

Spring 2017

# Member Matters

Young people's edition



## Taking part in a clinical trial

Read Teigan's story on page 8

## Young people take over the hospital

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## WELCOME

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



I'm **Faiza** and I was recently elected as Chair of the Young People's Forum (YPF). The YPF aims to improve the experience of hospital life for patients at Great Ormond Street Hospital (GOSH). We're made up of young people aged 11–25 years old, and we're all either patients, former patients, or siblings of patients who have visited GOSH.

I hold GOSH close to my heart. It has been a home away from home since I was a few weeks old up until I was 19. When I was a baby, my parents noticed there was something wrong with me. Within a day, I'd gone from the GP, to the local hospital, to GOSH. I was diagnosed with a rare form of congenital heart disease known as tetralogy of Fallot. Without GOSH, I wouldn't be here today.

As young people, we should be involved as much as possible in our care. Members of the YPF have first-hand experience of being treated at GOSH and, together, we can unite and make life better for the patients of today and the future.

As Chair, I want to build a happy teen-centred community, so young people feel they are at the centre of GOSH's work – after all, the hospital motto is 'the child first and always'. I want to make sure our voices are heard and that we're empowered to make changes.

This edition of *Member Matters* includes lots of great stories about young people at GOSH. We meet Teigan on page eight, who undertook a gene therapy trial, and on page 15, siblings Morgan and Grace experiment with Computer Aided Design software as part of the Takeover Challenge (you can read more about the challenge on pages 10 and 11). Finally, on page 12, we hear about the great work of patient Ezara-Mai, who has encouraged her classmates to write stories about the ward animals at GOSH.

Wishing you happiness and health,



Faiza

PS Check out page 14 – can you believe Captain Jack Sparrow visited the hospital?

# FOUNDATION TRUST NEWS

## EPR supplier announced

In February, Great Ormond Street Hospital (GOSH) awarded the preferred supplier for our Electronic Patient Record (EPR) system to Epic and confirmed Aridhia as the preferred supplier for the research and innovation platform.

Once rolled out, the EPR will support clinicians to access information rapidly and from a single place. There will be a portal for patients, meaning better communication between the hospital, patients and their families.

For further information or to get involved in the programme, email [EPR@gosh.nhs.uk](mailto:EPR@gosh.nhs.uk)



EPR Programme Manager Helen Vigne meets Nurse Wendy at the Trust's 2016 Listening Event

## Going on a blood quest

GOSH has launched a brand new app called Blood Quest, which aims to help alleviate children and young people's anxieties when they have a blood test. The ORCHID research team (Centre for Outcomes and Experience Research in Children's Health, Illness and Disability) developed the app with GOSH Arts, the hospital's arts programme. The app includes a 'quest' game and quizzes about animals and their hearts, which aim to distract children and young people when undergoing a blood test. Blood Quest is free to download from the App Store.



which causes bone marrow failure and increases the likelihood of certain cancers. Despite their condition, Emma and James have organised and taken part in fundraising activities for GOSH. By raising awareness of their illness, more people in their community are now donating blood on a regular basis. Well done, Emma and James!



## Filmmaking: Always Welcoming

Our Always Values support GOSH staff to make a difference every day in everything we do and say. In winter, GOSH Arts and the Patient Experience team worked together to create a short film to help share our values with our patients. The film focuses on Our Always Welcoming value and what this means to families at GOSH. Look out for the film on the patient bedside entertainment system and on screens throughout the hospital! Watch the film at [youtube.com/GOSHCharity](https://youtube.com/GOSHCharity).



## Nikki is a vlogging star!

Congratulations to GOSH patient Nikki who recently won an ITV Pride of Britain award. Nikki has a facial AVM, a very rare and potentially life-threatening condition that gives her heavy nosebleeds and headaches.



Nikki proudly shows off her award

She was recognised for her inspiring work to raise awareness of the condition through her vlogging and her amazing fundraising efforts for research at GOSH and the UCL Great Ormond Street Institute of Child Health. Nikki is a rising star on YouTube and uploads new videos weekly, vlogging about baking, family, friends and her daily life.

