

Autumn 2016

# Member Matters

## A day in the life of a ward manager

Find out about Melissa and what her day at the hospital is like



Patients receive a call from out of this world

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# Contents



## WELCOME

Hello and welcome to your autumn edition of Member Matters!



I'm **George** and I represent patients from outside London on the Members' Council and this is my second term as a councillor. I have also chaired the Young People's Forum (YPF) since its creation in 2012. It's a privilege to lead a group of enthusiastic young people and help to ensure that the voice of young people is heard throughout Great Ormond Street Hospital (GOSH).

I'm **Hannah** and I was elected as Vice Chair of the Young People's Forum in September 2015 and I'm really excited to be introducing this issue of *Member Matters*.

We hope you enjoy reading this autumn edition. As usual, it's packed with interesting articles and news – find out all about a day in the life of a ward manager at GOSH and hear Jennifer's story as a patient here. You can also find out how patients received the long-distance call of a lifetime when British astronaut Major Tim Peake took time out of his day on board the International Space Station to link up live with the hospital!

We recently attended the Commonwealth Service annual multi-faith celebration, which takes place at Westminster Abbey. The YPF was also asked to host an NHS England forum event to inspire others across the country to set up similar groups and ensure that the voices of young people are heard and involved in the future of their healthcare.

We really hope you can spread the word about Foundation Trust membership at GOSH – we need more young people to join us and ensure their voice is heard too!

Please encourage your friends to join today – it's easy to join at [gosh.nhs.uk/join](http://gosh.nhs.uk/join)

To get in touch with your councillors, email us at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk)

Thank you for continuing to support GOSH and all our work. Enjoy the issue!

**George and Hannah**

## May the 4th be with you



Ossie with his BB-8 design

On *Star Wars* Day, 4 May 2016, at a hospital (not so) far away, Disney organised a host of activities and entertainment for patients – including exclusive screenings, goody bags, and more – under their campaign *Star Wars: Force For Change*, which helped to raise vital funds for the hospital.

Lion Ward patient and *Star Wars* super fan Ossie, 10, was presented with an award for his design of whistling robot sidekick, BB-8. He also received a framed picture of Watford FC, which was signed along with his BB-8. Ossie's design was part of a BB-8 auction that Disney held in support of Great Ormond Street Hospital (GOSH).

On Sky Ward, play specialists and patients were taught how to draw the characters that make up the *Star Wars* universe – such as the droids C-3PO, R2-D2, and BB-8.

Luke Skywalker himself, actor Mark Hamill, visited the hospital last year to meet patients and sign *Star Wars* posters. On *Star Wars* Day, he also supported the Force For Change campaign by editing a special edition of the *Sun* newspaper, to encourage readers to donate money to the cause.

All patients currently being treated at the hospital were also given goody bags, including masks, toys, the new *Star Wars: Rebels* animated series, and a special tumbler – just in time for tea. Disney really brought the *Star Wars* magic to patients and their families at GOSH.



## An inclusive Commonwealth

The Commonwealth Service is the UK's largest annual multi-faith celebration and takes place at Westminster Abbey. George and Hannah, Chair and Vice Chair of Great Ormond Street Hospital's (GOSH) Young People's Forum were invited to attend this year.

The Commonwealth organisers were looking to unite and celebrate organisations where young people make a difference, make improvements and help change the future. As our young people help us do all the above, they ticked a lot of boxes.

The one-hour service featured a mixture of testimonies, readings and musical performances – including a rendition of 'Fields of Gold' by Ellie Goulding. The theme was 'an inclusive Commonwealth' – aiming to celebrate unity and diversity, and to foster greater understanding of the Commonwealth's achievements and role, particularly among young people.

## Nutrition and Hydration Week

Earlier in the year, GOSH celebrated Nutrition and Hydration Week, a global event focusing on the health benefits of eating and drinking well. We spoke to patients and families about the positive changes we have made to our meal services in the past year, as well as asking them for their thoughts and ideas for future menus – with over 387 conversations being recorded.

The hospital held events every day – from 'Protected Mealtimes Monday' to 'Fantastic New Menu Friday'. The smoothie bike in The Lagoon was particularly popular, with over 100 smoothies brought. We are now looking at the information we collected to see what changes we can make to improve mealtime experiences at GOSH.

