News from Guy's and St Thomas' Issue 44 | 2024

the

A lifetime of care

Our sickle cell service is right by your side

THIS ISSUE

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Welcome

At the beginning of June, a criminal cyber-attack was carried out on our pathology service provider, Synnovis. As a result, our Trust experienced disruption to some of our services.

Very regrettably we had to delay some procedures and operations. We apologise unreservedly to all patients who were affected. I am incredibly grateful to our staff for their dedication

and hard work during this difficult time.

In more positive news, Evelina London Children's Hospital has become the first in the UK to launch a dedicated service for children and young people with rare bladder conditions. Find out how a specialist operation has improved the life of 17-year-old Jenny Allen, on page 8.

Our cover star, Ansella Aaron, has sickle cell disease and has been under the care of the haematology team for the last 60 years. You can read about her journey and find out how the team is supporting people in the community, on page 12.

Doctors at Royal Brompton Hospital are using microwave energy to destroy lung cancers in hard-to-reach areas of the lungs as part of a new trial. Find out more on page 7.

You can also find out about a pilot project to improve living kidney donation rates, particularly among Black African Caribbean communities, on page 10.

Did you know that Europe's first hospital palliative care team was set up at St Thomas' Hospital? Read about pioneering Dr Thelma Bates, who transformed the way we care for terminally ill patients, on page 21.

I hope you enjoy this issue of the GiST.

Professor Ian Abbs, Chief Executive Officer Guy's and St Thomas' NHS Foundation Trust

Meet the team

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Cover photo by David Tett.

Design: AYA-Creative www.aya-creative.co.uk

Print: O'Sullivan Communications

Front cover: Sickle cell patient Ansella Aaron with clinical nurse specialist Shola Shoyemi

TELL US WHAT YOU THINK

If you have any comments about the magazine or suggestions for future articles, please contact the communications department, St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH, or email press@gstt.nhs.uk

Visit us online at: www.guysandstthomas.nhs.uk

the GiST is published by Guy's and St Thomas'



Student Breanna Davis and Hayley Robinson-Allen

Supporting local students

An educational programme being trialled at Guy's and St Thomas' has boosted engagement, grades, and attendance for local students.

The pilot project, called Aspire 350, works with students across years 10 and 11 to help equip them with life skills and development opportunities beyond the school classroom, whilst offering them a route into NHS careers.

Funded by Guy's & St Thomas' Charity, the project's curriculum is designed with the students and delivered by NHS staff as well as local businesses.

Aspiring architect Breanna Davis is now considering a career in the NHS.

The 16-year-old, from Croydon, said: "The programme was quite life changing as it gives you an experience of how hospitals work, and makes you want to think of them as a career path. I can now look at hospital architecture as a career path too."

Hayley Robinson-Allen, schools widening participation manager and project lead at Guy's and St Thomas', said: "Alongside building on life skills, we want to help young people in our local community pursue the careers they want, but perhaps in the careers they didn't know existed within the NHS. At the Trust we are a 'little city', any job you can think of is here – nursery staff, engineers, chefs – and we need staff to fulfil all these roles."

First in UK: powerful scanner installed

A new scanner – the most powerful of its kind – has been installed at Royal Brompton Hospital.

The installation of the Magnetom Cima.X magnetic resonance imaging scanner means that Guy's and St Thomas' has the largest heart MRI scanning service for NHS patients in the country, and one of the largest in the world.

The Trust now has five specialist heart MRI scanners and will be able to conduct around 20,000 scans a year to diagnose and monitor patients with heart conditions.

The scanner was purchased with support from the National Heart and Lung Institute based at Imperial College London, and the Royal Brompton and Harefield Hospitals Charity.



The Trust has five specialist heart scanners

Dudley Pennell, director of the cardiovascular magnetic resonance unit at Royal Brompton, said: "This is a real jewel in the crown for the National Heart and Lung Institute, for Royal Brompton, and for Guy's and St Thomas."

IN THE NEWS

A round-up of media coverage featuring Guy's and St Thomas'.

BBC Morning Live

The INPUT pain management centre at St Thomas' Hospital featured on BBC Morning Live. The segment highlighted the residential pain management course offered as an alternative to medication for people living with chronic pain. It included interviews with two members of staff and three patients. One patient, Nick, said the course had changed his life.



BBC News

BBC News covered the story of a couple who ran the London Marathon to raise money for Evelina London Children's Charity after their niece was cared for at the hospital. Sarah and Danny Singh were inspired by Sophia Singh-Chauhan, seven, who needed "life-changing" surgery at the age of four after being diagnosed with a neurological development disorder that causes seizures and continuous involuntary movements.

Daily Mirror

The first patient to be treated at Evelina London with an eye gene therapy for children with a rare form of blindness ran in papers including the Daily Mirror and Daily Mail. Surgeons from Evelina London and St Thomas' Hospital joined with colleagues from Great Ormond Street Hospital and Moorfields Eye Hospital to deliver the treatment for three-year-old Khadijah.

Staff honoured by King

Two members of staff were recognised in the King's Birthday Honours List.



Professor Jane Davies, honorary consultant in paediatric respiratory medicine at Royal Brompton

Hospital, was made an OBE (Officer of the Order of the British Empire) for services to people with cystic fibrosis.

Her research focuses on designing and leading global clinical trials for ground-breaking new treatments.

These treatments are now licensed in the UK and suitable for around 85 to 90 per cent of people with cystic fibrosis.



Debra Holloway,

gynaecology nurse consultant, was made an MBE (Member of the Order of the British Empire) for

services to women's health. She recently retired after working for the Trust for more than 25 years.



In addition, **Anne Hamilton**, headteacher of the Evelina Hospital School, was

awarded an MBE for her services to education.

Anne has been a key figure in hospital education, leading the Evelina Hospital School for the past 11 years.



Guy's and St Thomas' held a week of activities to celebrate Nursing and Midwifery Week across its five hospital and community sites. There were awards, information stalls, a thanksgiving service, a cake competition and thank you hampers, with support from the hospital charities.

Your voice

We love to hear from our patients, staff and supporters so join the conversation by following us on Facebook, X (previously known as Twitter) LinkedIn, and YouTube.

