

Spring 2016

Member Matters



**Famous faces in
the hospital**

see page 10

**Harrison is taking part in a clinical trial.
Find out how many members of staff are
involved in his care**

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WELCOME

Hello, and welcome to your spring edition of *Member Matters*!

I'm Sophie, I represent patients from London on the Members' Council and this is my second term as a councillor.

I received 18 years of care at Great Ormond Street Hospital (GOSH) and am now studying medicine myself. For that I owe GOSH so much, and this is my main reason for getting as involved as I can. I'm active across lots of different areas of the hospital, from the Young People's Forum (YPF) to the development of Our Always Values.

In particular, I am keen to reach out to young people. Recently, with Staff Councillor and Consultant Neurologist Prab Prabhakar, I spoke to fellow students in the Paediatric Society at my university. It's important that we engage with our young members, hear their voice and represent their views.

I hope you enjoy reading this edition of *Member Matters*. It is full of exciting new developments for the hospital and real patient stories. If you fancy getting involved, there are many ways – our YPF update will tell you more!

Thank you for continuing to support GOSH and all of our work.

Sophie Talib

Enjoy the issue!



An artist's impression of the Morgan Stanley Garden

Morgan Stanley Garden to feature at RHS Chelsea Flower Show

"One of the most significant and poignant gardens of my career" is how plantsman and designer Chris Beardshaw has described the Morgan Stanley Garden for Great Ormond Street Hospital (GOSH), which will feature at the RHS Chelsea Flower Show on 24–28 May 2016.

The enclosed, courtyard-style garden has been designed by Chris to work as a show garden and as a permanent garden scheme. It will provide a private and reflective space for parents and families of the children undergoing care at GOSH and will appear at RHS Chelsea Flower Show prior to being completed at the hospital in summer 2016.

Give to GOSH appeal

Over the festive period and into the New Year, Great Ormond Street Hospital Children's Charity was the partner for *The Independent*, *Evening Standard*, *i* and London Live Give to GOSH appeal.

Ending on 14 February 2016 – the hospital's birthday – funds raised by the appeal will help support research programmes for children with rare diseases, the creation of a new unit for children with heart failure, the Louis Dundas Centre for Children's Palliative Care, and patient and family support programmes at the hospital.

Visit gosh.org/givetogoshappeal to see the coverage and exciting video content.



Care Quality Commission report rates GOSH as 'good'

In April and May 2015, the Trust was visited by the Care Quality Commission (CQC). The CQC are the independent healthcare regulator for England. They look at hospital services to make sure they are meeting standards of quality and safety.

We are very pleased to have been rated as 'good' overall, with the report highlighting many areas of outstanding practice.

Full reports for the inspection have been published on the CQC website.

“The children and young people we met were extremely positive about the treatment they received.”

Professor Sir Mike Richards,
CQC Chief Inspector of Hospitals

While the report is good, there are always areas we need to improve. We know that our record keeping and administration processes have not been as good as our clinical care. Work is now well under way to make this better.

GO Create! goes under the microscope

Under the Microscope is a year-long arts research project led by artist Sofie Layton, working with GO Create! and the National Institute for Health Research Biomedical Research Centre.

The project looked at how children and their families see medical information and understand disease. It concluded in a two-part exhibition made by Sofie with the help of clinicians, researchers, and patients



and their families at GOSH in February and March 2016.

Want to know more about GO Create!? Go online at gosh.nhs.uk/gocreate or



follow GO Create! on Twitter @gocreateGOSH

GO Create! is funded by Great Ormond Street Hospital Children's Charity.

BEHIND THE SCENES



Behind the scenes
with hospital Porter
Hayden Peters

Hayden Peters has been working at Great Ormond Street Hospital (GOSH) since February 2015 after being in the construction industry

Daily duties

"The role of a porter is really diverse. One day I could be doing lots of patient transfers. Another day I could be running around transporting beds and cots. It keeps me on my toes.

"We have a number of different tasks: we collect blood products and deliver them to wards, we transfer patients across the hospital, we ensure the corridors are clean and pristine, and we make sure we're on top of health and safety. We're like the veins of the hospital – we deliver everything and keep GOSH moving and running.

"The nurses in particular are always happy with us – if they request something, we're usually able to help within 10 minutes or so. I'm a general porter, but there are also theatre porters and kitchen porters to look after those areas, so we cover all bases.

"If it's really busy, you hardly get a moment to sit down. You finish a job and the next job will come in straight after, so the day flies by!"

