

## STSTN News

## Easter Issue 14



### LEAD STORY HEADLINE

**STSTN** are back with another fantastic Easter issue (14)!

We kick started 2020 with an educational event entitled “A celebration of Sickle Cell Disease care in South East England: Looking forward to the next decade”. We had a magnificent turn out of more than 50 delegates from across the country. We had some great talks from our new professors within the STSTN network.

NHS England has established 10 Haemoglobinopathy Coordinating Centres (HCCs) across England to form networks of care to ensure that every child and adult with a haemoglobinopathy has access to expert clinical management. King’s College Hospital, Guy’s and St Thomas’ Hospitals and the Evelina Children’s Hospital were successful in their joint application to host the HCC for the South East region. A National Haemoglobinopathy Panel (NHP) was created to provide expert multidisciplinary advice on difficult decisions about the management of patients with sickle cell disease, thalassaemia and other rare anaemias. King’s Health Partners won the bid to host this panel and will work closely with the STSTN and other HCCs across England. The network will be recruiting an additional four posts.

Unfortunately, after such a strong start, the COVID-19 pandemic resulted in many cancellations and a temporary new way of life for all of us. COVID-19 is a new illness that affects lungs and airways. It is caused by a virus called the Coronavirus. COVID-19 started in China and has spread around the world. Due to COVID-19, the network has had to delay many plans for the year. However, the network continues to work hard to protect and care for our patients and staff during the pandemic.

We hope you enjoy reading our new Easter issue 14!  
STSTN Network Manager: Daud Daud

### Contact Info:

TEL: 020 3299 5102

EMAIL: [INFO@STSTN.CO.UK](mailto:INFO@STSTN.CO.UK)

TWITTER: [@STSTNNETWORK](https://twitter.com/STSTNNETWORK)

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# COVID-19

COVID-19 is an infectious disease caused by a newly discovered coronavirus. Most people infected with COVID-19 virus have a mild to moderate respiratory illness and recover without special treatment. Older people, and those with underlying medical problems like cardiovascular disease, diabetes, chronic respiratory disease, cancer and those with certain illnesses, including sickle and some thalassaemia patients, are more likely to develop serious illness.

COVID-19 spreads through droplets of saliva or discharge from the nose and mouth when an infected person coughs or sneezes. The most common symptoms of coronavirus (COVID-19) are recent new continuous cough and/or high temperature (> 37.8 °C)

**What is shielding?** Shielding is a measure to protect extremely vulnerable people by minimising interaction with others to avoid infection. Individuals with sickle cell disease (HbSS, HbSC, HbSBeta +/o) and some thalassaemics (with severe iron overload, cardiac complications or splenectomy in combination with another risk factor e.g. diabetes) are in the list of extremely vulnerable patients and should have received a letter from NHS England to strongly advise shielding for at least 12 weeks.



Nora Molongwe & Dr Sara Stuart-Smith

## DO:

- strictly avoid contact with someone with symptoms of coronavirus
- stay at home – don't leave your home to buy food, collect medicine or exercise
- keep in touch using remote technology such as phone, internet, and social media
- stay at least 2 metres away from other people in your home as much as possible
- get food and medicine delivered and left outside your door – ask friends and family to help or [register at GOV.UK to get coronavirus support](#) if you need it
- prepare a hospital bag, and a list of your medicines, in case you need admission
- wash your hands with soap and water or sanitiser gel often for at least 20 seconds
- ensure anyone coming into your home washes their hands
- clean objects and surfaces you touch often (door handles, kettles, phones)
- clean a shared bathroom each time you use it

## Don't:

- have visitors in your home, including friends/family, unless providing essential care
- don't stop taking prescription medicines without speaking to your doctor

## How is shielding different from social distancing for vulnerable people?

Shielding individuals are strongly advised to **stay at home at all times** for a period of at least 12 weeks from the day you receive your letter. Avoid going out even for food and medicine.

## How I conquered COVID-19 – by Nora Molongwe, COVID survivor

It was the fateful weekend after partying with friends celebrating my award for Inspiring Young People 2020. I got home on Sunday and by the evening started feeling so much chest pain. My pain killers proved futile, so I hurried to King's Day Unit the next day. My doctor checked me and told me my chest was OK, but my haemoglobin had dropped. She ordered two units of blood. Due to clinic closing time, only one unit could be transfused. I returned on Tuesday morning with a high fever of over 40°C. I couldn't breathe well. This prompted my doctors to do a COVID-19 throat swab test.

