

Autumn 2019

# Member Matters



**GOSH Play Street**  
An afternoon of  
fun and games  
**Page 14**



## Music to our ears

Meet GOSH's first Music Therapist  
See page 6



# LONDON SANTA DASH



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## Introduction

Welcome to the Autumn 2019 edition of *Members Matters*.

Hi everyone

My name is Claire Cooper-Jones and I am the Lead Governor at Great Ormond Street Hospital (GOSH). I'm really happy to welcome you to this special, final edition of *Member Matters*. After many years producing this twice-yearly magazine, we're going fully digital and environmentally friendly. All the latest hospital news will now arrive direct to your inbox, each month via *Get Involved*. You can read more about this in the council update on page 10.

A little about me: my involvement with GOSH started with a referral for my now 13-year-old son, who has complex medical conditions. I wanted to give something back to the hospital, and I knew I could use my training in psychology to help develop the hospital. I was chosen as a parent/carer representative for people living outside of London and, one year after my appointment, I became Lead Governor.

Being Lead Governor is hugely important to me. I am so pleased to see how our team has grown, especially with more and more young people who are, or have been,

patients at GOSH. I love hearing their ideas. I also secretly enjoy the 400-mile round trips I take to meetings, training and other events (being a mum to two children means the train journeys are the only chance I have to indulge my passion for reading!).

During my time at GOSH I have been amazed by how kind and brilliant all the staff are, and their determination to help children and young people live their lives to the fullest, even as they face challenges. This is why I am determined to help GOSH continue the excellent work it does.

In this edition of *Member Matters*, we look behind the scenes of what happens when you close the street outside the hospital for an afternoon of play. You can also read about how artificial intelligence is helping children with Duchenne Muscular Dystrophy, and find out what our members have been up to.

Thank you for your support of *Member Matters* and the membership of GOSH. I look forward to seeing you soon at Council of Governors' meetings.

**Claire**



# FOUNDATION TRUST NEWS

## Hospital for the future

Many patients and their families came to our Open Day in July. Through a fun time trail across the hospital, we showed the teams and services here to support them, and also got feedback on what they think the future of GOSH should look like.



## Paul O'Grady's Little Heroes

We were thrilled to have Paul O'Grady back in the hospital this summer to film series two of ITV's *Paul O'Grady's Little Heroes*. The heart-warming six-part series tells the stories of some of the brave children and families who walk through the hospital's doors, like 14-year-old Conor (pictured), and the incredible staff who work at the hospital. You can catch up (or watch again!) on the *ITV* hub.



## Partnership power

Staff, patients and special guests came together in July to celebrate the completion of the Zayed Centre for Research into Rare Disease in Children. A plaque was unveiled to show the building had been completed, and patients, researchers and clinicians will be moving into the centre later this year.

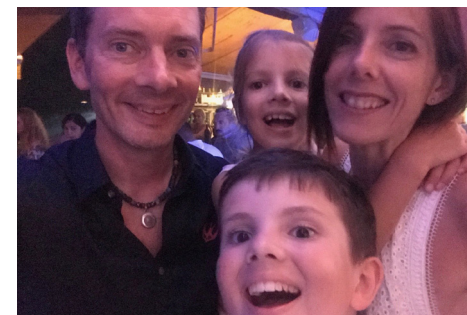
The Zayed Centre for Research means hundreds of medical experts can all work together under one roof to develop treatments for children with rare and complex diseases. Over the coming years, some GOSH outpatient clinics will take place at the centre – which is where children and young people come for treatment but not stay overnight. Read more about the teams who are making the centre possible on page 8.