@hashimi_bashir (from X)

Our daughter, Haneen, 23-years old Pharmacist was diagnosed with mouth cancer last Oct. She had a major operation, learnt how to speak & eat again, thanks to the amazing NHS staff @GSTTnhs she is back at work since Jan & this has been so important to her recovery & mental health.

@southwarksista (from X)

facebook.com/gsttnhs

Another friendly helpful service today from @GSTTnhs #urgentcare team and a speedy instant prescription for antibiotics from the hospital pharmacy. So grateful to have this @NHSEnglandLDN hospital as my local. Thank you to you all for your support as always!

> X/Twitter @GSTTnhs @RBandH @EvelinaLondon



@paridhi_lilha (from X)
@EvelinaLondon Thank u team
Evelina for spoiling my little one on international play day awesome team...special shout out to Nurse
Eloise for being so patient and caring.

Sheila Kirby (from Facebook)

Thank you to all the nurses that looked after me on Sarah swift ward at St Thomas' Hospital in 2020 and again in 2021 you were all amazing the care I received was brilliant.





Leading heart transplantation centre in England

The specialist heart and lung transplant teams at Harefield Hospital have completed the most heart transplants and the second most lung transplants in England over the past year.

They carried out 44 heart transplants, 28 lung transplants and one combined heart and lung transplant.

Harefield's surgical team have been described as "pushing the boundaries" to ensure every organ donor is carefully considered to see whether their heart or lungs would be suitable for patients waiting for new organs.

The team said this was a significant factor behind the high rate of transplants in the past year.

Dr Fernando Riesgo Gil, a consultant cardiologist and lead of the heart

The success of the service is down to teamwork

transplantation service at Harefield Hospital, said: "The success of the heart transplant programme is a reflection of the genuine teamwork across the hospital."

The hospital runs an outreach programme to highlight Harefield's expertise and specialism in transplantation to doctors at other hospitals who are responsible for referring patients needing transplants.

This consists of carrying out virtual meetings with referring hospitals, introducing a new online referral platform and delivering education and training for respiratory trainees.

Dr Vicky Gerovasili, a consultant in respiratory medicine and lead for the lung transplantation service at Harefield Hospital, said: "We are proud of our reputation as a leading cardiothoracic transplant centre, and of the dedication shown by our colleagues in providing excellent care for our patients."

Cancer team success

Guy's and St Thomas' specialist oesophageal and gastric (stomach) cancer surgery team has been recognised as the biggest and safest centre in the UK.

The latest national oesophago-gastric cancer audit results show no patient deaths within 30 days of surgery for patients who are operated on at the Trust, and the joint shortest length of hospital stay in the UK.

James Gossage, a consultant specialising in oesophageal and gastric surgery, said: "Our success is down to team work – with our radiology, oncology, surgery, dietetics, histopathology and nursing teams all working closely together to give our patients the very best care."



Surgeon James Gossage

New outpatient pharmacy services



Assistant manager Bhaktipriya Kapadia

Guy's and St Thomas' has launched a new outpatient pharmacy service with Boots.

Boots took over management of the two outpatient pharmacies at Guy's Hospital and St Thomas' Hospital in June, which were previously run by Lloyds.

Boots has also set up a separate pharmacy and distribution hub for patients of the Trust.

This includes a service for some eligible patients, in consultation with their clinical team, delivering medicines to their home or to one of a list of approved Boots pharmacies closer to where they live.

This is available for eligible patients across Guy's, St Thomas', Evelina London, Royal Brompton and Harefield hospitals.

The new hub will support the busy hospital pharmacies, providing additional resource to enable them to run a faster, safe and confidential service for all patients.

Keith Thompson, chief pharmacist and clinical director for pharmacy and medicines at Guy's and St Thomas', said: "It's really important to us that our patients get their medicines appropriately and in good time, and the new service should provide a good experience for our patients and carers."

SPOTLIGHT

Kelly Cook

finds out about the volunteers who are providing a listening ear to patients receiving end of life care.



Volunteers with Matthew Reed, Chief Executive of Marie Curie

The power of friendship

A team of volunteers are making sure everyone has the right support when approaching the end of their life, and are not facing it alone.

The Marie Curie hospital companionship service, which is supported by Guy's & St Thomas' Charity, is available to patients receiving end of life care or people with a terminal illness, particularly those with few or no visitors.

The specially trained volunteers offer one to one support and provide a friendly ear and someone to talk to at the patient's bedside in hospital, or in their own home.

Since launching in August 2023, the I know there would always be someone service has supported more than 80 people. there for me – you forget that not everyone

Eija Buckoke, from Forest Hill in south east London, has been volunteering for a year. She said: "I really enjoy it because every day is different. It can be challenging sometimes, but the power of a simple conversation is huge.

"It really makes my day when I have a breakthrough and a patient starts talking and laughing."

Patrick Mulhern, a retired educational psychologist, has been volunteering twice a week since September 2023.

He said: "The role is anything but depressing. I have spent 40 minutes laughing with a patient despite the fact she has a very serious condition."

He added: "Listening to a patient's life story is a privilege – everything is stripped back because of the illness and you find real people.

"It keeps you very grounded and focused on what really matters. It's changed my view about what happens in hospitals. The kind of care the staff provide to patients is so impressive."

Amriya Issa, a university student, has been volunteering for a year.

The 21-year-old said: "I'm so privileged to have lots of family members and cousins so I know there would always be someone there for me – you forget that not everyone has got that."

She added: "By volunteering for just one hour you can make such a big difference to someone's life.

"I thought it would be a little bit scary at first, but it's really rewarding and fascinating to hear how each person lives their life so differently."

The volunteers also provide practical information and offer respite to carers, allowing them to take a break for a few hours.

Allegra Goldsworthy, service manager for palliative care and end of life care at Guy's and St Thomas', said: "I am immensely

grateful to the Marie Curie companionship service for their invaluable impact on our palliative care patients.

"Their extraordinary efforts have profoundly benefited both our patients and staff, providing exceptional support to those facing the end of life.

"The feedback has consistently expressed awe for what the volunteers provide to our patients. I hope we can continue to benefit from this remarkable project for many years to come."

