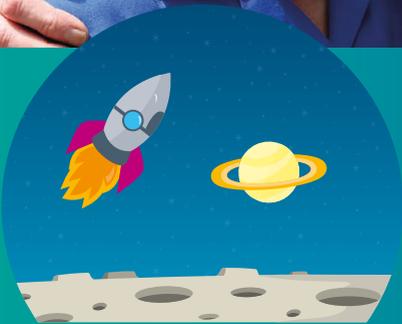
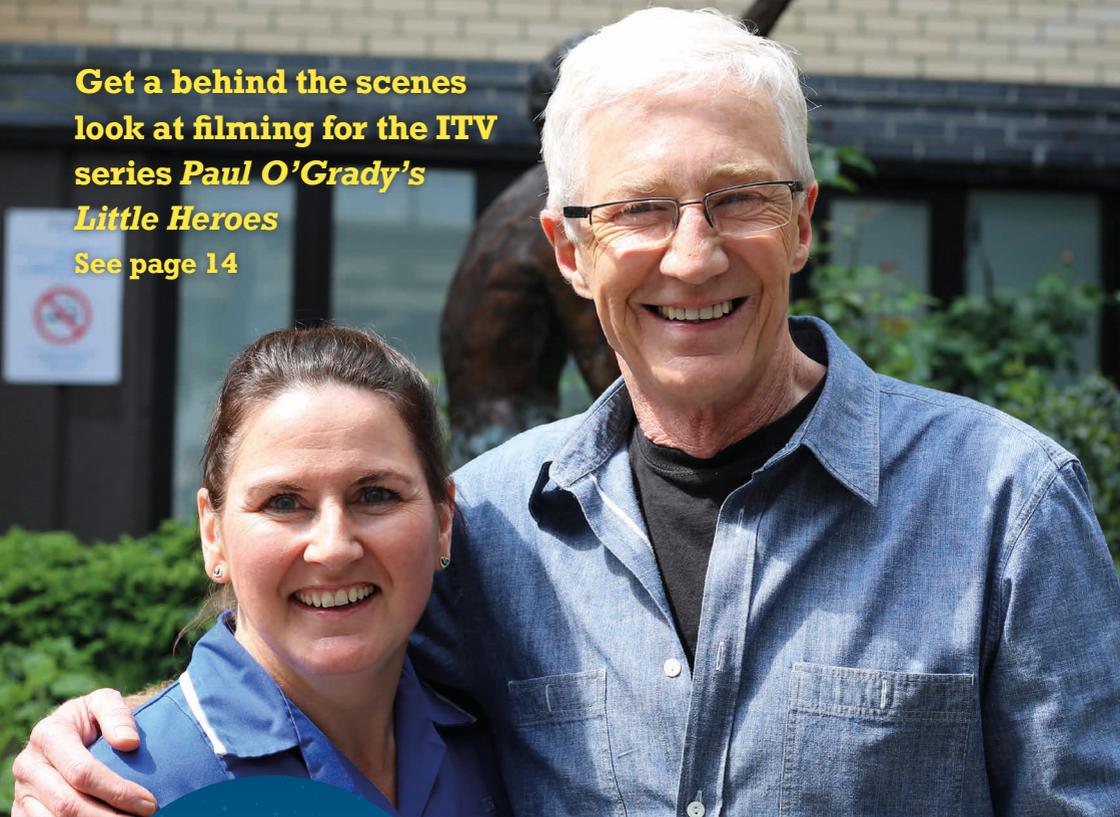


Spring 2019

# Member Matters

**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



Kids go 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](http://gosh.org/rbcraceforthekids)

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## Introduction

Welcome to the spring 2019 edition of *Members 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's 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!