We would love to hear your thoughts and feedback on your experiences of food and drink at the Trust, so that we can improve our services for everyone who uses them. This could include the food in The Lagoon restaurant, hot and cold drinks sold in the coffee bar, or the meals we serve on the wards.

Please share your views by emailing [catering.feedback@gosh.nhs.uk](mailto:catering.feedback@gosh.nhs.uk)



# BEHIND THE SCENES

## A day in the life of a ward manager



**Ward Manager Melissa Strickland has worked at Great Ormond Street Hospital (GOSH) for more than 20 years, and recently won an award for nursing at GOSH's Annual Staff Awards. Here's what her day looks like...**

Melissa is in charge of Koala Ward, which looks after patients with neurological and craniofacial conditions, and acts as an emergency ward for brain injuries.

Koala is one of the busiest neurosurgery wards in the country and the biggest centre for children needing brain surgery. Next year, it will get even bigger, with eight more beds added to the ward.

Melissa's usual shift starts at 7am, when the night team briefs her on all 24 children on the ward.

Melissa then makes her ward round, speaking to patients and parents to ensure they are kept informed and updated. Melissa finds this time really useful as it allows her to deal with any concerns or questions that families might have, and make sure they're being looked after.

Throughout the morning, doctors carry out their rounds and Melissa is on hand to help make sure that everything goes smoothly. By the end of the morning, Melissa has seen every child on the ward, found beds for new patients, and talked to families to check that everything's okay.

**Koala is one of the busiest neurosurgery wards in the country, and the biggest centre for children needing brain surgery. Next year, it will get even bigger.**

Her afternoons are then spent catching up on paperwork, monitoring patients, and taking care of any emergencies.

At the end of the day, Melissa heads home to her partner and five-year-old daughter. The pedometer on her phone shows that she's walked over 20,000 steps!



## Jennifer's story

Jennifer, now 17 years old, has lived with multiple sclerosis (MS), a condition that can cause symptoms such as muscle weakness and loss of vision, for three years. Once a month, Jennifer visits the MS clinic on Starfish ward at Great Ormond Street Hospital (GOSH) for a check-up and two-hour infusion. Here's her story...

Jennifer with Dr Cheryl Hemingway

When I was 14, I was on the bus into school when I looked out the window and it looked like it was smudged. I wiped it to try and remove the smear, but it wouldn't go – so I started to rub my eye instead, thinking the problem must be an eyelash.

I remember still rubbing my eye later on in my GCSE English lesson, sure that the problem would disappear eventually. But the next day there was no improvement. I struggled to read things, and when I closed my good eye it looked like the colour had been washed out of the world.

My eye got worse as the week went on. When I shifted my gaze, it felt as though something was trying to pull the eye back. I was only 14 and I was terrified I was going blind.

### Diagnosis

Moorfields Eye Hospital diagnosed me with optic neuritis, a condition where the optic nerve becomes inflamed and has difficulty carrying messages from the eye to the brain.

The doctor described it as though your eyes are a TV and the plug is your brain, but the wire between is chewed up and the signal can't be transmitted properly. After a series of tests, the doctors told me I also had nerve damage. And when I went home, I began to feel stiffness and cramp in my legs. It took a few weeks for the pain in my eye and my legs to go away.

In July 2014, I began experiencing painful headaches, and the blurred vision returned – but this time, in my other eye. As I'd experienced two bouts of optic neuritis, Moorfields Eye Hospital referred me to see Dr Cheryl Hemingway, a paediatric neurologist at GOSH, for further assessment, including an MRI scan.

Dr Hemingway is one of the few doctors in the UK to specialise in paediatric multiple sclerosis, and finally diagnosed me with MS. I tried to block out the news at first as it was too much to take in. I had read about MS online and was terrified. I felt like I was in a nightmare and I just wanted someone to wake me up.

But as I began to receive treatment at GOSH, I started to feel more positive about the future. I've learnt that with the right support the condition can be managed, and you can get on well in life. Now I'm proud to have MS – it's part of what makes me the person I am.

I haven't had any major symptoms this year since I started my current medication. I still get stiffness in my legs, my muscles can ache and I get mental fatigue, but it's nowhere near as bad as before.

