

the GIST

News from Guy's and St Thomas' Issue 24 | 2017

Speaking out

Helping Cortez
find his voice





Welcome

Guy's and St Thomas' staff provide not only hospital but also community services for adults and children, as showcased in this issue of *the GiST*.

A team of staff from our new Lambeth Reablement team gave an inspiring presentation at our Annual Public Meeting in September.

They told the story of one of their patients, Betty, who has been able to continue living at home thanks to their support.

This team combines the talents of physiotherapists, occupational therapists, social workers and rehabilitation support workers to make a big difference to local people like Betty – find out more on page 7.

Our cover star, Cortez Nelson, has benefited from the expertise of staff in our Assistive Communication Service who have helped to empower him and increase his independence – you can read his story on page 16.

And there is an opportunity to follow a 'Day in the life of' our @home team – highly skilled nurses who ensure patients can be treated at home rather than being admitted to hospital – on page 18.

I hope you enjoy this edition of *the GiST*.

Amanda Pritchard

Amanda Pritchard, Chief Executive
Guy's and St Thomas' NHS Foundation Trust



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Patient Cortez Nelson with Cristiana Atherton (Speech and Language Therapist), Meike Currie (Rehabilitation Engineer) and Fumi Hiraide (Occupational Therapist)

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

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New Resuscitation area opens

The development of a new Emergency Floor on the ground floor of Lambeth Wing and East Wing at St Thomas' Hospital is more than 75% complete.

It will ensure that the 140,000 patients who visit our Emergency Department (A&E) each year are cared for safely in a better environment.

A bigger and better Resuscitation area opened on 26 September. It has larger treatment cubicles and dedicated trauma and isolation rooms.

A&E Consultant Dr Nicola Drake says: "The new Resus area has more space, with all our equipment within each cubicle, so everything is immediately to hand.

"We now have places to plug in vital equipment immediately next to the patient, there is good lighting, and all of this helps us do things quickly and safely."

Lee Patient, Advanced Nurse Practitioner, adds: "Our new Resus area has an additional two cubicles, including a negative pressure room for patients who need to be treated in isolation, an amazing trauma room, and a



A staff training session before the new Resuscitation area opened to patients

dedicated Resus room for children.

"The new unit will improve the dignity and privacy of our patients and relatives."

The Emergency Floor development is due to be completed in Spring 2018.

IN THE NEWS

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

BBC Radio 4

The *Today* programme on Radio 4 highlighted the work of the Evelina London Resolution Project to support families and staff in Evelina London Children's Hospital.

Dr Sara Hanna, Evelina London Medical Director, explained that maintaining trust between a child's family and the staff caring for them is essential.



Evening Standard

The *Evening Standard* featured Patricia Carroll (pictured above centre), whose daughter died waiting for a transplant, as she urged people to join the Organ Donor Register. Dr Marlies Ostermann, clinical lead for organ donation at Guy's and St Thomas', said it was crucial for people to discuss their wishes with their families.

Daily Mail

National newspapers including the *Daily Mail* and *The Sun* reported on a new blood test that can diagnose a heart attack in 15 minutes, which was developed by researchers based at St Thomas' Hospital. It is thought the test could save money for NHS trusts and free up beds.

Sports stars back heart research

Former England cricketer James Taylor and Sky Sports football pundit Graeme Souness called for more funding for heart research during a visit to St Thomas' Hospital in September.

James Taylor has become a British Heart Foundation (BHF) ambassador after being forced to retire from cricket last year when he was diagnosed with an inherited heart condition.

He said: "More needs to be done to prevent a dozen young people dying every week from undiagnosed heart conditions."

Graeme Souness, the BHF's ambassador for research, was diagnosed with coronary heart disease in his late 30s and suffered a



Heart patient Peter Hibbert with Cardiology Consultant Dr Gerry Carr-White, Graeme Souness and James Taylor at St Thomas' Hospital

heart attack in 2015. He noted that research is helping to save lives but much more needs to be done.

Michael Marber, Professor in Cardiology at St Thomas', is investigating new ways to detect heart attacks – his research is funded by the BHF.

He explained: "Heart disease is one of the leading causes of death in the UK. But our research, alongside the efforts of ambassadors like James and Graeme to raise awareness, can save the lives of thousands of heart patients."

Babies to benefit from milk allergy guidance



Credit: Mel Wilde Photography

Richard, George, Iris and Lucy Wronka

New guidelines are set to benefit babies around the world who are allergic to cow's milk.

The international milk allergy in primary care (iMAP) advice is a collaboration between the world's leading children allergy experts, led by Dr Adam Fox, who is a Consultant Children's Allergist at Evelina London Children's Hospital.

Dr Fox says: "The iMAP guidance can help primary care physicians to correctly diagnose, manage and follow up patients, alleviating their symptoms."

"We're very proud to bring together experts from around the world to create this advice."

Lucy Wronka attended the Evelina London Allergy Clinic after her son George, aged four, became sickly, unsettled, and had colic and reflux. After being diagnosed with non-IgE milk allergy, George was prescribed a hypoallergenic formula, an alternative to cow's milk.

Lucy explains: "Within a week it was like we had a different child. George was much happier, his skin improved, his cradle cap disappeared, and he started sleeping. I don't know what we would have done if we hadn't seen the team."

Finding the next Florence

The Nightingale Nurse Award, a new professional accolade to recognise outstanding nurses and midwives, was launched at St Thomas' Hospital on 13 September.

It is named in honour of the pioneering nurse Florence Nightingale, who established her first nursing school at St Thomas' in 1859.

The launch event was attended by more than 200 staff and included a procession with Florence's lamp from the Florence Nightingale Museum.

Dame Eileen Sills, Chief Nurse at Guy's and St Thomas', said: "I am so proud of our nurses and midwives here at Guy's and St Thomas'. They do fantastic work day in, day out, and always put our patients first."



Dame Eileen Sills speaks at the official launch

"To be able to recognise our most outstanding nurses and midwives is incredibly important."

The Nightingale Nurse Award includes the completion of a work-based learning module and will give staff the opportunity to start or complete a Masters qualification.

The first awards to staff will be made in May 2018.

Sidcup centres officially opened



Members of the Guy's Cancer at QMH Patient Reference Group with James Brokenshire MP

James Brokenshire MP officially opened Guy's and St Thomas' two new centres for cancer treatment and kidney dialysis at Queen Mary's Hospital (QMH), Sidcup, on 19 September.

He said: "Both the cancer and kidney treatment centres will make a huge difference to patients by delivering world leading treatments close to home. Rather than having to travel up to London, people will now be able to get the specialist treatment they need here in Sidcup."