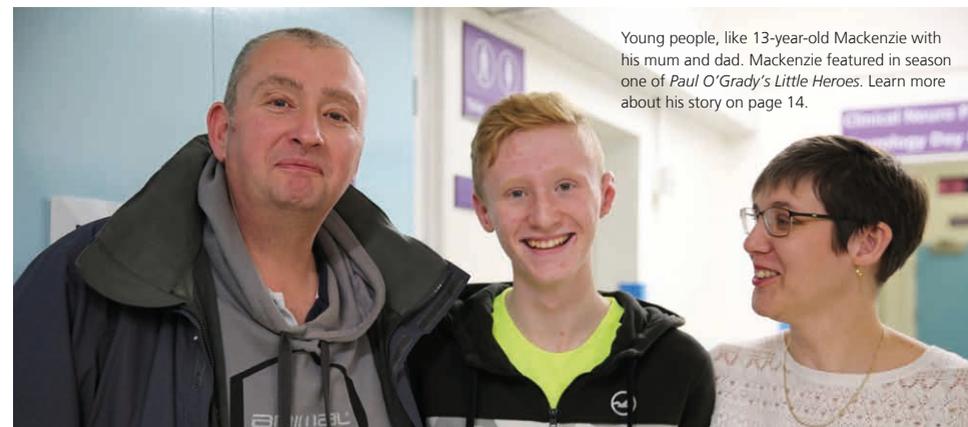
**Emma and Josh**

# FOUNDATION TRUST NEWS

## 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 from 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](https://gosh.nhs.uk/your-hospital-visit/growing-gaining-independence).



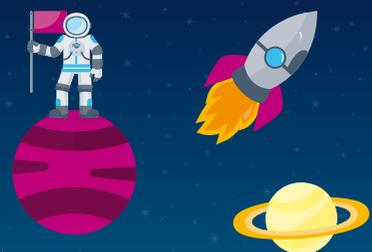
## Ground-breaking new cancer therapy

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](https://gosh.nhs.uk/news/gosh-patient-first-receive-ground-breaking-new-cancer-therapy-nhs).

## 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.



**FUTURE PROOF**  
ELECTRONIC  
PATIENT RECORDS

# MAT SHAW INTERVIEW

Mat Shaw and his children  
after RideLondon.



## Meet Mat Shaw

GOSH's new CEO Mat Shaw discusses 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 people who were massively motivated. It's an organisation that wants to do the best for children, to seek new treatments and provide the best care possible. GOSH has a strong reputation, and scale and breadth of services that most other hospitals don't have. The amount of innovation here is higher than in any other hospital in the UK and that is exemplified by the number of research papers we produce.

### Tell us about your medical background

I'm a spinal surgeon by background and mainly operate on children. My specialism 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. The commonest type of scoliosis is teenage scoliosis, where young people between the ages of 10 and 15 get a gradually progressive curvature of the spine, which worsens when they have growth spurts.

In severe cases it can affect lung function.

The operation involves putting screws around the spinal cord and into the bone. You begin with a bent spine at the start of the operation and have a straight one at the end.

### 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. I also have a lot of management experience to bring to the role. I was a Medical Director and then Deputy Chief Executive at the Royal National Orthopaedic Hospital and then I moved to BUPA as a Medical Director.

### What challenges do you foresee for GOSH?

There are two big challenges in my mind, the first one is around financial sustainability. This financial year is going to be a tough year, and to run a world-class hospital, we're very much dependant on the incredible support of the charity and people's donations. The second challenge is culture – GOSH can be a tense place to work. Working with seriously ill children is incredibly difficult and we need to find a way to make it a less stressful environment.

### 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. She had a very unusual type of migraine, which caused her to have a speech deficit and muscle weakness. She's had a few speech issues since but thankfully hasn't had that level of weakness again. She's 12 now and things are fine, but it was a very worrying time. Going through that experience helps me to empathise with the families who come to the hospital.

## 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?

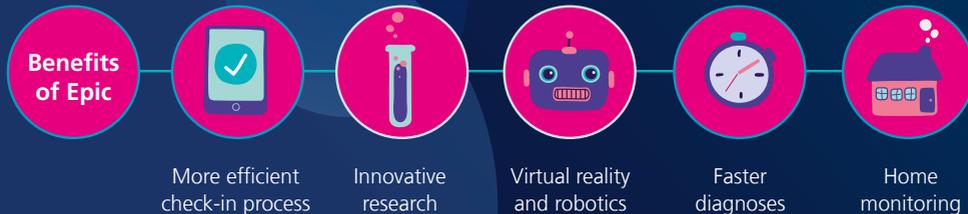
Epic is an online system that brings together all patient information in one place. Reducing the need for paper records, the most up-to-date information can now be accessed by a patient's entire clinical team at the tap of a screen. Epic will transform the way GOSH staff access patient data, meaning 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.