## CAR-T research trial

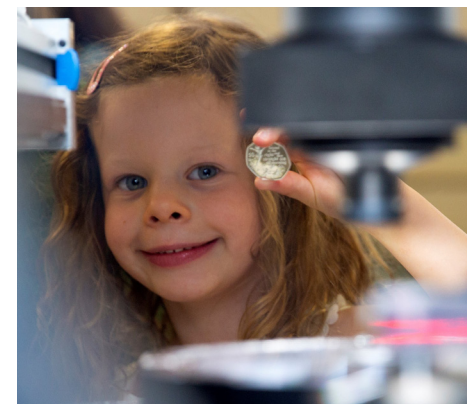
A ground-breaking new CAR-T cell therapy has shown really promising results for children with previously incurable leukaemia. Austin (pictured with his family) was one of children who took part in the trial, which was run by GOSH and UCL.

CAR-T therapies use the body's own immune system to fight cancer, and this therapy was designed to target cancer cells more quickly and cause fewer side effects.



## Peter Pan coins

Special *Peter Pan* coins were made to celebrate the 90th anniversary of author JM Barrie gifting the rights of his much-loved story to GOSH. Launched by GOSH patient Olivia (pictured), the coins have been produced by The Westminster Collection, in aid of Great Ormond Street Hospital Children's Charity (GOSH Charity), and feature well-known characters from *Peter Pan*. Scottish-born Barrie gave the copyright of his *Peter Pan* book and play to GOSH in 1929 and the hospital has received royalties (payments) from productions of the play, as well as sales of *Peter Pan* books and other products ever since.



## We're keen on green

We're working hard to make GOSH environmentally friendly by looking at ways to make lasting changes to how we do things. From August, the Lagoon stopped using single-use plastics. There's already wooden cutlery available, and watch out for reusable coffee cups coming soon. The team is also looking at how we can move to compostable versions of disposable packaging like take away boxes.



## It's all about you

GOSH nurse Beth Porch was interviewed on *Good Morning Britain* after a video of her singing 'It's All About You' by McFly for a patient became an internet sensation! She was joined in the studio by band member Danny Jones. Danny then visited the hospital and sung a song with Beth on Giraffe Ward!







## Music to our ears

“My job is to help young people find happiness, strength, and learn how to express themselves freely through music. I can’t think of a better place to do that than at GOSH.” – Katya, our first full-time Music Therapist.

Music therapy is when music is used in hospitals and similar environments to help patients be as creative as possible, connect with other people in a comfortable and safe environment and have a great time while doing so.

“Within a hospital like GOSH, patients are coming here for many different reasons, so every music session is designed especially for each person and they are all completely different,” says Katya.

“The only common goal – in almost every session – is to have fun. Being in the hospital can be a difficult time for young people and their families. Anything that makes them smile, laugh, or connect can be something the whole family needs.

“While sharing a fun musical connection might be the first goal, it’s part of a much bigger process. I then work with the many other teams in the hospital to find out what else is important for the patient. This can include anything from a patient developing their coping skills, working on fine motor skills (the smaller movements made by

hands and feet) or gross motor skills (the bigger movements through arms, legs and the whole body) through music, or helping a patient express how they’re feeling.

“Children in the hospital have a lot that’s done to them. Music is something that can be done with them and by them.”

Katya says her favourite part of the job is watching a young person find their voice through music or seeing them discover a new way for that voice to be heard.

You may have started to see Katya around the hospital. Her main instrument is the harp, but you’ll also see her in the hospital carrying around her guitar, keyboard, ukuleles, and a huge number of percussion instruments.

Want to know more about music therapy? Get in touch with Katya: [Katya.Herman@gosh.nhs.uk](mailto:Katya.Herman@gosh.nhs.uk).

This project is being delivered in collaboration with Chiltern Music Therapy and has been generously funded by The Peterson Family Foundation, via GOSH Charity.



Judging panel (L-R): Miranda France (author), Mariam Ali (Hospital Governor), Sarah Wolf (Peter Pan Lead, GOSH Charity), Cymbeline Moore (Director of Communications).

## Taking Flight

Authors, and the wonderful stories they create and share with us, have long been linked with the hospital.

