



South Thames
Sickle Cell &
Thalassaemia
Network



STSTN

Christmas is fast approaching and we'd like to welcome you to issue 15 of the STSTN newsletter, which is full of news, updates and helpful advice.

In our Easter edition we updated you on the ten Haemoglobinopathy Coordinating Centres (HCCs) set up by NHS England. These form care networks so that everyone with a haemoglobinopathy has access to expert clinical management. King's College Hospital, Guy's and St Thomas' and the Evelina London Hospitals were appointed as hosts for our region and we're pleased to announce that our team is now ready to support this work. You can meet our new staff members on the next page.

COVID-19 has presented many challenges and on page 3 you can read about the changes to care and support that have been introduced across the network. There have also been positive developments, such as virtual working, team support and virtual educational events for our clinical teams. Meanwhile, our patient support groups and forums have hosted debates and catch-ups on our virtual platforms.

On page 7, you can find out more about the work of the National Haemoglobinopathy Panel (NHP), a newly created panel which provides expert multidisciplinary advice at a national level. UKTS has been keeping busy during the pandemic and you can find out more on page 8. We finish this edition with some helpful tips for your wellbeing in Patient Zone, plus well-deserved congratulations to a very special nurse on page 10.

We hope you enjoy this latest edition and we would like to send everyone best wishes for Christmas and the New Year.

To stay up to date with news and events, you can visit our website ststn.co.uk our twitter account [@STSTNetwork](https://twitter.com/STSTNetwork) or contact your local support group.

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Welcome to our new team members

Sarah Kemp (HCC Operational Manager)

I'm Sarah Kemp and I joined the HCC in June 2020 as the HCC Operational Manager. I manage the HCC team, which provides support to the clinical team, as we seek to deliver improvements in care to our patients across the network with

Sickle Cell, Thalassaemia and Rare Anaemias. I have worked in operational roles in the NHS for four years and I'm excited to join the HCC at this time. I'm looking forward to working with clinicians and patients across the network.

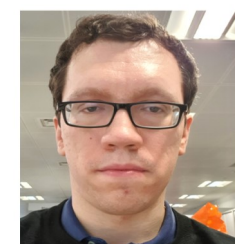


Shane Nagle (NHP Operations Support Officer)

I'm Shane Nagle and since the start of August I have been the new Operations Support Officer for the National Haemoglobinopathy Panel. It is my job to provide all-round administrative support for the Panel and to help things run smoothly for the clinicians involved in running the Panel. Previously, I was a service coordinator in gastroenterology at Great Ormond Street Hospital for

Children, which also involved coordinating the national highly specialised service for paediatric intestinal pseudo-obstruction.

So, while my last job did prepare me to an extent for this role, starting a completely new position in a new service has certainly been a learning experience for me but I'm really enjoying the challenge.



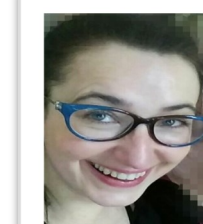
Marta Gruszka (Data Coordinator for the HCC)

I'm Marta Gruszka and in April 2020 I was appointed Haemoglobinopathy Coordinating Centre (HCC) data coordinator for South London and South East England.

The role of the HCC is to support and develop the network in order to enhance access to expertise and standards of care for all haemoglobinopathy patients.

I have an interest in Red Cell Haematology and have recently graduated with an MSc in Medical Statistics from the London School of Hygiene and Tropical Medicine. My previous work experience includes data analytics and database management in NHS and telecommunication settings.

I work on improving communication between Local and Specialist Haemoglobinopathy Teams via gathering, collating and analysing the information provided. The goal of my work is the evaluation and enrichment of patient experience across the HCC network.



Nina Gorman (Advanced Nurse Practitioner) & Steven Okoli (Haematologist Consultant)

King's College Hospital Red Cell team are also excited to announce the recent appointments of Dr Steven Okoli as an additional Red Cell Consultant and Nina Gorman as our first Red Cell Advanced Nurse Practitioner.

Steven Okoli is a consultant haematologist with previous links to King's as a pharmacist, junior medical trainee and previous locum red cell consultant. He has returned to King's as a consultant following completion of his PhD.