# 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](http://gosh.nhs.uk/mygosh)



# MEMBERS' ACHIEVEMENTS

## Improving healthcare, advising on research

The GOSH Young Persons' Advisory Group (YPAG) is made up of 27 members aged 8–21 years and advises researchers on how to make research information easier for people of all ages to understand.

### Some of our recent highlights include:

- Setting up a new group of five online members via a virtual YPAG, which allows even more feedback to be given to researchers on content used in patient information sheets and summaries.
- Raising the profile of YPAG by attending workshops and steering groups outside of GOSH, writing blogs for the Generation R website, speaking at events, and engaging with the public at the annual National Institute for Health Research (NIHR) Great Ormond Street Biomedical Research Centre Family Fun Day.
- Hosting a Generation R Healthtech workshop at GOSH's Digital Research, Informatics and Virtual Environments (DRIVE) unit, which assessed how DRIVE can make the most of game-changing technologies like virtual reality and robotics to support clinical care and patient experience.



If you'd like more information on the YPAG, visit [gosh.nhs.uk/research-and-innovation/nihr-gosh-brc/patient-and-public-involvement](https://gosh.nhs.uk/research-and-innovation/nihr-gosh-brc/patient-and-public-involvement) or contact [research.ppi@gosh.nhs.uk](mailto:research.ppi@gosh.nhs.uk).

# COUNCIL ACHIEVEMENTS



## Our ever-growing membership base

In February, a few of our members – including Staff Governor Paul and Public Governor Simon (L-R, pictured) – hosted a stall in the Lagoon to chat to patients and families about the benefits of Trust membership.

They met some inspiring people and signed up 25 new members in the process! Here's what some of our members had to say.

Zoe, Chair of the Membership Engagement, Recruitment and Representation Committee: "That's great news and I'm really glad it was so successful! Hopefully we can get another one planned and more members join the Trust. Thank you, Paul and Simon!"

Simon, Public Governor: "It was great to meet with families. What struck me was that while

visits are challenging times for parents and patients, everyone we spoke with was very kind, respectful and more often than not, they either listened and signed up, or they were already members."

We're always keen to hear ways we can engage and recruit members, so we'll be hosting more events throughout the year. Get in touch at [Foundation@gosh.nhs.uk](mailto:Foundation@gosh.nhs.uk) to take part and share your ideas.

# PIONEERING RESEARCH

## Spina bifida surgery in the womb

Last year, GOSH surgeons performed the UK's first two operations to repair the damaged spinal cords of babies while they were still in the womb.

Pregnancy scans had shown that the unborn babies had spina bifida, a condition where the spinal cord does not develop properly before birth, leaving a gap in the spine where the spinal cord is exposed and can be easily damaged.

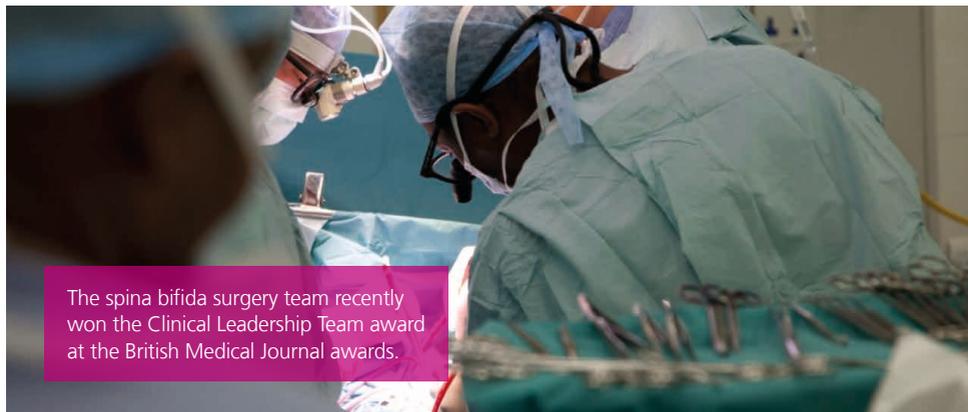
"Spina bifida results in changes to the brain as well as severe injuries to the nerves in the lower half of the body," says GOSH Lead Neurosurgeon Dominic Thompson.