On collecting her award, Nikki said: "Despite it being a nerve-wracking evening, it was so amazing to be there. It was the best night of my life. The key thing I want people to know is there's no such thing as 'I can't', despite what you're going through."

## Improving our text messaging appointment service

The Members' Council believe it's important to hear your views on how GOSH can improve services. George Howell, Councillor representing patients from outside London, explains: "Last year, when speaking to some of our hospital community, concerns were raised about the text messaging appointment service – the old system was not delivering clear enough messages. We spoke about these issues at the Members' Council meeting and are pleased to say that GOSH is working with DrDoctor, a patient messaging provider, to look at how we can bring a new, better way of messaging to our patients and families."



# BEHIND THE SCENES



## Intensive care on the move

**Meow! Have you heard of CATS? No, not that type of cat – but the Children's Acute Transport Service (CATS). Similar to an ambulance, CATS provides urgent care transport for children requiring transfer to a paediatric intensive care unit (PICU). Based at Great Ormond Street Hospital (GOSH), CATS supports around 50 hospitals in the North Thames and East Anglia regions.**



Beverley Halverson-Steele is a Senior Staff Nurse for CATS and forms part of the core team of nurses. She has worked as part of the intensive care transport team since 2007. Recently, Beverley had her 1,000th patient transport journey – the first time anyone at GOSH has reached this milestone!

Over the course of those 1,000 journeys, Beverley has cared for many seriously ill children. Their age range varies greatly – from tiny babies with respiratory infections, to 16-year-olds who might develop a severe infection that requires urgent transfer into intensive care.



### CATS MIGHT FLY

Did you know that CATS can fly? When a child is very unwell, the CATS team can use a helicopter ambulance to fly to them. It's not always easy transporting a quarter of a tonne of equipment and personnel to a sick child, but the helicopter helps to transport an expert team to a child quickly.

When a patient is coming to GOSH, the helicopter lands at Regent's Park. It can be difficult landing in the park, especially when people are around, in bad weather or at night time. Once the helicopter touches down, it takes about 15 minutes to carefully unload the patient into a CATS ambulance, and then it's a five-minute journey to GOSH. It's hoped the time saved by flying makes a difference.



When it's decided that a referral requires admission to intensive care, CATS sends a team to the local hospital. The team assesses and stabilises patients using mobile intensive care equipment and transports the patient to a specialist care centre.

Many of the children requiring intensive care are transferred to GOSH.

There are some differences between CATS and the services provided by local ambulances. One is the make-up of the team – every CATS team has an experienced intensive care nurse and doctor. The other difference is in the ambulances themselves – CATS ambulances are custom-made vehicles with extra seats. This space means that parents can accompany their child on the journey, and the team can explain to the family everything that they are doing.

Beverley says: "Often, taking care of the family is more difficult than helping the child.

"When a family's child is being transported into intensive care, it could very well be the worst day of their lives. It's important that we take them through everything that we're doing, step-by-step."

To find out more about CATS, visit [site.cats.nhs.uk](http://site.cats.nhs.uk)

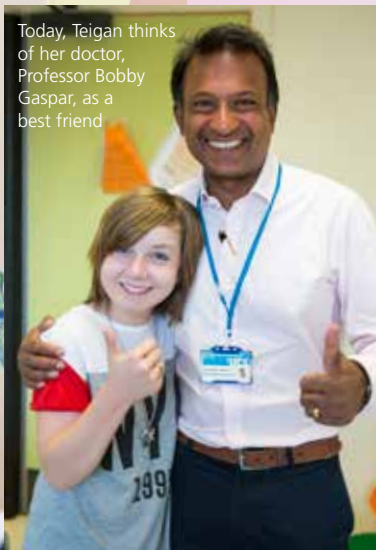




## A critical role in vital research – Teigan's story

At the age of one, Teigan's kidneys began to fail and she was rushed into intensive care. Seven months later, she was diagnosed with an immunodeficiency. With more conventional treatments deemed too risky, experts at Great Ormond Street Hospital (GOSH) suggested that Teigan take part in a pioneering gene therapy trial.