### My advice

If I was to give advice to other children and teenagers who have just been diagnosed with MS, it would be don't worry – it might seem scary at first, but things do get better. Keep smiling, there is always light at the end of the tunnel!

Could you share your story with us to help other young people? Get in touch at [gosh.nhs.uk/shareyourstory](https://gosh.nhs.uk/shareyourstory)



# FAMOUS FACES IN THE HOSPITAL



## Robert Downey Jr surprises patients

Our friends at Disney continued to spread magic and joy at the hospital, arranging for Robert Downey Jr, the star of *Iron Man* and *The Avengers*, to make a surprise visit to Lion, Giraffe and Elephant Wards. The actor was in London ahead of the European premiere of *Captain America: Civil War* but took time out to visit young patients and their families, including Chloe (pictured).



## A special visit from Nick Jonas

US popstar Nick Jonas paid a visit to the hospital on 27 May and spent some time chatting to Ella and other young fans on Badger Ward, the Cardiac Intensive Care Unit (CICU) and Sky Ward. Nick tweeted about his Great Ormond Street Hospital (GOSH) experience, which was featured in Capital FM's top five Twitter highlights.

## Mayor of London meets patients from Badger Ward

On 5 July – the 60th anniversary of the Clean Air Act – the Mayor of London, Sadiq Khan, visited the hospital to launch his proposals to tackle air quality in the capital, speaking alongside Chief Executive Peter Steer. The Mayor visited Badger Ward to understand the impact pollution has on the health of respiratory patients – meeting Fredi, nine, who has cystic fibrosis, and nine-year-old Scarlett, who recently had lung surgery.



# GOSH IN THE 21st CENTURY

## A call from out of this world

Great Ormond Street Hospital (GOSH) patients received the long-distance call of a lifetime in May, when British astronaut Major Tim Peake took time out of his day on board the International Space Station to link up live with the hospital.

Around 30 patients assembled in the Activity Centre and discussed how he spends his day carrying out scientific research, just like the pioneering research carried out at the hospital. He had many similarities with some of our patients, including being isolated from his family and needing a restricted diet.

Tim was also asked questions about how you stop things floating around on the space station, how he cleans his clothes, and what he misses about home.

After Tim became the first person to run the London Marathon in space on Sunday 24 April, nine-year-old patient Zak asked for some training tips for his own special race, the RBC Race for the Kids, a 5k family fun run which took place on Sunday 15 May in aid of the hospital.

Zak was advised by Tim to have lots to drink before he runs so he doesn't get dehydrated, but mainly to enjoy himself and have some fun!

To say goodbye, patients were treated to an incredible view of the sun rising over the Earth from space.



# MEMBERS' COUNCIL ACHIEVEMENTS



There was a race for recruitment at the RBC Race for the Kids at the Queen Elizabeth Olympic Park in May. A team of 11 – including members, councillors and Great Ormond Street Hospital (GOSH) staff – signed up 74 new members on the day, with many more signing up after the event.



More than 7,500 people took part in the 5k race to raise funds for Great Ormond Street Hospital Children's Charity. The Foundation Trust team were on hand to thank runners, meet members, as well as former and current patients, and many more whose lives have been touched by the hospital. Councillors were also interviewed live on the roving camera, which was then beamed across the park – and three of our recruitment team even ran the event!

Sophie, councillor representing patients from London, said: "I've met so many children and young people who can't wait to show off their medal! It's been so lovely to see such a range of people take part – from super-fast sprinters to babies in buggies and even dogs!"

Thank you to everyone who took part in the event and sponsored those running. If you'd like to take part next year, just head to [gosh.org/register-your-interest-rbc-race-kids](http://gosh.org/register-your-interest-rbc-race-kids)

## Cooking up the youth voice in the NHS

Impressed by the success of Great Ormond Street Hospital (GOSH)'s Young People's Forum (YPF), NHS England asked representatives to host an event to inspire others across the country to set up similar groups – to ensure that young people are involved in the future of their healthcare.

140 people from a range of healthcare organisations attended, with our YPF members running opening speeches, workshops, and acting as 'special advisors'.