The team, that included GOSH surgeons, Dominic Thompson, Zubair Tahir and Paolo De Coppi, repaired the holes in the babies' spines in two 90-minute operations, in what are the first surgeries of their kind in the UK.

The operations brought together over 30 staff, including doctors from GOSH and UCLH, and researchers from University College London (UCL) and the UCL Great Ormond Street Institute of Child Health.

Until now, mums could choose to have the surgery abroad or have surgery after the baby is born. While the pioneering new operation does not cure the children of spina bifida, closing the hole in the spine before birth avoids further damage to the spinal cord in the last third of the pregnancy.

Babies with spina bifida are often unable to walk and may require a series of operations to drain fluid from the brain using small tubes called shunts. Surgery in the womb will give the baby a significantly better chance in life as research has shown that repairing the hole in the spine before birth can reduce the need for these shunts and improve brain function.



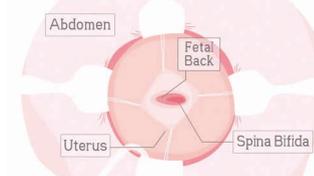
The spina bifida surgery team recently won the Clinical Leadership Team award at the British Medical Journal awards.

## How it works

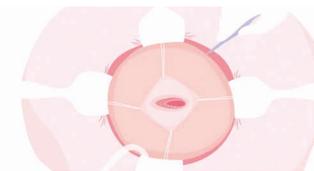
1. The mother is given an anaesthetic which passes to the baby.



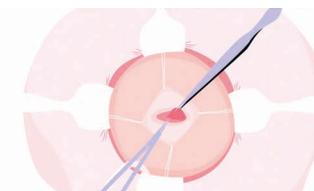
2. Surgeons open the stomach and womb, exposing the spina bifida defect in the unborn baby.



3. The surgeon cuts around the exposed spinal cord which is sticking out through a hole in the baby's back.



4. The spinal cord is put back into the spinal canal and a new protective tube is created around it.



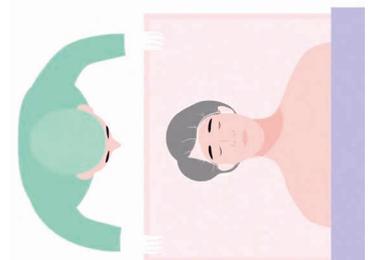
5. The muscles and skin are stitched closed to stop spinal fluid leaking out.



6. The womb and stomach are stitched closed.



7. The mother can recover from the operation.



The research was supported with funding from GOSH Charity and UCLH Charity and underpinned by support from the NIHR Biomedical Research Centres at UCLH and GOSH.

# BEHIND THE SCENES



## 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."

## 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.



## 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](mailto:foundation@gosh.nhs.uk)

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## Council of Governors meeting

Wednesday 17 July  
Starts at 3pm

Tuesday 26 November  
Starts at 3pm

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## 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](http://gosh.nhs.uk/trustboardmeetings).

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## Annual General Meeting

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

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## YPF meeting

Saturday 13 July

Saturday 10 August

Saturday 12 October

Saturday 14 December

Want to attend? Email: [ypf.member@gosh.nhs.uk](mailto:ypf.member@gosh.nhs.uk) or find out more at: [gosh.nhs.uk/young-peoples-forum](http://gosh.nhs.uk/young-peoples-forum).

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Website:  
[gosh.nhs.uk/foundation](http://gosh.nhs.uk/foundation)

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