Guy's Cancer at QMH and the new Kidney Treatment Centre, which is run in partnership with kidney dialysis specialists Diaverum, bring care closer to where patients live.

The development of Guy's Cancer at QMH means that for the first time people living in the borough of Bexley and the surrounding area can receive radiotherapy treatment locally – previously, cancer patients had to travel into central London.

Chemotherapy treatment facilities have been expanded and there is also a Dimpleby Macmillan Support Centre for people living with cancer and their families.

The new Kidney Treatment Centre is a purpose-built facility which replaced an ageing unit on the QMH site. The number of kidney dialysis stations has increased from 12 to 20 and the centre also includes rooms for outpatient appointments.

Charlotte is youngest to have ear op

A little girl who was the youngest person in the UK to have a middle ear implant has experienced life-changing benefits from the pioneering surgery.

Charlotte Wright, from Teddington, was three when she had surgery at St Thomas' Hospital to implant the device. She was born with microtia, when the outer ear is underdeveloped, and atresia, absence of the ear canal, so sound could not travel to the inner ear on her right side.

Her mother Sophie Wright, 42, explains: "Charlotte's hearing difficulties meant her speech was delayed, when she spoke no one could understand her, and she had behavioural problems because she was frustrated at not being able to hear."

Doctors at St Thomas' Hearing Implant Centre's specialist microtia and atresia clinic found that she was suitable for a

Vibrant Soundbridge middle ear implant, which replaces the function of the middle and outer ear.

Charlotte had the procedure in July 2016 and the device was turned on 12 weeks later.

Sophie says: "Charlotte heard things she had never heard before. It made a big difference straightaway."

Since then the audiology team has adjusted the settings to get the sound perfect for her. Charlotte, who is now aged five, has experienced dramatic improvements in both her speech and behaviour.

Professor Dan Jiang, Consultant Otolaryngologist at St Thomas', says young children with other types of hearing loss, chronic ear infections or tumours may also benefit from the implant. He adds: "This is a world-leading intervention."



Charlotte Wright is all smiles

Become a Foundation Trust member today

Joining Guy's and St Thomas' as a member of our Foundation Trust is the best way to support your local hospitals and community health services.

You can get involved and help shape the future of patient care.

It's free to join and you can become a member if you are aged 18 years or over and live in Lambeth, Southwark, Lewisham, Wandsworth or Westminster, or if you have been a patient at Guy's and St Thomas' in the last five years.

As a member you will receive a copy of this magazine through your door four times a year, you will also be sent our monthly email newsletter, and benefit from discounts on products and services.

You will be invited to attend meetings and



Foundation Trust Governor James Palmer signs up more local people as members

events, take part in surveys and consultations, and vote for your representatives on the Council of Governors – you can even stand for election if you are interested in becoming a governor.

- Complete an online form at www.guysandstthomas.nhs.uk/membership
- Call us on 0800 731 0319
- Email us at members@gstt.nhs.uk.

TOP TWEETS



@hmthompson_

Thank you to the wonderful team at @GSTTnhs Dental Department this morning for easing my nerves around my pesky wisdom teeth! #appreciated.



@cindygallop

From the doctors to the nurses to the orderlies – everyone on Albert Ward at St Thomas' @GSTTnhs is fantastic. So happy my father is here.



@AbsHSE22

Thanks to all in the Eye clinic for looking after me so well today. Very good care @GSTTnhs.



@Crundwell

Huge thanks to all the nursing and physio staff yesterday @GSTTnhs OPAU who were funny, caring, professional – and generally just lovely!



@saze72

Thanks to the great team @GSTTnhs renal department for looking after me today, & the past 11 years since #kidney #transplant. Superb unit.



@lynn457

@GSTTnhs Thank you Hedley Atkins Ward! Fantastic staff in this ward. Will miss you all. Thanks for Anne's care and love. Please commend! X



@Magnetacs

@GSTTnhs Thank you for your service. Twisted foot swollen, you got me looked at and x-rayed and on my way home last night... You guys rock.



@LessGrumpy

@GSTTnhs I was treated for anaphylaxis at St Thomas' today. Your staff are wonderful. Professional & caring. Thank you so much.

Patients can feel anxious if they need a device to keep their heart beating normally. A unique group set up at Guy's and St Thomas' is providing vital support, as **Cara Lee** explains.

A lifeline for heart patients



Bob Lowrie with Arrhythmia Nurse Sharlene Hogan

Bob Lowrie's life changed forever in 2010 when he was diagnosed with heart failure. He needed to have a device called an implantable cardioverter defibrillator (ICD) fitted. It uses electricity to shock the heart back into a normal rhythm if it goes into a life-threatening rhythm.

Bob, 71, from Southwark, recalls: "I'd had symptoms including pain and tightness in my chest, arms, legs, shoulders and neck for a while but never thought it was that bad. I was glad the doctors found what the problem was but I was worried that getting shocked by the device would be painful and I had no idea if and when I'd get one."

At the time he worked as a coach driver in Europe but was unable to stay in his job due to his diagnosis.

Bob, who has 13 grandchildren and two great-grandchildren, was later told by the cardiac rehabilitation team about a new support group for patients with ICDs at Guy's and St Thomas'. He attended his first session five years ago and has been going ever since.

He says: "Without a doubt, the group

has been hugely helpful and I now feel less anxious about living with my ICD. It's very useful listening to other people who are in the same boat as me. I've made good friends and seen how other people have become less anxious after going to the sessions.

"The group have provided invaluable reassurance. The staff are helpful and have time to talk to you one-on-one to give any advice you need.

"I have also shared my experiences with the group. I explained how seeing a psychologist can be beneficial and encouraged others to do the same, as sometimes there can be a stigma around asking for this kind of help.

"I think most people who need an ICD device would find the group as beneficial as I have."

The support group was set up by Sharlene Hogan, Arrhythmia Nurse, with the help of Ellie Hoad, Cardiac Rehabilitation Nurse, and Leanne Maddock, Cardiac Physiologist. Meetings take place four times a year, with up to 40 people attending each session.

Sharlene explains: "It's very normal to feel anxious if you need an ICD. It is a life-changing event and can affect your job, family life and ability to drive, so in turn it impacts on your independence. There is a fear of the unknown about receiving shocks from the device so patients need to find ways to cope with this anxiety.

"The group focuses on all aspects of living with an ICD, including medication, exercise and diet. We invite patients to share their stories about how they cope – and hold question and answer sessions with experts such as doctors, specialist nurses, pharmacists, dietitians, psychologists and physiologists.

"While this group is very beneficial, few hospitals have groups like this so they are not easily accessible. People come from all over to attend the sessions, and seeing the difference it can make to patients is very rewarding."