‘Taking Flight: A Month of Stories at GOSH’ – the hospital’s first flash-fiction (very short stories) writing competition, which ran in May – was inspired by an author who has a long and proud history with GOSH.

This year is the 90th anniversary of JM Barrie, author of Peter Pan, who gifted the rights to his famous book and play to the hospital.

We invited patients and staff across the Trust to use up to 500 words to create a story that best interpreted the title ‘Taking Flight’ – the response was both creative and inventive!

The judging panel met in June to choose the winning stories, with a very special award of commemorative Peter Pan coins as the prize.

“We had such fun reading the stories. The standard was very high, with a great variety of styles, from traditional storytelling to magical worlds,” judge Miranda France said.

Get swept up in the storytelling – read all the winning and highly commended submissions at [gosh.nhs.uk/takingflight](http://gosh.nhs.uk/takingflight).



### Patient category

Winner – Aasiya Bakhrani, 11

Highly commended – Jim Cassidy, 12



### Staff category

Winner – Sian Spencer-Little, Play team

Highly commended – Alberto Montalbano, Estates and Facilities team

Highly commended – Eleanor Richardson, Built Environment team



## Building the future of research

The Zayed Centre for Research has a clear vision – to turn groundbreaking research into better treatments for children with some of the rarest and difficult-to-treat conditions. The building works finished in July and now its work to make it one of the world's leading research centres has begun.

We talked to some of the hardworking GOSH team who are making the centre a reality.

### Joe McGonagle, Senior Clerk of Works

Joe leads a team of project managers who oversee major building and renovation projects at GOSH, including the Zayed Centre for Research.

"We make sure everything is on track to finish on time, is of the highest quality and that everything is done within the right regulations," said Joe.

Joe is excited about the building: "I hope the building performs well in energy efficiency, that it provides a pleasant patient experience and is the perfect workspace for researchers and doctors to come together to develop new treatments and cures for seriously ill children."



**ZAYED CENTRE  
FOR RESEARCH  
INTO RARE DISEASE  
IN CHILDREN**



### Maggie Llewelyn, Head of Operational Commissioning

Maggie is the Operational Commissioning Lead for the Zayed Centre for Research, which means her team gets the building ready for people to move in and organises the moving-in plans.

"The reason you do this job is the satisfaction of turning an empty shell into an inspiring building that works well for all in it. From the waiting areas, young patients will be able to see scientists at work in the labs. We hope the stunning design and playful artwork will inspire staff and patients alike."



### Going green

A bird's eye view of the roof on Level four of the Zayed Centre for Research shows 134 solar panels (pictured).

Capable of generating up to 34,000kW hours per year – that's the same as boiling a kettle 22,667 times – the panels are just one of the many energy-efficient features that have been designed into this building.

Gaining an "Excellent" rating from the organisation that measures and rates how energy efficient a building is – called the Building Research Establishment Environmental Assessment Method (BREEAM) – the Zayed Centre for Research is an excellent example of a green and sustainable building design.

The hospital's Head of Sustainability, Nick Martin, says: "We're so pleased the Zayed Centre for Research has achieved an 'Excellent' rating. It shows our commitment to using resources as carefully as possible."



### Facts and figures

- 170,000 bricks
- 4,520 tonnes of steel
- 13,000 sqm of floor space
- 3,467 pieces of furniture
- 22 consulting rooms
- 8 clinical investigation rooms
- 800 academics and clinical staff
- 150 laboratory bench positions

The Zayed Centre for Research is named in recognition of the extraordinary philanthropic support of Her Highness Sheikhha Fatima bint Mubarak – wife of the late Sheikh Zayed bin Sultan Al Nahyan, Founder Father of the United Arab Emirates – and it embodies the partnership between GOSH, UCL Great Ormond Street Institute of Child Health, and GOSH Charity.



# COUNCIL UPDATES



## Keeping you updated with all the latest

Our membership is a strong community – there's 10,000 of you across the UK helping to shape the hospital's future by getting involved with all things GOSH.

