

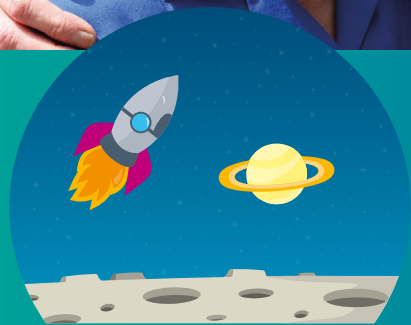
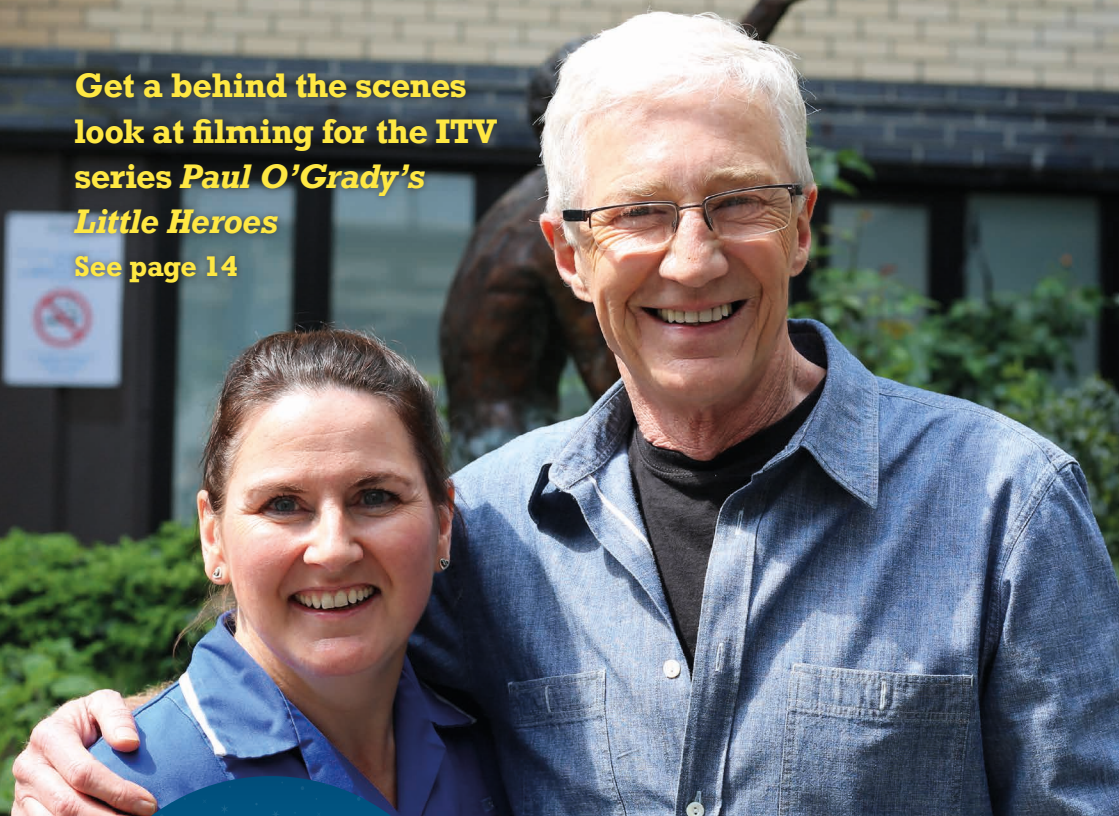
Spring 2019

Member Matters

Youth Edition

**Get a behind the scenes
look at filming for the ITV
series *Paul O'Grady's
Little Heroes***

See page 14



The future at our fingertips

Launching GOSH's electronic
patient record system

See page 8



GREAT
ORMOND
STREET
HOSPITAL
CHARITY

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FREE!

Adult early bird
registration is **£18** for a
limited time only.

