, for children to see, touch and smell.
- Specially commissioned artwork throughout the building that incorporates bespoke sensory elements, thanks to GOSH Arts.

# MEMBERS' ACHIEVEMENTS

## Diana Award

Foundation Trust and Young People's Forum (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, considerate and mindful of the needs of others. She is also quick to offer advice to new or younger members. Ezara-Mai has great enthusiasm and a passion for supporting current and future patients, which is shown through her own initiative of setting up a fundraising page specifically for the YPF. Congratulations Ezara-Mai!



## 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 the pair gave examples of what they felt would help support young people coming to hospital.

## 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.



## Encourage your young person to get involved!

Our YPF 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

## A refreshed constitution for an ever-growing Trust

Since GOSH became a Foundation Trust in 2012, we've had a constitution – a set of fundamental principles, or 'rulebook' by which the Trust operates.

To ensure the constitution is fit for purpose and adapts as the organisation continues to grow, the former Members' Council and Board agreed that a revision was due, and established a Constitution Working Group in 2017 made up of Board members, staff, councillors and legal advisors.

The Working Group has now met several times, and in July 2018 it submitted its recommendations to the Council and Board.

### The following key changes were approved:

- The Members' Council would be renamed the 'Council of Governors' and Councillors referred to as 'Governors', in line with national guidance.
- The tenure of Governors would be aligned with that of non-executive directors, and Governors will be elected/appointed for a lifetime maximum of six years with no return. This will ensure that the Council of Governors constantly benefits from fresh ideas.
- The rule by which a member can remain a patient/parent/carer member following their final contact with the hospital would be extended from six to 10 years.
- The Council of Governors would be regularly evaluated, and the Code of Conduct revised to ensure that we're getting the best from our Governors.

Thank you to all those in the Working Group who took part in the revision. The constitution can be viewed at: [gosh.nhs.uk/foundation](http://gosh.nhs.uk/foundation).

## Not your average GOSH recruitment panel

Foundation Trust and YPF members held their own stakeholder panels in July, as the hospital was in the process of recruiting a Non-Executive Director: Kathryn Ludlow.

The three young panel members were eager to see how the applicants engaged with them, and the candidates were faced with challenges that tested their 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. By helping candidates gain insight into GOSH from the perspective of both a patient and young person, hopefully it will lead to appointees being able to understand patient life and how their contributions are valuable in bettering this."  
– Sandra, panel member.

Young people were also involved in recruiting GOSH's Chief Finance Officer, Helen Jameson.

# 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 dispensing 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 dispensing medicines, to supporting around 250 clinical trials at any one time.

### Hospital pharmacies have robots

While the pharmacists support other teams across the hospital, they've got Robbie on hand to support them.

Robbie is the nickname for the Pharmacy team's 12-metre-long robot who holds most of the hospital's medicine. A bit like a giant vending machine, Robbie has two main benefits – he increases the accuracy of selecting the right medicine and reduces the amount of storage space needed. Robbie is also very efficient, as he can store things randomly and doesn't need to rely on sorting drugs alphabetically in order to find them.

The system has some limitations though. Robbie can't store liquid medicines because the bottles come up in the chute and they might smash. So the medicine 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 or preparations for children. At GOSH, the Pharmacy team has to take medicines made for adults and tailor them to make them more appropriate. The team can't do too much though, or else they'd become legally responsible for the medicines and the effects they may have.

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



## Sophisticated drugs

The Pharmacy team is responsible for proving that a medicine is effective, appropriate and affordable. As our understanding of rare and complex conditions improves, so do the treatments offered. As drugs become more sophisticated, their preparation is more technical, making them more difficult to make and more costly.

There's a large amount of research going on in the Institute of Child Health and many consultants want to put their research findings into practice. The consultant and pharmacist often work together on an application, which is then submitted to a committee who will decide whether the drug is approved – if it is, the pharmacist writes a set of guidelines to help people understand how to use it.

## 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

# 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](mailto:foundation@gosh.nhs.uk)

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## Council of Governors meeting

Wednesday 7 November 2018  
Starts at 4:30pm

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## 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](http://gosh.nhs.uk/trustboardmeetings).

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## 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](http://gosh.org/londonsantadash)

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## 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.

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## YPF meeting

Saturday 15 December 2018  
10am-4pm

Want to attend? Email: [ypf.member@gosh.nhs.uk](mailto:ypf.member@gosh.nhs.uk) or find out more at: [gosh.nhs.uk/young-peoples-forum](http://gosh.nhs.uk/young-peoples-forum)

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