Nina has worked in specialist haematology services for 5 years, most recently at UCLH. She can prescribe medication, assess and manage unwell patients, and is launching an Annual Review clinic. She is completing line insertion training so she can put in femoral Vascath lines to enable red cell exchange transfusion in emergency and planned settings.

Steven and Nina are already contributing to the management of our patients and improving services.



Changes to care during COVID-19

It has been a difficult year, with challenging expectations from Public Health England and the UK Government, including shielding, self-isolation and social distancing measures, which have changed the way we live. More than 250 people with haemoglobin disorders have become infected with COVID-19 and more than 90% survived. Children and young adults have mostly avoided the worst complications, with no deaths or ITU admissions in the under-21 age group.

Working within our local Haemoglobinopathy Coordinating Centre (South Thames Sickle and Thalassaemia Network), it was great to see the adaptability and resilience of individuals and institutions. Everyone has adjusted to the 'new normal' and kept up with new practice and policy. There have also been positive changes to care and support access, most of which will continue as we return to routine work. You can find out more below.



Telephone appointments allow care to be delivered at home, so there's no need to travel to hospital and wait to be seen by a nurse or doctor. This has been very effective, as a lot of information can be communicated by phone. Only those with worrying symptoms, or those who need blood or urine tests, have to attend a face-to-face review. Telephone clinics will continue to be an option for routine follow-up.



Home delivery of specialist medications e.g. hydroxycarbamide and iron chelating agents (Exjade), as well as emergency analgesia and antibiotics, has allowed patients to avoid travelling to hospital to get a prescription, present it to the pharmacy and collect medication.



Virtual video call clinics allow users to access several healthcare providers in a single session (e.g. transition clinics for young people moving from children's to adult services). Patients can meet an extended team without taking time out of work or education. It also avoids travel and ensures social distancing can be maintained.



Satellite phlebotomy clinics in local car parks avoid the inconvenience and risk of going to hospital and can mean convenient blood testing nearer to home. Pre-bookable clinics include Thamesmead Dialysis Unit Car Park, Lewisham Shopping Centre Car Park, Dulwich Community Hospital and Beckenham Place Car Park.



Zoom videoconferencing for patient awareness, education and support groups means patients can attend without leaving home. Many who previously didn't attend because of childcare issues, travel costs, bad weather or shyness have been able to access support and education.



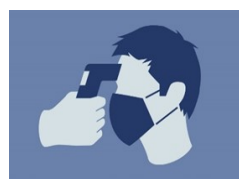
Microsoft Teams for doctors, nurses and others in the multidisciplinary team has enabled meetings to go ahead despite social distancing, shielding, isolation and quarantine requirements. Services continued, including regular South Thames network complex case discussions, with expert input from other sites to avoid delays to treatment.



Improved access to users' contact details, including mobiles and email, allows information to be shared quickly, including pandemic information, education sessions, WhatsApp groups etc. Electronic clinic lists ensure complex cases are reviewed by consultants, helping the team share the workload even when working remotely. Every patient has a clear electronic management and follow-up plan.



Direct admission of those with haemoglobin disorders to haematology wards was set up to offload our Emergency Department and medical colleagues during the pandemic. There are now haematology registrars on site in the hospital 24/7. From a patient perspective, you will be seen within 30 minutes by a member of your team, have an early decision about admission or discharge, earlier access to specialist treatments and hopefully a better experience and outcome.



Separate day units for those with and without COVID-19 symptoms and separate wards for inpatients with and without COVID-19. There are now also temperature and symptom checks before entry and a COVID-19 test before admission. So, you can attend hospital confident that you are safe from hospital-transmitted infection but you will also be cared for by your specialist team if you do get COVID-19.



New infection control procedures throughout the hospital, including weekly COVID-19 testing for staff, tri-weekly COVID-19 testing for inpatients, enhanced PPE, security imposed restrictions on hospital entry, a one-way system to enable social distancing, and hand sanitising stations.



Improved remote access allows staff to access the hospital computer system from home, enabling better patient care, including out of hours.



Despite very challenging times, service improvements continue.

You can keep attending for routine and emergency care, safe in the knowledge that your unit and team has strict infection control and the capacity to deliver your care.

Looking after your wellbeing

As the world continues to face the uncertainty and threat of the COVID-19 pandemic, many people are experiencing different emotional responses.