Join our family festival and 5k fun run

Walk, jog, scoot or wheel 5k with your family and enjoy a day full of entertainment. Sign up to RBC Race for the Kids and help seriously ill children at Great Ormond Street Hospital.

Saturday 12 October, Hyde Park

Race starts 10am with entertainment until 2pm.

gosh.org/rbcraceforthekids

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Introduction

Welcome to the spring 2019 edition
of *Member Matters*.

Hi everyone,

Welcome to another edition of *Member Matters*, your one-stop magazine for all the goings on at Great Ormond Street Hospital (GOSH). This is a special welcome, because it's from us – your two new Young People's Forum (YPF) representatives on the Council of Governors – Emma and Josh.

Our role as YPF Governors is to ensure that the voice and opinions of children and young people are heard all the way up to the top and are taken into consideration when big decisions are being made.

Emma: I've been a patient at GOSH for the last 13 years until I transitioned to adult services in March. As a member of the YPF for the last four years, I've made lots of friends who all know what it's like to be a young person in hospital. During my time at GOSH the hospital has changed dramatically and I've seen how facilities such as the Lagoon and Morgan Stanley Garden have made a real difference to patients, their parents and their siblings.

Josh: I've been coming to GOSH as both an inpatient and outpatient since the age of 8. More recently, I've transferred to University College London Hospital (UCLH) and remain under neurology here. I've also been part of the YPF since December 2017. GOSH is an inspiring place and has encouraged me to make the most of every opportunity. Without GOSH, my life would be very different today.

In this edition of *Member Matters*, you'll get to know the hospital's new Chief Executive, Mat Shaw. We take a look behind the scenes of filming for *Paul O'Grady Little Heroes*, which is back for a second season this summer. We'll also fill you in on what our members have been up to.

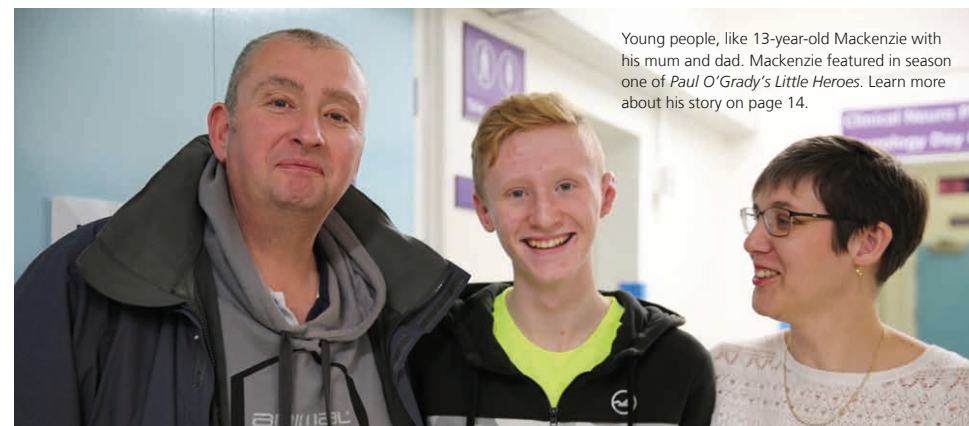
GOSH provides so many children and young people with a positive future, and we're lucky to represent the YPF on the Council of Governors. We're looking forward to meeting more of you, our amazing members!

Emma and Josh

Welcome!

In December, **Mat Shaw** became the hospital's new **Chief Executive**. You may recognise Mat's face from *Member Matters* this time last year, when he joined the hospital as Medical Director. Mat's background is in orthopaedic spinal surgery, particularly scoliosis – fixing a curved spine. Mat is a keen cyclist and is riding Paris to London this year for Great Ormond Street Hospital Children's Charity (GOSH Charity). Get to know more about Mat on page 6.

Caroline Anderson is really excited to join GOSH as the new **Director of Human Resources and Organisational Development**. It's her third director role, having previously worked at the Land Registry (at Hackney and Greenwich Councils) as well as in the electricity industry. Caroline is all about empowering staff and wants to make GOSH a great place to work. She brings lots of energy and passion to the Trust.