Rewarding work

"I like my role because I get to help everybody and everyone's a team player. I've met some great people. They'll always point me in the right direction for a job and they've made me become a better porter for it.

"To be part of the team that cares for the children here is something I am very proud of. I never had this same pride working on building sites. The porters are a small but very close-knit team. It is genuinely a pleasure to work here.

"The best thing is keeping everyone smiling, busting jokes and making the children laugh. Some of the parents are really kind so you have a chat with them and a giggle in the lift. It brightens my day and makes it go quickly.

"When I'm happy and I'm having a really good day at work, I tend to sing and dance along the corridors!"

Did you know?

There are 28 porters at the hospital, operating 24 hours a day, 365 days a year.

Talking to Mark Davis, Head of Portering

"Every single patient that is treated at GOSH has some input from my teams. When a patient arrives they lie in a bed delivered by us. The forms completed by the medical staff were delivered by us using pens transported

by us. The food families and staff eat was delivered by us in its raw state and then redelivered by us once prepared. The oxygen that patients breathe is supplied via masks that we delivered. All of this is usually done

without any patient or family ever seeing us. The things we are best known for, such as moving patients or collecting specimens, make up only a tiny percentage of what we do."

MY STORY

Charlotte is 16 years old and in 2012 was diagnosed with Tourette syndrome, a neurological condition where people experience tics in the form of uncontrollable movements or sounds. Charlotte visits the Tourette syndrome Clinic at Great Ormond Street Hospital (GOSH) to undergo treatment, and has raised more than £1000 to support the hospital. Here's her story

Charlotte's diagnosis

I can only describe having Tourette's as a constant, painful itch that you can't quite reach. I started getting leg cramps in early 2010, followed by a hand tic in May 2011. I was diagnosed with the syndrome in November 2012, after developing vocal tics. Three years and 16 types of tic later, GOSH has helped me enormously in finding the right medication, confidence and general happiness.

Living with Tourette syndrome

It is hard living with Tourette's, especially considering how little people know about what's actually a relatively common condition. One thing that makes it so hard is all the myths surrounding the syndrome, for example, only 10 per cent of people actually swear as part of their Tourette's.

At the start of my treatment in November 2012, I suppressed my tics all day at school as I didn't want anyone to see them. This resulted in a lot of

pain, distress and unhappiness. I felt I was unable to be myself, which made going to school an enormous struggle.

GOSH supported me, liaising with my brilliant school about what support I needed and giving me habit reversal therapy, starting with the arm tic. Habit reversal therapy is a way of combatting the pain and distress of tics by replacing the movements with ones less obvious and painful.

In February 2015, I started a course of exposure and response prevention, or, put simply – 'try to suppress all your tics at once'. This was extremely difficult, and involved timing how long I could suppress my tics at the same time. When I managed longer lengths of time, my mum and the doctors would describe the tic to me, and then my family would do my tic in front of me, with the aim of exposing me to the feeling of wanting to tic (which in itself can be worse than the actual tic), so that I could learn how to ignore the feeling. That bit was especially horrible!

When I was discharged in October of last year, the severity of my tics was scored. In clinical trials (which tend to show the very best case results), the improvement of tics is, on average, 30 per cent. For me, in the space of six months, my tics had improved by 58 per cent!

Fundraising for GOSH

I raised more than £1000 for GOSH with the help of my friends and school by selling cakes and badges. During Year 10, I also gave a speech to my year group about having Tourette's – only a year earlier I was unable to tell anyone except about five close friends. I've also been on an inspirational part-volunteer trip to India, which greatly helped me to cope with my Tourette's, where I helped children from slums have an education, as well as learning more about myself.

GOSH is a lovely hospital to be a part of, all the staff are caring, the facilities are fantastic and the treatment is exceptional.

Could you share your story with us to help other young people?
Get in touch at gosh.nhs.uk/shareyourstory



Famous faces in the hospital

Mark Hamill pays not one, but two, special visits to the hospital

Mark Hamill, also known as **Luke Skywalker**, visited the hospital before Christmas and enjoyed the experience so much he wanted to come back and meet more children and young people.

He visited the wards, where he handed out goody bags and signed *Star Wars* posters. Mark tweeted about the visit which received more than 1,000 likes!