Fast Facts

- There are currently **29 hospital companion volunteers** who visit people at Guy's Hospital and St Thomas' Hospital, as well as patients at home in Lambeth and Southwark
- Volunteers receive training from Marie Curie and Guy's and St Thomas' before being matched with a patient
- For more information about volunteering at the Trust, visit www.guysandstthomas.nhs.uk/ get-involved/volunteering

A new treatment for lung cancer is being trialled. Lucy Lisanti finds out more.

Pioneering robotic treatment

Doctors at Royal Brompton Hospital are using microwave energy to destroy lung cancers in hard-to-reach areas of the lungs as part of a new trial.

Lung cancer is the UK's third most common cancer, with more than 43,000 cases diagnosed each year. Survival rates vary widely, depending on how far the cancer has spread at the time of diagnosis.

The first patient treated on this new trial was Margaret Kirkham, a retired careers officer from Chiswick.

Margaret's tumour measured 11mm and was treated within three minutes using the new technology.

Margaret said: "After the surgery I felt fine, and with no pain. It put a smile on my face to learn that I was the first to have this procedure - I'd never been first at anything before.

"I'm not on any medication and feel well and positive, and I am making up for lost time — I've just been on a painting trip to Cadiz. I'm extremely grateful to have been on this trial, which will hopefully benefit many others."

Margaret had previously been treated with chemotherapy and radiotherapy for

lung cancer in 2022 and found that she responded well to the treatment. However, a scan later that year found that a small nodule on her lungs still

remained.

The 77-year-old said: "It wasn't safe to have any more radiotherapy, and I couldn't have surgery. But my consultant mentioned a new technique was being trialled for smaller, hard-to-reach lung

tumours like mine. That was how I ended up being referred to the Royal Brompton."

Professor Pallav Shah. consultant respiratory physician at Royal Brompton Hospital and lead of the new trial, said: "Lung cancer does not cause obvious symptoms so is often picked up at an advanced stage, during investigations for complaints such as persistent cough, weight loss or chest pain.

"Currently, most people are diagnosed when the tumour is above 30mm, where the cure rate is 68 per cent.

"But if we can treat tumours when they're smaller than 10mm, the cure rate is 92 per cent."

This new method of treating lung cancers with microwave energy, known as

microwave ablation, has the potential to offer benefits over radiotherapy by

Patients who are suspected of having affected.

The CT scans are then processed by access the tumour, similar to a sat-nav.

Patients undergo a general anaesthetic and a new device, called Microblate Flex, is fed through a tube in their mouth directly to the part of their lungs where a tumour is suspected.

Microwave energy is then administered to the cancerous tissue which precisely kills the cells in the treatment area.

Microwave energy is used to destroy lung cancers

reducing the number of side effects.

tumours in their lungs are given a CT scan to identify which parts of the lungs may be

computer software to plot the route the doctors will take through the lungs to

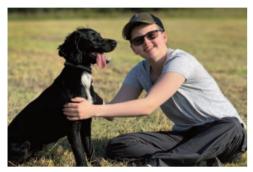






IN FOCUS

A new service is changing young people's lives. **Daisy Holden** finds out more.



Jenny Allan was the first teenager to have bladder neuromodulation surgery

Life changing specialist care

<image>

Evelina London Children's Hospital has become the first in the UK to launch a dedicated service for children and young people with rare bladder conditions.

The paediatric bladder neuromodulation service offers specialist operations for young people who have urinary incontinence, where they are unable to control when they urinate.

It is also available for those who are unable to empty their bladder without a catheter, and haven't responded to standard treatment.

A catheter is a flexible tube used to empty the bladder and collect urine in a bag.

Bladder neuromodulation is an operation which involves the patient having an electrical stimulation device, similar to a pacemaker, surgically implanted into their lower back.

Electrode wires run from the device

to connect to the nerves in the base of the spine. Once the device is switched on, it sends electrical impulses through the wire to the nerves, to change the nerve messages going

to the bladder.

These changes prevent incorrect or unwanted nerve messages in the bladder which cause urinary incontinence or the need for a catheter.

This procedure is sometimes referred to as sacral nerve stimulation.

Thanks to funding from Evelina London Children's Charity, this is the first time in the UK a bladder neuromodulation service has been used to treat young people.

Jenny Allan, from Kent, was the first teenager to undergo the procedure at

Evelina London.

Jenny has a condition similar to Fowler's syndrome, a rare condition that typically causes urinary retention in

> young women. She's unable to pass urine without self-catheterising, and has been under the care of Evelina London for the past eight years.

Jenny said: "I'm a very outdoorsy person and will be studying ecology at university in September, and then hope to get a job in the field.

"This operation has meant that I won't need to self-catheterise six times a day. Doing so is quite difficult even on a day hike in the Kent Downs where there aren't toilet facilities every few hours, let alone in the middle of a rainforest or up a

"The operation has allowed me to have a whole new freedom and be able to do what I want in my life."



Jenny took part in the Duke of Edinburgh sailing expedition





mountain. The operation has allowed me to have a whole new freedom and be able to do what I want in my life."

The 17-year-old added: "It's quite cool to be the first person to have this procedure as part of the new service at Evelina London."

Arash Taghizadeh, a consultant paediatric urologist and lead for the bladder neuromodulation service at Evelina London, said: "Bladder problems in children are common, and the majority can be simply and effectively treated to improve symptoms.

"However, there is a small minority of

Jenny enjoys being active and outdoors

children and young people who do not respond to standard treatments. They may be left with either distressing urinary incontinence or they

may be unable to empty their bladder without passing a tube into the bladder.

"Bladder neuromodulation is a specialist procedure that has been available to adults for more than 20 years. It's great that we're now able to offer it to children and young people to improve their symptoms, and give them greater independence."

Evelina London is the largest centre in the UK performing standard and complex bladder investigations, known as urodynamics.

The specialist children's hospital also has wider expertise in using nerve

"Bladder problems in children are common, and the majority can be simply and effectively treated to improve symptoms."

stimulator devices in children, including running the oldest and largest paediatric deep brain stimulation service in the world.