There's lots happening at the hospital, and we want to make sure you receive all the latest news and information so, from November, we're excited to be going fully digital!

While this may be the final edition of *Member Matters*, we're going to continue sharing stories from across the hospital – including memberships news, events, research breakthroughs, patient stories and behind

the scenes features – directly to your inbox via *Get Involved*.

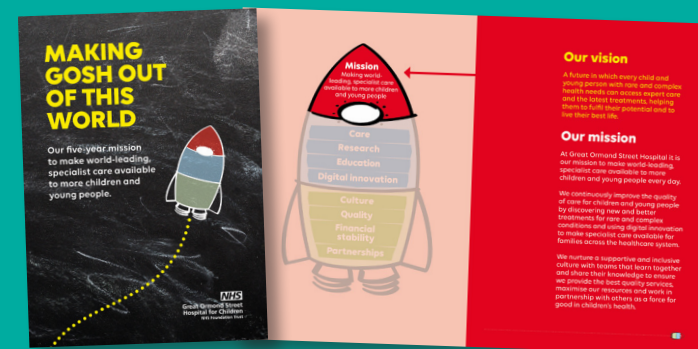
Want more? You can also keep up-to-date with the hospital via the website, [gosh.nhs.uk](https://gosh.nhs.uk), and on Twitter, Instagram and Facebook.

### What you need to do

If you don't already receive the Foundation Trust's monthly email, *Get Involved*, please get in touch with us at [foundation@gosh.nhs.uk](mailto:foundation@gosh.nhs.uk).

## Highlights from our recent Council of Governors' meeting

- Work is underway to develop an outline business case for the Children's Cancer Centre, which was taken to the hospital and charity boards in September for consideration.
- Governors heard about GOSH Play Street – where Great Ormond Street was closed to traffic and transformed into a rainbow-themed play area. Read more on page 14.
- Appointment of Mr Richard Collins as the Trust's new Director of Transformation. Richard led the hospital's Electronic Patient Record programme prior to taking on this 12-month secondment role.
- Opportunities for staff and governors to feed into the Trust's strategy refresh. Look out for more information in *Get Involved*.



- The Council approved the reappointment of Mr James Hatchley, Senior Independent Director, for a second term of three years on the board.

See you at our next Council of Governors' meeting – Tuesday 26 November 3-5.30pm.



# PIONEERING RESEARCH

## The power of artificial intelligence

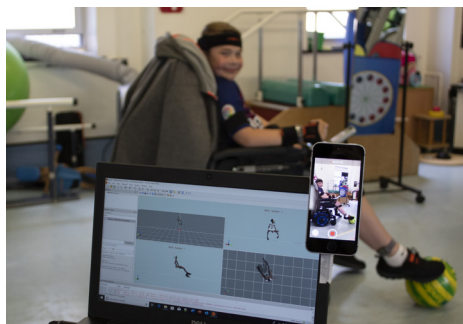
Artificial intelligence (AI) is increasingly being used to improve our everyday lives and, at GOSH, we're proud to be leading the way in applying this sophisticated technology to healthcare research.

A team of GOSH researchers, clinicians and physiotherapists are currently pioneering an innovative research project, harnessing the power of AI to understand how movement ability declines in boys with the severe muscle-wasting disease, Duchenne Muscular Dystrophy (DMD).

Dr Valeria Ricotti is lead clinical investigator on the KineDMD project. In partnership with colleagues from Imperial College, the team are tracking movement using a special bodysuit equipped with 17 sensors and using advanced AI software and machine learning to process the data.

Physiotherapist Victoria Selby explains: "Boys who take part in the study wear the bodysuit for a day in the hospital. They then take home four sensors the size of a watch, to wear on their wrists and ankles, and measure movement in day-to-day life. They'll wear these for six months before coming back for a follow-up visit where we can see if their movement ability has changed."