Hospital celebrates importance of play

Our roving reporter Bernard Bear went to check out all the action during the annual Play in Hospital Week. There was a fun event in The Lagoon restaurant and Bernard ran in to Herb, from the BBC Two documentary *Great Ormond Street* and CBeebies star **Chris Jarvis**



Gordon and Tana Ramsay launch partnership

Gordon and Tana Ramsay met patients and staff at Great Ormond Street Hospital (GOSH) as they announced a new partnership between The Gordon and Tana Ramsay Foundation and Great Ormond Street Hospital Children's Charity. The couple took part in cake decorating and colouring activities with children who were preparing for dialysis treatment. They met patients and their parents, aged from six to 12, as well as staff from the hospital's Play team.

GOSH in the 21st century



3D printing makes difficult procedure easier to carry out in children

An exact model of a windpipe, created using a 3D printer, has been used at Great Ormond Street Hospital (GOSH) to practice a difficult operation before it was carried out on a patient.

The model windpipe, which can be created in just a few hours, means equipment that is best matched to a patient's size and shape can be chosen before surgery, so they spend less time in the operating room.

3D printing is already used to help doctors explain to patients what is happening inside them. Doctors at GOSH have now shown that 3D models could also make difficult surgery even safer for children.

The 3D model was first used in six-year-old Katie, who has a lung condition. Her lungs have to be 'washed out' regularly to keep her healthy.



Katie with her mum and dad

Tailor-made

"Each time a child comes in to have their procedure, they will have grown and so need different equipment to carry out their treatment. A model that is tailor-made to the child each time they come in for surgery means that we can carry out operations more quickly and safely."

Colin Wallis
GOSH Respiratory Consultant Physician



Young People's Forum update



Annabel aged 15, has been an active member of the Young People's Forum (YPF) since January 2015. She has always been interested in Great Ormond Street Hospital (GOSH) and, despite having never been a patient, wants to help make a positive difference. Below, Annabel tells us the latest with the YPF



The YPF is a group of young adults aged 11–25 who have one common passion: ensuring that the voices of young people at GOSH are heard. We meet up at the hospital at least six times a year to help us achieve this goal.

The YPF is involved in a number of exciting projects. Most recently, we met with Dr Peter Steer, the Chief Executive at GOSH, and were given the chance to ask him lots of questions. Look out for the highlights from that session in the next edition of *Member Matters*.

We also had a meeting with the Redevelopment team and put forward our ideas for the 'GOSH of the future'. I personally really enjoyed the creativity of this session.

At the end of 2015, the forum had the fantastic opportunity to work in an area of the hospital very important to us – food! We met with the Head of

Catering, toured the kitchen and put forward our ideas for new menus. Suggestions included sweet potato fries and a burrito bar. You can read more about this on the next page.

In early December 2015, Great Ormond Street Hospital Children's Charity held its first London Santa Dash on Clapham Common! With 1,700 supporters dressed as Santa and running 5k or 10k routes, it was a fantastic way to kick off the festive season.

I organised a team of 13 people from my school, which actually included a former GOSH patient. Together, we ran 5k and raised more than £1,200 for the charity. For most of the team it was their first time fundraising and getting involved with GOSH. However, the event was so much fun that they are all already excited about signing up for the London Santa Dash 2016!

If you want to read more about the YPF, check out the teenagers' section of the website at gosh.nhs.uk/teenagers

Want to join Annabel and the YPF? The YPF is open to anyone aged between 11 and 25 who's interested in making the voice of young people at GOSH heard. Contact the YPF at ypf.member@gosh.nhs.uk

MEMBERS' COUNCIL what we have achieved



Camden Council, on behalf of the Food Standards Agency, gave GOSH five out of five for food hygiene in December 2015.

A taste for improvement

Thanks to our Foundation Trust (FT) members and the Young People's Forum (YPF) the food has been made better at Great Ormond Street Hospital (GOSH).

- There's more fruit and veg on the menu, and the menu is changed four times a year.
- Food ingredients are of a higher quality and come from nearby, like farms in the southeast of England.
- The number of fresh fish options on the menu has gone up.



The changes to our menu were made without costing the hospital any more

money. The Catering team worked hard to make savings on fresh fruit, vegetables and dairy. This meant we could spend more money on things like meat and fish. We now make more of our dishes on site, in the hospital's very own kitchen.

Back in November 2015, the YPF and FT members were treated to a tour of the kitchen and a food tasting session. They gave their opinions on hake and basil mash and a shepherdess pie, as well as sweet treats like chocolate orange bread and butter pudding.



Protected mealtimes launched

The protected mealtimes scheme launched at GOSH in February 2016. Protected mealtimes help children and young people eat for good health by allowing more time to focus on eating and bottle/ breastfeeding with their parent or carer. It also gives children and young people time to eat their meals in an uninterrupted environment. Implementing this initiative across the hospital is part of the ongoing work to improve patient and parent experience at the Trust.