If you would like to find out more, please contact ICDsupportgroup@gstt.nhs.uk

Betty Mullins and
Rehabilitation Support
Worker Lorraine Boateng



Supporting independent living

Maxine Hoeksma

finds out more about a service which helps patients in Lambeth stay in their own homes after an illness.

Betty Mullins, 95, looks incredibly young and fit as she reels off a list of activities she still enjoys doing including twice weekly ballroom dancing.

After a fall in January left her with a fractured shoulder which led to a hospital stay, Betty was adamant that she wanted to regain her independence as quickly as possible.

Thankfully she was helped to get the targeted support she needed at home, and was back on her feet within six weeks because of the Lambeth Reablement Service.

Betty says: "I was in St Thomas' Hospital for nine days and they looked

after me very well. When I got home I had lots of people to help, taking me for walks, making me meals.

"I couldn't fault the excellent way they worked together, so friendly and dedicated to what they do. Everybody was doing a job until gradually I could say I didn't need them anymore."

The Reablement team, based at the Akerman Health Centre in Brixton, has social workers from Lambeth Council sitting alongside health professionals from Guy's and St Thomas', including therapists and rehabilitation support workers.

Close working means the team provides the right support at the right time, from intensive physiotherapy and arranging specialist equipment such as handrails which improve safety in the home to help with taking medication, shopping, washing, dressing and meal preparation.

Rehabilitation support workers are at

Lambeth Reablement Service

Our staff:

- Social workers and assessors
- Physiotherapists and occupational therapists
- Rehabilitation support workers.

Our patients:

- Adults living in Lambeth who require support with daily living
- Adults referred from the hospital or the community.

Our outcomes:

- Checks carried out at 91 days of care by the Lambeth Reablement Service show that more than 90% of our patients remain at home
- In 2016, 686 people were treated by the team and more than 60% fully regained independence without the need for ongoing social care support.

the core of the service, following carefully designed plans prepared by social workers and therapists to ensure patients make a quick recovery and become less reliant on the support of carers.

Sian Eke, Registered Manager for the Lambeth Reablement Service, says: "Sometimes it can be really overwhelming for patients when they first come out of hospital. By working together we gradually reduce the number of visits, giving patients more time to practise their exercises, meet with friends and recover.

"From the minute we knock on the door we're helping our patients to become more confident, until they are able to do things themselves."

- For more information about the Lambeth Reablement Service, call 020 3049 6599.

Ruth Shepherd talks to frontline staff who have pitched their bright ideas to get funding for projects to improve patient care.

Dragons' Den winners reveal all

Since 2013 a total of 40 projects have been funded through Guy's and St Thomas' Dragons' Den competition, from apps and 3D printing technology to diabetic foot checks and hot food lids.

The competition enables any member of staff to get their idea funded and turned into reality. To succeed, they need to make the shortlist and then pitch their idea to a panel of expert judges – the dragons.

Director of Improvement, Hannah Coffey, who is one of the dragons, says: "Our 15,000 staff, who care for patients day-in day-out, have great ideas about how we can improve things. The Dragons' Den competition is one way we can make the most of that potential. It's fantastic to see projects come to life and improve the experience of our patients."

Consultant Obstetrician Dr Daghni Rajasingam and Nicola Spray and Megan Winters from the Children's Community Speech and Language Therapy team have developed winning projects.



Consultant Obstetrician Dr Daghni Rajasingam

Daghni's idea – an app for pregnant women

What was your pitch?

My idea was the One-to-One app. It allows women to communicate directly and quickly with midwives on the Maternity Unit.

Women told us that they don't always want to use the alert bell when they're on the ward, particularly when they just need a glass of water or want to discuss something that is worrying them.

By using the One-to-One app, they can make requests via their smartphones. It doesn't replace the existing alert systems we have, but it offers an alternative way to communicate with the midwives.

How does the app support women?

It improves their experience, reduces anxiety and also enables our staff to be more responsive. It's about bringing the

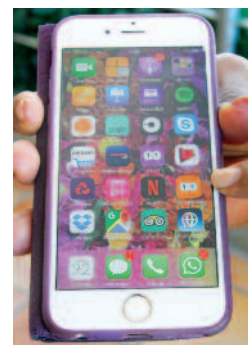
technology that women use in every other aspect of their lives into the ward setting.

We completed a two-week pilot on the Labour Ward. All the women who arrived were given the opportunity to download the app.

Women liked knowing that their midwife had received their message, and having an alternative to the alert bell. The maternity teams liked using the app as it meant they knew straight away what their patients wanted and could be more responsive.

What's next?

We will do another pilot on the Postnatal Ward and we then plan to extend use of the app across all our maternity services.





Children's Speech and Language Therapist Nicola Spray



A scene from the film

Nicola and Megan's idea – a film to promote children's speech and language therapy

What was your idea?

There is lots of written information available about children's speech and language therapy in Lambeth and Southwark, but we work with communities with low literacy levels so we wanted to provide information in a more accessible way. We decided to pitch the idea of creating a short film about our service to the Dragons' Den.

How did you develop the film?

We had a good idea of what the film should include, and approached a company called NKD Learning to make it. The key message we wanted to get across was that communication is everyone's business. Everyone has a role to play in helping a child to communicate.

We asked our speech and language therapy team to approach patients and schools who might like to take part in the film. It features an assessment clinic, our work in schools, and also our work in children's clinics and special schools.

What impact has the film had?

Since we launched the film in April this year, more than 2,300 people have viewed it. We know that more people are looking at the online information we have about our services, and parents have given us lots of positive feedback.

We get a lot of last minute cancellations and no-shows so have included a link on our appointment letters, and we hope this will result in more families keeping their appointments. The film also won a *Giving Voice Award* in September.

The film helps families know what to expect from therapy. Parents sometimes have pre-conceived ideas, and the film helps to give the full picture.

Local schools are also putting the film on their websites to highlight our work in schools.

What would you say to other staff who are considering applying for Dragons' Den funding?

Pitching our idea to the Trust's dragons was a little daunting, but we are so pleased we did it.

It's brilliant to see our project come to life, and see it helping and informing local families.



YouTube

Watch the film on the Trust's Youtube channel: www.youtube.com/gsttnhs

When Michelle Ticktin was told she had a high genetic risk of developing breast cancer, staff at Guy's Hospital supported her to make the decision she felt was best for her. She told her story to **Hamza Omaar**.

Michelle's choice

Michelle Ticktin, 38, who is originally from Glasgow and now lives in Brixton, has a history of breast cancer in her family. And so she wasn't surprised when a genetics counsellor at Guy's Hospital told her she had a BRCA1 gene mutation, which meant she was at a high risk of developing the disease herself.

She recalls: "It was still a blow, and I saw the genetics counsellor at Guy's both before and after the test. She clearly outlined the risks and choices ahead, and was both direct and kind."