Young people, like 13-year-old Mackenzie with his mum and dad. Mackenzie featured in season one of *Paul O'Grady's Little Heroes*. Learn more about his story on page 14.

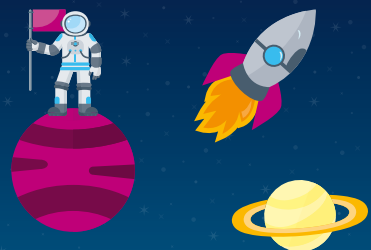
Preparing for adulthood

'Growing Up, Gaining Independence' is GOSH's new framework to support young people and families to get ready for adult care. It's been developed together with the YPF, GOSH families and those working in healthcare. There's lots of resources for young people and families, so check it out on our website at gosh.nhs.uk/your-hospital-visit/growing-gaining-independence.



Ground-breaking new cancer therapy

In a similar way that we use cars and GPS to help us reach a destination, researchers like Dr Sara Ghorashian (pictured) are now using patients' immune systems as vehicles, and then preparing them with the navigational know-how to reach and destroy cancer cells. In January, a GOSH patient became the first NHS patient to have this therapy, known as CAR-T. You can read more about CAR-T therapy at gosh.nhs.uk/news/gosh-patient-first-receive-ground-breaking-new-cancer-therapy-nhs.



FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

Our 'Epic' launch

GOSH's electronic patient record (EPR) system, Epic, is here!

Not only will Epic help our staff at the hospital, the new MyGOSH portal will allow patients to plan appointments, view results, contact their clinical teams, and even request some prescriptions. It's the largest clinical transformation we've seen at the hospital and it's going to revolutionise the care we provide to patients and families! Learn more about Epic and MyGOSH on page 8.

MAT SHAW INTERVIEW

Meet Mat Shaw

GOSH's new CEO Mat Shaw shares his background, hopes for the hospital, and his daughter's experience at GOSH.

What made you choose GOSH as a place to work?

What better place could I work than GOSH? It has an excellent reputation for research and offers some great opportunities.

What were your first impressions?

I met a lot of smart and motivated people. It's an organisation that wants to do the best for children, to find new treatments and give the best care possible.

Tell us about your medical background

I'm a spinal surgeon by background and mainly operate on children. My focus is fixing scoliosis, which is when children have curved spines. Their bones either bend forward or to the side. Over time those bends worsen and the child becomes imbalanced and in a lot of pain. I stop those curves from getting worse.

What inspired you to become CEO?

I have a real passion for health and equality. In England, children tend not to receive as good treatment as adults. For example, some hospitals only have a couple of anaesthetists that can put children to sleep, so children wait days for treatment, whereas adults get it immediately. That's something I want to help change.

Tell us about your personal experience at GOSH

When my daughter was younger, she was playing with some Lego and said her hand felt funny. I thought she'd been lying on her hand. We started to walk to the cinema and I noticed her face had drooped on one side – it looked like she was having a stroke. We came to GOSH and the treatment she got was amazing.



Mat Shaw and his children.

FAMOUS FACES IN THE HOSPITAL

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



Actor Tom Hiddleston visited patient Angel on Eagle Ward.



Actor and presenter Cel Spellman with Sofiyat at the hospital's Tree of Life workshop.



Olympic cyclist Dani Rowe MBE meets India on Bear Ward.



TV presenter Stephen Mulhern with Paris, an audiology patient at GOSH.

The future at our fingertips

After three years of planning, building and testing, GOSH went live with its EPR system, Epic, over the Easter weekend.

What is Epic?

Epic is an online system that brings together all patient information in one place. Reducing the need for paper records, the most up-to-date information can now be accessed by a patient's entire clinical team at the tap of a screen. Epic will transform the way GOSH staff access patient data, meaning they can spend less time on day-to-day admin and more time delivering the best patient care and experience.

