

Autumn 2017

Member Matters

Young people's edition



What happens to your blood in the lab?

Toby, 11 years old, finds out on page 14

Spider-Man drops into the hospital

See page 10



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WELCOME

Hello and welcome to the spring edition of *Member Matters*!



I'm Thomas and I'm one of the youngest members of our Young People's Forum (YPF). I have been a patient at Great Ormond Street Hospital (GOSH) for two years and joined the YPF in July last year. Since being a YPF member I've had a chance to work in the pharmacy as part of the Takeover Challenge, and have a tour behind the scenes at GOSH, visiting a theatre and seeing the rooftop garden. As well as all these great opportunities, I've made new friends and shared my experiences with other young people at GOSH who know how it feels to be in hospital.

In this edition of *Member Matters* I tell my story. I have always liked climbing mountains, and was worried that after

getting sick I wouldn't be able to climb anymore – but this wasn't the case. Read page eight to see me on my way up Snowdon, the highest mountain in Wales. This magazine also includes a behind the scenes look at volunteering at GOSH. Did you know we have more than 1000 volunteers who donate their time to support patients and staff? You'll also be able to see what happens to your blood sample in the labs, it's an interesting process

I hope you enjoy this edition!

Thomas

Thomas

DisneyLife pilot

Over the summer, patients and their siblings in Eagle and Badger Wards have enjoyed unlimited access to Disney games, books, music and films on their smartphones and tablets.

The two wards have been part of a pilot thanks to Disney generously donating free licences for their DisneyLife app.

For patients in isolation or those who have to sit still for a long time, such as for dialysis, the app has been a welcome distraction. It has also proved invaluable for siblings spending long periods

of time waiting in the hospital – relieving parents of added stress and anxiety.

The pilot has been an all-round success – Eagle Ward even had a Frozen sing-along party!

“I think the DisneyLife app is good as it gives me something to do. It takes my mind off everything around me.” – Alex, GOSH patient.

Meet the new Chairman

We are delighted to welcome Sir Michael Rake as our new Trust Chairman.

Starting in November, Sir Michael Rake brings to GOSH a wealth of successful leadership experience in business and service industries like 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.



Welcome to Sir Michael Rake, our new Chairman.



One day at GOSH

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

Launched in March, the campaign 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.

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 Young People's Forum (YPF) has started the Teen Cafe.

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



Digital connections

Exciting times are ahead, as we use new technology to make it easier for patients and families to connect with GOSH.

Our Electronic Patient Record (EPR) system and research and innovation platform will enable clinicians to quickly access patient information in one place. There will also be a patient portal that includes online appointment booking.

Contracts are now signed with suppliers Epic and Aridhia. The research area will go live later this year, followed by the EPR in April 2019.

Faiza, who is our EPR Patient Representative and a member of the Foundation Trust, told us she can't wait for “patients and families to use technology to connect with the hospital in the same way they connect with the rest of the world.”

The EPR team would love to hear from you. Email EPR@gosh.nhs.uk.

FUTURE PROOF

ELECTRONIC
PATIENT RECORDS

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 GOSH community."

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."

MY STORY



Thomas climbs high!

Great Ormond Street Hospital (GOSH) patient Thomas is an avid mountaineer. After recovering from cancer, Thomas recently reached the summit of one of the highest mountains in Britain.

Before he became unwell, 12-year-old Thomas, who is one of the youngest members of the Young People's Forum and a Foundation Trust member, loved walking and scrambling on mountains with his dad, explains Thomas's mum Annette

The adventures had to be put on pause when Thomas was diagnosed with cancer and, during the most difficult days at GOSH, Thomas feared he may never go climbing again.



Conquering Snowdon, the highest mountain in Wales, was Thomas' first climbing trip in the two years since his diagnosis.

Annette said: "Even when he was very little, Thomas loved scrambling on the rocks at the beach with his dad. When Thomas got a bit older he set himself the challenge to climb Snowdon and Scafell Pike, which he loved, and he was gearing up for Ben Nevis when he was diagnosed with cancer.

"Thomas has been through a lot in the last couple of years. At his lowest time in the hospital, he feared he would never climb a mountain again and was very upset.