As Michelle explains, she was supported every step of the way from that point onwards.

She says: "The next steps in the process moved swiftly. The genetics counsellor told me I was BRCA1 in February 2016, and I had a three-hour session with the gynaecology and breast teams in April. My ovaries and fallopian tubes were removed in July, and I had breast surgery in September.

"I was offered several options for breast reconstruction, and chose to go with nipple-sparing pre-pectoral

implants. In this procedure, you go into the surgery with breasts and come out of it with breasts. Any subsequent cosmetic surgery is optional. I had counselling from start to finish.

"There were bumps in the road. The surgical and other teams took fantastic

care of me throughout, treating me quickly and effectively. My breasts are different now, but they look great – I'm not giving them back!"

Breast cancer is the most common cancer in women, affecting 1 in 8 women, and ovarian cancer affects a further 1 in

52 women. In men, breast cancer is rare but prostate cancer affects around 1 in 8 men.

Some families have a higher risk of developing breast, ovarian and prostate cancers due to a genetic mutation.

The BRCA family service at Guy's Hospital, which was set up in 2006, helps patients who have been found to carry a BRCA1, BRCA2 or other high risk breast cancer susceptibility gene mutation.

The service holds an annual patient information day which is an opportunity

"The surgical and other teams took fantastic care of me throughout, treating me quickly and effectively."



Michelle Ticktin

for former and current patients to meet each other, share their experiences, and learn more about the latest innovations and research into hereditary cancer from staff at Guy's and St Thomas'.

Staff also offer guidance and support to patients and their families, who can often find both the results of their genetic test and the options available to them complex and daunting.

Dr Vishakha Tripathi, Consultant Genetic Counsellor who leads the BRCA family service, says: "Our patient information days have been a huge success. We are delighted to have been able to help patients share their experiences with other people going through the same journey.

"It is also a great opportunity for our experts to share key points from their leading edge clinical practice and



The BRCA clinic team – Hisham Hamed, Michelle Weston, Clare Turnball, Vishakha Tripathi, Clare Firth, Sarah Rose, Cecilia Compton, Louise Hopkirk, Kathrine Hilario, Isabelle Jendrulek and Rachel Painter

research directly with the patients on whom it will impact.”

In addition to the patient information days, patients are invited to attend the BRCA clinic for a face-to-face appointment. They are encouraged to bring a family member or friend to support them during their visit which usually lasts half a day.

Visits involve a multi-disciplinary team of staff including an oncologist (cancer specialist), clinical psychologist, breast surgeon, plastic surgeon, breast nurse, gynae-oncologist, clinical geneticist, genetic counsellor, researchers and a BRCA co-ordinator.

“Breast cancer is the most common cancer in women, affecting 1 in 8 women, and ovarian cancer affects a further 1 in 52.”

Patients choose which specialists they would like to see on the day, depending on their needs, and the specialists will see the patients in turn.

Patients are discussed at a multi-disciplinary meeting to ensure high quality, consistent care is provided to each patient.

Patients unable to access the clinic due to illness can have telephone appointments.

During the appointments, patients are able to discuss any worries or concerns they may have. They also review information about topics such as screening options, risk-reducing options,

talking to their family members, and reproductive options.

Issues raised during the patient's visit to the BRCA clinic are followed up by the relevant clinician. If patients want to proceed with risk-reducing surgery, their GP will refer them to the relevant specialist to take this forward.

The number of patients has been steadily increasing, resulting in additional clinics being added, and patient satisfaction rates are high.

What is it like for parents when their child is diagnosed with autism spectrum disorder (ASD)?

Rosamunde Wells met the Demmer family to find out.

It's good to share

Autism spectrum disorder (ASD) is a well-known but sometimes confusing condition. Being a spectrum condition, people with ASD are affected in many different ways, dependent on their personalities and whether they have any learning difficulties, mental health issues or other conditions.

Families are often unsure how to respond to a diagnosis. Amoreen and Ryan Demmer, from East Dulwich, recall how they felt when they were told their son, Thomas, aged three, had ASD.

Amoreen reflects: "It was quite a relief actually. We were just glad to have it confirmed."

Ryan agrees: "We had suspected that Thomas might have ASD as we'd read up on it and he has some of the classic signs. He didn't answer to his name and he doesn't do 'hello' and 'goodbye'.

"Like many people with ASD, he also has very intense interests. Thomas loves buildings, especially buildings in London. He likes to look at them, draw them and visit them. We asked for a GP referral and it was quite a slow process, so when we finally received a diagnosis we were ready."

The Evelina London Community

"The workshops were a chance to talk to other parents who were going through the same process."

Speech and Language Therapy team has set up a series of parent workshops to support families when they first receive a diagnosis. The workshops are a chance for parents and carers of children with ASD to meet other parents and learn from each other's experiences. They're run by a mixed group of staff including speech and language therapists and psychologists.

Ruth Fine, Highly Specialist Speech and Language Therapist, explains why the workshops are so essential. "It's really important that children and their families can get

support from other people in the same position as them, as well as from healthcare professionals. The impact that ASD can have on a child changes as they grow so we've tailored each workshop for different age groups.

"We tend to start with a presentation about what it is, discussing myths and facts, and we show some videos which help explain autism. Then we'll use this as the basis for a group discussion where parents can ask questions and others can provide their perspective.

"Parents like to share success stories which other parents can learn from, such

as how to create a new routine for a child. It's also an opportunity to develop strategies to deal with some of the more challenging behaviours that their children may display.

"We have asked the parents which issues they'd like to know more about and we have also created a series of workshops around topics such as transitioning from primary to secondary school, creating visual aids to support communication, and understanding behaviour."

Amoreen and Ryan attended one of these workshop for families with children who had been newly diagnosed with ASD.

"We were given a lot of information and leaflets when we first learned Thomas





Thomas Demmer with his mum Amoreen and dad Ryan

had ASD," Amoreen remembers. "The workshops were a chance to talk to other parents who were going through the same process."

Ryan adds: "It wasn't something we would have thought of going to but then we realised we had to get ourselves involved so that we could have that support network. The group was so relaxed. You just grab a seat and go! They talked us through what ASD is and helped to dispel some of the myths around it which was really helpful."

Amoreen agrees: "Every family's experience is unique but there will always be some things that someone else will have gone through. I remember there was a family who were further along the

process than us so they provided really useful information about where to go for different types of support, such as speech and language therapy and toilet training."

The team provides workshops to support families from diagnosis through to adulthood and so Amoreen and Ryan plan to go to more sessions.

"As Thomas grows older his needs will change," says Amoreen. "Next year he'll be moving up to primary school which will be a big change for him. It's really great that we've got this local support network of parents and professionals to help us when we need it."