Given the many changes and restrictions to our daily lives, it's perfectly natural to feel worried or stressed. You might even be able to take some positives from the pandemic, for example, more time to reflect and less hustle and bustle.

Every person reacts differently, so it's really important to listen to your body and pay close attention to what you're experiencing.

**There is no 'right' way to feel.
Here are some of the emotions
you might experience.**



10 tips to support your wellbeing

1. Stay active and try and stick to a routine
2. Find new ways to do things that matter to you
3. Stay connected with others
4. Talk about your worries
5. Look after your body - eat well-balanced meals, drink lots of water and take regular exercise
6. Re-evaluate your relationship with the news and social media - stick to the facts
7. Take things day by day - focus on the present and the things that you can control
8. Take time to relax and get plenty of quality sleep
9. Do things you enjoy, however small
10. Remember you are the expert of you – use all the skills you already have



Compiled by The Adult Haematology Health Psychology Team at Guy's Hospital, 2020

For extra support, please contact:
Your sickle cell team (including psychology)
Samaritans (Tel 116 123)
Shout (text 85258)

Visit www.ststn.co.uk or the website below for more detailed tips and information.
www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-anxiety-tips

Keep well and keep safe!

COVID-19 impact on Sickle Cell Community Services

At the beginning of the year, emails from the trust alerted us to Novel coronavirus (2019-NCoV). We displayed leaflets around the clinic advising staff and patients to exercise caution around anyone who had travelled to Wuhan or Hubei Province in China in the previous 14 days.

The situation intensified, then in March everything changed in terms of our work, team interaction and how we serve patients. COVID-19 has had a huge impact on how we run community services. The team quickly implemented social distancing and quarantine rules and we switched appointments to virtual in a matter of days. Here's what else has changed.

Changes to centre activities

Historically all pregnant women are booked by midwives very early in their pregnancy, ideally before by 10 weeks. This allows sickle cell nurse counsellors to organise a blood test for the baby's father and to offer the couple genetic counselling. Due to COVID-19 restrictions, maternity bookings were carried out later in the pregnancy, which had a knock-on effect on our service provisions. All face-to-face genetic counselling for pregnant women, and testing biological fathers, was suspended. We also had to move communication with expectant parents to virtual, phone or post – light years away from what we were used to as a service team.

In fact, COVID-19 restrictions removed all face-to-face contact, making counselling and distributing information very difficult, if not almost impossible.

From April to 1 August, NHS/PHE made it mandatory for children and adults with Sickle Cell and Thalassaemia disorders (Haemoglobinopathies) to shield in their homes, unless they required urgent care, such as blood exchange transfusions.

This created anxiety for our patients, the majority of whom sit within the BAME group and, according to research, are the most vulnerable to COVID-19. Within my team alone, we have a 90% BAME group, and there was also added worry for members shielding due to health issues.

However, despite the challenges and new ways of working, my team worked tirelessly to ensure service worked as close to pre-Covid as possible. We continued to ensure that patients' care was our top priority and we didn't allow the pandemic to get the better of us.

Supporting staff during COVID-19

Prior to COVID -19, all community directorate staff were given laptops and tablets so everyone would be set up for remote working when it was needed. This turned out to be much sooner than expected, but we took it in our stride and put our IT skills to the test as we adapted to a new way of working.

Initially, the service lead and team leaders attended the daily Evelina Community Directorate meetings, to keep up-to-date with the transition. This has since been reduced, so the team can stay on top of COVID-19 planning, pandemic management and restorative issues.

Locally at Wooden Spoon House we had twice-weekly briefing meetings and we checked on each other's wellbeing daily. Staff also created a WhatsApp group to share tips on how to make home-working more efficient.

During lockdown we had groceries, fruit, flowers and toiletries (including plenty of hand cream) delivered to the health centre from the trust, in appreciation of staff going the extra mile under challenging circumstances. This was welcomed, as

was the Thursday night applause for NHS staff that took place on all over the country, recognising the challenging yet inspiring work carried out by NHS staff now more than ever.

Following the first COVID-19 restrictions, community services gradually began to revert to face-to-face activities, with in-person clinics and home visits, in line with the trust's restoration plan.