"When Thomas got better, he started thinking about whether such an adventure would be possible. He was still very much getting his strength and energy back but wanted to get out there and decided to try Snowdon again. It was a hard hike for him and there were lots of midges too, but he made it to the top with his Dad and his cousin.

"On his return back down the mountain, I got the biggest cuddle from him, which showed how excited he was to have got through his treatment and be back out on the mountain. It was a very proud moment.

"Thomas is now planning to climb Ben Nevis next year and wants to raise money for GOSH Charity to say thank you for helping him.

"Thomas's achievement will hopefully inspire other children and give them hope that no matter how low they are feeling, they will one day be able to do the things they love."



Thomas's experience as a YPF member

Thomas and his mum met our Children and Young People's Participation Officer in The Lagoon one day where he learnt more about the YPF. Thomas has lots of fun when he goes to the meetings and finds being a member gives him lots of opportunities he wouldn't get otherwise.

Last year Thomas loved taking part in the Takeover Challenge. Thomas is fascinated by laboratories and all the technology in the hospital and got to 'take over' the pharmacy – he was captivated by the robots that pull out the medication. The day was a chance to see the inner workings of the hospital and he found it really interesting.



FAMOUS FACES IN THE HOSPITAL



GOSH nurses with
Spider-Man actor
Tom Holland.

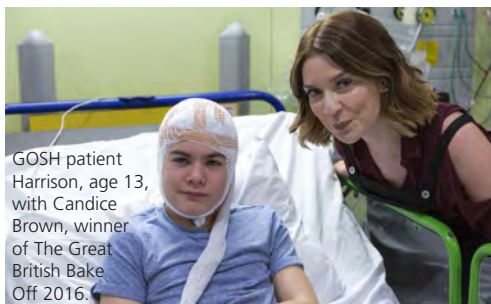
Many famous faces have been spotted meeting patients and staff around Great Ormond Street Hospital (GOSH) wards. Here are just a few...



GOSH patient Zach, age five, with rugby union legends Warren Gatland (OBE) and Jonny Wilkinson (CBE).



Peter Rabbit with Xavier, age 10. Launching a new Peter Rabbit toy to raise funds for GOSH.



GOSH patient Harrison, age 13, with Candice Brown, winner of The Great British Bake Off 2016.

GOSH IN THE 21st CENTURY



The CSC recreates different scenarios using mannequins.

Mannequin challenge

Hidden away on the fourth floor of Great Ormond Street Hospital (GOSH), something unusual is happening... lifelike mannequins are being treated for what appear to be real conditions.

The mannequins are being used in training run by the Clinical Simulation Centre (CSC). "Teams run through different procedures and scenarios," says Dr Richard Paget, Medical Lead at CSC. "For example, we can practise diagnosing a condition or dealing with an emergency."

The scene is set

Two rooms are carefully staged to be as realistic as possible – a ward 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

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. For example, 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.

Future perfect

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

Elizabeth Akers, Non-Medical Lead for Clinical Simulation at CSC says: "We guide participants to come up with solutions for themselves. Doing it this way is more likely to have an impact on their future behaviour and performance."

MEMBERS' ACHIEVEMENTS

Transplant Games

The Transplant Games bring together the transplant community and promote organ donation.

The **British Transplant Games** are held every year. The 2017 Games were in Scotland (27–30 July). More than 1,000 transplant recipients took part in over 20 different sports.

Great Ormond Street Hospital (GOSH) entered two teams of children – the GOSH Renal team and the GOSH Heart and Lungs team.

The **Summer World Transplant Games** are held every two years. This year, they were in Malaga, Spain (25 June–2 July). More than 50 countries took part.



Charlotte and Robert won gold at the World Transplant Games.

After a fantastic week, Charlotte Archer-Gay won gold in Doubles Badminton, Robert Collins won gold in Singles Badminton and Rhys Bonnell won five golds for Swimming. Their success helped Team Great Britain and Northern Ireland reach the top of the medals table.

Congratulations to all members who took part – we are all so proud of them!

Rated by you

Once a year, patients and parents come in to GOSH 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 inspection team.