Although taking part in the clinical trial was challenging, Teigan is proud of her contribution to medical knowledge



Today, Teigan thinks of her doctor, Professor Bobby Gaspar, as a best friend

Teigan came to GOSH from her home in Scotland when she was three years old. She'd been diagnosed with severe combined immunodeficiency, which meant that her immune system didn't work properly.

"The first memory I have is a sad one," says Teigan. "I was in the back of an ambulance in Scotland being

rushed to hospital in Glasgow when my kidneys had failed. I still remember it clearly – I could see my dad driving behind me. The doctors said I could've died in a few hours."

### Life on an isolation ward

Teigan was on Robin Ward at GOSH, where patients with immune problems are cared for if they need to be in isolation.

As a result of her condition, Teigan was at a high risk of infection, so spent long periods in isolation. She said: "I was

in this room with big glass windows, talking to my family using an intercom because they weren't allowed in. To keep myself entertained, I drew loads of pictures – and I mean loads!"

### Taking on the trial

Specialists at GOSH told Teigan and her family that the prescribed drugs she was taking would become less effective as she grew and that her health would be increasingly at risk. They decided to join a gene therapy trial that would help treat Teigan's condition.

"When I first started receiving the treatment, I was casually like 'oh, I'm just having gene therapy, la-dee-da-dee-da'. Nowadays, I really can't believe how much I went through. I look back at myself in the hospital and I am always surprised at how much I was able to go through at such a young age. My doctors were a huge help.

"All my hair had fallen out and I was bald. I got quite self-conscious and sensitive about it and wore a bandana. But I've got loads of hair now, and my pet bird, Rio, uses it as a nest," says Teigan.

### Part of a family

Today, Teigan returns to GOSH once every six months for a check-up. "I was really well taken care of by everyone who worked there – I felt like part of a family who really cared for me. When I think about Bobby, my doctor, I think of one of my best friends – he's one of the reasons I'm alive today."

Taking part in clinical trials was a real challenge, but Teigan is proud to have taken part in important research that will help others. "My advice to anyone else on a similar clinical trial would be to stay strong – always remember that what you're going through is for the greater good."



# WHAT HAPPENED WHEN ...

## Young people took over GOSH!

The Takeover Challenge is an annual event from the Children's Commissioner for England. Organisations across the UK invite children and young people to take over jobs and be involved in decision-making. In November 2016, the young people at Great Ormond Street Hospital (GOSH) took over the hospital for a week.

Ten GOSH teams welcomed 27 young people to take over jobs at the hospital from 14 to 18 November. The young people gained some insight into services at GOSH and how decisions are made, and they helped influence the people that make some of those decisions.

"When you are a patient, you don't get a look behind the scenes, it was really exciting to see all that happens and all the people involved." – Young person

The Takeover Challenge gave young people behind the scenes access to the hospital. One benefit was allowing staff without regular patient contact a chance to work with young people who have personal experience of the hospital.



"Everyone appreciated having young people around with such a refreshing and different perspective - great to know the future is in good hands!" – Staff member

On Monday, Ethan, Ezara and Charlie took over the Redevelopment team and got a close look at the new Premier Inn Clinical Building site. They also had a photography lesson and took some stunning photographs of the new building.

Later in the week, GOSH Arts worked with Sara, Eve, Faye, Jamie, Faiza and Francesca, turning those photos into beautiful prints. In the space of a day, they curated, framed and installed an exhibition, which will be on display in the main entrance of the hospital until May.

### Takeover Challenge



### Radio Lollipop

Inpatients Niamhee and Demi, both 11 years old, were chosen by play workers to take over the show for one evening. The girls took control of the decks – picking songs, taking requests and even setting listeners a competition with the help of Radio Lollipop volunteer Smiley Kylie.



### Pharmacy

Judith Cope, Chief Pharmacist, invited three young people to take over the pharmacy. Emma, Thomas and Charlotte spent the day learning all about prescriptions and the careful process of dispensing vital medicines. They also shared their own experiences as patients with the team.



### CEO office

James, Susanna, Maisie and Pavan joined Deputy Chief Executive Nicola Grinstead and former Medical Director Vin Diwakar to chair the monthly divisional review meeting. The divisions reported on their usual measures, such as complaints, compliments and finances, and shared presentations about how young people are engaged in their services. The young people taking over had some great advice for them!