Epic will also make it much easier for staff to identify patients who are involved in research. Staff can simply click to find out more about the study and can easily flag up any concerns around research trial participants. We'll also be able to track the number of studies run by each speciality, giving greater visibility for the exciting research happening at GOSH.

The benefit to patients and families

The EPR system will also make patients' and their families' lives easier. Through MyGOSH, they can now have secure remote access to information about their care, including scheduled appointments, test results and more.

The roll out of Epic is the largest clinical transformation the hospital has ever seen, involving hundreds (if not thousands) of hours of training and preparation. Thanks to crucial funding from GOSH Charity, the hospital can give, through Epic, every child and family the best care and experience possible. The move to an online patient record system will also allow GOSH to invest in new technologies in the future, including virtual reality and robotics.

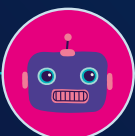
Benefits of Epic



More efficient
check-in process



Innovative
research



Virtual reality
and robotics



Faster
diagnoses



Home
monitoring

MyGOSH

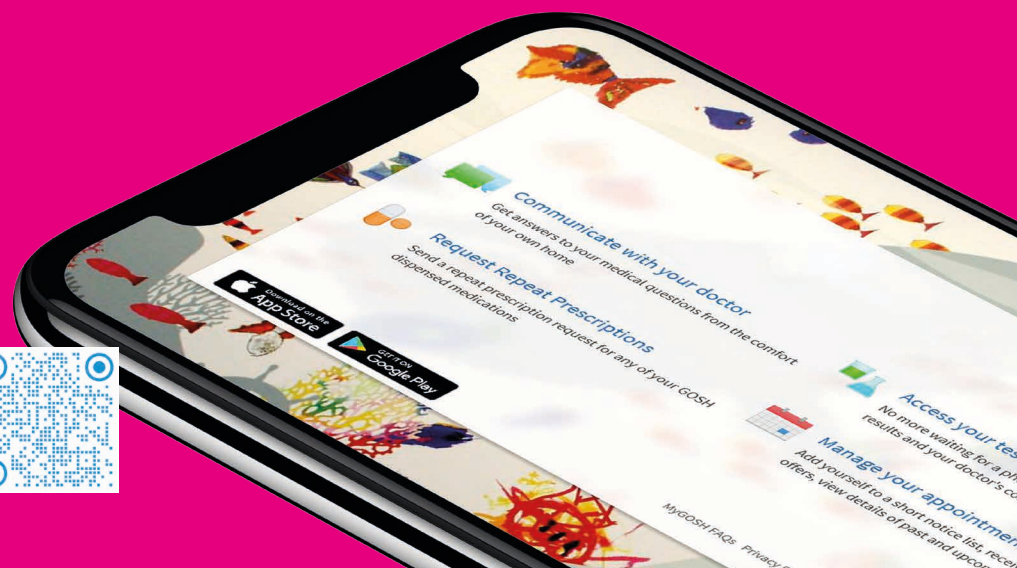
Get connected to your health

Access your online portal, anywhere, anytime.

Log in to see test results, view or change appointments online, accept earlier appointment offers and more.

Not signed up yet?

Visit gosh.nhs.uk/mygosh



YOUNG PEOPLE'S FORUM UPDATE



From presenting at conferences to participating in forums and workshops (both in and out of London), our YPF has been very busy over the last six months.