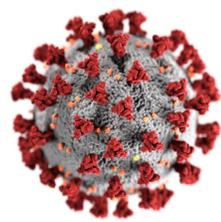
At about 6pm my doctors walked in wearing protective clothing and broke the news that I had tested positive for COVID-19. This was the saddest news I had heard in recent times. My heart sank and I asked my consultant whether I would ever see my children again. My doctor kept filling me with positive words. I was so broken. I was wheeled into isolation. Sitting in that room alone was one experience I won't forget in a hurry. Seeing the nurses and doctors coming into my room all covered up made me feel like I wouldn't see the next day

But the nurses kept reassuring me I would be well again, and go home to my kids. They told me they had had others that got well. I was so ill until two days later, when I accepted and told myself "Nora, you are leaving this bed alive!"

I started to focus on my kids. I called them all the time. I took fears away from my mind and the next day I was amazingly improved. I could breathe on air without the oxygen mask and all my observations were great, and the doctor said I looked so strong and could go home the next day because I was doing so well.

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I thank my doctors and nurses for taking good care of me, for uplifting me immensely. Positivity made me beat COVID-19. And my medical team will remain my gods for life.



# HAEMOGLOBINOPATHY COORDINATING CENTRES & NATIONAL HAEMOGLOBINOPATHY PANEL

NHS England has established 10 Haemoglobinopathy Coordinating Centres (HCCs) across England to form networks of care to ensure that every child and adult with a haemoglobinopathy has access to expert clinical management. These HCCs are responsible for ensuring that all patients in the network have annual reviews of care, that transcranial Doppler scans are performed and interpreted appropriately, and that expert acute medical care is available locally. The creation of HCCs should standardise care across the country and allow collection of data to ensure that this is happening.

King's College, Guy's and St Thomas' and the Evelina Children's Hospitals successfully applied to host the HCC for our south east region. This HCC will largely duplicate the South Thames Sickle Cell and Thalassaemia Network (STSTN), with some slight geographical changes. Most notably, St George's Hospital, which was part of the STSTN will now host the HCC for its own network. We expect that the STSTN will largely continue to function as before although we now have funding for another network manager, a data manager and time to facilitate the organisation of educational events for patients, nurses, doctors and other health care professionals. It should also be possible to offer more support to hospitals in the network, with the network and data managers visiting hospitals across the region regularly, to help with data collection and entry, particularly on to the National Haemoglobinopathy Registry. The exact details are not clear yet, but ultimately it should lead to better patient care. We plan to call our HCC the South East London and South East Haemoglobinopathies Co-ordinating Centre.

A National Haemoglobinopathy Panel (NHP) was also created to provide expert multidisciplinary advice on difficult decisions about the management of patients with sickle cell disease, thalassaemia and some other rare anaemias. King's College, Guy's and St Thomas' and the Evelina Children's Hospitals were also appointed to jointly host this panel, which will work closely with the STSTN and other HCCs across England.

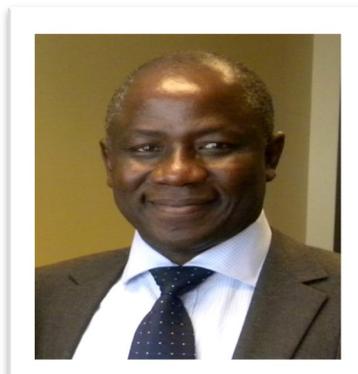


The following hospitals and trusts are part of the reconfigured STSTN:

- \* Princess Royal Hospital, Royal Sussex County Hospital
- \* Royal Alexandra Children's Hospital
- \* Croydon University Hospital
- \* Darent Valley Hospital
- \* Kent and Canterbury Hospital
- \* William Harvey Hospital Ashford
- \* Queen Elizabeth the Queen Mother Hospital, Margate
- \* Eastbourne District General
- \* Conquest Hospital
- \* Guy's Hospital
- \* St Thomas' Hospital
- \* Evelina Children's Hospital
- \* King's College Hospital
- \* Princess Royal University Hospital
- \* University Hospital Lewisham
- \* Queen Elizabeth Hospital, Woolwich
- \* Maidstone Hospital
- \* Tunbridge Wells Hospital
- \* Medway Maritime Hospital
- \* East Surrey Hospital, Redhill
- \* St Richard's Hospital Chichester
- \* Worthing Hospital



Professor Jo Howard,  
Haematologist, GSTT  
(STSTN) HCC LEAD



Professor Baba Inusa  
Paediatrician, GSTT  
(STSTN) NHP LEAD

# INFECTION & SEPSIS IN SICKLE CELL

There is increased risk from infection in sickle cell disorder (SCD). This is because of reduced spleen function. The spleen is a small organ on the left side of the abdomen. It forms part of the immune system and protects you from infections. In most people with SCD, the spleen stops functioning during childhood. This can lead to severe infections such as meningitis, pneumonia and sepsis. You are also more prone to developing severe illness from viruses such as influenza and malaria.