Barbara Kasumu, Executive Director of Evelina London Children's Charity, said: "We are committed to supporting the hospital to provide the latest innovative models of care. We are so proud to have funded the new bladder neuromodulation service which, for the first time in the UK, will offer young people like Jenny a new sense of freedom."

SPOTLIGHT

Lesley Walker

finds out about a pilot project to raise awareness of living organ donation in Black communities.

Giving the gift of life

Eric Douglin had a kidney transplant at Guy's Hospital in 2010, which has given him the chance to enjoy time with seven more grandchildren and walk his daughter down the aisle.

Now, Eric is taking part in the phone buddy pilot project at Guy's and St Thomas' to improve living kidney donation rates, particularly among Black African Caribbean communities.

The project links potential patients with someone from the same heritage to answer questions, share knowledge and dispel any myths.

Between 2000 and 2020, of the 4,109 kidney transplants that took place at the Trust, only 6.5 per cent of transplants to Black patients were done before dialysis, compared to 24 percent for white patients.

So, along with two other London trusts, Guy's and St Thomas' has partnered with the organisation Gift of Living Donation – known as GOLD – on a project to encourage more people from the Black community to consider pre-emptive living kidney donation.

A pre-emptive kidney transplant is a transplant that takes place before dialysis begins and gives the best



Eric Douglin had a second chance at life after his wife Mandi donated one of her kidneys

life-prolonging option for eligible patients compared to dialysis.

During the phone buddy project between February 2023 and February 2024, 342 Black and mixed Black

patients at Guy's and St Thomas' were considered eligible for referral to the programme.

Some 63 patients chose to be referred, and seven of these spoke to their families, found potential donors and were connected with the living donor team at Guy's Hospital.

Eric, whose wife Mandi donated a kidney to him after he was diagnosed with chronic kidney disease,

has four "buddies" he speaks to at least once a week through the programme.

The 61-year-old, from Kent, said: "If I hadn't had my kidney donation, I wouldn't have seen at least seven of my grandchildren, and I wouldn't have walked my daughter down the aisle to get married.



Dr Dela Idowu set up the organisation Gift of Living Donation

"With Black communities, and especially Black men, we don't talk. When we are ill, we see it as a sign of weakness and we don't share. We need to share stories, dispel myths and improve understanding

about a living donor kidney transplant.

"The people I speak to say they find it really helpful there is someone they can talk to. They know someone who has gone through that journey. They are not alone. Their feedback makes me feel like this happened to me for a reason."

Dr Dela Idowu set up GOLD after coming forward as a living donor for her brother.

Unfortunately, tests found she was not

compatible, however, she decided to use her experiences to raise awareness of kidney donation in her community.

Dela said: "The feedback we receive from the phone buddy scheme is very positive. Patients say it is much easier talking to someone from their own

committed to reducing health inequalities and working with GOLD provides more time for our patients to learn about the benefits of living kidney donation."

"We're really



Derricka donated a kidney to her dad Derrick

community – it's about cultural identity. Speaking to someone who has been through that journey gives patients a glimmer of hope."

In addition to developing the phone buddy scheme, Dela also created The Black Living Donor Choir whose members are all living donors.

One member of the choir is Derricka Simpson. The 27-year-old, who works at the Trust, donated a kidney to her dad



Dr Sumoyee Basu has led the phone buddy pilot project at the Trust

Derrick at Guy's Hospital in 2019.

Derricka, from Luton, said: "I volunteered through the love of my dad. I really wanted to give him another chance of life. I had the support of GOLD and people with lived experience. That motivated me and supported me through the reality of surgery and after.

"My dad is now completely fine – he's living a healthy life, playing sports, eating

and doing all the daily activities he couldn't do while on dialysis."

She added: "Representation is important as organ donation is still a taboo in Black African communities. It's important we share our message – the more awareness raised, the more chances of saving lives."

Dr Sumoyee Basu, a renal registrar, has led the pilot project at Guy's and St Thomas'. Dr Basu said: "We have one of the most diverse groups of patients with chronic kidney disease in the country, yet Black people are still under-represented in the number of people receiving kidney transplants.

"We're really committed to reducing health inequalities and working with GOLD provides more time for our patients to learn about the benefits of living kidney donation outside a busy clinic appointment.

"Empowering people with tailored information and supporting conversations with friends and family is critical in improving patient health outcomes. We're really grateful to all the buddies at GOLD for volunteering their time and commitment to help others."

For more information about Gift of Living Donation or to read their pilot project report, visit

www.giftoflivingdonation.co.uk

TRUST LIFE

Kelly Cook meets some of the patients living with sickle cell disorder who have been cared for by the haematology team.



Patient Toby Bakare received a life-changing stem cell transplant from his sister

Here for you

Ansella Aaron has been under the care of the haematology team at Guy's and St Thomas' for the last 60 years.

At 80 years old, she's one of the department's oldest patients being treated for sickle cell disorder, an inherited condition that affects the red blood cells.

Sickle cell can cause severe painful episodes called "crises", and can put people at an increased risk of serious infections, anaemia, stroke and lung problems.

It is particularly common in people with an African or Caribbean family background.

Ansella, who has three children and four grandchildren, said: "I've

had excellent care over the years and have been able to reach this age thanks to all the fantastic staff I've met along the way – they have looked after me so well and are more like friends."

Ansella's children were born via caesarean section at St Thomas' Hospital, and she underwent two hip replacements at Guy's Hospital.

The retired auxiliary nurse said: "Whenever I've had surgery the haematology team have worked closely together with the doctors and nurses from the other departments to help me come through it, and the ward staff have been amazing."

Although there are some medicines available to help reduce symptoms, the

only cure for sickle cell disorder is a stem cell transplant.

Toby Bakare has been a patient at Guy's and St Thomas' for 17 years and received a stem cell transplant from his sister in December 2022.

The 35-year-old said: "Sickle cell is such

"I've had excellent care over the years and have been able to reach this age thanks to all the fantastic staff I've met along the way." a horrible condition to deal with day to day but the transplant has been life changing. I'm now able to cycle everywhere and do things I wasn't able to before. It's a huge relief not to keep getting ill and my quality of life is on the up and up."

Toby, a TV producer, added: "I'm so grateful that

my sister agreed to donate her stem cells and for the care I've received from my clinical team."