"The data is much more powerful than the human eye could capture with any type of assessment," Valeria says. "This technology is really useful for tracking movement in progressive diseases where the changes over time are relatively subtle. This is key for developing new therapies." Many clinical trials for DMD test the effectiveness of new medicines by measuring how far patients can walk in six minutes, before and after treatment. However, that does mean patients who are no longer able to walk cannot take part in the trials.



"The AI bodysuit means we could track movement in all boys with DMD, irrespective of whether they have the ability to walk," Valeria says.

"Potentially, we can see if treatments are working in much smaller groups of patients. And, it could help with determining the correct dose for individual patients or help us work out when the next dose is needed. Ultimately, this could mean faster times to develop therapies for children who need them.

"We were a bit concerned we would have difficulty recruiting as the patients who take part won't actually benefit directly.

"But we have had an amazing response. The boys have really enjoyed the experience and are happy to contribute with their time to facilitate future clinical trials for the development of new therapies."

## Meet the patients



James (pictured)

Leicester-based football fan James, 10, is also taking part in the AI bodysuit trial. He visited GOSH this summer with his mum Mazz and dad Darren.

"When we got a phone call asking if we wanted to be involved in the AI bodysuit trial at GOSH, we were keen to take part as it could help James and other children in the future," Mazz explains.

"Research like this is so important. Being part of the trial has been quite easy. We first came down to GOSH about a year ago to try the bodysuit. James wore the tracker bands all over his body. Then he played around in the gym and did exercise tests with Vic the physiotherapist while the bands tracked his movements. We then took four sensor watches home for him to wear every day on his arms and legs. We just take them off at night when he goes to bed and charge them up. We've come back for a follow-up visit. He was more physically able last time but, since then, his condition has progressed. The bodysuit monitors his movements, so they'll be able to track that change."



Gavriel (pictured)

17-year-old Gavriel was diagnosed with DMD when he was four years old. "We noticed something wasn't quite right when he was about three and started waking up with severe leg cramps," mum Kerry says.

Gav, a keen horse rider, is taking part in the AI bodysuit research along with his brother Joshua who doesn't have the condition and is involved as a healthy "control". Researchers will be able to compare movements in children with and without the condition to see how DMD affects the muscles and joints.

"We want to turn what potentially was a tragedy into an opportunity by knowing we are helping future generations with this research," Kerry says.

Dr Ricotti adds: "When I mentioned the trial, I knew the family would want to get involved, even if it didn't benefit Gav directly. His family are very supportive."

This research was supported by the Duchenne Research Fund and the trial was underpinned by the National Institute for Health Research GOSH Biomedical Research Centre.



# WHAT HAPPENS WHEN...

## ...you close Great Ormond Street for an afternoon of play!

To celebrate Clean Air Day on Thursday 20 June, and London Car-Free day on Thursday 19 September, the street outside the hospital was closed to traffic for four hours. It was then turned into a rainbow-themed play area, with lots of fun activities in a safe, clean-air environment.

Hospital patients and children from the local area were invited to enjoy the play space and play equipment. This included a rainbow-themed racetrack and slide designed by patients, as well as activities including hopscotch, ball games and face painting. There was fun for everyone!

Play Street is part of GOSH's ongoing work to help the health of patients and their families, staff and the local community by improving air quality in and around the hospital.

GOSH Chief Executive, Mat Shaw, says: "Every day at GOSH we see how important clean air is in helping people live healthy lives.

"That's why we hope our Clean Air Hospital Framework will support hospitals around the country to create healthier environments for their patients, staff and surrounding communities.

"GOSH is proud to deliver Play Street. We'll keep on searching for creative ways to make air quality better, in and around the hospital."

You can read more about the hospital's Clean Air Framework at [gosh.nhs.uk/CAHF](https://gosh.nhs.uk/CAHF)





# 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

Tuesday 26 November  
3–5.50pm

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## Trust Board meeting

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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## YPF meeting

Saturday 14 December

10am–4pm, Weston House

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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