Now, as we manage the second wave of Covid-19, we are still unsure what the future holds in terms of how we deliver services. However, we can be certain that the community services will continue to support our Sickle cell and Thalassaemia patients to live well with their conditions by increasing their coping strategies in these challenging times.



Nkechi Anyanwu
(Community Nurse)



The UK National Haemoglobinopathy Panel

The NHP provides expert and evidence-based advice on the management of adults and children with Sickle Cell Disease, Thalassaemia and Rare Inherited Anaemias, when requested by clinicians

The National Haemoglobinopathy Panel (NHP) is a national partnership in collaboration with haematology centres and experts in the NHS. It is led by Professor Baba, Consultant Paediatric Haematologist, London Evelina Children's Hospital and King's College London.

Leadership and direction

The NHP provides strategic leadership and direction for haematology care and a structure to support and coordinate the work of the local haematology coordinating centres (HCCs) in delivering care to complex patients. The objectives are to drive the delivery of a nationally consistent approach to care, coordinate local actions by specialist teams and HCCs to reduce the variation in investigation and treatment, and provide local teams with access to expert clinical opinion for complex and challenging cases. The NHP also supports the introduction of new and innovative therapies and treatments, which are available to the patients most likely to benefit from them, regardless of where they live.

Clinical network

The NHP runs a monthly clinical MDT for the expert discussion of complex patients with the HCCs represented by a national membership of leading specialists in haematology. We also maintain an email network of experts in haematology and other specialties who can be contacted for urgent opinions and recommendations.

The email MDT also provides an additional discussion forum for cases referred to the monthly MDT. Together, these MDTs comprise a large clinical network that covers all HCCs and major haemoglobinopathy centres. This reflects the breadth of specialist services, the relevant clinical issues and the level of engagement the NHP is aiming for.

Since the onset of the COVID-19 pandemic in the UK, the NHP has also promoted collaboration among haematology experts in the research and management of the disease in patients with haemoglobinopathies, and has produced advice and guidance for both clinicians and patients.

Working together

At the heart of the NHP's work is a collegiate approach. Our main aim and principle, by working with the HCCs and other partner organisations in the NHS, and with patient representative groups, is to ensure that clinicians have access to expert opinion, provide leadership and oversight and facilitate cooperation between HCCs and partner organisations. We also ensure that HCCs and local teams have access to training and educational development.

Visit our website to learn more about the objectives of the NHP, our MDT pathways, the clinicians involved with the NHP, and our published resources: www.nationalhaempanel-nhs.net. We are also on Twitter @PanelNational.



UKTS updates

What a year 2020 has been. Back in March we celebrated our 42nd anniversary and, although the outbreak of COVID-19 meant we had to delay or cancel planned activities, such as the London Marathon, we didn't let that stop us.

During lockdown, patients remained our top priority. We continued supporting patients by making sure they had the latest shielding and social distancing guidelines. We ran yoga sessions via zoom and offered nutritional advice tailored to Thalassaemia patients' needs, as well physical activity and a balanced diet is vital to keep healthy, especially during the pandemic.

We also continued to raise awareness and encouraged people to donate blood, as it was more important than ever to ensure blood stocks did not deplete. We ran an online summer school for children aged 7-14 so they could meet others with Thalassaemia. We played games, did arts and crafts and added facts about Thalassaemia.

One of our proudest moments during lockdown was our art competition, which was open to entrants globally. It was a great way for children and parents to get involved in encouraging people to donate blood.



Once the lockdown restrictions were eased, we created patient packages which were delivered to 61 hospitals across the UK. These included a UKTS branded face covering, a copy of our standards, a membership form, a copy of our latest magazine, colouring books, story books and lots more information. Our ambassador programme was also launched recently too.