Update from our Young People's Forum

Faiza Yasin from our YPF, tells us what the group is up to.

"Being a YPF member is like being a VIP with a backstage pass. We tour secret areas which are not always open to the public – operating theatres, religious spaces, kitchens and even rooftop gardens that we didn't know existed.

"We also get to invite guest speakers to our meetings (we meet six times a year). At our August meeting, we had Great Ormond Street Hospital's (GOSH) Chief Information Officer – it was great to discuss our concerns about Wi-Fi access with the person in charge of the network!"

Our Chief Information Officer, Ward Priestman, attended the August YPF meeting.



The YPF needs you!

Do you want to have your say and help improve the experience of teenage patients at GOSH? Any patients, ex-patients or siblings of patients aged 11–25 are invited to join us.

Contact ypf.member@gosh.nhs.uk.

YOUNG PEOPLE'S FORUM UPDATE



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

Exciting times

"We are currently involved in planning the first ever national YPF meet-up with hospital youth forums from across the country! We have been busy creating the agenda, inviting speakers and even helping to decide on branding. The event took place on Saturday 14 October, look out for photos on social media under #nhscypmeetup.

"We're also planning the biggest takeover of GOSH yet. In November, the Takeover Challenge returns, and will see us go behind the scenes and find out how the hospital works day-to-day. We've asked to visit the hospital's charity this year to learn about fundraising. It's amazing how many teams value YPF voices."

WHAT HAPPENS WHEN...

What happens to your blood in the lab?

Blood tests are taken for many reasons – from diagnosing illness to monitoring your health. Most of us will have a blood test at some point in our lives, but what happens to our blood? Toby, 11 years old, went to the Great Ormond Street Hospital (GOSH) laboratory to find out.

STEP 1 A small blood sample is taken, usually from a blood vessel in your arm. It is labelled with your personal details and which tests are needed.

STEP 2 Your blood sample is put in a protective canister and sent through a chute to the lab.



STEP 3 At the lab, your details are entered into the computer and your blood sample is given a unique barcode.



STEP 4 Your blood is tested on a full blood count analyser to count the number of red cells, white cells and platelets.



Harvey's Gang launched at GOSH in July 2017.

STEP 5 Your blood is examined under microscope or tested depending on the reason for your blood test.



STEP 6 Your results are checked by a biomedical scientist. A report is written and sent to your health professional.

STEP 7 With results in hand, your doctor now has vital information about what's going on inside your body so they can make sure you get the right treatment.

STEP 8 If your results show that you need a blood transfusion, suitable blood is prepared by the Blood Transfusion Laboratory.

Harvey's Gang comes to GOSH

Harvey's Gang is a new opportunity for young patients to tour labs. You can find out what happens to your blood samples and discover where blood transfusions come from.

Harvey's Gang originated at Worthing Hospital in Sussex when seven-year-old patient, Harvey Baldwin, asked where his blood samples went as they disappeared into the chute. Harvey wanted to know what happened to them once they got to the laboratory and where his blood transfusions came from.

Harvey visited the laboratory with a biomedical scientist at Worthing Hospital. He really enjoyed the tour and got lots out of it. Harvey then went on to tell his ward mates, who were also given a tour, and as a result, Harvey's Gang was born!

In 2014, Harvey sadly passed away, but his memory lives on through Harvey's Gang.

In July, Toby, 11 years old, helped launch Harvey's Gang at GOSH. The hands-on tour gave Toby and his family an insight into the workings of the Haematology, Coagulation and Blood Transfusion labs. The blood coagulation process was really helpful for Toby, as he is on a medicine that helps prevent blood clotting. He now knows how his medicine works.



Toby and his family with Biomedical scientists Munnar and Amanda

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

Held at the 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

Use your vote in our 2017/2018 Members' Council election!

In January next year, we'll be holding our Members' Council elections. As a Foundation Trust, Great Ormond Street Hospital (GOSH) holds elections every three years to elect the Members' Council. The Members' Council is made up of patients, parents and carers, the public, local stakeholders and staff. As a GOSH Foundation trust member, you'll be able to vote for your preferred candidate between 8–31 January 2018. Keep an eye out for your voting pack!

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