### Floor Manager

Costa joined Floor Manager Michael Glynn for the day, learning about the importance of different levels of cleaning for each area, serving food on the ward, checking equipment, organising supplies and liaising with staff, patients and families at all levels.

If you would like to be involved in the Takeover Challenge this year, please email the Patient Experience team at [patient.experience@gosh.nhs.uk](mailto:patient.experience@gosh.nhs.uk)



## MEMBERS' ACHIEVEMENTS



# A book for bedtime – Ezara-Mai's story

In her early school years, when the pain was at its worst, Ezara-Mai was often unable to sit down in class. Now aged 12, she regularly competes in Latin and Ballroom dancing (in which she holds an under-16 world title), and raises money for Great Ormond Street Hospital Charity – all while regularly attending Great Ormond Street Hospital (GOSH) for treatment.

"When I was first diagnosed, JDM had a big effect on my life," explains Ezara-Mai. "One day, I was really bad, so we went to see the doctor. He immediately sent me to hospital and from there I was referred to GOSH."

"At first, I was in hospital a lot. I was put on medication and, gradually, I've improved. My JDM will never completely go – it just sort of has its moments."



## Fundraising with fairy tales

Ezara-Mai is a member of the Foundation Trust and the Young People's Forum (YPF). She recently created a book of animal stories inspired by the ward names at GOSH.

"I know that children feel like there's not always a lot to do in hospital," says Ezara-Mai. "I thought if they had some stories, they could read them before they go to sleep, and the money raised from the book could go towards new things to help them get better."

Ezara-Mai's fellow school friends wrote 13 different stories, all inspired by ward names at GOSH. "My favourite story was written by Sophie in year three who wrote a story about a kingfisher."

Find out how you can get involved and  
fundraise for GOSH at [gosh.org/joinin](https://gosh.org/joinin)



# YOUNG PEOPLE'S FORUM UPDATE



During the January YPF meeting, members toured an operating theatre.

## Update from our Young People's Forum

In 2017, the Young People's Forum (YPF) will celebrate its fifth birthday. Meeting six times a year, YPF members have a say in improving the experience of teenagers treated at Great Ormond Street Hospital (GOSH). Fiona Jones, Children and Young People's Participation Officer, tells us about the role of the YPF and what they've been up to over the past few months.

"The group is for patients, former patients and siblings aged 11–25 years old who want to use their experiences and opinions of GOSH to make sure the hospital provides the best care and listens to patients," says Fiona.

"When we meet, the group discusses what they think GOSH needs to take action on, we reflect on what GOSH is doing well and hear how patient feedback has made a difference."

## A busy six months

"The YPF have been involved in a number of activities across the hospital.

"In November last year, YPF members and other patients took part in two big events at GOSH: the Takeover Challenge and the Listening Event."

The Takeover Challenge lets young people go behind the scenes and find out how the hospital works on a day-to-day basis. The Listening Event invited families to talk about their experience of the hospital, ask questions and suggest ways to improve.

"Both of these events let young people have a say in the daily life of the hospital, allowing staff at GOSH to see things from a young person's perspective," says Fiona.

## Getting involved

"Another activity we were involved in last year, was learning how to be part of staff interview panels," says Fiona. "It's hoped members of the YPF will have a chance to be on some interview panels later this year."

"This is important, as it not only lets young people have a say, but it also shows new staff how much the voices of young people matter at GOSH.

"For the first meeting of 2017, the YPF had a tour of an operating theatre, learnt about how patient feedback is collected and used, and had a chance to design temporary tattoos with GOSH Arts, the hospital's arts programme."

## YPF MEMBERS WANTED!

Are you aged 11–25 years old and want to join the YPF? The next meeting is scheduled for Saturday 8 July 2017. Contact [ypf.member@gosh.nhs.uk](mailto:ypf.member@gosh.nhs.uk) to join today and have your say in improving the experiences of patients at GOSH.