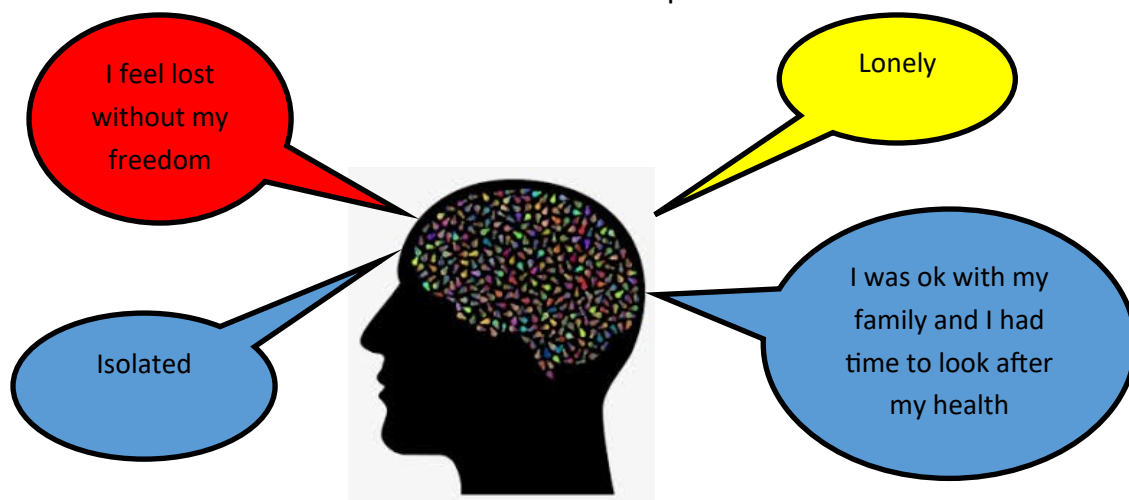


Going forward, we have exciting plans that we can't wait to share with you. We have been working with a ventriloquist to create a 10-episode educational series for children about all things Thalassaemia. Also, we will be celebrating our National Thalassaemia day virtually on 19 October 2020. Keep an eye out for the launch of our creative campaigns to help us support the day.

Our latest magazine will be available via our website very soon (www.ukts.org)

Patient Zone

During the first and second lockdowns, we captured some of our patients' comments about their experiences.



Patient's thoughts by Karla Frater

This year has been a mind-over-matter challenge during which I've learnt to be content with what I have, rather than what I don't have. It's a reminder to appreciate family, friends and the simple things in life, like a walk in the woods, or choosing my own fresh fruit and vegetables, rather than shopping in whichever supermarket has a delivery slot.

I don't personally associate shielding with negative experiences but I am aware that others have had a difficult time, depending on their individual circumstances. I continue to have a positive shielding experience, which is a huge reminder of how fortunate I truly am.

'It's been a time to slow down, reflect and identify what's working and what's not working in my life.'

Shielding has provided me with the chance to work from home, rest, eat well and to take daily walks, so I log at least 10,000 steps on my Fitbit. It's been a time to slow down and identify what's working and not working in my life, and the changes I want and need to make. It has been a time to heal (physically and emotionally) and get off the daily grind hamster wheel.

Although 2020 will be a year for the history books, it's been a great eye opener and shielding has given me a welcome bird's eye perspective.

We're recruiting patient representatives

WE NEED YOU!



We need individuals who use our services (parents, carers and patients) to share their views and contribute to discussions on service developments. You will need to attend up to four virtual network meetings a year, hosted on Microsoft Teams.

If you're interested in getting involved, please email the team at **info@STSTN.co.uk**

Please also get in touch if you have any articles or comments for future newsletters.

Patient Zone

King's College Hospital nurse wins award

We are extremely proud to congratulate Giselle Padmore-Payne, lead Haemoglobinopathy Clinical Nurse Specialist at King's College Hospital, for winning the Royal College of Nursing Child health award 'Nurse of the Year' in October 2020.

This award recognises her outstanding work in supporting teenagers and young adults with sickle cell disease, as they make the transition from children's to adult services. She has shown incredible dedication to our patients and families and her excellent teaching provision has helped so many people, including ward and emergency department staff, parents and patients.



The network is proud to announce that we now have a youtube channel ([STSTN](#)) which has plenty of content including our network educational events.

Please don't forget to:

LIKE, COMMENTS, SHARE & SUBSCRIBE.



The **Sickle Cell Society South London Link** offers 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



Do you have a story to tell?

Email info@ststn.co.uk if you'd like to share your experiences or you would like to contribute to the newsletter.

Visit Patient Zone on our website

Go to www.ststn.co.uk to find patient information, clinic times, support group information and previous editions of the newsletter.