More than 1,000 adults are treated by Guy's and St Thomas' for sickle cell disorder each year.

Dedicated psychologists in the haematology department offer one to one therapy to patients, as well as a weekly virtual support group.

The Trust is working with NHS South East London to launch a community pilot project, which aims to improve care for people living with the condition across Lambeth, Southwark, Lewisham, Greenwich, Bromley and Bexley.

The project will see an increase in community support for patients with sickle cell, including provision of specialist



Patient Ansella Aaron has been supported by a range of st

community nurses for adults and children, and further roll out of a peer to peer mentoring programme for children and young people in partnership with the Sickle Cell Society.

Community nurses will also work closely with a new team of healthcare staff, including



 Sickle cell disorder is caused by a gene that affects how red blood cells develop. If both parents have the gene, there is a 1 in 4 chance of their children being born with the condition.

 Normally, red blood cells are disc-shaped and flexible enough to move easily through the blood vessels. In sickle cell disorder, red blood cells become crescent - or sickle shaped. These cells do not bend or move easily and can block blood flow to the rest of the body.

aff from the haematology team

specialists in psychology, pharmacy, physiotherapy, dietetics and welfare support. was left behind in every aspect of Dr Rachel Kesse-Adu, a consultant haematologist at Guy's and St Thomas', said: "Sickle cell disease is a serious and lifelong health condition, although treatment can help manage many of the symptoms.

"For a long time, the condition healthcare but things are changing. The future treatment for sickle cell disease is bright, with new drug and curative options in late stages of clinical trials."



Members of the paediatric haematology team

A specialist service

Evelina London Children's Hospital cares for around 450 children with sickle cell disease each year, from birth until 17 years old.

The centre provides a range of specialist services including full transcranial doppler scanning - a test that uses ultrasound to measure how fast the blood flows through the blood vessels within the brain.

There is also a stroke prevention blood transfusion programme, and a major research and clinical trials programme.

Dr Samah Babiker, a consultant haematologist at Evelina London, said: "Our goal is to help educate parents about the condition so we can prevent sickle cell crises and admissions to hospital. Our team is here to help support patients so they can achieve whatever they want in life."

The service has two dedicated psychologists who also lead a support group for parents.

Evelina London is one of 17 sites piloting the ACT NOW training programme, which has been codeveloped by clinicians, patients and their families to improve the care given to patients during a sickle cell crisis.

Mercy Taiwo's seven-year-old son, Andrew, has been under the care of the team since he was three months old.

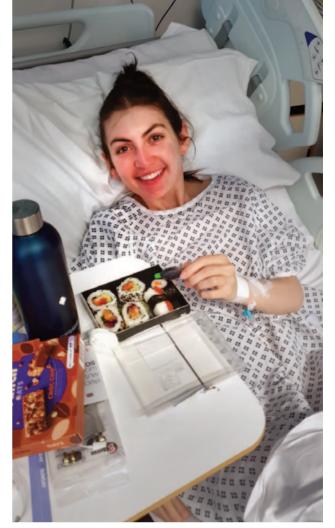
She said: "The team are very good and understanding. They are very much a listening ear for the whole family. The psychologist has supported us all."

IN FOCUS

Maxine Hoeksma finds out how robotic surgery is transforming the lives of people living with inflammatory bowel disease.



Francesca Porter with her fiancé James



Francesca Porter had life changing robotic surgery at St Thomas' Hospital

A brighter future

Francesca Porter is looking forward to walking down the aisle with confidence next year, after 20 years of living with a crippling bowel condition that made everyday life very challenging.

The 30-year-old, who regularly experienced diarrhoea, stomach aches, chronic fatigue and weight loss, was diagnosed with Crohn's disease – a type of inflammatory bowel disease – when she was 11.

It happens when your immune system attacks your bowel causing significant inflammation.

But thanks to surgeries to remove Francesca's large bowel and rectum carried out at St Thomas' in 2021 and 2023, the management consultant is now enjoying a new found freedom.

Francesca said: "I went from going to the toilet 30 times a day to emptying my

stoma bag just four times a day. Now the urgency has gone, the pain has gone, the anxiety around the toilet has gone. It's so different."

Born in Yorkshire and now living in Wandsworth, Francesca explained that by June 2021, she resorted to a low fibre liquid diet, because medicines no longer kept the symptoms under control.

She said: "I was going to the toilet countless times a day and was really quite

bloated. My parents came to visit me and when they saw how ill I looked they told me to go to A&E."

Following many tests and scans, Francesca had her large bowel removed and a stoma fitted using keyhole surgery. A stoma is a small opening in the abdomen that is used to remove poo and urine into a collection bag.

"I no longer have stomach pains and can go out without being worried about needing the toilet." Francesca said: "The stoma gave me my entire life back, it's the easiest thing to look after, and even though I still have to be careful about what I eat, it's miles better than before.

"I no longer have stomach pains and can go out without

being worried about needing the toilet, or having to think about where the nearest toilet is. I have much more energy inside and outside of work."

The final stage of Francesca's treatment in May 2023 involved





Surgeon Katie Adams uses the da Vinci robot

The surgery has given Francesca her life back

removing her rectum using the precision of robotic surgery.

Because of the rectum's proximity to the pelvis. Francesca and

her fiancé, James, chose to freeze their embryos, to give them the option to start a family in the future.

Francesca said: "The surgery was done robotically and it's crazy how quickly I felt better. I have very minimal scar

tissue and so the chances of infertility are minimal – I should be able to conceive naturally."

Katie Adams is the consultant colorectal surgeon who carried out both of Francesca's procedures at St Thomas'.

She uses the da Vinci surgical system to treat patients with inflammatory bowel

disease and has performed the greatest number of these operations using this technology in the UK.

"The stoma gave me my entire life back, it's the easiest thing to look after." Robotic surgery allows smaller scars, less scar tissue, a shorter stay in hospital as well as fewer complications such as blood loss and hernias. Supported by a team of specialist nurses, a

psychologist, and dietitians, Katie emphasises the importance of quality of life for her patients, many of whom are diagnosed at a young age.