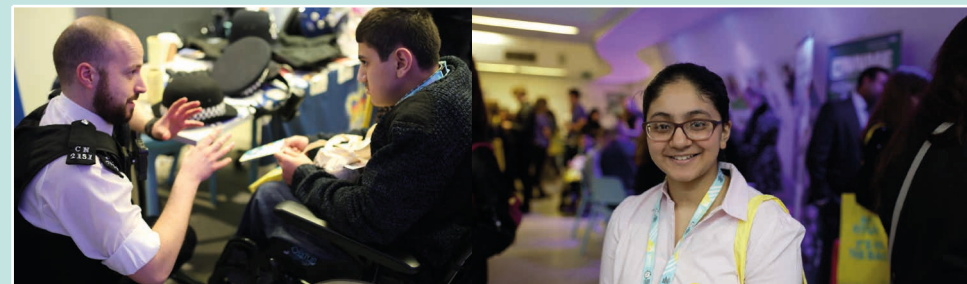
Fourteen-year-old Foundation Trust member Hannah presented at the **GOSH Conference 2018**. Hannah's brother is a patient at GOSH and she gave an incredibly mature and inspiring talk on how her family's life has been affected by her brother's condition. It was a very impressive performance and set the bar very high for the rest of the speakers.



YPF Governor Emma has successfully become a lay member for the **National Institute for Health and Care Excellence**. This means that she will be influencing the creation of new guidelines about babies, children and young people's experience of healthcare to ensure young people have a voice.



YPF members travelled to Derbyshire Children's Hospital in November for the second **BIG Youth Forum Meet Up** and met with youth forums from all over the country. At the first BIG Youth Forum Meet Up, which was hosted by GOSH, mental health and wellbeing was voted the most important issue for young people in hospital and so this was the theme for November's meeting, with the youth forums discussing ideas on how their hospitals could improve these services.



GOSH Teens Careers Festival, an exclusive event for GOSH patients aged 14–18, took place in February. Foundation Trust members who are also patients or ex-patients were offered the opportunity to meet a diverse range of organisations such as Microsoft, Disney and the Metropolitan Police, and take part in workshops to find out how to make it in the world of work.



For a week last November, 26 children and young people took over jobs in both the hospital and GOSH Charity as part of the Children's Commissioner's **Takeover Challenge**. The annual challenge puts young people into decision-making positions, allowing them to learn about different roles in the workplace and to gain confidence and valuable life skills. It also gives staff and organisations the opportunity to benefit from a fresh perspective.

Grace (pictured) said of her experience: "I took over the role of a matron for the day and my favourite part was meeting patients and families as well as learning how to do observations on student nurses. It was a fantastic opportunity and I had an AMAZING day!"

If you would like to join the Takeover mailing list, email Amy.Sutton@gosh.nhs.uk.



YPF members hosted **Q&A sessions** with gold-medal winning **Paralympian** and ex-GOSH patient **Ollie Hynd** (pictured) and motivational speaker and ex-GOSH patient Ant Bennett, who gave amazing advice on how to achieve your goals.



Members Al, Emma, Josh and Sandra were part of a group of young people, paediatricians, parents and carers that attended a **workshop** at the **Royal College of Paediatrics and Child Health** to help develop a training strategy for paediatricians.

PIONEERING RESEARCH

A new drug for a rare bone disease

Thanks to research, children with a bone disease called X-Linked Hypophosphataemic rickets (XLH) are now getting a new medicine that can make their bones stronger and improve growth.

There are about 300 children in the UK with XLH. It runs in families and is due to too much of a substance called phosphate being lost in the urine. With less phosphate the bones can swell, which causes the legs to be weaker and can be painful. Previously, the only medicines for XLH were a special vitamin and large doses of bad-tasting phosphate, which had to be taken several times a day and caused stomach problems. The new drug, which is called burosumab, helps stop so much phosphate being lost and can strengthen the bones and reduce pain.

Staff at GOSH and other hospitals carried out research where they offered the new medicine to some children with XLH for the first time. At the end of the research they found that burosumab improved the children's bones and helped them grow better. Burosumab was much more convenient as children only needed to have one injection every two weeks, rather than taking phosphate many times a day. Following the trial, burosumab was approved by the NHS and is now being offered to children with XLH from all over the UK.



L-R: Ashley and Lottie.



L-R: Dr van't Hoff, Ashley, Lottie, and nurse Terrie at the beginning of the trial.