# FAMOUS FACES IN THE HOSPITAL



## Famous faces bring festive cheer

Just before Christmas, Johnny Depp came to visit patients, families and staff at Great Ormond Street Hospital (GOSH) dressed as his famous *Pirates of the Caribbean* character, Captain Jack Sparrow. After his visit, he wrote a letter thanking staff at the hospital, telling them what an “incredible and amazing job” they do and how “deeply inspired” he was by their passion and commitment.

Other famous friends brought festive cheer to hundreds of GOSH patients when they joined them for a special Christmas party. Guests included Davina McCall, Emma Bunton, Radio 1 DJ and CBBC presenter Cel Spellman, and Gogglebox’s Scarlett Moffatt.



GOSH patient  
Jack, 10 with  
Cel Spellman



GOSH patient Gabriella, 11,  
and brother Joe, 9, with  
Scarlett Moffatt

Morgan and Grace review  
plans as part of the  
Takeover Challenge

## GOSH IN THE 21st CENTURY

## CAD is rad!

As part of Great Ormond Street Hospital’s (GOSH) participation in the Takeover Challenge, 10-year-old patient Morgan and his 13-year-old sister, Grace, tell us what they learned about Computer Aided Design (CAD) while spending a day with the Development and Property Services team.

Morgan and Grace were interested to find out about the technology used to design new buildings being built as part of the hospital’s redevelopment.

“I learnt that the property development team use something called CAD to see what the hospital will look like in the future,” says Morgan.

“Using CAD, the team can look at the hospital buildings as a whole. They create them in 3D, which means they can rotate and see exactly how it will look and fit from all angles.

“It’s a bit like when you build a structure on Minecraft!”

CAD Manager Vincent Lee explains: “When I first started as a draughtsman, we used set squares, ink pens, water colours and razor blades (to scratch the ink off the tracing film).

“Today, we use CAD drawings of our floorplans to manage how much space we have, who occupies it and what it is used for. We can edit drawings much quicker, which probably explains why things change so often.

“The next technology progression will be using 3D models that have all building related information integrated into them and possibly augmented or virtual reality. In the future, expect to see people with space-age sunglasses looking up at the ceilings and walls!

“It was great to have Grace and Morgan on board and show them the work we do, as well as hear their thoughts about the future design of GOSH.”

As part of the Takeover Challenge, Morgan discovered some of the other technology used to help keep the hospital running.

“I went inside one of the new generators,” he says. “The generators are a back-up system in case there is a power cut. The system is automated, so when needed, a double-sided wall of transformers start to produce electricity and makes sure vital equipment, such as life support machines, are kept running at all times until the power comes back on.”

**Read more about the hospital’s involvement in the Takeover Challenge on pages 10 and 11.**



# 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 26 April 2017

Wednesday 28 June 2017

All meetings are from 4–6.30pm

### Trust Board meetings

May 2017 (date TBC)

Friday 21 July 2017

Members are welcome to attend the public session, usually from 1pm. Exact timings will be given nearer the date. Please visit [gosh.nhs.uk/trustboardmeetings](http://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](mailto:foundation@gosh.nhs.uk)

## Patient summer party

Thursday 22 June

The Lagoon restaurant  
Summer is here! Celebrate with this seaside-themed event.

## YPF meetings

Saturday 8 July (TBC)

Saturday 19 August (TBC)

Saturday 21 October (TBC)

Saturday 16 December (TBC)

Meeting times, dates and locations will be confirmed closer to the date. Are you aged 11–25 years old and want to attend YPF meetings? Contact [ypf.member@gosh.nhs.uk](mailto:ypf.member@gosh.nhs.uk) to become a member and have your say in improving the experiences of patients at Great Ormond Street Hospital (GOSH).

## RBC Race for the Kids

Saturday 7 October

Wanting to race for GOSH? This year's RBC Race for the Kids has moved! In 2017, the 5k family fun run will be held on 7 October at a new venue. Head to [gosh.org/raceforthekids](http://gosh.org/raceforthekids) for updates and to register to take part.

## Membership on the move!

As a children's hospital, it's really important that we hear the views of children and young people. We like to go out to schools and speak to students about GOSH and share ways young people can get involved. If you'd like us to visit your school and help make our membership grow, please get in touch! Contact Deirdre Leyden, Membership and Governance Manager, at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk)

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