Katie said: "A lot of my patients have been living with their disease for a long time when I meet them. They are trying to finish school, go to university, stay in

Fast Facts

- Inflammatory bowel disease affects more than 500,000 people in the UK
- About 3 in 4 people with Crohn's disease and 1 in 4 people with ulcerative colitis will eventually need at least one operation.

work, form relationships, get married, or have kids. That's why I believe this type of surgery can enable patients to pursue what truly matters to them in life."

She added: "Operating robotically allows us to make smaller incisions, which is obviously nice from a cosmetic point of view, but the real benefit is you can recover faster and be left with less scar tissue. Also, if you need another operation in the future you can have it minimally invasively again." Daisy Holden speaks to a mum whose daughter has battled against the odds.

A little fighter

"All of the teams

It's because of

she's alive."

who have cared for

Amelia are amazing.

Evelina London that

Four-year-old Amelia Kan has been treated at Evelina London since she was born.

She has a rare genetic condition called tuberous sclerosis complex, which causes non-cancerous tumours to grow in different parts of her body.

Thanks to the life-saving care she's received from teams across the specialist children's hospital, Amelia is getting ready to start school in September.

Amelia's condition was first identified during mum Weeta's routine antenatal scan.

A sonographer noticed a dot on the left side of Amelia's heart and referred her for further investigations. The dot on the scan was later diagnosed as a tumour.

Weeta, from Bromley in Kent, said: "It became routine during my pregnancy that we had scans on a Tuesday and blood tests on a Friday. Sadly, we kept being told the tumours were multiplying and growing, it was just bad news every time.

"As the scans continued we realised how serious Amelia's condition was. She had so many tumours, one was squashing her lungs and another on the mitral valve in her heart. We decided on the name Amelia as it meant fighter – and she's lived up to her name."

Weeta went into labour early at 36 weeks and was transferred to St Thomas'

Hospital maternity department for specialist care.

Amelia was born with multiple tumours throughout her heart, including a large tumour next to her heart which was the size of a lemon.

She was rushed to Evelina London's neonatal intensive care

unit, where she spent several months receiving chemotherapy to reduce the size of the tumours.

The effects of the tumours and chemotherapy damaged a valve in Amelia's heart, and so she needed three open heart surgeries when she was just one-year-old. The first and second to repair and then replace the damaged valve, and the third to fit a pacemaker.

Aaron Bell, a paediatric cardiologist and head of service at Evelina London Children's Hospital, said: "Tuberous

Amelia Kan received specialist care at Evelina London Children's Hospital

sclerosis complex isn't common, we typically see around six children a year with it. However, Amelia had some of the biggest tumours that we've ever seen, and there was a real concern that she wouldn't survive being born as some of the tumours were compressing her lungs but Amelia surprised us from day one."

Amelia's condition means that she's prone to tumours growing anywhere in her body, so she has been cared for by a number of different teams across Evelina London, including the neonatal, cardiology, genetics, paediatric intensive care, kidney and bladder teams.

Weeta said: "Amelia has grown into a crazy little monkey who doesn't listen. She's my amazing little hero who has a very strong character. All of the teams who have cared for Amelia are amazing. It's because of Evelina London that she's alive.

"In particular Sujeev Mathur from the cardiology team is incredible, we've had to make lots of difficult decisions but we agree with everything he has said. Pankaj Mistra from the urology team treated Amelia like a VIP from day one. Trying to make friends, and put her at ease. We are so lucky to have them on Amelia's team, without them she wouldn't be here."

Last year, Amelia developed a rare



16 the GiST

IN FOCUS



Amelia with her parents Weeta and Chi

cancer after a tumour was found in her kidney. She underwent an operation to remove the tumour and part of her kidney, in a procedure known as a partial nephrectomy.

Pankaj Mistra, a paediatric consultant urologist at Evelina London, said: "Amelia's operation was a huge team effort. After discussing her treatment with the clinical team at The Royal Marsden, two oncology surgeons from St George's Hospital joined us for the procedure. In total there were eight different specialist teams from across Evelina London who inputted into her operation, along with the two oncology surgeons.

"Her tumour in her kidney was rare in small children. However, the operation was a success and only part of her kidney containing the tumour was removed. Amelia continues to make great progress and we're pleased to see how well she is doing."

Amelia will continue to be monitored by the different specialist teams across Evelina London as she grows up.



Now four years old, Amelia is getting ready to start school in September

Lesley Walker

looks at a rare procedure transferring a patient's toe to become a new thumb.

Transplant restarts carpenter's career

<image>

Craftsman Marcin is preparing to return to his trade after an unusual operation

A devastating work accident nearly ended the 30-year career of carpenter Marcin Michalec after he lost his thumb and index finger in one hand.

However, with the expertise of his surgical team at Guy's and St Thomas',

one of Marcin's toes was transplanted to his hand to create a new thumb, giving him the chance to return to the craft he loves.

Dad-of-two Marcin had been working in his workshop in April 2023 using a table milling machine when his hand slipped and the machine sawed off his

thumb, index finger and the tops of two other fingers on his left hand.

Helped by his son Stawomir, who was working with him, Marcin managed to apply a tourniquet while he was taken to hospital.

Doctors were unfortunately unable to reattach his fingers and thumb, and

suggested he have a prosthesis.

However, this would have ended Marcin's carpentry career as he needs to be able to use his left hand to guide his tools.

Marcin, 46, who now lives near Leicester, said: "I was devastated. I thought my life was over and a nightmare would

begin because I couldn't imagine any other life. I love the carpentry profession."

He met with George Murphy, a consultant plastic surgeon at Guy's and St Thomas', who offered Marcin the opportunity to have a toe-to-thumb transplant.

This procedure is mostly undertaken for children who are born with missing fingers and is rarely done in adults.

Marcin's surgery was the first time in at least 30 years an adult had been operated on using the procedure at Guy's and St Thomas'.

In the nine-hour long operation, surgeons at St Thomas' Hospital removed the second toe of Marcin's right foot and transplanted it to become a new thumb for his injured left hand.

Marcin is now gaining feeling and movement in his new digit and is aiming to get back to the job he loves later in the year.