Lottie and Ashley's story

Lottie, 15, and her younger brother Ashley, 13, heard about a new research study called a clinical trial for children with XLH from their consultant at GOSH, Dr William van't Hoff.

Ashley said: "I thought it could help other people with our condition and it would help my family too as lots of us have XLH". Their mum Gemma said: "Our whole family was excited when Lottie and Ashley entered the clinical trial."

While they were on the trial Lottie and Ashley regularly visited the National Institute for Health Research Great Ormond Street Hospital Clinical Research Facility – one of the wards where children can take part in research – and had their injections of the new burosumab drug. "To start with the injections were quite hard but eventually I got used to them," said Ashley.

Every few months Lottie and Ashley also had assessments with a physiotherapist to see how well the drug was working. "We had our height and leg length measured, and a test to see how far we could walk around a track in six minutes," said Lottie.

Gemma said: "Ashley is very energetic and Lottie can walk further since being on the trial so we have definitely seen a difference." Ashley said: "It's much better. I don't get aches and pains anymore."

Now the drug has been approved for the NHS, Lottie and Ashley can have the injections at home but they still come back to GOSH every few months for check-ups. "I didn't expect the nurses and doctors to be so nice. They are kind and they all spend lots of time with my brother and I," said Lottie.

BEHIND THE SCENES



Filming for the ITV series *Paul O'Grady's Little Heroes*

A very special visitor has been in the hospital for the last few months. His recognisable face has become a familiar sight, and his laugh can be heard echoing through the corridors...

Following the successful first series of *Paul O'Grady's Little Heroes* last summer, Paul has been back at GOSH filming series two!

The six-part series introduces a handful of the 619 children who pass through GOSH's doors every day.

Each 30-minute episode is focused on 2-3 children and their journey through GOSH. Over the course of the filming, the crew spent nearly 400 hours in the hospital and met with 24 patients and families, with around 98 staff members and volunteers being involved in the series in some way.

Paul said of his experience: "It has been an absolute honour to film at GOSH, meeting the children and their families as they go through some of their toughest days. They were truly inspiring. I have so much admiration for the truly dedicated staff who treat and care for them."

Keep an eye out for series two of *Paul O'Grady's Little Heroes*, coming this summer on ITV.

Denise Thew (pictured below) is a Play Worker on Panther Ward.

She worked with the production team during series one with a number of patients, including Mackenzie, who shares his story below. Denise said: "Meeting and filming with Paul O'Grady was very rewarding. Paul has a great way of calming the patients and their families during very difficult and stressful times – he showed a wealth of compassion and understanding."

"He was also great fun to be around. A moment that particularly stands out is during one session when we were creating bubble paintings, so that a patient could make her room in the hospital feel more like home. Paul was so laid-back during the session (literally!) that he broke his chair. Thankfully he saw the funny side though!"

"The ward staff really appreciate the effort and time that has gone into filming the series, and it will provide a positive outlook on the work that is done every day at the hospital, the staff who work here and the families and patients who walk through our doors."



Thirteen-year-old Mackenzie (pictured above left), from Norfolk, was one of the stars of series one, episode one.

He has microtia, a condition where you are born with a small or absent ear. Paul witnessed his reconstruction surgery where his new ear was made from cartilage taken from his ribcage.

Mackenzie said: "It was nice being on the show, I really did enjoy it. It was an amazing experience which I will never forget."

"I really enjoyed taking part because I could tell my story and meet Paul O'Grady. He was so funny and is a really nice person to be around, and when I was in pain, he could always put a smile on my face."



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 17 July
Starts at 3pm

Tuesday 26 November
Starts at 3pm

Trust Board meeting

Wednesday 22 May

Thursday 18 July

Wednesday 18 September

Wednesday 27 November

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.

Annual General Meeting

Tuesday 1 October
5–7.30pm, the Lagoon, GOSH

YPF meeting

Saturday 13 July

Saturday 10 August

Saturday 12 October

Saturday 14 December

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

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