For now, Thomas is enjoying being at a pre-school where there's a panoramic view of the London skyline from the window.



The Demmer family with staff from the Evelina London Community Speech and Language Therapy Team – Gill Davies, Ruth Fine and Laura Alcock

What is autism spectrum disorder (ASD)?

A lifelong disorder that affects the brain, changing how people experience the world around them.

It affects everyone differently, however some common traits are:

- Difficulties with interpreting both verbal and non-verbal language like gestures or tone of voice
- A very literal understanding of language, thinking people always mean exactly what they say
- Difficulty 'reading' other people which can make it hard to recognise or understand other people's feelings or intentions
- Difficulty expressing emotions
- Intense and highly-focused interests
- Difficulty changing an established routine
- Under or over-sensitivity to sounds, touch, tastes, smells, light, colours, temperature or pain.

For more information about ASD visit www.autism.org.uk

Éilis McGrath meets Sean Whittaker, Consultant Dermatologist at Guy's and St Thomas', Professor of Cutaneous Oncology at King's College London and joint lead for the Cancer Clinical Academic Group of King's Health Partners.



Abnormal chromosomes from a patient with a cutaneous lymphoma, a rare skin cancer affecting 500-600 people a year in the UK, one third of whom are seen at Guy's and St Thomas'

Talking genomics

Q What is genomics?

A Genomics is the study of changes in our DNA which can cause diseases, specifically inherited diseases, which are often the cause of rare conditions. Damage to DNA is one of the main causes of cancer.

In England there is a national genomics programme called the 100,000 Genomes Project which aims to sequence 100,000 genomes from around 70,000 NHS patients with a rare disease, plus their families, and patients with cancer.

Q How is Guy's and St Thomas' involved?

A Guy's and St Thomas' is leading the South London NHS Genomic Medicine Centre, covering the populations of South London and Kent, Surrey and Sussex. We're working with our partners at St George's Hospital, King's College Hospital and South London and Maudsley, as well as NHS trusts across Kent, Surrey and Sussex, to deliver the national project locally and unravel the basic causes of rare, inherited diseases and cancers.

By working collaboratively, we will develop standard genomic tests for patients with complex conditions. These tests will ensure our patients have access to the same diagnostic tools, with the same accuracy as anywhere else in the country.

We've had great success so far. South London is the top recruiter of cancer patients to the 100,000 Genomes Project and we are one of the highest recruiters of patients with rare and inherited diseases and their families. To date we have recruited more than 6,000 participants to the project.

Q What does it mean for patients?

A Advances in genomics will mean patients may be offered a diagnosis where there wasn't one before. In time, there is the potential for new and more effective treatments.

We've already had some successes in treating rare, inherited diseases based on a better understanding of gene mutations and gaining the ability to identify damaged genes earlier.

We've created drugs that can target specific damaged genes and reverse the damage that cancer has caused. We even have a tablet for advanced cases of melanoma that can make cancer disappear.

Drugs are now becoming available for breast, lung and colon cancer.

Q What is your main area of interest?

A My main area of interest is in complex skin cancers, both melanoma and lymphoma in the skin. My work is all about studying and analysing the causes of DNA damage, finding out which genes are damaged and, from there, finding new treatments.

I work collaboratively with teams across universities and NHS trusts to gather information and research on mutations and damage. The more knowledge we have, the more options we will have for future treatments.

Q What are the challenges?


A One of the main challenges in genomics is getting people to participate in our research.

We need people to take part in initiatives like the 100,000 Genomes Project so it can achieve its full potential and make a difference to how we diagnose and treat patients.

When it comes to rare and inherited diseases, the biggest concern for patients and their families is the lack of a clear diagnosis.

Without a diagnosis, it is difficult for patients and families to understand the condition and to access the care they need.

In cancer the challenge is improving our knowledge. Most patients understand this is critical not only for them but for the future.



"I believe diagnostic tests and treatment will be greatly impacted by genomics in the next five years."

We need to encourage patients and give them confidence to take part in genomic tests. We have staff who are specially trained to help people make these decisions, give patients time to ask questions, and get the reassurances they need.

Q How will genomics improve healthcare in the future?

A I believe diagnostic tests and treatment will be greatly impacted by genomics in the next five years. Already we are working with lung cancer patients on diagnosing cancer through a blood test and treating their cancer with one tablet.

Analysing DNA from a blood sample is a much less invasive procedure than a traditional biopsy and can be repeated throughout the course of treatment to monitor progress and inform future treatment decisions.

We're hoping to repeat this blood test, as well as one tablet treatments, for a range of cancers in the future.

You can get involved in the 100,000 Genomes Project by visiting www.genomicsengland.co.uk/taking-part

Maxine Hoeksma finds out how staff at Bowley Close Rehabilitation Centre in Crystal Palace are opening the door to a wider world of communication for patients.

"The team are amazing! Without them I would have given up. I think they are angels."

It doesn't take long to realise that Cortez Nelson has plenty to say for himself.

Cortez, 30, has always found communicating with people extremely challenging because his cerebral palsy makes speaking difficult. But with the help of a hi-tech communication aid, getting his voice heard has become easier.

Cortez is one of 100 adults and children with complex communication problems who have been referred to the Assistive Communication Service at the Bowley Close Rehabilitation Centre since 2016.

The service covers 11 London boroughs including Lambeth, Southwark and Lewisham. It supplies, fits and trains patients to use a range of hi-tech communication aids, and trains speech and language therapists from these boroughs to support patients.

Working in partnership with therapists, the service also makes recommendations for low-tech devices such as alphabet charts, communication books and boards.

In Cortez's case, eye tracking software with a special camera allows him to use his eyes to move a mouse cursor on a tablet, forming words and sentences that are turned into an electronic voice.

These types of aids help people with speech difficulties, as is the case with motor neurone disease, to communicate more freely and access social media independently. Professor Stephen



Cortez Nelson with Speech and Language Therapist Cristiana Atherton

The power of communication

Hawking is one famous user of a communication aid.

Cortez, who was referred to the service by a speech and language therapist in Newham in October 2016, explains: "The communication aid helps me communicate with people socially and professionally through social media. I use Facebook, I listen to music on YouTube, watch broadcasts and take selfies. I use it a lot in replying to emails.

"Before it was frustrating for people who don't know me that well to understand me. They could see that I had a lot to say.

"When I first got the communication aid I spent a lot of time exploring and finding out where everything was. Now I take it

out on Wednesday evenings to Bible Studies at church, just saying hello to people and asking how they are. People are amazed at what the computer can do.

"I love the technology! It has been life-changing. Before I would depend on mum, close friends, and my carers to check emails and social media. Now I can do this on my own, in my own time."