What happens...

when you take part in research?

A multidisciplinary approach to research

Our patients and their families come into contact with many members of staff from across Great Ormond Street Hospital (GOSH). This multidisciplinary approach ensures that they receive the best level of care that we can provide.

For those patients taking part in research, it's no different. The Dubowitz Neuromuscular Centre at GOSH is a leading clinical and research centre specialising in neuromuscular disorders affecting children.

Nine-year-old Harrison has Duchenne muscular dystrophy (DMD), a condition that causes the gradual deterioration of muscle strength. He is taking part in a clinical trial at the centre to help him with his condition.

Here, we meet some of the members of the neuromuscular and Somers Clinical Research Facility (CRF) team who care for Harrison when he comes to GOSH.

1 Professor Francesco Muntoni, Principal Investigator

"My role as the lead for this trial is to ensure that my team is trained and up to speed with the protocol. I ensure that the study is delivered safely and timely. I explain the trial to Harrison and his family, gaining their consent and assent."

2 Jonathan Goddard, Medical Laboratory Assistant, CRF

"I work in the CRF laboratory, processing Harrison's samples so they can be analysed. The CRF offers a friendly face and warm welcome for children and young people with diverse and sometimes very severe illnesses."



3 Rasha Said, CRF Research Pharmacist

"I follow procedures outlined by the study protocol to make sure that the trial medication given exactly matches what the study stipulates. I really enjoy working in research because I feel that I am contributing to a patient's treatment that might be cutting-edge."

4 Lawrence Vermeir, Data Manager

"I am responsible for entering data collected from Harrison's visits onto an electronic system used to collate clinical trial data. Clinical research is vital to the development of safe and effective new treatments, which is especially important here at GOSH as the hospital specialises in looking after children with rare and complex conditions."

5 Karen Walker, CRF Receptionist

"I have been at GOSH for over a month now and meet Harrison and his family on arrival to the CRF."



8 Chilenwa Uzowuru, Clinical Trial Co-ordinator

"I co-ordinate the set-up of neuromuscular clinical trials. This involves submitting information to the Research and Development office, as well as the Research Ethics Committees, in order to gain the ethics approvals and regulations that allow a trial to start."

9 Mario Iodice, Research Physiotherapist

"I have worked at GOSH for nearly a year and assess Harrison in order to evaluate whether his functional activities have improved. I am really proud to work in such a place."

10 Katie Groves, Senior Neuromuscular Research Nurse

"I look after Harrison when he comes to the CRF for his visit and administer the study drug. I am also the contact for the family in between hospital visits should they have any questions."

11 Jessica Cooper, Superintendent Radiographer of MRI

"I have an interest in research MRI, so I am a member of a small team of MRI-trained research radiographers here at GOSH."

"For research studies it is very important that all the scan settings we use each time are exactly the same so the data will be a good comparison."



6 Lorraine Pratt, CRF Play Specialist

"I provide fun activities, games and lots more to keep patients happy when they are on the CRF. I help when a child or young person is worried about any aspect of being in hospital, or taking part in a trial, and provide therapeutic play to help them express any feelings or concerns."

7 Joana Domingos, Clinical Research Fellow

"I see Harrison at every visit and discuss with his parents how he's been getting on. My role is to evaluate any possible adverse events, perform examinations and prescribe the study drug."



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 2016

All meetings run 4 – 6.30pm

Wednesday 27 April
Wednesday 29 June
Wednesday 28 Sep

Trust Board meetings 2016

Please visit gosh.nhs.uk/trustboardmeetings for further details on times for the Trust Board meetings.

Members are welcome to attend the public session.

Friday 1 April
Friday 20 May
Wednesday 20 July
Wednesday 28 Sep

Annual General Meeting and Annual Members' Meeting

Thursday 15 Sep 2016

Lecture Theatre
Weston House
63-67 Great Ormond Street
London WC1N 3HZ

5.30 – 7pm

For further information, please contact us at foundation@gosh.nhs.uk



RBC Race for the Kids

Sunday 15 May 2016

Our 5k family fun run is back and bigger than ever! The event is taking place in a brand-new location – London's iconic Queen Elizabeth Olympic Park.

RBC Race for the Kids is open to everyone, and you can make your way around the course however you like. Visit raceforthekids.co.uk to sign up.

foundation@gosh.nhs.uk gosh.nhs.uk/foundation

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