They shared recipes for success, including an information stand showing how they'd been involved in food tasting and menu development.

Many spoke about their overwhelming sense of empowerment. "I remember sitting in NHS events and being ignored by healthcare professionals.

## YOUNG PEOPLE'S FORUM UPDATE



"And now we have events just for young people – fab!" said Sophie, from the Birmingham Young People's Advisory Group.

## Staff and patient councillors reach out to students at St George's University

A really important part of our role as a Foundation Trust and as a children's hospital is to reach out and engage more with young people.

Early this year, our patient councillor and second-year medical student Sophie Talib organised a visit to the Paediatric Society at St George's University in Tooting, teaming up with staff councillor and GOSH Consultant Paediatric Neurologist Dr Prab Prabhakar.

Sophie and Prab spread the word about Foundation Trust membership, offered career advice, and gave students the opportunity to hear more about the Neurology team at GOSH. They were thrilled to see over 20 students join as Foundation Trust members, and will run another session next year!

If you would like us to come out to your school to speak about GOSH and Foundation Trust membership, email [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk)





# WHAT HAPPENS ...

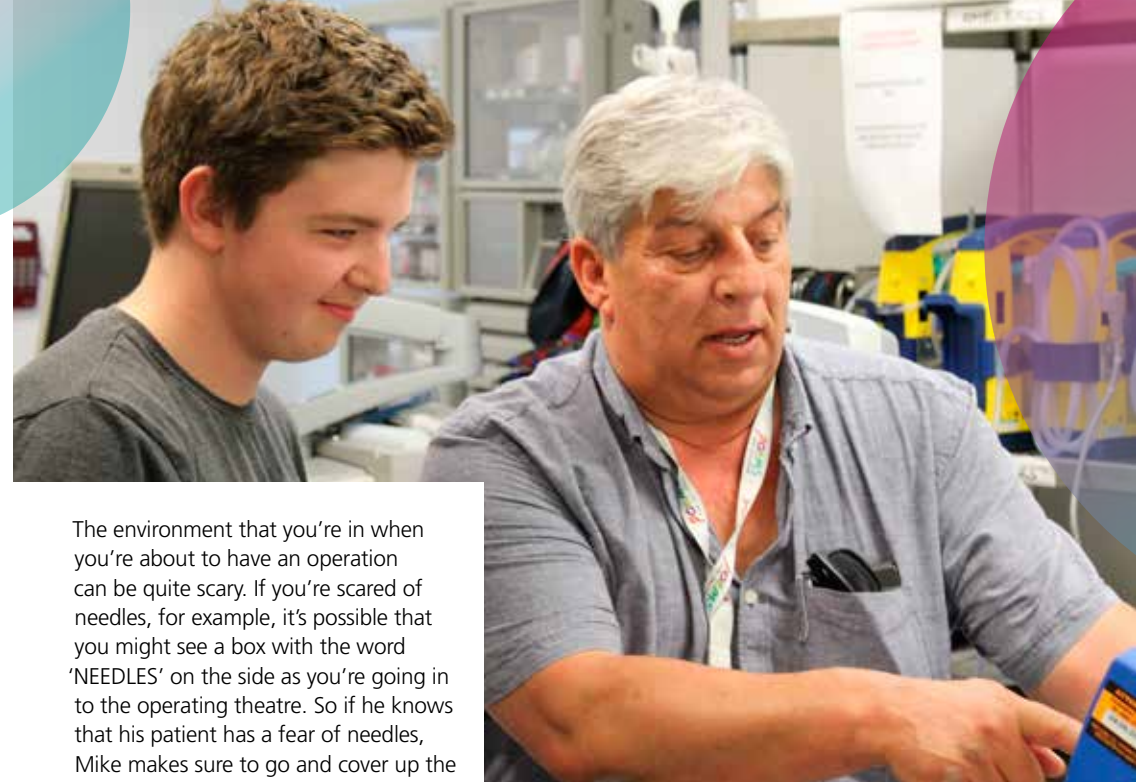
## before I have an operation?