Mr George Murphy, who led the team which undertook the complex operation, said: "Marcin told us that he really

"I'm full of optimism for the future now. I will return to carpentry as soon as the doctor tells me I

can – I can't wait."



wanted to be able to use his left hand to work, which he felt wouldn't have been possible if he had a prosthesis.

"It's relatively unusual for adults to have a toe transplanted to their hand – this is the first such transplant which has taken place for an adult at St Thomas' in recent decades, and there are only a few centres in the UK performing this surgery.

"I thought Marcin would be a good candidate for this rare surgery. I'm glad he is making an excellent recovery and we hope he can start working again soon."

Marcin said: "Mr Murphy explained the



Marcin's hand after surgery



Marcin with his wife Monika and son Stawomir

"I'm glad he is making an excellent recovery and we hope he can start working again soon."

risks of the transplant to me. I understood them, but to me it was the best option which would give me a chance to continue in the profession I love. I need to be able to feel the tools, and to guide my

chisel with my left hand.

"I'm full of optimism for the future now. The doctors and nurses have been fantastic. I will definitely return to carpentry as soon as the doctor tells me I can – I can't wait."



Surgeon George Murphy

Fast Facts

- The first toe-to-hand transplant was performed in April 1968 at the Queen Victoria Hospital in East Sussex. The patient had a similar experience to Marcin, in an accident where he sawed off his left thumb. He regained movement and returned to his woodworking job.
- Since then, these transplants are still rare in adults and usually involve a series of operations. The second toe, next to the big toe, is usually used as it has the blood vessels, tendons and tissue needed for a successful transplant.
- Removal of this toe doesn't affect a person's balance or ability to walk and run. If successful, the transplanted toe can provide a degree of feeling and movement although it won't get the full range of movement that a natural finger or thumb would have.

Behind the scenes

Dawn Clarke, senior accounts payable manager

Q What does your job involve?

A I am the head of the accounts payable team. There are 22 members of staff in this team across the Trust, and we are responsible for paying all of the Trust's bills.

Every year we process about 368,000 invoices. We follow the Better Payment Practice Code and aim to pay at least 95 per cent of invoices within the agreed terms.

My role involves managing projects and helping to make accounting processes more efficient. I need to make sure that the Trust's financial position remains secure and that our money is being spent appropriately.

Q Who do you work with?

The accounts payable team deals with almost 1,000 queries a

day. This includes questions from staff about how to receipt orders and when invoices will be paid. Staff often ask us how to request goods or services. We also get questions from the suppliers of these goods or services.

My team has important relationships with the rest of the finance department, the wider organisation and external suppliers.

Q How does your team help the Trust to run smoothly?

A Our Trust needs to purchase a variety of goods and services, for example medical equipment, medicines, food, water, transport, printers and stationery.

The accounts payable team arranges to pay for all of these essential goods and services. Otherwise, the hospitals and our community services would not be able to function.



What do you enjoy about your job?

A l enjoy solving people's problems and using my analytical and organisational skills.

We are always busy, but I try to stay calm under pressure and appreciate working in a supportive team. I know that the work we do makes a real difference to our staff and patients.

I feel proud working for such a large Trust that has strong values and always strives to improve its processes.

From the frontline

Nathalie Roche, specialist mental health midwife

I started working in the hospital birth centre, also known as the labour ward, at St Thomas' Hospital in 2016.

After this, I joined one of the high-risk maternity teams called the Tower team. This gave me valuable experience of caring for people with various physical and mental health conditions during their pregnancy.

Since 2022, I have been employed as the Trust's sole specialist midwife in perinatal mental health.

My role is to support people using our maternity services who have severe mental health conditions, including schizophrenia and bipolar disorder.

Every week, I hold an online mental health and wellbeing session for people during their pregnancy. To support



their wellbeing, I also work closely with the safeguarding staff, local perinatal mental health teams and other services.

I believe that the mind and body are strongly linked. It is especially important to offer mental health support throughout pregnancy when people can feel more vulnerable and isolated. I give people lots of information and advice to help them make informed choices about their own care.

Pregnancy can sometimes trigger mental health issues, such as depression or anxiety. Individuals may get symptoms for the first time, or their existing conditions may become worse. My work is intended to reduce safety risks and encourage positive outcomes.

I support people to stay well in pregnancy and prepare for their lives as new parents. Maxine Hoeksma learns more about palliative care pioneer Dr Thelma Bates.



Sister Barbara Saunders with Dr Thelma Bates, second left, on a ward at St Thomas' Hospital in 1978

Smashing through the glass ceiling

"Determined", "pioneering", "enlightened" – these are just some of the words that have been used to describe Dr Thelma Bates who defied convention to become St Thomas' Hospital first female clinical consultant in 1967.

A decade later the breast cancer specialist set up Europe's first hospital palliative care team at St Thomas',

winning over sceptical colleagues to care for terminally ill patients.

Before this, the focus was to find a cure for conditions like cancer, and it was not uncommon for relatives to be told a diagnosis without informing the patient themselves. But for Dr Bates end of life care was not an afterthought.

She took inspiration from another trailblazing woman, Dame Cicely Saunders, who set up St Christopher's Hospice in Sydenham and the first home care team in 1969.

Recognising that the answer was to bring the hospice to the patient, Dr Bates visited the innovative St Luke's Hospital Hospice team in New York, and copied many of their ideas, for which she was grateful.

When it opened in December 1977,

St Thomas' Hospital terminal care support team used gentle palliative radiotherapy or chemotherapy to relieve symptoms for people with life-limiting illnesses.

The original team was made up of Dr Bates, an experienced nurse Barbara Saunders, Dr Andrew Hoy, a part-time social worker and the hospital's chaplain, Reverend Michael Stevens.

> "Most Christmas days mum would come to the hospital to visit her patients who couldn't go home."

In its first year the team worked in 26 wards with patients referred by consultants and GPs.

By year three, it had expanded to include four specialist nurses, caring for up to 20 inpatients and 40 outpatients at a time, 24 hours a day, seven days a week, along with bereavement care.

The success of the team paved the way for similar services to follow. By 1987, there were 20 hospital palliative care teams across the UK, and now there are hundreds.