Cortez's mum, Linnet, says: "I can generally understand what Cortez is saying but sometimes it takes a while. This can be difficult for both of us, especially when time is a factor or there is background noise.

"The potential for Cortez using this computer is vast. We'll start to hear more from him and he can join in conversations."



Speech and Language Therapist Cristiana Atherton is part of a team of therapists, technicians and engineers at Bowley Close who have supported Cortez.

She says: "Communication is the essence of being human. We all need to make ourselves understood on some level. Our team's aim is to help improve or maintain our patients' communication and their quality of life."

Cortez says of the team at Bowley Close: "I think they are amazing! Without them I would have given up. I think they are angels."

Robotic surgery transforms patients' lives

Surgeons at Guy's Hospital have become the first in the world to routinely perform a type of robotic surgery which transforms the lives of patients who are at risk of kidney failure.

If left untreated, patients with retroperitoneal fibrosis (RPF) can develop kidney failure because the condition causes scar tissue to form

around their ureters – the tubes which pass urine from the kidneys to the bladder – which stops them working properly.

Patients with RPF are usually treated with stents – internal tubes which are inserted into the ureters to stop the tubes getting blocked. However, stents can irritate the bladder, cause blood in the urine, and make patients constantly need the toilet. The stents also need to be changed every six months.

Urological surgeons at Guy's Hospital are now treating patients in a pioneering procedure, known as robotic ureterolysis.

They use robots to snip away at the scar tissue with accuracy and precision, freeing the ureters. This relieves the blockage, allowing the tubes to drain properly.

Terry Iddenden, a 49-year-old father of two from Chichester in West Sussex, was one of the first patients to benefit from the innovative procedure.

He says: "Being able to function without having to plan your life around toilet routes is amazing. After two hard years with stents it was fantastic to get rid of them."

Ms Archie Fernando, Consultant Urological Surgeon at Guy's, explains: "We have carried out the robotic procedure on around 40 patients and are excited about the results. After surgery patients can have the stents removed and their kidneys are able to drain well, which can have a hugely positive impact on their lives."



Terry Iddenden

Terry Iddenden

Debi Miller, Deputy Head of Nursing, tells **Maxine Hoeksma** about the @home service based at Walworth Road Clinic near Elephant and Castle.

At home with the @home service

Our job is exactly what it says on the tin. We keep people out of hospital or help them to return home sooner by providing intensive clinical care at home, much like a hospital ward.

We are a team including nurses, therapists, geriatricians (elderly care doctors), GPs, pharmacists, social workers, and rehabilitation support workers, and we are all here to help people stay well in their own home.

Today, among the 65 patients we'll be seeing, are people with heart problems and chronic breathing problems. The service runs seven days a week, 8am to 11pm.

Our sister night-time service, pal@home, supports patients nearing the end of their lives by providing pain relief, for example. It operates from 8pm to 8am seven days a week.

8:00am – As usual we start the day with a handover. The team discusses the patients to be seen and any we may be particularly concerned about. If a nurse is worried about a patient they've seen they can raise it with our GPs at this meeting.



The @home team outside Walworth Road Clinic – Ruby Groome, Sandra Silva, Priti Patel, Adam Fitzgerald, Paulette Jackson, Debi Miller and Tiziana Ansell

9:00am – Our team of expert nurses are on their way out to see patients. A nurse assesses the kind of care needed, following a telephone referral from other health professionals like paramedics from the London Ambulance Service or a local GP. They match staff to patients, sending nurses and therapists to see a patient within two hours, up to four times a day for up to seven days.

12noon – The team are supported four days a week by geriatricians who are consultants from Guy's and St Thomas' and King's College Hospital. They are specialists in elderly care and carry out a 'virtual ward round' from the office. Sitting with a matron and other

staff, like our pharmacist, they work through the entire patient caseload, deciding what action is needed for individual patients.

In winter we often see more patients with long-term conditions such as heart or kidney problems or breathing problems. They may need more care than usual but this does not always need to be provided from a hospital bed.

4:00pm – Our team are back at base. The duty matron carries out a handover and staff provide an update on patients who may need extra support or people with more complex needs who need to see a GP or hospital doctor.



5:30pm – We get a call from our In Reach colleagues who are based at St Thomas' Hospital and King's College Hospital. They proactively attend hospital ward rounds, finding patients who could be cared for by our team at home.

8:00pm – At this time of the evening we have a smaller team making visits to those patients who perhaps need another dose of intravenous antibiotics and help getting into bed.

10:30pm – It's back to base for the remaining members of our team who finish the day by writing up their notes on individual patients they've seen and the care provided.

Everything is in place for another busy day tomorrow.



Why I fundraise

Georgie and James Melville-Ross have spent more time at Evelina London than many of the staff. Their 13-year-old twins, Alice and Tommy – dubbed the Twinvincibles – were born at St Thomas' Hospital four months early and were only given a 20% chance of surviving.

The twins have severe quadriplegic cerebral palsy with dystonia, giving them uncontrolled muscle contractions, and are supported by Dr Jean-Pierre Lin and his team in our Complex Motor Disorder Service (CMDS).

Both children have had deep brain stimulator surgery which implants electrodes into the brain to deliver electrical currents to help reduce the involuntary muscle spasms. Tommy was a pioneer to receive a new, rechargeable device but sadly, it became infected in November 2012 and he needed emergency surgery.

"Very gradually Tommy started to calm and his body repaired itself," Georgie says. "The tireless and dedicated work of Dr Lin and the CMDS team, together with the Paediatric Intensive Care Unit and the Savannah Ward nurses, saved my son's life."

To say thank you to the team, the whole family started fundraising, setting a target of £40,000.

Georgie and her sister ran the London Marathon, the whole family – wheelchairs and all – used a highly sophisticated rope system to pull the twins to the summit of Britain's tallest mountain, and James, his brother, sister and brother-in-law scaled three mountains in three different countries in a week.

And finally the whole family tackled the fittingly named Superhero Triathlon.

- You can help the family reach their target by donating at www.supportevelina.org.uk/twins
- If they have inspired you to get involved, go to www.supportevelina.org.uk to find out more.



Ask us: How are we making it easier for patients to contact services?

Alastair Gourlay, Director of Essentia at Guy's and St Thomas', explains how we are improving communication with patients.

Our Foundation Trust Council of Governors regularly asks questions of the Trust Board – on behalf of our members – based on 'hot topics'

such as the issue of contacting the Trust by telephone.

We have identified that telephone calls are answered much better when we have a call centre or team approach in place, using a single contact number. We are working with our clinical directorates to understand the best way of moving towards this system.

We have developed quality measures that set out the standards that patients should expect when they phone the Trust,

including reducing the amount of time it takes for a call to be answered, and ensuring that staff provide a professional and courteous response.