## THREE STEPS TO REDUCE INFECTION RISK:

### A. Prophylactic (preventative) antibiotics, particularly recommended if:

1. You are under 18 years or over 50 years of age
2. You have not responded adequately to the pneumococcal vaccine
3. You have not had the pneumococcal vaccine
4. You have had previous pneumococcal infections

First choice of antibiotic is penicillin V 250mg twice daily, or erythromycin 250mg twice daily if you are allergic to penicillin. In order for preventative antibiotics to be effective, you should take them every day. Some people forget or decide only to take the antibiotics when they are ill.

### If you are struggling to take your antibiotics twice a day:

1. Put a reminder on your mobile phone
2. Use a dosette box
3. Place antibiotics next to your toothbrush or in at your bedside

If you do not take regular antibiotics, it is important that you have an emergency supply. If you have a temperature  $\geq 38^{\circ}\text{C}$ , you should be reviewed urgently by a doctor – GP, Haematology Day Unit, clinic or Accident and Emergency Department.

**THERMOMETER** – act quickly if you have a fever of  $38^{\circ}\text{C}$  or higher



2.

**DOSETTE BOX**



**SUPPLY OF ANTIBIOTICS**



**Prompt treatment of infection:** Keep a thermometer and emergency antibiotics at home

If not taking regular prophylactic antibiotics, start taking emergency antibiotics (e.g. Penicillin V 500mg four times a day for a week) at the first signs of infection (e.g. fever of  $38^{\circ}\text{C}$  or higher, sore throat, shivers, cough).

If taking the lower (preventative) dose, increase to the higher treatment dose if you have symptoms of infection.

If infection symptoms last  $> 24$  hours, see your General Practitioner or go to hospital for assessment. If symptoms are severe or not responding to antibiotics, attend the Emergency Department.

### 3. Vaccination:

- ◆ **Pneumococcal vaccination (PPV23) every five years**
- ◆ **Annual influenza vaccination every autumn**
- ◆ **Hepatitis B vaccine** (if on transfusions and not immune: anti HBsAb  $< 100\text{mIU/ml}$ )
- ◆ You may be advised to have other vaccines, such as meningococcal ACWY and B or Haemophilus Influenza type B if you have not had them before.

**Red flag symptoms:** Fever (temperature of  $38^{\circ}\text{C}$  or higher), marked pallor, drowsiness, persistent vomiting and/or diarrhoea, chest pain, breathing problems, limb weakness, unusual pains - **come to hospital urgently**

Some symptoms you have to watch out for



## A TALENTED SICKLE PATIENT TAKES PART IN JUNIOR BAKE OFF!

I got into baking when I was 7 after I had an operation and was in recovery. I've been baking ever since.

Someone sent my dad the application for Junior Bake Off and they heard I like baking, so I decided you only live once and it's the last year I could apply, and we should take the opportunities given, so I signed up. To my surprise I got a call back and after a telephone interview, taster interview and a mini challenge, with blessings and perseverance I made it onto the baking show.

It was nothing like i had ever experienced before. The team and

support from my family and the community was amazing and I got to meet some lovely people, both my age and younger, just as passionate as myself. This has definitely changed my life for the better and has upped my business and social standing. I am looking forward to the future and all the things planned yet to come!

**Dru Brown** - Bake Off participant



## Pain Management Tips!!!



The **Sickle Cell Society South London Link** offer free activities, social events, support groups, and information and education workshops for people affected by sickle cell disease or thalassaemia living in the network region.

Contact: **020 3879 9535**

[www.sicklecellsociety.org/sickle-cell-south-london-link-service](http://www.sicklecellsociety.org/sickle-cell-south-london-link-service)



### Do you have a story to tell:

Email [info@ststn.co.uk](mailto:info@ststn.co.uk) if you'd like to share your experiences or would like to contribute to red cell news in any way.

### Visit patient zone on our website:

[www.ststn.co.uk](http://www.ststn.co.uk) to find patient information, clinic times, support group information and previous editions of the red cell newsletters.