Today, thanks to Dr Bates and her

pioneering colleagues, the Trust continues to be at the forefront of supporting patients and their loved ones during very difficult and challenging times.

Specialist teams provide round-theclock care in the hospitals and the community for thousands of terminally ill patients each year.

Services like the Pal@home team offer essential overnight palliative nursing care at home, including assessment and medicines.

Dr Bates retired from her post at St Thomas' in 1991 having been recognised internationally as a major figure in palliative care.

Dr Dominique Wakefield, a palliative medicine consultant and service lead for palliative and end of life care at Guy's and St Thomas' today, said: "We feel an immense sense of pride in building upon Dr Bates' remarkable legacy.

"She is a truly inspirational figure whose influence continues to drive advancements in the design and delivery of specialist palliative care services to this day."

A memorial bench has been installed in the gardens at St Thomas' in honour of Dr Bates who died age 93 in June 2023.

Annie Bates, Dr Bates' daughter, said: "I know that mum absolutely loved St Thomas'. She was very proud to work there. Most Christmas days mum would come to the hospital to visit her patients who couldn't go home."

Meet the governor

Newly elected governor **Sheila Reddy** reveals how she plans to champion the needs of people in the community.

The Council of Governors are the voice of the community, ensuring that patients, local people and staff members have a say in the running of Guy's and St Thomas'.

Sheila Reddy stood for election in May and is one of nine public governors who will be in the role for three years.

Her journey with the NHS began as a hospital pharmacist in Manchester, and she now works in marketing for pharmaceutical companies launching new drugs.

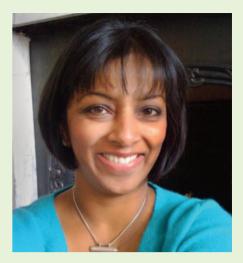
Sheila, who has lived in Wandsworth for more than 10 years, said: "I have directly benefited from the exceptional care provided by Guy's and St Thomas' so I have a deep appreciation for the commitment and compassion of the staff. "My background provides a unique perspective into patient needs and healthcare delivery, and my experiences have also focused my desire to help the Trust in areas where improvements are needed."

Sheila's aim as a governor is to ensure everyone receives the best possible care.

She said: "I am committed to representing everyone in our community, especially those who may find it hard to speak up."

Sheila is encouraging more people to become members of the Trust, and to consider standing for election when the opportunity arises.

She said: "If you're passionate about healthcare and itching to make a real difference, think about joining us — it's a



chance to help shape the future of our local health services."

The governors are your elected representatives and are keen to hear your views. If you have a question, comment or idea please email **governors@gstt.nhs.uk** or call **020 7188 7346.**

Meet the member

Elena Rolandi explains why she was inspired to become a member.

Guy's and St Thomas' counts on its members for feedback, local knowledge and support.

Membership is divided into patient, public and staff constituencies, and each constituency votes for its representatives on the Council of Governors.

Elena Rolandi, from Surrey, became a member earlier this year after her daughter was a patient at Evelina London Children's Hospital.

She said: "I want to support the Trust in any way that I can. My daughter has been under Evelina London for a number of years and we have always felt cared for – it was like meeting friends."

Elena's daughter was diagnosed with dystonia, a movement disorder that causes the muscles to contract involuntarily.

Elena said: "I saw my daughter deteriorating and losing mobility but



other hospitals couldn't help. We went to a hospital in Italy for a consultation and they referred us to Evelina London.

"My daughter underwent deep brain stimulation in August 2023 and it has made a huge difference to her quality of life. We had a lot of fear around the treatment but the doctors were certain it could help her and were very caring and patient with us."

She added: "Guy's and St Thomas' is an excellent representative of the NHS system. It's a multicultural, open minded organisation where everyone feels welcome.

"You can find excellent brains from all over the world and be reassured that the top experts are working together to improve research and healthcare."

To become a member, call **020 7188 7346**, email **members@gstt.nhs.uk** or visit www.guysandstthomas.nhs.uk/ membership

Get involved and make a difference

Sign up and help us shape your services

We involve patients, their families, carers and Foundation Trust members in planning, designing, improving and monitoring the services and care that we provide.

How to sign up

Complete this form – https://bit.ly/PPInvolvement – to tell us what interests you. We will get in touch when there are opportunities to get involved.

Current opportunities for children's services

Right now, we're looking for patients and carers to join our Youth Forum and our Parent and Carer Forum. To find out more and to get involved, please email **ELCHEngagement@gstt.nhs.uk**

Other opportunities

You can also help us to improve our:

- heart and lung services
- cancer and surgery services
- local community health services

Events and activities

We involve people in different ways, such as workshops, interviews and advisory groups. Some events are held online and others face-toface. We will adapt activities to help you take part wherever we can.

Find out more

If you have any questions, email getinvolved@gstt.nhs.uk or call 020 7188 6808.

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We have a pair of adult tickets for **Thames Rockets Ultimate London Adventure**. To be in with a chance of winning, simply complete the wordsearch below.

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Send your entry by 21 October 2024 to the GiST competition													

Send your entry by **21 October 2024** to the GiST competition, Communications Department, 4th floor, Staircase C, South Wing, St Thomas' Hospital, Westminster Bridge Road, SE1 7EH; or you can email **gist@gstt.nhs.uk**.

The winners will be selected at random and notified within seven days of the draw. The result will be final and we will not enter into any correspondence regarding the competition winners. The prize is non-transferable. Your name and details will be collected solely for the purposes of this competition and in order to be able to contact the winner and send them the prize. By entering this competition, you give your consent for us to use the data you provide in this way.

Thames Rockets T&Cs: The prize winner will be able to redeem the prize using the code provided online or over the phone. Prize is valid 12 months from the date of issue. There are no age restrictions- however children under 14 must be accompanied by an adult on board. Please note those with past or current back or neck conditions are strongly advised not to travel with us. Without exception, expectant mothers are not permitted on-board at any stage of their pregnancy.

Guy's & St Thomas' Charity &...

fundraising 8...

There are many ways you can fundraise to support the incredible staff and exceptional care at Guy's and St Thomas'.

Find out how you can make a difference.



Scan the QR code, or visit gsttcharity.org.uk/fundraising

Care never stands still. And neither do we.



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