We are also reviewing and updating the contact information on our website and in our appointment and clinic letters.

And through our Digital Patient Journey programme, we are looking at different ways in which patients may be able to stay in touch in future, for example by managing their outpatient appointments through an online portal.

If you would like to send any questions to our governors for future issues of *the GiST*, please email members@gstt.nhs.uk or call 020 7188 7346.

Capturing the miracle of birth

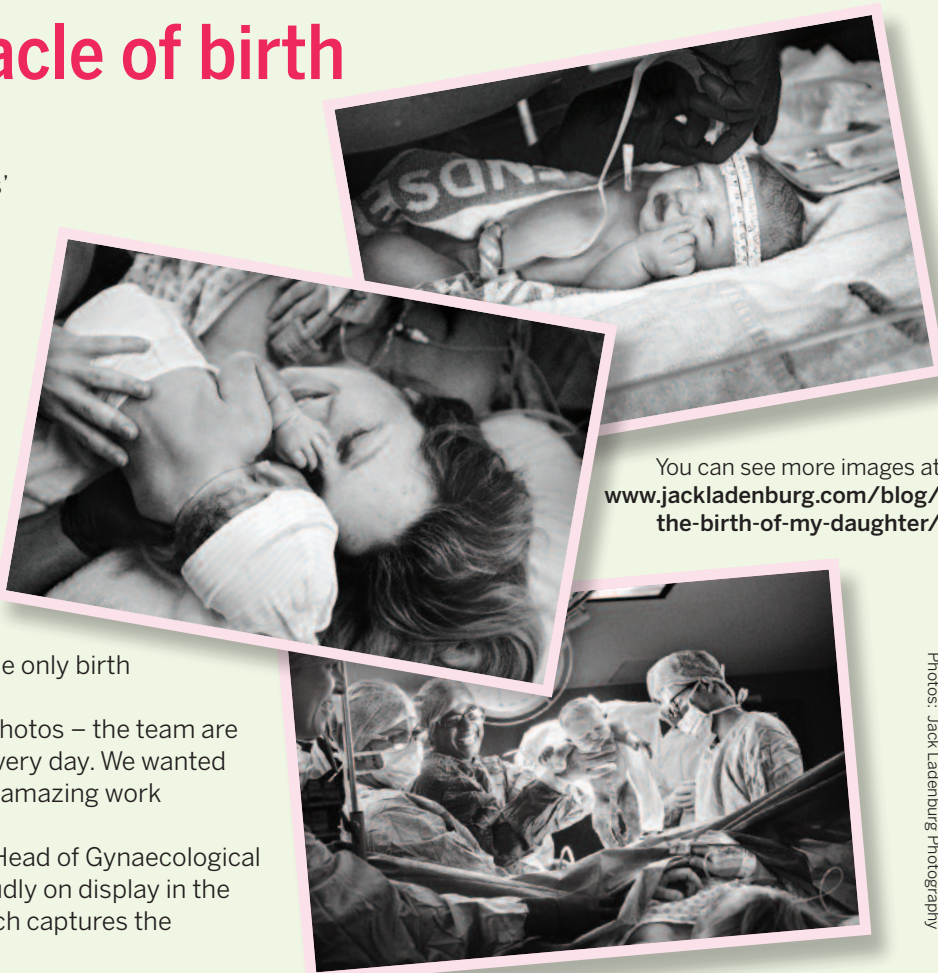
A couple whose daughter was born at St Thomas' Hospital earlier this year have thanked staff with heartwarming photos of the moment she was born.

Photographer Jack Ladenburg, 38, took images of his wife Naomi, 37, to capture baby Emmeline's arrival into the world – she was born after the couple had IVF treatment in the Assisted Conception Unit at Guy's Hospital.

Naomi says: "Jack felt helpless before Emmeline's birth so he did what he knew best by documenting it, after checking the staff were happy for him to do so. It's a moment that wouldn't have been possible without the maternity team who were so calm, kind and thoughtful. They made it feel like ours was the only birth that day – it was really special.

"We wanted to give something back with the photos – the team are part of life-changing moments in people's lives every day. We wanted them to cherish something which celebrates the amazing work they do."

Lynne Pacanowski, Director of Midwifery and Head of Gynaecological Nursing, adds: "These wonderful photos are proudly on display in the Maternity Unit. It's lovely to have a keepsake which captures the dedication of the team."



You can see more images at www.jackladenburg.com/blog/the-birth-of-my-daughter/

Photos: Jack Ladenburg Photography

The Florence Nightingale Museum at St Thomas' Hospital is the perfect place to rediscover the life of a woman known for her revolutionary influence on modern healthcare, as **Shanique Wahrmann** discovers.

Florence's legacy

Tucked away in the basement of St Thomas' Hospital, the museum brings Florence's legacy to life through its unique collections, art and interactive displays.

Visitors can travel through three iconic stages. The first focuses on Florence's education and Victorian childhood. The second takes visitors on a journey through her experience of the Crimean War where she became known for her exceptional work providing care to wounded soldiers with her dedicated team of nurses. The third showcases Florence's influence on global health reforms, which still remains relevant for nurses today.

In many ways, her greatest achievement was to establish nursing as a respectable profession for women. But Florence had to overcome significant opposition.

Learning and Access Manager Hajira Williams says: "Florence was prevented from pursuing nursing for a long time. Although she came from a very wealthy background, nursing wasn't very respectable and wasn't seen as much of a profession. But Florence was determined to change that."

Taking her experiences from the Crimean War in the 1850s, Florence campaigned tirelessly to improve standards of health, as Hajira explains.

"She was innovative and made a



The museum is full of fascinating interactive displays

profound contribution to the design of St Thomas' Hospital. She worked closely with architects, advocating the pavilion style of hospital. This meant having separate wings and connecting corridors to allow more space, ventilation and sunlight, as well as matrons on each ward."

In 1860 Florence successfully established the Nightingale Training School at St Thomas' Hospital, the first official nursing school in England.

The museum opened in 1989 and today houses approximately 3,000 items including letters, Florence's iconic lantern which earned her the nickname of the Lady with the Lamp, and even a medicine chest which was brought back from Crimea.

Museum Director David Green says: "More than 50,000 people come here every year. Apart from visitors from the UK, we most commonly meet people



The Florence Nightingale Museum team – David Green, Emma Hixson (as Florence Nightingale), Haidee Chuter and Holly Carter Chappell

from the USA, Canada, Australia, Japan and China who want to pay their respects to a figure who inspired their careers."

It's not just about nursing

● Support for students –

The museum runs a learning programme for schools including KS1 workshops, as well as family activities and a lively events programme.