**Ethan has been coming to Great Ormond Street Hospital (GOSH) for as long as he can remember.**

**In 2000, aged just seven months old, Ethan had a heart transplant after a virus caused his heart to become weak and stretched, a condition called dilated cardiomyopathy. Now 16, Ethan is a member of the Young People's Forum and a member of the Foundation Trust. Recently, he met GOSH staff to ask how they help young people feel at ease before an operation – Mike Stylianou (the person you'd see before you fall asleep) and Riaz Ahmed, from the IT department. Here's what Ethan found out...**

About 75 per cent of children who come in to GOSH for surgery experience anxiety at some point – and it can really affect them. Twelve per cent of children who go through surgery still experience anxiety up to a year after their treatment. So it's Mike's job to make sure that patients are as comfortable as they can be before an operation.

"Even if children don't seem it, they might actually be anxious," says Mike. "Anything that we do could cause anxiety – or even make it worse." So Mike tries asking questions to defuse the tension of the moment – like: "do you have any pets?" Or even jokes: "Hello Ethan, can you tell me your name?" (That one can take a while to sink in.) Laughing, or thinking about the answer to a question, can relieve tension and make you feel more at ease.



The environment that you're in when you're about to have an operation can be quite scary. If you're scared of needles, for example, it's possible that you might see a box with the word 'NEEDLES' on the side as you're going in to the operating theatre. So if he knows that his patient has a fear of needles, Mike makes sure to go and cover up the labels with sticky tape beforehand.

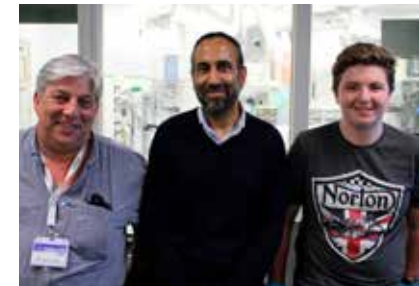
The last time I had an operation, the mask that put me under anaesthetic made me feel a little bit ill. And the anaesthetic that's used to put people to sleep before their operation can smell quite horrible. So Mike has a range of scented oils to put on the masks – chocolate, mango, vanilla, and lavender – the smells help to make young people in his care more comfortable.

**About 75 per cent of children to come in to GOSH for surgery experience anxiety at some point – and it can really affect them.**

The way that Riaz and the IT department help to make patients feel better about their operations is through technology. As Riaz says, it's all about "the way you use equipment to change things for the better".

Research has shown that using handheld devices – like a phone or a tablet – can be good for managing anxiety. So Riaz got hold of some iPads for young patients to use before their operations – helping them to focus on something else and minimising their anxiety.

After meeting Mike and Riaz, I was shown around behind the scenes, to see some of the techniques they use when patients come in for operations. Knowing I have my own procedure soon, I'm definitely more comfortable with the whole process now. As Mike told me: "Everyone's primary objective is to make sure that you're looked after."





# 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

**Wednesday 7 December 2016**  
**Wednesday 1 February 2017**

All meetings run 4–6.30pm  
Charles West Board Room  
Paul O'Gorman Building  
Great Ormond Street

### Trust Board meetings

**Wednesday 7 December 2016**  
**Wednesday 1 February 2017**

Members are welcome to attend the public session, usually from 1.30pm. Exact timings will be given nearer the date.

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

For more information or to contact your councillor, please email [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk)

## Play in Hospital Week

**Wednesday 28 September**

Great Ormond Street Hospital

## Annual General Meeting (AGM) and Annual Members' Meeting

**Tuesday 11 October**

5.30–7pm  
Lecture Theatre  
Weston House  
63–67 Great Ormond Street  
London WC1N 3HZ

## Halloween party

**Tuesday 1 November**

2–4pm  
The Lagoon restaurant  
Come along to enjoy some spooky treats – including a dedicated area for teenagers!

## Takeover Day

**Monday 14 November –  
Friday 18 November 2016**

In November, young people will take over roles at Great Ormond Street Hospital (GOSH) to celebrate the Children's Commissioner for England's Takeover Day. To find out more contact [fiona.jones@gosh.nhs.uk](mailto:fiona.jones@gosh.nhs.uk)

## Listening Event

**Saturday 19 November**

10am–2pm  
Patients and parents are invited to come along to share their experiences of GOSH. For more information, contact [emma.james@gosh.nhs.uk](mailto:emma.james@gosh.nhs.uk)

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