● Support for teachers –

The museum hosts a teachers' evening on 22 November.

Find out more at

www.florence-nightingale.co.uk

The Florence Nightingale Museum at St Thomas' Hospital is open daily from 10am-5pm.

Free entry for Guy's and St Thomas' staff and children under five.

Get 2 for 1 entry with a copy of this magazine.

Say what?

Physiotherapy Technical Instructor **Cathy Stead** has worked at Guy's and St Thomas' for more than 25 years.

Q What do you remember from your first day in the Trust in 1991?

A We were given a second-hand uniform – my top was far too large at the time! And I was given a navy blue cardigan, as we had several different sites to travel between. We were told to look after the cardigan, and give it back when we left, or we had to pay £18! I've still got it.

Q If you could have three guests (past or present) at a dinner party, who would they be?

A Gandhi, Princess Diana and Elvis Presley. Elvis and Diana could dance while I had a chat with Gandhi.

Q What are you most proud of achieving?

A The accumulated knowledge of working with so many different people and medical conditions.

Q What is the best piece of advice you've ever been given?

A Chill. Whether you're upset or wound up, just take a moment and relax.

Q What's the best experience you've had?

A I ran an orthopaedic Knee School session recently, and a lady told me that, after her stroke 10 years ago, I'd been the one that got her



back on her feet. It is lovely to be remembered for doing a great job.

Q What's your philosophy on life?

A Be there for other people – family, friends or even strangers. Don't judge people.

Q What do you like to do in your spare time?

A I love gardening and seeing my family. I have two daughters and five grandchildren, as well as two cats, so there's always plenty going on.



From the frontline

Phlebotomist **Dionne Harrington** works for Viapath, our pathology services provider.

Dionne trained as a phlebotomist (a specialist in taking blood) last year and her clinical placement was at St Thomas' Hospital.

She enjoyed it so much that she applied for a post and has been here for nearly a year and is now a trainer for new students on their placements.

The Phlebotomy team work on both Guy's and St Thomas' sites, at health clinics in the community, and also on the wards.

Dionne says: "We visit very poorly

patients on their ward which can be challenging as some need tests every day and can easily get distressed. It's so important to me to make every patient I see as comfortable as possible so their blood test is done quickly and without pain."

There are plenty of opportunities for Dionne to continue her training and she has just finished peripherally inserted central catheter (PICC) line training. This means she can now work in the Cancer Centre at Guy's Hospital to take blood tests from patients directly through their PICC or Hickman line. This saves patients the discomfort of her trying to find another vein when they could be

hardened as a result of chemotherapy.

All staff receive customer service training so they know how to communicate well with their patients.

Dionne's manager, Vicky Shah, explains: "When I am recruiting, I really focus on the candidate's personality. I can teach them the skills but I can't teach them how to be nice."

The demand for the service is always increasing as many clinics now require their own phlebotomists so that patients can get blood tests done there and then within their clinics.

Viapath, which is a partnership between Guy's and St Thomas', King's College Hospital NHS Foundation Trust and Serco, has been operating the Phlebotomy Service at Guy's and St Thomas' since 2009. Staff see approximately 1,500 patients every day and the laboratories analyse around 30,000 blood tests a day.

What's On

Free Public Tours (weekly event)

Florence Nightingale
Museum

Tuesdays at 3.30pm
(except during school
holidays)
Call 020 7188 4400 or visit
florence-nightingale.co.uk

14 November

World Diabetes Day

29 November

Friends of Guy's and
St Thomas' Hospitals
Book Sale
10am - 3pm,
Birdsong Corridor,
St Thomas' Hospital

1 December

World AIDS Day

7 December

Friends of Guy's and
St Thomas' Hospitals
Christmas Market
11am - 3pm,
Central Hall and
Birdsong Corridor,
St Thomas' Hospital

11 December

Carols by Candlelight
7-8.15pm
St George's Cathedral,
Lambeth Road, SE1 6HR
Call 020 7848 4701
or visit
www.supportgstt.org.uk/carols
to book tickets

14 December

Friends of Guy's and
St Thomas' Hospitals
Christmas Market
11am - 3pm,
Atrium 1,
Guy's Hospital

Free film screenings:

MediCinema (gsttmedicinema@medicinema.org.uk) shows
the latest releases for patients and staff

Guy's Tuesdays, 1.30pm and Thursdays, 7pm

St Thomas' Saturdays, 7pm and Tuesdays, 7.30pm

Evelina London screenings on Wednesdays, 6.30pm

Free lunchtime concerts:

Mondays 1–2pm, Central Hall, St Thomas'

Wednesdays 1–2pm, Atrium 1, Guy's

Raise money for your hospitals and community services

For all the latest news about
our amazing fundraisers and how you can support
Guy's, St Thomas' and Evelina London,

follow  @SupportGSTT

and like  facebook.com/SupportGSTT

and  facebook.com/SupportEvelina

Competition



We have a pair of tickets for a fabulous B-Bakery Bus Tour
with Afternoon Tea up for grabs. To be in with a chance of
winning, simply complete the wordsearch below.

I	M	L	P	H	S	V	X	S	A	O	S
N	M	U	T	U	A	R	K	L	C	X	E
B	S	Q	U	I	R	R	E	L	O	R	V
D	S	D	R	U	O	G	V	K	R	E	A
W	C	O	B	W	E	B	H	E	N	B	E
B	C	H	E	S	T	N	U	T	S	O	L
O	B	R	E	B	M	E	V	O	N	T	C
N	I	K	P	M	U	P	K	R	W	C	R
F	G	K	K	O	C	M	O	A	C	O	V
I	Q	M	O	C	D	I	H	N	R	L	R
R	B	E	T	A	N	M	W	G	U	V	T
E	S	T	W	D	H	C	D	E	Y	G	B

Acorns

Autumn

Bonfire

Chestnuts

Cobweb

Conkers

Fireworks

Gourds

Harvest

Leaves

November

October

Orange

Pumpkin

Rake

Squirrel

Name

Address

Email

Send your entry by **8 December** to the GiST competition,
Communications Department, 4th floor, Staircase C, South
Wing, St Thomas' Hospital, Westminster Bridge Road, SE1 7EH;
or you can email communications@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.

Support

Guy's and
St Thomas'

Support

Evelina
London
Children's Hospital

Carols by Candlelight

Monday 11 December
7pm-8.15pm

St George's Cathedral,
Lambeth Road
SE1 6HR

Join us for
some festive
cheer and inspiring
stories about our
hospitals followed by
mulled wine and
mince pies.



**Tickets are £14 for adults,
£3 for children aged 5-16yrs and under 5's go free**

**To book visit www.supportgstt.org.uk/carols
or call 020 7848 4701**